PREVALENCE AND DETERMINANTS OF THE USE OF SELF-TESTS BY MEMBERS OF THE PUBLIC TO DIAGNOSE OR SCREEN FOR CONDITIONS WITHOUT THE INVOLVEMENT OF A HEALTH PROFESSIONAL

by

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ABSTRACT

Self-tests that involve taking a biological sample to diagnose or screen for conditions without a health professional are available to the public, but they could potentially cause harm, such as false reassurance. This study aimed to describe the prevalence of their use and factors associated with using them. A systematic internet search established the availability of self-tests and informed the design of an initial questionnaire about whether people registered with general practices had used them. Interviews with respondents and a systematic literature review informed the design of an in-depth questionnaire to confirm use and investigate associated factors. It was estimated that 55 (95% confidence interval 41-68) per 1000 men and 95 (81-110) per 1000 women have self-tested excluding for pregnancy. Use was predicted ($p<0.1$) by: knowing about a range of tests, seeking health information, exercising less frequently, reporting not good health, having worked as a health professional, and believing health was controlled by chance and not powerful others. Being less satisfied with GP consultations and strongly agreeing that you should only see the doctor if you have serious symptoms also predicted use, implying that some use may be motivated by needs that have not been met by conventional services.

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BP	Blood pressure
CAM	Complementary and alternative medicine/therapies
CI	Confidence interval
df	Degrees of freedom
GP	General practitioner
GPAQ	General Practitioner Assessment Questionnaire
IMD	Index of Multiple Deprivation
IQR	Interquartile range
IVD	In vitro diagnostic medical device
MHRA	Medicines and Healthcare products Regulatory Agency
NHS	National Health Service
OMR	Optical mark recognition
OTC	Over-the-counter
PCT	Primary Care Trust
PSA	Prostate specific antigen
UK	United Kingdom
USA	United States of America

1 INTRODUCTION

1.1 Introduction to this chapter

This chapter summarises the rationale for this thesis, and the initial definition of a self-test used during the thesis is introduced. The aims of the thesis are then set out before being broken down into objectives.

1.2 Summary of rationale for this study

As technologies to design and manufacture diagnostic tests have developed, a range of self-tests to diagnose or screen for conditions have become available to buy over-the-counter and via the internet, for example tests for bowel cancer (blood in faeces), prostate cancer (prostate specific antigen in blood) or diabetes (glucose in urine or blood) [1]. These self-tests do not require the user to talk to a doctor before obtaining the test or when receiving the results: the results are available at home in minutes or a sample is sent to a laboratory and the results are returned directly to the user.

Self-testing has potential benefits, for example privacy and convenience [2], but also potential harms, such as false reassurance from false negative results or distress caused by false positive results [3]. Self-testing also has the potential to reduce or reinforce inequity: the use of self-tests by people who can afford and/or easily access them and who simply wish to routinely check on their health could free conventional services for others, but people who are unable to adequately communicate their needs to a health professional may instead end up buying expensive and perhaps undesirable self-tests. The use of self-tests could also result in demands on health services to investigate false positive or clinically insignificant true positive results.

Despite the potential impact of self-tests, there had only been one survey in the United Kingdom (UK) at the start of this study that asked people about whether they had used self-tests, and this was part of a study on attitudes to genetic testing [4]. Nearly a third (32%) of respondents in 2003 had ever bought a health testing kit to use at home, although this was not broken down further and the examples given in the question included the commonly used pregnancy test. A 1993 Omnibus survey asked about preferences for self-testing, and 18% of respondents said that they would prefer buying a self-test to going to the doctor to have the test, suggesting that there was considerable interest in the concept [5]. In line with this, commercial reports suggest that the UK market for self-diagnostics (any product, device or test used by a consumer without medical or professional help to identify or monitor a specific condition) grew to £99 million by 2007, a 29% increase from 2002 [6].

Nevertheless, the self-tests that were available, the types of tests used, how they were accessed, the level of use, who used them, and their reasons for using them were all largely unknown. The potential uses of such information include targeted education about the appropriate and safe use of self-tests, recommendations about changes to conventional services that may be needed to enable particular groups of people to use them rather than feeling that they must use private resources, and information to prepare health professionals for patients who are using self-tests.

1.3 Definition of a self-test

For the purposes of this thesis, a self-test was initially defined as follows:

- Used by members of the public to diagnose or screen for a medical condition.
- Bought without a referral from a doctor or nurse.
- Person takes their own biological sample.
- Sample processed at home or sent to a laboratory.
- Results available immediately or after sending the sample to a laboratory, but no contact with a doctor or nurse.

The rationale for this definition is described in section 2.8.

1.4 Aims

The aims of this study were:

- To describe the prevalence of the use of self-tests by members of the public to diagnose or screen for medical conditions without the involvement of a health professional.
- To determine factors that are associated with the use of self-tests by members of the public to diagnose or screen for conditions without the involvement of a health professional.

1.5 Objectives

To meet these aims, they were broken down into objectives:

- To identify the range of self-tests that were available to buy by adults in the UK.
- To use this information to design a short questionnaire to initially assess whether people had used self-tests.
- To conduct a population-based survey using this questionnaire.
- To explore experiences of self-testing by interviewing respondents to the initial questionnaire who reported self-test use.
- To generate a list of factors potentially associated with self-test use by interviewing respondents to the initial questionnaire who reported use, and by systematically reviewing evidence for factors that may be associated with using self-tests and, because of the lack of evidence in this area, similar activities.
- To use this information to design an in-depth questionnaire to describe and, therefore, confirm self-test use reported on the initial questionnaire and describe factors that may be associated with confirmed self-test use.
- To conduct a survey of people who responded to the initial questionnaire and who had and had not reported self-test use using this in-depth questionnaire.
- To use this information to estimate the prevalence of the use of self-tests by adults in the UK and determine factors associated with confirmed self-test use.

1.6 Summary of this chapter

This chapter introduced the rationale for this thesis. Self-tests to diagnose or screen for medical conditions without involving a doctor or nurse are available to the public. These tests have possible benefits, for example convenience, but they also have possible harms, for example false reassurance. Despite this and commercial reports that suggested that the level of self-testing had been increasing, there was a lack of research in this area. The self-tests that were available, the types of tests used, how they were accessed, the level of use, who used them, and their reasons for using them were all largely unknown. The aims of the project were then described – to fill some of the research gaps by describing the prevalence of the use of self-tests by members of the public and determining factors that are associated with using them – before being broken down into objectives.

The next chapter describes the background to the emergence of self-tests, and the rationale for the initial definition of a self-test. The reasons why it was felt that this project was important are then described in more depth.

2 BACKGROUND

2.1 Introduction to this chapter

In this chapter, self-testing will be considered in the context of the renewed emphasis on self-care and the general move towards increased patient involvement in healthcare. First, self-care will be defined. The history and current evidence about the extent of self-care activities by the public will then be described. The importance of self-care to individuals and a state-run health service will be considered, and the reasons for the Government's recently renewed and increased emphasis on self-care will be explored. The wider context of this move to encourage self-care will then be addressed, that is the move over the last thirty years from a purely medical model of disease where doctors treat patients without question to a partnership where patients are involved in decision-making and have some responsibility for their own healthcare. The emergence of self-tests will then be described. The Medicines and Healthcare products Regulatory Agency's (MHRA) definition of a self-test will be presented with the rationale for the initial definition of a self-test used during this study. Finally, the reasons why it was felt that this project was important are described in more depth, before the rationale for focusing on the UK is addressed.

2.2 Definition of self-care

Self-care is the care taken by individuals towards their own health and wellbeing [7]. Activities range from things that people do to stay healthy (such as increasing their fruit and vegetable intake) through to things that they do when they have symptoms (assessing their own condition, for example by taking their temperature, and then taking action, for example by taking over-the-counter (OTC) medicine) and things that they do when they have long-term conditions (such as taking medicine) [8].

2.3 History of self-care

Self-care has always been common. The monopoly of the medical profession only emerged during the early twentieth century as doctors joined state-administered schemes [9]. Much healing before then had been due to self-care or lay-care rather than because of the intervention of formal medical practitioners, at least partly because of their cost and shortage [10]. In the eighteenth century, for example, there is evidence for a wide knowledge of self-help remedies, including for serious illnesses such as persistent fever [11]. Even though the public had free access to doctors by the second half of the twentieth century, studies showed that symptoms presented to doctors were still only the tip of an iceberg [12]. Nearly one quarter of a population-based sample in 1972, for example, had a serious or severe symptom but did not seek medical assistance [13, 14]. Among two groups of women in the UK aged 20-44 and 16-44 years who kept health diaries in the 1970s and early 1980s, there was only one medical consultation for every 37 and 18 symptom episodes respectively [15, 16]. Mothers have also continued to manage children's symptoms themselves, only contacting their general practitioner (GP) if symptoms do not clear up or become more serious [17].

2.4 Importance of self-care

The existence of a clinical iceberg highlights the continuing importance of self-care in people's lives. People treat minor illnesses themselves, for example about 40% of people reported buying an OTC medicine from a pharmacy in the previous month [18], allowing them to cope with episodes of illness as they go about their daily lives. Self-care is also important, however, to a state-provided health service. It has been suggested that a decrease in self-care behaviours could have a large impact on the demand for formal care [19]. The cost to the National Health Service (NHS) of patients seeing their GP for ailments that could be self-treated is estimated to be £2 billion each year [20].

2.5 Renewed emphasis on self-care

Recently, there has been a renewed and increased emphasis on self-care by the Government. Recent initiatives to support self-care include the Expert Patients Programme [21, 22] and NHS Direct [21, 23]. Several drivers have made self-care an attractive policy. Many people want to participate in decision-making and be helped to help themselves [24], and the Government has promoted self-care on the basis that the public favour more control over their health [7]. Using research evidence to formulate policy is now seen as essential [25], and the Government has also promoted self-care on the basis that self-care has been shown to improve health outcomes and the appropriate use of health and social services [26]. For example, a "credit card" with personalised guidelines given to people with asthma led to an increase in their mean peak flow rate and a reduction in emergency care [27].

Changing patient expectations, advances in medical technologies, changing health needs of the population, and increases in prices for health service resources have all also increased the costs of providing a comprehensive health service [28]. The report by Derek Wanless estimated that NHS spending would rise from £68 billion in 2002/3 to £154-184 billion in 2022/3 [28]. This led to the need to explore innovative methods of care that could lead to cost savings, and it is anticipated that increased use of self-care activities has the potential to reduce the use of conventional services and, therefore, save costs [7]. The Department of Health estimated that GP visits could fall by 40%, outpatient visits could reduce by 17%, and accident and emergency visits, hospital admissions, hospital length of stay and days off work could all be halved [7].

2.6 Increased patient involvement in healthcare

This renewed emphasis on self-care has taken place within the context of a wider move away from a purely medical model of disease where doctors diagnose illnesses and patients take prescribed medicines without question. In the 1980s, the concept of the patient as a consumer was introduced to the NHS, although patients had little direct power with managers acting as proxy-consumers [29]. During the 1990s, new models of health emphasised the role of prevention and social factors, such as education [30]. Towards the end of the decade, the emphasis shifted to the patient as a partner [31] with individual responsibility and empowerment emphasised [21, 32]. Patients were generally reported as wanting a more patient-centred approach [33], focusing on communication, partnership, and health promotion [34]. They were seen as being more questioning, fuelled by cases of medical negligence exposed by the media, for example Rodney Ledward [35] and paediatric cardiac surgery at the

Bristol Royal Infirmary [36]. Such cases also contributed to the call to make medical professionals more accountable [37]. As well as being more involved in decisions about conventional care, patients have extended their involvement in healthcare by accessing and using non-conventional treatments, highlighted by the increasing popularity of complementary and alternative therapies (CAM) [38].

2.7 Emergence of self-tests

As self-care has been emphasised and patient partnership has developed, members of the public have become increasingly comfortable using monitors or tests recommended by their doctors. They test urine samples to diagnose pregnancy [39], use home blood pressure (BP) monitors [40, 41], and test their own blood to assist in the control of long-term conditions, such as diabetes [42]. Alongside this increasing confidence in the use of tests that were previously only used by professionals, technologies have advanced to enable the manufacture of a range of tests that allow the user to process a biological sample at home to diagnose or screen for conditions [43], for example sperm tests to assess fertility potential [44]. In turn, this has led to commercial opportunities: the market for self-diagnostics (products, devices or tests used without professional help to identify or monitor a specific condition) grew to £99 million by 2007, a 29% increase from 2002 [6].

Many self-tests provide almost immediate results, for example cholesterol tests that involve taking and processing a pinprick sample of blood [45], but some require that a sample is sent to a laboratory with results returned to the user usually within days, for example tests for chlamydia using a urine sample [46]. Either way, people who buy self-tests do not need to discuss when or why to have the test or the results with anyone. Self-tests are being marketed directly to members of the public [1], and they can be bought at pharmacies [47]. The direct marketing of self-tests is also facilitated by access to consumers provided by the internet [48], and 70% of households had internet access by 2009 [49]. This widespread presence and direct marketing of self-tests might mean that members of the public assume that self-tests are part of the spectrum of desirable self-care activities promoted by the Government.

2.8 Definition of a self-test

The MHRA defines an in vitro diagnostic medical device (IVD) for self-testing as "a device intended by the manufacturer to be able to be used by lay persons in a home environment" [50]. The MHRA says an "IVD" is "Any medical device...intended by the manufacturer to be used in vitro for the examination of specimens…derived from the human body" and "'Medical device' means any instrument, apparatus, appliance, material or other article…intended by the manufacturer to be used for human beings", including "for the purpose of diagnosis" [50].

The intention at the outset of this project was to study the use of tests that are used by lay people but, until recently, have only been performed by clinicians in a healthcare setting. The important aspects were, therefore, considered to be that the test involved taking a biological sample and that it was used to diagnose or screen for medical conditions. Based on this intention and the MHRA’s definitions, a self-test was initially defined as follows:

- Used by members of the public to diagnose or screen for a medical condition.
- Bought without a referral from a doctor or nurse.
- Person takes their own biological sample.
- Sample processed at home or sent to a laboratory.
- Results available immediately or after sending the sample to a laboratory, but no contact with a doctor or nurse.

Depending on whether pregnancy is defined as a medical condition, pregnancy tests might be covered by this definition. Nevertheless, other than for validation purposes, they were excluded from this study because they have been used by women for some time and their results are relied upon by doctors [51]. This decision to exclude pregnancy tests was in line with the desire to study new patterns of behaviour by members of the public.

The universal features of activities described as screening have been stated as “People being screening either do not have or have not recognised the signs and symptoms of the condition being tested for” and “The purpose…is either to reduce the risk of future ill health…or to give information, even though risk cannot be changed” [a]. There is, however, acknowledged to be some confusion around the use

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[a] Raffle A, Gray M. What screening is, and is not. In: Raffle A, Gray M. Screening: Evidence and Practice. 1st edition. Oxford: Oxford University Press; 2007. p. 34.

of the term “screening” as it can be used to mean “A screening test offered opportunistically to one person” or “A screening test offered systematically to a group of people or a whole population” [a]. In this thesis, self-testing is referred to as a screening test as it can be used opportunistically by a member of the public when they have no symptoms of a condition, for example use of a faecal occult blood test. In contrast, a diagnostic test is “designed for an individual with symptoms of a disease to confirm they have it” [b] and self-tests can also be used by members of the public in this way, for example the use of tests for urinary infections.

2.9 Relevance of this project

Members of the public may choose to self-test because of perceived benefits of being tested outside a conventional medical setting. It has been suggested in an editorial from the USA about home access testing for HIV-infection that people who would not visit a health professional may test themselves because it is more convenient and private [2]. One hundred and twenty seven (76% of 176 eligible) young adults aged 18-25 in the United States of America (USA) were asked about their attitudes, beliefs and feelings about testing for curable sexually transmitted infections outside of clinic setting during a telephone interview. They were purposefully selected to provide a diverse sample based on sex (55% or 70/127 were female), age (61% or 78/127 were 18-21) and race or ethnicity (41% or 52/127 were

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[a] Raffle A, Gray M. What screening is, and is not. In: Raffle A, Gray M. Screening: Evidence and Practice. 1st edition. Oxford: Oxford University Press; 2007. p. 35.

[b]Sense about Science. Making Sense of Screening. Available at http://www.senseaboutscience.org.uk/index.php/site/project/415/. Accessed 13 January 2011.

white, 22% or 28/127 were black, and 33% or 42/127 were Latino). Seven refused to complete the part of the interview about sexually transmitted infections, but the remaining 120 young adults felt that there were advantages, including privacy, increased testing, convenience and avoiding the cost of going to the doctor [52]. There are also potential population benefits. Self-tests could increase the coverage of testing for diseases where it is important to get an early diagnosis, for example diabetes or HIV-infection [2], and increase coverage among people who find it difficult to take time off work to visit the doctor or who are embarrassed or worried about confidentiality, particularly for HIV-infection.

There are also, however, theoretical harms that could arise from being tested outside a conventional medical setting even when results are accurate. People who receive a true positive result without an interpretation of the whole picture, including signs and symptoms, could label themselves as having a disease inappropriately. Someone with a positive faecal occult blood test might, for example, assume that he/she has bowel cancer when the blood could be from haemorrhoids, a stomach ulcer or an adenoma [53]. Alternatively, a person may delay seeking treatment after a true negative result when their symptoms are actually due to something else. Non-specific symptoms of weight loss and tiredness, for example, might be discounted after a negative blood glucose test when they are actually due to hyperthyroidism [54]. Furthermore, people with positive results may not actually go on to get treated [52].

Members of the public in the USA expressed doubts about the accuracy of self-tests [52]. This scepticism is not unwarranted: there is a lack of research into the performance of diagnostic and screening tests in a lay setting even though there are several reasons why such tests may be less accurate than when done in a healthcare setting. Most screening tests are expected to have some false positive and negative results, but the performance of the test depends, at least to some extent, on the ability of the person doing the test to accurately follow the instructions [55]. Performance of diagnostic and screening can also vary according to the severity, clinical presentation and prevalence of a disease [56, 57, 58]. The positive predictive value of a screening test, for example, which is the proportion of people with a positive test who actually have the disease, will be lower among people at low risk of the condition [58]. People with the greatest healthcare needs, most obviously the elderly or deprived, are less likely to have access to the internet [59]. The widespread internet advertising of self-tests may mean, therefore, that people who are at lowest risk of many conditions may be most likely to purchase self-tests, such as young men purchasing prostate specific antigen tests. These people would be less likely to actually have the condition if they got a positive result, and there have been reports of false positive results arising from the use of self-tests leading to unnecessary anxiety [3].

When testing is done in a conventional medical setting, health professionals use their knowledge of the test's sensitivity and specificity, the prevalence of the condition in the population, and each person's symptoms and risk of the condition to assist the person in considering whether a test is relevant and appropriate, and then to interpret the significance of the result. Self-tests, however, are likely to be used without an independent or educated assessment of the harms and benefits. For a screening programme to be introduced, several criteria have to be met to ensure that benefits outweigh harms, including that the information provided about the test and its outcome must be of value and readily understood by the individual being screened [60]. People who perform diagnostic or screening tests at home have, at best, a telephone hotline to assist them and usually only the written information supplied with the test. A British Medical Association report highlighted that ad hoc screening can put people at risk because of a lack of accompanying information: “people are also unlikely to receive sufficient information to enable them to make an informed decision as to whether or not to undertake the screen” [61]. Even if the information is sufficient and people take time to read it, they may not fully understand it and be able to adequately consider whether the harms outweigh the benefits for them.

The British Medical Association report also highlighted that ad hoc screening can put people at risk because of a lack of evidence underpinning tests and insufficient quality assurance [61]. The criteria for the introduction of a screening programme include that there is a simple, safe, precise and validated test, and that there is high quality evidence that the screening programme is effective in reducing mortality or morbidity or, where screening is aimed solely at providing information to make an “informed choice”, for example antenatal screening for Down’s syndrome, that the test accurately measures risk [60]. Even if members of the public only used tests that were assessed as being beneficial when used during conventional screening programmes, for example the faecal occult blood test offered to men and women aged 60 to 74 years in England [53], their use would be outside the managed and quality assured screening programme. Quality assurance procedures exist to ensure that screening programmes are delivered to pre-set standards, for example that particular tests are used and that those tests perform as consistently and reliably as expected: a screening programme based on good evidence may do harm and little good if it is not quality assured [62].

Self-tests may also impact upon healthcare provision. The move towards a primary-care-led NHS resulted in many GPs reporting that their workload had increased, that their prescribing behaviour had been affected by patient demand, and that the number of demanding patients had increased [63, 64, 65]. These trends may be exacerbated by self-test use as people seek an explanation of results or further investigation. Direct access to self-tests also has the potential to either reduce or reinforce inequity of healthcare provision. People who can afford a test may simply wish to check on their health, for example with a home cholesterol test, which could free conventional services for other people. Alternatively, people who feel unable to communicate their needs to a health professional could turn to expensive and perhaps undesirable self-tests.

It was, therefore, felt to be important to understand who uses self-tests to enable policymakers to ensure that targeted education about appropriate and inappropriate tests and testing could be provided to the public and equitable access to corresponding conventional services could be assured. There had been very few studies looking at self-tests. A comprehensive search of the literature at the start of this study identified only one UK survey that had asked about the use of self-tests, and this was part of a study on attitudes to genetic testing [4]. This survey found that nearly a third (32%) of 2510 respondents in 2003 had ever bought a health testing kit to carry out at home, but this was not broken down further and examples given in the question included the commonly used pregnancy test. The sample of 5738 people for this survey was selected from a panel of 100,000 to be representative of the UK population. The response rate was only 44% (2510/5738) though and respondents were more likely to be middle-aged (44% of 2508 who gave their age were 30-50 compared with 38% aged 30-49 for the UK population[a]) and male than the UK population (54% of 2508 respondents who gave their sex were male compared with 48% of the UK population [a]).

Self-tests that were available, the types of tests used, how they were accessed, the level of use among the general public, who used the tests, and their reasons for using them all remained unknown at the start of this study. This study is the first to address these issues: to systematically determine the range of self-tests that were available to buy by the UK public, to describe the views and experiences of a sample of users, to describe the prevalence of having used a self-test in the UK, to describe the tests that were used and how they were accessed, and to describe factors that were associated with self-test use. The potential uses of such information include

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[a] Office for National Statistics. Mid-2003 Population Estimates: United Kingdom; estimated resident population by single year of age and sex. Available at: http://www.statistics.gov.uk/statbase/Product.asp?vlnk=15106. Accessed 13 January 2011.

targeted education about the appropriate and safe use of self-tests, recommendations about changes to conventional services that may be needed to ensure that particular groups of people can use NHS services rather than having to rely on their private resources, and information to prepare health professionals for patients who are using self-tests.

2.10 Focus on the United Kingdom

This project focused on the UK because it was felt that the context of the availability of a national health service with specific policies would be important in influencing the use of self-tests. People who are resident in countries without a health service that is free at the point of delivery, for example, may be more likely to self-test in the hope of avoiding the costs of going to the doctor [52].

2.11 Summary of this chapter

In this chapter, self-testing was considered in the context of the renewed emphasis on self-care and the general move towards increased patient involvement in healthcare. Self-care was defined as the care taken by individuals towards their own health and wellbeing. The history and extent of self-care activities were then described: self-care has always been common and activities range from healthy behaviours, such as exercise, to managing chronic conditions, for example injecting medication. The importance of self-care to individuals, to enable them to continue with their daily lives, and the state, to manage health service costs, were considered. The reasons for the Government's recently increased emphasis on self-care were described: the public favour more control over their health, self-care improves outcomes, and self-care could reduce costs.

The wider context of this renewed emphasis on self-care was then explored. Over the last thirty years, there has been a shift in how doctors and patients view their relationship. Patients are reported as wanting a more patient-centred approach. As well as being more involved in decisions about conventional healthcare, patients have also taken the initiative by using non-standard treatments, such as CAM.

The emergence of self-tests that are available to buy by members of the public was then described, which has been driven by advances in technology and resulting commercial opportunities. Based on the MHRA's definitions and the intention to study the tests that are used by lay people but that, until recently, have only been performed by clinicians, a self-test was initially defined for this study as: used to diagnose or screen for a medical condition; bought without a referral from a doctor or nurse; involves taking a biological sample, which is processed at home or sent to a laboratory; and provides immediate results or results are provided after the sample is sent to a laboratory, but there is no contact with a doctor or nurse.

The reasons why this project was considered to be important were outlined. There are potential benefits from using self-tests: members of the public perceive advantages such as privacy, and there are also potential population benefits, for example increased coverage of testing. There are also, however, theoretical harms.

These could be associated with false results, for example false reassurance, or true results, for example delays seeking treatment after true negative results among people with symptoms due to other conditions. Other problems associated with using tests outside managed screening programmes are a lack of sufficient information or an independent person to enable the user to adequately weigh up harms and benefits, the lack of a firm evidence base for tests, and insufficient quality assurance.

The potential for self-tests to impact upon healthcare provision was discussed. Most directly, self-tests may impact on primary care as people seek an explanation of results or further investigation, but self-tests could also reduce or reinforce inequity of healthcare provision. People who can afford a test may simply wish to check on their health, freeing conventional services for other people, whereas people who are unable to communicate their needs to a health professional could instead buy undesirable and expensive self-tests.

Despite this, there had been very few studies looking at self-tests. This project is the first to address a number of issues: to systematically determine the range of self-tests that are available to buy by members of the UK public, to describe the views and experiences of users, to describe the prevalence of having used a self-test in the UK, to describe tests that are used and how they are accessed, and to describe factors associated with self-test use. Potential uses of such information include targeted education about self-tests, recommendations about changes to conventional services to ensure that particular groups of people feel able to use them rather than relying on private resources, and information to prepare health professionals for patients using self-tests.

Finally, the rationale for focusing on the UK was described, that the context of a national health service with specific policies might be important in influencing self-test use. The next chapter outlines the methods used to meet the aims of this study.

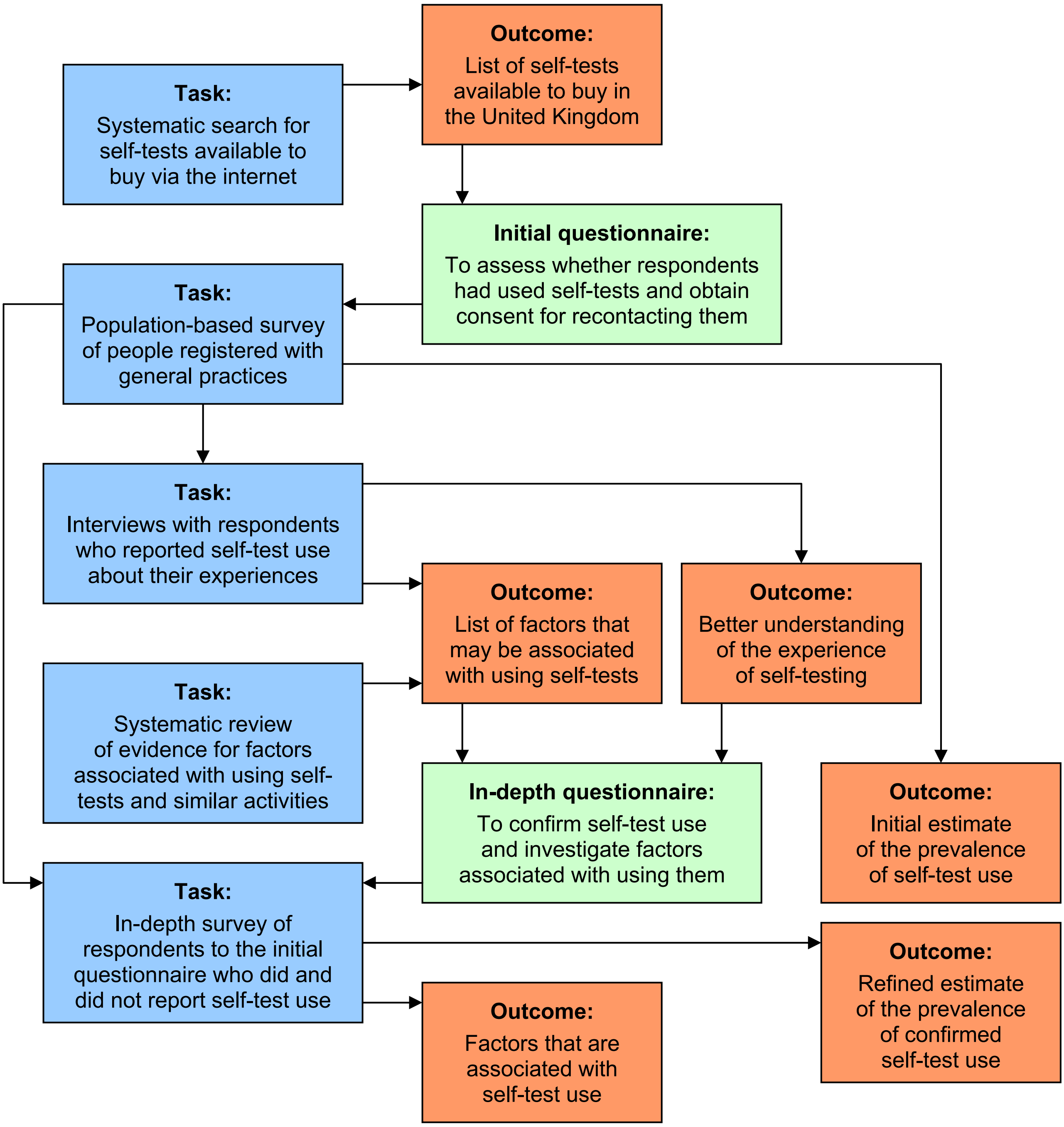
3 METHODS

3.1 Overview of methods

In this chapter, the methods used to meet the aims of the study (to describe the prevalence of the use of self-tests by members of the public and determine factors associated with their use) are fully described. The methods are summarised below and in figure 1. The published protocol is included in appendix 1 [66], and flowcharts for each component of the study are also included in appendices 2 to 8.

A systematic search of self-tests available to buy via the internet informed the design of an initial questionnaire about whether people had used them. A population-based survey of adults was then conducted using this questionnaire, which lead to an initial assessment of the prevalence of self-test use. A sample of respondents who reported use were interviewed about their views and experiences, and evidence for factors that may be associated with using self-tests and similar activities was systematically reviewed. This generated a list of candidate factors that may be associated with self-test use, which informed the design of an in-depth questionnaire. This was sent to willing respondents to the initial questionnaire who had and had not reported self-test use. Questionnaires sent to people who had used self-tests also included a section asking for more details of use so that this could be confirmed, leading to a more accurate estimation of the prevalence of self-test use and enabling determination of factors that are associated with confirmed self-test use.

Figure 1: Overview of methods used to describe the prevalence of self-test use and determine factors associated with their use.



3.2 Systematic internet search

3.2.1 Overview of this section

This section describes the methods used for the systematic search of the internet for self-tests available to buy by UK adults. The objective of this part of the study was to identify a list of these self-tests, which would then be used to assist in the design of a short questionnaire to initially assess whether people had used self-tests. The published paper for this part of the thesis is included in appendix 9 [48].

3.2.2 Search strategy

The search was done in two stages: the internet was searched to identify relevant websites, and then relevant websites were searched to identify relevant tests. Searches for relevant websites were conducted in April 2006 using search.msn.co.uk, www.google.co.uk, uk.ask.com, uk.search.yahoo.com and search.yahoo.com. These search engines were chosen because, at that time, about 95% of searches in the UK were powered by Google, Yahoo, MSN, and Ask [67]. The www.google.com, www.ask.com and www.msn.com engines were not searched separately as they simply redirect to the UK sites. Searches were not restricted to the UK, when that option was given, to ensure that tests being sold from other countries to UK customers were also identified. The search term used initially was (“self test” OR “self diagnosis” OR “home test” OR “home diagnosis”), but searches were subsequently done using each term on its own to ensure that all relevant websites were identified.

As nearly 70% of users move on if they have not found what they are looking for on the first two pages [68], only descriptions of the first 20 websites returned from each search and any sponsored links on those pages were read. Directories of websites, websites that were obviously not relevant, for example because they did not relate to healthcare, and websites that obviously met the exclusion criteria were immediately rejected. The remaining websites were visited to assess if they should be included. Inclusion and exclusion criteria for websites are set out in box 1 in section 3.2.3.

Included websites were explored in April and May 2006, and details of tests that, based on the description given, met the inclusion criteria and did not meet the exclusion criteria were collected. The inclusion and exclusion criteria for self-tests are set out in box 2 in section 3.2.3. The condition described as being related to the test, what the test was described as detecting, the sample required, and whether the test was processed at home or sent to a laboratory were collected. The cost of each self-test was also collected, including shipping and tax where this information was given. Some self-tests were sold in packs or were for more than one condition, and the cost per test and condition was calculated. Where prices were only given in dollars, they were converted to pounds using the exchange rate in May 2006 (£1=$1.82) [69]. The test name and manufacturer were also retrieved so that duplicate tests sold by different retailers could be identified and the number of unique tests counted.

3.2.3 Inclusion and exclusion criteria

The inclusion and exclusion criteria for websites and tests are described, respectively, in boxes 1 and 2. The criteria specified that use was without involving "a doctor, nurse or other health professional" rather than just "a doctor or nurse" because websites usually stated that a health professional was involved without further clarification [70, 71]. This also agreed with the definition of a self-test that would be used on the initial questionnaire - "Self-tests are bought from shops or over the Internet. They are used to test for conditions or diseases **without** involving a doctor, nurse or other health professional". The ethics application for this study had originally stated that self-tests were used without involving a doctor. The ethics committee, however, had asked for the expanded definition to be used as they felt that it was more appropriate to refer to a health professional rather than just a doctor.

3.2.4 Summary of this section

This section has described the methods used for the systematic search of the internet for self-tests available to buy by UK adults. The search was done in two stages – the internet was searched to identify relevant websites and these websites were then searched to identify relevant self-tests – and the inclusion and exclusion criteria for websites and self-tests were defined. The objective of this part of the study was to identify a list of self-tests that would then be used in a short questionnaire to initially assess whether people had used self-tests, and the next section describes the methods for the population-based survey that used this questionnaire.

Box 1: Inclusion and exclusion criteria for websites identified during the systematic internet search.

A <u>website</u> was **included** if it met **all** of the following criteria:

- Sold test(s) to members of the UK public.
- Sold test(s) that could be used without involving a doctor, nurse or other health professional.
- Sold test(s) that detected a disease or condition that may need treatment, or a risk factor or marker for such diseases or conditions.
- Sold test(s) that required the user to take a sample, and process it at home or send it to a laboratory with results returned directly to the user.

A <u>website</u> was **excluded** if it met **any** of the following criteria:

- Did not sell test(s) to members of the UK public.
- Only sold test(s) for pregnancy or other normal states [a] or for monitoring existing conditions.
- Only sold test(s) in large batches unless it specifically stated that the tests were for home use.
- Only sold test(s) with approval from a health professional, a prescription, or correctly answered screening questions.
- Only sold test(s) that required a separate meter or testing device.

[a] An example of a test for a normal state, as described in the exclusion criteria, is a test for measuring hormone levels, such as testosterone and cortisol, with the aim of optimising athletic performance [72].

Box 2: Inclusion and exclusion criteria for self-tests identified during the systematic internet search.

A <u>test</u> was **included** if it met **all** of the following criteria:

- Could be purchased and used by a member of the UK public without involving a doctor, nurse or other health professional.
- Detected a disease or condition that may need treatment, or a risk factor or marker for such diseases or conditions.
- Required the user to take a sample and process it at home or send it to a laboratory with results returned directly to the user.

A <u>test</u> was **excluded** if it met **any** of the following criteria:

- Could not be purchased by a member of the UK public, including if it was reported as being out of stock.
- Was for pregnancy or other normal states [a] or for monitoring existing conditions.
- Was only sold in large batches, unless it was specifically stated that the test was for home use.
- Purchase required approval from a health professional, a prescription, or correctly answered screening questions.
- Required a separate meter or testing device.

[a] An example of a test for a normal state, as described in the exclusion criteria, is a test for measuring hormone levels, such as testosterone and cortisol, with the aim of optimising athletic performance [72].

3.3 Population-based questionnaire survey

3.3.1 Overview of this section

This section describes the methods used for the population-based questionnaire survey. This part of the study is described in the published paper included in appendix 10 [73]. The questionnaire asked whether respondents had used any of a list of self-tests generated from the systematic search of the internet for self-tests available to buy by members of the UK public or pregnancy tests or tests for high BP. The questionnaire also sought consent for recontacting them. This survey facilitated the initial estimation of the prevalence of self-test use and provided samples of people who were willing to be contacted about taking part in an interview or receive a longer in-depth questionnaire.

3.3.2 Questionnaire design

This questionnaire (appendix 11) aimed to initially assess whether people had used self-tests and gain consent to recontact responders about taking part in an interview or send them an in-depth questionnaire. It covered two sides of an A4 card and, on the first side, asked for age, sex, ethnic group, health status and employment status. It was felt that the questionnaire should be kept short to improve the response rate, but that it would be useful to obtain some background information. Age, sex, health status and employment status were chosen because it was hypothesised that these variables may affect whether someone would self-test. The wording and coding categories for the questions about ethnic group, health status and employment status were taken from the last Census [74], facilitating assessment of the sample's representativeness by comparison with Census data.

A definition of a self-test was then provided on the second side of the questionnaire in keeping with the initial definition of a self-test for this study (see section 2.8). This was kept short to reduce the length of the overall questionnaire and improve response rates – "Self-tests are bought from shops or over the Internet. They are used to test for conditions or diseases **without** involving a doctor, nurse or other health professional". The ethics application for this study had originally stated that self-tests were used without involving a doctor. The ethics committee, however, had asked for the expanded definition to be used as they felt that it was more appropriate to refer to a health professional rather than just a doctor.

The questionnaire then asked whether the person had used named self-tests identified by the systematic internet search [48]. As it was not possible to list all types of tests identified during the search on this short questionnaire (see section 4.2.3), the most frequently identified eligible tests were listed. For this purpose, an eligible test was counted each time it was identified even if the same test had already been found on another website. The self-tests listed were for allergies, blood in the stool, chlamydia, cholesterol, diabetes, HIV-infection, kidney disorders, low blood count, menopause, prostate disorders, sperm count, urine infection and vaginal infection. Alternative names were also included on the questionnaire, for example glucose or sugar in the blood or urine for diabetes. Although not included in the definition of self-tests used for this thesis, tests for pregnancy and high BP were also listed so that the results could be compared with studies where these tests were included. There was also a free text option to provide details of any other self-test not already mentioned.

There were two mailings of the initial questionnaire so that potential interviewees could be identified from the first mailing, thereby enabling the design of an in-depth questionnaire (see sections 3.6.2 and 4.5). Respondents who were willing to receive the in-depth questionnaire were then identified during the second mailing, ensuring that the gap between consenting to and receiving an in-depth questionnaire was as short as possible. Self-test for gonorrhoea was listed on questionnaires sent out during the first mailing, but this was removed for the second mailing because no-one had reported its use and its removal facilitated better spacing of the remaining tests on the questionnaire. The initial questionnaire sent out during the first mailing asked for consent to recontact people taking part in an interview, and the initial questionnaire sent out during the second mailing asked for consent from respondents to send them an in-depth questionnaire.

3.3.3 Pilot of initial questionnaire

The initial questionnaire was piloted with non-academic staff members from the Department of Primary Care Clinical Science at the University of Birmingham to assess comprehension and ease of completion. The questionnaire was then sent to a restricted number of eligible subjects (n=400) before a large number were distributed. The responses suggested that there were no major difficulties completing the questionnaire and, therefore, no further changes were considered necessary.

3.3.4 Sample size

At the start of this project, there had only been one survey in the UK that asked participants about self-test use [4]. This reported that nearly a third (32%) of respondents had ever bought a health testing kit to carry out at home, although this was not broken down further and the examples given in the question included the commonly used pregnancy test. Based on a conservative 10% prevalence of self-test use, it was calculated that a sample of 4200 people would allow estimation of the prevalence of use with at least +/-1% precision and 95% confidence [75]. Assuming a response rate of 40%, which is less than other large prevalence surveys [76, 77], it was initially estimated that the questionnaire would need to be sent to 10500 people, although this would be revised based upon the actual response rate. Conservatively assuming an average list size of 4500 people [78], 75% of whom were 18 years or older [79] and 5% of whom the GP excludes as inappropriate to receive the questionnaire [77], it was estimated that four general practices should be sufficient, but it was anticipated that up to 10 would be recruited to increase generalisability.

3.3.5 Study population

For the first mailing, 19 general practices were approached by letter (appendix 12) and asked to return a reply slip (appendix 13) indicating their interest in the study. These practices were selected from Birmingham East and North Primary Care Trust

(PCT), Heart of Birmingham Teaching PCT, Solihull PCT and South Birmingham PCT. Selection was based on the Index of Multiple Deprivation (IMD) 2004 rank and population density to try to ensure that people from a range of economic backgrounds and urban and rural settings were included. The IMD score brings together indicators chosen to cover different aspects of deprivation, which are weighted and combined into a single score for each of 32482 super output areas in England [80, 81]. Each practice was assigned a high or low grade based on whether the IMD 2004 score for the super output area for that practice was in the top or bottom half of the ranking of scores for all super output areas in England. Ranks were provided with details of eligible practices by the Midlands Research Practices Consortium. Practices were also assigned a high or low grade based on whether the population density for the ward for that practice was in the top or bottom half of the ranking of population densities for all wards in England [82]. Four groups of practices were formed – high population density and high IMD rank, high population density and low IMD rank, low population density and high IMD rank, low population density and low IMD rank – and the 19 practices were selected from across these groups. Seven practices responded: five declined and two agreed to take part in the study.

For the second mailing, 60 general practices were approached with details of the study. The same selection procedure was used [83, 84], but Worcestershire PCT and what was previously South Warwickshire PCT were also included [a]. Thirty two

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[a] On 1 October 2006, North Warwickshire PCT, South Warwickshire PCT and Rugby PCT merged to form Warwickshire PCT, but approvals had only been gained for the former South Warwickshire PCT.

practices responded of which 22 declined, six asked for further information but did not decide to participate, and four agreed to take part in the study.

The study population comprised adults aged 18 years or older registered with the participating general practices. The practices were asked to generate random samples of eligible adults (table 1). They were then asked to exclude anyone who might be distressed by the questionnaire, for example because of recent illness or bereavement, and people who lived with them were also excluded.

Table 1: Approximate list size of participating general practices and numbers of patients sampled, excluded and mailed.

Practice	Approximate list size [a]	Original sample	Excluded	Mailed
1	4900	1500	139	1361
2	11000	1000	26	974
Subtotal	*15900*	*2500*	*165*	*2335*
3	2000	2034 [b]	55	1979
4	10700	1500	20	1480
5	10500	1570	32	1538
6	5700	785	69	716
Subtotal	*28900*	*5889*	*176*	*5713*
Total	**44800**	**8389**	**341**	**8048**

[a] Adults aged 18 years or older to the nearest 100 adults.

[b] This practice provided their full list.

3.3.6 Questionnaire mailings

The first mailing was conducted during June and July 2006. Questionnaires were sent to 2335 adults aged 18 years or older registered with two general practices from

Birmingham East and North PCT. The second mailing took place from October 2007 to January 2008. Questionnaires were sent to a further 5713 adults registered with four practices from Warwickshire and Worcestershire PCTs. The total sample was 8389 people and 341 were excluded by the practices, leaving a sample of 8048 people (table 1). A covering letter (appendix 14) and prepaid envelope were sent with the questionnaire. A reminder letter (appendix 15) plus replacement questionnaire and prepaid envelope were sent to non-responders after three to four weeks. The letters included the option of returning a blank questionnaire to indicate that the person did not want to take part.

3.3.7 Data entry

Because of the large number of people being mailed, the questionnaires were designed so that they could be scanned and read using optical mark recognition (OMR) software (Remark Office OMR Version 6) [85]. This involved asking respondents to fill in a circle to show their answers rather than, for example, ticking them. Data from the first 99 questionnaires returned were entered using the software and then checked visually against the hard copy of the questionnaire. As there were 48 OMR readable fields, this comprised 4752 data items. There were 37 errors across four questionnaires, but 35 were where the respondent had written across the questionnaire, rather than just filling in the circle, and 34 of these were on one questionnaire. It was, therefore, decided that questionnaires would be divided into “well-completed”, that is where circles were filled in as requested, and “poorly-completed”. The former group were entered using the OMR software alone. The latter group were also entered using the OMR software, but the resulting data was always checked against the hard copy of the questionnaire.

3.3.8 Data analysis

Response rates were calculated. The representativeness of responders was examined by comparing characteristics from the initial questionnaire with population-based data from the 2001 Census. The crude prevalence was calculated as the proportion of eligible responders reporting use. The crude prevalence of the reported use of each self-test was calculated, and a combined analysis calculated the crude prevalence of the reported use of any self-test. A test for pregnancy was included on the initial questionnaire, but the overall prevalence of the use of any self-test was calculated excluding pregnancy tests because their use is now routine [51]. A test for high BP was also included on the initial questionnaire, but they were also excluded from the calculation of the prevalence of the use of any self-test because, unlike the other named self-tests, the user does not need to take their own biological sample. Separate analyses for tests for high BP and tests for pregnancy and combined analyses for any self-test plus tests for high BP but excluding tests for pregnancy and any self-test plus tests for high BP and pregnancy were also conducted, however, to enable comparison with other published data.

The prevalence estimates were directly standardised to the population of England and Wales in 2006 [86, 87]. Sex- and age-specific rates of self-test use were multiplied by the number of the standard population in the relevant age group and then summed to give the estimated total number of self-test users in England and Wales. This was divided by the total population to give the directly standardised prevalence. Ninety five percent confidence intervals (CI) were calculated [87].

3.3.9 Summary of this section

This section described the methods used for the population-based questionnaire survey. The questionnaire asked whether respondents had used any of a list of self-tests generated from the systematic internet search for self-tests available to buy by members of the UK public and sought consent for recontacting them. This facilitated the initial estimation of the prevalence of self-test use and provided samples of people who were willing to be contacted about taking part in an interview or receive a longer in-depth questionnaire.

The design of the questionnaire and how it was piloted were explained. The sample size calculation was set out and the study population was described. The strategy for sending out the questionnaires and the methods used for entering and analysing data were outlined.

The next section describes the methods used for interviews with a sample of respondents to this initial questionnaire about their experiences of using self-tests.

3.4 Interview survey

3.4.1 Overview of this section

A sample of respondents to the initial questionnaire who reported that they had used self-tests were interviewed about their experiences and this section describes the methods used. Interviews are suitable for gaining an in-depth understanding of personal experience and perspectives [88]. The objectives of the interviews were to better understand experiences of self-testing, that is how self-tests had been accessed and why they had been used, and to generate a list of factors that may be associated with self-test use. This information would then be used to inform the design of an in-depth questionnaire. The published paper for this part of the study is included in appendix 16 [89].

3.4.2 Study population

The initial questionnaires sent to 2335 adults aged 18 years and older from the two general practices in North Birmingham during June and July 2006 sought consent to contact people about taking part in an interview about their experiences of self-tests. The practices generated a random sample of 2500 adults but excluded 165 people who were felt to be inappropriate, for example because of recent illness.

Purposeful sampling of respondents was then used to select people to invite to interview [90]. Reasons for self-testing may vary depending upon the person's sex and age and the type of test that they had used. Potential interviewees were, therefore, placed in groups based on their sex and age (under 50, 50 and older) and the type of self-test they said they had used: (1) allergies, (2) cancer i.e. prostate disorders or blood in the stool, (3) cholesterol, (4) diabetes, (5) fertility i.e. menopause or sperm count, (6) kidney disorder, (7) low blood count, (8) sexually transmitted infections i.e. chlamydia or vaginal infection, (9) urine infection. The age cut-off was selected with the aim of roughly dividing the potential interviewees into two equally sized groups, rather than on a presumption of when behaviours change.

3.4.3 Mailing invites to interviews

The plan was to invite people from as many of these age-, sex- and type of test-specific groups as possible, randomly selecting from groups with more than one person. People who were selected were sent a covering letter (appendix 17), information leaflet (appendix 18), reply slip (appendix 19) to confirm whether they would like to take part in an interview, and a prepaid envelope for its return. People who were willing to be interviewed were contacted by telephone and given the option of being interviewed at home or The University of Birmingham. Invites were sent out in two batches to facilitate analysis being conducted alongside interviews. No reminders were sent as it was felt that, perhaps unlike a questionnaire, taking part in an interview is a substantial undertaking and, therefore, that non-response should be accepted.

3.4.4 Conduct of interviews

All interviews were conducted by the author of this thesis (medically trained white female aged 38 years) from September to December 2006. Informed consent was obtained immediately before the interviews (appendix 20), which were digitally recorded. Respondent validation was sought by sending participants a summary of their interview and asking them to return a reply slip saying whether they thought that the summary was complete and accurate (appendix 21).

A semi-structured topic guide was used during the interviews (appendix 22). This was based on the areas that it was felt should be covered based on the objectives of the study [91]. Key areas for discussion were signposted, for example how the person found out about and decided to use the self-test, and further subsidiary questions were included in case the interviewee needed guidance about the type and amount of detail required. The questions were intended to be open-ended, precise and clear [92], although it was anticipated that the exact wording could be adapted to suit the interviewee [93]. It was anticipated that the interviews would always start with questions about how the person found completing the initial questionnaire and the tests that had been used as it was considered that these were easily answered questions that would, therefore, put the person at ease. The order of the other questions was expected to vary depending on the flow of the interview.

3.4.5 Analysis

3.4.5.1 Method of analysis

Thematic analysis was used. This involves the researcher grouping the data into themes and examining all the cases in the study to make sure that all occurrences of each theme have been accounted for and compared [94]. Thematic analysis can be used to get a full description of the entire data set to get a sense of the predominant or important themes, and this has been suggested to be particularly useful when investigating an under-researched or “fuzzy” area or when working with participants whose views on a topic are not known [95, 96]. If the research is exploratory or part of a mixed-methods study, as in this study, these thematic groupings may simply be reported or described, rather than identifying relationships between them [94].

Themes can be identified in two main ways, inductively from the raw data or deductively from theory and prior research [95]. In a bottom-up or inductive thematic analysis, the data is coded without trying to fit it into a pre-existing coding frame [96]. The selection of themes is driven by the data rather than, for example, questions asked of participants or the researcher’s theoretical ideas [96]. In contrast, a top-down or theoretical thematic analysis is more explicitly analysis driven, for example by the researcher’s theoretical or analytic interest in the area [96]. It has been suggested that the choice between these approaches is related to why the data are being coded [96]. Coding the data for a specific research question is associated with a more theoretical approach. Alternatively, the research question can evolve through the coding approach, which equates to a more inductive approach [96]. As the objective of this part of this study was to generate a list of factors associated with self-test use, it was expected that this would be a predominantly inductive thematic analysis. It was also realised, however, that this type of analysis often includes themes that emerge from the data and that are anticipated, for example in this study interviewees would be asked about their explicit reasons for self-testing [94].

Furthermore, it was also acknowledged that researchers cannot easily free themselves of their existing knowledge or theoretical preconceptions [96].

A thematic analysis also usually focuses exclusively on identifying themes at an explicit or latent level [95, 96]. With the former approach, themes are identified within the surface meanings of the data [96]. The analyst does not look beyond what the participant has said, which was anticipated would be the case with this analysis.

Qualitative researchers usually treat counting with caution. This is because the methods used are intended to identify subjective meanings and generate theory rather than to be statistically representative [97]. In a qualitative study where the sample has not been selected to be numerically representative of the population and where the interview technique is not necessarily consistent, for example not all questions are asked of all respondents or questions are phrased differently or delivered at different stages of the interview, it can be misleading to report relative frequencies [97]. It was decided, therefore, that counts would not be undertaken.

3.4.5.2 Process of analysis

Braun described six phase in thematic analysis, shown in box 3 [96], and the process of analysis mirrored this description. Initially, as in the first phase of analysis described by Braun, the author of this thesis transcribed all the transcripts verbatim and then read and re-read them to familiarise herself with the data.

Box 3: The six phases of thematic analysis described by Braun [96].

Phase 1: *Familiarising yourself with the data* – transcribing, reading and re-reading the data, noting down initial ideas.
Phase 2: *Generating initial codes* – Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
Phase 3: *Searching for themes* – Collating codes into potential themes, gathering all data relevant to each potential theme.
Phase 4: *Reviewing themes* – Checking if the themes work in relation to the coded extracts and the entire data set, generating a thematic map of the analysis.
Phase 5: *Defining and naming themes* – Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
Phase 6: *Producing the report* – Selection of vivid, compelling extract examples.

Following on from this, as in the second phase of analysis described by Braun, an initial list of codes was generated from the raw interview data. Codes refer to the most basic segment of the raw data that can be assessed in a meaningful way, and they identify a feature of that data, explicit content in this instance, that appears interesting to the analyst [96]. Initially, the transcripts were printed and then highlighted and labelled by hand. Dialogue about a test was considered relevant, regardless of how it had been accessed, as long as no clinician had been involved before the test was used. As much of the data was coded as possible, some sections receiving multiple codes [98], and then the coded extracts were cut out and sorted into piles with the same code. Using a word processing package, the extracts were then cut and pasted into separate electronic files. An example of a coded segment of text is shown in box 4.

Box 4: Example of coded segment of text from interview transcript.

Check on known risk

Difficult to read result

165 – Female aged 35-49 years:
I haven't, sounds as if I'm like a hypochondriac. My mum has high cholesterol. Um my dad died of a heart attack, so I'm always aware. I mean I've sort of hopefully countered for that, but I like to check. If you ask the doctor, they say well why, you know, what's your problem, and you think well why waste the doctor's time. You know I mean they get enough to do without just sort of I want a test. Um so I did that over the counter. It wasn't as, I didn't feel as confident with that one as the one at Boots. It was one of these little pinprick in your finger. It was not clear, not clear enough to think oh yes that's definitely whatever.

Avoid bothering the doctor unless really necessary

During the next phase, the analysis was focused at the broader level of themes [96]. A theme is a pattern found in the information that at the minimum describes and organises possible observations and at the maximum interprets aspects of the phenomenon [95]. This phase involved sorting the different codes into potential themes and ended with a collection of candidate main themes and sub-themes. Again, this was done initially by grouping piles of paper extracts with the same code and then by using a word processing package to place documents with groups of codes together in the same folder.

These first three phases of analysis were carried out for the first seven interviews before the remaining interviews were conducted. The same process was then repeated for the other interviews. The transcripts were coded independently (first phase of analysis) by another researcher, Dr Sheila Greenfield (PhD supervisor), and the researchers met before the fourth phase of analysis to ensure that the full list of codes, themes and sub-themes had been identified. It was also agreed that no new relevant data were emerging in the later interviews to warrant new themes or sub-themes or regarding existing ones, that is that saturation had been reached and that no more interviews were needed [99].

The candidate themes and sub-themes were then reviewed, refined and finalised, as in phase four and five of Braun's model of thematic analysis [96]. The codes within each candidate theme were read and re-read to ensure that they formed a coherent pattern, and the candidate sub-themes and themes were reviewed to ensure that they reflected the meaning present in the whole dataset. The relationships between the sub-themes and main themes were also revisited and then refined by reviewing them with another researcher, Dr Jon Ives (Research Fellow). This was to ensure that a sensible and coherent map of the data was produced.

3.4.6 Summary of this section

This section has described the methods used for interviews with respondents to the initial questionnaire who had reported self-test use about their experiences. The objectives were to better understand experiences of self-testing and generate a list of factors that may be associated with self-test use. This information would then be used to inform the design of an in-depth questionnaire.

This section described the study population from which the interviewees were sampled and how this was done. Details of how invites to interviews were mailed were given. How interviews were conducted was outlined, including the design of the topic guide. Finally, the rationale for undertaking a thematic analysis and how this was conducted were described.

The next section describes the methods for the systematic review of evidence for factors that may be associated with using self-tests and, because of the lack of evidence about self-testing, similar activities. This added to the list of factors that may be associated with self-test use generated during the interviews.

3.5 Systematic review of evidence

3.5.1 Overview of this section

This section describes methods used for the systematic review of evidence for factors that may be associated with self-testing. After starting the review, it became clear that there was very little published work related to self-testing. The review was, therefore, expanded to include similar activities, that is health-related activities that could be initiated without a conventional health professional, for example use of OTC medicine. The objectives of this part of the study were to add to the list of factors that may be associated with self-testing generated during the interviews. This information would then contribute to the design of an in-depth questionnaire to investigate factors that were associated with self-test use. The published paper for this part of the study is included in appendix 23 [100].

3.5.2 Scope of the review

In addition to self-testing, because initial scoping searches indicated a lack of evidence directly related to self-testing, activities under review were use of OTC medicine, private healthcare, CAM, and home BP monitors. These were chosen because they also relate to self-care and can be initiated without the involvement or recommendation of a conventional health professional and this is a defining feature of self-testing. Furthermore, they usually necessitate the user taking an active role, for example visiting a pharmacy, which is similar to buying a self-test. The review was restricted to studies involving UK residents because use of these activities is likely to be related to the accessibility of the health care system. The review was also restricted to studies published in the previous 15 years (1993 to 2007) because use of the activities may have altered as fashions, cultural norms, technologies and healthcare policies have changed [101, 102].

3.5.3 Search strategy

Databases searched are shown in box 5. A search strategy was designed for each activity. To look for studies about self-test use, for example, titles of papers were searched for the terms “self diagnos$” or “self test$” or “home test$” or “home diagnos$”, where $ denotes truncated terms. This was then adapted for each database. Databases where MeSH headings are assigned to papers, for example, were also searched using appropriate headings, such as “self medication” to look for studies about OTC medicine use in Medline. Searches were conducted during April 2007. More recent searches of Medline were conducted in July 2008 and February 2010, but the in-depth questionnaire had been designed and distributed by then so the search was restricted to papers about self-testing to contribute to the interpretation of the findings of this study.

Box 5: Databases searched during systematic review of evidence for factors associated with self-care activities.

Allied and Complementary Medicine Database (via Ovid)

Applied Social Sciences Index and Abstracts (via CSA)

Arthritis and Complementary Medicine Database
(http://www.compmed.umm.edu./integrative/Databases.html)

British Nursing Index (via Ovid)

Complementary and Alternative Medicine and Pain Database
(http://www.compmed.umm.edu./integrative/Databases.html)

Cumulative Index to Nursing and Allied Health Literature (via EBSCO)

Embase (via Ovid)

International Bibliography of the Social Sciences (via Ovid)

Medline (via Ovid)

PsycINFO (via Ovid)

Sociological Abstracts (via CSA)

Where too many papers were returned by the initial search criteria to review each abstract, searches were refined with filters to identify appropriate study designs. For example, titles were searched for terms related to relevant outcomes such as “factor$” or “characteristic$”, and databases where MeSH headings are assigned were searched using headings such as “Epidemiologic Studies” or “Health Surveys”. A filter to identify studies conducted in the UK was also used: the title, abstract, institution and country of publication were searched for “UK”, “United Kingdom”, “GB”, “Britain” and the constituent countries. Finally, where possible within each database’s options, searches were limited to studies involving humans, written in the English language, and published from 1993 to 2007. Appendix 24 gives examples of search strategies used to look for studies related to OTC medicine in Medline.

References of eligible papers were reviewed to identify any relevant citations that had not otherwise been identified. As studies related to private care could have been published in economic as well as medical journals and all relevant papers from such journals may not be indexed in biomedical bibliographic databases, The Journal of Health Economics, The Journal of Public Economics and The Economic Journal were also hand-searched. These journals were chosen because some relevant papers were identified that had been published in these journals during the electronic searches and from the references of other papers.

3.5.4 Inclusion and exclusion criteria

Abstracts of potentially relevant studies were reviewed. Where it was unclear whether the study was eligible, the paper was retrieved and assessed. Studies were included if they were published during the last 15 years (1993 to 2007) and they reported factors, reasons or characteristics associated with a relevant self-care activity among adults resident in the UK.

Studies were excluded if they did not concern a relevant activity as listed in section 3.5.2 or report factors, reasons or characteristics associated with a relevant activity. Remaining studies were then excluded: if they did not involve adults or did not differentiate between children and adults; if they specified that the activity was initiated by a doctor or nurse; if they only studied intention or willingness to do an activity rather than actual behaviour; if they involved people with specific conditions where the results would not be generalisable, such as the use of non-prescription medicine in a multiple sclerosis clinic population [103]; or if they did not involve UK residents or differentiate between residents of the UK and other countries. Finally, reviews, letters and opinion pieces were excluded, although reviews were retrieved so that relevant references could be identified.

3.5.5 Quality assessment

Proformas based on tools from the Critical Appraisal Skills Programme [104, 105] were used to assess the quality of eligible studies. The quantitative proforma included questions about whether the results of the study were likely to be valid, for example whether the study population was recruited appropriately (appendix 25). The qualitative proforma included questions about whether the study was likely to be rigorous and credible, for example whether the recruitment strategy was appropriate to the aims (appendix 26). Each paper was independently given a score out of ten by two reviewers (the author and either Professor Sue Wilson, PhD supervisor, or Dr Aliki Taylor, Clinical Research Fellow) with discrepancies resolved by discussion. Papers with scores of eight or more were arbitrarily termed high quality, papers with scores of more than five but less than eight were termed medium quality, and papers with scores of five or less were termed low quality. Low quality publications were included to give a complete picture and because such studies could indicate areas where higher quality research is needed.

3.5.6 Data extraction

Data was extracted from eligible papers by the author of this thesis. The following headings were used: year of publication, study design, population studied, year of the study, exposure (for example visited a CAM practitioner in the last 12 months [106]), denominator (for example number of questionnaires distributed or people invited to interview), numerator or response rate, and significant or key results.

3.5.7 Summary of this section

This section has described the methods used for the systematic review of evidence for factors that may be associated with self-testing and, because of a lack of evidence in this area, activities that were considered to be similar. The objectives of this part of the study were to add to the list of factors that may be associated with self-testing generated during the interviews so that an in-depth questionnaire to investigate factors associated with use could be designed.

Initially, the scope of the review was described, that is the activities, geographical area and time period covered. Searches were conducted during April 2007 for studies published from 1993 to 2007, but Medline was searched again in July 2008 and February 2010 for more recently published papers about self-testing. The search strategy was outlined, including the databases that were searched and the search terms. The criteria for including and excluding papers were reviewed. Finally, the methods used for assessing the quality of papers and extracting data were outlined.

The next section describes the design of the in-depth questionnaire from the information gathered during the interviews and systematic literature review, and the methods used for its distribution and analysis.

3.6 In-depth questionnaire survey

3.6.1 Overview of this section

Information from the interviews and systematic literature review was used to design an in-depth questionnaire to obtain information on factors that may be associated with self-test use. This was sent to willing respondents to the initial questionnaire who had and had not reported self-test use. Questionnaires sent to people who said that they had used self-tests included a section asking for details so that use could be confirmed, leading to a more accurate estimation of the prevalence of use and the determination of factors that were associated with confirmed use. This section reviews how the questionnaire was designed and piloted. The study population is then described and the process for sending out questionnaires is summarised. Methods used to enter data and check data entry are described. Finally, the analysis of data is outlined. This is divided into refining the prevalence of self-test use and determining factors associated with use.

3.6.2 Design of in-depth questionnaire

Interviews were conducted with 23 respondents to the initial questionnaire who reported self-test use. These interviews, supplemented by the systematic literature review, informed the design of an in-depth questionnaire (appendix 27).

3.6.2.1 Factors associated with self-test use

The original objective of the in-depth questionnaire had been to investigate factors that may be associated with self-test use. Results from the interviews and the systematic literature review were collated and a set of questions to describe factors that were potentially associated with self-test use were developed. The full rationale for including each question is described after the results of the interviews and systematic review have been presented, in section 4.5 of the results chapter.

3.6.2.2 Self-test use

It became clear during the interviews that some people who had indicated self-test use on the initial questionnaire had only actually used those tests with the involvement of a clinician. The original objectives of the in-depth questionnaire were, therefore, extended to include confirmation of self-test use reported on the initial questionnaire. In-depth questionnaires sent to people who had reported the use of self-tests (excluding pregnancy tests) and/or tests for high BP on the initial questionnaire included a separate section for each of these tests asking how it had been obtained and why it had been used (figure 2). Use was considered relevant as long as no clinician was involved before the test was used. If the respondent indicated on the in-depth questionnaire that either “The test was given to me by a doctor or nurse to use at home” or “The test was suggested to me by a doctor or nurse”, the test use was excluded.

Figure 2: Questions about self-test use from the in-depth questionnaire (continued on next page).

SECTION 2: In the last questionnaire, you said that you had used a self-test for urine infection (or cystitis or bladder infection). This section asks about this.

In the first column, please tell us about the times you used this self-test in the last 12 months.
In the second column, please tell us about the times you used this self-test more than 12 months ago.
In the last column, please tell us about the times you used this self-test but you're not sure when you did so.

1 How did you get hold of this self-test? **Please fill in circles for all the options that apply to you in every column that applies to you.**

	In the last 12 months	More than 12 months ago	Not sure when
The test was given to me by a doctor or nurse to use at home	O	O	O
I bought the test over the internet to use at home	O	O	O
I bought the test from a pharmacy or chemists to use at home	O	O	O
I paid to have the test done at a pharmacy or chemists	O	O	O
I had the test done for free at a pharmacy or chemists	O	O	O
I used testing equipment that was available at my work	O	O	O
I used a friend's or relative's testing equipment	O	O	O
Other – please say how________________	O	O	O

If either of these statements were marked for a time period, the test use in that period involved a healthcare professional and, therefore, was not valid self-test use.

Free text was also reviewed to determine whether it indicated involvement of a healthcare professional.

2 Why did you use this self-test? **Please fill in circles for all the options that apply to you in every column that applies to you.**

	In the last 12 months	More than 12 months ago	Not sure when
The test was easily available	O	O	O

I was curious	O	O	O
I like to do routine checks on my health	O	O	O
I wanted to reassure myself that I was well	O	O	O
I had some symptoms and wanted to get a diagnosis	O	O	O
I have a family risk of the condition	O	O	O
I have a higher risk of the condition for other reasons	O	O	O
I didn't want to bother the doctor	O	O	O
It was easier and / or more convenient than visiting the doctor	O	O	O
I was embarrassed to go to the doctor	O	O	O
I didn't think it was suitable to go to the doctor about this	O	O	O
I wanted evidence to justify going to the doctor	O	O	O
I'd been to a doctor but he / she didn't test me or solve the problem	O	O	O
The test was suggested to me by a doctor or nurse	O	O	O
Other – please say why_______________________________	O	O	O

3.6.3 Pilot of in-depth questionnaire

Questions on the in-depth questionnaire were organised in what was felt to be the most logical order. The questionnaire was then piloted with non-academic staff members from and two lay advisers to the Department of Primary Care Clinical Science at the University of Birmingham to assess comprehension and ease of completion. This resulted in simplification of the explanation for completing the health locus of control section of the questionnaire (section 8 of the final in-depth questionnaire reproduced in appendix 27).

Eleven interviewees were also asked to complete the questionnaire to assess comprehension and ease of completion, and to determine whether the section that aimed to obtain details of self-test use accurately recorded use, that is as described during the interviews. The interviewees were sent the questionnaire with a covering letter (appendix 28) plus a short reply slip (appendix 29) that asked how long it took to complete the questionnaire, how easy or difficult this was, whether any particular questions were difficult to complete, and for any other comments.

Eight interviewees returned the reply slip and a completed questionnaire. Four said it took less than 15 minutes to complete the questionnaire, three said it took about 20 minutes, and the other person said it took about 30 minutes. Seven of them said the questionnaire was fairly easy to complete and the other interviewee said it was very easy. Only two people had difficulty with particular questions. One felt that the question about long-term illness was ambiguous, which led to the question being split into two parts (as in question 3 of section 1 of the final in-depth questionnaire reproduced in appendix 27). The other interviewee's comments related to the pilot section about self-test use, which is shown in figure 3. She felt that it was difficult to say how many times she had used a self-test because she did so fairly frequently. This question was, therefore, removed as it was not needed to confirm use.

In response to the second and third questions of the pilot section about self-test use (figure 3), three interviewees marked time periods that did not agree, two of them in one of their two self-test sections and one in the only self-test section. One of them, for example, marked "Within the last 12 months" for the second question about when they had used the self-test but then marked that they had accessed the test in one way "Within the last 12 months" and in another way "More than 12 months ago" for the third question. For this person and one of the other two interviewees, the responses to the third question about how they had got hold of the test accurately reflected the descriptions given at interview, and all of the other interviewees indicated how tests had been accessed and why they had been used in line with descriptions given at interview. As a result, the separate question about when tests had been used was also taken out and interviewees were simply asked to indicate how they had got hold of tests and why they had used tests and the time periods to which this related. The accompanying text about how to complete the section was also made more explicit. The amended section in shown in figure 4.

Figure 3: Questions about self-test use from the pilot version of the in-depth questionnaire sent to interviewees.

SECTION 2: In the last questionnaire, you said that you had used a self-test for urine infection (or cystitis or bladder infection). This section asks for some more information about this.

1 How many times have you used this self-test? **Please write the number in the box.**

[ ] **times**

2 When did you use this self-test? **Please fill in circles for all the options that apply to you.**

Within the last 12 months	More than 12 months ago	Not sure when
O	O	O

3 How did you get hold of this self-test? **Please fill in circles for all the options that apply to you in each column.**

	Within the last 12 months	More than 12 months ago	Not sure when
I bought the test over the internet to use at home	O	O	O
I bought the test from a pharmacy or chemists to use at home	O	O	O
I paid to have the test done at a pharmacy or chemists	O	O	O
I had the test done for free at a pharmacy or chemists	O	O	O
I used testing equipment that was available at my work	O	O	O
I used a friend's or relative's testing equipment	O	O	O
Other – please say how ____________________	O	O	O

4 Why did you use this self-test? **Please fill in circles for all the options that apply to you.**

- O The test was easily available
- O I was curious
- O I like to do routine checks on my health
- O I wanted to reassure myself that I was well
- O I had some symptoms and wanted to get a diagnosis
- O I have a family risk of the condition
- O I have a higher risk of the condition for other reasons
- O I didn't want to bother the doctor
- O It was easier and / or more convenient than visiting the doctor
- O I was embarrassed to go to the doctor
- O I didn't think it was suitable to go to the doctor about this
- O I wanted evidence to justify going to the doctor
- O I'd been to a doctor but he / she had not tested me or sorted out the problem
- O Other – please describe below

____

Figure 4: Questions about self-test use from the in-depth questionnaire following the input of interviewees.

SECTION 2: In the last questionnaire, you said that you had used a self-test for urine infection (or cystitis or bladder infection). This section ask for some more information about this.

Please fill in circles for all the options that apply to you in every column that applies to you.
In the first column, please tell us about any times that you used this self-test in the last 12 months.
In the second column, please tell us about any times that you used this self-test more than 12 months ago.
In the last column, please tell us about any times that you're not sure when you used this self-test.

1 How did you get hold of this self-test?	In the last 12 months	More than 12 months ago	Not sure when
I bought the test over the internet to use at home	O	O	O
I bought the test from a pharmacy or chemists to use at home	O	O	O
I paid to have the test done at a pharmacy or chemists	O	O	O
I had the test done for free at a pharmacy or chemists	O	O	O
I used testing equipment that was available at my work	O	O	O
I used a friend's or relative's testing equipment	O	O	O
Other – please say how________________________________	O	O	O

2 Why did you use this self-test?	In the last 12 months	More than 12 months ago	Not sure when
The test was easily available	O	O	O
I was curious	O	O	O
I like to do routine checks on my health	O	O	O
I wanted to reassure myself that I was well	O	O	O
I had some symptoms and wanted to get a diagnosis	O	O	O
I have a family risk of the condition	O	O	O
I have a higher risk of the condition for other reasons	O	O	O
I didn't want to bother the doctor	O	O	O
It was easier and / or more convenient than visiting the doctor	O	O	O
I was embarrassed to go to the doctor	O	O	O
I didn't think it was suitable to go to the doctor about this	O	O	O
I wanted evidence to justify going to the doctor	O	O	O
I'd been to a doctor but he / she didn't test me or solve the problem	O	O	O
Other – please say why________________________________	O	O	O

The questionnaire was then initially sent to a restricted number of eligible subjects (n=89) and the following final changes were made to sections about factors that may be associated with self-test use before the remaining eligible subjects were mailed (as shown in the final version of the in-depth questionnaire in appendix 27). A faint line was added to question 3 of section 1 to clearly separate the two parts of the question. The first response option for questions 2 to 4 in section 3 was changed from "More than five days a week" to "Five days a week or more" so that all possibilities were covered. In line with other questions, the response options for questions 1 and 2 of section 5 and for the health locus of control section (section 8) were switched around so that they ran from positive options (three or more times and strongly agree respectively) on the left to negative options (not sure and strongly disagree respectively) on the right. Professor Ken Wallston, who designed the health locus of control scale, felt that this would not affect the validity of the scores [107].

Finally, the following changes were made to the section collecting details of self-test use (as shown in the final version of the section in figure 2). Rather than leaving respondents to mark the "Other" option and add free text if a clinician had been involved, it was felt that a more accurate and complete confirmation of self-test use would be obtained if explicit statements were added – "The test was given to me by a doctor or nurse to use at home" to the question about how the person had got hold of the self-test and "The test was suggested to me by a doctor or nurse" to the question about why the person had used the self-test.

3.6.4 Sample size

Factors associated with self-care were used to calculate a likely sample size for the multivariable analysis of factors that predict use of self-tests (section 3.6.9.5). A Spanish study found that self-medication was more prevalent among people who lived alone [108]. About 15% of adults aged 16 years or older lived alone in 2001 [109, 110]. If 15% of people who had not used a self-test also lived alone, it was estimated that data from 207 people who had used self-tests and 207 people who had not done so would detect a doubling of the odds of living alone among people who had used a self-test with 80% power and 5% significance [75].

3.6.5 Study population

The initial questionnaire sent to people from the final four practices asked if they would be willing to receive a second in-depth questionnaire. People were excluded if the sex and/or age (+/- two years) given on the initial questionnaire did not match the practice records, indicating that they were not the intended recipient.

3.6.6 Questionnaire mailing

The in-depth questionnaire was then sent to the remaining respondents with a covering letter (appendix 30) and prepaid envelope from December 2007 to March 2008. One reminder letter (appendix 31) with a replacement questionnaire and prepaid envelope was sent to non-responders after three to five weeks.

3.6.7 Data entry

Data entry was done by hand into an Access table using a front end form. For the sections of the questionnaire that investigated factors that may be associated with self-test use, data entry was done by six people, including the author. Data from these sections for about 15% of randomly selected questionnaires (n=241) were double-entered into a separate table by one of three people, including the author, who was different to the person who had originally entered the data. Data entry clerks were asked to keep a record of any data items where they had difficulty and these were reviewed by the author who made a final decision and amended the relevant single or double entry tables. The single and double entry tables were then compared in Access using multiple queries.

For sections of the in-depth questionnaire that collected details of self-test use, data was entered into a separate table to the rest of the questionnaire as respondents may have completed more than one of these sections. Data entry was done by the author, and data from about 10% of randomly selected sections (n=65) from 50 questionnaires were double-entered by another person. Again, this person was asked to keep a record of any data items where she had difficulty making a decision and these were reviewed by the author who amended the relevant single or double entry table. The single and double entry tables were then checked in Access using multiple queries.

3.6.8 Data analysis: refinement of the prevalence of self-test use

To calculate the refined crude prevalence of test use, the number of people who gave answers that indicated that they had actually used the test without the involvement of a clinician was divided by the number of people from the final four practices who returned the initial questionnaire and had been eligible for inclusion in the initial prevalence estimate (see section 3.3.8). This was done for each self-test and test for high BP separately, and combined analyses were conducted for any self-test excluding tests for high BP and any self-test plus tests for high BP to enable comparison with other published data.

These estimates were directly standardised to the population of England and Wales in 2006 [86, 87]. Sex- and age-specific rates of use were multiplied by the number of the standard population in the relevant age group and then summed to give the estimated total number of users in England and Wales. This was divided by the total population to give the directly standardised prevalence. Ninety five percent CIs were calculated [87].

An exploratory analysis was also conducted. This involved assuming that everyone who had been eligible for inclusion in the initial prevalence estimate and who reported use on the initial questionnaire but who did not consent to, was not eligible for, or did not respond to the in-depth questionnaire had the same sex- and age-specific rates of confirmed use as eligible responders to the in-depth questionnaire.

3.6.9 Data analysis: factors associated with self-test use

3.6.9.1 Outcome variable

The outcome variable was whether the respondent had ever used or never used a self-test without clinical involvement. Individuals who reported no self-test use on the initial questionnaire were categorised as never having used a self-test. Individuals who reported self-test use on the initial questionnaire were recategorised as never having used a self-test or having used a self-test depending on the answers they provided about how the self-test(s) had been obtained and why the self-test(s) had been used, as described in section 3.6.2.2.

3.6.9.2 Explanatory variables

Table 2 lists the explanatory variables, their type and origin. Most originated from the in-depth questionnaire, but three (ethnic group, self-rated health and employment status) came from the initial questionnaire. Respondents were also assigned an IMD score and further details of how this was done are provided in section 3.6.9.2.2. For some variables, answers provided on the in-depth questionnaire were manipulated to generate a score and further details are provided in sections 3.6.9.2.3 to 3.6.9.2.8. For some categorical variables, categories were grouped, where no-one in that category had used a self-test or where the category included less than about 30 people, and it is indicated where this has been done in the results section.

Table 2: Explanatory variables used in the determination of factors that were associated with self-test use.

Variable	Type	Source
Background information		
Age	Numerical	In-depth questionnaire [a] (initial if blank), section 1, question 1
Sex	Categorical	In-depth questionnaire (initial if blank), section 1, question 2
Ethnic group	Categorical	Initial questionnaire [b], section 1, question 3
Index of multiple deprivation score	Numerical	Derived from respondent's postcode
Index of multiple deprivation rank	Numerical	
Index of multiple deprivation quartile	Numerical	
Qualifications	Categorical	In-depth questionnaire, section 1, question 5
Worked as a health professional	Categorical	In-depth questionnaire, section 1, question 4
Employment status	Categorical	Initial questionnaire, section 1, question 5
Knowledge and views of self-tests		In-depth questionnaire, section 2
Confidence using self-test	Categorical	Question 1
Knowledge of any tests listed	Numerical	Question 2
Knowledge of tests listed except pregnancy test	Numerical	
Knowledge of tests listed except test for high blood pressure	Numerical	
Knowledge of tests listed except pregnancy test or test for high blood pressure	Numerical	
Habits and lifestyle		In-depth questionnaire, section 3
Smoking	Categorical	Question 1
Exercise	Categorical	Question 2
Fruit and vegetables	Categorical	Question 3
Internet use	Categorical	Question 4

[a] The in-depth questionnaire is shown in appendix 27.

[b] The initial questionnaire is shown in appendix 11.

