

**PERSPECTIVES ON PRACTICE AND THE INTERPRETATION OF
PERSONALISATION BY HEALTHCARE PROFESSIONALS
WORKING WITHIN THE NHS IN ENGLAND**

by

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ABSTRACT

This study examined perspectives on practice and the interpretation of personalisation by healthcare professionals working within the NHS in England. It revealed that notions of responsiveness to individuals and increased voice and choice were fundamental to the majority interpretation of personalisation, as was the assumption that personalisation improves outcomes for patients. Yet, there was a lack of agreement regarding the expected roles and responsibilities of, and resultant relationship between, patients and professionals, with voice and choice posing alternative approaches to responsiveness. Critically, these interpretations were compatible with the shallow version of personalisation, wherein patients are seen as dependent on professionals and the state. Deeper interpretations of personalisation as co-production and self-organisation were not evident. The study established that time pressures, standardised resources and financial constraints were perceived as major issues confronting responsiveness and there was a common perception that demands were increasing whilst supplies were decreasing. These public service gaps were problematic in themselves but they have also resulted in a number of role conflicts, which were also derivations of the various accountabilities impacting on practice. Nonetheless, participants were inclined to strongly identify with personalisation on the basis that, in their views, it would improve outcomes for patients.

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1. INTRODUCTION

There is an extensive literature that examines the meaning and interpretation of personalisation (Cribb and Owens, 2010; Leadbeater, 2004; Needham, 2011; Parker and Heapy, 2006). Cribb and Owens focused on discourses surrounding personalisation in the United Kingdom (UK), drawing attention to the 'fudge' that occurs between a National Health Service (NHS) tailored to needs and preferences (2010). Leadbeater advocated for 'deep' personalisation, defining five script for organising public services and describing their divergent implications for practice (2004). Needham has described five separate storylines, or themes, that integrate to form a single overarching narrative of personalisation, drawing attention to the framing of personalisation as both an evolution and transformation of practice. Parker and Heapy have explained the differences between personalisation as 'mass customisation' and 'co-production' (2006). Critically, the diversity of interpretations evident across and within these literatures highlights the ambiguity of personalisation. Yet, there has been lacking study on how relevant policy stakeholders experience this ambiguity in practice and, in particular, how they interpret personalisation in context of ambiguity. This is crucial as it is within the gift of audiences to interpret personalisation towards divergent means and ends of practice.

On the other hand, there has been extensive examination of the practice, or implementation, of personalisation across the UK. Particular focus has been given to personalisation in the form of budgetary control, such as direct payments (Clark et al., 2004; Ellis, 2007; Spandler and Vick, 2004), personal budgets (Hamilton et al., 2015, 2016; Whitaker, 2015) and personal health budgets (Forder et al., 2012). However, there have been relatively fewer studies of personalisation in its alternative forms, such as personalised care and support planning and personalised medicine. Particularly excluded from study is the practice of personalisation in a general sense, as part of the

routine practice of professional work, outside of technologies such as budgets and care planning. Moreover, the majority of studies have attended to adult social care and there is a comparatively low volume of research on the personalisation of healthcare. Most problematic is the lacking consideration of interpretation within the majority of studies. Without understanding the interpretation of personalisation to which practice pertains, how are findings to be appropriately interpreted? This study contends that perspectives on and experiences of personalisation are necessarily dependent on its interpretation. Therefore, without explicit consideration of policy interpretation and meaning, findings are lacking in essential context from which they can be appropriately understood.

Based on this analysis, the study was designed to examine the interpretation of personalisation by healthcare professionals working within the NHS in England. The objective was to explore how personalisation is interpreted by professionals in practice and the consequences of these interpretations for practice. In particular, the research was interested in the practical implications of healthcare professional interpretations for the expected roles of patients and professionals and the relationship between NHS patients, professionals and the state. Based on their relative autonomy and discretion, healthcare professionals were theorised to possess significant influence over the practice of personalisation. Therefore, drawing on the inherent ambiguity of personalisation and theorised significance of meaning to practice, the interpretations of healthcare professionals was postulated as essential to personalised practice. Beyond interpretation, the research also intended to examine professional perspectives on personalisation in practice. The intention was to investigate professional experiences of personalisation in order to comprehend the dynamics that influence practice. To structure the study of these objectives, two primary research questions were pursued:

- 1. How do professionals working in the NHS in England interpret personalisation?*
- 2. What are the perspectives of professionals on the practice of personalisation?*

The remainder of this chapter sets out the context of the thesis in greater detail. It will briefly outline the history of personalisation within the public sector of the UK and summarise literatures on the meaning of personalisation (both subjects will be further examined within the second chapter), advocating for an interpretive approach to policy analysis. Following this, the chapter will use the concept of professionalism to theorise the significance of professional autonomy and discretion to the practice of personalisation within the NHS in England, providing a robust justification to the examination of healthcare professional interpretations and perspectives. Finally, professional discretion and autonomy will be posited as conducive to street-level bureaucracy and it will be argued that there are valuable insights to be gained from this theory for this study.

Personalisation and Policy Translation

Adult social care was the first sector within which the personalisation agenda gained traction in the UK public sector, and it was the perceived success of reform in this environment that acted as a catalyst for the translation of personalisation into other sectors. Personalisation within adult social care has been comprised of a broad range of approaches to reform, being labelled with various terms such as person-centred planning (DoH, 2010b) and self-directed support (Scottish Government, 2010). The agenda is frequently related with direct payments (DoH, 1997, 2003) and personal budgets (ADASS, 2009; HM Government, 2007, 2010, 2012; PMSU, 2005), yet personalisation is also broader than the devolution of budgetary control. Nonetheless, although the personalisation of social care is about more than devolved budgets, it was the introduction of direct payments that symbolised a significant policy change, enabling individuals to obtain a budget through which they could purchase and manage their own care and support. Both direct payments and personal budgets should be seen as precursors to personal health budgets in the NHS. It was the *Putting People*

First concordat between central and local government, and the adult social care sector (i.e. professional leadership, providers and the regulator), that widened the agenda by formalising their intention to personalise the system (HM Government, 2007: 5):

By signing this historic protocol, we accept our shared responsibility to create a high quality, personalised system which offers people the highest standards of professional expertise, care, dignity, maximum control and self-determination

Personalisation can be understood as a bottom-up movement, developing from the campaigns and activities of grassroots organisations comprised of disabled people (Glasby and Littlechild, 2009; Needham, 2011). Emerging from these groups was, “a diverse set of stories, rather than a single message”, yet it is possible to identify two essential elements (Needham, 2011: 66-67):

innovation arose from the independent living movement, centred on people with physical disabilities, and from the move to more inclusive approaches for people with learning disabilities, linked to the social model of disability

Policy entrepreneurs also played a role in constructing and spreading ideas of personalised adult social care (Glasby and Littlechild, 2009; Needham, 2011). Defining policy entrepreneurs as, “people who ‘couple’ policy solutions to problems, taking advantage of a ‘window of opportunity’”, Needham has observed that, “they are people who built on the somewhat narrow achievements of the direct payments approach...and called for much broader transformation based around personal budgets” (2011: 72). Prominent policy entrepreneurs included disability campaigners that Leadbeater and Cottam (2007) have described as lead users, who innovated with their own care whilst telling stories to other disabled people about what could be achieved. Further to individuals sharing stories, networks of support provided an additional platform from which entrepreneurs could disseminate their stories. The contribution of *In Control* was particularly

important (Glasby and Littlechild, 2009; Needham, 2011). It has also been argued that the congruence of personalisation with the broader political, economic and social contexts in which it was constructed, including a full generation of political and intellectual critiques of the post-war welfare state, contributed to its enactment.

Over the past two decades, successive governments of different political parties have expressed a determination to implement personalisation within the NHS in England (DoH, 2000, 2004a, 2004b, 2006, 2008b, 2010b; NHS England, 2014a, 2014b, 2015a, 2016b, 2016c, 2016e, 2017). There have been official papers on the implementation of personalisation across the full suite of services, including mental health (DoH, 2004c, 2008a; NHS England, 2016a), secondary care (DoH, 2008b, 2010a), primary care (DoH, 2014; NHS England, 2015b), community care (DoH, 2010b; NHS England, 2015c), and services for children and young people (DoH, 2004b, 2008b; NHS England, 2016d). Three prominent methods have been embraced within the sector, including personalised care and support planning (NHS England, 2016b, 2016c), personal health budgets (NHS England 2014a, 2015a) and personalised medicine (NHS England, 2016e). Personalised care and support planning represents a series of conversations in which patients participate in the exploration of their health and wellbeing with professionals, resulting in a care plan that addresses patients as individuals and accounts for their life as a whole. Personal health budgets build on direct payments and personal budgets within adult social care. They encompass the devolution of budgetary responsibility to the patient, providing them with greater choice and control over how money is spent in order to meet their health and wellbeing needs. Receipt of personal health budgets is one possible outcome of personalised care and support planning, drawing attention to the overlap between technologies. Personalised medicine involves the specific targeting of therapy to the biology, lifestyle and environment of the patient.

It is critical that we are able to recognise how personalisation has been able to move from one sector to another. Needham has suggested that, “presence in multiple sectors is to some extent intrinsic to the personalisation storyline itself, with its emphasis on the need to treat people holistically, rather than in silos” (2011:81). Furthermore, the interviews that Needham conducted with stakeholders within the NHS discovered the perspective that “it was people with long-term conditions who pushed for the introduction of personal health budgets, based on their experiences” (2011: 81). In other words, it is argued disabled people themselves played a role in shifting personalisation from social care into healthcare, centred on positive experiences of individual budgets. The movement of personalisation from social care to other public sectors is also explained by the distinctive policy problems faced in each sector, which leads to the importation of a policy ‘solution’ that is perceived to have worked in another sector (Needham, 2011). For example, within the NHS in England there has been a gradual increasing acknowledgement that growing patient/public expectations, imperatives to improve quality and outcomes and the changing health needs of the population – including the growth of long-term conditions and increased life expectancy – represent a significant threat to the financial viability and sustainability of the NHS (Wanless, 2002). Crucially, the introduction of personalisation reforms can be seen as a measure intended to solve this problem. As Needham has noted, “Expert patient and self-care approaches were felt to contribute to the continued financial viability of the health service” (2011:81).

One way of understanding the movement of policy from one context to another is the theory of policy transfer. Policy transfer is intentional and rational, and includes the movement of policies that proactively use knowledge and learn lessons from policy applied elsewhere (Stone, 2012). Crucially, the assumptions of transfer are questionable in the context of personalisation, especially when an interpretive perspective on

policy analysis is considered (as outlined below). As Needham has noted, “Approaching personalisation with interpretive tools means abandoning the assumption that policies have fixed meanings” (2011: 14). Policy is perceived as socially constructed and contingent on context, lacking the fixed meaning and transferability required by policy transfer. Policy translation acknowledges that the movement of policy across settings is frequently characterised by, “Divergence and hybridisation, adaption and mutation” (Stone, 2012: 487). Crucially, this approach contests the assumption that policy transfers in an unmediated fashion, disputing the rationalist bias inherent with transfer. The advantage of the translation literature is that it, “offers a view of policy that is much less stable and portable than the account offered by the transfer model” (Needham, 2011: 83). Thus, “a sociology of translation works with a much more fluid and dynamic framework” (Lendvai and Stubbs, 2007: 179). This draws attention to the ways in which policies are translated, interpreted, altered and transformed as they migrate from one sector to another and is particularly appropriate to this study given the inherent ambiguity of personalisation (as described within the second chapter). Therefore, it is appropriate to analyse the movement of personalisation to the NHS as an example of translation.

Attention will now be given to identifying some of the transformations that have been undertaken in the name of personalisation across the public sector. Rather than providing a comprehensive account, a snapshot of reforms is outlined in order to provide an overview. These should be treated as further examples of policy translation.

Children and Families: The evolution of personalised children’s services overlapped with adult social care. Yet, disconnection is recognised (Needham, 2011: 33):

Although some of the early work on personal care planning and budgets was done with disabled children, much of the recent focus...has been on adults...it is proceeding in a less focused and more ad hoc way in children’s services

Indeed, personalisation for children and their families is considered to have adopted distinctive language when compared to adult social care terminologies – “Prior to introduction of austerity, the language of personalisation in children’s services had its own distinctive tone detached from its sibling in adult social care” (Whitaker, 2015: 277). It is here, in particular, that reforms now associated with personalisation, but not explicitly acknowledged as such at the time, are most evident. As Whitaker has noted, “it was rarely spoken of as ‘personalisation’ at all; rather devising bespoke support was seen as providing early help, integrated services and coordination for families” (2015: 277). The introduction of budget-holding lead professionals is one example of methods employed to personalise services for children and families (DfES, 2005: 52):

A key element of delivering better integrated services around the needs of the child and family is...the ‘lead professional’, a new innovative concept that will make a substantial contribution to ensuring that children and families who need extra support receive it in a coordinated and integrated way

The idea was that the lead professional would have access to a defined budget for the children and families, with personalisation requiring the professional and family to work together to address their needs and take limited choice and control over the budget.

Despite some clear overlap with personalised adult social care, the central role assigned to the budget-holding lead professional and the somewhat lesser-active role of children and families can be understood as having relatively, “little in common with the language of personalisation adopted in adult’s services at that time with its talk of ‘choice and control’ and...emphasis on active-citizens spending their way to inclusion” (Whitaker, 2015: 278), revealing the diversity of understandings of personalisation that coexisted in parallel sectors at the same time. Attentive to a perceived requirement to improve transparency about entitlement and services through the provision of timely

and detailed information to families with disabled children, *Aiming High for Disabled Children* concentrated on the, “minimum standards on information, transparency, participation, assessment and feedback” (DCSF, 2007: 6). More radically, and consistent with the emphasis on choice and control in adult social care, individual budgets were to be piloted with the intention to, “give families and disabled young people real choice and control to design flexible packages of services which respond to their needs” (DCSF, 2007: 6). It was planned to transfer more responsibility to the families of disabled children and, whereas the budget-holding lead professional reforms, “placed parents within the map of support as relational actors”, viewing families’ role as supporting disabled children, the introduction of the individual budget pilots, “appeared to shift this identity towards one of orchestration and conditionality to meet their child’s needs”, reinterpreting personalisation in child services (Whitaker, 2015: 279).

Housing: Personalisation has also been advocated as a methodology for addressing the housing requirements of individuals with care needs (ADASS, 2010; SCIE, 2009, 2012; TLAP, 2011). Think Local Act Personal (TLAP) signposted that the personalisation of social care would necessitate, “a broad range of choice in the local care and support market, including housing options, and (the personalisation of) the way in which care and support services are delivered wherever people live” (TLAP, 2011: 2). This is based on the notion that, “the places where people live, their homes and neighbourhoods, make up a huge part of people’s experience and are central to well-being and requirements for care and support” (ADASS, 2010: 2). For housing providers, personalisation has been variously defined as (SCIE, 2012: 1):

...tailoring services to individual needs to enable people to live full, independent lives; ensuring housing and the local environment improve people’s ability to live independently; offering people a choice in how and where they live, ensuring that homes and support are...flexible to meeting their needs

Employment: The employment sector has also adopted a personalised approach, particularly in relation to people in receipt of long-term unemployment assistance. The Jobcentre Plus Initiative is one example, focused on the delivery of, “a personalised system where all new claims start with a Work Focused Interview to assist customers back to work and provides support for those who cannot work” (DWP, 2008: 26). The term ‘conditionality’ has been associated with personalisation in employment, first presented in the Gregg Report (2008). This symbolises a move to associate the provision of personalised support with conditions in order to incentivise changes in the behaviour of unemployed people. Emphasis is placed on responsibility and the expectation that support is conditional on acceptance of job opportunities (DWP, 2008: 12):

We will enshrine the responsibility to work at the heart of our approach in a simple deal: more support but greater responsibility. We will help people find and retain work through support more personalised to individual need but, in return, those who are able will be expected to take a job if it is available

Education: Personalisation within the education sector recognises that, “Every child is unique and will benefit most from an approach tailored to their needs” (DCSF, 2007: 59). Tailoring was intentionally designed to, “take into account children’s different rates of progress and their different backgrounds and life experiences” (DCSF, 2007: 59). Through the Pupil Guarantee, the Department for Children, Schools and Families (DCSF) created a national expectation that students should have an individual learning plan and that support must be tailored to students falling behind on literacy and numeracy skills. The intention was to create a school system that was, “more tailored to the needs, talents and aptitudes of each pupil”, and guarantee that there exists a, “system that creates opportunities for every child to find and develop their talents and stretches

them to make the best of themselves” (DCSF, 2009: 25). Critically, the personalisation of education fits within a wider group of services supporting children (DCSF, 2007: 55):

... young people will have opportunities to grow and develop, and their individual needs will be addressed in the round by the complete range of children’s services...making it standard practice across the system. This new approach will look widely at all barriers to learning inside or outside the classroom...and will, working collaboratively with other services, work to overcome them

Ambiguity and Interpretive Policy Analysis

Needham contends that personalisation ought to be understood as a narrative, observing that, “Personalisation is primarily a way of thinking about public services and those who use them, rather than being a worked-out set of policy prescriptions” (2011: 22). The consequent ambiguity ensures that the interpretation of personalisation varies pointedly – “This guide to action makes personalisation highly mutable when translated into specific policy agendas, being applicable to a range of different ways of reforming the welfare state” (Needham, 2011: 22). Narratives can be defined as, “shared stories through which policies are shaped, ordered, placed in historical context and used to effect substantive change” (Needham, 2011: 18). Methods of narrative policy analysis conceive of policy as a story, with policy audiences telling and listening to the stories of others and translating their meanings to fit with their own circumstances. Narratives simplify social complexity, constructing social meaning by providing a clear and intelligible interpretation of a policy problem and policy solution, within which various meanings can be communicated (Fischer, 2003). Needham has concluded that, “it is possible to identify not a simple or one-dimensional definition of personalisation, but a set of related stories about public service reform” (Needham, 2011: 48). These storylines recognise a set of shared problems and solutions, founded on common diagnoses of

what has gone wrong and a range of simplified assumptions for how personalisation realises improvement. They feature a common troupe of participants – “professionals (usually bad) and service users (often heroic)” (Needham, 2011: 48). However, the key contention is that personalisation is inherently ambiguous and subject to interpretation.

Needham has identified five themes, or storylines, of the personalisation narrative – “separate storylines, which weave together to form an overarching narrative of personalisation” (2011: 48). These five stories are as follows (Needham, 2011: 49-56):

1) Personalisation works, transforming people’s lives for the better; 2) Personalisation saves money; 3) Person-centred approaches reflect the way people live their lives; 4) Personalisation is applicable to everyone; 5) People are experts on their own lives

The first theme is based on evidence that personalisation is associated with improved outcomes for service users, particularly within the adult social care sector. The second theme is based on the idea that the assumed improved outcomes of personalisation will not cost more than standard care. The third theme is based on the perception that, “support for people with care needs cannot be contained within service sector boundaries, because that is not how people live their lives” (Needham, 2011: 52). The fourth theme proposes that, “personalisation...is a relevant policy for all users of public services” (Needham, 2011: 53). Finally, the fifth theme promotes the notion that service users are appropriately viewed as experts in their own lives. The themes are described in more detail within the second chapter. The content of these storylines is sufficiently ambiguous to open personalisation up to interpretation and is further supported by the varied temporal framing of personalisation as both continuous and discontinuous. This offers divergent accounts of the past, present and future. Personalisation is viewed as evolutionary and revolutionary; as building on the status quo and transforming practice.

Leadbeater defined personalisation as a script for the organisation of public services (2004). He describes the personalisation script as a product of, “two very different accounts of how the public good is created” (2004: 16). The first story competes that the public good originates from, “the state providing services to society ever more efficiently and effectively” (Leadbeater, 2004: 16), connecting personalisation with state intervention in the lives of citizens. The second story suggests that the actions of individuals collectively generate the public good. Therefore, personalisation is perceived as both participatory and democratic – “the state does not act upon society; it does not provide a service. Instead the state creates a platform or an environment in which people take decisions about their lives in a different way” (Leadbeater, 2004: 16). Whilst these accounts are not necessarily in conflict, both endorse divergent accounts of the roles and responsibilities of patients and professionals in the delivery of NHS services. Described as shallow, the first story presents patients as dependent on the care that is provided to them in a personalised manner. In contrast, the second account presents patients as co-producers and active participants in the management of their own lives, being independent from the state. This is described as deep personalisation and emphasises patient empowerment, with professionals playing a supportive role. In contrast, shallow personalisation requires professionals to apply their knowledge and experience to solve problems for patients. Evidently, the ambiguity of personalisation enables multiple interpretations with divergent practical implications to emerge.

Cribb and Owens have proposed that personalisation is best understood as a continuum between tailoring to the needs and preferences of individuals (2010). They have contended that there is a multiplicity of models between tailoring to individual needs and tailoring to individual preferences – “there is a range of intermediate posi-

tions in which various degrees of negotiation, compromise and customisation are possible” (Cribb and Owens, 2010: 313). This recognises the key distinction in the roles of patients and professionals in tailoring to needs or preferences. Arguably, needs are objective in the sense that they are independent from individual opinions. Hence, they are ontological and unintentional, derived from the reality of existence. As a result of their subject matter expertise – the clinical needs of patients (being objective and independent of perception) – tailoring to needs necessitates professional input. In contrast, preferences are subjective, intentional and epistemological, based on individual perceptions of reality. Whilst the clinically defined needs of patients differ as a result of their dependence on the patient and biological differences that impact needs (variation is objective), patient preferences are subjective and dependent on, “the beliefs of that person and the environment in which the claim is made” (Cribb and Owens, 2010: 312). Deriving from exclusive knowledge of their own preferences, this form of tailoring necessarily requires the input of patients. Tailoring to both needs and preferences involves a combination of both models. Critically, however, the status of the professional is retained with both versions of tailoring since the very concept of tailoring frames the professional as a tailor who ensures that the care provided to patients is tailored to them.

Crucially, the ambiguity of personalisation has permitted audiences to apportion numerous meanings and align the policy with potentially contradictory philosophical arguments that can be associated with democratic and neo-liberal ideologies. For example, personalisation can be interpreted as favourable to the democratic principles of citizenship and social justice (Christensen and Pilling, 2014; Duffy, 2010a, 2010b; Lymbery, 2014). Nonetheless, despite its congruence with democratic ideals, it is also possible to interpret personalisation as consistent with neo-liberal ideals of individualisation, consumerism and responsabilisation (Ferguson, 2007, 2012; Lymbery, 2012, 2014; Scourfield, 2005). Arguably, ambiguity has been indispensable to the dominance

of personalisation, with authors classifying it as an orchestrating label (Cribb and Owens, 2010), epochalist narrative (Cutler et al., 2007) and keyword (Ferguson, 2007). Aligning these labels is the contention that ambiguity serves to construct consensus through the absorption of many meanings, providing a simplified set of stories through which change can be demanded. On the other hand, ambiguity also represents a problem. For example, Cutler et al. contend that the level of abstraction can contribute, “to difficulties in defining the concept and hence developing a coherent approach to policy implementation” (2007: 848). With these epochalist narratives (i.e. personalisation), it is argued that, “problems invariably arise when it comes to the nitty-gritty of practical changes” (Du Gay, 2003: 671). Ambiguity is likely to contribute to difficulty in defining personalisation and developing a consistent approach to practice. Necessarily subject to interpretation, studies of personalisation must adopt an approach that accounts for ambiguity and integrates the social reality that a world of multiple interpretation exists.

There are several problems to studying personalisation from the more ‘rational’ and positivistic perspective that traditional approaches to policy analysis involve. First, “personalisation cannot be defined without reference to the different ways in which policy actors frame it” (Needham, 2011: 5). This draws attention to the challenges of measuring and evaluating personalisation when multiple definitions are coexistent, as explained in the second chapter. As Yanow has observed, “there is no single, correct solution to a policy problem any more than there is a single correct perception of what that problem is” (1996: 3), since multiple interpretations of the problem and solution are available. This is particularly pertinent to the interpretation of personalisation since, “Problems of definition attach to both the problems that personalisation aims to solve and the solution it offers” (Needham, 2011: 5). Second, as explained in the third chapter, since the interpretation and application of personalisation has diverged within and across public sectors, “personalisation cannot be measured in a way that looks across

public services” (Needham, 2011: 5). This is not problematic to this study since it focuses on personalisation within a single sector – the NHS in England. Yet, to extend the argument of Needham, the interpretation and application of personalisation has varied within distinct public sectors, including the NHS in England, and this is problematic to the measurement of personalisation in this context. Finally, it is also contended that personalisation, “cannot easily be evaluated because its definition and goals are too fluid to allow a formal test of whether or not it has worked” (Needham, 2011: 5).

An ‘interpretive turn’ has witnessed various scholars working towards an interpretive approach to policy analysis (Fischer 2003, 2007 Hajer and Wagenaar, 2003; Yanow, 2007), resulting in the reasonably modern development of Interpretive Policy Analysis (IPA). Yanow describes the ‘hallmarks’ of the interpretive approach as, “its focus on meaning as central to individual and collective endeavours” (2007: 111). Public policy is understood to, “take shape through socially interpreted understandings”, and IPA, “calls for the use of interpretive methods to probe the presuppositions that discursively structure social perceptions” (Fischer, 2007: 101). On the individual level, “any analysis of such human endeavours must take into account what is meaningful to actors in those situations” (Yanow, 2007: 111). Attention is given to, “the crucial role of language, rhetorical argument, and stories in framing debate and, in the process, on structuring the deliberative context in which policy is made” (Fischer, 2007: 103). Critically, policy meaning is perceived to be dependent on the context in which it is generated – “Rejecting universalist and context-free research, interpretive approaches instead explore how policy is rooted in particular settings” (Needham, 2011: 13). Thus, the study of meaning prioritises the pursuit of context above generalisation, recognising the agency that policy audiences have in the interpretation of meaning and allowing for variation. IPA also recognises the meaning-making capacity of researchers, noting that their position relative to the situations examined includes them in the meaning-

making process – “the researcher-analyst is herself shaping and being shaped by the people, settings, and/or events that she encounters” (Yanow, 2007: 111).

Approaching personalisation from the perspective of IPA, “means abandoning the assumption that policies have fixed meanings” (Needham, 2011: 14). Instead, policy should be understood as a tool that conveys meaning to policy audiences, with the intention to persuade them that the policy is valuable. In other words, policy represents a mode within, “the world of rhetorical practices designed to persuade” (Yanow, 1996: 60). Nevertheless, “This is not to say that policy cannot have substantive and material impacts” (Needham, 2011: 14). Rather, it is to advise that policy has, “recourse only to symbolic representations to accomplish their purposes, and these purposes can be understood only by interpretations of those representations” (Yanow, 1996: 12). Policies are constructed on normative assumptions that invoke symbols and utilise categories of the problem that needs to be solved and the perceived solution to the problem. Hence, the policy process represents, “a struggle over the symbols we invoke and the categories into which we place different problems and solutions, because ultimately these symbols and categories will determine the action that we take” (Fischer, 2003: 59). The way that policies are framed is important because frames provide a structure to meaning, defining the context within which policy attends to problems and solutions. Crucially, IPA provides a useful, “set of practices that return persons, their meanings, and their very human agency to the center of analytic focus” (Yanow, 2007: 118). It recognises the intricacy of social reality and emphasises the importance of attending to the ‘lived’ experience, or reality, of audiences as they interact with policy. Given the ambiguity of personalisation, attendance to interpretation is particularly pertinent.

Professionalism & Street-Level Bureaucracy

A considerable volume of the NHS workforce can be identified as professionals. There is, “no absolute agreement as to the definition of a profession” (Engel, 1969: 31). However, there is a wide consensus that professionalism comprises autonomy (Engel, 1969; Evetts, 2003; Friedson, 1984; Haug and Sussman, 1969; Timmermans and Oh, 2010). Additional shared characteristics of professionalism have been identified as a service orientation as well as the monopolisation of scientific knowledge. Professional autonomy has been theorised to occur on two levels and both are apparent in the case of healthcare professionals working within the NHS in England. First, autonomy is evident at the individual unit of analysis. Being autonomous, professionals typically experience, “autonomy in decision-making and discretion in work practices” (Evetts, 2003: 407). Second, autonomy has a collective characteristic. This type of autonomy represents, “the control an occupational group possesses over its decisions and activities in the community in which it functions, or its freedom to direct the activities of the profession” (Engel, 1969: 31). As Friedson has observed, this kind of autonomy means that professionals, “are largely free of the hierarchical forms of social control characteristic of other kinds of occupations...they are self-regulating, subject only to informal collegial control” (1984: 1). Given their autonomy, it is hypothesised that healthcare professionals will have significant influence over the practice of personalisation. Moreover, given its ambiguity, professionals will exert influence through interpretation. Therefore, this study was designed to examine the interpretation and practice of personalisation by healthcare professionals working within the NHS in England.

The discretion and autonomy afforded to healthcare professionals aligns with the requirements for categorising them as street-level bureaucrats, who have been delineated as, “Public service workers who interact directly with citizens in the course of their jobs, and who have substantial discretion in the execution of their work” (Lipsky,

2010: 3). Street-level bureaucrats are viewed as policy-makers in the implementation of policy, deriving their influence from, “relatively high degrees of discretion and relative autonomy from organizational authority” (Lipsky, 2010: 13). Thus, they are considered to wield extensive discretion over, “the nature, amount, and quality of benefits and sanctions provided by their agencies” (Lipsky, 2010: 13). However, this is not to argue that street-level bureaucrats exert boundless discretion. Rather, discretionary power is a necessary factor of street-level bureaucracy owing to the complicated nature of their work and dependence on interaction with their clients – “street-level bureaucrats often work in situations too complicated to reduce to programmatic formats” (Lipsky, 2010: 15). Developing from the inevitability of discretion, street-level bureaucrats are also relatively autonomous from managers – “it is the discretionary role of street-level bureaucrats and their position as de facto policy makers that critically affects managers’ dependence upon their subordinates” (Lipsky, 2010: 24). Dependence on street-level bureaucrats also derives from their command of expertise and direct access to clients. As above, there is a clear overlap between street-level bureaucracy and professionalism, given emphasis on discretion and autonomy. Therefore, it is argued that there are valuable insights to be gained from street-level bureaucracy for the study of personalisation. This theory will be used to frame the discussion of findings in chapter seven.

It is advantageous to consider the relative discretion and autonomy of street-level bureaucrats in relation to accountability (Hupe and Hill, 2007; Thomann, 2015). Accountability refers to a relationship where one individual experiences a perceived obligation to justify their behaviour to other individuals – “a social relationship in which an actor feels an obligation to explain and to justify his conduct to some significant other” (Bovens, 1998: 172). For example, a nurse may experience a perceived responsibility to justify care to the family of their patients. Similarly, a teacher may be required to justify teaching practices to the headmaster of the school. In practice, street-level

bureaucrats are held variously accountable as a result of relationships with a variety of relevant individuals (Hupe and Hill, 2007; Thomann, 2015). Accountability is both vertical and horizontal, and can be grouped according to three forms of public accountability (Hupe and Hill, 2007; Meijer and Bovens, 2005). On the horizontal level, street-level bureaucrats are held accountable by service users. Described as participatory accountability, obligation derives from the perceived legitimacy of democratic, deliberative and participatory citizenship. Vertically, street-level bureaucrats are accountable to their management. Defined as public-administrative accountability, this derives from the perceived legitimacy of superordinate authorities over the conduct of the accountable agent. Finally, street-level bureaucrats are held accountable by their professional peers – horizontally by their professional colleagues and vertically by professional organisations. Premised on the perceived legitimacy of professional expertise, this is delineated as professional accountability. Therefore, through their relationships with managers, professionals and patients, professionals may be held variously accountable in practice. This analysis helps to frame autonomy and will support analysis of professional perspectives on practice, highlighting the impact of accountability on practice.

Pertinently, Lipsky has acknowledged the accountability of street-level bureaucrats to superior agents such as managers, recognising the consequence of public-administrative accountability to street-level work – “Street-level bureaucrats have some claims to professional status, but they also have a bureaucratic status that requires compliance with superiors’ directives” (2010: 19). Professional accountability is also referenced – “This is not to say that street-level workers are unconstrained by rules, regulations, and directives from above, or by the norms and practices of their occupational group” (Lipsky, 2010: 14). Participatory accountability is also recognised, supplemented by the observation that the non-voluntary nature of their clients makes them less influential in holding street-level bureaucrats to account. Clients are labelled as

non-voluntary because street-level bureaucracies, “often supply essential services which citizens cannot obtain elsewhere” (Lipsky, 2010: 54). This is explained as a product of the following – “Government agencies may have a monopoly on the service, clients may not be able to afford private services, or they may not have ready access to them” (Lipsky, 2010: 54). Thus, it is contended that street-level bureaucrats are not held accountable as, “non-voluntary clients cannot avoid or withdraw” (Lipsky, 2010: 55-56). In other words, client dependency on the service necessarily controlled by professionals constrains their ability to hold them to account. However, “this does not mean that clients are helpless in the relationship” (Lipsky, 2010: 57). Since they are interdependent, clients can hold street-level bureaucrats to account – “Clients have a stock of resources and thus can impose a variety of low-level costs” (Lipsky, 2010: 57). This proposition is particularly pertinent to personalisation since the increased participation of patients is emphasised. Thus, it is argued that the three forms of accountability have the potential to impact on personalisation in practice.

Goal ambiguity and conflict is typical in street-level bureaucracies – “Street-level bureaucrats characteristically work in jobs with conflicting and ambiguous goals” (Lipsky, 2010: 40). This is because public policy tends to be somewhat idealised and this makes these policies, “difficult to achieve and confusing and complicated to approach” (Lipsky, 2010: 40). Personalisation is a pertinent example of this ambiguity, as described within the second chapter. Lipsky gives the following example – “Is the role of public education to communicate social values, teach basic skills, or meet the needs of employers for a trained work force?” (2010: 40). Role conflicts are understood as typically emerging from the discordancy of individual-centred goals with social engineering and organisation-centred goals. For example, “programs fostering the health and well-being of individual recipients conflicts with the goals of eliminating depend-

ency” (Lipsky, 2010: 42). Furthermore, there is often an inherent conflict between, “individual client treatment versus routinization and mass processing, and response to the needs of individual clients versus efficient agency performances” (Lipsky, 2010: 44-45). An additional source of conflict emerges from the accountability that street-level bureaucrats experience – “conflicts and ambiguity arise from the contradictory expectations that shape the street-level bureaucracy role” (Lipsky, 2010: 45). As outlined, professionals are likely to be held accountable by managers, professional peers and patients, influencing the practice of personalisation. Thus, it is suggested that compatibility between personalisation and accountabilities may shape practice. Perceptions of conflict between accountabilities may also impact attitudes towards practice.

Drawing on roles – “a pattern of behaviours perceived by an employee as behaviours that are expected” (Tubre and Collins, 2000: 156) – the concept of role conflicts is used to understand the dilemmas that street-level bureaucrats face in frontline practice (Thomann, 2015; Tummers et al., 2009, 2012b). It can be defined as follows – “the simultaneous occurrence of two or more role expectations such that compliance with one would make compliance with the other more difficult” (Katz and Kahn, 1978: 204). In context of frontline practice, it has been acknowledged that, “When implementing a policy, professionals face different demands from a range of role providers. Role conflicts arise when professionals perceive these demands to be incompatible” (Tummers et al., 2012b: 1042). Three types of role conflict are charted (Tummers et al., 2012b). First, a policy-professional role conflict occurs when street-level bureaucrats, “perceive the role requirements demanded by the policy contents to be incongruent their professional attitudes, values and behaviour” (Tummers et al., 2012b: 1044). This conflict arises when roles demanded by policy conflict with roles that materialise from professional accountability. Second, a policy-client role conflict occurs when, “street-

level bureaucrats perceive the role behaviour demanded by their clients to be incongruent with the role behaviour demanded by the policy” (Thomann, 2015: 181). This is dependent on the perceived level of conflict between the roles demanded by a policy and roles arising from participatory accountability. Finally, organisational-professional role conflict occurs when professionals perceive roles, “demanded by the organization...to be incongruent with their professional attitudes, values and behaviour” (Tummers et al., 2012b: 1045). This signifies a perceived conflict between the roles that are generated by professional accountabilities and public-administrative accountabilities.

As described within the second chapter, there is a wealth of literature on the interpretation of personalisation, drawing attention to multiple potential meanings and diverse ways in which the welfare state might be reformed. At the shallow end of the spectrum are reforms aligned to traditional practice, emphasising tailored care and framing patients as consumers (Leadbeater, 2004). At the deep end, personalisation invites patients to co-produce services, representing a more transformational reform where the roles of patients and professionals are relatively more changed. As outlined, professionalism is characterised as a mixture of professional autonomy, the monopolisation of scientific knowledge and the presence of service orientation (Engel, 1969; Evetts, 2003; Friedson, 1984; Haug and Sussman, 1969; Timmermans and Oh, 2010), all of which are evident in the case of healthcare professionals working within the NHS in England. There are at least two reasons why professionalism, and the expectations that it generates, may conflict with personalisation – particularly in relation to individual autonomy, which involves discretion over decision-making and working practices. First, the framing of patients as experts (Needham, 2011) contradicts the monopolisation of medical expertise by professionals and may lead to a perceived conflict between the decisions of the patient and the professional. Second, the comparatively greater participation of patients (Leadbeater, 2004; Needham, 2011) has the potential to conflict

with the autonomy and discretion of professionals. Critically, the extent to which professionalism is compatible with personalisation may differ according to the depth of its interpretation, since the extent of change increases as interpretation deepens. Thus, it is proposed that role conflicts may influence the frontline practice of personalisation.

Lipsky observes that street-level bureaucrats are expected to advocate on behalf of their clients – “to use their knowledge, skills, and position to secure for clients the best treatment or position consistent with the constraints of the service” (2010: 72). However, this role is perceived to be, “incompatible with their need to judge and control clients for bureaucratic purposes” (Lipsky, 2010: 73). In other words, there is an inherent contradiction between assessing and serving their clients – “The street-level bureaucrat is almost always a judge as well as a server. Yet it is hard to do both at the same time” (Lipsky, 2010: 74). Linking this to the concept of alienation – “the relationship of workers to their work, from which, we may infer, attitudes arise” (Lipsky, 2010: 75) – it is suggested that street-level bureaucrats are often alienated from their role as advocates as, “the compromises required of advocates reduce the extent to which street-level bureaucrats are able to respond to clients in a fully human way” (Lipsky, 2010: 76). Moreover, Lipsky has argued street-level bureaucrats are often alienated for the following reasons (Lipsky, 2010: 76):

(1) they tend to work only on segments of the product of their work; (2) they do not control the outcome of their work; (3) they do not control the raw materials of their work; and (4) they do not control the pace of their work

Regardless of these factors, it should be observed that the discretion of street-level bureaucrats contradicts alienation as, “some of the shared working conditions of street-level bureaucrats appear to be characteristically unalienated” (Lipsky, 2010: 75). One other alienation that professionals may experience is policy alienation (outlined below)

The literature on change management evidences that the willingness of employees to implement change is a critical factor in the success or failure of change (Higgs and Rowland, 2005; Judson, 1991; Kickert, 2010; Lewin, 1951; Metselaar, 1997; Weick, 2000). The change willingness of public workers can be defined as, “a positive behavioural intention towards the implementation of modification in an organization’s structure, or work and administrative processes, resulting in efforts from the organization members’ side to support or enhance the change” (Metselaar, 1997: 42). In considering the willingness of professionals to implement change organised in the form of public policy, such as personalisation, the concept of policy alienation has been defined (Tummers et al., 2009, 2012a; Tummers, 2011, 2012). This is defined as a, “cognitive state of psychological disconnection from the policy programme being implemented” (Tummers, 2011: 560). Drawing on wider alienation literature (Blauner, 1964; Kalekin-Fishman 2000; Kanungo, 1982; Sarros et al., 2002; Seeman, 1959), policy alienation is said to derive from a combination of powerlessness and meaninglessness, separated into five dimensions (Table 1.1). Critically, the presence of powerlessness is assumed to reduce willingness to implement change – “an increase in employee influence on change decisions...leads to increased commitment and performance, and reduces resistance to change” (Tummers, 2011: 563). Perceptions of meaninglessness are also assumed to influence willingness to implement change – “If employees agree that a change has good and necessary objectives, they should be more supportive of this change” (Tummers, 2011: 565). Thus, it can be expected that perceptions of power and meaning have the capacity to impact the willingness of healthcare professionals to implement personalisation in practice.

