ARE PERSONAL HEALTH BUDGETS DELIVERING CHOICE AND CONTROL FOR PEOPLE WITH COMPLEX HEALTHCARE NEEDS? AN ETHNOGRAPHIC CASE STUDY

by

EDITOR MUSEKIWA

A thesis submitted to the University of Birmingham for the degree of

DOCTOR OF PHILOSOPHY

Health Services Management Centre

School of Social Policy

College of Social Sciences

University of Birmingham

January 2022

Abstract

Background: This doctoral thesis explores Personal Health Budgets (PHBs) in the English National Health Service, a new and evolving policy initiative and part of the wider personalisation agenda. As a policy direction, the personalisation of services in health and social care continues to be surrounded by debate and controversy. This thesis, therefore, seeks to advance our understanding of the opportunities and challenges of the practice of choice and control within personal health budgets, through the eyes of budget holders.

Methods: The research was carried out in England over a 2-year period (January 2018 – January 2020). The study used ethnographic case studies combined with realist evaluation to identify and examine the broad evidence alongside a realist interrogation to evaluate programme theories of how PHBs are supposed to work in practice. Three participants from different geographic locations and Clinical Commissioning Groups (CCGs) took part. Taking a longitudinal approach, the study sought to answer the question: "***Are personal health budgets delivering choice and control for people with complex healthcare needs?"*** The research was done in a natural setting and provided a unique opportunity to explore the relationships between choice and control as a dynamic process over time.

Findings: PHBs can deliver choice and control for people with complex healthcare needs if: there is sufficient access to resources, if decision-making is shared, and if professionals are willing to accept the knowledge claims of PHB holders. Time is an important factor: the experiences of budget holders improved with time as personal health budgets become more embedded in practice.

Limitations: This study only focused on three PHB holders in England, so the scope is limited. However, there are important lessons that can be drawn from the findings to shape future policy and practice within the wider context.

WITH DIVINE GUIDANCE I DEDICATE THIS THESIS TO JOHN, LEIGH-ANNE, AND DION

ACKNOWLEDGMENTS

This thesis would not have been possible without the help and support from key people, and I would like to give them a heartfelt thank you. Firstly, Professor Catherine Needham and Dr Kerry Allen, my two supervisors for your relentless support, kindness, advice, and guidance throughout the project. You continued to cheer me on when faced with challenges, gave me opportunities to enhance my experience when they arose, you have been so generous with your gifts, and I am very fortunate to have met you.

Secondly, I am indebted to the participants who took part in this research. You opened your homes to a total stranger, allowed me to freely immerse myself into your lives, and share some of your nuanced experiences of being a PHB holder. Without your participation, this empirical work would not have been possible and for that, I am most grateful. I also give many thanks to those I reached out for funding during my fieldwork, while you considered it a small gesture the £200 went a long way to pay for the journeys I made and to my partner John for helping me self-fund the project.

Thirdly to Dr Ruth and the late Tim Joplin for encouraging me to embark on this PhD journey and believing in me. Academic staff at the School of Social Policy and HSMC, Professor Jon Glasby, Professor Jerry Tew, and Dr Iestyn Williams. To Dr Sarah-Jane Fenton for your guidance and support in my academic career as well as all other members at the University of Birmingham for enabling me to rediscover myself.

Finally, but not least, my thanks go to my maker and family, John my partner, my two children Leigh-anne and Dion to whom this thesis is dedicated, and my friends who have continued to support and encourage me through this journey.

Appendices - List

Glossary Terms and Abbreviations

Term	Other Terms Used	Definition
Care and Support Planning	Care planning	A mechanism for deciding how an individual will spend their personal health budget to best meet their support needs and achieve their identified outcomes in agreement with professionals (Alakeson, 2014).
Clinical Commissioning Groups	CCGs	General Practitioner (GP)-led clinical commissioning groups responsible for NHS commissioning budgets and overseeing funding for PHBs (NHS Choice, 2015).
Complex healthcare needs	Complex care needs, complex care	Term related to people with multiple chronic illnesses needing input from a range of health and social services (Kirk and Glendinning 2007).
Continuing Health Care	CHC	NHS funded care for ongoing health needs (NHS England 2014a).
Individual Budgets	IBs	A sum of money given to people with which they can purchase the services and equipment they require to meet their care and support needs (In-Control 2017).
Individual Personal Commissioning	IPC	A new way of supporting individual needs that is strengths-based and considers the family and wider access enabling people to identify what is important to them (The Kings Fund, 2017).

Personalisation	Self-directed or individualised care and support	A term used to describe the concept of enabling choice and control to individuals across public services. (Alakeson, 2014a)
PHB Roll-out	Roll -out phase	The staged implementation process of PHBs in the NHS in 2014 [beginning with those in receipt of CHC funding before PHBs became routinely available in March 2021]
Personal Budgets	PBs	The term is associated with money that is available to someone who needs support. The money is means-tested and comes from local authority social services and is allocated to the individual to spend on help and support to meet their assessed eligible needs and agreed outcomes. The term is often used by user groups as an umbrella term for both budgets in health and social care (In-Control 2016)
Personal Health Budgets	PHBs	It is an allocation of NHS money that can be used to meet identified health and well-being need and can be used in innovative ways and outside of the traditional service provisions (Alakeson and Rumbold, 2013).
Review Panel	Panel or Review	Review panel members from the CCGs who identify primary needs and evaluate eligibility for NHS continuing care funding (NHS England, 2014).
Professionals	Care managers, CCGs and clinicians	In the context of this thesis – the collective term for all the NHS workers that interacted with PHB holders [during this study] while they were managing their PHBs.

List of Tables, Figures, and Artifacts

ARE PERSONAL HEALTH BUDGETS DELIVERING CHOICE AND CONTROL FOR PEOPLE WITH COMPLEX HEALTHCARE NEEDS? AN ETHNOGRAPHIC CASE STUDY

Chapter 1: Background

This thesis focuses on Personal Health Budgets (PHBs) in the English National Health Service (NHS). As a policy initiative PHBs are part of the wider personalisation agenda of public services, still a relatively new and evolving policy initiative. The right for individuals to have choice and control over service provision continues to gain policy traction as a principle underpinning health and care (Care Act, 2014; NHS England, 2014a). However, the personalisation of services in health and social care continues to be surrounded by debate and controversy (Epstein et al., 2010; Mathers et al., 2012; Glasby et al., 2013; Alakeson, 2014a; Needham & Glasby, 2014; Slasberg et al., 2014; Slasberg & Beresford, 2016).

With pressures on the funding of health and social care and rising demand (Public Accounts Committee, 2017; 2019; 2020), personalisation and its promise of self-direction and cost- effectiveness have become an attractive option (Care Act, 2014; NHS England, 2019a). The immediate heightened danger of the Covid-19 pandemic presents an important context for PHBs and the need to pay even more attention to this policy initiative as part of a wider reconfiguration of health and care. While the pandemic highlighted the vulnerability associated with congregate services which place people at high risk (Bottery, 2020; Daly et al., 2020; Glynn et al., 2020), others suggest that those in receipt of direct payments have been safer and more resilient than those in conventionally commissioned services (Think Local Act Personal, 2021). Although the fieldwork for this thesis was conducted before the pandemic, Covid-19 is a key contextual factor that will shape the future of health and care provision, including the deployment of PHBs.

Internationally, evaluations and larger-scale research have sought to provide evidence to increase understanding of self-directed support through the various mechanisms that support choice and control (Ungerson & Yeandle, 2007; Arksey & Kemp, 2008; Da Roit et al., 2010; Arntz & Thomsen, 2010; Spaulding-Givens & Lacasse, 2015). While their work has helped to advance personalisation in the UK health and social care sector, the evidence base for PHB implementation remains relatively small (Forder et al., 2012; Jones et al., 2017). With little known about how effective PHBs are in supporting choice and control for people with complex healthcare needs, there is a requirement for research in this area to supplement existing knowledge. Therefore, this thesis set out to explore 'are personal health budgets delivering choice and control for people with complex healthcare needs?'

1.1 Introduction

This study advances an understanding of the practice of choice and control within PHBs through the eyes of the PHB holders, to reveal some of the hidden meanings situated in everyday life. I chose to focus on individual cases to get a deep and nuanced understanding of the opportunities and challenges presented by PHBs, specifically, the factors which may trigger, block, or modify the desired outcomes of the intervention and the wider issues surrounding the policy initiative that will help inform future policy and practice.

I focused on the micro-level, capturing the experiences of the PHB holders over time. I used an ethnographic case study method to facilitate the examination of this complex policy initiative and drew on the realist evaluation approach to enrich my appreciation of context, mechanism, and outcome (CMO). The realist evaluation approach forms an important conceptual thread throughout the whole research design in this study. As a theoretical framework, realist evaluation is built on the premise that policy implementation tests a theory or an assumption about what might cause a change to happen, and the theory may be explicit or implicit (Pawson & Tilley, 1997). Through observing PHBs in action, my task was to make the theory explicit, using CMO propositions, and draw inferences about how, why, for whom, and under what conditions PHBs deliver choice and control (Pawson, 2013).

This chapter provides a background to the thesis and the PHB policy landscape. While not intended to be a comprehensive account of PHBs or personalisation, the chapter discusses policy developments within the wider personalisation context in health and social care, drawing on both UK and international literature as context. In the chapter I give a brief overview of PHBs and the implementation process, locating the reform within the broader literature on personal budgets, which has its roots in social care. I also explore the concepts of choice and control in shaping service provision. A more thorough account of the evaluation literature on PHBs informs the realist synthesis and this is detailed in chapter three. Below I also explain why I focused on people with complex healthcare needs and conclude the chapter with an overview of the thesis and its structure.

1.2 Locating PHBs in Personalisation

PHBs are part of wider moves to create a health and care system that individualises funding and places the service user in the central role of consumer (DH, 2006). Individualised approaches are furthest established in the means-tested system of social care (providing long-term support to older and disabled people) and are gradually becoming more mainstream in the NHS. Such quasi-market developments are aimed at driving up quality, efficiency, and service responsiveness through competition and consumer choice (Clarke et al., 2006; Glendinning, 2008; Rodrigues & Glendinning, 2015). A key concept behind PHBs is the flexibility for service users to take charge of their health rather than passively accepting services provided by professionals (DH, 2009).

Alakeson defines a PHB as ‘an amount of money to support a person's identified health and wellbeing needs, planned and agreed between the person and their local NHS team’ (2014a, p. 21). It is envisaged that PHBs will give patients in the health system more autonomy over spending, and with greater choice and control individuals will be able to purchase services they consider important in the management of their long-term conditions (DH, 2009; 2012a). In that respect, people can self-direct their care and support, which it is hoped will lead them to stay healthier, thereby reducing the use of inpatient and emergency services which will result in cost savings to the NHS (HM Government, 2007; DH, 2012b). In theory, PHBs are expected to bring culture change and transformation into the NHS in the way services are delivered (DH, 2012c). However, how people exercise choice and control in practice is much more complex.

The desire to increase patient choice, improve quality and reduce the escalating cost of healthcare can be traced back several decades and has been advanced through a series of policies. Changes were introduced in the English NHS white paper, *Saving Lives: Our Healthier Nation* (DH, 1999), which sought to achieve a partnership with patients and help them lead healthier lives. This was followed by the Wanless Report (2002) which emphasised the role of patients as independent agents of their health. The report argued for the full engagement of patients in their health and healthcare. In 2008, Lord

Darzi published the report *High-Quality Care for All*, which set out the government's desire for health care system reform and included an emphasis on enabling people to shape the nature of services they receive (DH, 2008).

Following the perceived success of personal budgets in social care, in 2009-12, PHBs were introduced into the NHS as pilots (DH, 2009; Forder et al., 2012). Even before these pilots were completed, the Government set a mandate for NHS Commissioning Boards to involve patients and their carers and empower them in decisions about their care and treatment (DH, 2012a). The mandate set the expectation that PHBs would be made available in the NHS, with those in receipt of continuing healthcare funding (due to long-term health conditions) considered to have the most pressing needs (Alakeson, 2014a). For a patient to access continuing healthcare and subsequently a PHB, they must meet eligibility criteria set out in the continuing healthcare framework. Those with complex healthcare needs would have already been assessed and met the criteria before being offered a PHB (DH and Social Care, 2018).

From 2014, PHBs moved into the roll-out phase, marking an incremental implementation process, starting with individuals in receipt of continuing healthcare funding having the right to request a PHB (NHS England, 2014a). This legal right to have a PHB in continuing healthcare was enshrined into law in 2014. The PHB programme was also extended to children with special education needs and disabilities who would be able to receive an integrated budget from education, health, and social services.

Clinical Commissioning Groups (CCGs) were also expected to offer PHBs to anyone with long-term conditions who could benefit, which could include chronic obstructive pulmonary disease, diabetes, neurological conditions, mental health, and stroke (DH, 2009; 2014; NHS England, 2014a). The ***Five Year Forward View*** for the NHS was published, with a new commitment to introduce Integrated Personal Commissioning (IPC), linking PHBs to personal budgets in social care (DH, 2014).

In 2016, the NHS Mandate was published, and *Personal Health Budgets and Integrated Personal Commissioning Expansion Plan s*et a clear expectation that 50-100,000 people would have a PHB by 2020/21 (NHS England 2016, 2017). Currently, the right to PHBs is for people eligible for NHS continuing healthcare, maternity care, end of life care, children, and young people, and learning disabilities. That right has also been extended to include people eligible for section 117 aftercare in mental health and personal health budgets for wheelchair users (NHS England, 2019a).

The NHS data for 2019/20 shows that 88,953 people are using PHBs (NHS Digital, 2020). Recent rises in numbers include children and wheelchair budget holders (46,360), with a relatively small uptake amongst those in receipt of continuing healthcare (CHC). According to the data in total, 19,560 PHB holders are using continuing healthcare funding (this figure represents some of the sample in my study), out of a total of over 56, 000 who receive CHC funding in England. The number of those who opted for PHBs jumped from 4,700 to 15,800 throughout one year (2014/15) (NHS Digital, 2020). Since then, take-up has slowed amongst those in receipt of continuing healthcare with only a further 3,372 taking up PHBs in the period 2019/20 (NHS Digital, 2020). Nonetheless, PHBs continue to be a key policy in the English NHS. The *2023/24 NHS Long Term Plan* made PHBs routinely available as mainstream provision from March 2021 (NHS UK, 2019). Amongst the aims of the NHS PHB Expansion Plan is to increase the number of PHB users to 200,000 (NHS England, 2019a).

1.3 How is Personalisation Implemented in Practice?

Given the growing importance of individualised funding in the NHS, it is important to locate PHBs within broader debates about personalisation, choice, and control. In social care, personalisation is a well-developed policy objective with key practices implemented through various mechanisms such as direct payments and personal budgets.

Direct payments were introduced following the Community Care (Direct Payments) Act (1996) and came into force in 1997. They enable individuals to have the cash equivalent of the cost of services directly provided through mainstream social care services if they have been assessed for community care services under section 47 of the NHS and Community Care Act (1990). Direct payments have since been extended to other groups including older people and carers (Riddell et al., 2006). With direct payment, recipients can purchase a range of support options including recruiting personal assistants (PAs) and taking on the role and responsibilities of an employer (Glasby & Littlechild, 2016).

Personal budgets were pioneered by the social movement In Control in the early 2000s to expand the scope and take-up of individualised funding (Glasby & Littlechild, 2016). They are associated with a sum of money allocated by a local authority to service users that can be spent on services to meet their care needs (Public Accounts Committee, 2016). Although initially their advocates emphasised the distinctiveness of personal budgets from direct payments and tried to expand them beyond social care as Individual Budgets (Glendinning et al, 2008), their scope settled back to being within social care. According to Baxter et al., (2011) 'personal budgets' is an umbrella term for user-controlled budgets for the purchase of social care support and the term encompasses direct payments, managed personal budgets, and individual service funds. Personal budget holders can use their budget as a direct payment or use council commissioned services or use a third party to hold it (Glasby & Littlechild, 2016). According to Glasby and Littlechild, 'a personal budget involves being clear with the person at the start how much money is available to meet their needs, then allowing them maximum choice over how this money is spent on their behalf and over how much control they want over the money itself' (2016, p. 69).

As a strand of policy thinking, everyone eligible for adult social care funding should have access to a personal budget to meet their agreed social care outcomes (Alakeson, 2014a). As part of the broader personalisation agenda, people are encouraged to have choice and control over the money, and over their care and support arrangements, and they can be supported by family, friends, and not just the system (Glasby & Littlechild, 2016).

In the health system, ‘personalisation’ is operationalised through a range of personalised packages (the ‘Personalised Care Model’) as a response to the challenge of meeting the increasing complexity of healthcare needs and public expectations (NHS England, 2019b). The model comprises six components: shared decision making; personalised care and support planning; enabling choice; social prescribing and community-based support; supported self-management; and PHBs (some of these components are covered in more detail in the review of the literature in chapter three) (NHS England, 2019a). PHBs are said to offer the greatest choice and control in how services are organised, planned, delivered, and evaluated (Alakeson 2014a, NHS England, 2019a).

PHBs share common principles, delivery mechanisms, and similar designs with personal budgets in social care, although the context in which they operate is different (DH, 2012a). While PHBs replicate the key elements of personal budgets, the designers of the policy have been very explicit about trying to control the rising cost of healthcare as well as acknowledging the significant impact of long-term health conditions on people’s lives (Alakeson, 2014a; Forder et al., 2012).

The Department of Health (2012a) offered guidelines as to how PHBs should be implemented. Within the policy guidance, there are key features to PHBs, with similarities to personal budgets. Table 1, below shows the basic overview of PHBs process; however, the guidance is implemented according to local frameworks (Brewis et al., 2012; Alakeson, 2014a)

Table 1. Essential Features of PHBs

- The PHB holder should have an indicative budget and know how much money is available for their healthcare and support.
- The PHB holder should be central in developing their personalised care and support plan and agree on who is involved.
- Both the PHB holder and professionals should agree on health and wellbeing outcomes to be achieved.
- The PHB holder should be able to decide how the money is managed and have an option to choose from: direct payments, third-party option, and notional budgets, or a mixture of the approaches.
- The PHB holder should be able to use the money to meet the outcomes agreed in their care and support plan, in ways and times that make sense to them.
- The PHB holder should have enough money in the budget to adequately meet health and wellbeing outcomes agreed in the care and support plan.

Adapted from NHS England, (2014a, revised 2019. P7)

The guidance in Table 1, reflects a policy change: in the older version (NHS England, 2014a) there were only five key features. The last point was added in NHS England (2019 revised), ensuring that budgets are adequate. The features presented in the table above reflect the different abilities amongst budget holders and therefore the need for people to choose the options they feel will offer them choice and control within their capabilities. Furthermore, there is an expectation that the allocation of resources by

CCGs should be open and transparent with budget holders having clarity about which elements are included in their PHBs and how the budget has been calculated. CCGs are also supposed to ensure there is infrastructure for PHBs such as information and support in place to support PHB holders in their decision making (NHS England, 2019 revised).

There are three ways in which PHBs can be managed and CCGs are required to ensure that all options are made available for budget holders to choose the ones they feel offers them the choice and control they are most comfortable with (NHS England, 2019 revised). Such decisions should be informed and agreed upon as part of the care and support planning process (Alakeson, 2014a) and budget holders can choose to combine the options if they wish to do so. According to NHS England (2019, revised), the management options are:

- A direct payment is transferred to the person, their representative, or nominee, and they can purchase their care and support directly and negotiate contracts with service providers. The direct payment route is said to offer the maximum choice and control (Fitzgerald et al., 2012).
- A notional budget, whereby the CCGs hold the money and use it to secure services agreed in the outcome discussion with the person, their representative, family, or carer.
- A third party, independent of the person and NHS commissioners, manages the budget on behalf of the person and arranges the purchasing of support in line with what was agreed in the care and support plan. With the third-party option,

responsibilities are shared, the PHB holder will still have choice and control over the day-to-day management of the budget such as hiring staff, setting pay rates, and supervising the quality of care provided (Fitzgerald et al., 2012).

These three options mirror the options which are available within the social care system on which PHBs were modelled (Glasby & Littlechild, 2016). PHBs for wheelchair users can also be managed as notional, third party, or through the NHS conventional ways as before – there are currently no direct payments for wheelchair budgets. Of those in receipt of continuing healthcare funding who have taken up PHBs so far, 12,694 opted for notional budgets while 6,111 used direct payments and 1,517 the third-party option (NHS Digital, 2020).

Since PHBs are an adapted term from social care, confusion exists in practice, where people do not always distinguish personal budgets found in social care from the PHBs found in the NHS. For this thesis, the term personal budgets will only be used when referring to personal budgets in social care and PHBs when referring to the personal health budgets found in the NHS.

1.4 The Challenges of Extending Personalised Budgets into the NHS

Extending personalised budgets into the NHS has raised a lot of issues surrounding the different meanings of choice and control, how that may translate in practice and be reconciled with universal principles as well as eligibility criteria based on need (Beresford, 2009; Gadsby, 2013; Slasberg et al., 2014). For instance, what constitutes choice and control when using a PHB (Gadsby, 2013)? Is everyone able to exercise choice and control and which groups of patients could benefit from PHBs (Slasberg et al., 2014; Webber et al., 2014)?

The political consensus around PHBs has been more fragile than that in social care (Glasby & Littlechild, 2016). Former Prime Minister Gordon Brown in his opening remarks to a report about the use of personalised funding in the NHS highlighted the ethos of the NHS in explicitly non-consumerist terms:

> *'Healthcare is not a privilege to be purchased but a moral right secured for all' (DH, 2008, p. 2).*

This framing raises debates about how to reconcile choice and control, which privileges the autonomy of the individual, within a collective healthcare system (Beresford, 2009) and a cash-constrained NHS (Williams & Dickinson, 2015). Such issues have continued to dominate the debates with some arguing that personalisation does not fit within a collective system of funding because of the way healthcare is financed and provided (Slasberg et al., 2014). Beresford (2009) cited evidence from direct payments in social care, showing how a few who are assertive, confident, and most experienced have been able to exercise choice and control thereby increasing inequalities which he regards as inconsistent with NHS values, a view supported by Lamb (2014).

Others argue that the PHB policy is being driven on weak evidence, for instance in terms of cost-effectiveness both at the individual and systems-level (Mathers et al., 2012; Martinez & Pritchard 2019). For some authors, the evidence base on personal budgets in social care has remained weak, disputing the inferences being drawn and their extension to the NHS (Slasberg et al., 2014; Martinez & Pritchard 2019). However, counterarguments have been put forward that cost-effectiveness can be derived at the individual level through self-direction whilst also enabling people to have better outcomes (Alakeson, 2010; 2014a).

Further concerns have been expressed around how PHBS can fit into the culture of the NHS, where clinicians are seen as the only competent decision-makers, with an expectation that they will make decisions for rather than with patients (Alakeson, 2014a). For staff groups, personalisation in the NHS can be seen as problematic because of environmental constraints such as underfunding, and a clash with established systems and practices (BMA, 2012), with personalisation considered by some to undermine the welfare state by burdening the system while deprofessionalising workers (Ferguson, 2007). Some have highlighted the risk that PHBs will only exacerbate levels of bureaucracy, citing social care examples (Slasberg et al., 2014). Others have raised concerns around whether PHBs will remain sustainable when the number of patients wanting PHBs increase (Alakeson & Rumbold, 2013).

Controversies about PHBs, and indeed social care personal budgets, are nested within broader debates about the concept of personalisation within public services. The next sections consider broader issues of personalisation and public service consumerism before returning to the more specific issue of *choice and control.*

1.5 'Personalisation': A Concept

As a concept, 'personalisation' has been a high-profile issue in public services and continues to be a key policy extending beyond health and social care with far-reaching implications internationally (Alakeson, 2010; Needham, 2011; Glasby & Littlechild, 2016; Gadsby, 2013). Although the language of personalisation is distinctive to the English system, the international literature highlights similar shifts to more person-centred approaches (Da Roit et al., 2010; van Ginneken et al., 2012; McDonald, 2014; O' Shear & Bindman, 2016). Choice and control is operationalised through various mechanisms such as cash for care payments, individual budgets, consumer-directed care, self-directed support, and cash and counselling (Ungerson & Yeandle, 2007; Arksey & Kemp, 2008; Da Roit et al., 2010; Arntz & Thomsen, 2010; van Ginneken, et al., 2012; McDonald, 2014).

Within England, the concept of personalisation is attributed to Charles Leadbeater (2004). It has generated controversies and debates, while its meaning remains elusive with no single unifying narrative (Needham, 2011). Glasby and Littlechild (2016) contend that the roots of personalisation of public services lie in much older campaigns in social care to increase choice and control for people with learning disabilities. Advocates of personalisation call for services and support that are tailored and customised to match the needs and preferences of an individual (Leadbeater, 2004; Glasby & Littlechild, 2009; Boxall et al., 2009; Duffy et al., 2010). As part of this policy, people eligible for publicly funded health and social care support should be able to exercise maximum choice, control, and power over how any funding allocated to them is used (DH, 2007). Offering 'choice and control' gives control of the funding to service users on a consumerist model (LeGrand & Bartlett, 1993; Spandler, 2004) as well as demanding the redesigning of service options to reflect the priorities of service users (Leadbeater 2004; Alakeson & Rumbold, 2016).

As stated by Morris (2006), personalisation may be an answer to the growing dissatisfaction about the limitations of existing services, such as the 'one-size-fits-all' approach of traditional services by offering more personalised services (Baxter et al., 2009). Such dissatisfaction among service users is common in public services according to Carr (2008). Personalisation is seen as a way of putting service users in control of their decision-making (Duffy et al., 2010*).* Personalisation then becomes a more radical concept that is supposed to shift culture and attitudes, challenging professionals to change and adapt to new ways of working that put the individual at the centre of service provision (Carr, 2010). In this context, individuals are seen as experts in managing their own needs and such orientation draws heavily on co-production which seeks to create a reciprocal relationship where service users have assets and capabilities and can jointly make decisions with professionals as facilitators (Boyle, 2013; Bovaird and Loeffler, 2013). PHBs can be the basis for co-commissioning at the micro-level (Musekiwa and Needham, 2020). [1]

Put more radically, Duffy (2014, p. 171) points to how 'personalisation challenges the paternalism prevalent in health and social care'. He highlights the scope for professionals to be a block to personalisation, because of the way it threatens to disrupt the traditional approaches to clinical practice and decision making still prevalent in public service provisions. This disruptive potential of personalisation has led to a polarisation of views about it (Needham 2008; 2009; 2010). As Needham and Glasby pointed out, 'depending on where you sit, personalisation is either the best thing since sliced bread or the end of the welfare state as we know it (2014, p.5).

Whilst a consumerist model appears to work well in some markets, some authors have raised concerns about personalisation within welfare systems (Ferguson, 2007; Scourfield 2007; Beresford, 2008; Daly 2012; Needham 2013; Burchardt et al., 2015). Personalisation has been criticized for heavily relying on the assumptions that all consumers can make rational choices (Timberlake et al., 2014), with markets seen as well-functioning, resourced, and able to respond to variations in consumer needs (Williams & Porter, 2017). Some have cast doubt as to whether personalisation will promote inclusive citizenship and enable people to become active consumers able to choose between services provided in the marketplace (Beresford, 2012; 2014; Kendall

---

[1] This book chapter does not duplicate material in this thesis but takes a different focus.

& Cameron, 2013). Anxieties have also been around increasing risks to the user as well as responsibility and accountability to the workforce (Manthorpe et al., 2009, 2011). There are also demands investment in safeguarding training, alongside a change in leadership, upskilling the workforce and funding to support transition (Carr, 2011; Newbronner et al., 2011, Manthorpe et al., 2015b). There have been concerns that personalisation will increase inequalities with those more able to articulate their needs pushing their demands (Ferguson 2012; Slasberg et al 2012a). According to Kendall and Cameron (2013), such consumerist discourse marginalises some groups of people, in particular, those with disabilities, and departs from the original ethos of the disability movement.

1.6 Personalisation and Outcomes

Personalisation is often associated with improved outcomes (HM Government, 2014). These include more choice and control, people's dignity and freedom are protected, and the quality of life enhanced, leading to less usage of services (DH, 2006). With the rising costs of public service provision, personalisation is seen by some as a 'vital cost-cutting tool, harnessing the creativity of users to help target resources most efficiently' (Needham, 2011, p3). There is growing evidence to suggest that personalisation is linked to improved individual outcomes, although the evidence has been much stronger in social care than health (Glendinning et al., 2008; Rabiee & Glendinning, 2010; Manthorpe et al., 2011; Woolham & Benton, 2012; Rabiee et al., 2013; Webber et al., 2014; Larsen et al., 2013; 2015; Woolham et al., 2017).

Glendinning et al., (2008) evaluated individual budgets in social care and reported positive outcomes with budget holders reporting having more control over their day to day lives and overall quality of life had improved. Similar reports have been seen in outcomes indicators from the POET surveys which attributed the positive outcomes to greater choice and control, with service users explaining that they were able to specify their needs, decide the type of service they wanted and flexibly manage their budget (Hatton & Waters, 2011; 2014;). These studies have also been supported by individual testimonies (Glasby & Littlechild, 2016). With the evidence pointing to improved well-being and other outcomes, there are theoretical arguments to suggest there is a possibility to save money with the reduction in usage of services (Glasby & Littlechild, 2016). However, currently, there is little evidence to suggest mechanisms for personalisation are cost-effective long-term (Woolham & Benton, 2013; Gadsby, 2013; Webber et al., 2014).

The suitability of the personal budget programme for some service users has been called into question and there is limited comparative information about the value of personal budgets for different groups of service users (Webber et al., 2014). Some studies have found benefits for those with mental health problems; Hitchen et al., (2015) concluded that moving to personal budgets can be empowering for mental health services users but it may present challenges to service users with fluctuating mental health. Challenges when implementing personal budgets with older people have been reported (Newbronner et al., 2011; Moran et al., 2012; Woolham & Benton, 2012; Webber et al., 2014; Woolham et al., 2017).

Webber et al., (2014) evaluated empirical evidence presented in the literature on personal budgets and reported considerable methodological limitations. Of the 15 studies reviewed in the systematic review, many reported positive outcomes in terms of choice and control and quality of life. However, owing to methodological shortcomings of the reviewed studies they concluded that little is known about the types of people that individualised budgets may be most suitable for (Webber et al., 2014).

Most of the international evidence on outcomes is from the US and suggests that some improvements in service outcomes are possible from individualised care budgets, but the literature is far from conclusive, and studies are small and open to challenge (The Health Foundation, 2010; Gadsby, 2013). The evidence available points out the importance of understanding how programmes were implemented in practice and how they influenced the ultimate autonomy and degree of choice afforded to the service users (Ungerson & Yeandle, 2007; Arksey & Kemp, 2008; Da Roit et al., 2010; Arntz & Thomsen, 2010; van Ginneken et al., 2012; McDonald, 2014; Carey et al., 2018). Perhaps the most widely reported negative impact of individually held budgets is that of the Netherlands (Gadsby, 2013). Problems were cited with some care mediation offices taking too much control from individuals, costs were spiralling out of control and there were high levels of fraud, leading to the programmes being frozen (van Ginneken et al., 2012). The Netherlands experience showed that a permissive approach to individually held budgets created several risks, such that restrictions to access of the budgets have been applied (van Ginneken et al., 2012).

Apart from these variations in design, the contexts in which the programmes were implemented internationally differed in many ways. Different countries had different categories of services between health and social care (Gadsby, 2013). In the US, funding is provided by long-term care insurance (Ungerson, 2004). In the Netherlands, the criteria for long-term care entitlement were much broader than elsewhere (van Ginneken et al., 2012). The motivations for introducing personalised budgets programme also differed across countries. In Australia, they have been used to reduce the fragmentation of services in rural remote areas (Gordon et al., 2012). In Germany, they were used as a cost-cutting mechanism for health and social care budgets and in the US, they were for cash and care counselling (Arntz & Thomsen, 2008).

Owing to the complexity and variety of the programmes in different countries, it is not possible to generalise about what were the key success factors in any reported health outcomes (Gadsby, 2013). While the implementation of individually held budgets varies considerably in different countries, with the degree of patient choice and control varying significantly, all are based on a premise that giving individuals the control of a budget with which to purchase services allows them to tailor their care to meet their specific needs (Alakeson, 2010; The Health Foundation, 2010; Gadsby, 2013).

1.7 Choice and Control in Personalisation

In many of the studies of individualised care budgets, including in England, it has been noted that giving people choice and control was an outcome as well as an intermediate factor in helping to achieve broader outcomes such as improved health or reduced costs (Davidson et al., 2012; Forder et al., 2012; Gadsby, 2013; Alakeson, 2014b). This section focuses on the different meanings, opportunities, and challenges that choice and control present. Whilst in-depth examination of PHBs is presented later in chapter three through a realist synthesis, this section specifically deals with the different meanings of 'choice and control' in a personalised health and social care context.

The concepts of choice and control are central to personalisation and considered important aspects that govern human behaviour, in particular the right to exercise choice and control over service provision (DH, 2014). It is assumed that allowing people to make decisions and choose services that improve the management of long-term conditions results in better outcomes and positive patient experiences, as well as being good (DH, 2012; NHS England, 2014a). According to Alakeson, (2014a) PHBs offer real control to service users through transferring budgetary control from the professional to the individual. The assumption is that services users will be empowered resulting in a complete shift of power and decision-making thereby allowing the individuals to tailor care exactly to their needs and preferences (Alakeson, 2014a). This suggests that through choice and control, people will be able to reclaim control over their lives, learn more effective strategies for managing symptoms, but more importantly, have their aspirations and rediscover meaning and purpose in life (Leamy et al., 2011).

Choice assumes the ability to select preferred options while control is regarded as influencing the decisions, resources, and actions taken (Kendall & Cameron, 2013) thereby creating a sense of empowerment and increased satisfaction (Dolan & King, 2011). As Clarke (2010) observed, making a complex choice requires reacting to the world, appraising it, making sense of contextual information, and identifying a response. Clarke argues that these processes are intellectually demanding, and that choice can be a process of delegation or joint decision-making rather than a lone action. For instance, care and support planning may require professional support with the decision-making process. Such delegation, however, need not imply a reduction in autonomy, and the relationship between the budget holder and professionals makes both parties less likely to let the other down (Burchardt et al., 2015).

Greener (2002) argues that because wider socio-economic inequalities and barriers continue to influence how choice is exercised by individuals and groups of service users, not all people experience choice and autonomy equitably. For example, some service users have embraced personal budgets, and they are using them in innovative ways. Others have continued to purchase mainstream services and Daly (2012) attributes this perhaps to a fear of taking responsibility for making difficult decisions. Therefore, the increased choice may not necessarily reduce inequalities but exacerbate them (Clark et al., 2005), because those with access to more social and material resources can make better use of choices and take opportunities (Pickard, 2010).

Opportunities for choice can be overwhelming and burdensome. In a qualitative study, Larkin and Mitchell (2016) concluded that choice can cause anxiety, and administering personal budgets was stressful because it required complex and demanding specialist skills for example being an employer. Others highlighted how choice creates a burden due to the increased responsibility of managing the budget (Greener, 2002; Arksey & Glendinning, 2007; Scourfield, 2007; Daly, 2012; Sandel, 2012; Larkin & Mitchell, 2016). People with health and care needs often use multiple services and being their own care manager means they must take on responsibilities once performed by professionals. For example, having to deal with administrative rules, allocation of budgets, and negotiating suitable services, which are all different layers of complexity, and then having to deal with their own day-to-day health needs. Those views are echoed by Turnpenny and Beadle-Brown (2015) who cite how choice may be hindered by excessive information.

Indeed, it is argued that people may avoid choice due to fears of potential or anticipated negative consequences (Baxter & Glendinning, 2013), which could explain why uptake of PHBs is still low (Alakeson et al., 2016). Lewis and West (2014) looked at how older people make choices and some of the issues they raised included the difficulty of making choices in a time of crisis. They noted that people may encounter care services at a time when choice and control are particularly hard to exercise because they are too ill to cope or because health conditions may fluctuate or deteriorate.

Whilst the literature surrounding the concept of ‘choice’ is diverse, it is often presented as the outcome of processes involving assessment, judgment, and evaluating different options, and deciding about which options to choose (Beresford & Sloper, 2008). The empirical research on how people make choices in their decision-making process covers a range of different people in different situations (Schwartz, 2004). For instance, in personal health and care budgets, that ranges from choosing who looks after you and how to what services to buy with the budget to get the best outcomes. Therefore, a decision is defined by the options among which one must choose, and the possibility and contingencies of the related outcomes of the choice (Beresford & Sloper, 2008).

Human beings have a set of cognitive skills which makes them act differently in given circumstances, making different choices and decisions and being able to reflect on those choices (Hastie & Dawes, 2009). However, these cognitive skills have limitations that are influential in constraining choices, such as being presented with information at a time when one is too ill and not being able to retain the information or understand it in a way that enables one to make informed choices (Stevens et al., 2011). Not surprisingly, the complexity of health and social care information may impact people’s ability to make choices and decisions about healthcare or participate in research and manage everyday life choices and decisions (Stevens et al., 2011).

A separate body of literature on the meaning of choice and the exercise of choice argues that social and environmental factors also have a significant role to play in developing decision-making skills and facilitating and supporting decision-making (Lammers et al., 2016). Within a care setting, certain preconditions for choice are noted, such as understanding the care system, resources, having accessible information, and an opportunity to choose between at least two positively viewed alternatives (Arksey & Glendinning, 2007; Beresford & Sloper, 2008; Williams & Tyson, 2010; Williams et al., 2014; Larkin & Mitchell, 2016). This literature suggests that if personal budgets are to enhance choice and control, there needs to be adequate financial resources and a range of positively valued options to choose from (Larkin & Mitchell, 2016).

Whilst discussions continue in the literature about the appropriateness of choice and control in a care setting, not enough focus is given to the lived experience of individual budget holders in navigating some of these challenges. The lack of sufficient longitudinal and in-depth qualitative investigations on how PHB holders experience choice and control has prompted my research project. Working with a small number of PHB holders over two years provided a unique opportunity to explore the relationships between choice and control as a dynamic process over time. I was particularly interested in choice and control as an outcome, rather than as a means to an end of other outcomes. Much of the promise of PHBs rests on the claim that it brings choice and control but not enough is understood about how and for whom this happens.

1.8 Why People with Complex Health Care Needs

I am a practising nurse specialising in complex healthcare needs, and I have had first-hand experience of PHB implementation therefore I come from a professional perspective, and I recognise that this is a relevant factor when considering the role that professional power plays in PHBs. I chose to focus on people with complex healthcare needs because not enough is known about how this group of patients experience PHBs. There are over 56 000 patients with complex healthcare needs eligible for continuing healthcare funding in England (NHS England, 2014a). While they make up only 5% of NHS users, as a group, they are regarded as the highest users of NHS resources (NHS England, 2019b). For example, having multiple chronic conditions is associated with poor health outcomes, greater utilisation of healthcare services, and higher healthcare costs (O' Shear & Bindman, 2016; Hudon et al., 2018). Following the roll-out of PHBs in the NHS, as of April 2014, those in receipt of continuing healthcare funding (including people with complex healthcare needs) gained the right to a PHB (DH, 2014).

Research in the field of complex healthcare needs is very limited (Gridley et al., 2014) and has tended to mainly focus on children and their families (Kirk & Glendinning, 2004, Abbot et al., 2005; Bird et al., 2007; Kirk, 2008). There is a dearth of evidence, with very few studies in social care focusing on adults and older people with complex needs who have used person-centred approaches or personal budgets (Henwood & Hudson, 2007; 2008; 2009; Kirk et al, 2012; Brooks et al., 2014). No studies of personalisation in health care have specifically explored the experiences of adults with complex healthcare needs who use PHBs. Focus instead has been on people with long term conditions such as chronic obstructive pulmonary disease, diabetes, or long-term neurological conditions

(Forder et al., 2012; Irvine et al., 2011; Davidson et al., 2013; Welch et al., 2013; 2016; Jones et al., 2010; 2013; 2017).

As a concept, there is no generally agreed definition for ’complex healthcare needs’, however the term is generally related to people with multiple chronic illnesses requiring access to a range of health and social service thereby increasing the complexity of organising and coordinating their care and support (Glendinning et al., 2001; Abbott et al., 2005). Different terminologies are also used in the literature to refer to this group of patients: complex chronic conditions, long-term illness, medical complexity, and long-term conditions (Bird et al., 2007). For clarity, in this thesis the term complex healthcare needs will be used.

To ascertain how PHBs are delivering choice and control, I set out to recruit a small number of participants across England, comprising of adults (people over 18 years old) with complex healthcare needs who were recipients of a PHB package for the provision of their care and support. These are adults who frequently access inpatient service for ongoing complex healthcare needs, require support of a range of professionals, agencies and may use medical technology (Glendinning et al., 2001; Abbott et al., 2005; Kirk, 2008, Hudon et al., 2018). To make the project manageable, its scope was limited to adults with complex healthcare needs who were in receipt of a PHB package and had been using it for a minimum of a year. I focused on people who were using it in the so-called ‘roll-out’ phase, which started in April 2014, following the initial pilot.

Given the target population (people with complex healthcare needs) and the ethnographic focus, the expectation was that around three to five cases would be a maximum feasible number. Following the sampling approach set out in chapter four, three participants from different geographical areas and different local Clinical Commissioning Groups (CCGs) took part in the study. These were Cora, Steve, and Karen (pseudonyms). I focused on these few individual cases to get a deeper and nuanced understanding of the opportunities and challenges presented by PHBs and contribute to theory development. All the participants who took part in the study had used personal budgets or direct payments in social care before coming to the PHB roll-out programme and so could draw comparison with those other approaches. One of them had participated in the pre-pilot and pilot programmes for PHBs, as well as the roll-out phase. More details on the research design, sample and its limitations are given in chapter four.

1.9 Thesis Structure

This **introductory chapter** has provided an overview of the thesis and its key concerns. It highlighted how personalisation of services in health and social care continues to be surrounded by debate and controversy. It also explained how rising pressures on the funding of health and social care and rising demands are driving personalisation because of its promise of self-direction and cost effectiveness. The chapter also explored developments in personalisation in English health and social care, as well as international developments in similar individualised initiatives. This broader personalisation focus contextualises my overall research in relation to choice and control in shaping service provision. It provided an account of the policy landscape within the broader personalisation policy agenda in health and social care and where PHBs are situated. I also explained why my focus is on people with complex healthcare needs.

In **Chapter Two** I introduce the realist evaluation approach I used in the study. Adopting the realist approach provides a lens to process and think through how the intervention reaches the desired outcomes by examining the different assumptions that stakeholders have about how PHBs are supposed to work and then testing these emergent propositions (Pawson & Tilley, 1997). In the chapter, I will also introduce the realist synthesis and explore in detail this approach and how I use it to synthesise the evidence pertaining to PHB policy, implementation, and impact.

Chapter Three builds on what has been presented in chapter one and two and it is central in guiding the case study analysis later, forming a conceptual thread through the whole research. It presents a literature review of existing knowledge on PHBs. I also consider the ideas and theories of choice and control in the context of PHBs and personalisation and their relevance to the research study, highlighting why this research is relevant and required. This chapter is where I also develop the programme theory that I will be testing with empirical work.

Chapter Four details the methodological approach for the fieldwork, based on the interpretive method of inquiry. My aim was to attend carefully to details of complexity and where meaning is situated in the everyday experiences of using a PHB (Geertz, 1983; Clifford 1983; Guba & Lincoln, 1985). The interpretive approach helped me to explore the understanding and experiences of the PHB holders, the social processes, institutions, and relationships that formed their world and the meanings generated (Mason, 2002). These naturalistic approaches to knowledge and understanding of the social world ensured that ethnography was the most suitable methodology (Brewer, 2000) to explain and understand the meanings ascribed and interpreted in this study.

Chapter Five provides an analysis of the findings and case reports from the individual ethnographies. I explore the experiences of participants with complex healthcare needs who were using PHBs. Through reporting of the findings case by case, I provide richness of detail in the evidence. The case studies therefore contain nuanced data which illustrate what was happening to the PHB holders in the context of how they perceived choice and control in the day-to-day use of PHBs. Chapter five also provides thematic insights that forms the foundational basis for developing context-mechanism-outcomes that are explored in chapter 6.

Chapter Six reports the key findings through the context-mechanism-outcome (CMO) lens and reports the CMO configurations leading to the refinement of the programme theory. In this chapter, I discuss how the contextual factors influenced the reasoning and resources (mechanisms) resulting in the observed outcomes. Through the evidence I explain how PHBs deliver choice and control or not, why, for whom and under what circumstances. I finish the chapter by presenting a set of refined and articulated programme theories that can be applied to the wider context of the PHB programme intervention.

Chapter Seven offers a discussion of what the thesis adds to the overall literature, policy, and service improvement. The chapter considers my findings in the context of the wider literature on personalisation and presents four overarching themes that are explored: access to resources, shared decision-making, professional power and change over time. These themes cut across all cases in relation to choice and control within the PHB programme. The themes resonate with each PHBs holder’s experiences within the findings chapters and have implications for the reasoning and resourcing, resulting in positive or negative experiences for the PHB holders (as set out in the CMOs).

Finally, in **Chapter Eight** I reflect on my role as a researcher alongside my own learning from the process. I consider the challenges presented by my chosen methods and methodology, alongside fieldwork challenges which are all important aspects of ethnographic case studies. The chapter also highlights the study limitations and considers important lessons to take forward as a researcher. The chapter concludes the thesis, offering recommendations and areas where further investigations could be carried out.

1.10 Chapter Summary

This chapter provided an account of the policy landscape and discussed the origins of personalisation. I provided a rationale for why I had focused on people with complex healthcare needs. The chapter discussed the concept of personalisation and highlighted that it remains a contested concept with far-reaching implications in public service provision. It contextualised my overall research in relation to choice and control and how it is shaping public service provisions. I further discussed policy developments within the wider personalisation context in health and social care. The concept of choice and control was also discussed including the key issues and debates. Whilst evaluation literature on PHBs has not been explored in depth in this chapter, it is covered in detail through a realist synthesis in chapter three. In chapter two below, I set out the realist method which – along with ethnography – was the approach I took to better understand choice and control within PHBs.

Chapter 2: Studying Personal Health Budgets Through a Realist Approach

Chapter 1 presented the policy landscape for PHBs, developments, implementation, and thesis overview. This chapter presents the realist evaluation approach I used in the study. The question being addressed in this thesis is 'are personal health budgets delivering choice and control for people with complex healthcare needs?' This is an evaluative question with far-reaching policy implications. It was therefore important to find methodological frameworks that offered explicit and valid information when applied to new, complex, and dynamic interventions, but also allowed in-depth and longitudinal exploration derived from PHB holders' perspectives.

The chapter outlines my plan for answering the research question and explains the strategy I used to implement the plan. The overall aim of the research was to improve understanding of how, why, for whom and in what circumstances PHBs deliver choice and control for people with complex healthcare needs and contribute to theory development. To do that, I used a realist synthesis and evaluation framework (Pawson & Tilley, 1997; Pawson, 2006). As previously mentioned, the realist approach forms the backbone of this study and as a conceptual lens, it will thread through all the chapters that follow.

2.1 Introduction

There have not been many studies of PHBs in the UK. Most of them have used quantitative survey-based approaches, and some have been randomized controlled trials (RCT) with little evidence to draw on outside these large-scale national evaluations (Gadsby, 2013; Alakeson, 2014a). Theory driven approaches offer a useful complement to these because they respond better to dealing with complexity than quasi-experimental research designs (Pawson and Manzano-Santaella, 2012; Marchal et al., 2012; Pawson, 2013). The realist evaluation approach offers a lens to explore different elements of complexity within PHBs because the approach acknowledges that context matters, and it influences the choices that people make in different circumstances (Pawson & Tilley, 1997).

Realist evaluation has its roots in realism, and it is a broad logic of inquiry grounded in the philosophy of science and social science (Bhaskar, 2010). The philosophical thinking behind it is that we live in a real world, every change is real and can have real effects. However, the social world is a dynamic open system, and the importance of social actors cannot be ignored because both society and actors have potential to influence outcomes (Pawson, 2006). Within these philosophical insights is the understanding that events are connected and what may be happening here may trigger another change under the right conditions in each context, and as such human actors are embedded in wider social processes (Sayer, 1992). These are orientations I also share, and I believe that even though people respond differently under different circumstances, it is still possible to work towards understanding what causes the change.

2.2 Realist Evaluation Principles

The term 'realist evaluation' is drawn from Pawson and Tilley's seminal work (1997). As a philosophical approach, it is still relatively young and has grown exponentially in recent years. Its 'key feature is its stress on the mechanics of explanation, and its attempt to show that the usage of such explanatory strategies can lead to a progressive body of scientific knowledge' (Pawson & Tilley 1997, p. 56-57). This is key when exploring PHBs because different types of evidence are required to evaluate this important policy intervention and add to the evidence base.

Another aspect of realist evaluation is that, because 'programmes are embedded in social systems,' evaluations must look at the complexity of micro, meso and macro-level processes of change and how actors' choices and use of the resources lead to the outcome (Pawson, 2004 p. 4). This requires attention to the different layers of social reality which make up and surround a programme (Marchal et al., 2016). Pawson (2004) further explain that it is the workings of the entire system of social relationships that might bring change and therefore context is very important.

While realist evaluation is grounded in realism, its premise is that programmes work differently under certain conditions and are influenced by the way different stakeholders respond to them and as such they work differently for different groups and trigger different changes (Westhorp, 2018). According to realist principles, programmes attempt to address existing social problems to bring about some level of change and therefore are heavily influenced by the way different stakeholders react to them, enabling programme participants to make different choices (Pawson & Tilley, 1997).

Since problems and interventions operate at both the individual and societal level, with multiple dimensions that are interconnected, they need to be delivered with an understanding of how the individual, community, and population level (micro, meso and macro) responses impact the wider context (Pawson, 2004). Since programmes work differently in different contexts, they cannot be simply replicated in another location to get the same outcomes, therefore what works for whom under what circumstances is important and needs to be understood (Pawson, 2004).

The word 'theory' has many connotations. In realist evaluation, there are four kinds of theory: the first deals with realist ontology and epistemological position; a second deals with the methodology that realist philosophy applies; a third covers the formal theories used to design programmes; and the final one is that concerned with the programme, i.e., how it is supposed to work (Pawson & Tilley, 1997; Wong et al., 2013). It is this fourth type which is the focus of my study. In realist theory, further terms are used such as 'initial rough theory' or 'initial rough programme theory' which is the initial theory that guides the realist synthesis or evaluation (Pawson, 2013, Wong et al., 2013). 'Refined theory' is a by-product of a review and middle-range theory is abstract and specific enough to generate hypotheses that can be tested to link the findings to the wider context (Wong et al., 2016). These terms will be applied to the realist processes in the overall project.

The realist evaluation makes these theories within a programme explicit, by developing clear hypotheses about how, why, for whom and under what circumstances, programmes might work (Pawson & Tilley, 1997). To understand how the programme theory might generate different outcomes in different circumstances requires the researcher to examine how different programme mechanisms are triggered in particular contexts (Manzano-Santaella, 2016). Through this, it is possible to test the theories to affirm, refute or refine the elements of the programme theories (Pawson & Tilley, 1997).

2.3 Context, Mechanisms and Outcomes

Mechanisms are crucial to realist evaluation, yet they are sometimes confused with contextual factors, activities, or specific resources (Marchal et al., 2010). Mechanisms constitute the conceptual logic or explanation of programme theory, they are hidden but real and there are elements of reasoning and reactions of actors with regards to resources, contextual factors, relationships, and systems that bring about change (Pawson et al., 2005). They form the invisible part of the design of an evaluation and only come to light during the evaluation process (Pawson, 2013).

Herepath and colleagues (2015) point out that most healthcare studies that have applied realist evaluation principles, with rare exceptions (see Greenhalgh et al., 2009 and Byng et al., 2008), have tended to conflate context with intervention. Many of these studies (Rycroft-Malone et al., 2008; Marchal et al., 2010; Manzano-Santaella, 2011; Randell et al., 2014) applied a wide array of approaches to conceptualise context and many failed to agree on what elements of context were most important (Dalkin et al., 2015; Greenhalgh et al., 2015). According to Pawson, 'in the notion "context", lies the realist solution to the panacea problem' (2004, p. 7). Context is therefore perceived to be the features of the conditions in which the programme was introduced and is very relevant to the operation of the programme mechanisms (Dalkin et al., 2015).

Contextual factors may enable or prevent mechanisms from being triggered and these may be socio-economic, political, environmental, organisational, or cultural differences (Pawson et al., 2004). Attitudes and behaviours also contribute to how mechanisms are fired in programmes (Westhorp, 2014). Since programs are products of the foresight of policymakers, their ultimate outcome will depend on the imagination of practitioners and participants (Pawson, 2013). What may be expected by policy makers may be affected by unanticipated events anywhere along the policy process chain through intended and unintended events (Jagosh et al., 2015). Put that way, a relevant contextual factor for PHBs may be the way in which the programme has been evolving, given that it was implemented initially as a pre-pilot, then pilot, followed by roll-out and now as an integrated approach with social care. How the system, organisations, workforce, and individuals respond to these changes may impact the programme outcomes.

A combination of reasoning and resources constitute the mechanisms that make a programme work (Pawson, 2004). Reasoning includes for instance the implementation process, values, and attitudes while resources include the money, skills, information, and support etc. (Marchal et al., 2012; Jagosh et al., 2019). Mechanisms explicate the logic of an intervention, clearly showing how they trace a programme theory and pinpoint the ways in which the resources on offer may permeate into the reasoning of the subjects (Pawson, 2004).

Like context, unpacking and conceptualising mechanisms in PHBs can also be fraught with difficulty because choice and control may operate within different, and often contradictory contexts of the programme theory (Greenhalgh et al., 2009). Pawson and Tilley (1997) warn that empirical work in programme evaluation can only be as good as the theory which underpins it. Therefore, the identification of the different ways in which the causal mechanisms may operate in each context to generate outcomes for particular groups of people is rather important (Pawson & Tilley, 1997).

Realist teams have always met challenges when trying to articulate what are causal and generative mechanisms in a programme (Greenhalgh et al., 2009; Marchal et al., 2012;

Williams et al., 2013). Generative mechanisms are often hidden and not directly observable but are real and interact with one another in a specific context whereas causal mechanisms are the processes that brings about outcomes (Pawson, 2002). The lack of a conceptual consensus stems from how some researchers fail to separate out resources from reasoning (Greenhalgh et al., 2015). Some scholars have suggested being more flexible in the articulation of CMOs, and acknowledging the complexities of healthcare systems, interventions and the methodological challenges for researchers who opt for realist evaluation (Astbury, 2013; Dalkin et al., 2015). This difficulty in operationalising the concept of a mechanism has been one of the criticisms of realist evaluation (Porter, 2015; Marchal et al., 2015).

Outcomes in realist inquiry are the multifaceted elements of an intervention (Wong et al., 2013). According to Pawson (2004) outcomes can result from intended and unintended consequences because of the activation of mechanisms in a given context. Outcome patterns can take many forms which is why programmes are tested against a range of outcomes (Pawson, 2004). As such, it is essential that outcomes have been properly specified and assessed during the evaluation (Westhorp, 2014). Outcomes are therefore supposed to be supported by CMO configurations which set out a clear explanatory argument, emphasised by Pawson and Tilley (1997).

The need to explain why programmes work or not puts emphasis on the importance of theory and how the actors respond to the programme (Adams et al., 2016). To explain how this works in realist terms, Pawson and Tilley (1997) proposed the ‘context, mechanism, outcome (CMO) configuration’ which they put in a formula: context + mechanisms = outcomes and defined it as a hypothesis that the programme works (O) because of actions of underlying mechanisms (M), which is triggered by a particular context (C). Therefore, under the right processes and conditions, the programme will have a particular set of outcomes and they stressed, it is the nature and source of these internal differences, that is a key focus of attention in realist evaluation (Pawson & Tilley, 1997; Pawson, 2004).

Understanding how particular aspects of the context shapes the mechanism which leads to outcomes is important because it helps specify which mechanisms will generate the outcomes and the features of context which will affect whether the mechanisms operate (Pawson & Tilley, 1997). The CMO configuration is the unit of analysis on which realist evaluation is built and it helps to elicit the programme theory, refine, test with empirical work, further refine, and then articulate the programme theory considering the evidence of what is actually happening in practice (Greenhalgh et al., 2015).

2.4 Realist Evaluation and Application to this Study

The scope of the overall research question compared policy expectations with actual practice. I followed the realist approach which starts with an initial programme theory of how a programme is supposed to work, which is developed from existing theories that are supported by empirical studies across a range of fields (Pawson et al., 2005;

Randell et al., 2014). I began with a realist synthesis (Pawson, 2006) which enabled me to identify and articulate the initial programme theories for testing with empirical work. The terms realist synthesis and review are used interchangeably in the realist literature. Realist synthesis is a relatively new strategy for synthesising research and has an explanatory focus (Wong et al., 2013). It is set within theory-based approaches to evaluations, whose relevance to policy is widely recognised and firmly rooted in realist philosophy (Pawson 2006; Greenhalgh et al., 2013). Like realist evaluation, it is gaining prominence in contemporary health service research and evidence-based policy (Herepath et al., 2015).

As a method of weighing the evidence, realist synthesis draws on the literature to identify and interrogate the programme theories, that is the hunches or assumptions about how a programme will achieve its objectives (Pawson et al., 2005). According to Pawson (2006), programme theories are important in realist synthesis as they provide the plausible explanation of why a programme brings the expected change or not. There are arguments put forward that evaluators can look 'for empirical evidence to populate this theoretical framework, supporting, contradicting, or modifying the programme theories as it goes' (Pawson et al., 2005, p. 21).

Similarly to realist evaluation, the realist synthesis follows an interpretative and theory-driven approach to synthesise various sources of evidence (Rycroft-Malone et al., 2012) such as published studies, grey literature, policy documents etc. that may otherwise not have been possible with for example meta-synthesis and meta-narratives (Bryman, 2016). The approach acknowledges the relationship of context, mechanisms and outcomes within a given programme theory. For instance, in PHBs, the conditions such as values, culture, existing relationships and the way services are configured in the English NHS are contextual factors. Mechanisms are the reasoning and resources, which may include, care and support plans, information, support structures, decision-making etc. Some examples of outcomes include psychological well-being, user involvement and empowerment. I used realist synthesis to explore choice and control as one of the expected outcomes of the PHB programme.

While the literature on realist synthesis suggests a set of protocols (the Realist And Meta-narrative Evidence Synthesis: Evolving Standards (RAMESES I and II) as guidance, they do not provide a step-by-step methodology, but rather argue for an iterative process (Wong et al., 2013). Scholars in the field have used various approaches to elicit theories (Westhorp, 2012; 2013; 2018; Rycroft-Malone et al., 2012, 2014; Jagosh et al., 2015). The theories may be in policy guidance, position papers, professional journals, and various pieces of grey literature such as blogs, critiques and opinion pieces (Adams et al., 2016). Pawson (2006) developed a series of steps that can be used to locate and articulate initial programme theories, and these are illustrated in Fig 1 below.

Fig 1. Illustrating the Realist Synthesis Steps Undertaken

Phase 1.Define Scope of Review

Preliminary search, develop reseach questions

clarify concepts

and develop search strategy

Phase 2. Develop Initial Programme Theories

Draft initial programme theories for refinement

Phase 3. Search for Evidence

Systematic search of databases and other sources

Phase 4. Selection and Appraisal of Evidence

Appraise the evidence for relevance and rigor

Phase 5. Data Extraction and Synthesis

Identify the link between context, mechanisms, and outcomes and present in logic framework

Articulate programme theory for testing

Approach to realist synthesis adapted from Pawson (2006, p. 83)

Following the steps presented in Fig 1. above, I conducted a scoping process to get a feel for the literature and to ascertain what form of evidence, where they were located as well as how much evidence was available. The preliminary literature search also focused on uncovering the many different understandings associated with the PHB programme such as concepts used, implementation and practice. To identify the literature, I searched various academic databases, such as HMIC, ProQuest, EBSCO, EMBASE, Web of Knowledge, MEDLINE, and the Cochrane Library. I also undertook keyword searching in Social Science Citation Index, Social Services Abstract, Social Care Online and Google Scholar for reviews and primary studies on PHBs. Due to the limited evidence base, I expanded the search to grey literature, and expanded the focus to encompass personal budgets, wider personalisation, in the UK and internationally. In the English literature, PHB are sometimes called personal budgets in some studies and by user groups, although this term generally refers to social care rather than health budgets.