Table continued on next page

Variable	Type	Source
Knowledge of health recommendations		In-depth questionnaire, section 4
Recommendation about fruit and vegetables	Categorical	Derived from question 1
Recommendation about days of exercise	Categorical	Derived from question 2
Advice about health problems		In-depth questionnaire, section 5
Health advice from anyone listed	Numerical	Derived from question 1
Health advice from lay person	Numerical	
Health advice from health professional	Numerical	
Health advice from complementary therapist	Numerical	
Information about health problems		In-depth questionnaire, section 5
Health information from any source listed	Numerical	Derived from question 2
Health information from any source listed except NHS Direct	Numerical	
Health information from NHS Direct	Numerical	
Health status		
Self-rated health during last 12 months	Categorical	Initial questionnaire, section 1, question 4
Limiting long-term illness	Categorical	In-depth questionnaire, section 1, question 3
SF-8 Physical Health Measure	Categorical	Derived from in-depth questionnaire, section 6, questions 1 to 8
SF-8 Mental Health Measure	Categorical	
Thoughts about how to stay healthy and future illnesses		In-depth questionnaire, section 6
Things to stay healthy	Categorical	Question 11
Future illnesses	Categorical	Question 12

Table continued on next page

Variable	Type	Source
Views about health checks and medical tests		In-depth questionnaire, section 7
Medical tests are reassuring	Categorical	Question 1
Curious about health	Categorical	
Like routine health checks	Categorical	
Medical tests cause anxiety	Categorical	
Only go to doctor if symptoms	Categorical	Question 2
Need symptoms for test	Categorical	
Do not like to bother doctor	Categorical	
Only go to doctor if severe or serious symptoms	Categorical	
Evidence to justify a visit to the doctor	Categorical	
Embarrassed to tell doctor about personal problems	Categorical	
Happy to ask doctor for a check-up	Categorical	
Confident doctor would do test	Categorical	
Access to the GP		In-depth questionnaire, section 7
Appointment as soon as would like	Categorical	Question 3
Appointment at suitable time	Categorical	Question 4
Travel to GP surgery	Categorical	Question 5
Satisfaction with healthcare		In-depth questionnaire, section 7
Satisfaction with GP consultations	Categorical	Derived from question 6
Satisfaction with own care	Categorical	Question 7
Satisfaction with other's care	Categorical	Question 8
Health locus of control		In-depth questionnaire, section 8
Internal control	Numerical	Statements 5, 10, 12, 16, 17 & 21
Chance	Numerical	Statements 6, 8, 13, 15, 19 & 20
Powerful others	Numerical	Statements 7, 9, 11, 14, 18 & 22
Health value	Numerical	Statements 1 to 4

3.6.9.2.1 Age and sex

Age and sex were taken from questions 1 and 2 of section 1 of the in-depth questionnaire (page 1 of appendix 27) except for one person who did not enter their sex and nine people who did not enter their age. For these 10 people, the missing data were taken from their initial questionnaires.

3.6.9.2.2 Index of Multiple Deprivation

Respondents were assigned an IMD 2007 score based on their area of residence [81, 111]. The IMD 2007 brings together 37 indicators chosen to cover different aspects of deprivation: income, employment, health and disability, education, skills and training, barriers to housing and services, living environment and crime [81]. These have been weighted and combined into a single score for each of 32482 small lower super output areas in England [80, 81]. Only about 1000 to 3000 people live in each of these areas, which are usually smaller than wards, thereby allowing the identification of small pockets of deprivation [81, 112]. The scores allow each area to be ranked relative to one another according to their level of deprivation. Subjects were also assigned an IMD rank and quartile. The IMD rank is the rank of the score for the relevant super output area among all super output areas in England. Quartiles were created by dividing the super output areas in England into four equally sized groups based on their rank and then assigning respondents to a quartile based on their super output area of residence.

3.6.9.2.3 Knowledge of self-tests

Respondents were asked if they knew whether any of a list of named self-tests or any other self-test was available before they received the initial questionnaire (question 2 of section 2 on page 2 of appendix 27). This was converted into a score by adding one for each test that was marked but nothing for “No” or “Don’t know”. An overall score and scores excluding pregnancy and high BP tests were then calculated. Respondents who left all the answers blank were treated as having a missing score.

3.6.9.2.4 Advice about health problems

Respondents were asked how often during the last 12 months they had asked for advice about health problems from a range of lay and professional people (question 1 of section 5 on page 4 of appendix 27). This was converted into scores for advice from (1) a health professional (GP or family doctor, general practice nurse, hospital doctor, hospital nurse, pharmacist or chemist), (2) a lay person (husband or wife or partner, other family member, friend, work colleague), and (3) any of these people or a complementary therapist or another person stated by the respondent. This was done by adding two points if “Three or more times” was marked for a relevant person, one point if “Once or twice” was marked for a relevant person, but zero points if “Not at all” or “Not sure” was marked. Respondents who left all the components blank were treated as having a missing score.

3.6.9.2.5 Information about health problems

Respondents were asked how often during the last 12 months they had sought information about health problems from a range of sources (question 2 of section 5 shown on page 4 of appendix 27): NHS Direct, the internet or websites, CDs or DVDs, books, newspaper or magazine articles, radio or television programmes, adverts in newspapers or magazines, adverts on radio or television, adverts in pharmacies or chemist, or another source specified by the respondent. NHS Direct was considered to be different from the other sources listed as the information comes directly from approved conventional health professionals. An overall score and a score excluding NHS Direct were, therefore, calculated. This was done by adding two points if “Three or more times” was marked for a relevant source, one point if “Once or twice” was marked for a relevant source, but zero points if “Not at all” or “Not sure” was marked. Respondents who left all the answers blank were treated as having a missing score.

3.6.9.2.6 Satisfaction with GP consultations

The in-depth questionnaire included eight questions about respondents’ experiences of consultations with their doctor adapted from the General Practitioner Assessment Questionnaire (GPAQ) [113] (question 6 of section 7 on page 8 of appendix 27). The reply options were slightly modified: the “Excellent” option offered in the GPAQ was omitted to give a balanced range of possible positive and negative responses in line with other questions on the questionnaire. Answers to these questions were combined to give a score by adding five for “Very good”, four for “Good”, three for

"Fair", two for "Poor", one for "Very poor", and three for "Don't know". It was decided that the same score should be assigned to "Don't know" and "Fair" as both are neutral answers. It was also decided that if one or two of the eight answers were missing, the total score would be imputed by calculating the average for the given answers and then multiplying by eight. If more than two answers were missing, the score was treated as missing.

3.6.9.2.7 Health locus of control

The in-depth questionnaire also considered whether respondents perceived health to be controlled internally, by powerful others or by chance [114] (section 8 on page 9 of appendix 27). Respondents were asked whether they strongly agreed, moderately agreed, slightly agreed, slightly disagreed, moderately disagreed or strongly disagreed with six statements related to each of these loci of control. Scores were generated for each loci by adding from six for "Strongly agreed" down to one for "Strongly disagreed" for each of the relevant six statements [115]. In line with the guidance given [116], if one or two of the six answers were missing, the total score was imputed by calculating the average for the given answers and then multiplying by six. If more than two answers were missing, the score was treated as missing.

3.6.9.2.8 Health value

Respondents were asked whether they strongly agreed, moderately agreed, slightly agreed, slightly disagreed, moderately disagreed or strongly disagreed with four statements related to the value that they placed upon their health [117] (section 8 on page 9 of appendix 27). These were included as it is argued that health locus of control cannot be properly interpreted unless account is taken of the value placed on health by an individual [118, 119]. A score was generated by adding six for answers showing most value for health down to one for answers showing least value for health. If one of the four answers was missing, the total score was imputed by calculating the average for the given answers and then multiplying by four. If more than one answer was missing, the score was treated as missing.

3.6.9.3 Descriptive analysis of respondents

Initially, a simple descriptive analysis was conducted for each explanatory variable, that is the proportion of respondents with each possible option. This was compared with population-based data from other sources, where available.

3.6.9.4 Univariate analysis

3.6.9.4.1 Null hypotheses and p-values

Simple univariate analyses were then used to explore the relationship between the outcome variable (self-test use) and each explanatory variable. Appropriate statistical tests were used to test the null hypothesis, either that the mean or median value of a numerical explanatory variable was the same among people who had and had not used self-tests, or that the proportion of people who had used a self-test was the same in each category of an explanatory variable. Statistical tests look for evidence against a null hypothesis, that the effect of interest is zero [120]. The tests calculate the probability, if the null hypothesis were true, of getting an effect as large as or larger than was observed. This probability is called the p-value: the smaller the p-value, the lower the probability and the stronger the evidence against the null hypothesis [121]. Conventionally, a cut-off is chosen for a significant result (usually 0.05) and the null hypothesis is rejected if the p-value is smaller than this [122].

3.6.9.4.2 Categorical explanatory variables

For categorical explanatory variables with two categories, the chi-squared (chi^2) test was used to test the null hypothesis that the proportion of people who had used a self-test was the same in each category: if the p-value was below the cut-off set for significance (see section 3.6.9.4.4), the observed difference in the proportions of people who had used a self-test between the two categories was greater than that expected by chance and the null hypothesis was rejected [123]. For categorical explanatory variables with more than two categories, the chi^2 test was used to test the null hypothesis that the use of self-tests was equally common in all of the categories under investigation: if the p-value was below the cut-off set for significance (see section 3.6.9.4.4), the observed differences in the proportions of people who had used a self-test between the categories was greater than that expected by chance and the null hypothesis was rejected [124]. Where there were more than two categories and there was an order to those categories, for example good, fairly good and not good for self-rated health, the chi^2 test for trend was used to assess whether there was an increasing or decreasing trend in the proportions of people who had used a self-test across the categories [125]. All analyses were carried out using Stata (release 11) [126].

3.6.9.4.3 Numerical explanatory variables

For numerical explanatory variables, the range and mean and median values were compared for people who had and had not used self-tests. The mean (or average value) takes each individual observation into account, but the median was also calculated because high or low outliers can make the mean unrepresentative of most of the data [127]. Dissimilar mean and median values would indicate that the data was not normally distributed [127] and that a non-parametric test comparing median rather than mean values would, therefore, be more appropriate to consider whether there was a significant association. The two-sample t-test was used to test the null hypothesis that the mean value of the variable under investigation was the same among people who had and had not used a self-test: if the p-value was below the cut-off set for significance (see section 3.6.9.4.4), it was very unlikely that the mean values were the same in the two groups and the null hypothesis was rejected [128]. The Wilcoxon rank sum test was used to test the hypothesis that the median value of the variable under investigation was the same among people who had and had not used a self-test: if the p-value was below the cut-off set for significance (see section 3.6.9.4.4), it was very unlikely that the median values were the same in the two groups and the null hypothesis was rejected [129]. All analyses were carried out using Stata (release 11) [126].

3.6.9.4.4 Correction for multiple comparisons

A type I error occurs when a null hypothesis that is true is incorrectly rejected [130]. For a null hypothesis that is true, when the cut-off for a significant result is set as

0.05, the probability of coming to a not significant, that is correct, conclusion is 0.95 and the probability of coming to a significant, that is incorrect, conclusion is 1-0.95=0.05 [131]. Incorrect conclusions, however, become more likely as more hypotheses are tested. When 20 independent true null hypotheses are tested, the probability that none will be significant is 0.95^{20}=0.36, giving a probability of 1-0.36=0.64 of getting at least one significant result even though the null hypothesis is true in all 20 instances [121]. The probability of making one or more type I errors in a set (or family) of tests is called the family-wise type I error rate [132].

The Bonferroni correction allows for the increased probability of type I errors when a family of significance tests are being conducted by holding the family-wise error rate to a preselected value [133, 134]. If c is the number of comparisons in the family, Bonferroni states that, in order to hold the overall family-wise type I error rate to the nominated significance cut-off of α, each separate test will only be declared significant if the p-value is less than α divided by c [132, 134].

The conventional value of 0.05 was chosen for the significance cut-off [122], but the family of tests to which the Bonferroni correction should be applied also needed to be defined before it could be used [132]. It is generally accepted that unrelated hypotheses, for example in terms of content, should be treated separately, that is placed in different families [132]. Based on these considerations, it was decided that a family would be defined as those explanatory variables that arose from each section of the questionnaire, for example background information. The rationale for this was that variables within each section are related, whereas those from different sections concern separate behaviours, views or experiences.

A type II error occurs when a null hypothesis that is false is incorrectly accepted, that is a significant result is incorrectly deemed to be non-significant [130]. It has also been recommended that the decision about what constitutes a family should be based, at least in part, on the relative importance of type I versus type II errors [132]. This is because the correction depends upon the size of the family: the family-wise error rate is held at the nominated significance cut-off (α), but more tests mean that α is divided by a larger number and, therefore, that the significance cut-off for individual tests is lower. This lowering of the cut-off for a significant result for individual tests reduces the risk of type I errors but increases the likelihood of type II errors. It has been suggested that higher cut-offs for p-values to reduce the risk of type II errors may be appropriate in discovery-oriented studies where it is important not to miss a truly significant result [135]. Given that this was the nature of this study, grouping the variables in sections seemed appropriate. This is because it created a balance between reducing the risk of type I errors, by still applying a correction for multiple comparisons, but minimising the chance of type II errors, by applying a limit on the size of the family to which the correction would be applied and, therefore, the number by which α would be divided to calculate the significance cut-off for individual tests.

3.6.9.5 Multivariable analysis

A forward stepwise multiple logistic regression analysis was then used to identify those variables that together best predict self-test use [136]. This involves initially fitting an “empty” model [137, 138]. The most significant excluded term, based on the level specified, is then added and the step is repeated. The model then removes the least significant included term if it has become non-significant based on the level specified. These steps are repeated until neither is possible. Stepwise procedures are considered useful in studies where the outcome being studied is relatively new and the important covariates may not be known as a stepwise selection procedure can provide a fast and effective way to screen a large number of variables [139]. Stepwise procedures tend to give an over-optimistic impression, for example the p-values will be too small, and it has been suggested, therefore, that it is advisable to use a higher p-value than usual [140]. The p-values specified for inclusion and exclusion were, therefore, 0.1 and 0.2 respectively.

Initially, a forward stepwise multiple logistic regression analysis was carried out with all of the explanatory variables. It is considered important to distinguish between models that are aiming to be explanatory and predictive [141]. In the former situation, where the goal is to correctly characterise the relationship of each explanatory variable to the outcome variable, deciding on the correct variables to include in the analysis and their format is considered essential. For the predictive model, as in this situation, achieving a model that is accurate and performs well is considered to be more important than the number of variables entered into the model.

For comparison, forward stepwise multiple logistic regression analyses were carried out with the explanatory variables from each section of the in-depth questionnaire, for example background information (as shown in table 2). A further analysis was then conducted with the variables that were included in the final models arising from each of these analyses. It was felt that this would test the robustness of the analysis including all variables without selection and may give a model that included important factors from a fuller range of areas. All analyses were done using SPSS (release 17) [142] and checked using Stata (release 11) [126].

Various tests were used to assess the resulting models. The likelihood ratio chi^2 test was used to test the null hypothesis that the final model and a model with the constant only were the same [143, 144]: a low p-value ($p<0.05$) indicates that the null hypothesis should be rejected and that the final model is a significant improvement on a model with the constant only. The Hosmer Lemeshow test was used to assess the goodness of fit of the final model [145]. Respondents are placed in ten groups and the number of expected and observed self-tests users and non-users in each group are compared. The null hypothesis is that the observed and model-generated numbers of users are not significantly different: a high p-value ($p>0.05$) indicates that the null hypothesis should not be rejected, that is that the model-generated numbers of users in each group are not significantly different from the observed numbers. Finally, R^2 statistics (Cox & Snell and Nagelkerke) were used to assess the effect size, that is how useful the explanatory variables are in predicting the response variables [145]. Values closer to one indicate that the model is more useful. All these tests were performed in SPSS (release 17) [142] except the likelihood ratio chi^2 test, which was available from Stata (release 11) [126].

3.6.10 Summary of this section

Information from the interviews and systematic literature review was used to design an in-depth questionnaire to obtain details of self-test use reported on the initial questionnaire and information on factors that may be associated with use. This section reviewed the process for designing the questionnaire. The pilot and the changes made as a result were then outlined. The study population was described and the process for sending out questionnaires was summarised. The methods used to enter data and check data entry were described. Methods used for analysing data were divided into those used to refine the prevalence of self-test use, that is calculation of crude and age-standardised prevalence with 95% CIs, and those used to determine factors associated with use. For factors associated with use, the outcome variable, whether someone had actually used a self-test, and the explanatory variables were described. The analysis was then broken down into a descriptive analysis of explanatory variables among respondents, a univariate analysis to explore the association between the outcome and each explanatory variable, and multivariable forward stepwise regression analyses to determine the explanatory variables that best predict self-test use. The final section in this chapter summarises the methods chapter.

3.7 Summary of this chapter

In this chapter, the methods used for this study were fully described. Initially, the systematic search for self-tests available to buy via the internet was outlined. This informed the design of an initial questionnaire about whether people had used self-tests, and the methods used to undertake a population-based survey of adults using this questionnaire were described. The entry and analysis of data from these questionnaires were explained, leading to an initial assessment of the prevalence of self-test use. A sample of respondents who had used self-tests were then interviewed about their views and experiences, and methods used for this part of the study were outlined. The systematic review for evidence for factors that may be associated with the use of self-tests and, because of a lack of evidence about self-tests, similar activities was also described. This generated a list of factors that may be associated with self-test use. The processes of developing an in-depth questionnaire from this information and then sending this questionnaire to willing respondents to the initial questionnaire who had and had not reported self-test use were reviewed. Methods used to enter and analyse data from these questionnaires were outlined, leading to a more accurate estimation of the prevalence of self-test use and the determination of factors that together best predicted confirmed use. The next chapter details the results from each of these components.

4 RESULTS

4.1 Overview of results

This chapter presents the results of the various components of the study. The first section outlines the results of the systematic internet search for self-tests that were available to buy by UK adults. The second section describes the results of interviews with a sample of people who reported self-test use on the initial questionnaire. This part of the study was designed to describe people's experiences of self-test use and generate a list of factors that may predict use. The third section describes the results of the systematic search for evidence for factors that may be associated with self-test use, which added to the list of potential factors generated from the interviews. The fourth section brings the information from the interviews and systematic literature review together to inform the design of an in-depth questionnaire to describe self-test use and factors that may be associated with use. The penultimate section presents the prevalence of self-test use. The first part of this section details the results of the initial assessment of prevalence arising from the initial questionnaire. In the second part, the prevalence estimates are refined following confirmation or non-confirmation of self-test use with the in-depth questionnaire. The final section of the chapter then goes on to consider factors that predict self-test use using data derived from the in-depth questionnaire. Appendices 2 to 8 are the flowcharts for the different components of the study, which will be referred to throughout this chapter.

4.2 Range of self-tests available to buy in the United Kingdom

4.2.1 Overview of this section

This section details the results of the systematic internet search, which aimed to identify self-tests that were available to buy by adults in the UK in 2006. In April 2006, popular search engines (see section 3.2.2) were searched for eligible websites (see section 3.2.3 for eligibility criteria). Eligible websites were then searched in April and May 2006 for self-tests that could be sold to members of the UK public without involving a health professional, that detected a disease or condition that may need treatment or a risk factor for such diseases or conditions, and that required the user to take a sample and either process it themselves or send it to a laboratory with results returned directly to them. Details of eligible tests were then collected. The results of the systematic internet search have been published in a peer-reviewed journal and this paper is reproduced in appendix 9 [48].

4.2.2 Eligible websites

There were 277 unique websites returned by the search engines. Directories of websites, websites that were obviously not relevant, for example because they did not relate to healthcare, and websites that obviously met the exclusion criteria were immediately rejected. This left 42 websites that appeared relevant and that were, therefore, visited to determine if they should be included: 28 of them met the inclusion criteria and were not excluded (table 3). There were also 33 unique sponsored links returned by the search engines: five appeared relevant and all of them met the inclusion criteria and were not excluded (table 4).

Table 3: Numbers of websites returned by different search strategies during the systematic internet search [a].

	www.yahoo.co.uk			www.yahoo.com			www.google.co.uk			www.ask.co.uk			www.msn.co.uk			Total		
	Unique	Rel	Inc	Unique	Rel	Inc	Unique	Rel	Inc	Unique	Rel	Inc	Unique	Rel	Inc	Unique	Rel	Inc
Self test	20	0	0	20	0	0	20	0	0	17	0	0	17	1	1	61	1	1
Self diagnosis	18	1	1	18	0	0	18	0	0	17	0	0	19	1	1	65	1	1
Home test	20	10	5	20	11	6	18	5	2	20	10	7	16	9	8	63	27	19
Home diagnosis	17	0	0	17	0	0	14	0	0	16	1	0	16	0	0	55	1	0
Self test OR Self diagnosis OR Home test OR Home diagnosis	18	8	5	19	6	2	19	1	0	20	5	3	17	9	6	74	22	14
Total	86	14	8	87	13	6	70	5	2	83	12	8	82	20	16	277	42	28

[a] The table shows the number of unique, apparently relevant (Rel) and included (Inc) websites returned by different search engines searched with different search terms. Descriptions of the first 20 websites returned from each search were read. Directories of websites, websites that were obviously not relevant, for example because they did not relate to healthcare, and websites that obviously met the exclusion criteria were immediately rejected. The remaining apparently relevant (Rel) websites were visited to determine if they should be included (Inc).

Table 4: Numbers of sponsored links returned by different search strategies during the systematic internet search [a].

	www.yahoo.co.uk			www.yahoo.com			www.google.co.uk			www.ask.co.uk			www.msn.co.uk			Total		
	Unique	Rel	Inc	Unique	Rel	Inc	Unique	Rel	Inc	Unique	Rel	Inc	Unique	Rel	Inc	Unique	Rel	Inc
Self test	4	2	2	1	1	1	2	0	0	5	1	1	1	1	1	9	3	3
Self diagnosis	0	0	0	0	0	0	6	0	0	6	0	0	0	0	0	8	0	0
Home test	3	2	2	2	1	1	10	2	2	10	1	1	4	2	2	15	2	2
Home diagnosis	0	0	0	0	0	0	4	1	1	6	1	1	0	0	0	6	1	1
Self test OR Self diagnosis OR Home test OR Home diagnosis	2	0	0	1	0	0	9	2	2	7	1	1	0	0	0	13	2	2
Total	7	3	3	3	1	1	18	3	3	20	2	2	4	2	2	33	5	5

[a] The table shows the number of unique, apparently relevant (Rel) and included (Inc) sponsored links returned by different search engines searched with different search terms. Descriptions of sponsored links on the pages with the first 20 websites returned by each search were read. Directories of websites, websites that were obviously not relevant, for example because they did not relate to healthcare, and websites that obviously met the exclusion criteria were immediately rejected. The remaining apparently relevant (Rel) links were visited to determine if the websites should be included (Inc).

The search term “Home test” generated the most apparently relevant and included websites (27 relevant and 19 included out of 63 unique websites) (table 3), but the term “Self test” generated the most apparently relevant and included sponsored links (3 relevant and 3 included out of 9 unique sponsored links). The MSN search engine returned the most apparently relevant and included websites (20 relevant and 16 included out of 82 unique websites) (table 3), whereas Yahoo UK and Google returned the most apparently relevant and included sponsored links (3 relevant and 3 included for both out of 7 and 18 unique sponsored websites respectively).

Overall, including websites and sponsored links returned by search engines, the systematic internet search identified 306 unique websites, 46 of which appeared relevant. Fourteen websites were excluded (table 5): three only gave descriptions of products, it was not possible to order tests from the UK from seven of them, three required physician approval or detailed medical information, and one was simply not available. The 32 websites that met the inclusion criteria (table 6) were run by 19 retailers: nine were based in the UK, seven in the USA, one in The Netherlands, one in Taiwan, and one did not state where they were based.

Table 5: Apparently relevant websites that were then excluded during the systematic internet search.

Website	**Excluded**	**Reason**
www.personal-screening.com	Excluded	Description of products only
www.promolife.com	Excluded	Description of products only
www.vielle.co.uk	Excluded	Description of products only
www.athometests.com	Excluded	Not able to order tests from the UK
www.healthgoods.com	Excluded	Not able to order tests from the UK
www.homeaccess.ashastd.org	Excluded	Not able to order tests from the UK
www.homeaccess.com	Excluded	Not able to order tests from the UK
www.home-hepatitis-test-access.com	Excluded	Not able to order tests from the UK
www.hometestmed.com	Excluded	Not able to order tests from the UK
www.testcountry.com	Excluded	Not able to order tests from the UK
www.hiv-home-test.net	Excluded	Requires medical information
www.home-thyroid-tsh-test.com	Excluded	Requires physician approval
www.psa4-prostate-cancer-test.com	Excluded	Requires physician approval
www.gwaymedical.com	Excluded	Website not available

Table 6: Included websites identified during the systematic internet search.

Website	Retailer	Based in
www.accessdiagnostics.co.uk www.drugtest.freeserve.co.uk www.homescreen.co.uk www.valuemed.co.uk	Access Diagnostic Tests UK	UK
www.ezdetect.com	Biomerica Inc	USA
www.craigmedical.com	Craig Medical Distribution Inc	USA
www.ddrthom.com	DrThom	UK
www.hiv-glucose-testyourself.com	Hanson Meditech	Not stated
www.homedrug-test.com www.homehealthtesting.com	Home Health Testing	USA
www.home-menopause-test.com www.hormonecheck.com	HormoneCheck.com	USA
www.livingaidsonline.co.uk	Livingaidsonline	UK
www.med-direct.com	Med-Direct International	UK
www.meditests.com	Medimpex United Inc	USA
www.mirates.co.uk	MiraTes	The Netherlands
www.allmedicaltests.com www.drug-test.jumora.net	MUI – drug-test.jumora.net	USA
www.pharmacy2u.co.uk	Pharmacy2U	UK
www.preventx.co.uk	Preventx	UK
www.selfdiagnosis.co.uk	SelfDiagnosis Ltd	UK
www.colon-fecal-occult-blood-test.com www.home-cholesterol-test-kit.com www.home-drug-test-kits.com www.home-health-test-kits.com www.home-menopause-test-kits.com www.male-sperm-infertility-test.com www.testsymptomsathome.com	TestMedicalSymptoms@Home	USA
www.testnow.co.uk	Testnow Ltd	UK
www.onestephivtest.com	Tyson Bioresearch Inc	Taiwan
www.allergy.co.uk www.yorktest.com	YorkTEST	UK

4.2.3 Eligible self-tests

Details of 167 self-tests were collected (table 7), but some self-tests were sold by more than one retailer and there were 104 unique tests. These tests relate to 24 named conditions, including cancers (e.g. tests for faecal occult blood and prostate specific antigen), chronic conditions (e.g. tests related to diabetes and cardiovascular disease), acute infections (e.g. tests for urinary and sexually transmitted infections), and serious chronic infections (e.g. tests for HIV-infection). Self-tests related to male and female infertility and allergies were also available. Some self-tests were for more than one condition, for example chlamydia and gonorrhoea.

The self-tests required a variety of samples, most commonly blood, stool, urine, vaginal or cervical discharge or secretions, and semen (table 7). A finger prick blood sample obtained with a lancet was used for tests for allergy, anaemia, cardiovascular disease, diabetes, glandular fever, HIV-infection, prostate disorders and stomach disorders. Tests for bowel disorders required stool samples obtained by placing a pad in the toilet, by wiping, or with a stick. Urine samples were used for tests for chlamydia, gonorrhoea, diabetes, kidney and urinary tract disorders including infection, the menopause, osteoporosis, reduced fertility, and multiple conditions. Swabs, tampons, gloves and panty liners were used to obtain samples from the vagina or cervix for amniotic fluid, bacterial vaginosis, chlamydia, group B streptococcus, human papillomavirus, and gonorrhoea. Semen was used to test for reduced fertility. Samples were processed at home with results available in minutes or sent to laboratories with results returned by email or post after several days.

Prices per self-test and condition, including postage or shipping where this was available, ranged from less than one pound for a variety of urine tests or a test for vaginal infection, to £76 for a test for human papillomavirus (table 7). Over 80% (n=86) of the 104 unique self-tests had a maximum price of less than £30.

Table 7: Self-tests identified during the systematic internet search.

Condition described as being related to the test	Sample required	Test described as detecting	Where processed	Cost per test or condition		Number of:	
				Min	Max	Tests identified	Unique tests
Allergy	Blood obtained with lancet	IgE	Home	£10	£12	13	6
	Blood obtained with lancet	IgE	Lab	£15	£31	6	3
Amniotic fluid leak	Obtained with panty liner	Amniotic fluid	Home	£4	£6	2	1
Anaemia	Blood obtained with lancet	Haemoglobin	Home	£11	£24	5	1
Bacterial vaginosis	Vaginal swab	pH/alkali amines	Home	£5	£9	1	1
Bowel disorders	Stool obtained with pad in toilet	Blood	Home	£1	£15	6	2
	Stool not otherwise stated	Blood	Home	£6	£6	1	1
	Stool obtained by wiping	Blood	Home	£3	£3	1	1
	Stool obtained with stick	Blood	Home	£5	£16	4	3

Table continued on next page

Condition described as being related to the test	Sample required	Test described as detecting	Where processed	Cost per test or condition		Number of:	
				Min	Max	Tests identified	Unique tests
Cardiovascular disease	Blood obtained with lancet	Triglycerides/total, HDL, LDL cholesterol	Lab	£17	£26	1	1
	Blood obtained with lancet	Total, HDL cholesterol	Home	£13	£23	7	3
	Blood obtained with lancet	Total cholesterol	Home	£3	£15	16	9
	Blood obtained with lancet	Homocysteine	Lab	£75	£75	1	1
Chlamydia	Cervical swab	Chlamydia-specific enzyme	Home	£15	£18	4	1
	Cervical swab/ urine	Chlamydia-specific enzyme/not stated	Home/ lab	£26	£26	1	1
	Urine	Chlamydia	Lab	£42	£61	4	2
	Urine	Not stated	Lab	£40	£40	1	1
Chlamydia/ gonorrhoea	Urine	Chlamydia/ gonorrhoea	Lab	£30	£38	2	1
	Urine	Not stated	Lab	£33	£36	2	1
Chlamydia/ group B strep	Urine/vaginal and anal swabs	Chlamydia/group B strep	Lab	£29	£29	1	1
Diabetes	Blood obtained with lancet	Glucose	Home	£3	£9	5	3
	Blood obtained with lancet	Ketones	Home	£2	£2	1	1
	Urine	Glucose	Home	<£1	£9	6	5
Glandular fever	Blood obtained with lancet	Antibodies	Home	£8	£8	1	1
Gonorrhoea	Urine	Gonorrhoea	Lab	£42	£61	4	2
HIV-infection	Blood obtained with lancet	Antibodies	Home	£9	£11	3	2
HPV	Obtained with tampon	HPV	Lab	£76	£76	1	1
HPV/chlamydia	Obtained with tampon	HPV/chlamydia	Lab	£45	£45	1	1

Table continued on next page

Condition described as being related to the test	Sample required	Test described as detecting	Where processed	Cost per test or condition		Number of:	
				Min	Max	Tests identified	Unique tests
HPV/chlamydia /gonorrhoea	Obtained with tampon	HPV/chlamydia/ gonorrhoea	Lab	£38	£38	1	1
Influenza	Nasal discharge swab	Influenza virus	Home	£14	£21	1	1
Kidney/urinary tract disorders	Urine	Protein	Home	<£1	<£1	1	1
Kidney disorders	Urine	Albumin	Home	£14	£14	1	1
	Urine	Albumin	Lab	£11	£11	1	1
Menopause	Urine	FSH	Home	£2	£14	14	11
Not stated	Urine	Ketones	Home	<£1	<£1	1	1
	Urine or saliva	pH	Home	<£1	<£1	1	1
Osteoporosis	Urine	Marker	Lab	£43	£49	2	2
Prostate disorders	Blood obtained with lancet	PSA	Home	£2	£17	5	4
	Blood obtained with lancet	PSA	Lab	£15	£28	1	1
Reduced fertility	Semen	Sperm quality	Home	£8	£32	11	2
	Semen/urine	Sperm quality/FSH	Home	£8	£8	1	1
	Urine	FSH	Home	£2	£15	5	2
Stomach disorders	Blood obtained with lancet	Exposure to h. pylori	Home	£10	£14	2	1
Thrush	Not stated	Not stated	Home	£12	£13	1	1
Urinary tract disorders	Urine	Blood	Home	<£1	<£1	1	1
UTI	Urine	Multiple parameters	Home	£4	£4	1	1
Vaginal infection	Obtained with panty liner	pH	Home	£6	£15	3	1
	Obtained with glove	pH	Home	<£1	<£1	1	1

Table continued on next page

Condition described as being related to the test	Sample required	Test described as detecting	Where processed	Cost per test or condition		Number of:	
				Min	Max	Tests identified	Unique tests
Multiple disorders	Urine	Multiple parameters	Home	<£1	£6	11	11
					Total	167	104

4.2.4 Summary of this section

This section presented the results of the internet search, which aimed to systematically identify self-tests that were available to buy by the UK public in 2006. This part of the study has demonstrated that a wide range of self-tests were available, many at a reasonable price. The search identified 104 unique self-tests related to 24 named conditions, including cancers, chronic conditions and infections. These self-tests required a variety of samples, including blood obtained using a lancet. The samples were processed at home with results available in minutes or sent to a laboratory with results returned to the individual by email or post. Prices per self-test and condition range from less than one pound to £76.

The initial questionnaire sent to people registered with general practices asked if they had ever used any of a list of self-tests informed by the internet search. The assessment of the prevalence of self-test use from the initial questionnaire is presented later in this chapter in section 4.6.2, alongside the refined estimate based on confirmation of use using the in-depth questionnaire. The next section describes the results of the interview survey, designed to gain a better understanding of self-test use and contribute to a list of factors that may be associated with use.

4.3 Interview survey

4.3.1 Overview of this section

This section details the results of interviews with 23 people who responded to the initial questionnaire saying that they had used self-tests. The objectives of these interviews were to gain a greater understanding of self-testing, for example how tests were accessed and what prompted people to use them, and to contribute to a list of factors that may be associated with self-test use. The published paper for this part of the study is included in appendix 16 [89].

Initial questionnaires sent to people registered with the first two general practices asked whether they were willing to be recontacted about taking part in an interview. This section describes the response rate among this group, the numbers and proportions of respondents who reported self-test use and who were willing to be contacted, reasons for excluding people and the number of people who were excluded, and the resulting potential number of interviewees. Responses to invites to interview are then detailed, leading to the final 23 interviewees.

Feedback from interviewees about summaries of interviews sent to them is reviewed to assist in the interpretation of the results. The interviewees themselves are then described, before their interpretation of the definition of self-testing from the initial questionnaire and their actual use of self-tests, as described during the interviews, are described. The emerging findings of the interviews are then outlined.

4.3.2 Study population

Questionnaires were received from 1592 (68%) people registered with the first two general practices and 1490 (64%) were completed (see flowcharts in appendices 2 and 3). Twenty two people had given a different sex and/or age than the general practice record (greater than +/- two years). As they did not appear to be the intended recipient, these people were excluded, leaving 1468 eligible respondents (see flowchart in appendix 3). Excluding pregnancy tests and tests for high BP, 188 people (13%) reported using a self-test and 114 (60%) of them were willing to be contacted about talking to a researcher (see flowchart in appendix 5). One questionnaire was received after the invitations to interview had been mailed and 10 people were excluded (see flowchart in appendix 5): three marked “other” self-test but did not specify a test, three added free text that contradicted their willingness to be contacted, three gave ages on the initial questionnaire that were (up to two years) different to the age provided by the practice, and one did not supply age or sex on the initial questionnaire. This left 103 possible interviewees (see flowchart in appendix 5).

In the first batch of invites sent out (see flowchart in appendix 6), 23 people were mailed, 15 replies were received, nine people expressed willingness to be interviewed, and seven interviews were conducted. One person was not interviewed because they replied after the first round of interviews had ended. The other person was not interviewed because the tests had been used at work and sufficient interviews had taken place or been planned with people who had accessed tests in this way. It became apparent after the second interview that, rather than buying self-tests, people also borrowed devices or used them at work. As a result, potential interviewees were asked how they had accessed tests before interviews were arranged. This was to allow purposive sampling based on how self-tests were accessed to ensure that sufficient people who had bought self-tests were interviewed.

In the second batch of invites sent out (see flowchart in appendix 6), 53 people were mailed, 33 replies were received, 25 people were willing to be contacted, and 17 appointments were made. Appointments were not made with four people who had used tests at work or borrowed devices, one person who had not actually used a self-test, one person who replied after the interviews had ended, and two people who did not reply to messages left by telephone or email. One person cancelled the appointment and 16 interviews were conducted.

4.3.3 Respondent validation

Twenty one of the 23 interviewees returned the respondent validation slip and all agreed that the summary reflected what they had said.

4.3.4 Characteristics of interviewees

The 23 interviews involved at least one person from 18 of the 26 age-, sex- and test-specific groups that were populated. The interviewees comprised five men and 18 women (table 8). Three women were aged 18-34 years, two men and seven women were aged 35-49 years, and three men and eight women were aged 50-64 years.

Twenty two people were white and one was Asian. Most of the interviewees (n=17) described their health as good or fairly good. Most (n=17) were employed or self-employed – one interviewee reported being both employed and self-employed.

Table 8: Characteristics of interviewees from their responses to the initial questionnaire.

	Male	**Female**
Age		
18-34 years	--	3
35-49 years	2	7
50-64 years	3	8
Total	5	18
Ethnic group		
White	4	18
Asian	1	--
Total	5	18
Health status		
Good	3	8
Fairly good	--	6
Not good	2	4
Total	5	18
Employment status		
Employed	2	12
Self-employed	1	3
Part-time student	--	2
Retired	1	2
Looking after home/family	1	3
Long-term sick /disabled	2	2
Total [a]	7	24

[a] One female participant reported that she was both employed and self-employed.

4.3.5 Interpretation of self-testing

Interviewees consistently stated that they had understood the definition on the questionnaire. Despite this, four interviewees had used one of the tests that they had marked on the questionnaire with the involvement of a clinician and three others had only marked tests on the questionnaire that they had used with a clinician's involvement.

4.3.6 Use of self-tests

Twenty interviewees had used tests without a clinician's involvement (table 9). Interviewees had accessed tests in a variety of ways: bought (n=12), borrowed (n=8), done at pharmacies or other commercial locations (n=4), and done at work (n=4). Buying a test was the most common way to access a test, and 12 of the 23 interviewees had bought at least one of seven different types of tests for home use. The next most common way was borrowing a testing device. Eight of the 23 interviewees had used a friend's or relative's testing device, although the only tests accessed in this way were blood or urine glucose tests. Only four interviewees had done tests at work, but all of them had accessed at least two different tests.

Twelve interviewees had used only one type of test, five had used tests for two different conditions, and three had used tests for three conditions. Four of the eight interviewees who had done more than one type of test had accessed at least two different tests at work, and five of them had borrowed a friend's or relative's testing device to do a glucose test.

Table 9: Self-tests used by interviewees and how they were accessed.

Identification number	332	1260	165	673	1245	2280	1100	1868	1697	1698	1004	314	851	1334	365	1956	2121	1155	258	2292
Sex	M	F	F	M	F	F	F	F	F	F	F	F	F	M	F	F	F	F	F	F
Age	50-64	50-64	35-49	35-49	50-64	35-49	50-64	35-49	35-49	50-64	35-49	18-34	35-49	35-49	50-64	50-64	50-64	35-49	50-64	18-34
Allergies									✓	✓	✓									
Cholesterol	✓	✓	✓	✓													✓			
Fertility								✓												
Glucose	✓				✓	✓	✓				✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Haemoglobin																	✓		✓	
Homocysteine											✓									
Urine pH													✓							
Urine infections																		✓	✓	✓
Vaginal infections												✓[a]								
Bought device for home use		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓							
Had test done in other setting e.g. pharmacy	✓	✓	✓											✓						
Used friend's or relative's testing device											✓	✓	✓	✓	✓	✓	✓	✓		
Did test at work																	✓	✓	✓	✓

[a] One interviewee found it difficult to recall the exact details of her test use for vaginal infections, but this has been included in the analysis.

4.3.7 Emerging themes

The findings from the interviews can be organised around two main themes (box 6), which are described in the following sections. The first theme, called “Motivations for self-testing”, describes the motivating factors that appear to have influenced participants’ choices to use self-tests. These factors can be organised into four sub-themes: (1a) diagnosis or speculation, (1b) perceived personal costs and benefits of self-testing, (1c) general attitudes to and experiences of healthcare, and (1d) general attitudes to health. The second theme, called “Experience of self-testing”, can be organised into three sub-themes: participants accounts of how they came to access tests ((2a) opportunistic awareness and access), how they found using them ((2b) use and application), and the impact of the test ((2c) impact on life). Selected quotes are presented for illustration. Interjections by the interviewer that merely signalled continued interest and did not affect the interviewee’s train of thought and fillers, such as “um”, have been removed to improve clarity.

Box 6: Themes and sub-themes emerging from interviews.

Themes	Sub-themes
Motivations for self-testing	Diagnosis or speculation Perceived personal benefits of self-testing General attitudes to, and experiences of healthcare General attitudes to health
Experience of self-testing	Opportunistic access and awareness Use and application Impact on life

4.3.7.1 Motivations for self-testing

4.3.7.1.1 Diagnosis or speculation

Everyone who had used self-tests commented on their reasons for using them and these were usually multiple and complex. Generally though, interviewees tended to use self-testing either speculatively or for a specific diagnostic outcome. One participant, for example, made the decision to self-test for food allergies to try and diagnose the cause of her inability to maintain weight loss.

> ***1698 – Female aged 50-64 years****: Well I'd always been fairly slim, all through my twenties and thirties and then I started to gain a lot in my forties. Didn't feel I'd changed my diet in any way. I had thyroid tests. Still couldn't, I could lose a couple of stone but it would go on again very quickly so I suppose that was an avenue to think was I allergic to something or to find out.*

Participants described a number of speculative reasons for self-testing: to routinely check on their health, to check on a known risk, because they were curious, or for reassurance. Regular health checks were seen as important by several participants even though their perception was that their doctors were not keen on this type of preventative care. They tended to see self-tests as a useful tool to enable them to carry out these routine checks.

> ***165 – Female aged 35-49 years:*** *However, saying that, I do when I go to the doctors, and they always look at me madly, but I ask them for a, just check my blood pressure. That's so I'm not a hypochondriac, but I just think it's really good to know, you know, are things within the right scale.*

One participant, for example, described that he generally kept fit but had a stressful job and that he used self-tests to keep a routine check on the state of his health.

> ***673 – Male aged 35-49 years:*** *And yeah cholesterol really because I'm fairly fit, I play rugby every weekend, go training and try and keep fit in that sort of way, and it was just a case of seeing, you know, am I going to clog up in 20 years time or not. And whether that's just a sole factor I don't know, but I suppose you can just take it on in that way. My blood, I monitor my blood pressure just because I'm involved in work and, you know, you have a hectic day and you just make sure life is going along.*

Another participant, knowing that she was at risk of cardiovascular disease because of her family history of heart problems, decided to use a self-test to monitor the health of her heart.

> ***1004 – Female aged 35-49 years:*** *And the heart one was because my mum nearly died from a heart attack and she had, you know thank god she survived and everything, but she had a horrendous time, so I thought oh I'll check that because they say again that heart conditions can be hereditary.*

Other kinds of speculative testing were undertaken by participants, who talked about being curious, for example about their cholesterol level, or wanting to reassure themselves that there were well, that is that they did not need to worry about a particular issue any longer and could return to their usual life.

> ***165 – Female aged 35-49 years:*** *I hadn't got a complaint that required that I needed to go and check it out, but it was available and I thought that's something I'd really like to know.*
>
> ***258 – Female aged 50-64 years:*** *You know you think well there's no problem there so you get on with life and whatever the problem you think you might have had you know you just forget it.*

4.3.7.1.2 Perceived personal benefits of self-testing

Having decided to self-test for a specific reason, participants generally described weighing up benefits and costs in a relatively superficial manner. When weighed against benefits, costs tended to be referred to in monetary terms with only minor consideration given to any practical or emotional burdens of carrying out or accessing the test. One participant, for example, described monetary cost as a possible barrier to self-testing even though testing was thought to be beneficial.

> ***851 – Female aged 35-49 years:*** *I mean it's probably worth having it done if you've got a problem in that direction and you think it's, you know I would, I would pay to have that done if I thought that was, you know, a good idea, but it is expensive and that's the trouble with a lot of these tests, they do cost money.*

Although interviewees did not tend to think about the practical or emotional burdens of carrying out a test without conventional support when weighing up costs and benefits, they did recognise that there were drawbacks. These tended to be divided into the emotional aspect of anxiety or the practical implications of false results. One interviewee, for example, described how "panic" could result from imagining the potentially catastrophic outcomes of a high result, whereas another, more practically, described how false reassurance could result when a person's symptoms were actually due to another condition.

> ***1956 – Female aged 50-64 years:*** *You know and then they're getting a high result and putting themself into a panic because I think a lot of people, they're no doing it properly, a high result, and then it'd be oh yeah, I'm ready to kick the bucket.*

> ***2292 – Female aged 18-34 years:*** *That would be the main thing in the patient's mind that gosh this could be cancer and if it comes out negative that they'd never actually go to their GP and follow through with those signs and symptoms of what it could be.*

On the other hand, a range of perceived benefits were described, which tended to be weighed against the monetary cost. The reported benefits were predominantly about being in control of one's own health, being anonymous, and the convenience of self-testing contrasted with the practical difficulties of visiting the doctor. One participant, for example, described how using self-tests empowered her to be in control of her own health, rather than having to relinquish control over to her doctor.

> ***1260 – Female aged 50-64 years:*** *I think it puts you more in control because you're thinking well I'm making this decision to go and buy this and I'm looking at this and testing for myself and I think that I'm then in control rather than sort of abdicating it over to your doctor again, you know.*

Anonymity was another key benefit described by some participants. They contrasted this with the potentially embarrassing interaction with a doctor that would be needed for certain symptoms or illnesses and the possibility of disclosure of confidential personal information.

> ***1697 – Female aged 35-49 years:*** *There's two elements involved because there's the, if you like, the embarrassment factor of well, you know, that's a part, I don't mind talking to the doctor about my nose, but I'm not so keen to talk to him about what I do on the toilet.*

One person described the possibility of disclosure not just in terms of the doctor but also the reception staff and other patients

> ***1021 – Male aged 50-64 years:*** *I might understand a lot of people want to do a few things, just out of pure confidentiality. To go to a doctor's and I don't think it's that confidential because you walk in and you're in a great big reception space. Half your neighbours could be there. A lot of the receptionists aren't as discreet as they could be.*

Some interviewees felt that self-tests could avoid some of the practical difficulties of visiting the doctor. One person, for example, described how self-tests could help reduce delays because of the difficulty of finding a suitable appointment.

> ***1697 – Female aged 35-49 years:*** *It might be hard to fit that in around the times that are available and the times that you're available so that's a delay. There's then the time involved in actually getting something tested and whether that's something the doctor does and sends off or whether you go down a hospital and do it, and it's not huge delays but if you can compare that to a pregnancy test is a good example, you know you can just go and buy it and do it there and then and five minutes later you've got your answer.*

Another participant had similar feelings but described practical benefits in terms of avoiding the need to find a parking space. It was not always easy to simply drop into the surgery and it would, therefore, be much easier to do the test at home.

> ***2280 – Female aged 35-49 years:*** *Well yes because then, because usually they'd say oh well we want to do a test, bring a sample in tomorrow so that we can test it. Well it'd save you a journey then if you've done it already. You know, you can do it at home and say well this is what the results were. So that would be a good way. Because it's always parking as well at doctors, you can never get parked, so that's another good reason.*

This perceived benefit of avoiding the difficulties of a visit to the doctor tended to be discussed amid a general belief that self-testing was more convenient, for example quick in terms of the time taken to buy and do the test, and uncomplicated.

> ***2292 – Female aged 18-34 years:*** *I think probably convenience of it, sort of simple, quick, effective, gives you a definitive result, all impacts on that, and if you get a definitive result that says yes or no you've got this and it's simple and it's quick.*
>
> ***1004 – Female aged 35-49 years:*** *I just feel with the diabetes one, it never costed me any money so I don't feel so foolish, and I just think it's easy and convenient to do.*

One participant, for example, compared the convenience of self-tests to the convenience of internet banking or cashpoints.

> ***673 – Male aged 35-49 years:*** *No, but the thing is I can do the cholesterol five minutes at home. Going to the doctor, I'm going to sit there for 40 minutes or so. I'm going to have to take time out at some stage and it's just inconvenience really. It's like going to a bank. I don't go to a bank anymore, I go to a cashpoint, or I do it on the internet or I do it over the phone, you know.*

4.3.7.1.3 General attitudes to, and experiences of healthcare

Many of the perceived benefits described by interviewees were likely to be significant positive motivating factors to engage in self-testing, but some participants described what were likely to more negative motivating factors related to their attitudes to and experiences of healthcare. Some people were simply dissatisfied with the care provided to them in the past. One participant, for example, described how she felt that her doctor had trivialised her concerns.

1697 – Female aged 35-49 years: *But I think you have it quite often. I mean I think I can give you another, I can think back to a time when I was having problems with, after I'd had my second child having problems with taking the pill, triggering really bad PMT and having the doctor sit there telling me that that was all in my head as well, you know, and thinking OK well I'll just sort myself out, shall I?*

Many participants also felt that GPs were very busy and health services were under considerable pressure leading to less than ideal care. Participants tended to feel that their problems were not being listened to and that they were being hurried along, for example by the doctor restricting them to one problem per consultation or writing a prescription before they had finished speaking.

851 – Female aged 35-49 years: *I have found just recently in the last couple of years probably that the doctors themselves seem to be under a lot of pressure, and I don't, they don't seem to give you the time that you need. I'll give you one example. I went to see a doctor about a couple of problems because I usually, if I go, I don't go very often, but when I do I've usually got a shopping list, and she said to me I can only deal with one problem at one time, you'll have to make another appointment and come back another day for the second problem, you know, and I thought well that's not very helpful really because what happened then I thought oh I can't be bothered and I didn't go back, and because, you know, my life is very full, I'm very busy. I mean I know health's important, but I'll probably think oh well I'll look after that myself, you know, I won't bother them with it.*

1956 – Female aged 50-64 years: *The doctors are too busy and I think sometimes you go in and they've got their prescription and they're writing and you haven't finished saying what was the matter, but they're writing out a prescription for you, you know.*

Another participant described how the pressure on health services meant that she felt that she had to provide “ammunition” to justify a visit to her doctor.

> ***2121 – Female aged 50-64 years:*** *So it’s almost like getting ammunition to go to the doctor because they’re very busy.*

Other participants felt that the pressure on health services meant that they should ration themselves, that is they should avoid bothering the doctor unnecessarily, saving visits for what were likely to be severe problems and self-caring in other situations.

> ***1004 – Female aged 35-49 years:*** *I suppose the only reason we do it is just because I think you feel that the doctors are under that much pressure that you haven’t got, you can’t go to see them about every little thing that comes in your head, and it’s like if you go and you’ve got a cold and they say, I mean you feel such a plonker when they say oh it’s just a virus, just paracetamol, and you come out thinking oh god, like you know, whereas if you come out and you’ve got antibiotics you think oh god it was a good job I went to the doctors, like you know.*

> ***1868 – Female aged 35-49 years:*** *Yes, but I think if people were encouraged more to help themselves then it would take a lot of the pressure off the GPs and the casualties, and it is out there. You’ve only got to ask.*

More generally, participants tended to see the GP’s time as valuable and self-tests were viewed as a useful vehicle for avoiding bothering the doctor for what might be trivial matters, thereby enabling the doctor to see more deserving cases.

> ***1100 – Female aged 50-64 years:*** *They can save a lot of time and probably a lot of money as well so that, you know, people with more serious illnesses can be attended to rather than, you know, something that might be nothing at all.*

> ***365 – Female aged 50-64 years:*** *And I'm just thinking of freeing the doctor up really. So I suppose in a way these self-tests are a good thing because if you go and you think ooh I've got this and it comes up that you've haven't then you've not wasted the doctor's time but you, that time could have been valuable for somebody else.*

Following on from this, some participants were reluctant to ask their doctors for routine checks because, apparently based on experience, they felt that, unless they had symptoms or, at the very least, risk factors, their request would be declined. Taking this further, some participants felt that their doctor would only be likely to be interested in their concerns if they had "severe" symptoms.

> ***2121 – Female aged 50-64 years:*** *I think that there's a reluctance to go to the GP, to go and say I think I'd like to have my blood sugar checked as a matter of routine. Our GPs happen to be very good, but past experience tends to say, well, why are you worrying, you've got no symptoms.*

> ***1260 – Female aged 50-64 years:*** *And at our particular surgery, unless you've got a problem, it's not an automatic thing to have done unless you've particularly got a high cholesterol or, you know, blood pressure or heart condition or something.*

> ***1698 – Female aged 50-64 years:*** *I think I felt the doctors would say, you know, just eat less there's nothing wrong with you. I didn't, I think unless you've got really severe symptoms from food intolerance, you know I, problems with your bowel and that sort of thing, I wouldn't have thought they were that interested really.*

In contrast to these potentially negative motivating factors, some interviewees simply described taking an active role in their healthcare as their usual custom, which could be seen as a more positive motivating factor in their decision to self-test. One person, for example, described "self-referring" herself to a private practitioner for another problem and how this type of action often leads to a quicker resolution, and another participant described how self-care, before visiting the doctor, was simply her habit, learned over a number of years.

> ***1698 – Female aged 50-64 years:*** *I've just had a problem with my foot, real pain in my foot, went to my GP who said it was arthritis, self-referred myself to a physio at the Nuffield where I go who said it was soft tissue damage, eventually self-referred myself to a consultant because I had seen him before, who said no no no you've got tendonitis, so he injected it. Doctor had said keep using it for arthritis, consultant said rest it for two weeks. So in a way, I think somehow if you can help yourself you might get to the root of it a little bit quicker.*

> ***165 – Female aged 35-49 years:*** *You've learned it over the years and you'll think this feels quite like, and I, more often than not, before I go to the doctor, I'll have tried, you know, whatever I can possibly try.*

4.3.7.1.4 General attitudes to health

For many participants, the decision to self-test was located within a broader narrative about their generally positive attitude to health. Several people related self-testing to the fact that taking care of one's health was simply a fundamental responsibility. One person, for example, described how she felt that her health should generally be her responsibility and how self-testing empowered her to gain control over her health.

> ***1260 – Female aged 50-64 years:*** *Because primarily I think your health should be your concern not your GP's unless it's gone wrong really. And then by looking at these things it means you're taking an interest in keeping yourself as healthy as you can really.*

Taking this responsibility further, a number of participants described that they felt that they could positively influence their health, either by their behaviour or by taking steps to ensure that they were diagnosed with any illness at an early stage.

> ***165 – Female aged 35-49 years:*** *I mean if I need to go to the doctor, I go to the doctor. I'm not sort of so mad about it that I wouldn't take tablets obviously but prevention, you know prevention is far better.*

> ***673 – Male aged 35-49 years:*** *I'd like to know that my blood is right. I'd like to know that there's no illnesses in me in terms of, you know, the main killers really, you know. I mean you going to die of something but if you can try and do something about it and react towards, that'd be great.*

Several interviewees gave examples of the routine steps that they took to safeguard or improve their health, for example watching their diet and taking exercise.

> ***1334 – Male aged 35-49 years:*** *Things I do, I watch what I eat, I try to eat more fruit and fibre, and I'm, I don't eat many sort of puddings, sweets, things like that, and I take a fair bit of, as I say, I run and I cycle as well.*

Interviewees appeared knowledgeable about health and described getting information about health-related issues from a range of sources, notably television, radio, magazines, newspapers, books, DVDs, the internet, and family and friends. One participant, for example, described how she used the internet to find out about treatments for her thyroid condition and how she then approached a different set of doctors on the basis of this, and another described how she derived support by talking to a friend about her weight problem.

> ***1697 – Female aged 35-49 years:*** *And after a little bit of internet research, because one of the things that's happened is I couldn't sleep, I found this particular treatment protocol, particular set of doctors that deal with it, trot off to them, get this slightly different thyroid medication, and now I'm fine, you know, and I've been fine for years.*

> ***1155 – Female aged 35-49 years:*** *I talked to my friend because she's like put loads of weight on as well but hers is the fibromyalgia so, and we've always gone slimming together. We've always done this together, pooh let's go and have a binge today, you know, that sort of thing, and I talk to her about it and I still, we still talk about it now.*

4.3.7.2 Experience of self-testing

4.3.7.2.1 Opportunistic awareness and access

Even though most participants were able to identify benefits of self-testing, many did not actively seek out self-tests. They may have had pre-existing health problems or an idea that they wanted a particular test, but, in many cases, this did not lead to them actively searching for a test. Instead, many participants accessed tests opportunistically because they were presented to them "on the shelf", through advertising, or by family and friends. One participant, for example, described simply coming across the test he used while he was shopping.

> ***673 – Male aged 35-49 years:*** *Why cholesterol testing I don't know to be honest. It was just an available product on the shelf.*

Another participant described how her opportunistic purchase of a self-test was motivated by a pre-existing health concern but prompted by an advertisement.

> ***1697 – Female aged 35-49 years:*** *Sitting in the chemist waiting to, for your prescription to turn up, you know you read everything's that's available because it's, you're a bit bored. And saw it there originally and probably had, it had been kind of latently in the back of my mind for some time.*

Other participants described finding out about self-tests from family and friends. For some, they then simply went on to borrow the testing device from the informant.

> ***365 – Female aged 50-64 years:*** *Well, we'd seen him, we knew of it anyway, so we knew he was testing it, himself with it. So I don't think we went into a lot of conversation about it really. He just happened to get the equipment out and we were just talking about it then.*

Another person described how she decided to buy an allergy test after finding out about her friend's positive outcome from using the test.

> ***1004 – Female aged 35-49 years:*** *She'd put on weight, and she had this food test and she said she couldn't get over how much better she felt. She said I feel so well and everything. I thought blooming hell I'm going to try that and see if I can lose some weight.*

4.3.7.2.2 Use and application

Most participants who had used self-tests described the process and experience as unproblematic: they found instructions easy to understand and tests easy to perform. One participant, however, highlighted a concern that it was difficult to read the result of a cholesterol test and how this led to uncertainty.

> ***165 – Female aged 35-49 years:*** *You've got to have a little piece of paper and you're just looking and you can't really see it and you think hmmm. And you always doubt because it's the thing with cholesterol tests it has to be quite quick, and you think have I looked at it quick enough or at the right time. You leave it so many minutes before you read it. You're always sort of slightly doubting.*

Although most participants had no problem with the idea of taking blood for self-tests, some had found this difficult and thought that this might restrict their future use.

> ***365 – Female aged 50-64 years:*** *I let him do it because I couldn't, I couldn't do that because I know some tests, well that test I know you've got to, you know, and I was going, and he said well come here and he did it. So I suppose going on from that some tests I probably would think oh no I don't think I can do that if it means that you've got to.*

4.3.7.2.3 Impact on life

Most participants spoke of the positive impact of having used self-tests. One, for example, described how finding out she was allergic to milk was "revolutionary" and that eliminating this from her diet had lead to significant improvements, and another described the positive reaction that she received when she told her doctor about the self-tests that she had used.

> ***1697 – Female aged 35-49 years:*** *Almonds I think might have been one of them that was sort of slightly sensitive, but the one that really stood out was milk, and, I mean depressing though it was, that was kind of pretty revolutionary because cutting milk out my diet has made a huge difference.*

> ***2280 – Female aged 35-49 years:*** *I just said oh by the way I've done this test for my sugar with one of the sticks, and she said oh good, what result did you get, and she was very helpful.*

Not everyone had such a positive experience though: one participant described how her hopes for a significant outcome from self-testing had been unfulfilled because she was unable to access the aftercare and how this had tainted her experience.

> ***1004 – Female aged 35-49 years:*** *And I think as well if I had have spoken to the (company's) consultant I might have carried on with the food allergy thing, but I didn't understand it and they weren't, they haven't contacted me back or anything, so I'm just knocked it on the head as a bad thing.*

Neither did all participants experience the empowerment and positive reinforcement of sharing their experience of self-testing with their doctor. One participant, for example, said that she would not mention a self-test because of embarrassment about the cost, and another did not mention an allergy test because she thought that her doctor would be sceptical about a test for this condition.

> ***1004 – Female aged 35-49 years:*** *I went on the internet and spent nearly three hundred pound and it was just, I suppose I just feel a bit embarrassed I just dived in and like that and done it because I was thinking oh, and you start thinking oh god, you know, perhaps I should get that done, I've never heard of that before and that's better than cholesterol, and I thought oh I'll do it.*

> ***1697 – Female aged 35-49 years:*** *It's not so much that they might feel, that they might think badly of me having gone off and found this out myself as they might treat it with an element of scepticism, and I think that's different to say going in with a pregnancy test result or going in with a chlamydia test result, you know, because they are what they are.*

4.3.7.3 Summary of findings from thematic analysis

The findings from the interviews were organised around two main themes, called "Motivations for self-testing" and "Experience of self-testing". The theme called "Experience of self-testing" described participants' accounts of using self-tests and was divided into three sub-themes focused on how participants came to access self-tests, how they found using them, and the impact on their life. Participants may have had an existing health problem or an idea that they wanted a particular test, or they may have known that self-tests were available and had an idea of the possible benefits, but they did not tend to aggressively seek out self-tests. Instead, they usually described coming across self-tests opportunistically. Participants then generally found the tests easy to use and did not mind taking their own samples, for example pinprick blood samples. Overall, participants tended to talk about the positive impact of self-testing, from changes made as a result of a diagnosis or from the experience of being able to discuss the test with their doctor.

The theme called "Motivations for self-testing" described the motivating factors related to participants' choices to use self-tests. The second objective of the interviews was to generate a list of factors that might be associated with self-testing for inclusion in the in-depth questionnaire, and participants' choices appear to have been influenced by a number of factors that were centred around four sub-themes (box 7): (1a) diagnosis and speculation; (1b) perceived personal costs and benefits of self-testing; (1c) general attitudes to, and experiences of healthcare; and (1d) general attitudes to health.

Box 7: Motivating factors related to participants' choices to use self-tests.

Sub-themes	Motivating factors
Diagnosis or speculation	For a specific diagnostic outcome Speculative self-testing: ▪ Routine check on health ▪ Check on a known risk ▪ Satisfy curiosity ▪ For reassurance
Perceived personal benefits of self-testing	Being in control of one's health Being anonymous Convenience of self-testing contrasted with the practical difficulties of visiting the doctor
General attitudes to, and experiences of healthcare	Dissatisfied with past care Health services under pressure: ▪ Less than ideal care ▪ Need evidence to justify visit to doctor Avoid bothering the doctor unless really necessary Need symptoms or risk factors to be tested by the doctor Need severe symptoms to visit the doctor Take an active role in healthcare: ▪ Advocates independent care ▪ Favours self-care
General attitudes to health	Responsible for health Able to influence health Take routine steps to improve health Seek information about health

The first sub-theme, called “Diagnosis or speculation”, described the reasons given by participants for using self-tests. They tended to have self-tested either with the aim of a obtaining a specific diagnostic outcome or on a more speculative basis, that is to routinely check on their health, to check on a known risk, because they were curious about what the test would show, or for reassurance that they were well.

The second sub-theme of the “Motivations for self-testing” theme, called “Perceived personal benefits of self-testing”, detailed participants’ descriptions of their views about the benefits of self-testing. Although they did recognise that there were practical and emotional costs of self-testing without conventional medical support, they tended to describe weighing benefits against monetary costs when talking about the decision to use self-tests. The perceived benefits talked about were mainly being able to be in control of one’s health, being able to be anonymous and thereby avoid embarrassment or the disclosure of confidential information, and the convenience of self-testing contrasted with the practical difficulties of visiting the doctor.

The third sub-theme of the “Motivations for self-testing” theme detailed participants’ general attitudes to and experiences of healthcare. Many benefits talked about by interviewees were likely to be positive motivating factors for self-testing, but some participants described what were likely to be negative motivators related to their attitudes to and experiences of healthcare. Some participants were dissatisfied with the care that they had received and many participants also felt that health services were under pressure leading to hurried care and a need to provide evidence to justify a visit to the doctor. More generally, participants tended to believe that there was a responsibility to avoid bothering the doctor unnecessarily. Some felt that, unless they had symptoms or risk factors, requests for routine checks would be declined, and some even felt that their doctor would only be interested in severe symptoms.

In contrast to this, however, some participants simply described a positive proactive attitude to healthcare, such as seeking out independent care to quickly resolve a problem or initially self-caring because that was simply their habit, and this attitude could be postulated to extend to a proactive and positive choice to self-test.

Similar to this, the fourth sub-theme of the “Motivations for self-testing” theme concerned the broader background of some participants’ generally positive attitude to maintaining their health. They described a general belief that their health was their responsibility. They believed that they could positively influence their own health and gave examples of the routine steps that they took to safeguard or improve their health. They appeared knowledgeable about health, obtaining information from a variety of sources, and they used their knowledge to obtain a desired outcome.

Broadly speaking, factors generated by the interviews can be seen as positive or negative motivators for choosing to self-test. Interviewees generally spoke about a mix of positive and negative factors, but more extreme profiles were noticeable. At one end, participants tended to have a positive attitude towards their health. They liked to be in control of their health and self-testing enabled them to carry out a routine check on their health, for example their cholesterol level. They tended to have more positive experiences of healthcare, and self-tests were simply preferable to visiting the doctor because they were convenient or did not take up their doctor's valuable time. At the other end of the spectrum, participants self-tested to diagnose a specific problem. They tended to want to avoid conventional services because they had been dismissed repeatedly in the past or they felt that doctors would dismiss what, to the medical profession, might be considered a minor problem. Box 8 gives examples of these two extreme journeys.

4.3.8 Summary of this section

This section has detailed the results of interviews with 23 people who responded to the initial questionnaire saying that they had used self-tests. The published paper for this part of the study is included in appendix 16. The objectives were to gain a greater understanding of self-testing, for example how tests are accessed and what prompts people to use them, and to contribute to a list of factors that may be associated with self-test use (see box 7 and section 4.5.11).

A minority of the interviewees had used the tests that they had marked as self-tests on the initial questionnaire with the involvement of clinicians, highlighting the opportunity of the in-depth questionnaire to confirm self-testing reported on the initial questionnaire. Interviewees had also accessed tests in a variety of ways, rather than simply buying a test, again highlighting the opportunity for investigating the details of how self-tests were accessed using the in-depth questionnaire.

Box 8: Contrasting motivations of two interviewees who had used self-tests.

50-64 year old female

This interviewee did a home cholesterol test. She wanted to check her cholesterol because she thought that it was important to take care of her health. She felt that her GP might not do the test because she didn't have a particular problem, but she also felt that her health should be her concern and that doing a test at home puts you in control. Generally, she wished that there was more preventative care, that is health professionals that you could see before there was a problem.

She had not had any bad experiences with health services, although she felt that they were busy. She thought that doing the test herself saved the doctor's time, and she wouldn't want to bother the doctor with something that she could sort out on her own.

The test was easy to do. She didn't change anything as the result was normal and she was already quite careful about her diet. She would have been happy to tell her GP about the test if the results had been high as she sees self-testing as complimentary to, rather than instead of the doctor.

35-49 year old female

This interviewee did an allergy test. She read about it in a leaflet while at the chemists. She had been having symptoms for years but decided to try this because they had got much worse. She didn't go to her GP for several reasons. She had seen the doctor about this in the past and had an invasive investigation, but the problem had not been resolved. Her GP and a specialist had been very dismissive of other problems. Furthermore, she thought that the doctor would probably just say use over-the-counter medication, and a relative also had had a bad experience of allergy testing at a hospital.

She bought the test after checking with a doctor doing her medical at work that there was a rationale for such tests. She was sent the test, which involved pricking her finger, sucking the blood up into tubes, and posting them back. The results were returned after a week or two. One food stood out, and she felt better almost immediately after cutting it out.

She had not mentioned the test to her doctor. She did not think it was relevant as she had her answer, but she also felt that the doctor might be sceptical and that it would be another thing to mark her out as a neurotic woman.

The findings of a thematic analysis were described. These were organised around two main themes. The theme called “Experience of self-testing” described participants’ accounts of using self-tests and was divided into three sub-themes focused on how participants accessed self-tests, how they found using them, and the impact on their life. Participants usually described coming across self-tests opportunistically. They generally found the tests easy to use and talked about their positive impact, either from changes made as a result of a diagnosis or from the experience of being able to discuss the test with their doctor.

The theme called “Motivations for self-testing” described motivating factors related to participants’ choices to use self-tests centred around four sub-themes. The first sub-theme, called “Diagnosis or speculation”, described participants’ reasons for using self-tests. They tended to self-test for a specific diagnostic outcome or more speculatively, for example as a routine check. The second sub-theme detailed the perceived personal benefits of self-testing, which were mainly being in control of one’s health, being anonymous, and the convenience of self-testing versus the practical difficulties of visiting the doctor. The third sub-theme focused on participants’ general attitudes to and experiences of healthcare. Many of the benefits described were likely to be positive motivating factors for self-testing, but some participants described possible negative motivators related to their experiences of healthcare, for example dissatisfaction with past care. The fourth sub-theme concerned the broader background of some participants’ positive attitude to their health, for example they believed that they could positively influence their health and took routine steps to safeguard or improve their health.

Broadly speaking, factors generated by the interviews can be seen as positive or negative motivators for self-testing. Interviewees generally spoke about a mix of positive and negative factors, but there were more extreme profiles. At one end, participants had a positive attitude towards health and healthcare and self-testing simply enabled them to carry out a routine check on their health, for example on their cholesterol level. At the other end, participants wanted to avoid conventional services because of their past experiences and they used self-tests to try and diagnose a specific problem.

The next section outlines the results of the systematic review of the literature for evidence for factors that may be associated with self-test use.

4.4 Systematic review of evidence

4.4.1 Overview of this section

This section outlines the results of the systematic review of the literature for evidence for factors that may be associated with the use of self-tests and, because of the lack of evidence in this area, use of OTC medicine, private health care, CAM and home BP monitors. The objective was to add to the list of factors that may be associated with the use of self-tests for inclusion in the in-depth questionnaire. The published paper for this part of the study is included in appendix 23 [100].

The methods for this part of the study are described fully in section 3.5. The review was restricted to the UK and studies published in the 15 years before the main searches were conducted (1993 to 2007). More recent searches of Medline were conducted in July 2008 and February 2010, but this was restricted to papers about self-testing to assist with interpreting the results of the study. A search strategy was designed for each activity using relevant terms and then adapted for each database. Geographical filters and filters to identify appropriate study design were additionally used where many papers were returned and references of relevant papers were also searched. Abstracts were initially reviewed against pre-specified inclusion and exclusion criteria and, where it was unclear if the study was eligible based on the abstract, the full paper was retrieved and assessed. Proformas were then used to assess the quality of eligible studies before retrieving data using standard headings.

This section sets out the number of potentially eligible papers that were identified for each activity and by each bibliographic database. Exclusions are then described, leaving 49 eligible papers that were identified in April 2007. The characteristics, quality and findings of the eligible studies are then described for each activity under consideration. Finally, the findings for each different activity are drawn together.

4.4.2 Numbers of papers identified by search strategies

Two hundred and six potentially relevant papers were identified in April 2007: 49 were eligible (table 10) and 157 were excluded (table 11). Most papers (n=54) were excluded because they simply did not identify factors, reasons or characteristics associated with a relevant activity (table 11). The 49 eligible papers comprised 26 identified during searches related to CAM only, 12 identified in searches related to OTC medicine only, three identified during searches related to CAM and OTC medicine, six identified during searches related to private care only, one identified during searches related to CAM and private care, and one identified during searches related to home BP monitors. No papers were identified related to self-testing in April 2007, but one eligible paper was identified in July 2008 during the supplementary search related to self-tests [146].

Table 10: Potentially relevant and eligible papers identified during the systematic literature review in April 2007 by activity and database.

Activity	Complementary and alternative medicine		Over-the-counter medicine		Private care		Home blood pressure monitors		Self-tests		Total [b]	
Database [a]	Eligible	Total	Eligible	Total	Eligible	Total	Eligible	Total	Eligible	Total	Eligible	Total
Medline	16	64	8	37	4	7	0	1	0	3	28	106
Embase	9	53	11	28	1	3	0	3	0	5	18	86
Cumulative Index to Nursing and Allied Health Literature	13	29	2	7	0	0	0	0	0	0	15	36
Applied Social Sciences Index and Abstracts	9	30	3	7	1	2	0	0	0	0	12	38
PsycINFO	8	20	3	8	1	2	0	0	0	0	12	29
British Nursing Index	4	30	0	4	0	1	0	0	0	0	4	35
Allied and Complementary Medicine Database	2	9	0	0	0	0	0	0	0	0	2	9
Sociological Abstracts	0	1	0	0	0	1	0	0	0	0	0	2
International Bibliography of the Social Sciences	1	1	0	4	0	0	0	0	0	0	1	5
References of other papers	3	3	1	1	2	2	0	0	0	0	6	6
Grey literature	1	1	0	0	0	0	1	1	0	0	2	2
Total [b]	30	135	15	62	7	13	1	4	0	5	49	206

[a] The Arthritis and Complementary Medicine Database and the Complementary and Alternative Medicine and Pain Database were also searched but no potentially relevant papers were identified.

[b] Totals may be less than the sum of the components because some papers were identified by different databases and some papers were identified during searches related to more than one subject area: 193 papers were identified during searches related to one activity (122 related to CAM, 50 related to OTC medicine, 12 related to private care, four related to home BP monitors, and five related to self-testing) and 13 were identified during searches related to two activities (12 related to CAM and OTC medicine, and one related to CAM and private care).

Table 11: Reasons for excluding potentially relevant papers identified during the systematic literature review in April 2007.

Reason / Activity	Complementary and alternative medicine	Over-the-counter medicine	Private care	Home blood pressure monitors	Self-tests	Total [a]
Study did not identify factors, reasons or characteristics associated with a relevant activity (1)	21	25	3	2	4	54
Study did not involve adults differentiate between children and adults (2)	11	5	0	0	0	14
Activity was initiated by a conventional health professional (3)	2	0	0	0	0	2
Outcome was simply the intention or willingness to do an activity (4)	1	3	0	0	0	4
Study involved a selected population (5)	56	12	2	1	0	65
Study did not relate to UK residents (6)	8	1	1	0	0	10
Review, letter or opinion (7)	6	1	0	0	1	8
Total	105	47	6	3	5	157

[a] Totals may be less than the sum of the components because some papers were identified during searches related to more than one subject area.

Medline identified most (n=28) of the 49 eligible papers identified in April 2007 (table 10). Embase identified the next highest number (n=18), but there was considerable overlap with Medline: adding Embase only identified three more papers, whereas the Applied Social Sciences Index and Abstracts and PsycINFO databases both identified five more papers.

4.4.3 Complementary and alternative medicine

4.4.3.1 Eligible papers

Thirty eligible papers were identified. Three were also identified in searches related to OTC medicine. One of them looked at practitioner-delivered and OTC treatments [106]: the results related to practitioner-delivered treatments are presented in this section and the results related to OTC treatments are presented in the OTC medicine section. The other two papers did not make this distinction and all their results are discussed in this section as the authors described them as being about the use of CAM [147, 148]. Another paper was also identified in searches related to private care, but the results are also presented in this section as the study involved CAM patients [149]. This study and two others were reported across two papers [149 & 150, 151 & 152, 147 & 153], leaving 27 studies. Appendix 32 summarises the design, population, period, exposure under investigation and results of these studies.

Eligible studies looked at different therapies, for example acupuncture [154] or alternative medicines not prescribed by a doctor [155], during different periods, for example ever [147 & 153] or currently [154]. One study involved interviews [156], one was a qualitative questionnaire survey [157], three used questionnaires plus interviews [149 & 150, 158, 159], and one was a case note review [160]. The other 21 studies were questionnaire surveys, but only seven of them used population-based samples, for example people registered with general practices [151 & 152]. The remainder used selected samples, for example people visiting a practitioner [154] or students [148].

One questionnaire survey had a high quality score [151 & 152], 18 had medium scores, and two had low scores [161, 162]. Three of the qualitative studies and the case note review had medium scores [156, 157, 159, 160] and two of the qualitative studies had low scores [149 & 150, 158].

4.4.3.2 Results

Using adjusted analyses, the high quality population-based survey found that being female was linked with visiting a CAM practitioner in the last three months [151 & 152], a medium quality population-based survey reported that taking non-prescribed alternative medicines was more likely in women than men [155], and another medium quality study found that lifetime CAM use was more likely among female than male GP attendees [147 & 153]. Although samples and analysis methods varied, 10 other studies reported a link between being female and CAM use [38, 106, 154, 157, 158, 160, 163, 164-166].

Using adjusted analyses, the high quality population-based survey found that people aged 34-49 were most likely to consult a chiropractor or osteopath [151 & 152], and a medium quality survey found that past CAM use was more likely among GP attendees under 70 than older attendees [147 & 153]. Three medium quality population-based surveys used unadjusted analyses to show that use was most common among people aged 45-64 [106], 35-64 [163] and 45-54 [167], and another medium quality study described higher proportions of acupuncture patients being aged 35-64 than the general population [154]. Two medium quality surveys described that CAM users were most commonly aged 30-49 [38] and 35-44 [157], and another medium quality study described CAM patients as having a median age of about 45 [160]. A low quality population-based survey also described a peak in use at age 45 [158]. Three further medium quality studies looked at age [164, 168, 169], but they compared people visiting CAM practitioners with GP and/or outpatient attendees. In line with several of the other studies though, the CAM patients were mainly aged 41-50 years [169] or their mean ages were from 43 to 53 years [164, 168].

Only three studies, all of medium quality, looked at ethnic origin. Using an adjusted analysis, one found that people of black African origin were more likely than white people or people of South Asian origin to take non-prescribed alternative medicines [155]. Another reported that white students did not have a tradition of CAM use, although the analysis was limited by small numbers [159]. In contrast, the third found that most patients at a CAM hospital were white, although there was no comparison group [165].

Using population-based surveys and adjusted analyses, a high quality and a medium quality study found, respectively, that people from higher social classes were more likely to have visited a CAM practitioner in the past three months [151 & 152] or be taking non-prescribed alternative medicines [155] than other people. Using unadjusted analyses, two medium quality population-based surveys found that CAM use was more common among affluent than non-affluent groups [163, 167], and another medium quality study reported that use was more common among GP attendees with higher incomes [147 & 153]. Three further medium quality studies found that CAM patients had higher incomes [169] or occupational status [164] than GP patients, although again these analyses were unadjusted, and that people visiting a Chinese medicine practitioner had disposable income [160].

Three medium quality studies linked education and CAM use, although they all used unadjusted analyses. A population-based survey found that use was more likely among people who were 19 or older when they left education than those who left before then [167]. Another found that use was more common among GP attendees with higher than lower educational attainment [147 & 153]. The third study found that CAM patients generally had a longer education than GP patients [170].

A link with poor health was supported by several studies. Using adjusted analyses, the high quality population-based survey found that people with a long-standing illness or who saw their GP more often were more likely to have seen a CAM practitioner recently than other people [151 & 152], and a medium quality study found that CAM patients were more likely than GP patients to have psychiatric morbidity [169]. Using unadjusted analyses, a low quality population-based survey found that CAM users had higher GP attendance rates and were more likely to have severe or chronic conditions than non-users [158], and two medium quality studies found that CAM patients were more likely than GP patients to have had a chronic illness [168], serious illness [168] and longer illness [168, 171]. Two medium quality studies looked at symptom length: one described most Chinese medicine patients as having symptoms for over a year [160], and the other described new CAM patients as having longer symptoms than GP patients, although CAM patients also had lower pain scores [170].