Table 1.1: Dimensions of Policy Alienation

Dimension	Definition
Strategic powerlessness	The perceived influence of the professionals on decisions concerning the content of the policy, as it is captured in rules and regulations
Tactical powerlessness	The perceived influence on decisions concerning the way policy will be implemented within their own organization
Operational powerlessness	The perceived influence on the sort, quantity and quality of sanctions and rewards on offer when implementing the policy
Societal meaningfulness	The perceived added value of the policy to socially relevant goals
Client meaningfulness	The perceived added value of the policy for their own clients

Resource constraints are a common problem in street-level bureaucracies. As Lipsky has noted – “There are several ways in which street-level bureaucracies characteristically provide fewer resources than necessary for workers to do their jobs adequately” (2010: 29). First, the caseloads of street-level bureaucrats are relatively high when they are considered alongside their overall responsibilities – “Street-level bureaucrats characteristically have very large case loads relative to their responsibilities...actual numbers are less important than the fact that they typically cannot fulfil their mandated responsibilities with such case loads” (Lipsky, 2010: 29). Second, the time provided is often insufficient to meet the demands placed on them – “high case-loads affect time for decision making...emphasis on housekeeping chores, such as filling out forms or drawing up lesson plans, affects the amount of time available to clients” (Lipsky, 2010: 30). Other resource deficiencies are also observed – “Street-level bureaucrats may also lack personal resources...They may be undertrained or inexperienced” (Lipsky, 2010: 31). The problem of resources is perceived to be intractable – “the resource problem in most cases is not resolvable” (Lipsky, 2010: 37) – because demand tends to increase to equal supply. In a period where NHS finances

are profoundly constrained by austerity measures, having been under pressure for some time following several years of low-level funding growth (Kraindler et al., 2018; NHS England, 2014b, 2017; Robertson et al., 2017), the posited impact of resources on practice is particularly relevant – “Having a structural character, the tensions...are likely to be even more pronounced in the contemporary contexts in which public agencies see themselves confronted with massive budgetary cuts through the adoption of austerity measures” (Hupe and Buffat, 2014: 555-556).

Hupe and Buffat provide the concept of a public service gap as a heuristic device for specifying context, “in terms of differences between what is expected of public servants working at the street level...and what is given to them” (Hupe and Buffat, 2014: 549), extending the analysis of resource constraints to enable the specification of supply and demand at the street-level. With the demand side, constraints represent the action prescriptions that are derived from the multiple accountabilities of street-level bureaucrats – “On the demand side, there are constraints, which take the form of prescribed courses of action” (Hupe and Buffat, 2014: 556). As delineated, via relationships with managers, peers and clients, street-level bureaucrats are held accountable – role expectations deriving from these relationships represent the demand side within the public service gap construct. The action prescriptions deriving from these accountabilities, “have as a joint characteristic that they all are meant to prescribe – if not to determine, at least to indicate – preferred behaviour of others” (Hupe and Buffat, 2014: 556). In terms of supply, the concept of enablements defines, “the range of acts that enable street-level bureaucrats to fulfil their tasks” (Hupe and Buffat, 2014: 556). In practice, enablements are diverse – “Enablements consist of various kinds of action resources such as training, education, professional experience, time, information, staff, and last but not least, the budget itself” (Hupe and Buffat, 2014: 556). Therefore, public service gaps are defined as occurring when the expectations placed on street-level

bureaucrats are insufficient relative to the enablements at their disposal – “A public service gap occurs when what is required of street-level bureaucrats exceeds what is provided to them for the fulfilment of their tasks” (Hupe and Buffat, 2014: 556).

Considering public service gaps at a single point in time, there are two logical situations. First, a public service gap exists, “When the number and/or nature of action prescriptions exceed action resources” (Hupe and Buffat, 2014: 557). Conversely, no public service gap exists when, “the number and/or nature of action resources exceed or equate action prescriptions” (Hupe and Buffat, 2014: 557). When considered temporally, various situations can emerge from changed action prescriptions (APs) and action resources (ARs) over time (Table 1.2). Most pertinent are situations in which a public service gap is evident – doing more with less, doing the same with less and doing more with the same. Discussing resource constraints, Lipsky acknowledges the significance of perception – “salience of solutions to problems of resource inadequacy varies not only with the demands on service and the resources available, but also with the importance to an individual of deriving a satisfactory solution to these problems” (Lipsky, 2010: 33). The public service gap notion also recognises the subjectivity of perception – “The same empirically observable...situation may ‘subjectively’ be perceived and evaluated in different ways by the individual street-level actors” (Hupe and Buffat, 2014: 560). In other words, the influence of public service gaps can vary according to the individual perception of supply and demand. Thus, it is proposed that perception of public service gaps may impact on personalisation in practice.

Table 1.2: Public Service Gaps

ARs	APs Increase	APs Diminish	APs Stabilise
Increase	No significant change	Doing less with more	Doing same with more
Diminish	Doing more with less	No significant change	Doing same with less
Stabilise	Doing more with same	Doing less with same	No significant change

Conclusion

This chapter explained the context of the thesis, advocating an interpretive approach to studying personalisation and highlighting the critical role of healthcare professionals in the interpretation and practice of policy. Professional discretion and autonomy were noted as conducive to street-level bureaucracy and valuable insights for the practice of personalisation were delineated – findings will be discussed through this frame in chapter seven. The second chapter will examine the meaning of personalisation, providing an overview of the existing literature and analysing the consequences for practice, particularly as it relates to the anticipated roles of professionals and patients. A framework covering the various interpretations and meanings of personalisation will be developed. The third chapter will scrutinise the emergence of personalisation in social care and trace its translation from social care to the NHS in England, describing and analysing a range of critical transformations within the NHS in England. The fourth chapter will describe the methodology, research design and research methods used within the study, covering the processes undertaken to recruit participants, conduct interviews and analyse the data. The fifth chapter will describe the findings on professional interpretations of personalisation and the sixth chapter will delineate findings that address professional perspectives on the practice of personalisation. The seventh chapter will discuss findings in relation to the literatures described within in the thesis, with a focus on evaluating the consequences of professional interpretations and perspectives for personalisation in practice. The eighth chapter will summarise key contributions and limitations, highlighting subjects for further study.

2. MEANING OF PERSONALISATION

There is a considerable literature on the meaning of personalisation (Cribb and Owens, 2010; Leadbeater, 2004; Needham, 2011; Parker and Heapy, 2006), drawing attention to its ambiguity and associated diversity in the meaning and interpretation of personalisation. Whilst valuable for building consensus, policy ambiguity is problematic for practice as there are numerous ways in which personalisation can be interpreted and, as a consequence, implemented. For example, whereas some interpretations retain the characteristics and features of contemporary practice, wherein the distribution of power favours the professional and patients are framed as dependent recipients of care, other interpretations are more transformational, requiring the reinvention of traditional roles and relationships between patients, professionals and the state. Based on this analysis, the study that forms the basis of this thesis was designed to examine interpretations of personalisation by healthcare professionals working in the NHS in England. The intention was to understand what personalisation means and the practical implications of professional interpretations for practice – especially as it relates to the expected roles of patients and professionals in the delivery of care. To facilitate this endeavour, this chapter will examine the meaning and interpretation of personalisation, providing an overview of existing literature and analysing the implication of interpretation for practice. A framework summarising potential interpretations of personalisation will be defined, comprised of twelve themes that are grouped three overarching narratives (Table 2.1). This framework will be used to structure the thematic analysis of healthcare professional interpretations of personalisation within the fifth chapter.

The Personalisation Narrative

Needham contends that personalisation should be understood as a narrative, observing that, “Personalisation is primarily a way of thinking about public services and

Table 2.1: Themes of Personalisation

Justifications for Personalisation
Theme 1: Personalisation works, transforming people’s lives for the better
Theme 2: Personalisation saves money
Theme 3: Person-centred approaches reflect the way people live their lives
Theme 4: Personalisation is applicable to everyone
Theme 5: People are experts on their own lives
Perceptions of Personalisation
Theme 6: Personalisation is evolutionary, continuous and consolidating
Theme 7: Personalisation is revolutionary, disruptive and transformational
Nature of Personalisation
Theme 8: Increasing responsiveness by tailoring to needs and/or preferences
Theme 9: Giving users more say, keeping them informed and offering choice
Theme 10: Direct say over money, enabling individuals to make their own decisions
Theme 11: Co-production, active participation, choosing outputs and shaping inputs
Theme 12: The public good emerging collectively through individual decisions

those who use them, rather than being a worked-out set of policy prescriptions” (2011: 22). This notion fits with the analysis that personalisation, “means thinking about public services...in an entirely different way – starting with the person rather than the service” (Carr, 2012: 80). As Needham evaluates, “This guide to action makes personalisation highly mutable when translated into specific policy agendas, being applicable to a range of different ways of reforming the welfare state” (2011: 22), resulting in considerable variation in the types of reforms associated with personalisation within and between sectors – as outlined in the third chapter. Consequently, personalisation is frequently presented as both ambiguous and elastic (Cutler et al., 2007; Duffy, 2010a; Ferguson, 2007; Leadbeater, 2004; Needham, 2011; Parker and Heapy, 2006). In practice, understanding personalisation as a narrative means observing it as, “a set of stories that were being told about public services and the people who use and work in them” (Needham, 2011: 4). Crucially, the application of the term narrative should not degrade or discredit personalisation as either trivial or unsophisticated. Narratives encompass stories that, “suggest unity in the bewildering variety of separate discursive component parts of a problem” (Hajer, 2005: 56). Furthermore, narratives reduce,

“large amounts of factual information intermixed with the normative assumptions and value orientations that assign meaning to them” (Fischer, 2003: 87). Hence, narratives are simplifications of complexity, within which various meanings can be communicated.

Narratives are described as, “shared stories through which policies are shaped, ordered, placed in historical context and used to effect substantive change” (Needham, 2011: 18). Forms of narrative policy analysis conceive of policy as a story, with policy actors telling and listening to the stories of others and translating the meaning of these stories to fit with their own context. Narratives simplify complexity, constructing social meaning through the provision of a clear and intelligible interpretation of a policy problem and solution – “Narratives create and shape social meaning by imposing a coherent interpretation of the whirl of events and actions around us” (Fischer, 2003: 162). Consequently, policy narratives represent, “those stories – scenarios and arguments – that are taken by one or more parties in the controversy as underwriting and stabilizing the assumptions for policy-making in the face of the issue’s uncertainty, complexity and polarization” (Roe, 1994: 3). Narrative policy analysis acknowledges the important role of language within meaning. As Needham explains, “Words carry meaning, shape possibilities, close down alternative courses of action and create coalitions of actors” (2011: 1). Language can be utilised as a tool to make the implications of new policy transparent but can also be used to disguise ambiguity and make policy more difficult to comprehend. Whilst language and particular words selected to convey meaning are not, in themselves, equivalent to action, “it is also problematic to assume that language is just words, with no value to observers of policy analysis” (Needham, 2011: 1). Language has a value and plays a critical role in change – “The choice of one set of words over another set, or the replacement of accepted terms of reference for new vocabularies, can be indicative of important shifts in the policy terrain” (Needham, 2011: 1).

Narratives are an effective device for change for six reasons (Needham, 2011). First, stories are compelling and draw attention to the story. As Ospina and Dodge have explained, “Stories are compelling. When someone tells us a story about his or her experience, we become alert, tuned in, curious” (2005: 143). However, some stories are more captivating than others; novelty and defamiliarisation can be compelling (Barry and Elmes, 1997) and it is crucial that narratives are articulate, consistent and told by a dependable narrator (Fischer, 2009). Second, narratives provide their audiences with a temporal ordering and they also, “help to explain the links between the past, present and future, offering a sequence of events that leads to the transformation” (Needham, 2011: 19). This reasoning enables the audience to make sense of the narrative and offers them a convincing justification for change (Peck and 6, 2006: 18):

The sense-making process must encompass stories about the past – because it is important to define what is believed to be causing a problem, and often who is to blame – and also stories about the future, in order to define aspirations, fears, opportunities and threats...standards or models of behaviour

Third, narratives are elicited an emotional and value-based response from the policy audience through the delivery of emotive content. As Fischer has explained, “Narrative storytelling, unlike the giving of rational reasons, is designed not just to persuade people intellectually but emotionally as well” (2009: 191). Moreover, narratives use emotive content to establish a more persuasive moral imperative for change (Morrell, 2006).

Fourth, the telling of stories is an inherently social activity. Therefore, through the storytelling process, shared meanings are constructed. As Fischer has observed, “All of the elements of a story – plot, structure, meaning, resolution, and so forth – are created by people conversing and arguing with others” (2009: 194). The development

of shared stories is essential as it stimulates desired action – “Shared meanings motivate people to action and meld individual striving into collective action” (Stone, 2005: 11). Fifth, “narratives simplify complex and contested terrains in order to make action possible” (Needham, 2011: 20). A narrative provides the audience, “a set of symbolic references that suggest a common understanding” (Hajer, 2005: 62). This is the case even when parts of a narrative and the arguments comprising a narrative are contradictory, with narratives purposively drawing on ambiguity to accommodate multiple policy goals and, ultimately, leave the narrative open to a multitude of interpretations – “Ambiguity, in fact, may at times be used strategically in the political and policy worlds to accommodate multiple and conflicting values and meanings” (Yanow, 1996: 129). Finally, narratives are purposive in that they strive to promote certain preferred actions as well as discourage other, undesirable actions. Narratives may not explicitly reference arguments and yet they are also not passive and without real consequences – “it is a way of seeing events and of legitimising certain kinds of responses” (Fischer, 2003: 163). As Hajer has enlightened, “Story-lines are devices through which actors are positioned and through which specific ideas of ‘blame’ and ‘responsibility’ and of ‘urgency’ and ‘responsible behaviour’ are attributed” (2005: 64-64). Accordingly, narratives purposively influence the perceived appropriateness of actions taken to solve a problem.

This section will now describe the interpretation of the personalisation narrative presented by Needham (2011). Based on an examination of relevant documents and interview data, Needham has usefully shown that, “it is possible to identify not a simple or one-dimensional definition of personalisation, but a set of related stories about public service reform” (2011: 48). These five stories commonly discern similar policy problems and policy solutions, “based on ostensibly common (and common-sense) diagnoses about what is wrong with existing policy and a set of self-evident assumptions

about how services can be improved” (Needham, 2011: 48). These stories are presented as featuring a commonly perceived troupe of participants – “professionals (usually bad) and service users (often heroic)” (Needham, 2011: 48) – in addition to simplified assumptions about how personalisation might realise the desired outcomes. Whilst recognising the imperfect nature of categories, Needham has identified five themes of the personalisation narrative (Table 2.2) and has recommended that, “These can be understood as separate storylines, which weave together to form an overarching narrative of personalisation” (Needham, 2011: 48).

Table 2.2: Justifications for Personalisation

Justifications for Personalisation
Theme 1: <i>Personalisation works, transforming people’s lives for the better</i>
This theme suggests that personalisation improves outcomes for service users and is supported by formal and informal evidence and common sense assumptions.
Theme 2: <i>Personalisation saves money</i>
This theme advises that personalisation improves the cost-effectiveness of care by reducing costs or providing better value-for-money through improved outcomes.
Theme 3: <i>Person-centred approaches reflect the way people live their lives</i>
This theme acknowledges people as individuals with a diversity of requirements that are more appropriately considered in a holistic manner through person-centred care.
Theme 4: <i>Personalisation is applicable to everyone</i>
This theme contends that personalisation applies to all individuals and should not be applied in an exclusive or restrictive manner, solely for particular cohorts of patient.
Theme 5: <i>People are experts on their own lives</i>
This theme characterises patients as experts in their own lives and advises that they are capable of participating, challenging the orthodoxy of the professional gift model.

The first theme is based on the formal evidence that personalisation is associated with improved outcomes for service users, particularly in the adult social care sector (Glasby and Littlechild, 2009; Glendinning et al. 2008; Tyson et al., 2010a). For example, the evaluation of individual budget pilots found that participants generally welcomed the pilot and believed that individual budgets had given them greater control over their lives (Glendinning et al., 2008). Within the NHS in England, the personal health budgets pilot found that they, “had a significant impact on well-being and quality

of life” (Forder et al., 2012: 60). Furthermore, interviews revealed that personal health budgets, “increased the amount of choice and flexibility people had over their healthcare, and that choice was viewed positively” (Forder et al., 2012: 76). Alongside formal policy evaluation, “Case studies and vignettes are regularly deployed in government documents and reports from other organisations promoting personalisation” (Needham, 2011: 49). This supports the personalisation storyline by providing anecdotal evidence that personalisation has worked for individual service users and can, consequently, make a difference to the experiences of others. This storyline is also often supported by, “claims to self-evidence and common sense” (Needham, 2011: 49). Here it is argued that the benefits of personalisation are self-evident and common-sense. As a participant in her research noted, “people say things like personalisation won’t work for everyone, but if it’s personalised to you of course it will” (2011: 50).

The second theme is centred on the notion that the improved outcomes of personalisation will not cost more than traditional care. Extending this argument, it has been argued that, “emerging evidence suggests that this way of working may also be more cost-effective than the previous system, largely because it helps to unleash the creativity of people who have previously been passive recipients of services” (Glasby and Littlechild, 2009: 125). Whereas the evaluations of individual budgets and personal health budgets found them to be, in general, cost-neutral and cost-effective (Forder et al., 2012; Glendinning et al., 2008), there is evidence that personalised approaches can reduce costs (Duffy, 2010a). As with the first theme, the formal evidence base is regularly bolstered by, “individual stories of the cost-savings that have been achieved through personalisation”, with accounts provided of, “ending expensive out-of-borough placements and developing local alternatives at a much lower cost” (Needham, 2011: 50). Contentions of self-evidence and common-sense are also apparent, as revealed by a participant that was interviewed by Needham – “there’s only so much money to

go around, but surely if the money that you've got is spent better on people in a way that makes sense for them, that's got to be better" (2011: 510). In addition, this storyline draws on a 'wisdom of crowds' rationale (Surowiecki, 2004), wherein it is assumed that, "by turning people into participants in the design of services, they become innovators and investors, adding to the system's productive resources" (Leadbeater and Cottam, 2007: 98). Critically, the first two themes are explained as follows – "Together the 'it works' and 'it saves money' rationales are the key 'hard' indicators that justify personalisation, and are used to indicate that improved outcomes need not be dependent on increased spending" (Needham, 2011: 51-52).

The third theme of the personalisation narrative is based on the idea that, "support for people with care needs cannot be contained within service sector boundaries, because that is not how people live their lives" (Needham, 2011: 52). As an *In Control* report has explained, "The boxes which government uses to categorise us such as health, social care and physically disabled are not how we think of ourselves – at best they describe one aspect of our lives" (Tyson et al., 2010b: 11). Furthermore, a Cabinet Office interviewee in Needham's research observed that, "Personalisation couldn't stay with one department, because personalisation is about the whole person" (2011: 51). In part, this storyline and the arguments that reinforce it have contributed to the translation of personalisation from adult social care to other public sectors, as described within the third chapter; by centring the narrative on service user lives, this storyline provides a common-sense rationale for the importation of personalisation to other services impacting on their lives. The fourth theme is closely related to the third theme, presenting the arguments that, "personalisation is not only about recognising the multiple and interacting needs of people who require care, but is a relevant policy for all users of public services" (Needham, 2011: 53). As with the third theme, this story adds further weight to the argument that personalisation should be extended beyond its

origin in adult social care to all services that service users interact with, contributing to the impetus behind the translation of personalisation into the NHS in England.

The fifth theme promotes the notion that service users are appropriately characterised as experts in their own lives. This challenges the orthodoxy of the professional gift model in which service users are perceived to be dependent on the receipt of care and support. Needham has pertinently observed that there is, “a strong assertion of personhood underlying the personalisation agenda, with people with disabilities recognised as individuals” (2011: 53). Tyson has illuminated the relationship of personalisation to notions of personhood as follows (2007: 26):

Older and disabled people are no longer passive recipients of the ‘gift’ of care or welfare. They are active citizens, with gifts themselves and a contribution to make, people who take risks and have a life within...their communities

A similar argument is deployed by Hutchinson et al., who have observed that, “direct payments not only give [people with disabilities] a new way of obtaining assistance, but also offer them a whole new type of life” (2006: 74). As well as the assertion of personhood in this story, “there is also a redefining of expertise, to recognise that it can be held by the service user, or carer, as well as the professional” (Needham, 2011: 54). Hence, “User-experts are expected to put that expertise into practice through taking a more active role in meeting their own needs” (Needham, 2011: 54). One key mechanism for achieving this in practice is the transfer of budgetary control.

Needham acknowledges that the five storylines of the personalisation narrative are evident more in some texts than others and that the same phenomena is in force in consideration of individual interpretations of personalisation. Yet, “they constitute the core claims of the personalisation narrative, recurring throughout the documents and interviews” (Needham, 2011: 55). Earlier in the chapter, six elements of narratives were

defined as critical to the efficacy of policy change and it is possible to detect each of these features within the personalisation narrative. However, the framing of time is a particularly important factor in understanding personalisation (Needham, 2011). Pollitt has defined analysis of time as, “a vital, pervasive, but frequently neglected dimension in contemporary public policymaking and management” (2008: xi). Time is crucial as, “Stories about the future – which are the essence of strategy – cannot be made intelligible without closely related stories about the past” (Peck and 6, 2006: 51). To understand the ways in which personalisation engages with time, Needham draws on three frames – continuity and discontinuity, cycles and arrows, slowness and speed (2011).

The personalisation narrative should be understood in relation to claims about both continuity and discontinuity, leading to divergent perceptions of personalisation as both evolutionary and revolutionary (Table 2.3). First, “Part of the justification for personalisation rests on the assertion that it is timeless” (Needham, 2011: 57), establishing a claim of continuity between past, present and future practice. Many of her participants professed that personalisation was not new and was something that organisations and staff were already doing. In addition, “Running alongside the claims to timelessness...was a rival assertion that personalisation constitutes a new approach to service delivery” (Needham, 2011: 58), characterising personalisation reforms as a disjuncture from the past. Consequently, personalisation is perceived as a narrative of both continuity and discontinuity, “of a timelessness, which establishes credibility”, in addition to, “an unfamiliarity, which garners attention” (Needham, 2011: 60). Drawing on the idea of cycles and arrows (Pollitt, 2008), in which a cycle refers to the movement back and forth between iterations of familiar and stable policy and arrows refer to a sequential and progressive move from policy to policy, both framings of time are evident. On one hand, personalisation is framed in terms of arrows – “personalisation is

the end of a long road towards empowerment and justice for disabled people” (Needham, 2011: 60). On the other hand, “it is possible to find expressions of the ‘cycle’ view of time as well, in the sense of personalisation being a process of ‘getting back’ to something valuable that has been lost” (Needham, 2011: 61), such as a return to ‘real’ social work. Finally, there is an ambivalence to speed. Needham observes uncertainty on, “whether it is now best characterised as an agenda that is speeding ahead or inching along at a slow pace” (2011: 63). In summary, personalisation, “offers a compelling, if at times contradictory, account of the past present and future” (Needham, 2011: 63).

Table 2.3: Perceptions of Personalisation

Perceptions of Personalisation
Theme 6: <i>Personalisation is evolutionary, continuous and consolidating</i>
This theme presents personalisation as timeless, representing an evolution of prior practice and establishing continuity between the past, present and future.
Theme 7: <i>Personalisation is revolutionary, disruptive and transformational</i>
This theme defines personalisation as a radical departure from the past, designed to transform how care is delivered. The change is a revolution as opposed to evolution.

Consideration of the personalisation narrative within the National Health Service reveals that it is, “located in a discourse of organizational decline and disruption, emphasizing the need for patient exit and voice” (Needham, 2009: 204). Personalisation is viewed as transformational – “a radical departure from existing service models, deliberately designed to be a disruptive response to failure” (Needham, 2009: 210). For example, in *Our Health, Our Care, Our Say* it is suggested that, “There will be a radical and sustained shift in the way in which services are delivered” (DoH, 2006: 6-7). Exogenous and endogenous factors are offered to justify the disruption brought about by personalisation. Endogenous reasons include the idea that personalisation has been driven by patients, “responding to public demands for services that are no longer one size fits all” (Needham, 2009: 211). It also derived from a recognition that patients are experts in their own lives, and a valuable source of knowledge, and greater emphasis

on patient control, in terms of empowering patients and shifting responsibility. Therefore, “personalization is positioned as a response to broader social change, which renders existing organizational models inadequate” (Needham, 2009: 210). Nevertheless, “there is a clear agenda to encourage further destabilization, an endogenous form of change” (Needham, 2011: 212) – disruption is intentional and proactive as opposed to unintentional and reactive. Services are intended to be disrupted via, “the encouragement of a diverse range of providers, encouraging exit by patients and commissioning bodies” (Needham, 2009: 212). Expectations that personalisation will drive changes in NHS funding is essential at the macro and micro level, disrupting the tradition of risk-pooling through the individualisation of funding and challenging patient and professional roles by critiquing the implications of rationing and budgetary control.

On the other hand, personalisation can also be perceived in terms of, “consolidation, trust and equity, emphasizing loyalty to shared welfare services” (Needham, 2009: 204). In this account, personalisation is an evolution rather than a revolution, building on existing models of trust and interaction; personalisation consolidates rather than disrupts. Consequently, personalisation is presented as congruent with NHS solidarity and equity values. For example, *High Quality Care for All* noted that, “Providing personalised care should also help us to reduce health inequalities, as the households with the lowest incomes are most likely to contain a member with a long-term condition” (DoH, 2008b: 28). Personalisation is also presented, “in terms of a partnership between patients and professionals”, disavowing the language of consumerism and comprising a shift to public service as a product of coproduction between patients and professionals, “rather than the product of an adversarial struggle between consumers and producers” (Needham, 2009: 214). Nonetheless, “apparent commitment to stability and continuity of values and relationships within the health service clearly clashes with the

disruptive themes also expressed” (Needham, 2009: 14). Labelled as a dual imperative, “There is an attempt to position personalization as an agenda of radical and rapid institutional change”, at the same time as it is promoted as an, “agenda of consolidation and solidarity” (Needham, 2009: 214). Personalisation is ambiguous and interpretable, comprised of critical tensions between disruption and consolidation, and continuity and discontinuity, wherein, “Frontline staff and service users are left to negotiate an agenda which positions them as both partners and adversaries” (Needham, 2009: 204).

Shallow and Deep Personalisation

Given the inherent ambiguity of the personalisation narrative, Needham has argued that, “there is an assumption that this ambiguity weakens the case for personalisation and is a problem to be solved through tighter definitions of more comprehensive categorisations of different types of personalisation” (2011: 22). Prominent examples of this approach include Leadbeater (2004), Cribb and Owens (2010) and Parker and Heapy (2006), each of whom have developed valuable categorisations of personalisation policy. Leadbeater has described personalisation as a script for organising services, and has argued that, “All services are delivered according to a script, which directs the parts played by the actors involved” (2004: 35). Disagreeing with the typical characterisation of personalisation as a script, Needham has observed that the notion of a script, “implies a fixed content” (2011: 4), suggesting that personalisation can be defined in a manner that removes ambiguity. Critically, scripts are dependent on the collective actions of producers and consumers of services, who must assume harmonious roles in order for script to succeed. As Leadbeater has pertinently observed, “It is very difficult for service producers to innovate unless the users also adopt the new roles in the script” (2004: 34-35), recognising the bottom-up nature of scripts. On the other hand, service consumers are dependent on the scripts endorsed by producers

and, as a consequence, top-down stimulus matters. In other words, personalisation depends on patients and professionals adopting roles compatible with the script and without the engagement of both, it is unlikely that a script will succeed in practice.

Crucially, the personalisation script is presented as a storyline which encompasses, “two very different accounts of how the public good is created” (2004: 16), leading to ‘shallow’ and ‘deep’ variants of the personalisation script. The first account presents the public good as stemming from, “the state providing services to society ever more efficiently and effectively” (Leadbeater, 2004: 16), equating personalisation with state intervention in the lives of its citizens. The second account adopts a bottom-up perspective, with the actions of individuals collectively generating progression in the public good. Within this account, “the state does not act upon society; it does not provide a service. Instead the state creates a platform or an environment in which people take decisions about their lives in a different way” (Leadbeater, 2004: 16). Whilst these accounts are not necessarily conflicting, both endorse, “different accounts of the roles of users, professionals and public service providers” (Leadbeater, 2004: 17). Within the first account, “users are patients in need of timely and effective services from the NHS that are personalised to their needs” (Leadbeater, 2004: 17). The second account treats patients as co-producers who are, “active participants in the process - deciding to manage their lives in a different way - rather than dependent users” (Leadbeater, 2004: 17-18). Whilst the first story requires professionals employ their skills, knowledge and experience to solve problems for their patients and deliver personalised services, the second promotes patients as managers of their own health, with professionals playing a supportive role. Described as shallow, the first account is a, “modest modification of mass-produced, standardised services to partially adapt them to user needs” (Leadbeater, 2004: 20). The second account is defined as deep personalisation and requires the transfer of various roles and responsibilities from professionals to service users.

Leadbeater has presented deep and shallow variants of personalisation as two opposite ends of a personalisation continuum, within which five different meanings of the personalisation script for public services are discernible. At the shallow end of the spectrum, Leadbeater recommends that “personalisation could mean providing people with a more customer-friendly interface with existing services” (2004: 21). This approach is designed to, “make it easier for people to get access to the services they want, when they want them” (Leadbeater, 2004: 21), having minimal disruption to existing service scripts – personalisation progresses rather than transforms service scripts. This interpretation of personalisation is equated with greater responsiveness to service users, “giving users a more direct and effective voice and streamlining services” (Leadbeater, 2004: 40). Moving towards the deeper end of the continuum but continuing to signify a shallow interpretation, “personalisation could also mean giving users more say in navigating their way through services once they have got access to them” (Leadbeater, 2004: 21). This would involve greater voice and choice, with professionals expected to account for their patients in relation to, “the way that they deliver the service to them, keeping them informed and giving them ample opportunities to choose between different courses of action” (Leadbeater, 2004: 22). Further along the spectrum, Leadbeater notes that personalisation can mean, “giving users more direct say over how money is spent” (2004: 22). With the second and third generations of this script, choice and voice are central and it is imperative that sufficient information is provided in order to ensure that patient choices are comprehensive and informed.

At the deeper end of the script, Leadbeater notes that, “personalisation could mean users are not just consumers but co-designers and co-producers of a service: they actively participate in its design and provision” (2004: 22-23). With this personalisation script, “professionals help build up the knowledge and capacity of the users to create their own solutions” (Leadbeater, 2004: 23), actively enabling patients to take

control over their health. Defining this as 'personalisation through participation', this form of personalisation empowers patients to exert, "a more direct, informed and creative say in rewriting the script by which the service they use is designed, planned, delivered and evaluated" (Leadbeater, 2004: 57). Patients are not seen as dependent on professionals. Instead, "they should be able to question, challenge and deliberate with them" (Leadbeater, 2004: 60). They are also not perceived as mere consumers who choose between the options presented by professionals. In practice, this requires that patients are more, "intimately involved in shaping and even co-producing the service they want" (Leadbeater, 2004: 60). Recognising that this script requires producers and consumers to collaborate, it is advised that the role of professionals moves away from directly providing solutions towards becoming, "advisers, advocates, solutions assemblers, brokers" (Leadbeater, 2004: 60), helping patients to find the optimum ways to solve their problems themselves. Finally, at its deepest, personalisation is defined as, "self-organisation: the public good emerging from within society, in part, through the way that public policy shapes millions of individual decisions" (Leadbeater, 2004: 23). With this script of personalised public services, it is advised that the, "professionals would help to create platforms and environments, peer-to-peer support networks, which allow people to devise these solutions collaboratively" (Leadbeater, 2004: 24).

In summary, there are five different meanings of personalisation, with five potential scripts for public services (Table 2.4). Moving from shallow to deep scripts of personalisation, the roles and responsibilities transferred from professionals to patients increases; at the shallow end patients are largely dependent on professionals and at the deep end patients are more independent and they retain roles and responsibilities that were formerly held by professionals. Correspondingly, the roles and responsibilities of healthcare professionals also diverges (Leadbeater, 2004: 24):

As we move from the first to the fifth of these options the implications become more radical and disruptive: dependent users become consumers and commissioners, and eventually co-producers and co-designers. Their participation, commitment, knowledge and responsibility increases...

...In the first two options professionals are still providing solutions for dependent users, albeit in a more personalised fashion. In the fifth, the professionals are designing environments, networks and platforms through which people can together devise their own solutions.

Critically, personalisation represents a continuum wherein each consecutive iteration between the shallow and deep ends of the script are relatively similar but the extremes are entirely inconsistent. As Cutler et al. analysed, viewing personalisation as a spectrum, “appears to imply that all points on the spectrum are forms of personalization and hence variants on the transition to person-centred services” (2007: 852), despite the fact the, “implications of different points are radically different” (2007: 852-853).

Table 2.4: Nature of Personalisation

Nature of Personalisation
Theme 8: <i>Increasing responsiveness by tailoring to needs and/or preferences</i>
This theme advocates greater responsiveness to patients who should, as a result, have a more direct and effective voice. Care is tailored to needs and preferences.
Theme 9: <i>Giving users more say, keeping them informed and offering choice</i>
This theme centres on patient voice and choice. Professionals are expected to inform patients and support them by enhancing their ability to choose between outputs.
Theme 10: <i>Direct say over money, enabling individuals to make their own decisions</i>
This theme defines personalisation as giving patients a more direct say over how money is spent – for example, as a personal health budget that they directly manage.
Theme 11: <i>Co-production, active participation, choosing outputs and shaping inputs</i>
This theme frames service users as co-producers in a collaborative relationship with professionals, actively participating in the production and consumption of services.
Theme 12: <i>The public good emerging collectively through individual decisions</i>
This theme views personalisation as self-organisation, asserting that the public good emerges from within society and arguing that individuals should work collaboratively.

Tailoring to Needs and Preferences

This section will examine the ways in which the theme of responsiveness has been interpreted (Theme 8). Similar to Leadbeater (2004), Cribb and Owens recommend that personalisation is best understood in terms of a continuum between tailoring to the needs of patients and tailoring to preferences (2010). Numerous definitions of personalisation recognise tailoring as essential. For example: “tailoring support to people’s individual needs” (Carr, 2012: 2); “the tailoring of services to fit individual needs” (Lymbery, 2014: 308); “services being tailored to the needs of individuals” (Ferguson, 2007: 389). These definitions suggest that personalised services should be responsive and tailored to individuals, in contrast with traditional standard, one-size-fits-all care where every patient receives an equivalent service, regardless of their requirements as an individual. Cribb and Owens have argued that, “policy calls for personalization or ‘tailored’ services derive a large part of their appeal from the way they ‘fudge together’ a great many things” (2010: 310). They propose that the most significant fudge is between notions of tailoring to individual needs and tailoring to preferences and have contended that ambiguity is typical of orchestrating labels, such as personalisation. Orchestrating labels are seen as, “benign sounding but very general and vague” (Cribb and Owens, 2010: 310). This idea recognises that personalisation is, “sufficiently conceptually elastic and potent to absorb or reflect many of the other key ideas in contemporary health policy” (Cribb and Owens, 2010: 311). Nevertheless, tailoring is central.

Cribb and Owens (2010) apply the terms personalised medicine and personalised healthcare to discern between the different types of personalisation. Personalised medicine is equated with tailoring to needs, “taking into account the specific biological characteristics of the person being treated” (Cribb and Owens, 2010: 312). This interpretation of personalisation necessitates that, “diagnosing, treating or preventing the disease has to be adapted to suit the body in question” (Cribb and Owens, 2010: 312).

This definition ought to be taken further, encompassing the tailoring of service to a wider category of needs than pure biology, including mental health and psychological wellbeing. However, the inference remains that personalisation is appropriately interpreted as tailoring to individual needs. Cribb and Owens also have noted that, “reference to personalization in health care invokes a concern with being responsive to something rather different from biological variation, namely the preferences of consumers” (2010: 312). They have defined this as personalised healthcare, which can be equated with tailoring services to the preferences of individuals, in contrast with tailoring to needs evident in personalised medicine. Whereas personalised medicine, “deals with the solid scientific business of adapting medicine to individual needs”, personalised healthcare signifies, “the humanistic and fuzzier business of catering to people’s preferences about those things that surround medical interventions” (Cribb and Owens, 2010: 312). Critically, fundamental tensions are present regarding the roles and relationships of patients and professionals in tailoring to needs versus preferences.

Needs are defined as, “the things each human being requires in order to function as a human being” (Cribb and Owens, 2010: 312). Arguably, needs are objective in the sense that they are independent from the beliefs of the individual – “needs are unintentional in the sense that they are independent of any person’s beliefs about what it is harmful or beneficial to human beings” (Cribb and Owens, 2010: 312). Therefore, needs are ontological and unintentional, derived from the reality of individual existence as opposed to the individual perception of reality. Given this definition, it can be argued that, “it is possible to draw up a list of universally beneficial goods that all people need in order to enjoy at least the minimal amount of functioning” (Cribb and Owens, 2010: 312), on the basis that there is considerable overlap in the needs of individuals – for example, all people need food and water. In contrast, “those things that a person wants or desires depend on the beliefs of that person” (Cribb and Owens, 2010: 312). In other

words, preferences are subjective, intentional and epistemological; they are dependent on, “the beliefs of that person and the environment in which the claim is made” (Cribb and Owens, 2010: 312). Thus, Cribb and Owens have contended that, “desires are subjective in the sense that they are generated by and specific to a particular agent in a way that basic needs are not” (2010: 312). However, they have also recognised that, “any distinction between basic needs and desires is in practice more complicated” (Cribb and Owens, 2010: 312). For example, notions of tailoring to needs necessarily identifies that needs are individual – “There is sufficient variation in the environmental, genetic and bio-chemical constitution of individuals for us to have to be able to make discriminations between the clinical needs of people” (Cribb and Owens, 2010: 313).

Between tailoring to needs and tailoring to preferences, Cribb and Owens have remarked on the plurality of personalised public services – “There is a plurality of models of personalization, from those that offer patient choice on a very limited scale, to those that, in principle, allow users to determine the ends and means of services” (2010: 313). With tailoring to needs, the professional has ultimate responsibility for deciding the most appropriate course of action – “At one extreme the tailor is the judge of what is appropriate...Under these circumstances the role of the client is really no more than being a co-operative body” (Cribb and Owens, 2010: 313). As needs are objective and unintentional, the patient submits to the assessment of the professional, who is perceived to be the expert in the subject matter. This model is compatible with the theme of responsiveness outlined by Leadbeater (2004). Critically, “At the other extreme the client can decide what is appropriate” (Cribb and Owens, 2010: 313), since the goal of the service is to meet the preferences of patients. The role of the professional is necessarily reduced – “Under these circumstances the role of the tailor is really no more than being a co-operative technician” (Cribb and Owens, 2010: 313). However, the professional remains the tailor and controls the process of tailoring care;

the patient articulates their preferences and the tailor interprets these preferences to provide a tailored service. Between these two models there exists, “a range of intermediate positions in which various degrees of negotiation, compromise and customisation are possible” (Cribb and Owens, 2010: 313), wherein the individual needs and preferences of patients are combined as inputs into the process of tailoring.

Moving between tailoring to needs to tailoring to preferences, the roles and responsibilities expected of patients and professionals vary dramatically; from a position where patients submit to professional expertise, to a situation wherein patients shape care through the articulation of their preferences. At the shallow end, “It can range from merely encouraging practices that are very similar to current arrangements, that retain the dynamics, features and characteristic relationships of much of contemporary practice” (Cribb and Owens, 2010: 313). In contrast, personalisation may also encompass, “far more radical changes which reinvent the roles, relationships, structure and content of public services” (Cribb and Owens, 2010: 313). In other words, whereas tailoring to needs fits with the traditional model for delivering care, tailoring to preferences, “would seem to reorientate the welfare state away from its mission being specified by the satisfaction of citizen’s basic needs towards one that aims to meet goals specified by individual agents” (Cribb and Owens, 2010: 312). Different points on the spectrum may introduce, “a variety of ends and means that may have previously been considered inappropriate” (Cribb and Owens, 2010: 312), constituting a significant reorganisation of the welfare state. Critically, however, the privileged status of the professional and the state is retained as the concept of tailoring necessarily frames them as the tailors.

Customisation and Co-Production

This section will examine differences between the definition of personalisation as a model of mass customisation (Theme 9) and a model of co-production (Theme

11), drawing on the work of Parker and Heapy (2006). Critiquing growth and a shift towards the service economy in the public sector – “the public sector has expanded. Public service jobs have grown, as have the levels of investment being poured into our schools, hospitals, cultural institutions and security infrastructure” – they have noted a problematic disconnection between public services and the people who use them, suggesting that there is a distinct absence of concentration on service users – “Too often as recipients of services we feel that someone other than us is benefiting. Too often it feels like ‘producer interests’ or profit incentives matter more than how we feel” (Parker and Heapy, 2006: 7). Two problems have been identified as the cause of this disconnection. First, it has been argued that, “people are changing faster than organisations are” (Parker and Heapy, 2006: 8). Growing expectations of choice, control, autonomy, independence, empowerment and recognition, “have left people looking for more than simply quality products and services” (Parker and Heapy, 2006: 8). In other words, people expect to have greater input into services. The second issue, “is that service is still seen as a commodity rather than as something deeper, a form of human interaction” (Parker and Heapy, 2006: 8). This leads institutions to undervalue human aspects of service – “organisations still seek to provide service for the lowest cost and maximum profit. This...eats away at the fundamental purpose of service: to provide support and to help people live their lives to their full potential” (Parker and Heapy, 2006: 8).