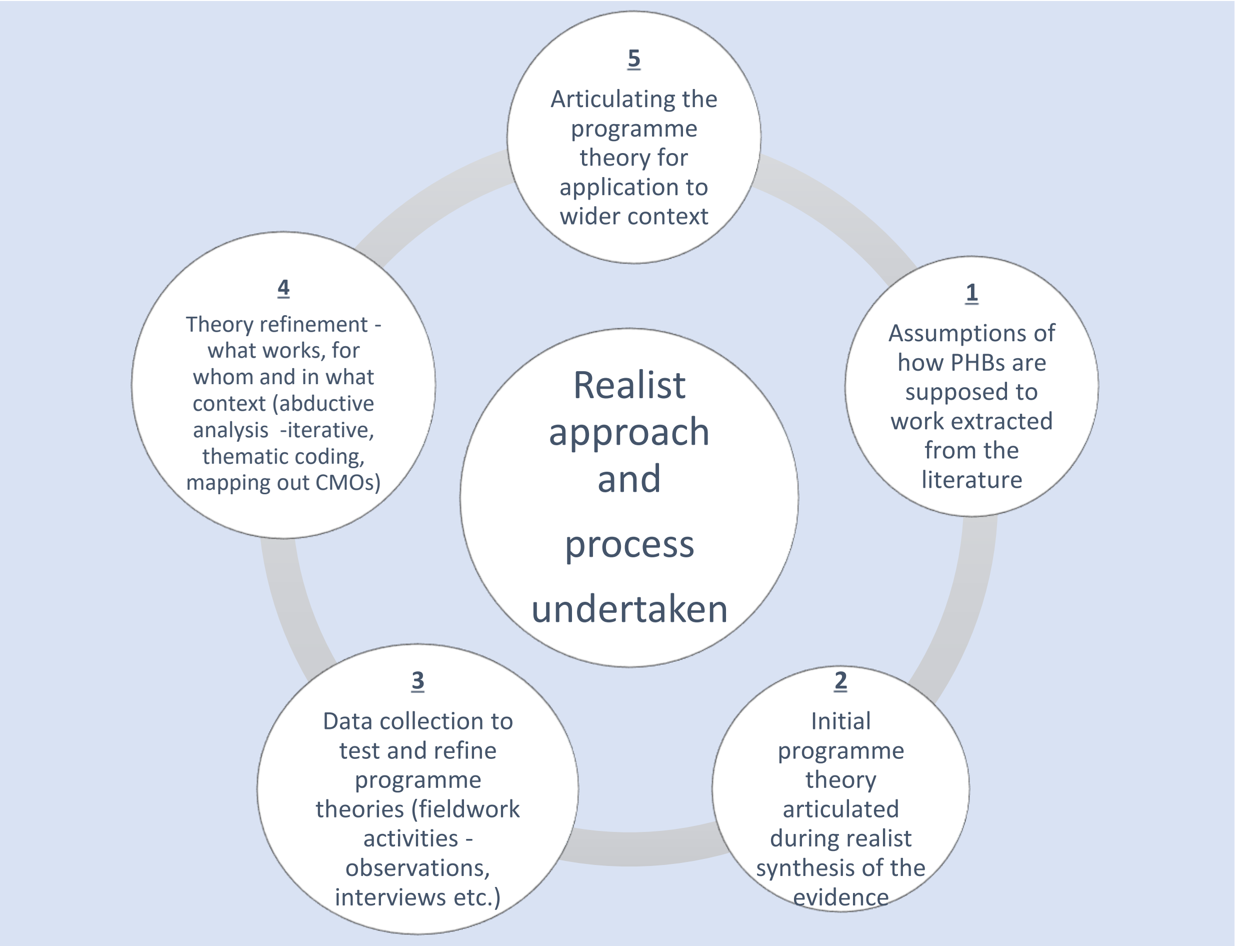
Most researchers who have used realist synthesis or realist evaluations started with a review of the literature to identify their programme theories and then refine those theories through stakeholder interaction (Westhorp, 2012; 2013; Randell et al., 2014; Wong et al., 2015). I tried to do that, and I had challenges accessing stakeholders (this is covered in more detail in chapter three). Pawson (2006) argues theories can be refined through stakeholder interaction or using realist synthesis – synthesising various sources of evidence to come up with a hypothesis that can be tested with empirical work. Faced with the challenges described above and later, I chose to do the latter, with the aim of locating what Pawson (2006) terms ‘initial rough programme theories’ from policy, service documents etc. and refine them through synthesis of various sources of evidence, then test with empirical work.

Designing the review in this way also served to identify and examine the broad evidence alongside a realist interrogation, taking the realist synthesis approach described above, (Rycroft-Malone et al., 2012; Randell et al., 2014; Wong et al., 2015). Data collection and analysis can then take place to observe the interaction of CMOs which illuminate the theory of what works for whom, how, why and in what circumstances (Randell et al., 2014). Through theory refinement, the CMOs are altered to reflect what is taking place culminating in articulated CMOs to capture the key factors and processes for the observed outcome in the programme theory in light of the evidence (Jagosh et al., 2016).

Following all the principles derived from Pawson and Tilley (1997) and Pawson (2006), set out below in fig 2. the realist approach was structured to answer the research question ‘are personal health budgets delivering choice and control for people with complex healthcare needs?’ During the scoping phase I defined the concepts and developed the initial programme theories and some of that work informed the background information in chapter one.

Following that, I carried out a systematic evidence search of selected databases and appraised the evidence. I then extracted and synthesised the evidence which I used to build the theories on how PHBs are supposed to deliver choice and control for people with complex healthcare needs. Therefore, the realist synthesis was used to identify the initial programme theories which I then articulated through synthesis of the evidence using CMO configurations into refined programme theories for testing. The articulated programme theories were then tested in practice through fieldwork activities culminating in the answering of the research question. These processes are explored in more depth in chapters three, four, five and six of this thesis. The use of realist evaluation as a theoretical framework enabled me to link the observed accounts to contexts in which PHBs operate, using an abductive approach (explained more in chapter four).

Fig. 2 Depicting Realist Evaluation Process for Answering the Research Question



Realist Evaluation Cycle adapted from Pawson and Tilley (1997, p. 85)

Pawson and Tilley (1997) suggest a realist evaluation is not a final judgement and rather takes the form of revision hence the cycle in fig. 2. However, in this study, I only went as far as testing the initial programme theory with empirical work, which was sufficient to answer the research question ‘are personal health budgets delivering choice and control for people with complex healthcare needs?’

2.5 Why Use Realist Evaluation in This Study?

Many studies are using realist evaluation principles in healthcare research across a wide range of disciplines (Evans and Killoran, 2000; Byng et al., 2008; Rycroft-Malone et al., 2008; Greenhalgh et al., 2009; Marchal et al., 2010; Manzano-Santaella, 2011; Wand et al., 2011; McCormack et al., 2013; Randell et al., 2014; Wong et al., 2016; Jagosh et al., 2016; Williams et al. 2016; Goodridge et al., 2018; Nurjono et al., 2019; Weich et al., 2020) and they address an array of topics within healthcare (Wong et al., 2015). This proliferation of studies indicates that healthcare interventions are complex and call for evaluations that can tackle complexity (Greenhalgh et al., 2015). It points to, 'the realisation by many evaluators and commissioners that coming up with solutions to complex problems is challenging and requires deeper insights into the nature of programmes and implementation contexts' (Wong et al., 2016, p 1).

I chose to use realist evaluation to understand the operation of choice and control for people with PHBs as I was convinced this was the best methodological approach to advance understanding of choice and control from a user perspective. From the realist principles presented earlier in the chapter, the approach offers scope for exploring choice and control offered by PHBs which can be grasped through theory building. Existing evaluation studies on PHBs have focused on establishing change in outcomes, cost effectiveness and the process and operation to explain improved impact using quasi-experimental and process evaluation (Forder et al., 2012; Jones et al., 2011; 2017). Realist evaluation can explain how PHBs work and offer choice and control and under what circumstances, making it an appropriate framework for deeper and longitudinal exploration of how they can work best for the PHB holders. This research was born from a desire to understand the inner workings of PHBs, policy developments and implementation at a micro-level. For example, what it is about PHBs that provides choice and control to people and which factors support their successful embeddedness into routine service provision. Realist evaluation allows examination of these attributes of mechanisms that reflects embeddedness of a programme through CMO propositions (Pawson, 2004).

Realist evaluation can specify the generative mechanisms that are generally hidden, since the logics in people's choices (when activated in specific contexts) can be identified through the CMO configuration (Marchal et al., 2015). Through the CMO configurations, I was able to identify aspects of the PHB programme such as how care is purchased, organised, and provided to offer people choice and control. For example, the decision by the NHS not to offer training to staff who are implementing PHBs causes a lack of knowledge meaning that staff will not be able to appropriately support PHB holders because they themselves are ill informed. Since the budget holders have not received the right information and support, they may find it difficult to work with the budget and feel they have no choice and control. Similarly, if the staff implementing PHB are trained and knowledgeable, they may be able to implement PHBs successfully and appropriately support PHB holders, who will then perceive that they have choice and control.

The focus should also be on how individuals respond to the reasoning and resources in the intervention because it is the people affected by the programme who enable change to take place (Pawson, 2006). PHBs are supposed to make people active participants in their care and, therefore, are seen as having the potential to empower PHB holders. Some PHB holders might have the capability to manage the budget and will embrace such an opportunity and feel empowered. However, others may struggle to manage the budget and will require information and support that may not be readily available and will feel disempowered. Therefore, causal mechanisms when combined with the right contextual factors, trigger generative mechanisms (Pawson, 2004).

Pawson and Tilley (1997) highlighted that context matters and programmes involve multiple contexts, and the operation of the programme mechanism is contingent on these contexts. Pawson (2006) further reiterates that context does not only refer to the geographical/ institutional location, but the prior set of social rules, norms, and values that influence the efficacy of the programme outcomes. Within the NHS system, there are fears that PHBs will pose a real threat to NHS principles as well as increasing inequalities. Therefore, acceptance of the programme for some groups of people may be problematic and such elements may be present but not explicit (Mathers et al., 2012; Slasberg et al., 2014). Realist evaluation enables the identification of these elements through CMO configurations.

Theoretical assumptions are made by policy makers, user groups and academics with regards to choice and control offered by PHBs, how they allow individual patients a wide range of services to choose from, who they receive care from and when (NHS England, 2014a; Alakeson & Rumbold, 2013). Also, when people are given choice and control, they may choose some services the NHS does not currently provide, alongside traditional NHS ones (DH, 2009). The PHB policy is also one example of an intervention operating at the individual (micro), organisational (meso) and institutional (macro) level context of the NHS system. Therefore, targeting change at one level is likely to impact the wider system but also requires acknowledgement that the programme will have different impact for different people in different situations. Realist evaluation takes account of this broader context of the underlying conditions and enables identification of the different layers of social reality that are at play. The approach also allows space to challenge and explore some of the policy assumptions being made from a user perspective (Pawson, 2004).

A further principle of realist evaluation is that ‘programmes are open systems’ (Pawson, 2004 p.5). This suggests that implementing changes alongside the changing policy landscape (and now Covid-19) may have an impact on PHBs as a policy direction which could have real consequences for the programme outcomes. Also, within the NHS, different Clinical Commissioning Groups have local policies and implementation processes that may cause PHBs to be implemented differently, depending on local interpretation of the policy and local priorities. Taking a realist approach enables the researcher to collect and analyse longitudinal data, not just about programme impacts, or the processes of programme implementation, but also about the specific aspects of programme context that might impact on programme outcomes, and about the specific mechanisms that might be creating change (Pawson, 2004). This enables exploration of deeper meanings of choice and control and how it is being shaped by the resources and reasoning at the individual level as they adopt, adapt, engage, or reject the programme theory altogether.

Furthermore, with realist evaluation, it is possible to explain why ‘winners are winners’ and ‘losers are losers’ (Pawson & Manzano Santaella, 2014, p.178). For instance, it can help in bringing an understanding of why PHBs may provide choice and control for some and not others – having excess options can be a burden for some, while for others it can be liberating. With realist evaluation, such mechanisms in PHBs can be identified and explained as well as enabling a focus on what facilitates or prevents change or triggers unintended consequences. Therefore, realist evaluation is a good fit for this project because it addresses these salient mechanisms by answering questions of how and why PHBs offer choice and control, for whom and under what circumstances (Pawson & Tilley, 1997).

While most of the realist evaluation studies have used mixed methods, qualitative or quantitative methods can be adopted, even though the challenge for evaluators has been the tension that exists between these philosophical stances (Pawson, 2004).

Realist evaluation is also compatible with qualitative and ethnographic methods, which for my study allows me to focus on experiences at the micro level. The longitudinal and in-depth case work that is required to understand the experiences of people with complex healthcare needs necessitates an ethnographic type of realist evaluation. The issues of combining realist evaluation and ethnographic research are discussed in detail in chapter four.

2.6 Summary of the Chapter

This chapter explored the theoretical basis behind the research strategy I adopted. It provided a detailed description of the philosophical foundations of realist evaluation and the different aspects that sets it apart from other evaluations. I explored the different meanings of theory, context, mechanism, and outcome and explained the CMO configurations, and how that can be applied to PHBs and explain how they work or not. I also discussed the realist synthesis used to generate the initial programme theories. The realist evaluation cycle and its application to this study was explained. I also set out why realist evaluation was the right philosophical lens to explain and understand the transaction and processes that PHBs holders may go through in trying to exercise choice and control. Realist evaluation can also assist with the challenges of unpacking complexity within the different layers of the NHS, because it responds well to exploration of complexity. Furthermore, I set out my plan to combine realist evaluation and ethnographic case studies because together they enable in-depth and longitudinal exploration of choice and control from the PHB holders' perspectives.

Chapter 3: Literature review – A Realist Synthesis

Chapter 2 presented realist evaluation as a lens for exploring PHBs and introduced the realist synthesis, a framework used to identify and interrogate the literature in this study. The scope of the overall research question is to compare policy expectations with actual practice. Taking the realist synthesis approach (Pawson, 2006), I began by conducting a scoping review of the literature to help define the concepts and this has been presented in chapter one. I also developed the initial programme theories and some of that work informed the background information in chapters one and two.

3.1 Introduction

This chapter builds on what has been presented in chapters one and two and it is central in guiding the case study analysis later. It forms a conceptual thread through the whole research. As such, the literature retrieved during the scoping process guided the development of search terms, search strategy and how to weigh the evidence. It is therefore important to highlight that the literature search for this study was completed in late 2017. Included in the synthesis is a literature review that covered both health and social care personal budgets and included international evidence (Gadsby, 2013). According to Gadsby (2013) it is difficult to reconcile or make comparisons between countries for programmes that aim to offer choice and control to health and social care service users because of the different contexts in which they operate. Hence I chose to focus on PHBs – an NHS context.

The preliminary search also informed the construction of the following research questions for the review:

1. What are the key assumptions about how PHBs will work?
2. How are PHBs implemented?
3. How are the budgets used by different groups of people?
4. What are the outcomes?
5. Which groups of people experience these outcomes?
6. Which mechanisms and context were linked to these outcomes?

These research questions were used to guide the data extraction and to build the programme theories. While choice and control are not mentioned explicitly in the above questions, the scoping review demonstrated that choice and control was framed as an outcome of the implementation process, an end in itself as well as a means to the end of better health. This will be explored in more detail through the evidence.

It was apparent at the scoping stage of the review that PHBs were complex, new in the NHS, and there were several factors at play that could influence how people exercise choice and control. These factors included capability of the individual and availability of resources in the NHS, both of which can be catalysts to whether PHBs enhance choice and control. The scoping review also highlighted the social structures and multiple layers of context (institutional, organisational and the individual level) in the programme theory that necessitated a framework for looking at the theories (Pawson, 2006; Westhorp, 2012; 2014).

3.2 Developing the Initial Programme Theory

Pawson (2006; 2013) argues that researchers can utilise policy, service documents, position papers etc. to develop initial programme theories. Other researchers who have used realist synthesis have taken a similar approach advocated by Pawson (Greenhalgh et al., 2013). I followed the same approach and used policy documents, position papers, professional journals and opinion pieces. Given my focus on choice and control it was the claims made around choice and control that were of particular interest, although I also was keen to surface other logic statements to understand other dimensions that were likely to shape implementation and the achievement of choice and control. I followed a similar approach taken by Rycroft-Malone and colleagues (2012) to find and articulate the programme theories, which Pawson (2013) termed 'initial rough programme theories' from various sources of evidence. I drew up a list of these programme theories in the form of logic statements to differentiate them from the refined theories I would be testing. I grouped and categorised them as Rycroft-Malone et al. (2012) suggested using bespoke data extraction processes. According to Pawson (2013), the initial programme theories may be extracts of passages of theory fragments or theories. I identified a series of logic statements from my source material and grouped them according to key themes: choice and control; shared decision-making; inequalities; accountability, responsibility, and risks; culture change; power. Table 2 below highlights the initial logic statements. As well as presenting the dominant logic statements, I also include rival framings which suggest that the programme theory will not work as intended.

Table 2 Initial Logic Statements from the Synthesis

Theme	Logic Statements	Rival Framing
Choice and Control	PHBs will give people control of the money and ‘allow individuals to tailor care exactly to their needs and preferences’ thereby maximising engagement (Alakeson, 2014a, p. 54) With more choice and control, people’s dignity and freedom will be protected, and the quality of life enhanced, leading to less usage of critical care thereby reducing cost of care (DH, 2012b). Giving people choice, control, and flexibility over how the budget is managed will have positive outcomes (Forder et al., 2012). PHBs will encourage choice of service providers and allow people to tailor make services that respond to their needs (DH, 2012b). PHBs have the potential to help people shape their own services and lives which will create a more tailored service that responds to individual needs and is more likely to be effective (Alakeson, 2014b). PHBs can be used in innovative ways that can improve psychological wellbeing resulting in reduction in the use of emergency services and inpatient services (Forder et al., 2012).	If people make ill-informed choices that is likely to impact negatively on their quality of life (Mathers et al., 2012; Alakeson, 2014a). Healthcare is not like other commodities and personalisation of the NHS may not necessarily lead to improved outcomes but may exacerbate the existing challenges (Williams & Dickinson, 2015) PHBs threaten the founding principles of collective citizenry on which the NHS was built (Mathers et al., 2012; Slasberg et al., 2014).

Shared Decision Making	PHBs will enable individuals to be more involved in the decision-making process and work jointly with professionals as co-producers rather than passive recipients of care and enables accountability because they will explicitly know the cost of their healthcare (DH, 2012c). PHBs will provide a clear mechanism for improving patient engagement and empowerment in health (DH, 2009). Involving people in managing their own health and care, will help in staying well and can minimise the use of services (DH, 2012b). PHBs will enable full engagement of patients in their own health and healthcare, and they will be able to shape the nature of services they receive directly (NHS England, 2014c). Personalised budgets enable budget holders to make decisions in partnership with professionals and take control of the combination of services which works better for them (TLAP, 2015) The care and support plan in PHBs is central and will be driven by the individual, enabling them to identify what is important to them and what they want to achieve, and considers the needs, strengths, and skills of the individual and their social context (Alakeson, 2014a). PHBs acknowledge lay forms of knowledge and expertise and promote greater choice and control in the decision-making for service users (DH, 2009; Duffy, 2010a). The allocation of money to the PHBs holders will transfer power from the professional to the individual allowing a	

	complete shift of power and decision making (Alakeson, 2014a). Individuals who are supported with their PHB will engage more effectively with their condition and can have a positive experience of their care and can experience better health outcomes (TLAP 2015).	
Inequalities	PHBs can address inequalities and improve outcomes by targeting those with worst health status. They have the potential to help the NHS become more tailored to individual needs and therefore can be extended to all people who could benefit (NHS England, 2014c). ‘Personal health budgets and the overall movement to personalise services could be a powerful tool to address inequalities in the health service’ (DH, 2009, p. 9) PHBs have the potential to address some of the inequality challenges facing the health and social care systems (Alakeson, 2014a).	Certainly, PHBs will increase inequalities that already exist in the NHS (Mathers et al., 2012; Slasberg et al., 2014)
Accountability, responsibility, and risks	PHBs will make the financial aspect of healthcare more explicit at the individual level .People will have more say and it puts a duty on the individual to identify and potentially source the most appropriate services, and to varying degrees, manage the budget and be accountable for how it is spent (DH, 2009; 2012).	PHBs will transfer risks from the NHS and will increase responsibility and accountability to the service user (Irvine et al., 2011; Slasberg et al., 2014). PHBs are likely to increase demand for care thereby increasing the cost of healthcare (Mathers et al., 2012)
Culture change	PHBs will support cultural change needed to create a more personalised NHS that is taking away state	

	responsibility and giving it to the citizen (Irvine et al., 2011). PHBs enable partnership working between professionals and PHB holders as co-producers changing the way services are often provided in the NHS ('one size fit all') and generating pressures for cultural change (DH, 2012a). Giving service users greater control and choice over service will bring transformational change into the NHS and challenge paternalism (Leadbeater, 2004).	
Power	PHBs will empower people and they will be equal partners changing the nature of the relationship that currently exists (DH, 2009). Offering choice and control through a PHB is supposed to challenge these hierarchical structures and paternalism (Duffy, 2010b; Welch et al., 2013). PHBs challenge the traditional ways of thinking and behaving where professionals have been the primary decision makers and patients passively receive care (Duffy, 2014). PHBs will promote user involvement and empowerment, enabling service users to become active participants and not passive recipients of services (HM Government, 2007; 2011). PHBs have the potential to empower service users by putting them in control of the decision-making (McDonald, 2014).	

Realist syntheses have mostly tested programme theory through scoping reviews, which are then refined through stakeholder interaction and tested using empirical studies (Westhorp, 2012; 2013; Greenhalgh et al., 2013; Jagosh et al., 2015; Randell et al., 2014; Wong et al., 2015). As a doctoral researcher, I was limited in the access that I had to policy stakeholders. Instead of engaging with stakeholders, I used the literature synthesis to refine the programme theories ahead of my empirical work. Rycroft-Malone et al. (2012) used a similar approach and extracted data that offered both confirmatory and contradictory findings, then refined their programme theories considering their findings. They argued that while realist analysis demands flexible thinking and ability to deal with complexity, it has potential for more pragmatic approaches which can be rewarding and bring valued conclusions. While my approaches have refined the initial programme theories without a second member to validate them, I argue, they have been valuable in evaluating the evidence. These different types of evidence are required to access the different dimensions of the PHB programme to build an overall picture (Glasby et al., 2013).

3.3 Search for Evidence

Having identified the logic statements in table 2 above, I needed to refine them into programme theories that could be tested. The next stage was to understand the programme implementation process, how and why PHBs would achieve those anticipated outcomes in table 2 and under what conditions. To do that required interrogation of the evidence therefore warranting a systematic search of the literature.

I developed a search strategy to retrieve literature in a systematic way, and below in table 3, I present the strategy undertaken for a systematic literature search.

Table 3: Systematic Search Strategy

Search terms with Boolean operators AND, OR, NOT applied		
Personal health budgets	Choice	Complex healthcare needs
Personal budgets	Control	Complex care needs
Individualised budgets	Decision making	Complex health care
Direct payments		Long-term conditions
Personalisation		Medical complexity
Cash for care		Complex chronic condition
Consumer directed care		Complex health needs
Self-directed care		Acquired brain injury
Cash and counselling		
Inclusion		
No restriction on design		
Any sources including grey literature (research studies, opinion papers, guidance, policy papers, reviews)		
Citation searches		
Any source with any form of personalisation in health or social care context (PHBs, PB, IB etc.)		
International		
All patient groups		
Exclusion		
Papers not written in English Language		
Studies that integrate health and social care		
Any papers with choice and control not linked to personalisation		
Any paper with complex healthcare needs or related terms not linked to personalisation		
Limited		
Jan 2009 – Nov 2017		

Using the search terms and parameters outlined in Table 3 above, I systematically searched electronic databases. I targeted my search to the following electronic databases from Jan 2009-November 2017: Medline, EMBASE, CINAHL, EBSCO and Psycinfo as well as applying search operators and identified 548 hits. Using this approach meant I could identify relevant literature systematically starting from the pilot phase but also taking account of all other terminologies that are used in the literature for self-directed care.

3.4 Selection and Appraisal of Evidence

The retrieved literature was screened by title and abstract then full text and removal of duplicates, after which 164 sources remained. These articles were read in full and further screened for relevance to the research questions (see criteria for study selection – relevancy to theory development in appendix 6 page 374). The literature indicated that the context in which PHBs operate make it difficult to draw comparison from other forms of budgets that are offered in other countries and these contextual differences will have a different impact in different systems. Therefore, the full review focused on 20 English PHB articles which comprised 13 primary studies, including qualitative, quantitative, surveys, evaluations, and 7 items of grey literature (peer review, research summary, reports, and opinion papers). The evidence on PHBs remains limited and table 4, below provides a record of the articles reviewed.

Table 4: Record of Articles Appraised for the Realist Synthesis

No.	Author/ Year	Study	Aim	User Group/ Audience	Commissioner
1	Forder et al., (2012)	Quasi-experiment	Compared the experiences of PHB holder in a controlled trial	Chronic obstructive pulmonary disease, diabetes, long-term neurological conditions, mental health, stroke, patients eligible for NHS continuing health care	Department of Health
2	Jones et al., (2017)	Process evaluation	Study sought to infer key mechanisms of effect to see if implementation process had changed post pilot phase	Organisational representatives and 23 PHB holders (7 participated in pilot, 7 from roll-out and 9 had received budgets during evaluation)	Department of Health
3	Davidson et al., (2013)	Qualitative study	Explore the experience of receiving and using PHBs	Chronic obstructive pulmonary disease, diabetes, long-term neurological conditions, mental health, stroke, patients eligible for NHS continuing health care	Department of Health
4	Cattermole (2012)	Case study	Practice guide	Mental health and commissioners	Department of Health
5	Irvine et al., (2011)	Quasi-experiment	Looked at the early experiences of PHB holders and their representatives and used qualitative data - part of national evaluation pilot	Chronic obstructive pulmonary disease, diabetes, long-term neurological conditions, mental health, stroke, patients eligible for NHS	Department of Health
6	Jones et al., (2011)	Qualitative study	Focused on the PHB implementation process - semi structured interviews using a strand of the evaluation pilot.	Operational staff, health professionals, commissioning lead and third-party budget holders	Department of Health
7	Jones et al., (2010)	Evaluation – qualitative strand	Focused on the PHB implementation process used a strand of the evaluation pilot.	Organisational representatives	Department of Health
8	Jones et al., (2013)	Quasi-experiment	Compared the outcomes and related costs for those selected to receive PHBs and those in the control group who were continuing receiving conventional support - used quantitative data from the pilot	Chronic obstructive pulmonary disease, diabetes, long-term neurological conditions, mental health, stroke, patients eligible for NHS	Department of Health
9	Welch et al., (2013)	Evaluation - longitudinal	Controlled trial to compare the experiences of PHB holders and those using conventional substance misuse treatment support arrangements	People who have drug or alcohol addiction	Department of Health
10	Welch et al., (2016)	Qualitative study	20 semi-structured interviews – at two time points with 10 organisational representatives in substance misuse	Project leads/managers Commissioning managers, health professionals, support workers. Frontline operational staff who had assisted PHB implementation during the pilot	Department of Health
11	Hatton and Waters (2014)	POET survey practice-based information	Experiences of budget holders and carers (separately). 4000 individuals included 20 NHS organisations	Programme implementers, service users, policy makers, researchers	In Control and University of Lancaster

12	Alakeson (2014b)	Qualitative study	Provides insight into PHBs in Northamptonshire over a 5-year period - used data from the in-depth interviews with participants from one of the pilot sites in the evaluation	16 participants with mental health issues	Northamptonshire NHS Trust
13	Williams and Dickinson (2015)	Critical evaluation paper	To critique IBs and personalisation of healthcare in the English NHS system	Policy makers, researchers, and practice	University of Birmingham/ Melbourne
14	NHS Confederation (2015)	Policy briefing	Workshop consultation to find ways to allocate funding for PHBs within existing budgets	TLAP, Leaders and managers in clinical commissioning	NHS Confederation
15	Mathers et al., (2012)	Position paper	Offered caution and advocated for the outcomes from the pilot sites to be fully evaluated and discussed	Policy makers and programme implementers	Position statement from RCGP
16	Alakeson and Rumbold (2013)	Research summary	Reviewed evidence from evaluation and explored issues for commissioners and policy makers	Commissioners and policy makers	Nuffield Trust
17	Glasby et al., (2013)	Policy paper	Explores what comprises valid evidence for the future of PHBs	Healthcare professionals, researchers, and policy makers	University of Birmingham
18	Slasberg et al., (2014)	Peer reviewed paper.	Critically reviews the evidence used by government to justify the roll-out of PHBs	UK govt, healthcare systems implementing PHBs and policy makers.	Authors
19	Alakeson et al., (2016)	Peer review and vignettes	Extend the debate on the use of PHBs and their value in mental health services	Mental health	Policy Unit and the PHBs Advisory Group of the Royal College of Psychiatrists
20	Gadsby (2013)	Literature review	280 papers including evaluation reports, (n=9), accounts of empirical research, (n=29), comparative studies, (n=14)	Practice, researchers, and policy makers	Policy Research Unit in Commissioning and the Healthcare System

I used the following questions and only sought data relevant to the theory of how PHBs are supposed to work:

- What are the key assumptions about how PHBs will work?
- How are PHBs implemented?

- How are the budgets used by different groups of people?
- What are the outcomes?
- Which groups of people experience these outcomes?
- Which mechanisms and context were linked to these outcomes?

I extracted data from literature presented in Table 4 above with the full summary of appraisal of evidence included in appendix 7 on pages 375 – 385. Rycroft-Malone et al. (2012; 2015) suggested screening the evidence for relevance – to see if it contributes to theory building or testing – as well as rigour, i.e. the methods used to generate that piece of the evidence, including whether it is credible and trustworthy. This validation phase is often carried out by a team of researchers allowing extraction of theories by one team and then the theories validated by an independent team. Those that have used the approach have been more than one reviewer (Rycroft- Malone et al., 2012; Randell et al., 2014; Keen et al., 2019). I screened the evidence for relevance, although as a single researcher, there are limitations to what I could achieve with the available resources.

With any evidence synthesis, there are risks and limitations (Pawson, 2013) and my methods have certainly presented challenges of validating the programme theory. I had to work iteratively going back and forth many times to link the evidence to theories. I was able to interrogate the evidence to assess how far it supports the chains of reasoning in the programme (Rycroft-Malone et al., 2012; Pawson, 2013). Using the summary of appraisal of evidence and visual mapping of themes and CMOs in appendix 8 on page 386 and in appendix 9, page 387 , I organised the extracted data, developed themes and made inferences that link context, mechanisms, and outcomes in the logic of how PHBs are supposed to work (Randell et al., 2014).

3.5 Reporting of the Findings

My analysis enabled me to evaluate the evidence to see whether the programme theories were supported or undermined by the evidence. In the reviewed literature and the programme logics, PHBs are framed around giving people choice and control as an outcome as well as an intermediate factor in helping people to achieve broader outcomes such as improved health or reduced costs. For example, Alakeson (2014b) suggests choice and control will create a patient centred NHS that supports people to improve their own health and well-being. Similarly, Davidson et al. (2013) framed choice and control as leading to improved physical health in mental health, while others concluded having choice and control through a PHB enabled people to improve more complex and higher aspects of their quality of life (Forder et al., 2012; Jones et al., 2017).

Following on from the above arguments, I focused on those aspects of the programme theories which were relevant to choice and control (Pawson, 2013). I followed Rycroft-Malone and colleagues' (2012) advice that a researcher has the flexibility to decide on which programme theories and key elements of those theories to explore in-depth.   I drew on the themes presented in Table 2, pages 60 – 63, and Fig 3, page 72, in my analysis which I modified as required until I was able to make connections in the logics.

It was apparent from looking across the logic statements in Table 2, that the programme theories were located at different levels of the NHS: institutional, organisational, and the individual level, hereafter termed macro, meso, and micro levels. What was also evident in the literature was that what happens on the macro level potentially could affect outcomes at the meso and micro level and vice versa. For example, inadequate funding in the NHS may result in the rationing of the PHBs implicitly or explicitly for the individual. I, therefore needed to ensure that the logic framework incorporated the interaction of these different levels of the programme theories. As such the data extraction process paid attention to the context, mechanism, and outcome (CMO) aspects that were found at the different levels of the NHS:

- Macro level: these are CMOs at the institutional level (i.e., the whole NHS) leading to improvements at population level.
- Meso level: these are CMOs linked to interactions at organisational level (e.g., the CCG).
- Micro level: CMOs at the individual PHB holder level

These three levels are presented in Fig. 3 below along with the themes that emerged through the literature synthesis, discussed in more detail below.

Fig 3. PHBs Programme Logic Framework

	Context	+	Mechanism	=	Outcome
Macro - system level	• Ability of the system to respond to the changes that PHBs require		• Financing healthcare in a sustainable way		• Improved outcomes and quality of life for patients • Reduced use of acute services and institutional care • More efficient use of resources
Meso - organisation level	• Knowledge and skills to support PHBs • Culture and attitudes that may hinder PHB • Funding for PHBs and competing local priorities • Bureaucratic structures and systems		• Develop provider market • Implementation process that supports PHBs • Co-production • Transparent allocation of funding • Changes in commissioning		• Better use of services and resources • Person centred and holistic approaches to healthcare service provision • Improved quality in provision
Micro - individual level	• Being your own care manager • Dynamics of power • Implementation process		• Management options • Decision making • Access to resources • Care and support planning • Information and support		• Perceived choice and control • Improved patient experiences • Improved health and wellbeing outcomes • Better management of long-term conditions

It was useful to set out the logic framework at the macro, meso and micro levels and identify how they were inter-related. However, given that my focus was on experiences of choice and control, it became clear that the most appropriate focus for my study was the micro level of individual experiences and decision-making. It was here that choice and control came to be operationalised and meaningful for budget-holders. Hence, I focused attention on the micro-level CMOs, and not on the CMOs for the macro and meso level. Although the institutional and organisational levels are relevant for understanding the individual experiences (and I return to them later in the thesis), they were of second order interest for my programme theory development. That is not to say the macro and meso levels of analysis are being neglected. Pawson and Tilley (1997) highlighted how interrelated the three levels are in complex and dynamic systems, and in developing the programme theories through the cases in later chapters it is even more clear that individual experiences can only be understood in the context of organisations and institutions.

3.5.1 Dealing With the Conceptual Ambiguity in the Literature

The complex and paradoxical nature of choice and control has continued to overshadow policy debates and to loom over the available evidence, with choice and control being framed as an outcome as well as an intermediate factor in helping people to achieve broader outcomes. The processes involved in my analysis reflect this complexity, and the broader conceptual messiness found in the literature, in which there was slippage between what was considered a context, a mechanism and an outcome. Opening the 'black box' meant dealing with that messiness. This involved refining and consolidating themes to identify a clearer programme logic that could be used within this study. I had to interact with the evidence iteratively as explained earlier given those limitations (Wong et al., 2013) and develop themes that would guide me as a thread through the available evidence (Rycroft-Malone et al., 2014, Keen et al., 2019).

This synthesis evaluates the claims presented in the logic statements in Table 2 on pages 60-63, and identifies the link between context, mechanisms, and outcomes (reflected in Fig 3. page 72 above) to explicitly articulate the initial programme theories as presented in Table 5, on page 97 of this chapter. Through this I identify the components of the PHB programme that are expected to bring the desired change. The focus is on making the elements (context, mechanism, outcome) more explicit ahead of testing the different workings of the programme theory in the empirical chapters that follow.

3.5.3 Context

Following the realist logic, I explored the contextual factors necessary for the propositions stated in the logic statements in Table 2 (pages 60-63). The overarching contextual factors that the literature indicates are supposed to interact with mechanisms to bring the expected outcomes are listed below and discussed in more detail:

- PHBs and their fit with the NHS
- Culture of the organisation
- Infrastructure and resources
- Budget holder capability

PHBs and Their Fit With the NHS

The first contextual factor is the extent to which PHBs can fit into the NHS. According to the logic statements presented in Table 2, pages 60-63, there are concerns that PHBs will disrupt the principles on which the NHS is built. That is, to meet the needs of everyone, free at point of delivery with provision based on clinical need not ability to pay, and that the NHS should 'operate fairly, effectively and use the resources sustainably' (NHS Constitution updated version, 2015). Introducing PHBs can be viewed as threatening those values because PHBs allow individual choice and control in a collective system that has always pooled risk and considered equity and equality (Slasberg et al., 2014; Williams and Dickinson, 2015). The NHS principles can work well when offering block contracts of interventions based on cost effectiveness and fair resource allocation (Slasberg et al., 2014). Unlike other commodities, health cannot be divided neatly into individual allocations (Williams and Dickinson, 2015). The claim that PHBs threaten the founding principles is based on a logic that PHBs turn patients into consumers enabling individual purchasing outside the NHS according to their needs and preferences (Jones et al., 2017). This may include some treatments that are not evidence based and whose therapeutic value maybe questionable to meet their needs (Forder et al., 2012; Mathers et al., 2012; Jones et al., 2017) which is a departure from how NHS treatments are provided, based on best evidence through NICE Guidelines (Irvine et al., 2011).

Advancing individual choice and control can be perceived as giving preference to individual wants rather than needs. For example, during the national pilot, people purchased items with their PHBs that may be considered a luxury such as gym membership, beauty treatments, mobile phones, and gardeners (Irvine et al., 2011). Such use of scarce resources may have therapeutic value to the PHB holders but be controversial when the body of evidence surrounding the use of PHBs has remained questionable (Slasberg et al., 2014).

In the ‘rival theories’ presented with the logic statements there are points that suggest healthcare is not like other commodities in the market (Williams and Dickinson, 2015) and people will make ill-informed decisions, and impact negatively on health and wellbeing outcomes and increase inequalities (Mathers et al., 2012). There are theoretical arguments that PHBs will identify greater needs than the level of resources available making it difficult to prioritise individual needs against local priorities therefore increasing inequalities (Slasberg et al., 2014). There are some insights into how PHBs may be increasing inequalities. From the pilot studies, there were 6 patient groups that were offered PHBs, and the findings concluded that PHBs offered better outcomes to people who had high value packages, those receiving CHC and users of mental health services (Forder et al., 2012). As a result, in the roll-out programme the right to PHBs was given to some groups, for instance continuing health care, mental health etc., but not all the groups that had participated in the pilot scheme. In some CCGs those who had long-term conditions and had held PHBs during the pilot had their eligibility withdrawn because funding was no longer available (Jones et al., 2017).

Culture of the Organisation

The second contextual factor relates to the culture of NHS organisations and the extent to which PHBs can deliver culture change. The logic statements suggest that PHBs will generate pressures for cultural change in the NHS, away from a ‘one size fits all’. PHBs acknowledge lay forms of knowledge and expertise and promote greater choice and control in decision-making for service users and this is expected to bring transformational change into the NHS (DH, 2009). In this context, PHBs are seen as a solution to the challenges facing the NHS by enabling people to have more say in how their care is provided (Duffy, 2010a). The presumption is that with the money people can buy services that are conveniently tailored around their needs and preferences because they will be consumers and can decide what is best for them. The argument is that people can decide the service they want or find alternative ways if not satisfied with the quality, driving out inefficiencies and inviting changes in the way current provisions work (Alakeson, 2014b). However, the extent to which individual choice and control will achieve this culture change is not clear in the existing literature.

The national evaluation pilot indicated that PHBs were implemented differently across organisations (Forder et al., 2012). There were delays in implementation during the national evaluation pilot with some organisations claiming that PHBs did not fit with existing ways of working (Jones et al., 2013). These findings bear similarities to social care budget implementation that took time to be embedded in local service systems (Gadsby, 2013). The PHB pilot evaluation found that attention to the structures that created the context in which choice and control must operate was an important element for implementing PHBs and achieving culture change (Forder et al., 2012). Evidence from the substance misuse study which used a small sample from the in-depth pilot sites offered some insights which suggests a closer relationship with professionals can be fostered by having a PHB. The participants in the study felt empowered and as equals in the relationship because they were listened to, given more time, and understood better while professionals acknowledged the potential of PHBs to neutralise the power base professionals had on people's journeys to recovery (Welch, 2013; 2016).

Infrastructure and Resourcing

The third contextual factor is around the resourcing of the NHS and the extent to which there is an adequate infrastructure to support implementation. With the current financial climate, there may be funding constraints to support the level of change required by the PHBs, for instance changing the way healthcare services are purchased, organised, and provided (Slasberg et al., 2014; NHS Confederation, 2015). For example, CCGs are expected to increase the number of PHB holders, ensure everyone who is eligible has access to appropriate care and support, while CCGs continue to meet population needs, improve the quality of services, and remain clinically and financially sustainable (NHS England, 2014). This has the potential to put high demands and pressure for managing scarce resources in an already restricted environment which will make PHBs less of a priority (TLAP, 2017).

Responding to the unique context of the individual versus population needs in a system that commissions a range of services at the beginning of the year through block contracts might be problematic (Slasberg et al., 2014). In the pilot programme, extra funding was made available to enable people to be offered PHBs (Forder et al., 2012) which was not the case in the roll-out (Alakeson et al., 2016). Delivering PHBs without sufficient levels of resources and infrastructure risks limiting choice and control for people and not bringing the best health and well-being outcomes (Alakeson, 2014b). Questions have continued with regards to whether the NHS will be able to support and sustain the innovative and flexible approach of PHBs for the different groups of people over the long-term (Slasberg et al., 2014). Calls have been made for effective implementation to guarantee efficiencies (Alakeson and Rumbold 2013; Alakeson et al., 2016; NHS Confederation, 2015; Jones et al., 2017).

There is consensus in the literature that PHBs can improve outcomes for people, but this will be dependent on having a supportive environment, e.g. availability of provider markets, training, information, and support for the workforce (Forder et al., 2012; Jones et al., 2011; 2017; Alakeson et al., 2016). Others argue that PHBs for CHC packages may not present challenges in funding because the packages are commissioned on an individual basis. However, people with complex healthcare needs have conditions unique to the individual that can fluctuate and might be difficult to predict, which raises problems if the budget is fixed (Alakeson and Rumbold, 2013). There is acknowledgement that the expansion of PHBs to other groups will be problematic because the monies are usually tied up in block contracts (Alakeson and Rumbold 2013). A further argument has been about resources being tied up in acute services and the challenge of freeing up those resources to accommodate PHBs (Slasberg et al., 2014). The evidence continues to show that the uptake of PHBs remains low, making it difficult to realise economies of scale and rationalise developing new innovative markets for PHBs among service providers (Jones et al., 2017). This has led to calls for PHBs that integrate health and social care as a potential for streamlining processes such as referrals, assessments, planning and systems of allocating resources (Forder et al., 2012; Alakeson and Rumbold 2013).

Budget Holder Capability

The fourth contextual factor relates to the capabilities of PHB holders. An assumption made in the logic statements is that offering choice and control through PHBs will make the financial aspect of healthcare more explicit at the individual level and they can decide the most appropriate services to purchase and improve their health and wellbeing outcomes. One must meet the eligibility criteria set out in the national framework (DH, 2018) to have a 'right to' PHBs (NHS England, 2014a). The policy documents – *Guidance on the legal rights to have a PHB* (NHS England, 2014a revised 2019) and the mandate from government to NHS England (DH, 2014; DH and Social Care, 2019) to CCGs – set out the essential features for setting PHBs that should be followed by professionals in agreement with PHB holders. For example, the budget holder must decide how to manage the budget in a way that makes sense as agreed in the care plan. The budget holder can choose one of three deployment options: direct payment, notional budget, or third-party option, depending on level of responsibility, accountability and risks they are willing to take (NHS England, 2014a revised 2019). The evidence so far suggests real choice and control was achieved by those who chose to use a direct payment and could make informed decisions, articulate their needs, and self-manage their health and care (Jones et al., 2017).

Embedded in this policy guidance is the assumption that people possess the skills and knowledge to make informed decisions on matters of health and will be able to choose services they feel will improve their health and well-being outcomes. Evidence from the pilot experiences indicated that both professionals and PHB holders were anxious or apprehensive about the process and while there was some creativity and innovation with the PHBs, many people continued to access services they were already purchasing through mainstream provision (Jones et al 2010; Irvine et al 2011; Davidson et al., 2013).

While some people may be able to self-direct their care, a continued theme across the literature is that people will need support from professionals, brokers, or peers to be able to manage PHBs (Forder et al., 2012; Alakeson, 2014b; Hatton and Waters, 2014; Welch et al 2013; 2016; Jones et al., 2017). In Control (2017) advocated a whole family approach when implementing PHBs, given that people with complex healthcare needs and other qualifying conditions often depend on their family or carers for support.

3.5.4 Mechanisms

This section discusses the mechanisms that shape the ability of individual PHB holders to exercise choice and control in the different contexts. In this section, the following mechanisms are relevant to understanding how PHBs are expected to get the intended outcomes:

- access to resources
- shared decision-making
- implementing the care and support plan
- managing the budget
- information and support
- professional power

Access to Resources

The mechanism ‘access to resources’ was related to service eligibility, value of the budget, management options, what people were allowed to buy and being able to find the services to purchase with the money. The assumptions are that by giving individuals an upfront allocation of the money, it gives them flexibility to be more innovative and creative in how the money is spent, and they can tailor care exactly to their needs and preference. Not only should people have an upfront allocation, according to the policy guidance, the process of calculating the indicative budget must be transparent and all PHB holders should know how their budgets were calculated (NHS England, 2014b). The logic is that because people hold the purse, they will have more say over how the budget is managed, they can decide which services and providers to use, increasing competition amongst providers and driving-up quality (DH, 2012; Alakeson, 2014a). Services will be responsive to individual needs and people will be aware of the costs of healthcare, and it is likely to be a more effective way of using resources to improve health and wellbeing outcomes for people (DH, 2012c). Having the money allocated upfront in the form of an indicative budget should make individuals aware of how much they must spend and enable them to plan their care knowing exactly what they can or cannot afford (NHS England, 2014a). Therefore, this was an important mechanism for planning and setting the outcomes people wanted to achieve with the PHB, bringing greater awareness of the cost of healthcare (DH, 2012).

Evidence from the pilot and evaluation showed that there was a significant number of PHB holders who did not know the value of their PHBs upfront, whether it was adequate or was sufficient money to pay for future needs, and how it had been set (Jones et al., 2010; Irvine et al., 2011; Davidson et al., 2013; Alakeson, 2014b). Also, various methods were being used, for example one-off payments, based on existing budgets, and based on need. Reflecting on those methods, Alakeson and Rumbold (2013) found that allocating the budget based on need was best while the one-off payment was regarded as unsustainable. In the roll-out programme, from those who were interviewed, the majority had known upfront the value of their budget, but not how it had been calculated and the resource allocation system (RAS) that had been used (Jones et al., 2017). Some organisation leads thought the RAS was complex and an unnecessary process because PHBs were not about saving money but providing the best quality care tailored to individual needs (Jones et al., 2017). Slasberg and colleagues (2014) also found, based on the available evidence, that the RAS process was complex and not reliable.

Another important aspect to choice and control in regard to access to resources is what people are able to purchase with the money to improve their health and wellbeing. The available evidence has so far highlighted that PHBs were implemented differently during the pilot phase with some areas encouraging creativity, innovation, and flexibility over what could be purchased, the value of budgets being generous enough, while others offered tight budgets and less flexibility. Also, people purchased a range of non-traditional items including electronic gadgets, outdoor activities, and complementary therapies (Davidson et al., 2013; Forder et al., 2012; Jones et al., 2013). During the roll-out phase from 2014, CCGs were getting tighter in the way they allocated funding for PHBs, and there were reports of less flexibility with some items such as complementary therapy no longer allowed (Jones et al., 2017). Eligibility criteria were also raised making it impossible for some to remain PHB holders (Jones et al., 2017). Those that reported greater flexibility related it to having continuity of care because of directly employing PAs rather than receiving care provided by agencies. In such cases, it was the act of holding a budget which was considered empowering for many (Forder et al., 2012; Jones et al., 2017; TLAP 2017).

Having access to services that one can choose from is equally important if the theoretical assumptions behind the intervention are to work. For instance, many people with complex healthcare needs require a high-level support package. Needing 24-hour care and managing their own care may require employing and managing several staff who are appropriately trained alongside using an agency as a contingency (NHS Choice, 2015). Evidence from the pilot showed that many people were purchasing services they were already getting through conventional methods (Forder et al., 2012). Similarly, evidence from the roll-out indicated that such trends of continuity in purchasing continued and attributed this to lack of choice of providers in the market (Jones et al., 2017).

Another logic statement underpinning the PHB policy is that having choice and control will stimulate the market to provide services that people want and drive out those services that are not required (DH, 2009). In theory this should increase competition and improve the quality of services. However, the logic assumptions are not supported by the evidence available so far. There is an acknowledgement that the current market of providers is not able to effectively accommodate the diverse needs of individual PHB holders (Slasberg et al., 2014; NHS Confederation, 2015; Alakeson et al., 2016). The findings from the national evaluation pilot highlighted challenges faced by PHB holders such as PA recruitment, staff retention and lack of skills (Forder et al., 2012). Those challenges have continued in the roll-out programme and the existing gap in the market of service providers for PAs may increase for people with complex healthcare needs who need specialised support (Jones et al., 2017).

Shared Decision-Making

The mechanism of shared decision- making was seen as important in stimulating the move to PHBs, although there were some differences in opinion as to what constituted shared decisions. There is support from a policy perspective for theoretical arguments for user involvement in decisions-making about health and other aspects of life in general (DH, 2012; NHS England, 2014c). The assumptions are that PHB will enable partnerships through collaborative working because individuals will be more involved in the decision-making not just about treatment options but on broader health and well-being goals (Alakeson, 2014 a). PHBs draw on co-production principles and aim to make budget holders active participants rather than being passive recipients of care (DH, 2012a). Following this logic, people are then seen as contributors with an equal say in matters of health and wellbeing.

Such assumptions can work when there is willingness from professionals and PHB holders to work collaboratively with each other, recognising the expertise that each bring into the process (Alakeson, 2014a). Views are mixed and available evidence is limited, for instance in the pilot and evaluation, some budget-holders found it useful to discuss their needs, goals, and preferences with professional and appreciated being included in the conversations. However, there were others who did not recall getting involved in that manner (Forder et al., 2012). The evidence from mental health PHBs suggested that while PHBs allowed recovery to take place, the relationship with professionals was embedded in a culture that was not changing to facilitate sharing of power (Alakeson, 2014b). Others have shown the potential that PHBs hold for shared decision-making through the care and support plan – for example in substance misuse where both clinician and the budget holder were able to identify the best treatment and agree on the best option to manage the health condition (Welch et al., 2013). Indeed, PHBs can go beyond facilitating joint working between patients and clinicians to create opportunities for self-help, for example in mental health (Alakeson, 2014b).

Implementing the Care and Support Plan

Developing a care and support plan is a key mechanism in PHB implementation (DH, 2012a; Alakeson, 2014a). Everyone should have a care and support plan that considers their needs, strength, and skills, as well as their social context with regards to what is important to them and want to achieve (Alakeson, 2014a). A good care and support plan needs to address the outcomes, value of the budget and how the money is going to be used to meet the assessed needs and agree on outcomes related to health and wellbeing (NHS England, 2014a revised 2019). Through development of the plan, needs can be fully identified, and care and support tailored to individual needs therefore enabling better outcomes, patient satisfaction and better management of health conditions.

The available evidence indicates that the care and support plan is a vital tool for identifying needs and setting goals about what individuals want to achieve with a PHB. Glasby and colleagues (2013) put forward theoretical arguments suggesting PHBs enable needs to be tailored beyond symptoms management to address wider aspect of a person's life, therefore people can have something that is truly personal and fundamental to a quality service. However, people were not always included in the planning process. Those that were involved, reported more positive outcomes (Forder et al., 2012; Hatton and Waters, 2014; Jones et al., 2017). The evidence also suggests that some groups of service users found the planning process difficult (Hatton and Waters, 2014). There was variation across organisations with some care and support plans approved very quickly while others had lengthy processes and lacked clarity over the items that were allowable, which caused frustration, distress, and anger because the same items were considered appropriate in other areas (Forder et al., 2012). There were mixed views in the roll-out programme: some participants considered their care and support planning experience to be holistic. However, others felt it was confusing and detached, health practitioners were ill-informed to support the process, lacked rapport and only focused on a single clinical outcome rather than overall health and wellbeing (Jones et al., 2017).

Managing the Budget

Following the support planning process, individuals are allocated a budget to manage, and this management process is another mechanism affecting PHB implementation. The assumption is that PHBs will make the financial aspect of healthcare more explicit at the individual level, people will have more say and this puts a duty on the individual to identify and potentially source the most appropriate services (DH, 2009; 2012b). Involving people in managing their own health and care, will help in staying well and can minimise the use of services (DH, 2012b). Furthermore, PHBs can enable full engagement of patients in their own health and healthcare, so they can shape the nature of services they receive directly (NHS England, 2014a). In that respect, the logic is that budget holders will self-direct their care, and are willing to take responsibility, accountability, and the associated risks. Through self-direction, this will result in effective management of long-term conditions and people will have more say in how the budget is managed.

Findings from the pilot evaluation and other studies indicated that only a minority of budget holders had a choice of how to manage the budget. The direct payment was not a possible option for some groups of patients, yet only some recalled being told there were third-party and notional budgets available (Irvine et al., 2011; Forder et al., 2012; Davidson et al., 2013; Alakeson et al., 2016; Welch et al., 2016). In the guidance, CCGs have the discretion to deny access to direct payments to those they feel will not benefit (NHS England, 2014a revised 2019). The logic is based on a report that used vignettes to explore the third-party option. The report highlighted that there is limited understanding of the value of the approach, but it had the capability to offer less responsibility, stress and had fewer risks than direct payments (DH, 2012). However, evidence from the pilot evaluation reported greater risks of delays in procuring goods and services associated with third-party options and notional budgets (Forder et al., 2012).

In the roll-out study by Jones et al., (2017), many of the participants were using direct payments with a few having a third-party or notional budgets options. Most of those who had direct payments transitioned from social care with their PAs, employed family members or friends and they reported that the direct payment route allowed them to employ their own staff and purchase items not offered in the NHS (Jones et al., 2017). Overall, the evidence suggests direct payments offer more choice and control, better health, and wellbeing compared to third party or notional budgets (Forder et al., 2012; Jones et al., 2017).

One of the rival framings presented in Table 2, pages 60-63, is that offering choice and control through a PHBs will transfer risks from the NHS and will increase the burden of responsibility and accountability on the service user. Much of the increased responsibility and accountability identified in the PHBs literature is associated with the direct payment deployment option, with regards to managing care and support (Forder et al., 2012; Alakeson, 2014b). Budget holders must manage administrative task such as procurement issues, quality assurance and tasks associated with day-to-day management of their condition and lifestyle. They may also take on the legal responsibility of being an employer. While there is support available for financial management, employer responsibility and payroll administration, the responsibility, accountability, and risk still remain for PHB holders (NHS England, 2014c). Evidence from the roll-out highlighted the transactional costs associated with doing some of these tasks. For instance, the participants reported that the direct payment was associated with administrative burdens, greater stress, anxiety, and uncertainty. The perception from the participants was that direct payments worked best for people who had coping skills, were assertive and had managerial experience (Jones et al., 2017).

Information and Support

The provision of information and support is seen as a critical mechanism for PHBs to promote choice and control (Forder et al., 2012). As part of the guidance on the implementation process, NHS England (2014a revised 2019) stressed the importance of including information, advice, and support as part of the infrastructure for PHBs. The logic is that, with access to information and support, budget holders will be fully informed in their decision and choice making and more empowered to manage their conditions. However, information and support are currently not readily available to PHB holders (Jones et al., 2017). The PHB pilot evaluation demonstrated that access to the right information was critical, and during the pilot, those that had received information were more satisfied with their PHBs than those that had not had access to information (Forder et al., 2012).

The pilot evaluation also highlighted that many of the participants also valued on-going support from professionals, independent brokers, and peers, not just at the initial care and support planning stage (Forder et al., 2012). The participants in the roll-out programme also expressed the importance of ongoing support to manage the budgets and frustration due to lack of support that was available (Jones et al.,2017). Those that had participated in the pilot indicated that support had reduced, and they still needed information and guidance to help them understand the changing context of PHBs as to what was acceptable and legal to purchase. Those that were new to PHBs felt the information provided was not always helpful because it was hard to read and overwhelming (Jones et al., 2017).

Professional Power

Frontline workers and managers are a key mechanism shaping if and how PHBs can deliver choice and control (Forder et al., 2012). The logic underpinning PHBs is that they will transform patients into consumers rather than passive recipients, challenging the norms of expertise and authority where professionals have been the primary decision makers and patients are passive recipients of care (DH, 2009; Duffy, 2010a). PHBs by their nature are considered a disruptive innovation that challenge the hierarchical structures and paternalism in the NHS, especially the patient-clinician power relationship (Glasby, 2013). Professional power is therefore seen as another key mechanism that expands or limits the choice and control that people could derive from using PHBs.

The expectation is that professionals will support service users with their PHBs (NHS England, 2014a), although there is a paradox at work here. Frontline professionals with knowledge and skills to support the implementation process of PHBs are regarded as an important facilitating mechanism (Forder et al., 2012). However, on the other hand, PHBs are supposed to challenge paternalistic tendencies of professionals and act as a disruptor in the system (DH, 2016). Such conflicting message can cause difficulties of translating the values of PHBs into frontline priorities and practice. Evidence suggests a lack of buy-in to the PHB programme among professionals during implementation, aside from those directly involved with the pilot (Forder et al., 2012; Jones et al., 2011). Evidence from the roll-out suggests those attitudes are still very present (Jones et al., 2017).

Evaluations of the early experience of PHBs showed that there were reports of delays in sign-offs, lengthy paperwork and less flexibility, highlighting gatekeeping behaviours amongst professionals (Jones et al., 2010; Irvine et al., 2011., Davidson et al., 2012). In one of the national evaluation pilot sites, professionals found it difficult to trust people to manage their budgets in case they had a relapse (Alakeson et al., 2016). The findings mirror evidence from research with people with drug/alcohol misuse in which PHBs were not offered as direct payments because it was considered they may increase risks (Welch et al., 2013). The evidence available from the roll-out suggests professionals continue to have a considerable degree of control over people's day-to-day lives by imposing arbitrary spending limits on care and support and restricting how money is used (Jones et al., 2017)

While PHB are supposed to encourage partnership working there are also concerns that they conflict with the way the duties of clinicians have always been carried out in the NHS such as recommending best clinical evidence and practice (Alakeson et al., 2016). Allowing individuals to choose complementary therapies that are unproven or a holiday instead of respite services may have risks and causes dilemmas for clinicians on whether to allow these choices (Alakeson et al., 2016). Evidence from the national evaluation pilot demonstrated that people were purchasing conventional (physiotherapy, speech therapy, sanitary pads etc.) and non-conventional treatments (acupuncture, reiki, gym membership, Chinese medicines, amongst others) (Forder et al. 2012). However, there was some evidence to suggest some of the requests were being refused. The PHB holders perceived that the items requested were declined because they were not seen as adequately health related or because of the risks they posed (Davidson et al., 2013). Staff attitudes and professional culture were perceived to influence judgements about who should use PHBs, for example when they moved from acute services to primary care in mental health, thereby limiting choice and control for people who otherwise could benefit (Alakeson, 2014b). By the time of the roll-out evaluation, PHB clinical leads and commissioners reported that the culture and perceptions around PHBs were changing but very slowly (Jones et al., 2017).

3.5.5 Outcomes

A consistent message that emerged from the literature review was the potential that PHBs hold to improve outcomes for some people, but only if the context is favourable. The study conducted by Jones et al., (2017) indicated that implementation conditions and policy context had changed and was no longer as favourable to PHBs during the roll-out phase. This highlights that context matters and the changing context could have real implication for PHB outcomes long-term.

The review highlighted the lack of studies that paid attention to the micro-level workings or studies with in-depth and longitudinal perspective. While the studies were able to tell us of the opportunities presented by PHBs little is known about how effective PHBs are in supporting choice and control for people with complex healthcare needs. Furthermore, the review highlighted the need for research that provides explanations of how PHBs work, why they may work or not, for whom and under what circumstances. There is a clear need for work which enables in-depth and longitudinal examination of context, mechanism, and outcome (CMO) – in particular looking at how they influence change at the micro level, i.e., for the individual holding a PHB.

There is insufficient evidence on whether PHBs as an innovation have an impact on health-related outcomes (Forder et al., 2012; Gadsby, 2013; Jones et al., 2017). The evidence from the pilot and evaluation suggests that those who had PHBs had better outcome with regards to care related quality of life measured through the Adult Social Care Outcomes Toolkit - ASCOT - and on psychological well-being measured through the General Health Questionnaire - GHQ-12 (Forder et al., 2012). Concerns remain amongst professionals and some academics on whether PHBs will have widespread, inclusive positive outcomes, improve cost effectiveness and be sustainable (Mathers et al., 2012; Gadsby, 2013; Slasberg et al., 2014).

This research is focused on the question, 'are personal health budgets delivering choice and control for people with complex healthcare needs?' The focus of the study is on choice and control as an outcome, whilst recognising that choice and control could be framed as a mechanism to achieve broader outcomes such as better health or wellbeing. In the logic statements in Table 2, pages 60-63, there are explicit and implicit theories suggesting that offering choice through a PHB will result in improved health outcomes, better management of conditions and therefore people will stay well, minimising use of critical care, which is more cost effective. There are assumptions that PHBs will drive competition because people will be able to purchase services they consider most appropriate thereby improving quality.

However, there is limited evidence related to these health and wellbeing outcomes to support these assumptions. The national evaluation did not report any improvement on health or clinical outcomes for PHB holders (Forder et al., 2012; Jones et al., 2017). Evidence showed that much of the improvement in the participants' quality of life and well-being was attributed to increased choice and control itself (Irvine et al., 2011). Offering choice and control through a PHBs was associated with significant improvement in patients' care-related quality of life and psychological wellbeing outcomes at 12 months (Forder et al., 2012). Likewise in another evaluation, choice and control was important as a PHB outcomes (Davidson et al., 2013). Consistent with the previous national pilot programme, the roll-out evaluation found that giving people greater choice and control was empowering (Jones et al. 2017),

Thus, choice and control can be understood as one of the outcomes of PHBs rather than only a means to achieving other goals. The operation of contexts and mechanisms will shape the extent to which people can exercise choice and control through PHBs. This was a common insight across the literature, although what was meant by the terms choice and control was often left undefined (Forder et al., 2012; Gadsby, 2013; Alakeson & Rumbold, 2013; Glasby et al., 2013; Hatton and Waters 2014; Slasberg et al., 2014; NHS Confederation, 2015; Welch et al., 2016; Jones et al., 2017). There is a clear need for work which unpacks the concepts of choice and control in the lives of PHB holders in the way that follows in later chapters of this thesis.

Initial Programme Theory

I began this chapter with broad assumptions which Pawson (2013) termed 'rough initial programme theories' which needed to be articulated and refined for testing. I also set out to identify from the evidence what context and mechanisms are supposed to deliver choice and control as an outcome of PHBs. In the discussion above, I set out the approach I took to my data analysis, the connections, explanations, and inferences I made, along with rationale for some of the pragmatic decisions I made with regards to what parts of the analysis were useful where, and why. PHBs are complex and contain many interacting elements, making opening the ‘black box’ very challenging. I brought out how the components of the PHB programme are supposed to work and in what context, to bring the desired outcome of choice and control. Having explored the logic statements and the CMOs considering the evidence, here in Table 5 below, I provide a summary of the initial programme theories that I will be testing in this study.

