Designing Socio-technical Responses with Disabled Citizens and their Unpaid Carers for Enhanced Access to Personal Health Budgets

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Abstract

Over the past decade, the field of Human-Computer Interaction (HCI) has attended to the experiences of unpaid carers, specifically, the challenges they face in integrating siloed healthcare systems. Such challenges have been found to be exacerbated for those individuals with long-term complex conditions and their unpaid carers when they receive Personal Health Budgets' (PHBs). PHBs are one aspect of a personalised care model in the global north, designed to offer individuals with long-term complex conditions and their unpaid carers the flexibility to tailor healthcare services to fit their personal needs and preferences, aiming to enhance their autonomy and improve overall wellbeing. However, the pragmatic application of PHBs within neoliberal service provision raises questions concerning the offloading of labour and responsibilities onto an already marginalised and underserved population. HCI has yet to investigate the impact of such budgets on disabled citizens and unpaid carers, on how research can contribute to service design and policymaking for PHBs and, explore how Participatory Design (PD) can be configured to engage with this time-constrained population characterised by their priority of caregiving.

This study examines the experiences of disabled individuals and their unpaid carers, and how participatory engagements can support their ongoing efforts to improve access to the benefits of PHBs.

A mixed-methods approach was taken to engage with 64 participants, comprising disabled citizens, unpaid carers, voluntary sector staff, and healthcare officials. Participatory methods, including longitudinal asynchronous / synchronous remote group engagements, were used to develop understanding of their challenges and facilitate the co-creation of a sustainable digital common-pool resource.

I describe and evaluate how the resource, "MyCareBudget", was co-designed with the citizen participants to provide peer-produced care documentation for recipients of PHBs and has been in use since 2021, serving over 5,500 individuals globally.

The research contributes innovative configurations of methodologies and tools for engaging with this population, and insights regarding relational care, invisible labour, power dynamics with authority figures, and the pursuit of socio-technical capability.

I discuss implications for HCI concerned with the creation of more effective and equitable healthcare responses for marginalised communities, including challenges at play in coproduction, appropriate engagement methods for the co-design of sustainable socio-technical interventions, and conceptual frameworks for their assessments.

For Helen. This would not have been possible without you.

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This study centred on participants who were disabled citizens with long-term complex needs and unpaid carers of disabled children with long-term complex needs. These participants were always keen to engage and happy to take part in whatever crazy-seeming design method I was trying out. Thank you. It has been a journey, and I am humbled that you came along for the ride. A VCSE organisation is now funding the digital commons that was co-created within this study, the directors were with me all the way and so deserve a special thank you.

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Chapter 1. Introduction

1.1. Prelude

"I was his carer, now I'm his care home manager. I want to be his mum" -
Amelia, mother of a profoundly disabled child.

The above quote, sourced from an interview conducted later in this study, serves as an illustration for the motivation and context for this doctoral research.

The vignette begins with Amelia[1], a mother who has cared for her disabled son night and day for the first 17 years of his life. Her role as an unpaid carer has subjected her to sleep deprivation, social isolation, and intense and enduring stress.

Her life shifted when she discovered she was eligible for a Personal Health Budget (PHB) from the National Health Service in England (NHSE). This budget provided her with the funding to employ a team of paid carers to assist in the care for her son, allowing her respite and the benefit of choice and control in his care. The unexpected consequences for Amelia were that she became accountable and responsible for all aspects of employing paid carers and administering a substantial budget. Her duties ranged from recruiting, interviewing, training, and managing staff to procuring equipment, performing risk assessments, and undertaking financial audits. Amelia found herself fighting against her healthcare authorities to maintain her paid carers' pay rates to attract new staff and to justify all expenditure. In essence, she had been tasked with the roles of a chief executive, human resources director, and financial director of what equated to a residential care home - working alone and without support from her healthcare authorities.

Amelia's wish to be 'simply' a mother to her child is a seemingly unobtainable aspiration. While the state in England provides funding for her son's care, it steps back from taking on the responsibilities or financing of the operational aspects of managing a care team, which would free Amelia to focus on her maternal role.

This doctoral research on managing PHBs aims to explore how Human-Computer Interaction (HCI) might inform the design of supportive tools for unpaid carers, like Amelia, who

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[1] A pseudonym.

manage a PHB on behalf of a disabled citizen, and for those disabled citizens that can manage their own PHB. In what follows, I provide a description of this study's context - personalised care in the United Kingdom (UK) - and then position this research within HCI.

1.1.1. The Personalised Care Paradigm

This longitudinal study centres on disabled citizens who require intensive and enduring care and the unpaid carers who support them. These are citizens with, for example, profound learning disabilities, cerebral palsy, spinal injury, genetic disorders, and multiple sclerosis.

In the UK, care is increasingly delivered through a personalised care paradigm (Jones *et al.*, 2010), designed to account for an individual's preferences when planning and providing healthcare. This model, also adopted in other countries in the global north (Gadsby, 2013), seeks to enable citizens' control of their healthcare.

For those that require the highest levels of care, the topic of this study, the personalised care model allows them to arrange their care through 'self-directed care budgets', known as PHBs in the United Kingdom (UK) (Jones *et al.*, 2010; NHS England, 2019a). PHBs have been designed to provide citizens with agency over their care services, enabling them to "use the money to meet their outcomes in ways and at times that make sense to them" (NHS England, 2019a). A method for delivering this budget is to hand the funding directly to the disabled citizen or their unpaid carer as a 'direct payment' (Jones *et al.*, 2010), allowing them to recruit and manage paid carers who align with their personal values, preferences, and life choices.

However, these budgets place responsibilities on the citizen, both to procure care and to deploy the care efficiently on behalf of the state - this receipt of care forming a democratic process (Glendinning *et al.*, 2008; Tyson *et al.*, 2009; Alam and Houston, 2020). No matter how well-meaning PHBs are, the responsibilities are onerous, assigned onto the citizen within a neoliberal market, the state stepping back from providing support (Owens, Mladenov and Cribb, 2017). As a consequence, the citizen is faced with the burden of planning and procuring their care, together with the ensuing financial and legal duties, privileging those empowered as a result of their intersectionality, such as that from gender, ethnicity, and class (Beer, Paxman and Morris, 2013; Slasberg *et al.*, 2014; Mladenov, Owens and Cribb, 2015; Owens, Mladenov and Cribb, 2017).

PHBs further impact on healthcare professionals, who work under a regime of restrictive management and budget constraints, where the handing of choice and control to the citizen has removed these functions from frontline staff, decreasing their roles to those of budgetary gatekeeping (Owens, Mladenov and Cribb, 2017).

1.1.2. HCI's Attention to Unpaid Carers

HCI's contribution to supporting the needs of marginalised populations in healthcare extends to various contexts. These have included the support of ageing family members (Bouma *et al.*, 2004; Durick *et al.*, 2013; Vines *et al.*, 2015; Righi, Sayago and Blat, 2017; Kakera *et al.*, 2023; Li, Arnold and Piper, 2023); individuals with dementia (Piper *et al.*, 2016; Morrissey *et al.*, 2017; Morrissey, McCarthy and Pantidi, 2017; Unbehaun *et al.*, 2018); autism (Albinali, Goodwin and Intille, 2009; Li *et al.*, 2018); mental health problems (Yamashita *et al.*, 2013; Topham *et al.*, 2015; Lattie *et al.*, 2020; Siddiqui *et al.*, 2023); and self-management of chronic conditions (Mamykina *et al.*, 2008; Eschler *et al.*, 2015; Nunes *et al.*, 2015; Park and Chen, 2015; Bhat *et al.*, 2023; Sepehri *et al.*, 2023).

This corpus of work is founded on the interdisciplinary nature of HCI that provides a holistic approach to technology, focusing on human needs and interactions to ensure that research outcomes are technically sound, accessible, and critically for this thesis - socially relevant (Hartson, 1998). Founded in computer science but drawing on and contributing to fields that include sociology, psychology, policymaking, and healthcare services amongst others (Singh *et al.*, 2017; Manuel and Crivellaro, 2020), HCI demonstrates "ways of deploying and engaging with knowledge in a technological setting" (Blackwell, 2015).

However, attention to the unpaid carers of family or friends who require intense and enduring care is less well studied. However, HCI has devoted research in the last decade to understanding and designing for the unique responsibilities and challenges of home-based unpaid care. This growing field of study gains significance when considering the increasing population of disabled citizens and hence their carers (World Health Organization, 2017; National Alliance for Caregiving and AARP, 2020; Office for National Statistics, 2022).

Chen, Ngo, and Park (2013) interviewed unpaid carers to understand their behaviours as a means to generate design implications, asking for health and wellbeing designers to consider their impact on the individual. Tixier, Gaglio, and Lewkowicz (2009) looked to technology to provide social support, with Ammari and Schoenebeck (2015) finding that social media facilitated unpaid carers of children with complex needs to make sense of their healthcare infrastructure. Others have found unpaid carers are typically left to manage end-to-end care without support, forced to build personal infrastructures that stitch together the multiple, siloed healthcare service providers they depend upon (Chen, Ngo and Park, 2013; Yamashita *et al.*, 2013; Nunes *et al.*, 2015; Park and Chen, 2015; Miller *et al.*, 2016; Gui, Chen and Pine, 2018; Tang *et al.*, 2018; Gui and Chen, 2019; Bhat *et al.*, 2023). Bosch and Kanis (2016) further investigated how HCI can support unpaid carers, concluding that any design response must be co-developed in close collaboration with the unpaid carers.

Such design collaborations with unpaid carers and disabled citizens are an important and growing theme in HCI. Research has focused on the inclusion of disabled citizens and their unpaid carers in the design of systems that are to benefit them and for the design to be centred around their matters of concern (Karasti and Baker, 2008; Sanders and Stappers, 2008; Björgvinsson, Ehn and Hillgren, 2010, 2012; Harrington, Erete and Piper, 2019).

1.1.3. HCI's Use of Research Methodologies and Approaches with Unpaid Carers

HCI's participatory processes, and in particular Participatory Design (PD), have played an important role for citizens seeking to improve service from the state, as they stimulate ownership, political engagement, mutual learning, and development of participants' skills (Taylor *et al.*, 2013; Spade, 2015; Poderi and Dittrich, 2018; Manuel and Crivellaro, 2020; Hamm *et al.*, 2021).

Yet, research in this area has seen challenges. HCI has highlighted issues of access, equity, and power dynamics when engaging with this marginalised population in design processes (Light and Akama, 2012; Harrington, Erete and Piper, 2019; Bates *et al.*, 2020; Clarke *et al.*, 2021; Cook, 2021). Further, researchers can struggle to understand these unfamiliar, complex ecosystems, potentially leading to misguided assumptions and ineffective interventions with negative consequences (Suchman, 2002; Williams and Gilbert, 2019; Shew, 2020).

Moreover, the sustainability of HCI interventions designed for marginalised populations has also been problematised (Silberman, 2015; Sun, McLachlan and Naaman, 2017; Poderi and Dittrich, 2018; Bettega, Masu and Teli, 2021). Sustainability becomes a concern given the short-term nature of university research projects and HCI work. These bounded by funding cycles that focus on the design of novel products, rather than democratic considerations for the learning and empowerment of participants (Taylor *et al.*, 2013; Olivier and Wright, 2015; Bødker and Kyng, 2018).

The study further looks to Digital Civics with its ethos of citizens' democratic participation with public services (Crivellaro *et al.*, 2014; Olivier and Wright, 2015; Corbett and Le Dantec, 2019) and the configuration of safe design spaces for the co-creation of socio-technical resources that allow a community to flourish (Crivellaro *et al.*, 2019). Indeed, with my participation in the Digital Civics Centre for Doctoral Training at Open Lab within Newcastle University (Olivier and Wright, 2015), I was immersed in community participation and personally committed to a long-term engagement, working with communities to design for their benefit.