Introducing personalisation, Parker and Heapy observe that, “the common challenge that all service organisations face is how to create more intimate and responsive relationships with their users and customers” (2006: i). They advocate for personalisation as a model that is, “less about competition and contestability and more about closing the gap between what people want and need, and what service organisations do” (Parker and Heapy, 2006: i). Critiquing the nature of providing a good service, Parker and Heapy have noted that, “Good service cannot be reduced to nothing more than an

efficient operation: its value lies in the less tangible sense that the service is supporting you, meeting your needs, working for and on behalf of you” (2006: 10). However, noting the commodification of service delivery, they have argued that the model of mass production – “the greatest number of goods for the lowest cost and the largest number of people” (Parker and Heapy, 2006: 11) – dominates the way that public services are delivered. With this model, services are standardised, production is separated from consumption and service managers prioritise efficiency. Within these constraints (i.e. as personalisation interacts with mass production), “a very particular form of personalisation is created” (Parker and Heapy, 2006: 11). This form of personalisation can be defined as mass customisation and comprises, “the breaking down of a particular service or product into modules which customers can then pick and choose from, or add and subtract elements of” (Parker and Heapy, 2006: 11). This variety of personalisation has been associated with, “consumer models of mass customisation, where particular services are modularised and people are able to choose” (Parker and Heapy, 2006: 82). This involves choices made by service users and, “is seen as a means of enabling greater user autonomy, and a way of engaging people in the creation of outcomes” (Parker and Heapy, 2006: 84), focusing on the outputs and not the inputs of services.

Critically, the exercise of choice requires that, “these decisions are surrounded by dialogue, useful and accessible information, recognition and support” (Parker and Heapy, 2006: 84). Nonetheless, with mass customisation, this facilitative environment is not prioritised and the impact of unaided choice is limited – “Being asked to choose from a menu of options, none of which appear to reflect your needs and the kinds of social and cultural contexts you are operating within, can be as disengaging and frustrating as a situation where there is no choice at all” (Parker and Heapy, 2006: 84). In promoting an alternative personalisation, Parker and Heapy have commented that, “To achieve the desired outcomes, public services need people to get involved” (2006: 13).

In contrast with mass customisation, in which production is separated from consumption, personalisation can be defined in terms of co-production, whereby production and consumption are simultaneous. Co-production focuses on, “how people engage...and how they can be mobilised, coached and encouraged to participate in the ‘common enterprise’ of generating positive outcomes” (Parker and Heapy, 2006: 13). This form of personalisation necessitates, “mechanisms and channels for engaging people not only in choosing between services, but also in shaping those services in the first place” (Parker and Heapy, 2006: 85). This approach means, “starting with people themselves, not organisational norms or institutional parameters”, using a process of, “co-design and co-creation rather than mass customisation” (Parker and Heapy, 2006: 87).

The mass customisation form of personalisation is closer to the traditional model of providing services, wherein the healthcare professional is responsible for providing services to patients, and patients are largely dependent on professional expertise. Professionals are responsible for deciding which choices are available to their patients and their patients are expected to choose between the options with which they are provided. Therefore, the mass customisation form of personalisation can be equated with shallow forms of personalisation (Leadbeater, 2004) and represents an approach to tailoring wherein the professional is the judge of what a tailored service comprises for individual patients (Cribb and Owens, 2010). On the other hand, the co-production form of personalisation is compatible with deeper forms of personalisation, wherein patients are enabled to achieve greater levels of independence, taking on various roles and responsibilities formerly held exclusively by healthcare professionals (Leadbeater, 2004). With co-production, patients actively participate in service design and professionals actively facilitate empowerment; patients are independent and treated as equal

participants in service co-production. Again, both forms of personalisation – mass customisation and co-production – exist in contradiction of the other, with divergent implications for the roles of and relationship between individual patients and professionals.

Policy Ambiguity and Practice

As outlined in the above discussion, there is a wealth of literature on the interpretation of personalisation which draws attention to multiple potential meanings and diverse ways in which the welfare state may be reformed. For example, Needham has revealed five themes that signify separate storylines, “which weave together to form an overarching narrative of personalisation” (2011: 48). This is pertinently supplemented by the observation that personalisation comprises conflicting accounts of its own relationship between the past, present and future. Personalisation is perceived to be continuous with the past and an evolution of traditional and contemporary practice whilst also representing a critical disjuncture from previous practice, being discontinuous and transformational. Leadbeater has defined personalisation as a script for public services, arguing that there are five potential scripts that diverge on a spectrum between shallow and deep forms (2004). At the shallow end of the spectrum are reforms akin to traditional practice, emphasising tailoring and framing patients as consumers of care. At the deeper end, personalisation invites patients to become co-producers of care, representing a more transformational reform agenda. Critical ambiguity also originates from the relationship of personalisation with responsiveness (Cribb and Owens, 2010), co-production (Parker and Heapy, 2006) and patient voice and choice.

Central to the personalisation narrative is the supposed need to, “construct a new relationship between service users and staff, resisting conventional norms of expertise and authority” (Needham, 2011: 137). Personalisation is often assumed to signify a new and changed role for service users and professionals. There are two central

assertions. The first claim is that, “professional expertise must be challenged and the privileged status of professionals resisted” (Needham, 2011: 137). Personalisation has been associated with the idea that service users possess expertise that contradicts the traditional model of professionals as experts. This legitimises the knowledge of service users and recognises the authority of their voice in the delivery of care. Consequently, professional authority is problematised, albeit professional expertise is not diminished. Pertinently, “This challenge to professional power is also congruent with the moves to consumerism” (Needham, 2011: 140), as evidenced by the centrality of the consumer within the personalisation narrative (outlined below). The second assertion reinforcing a necessity for a new relationship is that personalisation requires, “close collaboration between front-line staff and users based on co-production principles” (Needham, 2011: 137). With this account, patients are perceived as co-producers, actively participating in the production and consumption of care. Therefore, “professionals and empowered patients work together to improve services, in a positive-sum game, rather than being placed in a zero-sum relationship in which they battle for authority” (Needham, 2011: 140). Significantly, these claims are in conflict, characterising the patient-professional relationship as both adversarial and collaborative. This is representative of an additional source of ambiguity on which the personalisation narrative has been constructed.

The ambiguity of personalisation has permitted audiences to apportion various meanings and align it with potentially contradictory philosophical arguments, associated with democratic and neo-liberal ideals. Consequently, the personalisation narrative facilitates the interpretation of service users (or patients) as both citizens (democratic) and consumers (neo-liberal) – or as a citizen-consumer (combination of both). The citizen is a democratic archetype, drawing on notions of liberty, equality and solidarity. Citizens are located in a relationship with the state, summoning notions of mutual obligation and production – “It is the consent of the citizen that empowers the state;

while the state provides and secures the conditions that enable citizens to lead their lives” (Clarke et al., 2007: 2). In contrast, the consumer is positioned in terms of an economic relationship. Consumers are, “engaged in economic transactions in the marketplace, exchanging money for commodified goods and services” (Clarke et al., 2007: 2). This can also be understood as a relationship of liberty and equality of a different sort, based on the capacity of consumers to self-direct and choose how their own well-being can be pursued – “All individuals (subject to certain legal restrictions) are equally endowed with the capacity to be self-directing” (Clarke et al., 2007: 2). Nonetheless, there is a key distinction – “The market responds to ‘price signals’ rather than personal characteristics. The market...reconciles the wants of many producers and consumers” (Clarke et al., 2007: 2). Furthermore, whereas the citizen is perceived as a public figure, fulfilling their obligations to society in the public realm, the consumer is a private figure driven by personal desires and pursuing their own interests.

The personalisation narrative can be interpreted as favourable to democratic principles of citizenship and social justice (Christensen and Pilling, 2014; Duffy, 2010a, 2010b; Lymbery, 2014). For example, Lymbery analyses that the leading theme within the policy rhetoric, “associates personalisation with the concept of social citizenship – whereby all previously disadvantaged people will be enabled to enjoy the full benefits of society, which had previously been denied to them” (2014: 295). In support of this interpretation, Duffy has noted that public services have traditionally required individuals to forsake their rights as citizens, accepting a reduced level of autonomy and independence in their lives – “In the old system of social care a disabled person who accepted support from the state would find that they could only receive support if they were prepared to: (a) sacrifice control over that support and thereby large parts of their lives; and (b) accept services that then excluded them from meaningful engagement in community life” (2010b: 257). In contrast, personalisation is viewed as turning, “this

old paternalistic system on its head. Self-directed support assumes, as a default, that people who need support should still be in as much control of their lives as possible” (Duffy, 2010b: 257). From this perspective, personalisation can be viewed as enabling the rights of individual service users to citizenship, “because it gives people who have been effectively disenfranchised enhanced opportunities to play a full role in society” (Lymbery, 2014: 300). Critically, Duffy has analysed personalisation in terms of his Citizenship Theory of social justice (2010b). Noting that, “Social justice demands that we seek to organise society in a way that is fair” (Duffy, 2010b: 259), he has noted that, “a fair society organises itself so that everyone gets sufficient support to be able to achieve effective citizenship” (Duffy, 2010b: 263). From this perspective, personalisation can be perceived as conducive to both notions of citizenship and social justice.

Despite its congruence with democratic ideals, it is also possible to interpret personalisation as consistent with neo-liberal ethics (Ferguson, 2007, 2012; Lymbery, 2012, 2014; Scourfield, 2005). For example, Ferguson has critiqued that, “personalisation is also consistent with a neoliberal social and economic agenda which limits, rather than extends, social justice” (2012: 55). This should be viewed in context of a wider, global trend towards the incorporation of neo-liberal principles into public sectors (Gamble, 2001; Harvey, 2005; Pollitt and Bouckaert, 2011). The portrayal of individual citizens as consumers and the associated incorporation of consumerist ideals such as choice is central to neo-liberalism (Clarke, 2007a, 2007b; Clarke et al., 2006; Vidler and Clarke, 2005). Defining citizen-consumers as knowledgeable and self-directing, “capable of identifying and articulating individual wants as choices” (Vidler and Clarke, 2005: 34), neo-liberalism ideology promotes, “an individualised and marketised image of the consumer as a self-directing, rationally choosing individual” (Clarke, 2007a: 438-439). Therefore, “the role of public agencies is to support their ability to act in this way” (Lymbery, 2014: 301). Linked to consumerisation, neo-liberalism asserts a, “politics of

individual recognition over the politics of collective redistribution” (Webb, 2006: 38). Critical scholars have reinterpreted individualisation in terms of responsabilisation (Ferguson, 2007, 2012; Scourfield, 2005, 2007), which is viewed as one of, “the characteristic technologies of neo-liberal rule” (Clarke, 2007b: 2). Scourfield has noted that, with personalisation, “collectivised responsibility for health and welfare has given way to the individualisation of risk”, as well as “the ‘double movement’ of autonomisation and responsabilisation” (2005: 471-472). Furthermore, “managerialisation of the self becomes both extended and ‘deepened’ by the requirement that the service user takes on more of the functions, risks and responsibilities which formerly would have been the remit of the state” (Scourfield, 2007: 116). Hence, it is apparent that the narrative of personalisation can also be interpreted as compatible with neo-liberal philosophical ideals.

Regardless of which position is taken, it has been argued that the ambiguity of personalisation is essential to its dominance (Cribb and Owens, 2010; Cutler et al., 2007; Ferguson, 2007; Needham, 2011). Cribb and Owens have described personalisation as an ‘orchestrating label’, which they define as, “benign sounding but very general and vague. They seem to point to some broad but important goods” (2010: 310). They have observed that orchestrating labels like personalisation, “serve as consensus and plausibility building tools in the policy tool kit; and their – very standard – ideological function is to mask value questions and disputes and to help secure assent and build coalitions” (Cribb and Owens, 2010: 311). Describing personalisation as an ‘epochalist narrative’ – “epochalist narratives provide a simple and easily digestible set of slogans through which to catalyse the demand for change” (Du Gay, 2003: 671) – Cutler et al. have advised that the level of abstraction evident within the personalisation narrative – in other words, its ambiguity – has combined with supposed normative imperatives to modernise services and the appearance of inevitability to encourage its implementation (2007). Drawing on the work of Williams (1975), Ferguson has defined

keywords as, “capable of incorporating multiple meanings, which often bear little relationship to each other and are sometimes contradictory” (2007: 388). A second characteristic is that, “the connotations of keywords are often overwhelmingly positive and they are therefore very hard to be against” (Ferguson, 2007: 388). Consequently, he has pertinently rationalised that, “the current popularity of the notion of personalization amongst politicians and policy makers in the UK derives precisely from its ambiguity” (Ferguson, 2007: 389). Thus, the ambiguity of personalisation comes to represent, “a key element of its success as a catalyst for reform” (Needham, 2011: 23).

However, it can also be argued that ambiguity inhibits effective policy implementation (hence practice). Cutler et al. have contended that the level of abstraction contributes, “to difficulties in defining the concept and hence developing a coherent approach to policy implementation” (2007: 848). It has been recommended that, with epochalist narratives (i.e. personalisation), “problems invariably arise when it comes to the nitty-gritty of practical changes within governmental institutions” (Du Gay, 2003: 671), and that, as a consequence, “there is arguably a disjuncture between the role of epochal arguments in setting a political agenda as against providing a guide to policy implementation” (Cutler et al., 2007: 854). In other words, policy ambiguity contributes to the difficulty of defining personalisation and developing an articulate and consistent approach to practice. Matland has argued that policy ambiguity can be related to policy goals or means (1995). He recognises ambiguity as necessary at the legislative stage of the policy process – “Many legislative compromises depend on language sufficiently ambiguous that diverse actors can interpret the same act in different ways” (Matland, 1995: 158). Nonetheless, he has also acknowledged the impact of policy ambiguity on policy implementation, giving the following detailed explanation (Matland, 1995: 159):

The degree of ambiguity inherent in a policy directly affects the implementation process in significant ways. It influences the ability of superiors to monitor activities, the likelihood that the policy is uniformly understood across the many implementation sites, the probability that local contextual factors play a significant role, and the degree to which relevant actors vary sharply

Conclusion

This chapter examined the meaning of personalisation, providing an overview of existing literature and analysing implications for practice. It has been demonstrated that personalisation can be interpreted in a variety of diverse ways, resulting in a varied and inconsistent set of guides to practice. In particular, diversity in the expected roles of patients and professionals and, as a consequence, the relationship between them, has been established. This research has been designed with the primary intention of investigating the interpretation of personalisation by healthcare professionals working within the NHS in England. The objective is to understand how personalisation is interpreted and what the practical implications of these definitions are – especially as it relates to the expected roles of patients and professionals in the delivery of care. To facilitate this endeavour, the literature summarised was used to develop a framework to encompass the meanings of personalisation. This framework will be applied to structure the thematic analysis of participant interpretations of personalisation within the fifth chapter. The following chapter will examine the emergence of personalisation in adult social care and trace its translation into the NHS in England, analysing a key selection of critical transformations.

3. PERSONALISED PUBLIC SERVICES

Adult social care was the first sector within which the personalisation agenda gained traction in the UK public sector and it was the perceived success of reform in this environment that acted as a catalyst for the movement of personalisation to other sectors, such as the NHS in England. This chapter will describe how personalisation evolved in adult social care, drawing attention to its origins within the campaigns and activities of grassroots organisations of disabled people and the role of various policy entrepreneurs in constructing and spreading the idea of personalised public services. Next, reforms undertaken to personalise healthcare within the NHS in England will be identified. Three prominent modes of personalisation – personalised care and support planning, personal health budgets and personalised medicine – will be described, highlighting diversity in the application of personalisation. Finally, the migration of personalisation will be explained as a consequence of the distinctive problems within the NHS, leading to the importation of personalisation as a perceived policy solution. Framed as an example of policy translation, the migration of personalisation will be described as a process of adaptation, interpretation and transformation, drawing attention to the fluidity of translation and acknowledging the ambiguous meaning of personalisation.

Personalisation in Adult Social Care

It makes most sense to commence any account of personalisation within the UK public sector with a discussion in the context of adult social care, since it is in this sector that personalisation was first evident and has advanced the furthest, and it is the perceived success of these reforms that contributed to its translation to other sectors. As Needham explains, “Personalisation is furthest advanced within adult social care, reflecting the extent to which its emergence and apparent success in that sector has been a catalyst to broader implementation” (2011: 30). Personalisation within adult

social care is comprised of a broad range of approaches to reform, being labelled with terms including person-centred planning (DoH, 2010b) and self-directed support (Scottish Government, 2010). The policy agenda is often associated with direct payments (DoH, 1997, 2003) and personal budgets (ADASS, 2009; HM Government, 2007, 2010, 2012; PMSU, 2005), yet it is also much broader than budgets (DoH, 2008b: 9):

Central to the transformation of social care...is the concept of personalisation as an approach to the delivery of public services, self-directed support as a manifestation of this concept in health and social care and personal budgets as the operating system that will deliver choice and control to citizens

Nonetheless, although personalisation of adult social care is about more than devolved budgets, it was the introduction of direct payments that symbolised a significant policy change, enabling people in receipt of adult social care to obtain a budget through which they could manage their own needs and purchase care and support.

Direct payments are described as, “monetary payments made by councils directly to individuals who have been assessed as having needs that are eligible for certain services” (DoH, 2009b: 5). Control of the money and support package is passed to the service user, who assumes overall responsibility for ensuring that, “it is properly spent on the care and support required, and who is best placed to judge how to use available resources to achieve the desired outcomes identified in the care plan” (DoH, 2009b: 9). Direct payment are designed to, “provide people with the freedom to design services around their specific circumstances and needs” (DoH, 2009b: 9). They are intended to promote, “independence, choice and inclusion, by enabling people to purchase the assistance or services that the council would otherwise provide” (DoH, 2009b: 5). Ultimately, direct payments enable people to direct their own care and support, facilitating and maintaining the ability of individuals to, “live in their own homes,

to be fully involved as active citizens in family and community life, and to engage in work, education and leisure” (DoH, 2009b: 6). Personal budgets represent, “An amount of funding set aside specifically to meet the assessed need of a named individual” (HM Government, 2010: 157). This is intended to provide choice and control to clients – “Rather than being told what services they will receive, people will have to be offered a personal budget, giving them much more choice about how their care and support entitlement is spent” (HM Government, 2010: 15). This guarantees that the care delivered is, “tailored to each person’s needs and circumstances and what they want to achieve” (HM Government, 2010: 135). A direct payment is one way of receiving a personal budget. However, service users can request that the Local Authority or a third party manage the budget. Both direct payments and personal budgets are pioneers to personal health budgets in the NHS.

It was the *Putting People First* concordat between central and local government, and the adult social care sector more broadly, that widened the personalisation agenda beyond budgetary devolution (HM Government, 2007). One of the key elements of the proposed personalised adult social care system was described in relation to Local Authority leadership and partnership, working with the NHS, third sector and private sector providers and users, their carers and local communities, “to create a new, high quality care system which is fair, accessible and responsive to the individual needs of those who use services and their carers” (HM Government, 2007: 2). Emphasis was placed on greater integration between services, which was seen as facilitating a more tailored approach. An essential element of this approach to personalised adult social care was described as a wider focus on agreed and shared outcomes that should ensure that recipients of adult social care are supported to (HM Government, 2007: 2-3):

live independently; stay healthy and recover quickly from illness; exercise maximum control over their own life and...lives of their family members; sustain a

family unit which avoids children being required to take on...caring roles; participate as active and equal citizens, both economically and socially; have the best possible quality of life, irrespective of illness or disability; retain maximum dignity

In this instance, personalisation comes to represent any tool that empowers individuals to be more independent, maintain their health, exercise choice and control, sustain the family unit, participate economically and socially, improve their quality of life and retain dignity and respect, highlighting the versatility of personalisation in adult social care.

Emphasis will now be placed on the origins of personalisation within social care, drawing attention to the process through which personalisation was established as a central approach to delivering public services. Although it is overly simplistic to assert that personalisation merely transferred from social care to other sectors of the welfare state, “it was within social care that personalisation developed as a transformative policy narrative, offering a rationale and set of policy mechanisms that could be the basis of innovation in other sectors” (Needham, 2011: 65). Therefore, it is important to understand the origins of personalisation in social care in order to place personalisation within the NHS in England in its appropriate context. Deliberation of origins draws attention to the question of whether personalisation was ever an intended policy with a master plan that can be revealed and examined; as an initiative with a clear purpose, definition and agenda for reform. In practice, this was not the case – “As with almost all policy innovation, there was no master plan for personalisation...and even the label personalisation was only adopted part-way along the process” (Needham, 2011: 65). Transformative policy like personalisation tends to emerge gradually through iterative developments and the coalescence of ideas and perspectives (Hall, 1993; Kingdon, 1995). This certainly appears to fit the case of personalisation within adult social care,

with the adoption of personalisation as a formal policy commitment in the *Putting People First* concordat (HM Government, 2007) emerging from a long-term movement towards the personalisation of social care, nationally and internationally.

Personalisation can be understood as a bottom-up movement, developing from the campaigns and activities of grassroots organisations of disabled people (Glasby and Littlechild, 2009; Needham, 2011). Emerging from the campaigns was, “a diverse set of stories, rather than a single message”, yet it is possible to identify two essential components of its development – “innovation arose from the independent living movement, centred on people with physical disabilities, and from the move to more inclusive approaches for people with learning disabilities, linked to the social model of disability” (Needham, 2011: 66-67). Traditionally, the medical model of disability assumed that, “the ‘problem of disability’ was located in the body of the person” (Duffy, 2010b: 258). The social model of disability counters this notion (Barnes, 1991; Finkelstein, 1980, 1981; Oliver, 1990, 1996). As Boxall et al. have analysed (2009: 505):

The social model of disability that has underpinned much of the work of the UK disabled people’s movement locates disability in barriers to inclusion in mainstream society, rather than in individual impairment

Accordingly, public services have been pertinently subjected to various criticisms about, “the way they constructed disabled people as passive welfare recipients – ‘clients’ of controlling and paternalistic professionals” (Scourfield, 2007: 113). Instead, it has been competed that disabled people should really be regarded, “not as dependent people in need of support, but people with impairments facing societal barriers, who will require additional support to live on more equal terms with non-disabled people”

(Boxall et al., 2009: 510). Consequently, care and support is construed as an entitlement determined on the basis of need. Pertinently, this theme is replicated within the independent living movement – the history of which is briefly delineated below.

The concept of independent living first emerged in the United States in 1973, leading to the establishment of a network of user-led Centres for Independent Living (CIL) – organisations run by and for disabled people which sought to empower disabled people to take greater control over their own lives (Glasby and Littlechild, 2009; Needham, 2011). Within a decade there were 200 CILs across the United States and the concept of independent living began to be adopted overseas, including within the UK. Furthermore, formation of the British Council of Disabled People and European Network on Independent Living established both national and international focal points for the promotion of independent living in Britain and across Europe (Glasby and Littlechild, 2009). Critically, the philosophy of the Independent Living Movement is based on four assumptions, which have been delineated by Morris as follows (1993: 21):

1. *All human life is of value;*
2. *Anyone, whatever their impairment, is capable of exercising choices;*
3. *People who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives;*
4. *Disabled people have the right to participate fully in society*

Although definitions of independent living vary, choice and control are central (Glasby and Littlechild, 2009: 13). It is all about empowering disabled people to exercise choice and control over their own lives, as part of a broader movement to ensure equal rights, equal opportunities, self-respect and self-determination for disabled people. Disabled

people are thus portrayed as individuals with impairments who require additional support to overcome the barriers levied by society; not as dependent people in need of support, but as people with rights to independence.

The term independence is central to independent living. Traditionally, independence was delineated as the absence of dependence (Leece and Peace, 2010; Reindal, 1999; Secker et al., 2003). As Reindal has observed, “This ideology equates independence with the ability to do things without help or assistance” (1999: 353). In this model, independence signifies, “the absence of dependence in the sense of not being reliant on others to carry out everyday activities” (Secker et al., 2003: 378). This definition of independence relates to Collopy’s ‘autonomy of execution’ (1995, 10), which can be defined as, “the ability to implement, act upon and operationalise choices” (Leece and Peace, 2010: 1850). The traditional interpretation of independence is widely rejected within the movement for disabled people (Barnes, 1991; Oliver, 1990, 1996; Reindal, 1999; Rock, 1988; Secker et al., 2003; Shakespeare, 2006). Independence should not be defined in relation to physical abilities. Instead, independence, “indicates someone who is able to take control of their own life and to choose how that life should be led” (Barnes, 1991: 129). Independence embodies, “a thought process not contingent upon physical abilities” (Barnes, 1991: 129). Therefore, “Independence is...not linked to doing things alone or without help, but by obtaining assistance when and how one requires it” (Reindal, 1999: 354). This is related to ‘decisional autonomy’ (Collopy, 1988, 12), which can be defined as, “the ability to make decisions, to have personal preferences and values, even though one may not be able to act on them independently or accomplish them without assistance” (Leece and Peace, 2010: 1850). It is this definition of independence that the independent living movement seeks to achieve and has, thus, been integral to the process via which personalisation was adopted in social care.

Policy entrepreneurs also had a key role in constructing and spreading the idea of personalised public services in social care (Glasby and Littlechild, 2009; Needham, 2011). Defining policy entrepreneurs as those, “people who ‘couple’ policy solutions to problems, taking advantage of a ‘window of opportunity’”, Needham has observed that, “they are people who built on the somewhat narrow achievements of the direct payments approach...and called for much broader transformation based around personal budgets” (2011: 72). Prominent policy entrepreneurs included the disability campaigners that Leadbeater and Cottam (2007) have described as lead users, who innovated with their own care and support whilst telling stories to other disabled people about what could be achieved. In addition to those individual entrepreneurs sharing their stories, networks of support provided an additional platform from which policy entrepreneurs could disseminate their stories. The contribution of In Control was particularly important (Glasby and Littlechild, 2009; Needham, 2011), contributing to the spread of personalisation via the combination of, “gathering information, setting up experiments, supporting lead users and telling their stories, and creating networks” (Needham, 2011: 72). Leadbeater is viewed as a key policy entrepreneur, translating personalisation into a broadly-defined policy programme for public services (2004) and promoting personalised approaches to service reform (Cottam and Leadbeater, 2004; Leadbeater and Cottam, 2007; Leadbeater et al., 2008). Simon Duffy represents another critical example of influential policy entrepreneurs (2010a, 2010b). Government ministers, policy advisers and institutions such as the Prime Minister’s Strategy Unit (PMSU) have also been acknowledged to have exercised an influential role in the growth of personalised approaches to reforming social care and the wider public sector (Needham, 2011).

Campaigning by disabled people and advocacy by policy entrepreneurs played a central role in the application of personalisation as a key approach to reforming social care. It has also been argued that the congruence of personalisation with the broader

contexts in which it has been constructed, such as a generation of political and intellectual critiques of the post-war welfare state, have contributed to its adoption within adult social care (Needham, 2011). This draws on Coleman's analysis that, "New discourses will emerge and gain widespread acceptance if they are more or less congruent with the prevailing culture into which they are being introduced" (2007: 202). In the context of personalisation, Needham has summarised this impact as (2011: 66):

...coherence with the broader context, in which new interactions between the individual and the community were being promoted politically, but also being made possible through technological innovation

Moreover, coherence with the broader political strategies of the Government helped to advance personalisation. For example, Glasby and Littlechild observe that while direct payments are often presented as a victory for disabled campaigners (2009: 27-28):

...they were also championed by a Conservative government committed to neo-liberal social policies aimed at rolling back the frontiers of the welfare state and promoting greater consumer choice through the creation of markets

Similarly, personalisation fit with various aspects of New Labour political strategies that sought to distance itself from previous iterations (Needham, 2011). In summation, the adoption of personalisation in adult social care arose from pressure from disabled people and policy entrepreneurs in context of broader political and socio-cultural changes.

Personalisation within the NHS in England

Attention will now be given to identifying some of the critical transformations that have been undertaken with the name of personalisation within the NHS in England. In order to do so, it is necessary to define the boundaries of what to include as an instance of personalisation, which can be problematic. As Needham noted when undertaking a

similar task, “Some of the people interviewed for the research described personalisation as a new word for an approach that they had always taken” (Needham, 2011: 29) – participants in this study had a similar perception. Furthermore, it can be challenging to decide what counts as an example of personalisation since the word itself may not have been utilised. For example, the Expert Patients Programme can be considered as an early example of personalisation within the NHS in England. However, while later documents explicitly associate this reform with the personalisation agenda (DoH, 2004a), earlier papers do not make an explicit connection (DoH, 1999). Within the scope of this review, only those initiatives promoted or endorsed by central government will be included, excluding instances of personalisation that are external to the public sector. Adopting the same criteria as Needham, this review will be focused on those, “public service delivery mechanisms that aim to modify the service to meet the specific circumstances facing individual users” (2011: 30). In other words, focus will be given to “how services are tailored to the person, with the individual as the unit of analysis” (Needham, 2011: 30). Following a brief synopsis of the development of personalisation, three forms via which the policy has been enacted will be described – personalised care and support planning, personal health budgets and personalised medicine.

During the past two decades, successive governments comprised of different political parties have expressed a desire to implement personalisation within the NHS in England (DoH, 2000, 2004a, 2004b, 2006, 2008b, 2010b; NHS England, 2014a, 2014b, 2015a, 2016b, 2016c, 2016e, 2017). There have been formal papers on personalisation across the range of NHS services, including mental health (DoH, 2004c, 2008a; NHS England, 2016a), secondary care (DoH, 2008b, 2010a), primary care (DoH, 2014; NHS England, 2015b), community services (DoH, 2010b; NHS England, 2015c) and services for children and young people (DoH, 2004b, 2008b; NHS England, 2016d). Rather than providing a comprehensive account of all White Papers and

documents advocating personalised reform in the NHS, a snapshot of relevant articles will be described. Attention will then be given to three prominent approaches that have been implemented – including personalised care and support planning (NHS England, 2016b, 2016c), personal health budgets (NHS England 2014a, 2015a) and personalised medicine (NHS England, 2016e). These technologies are approaches to the delivery of personalisation that cut across the diverse types of service offered by the NHS.

In *The NHS Plan. A Plan for Investment. A Plan for Reform*, the Labour Government set out a vision to deliver personalisation via tailoring (DoH, 2000: 17, 26):

The vision of this NHS Plan is to offer people fast and convenient care delivered to a consistently high standard. Services will be available when people require them, tailored to their individual needs...over the next ten years the NHS must be redesigned to be patient centred – to offer a personalised service.

...services thrive on their ability to respond to the individual needs of their customers...Services have to be tailor-made not mass-produced, geared to the needs of users not the convenience of producers. The NHS has been too slow to change...to meet modern patient expectations for...personalised care

The NHS Improvement Plan: Putting People at the Heart of Public Services continued the commitment to personalisation, referencing choice and voice (DoH, 2004a: 9, 30):

Patients' desire for...personalised care will drive the new system. Giving people greater...choice will give them control over these issues, allowing patients to call the shots about the time and place of their care, and empowering them to personalise their care to ensure the quality and convenience that they want

Expanding choice and developing a personalised service...depends on giving patients a stronger voice. Where patients choose to go will be important, as it

will affect where resources go...But there will also be a greater readiness, nationally and locally, to seek and listen to the views of patients...to act on them

In cooperation with the Department of Health, Lord Darzi led a wide-ranging review of the NHS, concluding in the publication of *High Quality Care for All: NHS Next Stage Review Final Report* (DoH, 2008b). The immediate steps identified by the report included a plan to, “Ensure everyone with a long-term condition has a personalised care plan” (DoH, 2008b: 10), in order to make sure that services are organised around the needs of patients. A trial of personal health budgets was also planned, “giving individuals and families greater control over their own care” (DoH, 2008b: 10), and patient choice was upheld as a central feature – “choice should become a defining feature of the service. A health service without freedom of choice is not personalised” (DoH, 2008b: 38). Continuing the trajectory of the previous administration, the Coalition Government published *Equity and Excellence: Liberating the NHS* (DoH, 2010b). Patient choice and control continued to be essential to personalisation (DoH, 2010b: 3, 16):

We will put patients at the heart of the NHS, through an information revolution and greater choice and control...The system will focus on personalised care that reflects individuals’ health and care needs

Within *Equity and Excellence: Liberating the NHS* (DoH, 2010b) and *Liberating the NHS: No Decision About Me, Without Me* (DoH, 2012), personalised care planning and personal health budgets were endorsed for practice in discrete cases across the NHS.

During the lifetime of the previous Labour administration, the NHS Constitution was published (DoH, 2009a). Whilst personalisation was not explicitly referenced, its central principles were essential – “services must reflect the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care” (DoH,

2009a: 3). This was refreshed following the election of the Conservative Government, and the emphasis on tailoring and self-management was retained (DoH, 2015: 3):

The patient will be at the heart of everything the NHS does. It should support individuals to promote and manage their own health. NHS services must reflect, and should be...tailored to, the needs and preferences of patients

The *Five Year Forward View* promoted contemporary advances made in personalised medicine – “Medicine is becoming more tailored to the individual; we are moving from one-size-fits-all to personalised care” (NHS England, 2014b:33). It made reference to, “a ground-breaking new initiative launched by the Prime Minister which will decode 100,000 whole genomes within the NHS” (NHS England, 2014b:33), aimed at improving the diagnosis and treatment of rare diseases and cancers, delivering higher cure rates and fewer side effects via personalisation. Finally, *Next Steps on the NHS Five Year Forward View* described progress on the *Five Year Forward View*, highlighting further reforms intended to personalise the NHS (NHS England, 2017: 43, 61, 65):

Expand the Diabetes Prevention Programme...which provides tailored, personalised help to reduce risk of Type 2 diabetes, including education...help to lose weight and bespoke physical exercise programmes.

Providing more personalised, safer maternity services...Women will be better able to make choices about their care and have more continuity of care during the ante natal, birth and postnatal period.

...NHS Choices to become NHS.UK, which will offer a more personalised and tailored experience. It will then be possible for patients to book appointments and access their personal health record...

Personalised care and support planning is a key technology for personalisation within the NHS in England (DoH, 2011; NHS England, 2016b, 2016c). Central to this approach is the care and support plan – “A care plan quite simply records the outcomes from a care planning discussion, including any actions agreed” (DoH, 2011: 3). Personalised care and support planning has been promoted as a core part of the program towards a future NHS. There is emphasis placed on the development of, “a new relationship with patients and communities that supports people to gain far greater control of their own care” (NHS England, 2016b: 5), characterising personalisation as an innovative reform that is discontinuous with previous approaches to care – “The term care planning has been used for many years in many different settings. The approach of personalised care and support planning as a collaborative and person-centred process is distinctly different” (NHS England, 2016b: 16). Crucially, it is described as transformational to patient experiences of the NHS – “It transforms their experience from a largely reactive service, which responds when something goes wrong, to a more helpful proactive service, centred on the needs of each individual patient” (NHS England, 2016b: 5). However, it is also advised that personalised care and support planning is, “not a new concept”, and has been, “part of the rhetoric of the engaged patient and a commitment from central government for many years” (NHS England, 2016b: 5).

The personalised care and support planning handbook describes personalised care and support planning as, “an essential prerequisite for helping people living with long term conditions” (NHS England, 2016b: 5). Furthermore, it is argued that, “it can be beneficial to anyone with ongoing health and care needs” (NHS England, 2016b: 11). The technology is framed in context of people with long-terms conditions, in relation to whom it has been observed that, “These are conditions which cannot at present be cured but can be managed or improved through person-centred approaches” (NHS England, 2016b: 6). Contending that this approach leads to the most appropriate use

of resources, it is claimed that, “People who are engaged in their health and care are more likely to receive care and treatment that is appropriate to them; to take up appropriate prevention services...and to adopt more healthy behaviour” (NHS England, 2016b: 6). In addition to improving patient outcomes, personalised care and support planning is framed in relation to the costs of delivering care (NHS England, 2016b: 6):

Consultations with people with LTCs account for more than 50% of GP appointments, 64% of all outpatient appointments, and over 70% of inpatient bed days. £7 from every £10 of health and social care spend is targeted towards this 30% of the population

Incentives for commissioners to enact personalised care and support planning are described as, “Greater value for money, as services provided meet individual needs, deliver improved health outcomes and reduce medicine wastage” (NHS England, 2016b: 22), with the implication that personalised care and support planning helps to deliver a more sustainable use of public money.

The personalised care and support planning handbook defines personalisation as, “Recognising people as individuals who have strengths and preferences and putting them at the centre of their own care and support” (NHS England, 2016b: 31). This involves centring care on the needs of the patient as an individual – “a more helpful proactive service, centred on the needs of each individual” (NHS England, 2016b: 5). The individual patient plays a crucial role in identifying their needs – “Personalised approaches involve enabling people to identify their own needs” (NHS England, 2016b: 31). It is also suggested that patients should be empowered to discuss, “what is important to them, setting goals they want to work towards” (NHS England, 2016b: 11). The discussions with professionals, “should be focused on what is being aimed for, from the individual’s perspective,” (NHS England, 2016b: 15). Hence, personalised

care and support planning is a person-centred approach that focuses on the individuals, tailoring care and support to individual needs and preferences. Moreover, personalised care and support planning signifies a holistic method – “Rather than considering each condition in isolation, personalised care and support planning takes a more holistic approach” (NHS England, 2016b: 12). This requires that, “All of the individual’s needs and outcomes should be considered” (NHS England, 2016b: 14), in order to ensure that interdependencies are known and incorporated into the delivery of care.

The personalised care and support planning handbook describes personalisation in relation to patient choice – “Personalised approaches involve enabling people to identify their own needs and make choices about how and when they are supported to live their lives” (NHS England, 2016b: 31). Alongside choice, personalised care and support planning is described as a process of collaboration – “a collaborative process between equals, whereby people with health and care needs, along with their family and/or carer, work together with care practitioners” (NHS England, 2016b: 11) – which is intended to encourage patients and their professionals to, “work together to clarify and understand what is important to that individual” (NHS England, 2016b: 6). Extending on this theme, personalised care and support planning demands, “more productive and equal conversations” (NHS England, 2016b: 11), and partnership is advocated – “the person with a long-term condition is an active and equal partner” (NHS England, 2016b: 6). Patients must be, “supported to be active and engaged in discussions about their care and support, with relevant and accessible information to help them make decisions” (NHS England, 2016b: 10). Acknowledging that, “People live with their conditions and/or disability every day and make decisions about how to manage them”, it is observed that, “Over time, they learn what works best for them, what information, care and support they need and how it fits into their life” (NHS England, 2016b: 11). Patients are recognised as experts in their own lives and there is an evident respect

for, “the assets and value that patients, carers and communities can bring to help deliver more effective, person-centred and sustainable care” (NHS England, 2016b: 5).

Personal health budgets represent another approach to personalise services within the NHS in England (NHS England 2014a, 2015a). Originally enacted as a pilot programme (DoH, 2008b), patients in receipt of NHS Continuing Healthcare and Continuing Care for Children now have the right to receive a personal health budget (NHS England, 2014a), and there has been a move towards the use of personal health budgets for other services (NHS England, 2015a). Personal health budgets are inherently linked to personalised care and support plans, which are required in order to, “clearly set out the health and well-being needs that the personal health budget is to address, the intended outcomes that the plan is to achieve, the amount of money in the budget and how this is going to be used” (NHS England, 2014a: 1). Personal health budgets have been associated with improved outcomes for patients. For example, it is documented that personal health budgets lead to, “an improved quality of life”, in addition to, “reduction in the use of unplanned hospital care”, particularly for, “people with high levels of need” (NHS England, 2014a: 8). Alongside improved outcomes is the suggestion that personal health budgets improve the cost effectiveness of care – “This will lead to individuals and the NHS benefitting from the improved outcomes, cost effectiveness and positive experience that personal health budgets can provide” (NHS England, 2014a: 9). They are often described in relation to increased, “value for money” (NHS England, 2014a: 15), drawing further attention to the suggestion that personal health budgets are a cost-effective model that delivers improved outcomes for patients.