As stated earlier, I was particularly concerned with the claims made around choice and control given that my research question is ‘are personal health budgets delivering choice and control for people with complex healthcare needs?’ This led me to taking only some parts of the programme theory that were testable through a focus on the experiences of PHB holders and setting aside those that I felt could not be tested through the lens of individual experiences. From the logic statements in Table 2, pages 60-63, the themes set out in Fig. 3 page 72, and the evidence discussed here, I distilled three programme theories (CMO configurations) that seemed to be particularly relevant to the issue of individual choice and control. These were: access to resources; shared decision making; and professional power. Table 5 below set outs each of these CMOs to show how PHBs are supposed to work, why, for whom and in what context, to bring the desired outcome of choice and control. Where I also found evidence in the literature for a rival programme theory, this is also presented in the table.

Table 5. Initial Programme Theory from the Realist Synthesis

Theory	*Initial Programme theory*
Access to resources	PHBs make the financial aspect of healthcare more explicit at the individual level **(C)**, assigning people a budget **(M)**, and enabling people to have choice and control of the financial resources to purchase the most appropriate services to improve their health and wellbeing **(O)**
	Rival Framing of Theory
	The lack of flexibility in the PHBs process **(C)** increases bureaucracy associated with administrative tasks and transactional cost of managing the budget **(M)** thereby making choice and control a burden on budget holders **(O)**
Shared Decision-Making	Budget holders bring their expert knowledge of living with the condition and professionals bring evidence-based practice, information, and support **(C)**. Budget holders and professionals work collaboratively and in partnership **(M)** to implement care and support plans that are person centred and holistic and enable ongoing choice and control **(O).**
Professional Power	Some of the challenges of professional dominance in the NHS **(C)** can be addressed by shared decision-making **(M)** through which service users gain more choice and control **(O)**

3.6 Chapter Summary

I took a pragmatic approach to literature reviewing to overcome the challenges presented by the quality and variety of literature on PHBs. I used a realist synthesis following Pawson's (2006) five steps as shown in Fig 1. page 46, in line with other researchers who have used this method to synthesise evidence (Rycroft-Malone et al., 2012, 2014; Greenhalgh et al., 2013). I followed what Pawson (2013) termed 'initial rough programme theories' which were assumptions from policy documents and academic debates etc. on PHB implementation in the English NHS. Synthesising the evidence through an iterative process allowed me to review the evidence systematically. That way, I was able to cope with the variety and quality of the evidence. This approach of refinement through the CMOs as illustrated above helped to refine the initial rough programme theories and the development of key themes.

Consistently, throughout the literature a key message that emerged was the potential that PHBs hold to offer greater choice and control. However still little is known about how effective PHBs are in supporting choice and control for people with complex healthcare needs. The synthesis also explored the overarching contextual factors that were directly linked to choice and control offered by PHB and explored these contexts in more detail against the claims made in the propositions to see if they were supported by the available evidence. Furthermore, the review discussed the influences on individual behaviour that are expected to promote choice and control within the different contexts. There was no consensus as to what constitute choice and control and following examination of evidence, I considered ‘choice and control’ to be an outcome pattern derived from the interactions of contexts and mechanisms in PHBs implementation.

The synthesis highlighted that there is limited evidence available on PHBs and many questions remain unanswered (Gadsby, 2013; Jones et al., 2017). The reviewed literature accentuated that context matters and the changing context following roll-out of PHBs, does not have the same impacts which were observed in the national pilot. The review drew attention to the need for research that enables in-depth and long-term exploration of PHBs. It also highlighted the need for evaluative research to help our understanding of how PHBs work, why, for whom and under what circumstances. The use of an ethnographic case study underpinned by realist evaluation was chosen as a method that would overcome some of these shortcomings.

The realist synthesis enabled the development of the initial programme theory and provides a focus for the later chapters. At this stage, there was articulation of assumptions and ideas (theories) that informed the PHB programme (Pawson & Tilley,1997). The realist synthesis provided the foundations for the research design, methodology and testing of the initial programme theory with empirical work. I also discussed the challenges of doing realist analysis as a single researcher, and the pragmatic approach I took to overcome some of those challenges. The approach enabled me to develop theoretical understanding of how the programme is supposed to work thereby allowing themes to be linked to a chain of inferences, as well as decide which programme theories and key elements of those theories I could explore in-depth. As such I have been able to refine the programme theory of how PHBs are supposed to work to deliver choice and control, which I will be exploring further using empirical work.

Chapter 4: Research Methods and Methodology

The evidence presented in chapter three, has demonstrated that PHBs are a relatively new initiative and there is a dearth of evidence especially with a focus on people with complex healthcare needs. There is also paucity of empirical work that gives us a long-term perspectives and in-depth analysis of using PHBs. The contribution of this thesis is to fill that gap.

Having established this gap in the previous chapter, here I present a methodological discussion, description of my research design, strategy and methods used for data collection and analysis. The study was evaluative research, and it was concerned with PHB implementation at the micro-level. It explored the lived experience of managing a PHB on a day-to-day basis from the PHB holders' perspective, how people with complex healthcare needs exercised choice and control over the budget. This could only be obtained through interaction with participants and called for a qualitative design that was flexible and able to accommodate the complexity of PHBs. Therefore, the methodology and methods being described in this chapter, played an important role in discerning some of the salient features of the landscape emerging from the PHB intervention.

4.1 Introduction

Building on chapter three, the initial programme theory development through a realist synthesis of the evidence, led to the development of CMO configurations that could be tested through empirical work (as set out in Table 5 in the previous chapter). Given the focus on the micro level, the research participants were PHB holders whom I followed through fieldwork activities to test the programme logic of how PHBs deliver choice and control. By engaging in ethnographic fieldwork within realist principles, I was able to refine the understanding of how PHBs are working for people with complex healthcare needs. Obtaining nuanced understandings of PHBs helped to explain and unravel some of the complexity and paradoxes of choice and control within the programme theory.

Therefore, in this chapter, I present my research strategy and methodology for data collection and analysis. My intention is to provide a detailed account of what I have done, how I have done it and why, so that conclusions drawn are weighed accordingly. I begin by providing the broad aim of the study and my positionality as a researcher looking into PHBs. I will then explore the theoretical framework guiding this research. Following that I will discuss the study design and methods and how they are a good fit to explore the phenomenon. I will also explain how I tested the initial programme theory with empirical work. The aim of the research strategy was to enable examination of the micro-level transaction and processes that PHB holders went through in the day-to-day management of the budget and the challenges they encountered because of the intervention. The data collection processes were constructed to collect information that PHB holders had, thereby enabling me to refute or refine theories about how, why and for whom and under what circumstances the PHB programme delivers choice and control.

4.2 Aims of the Study

I set out to explore how PHBs are working in practice to deliver choice and control for people with complex healthcare needs. I focused on understanding the operation of choice and control when using a PHB. The objective was to collect information in-depth over a long period of time that could unravel the complexities of PHBs, and I addressed the research question:

> *Are personal health budgets delivering choice and control for people with complex healthcare needs?*

As discussed in earlier chapters this is an important question for practice as well as researchers because PHBs are being scaled up in the NHS.

4.3 Positionality

The research study was informed by my own personal experience. As a nurse practitioner, optimising use of NHS resources and placing people at the centre of decision making is paramount. Moreover, improving outcomes for people is always the focus alongside evaluating the effectiveness of interventions we provide. So, when PHBs were introduced in the NHS, for me, this represented a real desire to improve the quality of care and system responsiveness. My interest in PHBs grew even further when I implemented PHBs as a community nurse working with people with complex healthcare needs. I wanted to make sense of how the work I was doing offering choice and control would improve experiences for people. Although the policy intention is to encourage a more responsive health and care system, it has been surrounded by so much controversy and complexity making it very difficult to unpack.

It was important for me to understand what having a PHB meant for people in real terms, having choice and control, and what that translated to in practice. This could only be achieved through a study that enabled hearing the views and perspectives of those who are in receipt of PHBs and what their real experiences mean. By conducting this research and utilising my life experiences, I could help unravel some of the paradoxes and complexities surrounding PHB policy and implementation. That way I could build a deeper understanding of the policy initiative to improve practice, processes, and outcomes. Therefore, this research was an attempt to add value to the body of existing evidence and it enabled me to bring along clinical expertise and practice experience into the research process. It does though mean that I come from a professional perspective, and I recognise that this is a relevant factor when considering the role that professional power plays in PHBs.

4.4 The Research Design

Chapter two explored realist evaluation as a framework used to guide the design strategy and methodology in this research. Chapter three examined the CMO configurations, their applications, and the challenges they presented that needed to be taken into consideration when choosing the methodology and methods of data collection and analysis. The chapter concluded by detailing the process of synthesising the evidence used in the development of the initial programme theory that could be tested using empirical work.

This chapter provides a methodological description of the research process used for data collection and analysis. The chapter is in two parts. The first part details the methodology adopted in this study highlighting the epistemological and ontological position of the researcher. This is then followed by a detailed description of the methods used for empirical work to collect and analyse the data in this research.

The Methodology

This research project is positioned within the constructivist and interpretive research philosophy. It used qualitative research methods, employing ethnographic approaches in its research design, and utilising realist evaluation as a theoretical framework to link the observed accounts to context. Using ethnography combined with realist evaluation, expands our social understanding of the phenomena by unpacking the underlying social mechanism in operation in the PHBs programme. Since interventions are theories and evaluations test programme theories, consequently, the use of ethnographic methods of data collection, monitored over time could explain how PHBs are being implemented, interpreted, and acted upon by the participants. Taking a longitudinal approach to the study also provided a unique opportunity to explore the relationships between choice and control as a dynamic process over time.

Rationale for Methodological Approach

The approach I used in my inquiry integrated subjective meaning into the study. This is because I share an epistemological and ontological position with proponents of interpretive approaches in my understanding of the complex world of lived experience from the point of view of those who live it (Geertz, 1983; Clifford, 1983; Lincoln & Guba, 1985). Using the interpretive approach helped me to explore the understanding and experiences of the PHB holders, the social processes, institutions, and relationships that formed their world and the meanings generated (Schutz, 1967; Mason, 2002).

I acknowledge that in the broader context of social science, I had the option to choose an inquiry based on positivist assumptions. However, because of the nature of the study, I felt that using the mixed method quasi-experimental approaches to evaluation of PHBs, as done by Forder et al (2012) or using a process evaluation as Jones et al., (2017) did, would not yield new insights or answer my research question. Therefore, naturalistic approaches to knowledge and understanding of the social world were appropriate, with ethnography being the most suitable methodology (Brewer, 2000). In accepting ethnography as a methodology, I am asserting that this research was concerned with meanings and actions that are yielded because of insider accounts.

Ethnography shapes, limits, and defines social actions and these were central to the explanations and understanding of meaning that are interpreted in this study. Greenhalgh and colleagues (2015) argue that exploration of complex interventions may require approaches tailored to the individual studies and there is no one right way for designing qualitative research (Hammersley,1992; Maxwell, 2012; 2013). Yin (2009) points us to the importance of recognising the contextual factors in our designs. Qualitative approaches can help in identifying contextual explanations of mechanisms at play (Sayer, 1992). Other researchers who have used realist evaluation have utilised a variety of data collection methods (Rycroft-Malone et al., 2008; Greenhalgh et al., 2009; Manzano-Santaella, 2011., Randell et al., 2014) arguing that methods are selected because they are the best fit to uncover patterns and irregularities. I chose ethnography because it was the best fit for generating and understanding the meanings that PHB holders ascribe to using the PHBs.

My philosophical approach was that inquiry begins with concerns of the participants and unfolds through 'joint construction of the case' (Guba & Lincoln, 1989. P179). This research was interested in the nuanced elements of the programme that allows people to have choice and control when using PHBs. Also, the methods of analysis, explanation and argument building needed to be iterative and inductive (Hammersley, 1992) and that could only be achieved through a two-way dialogue with participants. That way, the study could produce thick, rich, nuanced explanations on how PHBs deliver choice and control for the participants (Pawson & Tilley, 1997), thus placing this study in the field of theory-driven evaluation research.

Realist evaluation and ethnography are not often undertaken together and combining the two invites scrutiny - although others have successfully combined them (see for example Manzano-Santaella (2011) and Randell et al., (2014)). While early ethnographers adopted a positivist stance and offered little reflection to their philosophical beliefs, ethnography can be combined with a range of other sets of research paradigms (Fetterman, 1998; Brewer, 2000). Combining realist evaluation and ethnography here has been carefully considered and is based on the complementary tools that they offer for understanding PHBs. Realist evaluation provides the programme theory which specifies how PHBs are supposed to work in relation to choice and control, and ethnography provides the methodology for finding out whether or not the theory is valid.

Ethnography reveals the links between the subjective meaning and their structural social origins, whilst realist evaluation explains complexity in a robust philosophical manner; ‘what works, for whom, how and in what circumstances’ (Pawson & Tilley, 1997). Williams et al., (2013) further argues that both approaches attempt to explain rather than merely describe the phenomena. Ethnography is greatly dependent on fieldwork, an iterative process, depth, and detail as the focus (Atkinson et al., 2007), which make it a real good fit with realist evaluation. Together the two can reveal the complexity of PHBs from the users’ perspective.

4.5 Methods Used During Empirical Work

The previous section has set out the research strategy used in the study and why qualitative methods were employed. The section also demonstrated how ethnographic methods combined with a realist framework was the right approach to enable the in-depth and longitudinal element of the study without compromising rigour of the research. In this section, I will provide a detailed account of fieldwork activities undertaken and the methods of data analysis utilised.

Using A Case Study

I chose to capture individual case studies of PHB holders for this study. Using case studies meant I could use various sources of data (Yin, 2015). The case study complemented realist evaluation and ethnography which also encourage diverse sources of data (Rycroft-Malone at el., 2010), while recognising the importance of context and particularities (Atkinson et al., 2007). The study aimed to collect 'rich' data from PHB holders to give a nuanced account of the phenomena and build an understanding of how PHBs deliver choice and control and why it might be the case. This approach allows interpretation of change over time and processes in context (Yin, 2015) and the development of knowledge through a wide array of data collection methods (Stake, 2010; Bryman, 2016).

Selection of Cases

Manzano-Santaella (2016) suggests a theory-based approach to sampling for realist interviews and highlights the importance of selecting participants that can shed light on the particular aspects of the programme theory being evaluated. In this study, the participants were in receipt of a PHB package and had been using it for a minimum of a year, and therefore were deemed able to give a perspective on how PHBs were delivering choice and control. It is worth noting that the cases who took part may not been typical of most people with complex healthcare needs. Their experiences may have influenced how they chose to use the budget, as well as why they chose to take part in this research.

Inclusions/ Exclusion Criteria

To make the project manageable, its scope was limited to adults with complex healthcare needs. All participants had capacity to consent under the Mental Capacity Act (HMSO, 2005), ability to communicate in English verbally or with use of aids and to take part in research. The reason to exclude non-English speaking participants was because this would have made parts of the data gathering very difficult. This was also a self-funded project, and the financial commitment of interpreters' service was beyond resources available. The research was open to all adults with complex healthcare needs from various backgrounds, social groups, ethnicity, gender who met the criteria, who expressed interest in taking part and participation remained voluntary.

Recruitment Strategy

Statistical sampling would not have been appropriate for this study due to the complexity of the service users which would have made probabilistic sampling impossible, and it could never be representative of the larger population of programme participants (Robson & McCartan, 2016). Fetterman (1998) highlights the value of using a small number of cases to allow detailed exploration. Given the target population (people with complex healthcare needs) and the ethnographic focus, the expectation was that around 3-5 cases were the maximum feasible number (Patel et al., 2003; van Wijk, & Harrison, 2013). The terms participant/s and case/s will be used interchangeably in this study.

Identification of participants

Participants were identified through key informants, e.g., known contacts, UK service user participation forums, voluntary sector networks, and these differed in region and demographic profiles. Much has been written on doing research with hard-to-reach groups (Bonevski et al., 2014; Levin et al., 2018). The associated challenges were explored by Bonevski et al. (2014) in their systematic review. These included selection bias, gatekeeper bias, low recruitment rate and retention, and I encountered similar challenges. From the outset, I assumed there would be issues of retention due to ill health and aimed to recruit a bigger number than I would require. For appreciation of the context in which this research was conducted, I briefly give a background of the participants' health and setting.

The participants comprised adults with complex healthcare needs. These are people with ongoing or long-term health and social care needs. In addition to episodic acute care, they are cared for in the community. According to the NHS website, these are people 'with needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone' (NHS England, 2018). They would have been assessed by the Clinical Commissioning Groups CCGs to determine whether they have a primary health need warranting fully funded NHS continuing healthcare or a joint care package (health and social care). Depending on their situation, they may become eligible for PHBs (NHS Choice, 2015).

As a group, people with complex healthcare needs are generally associated with multiple long-term health conditions, frequent hospital admissions, limitations in their ability to perform basic daily functions due to physical, mental, and psychosocial challenges as well as living with long-term health conditions and life-threatening medical conditions (DH, 2012a). They are known to be difficult to recruit and participants are likely to have their health deteriorate and withdraw from the study (Patel et al., 2003; van Wijk, & Harrison, 2013).

With self-management of long-term conditions, many people are leading full active lives and providing much of the care themselves in their own homes with help from paid personal assistants (PAs), family members, friends, and occasional contact with healthcare professionals (NHS England, 2014a). With the introduction of PHBs they may not use mainstream provisions such as day centres, making them even more 'hard to reach' - this is already happening in social care where fewer people are attending services such as day centres (Power et al., 2016).

I initially planned to identify cases through my own professional links in continuing healthcare. I knew some service managers and had good professional relationships within organisations. However, when I contacted them, most people had moved on during the time I had been at university. Instead, I wrote to user participation forums and volunteer networks, but this was also unsuccessful. My supervisors also tried their networks and one person with complex healthcare needs and a PHB showed interest. I followed up the lead and from there, I recruited other participants through a snowballing approach (Noy, 2008). I identified another participant through a local paper where she had advertised and was looking for other PHB holders in her area so that they could come together and give each other peer support. One of the strengths of ethnographic design is the open-ended approach to real situations which allowed me to be adaptable in the process of selecting cases and setting (Atkinson et al., 2007).

Six participants were initially identified. Of the six, three dropped out during the selection process: one was because of risk factors associated with his aggressive behaviour and the other two became too ill to take part in the research. This meant that I had three participants for the study. One of these withdrew towards the end of the research, although consented to me using the data gathered. However, with this third case, I was unable to validate her data through member checking so that she could confirm accuracy of the data being reported (Holloway et al., 2010).

Research was carried out in England over a 2-year period (January 2018 – January 2020). Participants were geographically spaced, i.e., East of England and Yorkshire. The research was carried out in people's own homes and the community. This was an appropriate natural setting (Atkinson et al., 2007) because most people with complex healthcare needs are usually living at home. The 'problem of gaining access to data in ethnography' is known to be substantial (Hammersley and Atkinson, 2007, p. 41) and this setting presented challenges such as suitability and feasibility to conduct research. Fieldman et al., (2003) argued that obtaining access can come as a rude surprise to most researchers and I anticipated real challenges due to the nature of the cases I was studying. Most people with complex healthcare needs rely on their care givers, professionals, and agencies to meet their needs. Therefore, to access them, I had to go through these gatekeepers highlighting some of the initial challenges I encountered (LeCompte & Schensul, 2010).

4.6 Ethical Consideration

Due to working with adults who were considered vulnerable, ethical approval was required from the national Social Care Research Ethics Committee (SCREC). The University of Birmingham acted as research sponsor. Ethical challenges for conducting research with this group of people had to be addressed clearly spelling out how risk would be managed prior to fieldwork. The study recruitment materials (see appendices 1-5 on pages 358-362) were approved by the SCREC (Health Research Authority 17/IEC08/0034).

Consent and the Likelihood of Causing Harm

There was potential to cause harm in the sense that these people are defined by SCREC as vulnerable, have life limiting illnesses and being studied can create anxiety and worsen situations (Cox & McDonald, 2013; Bryman, 2016). Avoiding harm to research participants required that participation was voluntary, and written informed consent was given. Hammersley & Atkinson (2007) highlighted that the eliciting of free consent in ethnography is not always straightforward and can be a source of vulnerability. I checked that participants were still happy to continue with the research at each contact and had to continually assess potential vulnerability within the context of the research. Due to their complex healthcare needs, for instance a seizure attack could occur at any time – I had to be prepared for a range of possible issues during a visit. Prior to carrying out a visit, I checked that participants were well enough to take part in the face-to-face contacts and used my own clinical judgement as guidance. I drew on the literature from critical care which puts responsibility on the investigator to ensure risks, benefits and study activities are clearly understood by patients (Silverman, 2011; Bruce et al., 2013).

Confidentiality and Anonymity

A further issue was confidentiality and anonymity. While every effort was made to anonymise the data collected, this issue had to be discussed with participants prior to fieldwork and during fieldwork, since these are unique cases and could be identifiable (Boddy et al., 2016). Due to the vulnerable nature of the participants, I found myself in a position of increased responsibility. Some of the participants knew one another in their own network, therefore I had to make it clear that we would only discuss the participant's own experiences and not friends and colleagues. During visits family carers or paid care workers were always present or within earshot. Although family and care workers were present during these contacts and included as part of the research process, their inclusion was to accommodate observations of activities that they would be involved in while assisting the budget holder. Therefore, their voices and opinions did not form part of any data collected during the observations, interviews and in audio recordings. However, their presence, meant they could hear some of the conversations we were having highlighting limitations to confidentiality and anonymity.

Risk and Personal Safety

The risks to me were associated with the practicalities of driving and covering a large geographical area and keeping safe. One of the mechanisms to keep myself safe was to let supervisors know where I was going. I would also send a text message prior to walking into a participant's house and when I had come out. The participants had routines such as personal care and I ensured observations and interactions did not disrupt normal activity or compromise privacy of individuals and took account of health needs. Being a practising nurse with experience of working with this client group, I was aware people may become ill at any time which can be distressing and could potentially happen during my visit. The contacts were tailored to fit with participants and centered around the on goings of their day to day lives.

4.7 Data Collection

The theoretical assumptions behind the sampling process were to enable examination of the transaction and processes that PHB holders went through in everyday management of the budget and the challenges they encountered as a result of the programme intervention. Hearing first-hand experience from those who use the service was deemed an important element for understanding PHBs. Therefore, the data collection processes were constructed to collect the information that PHB holders had, and thereby refute or refine theories about how PHBs deliver choice and control. It is against these arguments that this empirical data collection process is situated, enabling me to design the data collection methods with a focus on testing the different elements of the programme theory.

Designing the Data Collection Methods

During the ethical review stage, I had to demonstrate that I had thought through my strategy for data collection and methods. Table 7 below shows the details of the contact points I had planned for each participant. While most of the contact points took place as planned with two of the participants, I had only two face to face contacts with the third participant. She dropped out towards the end of the study and I retained the data with consent. Also, when I got to people's houses as planned, there were sometimes changes because people were running behind in their daily routines. Therefore, I had to wait to accommodate such changes of everyday life context and visits became one-to-two-hours.

Table 6. Details of Contact with Participants

Contact Details	Contact point	Duration	Where and how contact will be carried out?
Preparation: Telephone/ email/ face to face contact to introduce self, discuss study requirements, follow-up leads and feedback	3	30 minutes	Research student to make formal and informal contact with key informant's potential participants and gatekeepers
Introductory meeting with participants to give information, discuss the research process, protocols, expectations, give information handouts and answer questions	1	1 hour	Research student will meet with participant alongside their care givers in participant's home and community

Gaining consent and clarifying any queries and participants signing a consent form (30 days after introductory meeting)	1	1 hour	Research student will meet with participant alongside their care givers in participant's home and community
Semi structured interviews to gain participant understanding of PHB and how they are using it and what has changed	1	1 hour	Research student will interview participant in participant's home and community
Observation of naturally occurring interactions and conversations - real time activities (as set out in observation protocol Ver.1)	1	1 hour	Research student will observe participant alongside their care givers in participant's home and community
Observation of an activity bought using a PHB, look at documents and collecting artifacts	1	1 hour	Research student will observe participant alongside their care givers in participant's home and community
Interaction and conversation exploring concepts of choice and control	1	1 hour	Research student will meet with participant alongside their care givers in participant's home and community
Interaction and conversation clarifying any raised points, ideas, and themes	1	1 hour	Research student will meet with participant alongside their care givers in participant's home and community
Termination Point	1	1 hour	Research student will meet with participant

I had eight face to face contacts with each participant planned over a 2-year period and other contacts by phone. The extended period of visits to the field meant people got used to me being around and the interactions became natural as the study progressed allowing me to capture spontaneous moments. According to Fielding (1993) the capturing of these important spontaneous moments in the ordinary events of daily lives conveys a sense of rapport. For instance, each contact I had was different and I was able to witness a wider range of activities related to PHBs than originally intended and interactions that added to sense making with regards to power dynamics and how these were negotiated in everyday activities and within the different levels of the logic framework. Agar (1980) and Hammersley (1997) assert that long-term fieldwork enables an ethnographer to discern what is real versus ideal and what is explicit from the tacit, arriving at what is valid.

Methods of Data Collection

Data collection comprised of:

- Observations
- Semi-structured interviews
- Collection of materials

I used a combination of data collection methods. The methods I used were selected for their utility in complementing and enhancing the data. Mason (2017) highlighted the role of the researcher in working out how best to collect data from their chosen source. Stake (2010) highlighted the importance of triangulation of data to address validity, reliability, and objectivity. In this study in line with ethnography, some of the actions I took were checking for data consistence, drawing insight from different angles and not being disruptive to people’s daily routines (Newman, 2003). In line with ethnography and realist evaluation, I was not seeking to find universals in the cases. Instead, I sought a full rich understanding of how PHBs deliver choice and control to inform theory development. Ethnography enabled a long-term perspective and in-depth analysis, which were some of the shortcomings of previous studies in this field.

Observations

I developed an observation protocol that was approved by the SCREC (see full details in appendix 2 on pages 363-364) and below is the remit of what could and could not be observed.

Observations

- Observations will take place in people's own homes and their community.
- Observations will be carried out at times that are convenient for the participants.

Purpose of observations

- To record situations as they happen
- To record meanings of these events at the time of observation

Who will be observed?

- Participants
- Carers
- Their network

What will be observed

- Activities of daily living paid for through a PHB (housework, preparing meals, health management and maintenance, use of personal assistance etc.).
- Events and sequence in which PHBs are being used (equipment purchase, training for personal assistance, community access etc.)
- Setting and participation structure in which activities occur
- Behaviours of individual people
- Conversations
- Interactions

What will not be observed

- Personal care/ washing.
- Night-time routines including getting ready for bed and bedtimes.
- Any activities participants are not comfortable being observed.
- Carers/ Family members who have not consented to be observed.

Duration of Observations

1 hour

Processes

- Written fieldnotes
- Audio recorded fieldnotes
- Records of informal conversations

- Observational checklist
- Records of field diaries
- Artifacts

The participants were using their budgets in four different ways: accessing PAs, accessing the community, buying equipment, and purchasing care and support services. They had either a direct payment or a third-party option as their preferred management option. Therefore, I could observe a variety of activities paid for by PHBs.

Observations of an activity paid for by the PHB were carried out with two of the participants. During these periods of observations, I interacted with participants, recording using a digital voice recorder, and collecting data from them. I followed each case in a real-life context, obtaining (with consent) rich data from spontaneous and casual conversations that were taking place for instance between participants and other professionals. While I could record only what was being said by the participants, being in people's own homes enabled me to observe what was happening, listening to what was being said and documenting in a fieldwork diary which added to the richness of the data.

Documents and Artifacts

I collected several documents and artifacts as sources of data: care and support plans, photographs of activities purchased through PHBs, brochures from places visited, local policy documents, budget review reports, correspondence, and emails. While some of the documents were in the public domain, others were private correspondence between the participants and local CCGs and external bodies. The documents were anonymised. Any photographs looked at or used, if they included images of other people e.g., families and friends, their consent to share the image was sought first. Care and support plans were copied, using a smartphone, given back to the participant and did not leave participants homes. These were then moved onto a password protected laptop as soon as I got home and deleted the phone versions. These documents and artifacts were linked to other events to build inter-textual links between and among events often inscribed in such documents. This was invaluable in opening the 'black box' of the PHB process because such accounts could only be uncovered through multiple forms of data.

Conducting Interviews

The use of qualitative interviews for theory building is regarded as a highly efficient way to gather rich data in case studies (Bendassolli, 2013). In addition to the observations and artifacts, I used an interview schedule that I developed and was approved by SCREC (see appendix 3 on pages 365-367). In the literature, choice and control is seen as an outcome of the implementation process and often expressed implicitly as one of impacts of PHBs. Therefore, I had to frame the interview questions to reflect this, but also enable participants to express their views how they wanted. Bryman (2016) suggests that the interview is a prominent data collection strategy in both quantitative and qualitative research. I used it to gather data allowing a focus on aspects of the programme theory that were not easily captured by other forms of data collection methods.

The interviews were 1-2 hours (accommodating changes in people’s routines) and even though written consent was given in advance, I also sought oral consent before the interview and checked during the interview if participants were still happy to continue. Three interviews were conducted (one with each participant), and these were audio recorded. Audio files were transferred to my password protected laptop as soon as I got home, and the original versions deleted. I then transcribed them verbatim into written form. The interviews were conversational in nature and generated rich and nuanced accounts to add to the volume of other sources of data collected. The interview transcripts were shared with two of the participants so that they were happy with the content and meaning and they could also modify the content. The other participant had withdrawn from the study highlighting the challenges of conducting research over a long time with this patient group.

Semi-structured interviews are flexible, they are a powerful tool in capturing the voices of participants thereby providing depth and detail (Robson & McCartan, 2011; Silverman, 2013). The semi-structured interview gave me detailed insight into PHBs and allowed me to understand what lay behind the words and actions in the non-verbal cues but also understand the ways PHB holders made meaning of their experiences (Kvale, 2009). However, I had to be aware of bias in the interviews that could be a threat to reliability and validity (Bryman, 2016). Interviews were also complemented by data from observations, artifacts, and documents.

Managing the Copious Data

The cases were anonymised through use of pseudonyms and after screening the data for any personal information, e.g., names, address, NHS number, the data was filed case by case and classified according to the source e.g., fieldnotes, reflections, interviews, observations, documents, and artifacts, using Microsoft Access as an information management tool. The activities were arranged case by case for easy uploading and were entered into NVivo 11, for indexing. Use of NVivo helped in organising the large volume of data so that it was easier to navigate.

4.8 Analysis

For this study, each of the three participants constitutes a case study. The documents and artifacts were examined for links to other events and formed analyses that build inter-textual links between and among events often inscribed in such documents. Observations were analysed initially iteratively using Srivastava & Hopwood's (2009) framework. The transcribed audio recordings were coded thematically using Braun & Clarke's (2006) six steps and then analysed as triangulated data using realist analysis to map out the programme theory. More detail is given on these below.

Abductive Analysis

The complexity of PHBs demanded ongoing processes of trying to puzzle out what was happening in the data to come up with plausible explanations that would best fit the materials to help develop the theory and that required double checking with more data. Inherent in any design are strengths and weaknesses and ethnographies suffer from subjectivity and lack of generalisability because of using small cases (Bryman, 2016). Hence any inductive analysis does not reach general conclusion because the results are based on individual responses and outcomes that cannot be applied beyond where the study was conducted (Robson and McCartan, 2016). However, Eisenhardt & Graebner (2007, p. 27) argued that use of case studies in theory building is equally important and the use of multiple cases create more 'robust theory' because of the varied empirical evidence.

Drawing on the work of Peirce cited in Burks (1946), abduction is the reasoning through which we perceive the phenomenon as related to other observations allowing us to reach explanatory logic inferences. Through an abductive approach I could make connections between the fieldnotes, documents, artifacts and interview transcripts and cross check with relevant literature to come up with the most plausible explanation as to how, PHBs deliver choice and control for this group of people.

Building on the realist synthesis work reported in chapter 3, the fieldwork data was analysed in three stages as follows:

- Iterative - during fieldwork
- Thematic coding – descriptive and inferential analysis
- Mapping out CMOs – checking for patterns in the data that affirms or refute the programme theory

The Iterative Process

Initially, I used the framework in Table 7. below, that I adopted from Srivastava and Hopwood (2009) because of its practicality as a reflexive process that brings in researcher insight and the development of meaning. Immersed in fieldwork, I was an observer of and interacted with participants, recording, and collecting data about them, bringing my subjective interpretation into the study.

Table 7. A practical iterative framework for qualitative data analysis

Q 1	What are the data telling me? (Explicitly engaging with theoretical, subjective, ontological, and epistemological understanding)
Q 2	What is it I want to know? (According to research objectives, question, and theoretical points of interest)
Q 3	What is the dialectical relationship between what the data are telling me and what I want to know? (Refining the focus and linking back to research question)

Framework adopted from Srivastava and Hopwood (2009, p. 78)

Not only was I collecting data, but I was also transcribing the data immediately after fieldwork. I also reflected on each contact that took place, recording my own thoughts, meaning, and making connections in the context of what I had observed, read, or heard. Where meaning was unclear, I would go back and double check such understanding with the participant.

The process was to ascertain which programme theories I needed to refine and generative mechanisms I needed to observe. I was analysing the data continuously, raising questions in the field, modifying, and clarifying ideas, and information relevant to the research question. This became an important part of the study methods and complemented the interview schedule that I had developed very early on in the project for the ethics review process. It was not a mechanical task that I was performing but a deep reflexive process that led to a refined focus and understanding (Patton, 2002), an ongoing process until I reached data saturation.

The iterative process enabled me to ask questions that focused more on testing the different elements of the programme theory and thereby refute or refine theories about how PHBs delivers choice and control. The interviews were only loosely structured to allow users to shape the direction of the discussion, the broad questions asked were focused on answering these questions.

- What are the intended outcomes of PHBs being experienced by the participants?
- What mechanisms (reasoning and resources) are said to offer choice and control?
- What contextual factors are causing the mechanisms to produce the observed outcomes?

The interactions were grounded in what was occurring in the local context, both within and across time giving me insider information about what I was observing. The framework enabled the development of familiarity with the individuals that proved invaluable throughout the project (LeCompte & Schensul, 2010). The circumstances of being in social settings for the purposes of gathering data (Lofland & Lofland, 1971) gave me a nuanced understanding of context that could come only from personal experience in unstructured ways. This enabled me to capture the individual stories as well as conduct a methodologically rigorous in-depth data analysis.

Thematic Coding

Thematic coding was carried out using Braun & Clarke’s (2006) approach to data analysis, which is suitable for analysing data that is collected through a range of methods. Braun and Clarke describe thematic analysis as an iterative process to help refine your messy data into important themes, thereby complementing the analysis initial carried out. They suggested a 6-step process:

- Familiarize yourself with your data.
- Assign preliminary codes to your data to describe the content.
- Search for patterns or themes in your codes across the different data.
- Review themes.
- Define and name themes.
- Produce your report.

I was able to familiarise myself with the data, as I listened to the audio recordings when I transcribed them. Reading all the other documents and looking at artifacts as I worked with the data and taking some notes enabled me to reflect on the data as I developed ideas for codes that describe the content. The data was organised thematically and some of the themes were used to write the ethnographies in chapter 5, while themes and excerpts that were not used for the individual case stories were used in the realist analysis in chapter 6.

This approach was designed to bring understanding of the programme and create the foundations for further development of the programme theories retained from chapter 3 (Table 5. page 97). This approach to data analysis enabled me to start unpacking where complexity lay within the PHBs programme.

Realist Analysis

Despite increasing use of realist evaluation in healthcare, few studies provide enough details of how they conducted their realist analysis (Marchal et al., 2012; Salter & Kothari, 2014; Gilmore et al., 2019). My approach to realist analysis was to explore empirical data to further refine and develop the initial programme theories articulated in chapter 3. I was guided by the approach used by Weich and colleagues (2020) in their EURIPIDES study to identify approaches to collecting and using patient experience data for supporting improvements in inpatient mental health. They used a qualitative realist methodology and, in a two-stage data analysis process, used thematic and realist analysis to link patterns observed, develop, and refine CMOs. I adapted this approach to suit my study to maintain a conceptual thread and help me navigate the complexity of PHBs.

Guided by overarching themes developed in the thematic analysis, I was able to identify CMOs, link them and use them to refine the initial programme theories developed from the realist synthesis. One new additional CMO was added which originated from the fieldwork. I report on the CMOs and refined programme theories in chapter 6. Examples of coded excerpts, CMO configurations and analysis drawn can be found in appendices 8-15 and realist analysis of context-mechanisms-outcome, see pages 386-395).

4.9 Reporting of the Findings

The findings are reported in the next two chapters as follows: Chapter five reports the findings as separate cases through the individual stories of Cora, Steve, and Karen, while chapter six focuses on the realist evaluation. Chapter six begin with the refinement of key themes and developing of the 'Concept Frame' for mapping out CMOs. This is followed by a reconfiguration of CMOs using overarching themes and finally theory refinement and how that applies to wider context.

4.10 Summary of the Chapter

The chapter presented a methodological description of how I went about answering the research question: are personal health budgets delivering choice and control for people with complex healthcare needs? I also described the theory building approach taken and the research process used in this study. The research design, methodological issues, debates, and approaches were considered in each stage of the research process. The rationale was to give a clear path of what I did and why. The use of ethnography and the various debates that I used to inform the use of qualitative data, were discussed. In narrating the experience of doing the research, I explained how ethnographic case studies and realist evaluation framework guided the research process and data collection. The use of observations and interviews for data gathering was also set out. I discussed how data was analysed and in what way the data related to the research question and aims.

I described the process of obtaining ethical approval, the challenges I faced and debated some of the ethical issues that are important when conducting research with people with complex healthcare needs. Taking account of this and the methods chosen, the study explored these areas through rich and nuanced accounts of the lived experience of PHBs holders, linking specific contexts to mechanisms in a way that explained the expected outcome. I argued that my methods were a good fit for exploring PHBs. The empirical investigation enabled me to gauge and obtain additional information that would help in exploring the extent to which the initial programme theory was validated within the complex contextual circumstances of the implementation of PHBs (Pawson & Manzano-Santaella, 2014). The findings from this study are presented in the next two chapters.

Chapter 5: Reporting of the Findings - Individual Stories

Chapter 4 presented the methodology and methods that have resulted in the findings being reported here. The chapter builds on the findings from Chapter 3, a realist synthesis that I carried out on the literature that explored PHBs. That chapter surfaced stakeholder theories about how PHBs are supposed to deliver choice and control for people with complex health care needs. The theory was built from knowledge derived from the literature on what scholars, policy makers, managers and clinicians' thought would happen when service users take on PHBs.

In the realist synthesis, I examined data pertaining to PHB implementation and compared it to stakeholder theories on how they deliver choice and control in practice. The chapter highlighted the various claims being made about PHBs and their complex nature. The findings also highlighted the continuous shifting of policy ideas within PHBs. During the synthesis, I also generated themes and refined the programme theory prior to fieldwork. The identified themes and programme theory were then used to shape the empirical work that I am reporting in this chapter.

The literature review demonstrated that choice and control were framed as an outcome of the implementation process, an end in themselves as well as a means to the end of better health. My fieldwork was designed to get more nuanced understanding of PHBs through the experiences of the PHB holders. To test the initial programme theory from the realist synthesis, I spent a prolonged period doing fieldwork, listening, and observing what was going on in the lives of PHB holders and collecting data that explain how far PHBs deliver choice and control. My approach was to analyse the data by including any evidence that supported or refuted the initial programme theory, leading to refinement and articulation of theory in the PHB programme. This generated data that led to the descriptive and inferential analysis I am reporting in this chapter.

This chapter focuses on individual stories (ethnographies). The insights being reported in this chapter of the findings, were drawn from observations, interviews, artifacts, and document analysis. My focus is on what I observed, and the overarching interactions that took place around PHB holders' ability to manage their long-term conditions, how they used the PHB to exercise choice and control and the challenges posed. All the PHB holders had used direct payments from social care before taking on PHBs which they also received as direct payments. One of the participants had moved from using a PHB direct payment to a third-party option. Therefore, the ethnographies highlight the different perspectives of choice and control that derive from these delivery mechanisms.

5.1 Introduction

The case studies being presented here are examples of the experiences of people with complex healthcare needs who use PHBs. In my reporting of the findings, I focus here in looking at each case in turn to provide richness and nuance in the evidence. The case studies therefore contain data which illustrate what was happening to the PHB holders in the context of how they perceived choice and control in the day-to-day use of PHBs, the processes they went through, resourcing, the interactions they had with professionals and challenges they faced at local level that facilitated or hindered choice and control. The professionals involved were mostly care managers and CCG representatives, and sometimes clinicians.

As set out in chapters two and three, from the realist synthesis, I developed a set of initial rough programme theories (logic statements) and interrogated the literature for contexts, mechanisms, and outcomes. I drew on themes from the realist analysis to understand the logical connection of context, mechanisms, and outcomes and to develop the initial programme theory. I developed three CMO configurations. These focused on access to resources, shared decision-making and professional power.

Following analysis of fieldwork data, other themes were identified in people's experiences of using PHBs, which come under the broad CMO headings. These are discussed in this chapter and the next chapter. They are set out in full in Table 8 on pages 195-198. The themes covered in this chapter are those which best tell the story of the individual experiences of the three participants. These are:

- Complexity of health and social care needs,
- Being your own care manager,
- Capability and experience,
- Implementing the care and support plan

Further cross-cutting themes are covered in the discussion in the next chapter.

Therefore, here I start on the thematic analysis with excerpts from the cases to support the presented ethnographies. While the themes are present in each case, they manifest in very different experiences depending on how PHB holders chose to manage the budget, the challenges they were facing at the time and how their local CCG addressed their concerns or requests. Each case had a preference for how they chose to manage their budget, either through direct payments or third-party options.

Here, I briefly recap on some aspects of PHBs from earlier chapters that are most relevant to the individual stories. The PHB holders in my study, were using their budgets in four different ways: accessing PAs, access the community, buying equipment, and purchasing care and support services. They had either a direct payment or a third-party option as their preferred management option. The PHB direct payment route is said to offer the maximum choice and control (Fitzgerald et al., 2012). Under this option, individuals are fully responsible for managing the money and can negotiate with providers directly and take on the financial, employment, clinical quality and legal responsibilities associated. In a third-party option, there is more shared responsibility. The PHB holder appoints an organisation to handle the finances on their behalf, the third party becomes the employer and supports the PHB holder with financial and administrative responsibilities (Alakeson, 2014a).

Also, it is worth noting, that CCGs commission services on behalf of their local population from service providers. Therefore, commissioning of PHBs fall under their remit as do all continuing healthcare packages. According to NHS England (2014a), CCGs may reduce the level of funding or remove a PHB altogether following an annual review, if people no longer meet the criteria set in the framework for continuing healthcare. Should that happen, PHB holders can appeal to a review panel. The panel is independent and is there to ensure that the care plan is lawful, effective, affordable, and appropriate (NHS England, 2014a).

5.2 The Ethnographies - Case by Case

5.2.1 Case 0ne, Cora's Story – *'Being in Limbo'*

In this ethnography, I report on Case 1. Cora, which I have entitled 'Being in limbo'. This is a phrase that came up over and over in our interactions as well as in the interview I had with Cora. This related to how Cora found it problematic to plan or make some key decisions because she was waiting for a long time for her local CCG to reach an outcome on her budget application and appeal, following the review process. Cora had experience of using personal budgets in social care and PHBs. She had participated in the PHBs pre-pilot, pilot scheme and used PHB direct payments in the national roll-out programme before transitioning to a third-party option. Her reporting of her experience of using PHBs starts as very positive in the pre-pilot through the pilot phase (2009-2013), followed by a very bad experience in the first three years of the roll-out programme (2014-2017). Fig. 4 below shows the change over time that took place when Cora moved from pilot stage to the PHBs roll-out phase.

Fig. 4- Change Over Time in Cora's Experiences of PHBs After Transition from Pilot to Roll-Out Phase

Negative experiences using direct payments in health following at roll-out phase

Experiences at the start of roll-out phase

Since being on PHBs roll-out Cora found it difficult to manage her long term conditions because:

Her budget was reduced and could not cover complementary therapies that were funded during the pilot phase

Her budget was inadequate to cover the cost of care and the burden of caring fell on her husband who was her main carer

She felt the CCG was making too many bureaucratic demands on the direct payment route of the PHB process which was causing stress and anxiety. She gave up direct payments and opted for a third party option

She had no indicative budget

She was not involved in care and support planning and had no budget reviews

She had no choice and control over the money and how to spend it

There was no active involvement or trust

Bottom-up demand for culture change through the appeal process

The Changes that Took Place

Appealed against her CCG's decision and the independent review panel ruled in her favour

Formed local peer support networks

Got involved in implementation process to bring in service user input and shared decision at strategic level

Review of information and local guidance

Review of all budgets, and new systems in place

Co-production principles in place

The implementation process simpler and transparent

Continued with advocacy work to ensure other PHB holders in the locality had equal access to resources and support

New care plans pilot - organisation actively trying to improve services

Culture change

Improved Outcomes

Experiences at end of fieldwork

Full assessment of needs and individual outcomes identified

Had indicative budget

Care and support plan with nearly all elements agreed

Increase in budget award from the original value to purchase all complementary therapy

She was reimbursed for what she had paid herself, able to bank hours and use to purchase alternative care

Shared decision making with third party and maintaining autonomy over care and support, decisions with choice and control over the money

Felt empowered and valued as an expert of her condition

PHB flexible, less restrictive and positive risk management

Actively involved and having purpose and community presence

Positive experiences and outcomes reported

As shown in Fig. 4 above, the experiences improved with time, culminating in a positive experience (from October 2018 to when my fieldwork ended in November 2019), reflecting embeddedness of the PHB programme as routine practice. As such, Cora was able to give a comparison of these different stages of the implementation of PHBs in her narration of the PHB experience.

I conducted the research with Cora, a white British married female in her mid-40s. Cora lived in a remote village in the East of England. She self-enrolled in the research and was able to participate for the full duration of the study. I had 8 contact points with Cora as per the ethics protocol (see appendix 2 on pages 363-364). The observations went as planned. Apart from purchasing PA support, she was using her PHB to access respite care provision, complementary therapies and to get a spa bath. I visited the respite place with her and her husband who was the main carer. I was able to look around the place, the room she used, communal areas, the grounds and saw the spa bath she used. We had lunch together and I tasted the food she ate and got a sense of why this place was important for her and why she was fighting her CCG to keep the funding going when the CCG tried to reduce it. The observations highlighted the potential that PHBs hold, although Cora reported several frustrations echoed in the literature on PHBs and these are discussed below.

Complexity of Health and Social Care Needs

The complexity of health and social care needs was important in understanding the context in which Cora was eligible for PHBs and her ability to use the budget to manage her long-term condition. Cora lived with her husband who was her main carer. They shared their bungalow with their cats. I had several face-to-face contacts with Cora, and it was during these times that I discovered Cora had mild dyslexia, suffered from neurological hearing loss in both ears and wore hearing aids, but could also lip read to aid her communication. Cora told me:

> *"When I was young, I didn't have any significant impairments although later on in life I found out that I was dyslexic, which explains a lot why I struggled to learn and my short memory issues."*

As she progressed through life, Cora started to get health issues, and these have since progressed to chronic health and physical disabilities, hence qualifying for continuing healthcare funding and subsequently PHBs. Cora described the onset of her condition which she found at times difficult to cope with mentally:

> *"When I reached sort of 17, I had my odd knee problems, they seem now more significant since then. I sort of found it difficult to walk and kneel, so my physical mobility was starting to go downhill. Being adolescent time, it was taken as growing pains but didn't go away and I was later diagnosed with Dystonia and my mobility was getting worse."*

She also had pain in her left shoulder which exacerbated her limited mobility. She used walking aids, wheelchair, and mobility scooter to get around and because of the remoteness of where she lived, she also had an adapted mobility car to get her to places.

Apart from mobility issues, Cora also suffered from generalised chronic dystonia (sudden ballistic movements which she had little control over) and non-epileptic attacks that presented like an epileptic seizure and I witnessed some of these ballistic episodes. Cora's condition could change quickly, and it was difficult to manage, therefore requiring regular medication alongside complementary therapy and 24-hour care support because she was at risk of injuring herself. According to Cora:

> *"Dystonia is not very easy to treat. There are not many drug options plus I knew I wanted to have a family. So, I opted for acupuncture and alternative therapy"*

Cora had other chronic health issues; she would get episodes of stridor (blockage in the throat) which could be prolonged, making it difficult to breath and she used inhalers to manage this. She also had swallowing difficulties and ate puree, soft diet, and thickened drinks. Such complex health needs and where she lived, meant it was not always easy for her to find the right PAs with the skills to support her.

My analysis suggests that despite Cora having such complex health and social care needs, she appeared to have full insight into her condition, her strengths, and limitations. Having a chronic condition that was complex did not seem to hinder her ability to access and use PHBs.

Being Your Own Care Manager

From the conversations I had with Cora, she spoke positively about how direct payments in health had the potential to help her manage her own care needs. She also valued the opportunity PHBs offered her to use the funding in ways that made sense to her. With the budget, she felt there was the possibility to use resources differently to manage long-term conditions at low cost, reduce hospital admissions and use of emergency services. Cora referred to her experience of the pilot scheme of PHBs programme as follows:

> *"When I was on the pre-pilot and pilot scheme, I proved that I could actually save money because rather than going to hospital to have my knee injections every three weeks which cost a grand and a half, I could work it out, so that was easy to show that I was able to save money [with complementary therapy]. When it came to the actual budget [PHBs roll-out] because I wanted to use it for things like acupuncture, I was able to show I can save money."*

Cora felt that the direct payment route was able to empower people and offered more choice and control. She could make decisions and work out how to use the budget innovatively and get the best outcomes. For example, Cora had long standing challenges finding suitable PAs. She was able to employ her own husband as part of her care team, which helped to resolve some of the issues, and she was able to continue managing her fluctuating condition when she was short staffed:

> *"I had managed to employ a member of the family under very special circumstances, and I wanted that to actually stay. So that I have always got care and if my husband were not in the picture, I do not know what I would do. I have not got an agency or someone who could just come in and keep an eye on me."*

Having her husband in the team appeared to be an important factor that enabled her to have continuity of care and support from someone with intuitive knowledge of her needs when she was having staffing issues.

The direct payment gave Cora the flexibility and choice to purchase other services she felt would improve her health and well-being:

> *"I used a small part of my budget to fund my complementary therapies on a weekly basis which helped both my physical and mental wellbeing [referring to the pre and pilot phases]. Having a PHB made a huge difference to the quality of my life for the better and I was meeting my goals as set out in my care and support plan."*

Cora felt that the ability for PHBs to bring positive experiences, health and wellbeing outcomes was dependent on the processes, resources, and context in which PHBs operated. For example, the pre-pilot and pilot context she describes above seemed to be conducive for PHBs to flourish in that she was allowed to spend the money on things she felt were important, even if they were not conventional health interventions. She acknowledged the potential that PHBs hold and seemed to enjoy positive outcomes from managing her own care. However, the transition from pilot scheme to roll-out made it difficult for her to maintain the direct payment route due to resources and implementation challenges.

Cora compared her pre-pilot and pilot experiences with the PHBs roll-out programme and felt PHBs had become more demanding. According to Cora, managing PHB direct payments had changed, it had greater risks, more responsibilities and it was more stressful, and she felt processes had become insensitive to PHB holders' circumstances:

> *"In fact, you are not well in the first place which is why [you] need support and then you have too many systems when you have your personal health budget."*

Cora considered the PHBs roll-out programme to be inhibitive and imbued with bureaucratic processes, causing anxiety and stress to PHB holders:

> *"To meet the requirements of this funding stream and to employ my own staff involved a lot of paperwork, assessments, justifying and explaining how I meet the care domains and having to admit or recognise the impact my impairments are having on my life - in particular, work logs - all of which is something I find emotionally and mentally difficult."*

While she appeared to have the organisational skills and management abilities, it was the demands and emotions attached to the tasks that she found difficult to deal with. Cora also felt the funding rules for PHBs had changed dramatically which made her funding inadequate and difficult to manage compared to the various budget schemes she had participated in.

During the pilot scheme, Cora did not have to justify her choice making with so much administrative paperwork, if anything, she was supported by clinicians and encouraged to be imaginative with her budget. Therefore, her understanding of PHBs was based on holistic approaches to health and well-being. When she went on the roll-out programme, she thought PHBs were now narrowly focused on clinical outcomes which were 'need' based. In contrast to the pre pilot and pilot phases, she no longer had enough money in the budget to cover complementary therapies, there was less flexibility in the use of the budget besides PA support. There was no longer information and support readily available from clinicians, and peer support groups formed during the pre-pilot phase had been discontinued during the roll-out programme. As such, she became uncertain about PHBs and their sustainability:

> *"I have however found that due to funding and other reasons my budget tends to only focus on more of what you need rather than want and that was why I felt I had lost my way for a while because I was thinking of a care package that included doing things in a different way and not only covered PA hours."*

It is clear from Cora's account that the transition from the pilot to roll-out phase, PHBs became more restrictive, and Cora was constrained by the way PHBs worked. As a result, she opted out of direct payments and went onto a third-party option. That way, Cora felt she could cope emotionally with the challenges the PHB was presenting and not have to deal with the administrative challenges of managing the financial aspects of the PHB and being an employer.

Having found the direct payment route unnecessarily restrictive, Cora opted for a third-party option so that she could get the support she needed with the things she found difficult (such as employing staff) and continue to use PHBs. The third-party organisation was a private company that provided a one-stop shop service to help budget holders direct their support. It offered services such as choosing and managing PAs, manage finances, support with all the paperwork and processes involved in the day-to-day management of the budget etc. There is very little written about the PHB-third party option and Cora was able to offer a unique perspective of her experience of using a third-party option. The idea for opting for third-party was so that Cora could still have some choice and control, for example she could choose her own staff and the third-party organisation took care of the employment and legal responsibilities. That way, she could maintain the flexibility of choosing PAs, set rotas, do the time sheets, agree on holidays, and shift cover:

> *"In November 2016 I started using a third-party option to help manage my own dedicated PA team and it helped with reducing stress."*

Apart from help with administrative duties that caused stress, Cora used the third-party organisation to help her manage her money and to negotiate on her behalf with clinicians. The third-party option also meant she was removed from being a direct employer to her husband:

> *"I think what they do is negotiate with health. So, if I find it too much, I can say I need you to deal with this and just let me know what is going on. Which I have had to do on a couple of occasions because it was just too much."*

There were limitations associated with decision-making because of her circumstances. For example, for the third-party option to work well, Cora was required to appoint a responsible person to co-ordinate the care. Usually, this role is taken by a family member. However, this was not an option in her case because of her husband being employed to provide her care by the third-party organisation:

> *"You need a responsible person which is not normally catered for so the responsible person tends to be me, and I got responsibility of doing the time sheets, managing rotas and other things and I can't actually cover my own or husband's duties I need him to do in the first place. So, there is this level of risk and we decided that if I employed my own staff, we would have the same problem anyway so we agree that there is not a lot we can do about it."*

Cora had to be the responsible person because her husband was an employee, highlighting the complexity of PHBs and the unique nature of some of the challenges that may arise that are context specific.

When she took the third-party option, which is more costly than direct payments because she had to pay charges, the budget was unable to cover complementary therapy and therefore she lost the acupuncture:

> *"When I went over to a third-party option acupuncture stopped as well, as the third-party option cost more and these treatments were seen as extras and not a core need, so I ended up self-funding them."*

It also appeared there was limited information and guidance to help with some of the decision-making process:

> *"I have struggled with this different way of working because being the responsible person, I have to do the day-to-day stuff and it works ok and the issue is I've only got one PA, and if they go to the training, do I go with them or do I get some friends who could just keep an eye on me or what. And what then happens, do they get paid for travel, do I get them paid petrol money, so you have all these extra issues to deal with."*

Cora also thought there was not always the support to deal with some of the employment issues linked to her own responsibilities, for example if PAs did not turn up for duties, she had little control because she was not the employer although she would have allocated the shift:

> *"But I don't think I got the support from the third party to deal with those sorts of problems. Can you give me support, advice, what are the rules about people not turning up? And they said because every situation was different, they haven't got set rules. So, I found that quite challenging."*

Cora also pointed to challenges around communication and the need to streamline processes because it was causing delays:

> *"I think it only slows things down [….] They have to ask me, I tell them then they tell health, health makes a decision, tell them then they have to tell me. So, I did start asking health and third-party option provider directly to try and speed things up and vice versa.*

Cora felt the third-party option allowed the redistribution of power and responsibilities which solved some of the issues but also created another set of power dynamics:

> *"What I liked to do was especially when I had more hours was to bank them so I could make a meaningful shift and [the third party] had to sort of dictate how many hours were care and how many hours were support activities and now it's very grey."*

According to Cora, having a third- party option holding the money also meant she was unable to evidence how she was saving money to her local CCG, so she lost the additional services she was purchasing with her direct payment:

> *“When I went over to the third-party option, [the CCG said] you haven’t saved that money so these extra services are not seen as a core or essential need [the spa baths and respite at the hotel], so you can’t have that.”*

Cora perceived third-party options to be costly and selecting a good third-party organisation was not that simple. She also felt when you choose one, you don’t always know some of the hidden costs and then the NHS sometimes asks you to justify your choice, and that is not always simple:

> *“I think the other problem with third party option is that they are expensive. When I started using them it costed an extra £3 an hour and I thought yeah that’s good, you got PA rates at £10, and you got to put £3 on top and that not too bad. But it actually does not work that way, you got your PA rates, £3 charge, you got your own cost of national insurance, you got your own pension on top of that, training on top and CRB checks on top, so it gets quite expensive you see, [………] and they only cover two trainings per year and any more than that they charge.”*

Cora’s experience suggests that using the third-party option helped to reduce stress, but it also created a different set of challenges and power dynamics. As a management option, it allows PHB holders to have some choice and control. However according to Cora, the cost associated with using a third party means you may not have enough funding to purchase additional services thereby reducing the choices available to you.

The implementation process of the PHB roll-out programme appeared to have actively disempowered Cora even though she was more than capable of using a PHB. When compared to her previous experiences of budgets, it highlights the constraints of the medical model that limited the choices she was able to make. By imposing bureaucratic processes, it highlights the role of professionals and organisations in promoting or restricting choice and control.

Capability and Experience

Cora was educated to degree level, and she had done management training. While Cora was at university, she experienced discrimination and described herself as having had to develop resilience. Cora was also able to form relationships; she had moved into a new area when she bought her home away from her family support and built links in her new community. She had used her experiences to develop her career in advocacy:

> *"I faced discrimination and towards the end of my last course found the practical side of the course difficult. During my time as a student, I was a building rep for a year and supported 1st years through any problems they might have [……]. This I suppose was the start of my journey into equality, helping people and fighting for better services. I have always found it easier to fight for other people's rights more than my own."*

After university, Cora held many positions at senior level in the public and voluntary sector. She ran training programmes and empowered other people to become trainers. She also supported individuals that were taking on personal budgets with information and in meetings with regards to managing the changes. She also attended occasional local groups and was a volunteer and did advocacy work for disabled groups. Explaining her roles and experiences, she said:

> *"I still continued to be a trainer for [name of organisation] and help to plan and run courses for people with learning difficulties to become trainers in their own right. I also volunteered, sorting out policies and procedures and later became a member of the management committee. [……] I supported existing groups through the different changes they faced i.e., Personal Budgets. I also ran meetings to support voluntary and other organisations through the changes, had information stands and was involved in projects that were important for the area. I often worked across the whole of the county. [….] I was in a unique position as I had an understanding of the care system and services from both sides of the fence."*

Apart from her academic background and extensive work experience, Cora had first-hand experience of PHBs prior to roll-out:

> *"I was one of six people in the pre-pilot group in the area and all of us had different conditions. We had to learn how to do care plans, what sort of things needed to be in there and what documents would you include."*

Even with all her background knowledge, experiences, ability to function at a high level and articulate her needs, she had found PHBs challenging:

> *"I have been in the voluntary sector anyway and I have learnt how to explain what I want, how I want it and why, so I have the reporting skill."*

Cora clearly felt there was a high level of decision-making, experience and skills needed to manage some of the aspects of PHBs. She reported that even with her extensive managerial skills and experience at senior level, she found the administrative processes difficult and stressful. While Cora had received training and support during the pre-pilot phase to devise her own care and support plan, she still found the roll-out processes difficult. In particular this related to the assessments and having to justify her choice making with evidence, highlighting the complexity of the processes that PHB holders were expected to work with that created barriers to access as well as limiting choice and control.

Implementing the Care and Support Plan

The care and support plan that Cora went through when she initially went on the PHBs roll-out programme did not seem to have fully assessed her needs compared to the pre and pilot schemes. During the pilot phase, she had additional funding to manage her fluctuating condition effectively, which enabled her to purchase acupuncture, a bathing service, and two weeks respite at a hotel facility that she had found and was able to cater for her needs and keep her safe. When she went on the roll-out programme she lost that funding. Cora felt the focus had shifted to cost savings rather than overall well-being:

> *"So, yeah because I was employing my own PAs and the employment budget was free, I had enough money in my indicative budget. I stayed within my budget and did a few more things. Before my breathing got better, I was able to pay for respite care."*

Having a care and support plan in place that was holistic during the pilot, meant she could plan and manage risks and cater for those periods when her condition was not so good.

During the roll-out, she lost most aspects of the care package she was using which had proved essential in the management of her long-term condition:

> *"When I was involved in the pilot and my first 2 years or so of my personal budget (in social care), I did have acupuncture and other complementary therapies which helped me to manage my conditions. It was reduced to just acupuncture when I went over to PHBs [roll-out]."*

According to Cora, during the roll-out, she did not have an indicative budget and her funding was inadequate to cover her care and support needs. While the cost of care had increased, her budget value had remained the same and did not reflect the rise in the cost of care:

> *"It seems there should be an indicative budget, and also it should cover the cost of care in the care and support plan which mine doesn't have and the cost of care staff has gone up since I had mine, and this is 4 years later."*

The budget had also become more restrictive about what she could buy, compared to previously. While the care and support plan remained central to management of long-term conditions, according to Cora, the process was often confusing, not always individualised, and bureaucratic:

> *"There are your eligibility criteria, which in my case happened in November and there is the budget itself [………] So, I have met the criteria and I am on a health budget, but [the amount of] my new budget has not been approved yet."*

There were often long delays between eligibility, budget approval, and sign-off which delayed her access to the funding. Due to the way the implementation process was designed, it meant, even though Cora had qualified for PHBs, she was still far from using the budget and she found it difficult to plan. For example, she was purchasing bathing services which she valued greatly (see insert 1. of bath below).