1.1.4. Context of This Study

The topic of self-directed care budgets, together with their impact on a citizen's personal healthcare infrastructuring, is new to HCI, excepting the papers arising from this project (Glick, Clarke and Crivellaro, 2022; Glick and Crivellaro, 2023). It is within this context that the study is located, responding to HCI in its call for an increased understanding of patient engagement and empowerment in relation to their healthcare systems (Kaziunas, Klinkman and Ackerman, 2019).

1.2. Motivations for Research

My positionality as an unpaid carer and co-holder of a PHB for a family member with long-term complex needs provided a personal motivation. Further, this allowed a novel perspective to the research, a trust that facilitated the recruitment of PHB holders, insights to enhance the configuration of engagements, and an appreciation of this context that an outsider would find difficult to attain.

My motivation led to a desire to support PHB holders, to intervene in the power dynamics at play between the budget holder and their state healthcare authorities, and to add to HCI literature regarding PHBs and their equivalents around the globe.

A discussion of my positionality is offered in section 3.2.1.

1.3. Research Aims and Questions

The aim of this study has been to investigate how HCI can deliver positive, meaningful, and sustainable support to disabled citizens with long-term complex needs and their unpaid carers. This in the context of the infrastructuring work they perform to realise benefit from their PHBs within the personalised care paradigm in operation in England.

An overarching research question directed this study,

> ***Main Research Question:*** *How might HCI support disabled citizens with long-term complex needs and their unpaid carers to the challenges in managing Personal Health Budgets?*

Three research sub-questions supported the main question. First,

> ***Research Sub-Question 1:*** *What are the experiences and practices of holders and providers of Personal Health Budgets?*

This first empirical research sub-question acts as a guide for this study. Previous HCI studies have detailed the lives of unpaid carers (Mamykina *et al.*, 2008; Tixier, Gaglio and Lewkowicz, 2009; Yamashita *et al.*, 2013; Nunes *et al.*, 2015; Park and Chen, 2015; Miller *et al.*, 2016; Tang *et al.*, 2018; Bhat *et al.*, 2023), finding infrastructuring duties placed upon them by their healthcare providers (Chen, Ngo and Park, 2013; Bosch and Kanis, 2016; Gui, Chen and Pine, 2018; Chen *et al.*, 2019; Gui and Chen, 2019; Schurgin *et al.*, 2021; Shin *et al.*, 2021). HCI has yet to examine, i) the power dynamic between unpaid carers and their state healthcare providers, ii) how self-directed care budgets impact their lives, and iii) how these budgets impact on a disabled citizen who takes on their own infrastructuring work.

Early findings from this first research sub-question were planned to guide responses to the methodological second research sub-question,

> ***Research Sub-Question 2:*** *What methods are required to engage effectively with disabled citizens with long-term complex needs and their unpaid carers that account for and are respectful of their lives of caring?*

This second sub-question is based on the need for a configuration of participation for disabled citizens and their unpaid carers that accommodates for their care-prioritised lives, which inhibit face-to-face group engagements.

A final methodological research sub-question examined one response to the main research question, a healthcare digital commons. The intent here was to create a method that can determine the worth of a socio-technical intervention in healthcare to its end-users,

> ***Research Sub-Question 3:*** *How might a socio-technical response in a healthcare context be evaluated for its usefulness and sustainability?*

1.4. Thesis Structure

This thesis comprises nine chapters with four Action Research (AR) cycles that together respond to the above research questions - see Figure 1.

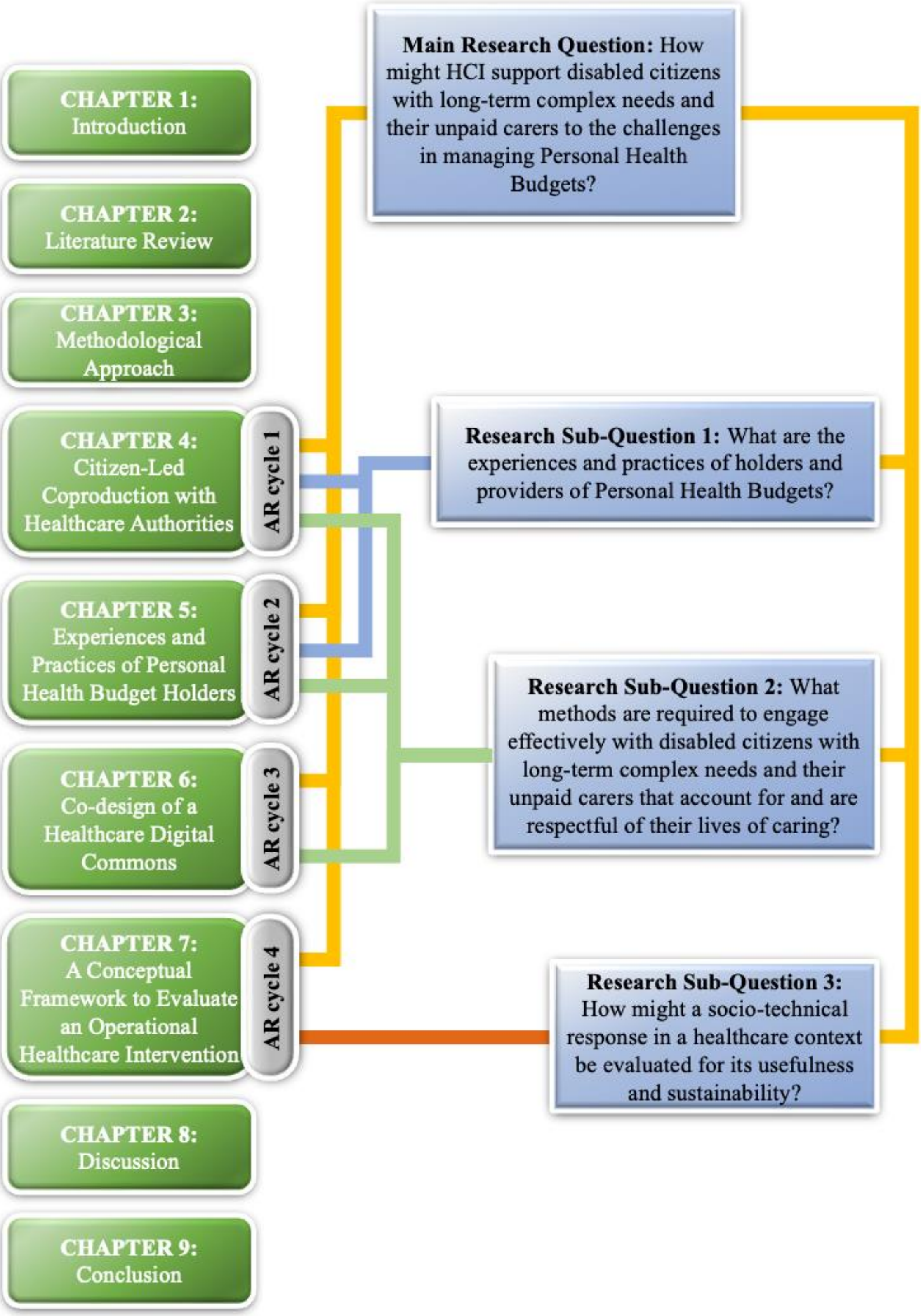

Figure 1: Mapping of chapters, AR cycles, and research questions

The literature review in Chapter 2 focuses on citizens' infrastructuring work demanded for disabled individuals with long-term complex needs and their unpaid carers within a personalised care paradigm. To begin the discussion, the broad topic of caring is introduced, offering literature that surfaces the need for relational caring for long-term needs, why this caring typically takes place in the home, and the impacts of this caring work. The chapter then progresses to examine the concepts of infrastructures (Star and Ruhleder, 1996) and infrastructuring (Pipek and Wulf, 2009), their roles in healthcare, and how HCI has studied these in relation to unpaid carers (Chen, Ngo and Park, 2013; Long *et al.*, 2017; Gui, Chen and Pine, 2018; Chen *et al.*, 2019; Schurgin *et al.*, 2021; Bhat *et al.*, 2023). The final section explains how a personalised care paradigm can deliver the need for relational caring. This paradigm arose from disability justice movements that formed a social model of disability (Union of the Physically Impaired Against Segregation, 1976) in response to the medical model that was dominant up to the 1980s in the global north (Frauenberger, 2015; Shyman, 2016). The chapter ends with how PHBs, which can provide funding direct to those needing long-term care (Gadsby, 2013), bring the potential for choice and control (Forder *et al.*, 2012) but demand personal infrastructuring that can restrict their use to those citizens with the necessary social capital (Owens, Mladenov and Cribb, 2017).

Chapter 3 delivers the research paradigm for this study, one of a critical realist approach (Frauenberger, 2015) that leads to a constructivist philosophy (Frauenberger, 2020), in part stemming from my positionality where I witnessed differing beliefs between unpaid carers and healthcare authorities. As the focus of this research is on activities of caring, the theory of care ethics is introduced (Fisher and Tronto, 1990; Tronto, 1998), explaining its qualities and how these assist with this research. Two core methodologies are then discussed that are foundational for this study. First, Action Research (AR) (Hayes, 2011) and how it aligns with the research paradigm, offering a structure for forming and managing this research in cycles comprised of planning, acting, and reflecting. A further facet of AR that is key to supporting the marginalised population of this study is that of sustaining research outcomes, with a section providing a discussion on the challenges to HCI in achieving this, along with potential mitigations. Participatory Design (PD) (Spinuzzi, 2005) is the second methodology employed, its sharing of power with participants (Harrington, Erete and Piper, 2019) and associated elevation of their role to one of collaborator, crucial to researching with disabled citizens and their unpaid carers. The shift of PD at the end of the 20th century away from its political roots is responded to with the use of new PD (Bødker and Kyng, 2018), which focuses on participants' social and political lives beyond the research project. Research designs are then introduced, examining how HCI has worked with marginalised populations, the use of "respectful design" (Rajapakse, Brereton and Sitbon, 2021), and the Asynchronous Remote Communities (ARC) method (MacLeod *et al.*, 2016) to address issues of engagement. The chapter ends by discussing coproduction, where groups of citizens work with their service providers to deliver change, and commoning, where citizens can work independently of their providers to create a digital commons.

The following four chapters embody the four cycles of AR within this study. An end-to-end timeline for these is presented in Figure 2, which shows the cycles' sequential but overlapping nature, with two research outcomes remaining in operation: a Community of Action and a digital commons named "MyCareBudget". Within these AR cycles, 52 interviews, 15 group meetings, and three surveys were performed with 51 disabled citizens and unpaid carers, 10 state healthcare officers, and three Voluntary Community and Social Enterprise (VCSE) staff - see Appendix A.