A personal health budget is, “an amount of money to support a person’s identified health and wellbeing needs” (NHS England, 2014a: 8). It represents a more flexible approach to spending money – “It is not new money, but is money that would normally have been spent by the NHS on a person’s care being spent more flexibly to

meet their identified needs” (NHS England, 2014a: 8). There are three ways in which patients can choose to receive a personal health budget (NHS England, 2014a: 10):

1. *A notional budget - where the commissioner...holds the budget but utilises it to secure services bases on the outcome of discussions with the service user*
2. *A third party budget - where an organisation independent of the individual and the NHS manages the budget...and arranges support by purchasing services...*
3. *A direct payment - where money is transferred to a person or his or her representative or nominee who contracts for the necessary services*

The patient should be enabled to choose between these options, which reflect distinct levels of choice and control – “CCGs should ensure all three options are available to enable people to make a choice about the level of control they feel comfortable with” (NHS England, 2014a: 10). Critically, patients with a personal health budget should be enabled to, “spend the money in ways and at times that make sense to them” (NHS England, 2014a: 9), having direct control over its use, enabling them to have flexibility.

Personal health budgets are described as an approach that involves a combination of tailoring and patient choice – “The use of personal health budgets is just one way in which the NHS can tailor services and support for people to enable them to have choice, control and flexibility over their care” (NHS England, 2014a: 8-9). Supported by, “clear information about personal health budgets, tailored to people’s needs” (NHS England, 2014a: 9), patients should be, “enabled to choose the health and well-being outcomes they want to achieve, in dialogue with one or more healthcare professionals” (NHS England, 2014a: 9). Moreover, patients should be, “involved in the design of their care plan”, and able to, “request a particular model of budget that best suits the amount of choice and control with which they feel comfortable” (NHS England, 2014a: 9). The type of choice enabled should be flexible – “People are given a high

degree of flexibility and choice to spend their budget on services that make sense to them, which may include those not traditionally provided by the NHS” (NHS England, 2014a: 9). Therefore, all requests where patients, “can demonstrate that the proposed use of a budget is a reasonable way to achieve their health and wellbeing outcomes” (NHS England, 2014a: 16), should be enabled. Tailoring and choice require the provision of a service that is specific to the individual patient and care should be organised according to a holistic consideration of the individual, “including their aspirations, wishes and needs” (NHS England, 2014a: 9). It is recommended that personal health budgets, “adopt a positive approach to managing risk” (NHS England, 2014a: 9), taking into account the circumstances of the patient as well as their needs and preferences.

Personalised medicine is an additional approach to delivering personalisation within the NHS in England (NHS England, 2016e). It is presented in the context of scientific and technological advances, which are perceived as the foundations for a new, advanced age of medicine – “we stand on the brink of a new era of medicine” (NHS England 2016e: 4). Framed in global terms, a healthcare revolution is acknowledged – “Across the world, we are witnessing a healthcare revolution driven by scientific and technological advances – in genomics, informatics and bio nanotechnology” (NHS England 2016e: 4). Such is the novelty of personalised medicine, it is contended that, “If we get our approach right, the NHS will become the first health service in the world to truly embrace personalised medicine” (NHS England 2016e: 4). Nonetheless, there is also a conflicting narrative which suggests that personalised medicine is not transformational – “The concept of personalised medicine is not new” (NHS England 2016e: 5). Previous efforts to personalise are observed – “Clinicians have been working to personalise care, tailored to people’s individual health needs, throughout the history of medicine” (NHS England 2016e: 5). Consequently, to some extent, it is argued that personalised medicine builds on already present approaches to medicine.

Nonetheless, the essential difference is that, “never before has it been possible to predict how each of our bodies will respond to specific interventions, or identify which of us is at risk of developing an illness” (NHS England 2016e: 5). Hence, medical innovations, “make it possible to move to truly personalised care” (NHS England 2016e: 5).

Existing standardised approaches to medicine and treating illness and disease are presented as ineffective, or less effective, when contrasted with personalised medicine – “All patients with the same condition receive the same first line treatment even though it may be only 30 to 60% effective” (NHS England 2016e: 7). Personalised medicine is viewed as more effective in the prediction and prevention of disease – “Using genomic technologies and other diagnostics we will be able to identify people most at risk of disease” (NHS England 2016e: 12). Earlier detection has, “the potential to reduce the growing burden of disease, particularly for long term conditions such as cardiovascular diseases, cancer, chronic respiratory diseases and diabetes” (NHS England 2016e: 12). There is also an assertion that personalised medicine will lead to more precise diagnoses and improved outcomes (NHS England 2016e: 12):

Knowledge of each individual’s complex molecular and cellular processes, informed by other clinical and diagnostic information, will enable us to fully understand the abnormal function and determine the true cause of the symptoms.

Knowledge of the genetic variants responsible for individual drug response can be used to create an individual’s ‘pharmacogenomic’ profile, identifying optimal treatment

Personalised medicine is presented in relation to the challenge of rising demand – “We are facing a challenging time in the NHS. Demand continues to rise, placing our services and our staff under huge pressure” (NHS England 2016e: 14). This is framed in relation to challenges triggered by financial pressures – “it is clear, when funding is so

tight, that the pressures on the NHS cannot be relieved by continuing with business as usual” (NHS England 2016e: 14). Personalised medicine is viewed favourably in this context; advocated as an approach that will help to maximise the value secured in relation to the money spent on medicine – “Personalised medicine will help to maximise the value we can secure from the £15billion that the NHS currently spends on drugs each year” (NHS England 2016e: 8). Arguing that personalised medicine will generate, “the opportunity to find new purposes for, and better use of, existing medicines including generics and biosimilars” (NHS England 2016e: 8), and to strengthen the competency, “to design appropriate health and care for our local populations through a more sophisticated understanding of the impact of age, gender and ethnicity or lifestyle factors that influence the onset of disease” (NHS England 2016e: 13), it is competed that the introduction of personalised medicine, “will enable us to be far smarter in the way that we manage and leverage the limited resources that we have” (NHS England 2016e: 13). In other words, it is suggested that personalised medicine will enable the NHS to achieve greater value-for-money.

Personalised medicine involves the tailoring of treatment to the individual – “We will create a healthcare system focused on improving health, not just treating illness, able to accurately predict disease and tailor treatments” (NHS England 2016e: 4). This represents the opposite of standardisation, with treatment specifically tailored to the needs of the patient as an individual – “a move away from a ‘one size fits all’ approach to the treatment and care of patients with a particular condition, to one which uses new approaches to better manage patients’ health and target therapies” (NHS England 2016e: 6). This is achieved via the identification of patterns – “By combining and analysing information about our genome, with clinical and diagnostic information and then comparing that with data from others” (NHS England 2016e: 6). This pool of data is

then applied to personalise medicine for the patient – “this information can help to determine our individual risk of developing disease, detect illness earlier, provide an accurate diagnosis, and determine the most effective interventions to help improve our health” (NHS England 2016e: 6). Finally, a more participatory role for patients is defined – “We will create a healthcare system focused on improving health, not just treating illness, able to accurately predict disease and tailor treatments, with shared decision making at its heart” (NHS England 2016e: 4). It is explained that significant advances in genome sequencing, increased knowledge of lifestyle and environmental factors and utilisation of wearable technology will broaden the discussion and, “drive a new type of conversation” (NHS England 2016e: 13). An emphasis is placed on patients using information to assess their options and make more informed choices.

Personalisation and Policy Translation

Attention will now be given to understanding how personalisation has progressed from adult social care to healthcare. Needham has pertinently concluded that, “presence in multiple sectors is to some extent intrinsic to the personalisation storyline itself, with its emphasis on the need to treat people holistically, rather than in silos” (2011:81). Moreover, interviews she conducted with NHS stakeholders revealed the perspective that, “it was people with long-term conditions who pushed for the introduction of personal health budgets, based on their experiences of utilising social care services” (Needham, 2011: 81). In other words, disabled people themselves played a role in shifting personalisation from adult social care to healthcare, centred on positive experiences of individual budgets. The movement of personalisation from social care to other sectors can also be explained by the distinct policy problems faced within each sector, leading to the import of personalisation as a policy solution that has been demonstrated to have worked elsewhere (Needham, 2011). For example, within the

NHS in England, there is a recognition that increasing patient and public expectations, imperatives to improve quality and outcomes and the changing health needs of the population – such as the growth of long-term conditions and increased life expectancy – signify a threat to the financial viability of the NHS (Wanless, 2002). Personalisation can be seen as a measure enacted to solve this problem. As Needham observes of initial personalisation reforms, “Expert patient and self-care approaches were felt to contribute to the continued financial viability of the health service” (2011:81).

High Quality Care for All outlined the intention to pilot personal health budgets and ensure that everyone with a long-term condition had a personalised care plan (DoH, 2008b). The document hypothesised many challenges that made the movement towards such personalised approaches imperative. First, the challenge of ‘ever higher expectations’ linked new technologies to recent generations’ experiences of control and personalisation and argued that, “They expect not just services that are there when they need them, and treat them how they want them to, but that they can influence and shape for themselves” (DoH, 2008b: 26). Second, the issue of ‘demand driven by demographics’ was seen as requiring the NHS, “to be forward-looking, proactively identifying and mitigating health risks” (DoH, 2008b: 27). Third, the challenge of the changing nature of disease required that the NHS needed to respond by delivering personalised care for people with long-term conditions. Adopting the argument that, “migration from social care into other sectors may be explained in part by the distinctive policy problems facing each sector, which led them to import a policy ‘solution’ from elsewhere” (Needham, 2011: 81), it is evident that the challenges presented alongside the promotion of personalisation played a significant role in the passage of personalisation from social care to the NHS in England, viewed as the problems to which personalisation may solve. That this dispersal was impacted by the perceived success of personalisation in social care is evident in the contents of the report itself, wherein it is clear

that support for personal health budgets was linked to experiences of individual budgets in social care and similar reforms to healthcare internationally – “Learning from experience in social care and other health systems, personal health budgets will be piloted” (DoH, 2008b: 10).

Attention will now be given to conceptually categorising the movement of personalisation to health from social care. Policy diffusion is a, “process by which an innovation is communicated through certain channels over time among members of a social system” (Berry and Berry, 1999: 171). In other words, “Diffusion describes a trend of successive or sequential adoption of a practice, policy or programme” (Stone, 2012: 484). The diffusion of policy does not constitute an intentional process. Instead, policy is considered to spread unintentionally from one system, or environment, to another – “Policy is presumed to be contagious rather than the end result of political interactions” (Stone, 2012: 485). It focuses on the influence of external factors and the role of structure on the movement of policy across systems. It postulates, “incremental changes in policy as knowledge and pressure for it spreads” (Stone, 2012: 484). Some agency is required to implement the policy that diffuses, but the diffusion in itself is unintentional. Intentionally advocated on the basis that it offered a solution to perceived policy problems, the movement of personalisation from adult social care to the NHS in England is not appropriately categorised as an example of policy diffusion.

In contrast with diffusion, policy transfer explains the movement of policy between systems in terms of agency and internal decision-making dynamics. As Stone has explained, “The logic of choice in selection of policy ideas, the interpretation of circumstances or environment and (bounded) rationality in imitation, copying and modification by decision-makers were central to many analyses” (2012: 485). Policy transfer is intentional and rational, and includes policies that proactively utilise knowledge and learn lessons from other policies employed elsewhere – “transfer is a voluntary

process undertaken by civil servants and politicians seeking to emulate ‘best practice’” (Stone, 2012: 485). Transfer does not necessarily involve convergence between the policy studied and the policy adopted, “especially when negative lessons are drawn from experience elsewhere and contribute to divergence” (Stone, 2012: 485). There are various different types of transfer, from the transfer of policy goals and ideals to transfer of institutions or regulatory, administrative or judicial tools. The assumptions of transfer are questionable in the context of personalisation, especially when an interpretive perspective on policy analysis is considered. As Needham has evaluated, “Approaching personalisation with interpretive tools means abandoning the assumption that policies have fixed meanings” (2011: 14). In its place, policy is perceived as socially constructed and contingent on context, lacking the fixed meaning and associated portability necessitated in order to categorise its movement as policy transfer.

Policy translation recognises that the movement of policy from one setting to another is often characterised by, “Divergence and hybridisation, adaption and mutation” (Stone, 2012: 487). It also recognises that, “a series of interesting, and sometimes even surprising, disturbances can occur in the spaces between the creation, the transmission and the interpretation or reception of policy meanings” (Lendvai and Stubbs, 2007: 175). Critically, this questions and contests the assumption that policy diffuses or transfers in an unmediated fashion, criticising the rationalist bias inherent with these approaches and placing emphasis on the complexity of context and the need for interpretation and experimentation in the creation, transmission and implementation of policy. Crucially, the idea of policy translation acknowledges that policy cannot always be simply dragged and dropped from one context to another – “Often policies and practices are simply not ‘transferable’ since they have grown out of the legal, educational and social systems of their ‘host state’ and are neither ideologically nor culturally prox-

imate” (Stone, 2012: 488) – requiring adaptation to fit within the specific context a policy is translated into. The advantage of the translation literature is that it, “offers a view of policy that is much less stable and portable than the account offered by the transfer model” (Needham, 2011: 83). Thus, “a sociology of translation works with a much more fluid and dynamic framework” (Lendvai and Stubbs, 2007: 179). This draws attention to the way in which policy is translated, interpreted and transformed as it migrates and is particularly appropriate given the ambiguous and multi-interpretable nature of personalisation (as outlined in chapter two). As Needham has explained, “As personalisation develops, it is possible to observe it mutating as well as migrating” (2011: 84). Personalisation adopts distinctive local characteristics that have depended on the sector in which it is operates. Consequently, it is appropriate to consider personalisation as an example of policy translation.

Conclusion

This chapter examined the emergence of personalisation within social care and traced its translation from social care to its application within the NHS in England, describing and analysing a selection of critical transformations. Attention was given to its origins in the campaigns and activities of grassroots organisations of disabled people, the role of policy entrepreneurs in constructing and spreading the idea of personalised public services in addition to the broader political contexts in which it was constructed. Explained as a consequence of the distinctive policy problems facing the NHS – threats to financial sustainability arising from increasing expectations, imperatives to improve quality and outcomes and the changing health needs of the population – movement of personalisation from social care to healthcare was explained as an example of policy translation. This acknowledges the socially constructed and contingent nature of personalisation, contesting the assumption that policy simply transfers in an unmediated

fashion and highlighting the way in which policy is redefined, reinterpreted, and transformed as it moves from one sector to another. This draws attention to the variability of policy meaning and interpretation, and highlights the importance of analysing policy within the specific context in which it is constructed. The fourth chapter will explain the approach to examining the interpretation of personalisation within the NHS in England.

4. METHODOLOGY AND METHODS

This chapter describes the methodology and research methods applied to study the interpretation of personalisation by healthcare professionals working in the NHS in England. First, the ontological, epistemological and methodological bases of the interpretive paradigm will be explained and its appropriateness to understanding the interpretation of personalisation will be established, drawing on theories of Interpretive Policy Analysis. Second, the research questions will be defined and the research design will be delineated, to explain how the research intended to examine the interpretation of personalisation and perspectives on practice. Required criteria for individuals to participate in the study will be demarcated and the sampling frame will be described, drawing on an interpretive reinterpretation of generalisation. Justification will be provided for examining personalisation from a diversity of perspectives, using heterogeneity to facilitate triangulation and transferability. Third, the process and rationale behind the recruitment of participants will be explained, providing detailed insight into the practical steps implemented to recruit healthcare professionals. The problem of sample size will be considered and the recruited sample will be described in order to provide context on the findings reported in the fifth chapter. Fourth, the application of semi-structured interviews will be described and justified. The topic guide will be demonstrated and the advantages and disadvantages of telephone interviews compared to face-to-face interviews will be discussed, drawing attention to rapport and probing as critical to data quality and highlighting the proactive measures undertaken. Finally, the thematic data analysis will be explained, providing a step-by-step guide to the analysis of data.

Interpretive Methodology

A first step in the research process is the justification of the methodology utilised to acquire knowledge. Defined as, “the strategy, plan of action, process or design lying

behind the choice and use of particular methods and linking the choice and use of methods to desired outcomes” (Crotty, 1998: 3), Denzin and Lincoln have observed that the notion of methodology, “focuses on the best means for gaining knowledge about the world” (2011: 91). It is absolutely critical to justifying the application of specific research designs and research methods to the study of specific research problems. Described as, “the three musketeers” (Moses and Knutsen, 2007: 5), methodology derives its foundations from the consideration of ontology and epistemology. Ontological concerns relate to the nature of being (Bryman 2008, Crotty, 1998; Denzin and Lincoln, 2011; Moses and Knutsen, 2007; Neuman, 2014). The key question is whether social phenomena, “should be considered objective entities that have a reality external to social actors, or...social constructions built up from the perceptions and actions of social actors” (Bryman, 2008: 18). Epistemology denotes the nature of knowledge (Bryman 2008, Crotty, 1998; Denzin and Lincoln, 2011; Moses and Knutsen, 2007; Neuman, 2014) and focuses on, “how we know what we know” (Neuman, 2014: 95). The epistemological question concerns whether there is an objective truth or whether knowledge derives from a subjective process of meaning-making.

The term ‘paradigm’ has been utilised to describe overall approaches to research, encompassing complementary positions on ontology, epistemology and methodology (Denzin and Lincoln, 2011; Neuman, 2014). Being defined as, “a basic set of beliefs that guide action” (Denzin and Lincoln, 2011: 91), Neuman has observed that paradigms are, “A general organizing framework for theory and research that includes basic assumptions, key issues, models of quality research, and methods for seeking answers” (2014: 96). In the study of the social sciences, several paradigms coexist – for example, positivism and interpretivism – providing distinct approaches to research (Denzin and Lincoln, 2011; Neuman, 2014). These offer diverse viewpoints, “not only on the social event we wish to study but also on the most important questions, the

types of relevant data, and the general way to go about creating knowledge” (Neuman, 2014: 93). Drawing on the study of the natural world, positivism adopts realist ontology wherein, “social phenomena and their meanings have an existence that is independent of social actors” (Bryman, 2008: 19). The idea is that the ‘real’ world is independent of, “humans and their interpretations of it” (Neuman, 2014: 94). Positivism also adopts an objectivist epistemology, where, “we all share the same fundamental experience of the empirical world” (Neuman, 2014: 100). This means that researchers are able to study social phenomena objectively, without influencing or being influenced. Consequently, positivist methodology focuses on empirical observation to develop law-like generalisations in an endeavour to, “discover and confirm a set of probabilistic causal laws that can be used to predict general patterns of human activity” (Neuman, 2014: 97).

There are several problems to studying personalisation from the more ‘rational’ and positivistic perspective that traditional approaches to policy analysis involve. First, “personalisation cannot be defined without reference to the different ways in which policy actors frame it” (Needham, 2011: 5). This draws attention to the challenge of measuring and evaluating personalisation when multiple definitions are evident in practice, as recognised by the personalisation literature (Duffy, 2010a; Ferguson, 2007; Leadbeater, 2004; Needham, 2011; Parker and Heapy, 2006) and as outlined in chapter two. As Yanow has analysed, “there is no single, correct solution to a policy problem any more than there is a single correct perception of what that problem is” (1996: 3). In other words, as Needham has explained, “Problems of definition attach to both the problems that personalisation aims to solve and the solution it offers” (2011: 5). Second, as it was delineated within the third chapter, as the interpretation and application of personalisation diverges between public sectors, “personalisation cannot be measured in a way that looks across public services” (Needham, 2011: 5). This is not problematic to this study as it focuses on personalisation within a single sector – the NHS

in England. Yet, as described within the third chapter, the application of personalisation has varied within distinct public sectors – including the NHS in England – and this is an issue for the measurement of personalisation in this context. Finally, it is argued that personalisation, “cannot easily be evaluated because its definition and goals are too fluid to allow a formal test of whether or not it has worked” (Needham, 2011: 5).

There has been an acknowledged ‘interpretive turn’ in policy analysis (Fischer, 2003; Hajer, 2005; Yanow, 1996, 2000). Rejecting the positivistic assumptions of traditional approaches, the interpretive approach is founded on the pertinent, “presupposition that we live in a social world characterized by the possibilities of multiple interpretations” (Yanow, 2000: 5). Consequently, IPA focusses on, “meanings of policies, on the values, feelings, and/or beliefs which they express, and on the processes by which those meanings are communicated to and ‘read’ by various audiences” (Yanow, 1996: 14). In other words, interpretive approaches advise that (Needham, 2011: 14):

...policy analysis is best approached as an attempt to understand how a wide range of actors use policy to convey certain meanings, how far meanings are shared, how some meanings come to be dominant and how they shape practice

This approach is compatible with the ontological relativism and epistemological subjectivism of the interpretive paradigm, recognising the essential role of interpretation in the sense-making process (Denzin and Lincoln, 2011; Moses and Knutsen, 2007; Neuman, 2014). In contrast with positivist approaches to policy analysis (Yanow, 2000: ix):

...interpretive policy analysis shifts the discussion from values as a set of costs, benefits, and choice points to a focus on values, beliefs, and feelings as a set of meanings, and from a view of human behaviour as, ideally, instrumentally and technically rational to human action as expressive (of meaning)

Where a positivist approach may involve the comparison of costs and outcomes across sites, interpretivists focus on meaning and the people for whom a policy has meaning.

Although there is not a shared standard definition of interpretive methodology, there are various consistencies that unite advocates of the interpretive paradigm. First, they align under an assumption of relativist ontology (Denzin and Lincoln, 2011; Moses and Knutsen, 2007; Neuman, 2014) – “there is no clearly delineated social world: there are many” (Moses and Knutsen, 2007: 193). As Neuman has explained, “Social reality is largely what people perceive it to be; it exists as people experience it and assign meaning to it” (2014: 103). In other words, reality is subjective. This draws attention to the perception of personalisation by participants, recommending that personalisation is subjectively perceived and not objectively observed. Consistent with ontological relativism, interpretive methodology strives to understand reality as it is experienced by the individual, recognising that social reality does not exist independently of the individual and their perception (Denzin and Lincoln, 2011; Moses and Knutsen, 2007; Neuman, 2014). Based on the perspective that, “the beliefs and meaning that people create and use fundamentally shape what reality is for them”, studies adopting an interpretive methodology strive to, “learn what is meaningful or relevant to the people he or she is studying” (Neuman, 2014: 104). This draws attention to the importance of empowering participants to reveal their perceptions of personalisation independently to ensure that the researcher can more fully comprehend the social reality within which they interpret personalisation and construct their perspectives and attitudes towards practice.

Second, interpretivist methodology generally adopts a subjectivist perspective on epistemology. Knowledge is perceived as subjective and dependent on the contexts in which it is constructed (Denzin and Lincoln, 2011; Moses and Knutsen, 2007; Neuman, 2014). As Moses and Knutsen have noted, “Knowledge...is always knowledge-in-context” (, 2007: 194). Critically, the use of subjectivist epistemology recognises that

knowledge of personalisation necessarily depends on the specific contexts in which it is acquired and constructed. Consistent with epistemological subjectivism, interpretive researchers seek to scrutinise the contexts in which social reality is experienced and knowledge is constructed (Denzin and Lincoln, 2011; Moses and Knutsen, 2007; Neuman, 2014). In other words, interpretive methodology tends to favour, “approaches that allow them to interrogate and appreciate the details of a particular story” (Moses and Knutsen, 2007: 221), as this recognises that all knowledge depends on the contexts in which it is constructed. In studying the interpretation of personalisation, this draws attention to the significance of situating any and all findings within their relevant contexts.

Approaching personalisation from an interpretive perspective offers the potential to understand and explain the policy in terms of the meaning that policy audiences interpret as they come into contact with personalisation in practice. As Needham has analysed, “Approaching personalisation with interpretive tools means abandoning the assumption that policies have fixed meanings” (2011: 14). Personalisation should be studied using approaches that acknowledge the subjective, socially constructed, contingent and fluid nature of policy meaning, recognising the validity of multiple interpretations of personalisation and seeking to understand and explain the meanings that are conveyed by relevant audiences. In relation to relevant policy audiences, drawing on bottom-up theories of policy implementation (Berman, 1978; Hjern, 1982; Hjern and Hull, 1982; Hull and Hjern, 1987; Lipsky, 2010), it should be acknowledged that, “Policy is not something that proceeds in one direction, from centre to periphery, rather it is also made in the interactions of local staff, and in the communications they make back to central policy actors” (Needham, 2011: 14). Clients and citizens should not be perceived as, “passive recipients of a policy’s meaning, but as active readers themselves of legislative language and agency objects and acts” (Yanow, 1996). These groups are more than audiences; through the interpretation of meaning they construct policy. For

this reason, it is important to understand how these policy audiences interpret personalisation and the implications of these interpretations for practice. This study concentrates on interpretation of personalisation by healthcare professionals. In the future, a similar study should be applied to examine patient interpretations of personalisation.

Research Design

The research for this thesis was designed to examine the interpretation of personalisation by healthcare professionals working within the NHS in England. The objective was to explore how personalisation is interpreted by professionals in practice and the consequences of these interpretations for practice. In particular, the research was interested in the practical implications of healthcare professional interpretations for the expected roles of patients and professionals and the relationship between NHS patients, professionals and the state. Based on their relative autonomy and discretion, healthcare professionals were theorised to possess significant influence over the practice of personalisation. Therefore, drawing on the inherent ambiguity of personalisation and theorised significance of meaning to practice, the interpretations of healthcare professionals was postulated as essential to personalised practice. Beyond interpretation, the research also intended to examine professional perspectives on personalisation in practice. The intention was to investigate professional experiences of personalisation in order to comprehend the dynamics that influence practice. To structure the study of these objectives, two primary research questions were pursued:

1. *How do professionals working in the NHS in England interpret personalisation?*
2. *What are the perspectives of professionals on the practice of personalisation?*

In order to study the interpretation of personalisation by healthcare professionals it was essential to define criteria, or scope, to specify when an individual should be included or excluded from participation (Table 4.1). In practice, the study focused on regulated

professionals working directly with patients within the NHS in England. The first criterion precludes non-medical, clerical, administrative and other similar staff from participating on the basis that personalisation centres on the relationship between patients and healthcare professionals. The second criterion excludes individuals employed outside of the NHS in England from participating in the study, on the basis that the Governments in Scotland, Wales and Northern Ireland all have devolved authority over the NHS in their nations. Consequently personalisation policy has diverged, as evidenced by the connection between personalisation and self-directed support in Scotland (Scottish Government, 2010) but not elsewhere. The final criterion prevents managers and other professionals without frontline responsibilities from participating in the research. Whilst other stakeholders may have an influence on the interpretation and practice of personalisation, most critical are those professionals working directly with patients.

Table 4.1: Recruitment Criteria

Criteria	Specification
Healthcare professional	The individual must be a practicing healthcare professional. In the UK, several organisations oversee the professions via regulation. For example, all doctors are regulated by the General Medical Council. Individuals satisfy this criteria provided their profession is regulated by such an organisation.
Employed by the NHS in England	The individual should be currently employed by the NHS in England. There are no further limits to location – individuals can work within any of the regions. The type of NHS employer is not limited to particular organisations. Therefore, individuals can be employed within Clinical Commissioning Groups, General Practices and NHS Trusts. Individual can be employed full-time, part-time and also in multiple roles.
Works directly with patients	The healthcare professional should work directly with patients. This can be in a variety of forms, including assessing needs and providing care and support. This is critical since it is patients to whom care is expected to be personalised.

In the recruitment of participants to take part in this study it was necessary to consider the purpose of the study and the implications of different approaches to sampling. The study is oriented towards understanding the interpretation of personalisation

by professionals. Another approach would have been to have studied particular cases, investigating personalisation with a particular professional cohort or particular location. Due to this orientation, particular professionals will be studied in order to provide insight into the wider phenomena of professional interpretations and perspectives on practice. Individuals will be studied in depth, context will be scrutinised in detail and findings will be situated in context (fitting with interpretive methodology) but they will be researched for their instrumental (i.e. not intrinsic) value. Therefore, the research will be designed to maximise the capacity to transfer the findings from the sample – “the segment of the population that is selected for investigation” (Bryman, 2008: 168) – to wider populations – “the universe of units from which the sample is to be selected” (Bryman, 2008: 168). Generalisation will be reinterpreted in interpretive terms, ensuring that the particularity of individual interpretations and context-dependent nature of knowledge is recognised within the design, fieldwork, analysis and reporting of the study. Critically, overcoming the false dichotomy between particularity and generalisation represents a fashionable movement in qualitative research (Bassegy, 2001; Lincoln and Guba, 2000; May, 2011).

Traditional methods of generalisation are associated with the positivistic study of the natural sciences, using mathematical probability to generalise a finding from the sample to the population (Bryman, 2008; May, 2011; Neuman, 2014). Using probability sampling, the mathematically random choice of samples ensures they are representative of the population as, “each person in the population of interest has an equal chance of being part of the sample” (May, 2011: 99). Observing that, “While those techniques are a very effective basis for generalization, they are not essential” (2000: 104), Gomm et al. have defined an alternate tactic for representativeness, advocating consideration of, “relevant respects in which the target population might be heterogeneous” (2000: 105). They suggest that researchers should, “select a case that is, as far as possible, typical in relevant respects”, or, “study a small sample of cases that have been selected

to cover the extremes of expected relevant heterogeneity” (Gomm et al., 2000: 107). Both approaches are problematic in relation to interpretive methodology. Although they acknowledge the effect of context, these methods pursue forms of knowledge which transcend context. In other words, representativeness accounts for heterogeneity but its primary function is to enable the derivation of findings which apply to the population, independent of the contexts in which they are constructed. Particularity is obscured, discounting the context-dependent nature of knowledge advocated in interpretivism.

Interpretive commentaries on generalisation have reached agreement that it is, “in the sense of producing laws that apply universally...not a useful standard or goal” (Schofield, 2000: 75). However, a rejection of generalisability, “as a search for broadly applicable laws is not a rejection of the idea that studies in one situation can be used to speak to...other situations” (Schofield, 2000: 76). Therefore, various scholars have reconceptualised generalisation to align with interpretive methodology (Bassey, 2001; Goetz and LeCompte, 1984; Lincoln and Guba, 2000). These approaches commonly identify thick description (Geertz, 1973) as a foundation for facilitating the transferability of findings from one context to another (Schofield, 2000). For example, in discussing the concept of fuzzy predictions, Bassey contended that the, “emphasis is on defining the characteristics of x, y, z and of the situation” (2001: 11). Promoting transferability – “How can one tell whether a working hypothesis developed in Context A might be applicable in Context B?” (2000: 40) – Lincoln and Guba have noted that, “the degree of transferability is a direct function of the similarity between the two contexts...Fittingness is defined as the degree of congruence between sending and receiving contexts” (2000: 40). To facilitate transferability, they have recommended that it is imperative for the researcher to provide, “sufficient information about the context in which an inquiry is carried out so that anyone else interested in transferability has a base of information appropriate to the judgement” (Lincoln and Guba, 2000: 40).

Since generalisability is appropriately regarded as, “a matter of the ‘fit’ between the situation studied and others to which one might be interested in applying the concepts and conclusions of that study” (Schofield, 2000: 93), this study will facilitate transferability by describing the participants studied alongside the presentation of findings. This will enable readers to make their own judgements about transferability. To further enhance transferability, the researcher will implement the fieldwork with a variety of healthcare professionals, across a cross-section of NHS services. This approach will be implemented since, “a finding emerging repeatedly in the study of numerous sites would appear to be more likely to be a good working hypothesis” (Schofield, 2000: 79). In particular, selection of participants according to factors on which the population is heterogeneous can facilitate greater transferability – “a finding emerging from the study of several very heterogeneous sites would be more robust and thus more likely to be useful in understanding various other sites” (Schofield, 2000: 79-80). To achieve this, purposive sampling will be operationalised – “researchers use their special knowledge or expertise about some group to select subjects” (Berg and Lune, 2012: 52) – in order to ensure that participants reflect a diversity of contexts. This will enable transferability through triangulation – “a phrase used by different schools of thought to represent how to handle multiple sources of data. This process entails making sure that evidence from different sources can corroborate the same fact or finding” (May, 2011: 235).

Various criteria were considered to distinguish between the diverse contexts into which healthcare professionals interpret and practice personalisation (Table 4.2). A mixture of service (major), patient (condition) and patient (demographic) were selected as the primary sampling criteria. Five groups were used to illustrate these contexts: 1) primary care; 2) secondary care; 3) community services; 4) services for children and young people; and, 5) mental health services. There is some overlap between

groups. For example, primary care is provided to children and young people and mental health services are often delivered in a community setting. Participants will only be assigned to ‘children and young people’ and ‘mental health’ groups provided they work specifically and solely with these patient. The study will also apply a secondary criteria to purposively sample participants. Provided the attention to professionals, three discrete healthcare professions will be sampled: 1) doctors; 2) nurses; and, 3) all others.

Table 4.2: Sampling Criteria

Criteria	Justification
Organisation	NHS services are provided by a variety of organisations, which are funded and organised differently, providing different types of services. Moreover, given the devolution of authority to the local level, there are likely to be variances in experiences of personalisation.
Patient (condition)	The NHS delivers services to patients with various conditions. Personalisation may be interpreted differently for different patients.
Patient (demographic)	Patients can be categorised into a variety of demographic factors. Personalisation may be interpreted differently for different patients.
Profession	NHS services are delivered by a variety of professionals. Personalisation may be interpreted differently by different professions.
Service (major)	The NHS is organised to primary, secondary and community care. Personalisation may be interpreted differently in different contexts.
Service (minor)	NHS services (major) can be divided into discrete services (minor). For example, accident and emergency is a category of secondary. Personalisation may be interpreted differently in different contexts.

Consideration of ethics is part of research design and it was necessary to seek ethical approval before conducting the fieldwork. Ethics were assessed and guided by the University of Birmingham’s (UOBs) ethical review process. Three dimensions of ethical study are informed consent, confidentiality and anonymity (Arksey and Knight, 1999; Bryman, 2008; Patton, 2002; Ritchie and Lewis, 2003). The concept of informed consent requires that the participants, “should be given as much information as might be needed to make an informed decision about whether or not they wish to participate” (Bryman, 2008: 694). Within this study, the interviewer requested that participants sign and initial a consent form before the interview. With telephone interviews, oral consent

was attained pre-interview and consent forms were completed post-interview. To make sure that all consent was informed, information was provided to participants through a participant information sheet, that summarised the study, and conversations between the researcher and participants, in which participants asked questions. Confidentiality requires that participant identities should not be revealed, which means, “not disclosing the identity of study participants...attributing comments...in ways that can permit the individuals...to be recognized” (Arksey and Knight, 1999: 132). This was achieved through the anonymisation of participants in reporting – though contextual information will be provided to place participants in context. Finally, the researcher took purposive steps to safeguard collected data. Interview data was collected utilising a digital audio recorder to capture conversations verbatim, providing an accurate record compared to written notes (Arksey and Knight, 1999), and, following transcription, recordings were deleted and transcripts were stored securely, accessible only to the researcher.

Participant Recruitment

Ritchie et al. have noted that, “Qualitative studies are almost invariably confined to a small number of geographical, community or organisational locations” (2003: 100). Scrutinising that, “This is partly so that the context in which the research is being conducted is known and partly for reasons of resource and efficiency”, they further critique that, “the locations selected are usually chosen because of their salience to the subject under enquiry” (Ritchie et al., 2003: 100). Within this study, the location of participants was inevitably tied to the process for research approval within the NHS in England – at the time of the study, proposals were subject to Health Research Authority (HRA) Approval. Following the completion of the University Of Birmingham’s ethical review process, an application for HRA Approval was approved. Within this system, research

is structured around the organisations via which NHS services are delivered. Therefore, the sampling of participants was necessarily tied to the selection of organisations. In practice, the study adopted a convenience strategy – “A convenience sample is one that is simply available to the researcher by virtue of its accessibility” (Bryman, 2008: 183) – limiting the consideration of organisations to those that were within an estimated two-hour journey from the researcher’s base location (Table 4.3), owing to the financial and temporal costs that arise from conducting fieldwork. Next, the researcher categorised organisations according to services using the primary sampling criteria. Categorisation was determined through a systematic content analysis of the formal documents that were collected from the websites of organisations within the geography of study.

Table 4.3: Sample Locations

Region	Areas (County/Metropolitan Borough/Unitary Authority)
East Midlands	Leicester, Leicestershire, Northamptonshire, Rutland
West Midlands	West Midlands (Birmingham, Coventry, Solihull), Warwickshire
East of England	Bedfordshire, Cambridgeshire, Peterborough
South East	Milton Keynes

At first, the researcher contacted a restricted quantity of NHS organisations – specifically, their departments for Research and Development (R&D) – by email and telephone, to request their participation in the research. Owing to the observation that there was a lack of capacity to participate among organisations, the researcher began to contact the full list of organisations. Of the organisations contacted, four agreed to participate. Within each site, the researcher requested a local contact to facilitate the fieldwork – either by inviting professionals to participate or providing the contact details of appropriate professionals. Three R&D departments complied with this invitation. Owing to difficulties in recruiting professionals within the remaining site, and despite repeated attempts to identify a local contact, this site was excluded. Of the three sites where a local contact was identified, only one local contact engaged with the study –

this individual provided the contact details of three professionals who had expressed an interest in the study. In order to supplement these interviews, a snowball approach was applied – “the researcher makes initial contact with a group of people...and then uses these to establish contacts with others” (Bryman, 2008: 184). Participants were requested to invite other professionals or provide contact details, leading to the recruitment of two participants. In one site where the local contact did not engage, issues lead to the exclusion of the site. In the remaining site, the researcher was able to recruit two professionals using contact details located on the organisation’s website. Overall, practical issues meant that it was not fully possible to purposively recruit participants to achieve a cross-section based on the primary and secondary sampling criteria.

To increase the sample size, and to ensure that primary and secondary groups were adequately sampled, the study adopted an alternative approach in the recruitment of further participants. Following re-approval within the UoB’s ethical review process, the study contacted five professional membership bodies – by email and telephone – to request participation. Organisations were selected purposively to represent the categories and participants that the study intended to sample (Table 4.4). Each of these organisation agreed to forward details of the research to members, encouraging professionals to get in contact with the researcher to participate. The researcher then made contact with those professionals who engaged to arrange participation. Through this method, ten professionals were recruited to participate: seven participants through the Royal College of Psychiatrists (RCPsych); one participant each through the Royal College of General Practitioners (RCGP), Royal College of Nursing (RCN) and Royal College of Physicians of London (RCP). Zero participants were identified via the Royal College of Paediatrics and Child Health (RCPCH). Following the approach used in the first method of recruitment, snowball sampling was used to identify further professionals, leading to the recruitment of four additional participants. As noted, the purposive

sampling of location is advocated (Ritchie et al., 2003). However, as participants were necessarily convenience sampled, it was impossible to purposively sample in this way.

Table 4.4: Professional Organisations

RCGP: The Royal College of General Practitioners (GPs) is the professional membership body that represents GPs in the UK. It was selected to enable the recruitment of doctors, nurses and other professionals working in the context of primary care.
RCP: The Royal College of Physicians of London is the professional body that represents physicians/doctors within England. This organisation was selected to enable the recruitment doctors working across a variety of services in the NHS in England.
RCPsych: The Royal College of Psychiatrists is the professional body representing Psychiatrists within the UK. This organisation was selected to enable the recruitment of doctors, nurses and other professionals working in the context of mental health .
RCPCH: The Royal College of Paediatrics and Child Health is the professional membership body that represents paediatricians within the UK. It was selected to enable the recruitment of doctors, nurses and other professionals working with children.
RCN: The Royal College of Nursing is the professional body that represents the nursing profession in the UK. It was selected to enable the study to recruit nurses.

The issue of sample size is pivotal, but complicated, in the context of qualitative research (May, 2011; Ritchie et al., 2003; Patton, 2002). Relating qualitative methods to depth, Patton notes that, “Qualitative methods permit inquiry into selected issues in great depth with careful attention to detail” (2002: 227). Put differently, “the type of information that qualitative studies yield is rich in detail. There will therefore be many hundreds of 'bites' of information from each unit” (Ritchie et al., 2003: 83-84). Since qualitative research aims at depth, sample sizes are relatively small: “qualitative methods...produce a wealth of detailed data about a much smaller number of people and cases” (Patton, 2002: 227); “qualitative samples are usually small in size” (Ritchie et al., 2003: 83). Nonetheless, issues of breadth are also applicable – “we could look at a narrow range of experiences for a larger number of people or a broader range...for a smaller number” (Patton, 2002: 227). Within this study, interpretivist methodology privileges the pursuit of depth. The purposive sampling of participants across diverse contexts, to improve transferability, is indicative of the pursuit of breadth. In order to

attain an appropriate degree of depth, the study sampled multiple participants within each of the primary and secondary sampling criteria, facilitating triangulation. To facilitate a satisfactory degree of breadth, the study intended to sample participants across the primary and secondary sampling criteria, enabling triangulation through cross-category comparison. In total, twenty-one healthcare professionals were successfully recruited to participate in this research. They were given a participant identification number based on classification within the primary sampling criteria.