The high quality population-based survey reported that non-smokers and people who took regular exercise were more likely to have seen a chiropractor or osteopath than other people [151 & 152]. Two medium quality studies with adjusted analyses also reported a link with healthy living: compared to GP patients, CAM patients had healthier lifestyles [168] and were more likely to believe in healthy living [169]. Similar to this, a low quality unadjusted survey found that patients at alternative therapy centres were more likely to be health conscious and know about health than health centre attendees [161]. A medium [169] and a low quality study [161] also reported that CAM users were more likely to believe that they controlled their health [169] or less likely to believe that doctors controlled their health than users of orthodox medicine [161].

Some studies described reasons for using CAM, for example an acquaintance's recommendation [149 & 150, 172] or because a family member had done so [148]. Others cited users' views about orthodox medicine's disadvantages, for example rushed appointments [149 & 150] and its limited effectiveness [149 & 150, 156, 166], compared with CAM's attractions, for example its effectiveness [166] and sensitive practitioners with time to listen [168].

4.4.3.3 Summary of results

Being female was associated with CAM use in 13 of 27 studies. Four studies reported that use was most common among middle-aged people, that is in the range from 34 to 64 years, and a fifth found that use was more likely among GP attendees under 70 than older attendees. In line with this, another study found that a higher proportion of CAM patients were aged 35-64 than the general population, three studies reported that CAM users were most commonly aged 30-49, 35-44 and 41-50, and four other studies found CAM patients had median, mean or peak ages in the range from 43 to 53 years.

Four studies reported that people from more affluent or higher social groups were more likely to have used CAM than other people, and another study found that use was more common among GP attendees with higher incomes. In line with this, three other studies found that CAM patients had higher incomes or occupational status than GP patients or that they had disposable income. One study found that use was more likely among people who stayed in education until they were older than people who left at a younger age. In line with this, another study found that use was more common among GP attendees with higher than lower educational attainment, and a third reported that CAM patients generally had a longer education than GP patients.

A link with poor health was supported by seven studies. One study found that people with a long-standing illness or who saw their GP more often were more likely to have seen a CAM practitioner recently than other people. Four studies found that CAM users were more likely to have psychiatric morbidity than GP patients, to see their GP than non-users, and to have or have had severe or chronic conditions than non-users or GP patients. Two further studies found that CAM patients had either long-standing symptoms or longer symptoms than GP patients.

Four studies reported an association with healthy living: one found that people with healthy lifestyles were more likely than other people to have seen a CAM practitioner, two reported that CAM patients had healthier lifestyles than GP patients, and another found that patients at CAM centres were more likely to be health conscious and know about health than health centre attendees. Two studies also reported that CAM users were more likely to believe that they controlled their health or less likely to believe that doctors controlled their health than users of orthodox medicine.

Although the quality and design of the studies varied considerably, no studies contradicted the associations between CAM use and being female, middle-aged, affluent, educated, and having a healthy lifestyle or outlook. In contrast to the generally consistent association between CAM use and measures of poor health, one study found that CAM patients had lower pain scores as well as longer symptoms than GP patients, suggesting that there are certain measures of health status that may be more important. The association with ethnic origin was only looked at by three studies and the results were inconclusive. Some studies considered reasons for using CAM, which tended to relate to an acquaintance's suggestion or CAM's advantages versus orthodox medicine's disadvantages.

4.4.4 Over-the-counter medicine

4.4.4.1 Eligible studies

Fifteen eligible papers relating to 15 studies were identified. Two are discussed in the CAM section [147, 148], leaving 13 studies. Appendix 33 summarises the design, population, period, exposure under investigation and results of these studies. Some looked at the use of any OTC medicines [173-175], but the others considered use or purchase of specific medicines, such as H2 antagonists [176], or types of medicines, such as analgesics [177] or herbal medicines [178]. Two were qualitative studies [178, 179] and 11 were surveys. Four surveys used population-based samples, for example from health authority registers [18, 106, 180] or the electoral roll [177]. One survey sampled people who were shopping [175] and two sampled people attending general practices [174, 181]. The other four surveys looked at OTC purchasers without a comparison group [173, 176, 182, 183]. Four surveys [18, 177, 180, 181] had high quality scores. Three surveys [106, 174, 175] and the two qualitative studies

[178, 179] had medium scores. The other four surveys had low scores [173, 176, 182, 183].

4.4.4.2 Results

Two low quality surveys described the sex of purchasers of OTC medicines and found that most were female [182, 183]. Four population-based surveys agreed that use or purchase was more common in females: three were high quality and used adjusted analyses [18, 177, 180] and one was medium quality but unadjusted [106]. Using unadjusted analyses, a high quality survey of GP attendees [181] and a medium quality survey of shoppers [175] also found that being female was linked with using or purchasing OTC medicines.

Only one high quality population-based survey reported on ethnicity: this found that people who were white were more likely to use herbal supplements than other people [180]. In contrast, most studies looked at age. Three high quality population-based surveys found, using adjusted analyses, that purchase or use of OTC medicines was more common in people aged 35-44 [18], 45-64 [180], and under 60 [177] than other age groups. One medium quality adjusted survey found that GP attendees aged under 60 were more likely to use OTC medicines than older people [174], and another medium quality unadjusted survey reported a similar result for shoppers [18]. Using unadjusted analyses, a high quality survey of GP attendees [181] and a medium quality population-based survey [106] found that use or purchase of OTC medicines was highest in the 45-64 age group, and two low quality surveys reported that most OTC buyers were 46-60 [182] and 36-45 [183].

Three high quality population-based surveys [18, 177, 180], one high quality survey of GP attendees [181] and one medium quality survey of GP attendees [174] found that OTC medicine use or purchase was associated with affluence. The studies used different measures though – occupation [18], social class [181], rented or private housing [180] and the Carstairs deprivation category [174, 177] – and only two found the association remained after adjusting for other variables [18, 180]. One of the high quality surveys reported that both affluence and education were associated with OTC use, but only education remained significant in the adjusted analysis [177]. This could suggest that the association with affluence may be related to education, but there was also an association with paying for prescriptions in the adjusted analysis and this could be a surrogate for affluence. A low quality but adjusted survey of pharmacy customers also found an association with paying for prescriptions [176], and two medium quality unadjusted analyses of GP attendees [174] and shoppers [175] reported a similar association.

Only three studies found a link between purchase or use of OTC medicines and poor health, but all were high quality population-based studies with adjusted analyses. Two studies looked at self-reported health [18, 177] and the third looked at psychiatric morbidity [180].

Two high quality population-based surveys examined behaviour. One found that herbal supplement use was associated with not smoking and being active, although only being active remained significant after adjusting for other variables [180]. This suggests that use may be associated with healthy behaviours. The other survey found an unadjusted association between non-prescription analgesics and drinking alcohol, but this is probably not a healthy behaviour because the comparison was with non-drinkers [177].

Some low quality surveys described reasons for OTC use, for example habit [182], a prompt by an acquaintance [183], homeopathic remedies being more natural [183], or symptoms not being severe enough for the doctor [173]. Some of the reasons were echoed in qualitative studies, for example influence and experience of relatives [179], doctors being unable to help with some problems [178], and prescription medicines being chemical [178].

4.4.4.3 Summary of results

Being female was associated with OTC medicine use in eight of 13 studies. Four studies found that purchase or use was more common in middle-aged people, that is in the range from 35 to 64 years, than other age groups, and two more found that most OTC buyers were in this age group. Similar to this, three studies found that use was more likely in various groups of people aged under 60 years than older people. No studies contradicted these associations with being female or middle-aged. Only one study looked at ethnicity, making it hard to draw firm conclusions.

Four population-based or GP attendee surveys found associations between OTC medicine use or purchase and measures of affluence, but only two found an association after adjusting for other variables. Another population-based survey reported that affluence, education and paying for prescriptions were associated with use, but only the last two had an adjusted association, suggesting that these factors may be related. Three more surveys of pharmacy customers, GP attendees and shoppers found adjusted or unadjusted associations with paying for prescriptions.

Three studies reported associations between purchase or use of OTC medicines and self-reported poor health or psychiatric morbidity, and none found a contradictory association with good health. One study found that herbal supplement use was associated with healthy behaviours, but another found that OTC analgesic use was more common in drinkers than non-drinkers, suggesting that some OTC use is associated with unhealthy behaviours. Finally, some studies reported reasons for OTC medicine use, including the influence of others and the advantages of non-prescribed medicines versus the disadvantages of prescribed medicines.

4.4.5 Private sector

4.4.5.1 Eligible studies

Seven eligible papers were identified. One was also identified in searches related to CAM and is discussed in the CAM section as it involved CAM patients [149]. The remaining six papers related to six studies. Appendix 34 summarises the design, population, period, exposure under investigation and results of these six studies. Five used data collected during surveys to look at determinants of insurance [184-186] and who actually uses private care [187, 188]. The sixth study used data from general practice records to look at who was most likely to be privately referred [189]. The study that used general practice data had a high quality score [189], three studies had medium scores [185, 186, 188], and two had low scores [184, 187].

4.4.5.2 Results

One medium quality study, using an adjusted analysis, reported that women were less likely to have private insurance than men [185]. A link with age was found in four studies. The high quality study used an adjusted analysis to show that people aged 45-54 were most likely to be privately referred [189]. Another medium quality study, also using an adjusted analysis, found that private insurance increased with age but fell for older people [186]. A low quality study gave the same result [184], although it was unclear if the analysis was adjusted. In contrast, a medium quality study with an adjusted analysis found that private insurance increased with age [185].

Private care or insurance was positively associated with affluence and/or negatively associated with deprivation in all the studies. The high quality study [189] and two medium quality studies [185, 186] used adjusted analyses, whereas the other medium quality study used an unadjusted analysis [188] and it was unclear if the two low quality studies had adjusted for other variables [184, 187]. The measures used – occupation [185], income [184-188], being in paid employment [185, 187], being a homeowner [184], living in rented housing [187], and the IMD [189] – also varied.

Being privately insured was found to be more likely among people with than without a basic qualification in a medium quality study that used an adjusted analysis including the possible confounders of income and occupation [185]. A similar link was found in a low quality study, but it was unclear whether the analysis was adjusted [184].

Only one study reported on the relationship with health status [187]. This reported a negative association between private care and being limited in one's daily activities, but the study was low quality and it was unclear if the analysis was adjusted.

4.4.5.3 Summary of results

One study reported that women were less likely to have private insurance than men. A link with age was found in four studies. One found that people aged 45-54 years were more likely to be privately referred and, in line with this, two found that private insurance increased with age but fell for older people. In contrast, however, a medium quality adjusted analysis found that private insurance increased with age. Private care or insurance was positively associated with some measure of affluence and/or negatively associated with some measure of deprivation in all six studies, whereas being privately insured was reported to be more likely among people with higher educational attainment in only two studies. Only one low quality study reported on the relationship with health, making it hard to draw firm conclusions.

4.4.6 Home blood pressure monitors

One eligible medium quality survey of 5545 people registered with general practices was identified (54% response rate: 2925 completed of 5392 delivered) [190]. Being retired, being not in employment, having a long-term illness and/or not good health, being a non-smoker, and having used other self-tests were significantly associated with self-testing for high BP but only in a univariate analysis. Increasing age, being female, having a degree and living in a more affluent area remained significant after adjusting for other variables.

4.4.7 Self-tests

One eligible paper about self-testing was identified during a supplementary search in July 2008 [146]. This presented results for self-tests related to cancer from the survey that had been identified in searches related to home BP monitors [190]. Using an adjusted analysis, the study found that significant predictors of the use of a prostate specific antigen (PSA) test were being male, white ethnicity and older age, and that use was lower among people who were relatively deprived, that is in quartile 3 derived from the IMD. In contrast, use of a haematuria test was significantly associated with being relatively deprived, as well as giving one’s employment status as looking after the home and/or family.

4.4.8 Amalgamation of results from studies related to different activities

Overall, 49 eligible papers were identified during the original search in April 2007. Most (n=28) were identified by Medline and most (n=30) were related to CAM. There were 46 unique studies and most (n=36) had high or medium quality scores. Most (n=37) studies were questionnaire surveys or used data from established surveys, although only 16 of them were population-based. Survey analysis methods varied from simple descriptive to adjusted analyses, but studies generally looked at five areas: demographic factors (sex and age), affluence/deprivation, education, health status, and health behaviours and beliefs. One further eligible paper was identified during a supplementary search for papers related to self-testing in July 2008 [146]. This presented results for self-tests related to cancer from a medium quality survey already identified during searches related to home BP monitors [190], giving an overall total of 50 papers and 46 studies discussed in this section.

Being female was associated with the activity in 13 of 27 studies about CAM, eight of 13 studies about OTC medicine, and the single study about home BP monitors. Thirteen studies about CAM, nine studies about OTC medicine, and three studies about the private sector reported that people in the 30 to 64 year age range were more likely to undertake the activity, that users were most commonly in this age range, that a higher proportion of users were in this age range than the general population, that users had median, mean, or peak ages in this age range, or that use declined after 60 or 70 years. One study, however, found that private insurance was more common in men than women and as age increased [185], and the studies about the use of home BP monitors [190] and PSA self-tests [146] reported that use became more likely as age increased. The study about PSA self-tests also found that use was significantly associated with being male [146], but this presumably simply reflects the fact that the test is for a sex-specific condition.

An association with affluence was presented in eight studies about CAM, all six studies about the private sector, and the study about home BP monitors. An association was also presented in five studies about OTC medicine, but only two found an association after adjusting for other variables. Higher educational attainment was associated with the activity in three studies about CAM, one study about OTC medicine, two studies about the private sector and the study about home BP monitors. The study about OTC medicine found that both education and affluence were associated with use, but only education had an adjusted association. Education and affluence may be related, but many studies only looked at one of these factors or used unadjusted analyses, making it hard to draw conclusions about the relationship. Given the different measures of affluence used, it is also unclear whether only particular aspects of being affluent are associated with these activities. These associations were generally consistent though. The self-test study found that use of haematuria self-tests was associated with being relatively deprived (quartile 3), but, in contrast, use of PSA self-tests was less likely among people from this quartile.

Six studies about CAM, three studies about OTC medicine, and the study about home BP monitors suggested a link with various measures of poor health, but the analyses were often unadjusted. Conflicting evidence was presented by two more studies: one found that CAM patients had longer symptoms than GP patients but also lower pain scores [170], and the other reported that private care was less likely among people who were limited in their daily activities than other people [187].

Three studies about CAM and one about OTC medicine suggested an association with healthy lifestyles, for example being a non-smoker or being active in two high quality population-based surveys about the use of CAM [151 & 152] and herbal supplements [180]. Similar to this, another study about CAM use found an association with being health conscious and knowledgeable about health [161]. Two studies also found that CAM users were more likely to believe that they controlled their health [169] or less likely to believe that doctors control their health than users of orthodox medicine [161]. Finally, some studies considered reasons for using CAM or OTC medicine, which tended to focus on an acquaintance's influence or the advantages of the activity compared with orthodox medicine's disadvantages.

4.4.9 Summary of this section

This section set out the results of the systematic review of the literature for evidence for factors that may be associated with the use of self-tests and, because of the lack of evidence in this area, CAM, OTC medicine, private health care, and home BP monitors. The objective of this part of the study was to add to the list of factors that may be associated with self-test use (see section 4.5.11).

The number of potentially eligible papers that were identified for each activity and by each bibliographic database were described. Exclusions were then outlined, leaving 49 eligible papers that were identified in April 2007. Most (n=28) were identified by Medline and most (n=30) were related to CAM. These 49 papers described 46 unique studies. One further eligible paper was identified during a supplementary search for papers related to self-testing in July 2008. This presented further results from a medium quality survey already identified during searches related to home BP monitors, giving an overall total of 50 papers and 46 studies.

The reviewed evidence suggests that CAM and OTC medicine users tend to be female, middle-aged, have some measure of affluence and/or are well-educated with some measure of poor health, and that people who use the private sector are generally middle-aged and have some measure of affluence and/or are educated. Some other factors may also be associated with using these activities, but they were not as universally studied so the results are less conclusive. Four studies about CAM and one about OTC medicine suggested a link with healthy lifestyles or being health conscious and knowledgeable about health. Two studies also found that CAM users were more likely to believe that they control their health or less likely to believe that doctors control their health than users of orthodox medicine.

The next section describes the design of the in-depth questionnaire, bringing together evidence from the interviews with respondents to the initial questionnaire who had used self-tests and the systematic literature review.

4.5 Design of in-depth questionnaire

4.5.1 Overview of this section

The interviews lead to a better understanding of the experience of self-testing, and the interviews and systematic review generated a list of factors that may be associated with self-test use. This informed the design of an in-depth questionnaire to obtain details of self-test use reported on the initial questionnaire and information on potentially associated factors. This section describes the design of the in-depth questionnaire, bringing together the evidence from the interviews and systematic literature review. The rationale for including each question in the order that they appear on the questionnaire, that is the supporting evidence from the interviews and/or systematic literature review, is summarised in table 12 and described in detail in the following sections. The questionnaire is reproduced in appendix 27. This is the version sent to respondents to the initial questionnaire who had not reported self-test use: questionnaires sent to people who had reported use included a section asking for details so that use could be confirmed (see figure 2).

Table 12: Rationale for the content of the in-depth questionnaire (appendix 27).

Questions about:	Factors identified by systematic review:	Factors identified by interviewees:	Other rationale:
Section 1: *Background information*			
Q1 – Age	Middle-aged		Check correct person completed questionnaire
Q2 – Sex	Female		
Q3 – Long-term illness	Poor health		
Q4 – Working as a health professional		Accessed tests at work	
Q5 – Qualifications	Educational attainment		
Section 2: *Knowledge and views of self-tests*			
Q1 – Confidence using self-tests			Self-efficacy moderates health locus of control (see section 8)
Q2 – Knowledge of self-tests			Users might simply know about self-tests
Section 3: *Habits and lifestyle*			
Q1-3 – Smoking, exercise and diet	Healthy behaviours	Took routine steps to improve their health	
Q4 – Use of the internet		Used the internet to seek information about health	
Section 4: *Knowledge of health recommendations*			
Q1-2 – Health recommendations	Knowledgeable about health	Sought information about health	
Section 5: *Information about health*			
Q1-2 – Use of information sources	Knowledgeable about health Knew about activities from family and friends	Sought information about health from a variety of sources	
Section 6: *Health status*			
Q1-8 – SF8	Poor health		
Q9-10 – History of relevant conditions or tests			Non-users might simply think they do not have the condition or have been tested elsewhere
Q11 – Frequency of thoughts about improving health		Believed they were able to influence their health Took routine steps to improve their health	
Q12 – Frequency of thoughts about future illnesses		Self-tested because of a known risk	

Table continued on next page

Questions about:	Factors identified by systematic review:	Factors identified by interviewees:	Other rationale:
Section 7: *Views and experiences of healthcare*			
Q1 – Views about health checks and medical tests		Self-tested as a routine check, to satisfy curiosity, for reassurance	
Q2 – Views about visiting GP		Believed benefits of self-testing included being anonymous Believed evidence was needed to justify a visit to the doctor, the doctor should not be bothered unless it was really necessary, symptoms or risk factors were needed to be tested by the doctor, severe symptoms were needed to visit the doctor	
Q3-5 – Access to care		Believed self-testing was convenient contrasted with the practical difficulties of visiting the doctor	
Q6 – Satisfaction with GP	Reasons included orthodox medicine's drawbacks e.g. rushed appointments	Dissatisfied with past care	
Q7-8 – Overall satisfaction		Believed they had less than ideal care due to the pressure on health services	
Section 8: *Beliefs about health*			
Statements 1-4 – Health value			Health value is a moderator of health locus of control
Statements 5-22 – Health locus of control	Believed in ability to control own health and that doctors did not do so	Believed being in control of their health was beneficial Believed they were able to influence their health	Health locus of control scale assesses person's belief about whether his/her health depends on his/her actions

4.5.2 Background information

Section 1 of the in-depth questionnaire (appendix 27) asked for socio-demographic background information. The first and second questions asked for age and sex as being female and middle-aged was consistently associated with use of similar activities in the systematic literature review (see section 4.4.8). These details would also be used to confirm that the same person completed the initial and in-depth questionnaires. The third question asked about long-term illness because there is a fairly consistent association in the literature between various measures of poor health and the use of similar activities (see section 4.4.8). The fourth question asked whether the respondent had worked as a health professional because the interviews suggest that some self-test use is associated with access to tests at work (see section 4.3.6). The fifth question asked for qualifications because the systematic literature review suggested that similar activities may be associated with higher educational attainment (see section 4.4.8). The wording for this question and the third question about long-term illness are taken from the Census [74]. There was also a consistent association in the literature between being affluent and activities that are similar to self-testing (see section 4.4.8), but this was assessed with the IMD derived from respondents' postcodes [80, 81] rather than via the in-depth questionnaire.

4.5.3 Knowledge and views of self-tests

Section 2 of the in-depth questionnaire (appendix 27) asked about the person's knowledge and views about self-tests. The health locus of control scale assesses a person's belief about whether his/her health is dependent on his/her actions [114].

This was included in section 8 of the in-depth questionnaire because there is some evidence from the literature that people who take part in similar activities believe that they can control their own health (see section 4.4.8), and interviewees felt that they could affect their own health and that self-testing assisted them in controlling their health (see box 7). Self-efficacy refers to a person’s belief that he or she can actually carry out a behaviour [118]. This is theoretically likely to be a moderator of the relationship between health locus of control and behaviours such as self-testing because someone could believe that they can control their own health, but they may not believe that they can actually carry out the behaviour in question. The first question of section 2, therefore, asked about how confident respondents would be using self-tests. The second question asked about respondents’ knowledge of self-tests as the only difference between users and non-users might be that users knew that self-tests were available.

4.5.4 Habits and lifestyle

Section 3 of the in-depth questionnaire (appendix 27) asked about habits and lifestyle. The interviews suggest that self-test use may be related to having a positive attitude to health, particularly believing you can positively influence your health and/or taking routine steps to improve or safeguard your health (see box 7). There is also some fairly consistent evidence from the literature that, although people who undertake similar activities have relatively poor health, they tend to engage in healthy behaviours, for example not smoking (see section 4.4.8). Questions 1 to 3 of section 3, therefore, asked about behaviours related to health, specifically smoking, exercise and diet. Question 4 asked about the internet as some interviewees had used the internet to seek out information about health-related issues (see section 4.3.7.1.4).

4.5.5 Knowledge of health recommendations

Section 4 of the in-depth questionnaire (appendix 27) asked about knowledge of recommendations about how to stay healthy [191, 192] as interviewees who had used self-tests described finding out about health-related issues (see box 7). There is also some weak evidence from the literature that people who use similar activities are knowledgeable about health (see section 4.4.8).

4.5.6 Health information

Section 5 of the in-depth questionnaire (appendix 27) asked about getting advice about a health problem or how to stay healthy. Having a positive attitude towards and taking an active role in your health was a key finding from the interviews (see box 7 and section 4.3.7.3) and interviewees obtained health information from a variety of sources, for example friends and family or the media (see section 4.3.7.1.4). There is also some evidence from the literature that people who take part in similar activities take an active role in understanding their health and illnesses (see section 4.4.8) and that they know about the activities from friends or family (see section 4.4.8). Section 5, therefore, asked how many times respondents had used different information sources, including advice from different people, over the last 12 months. The lists were based on information sources mentioned during the interviews (see sections

4.3.7.1.4 and 4.3.7.2.1), although other relevant sources or people were also included, for example NHS information sources or professionals.

4.5.7 Health status

Section 6 of the in-depth questionnaire (appendix 27) asked for information about the person's health status and how often they thought about how to stay healthy or future illnesses. As well as the question about long-term illness in the first section, section 6 asked about health status because there is a fairly consistent association in the literature between measures of poor health and similar activities (see section 4.4.8). Questions 1 to 8 are the SF-8, which is a validated measure of health status [193].

Questions 9 and 10 asked whether the person thought they might have or have been recently tested for any of the conditions listed, which were taken from the list of self-tests on the initial questionnaire (appendix 11). The first question was included because the only difference between users and non-users might be that non-users did not think that they had any condition for which there are self-tests. The second question was included because people who have recently been tested for a condition may be at a lower risk of testing themselves for that condition.

Believing you can influence your health and taking steps to do so and believing you were at risk of a condition arose as factors potentially associated with self-testing during the interviews (see box 7). Although taking steps to influence your health was addressed by asking about healthy behaviours, questions 11 and 12 asked directly about whether the respondent frequently thought about ways to improve their health or about illnesses that they might get in the future.

4.5.8 Views and experiences of healthcare

Section 7 of the in-depth questionnaire (appendix 27) asked about the person's views and experiences of healthcare. Questions 1 and 2 asked whether the respondent agreed or disagreed with statements generated from the interview transcripts related to possible motivators for self-testing (see box 7). The questions were included to determine whether these statements translate to attitudes that are associated with using self-tests. The statements expressed by self-test users are the first three statements in the first question and the first six statements in the second question. Questions 3 to 5 dealt with access issues as some interviewees felt that self-testing was more convenient than visiting the doctor (see box 7).

Experiences of and attitudes to healthcare was a key sub-theme in the interviews. Some people may have been motivated to use self-tests by dissatisfaction with past care, and interviewees also described less than ideal care, which they perceived was due to the pressure on health services (see box 7). Similar to this, there is evidence in the literature for push factors related to dissatisfaction with conventional care being associated with CAM use, for example rushed appointments (see section 4.4.8). Question 6, therefore, asked about satisfaction with different aspects of GP consultations. This was adapted from the GPAQ [113]: the "Excellent" option was omitted to give a balanced range of possible positive and negative responses in line with other questions. Questions 7 and 8 asked about overall satisfaction with care provided to respondents and their relatives.

4.5.9 Beliefs about health

Section 8 of the in-depth questionnaire (appendix 27) asked about beliefs about health. There is some evidence from the literature that people who take part in similar activities believe that they can control their own health (see section 4.4.8), and interviewees felt that they could affect their own health and that self-testing assisted them in controlling their health (see box 7). Section 8, therefore, included the health locus of control scale [194]. This assesses a person's belief about whether his or her health status is determined by the actions of individuals or chance and, if it is determined by individuals, whether the locus of that control is internal, that is dependent on the person's own actions, or external, that is dependent on the actions of others [114]. The general hypothesis for the health locus of control scale is that people who score highly on the internal dimension, that is who believe that their own behaviour determines their health, are more likely to carry out healthy behaviours than people who have a low score on that dimension or who score highly on the chance subscale, that is who believe that chance determines their health [195].

Health locus of control does not operate alone to determine behaviour potential [118, 119, 195]. There are several moderators that are postulated as being possibly important from a theoretical viewpoint, most usually self-efficacy and health value. Social learning theory states that the potential for a behaviour to occur is a joint function of an expectancy that the behaviour will lead to a particular reinforcement and the value of that reinforcement to the individual: health locus of control should only predict behaviour potential if the outcome in question is valued [118]. In line with this, the importance of health to an individual is believed to influence his/her behaviour with respect to health, and there is some evidence to indicate that the health locus of control scale predicts behaviour better if health is highly valued [119]. The first four statements of section 8, therefore, assessed the value placed on health.

Self-efficacy refers to a person's belief that he or she can actually carry out a behaviour [118]. This is theoretically likely to be a moderator of the relationship between health locus of control and behaviour because someone could value health and believe that they could affect their own health, but they may not believe that they can actually carry out the behaviour in question or believe that doing it would lead to good health. Question 1 of section 2, therefore, asked about self-efficacy, that is respondents' belief that they could actually do a self-test (see section 4.5.3).

Health locus of control and its moderators, health value and self-efficacy, could be the mechanism by which other factors lead to self-testing. Higher educational attainment, for example, has been associated with self-efficacy and not believing that chance determining health status [196]. Similar to this, socioeconomic differences in healthy lifestyles have been associated with different beliefs about health, such as health locus of control, leading to the conclusion that these beliefs may arise through variations in life opportunities and exposure to material hardship and ill health [197]. Higher educational attainment and sociodemographic status may, therefore, be associated with self-testing because they lead to an internal health locus of control, a high value given to being healthy and high self-efficacy. Including health locus of control and its moderators, therefore, provided an opportunity to start to explain the pathways by which the other variables may operate to lead to self-testing.

4.5.10 Self-test use

For people who said on the initial questionnaire that they had used a self-test and/or test for high BP, an additional section for each of these tests was included after the first section of the in-depth questionnaire (figure 2). This aimed to describe why respondents had used tests and how they had accessed them, particularly as a substantial proportion of interviewees had used a friend's testing equipment or tests that were available at work, rather than buying a test (see section 4.3.6).

Some interviewees who had marked self-tests on the initial questionnaire had only actually used those tests with the involvement of a clinician. This section, therefore, also aimed to enable the exclusion of respondents who obtained the test from or who used the test because it was suggested to them by a clinician. The pilot work (see section 3.6.3) indicated that including specific statements – "The test was given to me by a doctor or nurse to use at home" and "The test was suggested to me by a doctor or nurse" – was more reliable than expecting respondents to mark the "Other" option and describe this in the space provided. Use was considered relevant as long as no clinician was involved before the test was used. If the person indicated that a clinician was involved, either by marking one of these statements or adding free text, the test use was excluded.

4.5.11 Summary of this section

The interviews generated a better understanding of the experience of self-testing, and the interviews and systematic literature review generated a list of factors that may be associated with self-test use. This section described the rationale for the design of the in-depth questionnaire (appendix 27), bringing together evidence from the interviews and the systematic literature review. The factors identified by the interviews and systematic literature review and the resulting sections and questions, where the whole section is not relevant, are summarised in boxes 9 and 10. The next section estimates the prevalence of self-test use based on use reported in the initial questionnaire and use confirmed by the in-depth questionnaire.

Box 9: Factors potentially associated with self-test use identified by interviewees.

Factors identified by interviewees [a] with resulting sections and questions, where the whole section is not relevant, from the in-depth questionnaire (appendix 27):

- Used tests marked on the initial questionnaire with the involvement of a clinician (additional section for respondents who had used self-tests).
- Accessed self-tests in a variety of ways rather than just buying one (additional section for respondents who had used self-tests).
- Worked as a health professional (Section 1: Background information, question 4).
- Favoured routine health checks (Section 7: Views and experiences of healthcare, question 1).
- Believed they were at risk of a condition (Section 6: Health status, question 12).
- Curious about health (Section 7: Views and experiences of healthcare, question 1).
- Believed medical tests can be reassuring (Section 7: Views and experiences of healthcare, question 1).
- Believed being in control of their health was beneficial (Section 8: Beliefs about health).
- Believed being anonymous was beneficial (Section 7: Views and experiences of healthcare, question 2).
- Believed that self-testing was more convenient, contrasted with the practical difficulties of visiting the doctor (Section 7: Views and experiences of healthcare, questions 3 to 5).
- Dissatisfied with past care (Section 7: Views and experiences of healthcare, questions 6 to 8).

[a] Following the order they are presented in box 7.

Box continued on next page

- Had less than ideal care due to the pressure on health services (Section 7: Views and experiences of healthcare, questions 6 to 8).
- Believed evidence was needed to justify a visit to the doctor due to the pressure on health services (Section 7: Views and experiences of healthcare, question 2).
- Believed the doctor should not be bothered unless it was really necessary (Section 7: Views and experiences of healthcare, question 2).
- Believed symptoms or risk factors were needed to be tested by the doctor (Section 7: Views and experiences of healthcare, question 2).
- Believed severe symptoms were needed to visit the doctor (Section 7: Views and experiences of healthcare, question 2).
- Believed they could influence their health and/or took routine steps to safeguard their health (Section 3: Habits and lifestyle, questions 1 to 3; Section 6: Health status, question 11; Section 8: Beliefs about health).
- Actively sought information about health-related issues and obtained information from a variety of sources (Section 3: Habits and lifestyle, question 4; Section 4: Knowledge of health recommendations; Section 5: Information about health).

Box 10: Factors potentially associated with self-test use identified by the systematic literature review.

Factors identified by the systematic literature review [a] with resulting sections and questions, where the whole section is not relevant, from the in-depth questionnaire (appendix 27):

- Female and middle-aged (Section 1: Background information, questions 1 and 2).
- Affluence (IMD derived from respondents' postcodes).
- Higher educational attainment (Section 1: Background information, question 5).
- Poor health (Section 1: Background information, question 3; Section 6: Health status, questions 1 to 8).
- Healthy behaviours (Section 3: Habits and lifestyle, questions 1 to 3).
- Knowledgeable about health (Section 4: Knowledge of health recommendations; Section 5: Information about health).
- Prompted or influenced by acquaintances or family members (Section 5: Information about health, question 1).
- Believed in ability to control own health and that doctors did not do so (Section 2: Knowledge and views of self-tests, question 2; Section 8: Beliefs about health).
- Push factors related to dissatisfaction with conventional care (Section 7: Views and experiences of healthcare, questions 6-8).

[a] Following the order they are presented in section 4.4.8.

4.6 Prevalence of self-test use

4.6.1 Overview of this section

This section sets out estimates of the prevalence of self-test use derived from the initial questionnaire and more robust estimates based on use confirmed by the in-depth questionnaire. The initial questionnaire asked whether a population-based sample had used any of a list of self-tests, a pregnancy test or a test for high BP. The in-depth questionnaire was sent to willing respondents to the initial questionnaire. Questionnaires sent to people who had reported use of a self-test or a test for high BP included a section asking for details so that use could be confirmed. Appendices 2 to 4, 7 and 8 show the flow of participants through these parts of the study and the published paper is included in appendix 10 [73].

This section describes numbers of initial questionnaires that were sent out, returned because they were undelivered, sent back blank and completed, and excluded and included in the prevalence estimate. Response rates for men and women of different ages are compared, as are the sex- and age-profiles of respondents, the mailed population and the population of England and Wales. Characteristics provided by respondents (ethnic group, self-rated health and employment status) are compared with the population of England. Crude and sex- and age-standardised prevalence are set out for each self-test and tests for pregnancy and high BP separately. Combined analyses calculate the crude and standardised prevalence for (1) any self-test, (2) any self-test and/or test for high BP but excluding a test for pregnancy, and (3) any self-test and/or tests for high BP and pregnancy.

The section then sets out the number of respondents to the initial questionnaire who reported use of a self-test and/or test for high BP and who consented to an in-depth questionnaire. The numbers of in-depth questionnaires that were sent out, returned because they were undelivered, sent back blank and completed, and excluded and included in the refined prevalence estimate are described. The sex- and age-profiles of people who reported use on the initial questionnaire, people who were sent in-depth questionnaires and eligible respondents are compared.

For each test, the proportion of respondents who initially reported use who had actually used the test without a clinician is described. Crude prevalence is then re-estimated by dividing the number of people who had used a test without a clinician by the number of people from the final four practices who returned the initial questionnaire and were eligible for inclusion in the initial prevalence estimate, and sex- and age-standardised prevalence is also re-estimated. This bottom-line estimate is done for each self-test and test for high BP separately, and for (1) any self-test excluding a test for high BP and (2) any self-test and/or test for high BP. The results of exploratory analyses are also set out. These involved recalculating the standardised prevalence assuming that everyone who was eligible for inclusion in the initial prevalence estimate and who reported use on the initial questionnaire but did not return an eligible in-depth questionnaire had the same sex- and age-specific rates of confirmed use as eligible responders. Lastly, the ways that respondents said that they accessed different tests and their reasons for using them are compared.

4.6.2 Initial questionnaire

4.6.2.1 Study population

Eighty four of 8048 initial questionnaires that were mailed were undelivered, for example because the addressee had moved away (table 13), leaving 7964 questionnaires. Two thirds were returned (n=5344, 67%): 259 were returned blank and 5085 (64%) were completed, as shown in the flowchart in appendix 2.

Table 13: Reasons why initial questionnaires were undelivered.

Reason	Number
Addressee gone away	48
Addressee unknown	24
Addressee in care home or hospital	3
Addressee/partner died [a]	3
Incomplete address	2
Building had been demolished	1
Addressee misinterpreted [b]	1
Not given	2
Total	84

[a] Partners were also excluded in cases of recent bereavement to save distress.

[b] A father and son had the same name and address. The son's questionnaire was returned by the father who enclosed a note saying that he had already completed and returned a questionnaire.

Six people who marked non-sex-appropriate tests were excluded, as shown in the flowchart in appendix 3: three women reported self-tests for sperm count, two women reported self-tests for prostate disorders, and one man reported a self-test for the menopause. Some of them had also marked other tests (box 11), but they were completely excluded as their non-sex-appropriate answers indicate that the questionnaire may have been misunderstood. Men who reported use of pregnancy tests (n=14) were not excluded though as it was felt that this probably related to use as part of a couple and did not indicate that the questionnaire had been misunderstood, although analysis of the use of pregnancy tests was restricted to women.

Box 11: Self-tests reported by respondents who marked non-sex-appropriate tests.

A **female** who reported use of a self-test for **sperm count** also reported use of tests for cholesterol, diabetes, high blood pressure, menopause, pregnancy, urine infections and vaginal disorders.

A **female** who reported use of a self-test for **sperm count** also reported use of tests for pregnancy and urine infections.

A **female** who reported use of a self-test for **sperm count** also reported use of a pregnancy test.

A **female** who reported use of a self-test for **prostate disorders** also reported use of tests for diabetes and high blood pressure.

A **male** who reported use of a self-test for the **menopause** also reported used of tests for blood in the stool, high blood pressure, prostate disorders, sperm count and urine infections.

One hundred and six people had given a different sex and/or age (>2 years) from the details provided by the general practice, as shown in the flowchart in appendix 3. Fifty two of these discrepancies were resolved: five were due to data entry errors and 47 were the result of people living at the same addresses completing each other's questionnaires. This left 54 people who did not appear to be the intended recipient, and these people were, therefore, excluded.

This left 5025 (63%) eligible completed questionnaires, as shown in the flowchart in appendix 2. Nine “other” self-tests were excluded because the free text indicated that the test did not involve a biological sample (body fat percentage, body mass index, depression, fitness levels, heart rate monitor, high temperature, and oxygen/pulse test written by one person, and peak flow written by two people). The respondents were not excluded though, that is they still contributed to the denominator and other self-tests that they had marked were included, because it was felt that the free text answer did not necessarily indicate that they had incorrectly completed the named self-tests section. Another person had checked the “other” self-test box but written “indigestion pills”. This “other” self-test was similarly excluded and the respondent, who had not checked any named self-tests, was included.

The sex and age profile of the 5025 people who completed eligible questionnaires was broadly similar to the population of England and Wales in 2006 (table 14). The highest proportions of women in England and Wales (19%) and the study population (20%) were aged 35-44 and the lowest proportions were aged 85 years or over (4% and 2% respectively). The highest proportion of men in England and Wales (20%) were aged 35-44 and 19% of men in the study population were in this age group. The lowest proportion of men in England and Wales (2%) and the study population (2%) were aged 85 or over. Response rates varied by age group. Women had higher response rates than men until retirement age. The youngest age groups had the lowest response rates, but, in line with the general pattern, women aged 25-34 had a considerably higher response rate (54%) than their male counterparts (34%).

Table 14: Response rates to the initial questionnaire and age and sex of recipients and eligible respondents compared with the population of England and Wales.

	England & Wales [a]		Study population [b]		Returned eligible questionnaire [b]		
	n (1000s)	% of total	n	% of total	n	% of total	Response rate (%)
Male	20404	48	3891	49	2285	45	59
Female	21688	52	4073	51	2740	55	67
Total	42091		7964		5025		
Male							
18-24	2548	12	360	9	114	5	32
25-34	3517	17	536	14	180	8	34
35-44	4080	20	758	19	397	17	52
45-54	3419	17	714	18	429	19	60
55-64	3118	15	737	19	543	24	74
65-74	2111	10	473	12	374	16	79
75-84	1267	6	250	6	204	9	82
85+	344	2	63	2	44	2	70
Female							
18-24	2436	11	360	9	136	5	38
25-34	3523	16	526	13	283	10	54
35-44	4134	19	796	20	513	19	64
45-54	3482	16	725	18	517	19	71
55-64	3224	15	735	18	582	21	79
65-74	2333	11	522	13	419	15	80
75-84	1778	8	316	8	234	9	74
85+	778	4	93	2	56	2	60

[a] Office for National Statistics. Mid-2006 population estimates: estimated resident population. Available at http://www.statistics.gov.uk/STATBASE/Product.asp?vlnk=15106. Accessed 17 June 2008.

[b] Age and sex from practice records.

Nearly 97% of 4992 respondents who gave their ethnic group were white (n=4838), more than the estimated 89.9% (n=34533.7k) of the population of England in 2006 (n=38421.8k) [198]. Most people who answered the question (n=5002) reported good (61.1%, n=3058) or fairly good health (30.6%, n=1529) and only 8.3% (n=415) reported not good health. Respondents to the 2001 Census in the same age group (n=37194.4k) had a similar pattern [199]: 62.7% (n=23309.4k) reported good health, 26.3% (n=9766.8k) reported fairly good health, and 11.1% (n=4118.1k) reported not good health. Most of the 4999 respondents who gave their employment status were employed (47.6%, n=2379), retired (27.2%, n=1362) or self-employed (11.2%, n=560). Again, the pattern was similar to Census respondents [200]: most were employed (54.0%, n=18519.2k) followed by retired (14.0%, n=4810.5k) and self-employed people (8.6%, n=2951.5k). The Census reported, however, that only 14.0% of people were retired compared with 27.2% of people from this survey. The Census data are for people aged 18-74 years (n=34300.8k), but 19.1% of people from this survey under 75 years (855/4468 based on age from practice records) said that they were retired, still considerably more than the population of England in 2001.

4.6.2.2 Prevalence of use

Six hundred and seventy eight (135 per 1000) people said that they had used a test other than for pregnancy or high BP, as shown in the flowchart in appendix 4, ranging from 118 per 1000 in men to 149 per 1000 in women (table 15). The age-standardised prevalence was 102 (95% CI 89 to 116) per 1000 men and 144 (95% CI 129 to 159) per 1000 women (table 16). Most people (n=537, 79%) said they had used one type of test, but 103 reported two types of tests, 24 reported three types of tests, and 14 reported four or more types of tests. The most commonly reported test, by 341 (68 per 1000) people, was for diabetes.

Table 15: Crude prevalence of test use reported on the initial questionnaire.

Test	All (n=5025) n	All (n=5025) Prevalence [a]	Men (n=2285) n	Men (n=2285) Prevalence [a]	Women (n=2740) n	Women (n=2740) Prevalence [a]
Diabetes	341	67.9	136	59.5	205	74.8
Urine infection	127	25.3	21	9.2	106	38.7
Cholesterol	120	23.9	57	24.9	63	23.0
Blood in the stool	114	22.7	66	28.9	48	17.5
Vaginal infection					27	9.9
Allergies	48	9.6	15	6.6	33	12.0
Menopause					25	9.1
Prostate disorders			11	4.8		
Low blood count	20	4.0	9	3.9	11	4.0
Sperm count			8	3.5		
Kidney disorders	10	2.0	**	**	**	**
Chlamydia	9	1.8	**	**	**	**
HIV infection	**	**	**	**	**	**
Other	18	3.6	6	2.6	12	4.4
Subtotal [b]	**678**	**134.9**	**269**	**117.7**	**409**	**149.3**
High blood pressure	822	163.6	389	170.2	433	158.0
Subtotal [c]	**1232**	**245.2**	**539**	**235.9**	**693**	**252.9**
Pregnancy					1023	373.4
Total [d]					**1450**	**529.2**

[a] Prevalence per 1000 respondents.

[b] Refers to use of any self-test excluding a test for high blood pressure or pregnancy and is less than the sum of the components because some respondents used more than one type of test.

[c] Refers to use of any self-test and/or a test for high blood pressure but excluding a test for pregnancy and is less than the sum of the components because some respondents used more than one type of test.

[d] Refers to use of any self-test and/or tests for high blood pressure and pregnancy and is less than the sum of the components because some respondents used more than one type of test.

** Numbers less than five and results that could lead to the deduction of numbers less than five have been masked to protect against deductive disclosure.

Table 16: Age standardised prevalence of test use reported on the initial questionnaire.

Test	Men (n=2285) Prevalence [a]	Men (n=2285) 95% confidence interval	Women (n=2740) Prevalence [a]	Women (n=2740) 95% confidence interval
Self-test excluding for high blood pressure or pregnancy	102.4	88.8 to 116.1	144.2	129.3 to 159.2
High blood pressure	142.8	127.2 to 158.5	140.9	126.9 to 155.0
Subtotal [b]	197.8	179.3 to 216.2	236.4	217.6 to 255.2
Pregnancy			423.1	395.6 to 450.5
Total [c]			**554.6**	**524.1 to 585.1**

[a] Prevalence per 1000 respondents.

[b] Refers to use of any self-test and/or a test for high blood pressure but excluding a test for pregnancy.

[c] Refers to use of any self-test and/or tests for high blood pressure and pregnancy.

Use of a test for high BP was reported by 822 (164 per 1000) people (table 15), as shown in the flowchart in appendix 4, and most (n=554, 67%) reported no other use or only having also used a pregnancy test. The crude prevalence of the reported use of a self-test for high BP was 170 per 1000 men and 158 per 1000 women. The age-standardised prevalence was 143 (95% CI 127 to 159) per 1000 men and 141 (95% CI 127 to 155) per 1000 women (table 16).

Overall, use of a test for high BP and/or another test other than for pregnancy was reported by 1232 (245 per 1000) respondents, as shown in the flowchart in appendix 4, ranging from 236 per 1000 in men to 253 per 1000 in women (table 15). The age-standardised prevalence was 198 (95% CI 179 to 216) per 1000 men and 236 (95% CI 218 to 255) per 1000 women (table 16).

Use of a pregnancy test was reported by 1023 (373 per 1000) women (table 15), and most (n=757, 74%) reported not using any other tests, as shown in the flowchart in appendix 4. The age-standardised prevalence of having used a pregnancy test was 423 (95% CI 396 to 451) per 1000 women (table 16). Overall, 1450 women reported having used any test, that is a test for high BP and/or a pregnancy test and/or another test. The crude and age-standardised prevalence of having using any test were 529 and 555 (95% CI 524 to 585) per 1000 women respectively.

4.6.3 In-depth questionnaire

4.6.3.1 Study population

Nine hundred and four people from the final four practices who were eligible for an in-depth questionnaire said that they had used a test for high BP and/or another test other than a pregnancy test, as shown in the flowchart in appendix 7. Six hundred and sixty five of them consented to an in-depth questionnaire, but 658 were sent out: four people were excluded because it was not possible to confirm if they were the intended recipient as they did not give an sex and/or age on the initial questionnaire, and three people returned the initial questionnaire after the second questionnaires had been mailed. Two questionnaires were undelivered, as shown in the flowchart in appendix 8, leaving 656 (table 17). Over three quarters were returned (n=497, 76%) of which 26 were blank, leaving 471 (72%) completed questionnaires. Three were excluded because the person gave a different sex and/or age than the details held by the practice, leaving 468 (71%) eligible questionnaires. These people had a similar age and sex profile to people who initially reported having used a test for high BP and/or another test other than for pregnancy (table 17).

Table 17: Response rates to the in-depth questionnaire and age and sex of recipients and eligible respondents compared with people who initially reported use.

	Reported use [a, b]		Study population for in-depth questionnaire [b]			Returned eligible in-depth questionnaire [b]		
	n	% of total	n	% of total	% of initial use	n	% of total	Response rate (%)
Male	408	45	296	45	71	215	46	73
Female	496	55	360	55	72	253	54	70
Total	904		656		72	468		71
Male								
18-34	22	5	11	4	50	7	3	64
35-44	39	10	30	10	75	18	8	60
45-54	61	15	47	16	76	33	15	70
55-64	141	35	103	35	71	78	36	76
65-74	98	24	73	25	74	56	26	77
75+	47	11	32	11	68	23	11	72
Female								
18-34	56	11	38	11	68	22	9	58
35-44	73	15	53	15	73	41	16	77
45-54	94	19	75	21	79	54	21	72
55-64	141	28	106	29	75	76	30	72
65-74	90	18	62	17	68	42	17	68
75+	42	8	26	7	62	18	7	69

[a] Use of any self-test and/or tests for high blood pressure but excluding tests for pregnancy.

[b] Age and sex from initial questionnaire or from practice if not available from initial questionnaire.

4.6.3.2 Prevalence of use

One hundred and thirty two (56%) of the 235 people who initially reported use of a test other than for high BP or pregnancy indicated that they had used this test without clinical involvement (table 18), as shown in the flowchart in appendix 8. Use was usually confirmed for the tests most commonly reported on the initial questionnaire: 74 of 119 people who originally reported having used a diabetes test, 26 of 39 people who originally reported using a test for urine infections, 28 of 35 people who originally reported having used a cholesterol test, five of 7 people who originally reported using a test for vaginal infections, and 11 of 15 people who originally reported using a test for allergies confirmed their use. In contrast though, less than five of 49 people who initially said they had used a self-test for blood in the stool without a health professional had actually done so. No valid use was reported for less frequently reported tests for sperm count, kidney disorders, chlamydia or HIV infection.

The crude prevalence of the confirmed use of tests other than for high BP or pregnancy ranged from 23 per 1000 in men to 49 per 1000 in women (table 18). The age-standardised prevalence was 22 (95% CI 14 to 30) per 1000 men and 47 (95% CI 37 to 57) per 1000 women (table 19). If everyone who initially reported use but was not sent or did not return an eligible in-depth questionnaire had the same sex- and age-specific rates of confirmed use as eligible responders, the age-standardised prevalence would increase to 55 (95% CI 41 to 68) per 1000 men and 95 (95% CI 81 to 110) per 1000 women (table 19).

Table 18: Tests initially reported by eligible respondents to the in-depth questionnaire and crude prevalence of confirmed test use.

Test	Eligible questionnaire	Confirmed use					
		All (n=3547)		Men (n=1640)		Women (n=1907)	
	n	n	Prevalence [a]	n	Prevalence [a]	n	Prevalence [a]
Diabetes	119	74	20.9	19	11.6	55	28.8
Urine infection	39	26	7.3	**	**	**	**
Cholesterol	35	28	7.9	12	7.3	16	8.4
Blood in the stool	49	**	**	**	**	**	**
Vaginal infection	7					5	2.6
Allergies	15	11	3.1	**	**	**	**
Menopause	5					5	2.6
Prostate disorders	**			**	**		
Low blood count	**	**	**	0	0.0	**	**
Sperm count	**			0	0.0		
Kidney disorders	**	0	0.0	0	0.0	0	0
Chlamydia	**	0	0.0	0	0.0	0	0
HIV infection	0	0	0.0	0	0.0	0	0
Other	8	8	2.3	**	**	**	**
Subtotal [b]	235	132	37.2	38	23.2	94	49.3
High blood pressure	330	254	71.6	119	72.6	135	70.8
Total [c]	468	328	92.5	139	84.8	189	99.1

[a] Prevalence per 1000 respondents to the initial questionnaire.

[b] Refers to use of any self-test excluding a test for high blood pressure or pregnancy and is less than the sum of the components because some respondents used more than one type of test.

[c] Refers to use of any self-test and/or a test for high blood pressure but excluding a test for pregnancy and is less than the sum of the components because some respondents used more than one type of test.

** Numbers less than five and results that could lead to the deduction of numbers less than five have been masked.

Table 19: Age standardised prevalence of confirmed test use and postulated age standardised prevalence.

Test	Men (1640)		Women (n=1907)	
	Prevalence [a]	95% confidence interval	Prevalence [a]	95% confidence interval
Confirmed use				
Self-test excluding for high blood pressure or pregnancy	21.9	14.1 to 29.8	46.9	36.9 to 56.8
High blood pressure	57.5	46.0 to 69.1	63.2	51.9 to 74.5
Total [b]	**68.6**	**55.9 to 81.3**	**91.5**	**77.7 to 105.3**
Postulated use [c]				
Self-test excluding for high blood pressure or pregnancy	54.7	41.4 to 67.9	95.2	80.6 to 109.9
High blood pressure	112.2	95.0 to 129.3	122.8	106.7 to 138.8
Total [b]	**144.3**	**124.7 to 163.8**	**182.3**	**162.5 to 202.1**

[a] Prevalence per 1000 respondents to the initial questionnaire.

[b] Refers to use of any self-test and/or a test for high blood pressure but excluding a test for pregnancy.

[c] Postulated age standardised prevalence if everyone who initially reported use but was not sent or did not return an eligible in-depth questionnaire had the same sex- and age-specific rates of confirmed use as eligible responders.

Use of a test for high BP was confirmed for 254 (77%) of 330 people who initially reported use, as shown in the flowchart in appendix 8, ranging from 71 per 1000 in women to 73 per 1000 in men (table 18). The age-standardised prevalence was 58 (95% CI 46 to 69) per 1000 men and 63 (95% CI 52 to 75) per 1000 women (table 19). If everyone who initially reported use but was not sent or did not return an eligible in-depth questionnaire had the same sex- and age-specific rates of confirmed use as eligible responders, the age-standardised prevalence would increase to 112

(95% CI 95 to 129) per 1000 men and 123 (95% CI 107 to 139) per 1000 women (table 19).

Overall, use of a test for high BP and/or another test other than for pregnancy was confirmed for 328 (92 per 1000) respondents, as shown in the flowchart in appendix 8, ranging from 85 per 1000 in men to 99 per 1000 in women (table 18). The age-standardised prevalence was 69 (95% CI 56 to 81) per 1000 men and 92 (95% CI 78 to 105) per 1000 women (table 19). If everyone who initially reported use but was not sent or did not return an eligible in-depth questionnaire had the same sex- and age-specific rates of confirmed use as eligible responders, the age-standardised prevalence would increase to 144 (95% CI 125 to 164) per 1000 men and 182 (95% CI 162 to 202) per 1000 women (table 19).

People accessed different tests in different ways (table 20). People who had used cholesterol tests and tests for high BP were most likely to have bought them from a pharmacy to use at home. In contrast, people who had used tests for diabetes had usually borrowed a friend's or relative's testing equipment, and people who had used tests for urine infection had most often accessed testing equipment at work.

People also used tests for different reasons (table 21). The most common reasons for people who had used tests for high BP were because the test was available, a desire for reassurance and curiosity. Similar to this, the most common reasons for people who had used a cholesterol test were a desire for reassurance, because the test was available and curiosity. For diabetes, the most common reason was because of the family risk of the condition, followed by because the test was available, a desire for reassurance and curiosity. In contrast, although the number of users was smaller, most people who had used tests for urine infection said that this was because they had symptoms and wanted a diagnosis. This was also one of the most common reasons for using a test for allergies, although a similar number of users said that they had used the test simply because it was available.

Table 20: Methods reported on the in-depth questionnaire for accessing tests.

Test	High blood pressure		Diabetes		Cholesterol		Urine infection	
How accessed	n	% of users	n	% of users	n	% of users	n	% of users
Bought over the internet to use at home	16	6.3	**	**	**	**	**	**
Bought from pharmacy or chemists to use at home	143	56.3	18	24.3	15	53.6	9	34.6
Paid to have done at pharmacy or chemists	**	**	**	**	**	**	0	0
Done for free at pharmacy or chemists	11	4.3	8	10.8	5	17.9	**	**
Used equipment at work	23	9.1	19	25.6	**	**	13	50.0
Used friend's or relative's equipment	73	28.7	40	54.1	**	**	**	**
Other	23	9.1	**	**	**	**	0	0
Number of users [a]	254		74		28		26	

[a] Number of users is more than the sum of the ways tests were accessed as respondents were able to specify more than one way that they had accessed the test.

** Numbers less than five and results that could lead to the deduction of numbers less than five have been masked.

Table 21: Reasons reported on the in-depth questionnaire for using tests.

Test	High blood pressure		Diabetes		Cholesterol		Urine infection		Allergies	
Reason	n	% of users	n	% of users	n	% of users	n	% of users	n	% of users
Available	128	50.4	31	41.9	11	39.3	11	42.3	7	6.4
Curious	108	42.5	30	40.5	9	32.1	**	**	**	**
Like to do routine health checks	101	39.8	21	28.4	6	21.4	**	**	**	**
Reassurance	119	46.9	30	40.5	15	53.6	5	19.2	**	**
Symptoms and wanted diagnosis	34	13.4	20	27.0	0	0	21	80.8	6	5.5
Family risk of condition	58	22.8	32	43.2	**	**	0	0	**	**
Higher risk for other reasons	14	5.5	**	**	0	0	0	0	**	**
Didn't want to bother doctor	30	11.8	11	14.9	**	**	8	30.8	**	**
Easier and/or more convenient than visiting doctor	77	30.3	23	31.1	8	28.6	10	38.5	**	**
Embarrassed to go to doctor	0	0	0	0	0	0	0	0	0	0
Didn't think was suitable for doctor	22	8.7	10	13.5	**	**	**	**	**	**
Wanted evidence to justify visit to doctor	21	8.3	**	**	**	**	10	38.5	0	0
Been to doctor but not solved problem	0	0	**	**	0	0	**	**	**	**
Other	29	11.4	**	**	5	17.9	**	**	0	0
Number of users [a]	254		74		28		26		11	

[a] Number of users is more than the sum of the reasons given for using tests as respondents were able to specify more than one reason.

** Numbers less than five and results that could lead to the deduction of numbers less than five have been masked.

4.6.4 Summary of this section

This section set out estimates of the prevalence of self-test use derived from the initial questionnaire and based on use confirmed by the in-depth questionnaire. The initial questionnaire asked whether people from a population-based sample had used any of a list of self-tests or a pregnancy test or test for high BP. An in-depth questionnaire sent to people who had reported use of a test for high BP and/or another test other than for pregnancy included a section asking for details so that use could be confirmed, leading to a refinement of the prevalence estimate.

The initial questionnaire suggests that about one in 10 men and one in seven women have used a self-test other than for pregnancy or high BP. This was based on questionnaires received from 5025 people (63% of 7964 delivered) who had a broadly similar sex- and age-profile to the general population, although higher proportions of them were from white ethnic groups or retired rather than economically inactive for other reasons. The most commonly reported test was for diabetes.

The in-depth questionnaire sent to respondents to the initial questionnaire who reported use of a test for high BP and/or another test other than for pregnancy had a response rate of 71% (468 eligible completed of 656 delivered). This represented only 52% of such use reported on the initial questionnaire (904 people reported use of a test for high BP and/or another test other than for pregnancy on the initial questionnaire), but the sex- and age-profile of respondents was broadly similar to people who reported having used these tests on the initial questionnaire.

One hundred and thirty two (56%) of the 235 people who initially reported use of a test other than for high BP or pregnancy had used the test without clinical involvement. This meant that a lowest limit for prevalence could be calculated, that about one in 46 men and one in 21 women have used a test other than for high BP or pregnancy. This, however, did not take account of respondents to the initial questionnaire who were not sent or did not return an eligible in-depth questionnaire and who, therefore, could not contribute. To allow for them, an exploratory analysis was conducted. It was assumed that everyone who initially reported use but was not sent or did not return an eligible in-depth questionnaire had the same sex- and age-specific rates of confirmed use as eligible responders. As a result, it was estimated that around one in 18 men and one in 11 women have used a self-test other than for pregnancy that required them to take their own biological sample.

Finally, the in-depth questionnaire confirmed that people had accessed self-tests in a variety of ways, which varied depending on the type of test. People who had used cholesterol tests, for example, were most likely to have bought them from a pharmacy to use at home, whereas people who had used tests for diabetes had usually borrowed a testing device. People had also used tests for a range of reasons. People who had used cholesterol tests, for example, were most frequently looking for reassurance, whereas people who had used tests for urine infection usually had symptoms and wanted a diagnosis. The next section describes the results from the sections of the in-depth questionnaire that dealt with factors that may be related to self-test use.

4.7 Factors associated with self-test use

4.7.1 Overview of this section

Interviews with a sample of respondents to the initial questionnaire and a systematic literature review led to the design of an in-depth questionnaire to collect data on factors that may be related to self-test use. This was sent to willing respondents to the initial questionnaire who had and had not reported self-test use. Questionnaires sent to people who had used self-tests included an extra section asking for details of use so that this could be confirmed, enabling the determination of factors that predict confirmed self-test use.

This section presents an analysis of data from the in-depth questionnaire with the aim of determining factors that predict confirmed self-test use. The outcome variable was whether the respondent had ever used or had never used a self-test without clinical involvement. The explanatory variables in the analysis mostly originated from the in-depth questionnaire, although three (ethnic group, self-rated health and employment status) came from the initial questionnaire and IMD 2007 scores were assigned based on respondents' postcodes.

Initially, the mailing of the in-depth questionnaires is described: the sample of people who were eligible for an in-depth questionnaire, the subset who consented to a questionnaire, the number of people who were excluded and the reasons for exclusion, and the numbers of questionnaires that were sent out, undelivered, returned, completed and eligible for analysis. The accuracy of data entry is then reviewed, for sections about self-test use and sections collecting data on factors that may be associated with use.

A descriptive analysis is conducted for each explanatory variable, that is the proportion of people with each option. This is compared with population-based data from other sources, where available. Simple univariate analyses are then used to explore the association between the outcome variable and each explanatory variable. Appropriate statistical tests are applied and significant results are highlighted. Finally, forward stepwise multiple logistic regression analyses are used to identify those variables that together best predict self-test use. Two approaches are used: for the first, all explanatory variables are entered without selection; for the second, variables are selected for entry based on analyses of explanatory variables grouped according to their focus, for example personal characteristics. It was felt that the second approach would test the robustness of the analysis of all variables without selection and may give a model that indicates important factors from a fuller range of areas.

4.7.2 In-depth questionnaire mailing

Thirty eight of 5713 initial questionnaires mailed to people from the final four general practices were undelivered, leaving 5675. Two thirds were returned (n=3752, 66%): 157 were blank and 3595 (63%) were completed, as shown in the flowchart in appendix 2. Six people who reported using non-sex-appropriate tests (see section 4.6.2.1) and 84 people who gave a different sex and/or age from the details provided by the practice were excluded, although some of the age/sex discrepancies were later resolved, as shown in the flowchart in appendix 3. This left 3505 people from the final four practices who were eligible to be sent an in-depth questionnaire.

Two thousand two hundred and five (63%) of the 3505 people had consented to an in-depth questionnaire, but 2174 (98%) were sent out. Thirty one people were excluded, as shown in the flowchart in appendix 7: it was not possible to confirm if 11 people were the intended recipient as they did not give their sex and/or age on the initial questionnaire, three people added free text that contradicted their willingness to be sent another questionnaire, and 17 people returned the initial questionnaire after the in-depth questionnaires were mailed. Eight questionnaires were undelivered, leaving 2166. Three quarters were returned (n=1615, 75%), but 78 were blank, leaving 1537 (71%) completed questionnaires. Sixteen were excluded because the person gave a different sex and/or age (>2 years) from the general practice, leaving 1521 (70%) eligible questionnaires, as shown in the flowchart in appendix 8.

The 3505 people who were eligible to be sent an in-depth questionnaire included 904 people already described in section 4.6.3.1 who initially reported use of a test for high BP and/or another test other than for pregnancy, as shown in the flowchart in appendix 7. These 904 people included 487 people who initially reported use of a test other than for high BP or pregnancy, also as shown in the flowchart in appendix 7. Three hundred and sixty eight of them (76%) consented to an in-depth questionnaire, but 363 (76%) were sent out. Five people were excluded, as shown in the flowchart in appendix 7: it was not possible to confirm if four people were the intended recipient as they did not give their sex and/or age on the initial questionnaire, and one person returned the initial questionnaire after the in-depth questionnaires were mailed. Two questionnaires were undelivered, leaving 361. About 70% were returned (n=254), but 16 were blank, leaving 238 (66%) completed questionnaires. Three were excluded because the person gave a different sex and/or age (>2 years) from the practice, leaving 235 (65%) eligible questionnaires, as shown in the flowchart in appendix 8.

4.7.3 Report on data quality

4.7.3.1 Sections collecting data on potentially associated factors

One hundred and fifty six single- and double-entered data items were compared for 241 questionnaires (approximate 15% sample) (see section 3.6.7). There were 480 discrepancies concerning 180 questionnaires, although most had few discrepancies: 158 had one to four and only 22 had five or more discrepancies.

There were no discrepancies for 48 of the 156 data items. Eighty data items had only one to three discrepancies (discrepancy rate, that is discrepancies divided by people with data entered in this field in the single or double entry databases, less than 1.5%) and they did not appear to be systematic errors. Six data items had higher discrepancy rates, but the discrepancies were minor differences in free text fields or concerned data items that would not be included in the final analysis (date received and title). Sixteen data items also had higher discrepancy rates but the discrepancies did not appear to be systematic errors and were usually differences in the degree of an answer, for example “Slightly agree” and “Moderately agree”, or between a negative answer and a “BLANK” field rather than between a positive and negative answer. It was decided, therefore, that no further action would be taken for these 150 data items, although discrepancies identified in this sample of questionnaires (except for those concerning free text fields or data items that would not be included in the final analysis) were resolved.

Six data items had discrepancy rates greater than 1.5% and the discrepancies appeared to indicate systematic errors in data entry. This was confirmed during the process of checking the questionnaires and entering the correct data in the single entry database, for example the person entering data had consistently picked “Fairly easy” from the drop-down menu instead of “Fairly difficult”. For one of these data items though, the discrepancy rate was still fairly low (3.3%) and the errors would not have had an important impact on the analysis: “Not at all” had been entered rather than “BLANK” or vice versa. No further action was, therefore, taken for this data item other than correcting the discrepancies for this sample of questionnaires. For two other data items, most of the errors (83 of 87 and 85 of 86) had been made by one person, who had entered “BLANK” instead of “No” in these fields. As well as resolving the discrepancies for this sample of questionnaires, all questionnaires entered by this clerk with “BLANK” in either of these fields but without “Yes” in the other field (as “Yes” in one of the fields made the other redundant) were checked and correct answers entered in the single entry database. As a result, another 492 of 512 “BLANK” entries were amended to “No”. For the other three data items, the errors were made by several data clerks and, therefore, as well as resolving the discrepancies for this sample of questionnaires, all questionnaires with the relevant entry in those fields were checked. As a result, another 29 of 297 data entries, 15 of 719 data entries, and 11 of 734 data entries were amended.

The discrepancy rate for each person who had entered data was also reviewed based on discrepancies identified during the comparison of the single and double entry databases. After removing discrepancies related to the misinterpretation of data entry for two data items by one person, as described above, discrepancy rates varied from 0.13% to 0.88%. It was considered that this was acceptable, and no further checks were conducted for individual data entry clerks.

4.7.3.2 Sections collecting data on self-test use

For the 10% sample of sections that collected details of self-test use, there were 62 discrepancies involving 10 (of 50) questionnaires and 14 (of 65) sections on self-test use. At least one discrepancy was found for 14 of the 77 data items that were compared. Three had one discrepancy: two were true discrepancies where the original entry was correct and the third was a free text field with a minor difference. Four data items had two discrepancies: two were true discrepancies where the original entry was correct and the other two were free text fields with minor differences. One data item had three discrepancies, but this was a free text field with minor differences. Finally, six data items had eight discrepancies. The affected data items had all been added after the questionnaire had been sent to a restricted number of respondents (see section 3.6.3). In all except one of these discrepancies, the single data entry database had been left empty, whereas “BLANK” had been entered in the double data entry database. The outstanding discrepancy was an incorrect entry other than “BLANK” in the double data entry database. In all the discrepancies identified, the original database was correct or no amendments were needed and, therefore, no further action was taken.

4.7.4 Descriptive analysis of respondents

4.7.4.1 Overview of this section

This section describes characteristics of the 1521 eligible respondents to the in-depth questionnaire based on their responses to the initial and in-depth questionnaires. The characteristics are described for each section of the questionnaire. Population-based data, where available, are presented for comparison.

4.7.4.2 Background information

4.7.4.2.1 Sex

Only one of the 1521 people did not give their sex on the in-depth questionnaire, but this was available from their initial questionnaire, which had been checked against information from their practice. Just over 57% (n=873) of the group were women and 42.6% (n=648) were men, significantly different ($p<0.001$) from the 51.3% (n=20579.3)/48.7% (n=19678.8k) split in the population of England in 2008 [201].

4.7.4.2.2 Age

Nine of the 1521 people did not give their age on the in-depth questionnaire, but this was available from their initial questionnaire, which had been checked against practice records. Ages ranged from 18 to 100 years (interquartile range (IQR) 43-64) and the mean (53.9) and median (55) ages were similar. When using 10 year age bands, respondents were most commonly 50-59 years (table 22). This contrasts with the population of England in 2008 [201]: the mean (47.6), median (46) and 25th percentile were lower (IQR=32-63) and people were most commonly aged 18-29.

Table 22: Age of in-depth questionnaire respondents compared with the population of England in 2008 [a].

	Respondents		England [a]	
Sex	n	%	n	%
18-29	98	6.4	8,330,400	20.6
30-39	175	11.5	7,010,500	17.3
40-49	287	18.9	7,595,100	18.8
50-59	384	25.2	6,177,900	15.3
60-69	376	24.7	5,320,500	13.2
70-79	142	9.3	3,648,900	9.0
80+	59	3.9	2,354,800	5.8
Total	1521		40,438,100	

[a] Office for National Statistics. Mid-2008 Population Estimates: England; estimated resident population by single year of age and sex. Available at: http://www.statistics.gov.uk/statbase/Product.asp?vlnk=15106. Accessed 20 April 2010.

4.7.4.2.3 Ethnic group

Everyone included in this analysis gave their ethnic group on the initial questionnaire, and the overwhelming majority of them were white (98.6%, n=1500), compared with an estimated 89.4% (n=34633.8k) of the population of England in 2007 (n=38738.2k) [202].

4.7.4.2.4 Index of Multiple Deprivation

An IMD 2007 score was assigned to all 1521 respondents included in the analysis [111]. Scores ranged from 1.4 (more affluent) to 62.4 (more deprived) (IQR 9.0-16.8) and the mean and median were 13.2 and 11.6 respectively. The range of scores, mean and median for lower layer super output areas in England in 2007 were 0.4-85.5 (IQR 9.6-30.2), 21.7 and 17.1 respectively [80], suggesting that respondents to this survey were relatively more affluent than the population of England.

4.7.4.2.5 Qualifications

In line with the 2001 Census [203], respondents were categorised by the highest qualification attained: level 4-5 is the highest level (NVQ levels 4 and 5, HNC, HND, first degrees, higher degrees, and professional qualifications as a doctor, dentist, teacher or nurse), followed by level 1-3 (NVQ levels 1 to 3, O'levels and the modern equivalent, and A'levels), other qualifications or level unknown, and no qualifications.

Thirty one people (2.0%) did not answer the question and 58 people (3.8%) checked the other box and any free text given could not be fitted into levels 1 to 5. Most of the other respondents had level 1-3 (40.6%) or level 4-5 (40.4%) qualifications. Only 13.1% had no qualifications (table 23). Although a similar proportion of 2001 Census respondents (43.6%) had level 1-3 qualifications, a lower proportion had level 4-5 qualifications (20.6%) and a higher proportion reported no qualifications (28.7%) [204]. The Census results refer to people aged 18-74 years, but the proportion of respondents aged under 75 years from this survey with level 4-5 qualifications was still high (577 of 1402, 41.2%), suggesting that respondents to this survey are relatively more qualified than the population of England.

Table 23: Qualifications of in-depth questionnaire respondents compared with 2001 Census respondents [a].

Qualifications	Respondents n	%	2001 Census [a] n	%
Level 4-5	615	40.4	7,059,279	20.6
Level 1-3	618	40.6	14,951,568	43.6
Other or level unknown	89	5.9	2445753	7.1
None	199	13.1	9,844,225	28.7
Total	1521		34,300,825	

[a] Office for National Statistics. 2001 Census – standard tables. Table S105 Sex and age by highest level of qualification. Available at: https://www.nomisweb.co.uk/Default.asp. Accessed 17 August 2010.

4.7.4.2.6 Employment status

Categories provided on the initial questionnaire were in line with those used in the Census [200] and everyone included in this analysis answered this question. The highest proportion of respondents (47.6%) were employed, another 12.1% were self-employed, and another four said that they were working and studying (table 24). Just over a quarter (26.1%) of respondents were retired and another 13.9% (n=212) were economically inactive, that is they did not have an income and were looking after the home, sick, studying, looking for a job, or another option. The pattern for respondents was broadly similar to the 2001 Census [200]: most people from the Census were employed (54.0%) followed by retired (14.0%) and self-employed people (8.6%). The Census reported, however, that only 14.0% of people were retired compared with 26.1% of respondents to this survey. The Census data are for people aged 18-74 years, but 22% (n=303) of 1402 respondents to this survey aged under 75 said that they were retired, still considerably more than the population of England in 2001.

Table 24: Employment status of in-depth questionnaire respondents compared with 2001 Census respondents [a].

Employment status	Respondents n	%	2001 Census [a] n	%
Employed	724	47.6	18,519,165	54.0
Self-employed	184	12.1	2,951,461	8.6
Economically active full-time student	4	0.3	592,329	1.7
Retired	397	26.1	4,810,450	14.0
Looking after home/family	76	5.0	2,308,928	6.7
Sick/disabled	22	1.4	1,881,954	5.5
Economically inactive student	22	1.4	1,020,507	3.0
Looking for job	19	1.2	1,136,522	3.3
Other	73	4.8	1,079,509	3.1
Total	1521		34,300,825	

[a] Office for National Statistics. 2001 Census – standard tables. Table S028 Sex and age by economic activity. Available at: https://www.nomisweb.co.uk/Default.asp. Accessed 11 August 2010.

4.7.4.2.7 Work as a health professional

Most respondents (n=1508) completed this question. One hundred and fifty three of them (10.1%) had ever worked as a health professional, whereas 89.9% (n=1355) had not done so. Just over 9% (n=2012.9k) of employed people aged 18-74 years (n=21983.5k) in the 2001 Census were classified as working as health professionals, health and social welfare associate professionals or in the caring personal service occupations [205]. This does not include past occupations, which suggests that health professionals are not over-represented among respondents.

4.7.4.3 Knowledge and views of self-tests

4.7.4.3.1 Confidence using a self-test

Fifty three people did not answer the question about how confident they would be using self-tests. Only 3.7% of the remaining 1468 people said that they would be very unconfident and only 4.5% said that they would be fairly unconfident (table 25). Instead, most people said that they would be fairly (49.4%) or very confident (24.5%) using a self-test.

Table 25: Confidence using a self-test of in-depth questionnaire respondents.

How confident respondents felt using self-tests	n	%
Very confident	359	24.5
Fairly confident	725	49.4
Neither confident nor unconfident	263	17.9
Fairly unconfident	66	4.5
Very unconfident	55	3.7
Total	1468	

4.7.4.3.2 Knowledge of tests

Respondents were asked if they knew whether any of a list of named self-tests or any other self-test was available before receiving the initial questionnaire. A score was generated by adding one for each test that the respondent had checked but zero if the respondent had marked “No” or “Don’t know”. Forty three respondents who left all the answers blank were treated as having a missing score. For the other 1478 people, when all tests listed were included, the range of scores was 0-15 (out of 16) (IQR 2-5) and the mean and median scores were 3.9 and 4 respectively. This suggests a fairly poor knowledge of the availability of self-tests. Results were similar when pregnancy tests were excluded (n=1478, range=0-14 (out of 15), IQR=1-4, mean=3.0, median=3), when self-tests for high BP were excluded (n=1478, range=0-14 (out of 15), IQR=2-4, mean=3.3, median=3), and when both were excluded (n=1478, range=0-13 (out of 14), IQR=1-3, mean=2.4, median=2).

4.7.4.4 Habits and lifestyle

4.7.4.4.1 Smoking

Most people (n=1485) reported whether they smoked, and most (90.5%, n=1344) did not do so. Only 9.5% (n=141) said that they smoked, considerably lower than the 21% prevalence reported from the 2007 General Household Survey [206].

4.7.4.4.2 Exercise

Most people (n=1487) answered the question about how often they exercised in their free time so that they got at least a little warm, sweaty or out of breath (table 26). People who responded most commonly did this level of exercise on about one or two days (30.1%) or three or four days each week (28.3%). Less and more frequent exercise was less common: 15.5% of people, for example, exercised to this level on five days a week or more and 13.7% did so less than once a week but at least once a month. Much higher proportions of men (39%) and women (29%) surveyed for the Health Survey for England in 2008 said that they did 30 minutes or more of at least moderate activity on at least five days per week [207], but this included activities such as housework and is not, therefore comparable with the in-depth questionnaire.

Table 26: How often in-depth questionnaire respondents exercised [a].

How often respondents exercised [a]	n	%
Five days a week or more	230	15.5
About three or four days a week	421	28.3
About one or two days a week	448	30.1
Less than once a week but at least once a month	203	13.7
Less than once a month	65	4.4
Never or almost never	120	8.1
Total	1487	

[a] In their free time so that they got at least a little warm, sweaty or out of breath.

4.7.4.4.3 Fruit and vegetables

Most people (n=1487) reported how often they ate fruit or vegetables (table 27). Few ate them infrequently, that is never or almost never (0.9%), less than once a week (0.9%), or less than once a day but at least once a week (5.8%). Respondents most commonly said that they ate fruit or vegetables about three or four times each day (36.1%) or one or two times each day (33.1%). Nearly one quarter (23.3%) ate them five times a day or more in line with current recommendations. Broadly similar to this, the Health Survey for England in 2007 found that 29% of adults ate five or more portions of fruit and vegetables per day [208].

Table 27: How often in-depth questionnaire respondents ate fruit or vegetables.

How often respondents ate fruit or vegetables	n	%
Five times a day or more	347	23.3
About three or four times a day	536	36.1
About one or two times a day	492	33.1
Less than once a day but at least once a week	86	5.8
Less than once a week	13	0.9
Never or almost never	13	0.9
Total	1487	

4.7.4.4.4 Internet use

One thousand four hundred and eighty four people reported how often they used the internet (table 28). In terms of more frequent use, 26.1% of respondents used the internet about one or two times a day, 9.0% used it about three or four times a day, and 17.5% used it five times a day or more. In terms of less frequent use, 21.2% of respondents used the internet less than once a day but at least once a week, 6.3% used the internet less than once a week and 19.9% never used the internet. Levels of less frequent use were similar to the 2007 Omnibus survey [49] (24% of adults used the internet at least once a week but not every day compared with 21% from this survey), but levels of more frequent use, that is once a day or more, were lower (53%) than the Omnibus survey (67%) [49].

Table 28: How often in-depth questionnaire respondents used the internet.

How often respondents used the internet	n	%
Five times a day or more	259	17.5
About three or four times a day	133	9.0
About one or two times a day	388	26.1
Less than once a day but at least once a week	315	21.2
Less than once a week	93	6.3
Never or almost never	296	19.9
Total	1484	

4.7.4.5 Knowledge of health recommendations

Most people (n=1487) answered whether they knew the recommended daily number of portions of fruit or vegetables, and most who answered (92.3%, n=1372) correctly stated that the recommendation is five portions each day. In contrast, only 20.7% (n=307) of the 1486 people who answered the question knew that exercise is recommended on at least five days each week. No population-based comparison data was available for this question.

