# SELF-MONITORING BLOOD PRESSURE IN PATIENTS WITH HYPERTENSION: WHO SELF-MONITORS AND WHY?

by

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#### **DEDICATIONS**

This thesis is dedicated to my husband Steven and my two beautiful children Isla and Oscar

#### **ABSTRACT**

Self-monitoring blood pressure (SMBP) has been shown to more accurately estimate true underlying BP but it is unclear how commonly it is practiced in the UK and why patients engage in this behaviour from a psychological perspective. A survey was first sent to primary care patients with hypertension (n=955) in the West Midlands, UK to establish the prevalence of SMBP. Secondly, interviews with respondents (n=16) combined with a review of previous empirical research informed the design of an in-depth questionnaire sent in the final stage of the study (n=236) to confirm the investigative associated factors. A third of the survey population 293/955 (31%) reported SMBP which was predicted by education, self-efficacy and doctors' health locus of control (DHLOC) (p<0.01). Age and negative outcome expectations about SMBP potentially moderated this relationship. A lack of available guidelines and poor communication with the General Practitioner (GP) about self-monitoring however resulted in a negative perception about whether engaging in SMBP had any real benefit. Self-monitoring was practiced by an appreciable minority in the UK, potentially enabling patients to gain control over managing their own BP. Better education and shared decision making between the patient and the GP might remove negative perceptions about SMBP ensuring its long term practice.

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#### LIST OF ABBREVIATIONS

BP Blood Pressure

SMBP Self-Monitoring Blood Pressure

UK United Kingdom

ABPM Ambulatory Blood Pressure Monitoring

NSF National Service Framework

NHS National Health Service

DOH Department of Health

QOF Quality Outcome Framework
RCT Randomised Controlled Trial

CVD Cardiovascular Disease

US United States

CHD Coronary Heart Disease

HCP Health Care Professional

EPP Expert Patient Programme

GP General Practitioner

COPD Chronic Obstructive Pulmonary Disorder

INR International Normalised Ratio
SMBG Self-Monitoring Blood Glucose
SMUG Self-Monitoring Urine Glucose

HbA1c Glycated Haemoglobin

V-STITCH Veterans Study to Improve Control of Hypertension

MCS Mental Component Score -SF-12 Short Form Health Survey

TCYB Take Control Your Blood Pressure

HINTS Hypertension Intervention Nurse Telemedicine Study

HDM Health Decision Model
TTM Trans Theoretical Model

CI Confidence Interval

TASMINH Targets and Self-Management in Hypertension

HITS Telemonitoring-based service redesign for the management of

uncontrolled hypertension

EQ-5D Euro-Quality Of Life 5-D

HADS Hospital Anxiety and Depression Scale

SBP Systolic Blood Pressure

DBP Diastolic Blood Pressure

HBM Health Belief Model

SMART Self-Management of oral anti-coagulation therapy

QOL Quality of Life

ROSSO RetrOlective Study: Self-monitoring of blood glucose and

Outcome in patients with type 2 diabetes

T2DM Type 2 Diabetes Mellitus

DIGEM Diabetes Glycaemic Education and Monitoring

ESMON Efficacy of Self MONitoring of blood glucose in newly

diagnosed type 2 diabetes

UN United Nations

WHO World Health Organisation

PCT Primary Care Trust

PKD Polycystic Kidney Disease

df Degrees of freedom
GHS General Health Status

MAQ Medication Adherence Questionnaire

HCCQ Health Care Climate Questionnaire

STAI State Trait Anxiety Inventory

HLOC Health Locus Of Control

DHLOC Doctors Health Locus Of Control

OPHLOC Other People Health Locus Of Control

IHLOC Internal Health Locus Of Control
CHLOC Chance Health Locus Of Control

OES Outcome Expectancy Scale

POE Positive Outcome Expectancies

NOE Negative Outcome Expectancies

TB Tuberculosis

SPSS Statistics Package for Social Sciences

# CHAPTER 1 THE PSYCHOLOGICAL IMPACT OF SELF MONITORING INTRODUCTION AND BACKGROUND

#### 1.1 Chapter overview

This chapter summarises the aims and research questions for this thesis, the rationale for the study, and a background to self-monitoring blood pressure (SMBP) in the United Kingdom (UK) with a focus on SMBP from a psychological perspective, followed by an explanation of how the thesis is structured in relation to the aims and research question and the component studies.

# 1.2 A psychology perspective: Introduction, aim and research questions

Self-monitoring is perhaps the single most important element in changing any thought or behaviour. We forget we are constantly tracking nearly every pattern from which to move forward and assess progress (or lack of progress) towards a goal. It's a skill so engrained in our lives that we forget we are constantly monitoring ourselves in various ways, from pedometers, to looking at nutritional values on food packaging, to stepping on scales and counting calories. Self-monitoring allows us to uncover necessary changes and set realistic goals. It's perhaps a more novel method alongside taking medication that actively involves the patient in the treatment and on-going management of hypertension. The problem is that self-monitoring requires continuous planning, motivation and vigilance, things that most of us when trying to change behaviour often lack.

Fortunately we are in an era where there are a range of technologies which make monitoring our behaviour more effective than ever before. In contrast to monitoring in other chronic conditions such as asthma, warfarin therapy for anti-coagulation monitoring and diabetes, monitoring blood pressure for patients with hypertension is particularly unique as it is asymptomatic, that is a condition that mostly presents itself with no symptoms, therefore psychological effects could be more profound. Where self-monitoring for the aforementioned conditions will be from a GP recommendation, SMBP is more likely to be a self-initiated behaviour and therefore the motivations for engaging in it could be quite different. Furthermore self-monitoring requires one to be vigilant about tracking behaviour, and forces one to face the reality of their actions but is everyone ready to face the consequences of their actions?

The aims of this thesis are therefore to investigate SMBP from a psychological perspective, to ascertain the prevalence of self-monitoring in hypertension and the psychological factors associated with SMBP. More specifically the study's research questions were:

- 1) What is the prevalence of SMBP and the characteristics amongst primary care patients with diagnosed hypertension with and without a concurrent diagnosis of diabetes?
- 2) What motivational factors are associated with self-monitoring blood pressure?
  - i) Does this affect the likelihood of self-monitoring?
  - ii) Can this be explained by psychological theory?
- 3) Which of the psychological or motivational factors identified influence ongoing self-monitoring behaviour?

#### 1.3 The rationale for the study

This section outlines the main purpose of why this research was conducted. Similar to the above, it is a summary and therefore is not referenced.

Self-monitoring of blood pressure (SMBP), defined as 'patients measuring their blood pressure (BP) at home, that is, outside their usual clinic' is one method by which patients can actively participate in their own health care. Clinical evidence shows SMBP leads to a small but significant reduction in BP, but despite the wide availability of automated monitors there are little data conducted within the UK about how commonly or why it is practiced.

Monitoring of BP is a key aspect of the diagnosis and management of hypertension in British primary care. Self-monitoring in chronic disease is generally discussed as a wider part of self-management programmes in the UK and in this context is more widely researched in the literature. However self-monitoring as a standalone intervention to enable patients to be actively involved in the management of their own BP and the psychological impact this practice has on the patient is less well researched. Closer monitoring of BP means that for some patients, uncontrolled BP can be detected early and treated which can dramatically cut risks for further complications.

Recently, there has been an explosion of literature published on SMBP for patients with hypertension. Although this literature reports favourably on its practice and clinical guidelines recommend the practice for hypertensive patients in the diagnosis

and management of hypertension, the focus of this work is largely on the effectiveness of self-monitoring on clinical outcomes. There is very little or limited focus on the practice of SMBP from a psychological perspective. This is surprising given that the very act of self-monitoring denotes an active role for the patient and therefore implies that motivation is a key issue that precedes its successful implementation.

Taking a psychological perspective is thus important because understanding patients' beliefs and motivations about self-monitoring allows prediction of the practice of this behaviour and consequently can be a precursor for changing behaviour. Social cognition models are recognised to contribute to the greater understanding of who performs health behaviours and how extrinsic and intrinsic factors produce behaviour change. This thesis draws upon social cognitive models and theoretical frameworks embedded within health psychology to help explain and identify the factors that underlie self-monitoring which may ultimately provide a gateway to designing interventions to help modify the use of SMBP in clinical practice.

To best answer the research questions detailed in section 1.2 mixed methodologies were adopted (see section 1.9.3 for further detail about using mixed methods).

Justification for each type of methodology is provided in later sections of this thesis, but briefly: a postal survey was used to determine the prevalence of SMBP in British primary care, interviews with patients to explore the role of psychology in patient experiences of SMBP and a questionnaire to investigate what psychological factors are associated with engaging in the practice.

#### 1.4 Background Overview

The purpose of this section is to set the context in which the study takes place. It begins by providing a background to the practice of SMBP for patients and is considered within the overall self-management of hypertension. The global problem arising from increasing high BP prevalence rates are detailed and reasons for persistent poor BP control rates are highlighted. Factors related to BP control are examined with particular attention to psychological factors, under-recognised within the literature but important as they are potentially modifiable. Self-monitoring as a clinical practice is thus considered in the context of these modifiable psychological factors. The chapter then details a review of the existing literature on psychological aspects of self-monitoring followed by a brief outline of some psychological models and theoretical frameworks drawn from health psychology referred to that could potentially explain the practice of SMBP. Self-monitoring is then discussed within the context of policy and the clinical evidence around the effectiveness of selfmonitoring compared with ambulatory blood pressure monitoring (ABPM). The chapter concludes with an overview of the entire research study outlining the stages of the study and associated research questions.

#### 1.5 Hypertension and Screening

Hypertension (defined as persistent raised blood pressure over 140/90 mmHg)<sup>1</sup> is a common chronic condition in the UK: thirty-two per cent of men and twenty-nine per cent of women have high blood pressure (BP) or are being treated for high blood

pressure in England.<sup>2</sup> High BP is a key risk factor contributing towards cardiovascular diseases such as stroke, kidney and coronary heart disease.

Addressing this risk factor in people before cardiovascular disease develops is vital as persistently raised BP is preventable.

High BP is easily detected with a non-invasive screen and controlled with interventions including adherence to medications, lifestyle changes and positive health behaviours.<sup>3</sup> Routine periodic screening for high BP is now commonplace in the UK as part of the National Service Frameworks (NSF) for cardiovascular prevention. The diagnosis, treatment and follow up of patients with hypertension is consequently one of the most common interventions in UK primary care accounting for 12% of consultations and approximately a billion in drug costs in 2006.<sup>4</sup>

Randomised controlled trials (RCTs) demonstrate widely the benefits of medications which control BP with minimal side effects and thereby prevent cardiovascular disease (CVD) events.<sup>4</sup> There is however concern that the benefits demonstrated in these randomised trials of antihypertensive drug treatment are not optimised in everyday clinical practice.<sup>5</sup> Consequently, despite this massive cost in primary care expenditure both in drug costs and consultations, findings from international and national surveys consistently report substantial under-diagnosis, under-treatment and poor rates of BP control in the UK.<sup>6</sup> This is not only a national problem. Evidence from population based surveys of hypertension management shows this is a widespread serious global problem with poor adherence to blood pressure targets shown in studies conducted in the United States (US), Canada and Europe.<sup>7</sup> Many

countries within Europe have the poorest control rates globally with a sixty per cent higher prevalence of uncontrolled hypertension than the US or Canada.<sup>8</sup>

In the UK, despite some improvement since the 1990s, a nationally representative Health Survey for England shows that control rates (defined as systolic BP <140 mmHg and diastolic blood pressure <90 mmHg) of those deemed hypertensive (i.e. either systolic  $\geq$  to 140 mmHg or diastolic  $\geq$  or = 90 mm Hg or on treatment for hypertension) were only 52% in 2006, that is nearly half the people in the UK with hypertension do not have good control. Amongst those at higher risk of developing cardiovascular complications, 44 per cent had their BP controlled to <140/90 mmHg. For those with hypertension who did not have coronary heart disease (CHD) or stroke but who's estimated cardiovascular risk was  $\geq$ 20%, only 17% were controlled, demonstrating that for these higher risk groups the situation is worse. These results confers with community-based studies throughout the world showing BP goals are achieved in only 25-40% of patients on hypertensive drug treatment, thus more needs to be done to improve BP control rates as they remains far from optimal.

#### 1.6 Factors associated with blood pressure control

There are many potential factors reported within the literature that contribute to the low level of BP control which can be split into three distinct groupings: (1) health care professional (HCP), (2) system or organisational factors and (3) patient factors.<sup>3</sup>

For the HCP, common observations seen in clinical practice show either a complete failure of clinicians to increase or initiate therapy when the treatment goals are unmet or BP is above goal level or, the implementation of inappropriate treatment regimens that do not achieve target BP. The phenomenon of lack of action despite elevated BP is a process known as "clinical inertia". <sup>13</sup> Evidence of clinical inertia has mainly been described from studies conducted in secondary care or hospital settings. <sup>13</sup> Reasons for clinical inertia are complex, though a fundamental reason argued by some, is that most clinicians are unlikely to implement elements of guidance if they disagree with them. It seems clinical inertia is present even if they are given financial incentives such as that seen in Primary Care, <sup>14;15</sup> and the implementation of the UK pay performance incentive (the Quality and Outcomes Framework, QOF). <sup>16</sup> Clinical inertia sits within the wider system of the National Health Service (NHS), that is (2) 'organisational factors' which, amongst many, include factors such as lack of education and training and poor practice organisation aimed at achieving therapeutic goals. Combined with ever changing clinical guidelines, all these factors affect the ability of clinicians to practice and are therefore partly responsible for the existence of poor BP control.

Of the last category, (3) patient factors, one most widely reported in the literature is the problem of patients adhering to therapies prescribed by HCPs.<sup>3</sup> The clinical trials reported in the literature target both HCPs *and* patients and are designed with the shared expectation that the intervention used in the study will enhance adherence to medication or treatment guideline as a mechanism for improving BP control.<sup>17</sup> One cluster randomised trial for example investigated the use of an educational package delivered to 78 GPs in Karachi, Pakistan for the subsequent treatment of patients aged 40 and over with treated hypertension.<sup>18</sup> Adherence was measured using electronic drug monitors and data were available for 178 patients who completed the six week

follow up. The study took place six months after the GPs were trained. Adherence was found to be significantly higher in those whose GP's had received the intervention. A sub group analysis of people with good versus poor adherence showed a decline in systolic (8.3 mmHg; p=0.04) and diastolic blood pressure (3.8 mmHg; p=0.1). Whilst a much more reliable method of measuring adherence was used in the study, that is electronically versus traditional methods such as pill counts, the follow up period of six weeks was short<sup>19</sup> in the context of lifelong treatment for hypertension. Such studies and meta analyses <sup>20;21</sup> conclude many of the interventions focusing specifically on patient or provider factors are expensive, complex or labour intensive and lack methodological rigour. As a consequence the effects on improving patient adherence are limited. <sup>21;22</sup> Furthermore higher adherence rates to drugs are reported in randomised trials compared to observational studies. RCTs may include more motivated participants then generally observed. <sup>23</sup> Adherence to treatment may vary between people with newly diagnosed hypertension and those with more established disease.

A number of other factors alleviating BP control can also be identified from the literature varying from patients not knowing target BPs<sup>24</sup>, costs to the patient, poor social support, racial differences and limited health literacy.<sup>25;26</sup> Providing explanations and communicating with patients have also been shown to enhance adherence and therefore improve BP control. RCTs such as that of Qureshi and colleagues (2007) and other observational studies <sup>27</sup> show how education of health care professionals (HCPs) can achieve this goal.

Considering the factors detailed above, for an individual, living with high BP is thus a combined function of the following health behaviours: health compromising behaviours (e.g. alcohol consumption, excessive salt intake, smoking, engaging in stress related activities), health enhancing behaviours (e.g. exercising and eating healthy foods) and health preventative behaviours (e.g. self-monitoring).<sup>28</sup> These are all behaviours which, unlike the HCP and system factors that are relatively fixed, are modifiable. While much research has already been conducted in the application of psychology to health compromising and enhancing behaviours, less has been done on self-monitoring. Although pharmacological management is important and effective for treating high BP it is the combined individual actions of the patients that are also important alongside drug therapy, particularly for more efficient management of hypertension and other higher risk groups. Several trials have led to established clinical guidelines to tackle the interplay of various factors including following medication regimens, dietary and exercise regimens<sup>29</sup> and smoking cessation.<sup>30;31</sup> But despite the existence of these clinical guidelines adherence to medication and BP control still remains sub-optimal.

Other methods useful in the management of hypertension such as self-monitoring need more focus if optimal BP is to be achieved and to help prevent the frustration of HCPs from the difficult state of diagnosis and treatment. Being a predominantly patient led activity, understanding the psychological factors of patients' health beliefs, motivations, experiences and behaviours around SMBP may therefore be important pre-cursors for behavioural change and thus the primary focus of this thesis. The next section describes how self-monitoring is a key component for the self-management of hypertension.

## 1.7 The self-management of chronic disease: self-care, self - monitoring and the Expert Patient Programme (EPP)

Over the last 50 years the number of people age 60 years or over worldwide has tripled and is expected to triple again to almost two billion by 2050.<sup>32</sup> This ageing population has profound consequences on the health of individuals and implications for health care. This is because as the population ages the incidence and prevalence of chronic diseases increase. Heart disease, stroke, cancer, chronic respiratory diseases and diabetes, are by far the leading cause of mortality in the world, representing 60% of all deaths and are all more common in the elderly.<sup>33</sup> The economic burden of this is profound, accounting for 46% of the global burden of disease,<sup>34</sup> and putting intense pressure on health care resources. A major step forward in tackling this crisis has been in making some fundamental changes in what the focus should be on the process of patient care, particularly the patient's 'self-management' of their condition through appropriate monitoring and treatment plans <sup>35</sup> This thesis focuses on one of those aspects of self-management with the practice of self-monitoring blood pressure (SMBP).

In the UK, a report by Kennedy and colleagues in 2007 explain the three tier system for the care of patients with long term chronic conditions in the NHS.<sup>36</sup> First tier is 'case management' for patients with multiple, complex conditions who get intensive, proactive care to avoid admissions. Second tier is 'disease management' for patients at some risk and involves guideline based primary care, facilitated by financial incentives. The final tier is self-care support for low risk patients, estimated as 70-

80% of those living with long term conditions.<sup>37;38</sup> The third tier refers to 'self-care' which the Department of Health (DOH) define as

"the care taken by individuals towards their own health and well-being, and comprises of the actions individuals take to lead a healthy lifestyle to meet their social emotional and psychological needs to care for their long term condition, and to prevent further illness or accidents" (p.1).

Self-management of chronic illnesses are typified by self-care activities characterised by responsibilities regarding medication use, lifestyle changes, and behaviour to prevent long term complications.<sup>40</sup>

One means of providing this support is the Expert Patients Programme (EPP).<sup>41</sup> A six session group intervention is led by lay people who have experience of chronic disease and designed to improve skills and confidence in the management of long term conditions. It is designed to improve quality of life, enhance interactions with health professionals and reduce service use. At the time of introduction this programme represented a movement towards more compelling methods of patient care. Within the EPP, effective self-management programmes have included disease specific programmes for chronic conditions such as arthritis, based on pioneering work of Kate Lorig and colleagues <sup>42</sup> from heart disease<sup>43</sup> to more generic self-management programmes applied to a broad number of conditions. <sup>40;44</sup>

Evaluations in the UK have shown EPPs produce psychological improvements with studies in various diseases such as HIV/AIDS, rheumatoid arthritis, asthma or chronic obstructive pulmonary disease (COPD), diabetes and heart failure.<sup>36</sup> Such studies commonly have shown patients who engage in healthy diet, exercise or other aspects

of self-management experience benefits in terms of fewer symptoms, better functional capability and fewer complications than those who do not.<sup>45</sup>

#### 1.7.1 Self-monitoring as part of the self-management programme

Self-monitoring forms a part of self-care, an element of the EPP. Self-monitoring is widely reported within the literature as an increasingly common method to improve the adjustment of long term treatments with interventions delivered successfully to improve clinical outcomes for patients with Coronary Heart Disease (CHD) <sup>46;47</sup> asthma and COPD. <sup>48;49</sup>

A systematic review of 52 RCTs (10,388 patients) <sup>50</sup> published between 1950 and 2008 assessed interventions included in systematic reviews for four clinical problems that increase cardiovascular disease risk (heart failure, oral anti-coagulation therapy, hypertension and type 2 diabetes). This review described the ways in which self-monitoring has been applied in a number of conditions: Varying from heart failure (patients can self-monitor weight and adjust therapy to treatment)<sup>51</sup>, atrial fibrillation (requiring anticoagulation where patients can self-monitor their International Normalised Ratio [INR] levels),<sup>52;53</sup>, diabetes (patients can self-monitor blood glucose (SMBG) levels that can be tested in the home)<sup>54</sup>, asthma, (patients can monitor peak expiratory flow) and finally hypertension, (where patients can measure their BP at home).<sup>6;55</sup>

From the 14 trials in heart failure (4,264 patients); 14 oral anticoagulation therapy trials (3,049 patients), 18 BP trials (1,714 patients) and 6 SMBG trials (1,361 patients)

the results showed effectiveness for self-monitoring in all conditions but self-monitoring glucose. Heart failure (HF) was effective in reducing all-cause mortality (Relative Risk = 0.62 (95% CI 0.45 to 0.85). Self-monitoring in INR for patients on oral anticoagulation therapy led to fewer thromboembolic events (Odds Ratio(OR) = 0.27 Confidence Interval (CI) (0.12 to 0.59), and lower mortality (OR = 0.37 (CI 0.16 to 0.85) MBP led to reductions in systolic BP of 4.2 mmHg (95% CI (1.2 to 3.5) MBG which has been widely reported to be effective for Type 1 insulin dependent diabetes and for Type 2 diabetes if they are talking insulin, appears not to be effective in improving glycated haemoglobin (HbA1c) in patients with Type 2 diabetes using oral hypoglycaemic drugs. The use of SMBG for non-insulin treated diabetics has attracted particular widespread debate in the literature and is discussed in more detail in section 1.9.1.5 below.

This thesis focuses on the practice of measuring BP at home with a particular focus on the psychological correlates of self-monitoring because within the context of chronic disease, good adjustment predicts increased participation in self-management overall. Lorig and many others demonstrate how acquiring or possessing self-management skills are recognised and appreciated by many patients and therefore it these are possibly also valuable ingredients for self-monitoring BP. The psychological perspective of self-monitoring BP is the focus of the next section.

## 1.8 Self-monitoring in hypertension: The need for research from a psychological perspective

Self-monitoring requires behaviour change and to some, could be considered as a more subjective mode of self-assessment in relation to hypertension management.<sup>59</sup>

To be effective in the medical context, Ward and colleagues' systematic review (see previous section 1.7.1) used a specific criterion or framework breaking down self-monitoring into three important components which were suggested should be present for effective evaluation. The first was clinically significant changes in the condition are possible over time, secondly an objective test should exist that reliably detects these changes and finally a cost effective action in response to the test result should be possible. Such a breakdown denotes the active role required from patients and the high levels of self-motivation required if they are to engage effectively in self-monitoring. It therefore becomes necessary to also understand the factors that underlie people's motivation or intention to self-monitor if this practice is to be successfully implemented into the overall self-management of the condition.

There is now a clear evidence base reporting the effectiveness of SMBP for the diagnosis and monitoring of hypertension. It is considered an important part of clinical care for hypertension, reflected by its recommendations in current clinical guidelines. Less research however exists specifically on the motivational and psychological factors that are associated with SMBP. The vast majority of the studies, as described above investigating factors that might impact BP control have largely focused on interventions that improve medication adherence with little attention to the other aspects of self-management behaviours.

Within the health psychology literature, there is suggestion that patients may not adhere to treatment plans successfully because of the asymptomatic nature of hypertension. Where usually the presence of symptoms is a key trigger to motivate individuals to seek care or adhere to medical regimes, an asymptomatic condition

such as hypertension may inhibit a patient's willingness to comply with medical advice and particularly when medication is in most cases lifelong.<sup>64</sup> A potential danger exists for patients to adhere to medication when patients are unaware of the damage caused by high BP because they may not feel them immediately. A separate but important additional issue is a further challenge for medication adherence in this population given additional potentially troubling side effects of anti-hypertensive medication on sleep and sexual performance.<sup>65</sup>

Contrary to the asymptomatic nature of hypertension, some researchers have found that many patients experience symptoms before and after a hypertension diagnosis. 66,67 These studies are based on early research 88 showing in a series of laboratory studies that 'normotensives' and 'hypertensive' (patients with hypertension) people may even predict their BP based on their personal inference or somatic cues. Similarly, a more recent investigation showed this still occurs even though the inference may be inaccurate. 65 In a study of 54 mildly hypertensive men taking part in a larger double blind placebo controlled study of quality of life changes associated with anti-hypertensive medications, participants were asked to estimate their BP prior to their actual BPs being taken by a nurse in the clinic. Values were correlated and multiple measures of symptoms, moods, and perceived treatment effectiveness were also obtained at a series of clinic visits over several months. Between and within person's relations of symptoms and BP were evaluated using mixed model analyses. The results found that those with actual high BP levels also estimated their BP to be higher, although the authors note, the effect of this relationship was small. The authors' further report that even after controlling for cognitive and situational factors that may influence judgements about BP, there was

still a relationship between estimated and actual BP. This study is important as it highlights the importance of situational cues that can potentially influence participants' estimates of BP independently from their actual BP. Other factors or cues could include the participant's previous BP; treatment status (i.e. whether the participant was receiving medication vs. abstaining from medication); if taking medication, perceived medication status (i.e., the patient's belief that he was receiving placebo vs. an active drug) <sup>65</sup> and the use of home BP monitoring equipment.

Although none of the interaction terms were significant and therefore did not impact the relationship between estimated and actual BP it does highlight a number of situational variables that are involved when considering the role of self-monitoring and elucidates the powerful use that automatic devices have on removing the need for estimation of BP and therefore more accurate information for patients for which to base treatments decisions on.

#### 1.8.1 Considering social cognitive models

Within health behaviour research, social cognitive models provide a theoretical framework for the study of illness and behaviour in relation to self-management techniques. In the field of health psychology, the justification of the study of health behaviours is based on two assumptions: (1) a substantial proportion of the mortality from the leading causes of death in industrialised countries is due to particular behaviour patterns, and (2), that that these behaviour patterns are modifiable. Social-cognitive models state that behaviours are determined by cognitions (what people think) and social factors (how the environment reacts).<sup>28</sup> Identification of these factors underlying such 'health behaviours' has become a focus of research in psychology

and other health related disciplines since the mid-1980's. As mentioned in section 1.6 research on health behaviours is vast and can be categorised to vary from 'health enhancing' behaviours such as exercise, healthy eating to 'health harming' behaviours such as smoking and excessive alcohol consumptions through to 'health protective' behaviours such as vaccination against disease, condom use, health screening such as routine breast examinations, and in the present context home monitoring. The purpose of identifying factors underlying 'health behaviours' is firstly, to provide a gateway to design interventions to change the prevalence of such behaviours and ultimately produce improvements in individuals' and populations' health, and secondly, to gain an understanding of the reasons why individuals perform a variety of behaviours.

In a broader context, social cognition models are recognised to contribute to the greater understanding of who performs health behaviours<sup>69</sup> and ultimately can show how extrinsic and intrinsic factors produce behaviour change. In the case of self-monitoring, focusing on the social and cognitive determinants of the practice could be the first step in revealing the causes of such behaviour. This could further mediate the effects of other determinants (e.g. social class).<sup>70</sup> This demonstrable linking of factors is more open to change then factors such as personality that are perhaps more stable and therefore longer term. Effective interventions can thus be based on the manipulation of these social cognitive factors shown to determine health behaviours. The next section gives an insight into two possible theoretical models that could relate to SMBP identified from the literature.

#### 1.8.2 Self-regulation framework

There are a wide number of theoretical models reported in the health literature to help explain and understand varying health behaviours. Two that specifically relate to the practice of self-monitoring within the adult hypertension literature are described here. One most commonly reported theoretical framework is the Common Sense Model (CSM) <sup>71</sup> also known as the self-regulation framework. <sup>72,73;74</sup> The self-regulatory theory posits that persons with an illness or health threat such as hypertension form a cognitive representation or mental model of that illness/threat that guides health related and decision making behaviours for controlling the threat and termed illness representations. Individuals form illness representations based on their reaction to external and internal stimuli though two parallel pathways: cognitive and emotional representations. The components of the illness perception are illness identity (symptoms that an individual experiences in his/her illness), cause (causal attribution of the illness), timeline (individual perceptions about the duration of the illness), timeline-cyclical (changeability of the illness), personal control (beliefs about controllability of the illness by the patient) treatment control (beliefs about controllability or curability of the illness by treatment), consequences (impacts of the illness on the patient and his/her daily life) illness coherence (the coherence of usefulness of individual representations) and emotional representation (the emotional responses aroused by the illness). The model shows a pathway whereby patients can deal with illness more pro-actively, illustrating the active role that patients could have in adjusting to the challenges posed by their condition. This model has been applied widely to study processes of adjustment in a number of

diverse chronic conditions such as cancer, diabetes, HIV infections, asthma and rheumatoid arthritis.<sup>78</sup>

A meta-analysis of 45 empirical studies testing the model state that the analyses provide evidence for theoretical predictable relations between illness cognitions, coping and outcomes across a range of chronic illnesses<sup>74</sup> of which two studies related to hypertension.<sup>79;80</sup>

#### 1.8.3 Health locus of control (HLOC)

The Health Locus of Control (HLOC) construct is one of the most actively studied in the area of attitudinal predictors of patients health related behaviour and this spans over decades. 81;82

HLOC is conceptualised as the degree to which a patient attributes the cause of health related outcomes to internal factors under one's control (i.e. a patient's own actions) or to external factors (e.g. chance, actions of the providers). One study conducted in the US applies this model to patients with hypertension and diabetes. Both patient-provider dyads, (that is, the patient and provider partnership) completed the internal HLOC scale and medication adherence was measured. The study found patient and provider dyads that held highly similar beliefs regarding degree of personal control over treatment outcomes showed significantly higher medication adherence than in dyads where patients held a stronger belief in their own personal control then their treating providers. Thus symmetry in beliefs was crucial to effective treatment. The feasibility of matching up patient and provider beliefs based on their HLOC measures

prior to consultations is questionable in the UK health system, where consultations are in most cases restricted to just ten minutes. The authors of the paper suggest that perhaps more realistic would be for HCP's to tailor their style to fit with the patients attitudes and expectations, the congruence in beliefs and attitude could then encourage better adherence to medication. There is some evidence in the UK to show that this is potentially possible with the delivery of care to people with chronic conditions being increasingly organised around principles such as those embedded in the chronic care model briefly mentioned in section 1.6 of this chapter. This model sees quality improvement as requiring action on multiple fronts including better decision support, enhanced clinical information systems for practitioners and increased support for patient self-management. Primary care is central in this model with care for chronic conditions involving patients and primary care clinicians actively engaging in negotiations about care through a process of shared decision making.

Christen and colleagues' study<sup>83</sup> nevertheless has relative merit in supporting the use of HLOC in chronic diseases such as hypertension and diabetes and demonstrates how this sort of information can be applied pragmatically to the relationship between patient and provider and consequently to treatment adherence or in this context to self-monitoring.

#### 1.9 Literature review of psychological factors related to selfmonitoring blood pressure

#### **Justification and Strategy**

Considering the background information above, the primary aim of this thesis was to determine the psychological factors associated with the practice of SMBP. The following literature review thus aimed to assess current knowledge about the factors underlying people's motivation to self-monitor. To broaden the review, self-monitoring was considered as part of the wider self-management of hypertension. Studies were considered if they made any reference to characteristics of patients' SMBP and/or made any reference to theoretical frameworks or psychological models.

This section details the search methodology and the approach taken to search the literature. The nature of this investigation did not suit a formal systematic review for a number of reasons. Firstly it was important to identify all literature regardless of study design and disciplines and not just that published in the medical literature databases. The research study questions as a whole draw upon a number of disciplines (Psychology, Sociology, Medicine, and Epidemiology) therefore this cross-discipline approach to the study questions meant that search terms varied between bibliographic databases. Refinements within the searches were required for each one but to detail this would have been potentially cumbersome for the reader therefore the approach taken to searching the literature was described instead. Arksey and O'Mally (2005) describe this alternative approach to reviewing literature known as a 'scoping study'. 85

As the authors state, a scoping study differs from a systematic review in two ways: a scoping study addresses broader research questions than a systematic review where many different study designs may be applicable. A systematic review aims to provide answers to questions from a relatively narrow range of quality assessed studies whereas a scoping study and (indeed this research study) are less likely neither to need very specific research questions nor, to assess the quality of the included studies. Set in a wider context, the very nature of the study addresses the importance of a public health medical intervention but from a psychological perspective therefore it made sense to correspondingly take a broader approach to searching the literature on the topic of self-monitoring blood pressure across different study designs and disciplines with a view to have hopefully improved the integrity of the search and representation of the articles retrieved across a broader spectrum.

The search strategy was based upon using key words and medical subject headings (MeSH) including the terms 'self-monitoring' and 'blood pressure' OR 'hypertension' in the first instance and then further searches for behavioural interventions to identify the intervention under consideration and the patient group of interest. For this section a scoping search was initially conducted via OVID and Web of Science bibliographic databases up to the date 2008 week 45 and searches were updated every six months up until the present year (2013) No limits were placed on the publication of the studies. The databases were from various disciplines, as shown in Figure 1.

Figure 1: Databases searched in the literature review

Databases searched: **Nursing**: British Nursing Index (BNI), Current Index to Nursing and Allied Health Literature (CINAHL), **Medicine** MEDLINE **Psychology**: PsychInfo, PsychArticles, Sociology: CAB Abstracts, EMBASE, Social Policy and Practice, SPORTDiscuss **Policy**: Health Technology Assessment Programme (HTA), HMIC Health Management Information Consortium, Science Direct, Cochrane Collaboration Library, Other (Authors research, hand searching, contacting authors)

Initial search terms were wide, comprising; self-monitor (truncated) and combined with words to represent various aspects of monitoring. The search initially identified a large number of articles (>10000) many of which were not relevant to the research questions but this allowed the formation of a particularly relevant set of keywords. The criteria were applied to the following database search engines: OVID, Web of Science, Ebsco, the Cochrane Collection and PubMed. The searches were conducted in each type of database and tailored to suit the needs of each database. Terms were combined with terms using the 'AND' 'OR' Boolean operators. All the databases were repetitively searched and duplicates removed. Filters were set up to select only English language articles given constraints of the thesis and human to exclude all animal studies. All references obtained were managed and stored in a reference and bibliography software package, Reference manager. A full list of the search methodology, terms used and list of selected articles within the review is contained in Appendix 1.

The findings of the literature review are presented in the next section by study design. Studies that addressed self-monitoring in the context of hypertension are reviewed first followed by those looking at self-monitoring other chronic conditions. A salient on-going debate within the literature about the effectiveness of one of the closest practices to SMBP, self-monitoring blood-glucose follows this review.

### 1.9.1 Hypertension

### 1.9.1.1Observational - cohort studies

Two small survey studies in the UK suggested female patients who were older <sup>86</sup> and those with higher levels of education <sup>87</sup> were more likely to own a blood pressure monitor. A secondary analysis of baseline data from the randomised controlled trial Veterans Study to Improve Control of Hypertension (V-STICH), a trial testing two interventions designed to improve blood pressure control <sup>88;89</sup> also reported data about frequency and some of the characteristics of self-monitors. <sup>90</sup> This sub-study by Thorpe and colleagues of the V-STICH data reported factors associated with greater likelihood of monitor possession. These were having diabetes (OR, 1.61; 95% CI, 1.19 to 2.18), being married (OR, 1.50; 95% CI, 1.08 to 2.09) and older (OR, 1.02; 95% CI, 1.00 to 1.04). <sup>90</sup> Out of the observational studies mentioned above, the latter study was unique as it included an assessment of social environment characteristics; marital status, living status, social support and mental health. Mental health was measured using the Mental Component Score (MCS-12V) from their completion of the Short Form-12 (SF-12), a non-disease specific measure of quality of life. The study findings showed patients with higher scores on the mental health measure were

more likely to have a monitor (OR, 1.15, 95% CI, 1.01 to 1.32). Although the original V-STITCH trial and the aforementioned sub-study examined the overall frequency and potential determinants of patients SMBP, a major limitation was the sample included only US male participants and therefore its generalizability to the UK is restricted. Confirming whether female patients are more likely to own a monitor as found by a previous survey in the UK<sup>86</sup> is therefore also not possible. Additional questions investigating how participants obtained their BP monitors, and the reasons for home monitoring were also not determined by this study and although the authors describe measurement of perceived seriousness and control, there was no reference to the relationship of these variables to self-monitoring reported elsewhere in the study. Furthermore, the findings that individuals with better mental health are more likely to have a monitor are somewhat contradictory to more recent evidence showing no significant impact on anxiety or quality of life. 91 It has been known that HCPs can hesitate to intensify treatment for hypertension for those patients experiencing high levels of stress or psychological co-morbidity, an example of clinical inertia described earlier, <sup>13;92</sup> and therefore clarification of these contradictions is an important area for further investigation.

### 1.9.1.2 Randomised Controlled Trials (RCT)

Bosworth and colleagues <sup>93;94</sup> have conducted a series of studies varying in design focusing on self-monitoring and its relationship to BP control. One RCT, The Take Control of Your Blood Pressure Trial, (TCYB) <sup>93;94</sup> tested a tailored behavioural educational intervention on a sample of US hypertensive patients in the US (n=636). Patients were randomised to either usual care, a behavioural intervention (bi-monthly

tailored, nurse administered telephone intervention targeting hypertension-related behaviours) home BP monitoring 3 times weekly or the behavioural intervention plus home BP monitoring. The techniques used by the nurses to foster behaviour change included: motivational interviewing, problem solving, positive reinforcement, social support, and coping among others. Home monitoring involved patients receiving a home monitoring device and were trained on how to use the monitor. 95 Participants' came to the clinic every six months to demonstrate their accurate use of the monitors and to ensure they were configured properly. Participants were given a monitoring schedule and mailed their log of readings every two months in provided envelopes. The trial investigated a number of patient factors targeted in the tailored behavioural intervention that included perceived risk of hypertension and knowledge, medical and social support, and participants' relationship with their health care provider, and adverse effects of medication therapy, weight management, exercise, diet, stress, smoking and alcohol use. The primary outcome was BP control measured at 6 month intervals, secondary outcomes were knowledge and perceived risk associated with hypertension measured through the hypertension beliefs questionnaire, ability to continue with hypertension regime, and self-reported medication adherence. The study found the combined behavioural intervention had the greatest increase in the proportion of patients with BP control. Neither intervention alone improved BP control at 24 months; however, the combination intervention resulted in a clinically significant improvement in BP control of 11% compared with usual care. Patients in the combined intervention group also had a clinically meaningful decrease in systolic BP of 3.9 mmHg compared with usual care group.<sup>94</sup>

A key distinction of this trial to others was the focus of the design as it draws on social science theory. The authors outlined the use of the Health Decision Model<sup>96</sup> (HDM) and the Trans theoretical Model (TTM) of behavioural change, <sup>97;98</sup> models in health psychology and health promotion as frameworks for determining the factors to focus on and tailored the intervention accordingly. Briefly, the HDM is a thirdgeneration version of the Health Belief Model (HBM) which is described later in this thesis, (please see section 1.9.1.4) combining the HBM with patient preferences, including decision analysis and behavioural decision theory. 96;99 The TTM model includes a series of temporally ordered, discrete stages (pre-contemplation, contemplation, preparation, action, maintenance) and the movement between the five stages is influenced by the ratio of pros and cons of the problem behaviour, selfefficacy, temptations to revert to the problem behaviour and coping mechanisms. Providing a framework for an intervention that is guided by theory not only allows for both the systematic evaluation of the use of home BP monitors but also investigation of the effectiveness of using a nurse administered tailored intervention and is therefore considered is a key strength of this trial. There were however a number of limitations reducing generalizability of the TCYB trial to a wider population, two of which being the high rate of BP control (73%) in the study population at baseline and the academic health care setting. Interestingly, similar to the observational studies reported, there was no measurement of the psychological impact of the interventions which is surprising given the design of interventions were based on social science theories. The study nevertheless showed how a combined self-management intervention that includes on-going disease monitoring by the patients creates the opportunity to respond to new information thus supporting the utility of selfmonitoring. The authors further conducted the Hypertension Intervention Nurse

Telemedicine Study (HINTS) trial (n=593)<sup>100;101</sup> to determine which of 3 interventions was most effective in improving blood pressure (BP). In contrast to the TCYB study, the sample participants were recruited from primary care with inadequate BP control. Participants were randomised to usual care or 1 of 3 telephone based interventions to include a nurse and physician-administered medication management intervention. Medication management involved adjustment of medications by a study physician and nurse based on hypertension treatment guidelines. Both the behavioural management and medication management alone showed significant improvements at 12 months, 12.8% (95% CI 1.6 to 24.1) and 12.5% (CI 1.3% to 23.6%) respectively but this effect was not sustained at 18 months. For those with poor BP control at baseline, the effects were larger with the combined intervention group by 14.8 mmHg (95%CI -21.8 to -7.8 mmHg) at 12 months and 8.0 mmHg (CI -15.5 to -0.5 mmHg) at 18 months, relative to usual care. Although the design of the intervention in this study was not as theoretically based, with less focus on psychological outcomes, the Bosworth trials collectively have shown the importance of self-monitoring blood pressure and in identifying individuals most likely to benefit from potentially resource intensive programs.

Three RCT's, two from the Targets and self-monitoring in hypertension (TASMINH, n=441<sup>102</sup> and TASMINH2 trial, n=527)<sup>91</sup> and the most recently published Telemonitoring-based service redesign for the management of uncontrolled hypertension, (HITS trial, n=401)<sup>103</sup> are the only ones to report psychological outcomes in the United Kingdom. Although these studies do not base their intervention on a psychological framework as this was not the primary focus, they do report measurement of psychological outcomes of anxiety and quality of life. The

TASMINH trial assessed whether BP control in primary care could be improved with the use of patient held targets and self-monitoring in a practice setting. Secondary outcomes assessed the outcome on health behaviours and anxiety. Systolic blood pressure (SBP) in the intervention reduced significantly after six months (mean difference 4.3 mmHg (95%CI 0.8 to 7.9) but this was not sustained after a year. Although no difference was found in diastolic blood pressure (DBP) on anxiety and health behaviours practice based SMBP was well received.