The primary sampling criteria for the study was the work context within which a healthcare professional was working at the time of the interview. The final sample was comprised of six professionals working with children and young people, six professionals working in mental health, five professionals working in secondary care, three professionals working in the community and one professional working in primary care. The secondary sampling criteria was the profession of the participant and the final sample was comprised of eight professionals qualified as a doctor (various specialisms), seven professionals qualified as a nurse and six professionals from other professions. There were a total of three consultant psychiatrists, two speech and language therapists, two multiple sclerosis nurses, two physiotherapists and many other professions, including a midwife, consultant anaesthetist/intensivist and a learning disability nurse. From the twenty-one healthcare professionals that participated in the study, seven were working in Northamptonshire, five in Bedfordshire, four in Southwest London and one each was employed in Leicestershire, Birmingham, Northeast London, South London and West London. Therefore, a suitably diverse sample was recruited to participate in the study.

Semi-Structured Interviews

Research methods are the instruments that researchers utilise to collect data – “A research method is simply a technique for collecting data” (Bryman, 2008: 31). A

distinction is apparent between qualitative and quantitative methods (Berg and Lune, 2012; Bryman, 2008; Neuman, 2014). The quantitative approach emphasises quantity, adopting a structured approach to measurement and prediction. In contrast, qualitative methods focus on quality, applying an unstructured approach to describe and interpret. Given its overlap with the interpretive assumption that knowledge depends on context, qualitative methods will be used to investigate personalisation. Interviews will be the method adopted. Interviews are commonly used within social sciences. Indeed, they are so prevalent in society that it has been labelled an 'interview society' (Atkinson and Silverman 1997; Edwards and Holland, 2013; Fontana and Prokos, 2007; Silverman 1993). Various forms of interview are available, diverging along a spectrum between structured and unstructured approaches (Arksey and Knight, 1999; Edwards and Holland, 2013; Fontana and Prokos, 2007; Rubin and Rubin, 2012). This research will use semi-structured interviews, maximally combining the advantages of each method.

Unstructured interviews adopt a flexible approach: "the researcher will have decided only in general terms upon the main themes and topic areas to be explored, but will be flexible" (Arksey and Knight, 1999: 6); "It emphasizes flexibility of design and expects the interviewer to change questions in response to what he or she is learning" (Rubin and Rubin, 2012: 7). Flexibility is intended to facilitate a greater understanding of social phenomena from the perspective of the interviewee, enabling interviewees to describe their experiences within their own frames of reference and allowing interviewers to pursue emerging lines of enquiry. Researchers should endeavour to, "take the role of the respondents and attempt to see the situation from their viewpoint rather than superimpose his or her world of academia and preconceptions" (Fontana and Prokos, 2007: 46). In contrast, structured interviews are inflexible: "the structured interview is based on a questionnaire with a sequence of questions, asked in the same order and the same way of all subjects of the research, with little flexibility" (Edwards and Holland,

2013: 3); “The interviewer controls the pace of the interview by treating the questionnaire as...a theatrical script to be followed in a standardized and straightforward manner. Thus, all respondents receive the same set of questions asked in the same order” (Fontana and Prokos, 2007: 19). Structure is intended to facilitate the comparability of data across interviews, minimising the impact of context and ensuring topic coverage.

Since this research is designed to explore the interpretation of personalisation and perspectives on practice by healthcare professionals – in other words, since there are some topics that will need to be covered within each of the interviews – a certain amount of structure will be required. Nonetheless, interpretive methodology places an emphasis on the dependency of knowledge on context (epistemological subjectivism), encouraging researchers to investigate social phenomena from the perspective of participants (ontological relativism), which is a pursuit that demands flexibility of interview. Consequently, semi-structured interviews will be used. Flexibility will be applied within a malleable structure, combining the beneficial features of structured and unstructured interviews. Above, it was noted that there is a compromise between breadth and depth within qualitative modes of research (Patton, 2002). Pertinently, semi-structured interviewing enables breadth and depth. Depth is facilitated through the flexibility to probe responses, utilising the unstructured method - “Interviewers are free to follow up ideas, probe responses and ask for clarification or further elaboration” (Arksey and Knight, 1999: 7). Drawing on structured interviewing, breadth is facilitated by the application of a topic guide, ensuring that relevant topics are covered . In summary, “these interviews allow much more space for interviewees to answer on their own terms...but do provide some structure for comparison” (Edwards and Holland, 2013: 29).

Before the fieldwork commenced, a topic guide was designed for the interviews (Table 4.5). This served as an agenda based on the key topics that the study attempted to address – “The interview guide serves as a framework...and is based on the key

questions that the study is addressing” (Arksey and Knight, 1999: 97). The topic guide was based on open-ended questions, designed to encourage participants to answer the questions asked at greater length – “open questions are designed more as a trigger to stimulate the informant into talking freely about the particular area under discussion” (Arksey and Knight, 1999: 92). Whereas close-ended questions restrict answers, open-ended questions enable participants to interpret questions in line with their own experiences and respond accordingly. Questions were also framed in neutral terms, ensuring that interviewees could respond within their own frames of reference and were not guided to particular responses. Finally, ordinary language was used to ensure participants could easily understand the questions, following the recommendation given by Rubin and Rubin as follows – “Rather than asking about the academic theories themselves, which are often too abstract for an interviewee...you can ask about the behaviors or actions implied by the theory, which are more concrete” (2012: 135).

Table 4.5: Interview Guide

Subject	Questions
Roles and responsibilities	Can you describe your role and responsibilities? Can you describe the main challenges of your role?
Meaning of personalisation	What does personalisation mean to you? How do you feel about personalisation?
Practice of personalisation	What does personalisation mean for practice? What challenges are there for personalisation?
Conclusion of interview	Do you have any other comments on personalisation? Is there anything else you think I should know about?

In designing the topic guide, questions were ordered in a logical way. Rubin and Rubin have recommended that interviewers, “Begin by asking questions that provide the interviewees with a comfort level about their ability to respond” (2012: 108-109). To this end, the interviews commenced by asking participants various questions about their role and responsibilities, serving two purposes. First, the relatively straightforward

nature of these subjects enabled interviewees to familiarise themselves with the interview. Second, this provided contextual data which was used to situate participants, facilitating transferability. Logically, it was necessary to define personalisation prior to probing perspectives on personalisation in practice. Finally, interviewees were asked two unfocused questions to ensure sufficient space for discussion of further issues.

Crucially, the topic guide was implemented in a flexible manner. Although the interviewer ensured that all of the topics were covered, the ordering of topics varied dependent on the responses provided by the interviewees. Moreover, whilst questions were specified in advance they were implemented flexibly, drawing on the practice of unstructured interviewing (Arksey and Knight, 1999; Edwards and Holland, 2013; Rubin and Rubin, 2012). In addition, follow-up questions and probes – “questions, comments, or gestures used by the interviewer to help manage the conversation” (Rubin and Rubin, 2012: 118) – were applied. This practice enabled the interviewer to pursue emerging lines of enquiry, requesting further clarification and elaboration of responses – especially in relation to the identification of unanticipated themes and the implications of the perspectives participants were articulating. This is critical since, “Data that are insufficiently substantial, precise or clear may not constitute adequate evidence from which to draw conclusions” (Arksey and Knight, 1999: 98). For example, Arksey and Knight have noted that, “interviewees might use phrases or concepts that are open to a variety of interpretations...If meaning is not established, then the subsequent analysis stands to be flawed by unperceived misunderstandings” (1999: 100).

Text-book accounts of qualitative interviewing implicitly endorse face-to-face interviews as the preferred mode of implementation (Arksey and Knight, 1999; Edwards and Holland, 2013; Fontana and Prokos, 2003; Rubin and Rubin, 2012). Consequently, there has been relatively little exploration of alternative interview modes, such as telephone interviewing (Cachia and Millward, 2011; Carr and Worth, 2001; Novick, 2008;

Sturges and Hanrahan, 2004). Within this study, the researcher first set out to interview participants face-to-face. Of seven interviews conducted face-to-face, all were located at the organisation within which participants worked at a time, date and place convenient to them, arranged via a mixture of email and telephone communication. Pertinently, face-to-face interviewing was convenient owing to the short distance between interviewer and interviewee location, arising from the convenience sampling of location within the first phase of recruitment. Emerging from practical difficulties in participant recruitment, the study was expanded to enable recruitment within wider geographical locations. Thus, it was less convenient to conduct face-to-face interviews and the researcher offered subsequent participants the opportunity to participate in a telephone interview - all fourteen opted for this mode at a time and date of their choice, agreed through email and telephone contact. Critically, there is a growing literature endorsing the use of telephone interviewing in qualitative research (Cachia and Millward, 2011; Carr and Worth, 2001; Novick, 2008; Sturges and Hanrahan, 2004; Sweet, 2002).

Qualitative researchers tend to view telephone interviewing with a degree of scepticism, contrasting telephone interviews unfavourably with face-to-face interviews (Cachia and Millward, 2011; Carr and Worth, 2001; Novick, 2008; Sturges and Hanrahan, 2004). As Novick notes, "This attitude is implicit both in the omission of telephone interviews in qualitative research texts and in the small number of articles on telephone interviews" (Novick, 2008: 394). This attitude is also explicit in the descriptions of this method – "Methodical recommendations embody a clear preference for face-to-face interviews" (Cachia and Millward, 2011: 265). Methodologically, the use of telephone interviews has been criticised for its inhibition of rapport – "the degree of understanding, trust and respect that develops" (Arksey and Knight, 1999: 101). Telephone interviewing can also be criticised for its potential impact on the ability to probe, reducing

the depth of understanding that may be possible with face-to-face interviews. Opponents contend that lesser rapport and reduced probing can result in loss or distortion of data, compromising overall data quality – “Absence of visual cues could result in data loss or distortion, which, in turn, could harm data quality” (Novick, 2008: 395). These effects are often discussed in relation to the absence of visual cues since telephone interviews require that interviewer and interviewee contribute from independent locations. Sturges and Hanrahan note that, “The issue...is whether the lack of visual cues is critical to data quality and whether there are any compensating features” (2004: 114). The experience of this research suggests that the absence of visual cues is not necessarily harmful to data quality. Various methods can be applied to maximise verbal communication purposefully to the advantage of rapport, probing and data quality.

In designing interviews, the researcher proactively accounted for the facilitation of rapport between interviewer and interviewee. First, the interviewer engaged all participants in informal conversation prior to the interview commencing, attempting to ease nerves or anxieties and forming a relationship. Conversations often involved a mutual, brief discussion of how the day was going for the interviewee and the interviewer and what they had planned to do for the remainder of the day. The interviewer also used this opportunity to conduct introductions, demonstrating interest in the interviewee and providing interviewees with the background to the research and the researcher. From the reactions of interviewees it was clear that, in both face-to-face and telephone interviews, knowing the intentions of the researcher – which were described in terms of understanding practice from the perspective of professionals, using this knowledge to improve outcomes for patients and attaining a doctorate – encouraged a greater level of rapport, with interviewees often expressing identification with the ambitions of the interviewer. This also enabled the interviewer to verbalise the value of the interviewee, demonstrating a level of respect that helped in fostering a positive relationship and

rapport. Second, short verbal cues – “brief utterances like 'hmm', 'I see', or 'right'” (Arksey and Knight, 1999: 101) – were utilised in order to emphasise that the interviewer was listening, understanding and interested, reinforcing rapport through continuous verbalisation of the importance the interviewer placed on the contributions of interviewees. At the conclusion of many interviews, interviewees expressed their wishes of ‘good luck’ for the interviewer, satisfaction with the discussion and contribution to the research and a desire to view the final thesis. This can be interpreted as a positive indication of the rapport that had been fostered during the interviews. Therefore, while the lack of visual cues may restrict rapport, this research highlights the importance of strong verbal communication to facilitating rapport during telephone interviewing.

Telephone interviewing can be criticised for its potentially negative impact on the ability to probe, reducing the depth of understanding that may be possible compared with face-to-face interviews (Cachia and Millward, 2011; Carr and Worth, 2001; Novick, 2008; Sturges and Hanrahan, 2004). However, the experience of this study suggests that a sufficient level of probing is attainable within telephone interviews. Probing is significant since, “Data that are insufficiently substantial, precise or clear may not constitute adequate evidence from which to draw conclusions” (Arksey and Knight, 1999: 98). Within both types of interview – telephone and face-to-face – the interviewer implemented probing in a variety of situations. First, probing was applied when an interviewee had provided a summary response rather than a full description. In other words, probing was utilised to request an explanation from participants. Second, probing was applied where an interviewee had referred to concepts that have multiple interpretations in order to ensure that the meaning of these terms was clear. In other words, probing was exploited to attain the clarification of responses by establishing intended meaning, removing the potential for misinterpretation of responses. Third, non-visual cues provided opportunities for probing. For example, hesitations,

sighs, moments of silence and changes in tone of voice were perceived as potential verbal manifestations of unspoken thoughts and feelings that necessitated further probing by the interviewer. Hence, while the absence of visual cues removes the ability to probe on this basis, this study highlights the importance of verbal, non-visual cues to probing and the effective implementation of telephone interviewing. Furthermore, the interviewer experienced a similar outcome to that of Cachia and Millward – “The flow of the conversation is also sometimes regulated by the interviewee asking whether the response being given is that expected or if one is going into much detail” (2011: 272). This phenomenon can be interpreted as a form of self-probing, where the interviewees themselves ensure that the interviewer is able to achieve sufficient depth.

One advantage of telephone interviewing is that it can be more convenient for participants (Cachia and Millward, 2011; Carr and Worth, 2001; Novick, 2008; Sturges and Hanrahan, 2004). Within this study, issues in the recruitment of participants lead to the offering of telephone interviews, as an alternative to face-to-face, to potential participants. Informed by the feedback that healthcare professionals were stretched and had little time to participate in an face-to-face interview, subsequent offers of telephone interviews increased sample size dramatically – all of the fourteen participants recruited through this phase opted for a telephone interview. As with face-to-face interviews, participants were able to choose a time, date and place to suit their preferences. Participants variously elected to interview during their work breaks, after work and also over the weekend, either at home or at work, choosing a time, date and location that was convenient for them and undoubtedly facilitating recruitment. Telephone interviewees had the added convenience that telephone interviews can be more easily rearranged when compared to face-to-face interviews. Several of the interviewees had to postpone interviews on the day because something had come up at work or at home, with many expressing relief that they could rearrange for a time when they would be

more able to contribute. Additionally, if an interviewee was not able to postpone the interview in advance, they were able to cancel and rearrange when called at the agreed time – a few did so. For the interviewee, convenience enabled them to fit the interview into their busy schedules. It also meant that there was less impact on the researcher when interviews were rearranged as there was no time lost to travel. Finally, the use of telephone interviews enabled the interviewee and interviewer to control the environments. Some of the face-to-face interviews had experienced unavoidable disruptions from the environment, such as noise from nearby wards and offices. Although this did not decrease the quality of face-to-face interviews, a greater ability to control environments made telephone interviewing more convenient for interviewer and interviewee.

The importance of breadth and depth in qualitative research has been established. Pertinently, in the application of semi-structured interviewing, sufficient breadth was facilitated through the application of a topic guide which ensured that all topics were covered. There are no specific features of telephone interviews that differentiate the use of a topic guide for telephone interviews versus face-to-face interviews and, in practice, the interviewer ensured that all topics within the topic guide were covered in all interviews. Sufficient depth was facilitated via the probing of responses provided by interviewees, as outlined above. It has been suggested that, although the absence of visual cues removes the ability to probe on this basis, the expression of verbal and non-visual signals enables interviewers to achieve adequate degrees of depth during the implementation of telephone interviews. Using length as a surrogate for depth, face-to-face and telephone interviews had a relatively similar average and median length (Table 4.6). However, the range of telephone interviews was broader by comparison. This indicates that, although face-to-face and telephone interviews had comparable average depth, telephone interviews were more variable compared to face-to-face interviews, impacting data quality. Nonetheless, the range for both interview types

is impacted by three outliers. Excluding outliers (CS3, MH2, MH5), it is evident that the range is more comparable (Table 4.7), highlighting the equivalent quality of telephone and face-to-face interviews. Therefore, this research establishes that telephone interviews can be a valuable method for qualitative research, particularly when participants are faced with time constraints and the convenience of participation is imperative.

Table 4.6: Interview Comparison

Measure	Face-to-Face	Telephone
Average	00:28:09	00:30:38
Median	00:27:50	00:28:45
Minimum	00:17:45	00:09:09
Maximum	00:44:47	01:28:18
Count	7	14

Table 4.7: Comparison (continued)

Measure	Face-to-Face	Telephone
Average	00:25:23	00:27:37
Median	00:25:56	00:28:45
Minimum	00:17:45	00:16:54
Maximum	00:33:31	00:36:45
Count	6	12

Thematic Analysis

Data analysis refers to those measures which enable a researcher to organise and interpret the data they have collected. This research will use a thematic approach. Defined as, “Interpretive concepts or propositions that describe or explain aspects of the data” (Gale et al., 2013: 2), the application of themes within the thematic analysis enables researchers to identify, analyse and report patterns: “A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set” (Braun and Clarke, 2006: 82); “The development of themes is a common feature of qualitative data analysis, involving the systematic search for patterns to generate full descriptions capable

of shedding light on the phenomenon under investigation” (Gale et al., 2013: 3). Given emphasis on the identification of commonalities and particularities in the interpretation of personalisation by professionals, the application of thematic analysis – in terms of searching for patterns – is appropriate to this study. Furthermore, this approach is congruent with interpretive methodology, provided that emphasis is placed on describing and interpreting data in a manner such that derived themes are familiar to participants.

Qualitative data tends toward high volume owing to the richness of the data gathered via qualitative research methods and this can be difficult to manage (Ritchie et al., 2003; Spencer et al., 2003) – “the material is likely to be highly rich in detail but unwieldy and intertwined in content” (Ritchie et al., 2003: 211). Therefore, to manage qualitative data, it is necessary to specify a plan for its organisation – “organised steps to 'manage' the data are essential” (Ritchie et al., 2003: 211). Consequently, the study will adopt the Framework Method, which provides a systematic approach to the conduct of thematic analysis (Gale et al., 2013; Ritchie et al., 2003; Ritchie and Lewis, 2003; Smith and Firth, 2011). As Gale et al. have commented, “The Framework Method provides clear steps to follow and produces highly structured outputs of summarised data” (2013: 2). The advantages are outlined as follows (Smith and Firth, 2011: 52-53):

This enables the researcher to explore data in depth while simultaneously maintaining an effective and transparent audit trail, which enhances the rigour of the analytical processes and the credibility of the findings

Pertinently, this method also counters the pertinent critique that thematic analysis can often be underspecified and that, “If we do not know how people went about analysing their data, or what assumptions informed their analysis, it is difficult to evaluate their research...clarity on process and practice of method is vital” (Braun and Clarke, 2006: 80). A full account of the steps taken to analyse data will be provided to counter this.

The first step in the thematic analysis was the transcription of data (Braun and Clarke, 2006; Gale et al., 2013; Pope et al., 2000). Defined as, “A written verbatim (word-for-word) account of a verbal interaction” (Gale et al., 2013: 2), audio recordings obtained during interviews were converted to digital transcripts. It was critical that the transcription process retained the original meaning of the data – “What is important is that the transcript retains the information you need, from the verbal account, and in a way which is ‘true’ to its original nature” (Braun and Clarke, 2006: 88). Therefore, the researcher transcribed the audio recordings verbatim, ensuring that the contents of the transcripts accurately reflected the interviews. Following transcription, the researcher coded the transcripts. Defined as, “A descriptive or conceptual label that is assigned to excerpts of raw data” (Gale et al., 2013: 2), codes were used to summarise important aspects of the data. In practice, the researcher read individual transcripts line-by-line, manually applying codes to those parts of the transcript which seemed to be important to understanding participant perspectives and answering the research questions.

Prior to coding and based on extensive literatures on the meaning of personalisation, an index of codes was constructed to differentiate between various themes of personalisation (Table 4.8). Therefore, a deductive approach to coding was applied in relation to answering the primary research question. Deductive approaches tend to be, “driven by the researcher’s theoretical or analytic interest in the area, and is thus more explicitly analyst-driven” (Braun and Clarke, 2006: 84). Themes and codes are, “pre-selected based on previous literature, previous theories or the specifics of the research question” (Gale et al., 2013: 3). The principal justification for this approach is that the interpretation of personalisation has been analysed extensively in literature. Therefore, the range of potential interpretations was known in advance of the study, although this is not to say that other meanings are not possible. Braun and Clarke have observed that, “This form of thematic analysis tends to provide less a rich description of the data

overall, and more a detailed analysis of some aspect of the data” (2006: 84). This suggests that aspects of the data can be overlooked when using a deductive approach, representing a potential weakness. Nonetheless, given the comprehensiveness of the literature review, this problem was considered unlikely to have a real impact. Critically, despite adopting a deductive approach, it is also recognised that the researcher played an active role in the interpretation of the data during coding and that different researchers can interpret the same dataset differently, even when they are confronted with the same themes in a similarly organised and conducted deductive and thematic analysis.

Table 4.8: Coding Index

Justifications for Personalisation	Code
T1: Personalisation works, transforming people’s lives for the better	1
T2: Personalisation saves money	2
T3: Person-centred approaches reflect the way people live their lives	3
T4: Personalisation is applicable to everyone	4
T5: People are experts on their own lives	5
Perceptions of Personalisation	
T6: Personalisation is evolutionary, continuous and consolidating	6
T7: Personalisation is revolutionary, disruptive and transformational	7
Nature of Personalisation	
T8 Increasing responsiveness by tailoring to needs and/or preferences	8
T9: Giving users more say, keeping them informed and offering choice	9
T10: Direct say over money, enabling individuals to make their own decisions	10
T11: Co-production, active participation, choosing outputs and shaping inputs	11
T12: The public good emerging collectively through individual decisions	12

The second research question is about the perceived implications of personalisation for practice. Relatively little research has studied the perspectives of healthcare professionals on personalisation within the NHS in England – although there has been some interest (Banks et al., 2016; Coyle, 2011; Forder et al., 2012; Simpson et al., 2016). Therefore, the research applied an inductive approach to analysing the data. Inductive approaches are driven by data – “a process of coding the data without trying to fit it into a pre-existing coding frame, or the researcher’s analytic preconceptions” (Braun and Clarke, 2006: 83). In practice, “themes are generated from the data though

open (unrestricted) coding, followed by refinement of themes” (Gale et al., 2013: 3). However, given the subjective nature of interpretation, it is recognised that researchers are not able to, “free themselves of their theoretical and epistemological commitments, and data are not coded in an epistemological vacuum” (Braun and Clarke, 2006: 84). In other words, it is recognised that the researcher played an active role in the interpretation of the data throughout the coding process, resulting in the following themes (Table 4.9). The themes were the product of an iterative process where the researcher read individual transcripts line-by-line, manually applying codes to those parts of the transcript interpreted as relevant to the research question. This resulted in the development of a coding index which was used to apply codes uniformly across transcripts.

Table 4.9. Index (continued)

Personalisation in Practice	Code
Theme 13: Time pressures constrain personalisation	13
Theme 14: Standardised resources are problematic	14
Theme 15: Financial constraints hinder personalisation	15
Theme 16: Professional expertise retains importance	16
Theme 17: Management and organisation matter	17
Theme 18: Interpretation influences practice	18

Codes within the indices were systematically applied to each interview transcript. For recording purposes, codes were allocated a numerical value, noted in the margins of the transcript and the relevant text was highlighted on a paper copy. In cases where multiple codes applied to the same string of data, multiple codes were recorded. Following coding, the researcher developed thematic charts (Ritchie et al., 2003) – also known as a framework matrix (Gale et al., 2013). Utilising Microsoft Excel, charts were created for each of the themes identified. Within each chart, columns corresponded to a category within the theme and rows represented individual participants. Pertinently, this method enabled the researcher to maintain a transparent link between the raw data collected during interviews and the various levels of abstraction from the

data (i.e. the categories and themes) involved in the application of thematic analysis: “While in-depth analyses of key themes can take place across the whole data set, the views of each research participant remain connected to other aspects of their account within the matrix so that the context of the individual’s views is not lost” (Gale et al., 2013: 2); “It also allows the analyst to move back and forth between different levels of abstraction without losing sight of the 'raw' data” (Ritchie et al., 2003: 220). This is crucial because it counters criticism that, “thematic analysis...can result in sections of data being fragmented from the original, which can result in data being misinterpreted” (Smith and Firth, 2011: 54).

Once thematic charts had been developed, summarised data was charted into the framework – “charting is a process which refers to the summarising of the key points of each piece of data...and placing it in the thematic matrix” (Ritchie et al., 2003: 231). The researcher read coded transcripts, entering data into charts according to the codes that were recorded in the margins of the text. Involving the reduction of data into a more manageable format – “Unlike simple cut and paste methods that group verbatim text, the charts contain distilled summaries” (Pope et al., 2000: 116) – the charting process requires a certain amount of abstraction from and synthesis across the data. Nonetheless, the researcher aimed to balance the reduction of data with the retention of its’ original context and meaning, following best practice (Gale et al., 2013; Ritchie et al., 2003) – “emphasis is on appropriate synthesis – that is summarising without losing content or context – rather than transcribing the point or piece of data exactly as expressed in the transcript” (Ritchie et al., 2003: 231). This is critical because, “Over-condensed data lack the richness to properly describe...while including too much data can mean that the analyst remains 'bogged down' in the raw data, bereft of a 'viewing platform', from which to see it” (Ritchie et al., 2003: 231). In practice, inputs signified

an abstraction and synthesis of the data, being abridged rather than repeated. Nonetheless, original context and language were retained to facilitate improved accuracy.

The previous steps have been described as part of the process of managing the data. Nonetheless, the ordering of data into categories and themes also represented the product of descriptive analysis, whereby commonalities and particularities between the perspectives of participants were identified and, subsequently, operationalised in the management of the data. Resultant thematic charts denoted both the final product of data management and the final (pre-reporting) product of the descriptive analysis, providing the framework into which the data were summarised by category and theme. Drawing on these charts, the researcher developed descriptive accounts of the data, drawing attention to commonalities through the use of themes. Returning to the original data, and recognising the context-dependent nature of knowledge, accounts of individual participants were outlined, situating the themes within their original context. Where appropriate, the researcher developed typologies into which individual participants can be exclusively categorised. The final stage of thematic analysis involved explanatory analysis, using the data summarised in thematic charts to explore patterns of association between themes. For the purposes of this study, the researcher did not analyse themes by sub-group, as the purpose of participant heterogeneity was to enable triangulation and facilitate greater levels of transferability. Furthermore, the relatively small sample size within each category inhibited the validity of sub-group analyses.

Conclusion

This chapter described the methodology and research methods applied in order to research the interpretation of personalisation by healthcare professionals working within the National Health Service (NHS) in England. First, the ontological, epistemological and methodological foundations of the interpretive paradigm were explained

and its appropriateness to understanding personalisation was established, drawing on the theory of interpretive policy analysis. Second, the research questions were defined and the research design was delineated in order to explain how the research was designed to study the interpretation of personalisation and, therefore, answer the research questions. Required criteria for individuals to participate in the study were delineated and the sampling frame was described, drawing on an interpretive interpretation of generalisation and the purposeful intention to examine interpretations of personalisation from a diversity of healthcare professional perspectives, utilising participant heterogeneity to enable triangulation and transferability. Third, the process and rationale behind the recruitment exercise was delineated, providing comprehensive insight into the practical steps taken to recruit healthcare professionals to participate in the study. The issue of sample size was debated and the final recruited sample was described to provide context on the findings and analysis reported in the fifth chapter. Fourth, the utilisation of semi-structured interviews was described and justified. The topic guide was defined and strengths and weaknesses of telephone interviewing compared to face-to-face interviewing were deliberated, drawing attention to the importance of rapport and probing to data quality and highlighting the procedures undertaken to facilitate these principles in face-to-face and telephone interviews. Finally, the approach taken to conduct the thematic analysis of collected data was established, providing a step-by-step guide to how data were analysed. The chapters that follow will describe the findings that emerged from the implementation of this approach.

5. FINDINGS ON INTERPETATION

There is an extensive literature that examines the meaning and interpretation of personalisation (Cribb and Owens, 2010; Leadbeater, 2004; Needham, 2011; Parker and Heapy, 2006). Critically, the diversity of interpretations evident across and within these literatures highlights the ambiguity of personalisation. However, there has been lacking study on how relevant policy stakeholders experience this ambiguity in practice and interpret personalisation. This is crucial as it is within the gift of policy audiences to interpret personalisation towards divergent means and ends of practice. Based on their relative autonomy and discretion, healthcare professionals were theorised to have significant influence over the practice of personalisation. Therefore, the interpretations of professionals were postulated as essential to practice. Based on this analysis, the study was designed to examine the interpretation of personalisation by healthcare professionals working within the NHS in England. The objective was to explore how personalisation is interpreted by professionals and the consequences of interpretation for practice – particularly as it relates to the expected roles of patients, professionals and the state (and the relationship between them. This chapter contributes to this objective by explaining the findings of the study in relation to the primary research question:

1. How do professionals working in the NHS in England interpret personalisation?

As explained within the second chapter, a framework encompassing potential interpretations of personalisation (Table 5.1) was assembled to structure the thematic analysis of data – the process and rationale of which was outlined in the fourth chapter. Each theme will be explored individually and participant-level accounts of each theme will be written to enable a more detailed insight into each storyline and the frames through which they were constructed by healthcare professionals participating in the study.

Table 5.1: Themes of Personalisation

Justifications for Personalisation
Theme 1: <i>Personalisation works, transforming people’s lives for the better</i>
This theme suggests that personalisation improves outcomes for service users and is supported by formal and informal evidence and common sense assumptions.
Theme 2: <i>Personalisation saves money</i>
This theme advises that personalisation improves the cost-effectiveness of care by reducing costs or providing better value-for-money through improved outcomes.
Theme 3: <i>Person-centred approaches reflect the way people live their lives</i>
This theme acknowledges people as individuals with a diversity of requirements that are more appropriately considered in a holistic manner through person-centred care.
Theme 4: <i>Personalisation is applicable to everyone</i>
This theme contends that personalisation applies to all individuals and should not be applied in an exclusive or restrictive manner, solely for particular cohorts of patient.
Theme 5: <i>People are experts on their own lives</i>
This theme characterises patients as experts in their own lives and advises that they are capable of participating, challenging the orthodoxy of the professional gift model.
Perceptions of Personalisation
Theme 6: <i>Personalisation is evolutionary, continuous and consolidating</i>
This theme presents personalisation as timeless, representing an evolution of prior practice and establishing continuity between the past, present and future.
Theme 7: <i>Personalisation is revolutionary, disruptive and transformational</i>
This theme defines personalisation as a radical departure from the past, designed to transform how care is delivered. The change is a revolution as opposed to evolution.
Nature of Personalisation
Theme 8: <i>Increasing responsiveness by tailoring to needs and/or preferences</i>
This theme advocates greater responsiveness to patients who should, as a result, have a more direct and effective voice. Care is tailored to needs and preferences.
Theme 9: <i>Giving users more say, keeping them informed and offering choice</i>
This theme centres on patient voice and choice. Professionals are expected to inform patients and support them by enhancing their ability to choose between outputs.
Theme 10: <i>Direct say over money, enabling individuals to make their own decisions</i>
This theme defines personalisation as giving patients a more direct say over how money is spent – for example, as a personal health budget that they directly manage.
Theme 11: <i>Co-production, active participation, choosing outputs and shaping inputs</i>
This theme frames service users as co-producers in a collaborative relationship with professionals, actively participating in the production and consumption of services.
Theme 12: <i>The public good emerging collectively through individual decisions</i>
This theme views personalisation as self-organisation, asserting that the public good emerges from within society and arguing that individuals should work collaboratively.

Personalisation Works, Transforming People’s Lives for the Better

Fifteen participants interpreted personalisation as improving patient outcomes. Improved outcomes were variously identified as engagement, satisfaction and wellbe-

ing, the usefulness and effectiveness of care and patient independence and empowerment. This storyline was variously dependent on a combination of professional and personal experiences of personalisation further to assumptions that were perceived to represent a common-sense understanding of the potential impacts of personalisation on patient outcomes. Evidently, informal sources of evidence (i.e. direct experiences) and subjective perception (i.e. assumptions) were a factor of interpretation. In contrast, formal sources of evidence – for example, the report on the evaluation of the personal health budgets pilot (Forder et al., 2012) – were not found to have influenced the interpretation of personalisation as beneficial to patients amongst this cohort of professionals, despite the reality of formal evidence that personalisation can improve outcomes.

MH1 was a trainee psychiatrist undertaking Core Medical Training in a West London NHS Trust. They argued that patients should have choice because it is their life that the choice would impact on – “We want them to choose because it’s their life and you should, as much as you possibly can, maximise the choices available”. This notion was then extended to incorporate notions of comfort, independence and satisfaction as parts of life that can be improved by personalisation, providing a justificatory discourse – “I personalise care because it’s their life and I want them to be comfortable, independent and satisfied with the care that they receive, so I personalise everything”. It was also contended that personalisation empowers patients, which was related to independence and control – “It empowers patients. It is really important for our patients because it’s their life and it’s really important for them to make their own decisions, be in charge and control what happens because it gives them more independence”. MH1 buttressed this range of justifications through reference to their personal experiences of personalised support – “To give you a personal example, I do actually have dyslexia. That hasn’t once stopped me doing anything in my life because I have felt empowered by the support that I’ve had that’s been tailored to my needs when I’ve needed it”.

MH4 was employed as a senior house officer on a long-term schizophrenia and psychosis rehabilitation ward in a Southwest London NHS Trust. They suggested that personalisation might result in reduced time spent in hospital and increased lengths of time between relapses and readmissions – “I think you treat people quicker. Perhaps it is not cheaper but you could reduce the amount of time that people spend in hospitals and I also think that you would be able to increase the gap between relapses for people with chronic conditions and then particularly with mental health problems”. It was also suggested that personalisation would be beneficial to satisfaction and engagement:

I think that you would definitely increase people’s satisfaction level and, related to that, which is a big issue in psychiatry, how likely the person is to actually go along with the treatment plan and take the medication that you ask them to

MH5 was a locum psychiatrist working with elderly patients in a Southwest London NHS Trust. Personalisation was interpreted positively in relation to engagement:

If you are able to engage with people in a way that they are more able to engage with you then you have a much, much better chance of keeping them as well as possible for as long as you possibly can and that is all thanks to personalisation

Evidently, increased engagement was viewed as a factor in improved outcomes, with the justification that personalisation provides more engaged patients that professionals can more readily interact with and engage in proactive measures to improve health.

MH6 was a liaison psychiatrist working with frail and elderly patients in a South London NHS Foundation Trust. They identified improved outcomes and satisfaction as justifications for personalisation – “I think we'd get better outcomes and people would be more satisfied with their experience because they would get personalised support”. It was also suggested that, “If it's more personalised, it becomes much easier to accept

a new way of operating with their new diagnosed condition”, further strengthening their assumption that personalisation has the potential to transform outcomes for patients.

CYP1 was a children’s speech and language therapist working in the community and an outpatient hospital within an East Midlands NHS Trust. They clarified that they expected that the introduction of personalisation could result in improved cooperation between patients and professionals since patients would engage and feel supported:

Patient cooperation with therapy and also with the therapist should actually be much better because they will feel more signed up to what is going on with their care and I think they will feel a lot more supported with the care that they receive

Pertinently, this interpretation was based on assumption – not experience or evidence – as improved outcomes were articulated as what should happen with personalisation, as opposed to what they had experienced or the evidence had caused them to believe.

CYP2 was a children speech and language therapist working within an inpatient hospital and community setting within an East Midlands NHS Trust. Personalisation was interpreted in relation to improved satisfaction as a consequence of tailoring care:

I feel that working with children and their families to identify what their priorities and concerns are and trying to incorporate them into the management or going with those as a priority is going to mean that families and children will ultimately have more satisfaction with what they get from the service we provide

They also assumed that personalisation had the potential to improve engagement with the service – “They may be more likely to engage with the service and follow what you recommend or participate in any therapy you want them to do or other suggestions that you might give to them” – which was expected to improve their outcomes from therapy.

CYP3 was a community physiotherapist and team leader for child occupational therapy and physical therapy within an East Midlands NHS Trust. Personalisation was interpreted in relation to increased engagement in therapy, encouraging the child and family to access the therapy on offer – “Personalisation is important because if you are able to get the child and their family engaged they are more likely to access the therapy that they need to”. Founded on direct experiences of personalisation, engagement with therapy was associated with improved outcomes as a product of personalised care.

CYP4 was a physiotherapist working in a community setting within an East Midlands NHS Trust. They suggested that personalisation may improve engagement and ensure that professionals focus on delivering a service that is valuable to their patients:

I believe personalisation may mean that we're actually able to be more effective in the future because by doing what the family and child wants they may engage more because what we end up spending our time on is actually useful to them

This represented an assumption about the merits of personalisation for their patients, representing a positive interpretation that personalisation leads to improved outcomes. It was also based on their experience of non-engagement with non-personalised care.

CYP5 was a learning disabilities nurse working in respite for children and young people within an East Midlands NHS Trust. Personalisation was interpreted in relation to their experience that personalised care positively impacts wellbeing and satisfaction – “I think it impacts on their wellbeing because it makes them, if they've got that awareness of knowing that we actually care about what they want, much happier with care”.

CYP6 was a consultant child psychiatrist and clinical director of child and adolescent mental health services within a Southwest London NHS Trust. Personalisation was interpreted in reference to their experience of delivering personalised services. In practice, they observed that personalisation could improve engagement and efficacy:

If you don't work like that and then if I was to say 'well I think this person needs to sort out x, y, z' then they're just not going to engage and it's just not going to happen, so it can actually make the service a lot more relevant and helpful and it actually helps you to increase your efficacy as well

They defined engagement as important to patient outcomes – “I think personalisation is very important. It is so important that you engage the child or young person and that the family see that so that they fully engage and get the best outcomes that they can”.

SC1 was as a bank midwife working within an NHS Trust in Bedfordshire. Based on their experiences, they assumed that personalisation would improve engagement:

If patients are being treated as individuals then they feel like they are being met and are more likely to work with you. That's why I think that personalisation will be really important because it's their lives, it's their babies and it's their futures

Essential to the realisation of this assumed benefit to engagement was the treatment of patients as individuals with ownership over their lives, their babies and their futures.

SC5 was a consultant anaesthetist and intensivist working within an NHS Trust in the West Midlands. They drew on their experiences of personalisation to recommend that optimum outcomes when can be delivered when patients are treated as individuals – “the value is that they are treated as an individual and personalisation is the best way and also the optimum way of meeting their specific needs”. Personalisation contrasted with standardised approaches to care, which were viewed to lead to inferior outcomes:

If you have a standard portion of anything, let's compare it to clothes. If you buy off the shelf it's never as good as if somebody takes your specific measurements and tailors you a suit. It's very much the case for care. Tailored care is the best

Consequently, it was contended that, “there is nothing better than personalised care”.

CS1 was a community midwife working within an NHS Trust in Bedfordshire. They assumed that outcomes and satisfaction would be enhanced by personalisation

I think that if women feel more in control of their experience then they are more likely to be satisfied and their experience is then more likely to be positive and then it is more likely to result in a more positive outcome for the patient

Evidently, improved outcomes were assumed to emerge from improved patient control.

CS3 was a Multiple Sclerosis (MS) specialist nurse working for an NHS Trust in the East Midlands. Personalisation was perceived as beneficial to patient engagement, based on direct professional experience of providing personalised care and support – “The minute you move away from that is when you lose that engagement”. It was also recommended that greater control enables patients to manage their health more effectively – “if you can get them to take on board the fact that they have some control then they are able to manage things a whole lot better”. Consequently, it was endorsed that personalisation would improve outcomes as patients engaged and took greater control.

PC1 was a General Practice (GP) nurse working for a GP within Leicestershire. Based on their direct experience of personalisation in practice as a professional, they recommended that treating patients as individuals results in benefits for engagement:

If your patients see that you are just treating them as if they are a number and that you don't value them as an individual then the patient won't value the care, but if you give them more importance then the patient will give it their importance

Personalisation Saves Money

Zero participants defined personalisation in a manner conducive to this theme. None of the participants suggested that improved outcomes arising from personalisation would have a negative cost implication for the NHS. There was also no suggestion

that it may have a positive cost implication nor that improved outcomes would improve cost-effectiveness through greater value-for-money. Nonetheless, the absence of confirmation is not equal to refutation and contradictory opinions were not expressed.

Person-Centred Approaches Reflect the Way People Live their Lives

Four participants drew on the storyline that personalisation and person-centred approaches reflect the way that people live their lives, treating patients in holistic terms.