4.7.4.6 Advice and information about health problems

People were asked how often during the last 12 months they had sought (1) advice about health problems from a range of people, and (2) information about health problems from a range of sources. Scores were generated by adding two points if “Three or more times” was marked for a relevant person or source, one point if “Once or twice” was marked, but zero points if “Not at all” or “Not sure” were marked. Respondents who left all the options blank were treated as having a missing score.

4.7.4.6.1 *Advice about health problems*

Twenty two people had left all the options blank. For the other 1499 people, the ranges of scores for advice from any person listed was 0-17 (out of 22) (IQR 1-5) and the mean and median scores were 3.4 and 3 respectively. This suggests that respondents had not often asked for advice about health problems.

One hundred and seventy two people had not checked answers for any of the four lay people listed. For the other 1349 respondents, the range of scores for advice from a lay person was 0-8 (out of 8) (IQR 0-2) and the mean and median scores were 1.4 and 1 respectively. Only 34 respondents had not checked answers for any of the five health professionals listed. For the other 1487 people, the range of scores for advice from a health professional was 0-10 (out of 10) (IQR 1-3) and the mean and median scores were 2.0 and 2 respectively.

Only 1268 people marked an answer for how often they had asked for advice from a complementary therapist and most (85.3%, n=1082) had not done so. Fifteen people (1.2%) were not sure, but only 47 people (3.7%) had asked for advice three or more times and only 124 people (9.8%) had asked for advice once or twice.

4.7.4.6.2 *Information about health problems*

Thirty seven people had left all the options blank. For the other 1484 people, the range of scores was 0-15 (out of 20) (IQR 1-4) and the mean and median scores were 2.8 and 2 respectively. Similar to advice about health problems, this suggests that respondents did not often seek information from these sources. When NHS Direct was excluded, the range for the 1484 respondents was 0-14 (out of 18) (IQR 0-4) and the mean and median scores were 2.6 and 2 respectively.

4.7.4.7 Health status

4.7.4.7.1 Self-rated health over the last 12 months

Only two of the 1521 eligible respondents to the in-depth questionnaire did not reply to the question on the initial questionnaire about how their health had been over the last 12 months. Most people who did reply said that their health had been good (64.3%) or fairly good (28.6%) and only 7.1% felt it had not been good (table 29). Respondents to the 2001 Census in the same age group had a similar pattern: 62.7% reported good health, 26.3% reported fairly good health, and 11.1% reported not good health [199].

Table 29: Self-reported health status of in-depth questionnaire respondents compared with 2001 Census respondents [a].

Self-reported health over last 12 months	Respondents n	%	2001 Census [a] n	%
Good	976	64.3	23,309,403	62.7
Fairly good	435	28.6	9,766,825	26.3
Not good	108	7.1	4,118,129	11.1
Total	1519		37,194,357	

[a] Office for National Statistics. 2001 Census – standard tables. Table S016 Sex and age by general health and limiting long-term illness. Available at: https://www.nomisweb.co.uk/Default.asp. Accessed 11 August 2010.

4.7.4.7.2 Limiting long-term illness

Just over 35% (35.8%, n=536) of 1498 people who completed the question said that they had a long-term illness and 203 of them (13.6% of 1498) said that this limited their daily activities or the work they could do. This is less than the 21.2% (n=7891.7k) of respondents to the Census in 2001 in the same age group (n=37194.4k) who reported a limiting long-term illness [199].

4.7.4.7.3 SF-8 physical and mental health measures

The SF-8 is a validated set of eight questions that assesses physical and mental health status, with higher scores equating to better health [193]. Valid scores (replies to all eight questions) were available for 1490 of the 1521 people eligible for this analysis. Physical health measure scores ranged from 13.6 (minimum is 9.1) to 66.7 (maximum is 69.0) (IQR 46.7-56.7) with mean and median scores of 50.5 and 53.9 respectively. Values for the US population in 1999-2000 were only slightly lower, ranging from 10 to 67 (IQR 44.0-55.9) with mean and median scores of 49.2 and 51.9 respectively [193]. Mental health measure scores in the study population ranged from 15.1 (minimum is 5.5) to 68.8 (maximum is 71.7) (IQR 46.5-57.5) with mean and median scores of 50.1 and 52.3 respectively. Again, values for the US population in 1999-2000 were only slightly lower, ranging from 8 to 67 (IQR 44.2-57.5) with mean and median scores of 49.2 and 51.1 respectively [193].

4.7.4.8 Thoughts about how to stay healthy and future illnesses

4.7.4.8.1 Things to stay healthy

Most people (n=1509) gave an answer for how often they thought about things to keep themselves healthy. People who replied most commonly (36.0%) thought about such things every day (table 30). The proportions of respondents then decreased as frequency of healthy thoughts also decreased so that the lowest proportion of respondents (4.6%) said that they had healthy thoughts never or almost never.

Table 30: How often in-depth questionnaire respondents had healthy thoughts.

How often respondents had healthy thoughts	n	%
Every day	543	36.0
Every two or three days	325	21.5
About once a week	297	19.7
Less than once a week but at least once a month	169	11.2
Less than once a month	106	7.0
Never or almost never	69	4.6
Total	1509	

4.7.4.8.2 Future illnesses

Most people (n=1508) gave an answer for how often they thought about illnesses that they might get in the future. People who replied most commonly (31.6%) usually never thought about such things (table 31). In contrast to thoughts about how to stay healthy, the proportion of respondents decreased as frequency of thoughts about future illnesses increased so that the lowest proportion of respondents (6.6%) said that they thought about future illnesses every day.

Table 31: How often in-depth questionnaire respondents thought about future illnesses.

How often respondents thought about future illnesses	n	%
Every day	99	6.6
Every two or three days	125	8.3
About once a week	243	16.1
Less than once a week but at least once a month	258	17.1
Less than once a month	306	20.3
Never or almost never	477	31.6
Total	1508	

4.7.4.9 Views about health checks and medical tests

This section asked whether people agreed or disagreed with statements about health checks and medical tests (table 32). Most of the 1493 respondents agreed (51.7%) or strongly agreed (37.3%) that medical tests were reassuring. Similar to this, most of the 1474 people who replied agreed (55.0%) or strongly agreed (20.1%) that they were curious about their health, and most of the 1489 people who responded agreed (48.0%) or strongly agreed (37.6%) that they liked the idea of routine health checks. The final statement, that medical tests cause anxiety, gave a negative view of medical tests, whereas the previous three had highlighted positive aspects. In contrast to the positive statements where respondents had usually agreed, most of the 1481 respondents disagreed (31.1%) with the final negative statement.

Table 32: Views of in-depth questionnaire respondents about health checks and medical tests.

	Tests are reassuring n	%	Curious about health n	%	Like routine checks n	%	Tests cause anxiety n	%
Strongly agree	557	37.3	297	20.1	560	37.6	87	5.9
Agree	772	51.7	811	55.0	715	48.0	350	23.6
Neither agree nor disagree	150	10.0	305	20.7	177	11.9	410	27.7
Disagree	12	0.8	54	3.7	32	2.1	460	31.1
Strongly disagree	2	0.1	7	0.5	5	0.3	174	11.7
Total	1493		1474		1489		1481	

4.7.4.10 Views about visiting the GP

This section asked whether the person agreed or disagreed with eight statements about visiting the GP (table 33). For four statements, more than 70% of those who replied agreed or strongly agreed. The first was that the person would only go to the doctor if they had symptoms, and nearly all of the 1496 respondents strongly agreed (45.5%) or agreed (48.5%) with the statement. The second statement was that the person did not like to bother the doctor unless it was really necessary, and 54.2% of the 1490 respondents agreed and 32.1% strongly agreed. The third statement was that the person liked to have evidence to justify a visit to the doctor, and 52.2% of the 1486 respondents agreed and 20.6% strongly agreed with this. The final statement was that the person was confident that the doctor would try and do a test if asked, and about one quarter of the 1491 respondents strongly agreed (26.2%) or agreed (49.6%). The first three of these statements all described circumstances that legitimise a visit to the doctor and respondents' overwhelming agreement with them suggests that they may hold off visiting their doctor until certain criteria are met. In contrast, the last statement concerned visiting the doctor to ask for a test regardless of any criteria, and most respondents were confident that their doctor would help.

Table 33: Views of in-depth questionnaire respondents about visiting the GP.

	Only if symptoms n	%	Need symptoms for test n	%	Don't bother doctor n	%	Only if severe or serious symptoms n	%
Strongly agree	681	45.5	209	14.3	479	32.1	286	19.2
Agree	725	48.5	559	38.3	807	54.2	549	36.9
Neither agree nor disagree	51	3.4	410	28.1	117	7.9	218	14.7
Disagree	38	2.5	246	16.8	73	4.9	396	26.6
Strongly disagree	1	0.1	37	2.5	14	0.9	37	2.5
Total	1496		1461		1490		1486	

	Need evidence to justify visit n	%	Embarrassed to tell doctor n	%	Happy to ask for check-up n	%	Confident doctor would do test n	%
Strongly agree	306	20.6	79	5.3	273	18.4	391	26.2
Agree	776	52.2	242	16.3	723	48.6	739	49.6
Neither agree nor disagree	242	16.3	231	15.6	274	18.4	251	16.8
Disagree	145	9.8	699	47.2	194	13.0	96	6.4
Strongly disagree	17	1.1	231	15.6	23	1.5	14	0.9
Total	1486		1482		1487		1491	

For three other statements, higher proportions of people strongly disagreed or disagreed, although most still strongly agreed or agreed. The first statement was that symptoms or risk factors were needed to get a test done by the doctor. Over 50% of the 1461 respondents strongly agreed (14.3%) or agreed (38.3%), but 16.8% disagreed and 2.5% strongly disagreed. The second statement was that the person would only go to the doctor if symptoms were severe or might be serious. Over half of the 1486 respondents strongly agreed (19.2%) or agreed (36.9%) with this, but 26.6% disagreed and 2.5% strongly disagreed. The third statement was that the person would be happy to ask the doctor for a routine check-up. Nearly half (48.6%) of the 1487 respondents agreed and another 18.4% strongly agreed, but 13.0% disagreed and 1.5% strongly disagreed. The first two statements again described circumstances that legitimise a visit to the doctor or a request for a test. Most people agreed with these statements, again suggesting that they may delay seeing a doctor until certain criteria are fulfilled. In contrast, the last statement again concerned asking for a check-up regardless of any criteria and again most respondents were confident that their doctor would help.

The final statement was that the person would be embarrassed to tell their doctor about personal problems. In contrast to every other statement, more than half of the 1482 respondents disagreed (47.2%) or strongly disagreed (15.6%). This indicates that most did not see embarrassment as a bar to visiting the doctor, although the minority who strongly agreed (5.3%) and agreed (16.3%) may perhaps have been more likely to put off seeing their doctor in certain situations.

In summary, five of the eight statements described circumstances that legitimise a visit to the doctor or a request for a test, and most respondents agreed with them. This suggests that respondents to this survey may delay seeing the doctor until certain criteria are fulfilled. In contrast though, two statements concerned visiting the doctor to ask for a check-up or test regardless of any criteria, and most respondents were confident that their doctor would be open to these requests. Furthermore, most respondents did not see embarrassment as a bar to visiting the doctor.

4.7.4.11 Access to the GP

This section asked how respondents found making an appointment with their GP and then travelling to the surgery. Ten people did not reply to the question about how easy or difficult they found getting an appointment as soon as they would like and nine others had never had an appointment. Most of the remaining 1502 respondents found this very easy (34.5%) or fairly easy (46.7%) (table 34). Thirteen people did not report how easy or difficult they found getting an appointment at their GP surgery at a suitable time and nine others had never had an appointment. Again, most of the other 1499 respondents found this very easy (21.9%) or fairly easy (48.0%) (table 34). Eleven people did not report how easy or difficult they found travelling to their GP surgery and five others had never been there. Once again, most of the other 1505 respondents found this very easy (64.5%) or fairly easy (27.5%) (table 34).

Table 34: How easy or difficult in-depth questionnaire respondents found accessing the GP.

	As soon as would like		At a suitable time		Travel to surgery	
	n	%	n	%	n	%
Very easy	518	34.5	328	21.9	971	64.5
Fairly easy	702	46.7	719	48.0	414	27.5
Neither easy nor difficult	136	9.1	204	13.6	80	5.3
Fairly difficult	109	7.3	173	11.5	32	2.1
Very difficult	37	2.5	75	5.0	8	0.5
Total	1502		1499		1505	

4.7.4.12 Satisfaction with healthcare

4.7.4.12.1 Satisfaction with different aspects of GP consultations

This section included eight questions about consultations with the GP. Answers to the questions were combined to give a score by adding five for “Very good”, four for “Good”, three for “Fair” or “Don’t know”, two for “Poor” and one for “Very poor”. If one or two of the eight answers were missing, the average of the given answers was multiplied by eight. If more than two answers were missing, the score was treated as missing and 22 people had missing scores. For the other 1499 respondents, scores ranged from 9 (minimum is 8) to 40 (out of 40) (IQR 31-40). The mean and median scores were 34.1 and 35 respectively, which suggests that satisfaction with GP consultations was generally high.

This part of the questionnaire was adapted from the GPAQ: the true GPAQ includes an extra “Excellent” option. Despite this difference, it is useful to note that the benchmark summary score given for this section of the GPAQ based on data collected from 114123 respondents during 2005-6 is 76 [209]. As the GPAQ reports scores on a 0-100 scale, a score of 76 out of 100 equates to a score of 30 out of 40, which appears to confirm relatively high satisfaction for this group of respondents.

4.7.4.12.2 Overall satisfaction

This section asked about overall satisfaction with the person's own healthcare and healthcare provided to close friends and family. Nearly all of the 1508 people who responded were very satisfied (47.8%) or satisfied (43.6%) with their own healthcare (table 35). Most of the 1502 respondents were also satisfied (49.7%) or very satisfied (25.6%) with care provided to others, but the level of satisfaction was lower and 8.6% and 1.8% of respondents were dissatisfied and very dissatisfied respectively.

Table 35: Satisfaction of in-depth questionnaire respondents with healthcare.

	Own care		Other's care	
	n	%	n	%
Very satisfied	721	47.8	385	25.6
Satisfied	658	43.6	747	49.7
Neither satisfied nor dissatisfied	93	6.2	214	14.2
Dissatisfied	32	2.1	129	8.6
Very dissatisfied	4	0.3	27	1.8
Total	1508		1502	

4.7.4.13 Beliefs about health

4.7.4.13.1 Health locus of control

This section concerned whether health is perceived to be controlled internally, by powerful others, or by chance [114]. People were asked to indicate their level of agreement or disagreement with six statements related to each loci of control. Scores were then generated for each loci by adding six for strongly agree down to one for strongly disagree for the answers to each of the relevant six statements. If one or two of the six answers were missing, the average of the given answers was multiplied by six, but the score was treated as missing if more than two answers were missing.

Twenty six people did not give answers for at least three statements about internal control. For the 1495 respondents, scores ranged from six, the minimum possible, to 36 (out of 36) (IQR 22-27) with mean and median scores of 24.3 and 25 respectively. Twenty nine people did not give answers for at least three statements about chance. For the 1492 respondents, the lowest score was six, the minimum possible, and the highest score was 35 (out of 36) (IQR 14-21) with mean and median scores of 17.9 and 18 respectively. Twenty six people did not give answers for at least three statements concerning powerful others. For the 1495 respondents, scores ranged from six, the minimum possible, to 36 (out of 36) (IQR 13-21) with mean and median scores of 17.5 and 17 respectively. In line with these results, a population-based survey of about 11000 people in Wales in 2001 reported mean scores of 24, 18 and 18 for the internal, chance and powerful others scales respectively [210]. This suggests that respondents to both these surveys tend to perceive their health as being controlled internally, rather than by chance or powerful others.

4.7.4.13.2 Health value

As it is argued that health locus of control cannot be properly interpreted unless account is taken of the value placed upon health by an individual [117-119], people were asked to indicate their level of agreement or disagreement with four statements about this. A score was generated by adding six for answers showing most value for health down to one for answers showing least value. If one of the four answers was missing, the average of the given answers was multiplied by four. If more than one answer was missing, the score was treated as missing and 31 people did not give answers for at least two statements. For the 1490 respondents, scores ranged from four, the minimum possible, to 24 (out of 24) (IQR 15-21) with mean and median scores of 18.0 and 18 respectively, which suggests that respondents placed a fairly high value on their health.

4.7.4.14 Self-test use

One hundred and thirty two (8.8%) of the 1521 people who returned eligible in-depth questionnaires had used a self-test without clinical involvement, as shown in the flowchart in appendix 8 and described in section 4.6.3.2.

4.7.4.15 Summary of descriptive analysis

Most respondents were from white ethnic groups. The sample also included a significantly higher proportion of women than the population of England, and they appeared to be older, more affluent and more qualified. Levels of employment and self-employment were about the same as Census respondents, but respondents to this survey were more likely to be retired, whereas Census respondents were more likely to be economically inactive for other reasons. Comparison with Census data suggests that health professionals were not over-represented in this survey.

About three quarters of respondents would have been confident using a self-test, but most did not know about them. A much lower proportion of this sample smoked than the sample from a large national population-based survey. Most respondents said that they exercised about one to four days each week, although there were no appropriate comparison data. Levels of consumption of fruit and vegetables and less frequent use of the internet (at least once a week but not every day) were similar to large national population-based surveys, although more frequent use of the internet (once a day or more) was less prevalent in this survey. Most people knew the recommended number of portions of fruit or vegetables, but only about one fifth knew that exercise is recommended on at least five days each week.

The low mean and median scores for asking for advice for about health problems suggested that respondents did not often ask for such advice. Similar to this, the low mean and median scores for information about health problems suggested that respondents did not often seek information from the sources listed.

Over 90% of respondents felt that their health was good or fairly good, similar to the 2001 Census, and SF-8 mental and physical health measures also indicated that this sample was fairly healthy. In contrast though, just over one third reported a long-term illness, more than the one fifth of 2001 Census respondents. Respondents were most likely to have healthy thoughts every day but never think about future illnesses. They placed a fairly high value on health but tended to have a greater belief that health was controlled internally than by chance or powerful others, similar to a large population-based Welsh survey in 2001.

Respondents were asked whether they agreed or disagreed with statements about health checks and medical tests. They tended to agree with the positive statements, for example that tests were reassuring, but disagree with the negative statement that tests made them anxious. Respondents were also asked whether they agreed or disagreed with statements about visiting the GP. Five statements described circumstances that legitimise a visit to the doctor, for example having symptoms, and respondents tended to agree with them, suggesting that they delay seeing the doctor until certain criteria are met. In contrast, two statements concerned asking the doctor for a check-up or test regardless of any criteria, and most people felt that the doctor would help. Most also did not see embarrassment as a bar to visiting the doctor.

Most people found it easy to get an appointment as soon as they would like, at a suitable time, and to travel to their GP surgery. The mean and median scores for satisfaction with consultations also suggested that this was high, supported by comparison with benchmark scores for the scale. In line with this, over 90% of respondents were satisfied with their own care and about three quarters were satisfied with care given to friends and family.

Finally, 8.8% (n=132) of the 1521 eligible respondents were confirmed as having used a self-test without clinical involvement.

4.7.5 Univariate analysis

4.7.5.1 Overview of this section

This section presents a univariate analysis of self-test use for each explanatory variable from the initial and in-depth questionnaire. Appendix 35 summarises the results. Proportions are presented to one decimal place, but results from statistical tests, including p-values, are presented to three decimal places, where this was presented by the statistical package, for precision.

4.7.5.2 Background information

The threshold for significance for variables from this section is a p-value of 0.05/14=0.004 as 14 statistical tests were performed (see section 3.6.9.4.4).

4.7.5.2.1 Sex

Just under 11% of women (n=94) had used a self-test compared with only 5.9% (n=38) of men (table 36) and this difference was significant (chi^2=11.283, degrees of freedom (df)=1, p=0.001).

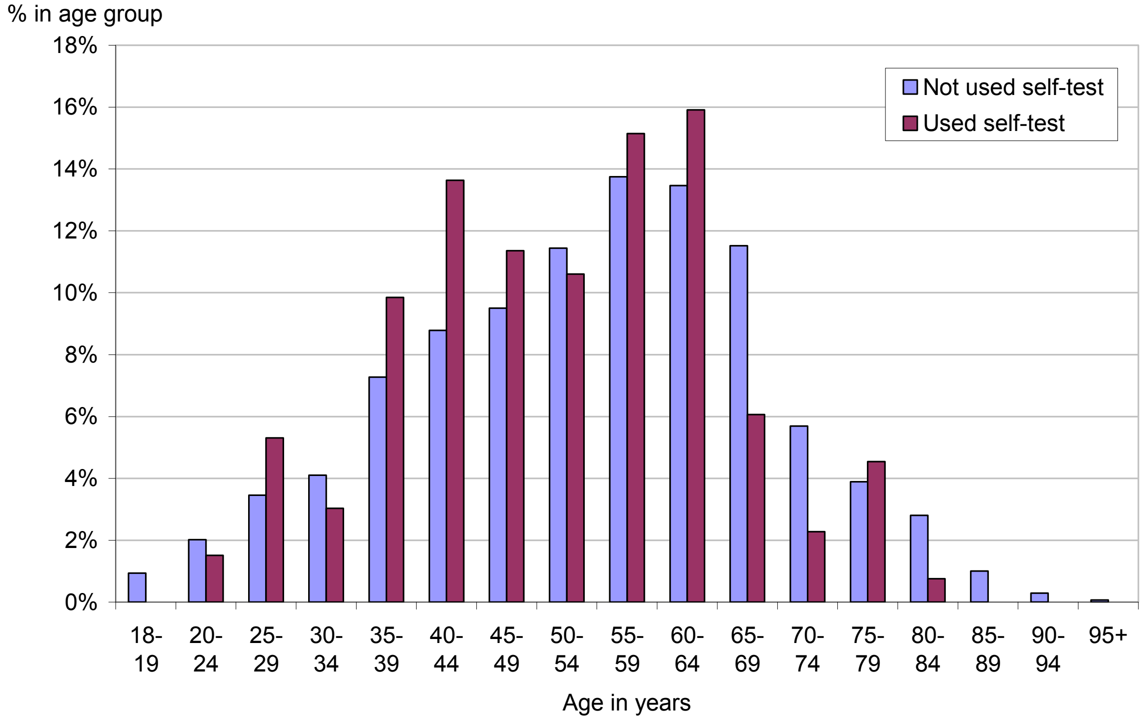
Table 36: Prevalence of self-test use among men and women.

	Self-test use				
	No		Yes		Total
Sex	n	%	n	%	n
Men	610	94.1	38	5.9	648
Women	779	89.2	94	10.8	873
Total	1389	91.3	132	8.7	1521

4.7.5.2.2 Age

The ages of people who had and had not used self-tests ranged from 23 to 84 and from 18 to 100 years respectively. When respondents were placed in five year age groups, people who had used self-tests were most commonly aged 60-64 (15.9%), but 15.2% were 55-59 and 13.6% were 40-44 (figure 5). People who had not used self-tests were most commonly aged 55-59 (13.8%), but there was no earlier peak. In line with this, people who had self-tested had a lower IQR (41-61) and lower mean (51.2) and median (52) ages than those who had not done so (44-65, 54.2 and 56 respectively). There were, however, no significant differences between the groups using the two-sample t-test (p=0.025) or the Wilcoxon rank sum test (p=0.016).

Figure 5: Age profiles of respondents who had and had not used self-tests.



4.7.5.2.3 Ethnic group

As most respondents were white and most self-test users were, therefore, white (table 37), no statistical tests were done on this variable.

Table 37: Prevalence of self-test use among people from different ethnic groups.

	Self-test use				Total
	No		Yes		
Ethnic group	n	%	n	%	n
White	1371	91.4	129	8.6	1500
Other ethnic groups	18	85.7	3	14.3	21
Total	1389	91.3	132	8.7	1521

4.7.5.2.4 Index of Multiple Deprivation

Scores ranged from 1.4 (more affluent) to 36.7 (more deprived) for the 132 people who had used self-tests and from 1.4 to 62.4 for the 1389 people who had not done so. Although the overall range was narrower for people who had self-tested, the IQR and mean and median scores were similar among the two groups (used: IQR=7.5-16.8, mean=12.8, median=11.4; not used: IQR=9.0-16.8, mean=13.2, median=11.6). Ranks ranged from 5687 (more deprived) to 32426 (more affluent) for people who had used self-tests and from 685 to 32426 for those who had not done so. Again, although the overall range was narrower for people who had self-tested, the IQR and mean and median ranks were similar among the two groups (used: IQR 16542-27015, mean=21504, median=21992; not used: IQR=16542-25075, mean=21163, median 21880). In line with this, there were no significant differences between the groups in mean scores (p=0.541) or ranks (p=0.570) using the two-sample t-test, or in median scores (p=0.667) or ranks (p=0.671) using the Wilcoxon rank sum test.

The highest rate of self-test use (11.4%) was in the second IMD quartile (table 38), but the lowest rate (7.1%) was in the more deprived first quartile and most users (104 of 132) were actually in the more affluent third and fourth quartiles. In line with this, there was no significant trend in use across the quartiles (chi^2=0.03, df=1, p=0.853) and use was not significantly different between the quartiles (chi^2=2.97, df=3, p=0.397). Given that none of the IMD variables were significantly associated with use, that is that there appeared to be no reason to use one rather than the other, it seemed most appropriate to use the original score in the regression analysis.

Table 38: Prevalence of self-test use among people from different Index of Multiple Deprivation (IMD) quartiles.

	Self-test use				
	No		Yes		Total
IMD 2007 quartile	n	%	N	%	n
Quartile 1 (most deprived)	65	92.9	5	7.1	70
Quartile 2	178	88.6	23	11.4	201
Quartile 3	587	92.3	49	7.7	636
Quartile 4 (most affluent)	559	91.0	55	9.0	614
Total	1389	91.3	132	8.7	1521

4.7.5.2.5 Qualifications

Respondents with a level 4-5 qualification, the highest level, had the highest rate of self-test use (10.1%), compared with rates of 8.9%, 3.5% and 5.5% respectively among respondents with a level 1-3 qualification, who checked the other qualifications option, and who reported no qualifications (table 39). There was, however, no significant evidence that use was different between the categories (chi^2=6.02, df=3, p=0.111) or that there was a trend of increasing use as qualifications increased (chi^2=5.03, df=1, p=0.025).

Table 39: Prevalence of self-test use among people with different qualification levels.

	Self-test use				
	No		Yes		Total
Level of qualifications	n	%	n	%	n
Level 4-5 (highest level)	553	89.9	62	10.1	615
Level 1-3	563	91.1	55	8.9	618
Other qualifications	56	96.6	2	3.5	58
No qualifications	188	94.5	11	5.5	199
Total	1360	91.3	130	8.7	1490

4.7.5.2.6 Worked as a health professional

The rate of self-test use among people who had ever worked as health professionals (19.0%) was more than double that among lay people (7.4%) (table 40). This is not unexpected as this study includes use of tests at work, and this difference was highly significant (chi^2=23.543, df=1, p<0.001).

Table 40: Prevalence of self-test use among health professionals and lay people.

	Self-test use				
	No		Yes		Total
Health professional	n	%	n	%	n
Yes	124	81.0	29	19.0	153
No	1255	92.6	100	7.4	1355
Total	1379	91.5	129	8.6	1508

4.7.5.2.7 Employment status

As some categories contained few people, it was felt that a better assessment would be achieved by combining them. Categories related to being economically inactive, except for being retired, were combined (economically inactive student, looking for job, looking after home, sick, other) and economically active full-students were added to the employment category as they were also employed. The rate of self-test use ranged from 5.7% among economically inactive people to 6.8% among retired people, 9.2% among self-employed people and 10.4% among employed people (table 41). The test for trend approached significance (chi^2=7.01, df=1, p=0.008), but there was no significant evidence that self-test use was different between the categories (chi^2=7.12, df=3, p=0.068).

Table 41: Prevalence of self-test use among different employment status categories.

Employment status	Self-test use No n	No %	Yes n	Yes %	Total n
Employed	649	89.6	75	10.4	724
Self-employed	167	90.8	17	9.2	184
Retired	370	93.2	27	6.8	397
Economically active full-time student	3	75.0	1	25.0	4
Economically inactive student	22	100.0	0	0.0	22
Economically inactive: looking for job	16	84.2	3	15.8	19
Economically inactive: looking after home	71	93.4	5	6.6	76
Economically inactive: sick	21	95.5	1	4.6	22
Economically inactive: other	70	95.9	3	4.1	73
Employed & Economically active full-time student	652	89.6	76	10.4	728
Self-employed	167	90.8	17	9.2	184
Retired	370	93.2	27	6.8	397
Economically inactive	200	94.3	12	5.7	212
Total	1389	91.3	132	8.7	1521

4.7.5.3 Knowledge and views of self-tests

The threshold for significance for variables from this section is a p-value of 0.05/5=0.010 as ten statistical tests were performed (see section 3.6.9.4.4).

4.7.5.3.1 Confidence using a self-test

People who felt very confident using self-tests had the highest rate of use (12.0%), falling to 9.1% among fairly confident people, 6.8% among those who felt neither confident nor unconfident, and very little use among unconfident people (table 42). After combining the “Very unconfident” and “Fairly unconfident” categories as only one person had self-tested, use was significantly different between the categories

(chi^2=15.55, df=3, p=0.001) and the test for a trend across the categories was also significant (chi^2=14.69, df=1, p<0.001).

Table 42: Prevalence of self-test use among people with different levels of confidence about using self-tests.

	Self-test use				
	No		Yes		Total
Confidence using self-test	n	%	n	%	n
Very confident	316	88.0	43	12.0	359
Fairly confident	659	90.9	66	9.1	725
Neither confident nor unconfident	245	93.2	18	6.8	263
Fairly unconfident	66	100.0	0	0.0	66
Very unconfident	54	98.2	1	1.8	55
Very confident	316	88.0	43	12.0	359
Fairly confident	659	90.9	66	9.1	725
Neither confident nor unconfident	245	93.2	18	6.8	263
Fairly unconfident & Very unconfident	120	99.2	1	0.8	121

4.7.5.3.2 Knowledge of self-tests

Respondents were asked if they knew of any of a list of named self-tests or another self-test before receiving the initial questionnaire and this was converted into a score. Scores ranged from 1 to 13 (maximum is 16) (IQR 4-7) and from 0 to 15 (IQR 2-5) respectively for people who had (n=130) and had not used self-tests (n=1348). The mean (5.2) and median (5) scores were higher among people who had self-tested than among those who had not done so (3.8 and 3 respectively), which suggests that the former group knew that more tests were available than the latter group. These differences in the mean and median scores were highly significant (p<0.001) using the two-sample t-test and the non-parametric Wilcoxon rank sum test respectively.

The patterns were similar if pregnancy tests were excluded (used/not used: range=0-12/0-14, IQR=3-6/1-4, mean=4.3/2.9, median=4/2), if tests for high BP were excluded (used/not used: range=1-12/0-14, IQR=3-6/1-4, mean=4.5/3.2, median=4/3) and if both were excluded (used/not used: range=0-11/0-13, IQR=2-5/1-3, mean=3.6/2.3, median=3/2), and all the two-sample t-tests and Wilcoxon rank sum tests were highly significant ($p<0.001$). As all these variables were significantly associated with use, that is there appeared to be no reason to use one rather than another, it seemed appropriate to use the score including all tests in the regression analysis.

4.7.5.4 Habits and lifestyle

The threshold for significance for variables from this section is a p-value of 0.05/7=0.007 as seven statistical tests were performed (see section 3.6.9.4.4).

4.7.5.4.1 Smoking

Only 6.4% of people who said that they smoked had used a self-test compared with 8.9% of non-smokers (table 43). The difference was not significant ($chi^2=0.989$, df=1, p=0.320), although this may be limited by the small number of smokers.

Table 43: Prevalence of self-test use among smokers and non-smokers.

	Self-test use				
	No		Yes		Total
Smoke	n	%	n	%	N
Yes	132	93.6	9	6.4	141
No	1225	91.2	119	8.9	1344
Total	1357	91.4	128	8.6	1485

4.7.5.4.2 Exercise

People who exercised about three or four days per week had the highest rate of self-test use (11.4%) (table 44) and the difference between the categories (chi^2=15.07, df=5, p=0.010) approached significance. There seemed to be no obvious trend across the categories though: people who exercised three or four days each week had a higher rate of use than those who exercised less (about one or two days each week=7.6%) and more (five days each week or more=5.2%). In line with this, there was no significant trend (chi^2=0.01, df=1, p=0.904) and this was also true when people who exercised less than once a week were put in one group (chi^2=0.16, df=1, p=0.689).

Table 44: Prevalence of self-test use among people with different exercise patterns.

	Self-test use				
	No		Yes		Total
Exercise	n	%	n	%	n
Five days a week or more	218	94.8	12	5.2	230
About three or four days a week	373	88.6	48	11.4	421
About one or two days a week	414	92.4	34	7.6	448
Less than once a week but at least once a month	184	90.6	19	9.4	203
Less than once a month	55	84.6	10	15.4	65
Never or almost never	115	95.8	5	4.2	120
Five days a week or more	218	94.8	12	5.2	230
About three or four days a week	373	88.6	48	11.4	421
About one or two days a week	414	92.4	34	7.6	448
Less than once a week but at least once a month, Less than once a month & Never or almost never	354	91.2	34	8.8	388
Total	1359	91.4	128	8.6	1487

4.7.5.4.3 *Fruit and vegetables*

Self-test use increased with frequency of fruit and vegetable consumption, ranging from none among people who ate them never or almost never to 8.1% among those who ate them less than once each day but at least once a week and 10.7% among those who ate them five times or more each day (table 45). After combining the categories where respondents ate fruit and vegetables less than once a day so that each category included some people who had self-tested, there was, however, no significant evidence that use was different between the categories (chi^2=3.14, df=3, p=0.370) and no significant trend across the categories (chi^2=2.99, df=1, p=0.084).

Table 45: Prevalence of self-test use among people who ate different amounts of fruit and vegetables.

	Self-test use				
	No		Yes		Total
Fruit and vegetables	n	%	n	%	n
Five times a day or more	310	89.3	37	10.7	347
About three or four times a day	490	91.4	46	8.6	536
About one or two times a day	454	92.3	38	7.7	492
Less than once a day but at least once a week	79	91.9	7	8.1	86
Less than once a week	13	100.0	0	0.0	13
Never or almost never	13	100.0	0	0.0	13
Five times a day or more	310	89.3	37	10.7	347
About three or four times a day	490	91.4	46	8.6	536
About one or two times a day	454	92.3	38	7.7	492
Less than once a day but at least once a week, Less than once a week & Never or almost never	105	93.8	7	6.3	112
Total	1359	91.4	128	8.6	1487

4.7.5.4.4 Internet use

The rate of self-test use (11.4%) was highest among people who used the internet less than once a day but at least once a week (table 46), with lower rates among people who used the internet less or more often, for example 5.1% among respondents who used the internet never or almost never and 8.5% among those who used the internet five times a day or more. There was no significant evidence that self-test use was different between the groups (chi^2=9.40, df=5, p=0.094) and there was no significant trend across the categories (chi^2=1.23, df=1, p=0.267).

Table 46: Prevalence of self-test use among people with different levels of internet use.

	Self-test use				
	No		Yes		Total
Internet use	n	%	n	%	n
Five days a day or more	237	91.5	22	8.5	259
About three or four times a day	124	93.2	9	6.8	133
About one or two times a day	349	89.9	39	10.1	388
Less than once a day but at least once a week	279	88.6	36	11.4	315
Less than once a week	85	91.4	8	8.6	93
Never or almost never	281	94.9	15	5.1	296
Total	1355	91.3	129	8.7	1484

4.7.5.5 Knowledge of health recommendations

The threshold for significance for variables from this section is a p-value of 0.05/2=0.025 as two statistical tests were performed (see section 3.6.9.4.4).

4.7.5.5.1 *Recommendation about fruit and vegetables*

Only 115 of 1487 respondents did not know the recommendation (five portions per day). They had a slightly lower rate of self-test use (7.0%) than those who did know (8.8%) (table 47), but this difference was not significant (chi^2=0.465, df=1, p=0.495).

Table 47: Prevalence of self-test use among people who knew and did not know the recommended intake of fruit and vegetables.

	Self-test use				
	No		Yes		Total
Knew recommendation	n	%	n	%	n
Yes	1251	91.2	121	8.8	1372
No	107	93.0	8	7.0	115
Total	1358	91.3	129	8.7	1487

4.7.5.5.2 *Recommendation about exercise*

Self-test use was very similar among those who knew (8.5%) and did not know the recommendation to exercise on at least five days each week (8.7%) (table 48) and there was no significant difference (chi^2=0.022, df=1, p=0.882).

Table 48: Prevalence of self-test use among people who knew and did not know the recommended frequency of exercise.

	Self-test use				
	No		Yes		Total
Knew recommendation	n	%	n	%	n
Yes	281	91.5	26	8.5	307
No	1076	91.3	103	8.7	1179
Total	1357	91.3	129	8.7	1486

4.7.5.6 Information about health

The threshold for significance for variables from this section is a p-value of 0.05/12=0.004 as 12 statistical tests were performed (see section 3.6.9.4.4).

4.7.5.6.1 Health advice from anyone listed

The score for advice from anyone listed for people who had used a self-test (n=130) ranged from zero to 13 (out of 22) (IQR 2-5) with a mean of 3.48 and a median of 3, and the values (0-17 (IQR 1-5), 3.40 and 3) were similar for people who had not used a self-test (n=1369). In line with this, there was no significant difference in mean or median scores between the two groups using the two-sample t-test (p=0.733) and Wilcoxon rank sum test (p=0.545) respectively.

4.7.5.6.2 Health advice from lay person

Scores for advice from a lay person for people who had used a self-test (n=116) ranged from zero to 7 (out of 8) (IQR 0-2) with mean and median scores of 1.66 and 1 respectively, compared with 0-8 (IQR 0-2), 1.33 and 1 respectively for people who had not self-tested (n=1233). People who had self-tested had a higher mean score, which might suggest that this group accessed advice from more lay people and/or more frequently than people who had not done so, but neither the two-sample t-test (p=0.034) nor the non-parametric Wilcoxon rank sum test (p=0.011) were significant.

4.7.5.6.3 Health advice from health professional

Scores for advice from a health professional for people who had used a self-test (n=127) ranged from zero to 8 (out of 10) (IQR 1-3) with mean and median scores of 1.87 and 2 respectively, compared with 0-10 (IQR 1-3), 2.03 and 2 respectively for people who had not self-tested (n=1360). In contrast to lay advice, people who had self-tested had a lower mean score, which might suggest that they accessed advice from a more restricted range of professionals and/or less frequently than people who had not done so. Again, however, there were no significant differences in the mean and median scores between people who had and had not used self-tests using the two-sample t-test (p=0.280) and Wilcoxon rank sum test (p=0.202) respectively.

4.7.5.6.4 Health advice from a complementary therapist

For people who responded to this part of the question, the highest use (12.1%) was among those who had asked a complementary therapist for advice one or two times (table 49). After respondents who had not asked for advice from a complementary therapist or who were not sure were placed in a single category as no-one in the latter group had self-tested, there was no significant evidence that self-test use was different between the categories (chi^2=3.68, df=2, p=0.159) and no significant trend across the categories (chi^2=0.08, df=1, p=0.775).

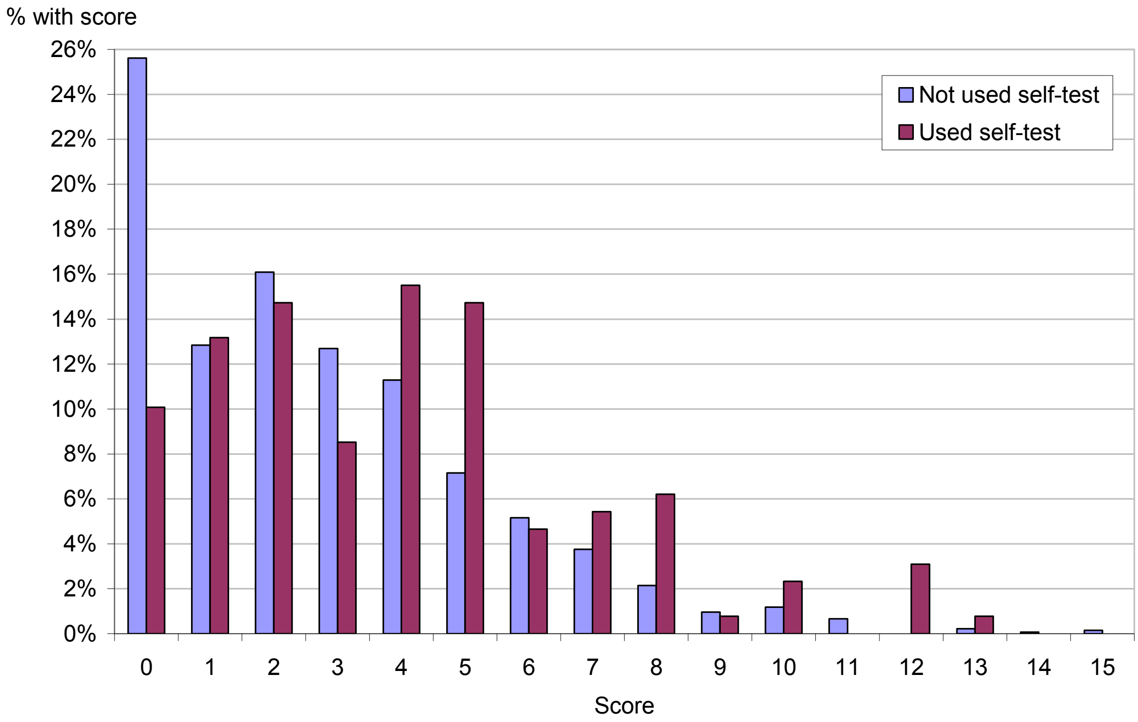
Table 49: Prevalence of self-test use among people who did and did not ask a complementary therapist for health advice during the last 12 months.

	Self-test use				
	No		Yes		Total
Frequency	n	%	n	%	n
Three or more times	45	95.7	2	4.3	47
Once or twice	109	87.9	15	12.1	124
Not at all	996	92.1	86	7.9	1082
Not sure	15	100.0	0	0.0	15
Three or more times	45	95.7	2	4.3	47
Once or twice	109	87.9	15	12.1	124
Not at all & Not sure	1011	92.2	86	7.8	1097
Total	1165	91.9	103	8.1	1268

4.7.5.6.5 Information about health problems

This score relates to information from NHS Direct, the internet or websites, CDs or DVDs, books, newspaper or magazine articles or adverts, radio or television programmes or adverts, adverts in pharmacies or chemists, or another source specified by the respondent. A higher score indicates that information was sought more often and/or from more sources. Scores for people who had used a self-test (n=129) ranged from zero to 13 (out of 20) (IQR 2-5) with mean and median scores of 3.97 and 4 respectively, compared with a range of zero to 15 but a lower IQR (0-4) and mean (2.72) and median (2) scores for people who had not done so (n=1355). These differences in the mean and median values were highly significant ($p<0.001$) using the two-sample t-test and the Wilcoxon rank sum test respectively. This suggests that people who had self-tested sought information more often and/or from more sources than people who had not done so (figure 6).

Figure 6: Proportion of respondents who had and had not used self-tests with different scores for obtaining health information from any source.



As NHS Direct involves conventional clinical professionals, in contrast to other sources listed, it was felt that excluding NHS Direct may be appropriate. The range of scores and mean and median scores were 0-13 (out of 18) (IQR 1-5), 3.72 and 3 respectively for people who had used a self-test (n=129), compared with 0-14 (IQR 0-4), 2.52 and 2 for those who had not done so (n=1355). The differences were similar to when NHS Direct was included and they were again highly significant using the two-sample t-test ($p<0.001$) and the Wilcoxon rank sum test ($p<0.001$). The direction of the result was also the same for the score for NHS Direct alone: people who had self-tested were more likely to have asked for advice (28/114=24.6%) than people who had not done so (248/1284=19.3%). This suggested that including or excluding NHS Direct was not critical and the score including NHS Direct was used.

4.7.5.7 Health status

The threshold for significance for variables from this section is a p-value of 0.05/7=0.007 as seven statistical tests were performed (see section 3.6.9.4.4).

4.7.5.7.1 Self-rated health during last 12 months

People who reported not good health had the highest rate of self-test use (13.0%), whereas only 8.8% and 7.4% respectively of people with good and fairly good health had used self-tests (table 50). There was no significant trend across the categories (chi^2=0.25, df=1, p=0.616) and no significant evidence that self-test use was different between the categories (chi^2=3.48, df=2, p=0.176), although the latter may be because only a small number of people (n=108) said that their health was not good.

Table 50: Prevalence of self-test use among people with different self-rated health.

	Self-test use				
	No		Yes		Total
Self-reported health	n	%	n	%	n
Good	890	91.2	86	8.8	976
Fairly good	403	92.6	32	7.4	435
Not good	94	87.0	14	13.0	108
Total	1387	91.3	132	8.7	1519

4.7.5.7.2 Long-term illness

Respondents who reported long-term illness had only a slightly higher rate of self-test use than those who did not do so (9.7% and 8.1% respectively) (table 51) and this difference was not significant (chi^2=1.103, df=1, p=0.294).

Table 51: Prevalence of self-test use among people with and without long-term illness.

	Self-test use				
	No		Yes		Total
Long-term illness	n	%	n	%	n
Yes	484	90.3	52	9.7	536
No	884	91.9	78	8.1	962
Total	1368	81.3	130	8.7	1498

The difference in self-test use between people who reported that their health was not good (13.0%) and who reported long-term illness (9.7%) probably reflects the fact that most people who reported a long-term illness rated their health as good or fairly good (table 52). Self-reported health, therefore, appears to be more discriminating.

Table 52: Crossover between reports of long-term illness and self-rated health.

	Long-term illness		
Self-reported health	Yes	No	Total
Good	219	745	964
Fairly good	230	197	427
Not good	86	19	105
Total	535	961	1496

4.7.5.7.3 SF-8 physical health measure

Scores among people who had self-tested (n=128) ranged from 21.0 (minimum is 9.1) to 62.4 (maximum is 69.0) (IQR 44.2-55.9) with a mean of 49.6 and a median of 52.1, compared with 13.6-66.7 (IQR 47.0-56.7), 50.6 and 54.0 for people who had not done so (n=1362). As a higher score indicates better health, this suggests that the latter group may be slightly more healthy. Both distributions had higher median than mean values, appearing to be negatively skewed by some very low scores. A non-parametric test might, therefore, more appropriately assess whether one of these groups tended to have higher values. The differences in the mean and median scores were, however, not significant using the two-sample t-test (p=0.226) and non-parametric Wilcoxon rank sum test (p=0.027) respectively, although the latter was much closer to significance.

4.7.5.7.4 SF-8 mental health measure

Scores for people who had used a self-test (n=128) ranged from 15.1 (minimum is 5.5) to 61.8 (maximum is 71.7) (IQR 45.1-57.2) with a mean of 49.0 and a median of 51.6, compared with 15.1-68.8 (IQR 46.6-57.5), 50.2 and 52.3 for people who had not done so (n=1362). A higher score equates to better mental health, but the two groups had fairly similar mean and median scores. As with the physical health measure, the medians were higher than the means for both groups, indicating that a non-parametric test may be more appropriate, but neither the mean nor median scores were significantly different using the two-sample t-test (p=0.167) and non-parametric Wilcoxon rank sum test (p=0.303) respectively.

4.7.5.8 Thoughts about how to stay healthy and future illnesses

The threshold for significance for variables from this section is a p-value of 0.05/4=0.013 as four statistical tests were performed (see section 3.6.9.4.4).

4.7.5.8.1 Things to stay healthy

The highest rate of use (10.1%) was among the largest group, people who had healthy thoughts every day (table 53). Rates were lower among those who had less frequent healthy thoughts, but there was no obvious trend. In line with this, there was no significant trend of increasing use with increasing frequency of healthy thoughts (chi^2=1.63, df=1, p=0.201) and there was no significant evidence that the use of a self-test was different between the categories (chi^2=2.80, df=5, p=0.731).

Table 53: Prevalence of self-test use among people with different frequencies of healthy thoughts.

	Self-test use				
	No		Yes		Total
Things to stay healthy	n	%	n	%	n
Every day	488	89.9	55	10.1	543
Every two or three days	297	91.4	28	8.6	325
About once a week	276	92.9	21	7.1	297
Less than once a week but at least once a month	156	92.3	13	7.7	169
Less than once a month	97	91.5	9	8.5	106
Never or almost never	64	92.8	5	7.3	69
Total	1378	91.3	131	8.7	1509

4.7.5.8.2 Future illnesses

People who thought about future illnesses less than once a week but at least once a month (10.4%) and every two or three days (10.1%) had the highest rates of use (table 54). Rates were lower among those who had such thoughts less and more frequently, for example never or almost never (7.3%) and every day (4.0%). In line with this, there was no significant trend across the categories (chi^2=0.01, df=1, p=0.915) and no significant evidence that use was different between the categories (chi^2=5.54, df=5, p=0.353).

Table 54: Prevalence of self-test use among people with different frequencies of thoughts about future illnesses.

	Self-test use				
	No		Yes		Total
Future illnesses	n	%	n	%	n
Every day	95	96.0	4	4.0	99
Every two or three days	112	89.6	13	10.4	125
About once a week	220	90.5	23	9.5	243
Less than once a week but at least once a month	232	89.9	26	10.1	258
Less than once a month	276	90.2	30	9.8	306
Never or almost never	442	92.7	35	7.3	477
Total	1377	91.3	131	8.7	1508

4.7.5.9 Views about health checks and medical tests

Respondents were asked if they strongly agreed, agreed, neither agreed nor disagreed, disagreed or strongly disagreed with statements that were based on the views of interviewees about health checks and medical tests. The threshold for significance for variables from this section is a p-value of 0.05/8=0.006 as eight statistical tests were performed (see section 3.6.9.4.4).

4.7.5.9.1 Medical tests are reassuring

Respondents who agreed that medical tests were reassuring had a slightly higher rate of self-test use (9.1%) than other people, but those who neither agreed nor disagreed had a lower rate (7.3%) and only 14 people disagreed or strongly disagreed, only one of whom had used a self-test (table 55). The few people who disagreed or strongly disagreed were kept in a single separate category as it was felt that disagreement is different to neutrality (“Neither agree nor disagree”). There was no significant evidence that self-test use was different between the categories (chi^2=0.53, df=3, p=0.912) and no significant trend across the categories (chi^2=0.08, df=1, p=0.784).

Table 55: Prevalence of self-test use among people with different views about whether medical tests were reassuring.

	Self-test use				
	No		Yes		Total
Medical tests are reassuring	n	%	n	%	n
Strongly agree	509	91.4	48	8.6	557
Agree	702	90.9	70	9.1	772
Neither agree nor disagree	139	92.7	11	7.3	150
Disagree	11	91.7	1	8.3	12
Strongly disagree	2	100.0	0	0.0	2
Strongly agree	509	91.4	48	8.6	557
Agree	702	90.9	70	9.1	772
Neither agree nor disagree	139	92.7	11	7.3	150
Disagree & Strongly disagree	13	92.9	1	7.1	14
Total	1363	91.3	130	8.7	1493

4.7.5.9.2 Curious about health

People who agreed that they were curious about their health had the highest rate of self-test use (9.9%) (table 56). Only 61 people disagreed or strongly disagreed and, after these categories were amalgamated because no-one in the latter category had used a self-test, there was no significant evidence that self-test use was different between the categories (chi^2=7.32, df=3, p=0.062) and no significant trend across the categories (chi^2=2.60, df=1, p=0.107).

Table 56: Prevalence of self-test use among people who were and were not curious about their health.

	Self-test use				
	No		Yes		Total
Curious about health	n	%	n	%	n
Strongly agree	272	91.6	25	8.4	297
Agree	731	90.1	80	9.9	811
Neither agree nor disagree	290	95.1	15	4.9	305
Disagree	50	92.6	4	7.4	54
Strongly disagree	7	100.0	0	0.0	7
Strongly agree	272	91.6	25	8.4	297
Agree	731	90.1	80	9.9	811
Neither agree nor disagree	290	95.1	15	4.9	305
Disagree & Strongly disagree	57	93.4	4	6.6	61
Total	1350	91.6	124	8.4	1474

4.7.5.9.3 Like routine health checks

Ignoring the high rate among the five people who strongly disagreed that they liked routine health checks, the highest rate of self-test use (10.7%) was among those who neither agreed nor disagreed (table 57). The lowest rate (3.1%) was among people who disagreed, but there were only a few such people (n=32) and there was no obvious trend. In line with this, after the “Disagreed” and “Strongly disagreed” categories were combined because of the small numbers, there was no significant evidence that self-test use was different between the categories (chi^2=1.90, df=3, p=0.594) and no significant trend across the categories (chi^2=0.39, df=1, p=0.534).

Table 57: Prevalence of self-test use among people who did and did not like routine health checks.

	Self-test use				
	No		Yes		Total
Routine health checks	n	%	n	%	n
Strongly agree	516	92.1	44	7.9	560
Agree	655	91.6	60	8.4	715
Neither agree nor disagree	158	89.3	19	10.7	177
Disagree	31	96.9	1	3.1	32
Strongly disagree	4	80.0	1	20.0	5
Strongly agree	516	92.1	44	7.9	560
Agree	655	91.6	60	8.4	715
Neither agree nor disagree	158	89.3	19	10.7	177
Disagree & Strongly disagree	35	94.6	2	5.4	37
Total	1364	91.6	125	8.4	1489

4.7.5.9.4 Medical tests cause anxiety

Respondents who agreed that tests made them anxious had the highest rate of self-test use (9.7%), but those who disagreed had a similar rate (9.3%) and those who strongly agreed had a lower rate (6.9%) (table 58). In line with this, there was no significant evidence that self-test use was different between the categories (chi^2=2.13, df=4, p=0.712) and there was no significant trend across the categories (chi^2=0.00, df=1, p=0.957).

Table 58: Prevalence of self-test use among people with different views about whether medical tests made them anxious.

	Self-test use				
	No		Yes		Total
Medical tests cause anxiety	n	%	n	%	n
Strongly agree	81	93.1	6	6.9	87
Agree	316	90.3	34	9.7	350
Neither agree nor disagree	380	92.7	30	7.3	410
Disagree	417	90.7	43	9.3	460
Strongly disagree	160	92.0	14	8.0	174
Total	1354	91.4	127	8.6	1481

4.7.5.10 Views about visiting the GP

Respondents were asked if they strongly agreed, agreed, neither agreed nor disagreed, disagreed or strongly disagreed with statements that were based on the views of interviewees about visiting the GP. The threshold for significance for variables from this section is a p-value of 0.05/16=0.003 as 16 statistical tests were performed (see section 3.6.9.4.4).

4.7.5.10.1 Only go to doctor if symptoms

Respondents who disagreed that they would only go to the doctor if they had symptoms had the highest rate of self-test use (10.5%), although only 38 people disagreed. Those who neither agreed nor disagreed had a lower rate of use (5.9%), but the rate increased again to 9.4% among respondents who strongly agreed with no obvious trend (table 59). In line with this, after categories where respondents disagreed or strongly disagreed were combined because no-one who strongly disagreed had used a self-test, there was no significant evidence that self-test use was different between the categories (chi^2=1.67, df=3, p=0.643) and no significant trend across the categories (chi^2=0.62, df=1, p=0.431).

Table 59: Prevalence of self-test use among people with different views about whether they would only go to their doctor if they had symptoms.

	Self-test use				
	No		Yes		Total
Only go to doctor if symptoms	n	%	n	%	n
Strongly agree	617	90.6	64	9.4	681
Agree	668	92.1	57	7.9	725
Neither agree nor disagree	48	94.1	3	5.9	51
Disagree	34	89.5	4	10.5	38
Strongly disagree	1	100.0	0	0.0	1
Strongly agree	617	90.6	64	9.4	681
Agree	668	92.1	57	7.9	725
Neither agree nor disagree	48	94.1	3	5.9	51
Disagree & Strongly disagree	35	89.7	4	10.3	39
Total	1368	91.4	128	8.6	1496

4.7.5.10.2 Need symptoms or risk factors to get test

Respondents who neither agreed nor disagreed that they would need symptoms or risk factors to get a test done at their GP surgery had the highest rate of self-test use (10.0%) (table 60), but rates were lower among respondents who agreed and disagreed and there was no discernible trend. In line with this, there was no significant evidence that self-test use was different between the categories (chi^2=3.55, df=4, p=0.471) and there was no significant trend across the categories (chi^2=0.05, df=1, p=0.830).

Table 60: Prevalence of self-test use among people with different views about whether they would need symptoms or risk factors to get a test done at their GP surgery.

	Self-test use				
	No		Yes		Total
Need symptoms or risk factors to get test	n	%	n	%	n
Strongly agree	196	93.8	13	6.2	209
Agree	510	91.2	49	8.8	559
Neither agree nor disagree	369	90.0	41	10.0	410
Disagree	228	92.7	18	7.3	246
Strongly disagree	35	94.6	2	5.4	37
Total	1338	91.6	123	8.4	1461

4.7.5.10.3 Do not like to bother doctor

Rates of self-test use were similar among respondents who agreed or disagreed with the statement that they did not like to bother their doctor unless it was really necessary, for example 9.3% among those who agreed and 8.2% among those who disagreed (table 61). In line with this, after categories where respondents disagreed or strongly disagreed were combined because there was no self-test use among people who strongly disagreed, there was no significant evidence that self-test use was different between the categories (chi^2=1.30, df=3, p=0.729) and no significant trend across the categories (chi^2=0.19, df=1, p=0.663).

Table 61: Prevalence of self-test use among people with different views about whether they did not like to bother the doctor unless it was really necessary.

	Self-test use				
	No		Yes		Total
Do not like to bother doctor	n	%	n	%	n
Strongly agree	439	91.6	40	8.4	479
Agree	732	90.7	75	9.3	807
Neither agree nor disagree	109	93.2	8	6.8	117
Disagree	67	91.8	6	8.2	73
Strongly disagree	14	100.0	0	0.0	14
Strongly agree	439	91.6	40	8.4	479
Agree	732	90.7	75	9.3	807
Neither agree nor disagree	109	93.2	8	6.8	117
Disagree & Strongly disagree	81	93.1	6	6.9	87
Total	1361	91.3	129	8.7	1490

4.7.5.10.4 Only go to doctor if severe or serious symptoms

Rates of self-test use were highest (12.4%) among people who neither agreed or disagreed that they would only go to the doctor if they had severe or serious symptoms, with lower rates among those who agreed and disagreed (table 62). In line with this, there was no significant evidence that self-test use was different between the categories (chi^2=9.98, df=4, p=0.041) and there was no significant trend across the categories (chi^2=0.20, df=1, p=0.658).

Table 62: Prevalence of self-test use among people with different views about whether they would only go to the doctor if they had severe or serious symptoms.

	Self-test use				Total
	No		Yes		
Only go to doctor if severe or serious symptoms	n	%	n	%	n
Strongly agree	256	89.5	30	10.5	286
Agree	516	94.0	33	6.0	549
Neither agree nor disagree	191	87.6	27	12.4	218
Disagree	360	90.9	36	9.1	396
Strongly disagree	34	91.9	3	8.1	37
Total	1357	91.3	129	8.7	1486

4.7.5.10.5 Evidence to justify a visit to doctor

People who disagreed that they would need evidence to justify a visit to their doctor had the highest rate of self-test use (12.4%) (table 63). Rates were lower in all other categories, although only 17 people strongly disagreed. In line with this, after the “Disagreed” and “Strongly disagreed” categories were combined because of the small numbers in the latter category, there was no significant evidence that self-test use was different between the categories (chi^2=2.40, df=3, p=0.493) and no significant trend across the categories (chi^2=1.98, df=1, p=0.160).

Table 63: Prevalence of self-test use among people who did and did not think that they would need evidence to justify a visit to the doctor.

	Self-test use				
	No		Yes		Total
Evidence to justify visit to doctor	n	%	n	%	n
Strongly agree	282	92.2	24	7.8	306
Agree	712	91.8	64	8.2	776
Neither agree nor disagree	220	90.0	22	9.1	242
Disagree	127	87.6	18	12.4	145
Strongly disagree	16	92.1	1	5.9	17
Strongly agree	282	92.2	24	7.8	306
Agree	712	91.8	64	8.2	776
Neither agree nor disagree	220	90.0	22	9.1	242
Disagree & Strongly disagree	143	88.3	19	11.7	162
Total	1357	91.3	129	8.7	1486

4.7.5.10.6 Embarrassed to tell doctor about personal problems

People who agreed that they would be embarrassed to tell their doctor about very personal problems had the highest rate of self-test use (11.6%), but there was no obvious trend and rates were similar in all the other categories (table 64). In line with this, there was no significant evidence that self-test use was different between the categories (chi^2=3.19, df=4, p=0.526) and no significant trend across the categories (chi^2=0.97, df=1, p=0.324).

Table 64: Prevalence of self-test use among people who would and would not be embarrassed to tell the doctor about personal or intimate problems.

	Self-test use				
	No		Yes		Total
Embarrassed to tell doctor	N	%	n	%	n
Strongly agree	73	92.4	6	7.6	79
Agree	214	88.4	28	11.6	242
Neither agree nor disagree	212	91.8	19	8.2	231
Disagree	643	92.0	56	8.0	699
Strongly disagree	212	91.8	19	8.2	231
Total	1354	91.4	128	8.6	1482

4.7.5.10.7 Happy to ask doctor for check-up

Respondents who neither agreed or disagreed that they would be happy to ask their doctor for a check-up had the highest rate of self-test use (12.4%), but rates were lower among those who agreed and disagreed with no obvious trend (table 65). After the "Disagreed" and "Strongly disagreed" categories were combined because of the small number of people who strongly disagreed, there was no significant evidence that self-test use was different between the categories (chi^2=6.43, df=3, p=0.093) and no significant trend across the categories (chi^2=1.90, df=1, p=0.168).

Table 65: Prevalence of self-test use among people who would and would not be happy to ask their doctor for a check-up.

	Self-test use				
	No		Yes		Total
Happy to ask doctor for check-up	n	%	n	%	n
Strongly agree	255	93.4	18	6.6	273
Agree	663	91.7	60	8.3	723
Neither agree nor disagree	240	87.6	34	12.4	274
Disagree	178	91.8	16	8.2	194
Strongly disagree	21	91.3	2	8.7	23
Strongly agree	255	93.4	18	6.6	273
Agree	663	91.7	60	8.3	723
Neither agree nor disagree	240	87.6	34	12.4	274
Disagree & Strongly disagree	199	91.7	18	8.3	217
Total	1357	91.3	130	8.7	1487

4.7.5.10.8 Confident doctor would try and do test

Respondents who strongly disagreed that their doctor would try and do a test had the highest rate of self-test use (14.3%) (table 66). There were only 14 such respondents, but use was also higher among respondents who disagreed (11.5%) than among those who strongly agreed (5.6%), agreed (9.3%) or neither agreed nor disagreed (10.4%). In line with this, after the “Disagreed” and “Strongly disagreed” categories were combined because of the small number in the latter category, the test for trend approached significance (chi^2=6.18, df=1, p=0.013), although there was no significant evidence that self-test use was different between the categories (chi^2=7.22, df=3, p=0.065).

Table 66: Prevalence of self-test use among people who were and were not confident that their doctor would do a test if asked.

	Self-test use				
	No		Yes		Total
Confident doctor would do test	n	%	n	%	n
Strongly agree	369	94.4	22	5.6	391
Agree	670	90.7	69	9.3	739
Neither agree nor disagree	225	89.6	26	10.4	251
Disagree	85	88.5	11	11.5	96
Strongly disagree	12	85.7	2	14.3	14
Strongly agree	369	94.4	22	5.6	391
Agree	670	90.7	69	9.3	739
Neither agree nor disagree	225	89.6	26	10.4	251
Disagree & Strongly disagree	97	88.2	13	11.8	110
Total	1361	91.3	130	8.7	1491

4.7.5.11 Access to the GP

The threshold for significance for variables from this section is a p-value of 0.05/6=0.008 as six statistical tests were performed (see section 3.6.9.4.4).

4.7.5.11.1 Appointment as soon as would like

Among people who replied and who had had an appointment, those who said that it was very difficult to get an appointment as soon as they would like had the highest rate of self-test use (10.8%) and those who reported that it was very easy had the lowest rate (6.8%) (table 67). After excluding respondents who had never had an appointment, there was, however, no significant evidence that use was different between the categories (chi^2=4.40, df=4, p=0.355) and no significant trend across the categories (chi^2=1.64, df=1, p=0.200).

Table 67: Prevalence of self-test use among people who expressed different levels of ease or difficultly getting an appointment as soon as they would like with their GP.

	Self-test use				
	No		Yes		Total
Appointment as soon as would like	n	%	n	%	n
Very easy	483	93.2	35	6.8	518
Fairly easy	633	90.2	69	9.8	702
Neither easy nor difficult	126	92.6	10	7.4	136
Fairly difficult	98	89.9	11	10.1	109
Very difficult	33	89.2	4	10.8	37
Never had an appointment	7	77.8	2	22.2	9
Total	1389	91.3	132	8.7	1511

4.7.5.11.2 Appointment at a suitable time

Among respondents who replied and who had had an appointment, those who said that it was neither easy nor difficult to get an appointment at a suitable time had the highest rate of self-test use (11.3%), and there was no discernible trend with lower rates among those who thought it was very easy (7.0%) and very difficult (8.0%) (table 68). After excluding respondents who had never had an appointment, there was no significant evidence that self-test use was different between the categories (chi^2=3.19, df=4, p=0.527) and no significant trend across the categories (chi^2=1.07, df=1, p=0.300).

Table 68: Prevalence of self-test use among people who expressed different levels of ease or difficultly getting an appointment with their GP at a suitable time.

	Self-test use				
	No		Yes		Total
Appointment at suitable time	n	%	n	%	n
Very easy	305	93.0	23	7.0	328
Fairly easy	660	91.8	59	8.2	719
Neither easy nor difficult	181	88.7	23	11.3	204
Fairly difficult	157	90.8	16	9.2	173
Very difficult	69	92.0	6	8.0	75
Never had an appointment	7	77.8	2	22.2	9
Total	1379	91.4	129	8.6	1508

4.7.5.11.3 Travel to GP surgery

Among respondents who replied and who had been to their GP surgery, those who reported that it was neither easy nor difficult to travel there had the highest rate of self-test use (16.3%), with lower rates among those in other categories, for example those who thought it was very easy (7.6%) and fairly difficult (9.4%) (table 69). After excluding respondents who had never been to their GP surgery and amalgamating the “Fairly difficult” and “Very difficult” categories because of very small numbers, there was no significant evidence that self-test use was different between the categories (chi^2=7.35, df=3, p=0.062) and no significant trend across the categories (chi^2=4.23, df=1, p=0.040).

Table 69: Prevalence of self-test use among people who expressed different levels of ease or difficultly travelling to their GP surgery.

	Self-test use				
	No		Yes		Total
Travel to GP surgery	n	%	n	%	n
Very easy	897	92.4	74	7.6	971
Fairly easy	377	91.1	37	8.9	414
Neither easy nor difficult	67	83.8	13	16.3	80
Fairly difficult	29	90.6	3	9.4	32
Very difficult	7	87.5	1	12.5	8
Never been to GP surgery	3	60.0	2	40.0	5
Total	1380	91.4	130	8.6	1510
Very easy	897	92.4	74	7.6	971
Fairly easy	377	91.1	37	8.9	414
Neither easy nor difficult	67	83.8	13	16.3	80
Fairly difficult & Very difficult	36	90.0	4	10.0	40
Total	1377	91.5	128	8.5	1505

4.7.5.12 Satisfaction with healthcare

The threshold for significance for variables from this section is a p-value of 0.05/6=0.008 as six statistical tests were performed (see section 3.6.9.4.4).

4.7.5.12.1 Satisfaction with GP consultations

This section included questions adapted from the GPAQ about satisfaction with consultations. Scores for people who had used a self-test (n=130) ranged from 10 (minimum is 8) to 40 (out of 40) (IQR 28-39) with mean and median scores of 32.6 and 32 respectively, compared with a range of 9-40 (IQR 31-40) and higher mean (34.3) and median (35) scores for people who had not self-tested (n=1369). This suggests that people who had self-tested were less satisfied than those who had not done so, and the differences in mean and median scores were significant using the two-sample t-test (p=0.002) and Wilcoxon rank sum (p=0.003) test respectively.

4.7.5.12.2 Satisfaction with own healthcare

Excluding very dissatisfied respondents as none of them had used self-tests, people who were dissatisfied had the highest rate of use (15.6%) and rates fell as satisfaction increased, to 6.1% among very satisfied people (table 70). As few people were very dissatisfied (n=4) and none of them had used self-tests, the “Very dissatisfied” and “Dissatisfied” categories were combined. Following this, there was a significant difference in use between the groups (chi^2=12.01, df=3, p=0.007) and a highly significant trend across the categories (chi^2=9.88, df=1, p=0.002).

Table 70: Prevalence of self-test use among people with different levels of satisfaction with their healthcare.

	Self-test use				
	No		Yes		Total
Satisfaction with own healthcare	n	%	n	%	n
Very satisfied	677	93.9	44	6.1	721
Satisfied	586	89.1	72	10.9	658
Neither satisfied nor dissatisfied	83	89.2	10	10.8	93
Dissatisfied	27	84.4	5	15.6	32
Very dissatisfied	4	100.0	0	0.0	4
Very satisfied	677	93.9	44	6.1	721
Satisfied	586	89.1	72	10.9	658
Neither satisfied nor dissatisfied	83	89.2	10	10.8	93
Dissatisfied & Very dissatisfied	31	86.1	5	13.9	36
Total	1377	91.3	131	8.7	1508

4.7.5.12.3 Satisfaction with other's healthcare

Respondents who were dissatisfied with care provided to friends and relatives had the highest rate of self-test use (12.4%) and rates then decreased as satisfaction increased, to 7.5% among people who were very satisfied (table 71). As few people were very dissatisfied (n=27), the groups where people were dissatisfied or very dissatisfied were amalgamated. Following this though, there was no significant evidence that self-test use was different between the categories (chi^2=2.36, df=3, p=0.500) and no significant trend across the categories (chi^2=2.24, df=1, p=0.134).

Table 71: Prevalence of self-test use among people with different levels of satisfaction with relatives' or friends' healthcare.

	Self-test use				
	No		Yes		Total
Satisfaction with others' healthcare	n	%	n	%	n
Very satisfied	356	92.5	29	7.5	385
Satisfied	683	91.4	64	8.6	747
Neither satisfied nor dissatisfied	194	90.7	20	9.3	214
Dissatisfied	113	87.6	16	12.4	129
Very dissatisfied	25	92.6	2	7.4	27
Very satisfied	356	92.5	29	7.5	385
Satisfied	683	91.4	64	8.6	747
Neither satisfied nor dissatisfied	194	90.7	20	9.3	214
Dissatisfied & Very dissatisfied	138	88.5	18	11.5	156
Total	1371	91.3	131	8.7	1502

4.7.5.13 Beliefs about health

This section concerns health locus of control, that is how respondents perceive health to be controlled. The threshold for significance for variables from this section is a p-value of 0.05/8=0.006 as eight statistical tests were performed (see section 3.6.9.4.4).

4.7.5.13.1 Internal control

The range of scores was 6 (minimum is 6) to 34 (out of 36) (IQR 22-28) and the mean and median scores were 24.4 and 24 respectively for people who had used a self-test (n=129), compared with 8-36 (IQR 22-27), 24.3 and 25 for people who had not done so (n=1366). This suggests that people who have and have not used self-tests have similar perceptions about whether health is controlled internally, and there was no significant difference in mean or median scores using the two-sample t-test (p=0.967) and the non-parametric Wilcoxon rank sum test (p=0.943) respectively.

4.7.5.13.2 Chance

The range of scores was 6 (minimum is 6) to 32 (out of 36) (IQR 15-22) and the mean and median scores were 18.4 and 19 respectively for people who had used a self-test (n=129), compared with 6-35 (IQR 14-21), 17.8 and 18 for people who had not used one (n=1363). This suggests that people who have used self-tests have a slightly greater belief that health depends on chance, but this difference in the mean and median scores between people who had and had not used self-tests was not significant (p=0.206 for two-sample t-test and p=0.191 for Wilcoxon rank sum test).

4.7.5.13.3 Powerful others

The range of scores was 6 (minimum is 6) to 33 (out of 36) (IQR 11-20) and the mean and median scores were 16.2 and 16 respectively for people who had used self-tests (n=129), compared with 6-36 (IQR 14-21), 17.6 and 17 for people who had not done so (n=1366). This suggests that people who have self-tested do not believe as strongly that health depends on powerful others, such as health professionals, and the difference in the mean scores was significant using the two-sample t-test (p=0.005). The Wilcoxon rank sum test also approached significance (p=0.007).

4.7.5.13.4 Health value

Respondents were asked whether they strongly agreed, moderately agreed, slightly agreed, slightly disagreed, moderately disagreed or strongly disagreed with four statements about the value that they placed upon health. These were included as it is argued that health locus of control cannot be properly interpreted unless account is taken of the value placed on health by an individual. The range of scores was 4 (minimum is 4) to 24 (out of 24) (IQR 15-21) and the mean and median were 17.9 and 18 respectively for people who had self-tested (n=130), compared with the same overall and interquartile range, a similar mean (18.1) and the same median (18) for people who had not done so (n=1360). This suggests that people who had self-tested and those who have not done so placed a similar value on health, and there were no significant differences in mean and median scores between the groups using the two-sample t-test (p=0.567) and the Wilcoxon rank sum test (p=0.568) respectively.

4.7.5.14 Summary of univariate analysis

This section has presented a univariate analysis of self-test use for each explanatory variable arising from the initial and in-depth questionnaire. The levels of significance for variables concerned with specific areas of interest, for example personal characteristics, were adjusted to allow for multiple comparisons (section 3.6.9.4.4). The levels of significance and results for each area are summarised in appendix 35.

Having ever used a self-test was significantly positively associated with: being female, having ever worked as a health professional, confidence using a self-test, knowing that a range of tests were available, seeking health information more frequently and/or from more sources listed on the questionnaire, being less satisfied with GP consultations, and being less satisfied with your overall healthcare. There was also a significant positive association with not believing as strongly that health depends on powerful others, such as health professionals. This association was only significant using the parametric two sample t-test, although the non-parametric Wilcoxon rank sum test also approached significance.

The next section presents results from forward stepwise multiple logistic regression analyses used to identify those variables that together best predict self-test use.

4.7.6 Multivariable analysis

4.7.6.1 Overview of this section

This section presents the results of forward stepwise multiple logistic regression analyses used to identify those variables that together best predicted whether someone had used a self-test. Two approaches were used: all explanatory variables without selection were entered into the first analysis, whereas the second used selected variables based on analyses of explanatory variables grouped according to their focus, for example personal characteristics. It was felt that the second approach would test the robustness of the analysis with all variables without selection and may give a model that indicated important factors from a wider range of areas. Variables used in the analyses and their categorisation are shown in appendix 36.

4.7.6.2 Regression analysis including all variables

When all of the variables were entered into a stepwise forward logistic regression analysis with self-test use as the dependent variable, there were 1091 individuals included in the analysis, 86 of whom had used a self-test, and the resulting model included 12 variables (table 72). Based on the likelihood ratio chi^2 test, the model itself was highly significant ($chi^2=109.83$, df=24, $p<0.001$). This test contrasts the full model with a model with the constant only and the low p-value indicated that the null hypothesis that the models were the same should be rejected [143, 144]. The Hosmer Lemeshow test assesses the goodness of the fit of the model [145]. The respondents were placed in ten groups based on the predicted probabilities and the number of expected and observed self-tests users and non-users in each group were compared. The p-value of 0.845 suggested that the null hypothesis, that the observed and model generated numbers of users were not significantly different, should not be rejected. The R^2 statistics do not measure the goodness of fit of the model but are measures of effect size, indicating how useful the explanatory variables are in predicting the response variables [145]. The Cox & Snell R^2 was 0.096, which was in broad agreement with the value for the Nagelkerke R^2 (0.226). The values were not close to one, indicating that, even though the model was significant, these variables together are not a very strong predictor of self-test use.

Table 72: Final model from stepwise forward logistic regression analysis including all variables [a].

Variables in the order they were added	Coefficient (β)	Standard error of coefficient	Wald	df	p-value	Odds ratio (exp (β))	95% confidence interval	
Knowledge of any tests listed	0.192	0.046	17.605	1	0.000	1.211	1.108	1.325
Health information from any source listed	0.115	0.042	7.340	1	0.007	1.122	1.032	1.219
Health locus of control score for powerful others	-0.080	0.028	8.306	1	0.004	0.923	0.874	0.975
Exercise								
Five days a week or more (reference)			16.438	5	0.006			
About three or four days a week	0.654	0.435	2.262	1	0.133	1.923	0.820	4.509
About one or two days a week	0.088	0.452	0.038	1	0.846	1.092	0.450	2.650
Less than once a week but at least once a month	0.507	0.487	1.086	1	0.297	1.661	0.640	4.312
Exercise less than once a month	1.879	0.569	10.896	1	0.001	6.548	2.146	19.985
Exercise never or almost never	0.046	0.674	0.005	1	0.946	1.047	0.279	3.921
Satisfaction with GP consultations	-0.048	0.024	4.200	1	0.040	0.953	0.910	0.998
Self-rated health during last 12 months								
Good (reference)			9.299	2	0.010			
Fairly good	-0.600	0.314	3.643	1	0.056	0.549	0.296	1.016
Not good	0.884	0.440	4.031	1	0.045	2.420	1.021	5.733

[a] Stepwise forward logistic regression analysis of having used a self-test compared with the reference category of not having used a self-test among 1091 in-depth questionnaire respondents and including all variables.

Table continued on next page

Variables in the order they were added	Coefficient (β)	Standard error of coefficient	Wald's χ^2	df	p-value	Odds ratio (exp (b))	95% confidence interval	
Only go to doctor if severe or serious symptoms								
Strongly agree (reference)			12.684	4	0.013			
Agree	-1.050	0.375	7.858	1	0.005	0.350	0.168	0.729
Neither agree nor disagree	0.107	0.385	0.078	1	0.780	1.113	0.524	2.365
Disagree	-0.167	0.348	0.231	1	0.631	0.846	0.428	1.674
Strongly disagree	-0.477	0.886	0.290	1	0.591	0.621	0.109	3.525
Confident doctor would do test								
Strongly agree (reference)			7.430	3	0.059			
Agree	1.080	0.431	6.281	1	0.012	2.944	1.265	6.850
Neither agree nor disagree	0.813	0.496	2.683	1	0.101	2.255	0.852	5.965
Disagree & Strongly disagree	0.504	0.604	0.698	1	0.404	1.656	0.507	5.404
Smoking (reference)								
Not smoking	1.012	0.559	3.272	1	0.070	2.751	0.919	8.236
Worked as a health professional (reference)								
Never worked as a health professional	-0.630	0.331	3.622	1	0.057	0.532	0.278	1.019
Curious about health								
Strongly agree (reference)			6.701	3	0.082			
Agree	-0.196	0.298	0.433	1	0.511	0.822	0.458	1.474
Neither agree nor disagree	-1.174	0.479	6.004	1	0.014	0.309	0.121	0.791
Disagree & Strongly disagree	-0.782	0.815	0.921	1	0.337	0.458	0.093	2.259

Table continued on next page

Variables in the order they were added	Coefficient (β)	Standard error of coefficient	Wald's χ^2	df	p-value	Odds ratio (exp (b))	95% confidence interval	
Health locus of control score for chance	0.047	3.356	3.356	1	0.067	1.048	0.997	1.102
Constant	-2.618	4.097	4.097	1	0.043	n/a	n/a	n/a

Footnotes: Statistics usually reported to three decimal places for precision, but fewer decimal places reported if fewer provided.