In the TASMINH2 trial participants were randomly assigned to self-management (SMBP at home, and self-titration of anti-hypertensive drugs combined with telemonitoring of home BP measurements compared to usual care). The intervention consisted of training participants to monitor their BP at home, where patients were given a BP monitor and monitoring schedule to measure their BP at home. Unlike the above trial where patients posted their readings, these patients transmitted their readings directly to the research team by use of a modem connected to the participants' telephone line within their home. This telemonitoring system was based on a traffic light system where patients colour coded their readings as green, amber or red based on their target information that was given to them. Titration schedules were agreed by the participants' doctor who received no further direction on medication choice other than provision of the then current clinical guidelines for the management of hypertension that existed at the time of study. The primary outcome was change in mean systolic BP at each follow up point of 6 and 12 months. The study found clinically important reductions in mean systolic BP which decreased by 12.9 mm Hg (95% CI 10·4–15·5) from baseline to 6 months in the self-management group and by 9.2 mm Hg (6.7-11.8) in the control group (difference between groups 3.7 mm Hg,

0.8–6.6; p=0.013). From baseline to 12 months, systolic blood pressure decreased by 17.6 mm Hg (14.9–20.3) in the self-management group and by 12.2 mm Hg (9.5–14.9) in the control group (difference between groups 5.4 mm Hg, 2.4–8.5; p=0.0004). As mentioned, unlike previous studies these studies also measured psychological outcomes anxiety and quality of life, measured by the Spielberger State and Trait Anxiety measure (6-item) and the EQ-5D, a short 5 item measure of quality of life or the Hospital Anxiety and Depression Scale. However, as this was not the primary focus of the studies, very little was stated about these measures. For all the trials, the findings showed no significant differences between groups at baseline or over time on anxiety, nor did quality of life, however for the TASMINH2 study after 12 months, 166 (71%) of 234 patients in the intervention group ranked selfmonitoring as their preferred method of blood pressure monitoring compared with 103 (43%) of 242 in the control group (p<0.0001). Patient preference for home monitoring has been cited in other studies.

The most recent RCT published to assess SMBP differed from the TASMINH studies to include an optional patient decision support system (text or email) and assessment of outcomes on daytime systolic and diastolic ambulatory BP in patients with uncontrolled BP. <sup>103</sup> In this multi-centre RCT of 20 primary care practices in south east Scotland (n=401) the mean difference in daytime systolic ambulatory BP was 4.3 mmHg (95%CI 2.0 to 6.2; P = 0.0002) and for daytime diastolic ambulatory BP was 2.3 mmHg (0.9 to 0.36; P=0.001), with higher values in the usual care group. Both the HITS trial and the TASMINH trials support self-monitoring by telemonitoring as an effective method for achieving clinically important reductions in BP however the long term follow up was not assessed in the HITS trial nor were secondary outcomes such as health anxiety.

It is evident from the research reported above that for this particular sub group that is patients with hypertension, the psychological impact of self-monitoring BP in the UK remains relatively under researched and the reasons why patients choose to self-monitor is under explored. Based on the results of just one RCT, SMBP seems to have minimal impact on anxiety. This finding mimics that found in another study of self-monitoring, albeit in warfarin therapy for anti-coagulation but with a similar concept of self-monitoring procedures. Recently it has been argued that minimal impact on anxiety exists because the patients participating in the McManus and colleague's trial randomised to the self-monitoring intervention could have exhibited higher motivation for self-monitoring therefore experienced less anxiety from the intervention. Further exploration of this relationship and the psychological factors such as anxiety and self-monitoring was therefore an aim of the present thesis.

### 1.9.1.3 Systematic reviews

Over the past decade a number of systematic reviews across the globe have been published quantifying the magnitude and mechanisms of benefit of home BP monitoring on BP reduction and in predicting target organ damage. In the UK, the most recent review published by Bray and colleagues included 25 RCTs and found self-monitoring reduced BP by a small but significant amount, weighted mean difference (WMD) systolic BP -3.82 mmHg (95% CI – 5.61 to -2.03), diastolic BP -1.45 mmHg (-1.95 to -0.94). Similar findings have been found in earlier reviews where self-monitoring was again associated with moderate net reduction in systolic and diastolic BP. A common agreement made collectively by all the authors of the reviews was significant heterogeneity between studies by the use of additional co-

intervention making it difficult to make comparisons and evaluate systolic blood pressure (SBP) and diastolic blood pressure (DBP) reduction, and whether achievement of target BP was associated with self-monitoring. Bray and colleagues state that meta-regression could only account for part of the observed heterogeneity. <sup>108</sup>

The systematic review and meta-analysis from Agarwal and colleagues in 2011<sup>109</sup> is however of particular interest to the present literature review. This review and meta-analysis of 37 RCTs (n=9446), similarly found a small but significant reduction in SBP and DBP compared with clinic based measurements. Different to previous reviews, the study investigate factors and suggest explanations that may lead to these small but significant improvements. For example, home BP monitoring was found to be associated with less therapeutic inertia (defined as unchanged medication despite elevated BP)<sup>109</sup>, relative risk for unchanged medication, 0.82 (95%CI, 0.68-0.99), provoked more down-titrations of anti-hypertensive drugs and favoured the idea of interventions such as telemonitoring, where reductions in home monitoring based therapy were greater when telemonitoring was used (i.e. BP readings obtained at home are relayed to the provider who can then take appropriate action). The recent assessment of telemonitoring interventions in subsequent trials described in more detail in the previous section provides further evidence to support its use. <sup>91;102;103</sup>

### 1.9.1.4 Other chronic conditions

The psychological impact of self-monitoring in other chronic conditions is more widely researched. In warfarin therapy for patients taking oral anticoagulation therapy for example, one RCT in the US<sup>112</sup> of 325 patients based their educational

element of the self-monitoring on a key concept from social learning theory, namely self efficacy<sup>113</sup> and the Health Belief Model (HBM).<sup>114</sup> Self-care, as already discussed in earlier parts of this chapter, is affected by the degree to which individuals feel confident that they can perform such behaviours and has been long established by researchers in areas of self-management for chronic conditions. This concept of self-efficacy, the belief that one can carry out a specific behaviour necessary to reach a desired goal and to monitor a chronic condition at home requires the learning of new skills and is illustrated by the case for warfarin therapy and the self-monitoring of prothrombin time. 112 Surprisingly, although within the study, the educational component of the self-monitoring intervention was based on social learning theory, echoing earlier studies, the psychological impact was not evaluated accordingly. A survey study in the UK however of 517 patients taking part in a larger RCT of selfmanagement of oral anticoagulation versus routine care (SMART)<sup>116</sup> reported the effects of patient self-management of oral anticoagulation therapy (n=275) versus routine care (n=275) where in addition to anxiety and quality of life, self-efficacy was found to have a statistically significant between-group difference. The patient self- management group demonstrated improvements in self-efficacy compared with routine care (OR 1.67 vs 0.43 p=0.01). Possible reasons for this improvement in selfefficacy was linked with self-monitoring helping patients to be more aware of changes of INR levels and increased knowledge. Patients could therefore act on this which in turn, was suggested to link to perceived therapeutic control. Other psychological measures that were included however found no significant difference in anxiety scores between the two groups.

Whilst self-efficacy is a well-established robust predictor of behaviour, 117 when deciding a course of action, people also consider what they stand to lose and gain from performing the behaviour. The latter aspect is a central tenet of expectancyvalue theories or 'outcome expectancy' of self-monitoring. 113;117 The original insight by Bandura in 1977, 118 showed a causal relationship, that is, self-efficacy causally influenced expected outcomes of behaviour but not vice versa. The direction of the relationship has since been challenged over the past two decades 117 such that, ratings of perceived capability are also influenced by outcome expectations 119 that is, what they say they are capable of (regardless of whether this is a valid indicator of selfefficacy) in turn has been shown to be highly predictive of behaviour. 117 Both selfefficacy and outcome expectancy are thus potentially important enabling factors within this self-care model and when considering the behaviour of SMBP. Both constructs are already well known in the diabetes self-management literature, and the interactive effect of self-efficacy and outcome expectations has been well illustrated in a study of adolescent adherence to diabetes regimens, for adolescents with Type 1 Diabetes. 120 This study suggested that stronger beliefs in the beneficial outcomes of adherence had a greater effect on self-efficacy.

The theoretical rationale for the inclusion of these constructs as potential factors comes from one other study where outcome expectancy was an especially pertinent factor predicting self-care, particularly when the person suffered from a medical condition without overt symptoms of hypertension.<sup>121</sup> These studies suggest that when patients have confidence in managing their disease, this confidence potentially fuels their internal drive or motivation.

The literature thus outlines a number of psychological factors that could impact on the motivation for self-monitoring in various chronic diseases with reference to a number of models based on social learning theory. The relationship of these factors to SMBP is however less clear. Although there are a few observational studies 86;87;90 and RCTs that include measures of psychological factors, 91;94;103;109;122 the findings of some of these studies are hard to generalise to the wider population, for example to female populations, as with the V-STITCH trial investigating a male only population. Overall the meaning and theoretical frameworks are also generally under-specified from a psychological point of view. Furthermore, as mentioned previously, it could be suggested that the populations in the trials could be more motivated participants and if this is the case, any findings on the impact on anxiety for example, may be misleading. Existing literature also shows a limited number of studies published specifically on patient experiences of SMBP and the psychological aspects of selfmonitoring. The small numbers of studies that do exist are detailed later within the qualitative chapter of this thesis (Chapter 3). Nevertheless, it can be argued that if these psychological factors have already been studied in the literature, these may also apply to SMBP. The aim of this study was therefore to determine the association of these psychological factors to the motivation to SMBP and to investigate whether this could also be explained by psychological theory.

## 1.9.1.5 Self-monitoring blood glucose, effective or not? The debate

The following section describes a salient and on-going debate within the academic clinical literature about self-monitoring blood glucose (SMBG). The reasons for highlighting this debate were twofold: Firstly, SMBG is perhaps the closest practice to SMBP where the skills required to self-monitor blood-glucose are comparable to those used for monitoring blood-pressure (other than the obvious physical extraction of blood samples), therefore it seemed logical sense to examine the evidence around the practice of SMBG. Secondly, many patients with diabetes also have comorbidities and one of the most prevalent is hypertension, (explained in more detail below). It could be suggested that if these patients are already self-monitoring blood glucose as an integral part of their blood glucose management regime (particularly for insulin dependent Type-1 diabetes) levels, this skills repertoire could also be applied to monitoring BP, in other words they are potentially also amenable to monitoring their BP and therefore could be individuals more likely to benefit from the practice.

Whether the practice of SMBG is effective or not is however a topic that still has not reached a definitive conclusion and this debate is highlighted below.

Diabetes mellitus is typically caused by lack of or resistance to insulin leading to raised blood sugar. It is a chronic disease state which is estimated to affect over 2 million people in the UK. 123 It has a major impact on the morbidity and mortality of patients resulting from long term microvascular complications as well as macrovascular disease in the form of cardiovascular pathologies. Trials have shown the benefit of tight glycaemic and blood pressure control, 124;125 but the multi-factorial

designs are often hard to reproduce in practice. UK database studies have shown that mean HbA<sub>1c</sub> levels are sub-optimal in many people with type 2 diabetes, who form the majority of those people with diabetes treated in the community. 126;127 Benefits of SMBG has been well documented in the literature and in clinical guidelines for Type 1 (Insulin dependent) Diabetes and Type 2 (on insulin therapy) Diabetes. <sup>123</sup> The utility of SMBG for Type 2 diabetes patients controlled through diet only or oral hypoglycaemic drugs has been the subject of debate and controversy within the literature. As outlined by McAndrew and colleagues in 2007, the efficacy of SMBG would depend on whether the interventions created a patient centred behavioural control system that would address patients skills, such as (amongst others) taking readings, perceived linkages between specific behaviours (e.g. the effect of diet or exercise on blood glucose levels) and implementing actions in response to SMBG. 128 These authors further describe that any perceived linkages in the self-management of conditions would act as a motivator to change behaviour. Unfortunately this relationship of SMBG alongside other lifestyle and health behaviours involved in the management of diabetes is misunderstood in the literature. The evidence base for the NICE clinical guideline 123 on the management of T2DM was mainly based on four observational studies<sup>129</sup>, the ROSSO (RetrOlective Study: Self-monitoring of blood glucose and Outcome in patients with type 2 diabetes)<sup>130</sup> and two others. <sup>131;132</sup>

In reviewing the evidence, NICE also mentioned two earlier RCTs<sup>133;134</sup> and recommendations stated that SMBG should be available to newly diagnosed patients and to those on insulin and oral agents. But more recent trials show conflicting findings. The DIGEM study<sup>135</sup> (Diabetes Glycaemic Education and Monitoring) and the ESMON study (Efficacy of Self MONitoring of blood glucose in newly diagnosed type 2 diabetes trial)<sup>136</sup> both found no significant improvements in HbA1c levels. The

DIGEM study was a three armed trial including a control group, a self-testing group and a self-management group (the latter group, in addition to self-testing were provided with training and support to encourage interpretation of readings and applications to goals for lifestyle change in order to reach treatment targets).

A recent meta-analysis of 10 of the highest quality RCTs in this area conducted by the Health Technology Assessment Programme (as part of an extensive review of all systematic reviews trials (n=11), randomised controlled trials (n=26) observational and non-randomised studies (n=36) investigating SMBG in type 2 diabetes patients)<sup>137</sup> showed that overall, for 'simple' SMBG versus no SMBG there was a small but significant reduction of HbA1c level with SMBG of -0.21% (95% CI -0.31 to -0.10, p<0.0001. None of the three RCTs comparing SMBG with SMUG (self-monitoring of urine glucose) found a significant difference, and there was no significant difference overall (-0.06%, 95% CI -0.69 to 0.56, no significant heterogeneity). Overall the statistically significant reduction in HbA1c of 0.21% was not considered clinically significant.<sup>137</sup>

The evidence from several recent trials and systematic reviews on the clinical effectiveness and cost effectiveness of SMBG is therefore to some extent conflicting and this lies at the centre of the debate.

Out of the 26 RCTs reviewed overall in Clar and colleagues review, seven studies reported on outcomes such as QOL, well-being, treatment satisfaction and depression. From the psychological outcomes reported, the results showed that for most of the measures there was no significant difference between

SMBG vs no SMBG in most of the trials. Both the DIGEM trial and the ESMON study however reported increased depression in the SMBG group, and that this was more for participants in the 'more intensive' self-monitoring intervention in the DIGEM trial measured by the Well-Being Questionnaire. The DIGEM trial and the ESMON trial have however since been criticised on the grounds that they were both trials using recently diagnosed patients whose control was poor and was going to improve with treatment whether SMBG was used or not. In the DIGEM trial, numerous commentaries proceeding the study highlight a particular aspect of the design where blood glucose control of the populations under study was initially quite good at baseline (mean HbA1c level = 7.5%) 144 and in the ESMON study in the control groups HbA1c level improved from 8.6% to 6.9%, subsequently leaving little scope to show benefit from SMBG. 137

Current NICE guidelines have since discounted the findings from the DIGEM trial on the grounds that they describe self-monitoring as a standalone intervention and not as an element of a full education programme and therefore cannot properly inform the appropriate use of self-monitoring. This illustrates the argument described earlier by Ward and colleagues, that the use of self-monitoring within trials is undervalued and misunderstood given the complexity of the interventions in which they are included. SMBG is not an end in itself but only an aid to management and therefore must be considered this way when looking at the use of it for patients.

The evidence base overall contains studies of different types of design giving different results and therefore the magnitude of any benefits found for the effectiveness of self-monitoring is hard to decipher. The issue of what harm SMBG could do for patients

and findings from studies that SMBG could increase anxiety only adds to the debate when evidence from studies investigating self-monitoring as an integral part of a self-management programme, on the contrary, show improvements on anxiety levels.

Unlike the literature on the effectiveness of SMBG, there is a much clearer more definitive representation of the psychological issues of diabetes self care <sup>145</sup> and on the effectiveness of psychological therapies relating to blood glucose control. <sup>146</sup> This is potentially due to the complexity of a management programme for diabetes and the psychological consequences of living with such a complex regime. Although the management for hypertension is not as complex as managing diabetes, some of the psychological issues such as self-monitoring and support from others and health care providers could nevertheless still be investigated in relation to blood pressure monitoring. The asymptomatic nature of hypertension makes this condition more distinct from other chronic diseases reported in the literature and therefore could have a major impact on the motivation to self-monitor BP at home. Investigating some of these issues and their impact on monitoring is therefore one of the aims of the thesis.

### 1.9.2 Clinical Evidence and Policy

Regular measurement of BP in the clinic is necessary to monitor the treatment of hypertension and has been said to be the cornerstone of decision making in hypertension. According to national and international guidelines issued by the National Institute of Clinical Excellence (NICE) in 2006, the strategy for managing hypertension required a diagnosis based on several clinic or office blood pressure measurements. In 2011 guidelines were changed to focus on home BP monitoring, (further detailed in section 1.9.4). Home BP monitoring is now uniformly advocated

for the evaluation and management of hypertension. <sup>30;147;149;150</sup> These guidelines on the primary care management of hypertension management state that to identify hypertension (persistently raised blood pressure above 140/90 mmHg), the patient must be asked to return for at least two subsequent clinical visits where BP is assessed from two readings under best conditions. Discussion around the guidelines available in the clinical academic literature reveals that such measurements may however be unrepresentative of a patient's true blood pressure because of random fluctuations and the white coat effect. <sup>12;35;149</sup> This is a term used to denote individuals who have blood pressures that are higher than normal in the medical environment but whose BP is normal when they are going about their daily activities. Up until recently the benefits of self-management (including SMBP) and self-management support were less certain for hypertension. <sup>17</sup> The meta-analysis reported by Walsh and colleagues (2008) showed that the largest improvements in hypertension control came from adding a health care team member other than a physician or health care provider e.g. a nurse or pharmacist to focus on hypertension care.

## **1.9.3 Ambulatory Blood Pressure Monitoring versus Home Blood Pressure Monitoring**

Ambulatory BP monitoring (ABPM) has established its role in the management of hypertension and is regarded as the essential 'gold standard' method for the accurate diagnosis of hypertension and the detection of white coat and masked hypertension phenomena. Research evidence shows that ABPM has better correlation than clinic measurements with a range of cardiovascular outcomes and end organ damage, and is typically used when there is uncertainty in diagnosis, resistance to treatment, irregular or diurnal variation, or concerns about variability. In 2011 the results of a

modelling study published in the Lancet reveal that ABPM at the time of diagnosis, would allow better targeting of treatment and is more cost effective. <sup>1</sup>, <sup>156</sup>

Home BP monitoring however is also recognized as a reliable alternative to ABPM for the assessment of out-of-office BP, because they both provide multiple BP measurements away from the office setting and in the individual's usual environment. The important differences are that home monitoring of BP is performed over multiple days or weeks but only in the sitting posture and at home, whereas ABPM is performed only for 24 hours but in fully ambulatory conditions that is at work, at home and during sleep. Both ABPM and home BP estimate "true" mean BP more accurately then clinic measurements because multiple readings are taken.

# 1.9.4 Increasing popularity of SMBP and the new recommendations in the UK National Institute of Health and Clinical Excellence

The routine use of automated ambulatory blood pressure monitoring (ABPM) or home monitoring devices in primary care was previously not recommended in NICE guidelines due to a lack of validation studies. Even then, the evidence indicated that doctors rarely measured BP according to recommended standards. With the introduction of readily available, cheap and reliable BP monitors, SMBP is now practiced by almost 10 % of the general population of the United Kingdom and as the next chapter will show, this prevalence goes up threefold in patients with hypertension. Furthermore, it has been shown to be patients' mainly preferred and accepted option over ABPM. European guidelines state that the introduction of

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<sup>&</sup>lt;sup>1</sup> http://www.bbc.co.uk/news/health-14629425

easy to use devices have led to new ways of monitoring BP in primary care and are slowly replacing the mercury sphygmomanometer<sup>159</sup> as it overcomes the large variations found in clinic measurements due to variability between observers, a key problem in the diagnosis and prognosis of hypertension. Measuring BP at home is thus becoming increasingly popular with doctors and patients and increasing prevalence amongst hypertensive populations in the United States and Europe. <sup>160-162</sup>

Consequently, in 2011, radical changes were made to the previously published national clinical guidelines CG18 and CG34 (2004 and 2006 respectively) on the diagnosis and treatment of high blood pressure. The new guidelines reported in CG1274 recommend that Ambulatory Blood Pressure Monitoring (ABPM) should be used to confirm a diagnosis of hypertension. The guidelines also recommend that home monitoring should be used as an adjunct to clinic BP measurements to monitor the response to hypertensive treatment with lifestyle modifications or drugs. NICE state that these recommendations are a significant change to practice and are a radical change to the way hypertension is diagnosed and treated.

### 1.9.3 An explanation of the selection of mixed methodology

The aims of the thesis as described at the beginning of this thesis were (1) to ascertain the prevalence of self-monitoring in hypertension (2) to determine the psychological factors associated with self-monitoring blood pressure (SMBP) and to help health care professionals (HCPs) identify who the practice is most suited to (3) to identify strategies which can help patients to implement the practice more effectively within the home.

The thesis was guided by a mixed methods design that is, collecting both quantitative and qualitative data. Using mixed methods was proposed to give more credibility to the research and enhance the integrity of findings to provide a more comprehensive account than quantitative or qualitative approaches alone. Quantitative data improves the integrity of research by providing the opportunity to confirm any hypotheses generated from the qualitative research. The strength of qualitative methods, and in the present research, an in-depth analysis of a small number of contexts is thus argued to provide rich detail about the 'goings-on' within the lives of the informants. It is believed that complementing this qualitative research with quantitative investigation to test such subjective findings provides more precise, realistic and generalizable information than if they were standalone studies.

The collective impact of 'qualitative research' to firstly, understand patients with hypertension reasons for self-monitoring is a crucial aspect in identifying the psychological factors that may influence the motivation and management of the practice and secondly, quantitative assessment of the prevalence of SMBP in this population and the influence of psychological factors on self-monitoring BP makes for a more comprehensive understanding of the practice then each methodology on their own.

### 1.9.3.1 The clinical implications of this research

This research has important clinical implications for the way in which SMBP is promoted in primary health care. This is discussed in more depth throughout the thesis but particularly in Chapter 5. It is timely given the very recent revisions to National UK Clinical Guidelines<sup>4</sup> that acknowledge the importance of SMBP and its inclusion within the routine management of blood pressure. The fact that BP control rates remain sub-optimal in the UK particularly those at higher risk of cardiovascular disease<sup>9</sup> emphasises a clear need to look beyond long term medication for the treatment and management of chronic hypertension. SMBP provides a novel, practical method which allows an active role for the patient to manage their high blood pressure and to date; the views and practice of patients regarding selfmonitoring BP in the UK focusing from a psychological perspective have not been established.

### 1.9.4 Restatement of Introduction, aim and research questions

As stated in section 1.2 this study aimed to provide such data through the following research questions.

1) What is the prevalence of SMBP and the characteristics amongst primary care patients with diagnosed hypertension with and without a concurrent diagnosis of diabetes?

- 2) What motivational factors are associated with self-monitoring blood pressure?
  - i) Does this affect the likelihood of self-monitoring?
  - ii) Can this be explained by psychological theory?
- 3) Which of the psychological or motivational factors identified influence ongoing self-monitoring behaviour?

### 1.9.5 Component studies and structure of the thesis

To answer the research questions stated in section 1.9.4 above, the structure of the thesis flows chronologically in three stages and is pictorially illustrated in the Figure 2 on the following page. Chapter one has introduced the background to the thesis. The component studies are then reported. A quantitative short survey comprises the first stage of the investigation (Study 1); qualitative interviews comprise the second stage (Study2), their outcomes provide the components for quantitative investigation in Stage Three, i.e. within a questionnaire (Study 3). Chapters 2, 3 and 4 contain the methods, results and discussion of each of the three studies respectively. Chapter 5 comprises an overall discussion of the project and its multi-stage approach summarising the main findings, conclusions, implications and areas for further study based on the findings of this research project.

Figure 2: Pictorial representation of the sequence of 3 stage study design

### Chapter 2: Study 1 – Stage 1 (n=955\*)

What is the prevalence of SMBP amongst primary care patients with diagnosed hypertension with and without a concurrent diagnosis of diabetes?



### Chapter 3: Study 2 – Stage 2 (n=16)

What motivational factors are associated with self monitoring blood pressure?



### Chapter 4: Study 3 – Stage 3 (n=236)

Which of the psychological or motivational factors influence on-going self monitoring behaviour?

<sup>\*</sup>original sample

# CHAPTER 2 PREVALENCE OF SELF MONITORING BLOOD PRESSURE IN PATIENTS WITH HYPERTENSION: A PRIMARY CARE SURVEY

### 2.1 Chapter Overview

The following chapter reports the first of three studies (Study 1) conducted within this doctoral research (please see Figure 2 on the previous page, to view how this study fits within the whole research study). A brief introduction to the literature relating to the prevalence of SMBP around the world is first outlined, by details of the survey methodology employed to determine the prevalence of SMBP in the UK. The results and a discussion of the study findings follow.

This prevalence survey has been published in the International Journal of Hypertension in 2012<sup>157</sup> a copy of which is included in Appendix 11.

### 2.2 Introduction

Monitoring of blood pressure (BP) is a key aspect of the diagnosis and management of hypertension. Self-monitoring of BP by patients at home is one strategy by which hypertensive patients can participate in their own health care and leads to small but significant reductions in BP. National surveys of adults in the UK show that BP control has gradually improved since the 1990s however, many patients remain uncontrolled and amongst those at higher risk of cardiovascular disease, such as those with other co-morbid conditions the situation is worse. Novel interventions are therefore needed if optimum BP control is to be achieved and with easy to use

electronic devices currently available today, self-monitoring appears to be a useful option.

The co-existence of hypertension and diabetes increases the CVD risk associated with any given BP, <sup>167;168</sup> and evidence from a large UK prospective study shows that tight BP control is the most important way for patients with type 2 diabetes to reduce cardiovascular complications and overall mortality. <sup>125</sup> This highlights a further high risk groups that could benefit from self-monitoring, especially where sub-optimal control is more marked those at higher risk of cardiovascular disease. Self-monitoring has the potential to be useful if combined with strategies such as goal setting to facilitate acquisition of desired behaviours. <sup>169;170</sup> The fact that many individuals with diabetes have existing skills and knowledge from monitoring blood glucose could make this group particularly suitable for monitoring BP.

Despite international surveys finding typically over 70% prevalence of self-monitoring amongst people with hypertension <sup>161;162;171;172</sup> previous data from the UK suggests much lower uptake in both specialist clinics<sup>173</sup> and the general population. <sup>86</sup> Limited data are available regarding self-monitoring in primary care hypertensive patients <sup>103</sup> and its use in populations at higher risk for cardiovascular complications such as patients with diabetes.

Surveys are an ideal way of gathering information to use for studies of a descriptive nature of enquiry. Postal surveys also enable a large amount of information to be gathered in a relatively short time span from a representative target population, and respondents can answer the questionnaire in their own time and space.<sup>174</sup> Considering

the target population, that is patients from a large range of age groups and in line with the methodologies employed by previous studies mentioned above that capture the prevalence of SMBP in populations, a mailed survey was the most appropriate methodology to use for collecting this particular data.

More specifically, the aims of the present study were to (1) determine the prevalence of self-monitoring of BP in primary care hypertensive patients with or without a concurrent diagnosis of type 1 or type 2 diabetes and (2) highlight the characteristics of those that self-monitor blood pressure.

#### 2.3 Methods

### 2.3.1 Survey questionnaire design

A two sided survey questionnaire (listed in Appendix 9) included a series of closed questions asking about whether patients suffered from hypertension or diabetes and whether they used medications for their condition(s). Respondents indicating they were taking antihypertensive medication were considered to be 'treated hypertensive'. The survey assessed current self-monitoring practices: patients who self-monitored BP were asked about the frequency of self-monitoring and the type of device used and those who did not were asked whether they intended to self-monitor BP in the future. Demographic characteristics including age, gender, ethnicity, and current status of employment were collected. Diabetes was pre-specified as a subgroup to assess the influence of a further co-morbidity that may involve self-monitoring.

### 2.3.2 Sample Size

In the absence of data on the prevalence of SMBP in UK primary care hypertensive populations it was assumed that approximately 20% of hypertensive individuals would be self-monitoring BP (twice that seen in a recent UK population survey<sup>86</sup>). To estimate the true prevalence of self-monitoring with 95% confidence and 5% precision, returned surveys from at least 246 patients were needed. Taking into account a predicted response rate of 60%<sup>86</sup> 410 participants would need to have been approached. A larger sample drawn from four practices was chosen to increase generalizability and account for the non-responders.

### 2.3.3 Study Population

To recruit the practices, a convenience sampling strategy was adopted. 22 general practices were approached by letter (Appendix 8) and asked to return a fax back return sheet 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 Care Trust, South Birmingham PCT and South Staffordshire PCT. Selection was based on the Index of Multiple Deprivation (IMD) 2004 rank and population density to ensure that people from a range of deprivation were included. The IMD score brings together indicators chosen to cover difference aspects of deprivation which are weighted and combined into a single score for each of the 32482 super output areas in England. 175;176 Each practice was assigned a high or low grade based on whether the IMD 2004 score for the super output are 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. 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 22 practices were selected from across these groups. Practices were also selected on the basis that they were within the PCTs for which ethical approval had been gained. Of the 22 practices mailed, 8 practices responded: four declined and four agreed to take part in the study, thus forming a convenience sample.

The study population comprised adult aged 18 years or older registered with the four participating general practices. The practices were asked to identify patients with a Read<sup>2</sup> (morbidity) code for essential hypertension, and were asked to exclude any participants who were deemed unwell, had recent bereavement or otherwise unsuitable to participate.

### 2.3.4 Questionnaire mailing

A survey questionnaire was sent to 1815 patients registered with the four participating general practices in the West Midlands between November 2008 and April 2009.

(Appendix 9) A covering letter (Appendix 8) and prepaid envelope were sent with the questionnaire. Patients were requested to return the blank questionnaire if they did

<sup>&</sup>lt;sup>2</sup> http://www.connectingforhealth.nhs.uk/systemsandservices/data/uktc/readcodes

not want to participate. A reminder letter plus replacement questionnaire and pre-paid 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.

### 2.3.5 Data Analysis

Analyses were undertaken using Statistics Package for Social Sciences Social SPSS (PASW version 17.0.3). The results presented were descriptive, reported as percentages and Odds Ratios with 95% confidence intervals. Demographic characteristics including age, gender, ethnicity and current status of employment were collected. Some descriptive categories were collapsed for the analysis. Diabetes was pre-specified as a subgroup to assess the influence of a further co-morbidity that may involve self-monitoring. The  $\chi 2$  test was used to compare groups for all noncontinuous variables. Forward Stepwise logistic regression was used to identify important predictive variables for self-monitoring BP.

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 SMBP. The prevalence estimates were directly standardised to the population of England and Wales in 2006. Ninety-five per cent confidence intervals (CI) were calculated.

#### 2.4 Results

Of the 1815 questionnaires mailed, 1062 were returned giving a return rate of 59%.

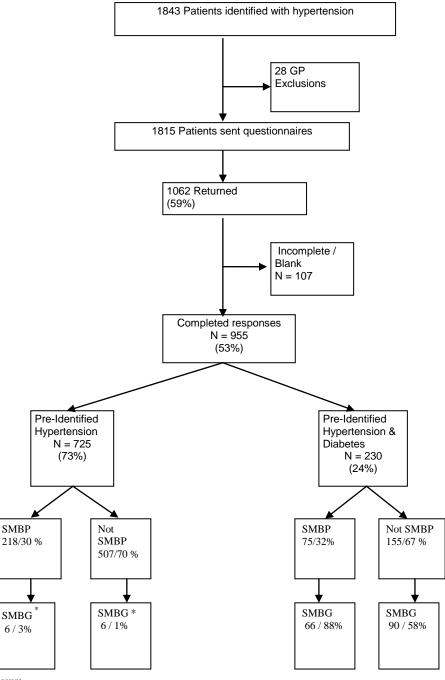
Of these, 107 (10%) were returned blank or incomplete and excluded from analysis.

Therefore, the analyses were based on 955 questionnaires (Figure 3), giving an overall response rate of 53%. Of the 955 respondents, 293 reported currently SMBP (30.7% crude prevalence, 95% CI 27.8 to 33.7). Nearly 90% (840/955) reported taking antihypertensive treatment. Of those reporting gender, 421/874 (48%) were male, and the age range was 21 to 81+. Of the 931 respondents reporting ethnicity, 81% were white, 6% Asian or Asian British, 7% Black or Black British and 3% were Chinese, Mixed or other not stated (data not shown). In view of the small numbers of non-white ethnicities, these groups were collapsed into one group for the rest of analysis.

A quarter of respondents (230, 24%) had concurrent diabetes, of whom 155 (67.4%) monitored blood glucose and 75 (32.6%). There was no difference in prevalence of SMBP in people with or without diabetes (OR = 1.13, 95% CI 0.82 to 1.55). However, those that did SMBG were 5 times more likely to monitor their BP compared to those that did not monitor their blood glucose. (OR = 5.30, 95% CI 2.46 to 11.39)

Characteristics of those measuring their own BP are shown in Table 1. Of the 293 respondents reporting they self-monitored, similar proportions were male and female (50.4% vs. 49.6%) and were not significantly different from those that did not self-monitor. The majority of the self-monitoring respondents were treated with anti-hypertensive medication 261/293 (89.1%; CI 95% 85.0 - 92.2). (Table 1). Of those

with diabetes, most took oral hypoglycaemic medication (72%; CI 95% 61.0 - 80.9) and over a third took insulin (26%; CI 95% 24.9 – 45.9).



SMBP - Self Monitor Blood Pressure SMBG - Self Monitor Blood Glucose

Figure 3 – Recruitment flow chart

<sup>\*</sup> These individuals may be misclassified as non diabetics or alternatively monitored blood sugar despite no diabetic diagnosis.

The younger age group (younger people defined as under 60, therefore between 18 to 60 years)<sup>3</sup> were 1.5 times more likely to measure their own BP than the older age group (over 60) (OR = 1.48, 95% CI 1.11 - 1.97). The odds of ratio for SMBP was 1.81 (95% CI 1.27 - 2.59) for any non-white ethnic group compared to the white ethnic group. Those in employment were also twice as likely to monitor their BP then those not employed (OR = 1.95, 95% CI 1.45 to 2.63).

Most people who self-monitored used an automated electronic BP device (247/293, 84.3%; CI 95% 73.5 – 94.3) with a small percentage (29/293, 9.9%) indicating they monitored using a manual machine. At least 65% reported monitoring at least once per month, most commonly twice a week (85/198, 43%). Self-reported frequencies are shown in (Table 2). Respondents with hypertension alone monitored more frequently than those with additional diabetes. This however was not tested formally given the high number of missing values amongst this group (146 / 63.5%). Of those respondents currently not-self monitoring, nearly 60% (384/575 58%) reported they would consider self-monitoring in the future.

The results of the logistic regression showed two variables predicted SMBP: ethnicity and employment status (Table 3). This however accounted for only 4% of the variance in the data (Nagelkerke R Square = 0.0040) therefore the model was considered a poor fit to the data.

<sup>&</sup>lt;sup>3</sup> The United Nations agreed cut off is 60+ years to refer to the older population, http://www.who.int/healthinfo/survey/ageingdefnolder/en/

Table 1: Characteristics of people self-monitoring and not self-monitoring

Demographics	Self-Monitor  n <sup>a</sup> (% of total number)	Do not Self Monitor n (% of total number)	Chi Square (P)	
Total Number	293 (31)	662 (69)	-	
Male Female	137 (50) 135 (49)	284 (47) 318 (53)	0.76 (0.382);NS	
Age range (years) 18 – 60 61 and over	116 (40) 177 (60)	201 (31) 453 (70)	7.13 (0.008)	
Ethnic Origin White Other	223 (77) 65 (23)	554 (86) 89 (14)	10.98 (0.001)	
Employed* Retired/ Unemployed	109 (38) 179 (62)	154 (24) 493 (76)	19.45 (0.001)	
Antihypertensive medication <sup>a</sup>	261 (90)	579 (88)	0.50 (0.479);NS	
Diabetes <sup>+</sup> Oral hypoglycemic medication <sup>†</sup> Insulin	75 (25) 54 (72) 26 (35)	155 (23) 111 (76) 42 (27)	0.53 (0.467);NS 0.00 (0.951);NS 1.39 (0.239);NS	

Table 2: Frequency of self-monitoring blood pressure

	Overall N (% of total number)				
More than once per day	9 (3)				
Once per day	33 (11)				
Twice a week	31 (10)				
Once per week	54 (18)				
Once per month	71 (23)				
Not on a regular basis	107 (35)				

a Numbers may not add up to total because of missing values
\* Part time or full time employment
b Patient report, may have indicated a combination of medication – i.e. multiple response options
† Patient may have indicated they are on both insulin and oral diabetes medication

<sup>+</sup> coded as having diabetes by GP clinical system

Table 3: Demographic variables predicting blood pressure

					95% CI for exp B		
	B (SE)	Wald	Df	p	Lower	Exp B	Upper
Included*							
Constant	- 0.092	0.234	1	0.628		0.912	
	(0.191)						
Employment	0.585	14.055	1	0.000	1.322	1.794	2.436
Status	(0.156)						
Ethnicity	0.584	9.842	1	0.002	1.245	1.794	2.583
•	(0.186)						

<sup>\*</sup> reported from step 2

Note  $R^2 = .55$  (Hosmer & Lemeshow), 0.025 (Cox & Snell), 0.040 (Nagelkerke), Model  $X^2$  (2) = 26.25

#### **Discussion** 2.5

## 2.5.1 Main findings

This survey found that approximately 30% of primary care patients with hypertension self-monitor blood pressure whether or not they have diabetes. People who selfmonitored were more likely to be younger (18-60), (younger defined as under 60+, by the World Health Organisation agreed cut off point)<sup>4</sup> in employment (full time or part time) and proportionally more from minority ethnic backgrounds, (Asian, Black or other ethnic groups) than those who did not self-monitor. People with diabetes who self-monitored blood pressure were more likely to also self-monitor blood glucose.

## 2.5.2 Comparison of findings with previous literature

These findings, in common with those of a local population based study<sup>86</sup> support findings from international studies that those with hypertension self-monitor blood

<sup>&</sup>lt;sup>4</sup> http://www.who.int/healthinfo/survey/ageingdefnolder/en/

pressure more commonly than normotensive populations. <sup>171;172</sup> A small Scottish study reported 31% of people with hypertension to own a monitor which is similar to the current study results. <sup>180</sup> Assuming figures for the present study are representative, then over 2 million people with hypertension may be currently self-monitoring in the UK. This result is validated by recent estimations from GPs completing a web-based survey that around 28% (95% CI 25,30, n=557) of their patients self-monitored <sup>181</sup> Despite this, the 30% prevalence rate found in the present study suggests that people in primary care self-monitor less frequently than those attending specialist clinics and that despite recent increased marketing of self-monitoring equipment, the UK possibly has some way to go before such monitoring achieves the prominence currently seen internationally. <sup>161;162;172</sup>

Frequency of monitoring in the present study for many respondents was low (42% monitoring more than monthly). This may reflect uncertainty of the appropriate frequency of monitoring: in the UK. The most recent revisions to national guidelines do not specify regimes for self-monitoring of blood pressure other than for diagnosis. Patients' and practitioners may need better information on which to base self-monitoring regimes. <sup>181</sup>

The younger age group (18-60) and employed people were more likely to self-monitor which contrasts with previous studies which have found more frequent self-monitoring activity in older and retired people<sup>86;162</sup> However, a more recent US survey concords with the present study results which might suggest a change in behaviour in younger people.<sup>161</sup> This may reflect recent changes in monitoring equipment meaning that finding time to self-monitor is no longer a problematic. Over

84% of respondents indicated they self-monitored using electronic BP machines. Perhaps the ease of use and simplicity of these devices suits a working, younger population and can be more easily integrated into active lifestyles. Reductions in cost and improved affordability of BP monitoring equipment may also have widened the market.

The high uptake of self-monitoring in ethnic minority groups could firstly perhaps reflect an increased awareness of the risks of cardiovascular disease amongst this group or by their GPs who may have recommended self-monitoring. <sup>183</sup> An alternative explanation could be that the West Midlands has the largest non-White population outside of London according to experimental population estimates for mid 2009. 184;185 According to these estimates 14 per cent of the population of the West-Midlands were classed as non-White, second behind London at 30 per cent. 184 Of those reporting ethnicity (n=931), the population of non-white ethnicities in the present study was almost a fifth of the population, (i.e. 20%) which indicates there could have been an over representation of non-white ethnicities in the present study population. Comparison of study data within each separate ethnic category however show proportions were similar to national figures (data not shown). 184 It is also possible however that this finding could have been confounded by age. The present study results show that those respondents from minority ethnic groups were younger compared to the white population (as is the case in the population in general)<sup>185</sup> and as self-monitoring was more common in younger people then this may be the explanation.

Surprisingly, the likelihood of self-monitoring of BP was not affected by diabetic status. There was however an association between SMBP and SMBG which presumably reflects previous self-monitoring experience. Overall the study suggests that blood glucose is much more likely to be monitored than BP in people with diabetes despite the relative lack of research evidence for the former. Please see section 1.9.1.5 of this thesis for further details.

Whether a patient self-monitored following GP recommendations or was self-initiated was not investigated in the current study, but has been recently investigated via a web-based survey detailed above. Combined with the findings of the present study, GPs are perhaps becoming increasingly aware that a sizeable minority of their patients may be self-monitoring on a regular basis. Nearly 60% of those currently not self-monitoring reported they would consider self-monitoring BP in the future. This suggests that GPs need to act on what is essentially a clear enthusiasm for the practice and that the market may still be expanding.

## 2.5.3 Study limitations

Despite several attempts to improve the response rate such as reminder mailings sent out to the non-responders, a short, two sided survey and a covering letter addressed from the patients GP practice, the response rate for this study was not as high as hoped. This response rate may have been improved by alternative completion methods particularly where 107 were excluded due to being incomplete or blank. Completion of surveys online or administered by the researcher at the GP practice for example could be possible alternatives and may have captured those respondents who have since moved or changed address though it was felt that postal surveys would be

more appropriate for the target population as many of them would be in the older age groups. Thus for practicality and economic reasons, postal methods were employed. Nevertheless, the proportion of males in the sample (48%, 95% CI 44.9% to 51.5%) was similar to the 2001 census of West Midlands<sup>185</sup> (49%) although the proportion of the people from a White ethnic background (84%, 95% CI 80.9% to 85.7%) was lower than the corresponding 2001 census figure (89%).