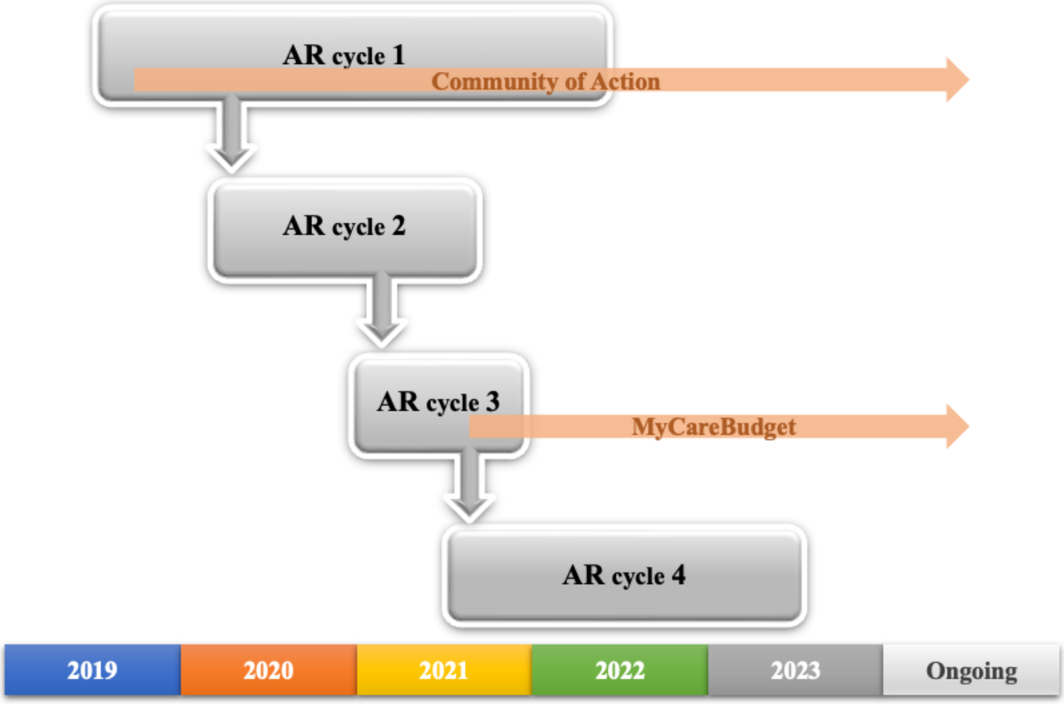

Figure 2: End-to-end project timeline showing the four AR cycles

The first AR cycle described in Chapter 4 responds to the main research question and research sub-questions 1 and 2 by working with unpaid carers who care for their children with long-term complex needs. One-to-one semi-structured interviews delivered an initial exploration of their lives of caring, pointing to the use of the ARC method for group engagements but reconfigured and extended with optional synchronous sessions. Following the interviews, I co-created a Community of Action (CoA) (Zacklad, 2003) with a group of unpaid carers local to the North East of England, of which I was a member. Our aim was to work in coproduction with local healthcare authorities to share understandings of our lives as unpaid carers and the infrastructuring issues with PHBs. Then, to work with the healthcare authorities in their role as service providers to ameliorate and alleviate the issues. Although the CoA was successful as a community and continues to this day, the coproduction failed to deliver apparent change, with little engagement from the authorities.

This led to AR cycle 2, as described in Chapter 5, where a wider group of unpaid carers from across England, together with disabled citizens, a VCSE organisation, and healthcare officers, were engaged to gain an additional understanding of their experiences and practices. The revised ARC method from AR cycle 1 was extended to form a continuous two-week focus group that was remote, asynchronous / synchronous, and text-only. The power dynamic at play meant the citizen participants were apprehensive of healthcare officers attending, so the officers were excluded from this focus group and the group engagements of the next AR cycle.

Chapter 6 describes AR cycle 3, where a decision from AR cycle 2 was taken forward into a co-design process for the co-creation of a digital commons, named MyCareBudget - an online repository of peer-produced care documents required to manage a PHB. Five co-design sessions were held, building on the reconfigured and extended ARC method with novel engagement tools that supported the need to elicit requirements, gain feedback on detailed design and prototypes, and discuss governance. An educational agenda that began in AR cycle 1 was extended in this cycle, as there was minimal awareness and experience within the participants of designing technology and concepts such as the governance of a digital commons.

The final AR cycle, as described in Chapter 7, evaluated the operational digital commons created in the previous cycle. HCI literature is rich in technology testing (Dix *et al.*, 2003, pp. 35–36; Klasnja, Consolvo and Pratt, 2011; Liebel, Alegroth and Feldt, 2013; Suman and Sahibuddin, 2019), but little exists to guide how to evaluate a publicly available digital commons (Morell, Salcedo and Berlinguer, 2016), none for one dedicated to healthcare. Hence, this chapter presents a novel, mixed methods conceptual framework that allows healthcare-related software to be evaluated for usefulness and sustainability. The framework is founded on concepts of usability, usage, sustainability, and caring, which lead to a set of mixed methods data collection points and analysis. When applied to MyCareBudget, the framework showed that MyCareBudget was usable as a website, had significant levels of usage, was sustainable, and cared for PHB holders as a proxy for its co-designers.

Chapter 8 provides a discussion based on the insights gathered from the four AR cycles. The first reflection discusses the benefits and infrastructuring challenges of PHBs. Such benefits were found to include PHBs’ abilities to accommodate a diverse range of citizens, allowing for a wide variety of lifestyles, providing choice and control. However, these benefits came at a cost to the citizens of employing and managing their teams of paid carers and infrastructuring a micro healthcare system in the home. A second reflection arose from the understandings sourced from interviews with disabled citizens and their unpaid carers. Their care-prioritised lives demanded a novel approach to group engagements that allowed them to take part at times that suited them - this was achieved through a reconfiguration and extension of HCI's ARC method (MacLeod *et al.*, 2016) that provided both asynchronous and synchronous sessions. However, conflict surfaced in the early group engagements between the citizens and their healthcare officers. This conflict and further insights regarding a power imbalance resulted in the officers being excluded from the remaining group engagements. The benefits and losses from their exclusion, together with potential methods for ways forward, are offered here. A third reflection discusses the use of the novel conceptual framework for evaluating a healthcare digital intervention. Insights showed that the framework was useful in guiding choices of a range of mixed methods for evaluation, with further insights on the success and limiting factors of MyCareBudget. A final reflection explores the experiences of the CoA when attempting to work in coproduction with their healthcare authorities and the potential unintended consequences of MyCareBudget together with its ensuing responsibilities.

The final chapter provides a conclusion to this study by summarising the work performed, responses to the research questions, contributions to research, and recommendations for future research.

1.5. Contributions

This study offers empirical and methodological contributions gained from explorations of the lives of disabled citizens and unpaid carers, novel engagement methods, and an evaluation method. These contributions are briefly expanded below.

An empirical contribution is presented of an understanding of the lives of PHB holders, both unpaid carers and disabled citizens, and their relationships and unbalanced power dynamic with their local healthcare authorities. The insights describe that although a PHB can provide valued benefits, the personal infrastructuring demanded to achieve these benefits incurs costs of time and stress. These costs arise from the PHB holders' challenges and efforts to employ a team of paid carers and their need to "*fight*" for support from their healthcare service providers.

A further empirical contribution sheds light on the methodological approaches within new PD (Bødker and Kyng, 2018). Insights describe the conflicts that occur in participatory collaborations and how HCI is to account for the frustration and anger of empowered assemblages of marginalised groups. Further, responsibilities in co-design can surface as interdependencies within a collective, dynamically shifting between researcher, participants, and end-users, rather than being assigned to individuals (Jansen *et al.*, 2020) or shared by all those within a community (Karasti and Baker, 2008). Finally, a subset of the benefits of coproduction can be realised even when the process fails and the citizens resort to work in commoning without their service providers.

A methodological contribution is presented for engaging with an underserved population who are time-poor, have difficulties with travel, are vulnerable to infection, and cannot commit to starting times for engagement due to their priorities of care and unpredictable health needs. This is a reconfigured and extended ARC method (MacLeod *et al.*, 2016) that addresses ARC's inability to move on from the collection of experiences and theoretical co-design (Harrington and Dillahunt, 2021). The reconfiguration achieved this by including optional synchronous engagements, an educational agenda, planning for a longitudinal engagement from the outset, using novel engagement tools, and the aim of co-creating a functional and sustainable socio-technical intervention.

Lastly, a methodological contribution describes the creation of a conceptual framework for evaluating an operational healthcare socio-technical intervention. This framework was then applied to MyCareBudget, showing it to be successful in terms of its usability, usage, sustainability, and caring.

Note that the two methodological contributions and the first empirical contribution above are not limited to HCI but extend into academic fields associated with healthcare services and social policymaking. Further, the contributions benefit non-academic areas that work with marginalised populations and deliver care-related interventions.

1.6. Rationale for Terminology

A key aspect of this study has been to respect its target population of disabled citizens and their unpaid carers. How I refer to these individuals and groups carries significance.

The terminology used to reference disabled individuals can deliver tension. This study has adopted the stance discussed in Oliver's "The Politics of Disablement" (1992) of identity-first language (IFL), such as '**disabled people**', rather than 'people with disabilities' (people-first language, PFL). This decision has been taken as IFL is the established norm in the locale of this study, the UK, and consistent with how participants referred to themselves and their children. However, I recognise this is a personal preference, with differing and shifting views across individuals, groups, and countries.

Unpaid carer was the term used by this study's participants for individuals who are not paid for their caring of a disabled family member or friend, and is increasingly used by the UK governments (mygov.scot, 2021; gov.uk, 2022). This term has a socio-political overlay, demonstrated by the use of the term by those who are not paid for their care work – this is a reflection of their economic sacrifices, their lack of recognition, their call for social justice, and their demand for policy change (Kelly, 2019; Congreve and Watts, 2021; Brimblecombe and Cartagena Farias, 2022). Finally, the use of this term was in preference to others commonly seen in HCI literature, including 'parent carers', 'caregivers', and 'informal carers'; I further rejected 'informal' as a term that can infer non-professional or casual (Yeandle *et al.*, 2017).

It is also of note to distinguish between **paid carers** and **Personal Assistants (PAs)**. Those performing paid care work for a disabled citizen with limited cognitive capacity are typically referred to as 'paid carers'. Those paid for caregiving for a disabled citizen with greater or full capacity are known as Personal Assistants or PAs, as this better describes how their duties extend into supporting the disabled citizen in the social, voluntary, and commercial worlds. I use paid carer as a generic term that includes PAs.

I also avoid the term 'hard to reach' when describing the recruitment of marginalised populations for research, as it can imply that the citizen bears the responsibility for engagement in research. Instead, I use the emergent term **seldom heard**, denoting "those who are often not included in recruitment" (Freeman *et al.*, 2021, p. 82) as a result of their marginalisation and experiences of adverse health experiences and outcomes (Sixsmith, 2022).

I also position the disabled citizens and unpaid carers as a **marginalised population**, based on the healthcare work of Meleis and Im (1999, p. 96), who stated,

> It is the extent to which they are stereotyped, rendered voiceless, silenced, not taken seriously, peripheralized, homogenized, ignored, dehumanized and ordered around. The inequities that people experience in the societies where they are living tend to marginalize them and to deprive them of quality care.

Finally, I use the generic term **participant** to encompass those non-academic individuals who took part in this research, ranging in their roles at different times as informants, collaborators, and partners (Vines *et al.*, 2013; Bødker and Kyng, 2018).

1.7. Operational Aspects of Personal Health Budgets

This section describes the actors and processes involved in the granting and management of Personal Health Budgets (PHBs), thereby acting as a background to this dissertation.

1.7.1. Personal Health Budget Policy

NHSE (2019a) define the delivery of PHBs in England as a reuse of existing funding for individuals with complex, long-term, health and wellbeing needs. The PHB is to be planned with and between the individual (or their unpaid carer as a proxy) and their local CCG officers, such that healthcare services can be individualised to achieve goals related to the individual's desired outcomes - providing control, choice, and flexibility in the delivery of healthcare services (NHS England, 2019a).

As a healthcare authority, CCGs own the accountability and responsibility for the provision and governance of PHBs, alongside their accountabilities for hospitals, community, and mental health services in their locality. The officers in CCGs are likely to have had a healthcare background, as CCGs were designed to be 'clinician-led', primarily by local doctors but also nurses and hospital consultants (Checkland *et al.*, 2016). However, administrators will also play a role in more 'back-office' functions, such as in Finance departments. In mid-2022, CCGs were replaced by 42 Integrated Care Boards (ICBs) that have the same accountabilities and responsibilities for PHBs but cover larger geographic areas. I will refer to CCGs, rather than ICBs, as they were the authorities in place at the time of this study's engagements.

1.7.2. Accessing and Operating Personal Health Budgets

Figure 3 illustrates the end-to-end process that a citizen in England undertakes to gain and operate a PHB for their own complex, long-term care needs, or for a family member with such needs.