Number of observations=1091 Cox & Snell R^2=0.096

Log likelihood=-246.087 Nagelkerke R^2=0.226

LR chi^2=109.83, df=24, p<0.001 Hosmer Lemeshow chi^2=4.133, df=8, p=0.845

The analysis indicated that the odds of having used rather than not having used a self-test were significantly affected by 12 variables, as described in box 12. Self-test use was predicted by knowing about a range of tests, seeking health information more frequently and/or from more sources, believing that health was not controlled by powerful others, exercising less than once a month rather than exercising five days a week or more, being less satisfied with GP consultations, not smoking rather than smoking, having worked rather than having never worked as a health professional, and believing that health was controlled by chance.

Four other categorical variables showed a significant association. The likelihood of having used a self-test was significantly increased by reporting not good rather than good health, although reporting fairly good rather than good health was associated with a reduced likelihood of use. The likelihood of having used a self-test was significantly increased by agreeing rather than strongly agreeing with the statement that the doctor would try and do a test if asked. Although non-significant, the odds of having used a self-test were also raised for “Neither agree nor disagree” and “Disagree & Strongly disagree” compared to “Strongly agree”. This supports strong agreement with the statement being associated with a decreased likelihood of use.

Box 12: Interpretation of stepwise forward logistic regression analysis including all variables [a].

Controlling for other variables, the odds of having used rather than not having used a self-test were:

- Increased by a factor of 1.21 for each unit increase in the score for knowledge of any tests listed on the initial questionnaire.
- Increased by a factor of 1.12 for each unit increase in the score for obtaining information about health from a range of sources.
- Decreased by a factor of 0.92 for each unit increase in the score for the belief that powerful others control your health.
- Increased by a factor of 6.55 for exercising less than once a month compared to exercising five days a week or more.
- Decreased by a factor of 0.95 for each unit increase in the score for satisfaction with GP consultations.
- Increased by a factor of 2.42 by reporting not good rather than good health but reduced by a factor of 0.55 by reporting fairly good rather than good health.
- Decreased by a factor of 0.35 by agreeing rather than strongly agreeing with the statement that you should only go to the doctor with severe or serious symptoms.
- Increased by a factor of 2.94 by agreeing rather than strongly agreeing with the statement that you would be confident that the doctor would try and do a test if asked.
- Increased by a factor of 2.75 by not smoking rather than smoking.
- Decreased by a factor of 0.53 by not having ever worked rather than having worked as a health professional.
- Decreased by a factor of 0.31 by neither agreeing nor disagreeing rather than strongly agreeing with the statement that you are curious about your health.
- Increased by a factor of 1.05 for each unit increase in the score for the belief that chance controls your health.

[a] Stepwise forward logistic regression analysis of having used a self-test compared with the reference category of not having used a self-test among 1091 in-depth questionnaire respondents and including all variables.

The likelihood of having used a self-test was significantly decreased by agreeing rather than strongly agreeing with the statement that you should only go to the doctor if you have severe or serious symptoms. Although non-significant, the odds of having used a self-test were also decreased for “Disagree” and “Strongly disagree” compared to “Strongly agree”, which supports strong agreement with the statement being associated with an increased likelihood of use. Finally, similar to this, the likelihood of having used a self-test was significantly decreased by neither agreeing nor disagreeing rather than strongly agreeing with the statement that the person was curious about their health. Although non-significant, the odds of having used a self-test were also decreased for “Agree” and “Disagree & Strongly disagree” compared to “Strongly agree”. This supports strong agreement with the statement being associated with an increased likelihood of use.

4.7.6.3 Regression analysis with selected variables

For comparison and to test the robustness of the analysis including all variables, a further stepwise forward logistic regression analysis was performed. This used those variables that were in the final models arising from stepwise forward regression analyses of variables grouped according to their focus, for example variables concerning personal characteristics. The groups and variables that were in the final model for each group (the cut-offs for inclusion and exclusion in the models were $p<0.1$ and $p\geq0.2$ respectively) are shown in box 13. Full details of the analyses are given in appendix 37.

Box 13: Summary of results from individual stepwise forward regression analyses of variables grouped according to their focus.

Group of variables	**Variables included in final model [a]**	**Variables excluded from final model**
Personal characteristics	Age Sex	Ethnic group
Associated with affluence or occupation	Economic activity Worked as health professional	IMD 2007 score Qualifications
Related to self-test use	Confidence using self-tests Knowledge of any tests listed	
Behaviours	Exercise	Smoking Fruit and vegetables Internet use
Knowledge of health recommendations		About fruit and vegetables About exercise
Information about health	Health advice from health professional Health information from any source listed	Health advice from anyone listed Health advice from lay person Health advice from complementary therapist
Health status	Self-rated health during last 12 months	Long-term illness SF-8 physical health measure SF-8 mental health measure
Thoughts about how to stay healthy and future illnesses		Things to stay healthy Future illnesses
Views about medical tests	Curious about health	Medical tests are reassuring Like routine health checks Medical tests cause anxiety
Views about visiting GP	Only go to doctor if severe or serious symptoms Confident doctor would do test	Only go to doctor if symptoms Need symptoms or risk factors to get test Do not like to bother doctor Evidence to justify visit to doctor Embarrassed to tell doctor Happy to ask doctor for check-up

[a] The cut-offs for inclusion and exclusion in the model were $p<0.1$ and $p\geq0.2$ respectively.

Table continued on next page

Group of variables	Variables included in final model [a]	Variables excluded from final model
Access to GP		Appointment as soon as would like Appointment at suitable time Travel to GP surgery
Satisfaction with healthcare	Satisfaction with GP consultations	Satisfaction with own care Satisfaction with other's care
Health locus of control	Health locus of control score for chance Health locus of control score for powerful others	Health locus of control score for internal control Health value

When the significant variables in the individual analyses were entered into a stepwise forward logistic regression analysis with self-test use as the dependent variable, there were 1355 individuals included in the analysis, 114 of whom had used a self-test. The resulting model included nine variables (table 73). Based on the likelihood ratio chi^2 test, the model itself was highly significant (chi^2=105.29, df=17, p<0.001). The low p-value indicated that the null hypothesis, that the full model and a model with the constant only are the same, should be rejected [143, 144]. The high p-value (0.974) for the Hosmer Lemeshow test indicated that the null hypothesis, that the observed and model generated numbers of users were not significantly different, should not be rejected [145]. The R^2 statistics, which are measures of effect size, indicated how useful the explanatory variables would be in predicting self-test use [145]. The Cox & Snell R^2 value was 0.075, which was in broad agreement with the value for the Nagelkerke R^2 (0.170). The values were not close to one though, indicating that, even though the model was significant, these variables together were not a very strong predictor of self-test use.

Table 73: Final model from stepwise forward logistic regression analysis including selected variables [a].

Variables in the order they were added	Coefficient (β)	Standard error of coefficient	Wald	df	p-value	Odds ratio (exp (b))	95% confidence interval	
Knowledge of any tests listed	0.184	0.038	23.492	1	0.000	1.202	1.116	1.295
Health information from any source listed	0.129	0.035	13.281	1	0.000	1.138	1.062	1.220
Health locus of control score for powerful others	-0.071	0.022	10.653	1	0.001	0.931	0.892	0.972
Exercise								
Five days a week or more (reference)			18.198	5	0.003			
About three or four days a week	0.908	0.373	5.920	1	0.015	2.480	1.193	5.156
About one or two days a week	0.309	0.390	0.628	1	0.428	1.362	0.635	2.923
Less than once a week but at least once a month	0.503	0.428	1.383	1	0.240	1.654	0.715	3.823
Exercise less than once a month	1.646	0.499	10.863	1	0.001	5.186	1.949	13.799
Exercise never or almost never	-0.073	0.625	0.014	1	0.907	0.929	0.273	3.162
Health locus of control score for chance	0.053	0.021	6.102	1	0.014	1.054	1.011	1.099
Self-rated health during last 12 months								
Good (reference)			7.508	2	0.023			
Fairly good	-0.293	0.252	1.346	1	0.246	0.746	0.455	1.224
Not good	0.809	0.368	4.824	1	0.028	2.246	1.091	4.623
Satisfaction with GP consultations	-0.040	0.017	5.645	1	0.018	0.961	0.929	0.993

[a] Stepwise forward logistic regression analysis of having used a self-test compared with the reference category of not having used a self-test among 1355 in-depth questionnaire respondents and including variables that were significant in analyses of variables grouped according to their focus.

Table continued on next page

Variables in the order they were added	Coefficient (β)	Standard error of coefficient	Wald's χ^2	df	p-value	Odds ratio (exp (b))	95% confidence interval	
Worked as a health professional (reference)								
Never worked as a health professional	-0.0607	0.281	4.680	1	0.031	0.545	0.314	0.945
Only go to doctor if severe or serious symptoms								
Strongly agree (reference)			8.578	4	0.073			
Agree	-0.567	0.303	3.512	1	0.061	0.567	0.314	1.026
Neither agree nor disagree	0.286	0.321	0.795	1	0.373	1.331	0.710	2.497
Disagree	-0.088	0.301	0.085	1	0.770	0.916	0.508	1.652
Strongly disagree	-0.044	0.685	0.004	1	0.948	0.957	0.250	3.665
Constant	-1.973	0.883	4.996	1	0.025	n/a	n/a	n/a

Footnotes: Statistics usually reported to three decimal places for precision, but fewer decimal placed reported if fewer provided.

Number of observations=1355 Cox & Snell R^2=0.075

Log likelihood=-338.609 Nagelkerke R^2=0.170

LR chi^2=105.29, df=17, p<0.001 Hosmer Lemeshow chi^2=2.202, df=8, p=0.974

This analysis indicated that the odds of having used rather than not having used a self-test were significantly affected by nine variables, as described in box 14. Self-test use was predicted by knowing about a range of tests, seeking health information more frequently and/or from more sources, believing that health was not controlled by powerful others, believing that health was controlled by chance, reporting not good rather than good health, being less satisfied with GP consultations, and having worked rather than never having worked as a health professional.

Two other categorical variables had a significant association. The likelihood of having used a self-test was significantly increased by exercising about three or four days a week and less than once a month compared to five days a week or more. Although non-significant, the odds of having used a self-test were also increased for all the other categories, which all also concerned a lower frequency of exercise. This supports exercising five days a week or more being associated with a decreased likelihood of use. The likelihood of using a self-test was significantly decreased by agreeing rather than strongly agreeing with the statement that you should only go to the doctor if you have severe or serious symptoms. Although non-significant, the odds of having used a self-test were also decreased for “Disagree” and “Strongly disagree” compared to “Strongly agree”, which supports strong agreement being associated with an increased likelihood of use.

Box 14: Interpretation of stepwise forward logistic regression analysis [a] including significant variables from analyses of grouped variables.

Controlling for other variables, the odds of having used rather than not having used a self-test were:

- Increased by a factor of 1.20 for each unit increase in the score for knowledge of any tests listed on the initial questionnaire.
- Increased by a factor of 1.14 for each unit increase in the score for obtaining information about health from a range of sources.
- Decreased by a factor of 0.93 for each unit increase in the score for the belief that powerful others control your health.
- Increased by a factor of 2.48 by exercising about three or four days a week and by a factor of 5.19 by exercising less than once a month compared to exercising five days a week or more.
- Increased by a factor of 1.05 for each unit increase in the score for the belief that chance controls your health.
- Increased by a factor of 2.25 by reporting not good rather than good health.
- Decreased by a factor of 0.96 for each unit increase in the score for satisfaction with GP consultations.
- Decreased by a factor of 0.55 by not having ever worked rather than having worked as a health professional.
- Decreased by a factor of 0.57 by agreeing rather than strongly agreeing with the statement that you should only go to the doctor with severe or serious symptoms.

[a] Stepwise forward logistic regression analysis of having used a self-test compared with the reference category of not having used a self-test among 1355 in-depth questionnaire respondents and including variables that were significant in analyses of variables grouped according to their focus.

4.7.6.4 Comparison of models

The p-value for the Hosmer Lemeshow test for the second model using selected variables (0.974) was higher than the p-value for the model generated when all variables were simply included in the analysis (0.845), suggesting that the second model was a slightly better fit. The R^2 measures, however, indicated that the original model would be more useful in predicting who had actually used a self-test: the Cox and Snell R^2 and Nagelkerke R^2 for the original model (0.096 and 0.226 respectively) were slightly higher than the values for the second model (0.075 and 0.170 respectively). In both cases, however, the R^2 values were not close to one, signifying that the models would not be strong predictors of self-test use. Most of the variables included in the models were the same – the second model included three fewer variables but all of the nine included variables were in the original model - and the size of their effects were also similar, as summarised in table 74.

Table 74: Comparison of variables included in the models generated by using all variables and selected variables.

Variable	Model generated from all variables: Included (at step)	Model generated from all variables: Odds ratio	Model generated from selected variables: Included (at step)	Model generated from selected variables: Odds ratio
Knowledge of any tests listed	Yes (1)	1.21	Yes (1)	1.20
Health information from any source listed	Yes (2)	1.12	Yes (2)	1.14
Health locus of control score for powerful others	Yes (3)	0.92	Yes (3)	0.93
Exercise	Yes (4)	6.55 for less than once a month	Yes (4)	2.48 for about three or four days a week, and 5.19 for less than once a month
Satisfaction with GP consultations (GPAQ)	Yes (5)	0.95	Yes (7)	0.96
Self-rated health	Yes (6)	0.55 for fairly good and 2.42 for not good	Yes (6)	2.25 for not good
Only go to doctor if severe or serious symptoms	Yes (7)	0.35 for agree	Yes (9)	0.57 for agree
Confident doctor would do test	Yes (8)	2.94 for agree	No	n/a
Smoking	Yes (9)	2.75	No	n/a
Worked as a health professional	Yes (10)	0.53	Yes (8)	0.55
Curious about health	Yes (11)	0.31 for neither agree nor disagree	No	n/a
Health locus of control score for chance	Yes (12)	1.05	Yes (5)	1.05

4.7.6.5 Summary of regression analyses

This section presented the results of stepwise multiple logistic regression analyses used to identify those variables that together best predict self-test use. Two approaches were used: all explanatory variables were entered without selection into the first analysis. This lead to a model with 12 variables: use was predicted by (1) knowing about a range of tests, (2) seeking health information more frequently and/or from more sources, (3) believing that health was not controlled by powerful others, (4) exercising less than once a month rather than five days a week or more, (5) being less satisfied with GP consultations, (6) reporting not good rather than good health, (7) agreeing rather than strongly agreeing that the doctor would try and do a test if asked, (8) strongly agreeing rather than agreeing that you should only go to the doctor if you have severe or serious symptoms, (9) not smoking rather than smoking, (10) having worked rather than never having worked as a health professional, (11) strongly agreeing rather than neither agreeing nor disagreeing that you were curious about your health, and (12) believing that health was controlled by chance.

The second approach involved entering selected variables based on analyses of explanatory variables grouped according to their focus, for example personal characteristics. It was felt that this approach would test the robustness of the analysis with all variables and may give a model that indicated important factors from a wider range of areas. This analysis lead to a model with nine variables: use was predicted by (1) knowing about a range of tests, (2) seeking health information more frequently and/or from more sources, (3) believing that health was not controlled by powerful others (4) exercising about three or four days a week and less than once a month rather than five days a week or more, (5) believing that health was controlled by chance, (6) reporting not good rather than good health, (7) being less satisfied with GP consultations, (8) having worked rather than never having worked as a health professional, and (9) strongly agreeing rather than agreeing that you should only go to the doctor if you have severe or serious symptoms.

The second model was a slightly better fit, but the first would be more useful in predicting use. The variables included in the models were similar, suggesting that their inclusion was appropriate: the first model only included three explanatory variables not included in the second (being confident the doctor would do a test if asked, smoking status, and being curious about your health), and the second did not include any explanatory variables not included in the first model.

4.7.7 Summary of this section

Interviews with a sample of respondents to the initial questionnaire and a systematic literature review lead to the design of an in-depth questionnaire to collect data on factors that may predict self-test use. This was sent to willing respondents to the initial questionnaire who had and had not reported use. Questionnaires sent to people who reported use included a section asking for details so that use could be confirmed. This section has presented an analysis of data from the in-depth questionnaire with the aim of determining factors that predict confirmed self-test use.

The mailing of the questionnaires was described. Two thousand two hundred and five (63%) of 3505 eligible people consented to another questionnaire and 2174 were sent out after exclusions. Eight questionnaires were undelivered, leaving 2166 that were delivered. Seventy eight blank and 1537 (71%) completed questionnaires were returned. After 16 exclusions, there were 1521 (70%) eligible questionnaires.

Data quality was also reviewed. For sections concerning factors that may predict self-test use, this was based on double data entry of around 15% of questionnaires. Only six of 156 data items had discrepancy rates greater than 1.5% and appropriate action was taken for these items. The discrepancy rate for each person who had entered data was also reviewed. After removing discrepancies related to the misinterpretation of two data items by one person, discrepancy rates varied from 0.13% to 0.88%, which was considered to be acceptable. For sections collecting details of self-test use, this was based on double data entry of around 10% of these sections. Fourteen of 77 data items showed at least one discrepancy, but the original database was correct or no amendments were needed in all cases and no further action was taken.

Characteristics of eligible respondents to the in-depth questionnaire were described based on responses to the initial and in-depth questionnaires and population-based data were presented, where available, for comparison. They appeared to be more likely to be female, older and from white ethnic groups than the population of England. They were also more affluent, more qualified, more likely to be retired than economically inactive for other reasons and less likely to smoke, although frequent internet use was less common than was reported from a national population-based survey. Most respondents described at least fairly good health, in line with other population-based estimates, but a higher proportion reported a long-term illness. Respondents were positive about the role of medical tests. They tended to agree that certain criteria, such as severe symptoms, legitimise a visit to the doctor, but they were also confident that their doctor would try and do a check-up or test if asked and embarrassment would not stop them consulting. Respondents had few problems making appointments or travelling to the GP and they were generally satisfied with GP consultations and healthcare overall. They placed a fairly high value on health and tended to believe that health was controlled internally, rather than by chance or powerful others. Finally, most respondents would have felt confident using a self-test, although most did not know about them and only 8.8% (n=132) of 1521 eligible respondents were confirmed as having used a self-test without clinical involvement.

A univariate analysis of self-test use for each explanatory variable arising from the initial and in-depth questionnaire was then presented. Having ever used a self-test was significantly positively associated with being female, having ever worked as a health professional, confidence using a self-test, knowing that a range of self-tests were available, seeking health information more frequently and/or from more sources, being less satisfied with GP consultations, being less satisfied with healthcare overall, and not believing as strongly that health depends on powerful others such as health professionals.

Finally, results of stepwise multiple logistic regression analyses used to identify those variables that together best predict self-test use were presented. In both models presented, use was predicted by: (1) knowing about a range of tests, (2) seeking health information more frequently and/or from more sources, (3) believing that health was not controlled by powerful others, (4) exercising less frequently, (5) being less satisfied with GP consultations, (6) reporting not good rather than good health, (7) strongly agreeing that you should only go to the doctor if you have severe or serious symptoms, (8) having worked rather than never having worked as a health professional, and (9) believing that health was controlled by chance. When all variables were entered into the analysis, weaker agreement (agreeing rather than strongly agreeing) that the doctor would try and do a test if asked, not smoking rather than smoking, and strongly agreeing that you were curious about your health were also in the final model. When variables were selected for entry into the analysis from analyses of explanatory variables grouped according to their focus, no additional variables were in the final model. The second model (selected variables) was a slightly better fit, but the first (all variables) would be more useful in predicting use.

The next section provides an overview of the whole results chapter.

4.8 Summary of this chapter

The results of the various parts of the study were presented in this chapter. The first section set out the results of the systematic search of the internet for self-tests that were available to buy by members of the public in the UK. A wide range was available: 104 unique self-tests were identified related to 24 named conditions, including cancers, chronic conditions and infections. These self-tests required a variety of samples, including blood obtained using a lancet. The samples were processed at home or sent to a laboratory with results returned by email or post. This information was used in the design of a short initial questionnaire, which asked if people registered with general practices had ever used any of a list of self-tests.

The second section described the findings from interviews with 23 respondents to the initial questionnaire who had reported self-test use. The objective was to gain a better understanding of the use of self-tests and generate a list of factors that may predict use. Most interviewees were women (n=18) and most were aged 35 to 64 years, employed, and in at least fairly good health. Some had actually used the tests that they had marked on the initial questionnaire with the involvement of clinicians. Interviewees had also accessed tests in a variety of ways, rather than simply buying a test. This highlighted the opportunity of the in-depth questionnaire to confirm use reported on the initial questionnaire and investigate how self-tests were accessed.

The findings from the interviews were organised around two themes. One focused on experiences of self-testing: self-tests were usually discovered opportunistically and interviewees found them easy to use and talked about their positive impact, for example from changes made as a result of a diagnosis. The other theme focused on motivations for self-testing centred around four sub-themes. The first sub-theme described reasons for self-testing, which tended to be a desire for a specific diagnostic outcome or more speculative reasons, such as a routine health check. The second sub-theme detailed perceived benefits of self-testing: being in control of one's health, being anonymous, and convenience compared with the practical difficulties of visiting the doctor. Although these were likely to be positive motivators for self-testing, some interviewees described possible negative motivators related to the third sub-theme, which concerned attitudes to and experiences of healthcare, for example dissatisfaction with past care. The fourth sub-theme focused on the broader context of some participants' positive attitude to their health, for example believing that they could improve their health and taking steps to do so. Interviewees generally spoke about a mix of positive and negative motivators, but extreme profiles were apparent. For some participants with a positive attitude towards health and healthcare, self-testing simply enabled them to carry out a routine health check, for example on their cholesterol level. In contrast, others described wanting to avoid conventional services because of past experiences and using self-tests to try and diagnose a specific problem.

The third section described the results of the systematic literature review for evidence for factors that may be associated with using self-tests and, because of the lack of evidence in this area, similar activities. The objective was to add to the list of factors generated from the interviews. Fifty eligible papers related to 46 studies were identified. The evidence from these papers suggested that users of CAM and OTC medicine were female, middle-aged, had some measure of affluence and/or were educated with some measure of poor health, and that people who used the private sector were generally middle-aged and had some measure of affluence and/or were educated. Other factors may also be associated with use of these activities, but they were not as universally studied so the results were less conclusive. Four studies about CAM and one about OTC medicine suggested a link with healthy lifestyles or being health conscious and knowledgeable about health. Two studies also found that CAM users were more likely to believe that they control their health or less likely to believe that doctors control their health than users of orthodox medicine.

The fourth section brought together information from the interviews and systematic literature review to feed into the design of an in-depth questionnaire to investigate factors that were potentially predictive of self-test use. Factors that were asked about in the questionnaire were: age, sex, having worked as a health professional, educational attainment, engagement in health-improving behaviours, knowledge related to health, health information-seeking behaviour, health status, concern with improving health or future illnesses, views about health checks and medical tests, views about when it is appropriate to visit the GP, access to conventional services, satisfaction with conventional care, and beliefs about how health is controlled. Employment status was also available from the initial questionnaire and affluence was assessed with the IMD derived from respondents’ postcodes. It was also considered important that the questionnaire clarified whether tests marked on the initial questionnaire had been used with or without the involvement of a clinician.

The penultimate section set out estimates of the prevalence of self-test use derived from the initial questionnaire and based on use confirmed by the in-depth questionnaire. The initial questionnaire suggested that about one in 10 men and one in seven women have used a self-test excluding tests for pregnancy or high BP. This was based on questionnaires received from 5025 people (63% of 7964 delivered) with a broadly similar sex- and age-profile to the general population, although higher proportions of them were from white ethnic groups or retired rather than economically inactive for other reasons. The most commonly reported test was for diabetes.

Eligible completed in-depth questionnaires were received from 235 people who had reported use of a test other than for high BP or pregnancy on the initial questionnaire. This was 65% of the 361 delivered questionnaires but only 51% of the 487 people who initially reported such use and were eligible for a questionnaire, mainly because only 368 (76%) of them consented to another questionnaire. One hundred and thirty two (56%) of these 235 people had used the test without clinical involvement and use was most often confirmed for tests for diabetes. This facilitated the calculation of a lowest limit for prevalence: it was estimated that about one in 46 men and one in 21 women have used a self-test other than for high BP or pregnancy. As this did not take account of respondents to the initial questionnaire who did not return an eligible in-depth questionnaire, an exploratory analysis assumed that everyone who initially reported use but did not return an eligible in-depth questionnaire had the same sex-specific rates of confirmed use as eligible responders. This lead to the estimate that around one in 18 men and one in 11 women have used a self-test.

The in-depth questionnaire also confirmed that people had accessed self-tests in several ways, rather than just buying a test, and this varied depending on the type of test. People who had used cholesterol tests, for example were most likely to have bought them from a pharmacy to use at home. Similar to this, reasons for self-test use also appeared to vary depending on the type of test. People who had used cholesterol tests, for example, were looking for reassurance, whereas people who used tests for urine infection had symptoms and wanted a diagnosis.

The final section considered factors that may predict self-test use using data mainly from the in-depth questionnaire. The analysis included 1521 in-depth questionnaires (70% of 2166 delivered). Eligible respondents were more likely to be female, older and from white ethnic groups than the national population. They were also more affluent, more qualified, more likely to be retired than economically inactive for other reasons and less likely to smoke and use the internet frequently. Most described at least fairly good health, in line with other population-based estimates, although a higher proportion reported a long-term illness. Respondents tended to be positive about medical tests. They also tended to agree that certain criteria legitimise a visit to the doctor, for example having symptoms, although they were confident that their doctor would try and do a test or check-up if asked and embarrassment would not prevent them visiting the doctor. Respondents described few problems accessing healthcare and satisfaction was generally high. They tended to place a high value on health and believe that health was controlled internally, rather than by chance or powerful others. Finally, most respondents would have felt confident using a self-test, although most did not know about them and only 8.8% (n=132) of 1521 eligible respondents were confirmed as having used a self-test without clinical involvement.

A univariate analysis of self-test use for each explanatory variable arising from the initial and in-depth questionnaire was presented. Self-test use was significantly positively associated with: being female, having worked as a health professional, confidence using a self-test, knowing that a range of self-tests were available, seeking health information more frequently and/or from more sources, being less satisfied with GP consultations, being less satisfied with overall healthcare, and not believing as strongly that health depends on powerful others, such as doctors.

Finally, the results of stepwise multiple logistic regression analyses used to identify those variables that together best predict self-test use were presented. In both models presented, use was predicted by: (1) knowing about a range of tests, (2) seeking health information more frequently and/or from more sources, (3) believing that health was not controlled by powerful others, (4) exercising less frequently, (5) being less satisfied with GP consultations, (6) reporting not good rather than good health, (7) strongly agreeing that you should only go to the doctor if you have severe or serious symptoms, (8) having worked rather than never having worked as a health professional, and (9) believing that health was controlled by chance. When all variables were entered into the analysis, weaker agreement (agreeing rather than strongly agreeing) that the doctor would try and do a test if asked, not smoking rather than smoking, and strongly agreeing that you are curious about your health were also in the final model. When variables were selected for entry based on analyses of explanatory variables grouped according to their focus, there were no additional variables in the final model. The second model (selected variables) was a slightly better fit, but the first (all variables) would be more useful in predicting use.

The next chapter presents a discussion of this study, including the main findings, the strengths and weaknesses, the results in the context of related literature, the meaning and implications of the study, and future research related to self-tests.

5 DISCUSSION

5.1 Overview of this chapter

This chapter presents a discussion of the study. The rationale for the study and its aims and methods are reviewed, followed by a summary of the main findings. This is followed by a review of the strengths and weaknesses of the study with the potential impact of the limitations. The results of the study are then discussed in the context of existing research in this area and related literature. The meaning of this study is then considered before the direction for future research related to self-tests is discussed.

5.2 Overview of rationale, aims and methods

The availability and range of self-tests to diagnose or screen for medical conditions without involving a health professional has increased [1]. This has been driven by advances in technology and the resulting commercial opportunities, but the emergence of self-tests has also coincided with and been fuelled by a renewed emphasis on self-care and patient participation. This has been partly driven by patients themselves, who increasingly favour greater involvement in decisions about their health and healthcare, and by policymakers, who are keen to capitalise on the popularity of self-care and its potential to improve outcomes whilst saving costs.

Self-tests undoubtedly have possible individual benefits, for example convenience and anonymity, and population benefits, for example increased coverage of testing for diseases where an early diagnosis is important. There are, however, possible individual harms. Harm could, for example, result from false positive results leading to false reassurance, and the risk of this could be increased by the lack of a firm evidence base for tests, insufficient quality assurance, and insufficient accompanying information or the lack of an independent person to enable the user to adequately weigh up harms and benefits before using the test. In terms of potential population harms, self-testing has the potential to reduce but also reinforce inequity: appropriate use of self-tests could free up conventional services, but people who are unable to adequately communicate their needs to health professionals might turn to expensive and perhaps undesirable self-tests. Self-test use is also likely to impact on healthcare due to demands to investigate false positive results or clinically insignificant true positive results.

Despite these potential impacts, there had been a lack of research in this area: this study was the first and only study in the UK to-date to examine the use of self-tests. The aims of this study were to describe the prevalence of the use of self-tests by members of the public to diagnose or screen for medical conditions without the involvement of a health professional and to determine factors that are associated with their use.

To meet the aims of the study, a systematic search of self-tests available to buy via the internet was initially conducted. This informed the design of an initial questionnaire asking about whether people had used self-tests. A population-based survey of adults registered with general practices in Birmingham, Warwickshire and

Worcestershire was then conducted, which lead to an initial assessment of the prevalence of self-test use and generated a sample of users who were willing to be interviewed. The interviews provided an opportunity to gain a better understanding of self-test use and generate a list of candidate factors that may be associated with their use. A systematic review of the literature for evidence for factors that may be associated with using self-tests and, because of a lack of evidence in this area, similar activities added to this list, which then informed the design of an in-depth questionnaire. This was sent to willing respondents to the initial questionnaire who had and had not reported self-test use. Questionnaires sent to people who had used self-tests also included a section asking for details of use so that this could be confirmed, leading to a more accurate estimation of the prevalence of self-test use and enabling determination of factors that predict confirmed self-test use.

5.3 Main findings of the study

The systematic search of the internet identified 104 unique self-tests that were available to buy by members of the public in the UK in 2006. These tests related to 24 conditions, including cancers (e.g. prostate specific antigen) and sexually transmitted infections (e.g. HIV-infection). The tests required a range of samples including blood obtained with a lancet and the sample was either processed immediately at home or sent to a laboratory with results returned directly to the user. Prices ranged from less than one to just over seventy five pounds.

The interviews with people who had reported self-test use on the initial questionnaire indicated that a minority of these tests had actually been used with the involvement of a clinician and that tests used without a clinician had been accessed in a range of ways. Rather than simply buying tests, people borrowed testing devices and health professionals used tests at work. The interviewees described self-testing as a generally positive experience: self-tests were easy to use and had a positive impact, for example from changes made as a result of a diagnosis. There was one exception, however, where an interviewee felt that the tests had been expensive in terms of their cost but worthless in terms of improving her health.

Interviewees described motivations for self-testing centred about four areas: expressed reasons, perceived benefits, attitudes to and experiences of healthcare, and attitudes to health. Expressed reasons tended to be either a desire for a specific diagnostic outcome or something more speculative, such as curiosity. Perceived benefits were being in control, being anonymous, and convenience compared with the practical difficulties of visiting the doctor. Some interviewees described possible negative motivators related to their experiences of healthcare, for example dissatisfaction with past care, whereas some spoke about the broader context of their positive attitude to health, for example believing that they could improve their health and taking steps to do so. Overall, participants tended to talk about a mix of positive and negative motivators, but more extreme profiles, possibly related to different types of self-tests, were apparent. Some people had a positive attitude towards health and healthcare and simply wanted to check on their health, for example their cholesterol level. In contrast, others described wanting to avoid conventional services because of past experiences and using self-tests to try and diagnose a specific problem.

Fifty eligible papers related to 46 studies were identified during the systematic review of the literature for evidence for factors that may be associated with the use of self-tests and, because of a lack of evidence in this area, similar activities. The evidence from these papers indicated that users of CAM and OTC medicine are female, middle-aged, have some measure of affluence and/or are educated with some measure of poor health, and that people who use the private sector are middle-aged and have some measure of affluence and/or are educated. Some other factors were also identified as being possibly associated with use of these activities, namely healthy lifestyles or being health conscious and knowledgeable about health, and believing that you control your health or that doctors do not do so.

The interviews and systematic review lead to a list of candidate factors that may be associated with self-test use, which fed into the design of an in-depth questionnaire to investigate those factors. Factors included in the questionnaire were: age, sex, having worked as a health professional, educational attainment, engagement in health-improving behaviours, knowledge related to health, health information-seeking behaviour, health status, concern with improving health or future illnesses, views about health checks and medical tests, views about when visiting the GP is appropriate, access to conventional services, satisfaction with conventional care, and beliefs about how health is controlled. Employment status was also available from the initial questionnaire and a measure of affluence was assigned based on respondents' postcodes. The interviews had also highlighted the need to clarify whether tests marked on the initial questionnaire had been used with or without the involvement of a clinician. In-depth questionnaires sent to people who initially reported use of self-tests, therefore, included a section asking for details.

Based on initial questionnaires received from 5025 people (63% of 7964 delivered) with a similar sex- and age-profile to the general population, it was estimated that about one in 10 men and one in seven women have used a self-test other than for pregnancy or high BP. The most commonly reported test was for diabetes.

In-depth questionnaires were received from 235 people who initially reported use of a test other than for high BP or pregnancy (65% of 361 delivered questionnaires but only 51% of 487 people who initially reported such use and were eligible for a questionnaire) and 132 of them were confirmed as having used the test without clinical involvement. This lead to a lowest limit for the prevalence of self-test use: about one in 46 men and one in 21 women have used a self-test other than for pregnancy or high BP without clinical involvement. Assuming that everyone who initially reported use but did not return an eligible in-depth questionnaire had the same age- and sex-specific rates of confirmed use as eligible responders, it was estimated that the prevalence of self-test use was actually around one in 18 men and one in 11 women. Use was most often confirmed for tests for diabetes, and such tests were most commonly used because there was a family risk of the condition and most commonly accessed by borrowing a testing device.

Based on a univariate analysis including data from 1521 in-depth questionnaires (70% of 2166 delivered), 132 of whom were confirmed as having used a self-test, self-test use was significantly positively associated with: being female, having worked as a health professional, confidence using a self-test, knowing that a range of tests were available, seeking health information more frequently and/or from more sources, being less satisfied with GP consultations, being less satisfied with healthcare overall, and not believing as strongly that health depends on powerful others, such as health professionals.

Stepwise multiple logistic regression analyses were conducted with (1) all explanatory variables, and (2) variables from the final models from analyses of variables grouped according to their focus. Both indicated that confirmed self-test use was predicted by: (1) knowing about a range of tests, (2) seeking health information more frequently and/or from more sources, (3) believing that health was not controlled by powerful others, (4) exercising less frequently, (5) being less satisfied with GP consultations, (6) reporting not good rather than good health, (7) strongly agreeing that you should only go to the doctor if you have severe or serious symptoms, (8) having worked rather than never having worked as a health professional, and (9) believing that health was controlled by chance. When all variables were entered into the analysis, weaker agreement (agreeing rather than strongly agreeing) that the doctor would try and do a test if asked, not smoking rather than smoking, and strongly agreeing that you were curious about your health were also predictive. Even though the models arising from the stepwise analyses were significant, the measures of effect size indicated that these variables together were not a very strong predictor of self-test use.

5.4 Strengths and weaknesses of the study

A clear definition of a self-test was constructed at the beginning of the study as it was felt that this was important to guide this research and aid future researchers wishing to interpret this work. Research related to testing by lay people is novel in the UK, but there is some literature from other countries. Although definitions were by no means uniform, there appeared to be some key features, notably “collecting samples (urine, blood etc) by themselves” [211] and “without involvement of a third party” [212]. This lead to a definition based on what were felt to be those integral components of lay-testing that represented a shift in behaviour, namely taking a biological sample to diagnose a medical condition without involving a doctor, nurse or other health professional. This was supported by definitions from the MHRA [50]. Although covered by the definition, pregnancy tests were purposefully excluded as their use is probably now expected by doctors [51], which is different to other self-tests. Prevalence estimates were, however, presented with and without tests for pregnancy and high BP to facilitate comparison with other studies.

This definition, however, excluded tests that did not involve taking a biological sample, such as self-initiated imaging or screening tests based on, for example, changes in mental state or perception. An “Early Alert Alzheimer’s Home Screening Test” has been reported as being available in the USA based on scratch-and-sniff style scents [213], and the definition may, therefore, need to be amended in the future. Nevertheless, the parameters set in this study, taking a biological sample without the involvement of a doctor, nurse or other health professional, set a clear baseline to enable future comparisons.

This study involved sending initial questionnaires to a large sample of about 8000 people registered with general practices. The study was population-based and general practices were only asked to exclude people who might be distressed by the questionnaire, for example because of severe mental illness, terminal illness or recent bereavement. Age alone was not a reason for exclusion. Three hundred and forty one people were excluded before the initial mailing: 226 were excluded by the general practice and 115 lived with someone who was excluded. The exact reason for exclusion was not given for 160 people, but a range of reasons were stated for excluding the other 66 people, for example frailty, dementia and terminal care. Although these exclusions may have lead to a slight under or overestimation of self-test use, depending on whether these people were more or less likely to have used self-tests, it seems unlikely that the results have been greatly affected.

The self-tests that were listed on the initial questionnaire arose from a systematic search of self-tests available to buy via the internet. During the search, an attempt was made to verify that each test identified could be purchased by a member of the public in the UK, but this was not always possible without actually purchasing the test. A small number of tests may, therefore, have been erroneously included, for example where the retailer would refuse to ship to the UK after credit card details were submitted. Retailers also provided varying amounts of information about tests on their websites. An attempt was made to determine the number of unique tests that were available by looking for duplicate tests, that is the same tests sold by different retailers, but this was limited by the amount of descriptive information available from some retailers. Even with background knowledge, it was sometimes difficult to determine from the information provided exactly what the test detected, what doing the test involved, and the sample that was required. These issues may mean that the total numbers of tests and unique number of tests available were slightly overestimated, but the identification of nine retailers based in the UK confirmed the general availability of self-tests.

The internet search was intended to be systematic rather than exhaustive. Only the first 20 sites returned from each search were examined and there will, therefore, have been relevant sites that were missed. Furthermore, other search terms, such as "Home test" with a relevant disease or disease category, may have identified more relevant sites. There will also have been tests available through other outlets that were not included, for example from high street pharmacies as described by interviewees, but the search was designed to be systematic and it gave an indication of the range available for different conditions. The results indicate that self-tests are available to buy by members of the UK public for at least 24 conditions, although they do not exhaustively list every website selling self-tests or every self-test available.

The resulting list of tests on the initial questionnaire included several that were potentially sensitive, for example for HIV-infection. Questionnaires were marked with a unique study number rather than the person’s name or address and the cover letter stated that answers would be confidential and only seen by the research team. The cover letter also said that respondents could leave out any question that they felt unhappy about answering. Despite this, prevalence, particularly for potentially sensitive self-tests, may have been underestimated because of respondents’ concerns about disclosing information about their use.

A small number of respondents to the initial questionnaire were excluded from the prevalence estimations (n=60) because they reported sex-inappropriate tests or because the age and/or sex they provided on the initial questionnaire suggested that they were not the intended recipient. A margin of two years difference was allowed before someone was excluded based on their age to allow for birthdays close to the mailing date. This measure was discussed with a GP, who advised that practice records were usually likely to be correct and, therefore, that these people were unlikely to be the intended recipient. It seemed plausible that people who chose to fill in a questionnaire about self-testing not addressed to them may have been more likely to have used or been interested in self-tests. As the intention was to obtain an unbiased population-based sample, it seemed correct, therefore, that they should have been completely excluded from the numerator and denominator. Excluding people who used sex-inappropriate tests also seemed appropriate, although these people were completely excluded with any other tests that they may have correctly reported, which may have lead to a very slight underestimation of self-test use.

The initial questionnaire was kept short to improve response rates and the response rate (64%) was high: a study of postal surveys published in journals from the USA found that the mean response rate was 60% among 42 surveys of patients or parents of patients [214]. Keeping the questionnaire short, however, limited the space available to define a self-test. The questionnaire was piloted before use for ease of completion and face validity. Despite this, interviews with respondents from the first two practices indicated that the definition had sometimes not been strictly followed. It became apparent during the interviews that the method of accessing the test had been interpreted more widely than simply buying a test: tests reported on the initial questionnaire had actually been accessed in a variety of other ways.

The two-stage process of sending out an initial questionnaire and then an in-depth questionnaire had originally been planned to ensure that response rates to the longer in-depth questionnaire remained high (70%): initially contacting people and asking for their consent to receive a longer questionnaire has been shown to increase response rates [215]. The in-depth questionnaire, however, also provided a means of exploring how people who reported use on the initial questionnaire had accessed tests. In line with the interviews, much of the use described on the in-depth questionnaire related to tests or testing devices that had not been bought, for example that had been borrowed from friends or relatives instead. There may, therefore, have been other respondents to the initial questionnaire who strictly followed the definition and did not mark tests accessed in other ways.

It also became apparent during the interviews that some interviewees had actually used tests marked on the initial questionnaire with the involvement of a clinician. The in-depth questionnaire again provided a means of investigating this and confirming whether tests reported on the initial questionnaire had actually been used without clinical involvement. As a result, it became clear that a sizeable proportion of initially reported use did involve a health professional, indicating a likely overestimation of the prevalence of self-test use from the initial survey. For example, the in-depth questionnaire demonstrated that the high prevalence of initially reported use of tests for blood in the stool in one practice related to a pilot of the NHS Bowel Screening Programme in that area. This highlighted the potential confusion for respondents between a test done at home but recommended by a clinician and a self-test done outside a clinical setting without clinical input.

Confirmation of use was, however, only possible for people who actually returned the in-depth questionnaire. The estimates of prevalence of confirmed use that are based on responses to the in-depth questionnaires, therefore, represent a lowest limit for the prevalence of self-testing. An exploratory analysis was used to indicate actual levels, but this depended on assuming that levels of use are similar among those who did consent and then respond to an in-depth questionnaire and those who did not consent or who did consent but did not respond. The two-stage process of sending out an initial followed by an in-depth questionnaire means, however, that the sample completing the in-depth questionnaire are likely to be selected, for example, more interested in, and amenable to self-testing, which may have led to an overestimate of prevalence based on the exploratory analysis. This selection bias is suggested by an increase in the proportion of people who initially reported use of self-tests other than for high BP or pregnancy among those who were eligible for an in-depth questionnaire (487/3505=14%) and those who consented to an in-depth questionnaire (368/2205=17%), as shown in the flowchart in appendix 7.

All prevalence estimates were sex- and age-standardised to take account of any differences between the age and sex profile of the study and the national population, but respondents to the in-depth questionnaire were different to the national population in other ways: they were notably more affluent and educated. These are factors that were postulated as being related to self-testing and the absence of their inclusion in the final models may reflect the fact that there was simply not enough diversity in this population to identify an association between those factors and self-testing. More generally, the age- and sex-standardised prevalence of self-testing may be overestimated because the sample includes a higher proportion of people who are likely to self-test than the general population.

Practices were selected to be invited to participate in the study from four groups. These were based on whether the IMD rank of the super output area and the population density of the ward, based on the 2001 Census, in which practices were located were high or low. Practices in each group were then ordered based on the proportion of the ward population that were from non-white ethnic groups, based on the 2001 Census, and practices were selected from across this range. The aim was to invite practices from a mix of economic and ethnic backgrounds and urban and rural settings. At least one of the six participating practices was from each of the four groups, but respondents to both questionnaires were overwhelmingly white and respondents to the in-depth questionnaire were more affluent than the national population, indicating that the aim had not been achieved. The IMD ranks for the six participating practices actually ranged from 5437 (most deprived) to 25634 (most affluent) out of 32482 super output areas in England, and the proportion of people from white ethnic groups ranged from 89% to 99% compared with 89% of the population of England in 2007 [202]. This indicates that no practices from very deprived areas or from areas with a very high proportion of people from non-white ethnic groups actually participated.

On reflection, the division into high and low IMD rank was too broad and finer division with oversampling of practices from deprived areas would have been likely to have achieved a more diverse population. Similar to this, a more sensitive strategy for selecting practices with a high proportion of people from non-white ethnic groups with oversampling of such practices would have been appropriate. This should also have been supported by the addition of text to the covering letter for the questionnaires in appropriate languages, which was not done because it was not prioritised highly enough within the available resources.

This study involved both quantitative and qualitative methodologies. A range of roles have been identified for the different methods within a mixed methods study [216]. These include defining a research question and designing study instruments, as in this study. Central to the effectiveness of a mixed methods study is a clear and strategic relationship between the methods to ensure that the data converge to produce greater insight than a single method could [217]: mixed methods studies have been criticised for simply using parallel methods without any integration [218]. The use of qualitative methods was integral to this study to facilitate the development of a quantitative measure. The initial questionnaire provided a sample of respondents who would be interviewed and these interviews fed into the design of a quantitative in-depth questionnaire. This is the instrument design model, where integration occurs at the data analysis stage and the researchers then use the qualitative analysis to inform the development of an instrument for data collection [219].

The design of the in-depth questionnaire depended on two independent sources, the interviews and the systematic literature review, increasing the likelihood that relevant predictive factors would be included. Each of these sources has different strengths and, therefore, reasons for their use during this study. The systematic literature review drew together existing evidence from related areas that may be relevant to the use of self-tests, whereas the interviews provided new insight into an area that had previously been little studied. The interviews were able, for example, to identify a broader range of ways of accessing tests than had initially been considered and potentially predictive factors, such as access to services and experiences of conventional services, that were not identified by the systematic literature review.

Most interviewees were white and the findings from the interviews may not apply to people from other backgrounds with, for example, other cultural influences about when is the right time to visit a doctor [220]. Most people interviewed were also women: there were fewer males to select because women were more likely to reply to the initial questionnaire and report self-test use. This may represent a true difference, that females appear to be more likely to self-test [146], but the hypotheses generated from these findings may not extend to males. The interviewees were registered with general practices that were in the middle of the ranking of areas in England based on the IMD 2004 score and the findings may also only relate to people from similar areas. Recruiting participants through general practices may also mean that they are less likely to report dissatisfaction with their doctors or healthcare generally. Interviewees also usually described positive experiences of self-testing, but people who had negative experiences may have been less likely to come forward and take part in this study. Similar to this, people who had used self-tests because of dissatisfaction with conventional care may have been less likely to come forward.

This study focused on the UK because it was felt that the background and context of the availability of a national health service with specific policies was potentially important in influencing self-test use, although there was little evidence available from this country and other countries to determine if this was true. This rationale also extended to the systematic literature review, which, therefore, only included studies conducted in the UK. The findings of the systematic literature review particularly and the wider study generally may, therefore, not be applicable to other settings.

As initial literature searches identified no papers focusing on self-testing and there was no clear directly equivalent activity, studies about activities with some similarities to self-testing were included in the systematic literature review. Each activity, however, also had differences to self-testing, for example complementary medicine has been defined as those therapeutic disciplines that exist outside or are extrinsic to conventional healthcare systems [221], whereas self-tests could be considered to be an extension of conventional or orthodox care. There were also differences between the activities and formally grouping together results from studies about different activities was not considered to be appropriate, for example people who use the private sector may be different to people who use the other activities.

Eligible studies included in the systematic literature review often defined use of the same activity in different ways. They also used different data collection and analysis methods. Questionnaire surveys were often not population-based or did not have a relevant comparison group so descriptive analyses were simply presented about the group using the activity. Even where there was a comparison, analyses were often not adjusted for confounding variables so it was unclear if associations, such as education and affluence, were independent. Factors examined also varied widely, even though more basic characteristics, such as ethnic group, were infrequently studied. It was also sometimes difficult to tell whether papers related to the same study, for example three papers with the same authors used similar methods, but the number of participants varied [166, 168, 171]. These issues meant that it was also not possible to formally pool analyses from studies within each area. As only one study each about home BP monitors and self-tests was identified, it was also not appropriate to draw firm conclusions about users of these activities. Despite these drawbacks, the literature review was able to add to the list of factors that may have been associated with self-test use to inform the design of the in-depth questionnaire.

The systematic literature review used a quality score, based on established principles [222], to assess whether reported results were likely to be valid. Quality scores are widely used in systematic reviews, but they have been criticised for being too variable when being used to weight results before combining them [223]. In this study, however, results were not combined and quality scores were simply used to indicate where results should be particularly trusted or not trusted.

As the definition specified tests used without involving a health professional, studies were excluded from the systematic literature review where it was recorded that the activity under investigation was initiated by a conventional health professional [224, 225]. The role of health professionals in the use of activities was simply not mentioned by many studies though despite the fact that private care and some CAM facilities may require referral from a conventional health professional. Even if there had been a referral from a conventional health professional, the idea for using private care or CAM may have come from the patient. Once again though, this was generally not reported or used to group people. This may be important as someone who is affluent and/or educated may be more able to influence a GP to arrange a referral, which could, at least, partly explain the link between affluence and use of these activities. Activities could also be recommended by health professionals and again this was often not asked about or, if asked about, used to group people. It would not, therefore, have been possible to determine whether factors associated with these activities were different among people who used them after a conventional professional's recommendation or without any such recommendation.

When designing a questionnaire, there has to be a balance between including enough important questions of sufficient breadth and the length and readability of the questionnaire: short questionnaires are more likely to be completed and returned [215]. Although most of the potentially relevant factors identified from the interviews and systematic literature review were included in the in-depth questionnaire, choices had to be made about the questions that were asked about those factors. Use of the internet, for example, focused on frequency rather than whether the person had access at home or at work. Where possible, validated questions from other studies were used, but it may be that, although the area was relevant, the question did not address the aspect that was relevant to self-testing. The in-depth questionnaire was piloted and the response rate (about 70%) was considerably better than similar two-stage surveys [76], suggesting that it was user-friendly.

It seems feasible that people who access tests in different ways and who use different types of tests may have different motivations. The interviews suggested that this may be the case, although it would be inappropriate to draw firm conclusions about this from a limited sample. The sample size for the initial questionnaire was based on the number of people needed to estimate a 10% prevalence of self-test use: it was estimated that a sample of 4200 people including 420 self-test users would be sufficient. It was not, however, anticipated that confirmation of self-testing would be required, which meant, combined with the eventual lower estimate of the prevalence of confirmed self-test use, that the number of people who had actually used a self-test was less than planned. As a result, the numbers of people who had used individual self-tests were small, restricting sex- and age-specific analyses by test. The multivariable analyses were also not powered to examine factors that predict the use of particular subsets of self-tests. It seems likely, therefore, that a greater proportion of self-test use could be explained if future studies concentrate on particular tests accessed via particular routes.

Neither of the final models generated by the regression analyses were strong predictors of self-test use as indicated by the R^2 values. This could be because the correct variables were not entered into the analysis, but it could also relate to the way participants were categorised for the analyses. People who were confirmed as having used self-tests that involved taking a biological sample other than for pregnancy were compared with all other respondents to the in-depth questionnaire. It may be, however, that users are similar to people who had, for example, used home BP monitors or pregnancy tests and that they should, therefore, have been compared with people who had used none of these tests or equipment. It may also be that the actual use of self-tests is not important as the interviews suggest that this appears to be, at least partly, driven by opportunity and it could also theoretically be driven by the presence of symptoms. Instead, it may be the intention or willingness to use them that is the important outcome variable in a regression analysis. The interviews for this study were directed towards exploring experiences of people who had actually used self-tests that involved taking a biological sample other than for pregnancy, but further qualitative work with people who have used other tests or equipment or who intend to use self-tests may be important to confirm if this is the case.

Attempts were made to minimise the impact of data errors on the project. The initial questionnaire was entered using OMR software, but the accuracy of this method was checked and where there were problems, because the respondent had ticked rather than filling in the response circle or had written across the questionnaire, data entered by the software was always checked against the hard copy of the questionnaire. The in-depth questionnaire was not, however, considered suitable for entry using OMR software for a couple of reasons. First, the OMR software is most accurate when the questionnaire being scanned is on a heavier grade of paper to ensure that what is written on the reverse of the scanned side is not also read. Second, it is more suitable for short single page questionnaires because longer questionnaires would need to be divided into single sheets and ordered correctly before being scanned.

Data from the in-depth questionnaire was, therefore, entered by hand into an Access database using a front end form. Ideally, it would have been desirable to double-enter all the data from the in-depth questionnaires, but the resources available for this project did not allow this. Double-entry was, therefore, done on a sample of questionnaires to determine whether further quality assurance measures were needed for any particular data item or data entry clerk. Errors identified in this sample were always rectified, but the whole set of questionnaires was only examined if the discrepancy rate was high and the errors appeared to be systematic. There are likely, therefore, to have been data entry errors remaining in the questionnaires that were not double-entered, but the double-entry process should have ensured that most, if not all of them, were random rather than systematic. Drop-down menus were used for selecting the correct response on the Access form. On reflection, where there were long lists of responses, for example the health locus of control section, data-entry was very repetitive increasing the likelihood of errors, particularly as some responses had the same first letter. It may, therefore, have been better to more directly mirror the layout of the questionnaire with data-entry clerks completing the correct circle as respondents had done when completing the questionnaire.

5.5 Findings in relation to other studies

There have been very few studies looking at the prevalence of self-test use in the UK. A survey of around 2500 people about public attitudes to genetic testing conducted between December 2002 and January 2003 reported that 32% said that they “had ever bought a health testing kit, for example a cholesterol, pregnancy or blood sugar test, to carry out at home” [4]. In the present study, there were 5025 eligible respondents to the initial questionnaire: 1450 women reported use of either a test for high BP, a test for pregnancy or another test and 539 men reported use of either a test for high BP or another test other than for pregnancy (table 15). In addition, 11 men reported use of a pregnancy test only, giving a crude prevalence of ever having used one of these tests of 40% (2000/5025). The higher prevalence in this study may reflect the fact that this population was more affluent and educated than the general population and, therefore, more likely to use a test at home than the population surveyed about genetic testing.

The higher prevalence in the present study may also reflect the fact that it was conducted around five years later and increased knowledge and availability of tests may have led to increased use. Prevalence estimates from the initial questionnaire in the present study for diabetes (7%) and cholesterol (2%) were similar to estimates from a survey of around 3000 adults registered with general practices in Birmingham conducted in June 2005 (8% and 2% respectively) [146]. The estimate from the initial questionnaire from the present study for the use of a test for high BP (16%) was, however, much higher than that reported from the survey in June 2005 (9%) [190]. Differences in the populations surveyed, for example their satisfaction with GP consultations, would probably have affected other tests and the wording and layout of the questionnaires were similar, suggesting that this may reflect a real difference. In the present study, the crude prevalence of the use of a self-test for high BP reported on the initial questionnaire was 15% (218/1478) for the first two practices and 17% (604/3547) for the final four practices, which further supports a real increase in the prevalence of use over time.

Although different practices were involved in the present study and the survey conducted in June 2005 [146], they were from some of the same areas. The previous survey could have lead to a locally increased awareness of self-testing, but again this would probably have affected other tests, not just tests for high BP. There is another local research programme specifically related to home monitoring of BP under clinical care [226], which may have locally increased awareness of home BP monitors. Interviewees from the first two practices mentioned adverts for home BP monitors though, suggesting that increased awareness and availability as a result of advertising could also have contributed to an increase in the prevalence of the use of home BP monitors since the previous survey in June 2005.

Prevalence estimates from the initial questionnaire in this study were, however, based on unconfirmed reports of self-testing, and the interviews demonstrated that some use reported on the initial questionnaire actually involved a health professional. The in-depth questionnaire did not aim to confirm the use of pregnancy tests, but 952 people from the final four practices either reported a pregnancy test on the initial questionnaire and/or had use of a self-test or a test for high BP confirmed using the in-depth questionnaire. Using the number of eligible respondents from the final four practices to the initial questionnaire (n=3547) as the denominator, this gives a crude prevalence of 27%. This is now lower than the estimate of 32% from the survey related to genetic testing [4] and the higher estimate in that survey could now reflect the lack of validation of reported self-test use in that study.

Apart from a recent study from the Netherlands with a similar focus to this project [227], most of the international literature comes from the USA, where the focus is predominantly on the use of home collection tests for HIV-infection with a view to increasing coverage and reaching hard-to-reach populations [a, b]. The sample is collected by the user, but results are returned by telephone. People with a negative result receive a recorded message, but all users who test positive or indeterminate or whose sample was unsuitable for testing are connected directly to a counsellor.

The recent study from the Netherlands reported that 16% of 7919 respondents to an online survey of people recruited via an internet-based panel had used at least one self-test [227]. The key features of the definition given to participants were similar to the present study [c] and participants were asked to either tick that they had not used a self-test or tick which of a list of self-tests they had used. The 16% crude prevalence estimate from the Dutch study is higher than the 13% (678/5025) crude estimate based on returns from the initial questionnaire in the present study. The in-depth questionnaire demonstrates that the figure of 13% overestimates the prevalence of self-test use, with a more realistic estimate, based on the exploratory analysis, being a sex and age-standardised prevalence of about 5% in men and 10% in women. Although there was no follow-up questionnaire to confirm self-test use in

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[a] Branson BM. Home Sample Collection Tests for HIV Infection. Journal of the American Medical Association 1998; 280: 1699-1701.

[b] Greensides DR, Berkelman R, Lansky A, Sullivan PS. Alternative HIV Testing Methods Among Populations at High Risk for HIV Infection. Public Health Reports 2003; 118: 531-539.

[c] “By self-test we mean a test on body samples (such as blood, urine, faeces or saliva) that can be used to detect a disease or the risk of getting a disease, and which you carry out, or have carried out, at your own initiative (so not on the advice of your own doctor). A blood pressure meter is not a self-test in this sense, as it uses no body materials. Pregnancy tests are excluded from this survey.”

the Dutch survey, the definition used on the questionnaire was fuller than that on the initial questionnaire in the present study, which may have lead to a more accurate initial assessment of prevalence. This suggests that there could be a true difference in the prevalence of self-testing in the populations studied. The response rate to the Dutch survey was similar to this study (7919/12529=63%), but the different estimates could also be related to the use of an online survey in the Dutch study leading to a population that is more likely to have self-tested. There may also be a true difference related to conditions favouring self-testing in the Netherlands.

A further study from the UK did ask about self-testing [228]: a maximum of 28 (7%) out of the 422 participants said that they had used a test that involved taking a biological sample. This study involved patients who had taken part in a randomised controlled trial of home versus hospital based cardiac rehabilitation though and who were, therefore, not comparable with a population-based sample.

Although previous articles mention that self-tests are available [1, 47], there have been no previous systematic studies detailing their availability in the UK. Similar to the present study, however, the Dutch authors conducted an internet search and found that self-tests for over 25 conditions, including cancers, infectious diseases and cardiovascular diseases, were available to the public in the Netherlands in 2006 [227]. This supports the findings from this study of the availability of self-tests for a range of conditions.

The initial aim of the systematic literature review was to review evidence about who used self-tests among UK adults. No relevant studies about self-testing were initially identified though. As a result, the scope was widened to look at similar activities, and this study is the first to draw together evidence from different areas about common factors that are associated with self-care activities.

This study is also the first in the UK or other countries to speak to people who have reported self-test use about their experiences. The data presented here suggest that the decision to self-test is complex and may be influenced by a number of factors, ranging from a desire to take control over one's own health to a desire to avoid a GP consultation. This is generally consistent with recognised patterns of health and illness behaviour, which point to the "heterogeneous assembly of factors that are known to influence decisions about medical consultation" [229].

Mechanic listed 10 variables that influenced consulting behaviour [230]. It could be postulated that some of these factors should apply to our interviewees, such as frequency of appearance of signs and symptoms, the extent to which they disrupt activities, and the tolerance threshold of the person concerned. There are, however, likely to be important differences between pathways leading to conventional care and pathways leading to self-care without clinical involvement. There may be different thresholds if symptoms are present and interviewees also self-tested when they had no symptoms, for example using a self-test for cholesterol as a routine check. Mechanic does, however, list available information, knowledge, and cultural assumptions and understandings of the evaluator, which could equate to the attitudes and experiences related to health and healthcare described during the interviews. Mechanic also listed availability of treatment resources, physical proximity, and psychological and monetary costs of taking action, which were also touched upon by these interviewees.

This study is the first in the UK to attempt to determine factors that predict self-test use, but the study from the Netherlands also considered factors that may be correlated with use [227]. Unlike the present study, however, the factors were assessed using the same questionnaire that was used to determine the level of use of self-tests. There was, therefore, no validation of use, although this meant that a much larger sample was included in the regression analysis. Based on 1263 users and 6656 non-users and a multiple logistic regression analysis, it was reported that self-testers, compared with non-testers, had a higher body mass index, ate less fat (or saturated fat), were more likely to use dietary supplements and homeopathic medicine, were more likely to report having a chronic disease, and were more likely to rate their health as reasonable, poor or very poor rather than good or very good. In addition, female self-testers had a higher level of education and were more likely to be blood donors, and male self-testers were less likely to be physically active. Both this and the Dutch study, therefore, suggested associations with reporting poorer health and less physical activity, although the latter variable was only significant among men in the Dutch study. The variables that were examined by both studies, that is where both studies could have shown a common association, were age, sex, education, self-rated health, presence of a long-term illness, smoking, physical activity, and fruit and vegetable consumption.

5.6 Meaning of the study

This study has demonstrated the potential for self-testing for a wide range of conditions by members of the public in the UK. People can find out about self-tests using the internet and purchasing such tests is fairly straightforward and does not require consultation with a health professional. The interviews explored the experience of self-testing and demonstrated that, as well as simply buying a test at a shop or via the internet, members of the public access tests in other ways. This increases the potential for people to test themselves without involving a health professional. The use of tests accessed in these other ways, for example at work or borrowed from friends or relatives, is less likely to have been driven by the emergence of self-tests in the marketplace, which suggests, supported by the interview narratives, that self-testing without involving clinicians has been occurring for a considerable time.

Interviewees tended to describe positive experiences of self-testing and did not feel the need to hide their experiences from their doctor. This suggests that self-testing itself does not generally lead to dissatisfaction or that it will necessarily lead to conflicts with conventional care. This finding does, however, need to be treated with caution because of the possible bias of people who are dissatisfied with self-testing or conventional care not wanting to admit to this and take part in this study.

The interviews were also able to provide some insight into the motivations of people who have used self-tests without involving health professionals. Although interviewees may have had a pre-existing health problem or idea that they wanted a particular test, they frequently did not actively search out tests. Instead, regardless of how they obtained tests, interviewees tended to access them opportunistically, for example buying a test when browsing in a shop or using a testing device when a friend did so. What does seem apparent though is that the use of different types of tests with different outcomes can arise from very different pre-existing motivations. The interviews suggest that, although most people were motivated by a mix of positive and negative factors, some were motivated by predominantly negative factors, such as dissatisfaction with past care. These people tended to have used tests, such as allergy tests, to try to diagnose the cause of their symptoms. This is an important finding as people who are dissatisfied with or who feel that their needs have not been met by conventional care may be turning to forms of care that are less likely to be quality assured, provide sufficient information to make an informed choice, or provide appropriate aftercare. One interviewee, for example, had not been able to access the promised aftercare after she did a home allergy test.

Nevertheless, some interviewees, who were generally satisfied and interested in their health, simply wanted to routinely check on their health without bothering the doctor. As long as self-tests that are used in this way are safe, quality assured and supplied with sufficient information, this type of use seems reasonable. None of these issues were, however, addressed in this study or have been addressed in other studies. Self-testing should not, therefore, be seen as a means of addressing any deficit in the provision of screening or testing that would usually be provided by the National Health Service until these issues have been properly studied. Guidance should also be made available for people who choose to use self-tests privately about the minimum level of information that they should expect with a test.

The in-depth questionnaire suggests that to get precise estimates of the prevalence of self-testing, self-reports should be validated by asking for details. In retrospect, this would be best done using a longer initial questionnaire. Nevertheless, the confirmed estimates of self-test use indicate that about one in 46 men and one in 21 women have used a self-test that involved taking a biological sample (other than a pregnancy test) without involving a health professional, but this represents a lowest limit for prevalence. Based on assuming that everyone who initially reported use but did not return an eligible in-depth questionnaire had the same sex- and age-specific rates of confirmed use as eligible responders, this study suggests that about one in 18 men and one in 11 women have used a self-test. Applying the results to the population of England and Wales in 2006 indicates that more than one million men and two million women have used a self-test (table 75).

Table 75: Estimated number of people in England and Wales that have used self-tests [a].

	In-depth estimates [b]		Postulated estimates [b]		Initial estimates [b]	
	Men	Women	Men	Women	Men	Women
Self-test excluding for pregnancy or high blood pressure	447,500	1,016,100	1,115,700	2,065,700	2,089,600	3,126,400
High blood pressure	1,173,800	1,371,300	2,288,600	2,662,500	2,913,900	3,056,400
Subtotal	1,400,100	1,985,000	2,943,900	3,953,900	4,035,700	5,126,700
Pregnancy						9,175,400
Total						12,028,300

[a] Calculated using the population in 2006[c] and age-specific rates of reported use from the initial questionnaire (initial estimates), age-specific rates of confirmed use from the in-depth questionnaire (in-depth estimates), and postulated age-specific rates of use if everyone who initially reported use had the same age-specific rates of confirmed use as eligible responders to the in-depth questionnaire (postulated estimates).

[b] Rounded to the nearest 100.

[c] Office for National Statistics. Mid-2006 population estimates: estimated resident population by single year of age and sex. Accessed 17 June 2008 from http://www.statistics.gov.uk/STATBASE/Product.asp?vlnk=15106.

Several factors were predictive of self-test use in stepwise forward regression analyses when the following variables were entered: (1) all explanatory variables, and (2) variables from the final models of analyses of variables grouped according to their focus. Having worked as a health professional was predictive, presumably because of access to tests and testing equipment. Knowing about a range of tests and seeking health information were also predictive in line with the profile suggested by the interviews of some people who self-test having a positive attitude towards health and, therefore, being interested in issues related to health. When all variables were entered, being curious about health was also predictive, which also fits with the profile of people who self-test having a positive attitude towards health.

The systematic literature review and interviews suggested that people who self-test may be more likely to engage in healthy behaviours. In line with this, not smoking was predictive of self-testing when all variables were entered into the analysis. In contrast, exercising less frequently was also predictive, but this could be related to poor health, which was a predictive factor in both analyses. It seems plausible that people who feel that they are in poor health may be more likely to want to test themselves than those who feel that they are in good health.

Both analyses found that being less satisfied with GP consultations was a predictive factor. It seems plausible that someone who has been dissatisfied would be more open to using tests where there is no need to access conventional services. This is also in line with the profile from the interviews of someone who has been dissatisfied with past healthcare using self-tests for diagnosis.

Strongly agreeing that you should only go to the doctor with severe or serious symptoms was predictive of self-testing in both analyses. When all variables were entered, weaker agreement (agreeing rather than strongly agreeing) that the doctor would try and do a test if asked was also predictive. These factors do not necessarily indicate dissatisfaction with conventional care, but it seems plausible that someone may not want or feel able to bother the doctor with what they perceive might be viewed as trivial symptoms or a trivial request and, therefore, that they could be open to other ways of dealing with those issues.

The systematic literature review suggested that people who believe that their health is not controlled by powerful others may be more likely to self-test themselves, and this was predictive in both analyses. Again, it seems plausible that someone who believes that health professionals are not pivotal to their health would be open to using tests without professional input. Believing that health was controlled by chance, however, was also a predictive factor in both analyses, which seems contrary to what might be expected. It seems more plausible that people who believe that their health is controlled by chance might be less likely to undertake any form of testing.

Overall, in line with the interviews, most of the predictive factors from the regression analyses can be divided into either those that are related to having a positive attitude to health or those that indicate some dissatisfaction with or needs not having been met by conventional services. When this project was being planned, it seemed that self-testing was a new phenomenon driven by advances in technology. Tests for serious and life-threatening conditions were easily available and there were reports of harm related to their use, notably a false positive result from a home HIV-test [3], but there had been very little related research. It was felt, therefore, that work in this area was important and that the first steps should be to consider how many people are using self tests, who they are and why are they using them. A particular concern was that people might self-test because they are, for example, too embarrassed to visit the doctor. It was hoped that a regression analysis to characterise people who had used self-tests would provide evidence about whether conventional care needed to be improved and the regression analyses did confirm that there is a link with needs not having been met by conventional care. The interviews, however, suggested that this is related to certain self-tests, notably for allergies. As the measures of effect size from the regression analyses indicated that the significant variables did not together strongly predict self-test use, test-specific analyses focusing on relevant groups of factors, for example tests for allergies and factors related to dissatisfaction with or needs not having been met by conventional care, may lead to models that explain a greater proportion of use.

5.7 Future research

The people who took part in this study are more affluent and qualified than the national population. It would be desirable to explore the level of self-testing, the experience of self-testing and factors associated with self-testing in a broader population. Any future survey looking at prevalence should also consider using a fuller definition of self-testing on the initial questionnaire and collecting further details of tests used at this point to enable confirmation of tests used among a full population-based sample.

Future test-specific studies should also be conducted confirming that factors that predict or that are motivators for self-testing are related to the type of self-test used. Initial studies should focus on tests that are used because a diagnosis is sought, such as self-tests for allergies, because of the possible negative motivators for the use of these tests. Such studies should further explore these motivations and the appropriateness of the use of such tests because of the potential link with dissatisfaction with or needs not having been met by conventional care.

Self-testing is likely to continue and, given the commercial possibilities, to increase and diversify: for example, genetic tests to provide tailored dietary and lifestyle advice to consumers have previously been offered to consumers and it is recognised that such tests are likely to be offered in the future [231]. This study suggests that people who use some types of self-tests are satisfied with conventional care but simply want to routinely check on their health. Nevertheless, consideration should be given to investigating the safety and accuracy of the full range of tests, as well as the information provided with them, to determine whether consumers are able to make a fully informed choice about their use. Consideration should also be given to setting out clear guidance for consumers about how to assess whether information provided is sufficient and how to then use that information to weigh up harms and benefits.

5.8 Summary of this chapter

This chapter presented a discussion of the study. The rationale for the study and its aims and methods were reviewed. Self-tests are known to be available and they have potential harms and benefits, but they have been little studied. The aims of the study were to describe the prevalence of the use of self-tests and determine factors that are associated with using them. A systematic search for self-tests available to buy via the internet informed the design of an initial questionnaire about whether people had used them. Interviews with respondents and a systematic literature review then informed the design of an in-depth questionnaire to confirm use and investigate associated factors, which was sent to willing respondents to the initial questionnaire.

The main findings of the study were reviewed. More than 100 self-tests, related to 24 conditions, were available to buy in 2006. Interviews indicated that some tests reported on the initial questionnaire had been used with the involvement of a clinician and that self-tests had been accessed in a range of ways. Interviewees were motivated by positive and negative factors, but extreme profiles, potentially related to different self-tests, were apparent. The systematic literature review indicated that sex, age, affluence, education, health status, lifestyle, attitude to, and knowledge about health, and health locus of control were potentially associated factors.

Assuming that everyone who initially reported use but did not return an eligible in-depth questionnaire had the same sex- and age-specific rates of confirmed use as eligible responders, 55 (95% CI 41 to 68) per 1000 men and 95 (95% CI 81 to 110) per 1000 women were estimated to have used self-tests. Use was predicted by: knowing that a range of tests were available, seeking health information more frequently and/or from more sources, exercising less frequently, being less satisfied with GP consultations, reporting not good health, strongly agreeing that you should only go to the doctor if you have severe or serious symptoms, having worked as a health professional, and believing that health was controlled by chance and not powerful others. Weaker agreement (agreeing rather than strongly agreeing) that the doctor would try and do a test if asked, not smoking, and strongly agreeing that you were curious about your health were also predictive depending on the variables entered into the model.

The strengths and weaknesses of the study were discussed. In brief, the study included a large population-based sample with initial exclusions solely based on whether a questionnaire would cause distress. Questionnaires were piloted and the two-stage process ensured that the response rate to the second questionnaire remained high. This in-depth questionnaire provided an opportunity to confirm use, the need for which had been highlighted during the interviews, but this was only possible for people who returned a questionnaire. The prevalence of confirmed use, therefore, represented a lowest limit. An exploratory analysis was used to indicate actual levels, but this depended on assuming that levels of use were similar among those who did respond and those who did not consent or who did consent but did not respond. In reality, the sample completing the in-depth questionnaire are likely to be selected, for example more interested in and amenable to self-testing, which may lead to an overestimate of prevalence based on the exploratory analysis. In retrospect, a more detailed definition on the initial questionnaire may have lead to more reliable initial estimates.

The definition of self-testing for this study, taking a biological sample without the involvement of a doctor, nurse or other health professional, set a clear baseline to enable future comparisons. The interviews also indicated, however, that participants interpreted self-testing more broadly than simply buying a test and marked tests on the initial questionnaire that had been accessed in a range of ways. This may have lead to an underestimate of the prevalence of the use of self-tests accessed in other ways as some respondents may have firmly adhered to the written definition when completing the questionnaire.

The study population were more likely than the population of England to be affluent and educated. These factors were potentially related to self-testing and their absence from the final models may simply reflect the fact that there was not enough diversity in this population to illustrate the association. More generally, the sex- and age-standardised prevalence of self-testing may be overestimated because the sample included a higher proportion of people who are likely to self-test than the general population. The interviews suggest that people who access tests in different ways and use different types of tests may have different motivations, but the numbers of people who had actually used individual self-tests were small, restricting sex- and age-specific analyses by test.

The findings were then reviewed in relation to other studies. Prevalence estimates were available from a survey related to genetic testing in 2002/3 [4], a smaller survey in the Midlands in 2005 [146, 190] and a recent survey from the Netherlands [227].

Attempts were made to make relevant comparisons based on definitions and methods used in each study. Differences in estimates may reflect a number of factors: the selected population in the present study leading to higher estimates than from the survey related to genetic testing, increases in the prevalence of self-testing over time leading to higher estimates from the present study than from the survey related to genetic testing and the smaller survey from the Midlands, the confirmation of testing in the present survey leading to lower estimates than from the survey related to genetic testing, use of an online survey in the Dutch study leading to a sample who make be more likely to self-test, and true differences in the prevalence of self-testing relation to local conditions in the Netherlands.

The study from the Netherlands also considered factors that may be correlated with self-test use. Both the present study and the Dutch study indicated associations with reporting poorer health and less physical activity, although the latter was only significant among men in the Dutch study. The variables that were examined by both studies, that is where both studies could have shown a common association, were age, sex, education, self-rated health, presence of a long-term illness, smoking, physical activity, and fruit and vegetable consumption.

The meaning of the study was then considered. This study has confirmed the potential for self-testing for a wide range of conditions by members of the public in the UK. The interviews demonstrated that, as well as simply buying a test, members of the public access tests in other ways, increasing the potential for self-testing without the involvement of a health professional.

Interviewees generally described positive experiences from self-testing and did not feel the need to hide their experiences from their doctor, suggesting that self-testing itself does not necessarily lead to dissatisfaction or conflicts with conventional care. The interviews, however, indicated that the use of different types of tests with different outcomes can arise from different motivations: some people, who tended to have used tests for diagnosis, such as allergy tests, were mainly motivated by negative factors, such as dissatisfaction with past care. This is an important finding as people who are dissatisfied with or who feel that their needs have not been met by conventional care may be turning to forms of care that are less likely to be quality assured, provide sufficient information to make an informed choice, or provide appropriate aftercare. Nevertheless, some interviewees were generally satisfied and simply wanted to routinely check on their health without bothering the doctor. As long as tests that are used in this way are safe, quality assured and supplied with sufficient information, this type of self-test use seems reasonable. These issues have, however, not yet been researched.

The in-depth questionnaire established that to get precise estimates of self-testing, self-reports should be confirmed by asking for full details. The confirmed estimates of self-test use indicated that an appreciable minority of the population have accessed and used tests for medical conditions without involving a health professional: this study suggests that about one in 18 men and one in 11 women have used a self-test that involved taking a biological sample other than a pregnancy test. Applying the results to the population of England and Wales in 2006 indicated that more than one million men and two million women have self-tested.

The measures of effect size for the models arising from the stepwise analyses indicated that the significant variables did not together strongly predict self-test use. In line with the interviews though, most of the predictive factors could be divided into those that were related to having a positive attitude to health and those that indicated some dissatisfaction with or needs not having been met by conventional care. It may be, therefore, that test-specific analyses focusing on relevant groups of factors, for example tests for allergies and factors related to dissatisfaction with or needs not having been met by conventional care, lead to models that explain a greater proportion of self-test use.

Finally, consideration was given to future research in this area. Exploration of the level of self-testing, the experience of self-testing, and factors associated with self-testing would be desirable in a broader population, but any future investigation should consider providing people with a fuller definition on the initial questionnaire and asking them for details of use to enable confirmation of self-testing among a full population-based sample. Future test-specific studies should also be conducted confirming that factors that are associated with or that are motivators for self-testing are related to the type of self-test used. Further consideration should also be given to investigating the safety and accuracy of the full range of tests, as well as information provided with tests to determine whether consumers are able to make a fully informed choice about their use.

The next section presents the final conclusions of this thesis. The tasks undertaken for this thesis are summarised with the key findings that have arisen. Finally, suggested areas for future research are summarised.

6 CONCLUSIONS

For this thesis, self-tests that were available to buy by adults in the UK via the internet were identified (sections 3.2 and 4.2). There were 104 unique self-tests related to 24 conditions, including cancers and sexually transmitted infections. This has demonstrated the availability of self-tests and the potential for self-testing for a wide range of conditions by members of the public in the UK. People can find out about self-tests using the internet and purchasing such tests is fairly straightforward and does not require consultation with a health professional.

The information about the available self-tests was used to design a short questionnaire to initially assess whether people had used self-tests, and a population-based survey was conducted using this questionnaire (section 3.3).

Experiences of self-testing were then explored by interviewing respondents to the initial questionnaire who reported self-test use (section 3.4 and 4.3). As well as being bought from a shop or via the internet, tests were accessed in other ways, for example borrowed from relatives, increasing the potential for people to test themselves without involving a health professional. Interviewees tended to describe positive experiences of self-testing and did not feel the need to hide this from their doctor, although this should be treated with caution because of the possible bias of people who are dissatisfied with self-testing or subsequent interactions with their doctor not wanting to take part in this study. Most interviewees were motivated to use self-tests by a mix of positive and negative factors, but some described mainly negative factors, such as dissatisfaction with past care. These people tended to have used tests, such as allergy tests, to try to diagnose the cause of their symptoms. This is important as people who are dissatisfied with or who feel that their needs have not been met by conventional care may be turning to forms of care that are less likely to be quality assured, provide sufficient information to make an informed choice, or provide appropriate aftercare. Nevertheless, some interviewees were satisfied and simply wanted to routinely check on their health without bothering the doctor. As long as tests that are used in this way are safe, adequately quality assured and supplied with sufficient information, issues which have not yet been addressed in research studies, this type of use of self-tests seems reasonable.