Insert 1. Picture of Bath that Cora Purchased with her PHB

The bath to her was not just another means of keeping her clean. She used it for therapeutic reasons. According to Cora, the bath made her knees unlock and she would be in less pain therefore reducing the injections and medication she needed to manage her pain.

The delays in processing her funding meant she could not use the facilities, and this was often frustrating. She also could not recruit staff or purchase additional services apart from PA support:

> *"If I had a full team to start, they will still get paid, but any of the extra bits, so things like training which is extra, you got respite which is extra, all those things I can't access, acupuncture, the respite or bathroom service, I can't access, I am in sort of a limbo."*

Irrespective of the delays, the budget was subject to annual assessment, which meant she could get the budget and soon it would be time to start the process all over again:

> *"So, what I thought might happen was I still got my budget 12 months onwards, but they said no it always runs from November to November and annual assessments starts in November regardless."*

According to Cora, these delays were common in her local CCG and other PHB holders were having similar experiences:

> *"There are so many problems going on with PHBs everywhere, I know the nurse from my third-party option had a meeting with the CCG. Although I am the worst one thanks God, I am not the only one having these long delays."*

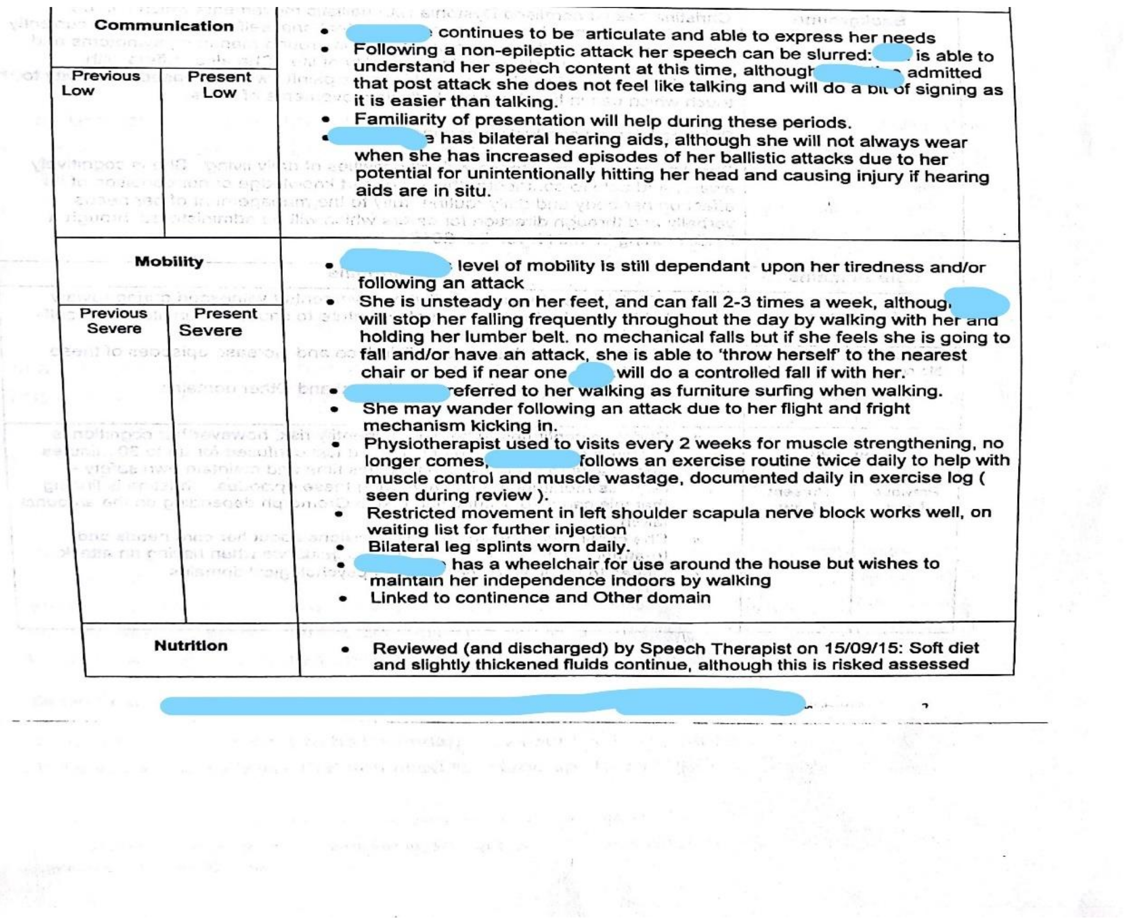
There was also often poor communication between the local PHB clinical lead, the third-party organisation and Cora, which meant issues were not always addressed on time:

> *"I have actually been in contact with my appointed person, and she has not got back to me not even acknowledging the email. When I wrote with all these questions about my PHB stating this and that etc., she didn't reply to me and I told her I still have all these issues and so she knows, and I haven't heard from her in two weeks. So yeah, I heard she is on leave and that was for a week and now its two weeks, so I don't know, I just now left it alone."*

With the PHBs, people can update their care and support plan if there are changes. When Cora updated hers and she included all the other therapies she had lost before, the CCG only partly approved the budget which delayed the process, but also made it more complex and difficult for her to understand how the PHB was going to work:

> *"They have now part approved it, they approved the fact that I have to have respite, the hourly rate, they have approved the number of hours, that sort of things [.......] they are not happy about my training, and they will not approve the budget until they have approved the whole components of it. So, when I thought they had approved it and I just got this training issue, they said no they are not going to start it."*

When I analysed her care and support plans starting from the roll-out period in 2015 and her current one which was being piloted in 2018, it became clear that at the beginning of PHBs roll-out, the care and support planning was very professional-led, and focus was on problems rather than asset based and did not look at the individual as a whole person. Cora appeared to have had very little participation, making it more of a tick box exercise than an assessment of care and support needs (see insert 2. below of part of the care and support plan).



Communication	Previous Low	Present Low	• [redacted] continues to be articulate and able to express her needs • Following a non-epileptic attack her speech can be slurred: [redacted] is able to understand her speech content at this time, although [redacted] admitted that post attack she does not feel like talking and will do a bit of signing as it is easier than talking. • Familiarity of presentation will help during these periods. • [redacted] has bilateral hearing aids, although she will not always wear when she has increased episodes of her ballistic attacks due to her potential for unintentionally hitting her head and causing injury if hearing aids are in situ.
Mobility	Previous Severe	Present Severe	• [redacted] level of mobility is still dependant upon her tiredness and/or following an attack • She is unsteady on her feet, and can fall 2-3 times a week, althoug [redacted] will stop her falling frequently throughout the day by walking with her and holding her lumber belt. no mechanical falls but if she feels she is going to fall and/or have an attack, she is able to 'throw herself' to the nearest chair or bed if near one [redacted] will do a controlled fall if with her. • [redacted] referred to her walking as furniture surfing when walking. • She may wander following an attack due to her flight and fright mechanism kicking in. • Physiotherapist used to visits every 2 weeks for muscle strengthening, no longer comes, [redacted] follows an exercise routine twice daily to help with muscle control and muscle wastage, documented daily in exercise log (seen during review). • Restricted movement in left shoulder scapula nerve block works well, on waiting list for further injection • Bilateral leg splints worn daily. • [redacted] has a wheelchair for use around the house but wishes to maintain her independence indoors by walking • Linked to continence and Other domain
Nutrition			• Reviewed (and discharged) by Speech Therapist on 15/09/15: Soft diet and slightly thickened fluids continue, although this is risked assessed

[redacted]

Insert 2. Copy of Care and Support Plan

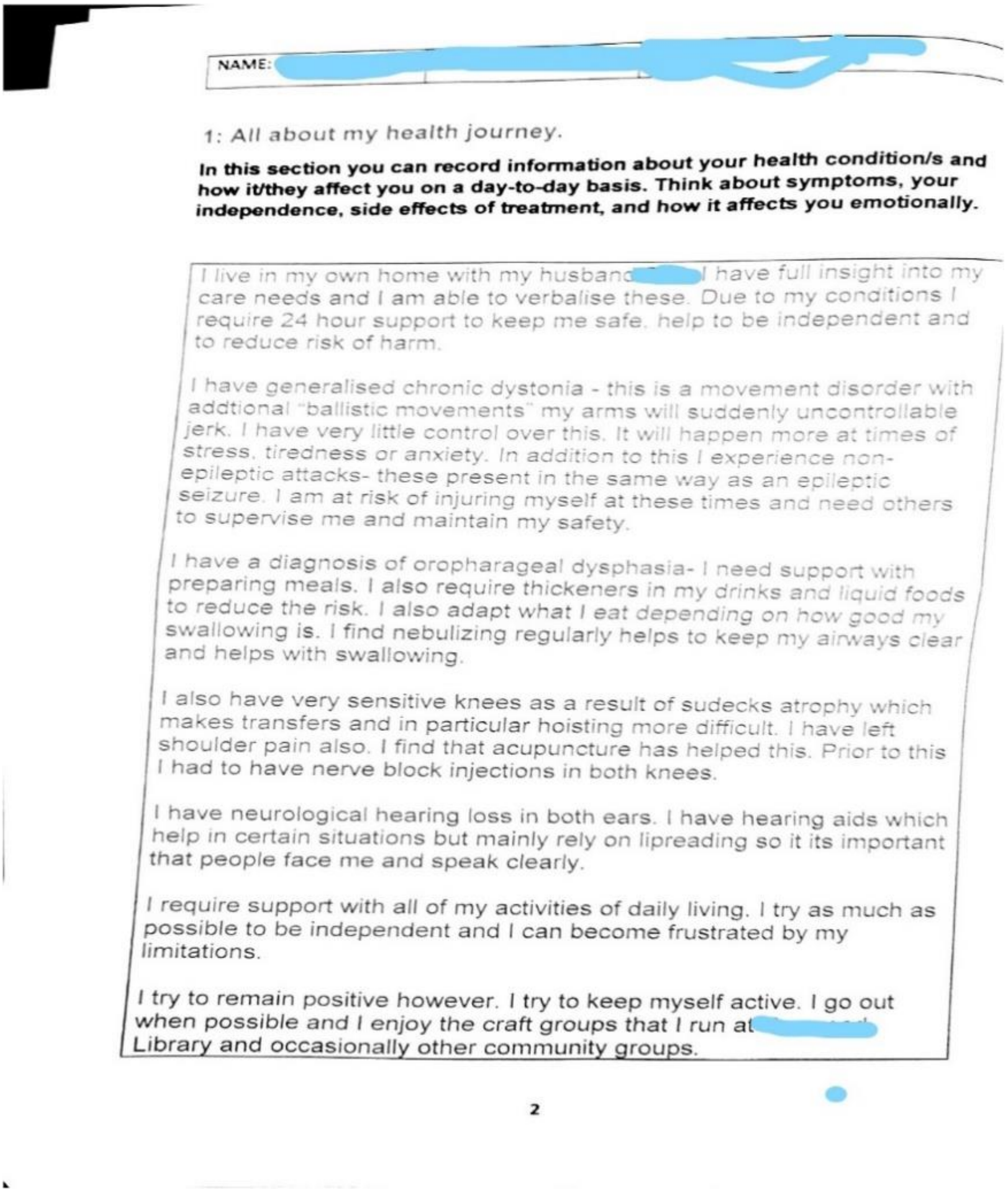
As well as being professional led, the care and support planning process was not co-produced. Cora had previously participated in care and support plans in which she had been actively involved. During those times, she and other pre-pilot budget holders had invested time and effort in materials for successful implementation of PHBs. Witnessing none of the implementer checklist being followed in the roll-out was frustrating for her. Comparing her roll-out experience and the pilot schemes:

> *"The pre-pilot and pilot had been co-produced, and we worked hard to set it up which is not the case now."*

As PHBs became more embedded, processes did start to improve and so did Cora's experiences. For example, her CCG trialled a new care and support plan that was more in tune with the PHBs framework. Compared to her 2014-2017 care and support planning, there was a remarkable difference to a similar page of her October 2018 care and support plan that was being piloted. Cora was no longer described as a" bundle of needs" (her words) and even though the signing off was delayed, the care and support plan appeared to address her needs fully resulting in an increase in her budget in March 2019. She explained how she had been actively involved in the process:

> *"I had a meeting in February with my PHB Support Officer (the person who dealt with my budget) and my…case manager (who deals with the support plan side of things) came to see me face to face and we went over my care and support plan and what I wanted. I was able to raise concerns about my budget and was able to explain things as things came up."*

Cora attributed the holistic approach to her care and support plan to the fact that she had participated fully, and everyone involved had contributed to the process rather that it being a top-down approach. Although the content was still very similar, the approach was different, it was more person centred and holistic (see insert 3. below for comparison).



NAME: [redacted]

1: All about my health journey.

In this section you can record information about your health condition/s and how it/they affect you on a day-to-day basis. Think about symptoms, your independence, side effects of treatment, and how it affects you emotionally.

I live in my own home with my husband[redacted] I have full insight into my care needs and I am able to verbalise these. Due to my conditions I require 24 hour support to keep me safe, help to be independent and to reduce risk of harm.

I have generalised chronic dystonia - this is a movement disorder with addtional "ballistic movements" my arms will suddenly uncontrollable jerk. I have very little control over this. It will happen more at times of stress, tiredness or anxiety. In addition to this I experience non-epileptic attacks- these present in the same way as an epileptic seizure. I am at risk of injuring myself at these times and need others to supervise me and maintain my safety.

I have a diagnosis of oropharageal dysphasia- I need support with preparing meals. I also require thickeners in my drinks and liquid foods to reduce the risk. I also adapt what I eat depending on how good my swallowing is. I find nebulizing regularly helps to keep my airways clear and helps with swallowing.

I also have very sensitive knees as a result of sudecks atrophy which makes transfers and in particular hoisting more difficult. I have left shoulder pain also. I find that acupuncture has helped this. Prior to this I had to have nerve block injections in both knees.

I have neurological hearing loss in both ears. I have hearing aids which help in certain situations but mainly rely on lipreading so it its important that people face me and speak clearly.

I require support with all of my activities of daily living. I try as much as possible to be independent and I can become frustrated by my limitations.

I try to remain positive however. I try to keep myself active. I go out when possible and I enjoy the craft groups that I run at[redacted] Library and occasionally other community groups.

2

Insert 3. Copy of Pilot Care and Support Plan

My analysis suggests that at the beginning of the roll-out programme the care and support plan that Cora underwent was very professional-led and Cora had very little input. It was medically dominated and failed to fully assess her needs. As PHBs became more embedded in practice, the processes improved. Cora was able to actively participate in the care and support planning with decision-making being a shared process.

The excerpts suggests that there was something unique about the pilot context that was very different in nature to the larger roll-out phase, and that it has taken time to get back to a more person-centred approach. This emphasises how context matters but also it suggests the need for caution when using pilot data to inform policy decisions and innovations such as PHBs. From these excerpts, it is also evident that co-production is an important part of PHBs implementation. Drafting the care and support plan was an opportunity to build relationships based on mutual respect and to take account of the value that PHB holders can bring to the process. The role of co-production, and other elements of Cora's experience of holding a PHB will be examined in more detail in the next chapter to link together the context and mechanisms with the outcome of choice and control.

5.2.2 Case Two, Steve's Story – 'The Power of Four'

Like Cora, Steve also had a story to tell, and he titled his '**the Power of Four'** when he was giving talks about PHBs. Steve went on PHBs during the roll-out phase in 2014 using a direct payment. In 2015, he requested that his PAs be trained to deliver his care including district nursing care, causing some resistance amongst professionals. Training of PAs was completed in 2017. By 2018/19 when this study took place, district nursing visits had reduced from 200 to single digit visits a year. Fig. 5 below shows a timeline of the change over time that took place when Steve used PHBs to exercise choice and control.

Fig 5- Time Line Denotes Change Over Time That Took Place When Steve Used PHBs to Exercise Choice and Control

All parties New to PHBs

Steve's requests minimal and professionals more flexible

2014

- **CCG embark on PHB programme roll out and ask Steve to take up PHBs. Both parties new to PHBs** (Steve accepts and negotiate terms)
- **PHB- Direct Payment commences** (Care assessment, care and support plan, and PHB value agreed)
- **Funding leve**l (2 hour physiotherapy, 24 hour PAs)
- **Cholorectal and Urology agree to train District nurses** (provision of bowel and catheter care)
- **Unscheduled review** (standing frame added to package)

Steve evaluated impact of care being provided by DNs and asks for change

2015

- **Care reviewed** (value of package remains the same)
- **Quality of District nursing (DN) service impacting negatively on Steve's quality of life** (-DN not turning up or turning up late, unable to go out, reduced work output, staying impacted, eating frozen foods, broken skin, PAs not sleeping on time) .

Lag in time due to professional resistance, power dynamics and negotiations taking place

2016

- **Care reviewed and value of package increased** (Respite care added)
- **March-Steve put proposal to get PAs trained** (Steve asks to use peristen. Delegation needed for bowel care, supra pubic catheter and Autonomic disreflexia management and DN to trained and supervise PAs at a cost)
- **August-** increased cost of physiotherapy
- **December -** PAs training approved and pay rates increase agreed

Both parties reach a compromise,

Changes in care and support and increase in cost

2017

- **Care reviewed** (value of package reflecting changes in 2016 -2 hour physiotherapy, 24 hour PA support, PAs training and wage increase. respite care included
- PA provision of delegated care and district nursing visits reduced and only offering routine care and emergencies (visits drop from over 200 to single digits)

Improved Outcomes and reduction in cost

Steve more innovative in his use of the PHB

CCG less flexible with spending

2018/ 19

- **Reduced his regular care hours to build in contigency care** (from 168-162 hours per week)
- **Another care provider added to the package** (6 hours per week)
- **Recruitment and DBS costs added**
- **Muscle stimulator machine included**
- District nursing visits so few and DN team wanting to discharge Steve
- No emergencies or hospital admissions
- Steve request high riser for his wheelchair and allowed to purchase
- Request riser for a bed outside NHS and that was refused -told to use conventional providers with NHS contracts
- Request ceiling hoist and that was refused - and redirected to block contract

Steve's story "**the power of four**" related to the timelines shown in Fig. 5 above – how he had used an innovation he purchased with his PHB which he felt had improved four things: his overall health and wellbeing, his PAs knowledge, and competences, reduced the district nursing visits and cut the cost of his healthcare.

Steve went around England giving his personal experiences of being a PHB holder and would tell his story. I observed one of these talks which gave me a lot of insight into Steve's experiences of PHBs. I had three observations, two opportunistic and one scheduled. Steve was using his PHB to also purchase physiotherapy performed at his flat. I had gone to observe this when the physiotherapist cancelled just before I got there. Since he was giving a presentation session to NHS professionals on PHBs at a community hospital, he asked me if I wanted to come along to that instead. Over the period of the study, wheelchair budgets were introduced, and I also observed him receiving his wheelchair. This was at an NHS community hospital where they were doing a video shoot of the presentation to promote wheelchair budgets.

Complexity of Health and Social Care Needs

Steve was of white British background. He was a male in his early 40s and lived independently with the help of PAs paid through his PHB. He shared his space with his cat and his PAs, who did day shifts and sleep-ins. I was able to conduct the research with Steve from the beginning of the study to the end and had all the 8 contact points approved in the research ethics.

During our conversations I learnt that Steve had suffered a serious accident resulting in spinal/ neurological injury. All four limbs were affected, and he had some minor movement and sensation in the arms. As a result, Steve required 24- hour care and support. Steve was not able to drink or feed himself without help. He had high level needs enabling him to qualify for continuing healthcare and subsequently PHBs. With the little movement in his right hand, he would manipulate most of his gadgets, assistive technology, phone, laptop, and remote controls that he attached to the arm of his wheelchair.

One complication of his condition was spasms, and he had some limb/ body pain and was at high risk of Autonomic Dysreflexia (AD), another symptom of his condition:

> *"Thankfully, my spasm and autonomic dysreflexia meant I did qualify for continuing healthcare."*

Indicators of AD included severe pain in catheter, increased spasms, severe headaches, or high body temperatures and could be fatal if not managed quickly. It is a life-threatening illness that requires access to emergency services and possible hospital admission if the condition is not managed properly. Having such complex needs meant he required PAs with enhanced skills:

> *"The first time anyone works with me, it takes longer to get ready just by default."*

Like Cora, not only was Steve's condition complex but also finding the calibre of people willing to take that level of responsibility could prove difficult. Although Steve had such high-level disabilities with life threatening conditions, greater needs and vulnerability, the severity of his condition did not seem to hinder his ability access and use a PHB.

Being Your Own Care Manager

Unlike Cora, Steve only had experience of using the direct payment route. However, he had also used a direct payment in social care before qualifying for continuing healthcare funding and subsequently being eligible for a PHB in 2014. Steve opted for a direct payment route to get more autonomy. With the direct payment, Steve felt he had full control over decisions that affected him, how he accessed resources, managed his care, and interacted with the healthcare system. Steve explained his reasons:

> *"I know there are the various methods in which one can have a budget e.g., notional, third party or direct payment, for me it was only going to be a direct payment because I wanted direct control over it."*

With his direct payment, Steve purchased 24-hour PA support, contingency care, respite care, PA training and physiotherapy. According to Steve, by employing his own PAs rather than using the agency, he had the freedom to decide and direct his care and associated outcomes. He could plan and control the quality of care and make decisions that he felt were important, enabling him to receive care and support that was responsive to his needs and preference. Just like Cora, Steve valued this aspect of PHBs. When explaining what employing his own PAs meant to him, Steve had this to say:

> *"[It means] being able to get up when I want to, have the care I need, when it is needed, have prompt and efficient PAs who know me well and are able to support*

> *me."*

Being a PHB holder using a direct payment also meant Steve was now a direct purchaser of services. With that, he had options over what to purchase, who provided it, how and when. He chose to employ the same team of PAs he had under the social care direct payment and transitioned to PHBs with them, enabling him to have continuity of care:

> *"It's the small things I do every day, what I want, when I want and how I want, rather than having to wait for a service."*

When Steve embarked on his PHB journey the commissioning of some aspects of his care moved from the Colorectal and Urology Clinic to the District Nursing team. At the time, he was receiving specialised care support from the district nurses to manage his catheter and bowels. However, having control of the budget meant Steve was now responsible for negotiating directly with providers. He felt he could get value for money because he was now controlling the financial resources and was accountable:

> *"I was raised in an environment where we were taught to be independent minded and not depend on the system. So, for me having to depend on the nurses and wait for them to turn up, that doesn't feel right or sit right at all."*

By turning up late or not turning up at all, Steve felt that the district nurses were undermining his ability to manage his condition effectively and have positive outcomes:

> *"I wanted to go and do more stuff and when you have to lie around waiting for two hours waiting for the nurses to turn up every single time, 180 times in a year, that's*

> *300 odd hours. Your life goes into waiting and when they don't turn up, it was increasing my chances of autonomic dysreflexia happening."*

Waiting for the district nurses to help him manage that aspect of his care was taking a toll on his health and quality of life:

> *"That whole thing of having to wait for district nurses, I never dismissed them for the service they provided because they have always done the best, they can but the impact it had on my life was just massive."*

Having reached breaking point, Steve decided to be more innovative and requested that he use his PHB to buy a peristeen and get his PAs trained to manage his care. A peristeen is a trans-anal irrigation system which is used for faecal incontinence and constipation. There are risks associated with the gadget, but also issues around accountability and professionalisation. Steve commented on the outcome of his decision:

> *"I am a lot less stressed than I was. It was just one of those things, running a business and you have all those restrictions, and I was limited so much in time [……] whereas now having that much more time in the day, I can do 10-6 and I have evenings free and the weekend free to do what I want. […….] it's a cumulative of a lot of little things."*

The PHB allowed Steve to be a manager of his own care. He was responsible for making decisions that he felt would help in the management of his long-term condition, improve his experiences and psychological wellbeing. By using the peristeen, the PAs were able to meet his daily needs while the district nurses provided back up service should complications arise. That way he was able to manage his bowels and be at low risk of autonomic dysreflexia, thereby increasing his ability to cope with adversity and reduce his need to access emergency services.

Capability and Experience

I was keen to understand how Steve was able to manage his PHB, considering his health and physical limitations. He attributed this to his education, family background and support networks:

> *"I have had a very fairly good education, very strong family background around me so I can navigate through the mess that is within the health and social care system and a lot of people can't."*

When the accident happened, Steve had just completed his GCSEs and went on to complete A-levels and progressed to university. He also ran his own business. He acknowledged that he used his past knowledge and skills to inform his decision-making and the choices he made as to the quality of care and support he was purchasing:

> *"Having run a business I know how things go in terms of paperwork, payroll and stuff like that, doing things like DBS, staff training, all those things"*

His previous experience of direct payments in social care also enabled him to use PHBs direct payment more easily:

> *"I have gone through adult social care, continuing healthcare and personal budgets."*

Steve considered himself to be knowledgeable and an expert:

> *"I am an expert in what it is you asking me and that is the general approach I take to doing this kind of stuff."*

Steve worked from home and had multiple business interests, one being technology. At the time of the study, he was helping people in a similar position to him to coordinate their PAs. Apart from running his own technology business he composed music. While he did most of his work, he required assistance from his PAs to set up his equipment, get to places etc. He sat on several organisational boards and was a member of peer support groups. As someone using a variety of services, he used to talk about his experience regularly to a range of health and social care professionals, and undergraduates at local universities. At the time of this study, Steve was working with NHS England championing the personalisation agenda through his lived experience story of managing his PHB.

From the interactions and observations that took place, Steve appeared to be very assertive and articulate, for example when he was telling me about the review of his care and support needs, he had this to say:

> *"So, because I was able to read about all this stuff, understand all this stuff, when they came to do my assessment and they said I had probable qualification [suggesting uncertainty about whether Steve would meet the eligibility threshold to qualify for funding], I said you fucking make sure I better qualify because I know I do."*

As with Cora, Steve's education and work experiences may have influenced how he navigated the PHBs landscape, accessed information, made informed decisions, and articulated his needs which other people without those skills and experiences might find difficult to do.

Implementing the Care and Support Plan

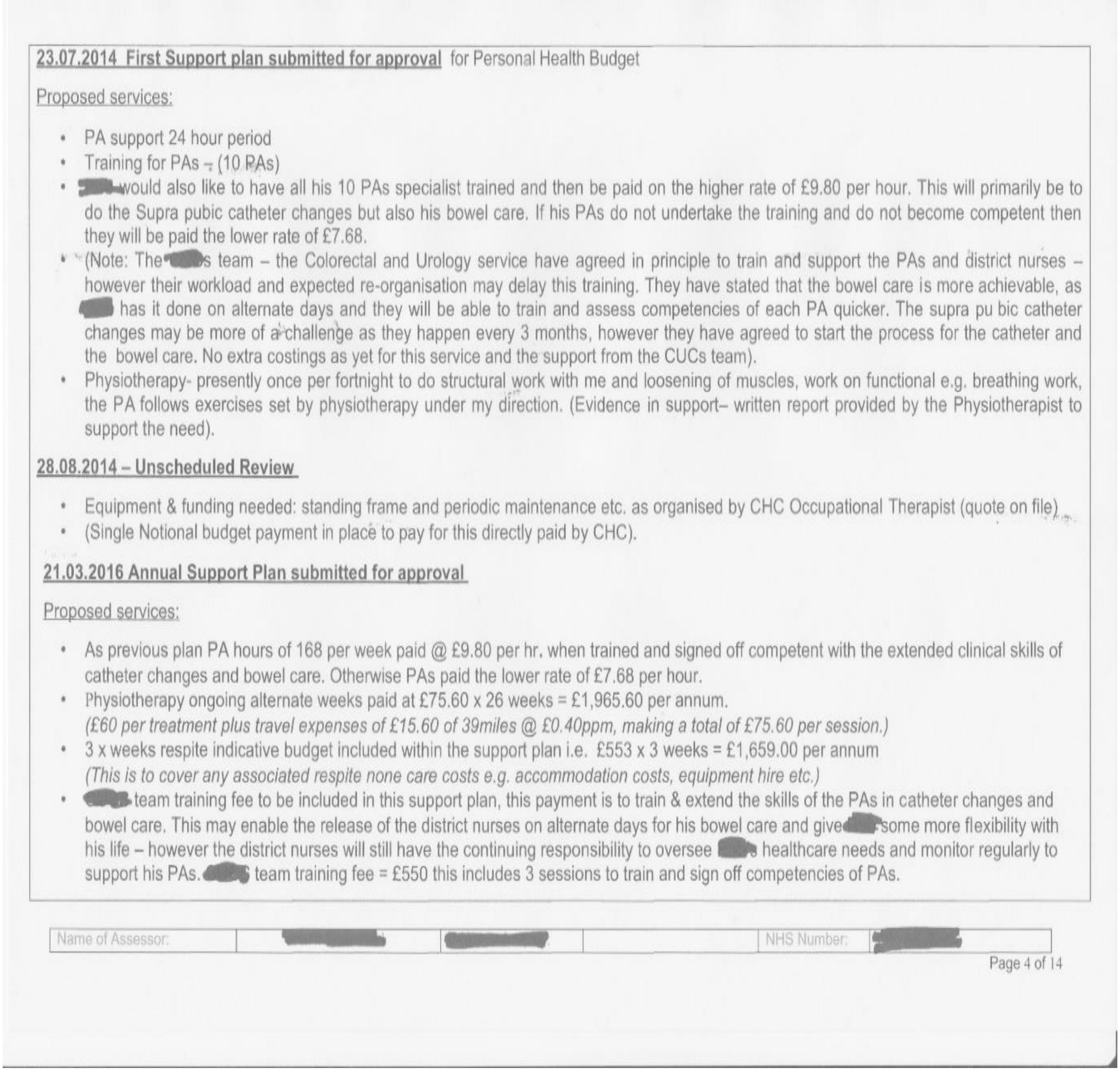
In contrast to Cora who had previous experience of the PHB pilot before the PHB roll-out, both Steve and the professionals in his area were new to PHBs at the roll-out phase, although they had had the social care experience. According to Steve, professionals were still trying to understand how to implement PHBs in practice and were open to learning:

> *"For me when my care plan was put together, my joint care manager came out and said we are only really getting started on this and we can all really learn a lot from you, what is it that you want to get out of this? And when they were putting my care plan together, I literally gave them a mini biography of my website and she copied and pasted that into my care plan. So that was co-production for me in its finest form."*

The excerpt highlights that, like Steve, the health care professionals did not have experience of the PHB implementation process. There was shared learning and co-production, in contrast to Cora's initial care and support planning, which was professionally led and focused on problems, with little input from Cora. Steve's care and support plan appeared to be centred around what he wanted to achieve with his PHB, and he had real input and the professionals had supported him to achieve his aspirations. This was a key factor in why Steve's initial experience of roll-out of PHBs was positive.

In Steve's care and support plans (see insert of Doc 1-3 below highlighting the annual budget values and yearly reviews), the care and support needs and funding were documented including the indicative budget.

Insert 4. Doc 1 – Steve Care and Support Plan -showing the yearly budget values



23.07.2014 First Support plan submitted for approval for Personal Health Budget

Proposed services:

- PA support 24 hour period
- Training for PAs – (10 PAs)
- [redacted] would also like to have all his 10 PAs specialist trained and then be paid on the higher rate of £9.80 per hour. This will primarily be to do the Supra pubic catheter changes but also his bowel care. If his PAs do not undertake the training and do not become competent then they will be paid the lower rate of £7.68.
- (Note: The [redacted]s team – the Colorectal and Urology service have agreed in principle to train and support the PAs and district nurses – however their workload and expected re-organisation may delay this training. They have stated that the bowel care is more achievable, as [redacted] has it done on alternate days and they will be able to train and assess competencies of each PA quicker. The supra pu bic catheter changes may be more of a challenge as they happen every 3 months, however they have agreed to start the process for the catheter and the bowel care. No extra costings as yet for this service and the support from the CUCs team).
- Physiotherapy- presently once per fortnight to do structural work with me and loosening of muscles, work on functional e.g. breathing work, the PA follows exercises set by physiotherapy under my direction. (Evidence in support– written report provided by the Physiotherapist to support the need).

28.08.2014 – Unscheduled Review

- Equipment & funding needed: standing frame and periodic maintenance etc. as organised by CHC Occupational Therapist (quote on file)
- (Single Notional budget payment in place to pay for this directly paid by CHC).

21.03.2016 Annual Support Plan submitted for approval

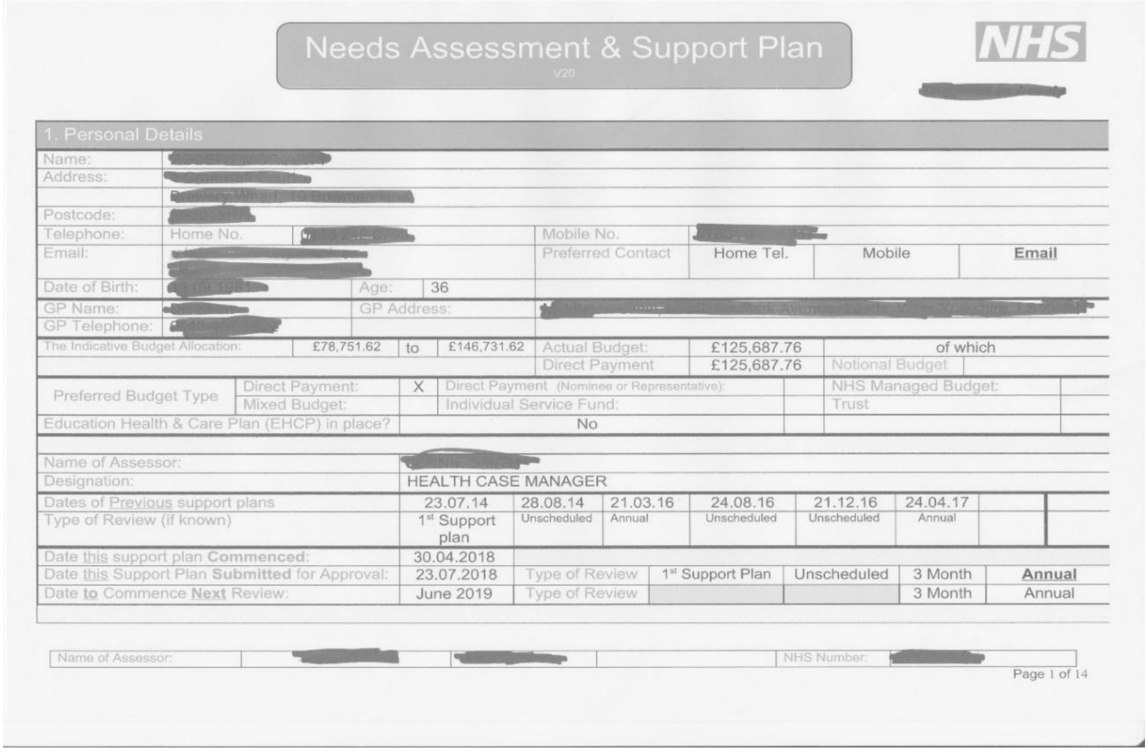
Proposed services:

- As previous plan PA hours of 168 per week paid @ £9.80 per hr. when trained and signed off competent with the extended clinical skills of catheter changes and bowel care. Otherwise PAs paid the lower rate of £7.68 per hour.
- Physiotherapy ongoing alternate weeks paid at £75.60 x 26 weeks = £1,965.60 per annum.
  (£60 per treatment plus travel expenses of £15.60 of 39miles @ £0.40ppm, making a total of £75.60 per session.)
- 3 x weeks respite indicative budget included within the support plan i.e. £553 x 3 weeks = £1,659.00 per annum
  (This is to cover any associated respite none care costs e.g. accommodation costs, equipment hire etc.)
- [redacted] team training fee to be included in this support plan, this payment is to train & extend the skills of the PAs in catheter changes and bowel care. This may enable the release of the district nurses on alternate days for his bowel care and give [redacted] some more flexibility with his life – however the district nurses will still have the continuing responsibility to oversee [redacted]s healthcare needs and monitor regularly to support his PAs. [redacted] team training fee = £550 this includes 3 sessions to train and sign off competencies of PAs.

Name of Assessor:	[redacted]	[redacted]		NHS Number:	[redacted]

Page 4 of 14

Doc. 2 – Steve Care and Support Plan – highlighting annual reviews



Needs Assessment & Support Plan
V20

NHS

[redacted]

1. Personal Details

Name:	[redacted]					
Address:	[redacted]					
	[redacted]					
Postcode:	[redacted]					
Telephone:	Home No.	[redacted]	Mobile No.	[redacted]		
Email:	[redacted]		Preferred Contact	Home Tel.	Mobile	**Email**
Date of Birth:	[redacted]	Age:	36			
GP Name:	[redacted]	GP Address:	[redacted]			
GP Telephone:	[redacted]					

The Indicative Budget Allocation:	£78,751.62	to	£146,731.62	Actual Budget:	£125,687.76	of which	
				Direct Payment	£125,687.76	Notional Budget	

Preferred Budget Type	Direct Payment:	X	Direct Payment (Nominee or Representative):		NHS Managed Budget:	
	Mixed Budget:		Individual Service Fund:		Trust	
Education Health & Care Plan (EHCP) in place?		No				

Name of Assessor:	[redacted]
Designation:	HEALTH CASE MANAGER

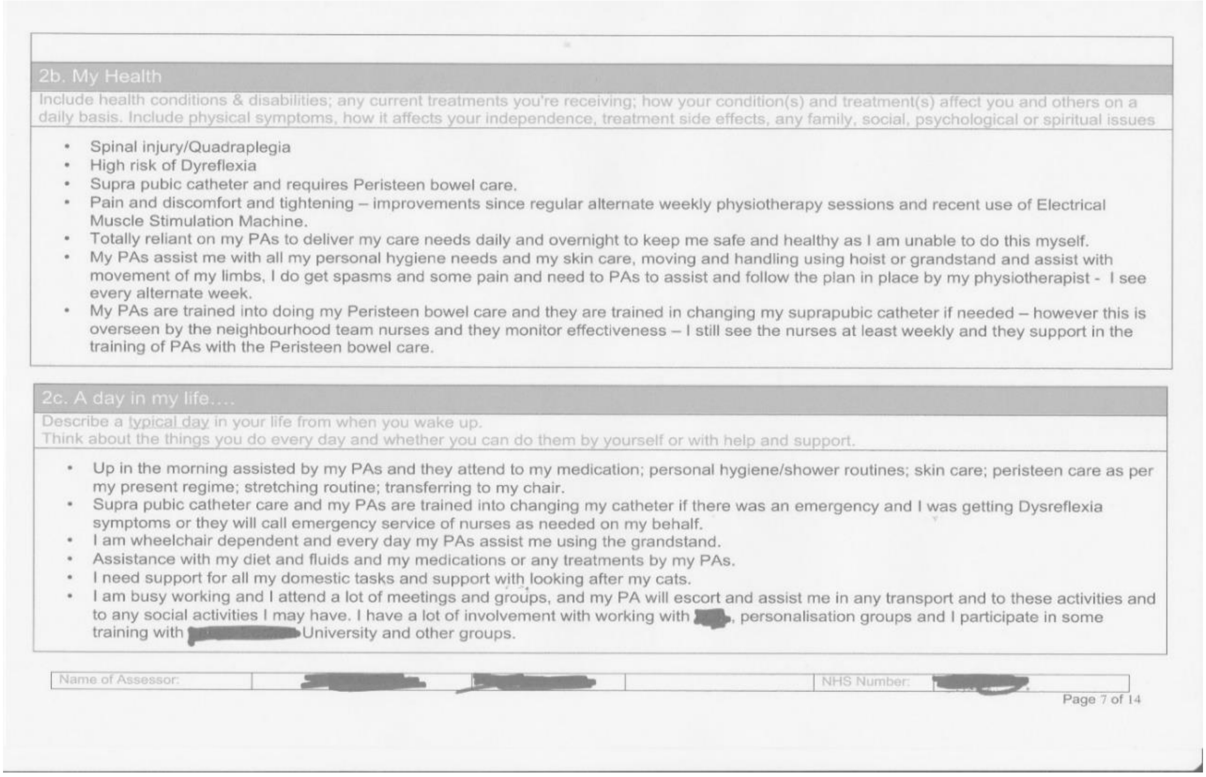
Dates of Previous support plans	23.07.14	28.08.14	21.03.16	24.08.16	21.12.16	24.04.17	
Type of Review (if known)	1st Support plan	Unscheduled	Annual	Unscheduled	Unscheduled	Annual	

Date this support plan **Commenced**:	30.04.2018					
Date this Support Plan **Submitted** for Approval:	23.07.2018	Type of Review	1st Support Plan	Unscheduled	3 Month	**Annual**
Date to Commence **Next** Review:	June 2019	Type of Review			3 Month	Annual

Name of Assessor:	[redacted]	[redacted]		NHS Number:	[redacted]

Page 1 of 14

Doc. 3 – Steve Care and Support Plan- continued



2b. My Health

Include health conditions & disabilities; any current treatments you're receiving; how your condition(s) and treatment(s) affect you and others on a daily basis. Include physical symptoms, how it affects your independence, treatment side effects, any family, social, psychological or spiritual issues

- Spinal injury/Quadraplegia
- High risk of Dyreflexia
- Supra pubic catheter and requires Peristeen bowel care.
- Pain and discomfort and tightening – improvements since regular alternate weekly physiotherapy sessions and recent use of Electrical Muscle Stimulation Machine.
- Totally reliant on my PAs to deliver my care needs daily and overnight to keep me safe and healthy as I am unable to do this myself.
- My PAs assist me with all my personal hygiene needs and my skin care, moving and handling using hoist or grandstand and assist with movement of my limbs, I do get spasms and some pain and need to PAs to assist and follow the plan in place by my physiotherapist - I see every alternate week.
- My PAs are trained into doing my Peristeen bowel care and they are trained in changing my suprapubic catheter if needed – however this is overseen by the neighbourhood team nurses and they monitor effectiveness – I still see the nurses at least weekly and they support in the training of PAs with the Peristeen bowel care.

2c. A day in my life….

Describe a typical day in your life from when you wake up.
Think about the things you do every day and whether you can do them by yourself or with help and support.

- Up in the morning assisted by my PAs and they attend to my medication; personal hygiene/shower routines; skin care; peristeen care as per my present regime; stretching routine; transferring to my chair.
- Supra pubic catheter care and my PAs are trained into changing my catheter if there was an emergency and I was getting Dysreflexia symptoms or they will call emergency service of nurses as needed on my behalf.
- I am wheelchair dependent and every day my PAs assist me using the grandstand.
- Assistance with my diet and fluids and my medications or any treatments by my PAs.
- I need support for all my domestic tasks and support with looking after my cats.
- I am busy working and I attend a lot of meetings and groups, and my PA will escort and assist me in any transport and to these activities and to any social activities I may have. I have a lot of involvement with working with [redacted], personalisation groups and I participate in some training with [redacted] University and other groups.

Name of Assessor:	[redacted]	[redacted]		NHS Number:	[redacted]

Page 7 of 14

The documents show a process that aligns with how care support planning should be. Steve was clear about the health and wellbeing outcomes he wanted to achieve and had made choices about how he was going to spend the budget. Steve also knew upfront how much he had to spend, and the CCG was transparent in its allocation of resources. From the care and support plan, it was evident that the CCG had met all essential features of PHBs (as outlined in Table 1. Page 11) in its implementation process which are key to co-production and principles of personalisation.

The care and support plan had also addressed health and well-being, considered the risks Steve had chosen to take for example with regards to his PAs taking over some of the district nursing responsibilities. When talking to Steve, he was generally happy with how his PHB had been implemented. Also, the care and support plan showed that Steve's care was also being reviewed regularly, reflecting that his local CCG, was to some extent responsive to the individual's needs.

The care and support plan also indicated that there were changes at each review point as to the services that Steve was purchasing. For example, there was a marked increase between 2014 and 2018 as to the level of services Steve had purchased. The document also highlights significant changes in the indicative budget allocation. There was an increase between 2014 and 2018 from £78 751.62 to £146 731.62, almost double the value. The changes were in line with how Steve's purchasing had also changed from initially using his PHBs to pay for PAs and physiotherapy to buying more innovations such as use of peristeen, equipment etc.

Apart from looking at the documents, I also observed Steve being given his wheelchair, which he bought partly out of the PHB. I collected an artifact taken during a video shoot to promote wheelchair budgets and below in insert 6. is a picture of Steve in the wheelchair.

Insert 5. Picture of Steve's High Riser Wheelchair

The processes had involved assessment of needs and identifying the right equipment to meet his care and support needs. Steve had left over money in his budget, and he decided to use £500 of that money alongside the wheelchair notional budget to jointly purchase a wheelchair with a high riser. During the video shoot, Steve was asked by the presenter about his experience of the process, and this was his response to the question:

> *"I would say for the first time I have sat with someone and looked at what my proper needs are for a wheelchair and looked at what's out there in the market"*

Steve had been actively involved in the assessment and choice process. Furthermore, Steve regarded the process as a joint action:

> *"My physiotherapist was present during the moulding process so that I could be positioned and fitted properly. So, for all of those reasons I am now sitting in the correct position and in far less pain than before, so I can actually do more work during work time and productively."*

As a result of working collaboratively, Steve felt that his needs were fully met. When compared to previous experience before he had a PHB. He commented:

> *"So, when I was assessed at the hospital, they didn't quite fully meet my needs and trying to put a backrest, it quite didn't fit."*

Steve explained how this had contrasted with his current experience of PHBs:

> *"So, treating those two fundamentals [choice and control] has been important. It means I have the flexibility to live that independent life I want to."*

The wheelchair goes up and down from a sitting to full-size standing position. It has automated functions and Steve can independently operate it, taking some of the work from

PAs such as adjusting his sitting and stretching his legs. It allowed Steve to socialise with friends at the same level when he went out or was clubbing. When working, or doing his presentations, he could adjust it to suit his audiences. The stretch function enabled him to stretch out and it had a comfortable back rest allowing him to spend more time in his wheelchair and work for long periods:

> *"PHB and wheelchair budget have fitted in very well with the whole personalisation impact I have had over the past 4 years. It's kind of looked at my whole life, not only my needs but my whole person, what I wanted to achieve in life, being able to contribute to society."*

Apart from meeting his physical needs, the process had been holistic, giving Steve a sense of purpose. He could see himself making meaningful contributions. Steve viewed the processes and experiences he was going through with his budget as moving away from the traditional methods of service provision. He had this to say:

> *"It's supposed to be having an equal conversation with someone, [……..] what we are trying to do is have you included as part of the discussion, feeling you're able to contribute, and you're treated as an equal."*

For Steve, both the care and support plan and wheelchair budget fitted in with co-production. While professionals had supported Steve, he also had a key role in deciding and activating what had been agreed. In that respect, he took responsibility for coordinating his own care and managing the budget.

5.2.3 Case Three, Karen's Story – *"Bully Me And I Will Bully You Back"*

I had two face to face contacts with Karen over an 8-month period. The other contacts were by phone and email which was her preferred way (first contact in April 2018) and she dropped out of the study. Due to the sensitive legal nature of her experiences, we had to discuss issues of confidentiality and risk management. So, the messages were encrypted, and emails deleted after retrieval.

Karen's experiences of PHBs were from 2014 – the roll-out phase – and were very negative. She faced many challenges at the beginning and the negative experiences appeared to be the extreme of the three case studies. These experiences however changed with time. Fig. 6 below denotes change over time in Karen's experience of PHBs between our first and the second encounter.

Fig. 6. Denotes Change Over Time in Karen's Experiences of PHBs Between Visit 1 and Visit 2 of the Ethnography

Negative experiences

All parties new to PHBs although Karen had experience in using direct payments in social care

Visit 1 - Experiences Before Change

Since being on PHBs, Karen was unhappy and was finding it difficult to manage her long term conditions because:

1) She felt professionals were exerting unnecessary power which she classified as bullying

2) She was not involved in care and support planning and her care plan was not being reviewed

3) Care and support plan had not been signed off

4) Her budget was inadequate to cover the cost of her care

5) She had no choice and control over the money and how to spend it

6) She had no indicative budget

7) She felt her CCG was making too many bureaucratic demands on her causing stress and anxiety

8) Any efforts to address this was being met with resistance

9) Karen was resisting and also putting pressure back

10) Mistrust and no active involvement, not keen on working with NHS England

Bottom-up demand for culture change and implementation process

The Changes that Took Place

1. Formed local peer support network

2. Collectively initiated a public investigation of the CCG

3. Sought support, information and learning from NHS England and user groups

4. CCG appoint new management team with clinical experience

5. Karen involved in implementation process bringing in service user input

6. Shared decision making in place at strategic level

7. Review of information and local guidance

8. Review of all budgets, and new systems put in place

9. Culture change

10. Co-production principles in place

11. Implementation process simpler and transparent in resource allocation

10. Continued with advocacy work to ensure other PHB holders in the locality had equal access to resources and support

Improved health and well-being outcomes for Karen

Visit 2 - Experiences After Change

1. Full assessment of needs and individual outcomes identified

2. Had indicative budget

3. Care and support plan with nearly all elements agreed

4. Karen knew value of the budget

5. Increase in budget award by £63 000 almost double the original value

6. Karen had autonomy over care and support, decisions, as well as choice and control over the money

7. Felt empowered and valued as an expert of her condition

8. PHB flexible, less restrictive and positive risk management

8. Actively involved and having purpose and community presence

9. Positive experiences and outcomes reported

10. Saving NHS money by giving back the £63 000, she had done without it and has learnt to cope

More resilient as a result of the experience

When I first had contact in April 2018, Karen was still experiencing the challenges highlighted in Fig. 6 above, and she instigated a collective public investigation into her local CCG through the office of the Ombudsman, which ruled out in favour of PHB holders. So, in our first contact, Karen was emotional with all this still going on. However, over the course of our contacts, those experiences changed and became positive as shown in Fig. 6 as PHBs became more embedded in practice, in line with the insights from the other cases about how PHB experiences change over time. Like Steve and Cora, Karen had used direct payments in social care prior to transitioning to PHBs.

Karen used her PHB to employ live-in carers (PAs) and I met with two of them during my visit. I was not able to observe an activity that she was purchasing with her PHB because personal care/ washes were excluded from what I could observe. Unlike the other 2 cases, I was not able to collect artifacts. Karen dropped out of the study because she had become too busy with her advocacy work and could not commit to the long period of the ethnographic study. Therefore, the data used in this ethnography was from analysis of the interview and documents. I present the findings below:

Complexity of Health and Social Care Needs

Karen was white British, a female in her 40s, and lived in a city flat in East of England. Karen suffered from spinal muscle atrophy since birth (spinal fusion of the spine to the pelvis) and scoliosis. Karen explained her condition as follows:

> *"I have got a degenerative condition and I was born disabled, and I have never been able to weight bear or walk, so functionally I have lost a lot of mobility, strength in my arms and legs and stuff but it is quite a stable condition, it's complex."*

Karen suffered from pain on movement resulting in limited strength and took regular medication. She used her powered wheelchair for transfer and a ceiling hoist. Due to the nature of her condition, Karen had poor function in her right arm and experienced muscle function loss and lacked energy to manoeuvre her wheelchair. She felt her condition was taking over and she would at times in our discussions get into a low mood. However, she did not seem to consider herself in a passive role as she described her approach to the illness:

> *"I am certainly not a victim of it, you know everyone has things that they don't like about themselves, mine is just a little bit more obvious than everyone else's, but as well in terms of my mentality, my approach to it more than makes up for it. What the universe has taken from me in physical weakness it has given me in mental strength, so you know swings and roundabouts really."*

She had limited lung capacity and a history of pleurisy and chest infection. Her condition although complex, was quite stable, in as much as she was respiratory compromised, it was not unpredictable. Karen used complementary therapeutic interventions alongside conventional methods:

> *"So, if I have a chesty cold, it can get a little bit nasty, that requires a lot of intervention in terms of steam bowls and chest physio and the like but yeah I am fairly stable and I'm very comfortable with my disability like it's a practical issue for me. I have always*

> *had it and I am always going to have it and its always going to get worse and there is nothing I can do about it so; I cope and make the most of it"*

As much as Karen was limited physically, she lived independently with the support of live-in carers or PAs (terms used interchangeably) who she employed using the PHB direct payment:

> *"I have been entirely independent [.....] there is nobody else involved, since 2001. I have been a fully-fledged employer doing everything completely independently "*

Not only was Karen independent in as far as decision making, but she also managed to form good support networks and friendships with those who supported her and actively participate in her community:

> *"So, they are live-in carers and I have a really good network of people who have previously worked as my carers who are now really good friends and support me."*

Karen also felt that having complex healthcare needs would not limit her ability to use PHBs. Like with the other two cases, having a complex chronic condition did not seem to deter her from accessing and using PHBs. These findings are consistent across the three cases and therefore, it can be perceived that under the right conditions and with the right skills and support, people with complex healthcare needs are able to access and make effective use of PHBs.

Being Your Own Care Manager

Karen transitioned over to PHBs in 2014 from social care. She started with a PHB at a time when the move from pilots to actual roll-out was taking place. In the roll-out, CCGs had no additional funding for PHBs, most were already struggling to manage overstretched budgets in a time of austerity measures. Karen was one of the first candidates in her locality to take on PHBs:

> *"I was assessed in 2014 …Obviously when personal health budgets came into play, they were all pilots. I think I was one of the first to be on the official roll-out."*

Karen had been at one of her advocate group meetings when she heard someone talking about continuing health funding and PHBs. Up until that point, she had not heard about PHBs, bringing insight into how little PHBs were being promoted locally:

> *"My first foremost reason for coming off a direct payment of social services was fear of having my budget cut and I jumped ship before that happened. So that was the reason why I transitioned over to NHS care, but I actually hadn't heard about it before that."*

Having transitioned to PHBs, Karen faced challenges when commissioning services:

> *"The personal health budget has been a problem. I have worked with it, and I am fighting to make it better, but I will say out of all my years of direct payment employment, this has been a pretty horrific 3 years."*

Through the direct payment in social services Karen was experienced as an employer for her own carers. She did all the recruitment, employment and all the associated administrative workload just like Steve. She had transitioned to PHBs as a manager of her own care, she was optimistic about what PHBs appeared to offer through the direct payment route:

> *“I enjoy like as I have said before being, like taking more responsibility for myself and being less of a financial cost to the local authority then but now the NHS. I do enjoy it, I enjoy the responsibilities of employing people, I enjoy the relationships that I have formed.”*

Karen valued being able to use the PHB to have choice and control, as she had had with the social care direct payment. The self-direction of care seemed to improve her experiences, quality of care and wellbeing. She appeared to value the ability to form relationships, highlighting the capability of individualised funding to improve the more complex aspects of quality of life such as community presence. Karen made comparisons to her previous care experiences prior to having a direct payment:

> *“Having a direct payment has been an incredibly positive experience for me. I came from agency care, and it was horrific, absolutely horrific [……] since I have been doing this myself it’s been fantastic.”*

However, after a positive experience in social care, she had a negative experience with PHBs, not because of her inability to manage her long-term condition but because of the bureaucratic processes as well as that PHBs were new and the implementation process following the pilot was not fully developed. Karen elaborated on the use of the budget:

> *"Like I still don't know whether I am allowed to spend it on this and that or the other as they are still looking into it, and it takes a long time [this was in May 2018]. When you are trying to live your life in real time, it's very difficult. I am having to personally subsidise things and when approval comes then I am going to have to reclaim from my personal health budget and that is difficult. I am lucky that I have financial stability to do that […….] it's very frustrating that it takes so long and mostly that is down more to bureaucracy than anything else."*

Like Cora, there were delays in the approval process within this CCG (which wasn't the same CCG as Cora). Karen's ability to be her own care manager was limited due to resource restrictions, implementation processes and bureaucracy. The reasoning for under resourcing was not really understood by Karen because continuing healthcare funding packages would have been already commissioned individually within existing funds.

Capability and Experience

Capability and experience were an important theme with regards to Karen's cognitive understanding of PHBs, how to use it and what she could get out of the budget. She was educated to degree level, was a volunteer for a local disabilities group and did advocacy work. Karen seemed to have a good grasp of PHBs and what they could achieve. When I asked her to explain her understanding of PHBs, this is what she had to say:

> *"From my own understanding, a personal health budget is an amount of money that would otherwise have been spent in very conventional ways, prescribed actually. [Instead] it's given to the individual, and they decide how best to maximise their*

> *potential with that money in a lot more flexible manner. You can use it in ways that aren't traditional and conventional so you can think a little outside the box and it will potentially give you an opportunity to get better results with the same amount of funding. Just purely because it's not so prescribed, you can be a bit more imaginative, and it works individually for people rather than for the system."*

I met Karen through a local paper where she had advertised and was looking for other PHB holders in her area so that they could come together, network and give each other peer support. She seemed to have access to resources and was confident in her own abilities. Karen explained how she was managing her budget and the demands:

> *"I have full capacity, so obviously I am able to manage it, well I'm not because they won't let me, but I would be able to manage it most effectively if I was allowed to."*

According to Karen, she was more than capable to manage her PHB effectively, however, she felt restricted because of the implementation process (discussed further in the next section). She also thought management of PHBs required experience and skills. Having managed her own care for a long time, she considered herself to have had experiential learning. She talked about her experience:

> *"I've got 20 years of experience well I guess from having care, 20 years of experience from having live-in carers so you know being able to manage that it's a skill and learnt skill and you have to have a lot of emotional intelligence to really read people and to understand the dynamics and to be able to manage tricky situations actually."*

The quote suggests not just superficial but deeper aspects of self-efficacy, being able to have the emotional skills to read people's feelings, understand dynamics of relationships at play and make sound decisions based on available information. It also suggests complex skills that Karen seemed to have developed through years of experience of using a direct payment in social care. This is of importance when thinking about the potential impact of PHBs long-term.

Like Cora and Steve, Karen had the experience and the capability to manage PHB direct payments. They all possessed high level functional skills and strong management experience and felt that this was a necessary (though not sufficient) factor in effective deployment of choice and control. It was clear across the three cases that there were some important mechanisms such as knowledge, skills, access to resources, information, and self-efficacy, that were part of understanding how PHBs delivered choice and control.

Implementing the Care and Support Plan

The care and support planning for PHBs is supposed to be driven by the individual and it forms an integral part of management of long-term conditions. According to Karen, this was contrary to the process she underwent, and she gave a description of what happened:

> *"So, the clinician comes out to assess your eligibility but doesn't actually discuss how you want to meet those needs. There was nothing in place for chatting with me about how I wanted to use the money or how I wanted to go forward with my PHB and that*

> *in itself is a massive fail because it's not person centred. They just trot off, make up a number and give it to me and that's it."*

What Karen was describing was an assessment of her needs from a deficit perspective rather than a more asset-based conversation centred around how she wanted to use the money, a contrast to Steve's experience.

It was after the Care Act in 2014 that Karen was assessed for her PHB. As far as she was concerned, the way things had happened was contrary to the person-centred aims and objectives as outlined in the Care Act. When she tried to get the issues addressed, she felt as though professionals were not responsive to her needs. Karen talked about her challenges:

> *"That is not person centered in any way and then when I do express an opinion, I am just shouted down [by the CCG], so no its absolutely not person centred in any way. In truth it goes against everything that is in the Care Act and yeah, it's still bureaucratic but it's a big organisation, it takes a lot of time and a lot of effort to change attitudes and we are still in a transitional period. We will get there, it just needs a few more people shouting about things."*

It appears that both the CCG and clinicians were failing to acknowledge and respect the expertise that Karen could bring into the process and were not willing to work with her. Rather than embrace the opportunity presented by Karen to discuss her concerns, work collaboratively, and reach shared decisions, her sense was that professionals became resistant. While there is no standardised way to devise a care and support plan, it appeared as though the process had failed the fundamentals of co-production principles of shared decision making.