The sample was a convenience sample of participants registered within one of four practice, see section 2.3.3 who had agreed to take part in the study. The IMD rank scores were: Practice 1 IMD rank score = 4423, practice 2 IMD rank score = 2924, practice 3 IMD rank score=438, practice 4 IMD rank score = 18934. The higher the rank scores the lower the deprivation status. Of the four groups identified in section 2.3.3 above that were formed on the basis of population density/IMD rank, one of the four groups 'high population density and low IMD rank' was not occupied by the four participating practices which potentially raises the question of generalizability of the results. Random sampling of practices within the Midlands Research Consortium would have reduced any response bias, however for purposes of time, practicality and ensuring practices were selected within the PCTs for which ethical approval was gained, convenience sampling was the only option.

It was also not determined how already engaged each of these practices were in self-monitoring, and practices that were interested were enrolled onto the study. So whilst much attempt was made for collaborating practices to represent a range of deprivation to increased representativeness it is possible that there could be a further response bias leading to over estimation of the prevalence of self-monitoring.

GPs identified and recruited patients with hypertension relying on appropriate Read codes. It is possible that variation in the use of Read codes between practices could have influenced results. It is anticipated however that inclusion of hypertension in the QOF should have improved consistency of coding.

Although the study included key demographic variables to describe the self-monitoring sample, the scope of investigation was limited. This was demonstrated by the poor predictive power that our logistic regression model had for explaining the variation in the data. The amount of data collected had to be balanced with maximising responses therefore a survey that was short, simple and easy to complete overrode the level of detail of information collected. Future studies should consider relationships of self-monitoring with other characteristics including clinical data (BMI, smoking, exercise, length of time since diagnosis) and education level. This could improve the potential predictive power of such variables and thus formed the focus of Study 3, further investigated in a longer questionnaire reported in Chapter 4.

#### 2.5.3 Conclusions

This study identified a group of individuals with hypertension currently self-monitoring blood pressure with or without GP recommendation. Whilst this could reflect a healthy self-empowered population where hypertensive patients are taking more responsibility for their own health, previous research generally indicates that patients may not be reporting this data to their GP or health professional. This is explored and investigated in the next two chapters (Chapter 3 and 4). Patients not sharing this data with GPs/HCPs represent an important lost opportunity which could

be exploited at little additional effort simply by GPs being more aware of the fact that a significant proportion of their hypertensive patients are self-monitoring. The more recent evidence published suggests that there is promising trend towards increasing awareness amongst GPs<sup>181</sup> however additional hurdles, principally in terms of the validation of monitoring regimes and monitors need further investigation before self-monitoring is fully accepted in daily practice but this is an important start.

Self-monitoring is becoming increasingly popular in UK primary care, with people diagnosed as hypertensive three times more likely to self-monitor than the general population. This is still well below the level of participation seen in international and specialist clinic surveys suggesting that further increases may follow. GPs should be made more aware of the opportunities that increasing uptake of self-monitoring BP amongst their patients could bring to daily management.

## 2.6 Chapter Summary

This chapter has reported the first of the three studies conducted in the overall thesis. This was a survey of a cross section of primary care patients with hypertension in the West Midlands to determine the prevalence and demographic characteristics of people self-monitoring. The survey found a prevalence of 31% SMBP whether they were recommended by a GP or not. Compared with existing survey studies this prevalence is twice that seen in the general population. The survey also showed that patients who were younger (18-60) in employment and of non-white ethnicity were more likely to report self-monitoring. Explanations of the findings are proposed in the discussion, and conclude with the suggestion for HCP's to be aware that a third of their population with hypertension could potentially be self-monitoring. The next chapter reports interviews with some of the patients who completed the present survey to further explore the survey findings.

# CHAPTER 3 PATIENT EXPERIENCES OF SELF-MONITORING BLOOD PRESSURE: INTERVIEWS WITH PRIMARY CARE PATIENTS WITH HYPERTENSION

## 3.1 Chapter Overview

The following chapter presents the second of the three studies within the thesis, Study 2 of Figure 2, page 48. This was a qualitative study of participants taken from the sample obtained in Study 1 reported in the previous chapter. Participants were interviewed to explore their experiences on the practice of SMBP and to ask the direct question "Why do patients self-monitor blood pressure?" The aim was to uncover psychological factors that may be involved and thereby explore the motivational processes involved in self-monitoring. At the time of the study, to the author's knowledge the evidence base focusing on hypertensive patient experiences and psychological aspects of self-monitoring was limited, other than those reported in the introduction chapter of this thesis, section 1.9. The findings from the survey conducted in Study 1 are explored further in the present study. The chapter begins with an introduction to the study, the rationale and methodology used to conduct the interviews follows the introduction section with the results reported subsequently after. The findings are then discussed in relation to psychological theory and conclude with a lead up to the third related study research questions described in the next chapter.

#### 3.2 Introduction

In Chapter 1 of this thesis, (section 1.9) a search of studies of varying design that made reference to psychological aspects of self-monitoring was exposed along with the potential advantages and disadvantages of SMBP. The search found a lack of literature about patient's views and experiences of SMBP with none specifically considering the practice in the context of psychological processes involved.

Study 1 reported in Chapter 2, provided a descriptive account of the prevalence and characteristics of patients with hypertension with and without experience of selfmonitoring. The information collected from the survey however is limited by the level of depth in which participants could respond with regards to self-monitoring. To further explore and understand this behaviour qualitative methodology was therefore employed in the present study to firstly, investigate further the quantitative findings of Study 1 and secondly, build on these findings to gain a more in-depth understanding about the motivational and psychological processes involved with engaging in selfmonitoring. It is only through exploring peoples personal accounts and perspectives can in-depth meaning be truly captured and illuminated about an individual's social world 186;187 and thus explore exactly why patients self-monitor blood pressure. Collection of qualitative data in combination with quantitative findings also fits in with the philosophical assumptions of mixed methods research, that collecting, analysing and mixing both quantitative and qualitative approaches in combination provides a better understanding of research problems then either approach alone.  $^{188}$ The next section reviews the handful of qualitative studies relating to patient experiences of SMBP specifically in the context of hypertension management in

primary care up to 2012. The search methodology is first detailed followed by the reasons for the choice of search terms. It then goes on to summarise the number of articles found from differing sources and the literature examined.

Searches were conducted in the same way as literature review 1, (Appendix 1). The aim of the review this time was to identify studies exploring SMBP in patients with hypertension but employing a qualitative design such as focus groups or interviews. The search used the basic comprehensive list of keywords identified in the previous search outlined in Chapter 1, and in Appendix 1, however instead of looking at all designs of studies the search was more specific to identify qualitative studies only. Similar to the previous search, the search was widened to include articles of broader scope in the context of 'self-management' of hypertension and to identify any that referred to psychological theory or considered a theoretical background.

After hand searching the titles and abstracts of 97 retrieved articles, 17 were deemed potentially relevant and the full text were obtained. Of these 5 were selected for review, 2 of which were purely qualitative, <sup>189;190</sup> one was a qualitative subcomponent of a questionnaire<sup>87</sup> and two were qualitative studies embedded in RCTs. <sup>91;103</sup> Full details of all the articles are listed in Appendix 2.

The studies reveal discordant findings concerning patients' knowledge about hypertension. Rickerby and colleagues interview study of 13 hypertensive patients undertaking self-monitoring found considerable knowledge of hypertension and its consequences<sup>189</sup> whilst findings of a second suggested patients had haphazard knowledge, routines and uncertainty.<sup>87</sup> It seems that patients are distinguished by

those willing to take part in self-monitoring at home and pleased to be involved in their own management, to some being less enthusiastic and preferring this to be the doctor's job.<sup>189</sup> A few reasons are suggested why self-monitoring suits some and not others ranging from patients finding SMBP a satisfactory way to identify spurious or 'white coat' hypertension to avoiding overtreatment of hypertension<sup>189</sup> and a third study of older adults reported provision of reassurance and aid in decision making as others.<sup>190</sup> None of the three studies however provided a conceptual understanding of why patients self-monitored other than one comment from an interviewee in Rickerby and colleagues' study suggesting that some patients had a low self-efficacy that is, confident in their ability to perform self-monitoring with some patients felt uncertain using the machine correctly (p.498).

Although two of the three studies were conducted in the UK, one interviewed from a small convenience sample chosen because they were currently self-monitoring <sup>189</sup> and the second, a commentary open response question section of a larger survey questionnaire. <sup>87</sup> The third study was conducted in the US but again <sup>190</sup> with a small convenience sample. Whilst there is merit for these studies for providing a basis for further exploration of patient experiences, their scope is limited due to small samples and studies not entirely qualitative in nature. It could be argued that these studies may paint a more favourable perspective for self-monitoring than if the sample was more representative. More recent findings from the qualitative components of randomised controlled trials where the self-monitoring was part of a larger self-management telemonitoring intervention however further support this favourable perspective and may also have inclusion bias. <sup>107;191</sup> In the TASMINH-2 qualitative sub-study, although the self-titration of medication aspect of the intervention was met with less

enthusiasm, patients felt confident about self-monitoring and trusted multiple home readings more than a single office based reading. Similarly, in the HITS qualitative study, patients using self-monitoring as part of the telemonitoring intervention became more engaged in the clinical management of their condition.

#### 3.2.1 Questions still unanswered

It is apparent from reviewing the literature that whilst there is some evidence on patient viewpoints, preferences and participation in this self-care activity, the studies are not considered enough outside the setting of a structured clinical trial. Self-monitoring is a practice that relies primarily on the motivation of the patient to carry out an active role in the management of their own hypertension. Acceptance and confidence in the technique is therefore critical if it is to be successfully used by patients as part of the management of their hypertension. Because the literature only reports a handful of qualitative studies exploring patient experiences and views, the following study was conducted to understand the views, thoughts, opinions and experiences of those who have never used or are currently SMBP independently. This study explored from the perspective of the patient why patients SMBP. The study aimed to tap into their experiences of self-monitoring and using a psychology lens unravels the psychological and motivational factors that potentially underpin this practice through consideration of theoretical models and application. The main research questions for this study were therefore:

What motivational factors are associated with SMBP?

i) Does this affect the likelihood of self-monitoring?

ii) Can this be explained by psychological theory?

#### 3.3 Methods

## 3.3.1 Sample and design

Study participants were primary care patients with hypertension registered in one of four practices in the West Midlands who had already participated in a previous related short survey on SMBP detailed in Chapter 2.<sup>157</sup> The sample of participants was therefore obtained from the conduct of Study 1, an existing database of patients who had previously participated who had indicated their willingness to talk about self-monitoring, characteristics of which are described in more detail in the previous chapter. Those who had consented to be re-contacted and who had left complete contact details were approached.

Qualitative methods were used to explore the psychological factors underpinning the motivation to SMBP and its relationship within the self-management of chronic hypertension. A purposive sampling technique was applied that is, where participants were selected to cover a wide range of variation of dimensions of interest. This study proposed to gain 'maximum variation' recruiting individuals from a range of different demographic backgrounds (age, gender, ethnicity, employment status) and to recruit patients that did or had never/did not currently selfmonitor, Table 4. The demographics of the sample from which they were taken from are detailed in Chapter 2 of this thesis.

#### Table 4: Initial selection criteria for sample

The criteria that were originally considered for purposive selection were:

- Age: to ensure a balanced demographic sample
- Gender: to ensure balance
- **Ethnic origin:** to ensure a balanced demographic sample and because ethnicity is potentially associated with self-monitoring blood pressure
- **Employment activity:** because it was hypothesised that that monitoring blood pressure at home may be affected by time constraints during working hours
- Diabetes Status: because it was hypothesised that having exposure to monitoring could influence the decision to self-monitor blood pressure
- **Self-monitoring status:** to enable a comparison of beliefs, attitudes, experiences, thoughts and opinion of between those who self-monitor blood pressure and those who do not.

## 3.3.2 Data collection and procedures

Ethical approval was granted from South Birmingham Research Ethics Committee on 2nd October 2009, Ref 09/H1207/116.

#### 3.3.2.1 Recruitment

Participants were re-contacted by letter reminding them of their participation in the survey and their previously expressed willingness to talk about their experiences. This step was taken initially to improve response rate rather than a direct phone call inviting them to interview as there had been some significant time since their participation in Study 1 (outlined in chapter 2). A covering letter and information sheet containing details of the study were enclosed with notification that they would receive a telephone call in the next week to invite them to interview. Those agreeing to be interviewed received a confirmation letter of appointment and a contact number of a researcher if participants decided they no longer wished to take part in the study. If individuals accepted their invitation over the phone this was taken as initial verbal consent informed consent with written consent retaken at the interviews scheduled at their homes.

Interviews were conducted in the participants' homes and were audio-taped. Each interview was subsequently transcribed verbatim. Using a brief questionnaire, format demographic data was collected on gender, ethnicity, education level and occupational level and is listed in Appendix 3.

## 3.3.2.2 In - depth interviews and topic guide

Interviews were conducted with the first seven participants who replied positively to the invitation. After the first few interviews had been conducted, the characteristics of these participants were determined and a purposive sampling technique (described earlier) was employed to recruit the remaining participants (total sixteen) until saturation was reached.

Participants were interviewed in depth to explore their individual experiences of SMBP. The interviews asked a series of broad, open ended, non-judgemental questions to elicit a conversation about how the patient came to know they had hypertension and their thoughts and feelings about it. This style of questioning at the beginning of the interview encouraged unanticipated statements and stories to emerge. For example the first questions asked at the start of the interview were variations of "Can you tell me how you came to know you had high blood pressure?" This opening question allowed the participant to slowly ease into the interview with their own story of how they came to the diagnosis of hypertension. The interviews followed the basic interview guide detailed in Table 5. Within each section there were prompts to aid eliciting responses about having high blood pressure and self-monitoring.

#### **Table 5: Interview topic guide**

- Patient's illness experience
- Contextual life world
- Home self-monitoring blood pressure
- Interaction with GP/HCP relating to SMBP

GP General Practitioner; HCP Health Care Professional; SMBP Self-Monitoring Blood Pressure

Using this guide ensured that at the very basic level, the same general areas of information were collected from each interviewee allowing more focus than the conversational approach, whilst also allowing a degree of freedom and adaptability in getting the information from the interviewee. The full topic guide and prompts is listed in Appendix 4.

Prior to interviews the researcher had a sense of some of the key issues that surrounded this topic identified from previous literature. To ensure that data collection remained neutral, the use of broad questions in the topic guide encouraged the participant to take the lead and to shape their own narrative. Questions would therefore start with 'tell me about', 'how', 'what' and 'when' which is a style reported to yield rich data where the researcher is essentially engaging in data collection and data analysis at the same time.(p.33)<sup>187</sup>

Interviews were conducted iteratively, that is, the questions were developed, tested and then refined based on what was learnt from asking people these questions. The set of issues that needed to be covered were broadly consistent with all participants but the questioning remained flexible to allow for full probing of any relevant issues raised spontaneously by the interviewee. This is a unique aspect for depth interviews as it allowed a change of course of the interview agenda. 196

#### 3.3.2.3 Pilot Interviews

The interview guide was piloted prior to actual use on a small sample of eight people recruited opportunistically by the researcher consisting of colleagues in Primary Care Clinical Sciences at the University of Birmingham and also to individuals selected from a cohort involved in ageing research at the University of Birmingham, called the Birmingham 1000 Elders.<sup>5</sup> The pilot sample therefore represented a range of different professions and ages. Minor alterations were made to the wording of the questions

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<sup>&</sup>lt;sup>5</sup> http://www.birmingham.ac.uk/research/activity/mds/centres/healthy-ageing/elders.aspx

mainly to contain fewer directives and phrased to allow the participant to share their experiences more.

### 3.3.3 Data Analysis

## 3.3.3.1 Approach

Descriptive statistics were used to provide a demographic and health profile of the group of participants. Data were analysed iteratively, that is the initial interviews were conducted and examined prior to additional interviewing 186 using grounded theory and the constant comparative method of qualitative analysis as described by Barny Glaser in 1965. 197 The purpose of the analytic procedure of constant comparison method is to have a process of joint coding and analysis to generate theory. This is more systematic, as Glaser describes, as it uses an explicit coding and analytic procedure and designed to aid the analyst to be able to generate theory which is integrated, consistent, plausible, close to the data and in a form which is clear enough to be readily, if only partially, operationalised for testing in quantitative research. 197 (p.437) This method was therefore proposed as an ideal analysis strategy for research with mixed design, that is, to identify potential factors through exploration of patient interviews with the view to further test these factors within a questionnaire to determine any relationship of these factors with self-monitoring. Glaser states the method can be described in four stages: (1) comparing incidents applicable to each category (2) integrating categories and their properties (3) delimiting theory (4) writing the theory.(p.439) In the analysis, responses from nonmonitors were compared with those who currently or had previously monitored as these were anticipated to have different outcomes.

## **3.3.3.2** Analysis

Interviews were audio-taped and transcribed for analysis. Listening to the tapes enabled the researcher to attend closely to the respondents' feelings and views and allowed the researcher to carefully go over and over what they were saying.

Each transcript was reviewed line by line and treated in the same way i.e. given the same analytic treatment. This allowed systematic and comprehensive coverage of the data set, an important step to ensuring that certain forms of analysis were not overseen or excluded. Analysis was therefore undertaken systematically and applied across the full data set. 198

Transcripts were read and re-read in order to identify general themes. The data in the interview transcripts were subject to analysis line by line with codes on the left hand side. Identification of key codes was developed based on common sense terms devised by the researcher using the participants' own terms to capture the essence of talk and interaction and ensured that the analysis remained, as described earlier, close to the data'. Themes were determined as the transcripts were read and added to the coding structure as necessary. Items in general themes were compared with each other and the coding was refined to produce sub categories based on similarities and differences between items. Broader categories, themes and subcategories were identified and all the items were discussed and reviewed by the author, and two supervisors SG and RM to ensure all categories emerging from the data were accurate and had all been identified. An example of a transcript and how the coding process was applied is depicted in Appendix 5.

## 3.3.3.3 Interim analysis

After the first seven interviews the codes were listed under each newly developed conceptual category. A list of codes and categories are shown in Appendix 6. At this point there were 101 codes. Raw data from the transcripts were placed with each relevant code and listed per participant providing textual chunks of data. Memos of this process were continuously logged recording how each category was developed and the reasons for the associated relationships between the categories. In qualitative methodology literature this is an important process when trying to construct theory. 193;197 The overall result of this process provided a matrix of categories and relative quotes per participant and allowed numeration of re-occurring categories per participant. It also kept the raw data explicit so that the conceptual meanings of the categories were not lost in the analysis and the raw data could always be accessed. 197

This matrix was triangulated with the supervisors (RM, AN, SG) to see if there was consensus on the conceptual structure of the categories and appropriate classification of quotes used to illustrate each code and associated category. Their analyses were compared and contrasted with the codes, categories and themes that emerged from the original interim analysis.

As this was an interim analysis further subsequent participants were selected on the basis of this matrix. Further lines of enquiry were pursued in the interviews based on the numbers of re-occurring themes and the existing characteristics of participants that had been sampled.

During the analysis process, data collection and conceptualisation continued until categories and relationships were 'saturated', that is no new data added to the developed themes. This, as Glaser and Strauss recommend marks the point for conducting no further subsequent interviews. <sup>199;200</sup>

#### Reliability and validity of the results

A one page summary of the analysis of the interviews was posted to the interviewees to check for accuracy and reliability of interpretation. A feedback sheet and pre-paid envelope was supplied for their feedback and to include any comments on the ordering, clarity and wording of the questions. This process helped to improve the quality of the data collection and validated the data by making final attempts to tease out any other important areas not covered by the guide pertinent to the subject of self-monitoring.<sup>201</sup> The feedback sheet pro-forma is listed in Appendix 7.

#### 3.4 Results

## Sample characteristics

Of the 44 participants identified with complete contact details, 16 participants were enrolled in the study. Through convenience and purposive sampling, this total was achieved on the basis of recruiting and interviewing until thematic saturation was reached or when no new concepts were emerging from the on-going analysis of at least four subsequent interviews. <sup>192</sup>

Patient characteristics of the sample are listed in Table 6. Nine females, (7 Caucasian, 2 Asian) and 7 males (4 Caucasian, 2 Black (Caribbean, 1 Asian) were

interviewed with ages ranging from 49-80 years old, employment status (Full/part time, or unemployed, retired and monitoring status (6 currently monitoring, 2 used to and 8 had never self-monitored) and deprivation, measured using the Index of Multiple Deprivation (IMD) 2010<sup>176;176</sup> which is further detailed in Chapter 2, (Section 2.3.3, page 48). The IMD is an estimate of the socioeconomic deprivation and brings together indicators chosen to cover different aspects of deprivation which are weighted and combined into a single score for each of the 32482 super output areas in England<sup>176</sup>.data of which was based on more recent figures of 2010 and linked to the patient postcode. The quartiles of the 32482 super output areas were ranked (Q1, 2, 3 &4) and each individual was assigned a score of 1-4 based on their resident postcode. Four had diabetes (3 of whom monitored blood glucose) and one described themselves as having borderline diabetes.

Table 6: Characteristics of the sample of patients interviewed

Interviewee no	Age	Gender	Ethnicity	Qualifications	Employment Status	Н	D	Marital status (others in household)	Monitors BP	Monitors Blood Sugar	IMD/Q*
1	68	F	White	No formal	Retired	Y	N	Married	Y	-	1
2	76	F	White	No formal	Retired	Y	N	Married	Y	-	2
3	79	M	Black/ Caribbean	No formal	Retired	Y	Y	Lives alone	Y	Y	1
4	62	F	White	No formal	P/T	Y	N	Shared accommodation	Y	-	1
5	74	M	White	Trade apprent'p	Retired	Y	N	Married	N	-	2
6	65	F	White	Nursing	Retired	Y	N	Married	Y (Used to)	-	3
7	49	F	White	No formal	Unemployed	Y	N	Married	Y (Used to)	-	1
8	66	M	White	No formal	Retired	Y	Y	Married		N	2
9	77	F	White	No formal	Retired	Y	N	Married	N	-	1
10	59	F	White	None	P/T	Y	BL	Married	N	N	1
11	80	M	White	Primary school	Retired	Y	No	Married	N	-	4
12	66	M	White	Primary School	Retired recently	Y	No	Married	N	-	2
13	69	M	Black/Brit	No Formal	Retired	Y	Yes	Married	No	Yes	1
14	52	F	Asian	Teaching	F/T	Y	No	Living with Partner	Yes	-	2
15	72	F	Asian/ Sikh	A-Level equiv	Retired	Y	No	Widowed	Yes	Yes	2
16	78	M	Asian	Nursing Quals	Retired Nurse	Y	No	Lives with family	Yes	-	2

<sup>\*</sup> IMD = Index of Multiple Deprivation 2010 based on patient postcode, (Q) quartile score based on ranking of 32482 super output areas; Y – Yes, N- No, BL – Borderline, H- Hypertension, D - Diabetes

## 3.4.1 Overview of themes and presentation of the results

The method chosen to present the results was to present the emergent thematic analysis within the results section and a separate discussion following this linking the analysis to the extant literature(p.76).<sup>202</sup>

Four main themes emerged from the analysis relating to the practice of self-monitoring: 'Self', 'Living with hypertension', 'The GP-Patient transaction', 'Self-monitoring behaviour'. The findings are presented in relation to these four themes. For each theme there were a number of categories and for some, sub categories. A visual representation of the themes and the hierarchical interrelationship of the themes, (yellow) categories (green) and sub categories (blue) are illustrated in Figure 4.

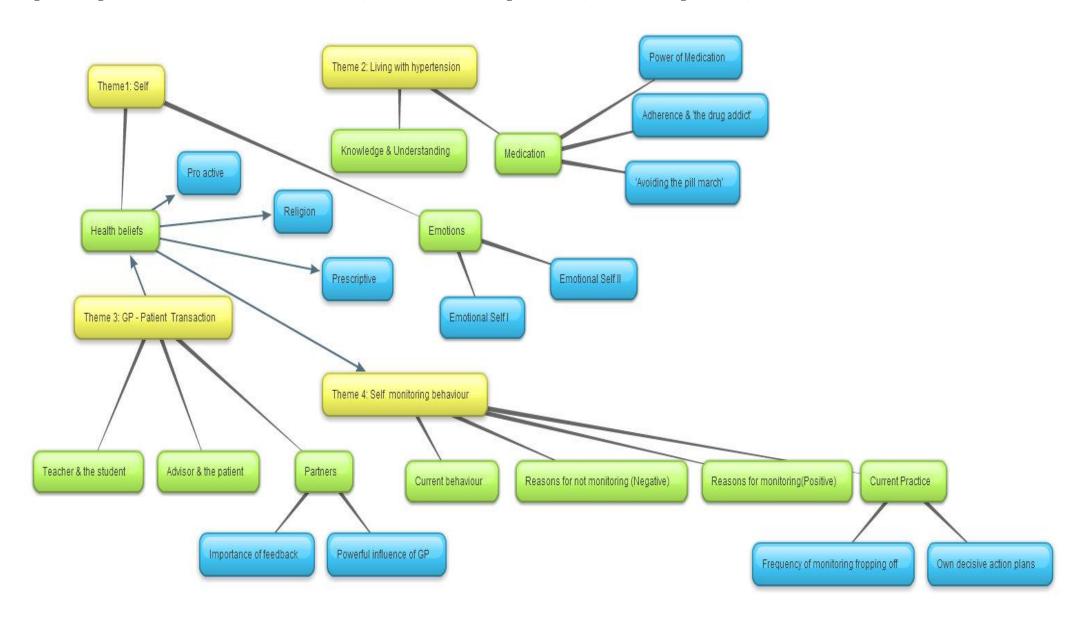
Descriptions of the salient themes and categories are presented in the next section along with excerpts of participants' interviews to help illustrate the different categories and subcategories for each theme. Not all 123 themes identified in the original analysis are discussed here, however are listed in Appendix 6, along with a screenshot of the raw data analysis. The themes selected for discussion in the following section were chosen on the basis that they helped to understand the motivations for patients to engage in self-monitoring with explanations linking with psychological theory. Prior to conducting the interviews, selection of interviewees was chosen to reflect a balance of participants with and without experience of self-monitoring, as it was initially hypothesised that the responses were would be different. The presentation of the data below aimed to reflect this balance including

illustrations of those self-monitoring and not self-monitoring to portray the differences.

It is important to note, that the purpose of the present study was to gain a conceptual understanding about performing self-monitoring and therefore say something in detail about the perceptions and understanding of these particular groups rather than prematurely make more general claims.  $^{202}$  This study was not a study to state for example '10 of 16 participants said X....'

Although analysis did quantify the comments during the coding process, this was to aid the decision about which themes were important to consider as salient issues in each individual experience. The aim of the overall analysis however was to preserve the whole patient experience and therefore analysis was based on a detailed case-by-case analysis. Quantifying responses was therefore not appropriate for the current study and results are presented using descriptor terms such as "some" or "the majority" of respondents to represent importance of particular themes.<sup>202</sup>

Figure 4: Diagram to illustrate how the four themes (Yellow) interrelate with the categories (Green) and the subcategories (Blue)



#### 3.4.2 Theme 1: Self

The first theme titled 'Self' refers to commonly expressed views about participants' own personal role in looking after their own health irrespective of whether they self-monitored or not.

Views and the emotions felt by individuals towards having hypertension are within the category named 'Emotions' as shown in the above in Figure.4 Sub categories within this theme were i) Emotional Self I: *Learning to live with high blood pressure*, ii) Emotional Self II: *Hypertension as the silent killer*.

The active role participants believed they took in looking after their own health was commonly expressed within a variety of lifestyle improving health behaviours.

'well a bit of each really I wanna keep fit so I walk to keep fit because I'm a great believer of if don't use it you lose it so I do walk a lot I mean it's getting more and more difficult the older I'm getting but I'm still doing it and while I can I will but I think that helps the blood pressure as well' (P1, SMBP)

Independent of whether they self-monitored or not nearly all participants could individually describe lifestyle factors considered important for BP control with most engaged in at least one lifestyle improving recommendation (ranging from diet, exercise, medication regulation, smoking cessation, eating less salt, low fat diet and reduced alcohol consumption). Knowledge about how to lead healthy and active lifestyles in order to help keep BP in control was sought from the media (television, newspaper articles) and not from their HCP. Exercise was the most common activity

participants felt they would like to improve saying increasing age and associated physical limitations were main reasons for lack of exercise. Salt consumption was also seen as important for keeping blood pressure in control. Lifestyle seemed to be inextricably linked with their beliefs and perceptions about capabilities to look after their own health independently. For most of the self-monitors this translated in a positive attitude towards looking after their own health and with regards to self-monitoring

'it's just being careful really...I think we have all got a responsibility to look after our own health really haven't we you know what I mean and some people through stubbornness ever go to a doctor or don't even feel ill' (P4, SMBP)

'to take action myself on my own life, I monitor everything, if there's something to monitor myself I will do it...I don't want to be dependent on others [she says fingers crossed] I'm a strong believer that you should be responsible for your own health...I don't think anyone should need to always depend on the GP there is so much information out there...but then if people don't have a medical background then there are people that want their health looked after by the GP so self-monitoring is probably not useful for them' (P6, SMBP)

One patient not monitoring expressed her beliefs about the importance of her religion in primarily maintaining good health.

'because when I was in hospital I was frightened but I pray a lot and when I pray then I am a lot calmer...I find prayer important because it does help you to calm well if you're asking the creator to calm you down he's going to do it isn't he but I don't know if that's what you feel but that's what I feel' (P9, NSMBP)

A clear distinction occurred between being personally 'pro-active' about general health and lifestyle and 'prescriptive' about who they believed to have important roles y in the control of their hypertension. Patients were certain about who they felt should largely be responsible for their BP. The perceived 'role' of their GP or HCP within the management of their overall health is described in more detail in theme 3 of this section of the thesis, 'The GP-Patient transaction'.

#### **Emotional Self I: Learning to live with high blood pressure**

The long term nature of hypertension treatment seemed to manifest in low emotional concern of having high BP.

'I mean over 30 years things have changed you know and perhaps things could be altered now but I was told at the time that erm you will have to take these tablets for the rest of your life' (P2, SMBP)

'no it wasn't a shock so and my thinking is fair enough if I have to take tablets and as long as its kept controlled so that's going to help me so that's fine' (P14, SMBP)

Such a low emotional concern was equally expressed amongst the non-self-monitors.

'I'm not worried about high blood pressure I can't be, there is enough to worry about in life' (P6, SMBP)

I always seem to think it's you know the muscles in your heart are not are erm over active I don't know I think it worries people don't it because if it stops you stop I know we should all be nine stone ringing wet but the world wouldn't be round if we were all if everybody was pencil thin and super fit...the bloke who invented jogging died at 54 yeah he was the first jogger they recognised it was too much exercise' (P12, SMBP)

One lady suffering from a more serious complex inherited chronic condition, polycystic kidney disease (PKD), puts having high blood pressure in perspective.

'I think I worry more about my kidneys then the blood pressure, I mean my mum died because of the polycystic kidneys so that's at the back of my mind and then I kind of think I don't want them to go I don't want them to deteriorate uhm generally as my health I suppose as I have got older I tend to worry about it'...no I have the attitude if I am going to die I am going to die [laughs] I am going to die of something or another' (P14,SMBP)

Through taking medication, participants felt able to forget they had high BP.

'otherwise never had any real effect on me I don't think you know not psychologically or anything like that you know I've never really took that much notice I just take my tablets and get on with life' (P8, Non SMBP)

'no not really no I don't really think about it so other then taking medication'(P10, NSMBP)

A factor that participants explicitly said was a cause for their low concern for having high BP was their age, describing their condition as a habitual part of their lives.

One participant aged 76 said:

'well at my age there is nothing you know I love politics I talk politics nothing bother me I just give it up if I think I can't control it..see when you reach the age of where I am there is nothing if you cannot solve the problem leave it' (P3, SMBP) Another participant aged 74 similarly describes:

'well when you have been taking something for 20 years you think well its great don't you and you think well that's the answer but I dunno' (P5, NSMBP)

#### Emotional Self II: Hypertension as the silent killer

Although participants were generally not very concerned about living day to day with hypertension, they were fearful of the risks associated with hypertension. Stroke and heart attacks were conditions most commonly feared. Self-monitors consequently described a need to watch their BP.

'yeah but I think stroke is one of them...well we have had quite a lot of heart trouble in the family and also strokes and I think that's why it's important that I watch my blood pressure because strokes...etc' (P1, SMBP)

'I know that uhm if it's too high it can cause heart attack or a stroke which I was warned when they first found out that I had got high blood pressure...because you see my father died with a stroke and he used to suffer with bad headaches and I used to think well is it anything to do with it (and his [hospital consultant] exact words were [laughs] tell your husband not to pay for your pension because if you don't do as your told you won't be around that long you will either die with Stroke or heart attack [pause] and I was so shocked' (P2, SMBP)

'well everybody has a threat haven't they it doesn't worry me until but it would be wrong to say that it aint going to hit me sometime'(P11, NSMBP)

The majority of self-monitors said they felt they had no control over hypertension for which there were no symptoms and this consequently made them feel anxious.

'I cannot describe what it is but I just know I have got it' (P1, SMBP)

'er I don't know really coz it's not you don't feel like you've got anything...well its frightening because people are walking around and they don't feel ill and they could just drop down dead' (P4, SMBP)

The fear of the silence of the condition was for these participants an underlying motivation for self-monitoring by helping participants to take back some control and subsequently alleviate the anxiety attached to the asymptomatic nature of hypertension.

"yeah and the doctors I think you know knowing that both of them had strokes and also had high blood pressure... it was fear because I didn't want a stroke...yes it... I'm not so worried now...' (P4, SMBP)

'it is very important extremely important because high blood pressure is a silent killer and you could have a stroke or cerebral haemorrhage if suddenly its gone up so therefore its important the person should be closely monitored either taught by medical staff or frequently checked' (P16, SMBP)

The worry and fear about the consequences of hypertension were not exclusive to self-monitors, some non-monitoring participants also expressed their concerns.

'but when you get it you think you're in for a stroke or something like you know what I mean' (P5, NSMBP)

'oh crumbs I worry yeah...coz I know it leads to the heart and everything but so far that hasn't Alan his hearts been affected but mine hasn't erm no its...it did go up once the bottom and he put me on Atival?' (P9, NSMBP)

'good idea [SMBP] because if you catch it early enough it stops a lot of heart problems in the future doesn't it that can catch you a lot of people don't know that they have got it do they' (P12, Non SMBP)

Conversely other participants felt it was easier to forget about hypertension by the very fact that the condition presented no symptoms. Patients would describe an 'out of sight out of mind attitude'.

'I don't really have symptoms some people do feel they have symptoms, if I did have symptoms then maybe I would worry but because I don't I don't worry about it that much, I know at the beginning it was kind of a worry and I remember thinking oh my god how am I going to control it, and does this mean I can't eat certain types of food and how am I going to get some exercise in so I think at the beginning it was a bit of a shock, because I think I have been quite lucky erm it's been quite stable so I haven't had too much problem' (P14, SMBP)

## 3.4.3 Theme 2: Living with hypertension

The second theme 'Living with hypertension' centred on the day to day aspects of living with the condition. Experiences varied from participants largely unaffected by the condition to those more aware and anxious about the condition.

Two salient categories/subcategories within this theme are described here: (i) knowledge and understanding (ii) medication: power of medications, patients taking medication to gain personal control and the concept of 'the drug addict'.

Most respondents had been living with hypertension for many years with many recalling their initial diagnosis from attending other health checks at their GP practice.

'Yes, I go because I take thyroxine and I have to have my thyroid checked regularly...I have my blood pressure checked every twelve months and blood tests and that and I found out when I went there for a check quite a few quite some time ago' (P1, SMBP)

'it was when you had to have jabs for going to Turkey so I went up for the jabs he said I haven't seen you for a well I don't think I'd ever seen that particular doctor it was er...think it was Dr X then and he said well we will have a full check-up...and he checked up on that and found out I'd got blood pressure' (P8, NSMBP)

#### Knowledge and understanding

Both people self-monitoring and not-self-monitoring appeared to have similar levels of knowledge about BP. Participants self-monitoring made further reference to BP values however both groups had a poor understanding of what systolic and diastolic meant and of their own BP targets:

'yeah there is a certain range but I haven't got a clue now' (P7, Non SMBP)

'no only that the bottom one is to do with the heart...I know that one is to do with the heart it's more well the tops a worry as well' (P9, NSMBP)

Participants with diabetes seemed to be aware of their added risk for developing high BP stating such information was sought from their GP.

'I have arthritis, and borderline diabetes but I'm not on treatment or anything but it's when I've erm had my bloods taken its about 6 or 7...well it's all connected from what I can gather what he said so' (P10, NSMBP)

'but er the doctor er worry about the high blood pressure the high sugar level because you know he says the two don't go don't work well together'

(P13, Non SMBP)

#### Medication

#### **Power of Medication**

Many of the participants believed that there was not much that could be done to control high BP other than taking medication.

'no I am happy with that treatment because I think my GP is er more like me on pressure rather to try and keep off medication for as long as possible, then if there is no alternative then to go on medication' (P13, Non SM)

In managing perhaps what she perceived to be a more serious condition, polycystic kidney disease, this participant describes an almost fatalistic health belief about having high BP.

...no I have the attitude if I am going to die I am going to die [laughs] I am going to die of something or another' (P14, SMBP)

#### Medication adherence and 'the drug addict'

Attitudes to taking medication were polarised from minimal concern to this behaviour as being essentially the same as a drug addict.

'I take my tablets when I have to... I'm not worried about high blood pressure I can't be, there is enough to worry about in life' (P6, SMBP)

'I'm a regular obsessive about my Atenolol' daily..(P6, SMBP)

'I take my tablets every morning without fail 365 days a year and I take one at night and I don't think about it no more...I take the tablets everyday' (P12, SMBP)

'I don't mind being on medication what I would have like was say that if your cholesterol was down you could come off whatever medication it is whether it's for cholesterol, for blood pressure for sugar levels when if it comes down you can come off your medication but it's when you start on medication and you're stuck with it for the rest of your life even if you don't need it because what they say if you come off it something may go wrong because your body is like used to the drugs so you can't go without it ...well in other words you are addicted to the drugs [laughs]' (P13, NSMBP)

### Avoiding the "pill march"

On the other hand, contrary to beliefs participants feared the prospects of taking medication long term. One participant explains this was what instigated them to start monitoring their BP revealing another underlying motivation for self-monitoring with the aim to delay seeking long term treatment.

I think what it is I don't think he wanted to start me on blood pressure tablets because he knows that I would have been them on for life if you know what I mean I think that's why he was trying to let me do it myself if you know what I mean. (P7, SMBP)

The participant below described her reasons for self-monitoring so that she could see for herself that she did not need to be on medication as her BP was ok.

'and because my friend said you must go the doctors and get medication because I'm not a tablet person all my life I don't pill pop I don't like all the pills people take do you know what I mean pain killers things like that'...so I didn't want to go the doctors at first I did try other things before I went to the doctors because I didn't want to start

on the pill march you know like you start at a certain age everybody's taking pills you know (P4, SMBP)

#### 3.4.4 Theme 3: The GP Patient transaction

The third theme 'The GP-Patient transaction related to the two-way perceived 'transaction' between the GP and the patient. Participants often made reference to their GP and how they viewed their GP with regards to their healthcare. An overall analysis of the responses revealed three differing viewpoints on this relationship forming the three categories within this theme (i) 'the teacher and the student', (ii) 'the advisor and the independent patient' and (iii) 'the partners' Common to all three was the powerful influence participants felt their GP could have in making any decisions to SMBP.

#### (i) 'Teacher and the student'

Participants with no experience of monitoring commonly held very high regard for their GP strongly believing they should be solely responsible for the management of BP. These participants were more prescriptive about the role of their GP and felt that as patients, they should simply absorb this knowledge and adhere to their advice.

'because it's going to go up at times isn't it according to the way you are uhm because I am the age I am the doctor takes more care of us...I have been quite a lot because I have had a lot of other things wrong and he always says let me take your blood pressure' (P9, NSMPB)

'well I trust the doctor to do everything' (P12, NSMBP)

One participant with diabetes felt competent enough to monitor and manage their blood glucose although this didn't seem to transfer to their competency to monitoring and managing BP.

'well I think that with the blood pressure it's probably managed better by medication and the same with the diabetes really but I can manage that better probably better than I can me blood pressure' (P8, NSMBP)

Such patient expectations of the GP being responsible for the control of their BP refer to the 'prescriptive' view of health described earlier. Such a view is potentially reflective of a low self-efficacy amongst these participants in ability to manage BP.

#### (ii) 'The advisor and the independent patient'

Conversely, participants self-monitoring viewed their GP as an advisor and that they (the patient) were independent in the 'driving seat' for making their own health care decisions and the GP would advise when necessary. One participant describes that the power of just one demonstration of how to monitor blood glucose was enough for the patient to continue independently.

'oh yes I virtually self-regulated from day one I went they put me on insulin and then the nurse at the Peel. [health centre] Said that you can adjust it and told me how to adjust it and ever since then I go back to my own doctor for the check for the blood tests and everything but I do monitor and do adjust it myself'(P8, NSMBP)

The need to take on more of an active role was also felt by some due to suspicion about their original diagnosis, which was often on the basis of one off readings.

'yeah because when you go the doctors er that's just one reading isn't it and it could be I don't know you could be just stressed out for the day or you've walked up a hill or something like that you know...whereas here you can take it at different times' (P4, SMBP)

"he [the doctor] said that most people when they come to surgery they have high blood pressure whether its surgery or the doctor or the time they have to wait one never knows '(P3, SMBP)

'so they [GP Practice] used to make me sit outside for ten minutes before I went in there to calm myself down sort of calm myself down...well I knew I weren't it's because I knew I'd got high blood pressure and I don't think the doctor believed me at first' (P7, SMBP)

#### (iii) 'The partners'

The 'partners' involved a mutual understanding between GP and patient where health care decisions about the patient was based on informed choices and sharing of information between respective parties as equal partners. Only one participant described this role, however in analysing the whole sample of participant responses there were some common positive benefits patients perceived for self-monitoring relating to a strong GP/Patient dyad:

- a) The importance of feedback about monitored results and evidence of limited or no sharing of BP monitored results between the patient and the GP.
- b) Seeking help
- c) Making subsequent lifestyle changes
- Detecting problems early and treating them early to prevent further complications
- e) Reducing visits to the doctor
- f) A mismatch between beliefs and behaviour
- g) Powerful influence of the GP

a) to g) are described below with quotes from participants to illustrate each one.