A list of factors potentially associated with using self-tests was generated from the interviews and by systematically reviewing evidence for factors that may be associated with using self-tests and, because of the lack of research evidence in this area, similar activities (sections 3.5 and 4.4).

This information was used to design an in-depth questionnaire to describe factors that may be associated with self-test use (sections 3.6 and 4.5). As the interviews indicated that some tests reported on the initial questionnaire had been used with the involvement of a clinician, the in-depth questionnaire also obtained details of use to confirm whether tests reported on the initial questionnaire had actually been used without the involvement of a clinician. A survey of people who responded to the initial questionnaire and who had and had not reported self-test use was then conducted using this in-depth questionnaire. This information was used to estimate the prevalence of confirmed self-test use and determine associated factors (sections 4.6 and 4.7).

The confirmed reports of self-test use indicate that about one in 46 men and one in 21 women have used a self-test that involved taking a biological sample (other than a pregnancy test) without involving a health professional, but this is a lowest limit. Assuming that everyone who initially reported use but did not return an eligible in-depth questionnaire had the same sex- and age-specific rates of confirmed use as eligible responders, this study suggests that about one in 18 men and one in 11 women have used a self-test. Applying these results to the population of England and Wales in 2006 indicates that more than three million people have used a self-test.

Self-test use was predicted by (sections 3.6 and 4.7): knowing about a range of tests, seeking health information more frequently and/or from a range of sources, exercising less frequently, being less satisfied with GP consultations, reporting not good health, strongly agreeing that you should only go to the doctor if you have severe or serious symptoms, having worked as a health professional, and believing that health was controlled by chance and not powerful others. Weaker agreement (agreeing rather than strongly agreeing) that the doctor would try and do a test if asked, not smoking, and strongly agreeing that you were curious about your health may also be predictive. These factors did not, however, together strongly predict use. In line with the interviews, most of the predictive factors can be divided into those that are related to a positive attitude to health and those that are related to dissatisfaction with or needs not having been met by conventional care. It may be that test-specific analyses focusing on relevant groups of factors, for example tests for allergies and factors related to dissatisfaction with or needs not having been met by conventional care, may lead to models that explain a greater proportion of self-test use.

In terms of future research, exploration of the level of self-testing, the experience of self-testing, and factors associated with self-testing would be desirable in a more diverse population than was sampled for this study. This would ensure that prevalence was correctly estimated and facilitate finding associations with affluence and education, should they exist, in a regression analysis. Test-specific studies should also be conducted confirming that factors that predict or that are motivators for self-testing are related to the type of self-test used. This is because of the possible link with dissatisfaction with or needs not having been met by conventional care for some tests, notably those that are used because a diagnosis is sought, such as tests for allergies, and initial studies should focus on those tests. Finally, although some people who use self-tests are satisfied and simply want to check on their health without bothering the doctor, consideration should be given to researching the safety and accuracy of the full range of tests, as well as whether sufficient information is provided to allow consumers to make a fully informed choice about their use.

REFERENCES

1. Parliamentary Office of Science and Technology. Postnote. Medical Self-test Kits. London: UK Parliament; 2003.
2. Merson MH, Feldman EA, Bayer R, Stryker J. Rapid self-testing for HIV infection. Lancet 1997; 349 (9048): 352-353.
3. Haddow LJ, Robinson AJ. A case of a false positive result on a home HIV test obtained on the internet. Sexually Transmitted Infections 2005; 81: 359-362.
4. YouGov Limited. Public attitudes to genetic testing. A quantitative study for the Human Genetics Commission. London: YouGov Limited; 2003.
5. Office of Population Censuses and Surveys. Social Survey Division, OPCS Omnibus Survey, September 1993 [computer file]. Colchester, Essex: UK Data Archive [distributor], September 1997. SN: 3670.
6. Mintel. Self-diagnostics – UK – September 2007. Is the Internet driving growth or hindering it? Available at http://oxygen.mintel.com/sinatra/oxygen/display/id=220182. Accessed 1 June 2010.
7. Department of Health. Self-care — a real choice. Selfcare support — a practical option. London: Central Office of Information; 2005.
8. Alliance for Self-care Research. About Self-care. What is Self-care? Available at http://www.ascr.ac.uk/selfcare.htm. Accessed 3 June 2010.
9. Larkin GV. Medical Dominance in Britain: Image and Historical Reality. The Millbank Quarterly 1988; 66(2): 117-132.
10. Porter R. The Patient's View: Doing Medical History from below. Theory and Society 1985; 14(2): 175-198.

11. King S, Weaver A. Lives in many Hands: The Medical Landscape in Lancashire, 1700-1820. Medical History 2000; 45: 173-200.

12. Last JM, Adelaide MB. The Iceberg. “Completing the Clinical Picture” in General Practice. Lancet 1963; 282 (7297): 28-31.

13. Hannay DR, Maddox EJ. Incongruous referrals. Lancet 1975; 306 (7946): 1195-1197.

14. Hannay DR. The ‘iceberg’ of illness and ‘trivial’ consultations. Journal of the Royal College of General Practitioners 1980; 30: 551-554.

15. Banks MH, Beresford SAA, Morrell DC, Waller JJ, Watkins CJ. Factors Influencing Demand for Primary Medical Care in Women Aged 20-44 Years: A Preliminary Report. International Journal of Epidemiology 1975; 4(3): 189-195.

16. Scambler A, Scambler G, Craig D. Kinship and friendship networks and women’s demand for primary care. Journal of the Royal College of General Practitioners 1981; 31: 746-750.

17. Cunningham-Burley S, Irvine S. “And have you done anything so far?” An examination of lay treatment of children’s symptoms. British Medical Journal 1987; 295: 700-702.

18. Boardman B, Lewis M, Trinder P, Rajaratnam G, Croft P. Use of community pharmacies: a population-based survey. Journal of Public Health 2005, 27(3): 254-262.

19. Rogers A, Entwistle V, Pencheon D. A patient led NHS: managing demand at the interface between lay and primary care. British Medical Journal 1998; 316: 1816-1819.

20. Banks I, Baker P, Dixon M, Fradd S, Haslam D, Kelly S, Chisholm J, Mitra G, Patel R, Pringle M, Richards S, Smith P, Smallwood D, Sparrow N, Stillman P, Summers S, Young L on behalf of the Self Campaign group. Self Care: An Ethical Imperative. London: Self Care Campaign group; 2010.

21. Department of Health. Saving Lives. Our Healthier Nation. London: Department of Health; 1999.

22. Expert Patients Programme. About Us. Available at http://www.expertpatients.co.uk/about-us. Accessed 10 February 2010.

23. NHS Direct. What is NHS Direct? Available at http://www.nhsdirect.nhs.uk/en/About/WhatIsNHSDirect. Accessed 27 July 2010.

24. Coulter A. The NHS revolution: health care in the market place. What do patients and the public want from primary care? British Medical Journal 2005; 331: 1199-1201.

25. Sackett DL, Rosenberg WMC, Muir Gray JA, Brian Haynes R, Scott Richardson W. Evidence based medicine: what it is and what it isn't? British Medical Journal 1996; 312: 71-72.

26. Department of Health. Research evidence on the effectiveness of self-care support. London: Department of Health; 2007.

27. D'Souza W, Crane J, Burgess C, Te Karu H, Fox C, Harper M, Robson B, Howden-Chapman P, Crossland L, Woodman K, Pearce N, Pomare E, Beasley R. Community-based asthma care: trial of a "credit card" asthma self-management plan. European Respiratory Journal 1994; 7: 1260-1265.

28. Wanless D. Securing our Future Health: Taking a Long-Term View. Final Report. London: HM Treasury; 2002.

29. Mold A. Patient Groups and the Construction of the Patient-Consumer in Britain: An Historical Overview. Journal of Social Policy 2010; 39: 505-521.

30. Dahlgren G, Whitehead M. Policies and strategies to promote social equity in health. Background document to WHO – Strategy paper for Europe. Stockholm: Institute for Future Studies; 1991.

31. Department of Health. Health Service Circular 1999/210. Patient and public involvement in the new NHS. London: Department of Health; 1999.

32. Department of Health. The NHS plan. A plan for investment, a plan for reform. London; Department of Health; 2000.

33. Kinnersley P, Stott N, Peters TJ, Harvey I. The patient-centredness of consultations and outcome in primary care. British Journal of General Practice 1999; 49: 711-716.

34. Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C, Ferrier K, Payne S. Preferences of patients for patient centred approach to consultation in primary care: observational study. British Medical Journal 2001; 322: 1-7.

35. Dyer C. News. Gynaecologist showed "lack of care and judgement". British Medical Journal 1998; 317: 965.

36. The Bristol Royal Infirmary Enquiry. The Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995. Learning from Bristol. Norwich: The Stationery Office Limited; Norwich 2001.

37. The Independent. The Bristol report must mark the end of doctors' lack of accountability. Available at: http://www.independent.co.uk/opinion/leading-articles/the-bristol-report-must-mark-the-end-of-doctors-lack-of-accountability-678194.html. Accessed 3 June 2010.

38. Emslie MJ, Campbell MK, Walker KA. Changes in public awareness of, attitudes to, and use of complementary therapy in North East Scotland: surveys in 1993 and 1999. Complementary Therapies in Medicine 2002, 10:148-153.

39. NHS Direct. The pregnancy care planner. Your NHS guide to having a baby. Finding out if you're pregnant. Available at http://www.nhs.uk/Planners/pregnancycareplanner/pages/Findingout.aspx. Accessed 10 August 2009.

40. Williams B et al. British Hypertension Society Guidelines. Guidelines for management of hypertension: report of the fourth working party of the British Hypertension Society 2004 – BHS IV. Journal of Human Hypertension 2004; 18: 139-185.

41. O'Brien E, Asmar R, Beilin L, Imai Y, Mancia G, Mengden T, Myers M, Padfield P, Palatini P, Parati G, Pickering T, Redon J, Staessen J, Stergiou G, Verdecchia P on behalf of the European Society of Hypertension Working Group on Blood Pressure Monitoring. Practice guidelines of the European Society of Hypertension for clinic, ambulatory and self blood pressure measurement. Journal of Hypertension 2005; 23: 697–701.

42. Diabetes UK. Position statements. Self-monitoring of blood glucose. Available at http://www.diabetes.org.uk/About_us/Our_Views/Position_statements/Self-monitoring_of_blood_glucose/. Accessed 11 February 2010.

43. Crook MA. Near patient testing and pathology in the new millennium. Journal of Clinical Pathology 2000; 53: 27-30.

44. Björndahl L, Kirkman-Brown J, Hart G, Rattle S, Barratt CLR. Development of a novel home sperm test. Human reproduction 2006; 21(1): 145-149.

45. Simplicity Health. HealthcheX CHO Cholesterol Test Instructions. Available at http://www.simplicityhealth.co.uk/popup_tests/HC_Cholesterol_Test_Instructions.htm. Accessed 18 February 2010.

46. Simplicity Health. Chlamydia Test Instructions. Available at http://www.simplicityhealth.co.uk/popup_tests/chlamydia_Test_Instructions.htm. Accessed 18 February 2010.

47. Ludgate S, Molyneaux A. How the MHRA can help pharmacists ensure the safety of OTC testing kits. The Pharmaceutical Journal 2004; 273: 64-65.

48. Ryan A, Wilson S, Greenfield S, Clifford S, McManus RJ, Pattison HM. Range of self-tests available to buy in the United Kingdom: an Internet survey. Journal of Public Health 2006, 28(4): 370-374.

49. Office for National Statistics. Statistical Bulletin. Internet Access. Households and Individuals 2009. Available at http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=5672. Accessed 18 February 2010.

50. Medicines and Healthcare products Regulatory Agency. Guidance Notes 19. In Vitro Diagnostic Medical Devices Directive 98 / 79 / EC. London: Medicines and Healthcare products Regulatory Agency; 2006.

51. NHS Direct. How accurate are home pregnancy tests? Available at http://www.nhs.uk/chq/Pages/2308.aspx?CategoryID=54&SubCategoryID=127. Accessed 5 February 2010.

52. Ford CA, Jaccard J, Millstein SG, Viadro CI, Eaton JL, Miller WC. Young Adults' Attitudes, Beliefs, and Feelings About Testing for Curable STDs Outside of Clinic Settings. Journal of Adolescent Health 2004; 34: 266-269.

53. Department of Health in association with NHS Cancer Screening Programmes, with advice and support from the Cancer Research UK Primary Care Education Group. Bowel Cancer Screening. The Facts. London: Central Office of Information; 2008.

54. NHS Direct. Symptoms of overactive thyroid. Available at http://www.nhs.uk/Conditions/Thyroid-over-active/Pages/Symptoms.aspx. Accessed 28 July 2010.

55. Raffle A, Gray M. Measures of test performance. In: Raffle A, Gray M. Screening: Evidence and Practice. 1st edition. Oxford: Oxford University Press; 2007. p. 113.

56. Ransohoff DF, Feinstein AR. Problems of spectrum and bias in evaluating the efficacy of diagnostic tests. The New England Journal of Medicine 1978; 299: 926-930.

57. Goehring C, Perrier A, Morabia A. Spectrum bias: a quantitative and graphical analysis of the variability of medical diagnostic test performance. Statistics in Medicine 2004; 23: 125-135.

58. Raffle A, Gray M. Measures of test performance. In: Raffle A, Gray M. Screening: Evidence and Practice. 1st edition. Oxford: Oxford University Press; 2007. p. 115.

59. Department of Health. Public attitudes to Self Care. Baseline Survey. London: Department of Health; 2005.

60. UK National Screening Committee. Programme appraisal criteria. Criteria for appraising the viability, effectiveness and appropriateness of a screening programme. Available at http://www.screening.nhs.uk/criteria. Accessed 28 July 2010.

61. British Medical Association Board of Science: Population screening and genetic testing. A briefing on current programmes and technologies. London: BMA publications unit; 2005.

62. Raffle A, Gray M. Quality assuring screening programmes. In: Raffle A, Gray M. Screening: Evidence and Practice. 1st edition. Oxford: Oxford University Press; 2007. p. 156-173.

63. Scott A, Wordsworth S. The effects of shifts in the balance of care on general practice workload. Family Practice 1999; 16: 12-17.

64. Stevenson FA, Greenfield SM, Jones M, Nayak A, Bradley CP. GP's perceptions of patient influence on prescribing. Family Practice 1999; 16: 255-261.

65. Weiss MC, Fitzpatrick R, Scott DK, Goldacre MJ. Pressures on the general practitioner and decisions to prescribe. Family Practice 1996; 13: 432-438.

66. Ryan A, Greenfield S, Wilson S. Prevalence and determinants of the use of self-tests by members of the public: a mixed methods study. BMC Public Health 2006; 6: 193.

67. Hitwise UK. Hitwise UK Search Update. Google powers three-quarters of UK searches. Available at http://www.hitwise.co.uk/press-center/hitwiseHS2004/uk-search-update-19042996.php. Accessed 24 April 2006..

68. iProspect. Search Engine User Behavior Study. April 2006. Available at http://www.iprospect.com/premiumPDFs/WhitePaper_2006_SearchEngineUserBehavior.pdf#search='Jupiter%20research%20iprospect'. Accessed 19 June 2006.

69. BBC News. Market Data. Available at http://newsvote.bbc.co.uk/1/shared/fds/hi/business/market_data/currency/11/12/three_month.stm. Accessed 20 June 2006.

70. Medisave. Personal Screening Osteoporosis Risk Assessment Home Test. Available at http://www.medisave.co.uk/personal-screening-osteoporosis-risk-assessment-home-test-p-335.html?cPath=8_84. Accessed 26 April 2006.

71. Natural Woman Ltd. Bodywatch osteoporosis. Available at http://www.natural-woman.com/p_bodyosteoporosis.htm. Accessed 26 April 2006.

72. Home Health Testing. Body Building Hormone Tests. Available at http://www.homehealthtesting.com/performance-hormone-tests.htm. Accessed 14 April 2005.

73. Ryan A, Wilson S, Greenfield S. Prevalence of the use of self-tests by adults in the United Kingdom: a questionnaire survey. Journal of Public Health 2010; doi: 10.1093/pubmed/fdq018.

74. Office for National Statistics. England Household form H1. Available at http://www.statistics.gov.uk/census2001/census_form.asp. Accessed 4 December 2009.

75. Gilman J, Myatt M. Epicalc 2000. Version 1.02. London: Brixton Books; 1998.

76. Wilson S, Roberts L, Roalfe A, Bridge P, Singh S. Prevalence of irritable bowel syndrome: a community survey. British Journal of General Practice 2004; 54: 495-502.

77. Webb R, Brammah T, Lunt M, Urwin M, Allison T, Symmons D. Opportunities for prevention of "clinically significant" knee pain: results from a population-based cross-sectional survey. Journal of Public Health 2004; 26(3): 277-284.

78. Royal College of General Practitioners. Profile of UK Practices. London: Royal College of General Practitioners; 2006.

79. Office for National Statistics. Estimated resident population at mid-year 2002 by quinary age groups and sex for local authorities in England and Wales. Available at http://www.statistics.gov.uk/statbase/ssdataset.asp?vlnk=7030&More=Y. Accessed 4 August 2004.

80. Communities and Local Government Office. Indices of Deprivation 2007. Available at http://www.communities.gov.uk/communities/neighbourhoodrenewal/deprivation/deprivation07/. Accessed 10 November 2009.

81. Communities and Local Government Office. Using the English Indices of Deprivation 2007: Guidance. Available at http://www.communities.gov.uk/communities/neighbourhoodrenewal/deprivation/deprivation07/. Accessed 10 November 2009.

82. Office for National Statistics. Population Density (UV02). Available at http://neighbourhood.statistics.gov.uk/dissemination/filesetSelection.do?step=5&datasetFamilyId=789&instanceSelection=13267&filesetIndex=11&JSAllowed=true&browserHeight=622&browserWidth=1003&%24ph=60_61_64&CurrentPageId=64&Next.x=14&Next.y=11. Accessed 13 January 2006.

83. Office for National Statistics. Population Density (UV02). Available at http://neighbourhood.statistics.gov.uk/dissemination/filesetSelection.do?step=5&datasetFamilyId=789&instanceSelection=13267&filesetIndex=11&rightPaneBoxHeight=419&JSAllowed=true&browserHeight=596&browserWidth=1007&%24ph=60_61_64&CurrentPageId=64&Next.x=15&Next.y=6. Accessed 9 August 2007.

84. Office for National Statistics. Indices of Deprivation for Super Output Areas, 2004. Available at http://www.neighbourhood.statistics.gov.uk/dissemination/instanceSelection.do?JSAllowed=true&Function=&%24ph=60_61&CurrentPageId=61&step=2&datasetFamilyId=800&instanceSelection=16472&Next.x=15&Next.y=13. Accessed 9 August 2007.

85. Principia Products. Remark Office OMR Version 6. The Innovative Solution To Your Data Entry Needs. User's Guide. Philadelphia: Principia Products; 2005.

86. Office for National Statistics. Mid-2006 population estimates: estimated resident population. Available at http://www.statistics.gov.uk/STATBASE/Product.asp?vlnk=15106. Accessed 17 June 2008.

87. Kirkwood BR, Sterne JAC. Standardization. In: Kirkwood BR, Sterne JAC. Essential Medical Statistics. 2nd edition. Oxford: Blackwell Science Ltd; 2003. p. 264-267.

88. Ritchie J. The Applications of Qualitative Methods to Social Research. In: J Ritchie, L Lewis, editors. Qualitative Research Practice. A Guide for Social Science Students and Researchers. 1st edition. London: Sage Publications; 2005. p. 36-37.

89. Ryan A, Ives J, Wilson S, Greenfield S. Why members of the public self-test: an interview study. Family Practice 2010; 27(5): 570-581.

90. Patton MQ. Designing Qualitative Studies. In: Patton MQ. Qualitative Evaluation and Research Methods. 2nd edition. California: Sage Publications; 1990. p. 169.

91. Britten N. Conducting interviews. Qualitative interviews. In: J Pope C, May N, editors. Qualitative research in health care. 3rd edition. Oxford: BMJ Publishing Group; 2006. p. 15.

92. Patton MQ. Depth interviewing. In: Patton MQ. How to Use Qualitative Methods in Evaluation. 2nd edition. California: Sage Publications; 1987. p. 124.

93. Patton MQ. Depth interviewing. In: Patton MQ. How to Use Qualitative Methods in Evaluation. 2nd edition. California: Sage Publications; 1987. p. 123.

94. Pope C, Ziebland S, Mays N. Thematic analysis. Analysing qualitative data. In: J Pope C, May N, editors. Qualitative research in health care. 3rd edition. Oxford: BMJ Publishing Group; 2006. p. 69-70.

95. Boyatzis RE. What is thematic analysis? The Search for a Codable Moment. In: Boyatzis RE. Tranforming Qualitative Information. Thematic Analysis and Code Development. 1st edition. California: Sage Publications; 1998. p. 4-5.

96. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology 2006; 3: 77-101.

97. Pope C, Ziebland S, Mays N. Counting and qualitative data. Analysing qualitative data. In: J Pope C, May N, editors. Qualitative research in health care. 3rd edition. Oxford: BMJ Publishing Group; 2006. p. 66.

98. Pope C, Ziebland S, Mays N. Initial steps. Analysing qualitative data. In: J Pope C, May N, editors. Qualitative research in health care. 3rd edition. Oxford: BMJ Publishing Group; 2006. p. 68.

99. Strauss A, Corbin J. Theoretical saturation. Theoretical sampling. In: Strauss A, Corbin J. Basics of Qualitative Research. Techniques and Procedures for Developing Grounded Theory. 2nd edition. California: Sage Publications; 1998. p. 212.

100. Ryan A, Wilson S, Taylor A, Greenfield S. Factors associated with self-care activities among adults in the United Kingdom: a systematic review. BMC Public Health 2009; 9: 96.

101. Siahpush M. Postmodern values, dissatisfaction with conventional medicine and popularity of alternative therapies. Journal of Sociology 1998; 34 (1): 58-70.

102. Wearn AM, Greenfield SM. Access to complementary medicine in general practice: survey in one UK health authority. Journal of the Royal Society of Medicine 1998; 91: 465-470.

103. Baron SE, Goodwin RG, Nicolau N, Blackford S, Goulden V. Use of complementary medicine among outpatients with dermatologic conditions within Yorkshire and South Wales, United Kingdom. Journal of the American Academy of Dermatology 2005; 52: 589-594.

104. Critical Appraisal Skills Programme. Making sense of evidence: 12 questions to help you make sense of a cohort study [http://www.phru.nhs.uk/Doc_Links/cohort%2012%20questions.pdf]. Accessed 13 September 2007.

105. Critical Appraisal Skills Programme (CASP). Making sense of evidence: 12 questions to help you make sense of a qualitative research [http://www.phru.nhs.uk/Doc_Links/Qualitative%20Appraisal%20Tool.pdf]. Accessed 13 September 2007.

106. Thomas KJ, Nicholl JP, Coleman P. Use and expenditure on complementary medicine in England: a population based survey. Complementary Therapies in Medicine 2001, 9: 2-11.

107. Professor Ken Wallston, Personal communication, 17 January 2008.

108. Figueiras A, Caamaño F, Gestal-Otero JJ. Sociodemographic factors related to self-medication in Spain. European Journal of Epidemiology 2000; 16: 19-26.

109. Office for National Statistics. KS20 Household composition: Census 2001, Key Statistics for local Authorities. Available at http://www.statistics.gov.uk/statbase/ssdataset.asp?vlnk=6582&More=Y. Accessed 25 November 2004.

110. Office for National Statistics. KS03 Living arrangements: Census 2001, Key Statistics for local Authorities. Available at http://www.statistics.gov.uk/statbase/ssdataset.asp?vlnk=6557&More=Y. Accessed 25 November 2004.

111. Census Dissemination Unit, Mimas, University of Manchester. GeoConvert. Available at: http://geoconvert.mimas.ac.uk/index.htm. Accessed 9 November 2009.

112. Improvement and Development Agency for local government. Local government glossary. Super Output Area (SOA). Available at http://www.idea.gov.uk/idk/core/page.do?pageId=7175806. Accessed 25 June 2010.

113. National Primary Care Research and Development Centre. Manual. General Practice Assessment Questionnaire (GPAQ). Version 2.1. Manchester: University of Manchester; 2007.

114. Wallston KA. Multidimensionial Health Locus of Control Scale. In: Christensen AJ, Martin R, and Smyth J, editors. Encyclopedia of Health Psychology. 1st edition. New York: Kluwer Academic / Plenum; 2004. p. 171-172.

115. Wallston KA. Scoring instructions for the MHLC scales. Available at http://www.vanderbilt.edu/nursing/kwallston/scoringmhlc.htm. Accessed 18 November 2009.

116. Wallston KA. Frequently asked questions. MHLC scales. Available at http://www.vanderbilt.edu/nursing/kwallston/FAQMHLC.htm. Accessed 18 November 2009.

117. Lau RR, Hartman KA, Ware JE. Health As a Value: Methodological and Theoretical Considerations. Health Psychology 1986; 5(1): 25-43.

118. Wallston KA. The importance of placing measures of health locus of control beliefs in a theoretical context. Health Education Research 1991; 6 (2): 251-252.

119. Smith MS, Wallston KA. How to measure the value of health. Health Education Research 1992; 7(1): 129-135.

120. Altman DG. Hypothesis testing. In: Altman DG. Practical Statistics for Medical Research. 1st edition. Florida: Chapman & Hall / CRC; 1999. p. 165-167.

121. Kirkwood BR, Sterne JAC. Comparison of two means. In: Kirkwood BR, Sterne JAC. Essential Medical Statistics. 2nd edition. Oxford: Blackwell Science Ltd; 2003. p. 62.

122. Altman DG. Hypothesis testing. In: Altman DG. Practical Statistics for Medical Research. 1st edition. Florida: Chapman & Hall / CRC; 1999. p. 167-168.

123. Kirkwood BR, Sterne JAC. Chi-squared tests for 2 x 2 and larger contingency tables. In: Kirkwood BR, Sterne JAC. Essential Medical Statistics. 2nd edition. Oxford: Blackwell Science Ltd; 2003. p. 166-167.

124. Altman DG. Comparing groups – categorical data. In: Altman DG. Practical Statistics for Medical Research. 1st edition. Florida: Chapman & Hall / CRC; 1999. p. 260.

125. Kirkwood BR, Sterne JAC. Chi-squared tests for 2 x 2 and larger contingency tables. In: Kirkwood BR, Sterne JAC. Essential Medical Statistics. 2nd edition. Oxford: Blackwell Science Ltd; 2003. p. 173.

126. StataCorp. Stata: Release 11. Statistical Software. College Station, Texas: StataCorp LP; 2009.

127. Kirkwood BR, Sterne JAC. Means, standard deviations and standard errors. In: Kirkwood BR, Sterne JAC. Essential Medical Statistics. 2nd edition. Oxford: Blackwell Science Ltd; 2003. p. 34.

128. Campbell MJ, Machin D. Appendix I: Techniques. In: Campbell MJ, Machin D. Medical Statistics: A Commonsense Approach. 3rd edition. Chicester: Wiley; 2000. p. 154.

129. Kirkwood BR, Sterne JAC. Relaxing model assumptions. In: Kirkwood BR, Sterne JAC. Essential Medical Statistics. 2nd edition. Oxford: Blackwell Science Ltd; 2003. p. 347-348.

130. Kirkwood BR, Sterne JAC. Calculation of required sample size. In: Kirkwood BR, Sterne JAC. Essential Medical Statistics. 2nd edition. Oxford: Blackwell Science Ltd; 2003. p. 425.

131. Bland JM, Altman DG. Multiple significance tests: the Bonferroni method. British Medical Journal 1995; 310: 170.

132. Quinn G, Keough M. Multiple testing. In: Quinn G, Keough M. Experimental design and data analysis for biologists. 1st edition. Cambridge: Cambridge University Press; 2003. p. 48-50.

133. Abdi H. The Bonferroni and Šidák Corrections for Multiple Comparisons. In Salkind NJ, editors. Encyclopedia of Measurement and Statistics. 1st edition. California: SAGE Publications Inc; 2007. p. 103-107.

134. Schafer WD. Bonferroni technieque. In: Lewis-Beck MS, Bryman A, Liao TF, editors. The SAGE encyclopedia of social science research methods. 1st edition. California: SAGE Publications Inc; 2004. p. 75.

135. Hancock GR, Klockars AJ. The Quest for α: Developments in Multiple Comparison Procedures in the Quarter Century Since Games (1971). Review of Educational Research 1996; 66: 269.

136. Kirkwood BR, Sterne JAC. Regression modelling. In: Kirkwood BR, Sterne JAC. Essential Medical Statistics. 2nd edition. Oxford: Blackwell Science Ltd; 2003. p. 340-341.

137. Dupont WD. Multiple Linear Regression. In: Dupont WD. Statistical Modeling for Biomedical Researchers. A Simple Introduction to the Analysis of Complex Data. Cambridge: Cambridge University Press; 2003. p. 96.

138. StataCorp. Stepwise – Stepwise estimation. In: StataCorp. Stata Base Reference Manual. Release 11. Texas: StataCorp; 2009. p. 1790.

139. Hosmer DW, Lemeshow S. Model building Strategies and Methods. In: Hosmer DW, Lemeshow S. Wiley Series in Probability and Statistics. Applied logistic regresssion. 2nd edition. United States of America: John Wiley & Sons Inc; 2000. p. 116.

140. Kirkwood BR, Sterne JAC. Regression modelling. In: Kirkwood BR, Sterne JAC. Essential Medical Statistics. 2nd edition. Oxford: Blackwell Science Ltd; 2003. p. 341.

141. Katz MH. Multivariable Analysis. A Primer for Readers of Medical Research. Annals of Internal Medicine 2003; 138: 644-650.

142. SPSS Inc. PASW Statistics. Release 17.0.2. Chicago: SPSS Inc; 2009.

143. Peng CJ, Lee KL, Ingersoll GM. An introduction to Logistic Regression Analysis and Reporting. The Journal of Educational Research 2002; 96(1): 3-14.

144. Kirkwood BR, Sterne JAC. Likelihood. In: Kirkwood BR, Sterne JAC. Essential Medical Statistics. 2nd edition. Oxford: Blackwell Science Ltd; 2003. p. 313-314.

145. Bewick V, Cheek L, Ball J. Statistics review 14: Logistic regression. Critical Care 2005; 9(1): 112-118.

146. Wilson S, Ryan AV, Greenfield SM, Clifford SC, Holder RL, Pattison HM, Fitzmaurice DA, McManus RJ. Self-testing for cancer: a community survey. BMC Cancer 2008; 8:102.

147. Featherstone C, Godden D, Selvaraji, Emslie M, Took-Zozaya M. Characteristics associated with reported CAM use in patients attending six GP practices in the Tayside and Grampian regions of Scotland: a survey. Complementary Therapies in Medicine 2003; 11: 168-176.

148. Greenfield SM, Innes MA, Allan TF, Wearn AM. First year medical students' perceptions and use of complementary and alternative medicine. Complementary Therapies in Medicine 2002; 10: 27-32.

149. Andrews GJ. Private complementary medicine and older people: service use and user empowerment. Ageing and Society 2002; 22: 343-368.

150. Andrews GJ. Placing the consumption of private complementary medicine: everyday geographies of older peoples' use. Health and Place 2003; 9: 337-349.

151. Ong C, Petersen S, Bodeker GC, Stewart-Brown S. Health Status of People Using Complementary and Alternative Medical Practitioner Services in 4 English Counties. American Journal of Public Health 2002; 92(10): 1653-1656.

152. Ong C, Doll H, Bodeker G, Stewart-Brown S. Use of osteopathic or chiropractic services among people with back pain: a UK population survey. Health and Social Care in the Community 2004; 12 (3): 265-273.

153. Featherstone C, Godden D, Gault C, Emslie M, Took-Zozaya M. Prevalence Study of Concurrent Use of Complementary and Alternative Medicine in Patients Attending

Primary Care Services in Scotland. American Journal of Public Health 2003; 93 (7): 1080-1082.

154. MacPherson H, Sinclair-Lian N, Thomas K. Patients seeking care from acupuncture practitioners in the UK: A national survey. Complementary Therapies in Medicine 2006; 14: 20-30.

155. Cappuccio FP, Duneclift SM, Atkinson RW, Cook DG. Use of Alternative Medicines in a Multi-Ethnic Population. Ethnicity and Disease 2001; 11: 11-18.

156. Cartwright T, Torr R. Making sense of illness: The Experiences of Users of Complementary Medicine. Journal of Health Psychology 2005; 10(4): 559-572.

157. Richardson J. What Patients Expect From Complementary Therapy: A Qualitative Study. American Journal of Public Health 2004; 94(6): 1049-1053.

158. Murray J, Shepherd S. Alternative or additional medicine? An exploratory study in general practice. Social Science and Medicine 1993; 37(8): 983-988.

159. Freymann H, Rennie T, Bates I, Nebel S, Heinrich M. Knowledge and use of complementary and alternative medicine among British undergraduate pharmacy students. Pharmacy World and Science 2006; 28: 13-18.

160. Wadlow G, Peringer E. Retrospective survey of patients of practitioners of traditional Chinese acupuncture in the UK. Complementary Therapies in Medicine 1996; 4: 1-7.

161. Furnham A, Forey J. The attitudes, behaviors and beliefs of patients of conventional vs. complementary (alternative) medicine. Journal of Clinical Psychology 1994; 50(3): 458-469.

162. Furnham A. Does experience of the 'occult' predict use of complementary medicine? Experience of, and beliefs about, both complementary medicine and ways of telling the future. Complementary Therapies in Medicine 2000; 8: 266-275.

163. Ernst E, White A. The BBC survey of complementary medicine use in the UK. Complementary Therapies in Medicine 2000; 8: 32-36.

164. Furnham A, Beard R. Health, just world beliefs and coping style preferences in patients of complementary and orthodox medicine. Social Science and Medicine 1995; 40(10): 1425-1432.

165. Sharples FMC, van Haselen R, Fisher P. NHS patients' perspective on complementary medicine: a survey. Complementary Therapies in Medicine 2003; 11: 243-248.

166. Vincent C, Furnham A. Why do patients turn to complementary medicine? An empirical study. British Journal of Clinical Psychology 1996; 35: 37-48.

167. Thomas K, Coleman P. Use of complementary or alternative medicine in a general population in Great Britain. Results from the National Omnibus survey. Journal of Public Health 2004; 26(2):152-157.

168. Furnham A, Vincent C, Wood R. The Health Beliefs and Behaviors of Three Groups of Complementary Medicine and a General Practice Group of Patients. The Journal of Alternative and Complementary Medicine 1995; 1(4): 347-359.

169. Furnham A, Bhagrath R. A comparison of health beliefs and behaviours of clients of orthodox and complementary medicine. British Journal of Clinical Psychology 1993; 32: 237-246.

170. Paterson C. Complementary practitioners as part of the primary health care team: consulting patterns, patient characteristics and patient outcomes. Family Practice 1997; 14 (5): 347-354.

171. Vincent C, Furnham A, Willsmore M. The perceived efficacy of complementary and orthodox medicine in complementary and general practice patients. Health Education Research 1995; 10 (4): 395-405.

172. Emslie M, Campbell M, Walker K. Complementary therapies in a local healthcare setting. Part 1: Is there real public demand? Complementary therapies in Medicine 1996; 4: 39-42.

173. McElnay JC, McCallion CR. Non-prescription drug use by elderly patients. The International Journal of Pharmacy Practice 1996; 4(1): 6-11.

174. Urquhart G, Sinclair HK, Hannaford PC. The use of non-prescription medicines by general practitioner attendees. Pharmacoepidemiology and Drug Safety 2004; 13: 773-779.

175. Wazaify M, Shields E, Hughes CM, McElnay JC. Societal perspectives on over-the-counter (OTC) medicines. Family Practice 2005; 22: 170-176.

176. Payne K, Ryan-Woolley BM, Noyce PR. Factors influencing consumers to purchase deregulated medicines over the counter. The Pharmaceutical Journal 1997; 259 suppl: R14.

177. Porteous T, Bond C, Hannaford P, Sinclair H. How and why are non-prescription analgesics used in Scotland? Family Practice 2005; 22: 78-85.

178. Vickers KA, Jolly KB, Greenfield SM. Herbal medicine: women's views, knowledge and interaction with doctors: a qualitative study. BMC Complementary and Alternative Medicine 2006; 6: 40.

179. Gray NJ, Cantrill JA, Noyce PR. 'Health repertories': an understanding of lay management of minor ailments. Patient Education and Counseling 2002; 47: 237-244.

180. Harrison RA, Holt D, Pattison DJ, Elton PJ. Who and How Many People Are Taking Herbal Supplements? A Survey of 21 923 Adults. International Journal for Vitamin and Nutrition Research 2004; 74(3): 183-186.

181. Bradley CP, Riaz A, Tobias RS, Kenkre JE, Dassu DY. Patient attitudes to over-the-counter drugs and possible professional responses to self-medication. Family Practice 1998; 15(1): 44-50.

182. Kayne S, Beattie N, Reeves A. Survey of buyers of over-the-counter homeopathic medicines. The Pharmaceutical Journal 1999; 263: 210-212.

183. Reid S. A survey of the use of over-the-counter homeopathic medicines purchased in health stores in central Manchester. Homeopathy 2002; 91(4): 225-229.

184. Besley T, Hall J, Preston I. The demand for private health insurance: do waiting lists matter? Journal of Public Economics 1999; 72: 155-181.

185. King D, Mossialos E. The Determinants of Private Medical Insurance Prevalence in England, 1997-2000. Health Services Research 2005; 40(1): 195-212.

186. Propper C, Rees H, Green K. The demand for private medical insurance in the UK: a cohort analysis. The Economic Journal 2001; 111: C180-C200.

187. Propper C. The demand for private health care in the UK. Journal of Health Economics 2000; 19: 855-876.

188. McGrath C, Moles D, Bedi R. Who Uses Independent Dental Services? Findings from a National Survey. Primary Dental Care 1999; 6(4): 157-160.

189. Mulvaney C, Coupland C, Wilson A. Hammersley V, Dyas J, Carlisle R. Does increased use of private health care reduce the demand for NHS care? A prospective survey of General Practice referrals. Journal of Public Health 2005; 27(2): 182-188.

190. McManus RJ, Ryan A, Greenfield S, Pattison HM, Clifford S, Marriott J, Wilson S. Self measurement of blood pressure: a community survey. Journal of Human Hypertension 2007; 21: 741-743.

191. Department of Health. At least five a day: Strategies to increase vegetable and fruit consumption. London: Department of Health; 1997.

192. Department of Health. At least five a week: Evidence on the impact of physical activity and its relationship to health. A report from the Chief Medical Officer. London: Department of Health; 2004.

193. Ware JE, Kosinki M, Dewey JE and Gandek B. How to Score and interpret Single-Item Health Status Measures: A Manual for Users of the SF-8 Health Survey. Lincoln, RI: QualityMetric Incorporated; 2001.

194. Wallston KA, Wallston BS, DeVellis R. Development of the multidimensional health locus of control (MHLC) scales. Health Education Monographs 1978; 6: 160-170.

195. Wallston KA. The Validity of the Multidimensional Health Locus of Control Scales. Journal of Health Psychology 2005; 10(4): 623-631.

196. Leganger A, Kraft P. Control Constructs: Do they Mediate the Relation between Educational Attainment and Health Behaviour? Journal of Health Psychology 2003; 8(3): 361-372.

197. Wardle J, Steptoe A. Socioeconomic differences in attitudes and beliefs about healthy lifestyles. Journal of Epidemiology and Community Health 2002; 57: 440-443.

198. Office for National Statistics. Estimated resident population by ethnic group, age and sex, mid-2006 (experimental statistics); England. Available at: http://www.statistics.gov.uk/statbase/Product.asp?vlnk=14238. Accessed 11 August 2010.

199. Office for National Statistics. 2001 Census – standard tables. Table S016 Sex and age by general health and limiting long-term illness. Available at: https://www.nomisweb.co.uk/Default.asp. Accessed 11 August 2010.

200. Office for National Statistics. 2001 Census – standard tables. Table S028 Sex and age by economic activity. Available at: https://www.nomisweb.co.uk/Default.asp. Accessed 11 August 2010.

201. Office for National Statistics. Mid-2008 Population Estimates: England; estimated resident population by single year of age and sex. Available at: http://www.statistics.gov.uk/statbase/Product.asp?vlnk=15106. Accessed 20 April 2010.

202. Office for National Statistics. Estimated resident population by ethnic group, age and sex, mid-2007 (experimental statistics); England. Available at: http://www.statistics.gov.uk/statbase/Product.asp?vlnk=14238. Accessed 20 April 2010.

203. Office for National Statistics. General Details: Qualifications (UV24). Available at: http://www.neighbourhood.statistics.gov.uk/dissemination/LeadMetadataDownloadPDF.do?downloadId=211. Accessed 19 June 2007.

204. Office for National Statistics. 2001 Census – standard tables. Table S105 Sex and age by highest level of qualification. Available at: https://www.nomisweb.co.uk/Default.asp. Accessed 17 August 2010.

205. Office for National Statistics. 2001 Census – standard tables. Table S033 Sex and occupation by age. Available at: https://www.nomisweb.co.uk/Default.asp. Accessed 17 August 2010.

206. Office for National Statistics. General Household Survey 2007. Smoking and drinking among adults, 2007. Cardiff: Office for National Statistics; 2009.

207. Joint Health Surveys Unit. Health Survey for England 2008. Volume 1. Physical Activity and Fitness. London: The NHS Information Centre; 2009.

208. The NHS Information Centre. Health Survey for England 2007. Adult Trend Tables. Fruit and Vegetable consumption. Available at: http://www.ic.nhs.uk/statistics-and-data-

collections/health-and-lifestyles-related-surveys/health-survey-for-england/health-survey-for-england-2007-latest-trends-%5Bns%5D. Accessed 22 April 2010.

209. National Primary Care Research and Development Centre. Postal version (2.0): GPAQ benchmarks for 2005-6. Available at: http://www.npcrdc.ac.uk/Consultation_version_20_GPAQ_benchmarks_for_20056.htm. Accessed 5 May 2010. National Primary Care Research and Development Centre: University of Manchester, 2009.

210. Poortinga W, Dunstan FD, Fone DL. Health locus of control beliefs and socio-economic differences in self-rated health. Preventive Medicine 2008; 46(4): 374-380.

211. Ito K. Self-testing using by OTC test kits and mail testing services – it's future prospect and problems. Rinsho Byori 2004; 52(6): 513-7.

212. Schopper D, Vercauteren G. Testing for HIV at home: what are the issues? AIDS 1996; 10: 1455-1465.

213. Kier FJ, Molinari V. "Do-It-Yourself" Dementia Testing: Issues Regarding an Alzheimer's Home Screening Test. The Gerontologist 2003; 41(3): 295-301.

214. Asch DA, Jedrziewski Mk, Christakis NA. Response Rates to Mail Surveys Published in Medical Journals. Journal of Clinical Epidemiology 1997; 50(10): 1129-1136.

215. Edwards P, Roberts I, Clarke M, DiGuiseppi C, Pratap S, Wentz R, Kwan I. Increasing response rates to postal questionnaires: systematic review. British Medical Journal 2002; 324: 1183-1190.

216. O'Cathain A, Murphy E, Nicholl J. Why, and how, mixed methods research is undertaken in health services research in England: a mixed methods study. BMC Health Services Research 2007; 7: 85.

217. Lingard L, Albert M, Levinson W. Grounded theory, mixed methods, and action research. British Medical Journal 2008; 337: 459-461.

218. Pope C, Mays N. Critical reflections on the rise of qualitative research. British Medical Journal 2009; 339: 737-739.

219. Creswell JW, Fetters MD, Ivankova NV. Desigining A Mixed Methods Study In Primary Care. Annals of Family Medicine 2004; 2(1): 7-12.

220. Waller J, Robb K, Stubbings S, Ramirez A, Macleod U, Austoker J, Hiom S, Wardle J. Awareness of cancer symptoms and anticipated help seeking among ethnic minority groups in England. British Journal of Cancer 2009; 101(S2): S24-S30.

221. Zollman C, Vickers A. ABC of complementary medicine. What is complementary medicine? British Medical Journal 1999; 319: 693-696.

222. Rosenberg W, Donald D. Evidence based medicine: an approach to clinical problem solving. British Medical Journal 1995; 310: 1122-1126.

223. Whiting P, Harbord R, Kleijnen J. No role for quality scores in systematic reviews of diagnostic accuracy studies. BMC Medical Research Methodology 2005; 5: 19.

224. Cartwright T. “Getting on with life”: The experiences of older people using complementary health care. Social science & Medicine 2007; 64: 1692-1703.

225. Duggan C, Bates I. A qualitative report on the use of alternative medicines in residential homes for the elderly in selected NETRHA residential homes in the United Kingdom. Journal of Geriatric Drug Therapy 1994; 8(4): 47-57.

226. McManus RJ, Mant J, Bray EP, Holder R, Jones MI, Greenfield G, Kaambwa B, Banting M, Bryan S, Little P, Williams B, Hobbs R. Telemonitoring and self-management in the control of hypertension (TASMINH2): a randomised controlled trial. Lancet 2010; 376(9736): 163-172.

227. Ronda G, Portegijs P, Dinant G, Buntinx F, Norg R, van der Weijden T. Use of diagnostic self-tests on body materials among Internet users in the Netherlands: prevalence and correlates of use. BMC Public Health 2009; 9: 100.

228. Greenfield S, Pattison H, Jolly K. Use of complementary and alternative medicine and self-tests by coronary heart disease patients. BMC Complementary and Alternative Medicine 2008; 8: 47.

229. Scambler G. Self-care, self-help and alternative therapy. Health and illness behaviour. In Scambler G, editor. Sociology as applied to medicine. 6th edition. Oxford: Saunders Elsevier; 2008. p. 51.

230. Mechanic D. Factors affecting the response to illness. The study of illness behaviour. In: Mechanic D. Medical Sociology. 1st edition. New York: Free Press; 1968. p. 130-131.

231. Human Genetics Commission. Genes Direct. Ensuring the effective oversight of genetic tests supplied directly to the public. A report by the Human Genetics Commission. London: Department of Health; 2003.

232. Cappuccio F, Cook G, Atkinson RW, Strazzullo P. Prevalence, detection, and management of cardiovascular risk factors in different ethnic groups in south London. Heart 1997; 78: 555-563.

233. Furnham A. Attitudes towards homoeopathy in particular and beliefs about complementary medicines in general. Psychology, Health and Medicine 2000; 5(3): 327-342.

234. Furnham A, Lovett J. Predicting the use of complementary medicine: A Test of the Theories of Reasoned Action and Planned Behavior. Journal of Applied Social Psychology 2001; 31(12): 2588-2620.

235. Trinder P, Rajaratnam G, Lewis M, Croft P. Prophylactic aspirin use in the adult general population. Journal of Public Health Medicine 2003; 25(4): 377-380.

LIST OF APPENDICES

Appendix 1: Published study protocol

BMC Public Health

Study protocol

Prevalence and determinants of the use of self-tests by members of the public: a mixed methods study

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Abstract

Background: Self-tests can be used by members of the public to diagnose conditions without involving a doctor, nurse or other health professional. As technologies to design and manufacture diagnostic tests have developed, a range of self-tests have become available to the public to buy over-the-counter and via the Internet. This study aims to describe how many people have used self-tests and identify factors associated with their use.

Methods: A postal questionnaire will elicit basic information, including sociodemographic characteristics, and whether the person has used or would use specified self-tests. Consent will be sought to recontact people who want to participate further in the study, and interviews and focus groups will be used to develop hypotheses about factors associated with self-test use. These hypotheses will be tested in a case-control study. An in-depth questionnaire will be developed incorporating the identified factors. This will be sent to: people who have used a self-test (cases); people who have not used a self-test but would use one in the future (controls); and people who have not used and would not use a self-test (controls). Logistic regression analysis will be used to establish which factors are associated with self-test use.

Discussion: Self-tests do have potential benefits, for example privacy and convenience, but also potential harms, for example delay seeking treatment after a true negative result when the symptoms are actually due to another condition. It is anticipated that the outcomes from this study will include recommendations about how to improve the appropriate use of self-tests and existing health services, as well as information to prepare health professionals for patients who have used self-tests.

Background

Members of the public have become more involved in their own care. They use pregnancy tests and tests to monitor diagnosed conditions, such as diabetes mellitus [1], and self blood pressure measurement is popular [2]. Initiatives such as NHS Direct and the need to control costs have contributed to the development of self-care [3,4], as highlighted by the increasing scope for self-medication [5]. While this has been happening, technologies to design and manufacture tests that can be used in the home have advanced. As a result, a wider range of diagnostic and screening tests have become available to the general public [6]. These include tests for chlamydia, prostate specific antigen and faecal occult blood. Results are available immediately or after sending a sample to a laboratory, but contact with a doctor, nurse or other health professional is not necessary. These "self-tests" are likely to become even more easily available and widely used as the Internet continues to reduce physical and intellectual barriers.

People may use self-tests because of benefits of being tested outside a conventional medical setting. For example, people who would not visit a health professional may screen themselves because it is more convenient and private [7]. There are, however, also potential harms from being tested in this way. For example, a person who receives results without an interpretation of the whole picture, including signs and symptoms, could think he/she has a disease inappropriately, or a person could delay seeking treatment after a true negative result when his/her symptoms are actually due to another condition. There will also be false positive and false negative results. Self-tests are used without a formal independent assessment of these harms and benefits. Even if members of the public use tests that have been assessed as being beneficial when used during conventional screening programmes, their use is outside those quality assured programmes. Possible doubts associated with such testing include test accuracy, that people who are most at risk may not use self-tests, and that people with positive results may not actually get treated [8].

Many general practitioners feel that their workload has grown due to the move towards a primary-care-led NHS, that their prescribing behaviour is affected by patient demand, and that the number of demanding patients has risen [9-11]. An expansion of the use of self-tests may also exacerbate this perceived increase in demand and workload as people seek an explanation of results or further investigation.

Despite the potential impact of self-tests, the extent of their use is not known. Other than market research, a comprehensive literature review identified only one recent survey in the United Kingdom that asked participants about whether they had used home testing kits, and this was part of a study on attitudes to genetic testing [12]. There is also an absence of studies about why people use self-tests and perceived and actual harms and benefits.

Pilot work

During September and October 2004, we sent questionnaires and prepaid envelopes to 380 addresses randomly selected from the Birmingham South West 2004/05 residential telephone directory. The questionnaire asked whether the respondent had used or would use specified self-tests, with room to add any not listed. We wanted to maximise responses from men and women because some self-tests, for example for prostate disorders, would only be used by one sex. We, therefore, sent two questionnaires to each address with a request for the addressee to give the additional questionnaire to any other adult living at the same address. The questionnaire asked whether the respondent lived alone to allow us to estimate the denominator.

Three questionnaires were returned because the addressee had died or moved, and 184 completed questionnaires were received from the remaining 377 households. The denominator for the response rate (n = 697) was estimated as the 57 respondents who reported that they lived alone plus two adults at each of the remaining 320 addresses, and the response rate was 26%. Excluding 22 people who had only used a pregnancy test, 28 (15%) respondents said they had used a self-test. Respondents most commonly reported using a test for diabetes (n = 18), but they also reported using tests for cholesterol, infertility, urinary infection, haematuria, prostate specific antigen and HIV-infection. Sixty two percent (n = 96) of the 154 respondents who had not used a self-test other than a pregnancy test said they would use one in the future.

Study aims

The primary aims of this study are to describe the prevalence of the use of self-tests by members of the public to diagnose or screen for conditions without the involvement of a doctor, nurse or other health professional, and to determine factors that are associated with their use.

Methods

Study design

Mixed methods two-stage study with (1) an initial survey comprising a postal questionnaire, interviews and focus groups, followed by (2) an embedded case-control study.

Selection criteria

Adults aged 18 years or older randomly selected from participating general practices will be asked to complete the initial questionnaire. Practices will be selected to reflect the diversity of the population based on deprivation indicators, population density and ethnicity.

Exclusion criteria

The initial questionnaire will not be sent to people who the general practitioner feels that it would be inappropriate to approach, for example people with a severe mental illness, terminal illness or recent bereavement.

Methods of data collection

The initial survey involves a postal questionnaire that will elicit basic information about sociodemographic characteristics (e.g. age, sex, ethnic group, employment status), health status, and whether the person has used or would use self-tests that have been identified as available from a search of the Internet. The questionnaire will be designed using lessons learnt from the pilot survey and will be piloted with a small sample of the target population before being widely distributed. A cover letter will outline the study in lay terms and ask people to complete the questionnaire and return it in the enclosed prepaid envelope. The letter will be on headed notepaper from the person's general practice and signed by a partner at the practice. People will be given the option of returning a blank questionnaire to indicate that they do not want to take part. One reminder will be sent to non-responders. This first questionnaire will seek consent for recontacting people about further participation in the study.

Interviews are suitable for gaining an in-depth understanding of personal experience and perspectives [13], and we will use interviews to investigate factors that may have influenced whether people used self-tests. Focus groups can be used to pilot ideas and questions [14,15], and we will conduct focus groups with people who have not used self-tests to reflect on the general applicability of factors identified in the interviews. People who consented to be recontacted about talking with a researcher will be sent an information leaflet and a reply slip to indicate if they would like to take part in an interview or focus group with a prepaid envelope to return the slip. To put people at ease and increase the likelihood of interaction, focus groups will include people of the same sex and similar ages. A semi-structured topic guide will be used for the interviews, and the topic guide for the focus groups will be based on factors identified during the interviews.

Results from the postal questionnaire, interviews and focus groups will be used to develop hypotheses about factors that may influence use of self-tests other than pregnancy tests: pregnancy tests will be excluded as women have used them for some time and their use is probably now expected by doctors. These hypotheses will then be tested in a case-control study. An in-depth questionnaire will be developed incorporating the factors of interest. The questionnaire will be piloted with a small number of people from the target groups before it is sent to: cases who have used a self-test; controls who have not used a self-test but would use one in the future; and controls who have not used a self-test and would not use one in the future. This staging of questionnaires has been successfully used in other studies and is believed to generate a better response rate then sending a longer initial questionnaire [16]. A cover letter will outline the study in lay terms and ask people to consider completing the questionnaire and returning it using the enclosed prepaid envelope. People will be given the option of returning a blank questionnaire to indicate that they do not want to take part. One reminder will be sent to people who do not return a questionnaire.

Justification of sample size

As pregnancy tests will be excluded, self-test in this and the next section refers to tests other than pregnancy tests. Conservatively assuming that 10% of people have used a self-test, a sample of 4200 people will allow estimation of the prevalence of the use of self-tests with at least +/-1% precision and 95% confidence. Based on a response rate of 40%, which is less than other large prevalence surveys [16], the questionnaire will be sent to 10500 people. Assuming an average list size of 4500 people, 75% of whom are 18 years or older [17], and 5% of whom meet the exclusion criteria, it would be sufficient to recruit four general practices, but up to eight will be recruited to reflect diversity and increase generalisability.

It is assumed that 75% (n = 315) of the 420 respondents who have used a self-test and 50% (n = 1890) of the 3780 respondents who have not used a self-test will agree to be recontacted. Purposive sampling will be used to select people for interviews and focus groups [18]. For the interviews, we will select men and women of different ages (younger and older) who have used self-tests for different conditions (cancers, other chronic conditions, sexually transmitted infections, other acute infections or conditions). The ideal size for a focus group is between four and eight people [15], and we anticipate that each group will include six people who have not used self-tests. To facilitate sharing of views [14], we will hold groups with people of the same sex and similar ages. To allow loose matching by age (younger or older) and sex (male or female), up to four groups will be held. We anticipate, therefore, that interviews and focus groups will involve up to about 24 self-test users and 24 non-users [19].

Assuming that 75% of people who have used a self-test and 50% of people who have not used a self-test respond to the invitation to take part in an interview or focus group, we will need to approach 32 people who have used a self-test and 48 people who have not used a self-test to take part in this part of the study. This will leave 283 self-test users and 1842 non-users who have agreed to be recontacted.

In the absence of data relating to self-testing, we used factors associated with self-care to calculate a likely sample size for the case-control study. A Spanish study found that self-medication was more prevalent among people who lived alone [20]. About 15% of adults aged 16 years or over live alone [21,22]. If the same proportion of people who have not used a self-test live alone, data from 207 cases and 207 controls should detect a doubling of the odds of living alone among people who have used a self-test with 80% power and 5% significance.

Assuming that 75% of the remaining 283 self-test users return the in-depth questionnaire, there will be data from 212 cases. The pilot survey suggests that 62% (n = 1148) of the remaining 1842 non-users would consider using a self-test in the future, whereas 38% (n = 694) would have no interest in using one. Assuming a response rate of 50%, the in-depth questionnaire will need to be sent to 424 people from each of these groups to generate 212 controls from each group.

Methods of data analysis

The prevalence of the use of self-tests will be estimated after appropriate standardisation to the national population, and 95% confidence intervals will be calculated. We will compare sociodemographic characteristics of people who have used, who have not used, who would use, and who would not use self-tests.

Interviews and focus groups will be recorded and fully transcribed. The transcripts will be read, coded, indexed and categorised, facilitated by appropriate software. We will use grounded theory, that is we will identify analytical categories as they emerge from the data and use these categories to develop hypotheses about factors that may be associated with using self-tests [23]. The analysis will be iterative: hypotheses will be tested as they emerge using analytic induction [23], and we will amend the anticipated number of interviews and focus groups depending upon whether new issues continue to emerge. Respondent validation will be sought by inviting feedback from participants who will be sent a written summary of the interview or focus group.

The data from the second in-depth questionnaire will be fully investigated and described using univariate and bivariate comparisons of people who have and who have not used a self-test. Stepwise logistic regression will then be used to test the hypotheses developed during the interviews and focus groups and examined by the second questionnaire, and to establish those factors that are associated with using a self-test.

Self-tests can be grouped according to the disease area, for example for cancer or sexually transmitted infections. Secondary analyses will be conducted to generate hypotheses about whether particular determinants of self-test use vary by the type of test and, therefore, whether future research should be test-specific.

Bias and confounding

We aim to maximise compliance and minimise selection bias by keeping the demands on people to a minimum, but we will compare the characteristics of responders and non-responders and standardise the results to the national population. People who have participated in interviews or focus groups will be excluded from the case-control study as their responses could be affected by the discussion. During the case-control study, it is anticipated that cases and controls will be matched by sex and age group because they may be confounders: possible determinants of self-test use, such as access to the Internet, may vary with age. The criteria for matching will, however, be finalised after further information is collected during the interviews and focus groups. As the first questionnaire may "educate" people and lead to self-test use, the second questionnaire will be analysed on the basis of reported self-test use when the first questionnaire was distributed. To minimise recall bias, respondents to the second questionnaire will be asked to report behaviours and experiences over the preceding year.

Ethical approval

This study has been approved by Solihull Local Research Ethics Committee, reference 05/Q2706/13.

Discussion

The pilot study suggests that some people are using self-tests. These findings are in line with a 1993 survey in which 18% of respondents said they would prefer self-testing to testing by a doctor [24]. A recent British Medical Association report highlighted, however, that ad hoc screening can put people at risk because of a lack of evidence underpinning tests and insufficient quality assurance and accompanying information [25]. Self-tests do have potential benefits, for example privacy and convenience, but also potential harms, for example distress caused by false positive results [26]. Other potential problems include extra pressure on primary health care professionals and NHS laboratories as people seek an explanation of results or further investigation [27]. Despite this, there is an absence of studies about self-tests. We think that important first steps are to describe the prevalence of the use of self-tests and to determine factors that are associated with using them.

Abbreviations

NHS = National Health Service.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

Angela Ryan, Sue Wilson and Sheila Greenfield designed the pilot questionnaire survey, and Angela Ryan conducted the survey and analysed the data. Angela Ryan drafted the study protocol with input from all authors. All authors read and approved the final manuscript.

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References

1. Coster S, Gulliford MC, Seed PT, Powrie JK, Swaminathan R: **Self-monitoring in Type 2 diabetes mellitus: a meta-analysis.** *Diabet Med* 2000, **17**:755-761.
2. O'Brien E, Asmar R, Beilin L, Imai Y, Mancia G, Mengden T, Myers M, Padfield P, Palatini P, Parati G, Pickering T, Redon J, Staessen J, Stergiou G, Verdecchia P, on behalf of the European Society of Hypertension Working Group on Blood Pressure Monitoring: **Practice guidelines of the European Society of Hypertension for clinic, ambulatory and self blood pressure measurement.** *J Hypertens* 2005, **23**:697-701.
3. Payne F, Jessop L: **NHS Direct: review of activity data for the first year of operation at one site.** *J Public Health Med* 2001, **23(2)**:155-158.
4. Erwin J, Britten N, Jones R: **General practitioners' views on over the counter sales by community pharmacists.** *BMJ* 1996, **312**:617-618.
5. Bradley C, Blenkinsopp A: **Over the Counter Drugs: The future for self medication.** *BMJ* 1996, **312**:835-837.
6. Parliamentary Office of Science and Technology: *Postnote. Medical Self-test Kits. London* 2003.
7. Merson MH, Feldman EA, Bayer R, Stryker J: **Rapid self testing for HIV infection.** *Lancet* 1997, **349(9048)**:352-3.
8. Ford CA, Jaccard J, Millstein SG, Viadro CI, Eaton JL, Miller WC: **Young Adults' Attitudes, Beliefs, and Feelings About Testing for Curable STDs Outside of Clinic Settings.** *J Adolesc Health* 2004, **34**:266-269.
9. Scott A, Wordsworth S: **The effects of shifts in the balance of care on general practice workload.** *Fam Pract* 1999, **16**:12-17.
10. Stevenson FA, Greenfield SM, Jones M, Nayak A, Bradley CP: **GPs' perceptions of patient influence on prescribing.** *Fam Pract* 1999, **16**:255-261.
11. Weiss MC, Fitzpatrick R, Scott DK, Goldacre MJ: **Pressures on the general practitioner and decisions to prescribe.** *Fam Pract* 1996, **13**:432-438.
12. YouGov Limited: *Public attitudes to genetic testing. A quantitative study for the Human Genetics Commission. London* 2003.
13. Ritchie J: **The Applications of Qualitative Methods to Social Research.** In *Qualitative Research Practice. A Guide for Social Science Students and Researchers* 1st edition. Edited by: Ritchie J, Lewis L. London: Sage Publications; 2005:24-46.
14. Krueger R, Casey M: *Focus groups. A practical guide for applied research* 3rd edition. California: Sage Publications; 2000.
15. Kitzinger J: **Qualitative Research: Introducing focus groups.** *BMJ* 1995, **311**:299-302.
16. Wilson S, Roberts L, Roalfe A, Bridge P, Singh S: **Prevalence of irritable bowel syndrome: a community survey.** *Br J Gen Pract* 2004, **54**:495-502.
17. Office for National Statistics: **Estimated resident population at mid-year 2002 by quinary age groups and sex for local authorities in England and Wales.** [http://www.statistics.gov.uk/statbase/ssdataset.asp?vlnk=7030&More=Y]. Accessed 4 August 2004
18. Patton MQ: *Qualitative Evaluation and Research Methods* 2nd edition. California: Sage Publications; 1990.
19. Morse JM: **Determining sample size.** *Qual Health Res* 2000, **10(1)**:3-5.
20. Figueiras A, Caamaòo F, Gestal-Otero JJ: **Sociodemographic factors related to self-medication in Spain.** *Eur J Epidemiol* 2000, **16**:19-26.
21. Office for National Statistics: **KS20 Household composition: Census 2001, Key Statistics for local Authorities.** [http://www.statistics.gov.uk/statbase/ssdataset.asp?vlnk=6582&More=Y]. Accessed 25 November 2004
22. Office for National Statistics: **KS03 Living arrangements: Census 2001, Key Statistics for local Authorities.** [http://www.statistics.gov.uk/statbase/ssdataset.asp?vlnk=6557&More=Y]. Accessed 25 November 2004
23. Pope C, Ziebland S, Mays N: **Qualitative research in health care. Analysing qualitative data.** *BMJ* 2000, **320**:114-6.
24. Office of Population Censuses and Surveys: **Social Survey Division, OPCS Omnibus Survey, September 1993 [computer file].** Colchester, Essex: UK Data Archive [distributor]; 1997. SN: 3670
25. British Medical Association Board of Science: *Population screening and genetic testing. A briefing on current programmes and technologies. London* 2005.
26. Haddow LJ, AJ Robinson: **A case of a false positive result on a home HIV test kit obtained on the internet.** *Sex Transm Infect* 2005, **81**:359-362.
27. Human Genetics Commission: *Genes Direct: Ensuring the effective oversight of genetic tests supplied directly to the public. A report by the Human Genetics Commission. London.* 2003.

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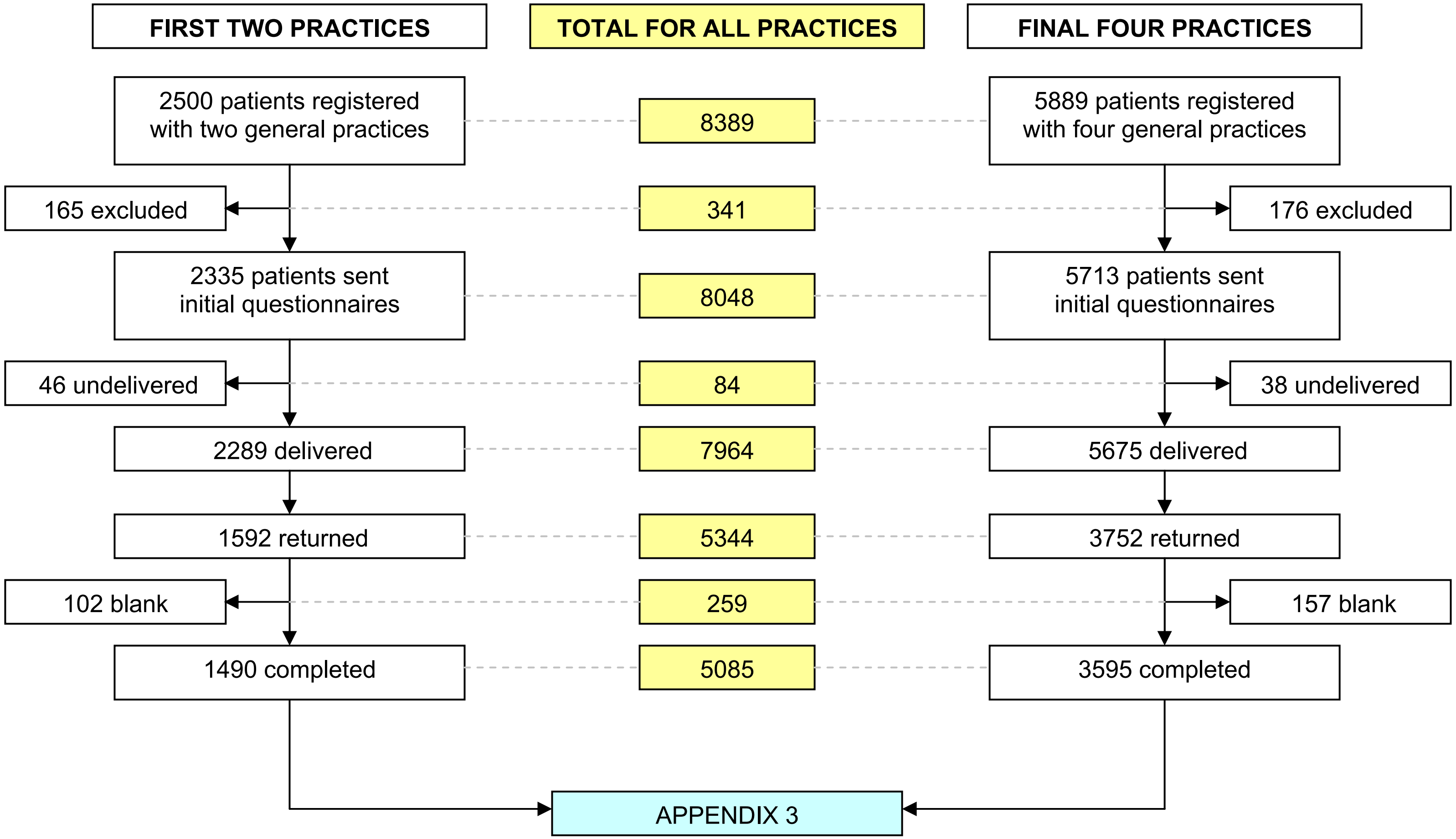
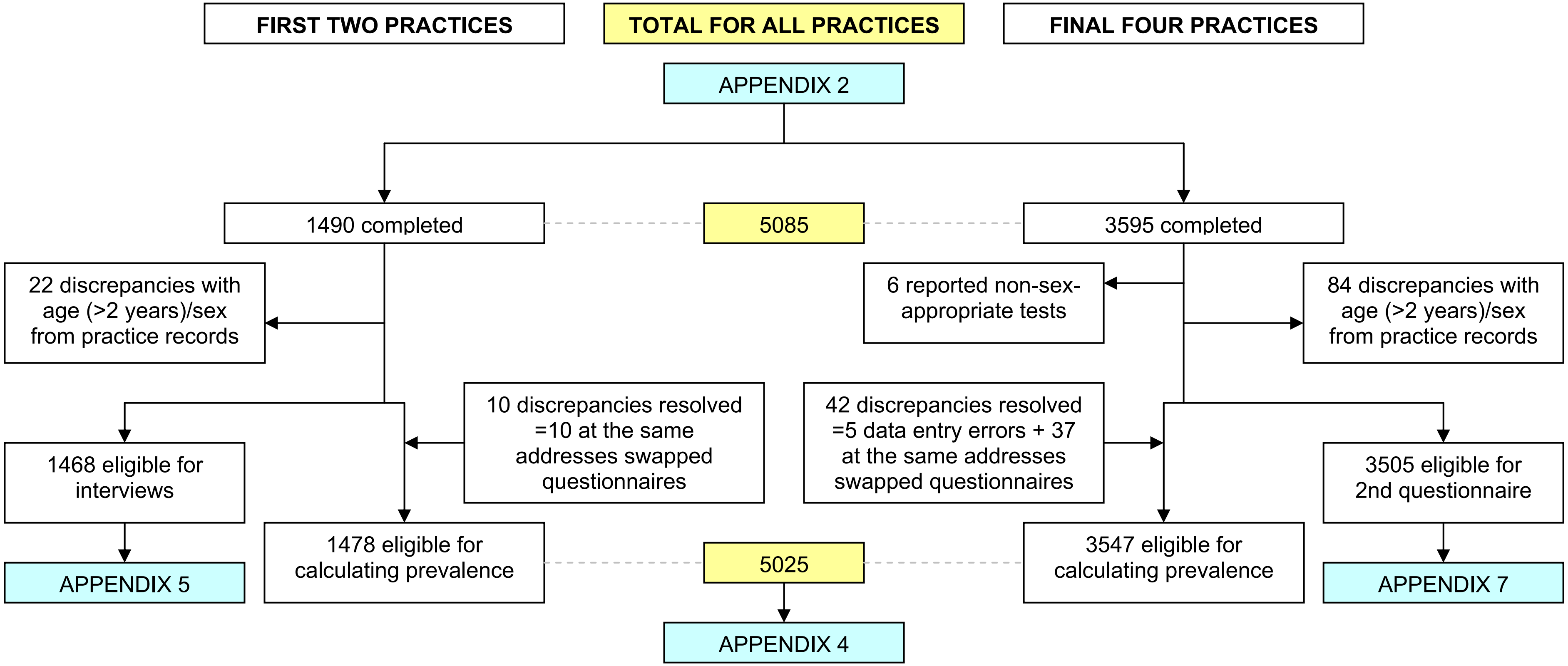
http://www.biomedcentral.com/1471-2458/6/193/prepub

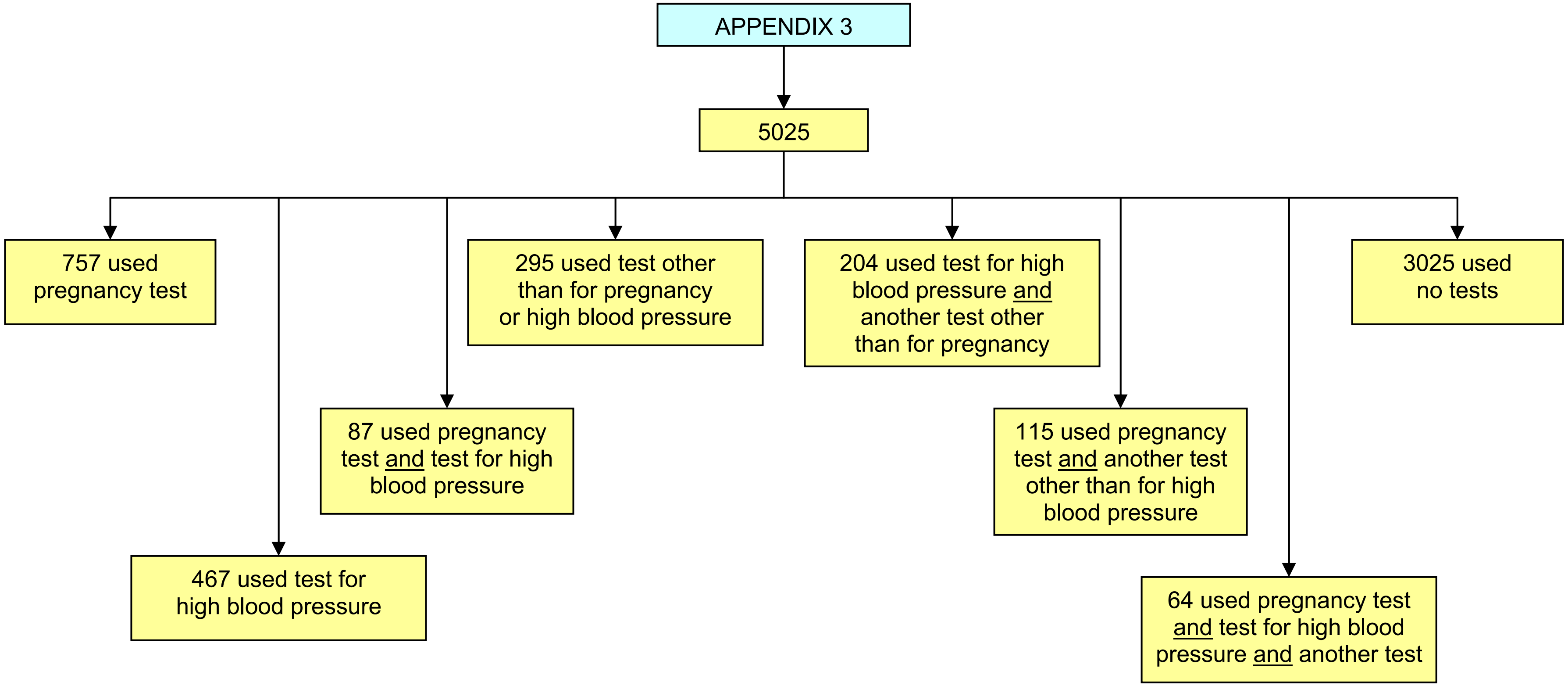
Appendix 2: Flow chart showing initial questionnaires sent out, undelivered and delivered, and returned blank and completed



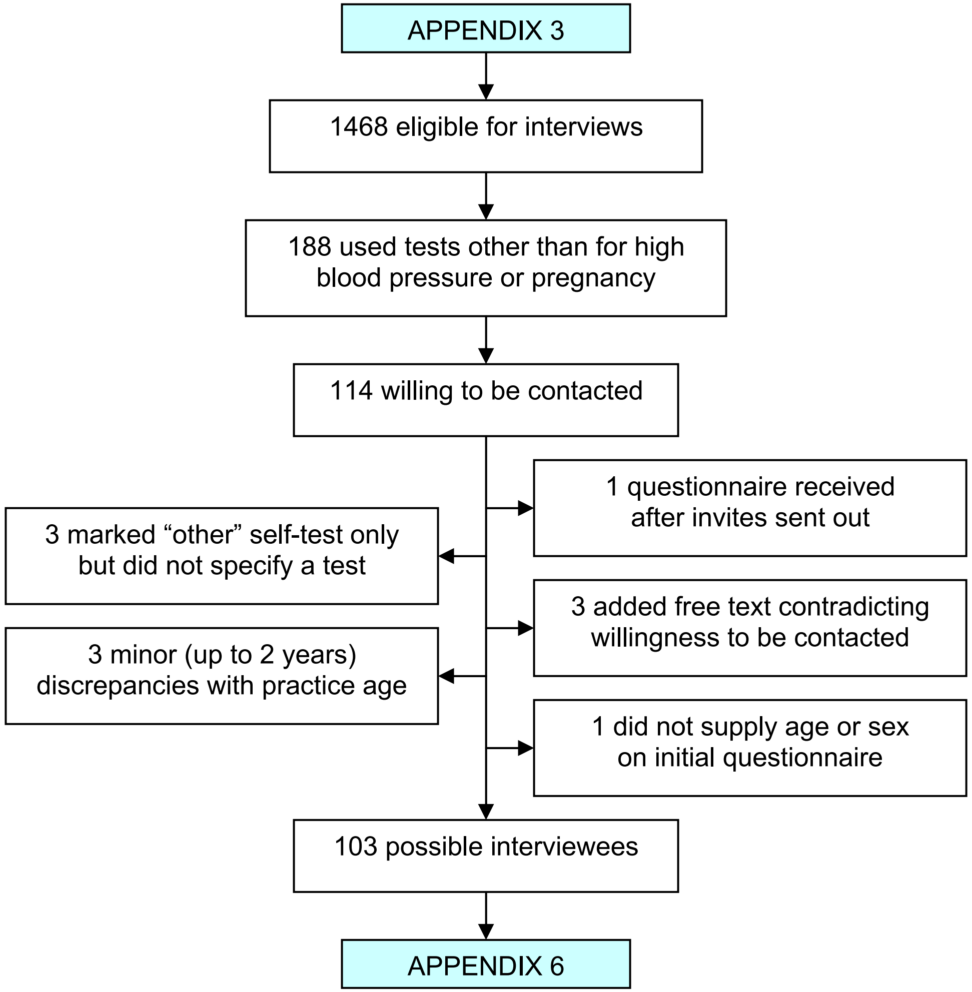
Appendix 3: Flow chart showing initial questionnaires that were completed and those that were then excluded, leading to samples of respondents who were eligible for calculating an initial assessment of prevalence, interviews, and the second in-depth questionnaire