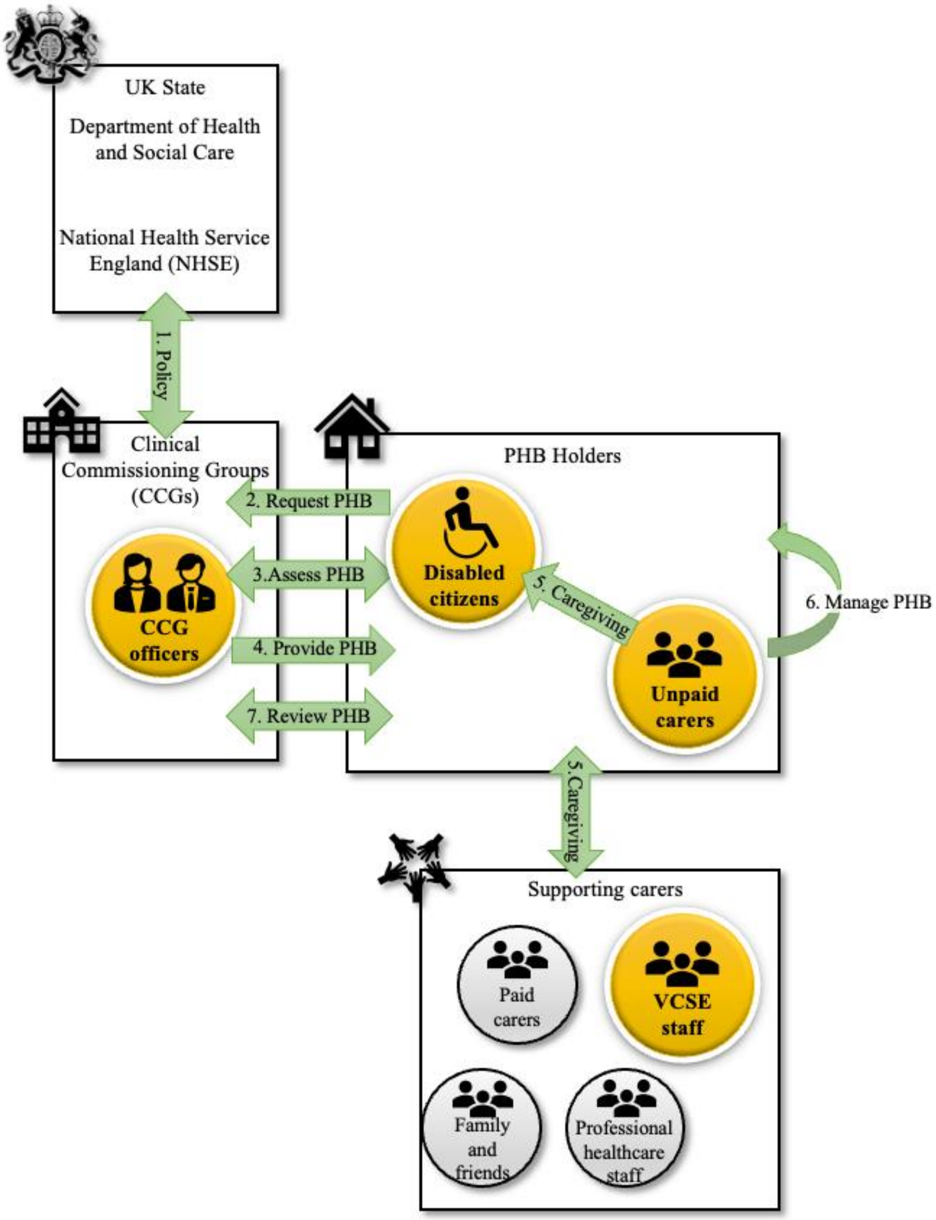

Figure 3: Gaining and operating a PHB in England (actors highlighted in yellow have participated in this study)

Arrow 1 - PHB Policy: The Department of Health and Social Care and the NHSE have created personalised healthcare policies that include PHBs, the CCGs owning their commissioning and individual assessment. Noting that some regions, including the North East of England, delegate aspects of this responsibility to social care within Local Authorities (LAs)[2].

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[2] LA's form the local government in England

Arrow 2 - Request PHB: A PHB can be requested from any source, such as from the citizen, their doctor, or their social worker (NHS England, 2019a).

Arrow 3 - Assess PHB: The request is either approved on a discretionary basis by the CCG, or assessed by the use of a Decision Support Tool (DST) (Department of Health and Social Care, 2018) that evaluates a citizen's need for continuing healthcare. The PHB then becoming a legal right. Using interviews and reports from across professions such as healthcare, social care, and education, a Multi-Disciplinary Team (MDT) known as a 'panel', collates evidence to assess the citizen across 12 categories that demand care. These categories encompass breathing, nutrition, continence, skin and tissue viability, mobility, communication, psychological and emotional needs, cognition (when aged 16 and over), behaviour, drug therapies and medication, altered states of consciousness, and 'other significant care needs'. These categories of need are scored related to their intensity and unpredictability. Scoring is subjective using government guidelines (Department of Health and Social Care, 2018), with no directive as to who is to perform this scoring - that is, it need not be clinicians or care professionals. The DST is manual, with technology used only for recording results.

Arrow 4 - Provide PHB: Once successfully assessed for a PHB, policy dictates the CCG are to work in coproduction with the citizen, or their proxy, to produce a personalised care and support plan (NHS England, 2019b). The plan contains not just clinical care, but also extends to the wellbeing and general life of the individual. As such, the plan is designed to be driven by the desired outcomes of the individual, rather than their needs. The funding is provided without charge, as part of the NHS principle of health service free at the point of delivery (Delamothe, 2008).

Arrow 5 - Caregiving: Caring is performed primarily by unpaid carers, paid carers, friends and family, and other healthcare professionals. The task of unifying this care into a cohesive whole falls onto the PHB holder (Forder *et al.*, 2012; Owens, Mladenov and Cribb, 2017).

Arrow 6 - Manage PHB: The PHB holder uses the funding for purchasing equipment, services, and employing a paid care team. The PHB holder becomes accountable and responsible for all aspects of caring and staff employment, such as recruitment, staff management, training, payroll, and financial accounting (Forder *et al.*, 2012; Owens, Mladenov and Cribb, 2017).

Arrow 7 - Review PHB: Annual reviews with frontline CCG officers are performed to ensure the PHB is delivering agreed outcomes, together with regular financial audits.

1.8. Research Outputs

This research aimed to support the lives of disabled citizens and their unpaid carers within the UK's personalised care paradigm, directly through their participation in this HCI research and its outcomes, but also through publishing and presenting at health conferences, as listed below.

1.8.1. Published Peer-reviewed Work

Glick, Peter, and Clara Crivellaro. 'MyCareBudget: Co-Creating a Healthcare Digital Commons with and for Disabled Citizens and Their Unpaid Carers'. In *CHI Conference on Human Factors in Computing Systems (CHI '23)*, 16. New York, New York, USA: ACM, 2023. https://doi.org/10.1145/3544548.3580934.

Glick, Peter, Rachel E Clarke, and Clara Crivellaro. 'Exploring Experiences of Self-Directed Care Budgets: Design Implications for Socio-Technical Interventions'. In *CHI Conference on Human Factors in Computing Systems (CHI '22)*, 14. New York, New York, USA: ACM, 2022. https://doi.org/10.1145/3491102.3517697.

Glick, P. (2021) 'Utilising digital services to empower the unpaid carers of individuals with long-term complex needs', *ACM SIGACCESS Accessibility and Computing*, January, pp. 1–6. https://doi.org/10.1145/3458055.3458060.

1.8.2. Awards

'Honorable Mention' award for my first author CHI2022 paper: "Exploring Experiences of Self-Directed Care Budgets: Design Implications for Socio-Technical Interventions", https://programs.sigchi.org/chi/2022/program/content/71913

'Highly Commended' in the 2022 National Academic Health Science Networks (AHSN) Innovate Awards for MyCareBudget, https://www.ahsnnetwork.com/news/first-set-of-innovate-award-winners-announced/

Winner of 2022 postgraduate Newcastle University Engagement & Place Award for MyCareBudget, https://www.ncl.ac.uk/who-we-are/engagement/awards/2022/#Postgraduate

1.8.3. Ongoing Research Outcomes

The Northumberland and Tyneside Coproduction Group. A Community of Action formed in 2019 comprising a small group of unpaid carers that continues to meet every month to offer mutual support, and endeavours to work alongside their local healthcare authorities to alleviate the challenges of PHBs.

MyCareBudget. A healthcare digital commons co-created by this study and launched in September 2021, hosting over 90 free to use care templates relevant to running a paid care team. As of June 2023, there have been over 5,500 end-users worldwide www.MyCareBudget.org.

1.8.4. Other Work

CHI2022: Workshop application accepted for "The Shift to a Personalised Care Ecosystem for the Care of Complex Health Needs”

IASSIDD2022 (International Association for the Scientific Study of Intellectual and Developmental Disabilities): Talk accepted on “The Shift to a Personalised Care Paradigm - Families Operating Self-Directed Care Budgets”, https://iassidd.org/conference2022/

EACD2022 (European Academy of Childhood Disability): Poster accepted for “The Power and Responsibility of Self-Directed Care Budgets”, https://www.eacd2022.org/

PMLD (Profound and Multiple Learning Disabilities) Link Vol 33 No 2 Issue 99 https://www.pmldlink.org.uk/ article: “I don’t want more advice, I want stuff done”

EACD2021 (European Academy of Childhood Disability): Talk accepted on “Duality of roles: partnering in research with families caring for children with complex disabilities, where the researcher is also a participant”

EACD2021 (European Academy of Childhood Disability): Poster accepted of “Moving online: partnering in research with families caring for children with complex disabilities in times of COVID”.

Chapter 2. Literature Review

2.1. Introduction

This literature review chapter focuses on the infrastructuring work placed upon disabled citizens with long-term complex needs and their unpaid carers, who receive care funding within a personalised care paradigm. The chapter examines issues and responses surrounding the relationship between disabled citizens, unpaid carers, and healthcare authorities, exploring the concepts and terms related to research in this context.

The focus on care demands a first section, section 2.2, that examines healthcare in the home for those with long-term complex needs, exploring who performs the caregiving, the work this entails, and its impact on the caregiver. Section 2.3 expands the range of care work to the demands of infrastructuring as performed by the unpaid carer within a siloed set of healthcare systems. This section also describes infrastructures and infrastructuring as concepts, their application and invisibility, and HCI responses to alleviate and ameliorate the burden of healthcare infrastructuring placed on the citizen. Section 2.4 examines the rights and justices of those that receive care, with a focus on the UK response to the calls for independent living from a healthcare standpoint. A reflection is offered on the shift in the last two decades to the personalisation of care in the global north that motivated this study, with attention to self-directed care budgets and their application in the UK as Personal Health Budgets (PHBs).

2.2. Caring for Disabled Citizens with Long-term Complex Needs

2.2.1. Home as a Place for Caring

This section looks back to where caring has occurred in history, moving forward to the present day.

For many centuries, caregiving for those who were frail, ill, or disabled took place in the home (Tronto, 1998). This began to change in the 19th century with the introduction of a positivist medical model as described in section 2.4.1, which led to the building of hospitals and asylums to both cure and confine (Foucault, 1965, p. 54; Lawrence, 2006, pp. 39, 43).

The welfare state introduced in the UK in the 1940s (Dencik, 2022) and The Mental Health Act of 1959 (HM Government, 1959) promoted the movement of care into the community. The UK government's 1990 NHS and Community Care Act (HM Government, 1990) further called for the closure of long-stay institutions and to move individuals into their family homes or "homely settings" (1989, quoted in Franklin, 2002, p. 174). The rationale for this move to the home was that it offered comfort, privacy, security, and freedom - a superior location for long-term care that demands continuous decision-making and management (Glenn, 2010, p. 9). It is also a cheaper option, as family members typically provide caregiving as unpaid.