MH4 was employed as a senior house officer on a long-term schizophrenia and psychosis rehabilitation ward within a Southwest London NHS Trust. They recognised that, “patients have needs, ideas, concerns and expectations”, and acknowledged the value of ensuring that all sides of the individual are reflected in their care and support:

It doesn't just matter how well you look after their physical needs. If you haven't met their expectations, ideas or wants then you won't have a happy patient and they won't do as well. That's why personalisation is so important

MH6 was a liaison psychiatrist working with frail and elderly patients in a South London NHS Foundation Trust. They described a stroke patient with further psychiatric illnesses and various other complexities for whom person-centred care was essential:

Interpreting the consequences of a stroke for that particular patient goes so far beyond understanding the protocols for the medication or the follow-up care in terms of rehabilitation because there are so many other things to think about. While this does address some of his needs, it doesn't take into account the fact that he becomes depressed quite easily. That needs a lot more thinking about

Consideration of the stroke without analysis of other facets of the individual patient and their circumstances was viewed as sub-optimal compared to a personalised approach which was interpreted as recognising the individual as a whole with the care delivered.

A further example of person-centred care was explained in relation to a diabetic patient for whom the provision of personalised care would ensure their holistic needs are met:

This particular individual in their particular situation, you know, is actually doing extreme sports twice a week and hence the recommended guideline and advice is not personalised enough for the way that they live their lives

CYP1 was a children speech and language therapist working in the community and also an outpatient hospital within an East Midlands NHS Trust. Their interpretation of personalisation centred on delivering services in context of the individual as a whole:

It means not just delivering a service but instead we're looking at the child in the context of everything – the family, the school, their future, their ability to function as human beings in the world – and tailoring the care that we provide

CS2 was an MS specialist nurse working for an NHS Trust in the East Midlands. They believed that personalisation is, “about the person and how the MS affects them individually”, and perceived that in practice it means, “you have to look at each person and how their MS affects them and remember that every single patient that we have is an individual”. Personalisation was viewed as particularly appropriate to MS patients:

MS does not affect any two people in the same way. It is a personal condition and individualised in every single person. No two people are the same, so you can't sit everybody with MS – even within a particular type of MS – in a box and say we will treat this particular type of MS in this way. There are lots of different symptoms and because of the nature of the condition some people have nerve pain but it'll be different in every single person so you've got to look at how any particular symptom affects that person and what we need to do to make it better

Emphasis was placed on analysing the specific symptoms of the individual and how it impacts on that particular person, embracing a holistic interpretation of personalisation.

Personalisation is Applicable to Everyone

Although none of the participants explicitly defined personalisation as applicable to everyone, one participant did suggest that personalisation is applicable to individuals lacking capacity. **MH3** was a consultant psychiatrist working in an intensive care unit within a Northeast London NHS Foundation Trust. Acknowledging the challenges that a lack of capacity can represent, they recommended that personalisation should apply:

Some of their autonomy and rights are taken away but even then, in terms of what will happen and how the patients are treated, we still try to tailor to these patients and their needs. That is what we try to do. We always have to treat the patient. It's always that concept. Treat the patient, see them as an individual

MH3 contextualised this statement – “all of them are detained under the Mental Health Act”. It was acknowledged that, “In the work I do there will always be a limit because of the harm that has happened to others. The patients that come to me have invariably harmed someone”. Despite this, it was advised that, “they have rights as human beings and I have to address these rights and make sure that their rights are given to them”.

People are Experts on Their Own Lives

Only one participant interpreted personalisation as acknowledging the expertise of patients. **MH6** was a liaison psychiatrist working with frail and elderly patients within a South London NHS Foundation Trust. Commenting on contemporary practices, they contended that professionals were not currently, “tapping enough into what that person knows about their life to personalise”, framing patients as experts within their own lives.

Personalisation is Evolutionary, Continuous and Consolidating

Four participants interpreted personalisation as an evolution of practice. Four of these participants recommended that personalisation had always been crucial to their practice, two observed that they had been taught to personalise at medical school, one advised that personalisation had always been central to medicine and one suggested that personalisation had always been essential to their profession, establishing a range of factors that can influence the temporal framing of personalisation.

MH1 was a trainee psychiatrist undertaking Core Medical Training within a West London NHS Trust. They identified personalisation as consistent with their practice and related this to their education at medical school, wherein personalisation was taught:

Personalisation is very natural to me because throughout medical school it has been sort of ingrained from day one that it's not just what the doctor says, it's a doctor-patient relationship with both of you making decisions together

MH3 was a consultant psychiatrist working in an intensive care unit in a North-east London NHS Foundation Trust. They interpreted personalisation to be continuous with medical traditions: "personalisation is not new, it has been in the core of medicine forever"; "It has been around even before scientific medicine so it isn't something new. It has always been with us. We always have said treat the patient and not the disease".

SC3 was a clinical trials nurse working for an NHS Trust in Bedfordshire. They confidently asserted that, "To me, personalisation has always been around". Described as a natural approach within medicine, personalisation was perceived to be consistent with the medical training that they had received, particularly in relation to holistic care:

It's a natural thing. I trained twenty years ago and we were taught about holistic care then. It was about not just looking at the patient in bed four with the broken leg but what about his other needs and looking at the whole picture

SC5 was a consultant anaesthetist and intensivist for an NHS Trust in the West Midlands. Personalisation was interpreted as consistent with the professional values of anaesthetism and intensivism, indicating a continuity between the past and present:

Personalisation fits into practice, traditionally, perfectly because anaesthetists and intensivists have always had to, and have always been taught to, adjust the management of each individual patient to the individual need. It's partly due to the nature of our work because anaesthetising is an individual process because of the comorbidities patients might have that generate special requirements

You have to personalise care if you want to be a good anaesthetist. You have to consider the individual and you have to look at their comorbidities and their personality – how you perceive their personality at least – and then tailor your approach very much to that individual. It is really important to personalise care

Personalisation is Revolutionary, Disruptive and Transformational

Three participants interpreted personalisation as transformational, framing it as a departure from established practice. There is an evident disjuncture between notions that personalisation is evolutionary and revolutionary. Yet, this study has revealed that professionals can interpret personalisation as both continuous and discontinuous with practice. Perhaps unsurprisingly, there were no overlaps between these themes, given that none of the participants viewed personalisation as evolutionary and revolutionary.

MH3 was a consultant psychiatrist working within an intensive care unit within a Northeast London NHS Foundation Trust. They contrasted personalisation with current practices which they defined in terms of business models that result in standardisation:

If you go to business world they try to adjust things to the client. The business model that we subscribe to is like Henry Ford Model-T conveyer belt. All patients go and have certain things done to them, rather than decisions made with them

MH6 was a liaison psychiatrist working with frail and elderly patients in a South London NHS Foundation Trust. Personalisation was contrasted with current models of healthcare, in the context of which personalisation was interpreted as a restructuring:

I think we've got enough evidence now that we really should be thinking about restructuring healthcare intervention completely and that means placing more weight on interventions and interactions that are personalised to the patient

This draws attention to the transformational nature of personalisation and recommends that personalisation should form the foundation around which services are redesigned.

SC1 was employed as a bank midwife within an NHS Trust within Bedfordshire. Personalisation was interpreted in context of negatively recollected historical practice:

Well, if I can go back a long way I'm tempted to think that was a lovely time but it wasn't lovely because women were being subjected to routines. It has always seemed very wrong to me that every woman had to have exactly the same thing

As a consequence, personalisation was seen as discontinuous with previous practice:

Now they are not being subjected to those routines because instead they have a more personalised service. Because of my experiences, I do think it is so very important to personalise the care that we give and treat people as individuals

Increasing Responsiveness by Tailoring to Needs and/or Preferences

Twenty participants defined personalisation as tailoring to individuals, requiring greater service responsiveness to patients. Ten interpreted personalisation as tailoring

to needs and two participants defined personalisation as tailoring to preferences. Eight interpreted personalisation as tailoring to the needs and preferences of individuals.

MH1 was a trainee psychiatrist undertaking Core Medical Training within a West London NHS Trust. They described personalisation in relation to the needs of patients and interpreted it as, “an approach in which individuals are recognised to have specific needs and so their care is personalised and tailored to them so they have their needs met”. They did not explicitly interpret personalisation as tailoring to the preferences of patients. However, implicit recognition of tailoring to preferences or ‘wants’ was apparent in discussion of choice – “If I see a patient about eczema I might give them a choice of different creams that they can choose that will benefit them and they might not want to use a certain one”. Hence, personalisation meant tailoring to needs and preferences.

MH3 was a consultant psychiatrist working within an intensive care unit within a Northeast London NHS Foundation Trust. Personalisation was interpreted as adjusting treatment to the needs of patients – “with personalisation, you get to know your patients and then you adjust the treatment to their needs”. In practice, this means that you need to, “know the person, you need to see that patient as a person and you will also need to know who they are, what is their story and what their values are”. Preferences were also essential to their interpretation of personalisation – “Part of personalised medicine is respecting personal values and listening to them and what they want”.

MH4 was employed as a senior house officer on a long-term schizophrenia and psychosis rehabilitation ward in a Southwest London NHS Trust. They interpreted personalisation as, “tailoring the treatment and where possible the environment and the nature of the treatment you give to a patient to them”. This was compared with standard care – “as opposed to it being a generic service, because of X give them Y and after Z days send them home”. With personalisation, “You tailor your approach and the things

that you discuss with patients, address lifestyle a bit more and try to be more holistic”. Crucially, it was recommended that, “To provide a more personalised service you have to take time at the beginning to actually get to know what someone needs and wants”.

MH5 was a locum psychiatrist working with elderly patients within a Southwest London NHS Trust. They interpreted personalisation as tailoring to needs – “I think that personalisation is all about providing a service that is tailored to what their actual needs are”. This was further explained as having flexibility – “Personalisation means that we have a flexible service that meets their needs, even when their needs are slightly odd” – and flexing patterns of work to fit the patient – “the patient doesn’t fit the patterns that we work so we move the pattern that we work to fit the patient as much as possible”.

MH6 was a liaison psychiatrist working with frail and elderly patients in a South London NHS Foundation Trust. Personalisation was framed around the individual and advocated as an approach that demands the tailoring of interventions to the individual:

Personalisation means that we must incorporate much more about the person in terms of where they are in their particular place in life, what it means for them to present with a specific set of symptoms or condition at this particular point in time and gearing the interventions around what it means for the individual

CYP1 was a children’s speech and language therapist working in the community and an outpatient hospital in an NHS Trust within the East Midlands. Personalisation was interpreted as tailoring to the needs and contexts of children and young people:

Not just delivering a service but instead we’re looking at the child in the context of everything, their family, school, future and their ability to function in the world and tailoring the care we provide to what we have found out about their needs

CYP2 was a children speech and language therapist working within an inpatient hospital and community setting within an East Midlands NHS Trust. They understood personalisation as, “taking the lead from the children and family about what their hopes and concerns and priorities are and delivering a service that tries to address some of those things”. This was compared with standardised care – “it involves us delivering a service to the children and family that’s specific to them rather than a one-size-fits-all service – trying to deliver a service that meets the needs of the child and family”. The following practical example was given to demonstrate the practice of personalisation:

I’ve got a young lady at the moment who is potentially looking into doing some out-of-school clubs and she has got quite severe eating and drinking difficulties so I want to find out who works with her at the clubs and offer to support staff to manage her eating and drinking difficulties safely. We are trying to deliver a safe service that is relevant, looking at what she needs in that situation at that point

Needs were explicitly referenced and priorities are consistent with preferences. Hence, personalisation was defined as tailoring care to the needs and preferences of children.

CYP3 was a community physiotherapist and team leader for child occupational therapy and physical therapy in an East Midlands NHS Trust. They described personalisation as providing an efficient service that ensures that their specific needs are met:

Personalisation is making the process of the child and family receiving therapy as efficient as it can be for them. If they have specific needs and there are specific things that would help them then we would try to incorporate it into therapy

This was further described as, “having empathy and understanding of the situation that children and families are currently in and what they’re able to do in terms of therapy”.

CYP4 was a physiotherapist working within a community setting within an East Midlands NHS Trust. They interpreted personalisation as tailoring to needs and wants:

Personalisation is about how we can meet what families and children need and what they want from their therapy and having it more tailored to what they feel they need or want, rather than just we state what we can provide

It was further explained that, “If you personalise for everyone then their opportunities are equal but they may not have exactly the same provision because it’s not what they need and want from their therapy”. In practice, therefore, personalisation would mean patients getting equal opportunities to receive tailored therapy. However, in tailoring to the needs and preferences of individual patients, some may receive more than others.

CYP5 was a learning disabilities nurse working for respite services for children and young people within an East Midlands NHS Trust. They defined personalisation in relation to person-centred care, which they defined as looking at the person as a whole:

I think that personalisation means looking at the person holistically and looking to make their care about what their actual needs are, what they really love and what they really care about. We would call it person-centred care

The following example was given of the implementation of personalisation in practice, drawing attention to the range of viewpoints that inform the delivery of personalisation:

An example would be doing reviews with the school and the parents will come and the social worker and any carers that are involved and ourselves. What we do is put a picture on the wall of the child, and the child will come as well, and we’ll talk about what’s working now, what would you like to do that you’re not doing and very much look at that child as a whole, with them and with the people

that know them, and put a very good picture together on their needs and what their preferences are and then we put the care in place to reflect that

Personalisation was defined as ensuring services reflect the needs and preferences of individual patients, forming this judgement on a holistic consideration of requirements.

CYP6 was a consultant child psychiatrist and clinical director of both child and adolescent mental health services for a Southwest London NHS Trust. They regarded personalisation as relevant to their work but also remarked that, “That’s not a term we use a lot because of the way we work. It’s implicit in our work so we haven’t then given it a specific name”. They interpreted personalisation as individualisation – “It refers to ensuring that, even if you are following the guidelines, care is provided in an individual and personalised way”. They further outlined that this meant delivering care to meet the goals of the child or their family – “any work we do with a child or family will involve having goals that they will set”. Therefore, personalisation was interpreted as tailoring to the preferences of children and families. Tailoring to needs was not referenced.

SC1 was as a bank midwife working in an NHS Trust in Bedfordshire. They were not confident in their knowledge of personalisation – “Personalisation, to me, is about, I mean, to be totally honest I haven’t read the dictionary definition”. Nonetheless, when pressed, they interpreted personalisation as flexing their training to patient needs – “I think it means meeting a person where they’re at and flexing my training to their needs”.

SC2 was a clinical trials nurse working in an oncology unit within an NHS Trust in Bedfordshire. They defined personalisation as treating patients as if they are special and individual – “Personalisation means making sure that the patient feels as special as they can, you know, not just another person coming through”. The ensuing practical example was provided – “To personalise, we always just make sure we go and have a little chat with them to make sure that they’re ok and to check if they have any problems

because if there are any then we can try and help with their specific needs”. Therefore, part of treating patients as individuals was interpreted as meeting their specific needs.

SC3 was a clinical trials nurse working within an NHS Trust within Bedfordshire. They defined personalisation as tailoring care holistically to the needs of their patients:

In my opinion, personalisation means treating each person holistically and then tailoring care to their specific needs rather than looking at a patient and because of this criteria we follow this formula and that means we do x, y and z

One practical example provided related to personalised medicine – “You have personalisation of medicine where you may not give them chemotherapy because they’ve got a tumour that won’t respond to it, so you personalise the treatment”. Another example was explained as tailoring the way in which professionals interact with patients – “some patients you have a joke with and some patient you just can’t do that. You can’t think every patient is the same so I’ll just be the same, you’re different with different patients”.

SC4 was a chemotherapy nurse working in an NHS Trust in Bedfordshire. They interpreted personalisation as recognising the intrinsic differences between individuals:

Personalisation is about recognising that everyone is different and that everyone will react to chemotherapy differently. Consultants and nurses have to accept that and understand that what works for some people won’t work for others

They further explained that personalisation means and tailoring to the needs of patients – “recognising patients as individuals and giving them the care tailored to their needs”.

SC5 was a consultant anaesthetist and intensivist for an NHS Trust in the West Midlands. The interview revealed that personalisation was unfamiliar – “Your research is actually the first time I have ever heard about that term”. Nonetheless, SC5 was able to provide a definition – “I think it means personalised care which would mean tailoring

the care and support a patient gets around their specific needs, so it's the opposite of standardisation". Therefore, personalisation was defined as tailoring to individual need.

CS1 was a community midwife working in an NHS Trust in Bedfordshire. They interpreted personalisation as, "meeting the particular needs of patients and ensuring that they have a chance to say what their needs are so that we can tailor to their needs".

CS2 was an MS specialist nurse working for an NHS Trust in the East Midlands. They described personalisation as a recognition of the individual and their individuality:

Personalisation is all about the person and how the MS affects them individually.

It means that you have to look at each person as an individual and how the MS affects them. We must remember that every patient we have is an individual

It was also explained that, "it's looking at what that individual wants, what the individual needs and putting everything together in a package and making it right for that person". Thus, personalisation was viewed as tailoring to the needs and preferences of patients.

CS3 was an MS specialist nurse working for an NHS Trust in the East Midlands. They described personalisation as tailoring care to the outcomes preferred by patients:

It's about realising that everybody that you see is very different. Two people can have the exact same problem but they could want very different outcomes. For me, it's about being clear I do the right thing for the right person at the right time

PC1 was a GP nurse working for a GP within Leicestershire. They interpreted personalisation as, "tailoring a care plan for that patient", on the basis of, "holistic care and individual targets", ensuring that, "whatever you deliver is a joint decision tailored for that particular patient". Patient preferences are central – "Where a patient declines certain treatments then you must accept their choice and work towards their priorities".

Giving Users More Say, Keeping Them Informed and Offering Choice

Thirteen participants defined personalisation in relation to greater patient voice and choice. Seven participants interpreted personalisation in terms of choice and four participants defined personalisation in terms of voice. Two of the participants defined personalisation in relation to voice and choice and five emphasised informing patients.

MH1 was a trainee psychiatrist undertaking Core Medical Training within a West London NHS Trust. They interpreted personalisation as choice, providing the following example – “If I see a patient about eczema I may give them a choice of different creams that they can choose”. It was advised that, “it’s not just what the doctor says”, promoting a greater voice for patients and advocating, “a closer relationship between patients and doctors, in which both are responsible for working together and making decisions”.

MH3 was a consultant psychiatrist working within an intensive care unit within a Northeast London NHS Foundation Trust. Personalisation was interpreted in relation to responsibility, choice and shared decision-making – “It means we give patients some of the responsibility, trust them with informed choice and a share in decision-making”.

MH4 was employed as a senior house officer on a long-term schizophrenia and psychosis rehabilitation ward within a Southwest London NHS Trust. They interpreted personalisation as empowering patients and enabling them to take control – “if we are going to empower people, which I think personalisation is all about, people need to feel they have some control and are being listened to” – in a manner consistent with voice.

MH5 was a locum psychiatrist working with elderly patients in a Southwest London NHS Trust. Informed choice was central to their interpretation of personalisation - “To personalise we show them the information they need to make informed decisions”. Nonetheless, it was apparent that choice was a problem in context of lacking capacity:

Personalisation is about choice but when someone lacks insight, personalisation will involve not allowing them choices in certain areas. So, with each person there will be certain things that they can choose and some things that they can't. They may have capacity to decide whether they need an aspirin, because they know if they're in pain, but they don't know if they need a mood stabiliser or not

Therefore, the incorporation of choice within personalisation is tailored to the individual – “you might need to take away choice in order to provide a more personalised service”.

MH6 was a liaison psychiatrist working with frail and elderly patients for a South London NHS Foundation Trust. Patient control was essential to their interpretation of personalisation – “it is about what the individual thinks they can gain from an interaction and being able to modify things and to have some control over what happens to them”. This involves ensuring, “patients have a say over their care”, aligning with patient voice.

CYP1 was a children's speech and language therapist working in the community and an outpatient hospital in an East Midlands NHS Trust. Personalisation was defined as a partnership between patients and professionals, necessitating choice for patients:

I think of it in terms of the service that I deliver is very much in discussion with and with the involvement of parents and, as the children get older and able to express themselves, with the children as well. Therefore, treatment planning is very much involving the whole family. It involves us saying to them ‘this is what we could do, but it's up to you to decide what you want and what works for you’

Providing information to patients was perceived as essential to informed patient choice:

If we are thinking about what sort of treatment a child needs then there is a lot of discussion about what it involves, why we think one thing over another. It is very much trying to make sure they have got as much information as possible

We involve them in decision-making and we try to empower them by giving them as much information as we can about what we think is going on with the child and what the treatment options are so that they can make an informed decision

CYP3 was a community physiotherapist and team leader for child occupational therapy and physical therapy within an East Midlands NHS Trust. Personalisation was described in terms of voice (i.e. listen to patients) and choice – “It means giving people choice and listening to what they have to say”. The following example was provided:

We have meetings where the professionals get together with the parents and the child and we talk about where we're going, what we're doing, what's going to work for them. We ask what their goals are and what is it that they want from therapy. We're not just imposing our view. We try and do it collectively because they may have a completely different goal to what we think they should work on

In summation, personalisation was interpreted as a collaborative undertaking between children, their parents and professionals, working together to deliver personalised care.

CYP4 was a physiotherapist working in the community within an East Midlands NHS Trust. Personalisation was interpreted as a shallow form of choice – “I understand it to be patients making their own choice about when and where they want to be seen”. Regarding choice of treatment, information to ensure informed choice is fundamental:

If patients are going to have more choices then they would benefit from having increased understanding of the options. It needs to be informed and healthcare professionals have a responsibility for ensuring that patient choice is informed

SC2 was a clinical trials nurse working in an oncology unit within an NHS Trust in Bedfordshire. They interpreted personalisation in relation to patient choice – “I think that personalisation can mean giving choice to individuals on which treatment to have”.

CS1 was a community midwife working for an NHS Trust in Bedfordshire. They described personalisation in terms of respecting the choices of patients and suggested that it was the role of professionals to provide patients with information to ensure that choices are informed – “Regardless of what we think are the best options for them, we have to respect their choices and provide the information they need to make decisions”.

CS2 was an MS specialist nurse working for an NHS Trust in the East Midlands. Personalisation was defined as, “tailoring the options to what the person wants as well as what they need and when an option conflicts with what they want then work together to find different solutions”. This interpretation is compatible with patient voice, wherein the patient articulates their needs and wants and has a say over the care they receive. The following example of working with a patient with symptoms of fatigue was provided:

Fatigue is all about lifestyle changes. We’ll say that for fatigue management you need to look at what you’re doing and if you’re overdoing things then you need to slow down and find another way. The person will still want to get everything done so personalisation will involve talking it through, looking at the options and really letting them have their say and working together to find different solutions

CS3 was an MS specialist nurse working for an NHS Trust in the East Midlands. They interpreted personalisation in relation to providing choice and voice to patients:

Personalisation means giving choice to patients. Patient choice means that you should give people a range of options they can choose from and ask them what their priorities are, how they would like you to assist them and where they want to go. You really have to listen to what they’re saying and work on those terms

PC1 was a GP nurse working for a GP within Leicestershire. They interpreted personalisation as making sure that, “you get to know your patients and whatever you do decide is a joint decision tailored for that particular patient”. This involved, “listening

to patients”, and, “working with the patient to find out what is acceptable to the patient”. Although choice was not referenced, it was apparent that patient voice was essential.

Direct Say over Money, Enabling Individuals to Make Their Own Decisions

Zero participants defined personalisation in a manner conducive to this theme.

Co-Production, Active Participation, Choosing Outputs and Shaping Inputs

Zero participants defined personalisation in a manner conducive to this theme.

The Public Good Emerging Collectively Through Individual Decisions

Zero participants defined personalisation in a manner conducive to this theme.

Conclusion

Personalisation is generally diagnosed as ambiguous (Cribb and Owens, 2010; Leadbeater, 2004; Needham, 2011; Parker and Heapy, 2006). Nonetheless, there has been lacking study of how policy audiences interpret personalisation for practice. This is critical as healthcare professionals have discretion over practice and, consequently, their interpretation of personalisation will construct the context in which it is practiced, structuring the boundaries of what is expected of patients and professionals. Based on this analysis, the study was designed to examine the interpretation of personalisation by healthcare professionals within the NHS in England. Using the themes identified in the second chapter, this chapter presented the findings of this study. While diversity of interpretation was evidence, the majority of participants interpreted personalisation in relation to responsiveness, voice, choice, and improved outcomes. The implications of these findings will be discussed in chapter seven, drawing on the applicable literatures.

6. FINDINGS ON PRACTICE

There is a robust literature on the practice, or implementation, of personalisation across the UK. Particular focus has been given to personalisation in the form of budgets, such as direct payments (Clark et al., 2004; Ellis, 2007; Spandler and Vick, 2004), personal budgets (Hamilton et al., 2015, 2016; Whitaker, 2015) and personal health budgets (Forder et al., 2012). Nonetheless, there have been relatively fewer studies of personalisation in its alternative forms, such as personalised care and support planning and personalised medicine. Particularly excluded from study is the practice of personalisation in a general sense, as part of routine practice. Furthermore, most research has attended to adult social care and there is a comparatively less research regarding the personalisation of health. Most problematic is the lacking consideration of interpretation within the majority of studies. However, without understanding the interpretation to which practice pertains, how are findings to be interpreted? This study contends that perspectives on personalisation are necessarily dependent on its interpretation. Thus, without explicit consideration of interpretation, findings are lacking in essential context from which they can be understood. Based on this analysis, the study examined professional perspectives on personalisation in practice. The intention was to investigate their experiences of personalisation to comprehend the dynamics that impact practice. To structure the study of this objective, the following research question was pursued:

2. What are the perspectives of professionals on the practice of personalisation?

As explained within the fourth chapter, an inductive thematic analysis resulted in the development of six themes (Table 6.1). Each theme will be explored individually and participant-level accounts of each theme will be given to enable a more detailed insight into each theme and the frames through which they were constructed by professionals.

Table 6.1: Themes on Perspectives

Perspectives on Practice
Theme 13: <i>Time pressures constrain personalisation</i>
This theme advises that time pressure are problematic to personalisation. It suggests that professionals often have insufficient time to personalise and acknowledges that personalisation requires more time when compared to standard approaches to care.
Theme 14: <i>Standardised resources are problematic</i>
This theme notes conflict between personalisation and standardisation. It is advised that an emphasis on the collective at the expense of individuals has resulted in the prevalence of standardised systems, processes, routines, treatments and services.
Theme 15: <i>Financial constraints hinder personalisation</i>
This theme reveals that financial constraints are problematic to personalisation. It is observed that personalisation often costs more when compared to standard options. The financial constraints are also associated with constraints on time (Theme 13).
Theme 16: <i>Professional expertise retains importance</i>
This theme acknowledges the enduring significance of professional expertise in the practice of personalisation, highlighting the ongoing need for professional discretion in the delivery of care. It suggests that the best interests of patients offsets choice.
Theme 17: <i>Management and organisation matter</i>
This theme recommends that the attitudes of managers and their relationship with professionals can impact the willingness of professionals to practice personalisation.
Theme 18: <i>Interpretation influences practice</i>
This theme observes that personalisation is ambiguous and that, as a consequence, professional interpretations of personalisation influence practice. It is recommended that consistency in the application of policy is dependent on the clarity of its definition.

Time Pressures Constrain Personalisation

Nineteen participants identified time pressure as problematic to personalisation. Of these, seventeen revealed that professionals are frequently too busy to personalise, resulting in partial or zero compliance with personalisation in practice. The importance of time was particularly emphasised by participants who observed that personalisation requires a greater input of time in contrast with the standard method, with professionals required to spend a larger volume of time with each of their patients. On the other hand, three participants recommended that they generally had sufficient time to personalise. Four participants observed that time pressures varied across services. Time pressures and their impact on personalisation were associated with an assortment of factors. For example, insufficient staff levels were perceived as a cause of time pressures and were often explained as a consequence of financial challenges. Participants also explained

administrative burdens as a negative force on time available for personalise. Caseload volume and complexity was also viewed to have impacted on time. Finally, it was noted that the demands on time are increasing, further reducing the capacity to personalise.

MH1 was a trainee psychiatrist undertaking Core Medical Training within a West London NHS Trust. They explained that time pressures limited capacity to personalise care and meet patient preferences – “There’s limits on how much you can actually give someone what they want with time pressures”. Pressures on time were constant – “We face time pressures constantly, over every aspect of our work. It impacts on the time you have available to spend with each patient that you need to see”. In addition, there was an effect on choice – “There isn’t enough time to give unlimited choice to patients”. They acknowledged that pressures on time were common across the NHS – “Everyone working in the NHS is always pushed for time. We are not a special case because we are all struggling with time”. They also indicated that time was not particularly an issue for them – “I’m incredibly conscientious and organised just because otherwise I think I would go crazy. I make sure I’m on top of my work so it’s not usually an issue for me”. Nonetheless, the observation was that time constraints reduce capacity to personalise.

MH2 was a consultant psychiatrist working for a community mental health team within a Southwest London NHS Trust. They identified time as problematic – “We just haven’t got enough time, energy or resources to manage expectations and personalise services”. This was explained as a result of insufficient staffing – “The central challenge at the moment is a serious lack of resources. There are not enough staff available to cope with patient expectations”. This lack of resources was perceived as impacting on the capacity of professionals to spend sufficient time with patients to tailor their service:

The lack of staff produces difficulties in relation to the time that patient are being seen for. Ideally I would like to see my patients not just for ten minutes but for

at least half an hour up to an hour to assess their needs. It is absolutely impossible to tailor the care when I don't have enough time to evaluate their needs

Critically, the lack of time was related to financial constraints – “There are a lot of things that we can't do because of a lack of finances and resultant lack of staff, both of which impact on time and capacity”. It was also related to the amount of administrative work:

There's too much data entry on the computer to record the patient's ethnicity, mental state, test results and making sure their care plan is up-to-date. I spend about a third of my time actually with patients and then half dealing with the data entry into the computer. It's all just pressing buttons on computer keyboards

Clearly, there was a perception that professionals had been asked to deliver too much comparative to the resources at their disposal, resulting in obstacles to personalisation.

MH3 was a consultant psychiatrist working within an intensive care unit within a Northeast London NHS Foundation Trust. They observed that, “Managing with an ever shrinking NHS, because the resources are being cut, is a huge challenge”. Explaining that, “our services are being cut left, right and centre”, they posed the following question – “How are we supposed to provide a personalised service with less resources? It takes more time so we actually need more resource” – drawing attention to the role of time. They framed personalisation in relation to earlier experiences on an acute ward:

On the acute ward it was really impossible to personalise care for patients because I just didn't have the time. I could not have had this conversation with you there because I didn't have the time but here I can give people more time and I can do things like this and I can take the time to personalise patient care

The attributed importance of time to personalisation was related to the assumption that it requires professionals to get to know their patients as individuals in much more depth:

To personalise care you need to get to know the patient and you also need to see that patient as a person and an individual. You need to know who they are, what their story is, what are their values and what do they want to be in their life

When time is restricted, “you just focus on fixing the problem because you don’t know the person very well. You see a diagnosis and then you just fix it”. Evidently, the impact of time was to enable care to be tailored to the needs of the individual – “When I have the time I can sit with them and I can go through their history. That means I can get to know them and then adjust the treatment to their needs as an individual”. Finally, time constraints were explained as a consequence of the extent of the administrative work:

I would like to see much less bureaucracy because I think it is one of the biggest obstacles. If you really want to personalise the care then we should be focused on patients and not the paper or the computer. You cannot personalise where it is sitting down behind a monitor and not with patients for half of your time

There was a feeling that completing paperwork took time away from treating patients.

MH4 was employed as a senior house officer on a long-term schizophrenia and psychosis rehabilitation ward in a Southwest London NHS Trust. They suggested that time was essential to tailoring – “To provide a personalised service, I think you have to take some time at the beginning to get to know what someone needs and wants”. This meant that, “you get to know them better so you can tailor your approach and you can address lifestyle and be a bit more holistic”. They further observed that – “If you spend time at the beginning then you don’t necessarily have to then spend loads of time with patients to personalise – you just need to do the leg-work at the beginning”. In practice, time could be used as an excuse – “I think because we are so rushed we use it as an excuse to not provide personalisation”. The impact of time was summarised as follows:

The brutal truth of it is that you don't get to do the same level of personalisation. If you have got too much to do then you're so busy running around that you may miss the opportunities where you could tailor something for the individual

MH5 was a locum psychiatrist working with elderly patients within a Southwest London NHS Trust. They identified the administrative workload as a negative influence on time available to personalise – “I would say that I am being used ineffectively in this job and my time to personalise is very restricted because I do so much administration”. Less stressed services were associated with greater flexibility to tailor and personalise:

When you have got a calmer, more relaxed and less stressed service then you can meet the needs of the patients in a more flexible manner. Whereas, when you have got a stressed service then the professionals tend to baton down the hatches and tend to entrench and then you don't get a personalised service

MH6 was a liaison psychiatrist working with frail and elderly patients in a South London NHS Foundation Trust. They observed that the volume of paperwork they were required to complete was an issue, reducing person-centeredness and limiting tailoring:

There's loads of paperwork. I'm working across a mental health system and the acute hospital system which means I document the same thing into both sets of notes. It's very clunky and time-consuming and it influences overall efficiency in terms of the number of patients we can see and what we can do to personalise care, be a bit more patient-focused and do things that are particular to patients

CYP1 was a children's speech and language therapist working in the community and an outpatient hospital within an East Midlands NHS Trust. Their role encompassed a lot of admin – “My role can be quite admin heavy as the treatment notes and reports I have to write up tend to be fairly extensive. We also write treatment plans and I spend

a lot of time on the phone”. This was described as time-consuming and it was observed that, “this might limit the time that we have to do other things”, such as personalisation:

This can all limit the time that we have available to personalise. Sometimes it’s easier not to personalise and to focus our attention on other things. It’s a shame but we have to prioritise other things and that impacts on the personalisation

Reduced funding and staff insufficiencies were identified as a cause of time pressures:

Working within the context of an NHS where there is reduced funding and further funding pressures is a big challenge. We’re constantly having to think about what we’re doing and spending money on. There are fewer staff around and the increased expectations can limit the time we give to individual patients

CYP2 was a children speech and language therapist working within an inpatient hospital and community setting within an East Midlands NHS Trust. The volume of their caseloads was perceived as a challenge – “The numbers of patients I see is obviously challenging. We all have quite large caseloads”. The complexity of their caseload was also problematic – “The complexity of our children is a challenge. The ones that I see have got multiple health needs and they have multiple different specialisms so there’s lots of complicated situations”. In practice, this could be problematic to personalisation:

We are generally under quite a bit of time pressure and when the children are complicated and we have so many of them to see then there can be a pressure to do a more rushed job and that can make it more challenging to personalise

There was also a suggestion that personalisation requires more of professionals’ time, as tailoring requires professionals to have a more informed knowledge of the individual:

I think that personalisation may be more time-consuming up front when you first see the patients. It will take quite a bit longer because you have to get to know a patient which means spending more time with them than you otherwise would

CYP3 was a community physiotherapist and team leader for child occupational therapy and physical therapy within an East Midlands NHS Trust. They identified cuts to budgets as having a negative impact on staff and the supply of time versus demand:

We have to have cuts on every year just to make savings every year. Our main outgoing financially is staff so if we've got less money then we've got less staff, but the expectations on our time are the same so we are under a time pressure

Resultant pressures were described as constraining the time available to personalise, acknowledging that the pursuit of personalisation requires a greater input of their time:

We have got to keep delivering the same quality of care to the same quantity of patients but within a much smaller resource. This can actually limit the time we have to spend with each patient and naturally this has a negative impact on the personalisation because providing personalised care requires more of our time

CYP4 was a physiotherapist working in the community within an East Midlands NHS Trust. They perceived that an increased demands, including personalisation, had coincided with a reduction in the supply of money and staff, constraining their capacity:

I think we're always going to have to find ways to do things more efficiently but it does feel like over the last few years there have been more demands placed on our time than their used to be. The staff we are losing are not being replaced because of the budget cuts – our main cost is on staff so when we have to save costs, which we have to do every year, the only way to do it is to have less staff

There was a perceived impact on the time available to spend with children and it was recommended that this could influence their capacity to deliver a personalised service:

There aren't any less children so there is a pressure and it restricts the time you spend with each child. That can impact on personalisation because you do not have the time available to personalise as well as you could if you had more time

Providing a personalised service tailored to preferences was particularly problematic:

To give them all what the families want, in line with personalisation, would often mean us doing the exercises with the children and that simply just isn't possible because we simply don't have the time required to deliver this in practice

CYP5 was a learning disabilities nurse working in a respite service for children and young people within an East Midlands NHS Trust. Financial pressures were linked to staff levels, which were negatively associated with the time available to personalise:

There is a financial challenge and that means we have fewer staff. Staffing issues come with the financial challenge because with fewer staff you do not have the time to do everything a child wants. You may just have to do what they need

Time was perceived as essential to providing care tailored to needs and preferences:

Sometimes it can be very difficult for you to go home feeling like you've done a good job. The impact of time demands is that we only do the minimum and meet their essential needs rather than meet their essential needs, educational needs and stimulating them. That is not the definition of a personalised service really

Time issues were further impacted by the volume of paperwork they had to complete, highlighting the conflicts (between personalisation and other goals) prompted by time:

We have absolutely ridiculous amounts of paperwork. Each young person has to have a file maintained and it is incredibly strict. That is a real pressure to my

job and it's a bit of the job I don't like because that can take over and then that can take away from the time that I can spend with the child delivering their care

CYP6 was a consultant child psychiatrist and clinical director of child and adolescent mental health services in a Southwest London NHS Trust. They explained that, “The main challenge we face is that the commissioners do not often reconcile demand and capacity”. Capacity was perceived as insufficient to meet demand, resulting in time pressures – “we have got about 240% of referrals against the capacity that the service was set up to manage. This has an impact on the time that we have available to treat the patients that come through the service”. This was related to budgetary constraints – “We are all under great pressure in terms of how tight the budgets are”. Furthermore, “pressure also comes from the fact that the Local Authority and schools have also cut resources, so the child is more quickly going to tip into a level of need for intervention”. Critically, personalisation was viewed as time-consuming and there was a recognition that this can be difficult for some to reconcile in context of high demand and low supply:

Obviously, if you need to work at great speeds then sometimes it can be easier just to say that this young person needs to stop cutting because that's the biggest risk factor in their current profile. Being realistic, it probably does take more time setting up work this way so it can be hard to reconcile the time required

SC1 was as a bank midwife working within an NHS Trust in Bedfordshire. They described the variability of their caseloads – “On a good day my caseload might be six women and six babies and on another day because of short staff it might be ten women with ten babies, which makes your caseload twenty”. They also described a variability within their caseload – “Sometimes you have ten women and everything is just straight forward but on other days you might have three patients, one with complex needs, and you will not get to the other two ladies because one person has taken all of your time”.

These issues could both lead to constraints on their time which would mean that, “You won’t have the time to provide something personalised to and tailored to your patients”. Paperwork was another demand on time, influencing personalisation – “The paperwork we have to do is endless and we must jump through so many hoops. It interferes with your thinking process and your ability to engage with women and personalise the care”.

SC3 was a clinical trials nurse working for an NHS Trust in Bedfordshire. They highlighted caseload volumes and time constraints as problematic to personalisation:

Sometimes you have a huge caseload and if you’ve only had a brief meeting then you haven’t had enough time to get to know them to be able to personalise.

New patients are not ingrained in your mind like your regulars so it can be difficult to remember the individual and what makes them individual to personalise

It can be really busy and it can get quite hard to juggle sometimes. You have to chase your tail a bit some days to try and get through it all. Sometimes you are rushing to deal with the next appointment and if you didn’t have another patient you would do more and be a bit more personalised but you are quite conscious of the time so there is a bit of timing watching which can limit the personalisation

SC4 was a chemotherapy nurse working in an NHS Trust in Bedfordshire. They observed that, “Patient volume is a key challenge”, and explained that increased expectations had coincided with a reduced staff-to-patient ratio. The implication was that each professional now had less time to spend with each patient – “We have increased our number of consultants from three to five in the last two years but within four years we have had a 100% increase in patients so we have less capacity”. They explained the influence of capacity on personalisation in reference to their previous experiences:

In the acute admissions unit it was conveyor belt nursing. You had a list of jobs.