## a) Importance of feedback about monitoring results: "the A- B complex, if A then B"

Strong opinions were held about the practice being relatively redundant unless there was feedback from readings given to the GP.

'no see that's what I mean unless there is feedback to the doctor then it's a peace of mind but your still not the doctor can't really monitor as such...if my blood pressure is high if it's really high then I should make an appointment to go and see my GP but otherwise then that I haven't got any medical experience er somebody to advise me what to do if it is high or low (P13 NSMBP)

...with my blood pressure and put it in the chart then and he would er go back to the GP but you need the feedback because I could wait and sign and its going somewhere into a pile and it's a waste of time that you are doing it' (P3, NSMBP)

#### b) Seeking help

Despite not monitoring themselves these participants recognised a number of benefits that self-monitoring could bring for someone such as in knowing when to seek help.

'well it would be a waste of time...well you could be taking your blood pressure yourself and keeping it to yourself and it might be the wrong one and that does you no good if your sharing it then people can pick it up and say you have got a problem that's the thing that's why I wouldn't mind doing it as I say I can't fault my doctor...I

think it is useful erm at least if you are feeling down and you take your own blood pressure you can get in touch with your doctor straight away I do take my own pulse regularly and erm I think it would be useful' (P11, NSMBP)

Making subsequent lifestyle changes and detecting problems early. Conversely self-monitors described that the practice was beneficial for reducing visits to the doctor. These are illustrated below.

#### c) Making subsequent lifestyle changes

Monitoring BP at home was viewed as an opportunity to be able to make behavioural changes to one's own lifestyle rather than simply committing oneself to a life of taking medication.

'yes pick things up and feedback like telling you call me and say your blood pressures high let's do something about it, you know you work together right and er I do something about my diet and he does something about medical side and you work together and if you save the NHS a heck of a lot of money then wait for people to really bad then put them on medication for the rest of their life... (P13, NSMBP)I

## d) Detecting problems early and treating them early to prevent further complications

Self-monitoring was also viewed as an opportunity to detect problems early and therefore take subsequent action on the basis of the readings.

'good idea because if you catch it early enough it stops a lot of heart problems in the future doesn't it that can catch you a lot of people don't know that they have got it do they?' (P12, NSMBP)

'yeah there probably is in the sense that if you are not monitoring your blood pressure could rise significantly you wouldn't really know and if it did at least you could get to the doctor and get something like that sorted out which could obviously prevent Stroke or anything like that...' (P8 SMBP)

#### e) Reducing visits to the doctor

Some felt it would mean less burden for the doctor and leave those appointments for illness considered more serious.

'If you know you have to take medication for the rest of your life and your medication can control it then you would save time of the doctor and monitor at home. I think it would be a good idea' (P2, SMBP)

'yeah coz it's checking aren't ya coz uhm I'm not up at the doctors all the time I've got no ailments or anything like that' (P4, SMBP)

#### f) A mismatch between beliefs and behaviour

There appeared to be a disparity between the beliefs of those with no experience of self-monitoring who believed that engaging in the practice could only be useful if there was feedback of shared results between patient and GP and the actual behaviour observed by participants in real practice. As mentioned previously, only one of the participants interviewed mentioned they fed back their readings to their GP or had made any subsequent action plans based on their readings. The rest of the participants were either unsure whether their GP even knew they were self-monitoring or if they did think they knew commented on the relatively unenthusiastic response from their GP when they told them.

'this [points to written readings] no I don't think he knows that I use it...no I did tell him that as I say it was the end of August with that funny turn that I had I did tell him that I took my own blood pressure and it was high but he didn't question me about it or say well how did you do it or whatever I suppose he just presumed' (P1, SMBP)

Further probing identified that feedback didn't seem to be something that participants felt they needed. Participants assumed that feedback or communicating their results was not necessary or could not see any benefits of doing so.

'I haven't ever taken readings to my doctor...'I don't know no no should I take it to them?' (P4, SMBP)

'well I don't know whether the doctors like you doing it yourself or not but er...'I never seem to tell them' (P2, SMBP)

One participant provided an insight into their reluctance to share readings through fear of their GP putting them on more medication based on these readings especially if they were higher than usual.

'...my friend said you must go the doctors and get medication, because I'm not a tablet person all my life I don't pill pop I don't like all the pills people take do you know what I mean pain killers things like that...so I didn't want to go the doctors at first I did try other things before I went to the doctors because I didn't want to start on the pill march' (P4, SMBP)

Thus what patients describe in theory about how self-monitoring can be useful is not practiced in reality with virtually no evidence of communication or feedback about self-monitoring activities from the GP. This finding has clear link with a) described

earlier, ('the importance of feedback about monitored results and evidence of limited or no sharing of BP monitored results between the patient and the GP'),

### g) The powerful influence of the GP

In ascertaining participants' general views about their GP, they described just how powerful a demonstration of BP monitoring could be on their decisions to self-monitor and this was irrespective of whether they self-monitored or not.

'why do I monitor ok because I have been told to [laughs] ... yes about 20 years so it was sad when she left er and she was very good she would erm spend time with you so obviously you can tell she went through things with me so I think it depends on the GP as well how much they are actually telling you ... she was very good I note down the time as well because I no it was different depending on the time as well so I tried to keep that consistent as well and also whether I had breakfast or not I don't know if that makes a difference but I think it did er and I used to have it...that's it that's what my doctor used to do and she has taught me to do that' (P14, SMBP)

'I don't know publicly you know people my er you know I am lucky to have a good GP's who interested in individuals and health and talk to you any time I see him it's a number of them actually we are lucky... you are able to discuss anything with them and they listen and they act on it and they give you the correct advice so we are lucky to have a good practice which I can attend... if you see your doctor interested and listening er I think the person will most likely to follow the treatment (P16, SMBP)

'if you are shown something then I would feel confident then it's easy to do...I think somebody would have to show you because you could get a reading to anybody you could read what you wanted to you got to know how to pump it up and all the rest of it' (P11, Non SMBP)

## 3.4.5 Theme 4: Self-monitoring behaviour

The fourth theme 'Self-monitoring behaviour' referred to commonly recalled accounts of participants' overall views about self-monitoring, current practice and reasons for monitoring. Reasons were also explored for patients not monitoring.

SMBP was generally welcomed by the majority of the patients. Illustrated above, even those not currently engaging in monitoring outlined some of the benefits this could bring for patients. Some of the positive benefits participants stated were in helping patients gain more control over the management of their high BP and providing relief from the worry of having a symptomless chronic condition.

'in terms of encouraging people to do more monitor themselves... yes I suppose so its if it's good for the individual yeah because if you know what's going on then its peace of mind isn't it...say if the person that doing it know he has a high reading then he will worry but if you got somebody who don't know they would worry them because they don't know because its high they don't know they don't care and then they die...' (P3, SMBP)

'I think it is coz it puts your mind at rest...yeah coz a lot of people don't realise how that they've got high blood pressure...I think it's only when like with pregnancy or like they go to the doctors for one thing and they might check your blood pressure so people there's a lot of people out there with really high blood pressure that are having strokes and they don't even know that they have high blood pressure so there should maybe chemists you can go for but people won't even do that will they won't even go and be checked a lot of them' (P4, SMBP)

Some negative opinions about monitoring were equally expressed by both non monitors and self-monitors. These referred to patients possibly becoming obsessive

about measuring BP, being too burdensome for both the individual and their doctor and added worry if patients were unsure what to do when they obtained a higher than usual reading.

'well entirely depends on the person because I mean you could recommend it to someone who was a bit of a hypochondriac type and if they got a reading that was just a little bit you know it would depend on how well I knew the person...if you recommend it to a patient who was highly strung any way and they see its say only a couple of digits above what it should be they would go into a blind panic and get high blood pressure any way' (P1, SMBP)

'It's not for everybody is it?, if they didn't have a nursing background then I would say little information can bring massive harm and worry and I could see how self-monitoring could be a burden for some' (P6, SMBP)

'[Daughter speaks: I think the worry was that if the readings were not what you were expecting that you start panicking and thinking is there something else that's wrong]' (P15, SMBP)

'I don't, otherwise from knowing what your blood pressure is I don't see it as any benefit to the patient because you know its er knowing that its high or low it don't really give you well er peace of mind' (P13, NSMBP)

'so I think if I had that monitor at home and I was taking it I would think oh my god I would have to go up the doctors and I can't keep bothering him really but in another way perhaps if it was permanently high then yes I could go up and see him but I just think in my case I've only got to see a blood pressure monitor and my blood pressure goes up I'm afraid...no not really but I suppose after at time I would get used to it I just feel it's not the thing for me I think the more I think about it the more I would get worked up about having high blood pressure' (P10, NSMBP)

#### **Current self-monitoring behaviour**

Through exploration of patients' current practice of self-monitoring, two main patterns of behaviour emerged from patients' experiences. Firstly, frequency of monitoring followed similar patterns across participants. Secondly, participants engaged in their own self-made action plans based on their home monitored readings. Underlying motivations behind monitoring were revealed through participants' descriptive accounts of the reasons for monitoring and reasons for not monitoring.

#### Frequency of monitoring dropping off

A similar pattern of frequency of monitoring was commonly observed amongst the participants from initially monitoring on a regular basis, daily for some, to monitoring monthly. This frequency however did not seem to be sustained where eventually monitoring ended on a very infrequent basis based only on the 'experience of symptoms' with a number revealing that they had stopped completely. Reasons for this pattern of frequency ranged from patients describing initial interest for engaging in self-monitoring to reports of gradual boredom or participants describing the novelty of self-monitoring eventually wearing off:

'I just got bored with it it was just a toy, that's what I do do you know what I do I pop things and get bored...after six months' (P7, SMBP)

'initially erm it was I think it was every day just kind of seeing what the measurements would be and how is effective I was quite interested on the blood pressure'
(P14, SMBP)

'it's slowed down for two years it's after that airport about three years so... I leave it there so I remind myself to do it but I don't want to do it because I don't want to know what my blood pressure is because I think that makes me feel worse...I still do it...I think I did once but I had a little booklet but I don't do that it was ages ago I don't do that was when it was first when I was checking it more you know what I mean when I first realised it was high and they put me on the tablets' (P4, SMBP)

There were however some distinct gains from the practice, most commonly for reassurance from their knowledge of BP variability and that their symptomless condition could be monitored in some way.

'yes, yes it's a safety blanket isn't it a comfort blanket' (P1, SMBP)

'it's a safeguard in a way...I get peace of mind to know that my blood pressure is more or less they say on a level' (P2, SMBP)

'I suppose you could say it helps because then it gives you something to say well I'm not high I'm not low I'm alright...peace of mind' (P3, SMBP)

#### Self-made action plans based on monitored readings

When asked what participants would do if they got a higher than usual reading, some participants would refer to the way they used their machine, saying for example, they may have positioned themselves incorrectly. Participants often said that upon receiving a higher than usual reading they would take it again and again until the reading was satisfactory comparing their current reading to previous readings to gauge whether it has got worse or improved.

'I monitor about once a week unless I have a high reading and if I've got a high reading then I'll do it as I said I will rest for a bit and then do it again' (P1, SMBP)

'yes it wasn't that easy to use at first but I worked it out and I must admit messed it up about twice and then I got it to come to what I wanted...if its nearer to what I put down first then I could check that it was closer to what it was before is there another one that' (P2, SMBP)

'well if I am using the machine and I get a high reading its either my position I'm doing something wrong because I go between what I supposed to have and what I get so if I get so high that thing then I'll do it again because if it's either me or the machine so I'll do it two or three times to to make sure it's not the machine it's not me' (l. 359) 'well that's why I do it more than once see if I have doubt the first one if I have doubts in that then I will do it again and do it again until I feel that there it's not the machine it's me' (P3, SMBP)

This behaviour seemed to be directed entirely by the individual, none of the participants mentioned that they would go and see a doctor if they obtained a higher than usual reading.

'well if you did it at home if you're worried about it you would probably see the doctor wouldn't you ...sometimes I can go months because I just get a repeat prescription' (P5, NSMBP)

Probing this aspect further it seemed that there was a reluctance to share readings with their GP primarily due to fear of being put on more or stronger medication:

'yes if it was going to help [seeking help] I don't know what good it would do but I would ask about that you know does my blood pressure readings over the next 12months...what's that going to do how is that going to help anybody because I can't do nothing about my readings can I and it would concern me if it went up and down a little bit he would say well I am going to put you on stronger drugs' (P12, SMBP)

'probably that would be good because you know definitely what it is when its going up and down but erm you would be back to the same thing which we know what the GP can do but that's not really what I like but can't be helped that's more medication stronger medication' (P13, NSMBP)

One participant described the limited advice their GP provided about taking medications.

'well to be honest with you I think we were talking about this the other day I was hoping that because I going on a new pill I'm hoping that you come to a stage where you might wean off kind of thing...but if you talk to him she says no no' (P5, SMBP)

A contrasting opinion given by one participant not self-monitoring describes some of the serious consequences of such independent behaviour.

'yes but Joyce next door she's 86, she's forever on hers [BP self-monitoring machine] I'm like...she does it regularly...yeah I just didn't want to do it like...I think you might over use it...she'll act on it and she will take that reading to the doctor...and she'll tell the doctor what the reading is so she's diagnosed herself like..but if the doctor gives her pills she won't take them because she says they make her bad that's the only reason when you said monitor at home I don't know whether you would it do it for them' (P5, NSMBP)

#### Positive reasons for monitoring

In addition to monitoring for reassurance one of the other key primary reasons for monitoring was to observe blood pressure variability:

'because you can because of the nature of blood pressure I mean you can be brilliant one day and rocket high the next '(P1, SMBP)

'if I lay down it was one if I stood up it was another if I sat down it was another one and that's what I could never worked that out why and that's why they worked it out when I had this monitor on as well' (P2, SMBP)

'usually when I've been walking or anything like that and if you take it like afterwards it's always a bit higher then when I relax you know....yeah coz it's not always the same is it when you've just come in from walking or you've eaten something or its all different isn't it' (P4, SMBP)

Self-monitoring also reassured some participants about whether they should be taking medications prescribed for them long term, but conversely one participant described it as an attempt to avoid the pill 'burden':

'I think what it is I don't think he wanted to start me on blood pressure tablets because he knows that I would have been them on life if you know what I mean I think that's why he was trying to let me do it myself if you know what I mean' (P7, SMBP)

Other reasons patients self-monitored their blood pressure ranged from using monitoring information to improve their understanding of high blood pressure and to alleviate their anxieties of being on long term medication plans based on essentially a one off blood pressure reading measured at the clinic.

'yeah because when you go the doctors er that's just one reading isn't it and it could be I don't know you could be just stressed out for the day or you've walked up a hill or something like that you know...whereas here you can take it at different times' (P4, SMBP)

'well when I go there I get high result...higher than here' (P3, SMBP)

#### **Negative reasons for monitoring**

Two main reasons for not monitoring emerged from the analysis. Firstly, those participants not monitoring felt that all self-monitoring would do was make them over obsessive about taking measurements at home. They further expressed the possibility of becoming over worried about their high blood pressure. Participants felt that this would subsequently make them anxious about having to make more visits to their GP.

'so I think if I had that monitor at home and I was taking it I would think oh my god I would have to go up the doctors and I can't keep bothering him really but in another way perhaps if it was permanently high then yes I could go up and see him but I just think in my case I've only got to see a blood pressure monitor and my blood pressure goes up I'm afraid...no not really but I suppose after at time I would get used to it I just feel it's not the thing for me I think the more I think about it the more I would get worked up about having high blood pressure' (P10, NSMBP)

'I think you might over use it...and then if it's up a bit you worry and then you know...well I always think whether I would look at it and keep doing it and wondering whether I had it or what' (l.466) 'oh yeah uhm I think I tend to be a bit of a worrier you know when you take it yourself like so I don't know whether that's beneficial or what like' (P5, NSMBP)

#### 3.5 Discussion

## 3.5.1 The effect of pre-conceptions on experience and reflexivity

When conducting qualitative research it is important to consider the role of the interviewer within the dyad of the in-depth interview between participant and interviewer. Researcher and participant have different roles in the interview

process and the aim for the interviewer, in this case myself (SG) was to seek and understand the topic of SMBP through participants' revelations about their experiences. As part of this attempt to understand the patients' perspective, field notes were taken immediately after each interview to capture any of the researcher/interviewer's (SG) thoughts and observations post interview that may have been important to consider during analysis.

In a depth interview key listening skills are required by the interviewer whilst observing with sensitivity to encourage the person to respond.<sup>204</sup> A more active role is therefore taken by the researcher moving the discussion through specific areas in response to people's experiences and thoughts. There were points in some of the interviews for example where participants would mention some very interesting thoughts and recall some relevant experiences. Instead of saying 'oh that's really interesting' further questions or probes were used such as 'how do you feel about this?' or 'why do you think you have come to this opinion?'

Part of the preparatory work for formulating a broad topic guide and questions considered the interviewers (SG) role as the researcher and the interviewer. In this context it was important neutrality remained to avoid any pre-conceived ideas that the patient may hold in their responses. The author/researcher's background in health psychology was never mentioned to the participants and the title of 'researcher' was stated at the beginning of all the interviews in order to avoid colouring their perceptions about SG as a researcher.

Whilst recognising the role of the interviewer and adopting strategies to achieve depth in the interview, it was also important to consider the analytical role of the researcher that is to adopt a reflexive approach. Undertaking these interviews for the primary purpose of a doctoral research programme of work, the author (SG)/interviewer was therefore heavily involved and knowledgeable of the research topic, with obvious vested interests for the overall outcomes. At the analysis and interpretation stage, the role of the researcher was thus different to the neutrality stance maintained at the data collection stage to forming an integral part of the interpretation offered. As Ritchie and Lewis outlines the implications of a reflexive approach:

'a reflexive reading will locate you as part of the data you have generated...You will probably see yourself as inevitably and inextricably implicated in the data generation and interpretation processes, and you will therefore seek a reading of data which captures or expresses those relationships'(p.205)<sup>194</sup>

## 3.5.2 Principal findings and reflection on the literature

The participants in this qualitative study described a wide range of ideas, thoughts and opinions about self-monitoring blood pressure (SMBP) that appeared influential in the decision for a patient to self-monitor their blood pressure. The following discussion centres around three main principal findings listed below:

 Communication and perceived relationship between the GP/HCP and the patient about self-monitoring

- 2. Emotional aspect of living with hypertension and symptom representation
- 3. Comparison of interviews of self-monitors and non-self-monitors.

The principal findings are discussed considering a number of relevant theoretical models within health psychology that potentially help explain the findings of the participants interviewed providing insight into how ultimately this affects motivation.

## 1. Communication and perceived relationship between the GP/HCP and the patient about self-monitoring

The major finding from the present study was clear evidence of a lack of communication between participant and GP/HCP about their home self-monitoring activities. Only one of the participants interviewed reported they fed back their results, the majority were unaware if their GP/HCP even knew they SMBP and if they did know, patients expressed a limited amount of enthusiasm expressed from their GP about self-monitoring. A lack of interest from the HCP has been observed in previous studies outside of specific trial situations where any feedback received from their GP was not necessarily constructive or encouraging 190 and further found in studies of patients with diabetes where similar levels of low enthusiasm were met with the exchange of self-monitoring practices for blood-glucose. Only one small practice based study describes an efficient communication feedback system. Even then, where patients were selected to take part because they undertook a period of self-monitoring, some expressed they did not get enough feedback or guidance on what readings should be.

Further questioning about their reluctance to share or communicate their selfmonitoring activity gave rise to two main reasons: firstly, that it simply did not occur to participants to tell their GP they were self-monitoring; secondly the fear that if they did share their readings, there was nothing more that the GP could do but to change or put them on more medication. This was contrary to the beliefs of those not self-monitoring who felt a demonstration from their GP on how to use the machine and feedback was perceived as essential and would be a primary motivator for them to engage in the practice.

A contrast to this can be seen in the management of blood glucose. For the patient, the conduct of blood glucose (sugar) checks at home is equivalent to attendance at GP clinics for screening. If the blood glucose level is found to be outside the normal range, the person can take action to change the balance and this early intervention can reduce some of the serious consequences. Success of such a feedback process has been widely documented in the diabetes literature from controlled clinical trials investigating self-monitoring of blood glucose interventions<sup>206</sup> to one of the few qualitative studies in the hypertension literature.<sup>189</sup>

These studies suggest that for feedback to be effective for interventions such as self-monitoring, information and knowledge is vital. Whilst knowledge seems to be present, these results show patients knowledge of practicing self-monitoring may be more limited. Sharing of such information is lacking, coupled with the possibility that currently patients have minimal trust in self-monitoring as a viable practice and as a consequence it appears patients ultimately use clinic BP as a more reliable marker for their BP. This gives reason to encouraging self-management in SMBP so that patients feel more confident in using SMBP over clinic BP.

What the present study observations do highlight is that the management of diabetes and hypertension have considerable overlap. Both require a complex set of behaviours: effective diabetes management requires a balance between diet, insulin and exercise, effective hypertension management also requires BP monitoring alongside the review of other lifestyle behaviours, such as, diet, exercise, alcohol consumption and cigarette intake as well as medication. The existing research however suggests that the combined effect of the overall management of all these factors seems to be more widely known by patients about diabetes than for hypertension. This represents a lost opportunity for HCPs to provide a valuable service to patients to involve and educate them so they too can effectively use selfmonitoring (alongside the balance of other lifestyle health behaviour) to their advantage and thus gain an optimal level of health care for the management of high BP in the same way that diabetes patients are cared for.

Most participants self-monitoring felt that, alongside regular medication, taking responsibility for BP rested with the individual. Conversely, those not monitoring felt the management of BP rested with their doctor given the absence of any symptoms and therefore limited trust in their own perceptions. The perceived relationship between the participant and the GP appeared therefore to be invariably linked with the amount of control they felt they had over their condition.

Within the health psychology literature the health locus of control (HLOC) construct has been one of the most actively studied attitudinal predictors of patients' health related behaviour for decades.<sup>82</sup> The concept is briefly outlined in Chapter 1 and can be applied to the observations within this study. Health locus of control is

conceptualised as the degree to which a patient attributes the cause of health related outcomes to 'internal factors' under one's own control (i.e. a patient's own actions) or to 'external factors' (e.g. chance, others or actions of the provider).<sup>207</sup>

An early study investigating HLOC and depression in end stage renal disease provides a possible hypothesis about HLOC and self-monitoring. In that study strong "internal" HLOC was associated with more positive adaptation to chronic disease when patient control over illness or treatment was realistic. Based on the HLOC theory, the findings of the present study suggests self-monitoring participants may have stronger 'internal' HLOC beliefs and therefore better adaptation to having high BP because these patients use self-monitoring to help them exercise more control and thus perceive treatment more realistic. Further adding to the perception of BP control was the added role for their GP and therefore participants may also have strong 'external' LOC.

It is also worth highlighting that the evidence around the theory also states that patient adaptation to chronic disease could also be maladaptive if there are impediments to exercising personal control. Applying this concept to self-monitoring, for the non-self-monitors, not knowing the benefits of self-monitoring for the overall management of BP, could present itself as one of the impediments for a patient to exercise this personal control. If self-monitoring and its associated benefits were made more salient to patients, it could be argued that they might be more inclined to take more personal control and engage in positive health practices and monitor their BP at home.

It was apparent from the study findings, that perceptions of control were also influenced by age, with older individuals preferring their GP to manage their BP, and younger ones more interested in taking control themselves. Identifying a potential demographic profile of patients more likely to self-monitor could be useful for HCPs although it is recognised that HCPs as well as patients differ broadly with regard to their health care related attitudes, beliefs and expectations, and therefore this needs to be considered before any recommendations are made.<sup>209</sup>

Previous surveys have found that some patients prefer to take a highly active role during a clinical encounter, whereas others prefer to remain passive. <sup>210;211</sup> These differences have also been observed with regard to clinicians with some holding a more autocratic clinician centred attitude towards clinical interactions and some holding more patient centred views. <sup>209;212</sup> Observations seen in the present study mirror such differences. Such potentially differing views about the amount of control patients want to have with managing their own blood pressure is an important consideration for HCPs/GPs when assessing the suitability of patients for selfmonitoring. HCPs need to realise that some patients are, more than others, eager to take a more active role and possibly hold stronger internal LOC and this should be identified and encouraged so that monitoring is targeted at the right patients who would practice and therefore benefit far more effectively.

## 2. Emotional aspect of living with hypertension and symptom representation

The second principal finding was clear evidence that living with hypertension had an emotional element around it and this emotion was linked to patients self-monitoring.

Although participants expressed very little concern for living day to day with

hypertension, they were fearful of the threat of having this condition long term and the prospect of having to adhere to a medication regime. Self-monitoring appeared to alleviate some of this anxiety, allowing patients to take back some of the control from this anxiety attached to the helplessness felt by experiencing no symptoms and not doing anything about it long term.

Similar behaviour has been observed in studies related to breast cancer screening uptake. One study for example, showed a sizeable proportion of a sample included women with a family history of breast cancer and it was these patients where perception of greater benefits was associated with screening attendance. <sup>213</sup> Theoretically this fits with the Health Belief Model, (HBM). According to the HBM, four factors are important in determining the motivation to perform a health behaviour: (a) perceived susceptibility, (b) perceived severity of the illness, (c) perceived benefits of performing the behaviour and (d) the barriers to performance. The HBM predicts that those who see themselves as more susceptible to a more serious illness will be more likely to perform relevant health behaviours to prevent that illness. In addition the model describes the benefits that people attach to the behaviour will influence whether they perform the behaviour; those rating the benefits to be high and the barriers as low are more likely to engage in the behaviour. Reference to this model has been made in Chapter 1 of this thesis (see section 1.8.1.2) as a foundation framework for the Health Decision Model. The health decision model combines the health belief model and patient preferences including decision analysis and behavioural decision theory.

The HBM can account for self-monitoring behaviour that is; the practice appears to be associated with positive benefits for patients in helping alleviate some of this anxiety. Perceived health is also an important predictor for patients who may go through this rational decision process where patients focus on their perceived risks of blood pressure related illnesses. It seems that the decision to self-monitor BP is pursued in order to avoid such consequences (i.e. Stroke, heart attack and death). This describes the concept of perceived risk and has been associated with several protective behaviours such as mammography screening<sup>214</sup> and influenza vaccinations.<sup>215</sup>

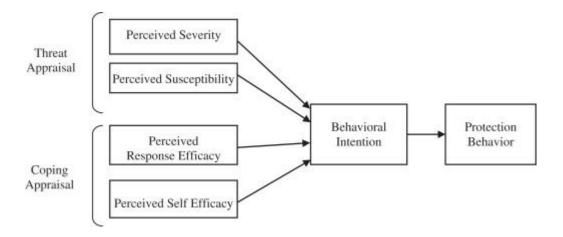
Hyman and colleagues<sup>213</sup> (study described above) found that some of these women with a family history of breast cancer, that is, higher susceptibility, were also less likely to attend for screening. This is contrary to the health belief model, but also similar to the present study results. Patients who were aware of their fluctuating high blood pressure would not go and feed this back to their doctor. An explanation for this phenomenon could be provided by the Protection Motivation Theory,<sup>216</sup> a model that predicts when a threat occurs, people cope in a way to minimize the threat. That is, 'fear' is an additional intervening variable between perceptions of severity and vulnerability. In the context of SMBP, it appears that the level of appraised threat drives this protective health behaviour, despite this behaviour not actually reducing the threat or protecting the individual. The model is illustrated in Figure 5 and bases itself on the constructs of the HBM. 'Coping appraisal' in the model, focuses on the coping responses available to the individual to deal with the threat. Factors such as following behavioural advice are proposed to potentially increase and decrease the probability of an adaptive response.

Both the belief that the recommended behaviour would be effective in reducing the threat *response efficacy* (similar to Bandura's construct of 'outcome expectations'), and the belief that one is capable of performing the recommended behaviour, *self-efficacy*, (described later in the chapter) are proposed to also increase the probability of an adaptive response.

The two appraisal processes result in 'protection motivation' (i.e. intention to perform a recommended behaviour), a positive function of perceptions of severity, vulnerability, response efficacy and self-efficacy. 'Protection motivation' therefore operates as a mediating variable between the threat and coping appraisal processes and protective behaviour.<sup>70</sup>

Perhaps an important issue to recognise is that one other manner of achieving the minimisation of the threat is through avoidance. The current findings mimic the findings of Hyman and colleagues study, that is, although patients are reducing the initial perceived threat from their chronic illness through engaging in the protective health behaviour (self-monitoring), it seems that there is similarly a perceived threat or anxiety from the readings they obtain if they are higher than usual evidenced from the behaviour of avoidance of any action or feedback of any results to the GP.

**Figure 5: Protection Motivation Model** 



Conceptual framework for Protection Motivation Theory (Adapted from Rogers 1983<sup>216</sup>

### 3. Comparison of interviews of self monitors and non-self-monitors

Comparisons of interviews of participants self-monitoring and not self-monitoring reveal several findings. Participants were accurate in describing the perceived risks associated with hypertension, most commonly reporting fears of Stroke or Heart Attack and this appeared to be independent of whether they monitored or not. Understanding risks and consequences has been previously shown to be a strong determinant for any successful goal setting self-management strategy<sup>217</sup> and therefore this finding reflects a positive aspect about the way in which GPs/HCPs currently convey risk information to patients. Those with co-morbid diabetes seemed particularly informed of their added risk of having both conditions and that 'the two don't go well together', as described in Theme 2 in the previous section of this chapter, section 3.4.3. This supports one of the conclusions drawn from the results of the prevalence survey (Study 1) described in Chapter 2 where a higher proportion of self-monitors were from non-white ethnic backgrounds and was concluded that perhaps this group are being made more aware of the risks of having high BP.

European guidelines on home monitoring BP<sup>63</sup> recommend the use of self-monitoring in high-risk populations stating that close control is mandatory for such groups of patients in pregnancy, renal and patients with diabetes. The findings from the current study and the aforementioned prevalence survey in study 1 therefore support the possibility that there is improved communication of risk between these 'high risk' populations and GPs/HCPs.

Participants monitoring appeared to be more aware than those not monitoring of BP values and variability. However although they could recall recent values obtained from their monitor, they were less informed about how to interpret the readings. A lack of knowledge on interpreting readings and failure to act on the results confirms findings from a large review of qualitative studies exploring home monitoring of blood glucose in patients with diabetes. <sup>137</sup> This review by Clar and colleagues reveals patients' understanding of BP variability, with participants recognising BP fluctuations at different times of day after food and exercise. In the present study participants would often describe that they could have a completely different BP value at different times of the day, and after events such as monitoring after a long walk up a hill. Clar et al's review also found a lack of feedback of results to clinicians which mimic the findings of the present study. Some recent evidence shows that the prognostic significance of 'clinic' visit to visit variability in BP on the risk of stroke is a strong predictor of subsequent stroke. 218 Self-monitoring on the other hand allows multiple measurements and therefore has been reported to provide a more accurate measure of 'true' BP and information about variability. 62 In the present study concern about variability was in one way reassured through the use of home monitoring but also useful for some patients who would describe their worry about the accuracy of a

diagnosis based on a one off reading at their GP practice. This is similar to findings from another study where variability in readings was a frequent observation from patients' self-monitoring and trusted to be accurate. Whilst this demonstrates a fundamental use for self-monitoring in terms of educating participants about high BP it also illustrates that self-monitoring potentially alleviates some of the anxiety and concerns patients hold about diagnosis and subsequent treatment based on one-off readings. Data from the TASMINH2 trail further supports this aspect, that patients do not get anxious when home monitoring, yet HCPs expect them to. 107

There were two opposing attitudes towards taking medication. For the respondents that had been living with hypertension for a number of years, it seemed that the long term nature of hypertension created an acceptance and general low emotional concern for having hypertension. Medication enabled them to forget about having the condition, with an out of sight of mind attitude. However, irrespective of whether they had self-monitored their blood pressure or not, there was the opposing fear of long term medication and desire to avoid the 'pill march'. Compliance with medication continues to be an on-going issue within hypertension management. The UKPDS  $38^{219}$  states to get good control,  $\geq$  to 35% of people need to take  $\geq$  2 blood pressure lowering drugs. The World Health Organisation<sup>33</sup> however reports that an increased pill 'burden' leads to lower adherence rates hence the move towards combination or 'polypills'. Nevertheless, further research indicates any strategy that helps to improve adherence is associated with lower rates of complications and hospitalisation.<sup>220</sup> The findings of the current study provide insight into how SMBP may contribute to helping adherence. This study suggests that SMBP is a method that helps patients to justify taking medication where they may have previously been

concerned about taking medication long term for a condition that presented no symptoms. The findings from Agarwal's systematic review of the role of home blood pressure monitoring in improving hypertension control serves to validate the present study's findings which showed home BP monitoring led to more frequent antihypertensive medication reductions.

### 3.5.3 Is the practice of self-monitoring misunderstood?

The act of monitoring at home was viewed as enough to make participants feel more involved in the management of hypertension with apparently no evidence of any further action taken from participants, this is described in the last theme 'Self-monitoring behaviour' (see section 3.4.5). Whilst this potentially reflects a group of empowered and motivated individuals, actively taking part in self-monitoring, this also indicates that monitoring is taking place with limited or no supervision from GP/HCPs.

If this sample was reflective of the rest of the national population, this would mean a substantial proportion is currently self-monitoring unsupervised. Findings from the interviews indicate the possibility that some patients may gain a false sense of reassurance from self-monitoring perceiving that self-monitoring at home is itself preventative against heart attack or stroke rather than the accurate perception of self-monitoring as a screening tool for early detection of disease, BP variability and interventions. Whilst self-monitoring is becoming increasingly popular and more prevalent in hypertensive populations, 157 simply monitoring home BP is of little value if the patients or clinicians do not act on the results. Patients may be missing a vital

step in communicating their self-monitoring efforts with their GP/HCP. This is critical if they are to gain any real clinical change or benefit from the practice, particularly where this behaviour appears to have a negative influence on the motivation to continue monitoring, with some stopping monitoring completely.

Hypertension control with home BP monitoring can only be enhanced further when accompanied by plans to monitor and treat elevated BP.<sup>109</sup> This requires decisions about monitoring and treatment being more equal between the patient and the GP or HCP. A key issue for patients not monitoring was the perception of themselves being anxious and obsessive about measuring BP all the time, already recognised in the practice of self-monitoring blood glucose.<sup>138</sup> and mentioned in one study on blood pressure.<sup>189</sup> Shared decision making is therefore suggested as an important and necessary process for the effective implementation of self-monitoring. Shared decision making could potentially rectify peoples' understanding and misconceptions about how self-monitoring is clinically useful for patients and how it can effectively be integrated in the 'day to day' management of hypertension and thus not just a novelty 'one off' procedure.

## 3.5.4 Findings in relation to European Guidelines

Recent European Guidelines on home monitoring state that patients should be consulting with their GPs and sharing their readings, that is, some form of supervised home monitoring by trained medical clinicians.<sup>63</sup> The guidelines also state this should be a dual process, where successful implementation of the recommendations is dependent upon acceptance and involvement of practicing physicians. Findings from

these interviews are at odds with current recommendations and highlight that in the majority of cases home monitoring is currently unsupervised with virtually no GPs/HCPs being consulted by participants regarding their home monitoring, and if they are GPs are not showing interest in the results of self-monitoring.

From a health psychology perspective this could be a positive step as patients could recognise the need for their own efforts to improve aspects of their lifestyle such as increasing exercise intake or looking at diet. From a medical perspective however, this could serve as a risky strategy if patients are making their own unsupervised treatment decisions based on their obtained readings, or using self-monitoring as a way of delaying treatment. With participants exercising their own methods for checking readings the participants in this study appear to be misguided about how to manage their BP and interpret readings and therefore potentially missing the opportunity to gain real clinical benefit from self-monitoring.

# 3.5.5 Towards a solution: considering psychological theory, the role of patient education and shared decision making.

In light of the discussion above that spotlights a clear problem of communication between patient and clinician about self-monitoring activities, there is a possible solution. If self-monitoring BP is accompanied by specific programmes to treat elevated BP such as through titration of antihypertensive drugs <sup>109</sup> this may be a more effective way of extracting clinical benefit from the practice and provide even better control. To use this as an example, considering the protection motivation model (PMT) depicted earlier in Figure 5, Page 118, the titration of medication plan (the action plan) could have a more powerful effect on the motivation for patients to

engage in self-monitoring, where the 'provision of behavioural advice', in this case the action plan, is purported to reduce any perceived threat about what to do if a patient receives higher than usual results or any unusual fluctuations in BP, as patients would have the information readily available detailing courses of action. This implicates the need for the development of easy-to-understand information for patients so they can make an informed decision about whether they are suitable to self-monitor. Provision of such information could prevent the misuse of selfmonitoring which, given the findings of the present study, is currently happening. Merely a demonstration of how to use monitoring equipment and further guidance around monitoring schedules as stated in current guidance for HCP's<sup>63</sup> is evidently not sufficient given its existence and observed lack of knowledge about personal BP targets amongst the sample in the present study. Lack of BP targets, ignorance of high/abnormal readings and feedback about self-monitoring mirrors the findings of studies described earlier <sup>217;221</sup> and for SMBG. <sup>137</sup> This mis-match between guidelines for HCPs and actual behaviour of patients further highlights a problem of whether this information is being accessed by patients.

It seems that the 'self-regulation' of monitoring is absent, in other words participants are unaware of and lack competency about how often to monitor their blood pressure and what to actually do with their results. In a previous study, even when there were regular BP measurements taken in the clinic, the information exchange related to lifestyle factors was limited to dietary modification such as salt intake. Monitoring schedules and clear plans of action agreed between the GP/HCP and the patient are necessary prior to engaging in a programme of home monitoring. Patients could thus be guided at home about what to do based upon readings in the form of; when to

contact the doctor, what to do if there was a high reading such subsequent lifestyle changes, what to do if perhaps they were feeling unwell or were on holiday, situations where participants felt unsure about what to do with self-monitoring.

In view of social learning theory and Bandura's self-efficacy model<sup>118</sup> described in previous sections of this thesis (see Chapter 1, Section 1.9.1.4, Page 34) improved patient education about how to self-monitor effectively could potentially reduce some of the uncertainties around the practice and raise the self-efficacy. This could subsequently increase patient acceptance and motivation, particularly for those more reluctant to self-monitor to engage in the practice. Evidence where this has been successfully carried out comes from the TASMINH2 trial, 91 a UK based RCT of hypertensive patients (n=527) investigating the effectiveness of a self-management intervention involving patient education about home telemonitoring BP and a preagreed self-titration plan of anti-hypertensive medication, further details of which are in Chapter 1 of this thesis, section 1.9). The emphasis of this trial was on selfmanagement and not as the authors' note, on the use of technology to prompt physician or nurse intervention investigated within other trials. 222;223 What these investigators state about the evidence from their own trial and across other trials investigating variations of self-management interventions for the control of hypertension, is the common theme of the design of interventions to empower the patient to self-monitor and self-titrate their own medication. Increasing patient empowerment raises a patient's self-efficacy to actively self-manage their condition and is a concept more widely researched within the diabetes literature. One study of collaborative goal setting for example in diabetes found that individuals who had

goals concordant with their clinicians reported better understanding and self-efficacy regarding their self-management.<sup>224</sup>

The participants not monitoring in this study appeared to display a low self-efficacy for coping with any outcome of self-monitoring or what Bandura would describe as low outcome expectancies. This is defined as the beliefs about the consequences of one's action and in social cognitive theory; (SCT) Albert Bandura's (1977) extensive work on the concept of self-efficacy describes its prominent role in human motivation, thought and action. <sup>113</sup>

As described in section 1.9.1.4, (Page 34) the combined effect of self-efficacy and outcome expectations is however much greater. From this model, it can be hypothesised that individuals would be more motivated to engage in behaviours (such as self-monitoring) if they expect primarily beneficial consequences (more positive outcomes and fewer negative outcomes). Evidence to support this proposed model comes from adolescent populations in the management of diabetes. Bandura points out that "outcome expectations may take the form of detrimental or beneficial physical effects, favourable or adverse social reactions, and positive or negative self-evaluative reactions" [p.20] The findings of the present study thus relate to Bandura's statement where self-monitoring outcome expectations expressed by participants had varying positive and negative outcomes that comprised of personal (increased control, reduced worry) physical (perceived reduced symptoms) or the option to cope instrumentally with health threats by taking preventative action.

Bandura has illustrated the way in which the different patterns of efficacy beliefs and

outcome expectations have different psychosocial and emotional effects which are shown in Figure 6.

Figure 6: The outcome expectancy efficacy model

	Outcome Expectation	
Self Efficacy	Low outcome expectation	High outcome expectation
High self-efficacy	Social activism Protest Grievance Milieu change	Assured, opportune action High cognitive engagement
Low self-efficacy	Resignation Apathy Withdrawal	Self-devaluation Depression

Behavioural and affective reactions as a function of different levels of self-efficacy and outcome expectations (Adapted from Bandura, Self-Efficacy: The exercise of control p.20)<sup>113</sup>

Considering Figure 6 above, for the behaviour of self-monitoring, the optimum belief / outcome expectation combination would be in the top right box. That is, appropriate self-monitoring and treatment plans together with patient education and collective shared decision making between the patient and the HCP/GP could raise patients' self-efficacy and high outcome expectations and result in what is illustrated by Bandura in 'assured, opportune action, with high cognitive engagement', an outcome however not observed by the participants in the present study where poor engagement with self-monitoring was evident and thus more reflective of the top left box of Figure 6.

The existing research and guidance found within the clinical literature is written primarily for use by health professionals. It is possible that the equivalent needs to be documented for patients particularly focussing on interpretation of results and what action to take based upon these results. Such documentation could potentially act to reinforce the behaviour of self-monitoring when considering the behavioural model. That is, if there are no positive (or observable) consequences of a behaviour, extinction of that behaviour is the likely outcome. A primary issue for patients (evident from the patient's behaviour of dropping the frequency for monitoring observed in the present study), is a lack of schedule from which to operationalize their home measurements. Patients could benefit from guidelines on varying aspects of a schedule, for example how often to measure, how many times a day, before or after medication, after eating breakfast etc. It is argued that the provision of such educational information/tools could enable GPs/HCPs to improve communication with patients whom they feel may benefit or are already engaged in self-monitoring.

Psychologically it is argued that this could not only raise patients' self-efficacy to monitor effectively but also their outcome expectations of self-monitoring, and thus ultimately influence motivation to engage in the practice. In Bandura's terms, it is not the act of self-monitoring that is important here but the act of self-management following self-monitoring. This also fits with the PMT as shown in Figure 5, (Page 123) which proposes behavioural advice to be a crucial element in the model for sustaining motivation for the practice. The model proposes that if behavioural advice is attached to any preventative health practice then it is more likely to be reinforced if the negative feeling is removed.