Karen thought the initial budget had been wrongly calculated, and the assessment had failed to capture her needs fully. Karen highlighted the anomalies:

> *"What I found with this calculation is that I am now going to be able to pay £11.60 an hour which is in line with almost band 5 nursing NHS scale, so that's reasonable [referring to her 2018/19 care and support plan]. This is unlike [the 2014 care and support plan] where they said that you can pay your carers £7.50 an hour or national minimum wage for complex care. There was no differentiation between complex care and social care then [referring to her 2014 care and support plan] which makes absolutely no sense."*

What emerged because of failure to co-produce Karen's initial care and support plan was a plan that did not meet Karen's needs and a PHB that was inadequate to cover her care costs. While Karen and professionals had resource issues to resolve, that also delayed the sign-off of the care and support plan leaving Karen with no care and support plan in place to work with. When I first had face to face contact with Karen in May 2018, her care and support plan was still not signed-off:

> *"I still don't have a support plan and I am now 2 years and 6 months into this personal health budget [.......]. There are issues related to the way I want to spend the money they are having to look into, it's taking a long time and that means everything is in a bit of limbo actually."*

When I discussed the care and support plan again with Karen during the phases of the ethnography, she was still experiencing delays and like Cora, felt she was in limbo:

> *"The problem I now have is that they haven't done anything for two and a half years and last year they just did update my care and support plan and they said you didn't need one every year. Which is actually very wrong cos it's all part of safeguarding should there be issues and there is legislation to say this should be updated every year, so the one I have is 2 and a half years old."*

This provides insight into the ambiguities and confusion that existed around PHB implementation processes locally. The perception of resistance and unwillingness to accommodate PHB holders' concerns, and lack of support seemed to be a real concern for Karen:

> *"There was not any support and if you went back to them to say it's not actually working for me, it was met with resistance, the default answer was no."*

According to Karen PHBs policy was being interpreted differently within different CCGs and there was so much discretion dependent on which parts of the policy were being implemented:

> *"I think for me there, is so much discretion around it, like it's just everybody is interpreting it differently and that for me is a real problem [.......] Obviously, what's happened here in our area is that it has just been mostly focused on making savings*

> *rather than promoting independence and choice, which means it's less sustainable in the long term."*

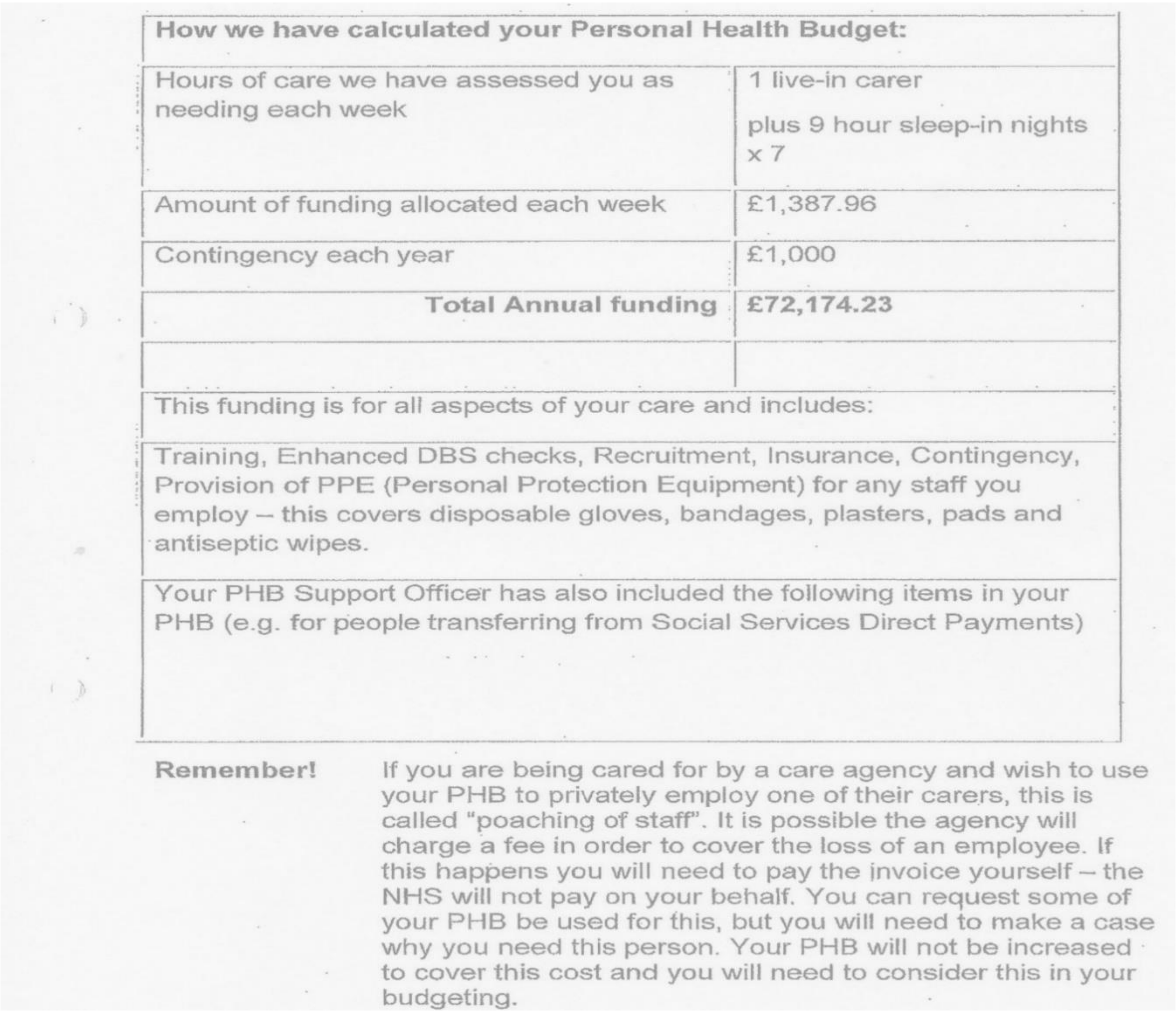
The quote suggests inequalities might arise if PHBs are implemented in the manner Karen was describing. According to Karen, she understood the challenges faced by professionals, but she felt they were exerting unnecessary power:

> *"I also understand there are safeguarding issues, things do need to be put in place, and I do need to be held accountable, so I am happy to cooperate with all of that, but it needs to be co-production. It can't be a dictatorship and that is what it is at the moment. It is still a dictatorship and people are really struggling to transition from continuing healthcare funding to personal health budgets."*

This comment highlights deeper issues of control and a perceived authoritarian approach amongst clinicians that did not seem to accommodate PHBs. While resources may have been an issue, it appears it was the behaviour of professionals that seemed to be a problem for Karen.

When I analysed Karen's care and support plan for 2014 (see insert below), there was cover for 24-hour support provided by a live-in carer plus 9 hours sleep-in, 7 days a week, see insert below.

Insert 6. Copy of part of care and support Plan 2014



How we have calculated your Personal Health Budget:	
Hours of care we have assessed you as needing each week	1 live-in carer plus 9 hour sleep-in nights x 7
Amount of funding allocated each week	£1,387.96
Contingency each year	£1,000
Total Annual funding	**£72,174.23**
This funding is for all aspects of your care and includes:	
Training, Enhanced DBS checks, Recruitment, Insurance, Contingency, Provision of PPE (Personal Protection Equipment) for any staff you employ – this covers disposable gloves, bandages, plasters, pads and antiseptic wipes.	
Your PHB Support Officer has also included the following items in your PHB (e.g. for people transferring from Social Services Direct Payments)	

Remember! If you are being cared for by a care agency and wish to use your PHB to privately employ one of their carers, this is called "poaching of staff". It is possible the agency will charge a fee in order to cover the loss of an employee. If this happens you will need to pay the invoice yourself – the NHS will not pay on your behalf. You can request some of your PHB be used for this, but you will need to make a case why you need this person. Your PHB will not be increased to cover this cost and you will need to consider this in your budgeting.

The budget was to cover all aspect of care, and included contingency, training, recruitment, insurance, disclosure and barring service check (DBS) and personal protective equipment (PPE) for the care workers. She also was required to pay 18.5% statutory sick pay and pension on the auto enrolment scheme unless her PAs opted out. Her family and friends, although they did not live with her, were expected to cover 7 x 9 hours waking nights and 2-hour daily breaks. It became evident that the PHB funding had been inadequate to cover her care and support needs and the burden of caring was being placed on her family and friends. This highlights the dangers of making assumptions that do not take account of the realities of the circumstances of real-life situations. It also brings to light some of the rival framing of theories that PHBs might be a way of relinquishing responsibilities to patients. This and the other CMO configurations are discussed in the next chapter.

5.3 Summary of Findings- Phase 1

From the ethnographies presented above, I explored the experiences of participants with complex healthcare needs who were using PHBs. The ethnographies showed the potential of PHBs to deliver choice and control. The thematic analysis was rich and provided nuance in understandings of PHBs through the experiences of the PHB holders.

Looking across all the three cases, the PHB holders had high-level disabilities with life limiting conditions, greater needs, and vulnerability according to the SCREC description. With PA support, the complexity of their health and social care needs did not seem to hinder their ability to use a PHB and carry out related tasks to manage their health and well-being. Therefore, it can be perceived that under the right conditions, people with complex health and social care needs are able to use PHBs.

During the PHBs roll-out programme, PHBs became more restrictive and each PHB holder faced a different set of challenges from their local CCG. This was dependent on the implementation process, decision making, the delivery mechanism and interactions with professionals. All the participants had high level functional and managerial skills. All felt that PHB direct payments required high levels of accountability, responsibility and there was risk associated with management of some aspects of PHBs.

Each case had different experiences of the care and support plan process based on how professionals interpreted PHBs locally. They all saw co-production as an integral part of the planning and purchasing of care and support, although it was not happening in all cases. For all three participants, choice and control was seen as both autonomy and a burden and there were two aspects to control taking place: internal control which related to PHB holders' ability to influence the day-to-day decisions around their care and support; and external control which was contingent on how the local CCGs and professionals made decisions which PHB holders had little or no control over.

However, there was change and the experiences improved with time as PHBs became more embedded in practice. These thematic insights provided the foundational basis for CMO configuration that I will undertake in chapter 6. The themes also emphasised the complexity and paradox of choice and control that requires further development and refinement to understand the link between context, mechanism, and outcome.

Chapter 6: Key Findings from the Realist Evaluation

Chapter five presented the individual ethnographies that were rich and nuanced and these thematic insights provided the basis for further development of understanding the relationship between context, mechanism, and outcomes in PHBs. This chapter is an extension of this realist work which started with the realist synthesis in chapter 3, and I build on that analysis, along with the empirical data presented in the previous chapter, to explain the complexity of delivering choice and control through PHBs. The chapter focuses on evaluating the CMOs of how PHBs are supposed to deliver choice and control. As discussed earlier in the thesis, there are other outcomes (for example improved health or wellbeing) but those are not the focus here.

In chapter 3, I built on a series of logic statements to develop initial programme theories related to choice and control in PHBs. I also analysed the existing literature to draw out key themes and used these to develop a set of CMOs. From the realist synthesis, I further refined the initial programme theories under three overarching themes (access to resources, shared decision making and professional power) and this initial work guided my fieldwork activities. I set out in chapter three why I chose to take such a pragmatic approach.

During fieldwork, I observed and interacted with participants and also asked questions derived from the CMO configurations relating to contextual factors that influenced the reasoning and resourcing resulting in the observed outcomes (Pawson and Tilley, 1997). I collected data using a variety of methods (observations, interviews, artifacts, and documents). Through thematic analysis, I was also able to develop a fourth programme theory that had not been present in the realist synthesis which related to change over time.

This evaluation chapter therefore uncovers how different combination of mechanisms and contexts intersect to bring about choice and control. My iteration of realist theory in this chapter is oriented towards developing further the material presented in the previous chapters (three and five) affirming, refuting, or deepening the programme theory.

6.1 Introduction

The approach taken in this chapter was guided by the method used in the EURIPIDES study, which used a combination of thematic and realist analysis to identify which approaches to collecting and using patient experience data are most useful for supporting improvements in inpatient mental health (Weich et al., 2020). They used a qualitative realist methodology to analyse and present their findings using a framework based on 4 stages of the patient experience data pathway which they called the CRAICh (collecting & giving; receiving & listening; analysing; quality improvement & change) (Weich et al. 2020). I adapted the framework to suit my study and it helped me make sense of the data and catalogue the evidence.

The findings are reported as follows:

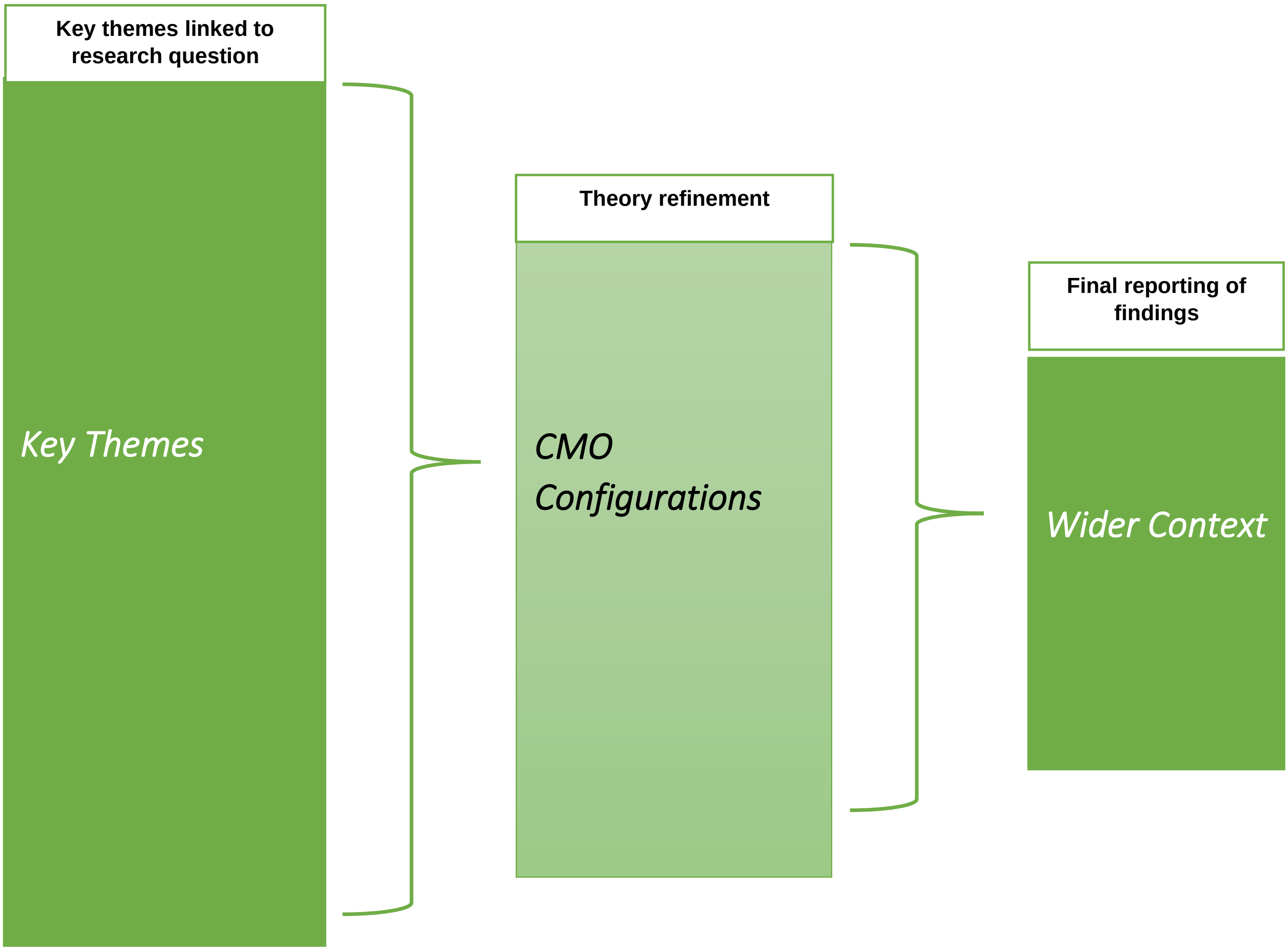
Phase 1 - Developing of ‘Concept Frame’ for mapping out CMOs

Phase 2 - Evaluating the CMOs

Phase 3 - Reconfiguration of CMOs and theory refinement and application to the wider context

Reporting the findings in this manner demonstrates the complexity of trying to open the ’black box’ within the PHB programme theory. Fig 7 below conceptualises the reporting of the findings.

Fig. 7 The Approach Taken in Reporting of the Key findings



6.2 Evaluation of Programme Theory

Chapter 5 presented themes used to write the individual ethnographies. Some themes and coded excepts were not used for telling the stories but were retained because together, they formed the foundational basis for mapping the CMOs. The retained themes that fed into the realist analysis are presented in table 10 below, in relation to the research question ('are personal health budgets delivering choice and control for people with complex healthcare needs?').

Table 8. Conceptual Framing of Themes and Relationship to Programme Theory and Research Question

CMOs	Meaning	Themes and Relevance	Relationship to Programme Theory and Research Question
Access to Resources	The theme addresses how PHB holders were allowed by their local CCGs and clinicians to purchase items with their funding as well as being able to access resources from the market.	**Delivery mechanisms** were concerned with the deployment options: direct payment, notional budget and third-party options. (i.e. how PHBs holders could manage the money) **Management of long-term conditions** related to lay forms of knowledge and expertise of living with the condition, knowing what works or not in the delivery of everyday care and support, sometimes evidenced through purchase of non-conventional treatments **Autonomy and burden**, concerned with the opportunities, flexibility, risk, responsibility, and accountability that came with using PHBs to access care and support.	Access to resources was an important CMO driving PHBs, influencing participants’ ability to access appropriate care and support, and tailor it to their needs as well as use PHBs to enhance choice and control.

		Recruitment and managing PAs referred to how PHB holders were able to access and manage PA relationships **Purchase of equipment** related to the various forms of innovations that PHB holders were able to purchase or not with the budget **The review** was the annual appraisal of health and well-being needs along with the PHB. It could be a valuable process of safeguarding, monitoring, and strengthening the person's ability to achieve the outcomes they wanted, but it was often used to review the budget and limit access and use of PHBs.	
Shared Decision making	The process by which clinicians and budget holders worked together to make decisions and work collaboratively or not through the PHB process.	**Complexity of health and social care needs** This related to the level of disability and health care needs of the PHBs holders that needed to be considered in the assessment of needs, to enable adequate support and budget level and eligibility to remain a PHB holder.	These processes enhanced or hindered PHB holders' decision making resulting in the observed outcomes.

		Being your own care manager focused on how PHB holders were able to work collaboratively and in partnership with clinicians to activate the agreed care and support and make key decisions on how to manage their health and well-being effectively. **Capability and experience** involved elements that enabled individuals to make key decisions. This included being able to organise and communicate and have the knowledge and skills to make key decisions on a day-to-day basis when using the PHB. It also encompassed interpersonal skills with regards to interaction with professionals while choosing health and wellbeing outcomes that they wanted to achieve or devising the care and support plan. **Implementing the care and support plan**, i.e. how professionals worked with PHB holders to identify needs, devise a plan, and set goals as well as agree on the level of support and resources and evaluate the PHB outcomes	
Professional Power	This was a dominant theme across all cases and related to how professionals	**Professional control** related to how professionals were perceived to use processes and systems to control the resources and budgets as well as	The actions of frontline workers were a CMO that enhanced or derailed the

	exerted authority over how PHB holders interacted with their PHBs.	attitudes that stemmed from paternalism that were not helpful in promoting choice and control of PHBs holders. **The dynamics of power** manifested as professional power and individual power through interactions as both parties adjusted to the changing relationship. **Individual power** was concerned with how PHBs holders challenged professional views and systems.	implementation of PHBs affecting the degree of choice and control that was possible.
Change over time	This related to the changes as the PHBs evolved over time as they got more embedded in practice.	**Perceived choice and control** fluctuated throughout the period of PHBs, indicating that experiences of choice and control were constantly changing rather than being fixed.	This was an important CMO focused on how, why, and what change took place from the PHB holders' perspectives.

Guided by the CMOs and their sub-themes (in Table 8 on pages 190-193), I was able to explore how PHBs are delivering choice and control. While some of the CMOs were originally developed during the realist synthesis in chapter three (access to resources, shared decision-making, professional power), a further CMO (change over time) originated from the fieldwork. They are analysed together in this chapter. The thematic analysis and full coded framework showing the interplay of context, mechanism and outcome is included in the appendix (see appendices 10-15 pages 388-395: Thematic analysis of fieldwork data and realist analysis, CMO configurations).

The four CMOs relating to choice and control in PHBs are.

- **Access to resources (CMO1) –** this addresses how PHB holders were allowed by their local CCGs and clinicians to purchase items with their funding.
- **Shared decision-making (CMO2) –** this relates to the processes by which professionals worked together or not with PHB holders to facilitate PHB implementation in practice.
- **Professional power (CMO3)** – this relates to how professionals exerted authority over PHBs. It is distinctive from shared decision-making because it focuses not on the processes of decision making but on the legitimacy of knowledge claims made by professionals and budget holders.
- **Change over time (CMO4) –** this relates to the changes that took place as the PHBs evolved over time and became more embedded in practice.

In the rest of the chapter, looking at each of the four CMO configurations in turn, I evaluate the elements of the CMOs that enabled PHBs to deliver choice and control or not, and I use the evidence to support or refute the propositions presented. I conclude the realist analysis with a refined programme theory that explains how, why, in what circumstances and for whom PHBs deliver choice and control.

6.3 CMO1: Access to Resources

The summarised CMO1 shown below was a key driver as to how PHB holders were able to access the money and use it to purchase services. Below, I set out the CMO:

Table 9. CMO 1

CMO1: Access to Resources
PHBs make the financial aspect of healthcare more explicit at the individual level (**C),** assigning people a budget **(M)**, and enabling people to have choice and control of the financial resources **(O)**
Rival Framing: Increased Burden
PHBs make the financial aspect of healthcare more explicit at the individual level (**C),** which because of administrative tasks and transactional cost **(M)** thereby increased risk, responsibilities, and accountability to the PHB holders which causes choice and control to be experienced as anxiety and stress**. (O)**

An important context that emerged from the literature is how PHBs make the financial aspects of healthcare explicit at the individual level, enabling individuals to have choice and control of the financial resources and how care is organised and purchased to manage the day-to-day aspects of health and well-being (Forder et al. 2012, Alakeson and Rumbold, 2013; Jones et al., 2017). The evidence from the literature synthesis indicated that having the financial aspect made explicit at the individual level in PHBs was not enough. PHB's potential can only be fulfilled if there is enough money in the budget, services in the market to buy and flexibility to purchase services that people feel will improve health and wellbeing. Until that point, the potential for real choice and control is limited. There was also evidence to suggest there were other mechanisms such as the implementation process that could determine how capacity was realised through PHBs.

In the fieldwork, choice and control was seen both as autonomy, based on the level of flexibility for the PHBs holders, and a burden, depending on the level of responsibility, accountability and risks associated. Two types of choice and control could be separated out:

a) Internal choice and control (who gets employed and delivers the care), which was based on PHB holders' power to influence the day-to-day decisions about who provides the care and support they wanted, how and when.

b) External choice and control (purchasing innovations or complementary therapy) as to the categories of items they could buy with the money. Budget holders were aware that choices were dependent on what the CCGs considered appropriate use of the budget.

The PHB holders were using direct payments or the third-party option as delivery mechanisms to access resources. Having a PHB through these mechanisms seemed to offer choice and control in different ways. To a degree, the budget holders were happy using the budgets to secure the care and support they would have otherwise got from the NHS. They valued being able to self-direct the care along with the flexibility that PHBs seemed to offer:

> ***Cora:*** *"I believe having a PHB, has enabled me to have my care package meet my needs, that's it in a nutshell. So, you can decide who works for you, how they work for you, when they work for you."*

Access to resources was also dependent on being able to find the services to purchase with the budget. The fieldwork data suggested at times that budget holders were having difficulties accessing PAs who were skilled to support the complexity of health and social care needs. This was a challenge for PHB holders and meant the money could not be used to exercise choice and control and therefore accumulated in the bank.

In instances where budget holders were able to recruit and get PAs trained and competent, participants felt that they offered greater choice and control. For example, in Steve's case, he wanted to access his local community, have a social life, and continue working. He was able to achieve this after recruiting and getting his PAs trained. As an international speaker, he was able to travel, and he would take his team of PAs and work away from home. When compared to his previous experiences of conventional methods of accessing NHS resources, he would have had to stay at home waiting for district nursing visits for support.

An important finding was that even though the three budget holders were not overly enthusiastic about how the budgets were being implemented locally, they still derived satisfaction from being able to self-direct their care and valued this about choice and control that PHBs offered. However, budget holders were concerned with the lack of flexibility from professionals that diminished their autonomy in the decision-making process when using their resources. They felt when it came to purchasing items outside what was ordinarily seen as care and support, CCGs were not flexible enough to give people greater sense of choice and control. For example, Karen had requested that she purchase a wet mattress cover for her bed when she came from the shower so that her bed would stay dry, and she was told to get an assessment done first by a tissue viability nurse. Also, Steve had requested that he use some of the money he had saved to purchase a ceiling hoist which worked out cheaper and of high quality. He had also inherited a bed from his grandmother that would suit his needs if it was fitted with a rising function instead of buying a new NHS bed that would cost thousands of pounds. All these requests were denied and such lack of flexibility in accessing resources was causing a lot of frustration.

The rival framing of this CMO highlighted how choice can be experienced as a burden. The fieldwork data demonstrated that alongside choice and control came mechanisms that were not always explicit such as the transaction costs of managing a PHB. The direct payment route was perceived to be imbued with administrative burdens and PHB holders felt sometimes that this was overwhelming and caused more stress. Steve felt that budget holders can be buried in paperwork if they do not manage all aspects such as payroll, timesheets, and time to stay on top of things. Karen felt even though she was good at managing the administrative tasks, the processes were bureaucratic and time-consuming. Cora considered the responsibility, accountability and the risks involved, to be quite high. She expressed this by drawing out different strands of choice and control in PHBs:

> ***Cora**: "You got choice and control, but you have, and you haven't. It's the different strands, it's not that straight forward and you can't just do as you like."*

The excerpt highlights the paradox of choice and control and the importance of drawing out the mechanisms that make PHBs work or not for budget holders. But also, it highlights how some people may value different strands of choice and control. This may depend in part on whether there is some form of improvement when compared to what they were originally getting before PHBs.

The review was potentially an important and valuable process of strengthening the budget holder's ability to achieve choice and control. However, my CMO analysis suggests that often it worked to the contrary. There was a perception amongst the PHB holders that the local CCGs were using the review process as an opportunity to cut down on resources and reclaim authority through arbitrary means, particularly in the roll-out phase when resources were not as generous as they had been for the pilot. As such, budget-holders approached the review process with anxiety, uncertainty, and fear. PHB holders were afraid to challenge the processes for fear of reprisal, being labelled difficult and subsequently losing their budget at the review.

Through the fieldwork analysis, I identified that even in well managed care, CCGs were clawing back budgets and any unspent money. There was evidence that the eligibility threshold was being raised making PHBs less accessible. This was causing a lot of despondency amongst budget holders, and they felt they were being penalised for saving money by being innovative. Budget holders also believed the CCGs were imposing burdensome monitoring systems that restricted choice and control.

There was real worry among participants that with pressures on funding in healthcare, PHBs may become less of a priority as other pressing needs take precedence. For instance, budget holders were concerned that some therapies which were previously funded were coming to be seen as luxuries (for example the trips to the spa bath). In such instances, even with clinical letters to support the choices, budget holders were still being asked to provide ever more evidence to support their choice making. From the evidence presented above, my analysis suggests that CMO1 (access to resources) was upheld both in its positive and negative assumptions - i.e., that people experienced choice as both autonomy and a burden. They welcomed the control that they gained through direct access to resources but felt acutely the administrative burden of resource management. They also recognised that many other budget holders would not have the level of administrative skills that they did, and indeed all three of the participants spent time giving peer support to other budget holders to help them to do this.

6.4 CMO2: Shared Decision- Making

Shared decision-making was an important CMO in the context of PHBs and took a broader approach that went beyond just clinician and PHBs holder bringing their expertise together to decide the best course of treatment to take. This is explored in more detail below.

Table 10. CMO 2

CMO2: Shared Decision-Making
Budget holders bring their expert knowledge of living with the condition and professionals bring evidence-based practice, information, and support (**C**). Budget holders and professionals work collaboratively and in partnership **(M)** to implement care and support plans that are person centred and holistic and enable ongoing choice and control **(O).**

Shared decision-making was an important CMO in PHBs when put in the context of implementing care and support plans derived from joint decision making. In the PHB programme, every PHB holder had the opportunity to go through the care and support planning process (NHS England, 2014a). Care and support planning is central to commissioning and provision of care for those receiving PHBs in continuing healthcare. According to the literature from the realist synthesis in chapter three, shared decision-making in the context of PHBs was expected to take a broader approach to health and well-being and included partnership, collaborative, and empowerment approaches (sometimes referred to as co-production) (Alakeson, 2014a).

The literature indicates that the PHB holder is supposed to identify goals that they want to achieve with their money, and these are then agreed with the healthcare professional co-ordinating the care. To promote successful shared decision-making, clinicians and PHB holders need to engage and participate fully in the process. Appropriate processes and systems need to be in place to allow that to happen. Furthermore, information and support aimed at empowering PHB holders should be made available and more accessible. With each part bringing their own expertise, they can work collaboratively and in partnership to agree on the right interventions that can be purchased with the budget. Budget holders can then activate the care and support plan and there is expectation of more adherence because they have set the outcomes together to be achieved. As such PHB holders will have choice and control at the point of making the plan and on an ongoing basis as the plan is implemented.

However, Cora's experiences shows how this was not always the case. The process for her was very professional led, leading to a budget that was not adequate and processes that were not fit for purpose:

> ***Cora:*** *"It seems there should be an indicative budget, and also it should cover the cost of care in the care and support plan which mine doesn't have and the cost of care staff has gone up since I had mine, and this is 4 years later."*

Karen's experiences were also not much different from Cora:

> ***Karen:*** *"The money still keeps coming in, but I am not being supported still."*

The lack of joint care and support planning at the start of the process meant that needs were not fully assessed, and the budgets were inadequate to cover all the cost of care and support. This was causing a lot of frustration according to Karen - decisions were being made for her rather than with her and the outcomes were not good:

> ***Karen****: "The decisions that they are making are bad. They are bad for me, and they are bad for them, this could be a win-win situation but they are making it to be a lose-lose [……] A personal health budget in essence, in theory it is the most beautiful thing, it was made for me, designed for me and it's just been implemented badly, very badly and nobody is listening"*

In contrast Steve's experiences of the care planning process were generally positive, and he attributed this to how the processes considered his needs and decisions:

> ***Steve****: "The process has looked at my needs and my outcomes with parity"*

People’s experiences of this were not fixed, they evolved over the time that I was working with them. Karen and Cora’s perspectives shifted following the review of the same process later in the fieldwork:

> ***Cora**: “This year things were a lot different [......] having both of these people in the same room meant that we could talk about money and how this would meet my needs at the same time.”*
>
> ***Karen**: “Whereas before there was nit-picking, there was arguing, there was resistance, I was not allowed this, I was not allowed that, and now they are just making sure I am.”*

In summary, CMO2 is based on the process through which professionals and budget-holders come together to support making informed choices. Together PHB holders and clinicians then make joint decision on the best course of action which the PHB holder will then activate through the care and support plans.

It is clear from these investigations that choice and control were related to the level of shared decision-making and participation that took place which either resulted in positive or negative experiences. For instance, Steve had better involvement and active participation in the process and had greater choice and control. In Karen and Cora’s case, where they had little involvement in the initial care and support process, budgets were inadequate to meet health and support needs. Their processes were not holistic, or person centred, and experiences were negative with budget holders feeling disempowered.

The budget holders described a lack of choice and control as well as a sense of being passive. They were frustrated because they were not able to exercise choice and control when managing their health and well-being as they intended because resources were inadequate. The evidence from the cases affirms the importance of the shared decision-making CMO2 but highlights that the outcome of choice and control will not be achieved if the mechanisms of shared decision-making do not operate as intended. Key elements of this failure include factors which are considered in the sections above and below: access to resources and professional power.

6.5. CMO3: Professional Power

The CMO professional power was concerned with the dynamics of power with regards to interactions in the relational space between budget holders and professionals (case managers, CCGs, and clinicians) which affected how the participants accessed and used the budget. Whereas CMO2 was about the process of shared decision planning, this CMO was about the legitimacy of certain kinds of knowledge claims linked to professional authority.

Table 11. CMO 3

CMO3: Professional Power
Some of the challenges of professional dominance in the NHS **(C)** can be addressed by empowerment **(M)** through which service users gain more choice and control **(O)**

There is an expectation that offering choice and control through a PHB will transfer power from professional to service users thereby addressing some of the limits to paternalism in the NHS (Duffy, 2010; DH, 2012b). There have been concerns raised in the literature on PHBs with regards to culture and attitudes of professionals that are linked to issues of power and authority (Jones et al., 2017). There is also a recognition of the importance of frontline professionals in promoting choice and control in the PHBs policy programme (DH, 2012c).

When it came to change, the fieldwork showed that professionals did not always feel the need to communicate or explain their actions and would just act without informing budget holders. Steve related his frustrations with this experience:

> ***Steve**: "And when I asked why I had not been notified about that change in their policy beforehand, they said just pay the money back and I said no no no, there*

> *is a contract between you and me and if we are going to change the terms, I want a bit of notice and I want 30-day notice then pay you the money back."*

While Steve felt that he had the ability to challenge professional attitudes and the barriers he faced in his use of the PHB, he acknowledged how relatively difficult it was for budget holders to challenge clinicians, given that others may not have the skills, knowledge and the resilience required to sustain the battles.

: **Steve:** *"You actually need to have the mental fortitude, ongoing resilience, stubborness whatever you want to call it to be able to fight the system and if you know how to do it, you got to be knowledgeable and articulate or have someone articulate it on your behalf. That way you can fight it and win and get what you want and work with them. The trouble is how many people can do that."*

Karen made a similar comment to Steve about how some of these burdensome processes and monitoring systems restricted choice and control, and how it was very difficult for her to bring forward any issues she was encountering while trying to use the budget. Karen thought professionals were using their power to suppress her concerns without a real rationale. The perception was that professionals were failing to interpret the PHBs policy locally and put it into practice or take the time to understand how PHBs were supposed to work, rather were making it up as they go along. Similarly, Cora commented on how the local CCG was using power to limit resources and she felt they were doing everything to make sure they did not spend money. According to Karen, there seemed to be no consistency as to how frontline professionals behaved and when faced with frontline pressures, frontline workers were exploiting PHB holders.

The PHB holders who took part in this study had skills that helped them to navigate through the complexity of PHBs. They all acknowledged the barriers and inequality that may arise because of the process:

> ***Karen:*** *"Because I have got a tremendous network of family and friends who have been happy to step in and help out as much as they possibly can. But other people aren't in my situation and it's you know I am fighting for them because I am alright but actually nobody else is like me you know, the other aren't as shouty and aren't as scrappy and don't have the connections that I have or the resources, they are getting into trouble."*

Having found the PHB-direct payment route stressful, Cora opted onto a third-party option. She found herself facing barriers, a direct contrast of what she thought PHBs were designed for.

While in this study, I did not speak to professionals, and I am limited to what can be said about their perspectives, attitudes and behaviour, the artifacts enabled me to witness professional practice and supplement the testimony of the participants. I identified deep rooted issues of control in the ways that the plans were written that did not seem to allow PHBs to deliver choice and control.

Participants suggested that there was lack of knowledge among professionals at the beginning of how PHBs are supposed to work. Instead of acknowledging the need to learn, professionals appeared to have resorted to using their position of power to dictate and deny budget holders choice and control and the individualisation that PHBs offered. This could be seen in the wording that was used in the care planning documents that I saw. In participant accounts, there was uncertainty surrounding PHBs that appeared to reinforce professional behaviour and made the experience of using PHBs difficult. These increased bureaucratic tendencies identified through CMO configurations were key mechanisms that were driving PHBs. For instance, the lack of buy-in to PHBs reported by Steve of some CCG managers appeared to make it difficult for other frontline professionals to implement PHBs as they should.

Budget holders perceived professionals as having attitudes that stemmed from paternalism, such as risk aversion and unwillingness to accommodate new ways of working. These were seen as unhelpful in promoting choice and control and causing lack of trust. The evidence seems to point to PHBs as a challenge to these ways of working, which may have caused some of the insecurity reported by PHB holders. For example, in Steve's case, the innovation caused change in the way the district nurses ordinarily worked, which he felt had resulted in resistance from the nurses.

The attempts by professionals to dominate and restrict the use of PHBs will have a differential impact depending on the ability of budget-holders to push back. Excessive restrictions placed on eligibility or on how budgets can be spent led to a need for people to fight the system to get the resources required. Whereas my participants were able to do this, other PHB holders may be too ill to manage the demands that PHBs require or lack the advocacy skills of my participants.

6.6 CMO4: Change Over Time

Change over time was a new CMO that originated from the fieldwork and revealed internal (participant driven) and external change (professionally driven or peer-led). It also highlighted important mechanisms such as development of peer support, negotiating challenges, sharing risk taking, making compromises etc and this is discussed in more detail below.

Table 12. CMO 4

CMO4: Change Over Time
Changes in PHB design and stakeholder knowledge over time **(C)** will reshape other CMOs (access to resources; shared decision-making; professional power) **(M)** such that levels of choice and control will fluctuate **(O)**

It was clear from analysis of the fieldwork data that changes took place as the PHBs evolved over time and became more embedded in practice. This was not a CMO that I had expected to come across at the individual level as it was not in the literature synthesis. The CMO of change over time was important in revealing the role of budget holders in bringing some of the reported systemic and culture change that was witnessed through artifacts to support the testimonies.

All PHB holders in the study, played an important part in bringing internal change to how their PHB worked as well as external change within their local CCGs that had real impact for broader PHB implementation and outcomes. For example, one internal change was driven by Cora through an appeal process. Cora appealed to her local CCG when they cut back most of the innovations she was getting because they were complementary therapies and regarded as a luxuries. When I analysed Cora's appeal report, there was a lot of cutbacks involved. Cora had chosen to use a spa bath, respite care and acupuncture sourced privately, and these were stopped. When I asked Cora why she had decided to make the appeal, she had this to say:

> ***Cora:*** *"It is important not to give up and to try and understand why things you want are not approved and if there is anything you can do to change it"*

Cora went through the appeal process and won which resulted in the reinstating of the services that had been stopped. Her budget was also increased to reflect the rise in cost of care. She was reimbursed the money she had self-funded for respite and some of the complementary therapies as a one off. She was also allowed to bank some hours when she was unable to recruit and use the money to get respite so that her husband could also take a break.

Whereas Cora had previous experience through the pilot scheme of how to use PHBs innovatively, at the start Steve and Karen were purchasing the same mainstream services they were getting before. With time both Steve and Karen's purchasing habits changed, and they were requesting more equipment and services. In trying to understand what had changed for Steve to purchase more services down the line, he said:

> ***Steve:** "I didn't know about the healthcare funding until I was asked to go on the PHB pilot in 2014 [……] Before I was not getting near that at all even though I was struggling, so once you understand how the system works then it gets easier."*

This comment highlights how people's experience of using PHBs also improved with time through experiential learning. For instance, with time, Steve also felt he could achieve more choice and control if his care transferred from district nursing provision to his PAs. According to Steve, professional attitudes changed after he requested that his PAs be trained. There was initial resistance followed by Steve's negotiations and eventually reaching a compromise where both parties were happy, and a care package agreed. The request was made in 2015 and PA training finished in 2017. Once Steve and the professional had reached a compromise, he was able to purchase the equipment he needed, get his PAs trained and pay them a higher rate. This was included in his budget so that it was adequate and would cover all the cost. Steve, reflected on the impact of the district nursing service after change had taken place:

> ***Steve**: "I didn't even realise at the time, you only realise when you have been able to try something different, I think. I just feel more centred really yeah."*

Towards the end of my study in November 2019, Steve had more experience of PHBs and became more innovative, buying things like technology. He was successful at managing his care, suggesting that when PHBs are implemented well, they do offer choice and control.

A focus on change over time highlighted the ways in which initial forms of choice and controlled on to other choices becoming available. For example, as budget holders became more informed and came to understand PHBs better, they tried new innovations. They purchased therapies from providers outside the NHS and used more private providers. This then had implications for NHS block contracts, and participants reported that at this point professionals tried to force them to use mainstream services. This highlighted how as change moved from internal (individual behaviour change in the day-to-day management of the budget) to external (change that affected not just the individual but the organisation as well) it had more implications for wider processes. The PHB holders in the study were able to resist the pressure and challenge their local CCGs.

While all the PHB holders' experiences improved over time, the change was greatest for Karen. When I first met Karen, she was very angry at how her PHB was being implemented. She reported the process as being very top down and designed to save money at the expense of budget holders. As pointed out earlier, Karen successfully led a bottom-up campaign for change through a collective appeal to the Ombudsman. At the beginning of my study, Karen regarded her local CCG as not approachable and any attempt to get her concerns addressed were met with some hostility:

> ***Karen:*** *"I had meetings with a couple of commissioners back in 2016 to discuss a few things and actually myself and my carers were just intimidated, like they were just bullies."*

Over the course of the study, there was evidence of externally driven change; the PHB implementation process in her locality appeared to have changed, and so did the management systems and the entire ethos. It appeared the CCG was listening more to Karen, and she was allowed much more flexibility than before. Emphasis seemed to have shifted from cost savings to enabling PHBs to work. A new management team was appointed headed by clinicians in an effort to change focus from purely a cost saving exercise and putting PHB holders first.

Karen was very positive by the time of our final contact and explained how things were so different now. It appeared there was more transparency: Karen had an indicative budget and the CCG had adjusted the way they were calculating the budgets enabling her to have adequate funding to cover the cost of care. The pay scale suggests Karen was able to pay for appropriately skilled carers to deal with the complexity of her health and social care needs. But also, she felt that there was more equity for other budget-holders, with those with most needs getting a budget that is adequate. Karen's budget was also increased by £68 000, an amount that she then gave back. When I asked her why she had given it back after fighting so hard for the budget not to be reduced, she had this to say:

> **Karen:** *“I didn’t need that, but I was making a point that do not take my budget away, let me have the choice and control and I can make the decisions that are best for me.”*

According to Karen, clinicians were now respecting her ability to make informed decisions and the awareness she had of the risks and responsibilities, and she thought there was mutual respect in that regard:

> **Karen:** *“I do, I very much make my own decisions now. So essentially the input that I have had from the clinicians was generating an indicative budget based on the care that they would provide based on the agency. Aside from that, I think my relationship with my PHB team is different and they recognise that I am quite capable of identifying ways I would like to spend the money and they have not been openly suggestive of different ways of doing things.*

Karen also talked about the strengths she had built because of her experiences of PHBs. While it was a challenge initially, the collective effort of stakeholders seemed to have paid off. The use of peer support was important in having a collective action and voice. From Karen’s account of events, the Ombudsman had ruled in favour of the budget holders resulting in a series of organisational changes. Karen felt she was now receiving adequate support but also an important message emerging from these experiences is that budget holders can build momentum for broader system change as well as changes within their own support.

My analysis of the fieldwork data through the CMO configurations suggests PHBs can challenge existing practice. The theme “change over time” brought to light that a PHB is an ongoing negotiation between the budget-holder, the lead professional and the organisation in which they are located. My analysis of the evidence presented suggests systemic and culture change took place among professionals and in the CCGs in which they worked, although I only have PHB-holders’ accounts of that.

Over time, emphasis seemed to have shifted from cost savings to a greater emphasis on choice and control. The way professionals were responding to PHB holders’ choice making and control seemed to be different by the end of the fieldwork. It appeared that clinicians were working towards improving implementation processes, for instance in Cora’s CCG, they were piloting new care and support plans. Cora was fully involved in the process, enabling all her needs to be identified and deciding herself how best she thought they could be met with the allocated budget. She was also able to decide how she could be innovative and save towards PA hours and offer longer shift to PAs, making it easier to recruit. Clinicians buy-in to PHBs seemed to have increased and there was willingness to learn. Over time, all three participants felt that they had moved to a more equal relationship with professionals.

The changes made over time illuminated some of the complexities and paradoxes of choice and control when using a PHB. In Steve’s case, the buying of equipment had real implications for resources, professionalisation and task-based job differentiation as the PAs took on additional responsibilities and district nurses faced changes in their role and potential loss of skill. The use of the peristeen came with changes in job role for the PAs as well. There was increased cost in training and wages to compensate for the change in job role. This links to the rival theories about the danger of PHBs increasing demands that may be difficult to meet and rise in cost. However, the findings suggest these concerns may have limited impact because over time the cost to the NHS reduced as Steve's use of district nursing services dropped by 200 visits to only 5 visits per year.

Another significant change over time that occurred was development of peer support. There was a lot of sharing of experience through peer support and building of strong networks. In Karen's case, the negative experiences of using the budget became the source of empowerment. Karen through frustration, was able to build resilience and she created a peer support group. Her idea of the peer support initially was to feel less alone and share her experiences with other users. According to Karen the group developed into a force that put pressure on the local CCG resulting in organisational, culture and systemic change. Karen also worked with other stakeholders such as NHS England to ensure PHBs were being implemented as they should in her area. This highlights the potential of PHBs to provide a bottom up as well as a professionally led approach to policy change.

6.7 Chapter Summary

This discussion of the CMOs, underpinned by the insights from the fieldwork, has provided a deeper understanding of the programme theory and the interplay of context, mechanism, and outcomes. According (2004) outcomes change under different contexts and these can be planned or unplanned and we saw how that was through the presented evidence. As such, my updated programme theory being presented here highlights the complexity of PHBs, and the paradox of choice and control. The chapter started with four CMOs for evaluation:

- CMO1 – access to resources
- CMO2 – shared decision-making
- CMO3 – professional power
- CMO4 – change over time.

The exploration of these in the chapter re-affirmed, refuted, and deepened the programme theory. As I result of this, I have reconfigured the CMOs to develop a refined programme theory of how PHBs deliver choice and control for people with complex healthcare needs. Table 13 below provides a summary of the refined programme theory. The thesis therefore adds to our understanding of the workings of PHBs: how, why, for whom and in what circumstances they deliver choice and control for the people using them.

Table 13. Summary of the Refined Programme Theory

People are likely to maximise Choice and Control when using a PHB (O) if:

- PHB holders have relevant existing skills and experience (e.g., budget and staff management **(C)**

- There is support for PHBs among frontline clinicians and the organisations in which they work(**C**)

- PHB holders have autonomy over financial resources and can purchase services **(M)** they think will enable them to achieve the level of choice and control they want.

- There is adequate information and support available to enable them to make informed choices in their purchasing of services (**M)**

- There is flexibility on spending enabling PHB holders to be innovative with the budget, take risks, responsibility, and accountability of their purchasing choices (**M**).

- There is sufficient time for budget holders and professionals to learn to use PHBs most effectively **(M)**.

Rival Framing Realist Theory following the configuration of CMOs

Choice and control will burden people (O) if

- Professionals are resistant to PHBs, seeing them as undermining their role or authority **(C)**

- PHBs put further demands on resources that are already under pressure making it difficult for professionals to prioritise resources and be flexible **(C)**

- Processes come with considerable administrative burdens making it difficult for PHB holders to cope (**M**).

The table above shows the potential of PHBs to deliver choice and control, but also the challenges that PHBs present. The findings suggest that PHBs can deliver choice and control for people with complex healthcare needs if: there is sufficient access to resources, if decision-making is shared, and if professionals are willing to accept the knowledge claims of PHB holders. In the three cases, all these factors became more favourable over time, partly through cumulative learning and partly through the persistence of PHB holders in fighting for more appropriate packages of support. The balance between choice as autonomy and choice as burden shifted over time. It is also important to note that for the participants in the study the positive and negative elements of choice and control operated concurrently: both framings presented in the table were part of their ongoing experience of PHBs.

The choice and control that PHBs offer caused a shift in purchasing patterns, and in the locus of control from professionals to PHBs holders. The PHB holders reported considerable shift in behaviour of professionals. There was an iterative process here: as PHB holders became more innovative they felt this prompted resistance and insecurity amongst professionals as they tried to hold onto power through the review process, perhaps through fear of losing authority. However, over time, either through learning or through external pressures such as the Ombudsman, professionals were sharing power and decision making. There was also shared learning amongst PHB holders through peer support networks.

CMO 4 emphasised the change over time that took place as the PHBs evolved and became more embedded in practice. This was a CMO that I had not found in the literature and is a contribution to theory development around PHBs. The artifacts and interview data revealed how budget holders were able to drive change and secure improvements over time. These insights drawn through CMOs from the case studies show that PHBs in the long-term, can offer greater choice and control so long as the appropriate resources (C) and mechanisms of negotiation and supported decision making (M) are in place.

Chapter 7: Discussion: How PHBs Deliver Choice and Control

Chapters five and six presented the findings that I am drawing on in this discussion chapter. Here I will consider, in the context of the wider policy literature, some of the overarching themes that have emerged during my thesis. To do that, I begin with an overview of the processes taken to answer the research question: *are personal health budgets delivering choice and control for people with complex healthcare needs?* I will consider the four overarching themes – access to resources, shared decision-making, professional power and change over time – in relation to wider literatures. The themes resonated with each PHBs holder's experiences within the findings chapters and had implications for the reasoning and resourcing resulting in positive or negative experiences for the PHBs holders. Each of them also speaks to broader debates about public services and the interplay of power and resources.

7.1 An Overview on How the Research Question Was Addressed

In trying to advance an understanding of how choice and control operate within PHBs through the eyes of the PHB holders, I undertook fieldwork using an ethnographic case study method to facilitate the examination of PHBs. I drew on the realist evaluation approach to enrich my appreciation of why PHBs enhance choice and control, how, for whom and under what circumstances. Adopting the realist approach was to either support, refute or refine aspects of the programme theory (Wong et al., 2013) that underpins how PHBs are expected to work. As explained earlier, I am a practising nurse specialising in complex healthcare needs and I have had first-hand experience of PHBs implementation therefore I come from a professional perspective, and I recognise that this is a relevant factor when considering the role that professional power plays in PHBs.

The realist approach is built on the premise that policy implementation tests a theory or an assumption about what might cause a change to happen, and the theory may be explicit or implicit (Pawson and Tilley, 1997). As an evaluator of the PHBs policy, my task was to make the theory explicit, using CMO propositions and make some inferences about how PHBs work and under what conditions they work (Pawson, 2006). My inferences are therefore drawn from developing the theory iteratively as emerging data was being analysed that was gathered through a variety of methods during fieldwork. My approach suggests that both top-down and bottom-up drivers along with local, practical engagement, appropriate structures, attitudes, and processes, are necessary to effect change in complex systems.

The research question was addressed as follows.

- By first conducting a realist synthesis to develop a testable initial programme theory that explained how PHBs are supposed to deliver choice and control.
- Through ethnographic accounts from PHB holders' experiences of how they exercised choice and control over the money, care, and support provisions. I was able to reveal how choice and control were seen as having temporal context where personal perception of choice and control changed over time, influenced by interrelated interpersonal and personal contexts.

- The ethnographies provided the foundational basis for CMO configurations leading to the development of the context and mechanisms that explain how PHBs may enhance choice and control. The theory refinement fostered deeper understanding of the opportunities and challenges presented by PHBs, which can inform future policy and practice. Many of the contexts were dependent on how PHBs were interpreted and implemented locally and how the PHBs holders tried to make sense of this new role, as the commissioner of service provision.

7.2 My Realist Interpretation of the Findings

The refined programme theories help in explaining some of the contingencies necessary in PHBs but also some of the barriers to choice and control that are not always explicit in the existing literature. The participants were experienced PHB holders, well connected and played important roles in advocating change in how PHBs were being implemented in their CCGs. I had not anticipated such rich and extensive knowledge from this patient group, highlighting issues of my own bias that I needed to be aware of, but it also helped in ascertaining which CMOs were in operation. Manzano-Santaella (2016) and Pawson (2013) suggested that cases help the evaluator to articulate middle range theories which are those theories concerned with contextual circumstances of how programme intervention may impact on behaviour and effectiveness. As elsewhere in the thesis, I focus here on the CMOs that operated at individual level, whilst bringing in relevant aspects of the organisational and institutional levels.

7.3 Access to Resources

What emerged from this study was that access to resources was an important CMO configuration driving PHBs and put in different contexts, it had the potential to make PHBs work or not. The theory was that PHBs will give people choice and control of the money and they will be able to purchase resources they consider important in the management of their long-term conditions (DH, 2009). In that respect, PHBs seek to improve outcomes for people by giving them greater choice and control over financial resources and decisions around care provision. There is considerable evidence suggesting when individuals are given the opportunity to manage resources available to them it will enhance their ability to access appropriate care and support, and tailor it to their needs (Ungerson, 2004; Arntz and Thomsen, 2010; Da Roit and Le Bihan, 2010; Gordon et al., 2012; van Ginneken, Groenewegen and McKee, 2012; Netten et al., 2012; Davidson et al., 2013; Forder et al., 2012; Jones et al 2017). Commentators have also noted the significance of access to resources in quasi-market and consumerist approaches such as individualised budgets (Dixon, Robertson, & Bal, 2010; Moberg et al., 2016, Schmidt & Carstensen, 2016).

What emerged from these findings was that what constituted choice and control was in how individuals accessed resources and the experiences they had when dealing with professionals. This differed from one individual to another depending on the local context, structures, processes, policy interpretation and implementation within local CCGs. My study therefore highlighted two types of choice and control that could be separated out: internal choice and control which operated at the personal level and external choice and control which was interpersonal and interrelated. All the participants valued the internal choice and control that they derived from PHBs. Karen valued having control of the funding alongside making the decisions about day-to-day management of her care and support. For Steve it was the enhanced autonomy and convenience that came with PHBs that he valued. He appreciated having the time to do things when and how he wanted and not having to rely on NHS service provision. Cora valued the decisions about how her care was provided and being able to make the changes she wanted in order to get the best outcomes out of her PHB package. These findings parallel research in both mental health and older people that revealed that people valued using personal budgets to arrange care to meet their individual needs and circumstance without having to rely on agencies or professional for such day-to-day arrangements of care (Manthorpe et al., 2011; Baxter at el., 2011).

My examination of the findings indicated that PHB holders had considerable autonomy over the decisions they made and authority over how care was delivered on a day-to-day basis. They had power to influence and decide who provided their care and support, how they wanted it and when. They had some control over their allocated budget to employ their own PAs, people they could form relationships with and purchase some of the services they wanted. For instance, Cora was able to employ her husband as the main carer providing night cover, that way she could go to bed when she wanted rather than be kept to a routine. These findings parallel the findings from the evaluations carried out by Forder et al., (2012) and the broader literature on personalisation (Gordon et al., 2012; Woolham, and Benton, 2012; Davidson et al., 2013; Jones et al., 2013; Webber et al. 2014; Hitchen, Williamson, and Watkins, 2015; Rabieeet al., 2015; Jones et al 2017) whereby choice and control sat typically at the micro-level of the individual. In that respect, PHBs improved the lives of people with complex healthcare needs and much of the improvement was from the fact that people had choice, control, and flexibility over the day-to-day aspects (internal control). The PHBs holders in my study, were using their budgets in four different ways: accessing PAs, access the community, buying equipment, and purchasing care and support services. They all reported that they were able to maximise choice and control with regards to who they could employ and what they could do with their time, and in that context, choice and control was seen as autonomy, based on the level of flexibility the PHBs holders had.

On another level, the participants reported challenges that emerged when choice and control is held by organisational gatekeepers (external control). Participants felt that professionals created resistance when they were trying to purchase equipment and some innovations such as complementary therapies. Access to resources was contingent upon being able to use the money in ways that made sense to professionals, which was not always the case. When battles with professionals were required, choice and control came to be considered a burden. The initial findings of the evaluation by Forder et al., (2012) noted that not all CCGs were flexible enough to give people greater sense of control and empowerment. Those sentiments were echoed by my participants, with CCGs controlling how people chose to use the money. They faced challenges in instances where they tried to be innovative with the budget. Professionals did not always see the value of innovations that were not supported by clinical evidence and sometimes they were being pressured to buy services in block contracts through the NHS. There was also a tendency for risk aversion through rigid processes which undermined what PHBs are meant to deliver.

These views echo some of the latest findings from the evaluation by Jones at el., (2017) and reiterate the findings from the national evaluation by Irvine et al., (2011) and Davidson et al., (2013). However, the findings from this ethnographic case study give us insights into the long-term embeddedness of PHBs which takes our understanding further than these existing studies. They enable us to see choice and control as a temporal unfolding over time rather than a static binary of choice as autonomy or choice as a burden. My refined theory also highlighted that giving people choice and control of the budget alone was not enough if the CCGs were going to control what the PHB holders chose to purchase with the money or if there were no services to purchase. As Karen put it, '*give me the money and let me decide what is best for me*'. The CMO configurations helped to identify some of these hidden mechanisms such as decision making of budget holders and professionals that are not always explicit.

Glendinning (2008) summarised some of the issues faced by social care service users in making choices, such as social capital, support, and information, which were taken to be important determinants of abilities to exercise choice (Glendinning, 2008). My study also identified further determinants. Being able to recruit PAs with the skill to support PHB holders as well as training them and paying the wages commensurate of changes in the skill set was important for this patient group. For instance, Steve could recruit, but his needs required specialised support that might not be readily available. He was able to facilitate dedicated training for his PAs, which improved his experiences and sense of well-being but brought along a complex set of challenges such as professional resistance from district nurses. On the other hand, Karen could recruit more easily but her live-in care arrangements meant being able to share a common space where she is a dependent, identifying the right candidate, people she could relate to but also having the emotional intelligence to manage the relational challenges that may exist between employer and employee. This affirms the importance of PHB-holders having a strong skill set, which is not just about financial management but also the emotional demands of being an employer. In Cora's case, although she had the funding to pay for PA support, she was unable to recruit partly because she lived in a remote rural community, but also because of the complexity of her needs, highlighting the limits of choice and control when there is little available to buy. These findings reiterate the concerns raised in the Public Accounts Committee report about lack of provider markets in the current care system (House of Commons Committee of Public Accounts, 2016)

Not much is written about the review process in continuing healthcare, yet this process has a major bearing on how PHB holders access resources and remain eligible for the funding. I was able to understand the review process from the perspective of the PHBs holders. According to NHS England, (2014a), the review is an important and valuable process of safeguarding, monitoring, and strengthening the person's ability to achieve the outcomes they want from using a PHB. PHBs should be subject to regular yearly reviews to appraise health and well-being needs and resources (NHS England, 2014a). From my research, it was clear that not all CCGs reviewed the budgets annually.

When prioritising resources, CCGs need to plan across whole populations. All the participants felt that the eligibility threshold for continuing healthcare (and therefore PHBs) was being raised, making it difficult to attain. These finding are consistent with findings in both health and social care (Arksey and Baxter, 2012; Alakeson, 2014b; Walters and Hatton, 2014; Jones et al., 2017) with regards to how organisations are responding to personalisation in a resource constrained environment. PHB holders also perceived the review process as an opportunity for CCGs to cut their budgets. As such the review process caused so much fear, anxiety, and uncertainty amongst PHBs holders. Such tightening of resources was also found in social care when there was an increase in demand for direct payments (Arksey and Baxter, 2012). The PHBs holders in my study felt that as more people take on PHBs it is likely that resources will become more constrained unless PHBs are prioritised, and funding is made available for PHBs to remain sustainable. The comments were similar to those presented by Jones et al. (2017) in their evaluation, where they found a general uncertainty among PHB holders on whether PHBs will continue to be offered.

The PHB holders who took part in this study had all used the direct payment route, which is said to offer far greater choice and control than conventional funding and service models. Glasby and Littlechild (2016) discussed the merits and challenges of direct payments in social care and my study found many similar features in health. For instance, direct payments offered more choice compared to the other deployment option. Yet they came with a lot of administrative responsibilities and risks. In addition, my study was able to offer some insights with regards to the third-party option of the deployment process. The third-party option provided a redistribution of administrative duties while still allowing the PHB holder to have some choice and control on who supports them. But this option brought along its own challenges such as delays in communication, lack of access to records on cost effectiveness when being asked to justify innovations, and an inability to manage PA behaviour because they were no longer direct employees.

Previous studies in mental health and older people indicated that identifying who can benefit from personal budgets remains complex (Newbronner et al., 2011; Hatton and Walters, 2014; Rabiee et al., 2016). My study cast some further light. It has been demonstrated through insights from the present research that access to PHBs was not linked to a particular condition. The participants in this study had conditions that were varied and complex and some with life limiting conditions. They were able to use the direct payment route and there were other deployment options they could choose from should they find the direct payment route challenging. The findings suggests that the complexity of health and social care needs may not hinder one from using PHBs.

An important aspect of personalisation is the promotion of equity by making choice available for all service users and not simply for those who are more able (Glasby and Littlechild, 2016). However, concerns have been raised about PHBs, how to manage risks and avoid exacerbating inequality in access to resources and at the same time give people choice and control (Slasberg , 2014). The present study highlighted that concerns around PHBs exacerbating inequality in access to resources was not because of PHBs per se but because of the systems and rationing processes that were in place within the CCG. For instance, implementation was down to local policies that were varied, and decisions were down to how PHB holders were able to justify their needs and the innovations they were choosing to purchase. The research offered the insight into the possibility that PHBs is an innovation that can address some of the inequalities that exist within the NHS for people with complex health needs (Marmot and Allen, 2014). There remains an issue of how best to make choice and control effective for people without the professional skills that the three participants had, although there are peer support networks to help with this. All the three participants were active in supporting other people to get the most out of a PHB.

While this research showed that PHBs can be tailored to the specific needs of everyone, another observation was that the complexity of PHB administration, may mean that some individuals will be able to use the system better than others and derive greater benefit. Furthermore, the CMO configurations highlighted practical challenges associated with the direct payment route, a notion supported by Glasby and Littlechild (2016) such as increased responsibilities, accountability and risks associated with choice and control. But my findings also confirmed some of the findings about the use of the direct payment route being suited to people with managerial experiences (Jones et al., 2017).

All the participants in this study were well educated, had held high positions at work or owned their own businesses and had advocacy roles within the health system. Higher socio-economic groups are said to draw greater benefit from public services due to individual skills and resources at their disposal (Glendinning, 2008; Hastings et al., 2018). Indeed, people with these resources, and the autonomy that they bring, draw wider benefits, beyond public services.

Marmot suggests,

> For people above a threshold of material wellbeing, another kind of wellbeing is central. Autonomy – how much control you have over your life and the opportunities you have for full social engagement and participation – are crucial for health, well-being, and longevity. It is inequality in these that plays a big part in producing the social gradient (2005: p2).

These perceptions appeared to mirror all the participants in this study. All of them were able to make complex choices that required reacting to the world, appraising it, making sense of contextual information, and identifying a response especially when dealing with professionals. The argument is further strengthened by work from Matthews and Hastings (2013) who through their research found that those in higher socio-economic groups derive more health and social benefits from services because of their ability to negotiate these complex and bureaucratic service systems.

Existing literature indicates that higher levels of cognitive ability will enable service users to use those resources to find relevant information about care, make informed choices and further increase their inherent advantage (Lent & Arend, 2004; Rogers & Mead, 2004; Corrigan, 2005). For example, Karen explained how she was able to challenge professional attitudes in her CCG because she had resources at her disposal which other people with complex healthcare needs may not have access to. Ultimately, with others, she was able to win support from the Ombudsman.