You triaged your patients, assessed them and moved them on as quickly as you

possibly could because you knew you had thirty more patients coming through. You get your observations done, your investigations done and your paperwork done and move them through the system as quickly as you possibly can. Time did not allow for personalisation because there were too many patients to see

SC5 was a consultant anaesthetist and intensivist for an NHS Trust in the West Midlands. They identified time as fundamental to personalisation but indicated that, “it just can’t always be delivered with the resources that we have available. Time is always a factor”. Whilst time was sufficient for their practice – “I am very lucky. I have a special clinic where I can allocate one hour slots because I see fewer patients by comparison” – caseload volume was viewed as a constraint on time and personalisation elsewhere:

If you compare that to the fifteen minutes that my surgical colleagues get in their clinic. That is a prime example of how personalised care would benefit patients but cannot be delivered in time because there are so many patients for them to see. If you personalise each one, many people would not get the care they need whereas, at the moment, they get acceptable care but just not very personalised

In other words, caseloads were described as determining the time a clinician can spend with a patient to personalise their care. Finally, there was a perception that increasing demands had complicated practice and reduced time available to personalise services:

Ever-changing goalposts, standards and guidelines are introduced all the time and this has invariably made the process more complex. New guidelines always add a layer of complexity to our work and this can limit the total volume of patients I can see in a day because of all the extra work I have to take on for each one. This interferes with the quality of the interaction and the personalisation

CS1 was a community midwife working in an NHS Trust in Bedfordshire. They recommended that, “The main challenge with delivering personalisation is time and the

size of caseloads". When professionals are rushed for time, it can be attractive to focus on safety at the expense of personalisation – "If you're very busy and you are pushed for time then you do the bare minimum, which means that you put safety first and then the personalisation gets side-tracked". Documentation was one priority restricting time:

The main documentation that we do is patient handheld notes. We also put that information into the GP computer system and then we do clinic lists for patients that we see. That is three lots of information for one patient you see in a fifteen minute slot and that really does restrict what you can achieve, especially when it comes to personalisation for the patient, because you just don't have the time

Spending more time with one patient than anticipated or permissible within the scheduling of appointments was said to reduce the ability to personalise for other patients:

They get a fifteen minute appointment and I do my best for them to have me for fifteen minutes. If there are complications then I do try to spend longer with them as necessary but then when you've spent more time with one you have to chase up your time to make sure that the clinic runs on time. Generally, that will throw your times off and your personalisation will not be as good as it could be

CS2 was an MS specialist nurse working for an NHS Trust in the East Midlands. They identified a combination of resources and referrals as causes of time constraints:

There are really not enough resources from the point of view of the MS nurses. There is not enough time. We're getting new referrals every single week and we just have to absorb that into the time that we have and we are already stretched. It is very hard to find the time to provide personalised support for each patient

PC1 was a General Practice nurse working for a General Practice in Leicestershire. They noted demands on time as an obstacle to personalisation – "If there is one

thing that stops services from being personalised then it is unfeasible demands on our time". The following example of a patient caseload was provided as a demonstration:

If you have ten patients and you're going to personalise for every single patient then that might mean you will only get through three of those patients. In those circumstances, you may not want to personalise because you really need to get through all ten. Sometimes personalisation isn't a good idea if you're managing a mass of patients. You prioritise, do the minimum and defer the personalisation

Constraints were exacerbated by pressures across the health and care system – "Time restriction and the lack of funding are major challenges across the public sector. Things are coming from elsewhere, which means you're doing more work with the same time".

Systematic Standardisation is Problematic

Seven participants highlighted standardisation as an issue for personalisation in the sense of tailoring care and support to the needs and preferences of individuals. Participants identified a variety of systems, structures, processes, routines, treatments and services that has been organised to deliver standardisation, contradicting tailoring. Five participants explained standardisation as a lacking focus on the individual and five related it to an emphasis on the collective. Various other explanations were provided.

MH3 was a consultant psychiatrist working within an intensive care unit within a Northeast London NHS Foundation Trust. They viewed application of business models as problematic for personalised care because of their association with standardisation:

The challenge is that we are living in a capitalist world and we apply business models. If you go to business world they try to adjust things to the client but the business model that we subscribe to is like Henry Ford Model-T conveyer belt.

Business models focus on money and, “the people are treated as statistics and we all become the same and so it becomes much harder to deliver something personalised”. Clearly, this contradicts the individualisation of services necessitated in order to tailor.

MH4 was employed as a senior house officer on a long-term schizophrenia and psychosis rehabilitation ward in a Southwest London NHS Trust. Observing that, “It is probably the logistics that stop us sometimes”, they recognised that, “We generally do have a one treatment fits all approach and that is a problem”. Providing tailored options in the context of standardised pathways was described as inconvenient because of the complications it could involve – “we often treat them as odd and inconvenient because it is more complicated for us”. This preference was reinforced by budgetary constraints:

When you've got a limited budget and you look at the personal health needs of a person, from that basic level there are certain levels of personalisation which you are never going to achieve. We are actually not geared up for personalising at the moment because there isn't a budget for it. It is cheaper for the NHS to provide standard treatment and this is especially important at the moment

MH6 was a liaison psychiatrist working with frail and elderly patients in a South London NHS Foundation Trust. They described contemporary healthcare interventions as being, “constructed around the system and not patients and their individual needs”. The system was viewed as a tool for standardisation – “The whole system is set up to provide standard care and there is not much thinking about what is unique to patients”. The following example was provided of the consequences of this approach for patients:

We have a highly medicalised model. You'll be placed on a stroke pathway with certain drugs that need to be instituted because there's robust evidence but that doesn't take into account the nuances of that person or their particular situation

CYP3 was a community physiotherapist and team leader for child occupational therapy and physical therapy in an East Midlands NHS Trust. They identified standards as problematic to delivery of a personalised service that treats patients as individuals:

We've got a set service that we've got to deliver and we've got set ways of doing that and we can be flexible with that but at the end of the day we've got to have some set standards so that everyone receives a fair and equitable service

Consequently, there was a perception that tailoring to the individual must comply with a set of standards in order to ensure that the collective are treated fairly and equitably.

SC1 was as a bank midwife working within an NHS Trust in Bedfordshire. One challenge was explained as a focus on the collective which results in standardisation:

Personalisation is great but the system doesn't lend itself because it is focused on the collective and that's why, sadly, you might get one baby in many thousands that is damaged and, because of that, everybody is subjected to a routine

This means that patients, "are not treated as individuals in the way that they should be with personalisation", because certain structures and processes are enforced upon all:

Personalisation isn't always possible. When a lady has had a baby, before they can leave the hospital her baby needs to be checked over by a consultant. There are certain structures that need to be in place and there is a standard process. Even if they want to go home you can't just let them go because there's a routine

SC5 was a consultant anaesthetist and intensivist for an NHS Trust in the West Midlands. They described the system as set up to provide standard care for everybody:

The availability of anything which caters for the individual needs of patients or anything unusual in any aspect of the care very quickly hits the buffers because

our system is quite rightly set up to deliver a high standard of average requirement care. As soon as there's anything unusual you will quickly hit the buffers

Evidently, the organisation of care to standard requirements is problematic to tailoring.

PC1 was a GP nurse working for a GP in Leicestershire. Commissioners were perceived to focus on the collective needs of the population as a consequence of their position, making decisions that contradicted personalisation in the form of tailored care:

CCGs look at the big picture and they look at a certain level of control in a larger population. They would set a target and a budget and say because a treatment is not cost-effective we don't recommend this but we do recommend that. However, they don't think about the individual patient and what they need. That can be an obstacle to tailoring because the system is set up around standard care

Financial Constraints Hinder Personalisation

Nine participants identified finances as problematic to personalisation. Seven participants associated financial constraints with time (Theme 13: Time pressures constrain personalisation), and the impact of finances on time was described in the above. All nine participants recommended that current finances were insufficient for personalisation and five recognised that finances continued to diminish. Distinct from time, two participants claimed that personalisation costs more when compared to standard care.

CYP2 was a children speech and language therapist working within an inpatient hospital and community setting for an East Midlands NHS Trust. They explicated that, "The NHS is a limited resource and that definitely does have a bearing on our ability to personalise". Whilst, "we have the freedom to do what we need to do for children within the resources that we've got, there's a clear limit to what we can afford to personalise". For example, "We just can't afford some of the specialised treatments that might work".

CYP5 was a learning disabilities nurse working in respite services within an East Midlands NHS Trust. They highlighted financial limits as a challenge to personalisation:

There are some obvious financial limitations to personalisation. I don't think the financial situation impacts on clinical care, as we've got the equipment required to meet their health needs, but we can't always personalise to what they want

The following shallow example was provided – “we can't afford to cook different meals for every child and we don't have a budget for any of the extra things they might want”.

Professional Expertise Retains Importance

Four participants recommended that professional expertise and discretion were fundamental to ensuring that patient choices would not conflict with their best interests.

CYP4 was a physiotherapist working within a community setting within an East Midlands NHS Trust. Lacking patient understanding was seen as a problem and it was proposed that professionals should apply their expertise to the benefit of their patients:

Families choosing and getting exactly what they think they need and what they want could be a problem because they don't have the expertise that they need. I worry that the patients would lose out if it's not broken down and explained to them properly. If patients are going to have more choice then they would benefit from more information and understanding, drawing on professional expertise

SC1 was a bank midwife working for an NHS Trust in Bedfordshire. Regarding the subject of personal health budgets, they alleged that patients may be exploitative and use them inappropriately – “I think that some women might use their £500 in ways that would suit them but may not be in their best interests”. They did hesitate, “because I feel judgemental but women might say that they're going to have a scan once a week and smoke loads and clearly that isn't going to be appropriate”. As experts in the best

interests of patients, it was recommended that professionals should maintain their role and discretion over public spending – “It’s so important that we hold them accountable”.

SC2 was a clinical trials nurse working in an oncology unit within an NHS Trust in Bedfordshire. While they saw personalisation as beneficial to patient outcomes, the idea of patient choice was viewed with scepticism in relation to professional expertise:

I don't really know what patient choice means because at the end of the day I'm the clinician. There is some patient choice but how much choice patients really have is debatable because I would say by very virtue of the fact you are coming to see a doctor that sort of negates any sort of choice you might have

Shallower choices were seen with less scepticism – “It really depends on what sort of choice patients are going to have. If it’s choice of where you have treatment, it’s entirely up to you”. More problematic were deeper choices such as patient choice of treatment:

If it's choice about treatments then actually there is often not a choice to be had. The experts say that there are only some things you can have. You can't have something that has no supporting evidence just because you want to try it out

Patient knowledge of treatment was problematised – “patients wouldn’t generally have the understanding to choose between treatments” – in favour of professional expertise:

Even being a nurse myself, I would still feel that if I'm going to see a consultant about a medical problem then I would still absolutely want them to tell me what to do about it because at the end of the day they're the expert and I'm not

PC1 was a GP nurse working within GP in Leicestershire. They relayed that, “At the end of the day, as the clinician, you are meant to be the expert so you have to take the correct action that is in the very best interests of the patient”. They further explained that professional expertise on the best interests of patients should be prioritised above

choice where necessary because, “Listening to patients and letting them make choices is one thing but you’re not going to go against best practice and allow harms to occur”.

Management and Organisation Matter

Two participants suggested that the approaches of managers and organisations and the relationship between managers and professionals influences personalisation.

CS3 was an MS specialist nurse working for an NHS Trust in the East Midlands. They observed the impact of managers and organisations on personalised practice – “In reality, it’s dependent on how your manager views it and also how your organisation views it. That has a real impact on what is possible where you work”. Strong leadership could be advantageous– “If you’ve got a strong leader who people are willing to follow then you can get better results”. However, authoritarian leadership can be problematic:

Sometimes what happens, particularly in big organisations, is that it feels like it is all imposed and when that happens it automatically sets up a retaliation where people resist and just don’t want to follow what they are being told to change

PC1 was a GP nurse working within GP in Leicestershire. Acknowledging the restrictions enforced by the system (Theme 14: Standardised resources are problematic), they proposed that senior managers could be critical to achieving personalisation:

There are ways around it. Luckily, where I work, once I have given my rationale to a GP they are quite happy to go with my plan. I can tailor something and the GPs do trust me enough to let me make that decision for the patient

However, they noted the opposite can also occur – “not all GPs are that approachable” – drawing attention to the critical role that managers can play in personalised practice.

Interpretation Influences Practice

One participant observed that personalisation is ambiguous and recommended that professional interpretations of personalisation influence practice. **CS3** was an MS specialist nurse working for an NHS Trust within the East Midlands. They identified the understanding of personalisation as problematic – “A key challenge to personalisation is clinician understanding of what it means for them in practice”. Since personalisation is reliant on interpretation, they acknowledged the diversity of interpretations available:

You will get some that are so woolly that they'll take personalisation to one end where suddenly the patient has absolutely all the control. Then you will get the person at the other end that is so draconian with what they're doing that they're not giving any control to the patient. Then you've got the people in the middle

As a consequence, they recommended that, “I think that it is crucial that, if we are going to head this way, we firmly understand what our responsibilities as professionals are”. Therefore, it was argued that further information was needed to enable personalisation:

We never seem to get what we need, which is that bit in the middle that actually makes sense of it and makes it workable for everybody. I think that is the trouble. There is not enough information about how we put personalisation into practice

Conclusion

The fifth chapter demonstrated that, whilst interpretation of personalisation was diverse, the majority of participants drew on themes of responsiveness, voice, choice, and improved outcomes. This chapter sought to examine professional perspectives on practice in context of these interpretations. Participants revealed that time, money and systems were common obstacles to responsiveness. They also contended that patient

choice could be problematic in context of professional expertise and the best interests of patients. Implications will be discussed in the next chapter, drawing on the literature.

7. DISCUSSION OF FINDINGS

As described in chapter one, this study examined the interpretation of personalisation by healthcare professionals working within the NHS in England. The objective was to explore how personalisation is interpreted and the consequences of these interpretations for practice. In particular, the research was interested in the implications of professional interpretations for the expected roles of patients and professionals and the relationship between patients, professionals and the state. Based on their relative autonomy and discretion, healthcare professionals were theorised to have significant influence over practice. Therefore, the interpretations of healthcare professionals were posited as essential to personalised practice. Beyond interpretation, the research also examined professional perspectives on personalisation in practice. The intention was to investigate professional experiences of personalisation in order to comprehend the dynamics that influence practice. Two primary research questions were pursued:

1. *How do professionals working in the NHS in England interpret personalisation?*
2. *What are the perspectives of professionals on the practice of personalisation?*

Findings in relation to the first research question were described in the fifth chapter and findings relating to the second research question were defined in chapter six. This chapter will discuss the implications of these findings for practice, drawing attention to the various literatures that were described within the first, second and third chapters.

Interpretations of Personalisation

As outlined in the second chapter, there is a wealth of literature on the interpretation of personalisation which draws attention to multiple potential meanings and diverse ways in which the welfare state might be reformed. For example, Needham identified five themes that represent separate storylines, “which weave together to form an

overarching narrative of personalisation” (2011: 48). This is pertinently supplemented by an observation that personalisation comprises conflicting accounts of its own relationship between the past, present and future. Personalisation is viewed as continuous with the past and an evolution of traditional and contemporary practice whilst also representing a critical disjuncture from previous practice, being discontinuous and transformational. Leadbeater (2004) has interpreted personalisation as a script for public services, arguing that there are five potential scripts that diverge on a continuum between shallower and deeper personalisation. At the shallower end of the spectrum are reforms aligning with traditional practice, emphasising tailoring, voice and choice and framing patients as consumers of care. At the deeper end, personalisation invites patients to become co-producers of services, representing a transformational agenda for practice. Ambiguity also originates from the relationship of personalisation to tailoring (Cribb and Owens, 2010) and co-production (Parker and Heapy, 2006). As the meaning and interpretation of personalisation has been widely studied, the existing literature was utilised to develop a framework to cover potential interpretations. Twelve themes were identified and grouped into three overarching sub-narratives (Table 7.1).

Table 7.1: Themes of Personalisation

Justifications for Personalisation
Theme 1: Personalisation works, transforming people’s lives for the better
Theme 2: Personalisation saves money
Theme 3: Person-centred approaches reflect the way people live their lives
Theme 4: Personalisation is applicable to everyone
Theme 5: People are experts on their own lives
Perceptions of Personalisation
Theme 6: Personalisation is evolutionary, continuous and consolidating
Theme 7: Personalisation is revolutionary, disruptive and transformational
Nature of Personalisation
Theme 8: Increasing responsiveness by tailoring to needs and/or preferences
Theme 9: Giving users more say, keeping them informed and offering choice
Theme 10: Direct say over money, enabling individuals to make their own decisions
Theme 11: Co-production, active participation, choosing outputs and shaping inputs
Theme 12: The public good emerging collectively through individual decisions

As described in the second chapter, the first theme (Theme 1: Personalisation works, transforming people's lives for the better) is based on evidence that personalisation improves outcomes for service users in receipt of care (Needham, 2011). Alongside the evidence provided by formal policy evaluation, "Case studies and vignettes are regularly deployed" (Needham, 2011: 49). This supports the personalisation narrative by distributing anecdotal evidence that personalisation has worked for individual service users and can make a difference to others. This is also supported by, "claims to self-evidence and common sense" (Needham, 2011: 49), wherein the advocates of personalisation claim that the benefits of personalisation are self-evident. The notion that personalisation can improve outcomes for patients was broadly supported by the professionals participating in this study. Improved outcomes were variously identified as engagement, satisfaction, wellbeing, usefulness, effectiveness, independence and empowerment, drawing attention to diverse improvements. Participants derived this theme from a combination of informal sources of evidence (i.e. direct experiences) and assumptions. In contrast, formal sources of evidence – for example, the report on the evaluation of the personal health budgets pilot (Forder et al., 2012) – did not contribute to this interpretation of personalisation, despite backing the claim that personalisation improves outcomes. Therefore, whilst formal evidence may be critical to explaining the adoption of personalisation by policy-makers, it was apparent that direct professional and personal experiences were more critical to professionals. Moreover, it was the perceived benefit for patients that motivated engagement with personalisation, drawing attention to the patient as the frame via which participants interpreted personalisation. This is a key contribution and advises that professionals are more likely to identify with policies, such as personalisation, that have perceived benefits for their patients.

The second theme (Theme 2: Personalisation saves money) is based on the notion that the improved outcomes of personalisation will not cost more than standard

care (Needham, 2011). This is supported by formal evidence which suggests that, “this way of working may also be more cost-effective than the previous system” (Glasby and Littlechild, 2009: 125). The implication of this narrative is that personalisation might provide better value-for-money, either by reducing the cost of care and support or by improving outcomes at a comparable cost. One example of how this might be achieved is by utilising personalised interventions to reduce the long-term needs of patients or prevent the escalation of their needs, resulting in decreased total expenditure on their care over time. Another example would be where personalised care might improve the health, wellbeing and satisfaction of patients without resulting in increased cost when compared to standard approaches. As with the first theme, this formal evidence base is also strengthened by, “individual stories of the cost-savings that have been achieved through personalisation” (Needham, 2011: 50). There are credible accounts of, “ending expensive out-of-borough placements and developing local alternatives at a much lower cost” (Needham, 2011: 50). Claims to self-evidence and assumptions are also evident. Critically, none of the participants interpreted personalisation in relation to cost-effectiveness or value-for-money. Consequently, it was not apparent whether the improved outcomes they identified were associated with an increase in, decrease in or maintenance of costs. However, this does suggest that outcomes are more important than costs from the perspective of professionals. This is a key contribution, suggesting that reflections on cost did not impact upon the interpretation of personalisation.

The third theme (Theme 3: Person-centred approaches reflect the way people live their lives) draws on the idea that care and support should be more holistic – “support for people with care needs cannot be contained within service sector boundaries, because that is not how people live their lives” (Needham, 2011: 52). Through placing emphasis on the lives of patients, this story provides a common-sense rationale for the introduction of personalisation to all services impacting on their lives. It also suggests

that consideration of needs should go beyond medical definitions. Critically, only five of the participants interpreted personalisation as recognising the multiple and interacting needs of patients, which indicates that personalisation was not widely viewed as a holistic method, despite its centrality to the personalisation narrative. The fourth theme (Theme 4: Personalisation is applicable to everyone) comprises the story that personalisation applies to all people (Needham, 2011). Only one of the participants identified with this theme, arising from consideration of patients lacking capacity, for whom it was contended that, whilst lacking capacity represents a challenge to personalisation, barriers can be overcome. Whilst not widely supported, none of the other professionals working in mental health identified the capacity of patients as problematic. Generally, personalisation was not interpreted in a restrictive manner. The fifth theme (Theme 5: People are experts on their own lives) interprets patients as experts in their own lives (Needham, 2011). This challenges the orthodoxy of the professional gift model in which patients are perceived as dependent on care. Just one of the participants interpreted personalisation in line with this theme. In summary, these themes were not relevant to understanding the majority interpretation of personalisation suggesting either they are not relevant in this context or that they were not properly understood by participants.

The sixth theme (Theme 6: Personalisation is evolutionary, continuous and consolidating) considers the framing of time, with personalisation interpreted as an evolution of practice (Needham, 2011). Accordingly, there is an assumed continuity between the past, present and future of care, wherein personalisation is seen as familiar and presented as congruous with traditional NHS values that include solidarity and equity (Needham, 2009). Five participants interpreted personalisation as an evolution of practice. Four participants interpreted personalisation as an evolution of practice. Four of these participants recommended that personalisation had always been crucial to their practice, two observed that they had been taught to personalise at medical school, one

advised that personalisation had always been central to medicine and one suggested that personalisation had always been essential to their profession. In contrast, theme seven (Theme 7: Personalisation is revolutionary, disruptive and transformational) interprets personalisation as a radical departure from the past, designed to transform the way that care and support are delivered (Needham, 2011). Personalisation is defined as a transformation of practice, departing from prior approaches as a disruptive response to service failure (Needham, 2009). As explained within the fifth chapter, three participants interpreted personalisation as transformational, framing it as a departure from established practice. Therefore, both themes proved to be relevant to understanding the personalisation narrative as interpreted by professionals and, perhaps unsurprisingly, there were no overlaps between the themes. Yet, there is an evident disjuncture between notions of personalisation as both evolutionary and revolutionary. One potential explanation for disparity could be divergent interpretations of personalisation. However, personalisation was defined under a narrow set of themes by the majority of participants. A more likely explanation is that personalisation is interpreted in context of experience and some had more experience of personalised approaches than others.

The eighth theme (Theme 8: Increasing responsiveness by tailoring to needs and/or preferences) can be defined as a shallow form of personalisation (Leadbeater, 2004) and advocates for greater responsiveness to individual patients (Cribb and Owens, 2010). Leadbeater describes personalisation as a script for organising services that originates from, “two very different accounts of how the public good is created” (2004: 16). The first account is associated with a shallow definition of personalisation and is founded on, “the state providing services to society ever more efficiently and effectively” (Leadbeater, 2004: 16). This links personalisation to state intervention in the lives of its citizens and presents patients as in need of and dependent on services that are provided to them by professionals and the state a personalised manner. Power

is given to professionals who are expected to solve problems for their patients. As an example of shallow personalisation, the responsiveness theme can be sub-divided into conflicting accounts of tailoring to needs and tailoring to preferences (Cribb and Owens, 2010). As defined within the second chapter, the needs of individuals are objective in the sense that they are independent of beliefs, derived from the reality of existence rather than the perception of reality. Therefore, based on their subject expertise, tailoring to needs requires the input of professionals. In contrast, preferences are subjective, originating from, “the beliefs of that person and the environment in which the claim is made” (Cribb and Owens, 2010: 312). Hence, tailoring to preferences necessitates the input of patients. Nonetheless, with either account, the professional is the tailor.

As explained in the fifth chapter, twenty participants defined personalisation as tailoring to individuals, requiring greater service responsiveness to patients. Ten interpreted personalisation as tailoring to needs and two participants defined personalisation as tailoring to preferences. Eight participants interpreted personalisation as tailoring to the needs and preferences of individuals. Cribb and Owens advise that there are various positions between tailoring to needs and tailoring to preferences, where there are a plurality of alternative models available – “there is a range of intermediate positions in which various degrees of negotiation, compromise and customisation are possible” (Cribb and Owens, 2010: 313). This recognises the critical distinction in the roles of patients and professionals in tailoring to needs and preferences. Whereas tailoring to needs privileges the input of professionals and tailoring to preferences privileges the input of patients, tailoring to needs and preferences necessitates the incorporation of patient and professional inputs. Best conceived as a spectrum, there are a range of possibilities available, wherein patients and professionals are variously responsible for providing input into the process of tailoring. Ultimately, the professional retains control of this process as the tailor of care, integrating the needs and preferences of patients

into the services delivered. Therefore, the definition of personalisation as tailoring does not challenge the traditional organisation of power or the resultant relationship between patients and professionals wherein professionals are the dominant force. As a shallow reading of personalisation, greater responsiveness reflects a progression of contemporary practice. The significance of responsiveness to the interpretation of personalisation by healthcare professionals represents a key contribution to knowledge.

The ninth theme (Theme 9: Giving users more say, keeping them informed and offering choice) involves greater voice and choice for patients, with professionals expected to keep patients informed and facilitate opportunities to choose between different courses of action. Leadbeater describes this as, “giving users more say in navigating their way through services once they have got access to them” (2004: 21). As explained within the fifth chapter, thirteen participants defined personalisation in terms of greater patient voice and choice. Seven participants interpreted personalisation in terms of choice and four participants defined personalisation in terms of voice. Two of the participants defined personalisation in relation to voice and choice and five emphasised the importance of informing patients. Choice was reflective of mass customisation (Parker and Heapy, 2006), wherein public services are standardised, production is separated from consumption and patients are given a selection of pre-determined solutions from which they can choose. With this model of mass customisation, choices are centred upon outputs and not inputs. Therefore, the power of the state and professionals to control the production of care and support is maintained and patients are merely able to select from a range of options deemed acceptable within the boundaries of care. Accordingly, voice and choice are reflective of the shallow interpretation of personalisation (Leadbeater, 2004). Critically, each of these models provides a different mechanism for tailoring care to the preferences of patients. Whereas increased

voice depicts the professional as a tailor who flexes care and support to patient preferences, patient choice requires the professional to tailor the provision of information and implement the choices made. Nonetheless, the professional remains the tailor and the balance of power remains in their favour. Critically, the importance of voice and choice to interpretations of personalisation represents a key contribution to knowledge.

The deep form of personalisation defined by Leadbeater (2004) corresponds with what Parker and Heapy (2004) have described as co-production. This model links production to consumption and requires the development of, “mechanisms and channels for engaging people not only in choosing between services, but also in shaping those services in the first place” (Parker and Heapy, 2006: 85). Leadbeater explains that, “users are not just consumers but co-designers and co-producers of a service: they actively participate in its design and provision” (2004: 22-23). This storyline recommends that the actions of individuals collectively generate the public good. Accordingly, personalisation is perceived as participatory and democratic and, rather than acting upon society and providing public services, “the state creates a platform or an environment in which people take decisions about their lives in a different way” (Leadbeater, 2004: 16). This frames patients as co-producers. They are active participants as opposed to dependent users of services, taking responsibility for their health and designing their own solutions. As explained within the fifth chapter, zero participants interpreted personalisation in terms of budgets (Theme 10: Direct say over money, enabling individuals to make their own decisions) co-production (Theme 11: Co-production, active participation, choosing outputs and shaping inputs) or self-organisation (Theme 12: The public good emerging collectively through individual decisions). Consequently, it is clear that the majority of study participants interpreted personalisation in shallow terms, emphasising tailoring to needs and preferences and facilitating varying degrees of patient voice and choice. This is a key contribution to knowledge and

the absence of deeper interpretations recommends that healthcare professionals define personalisation in terms that essentially maintain the status quo of practice.

Central to the personalisation narrative is the supposed need to construct a new relationship between patients and professionals. There are two central claims. The first is, “that professional expertise must be challenged and the privileged status of professionals resisted” (Needham, 2011: 137). Personalisation has been associated with the contention that patients have expertise that contradicts the traditional favouring of professionals as experts. This legitimises the knowledge of service users and recognises the authority of their voice in the delivery of care. Consequently, professional authority is problematised, albeit their expertise is not diminished. The second claim reinforcing the need for a new relationship is that personalisation necessitates a closer, “collaboration between front-line staff and users based on co-production principles” (Needham, 2011: 137). With this account, patients are perceived as co-producers of care and support and as active participants in production and consumption – “professionals and empowered patients work together to improve services, in a positive-sum game, rather than being placed in a zero-sum relationship in which they battle for authority” (Needham, 2011: 140). Significantly, these notions conflict, characterising the patient-professional relationship as both adversarial and collaborative. However, within this study, participants overwhelmingly presented personalisation as a collaborative endeavour between patients and professionals and there were very few references to conflict between these stakeholders. Nonetheless, the extent to which a new relationship was endorsed by participants is limited by the shallow terms in which they interpreted personalisation. Whilst voice and choice (Theme 9: Giving users more say, keeping them informed and offering choice) were more common interpretations, co-production was not recognised (Theme 11: Co-production, active participation, choosing outputs and

shaping inputs). This might explain the apparent absence of perceived adversity, since shallower versions of personalisation are less transformational to existing practices.

Crucially, the ambiguity of personalisation has permitted audiences to apportion various meanings and align the policy with potentially contradictory philosophical arguments, associated with democratic and neo-liberal ideals – as explained within the second chapter. Consequently, personalisation facilitates the interpretation of service users as both citizens (democratic) and consumers (neo-liberal) – or as a citizen-consumer (combination of both). The citizen is a democratic archetype, drawing on notions of liberty, equality and solidarity. Citizens are located in a relationship with the state, conjuring notions of mutual obligation and production – “It is the consent of the citizen that empowers the state; while the state provides and secures the conditions that enable citizens to lead their lives” (Clarke et al., 2007: 2). In contrast, the consumer is positioned in terms of an economic relationship. They are, “engaged in economic transactions in the marketplace, exchanging money for commodified goods and services” (Clarke et al., 2007: 2). This can also be understood as a relationship of liberty and equality of a different sort, based on the capacity of the consumer to self-direct and choose how their own well-being can be pursued – “All individuals (subject to certain legal restrictions) are equally endowed with the capacity to be self-directing” (Clarke et al., 2007: 2). Nonetheless, there is a key distinction – “The market responds to ‘price signals’ rather than personal characteristics. The market...reconciles the wants of many producers and consumers” (Clarke et al., 2007: 2). Furthermore, whereas the citizen is a public figure, fulfilling their obligations to society in the public realm, the consumer is a private figure driven by personal desire and pursuing their own interests.

As Needham has pertinently observed, “some of the strongest advocates of personalisation have positioned its appeal explicitly in terms of a fuller vision of citizen-

ship” (2011: 116). These advocates have observed that public services have traditionally obliged individual service users to forsake their rights as citizens, accepting a reduced autonomy and independence from the state in exchange for care (Duffy, 2010b). Arguably, with the adoption of personalisation, “citizens are promised a more tailored interaction with the state, fostering self-determination” (Needham, 2011: 116). From this perspective, personalisation enables the rights of service users to citizenship, “because it gives people who have been effectively disenfranchised enhanced opportunities to play a full role in society” (Lymbery, 2014: 300). Crucially, examples of the democratic narrative were evidently contained within participant interpretations of personalisation, exemplifying the characterisation of individual patients as citizens. First, personalisation was perceived as an improvement in patient independence and empowerment (Theme 1: Personalisation works, transforming people’s lives for the better), drawing on the concept of self-determination. Second, personalisation was presented as universal (Theme 4: Personalisation is applicable to everyone), acknowledging patients as citizens with equal rights. Third, personalisation was defined in terms of patient expertise (Theme 5: People are experts on their own lives), challenging the traditional dependence of patients on professionals and framing them as capable of contributing to care as equal citizens. It can also be argued that patient choice (Theme 9: Giving users more say, keeping them informed and offering choice) facilitates the rights of patients to participate as equals in the pursuit of their own health and wellbeing.

The characterisation of individual as consumers and the integration of consumerist ideals such as patient choice is central to the neo-liberal narrative (Clarke, 2007a, 2007b; Clarke et al., 2006; Vidler and Clarke, 2005). Vitaly, consumers can be defined as, “a knowledgeable and self-directing subject, capable of identifying and articulating individual wants as choices about services” (Vidler and Clarke, 2005: 34). The capacity and agency of consumers is assumed and, as a consequence, neo-liberalism adopts,

“an individualised and marketised image of the consumer as a self-directing, rationally choosing individual” (Clarke, 2007a: 438-439). Furthermore, neo-liberalism asserts a, “politics of individual recognition over the politics of collective redistribution” (Webb, 2006: 38). Critical scholars interpret individualisation to represent responsabilisation (Ferguson, 2007, 2012; Scourfield, 2005, 2007) – which has negative connotations regarding the increasing responsibilities placed on service users – drawing attention to the centrality of responsibility within consumerist narratives. Critically, within this study, three different terms were used by participants to describe individuals – person, patient and individual. Although these terms draw attention to the individual, this language was not explicitly neo-liberal and participants did not describe people, patients or individuals as consumers. Nonetheless, participant interpretations of personalisation did explicitly reference choice (Theme 9: Giving users more say, keeping them informed and offering choice). As a characteristic feature of neo-liberal philosophy, references to choice implicitly frame patients as consumers of care. Individualisation was evident in the central of the individual patient across all interpretations of personalisation and varying degrees of responsibility were evident between shallower and deeper definitions.

Critics of personalisation have remarked on what they perceive as problematic engagement with citizenship, commenting on the ambiguity of citizen location within the public sphere – “Many public service users, who may be constructed by policies as citizens with public rights and responsibilities are primarily concerned with ‘private’ matters – their own health and social care requirements” (Prior and Barnes, 2009: 194). As Needham explains, “traditional understandings of the citizen as a public figure may not accurately capture the experience of being a user of welfare services” (2011: 117). A further criticism is the claim that consumerism diminishes citizenship. This argument is supported by two critiques. First, it can be contended that democratic and neo-liberal accounts of citizens and consumers are contradictory, as explained above. Describing

personalisation as an empty signifier (Laclau and Mouffe, 1985), West considers personalisation, “a way of reconciling competing policy imperatives in an empty signifier around which there is ongoing hegemonic struggle” (2013: 653). This is acknowledged by Ferguson, who proposes that personalisation represents, “the offspring of two discourses or ideologies which, while both employing the language of independence, choice and control, have very different origins and aims” (2012: 58-59). Thus, it is asserted that democratic and neo-liberal narratives are incompatible and that existence of one necessarily diminishes the other. Second, some have suggested that the ideological underpinnings of the personalisation narrative are not equal (Ferguson, 2007, 2012; Lymbery, 2014; Scourfield, 2005). For example, Scourfield notes that neo-liberal ideas have been intentionally placed upon, “the disabled movement’s ‘social rights discourse’, producing a powerful hybridisation but one riddled with tensions” (2005: 473).

This statement has been resisted by authors such as Leadbeater (2004) and Keohane (2009) who insist that consumerism provides opportunities for new forms of citizenship. Such accounts place emphasis on, “inclusion within the broader community – something that disabled people historically lacked” (Needham, 2011: 118). This view rests on the claim that consumerism fits with citizenship (Needham, 2011: 119):

Personalised approaches invoke the freedom of disabled people to be consumers in the same way that other people are: spending their money on the same things, using the same services in the same spaces, rather than relying on segregated and distinctive provision

An alternative conception of service users as citizen-consumers provides a distinction that may more accurately reflect this approach (Clarke et al., 2007; Needham, 2003). Clarke et al. have noted that these terms, “exist in a degree of strain with one another, but they are also co-constitutive of each other” (2007: 3). In other words, whilst there

are antagonisms between consumers and citizens, embodying fundamentally different relationships, practices and principles of social coordination, they are undoubtedly interconnected in practice – evidenced by the implicit interpretation of individual patients as both citizens and consumers by participants within this study. In practice, personalisation signifies a balance between democratic and neo-liberal narratives, offering a conceptualisation of the patient as a citizen and consumer. Nonetheless, the concept of the citizen-consumer is problematic, not least because each of these terms is inherently, “less substantial or solid than their representation in the liberal social imaginary suggests” (Clarke et al., 2007: 4). As Needham analyses, “citizen and consumer and unstable categories making it difficult to specify what is implied by their hyphenation” (2011: 117). Yet, citizens and consumers are mutually fundamental representations of the individual within the personalisation narrative.

Importantly, there are pertinent criticisms of the democratic narrative in relation to the independence concept. The promotion of independence within personalisation has been criticised by some for ignoring the lived reality of dependence (Ferguson, 2012; Lymbery, 2010; Scourfield, 2007). For example, Lymbery observes that, “there are numerous other issues over which policy appears to skate, rather than engaging fully with their implications” (2010: 6). This includes the challenge of balancing independence against the reality that, for many, “dependence, vulnerability and the consequent need for protection are dominant” (Lymbery, 2010: 6). Similarly, Ferguson has critiqued the problematic nature of independence – “dependence is also part of the human condition. All of us will experience periods when we will be dependent on others, whether as a consequence of short-term illness or personal crises or as a result of age or long-term conditions” (2012: 59). Furthermore, it has been argued that the valorisation of independence may have negative implications for users who experience

dependence in their lives (Ferguson, 2007; Scourfield, 2007) – “Policies that keep proclaiming the value of independence run the risk of reinforcing negative constructions of people who use public services” (Scourfield, 2007: 117). Another criticism is given by Barnes, who contends that emphasis on independence devalues dependency and the dependent via the ‘exceptionalisation’ of care – “If care is deemed relevant only to the most needy, then both they and care become devalued” (2011: 160). Hence, “what the personalisation agenda appears to offer is a re-drawing of a boundary that could reinforce the marginalisation of those who are most vulnerable” (Barnes, 2011: 165).

Responding to the neo-liberal content of personalisation, criticism has been directed at individualisation and the integration of consumerist ideals (Ferguson, 2007, 2012; Lymbery, 2012, 2014; Scourfield, 2005, 2007). Neo-liberal narratives assumes consumers to be rational, self-determining and capable of exercising choice in the market. However, this is a problematic assumption as, “the combination of poverty, multiple discrimination, a lack of resources in every sense and (frequently) physical or mental impairment means that the typical user of social work services will often not match” (Ferguson, 2007: 396). Consequently, “educated and articulate service users are also much more likely to be able to realise their choices than many others” (Lymbery, 2014: 303). This need not signify a paternalistic view of patients – “it is simply to recognise the impact that their frailties will have on the levels of choice they are able to make, or the possibilities of that choice being realised” (Lymbery, 2014: 303). Thus, contrary to the assertions of the democratic narrative, the introduction of patient choice within personalisation may contribute to increased levels of inequality between more and less capable individuals. The individualisation of care is also criticised for failing to recognise the structural factors which create the impetus for care and the contexts in which choices must be made (Mladenov et al., 2015; Owens, 2010; Owens and Cribb, 2013). Critically, it is argued that, “creating the conditions for empowerment requires policies

that address the wider structural circumstances that enable or constrain personal autonomy” (Mladenov et al., 2015: 316).

Perspectives on Personalised Practice

There has been an extensive examination of the practice, or implementation, of personalisation in the UK public sector. Particular focus has been given to personalisation in the form of budget control, such as direct payments (Clark et al., 2004; Ellis, 2007; Spandler and Vick, 2004), personal budgets (Hamilton et al., 2015, 2016; Whitaker, 2015) and personal health budgets (Forder et al., 2012). However, there have been comparatively few studies of the policy in its alternative forms, such as personalised care and support planning and personalised medicine. Particularly excluded from study is the practice of personalisation in a more general sense, as part of the routine practice of professional work. Moreover, there is a comparative lack of study on personalisation within the NHS. Most problematic is the lacking consideration of meaning and interpretation within the majority of these studies. It is the contention of this study that practice depends on interpretation and, therefore, understanding meaning is critical to understanding practice –practice must be located with interpretation. Participants revealed that time (Theme 13: Time pressures constrain personalisation), standardisation (Theme 14: Standardised resources are problematic) and money (Theme 15: Financial constraints hinder personalisation) are problematic to tailoring. Furthermore, professional expertise was presented as problematic to patient choice (Theme 16: Professional expertise retains importance). Management (Theme 17: Management and organisation matter) and ambiguity (Theme 18: Interpretation influences practice) were also discussed. A summary of themes is provided below (Table 7.2). The remainder of this chapter will discuss the consequences of these themes for personalised practice.