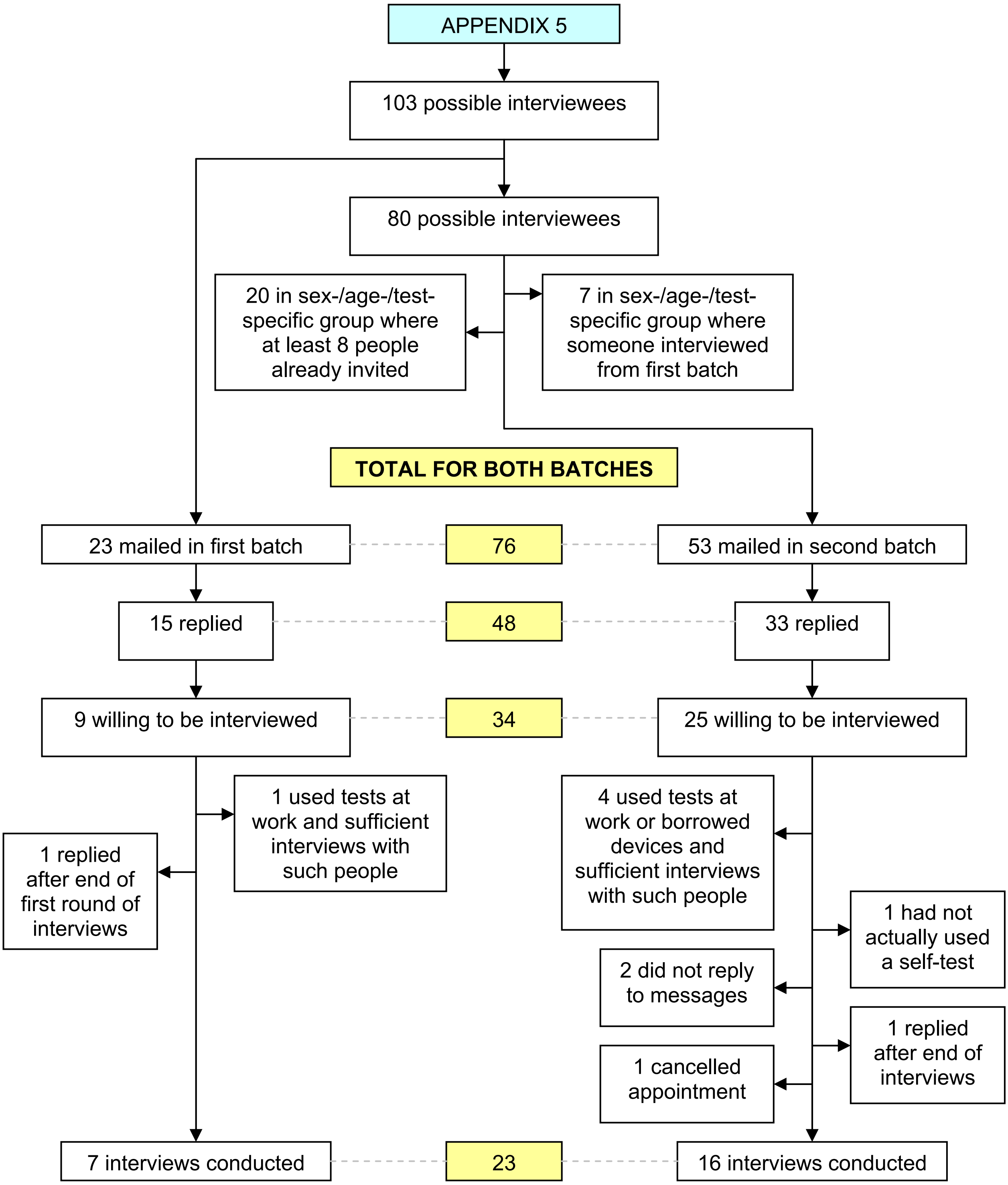
Appendix 4: Flow chart showing numbers of eligible respondents to the initial questionnaire who had used different types of tests



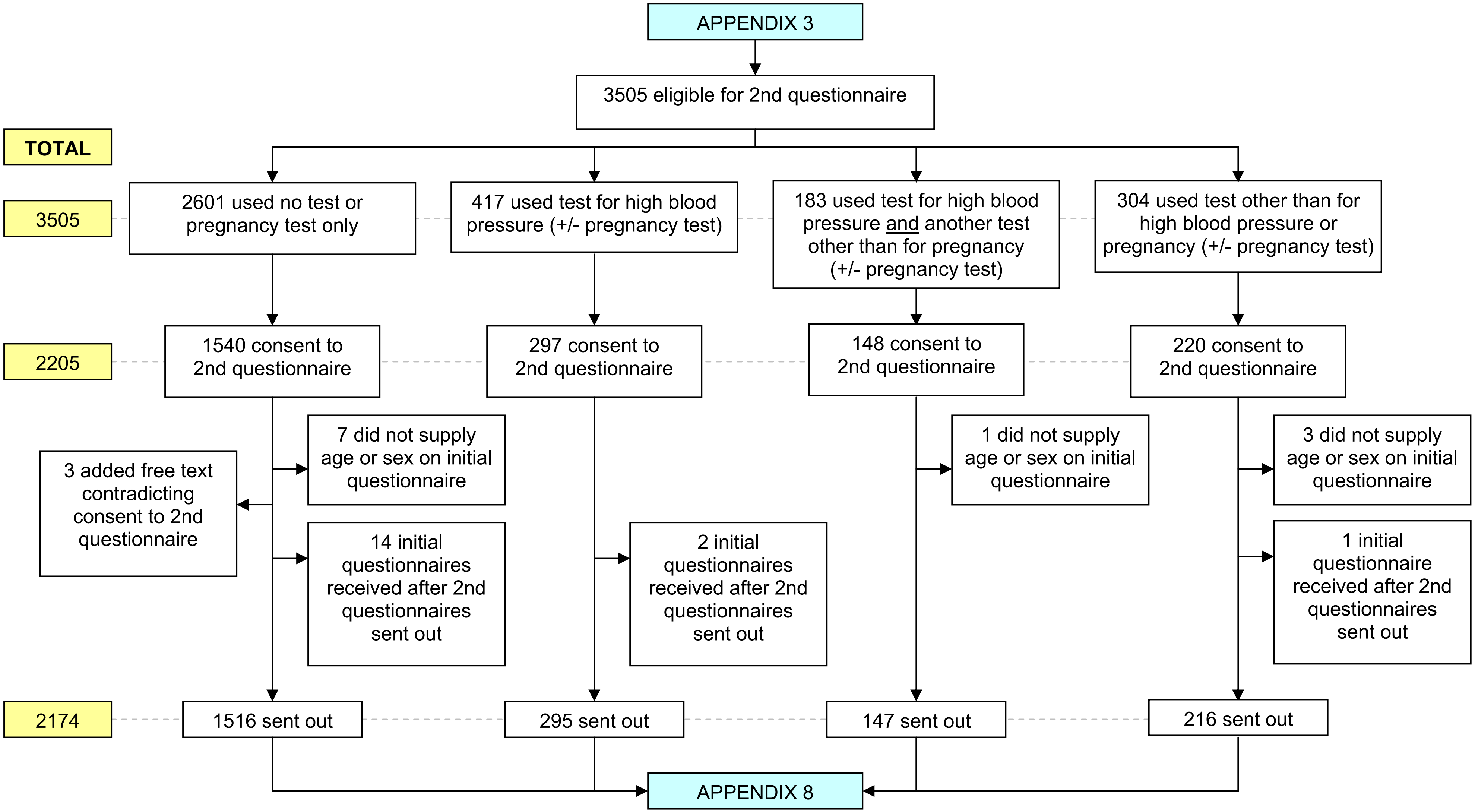
Appendix 5: Flow chart showing respondents to the initial questionnaire who were eligible for interviews, reported self-test use, were willing to be contacted, and were excluded, leaving possible interviewees



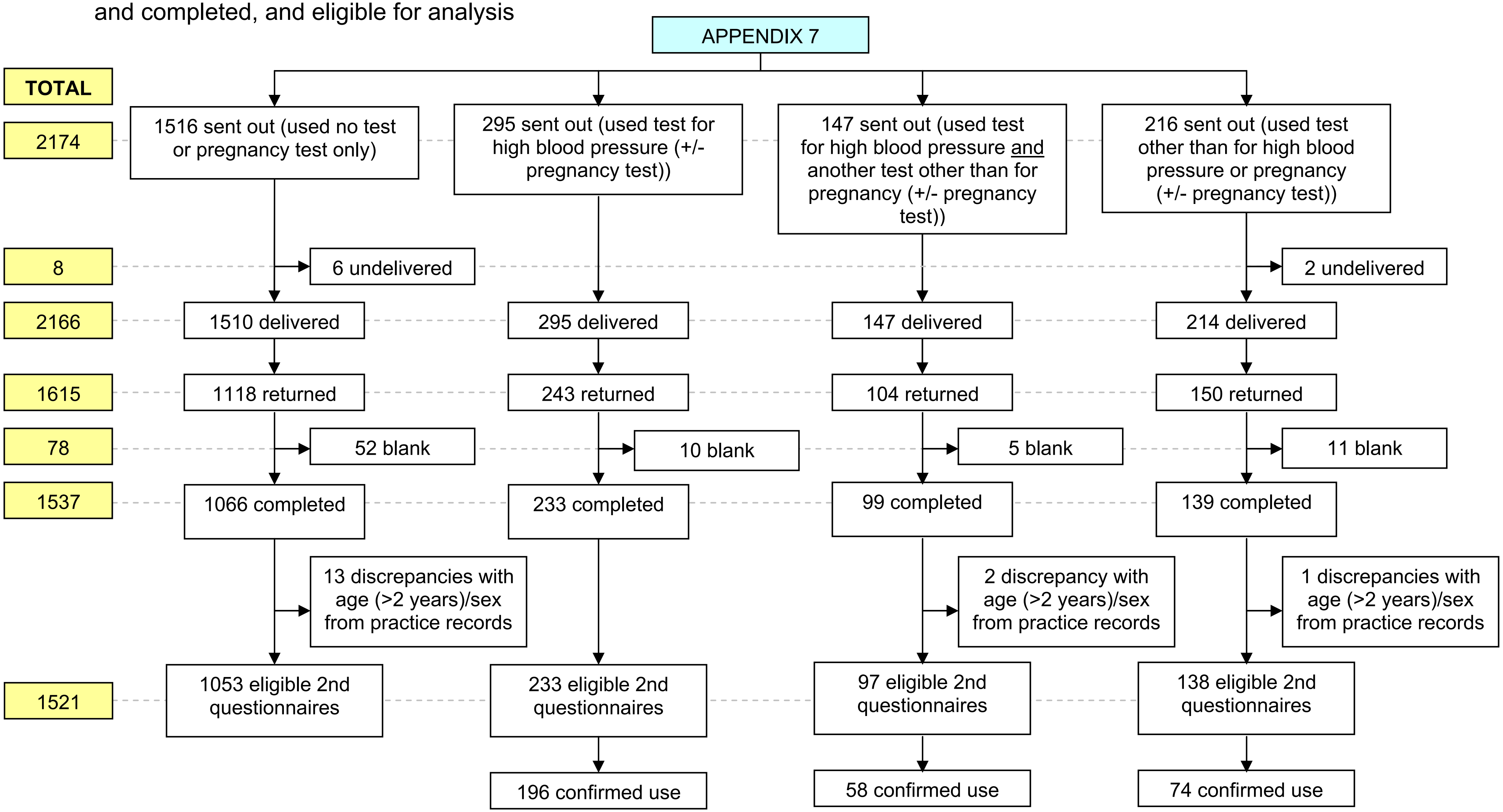
Appendix 6: Flow chart showing possible interviewees, those that were invited, those that were willing to be interviewed, and interviews that were conducted



Appendix 7: Flow chart showing respondents to the initial questionnaire who were eligible for the second in-depth questionnaire, those who consented, those that were excluded, and in-depth questionnaires that were sent out



Appendix 8: Flow chart showing in-depth questionnaires that were sent out, delivered and undelivered, returned blank and completed, and eligible for analysis



Appendix 9: Published paper for systematic internet search

Not available in the digital version of this thesis

Ryan A, Wilson S, Greenfield S, Clifford S, McManus RJ, Pattison HM.
Range of self-tests available to buy in the United Kingdom:
an Internet survey.
Journal of Public Health 2006, 28(4): 370-374.

http://dx.doi.org/10.1093/pubmed/fdl051

Appendix 10: Published paper for prevalence of self-test use

Not available in the digital version of this thesis

Ryan A, Wilson S, Greenfield S.
Prevalence of the use of self-tests by adults in the United Kingdom: a questionnaire survey.
Journal of Public Health 2010
http://dx.doi.org/10.1093/pubmed/fdq018

Appendix 11: Initial questionnaire

UNIVERSITY OF BIRMINGHAM

QUESTIONNAIRE

Study number

Use of medical self-tests by members of the public

SECTION 1: This section asks for some background information about you.

1 How old are you? **Please write your age in the box like this.** 59 **years**

[ ] **years**

2 What is your sex? **Please fill in one circle like this.** ●

- O **Male**
- O **Female**

3 What is your ethnic group? **Please fill in one circle.**

- O **White:** British, Irish, or any other
- O **Mixed:** White and Black Caribbean, White and Black African, White and Asian, or any other
- O **Asian or Asian British:** Indian, Pakistani, Bangladeshi, or any other
- O **Black or Black British:** Caribbean, African, or any other
- O **Chinese**
- O **Other**

4 Over the last twelve months would you say your health has on the whole been: **Please fill in one circle.**

- O **Good?**
- O **Fairly good?**
- O **Not good?**

5 What is your current employment status? **Please fill in circles for all the options that apply to you.**

- O **Employed**
- O **Self-employed**
- O **Looking for a job or waiting to start a job**
- O **Student in full-time education**
- O **Part-time student**
- O **Retired**
- O **Looking after home / family**
- O **Long-term sick / disabled**
- O **Other**

Please turn over to the next question.

SECTION 2: Have you ever used or would you ever use a self-test?

Self-tests are bought from shops or over the Internet. They are used to test for conditions or diseases **without** involving a doctor, nurse or other health professional.

Please fill in one circle in the first column and one circle in the second column for each self-test. If you are unhappy about answering the questions for any self-test, miss it out and go on to the next one.

	Have you used this self-test?			Would you use this self-test in the future?		
Self-test for:	Yes	No	Don't know	Yes	No	Don't know
Allergies	O	O	O	O	O	O
Blood in the stool (or bowel cancer or bowel disorders or bowel polyps)	O	O	O	O	O	O
Chlamydia	O	O	O	O	O	O
Cholesterol	O	O	O	O	O	O
Diabetes (or glucose or sugar in the blood or urine)	O	O	O	O	O	O
High blood pressure (or hypertension)	O	O	O	O	O	O
HIV (or AIDS)	O	O	O	O	O	O
Kidney disorders (or kidney damage or kidney failure)	O	O	O	O	O	O
Low blood count (or anaemia)	O	O	O	O	O	O
Menopause (or follicle stimulating hormone levels or FSH levels or falling fertility)	O	O	O	O	O	O
Pregnancy	O	O	O	O	O	O
Prostate disorders (or prostate cancer or prostate specific antigen or PSA)	O	O	O	O	O	O
Sperm count (or sperm concentration)	O	O	O	O	O	O
Urine infection (or cystitis or bladder infection)	O	O	O	O	O	O
Vaginal infection (or vaginal discharge)	O	O	O	O	O	O
Other - please state___________________	O	O	O	O	O	O

SECTION 3: May we contact you again?

We would like to send a more detailed questionnaire about self-testing to some people. May we send you another questionnaire? **Please fill in one circle.** We will only contact some of the people who say **yes**.

O **Yes**

O **No**

Thank you. Please return this questionnaire in the PREPAID envelope provided.

If you have any questions about the study, please contact Angela Ryan at the University of Birmingham on 0121 415 8015.

Appendix 12: Letter asking general practices to participate in the study

Contact: Angela Ryan
Telephone: 0121 415 8015
Fax: 0121 414 6571
Email: a.v.ryan@bham.ac.uk

UNIVERSITY OF BIRMINGHAM

School of Medicine

Division of Primary Care,
Public and Occupational Health

Department of Primary Care
and General Practice

Head of Department
Professor of Primary Care
and General Practice
Richard Hobbs FRCGP

30 July 2010

Dear Dr «M_02_Surname»,

Use of medical self-tests by members of the public

We are working on a study about "self-testing" and would like to ask for your practice's assistance.

Self-testing is where a member of the public buys a test to see if they may have a condition or disease without involving a doctor, nurse or other health professional. A wide range of self-tests are now available, for example for chlamydia, prostate specific antigen and faecal occult blood. This study aims to determine the prevalence of their use and factors that are associated with using them.

The Department of Health is funding the study, and Solihull Local Research Ethics Committee and your PCT R&D Department have approved it. We would be very grateful if your practice would consider being involved. Reimbursement of practice time would be available.

A copy of the study protocol is enclosed but the stages of the study in which your practice would be involved are:

- An initial short questionnaire (sample copy enclosed with this letter) is sent to a sample of adults. This collects basic sociodemographic information and whether the person has used or would use currently available self-tests.
- A more detailed questionnaire about self-testing is then sent to people who have said that they are willing to receive another questionnaire and who have (cases) or have not (controls) used a self-test. Their responses will establish those factors that are associated with the use of self-tests.

Your practice's involvement would be:

- To provide a list of adults aged 18 years or over.
- To check this list so that people who it would be inappropriate for us to send a questionnaire to, for example because of a terminal illness, severe mental illness or recent bereavement, could be excluded.

The initial questionnaire would be accompanied by a cover letter with your practice letterhead (sample copy enclosed with this letter). We could come into your practice to do this mailing, or we could take the list to the University, where it would be held securely, and send the questionnaires from there. We would send one reminder letter in a similar way.

We would be very grateful if you would complete the enclosed slip and return it in the enclosed PREPAID envelope to indicate if your practice would consider being involved. No stamp is needed.

We would be pleased to discuss your involvement by telephone or in person, and please also telephone or email us if you have any immediate questions about the study.

Thank you for your time and consideration in helping with this research.

Yours sincerely,

Angela Ryan
Clinical Research Fellow

Sue Wilson
Professor of Clinical Epidemiology

Screening Team Primary Care Clinical Sciences Building University of Birmingham
Edgbaston Birmingham B15 2TT United Kingdom
www.pcpoh.bham.ac.uk/primarycare

Appendix 13: Reply slip for general practices

Contact: Angela Ryan
Telephone: 0121 415 8015
Fax: 0121 414 6571
Email: a.v.ryan@bham.ac.uk

UNIVERSITY OF BIRMINGHAM
School of Medicine
Division of Primary Care, Public and Occupational Health
Department of Primary Care and General Practice
Head of Department
Professor of Primary Care and General Practice
Richard Hobbs FRCGP

Practice code: «Practice_Code»

REPLY SLIP

Use of medical self-tests by members of the public

Would you be willing for the Department of Primary Care and General Practice at the University of Birmingham to contact you about your practice being involved in this study?

Please tick one box.

☐ **YES**, we are happy to take part in the study.

☐ **YES**, but we would like to discuss the study in more detail by telephone before we decide whether to take part.

☐ **YES**, but we would like a practice visit to discuss the study in more detail before we decide whether to take part.

☐ **NO**, we do not wish to take part in the study.

If **YES**, please provide the following information so that we can contact you.

What is the **name** of the person we should contact? ______________________________

What is the **position** of this person? ______________________________

What is his / her **email address**? ______________________________

What is his / her **telephone number**? ______________________________

What is the **best day and time to telephone**? ______________________________

Thank you for your time.

Please return the completed reply slip in the PREPAID envelope. No stamp is needed.

If you have said your practice may be willing to be involved, we will contact you in the near future.

Screening Team Primary Care Clinical Sciences Building University of Birmingham
Edgbaston Birmingham B15 2TT United Kingdom
www.pcpoh.bham.ac.uk/primarycare

Appendix 14: Covering letter for initial questionnaire

Insert letterhead of general practice

Use of medical self-tests by members of the public

Insert date

Dear «Title» «Surname»,

I am working with the Department of Primary Care and General Practice at the University of Birmingham on a research study about "self-testing". Self-testing is where a member of the public, like yourself, buys a test to see if they may have a condition or disease without involving a doctor, nurse or other health professional, similar to a home pregnancy test.

We are writing to people from the practice to ask for their help with the study. **We would be very grateful if you would complete the enclosed short questionnaire and return it to the University in the enclosed PREPAID envelope. No stamp is needed.**

We want to understand how and why people use self-tests so that we can prepare health services to care for people who have used them. This questionnaire will help by telling us how many people have used or would use a self-test. **Your response is important to us whether or not you have ever used a self-test.**

It should only take 10 minutes to complete the questionnaire. Most of the questions just ask you to mark one of the answers. Your answers will be confidential and any information that you provide will only be seen by the research team, but please leave out any question that you feel unhappy about answering. During the study, your contact details would be kept on a secure database at the University in accordance with the Data Protection Act 1998. They would then be deleted.

We would like to ask some of the people who return this questionnaire to complete a more detailed questionnaire about self-testing. If you say on the questionnaire that you may be willing to receive another questionnaire and you are selected, this will be sent to you by the research team at the University of Birmingham in the next few weeks.

Even if you do not want us to contact you again about the study, we would be very grateful if you would complete and return this questionnaire. If you do not wish to take part in the study, you can let us know by sending back the blank questionnaire in the PREPAID envelope.

Thank you for your time and consideration in helping with this research. If you have any questions or concerns about the study, please contact Dr Angela Ryan in the Department of Primary Care and General Practice at the University of Birmingham on 0121 415 8015.

Yours sincerely,

Insert signature

Insert name

More information about the study is available at
http://www.pcpoh.bham.ac.uk/primarycare/research/Screening/selftesting.htm.

Appendix 15: Reminder letter for initial questionnaire

Insert letterhead of general practice

Use of medical self-tests by members of the public

Insert date

Dear «Title» «Surname»,

You may remember receiving a letter from me about a research study on "self-testing", which I am working on with the Department of Primary Care and General Practice at the University of Birmingham. Self-testing is where a member of the public, like yourself, buys a test to see if they may have a condition or disease without involving a doctor, nurse or other health professional, similar to a home pregnancy test.

We are writing to people from the practice to ask for their help with the study, and we would like to ask again if you would consider completing and returning the short questionnaire about self-testing. **Another copy of the questionnaire is enclosed, and we would be very grateful if you would complete and return it to the University in the enclosed PREPAID envelope. No stamp is needed.** Please disregard this letter if it has crossed in the post with your returned questionnaire.

We want to understand how and why people use self-tests so that we can prepare health services to care for people who have used them. This questionnaire will help by telling us how many people have used or would use a self-test. **Your response is important to us whether or not you have ever used a self-test.**

It should only take 10 minutes to complete the questionnaire. Most of the questions just ask you to mark one of the answers. Your answers will be confidential and any information that you provide will only be seen by the research team, but please leave out any question that you feel unhappy about answering. During the study, your contact details would be kept on a secure database at the University in accordance with the Data Protection Act 1998. They would then be deleted.

We would like to ask some of the people who return this questionnaire to complete a more detailed questionnaire about self-testing. If you say on the questionnaire that you may be willing to receive another questionnaire and you are selected, this will be sent to you by the research team at the University of Birmingham in the next few weeks.

Even if you do not want us to contact you again about the study, we would be very grateful if you would complete and return this questionnaire. If you do not wish to take part in the study, you can let us know by sending back the blank questionnaire in the PREPAID envelope.

Thank you for your time and consideration in helping with this research. If you have any questions or concerns about the study, please contact Dr Angela Ryan in the Department of Primary Care and General Practice at the University of Birmingham on 0121 415 8015.

Yours sincerely,

Insert signature

Insert name

More information about the study is available at
http://www.pcpoh.bham.ac.uk/primarycare/research/Screening/selftesting.htm.

Appendix 16: Published paper for interview survey

Not available in the digital version of this thesis

Ryan A, Ives J, Wilson S, Greenfield S.
Why members of the public self-test: an interview study.
Family Practice 2010; 27(5): 570-581.
http://dx.doi.org/10.1093/fampra/cmq043

Appendix 17: Covering letter for invite to interviews

Contact: Angela Ryan
Telephone: 0121 415 8015
Fax: 0121 414 6571
Email: a.v.ryan@bham.ac.uk

UNIVERSITY OF BIRMINGHAM

School of Medicine

Division of Primary Care,
Public and Occupational Health

Department of Primary Care
and General Practice

Head of Department
Professor of Primary Care
and General Practice
Richard Hobbs FRCGP

«Title» «Prefer» «Surname»
«Expr1»
«Expr2»
«Expr3» «Expr4»

Use of medical self-tests by members of the public

11 June 2010

Dear «Title» «Surname»,

You kindly completed a questionnaire about "self-testing" and returned it to the Department of Primary Care at the University of Birmingham a few months ago. You said on your questionnaire that you may be willing to talk with a researcher about your views and experiences of self-tests, and we would like to ask if you would consider taking part in an interview.

We would be very grateful if you would read the enclosed information leaflet, which gives some more information about the study and about talking with a researcher in an interview. It is then up to you to decide whether you would like to do so.

Please say on the enclosed reply slip if you would or would not like to take part in an interview. Please return the reply slip in the enclosed PREPAID envelope. No stamp is needed. If you say that you would like to take part in an interview, we will contact you in the near future to arrange a convenient date, time and place.

If you do not want to take part in an interview but would be willing to receive a longer questionnaire, please also say so on the reply slip. If you do not want to talk with a researcher in an interview or receive a longer questionnaire, please say so on the reply slip and we will not contact you again.

Thank you for your time and consideration in helping with this research. Please contact me on 0121 415 8015 if you have questions or concerns about the study.

Yours sincerely,

Dr Angela Ryan
Clinical research fellow

Screening Team Primary Care Clinical Sciences Building University of Birmingham
Edgbaston Birmingham B15 2TT United Kingdom
www.pcpoh.bham.ac.uk/primarycare

Appendix 18: Information leaflet for interviews

Contact: Angela Ryan
Telephone: 0121 415 8015
Fax: 0121 414 6571
Email: a.v.ryan@bham.ac.uk

UNIVERSITY OF BIRMINGHAM
School of Medicine
Division of Primary Care, Public and Occupational Health
Department of Primary Care and General Practice
Head of Department
Professor of Primary Care
and General Practice
Richard Hobbs FRCGP

Information leaflet

Version 1 05/07/06

Interviews about the use of medical self-tests by members of the public

You are being asked to talk with a researcher in an "interview".

Before you decide, it is important for you to understand why we are doing this research and what it will involve. Please take some time to read the following information carefully and discuss it with others if you wish. It will explain why we are doing this study, what your involvement would be and hopefully answer many of the questions that you may have at this stage.

What is self-testing?

Self-testing is where a member of the public uses a test or kit, bought from a chemist, supermarket or over the internet, to see if they may have a condition or a disease, and where they can get the result without having to talk to a doctor, nurse or other health professional.

With some self-tests, you get the test result immediately, similar to a pregnancy test, but with some self-tests you send a sample to a laboratory and the results are returned to you.

What is the purpose of this study?

The purpose of this study is to find out more about the use of self-tests. We want to understand how and why people use these self-tests so that we can advise people about how best to use them, and so that we can prepare health professionals and health services to care for people who may have used them.

Why have I been chosen?

We sent a short questionnaire to adults registered at your doctor's surgery. You kindly returned this questionnaire and said that you may be willing to talk with a researcher.

We would like to talk to some people to collect more detailed information about why they may have used or not used self-tests. This will help us to design a longer questionnaire about self-tests. We will then send this longer questionnaire to people who said that they may be willing to complete it.

What would taking part in an interview involve?

We are asking you to take part in an "interview". This involves talking with a researcher on a one-to-one basis.

The interview could be done at your home if that is acceptable and convenient for you, or we could arrange for the interview to take place in another location that is convenient for you. The interview should not take more than an hour.

At the beginning of the interview, the researcher would discuss the study and answer any questions. If you were happy to continue and take part, the researcher would ask you to sign a consent form.

The researcher would then ask you questions about self-tests and listen to your answers about your views and experiences. We would not ask you to do anything else. The conversation would be tape-recorded so that we would not forget what had been said.

If you decided to take part in an interview, we would not also ask you to complete the longer questionnaire.

Please turn over to the next page.

What are the benefits to me?

There are no direct benefits to you in helping us with this research. We hope that the information we get from this study will help us provide better information to the public about self-tests and identify any gaps in current NHS services.

What will happen to the information?

The tape recording of the interview will be typed up and used to help us design a longer questionnaire about self-tests. We will then ask other people who said that they may be willing to help us further with the study to complete this questionnaire.

If you decided to take part in an interview, we would not also ask you to complete the longer questionnaire that we will design after the interviews.

All the information we collect (for example questionnaires and typed-up interviews) will be stored at the University. We keep all information securely in locked filing cabinets and on password-protected computers in locked offices.

What information will I receive after the interview?

You will receive a summary of the interview, and we will ask you to feedback whether you think that the summary adequately reflects what was said.

When we have completed the study, we will let your doctor's surgery have a summary of the results for display. We will make sure that it is not possible to identify any individual from any summary, presentation or publication of the results of the study.

Who is organising and funding the research?

The study is being organised by researchers from the University of Birmingham. The study is being funded by a grant from the Department of Health.

Who has reviewed the study?

Solihull Local Research Ethics Committee have reviewed the design of the study and approved this research.

What if something goes wrong?

If you wish to complain or have any concerns about any aspect of the way you have been approached or are treated during this study, you can contact the lead researcher, Dr Sue Wilson, on 0121 414 7397. The normal NHS mechanisms are also available to you.

What happens now?

It is up to you to decide whether to take part in an interview. If you decide to take part, you are still free to withdraw at any time without giving a reason. A decision not to take part or to withdraw at any time will not affect the standard of care that you receive from your doctor or anyone else.

Please say on the enclosed reply slip if you would or would not like to take part in an interview. If you say that you would like to take part in an interview, we will contact you in the near future to arrange a convenient date, time and place.

If you do not want to take part in an interview but would be willing to receive the longer questionnaire, please also say so on the reply slip.

If you do not want to talk with a researcher in an interview or receive the longer questionnaire, please say so on the reply slip and we will not contact you again.

Please return the reply slip in the enclosed **PREPAID** envelope. **No stamp is needed.**

Thank you for your time and consideration.

Screening Team Primary Care Clinical Sciences Building University of Birmingham
Edgbaston Birmingham B15 2TT United Kingdom
www.pcpoh.bham.ac.uk/primarycare

Appendix 19: Reply slip for interviews

Study number «Study_number»

Contact: Angela Ryan
Telephone: 0121 415 8015
Fax: 0121 414 6571
Email: a.v.ryan@bham.ac.uk

UNIVERSITY OF BIRMINGHAM

School of Medicine

Division of Primary Care, Public and Occupational Health

Department of Primary Care and General Practice

Head of Department
Professor of Primary Care and General Practice
Richard Hobbs FRCGP

REPLY SLIP

Interviews about the use of medical self-tests by members of the public

Would you be willing for a researcher from the Department of Primary Care at the University of Birmingham to contact you about taking part in an interview?

Please tick one box.

☐ **YES**, I would be willing for a researcher from the Department of Primary Care at the University of Birmingham to contact me about taking part in an interview.

☐ **NO**, I do not want to take part in an interview, but I would be willing to receive the longer questionnaire that is designed after the interviews.

☐ **NO**, I do not want to take part in an interview or receive the longer questionnaire.

If **YES**, please provide the following information so that we can contact you to arrange a suitable date, time and place for the interview.

My name is: ____

My telephone number is: ____

Thank you for your time.

Please return the completed reply slip in the PREPAID envelope. No stamp is needed.

If you have said you would be willing to take part in an interview, a researcher from the University of Birmingham will contact you in the near future.

Screening Team Primary Care Clinical Sciences Building University of Birmingham
Edgbaston Birmingham B15 2TT United Kingdom
www.pcpoh.bham.ac.uk/primarycare

Appendix 20: Consent form for interviews

Contact: Angela Ryan
Telephone: 0121 415 8015
Fax: 0121 414 6571
Email: a.v.ryan@bham.ac.uk

UNIVERSITY OF BIRMINGHAM

School of Medicine
Division of Primary Care, Public and Occupational Health
Department of Primary Care and General Practice

Head of Department
Professor of Primary Care and General Practice
Richard Hobbs FRCGP

Consent Form

For interviews about the use of medical self-tests by members of the public

		Researcher: Please initial each section.	**Participant:** Please initial each section.
1.	I confirm that I have read and understood the information sheet dated 05/07/06, Version 1, about interviews for the above study, and that I have had the opportunity to ask questions.		
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected.		
3.	I agree to take part in the above study, and I consent to take part in an interview for the above study.		
4.	I agree to the interview being tape-recorded, and I understand that the tapes will be held at the University of Birmingham.		

Name of participant (please print)	**Date**	**Signature**

Name of researcher (please print)	**Date**	**Signature**

Screening Team Primary Care Clinical Sciences Building University of Birmingham
Edgbaston Birmingham B15 2TT United Kingdom
www.pcpoh.bham.ac.uk/primarycare

Appendix 21: Reply slip for respondent validation by interviewees

Contact: Angela Ryan
Telephone: 0121 415 8015
Fax: 0121 414 6571
Email: a.v.ryan@bham.ac.uk

UNIVERSITY OF BIRMINGHAM

School of Medicine

Division of Primary Care,
Public and Occupational Health

Department of Primary Care
and General Practice

Head of Department
Professor of Primary Care
and General Practice
Richard Hobbs FRCGP

11 June 2010

Dear «Title» «Surname»,

Use of medical self-tests by members of the public

You kindly took part in an interview with me on «Appt_date». I enclose a short summary of what I think were the main points of the interview, and I would be very grateful if you would use the slip below to let me know whether you think that this reflects what you said and to add anything. Please return the slip in the enclosed PREPAID envelope.

Thank you very much again for taking part in the interview. Your input has been very valuable.

Yours sincerely,

Dr Angela Ryan
Clinical research fellow

Screening Team Primary Care Clinical Sciences Building University of Birmingham
Edgbaston Birmingham B15 2TT United Kingdom
www.pcpoh.bham.ac.uk/primarycare

✄---

«Title» «Prefer» «Surname» Study number «Study_number»

Do you think that the summary reflects what you said? **Please circle YES or NO.** **YES / NO**

Please add any comments:____

____

____

____

____

____

____

____

Appendix 22: Topic guide for interviews

Topic guide for interviews

Start the tape recorder.

- So I've turned on the tape recorder, and we'll start the interview.
- I wanted to start with **how we described self-tests on the questionnaire**. We said:

  Self-tests are bought from shops or over the Internet. They are used to test for conditions or diseases without involving a doctor, nurse or other health professional.

  - How easy or difficult did you find understanding this?
  - Did you have any questions about what we meant when you read it?
- I wanted to go over **what self-tests you have used.**
- I wanted ask about **how you found out about and decided to use this self-test(s)**.
  - How did you find out about this self-test?
  - Did anything happen that lead to you deciding to do the self-test? What?
  - Did you speak to anyone else before deciding to do the self-test? Who and why?
  - Did you do any other research before deciding to do the self-test? What and why?
  - Why did you do a self-test rather than something else, like going to your GP?
  - What do you think are the pros and cons of a self-test compared with going to your GP?
- I wanted to ask about **when you bought the self-test(s)**.
  - Where did you buy the self-test?
  - How did you find buying the self-test?
  - Do you think the self-test was good value?
- I wanted to ask about **how you found doing the self-test(s)**.
  - Where did you do the self-test?
  - How did you find doing the self-test?
  - Did you ask anyone else's advice about how to do it? Who and why?
- I wanted to ask about **getting the result of the self-test(s)**.
  - What was the result of the self-test?
  - How sure were you about the result?
  - Did you ask anyone else's opinion of the result? Who and why?
  - What did you do after you got the result?
- That's all my questions.
  - So I think **the main points are**:
  - Is there **anything else you would like to add?**

Stop the tape recorder.

- Are you happy for me to use this recording?
- Thank you. That's been very useful. I'll send you a summary of the discussion in the next couple of weeks, and I'd be grateful if you could read it over, and use the reply slip to let me know if you are happy that it reflects what we said.

Appendix 23: Published paper for systematic literature review

BMC Public Health

BioMed Central

Research article

Open Access

Factors associated with self-care activities among adults in the United Kingdom: a systematic review

Angela Ryan, Sue Wilson*, Aliki Taylor and Sheila Greenfield

Address: Department of Primary Care and General Practice, The University of Birmingham, Edgbaston, Birmingham, B15 2TT, UK

Email: Angela Ryan - a.v.ryan@bham.ac.uk; Sue Wilson* - s.wilson@bham.ac.uk; Aliki Taylor - a.j.taylor@bham.ac.uk; Sheila Greenfield - s.m.greenfield@bham.ac.uk

* Corresponding author

Published: 5 April 2009

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Received: 22 July 2008
Accepted: 5 April 2009

This article is available from: http://www.biomedcentral.com/1471-2458/9/96

Abstract

Background: The Government has promoted self-care. Our aim was to review evidence about who uses self-tests and other self-care activities (over-the-counter medicine, private sector, complementary and alternative medicine (CAM), home blood pressure monitors).

Methods: During April 2007, relevant bibliographic databases (Medline, Embase, Cumulative Index to Nursing and Allied Health Literature, Applied Social Sciences Index and Abstracts, PsycINFO, British Nursing Index, Allied and Complementary Medicine Database, Sociological Abstracts, International Bibliography of the Social Sciences, Arthritis and Complementary Medicine Database, Complementary and Alternative Medicine and Pain Database) were searched, and potentially relevant studies were reviewed against eligibility criteria. Studies were included if they were published during the last 15 years and identified factors, reasons or characteristics associated with a relevant activity among UK adults. Two independent reviewers used proformas to assess the quality of eligible studies.

Results: 206 potentially relevant papers were identified, 157 were excluded, and 49 papers related to 46 studies were included: 37 studies were, or used data from questionnaire surveys, 36 had quality scores of five or more out of 10, and 27 were about CAM. Available evidence suggests that users of CAM and over-the-counter medicine are female, middle-aged, affluent and/or educated with some measure of poor health, and that people who use the private sector are affluent and/or educated.

Conclusion: People who engage in these activities are likely to be affluent. Targeted promotion may, therefore, be needed to ensure that use is equitable. People who use some activities also appear to have poorer measures of health than non-users or people attending conventional services. It is, therefore, also important to ensure that self-care is not used as a second choice for people who have not had their needs met by conventional services.

Background

Self-care is "the care taken by individuals towards their own health and well being [1]. The Government has promoted self-care on the basis that the public favour more control over their health [1] and self-care improves health outcomes and appropriate use of health and social care services [2].

Diagnostic self-tests for over 20 conditions can be bought in pharmacies or over the internet [3]. Some provide results at home or a sample is sent to a laboratory and results are returned by post or email. Either way, people who self-test do not need to discuss why they decided to have the test or the results with a clinician. Members of the public may consider that using self-tests is self-care and, therefore, desirable, but direct access to self-tests has the potential to reduce or reinforce inequity. People who can afford a test may simply wish to check on their health, for example with a home cholesterol test, and this could free up conventional services for other people. Alternatively, people who are unable to communicate their needs to a health professional could buy expensive and perhaps undesirable tests for home use. It is, therefore, important to understand who uses self-tests so that targeted education about appropriate testing can be provided and equitable access to corresponding conventional services can be assured. Our aim was to generate hypotheses about who uses self-tests by reviewing evidence for factors that are associated with self-testing and, because of a lack of evidence about self-tests, similar activities.

Methods

Scope of the review

Other than self-testing, activities under review were use of over-the-counter (OTC) medicine, private care, complementary and alternative therapies (CAM), and home blood pressure (BP) monitors. These were chosen because they can be initiated without the involvement or recommendation of a conventional health professional and this is a defining feature of self-testing. Furthermore, they usually necessitate the user taking an active role, for example visiting a pharmacy, similar to buying a self-test. The review was restricted to studies about the United Kingdom (UK) because use of these activities is likely to be related to the accessibility of the health care system. The review was also restricted to studies published in the last 15 years because the availability of the activities will have altered as fashions and technologies have changed.

Search strategy

A search strategy was designed for each activity: for example, to look for studies about self-test use, titles of papers were searched for the terms "self diagnos$" or "self test$" or "home test$" or "home diagnos$", where $ denotes truncated terms. This was then adapted for each database (table 1): for example, databases where MeSH headings are assigned to papers were searched using appropriate headings, such as "self medication" to look for studies about OTC medicine use. Searches were conducted during April 2007, but Medline was searched again in July 2008 for more recently published papers about self-testing.

Where many papers were returned, searches were refined with filters to identify appropriate study designs: for example, titles were searched for terms such as "factor$" or "characteristic$", and databases where MeSH headings are assigned were searched using headings such as "Epidemiologic Studies" or "Health Surveys". Filters to identify studies conducted in the UK were also used: the title, abstract, institution and country of publication were searched for "UK", "United Kingdom", "GB", "Britain" and the constituent countries. Finally, where possible, searches were limited to studies involving humans, written in the English language, and published from 1993 to 2007. As studies related to private care could have been published in economic as well as medical journals, The Journal of Health Economics, The Journal of Public Economics and The Economic Journal were hand-searched. References of eligible papers were also reviewed.

Inclusion and exclusion criteria

Abstracts of potentially relevant studies were reviewed. Where it was unclear whether the study was eligible, the paper was retrieved and assessed. Studies were included if they were published during the last 15 years in a peer-reviewed journal and they reported factors, reasons or characteristics associated with a relevant activity among adults resident in the UK.

Studies were excluded if they did not concern a relevant activity or report factors, reasons or characteristics associated with an activity. Remaining studies were then excluded: if they did not involve adults or did not differentiate between children and adults; if they specified that the activity was initiated by a doctor or nurse; if they only studied intention or willingness to do an activity; if they involved people with specific conditions where the results would not be generalisable; or if they did not involve UK residents or differentiate between residents of the UK and other countries. Finally, reviews, letters or opinions were excluded, although reviews were retrieved so that relevant references could be identified.

Quality assessment

Proformas based on tools from the Critical Appraisal Skills Programme [4,5] were used. The quantitative proforma included questions about whether the results of the study were likely to be valid, for example whether the study population was recruited appropriately (additional file 1). The qualitative proforma included questions about

Table 1: Number of potentially relevant papers identified and number of these papers that were eligible by activity and database[a].

Subject	Complementary and alternative medicine (CAM)		Over-the-counter (OTC) medicine		Private care		Home blood pressure (BP) monitors		Self-tests		Total[b]	
Database	Inc.	Total	Inc.	Total	Inc.	Total	Inc.	Total	Inc.	Total	Inc.	Total
Medline	16	64	8	37	4	7	0	1	0	3	28	106
Embase	9	53	11	28	1	3	0	3	0	5	18	86
Cumulative Index to Nursing and Allied Health Literature	13	29	2	7	0	0	0	0	0	0	15	36
Applied Social Sciences Index and Abstracts	9	30	3	7	1	2	0	0	0	0	12	38
PsycINFO	8	20	3	8	1	2	0	0	0	0	12	29
British Nursing Index	4	30	0	4	0	1	0	0	0	0	4	35
Allied and Complementary Medicine Database	2	9	0	0	0	0	0	0	0	0	2	9
Sociological Abstracts	0	1	0	0	0	1	0	0	0	0	0	2
International Bibliography of the Social Sciences	1	1	0	4	0	0	0	0	0	0	1	5
References of other papers	3	3	1	1	2	2	0	0	0	0	6	6
Grey literature	1	1	0	0	0	0	1	1	0	0	2	2
Total[b]	30	135	15	62	7	13	1	4	0	5	49	206

[a]The Arthritis and Complementary Medicine Database and the Complementary and Alternative Medicine and Pain Database were also searched but no potentially relevant papers were identified.
[b]Totals may be less than the sum of the components because some papers were identified by different databases during searches related to more than one subject area: 193 papers were identified during searches related to one activity (122 related to CAM, 50 related to OTC medicine, 12 related to private care, four related to home BP monitors, and five related to self-testing) and 13 were identified during searches related to two activities (12 related to CAM and OTC medicine, and one related to CAM and private care).

Table 2: Reasons why potentially relevant papers were excluded.

	Complementary and alternative medicine	Over-the-counter medicine	Private care	Home blood pressure monitors	Self-tests	Total[a]
Study did not identify factors, reasons or characteristics associated with a relevant activity (1)	21	25	3	2	4	54
Study did not involve adults or differentiate between children and adults (2)	11	5	0	0	0	14
Activity was initiated by a conventional health professional (3)	2	0	0	0	0	2
Outcome was simply the intention or willingness to do an activity (4)	1	3	0	0	0	4
Study involved a selected population (5)	56	12	2	1	0	65
Study did not relate to UK residents (6)	8	1	1	0	0	10
Review, letter or opinion (7)	6	1	0	0	1	8
Total	105	47	6	3	5	157

[a] Totals may be less than the sum of the components because some papers were identified by different databases.

whether the study was likely to be rigorous and credible, for example whether the recruitment strategy was appropriate to the aims (additional file 2). Each paper was given a score out of ten by two reviewers with discrepancies resolved by discussion. Papers with scores of eight or more were termed high quality, papers with scores of more than five but less than eight were termed medium quality, and papers with scores of five or less were termed low quality. Low quality publications were included to give a complete picture and because such studies could indicate areas where higher quality research is needed. Another proforma was used to extract information from eligible papers.

Results

Two hundred and six potentially relevant papers were identified in April 2007: 49 were eligible (table 1) and 157 were excluded (table 2). Medline identified most (n = 28) eligible papers. Embase identified the next highest number (n = 18), but there was considerable overlap with Medline: adding Embase only identified three more papers, whereas the Applied Social Sciences Index and Abstracts and PsycINFO databases both identified five more papers.

Complementary and alternative medicine

Eligible papers

Thirty eligible papers were identified. Three were also identified in searches related to OTC medicine: one looked at practitioner-delivered and OTC treatments and the former results are presented in this section [6], whereas the other two did not make this distinction and all their results are discussed here [7,8]. Another paper was also identified in searches related to private care: the results are presented in this section as the study involved CAM patients [9]. This study and two others were reported across two papers [7,9-13], leaving 27 studies (additional file 3).

Eligible studies looked at different therapies, for example acupuncture [14] or alternative medicines not prescribed by a doctor [15], during different periods, for example ever [7,13] or currently [14]. One study involved interviews [16], one was a qualitative survey [17], three used questionnaires plus interviews [9,10,18,19], and one was a case note review [20]. Twenty one studies were questionnaire surveys, but only seven of them used population-based samples, for example people registered with general practices [11,12]. The remainder used selected samples, for example people visiting a practitioner [14].

One questionnaire survey had a high quality score [11,12], 18 had medium scores, and two had low scores [21,22]. Three qualitative studies had medium scores [16,17,19] and two had low scores [9,10,18].

Results

Using adjusted analyses, the high quality population-based survey found that being female was linked with visiting a CAM practitioner in the last three months [11,12], a medium quality population-based survey reported that taking non-prescribed alternative medicines was more likely in women than men [15], and another medium quality study found that lifetime CAM use was more likely among female than male GP attendees [7,13]. Although samples and analysis methods varied, 10 other studies reported a link between being female and CAM use [6,14,17,18,20,23-27].

Using adjusted analyses, the high quality population-based survey found that people aged 34–49 were most likely to consult a chiropractor or osteopath [11,12], and a medium quality survey found that past CAM use was more likely among GP attendees under 70 than older attendees [7,13]. Three medium quality population-based surveys used unadjusted analyses to show that use was most common among people aged 45–64 [6], 35–64 [24] and 45–54 [28], and another medium quality study described higher proportions of acupuncture patients being aged 35–64 than the general population [14]. Two medium quality surveys described that CAM users were most commonly aged 30–49 [23] and 35–44 [17], and another medium quality study described CAM patients as having a median age of about 45 [20]. A low quality population-based survey described a peak in use at age 45 [18]. Three further studies looked at age but compared people visiting CAM practitioners with GP and/or outpatient attendees [25,29,30].

Only three medium quality studies looked at ethnic origin. Using an adjusted analysis, one found that people of Black African origin were more likely than white people or people of South Asian origin to take non-prescribed alternative medicines [15]. Another reported that white students did not have a tradition of CAM use, although the analysis was limited by small numbers [19]. In contrast, the third found that most patients at a CAM hospital were white, although there was no comparison group [26].

Using population-based surveys and adjusted analyses, a high quality and a medium quality study found, respectively, that people from higher social classes were more likely to have visited a CAM practitioner in the past three months [11,12] or be taking non-prescribed alternative medicines [15] than other people. Using unadjusted analyses, two medium quality population-based surveys found that CAM use was more common among affluent than non-affluent groups [24,28], and another medium quality study reported that use was more common among GP attendees with higher incomes [7,13]. Two medium quality studies found that CAM patients had higher incomes [29] or occupational status [25] than GP patients, although again analyses were unadjusted. A further medium quality study described people visiting a Chinese medicine practitioner as having disposable income [20].

Three medium quality studies linked education and CAM use, although they all used unadjusted analyses. A population-based survey found that use was more likely among people who were older than younger when they left education [28]. Another found that use was more common among GP attendees with higher than lower educational attainment [7,13]. The third study found that CAM patients generally had a longer education than GP patients [31].

A link with poor health was supported by several studies. Using adjusted analyses, the high quality population-based survey found that people with a long-standing illness or who saw their GP more often were more likely to have seen a CAM practitioner recently than other people [11,12], and a medium quality study found that CAM patients were more likely than GP patients to have psychiatric morbidity [29]. Using unadjusted analyses, a low quality population-based survey found that CAM users had higher GP attendance rates and were more likely to have severe or chronic conditions than non-users [18], and two medium quality studies found that CAM patients were more likely than GP patients to have had a serious illness [30], chronic illness [30] and longer illness [30,32]. Two medium quality studies also looked at symptom length: one described most Chinese medicine patients as having symptoms for over a year [20], and the other described new CAM patients as having longer symptoms than GP patients, although CAM patients also had lower pain scores [31].

Some studies described reasons for using CAM, for example an acquaintance's recommendation [9,10,33] or because a family member had done so [8]. Others cited users' views about orthodox medicine's disadvantages, for example rushed appointments [9,10] and its limited effectiveness [9,10,16,27], compared with CAM's attractions, for example its effectiveness [27] and sensitive practitioners with time to listen [30].

The high quality population-based survey reported that non-smokers and people who took regular exercise were more likely to have seen a chiropractor or osteopath than other people [11,12]. Two medium quality studies with adjusted analyses also reported a link with healthy living: compared to GP patients, CAM patients had healthier lifestyles [30] and were more likely to believe in healthy living [29]. Similar to this, a low quality unadjusted survey found that patients at alternative therapy centres were more likely to be health conscious and know about health than health centre attendees [21]. A medium [29] and a low quality study [21] also reported that CAM users were more likely to believe that they controlled their health or less likely to believe that doctors controlled their health than users of orthodox medicine.

Over-the-counter medicine

Eligible studies

Fifteen eligible papers relating to 15 studies were identified. Two are discussed in the CAM section [7,8], leaving 13 studies (additional file 4). The studies looked at use or purchase of any or specific medicines, such as analgesics [34]. Two were qualitative studies [35,36] and 11 were surveys. Four surveys used population-based samples [6,34,37,38], for example from health authority registers. One survey sampled people who were shopping [39] and two sampled people attending general practices [40,41]. The remaining four surveys looked at OTC purchasers without a comparison group [42-45]. Four surveys [34,37,38,40] had high quality scores. Three surveys [6,39,41] and the two qualitative studies [35,36] had medium scores. The other four surveys had low scores [42-45].

Results

Two low quality surveys described the sex of purchasers of OTC medicines and found that most were female [44,45]. Four population-based surveys agreed that use or purchase was more common in females: three were high quality and used adjusted analyses [34,37,38] and one was medium quality but unadjusted [6]. Using unadjusted analyses, a high quality survey of GP attendees [40] and a medium quality survey of shoppers [39] also found that being female was linked with using or purchasing OTC medicines.

One high quality population-based survey reported on ethnicity: this found that people who were white were more likely to use herbal supplements than other people [37]. Most studies looked at age. Three high quality population-based surveys found, using adjusted analyses, that purchase or use of OTC medicines was more common in people aged 35–44 [38], 45–64 [37], and under 60 [34]. One medium quality adjusted survey found that GP attendees [41] aged under 60 were more likely to use OTC medicines than older people, and another medium quality unadjusted survey reported a similar result for shoppers [39]. Using unadjusted analyses, a high quality survey of GP attendees [40] and a medium quality population-based survey [6] found that use or purchase of OTC medicines was highest in the 45–64 age group, and two low quality surveys reported that most OTC buyers were 46–60 [44] or 36–45 years [45].

Three high quality population-based surveys [34,37,38], one high quality survey of GP attendees [40] and one medium quality survey of GP attendees [41] found that OTC medicine use or purchase was associated with affluence. The studies used different measures though, for example occupation [38] or the Carstairs deprivation category [34], and only two found the association after adjusting for other variables [37,38]. One of the high quality surveys also reported an association with educational attainment, but only education remained significant in the adjusted analysis [34]. This could suggest that the association with affluence may be related to education, but there was also a link with paying for prescriptions in the adjusted analysis and this could be a surrogate for affluence. A low quality but adjusted survey of pharmacy customers also found an association with paying for prescriptions [43], and two medium quality unadjusted analyses of GP attendees [41] and shoppers [39] reported a similar link.

Only three studies found a link between purchase or use of OTC medicines and poor health, but all were high quality population-based studies with adjusted analyses. Two studies looked at self-reported health [34,38] and the third looked at psychiatric morbidity [37].

Two high quality population-based surveys examined behaviour. One found that herbal supplement use was associated with not smoking and being active, although only being active remained significant after adjusting for other variables [37]. This suggests that use may be associated with healthy behaviours. The other survey found an unadjusted association between non-prescription analgesics and drinking alcohol, but the comparison was with non-drinkers so this is probably not a healthy behaviour [34].

Some low quality surveys described reasons for OTC use, for example a prompt by an acquaintance [45], habit [44], homeopathic remedies being more natural [45], or symptoms not being severe enough for the doctor [42]. Some of these reasons were echoed in the qualitative studies, for example experience and influence of family members [35], doctors being unable to help with some problems [36], and prescription medicines being chemical [36].

Private sector

Eligible studies

Seven eligible papers were identified. One was also identified in searches related to CAM and is discussed in the CAM section [9]. The remaining six papers related to six studies (additional file 5). Five studies using data collected during surveys to look at determinants of insurance [46-48] and who actually uses private care [49,50]. The sixth study used data from general practice records to look at who was most likely to be privately referred [51]. The study that used general practice data had a high quality score [51], three studies had medium scores [47,48,50], and two had low scores [46,49].

Results

One medium quality study, using an adjusted analysis, reported that women were less likely to have private insurance than men [47]. A link with age was found in four studies. The high quality study used an adjusted analysis to show that people aged 45–54 were most likely to be privately referred [51]. Another medium quality study, also using an adjusted analysis, found that private insurance increased with age but fell for older people [48]. A low quality study reported the same result [46], although it was unclear if the analysis was adjusted. In contrast, a medium quality study, using an adjusted analysis, found that private insurance increased with age [47].

Private care or insurance was positively associated with affluence and/or negatively associated with deprivation in all the studies. The high quality study [51] and two medium quality studies [47,48] used adjusted analyses, whereas the other medium quality study used an unadjusted analysis [50] and it was unclear if the two low quality studies had adjusted for other variables [46,49]. The measures used, for example income [46] or the Index of Multiple Deprivation [51], also varied.

Being privately insured was found to be more likely among people with than without a basic qualification in a medium quality study that used an adjusted analysis including the possible confounders of income and occupation [47]. A similar link was found in a low quality study, but it was unclear whether the analysis was adjusted [46].

Only one study reported on the relationship with health status [49]. This reported a negative association between private care and being limited in one's daily activities, but the study was low quality and it was unclear if the analysis was adjusted.

Home blood pressure monitors

One eligible medium quality survey of 5545 people registered with general practices (54% response rate: 153 questionnaires undelivered and 2925 completed) was identified [52]. Being retired ($p < 0.05$), being not in employment ($p < 0.05$), having a long-term illness ($p < 0.001$) and/or not good health ($p < 0.05$), being a non-smoker ($p < 0.01$), and having used other self-tests ($p < 0.0001$) were linked with self-testing for high BP but only in a univariate analysis. Increasing age ($p < 0.0001$), being female ($p < 0.0001$), having a degree ($p < 0.05$) and living in a more affluent area ($p < 0.05$) remained significant after adjusting for other variables.

Self-tests

One eligible paper about self-testing was identified in July 2008 [53]. This presented results for self-tests related to cancer from the survey of 5545 adults that had been identified in searches related to home BP monitors [52]. Using an adjusted analysis, the study found that predictors of use of a prostate specific antigen test were being male ($p < 0.01$), white ethnicity ($p < 0.01$) and older age ($p < 0.01$), and that use was lower among relatively deprived people (quartile 3 of the Index of Multiple Deprivation, $p < 0.001$). In contrast, use of a haematuria test was predicted by being relatively deprived ($p < 0.05$), as well as giving one's employment status as looking after the home and/or family ($p < 0.01$).

Discussion

Main findings of this study

This study reviewed evidence for factors that are associated with self-testing and similar activities among UK adults. Forty nine eligible papers were identified. Most (n = 28) were identified by Medline and most (n = 30) were related to CAM. There were 46 unique studies and most (n = 36) had high or medium quality scores. Most (n = 37) studies were, or used data from established questionnaire surveys, but only 16 of them were population-based. Survey analysis methods varied from simple descriptive to adjusted analyses, but studies generally looked at five areas – demographic factors (sex and age), affluence/deprivation, education, health status, and health behaviours and beliefs.

Being female was associated with the activity in 13 of 27 studies about CAM, eight of 13 studies about OTC medicine, and the only study about home BP monitors. Ten studies about CAM, nine studies about OTC medicine, and three studies about the private sector reported that people in the 30 to 64 year age range were most likely to undertake the activity or that use declined after 60 or 70 years. One study, however, found that private insurance was more common in men than women and as age increased [47], and the study about home BP monitors reported that use became more likely as age increased [52].

A link with affluence was presented in eight studies about CAM, five studies about OTC medicine, all six studies about the private sector, and the study about home BP monitors. Higher educational attainment was associated with use in three studies about CAM, one study about OTC medicine, two studies about the private sector and the study about home BP monitors. Education and affluence are likely to be associated though and many studies used unadjusted analyses or looked at education or affluence. Even so, no study found that the activity was less common in more affluent or educated people.

Six studies about CAM, three studies about OTC medicine, and the study about home BP monitors suggested a link with various measures of poor health, but the analyses were often unadjusted. Conflicting evidence was also presented by two studies: one found that CAM patients had longer symptoms than GP patients but also lower pain scores [31], and the other reported that private care was less likely among people limited in their daily activities than among those not limited [49].

Four studies about CAM and one about OTC medicine suggested a link with healthy lifestyles or being health conscious and knowledgeable about health, and no studies contradicted this. Two studies also found that CAM users were more likely to believe that they control their health or less likely to believe that doctors control their health than users of orthodox medicine.

What is already known on this topic

The aim of this study was to review evidence about who uses self-tests among UK adults. No relevant studies about self-testing were initially identified though. As a result, the scope was widened to look at similar activities, and this study is the first to draw together evidence from different areas about common factors that are associated with self-care activities.

What this study adds

People who use CAM and OTC medicine appear similar. There is general consensus that they are usually female, middle-aged and affluent and/or educated. There is also fairly general agreement that people who undertake these activities have some measure of poor health. People who use home BP monitors appear similar to people who use CAM and OTC medicine except that use was associated with increasing age. The study about home BP monitors did not ask about hypertension though, and rising use could be related to the increased prevalence of this condition with age, perhaps unlike other conditions for which CAM and OTC medicines are used.

Similar to CAM, OTC medicines and home BP monitors, people who use the private sector appear to be affluent and/or educated. In contrast to users of other activities though, there is some evidence that males tend to have private insurance and people with good health tend to have private care. This suggests that it may not be appropriate to group studies about the private sector with studies about other self-care activities.

Limitations of this study

Only studies conducted in the UK were included because it was felt that the health care environment would have affected choices about the activities under consideration. The review may not, therefore, be applicable to other settings.

As there was no clear equivalent activity, studies about activities with similarities to self-testing were reviewed. Each activity, however, also has differences to self-testing, for example CAM is generally considered to be outside conventional medicine, whereas self-tests could be considered an extension of orthodox medicine. There were also differences between the activities, and grouping together results from such studies may not be appropriate, for example people who use the private sector may be different to people who use the other activities. As only one study about home BP monitors and self-tests was identified, it is probably not appropriate to draw firm conclusions about users of these activities.

Self-tests were defined for this study as tests that are bought and used without involving a doctor, nurse or other conventional health professional. As a result, studies were excluded where there was evidence that the activity was always initiated by a conventional health professional. Activities could also be simply recommended by health professionals though, and this was often not asked about or, if asked about, used to group people. It was not possible, therefore, to determine whether people who used an activity after a conventional professional's recommendation were different to people who used them without any such recommendation. Similar to this, use of private care and some CAM facilities may require referral from a conventional health professional, but the idea may have come from the patient. Again though, this was often not reported or used to group people. This may be important as someone who is affluent and/or educated may be more able to influence a GP to arrange a referral, which could, at least, partly explain the link between affluence and the use of these activities.

Eligible studies often defined use in different ways. Identified studies also used different data collection and analysis methods. Questionnaire surveys were often not population-based or did not have a relevant comparison group so descriptive analyses were presented about the group using the activity. Even where there was a comparison, analyses were often not adjusted for confounding variables so it was difficult to see if associations, such as education and affluence, were independent. Factors examined also varied widely, even though more basic characteristics, such as ethnic group, were infrequently studied. It was also sometimes difficult to tell whether papers related to the same study, for example three papers used similar methods and the same authors, but the number of participants varied [27,30,32]. These issues meant that it was not possible to formally pool analyses from studies within each area.

Future research

The government is encouraging self-care because of evidence that this will improve health outcomes and appropriate use of conventional services. The promotion of self-care may mean that self-tests are seen as desirable. It will be important, therefore, given the potential disadvantages of self-tests, to assess the impact of this policy on their use. There is a lack of evidence about who currently uses self-tests and why they use them though and a need for research in this area. It seemed sensible to collate evidence from studies about similar activities as a starting point, but it remains important, particularly given the potential disadvantages of self-tests, to use this knowledge to directly study who is using self-tests and why they are being used. The evidence from this review will, therefore, be used to design a questionnaire to look at factors that are associated with using self-tests. This review will also be useful to policy makers wishing to consider how best to promote general self-care activities by highlighting those groups who are not engaged in such activities. Further qualitative research among these groups about why self-care is not used and how this could be facilitated would be useful.

Conclusion

This review suggests that people who engaged in self-care activities were likely to be affluent and/or educated. Self-care is, therefore, likely to require targeted promotion to ensure that use is equitable.

People who have used some self-care activities may also have poorer health than non-users or people attending conventional services. It seems reasonable that people would use self-care activities when they feel unwell, but it is important to ensure that self-care is not a second choice for people who have been dissatisfied with, or not had their needs met by conventional services. There is weak evidence that dissatisfaction with orthodox medicine was a factor in some people's decision to use CAM and that some people used OTC medicine because their doctor was unable to help them. This requires further investigation as part of the evaluation of the promotion of self-care.

Abbreviations

OTC: over-the-counter; CAM: complementary and alternative therapies; BP: blood pressure; UK: United Kingdom.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

AR, SW and SG were responsible for the overall design of the study and designed the search strategy. AR conducted the searches, retrieved the papers and reviewed the literature. AR and AT or SW independently reviewed the quality of eligible papers. AR prepared the report with input from all authors.

Additional material

Additional file 1

Box 1. Proforma based on tools from the Critical Appraisal Skills Programme [4,5] that was used to assess the quality of eligible quantitative studies.
Click here for file
[http://www.biomedcentral.com/content/supplementary/1471-2458-9-96-S1.doc]

Additional file 2

Box 2. Proforma based on tools from the Critical Appraisal Skills Programme [4,5] that was used to assess the quality of eligible qualitative studies.
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Additional file 3

Table 3. Summary of eligible studies related to use of complementary and alternative therapy (CAM).
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Additional file 4

Table 4. Summary of eligible studies related to use of over-the-counter (OTC) medicine
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[http://www.biomedcentral.com/content/supplementary/1471-2458-9-96-S4.doc]

Additional file 5

Table 5. Summary of eligible studies related to use of the private sector.
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References

1. Department of Health: **Self Care – A Real Choice. Self Care Support – A Practical Option.** *London* 2005.
2. Department of Health: **Research evidence on the effectiveness of self-care support.** *London* 2007.
3. Ryan A, Wilson S, Greenfield S, Clifford S, McManus RJ, Pattison HM: **Range of self-tests available to buy in the United Kingdom: an Internet survey.** *Journal of Public Health* 2006, **28(4)**:370-374.
4. Critical Appraisal Skills Programme: **Making sense of evidence: 12 questions to help you make sense of a cohort study.** [http://www.phru.nhs.uk/Doc_Links/cohort%2012%20questions.pdf].
5. Critical Appraisal Skills Programme (CASP): **Making sense of evidence: 12 questions to help you make sense of a qualitative research.** [http://www.phru.nhs.uk/Doc_Links/Qualitative%20Appraisal%20Tool.pdf].
6. Thomas KJ, Nicholl JP, Coleman P: **Use and expenditure on complementary medicine in England: a population based survey.** *Complementary Therapies in Medicine* 2001, **9**:2-11.
7. Featherstone C, Godden D, Selvaraji , Emslie M, Took-Zozaya M: **Characteristics associated with reported CAM use in patients attending six GP practices in the Tayside and Grampian regions of Scotland: a survey.** *Complementary Therapies in Medicine* 2003, **11**:168-176.
8. Greenfield SM, Innes MA, Allan TF, Wearn AM: **First year medical students' perceptions and use of complementary and alternative medicine.** *Complementary Therapies in Medicine* 2002, **10**:27-32.
9. Andrews GJ: **Private complementary medicine and older people: service use and user empowerment.** *Ageing and Society* 2002, **22**:343-368.
10. Andrews GJ: **Placing the consumption of private complementary medicine: everyday geographies of older peoples' use.** *Health and Place* 2003, **9**:337-349.
11. Ong C, Petersen S, Bodeker GC, Stewart-Brown S: **Health Status of People Using Complementary and Alternative Medical Practitioner Services in 4 English Counties.** *American Journal of Public Health* 2002, **92(10)**:1653-1656.
12. Ong C, Doll H, Bodeker G, Stewart-Brown S: **Use of osteopathic or chiropractic services among people with back pain: a UK population survey.** *Health and Social Care in the Community* 2004, **12(3)**:265-273.
13. Featherstone C, Godden D, Gault C, Emslie M, Took-Zozaya M: **Prevalence Study of Concurrent Use of Complementary and Alternative Medicine in Patients Attending Primary Care Services in Scotland.** *American Journal of Public Health* 2003, **93(7)**:1080-1082.
14. MacPherson H, Sinclair-Lian N, Thomas K: **Patients seeking care from acupuncture practitioners in the UK: A national survey.** *Complementary Therapies in Medicine* 2006, **14**:20-30.
15. Cappuccio FP, Duneclift SM, Atkinson RW, Cook DG: **Use of Alternative Medicines in a Multi-Ethnic Population.** *Ethn Dis* 2001, **11(1)**:11-18.
16. Cartwright T, Torr R: **Making sense of illness: The Experiences of Users of Complementary Medicine.** *Journal of Health Psychology* 2005, **10(4)**:559-572.
17. Richardson J: **What Patients Expect From Complementary Therapy: A Qualitative Study.** *American Journal of Public Health* 2004, **94(6)**:1049-1053.
18. Murray J, Shepherd S: **Alternative or additional medicine? An exploratory study in general practice.** *Social Science and Medicine* 1993, **37(8)**:983-988.
19. Freymann H, Rennie T, Bates I, Nebel S, Heinrich M: **Knowledge and use of complementary and alternative medicine among British undergraduate pharmacy students.** *Pharmacy World and Science* 2006, **28**:13-18.
20. Wadlow G, Peringer E: **Retrospective survey of patients of practitioners of traditional Chinese acupuncture in the UK.** *Complementary Therapies in Medicine* 1996, **4**:1-7.
21. Furnham A, Forey J: **The attitudes, behaviors and beliefs of patients of conventional vs. complementary (alternative) medicine.** *Journal of Clinical Psychology* 1994, **50(3)**:458-469.
22. Furnham A: **Does experience of the 'occult' predict use of complementary medicine? Experience of, and beliefs about, both complementary medicine and ways of telling the future.** *Complementary Therapies in Medicine* 2000, **8**:266-2.
23. Emslie MJ, Campbell MK, Walker KA: **Changes in public awareness of, attitudes to, and use of complementary therapy in North East Scotland: surveys in 1993 and 1999.** *Complementary Therapies in Medicine* 2002, **10**:148-153.
24. Ernst E, White A: **The BBC survey of complementary medicine use in the UK.** *Complementary Therapies in Medicine* 2000, **8**:32-36.

25. Furnham A, Beard R: **Health, just world beliefs and coping style preferences in patients of complementary and orthodox medicine.** *Social Science and Medicine* 1995, **40(10)**:1425-1432.
26. Sharples FMC, van Haselen R, Fisher P: **NHS patients' perspective on complementary medicine: a survey.** *Complementary Therapies in Medicine* 2003, **11**:243-248.
27. Vincent C, Furnham A: **Why do patients turn to complementary medicine? An empirical study.** *British Journal of Clinical Psychology* 1996, **35**:37-48.
28. Thomas K, Coleman P: **Use of complementary or alternative medicine in a general population in Great Britain. Results from the National Omnibus survey.** *Journal of Public Health* 2004, **26(2)**:152-157.
29. Furnham A, Bhagrath R: **A comparison of health beliefs and behaviours of clients of orthodox and complementary medicine.** *British Journal of Clinical Psychology* 1993, **32**:237-246.
30. Furnham A, Vincent C, Wood R: **The Health Beliefs and Behaviors of Three Groups of Complementary Medicine and a General Practice Group of Patients.** *The Journal of Alternative and Complementary Medicine* 1995, **1(4)**:347-359.
31. Paterson C: **Complementary practitioners as part of the primary health care team: consulting patterns, patient characteristics and patient outcomes.** *Family Practice* 1997, **14(5)**:347-354.
32. Vincent C, Furnham A, Willsmore M: **The perceived efficacy of complementary and orthodox medicine in complementary and general practice patients.** *Health Education Research* 1995, **10(4)**:395-405.
33. Emslie M, Campbell M, Walker K: **Complementary therapies in a local healthcare setting. Part 1: Is there real public demand?** *Complementary therapies in Medicine* 1996, **4**:39-42.
34. Porteous T, Bond C, Hannaford P, Sinclair H: **How and why are non-prescription analgesics used in Scotland?** *Family Practice* 2005, **22**:78-85.
35. Gray NJ, Cantrill JA, Noyce PR: **'Health repertories': an understanding of lay management of minor ailments.** *Patient Education and Counseling* 2002, **47**:237-244.
36. Vickers KA, Jolly KB, Greenfield SM: **Herbal medicine: women's views, knowledge and interaction with doctors: a qualitative study.** *BMC Complementary and Alternative Medicine* 2006, **6**:40.
37. Harrison RA, Holt D, Pattison DJ, Elton PJ: **Who and How Many People Are Taking Herbal Supplements? A Survey of 21 923 Adults.** *International Journal for Vitamin and Nutrition Research* 2004, **74(3)**:183-186.
38. Boardman B, Lewis M, Trinder P, Rajaratnam G, Croft P: **Use of community pharmacies: a population-based survey.** *Journal of Public Health* 2005, **27(3)**:254-262.
39. Wazaify M, Shields E, Hughes CM, McElnay JC: **Societal perspectives on over-the-counter (OTC) medicines.** *Family Practice* 2005, **22**:170-176.
40. Bradley CP, Riaz A, Tobias RS, Kenkre JE, Dassu DY: **Patient attitudes to over-the-counter drugs and possible professional responses to self-medication.** *Family Practice* 1998, **15(1)**:44-50.
41. Urquhart G, Sinclair HK, Hannaford PC: **The use of non-prescription medicines by general practitioner attendees.** *Pharmacoepidemiology and Drug Safety* 2004, **13**:773-779.
42. McElnay JC, McCallion CR: **Non-prescription drug use by elderly patients.** *The International Journal of Pharmacy Practice* 1996, **4(1)**:6-11.
43. Payne K, Ryan-Woolley BM, Noyce PR: **Factors influencing consumers to purchase deregulated medicines over the counter.** *The Pharmaceutical Journal* 1997, **259(suppl)**:R14.
44. Kayne S, Beattie N, Reeves A: **Survey of buyers of over-the-counter homeopathic medicines.** *The Pharmaceutical Journal* 1999, **263**:210-212.
45. Reid S: **A survey of the use of over-the-counter homeopathic medicines purchased in health stores in central Manchester.** *Homeopathy* 2002, **91(4)**:225-229.
46. Besley T, Hall J, Preston I: **The demand for private health insurance: do waiting lists matter?** *Journal of Public Economics* 1999, **72**:155-181.
47. King D, Mossialos E: **The Determinants of Private Medical Insurance Prevalence in England, 1997–2000.** *Health Services Research* 2005, **40(1)**:195-212.
48. Propper C, Rees H, Green K: **The demand for private medical insurance in the UK: a cohort analysis.** *The Economic Journal* 2001, **111**:C180-C200.
49. Propper C: **The demand for private health care in the UK.** *Journal of Health Economics* 2000, **19**:855-876.
50. McGrath C, Moles D, Bedi R: **Who Uses Independent Dental Services? Findings from a National Survey.** *Primary Dental Care* 1999, **6(4)**:157-160.
51. Mulvaney C, Coupland C, Wilson A, Hammersley V, Dyas J, Carlisle R: **Does increased use of private health care reduce the demand for NHS care? A prospective survey of General Practice referrals.** *Journal of Public Health* 2005, **27(2)**:182-188.
52. McManus RJ, Ryan A, Greenfield S, Pattison HM, Clifford S, Marriott J, Wilson S: **Self measurement of blood pressure: a community survey.** *Journal of Human Hypertension* 2007, **21**:741-743.
53. Wilson S, Ryan AV, Greenfield SM, Clifford SC, Holder RL, Pattison HM, Fitzmaurice DA, McManus RJ: **Self-testing for cancer: a community survey.** *BMC Cancer* 2008, **8**:102.
54. Cappuccio F, Cook G, Atkinson RW, Strazzullo P: **Prevalence, detection, and management of cardiovascular risk factors in different ethnic groups in south London.** *Heart* 1997, **78**:555-563.
55. Furnham A: **Attitudes towards homoeopathy in particular and beliefs about complementary medicines in general.** *Psychology, Health and Medicine* 2000, **5(3)**:327-342.
56. Furnham A, Lovett J: **Predicting the use of complementary medicine: A Test of the Theories of Reasoned Action and Planned Behavior.** *Journal of Applied Social Psychology* 2001, **31(12)**:2588-2620.
57. Trinder P, Rajaratnam G, Lewis M, Croft P: **Prophylactic aspirin use in the adult general population.** *Journal of Public Health Medicine* 2003, **25(4)**:377-380.

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Appendix 24: Examples of search strategies used in Medline for studies related to use of over-the-counter medicine for the systematic literature review

Example 1

#	Search History
1	exp Population Characteristics/
2	exp Epidemiologic Factors/
3	exp Attitude to Health/
4	exp Health Behavior/
5	reason$.ti.
6	determinant$.ti.
7	factor$.ti.
8	explanat$.ti.
9	characteristic$.ti.
10	use$.ti.
11	exp Epidemiologic Studies/
12	exp Health Surveys/
13	exp Health Care Surveys/
14	exp Questionnaires/
15	exp Interviews/
16	exp Qualitative Research/
17	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
18	United Kingdom.ti,ab,in,cp.
19	UK.ti,ab,in,cp.
20	England.ti,ab,in,cp.
21	Scotland.ti,ab,in,cp.
22	Wales.ti,ab,in,cp.
23	Ireland.ti,ab,in,cp.
24	Britain.ti,ab,in,cp.
25	GB.ti,ab,in,cp.
26	exp Great Britain/
27	18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26
28	17 and 27
29	exp Self Medication/
30	28 and 29
31	limit 30 to humans
32	limit 31 to english language
33	limit 32 to yr="1992 - 2007"
34	limit 33 to (news or newspaper article)
35	33 not 34

Example 2

#	Search History
1	exp Population Characteristics/
2	exp Epidemiologic Factors/
3	exp Attitude to Health/
4	exp Health Behavior/
5	reason$.ti.
6	determinant$.ti.
7	factor$.ti.
8	explanat$.ti.
9	characteristic$.ti.
10	use$.ti.
11	exp Epidemiologic Studies/
12	exp Health Surveys/
13	exp Health Care Surveys/
14	exp Questionnaires/
15	exp Interviews/
16	exp Qualitative Research/
17	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
18	United Kingdom.ti,ab,in,cp.
19	UK.ti,ab,in,cp.
20	England.ti,ab,in,cp.
21	Scotland.ti,ab,in,cp.
22	Wales.ti,ab,in,cp.
23	Ireland.ti,ab,in,cp.
24	Britain.ti,ab,in,cp.
25	GB.ti,ab,in,cp.
26	exp Great Britain/
27	18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26
28	17 and 27
29	over the counter.ti.
30	over-the-counter.ti.
31	"over the counter".ti.
32	28 and 29
33	limit 32 to humans
34	limit 33 to english language
35	limit 34 to yr="1992 - 2007"
36	limit 35 to (news or newspaper article)
37	35 not 36

Example 3

#	Search History
1	exp Population Characteristics/
2	exp Epidemiologic Factors/
3	exp Attitude to Health/
4	exp Health Behavior/
5	reason$.ti.
6	determinant$.ti.
7	factor$.ti.
8	explanat$.ti.
9	characteristic$.ti.
10	use$.ti.
11	exp Epidemiologic Studies/
12	exp Health Surveys/
13	exp Health Care Surveys/
14	exp Questionnaires/
15	exp Interviews/
16	exp Qualitative Research/
17	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
18	United Kingdom.ti,ab,in,cp.
19	UK.ti,ab,in,cp.
20	England.ti,ab,in,cp.
21	Scotland.ti,ab,in,cp.
22	Wales.ti,ab,in,cp.
23	Ireland.ti,ab,in,cp.
24	Britain.ti,ab,in,cp.
25	GB.ti,ab,in,cp.
26	exp Great Britain/
27	18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26
28	17 and 27
29	exp Drugs, Non-Prescription/
30	28 and 29
31	limit 30 to humans
32	limit 31 to english language
33	limit 32 to yr="1992 - 2007"
34	limit 33 to (news or newspaper article)
35	33 not 34

Appendix 25: Proforma based on tools from the Critical Appraisal Skills Programme that was used to assess the quality of eligible quantitative studies

	Lead author and year	
	Are the results valid?	
1	Did the study addressed a clearly focused issue?	
2	Did the authors use an appropriate method to answer the question?	
3	Was the study population recruited in an acceptable way? Think about selection bias e.g. representative, clear exclusion and inclusion criteria.	
4	Was the exposure accurately measured to minimise bias?	
5	Was the outcome accurately measured to minimise bias?	
6	Have the authors identified all important confounding factors? Have they taken account of the confounding factors in the design and / or analysis?	
7	Was the analysis appropriate?	
8	Was the study population recruited in an acceptable way? Think about selection bias e.g. non response.	
	What are the results?	
9	What are the results and how precise are they?	
10	Do you believe the results?	
	Total (out of 10)	

Appendix 26: Proforma based on tools from the Critical Appraisal Skills Programme that was used to assess the quality of qualitative studies

	Lead author and year	
1	Was there a clear statement of the aims of the research?	
2	Is a qualitative methodology appropriate? Think about whether the research aims to interpret or illuminate actions or subjective experiences of participants.	
3	Was the research design appropriate to address the aims of the research? Think about whether the researcher has justified this.	
4	Was the recruitment strategy appropriate to the aims of the research? Think about how people were selected and whether there is discussion of non-participation.	
5	Were the data collected in a way that addressed the research issue? Think about the setting, the exact method, use of topic guide, how data were recorded, saturation.	
6	Has the relationship between researcher and participants been adequately considered?	
7	Have ethical issues been taken into consideration?	
8	Was the data analysis sufficiently rigorous? Think about potential bias i.e. selection of data for presentation.	
9	Is there a clear statement of the findings? And think about credibility i.e. triangulation, respondent validation, more than one analyst.	
10	How valuable is the research?	
	Total (out of 10)	

Appendix 27: In-depth questionnaire

UNIVERSITY OF BIRMINGHAM

QUESTIONNAIRE
Use of medical self-tests by members of the public

SECTION 1: This section asks for some background information about you.