Similarly, Steve explained how he went around facilitating and sharing his personal experience so that others could benefit from his support and knowledge of PHBs. He also explained how he would read every document so that he was well informed and could navigate the system. When discussing care and support with professionals, he could argue and justify the need for additional resources. This indicates that resources, such as social capital, are taken to be important when dealing with professionals or as advocates, but also exposing how inequalities may arise (Glendinning, 2008; Marmot & Allen, 2014; Hastings et al 2018). It is important to ensure that increased opportunities for choice and control come with access to relevant resources and support services (Proper et al., 2006; Thomson & Dixon 2006), without which the policy may worsen inequalities.

7.4 Shared Decision-Making

There is a consensus established from the literature that shared decision-making is an important element in achieving positive experiences and improved outcomes (Hibbard & Peters, 2004; Coulter & Ellins 2007; Nunes et al., 2009; Elwyn et al., 2000; 2012;

Ahmad et al., 2014; Hibbard et al., 2007; 2015; NHS England, 2019). Shared decision-making at the individual level of co-production can be defined as a process by which clinicians and patients work together to make decisions about care and treatment based on both clinical evidence and the patient's informed preferences (Ahmad et al., 2014). Shared decision-making is relevant in many clinical situations. This includes treatment decisions, managing chronic conditions, modifying treatment plans in hospital, prescribing of medicines, undergoing screening or diagnostic tests and advance care planning (O'Connor et al., 2009). Personalised care planning, as in the PHB context, is one such example.

Within personalised care planning there is recognition that the care and support needed to live with a long-term condition requires a radical re-design of services that allow patients to drive the care planning process (Coulter & Collins, 2011; Coulter et al., 2013; Alakeson, 2014a). From what the participants described, the assessment was the beginning of a process that should enable needs to be fully assessed and a budget matched to the needs of the individual. Consistent with the findings from this research, central to shared decision-making is the recognition that patients and clinicians bring different, but equally important, knowledge and expertise to the process (Coulter & Ellins, 2007). It was noted in my findings that during the care and support planning processes, at the early stages of roll-out, the process in Karen and Cora's local CCGs was professionally led. The participants commented that the initial process was not holistic (considered all their needs, physical, emotional, psychological dimensions etc), and therefore that the budget was not adequate. However, as PHBs became more embedded, PHB holders and professionals worked in partnership to identify support needs and agree on goals as well as develop action plans and agree on how to monitor progress. In cases where the assessment was a shared decision-making process, the budget was adequate, and people could buy the care and support they felt would give them the choice and control that they wanted.

There is evidence to suggest that shared decision making can improve people's understanding and level of participation, as well as their coping skills and confidence to self-manage, leading to better health outcomes (Hibbard et al., 2004). My investigations showed that in situations where PHB holders actively participated in the care and support planning process, experiences were positive. Steve commented that his experience of the care and support planning was '*co-production at its best*'. Steve and the professionals were both new to PHBs and he felt that they learnt together as they implemented his PHB. From previous research carried out by Hibbard et al., (2009) patients who actively participated in all aspects of care and support showed improved management of long-term conditions. According to Steve he assumed an active role in determining his own care and support needs and he was at the centre of the process, and he worked in collaboration with professionals. When I examined his care and support plans, the language used endorsed Steve's sense that he was explicitly at the heart of the process. The care and support plan showed how he had set his own goals and how he intended to manage his long-term condition within the context of every-day life. He commented that he was happy with his care and support plan. This supports the evidence from previous evaluations of PHBs pilots which found that a personalised approach had significant positive effects on patients' quality of life and emotional wellbeing (Forder et al., 2012).

Everyone taking on a PHB should have the opportunity to participate in a collaborative care planning process. However, the experiences of the other two participants suggests embedding the shared decision-making approach more widely would require fundamental changes in NHS organisations (Coulter et al, 2013). While the principle of personalisation offers people greater choice and control by providing opportunity to make care decision in partnership with professionals, some organisations still have a top-down approach to care and support services (Ham, 2014). According to Karen and Cora, there was no user involvement when their care and support plans were initially implemented. They reflected on how they had very little input into the process, and both commented on how frustrated they were at the beginning with their PHBs and how the PHBs were not working for them. Karen reported that there were no conversations about what she wanted to achieve with the budget and the process had been more of a tick box. Cora who had participated in the pilots remarked on how different the care and support plan had been for the roll-out phase, with a lack of active participation and co-production. Steve's experience of PHBs was very positive and that was down to being actively involved in the processes which enabled all his needs to be identified and addressed in his care and support plan. This suggests that improving care for people with long-term conditions will involve shifting away from a professionally dominated model (Coulter & Collins, 2011) to a proactive, holistic, and co-produced approach that encourage PHB holders to play a central role in managing their own care (Alakeson, 2014a).

7.5 Professional Power

The key to improved processes and outcomes lies in creating positive conditions that support change, such as environments conducive to harnessing both relationships and the skills and capacities of individuals within the system (Braithwaite et al., 2015). For instance, through the CMO configurations I found that the individual capacities of PHB holders alongside frontline professional were key mechanisms. Similarly, contextual elements at different levels of the system such as the NHS institutional ideologies and wider infrastructure systems and processes also played a significant part in the programme outcomes. The CMO configurations enabled location of discretion and street-level bureaucracy (Lipsky, 1980) in practice which was key in shaping access to choice and control. It is important to note that the perceptions being discussed here are perspectives of the participants. My study did not speak to professionals, which limits what can be said about their perspectives and behaviour in relation to PHBs, although the artifacts did enable me to witness professional practice to supplement the testimony of the participants. However, I am a practising nurse therefore, I come from a professional perspective, and I recognise that this is a relevant factor when considering the role that professional power plays in PHBs.

The CMO configurations highlighted discretion and street-level bureaucracy in practice as a key driver of PHBs. The notion of power is of central importance to this thesis and inescapable when considering the interactions that took place between the PHB holders and professionals from the PHB holders' perspective (Ellis,2011; Pederson et al., 2013). This links back to the important work of Parsons (1951) who formed the notion of the 'sick role', rendering patients' passive and compliant to medical instruction and advice. Freidson (1970) further discussed the potential 'conflict' that may exist in such a medical model. Whilst much of the literature considers the doctor-patient relationship, this can be extended to the wider healthcare professions and the overall professional-patient relationship within the NHS in general. Through the configuration of CMOs the study was able to highlight deeper issues of perceived control and authoritarian approach that was reported by the participants amongst professionals that did not seem to accommodate PHBs.

The role of professional power as a mechanism that shapes the extent of choice and control within PHBs cannot be underestimated and PHBs are unlikely to work well when there are high levels of ambiguity about what can be funded through a PHB and when there is high demand for scarce resources. When there are such high levels of tension such as ambiguity around individual choice, safeguarding, equitable disposition of public funds, pressures of managing scarce resources, including time and lack of knowledge, professionals may even behave in actively obstructive ways (Tummers, 2012; Tummers and Bekkers, 2014; Manthorpe et al., 2011; 2015, Tummers et al., 2015). From the evidence presented in this study, the challenge is likely to be around making the systems and processes easy and transparent for PHB holders.

Much has been written about the significance of discretion and street-level bureaucracy in shaping outcomes in policy implementation (Hill & Hupe, 2009; Tummers et al., 2009) at micro-level; how decisions in complex and contentious policy are often left to frontline workers and the challenges they face when they cannot identify with policy (Berkovich, 2011; Evans, 2011). Ellis & Hupe (2020) describe discretion as ideas of judgement, trust, and freedom to act. They further explain how the nature of judgement to be exercised, and the extent of the freedom within which it can operate, are open questions but also regard issues of power as a 'constraint on and potential within discretionary roles' (Ellis & Hupe, 2020 p.4). Such accounts capture what Lipsky (1980), in his classic account of policy implementation, termed 'street-level bureaucracy' to describe the spaces between and around formal rules which in the face of frontline pressures, workers exploit in order to control their encounters with service users.

The evidence demonstrated that when PHB holders were given autonomy, they were able to manage the risks associated with the treatments they chose to buy as well as save money, but the landscape in which choice and control operated was not conducive initially. There is recognition in the healthcare literature on how changes in complex systems are enabled by those on the frontline of care who may subtly alter practices or priorities causing variations from the original policy intent (Debono et al., 2012; Wears, et al., 2016; Hupe; 2019). Coiera (2011) pointed out that while there are local adaptations and variations in behaviour and practices that occur, there is also inertia of strong forces that inhibit change because of trade-offs amongst stakeholders, and role rigidities. PHBs holders narrated similar experiences when interacting with professionals while trying to exercise choice and control of the budget.

Commentators have noted how disconnection between professional aspirations and policy intention may cause professionals to adapt in order to cope with policy changes (Hupe, 2013; Ellis 2014; Tummers & Bekkers, 2014). In looking at this, I draw on two key ideas, policy alienation and coping. Tummers & Bekkers (2014) suggested policy alienation to be an attitudinal concept that conveys a sense of disconnection between policy aspirations and professional aspirations. They argued that the disconnection may arise because professionals feel what they are being asked to do is impossible, either because of insufficient resources or because they don't agree with policy intention and see the policy as unhelpful (Tummers & Bekkers, 2014). Coping is to do with how they behave and what they do in the process of public service delivery (Tummers & Bekkers, 2014; Evans, 2012) and such behaviours were noted mainly with Karen and Steve. The perception of the budget holders (which of course is only one perspective), was that rather than embrace the opportunity presented by PHBs, professionals became resistant to any suggestion of innovation or ways of working that were different. They also felt that the professionals did not understand a great deal about PHBs.

My findings indicated that not all CCGs were offering all the deployment options (direct payment, notional budget, third party) and the perception of PHBs holders was that professionals were making the allocation of funds too complicated and restrictive. It may be that the site of resistance is not at the frontline but at higher tiers of the organisations. According to Steve, some of the frontline clinicians mentioned how they were struggling to convince their managers that PHBs work. This confirms an important message that also emerged from Jones et al. (2017) in their process evaluation of PHBs which highlighted the importance of the implementation process in determining how the capability offered by PHBs was realised, such as the climate for implementation and professional perceptions of the innovation.

Furthermore, PHBs challenge the hierarchical structures by acknowledging 'lay forms of knowledge and expertise, as well as promoting greater autonomy for service users through the redistribution of power and the democratisation of choice and decision-making' (Mladenov et al., 2015, p. 309). According to Ellis (2007) implementing policies such as PHBs may invoke informal modes of discretion which in turn can trigger in professionals the kind of conservative, paternalistic and defensive practices found in this study. Participants in my study felt that professionals were rationing services and limiting choice and control by imposing bureaucratic processes that were designed to wear PHB holders out. PHBs holders often felt they were required to make a lot of justifications for their choice making. At times that was causing severe delays in the approval of budgets. In some instances, PHBs holders were being asked to continue to buy mainstream services through block contracts. This highlights lack of flexibility and the imposing of arbitrary limits, as found by Jones et al. (2017).

Participants in my study felt that professionals had the authority to respond flexibly to individual circumstances and they used their discretion as to which innovations they allowed PHB holders to purchase or not. There was denial of requests without giving PHB holders the rationale for such decisions. Karen felt that professionals were exerting unnecessary power and authority and yet they did not know much about PHBs. From the social care experiences in personal budgets, McDonald et al (2008) highlighted that frontline professionals are more likely to act defensively rather than seek proactive and creative ways to promote choice and control. Participants felt that bureaucratic processes were time consuming, diminished choice and control and made the experiences negative, but also took away the scope to use the budget in ways that made sense to the individual. While expenditure remains tightly controlled by CCGs and under the discretion of professionals, PHBs will remain restrictive and PHB holders will not be able to maximise choice and control.

Studies of direct payments have shown that increased bureaucracy combined with concerns about taking responsibility for assessing risk lead to professional scepticism or active resistance to their allocation (Riddell, 2006; Ellis, 2007; Priestley et al., 2010; Arksey and Baxter 2012; Woolham et al., 2017). My study had similar findings, for instance, when Steve chose to use a peristeen rather than rely on the district nursing service, there was initial resistance from professionals. This was the case even though what Steve was suggesting would improve his quality of life and experiences as well as save NHS resources. The innovation he was proposing challenged professional knowledge and training. It had implications for resources such as cost of training and increased wages, and de-professionalisation of district nurses as they lost their job-differentiation which may have triggered anxiety and uncertainty among professionals. Williamson (2010) pointed that the underlying driver for informal discretion at the frontline is the need to maintain or create order in the face of the uncertainty, tensions, and time constraints.

The findings showed that even Steve, who wanted total control of the budget, still acknowledged that the demands of the direct payment from a procedural point of view, could be stressful. In that respect not only was choice autonomy, but it was also a burden. There is growing literature pertaining to the administrative burdens of personalisation (Carey et al., 2020; Fleming et al., 2019; Herd & Moynihan, 2019). It is suggested that 'if programs bury people in paperwork and fill them with frustration, it undermines not only policy outcomes, but also people's faith in the capacity of government to do anything right' (Herd & Moynihan, 2019 p. 2). The CMO configurations identified these transactional costs and administrative burdens for example PHB holders reported going through a series of processes that were difficult and some did not know the level of the budget allocated. Even with third party options, the CCG was making demands and imposing burdensome processes that still restricted choice and control.

In the study of the National Disability Insurance Scheme (NDIS) in Australia carried out by Carey et al., (2018), administrative burdens were reported as causing serious challenges for participants. Carey et al., (2020) noted that the increased administrative burden, ‘it reflects a tension in the underlying logic of the scheme’ (p.1364). They gave an example of how personalisation is being driven by consumer choice, thus giving people responsibility over their care, whilst at the same time recipients are active consumers of state funded services which gives state responsibility. Therefore, administrative burdens increase in trying to decide who holds what responsibility.

The CMO configurations in my study drew attention to where some of the tension in PHBs was located. For instance, there is over-emphasis on how the policy is designed to challenge the dominance of professional power in the NHS. At the same time professionals are supposed to offer choice and control and empower service users as well as drive the implementation process. The ambiguity in the logics of PHB policy intervention seemed to increase tension and resistance. Other studies have looked at whether these administrative burdens were an essential part of change or were being used to exploit the shifting of responsibility, demanding too much of budget holders (Fleming et al., 2019; Carey et al., 2018; 2020). Fleming et al., (2019) argued that one of the features of personalisation is the shifting of power which also shifts responsibility, accountability, and risks along with unexpected and unfunded administrative burdens. The PHB holders in the study were all concerned with the increased responsibility and the lack of support and training available to help them enhance their decision making. Cora was getting so stressed and anxious that it was affecting her health and she opted out of direct payments for the third-party option which she thought would offer less choice and reduce her frustration.

Through the CMOs it was also possible to identify subtle practices that altered priorities and caused variations from the original policy intent such as general resistance to requests and over-exerting of power that caused frustration and despondency among the participants. This links to ongoing debates about how professionals use their discretional powers to make important decisions and how they deal with their discretion in day-to-day encounters with service users and alter policy intentions (Meyers and Timms, 1970; Brodkin, 2011; Tummers, 2012; Evans, 2013; 2015; Evans & Hupe, 2020). In line with other studies, I conclude that currently there is little to discourage the perpetuation of conservative and defensive practice on the front line of personalisation, when faced with managing the reputational and financial risks of PHBs under pressure of limited resources (Evans and Hupe, 2020).

7.6 Change Over Time

Casting a realist analytic lens to the experiences of budget holders over time placed emphasis on human agency and reasoning, by taking account of context and linking it to resources which facilitated change (Jagosh et al., 2015; 2016). While studies investigating change over time are more rarely conducted (Braithwaite, 2018), the longitudinal nature of this ethnography enabled an appreciation of how time was key to change taking place.

Best et al., (2012) assume health and social policy and systems evolve over time therefore contextual influences and experiences do not stop developing and are influenced by past and current developments. My study affirms that experiential learning took place, for example the PHB holders developed new skills and new relationships with professionals. From the CMO configuration, it was evident that policy change is a dynamic process evolving over a considerable time. The findings were consistent across all participants highlighting the limitations of studies focusing on experiences at one point in time. Together with professionals, participants engaged in learning throughout the implementation process. There was re-configuration of processes, re-adjustment of work practices and attitudes, power sharing and negotiation as they both professionals and PHB holders got to understand PHBs better.

Longitudinal perspectives are vital in understanding the complexity of policy change (Braithwaite et al., 2017; Greenhalgh & Papoutsi, 2018) and also how events unfold, for instance how the programme was taken up, resisted, or modified (Adam, 2014). At the beginning, budget holders' experiences were not all positive. They faced a lot of challenges such as resistance to ideas and treatments that were not conventional, and evidence based. The CMOs revealed some of these mechanisms and contexts such as delays in budgets approval, poor assessments leading to inadequate funding, lack of user involvement, limited choice and control, disempowerment and professional attitudes that felt authoritarian. These factors led to frustration, anxieties, lack of trust and poor relationships. Also, budget holders were purchasing mainstream services but with time, as they got to understand PHBs more, they became more innovative and their purchasing of services changed, and people felt they were getting more out of the budget.

Over time, I was able to explain ambiguity and confusion around PHBs and such explanations were in statements of what PHBs can offer and in the implementation process. For instance, while both budget holders and professionals were new to PHBs, there was lack of support and information. The perception amongst budget holders was that there was initial professional resistance and unwillingness to accommodate PHBs. This is consistent with the change management literature in general (Scott et al., 2003; Bazzoli et al., 2004; Cresswell & Abelson, 2012). With time, as PHBs became more embedded, my study shows that the environment altered as professionals and budget holders interacted, self-organised and learned collectively (Hawe, 2015).

Karen was able to organise a peer support group to counterbalance the discretional power of professionals in her local CCG. Peer support has been linked to empowerment, greater confidence, self-esteem, more skills, and a more positive sense of identity (Ratzlaff et al., 2006; Bracke et al., 2008; Gillard et al., 2014). Evans and Hupe (2020, p172) commented on how citizens could try to organize themselves to ‘counterbalance’ the discretionary power of the street-level bureaucrats or, when making use of open data or knowledge and information that is available on the internet, to question the decisions that are made by street-level bureaucrats. From those actions, the experiences of how PHBs were administered locally became very positive for Karen. She commented how the focus had aligned with principles of personalisation and the PHBs were working as intended.

Healthcare systems are said to be comprised of interacting agents, interconnected with activities in real time and altering over time (Plsek & Greenhalgh, 2001; Greenhalgh et al., 2016; Braithwaite, et al., 2013; Braithwaite, 2018). For example, in the study behaviours of both budget holders and professionals altered as they interacted with the PHBs and with others. Complexity approaches acknowledge the tensions and paradoxes inherent in contemporary healthcare systems and accept that interventions such as PHBs are designed to perturb the system over time. In complexity theory both patients and professional flex and adjust to each other, and circumstances over time, through their high degrees of interrelatedness, control is distributed (Rickles et al., 2007; Braithwaite et al., 2016). Uncertainty is recognised to be inevitable and dependent on contextual factors such as behavioural patterns of both clinicians and patients embodied in the structures, policies and culture and the interdependencies among them as they figure out how to move forward with the change (Plsek and Greenhalgh, 2001; Greenhalgh et al., 2016; Braithwaite, 2018). In my study, there was facilitation through sharing of lived experiences of their success stories of managing PHBs. This allowed both professionals and budget holders to learn from each other and work collaboratively. Commitment of PHB holders to the programme intervention created considerable power for change in Karen's CCG where there were high levels of unequal balance of power and authority. The change appeared to be not only in budget holders but professionals as well. Professional attitudes towards PHBs appeared to change as they were able to witness the benefits and latent capabilities that PHBs offer as well as the cost saving. I was able to see this in the way that the wording of care and support plans changed over time, and budget holders were given more discretion about the choices they could make.

Access to adequate and appropriate information and support is known to be important to choice and control (Braithwaite, 2016). In my study this also improved over time. The insights from the case studies show that PHBs, when implemented well, in the long-term, can offer greater choice and control. They also have the potential to enable management of long-term conditions and improve people's sense of health and well-being. PHBs may also reduce the cost of healthcare as people learn to be innovative in their use of the budgets as we saw through the eyes of Karen and Steve. The study has also revealed the importance of time to allow effective implementation of PHBs. Over time there was evidence suggesting PHB holders together with professionals were able to learn alongside each other and work collaboratively. Through the eyes of the budget holders, we learnt that there was a re-configuration of processes, re-adjustment of work practices and attitudes, power sharing and negotiations that took place in the relational spaces for mutual benefit. As a result of these actions, PHB holders reported culture and systemic change in the funding organisations.

7.7 Chapter Summary

In this chapter, I have taken into consideration the findings of my thesis with regards to how choice and control translate to practice from the perspectives of the PHBs holders. The findings indicated that PHBs have the potential to deliver choice and control. However much of that was dependent on the context and mechanisms that were firing the programme theory and in different contexts, benefits and challenges may arise.

I considered my findings in the context of the wider literature on personalisation, and I was able to link the findings using some of the overarching themes that emerged during my thesis, in relation to choice and control within the PHBs programme theory.

I also discussed the CMOs related to the power of professionals and PHBs holders in bringing transformational change in the healthcare system. In particular, this focused on how with time, professionals and PHB holders were able to enter ongoing negotiation and power sharing, allowing a policy intervention as complex and ambiguous as PHBs to work.

Chapter 8: Conclusion to the thesis

This thesis focused on PHBs in the English NHS and gave a theoretically informed and ethnographically rich account of participant experiences of choice and control. The thesis is presented in eight chapters. Chapter one provided background to the study. Chapter two presented the realist evaluation as a theoretical framework that formed the backbone to the study. Chapter three evaluated the evidence on PHBs using a realist synthesis, with chapter four presenting the methodology and methods applied. In chapters five and six, I presented the key findings that add new knowledge to the current body of research, while chapter seven provided a discussion of the findings. In this chapter, I present my methodological reflections and my own learning as well as outlining limitations of this study. I assert that my contribution is to theory development and not to generalisation to the PHB population. I conclude with a set of recommendation for consideration for those who use services, policy, research, and practice.

8.1 Reflections

The broad aim of the study was to explore if and how PHBs are delivering choice and control for people with complex healthcare needs. Recognising that choice and control are just one aspect of PHBs programme theory, this research evaluated those elements of the programme that relate to choice and control. The task was to make the theory explicit using CMO propositions, then test the theory and draw some inferences in our understanding of how PHBs work and under what conditions they work.

The Challenges of Using the Realist Approach

Here I reflect on my role as a researcher alongside my own learning from the process. I also consider the challenges presented by my chosen methods and methodology alongside fieldwork challenges which are all important aspects of ethnographic case studies.

Working within the realist philosophy using both realist synthesis and evaluation for the first time in combination with ethnography was ambitious on my part. However, this has been a very important learning experience and filled a gap in research on PHBs. I faced challenges associated with realist analysis when developing CMOs during both realist synthesis and fieldwork analyses. I initially developed loose conjectured CMOs during the realist synthesis for testing using empirical data. Developing an array of CMOs was a challenging exercise and maybe ambitious on my part considering those that have conducted realist synthesis and realist evaluations mostly have often been teams of researchers. The complexity is indicated in the CMO tables in the appendices (pages 389-395). It was very time consuming, and the challenge was further exacerbated by the fact that there was limited research that had looked at PHBs in the NHS using similar methods. However, it was very useful in fusing the conceptual thread throughout the research while unpacking the complexity that lies behind choice and control within PHBs.

The challenges were exacerbated by the fact that my data analysis coincided with the covid-19 outbreak. My whole family had to move back home, leaving me with no study space. I am also a practising nurse, so I had to go back to work full time as many of my colleagues self-shielded. Trying to focus and engage with the data and make conceptual connections became such a challenge in the confined space but also when tired and emotionally exhausted. So, I took a break from studies. Coming back into the data after a long period of detachment has had its own implications, both positive and negative from an ethnographic perspective. However, working within the confines of such challenges are realities of life that researchers must manage.

The Participants and Using Case Studies

People with complex healthcare needs are a unique group with reference to the complexity of their healthcare needs which had implications for my visits. Health conditions can change at any time which meant contact was sometimes cancelled on the day or when I arrived for fieldwork. Participants interact with different agencies which provide support services, and which may also cancel appointments of activities that I may be going to observe. Due to ill health, two participants dropped out. One of these was due to high risks associated with the participant's behaviour. Another one dropped out in towards the end of the study due to the longitudinal nature of the research and time commitment. Such uncertainty is something I had to grapple with alongside loss of opportunities and time due to the Covid-19 pandemic which started during my data analysis stage.

My recruitment strategy was to use snowballing alongside a self-referral process. This connected me to people who were highly intellectual with extensive knowledge, support networks and access to resources, who may not be typical of most people with complex healthcare needs. However, it is these skills that also made them more likely to take part in this study. Due to the self-referral process, participants could be from any part in England, therefore I had a large geographical area to cover, and my time was determined by the resources available. Faced with such challenges and on reflection, I decided during the first few field visits, what were the key issues I needed to address in my research question. I then managed interactions in such a way that conversations did not digress, and the participant and I could plan what was to be observed prior to each visit.

Case studies like all forms of research require attention to issues of validity and reliability. Hammersley and Atkinson (2019) suggest that ethnographers see accounts as important for what they may be able to tell us about people who produce them and the intellectual and discursive resources on which they draw. Ethnography is also a theory building approach. It is therefore an excellent investigative design to study PHBs and it provided rich longitudinal data, which other forms of designs might not have been able to collect. Although there were limitations to this research, a qualitative study, based on 3 cases, was not intended to be representative. Rather, the cases enable the testing and refining of the programme theories to generate an understanding of the ways in which context and mechanisms interact to generate desired outcomes. The CMO configurations generated here could be tested in large scale studies in the future.

The Novice Ethnographer

'Working within the ethnographic tradition is not an easy option for the beginner,' warn Robson and McCartan (2016, p.157). While the ethnographic approach was most appropriate, as a first attempt at ethnography it presented challenges for me on a practical level and the research process in general. The design was very time consuming, requiring large time commitment in the field as an observer and conducting long interviews that were intense. I produced large volumes of fieldnotes that required transcribing, theoretical work, and systematic analysis. I had not anticipated such volume and intense work in my planning. Mason (2002) is clear about trade-offs between breadth and depth and how soon one should transcribe the fieldnotes. My focus was on depth but what I had not anticipated is how a 1-2 hours of interaction could generate a large volume of data that would require transcribing as soon as was practical. Hammersley and Atkinson (2019) warned against data pile up and therefore data management became a priority as the fieldwork continued. However due to such constraints, it forced greater discipline and I had to focus on efforts with greater priority.

The Insider

While early ethnographers were regarded as objective outsiders, the starting point required for this study was having both insider and background knowledge and previous experience of working with the patient group. As a community nurse practitioner for many years working in the community with children and adults with complex healthcare needs and their families, that insider knowledge was useful to be comfortable with the general culture of the patient group. Being an actively licensed nurse, still practising, meant I could assess on-going participants' health deterioration and the emotional strain and manage the risks. Considering one cannot predict what happens in a research setting, I had to be prepared to adapt and maintain regular and intensive involvement in a field situation and learn through continuous reflection. Also, these experiences added to insights drawn because I come from a professional perspective, and I recognise that this is a relevant factor when considering the role that professional power plays in PHBs.

Fieldnotes facilitated the iterative and interpretive process as I also noted my own reactions to the observed experiences. Reflection is a skill that I acquired as a community nurse practitioner and came in very useful. I can build relationships quickly, but I also had to remind myself to be neutral in my approach to research and the starting point was an open-ended exploratory approach to the real-life experiences of being a PHB holder. I needed baseline knowledge about the cases and research setting to generate questions that enabled refinement of the programme theories.

When I entered the field, some of the participants were going through a series of emotions, fighting the CCGs to keep their PHBs entitlement. I was the person they wanted to tell their stories, someone who could listen without making judgements – the impartial and empathetic listener (LeCompte and Schensul, 2010), a position I had not anticipated. It was very difficult to listen to these strong and charged emotional claims of what PHBs should be and how processes should be applied and not share one's own thoughts or feel upset. To listen empathetically, mainly through body language, fieldnotes were audio recorded as well as taking detailed notes. My initial plan had been to use a field diary sheet and I had to improvise. On the way from these journeys, I would audio record my own thoughts and feelings. I would collectively transcribe these into detailed fieldnotes, leaving out unimportant aspect of the recordings that were not relevant to the theories. Regular reflection during preliminary analysis took place. However, as PHBs became more embedded in practice, the process became easier and the dynamics of fieldwork and stories changed. People's situations and experiences of managing the PHBs got more positive and less intense (this was explored in depth in the findings). Despite the limitations, there have been some useful messages and implications for policy and practice.

8.2 My Contribution to Knowledge

This thesis sits in the interface between health and social care policy and service improvement. It contributes to the wider personalisation agenda with emphasis on choice and control in public service provisions. It also covers areas such as decision-making, patient involvement, co-production, and patient centred approaches to healthcare delivery.

These insights have been a considerable contribution to knowledge development from this thesis. The element of time in bringing culture and systemic change was evidenced through the change in experiences of the PHB holders. Through experiential learning, the PHBs holders developed new skills such as assertiveness and they were able to challenge issues of power, build their own understanding of how PHBs are supposed to be implemented. They also reorganised themselves into peer support networks and re-discovered the real meaning of choice and control when using PHBs. Together with professionals, learning took place alongside the implementation, re-configuration of processes, re-adjustment of work practices and attitudes, power sharing and negotiation in the relational spaces for mutual benefit.

The longitudinal nature of ethnography and the use of realist synthesis was an important aspect of this research design that enabled this study to reveal some of the nuanced and deep meaning of choice and control that may not be addressed by other design approaches. Another new insight that the study offered related to the benefits and risks of using third-party options, a mechanism for delivering PHBs that has not been researched elsewhere.

The role of professional power as a mechanism that enables PHBs to work or not, cannot be underestimated. PHBs are unlikely to move beyond the pressures of high levels of ambiguity and high demand when there are scarce resources. There is a need for recognition within the PHBs programme of the subtle practices that alter priorities and cause variations from the original policy intent that must be addressed as part of policy process to reduce some of these obvious tensions. Also, the evidence demonstrated that any attempts at co-production require a trusting relationship as well as support and information for both parties. This needs to be addressed as part of new ways of working in this new policy landscape. However, the findings showed that there is potential for collaboration in PHBs over time.

The study was able to pinpoint where some of the tension in PHBs is located. This includes overemphasis on how the policy is designed to challenge professional practice while, at the same time, professionals are supposed to offer choice and control as a way of empowering service users and drive the implementation process. Such ambiguity in PHBs increases tension and resistance which has been witnessed in the study. The role of individual capacities, key actors, and interpersonal relationships alongside contextual elements at different levels of the system (such as the NHS institutional ideologies and wider infrastructure systems and processes) plays a huge part in how the programme is implemented.

We have seen from the case study that PHBs, when implemented well, in the long-term, are able to offer greater choice and control. They also have the potential to enable management of long-term conditions, improve people's sense of well-being, and reduce the cost of healthcare as people learn to be innovative in their use of the budgets as we saw in the experiences of Karen and Steve. The findings showed that PHBs can be empowering and have the potential to challenge systemic culture and attitudes through bottom-up approaches such as peer-support networks as people strive for improved service provisions. This again highlights the importance of change over time in the implementation of PHBs.

From the individual ethnographies and CMOs presented, there is considerable evidence showing that PHBs deliver choice and control (O). Context such as existing skills of both PHB holders and professionals played an important part in how choice and control was exercised and experienced by the PHB holders. During the process, the PHB holders developed new skills such as assertiveness and these mechanisms enabled them to challenge authoritarian behaviour and excessive use of power by professionals. The PHB holders were able to build their own understanding of how PHBs are supposed to be implemented through user groups and NHS England. Organisation of peer support networks meant they could influence and support other budget holders. Therefore, a key message that emerged from this study is that the experiences of PHB holders can improve with time as PHBs become more embedded in practice. This is likely to be the case if PHB-holders have the skills to challenge professionals and to cope with the administrative burden of managing a budget and staffing.

In addition, the findings revealed that the complexity of health and social care needs did not hinder people from using PHBs. With the right support and deployment options, alongside peer support from other PHB holders, there is a possibility that anyone can use PHBs. The study offered new insights into third-party options and the review process within the PHBs programme. It also demonstrated that choice and control were operating at two levels: PHBs holders valued the choice and control over day- to-day management such as deciding how their care was provided, by whom, when and how. However, they initially reported that they had little or no control over the money with regards to choice and control of what they could purchase. When PHB holders had choice and control on both levels, they reported positive experiences, enhanced health, and well-being. In this situation, PHB-holders felt that they were able to save the NHS money, realising the benefits anticipated by the designers of PHBs. The study was also able to highlight deeper issues such as power, attitudes and behaviours amongst professionals that did not seem to accommodate PHBs.

8.3 Implications for Research and Policy

The study is the only empirical work that has used longitudinal ethnographic methods of enquiry to evaluate PHBs for people with complex healthcare needs. The strengths of this study rest on its ethnographic methodology embedded in a realist framework to surface and refine the programme theory of PHBs in relation to choice and control. The study fosters deeper understanding of the opportunities and challenges presented by PHBs at a micro-level that can inform the meso and macro level policy context to shape future policy and practice.

8.4 Study Limitations

There are limitations to the evidence drawn on here. This study only focused on three cases at the individual level in exploring choice and control within PHBs. The sample for this evaluation was through snowballing. The participants who took part tended to be younger (under 50 years) and at the more able end of the spectrum of complex healthcare needs, particularly in terms of their managerial skills. Perceptions of the macro and meso level could only be expressed through the experiences of PHB holders, suggesting limitations when interpreting the findings. On the other hand, it aligns well with the objectives of my methods of enquiry which was to pursue in-depth participant experiences of PHBs. The study constructed realities that are complex, multifaceted, expressed differently, case specific and changing (Spradley, 2016; Denzin and Lincoln, 2011). My role as an ethnographer was to identify these real experiences, and continuously make the connections that are valid in confirming, falsifying, and refining the programme theory.

During the realist synthesis phase I tried to engage with stakeholders, in particular policy makers and managers of organisations that had implemented PHBs pilots, to help refine the programme logic. However, I was not successful. I managed to speak to academics that had extensively looked at personalisation in social care and others who had used realist evaluations in qualitative studies to help guide my analysis. Rycroft-Malone et al., (2010) had similar challenges of engaging stakeholders and Pawson (2013) in presenting the challenges of doing realist synthesis also highlighted that these issues are not uncommon.

8.5 Conclusions

In line with the aims of the study I have explored choice and control in the PHB programme using a realist evaluation approach and identified some of the contextual features and mechanisms necessary for exercising choice and control when using PHBs. This was done by advancing an understanding of choice and control within PHBs through the lived experience of PHB holders with complex healthcare needs over a two-year period, which allowed me to reveal some of the hidden meanings situated in everyday life.

This approach allowed me to consider in realist terms the mechanisms that might contribute to choice and control when using a PHB and the contextual factors that are required to enable PHB holders to exercise choice and control. That way I could seek out the patterns of these contexts and mechanisms that result in choice and control in PHBs programme.

Within this thesis, I have considered the policy context and engaged with the wider literature in relation to choice and control in personalisation allowing me to contextualise my overall research and present a rationale for my study. I have also presented the PHB programme and considered this in the context of the wider literature in relation to choice and control. I used a realist evaluation approach to build theories on how PHBs are supposed to deliver choice and control. The theories were developed from literature that included policy, opinion papers, blogs, reviews, and local policy documents of PHB pilot sites and the wider literature on personalisation, cutting across health and social care. The theories were expressed in the form of the following CMOs, which relate to PHBs programme implementation and impact:

CMO1 – Access to resources

CMO2 – Shared decision-making

CMO3 – Professional power

Designing the review in this way served to identify and examine the broad evidence alongside a realist interrogation to identify and articulate the initial programme theory that could be tested using empirical work.

To test the initial programme theory, I used qualitative case studies that employed ethnographic approaches to the research design and utilised a realist evaluation framework to link the observed accounts to context. Using ethnography helped to unpack the underlying social mechanism in operation in the PHB programme and develop an understanding of the phenomena. To do that, I focused on change at micro-level through the eyes of three individual cases to get a deeper and nuanced understanding of the experience of choice and control as a PHB holder. This was a way to better understand the emerging theory and mechanisms which may trigger, block, or modify the desired outcomes. The focus was on the implementation variations and differences in the experiences of the participants in the study, therefore providing an opportunity to make comparisons with the initial programme theories articulated during the realist synthesis.

The longitudinal nature of the study provided a unique opportunity to explore the relationships between choice and control as a dynamic process over time through

CMO4- Change over time, a new theory that I developed from the case studies which was not in the initial CMO configurations.

I was able to refine the realist theory underpinned by the insights from the study to deepen understandings of the programme theory and circumstances which prompt significant change over time. This led to an updated programme theory highlighting the complexity of PHBs, and the paradox of choice and control presented in Table 13, on page 224.

I have presented a discussion based on the CMO findings, using themes from the broader policy literature that I considered important to explain the findings. These themes related to resourcing of PHBs, decision-making, professional power and the change that occurred over time as presented in the CMO configuration. The thesis therefore adds to our understanding of how, why, for whom and in what circumstances PHBs deliver choice and control for the people using them. The findings suggest that PHBs can deliver choice and control for people with complex healthcare needs if: there is sufficient access to resources, if decision-making is shared, and if professionals are willing to accept the knowledge claims of PHB holders. In the three cases, all these factors became more favourable over time, partly through cumulative learning and partly through the persistence of PHB holders in fighting for more appropriate packages of support.

8.6 Recommendations

- The main areas for consideration for both policy, research and practice from these findings are the CMOs, the refined programme theory and the importance of allowing change to take place over time so that interventions are fully embedded in practice settings. This is particularly important for interventions with high levels of ambiguity and complexity such as PHBs so that they can deliver the desired outcomes.
- A further important recommendation is that to achieve choice and control, maximum flexibility on what the budget holder is allowed to purchase with their allocated money is necessary. My findings suggests where this was done, the budget holders reported positive experiences, enhanced health, and well-being. This accords with other literature on PHBs and personal budgets.
- Another recommendation with regards to PHB panel reviews, is for CCGs to reconsider their approaches to administrative structures and review processes so that they are less restrictive to budget holders. The findings indicated that these processes invoked so much fear, anxiety, and uncertainty amongst PHB holders. Participants perceived these processes as designed to limit access to resources, thereby limiting choice and control which is not what personalisation aims to achieve.
- Service user-initiated peer-support to ensure ongoing access to information and support could be more effectively supported and incorporated into mainstream service provision. We saw from the analysis that bottom-up approaches to support initiated by PHB holders in this study proved to be effective not only in

bringing internal change (building resilience, sharing of knowledge, and developing new skills) amongst budget holders but also as a force that is capable of bringing external change (change in attitudes, learning) for professionals and organisations.

References

Abbott, D., Townsley, R. and Watson, D. (2005) ‘Multi-agency working in services for disabled children: what impact does it have on professionals?’ *Health & Social Care in the Community*, *13*(2), pp. 155-163. Doi: https//:doi.org/10.1111/j.1365-2524.2005.00543.x

Adam, T. (2014) ‘Advancing the application of systems thinking in health’, *Health Research Policy and System,* 12(1), 50. Doi: https//:doi.org/10.1186/1478-4505-12-50

Adams, J., Hillier-Brown, F. C., Moore, H. J., Lake, A. A., Araujo-Soares, V., White, M. and Summerbell, C. (2016) Searching and synthesising ‘grey literature’ and ‘grey information’ in public health: critical reflections on three case studies. *Systematic reviews*, *5*(1), pp.1-11. Doi: https//:doi.org/10.1186/s13643-016-0337-y

Agar, M. H. (1980) *The professional stranger*. An Informal Introduction to Ethnography. Orlando au. https//: 9780120438501

Alakeson, V. (2010) *International developments in self-directed care*. Issue brief Commonwealth Fund Publication,78: pp. 1-11.

Alakeson, V. (2014a) *Delivering Personal Health Budgets: A guide to policy and practice*. London: Policy Press.

Alakeson, V. (2014b) *Personal health budgets for mental health: The experience in Northamptonshire,* Report. NHS England.

Alakeson, V. and Rumbold, B. (2013) *Personal health budgets Research Summary: Challenges for commissioners and policy-makers*. London: Nuffield Trust.

Alakeson, V., Boardman, J., Boland, B., Crimlisk, H., Harrison, C., Lliffe, S., Khan, M., O'Shea, R., & Patterson, J. (2016) 'Debating personal health budgets', *Royal College of Psychiatrists Bulletin,* 40 (1), pp. 34-37. Doi: https//:doi: 10.1192/pb.bp.114.048827

Alden, S. (2015) 'Discretion on the frontline: The street level bureaucrat in English statutory homelessness services', *Social Policy and Society*, *14*(1), pp. 63-77. Doi: https//:doi:10.1017/S1474746414000402

Arksey, H. and Baxter, K. (2012) 'Exploring the temporal aspects of direct payments', *British Journal of Social Work*, *42*(1), pp.147-164. Doi: https//:doi.org/10.1093/bjsw/bcr039

Arksey, H. and Kemp, P. A. (2008) D*imensions of Choice: A narrative review of cash-for-care schemes*. Social Policy Research Unit.

Arksey, H., and Glendinning, C. (2007) ‘Choice in the context of informal caregiving’, *Health and Social Care in the Community*, 15, pp. 165–175. Doi: https//:doi:10.1111/j.13652524.2006. 00671.x

Arntz, M. and Thomsen, S.L. (2010) ‘Are personal budgets a financially sound reform option for the German long-term care insurance?’ *Jahrbücher für Nationalökonomie und Statistik,* 230(4), pp. 378-402.

Astbury, B. and Leeuw, F.L. (2010) ‘Unpacking black boxes: mechanisms and theory building in evaluation’, *American journal of evaluation*, *31*(3), pp.363-381.

Atkinson, P. and Hammersley, M. (2019) *Ethnography: Principles in practice.* 4rdedn. London: Routledge.

Atkinson, P., Coffey, A., Delamont, S., Lofland, J and Lofland, L. (2007) *Handbook of Ethnography*. Doi**:** https://dx.doi.org/10.4135/9781848608337

Baker, L.M. (2006) ‘Observation: A complex research method’, *Library Trends*, 55(1), pp. 171-189.

Bandura, A. (1977) ‘Self-efficacy: Toward a unifying theory of behavioural change’, *Psychological Review,* 84(2), p. 191.

Barnes, Y. and Henly, J. R. (2018) ‘They are underpaid and understaffed: How clients interpret encounters with street-level bureaucrats’, *Journal of Public Administration Research and Theory,* 28, pp. 165–81.

Barnes, M. (2006) *Caring and Social Justice*. Basingstoke and New York: Palgrave Macmillan.

Barnes, M. (2011) ‘Abandoning care? A critical perspective on personalisation from an ethic of care’, *Ethics and Social Welfare,* 5 (2), pp. 153–67.

Bartlett, W. and Le Grand, J. (1993) The theory of quasi-markets. In *Quasi-markets and social policy*. London: Palgrave Macmillan.

Bartlett, Y.K., Haywood, A., Bentley, C.L., Parker, J., Hawley, M.S., Mountain, G.A. and Mawson, S. (2014) ‘The SMART personalised self-management system for congestive heart failure: results of a realist evaluation’, *BMC Medical Informatics and Decision Making*, 14(1), pp. 1–13.

Barton, L. (2004) The disability movement: some observations. In: Swain J., French S., Barnes C., Thomas C., editors. *Disabling barriers – enabling environments.* 2nd edn. London: Sage Publications Ltd.

Baxter, K. and Glendinning, C. (2013) 'The role of emotions in the process of making choices about welfare services: the experiences of disabled people in England', *Social Policy and Society*, pp. 439-450.

Baxter, K. (2017) The personalization and marketization of home care services for older people in England. In *The Routledge handbook of social Care work around the world.* London: Routledge.

Baxter, K., Glendinning, C. and Clarke, S. (2008a) 'Making informed choices in social care: the importance of accessible information', *Health & Social Care in the Community*, *16*(2), pp. 197-207.

Baxter, K., Glendinning, C., Clarke, S. and Greener, I. (2008b) *Domiciliary Care Agency Responses to Increased User Choice: Perceived threats, barriers, and opportunities from a changing market*. York: University of York.

Baxter, K., Wilberforce, M. and Glendinning, C. (2011) ‘Personal budgets and the workforce implications for social care providers: expectations and early experiences’, *Social Policy and Society*, *10*(1), p. 55.

Bazzoli, G.J., Dynan, L., Burns, L.R. and Yap, C. (2004) ‘Two decades of organizational change in health care: what have we learned?’ *Medical Care Research and Review*, *61*(3), pp. 247-331.

Bekkers, V., Moody, R. and Edwards. A. (2011) ‘Micro mobilization, social media, and coping strategies: Some Dutch experiences’,. *Policy & Internet* 3, pp. 1–29.

Bendassolli, P.F. (2013) ‘Theory building in qualitative research: Reconsidering the problem of induction’, In *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, 14: 1.

Bennett, S. (2012) *Personal Health Budget Guide: NHS commissioning*. Department of Health.

Bennett, D., Barrett, A. and Helmich, E. (2019) ‘How to… analyse qualitative data in different ways’, *The clinical Teacher*, *16*(1), pp. 7-12.

Beresford, P. (2009) '*Whose Personalisation?', Think Pieces No. 47*. London: Compass.

Beresford., B. and Sloper, P. (2008) *Understanding the dynamics of decision-making and choice: a scoping study of key psychological theories to Inform the design and analysis of the Panel Study,* Department of Health Paper 2215. Social Policy Research Unit: University of York, York.

Beresford, P. (2012) 'Are personal budgets necessarily empowering for service users? If not, what's it all about?' *Research, Policy and Planning* 29(1), pp. 37–43. Available at http://ssrg.org.uk/wp-content/uploads/2012/01/Beresford.pdf [Retrieved May 2017]

Beresford P. (2014a) *Personalisation: Critical and radical debates in social work.* Bristol: The Policy Press.

Beresford, P. (2014b) Advancing the positives of personalisation/person centred support. Chapter 14 in Needham, C. & Glasby, J. (2014) (eds.) *Debates on personalisation*. Bristol: The Policy Press.

Berkovich, I. (2011) 'No, we won't! Teachers' resistance to educational reform', *Journal of Educational Administration*, 49(5), pp. 563-578.

Best, A., Greenhalgh, T., Lewis, S., Saul, J.E., Carroll, S. and Bitz, J. (2012) ‘Large-system transformation in health care: a realist review’, *Milbank Quaterly,*90(3), pp. 421 –56.

Bhaskar, R. (2010) *Reclaiming reality: A critical introduction to contemporary philosophy*. London: Routledge.

Bird, S.R., Kurowski, W., Dickman, G.K. and Kronborg, I. (2007) ‘Integrated care facilitation for older patients with complex health care needs reduces hospital demand’, *Australian Health Review*, *31*(3), pp. 451-461.

Boddy, C.R. (2016) ‘Sample size for qualitative research’, *Qualitative Market Research: An International Journal*.

Bonevski, B., Randell, M., Paul, C., Chapman, K., Twyman, L., Bryant, J., Brozek, I. and Hughes, C. (2014) ‘Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups’, *BMC medical research methodology*, *14*(1), pp. 1-29.

Bottery, S. (2020) ‘How Covid-19 has magnified some of social care’s key problems’. How Covid-19 has magnified some of social care’s key problems| The King's Fund https//www.kingsfund.org.uk/publications/ (accessed January 2021)

Bovaird, T. and Loeffler, E. (2013) *We’re all in this together: harnessing user and community co-production of public outcomes.* Birmingham: Institute of Local Government Studies: University of Birmingham.

Boxall, K., Dowson, S. and Beresford, P. (2009) ‘Selling individual budgets, choice, and control: local and global influences on UK social care policy for people with learning difficulties’, *Policy & Politics*, *37*(4), pp. 499-515.

Boyle, D. (2013) *The Barriers to Choose Review. How Are People Using Choice in Public Services?* London: HM Government.

Bracke, P., Christiaens, W. and Verhaeghe, M. (2008) ‘Self-esteem, self-efficacy, and the balance of peer support among persons with chronic mental health problems’, *Journal of Applied Social Psychology, 38*(2), pp.436-459.

Braithwaite, J. (2018) ‘Changing how we think about healthcare improvement’, *BMJ* 361.

Braithwaite, J., Clay-Williams, R., Nugus, P. and Plumb, J. (2013) Health care as a complex adaptive system. In E. Hollnagel, J. Braithwaite, & R. L. Wears (Eds.), *Resilient Health Care*. Farnham, Surrey: Ashgate Publishing, Ltd.

Braithwaite, J., Herkes, J., Ludlow, K., Lamprell, G. and Testa, L. (2016) 'Association between organisational and workplace cultures, and patient outcomes: Systematic review protocol', *BMJ Open.* Doi: http://dx.doi.org/10.1136/bmjopen-2017-017708

Braithwaite, J., Wears, R.L. and Hollnagel, E. (2015) 'Resilient health care: turning patient safety on its head', *International Journal for Quality in Health Care, 27*(5) pp. 418-420.

Braithwaite, J., Churruca, K., Ellis, L.A., Long, J., Clay-Williams, R., Damen, N., Herkes, J., Pomare, C. and Ludlow, K. (2017) *Complexity science in healthcare.* Sydney: Australian Institute of Health Innovation, Macquarie University.

Braun V, Clarke V. (2006) 'Using thematic analysis in psychology', *Journal of Qualitative Research in Psychology* 3(2), pp. 77 –101

Brewer, J. (2000) *Ethnography*. Buckingham: McGraw-Hill Education.

Brewis, R. and Fitzgerald, J. (2013) *Personal Health Budget Guide: Advice, advocacy, and brokerage.* Department of Health.

British Medical Association (2012) The BMA's position on Personal Health Budgets. Available at https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/commissioning/personal-health-budgets (updated version September 2020)

Brodkin, E.Z. (2011) 'Policy work: Street-level organizations under new managerialism', *Journal of Public Administration Research and Theory*, *21*(2), pp. i253-i277.

Brody, D.S., Miller, S.M., Lerman, C.E., Smith, D.G. and Caputo, G.C. (1989) 'Patient perception of involvement in medical care', *Journal of General Internal Medicine*, *4*(6), pp. 506-511.

Brooks, J., Mitchell, W. Glendinning, C. (2017). Personalisation, personal budgets, and family carers. Whose assessment? Whose budget? *Journal of Social Work*, 17(2), pp. 147-166. Doi: https//:doi:10.1177/1468017316638554. (Accessed November 2017)

Bruce, J. (2013) ‘Understanding backstage and front stage work in restorative justice conferences: The benefits of using ethnographic techniques’, *Current Issues in Criminal Justice*, *25*(1), pp.517-526.

Bryman, A. (2016) *Social Research Methods*. Oxford: University Press.

Bunn, F., Goodman, C., Russell, B., Wilson, P., Manthorpe, J., Rait, G., Hodkinson, I. and Durand, M.A. (2018) ‘Supporting shared decision making for older people with multiple health and social care needs: a realist synthesis’, *BMC geriatrics*, *18*(1), pp. 1-16.

Burks, A. W. (1946) ‘Peirce’s Theory of Abduction’, *Philosophy of Science*, *13*(4), pp.301–306.

Burchardt, T., Evans, M. and Holder, H. (2015) ‘Public policy and inequalities of choice and autonomy’, *Social Policy & Administratio*n, *49*(1), pp. 44-67.

Byng, R., Norman, I., Redfern, S. and Jones, R. (2008) ‘Exposing the key functions of a complex intervention for shared care in mental health: case study of a process evaluation’, *BMC Health Services Research, 8*(1), pp. 1-10.

Campbell, N., Cockerell, R., Porter, S., Strong, S., Ward, L. and Williams, C. (2011) *Final Report from the Support Planning and Brokerage Demonstration Project*. Office for Disability Issues.

Campbell, J. & Oliver, M. (1996) *Disability politics: understanding our past, changing our future.* London: Routledge.

Care Act (2014) http://legislation.gov.uk (accessed 19/12/17)

Carey, G., Malbon, E., Olney, S. and Reeders, D. (2018) 'The personalisation agenda: the case of the Australian National Disability Insurance Scheme', *International Review of Sociology*, *28*(1), pp. 20-34.

Carey, G., Dickinson, H., Malbon, E., Weier, M. and Duff, G. (2020) 'Burdensome administration and its risks: Competing logics in policy implementation', *Administration & Society, 52*(9), pp. 1362-1381.

Carr, S. (2008) *Personalisation: A Rough Guide*. London: Social Care Institute for Excellence

Carr, S. (2010) *Enabling risk, ensuring safety: self-directed support and personal budgets*. London: Adults' Services SCIE Report 36

Carr, S. (2011a) ‘Uniformity or equality? Integration, equity, and the challenge of Personalization’, *Journal of Integrated Care,* 19 (3), pp. 42-47.

Carr, S. (2011b) *Personalisation and marketization: Policy construction and practice implementation – implications for third sector provision of adult social care and support in England.* 10th International Conference, Siena Italy: The International Society for Third Sector Research.

Cattermole, M. (2012) *Personal Health Budgets Guide: Market development case study.* Dorset: Department of Health.

Chen, H.T. and Rossi, P.H. (1992) *Using theory to improve program and policy evaluations* (No. 290). Praeger.

Cheyne, H., Abhyankar, P. and McCourt, C. (2013) ‘Empowering change: realist evaluation of a Scottish Government programme to support normal birth’, *Midwifery, 29*(10), pp. 1110-1121.

Clark, J. (2006) ‘Consumers, clients, or citizens? Politics, policy, and practice in the reform of social care’, *European Societies,* 8(3), pp. 423-442.

Clarke, J., Smith, N. and Vidler, E. (2005) ‘Consumerism and the Reform of Public Services: Inequalities and Instabilities’, *Social Policy Review,* 17, 167–182.

Clarke, J., Smith, N. and Vidler, E. (2006) ‘The Indeterminacy of Choice: Political, Policy and Organisational Implications’, *Social Policy and Society,* 5(3), pp. 327–336.
DOI: https://doi.org/10.1017/S1474746406003010

Clarke, M. (2010) *Challenging choices: Ideology, consumerism, and policy*. Policy Press.

Clay-Williams, R., (2013) ‘Re-structuring and the resilient organisation: Implications for health care’, In *Resilient Health Care*, pp. 123-133.

Clements, L. (2008) ‘Individual Budgets and irrational exuberance’, Community Care Law Rep, 11, 413–30.

Clifford, J. (1983) Observer Observed: Essay on Ethnographic field work. In Stocking G. W. Jr. Eds. *History of Anthropology Volume 1* Madison: University of Wisconsin Press.

Clifford, J., & Marcus, G. (Eds.) (1986). *Writing culture: The poetics and politics of ethnography*. Berkeley: University of California Press.

Coiera, E. (2011) 'Why system inertia makes health reform so difficult', *BMJ*, *342*. Doi: https://doi.org/10.1136/bmj.d3693

Community Care Act (Direct Payments) (1996). Available at: https://www.legislation.gov.uk/ (accessed 10 August 2017)

Corbin, J. and Strauss, A. (2014) *Basics of qualitative research: Techniques and Procedures for developing grounded theory*. Sage publications.

Corrigan, P. (2005) *Registering choice: how primary care should change to meet patient needs*. London: Social Market Foundation.

Coulter A, Collins A. (2011) *Making shared decision-making a reality no decision about me, without me.* London: The King's Fund

Coulter, A., Roberts, S., and Dixon, A. (2013) *Delivering Better Services for People with Long Term Conditions: Building the House of Care*. London: The King's Fund. Available at: http:// www.kingsfund.org.uk/publications/delivering-better-services-people-longterm-conditions (accessed 17 August 2017)

Cox, S.M. and McDonald, M. (2013) ‘Ethics is for human subjects too: participant perspectives on responsibility in health research’, *Social Science & Medicine*, *98*, pp.224-231.

Coyle, D. (2011) ‘Impact of person-centred thinking and personal budgets in mental health services: reporting a UK pilot’, *Journal of Psychiatric and Mental Health Nursing,* 18, pp. 796–803 Doi: https// Doi. 10.1111/j.1365-2850.2011.01728.x

Creswell, J.W. (2009) *Research design: qualitative, quantitative, and mixed methods approach*. London, Sage Publications Ltd.

Cresswell, J. and Abelson, R. (2012) A giant hospital chain is blazing a profit trail, *The New York Times*. Available at: http://www.nytimes.com/2012/08/15/business/hca-giant-hospital-chain-creates-a-windfall-for-private-equity.html (Accessed 3 March 2019).

Cribb, A., and Owens, J. (2010) ‘Whatever Suits You: Unpicking Personalization for the NHS’, *Journal of Evaluation in Clinical Practice,* 16(2), pp. 310–314.

Da Roit, B., and Le Bihan, B. (2010) ‘Similar and yet so different: cash-for-care in six European countries' long-term care policies’, *Milbank Quarterly,* 88(3), pp. 286-309.

Dalkin, S.M., Forster, N., Hodgson, P., Lhussier, M., Philipson, P. and Carr, S.M. (2019) ‘Exposing the impact of intensive advice services on health: a realist evaluation’, *Health & Social Care in the Community*, *27*(3), pp. 767-776.

Dalkin, S.M., Greenhalgh, J., Jones, D., Cunningham, B. and Lhussier, M. (2015) What’s in a mechanism? Development of a key concept in realist evaluation. *Implementation Science*. *10*(1), pp.1-7.

Daly, G. (2008) ‘Is choice the right policy?’ *Health Matters*, 72, pp. 16-17.

Daly, M. (2020) ‘COVID-19 and care homes in England: What happened and why?’ *Social Policy and Administration*, 54(7), pp. 985-998.

Daly, G. (2012) ‘Citizenship, choice, and care: An examination of the promotion of choice in the provision of adult social care’, *Research Policy and Planning,* 29 (3), pp. 179-189.

Daly, G., Roebuck, A., Dean, J., Bollard, M., & Taylor, C. (2009) ‘Gaining independence: An evaluation of service users’ accounts of the individual budgets pilot’, *Journal of Integrated Care,* 16(3), pp. 17-25.

Daly, G., and Woolham, J. (2010) *Do personal budgets lead to personalisation and what can their promotion tell us about the nature of citizenship and public accountability in? relation to social care? Reflections from a study of the impact of self-directed support and personal budgets*. University of Lincoln: Social Policy Association Annual Conference,

Department of Health. (2008) *High Quality for All NHS Next Stage Review: Final Report*. London: Department of Health.

Davidson, J., Baxter, K., Glendinning, C. and Irvine, A. (2013) ‘Choosing health: qualitative evidence from the experiences of personal health budget holders’, *Journal of Health services Research & Policy,* 18(2), pp. 50-58.

Dean, H. (2009) ‘Critiquing capabilities: the distractions of a beguiling concept’, *Critical Social Policy*, 29(2), pp. 261–73.

Dean, H. (2010) *Understanding human need*. 2nd edn. University of Bristol: Policy Press.

Debono, D. and Braithwaite, J. (2017) ‘Workarounds in Nursing Practice in Acute Care: A Case of a Health Care Arms Race?’ In *Resilient Health Care, 2*, pp. 53-68.

de Iongh, A., Redding, D. and Leonard, H. (2019) ‘New personalised care plan for the NHS’ *BMJ*, pp. 364: l470. DOI: https//doi 10.1136/bmj.l470

Denzin, N.K. and Lincoln, Y.S. (2008) *The landscape of qualitative research* (Vol. 1). Sage.

Denzin, N.K. and Lincoln, Y.S. (eds.) (2011) *The Sage handbook of qualitative research s*age.

Department of Health (2009) *Personal health budgets: first steps*, London: Department of Health.

Department of Health. Department of Health (2012a) Introduction to Personal Health Budgets. Available at: www.personalhealthbudgets.dh.gov.uk/Topics/ Toolkit/Intro/. (Accessed 9 December 2017).

Department of Health (2012b) *Personal health budgets update*. London: Department of Health.

Department of Health (2012c) *Liberating the NHS: no decision about me, without me - further consultation on proposals to secure shared decision making*.
London: Department of Health.

Department of Health (2009) *Personal Health Budgets: First steps.* Department of Health.

Department of Health (2009) *Saving Lives: Our Healthier Nation.* Department of Health: Stationary Office.

Department of Health (2015) *The NHS constitution for England*. Department of Health. Available at: https://www.gov.uk/government/publications/the-nhs-constitution-for-england. (Accessed March 2017).

Department of Health (2014) *The Mandate: A mandate from the Government to NHS England: April 2014 to March 2015*. London: Department of Health.

Department of Health (2016) *The Government's mandate to NHS England for 2016-17*. London: Department of Health.

Department of Health and Social Care (2018) *National Framework for NHS continuing healthcare and NHS-funded nursing Care.* Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/746063/20181001_National_Framework_for_CHC_and_FNC_-_October_2018_Revised.pdf (Accessed 12: December 2019)

Department of Health and Social Care (2019) *The government's mandate to NHS England for 2018-19.Revised version.* Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment-data/file/691998/nhse-mandate-2018-19.pdf (accessed 11 July 2019)

Department of Health (2006) *Our Health, Our Care, Our Say: A new direction for community services.* London: Department of Health.

Dilnot, A. (2011) *Fairer care funding: The report of the Commission on Funding of Care and Support* (Vol. 1). The Stationery Office.

Dixon, N. (2010) *Putting people first: Case study: Self-directed support and personal Budgets milestone.* Available at:http://www.puttingpeoplefirst.org.uk/_library/PPF/Self_Directed_Support_CaseStudy.pdf. (Accessed 27 February 2017).

Dixon-Woods, M., Shaw, R.L., Agarwal, S. and Smith, J.A. (2004) 'The problem of Appraising qualitative research', *BMJ Quality & Safety*, *13*(3), pp. 223-225.

Dolan, P. and King, D. (2011) *Personal health Budgets: Early experiences of budget holders: Fourth interim report.* London: Department of Health.

Donald, M., Ware, R. S., Ozolins, I. Z., Begum, N., Crowther, R. and Bain, C. (2011) 'The role of patient activation in frequent attendance at primary care: A population-based study of people with chronic disease', *Patient Education and Counselling,* 83(2), pp. 217-221.