However, this shift conflicted with the normative medical practices of that time that centred on treating acute infectious diseases and injuries, placing patients in a passive, dependent, and deferential stance to medical professionals (Anderson, 1995; Wagner *et al.*, 2005).

As a consequence of this move, an increasing distance opened between those receiving care and their clinicians (Glenn, 2010, p. 155). Clinicians were rarely seen once a patient left the hospital, with ancillary healthcare professionals likely being the only medical staff visiting the home. This shifts responsibility away from the medical professional to the unpaid carer, for them to organise and perform the caregiving in an environment not designed for intensive and often medicalised care (Yeandle *et al.*, 2017).

With care now placed in a home setting, the next section attends to those individuals that require the highest levels of care.

2.2.2. Defining Long-term Complex Needs

This research is located within the context of healthcare for an individual who is cared for in their home in England by unpaid and paid carers. This is for those members of society that demand the highest levels of care, requiring one or more carers to attend to them throughout the day and night due to their physical and mental conditions that inhibit self-care.

There is no standardised or formal definition for disabled citizens who have such enduring needs of intensive care - these arising from conditions such as profound learning disability, cerebral palsy, spinal injuries, genetic disorders, or multiple sclerosis. ‘Long-term complex needs’ is used in this study as it is referenced in literature, though still without definition (Yantzi, Rosenberg and McKeever, 2006; Cowan *et al.*, 2012; Evenblij *et al.*, 2019; Prieto *et al.*, 2022). The National Institute of Health Research (NIHR) in the UK discusses ‘complex care needs’ and ‘multiple long-term conditions’ with the following statement that suffices for this study,

> … Conditions with effects on multiple systems or areas of function, often encompassing both mental and physical health, which may interact, may lead to potentially conflicting treatment recommendations and frequently require interaction with multiple clinicians and services (Walker and Logan, 2019, p. 1).

The range, multiplicity and degree of disability will differ considerably, varying between individuals and over time for an individual. Hence, the caring required is unique to the individual and demands caregiving that is relational rather than transactional, requiring the caregivers to learn about the individual, not just their medical needs, but their values and preferences (Muir and Parker, 2014).

With the place and need now described, the following section moves on to the roles of caring.

2.2.3. Paid and Unpaid Caring

The intensity and enduring nature of the care work in the home for those with long-term complex needs demands time and effort from both unpaid and paid carers.

A paid carer working in a hospital or an institution will be formally trained, with specialists on hand for the technical tasks as part of a multidisciplinary care team. Within a home setting, the paid carer works alone or in a small team managed by an unpaid carer or disabled citizen. In both settings, the paid carers' care work is the entirety of their role, with days off and holidays.

This study focuses on the work performed by the unpaid carer, whether that be a family member or, as rarely seen in HCI literature, the disabled citizen who can act as their own unpaid carer when they have the capacity. This caregiving is supplemental to the normative care found within familial and friendship relations, arising from the complex needs caused by physical and mental health conditions.

The term 'unpaid carer' is used here for those who act as the primary caregiver within a home setting for an individual with long-term complex needs, noting the difficulty in providing a simple, static, and comprehensive definition (Murray and Barnes, 2010; Tarrant and Hall, 2020). Tang (2018) described an unpaid carer as a family member, friend or other layperson without formal medical training in caregiving but with a personal relationship to the cared-for. However, this description omits medical staff who can deliver such unpaid care to a family member or friend. Hence, I use the definition provided by Twigg (1992, quoted in Kirk and Glendinning, 1998, p. 371) of the unpaid carer's role as that which "… normally takes place in the context of family or marital relationships and is provided on an unpaid basis that draws on feelings of love, obligation and duty."

A list of the roles and tasks performed by unpaid carers is provided in a report from the European Commission in 2010 (Triantafillou. *et al.*, 2010). The report stated that the unpaid carer is non-professional, untrained, unpaid, lacking contracts for their caring responsibilities, performing a wide range of tasks, and with no limits on caring time and no entitlement to employment rights such as holidays or limits on working hours. Opposing some of these descriptors from the European Commission are that the unpaid carer becomes skilled in medicalised feeding, personal hygiene, mobility, medication management, and symptom management (Dixe *et al.*, 2019), blurring the role between unpaid carer and professional healthcare roles (Kirk and Glendinning, 1998). For example, unpaid carers can perform complex nursing tasks such as gastrostomy feeding, stoma care, urinary catheterisation, tracheostomy management, and intravenous therapy (Kirk, 1998; McDonald *et al.*, 2017).

A further set of tasks omitted from the European Commission is of core relevancy to this study - those surrounding the management of care and the ensuing need for skills and information. HCI researchers have discussed the care work placed on the unpaid carer (Mamykina *et al.*, 2008; Tixier, Gaglio and Lewkowicz, 2009; Chen, Ngo and Park, 2013; Yamashita *et al.*, 2013; Nunes *et al.*, 2015; Park and Chen, 2015), abstracting the unpaid carers' roles to distinguish between the more 'hands-on' care described above, and the management of care. In the latter case, authors utilised terms such as advocate, care manager, and navigator (Miller *et al.*, 2016; Bhat *et al.*, 2023), positioning the unpaid carer as entangled in day-to-day care activities (Chen, Ngo and Park, 2013; Miller *et al.*, 2016; Tang *et al.*, 2018; Gui and Chen, 2019).

HCI practitioners such as Gui, Chen, and Pine (2018) have examined the expertise required for this management of care, including the health literacy required to access, understand, judge, and leverage healthcare information and policy from multiple sources. The authors made a clear distinction between health literacy arising from abilities of numeracy and language abilities that promote the application of health information, against where health literacy is applied to promote the agency of the unpaid carer, the context of this study. This literacy is demanded to source services from complex healthcare systems that present as a "black box" (Gui, Chen and Pine, 2018, p. 9), where the unpaid carer has to input and receive output from the healthcare systems but with no sight of their inner processes or actors.

With this breadth and depth of care work, the following section discusses the impacts on the unpaid carer.

2.2.4. Impacts of Unpaid Caring Work

Health studies have found that unpaid carers are at greater risk of mental illness and depressive symptoms, with higher rates of heart disease, high blood pressure, and diabetes (Vitaliano, Zhang and Scanlan, 2003; Chen, Fan and Chu, 2020).

One factor that leads to these health risks is that the caregiving typically falls onto a single family member, this caregiving taking that person "to their physical, psychological and emotional limits" (Dixe *et al.*, 2019, p. 2), impacting the whole family (Valentine, 2001; Montagnino and Mauricio, 2004; Kirk, Glendinning and Callery, 2005; Kingston, 2007; Brehaut *et al.*, 2011; Flynn *et al.*, 2013; Buckner and Yeandle, 2017; Leonard, 2018). Tizard and Gath stated that the families of disabled children are "dominated by a burden of care" (1961, quoted in Gath, 1972, p. 211). Diehl, Moffitt and Wade (1991, quoted in Gravelle, 1997, p. 738) described the disabled child as requiring "an extraordinary quantity and quality of care which demands careful orchestration and which places enormous demands on the parents", which is "emotionally and physically exhausting for parents".

Within HCI literature, studies have also reported on unpaid carers' high levels of stress, anxiety, depression, financial issues, and difficulties with managing their family's day-to-day life (Chen, Ngo and Park, 2013; Miller *et al.*, 2016; Schorch *et al.*, 2016; Gui and Chen, 2019; Karusala *et al.*, 2023; Li, Arnold and Piper, 2023; Soubutts *et al.*, 2023). As discussed earlier, care work is typically performed at home, with little support, where even close family members are often unaware of the demands (Chen *et al.*, 2019). This lack of visibility is compounded by the unpaid nature of the work and that the role is predominantly filled by women. Care is seen as private and of the home, contextualised as "women's work" (Tronto, 1998, p. 16) and as acts of love and a natural part of life (Star and Strauss, 1999; Hill Collins, 2000; Tronto, 2015, p. 7; D'Ignazio and Klein, 2020, p. 178). Social isolation is also commonly reported, arising from the continual care work, lack of flexibility, and precarious nature of their caring lives (Long *et al.*, 2017). Long et al. (2017) also found that while communities of unpaid carers as peers were welcomed to alleviate this isolation, such groups had low representation, likely due to the time pressures on unpaid carers.

For such reasons, the care work has become devalued, unsupported, and "coerced" (Glenn, 2010, p. 5), though, at the same time, this unpaid care work underpins society, acting as a foundation to support capitalism (Karusala *et al.*, 2021). A 2021 report (Petrillo and Bennett, 2021) found this unpaid care work was equivalent to £162 billion a year in England and Wales - greater than the total funding of the NHS (National Health Service). Neoliberalism has further exploited unpaid care work, the state placing the responsibility of caregiving onto the citizen, but still applying state rules and processes (Gui and Chen, 2019; Chatzidakis *et al.*, 2020; Karusala *et al.*, 2023), assuming the citizen will perform repair work for lacks and failures in the state's governance (Tang *et al.*, 2018).

The negative aspects of unpaid caregiving can impact on research. Gaining access to disabled citizens and unpaid carers as research participants and maintaining this access is problematic - their priorities of care (Long *et al.*, 2017) overriding research meeting start times and attending synchronous events. Further, these citizens typically lack financial resources and social capital that can inhibit their meaningful participation, these resulting from structural system issues rather than the individual - indeed, their struggles against systems can deliver strength and resilience (Vyas, Durrant and Vines, 2022). Although this impact on research is discussed in HCI literature, the detail of its mitigations is less well seen, which this study attends to in later chapters.

Yet, caregiving can bring benefits, delivering fulfilment from caring and satisfaction from achievements across the multiplicity of roles undertaken (Glenn, 2010, p. 4; Chen, Fan and Chu, 2020). The social status of the unpaid carer within the home can be elevated, as can those providing paid care assistance, who shift from employees to becoming ‘one of the family’ (Soubutts *et al.*, 2023). Living close to a disabled individual can also deliver opportunities for self-reflection, bringing thankfulness for one’s own health, and raising priorities for seeking improved health for themselves and their families (Cohen, Colantonio and Vernich, 2002; Peacock *et al.*, 2010; Chen, Ngo and Park, 2013).

The significance here is not just the intense and enduring caregiving placed on the individual but the great and increasing numbers of people that are caring and are receiving care, described next.

2.2.5. Quantitative Significance of Research for Disabled Citizens and their Unpaid Carers

A World Health Organization report (2017) stated that 349 million people around the world required care, 4.6% of the global population. Schurgin et al. (2021) sourced their data from a United States (US) survey that showed 21% of Americans self-declared as unpaid carers, a 20% increase in five years (National Alliance for Caregiving and AARP, 2020). The England and Wales Census 2021 (Office for National Statistics, 2022) provided data on unpaid carers and disabled citizens, revealing that 8% of the population in England self-declare as providing unpaid care; 2.7% self-declare that they performed this care for more than 50 hours a week; and just over 1% (500,000 people) that their disabilities severely limited their ability to perform day-to-day activities.

The NHSE also publish data on the numbers of people with PHBs, which are for the most severe and profound disabilities that demand 24/7 care, the context of this study. March 2023 data (NHS Digital, 2023) showed that just under 33,000 children and adults in England had been placed in this category, though this represents just those individuals assessed by the NHSE.

It must be noted that data on the numbers of disabled citizens and unpaid carers is problematic, not just because of the lack of standardised terms. For example, data for unpaid carers is typically sourced on surveys where individuals self-declare, but it is known that people do not always recognise themselves as unpaid carers, hence introducing uncertainty (Long *et al.*, 2017; Urwin *et al.*, 2022).