1 How old are you? **Please write your age in the box.** ☐ **years**

2 What is your sex? **Please fill in one circle like this.** ●

- O Male
- O Female

3 Do you have any long-term illness, health problem or disability? **Please fill in one circle.**

- O Yes
- O No

If **YES**, does this limit your daily activities or the work you can do?

- O Yes
- O No

4 Have you ever worked as a health professional? **Please fill in circles for all the options that apply to you.**

- O Yes, during the last 12 months
- O Yes, more than 12 months ago
- O No

If **YES**, what is or was the title of your job? ____________________

5 Which of these qualifications do you have? **Please fill in circles for all the options that apply to you.**

- O O levels or CSEs or GCSEs or School Certificate
- O A levels or AS levels or Higher School Certificate
- O First degree (e.g. BA or BSc)
- O Higher degree (e.g. MA or PhD or PGCE or postgraduate certificates or diplomas)
- O NVQ level 1 or Foundation GNVQ
- O NVQ level 2 or Intermediate GNVQ
- O NVQ level 3 or Advanced GNVQ
- O NVQ level 4 or NVQ level 5 or HNC or HND
- O Qualified Teacher
- O Qualified Medical Doctor
- O Qualified Dentist
- O Qualified Nurse or Midwife or Health Visitor
- O No qualifications
- O Other qualifications – please describe below

____

Page 1 of 10

SECTION 2: This section asks about your knowledge and views of self-tests.

Self-tests are bought from shops or over the Internet. They are used to test for conditions or diseases **without** involving a doctor, nurse or other health professional.

1 How confident are you that you could use a self-test at home to test for a condition or disease without involving a doctor, nurse or other health professional? **Please fill in one circle.**

Very confident	Fairly confident	Neither confident nor unconfident	Fairly unconfident	Very unconfident
O	O	O	O	O

2 Did you know that these self-tests were available before you got our last questionnaire? **Please fill in one circle for each self-test.**

Self-test for	Yes	No	Don't know
Allergies	O	O	O
Blood in the stool (or bowel cancer or bowel disorders or bowel polyps)	O	O	O
Chlamydia	O	O	O
Cholesterol	O	O	O
Diabetes (or glucose or sugar in the blood or urine)	O	O	O
High blood pressure (or hypertension)	O	O	O
HIV (or AIDS)	O	O	O
Kidney disorders (or kidney damage or kidney failure)	O	O	O
Low blood count (or anaemia)	O	O	O
Menopause (or follicle stimulating hormone levels or FSH levels or falling fertility)	O	O	O
Pregnancy	O	O	O
Prostate disorders (or prostate cancer or prostate specific antigen or PSA)	O	O	O
Sperm count (or sperm concentration)	O	O	O
Urine infection (or cystitis or bladder infection)	O	O	O
Vaginal infection (or vaginal discharge)	O	O	O
Other - please say what ________________________	O	O	O

SECTION 3: This section asks about your habits and lifestyle.

1 Do you smoke cigarettes at all nowadays? **Please fill in one circle.**

- O Yes
- O No

If **YES**, about how many cigarettes a day do you usually smoke? **Please write the number in the box.** [ ] **cigarettes per day**

2 How often do you take exercise in your free time so that you get at least a little warm, sweaty or out of breath? **Please fill in one circle.**

- O Five days a week or more
- O About three or four days a week
- O About one or two days a week
- O Less than once a week but at least once a month
- O Less than once a month
- O Never or almost never

3 How often do you eat fruit or vegetables not including potatoes? **Please fill in one circle.**

- O Five times a day or more
- O About three or four times a day
- O About one or two times a day
- O Less than once a day but at least once a week
- O Less than once a week
- O Never or almost never

4 How often do you use the internet? **Please fill in one circle.**

- O Five times a day or more
- O About three or four times a day
- O About one or two times a day
- O Less than once a day but at least once a week
- O Less than once a week
- O Never or almost never

SECTION 4: This section asks how much you know about recommendations about how to stay healthy. Please try to answer these questions without asking anyone or looking up the answers.

1 At least how many portions of fruit or vegetables is it recommended that people should eat each day? **Please write the number in the box or put a cross if you do not know the answer.**

[ ] **portions**

2 At least how many days a week is it recommended that people should exercise? **Please write the number in the box or put a cross if you do not know the answer.**

[ ] **days**

SECTION 5: This section asks where you get information about health.

1 In the last 12 months, have you asked these people for advice about a health problem or how to stay healthy? **Please fill in one circle for each person.**

	Three or more times	Once or twice	Not at all	Not sure
GP or family doctor	O	O	O	O
General practice nurse	O	O	O	O
Hospital doctor	O	O	O	O
Hospital nurse	O	O	O	O
Pharmacist or chemist	O	O	O	O
Complementary therapist	O	O	O	O
Husband or wife or partner	O	O	O	O
Other family member	O	O	O	O
Friend	O	O	O	O
Work colleague	O	O	O	O
Other – please say who______________________________	O	O	O	O

2 In the last 12 months, have you used these other sources of information for advice about a health problem or how to stay healthy? **Please fill in one circle for each source.**

	Three or more times	Once or twice	Not at all	Not sure
NHS Direct	O	O	O	O
The internet or websites	O	O	O	O
CDs or DVDs	O	O	O	O
Books	O	O	O	O
Newspaper or magazine articles	O	O	O	O
Radio or television programmes	O	O	O	O
Adverts in newspapers or magazines	O	O	O	O
Adverts on radio or television	O	O	O	O
Adverts in pharmacies or chemists	O	O	O	O
Other – please say what______________________________	O	O	O	O

SECTION 6: This section asks for some more information about your health.

1 Overall, how would you rate your health during the past 4 weeks? **Please fill in one circle.**

Excellent	Very good	Good	Fair	Poor	Very poor
O	O	O	O	O	O

2 During the past 4 weeks, how much did physical health problems limit your usual physical activities (such as walking or climbing stairs)? **Please fill in one circle.**

Not at all	Very little	Somewhat	Quite a lot	Could not do physical activities
O	O	O	O	O

3 During the past 4 weeks, how much difficulty did you have doing your daily work, both inside and outside the home, because of your physical health? **Please fill in one circle.**

None at all	A little bit	Some	Quite a lot	Could not do daily work
O	O	O	O	O

4 How much bodily pain have you had during the past 4 weeks? **Please fill in one circle.**

None	Very mild	Mild	Moderate	Severe	Very severe
O	O	O	O	O	O

5 During the past 4 weeks, how much energy did you have? **Please fill in one circle.**

Very much	Quite a bit	Some	A little	None
O	O	O	O	O

6 During the past 4 weeks, how much did your physical health or emotional problems limit your usual social activities with family or friends? **Please fill in one circle.**

Not at all	Very little	Somewhat	Quite a lot	Could not do social activities
O	O	O	O	O

7 During the past 4 weeks, how much have you been bothered by emotional problems (such as feeling anxious, depressed or irritable)? **Please fill in one circle.**

Not at all	Slightly	Moderately	Quite a lot	Extremely
O	O	O	O	O

8 During the past 4 weeks, how much did personal or emotional problems keep you from doing your usual work, studies, or other daily activities? **Please fill in one circle.**

Not at all	Very little	Somewhat	Quite a lot	Could not do daily activities
O	O	O	O	O

9 In the <u>last 12 months</u>, have you thought that you might have any of these conditions? **Please fill in <u>one</u> circle for <u>each</u> condition.**

	Yes	No	Not sure	Not relevant as I already had this condition
Allergies	O	O	O	O
Blood in the stool (or bowel cancer or bowel disorders or bowel polyps)	O	O	O	O
Chlamydia	O	O	O	O
High cholesterol	O	O	O	O
Diabetes (or high glucose or sugar in the blood or urine)	O	O	O	O
HIV (or AIDS)	O	O	O	O
Kidney disorders (or kidney damage or kidney failure)	O	O	O	O
Low blood count (or anaemia)	O	O	O	O
Menopause (or high follicle stimulating hormone levels or high FSH levels or falling fertility)	O	O	O	O
Urine infection (or cystitis or bladder infection)	O	O	O	O
Vaginal infection (or vaginal discharge)	O	O	O	O

10 In the <u>last 12 months</u>, have you had a test done by a doctor or nurse to see if you had any of these conditions? **Please fill in <u>one</u> circle for <u>each</u> condition.**

	Yes	No	Not sure	Not relevant as I already had this condition
Allergies	O	O	O	O
Blood in the stool (or bowel cancer or bowel disorders or bowel polyps)	O	O	O	O
Chlamydia	O	O	O	O
High cholesterol	O	O	O	O
Diabetes (or high glucose or sugar in the blood or urine)	O	O	O	O
HIV (or AIDS)	O	O	O	O
Kidney disorders (or kidney damage or kidney failure)	O	O	O	O
Low blood count (or anaemia)	O	O	O	O
Menopause (or high follicle stimulating hormone levels or high FSH levels or falling fertility)	O	O	O	O
Urine infection (or cystitis or bladder infection)	O	O	O	O
Vaginal infection (or vaginal discharge)	O	O	O	O

11 How often do you think about things that you might do to keep yourself healthy or improve your health? **Please fill in one circle.**

O	Every day	O	Less than once a week but at least once a month
O	Every two or three days	O	Less than once a month
O	About once a week	O	Never or almost never

12 How often do you think about illnesses that you might get in the future? **Please fill in one circle.**

O	Every day	O	Less than once a week but at least once a month
O	Every two or three days	O	Less than once a month
O	About once a week	O	Never or almost never

SECTION 7: This section asks about your views and experiences of healthcare.

1 How do you feel about health checks and medical tests? **Please fill in one circle in each row.**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Medical tests are reassuring	O	O	O	O	O
I am curious about my health	O	O	O	O	O
I like the idea of routine health checks	O	O	O	O	O
Medical tests make me anxious	O	O	O	O	O

2 How do you feel about visiting your GP (or family doctor)? **Please fill in one circle in each row.**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
I would only go to the doctor if I had some symptoms	O	O	O	O	O
You need symptoms or risk factors to get a test done at my GP surgery	O	O	O	O	O
I don't like to bother the doctor unless it's really necessary	O	O	O	O	O
I would only go to the doctor if I had symptoms that were severe or might be serious	O	O	O	O	O
I like to have evidence to justify a visit to the doctor	O	O	O	O	O
I would be embarrassed to tell my doctor about very personal or intimate problems	O	O	O	O	O
I would be happy to ask my doctor for a routine check-up	O	O	O	O	O
I'm confident that my doctor would try and do a test if I asked for it	O	O	O	O	O

3 How easy or difficult do you find it to get an appointment at your GP surgery <u>as soon as you would like</u>? **Please fill in <u>one</u> circle.**

Very easy	Fairly easy	Neither easy nor difficult	Fairly difficult	Very difficult	Never had an appointment
O	O	O	O	O	O

4 How easy or difficult do you find it to get an appointment at your GP surgery <u>at a time that suits you</u>? **Please fill in <u>one</u> circle.**

Very easy	Fairly easy	Neither easy nor difficult	Fairly difficult	Very difficult	Never had an appointment
O	O	O	O	O	O

5 How easy or difficult do you find it to <u>travel</u> to your GP surgery? **Please fill in <u>one</u> circle.**

Very easy	Fairly easy	Neither easy nor difficult	Fairly difficult	Very difficult	Never had an appointment
O	O	O	O	O	O

6 How do you rate these aspects of the consultations that you have had with your GP (or family doctor) in the past? **Please fill in <u>one</u> circle in <u>each</u> row.**

	Very good	Good	Fair	Poor	Very poor	Don't know
How thoroughly the doctor asks about your symptoms and how you are feeling	O	O	O	O	O	O
How well the doctor listens to what you have to say	O	O	O	O	O	O
How well the doctor puts you at ease during your physical examination	O	O	O	O	O	O
How much the doctor involves you in decisions about your care	O	O	O	O	O	O
How well the doctor explains your problems or any treatment that you need	O	O	O	O	O	O
The amount of time the doctor spends with you	O	O	O	O	O	O
The doctor's patience with your questions or worries	O	O	O	O	O	O
The doctor's caring and concern for you	O	O	O	O	O	O

7 Overall, how satisfied are you with the healthcare that <u>you</u> have had in the past? **Please fill in <u>one</u> circle.**

Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied
O	O	O	O	O

8 Overall, how satisfied are you with the healthcare that <u>your family or close friends</u> have had in the past? **Please fill in <u>one</u> circle.**

Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied
O	O	O	O	O

SECTION 8: This section asks about your beliefs about health.

Please read each statement and **fill in the one circle** that represents the extent to which you agree or disagree with that statement. Please try and give an answer for every statement. This is a measure of your personal beliefs: there are no right or wrong answers.

	Strongly agree	Moderately agree	Slightly agree	Slightly disagree	Moderately disagree	Strongly disagree
If you don't have your health, you don't have anything	O	O	O	O	O	O
There are many things I care about more than my health	O	O	O	O	O	O
Good health is of only minor importance in a happy life	O	O	O	O	O	O
There is nothing more important than good health	O	O	O	O	O	O
If I get ill, it is my own behaviour which determines how soon I get well again	O	O	O	O	O	O
No matter what I do, if I am going to get ill, I will get ill	O	O	O	O	O	O
Having regular contact with my doctor is the best way for me to avoid illness	O	O	O	O	O	O
Most things that affect my health happen to me by accident	O	O	O	O	O	O
Whenever I don't feel well, I should consult a medically trained professional	O	O	O	O	O	O
I am in control of my health	O	O	O	O	O	O
My family has a lot to do with my becoming ill or staying healthy	O	O	O	O	O	O
When I get ill, I am to blame	O	O	O	O	O	O
Luck plays a big part in determining how soon I will recover from an illness	O	O	O	O	O	O
Health professionals control my health	O	O	O	O	O	O
My good health is largely a matter of good fortune	O	O	O	O	O	O
The main thing which affects my health is what I myself do	O	O	O	O	O	O
If I take care of myself, I can avoid illness	O	O	O	O	O	O
Whenever I recover from an illness, it's usually because other people (for example doctors, nurses, family, friends) have been taking good care of me	O	O	O	O	O	O
No matter what I do, I'm likely to get ill	O	O	O	O	O	O
If it's meant to be, I will stay healthy	O	O	O	O	O	O
If I take the right actions, I can stay healthy	O	O	O	O	O	O
Regarding my health, I can only do what my doctor tells me to do	O	O	O	O	O	O

SECTION 9: May we contact you again?

In the future, we may send out another questionnaire about self-testing. Would you be willing to receive another questionnaire? **Please fill in one circle.** We would only contact some of the people who said **yes**.

O Yes

O No

SECTION 10: Please add any other comments you would like to make about self-tests in the space provided below.

Thank you for your time.

Please return this questionnaire in the PREPAID envelope provided.

If you have any questions about the study, please contact
Angela Ryan at the University of Birmingham on 0121 415 8015.

Appendix 28: Covering letter for pilot of in-depth questionnaire

Contact:	Angela Ryan
Telephone:	0121 415 8015
Fax:	0121 414 6571
Email:	a.v.ryan@bham.ac.uk

«Title» «Prefer» «Surname»
«Expr1»
«Expr2»
«Expr3» «Expr4»

Use of medical self-tests by members of the public

11 June 2010

Dear «Title» «Surname»,

You may remember that you kindly completed a questionnaire and took part in an interview about "self-testing" last year. Self-testing is where a member of the public, like yourself, buys a test to see if they may have a condition or disease without involving a doctor, nurse or other health professional, similar to a home pregnancy test.

One of the aims of the interviews was to help us design a questionnaire to look at why people use self-tests. Using the information that you and others provided, we have drafted the enclosed questionnaire. **We would now like to ask for your help to test this questionnaire.**

We hope to send a different version of the questionnaire to groups of people who have and have not used self-tests to find out more about why people use them. Before we do that though, we would like to make sure that the questionnaire is understandable and easy to complete.

We would like to ask if you would try completing the questionnaire and then fill in the attached reply slip to tell us how you found this. As with the first questionnaire and the interview, any information that you provide will be confidential and only seen by the research team, but please leave out any questions that you feel unhappy about answering.

Please return the completed questionnaire and reply slip to the University in the enclosed PREPAID envelope. No stamp is needed. If you do not wish to complete and comment on the questionnaire, you can let us know by sending back the blank questionnaire and reply slip in the PREPAID envelope, and we will not contact you again.

Please contact me on 0121 415 8015 if you have questions or concerns, and thank you once again for your time and consideration in helping with this research. Even if you decide not to complete and comment on the questionnaire, your input so far has been very valuable.

Yours sincerely,

Dr Angela Ryan
Clinical research fellow

Appendix 29: Reply slip for pilot of in-depth questionnaire

Study number «Study_number»

Contact: Angela Ryan
Telephone: 0121 415 8015
Fax: 0121 414 6571
Email: a.v.ryan@bham.ac.uk

REPLY SLIP

Questionnaire about the use of medical self-tests by members of the public

1 How long did it take you to complete the questionnaire? **Please fill in <u>one</u> circle.**

O Less than 15 minutes

O About 20 minutes

O About 25 minutes

O About 30 minutes

O More than 30 minutes but less than an hour

O More than an hour

O I didn't finish it

2 Overall, how easy or difficult did you find it to complete the questionnaire? **Please fill in <u>one</u> circle.**

Very difficult	Fairly difficult	Neither difficult nor easy	Fairly easy	Very easy
O	O	O	O	O

3 Did you find any particular questions difficult to complete? **Please fill in <u>one</u> circle.**

O Yes

O No

If **YES**, **please tell us why you found the question(s) difficult to complete in the space provided on the other side of this reply slip.**

4 Do you have any other comments to help us improve the questionnaire? **Please write any other comments in the space provided on the other side of this reply slip.**

Thank you for your time.

Please return the completed questionnaire and reply slip in the PREPAID envelope.

No stamp is needed.

Appendix 30: Covering letter for in-depth questionnaire

Contact: Angela Ryan
Telephone: 0121 415 8015
Fax: 0121 414 6571
Email: a.v.ryan@bham.ac.uk

UNIVERSITY OF BIRMINGHAM

School of Medicine

Division of Primary Care,
Public and Occupational Health

Department of Primary Care
and General Practice

Head of Department
Professor of Primary Care
and General Practice
Richard Hobbs FRCGP

«Title» «First_initial» «Surname»
«Address1»
«Address2»
«Address3»
«Address4»
«Address5» «Postcode»

Study number «Study_number»

3 March 2008

Dear «Title» «Surname»,

Use of medical self-tests by members of the public

You kindly completed a questionnaire about “self-testing” and returned it to the Department of Primary Care at the University of Birmingham a few weeks ago. You said on your questionnaire that you may be willing to complete a more detailed questionnaire.

We would like to ask if you would complete the enclosed more detailed questionnaire and return it to the University in the enclosed PREPAID envelope. No stamp is needed.

We want to understand why people use self-tests so that we can advise health services about how to better care for them. This questionnaire will help by telling us about people’s views and experiences of self-tests, health and healthcare. We are asking people who have used self-tests and people who have not done so to complete this questionnaire so that we can compare their views and experiences. **Your response is important to us whether or not you have ever used a self-test.**

It should only take about 20 minutes to complete the questionnaire. Most of the questions just ask you to mark one of the answers. As with the first questionnaire, any information that you provide will be confidential and only seen by the research team, but please leave out any question that you feel unhappy about answering. During the study, your contact details will be kept on a secure database at the University in accordance with the Data Protection Act 1998. They will then be deleted.

Please return the completed questionnaire to the University in the enclosed PREPAID envelope. No stamp is needed. If you do not wish to complete the questionnaire, you can let us know by sending back the blank questionnaire in the PREPAID envelope, and we will not contact you again.

Please contact me on 0121 415 8015 if you have questions or concerns about the study. Thank you for your time and consideration in helping with this research. Even if you decide not to complete the questionnaire, your input so far has been very valuable.

Yours sincerely,

Dr Angela Ryan
Clinical research fellow

Screening Team Primary Care Clinical Sciences Building University of Birmingham
Edgbaston Birmingham B15 2TT United Kingdom
www.pcpoh.bham.ac.uk/primarycare

Appendix 31: Reminder letter for in-depth questionnaire

Contact: Angela Ryan
Telephone: 0121 415 8015
Fax: 0121 414 6571
Email: a.v.ryan@bham.ac.uk

UNIVERSITY OF BIRMINGHAM

School of Medicine

Division of Primary Care,
Public and Occupational Health

Department of Primary Care
and General Practice

Head of Department
Professor of Primary Care
and General Practice
Richard Hobbs FRCGP

«Title» «First_initial» «Surname»
«Address1»
«Address2»
«Address3»
«Address4»
«Address5» «Postcode»

Study number «Study_number»

28 March 2008

Dear «Title» «Surname»,

Use of medical self-tests by members of the public

You kindly completed a short questionnaire about "self-testing" and returned it to the University of Birmingham several weeks ago. You said on your questionnaire that you may be willing to complete a more detailed questionnaire.

You may remember receiving a letter from me about this more detailed questionnaire. We would like to ask again if you would consider completing it. **Another copy of the questionnaire is enclosed, and we would be very grateful if you would complete it and return it to the University in the enclosed PREPAID envelope. No stamp is needed.** Please disregard this letter if it has crossed in the post with your returned questionnaire.

We want to understand why some people use self-tests so that we can advise health services about how to better care for them. This questionnaire will help by telling us about people's views and experiences of self-tests, health and healthcare. We are asking people who have used self-tests and people who have not done so to complete this questionnaire so that we can compare their views and experiences. **Your response is important to us whether or not you have ever used a self-test.**

It should only take about 20 minutes to complete the questionnaire. Most of the questions just ask you to mark one of the answers. As with the first questionnaire, any information that you provide will be confidential and only seen by the research team, but please leave out any question that you feel unhappy about answering. During the study, your contact details will be kept on a secure database at the University in accordance with the Data Protection Act 1998. They will then be deleted.

Please return the completed questionnaire to the University in the enclosed PREPAID envelope. No stamp is needed. If you do not wish to complete the questionnaire, you can let us know by sending back the blank questionnaire in the PREPAID envelope, and we will not contact you again.

Please contact me on 0121 415 8015 if you have questions or concerns about the study. Thank you for your time and consideration in helping with this research. Even if you decide not to complete the questionnaire, your input so far has been very valuable.

Yours sincerely,

Dr Angela Ryan
Clinical research fellow

Screening Team Primary Care Clinical Sciences Building University of Birmingham
Edgbaston Birmingham B15 2TT United Kingdom
www.pcpoh.bham.ac.uk/primarycare

Appendix 32: Eligible studies from the systematic literature review about complementary and alternative therapy (CAM)

Year	Design	Population	Period	Exposure	Denominator	Numerator (response rate)	Results [a]	Quality
2002 [38]	Questionnaire survey	People from register of eligible to vote	1999	Used at least one type of CAM	800 questionnaires distributed	432 (54%) completed	*Descriptive analysis:* ▪ 67% of people who gave details of CAM use were women and highest proportion (46%) aged 30-49	6.0
2001 [106]	Questionnaire survey	Adults from health authority populations	1998	Visited CAM practitioner in last 12 months	5010 questionnaires distributed 269 undelivered, leaving 4741	2853 returned but 107 blank and 78 completed by wrong person 59% (2669/4556) response rate given	*Unadjusted chi^2 analysis:* ▪ More likely in women (12.5%, 10.7-14.3) than men (8.8%, 7.3-10.3) (p<0.01) ▪ Significant difference by age (p<0.001): 11.0% 18-44 (9.3-12.8), 12.9% 45-64 (10.6-15.2), 9.6% 65-74 (6.1-13.0), 4.2%>75 (1.5 to 6.5) *Descriptive analysis:* ▪ Usually for musculoskeletal problems (71%) and paid for by patients (79%)	7.5
2003 & 2003 [147 & 153]	Questionnaire survey	Patients attending practices selected to represent range of deprivation and rurality, list size, and CAM provision	2000	Use of CAM therapies or remedies	1987 received questionnaires OR 2032 questionnaires distributed and 32 undelivered, leaving 2000	1523 responded 348 incomplete Leaves 1175 but 1174 analysed OR 1198 responses received but 24 ineligible, leaving 1174 59% response rate quoted in both papers	*Descriptive analysis:* ▪ NHS prescription or referral for only 13% who had used CAM in the last month *Chi^2 analysis (unclear if adjusted or not):* ▪ Use (unclear if lifetime or concurrent) fell with increasing age (p<0.005), lower educational attainment (p<0.005) and lower household income (p<0.005) ▪ Use more likely in women than men (p<0.005) *Logistic regression analysis including factors significant in univariate analysis (education excluded as missing data):* ▪ Lifetime use more likely: - Female (odds ratio (OR) 1.6, 1.19-2.17) - All age groups relative to ≥70 (e.g. OR 3.6 for 30-49, 2.40-5.34) - CAM provided by GP relative to not (OR 1.5, 1.07-2.04) - OTC use in past month relative to not (e.g. OR 4.8 for 1-2, 3.40-6.73) ▪ Concurrent use more likely: - OTC use in past month relative to not (e.g. OR 5.7 for 1-2, 4.14-7.72) - 30-49 (OR 1.9, 1.22-2.86) and 50-69 (OR 1.8, 1.20-2.74) relative to ≥ 70	6.5

[a] This table only shows results that are significant or reported as key findings rather than the results of all variables tested in analyses.

Table continued on next page

Year	Design	Population	Period	Exposure	Denominator	Numerator (response rate)	Results [a]	Quality
2002 [148]	Questionnaire survey	Medical students	1999	Used CAM	211 students	150 (71%) returned 143 completed all questions	*Unadjusted analysis:* ▪ More likely to have used CAM if family member already used it (p<0.001)	7.5
2002 & 2003 [149 & 150]	Questionnaire and interview survey	Patients aged over 60 of CAM practitioners taking part in separate survey	Not given	Used CAM	400 questionnaires distributed	144 (36%) completed. 20 interviews but no response rate given	*Descriptive and qualitative analysis:* ▪ Reasons for adoption: - Most often (36%) introduced by friend - Inadequacies of orthodox medicine (OM) e.g. rushed appointments, over reliance on drugs and their side effects, waiting times, clinicians' lack of care and attention and lack of success in solving health problems - Attractions of CAM e.g. individual, holistic, natural, convenient, more sensitivity, interest and time from therapist	4.5
2002 & 2004 [151 & 152]	Questionnaire survey	Adults aged 18-64 registered with general practices	1997	Consulted CAM practitioner in past 3 months OR Consulted osteopath/ chiropractor or physiotherapist past 3 months	14868 questionnaires distributed	8889 eligible people completed questionnaires 64% response rate quoted after adjustment for returns from inappropriate or deceased addressees	*Regression analysis with age, sex, social class, chronic illness type, GP visits:* ▪ Predictors of visiting CAM practitioner: - Long-standing illness (OR 2.07, 1.73-2.49) - Non-manual social class (OR 2.00, 1.63-2.45) - Being female (OR 1.60, 1.33-1.92) - High GP use (OR 1.32, 1.09-1.58) *Regression analysis adjusted for back pain, age, sex and social class:* ▪ Predictors of osteopathic/chiropractic consultation: back pain (OR 5.11, 4.05-6.44), non-manual social class (OR 2.10, 1.58-2.78), non-smoker (OR 1.50, 1.12-2.03), >30 minutes exercise per week (OR 1.48, 1.16-1.90), being female (OR 1.26, 1.00-1.60), age (p=0.013, 34-49 most likely to consult) ▪ Predictors of physiotherapist consultation: back pain (OR 2.73, 2.15-3.48), non-manual social class (OR 1.76, 1.35-2.29), wants to take more exercise (OR 1.55, 1.15-2.08) *Additionally in univariate chi^2 analyses:* ▪ Predictors of osteopathic/chiropractic consultation: drinks alcohol relative to not (p=0.016), wants input to NHS decisions (p<0.001), worries about global environment (p=0.002), wants to do more exercise (p=0.005) ▪ Predictors of physiotherapist consultation were: signed healthcare petition (p=0.047), wants input to NHS decisions (p=0.005), worries about global environment (p=0.025)	8.5

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Year	Design	Population	Period	Exposure	Denominator	Numerator (response rate)	Results [a]	Quality
2006 [154]	Questionnaire survey	Patients seeing acupuncturists	2002	Consulting acupuncturist	Not given	638 (33%) of acupuncturists agreed to participate 9408 questionnaires completed but no response rate given	*Descriptive analysis* ▪ 74% female ($p<0.001$) compared with 51% female in 2001 Census ▪ Relatively higher proportions in 35-64 age range than 2001 Census ▪ Only 10% advised to consult by NHS professional: most common pathways were self-referral (40%) or friend's or relative's recommendation (34%)	6.0
2001 [155 & 232]	Questionnaire survey	Patients aged 40-59 years registered with GPs	1994 to 1996	Patients taking alternative medicines not prescribed by a doctor	3606 invitations distributed 952 undelivered, leaving 2654	1695 responded (64% response rate given) 117 excluded, but 1577 in analyses	*Regression analysis adjusted for age, sex, ethnic group and social class:* ▪ Use more likely in: - Black African than South Asians (OR 1.66, 1.07-2.59) or people of white ethnic origin (OR 1.78, 1.07-2.94) - Females (OR 2.09, 1.45-3.00) ▪ Use less likely in social class IV & V (OR 0.53, 0.31-0.90) than I & II	7.5
2005 [156]	Interview study	Adults visiting CAM practices	Not given	Recent use of, and commitment to CAM	Not given	11 interviews but no response rate given	*Qualitative analysis:* ▪ Main themes: - Initially got CAM to address specific problems - Dissatisfaction with OM - Holistic approach of CAM - CAM as natural and traditional - Side effects of OM - Limited effectiveness of OM - Empowering emphasis on one's own healing capacity	7.5
2004 [157]	Questionnaire and qualitative survey	Patients treated at NHS CAM clinic	Not given	Patient at clinic	327 questionnaires distributed	237 (72%) returned 86% recorded qualitative statements	*Descriptive analysis* ▪ Most were female (71%) ▪ Highest proportion (≈30%) treated in study period were 35-44 *Qualitative analysis* ▪ OM was not working for some patients and/or they wanted to reduce it's risks ▪ Symptom relief was the dominant theme and patients wanted to find ways to cope with their chronic problems ▪ Patients expressed a desire for a holistic approach	6.0

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Year	Design	Population	Period	Exposure	Denominator	Numerator (response rate)	Results [a]	Quality
1993 [158]	Questionnaire and interview survey	Patients registered with general practice	Not given	Tried alternative medicine in past 10 years	372 questionnaires distributed	233 (63%) completed 20 interviews with registered patients known to be users of alternative treatments but no response rate given	*Unadjusted descriptive analysis:* ▪ 46% of women and 34% of men had used alternative medicine ▪ Peak use at 45 ▪ 69% of users (49% non-users) had seen GP with severe or chronic condition *Log linear analysis:* ▪ Lower GP attendance rate among non-users than users (G^2=46.67, 2 df) *Interview analysis:* ▪ OM entails greater risk than mobilising body's natural healing ability ▪ Therapist's time and attention most valued aspect ▪ Widely accepted that NHS cannot give same attention	5.0
2006 [159]	Questionnaire and interview survey	Students at London School of Pharmacy	2004	CAM use	447 students approached	264 (59%) completed	*Unadjusted chi^2 analysis:* ▪ CAM not part of tradition of white students (not significant as small numbers)	5.5
1996 [160]	Case note review	Treated during survey period	1992	Being treated by practitioner on the register of traditional Chinese medicine	146 practitioners approached	94 (64%) responded 62 willing but only 24 eligible, 6 withdrew and one excluded, leaving 17 with 714 active patients	*Descriptive analysis:* ▪ 69% female and 31% male with median age of 45 and 46 ▪ 68% of 552 with duration recorded had symptoms for > one year ▪ 77% of 492 with occupation recorded considered to have disposable income ▪ 79% of 323 with referral recorded were referred via personal recommendation	6.0
1994 [161]	Questionnaire survey	Patients visiting GP or alternative practitioner	Not given	Attended alternative therapy clinic or health centre	200 questionnaires distributed to health centres 200 questionnaires distributed to alternative therapy clinics	160 included: 80 from alternative therapy clinics, and 80 from health centres 48% response rate quoted with no difference between health centres and alternative therapy clinics	*Unclear if analysis adjusted or not:* ▪ Alternative therapy patients more likely than health centre patients to: - Disagree that only need to see alternative practitioner when ill (p<0.001) - Disagree that treatment should concentrate on symptoms rather than the whole person (p<0.001) - Be more health conscious and aware (p<0.01 for 10 of 14 questions). - Have higher knowledge score (p<0.001) - Have lower general threat to health (diseases not controllable by anyone) score (p<0.001) - Have lower provider control (doctor can control health) score (p<0.001)	4.5

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Year	Design	Population	Period	Exposure	Denominator	Numerator (response rate)	Results [a]	Quality
2000 [162]	Questionnaire survey	Recruited from university panel and by market research agency	Not given	How many complementary therapies people had tried	Not given	159 participants, 80 from market research agency 98% response rate quoted	*Regression analysis including sex, smoker, religious, vegetarian, health, attitudes to medicine, heard of ways of telling future, tried ways of telling future, think ways of telling future works, think ways of telling future effective:* ▪ Number of complementary therapies tried predicted by number of ways of predicting the future they had tried ($p < 0.001$)	4.5
2000 [163]	Questionnaire survey	Adults using random-digit telephone dialling as part of regular weekly Omnibus survey	1999	Used CAM in previous year	Not given	1204 interviewed but no response rate given	*Descriptive analysis* ▪ Use of in past year higher in: - Females (24%) than males (17%) - 35-64 years (26%) than 25-34 (20%) or 65+ (11%) - Social class AB (25%) than C1 (23%), C2 (19%) or DE (16%) - People who were working (23%) than who were not working (17%) - Most commonly (25%) because it helps or relieves the illness or condition	6.0
1995 [164]	Questionnaire survey	Patients at outpatients, GP surgeries, and acupuncture and shiatsu clinics	Not given	At acupuncture or shiatsu clinic (CAM) At GP surgery or outpatients and had never seen CAM practitioner (OM only)	200 questionnaires distributed at acupuncture and shiatsu clinics and GP surgeries 100 questionnaires distributed at outpatients	187 completed: 31 from GP surgeries (47% response rate quoted) 69 from acupuncture (67% response rate quoted) and shiatsu clinics (58% response rates quoted) 87 from outpatients (no response rate given)	*One way analysis of variance:* ▪ Compared to OM only group, CAM group more likely to be: female ($p<0.05$), younger ($p<0.01$), more left wing ($p<0.01$), higher occupational status ($p<0.05$), less religious ($p<0.01$) *One way analysis of variance adjusted for age, sex, political beliefs, occupational status and religion:* ▪ Compared to OM only group, CAM group believed these factors were more important: psychological ($p<0.05$), environmental ($p<0.05$), emotional well-being ($p<0.05$), self-medication ($p<0.01$), medical treatment ($p<0.01$)	7.5
2003 [165]	Questionnaire survey	Outpatients at the Royal London Homeopathic Hospital	1997	Three consultations	786 eligible: 245 missed, did not attend, declined or excluded 541 questionnaires distributed	506 returned but 7 more excluded 93% response rate given	*Descriptive analysis* ▪ Most were female (81%) and white (81%) ▪ Most (79%) had asked GP for referral ▪ Most frequent reason for seeking CAM (304 of 493) was that other treatment had not helped	6.5

Table continued on next page

Year	Design	Population	Period	Exposure	Denominator	Numerator (response rate)	Results [a]	Quality
1996 [166]	Questionnaire survey	Patients waiting for treatment	Not given	Attended Royal Homeopathic Hospital, acupuncture centre, or British School of Osteopathy	Not given	268 patients: 87 homeopathy, 92 acupuncture, and 89 osteopathy 78% average response rate for three groups quoted	*Unadjusted descriptive analysis:* ▪ Females: 60% osteopathy, 81% homeopathy, 84% acupuncture ▪ Reason for treatment with mean rating ≥4 out of 5 in all groups: - OM ineffective for problem - CAM would be more effective - CAM allows active role - Value emphasis on whole person - Relaxed after CAM - Practitioner's explanation makes sense	6.0
2004 [167]	Questionnaire survey	Adult respondents to Omnibus survey	2001	Used practitioner to receive CAM in past 12 months	2761 eligible addresses	1794 (65%) respondents	*Unadjusted descriptive analysis:* ▪ 52% not told GPs of visits to CAM practitioners ▪ Used less in north (4.3%, 2.8-6.5) than England (10.0%, 8.6-11.7) ▪ Proportions using CAM varied with age (p = 0.012): highest (14%) 45-54 ▪ Use more likely if: - Income ≥£15.6k (14.4%, 11.6-17.7) than less (7.8%, 6.4-9.5) - Non-manual (14.1%, 12.0-16.4) than manual social class (4.9%, 3.6-6.8) - Full-time education to ≥ 19 (19.7%, 15.9-24.1) than < 19 (7.7%, 6.4-9.3)	7.5
1995 [168]	Questionnaire survey	Patients attending CAM and OM practitioners	Not given	Attended Royal Homeopathic Hospital, acupuncture centre, British School of Osteopathy, or general practice	Not given	256 patients: 76 homeopathy, 57 acupuncture, 65 osteopathy, and 58 general practice Response rate of 60% given for general practice patients and over 70% for other groups	*One way analysis of variance:* ▪ Significant differences between groups (p<0.05) with GP patients: least likely to be consulting another practitioner, oldest, shortest illness, least likely to have had serious illness in last 5 years, least likely to have chronic illness ▪ Significant differences between groups (p<0.001) with GP patients least agreeing, although all agreed, that CAM practitioners are more sympathetic and sensitive, better at explaining, and have more time to listen *Analysis of covariance adjusted for age, number of children, significant medical history variables:* ▪ GP patients have least healthy lifestyles (p<0.05) and place least importance on a healthy mind (p<0.05) ▪ Significant differences between groups (p<0.05) with GP patients: - Most satisfied with GPs, confident about prescribed drugs, faith in medical science, support for science - Least likely to read about health or be concerned about medicine's harmful effects or global environment	6.0

Table continued on next page

Year	Design	Population	Period	Exposure	Denominator	Numerator (response rate)	Results [a]	Quality
1993 [169]	Questionnaire survey	Patients visiting general practice, or Royal Homeopathic Hospital	Not given	Being a patient	100 questionnaires distributed to each setting	160 included: 80 completed by homeopathic patients 90 completed by general practice patients but last 10 discarded	*Unadjusted analysis:* ▪ Homeopathy patients more likely to be older (mainly 41-50 compared to 31-40, $p<0.05$) and have higher incomes ($p<0.05$) than GP patients *Multivariate analysis of covariance adjusted for age and income:* ▪ Homeopathy more likely than GP patients to: - Believe they will get asthma ($p<0.001$) - Believe they will get sleeplessness ($p<0.05$) - Believe good diet ($p<0.05$), relaxation ($p<0.001$), sleeping ($p<0.01$), meditation ($p<0.001$), less drinking ($p<0.01$), less smoking ($p<0.05$), less stress ($p<0.001$) prevents illness - Believe in treating whole person ($p<0.001$) - Believe that body can heal itself ($p<0.01$) - Have tried acupuncture ($p<0.001$) or osteopathy ($p<0.001$) - Be dissatisfied with OM ($p<0.001$) - Think they will live longer ($p<0.05$) - Have higher Langner mental health scores ($p<0.001$) - Believe they have greater self-control over health ($p<0.05$) ▪ Homeopathy less likely than GP patients to: - Like to leave their health in others' hands ($p<0.01$) - Be satisfied with last visit to practitioner ($p<0.001$) - Notice TV or radio health recommendations (p unclear)	7.0
1997 [170]	Questionnaire survey	New patients of CAM practitioner, or GP patients with symptoms for more than 7 days	1994 to 1995	Consulted practitioner	68 CAM patients 659 GP patients but 441 ineligible, leaving 218	254 initial questionnaires completed: 46 complementary practitioner and 208 GP 191 follow-up questionnaires completed: 34 CAM practitioner and 157 GP	*Descriptive analysis* ▪ 73% of CAM patients and 50% of GP patients had symptoms for > 12 weeks *Chi^2 analysis:* ▪ CAM patients more likely to have had longer education ($p=0.003$) *Mann-Whitney analysis:* ▪ CAM patients have lower bodily pain scores ($p=0.013$)	5.5
1995 [171]	Questionnaire survey	Patients attending CAM and OM practitioners	Not given	Attended Royal Homeopathic Hospital, acupuncture centre, British School of Osteopathy, or general practice	Not given	216 patients: 73 homeopathy, 47 acupuncture, 46 osteopathy, 50 general practice 60% initial response rate given with no difference between groups	*One-way analysis of variance:* ▪ Significant difference between groups for length of illness ($p<0.005$): GP patients had shortest illness	7.0

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Year	Design	Population	Period	Exposure	Denominator	Numerator (response rate)	Results [a]	Quality
1996 [172]	Questionnaire survey	Random sample of residents on a population health register	1993	Used CAM	500 questionnaires distributed 10 undelivered, leaving 490	341 (70%) completed	*Descriptive analysis:* ▪ Most often (58%) chosen because of friend's or colleague's recommendation ▪ Next highest proportion (28%) indicated that a doctor or health professional had either referred them or recommended CAM	7.0
2000 [233]	Questionnaire survey	Recruited from university panel and by market research agency	Not given	Ever tried CAM	Not given	430 participants, 70% from market research agency Response rates given as 95% for market research agency and 92% for university panel	*Regression analyses adjusted for number of therapies heard of, and used, sex, age, religious/political beliefs, history of serious illness, comparative/current health:* ▪ Less well disposed to homeopathy if tried fewer therapies ($p<0.05$) ▪ More well disposed to homeopathy if tried more therapies ($p<0.01$)	6.0
2001 [234]	Questionnaire survey	People approached at various locations	Not given	Homeopathy use assessed at 4 weeks	500 questionnaires distributed	343 (69%) returned 139 contacted at 4 weeks	*Regression analysis including sex, intention to use homeopathy, perceived behavioural control, self-efficacy, prior use of homeopathy:* ▪ Use associated with past use ($p<0.01$) and intention to use ($p<0.001$).	7.0

Appendix 33: Eligible studies from the systematic literature review about over-the-counter (OTC) medicine

Year	Design	Population	Period	Exposure	Denominator	Numerator (response rate)	Results [a]	Quality
2005 [18 & 235]	Questionnaire survey	Adults 35 years or older on health authority register	2000	Purchased OTC medicine in previous month	10000 questionnaires distributed 9469 excluding deaths and departures	6322 (67%) completed	*Unadjusted chi^2 analysis:* ▪ Less likely among people <60 who were exempt from charges than those who would have to pay (OR 0.75, 0.6-0.9) *Regression analysis adjusted for age, sex, social class, health, exercise, smoking, perceived vascular risk:* ▪ More likely: - Female (OR 1.86, 1.66-2.08) - Poor (e.g. OR 1.78, 1.32-2.41) and fair or good than excellent health - Perceive vascular risk than no risk (OR 1.21, 1.06-1.39) - Collecting prescription medicine (OR 2.02, 1.79-2.28) ▪ Less likely: - All ages than 35-44 (e.g. OR for 65-74 0.47, 0.39-0.57) - Intermediate or routine/manual (e.g. OR 0.77, 0.67-0.88) than professional/managerial occupation	8.5
2001 [106]	Questionnaire survey	Adults from health authority populations	1998	Purchased CAM OTC in past 12 months	5010 questionnaires distributed 269 undelivered, leaving 4741	2853 returned but 107 blank and 78 completed by wrong person 59% (2669/4556) response rate given	*Unadjusted chi^2 analysis:* ▪ More likely in women (32.6%, 30.0-35.1) than men (12.0%, 10.2-13.8) (p<0.001) ▪ Significant difference by age (p<0.001): 23.5% 18-44 (21.1-25.9), 24.6% 45-64 (21.6-27.5), 16.8% 65-74 (12.4-21.2), 15.5% > 75 (10.9-20.2)	7.5
1996 [173]	Questionnaire survey	Adults ≥ 65 at community pharmacies in Northern Ireland	1993 & 1994	Purchased non-prescription drugs	Not given for pharmacies or patients	515 completed Response rate not given for pharmacies or patients	*Unadjusted descriptive analysis:* ▪ Most common reason (about 19%) that symptoms not severe enough for doctor	4.0
2004 [174]	Questionnaire survey	People attending general practices	1999	Used non-prescription medicine in last 7 days	General practices purposively chosen 461 eligible patients approached	427 (93%) completed pre-consultation questionnaire 305 completed pre- and post-consultation questionnaires (71% response rate given)	*Stepwise regression analysis including age, sex, deprivation, prescription charges, used prescribed medicine in last seven days, and practice:* ▪ Use more likely in < 60 than > 60 (OR 1.85, 1.13-3.02) *Additionally in univariate chi^2 analysis:* ▪ Use more likely in not than exempt from charges (OR 1.71, 1.07-2.73) ▪ Use less likely in least than most affluent group (OR 0.28, 0.09-0.90)	7.0

[a] This table only shows results that are significant or reported as key findings rather than the results of all variables tested in analyses.

Table continued on next page

Year	Design	Population	Period	Exposure	Denominator	Numerator (response rate)	Results [a]	Quality
2005 [175]	Questionnaire survey	Members of the public in shopping centres	2002	Purchased non-prescription medicines	Not given	1000 participated (response rate not given)	*Unadjusted chi^2 analysis:* ▪ More likely to buy weekly or monthly than less often if: - Female (36%) than male (27%) (p<0.05) - ≤60 (36%) than >60 (21%) (p<0.001) - Pays for prescriptions compared with exempt (p<0.05)	6.0
1997 [176]	Questionnaire survey	Customers at pharmacies	1996	Bought H2 antagonists for dyspepsia, aciclovir cream for cold sores, imidazoles for thrush, nasal spray for hay fever, or got them on private prescription	311 pharmacies 3000 questionnaires distributed	679 (23%) returned 628 eligible	*Regression analysis including 18 (of initial 23) significant (p < 0.05) variables from chi-squared analysis (no significance levels given for regression analysis):* ▪ Top predictors of OTC purchase: - Preference - Knowledge of availability - Liability for prescription charge - Not taking prescription medicine	4.5
2005 [177]	Questionnaire survey	Adults on electoral roll	2002	Used OTC analgesics in last two weeks	3000 questionnaires distributed 292 people had died, moved or were excluded, leaving 2708	1501 (55%) completed	*Stepwise regression analysis with significant factors from chi^2 analysis:* ▪ Predictors of use: - <60 relative to ≥60 (odds ratio (OR) 1.52, 1.05-2.20) - Female relative to male (OR 1.70, 1.33-2.18) - ≥O'levels relative to up to O'level (OR 1.47, 1.12-1.94) - Poor/fair (OR 2.01, 1.20-3.36) and good/very good (OR 1.94, 1.28-2.94) relative to excellent health - Pays prescription fees relative to not (OR 1.55, 1.10-2.13) - Not relative to using prescription analgesics (OR 2.17, 1.49-3.14) *Additionally in unadjusted chi^2 analysis:* ▪ Use of non-prescription analgesics more likely if: - Married relative to other status (OR 1.32, 1.07-1.64) - Drinks alcohol relative to does not (OR 1.84, 1.41-2.39) - More relative to less affluent (p≤0.01 for trend, OR 2.69 for category 1 relative to 7, 1.45-5.01)	9.5

Table continued on next page

Year	Design	Population	Period	Exposure	Denominator	Numerator (response rate)	Results [a]	Quality
2006 [178]	Interview study	Women attending yoga groups, therapy centre and women's book group	Not given	Used herbal medicine in past 12 months	70 preliminary questionnaires distributed	18 herbal medicine users responded and all agreed to be interviewed	*Qualitative analysis:* ▪ Motivations: - Perceived advantages: most often (15 of 18) personal control - Disadvantages of conventional care: most often (6 of 14) that doctors are unable to help with some problems - Disadvantages of conventional medicines: most often (12 of 12) that they are chemical	7.0
2002 [179]	Focus group and interview study	Focus groups of 16-24s: students, mothers, job-seekers, people with asthma Interviews: people asking for advice about ailment or buying treatment	1997 to 1998	Management of minor ailments	Not given	48 focus group participants (response rate not given) 76 structured interviews (74% response rate) 9 in-depth interviews (90% response rate)	*Unadjusted descriptive and qualitative analysis:* ▪ Decision to ask for medicine most commonly (38%) influenced by mother ▪ Schemas to manage minor ailments drawn up from experiences ▪ Combine salient information from adverts with past experience	6.5
2004 [180]	Questionnaire survey	Adults on health authority general practice register	2001	Usually take herbal supplements	21923 questionnaires distributed	15465 (71%) completed	*Regression analysis adjusted for age, sex, housing tenure:* ▪ More likely in: - 45-64 than 18-44 (OR 1.45, 1.34-1.67) - Women (OR 3.11, 2.79-3.48) - White than non-white (OR 2.45, 1.75-3.44) - Active than sedentary (OR 1.29, 1.16-1.43) - Possible than unlikely psychiatric morbidity (OR 1.21, 1.08-1.34) - On than not on prescribed medication (OR 1.13, 1.02-1.26) ▪ Less likely in >75 than 18-44 (OR 0.88, 0.82-0.94) *Plus in regression analysis adjusted for age, sex:* ▪ More likely in private than rented housing (OR 1.74, 1.55-1.99) *Additionally in unadjusted analysis:* ▪ More likely in non-smoker than smoker (OR 1.14, 1.02-1.26)	9.0
1998 [181]	Questionnaire survey	Adults attending general practices	1995	Used OTC remedies regularly	3030 questionnaires distributed	2765 (91%) completed 141 excluded, leaving 2624	*Unadjusted chi^2 analysis:* ▪ More frequent in females than males (p<0.01) and social class I-IIINM than IIIM-V (p<0.01) ▪ Varied significantly with age (p<0.01) and highest (31%) in 45-64	8.5

Table continued on next page

Year	Design	Population	Period	Exposure	Denominator	Numerator (response rate)	Results [a]	Quality
1999 [182]	Questionnaire survey	Customers at pharmacies selling homeopathic remedies	1996 to 1998	Purchased homeopathic medicines	120 pharmacies approached 1090 questionnaires distributed	109 (91%) pharmacies participated 417 questionnaires returned 10 spoiled, leaving 407 (37%)	*Unadjusted descriptive analysis:* ▪ 78% of 404 who gave their gender were female ▪ Highest proportion (30%) of 404 who gave their age were 46-60 ▪ Most frequent prompt (67%) was that they always use them	5.0
2002 [183]	Questionnaire survey	People who had just purchased OTC homeopathic remedies in health food shops	2000 to 2001	Purchased OTC homeopathy	3 shops approached 75 people approached	All shops participated 2 people refused, leaving 73	*Unadjusted descriptive analysis:* ▪ 62 of 75 people approached were female ▪ Highest proportion of respondents (30%) were 36-45 years ▪ Most common reason (72% strongly agree) was more natural ▪ First purchase most often (45%) prompted by friend or relative	5.0

Appendix 34: Eligible studies from the systematic literature review about the private sector

Year	Design	Population	Period	Exposure	Denominator	Numerator (response rate)	Results [a]	Quality
1999 [184]	Estimation of model of demand for individually purchased private health insurance	British Social Attitudes survey respondents	1986 to 1991	Purchased private health insurance	Not given	Annual survey of about 3000 (no response rate given)	*Unadjusted descriptive analysis (no significance levels):* ▪ 50-65 highest proportion with insurance (27% v 22% with none) ▪ 66% with insurance and 37% with none have income >£15k ▪ 13% with insurance and 7% with none have degree ▪ 88% with insurance and 66% with none were home owners ▪ 59% with insurance and 33% with none supported the right *Estimates of demand for individually purchased private health insurance using more sophisticated model including regional dummy variables:* ▪ Positively associated with: - Income (z statistic=13.4) - Educational attainment (z statistic highest for A levels=7.2) - Age but falls > 65 years (z statistic highest for 50-65=7.0) - Being a home owner (z statistic=4.8) - Long-term NHS waiting lists (z statistic=1.8) ▪ Negatively associated with: - Number of adults in household (z statistic=-5.1) - Being employed in public sector (z statistic=-2.7)	3.5
2005 [185]	Panel survey	Adults taking part in British Household Panel Survey	1997 to 2000	Purchased private medical insurance	Not given	Sample in 1996 included 7910 individuals 7.6%, 8.0%, 8.0% and 8.1% lost, respectively, in 1997,1998, 1999 and 2000, but increased to 8529 in 2000 No response rate given	*Random effects logistic regression analysis:* ▪ More likely: - As age increases (odds ratio (OR) 1.29 per year, p<0.001) - Basic qualification relative to less (OR 8.54, p<0.001) - Paid work relative to not (OR 2.13, p=0.001) - As income increases (OR 1.0002 per £1 per month, p<0.001) - If professional or manager relative to semi-skilled, unskilled or unemployed (OR 1.84, p=0.005) - Centre-right relative to other (OR 3.44, p<0.001) - As supply surgeons in region increases (OR 1.67, p=0.041) - As inpatient waiting time increases (OR 1.04, p=0.002) ▪ Less likely if female (OR 0.32, p<0.001) and as outpatient waiting time increases (OR 0.98, p=0.02)	7.5

[a] This table only shows results that are significant or reported as key findings rather than the results of all variables tested in analyses.

Table continued on next page

Year	Design	Population	Period	Exposure	Denominator	Numerator (response rate)	Results [a]	Quality
2001 [186]	Cohort analysis	Family Expenditure Survey respondents	1978 to 1996	Purchased private medical insurance	Not given	Overall sample size of survey is 77601 (no response rate given)	*Weighted least squares regression analysis*: ▪ Increases with age but older less likely than younger cohorts ▪ Positively associated with income (significance unclear) ▪ Positively associated with number of part-time consultants and private hospitals in region (significance unclear) ▪ Negatively associated with number of NHS beds (significance unclear)	6.0
2000 [187]	Estimation of model of the use of health care services	British Household Panel Survey respondents	Not given	Used private medical or dental care	Not given	Annual survey of about 5000 households (no response rate given)	*Multinomial logit model of the use of public and private care:* ▪ Private care positively associated with: - Being employed (z statistic=1.5) - Income (z statistic=9.2) - Being a conservative voter (z statistic=5.6) - Being less supportive of NHS principles (z statistic=4.7) - Using private care last year (z statistic=36.4) ▪ Private care negatively associated with: - Living in rented housing (z statistic=10.3) - Being limited in daily activities (z statistic=2.4) - Used NHS care last year (z statistic=21.8)	3.5
1999 [188]	Questionnaire survey	≥ 16 and taking part in the Omnibus survey	Not given	Used private dental care	2668 eligible addresses 232 people uncontactable	571 people refused 1865 (70% of 2668) participated	*Chi-squared analysis with compensation for multiple testing:* ▪ Income most significant determinant ($p<0.05$, 46% if >£30k, 28% if £10-30k, 16% if <£10k)	7.0
2005 [189]	Prospective survey of GP referrals	General practices in Trent Focus Collaborative Research Network	2001	Referral to NHS or private sector	Not given	10 practices (no response rate given) 100263 registered patients	*Regression analysis including sex, age group, practice, specialty, deprivation:* ▪ Less likely as deprivation increases (OR 0.17 for most compared with least deprived quintile, 0.13-0.22) ▪ Most likely if 45-54 (OR 2.75 relative to < 5, 1.66-4.55) ▪ Associated with specialty and practice	8.5

Appendix 35: Summary of results from univariate analyses [a]

Variable	p values [b]	Notes
Background information	Significance cut-off=0.05/14=0.004	
Sex	chi^2 p=0.001	
Age	t-test p=0.025 Wilcoxon p=0.016	
Ethnic group	No tests performed	
Index of multiple deprivation score	t-test p=0.541 Wilcoxon p=0.667	
Index of multiple deprivation rank	t-test p=0.570 Wilcoxon p=0.671	
Index of multiple deprivation quartile	Homogeneity chi^2 p=0.397 Trend chi^2 p=0.853	
Qualifications	Homogeneity chi^2 p=0.111 Trend chi^2 p=0.025	
Worked as a health professional	chi^2 p=0.000	
Employment status	Homogeneity chi^2 p=0.068 Trend chi^2 p=0.008	
Knowledge and views of self-tests	Significance cut-off=0.05/10=0.005	
Confidence using self-test	t-test p=0.001 Wilcoxon p<0.001	
Knowledge of any tests listed	All: t-test p=0.000 Wilcoxon p=0.000	
Knowledge of tests listed except pregnancy test		Knowledge of any tests listed used in regression
Knowledge of tests listed except test for high blood pressure		
Knowledge of tests listed except test for high blood pressure or pregnancy		

[a] Results are reported to three decimal places for precision and significant cells are shaded

[b] The significance cut-off for each group of variables, based on the adjustment for multiple comparisons, is shown to the right of the name of the group.

Table continued on next page

Variable	p values	Notes
Habits and lifestyle	Significance cut-off=0.05/7=0.007	
Smoking	chi^2 p=0.320	
Exercise	Homogeneity chi^2 p=0.010 Trend chi^2 p=0.904	
Fruit and vegetables	Homogeneity chi^2 p=0.370 Trend chi^2 p=0.084	
Internet use	Homogeneity chi^2 p=0.094 Trend chi^2 p=0.267	
Knowledge of health recommendations	Significance cut-off=0.05/2=0.025	
Recommendation about fruit and vegetables	chi^2 p=0.495	
Recommendation about days of exercise	chi^2 p=0.882	
Information about health	Significance cut-off=0.05/12=0.004	
Health advice from anyone listed	t-test p=0.733 Wilcoxon p=0.545	
Health advice from lay person	t-test p=0.034 Wilcoxon p=0.011	
Health advice from health professional	t-test p=0.280 Wilcoxon p=0.202	
Health advice from complementary therapist	Homogeneity chi^2 p=0.159 Trend chi^2 p=0.775	
Health information from any source listed	t-test p=0.000 Wilcoxon p=0.000	Score including NHS Direct used in regression
Health information from any source listed except NHS Direct	t-test p=0.000 Wilcoxon p=0.000	
Health status	Significance cut-off=0.05/7=0.007	
Self-rated health during last 12 months	Homogeneity chi^2 p=0.176 Trend chi^2 p=0.616	
Limiting long-term illness	chi^2 p=0.294	
SF-8 Physical Health Measure	t-test p=0.226 Wilcoxon p=0.027	
SF-8 Mental Health Measure	t-test p=0.167 Wilcoxon p=0.303	

Table continued on next page

Variable	p values	Notes
Thoughts about how to stay healthy and future illnesses	Significance cut-off=0.05/4=0.013	
Things to stay healthy	Homogeneity chi^2 p=0.731 Trend chi^2 p=0.201	
Future illnesses	Homogeneity chi^2 p=0.353 Trend chi^2 p=0.915	
Views about health checks	Significance cut-off=0.05/8=0.006	
Medical tests are reassuring	Homogeneity chi^2 p=0.912 Trend chi^2 p=0.784	
Curious about health	Homogeneity chi^2 p=0.062 Trend chi^2 p=0.107	
Like routine health checks	Homogeneity chi^2 p=0.594 Trend chi^2 p=0.534	
Medical tests cause anxiety	Homogeneity chi^2 p=0.712 Trend chi^2 p=0.957	
Views about visiting the GP	Significance cut-off=0.05/16=0.003	
Only go to doctor if symptoms	Homogeneity chi^2 p=0.643 Trend chi^2 p=0.431	
Need symptoms for test	Homogeneity chi^2 p=0.471 Trend chi^2 p=0.830	
Do not like to bother doctor	Homogeneity chi^2 p=0.729 Trend chi^2 p=0.663	
Only go to doctor if severe or serious symptoms	Homogeneity chi^2 p=0.041 Trend chi^2 p=0.658	
Evidence to justify visit to doctor	Homogeneity chi^2 p=0.493 Trend chi^2 p=0.160	
Embarrassed to tell doctor about personal problems	Homogeneity chi^2 p=0.526 Trend chi^2 p=0.324	
Happy to ask doctor for check-up	Homogeneity chi^2 p=0.093 Trend chi^2 p=0.168	
Confident doctor would do test	Homogeneity chi^2 p=0.065 Trend chi^2 p=0.013	

Table continued on next page

Variable	p values	Notes
Access to the GP	Significance cut-off=0.05/6=0.008	
Appointment as soon as would like	Homogeneity chi^2 p=0.355 Trend chi^2 p=0.200	
Appointment at suitable time	Homogeneity chi^2 p=0.527 Trend chi^2 p=0.300	
Travel to GP surgery	Homogeneity chi^2 p=0.062 Trend chi^2 p=0.040	
Satisfaction with healthcare	Significance cut-off=0.05/6=0.008	
Satisfaction with GP consultations	t-test p=0.002 Wilcoxon p=0.003	
Satisfaction with own care	Homogeneity chi^2 p=0.007 Trend chi^2 p=0.002	
Satisfaction with other's care	Homogeneity chi^2 p=0.500 Trend chi^2 p=0.134	
Health locus of control	Significance cut-off=0.05/8=0.006	
Internal control	t-test p=0.967 Wilcoxon p=0.943	
Chance	t-test p=0.206 Wilcoxon p=0.191	
Powerful others	t-test p=0.005 Wilcoxon p=0.007	
Health value	t-test p=0.567 Wilcoxon p=0.568	

Appendix 36: Variables used in regression analyses and their recategorisation

Variable	Type	Categories	Recoding[a]
Background information			
Age	Numerical		
Sex	Categorical	Men	1
		Women	2
		(no BLANKs)	
Ethnic group	Categorical	White	1
		Other ethnic groups	2
		(no BLANKs)	
IMD 2007 score	Numerical		
Qualifications	Categorical	Level 4 (highest level)	1
		Level 1-3	2
		Other qualifications	3
		No qualifications	4
		BLANK	Empty
Worked as a health professional	Categorical	Yes	1
		No	2
		BLANK	Empty
Employment status	Categorical	Employed & Economically active full-time student	1
		Self-employed	2
		Retired	3
		Economically inactive	4
		(no BLANKs)	
Knowledge and views of self-tests			
Confidence using self-test	Categorical	Very confident	1
		Fairly confident	2
		Neither confident nor unconfident	3
		Fairly unconfident & Very unconfident	4
		BLANK	Empty

[a] Numerical variables did not need to be recoded and were already empty where the value was missing for a respondent.

Table continued on next page

Variable	Type	Categories	Recoding[a]
Knowledge of any tests listed	Numerical		
Habits and lifestyle			
Smoking	Categorical	Yes	1
		No	2
		BLANK	Empty
Exercise	Categorical	Five days a week or more	1
		About three or four days a week	2
		About one or two days a week	3
		Less than once a week but at least once a month	4
		Less than once a month	5
		Never or almost never	6
		BLANK	Empty
Fruit and vegetables	Categorical	Five times a day or more	1
		About three or four times a day	2
		About one or two times a day	3
		Less than once a day but at least once a week, Less than once a week & Never or almost never	4
		BLANK	Empty
Internet use	Categorical	Five days a day or more	1
		About three or four times a day	2
		About one or two times a day	3
		Less than once a day but at least once a week	4
		Less than once a week	5
		Never or almost never	6
		BLANK	Empty
Knowledge of health recommendations			
Recommendation about fruit and vegetables	Categorical	Five	1
		Other answers	2
		BLANK	Empty

Table continued on next page

Variable	Type	Categories	Recoding[a]
Recommendation about exercise	Categorical	Five	1
		Other answers	2
		BLANK	Empty
Information about health			
Health advice from anyone listed	Numerical		
Health advice from lay person	Numerical		
Health advice from health professional	Numerical		
Health advice from a complementary therapist	Categorical	Three or more times	1
		Once or twice	2
		Not at all & Not sure	3
		BLANK	Empty
Health information from any source listed	Numerical		
Health status			
Self-rated health during last 12 months	Categorical	Good	1
		Fairly good	2
		Not good	3
		BLANK	Empty
Long-term illness	Categorical	Yes	1
		No	2
		BLANK	Empty
SF8 physical health measure	Numerical		
SF8 mental health measure	Numerical		

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Variable	Type	Categories	Recoding[a]
Thoughts about how to stay healthy and future illnesses			
Things to stay healthy	Categorical	Every day	1
		Every two or three days	2
		About once a week	3
		Less than once a week but at least once a month	4
		Less than once a month	5
		Never or almost never	6
		BLANK	Empty
Future illnesses	Categorical	Every day	1
		Every two or three days	2
		About once a week	3
		Less than once a week but at least once a month	4
		Less than once a month	5
		Never or almost never	6
		BLANK	Empty
Views about health checks and medical tests			
Medical tests are reassuring	Categorical	Strongly agree	1
		Agree	2
		Neither agree nor disagree	3
		Disagree & Strongly disagree	4
		BLANK	Empty
Curious about health	Categorical	Strongly agree	1
		Agree	2
		Neither agree nor disagree	3
		Disagree & Strongly disagree	4
		BLANK	Empty

Table continued on next page

Variable	Type	Categories	Recoding[a]
Like routine health checks	Categorical	Strongly agree	1
		Agree	2
		Neither agree nor disagree	3
		Disagree & Strongly disagree	4
		BLANK	Empty
Medical tests cause anxiety	Categorical	Strongly agree	1
		Agree	2
		Neither agree nor disagree	3
		Disagree	4
		Strongly disagree	5
		BLANK	Empty
Views about visiting the GP			
Only go to doctor if symptoms	Categorical	Strongly agree	1
		Agree	2
		Neither agree nor disagree	3
		Disagree & Strongly disagree	4
		BLANK	Empty
Need symptoms or risk factors to get test	Categorical	Strongly agree	1
		Agree	2
		Neither agree nor disagree	3
		Disagree	4
		Strongly disagree	5
		BLANK	Empty
Do not like to bother doctor	Categorical	Strongly agree	1
		Agree	2
		Neither agree nor disagree	3
		Disagree & Strongly disagree	4
		BLANK	Empty

Table continued on next page

Variable	Type	Categories	Recoding[a]
Only go to doctor if severe or serious symptoms	Categorical	Strongly agree	1
		Agree	2
		Neither agree nor disagree	3
		Disagree	4
		Strongly disagree	5
		BLANK	Empty
Evidence to justify visit to doctor	Categorical	Strongly agree	1
		Agree	2
		Neither agree nor disagree	3
		Disagree & Strongly disagree	4
		BLANK	Empty
Embarrassed to tell doctor	Categorical	Strongly agree	1
		Agree	2
		Neither agree nor disagree	3
		Disagree	4
		Strongly disagree	5
		BLANK	Empty
Happy to ask doctor for check-up	Categorical	Strongly agree	1
		Agree	2
		Neither agree nor disagree	3
		Disagree & Strongly disagree	4
		BLANK	Empty
Confident doctor would do test	Categorical	Strongly agree	1
		Agree	2
		Neither agree nor disagree	3
		Disagree & Strongly disagree	4
		BLANK	Empty

Table continued on next page

Variable	Type	Categories	Recoding[a]
Access to the GP			
Appointment as soon as would like	Categorical	Very easy	1
		Fairly easy	2
		Neither easy nor difficult	3
		Fairly difficult	4
		Very difficult	5
		Never been to GP surgery & BLANK	Empty
Appointment at suitable time	Categorical	Very easy	1
		Fairly easy	2
		Neither easy nor difficult	3
		Fairly difficult	4
		Very difficult	5
		Never been to GP surgery & BLANK	Empty
Travel to GP surgery	Categorical	Very easy	1
		Fairly easy	2
		Neither easy nor difficult	3
		Fairly difficult & Very difficult	4
		Never been to GP surgery & BLANK	Empty
Satisfaction with healthcare			
Satisfaction with GP consultations	Numerical		
Satisfaction with own care	Categorical	Very satisfied	1
		Satisfied	2
		Neither satisfied nor dissatisfied	3
		Dissatisfied & Very dissatisfied	4
		BLANK	Empty
Satisfaction with other's care	Categorical	Very satisfied	1
		Satisfied	2
		Neither satisfied nor dissatisfied	3
		Dissatisfied & Very dissatisfied	4
		BLANK	Empty

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Health locus of control			
Health locus of control score for internal control	Numerical		
Health locus of control score for chance	Numerical		
Health locus of control score for powerful others	Numerical		
Health value	Numerical		

Appendix 37: Final models generated by stepwise forward regression analyses of variables grouped according to their focus

Personal characteristics:

Variables in the order they were added	Coefficient (β)	Standard error of coefficient	Wald	df	p value	Odds ratio (exp (b))	95% confidence interval	
Sex								
Male (reference)								
Female	0.607	0.202	8.994	1	0.003	1.834	1.234	2.728
Age	-0.010	0.006	2.812	1	0.094	0.990	0.978	1.002
Constant	-2.192	0.381	33.042	1	0.000	n/a	n/a	n/a

Footnotes: Statistics usually reported to three decimal places for precision, but fewer decimal placed reported if fewer provided.

Number of observations=1521 Cox & Snell R^2=0.010

Log likelihood=-441.477 Nagelkerke R^2=0.021

LR chi^2=14.54, df=2, p<0.001 Hosmer Lemeshow chi^2=7.111, df=8, p=0.525

Variables associated with affluence or occupation:

Variables in the order they were added	Coefficient (β)	Standard error of coefficient	Wald	df	p value	Odds ratio (exp (b))	95% confidence interval	
Worked as a health professional (reference)								
Never worked as a health professional	-1.089	0.233	21.826	1	0.000	0.337	0.213	0.531
Economic activity								
Employed (reference)			7.354	3				
Self-employed	-0.085	0.285	0.090	1	0.764	0.918	0.525	1.605
Retired	-0.494	0.245	4.057	1	0.044	0.610	0.377	0.987
Economically inactive	-0.711	0.336	4.488	1	0.034	0.491	0.254	0.948
Constant	-1.239	0.221	31.354	1	0.000	n/a	n/a	n/a

Footnotes: Statistics usually reported to three decimal places for precision, but fewer decimal placed reported if fewer provided.

Number of observations=1479

Cox & Snell R^2=0.018

Log likelihood=-419.638

Nagelkerke R^2=0.041

LR chi^2=27.05, df=4, p<0.001

Hosmer Lemeshow chi^2=1.160, df=3, p=0.763

Variables related to self-test use:

Variables in the order they were added	Coefficient (β)	Standard error of coefficient	Wald	df	p value	Odds ratio (exp (b))	95% confidence interval	
Knowledge of any test listed	0.181	0.032	32.310	1	0.000	1.199	1.126	1.276
Confidence using self-test								
Very confident (reference)			7.696	3				
Fairly confident	-0.203	0.212	0.912	1	0.340	0.816	0.538	1.238
Neither confident nor unconfident	-0.420	0.300	1.958	1	0.162	0.657	0.365	1.183
Fairly or very unconfident	-2.564	1.020	6.314	1	0.012	0.077	0.010	0.569
Constant	-2.891	0.243	142.061	1	0.000	n/a	n/a	n/a

Footnotes: Statistics usually reported to three decimal places for precision, but fewer decimal placed reported if fewer provided.

Number of observations=1459 — Cox & Snell R^2=0.035

Log likelihood=-408.032 — Nagelkerke R^2=0.077

LR chi^2=51.33, df=4, p<0.001 — Hosmer Lemeshow chi^2=11.751, df=8, p=0.163

Behaviours:

Variables in the order they were added	Coefficient (β)	Standard error of coefficient	Wald	df	p value	Odds ratio (exp (b))	95% confidence interval	
Exercise								
Five days a week or more (reference)			13.427	5				
About three or four days a week	0.824	0.335	6.070	1	0.014	2.280	1.184	4.393
About one or two days a week	0.408	0.346	1.389	1	0.239	1.504	0.763	2.964
Less than once a week but at least once a month	0.620	0.382	2.631	1	0.105	1.859	0.879	3.931
Exercise less than once a month	1.186	0.454	6.819	1	0.009	3.273	1.344	7.969
Exercise never or almost never	-0.219	0.545	0.161	1	0.688	0.804	0.276	2.338
Constant	-2.890	0.297	94.975	1	0.000	n/a	n/a	n/a

Footnotes: Statistics usually reported to three decimal places for precision, but fewer decimal placed reported if fewer provided.

Number of observations=1472 Cox & Snell R^2=0.010

Log likelihood=-425.410 Nagelkerke R^2=0.022

LR chi^2=14.24, df=5, p=0.014 Hosmer Lemeshow chi^2=0.000, df=3, p=1.000

Knowledge of health recommendations: No variables included in the final model.

Information about health:

Variables in the order they were added	Coefficient (β)	Standard error of coefficient	Wald	df	p value	Odds ratio (exp (b))	95% confidence interval	
Health information from any source listed	0.165	0.034	23.413	1	0.000	1.180	1.104	1.262
Health advice from health professional	-0.107	0.065	2.719	1	0.099	0.898	0.791	1.020
Constant	-2.799	0.193	209.591	1	0.000	n/a	n/a	n/a

Footnotes: Statistics usually reported to three decimal places for precision, but fewer decimal placed reported if fewer provided.

Number of observations=1254 Cox & Snell R^2=0.018

Log likelihood=-339.981 Nagelkerke R^2=0.041

LR chi^2=22.51, df=2, p<0.001 Hosmer Lemeshow chi^2=8.097, df=8, p=0.424

Health status:

Variables in the order they were added	Coefficient (β)	Standard error of coefficient	Wald	df	p value	Odds ratio (exp (b))	95% confidence interval	
Self-rated health during last 12 months								
Good (reference)			4.703	2				
Fairly good	-0.205	0.222	0.855	1	0.355	0.814	0.527	1.258
Not good	0.542	0.310	3.046	1	0.081	1.719	0.935	3.160
Constant	-2.357	0.116	416.201	1	0.000	n/a	n/a	n/a

Footnotes: Statistics usually reported to three decimal places for precision, but fewer decimal placed reported if fewer provided.

Number of observations=1467 Cox & Snell R^2=0.003

Log likelihood=-427.549 Nagelkerke R^2=0.007

LR chi^2=4.34, df=2, p=0.114 Hosmer Lemeshow chi^2=0.000, df=1, p=1.000

Thoughts about how to stay healthy and future illnesses: No variables included in the final model.

Views about medical tests:

Variables in the order they were added	**Coefficient (β)**	**Standard error of coefficient**	**Wald**	**df**	**p value**	**Odds ratio (exp (b))**	**95% confidence interval**	
Curious about health								
Strongly agree (reference)			6.811	3				
Agree	1.665	0.240	0.480	1	0.488	1.181	0.738	1.891
Neither agree nor disagree	-0.572	0.337	2.871	1	0.090	0.564	0.291	1.094
Disagree or strongly disagree	-0.256	0.558	0.210	1	0.647	0.774	0.259	2.312
Constant	-2.383	0.209	130.003	1	0.000	n/a	n/a	n/a

Footnotes: Statistics usually reported to three decimal places for precision, but fewer decimal placed reported if fewer provided.

Number of observations=1463

Cox & Snell R^2=0.005

Log likelihood=-418.381

Nagelkerke R^2=0.012

LR chi^2=7.71, df=3, p=0.053

Hosmer Lemeshow chi^2=0.000, df=2, p=1.000

Views about visiting the GP:

Variables in the order they were added	Coefficient (β)	Standard error of coefficient	Wald	df	p value	Odds ratio (exp (b))	95% confidence interval	
Confident doctor would do a test								
Strongly agree (reference)			9.489	3				
Agree	0.747	0.274	7.412	1	0.006	2.110	1.233	3.611
Neither agree nor disagree	0.768	0.323	5.670	1	0.017	2.155	1.145	4.056
Disagree or strongly disagree	0.985	0.380	6.712	1	0.010	2.679	1.271	5.645
Only go to doctor if severe or serious symptoms								
Strongly agree (reference)			10.922	4				
Agree	-0.735	0.277	7.037	1	0.008	0.479	0.278	0.825
Neither agree nor disagree	0.088	0.295	0.090	1	0.764	1.092	0.613	1.946
Disagree	-0.259	0.272	0.912	1	0.340	0.772	0.453	1.314
Strongly disagree	-0.178	0.640	0.078	1	0.781	0.837	0.239	2.935
Constant	-2.699	0.277	94.634	1	0.000	n/a	n/a	n/a

Footnotes: Statistics usually reported to three decimal places for precision, but fewer decimal placed reported if fewer provided.

Number of observations=1445 Cox & Snell R^2=0.014

Log likelihood=-410.301 Nagelkerke R^2=0.032

LR chi^2=20.68, df=7, p=0.004 Hosmer Lemeshow chi^2=2.010, df=7, p=0.959

Access to the GP: No variables included in the final model.

Satisfaction with healthcare:

Variables in the order they were added	Coefficient (β)	Standard error of coefficient	Wald	df	p value	Odds ratio (exp (b))	95% confidence interval	
Satisfaction with GP consultations	-0.045	0.014	9.662	1	0.002	0.956	0.929	0.983
Constant	-0.836	0.484	2.979	1	0.084	n/a	n/a	n/a

Footnotes: Statistics usually reported to three decimal places for precision, but fewer decimal placed reported if fewer provided.

Number of observations=1486

Log likelihood=-436.232

LR chi^2=9.26, df=1, p=0.002

Cox & Snell R^2=0.006

Nagelkerke R^2=0.014

Hosmer Lemeshow chi^2=2.588, df=6, p=0.859

Health locus of control:

Variables in the order they were added	Coefficient (β)	Standard error of coefficient	Wald	df	p value	Odds ratio (exp (b))	95% confidence interval	
Health locus of control score for powerful others	-0.060	0.018	11.335	1	0.001	0.941	0.909	0.975
Health locus of control score for chance	0.042	0.018	5.269	1	0.022	1.042	1.006	1.080
Constant	-2.087	0.385	29.336	1	0.000	n/a	n/a	n/a

Footnotes: Statistics usually reported to three decimal places for precision, but fewer decimal placed reported if fewer provided.

Number of observations=1485

Log likelihood=-431.697

LR chi^2=13.45, df=2, p=0.001

Cox & Snell R^2=0.009

Nagelkerke R^2=0.020

Hosmer Lemeshow chi^2=15.748, df=8, p=0.046