Duffy, S. (2004) 'In Control', *Journal of Integrated Care,* 12(6), p. 13

Duffy, S. (2010) 'The citizenship theory of social justice: exploring the meaning of personalisation for social workers', *Journal of Social Work Practice 24*(3), pp.253-267.

Duffy, S. (2014) After personalisation. In Needham, C. and Glasby, J. (eds), *Debates in Personalisation*. Bristol: The Policy Press.

Duffy, S. (2012) ‘The limits of personalisation’, *Tizard Learning Disability Review*, 17(3), pp. 111-123. DOI: https//doi10.1108/13595471211240951

Duffy, S., Waters, J. and Glasby, J. (2010) ‘Personalisation and adult social care: future options for the reform of public services’, *Policy & Politics*, *38*(4), pp. 493-508.

Eisenhardt, K.M. and Graebner, M.E. (2007) ‘Theory building from cases: Opportunities and challenges’, *Academy of Management Journal*, *50*(1), pp. 25-32.

Ellis, K. (2007) ‘Direct payments and social work practice: The significance of ‘street-level bureaucracy’ in determining eligibility’, *British Journal of Social Work*, *37*(3), pp. 405-422.

Ellis, K. (2011) ‘Street-level bureaucracy ’revisited: The changing face of frontline discretion in adult social care in England’, *Social Policy & Administration, 45*(3), pp. 221-244.

Ellis, K. (2014) ‘Professional discretion and adult social work: Exploring its nature and scope on the front line of personalisation’, *The British Journal of Social Work*, *44*(8), pp. 2272-2289.

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S. and Edwards, A. (2012) ‘Shared decision making: a model for clinical practice’, *Journal of General Internal Medicine*, *27*(10), pp. 1361-1367.

Elwyn, G., Edwards, A., Kinnersley, P. and Grol, R. (2000) ‘Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices’, *British Journal of General Practice*, *50*(460), pp. 892-899.

Epstein, A. M., Fiscella, K., Lesser, C. S., and Stange, K. C. (2010) ‘Why the nation needs a policy push on patient-centered health care’, *Health Affairs,* 29, pp. 1489-1495.

Eriksson, S. (2014) *Personal budgeting in municipal disability services: The first experiment in Finland.* Helsinki. The Finnish Association on Intellectual and Developmental Disabilities

Erwin, D.G. and Garman, A.N. (2010) 'Resistance to organizational change: linking research and practice', *Leadership & Organization Development Journal,* 31(1), pp. 39-56. Doi: https://doi.org/10.1108/01437731011010371

Evans, D. and Killoran, A. (2000) 'Tackling health inequalities through partnership working learning from a realistic evaluation', *Critical Public Health, 10*(2), pp. 125-140.

Evans, T. (2011) 'Professionals, managers and discretion: Critiquing street-level bureaucracy', *British Journal of Social Work,* 41(2), pp. 368 – 86.

Evans, T. (2012) 'Organisational rules and discretion in adult social work', *British Journal of Social Work Advance, 43*(4), pp. 739–758. Available at: http://www.jstor.org/stable/23723108 (Accessed July 2019).

Evans, T. (2013) 'Organisational rules and discretion in adult social work', *British Journal of Social Work,* 43, pp. 739–58

Evans, T. (2015) Professionals and discretion in street-level bureaucracy. In P.L Hupe, M.J. Hill & A. Buffat (Eds), *Understanding street-level bureaucracy.* Bristol: Policy Press

Evans, T. and Harris, J. (2004) ‘Street-level bureaucracy, social work and the (exaggerated) death of discretion’, *British Journal of Social Work,* 34(6), pp. 871– 95.

Evan, T., and Hupe, P. (2020) *Discretion and the Quest for Controlled Freedom*. London: Palgrave Macmillan

Fann, K.T. (2012) *Peirce’s theory of abduction*. springer science & business media.ebook available at: https//doi 10.1007/978-94-010-3163-9

Feldman, M., Bell, J. and Berger, M. (2003) *Gaining Access: A Practical and Theoretical Guide for Qualitative Researchers.* California: Altamira Press.

Ferguson, I. (2007) ‘Increasing user choice or privatizing risk? The antinomies of personalization’, *British Journal of Social Work*, 37, pp. 387 – 403.

Ferguson, I. (2012) ‘Personalisation, social justice, and social work: a reply to Simon Duffy’, *Journal of Social Work Practice*, *26*(1), pp. 55-73.

Fetterman, D.M. (1998) *Ethnography s*tep by step*: Applied Social Research Methods series*. 4thedn. London: Sage Publications.

Fielding, N. and Thomas, H. (1993) Researching social life, *Qualitative Interviewing. London: Sage Publications*.

Finlay W.M.L., Walton C. & Antaki C. (2008) 'Promoting choice and control in residential services for people with learning disabilities', Disability Society, 23, pp. 349–60.

Fisher, E.B., Coufal, M.M., Parada, H., Robinette, J.B., Tang, P.Y., Urlaub, D.M., Castillo, C., Guzman-Corrales, L.M., Hino, S., Hunter, J., and Katz, A.W. (2014) 'Peer support in health care and prevention: cultural, organizational, and dissemination issues', *Annual Review of Public Health, 35*, pp.363-383.

Fitzgerald, J., Brewis, R. and Tyson, A. (2012) *Personal Health Budgets Guide: Third party organisations – the families' perspective.* London: Department of Health.

Fleming, P., McGilloway, S., Hernon, M., Furlong, M., O'Doherty, S., Keogh, F. and Stainton, T. (2019) 'Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review', *Campbell Systematic Reviews*, *15(1-2), pp*. 1-77. Doi: https://doi.org/10.4073/csr.2019.3

Foot, C., Gilburt, H., Dunn, P., Jabbal, J., Seale, B., Goodrich, J., Buck, D. and Taylor, J. (2014) *People in control of their own health and care*. King's Fund. Available at: https://www.kingsfund.org.uk/ (Accessed May 2017).

Forder, J., Jones, K., Glendinning, C., Caiels, J., Welsh, E., Baxter, K., Davidson, J., Windle, K., Irvine, A., King, D. & Dolan, P. (2012) *Evaluation of the personal health budget pilot programme.* London: The Stationery Office.

Foster, J. (2010) 'Thinking on the front line: How creativity can improve self-directed support', *Journal of Social Work Practice,* 24(3), pp. 283 – 99.

Fox, A. (2012) *Personalisation: Lessons from social care*. London: RSA.

Freedman, R. I., and Boyer, N. C. (2000) 'The power to choose: Supports for families caring for individuals with developmental disabilities', *Health & Social Work,* 25(1), pp. 59–68.

Freidson, E. (1970) *Professional Dominance*. New York: Atherton Press.

Gadsby, E. W. (2013) *Personal Budgets and Health: a review of the evidence.* Centre for Health Services Studies: University of Kent

Geertz, C. (1973) Chapter 1: Thick description: Toward an interpretive theory of culture. In *The interpretation of Cultures.* New York: Basic Books

Geertz, C. (1983) *Local knowledge*. New York: Basic Books.

Gillard, S. (2019) 'Peer support in mental health services: where is the research taking us, and do we want to go there?', Journal of Mental Health, 28(4), pp. 341-344. Doi: https://doi.org/10.1080/09638237.2019.1608935

Gillard, S, Gibson, S.L., Holley, J. and Lucock, M. (2014) 'Developing a change model for peer worker interventions in mental health services: a qualitative research study', *Epidemiology and Psychiatric Sciences,* 24(5), pp. 435-445

Gillard, S., Holley, J., Gibson, S., Larsen, J., Lucock, M., Oborn, E., Rinaldi, M. and Stamou, E. (2015) 'Introducing new peer worker roles into mental health services in England: comparative case study research across a range of organisational contexts', *Administration and Policy in Mental Health and Mental Health Services Research, 42*(6), pp. 682-694.

Gilmore, B., McAuliffe, E., Power, J., and Vallières, F. (2019) 'Data Analysis and Synthesis Within a Realist Evaluation: Toward More Transparent Methodological Approaches', *International Journal of Qualitative Methods*. Doi: https://doi.org/10.1177/1609406919859754

Glasby, J. (2008) *Individual budgets and the interface with health: a discussion paper for Care Services Improvement Partnership*. Birmingham: health Services Management Centre

Glasby, J. (2010) *Whose Risk is it Anyway? Risk and regulation in an era of personalisation*. York: Joseph Rowntree Foundation.

Glasby, J. (2014) 'The controversies of choice and control: Why some people might be hostile to English social care reforms', *British Journal of Social work,* 44, pp.252–266. Doi: https://doi.org/10.1093/bjsw/bcs125

Glasby, J. and Littlechild, R. (2016) *Direct payments and personal budgets: putting personalisation into practice*. 3rdedn. University of Bristol: Policy Press.

Glasby, J. Alakeson, V. Duffy, S. (2013) *Doctor know best? The use of evidence in implementing self-directed support in health care.* Policy Paper 16. HSMC: University of Birmingham.

Glendinning, C. (2008)' Increasing choice and control for older and disabled people: a critical review of new developments in England', *Social Policy and Administration*, 42(5), pp. 451-469.

Glendinning, C. (2009) The consumer in social care: in (eds) Simmons R., Powell M., Greener I. (2009) *The Consumer in Public Services Choice: Choice Values and Difference.* Bristol: Policy Press.

Glendinning, C., Davidson, J. and Baxter, K. (2013) *Personal Health Budgets and Maternity Care.* Working Paper. London: Department of Health

Glendinning, C., Kirk, S., Guiffrida, A.E. and Lawton, D. (2001) 'Technology-dependent children in the community: definitions, numbers, and costs 1', *Child: Care, Health, and Development, 27*(4), pp.321-334.

Glendinning, C., Challis, D., Fernández, J.L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. and Wilberforce, M. (2008) *Evaluation of the* *individual budgets pilot programme. Final Report.* York: Social Policy Research Unit, University of York.

Glynn, J.R., Fielding, K. and Shakespeare, T. (2020) 'COVID-19: excess all-cause mortality in domiciliary care', *British Medical Journal,* 370, m2751.
Doi: https://doi.org/10.1136/bmj.m2751

Goffman, E. (1978) *The presentation of self in everyday life*. London: Harmondsworth.

Goodridge, D., Westhorp, G., Rotter, T., Dobson, R. and Bath, B. (2015) 'Lean and leadership practices: development of an initial realist program theory', *BMC Health Services Research, 15*(1), pp. 1-15. Doi: https//doi.10.1186/s12913-015-1030-x

Gordon, C., Leigh, J., Kay, D., Humphries, S., Tee, K.-S., Winch, J. and Thorne, W. (2012) *Evaluation of the consumer-directed care initiative.* Final Report: KPMG.

Gravel, K., Légaré, F. and Graham, I.D. (2006) 'Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions', *Implementation Science*, *1*(1), pp.1-12.

Green J. (2005) Qualitative interviewing. In: Green J., Browne J., edn. *Principles of social research*. Berkshire: Open University Press.

Greene, J. and Hibbard, J. H. (2012) 'Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes', *Journal of General Internal Medicine,* 27(5), pp. 520-526.

Greener, I. (2002) 'Agency, social theory, and social policy', *Critical Social Policy*, *22*(4), pp. 688-705.

Greenhalgh, T., Papoutsi, C. (2018) 'Studying complexity in health services research: desperately seeking an overdue paradigm shift', *BMC Med*, 16(95) Doi: https://doi.org/10.1186/s12916-018-1089-4.

Greenhalgh, T., Jackson, C., Shaw, S and Janamian, T. (2016) 'Achieving Research Impact Through Co-creation in Community-Based Health Services: Literature Review and Case Study', *Milbank Quarterly*, 94(2), pp. 392-429. Doi: https://doi: 10.1111/1468-0009.12197

Greenhalgh, T., Humphrey, C., Hughes, J., Macfarlane, F., Butler, C., and Pawson, R. (2009) 'How do you modernize a health service? A realist evaluation of whole-scale transformation in London', *The Milbank Quarterly, 87*(2), pp. 391-416.

Greenhalgh, J., Pawson, R., Wright, J., Black, N., Valderas, J.M., Meads, D., Gibbons, E., Wood, L., Wood, C., Mills, C. and Dalkin, S. (2013) *Functionality and feedback: a protocol for a realist synthesis of the collation, interpretation, and utilisation of PROMs data to improve patient care*. Southampton: NIHR

Greenhalgh, T., Wong, G., Jagosh, J., Greenhalgh, J., Manzano, A., Westhorp, G. and Pawson, R. (2015) 'Protocol—the RAMESES II study: developing guidance and reporting standards for realist evaluation', *BMJ open, 5*(8). Doi: http://dx.doi.org/10.1136/bmjopen-2015-008567

Gridley, K., Brooks, J. and Glendinning, C. (2014) 'Good practice in social care: the views of people with severe and complex needs and those who support them', *Health & Social Care in the Community, 22*(6), pp. 588-597.

Guba, E.G. and Lincoln, Y.S. (1989) *Fourth Generation Evaluation*. London: Sage Publications

Gubrium, J.F., Holstein, J.A., Marvasti, A.B. and McKinney, K.D. (2012) T*he SAGE handbook of interview research: The complexity of the craft*. Sage Publications.

Guest, G., Bunce, A. and Johnson, L. (2006) 'How many interviews are enough? An experiment with data saturation and variability', *Field Methods, 18*(1), pp. 59-82.

Handler, J. (1986) *The conditions of discretion*. New York, NY: Russell Sage Foundation.

Hamilton, S., Manthorpe, G., Szymczynska, P., Clewett, N., Larsen, J., Pinfold, V. and Tew, J. (2015) 'Implementing personalisation in integrated mental health teams',

J*ournal of Integrated Care,* 29 (5), pp. 488-493.
Doi: https//doi.10.3109/13561820.2015.1035777

Hammersley, M. (2008) Q*uestioning qualitative inquiry: Critical essays*. London: Sage Publications.

Hammersley, M. and Atkinson, P. (2007) *Ethnography: Principles in Practice.* 3thedn. London: Routledge.

Hammersley, M. and Atkinson, P. (2019) *Ethnography: Principles in Practice.* 4thedn. London: Routledge.

Hastie, R., and Dawes, R.M. (2009) *Rational choice in an uncertain world: The psychology of judgment and decision making*. London: Sage Publications.

Hastings, K.G., Boothroyd, D.B., Kapphahn, K., Hu, J., Rehkopf, D.H., Cullen, M.R. and Palaniappan, L. (2018) 'Socioeconomic differences in the epidemiologic transition from heart disease to cancer as the leading cause of death in the United States, 2003 to 2015: an observational study', *Annals of Internal Medicine*, *169*(12), pp. 836-844.

Hatton, C. and Waters, J. (2014) *Third National Personal Budget Survey: Think Local Act Personal.* London: In Control Publications

Hawe, P. (2015) 'Lessons from complex interventions to improve health', *Annual Review of Public Health*, 18 (36), pp. 307-23. DOI: https//doi.10.1146/annurev-publhealth-031912-114421

Health Foundation (2010) *Personal Health Budgets: Research scan*. Health Foundation.

Henwood, M. and Hudson, B. (2007) *Here to Stay? Self-Directed Support: Aspiration and Implementation: A Review for the Department of Health*. Heathencote: Melanie Henwood Associates

Henwood, M. and Hudson, B. (2008) 'Individual budgets and personalisation: a new model for integration?', *Journal of Integrated Care, Pp.* 16:8 –16.

Henwood, M. and Hudson, B. (2009) *Keeping it Personal: Supporting people with multiple and complex needs*. London: Commission for Social Care Inspection

Herd, P. and Moynihan, D.P. (2019) *Administrative burden: Policymaking by other means*. Russell: Sage Foundation.

Herepath, A., Kitchener, M. and Waring, J. (2015) 'A realist analysis of hospital patient safety in Wales: applied learning for alternative contexts from a multisite case study', *Health Services and Delivery,* 3(40). Doi: https://doi.org/10.3310/hsdr03400

Hibbard, J.H. and Peters, E. (2003) 'Supporting informed consumer health care decisions: data presentation approaches that facilitate the use of information in choice', *Annual Review of Public Health*, *24*(1), pp. 413-433.

Hibbard, J.H., Mahoney, E.R., Stock, R. and Tusler, M. (2007) ‘Do increases in patient activation result in improved self-management behaviors?’, *Health Services Research*, *42*(4), pp. 1443-1463.

Hibbard, J.H., Stockard, J., Mahoney, E.R. and Tusler, M. (2004) ‘Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers’, *Health Services Research, 39*(4p1), pp. 1005-1026.

Hibbard, J.H., Greene, J., Shi, Y., Mittler, J. and Scanlon, D. (2015) ‘Taking the long view: how well do patient activation scores predict outcomes four years later?’, *Medical Care Research and Review*, *72*(3), pp. 324-337.

Hitchen, S., Williamson, G. R. and Watkins, M. (2015) ‘Personal budgets for all? Implementing self- directed support in mental health services’, *Action Research,* 13(4), pp. 372-391.

HM Government (2007) *Putting people first: a shared vision and commitment to the transformation of adult social care.* London: HM Government.

HM Government (2010) *Equity and excellence: liberating the NHS*, London: HM Government.

Her Majesty Stationary Office (2015) *Mental Capacity Act*. London: HMSO

Holloway, M. and Fyson, R. (2016) ‘Acquired brain injury, social work, and the challenges of personalisation’, *The British Journal of Social Work, 46*(5), pp. 1301-1317.

House of Commons Committee of Public Accounts (2016) *Personal Budgets in Social Care Second Report of Session 2016-17.* London: UK Parliament

Huberman, A.M. and Miles, M.B. (2002) *The qualitative researcher’s companion.* Thousand Oaks, CA: Sage Publications.

Hudon, C., Chouinard, M.C., Aubrey-Bassler, K., Muhajarine, N., Burge, F., Bush, P.L., Danish, A., Ramsden, V.R., Légaré, F., Guénette, L. and Morin, P. (2020) ‘Case management in primary care for frequent users of health care services: a realist synthesis’, *The Annals of Family Medicine, 18*(3), pp. 218-226.

Hudson, J. and Lowe, S. (2004) *Understanding the Policy Process: Analysing Welfare Policy and Practice.* Bristol: The Policy Press.

Hudson, B. (2009) ‘Captives of bureaucracy: Personalisation Agenda’, *Community Care,* 1765, pp 30-31

Humphries R and Curry N (2011) *Integrating Health and Social Care: Where next?* The King’s Fund. Available at: https://www.kingsfund.org.uk/ (Accessed 16/12/2016)

Hupe, P.L. (2019) R*esearch handbook on street-level bureaucracy: The ground floor of government in context*. Cheltenham: Edward Elgar Publishing

Hupe, P. L. and Hill, M. J. (2007) ‘Street-level bureaucracy and public accountability’, Public Administration, 85, pp. 85–102.

Hupe, P. L. (2013) ‘Dimensions of discretion: Specifying the object of street level bureaucracy research’, Der 314modern staat–Zeitschrift für *Public Policy, Recht und Management,* 6, pp. 425–40. Available at: https://nbn-resolving.org/ urn:nbn:de:0168-ssoar-59188-7. (Accessed 12 May 2017)

In-Control (2017) POET Report for Adults in Receipt of Social Care Support.

Available at: http://www.in-control.org.uk/site

links/glossary.aspx (Accessed 9 October 2017).

Irvine, A., Davidson, J., Glendinning, C., Jones, K. C., Forder, J. E., Caiels, J., Welch, E., Windle, K., Dolan, P. and King, D. (2011) *Personal Health Budgets: Early experiences of budget holders. Fourth interim report.* London: Department of Health.

Jagosh, J. (2019) 'Realist synthesis for public health: building an ontologically deep understanding of how programs work, for whom, and in which contexts', *Annual Review of Public Health,. 40*, pp.361-372.

Jagosh, J., Tilley, N. and Stern, E. (2016) 'Realist evaluation at 25: Cumulating knowledge, advancing debates, and innovating methods', Evaluation, 22(3), pp. 267-269

Jagosh, J., Bush, P.L., Salsberg, J., Macaulay, A.C., Greenhalgh, T., Wong, G., Cargo, M., Green, L.W., Herbert, C.P. and Pluye, P. (2015) 'A realist evaluation of community-based participatory research: partnership synergy, trust building and related ripple effects', *BMC Public Health, 15*(1), pp. 1-11.

Jagosh, J., Macaulay, A.C., Pluye, P., Salsberg, J.O.N., Bush, P.L., Henderson, J.I.M., Sirett, E., Wong, G., Cargo, M., Herbert, C.P. and Seifer, S.D. (2012) 'Uncovering the benefits of participatory research: implications of a realist review for health research and practice', *The Milbank Quarterly, 90*(2), pp. 311-346.

Jones, K., Caiels, J., Forder, J., Windle, K., Welch, E., Dolan, P., Glendinning, C. and King, D. (2010) *Early experiences of implementing personal health budgets.* Canterbury: Personal Social Services Research Unit, University of Kent.

Jones, K., Welch, E., Caiels, J., Windle, K., Forder, J., Davidson, J., Dolan, P., Glendinning, C., Irvine, A. and King, D. (2011) *Experiences of implementing personal health budgets: 2nd interim report.* Canterbury: Personal Social Services Research Unit, University of Kent.

Jones, K., Forder, J., Caiels, J., Welch, E., Glendinning, C. and Windle, K. (2013) 'Personalization in the health care system: do personal health budgets have an impact on outcomes and cost?', *Journal of Health Services Research & Policy, 18*(2), pp. 59-67.

Jones, K., Forder, J., Welch, E., Caiels, J. and Fox, D. (2017) *Personal Health Budgets: Process and context following the national pilot programme.* Canterbury: Personal Social Services Research Unit, the University of Kent.

Keen, J., Greenhalgh, J., Randell, R. *et al.* (2019) 'Networked information technologies and patient safety: a protocol for a realist synthesis', *Systems Review,* 8, pp. 307. Doi: https://doi.org/10.1186/s13643-019-1223-1

Kendall, S. and Cameron, A. (2013) ‘Personalisation of adult social care: self-directed support and the choice and control agenda’, *British Journal of Learning Disabilities,* 46, pp. 264–271.

Kirk, S. and Glendinning, C. (2004) ‘Developing services to support parents caring for a technology-dependent child at home’, *Child: Care, Health, and Development,* 30(3), pp. 209-218.

Kirk, S. (2008) ‘Transitions in the lives of young people with complex healthcare needs’, *Child: Care, Health, and Development, 34*(5), pp. 567-575.

Kirk, S., Beatty, S., Callery, P., Milnes, L. and Pryjmachuk, S. (2012) ‘Perceptions of effective self-care support for children and young people with long-term conditions’, *Journal of Clinical Nursing, 21*(13-14), pp. 1974-1987.

Kvale, S. (1994) *Interviews: An introduction to qualitative research interviewing*. London: Sage Publications.

Kvale, S. and Brinkmann, S. (2009) *Interviews: Learning the craft of qualitative research interviewing*. London: Sage Publications.

Lakhani, A., McDonald, D. and Zeeman, H. (2018) ‘Perspectives of self-direction: a systematic review of key areas contributing to service users’ engagement and choice-making in self-directed disability services and supports’, *Health & Social Care in the Community, 26*(3), pp. 295-313.

Lamb, N. (2012) *Thousands set to take control with personal health budgets care for Care. Available at:* https://www.gov.uk/government/news/thousands-set-to-takecontrol-with-personalhealth-budgets-cash-for-care. (Accessed 1 January 2017).

Lammers, J., Stoker, J.I., Rink, F. and Galinsky, A.D. (2016) ‘To have control over or to be free from others? The desire for power reflects a need for autonomy’, *Personality and Social Psychology Bulletin, 42*(4), pp. 498-512.

Land, H. & Himmelweit, S. (2010) *Who Cares: who pays? A report on personalisation in social care.* London: Unison.

Larkin, M. & Mitchell, W. (2016) ‘Carers, choice, and personalisation: What do we know?’, *Social Policy and Society,* 15(2), pp. 189-205.

Larsen, J., Ainsworth, E., Harrop, C., Patterson, S., Hamilton, S., Szymczynska, P., Tew, J., Manthorpe, J. and Pinfold, V. (2013) 'Implementing personalisation for people with mental health problems: a comparative case study of four local authorities in England', *Journal of Mental Health, 22*(2), pp. 174-182.

Le Grand, J. and Bartlett, W. (1993) Quasi-markets and social policy: the way forward? In *Quasi-markets and social policy*. London: Palgrave Macmillan.

Leadbeater, C. (2004) *Personalisation through participation: A new script for public services*. London: Demos.

Leamy, M., Bird, V., Le Boutillier, C., Williams, J. and Slade, M. (2011) 'Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis', *The British Journal of Psychiatry, 199*(6), pp. 445-452.

Leece, J. and Leece, D. (2011) 'Personalisation: Perceptions of the role of social work in a world of brokers and budgets', *British Journal of Social Work,* 41(2), pp. 204 – 23.

Lent, A. and Arend, N. (2004) *Making choices: how can choice improve local public services?* London: New Local Government Network.

Lent, A., & Arend, N. (2004) *Making choices: How can choice improve local public services? New Local Government Network, London. Executive summary and introduction*. Available at; www.nlgn.org.uk/public/2004/making-choices-how-can-choiceimprove-local-public-services/ (Accessed May 2017)

Lewis, J. and West, A. (2014) ‘Re-shaping social care services for older people in England: policy development and the problem of achieving ‘good care,’ *Journal of Social Policy,* 43 (1), pp 1–18.

LeCompte, M.D. and Schensul, J.J. (2010) *Designing and conducting ethnographic research: An introduction* (Vol. 1). New York: Rowman Altamira.

Levin, J.L. and Philips Jr, B.U. (2018) ‘Improving Health in Hard-to-Reach Communities’, *Texas Medicine, 114*(2), pp. 28-32.

Lincoln, Y.S. & Guba, E.G. (1985) *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.

Lipsky, M. (1971) ‘Street-level bureaucracy and the analysis of urban reform’, *Urban Affairs Review,* 6(4), pp. 391–409.

Lipsky, M. (1980) *Street Level Bureaucracy: Dilemmas of the Individual in Public Services.* New York: Russell Sage Foundation.

Lipsky, M. (2010) *Street-Level Bureaucracy: Dilemmas of the Individual in Public Services*, (30th anniversary expanded edition). New York: Russell Sage Foundation.

Lloyd, L. (2003) Caring relationships: beyond 'carers' and 'service users'. In: Stalker K, editor. *Reconceptualising work with 'Carers'*. London: Jessica Kingsley Publishers Ltd.

Loeffler, E. and Bovaird, T. (2020) *The Palgrave handbook of co-production of public services and outcomes*. London: Palgrave Macmillan.

Lofland, J. and Lofland, L.H. (1971) *Analyzing social settings: a Guide to Qualitative Observation and Analysis.4th edn.* Belmont CA: Wadsworth Publishing.

McDonald, R., Harrison, S. and Checkland, K. (2008) 'Incentives and control in primary health care: findings from English pay-for-performance case studies', *Journal of Health Organization and Management*, 22 (1), pp. 48-62. Doi: https://
doi. 10.1108/14777260810862407

Manthorpe, J., Jacobs, S., Rapaport, J., Challis, D., Netten, A., Glendinning, C., Stevens, M., Wilberforce, M., Knapp, M. and Harris, J. (2009) 'Training for Change: early days of individual budgets and the implications for social work and care management practice. A qualitative study of the views of trainers', *British Journal of Social Work,* 39, pp. 1291– 1305.

Manthorpe, J., Hindes, J., Martineau, S., Cornes, M., Ridley, J., Spandler, H., Rosengard, A., Hunter, S., Little, S. and Gray, B. (2011) *Self-directed support: A review of the barriers and facilitators.* Edinburgh: Scottish Government Social Research.

Manthorpe, J., Martineau, S., Ridley, J., Cornes, M., Rosengard, A. and Hunter, S. (2015a) 'Embarking on self-directed support in Scotland: a focused scoping review of the literature', *European Journal of Social Work, 18*(1), pp. 36-50.

Manthorpe, J., Stevens, M., Samsi, K., Aspinal, F., Woolham, J., Hussein, S., Ismail, M. and Baxter, K. (2015b) Did anyone notice the transformation of adult social care? An analysis of Safeguarding Adult Board Annual Reports', *The Journal of Adult Protection*, pp. 19-30. Doi: https://doi.org/10.1108/JAP-03-2014-0011.

Manzano, A. (2016) 'The craft of interviewing in realist evaluation', *Evaluation, 22*(3), pp. 342-360.Doi: https://doi.org/10.1177/1356389016638615.

Manzano, A. and Pawson, R. (2014) ‘Evaluating deceased organ donation: a programme theory approach’, *Journal of Health Organization and Management,* 28(3), pp. 366- 85. Doi: https://doi. 10.1108/JHOM-07-2012-0131

Manzano-Santaella, A. (2011) ‘A realistic evaluation of fines for hospital discharges: incorporating the history of programme evaluations in the analysis’, *Evaluation, 17*(1), pp. 21-36.

Marchal, B., Dedzo, M. and Kegels, G. (2010) ‘A realist evaluation of the management of a well-performing regional hospital in Ghana’, *BMC Health Services Research*, *10*(1), pp. 1-14.

Marchal B, Belle S, Olmen J, Hoerée T, Kegels G. (2012) ‘Is realist evaluation keeping its promise? A literature review of methodological practice in health systems research’, Evaluation, 18(2), pp. 192-212. Doi: http://doi.10.1177/1356389012442444.

Marchal, B., Mukumbang, F.C., Van Belle, S., and Van Wyk, B. (2016) ‘Realist evaluation of the antiretroviral treatment adherence club programme in selected primary healthcare facilities in the metropolitan area of Western Cape Province, South Africa: a study protocol’, *BMJ Open*. *6*(4), pp.e009977. Doi: https://doi. 10.1136/bmjopen-2015-009977

Marmot, M. (2005) ‘Social determinants of health inequalities’, *The Lancet, 365*(9464), pp. 1099-1104.

Marmot, M., and Allen, J.J. (2014) ‘Social determinants of health equity’, *American Journal of Public Health*, 104, pp. S517-S519, Doi: https://
doi: 10.2105/AJPH.2014.302200

Martinez, C and Pritchard, J (2019) *Proceed with Caution: What makes Personal Budgets Works?* London: Reform.

Mason, J. (2017) *Qualitative Researching*. 3rd ed. London: Sage Publication.

Mason, M. (2010) Sample size and saturation in PhD studies using qualitative interviews. In *Forum qualitative Sozialforschung/Forum: Qualitative Social Research,* (11) 3.

Mathers, N., Thomas, M. and Patel, V. (2012) *Personal Health Budgets: RCGP position statement.* Royal College of General Practitioners, 63(606): e85–e87.

Doi: https://doi. 10.3399/bjgp13X660968

Matthews, P. and Hastings, A. (2013) ‘Middle-Class Political Activism and Middle-Class Advantage in Relation to Public Services: A Realist Synthesis of the Evidence Base’, *Social Policy & Administration, 47*(1), pp. 72-92.

Maxwell, J.A. (2012) *A realist approach for qualitative research*. Los Angeles: Sage.

Maxwell, J.A. (2013) *Qualitative research design: An interactive approach* (Vol. 41). Los Angeles: Sage publications.

May, P. J. and Winter, S. C. (2009) ‘Politicians, managers, and street-level bureaucrats: Influences on policy implementation’, *Journal of Public Administration Research and Theory,* 19(3), pp.453–76.

Mayer, J. E., & Timms, N. (1970) *The clients speak*. London: Routledge and Kegan Paul

McCormack, B., Rycroft-Malone, J., DeCorby, K., Hutchinson, A.M., Bucknall, T., Kent, B., Schultz, A., Snelgrove-Clarke, E., Stetler, C., Titler, M. and Wallin, L. (2013) ‘A realist review of interventions and strategies to promote evidence-informed healthcare: a focus on change agency’, *Implementation Science, 8*(1), pp. 1-12.

McDonald, C. (2014) Patients in control: Why people with long-term conditions must be empowered. *London: Institute for Public Policy Research (IPPR)*.

McDonald, A., Postle, K. and Dawson, C. (2008) 'Barriers to retaining and using professional knowledge in local authority social work practice with adults in the UK', *British Journal of Social Work*, 38(7), pp. 1370 – 87.

Mitchell, W. and Glendinning, C. (2008) 'Risk and adult social care: Identification, management and new policies. What does UK research evidence tell us?', *Health, Risk and Society,* 10(3), pp. 297 – 315.

Mladenov, T. Owen, J. and Cribb, A. (2015) 'Personalisation in Disability Services and Healthcare: A Critical Comparative Analysis', *Critical Social Policy,* 35(3), pp. 307-326. Doi: https://doi.10.1177/0261018315587071

Moberg, L., Blomqvist, P. and Winblad, U. (2016) 'User choice in Swedish eldercare– conditions for informed choice and enhanced service quality', *Journal of European Social Policy, 26*(3), pp. 281-295.

Moran, N., Glendinning, C., Wilberforce, M., Stevens, M., Netten, A., Jones, K., Manthorpe, J., Knapp, M., Fernández, J.-L., Challis, D. and Jacobs, S. (2013) 'Older people's experiences of cash-for-care schemes: evidence from the English individual budget pilot projects', *Ageing & Society,* 33(5), pp. 826–51.

Morris, J. (2006) Independent living: the role of the disability movement in the development of government policy. In Glendinning, C. and Kemp, P. (eds), *Cash and Care: Policy Challenges in the Welfare State*. Bristol: Policy Press.

Morse, J.M, (1995) 'The significance of saturation', *Qualitative Health Research,* 5(2), pp.147-149. Doi: https://doi.10.1177/104973239500500201.

Mowbray, C.T., Moxley, D. P. and Collins, M. E. (1998) 'Consumer as mental health providers: first personal accounts of benefits and limitations', *Journal of Behavioural Health Services and Research,* 25(4), pp. 397-411.

Musekiwa, E. and Needham, C. (2020) Co-commissioning at the micro-level: Personalized budgets in health and social care. In Bovaird, T. and Loeffler, Ed., (2020). *The Palgrave handbook of co-production of public services and outcomes.* London: Palgrave Macmillan.

Needham, C. (2008) 'Realising the potential of co-production: negotiating improvements in public services', *Social Policy and Society,* 7(2), pp. 221–231

Needham, C. (2009) ‘Interpreting Personalization in England’s National Health Service: A Textual Analysis’, *Critical Policy Studies,* 3(2), pp. 204-20.

Needham, C. (2010) Personalization: From Story-Line to Practice. *Social Policy and Administration.* 45(1) pp. 54–68. Doi: https://doi.10.1111/j.1467-9515.2010.00753.x

Needham, C. (2011) *Personalising public services: Understanding the personalisation narrative*. Policy Press.

Needham, C. (2013) Personalised commissioning, public spaces: The limits for the Market in English social care services. *BMC Health Services Research,* 13 (1), pp S1-S5. Doi: https://doi.org/10.1186/1472-6963-13-S1-S5

Needham, C. and Glasby, J. eds. (2014) *Debates in personalisation*. Policy Press.

Netten, A., Jones, K., Knapp, M., Fernandez, J.L., Challis, D., Glendinning, C., Jacobs, S., Manthorpe, J., Moran, N., Stevens, M. and Wilberforce, M. (2012a) ‘Personalisation through individual budgets: Does it work and for whom?’, *British Journal of Social Work, 42*(8), pp. 1556-1573.

Netten, A., Burge, P., Malley, J., Potoglou, D., Towers, A.M., Brazier, J., Flynn, T., and Forder, J. (2012b) *Outcomes of social care for adults: developing a preference-weighted measure. Health Technology Assessment,* 16(16), pp. 1-166. Doi: https// doi: 10.3310/hta16160

Newbronner, L., Chamberlain, R., Bosanquet, K., Bartlett, C. S. B. and Glendinning, C. (2011) *SCIE Report 40: Keeping personal budgets personal: Learning from the experiences of older people, people with mental health problems and their carers.* London: Social Care Institute for Excellence

Newman, D.A. (2003) ‘Longitudinal modelling with randomly and systematically missing data: A simulation of ad hoc, maximum likelihood, and multiple imputation techniques’, *Organizational Research Methods, 6*(3), pp. 328-362.

NHS Confederation (2011) *Personal health budgets: The views of service users and carers*. London: NHS Confederation

NHS Confederation (2015) *Joint up health and social care personal budgets: Key points on implementation.* Briefing 280. London: NHS Confederation

NHS Choices, (2015) Personal health budgets. Available at: https://www.nhs.uk/nhs-services/help-with-health-costs/what-is-a-personal-health-budget/. (Accessed 28 November 2015)

NHS Digital (2020) Personal Health Budgets – Quarter 3 2019/20 Publication. Available at: https://digital.nhs.uk/data-and-information/publications/statistical/personal-health-budgets (Accessed 2 April 2021)

NHS England (2014a) *Guidance on the "right to have" a personal health budget in adult NHS Continuing Healthcare and children and young people's Continuing Care*. Person Centred Care Team: NHS England.

NHS England (2014b) *Guidance on direct payments for healthcare: Understanding the regulations.* Leeds: NHS England.

NHS England (2014c) Five Year Forward View. Available at: http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf. (Accessed December 2017)

NHS England (2015) *Frequently asked questions: Introducing personal health budgets beyond NHS Continuing Healthcare*. Person Centred Care Team: NHS England

NHS England (2016) *People helping people: Year two of the pioneer programme.* Leeds: NHS England.

NHS England (2019a) *Personalised Care: Guidance on the legal rights to have personal health budgets and personal wheelchair budget (2014, revised version)*. London: NHS England.

NHS England (2019b) *Universal Personalised Care: Implementing the Comprehensive Model*. London: NHS England.

NHS UK (2019) NHS Long Term Plan. Available online: https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-termplan.pdf (Accessed 19 June 2019)

Norrie, C., Weinstein, J., Jones, R., Hood, R. and Bhanbro, S. (2014) 'Early experiences in extending personal budgets in one local authority', *Working With Older People*, 18 (4), pp176-185.

Noy, C. (2008) 'Sampling knowledge: The hermeneutics of snowball sampling in qualitative research', *International Journal of Social Research Methodology, 11*(4), pp. 327-344.

Noyes, J., Godfrey, C. and Beecham, J. (2006) 'Resource use and service costs for ventilator-dependent children and young people in the UK', *Health & Social Care in the Community, 14*(6), pp. 508-522.

Nuffield Trust (2012) *Where do personal health budgets fit in the new commissioning landscape? Nuffield Trust/Department of Health seminar, 23 May*. Available at: www.nuffieldtrust.org.uk/talks/where-dopersonal-health-budgets-fit-new-commissioninglandscape. (Accessed 9 December 2016)

Nurjono, M., Shrestha, P., Ang, I. Y. H., Shiraz, F., Yoong, J. S. Y., Toh, S. A. E. S. and Vrijhoef, H. J. M. (2019) 'Implementation fidelity of a strategy to integrate service delivery: learnings from a transitional care program for individuals with complex needs in Singapore', *BMC Health Services Research, 19*(1), pp.1-14.

O'Shea, L. and Bindman, A. B. (2016) 'Personal health budgets for patients with complex needs', *New England Journal of Medicine,* 375, pp. 1815-1817.

Oakley, A. (1981) Interviewing women: a contradiction in Terms. In Roberts, H. ed. (1981) *Doing feminist research*. London: Routledge and Kegan Paul

Oliver, D. (2019) 'What's the verdict on personal health budgets?', *BMJ*, 366, pp. 5138.

Owens, J. (2012) ‘Creating a Patient-led NHS: Some Ethical and Epistemological Challenges’, *Journal of Primary Care,* 4(2), pp 138–143.

Owens, J. (2015) ‘Creating an Impersonal NHS? Personalization, Choice and the Erosion of Intimacy’, *Health Expectations,* 18(1), pp. 22–31.

Owens, J. and Cribb, A. (2013) ‘Beyond Choice and Individualism: Understanding Autonomy for Public Health Ethics’, *Public Health Ethics*, 6(3), pp. 262–271.

Owens, J., Mladenov, T. and Cribb, A. (2017) ‘What justice, what autonomy? The ethical constraints upon personalisation’, *Ethics and Social Welfare, 11*(1), pp. 3-18.

Parsons, T. (1951) ‘Illness and the role of the physician: a sociological perspective’, *American Journal of Orthopsychiatry, 21*(3), p.452.

Patel, M. X., Doku, v. and Tennakoon, L. (2003) ‘Challenges in recruitment of research participants’, *Advances in Psychiatric Treatment*. Cambridge University Press, 9(30), pp. 229-238. Doi: https://doi.10.1192/apt.9.3.229

Patton, M.Q. (2000) *Qualitative evaluation checklist.* Available at: http://wmich.edu/evaluation/checklists. (Accessed 1 February 2016)

Patton, M. Q. (2005) Qualitative research. *Encyclopedia of statistics in behavioral science*, 3, pp.1633–1636.

Pawson, R. (2006) Realist synthesis: new protocols for systematic review. In *Evidence-based policy:* London: SAGE Publications.

Pawson, R. (2013) *The science of evaluation: a realist manifesto*. London: Sage Publications.

Pawson, R. and Manzano-Santaella, A. (2012) 'A realist diagnostic Workshop', *Evaluation, 18*(2), pp.176-191

Pawson, R. and Tilley, N. (1997) *Realistic Evaluation*. London: Sage Publications.

Pawson R, Greenhalgh T, Harvey G, Walshe, K. (2005) 'Realist review—a new method of systematic review designed for complex policy interventions', *Journal of Health Service Research & Policy,* 10 (1), pp. 21–34.

Pawson, R., Greenhalgh, T., Harvey, G. and Walshe, K. (2004) Realist synthesis: an introduction. *Manchester: ESRC Research Methods Programme, University of Manchester*

Pearson, C., Ridley, J. and Hunter, S. (2014) *Self-directed support: personalisation, choice, and control*. Edinburgh Dunedin Academic Press Ltd.

Pedersen, K. Z., & Pors, A. S. (2019) *Transforming Professional Discretion: The Displacement of Case-based Rationality in Frontline Encounters.* Paper presented at ISA RC52 Interim Meeting 2019, Florence: Italy. 04/07/2019 - 06/07/2019.

Pederson, J., Brereton, L., Newbould, J. and Nolte, E. (2013) *The puzzle of changing relationships*. London: The Health Foundation.

Pettigrew, A.M. (1990) 'Longitudinal field research on change: Theory and practice', *Organization Science*, *1*(3), pp. 267-292.

Pickard, S. (2010) 'The 'good carer': moral practices in late modernity', *Sociology,* 4 (3), pp. 471-487.

Pires, R.R. (2011) 'Beyond the fear of discretion: Flexibility, performance, and accountability in the management of regulatory bureaucracies', *Regulation & Governance*, *5*(1), pp.43-69.

Plsek, P. E. Greenhalgh T. (2001) ‘Complexity science: the challenge of complexity in health care’, *BMJ,* 323(7313), pp. 625. 21.

Poll C., Duffy S., Hatton C., Sanderson S. and Routlede, M. (2006) *A report on In Control’s first phase, 2003–3005*. London: In Control Publications.

Popper, K. (2005) *The logic of scientific discovery*. London: Routledge.

Porter, S. (2015) ‘The uncritical realism of realist evaluation’, *Evaluation, 21*(1), pp. 65-82.

Power, A., Bartlett, R. and Hall, E. (2016) ‘Peer advocacy in a personalized landscape: The role of peer support in a context of individualized support and austerity’, *Journal of Intellectual Disabilities, 20*(2), pp. 183-193.

Prashanth, N.S., Marchal, B., Hoeree, T., Devadasan, N., Macq, J., Kegels, G. and Criel, B. (2012) ‘How does capacity building of health managers work? A realist evaluation study protocol’, *BMJ Open*, *2 (*2), pp. e000882. Doi: https//doi.10.1136/ bmjopen-2012-000882

Priestley, M. (2004) Tragedy strikes again! why community care still poses a problem for integrated living. In: Swain J., French S., Barnes C., Thomas C., editors. *Disabling barriers – enabling environment,* 2nd (Edn). London: Sage Publications Ltd.

Priestley, M., Riddell, S., Jolly, D., Pearson, C., Williams, V., Barnes, C. and Mercer, G. (2010) 'Cultures of welfare at the front line: Implementing direct payments for disabled people in the UK', *Policy and Politics,* 38(2), pp. 307 – 24.

Propper, C., Wilson, D. and Burgess, S. (2006) Extending choice in English health care: the implications of the economic evidence. *Journal of Social Policy*. *35*(4) p. 537.

Public Accounts Committee (2017) *House of Lords Committee on the Long-Term sustainability of the National Health Service*. House of Commons. Available at: https://commonslibrary.parliament.uk/research-briefings/cbp-7903/ (Accessed 7 January 2021)

Public Accounts Committee (2019) *NHS pressure in England: waiting times, demand, and capacity.* UK Parliament. Available at: https://commonslibrary.parliament.uk/nhs-pressures-in-england-waiting-times-demand-and-capacity (Accessed 7 January 2021)

Public Accounts Committee (2020) *Adult Social Care Funding (England).* Briefing Paper Number CBP07903: House of Commons Library. Available at: https://commonslibrary.parliament.uk/research-briefings/cbp-7903/ (Accessed 7 January 2021)

Rabiee, P. Baxter, K. Glendinning, C. (2015) 'Supporting choice: support planning, older people, and managed personal budgets', *Journal of Social Work,* 0(0), pp. 1-17. Doi: https// Doi. 10.1177/1468017315581529

Rabiee, P., & Glendinning, C. (2010) 'Choice: What, when and why? Exploring the importance of choice to disabled people', *Disability & Society,* 25, pp. 827–839. doi:10.1080/09687599.2010.520896.

Rabiee, P., Glendinning, C. and Baxter, K. (2013) How far do managed personal budgets offer choice and control for older people using home care services? (SSCR Research Findings). London, England: NIHR School for Social Care Research. Available at: http://www.york.ac.uk/inst/spru/research/pdf/SSCRmpb.pdfAccessed 11 January 2017)

Rabiee, P., Moran, N. and Glendinning, C. (2009) 'Individual budgets: Lessons from early users' experiences', *British Journal of Social Work, 39*(5), pp. 918-935.

Randell, R., Greenhalgh, J., Hindmarsh, J., Dowding, D., Jayne, D., Pearman, A., Gardner, P., Croft, J. and Kotze, A. (2014) ‘Integration of robotic surgery into routine practice and impacts on communication, collaboration, and decision making: a realist process evaluation protocol’, *Implementation Science, 9*(1), pp. 1-8.

Ratzlaff, S., McDiarmid, D., Marty, D. and Rapp, C. (2006) ‘The Kansas Consumer as Provider program: Measuring the effects of a supported education initiative’, *Psychiatric Rehabilitation Journal*. *29*(3), p.174.

Repper, J. and Watson, E. (2012) ‘A year of peer support in Nottingham: lessons learned’, *The Journal of Mental Health Training, Education and Practice,* 7(2), pp. 70-78

Riccucci, N (2005) *How management matters: Street-level bureaucrats and welfare reform.* Washington DC: Georgetown University Press.

Riccucci, N.M. and Meyers, M.K. (2004) ‘Linking passive and active representation: The case of frontline workers in welfare agencies’, *Journal of Public Administration Research and Theory*, *14*(4), pp.585-597.

Rickles, D., Hawe, P. and Shiell, A. (2007) ‘A simple guide to chaos and complexity’, *Journal of Epidemiology & Community Health, 61*(11), pp.933-937.

Riddell, S., Priestley, M., Pearson, C., Mercer, G., Barnes, C., Jolly, D. and Williams, V. (2006) *Disabled people and direct payments: a UK comparative study*. *ESRC Award RES-000-23*, *263*.

Ritchie, J., and Spencer, L. (1994) Qualitative data analysis for applied policy research by Jane Ritchie and Liz Spencer. In A. Bryman and R. G. Burgess (eds.) *Analysing qualitative data,* pp.173- 194.

Robson, C. and McCartan, K. (2016) *Real world research: a resource for users of social research methods in applied settings*. 4thedn. Chichester: Wiley & Sons Ltd.

Rodrigues, R. and Glendinning, C. (2015) ‘Choice, Competition and Care: Developments in English social care and the impacts on providers and older users of home care services’, *Social Policy & Administration*, 49(5), pp. 649-666. Doi: https://doi.org/10.1111/spol.12099

Rogers, A. and Mead, N. (2004) ‘More than technology and access: primary care patients’ views on the use and non-use of health information in the Internet age’, *Health & Social Care in the Community*, *12*(2), pp.102-110.

Rolfe, S. (2019) ‘Combining theories of change and realist evaluation in practice: lessons from research on evaluation study’, *Evaluation*, *25*(3), pp. 294-316.

Roulstone, A. & Morgan, H. (2009) ‘Neo-liberal Individualism or self-directed support: are we all speaking the same language on modernising adult social care?’, *Social Policy Society,* 8, pp. 333–45.

Rycroft-Malone, J., Fontenla, M., Bick, D. and Seers, K. (2010) ‘A realistic evaluation: the case of protocol-based care. *Implementation Science*, 5(38). Doi: https://doi.org/10.1186/1748-5908-5.

Rycroft-Malone, J., McCormack, B., Hutchinson, A.M., DeCorby, K., Bucknall, T.K., Kent, B., Schultz, A., Snelgrove-Clarke, E., Stetler, C.B., Titler, M. and Wallin, L. (2012) ‘Realist synthesis: illustrating the method for implementation research’, *Implementation Science*, *7*(1), pp.1-10.

Rycroft-Malone, J., Williams, L., Burton, C. R., Edwards, S., Fisher, D., Hall, B., McCormack, B., Nutley, S. M., Seddon, D., & Williams, R. (2014) ‘Improving skills and care standards in the support workforce for older people: a realist synthesis of workforce development interventions’, *BMJ Open*, *6*(8), p. e011964. Doi: https://doi.org/10.1136/bmjopen-2016-011964

Rycroft-Malone, J., Burton, C.R., Wilkinson, J., Harvey, G., McCormack, B., Baker, R., Dopson, S., Graham, I.D., Staniszewska, S., Thompson, C. and Ariss, S. (2015) ‘Collective action for implementation: a realist evaluation of organisational collaboration in healthcare’, *Implementation Science*, *11*(1), pp. 1-17.

Rycroft-Malone, J., Burton, C., Williams, L., Edwards, S., Fisher, D., Hall, B., McCormack, B., Nutley, S., Seddon, D. and Williams, R. (2016) Improving skills and care standards in the support workforce for older people: a realist synthesis of workforce development interventions’, *Health Services and Delivery Research* Volume, 4 (12). Doi: https://doi.org/10.3310/hsdr04120

Saldaña, J. (2009) *The coding manual for qualitative researchers.* London: SAGE.

Sandel, M. (2012) *What Money Can’t Buy: The Moral Limits of Markets*, London: Allen Lane.

Salter, K.L. and Kothari, A, (2014) ‘Using realist evaluation to open the black box of knowledge translation: a state-of-the-art review’, *Implementation Science, 9*(1), pp. 1-14.

Sayer, R.A. (1992) *Method in social science: A realist approach*. London: Routledge

Schwartz, B. (2004) *The Paradox of choice. Why more is less.* New York: Harper Collins.

Schmidt, V.A. (2017) ‘Theorizing ideas and discourse in political science: intersubjectivity, neo-institutionalisms, and the power of ideas’, *Critical Review, 29*(2), pp. 248-263.

Scott, T.I.M., Mannion, R., Davies, H.T. and Marshall, M.N. (2003) ‘Implementing culture change in health care: theory and practice’, *International Journal for Quality in Health Care, 15*(2), pp.111-118.

Scourfield, P. (2007) ‘Social care and the modern citizen: Client, consumer, service user, manager and entrepreneur’, *British Journal of Social Work, 37,* pp. 107 – 22

Scourfield, P. (2007) ‘Are there reasons to be worried about the 'caretelization' of residential care?’, *Critical Social Policy*, *27*(2), pp.155-180.

Seidman, I. (2006) *Interviewing as qualitative research: A guide for researchers in education and the social sciences*. Amsterdam: Teachers' college press.

Series, L., and Clements, L. (2013) 'Putting the Cart before the Horse: Resource Allocation Systems and Community Care', *Journal of Social Welfare and Family Law,* 35 (2), pp. 207–226.

Silverman, D. (1993) *Interpreting qualitative data: Methods for analysing talk, text, and interaction*. Thousand Oaks, CA: Sage Publications.

Silverman, D. (2015) *Interpreting qualitative data*. London: Sage.

Slade, M. (2009) 'The contribution of mental health services to recovery', Journal of Mental Health, 18, pp. 367–7

Slasberg, C. (2014) Personal health budgets: A threat to the NHS? In Needham, C. & Glasby, J. (eds.) (2014) *Debates on personalisation.* Bristol: Policy Press.

Slasberg, C. and Beresford, P. (2016) 'The false narrative about personal budgets in England: smoke and mirrors?', *Disability & Society, 31*(8), pp. 1132-1137.

Slasberg, C., Beresford, P. and Schofield, P. (2012a) ‘Can personal budgets really deliver better outcomes for all at no cost? Reviewing the evidence, costs and quality’, *Disability & Society,* 27(7), pp. 1029-1034.

Slasberg, C., P. Beresford, and P. Schofield. (2012b) ‘How Self-Directed Support is failing to Deliver Personal Budgets and Personalisation’, Research, Policy and Planning, 29 (3), pp. 161–177.

Slasberg, C., P. Beresford, and P. Schofield, (2013) ‘The Increasing Evidence of How Self-Directed Support is failing to Deliver Personal Budgets and Personalisation Research’, *Policy and Planning,* 30 (2), pp. 91–105.

Slasberg, C., Beresford, P., and Schofield, P. (2014)’ Further Lessons from the Continuing Failure of Personal Budgets’, *Research Policy and Planning,* 31 (1), pp. 43–53.

Slasberg, C., Watson, N., Beresford, P., & Schofield, P. (2014) ‘Personalization of health care in England: Have the wrong lessons been drawn from the personal health budget pilots?’, Journal of Health Services Research & Policy, 19(3), pp. 183–188. doi:10.1177/1355819614527577.

Spandler, H. (2004) ‘Friend or Foe? Towards a critical assessment of direct payments’, *Critical Social Policy,* 24(2), pp. 187-209

Spandler, H. (2007) ‘Individualised funding, social inclusion, and the politics of mental Health’, *Journal of Critical Psychology, Counselling and Psychotherap*y, 8 (1), pp. 18-27.

Spandler, H. and Vick, N. (2006) ‘Opportunities for independent living using direct payments in mental health’, *Health and Social Care in the Community,* 14(2), pp. 107–115.

Spaulding-Givens, J. C. and Lacasse, J. R. (2015) ‘Self-directed care: Participants’ service utilization and outcomes’, *Psychiatric Rehabilitation Journal,* 38 (1), pp. 74-80. Doi: https://doi.org/10.1037/prj0000103

Spradley, J.P. (2016) *The ethnographic interview*. Long Grove: Waveland Press.

Srivastava, P. and Hopwood, N. (2009) ‘A practical iterative framework for qualitative data analysis’, *International Journal of Qualitative Methods, 8*(1), pp. 76-84.

Stake, R.E. (2010) Qualitative research: Studying how things work. New York: Guilford Press.

Stevens, M., Glendinning, C., Jacobs, S., Moran, N., Challis, D., Manthorpe, J., Fernandez, J.-L., Jones, K., Knapp, M., Netten, A. and Wilberforce, M. (2011) ‘Assessing the role of increasing choice in English social care services’, *Journal of Social Policy,* 40(2), pp. 257 – 74.

Strauss, A. and Corbin, J. (1998) *Basics of qualitative research techniques*. Thousand Oaks, CA: Sage Publications Ltd.

Tew, J., Larsen, J., Hamilton, S., Manthorpe, J., Clewett, N., Pinfold, V. and Szymczynska, P. (2015) ‘And the Stuff that I'm Able to Achieve Now Is Really Amazing: The Potential of Personal Budgets as a Mechanism for Supporting Recovery in Mental Health’, *British Journal of Social Work,* 45(1), pp. i79-i97.

The Health Foundation (2015) The Power of People. Available at: http://www.health.org.uk/node/10181 (Accessed June 2016)

The Health Foundation (2010) *Personal Budgets Research Scan.* London: The Evidence Centre.

Think Local Act Personal (2015) *Personal Budgets, Taking Stock, Moving Forwards*. London: TLAP

Think Local Act Personal (2021) *Direct Payment: working or not working?* London: TLAP

Think Local Act Personal (2017) *The Care Act 2014 Survey Results: Exploring the Impact of the Care Act on the Lives of People with Care and Support Needs*. London: TLAP.

Thomann, E., van Engen, N. and Tummers, L. (2018) 'The necessity of discretion: A behavioral evaluation of bottom-up implementation theory', *Journal of Public Administration Research and Theory, 28*(4), pp. 583-601.

Thomson, S. and Dixon, A. (2006) 'Choices in health care: the European experience', *Journal of Health Services Research & Policy, 11*(3), pp. 167-171.

Timberlake, M.T., Leutz, W.N., Warfield, M.E. and Chiri, G. (2014) 'In the driver's seat: Parent perceptions of choice in a participant-directed Medicaid waiver program for young children with autism', *Journal of Autism and Developmental Disorders, 44*(4), pp.903-914.

Townsley, R., Abbott, D. and Watson, D. (2004) *Making a difference? exploring the impact of multi-agency working on disabled children with complex health care needs, their families and the professionals who support them*. Journal of clinical Nursing, 11(3), pp. 367-375. Doi: https://doi.org/10.1046/j.1365-2702.2002.00623.x

Tummers, L.G. (2011) 'Explaining the willingness of public professionals to implement new policies: A policy alienation framework', I*nternational Review of Administrative Sciences,* 77, pp. 555–81.

Tummers, L, G. (2012) 'Policy alienation of public professionals: The construct and its measurement', *Public Administration Review,* 72, pp. 516–25.

Tummers, L. G., Steijn, B. S. and Bekkers, V. (2012) ' Explaining the willingness of public professionals to implement public policies: Content, context, and personality characteristics', *Public Administration*, 90, pp. 16–36.

Tummers, L. G., Bekkers, V. and Steijin, B. S. (2009) 'Policy alienation of public professionals: Application in a new public management context', *Public Management Review,* 11, pp. 685–706.

Tummers, L.G., and Bekkers, V., Vink, E. and Musheno, M. (2015) ‘Coping during public service delivery: A conceptualization and systematic review of the literature’, Journal of *Public Administration Research and Theory*, 24(4), pp. 1099–1126.

Tummers, L.G. and Bekkers, V. (2014) ‘Policy implementation, streetlevel bureaucracy, and the importance of discretion’, *Public Management Review,* 16, pp. 527–47.

Tyson, A., Brewis, R., Crosby, N., Hatton, C., Stansfield, J., Tomlinson, C. and Wood, A. (2011*) A report on In Control's Third Phase: evaluation and learning 2008-2009*. London: In Control Publications.

Ungerson, C. (2007) ‘Social politics and the commodification of care’, Social Politics, 4, pp. 362-381. https://doi.org/10.1093/sp/4.3.362.

Ungerson, C. and Yeandle, S. (2007) *Cash for Care in Developed Welfare States*. Basingstoke: Palgrave MacMillan.

Van de Walle, S. and S. Marien. (2017) ‘Choice in Public Health Services: A Multilevel Analysis of Perceived Primary Care Doctor Choice in 22 Countries’, Administration & Society, 49 (10), pp. 1471–1493.

Van Ginneken, E., Groenewegen, P. P., and McKee, M. (2012) ‘Personal healthcare budgets: what can England learn from the Netherlands?’, *BMJ,* 344(e1383), pp. 1–3. Doi: https://doi.org/10.1136/bmj.e1383

Van Wijk, E. and Harrison, T. (2013) ‘Managing ethical problems in qualitative research involving vulnerable populations, using a pilot study’, *International Journal of Qualitative Methods*, *12*(1), pp.570-586.

Walden D. and Ayling, R. (2013) A problem shared: making the best use of resources in Adult Social Care. London, Think Local Act Personal. Available at: http//www.thinklocalacpersonal.org.uk/_library/ Resources/Usefresources/1_UoR_A_Problem_Shared_full_ report.pdf (Accessed on 17 August 2013)

Wand, T., White, K. and Patching J. (2011) ‘Realistic evaluation of an emergency department-based mental health nurse practitioner outpatient service in Australia’, *Nursing and Health Sciences*, 13(2), pp. 199-206.

Wanless, D. (2002) *Securing Our Future: Taking a Long-Term View. Final Report.* The Public Enquiry Unit: HM Treasury.

Warr, D., Dickinson, H., Olney, S., Hargrave, J., Karanikolas, A., Kasidis, V., Katsikis, G., Ozge, J., Peters, D. and Wheeler, J. (2017) Choice, Control and the NDIS: Service Users' Perspectives on Having Choice and Control in the New National Disability Insurance Scheme. Melbourne: Melbourne Social Equity Institute, University of Melbourne.

Wears, R.L., Hollnagel, E. and Braithwaite, J. (2016) *Resilient health care, volume 2: the resilience of everyday clinical work*. 2nd eds. London: Routledge.

Weaver, T.D. and Patterson, S. (2009) 'The myth of complexity', *BMj*, *339*, pp. b3505. doi: https://doi.org/10.1136/bmj.b3505

Webber, M., Treacy, S., Carr, S., Clark, M. and Parker, G. (2014) 'The effectiveness of personal budgets for people with mental health problems: a systematic review', *Journal of Mental Health,* 23(3), pp. 146-155.

Weich, S., Fenton, S.J., Staniszewska, S., Canaway, A., Crepaz-Keay, D., Larkin, M., Madan, J., Mockford, C., Bhui, K., Newton, E. and Croft, C. (2020) 'Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study', *Health Services and Delivery Research, 8*(21), pp.1-338.

Weiss, C.H, (1998) *Evaluation: Methods for studying programs and policies*. 2nd edn. Upper Saddle River, N.J. : Prentice Hall

Welch E, Caiels J, Bass R, Jones K, Forder J, Windle K. (2013) *Implementing Personal Health Budgets Within Substance Misuse Services, Final Report*. Department of Health.