However, regardless of the level of confidence of the above numbers, it is evident that there are significant numbers of disabled citizens and unpaid carers in England and beyond, adding to the significance of research that can alleviate the challenges of caring that they experience in their lives.

2.2.6. Section Summary

This section has introduced the place, roles, and work required for the caring of disabled citizens with long-term complex needs, examining the need, impacts, and significance.

The following section expands on the care work demanded of the unpaid carer, framing this as infrastructuring, exploring the concept and its application to this study, the invisibility of infrastructuring, the impacts arising from the lack of support from healthcare authorities, and the HCI response.

2.3. Personal Healthcare Infrastructuring within HCI

2.3.1. Infrastructures and Infrastructuring

'Infrastructures' refer to the substrate of technical and physical systems that enable society to function (Star and Ruhleder, 1996). Star and Ruhleder (1996) identified dimensions that describe an infrastructure, such as the invisibility that is exposed on their failure, the longevity, the ongoing need for learning and maintenance, the interconnection and embedding with other infrastructures and technology, and the way they shape and are shaped by their users. Infrastructures were also found to be built upon an existing foundation, and as such, their development is closely tied to the society they serve.

'Infrastructuring' refers to the process of creating, configuring, and maintaining these infrastructures through design and development practices (Pipek and Wulf, 2009). This multi-faceted work links technical and social structures, adds new elements, mediates conflict, and repairs breakdowns (DiSalvo, Clement and Pipek, 2012, p. 202). Within HCI, infrastructuring has been proposed as a means to shift from products and technologies designed with little regard to the environments they are to operate in, to those embedded in the relationships and interdependences of socio-technical systems (Star and Ruhleder, 1996; Kaziunas, Klinkman and Ackerman, 2019).

Infrastructures and infrastructuring are of use to this study as they place the unpaid carer within an ongoing, interconnected world that demands maintenance and repair to operate (Kaziunas, Klinkman and Ackerman, 2019). This offers opportunities to HCI to design fair and just socio-technical interventions by considering the collective and individual responsibilities for the care of citizens (Tseng *et al.*, 2022).

2.3.2. Infrastructuring a Personal Healthcare System

Healthcare infrastructuring for unpaid carers is a growing area of interest in HCI research. Studies over the last decade have examined the work and challenges of parents and unpaid carers worldwide that provide care in a home setting, casting light on the coordination tasks of caregiving placed upon the unpaid carer and their burden of responsibilities (Chen, Ngo and Park, 2013; Bratteteig and Eide, 2017; Long *et al.*, 2017; Gui, Chen and Pine, 2018; Rajapakse, Brereton and Sitbon, 2018; Chen *et al.*, 2019; Gui and Chen, 2019; Kaziunas, Klinkman and Ackerman, 2019; Kou *et al.*, 2019; Schurgin *et al.*, 2021; Shin *et al.*, 2021; Bhat *et al.*, 2023; Karusala *et al.*, 2023; Wilcox *et al.*, 2023).

Across these studies, citizens were found to be operating between the gaps of a siloed set of healthcare service providers who offered little support in managing care, each citizen forced to assemble their individual care infrastructures (Gui, Chen and Pine, 2018; Rajapakse, Brereton and Sitbon, 2018; Chen *et al.*, 2019; Gui and Chen, 2019). This siloing arises from a diverse set of healthcare organisations with their own unrelated budgets, operating under differing legislation and policies (Chen, Ngo and Park, 2013). So although ‘the healthcare system’ is often referenced as a single entity, patients, carers, and healthcare staff have to work to ‘stitch’ together disparate organisations and systems (Gui and Chen, 2019).

This work is especially challenging to outsiders of the organisations, for example, patients and carers, as the systems present as a black box (Gui, Chen and Pine, 2018). The challenge is exacerbated for those new to these systems when they possess little knowledge of who and how to access the systems to gain benefits, compounded by their precarious lives and social isolation (Coles-Kemp, Jensen and Talhouk, 2018).

The infrastructuring work demanded is complex, with technical literacy required to traverse multiple system interfaces and to transfer information. Knowledge is needed to find out who and where to seek services, articulation skills to plan complex tasks, and social skills for selfadvocacy to source assistance from both formal and informal resources (Gui, Chen and Pine, 2018).

There is little choice for the unpaid carer taking on this infrastructuring work. Failure to do so would result in breakdowns of care that the unpaid carer and care receiver would suffer from (Gui and Chen, 2019), such as paid carers not turning up for shifts or care budgets not being available.

This lack of choice and the infrastructuring work described above are typically invisible to anyone other than the unpaid carer, leading to a lack of recognition, support, and exploitation of the caregiver (Chen, Ngo and Park, 2013). Gui and Chen (2019) commented on this from the US healthcare systems perspective, seeing that the profits of the healthcare corporations arise in part from the invisible labour of the isolated unpaid carers and patients. Indeed, Gui and Chen go further and label this as a form of “institutional cruelty” (2019, p. 10), where the unpaid carers are managed, exploited, and humiliated by their healthcare providers, where the US healthcare corporations “secretly move the burden of labor onto individual health consumers” (2019, p. 11).

A potential advantage for such infrastructuring tasks to be made visible is that they would be seen as ‘legitimate’ work and hence receive support from the state (Suchman, 1995; Star and Strauss, 1999). However, such formalisation delivers risks, including surveillance and additional burdens of being forced to adopt state-standardised processes (Suchman, 1995; Star and Strauss, 1999), removing choice and control from the citizen.

In summary, healthcare infrastructuring work is intensive, time-consuming, and enduring to the unpaid carer (Gui, Chen and Pine, 2018). HCI has looked to alleviate and ameliorate this work, discussed in the following section.

2.3.3. The HCI Response to Unpaid Infrastructuring Work in Healthcare

HCI has looked to deliver support and efficiencies to the caring performed by unpaid carers (Toombs *et al.*, 2018), whether by the provision of tracking (Pina *et al.*, 2017; Yamashita *et al.*, 2017; Bhat, Jain and Kumar, 2021), the collaboration of others (Berry *et al.*, 2017; Gutierrez and Ochoa, 2017; Puussaar, Clear and Wright, 2017; Tang *et al.*, 2018; Shin *et al.*, 2020), information sharing (Yamashita *et al.*, 2018), or through self-care (Yamashita *et al.*, 2013; Tixier and Lewkowicz, 2015).

Within the unpaid carer’s work of infrastructuring, Tang et al. (2018, p. 75) surfaced a lack of formal care documentation in their participants’ homes. The authors expressed surprise about this lack but explained it was caused by their participants being “mostly informal caregivers without medical training.” Albeit two of their participants were medical professionals and studies have witnessed families becoming medically literate about their healthcare conditions (Landsman, 2005; Fisher and Goodley, 2007; Bhat *et al.*, 2023). Tang et al. (2018) did find informal care documentation in some homes where incidents, such as incontinence episodes, were noted down and then handed to clinicians or shared between paid carers. The authors also found an absence of technology in the homes that might have assisted with this need for documentation and communication.

A risk here is the unintended harms of such technological interventions. HCI authors have asked researchers to consider the holistic needs of the carer, including their emotional and social needs, as well as the infrastructures and networks that are involved in caregiving (Bosch and Kanis, 2016; Schurgin *et al.*, 2021). HCI has responded to this call for a holistic approach, for example, Chen, Ngo, and Park (2013) interviewed unpaid carers to understand their behaviours as a means to generate design implications, asking for health and wellbeing systems to consider their impact on the lives of carers. Gui, Chen, and Pine (2018) called for HCI to expand the scope of design for this population, identifying the navigation of healthcare infrastructures as a critical part of their care work. Shin et al. (2021) looked not to the lacks of the unpaid carer but rather their implicit and explicit knowledge and skills, positioning the unpaid carer away from a role of an amateur administrator, to one of a skilled problem solver.

To understand these everyday settings of participants, HCI has looked in recent years to first-person research methodologies of autoethnography and autobiography. Autoethnographic researchers observe, record, and critically reflect on their personal encounters, allowing a deeper, empathic understanding of experiences (Rapp, 2018; Lucero *et al.*, 2019). Autobiographic design researchers embark on HCI design through their own genuine needs and personal history, as opposed to taking on the needs of others, allowing rapid and affective responses to real-life needs and conflicts, gaining insights into changing needs and behaviours (Neustaedter and Sengers, 2012; Lucero *et al.*, 2019). Noting that both methodologies, due to their personal intensity, can raise questions of generalisability .

Leveraging the knowledge unpaid carers have gained, explicitly and implicitly, is a core aspect of this study discussed in the Methodological Approach chapter.

2.3.4. Section Summary

HCI has considered and responded to the infrastructuring needs of the unpaid carer, with the exception of impacts stemming from a personalised care approach that this study focuses on.

The next section discusses this approach in more detail by examining disability rights, which led to calls for independent living and personalised care.

2.4. Personalised Care as a Response to Calls for Independent Living

Movements such as disability justice (Charlton, 1998) and health activism have advocated for the need to foreground participants' lived experience, for example, in HCI design, encapsulated by the statement, "Nothing About Us Without Us" (Charlton, 1998). These movements have challenged narrow understandings of disabled communities as a population with 'deficiencies' and needs (Metatla *et al.*, 2019; Williams and Gilbert, 2019; Bennett, Rosner and Taylor, 2020; Sum *et al.*, 2022) that the two primary models of disability explain and respond to.

2.4.1. Leveraging the Primary Models of Disability

The medical model of disability, in place during the 20th century in the global north, distinguishes between categories of 'disabled' and 'non-disabled' based on medically created levels of behavioural, physical, intellectual, and social functioning (Shyman, 2016). This model can lead to a reductive assessment of an individual as a patient who is given treatment or rehabilitation designed to alleviate 'abnormalities', to strive towards a 'normality' (Mankoff, Hayes and Kasnitz, 2010; Frauenberger, 2015; Spiel *et al.*, 2019). The disability is seen to belong to the patient and the treatment is external, owned by the medical profession.

Arising from this model is the establishment of a power base, that of the medical professional who decides what is normal, and the patient, who is to follow their commands (Lawrence, 2006). HCI work has used this model, for example, as a basis for determining a body's deficiencies and hence requirements for the design of Assistive Technologies. This approach perhaps at the expense of enlightening society's view of a disability (Mankoff, Hayes and Kasnitz, 2010; Frauenberger, 2015) and failing to consider the complex, precarious, and interrelated lives of the individual (Rogers and Marsden, 2013; Hook *et al.*, 2014; Sum *et al.*, 2022; Williams, Boyd and Gilbert, 2023). The medical model does remain of use - for example, this study has used it to understand the consequences of health conditions and the numbers of unpaid carers and disabled citizens.

In reaction to this medical model, global disability rights movements in the 1970s constructed a range of models to frame disability outside that of the medical. In the UK, the Union of the Physically Impaired Against Segregation (UPIAS) (1976) was formed by a small group of physically disabled individuals driven by Marxist principles. The movement turned away from the mainstream disability groups of that time by placing impairment into a physical, medical domain, with disability as a social oppression.

This social model looked to overcome disabled people's oppression through a demand for their complete participation in society (Frauenberger, 2015), becoming instrumental in driving legislation such as the 1995 Disability Discrimination Act[3] in the UK that requires buildings, transport, and services to be accessible. Hence, the social model emphasises the systemic changes demanded to include disabled people in society (Spiel *et al.*, 2019; Dixon, 2021; Yildiz, 2022). This social model can be used, for example, to support HCI's design of Assistive Technologies in a way that supports people to access the life experiences they want to attain, as opposed to 'correcting' lacks that society places upon them (Rogers and Marsden, 2013; Hook *et al.*, 2014; Ringland *et al.*, 2019).