Addressing the beliefs and negative feelings about sharing/feeding back results is the challenge for HCPs. Patient groups such as the Blood Pressure Association (BPA) in the UK<sup>6</sup>, and Inspire<sup>7</sup> contain a variety of useful sources of information and forums, yet the evidence from that observed in the present study suggests that perhaps these groups are not accessible enough. In view of the percentage of individuals currently self-monitoring HCPs have an important role in discussing SMBP more widely to those patients they recognise as interested and motivated to engage in the practice, and perhaps for signposting patients more directly to useful patient groups such as the BPA.

Based upon the results of this study, the aim for HCPs should thus be for a shift in patients' perception, from what is evidently an independent relationship between patient and the GP in relation to self-monitoring, to a more constructive 'partnership' between the patient and the GP. This would allow shared reciprocity and active health care decisions to be made between the GP and the patient on the basis of shared self-monitored readings

#### 3.6 Conclusions

The themes identified by this qualitative study indicate that the decision to self-monitor is primarily driven by a patient's need for reassurance from living with a largely asymptomatic condition that requires a lifelong regime of medication. The concern over the consequences of having variable high BP is also another motivator for patients to engage in self-monitoring in an attempt to gain some control over their

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<sup>&</sup>lt;sup>6</sup> http://www.bloodpressureuk.org/Home

<sup>&</sup>lt;sup>7</sup> http://www.inspire.com/groups/blood-pressure/

condition. In social cognitive theory, health perceptions (perceived risk, personal control, self-efficacy and outcome expectations (positive and negative) are seen as direct predictors of behaviour, and this study reveals a number of positive and negative outcome expectancies and health perceptions that appear to influence the decision to SMBP. What the patients gain from the practice of self-monitoring, or might negatively perceive from the practice seems to have a stronger impact on the take up or continued existence of self-monitoring than simply whether patients can self-monitor or not. Furthermore, patients' overall perception of their health was also found to impact upon whether they would self-monitor or not. An individual's perception of their own risks in turn influenced whether they felt the need to monitor their BP.

Despite participants showing considerable motivation to take control over managing their hypertension, these participants were monitoring unsupervised with little or no training on how to interpret and/or act upon their readings. Such information was not considered as necessary to be shared with their GP/HCP with all but one not sharing or feeding back any results about their efforts to self-monitor and there was misguided perception about exactly how self-monitoring can be done more effectively. There is a possible disconnection between what psychological theories propose for what motivates patients such as reducing risk, and what is actually happening in practice.

Communication, feedback and sharing of self-monitoring readings with GP/HCPs is essential for the effective use of self-monitoring yet this appeared to be grossly lacking. Instead, participants were hesitant or unaware that their provider should be made aware of their self-monitoring activities, and feared that if their provider knew

there was a risk of being put on further or increased medication. This highlights some potential barriers for the practice of self-monitoring, in terms of patients really understanding the true value of non-pharmacological interventions such as home monitoring in reducing risk. Importantly, vital information such as unusually high readings could be being missed by HCPs/GPs, and thus the problem of BP variability will therefore remain as problem.

The uncertainty around hypertension and fears of long term medication has potentially long term implications on anxiety. If self-monitoring is used properly with adequate supervision and there are active consultations between the GP/HCP and the patients regarding their home monitored reading then this uncertainty and anxiety can potentially be reduced. It is suggested that a 'shared decision making approach' would be ideal for this particular health preventative behaviour and which has increasingly been observed in hypertension consultations. <sup>27;226</sup> What is necessary, is information that describes the acceptability of an instrument that guides clinicians and patients through collaborative discussions of patients priorities, treatment planning, specific goals and follow ups. In the same way that these sorts of guides have been evaluated in research these could also be applied in real clinical practice in relation to SMBP in patients with hypertension. Currently, this style of consultation is minimally evident from the patients in this study and provides an important avenue of research to be explored further. The fact that patients in this study monitor with very little schedule and in a lot of cases on an infrequent basis is just an example of how current clinical guidance has not been translated to the patient. This ultimately has real clinical implications for the value of the role of GPs/HCPs to communicate more effectively with patients about the clinical guidelines about home monitoring in order

for them to gain any real clinical benefit. The challenge for HCPs is to consider the perceptions of their patients in the planning and delivery of health promotion programmes such as *self*-monitoring that are appropriate to this population.

# 3.7 Strengths and limitations

In contrast to the two previous qualitative studies exploring patient experiences of SMBP described in the introduction of this chapter, <sup>189;190</sup> the sample in the present study was much larger, interviewing participants registered within four general practices covering two local ward areas and therefore potentially a more representative spread of individuals from a range of deprivation. Through purposive sampling, every attempt was made to represent other sample demographics. The sample had a fairly even mix of ethnicity, age, sex, employment status and a proportion also had a co-morbid diagnosis of diabetes. It was also important to capture the views of participants both self-monitoring and non-self-monitoring to compare and contrast findings, the study sample had an equivalent number of participants monitoring and not monitoring.

As in any study, there are also limitations to the current study. The sample may have been limited by selection bias. It was possible that patients who participated came from practices that favoured self-monitoring blood pressure or whom may have already had recommendations from their GP to practice it at home. As it turned out, the majority of the participants in this sample had not had any communication with their GP/HCP about self-monitoring yet half had self-monitored or were self-monitoring. Patients recruited from other GP practices in surrounding areas may have

had different self-monitoring policies and thus differing attitudes towards self-monitoring whom may have shared completely different opinions and feelings about the topic. Prior knowledge about self-monitoring policies at the practice would therefore help validate the strength of the conclusions of this study.

Secondly, no conclusive statements regarding patients' motivations to self-monitor and existing behaviour can be made, as qualitative methodologies are typically used to generate rather than test hypotheses regarding unexplored observations.

Nevertheless the current qualitative study opened up consideration of the perceptions held by this sample relating to the practice of self-monitoring and the psychological factors associated with the motivation to engage in the practice.

# 3.8 Selection of factors associated with self-monitoring and the next phase

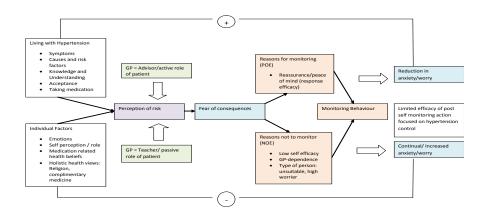
This study explored in depth patients' experiences, motivations and reasons for self-monitoring and unravelled some of the reasons preventing patients from self-monitoring. Qualitative methodology was used to gather information from the patients' perspectives to derive psychological factors thought to be associated with self-monitoring and to generate hypotheses about the relationship of these factors on the motivation to engage in SMBP.

The way in which various factors, themes, categories and subcategories are proposed to interrelate and influence self-monitoring behaviour is pictorially represented in Figure 7 on page 140. This figure builds on figure 4 which provided a more hierarchical relationship of the factors. Figure 7 is a visual illustration of how these

variables relate to the behaviour of self-monitoring BP given based on the evidence from the interviews. As mentioned, in the theme overview section 3.4.1, there were many other themes derived within the main analysis, but for purposes of clarity and in line with the research questions all of them were not shown. Some of these themes are however shown in Figure 7 illustrated on the next page. The main salient themes reported in the results are shown within the figure and the boxes are colour coded accordingly (i.e. Blue=Theme 1 'Self', Purple=Theme 2 'Living with hypertension', Green=Theme 3 'The GP-Patient Transaction', Orange=Theme 4 'Self-monitoring behaviour').

These are some of the psychological factors hypothesised to be associated with SMBP and form variables for investigation within the in-depth questionnaire, the next stage of the study and is reported in the next chapter. Factors for investigation thus concern health anxieties, health perceptions and the GP-Patient relationship in association with self-monitoring behaviour and are further detailed in the next chapter.

Figure 7: Towards theory: An illustration of the relationship of psychological factors with self-monitoring behaviour and selection of factors chosen for investigation in Study 3



Colour Code: Blue=Theme 1, Purple=Theme 2, Green=Theme 3, Orange=Theme 4

# 3.9 Chapter summary

This chapter detailed the second of a series of three studies, a qualitative study of patient interviews to explore and unravel patient experiences of monitoring BP at home. Using the constant comparative method the themes from the sixteen patient interviews centred on four main categories: Self, living with hypertension, the GP-Patient transaction and self-monitoring behaviour. These were discussed with excerpts from interviews to illustrate each theme and the categories and subcategories within that theme. The study went on to discuss the three principal findings that focussed on the perceived relationship between the doctor/HCP and the patient and self-monitoring, the emotional aspect of living with hypertension and a discussion of the discrepancies found between those self-monitoring and those with no experience of self-monitoring. How the findings relate to clinical evidence and policy was then discussed with a brief outline of the clinical implications of the study. The chapter ends with an outline of some of the factors thought to be involved that potentially relate to the practice of self-monitoring visually represented in a diagram. The salient factors proposed to influence the practice of self-monitoring were then investigated within a questionnaire, forming the basis of the third and final study, and is described in the next chapter.

# CHAPTER 4 PSYCHOLOGICAL FACTORS ASSOCIATED WITH SELF-MONITORING BLOOD PRESSURE: A PRIMARY CARE OUESTIONNAIRE

# 4.1 Chapter Overview

The following chapter describes the third and final study, Study 3 (please see Figure 2, page 49) of the research project which utilises the sample from Study one. This study is also questionnaire-based but investigates the practice of self-monitoring in more detail assessing the relationship of psychological factors and the behaviour of self-monitoring. A more detailed questionnaire was therefore sent to the participants identified from the original cohort who indicated their willingness to take part in further study. The questionnaire tests the association of the psychological factors derived from findings of both the prevalence survey described in Chapter 2, the qualitative interviews with patients described in Chapter 3, previous empirical literature and psychological theoretical frameworks described in earlier parts of this thesis (see Introduction Chapter, section 1.7 to 1.9) to self-monitoring. The chapter then goes on to discuss the findings in relation to current practice of self-monitoring in the UK and briefly outlines thoughts about the future clinical applications of the study findings.

#### 4.2 Introduction

Hypertension is an important risk factor for cardiovascular disease, and all patients with a diagnosis of hypertension in the UK should have a cardiovascular risk assessment.<sup>227</sup> High BP is easily detected with a non-invasive screen and controlled with interventions including medications, lifestyle changes and positive health behaviours.<sup>228</sup> Self-monitoring blood pressure (SMBP) may be a valid method for determining the blood pressure of patients with hypertension providing that the best practice recommendations for obtaining the measurements are followed. Currently, these recommendations are defined by a range of national and international clinical guidelines described in earlier parts of this thesis, for example see section 1.9.2 and 3.5.4.

Although, the benefits of SMBP are now clearly documented within the literature and briefly described in the introduction chapter of this thesis, (section 1.9.3 and 1.9.4) the psychological factors associated with the performance of this practice are however relatively under researched. To determine the successful implementation of such a practice, it is important to understand just how these factors affect the motivation to self-monitor.

The qualitative study described in the previous chapter uncovered a number of psychological and emotional factors that potentially influence the practice of SMBP culminating in Figure 7, Page 140. The figure showed a number of other possible factors drawn from the whole analysis proposed to influence self-monitoring behaviour. As described in section 3.8 of the previous chapter, this study utilised questionnaire based methodology. The rationale behind this choice of methodology

was for three reasons; firstly, to follow true philosophical assumptions for mixed methods research. That is, quantitative investigation of the qualitative findings serves to validate the previous stage/study findings, helping to improve the clarity and generalizability of the findings then using each method alone. Thus three linked research questions with different methodologies are conducted to build up an evidence base and construct a more whole picture about the psychological factors that are involved with SMBP. Secondly, the research questions derived from the qualitative study potentially tap into a number of psychological constructs, justification of which are given below. Questionnaire based methodology allows theoretically derived factors to be transformed into variables for quantitative investigation, enabling the measurement of these constructs in a larger number of representative participants at one point in time.<sup>229</sup> Finally, questionnaire based methodology enables data collection via a postal format, and therefore similar to Study 1, was employed again for the present study as this is relatively practical, economical quick and easy to analyse. Furthermore, self-completion of the questionnaire was viewed as particularly important where participants could complete self-report scales in their own time and space.

The selection of factors for investigation in the present study (of which highlighted in Figure 7), was based upon consideration of theoretical frameworks and constructs drawn from health psychology. Although a number of psychological models have been described prior to this point, the main models considered in the following study were the Health Behaviour Model, <sup>114</sup>Health Locus of Control<sup>207</sup>, The Protection Motivation Theory<sup>216</sup> and Self-Efficacy and Outcome Expectancy Theory. <sup>113;119;230</sup> Each of these models has previously proposed to explain and predict behaviour for a

number of other health preventative behaviours. The core components of such frameworks and theories are described in more detail in earlier parts of this thesis (For a more detailed insight into the models please refer to Chapters 1 and 3, sections 1.8.1/1.9.1.4 and 3.5.2 respectively). There is very little investigation of these conceptual factors applied to the practice of self-monitoring BP.

# 4.2.1 Justification of the selection of factors for further investigation

Reflecting on Figure 7, page 140 and section 3.1 of the previous chapter, the key themes or factors hypothesised to be related to SMBP group into three key areas, health anxieties, health perceptions and the GP relationship. The next section considers the themes reported in the previous chapter (section 3.4.2 to 3.4.5) and previous literature to provide a justification for inclusion in the present study.

#### 4.2.1.1 Health anxiety and worry

As mentioned in the Introduction of this thesis, (Chapter 1, section 1.9.1.1) health anxiety has been previously investigated quantitatively in relation to home self-monitoring BP but with contradicting findings. An analysis of baseline data collected in the V-STITCH study <sup>90</sup> showed those with higher mental health scores (better mental health) were more likely to have a monitor, yet more recent evidence has shown no significant impact of self-monitoring on anxiety or quality of life. <sup>86;91</sup> One of the limitations of the studies showing minimal impact on anxiety was the possibility of inclusion bias, that is, it was possible that trial participants were more motivated to self-monitor and thus less likely to be anxious about engaging in self-

monitoring. Investigating the relationship of anxiety with SMBP within a community dwelling sample therefore was proposed a more representative population in which to confirm or refute these contradictory findings. Embedded within Theme 1 'Self' and Theme 2 'Living with hypertension' of the results of the interview study (Study 2) conducted and reported in the previous chapter (Chapter 3, section 3.2.2 and 3.4.3) were examples of participants describing their fears of living with hypertension. Much of this fear surrounded the long-term nature of hypertension, its asymptomaticity and a worry of committing to a lifelong regime of medication and this was described to influence the engagement of self-monitoring BP.

Anxiety and worry were therefore proposed as key factors for further investigation in the present study.

#### 4.2.1.2 Health perceptions and the GP relationship

Embedded in Theme 2 'Living with hypertension' and Theme 3 'The GP-Patient relationship' of the results section in the previous chapter (section 3.4.2 and 3.4.3), participants interviewed also expressed worry over the likelihood of experiencing consequences of high BP, stroke being the most commonly described.

Communication with a GP or HCP was also particularly salient when participants considered SMBP, also discussed previously (see sections 3.4.4. and 3.5.2) Perceived seriousness and perceived health LOC control in relation to SMBP have also been previously investigated, (section 1.9.1.1) but surprisingly not reported in the main findings. Self-efficacy for self-monitoring, which is the confidence in ability for patients to self-monitor BP, was also commonly described in the patient

interviews. More salient however were participant's descriptions of what participants perceived to gain or lose from engaging in self-monitoring or 'outcome-expectancy', construct of which is described in more detail section 3.5.5 and illustrated within Theme 4 'Self-monitoring behaviour'. Within the literature 'self-efficacy' has been best described within other chronic conditions (section 1.9.1.4) such as for the selfmanagement of oral anti-coagulation versus usual care. Whilst anxiety was not found to be significantly different between these groups, self-efficacy however was. The authors' hypothesised reasons for this improvement in self-efficacy to be linked with self-monitoring by helping patients to be more aware of changes of INR levels and increased knowledge. Patients could therefore act on this which in turn, was suggested to link to perceived therapeutic control. This shed light on how SMBP could be similarly used. In the management of BP, the literature on self-efficacy and outcome expectancy to self-monitoring BP is more limited <sup>91</sup> <sup>121</sup>. With the findings of study 2 potentially indicating that self-efficacy and outcome expectancies were equated with patients' reasons for engaging in self-monitoring or not, served to justify the need to investigate these factors further.

Such information could help HCPs to identify a number of areas to focus on when assessing their patients' suitability for engaging in self-monitoring. Furthermore identifying the factors that potentially influence a person's motivation could help direct clinicians as to which patients are ideal for recommending the practice to and may provide suggestions for ways of helping their patients continue to practice at home effectively.

# 4.2.1.3 Study 3 research questions

To investigate these factors in more depth, the study's research questions were therefore:

- 1) Is self-monitoring blood pressure associated with health anxiety and perceived worry in patients with hypertension?
- 2a) Is there an interaction between patients' health perceptions: self-efficacy, outcome expectations, perceived risk, vulnerability and personal control and self-monitoring blood pressure?
- 2b) Are health perceptions associated with engaging in home self-monitoring of BP?
- 3) How does self-monitoring blood pressure relate to patients' perception of the relationship between the GP and the patient?

#### 4.3 Methods

# 4.3.1 Sample population

Participants were drawn from the sample of 955 participants obtained in Study 1 described in Chapter 2, section 2.3, (Page 53) who had completed the previous survey, indicated a willingness to complete a more detailed questionnaire and had left complete contact details (n=449). Those who already participated in the qualitative study were not approached again. For a full description of the sample population please refer to earlier sections of this thesis to Chapter 2, section 2.3.3.

# 4.3.2 Questionnaire design

## 4.3.2.1 Approach to questionnaire development

Conduct of the interviews led to a better understanding of the experience of self-monitoring BP and the interviews and literature review generated a list of factors that may be associated with self-monitoring. The interaction of the factors were illustrated in a conceptual model in Figure 7, Page 140, which also considered key concepts drawn from social cognitive theory and empirical literature as described in previous chapters, on the psychological correlates of hypertension self-monitoring behaviour. The generation of these factors i.e. surrounding health anxieties, health perceptions and the GP-Patient relationship and their relationship with self-monitoring behaviour thus informed the design of the more in-depth questionnaire. This section describes the design of the questionnaire bringing together the evidence from the interviews and literature review.

Data in table 7 lists each of the measures used in the questionnaire. The questionnaire sent to participants is listed in Appendix 9 The questionnaire comprised four sections (A to D) which are also detailed in Table 7.

# 4.3.2.2 Questionnaire components

A summary of the main components within sections A-D are given here. Table 7 on page 154 below details the measures used with an example item for each to illustrate how this was measured. Following Table 7 a descriptive account is given for each of the psychological factors measured.

Section A titled 'About your high blood pressure' asked a series of closed questions assessing current medication, diagnosis and length of diagnosis (indicated by year), self-report of last recorded BP reading at the clinic, co-morbidities and year of diagnosis, and a measure of patients adherence to medications (described in more detail below).

Section B titled '*Blood Pressure Monitoring*' assessed various aspects of self-monitoring behaviour through a variety of single and multiple response items, examples of which are shown in Table 7. This section was based on a previous blood pressure monitoring survey<sup>161</sup> but adapted to suit the needs of the present study. Respondents were asked if they were currently monitoring BP (defined as over the last 6 months). Respondents who had never self-monitored were directed straight on to section C of the questionnaire. The rest of section B asked questions about frequency of SMBP, self-reported last home recorded reading (mmHg), reasons for

SMBP, where devices were brought from and questions relating to their relationship with their GP or HCP. Example items are given for all the above in Table 7.

Section C titled 'Your views, thoughts and feelings about self-monitoring blood pressure' assessed psychological factors (outcome expectancies, self-efficacy, supportive autonomy', perceived seriousness, perceived worry and perceived vulnerability of having high blood pressure, general health status, state anxiety. A number of existing validated measured was included (Table 7). For some factors, existing measures were felt unsuitable and so were adapted slightly with the aim to improve the psychometric properties of the scales. This is indicated in Table 7 with further description below. For one psychological variable, 'outcome expectancies for self-monitoring', a new scale was developed due to no relevant existing scale in the literature (to the authors' [SG] knowledge). The development of this scale is detailed below in section 4.3.2.2.3.

Section D was titled 'Some Background Information' asking for demographic information on age, sex, ethnic origin, level of education, employment status and living status.(see Appendix 9, question D1-6, Page 8)

The following sections detail the existing, adapted and newly developed scales listed in Column 2 of Table 7 and where relevant previous studies that have used the measures are reported. The location of the measure within the questionnaire also detailed, please refer to Appendix 9 where indicated.

#### 4.3.2.2.1 Validated measures

General health status (GHS) is a single item that measures participants' perceived general health. Rated on a 7-point Likert Scale anchored from excellent (1) to poor (7). This question has been widely used in studies involving self-ratings of health<sup>232;233</sup> (Appendix 9, Question C7, Page 6).

*Medication Adherence Questionnaire* (MAQ)<sup>234</sup> comprises four items and measures medication taking behaviour, in this context for hypertension treatment. Items were scored as either 0 (yes) or 1 (no). All items were summed to report a total score, range 0-4, (0) categorised as adherent, (1-4) categorised as non-adherent. Similar measurement has been used in prior research, participants answering yes to at least one item were considered non adherent to medications.<sup>235</sup> (Appendix 9, Question A5, Page 1)

The Health Care Climate Questionnaire (HCCQ - 6-Item)<sup>236</sup> comprises six items and measures patients perceptions of the degree to which they experience their health care provider (in this case their doctor or nurse) to be autonomy supportive versus controlling in providing health care with respect to the specific health issue of managing blood pressure. A sample item is displayed in Table 7. Answers were on a Likert scale anchored from strongly disagree (1) to strongly agree (7). Higher average scores represent a higher level of perceived autonomy support. (Appendix 9, Question C3, Page 5)

The State Trait Anxiety Inventory (STAI-6)<sup>237</sup> comprises six items and measures anxiety. The original inventory contains two 20 item self-report scales designed to measure how much worry, tension or apprehension the subject experiences in his or her present circumstances (state anxiety) and how much anxiety represents a personality characteristic (trait anxiety). Items emphasise the frequency of particular symptoms ranging from not at all (1) to very much (4). Because the questionnaire contains a large number of other questions, the shorter 6-item version was used for the present study. The psychometric properties of the shorter version have been previously investigated showing high correlation with the 20-item STAI score with all internal consistency reliabilities greater than .90. (Appendix 9, Question C8, Page 6).

The Multidimensional Health Locus of Control Scale, (HLOC) Form C<sup>238</sup> comprises 18 Likert-scale 6 point items and measures individuals' beliefs regarding the extent to which they are able to control or influence outcomes (personal control beliefs)<sup>238</sup> Form C is designed to be condition specific therefore in this context the word 'condition' was replaced by 'high blood pressure'. Instead of a single 6 item 'powerful others' subscale as on the original 24 item scale, Form C has two independent 3 item subscales, doctors (DHLOC) and other people (OPHLOC) and therefore has more relevance to the population investigated in the present study. The subscales tap four potential perceived loci of control: internal (IHLOC) (range scores 6-36) chance (CHLOC) (range scores 6-36), doctors (DHLOC) (range 3 -18) and other people (OPHLOC) (3-18). The score on each subscale is the sum of the values circled for each item on the subscale. The actual items, along with reliability and validity data as presented by Wallston.<sup>81</sup> (Appendix 9, Question C9, Page 7).

Table 7: List of variables, pre-validated measures and sample items assessed in the questionnaire

Questionnaire Section	Variable	Choice of validated questionnaire / adapted or newly developed scale	Example items
Demographic	Age	-	-
Section D	Ethnicity	-	-
	Sex	-	-
	Education level	-	-
	Employment status	-	-
	Living status (married, co-habit, live-alone)	-	-
Section A	Co-morbidities, year of diagnosis - yes/no,	-	-
	(angina, heart attack, stroke, cancer, high cholesterol, diabetes I/II)*		
	Medication taking status (yes/no)	-	"Are you currently taking antihypertensive medication?"
	last recalled BP clinic reading (mm/hg)*		<u>-</u>
Blood Pressure Monitoring	Status (yes/no)	Adapted <sup>161</sup>	"Do you currently measure your own blood pressure?"
Section B			"Over the past 6 months have you ever used a home blood pressure monitoring device to check your blood pressure?"
	last recalled self-monitored reading (mm/hg)*	-	-
	Frequency	-	"Over the past 6 months how often have you monitored your blood pressure?"
	Reasons for self-monitoring blood pressure	-	"Please indicate your main reasons for monitoring your blood pressure"
	Type of device used	-	-
	Where device purchased from	-	-
	Intentions to self monitor BP in the future	-	<u>-</u>
	GP communication (yes/no)	-	"Do you show/send your GP your home monitored readings?"

Psychological	General health	-	"Would you say your health is generally?"
Section C	Medication taking behaviour	Medication Adherence Scale(MAS) <sup>234</sup>	"Do you ever forget to take your blood pressure medication?"
	Perceived support of HCP/GP	The Health Care Climate Questionnaire <sup>239</sup>	"I feel my doctor understands how I see things with respect to my high blood pressure".
	Anxiety	The 6-Item State-Trait Anxiety Inventory (STAI-6) <sup>237</sup>	"Over the last 6 months how often have you been bothered by the following problems? e.g. feeling nervous anxious or on edge?
	Health locus of control (HLOC)	The Multi-Dimensional Health Locus of Control Scale – Form C <sup>238</sup> **	"if my blood pressure worsens it is a matter of fate"
	Self-monitoring self-efficacy	Adapted scale	"How confident are you that you can measure your own blood pressuree.g. if you feel anxious?"
	The Worry Scale:	Adapted scale	
	Perceived seriousness of high BP		"How serious do you think having high blood pressure is?"
	Perceived general worry about high BP		"How worried are you about your high blood pressure?"
	Perceived disease specific worry of high BP Perceived risk of hypertension		"How worried are you about developing a blood pressure related condition in your lifetime?"
	Self-monitoring outcome expectations	Newly developed scale	"If I measured my blood pressure at home then it woulde.g. reduce my visits to the doctor?"

<sup>\*</sup> self report

<sup>\*\*</sup>Form C modified by substituting condition in each item with 'high blood pressure'

#### 4.3.2.2.2 Adapted scales

The worry scale was composed of five single items measuring perceived seriousness or 'attitude to hypertension' (also referred to in the literature<sup>235</sup>) 'perceived worry' and 'perceived risk'. Responses were on a 7-point Likert scale rated from Not at all (1) to Extremely (7).

Patients' beliefs about the worry of *their own* high BP have been used in a previous study. The distinction made above between general worry about high blood pressure and personal disease specific worry was highlighted by some of the participants involved in the pilot of the questionnaire (see below) and was also described by the interviewees in the qualitative study phase. This approach to the measurement of perceived worry about developing a particular disease has been used in previous studies with good test-retest reliability (Cronbach's  $\alpha$  was .85) and construct validity. And the previous studies with good test-retest reliability (Cronbach's  $\alpha$  was .85) and

Perceived Risk "How would you rate *your* likelihood of developing the following as a result of high blood pressure? The conditions listed in the questionnaire were stroke and heart disease identified as the two most common perceived consequences of having high blood pressure from the qualitative interviews.

All 5 items on the worry scale were rated on a scale from 'not at all' (1) to 'extremely' (7) worried about high BP. Metrics were made consistent to avoid measurement bias. The mean scores of the 5 items were calculated. During development, each single item was combined as collectively the five items together

improved the internal consistency of the scale (Cronbach's  $\alpha$  was .83). (Appendix 9, Question C4, C5a+b, C6a+b, Page 5/6)

Self-efficacy scale (self-monitoring) was a scale made up of 7 items measuring self-efficacy to self-monitor blood pressure, that is the extent that respondents feel confident in their ability to measure their own blood pressure at various times. This method of measuring self-efficacy has been used in a previous study with a similar population. An extra item "without guidance from a doctor or nurse" was included given the findings from the qualitative interviews described in Chapter 3. Bandura recommends assessing self-efficacy with at least a 10-point scale for response choices. However to keep the metrics throughout the questionnaire consistent with other validated inventories included within the questionnaire, a 7-point Likert scale was used. Cronbach's  $\alpha$  for the scale was .95, response choices anchored from 'not at all confident' (1) to 'extremely confident' (7). Participants could score within a range of 7-49. The higher the score the higher the reported self-efficacy. (Appendix 9, Question C2, Page 4)

#### **4.3.2.2.3** Newly developed scale: The Outcome Expectancy Scale (OES)

Outcome expectancy, that is measuring what people consider what they stand to lose or gain from performing the behaviour, was assessed using a newly developed scale because it was felt existing measures reported within the literature were not appropriate and none (to the authors' knowledge) were specifically related to the practice of SMBP in hypertension. Furthermore, a closer look at the scales measuring self-efficacy within aforementioned previous studies did not specifically relate to

outcome expectations. <sup>91;103;112;116</sup> The closest scale measuring outcome expectancies was found in the diabetes literature for self-monitoring blood glucose within an adolescent population therefore the methodology of developing the present scale was adapted from Iannoti et al's 2007 scale. <sup>120</sup> The development of this scale was in two phases. Phase I: item development and pre-testing, Phase II: scale development. The goal was to develop an outcome expectancy scale that addressed the core elements of hypertension self-monitoring. Therefore, findings from the qualitative interviews informed the development of the items of the outcome expectancy scale. For the full scale please. (Appendix 9, Question C1, Page 4).

#### Statistical analyses for the outcome expectance scale OES

Analyses were performed using SPSS statistical software (version 20.0). The factor structure of the OES was analysed by factor analysis using the principal factor method and Varimax rotation. The scale's consistency was assessed using Cronbach's  $\alpha$ .

#### **Phase 1: Item development**

Evidence from the interviews from Study 2 described in section 3.4 informed the development of the items for the present outcome expectancy scale. Various aspects of how patients integrate the practice into their lifestyles were explored and identified as positive and negative consequences of self-monitoring, in other words what were potentially the outcome expectancies. To confirm face validity, the items were reviewed by two experts in clinical and health psychology nominated by the author, and three of the patients who participated in the interviews. They were asked to identify inappropriate items and ensure adequacy of coverage of all relevant content areas.

The complete scale was tested with members from the Birmingham 1000 Elders, nominated members on anti-hypertensive medication (n=6), a cohort of older individuals who regularly take part in research within the Centre for Healthy Ageing Research at the University of Birmingham<sup>8</sup> and a convenience sample of colleagues in the department (n=4). Please see Appendix 10 for covering sheet relating to how items were rated. Respondents completed the questionnaire and analyses were performed to construct the final version of the OES and confirm its reliability and content validity, described below.

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## Phase II – Scale development

Item analysis and selection: Sixteen items were developed from phase I. Items were scored on how much a participant agreed with a stem statement "If I measured my blood pressure at home then it would ....?" rated from 'not at all' (1) to 'very much agree' (7). Table 8 shows the draft scale of the OES consisting of 16 items. The items related to POSITIVE: positive psychological subscale 4 items 1, 8, 9, 12 / positive practical subscale 4 items 2, 6, 10, 14, and NEGATIVE: negative psychological subscale 4 items 4, 11, 13, 15 / negative practical subscale 4 items 3, 5, 7, and 16.

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<sup>&</sup>lt;sup>8</sup> http://www.birmingham.ac.uk/research/activity/mds/centres/healthy-ageing/elders.aspx

Table 8: Draft scale of the outcome expectancy scale for self-monitoring BP

"If I	easured by blood pressure at home then it would	
Q1	*Make me worry less about my high blood pressure	

- Q2 \*Reduce my visits to the doctor
- Q3 \*Be too much responsibility
- O4 \*Be too much to think about
- Q5 \*Be too strict of a schedule
- Q6 Prevent a stroke or heart disease
- Q7 \*Cost too much
- Q8 \*Keep my high blood pressure in better control
- Q9 Make me feel good about myself
- Q10 \*Confirm I have high blood pressure
- Q11 Make me more anxious if I got high readings
- Q12 Make me feel in more control of my high blood pressure
- Q13 \*Pre-occupy my time constantly measuring my blood pressure
- Q14 \*Help me to make lifestyle changes
- Q15 \*Concern me having to see my doctor all the time about my high blood pressure
- Q16 Be a waste of my time as it is not relevant for me

Correlation between each item and the total score was then calculated (Item-total correlation). Items with correlations exceeding  $0.3 \, (p.672)^{242}$  were selected for inclusion in the final questionnaire. Factor analysis following principal factor method combined with Varimax rotation was also performed and items with factor loadings below 0.5 were removed, based on the alpha level of .01 two-tailed. Items remaining after this selection process were included as standard items in the final version of the OES. Internal consistency reliability of the scale was assessed by calculating Cronbach's alpha  $(\alpha)$ .

<sup>\*</sup> items ultimately selected for the final version of the outcome expectancy scale for self-care

#### Establishment of the OES

Table 8 shows the draft scale of the OES containing 16 items. Questions 6, 7, 9, 11 12 and 16 were ultimately excluded because of low item-total correlation. Factor analysis on the 12 remaining items was used to estimate the factor structure of the outcome expectations of hypertension self-monitoring (Table 9). Data in table 9 shows the scree plot suggested a two-factor solution and all items had loadings of at least 0.3 on each factor. This analysis identified two independent factors: factor 1 (eigenvalue = 4.03) was composed of 6 items representing negative outcome expectancies (NOE), while factor 2 (eigenvalue = 2.94) assessed positive outcome expectancies (POE). The same factors resulted with both orthogonal and oblique factor rotations and both subscales had good internal consistency: the 6-item POE scale had an alpha of .81; and the 6-item NOE scale had an alpha of .89. Items in the NOE subscale were scored so that high scores reflect beliefs that SMBP leads to fewer negative or adverse outcomes. In the final selection of items, one item (Item 12 of the final questionnaire, see page 257) within the NOE scale was re-worded for clarity "Concern me having to see my doctor all the time about my high blood pressure" was changed to "Make me anxious if I have to see my doctor about my blood pressure".

**Table 9: Factor loadings of outcome expectation items** 

"If I measured by blood pressure at home then it would	Factor	Factor
	1	2
Expected negative outcomes		_
(reverse scored)		
Be too much to think about	0.91	
Be too much responsibility	0.86	
Be too strict of a schedule	0.83	
Pre-occupy my time constantly measuring blood pressure	0.70	
Make me anxious if I have to see my doctor all the time about my	0.61	
blood pressure		
Cost too much	0.57	
Expected positive outcomes		
Help me to manage my blood pressure		0.88
Keep my high blood pressure in control		0.82
Help me to make lifestyle changes		0.76
Confirm I have high blood pressure		0.70
Make me worry less about my high blood pressure		0.69
Reduce my visits to the doctor		0.61

The 12 items were thus selected as standard items for inclusion in the OES. Cronbach's alpha for the 12 item OES was .70.

# 4.3.3. Pre/ Pilot testing

As mentioned above, the complete questionnaire was tested with the same sample of members from the Birmingham 1000 Elders<sup>9</sup> (n=6) and colleagues in the department (n=4). Respondents completed the questionnaire and analyses were performed to construct the final version of the OES and confirm its reliability and content validity, described below. Analysis for item selection and item scale development were based on this data. Table 10 outlines the changes made to the questionnaire preceding the pilot testing phase.

<sup>&</sup>lt;sup>9</sup> http://www.birmingham.ac.uk/research/activity/mds/centres/healthy-ageing/elders.aspx

Table 10: Changes made to the questionnaire following feedback

- 1 Changed the scales to 7 points for standardisation of metrics across the whole instrument
- 2 Excluded the word 'neutral' on the scales apart from the HLOC scale, and the HCCQ which are standardised scales therefore would weaken the validation properties.
- Added an item to measure general and specific worry as participants commented there may be a difference
- Where possible kept "Strongly Agree" to "Strongly Disagree" 1-6 in a constant direction.
- 5 Where possible, items were made less wordy and less use of fonts

# 4.3.4 Sample size calculation

To determine the sample size needed to detect a significant difference in scores of the psychological measures between the two groups (self-monitoring vs. none self-monitoring), a power calculation was performed. Due to the absence of previous studies containing the factors described within the present study, this calculation was based on a previous study with similar methodology with at least one of the factors under study and a similar population.<sup>243</sup> To detect a difference of three units or more assuming that the whole population was not monitoring, with a two-sided significance of 0.05, this study required at least 66 participants in each group for 80% power.

# 4.3.5 Questionnaire mailing

A questionnaire and covering letter reminding participants of their earlier participation in a related survey study was mailed out by the author (SG) to 449 eligible patients between October and December 2011. (Appendix 8) Completion and return of the questionnaire was taken as consent to take part in the study. Those wishing not to participate were requested to return the blank questionnaire in the stamped addressed envelope provided. A second questionnaire was mailed to non-respondents two weeks later.

# 4.3.6 Data Analysis

A preliminary analysis of the data was performed to screen, clean and check data and assess each variable for normality (outliers, missing data and internal consistency of the variables). Parametric tests were used for all data with a normal distribution and non-parametric tests were used otherwise.

Descriptive statistics (frequencies, percentages, means and standard deviations) were used to describe sample characteristics and summarize study variables. For purposes of analysis, variables were grouped as shown in Table 11.

Table 11: Description of the grouping of the variables for analysis

Demographic characteristics	age, sex, ethnicity, employment status,
	marital status, education, medication
	taking behaviour, antihypertensive
	treatment, duration of hypertension,
	comorbidities
Psychological characteristics	worry, general anxiety, positive outcome
	expectancy (POE), negative outcome
	expectancy(NOE), self-efficacy (SE),
	perceived autonomy support (HCCQ),
	health locus of control beliefs (HLOC)
	(internal (I), chance (C), doctors (D),
	other people (OP)

To determine any differences between groups on all variables, a series of  $X^2$  and t-test analyses were performed. For t-test comparisons, cases were excluded analysis by analysis. This pairwise approach to case retention was used to ensure the use of the data was from a uniform set of cases for each bivariate element in the model. Due to multiple testing, the alpha significance level was set to < 0.01.

To identify whether the demographic and psychological characteristics had any predictive value in explaining self-monitoring, logistic regression was used.

Variables ranged in nature from dichotomous to continuous; therefore a logistic

regression model was considered appropriate for use in the analysis as shown in Table 12. Prior to performing the logistic regression the data were checked for multicollinearity, particularly the variables anxiety and worry, as theoretically these were variables which could be highly correlated with each other. Collinearity diagnostics revealed tolerance values greater than 0.1, VIF values were not greater than 10 and the eigenvalues were fairly similar indicating that the derived model were likely to be unchanged by small changes in the measured variable.<sup>244</sup>

To investigate the main effects, a backwards step procedure was used where all fifteen variables were entered into the model and the non-significant variables were removed, sequentially, with least significant first, leaving the remaining significant variables.

This method of variable selection i.e. backwards step, was the most appropriate procedure as the process initially started with variables considered to be conceptually and clinically relevant on the basis of theory and empirical literature where gradually each one was taken out that seemed irrelevant.

Table 12: Description of the variables included within the regression model

Independent variables (Continuous)	age, worry, anxiety, positive outcome expectancy, negative outcome expectancy, self-efficacy, perceived supportive autonomy, perceived general health, and the health locus of control scales: internal, other people, chance, doctors
Independent Variables (Dichtomous)	sex, ethnicity, education
Dependent Variable (Dichtomous)	self-monitoring (1) or not self-monitoring (0)

To investigate whether any of the variables could potentially be moderators within the model, the logistic regression was repeated to include the interactions between all the predictor variables and the remaining significant variables left in the model in logistic regression one.

# 4.4 Results

## 4.4.1 Overview

This section presents the results of all the statistical analyses conducted for the current study. Demographic and psychological characteristics for the total sample and stratification by self-monitoring status are presented prior to reporting the findings from the regression analyses performed. The proceeding section describes the analyses conducted relative to each research question detailed at the end of the introduction section of this chapter.

Following distribution of the questionnaire, of the 449 eligible and mailed, 6 were undeliverable, 293 were returned, giving a return rate of 66.1%. Of these, 236 questionnaires were analysable; the remaining 57 were either incomplete or returned blank, giving a response rate of 53.3%. This is comparable to the sample response rate obtained in Study 1 of the prevalence survey described in Chapter 2 of this thesis, Page 48.

## 4.4.2 Descriptive characteristics of the whole sample

Table 13 presents the socio-demographic characteristics for the total sample of primary care adults with hypertension, along with a stratified summary by self-monitoring status. The total sample of 236 respondents included 124 men (52.8%) with a mean age of 66.8 years (SD =10.5). The majority of respondents were married (n=125, 54%) although a substantial proportion lived alone. Only a fifth were working (n=51, 21.9%) and most respondents were educated to secondary level or below, (n=133, 30.3%) had received higher education. The median duration of hypertension was 14 years. Participants last recalled clinic BP (self-report) had a mean systolic blood pressure (SBP) of 138 (SD = 15.16) mmHg and a mean diastolic blood pressure (DBP) of 79 (SD = 8.08) however this data was only available from 46 participants (19.5% of the whole sample). Just over 40% of the sample (41.9%) reported having at least one other disease.

## 4.4.3 Descriptive characteristics of the blood pressure selfmonitoring group

People who self-monitor were defined as those who answered "yes" to the question *Have you ever self-monitored your own blood pressure over the past 6 months?* The characteristics of the self-monitoring group (n=99) and the non-self-monitoring group (n=137), can be found in Table 13 Pearson chi-squared tests revealed that people who self-monitored were more likely to have received higher education ( $X^2 = 14.62$ , p <.01). Although not statistically significant, trends indicated that people who self-monitored were more likely to be of non-white ethnicity (23.5% vs. 14.2%) and were also less adherent to medication (24.7% vs. 14.4%).

Over a third of respondents (38/99; 38%)) indicated they monitored on a weekly basis or more using mainly electronic devices and purchased primarily from a pharmacy (74/96; 77%). When asked how respondents stored readings, most indicated they wrote them down (46/99; 46%), some were stored automatically in the memory of the BP device (20/99; 20%) and thirty respondents did not store readings at all. Most common reasons for monitoring were interest in knowing blood pressure (62/99; 62%), a doctor's recommendation (31/99; 31%) and to help check symptoms (27/99/27%) [more than one response possible]. Twenty three respondents monitored due to encouragement of family friends, media influence or because they liked trying new things and a small number indicated they self-monitored to help them adhere to medication (n=8 [multiple choice options]). When asked about communication with HCPs about self-monitoring, just over half of the respondents indicated their doctor recommended them to self-monitor (50/99; 50%). Seventy two respondents indicated their doctor knew about them self-monitoring, of which, 46 (64%) reported they had

shown/sent their home monitored readings to their doctor. A small proportion (19/95; 20%) of respondents reported they had had their device checked by a HCP.