Table 7.2: Themes on Perspectives

Perspective on Practice
Theme 13: Time pressures constrain personalisation
Theme 14: Standardised resources are problematic
Theme 15: Financial constraints hinder personalisation
Theme 16: Professional expertise retains importance
Theme 17: Management and organisation matter
Theme 18: Interpretation influences practice

The concept of public service gaps provides a tool for measuring the interplay between action prescriptions and enablements in the conduct of street-level work (Hupe and Buffat, 2014), drawing attention to the challenging resource environment into which public policies are expected to be enacted (Lipsky, 2010). As described within chapter one, action prescriptions represent the demands expected of healthcare professionals. Directing action and constraining discretion and autonomy, action prescriptions are a product of the public accountabilities that professionals experience in the conduct of their roles – accountability being defined as, “a social relationship in which an actor feels an obligation to explain and to justify his conduct to some significant other” (Bovens, 1998: 172). In practice, action prescriptions, “have as a joint characteristic that they all are meant to prescribe – if not to determine, at least to indicate – preferred behaviour of others” (Hupe and Buffat, 2014: 556). In other words, as the product of accountable relationships, action prescriptions provide a guide to justifiable courses of action. On the supply-side of the public service gap equation, the concept of enablements describes, “the range of acts that enable street-level bureaucrats to fulfil their tasks” (Hupe and Buffat, 2014: 556). Enablements are diverse, comprising a range of action resources, “such as training, education, professional experience, time, information, staff, and last but not least, the budget itself” (Hupe and Buffat, 2014: 556). Consequently, a public service gap is defined as occurring when action prescriptions outweigh action resources – “A public service gap occurs when what is required of

street-level bureaucrats exceeds what is provided to them for the fulfilment of their tasks” (Hupe and Buffat, 2014: 556). Pertinently, participants identified circumstances that aligned with this phenomena in their experiences of practice and personalisation.

As described in the sixth chapter, nineteen participants identified time pressures as problematic to personalised practice (Theme 13: Time pressures constrain personalisation), highlighting the importance of time as a resource that enables professionals to deliver personalisation. Of these participants, seventeen revealed that professionals are frequently too busy to personalise, resulting in partial or zero compliance with personalisation in practice and suggesting that they have struggled or would struggle to deliver personalisation with the amount of time that they have or have had available to do so. This indicates the presence of a public service gap, given that time is insufficient to enable personalised care. The importance of time was particularly emphasised by participants who observed that personalisation requires a greater input of time in contrast with the standard method, with professionals required to spend a larger volume of time with each of their patients. This suggests that participants were being asked to do more – in other words, action prescriptions had increased. Pertinently, reduced and insufficient staffing levels were perceived as a cause of time pressures and were often explained as a consequence of financial challenges (Theme 15: Financial constraints hinder personalisation). This reflection recommends that constraints on time had been exacerbated by a reduction in resources, both human and financial, resulting in a situation where action resources – or enablements – had diminished over time. Thus, professional perceptions were indicative of a public service gap wherein they are expected to deliver more with less, escorted by an observation that the demands are increasing, further reducing their capacity to personalise. Administration and caseload volume and complexity were also problematic to time. Critically, the conclusion that time and the demands on time influence personalisation signifies a key contribution to knowledge.

As mentioned, financial constraints were also perceived as problematic to personalisation (Theme 15: Financial constraints hinder personalisation), drawing attention to the significance of financial enablements to delivery. Seven participants linked financial constraints to staff and time pressures, highlighting the link between finances and time (Theme 13: Time pressures constrain personalisation). All nine participants suggested that current finances were insufficient to personalise, reflecting a situation in which action resources are perceived to have reduced over time, and five observed that finances would continue to diminish. Again, reduced resources were premised in context of rising demands, providing further evidence of a public service gap where the expectations placed on professionals have increased but the resources given to meet these expectations have decreased. Distinct from time, two participants asserted that personalisation costs more when compared to standard care and, as a consequence, standard options are frequently pursued at the expense of personalisation, providing further evidence that financial enablements are insufficient to enable personalisation. In a period where finances are constrained, following several years of low-level funding growth (Kraindler et al., 2018; NHS England, 2014b, 2017; Robertson et al., 2017), this problem is very likely to persist. Standardised systems, structures, processes, routines, treatments and services were also identified as a barrier to personalisation (Theme 14: Standardised resources are problematic), with the suggestion being that a systematic focus on the collective and associated lack of focus on the individual conflicted with personalisation. It was noted that the range of resources on which professionals could draw upon in the delivery of services had been, as a consequence of previous policy, designed to provide standard care. Crucially, the conclusion that the resources at the disposal of professionals inhibit personalisation is a key contribution to knowledge.

Roles are defined as, “a pattern of behaviours perceived by an employee as behaviours that are expected” (Tubre and Collins, 2000: 156). Directing practice and

constraining discretion and autonomy, role expectations are the product of the public accountabilities that professionals experience. This refers to a social relationship in which street-level bureaucrats, such as healthcare professionals, feel responsible for justifying their actions to another agent (Bovens, 1998). For example, this might include their managers, professional peers and individual patients. Role conflict is defined as, “the simultaneous occurrence of two or more role expectations such that compliance with one would make compliance with the other more difficult” (Katz and Kahn, 1978: 204). This acknowledges the interplay among role expectations, drawing attention to the potential for conflict between accountabilities. As described in the second chapter, there is a considerable literature on the interpretation of personalisation, which draws attention to multiple meanings and diverse approaches through which the welfare state might be reformed. There are at least two reasons why professionalism – defined as discretion and autonomy (Engel, 1969; Evetts, 2003; Friedson, 1984; Haug and Sussman, 1969; Timmermans and Oh, 2010) may conflict with personalisation. First, the framing of patients as experts (Needham, 2011) may contradict the monopolisation of medical expertise by healthcare professionals and may lead to a conflict between the decisions of the patient and professionals. Second, the increasing participation of patients (Leadbeater, 2004; Needham, 2011) conflicts with the autonomy and discretion of professionals because, to some extent, patient participation impinges both aspects of professionalism. Critically, the extent to which professionalism is compatible with personalisation also diverges according to the depth of its interpretation, since the extent of participation increases as the interpretation of personalisation deepens.

Four participants recommended that professional expertise and discretion were fundamental to ensuring that patient choices would not conflict with their best interests (Theme 16: Professional expertise retains importance), drawing attention to the need for professional discretion in the delivery of personalisation. There was some diversity

in the application of this theme, resulting in divergent implications for personalisation in the context of professionalism. One participant described professional expertise as essential to ensuring that patient choice is informed. Therefore, professionalism was perceived as compatible with personalisation, with professionals using their expertise to account for the relative lack of medical expertise possessed by patients. In contrast, the three remaining participants argued that their professional duty to ensure best interest outcomes for their patients should supersede patient choice on the basis of their relative expertise. This represented a perceived conflict between their role as experts and the practice of personalisation, in which the accountabilities generated by their roles as professionals was prioritised to the detriment of personalisation. To the extent that this represented a defence of professional expertise, it can be argued that this is an example of professional accountability (Hupe and Hill, 2007; Meijer and Bovens, 2005), where the perceived legitimacy of professional standards held them to account. To the extent that this represented an advocacy of best interests, it can also be viewed as an example of participatory accountability, wherein professionals are motivated to act on behalf of the interests of their patients – albeit in a paternalistic manner, given that this theme was raised as an objection to patient choice. Pertinently, this was not a rejection of patient expertise designed with the intention to maintain the professional monopoly. Rather, this represented a conflict between professional discretion and the increasing participation of patients. The perception that professional expertise can conflict with personalisation signifies a key contribution to knowledge on practice.

Discussing personalisation in the context of social care, Needham has observed that, “The personalisation narrative offers a transformative vision of the social care workforce” (2011: 143). Nonetheless, she also recognises the widespread presumption that professionals, “will try to thwart the reform agenda if they can, failing to recognise its opportunities” (Needham, 2011: 144). Indeed, the personalisation narrative itself

notes that it is professionals who have presided over the existing system, wherein service users have been required to forsake their rights to autonomy in exchange for care and person-centred approaches have been resisted. Accordingly, professionals have been framed as subversive agents, impervious to change and reluctant to part with control (i.e. autonomy and discretion), “either because of a conservative view of risk or because of a desire to protect their own status and jobs” (Needham, 2011: 150). Evidently, the desire to protect their own status as professionals was a critical factor in the assertion of professional expertise in the delivery of best interest outcomes for patients above personalisation (Theme 16: Professional expertise retains importance). Actions effecting this into practice can be viewed as subversive, contradicting the transformational intentions of personalisation. Nonetheless, this subversive view was confined to a minority of study participants and, where evident, made recourse to the outcomes of patients. Other barriers to personalisation, including time (Theme 13: Time pressures constrain personalisation), finances (Theme 15: Financial constraints hinder personalisation) and the standardisation of care (Theme 14: Standardised resources are problematic) were demonstrative of an intention to comply with personalisation, as was the sense of identification that participants expressed – as described below. This collective engagement with personalisation represents a key contribution to knowledge.

There were various role conflicts brought about by the existence of time constraints (Theme 13: Time pressures constrain personalisation). For example, several participants discussed time constraints in relation to the volume of patients that they were expected to see in a given day. As described above, perceiving that providing patients a personalised service requires a greater input of professional time, high volume caseloads were associated with a reticence to personalise. This was because of the logical argument that providing a personalised service would result in a proportion

of patients receiving personalised care at the expense of some patients receiving nothing. In other words, the expectation to treat the caseload was prioritised ahead of personalisation for the individual, representing a role conflict between the expectations to personalise for the individual and care for the collective. Evidently, conflict was generated as a consequence of time constraints and not from the incompatibility of these roles. Another example of conflict generated by time constraints was evident in the discussion of administrative duties. Perceived as cumbersome, participants noted that they were expected to complete a considerable amount of paperwork in the conduct of their work. This restricted time to provide personalised care and support. In other words, to the extent that there was conflict between their role as administrator and the expectation to personalise, the completion of paperwork was perceived as a higher priority, to the detriment of personalisation. This would not have been the case if sufficient time were available since these roles are not innately discordant. Critically, these examples demonstrate the relationship between public service gaps and role conflicts, drawing attention to the complex dynamics impacting on the capacity of professionals to personalise. Importantly, the apparent interaction between public service gaps and role conflicts represents a key contribution to knowledge on personalised practice.

In chapter one, policy alienation was defined as, “a cognitive state of psychological disconnection from the policy programme being implemented” (Tummers et al., 2009: 686). Subjective in nature, policy alienation is based on perceptions of meaningfulness, which can be defined as the extent to which professionals perceive a particular policy as capable of contributing to a greater purpose (Tummers et al., 2009, 2012a; Tummers, 2011, 2012). This can be divided into two categories. Societal meaning derives from the perception that policy delivers beneficial social outcomes – “The perception of professionals concerning the added value of the policy to socially relevant goals” (Tummers, 2011: 562). For example, personalisation may be socially meaningful if it

reduces costs of care. In contrast, client meaning derives from the perception that policy delivers beneficial outcomes for an individual client – “The professionals’ perceptions of the added value of their implementing a policy for their own clients” (Tummers, 2011: 562). For example, personalisation would be meaningful if it facilitates greater independence. Within this study, participants articulated the view that personalisation is beneficial to patient outcomes (Theme 1: Personalisation works, transforming people’s lives for the better), identifying a combination of engagement, satisfaction, well-being, independence and empowerment as the positive artefacts of personalisation. This signifies client meaningfulness, supporting the conclusion that professionals were not alienated from policy. Nonetheless, a minority of participants questioned the added value of personalisation in context of professional expertise and the best interests of patients (Theme 16: Professional expertise retains importance). Doubts about the benefits of personalisation for patients suggests the presence of policy alienation via client meaninglessness. As a consequence, these professionals exhibited lower levels of willingness to implement than their colleagues. The widespread identification of professionals with personalisation represents a key contribution to knowledge.

The perception of powerlessness is another contributor to policy alienation. Essentially, powerlessness denotes professional perceptions of their own influence (i.e. power) on a policy (Tummers et al., 2009, 2012a; Tummers, 2011, 2012). It can be divided into three categories. Strategic powerlessness concerns, “The perceived influence of the professionals on decisions concerning the content of the policy, as it is captured in rules and regulations” (Tummers, 2011: 562). Within this study, participants did not articulate any views on their participation, or lack thereof, in the construction of personalisation, neither supporting nor contradicting the relevance of this factor. Tactical powerlessness concerns, “The professionals’ perceived influence on decisions concerning the way policy is implemented within their own organization” (Tummers,

2011: 562). This did not appear to influence participant engagement with personalisation. Finally, operational powerlessness represents, “The perceived degree of freedom in making choices concerning the sort, quantity and quality of sanctions and rewards on offer when implementing the policy” (Tummers, 2011: 562). In other words, operational powerlessness occurs when professionals are prohibited from exercising their discretionary powers. Evidently, a minority of participants were alarmed about the potential for personalisation to reduce the role of professionals in the delivery of care (Theme 16: Professional expertise retains importance). Insisting on the prioritisation of professional expertise over patient choice, these participants implicitly identified personalisation as a potential restriction to their operational power, resulting in their alienation from the policy. Therefore, in practice, they were willing to forego personalisation in cases where they could justify their intervention by reference to best interests.

Accountability represents, “a social relationship in which an actor feels an obligation to explain and to justify his conduct to some significant other” (Bovens, 1998: 172). In theory, there are at least three types of accountability that influence the conduct of professionals (Hupe and Hill, 2007; Meijer and Bovens, 2005). Public accountability describes a social relationship wherein professionals perceive an obligation to justify their conduct in reference to their patients. Within this study, participants supported personalisation on the basis that it improves patient outcomes (Theme 1: Personalisation works, transforming people’s lives for the better) and treats them as holistic individuals (Theme 3: Person-centred approaches reflect the way people live their lives). Therefore, the patient is provided as the justification for personalisation, exemplifying public accountability. Professional accountability is related to professionalism, holding professionals to account through professional peers and organisations through claims to professional expertise. This accountability was evident amongst those participants for whom the value of personalisation was questionable in relation to best

interests and expertise (Theme 16: Professional expertise retains importance). Moreover, references to best interests provide further evidence of perceived accountability to patients, given the framing of professional expertise as imperative to ensuring optimal outcomes for patients. Professional accountability was also evident in the view that personalisation is essential to professional conduct within particular branches of medicine (Theme 6: Personalisation is evolutionary, continuous and consolidating). Finally, public-administrative accountability is defined as the accountability of professionals to their managers. Three participants noted the influence of management on practice and personalisation (Theme 17: Management and organisation matter), confirming the impact of this accountability on personalisation. The impact of these accountabilities on personalisation represents a key contribution to knowledge.

As described in the second chapter, there is a wealth of literature on the interpretation of personalisation which draws attention to multiple potential meanings and diverse ways in which the welfare state might be reformed. This ambiguity was reflected in the interpretations of personalisation articulated by participants in this study, as discussed above, for whom personalisation was chiefly defined as the product of tailoring (Theme 8: Increasing responsiveness by tailoring to needs and/or preferences) and patient voice and choice (Theme 9: Giving users more say, keeping them informed and offering choice), with a variety of additional themes evident (see chapter five). In the first and second chapters, the ambiguity of personalisation was presented as a catalyst for reform through its ability to build consensus by absorbing multiple meanings and providing a streamlined narrative for change (Cribb and Owens, 2010; Cutler et al., 2007; Ferguson, 2007; Needham, 2011). However, it was also argued that ambiguity contributes to difficulty in defining personalisation and developing a consistent approach to frontline practice. Critically, the evidence of this study supports this

hypothesis in two senses. First, given the diversity of interpretations articulated by participants, it is apparent that a consistent approach to practice was not shared. Second, whilst not a widely expressed perspective, one participant acknowledged the influence of interpretation on practice (Theme 18: Interpretation influences practice), observing the ambiguity of personalisation. Consequently, it is apparent that the overall ambiguity of personalisation is problematic to ensuring consistent practice.

Conclusion

This chapter has discussed the meaning and interpretation of personalisation, drawing on the findings described in the fifth and sixth chapters. It has demonstrated that personalisation has been commonly defined as tailoring to needs and preferences (Theme 8: Increasing responsiveness by tailoring to needs and/or preferences) and facilitating voice and choice (Theme 9: Giving users more say, keeping them informed and offering choice) in order to improve outcomes (Theme 1: Personalisation works, transforming people's lives for the better). Yet, it has also been shown that, despite this broad consensus, the various ways in which tailoring, voice and choice are framed and the ways in which they are related indicate a lack of agreement on the expected roles of patients and professionals and the relationship between them. Hence, it has been demonstrated that the ambiguity of personalisation is reflected in the ways in which healthcare professionals interpret it despite some consistency. The application of these themes are indicative of the shallow interpretation of personalisation, with deeper concepts of co-production not acknowledged by participants – this explains the shared identification with personalisation and the absence of perceived adversity, as the shallow account of personalisation much more closely aligns with traditional practice. Personalisation was discussed in relation to the interpretation of individuals as

citizens and consumers, and the presence of both within the articulations of participants was recognised. Critical perspectives on these themes were described, as were the problematic consequences of personalisation from a variety of critical perspectives.

Perspectives on personalised practice were also discussed within this chapter. Drawing on the perceptions that time constraints (Theme 13: Time pressures constrain personalisation), systematic standardisation (Theme 14: Standardised resources are problematic) and the challenging financial context (Theme 15: Financial constraints hinder personalisation) are problematic to tailoring, a public service gap was identified. Representing a situation in which the role expectations placed on professionals are perceived to have increased and the resources provided to enable them to meet these expectations are insufficient and reducing, it was demonstrated that the pursuit of personalisation in practice was compromised and could be expected to deteriorate in the current financial climate. This chapter also explained varying levels of identification and alienation from personalisation, highlighting the common view that personalisation improves outcomes but also drawing attention to problematic perceptions of personalisation in relation to professionalism. A number of role conflicts were also identified and associated with the presence of a public service gap, drawing attention to the complex dynamics impacting on the capacity of professionals to personalise, and the accountability to patients, professionals and managers (Theme 17: Management and organisation matter) was revealed to possess relevance in understanding professional perspectives on practice. Critically, this chapter has demonstrated that the interpretation of personalisation and perspectives on practice diverge among professionals, resulting in divergent implications for practice. The following chapter will provide an overview of the thesis, explaining the key contributions and highlighting future areas for research.

8. CONCLUSION

The meaning and interpretation of personalisation has been extensively examined within the existing literature (Cribb and Owens, 2010; Leadbeater, 2004; Needham, 2011; Parker and Heapy, 2006). Within these literatures it is commonly acknowledged that personalisation is ambiguous. For example, Needham identified five different themes, or storylines, that comprise the personalisation narrative (2011). These themes are difficult to dispute, providing a compelling narrative for service reform, and yet they provide a highly ambiguous guide to practice. Furthermore, the temporal framing of personalisation is unclear, presented as an evolution and transformation of practice. Leadbeater interprets personalisation as a script for public services, highlighting five potential scripts on a spectrum between shallow and deep personalisation (2004). At the shallow end, personalisation means greater responsiveness, voice and choice. At the deep end, co-production and the active participation of patients in the production and consumption of services is emphasised. Despite ambiguity, there has been lacking study on how policy audiences experience this ambiguity and how they interpret personalisation in practice. This is crucial as it is within the gift of healthcare professional to interpret personalisation towards divergent means and ends of practice. Necessarily subject to interpretation, the study of personalisation must adopt an approach that accounts for this ambiguity and integrates the social reality that a world of multiple interpretation is both possible and probable. Within this research, the application of an interpretive approach to policy analysis facilitated this endeavour.

An 'interpretive turn' has witnessed various scholars working towards an interpretive approach to policy analysis (Fischer 2003, 2007 Hajer and Wagenaar, 2003; Yanow, 2007), resulting in the reasonably modern development of Interpretive Policy Analysis (IPA). Yanow describes the 'hallmarks' of the interpretive approach as, "its

focus on meaning as central to individual and collective endeavours” (2007: 111). Public policy is understood to, “take shape through socially interpreted understandings”, and IPA, “calls for the use of interpretive methods to probe the presuppositions that discursively structure social perceptions” (Fischer, 2007: 101). On the individual level, “any analysis of such human endeavours must take into account what is meaningful to actors in those situations” (Yanow, 2007: 111). Attention is given to, “the crucial role of language, rhetorical argument, and stories in framing debate and, in the process, on structuring the deliberative context in which policy is made” (Fischer, 2007: 103). Critically, policy meaning is perceived to be dependent on the context in which it is generated – “Rejecting universalist and context-free research, interpretive approaches instead explore how policy is rooted in particular settings” (Needham, 2011: 13). Thus, the study of meaning prioritises the pursuit of context above generalisation, recognising the agency that policy audiences have in the interpretation of meaning and allowing for variation. IPA also recognises the meaning-making capacity of researchers, noting that their position relative to the situations examined includes them in the meaning-making process – “the researcher-analyst is herself shaping and being shaped by the people, settings, and/or events that she encounters” (Yanow, 2007: 111).

Approaching personalisation from the perspective of IPA, “means abandoning the assumption that policies have fixed meanings” (Needham, 2011: 14). Instead, policy should be understood as a tool that conveys meaning to policy audiences, with the intention to persuade them that the policy is valuable. In other words, policy represents a mode within, “the world of rhetorical practices designed to persuade” (Yanow, 1996: 60). Nevertheless, “This is not to say that policy cannot have substantive and material impacts” (Needham, 2011: 14). Rather, it is to advise that policy has, “recourse only to symbolic representations to accomplish their purposes, and these purposes can be

understood only by interpretations of those representations” (Yanow, 1996: 12). Policies are constructed on normative assumptions that invoke symbols and utilise categories of the problem that needs to be solved and the perceived solution to the problem. Hence, the policy process represents, “a struggle over the symbols we invoke and the categories into which we place different problems and solutions, because ultimately these symbols and categories will determine the action that we take” (Fischer, 2003: 59). The way that policies are framed is important because frames provide a structure to meaning, defining the context within which policy attends to problems and solutions. Crucially, IPA provides a useful, “set of practices that return persons, their meanings, and their very human agency to the center of analytic focus” (Yanow, 2007: 118). It recognises the intricacy of social reality and emphasises the importance of attending to the ‘lived’ experience, or reality, of audiences as they interact with policy. Given the ambiguity of personalisation, attendance to interpretation is particularly pertinent.

In contrast with the study of interpretation, there has been extensive study of the practice, or implementation, of personalisation. Particular focus has been given to personalisation in the form of budgetary control, such as direct payments (Clark et al., 2004; Ellis, 2007; Spandler and Vick, 2004), personal budgets (Hamilton et al., 2015, 2016; Whitaker, 2015) and personal health budgets (Forder et al., 2012), and there have been relatively limited studies of other forms of personalisation, such as personal health budgets and personalised care and support planning. Particularly excluded from study is the practice of personalisation in a general sense, as part of the routine practice of professional work, outside of technologies such as budgets and care planning. Moreover, the majority of studies have attended to adult social care and there is a comparatively low volume of research on the personalisation of healthcare. Most problematic is the lacking consideration of interpretation within the majority of studies. Without understanding the interpretation of personalisation to which practice pertains, how

are findings to be appropriately interpreted? This study contends that perspectives on and experiences of personalisation are necessarily dependent on its interpretation. Therefore, without explicit consideration of policy interpretation and meaning, findings are lacking in essential context from which they can be appropriately understood.

Based on this analysis, the study was designed to examine the interpretation of personalisation by healthcare professionals working within the NHS in England. The objective was to explore how personalisation is interpreted by professionals in practice and the consequences of these interpretations for practice. In particular, the research was interested in the practical implications of healthcare professional interpretations for the expected roles of patients and professionals and the relationship between NHS patients, professionals and the state. Based on their relative autonomy and discretion, healthcare professionals were theorised to possess significant influence over the practice of personalisation. Therefore, drawing on the inherent ambiguity of personalisation and theorised significance of meaning to practice, the interpretations of healthcare professionals were postulated as essential to practice. Beyond interpretation, the research also intended to examine professional perspectives on personalisation in practice. The intention was to investigate professional experiences of personalisation to comprehend the dynamics that influence practice. Two research questions were pursued:

- 1. How do professionals working in the NHS in England interpret personalisation?*
- 2. What are the perspectives of professionals on the practice of personalisation?*

As the interpretation of personalisation has been widely studied, existing literature was utilised to develop a framework encompassing potential meanings (see Chapter two). Twelve themes were grouped into three sub-narratives (Table 8.1) and this was used to analyse the interview data (see Chapter four). An inductive approach was utilised to analyse professional perspectives on practice, resulting in six themes (Table 8.2).

Table 8.1: Themes of Personalisation

Justifications for Personalisation
Theme 1: <i>Personalisation works, transforming people's lives for the better</i>
This theme suggests that personalisation improves outcomes for service users and is supported by formal and informal evidence and common sense assumptions.
Theme 2: <i>Personalisation saves money</i>
This theme advises that personalisation improves the cost-effectiveness of care by reducing costs or providing better value-for-money through improved outcomes.
Theme 3: <i>Person-centred approaches reflect the way people live their lives</i>
This theme acknowledges people as individuals with a diversity of requirements that are more appropriately considered in a holistic manner through person-centred care.
Theme 4: <i>Personalisation is applicable to everyone</i>
This theme contends that personalisation applies to all individuals and should not be applied in an exclusive or restrictive manner, solely for particular cohorts of patient.
Theme 5: <i>People are experts on their own lives</i>
This theme characterises patients as experts in their own lives and advises that they are capable of participating, challenging the orthodoxy of the professional gift model.
Perceptions of Personalisation
Theme 6: <i>Personalisation is evolutionary, continuous and consolidating</i>
This theme presents personalisation as timeless, representing an evolution of prior practice and establishing continuity between the past, present and future.
Theme 7: <i>Personalisation is revolutionary, disruptive and transformational</i>
This theme defines personalisation as a radical departure from the past, designed to transform how care is delivered. The change is a revolution as opposed to evolution.
Nature of Personalisation
Theme 8: <i>Increasing responsiveness by tailoring to needs and/or preferences</i>
This theme advocates greater responsiveness to patients who should, as a result, have a more direct and effective voice. Care is tailored to needs and preferences.
Theme 9: <i>Giving users more say, keeping them informed and offering choice</i>
This theme centres on patient voice and choice. Professionals are expected to inform patients and support them by enhancing their ability to choose between outputs.
Theme 10: <i>Direct say over money, enabling individuals to make their own decisions</i>
This theme defines personalisation as giving patients a more direct say over how money is spent – for example, as a personal health budget that they directly manage.
Theme 11: <i>Co-production, active participation, choosing outputs and shaping inputs</i>
This theme frames service users as co-producers in a collaborative relationship with professionals, actively participating in the production and consumption of services.
Theme 12: <i>The public good emerging collectively through individual decisions</i>
This theme views personalisation as self-organisation, asserting that the public good emerges from within society and arguing that individuals should work collaboratively.

Table 8.2: Themes on Perspectives

Perspectives on Practice
Theme 13: <i>Time pressures constrain personalisation</i>
This theme advises that time pressure are problematic to personalisation. It suggests that professionals often have insufficient time to personalise and acknowledges that personalisation requires more time when compared to standard approaches to care.
Theme 14: <i>Standardised resources are problematic</i>
This theme notes conflict between personalisation and standardisation. It is advised that an emphasis on the collective at the expense of individuals has resulted in the prevalence of standardised systems, processes, routines, treatments and services.
Theme 15: <i>Financial constraints hinder personalisation</i>
This theme reveals that financial constraints are problematic to personalisation. It is observed that personalisation often costs more when compared to standard options. The financial constraints are also associated with constraints on time (Theme 13).
Theme 16: <i>Professional expertise retains importance</i>
This theme acknowledges the enduring significance of professional expertise in the practice of personalisation, highlighting the ongoing need for professional discretion in the delivery of care. It suggests that the best interests of patients offsets choice.
Theme 17: <i>Management and organisation matter</i>
This theme recommends that the attitudes of managers and their relationship with professionals can impact the willingness of professionals to practice personalisation.
Theme 18: <i>Interpretation influences practice</i>
This theme observes that personalisation is ambiguous and that, as a consequence, professional interpretations of personalisation influence practice. It is recommended that consistency in the application of policy is dependent on the clarity of its definition.

The study provides a number of key contributions in relation to the first research question about interpretation. As described in the second chapter, the first theme (Theme 1: Personalisation works, transforming people’s lives for the better) draws on a mixture of formal policy evaluation, case studies and vignettes to assert the benefits of personalisation for individuals in receipt of care (Needham, 2011). Within this study, healthcare professionals drew on a variety of professional and personal experiences of personalisation as well as a collection of common-sense assumptions. This indicates that direct experiences (i.e. informal source of evidence) and perspectives (i.e. common-sense assumptions) were more persuasive to the interpretation of personalisation than formal sources of evidence. Furthermore, it was apparent that the perceived benefits for their patients motivated professionals to engage with personalisation. This included the views that personalisation may improve patient engagement,

satisfaction, wellbeing, usefulness, effectiveness, independence and empowerment. Crucially, this highlights the importance of patients to the interpretation of personalisation and indicates that professionals are more likely to identify with policies when they can be perceived and experienced to have benefits for patients. The second theme (Theme 2: Personalisation saves money) is founded on the notion that personalisation may provide better value-for-money by reducing costs or improving outcomes at similar cost (Needham, 2011). Critically, participant interpretations of personalisation did not reference cost. Thus, it was not clear whether the perceived improved outcomes of personalisation were associated with an increase, decrease or maintenance of costs. Nonetheless, this does suggest that healthcare professionals place more importance on how policies improve outcomes and are less concerned with the costs of these outcomes, influencing the frames through which they interpret policy.

The eighth theme (Theme 8: Increasing responsiveness by tailoring to needs and/or preferences) can be defined as a shallow form of personalisation (Leadbeater, 2004) and advocates for greater responsiveness to individuals (Cribb and Owens, 2010). As outlined in chapter five, twenty participants interpreted personalisation as tailoring, framing tailoring in three diverse ways: 1) tailoring to needs; 2) tailoring to preferences; and, 3) tailoring to needs and preferences. Eighteen referenced needs and ten referred to preferences, highlighting varied interpretations of the criteria to which professionals are expected to tailor. The ninth theme (Theme 9: Giving users more say, keeping them informed and offering choice) means greater voice and choice for patients (Leadbeater, 2004). As explained in chapter five, fourteen participants interpreted personalisation in terms of greater voice and choice. Critically, each of these models provides a different mechanism for tailoring care to the preferences of patients. Whereas increased voice depicts the professional as a tailor who flexes care to preferences, choice requires the professional to tailor information and implement the

choices made. Nonetheless, the professional remains the tailor and the balance of power remains in their favour. Deeper personalisation (Leadbeater, 2004) corresponds with what Parker and Heapy (2004) describe as co-production. This account was not applicable to understanding professional interpretations of personalisation. It was apparent that the majority interpreted personalisation in shallower terms, emphasising tailoring to needs and preferences and facilitating varying degrees of patient voice and choice. This is a key contribution to knowledge and the absence of deeper interpretations recommends that healthcare professionals defined personalisation in terms that essentially maintain the status quo of practice.

The study provides a number of key contributions in relation to the second research question about perspectives on practice. As explained in the chapter six, time constraints were perceived as problematic to personalisation (Theme 13: Time pressures constrain personalisation). One identified source of this problem was the perception that the delivery of personalisation requires a greater input of professional time. In context of decreasing human and financial resources, this perspective on the practice of personalisation was indicative of a public service gap (Hupe and Buffat, 2014) wherein professionals are expected to deliver more (i.e. personalised care and support) with fewer resources. This public service gap was revealed to have generated role conflicts between roles that were not inherently incompatible. Financial constraints were also perceived as problematic (Theme 15: Financial constraints hinder personalisation). Professionals observed that personalisation can frequently cost more and that, as a consequence, standard options were often provided instead of personalised care. This provides further evidence of the perceived insufficiency of enablements relative to action prescriptions, and the existence of a public service gap, and was framed in the context of growing expectations. This added further weight to the perception that

professionals were being expected to deliver more with less. Pertinently, during a period when finances are stretched, following a decade of low-level funding growth (Kraindler et al., 2018; NHS England, 2014b, 2017; Robertson et al., 2017), this problem is likely to continue. Finally, standardised systems, structures, processes, routines, treatments and services were also perceived as problematic to personalisation (Theme 14: Standardised resources are problematic). Critically, these themes identified challenges to personalisation-as-tailoring in the form of a public service gap, demonstrating the added value of linking practice to interpretation.

Personalisation was found to be operationally meaningful (Tummers et al., 2009, 2012a; Tummers, 2011, 2012) for the majority of healthcare professionals, who interpreted personalisation in relation to improved outcomes (Theme 1: Personalisation works, transforming people's lives for the better), identifying a combination of engagement, satisfaction, wellbeing, independence and empowerment as positive artefacts of personalisation. Nonetheless, a minority of participants questioned the added value of personalisation in context of professional expertise and the best interests of patients (Theme 16: Professional expertise retains importance). Doubts about the benefits of personalisation for patients suggests the presence of policy alienation via client meaninglessness. Insisting on the prioritisation of professional expertise over patient choice, these participants implicitly identified personalisation as a potential restriction to their operational power, resulting in their alienation from the policy. These participants recommended that professional expertise and discretion were fundamental to ensuring that patient choice would not conflict with their best interests. This represented a perceived role conflict (Thomann, 2015; Tummers et al., 2009, 2012b) between their role as experts and the roles demanded by personalisation. To the extent that this signified a defence of expertise, this is an example of professional accountability (Hupe and Hill, 2007; Meijer and Bovens, 2005). To the extent that this signified

an advocacy of patient best interests, it is an example of participatory accountability, where professionals are motivated to act on behalf of patients. This accountability was also evident in the importance professionals placed on improved outcomes for patients as a result of personalisation. Critically, accountability to managers was also evident (Theme 17: Management and organisation matter), drawing attention to the accountabilities that affect the practice of personalisation.

There are some limitations to the study that lead to a variety of recommendation for further study. The sample for this research was comprised of twenty-one healthcare professionals working within the NHS in England. They can be divided into service categories (Table 8.3) and profession categories (Table 8.4). It is reasonable to argue that the research could have benefitted from a greater total number of participants. Originally, the research intended to interview a sample of thirty total participants but this was hindered by recruitment issues, as described in the fourth chapter. Debatably, a greater sample size would have enabled the researcher to achieve a higher level of saturation and, therefore, it is feasible that relevant issues to the interpretation and practice of personalisation by healthcare professionals within the NHS in England have been missed as a consequence of small sample size. Nonetheless, the sample of twenty-one participants is insightful and plenty has been learnt during the fieldwork. Furthermore, through the achievement of a heterogeneous sample (according to service and profession), it has been possible to study personalisation from a variety of perspectives, facilitating greater transferability through the triangulation of findings across diverse contexts. This was essential as the study focused on knowledge about personalisation at the collective level, as opposed to studying defined cases with a distinct focus on the singular. Nonetheless, relatively few participants were in the community and primary care groups and it is recommended that further research should examine the interpretation of personalisation within these contexts in more detail.

Table 8.3: Sample by Service

Service Category	Participants
Mental health	MH1, MH2, MH3, MH4, MH5, MH6
Children and young people	CYP1, CYP2, CYP3, CYP4, CYP5, CYP6
Secondary care	SC1, SC2, SC3, SC4, SC5
Community services	CS1, CS2, CS3
Primary care	PC1

Table 8.4: Sample by Profession

Profession Category	Participants
Doctor	MH1, MH2, MH3, MH4, MH5, MH6, CYP6, SC5
Nurse	CYP5, SC2, SC3, SC4, CS2, CS3, PC1
Other	CYP1, CYP2, CYP3, CYP4, SC1, CS1

This study conducted semi-structured interviews with healthcare professionals to understand the interpretation of personalisation and perspectives on practice. Interviews enabled the researcher to spend a continuous length of time with participants in which the participant and their perspectives on personalisation were the sole focus of the interaction. Interviewees were encouraged to talk at length and in depth, and this enabled the researcher to achieve a deep appreciation of the participants and their perspectives and interpretations of personalisation. This was facilitated through the development of a strong rapport and application of several probing techniques. Critically, however, the interview method takes the participant out of the environment in which they enact their interpretations and perspectives and it relies on the accuracy and honesty of the interviewee to derive findings. Consequently, the quality of the data is only as good as the ability of the participant to recall their experiences. This is subjective and can vary according to a range of factors not limited to the competency of the participant. Therefore, whilst the validity of the method is not questioned, there are some weaknesses that could be rectified by future studies to triangulate the findings of this study. In particular, an observational study of personalisation would enable the

researcher to experience interpretation as part of the practice of healthcare professionals and, as a consequence, would result in an enhanced understanding of the dynamics that influence frontline practice. Follow-up interviews with healthcare professionals could be used to probe the experiences that are witnessed, enabling the researcher to achieve an improved insight into the practices and interpretations that are displayed.

The focus on healthcare professional interpretations and perspectives on practice emerged from the recognition that the discretion and autonomy afforded to professionals privileges their role in the delivery of personalisation within the NHS in England. Put another way, at the level of practice, the two most significant actors in healthcare are the professional and the patient, as it is between these agents that care is provided, received or co-produced. Given the historical dominance of the professional, they were theorised to be the most significant determinant of practice and, consequently, their interpretations of personalisation were assumed to have the greatest effect. Nevertheless, personalisation concentrates on the patient as an individual and there is an inherent rejection of professional dominance in favour of transferring various roles and responsibilities to patients, particularly within the deeper interpretations of personalisation wherein patients are presented as co-producers of public services. Furthermore, viewing policy as a product of interpretation and acknowledging the social aspect of interpretation draws attention to the relationship between patients and professionals and the potential for social negotiation – that is to say that the practice of personalisation may ultimately depend on the interpretations of both agents. Therefore, it is recommended that further research should investigate the interpretation of personalisation and perspectives on practice from the viewpoint of patients across a spectrum of services within the NHS in England. A study involving patients and professionals would be most useful and should focus on the relationship between patients and professionals in the interpretation of personalisation to examine the social dynamics of practice.

APPENDIX A: PARTICIPANT INFORMATION SHEET

We are inviting you to take part in our study. Before you decide whether to take part, it is important that you understand why the research is being conducted and what taking part will involve. Please take time to read the following information carefully. If you are unclear about any of the information, or have any questions, please contact us for further clarification. Shortly, a member of our research team will contact you to discuss the proposed study with you. They will also seek your consent to participate in the study. We want to be clear that your participation is entirely voluntary. We also respect your right to withdraw at any stage.

What is the purpose of the study?

National policy encourages the implementation of personalisation across the English National Health Service. Accordingly, individual patients should be enabled to exercise choice and control, and patients' healthcare experience should be personalised. Crucially, there is a degree of ambiguity regarding how healthcare professionals should interpret and implement personalisation within normal frontline practice. Professionals are also confronted with dilemmas which may influence their ability to implement personalisation. Given this context, the study aims to examine the practice of personalisation on the frontline of the English NHS, focusing on the context within which healthcare professionals' work is being conducted and the influence this context has on the interpretation and implementation of personalisation on the frontline.

What will participation in the study involve?

Participation in the study will involve taking part in a face-to-face or telephone interview with a member of our research team. For this purpose, we are looking to recruit a variety of healthcare professionals. The interview itself will be conducted at a location and time of your choice and will focus on your individual experience of personalisation as part of your normal practice. With your consent, the interview will be audio recorded. Finally, we anticipate that the interview process will take half an hour to complete.

What are the benefits of participation?

There are some potential social benefits to participation in this study. First, participation will contribute towards a better understanding of the practice of personalisation in the NHS. Second, participation will contribute towards a better understanding of the role of healthcare professionals in the local implementation of national policy. Both of these outcomes are potentially beneficial to healthcare professionals and patients since this knowledge can be used to evaluate practice and improve the service offered.

How will my data be protected?

Proactive measures have been taken to ensure the confidentiality and anonymity of study participants. The contents of the interview and details of participants are to be kept confidential – access will be restricted to the research team only. Although direct quotes from the interview may be published, participants will not be identified - findings will be reported anonymously. All recorded data will be stored centrally by the Chief Investigator. Audio files and written notes will be transcribed and stored securely on a password protected laptop, and saved files will be encrypted. All physical copies of the data will be destroyed following transcription and digital data will be stored securely for a maximum of three years before being destroyed.

For more information or to discuss concerns please contact:

Liam Spalding - Chief Investigator - lx321@student.bham.ac.uk

APPENDIX B: CONSENT FORM

This consent form is a formal request for your participation in the above study. Before you decide whether to take part, it is important you understand why the research is being conducted and what taking part will involve. You should have received a participant information sheet and had opportunity to discuss the research. At this time, the interviewer will discuss this document with you, and will also answer any additional questions you might have. When you are happy to proceed, please initial each box and complete the fields below. The interview will commence following indication of consent.

1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily by the researcher.
2. I understand that my participation in this study is entirely voluntary and that I am free to withdraw from the study at any time without giving any reason.
3. I agree to the use of an audio recording device to record data during interview and I understand that this recorded data will be retained by the interviewer.
4. I understand that direct quotes from this interview may be published by the research team, and I understand that all findings will be published anonymously.
5. I understand that the University of Birmingham will record details that identify me as part of this research, and that this data will be treated confidentially.
6. I agree that the information collected can be used to support other research in the future, and that it may be shared anonymously with other researchers.
7. I understand that it will be possible to remove my data from the study for a period of 3 months following the conduct of the interview.
8. I give my consent to take part in the above study.

Participant:

Date:

Signature:

Interviewer:

Date:

Signature:

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