Through the lens of Disability Studies, the medical model can be viewed as oppressive, placing disabled people to one side as they do not align with a perceived norm. The social model does not 'solve' the issues with the medical model, as no amount of social change can remove all the physical barriers experienced by a disabled person (Frauenberger, 2015). However, by adopting the social model, HCI can attend to the infrastructural, social, and environmental factors that create barriers for disabled people, striving towards more inclusive and accessible technologies (Parker *et al.*, 2012; Rodger, Vines and McLaughlin, 2016; Kaziunas, Klinkman and Ackerman, 2019; Ringland *et al.*, 2019; Yildiz, 2022).

2.4.2. The Demand and Response for Independent Living

Residing within the medical model, the UK state has a history of providing care as 'gifts' of service and equipment (Duffy, 1996). These gifts are delivered in a one-way transactional style (Ward and Meyer, 1999; Duffy, 2010; Muir and Parker, 2014), resulting in a rigid and unreliable 'one size fits all' care service (Owens, Mladenov and Cribb, 2017). This approach is unsuitable for long-term conditions (Owens, Mladenov and Cribb, 2017) and reflects on how the UK welfare state has lost sight of how it was purposed as a collective means to provide mutual care (Light and Seravalli, 2019).

This transactional style of service delivery in part led to the Independent Living movement in the 1970s, which established the rights of disabled citizens for choice and control in their

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[3] https://www.legislation.gov.uk/ukpga/1995/50/contents

care-receiving, seeking care funding to be directly provided (Forder *et al.*, 2012; Muir and Parker, 2014; Owens, Mladenov and Cribb, 2017). In this context, independent living is not living alone but focuses on interdependence and the relational aspects of care and support.

There is a range of HCI literature that addresses aspects of independent living, such as: the use of voice assistants (Kakera *et al.*, 2023); a digital tool for young people to manage their independent living when at risk of homelessness (Taylor *et al.*, 2019); for requesting video assistance for a person with complex needs (Salai, Cook and Holmquist, 2021); and to help with the experience of environments for those with chronic diseases (Janicki, Ziegler and Mankoff, 2021). This corpus of HCI literature has focused on vertical responses to the specific needs of a population, perhaps needing a broader infrastructural view of independent living that this study aimed to address.

In response to the demand for independent living, healthcare in the global north has shifted to personalised care. This paradigm emphasises the adaptation of medical advice to the individual, such as shared decision-making and patient-centred care (Winbladh, Ziv and Richardson, 2011; Duong-Trung *et al.*, 2020; Elahraf *et al.*, 2021; Bhat *et al.*, 2023). While personalised care has been shown to improve health outcomes and reduce referrals and diagnostic testing (McWhinney *et al.*, 1995), conflicts have arisen caused by the lack of a standard definition and confusion over the ensuing roles of clinician and patient (Stewart, 2001). There are additional complexities as the medical model allows the patient to hand their anxieties to the physician, whereas personalised care demands the patient takes on responsibilities for their care (Nunes, 2019; Jansen *et al.*, 2020; Bhat *et al.*, 2023), with the underlying assumption that tools and support will be provided for these (Winbladh, Ziv and Richardson, 2011).

Regardless of such complexities, the NHS has reformed its policies since the 1990s, adopting a personalised care paradigm (Jones *et al.*, 2010) to provide citizens with choice and control in their lives (Forder *et al.*, 2012). The paradigm includes ‘Personal Health Budgets’ (PHBs) for those with long-term complex health needs, designed for citizens to own and arrange their care. Known globally as ‘self-directed care budgets’ or ‘self-directed support’, these have been trialled across countries, including the US, Canada, Netherlands, Belgium, Germany, and Australia over the last 30 years. Each state adopted the guiding principle of empowerment, albeit with differing administrative processes (Gadsby, 2013) - this is also true within the UK, with this study located in England with that nation’s distinct legislation, policies, and processes.

A national evaluation of PHBs in England, funded by the UK government, showed significant improvement in the quality of life for citizens, with the improvements strongly correlated to those pilot sites that offered the widest choice of services (Forder *et al.*, 2012). Cost savings to the state were evident for those citizens requiring the highest levels of healthcare need, and overall, PHBs were found to be cost-effective or cost-neutral.

Doubts have since been discussed following these evaluations, with studies pointing out that the PHB holders in the initial assessment had procured additional services (Gadsby, 2013; Slasberg *et al.*, 2014). Gadsby stated, “It is perhaps unsurprising, therefore, that overall improvements were found in wellbeing amongst budget holders” (2013, p. 19).

Regardless, following the initial evaluation, the UK government announced a rollout of PHBs from 2014 (HM Government, 2012; NHS England, 2012), placing them as a legal right for those eligible (Department of Health, 2014). Other entitlements have since been added: for the purchase of wheelchairs, for those needing aftercare services following a hospital stay under the Mental Health Act 1983 (HM Government, 1983), and from 2015, anyone can receive a PHB on a discretionary basis of their healthcare authority. PHBs can also be offered alongside social care funding - known as ‘joint funding’ or ‘integrated health and social care funding’. The NHS forecasting that 200,000 PHBs would be active in England by 2024 (National Health Service, 2019).

A PHB is free of any citizen funding in England. The money can be handed directly to the disabled citizen or their unpaid carer, this designed to provide agency over their care services based on the citizen’s desired outcomes (NHS England, 2019a). However, drawbacks exist regarding their intent that the following section discusses.

2.4.3. Reflecting on Personalisation for Complex Care Needs

Personalisation is an approach to healthcare delivery that allows individuals to select services according to their unique preferences and needs. The citizens receive care in a democratic sense - by deploying the care efficiently to make the best use of the resources provided and by attaining a sense of ownership of their care and autonomy within their lives (Glendinning *et al.*, 2008; Tyson *et al.*, 2009; Alam and Houston, 2020). The state gains efficiency and hence lower costs (Leadbeater, 2004; Needham, 2011; Mladenov, Owens and Cribb, 2015).

Handing control to the citizen aligned with the neoliberal marketisation reforms of the UK’s Thatcher government in the 1980s that placed the disabled citizen as a consumer (Mol, 2008; Owens, Mladenov and Cribb, 2017). This personalised care approach was also used by the UK’s left wing groups as an advocation point for the reform of the welfare services (Darzi,

2008) and by right wing political groups as a citizen empowerment tool for their 'post-bureaucratic' age (The Conservative Party, 2010). However, it is also used by the state as a tool for cost-cutting rather than empowering the citizen (Owens, Mladenov and Cribb, 2017).

Further, research has shown how PHB holders, as disabled citizens or their unpaid carers, do not always achieve the autonomy they seek when the state fails to support them with the responsibilities of management and legal liabilities (Owens, Mladenov and Cribb, 2017; Leonard, 2020). Operating a PHB places the burden on the individual to plan and purchase their care and all the ensuing financial and legal duties (Owens, Mladenov and Cribb, 2017). The state stepping back from supporting the now 'autonomous' citizen has implications for those with lower social capital, forming a social injustice, privileging those who are empowered as a result of their intersectionality (Beer, Paxman and Morris, 2013; Slasberg *et al.*, 2014; Mladenov, Owens and Cribb, 2015; Owens, Mladenov and Cribb, 2017). The ability to choose has additional consequences on the PHB holder, as choice demands effort, time, and brings responsibility (Mol, 2008), so it is just those citizens with the capacity for these who gain the benefits.

This personalised care approach also has implications for healthcare professionals, as its delivery is adversely affected by long-standing regimes of restrictive management, where the strict auditing and accountabilities imposed on personalisation have delimited the professional's autonomy (Owens, Mladenov and Cribb, 2017). Personalisation, in its role of handing choice and control to the citizen, removes these functions from frontline staff, delimiting their roles to ones of budgetary gatekeeping (Owens, Mladenov and Cribb, 2017). Further, the care system still views the individual as a 'service user', and the siloed healthcare boundaries remain in place (Duffy, 2010; Cottam, 2020).

Similar issues in implementation and delivery have been reported worldwide (Gadsby, 2013) - for example, shortages of paid care staff, authorities not releasing control to the citizen, and a lack of inclusion and equity.

HCI has touched on aspects of personalised care, calling out for a greater understanding of how positives such as patient engagement and empowerment can become a burden to pressured and overworked healthcare systems (Kaziunas, Klinkman and Ackerman, 2019). Further, HCI has commented on the widening health inequalities, as it is the socially advantaged that have superior access to health information (Veinot, Mitchell and Ancker, 2018).

2.4.4. Section Summary

This section presented the state's personalisation of care as an outcome of the disability rights movement for independent living. PHBs are the UK's healthcare manifestation of this personalisation for those with long-term complex needs, aimed at providing choice and control to the citizen.

However, concerns and issues surrounding the implementation of PHBs have raised questions about the state's motives and constraints, with a lack of support for citizens needed to address the new responsibilities that come with PHBs. Excepting this study, HCI has yet to examine this aspect of healthcare infrastructuring and how citizens as PHB holders can be supported.

2.5. Chapter Summary

The core concepts of this study have been introduced in this chapter - caring that supports those with long-term complex needs, its place and actors, personal healthcare infrastructuring, and the right to independent living for disabled citizens, surfaced in the UK as PHBs.

The chapter leveraged literature from HCI and other sources to show how disabled citizens and their unpaid carers are immersed in a world of caregiving, the infrastructuring work to assemble siloed healthcare systems placed upon them by the neoliberal state in the global north. PHBs can provide independent living for disabled citizens by delivering choice and control, but a lack of state support adds to the burden and responsibilities of caring. This lack of support exposes the outsourcing of infrastructuring work from a neoliberal state onto citizens as an unjust power dynamic.

The infrastructuring demands of a PHB and its self-directed care equivalents throughout the world are yet to be examined within HCI, excepting the papers arising from this study (Glick, Clarke and Crivellaro, 2022; Glick and Crivellaro, 2023). Hence, this study contributes to HCI literature with its focus on PHB holders and their infrastructuring of PHBs.

The next chapter examines the methodology used for this research and its rationale, calling out gaps in HCI literature surrounding how a time-poor community of disabled citizens and their unpaid carers can be included in research to deliver operational socio-technical interventions.

Chapter 3. Methodological Approach

3.1. Introduction

This study aimed to deliver support to disabled citizens and unpaid carers in their work to realise benefits from their PHBs, with this chapter laying out the research paradigms, theories, methodologies, and methods selected to enable this support.

My positionality influenced these choices, so is described first, especially that of my status as an insider to unpaid carers and PHB holders. This positionality and my resultant principles guided the selection of a critical realist approach with a constructivist philosophy. These further aligned with this research by leveraging the theory of care ethics to place the individual, their caring activities, and relationships at the forefront of this research.

The research paradigm recognised the difficulties of understanding participants' lives of caring and how the ensuant multiple and interwoven complexities can be at odds with the need for clear technology design. Participating *with* the citizens is paramount here, hence Action Research (AR) (Hayes, 2011) and Participatory Design (PD) (Harrington, Erete and Piper, 2019) were selected as methodologies that promote this form of engagement. This chapter describes AR and PD, their origins and alignment to constructivism and democracy, and a need for PD to recover its political roots, as described by Bødker and Kyng when they called for a "new PD" (2018, p. 10).

Following the choice of methodologies, my research design considers "respectful design" (Rajapakse, Brereton and Sitbon, 2021) in the configuration of participation, before moving on to engagement methods for researching with a time-poor and care-prioritised population. These methods based on HCI's Asynchronous Remote Communities (ARC) technique (MacLeod *et al.*, 2016).

I then examine the question of how citizens can assemble to effect change in healthcare infrastructuring, looking to coproduction, its application to healthcare, and the option for citizens to develop a digital commons through commoning. Caution is expressed here as studies have identified where such assemblages have acted as safety nets to neoliberalism, rather than fighting society's shortcomings (Spade, 2020).

Four AR cycles are then summarised, with data collection methods, recruitment, and the use of Reflexive Thematic Analysis described, before this chapter ends with the ethics process for this study.