# 4.4.4 Psychological characteristics of the sample stratified by selfmonitoring status

Table 14 lists the sample ranges, means and standard deviations for all the psychological variables and between group differences for the two groups (self-monitoring and non-self-monitoring). The next section reports the results individually for each research question.

#### **Research Question 1**

Does self-monitoring BP have an association with patients' health anxiety and perceived worry of patients with hypertension?

Scores on the anxiety and worry scales were not statistically any different to the non-self-monitoring group. (Table 14) Responders in general showed moderate levels of worry, and according to the scoring structure of the STAI also moderate levels of state anxiety. <sup>237</sup>

#### Research Questions 2 and 3

- 2a) What is the interaction of self-monitoring blood pressure on patients' health perceptions: self-efficacy, outcome expectations, perceived risk, vulnerability and personal control?
- 2b) Do these health perceptions affect the likelihood of engaging in home selfmonitoring of BP?

3) How does self-monitoring blood pressure influence the perception of the relationship between the GP and the patient?

Data in Table 14 showed those reporting that they self-monitored had significantly higher self-efficacy scores (p<0.001), higher negative outcome expectations (p<0.05) about self-monitoring and scored lower than the non-monitors on the external HLOC sub scales (chance (p<0.05), other people (p<0.001), and doctors (p<0.001). Both groups reported similar ratings of average health scores and there were similar levels of perceived autonomy support between groups.

To investigate the main effects, a backwards step method was performed (logistic regression 1) where all fifteen variables were entered into the model and the non-significant variables were removed sequentially leaving the remaining significant variables. (Table 15). For further detail about the entering of variables for the logistic regression analyses please refer to earlier sections describing data analysis (Section 4.3.6, Page 159.)

At the 11<sup>th</sup> step the regression model included 5 variables, of which 3 were significant p<0.01, (Education, SES, DHLOC). All other non-significant variables were removed (p>0.1, Table 15). This model correctly classified 71.1% of participants. The final regression model explained 36.7% of the variance with patients self-monitoring having higher education, higher self-efficacy and lower doctors' health locus of control.

To determine whether a more complex model including interactions between variables could better explain relationships within the data, the backwards step logistic regression was repeated, as shown in Table 16 with the model including 15 main effects (predictor variables) and the interactions between the three significant variables identified in the first logistic regression (Education, SES, DHLOCS) and all the predictors (39 interactions). The results showed a number of differences; Education remained a significant independent predictor however DHLOC and selfefficacy as main effects were no longer significant independent predictors. Age and negative outcome expectancies were now significant, previously removed at the last step (p>0.1). Therefore the influence of age and negative outcome expectancy were reconsidered. Age, negative outcome expectancy and education, (p<.01) were therefore now significant main effects, (Table 16) and the interactions between age and doctors health locus of control and self-efficacy and negative outcome expectancy contributed significantly (p<.001). This model correctly classified 73.1% participants and explained 36.2% of the variance. This model explained a similar amount of variance to the previous model with a few differences. Within the main effects, as age and education increased, the odds of someone reporting that they self-monitored also increased. If negative outcome expectancies increased, the odds of someone reporting they self-monitored decreased. Analysis of the interactions showed that age and negative outcome expectancy were potentially effect modifiers, that is, their presence in the model modified the main effects of self-efficacy and DHLOC on selfmonitoring.

Exploring this outcome of the regression analysis further, inspection of the variables age and DHLOC revealed a significant difference between the mean scores of the

younger age groups (<60) and the mean scores of the older age group (>60). The mean scores of the younger age group were lower than those of the older age group, that is, locus of control health beliefs for doctors decreased as age increased. Analysis of the groups based on a median split of self-efficacy scores (high/low) on negative outcome expectancy scores however yielded no significant relationship. As self-efficacy scores increased, negative outcome expectations also increased, shown in Table 16.

To summarise, the analysis of the data showed that education, self-efficacy and DHLOC were all significant predictors of self-monitoring and this was confirmed by the logistic regression. Further analysis of the interactions of the variables revealed age and negative outcome expectancies affected the predictor model. Whilst age and negative outcome expectancies were also significant predictors when all interactions were included in the model, (P<0.01) they potentially moderated the impact of self-efficacy and DHLOC as main predictors of self-monitoring.

Table 13: Demographic factors of the entire study sample and stratified by self monitoring status

Variable		N (%) / Mean (SD)	N (%)	$X^{2}$ † $/t$ † †	p	
	Total (N=236)	Self-Monitoring (yes) (n=99)	Not self-monitoring (no) (n=137)			
Antihypertensive Medication	(n=235) 217 (92.3)	91 (91.9)	126 (92.6)	0.04 <sup>†</sup>	0.84	
Sex Male Female	(n=235) 124 (52.8) 111(47.2)	(n=99) 55 (55.6) 44 (44.4)	(n=136) 69 (50.7) 67 (49.3)	0.53 <sup>†</sup>	0.47	
Age (years)	(n=235) 66.8 (10.46)	(n=99) 67.5 (10.7)	(n=136) 66.2 (10.2)	- 0.93††	0.35	
Duration of Hypertension Median (years) IQ – range	(n=175) 14 9-22	(n=74) 15 9-23	(n=101) 14 9-22	-	_	
Co-Morbidities*		(n=99)	(n=137)	+		
CVD (Angina, Heart Attack or Stroke)	71 (30.1)	33 (33.3)	38 (27.7)	4.26	0.23	
Cancer High Cholesterol Diabetes	30 (12.7) 132 (55.9) 44 (18.6)	13 (13.1) 52 (52.5) 17 (17.2)	17 (12.4) 80 (58.4) 27 (19.7)	0.27 0.80 0.24	0.87 0.37 0.62	

Ethnicity White Non-White	(n=232) 190 (81.9) 42 (18.1)	(n=98) 75 (76.5) 23 (23.5)	(n=134) 115 (85.8) 19 (14.2)	3.30 <sup>†</sup>	0.07
Employment Status Full/Part Time Others	(n=233) 51 (21.9) 182 (78.1)	(n=98) 22 (22.4) 76 (77.6)	(n=135) 29 (21.5) 106 (78.5)	0.03 <sup>†</sup>	0.86
Marital Status Married / Co-habit Live alone	(n=221) 133 (60.2) 88 (39.8)	(n=95) 58 (61.1) 37(38.9)	(n=126) 75(59.5) 51(40.5)	0.05 †	0.82
Education Prim, Sec, None Higher	(n=234) 163 (69.7) 71 (30.3)	(n=98) 55 (56.1) 43 (43.9)	(n=136) 108 (79.4) 28 (20.6)	14.62†	0.00 **
Medication taking behaviour Adherent Non adherent	(n=207) 168 (81.2) 39 (18.8)	(n=89) 67 (75.3) 22 (24.7)	(n=118) 101 (85.6) 17 (14.4)	3.53 <sup>†</sup>	0.06
Last Home BP (Self report) SBP DBP	-	(n=46) 134 (13.30) 76 (13.12)			

<sup>\*</sup>participants may have answered more than one \*\* (p <0.5), †  $X^2$  - chi-squared tests/ † independent sample t-test

Table 14: Psychological factors stratified by self-monitoring

		Self-monitoring	Non self-monitoring			
		group (yes)	group (no)		Df	
Variable	Max range of scale	Mean (SD)	Mean (SD)	T		p
		(n=96)	(n=126)			
Worry Scale	9-35	24.9 (6.9)	24.9 (6.6)	-0.01	220	(0.99)
		(n=96)	(n=133)			
General Anxiety	6-24	10.8 (3.6)	11.0 (4.1)	-0.50	215	(0.61)
HLOC		(n=99) #	(n=130)			
Internal Scale	6-36	22.5 (7.8)	24.1 (7.1)	1.62	225	(0.11)
Chance Scale	6-36	14.5 (6.4)	16.9 (7.9)	2.51	224	(0.01)*
Doctors Scale	3-18	12.3 (4.1)	14.6 (3.5)	4.66	227	(0.00)**
Other People Scale	3-18	8.6 (3.5)	10.0 (4.0)	2.71	226	(0.00)**
		(n=96)	(n=132)			
General Health Rating	1-7	4.5 (1.5)	4.7 (1.4)	-0.84	226	(0.40)
Perceived Autonomy	1-42	(n=96)	(n=130)	0.06	224	(0.95)
Support		5.0 (1.5)	5.0 (1.7)			(0.52)
POE	1-42	(n=92)	(n=136)	0.45	226	(0.66)
FUE	1-42	$\binom{n=92}{3.8(1.8)}$	$\binom{(n=130)}{3.7(1.7)}$	0.43	220	(0.00)
NOE	1-42	3.0 (1.0)	3.7 (1.7)	-2.33	220	(0.02)*
		(n=86)	(n=136)			
		5.9 (1.4)	6.4 (0.8)			
Self-Efficacy	1-49	(n=96)	(n=128)			
		5.7 (1.3)	4.4 (2.0)	5.68	222	(0.00)**

Table 15: Backwards logistic regression (N=190), Step 11

	В	S.E.	Wald	Df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age	0.04	0.02	3.66	1	.056	1.04	1.00	1.08
Education	1.31*	0.39	10.97	1	.001	3.69	1.70	8.98
NOE	-0.31	0.17	3.36	1	.067	0.74	0.53	1.02
Self-efficacy	$0.58^*$	0.13	21.43	1	.000	1.80	1.40	2.30
DHLOC	-0.17*	0.06	11.05	1	.001	0.85	0.77	0.93
Adjusted $R^2$	.367~							
F	54.73**							
Constant	-2.07	1.82	1.30	1	.255	.126		

Nagelkerke \*p<0.01 \*\* p < 0.001; NOE – Negative outcome expectancy; DHLOC – Doctors health locus of control

Table 16: Logistic regression, interaction analysis (N=208)

	В	S.E.	Wald	Df	Sig.	Exp(B)	95% C.I. for EXP(B)	
							Lower	Upper
Age	0.07**	0.02	11.34	1	.001	1.08	1.03	1.12
Education	1.09**	0.36	9.08	1	.003	2.97	1.46	6.02
NOE	-0.81**	0.20	16.81	1	.000	0.44	0.30	0.65
Age x DHLOC	-0.00**	0.00	14.34	1	.000	0.99	0.99	0.99
Self-efficacy x NOE	0.09**	0.02	22.23	1	.000	1.09	1.054	1.135
Adjusted R2	.362~							
F	54.06							
Constant	-1.05	1.54	0.47	1	0.50	0.35		

Nagelkerke \*p<0.01 \*\* p < 0.001; NOE – Negative outcome expectancy; DHLOC – Doctors health locus of control

#### 4.5 Discussion

Self-monitoring blood pressure (SMBP) is being increasingly advocated for individuals with hypertension, yet other than knowing that the technique is feasible and acceptable, <sup>87;102;105;189;245;246</sup> little is known about the psychological factors related to the practice. The present study investigated some of these factors derived from qualitative interviews conducted in study 2 and their relationship with SMBP. This was investigated quantitatively with a questionnaire distributed to a wider population of primary care patients with hypertension in the West Midlands that participated in the study 1 presented in Chapter 2. The analysis was centred on three main research questions as stated in the introduction section this chapter and the following discussion reports the main significant findings and trends in the data with links to wider research.

## 4.5.1 Main findings

Overall, the study's main findings showed that increasing education was significantly associated with a greater likelihood of self-monitoring, as was having a higher self-efficacy for self-monitoring. People self-monitoring surprisingly were also more likely to report more negative outcome expectations of self-monitoring than those who did not self-monitor A somewhat more expected finding was that those self-monitoring scored significantly lower on all the external locus of control subscales (other people and doctors) than those not self-monitoring. Because this study used the same participants obtained in Study 1, comparisons of the sample characteristics of the present sample and participants in Study 1 are first presented followed by a

discussion of each of the significant factors and trends found in the present study to wider research.

# 4.5.2 Comparisons of sample characteristics to the sample in of Study 1

This data extends the survey used in study 1. The same demographic questions asked in the survey were also asked in the questionnaire, with notable changes to include additional questions about clinical and demographic data: a question about education was added and age was made into a continuous variable rather than categorical as it was previously in Study 1. The total samples in both groups were similar in terms of distribution of age, with the majority of study 1's participants in the '21 – 81+' age range vs. mean age 67, sex 48% male in Study 1 vs. 53% in the present study 3, and ethnicity 81% white in both Study 1 and Study 3. Of those self-monitoring in Study 3 there was no longer a significant relationship in employment and self-monitoring, with considerably fewer in employment than those in Study 1 (22% vs. 38%). This could have been due to the age range of the participants with many possibly retiring since earlier participation.

# 4.5.3 Significant factors associated with SMBP

#### Education

This study found that people who were more educated were more likely to self-monitor. Two previous questionnaire based studies also support this finding.<sup>86;87</sup> This could suggest a possible financial issue, that is, those with less education may not

have the resources to purchase BP monitors for example to enable them to self-monitor. Respondent scores on Item 6 of the outcome expectancy scale used in the questionnaire (see Appendix 9 for full questionnaire) however were low, that is "if I measured my blood pressure at home then it would be too costly" rated fairly low which could suggest that this explanation could be discounted.

Although not a significant interaction in the present study, another possible explanation for this could be that those more highly educated could have a stronger desire to gain positive outcomes for the practice such as control of one's BP. This explanation is supported by evidence from a clinical trial conducted in Iran that found higher education level of those self-monitoring for hypertension was also significantly associated with a higher intention for controlling blood pressure.<sup>247</sup> Such a finding spotlights that self-monitoring may not be a practice that suits all, as previously proposed in the literature and clinical guidelines<sup>62;63;248</sup> but rather for those who desire an outcome such as better control of BP. HCPs should determine from patients what their patients hope to achieve by self-monitoring, that is whether they are motivated to achieve better blood pressure control. With evidence showing the more successful impact of 'educating educated patients' on changing behaviour than when compared with non-educated patients, <sup>247</sup> these findings have implications for HCPs in focusing on this disparity. HCPs should instead make sure they identify and target patients that need the help the most such as those less educated. As the government continues to strive to tackle health inequalities, 249 it is perhaps the role of the HCPs to ensure that those who are less educated are not left out.

#### Doctors Health Locus of Control (DHLOC) and SMBP

The current study sought to investigate the health loci of self-monitors and to see if these were associated with the practice of self-monitoring.

Of the four HLOC subscales, self-monitors scored lower than those not monitoring on the external subscales (other people, chance and doctors' subscales). HLOC being the extent that health state was considered to be the direct result of HCPs or other people. The present study found, as scores on the DHLOC scale increased, the odds of someone reporting they self-monitored decreased, an expected outcome given the theoretical underpinnings of the HLOC theory (described in more detail in earlier parts of this thesis, see Section 1.8.3)<sup>207</sup> In the earliest research on HLOC scales, Seeman and Evans found that hospitalised tuberculosis (TB) patients who held internal HLOC beliefs knew more about their condition, asked doctors and nurses more questions and expressed less satisfaction with the amount of feedback or information they were getting about their condition from the hospital than did external patients.<sup>250</sup> This marked internal motivation to seek more information, together with similar findings of a similar but more recent study, 83 gave rise to the present hypothesis that self-monitoring patients would also show higher internal HLOC scores and view their BP control to be less to do with external sources of support and more their own responsibility.

Although scores were lower on the external HLOC subscales to that of those not monitoring, contrary to expectation self-monitors also scored lower on the internal HLOC subscales than patients not self-monitoring. This finding indicates that self-

monitors are perhaps not as internally driven as previously hypothesised and may explain why currently patients are poorly engaged with self-monitoring. Where perhaps they may have started off with high internal HLOC beliefs, it could be that inadequate support for engaging in self-monitoring has affected internal motivation to continue. This situation has been shown with longer term patient with diabetes where uncontrollable, unpredictable aspects of diabetes led 'internals' (those with high internal control beliefs) to find their normal response inadequate, and subsequently responded by relinquishing the degree of control they previously had.<sup>251</sup>

Patients may feel they have more control and independence over their condition from self-monitoring but that they also need more input from doctors or HCPs to advise them on monitoring and treatment to sustain the internal motivation. That is, ideally a combination of both internal *and* external LOC beliefs. People with higher external LOC have previously been found to be linked with more monitoring in patients with diabetes, <sup>252</sup> therefore it could be argued the same could be effective for patients with hypertension.

#### Age and DHLOC

The results also showed that age was associated with DHLOC. As patients got older, the extent that they believed their health state was dependent upon HCPs decreased. Although this is contrary to the findings of Study 2, reported in the previous chapter (where all patients interviewed were quite happy with their health being largely in the hands of their doctor), they agree with a previous survey study of the general population where self-testing for BP had peak penetrance in middle and older age

groups. <sup>86</sup> This suggests older patients are becoming more motivated to take up active self-care strategies such as self-monitoring, <sup>84</sup> which is positive given hypertension occurring more commonly with increasing age.

#### Self-efficacy and Outcome Expectations

Self-efficacy remained significantly associated with self-monitoring but as self-efficacy for self-monitoring increased there was a relationship with outcome expectations. Theoretically this fits with the expectancy-value theory previously described in Section 1.8.4, that the combined effect of self-efficacy and outcome expectations is much greater. 113:230 Outcome expectancies are not conceptualised as direct predictors of SMBP use as one can hold positive and negative outcome expectancies at the same time, instead it is assumed outcome expectancies to have motivational status through their effects on their self-efficacy beliefs. Based on this it was therefore assumed a priori, that those who had high sense of personal self-efficacy, that is have the requisite skills (such as to feel able to self-monitor), would also believe that the outcomes for the practice would also be positive. The present study however found that whilst people self-monitoring did have higher self-efficacy, they had more negative outcome expectations than people not self-monitoring.

Bandura proposes that people who regard outcomes as personally determined but who lack the requisite skills would experience a low sense of efficacy and view the activities with a sense of futility (p.21). This could suggest that people who monitor BP on a regular basis feel confident to do so but they may have also learned that doing so doesn't result in meaningful outcomes. In other words, participants may have

become more realistic in knowing that the act of self-monitoring doesn't change anything. This suggests a possible interaction between HLOC, Outcome expectancy, Self-Efficacy and skills in a) self-monitoring and b) understanding what to do with the results. That is a possible hypothesis that positive expectancies would motivate individuals to practice self-monitoring by enhancing their self-efficacy and that negative expectancies would be related to reduction in self-monitoring by decreasing self-efficacy.

The effects that different patterns of efficacy can have on outcome expectancies, behaviour, performance and affective states are illustrated in Figure 8. This is an adaptation of Figure 6 shown on Page 127 to show how the results of the present study fit with this theory.

**OUTCOME EXPECTANCIES** Protest Productive engagement **EFFICACY BELIEFS** Grievance Aspiration Personal satisfaction Social activism Milieu change Self-devaluation Resignation Apathy Despondency

Figure 8: The effects of outcome expectancy and efficacy beliefs on affective states

Figure adapted (p.20)<sup>113</sup>

On the basis of the findings of the present study, people self-monitoring could largely be placed in the top left of Figure 8 (that is self-monitors were associated with a high personal self-efficacy beliefs and more negative outcome expectations, i.e. a low environmental responsiveness). The obvious ideal situation for a self-monitor would

be the box in the top right of Figure 8, that is high self-efficacy and positive outcome expectations and therefore there is the argument that more work still needs to be done so that there are more positive outcome expectancies. A prerequisite being to address further the reasons for negative outcome expectations, that was surprisingly, higher amongst those performing SMBP.

Contrary to the findings of Study 2, the present study found a high percentage of people sharing results with this GP. In line with the above, this could suggest that patients are making efforts to change their 'social practice' and consequently improve their affective states by making an attempt to communicate their home practices with their HCP. If we take these findings into consideration, the significantly increased negative outcome expectations are evidence that whatever communication is being had is potentially not very profound and this is supported from a recent qualitative study of HCPs views and experiences about self-management of BP where GPs interpreted home readings variably with many not making adjustments for lower home BP.<sup>253</sup> Better two way communication, education and support for self-monitoring, advice and guidelines about treatment based on home measurements.<sup>181</sup> would potentially be more useful in the future to utilise this evidently highly self-efficacious and motivated group of individuals.

#### Adherence to medication and SMBP

The medication adherence questionnaire (MAQ) showed that although failing to reach significance, self-monitoring patients were also less adherent to medication. This contrasts with existing research on self-monitoring and treatment adherence that

generally shows self-monitoring to be associated with a greater likelihood for adhering to treatment. 22;122 The present study showed a new trend in data of an association between self-monitoring patients being less adherent to medication. Medication adherence has been recently found to be strongly related to medication adherence self –efficacy.<sup>254</sup> Therefore this finding, in conjunction with the findings of the qualitative interviews described in the previous chapter of this thesis, spotlights self-monitoring as a possible intermediate confirmatory process which patients use for empowering themselves to make important decisions about taking life-long medication, a reality most feared by the participants interviewed in Study 2. The relationship between self-monitoring and the decision to take medication is an important one because it has implications for clinical practice. On the one hand, it could be argued that this reflects positive challenges to the concept of 'compliance' showing evidence that patients are becoming more 'active, intentional and responsible participants in their health care management', <sup>255</sup> a demonstration of an evolving NHS. On the other hand, in respect of SMBP the findings could also however highlight a gap in this process which also states 'patients should work to maintain their health in collaboration with health care personnel' rather than simply adhering to instructions.<sup>67</sup>

It seems from the current findings that patients are taking critical decisions about the management/treatment of their health into their own hands. So although this indicates a shift in patients taking control over their own health, it is also vital that actions such as medication adherence are discussed properly between patient and HCP/GP if the patient recommends SMBP to their patient or knows the patient is self-monitoring at

home. This would avoid some of the more serious consequences from patients actively choosing not to adhere to medication regimes.

### 4.5.4 Limitations of the questionnaire study

The present study had a number of limitations. First the ability to detect causality may have been hampered because of the cross-sectional nature of the study; therefore caution must be taken in any interpretation of the results.

There could have also been potential bias in the selection of the sample due to the population being taken from Study 1, patients who had previously participated in an earlier related study. Although it was ensured that those taking part in the qualitative study were also not sent a questionnaire for Study 3 to avoid over-use of participants, these patients may view self-monitoring in a more favorable light than perhaps a completely different set of participants.

The present study also lacked reporting of any clinical data for e.g. patients' most recent clinic BP. Only limited clinical data were collected during the course of the study, which was insufficient to determine every individual's last reported clinic BP. To combat this, for the present study, *self-reported* last clinic BP reading was specified however data was only available for a small number of participants (n=46/20%), data was therefore not shown. Collection of actual recent clinic BP data and also calculation of each patient's Framingham risk score<sup>240</sup> for the patients in this study would have greatly improved the robustness of the study as comparisons could

have been made between groups on BP control improving the clinical applicability of the findings however consent for this was not available.

## 4.5.5 Implications for practice

Communication and changing the negative outcome expectations

These data have potentially important relevance to clinical practice. First, the current results suggest that it should not be assumed that SMBP is feasible for all patients. HCPs need to identify those that could be missing out from the benefits of self-monitoring such as those that are younger and less educated. Considering this within a psychological framework and the strong link between self-efficacy and outcome expectations a useful exercise for HCPs could be to ascertain their patients' motivations for engaging in self-monitoring, what they wish to gain from performing this behaviour. If the desired outcome is for example to achieve better BP control, then HCPs could emphasise that making changes to one health behaviour such as self-monitoring may serve as a catalyst to making other lifestyle changes. This serves as just one example of how communication could be improved between patients and HCP/GP.

Although patients say they are able and confident of self-monitoring this study highlights that HCPs need to ensure that they are methods are correct. Those highly self-efficacious people who cannot gain positive outcomes will not necessarily cease trying. HCPs should therefore capitalise on what is essentially a readymade and willing population who simply need these negative outcome expectations changed. This subsequently calls for a shakeup in patient information/clinical guidance on how

best to implement SMBP at home as part of the care of their hypertension. HCPs could help shape the perceptions or beliefs of patients regarding their blood pressure through the provision of improved communication between themselves and their patients on action plans, advice and goals based on home monitored activity.

#### 4.5.6 Conclusions

The current study proposed to investigate the characteristics and psychological factors associated with the practice of self-monitoring. Overall the study found that being older, more highly educated and highly self-efficacious was significantly associated with a greater likelihood of self-monitoring. Education, self-efficacy and doctor's health locus of control remained significant factors of self-monitoring after taking other factors into account but were potentially moderated by age and negative outcome expectations. The older the patients, the more likely to self-monitor, which was contrary to the findings within the study 2 but supportive of the findings from a previous study in the literature. Surprisingly, self-monitors were highly self-efficacious but reported more negative outcome expectations (for SMBP) than those not self-monitoring. Self-monitors were also less adherent to medication which shows that the current experience of self-monitoring is not overtly a positive one but one perceived to be possibly more anxiety provoking, furthermore made dangerous if patients are taking treatment decisions into their own hands.

Despite patients being confident in their ability to SMBP, without the provision of clear guidelines, instruction and effective communication between HCP and patients on activities based on home blood pressure measurements, it appears patients do not currently perceive positive gains for the practice. In light of the most recent

recommendations, for SMBP to become an important part of the diagnosis of hypertension, secondary to ABPM,<sup>4</sup> and indeed for the continued management of hypertension for patients, such findings highlight issues before SMBP can be successful. Good communication between HCP and patient about how to use the results, and major changes to patient education about self-monitoring are prerequisites for avoiding such negative implications which patients currently perceive and could help make self-monitoring an integral part of the management of hypertension.

## 4.6 Chapter Summary

This chapter reported the last of the three studies conducted to investigate which of the psychological or motivational factors influence on-going self-monitoring behaviour. The approach to questionnaire design and development was first detailed followed by the methodology and how the sample population was chosen. The results of sending the questionnaire out to 236 participants were then reported relative to the study's research questions. The relationship of these factors with wider factors tested in the questionnaire formed the content of the discussion with implications for practice and concludes with a brief summary of the main findings and future recommendations that GPs and patients should take if self-monitoring BP is to be implemented effectively. A brief outline of implications for practice are discussed here as an in depth discussion of the conclusions, limitations, implications and future directions is the focus of the next and final chapter.

**CHAPTER 5** 

MAIN DISCUSSION: CONCLUSIONS, LIMITATIONS, IMPLICATIONS

AND FUTURE DIRECTIONS

5.1 Introduction

In this final chapter of the thesis, the strengths of the study and original contribution

to knowledge are discussed. The findings are summarised, after which the limitations

and implications for practice and future research are highlighted.

5.2 Strengths and original contribution to knowledge

The benefits of mixing methods

In considering study design, the research was broken down into three linked research

questions, each with separate studies. (Please refer to Figure 2, Page 48). In order to

answer them most effectively, a mixture of quantitative and qualitative designs were

used. Survey methodology was used in Chapter 2, the first study to assess the

prevalence of SMBP in hypertension in UK primary care. This was seen as the most

appropriate method to answer the first research question, but was also conducted to

establish a participant sample base from which to obtain further participants for the

two studies following it. Qualitative interviews used in the second study were

appropriate because as outlined in Chapter 1, patient experiences of SMBP in patients

with hypertension from a psychological viewpoint were under-researched. An

exploratory design was therefore needed to identify what patients' motivations and

experiences were and what avenues needed to be explored. As Strauss and Corbin

(1998) suggest, qualitative research involves "getting out into the field and seeing

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what people are doing and thinking, and allows the minutia of the phenomenon and the accompanying emotions, beliefs, values and experiences to be uncovered" (p.11)<sup>200</sup> Study 1 also was important for the conduct of study 2 as many of the topics discussed on the topic guide were derived from these findings. The methods, findings and discussion of the qualitative interviews were presented in Chapter 3.

Sequentially, the findings of the qualitative phase were used to design the questionnaire used in the Study 3 meaning that the findings of patient experiences, thoughts, beliefs and emotions drove the questionnaire research forward. The questionnaire tested the main theoretical linkage of variables illustrated in Figure 7, Page 140 and hypotheses developed from the qualitative analysis. Quantitative results therefore allowed the qualitative findings to be clarified, developed and expanded upon and improve the generalizability of the findings. The results and discussion of the questionnaire, piloting and administration were presented in Chapter 4.

As well as gaining a sample of participants for interviewing from conducting Study 1, another strength of using quantitative methods after the qualitative interviews meant a wider range of participants could be sampled at more depth to test the hypotheses emerging from the qualitative findings, and meant those who might have been reluctant to participate in an interview study could be recruited.

Combining methods also highlighted some discrepancies in findings between the studies in important areas. One major discrepancy was on the topic of communication with GP/HCP and whether patients shared home measurement results. Within an overall theme called 'the GP-Patient Transaction' in Study 2, (Section 3.4.4) only one of sixteen patients interviewed described experiences of how readings were regularly

shown to a HCP/GP, with others never considering informing their GP/HCP they selfmonitored or shared readings. Whilst this could simply be reflective of the small sample size in Study 2, therefore not large enough to detect a balance in how many participants shared their self-monitored activities with their GP, this could also be a methodological issue about whether patients respond differently depending on the design employed. That is participants responses may be different when spoken to or when assessed on paper format. Contrasting study 2's findings, more than half the respondents in study 3 indicated their doctor recommended them to self-monitor and reported they had shown/sent their home monitored readings with their doctor. That is when formerly asked on paper format within a questionnaire (Study 3). Patients may find it easier to be more open and honest on paper given its anonymity and free from the researcher's own opinions influencing the respondent to answer in a certain manner. 164 Or vice versa, that is patients may find it easier to be honest face to face rather than on paper Aside from the clinical implications of this finding, (that is, a third still did not their readings even in Study 3 which supports previous work <sup>102</sup>) this discrepancy example highlights how combining methods complement one another when exploring issues and that the conclusions drawn from one method can be completely different to another on the same topic. Qualitative investigation brought up the important issue that a significant minority were not sharing results with their GP whereas quantitative design quantified findings and came up with contrasting results. Thus the complementing designs increased the robustness of the findings potentially improving the generalizability of any conclusions drawn.

This research makes an original contribution as it is (to the authors' knowledge, and at the time of publishing) the first to provide UK data on the prevalence of SMBP in a primary care hypertensive population. This part of the thesis, presented in Chapter 2 was published in the International Journal of Hypertension in 2012.<sup>157</sup>

Every attempt was made to make the original sample as representative as possible with the initial survey and for the sample of participants interviewed to represent a wide range of demographics (age, sex, ethnicity, employment and deprivation). As a result it elicited rich data to providing new information in an under-researched area. Whilst the findings of this research contribute to existing knowledge about people's experiences in SMBP and adds to a handful of studies acknowledging that understanding patient's reasons for self-monitoring BP are a crucial aspect in the motivation and management of the practice in the UK, it could be the first to conceptualize self-monitoring blood pressure as a clinical practice and the psychological processes involved.

As discussed in Chapter 1, reviewing the existing literature on SMBP showed that there were very few studies investigating the psychological processes and SMBP. It was clear in Chapter 3 (Section 3.2) from reviewing the qualitative literature that a more representative sample of participants with hypertension was required, since previous studies drew participants from convenience samples either from a single general practice or homogenous population in terms of age and sex. <sup>87;189;190</sup> The one UK based study that was found was qualitative commentary at the end of a larger questionnaire which could be argued to not have truly captured participant opinions, views and experiences about self-monitoring due to participants following study protocol rather than independently monitoring. <sup>87</sup> A mixed methods design was therefore chosen to firstly elicit in depth views, secondly to test the generalizability of

the findings drawn from the interview data with a larger more representative group and to formerly test any hypotheses generated from its analysis. The findings and conclusions are summarised in the next section.

## 5.3 Summary of research questions and main findings

The overall research questions for the study were: (1) What are the prevalence and characteristics of SMBP amongst primary care patients with diagnosed hypertension with and without a concurrent diagnosis of diabetes? (2) What motivational factors are associated with self-monitoring blood pressure? i) Does this affect the likelihood of self-monitoring? ii) Can this be explained by psychological theory? (3) Which of the psychological or motivational factors identified best predict on-going monitoring behaviour?

The studies were conducted in a chronological sequence and below, a summary of the findings and conclusions are presented for each of the studies detailing how the findings of one study fed into the next. The findings of the final study are reported reflecting on the findings of all three studies together.

The first research question asked: What is the prevalence and characteristics of SMBP amongst primary care patients with diagnosed hypertension with and without a concurrent diagnosis of diabetes?

Study one found thirty-one per cent of the population under study in this research reported SMBP. Participants showed people self-monitoring were more likely to be younger, in employment and from minority ethnic backgrounds (Asian, Black or Other) than those who did not self-monitor. Those with concurrent diabetes already

self-monitoring blood-glucose were also more likely to monitor their BP. This prevalence was more than that seen in normotensive populations<sup>86</sup> and is consistent with recent GP's estimates of their patients self-monitoring. 181 Whilst prevalence is more than normotensive populations, comparison to other studies showed selfmonitoring was practiced less commonly in primary care than specialist clinics<sup>173</sup> and despite increased marketing of self-monitoring equipment seen over the last decade, the current findings indicate that there is some way to go before it achieves the prominence seen in the studies conducted internationally. 161;162;172 The characteristics of self-monitors found in this study were contrary to expectation and a discussion of possible explanations for this are given within chapter (section 3.5). In context of the overall research, the results of this study needed more investigation to further understand these unexpected characteristics and the practice of SMBP from the perspective of the patient. Discovering why patients engage in SMBP and their motivations was useful for elucidating potential barriers to explain why the UK has much slower uptake of self-monitoring than seen internationally. The absence of any qualitative studies pertinent to this topic and the aims of the study derived from the finding of Study 1 thus provided the rationale for Study 2.

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The second research question asked: What motivational factors are associated with self-monitoring blood pressure? i) Does this affect the likelihood of self-monitoring? ii) Can this be explained by psychological theory?

This qualitative study interviewed sixteen patients and suggested a number of factors to be associated with self-monitoring. These were grouped into health perceptions (self-efficacy, outcome expectations, perceived risk, vulnerability, and personal

control), emotions (health anxiety, worry) and perceived autonomy support (of HCP/GP). Below is a summary of the study findings to show how these factors could possibly affect the likelihood of self-monitoring drawing on theoretical models from health psychology to help explain this behavioural process.

Four main themes emerged from the analysis of the interview data named as; 'Self', 'Living with hypertension', 'GP-Patient transaction' and 'Self-monitoring behaviour'. The hierarchical relationship of each theme and its categories/sub-categories are illustrated in Figure 4. Theme 1 the 'Self' was titled as it was because it appeared that the perceived role of the individual (the self) had in their own health care would have an important influence on whether one self-monitored or not. Whilst this seems fairly obvious, many patients appeared to be internally motivated in looking after their own health irrespective of whether they self-monitored or not. This was illustrated by patients' views and descriptive accounts of their daily regimes of healthy eating and exercise. This suggests that interventions that require the active participation of patients could be well received amongst these patients who display an inner motivation for looking after one's health.

In the second theme 'Living with hypertension' the longevity of hypertension and patients living with it day to day seemed to be of low concern for most patients, but it was the asymptomatic nature of it and knowledge of the consequences of having high BP over a long time that produced a large amount of fear and anxiety in patients. This appeared to also be irrespective of whether patients self-monitored or not. What distinguished those self-monitoring from those who did not was the drive for more control and reassurance exemplified by self-monitors. Patients would describe how

self-monitoring BP made them feel more reassured about their blood pressure, whether it was fluctuating and would also self-monitor to help rationalise the prospects of taking long term medication.

SMBP as explicitly described by the patients, was seen as a method to help reassure patients from the mystery and uncertainty around having high BP and what could be otherwise described as providing a voice for BP. Patients stated that this empowered them through allowing them to take more responsibility over their own BP other than simply adhering to a medication regime. This empowerment was particularly felt by those patients who viewed themselves at more risk from either observations of what may have happened to a close relative, friend or immediate relatives. Whether this reassurance was falsely led was discussed in depth in this chapter. It appeared that patients' perception of engaging in the act itself was preventative for having a heart attack or stroke. A more accurate perception is that it is the actions following self-monitoring that may reduce or lead to better controlled BP (such as improving lifestyle, changing medications) and not the act itself. This aspect of self-monitoring is therefore something important to recognise if this conception reflects current practice.

Such behavioural activity fits with a popular health behaviour framework, The Health Belief Model, drawn from health psychology which is described and discussed in more detail in various sections throughout this thesis, but is mainly described in section 3.5.2 of Chapter 4 The HBM proposes health perceptions such as perceived susceptibility, risk or threat and the presence of perceived benefits of engaging in a preventative action such as reassuring a patient or helping patients to feel more in

control is more likely to increase the likelihood of engaging in that preventative action i.e. self-monitoring. The fear element of the findings relate to a second theoretical model also described within the chapter known as the Protection Motivation Theory (PMT). The importance of fear appeals is central to this theory. The model proposes fear appeals to initiate two independent appraisal processes: threat appraisal and coping appraisal. The belief that self-monitoring can potentially reduce the threat or fear/anxiety (response efficacy) experienced from the patients is what is termed 'protection motivation' (i.e. the intention to perform a recommended behaviour, self-monitoring). Protection motivation is therefore viewed as a positive function of perceptions of severity, vulnerability, response efficacy and self-efficacy. In addressing these models, the factors: perceived risk, vulnerability, health locus of control, self-efficacy and the emotions of anxiety and worry were thus factors proposed to be associated with the health preventative behaviour of self-monitoring.

The third theme 'the GP-Patient transaction' embedded the salient issue about the relationship between the doctor/HCP and the patient. Patients described many of their experiences (general and specifically about self-management) with their doctor and appeared to be quite polarised in how they perceived their relationship with their GP, from passive recipients of health care, to those that were pro-active seekers of information which essentially typified the non-self-monitor from the self-monitor respectively. The perceived relationship with the GP was consequently a factor investigated within the larger questionnaire in Study 3. Patients who self-monitored primarily viewed themselves as active independent patients, that is, in the 'driving seat'. These patients perceived their GP as merely an advisor and thus felt their GP had relatively little influence on the decisions made about their own health care.

Patients described that they would consult their GP when required. Considering self-monitoring, patients appeared to be making their own decisions about treatment, on the basis of one off sporadic readings or measurements. The concern of making such decisions without clinical judgement is discussed in detail in Chapter 3. Whilst there is merit in self-titration with self-monitoring as seen in RCTs and where patients follow a study protocol with adequate training provided, 91;103 there is potentially a very real clinical problem for the treatment of BP in the UK if patients outside the research environment are taking matters into their own hands.

A second major issue within this theme was an evident mismatch between what patients (mainly not self-monitoring) believed were key ingredients for successful self-monitoring and what was practiced in reality illustrated by those who were self-monitoring. The importance of a two-way dyad between patient and doctor/HCP of sharing, feeding back readings or measurements was clearly expressed by patients not self-monitoring which did not match the experiences of how patients currently monitored, which were in fact quite the contrary. All but one of them had never shown their readings to their GP or a HCP with the thought never occurring for some. Further probing of this potential barrier to communication revealed a commonly felt rooted sense of fear and anxiety that if patients told their GP/HCP about their readings, and were subsequently suspected to be higher than usual then there was a perceived risk that they would end up on more medication.

This finding is important for the practice of self-monitoring for two reasons. Firstly, this re-iterates the problem that patients may be falsely reassured by self-monitoring. The patients interviewed in this study explained that monitoring itself was

preventative of their blood pressure becoming uncontrolled regardless of whether they did anything with the results. This brings into question whether patients misunderstand the purposes of self-monitoring. Secondly this is important as it reveals a new potential barrier for self-monitoring to ever become effective in real clinical practice if patients fear communicating these efforts to their doctors and/or HCPs.

The last theme within this study, 'Self-monitoring behaviour', covered a range of observations about current practice. The decision for patients to self-monitor centred around four main 'triggers'. Firstly participants talked about family history of close relatives or loved ones experiencing a Stroke or Heart Attack which were viewed as a stimulus for self-monitoring as it made patients more aware of their own mortality. This was termed 'perceived risk' of having high BP and became one of the factors tested within Study This led onto the second main trigger and their need for reassurance of BP variability and over the silent nature of having high BP and therefore uncertainty about what would happen to them without monitoring BP. Thirdly patients were fearful of taking long term medication and many explained how self-monitoring BP allowed them to see for themselves that the medication they took daily was necessary for controlling their BP. Finally, participants' descriptions of current behaviour of self-monitoring seemed to highlight unusual activity. Selfmonitoring initially appeared to be practiced regularly but this would soon reduce and in most cases only on an occasional basis, or when patients 'felt a bit funny', which itself contradicted their fears of hypertension presenting itself with no symptoms. This indicates a possibility that patients use self-monitoring BP initially to get an idea of their BP and then don't feel the need to measure afterwards.

When asked what patients did if they ever obtained higher than usual or alarming readings, patients often described the behaviour of taking readings again and again until they were happy with the reading they obtained, or until they 'felt' their BP had settled down, so effectively creating their own schedule for self-monitoring. Taking repetitive readings is something more recently endorsed in the new NICE guidance of 2011<sup>4</sup> as there is evidence that BP settles down after multiple readings<sup>256</sup> however for the patient, this behaviour calls into question whether the behaviour 'of getting what they want their reading to be' can be classed as genuinely being involved in the management of their BP. Furthermore it is questionable whether patients fully trust their home monitored readings as a viable method of monitoring BP. This is possibly the consequence of a lack of recommended schedules for self-monitoring and thus points to some important areas for further research and implications for clinical practice which are discussed in more detail later in this chapter.

The way in which each of these concepts were proposed to relate to SMBP were pictorially represented in Figure 7, Page 140.

The final research question asked: Which of the psychological or motivational factors identified best predict on-going monitoring behaviour?

The final study investigated the factors derived from exploratory investigation in the former study to determine quantitatively the relationship of these factors with the practice of self-monitoring behaviour.

Overall, the results found people self-monitoring had significantly higher self-efficacy (SE) scores, higher negative outcome expectancies (NOEs) about self-monitoring and scored lower than those not monitoring on the external health locus of control (HLOC) sub scales (Chance and Other people). Anxiety and worry scores were not significantly different between self-monitors and non-self-monitors and were moderate but education, self-efficacy and doctors' health locus of control (DHLOC) all appeared to independently predict self-monitoring and this was confirmed by the logistic regression. Further analysis of the interactions of the variables revealed age and NOEs affected the predictor model in that they were potentially effect modifiers, that is, their presence in the model modified the main effects of self-efficacy and doctors health locus of control, such that an interaction was found between age and doctors health locus of control, and self-efficacy and negative outcome expectancies.