Welch, E., Jones, K., Caiels, J., Windle, K., Bass, R. (2016) 'Implementing personal health budgets in England: a user-led approach to substance misuse', *Health & Social Care in the Community*, 25(5), pp. 1634-1643.

West, K. (2013) 'The Grip of Personalization in Adult Social Care: Between Managerial Domination and Fantasy', *Critical Social Policy,* 33 (4), pp. 638–657.

Westhorp, G. (2012) 'Using complexity-consistent theory for evaluating complex systems', *Evaluation, 18*(4), pp. 405-420.

Westhorp, G. (2014) 'Developing complexity-consistent theory in a realist investigation', *Evaluation, 19*(4), pp. 364-382.

Westhorp G. (2018) Understanding mechanisms in realist evaluation and research. In: Emmel, N., Greenhalgh, J., Manzano, A., Monaghan, M. and Dalkin, S. (eds.) *Doing realist research.* London: Sage.

White, C. (2011) *The personal touch: The Dutch experience of personal health budgets.* London: The Health Foundation.

Wilberforce, M., Glendinning, C., Challis, D., Fernandez, J.L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A. and Stevens, M. (2011) 'Implementing consumer choice in long-term care: The impact of individual budgets on social care providers in England', *Social Policy & Administration, 45*(5), pp. 593-612.

Williams, B. and Tyson, A. (2010) 'Self-direction, place and community: Re-discovering the emotional depths: A conversation with social workers in a London borough', *Journal of Social Work Practice,* 24(3), pp. 319– 33.

Williams, I. and Dickinson, H. (2015) 'Going it alone or playing to the crowd? A critique of individual budgets and the personalisation of health care in the English National Health Service', *Australian Journal of Public Administration*, *75*(2), pp. 149-158.

Williams, L., Burton, C. and Rycroft Malone, J. (2013) 'What works: a realist evaluation case study of intermediaries in infection control practice', *Journal of Advanced Nursing*, 69(4), pp. 915-926.

Williams, L., Rycroft-Malone, J., Burton, C.R., Edwards, S., Fisher, D., Hall, B., McCormack, B., Nutley, S.M., Seddon, D. and Williams, R. (2016) ‘Improving skills and care standards in the support workforce for older people: a realist synthesis of workforce development interventions’, *BMJ Open*, *6*(8), p.e011964.

Williams, M. (2018) Making up mechanisms in realist research. In: Emmel, N., Greenhalgh, J., Manzano, A., Monaghan, M. and Dalkin, S. (eds.) *Doing realist research*. London: Sage.

Williams, S. (1998) ‘An organizational model of choice: A theoretical analysis differentiating choice, personal control, and self-determination’, *Genetic, Social, and General Psychology Monographs*, *124*(4), p. 465.

Williams, V., & Porter, S. (2017) ‘The meaning of ‘choice and control’ for people with intellectual disabilities who are planning their social care and support’, *Journal of Applied Research in Intellectual Disabilities,* 30(1), pp.97–108. Doi: https://doi.org/10.1111/jar.12222.

Williams, V., Porter, S. and Marriott, A. (2014) ‘Your life, your choice: Support planning led by disabled people's organisations’, *British Journal of Social Work, 44*(5), pp. 1197-1215.

Wong, G., Pawson, R. and Owen, L. (2011) ‘Policy guidance on threats to legislative interventions in public health: a realist synthesis’, *BMC Public Health*, *11*(1), pp. 1-11.

Wong, G., Greenhalgh, T., Westhorp, G. and Pawson, R. (2012) ‘Realist methods in medical education research: what are they and what can they contribute?’, *Medical Education*, *46*(1), pp. 89-96.

Wong, G., Westhorp, G., Pawson, R. and Greenhalgh, T. (2013) *Realist synthesis. RAMESES training materials*. London: The RAMESES Project.

Wong, G., Westhorp, G., Manzano, A., Greenhalgh, J., Jagosh, J. and Greenhalgh, T. (2016) ‘RAMESES II reporting standards for realist evaluations’, *BMC Medicine*, *14*(1), pp. 1-18.

Wong, E.L., Yeoh, E.K., Chau, P.Y., Yam, C.H., Cheung, A.W. and Fung, H. (2015) ‘How shall we examine and learn about public-private partnerships (PPPs) in the health sector? Realist evaluation of PPPs in Hong Kong’, *Social Science & Medicine*, *147*, pp. 261-269.

Woolham, J. and Benton, C. (2013) ‘The costs and benefits of personal budgets for older people: evidence from a single local authority’, *British Journal of Social Work*, *43*(8), pp.1472-1491.

Woolham, J., Daly, G., Sparks, T., Ritters, K. and Steils, N. (2017) ‘Do direct payments improve outcomes for older people who receive social care? Differences in outcome between people aged 75+ who have a managed personal budget or a direct payment’, *Ageing & Society*, *37*(5), pp. 961-984.

Yin, R. K. (2015) *Qualitative Research from Start to Finish*. 2ndedn. London: The Guildford Press.

Yin, R. K. (2009) *Qualitative Research from Start to Finish*. New York: Guildford Press.

Appendices

Appendix 1 – SCREC Ethical Approval

Health Research Authority

Social Care REC

04 January 2018

Miss Editor Musekiwa

Dear Miss Musekiwa

Study title:	**Exploring how Personal Health Budgets are working in practice to deliver choice and control for people with complex healthcare needs: an ethnographic case study.**
REC reference:	**17/IEC08/0034**
Protocol number:	**RG_16-078**
IRAS project ID:	**224464**

Thank you for your letter of 21 December 2017, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where an NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC, but you should do so at the earliest opportunity e.g., when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances nonregistration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only)	V.10	26 June 2017
Interview schedules or topic guides for participants	V 1.0	21 June 2017
Letter from sponsor	V.10	23 June 2017
Letters of invitation to participant	V 1.0	21 June 2017
Other [CV for Supervisor 1]		23 June 2017
Other [CV for supervisor 2]		23 June 2017
Other [Checklist of general understanding and capacity]	V 1.0	21 June 2017
Other [Observation Checklist]	V 1.0	21 June 2017
Other [Expression of Interest]	V 1.0	21 June 2017

Other [Professional Indemnity Insurance Letter]		26 July 2017
Other [Sponsor and CI agreement]		26 July 2017
Other [Generic Indemnity Insurance Letter]		26 July 2017
Other [Employers Liability Insurance Letter]		26 July 2017
Other [Research Protocol]	ver.2.0	26 October 2017
Other [REC letter with amendments]		26 October 2017
Other [care worker informaton sheet]	ver.2.0	26 October 2017
Other [care worker consent form]	ver.2.0	26 October 2017
Other [care worker/ family carer expression of interest]	ver.2.0	26 October 2017
Other [Family carer information sheet]	ver.2.0	26 October 2017
Other [Family carer consent form]	ver.2.0	26 October 2017
Other [gatekeeper/ key informant information sheet]	ver.2.0	26 October 2017
Other [support groups for personal health budgets contact details]	ver.2.0	26 October 2017
Other [participant consent form clean ver.2.0]	ver.2.0	26 October 2017
Other [Participant information sheet clean ver.2.0]	ver.2.0	26 October 2017
Other [Research Protocol clean ver.2.0]	ver.2.0	26 October 2017
Participant consent form	V 1.0	21 June 2017
Participant consent form [participant consent form]	ver.2.0	26 October 2017
Participant information sheet (PIS)	V 1.0	21 June 2017
Participant information sheet (PIS) [Participant information sheet]	ver.2.0	26 October 2017
REC Application Form [SC_Form_29062017]		29 June 2017
Research protocol or project proposal	V 1.0	21 June 2017
Summary CV for Chief Investigator (CI)		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high-quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known, please use the feedback form available on the HRA website:

http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/IEC08/0034	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Email: nrescommittee.social-care@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Dr ……………………….*

Appendix 2 – Observational Protocol

Ver. 1

Observational Protocol

Where research takes Place

- Research will be carried out in people's own homes and their community.

Recruitment

Potential participants will be recruited as follows:

- Key informants (professionals contacts in continuing care, UK service user participation forums, voluntary sector networks) will be contacted by the research student via telephone, email, and face to face.
- The research student will request assistance in identifying potential participants.
- The key informants will contact people known to them that fit criteria and share participant information sheet with potential participants
- Information sheet will contain details about the study, person specification and how to contact research student if interested.
- If potential participants are interested, then key informant will pass on the contact details to the research student with full agreement of that participant to do so.
- Individuals who would have shown interest and are happy will have their details passed to the research student
- The research student will then contact potential participants and arrangements for a face-to-face meeting.

Information giving

- During the face-to-face meeting, potential participants will receive information about the research.
- Potential participants will be given the opportunity to talk through this information, clarify understanding and ask questions.
- The research student will check and ensure potential participants can give informed consent.

Consent

- All participants will be given the opportunity to give informed consent and agree to be observed.

Introductory Meeting

- Participant will have an introductory meeting with the research student to discuss in detail the nature of the study, participation, and expectations.
- Participants will be informed of their right to withdraw their consent at any given time.

Observations

- Observation will take place in people's own homes and their community.
- Observations will be carried out at times that are convenient for the participants.

<u>Purpose of observations</u>

- To record situations as they happen

- To record meanings of these events at the time of observation

Who will be Observed?

- Participants
- Carers
- Their network

What will be observed

- Activities of daily living paid for through a PHB (housework, preparing meals, health management and maintenance, use of personal assistance etc.).
- Events and sequence in which PHBs are being used (Equipment purchase, training for personal assistance, community access etc.)
- Setting and participation structure in which activities occur
- Behaviours of individual people
- Conversations
- Interactions

What will not be observed

- Personal Cares/ washing.
- Nighttime routines including getting ready for bed and bedtimes.
- Any activities participants are not comfortable being observed.
- Carers/ Family members who have not consented to be observed.

Duration of Observations

1 hour

Processes

- Written fieldnotes
- Tape recorded fieldnotes
- Records of informal conversations
- Observational checklist
- Records of Field diaries
- Artifacts

The research student will ensure observations and interactions do not disrupt normal activity or compromise privacy of individuals and a balance will be maintained to ensure the research itself remain profoundly an emergent property of the processes of data collection.

Risk Management

- Participants' will receive confirmation of the research student's DBS status.
- The research student will leave participants' homes at reasonable times.
- The research student will maintain a clock in/ out system with the supervisors.
- If participants reflect on negative experiences the research student will be sensitively and supportive.
- The research student will take time to reflect and discuss with supervisors any difficult or distressing issues.
- If the research student identifies issues relating to abuse, harm or malpractice, the research student will immediately report these to the supervisors to identify what further action should be taken or to the police if there is believed to be a criminal activity being undertaken.

Appendix 3 – Interview Schedule (Semi-structured)

IRAS ID: 224464 V1.0
(21/06/2017)

Full name and title: Miss Editor Musekiwa

Sponsor RG number: RG_16-078

Research Title

Exploring how Personal Health Budgets are working in practice to deliver choice and control for people with complex healthcare needs: an ethnographic case study

Personal Health Budget (PHB) - Interview Schedule (semi-structured)

[Note: Information sheet given, and interview process explained on a separate visit prior to interview. Verbal consent given before interview and interview duration 1 hour]

1. Think about your PHB.
    - Can you tell me about your experience of using the PHB?
    - What do you understand by PHB?
    - Do you know which package you are getting?
    - What does have a PHB mean to you?

   [PROBE: How important is the PHB for meeting your healthcare needs]

2. Think about how you got your PHB, what you went through and now?
    - How easy or difficult was it to access?
    - What processes did you have to go through?
    - How do you keep track of things?

[PROBES: Where did you get information? How did you know which package to get? What services to purchase? When? Where? How? What systems do you have or use? How did you find them? Did someone recommend them to you? Do you get support to do this? Who supports you? How are they paid]

3. I want you to think about your healthcare needs.
    - How did you know what your healthcare needs are?
    - How did you decide what money would be needed to meet these needs?

[PROBE: Did you do a care plan? Did you do it alone or you had help? Who helped you? How did you know where to get help? Are you able to share your care plan with me?]

4. Think of the ways you have used the PHB.
    - Can you describe them?

[PROBES: What do you use it for? What services do you buy? Is there anything you bought or did that I can see? How flexible can you use it? Does the PHB cover all cost?]

5. I want to take you back to the time you thought a PHB is what you need.
    - Was it all your choice?
    - How did you come to that decision?
    - Do you feel you have control over the decisions you make?
    - What made you decide the PHB was the best way to meet your healthcare needs?

[PROBE: Did you have any difficulties making the decision? Who decided what you needed? Where other people involved? What was their level of involvement? Were the decisions shared? Did you have much say on what goes on?]

6. Now think of the time when you did not have a PHB.
    - How were your healthcare needs met?
    - What sort of changes has the PHB made to your life?

   [PROBE: Are things better or worse? What is better and what is worse]

7. Is there anything else you would like to tell me? Or you want me to explain, any comments or questions you have for me?

Appendix 4 – Participant Consent Form

UNIVERSITY OF BIRMINGHAM

PARTICIPANT CONSENT FORM IRAS I.D: 224464 (26/10/17)

I have read the information sheet, or had it explained to me	**YES**	**NO**
I have had time to ask questions, and am happy with the answers	**YES**	**NO**
I understand what taking part in the project will involve	**YES**	**NO**
I understand that information collected during interviews must be kept confidential	**YES**	**NO**
I understand that if I lose capacity, I will be withdrawn from the study and information collected can still be used anonymously	**YES**	**NO**
I understand if my health deteriorated, I could withdraw from the study and information collected can still be used anonymously	**YES**	**NO**

I agree to be audio recorded	**YES**	**NO**
I agree to be observed alongside my care worker/ family carer in an activity funded through a PHB	**YES**	**NO**
I understand that I can still take part in the interview and request not to be audio recorded	**YES**	**NO**
I agree to take part in the project	**YES**	**NO**

____________________ __________________ ______________________________

Name of participant **Date** **Signature**

_____________________ __________________ ______________________________

Person taking consent **Date** **Signature**

Appendix 5 – Conditional Offer with Following Additional Information Required

UNIVERSITY OF BIRMINGHAM

IRAS I.D: 224464

26 October 2017

Social Care REC

Dear Dr (Chair)

Research Title: Exploring how Personal Health Budgets are working in practice to deliver choice and control for people with complex healthcare needs: an ethnographic case study

REC Reference: 17/IEC08/0034

Thank you for your letter dated 16 October 2017, with a favourable opinion on condition that I provide further information. I have responded to the Committee's request as follows:

Further information or clarification required

The changes highlighted below, have been included in the research protocol ver1.1 and these parts following parts of the protocol have been affected; **selection of participants, gaining access, consent, anonymity/ confidentiality, observations, risk quality & monitoring management procedure and dissemination.** The option to be audio recorded was already in the **conducting interview** section, therefore it was only added to the PISs and consent forms.

1. **Recruitment of care workers/ family carers.**
   To respect and preserve the privacy of care workers/ family carers, the participants will be given care worker/ family carer information sheets that explain the study and the role of the care worker/ family carer as well as an expression of interest form. If the care worker/family carer decide

to take part, they will complete an expression of interest allowing the participants to pass their details to the research student. This enables the research student to contact care worker/ family carer and go through the consent process as detailed in the protocol. For observations to take place, both the participant and care worker/ family carer would have to agree to jointly take part. If one part agrees and the other part refuses, no observations will be conducted. The relevant documents have been updated to reflect this. (See relevant PISs, consent forms and research protocol ver.1.1, care worker/ family carer expression of interest ver1.0)

2. **Including service users who can consent but can't speak.**
    - Every effort will be made to develop methods of seeking consent that are appropriate to the individual participant, for example video record the consent using university-based recording equipment and this will be transferred onto the university storage network.

3. **Confidentiality and anonymity of individuals who may have highly identifying features and those who might want their stories told**.
    - Every effort will be made to maintain confidentiality and anonymity and to protect everyone, the results will be reported collectively, and individual story telling falls outside the parameters of the study and therefore not justified

4. **Details of how quotes used in the report will be checked back with participants**.

    - The participants will be given an opportunity to confirm the accuracy of interview transcripts, however one needs to proceed with caution because participants may not be able to cope with the complexity and volume of this kind of data. Because there is no user involvement in the designing of the research, this would be a good way of getting them involved and they will only be able to check the transcript of their own interviews.

5. **Information of how 'distress in the moment' of participants will be handled.**

    - While every attempt is made to assess potential vulnerability within the context of the research and being sensitive in the way interviews are conducted, there is the likelihood that people may get upset if their PHB package is not working well (e.g., having to explain these experiences). It is important that people know at the start of the interviews that they don't have to answer any questions they are not comfortable with, and they can ask me to stop the interview at any time and they don't have to say why they have stopped. The research student must also observe the non-verbal clues. However, the worst-case scenario is the unfortunate circumstances where the participant become distressed, I will show empathy by listening, offering tissue, cup of tea, asking to take a break, asking to stop the interview, and signposting to available support networks.

6. **Inclusion/ exclusion of participants currently funded by the continuing healthcare budget who may fall out of this funding stream and return to adult social care funding.**

    - This research involves participants currently receiving PHBs, however it is recognised that a person who was having a PHB could potentially have their health needs improve and fall out of this funding stream. Should this happen, and the participant moves to e.g., direct payments, they will continue to take part in the research during transition period and will be excluded from the study once they are on a personal budget. Data already collected will be retained and used anonymously and confidentially for the purposes for which consent was being sought.

7. **Confirm that a link to the whole research report, not just the summary will be provided and change the PISs accordingly**.

    - A link to the whole research report will be made available to the participants and it can be accessed from the University of Birmingham website at http://etheses.bham.ac.uk/in 2019 and will be available for a minimum duration of a year.

    - The above statement has also been updated and appears on all PISs.

8. **A list of support groups which can be given to participants who are having problems with their personal health budget has been developed.**
    - See list of personal health budget support groups.

9. **Changes effected on PISs and consent forms.**

a) Information sheet for key informants/ gate keepers, care worker and family carer explaining their role has been included.

b) The statement ‘if the service user says they would like to be involved but the care worker/ family carer says no (or vice versa) observation are not viable’ has been added to all relevant PISs

c) The range of activities to be observed and the frequency has been added to all relevant PISs and protocol ver. 2.0

d) The breaching of confidentiality statement has been added to all relevant PISs.

e) The statement has been replaced by ‘I understand that everything I say/report is confidential unless I tell you something that indicates that I or someone is at risk of harm.

f) The statement ‘I agree to be audio recorded’ has been added to the consent forms.

g) The terms ‘deteriorating health’ and ‘losing capacity’ have been separated on the consent form.

h) The option for those who want to participate in an interview and not be audio recorded has been included on the PISs and consent forms.

i) Proof reading done on all participant documents.

Yours sincerely

Editor Musekiwa

Appendix 6 – Criteria for Study Selection – Relevance to Theory Development

Appendix 2(a) Criteria for Study Selection – (Relevancy to Theory Development)
High: if it mentions choice and control, personalisation implementation and answer all the research questions • What are the key assumptions on PHBs? • How are PHBs implemented? • How are the budgets used by individual groups of people? • What are the outcomes on health and wellbeing? • What groups of people experiences these outcomes? • What mechanisms and context resulted in these outcomes?
Moderate: if it mentions choice and control, personalisation implementation and answer four of the questions • What are the key assumptions on PHBs? • How are PHBs implemented? • How are the budgets used by individual groups of people? • What are the outcomes on health and wellbeing? • What groups of people experiences these outcomes? • What mechanisms and context resulted in these outcomes?
Low: if it mentions choice and control, personalisation implementation and answer two of the questions
No relevance Does not meet above criteria

Appendix 7 – Summary of Appraisal of Realist Review Evidence

Author/ Year	Study	Aims	User Group/ Audience	Evidence Value and Limitations	Key Issues	CMOs
Forder et al (2012)	Quasi-experiment used qualitative and quantitative data from 64 pilot sites (over 1000 sample wider cohort) and 20 sites in-depth interviews.	compared the experiences of people in a controlled trial between those receiving PHBs and those using conventional support arrangements. Measure: patient outcomes, experiences, service use and costs	chronic obstructive pulmonary disease, diabetes, long-term neurological conditions, mental health, stroke, patients eligible for NHS continuing health care	Yes – (High) focused on Impact on health outcomes on the system. Small sub-group analysis not always statistically reliable. Not designed to answer how, why, for whom and under what circumstances PHBs deliver choice.	Linked to the broader personalisation outcomes- encourage the NHS to - become more responsive to the needs of patients by providing greater choice and control leading to improved efficiency. Improvement in care related quality of life (ASCOT) and psychological well-being (GHQ-12) linked to value budgets. No impact on health status. PHBs implemented in different ways. Varying choices about what services could be purchased with the budget and level of flexibility as to how the budget could be managed, level of transparency on	Improvements in outcomes linked to the flexibility, increased levels of choice and control and how PHBs were implemented. (C) How PHBs were configured (allocation). Value of the budget. support planning. Deployment options. Information, decision making on how resources are used. Culture shift, financing of programme, designing a clear process to support direct payments, engaging stakeholders to manage the cultural shift require, workforce training, peer support system, understanding of the cost of previous care packages managing double running costs from disaggregation (M)

					how the size of the budget was calculated.	
Jones et al (2017)	process evaluation approach (semi structured telephone interviews framed against hypothesised process factors with organisational representatives and with budget holders).	The study sought to infer key mechanisms of effect and reflect on the contexts in which they operated to understand why the national evaluation had the outcomes observed and speculate impact in changing context- post pilot.	Organisational representatives (6 interviews from sites that participated in in-depth pilot site with over 100 enrolled and 2 from site in wider cohort at early stages of implantation with few participants) 23 PHB holders (7 participated in pilot, 7 from roll-out and 9 had received budgets during evaluation)	Yes – (High) Lack of long-term perspective of the roll-out. Uniqueness of cases and complexity of healthcare needs that are likely to be asking for PHBs that may not have been encountered in the pilot and evaluation. Changes in context of following roll-out	PHBs can improve outcomes by giving individuals greater sense of control, empowerment, through a supported care planning process, allowing individual to secure services flexibly and innovatively to meet their specific care needs. Variations in budget setting processes. Care planning still being done by clinicians, facilitators, or external organisation as was in the pilot.	Changing context in PHB policy deployment, funding, and eligibility and less flexible. Changing culture context for PHBs. Cessation of PHBs to conditions outside CHC. No additional funding like the pilots and working within existing budgets and budget cuts. Variations in deployment options based on participants and local requirements. (C). recruiting and retaining staff. implementing the care plan. Shared decision making. Engagement with PHB holders. Limited-service providers and need to be innovative and creative. Flexibility on what can be purchased. Volunteer provider entrant into the market. larger providers being more flexible. Block contracts. Budgets to reflect changing needs (M).
Davidson et al. (2013)	Qualitative evidence forms the 20 pilot sites in multi-method evaluation pilot of PHBs. Semi structured interviews with 58	Explore the experience of receiving and using PHBs	chronic obstructive pulmonary disease, diabetes, long-term neurological conditions, mental health, stroke, patients eligible for NHS continuing health	Yes – (High)	Positive impact on health, health care and relatives/families and on other domains not related to condition. Rarely knew level of the budget. Difficulty in agreeing use of the budget. Delays in	Improving experiences and effectiveness of care. Enabling the NHS to be responsive to patient needs. Variations in allocation and processes (C). Flexibility in how budgets can be used Information and support/ peer support required; Decision making; care

	participants at 3 months and 52 at 9 months.		care (Forder and others, 2012)		securing service and equipment. Improve efficiency in the NHS, gains in well-being, choice, and control (O)	planning; implementation process [holistic assessments and approval] (M)
Cattermole (2012)	Case study -market development	Practice guide for commissioners to provide services differently	Mental health commissioners	Yes – (Moderate)	PHBs become part of the routine clinical practice. PHBs enable people to make choices in innovative ways and contribute to people having a chance to move on and rebuild their lives.	Recovery focus (building life beyond illness without eliminating symptoms) (C). support planning and brokerage through voluntary sector. Information. Clear care plan signs off procedures and risk management. Peer support and coproduction. Funding to support infrastructure for PHBs
Irvine et al (2011)	Quasi-experiment used qualitative data from semi structured interviews (at 3 month) with 58 participants from 17 pilot sites (study part of a larger cohort)	Looked at the early experiences of PHB holders and their representatives (part of national evaluation pilot) to identify whether personal health budgets deliver better outcomes for patients than conventional	chronic obstructive pulmonary disease, diabetes, long-term neurological conditions, mental health, stroke, patients eligible for NHS variations in the type, severity/complexity, and duration of health conditions	Yes – (High) Some people had not yet received their budgets when the interviews took place. These are early experiences and context has changed	Create a more patient-centered, responsive NHS- (overarching outcome). Appeared to be few major anxieties or obstacles to try PHBs. Health and well-being outcomes (Individual level) - better health, improved morale, and motivation, and enhanced social inclusion. User involvement	Meeting specific needs. Maintaining existing support. Culture and organisational changes [service, professional and patients] (C). Information and support, allocation process, knowing value of the budget, care planning. User involvement (M).

		health services and, if so, how they should best be implemented				
Jones et al (2010)	Qualitative strand of the evaluation pilot and (43 interviews) of the 20 sites selected for in-depth interviews	focused on the PHB implementation process.	operational staff, health professionals, commissioning lead and third-party budget holders	Yes – (Moderate) Delays as people were not in post and this was based on the potential of PHBs rather than the actual experience. Changes at local level from PCT to CCGs and change in priorities overshadowing PHBs	Wider outcomes to give greater choice and control over services. Positive impacts expected on PHB holders and carers attributed to choice and control over services, flexible and creative services. Improved confidence, self-esteem, and sense of purpose. Improved relations between the NHS and PHB holders as views are being listened to. Increased cost and workload. Uncertainty due to little guidance on the process as well as sustainability long-term of PHBs.	Impact on workforces. Accountability and risk management. A cultural shift across all levels of the NHS. Resourcing of the system to support PHBs implementation. Abolition of PTC. Anxiety and worries about the change. Long-term sustainability of PHBs (C). Transparent allocation. Deployment process. Care planning. Information and support. Flexible services that fit individual lifestyle. Develop provider market development. Knowledge and skills of the workforce.
Jones et al. (2011)	Self-reporting of implementation cost of PHBs from the 20 sites selected for in-depth study in the evaluation pilot.	Explore likely implementation cost of PHBs following roll-out	Organisational representatives	Yes – (Low) These are estimates and may not reflect the actual cost when programme is rolled out.	The implementation of PHBs may result in additional cost being incurred (O)	Cost of designing system (C). Workforce training. Support planning/ brokerage. Managing the market. Project management structure. (M)

Welch et al. (2016)	Qualitative- 20 semi- structures interviews- two time points with 10 organisational representatives from 2 sites selected for in-depth study in the evaluation pilot.	Substance misuse	Project leads/managers Commissioning managers, health professionals Support workers Frontline operational staff who had assisted in the pilots	Yes – (Moderate) Data reported was collected during pilot and context has since changed. Views do not include perspective of budget holders.	Positive impact on budget holders, families, and system as a whole. Potential to links with after care services. Increased confidence, self-esteem, and a sense of purpose. Greater knowledge and improved understanding of needs. breaking barriers and getting respect. Services more responsive to service users. Increased staff workload. Shift in power towards commissioners from providers (O)	The right time to offer PHBs referrals often made during crisis. What to offer in terms of services available in the market. Deployment options that offered real choice not made available [direct payment – only notional budgets were on offer] client vulnerability, risk accountability and safety. Cultural challenges -how to recommend non-evidence-based treatments(C) Recipience having PHBs post detox and not during crisis. Active participation and engagement. Support planning. Structural and process changes to existing services. Reduce block contract. Flexibility in the deployment options. Individuals taking more responsibility with support. (M)
Jones et al. (2013)	Quasi-experiment (quantitative data from the evaluation pilot)	To compare the outcomes and related costs for those selected to receive PHBs and those in the control group who were continuing receiving conventional support.	chronic obstructive pulmonary disease, diabetes, long-term neurological conditions, mental health, stroke, patients eligible for NHS	Yes – (Low) Based on assumptions PHBs new at the time. Profoundly different, structures and support not developed for roll-out. Limitations in designing study criteria in advance. Researcher were unable to establish what PHBs were for, and which services could be purchased.	A neutral impact on costs was found and this suggested PHBs could be cost effective in improving care related quality of life outcomes without impacting on health status. (O)	Process changed during the pilot stage (C). Used care plan (M)

Welch et al (2013)	Implementing personal health budgets within substance misuse services	The study used a controlled trial to compare the experiences of those people receiving a personal health budget and those using conventional substance misuse treatment support arrangements	An evaluation and adopted a longitudinal approach with people who have drug or alcohol addiction.	Yes – (High) A mixed design was followed where both quantitative and qualitative methodologies were used to explore patient outcomes and experiences, service use and costs, as well as the experiences of those implementing the initiative	Were PHBs were implemented well, there was increased service user satisfaction facilitated a positive relationship with healthcare professionals and improved quality of life and recommended support of a wider roll-out. Increased choice and control for budget holders	Implementation process (C) Increased flexibility, encouraging innovation and creativity, greater person-centered care, and support planning, accessing alternative services or providers of services (M).
Hatton and Waters (2014)	POET Survey 4000 individuals (included 20 NHS organisations) practice-based information.	Experiences of budget holders and carers (separately)	Programme implementers, service users, policy makers, researchers	Yes – (Moderate) Explained in detail how data was analysed. design limitations and lack of depth for example open questions, not specified how themes developed. 30% had support completing the survey but no mention of proxy responses bias.	PHBs had made things better in majority of life areas. People found the process difficult. Variations in delivery and frustration amongst budget holders.	Experiences of the budget processes and impact (C) knowing value of budget. Understanding restrictions placed, information and advice, support. User involvement
Alakeson (2014b)	used data from the in-depth interviews with participant from one of the	Provides insight into PHBs in Northamptonshire over a 5-year period and	16 participants with mental health	Yes – (Moderate) Small sample and Mental health specific, also suffered from	PHBs in mental health improve people's quality of life, wellbeing, and sense of being in control. Choice	PHBs used to meet clinical needs and wider context health needs. Tailor needs to recovery. Seeing purchases considering

	pilot site in the evaluation	summarises approach taken, lessons leant and plan for the future		methodological weaknesses	changes as recovery progresses. Being able to manage health and have improved lives. Greater choice on services offered and who support them. Reduced use of hospital and crisis service. Responsibility and renewed confidence. Inability of PHBs to support people to stay well once they have been discharged to secondary care (O)	outcomes. Significant culture change in the relationship (C) Individuals designing own care packages and support, care planning. Allocation of resources through cluster system, upfront allocation. Training of clinician who are involved in PHB implementation. Process redesign (streamline paperwork) and still maintain relationships. Transformation of primary care to accommodate PHBs.
NHS Confederation (2015)	Policy briefing. Workshop consultation	Ways to allocate funding for PHBs within existing budgets	TLAP, Leaders and managers in clinical commissioning	Yes – (Moderate) Not research but relevant issue to answer research questions.	enable budget holders to make decisions in partnership with professionals and take control of the combination of services which works better for them. (O) Establish eligibility prior to commencing PHB allocation process. Less time-consuming processes to reduce delays in the process (M)	Developing shared plans and understanding of implementing PHBs and managing risks. Practical and cultural way of working different (C); chose an approach to allocation learn and build on it. Allocation that is needs driven rather than process driven. Information on actual cost of implementing PHBs for different groups. Phased implementation to allow system to adjust to the change incrementally. providers to develop services that responds to PHBs and mitigate risks. (M)
TLAP (2017)	POET survey	Online survey, optional printed in accessible formats	Open text responses, numerically recorded Excel and SPSS for	Looked at evidence for self-directed care including PHBs but much	2/3s of respondents IBs made life better in 11 from 15 areas.	Specified more clearly how analysis was undertaken, however open

		10% survey completed during meeting.	non-parametric analysis undertaken.	of the evidence was on social care studies	Over 25% report difficulties in planning processes, (support/amount/planning). Budgets used in community rated higher than traditional services.	questions not specified how themes developed. 30% had support completing the survey, no mention of proxy responses bias 8.7% return. Manifesto from TLAP NB In Control 2010 indicated 30,000 IBs small
Mathers et al (2012)	Position Statement of the Royal College of GP Practitioners	Offer caution and advocates for the outcomes from the pilot sites to be fully evaluated and discussed, and for conclusions concerning the implications for future policy to be drawn, maximise benefits to patients, while mitigating the main areas of risks.	Policy makers and programme implementers	Yes – (Moderate) Opinion paper and not research	PHBs implementation to achieve the appropriate balance of responsibilities for ensuring the clinical effectiveness and quality of services that are purchased. CCGs can manage the impact of the introduction PHBs such as costs and the financial sustainability of existing NHS services. Setting PHBs in line with the principle of the NHS that offers services based on clinical need, free at the point of use. Ensuring that PHBs do not give rise to new health inequalities.	PHBs are developed in line with NHS principles (**C**) Sufficient resources are available to support upfront cost and infrastructure for PHBs. PHBs meet the full cost of care. Patients are fully informed of potential risks associated with PHBs. Top-ups are not used for PHBs. CCGs have frameworks for decision making on what treatments can be purchased. CCGs have flexibility to refuse direct payments where processes are not in place. (**M**)
Alakeson and Rumbold (2013)	Research Summary Used evidence from evaluation pilot and	Describes how PHBs are supposed to work, review evidence	Commissioners and policy makers	Yes – (High)	No. of PHB holders remain low (100). CCGs to be ready to decommission services to allow change and minimise	New infrastructure to support PHBs **(C).** Budget setting, (Key essential features of PHB), care planning, financial monitoring

	personal stories of users	from evaluation and explore issues for commissioners and policy makers		Peer reviewed, not research	risk. Policy makers to be aware of post-code lottery emerging. Potential for efficiency and creating integrated Individual budgets. Individual empowerment. Develop budget allocation that is sustainable.	Decision making remaining in hands of CCG will bring variations in eligibility, value, and availability of PHBs to particular conditions. Clinical sign-off on care plans to manage risk, PHB implementation process (7 step) **(M)**
Glasby et al., (2013)	Policy Paper	Explores what comprises of valid evidence for the future of PHBs	Healthcare professionals, researchers, and policy makers	Yes – (Moderate) Policy briefing	Respecting the expertise of patients. PHBs to be viewed as a 'tipping the balance' of power from clinicians towards patients, while maintaining partnership working. Change of focus to outcome.	Self-direction becoming a reality in the NHS. (**C**) Acknowledgement of the role of patients in identifying what works for them. Change in focus from a deficit perspective to seeing patient as having assets and expertise. PHB holders know how much money is available upfront. Scope in the budgets for creative and flexible in meeting needs. PHBs are truly personal.
Slasberg et al. (2014)	Peer review paper.	Critically reviews the evidence used by government to justify the roll-out of PHBs.	UK govt, healthcare systems implementing PHBs and policy makers.	Yes – (Moderate) Reviewed evidence to support critique.	PHBs place patients at the center of decisions about the health services they receive to improve efficiency and make the service more responsive to the needs of patients.	The context of pilots different to roll out and unlikely to be repeated. Allocating resources based on needs in a cash constrained system. Knowing the budget upfront. Pilots were fully resourced which PHBs are not. (C.) flexibility through

					potential for PHBs to weaken the service through confused process and practice and more bureaucracy. Upfront allocation not seen as key to PHB outcomes (O)	partnership working (M). Freeing up resources. Framework for allocation. Moving away from block contracts and using cash. Cost towards reconstruction of service (M)
Gadsby (2013)	Personal Budgets and Health: a review of the evidence Literature Review 280 papers including evaluation reports, (n=9), accounts of empirical research, (n=29), comparative studies, (n=14)	Web of Knowledge, MEDLINE, the Cochrane Library, Google Scholar, the WHO library, and Health Management Information Consortium 2008-2012 Terms: personal health budgets, personal budgets, individual budgets, 384individualized budgets, 384 individualized funding, cash for care, direct payment, consumer-directed care and	Practice, researchers, and Policy makers-	Yes – (High) Strong presentation of international schemes including PHBs, development, and features	Most studies lack rigour in terms of empirical method or criteria, Supports findings of Forder *et al.*, Glendinning, Shen *et al.* that no direct evidence of to link PHBs to improved health outcomes. cost containment and dissatisfaction with current provision were central aims for most of the studies. Schemes also were aimed at increasing consumer choice, autonomy, and satisfaction. Suggests also that proxy sources of evidence linked to patient activation and control of health have positive health correlation.	Highlighted that contextual differences such as programme design, value of budgets and implementation processes which make it difficult for comparison between autonomy and improved health to be drawn. Also, long-term views missing. The meaning of choice and control and what it translated to in practice was not Known. Mechanisms: personalised care planning, addressing an individual's full range of needs, having access to the money.

		cash and counselling				
Alakeson et al (2016)	Peer review and used vignettes	Extend the debate on the use of PHBs and their value in mental health services	Mental health	Yes – (Moderate) Peer reviewed, not research	Opinion on PHBs is divided. Manage ongoing condition, reduce inpatient use and crisis care. Bad choices can increase risk and exhaust their PHB without needs being met (RF). Create dependency, sense of entitlement. May be difficult to maintain community mental health teams for non-PHB users. Increase inequality Supporting people to have choice and control through PHB can be an effective way to increase a sense of personal control and opportunities (O)	Making choices on treatments that are not recommended by clinicians (C) investment in the infrastructure for PHBs. Conflict and risk Engagement during care and support planning. Working in partnership to minimise risk. Arbitrary decision making, increased bureaucracy (M)

Appendix 8 – Visual Mapping of Realist Review Themes and CMOs

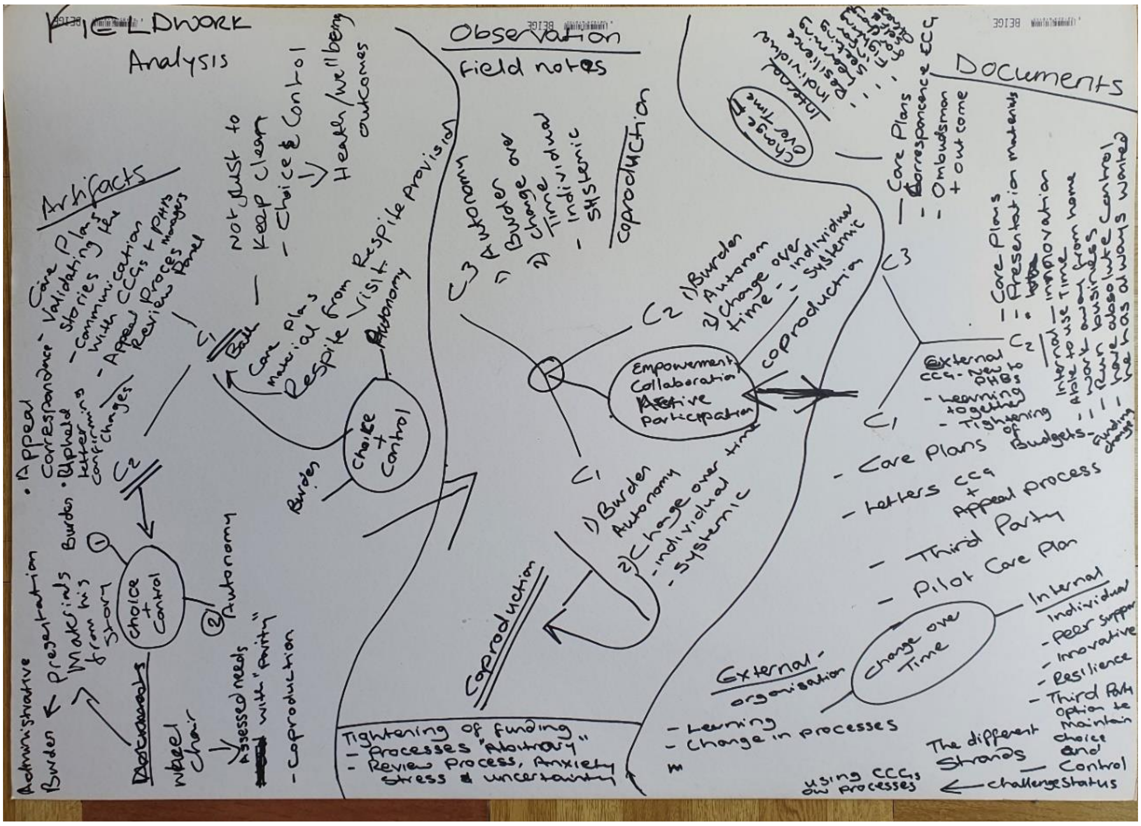
Appendix 9– Example of how CMOs were Coded analysed for Realist Synthesis to inform logic Framework (presented in Fig. 3 P73.)

Context			**Mechanisms**		**Outcome**	**Codes**
Levels	**Themes**	**Context in which they operate**	**Reasoning**	**Resourcing**		
Macro Level						
Meso						
Micro						

Thematic coding and sequencing of CMOs adapted from Weich et al (2019, p114) to suit this study

Appendix 10– Fieldwork Analysis

3 (a) – Iterative Process (Thematic and CMOs Informed by Realist Synthesis)



Appendix 11 – Examples of how Some of the CMOs were Confirmed or Refuted

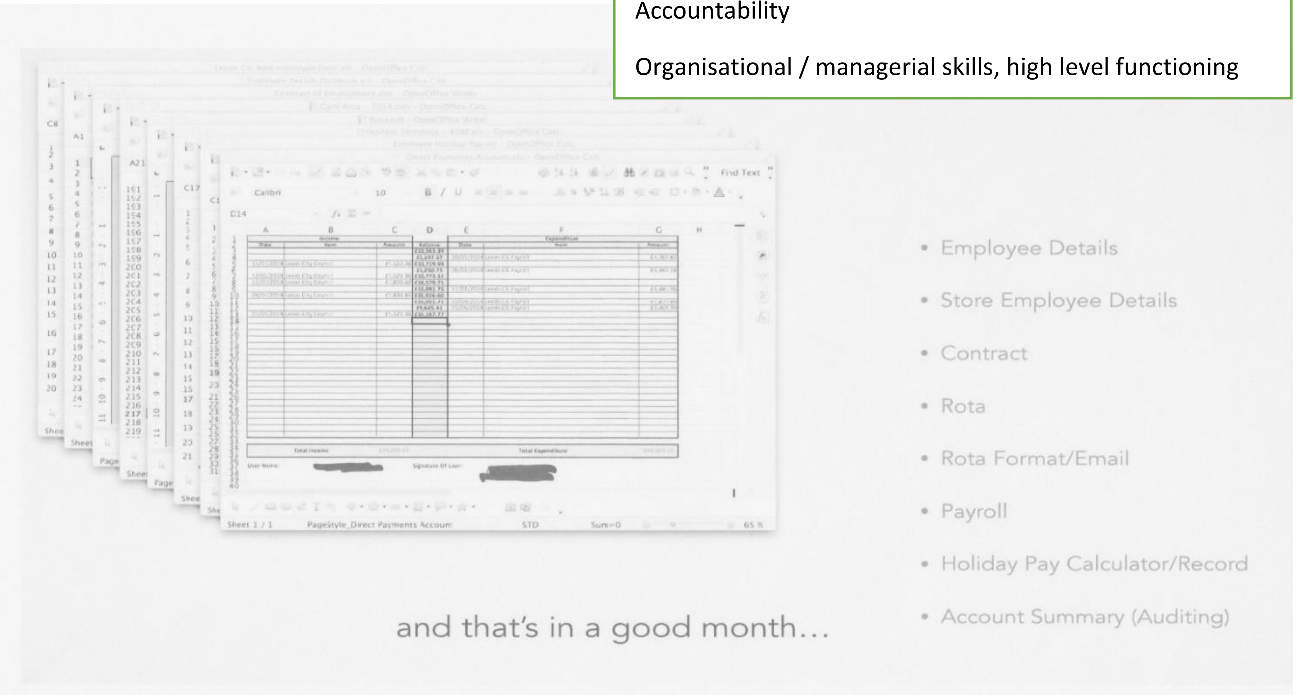
Choice as Burden – document illustration by the participant – collected during fieldwork.

Administrative burden **my notes**

Employment responsibility

Accountability

Organisational / managerial skills, high level functioning



- Employee Details
- Store Employee Details
- Contract
- Rota
- Rota Format/Email
- Payroll
- Holiday Pay Calculator/Record
- Account Summary (Auditing)

and that's in a good month…

SOUNDS EASY, NO?

- Organisation
- Paperwork
- Responsibility
- Insurance
- Laws

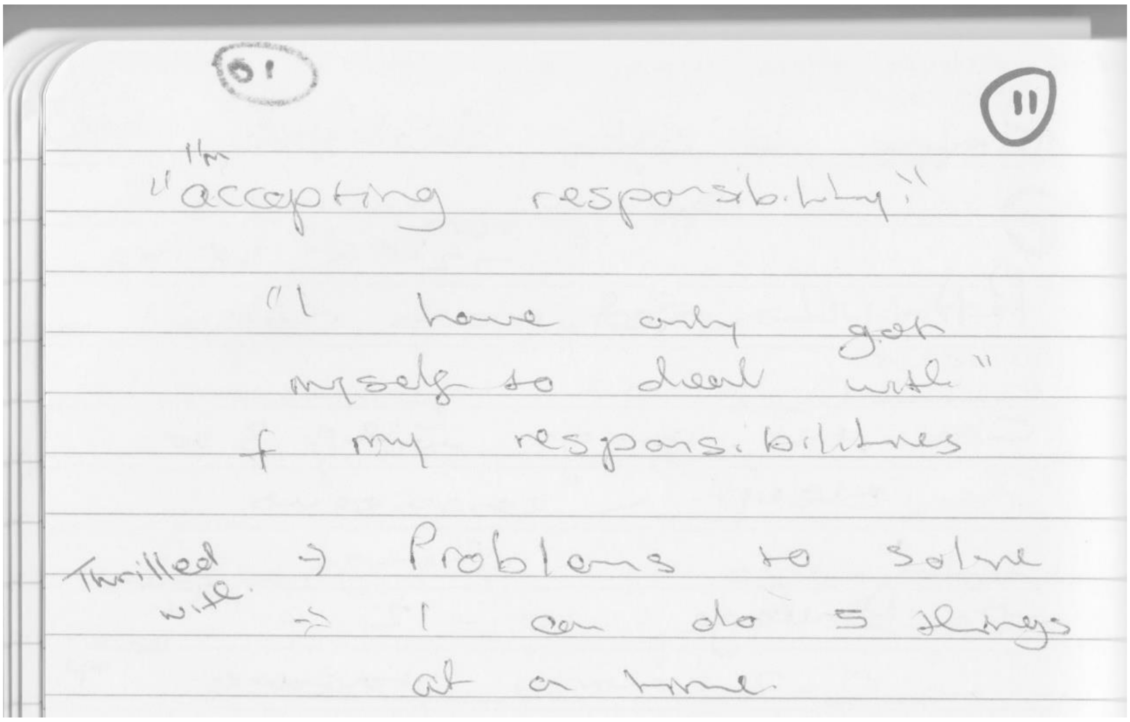
My analysis

Drowning in paperwork

Administrative burdens- **M**

Responsibilities - (do PHBs have to that or there may be simpler ways? Processes – sustainability?)

Appendix 12 – Continued - Example of Fieldnotes & Thematic Analysis



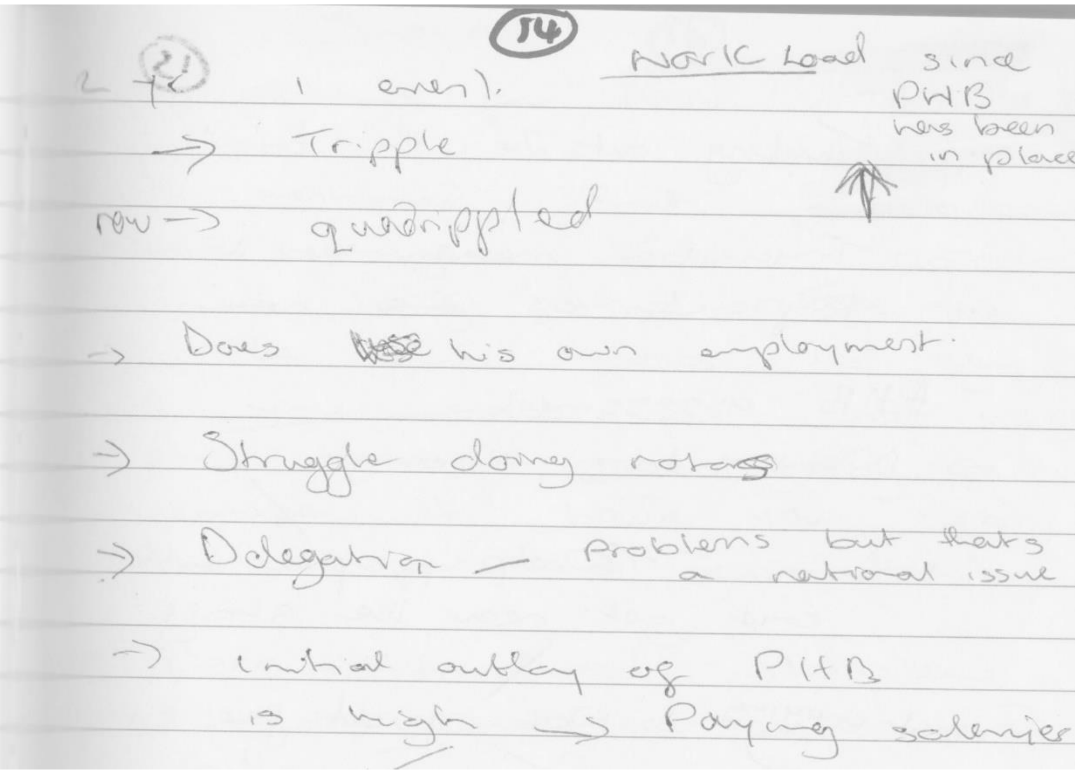
01

11

I'm
"accepting responsibility"

"I have only got myself to deal with"
+ my responsibilities

Thrilled with. → Problems to solve
→ I can do 5 things at a time.



J4

21

2 yrs 1 even).

Work Load since PHB has been in place ↑

→ Tripple

now → quadrippled

→ Does his own employment.

→ Struggle doing rotas

→ Delegation — problems but thats a national issue

→ initial outlay of PHB is high → Paying salaries

Appendix 13 – Analysis of Choice and Control Outcome (Internal v External)

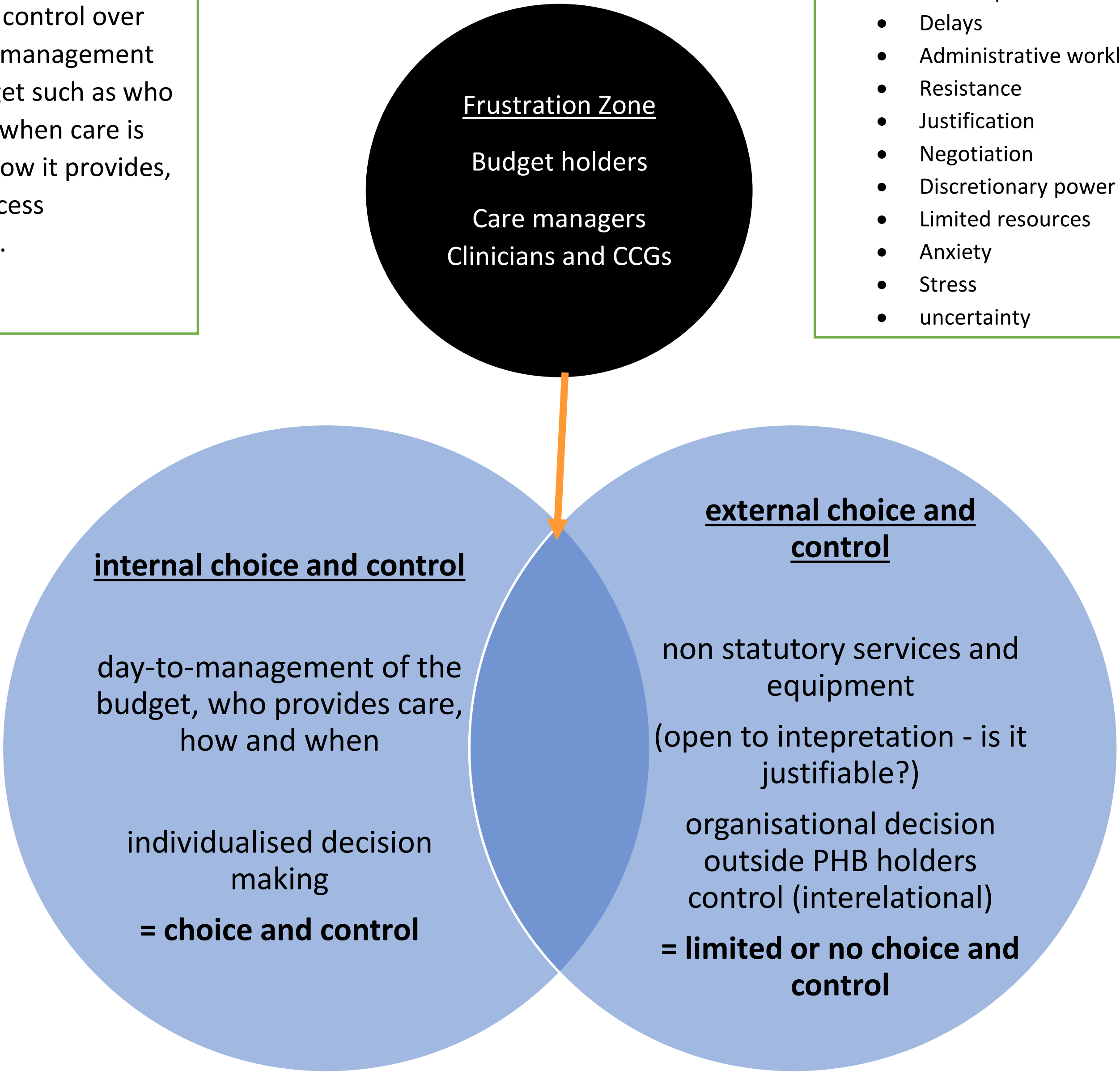
Choice and control as autonomy and burden

Autonomy

Choice and control over day-to-day management of the budget such as who to employ, when care is provided, how it provides, when to access community.

Burden – transactional cost associated

- Power struggle
- Review process
- Delays
- Administrative workload
- Resistance
- Justification
- Negotiation
- Discretionary power
- Limited resources
- Anxiety
- Stress
- uncertainty



Frustration Zone

Budget holders

Care managers
Clinicians and CCGs

internal choice and control

day-to-management of the budget, who provides care, how and when

individualised decision making

= choice and control

external choice and control

non statutory services and equipment

(open to intepretation - is it justifiable?)

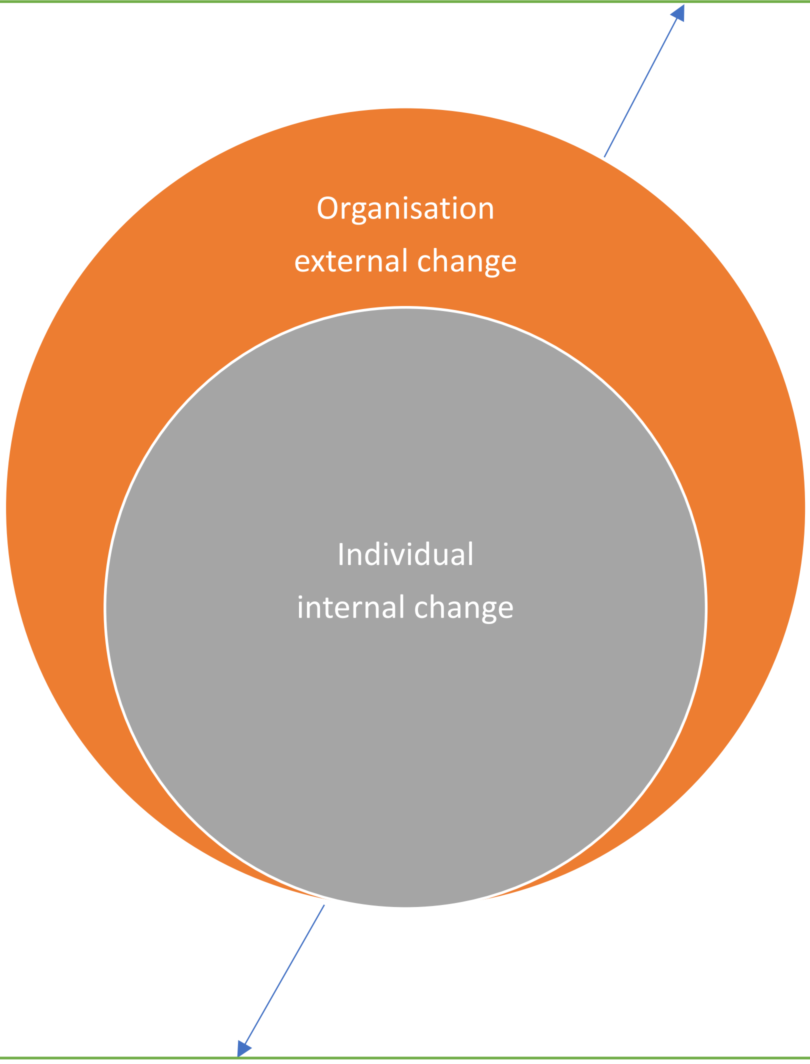
organisational decision outside PHB holders control (interelational)

= limited or no choice and control

Appendix 14 – Analysis of Change Over Time (Contribution to Theory Building)

External changes – local managers, clinicians, and CCGs

Focus changed from cost to offering choice and control, pilot of care plans that are holistic, coproduction – user involvement, shared decision making, better engagement, increased cost short-term, possible deprofessionalisation of DN, loss of training ground, reduced cost long-term, PAs taking roles with more responsibility etc. risks and safeguards, improved attitudes and culture change, willingness to learn, enabling systems and processes, willingness to accommodate PHBs amidst funding constraints, allowing innovations that are not conventional improved PHB implementation process. **Wider context outcomes**



Internal changes -Individual and collectively

Challenge existing practice, organising peer support, shared learning, collective bottom- up demand, empowerment, force for systemic change, culture change (active participation), building of resilience, improved skills (negotiation and interpersonal skills -improved articulation of needs)

Outcomes

Choice and control for individuals, positive experiences, improved wellbeing

Appendix 15 – Example of Analysis of CMOs -Fieldwork Data

CONTEXT **Being able to use money in ways that make sense to PHB holders**		**MECHANISMS**		**OUTCOME**
CMOs and linked to overarching Theme/ CMO 1	**themes**	**Reasoning**	**Resourcing**	
C2S- CMOs 1- Delivery Mechanisms **C2S- CMO 2- Recruitment of PA**	- **Management of long-term conditions** direct Payment autonomy to employ on PAs and increased choice and control of budget burden that comes with administrative responsibility, accountability and risks associated. Skills to manage both the administrative tasks and dynamics of employer and	Having adequate funding and availability of resources to purchase Ways of managing money to suit-individual capability Being able to use the budget in ways that make sense Budget holders having the flexibility to purchase items they feel will improve health and well-being using their allocated budgets Being innovative with the budget and save money and allowed to use the money to purchase other services they feel will further improve their health and well-being	CCGs having adequate resources and not cut back on services Increase in the availability of resources to purchase Budget holders having choice and control as to what items they could purchase with their budget and not having to seek authorisation from CCGs for every item or additional resources rationing and prioritising resources were key elements in accessing resources that promoted or hindered choice and control.	A. Increased choice and control over day-to-day management of the budget resulting in improved psychological, health and wellbeing outcomes Limited choice and control over use of resources Budget holders feeling penalised for having taken on PHBs and for being innovative Long-term impact and sustainability limited Increased choice and control over day-to-day management of the budget resulting in

C2S- CMO 3- Purchase of Equipment **C2S- CMO 3- The review or panel (as known by PHBs holders)**	employee as well as being the dependent person. Emotional capacity and intelligence to handle those dynamic of the relationship. Thinking and deciding the various ways on which money could be spent to improve health and well-being A crucial process of safeguarding, and strengthening the person’s ability to achieve the outcomes they want with their PHB -annual appraisal of health and well-being needs	Budget holders required to do a lot of justification for their choices CCGs not taking away resources where there has been improvements and savings	Accessing appropriate care and support services Accessing PAs, Accessing community services Purchasing treatments and equipment PHBs competing with other local priorities in resources constrained environment and seen as less of a priority. Use reviews to judge the effectiveness of care and support plans, safeguarding, and strengthen the person’s ability to achieve the comes they want with their PHB rather than a rationing process to save money. PHBs were subject to regular reviews (annual and unscheduled reviews) to ascertain if the individual was still eligible for funding. Incentivise those individuals who have been innovative with the budget and saved money Review process that promotes sustainability of PHBs	improved psychological, health and wellbeing outcomes PHB holders feeling penalised for having taken on PHBs and for being innovative Long-term impact and sustainability of PHBs limited Frustration with the system Increased anxiety, uncertainty, fear Increased responsibility, accountability, and risks Efficient/ inefficient use of resources perceived as challenging to professionals The review process appeared to be a good time to ration resources, limiting choice and control and undoing the gains made in well managed care, bringing into question, the level of buy-in into PHBs amongst professionals **Rival framing of theory**

	- identify vulnerability and safeguards -monitoring and strengthening		Putting in place information, advice, and support for budget holders to understand the review process and purpose. Purchase of non -conventional treatments and innovation CCGs having adequate resources and not cutting back on services. PHBs competing with other local priorities in resources constrained environment and seen as less of a priority.	Limited choice and control over use of resources The review process appeared to be a good time to ration resources, limiting choice and control and undoing the gains made in well managed care, bringing into question, the level of buy-in into PHBs amongst professionals. With limited resources, PHBs may become less of a priority and unsustainable. PHBs becoming a burden to budget holders Budget holders feeling penalised and not maximising choice and control and innovation Budget holders anxious of having to live with the uncertainty and the stress which the review process brought.

Thematic coding and sequencing of CMOs adapted from Weich et al (2019, p114) to suit this study