Below, these main findings are discussed in light of the findings of the previous two studies conducted within this thesis. The discrepancies mentioned and varying parts of the three studies conducted that supports or oppose one other collectively highlights the powerful affect and strength of mixing designs to answer study research questions in the best possible way.

Although collecting demographic characteristics of patients self-monitoring was an integral part of the research questions for Study 1, this was repeated again in Study 3 as additional demographic information was collected (Education) and some demographics (namely employment) may have changed since conducting Study 1.

Of the demographic data, education was an associative factor for self-monitoring. That is, an increasing education was associated with an increased likelihood of self-monitoring. An exploration of the qualitative data collected in Study 2 reveals some interesting links with this finding. Although not considered salient enough to be a theme within Study 2, patients described one of their main reasons for self-monitoring was to feel in more control of BP. Discussed within Chapter 5 this finding is supported by a previously conducted trial investigating the same associative relationship between education and self-monitoring suggesting that the more educated may benefit from educational training as they desire more goals from the practice such as to control BP. The implications of this for GPs or HCPs are discussed in the next section of this chapter.

Briefly mentioned above an interesting aspect of the results was the interaction between age and doctors' health locus of control (DHLOC). The results showed increasing age was associated with decreasing DHLOCS, that is, perceived control of high BP to be less so with the doctor. This suggests a possibility that older patients are becoming more self-empowered. Knowing the constraints of an ageing population in the UK's NHS described in detail in Chapter 1, this indicates promise for SMBP. The related finding that people self-monitoring had significantly lower external subscales overall compared to the non-self-monitors, potentially demonstrates that SMBP is essentially an internally driven practice and thus patients engaging in these participatory practices have considerable internal drive and are measuring their own BP off their own accord.

Given the above, there was the expectation that self-monitoring patients would therefore score higher than non-self-monitors on internal HLOC. In actual fact the present study found lower internal HLOC than the non-monitors. This potentially sheds light on one of the conclusions drawn in the qualitative study that perhaps patients are falsely reassured from the practice. Where patients may theoretically perceive they felt more independent and in more control over their BP, over time a closer inspection of this construct reveals that this practice in actual fact could make no difference at all to the overall perception of internal control.

The above details the broad number of findings spanning across the three studies.

Although the studies were conducted chronologically each one was linked to the next to eventually build up a picture about why patients self-monitor their BP. The next section discusses the implications of each of the findings considering more recent research and changes in clinical guidelines since conducting each study.

# 5.4 Improvements to the research

In summary of the strengths and weaknesses outlined within each chapter, (please see section 2.5.3; page 61, 3.7; page 132, 4.5.4; page 182 and section 5.2; page 186) some suggestions of how the study could be strengthened are given below.

Every effort was made to ensure representation of the sample by choosing practices to represent a range of ethnic diversity and deprivation of the patient population. The sample nevertheless was a convenience sample and some of the limitations of this are discussed in Chapter 1. For the purposes of practicality a postal survey was the best option. Random sampling of practices eligible would have improved the representativeness of the population. The original sample gained from conducting

study 1 were however not generalizable to the population in the UK in terms of ethnicity, with a higher proportion of non-white ethnicities in the sample compared to the UK as a whole. Undertaking a concurrent study with the same survey in another different geographical area of the UK to the West Midlands, that is, of a different demographic profile to the West Midlands, would have not only increased the sample size of the study but also comparisons could have been made between the results of each of the two areas two to determine whether the findings were similar thus helping to determine whether the results are generalizable or not.

For both study 1 and 3, the response rate of 53% was relatively poor when the goal for survey research considered for publication in reputable journals is 60 %.<sup>257</sup> The initial return rate for the survey was 59% (1062/1815), however of these 107 (10%) were returned blank and some were not analysable due to being incomplete. The overall response rate of 53% therefore means the study suffers from a 47% non-response bias. Unfortunately it was not possible to analyse the non-responders as participants were requested to return the survey blank if they wished not to participate. This aspect of the survey design could have been improved by instructing those who wished not to participate to complete the demographic details, and a simple tick box question at the end to ascertain whether patients self-monitored or not, so that at the very least comparisons could have been made to see if there were any difference between the non-responders and responders on those variables. This major limitation of study 1 was however compensated for in Study 3 where an option was put down at the end of the questionnaire to leave their contact phone number. This helped to increase the number of completed responses and clarify any missing data on the questionnaires.

The study was limited to those patients already diagnosed with hypertension. It would have been better to consider additional cohorts of patients who were at differing stages of diagnosis, such as initial stage of BP evaluation, pre-diagnosis, newly diagnosed and long term diagnosed. Sub analyses could then have been conducted to determine whether variables associated with self-monitoring were different between groups and similarly if views about self-monitoring were different to patients on treatment. Despite these limitations, the questionnaire phases has meant self-monitoring and the psychological issues that surround the practice have been explored and investigated in depth and avenues for further research have been opened up.

## 5.5 Implications for further research and practice

#### Bridging the gap with effective patient education and guidance

The thirty one per cent prevalence rate of SMBP found in this research shows self-monitoring is practiced by an appreciable minority in UK primary care and that people diagnosed as hypertensive could be potentially three times more likely to self-monitor than the general population. Evidence of its popularity amongst this patient group supports guidelines that advocate the use of home BP monitoring for the evaluation and management of hypertension. GPs should be aware of this prevalence data that suggests around a third of their patients with hypertension could be monitoring their own BP and of the opportunities that this could bring for daily management especially as recent research shows patients are confident about self-monitoring as an integral component of a self-management plan. 258

The evidence in the present study suggests that unless changes are made to current practice, patients could well be better off going to their clinic for regular BP monitoring as opposed to self-monitoring. The behaviour observed within the qualitative component of this research indicated that currently the practice of SMBP is fairly unregulated and needs better organisation. Self-monitoring was described by patients in this research to essentially give a voice to what was perceived as a silent condition. Self-monitoring was practiced to primarily reassure them from the fear and anxiety attached to a condition that largely presented itself with no symptoms, and to make patients feel more empowered from the lack of control this posed. When anxiety was tested within the questionnaire however, fear and anxiety were not shown to be significantly different from patients currently not self-monitoring, in line with prior research to show no link between anxiety and self-monitoring. It is possible that perhaps patients use self-monitoring as a tool to temporarily reassure them from their fears, which again brings into question the issue about whether patients are being falsely reassured.

Considering the findings of the study, the primary implications begin with a focus for HCPs to prioritise self-monitoring for their patients and educate patients about their home self-monitoring activity. Structured guidance on scheduling for self-monitoring is evidently necessary, for example guidance on how often to monitor, time of day to monitor, potential readings to ignore, whether to monitor before medication and before breakfast could be useful. Furthermore information on what constitutes an alarming or higher than usual result is necessary, what to do if that happens, whom to contact, when to contact the GP/HCP and if possible a plan about the patient's

medication on the basis of the readings that is agreed between the patient and HCP or GP is also important.

Previous studies such as those of McManus and colleagues in the UK <sup>91;103</sup> and others <sup>259</sup> show that interventions that use home BP telemonitoring linked with patient feedback and medication titration may enhance access and improve outcomes for adults with hypertension. More research however needs to be conducted in a UK context along similar lines to those conducted by Bosworth and colleagues in the US <sup>94;101</sup> that have shown tailored interventions incorporating nurse and physician led behavioural management, and medication management based on home monitored BP readings also have significant improvements in BP control. Whilst intervention effects were moderate, with benefits not seen beyond 18 months, for all the studies concerned, they collectively demonstrate the powerful effects home self-monitoring may have in improving the quality of shared decision making. As Bosworth and colleagues point out, such interventions provide the on-going surveillance required for timely interventions for poor BP control all be it more resource intensive than traditional clinic visits. <sup>101</sup>(p.1173)

Considering this from a psychological perspective, undertaking a self-management programme that combines a home BP monitoring programme with shared decision making between patient and clinician on behavioural and medication management creates the opportunity for both parties to respond to new information. This could thereby reverse some of the patients' negative outcome expectations identified from both Study 2 and Study 3 outlined in Chapters 3 and 4 respectively, such as the fear of becoming too obsessed about taking readings all the time, and the fear of being put

on more medication. If a standardised schedule for SMBP was provided patients would understand that BP should be taken at regular standard intervals and not simply on a one off basis as currently observed in the group of patients interviewed in Study 2.

To truly self-empower a patient, self-monitoring must be regulated more as currently the evidence from Study 2, in this research indicates that patients are using self-monitoring as a tool to help them rationalise their own decisions about treatment based on essentially one off readings varying from delaying treatment to not take their meds altogether, illustrated from both Study 2 and a trend in the quantitative study 3 that self-monitors were less adherent to their medication. The current research highlights the powerful and important role of feeding back readings/results to HCPS for reassurance about interpretation, something evidently misunderstood by the patients in this study.

The powerful influence of the doctor or HCP so commonly expressed by the patients interviewed in this research highlights the important role that health care professionals could have in ensuring a smooth implementation of a practice such as self-monitoring. The evidence presented here indicates that patients are self-monitoring relatively unguided.

What is clear is the potential benefit from a more two way partnership, a combination of external HLOC and internal HLOC. Clinicians should utilise the powerful role perceived by patients in helping them to either initiate self-monitoring or continue the practice effectively. One possible strategy to engage both patient and HCP in the

process of self-management is collaborative goal setting and has been explored in older adults with hypertension attempting to manage their own hypertension. <sup>217</sup> In the study, some of the specific goals patients felt they lacked also mimicked the findings of the present research. Participants for example, still appeared to lack the training or necessary skills for effective self-management such as no timeline, some were monitoring but no use of information, no feedback about successful goals or activities and no specific information about implementation intentions or plans. These goals and activities were subsequently shown to impact efficacy for self-management. The authors describe effective self-management should have goal setting as the precursor, followed by monitoring, responding to monitoring feedback (i.e. self-regulation) by deciding if a change in self-care is necessary, planning and implementing the change and evaluating the outcome. Some major trials have already undertaken what is proposed from such a study combining self-monitoring with self-titration and feedback 91;94;102;103 and nurse and/or physician behavioural interventions 101;259 all with promising findings. Such studies, along with more investigating the role of the pharmacist in SMBP, indicate the direction of research in the future.

An important aim it seems for a primary HCP, is in finding ways to raise the self-efficacy for patients to be able to interpret their readings correctly. Clearer lines of communication could allay additional patients' fears that they are bothering the doctor but instead provide a shared understanding of patients' engagement in home monitoring. Furthermore mutually agreed medication plans would prevent patients from experiencing the fear they currently perceive of being put on more medication. Patients would clearly know what to expect if they were to present their GP/HCP with higher than usual readings and is something successfully implemented in the self-

management of hypertension in clinical research  $^{91}$  and one that patients feel competent to do.  $^{258}$ 

In conclusion the evidence presented here shows a distinct gap in knowledge for patients to effectively self-monitor at home. The most recent UK clinical guidelines published by NICE advocate the important role of self-monitoring as an integral part of the self-management of hypertension. The guidelines further state that self-monitoring should be offered as an alternative if ambulatory monitoring is not suitable for a patient. If this is to occur patients must first confidently accept and trust it as a reputable and viable practice which clinical research is only just starting to recognise.

254;258;260-263 Thus, there is some way to go for the equivalent to be achieved in real clinical practice. HCP's must understand the perceived needs and outcomes this practice has for the patient and seek to match those needs through effective communication and patient education.

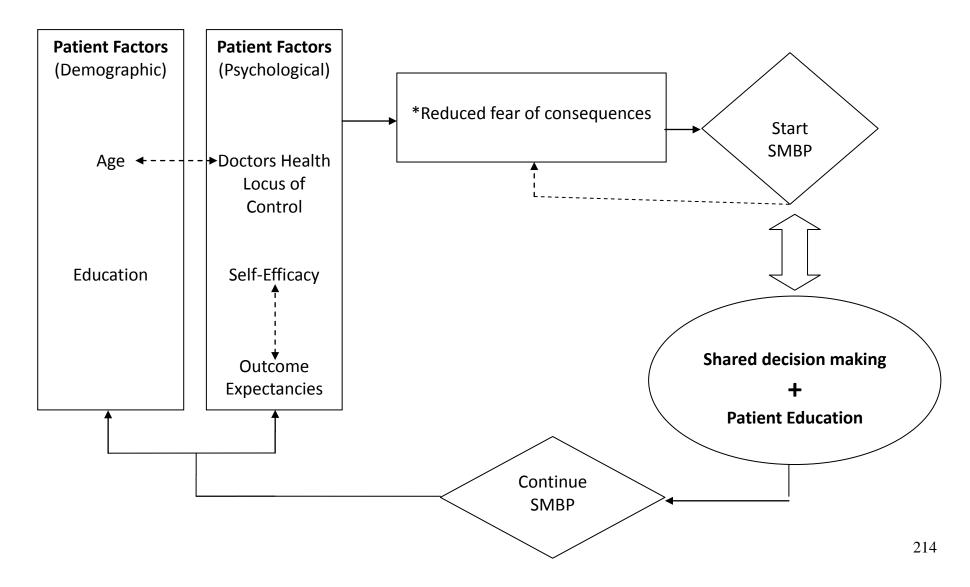
# 5.6 Suggested framework: psychological factors associated with self-monitoring blood pressure / the developing theory?

Figure 9 considers the main findings from the literature review, the survey, interview findings and the questionnaire results and forms what is a tentative theory about patients' experiences of self-monitoring blood pressure, psychological factors of patients' involvement in the practice, the nature of their experiences, and consequences of their experiences. The suggested framework builds on Figure 4 (the hierarchical presentation of the themes, categories and subcategories) and Figure 7, developed on the basis of the qualitative findings. Modifying an originally proposed model based on further quantitative investigation of its elements is thus proposed to

provide a more robust framework or model, that is the one depicted in Figure 9. The framework proposes that patient education should be given to patients, but HCPs should be mindful of patients' age and level of education when assessing suitability. If effective shared decision making and patient education collectively is exercised between patient and HCP, this could have psychological impact, that is, it is possible this could influence or change the individuals' perception of how useful their GP is in helping them to self-monitor at home, and what patients perceive that they gain from the practice. This ultimately could have an influence on how confident they feel to use self-monitoring data to make changes to lifestyle behaviours thereby reducing the fear of (perhaps medication changes) and maintaining self-monitoring in the long term.

Figure 9: Tentative framework of the psychological factors associated with self-monitoring blood pressure

\*fear of consequences is just one factor, other factors exist, but for purposes of model this factor is included



### 5.7 The next stage

It is anticipated that the next stage following this doctoral research could be to firstly, administer the questionnaire to another population of hypertensive males and females to see if the findings would replicate, thus examining the external validity of this research. Though these findings suggest ways in which the identified factors may underlie the likelihood of self-monitoring, prospective study is needed to establish causation and confirm the factors identified in the present study to be associated with SMBP. It would be useful to conduct a longitudinal study (for example involving a self-monitoring educational intervention), similar to that of Bosworth and colleagues <sup>94;100</sup> outlined in Chapter 1, considering newer versions of traditional health behaviour models such as the Health Decision Model and to extend the study to investigate the impact of interventions on psychological outcomes, most notable the psychological constructs identified within this study to see if they were to change in any way.

Future research could also perhaps focus on the development of a tool that helps recognise whether patients are more or less likely to self-monitor. Identifying non-compliant (to self-monitoring BP) individuals is essential to avoid wastage of time of HCPs and resources in advocating the practice. A single instrument capable of identifying individuals unlikely or likely to monitor would be valuable, particularly in light of the present thesis findings that distinct factors are associated with self-monitoring. Clinicians could utilise such a tool to evaluate self-monitoring for a given patient and subsequently facilitate appropriate targeting of other lifestyle behaviours within the self-management package of care.

Before HCPs can begin to educate their patients effectively a particularly important next step for self-monitoring is for the availability of a pragmatic and practical schedule for patients to implement in relation to self-monitoring. Guidelines available within the UK<sup>4</sup> and Europe's equivalent<sup>63</sup> are primarily available for clinicians. Some guidelines, advice and practical information is offered from some patient groups such as the Blood Pressure Association and other forums. Based on the present research findings however, it is reasonable to argue whether the present state of patient guidance on monitoring is enough for patients to continue self-monitoring long term or indeed accessible. There is an important role for HCPs here in addressing such information to patients and is another area of research that needs further study and providing a forum for shared decision making.

What is apparent is the valuable role the GP or HCP potentially has for helping patients interpret self-monitored results, making for more informed and shared decisions about action or treatment. This style of consultation and communication should be continuous, guiding and advising patients about what is available for patients as they continue to monitor in the longer term. Developing effective communication strategies for e.g. goal based interventions appropriate for self-monitoring such as those of Brown et al<sup>217</sup> should also be investigated further with patients and health care professionals and to consider focussing their efforts on those with less education or those of younger age groups.

Finally, it is suggested further work investigates in more detail, the elements proposed in Figure 9. That is, constructs such as self-efficacy, outcome expectancies and perceived health locus of control to self-monitoring BP. Further work needs to look at

the impact of HCPs identifying what patients hope to gain or benefit from self-monitoring. Investigating the effects of shared decision making on areas such as fear appeals and health decision models is also important given its relationship with driving preventative behaviour. All of this, together with appropriate patient education is perhaps a key focus for a future large study.

# 5.8 Concluding remarks

Knowing there is a possible relationship between patients' motivations, thoughts and opinions and self-monitoring is something HCPs could really look to the future with when considering its effective implementation within clinical practice. Hypertension is a chronic condition that requires lifetime management and this influences patient's opinions, views, about treatment and the way their BP is managed. If self-monitoring is to be an integral part of the management of blood pressure, and patients are to use this, it is important to ensure that this is an accepted, trusted way of controlling blood pressure. Patient satisfaction, involvement in medical decisions, confidence in alternative ways to measure pressure as well as acceptance, minimal disturbance to daily life are all important factors to consider.

This was the last chapter of the thesis, a main discussion of the findings of all three studies comparing and contrasting one from another, and reflecting upon previous literature. The chapter began with a summary of the main findings for each study, and follows with an outline of the strengths and original contribution of the research to knowledge. The implications of the research to clinical practice and possible ideas for further research are then detailed. The chapter concludes with a tentative framework

of the psychological factors associated with self-monitoring blood pressure to serve as a developing theory that concludes the findings of all 3 studies, together with an utline of the next stage of research proposed to be undertaken after this thesis.

#### APPENDIX LIST

#### Appendix 1 Search methodology for literature review 1

The literature search aims to identify studies on the practice of self-monitoring blood pressure (SMBP). The aim is to encompass all designs at this stage. Wider search terms are used to find articles that cover some or all of aspects of self-monitoring, such as 'self-management'.

The population of interest is patients with hypertension, whether they have a diagnosis of diabetes or not. Although the main group of interest is those who have self-monitored blood pressure those who are normotensive who do not are also of interest. A general term of 'self-monitoring' is therefore used..

A scoping search was conducted in databases of various disciplines via Ovid, The Science Citation Index Expanded and Social Sciences Citation Index (ISI Web of Science), Ebsco and the Cochrane Collection in 2008 and updated yearly till 2013. Due to differences between disciplines in terms addressing self-monitoring the search in each type of database was tailored to accommodate differences. The databases within each discipline are outlined below. Minor changes made between each database, number of articles initially found, duplicates removed from each and previous searches follow.

ur	

CINAHL Plus, British Nursing Index

#### Medicine

**MEDLINE** 

#### **Psychology**

PsychInfo, PsychArticles

#### **Sociology**

Science Direct, Sociology: CAB Abstracts, EMBASE, Social Policy and Practice

SPORTDiscus, AMED - The Allied and Complementary Medicine Database

#### **Policy**

Cochrane Collaboration Library

Health Technology Assessment Programme (HTA)

HMIC Health Management Information Consortium

#### Other

Authors research, hand searching, contacting authors

## **Table to show article selection**

Database(s)	Terms	Initial articles selected (n=355)	Articles remaining (n=19)
Evaluating each study in terms of sample, design, theoretical framework, intervention delivery and outcome From 43 articles: abstracts reviewed and screened, articles collected: (41 excluded for the following reasons: adolescent or children populations, gestational hypertension, no abstract given, not directly/related to research questions, identified in previous searches)	Key words: self monitor* OR self monitoring used as a topic heading; self-management OR self-care OR managed care AND hypertension OR blood pressure AND psycholog* OR psychological impact OR health behaviour OR motivation OR attitude OR patient perception OR health education OR locus of control OR self-efficacy OR coping behaviour OR patient compliance OR physician behaviour AND survey OR preventative health sciences OR research synthesis OR screening OR meta-analysis OR randomised controlled trials	43	2
Ovid	Key word search self monitoring as a mapped heading AND self management OR AND blood pressure OR hypertension AND Psycholog* OR psychological impact OR motivation OR attitude patient perception OR health education OR locus of control OR	42	15

Embase, Medline - in process, and other non indexed citations, Psychinfo (1987 to 2011)  Limitations: Human, English Language, Abstracts, all adults 19+ 42 articles, duplicates removed = 31 abstracts reviewed and screened, articles collected: (27 excluded for the following reasons: adolescent or children populations, gestational hypertension, no abstract given, not directly/related to research questions) = 3	self-efficacy OR coping behaviour OR patient compliance OR physician behaviour AND survey OR preventative health sciences OR research synthesis OR screening OR treatment compliance OR meta-analysis OR randomised controlled trials			
PsycARTICLES, CINAHL Plus, MEDLINE, SPORTDiscus, AMED - The Allied and Complementary Medicine	Key word search self monitoring blood pressure (no other restrictions)	136	0	
Database Limitations: Human, Adult population, 1980-2011				
After duplicates removed: 136 articles: PsychArticles 104, Medline 32,				

Sportdiscuss 1			
abstracts reviewed and screened, articles collected: all were excluded due to being identified in previous searches-			
Cochrane	Key word: self monitoring blood pressure (no other restrictions)	59	2
59 articles abstracts reviewed and screened, articles collected: (56 excluded for the following reasons: adolescent or children populations, gestational hypertension, no abstract given, not directly/related to research questions)			
PubMed	Keywords home monitor* OR home measure * OR self monitor* OR self management AND blood pressure OR BP or Blood pressure monitoring OR hypertension AND motivation* OR psycholog* OR patient compliance patient perception OR health education OR locus of control OR self-efficacy OR coping behaviour OR patient compliance OR physician behaviour AND survey OR preventative health sciences OR research synthesis OR screening OR treatment compliance OR meta-analysis OR disease detection OR randomised controlled trials	75	0
75 articles, reviewed and screened, articles collected; all excluded as had			
been found in the previous searches			

Reference Number	Authors, Year,	Design	Focus of study	Participants	Theoretical
	Country(ref)				framework and/or psychology factors investigated*
1	Tyson et al. (2003), UK <sup>87</sup>	Observational: cohort survey study	To survey patients response to, requirement for and response to training in SMBP	Primary care patients with hypertension (n=133),30years+	No specific reference to psychological framework but reference to behavioural interventions
2	McManus et al. (2007) <sup>86</sup> , UK	Observational cohort survey study	To determine the use of self-testing	General population (n=2931)	Not specified
3	Thorpe et al. (2008) <sup>90</sup> , US	Cross sectional substudy of V-STITCH (RCT), assessment of baseline data and clinical records	To examine individual and social environment characteristics that were related to SMBP	Primary care patients with hypertension, male veterans n=587	Health Decision Model, Psychosocial factors (Cognitive & Emotional): Hypertension knowledge, perceived seriousness, perceived control, perceived stress, mental health status
4	Bosworth et al (2002) <sup>231</sup> , US	Theoretical, Primary Outcome (PO) BP control	Theoretical design using a literature review and model to explain the psychosocial and cultural antecedents	Hypertensive patients,, African American	Health Belief Model, Autonomous regulation, self- efficacy, Perceived risk of hypertension, motivation, avoidance

5	Bosworth et al (2009) <sup>94</sup> , US	2x2 RCT, UC vs. behavioural intervention (nurse administered) vs. home BP monitoring vs. behavioural intervention + home BP monitoring, 2 year follow up, PO BP control at 6 month intervals over 24 months, setting: 2 university affiliated	of blood pressure control,  To compare two self-management interventions for improving blood pressure control among hypertensive patients.	Hypertensive patients (n=636)	of coping lifestyle, memory, social support, depression and the patient- provider relationship Health decision model, Trans theoretical Model: Perceived risk of hypertension, memory, social support, patient- provider relationship, hypertension knowledge and self- efficacy (not reported on paper)
6	Bosworth et al. (2011) <sup>101</sup> , US	university affiliated clinics  4x4 RCT Hypertension Intervention Nurse Telemedicine Study (HINTS), UC vs. (1 of 3 telephone based intervention groups) nurse administered behavioural management, nurse	To determine which of 3 interventions was most effective in improving BP control	Primary care hypertensive patients (n=593)	Patient centred medical home model of health care; hypertension knowledge, medication memory, stress reduction, patient-HCP relationship

		and physician administered medication management, combination of both, PO BP control at 6 month intervals over 18 months			
7	McManus et al. (2005) <sup>102</sup> , UK	RCT	To see if BP control could be improved using patient held targets and self-monitoring in practice setting, To assess the impact on health behaviours, anxiety, AH drugs, patient preferences and cost	Primary care hypertensive patients, treated but poorly controlled (< 140 / 85 mmhg, (n=441)	Psych framework not specified, change in health behaviours and anxiety.
8	McManus et al. (2010) <sup>91</sup> , UK	RCT, 1:1 ratio, UC vs. self-management (SMBP + self- titration of AH drugs + telemonitoring, PO BP change in mean SBP (baseline, 6 and 12 months)	To see whether self- management in poorly controlled hypertensives resulted in better BP control compared to usual care.	Poorly controlled primary care patients from 8 practices with poor control < 140/85 mmHg, (n=527)	Psych framework not specified, self-efficacy, anxiety
9	McKinstry et al. (2013) <sup>103</sup> , UK	Multi-centre RCT, , UC vs. telemonitoring + supervision of	To see if the intervention leads to clinically important	Patients from 20 primary care practices uncontrolled blood	No specific reference to psych framework or variables

		SMBP + optional patient decision support, PO mean daytime ambulatory measurement	reductions in daytime SBP and DBP (ambulatory)	pressure (mean daytime ambulatory measurement ≥ 135/85 mm Hg but ≤ 210/135 mm Hg).(n=401)	
10	McCahon et al. (2011) <sup>106</sup> , UK	Observational cohort survey (sub study), PO change in anxiety and TRQoL scores between PSM and RC	to evaluate the effect of patient self-management (PSM) of oral anticoagulation on treatment-related quality of life (TRQoL) and anxiety in comparison with routine care (RC) and to explore the effect of level of therapeutic control on TRQoL and anxiety across and within each model of care	RCT trial participants (SMART) (n=517), primary care patients	State anxiety,TRQoL (self-efficacy, general treatment satisfaction, daily hassles, strained social network, psychological distress)
11	Cappucio et al. (2004) <sup>58</sup> , UK	Meta-Analysis (18 RCTs)	To determine the effect of home blood pressure monitoring on blood pressure levels and proportion of people with essential hypertension	People with essential hypertension (n=2714)	No specific reference to psych framework or variables

			achieving targets		
12	Bray et al (2010) <sup>108</sup> , UK	Meta-Analysis with meta-regression(25 RCTs)	to evaluate the systolic and diastolic BP reduction, and achievement of target BP, associated with self-monitoring	Hypertensive patients, Office systolic BP (20 RCTs, 21 comparisons, (n=5,898) and diastolic BP (23 RCTs, 25 comparisons, (n=6,038)	No specific reference to psych framework or variables
13	Agarwal et al. (2011) <sup>109</sup> , US	Systematic review and meta-analysis (37 RCTs)	to quantify both the magnitude and mechanisms of benefit of home BP monitoring on BP reduction	Hypertensive patients (n=9446)	No specific reference to psych framework or variables
14	Ward et al. (2010) <sup>50</sup> , UK	Systematic review(52 RCTs)	To examine the interventions included in systematic reviews of self-monitoring for four clinical problems that increase cardiovascular disease risk	Patients (n=10,388)	No specific reference to psych framework or variables
15	Glynn et al. (2010) <sup>111</sup> , UK	Systematic review (72 RCTs),	To determine the effectiveness of interventions to improve control of blood pressure in	Primary and ambulatory care setting	No specific reference to psych framework or variables

			patients with hypertension		
16	Beyth et al. (2000) <sup>112</sup> , US	RCT	To develop a multicomponent program of management of warfarin therapy and to determine its effect on the frequency of warfarin-related major bleeding in older patients	Patients 65+(n=325)	No specific reference to psych framework or variables
17	Fitzmaurice et al. (2005) <sup>116</sup> , UK	RCT,SMART PO Percentage of time spent within the therapeutic range of international normalised ratio	To determine the clinical effectiveness of self-management compared with routine care in patients on long term oral anticoagulants	Patients receiving warfarin, (n=617)	No specific reference to psych framework or variables
18	Iannoti et al. (2006) <sup>120</sup> , US	Observational cohort study	to develop and evaluate measures of adolescent diabetes management self- efficacy and outcome expectations that reflect developmentally relevant, situation- specific challenges to	adolescents with Type 1 diabetes (10- 19years), (n=168)	Self-efficacy, Outcome Expectancy

			current diabetes		
			regimens		
19	Scisney-Matlock et al. (2001) <sup>121</sup> , US	Secondary analysis of data	to investigate the interaction of age and cognitive representations of hypertension in	Hypertensive adult outpatients (n=224)	Illness perception model, Self-Efficacy, Outcome Expectancy
			predicting blood pressure		

<sup>\*</sup>studies may have had more secondary outcomes, only relevant ones with psychological component are stated.

NB – not all columns of the data extracted from the studies are listed here as the table was extensive, the main parameters for which the studies were search are included

Appendix 2: Details of included qualitative studies

	Authors, Year, Country(ref)	Design	Focus of study	Design/participants	Theoretical framework or psychology factors investigated
1	Rickerby et al. (2003) <sup>189</sup> , UK	Semi-Structured interviews	to investigate the experiences of individuals who have carried out home BP measurement	Hypertensive adults (n=13)	Social learning theory, locus of control
2	Viverais-Dresler et al. (2004) <sup>190</sup> , US	In –depth interviews	to report the qualitative findings on older adults' perceptions of blood pressure measurement and its meaning to their health	Older community dwelling adults (n=51)	
3	Tyson et al <sup>87</sup> . (2003), UK	Sub component of a questionnaire (see Appendix 1), commentary	To gain qualitative commentary on training for self-monitoring	Primary care hypertensive patients	Not specified
4	Jones et al. (2012) <sup>253</sup> , UK	Substudy from TASMINH2, semi structured interviews	To explore health professionals' views and experiences of patient selfmanagement, particularly with respect to future	Trial participants (TASMINH2),	Not specified

			implementation into		
			routine care		
5	McKinstry et al.	Substudy of RCT	To explore the	25 Patients, 11	Not specified
	$(2013)^{103}$ , UK	HITS, semi structured	experiences of	doctors, 9 Doctors,	
		interviews	patients and	from 6 primary care	
			professionals taking	practices (Scotland)	
			part in a randomised		
			controlled trial		
			(RCT), HITS of		
			remote blood pressure		
			(BP) telemonitoring		
			supported by primary		
			care. To identify		
			factors facilitating or		
			hindering the		
			effectiveness of the		
			intervention and those		
			likely to influence its		
			potential translation		
			to routine practice		

Appendix 3: Data Collection (Study 2): Demographic profile information proforma

Please state which box describes your ethnicity

- react class irriter were accornice from currently					
White		Indian	6		
Black – African		Pakistani	7		
Black – Caribbean		Bangladeshi	8		
Black – Other (please specify)		Chinese	9		
Mixed Race (please specify)	5	Asian - Other (please specify)	10		

# Please indicate your occupation

Job Label	Examples		
Professional	Doctor, Accountant, Lawyer		
Managerial and technical	Teacher, Pilot, Farmer		
Skilled manual	Carpenter, Hairdresser, Bus driver		
Skilled non-manual	Secretary, Sales assistant, Clerk		
Partly skilled	Postman, Traffic warden, Barstaff	5	
Unskilled	Cleaner, Labourer, Window cleaner	6	
Unemployed i/	Not currently working	7	
Unwaged		1	
Unemployed ii/	Retired, Carer, Homemaker	8	
Waged		0	

# Please state the following qualifications you have achieved

Higher Degree		First Degree	7
Teaching/ nursing qualifications		BTEC; HNC/ HND	8
BTEC; ONC/ OND		City and Guilds parts I – III	9
A-level or equivalent	4	Trade apprenticeship	1 0
GCSE grade A*-C, O-Level, CSE grade 1	5	CSE below grade 1	1 1
Other (please state)		No formal qualifications	1 2

#### Appendix 4: Data collection (Study 2) Full topic guide and prompts

#### Interview aims / objectives

Main aim: to understand and explain the behaviour of people self-monitoring BP

- To establish their understanding of their condition (hypertension or hypertension and diabetes)
- To determine their awareness of the risks of hypertension
- To determine their illness beliefs about their hypertension (whether they have strong health beliefs about cause, concern, timeline of the condition)
- To establish their understanding of the term SMBP and importance of SMBP to them
- To explore their current experiences of SMBP
- To determine factors that are relevant to motivate the respondent to SMBP
- To determine the health beliefs of those not self-monitoring and establish the different factors that influence the decision not to self-monitor
- To gather respondents thoughts on whether SMBP should be promoted more and best ways to do this

#### **Interview Questions/ Prompt Guide**

#### Intro-

- My name is Sabrina Grant, and I would like to welcome you to this study which aims to look at your experiences of self-monitoring blood pressure.
- Brief them first about the first survey they completed and how this is follow on from that, to talk more in-depth about your experiences of self-monitoring.
- This interview should take no longer than 1 hour and will be conducted in English
- I would also like to remind you that your participation is entirely voluntary and you have the right to withdraw at any time.
- This interview will be recorded for research purposes and parts of it may be reported in the form of direct quotes. Your anonymity is protected and any data collected is kept strictly confidential.
- Do you have any questions?, Obtain signatures from the consent form.

ON all sections PROBE FULLY using example questions detailed below – Use WHY a lot

#### PATIENT ILLNESS EXPERIENCE

• To introduce respondent and highlight any key personal back ground issues that might influence their decision to self-monitor

Age: household circumstances (whether live alone or with others): Marital Status: Ethnicity (show Sheet)

Main daytime activity, whether working or not: details (show sheet)

Highest level of education/ qualifications

What is your understanding of (high BP)/hypertension.

How did you find out you had high blood pressure? -

- when was this?

#### **CONTEXTUAL LIFE WORLD**

What do you believe caused your high blood pressure?

Do you think there is anything that you can do to prevent your high blood pressure? How long do you think high BP will last?

How do you feel about having high blood pressure?)

Tell me, has high blood pressure/ hypertension affected your life/ changed your life? Are you currently prescribed medication for high BP?

Do you feel that this is necessary for controlling your blood pressure?

#### **HOME MONITORING**

In your own words, how would you describe home monitoring?
What do you understand by the term home monitoring?
Why would someone SMBP?
Tell me, do you think self-monitoring of blood pressure is important to you?

#### To explore their past and current experiences of SMBP

Have you ever considered SMBP actively?
What is, or has been your experience of home monitoring?

Do you currently use a home BP monitoring device? Is it your own?

- If yes, which one do you use? How did you find the instructions? Easy, difficult... Are you satisfied with its accuracy?

Did anyone show you how to use them or introduce you to the technique? (E.g. a significant other experienced individual)

Has your Dr/nurse ever checked your BP device to make sure it works properly?

- Do you feel you are adequately informed about what to do with the results/ readings?
- What is your understanding of owning a BP machine

How easy / hard is to self-monitor BP?

How does self-monitoring blood pressure help you?

Does self-monitoring blood pressure affect your everyday work, day to day life? (Negative or positive?)

How confident are you at using the equipment?

How confident are you that your readings are correct?

What do you do with the readings?

Do you find the machine/device easy to use?

Do you find it easy to measure your BP on regular basis (e.g. away from home etc) Are there potential barriers/circumstances under which it will be hard to smbp (e.g, busy)

Do you think that you are doing it right?

For diabetes patients: Do you think your existing diabetes management helps you in any way

- to understand about high blood pressure
- to perform home self monitoring BP

#### If they HAVE NOT BEEN self monitoring:

- To determine the health beliefs of those not self monitoring
- To establish the different factors that influence the decision not to self monitor

Are you happy with your current treatment for your high blood pressure? How do you feel about measuring your own blood pressure?

Do you think you could measure your own blood pressure? Have you ever considered buying a blood pressure monitor?

Are you interested in self monitoring?

Do you think you could gain anything out of self monitoring?

Do you have a primary reason for not using home blood pressure monitoring? Why are you not using a .....

What prevents you from doing home self monitoring?

- do you find SMBP to be problematic
- personal shortcomings or situational conditions?

Is there anything that may have influenced you in deciding not to self monitor?

Besides your (response to previous questions) what else might help you to practice

home self monitoring BP

How have you come to self monitor?

What do you think prompted/ motivated you to begin to self monitor you own blood pressure?

Has SMBP changed your life? If so, how, in what ways?

Was SMBP recommended or own initiative.

- if recommendation who recommended it?

Why do you still currently self monitor?

For all answers, sub-question (e.g., are there any other reasons... etc. until no further reasons are given)

Do you feel SMBP helps you in any way? What do you use home self monitoring for? Do you get satisfaction from monitoring

Do you know what a high/low reading is?

What do you do with your home blood pressure readings?

Do you take your readings to your GP, show them?

At what BP reading would you contact your GP?

What do you do when you have a problem with the readings you obtain from self monitoring your blood pressure?

- Did you gain anything from this?

Have you had to make any changes in your life as a result of your blood pressure readings?

What action did you take?

Have you ever adjusted your medication based on your readings?

People try various things to improve or cope with their condition, are you doing anything else now besides SMBP? E.g.. monitor BG/ yoga, relaxation, exercise, dietary changes

If yes,

Do you think that these are direct changes since you were diagnosed with hypertension/high BP or is this something that you did before? Do you do any other activities to lower your BP?

Do you think this brings anything to your general health?

(For Diabetics)

Do you think that your current self management activities encourage you to think about blood pressure?

- in what way, expand, describe

#### SMBP - Other psychological issues (optional if time)

Are there things that might worry you about self monitoring your own blood pressure? If so what are they?

Do you think that these worries effect your decisions to self monitor? What do you do when you have a problem that you feel may be caused by your high blood pressure?

#### **HCP INTERACTION / FUTURE SUGGESTIONS**

Within the last 6 months have you been to see your GP about your blood pressure? Has your GP ever recommended that you use a BP monitoring device to check your blood pressure?

What does your GP think of you self monitoring at home?

What would give you greater encouragement to self monitor your blood pressure? (advice from professionals etc)

Do you think self monitoring blood pressure should be recommended by HCP's? If yes,

What advice or recommendations would you give to health professionals regarding home SMBP?

Anything else you would like to add?

#### **ENDING**

- reminder how data will be used in form of anonymous extracts of interview
- reassure about confidentiality
- obtain permission to inform GP
- thanks for taking part
- explain follow up element to research and confirm how re-contact for summary overview

#### Appendix 5: Data Analysis (Study 2) Example of a transcript summary and coding process

An example of a transcript summary from a participant is first presented, followed by codes/theme construction of the same transcript summary. This was the first steps of the analysis and was done for all participants.

#### Analysis Summary 4 – Transcript 4 – Interview 4

Female, White, 62, Self Monitors BP, Hypertension, Part Time

Recalls first self monitoring episode – had gestational hypertension in the past, carried it for years without checking – was at airport with a friend of 3 years who had suffered from a Stroke– free BP checking service at the airport - 'yeah they had it set up and it was really frightening it was so high that I have never ever had blood pressure that high don't know if it was the thought of the plane or what but uhm when I come back I went to the doctors and its got sorted' (1.13) – behavioural reaction – sought help

Explains concern over having high BP due to <u>fear</u> of stroke as friend had a Stroke and parents passed away due to hypertension – states Stroke is their biggest fear – and also states doctors know of F/H therefore they are also concerned about her high BP *motivator is fear?* 

When asked about the causes of hypertension – explains not sure at all, weight? Stress? Age 'uhm I'm going to go back to the doctors because I don't think its going right down I don't I think normally its 120/80 70/80 I don't know...but I'm older now so I don't know whether it goes up with age I don't know' (1.86) – *not enough education* 

When asked about the risks – 'other than stroke not sure 'its not like you don't feel like you've got anything (1.49) – the asymptomatic nature of hypertension

When asked about medication is necessary 'yes whether it helps I don't know coz its not going right down to 120/80 I haven't got that' – aware of readings

Timeline – thinks it is probably something that will last – 'probably if I keep taking tablets anyway' (1.72) – *medication control* 

When asked about whether having hypertension makes her emotional in any way – 'not really because I think we have all got a responsibility to look after our own health really haven't we you know what I mean and some people through stubbornness ever go to a doctor or don't even feel ill...some people don't ever get ill do they till they are older' – *control/high internal control/intrinsic* 

Knowledge of readings – knows through monitoring that Bp is still the same about 145/85 'mm coz it tells you on the little booklet I've read it many times you know when that's not good this is you know like that's too high er sort of a basic reading you know what I mean and then mines always just er its not classed as high blood pressure its just underneath that I think that's what it says' (1.305) borderline hypertension – perhaps these are who SMBP is useful for

BP monitoring Device /purchase reasons – Lloyds own one, electric, are one – on offer at chemist – not through recommendation - finds easy to use – uses instructions and guidelines contained in about BP values 'because you don't know ive got high blood pressure and it was on offer at the chemist so I'd thought I would get one' (l. 120)

Frequency – regularly since airport incident 3 years ago – not so frequently now – but now is apprehensive of doing it well you know I leave it there so I remind myself to do it but I don't want to do it because I don't want to know what my blood pressure is because I think that makes me feel worse (1.141) – avoidance behaviour?...I still do it (1.147).

# Monitoring BP reasons / Why?

- 'it was fear because I didn't want a stroke' (1.330)
- Check 'yeah coz its checking aren't ya coz uhm I'm not up at the doctors all the time I've got no ailments or anything like that'(1.156)
- Started monitoring before put on medication wanted to see the effects of medication as well
- not a regular goer to the doctors 'so so I'm not a visitor to the doctor so its only when I go uhm I dunno not serious problems' monitoring at home means that there is no need to go to the doctors for what is perceived as a not so serious issue is this misconceived? actually monitoring at home means that high BP is getting missed as patients strive to self diagnose and not treated appropriately
- check for accuracy of BP yeah coz when I go the doctors its about the same its just being careful really as I said if it went sky high Id go to the doctors again...(1.283)
- 'I think it is (SM useful?) because it puts your mind at rest' (1.421)
- 'and because my friend said you must go the doctors and get medication because I'm not a tablet person all my life I don't pill pop I don't like all the pills people take do you know what I mean pain killers things like that (1.334) strong health beliefs of responsibility for own health initiating self monitoring BP

Helps her understand BP changes / variability 'usually when I've been walking or anything like that and if you take it like afterwards its always a bit higher then when I relax you know' (1.365) — as a result monitors at different times of the day 'yeah coz its not always the same is it when you've just come in from walking or you've eaten something or its all different isn't it' (1.390)

Recalls friend losing her leg from a Stroke from not understanding the importance of taking medication

Gains from self monitoring – 'yes it I'm not so worried although sometimes when I take a reading I think oh and then I calm down a bit more I take it another half hour something like that and it goes down then do you know what I mean' (1.359)

GP Consulting – never taken machine to doctors – but GP requested her to bring it in

to check with their own – GP is happy with her monitoring however has never asked to see her readings etc. 'yeah I think he knows its not going to do me any harm' (1 190)

Hasn't had a BP check up since been on medications for 2 years

SM behaviour - 'well you know I leave it there so I remind myself to do it but I don't want to do it because I don't want to know what my blood pressure is because I think that makes me feel worse' (1.141)... I still do it (1 147)

get the reading they want to – take reading, calm down and if bit high again take it again

When asked about general lifestyle

- does lots of walking

Independent side of monitoring is good – 'yeah because when you go the doctors er that's just one reading isn't it and it could be I don't know you could be just stressed out for the day or you've walked up a hill or something like that you know whereas here you can take it at different times' (1.396)

Recommendations – patients thinks self monitoring BP is really important for people to do as 'no I think that you know if people can afford it they should do it because its one of the things that you can check yourself' (1.509)

Asymptomatic nature of hypertension is a concern and SM can help identify those people

'well its frightening because people are walking around and they don't feel ill and they could just drop down dead'

'I don't know what the world is like now but I didn't know anything about high blood pressure until I had the children and pregnancy's because your never checked nobody checks you for it so if you don't have children you wouldn't be aware that you could be a walking time bomb'

'you don't bother with high temperature because you just know your not right and you can feel but you cant with blood pressure'

General comments – active seeker of info for Hyp due to past experiences of friends and family having hypertension and dying of Strokes.

### **Coding/ Theme Construction**

Analysis Summary 4 – Transcript 4 – Interview 4

Female, White, 62, Self Monitors BP, Hypertension, Part Time

Recalls first self monitoring episode – had gestational hypertension in the past, carried it for years without checking – was at airport with a friend of 3 years who had suffered from a Stroke– free BP checking service at the airport - 'yeah they had it set up and it was really frightening it was so high that I have never ever had blood pressure that high don't know if it was the thought of the plane or what but uhm when I come back I went to the doctors and its got sorted' (1.13) – behavioural reaction to finding out she had high BP – sought help

<u>Fear of Stroke</u> – F/H and Friend - Explains concern over having high BP due to <u>fear</u> of stroke as friend had a Stroke and parents passed away due to hypertension – states Stroke is their biggest fear – and also states doctors know of F/H therefore they are also concerned about her high BP *motivator is fear / high concern* 

When asked about the causes of hypertension – explains not sure at all, weight? Stress? Age 'uhm I'm going to go back to the doctors because I don't think its going right down I don't I think normally its 120/80 70/80 I don't know...but I'm older now so I don't know whether it goes up with age I don't know' (1.86) – *not enough education* 

<u>Asymptomatic nature of hypertension</u> When asked about the risks – 'other than stroke not sure 'its not like you don't feel like you've got anything (1.49) –

<u>Accurate knowledge of readings</u> - When asked about medication is necessary 'yes whether it helps I don't know coz its not going right down to 120/80 I haven't got that' - aware of readings

Timeline – thinks it is probably something that will last – 'probably if I keep taking tablets anyway' (1.72) – *medication control* 

# Strong self control health beliefs – Pro-active

When asked about whether having hypertension makes her emotional in any way – 'not really because I think we have all got a responsibility to look after our own health really haven't we you know what I mean and some people through stubbornness ever go to a doctor or don't even feel ill...some people don't ever get ill do they till they are older' – *control/high internal control/intrinsic motivation?* 

When asked about general lifestyle

- does lots of walking

Accurate knowledge of readings – knows through monitoring that Bp is still the same about 145/85 'mm coz it tells you on the little booklet I've read it many times you know when that's not good this is you know like that's too high er sort of a basic reading you know what I mean and then mines always just er its not classed as high blood pressure its just underneath that I think that's what it says' (1.305) *borderline* 

hypertension – perhaps these are who SMBP is useful for

# BP monitoring Device /purchase reasons

# Desire for a Novelty purchase 'On offer at the time '

Lloyds own one, electric, are one – on offer at chemist – not through recommendation - finds easy to use – uses instructions and guidelines contained in about BP values 'because you don't know ive got high blood pressure and it was on offer at the

chemist so I'd thought I would get one' (1. 120)

## Frequency dropping off

Frequency – regularly since airport incident 3 years ago – not so frequently now – but now is apprehensive of doing it well you know I leave it there so I remind myself to do it but I don't want to do it because I don't want to know what my blood pressure is because I think that makes me feel worse (1.141) – avoidance behaviour?...I still do it (1.147).

# Monitoring BP reasons / Why?

# Fear – of consequences of high BP

- 'it was fear because I didn't want a stroke' (1.330)

### Save time to see GP for lifelong condition

- Check 'yeah coz its checking aren't ya coz uhm I'm not up at the doctors all the time I've got no ailments or anything like that'(1.156)

# Monitoring the effects of medication

- Started monitoring before put on medication wanted to see the effects of medication as well
- not a regular goer to the doctors 'so so I'm not a visitor to the doctor so its only when I go uhm I dunno not serious problems' monitoring at home means that there is no need to go to the doctors for what is perceived as a not so serious issue is this misconceived? actually monitoring at home means that high BP is getting missed as patients strive to self diagnose and not treated appropriately

<u>check for accuracy of BP taken at the doctors</u> – 'yeah coz when I go the doctors its about the same'

#### Re-assurance

- its just being careful really as I said if it went sky high Id go to the doctors again...(1.283)
- 'I think it is (SM useful?) because it puts your mind at rest' (1.421)

# Delay onset of medication

- 'and because my friend said you must go the doctors and get medication because I'm not a tablet person all my life I don't pill pop I don't like all the pills people take do you know what I mean pain killers things like that (1.334) strong health beliefs of responsibility for own health – initiating self monitoring BP

# Improve understanding of BP and BP variability

'usually when I've been walking or anything like that and if you take it like afterwards its always a bit higher then when I relax you know' (1.365) – as a result monitors at different times of the day 'yeah coz its not always the same is it when you've just come in from walking or you've eaten something or its all different isn't it' (1.390)

Recalls important influence from friend losing her leg from a Stroke from not

#### understanding the importance of taking medication

When asked about gains from self monitoring – Get their home monitored reading to be what they want it to be get the reading they want to – take reading, calm down and if bit high again take it again

'yes it I'm not so worried although sometimes when I take a reading I think oh and then I calm down a bit more I take it another half hour something like that and it goes down then do you know what I mean' (1.359)

<u>Unshared recorded readings / GP aware of SM but not followed up</u> – never taken machine to doctors – but GP requested her to bring it in to check with their own – GP is happy with her monitoring however has never asked to see her readings etc. 'yeah I think he knows its not going to do me any harm'  $(1\,190)$ 

Hasn't had a BP check up since been on medications for 2 years

SM behaviour - 'well you know I leave it there so I remind myself to do it but I don't want to do it because I don't want to know what my blood pressure is because I think that makes me feel worse' (1.141)... I still do it (1.147)

#### Doubt with one off BP measure at the GP's

Independent side of monitoring is good – 'yeah because when you go the doctors er that's just one reading isn't it and it could be I don't know you could be just stressed out for the day or you've walked up a hill or something like that you know whereas here you can take it at different times' (1.396) – *extrinsic motivation?* 

## Thoughts about patients SMPB

Beneficial as help individual to take more control of their own condition—patients thinks self monitoring BP is really important for people to do as 'no I think that you know if people can afford it they should do it because its one of the things that you can check yourself' (1.509)

### Prevention of the 'silent killer'

Asymptomatic nature of hypertension is a concern and SM can help identify those people

'well its frightening because people are walking around and they don't feel ill and they could just drop down dead'

'I don't know what the world is like now but I didn't know anything about high blood pressure until I had the children and pregnancy's because your never checked nobody checks you for it so if you don't have children you wouldn't be aware that you could be a <u>walking time bomb'</u>

'you don't bother with high temperature because you just know your not right and you can feel but you can't with blood pressure'

General comments – active seeker of info for Hyp due to past experiences of friends and family having hypertension and dying of Strokes, slightly younger then others interviewed and has higher self control of condition then medication – 'not a pill popper'.

#### Appendix 6: Data Analysis: (Study 2) List of codes and conceptual categories

#### Health Beliefs

First Diagnosis on the back of other health checks

Importance to watch BP due to friends & FH

Stress as a cause

High BP as a side effect from other conditions

Linkage of symptoms to high blood pressure

Concern over increasing age as a cause for high BP

Limited understanding of duration of hypertension

Awareness of length of duration

Hypertension as an accepted living in condition

Low emotional concern for having high BP

Low self control in managing BP

Poor understanding of what BP range / targets should be

# Reasons for monitoring BP

Fear of asymptomatic nature of Hypertension

Fear of Stroke as a consequence of high BP

Monitors blood pressure to check symptoms

Monitors blood pressure to look at blood pressure variability

Monitors blood pressure for reassurance

Monitors blood pressure for personal satisfaction

Low concern for hypertension from belief blood pressure is controlled through self monitoring (although it may not be)

High concern for having high BP only when high reading

Monitors BP to help understand more about high blood pressure

Monitors blood pressure for confirmatory reasons

Personal belief of white coat hypertension

Concern over treating high blood pressure based on one off office BP measurements

Monitors BP from a fear of long term medication

Monitors BP as fear of losing independence

#### Beliefs about medication

Strong medication beliefs for controlling BP

Perception only for more medication to help improve blood pressure control

High medication compliance

Acceptance of long term medication adherence\*

Cause of hypertension due to habituation to medication

# Pro-active lifestyle

Active seeker of information relating to high BP

High self awareness of state of self

Existing active and healthy Lifestyle

Pro-active self control health beliefs

#### Reasons for Purchase

Novelty purchase of blood pressure testing device

# Monitoring BP method issues

Self education about using blood pressure monitoring device and values

Good knowledge of blood pressure values (based on booklet)

High confidence of using the blood pressure machine

Frequency of monitoring drop off

Self check method for accuracy

Happy measuring own blood pressure but not sure if correct value or not

Self education through observation of health care professionals

Monitoring using own frequency schedule

# **GP-Patient** Issues

GP unaware of home monitored readings

Limited GP interaction regarding BP values/ Never shared readings with GP

Distrust in Doctors opinion regarding having high blood pressure

Limited discussion of blood pressure management with GP

Content with GP management of BP

Desire for needed education regarding targets and BP management

GP recommendation of SMBP not necessary

Good knowledge of blood pressure values (based on GP explanation)

#### Self monitoring behaviour

SMBP ers s.f. more autonomous and motivated in their inclination to change behaviour? - is this evidence that behaviour is self determined

Get home monitored reading to be what they want it to be - not to seek help Seeks help if high reading judged from instructions booklet with device Behavioural reaction to monitoring

# SMBP relating to diabetes

Regular glucose monitoring but infrequent BP monitoring

Monitoring blood pressure is not linked to exposure of monitoring blood glucose

Attributes any symptoms experienced to Diabetes not to Hypertension

# Patient opinions of SMBP

Perception of SMBP important for everyone

Perspective that SMBP should be recommended by GP's as routine like breast screening

Perspective of SMBP helpful for encouraging people to manage BP themselves

Perspective of SMBP as a prevention measure for the worry of asymptomatic nature of hypertension being a silent killer

Perspective of SMBP helpful to reduce visits to GP for long term chronic conditions\*\*

Perspective of SMBP as good as helps patients confirm BP variability

# Barriers to SMBP

Concern for 'high worriers' self monitoring BP

Apprehension for monitoring BP due to observed obsession

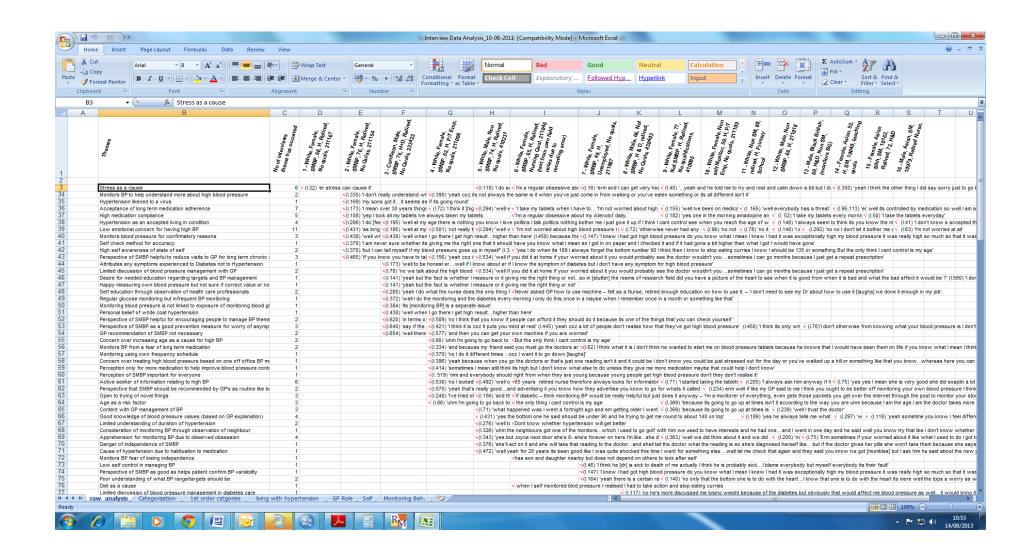
Danger of independence of SMBP

Belief home monitoring BP is useful only for those with past BP problems

Themes that don't fit in anywhere

Hypertension likened to a virus Social support (partner) Consideration of monitoring BP through observation of neighbour

How each theme was illustrated with interview excerpts is how below.(raw analysis)



Appendix 7: Data Analysis (Study 2) Interview feedback sheet

INTERVIEW APPRAISAL FORM	
Before or at the beginning of the interview	Answer: Yes/No & comments
Did the interviewer provide you with information about the	
research project and what they were researching before	
commencing the interview?	
Did the interviewer explain the interview process to you before	
beginning?	
Did the interviewer request your permission to record the	
interview?	
Did you feel comfortable and ready to begin the interview?	
Was there any other information that you would have liked to	
receive before starting the interview?	
Was there anything that the interviewer could have done (or not	
done) to have improved the pre-interview stage?	
The interview questions	
Did the opening questions ease you into the interview? Did they	
help you to feel comfortable or did you feel challenged by them?	
Were the questions clear? Did you need to clarify what was being	
asked?	
Did the interviewer effectively follow up on your answers?	
Did the questions used fully exhaust your knowledge or feelings	
about the subject? Do you feel that you could have given more	
information had more or different questions been asked?	
The interviewer	
Did you feel comfortable with the interviewer? Did the interviewer	
make you feel at ease?	
Did you feel that you could trust the interviewer with the	
information that you supplied?	
Did the interviewer provide you with sufficient time to answer the	
questions?	
Did you feel that the interviewer was listening to your responses	
and giving you their full attention during the interview?	
Was the interviewer in control of the interview?	
Closing the interview	
Was it made clear to you that the interview was finishing?	
Were you allowed the opportunity to add further comments or to	
raise any questions at the end of the interview?	
Any other comments?	
Are there any other comments you would like to make about the	
interview experience as a whole?	
<del>-</del>	

Please can you read the summary below of the interview between	Answer: Yes/No & Comments
yourself and the researcher (SBG) and indicate whether you feel	
this is an accurate representation of what was discussed. Please add	
any comments on the right hand side.	

Please return this form in the stamped addressed envelope to Sabrina Baral-Grant, University of Birmingham, Primary Care Clinical Sciences, B15 2TT. THANK-YOU FOR YOUR PARTICIPATION

#### Appendix 8: Consent forms, information sheets and covering letters (Study 1, 2 & 3)

#### **Study 1: Practice invitation letter**

```
<<Insert date>>
<<insert Dr/Practice Manager Name>>
<<insert address>>
<< >>
<< >>
<< >>
</ >>>
```

Dear << Dr / Practice Manager>>

#### Prevalence of Self-Monitoring – A Postal Survey

We are writing to invite your practice to take part in this RCGP funded study which is investigating the prevalence of "self-monitoring" in patients with hypertension and/or diabetes. Self-monitoring in this case is where someone takes day-to-day readings of blood pressure or blood sugar anywhere outside their usual visits to the practice.

Whilst trials have shown the benefit of tight glycaemic and blood pressure control, this is often hard to reproduce in practice. Self monitoring of blood pressure (SMBP) and glucose (SMBG) are methods which might lead to better blood pressure and glycaemic control however there is very little data in the UK determining the prevalence of self monitoring for blood pressure and blood glucose in the community.

#### What does this study involve?

This study involves a short 10-minute postal questionnaire that will be sent from the practice for patients to complete at their homes. Once patients complete the survey they return it to us at the university in an enclosed PREPAID envelope.

#### What do we have to do if we agree to take part?

- Identify eligible patients through your in-practice clinical system. We can provide on-site assistance to undertake the initial searches.
- These lists will then be verified by a GP(s) to ensure the patients are suitable to send a questionnaire out to their home.
- Invitations to take part and a questionnaire will then be sent from the practice. You will receive appropriate help and we will pay you for your practice staff time.

#### Which patients are eligible to take part?

• The patients that we would like you to identify are those with *Diabetes (type 1 or 2)*, <u>and/or Hypertension</u>.

# Will our patients contact details be kept confidential?

 YES, all patient details will be kept confidentially in accordance with the Data Protection Act 1998.

#### Where will patients return their questionnaires?

• Patients are instructed to return their questionnaires back to us at the university in the PREPAID envelope, therefore you will not receive any of the questionnaires at you practice.

Our researcher will contact you shortly to see whether you would like to take part. If you would like any more information to assist your decision about taking part in this study, please do not hesitate to contact me **Sabrina Baral** on .

Thank you for your time and consideration in helping with this research. Yours sincerely,

#### Ms S Baral

# Study 1: Participant information covering letter, consent was given by participants completing and returning the survey.

<< Practice Address>>

# **Use of Self-Monitoring – A Survey**

We are collaborating with the University of Birmingham, Department of Primary Care General Practice, on a research study about "self-monitoring" undertaken by people with high blood pressure and/or diabetes. Self-monitoring is where someone like yourself takes day-to-day readings of blood pressure or blood sugar anywhere outside your usual visit to the practice.

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. You do not need a stamp.

We want to understand how people self-monitor so that we can improve our health services and advice for people that do perform self-monitoring. This questionnaire will help by telling us how many people have used or would self monitor. Your response is important to us whether or not you have ever self-monitored.

It should only take 10 minutes to complete the questionnaire. All of the questions just ask you to fill the appropriate circles. 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 of Birmingham 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 help further with this study. If you say on the questionnaire that you may be willing to help further and you are selected, a researcher from the University will contact you in the future with more information.

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.	Your
decision to take part will not affect in any way the usual care, treatment or serv	vices
you currently receive. If you have any questions please call Sabrina Baral	
for independent advice please contact Ms Ros Salter,	
Yours sincerely,	
rours sincerery,	
< <gp signature="">&gt;</gp>	
• '	

## What Motivates You to Self Monitor Your Blood Pressure?

# **Interview Study**

You are invited to take part in an interview as part of a research study. Before you decide if you are willing to be interviewed it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with friends and relatives if you wish. Ask us if there is anything that is not clear or if you would like more information.

## What is the purpose of the interview study?

The purpose of the interview study if to find out about patients views and experiences of measuring their own blood pressure.

## Why have I been chosen?

We hope to interview about 20 patients who have previously taken part in a short survey about self monitoring blood pressure. We have identified your name from your previous response to the survey where you gave permission for us to re-contact you.

## What do I have to do?

We are asking you to be interviewed by a researcher in your home or other place that is convenient for you. The interviews will be tape recorded. Any costs you may incur will be re-imbursed.

We will also ask for your feedback about our interpretation of your interview. This will be by post and will take no longer then 30 minutes. This process is entirely voluntary, under a no obligation basis. We expect each interview to last up to an hour and a half (including feedback) and will be conducted in English.

#### Do I have to be interviewed?

We will telephone you to take part in an interview. It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason.

#### Will my taking part in this study be kept confidential?

Your name will not be on the tape and we will remove your name from the

interview transcripts to keep your identity confidential. Direct quotes may be used in publications but these will be numbered and anything which could identify you will be removed. Nothing that you say will be fed back to the doctors and nurses involved in your care unless you give permission for us to do so.

#### **Data Protection Act 1998**

The information you give us in the interviews will only be used for the purpose of the study. The information will be kept securely for a period of 7 years after the study ends and then will be destroyed.

#### **Further Details**

If you decide upon reading this information sheet that you no longer wish to participate or if you would like more information you can telephone Sabrina Grant on

#### **Contact for Further Information**

If you decide to take part, you will be given another of these information sheets to read and keep, together with a copy of the signed consent form.

Thank you for reading this information. If you have any matters which may concern you, or further questions you would like to ask independently you may contact the Patient Advice & Liaison Service (PALS), University Hospital Birmingham NHS Foundation Trust, Oak Tree Lane Offices, Selly Oak Hospital, Oak Tree Lane, Selly Oak, Birmingham, B29 6JF, 0121 627 8820.

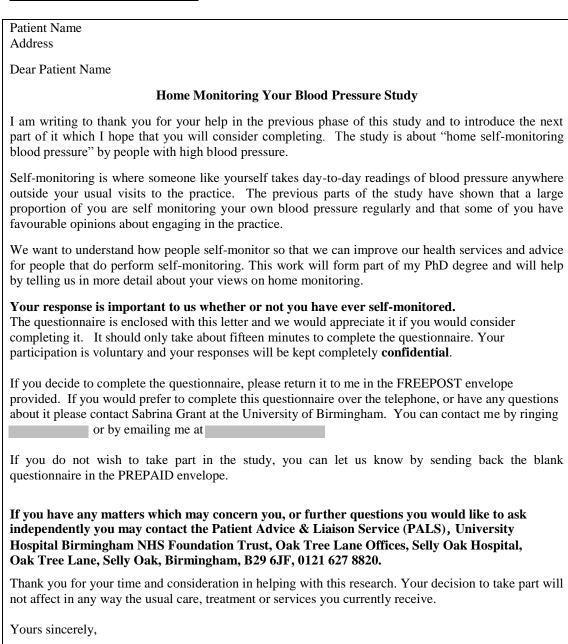
# **Study 2: Patient interview confirmation letter**

Participant Address
Dear Participant
What motivates you to self monitor your blood pressure? Interview study
Thank you for agreeing to be interviewed for this study on <date> at <time>.</time></date>
I enclose an information sheet to explain the purpose of the interview. Your views on self-monitoring of blood pressure are very important for the study. Please contact me <b>Sabrina Baral</b> on if you have any questions about the interview.
I look forward to talking to you.
Yours sincerely
Sabrina Baral

# **Study 2: Patient consent form**

08/06/09: Version 2	
Practice Number:	
Participant ID:	
Participant Consent Form	
What motivates you to self monitor your blood pressure?	
Interview study	
I confirm that I have read and understand the information sheet dated 08/06/09 for the above study and have had the opportunity to ask questions	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected	
I agree to take part in the above study	
I agree to my interview being taped	
I agree to give feedback on the results from my interview	
I agree to my GP being informed of my participation in the study	
I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from University of Birmingham, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to these records.	
Please initial each box and sign below	
Name of participant Date Signature	
Name of person taking consent Date Signature	
When completed, 1 for patient; 1 for researcher file; 1 (original) to be kept in medical notes	

# Study 3: Patient invitation covering letter, consent was given by completing and returning the questionnaire



Sabrina Grant

# Appendix 9 Survey and questionnaire for Study 1 & 3

# Study 1 – Survey questionnaire

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#### **Self-Monitoring Survey**

Your response on whether or not you have ever self-monitored is important to us 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.

,,	, ,							
Example of how to complete this	Yes survey							
Section A – Your Current Health								
Q1. Do you suffer from any	of the following co	onditions?						
Hypertension O								
Diabetes O								
Q2. Are you currently takin	g any medication fo	or the following:						
High blood pressure O								
Raised blood sugar O								
Q3. What medications are y	ou currently taking	<b>j</b> ?						
Blood pressure tablets	0							
Oral diabetes tablets	0							
Insulin	0							
Diet alone	0							
I do not receive treatment	0							
Section B – Monitoring of Y	our Condition(s)							
Q4. Do you take your own i	readings (self moni	tor) for your blood pressure and	d/or blood sugar levels?					
Blood pressure O								
Blood sugar O								
If you have answered 'yes' to Q7:	to any part of Q4 at	oove then please answer Q5 and	I Q6, if not go straight					
Q5. How often do you take	your own readings	for blood pressure and/or bloo	d sugar?					
Blood pressure (BP): Once per day More than once per day	0	Blood sugar (BS): Once per day More than once per day	0					
Once per week	Ö	Once per week	Ö					
Twice a week	ŏ	Twice a week	ŏ					
Once per month	0	Once per month	O					
Not on a regular basis	0	Not on a regular basis	0					
			PTO					

Page 1

Q6. How do you take	your o	own rea	adings	s for bloo	d pressu	re and/or	blood	sug	ar? (s	elf mon	itor)
Electronic blood pressu	re mor	nitor		C	)						
Electronic blood sugars	(glucc	ose) mo	nitor	C	)						
Manual (pump up) blood	d pres	sure m	onitor	C	)						
Blood sugar (glucose) s	trips			C	)						
Urine sugar (glucose) st	ticks			C	)						
I do not self-monitor				C	)						
Q7. If you have never consider doing so?	taken	your o	own re	eadings fo	or blood p	pressure	and/or	blo	od su	gar wou	ild you
Luculd consider monito	-i	u blasa		ours at bas		Yes O	No O				
I would consider monito I would consider monito	_	-	-		ne	0	0				
			Jouga	acrionic		•	•				
Section C – A bit abou	t you	rself									
Q8. Please indicate your a	ge:										
0 <20		0	31-40		0	51-60			0	71-80	
O 21-30		O	41-50	)	0	61-70			O	80+	
Q9. Are you:											
Male O		Femal	le	O							
Q10. Please indicate y	your e	thnic g	group:	:							
White	O	Black o	or Blad	k British	0	Mixed			O		
Asian or Asian British	О	Chines	e		0	Other no	ot state	d	О		
Q11. Please indicate y	your c	urrent	statu	s of emplo	oyment:						
Unemployed	0			nployment	_	Retired			О		
Seeking employment	0	Full tir	ne em	ployment	0						
Q12. May we contact y	ou ag	jain?						Yes	No		
(i) I would be prep	pared t	to comp	olete a	more deta	ailed que	stionnaire		0	0		
(ii) I would be prep								0	0		
(iii) I would rather r (iv) You may review				-	arch num	oses only		0	0		
If you answered yes contact you:	•					•		_	_	details	for us to
Name: Address:		Contac	t Tele	ephone:							
Q13. May we feed bac	k any	inform	nation	to your G	P? Ye	s / No					
(PLEASE NOTE: Me	dical re	ecords, i	informa	ation will on	ly be revie	wed where	replies	state	e Yes v	with a sig	nature)
If Yes then: Name				Date	of Birth		Si	gnat	ure		
Please <u>do not</u> return t Baral at the University of		-		•			•		•		
THANK YOU FOR TAKIN	IG THE	TIME	го со	MPLETE T	HIS SURV	/EΥ.					

v2/23-0	8-2011				п	) Number				
			Home	Monitoring Your Blood P	ressure					
importa	Your response whether or not you have ever self-monitored your own blood pressure at home is important to us.  Your answers will be confidential and will only be seen by the research team.									
				where appropriate please ti		ant boxes	e.g. 🗹			
	n A: About yo									
	A1) Are you currently taking tablets to control high blood pressure?									
,	, yyy to contact ingl. stock procedure.									
,	Yes 🗌		No	Not	sure 🗌					
				gh blood pressure (hyperte ne box e.g. 1990	nsion)?					
(If unkr	nown please put	a tick in	the box	x)						
	A3) What was your last recorded blood pressure reading at the clinic (GP, nurse or hospital)? (please insert e.g. '140/90', or tick the box if not sure, e.g.)									
	mm/hg Not sure									
				lowing conditions? Please osis. If not sure of date please						
Angina		Yes	No	Year of Diagnosis						
Heart A	Attack	Yes	No	Year of Diagnosis						
Stroke		Yes	No	Year of Diagnosis						
Cancer		Yes	No	Year of Diagnosis						
High C	holesterol	Yes	No	Year of Diagnosis						
Diabete	es	Yes	No	Year of Diagnosis						
If you	do not take med	lication	for hig	jh blood pressure tick he	re 🗌 and	skip to Se	ection B, Page 2			
	Please circle the raking behaviour.	respons	e that b	est applies to you and you	r blood pres	sure (BP)	medication-			
Do you	ever forget to tal	ke your	blood p	oressure medication?	Yes	s No	Not sure			
Are you	ı careless at time	es abou	t your b	lood pressure medication?	Yes	No No	Not sure			
When y	ou feel better do	you so	metime	s stop taking your medicine	e? Yes	s No	Not sure			
	mes if you feel w tion, do you stop			take your blood pressure	Yes	No No	Not sure			

Page 1

1

# Section B: Blood Pressure Monitoring

B1) [	Do you currently measure your own blood pressure at home?	
Yes	Go to B3	
No	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	home blood pressure  to Section C, Page 4
B2)	Over the past 6 months how often have you checked your own blood pressure? (please tick one answer)	
	Several times a day	3
	Once a day	
	Twice a week	
	Once per week	
	Once per month	]
	Not on a regular basis	
B3)	What was your last home recorded reading? (please insert e.g. '135	<b>/</b> 85')
	mm/hg Not sure	
B4)	What are your main reasons for using home blood pressure monito (please tick as many answers that apply)	ring?
	My doctor advised or recommended it	
	I am just interested in knowing what my blood pressure is	
	A family member or friend encouraged me to do it	
	I like trying new things	
	I want to confirm I have high blood pressure	
	To help check my symptoms	
	To help me make sure I take my blood pressure medication	
	Influence from the newspapers magazines internet television etc.	

B5)	How do you record your home monitored readings?		
	Stores automatically in the memory of the BP device		
	I write them down on paper or log book		
	I do not store my readings		
B6)	Who would you say was the most influential in encourage your BP at home?	ing you to monitor	
	Myself		
	Doctor, Nurse or other Health Care Professional		
	Partner, Relative or Friend		
D7\ /	Over the part 6 months do you intend to shock your bleed	progrum at home?	
БГ)	Over the next 6 months do you intend to check your blood	pressure at nome?	
,	Yes No		
	Which automatic blood pressure monitor do you use: Plea Omron M2 Basic, HEM-7111-6	ase state (if known,	the brand and model)
		Not sure	
B9)	Where did you get your blood pressure device?		
	Purchased from a pharmacy / chemist		
	Purchased at a department store or supermarket		
	A gift from a family or friend		
	My doctor's surgery		
	An online purchase on the internet		
	Other, please state		
B10)	) Has your doctor ever recommended you to monitor you	ır own BP outside y	our usual GP clinic?
	Yes No		
B11	a) Does your GP know you are monitoring your BP?		
	Yes No		
	b) If yes, do you show/send your GP your home moni	tored readings?	
	Yes No		
	c) Has your doctor/ nurse / other health care provider to make sure it works properly?	ever checked your	blood pressure device
	Yes No		

#### Section C - Your views, thoughts and feelings about self monitoring blood pressure

C1) Below contains a number of statements relating to how you feel about self monitoring your blood pressure at home. Whether you currently self monitor your blood pressure or not please read ALL statements carefully and indicate by circling the appropriate number that reflects how far you agree from '1' to '7'

	I measured my blood pressure at me then it would"	Not at al					Ver	y much
1	Make me worry less about my high blood pressure	1	2	3	4	5	6	7
2	Reduce my visits to the doctor	1	2	3	4	5	6	7
3	Be too much responsibility	1	2	3	4	5	6	7
4	Be too much to think about	1	2	3	4	5	6	7
5	Be too strict of a schedule	1	2	3	4	5	6	7
6	Cost too much	1	2	3	4	5	6	7
7	Keep my high blood pressure in control	1	2	3	4	5	6	7
8	Confirm I have high blood pressure	1	2	3	4	5	6	7
9	Help me to manage my blood pressure	1	2	3	4	5	6	7
10	Pre-occupy my time constantly measuring my blood pressure	1	2	3	4	5	6	7
11	Help me to make lifestyle changes	1	2	3	4	5	6	7
12	Make me anxious if I have to see my doctor about my high blood pressure	1	2	3	4	5	6	7

C2) How confident are you that you can measure your own blood pressure.....? (please circle the appropriate number on the scale 1-7)

		Not at all confident						tremely infident
1	on a regular basis	1	2	3	4	5	6	7
2	when you are busy	1	2	3	4	5	6	7
3	if you feel unwell	1	2	3	4	5	6	7
4	if you feel depressed	1	2	3	4	5	6	7
5	if you feel anxious	1	2	3	4	5	6	7
6	during holiday times	1	2	3	4	5	6	7
7	without guidance from your doctor or nurse	1	2	3	4	5	6	7

C3) This question contains statements that are related to your visits with your health care practitioner. Health care practitioners (doctors, nurses, counsellors, etc) have different styles in dealing with patients and we would like to know very specifically about how you felt about your encounters with the individuals you have met with and discussed your high blood pressure. Your responses will be kept confidential, so none of the practitioners will know about your responses. Please be honest and open.

Please circle the number that best represent your feelings.

		Strongly Disagree			Neutral			Strongly agree
1	I feel that my doctor/nurse has provided me with choices and options about managing my blood pressure.	1	2	3	4	5	6	7
2	I feel my doctor understands how I see things with respect to my blood pressure.	1	2	3	4	5	6	7
3	My doctor conveys confidence in my ability to make changes regarding my blood pressure	1	2	3	4	5	6	7
4	My doctor listens to how I would like to do things regarding my blood pressure	1	2	3	4	5	6	7
5	My doctor/nurse encourages me to ask questions about my blood pressure	1	2	3	4	5	6	7
6	My doctor/nurse tries to understand how I see my blood pressure before suggesting any changes	, 1	2	3	4	5	6	7

C4) How serious do you think having high blood pressure is? (please answer by circling appropriate number on the scale from (1-7)

No	ot at all						Extremely
	1	2	3	4	5	6	7

C5a) How worried are you about your high blood pressure? (please respond by circling the appropriate number on the scale from (1-7)

Not at all						Extremely
1	2	3	4	5	6	7

C5b) How worried are you about developing a blood pressure related condition in your lifetime?

Not at all						Extremely
1	2	3	4	5	6	7

C6) How would you rate your likelihood of developing the following as a result of high blood pressure? (please respond by circling the appropriate number on the scale from (1-7)

#### a) A Stroke

Not at all						Extremely
1	2	3	4	5	6	7

#### b) Heart Disease

Not at all						Extremely
1	2	3	4	5	6	7

C7) Would you say your health is generally: (please respond by circling the appropriate number on the scale from (1-7)

Poor						Excellent
1	2	3	4	5	6	7

C8) A number of statements which people use to describe themselves are given below. Read each statement and then circle the most appropriate number to indicate how you feel right now at this moment. Please give an answer for every statement. There are no right or wrong answers. Do not spend too much time on any one statement but give that seems to describe your present feelings best.

		Not at all	Somewhat	Moderately	Very Much
1.	I feel calm	1	2	3	4
2.	I am tense	1	2	3	4
3.	I feel upset	1	2	3	4
4.	I feel relaxed	1	2	3	4
5.	I feel content	1	2	3	4
6.	I am worried	1	2	3	4

C9) Each item below is a belief statement about your high blood pressure with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6).

Please make sure that you answer every item and that you circle only one number per item. This is a measure of your personal beliefs; there are no right or wrong answers.

		Strongl Disagre	-				Strongly Agree
1	If my high blood pressure worsens, it is my own behaviour which determines how soon I will feel better again.	1	2	3	4	5	6
2	As to my high blood pressure, what will be will be.	1	2	3	4	5	6
3	If I see my doctor regularly, I am less likely to have problems with my high blood pressure.	1	2	3	4	5	6
4	Most things that affect my high blood pressure happen to me by chance.	1	2	3	4	5	6
5	Whenever my high blood pressure worsens, I should consult a medically trained professional.	1	2	3	4	5	6
6	I am directly responsible for my high blood pressure getting better or worse.	1	2	3	4	5	6
7	Other people play a big role in whether my high blood pressure improves, stays the same, or gets worse.	1	2	3	4	5	6
8	Whatever goes wrong with my high blood pressure is my own fault.	1	2	3	4	5	6
9	Luck plays a big part in determining how my high blood pressure improves.	1	2	3	4	5	6
10	In order for my high blood pressure to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
11	Whatever improvement occurs with my high blood pressure is largely a matter of good fortune.	1	2	3	4	5	6
12	The main thing which affects my high blood pressure is what I myself do.	1	2	3	4	5	6
13	I deserve the credit when my high blood pressure improves and the blame when it gets worse.	1	2	3	4	5	6
14	Following doctor's orders to the letter is the best way to keep my high blood pressure from getting any worse.	1	2	3	4	5	6
15	If my high blood pressure worsens, it's a matter of fate.	1	2	3	4	5	6
16	If I am lucky, my high blood pressure will get better.	1	2	3	4	5	6
17	If my high blood pressure takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6
18	The type of help I receive from other people determines how soon my high blood pressure improves.	1	2	3	4	5	6

Section D – Some Background Information							
D1) What is your age?							
D2) What sex are you?	Male Female						
D3) What is your ethnic ori	igin?						
White	Asian or Asian British   Black	or Black British					
Mixed	Other  please specify						
D4) What is the highest lev	vel of school education that you have con	npleted?					
Primary	Secondary	Higher					
None	Other please specify						
D5) What is your current e	mployment status?						
Employed F/T	☐ Employed P/T ☐ Unen	nployed					
Retired	Other (please specify)	••					
D5) What is your current liv	ving status						
Married	Co-Habit Live A	Alone					
Other (please specify)							
Thank you for taking the time to complete this survey – please return your completed questionnaire to me in the FREEPOST envelope provided.							
If we have any reason to co box if you give permission f	ontact you about the completion of the quifor us to contact you.	estions in this survey please tick the					
If you have ticked the box p	If you have ticked the box please provide a contact phone number:						

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#### **Appendix 10: Pilot test instructions**

Dear Colleague,

Thank you for agreeing to complete this questionnaire as part of the pre test process before I send it out to a wider population.

I have listed a couple of points to consider after you have completed it. (I would be grateful if you complete it first before giving feedback so I have an accurate estimate of the time it is taking to complete.

- · Ease of understanding the questions
- Spelling errors
- Visual layout
- · Length of time to complete

(Scribbling points anywhere on the questionnaire is fine).

Thank you again in advance for helping me with my research.

If you could return it to me - Room 221, Clinical Sciences Building or I will come and pick it up from you at some point over the next two weeks.

Best Wishes

Sabrina Grant

#### Appendix 11: Baral-Grant et al 2011, Authors own publication, International Journal of **Hypertension**

Hindawi Publishing Corporation International Journal of Hypertension Volume 2012, Article ID 582068, 4 pages doi:10.1155/2012/582068

#### Research Article

# Self-Monitoring of Blood Pressure in Hypertension: A UK Primary Care Survey

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This study aimed to determine the prevalence of Self-Monitoring Blood Pressure amongst people with hypertension using a cross-sectional survey. Of the 955 who replied (53%), 293 (31%) reported that they self-monitored blood pressure. Nearly 60% (198/331) self-monitored at least monthly. Diabetic patients monitoring their blood glucose were five times more likely than those not monitoring to monitor their blood pressure. Self-monitoring is less common in the UK than internationally, but is practiced by enough people to warrant greater integration into clinical practice.

#### 1. Introduction

Monitoring of blood pressure (BP) is a key aspect of the diagnosis and management of hypertension [1]. Self-monitoring of BP by patients at home is one strategy by which hypertensive patients can participate in their own health care and leads to small but significant reductions in blood pressure [2]. National surveys of adults in the UK show that blood pressure control has gradually improved since the 1990s; however, many patients remain uncontrolled and amongst those at the highest risk, such as those with other comorbid conditions, the situation is worse [3]. Novel interventions are therefore needed if optimum blood pressure control is to be achieved, and self-monitoring appears to be a useful option.

International surveys have found that over 70% of people with hypertension self-monitor blood pressure [4-7]. Available data from the UK suggest much lower uptake in both specialist clinics [8, 9] and the general population [10]. Limited data are available regarding self-monitoring in primary care hypertensive patients.

This study aimed to determine the prevalence of selfmonitoring of BP in primary care hypertensive patients and to highlight the characteristics of those that self-monitor blood pressure.

#### 2. Methods

A questionnaire was sent to 1815 patients with hypertension registered with four general practices in the West Midlands, UK between November 2008 and April 2009, to determine the prevalence and patterns of use of selfmonitoring of blood pressure. Self-monitoring was defined in the questionnaire and information sheet as "taking your own measurements of blood pressure outside your usual visit to your GP practice, usually within the home." Participating practices were chosen to represent a range of ethnic diversity and affluence of the patient population using the Index of Multiple Deprivation, an estimate of the socioeconomic deprivation of the practice population [11] linked to the practice postcode. Participants were adult patients (18+) identified by Read (morbidity) code with or without a Read code of Diabetes (Type 1 and 2). Patients were requested to return the blank questionnaire if they did not want to participate. A second questionnaire was mailed to nonrespondents approximately two weeks

Analyses were undertaken using SPSS (version 15, http://www.spss.com). The results presented are descriptive, reported as percentages and odds ratios with 95% confidence

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