3.2. Research Paradigm

This research aimed to deliver positive, meaningful, and sustainable support to disabled citizens and unpaid carers in the context of their PHBs. The ontological, epistemological, and methodological perspectives have been selected to deliver this aim - influenced by my positionality.

3.2.1. Positionality and Principles

In the context of this research, I held the privileged position of researcher, research budget holder, experienced software developer, unpaid carer, and co-holder of a PHB for a family member. These roles allowed me both insider and outsider status.

Within healthcare research, an ‘insider’ is typically applied to individuals working within healthcare organisations, with patients and carers positioned as outsiders (Gui, Chen and Pine, 2018). This outsider stance is appropriate in this study’s context, where the citizen has to navigate the healthcare systems to obtain service, but without sight of their internal processes and actors.

I held insider status in respect to the unpaid carers that participated in this study. With the citizen at the forefront of this study, my positionality as an insider to the unpaid carers allowed for a sharing of identity, language, values, and experiences (Dwyer and Buckle, 2009). This further provided a rapidity of acceptance, legitimacy, and empathy that can allow participants to be quicker to open up and provide a greater depth and richness of data collected (Dwyer and Buckle, 2009).

My privileged insider status to unpaid carers was tempered by my outsider status to disabled citizens, as I claim little insight into their lives. A researcher as an outsider will lack the depth of understanding of a study’s population (Kanuha, 2000; Greenwood and Levin, 2007). This lack is foregrounded with marginalised populations, where researchers can struggle to understand complex ecosystems they are distant from, risking false assumptions and unhelpful interventions with negative consequences (Suchman, 2002; Williams and Gilbert, 2019; Shew, 2020).

Greenwood and Levin further placed the AR researcher in the role of a “friendly outsider” (2007, p. 124), using the researcher’s facilitation and research skills to work with participants to co-design change and its evaluation (Hayes, 2011). My positionality changes this to more of a ‘friendly insider’ - with the same role and function as discussed by Greenwood and

Levin, but with the added experience of the context under examination and ease of empathy with participants.

Finally, my positionality and experiences as an unpaid carer gave rise to my principles that directed me to ensure this study's research engagements were to be planned and performed with respect; that the citizens in this study were to be empowered by leveraging the knowledge that arises from their backgrounds and experiences; and that the research outcomes must be sustainable.

3.2.2. The Research Paradigm

Arising from my positionality and principles was the selection of an ontological stance that encouraged the researcher to be embedded in the field of study, that the researcher will bring their own set of beliefs and values to the understandings gained through data collection and analysis (McNiff and Whitehead, 2011).

Hence, this research had to acknowledge the entanglement of a researcher with their communities (Suchman, 2002; Dimond *et al.*, 2013; Bettega, Masu and Teli, 2021). The ensuing subjectivity arising from my positionality was to be viewed as a positive, partial "situated knowledge" resource (Haraway, 1988, p. 581; Howard and Irani, 2019; Braun and Clarke, 2021, p. 39; Bowman *et al.*, 2023). The beliefs and values I possess from my positionality were not to be deprecated as bias but observed as leading to the social construction of knowledge (Haraway, 1988; Hayes, 2011). This stance aligned with the research questions posed in the Introduction chapter that relate to the personal experiences and practices of disabled citizens and unpaid carers as PHB holders and their relationships with the ones they give care to, their peers, and their healthcare authorities.

As such, a critical realist approach (Frauenberger, 2015) leading to a constructivist philosophy (Frauenberger, 2020) was appropriate, as this accepts the existence of an objective reality yet recognises personal understandings and knowledge, and hence interpretations, of that reality. This approach is derived from the creation of our knowledge and beliefs based on our unique experiences, grounded within our social and cultural environments, knowledge evolving the further we explore and interpret our findings (Braun and Clarke, 2013, pp. 27–30; Frauenberger, 2015; Duarte and Baranauskas, 2016; Varpio *et al.*, 2021).

This provided an ontological view that was "softer, personal" (Cohen, Manion and Morrison, 2007, p. 8), delivering an epistemological perspective that directed this research to gather and analyse personal experiences, values, and beliefs, with the researcher working alongside and with the participant. In the context of HCI, the participants' and the researcher's knowledge and beliefs would influence how technology was to be shaped and interacted with, the philosophical standpoint surfacing the complex intersections between technology and individuals' social and cultural practices (Frauenberger, 2015).

Qualitative methods are suited to a constructivist stance as they can collect multiple perspectives, with interviews and focus groups working well to capture participants' subjective experiences (Duarte and Baranauskas, 2016). Such methods provide rich datasets of personal contexts and allow the participants to become involved in the research. These benefits further led to my discounting the use of first-person methodologies such as autoethnography and autobiography, as these would have limited the emphasis and collection of data from a variety of perspectives other than myself (Lucero *et al.*, 2019), such as different cohorts of PHB holders including unpaid carers and disabled citizens, different CCGs, and from citizens across England.

This involvement of the participants can lead to a more user-centric, democratic, and socially responsible design that reflects the needs and values of the community that the technology is intended for (Bannon, 2011). Though of note is that the participants often comprise a small group compared to the population targeted, so only a partial representation becomes available. This is because the time demanded for participatory engagements dictates that they do not readily scale to involve larger groups (Spinuzzi, 2005), especially within the resource constraints of a PhD project.

Critical realism as a philosophical approach can deliver shortcomings, as although it provides a means to gain insights and understandings of people's lives, these are inherently complex and may not lead to clear design considerations for technological interventions (Frauenberger, 2015). As a balance, Participatory Design (PD) was employed in this study as a methodology that actively involves participants in the design process to gain their understandings (Spinuzzi, 2005; Frauenberger, 2015; Bardzell and Bardzell, 2016). PD was used alongside Action Research (AR), leveraging AR's iterations of reflection and learning to verify and progress these understandings (Hayes, 2011; Frauenberger, 2015).

In summary, applying a critical realist approach and a constructivist philosophy provided for the multiple beliefs of the researcher and participants, with data to understand these beliefs collected through the qualitative methods within AR and PD.

3.2.3. Leveraging the Theory of Care Ethics

This research surrounded the lives of caring of disabled citizens and unpaid carers, demanding that the activities of care be described.

Glenn (2010, p. 5) defined care "as the relationships and activities involved in maintaining people on a daily basis and intergenerationally." Puig de la Bellacasa (2011, p. 90) described caring as a material activity that involves "doing". Fisher and Tronto (1990, p. 6) defined care as,

> … a species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web.

Such definitions from feminist scholars are centred on the activities and relationships of care, embedded in the social and the political, forming an essential element of the democratic citizen (Tronto, 1993; Mol, 2008; Puig de la Bellacasa, 2011).

The theory of care ethics[4] is founded on such caring activities and their relations. An alternative to considering care as an abstract, individualised, internal set of morals or virtues aligned to societal obligations, to one that focuses on real people in real need (Held, 2004; Toombs, Bardzell and Bardzell, 2015; Light and Seravalli, 2019; Alam and Houston, 2020). Care ethics looks to the interdependence of individuals and the importance of caring with empathy and compassion. This stance allows aspects of caring more traditionally thought of as care work, such as familial care and healthcare, to be extended onwards to social justice, care research, and sustainability of research outcomes (Toombs *et al.*, 2018).

The theory arose from the work of feminist care ethicists Gilligan (1977), Fisher, and Tronto (1990; Tronto, 1998), who responded to the more traditional moral theories that focused on individual rights and duties. Fisher and Tronto (1990; Tronto, 1998, 2013, p. 23) defined care ethics in terms of five activities of care that establish "to care well" (Tronto, 2015, p. 5). This as a process and a practice, providing a framework for both examining care work and for political change.

The first activity within care ethics is *caring about*. This is when the need for care in another person is identified, requiring the care quality of *attentiveness*. This quality allows caregivers to recognise accurately the need for care from the perspective of the cared-for, and to understand who controls the nature and priorities of the care.

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[4] Also known as care ethics, the ethics of care, or EoC.

Caring-for takes on the duty of providing care, with the care quality of *responsibility* as an internalised personal decision or an obligation enforced by societal norms, such as within a contract of employment.

Caregiving requires the quality of *competence* for providing care, not in a personal, introspective sense, but for the caring tasks delivered.

Care receiving demands *responsiveness* from the cared-for to establish whether the caregiving is meeting the care needs, this in turn requiring a cyclical return to *caring about* and the attentiveness of the caregiver to the cared-for.

Caring with is a supplemental activity for collective caring, which moves from the individual caregiver to that of collective responsibility for caring within a democratic society, encompassing aspects of solidarity, justice, and equality.

A further type of caring is when the caregiver has little or no interest in reacting to negative feedback from the cared-for, described as *virtue caring* by Noddings (2012, p. 53). In this scenario, the caregiver highlights their virtuous acts of care and moves responsibility onto the cared-for to use the provided care effectively.

Care ethics has been extended by authors such as Engster, who added to the work of Fisher and Tronto to place the theory more at the personal level, where one person confronts another and reacts to their needs, caring then focused on the "development and well-being" of the cared-for (Engster, 2005, p. 51). This led Engster to three approaches for how someone can be cared for: first, the five qualities above from Fisher and Tronto; second, by supporting the caregivers of that person; and third, by developing programmes of care that directly support the cared-for. These latter two approaches resonate to this study with its focus on unpaid carers and disabled citizens.

The theory of care ethics acknowledges that care is interleaved with conflict, with a seemingly never-ending need, shifting priorities, and limited resources - at the personal, organisational, and political levels.

Designing and evaluating technologies in HCI can leverage care ethics as it offers a framework that supports care practices and equitable, responsible relationships (Key *et al.*, 2021; Tseng *et al.*, 2022), placing designers as "custodians of care" (Light and Akama, 2014, p. 160) - responsible for care in the design of technologies (Toombs, Bardzell and Bardzell, 2015). Care ethics can inform HCI as a lens to the needs and experiences of caregivers and care receivers, their relationships with their healthcare authorities, and the implications of technologies that affect these actors, their practices, and relationships (Toombs, Bardzell and

Bardzell, 2015; Toombs *et al.*, 2017; Howard and Irani, 2019; Alam and Houston, 2020; Karusala *et al.*, 2021). Further, HCI has extended care ethics to the more-than-human, for example, the Internet of Things (IoT), where the qualities of caring can be applied to the design and assessment of technology (Puig de la Bellacasa, 2011; Meng, DiSalvo and Zegura, 2019; Key *et al.*, 2021).

Hence, the theory of care ethics is well-placed for this study, with its focus on: the activities of caregiving and care receiving as opposed to abstracted notions of care; the relationships between the caregiver and the care receiver, the unpaid and paid carers, and the state and the citizen; and the inclusion of technology and its assessment.

However, the use of care ethics in HCI needs to be questioned in its ability to address issues of power and inequality, particularly in terms of its intersection with race and gender (Rankin, Thomas and Joseph, 2020). Patricia Hill Collins and her work on intersectionality, power, and social structures, argued that traditional ethics does not address marginalised groups, declaring that factors such as power dynamics and social inequalities are to be considered, thus providing a more inclusive and equitable approach (Hill Collins, 2000). Hill Collins' emphasis on the perspectives of marginalised groups can help HCI to identify gaps in design. This is by ensuring that the technologies created are more inclusive and accessible, to include marginalised groups' voices and act upon them (Rankin, Thomas and Joseph, 2020; Erete *et al.*, 2021), rather than viewing this disabled population as one of needs and lacks. Rankin, Thomas, and Joseph (2020) also ask HCI to consider intersectionality in our designs by asking questions such as: Who are we considering in our designs? Who inputs into our designs and do they represent the marginalised community we are addressing? Are we researching with, not on, our participants? These questions demand consideration within this study, which are responded to in the Discussion chapter, section 8.3.1.

In summary, the theory of care ethics can be leveraged to inform the design and evaluation of technologies, stressing the importance of examining power dynamics and social inequalities when designing for a marginalised population. This aligns with constructivism, which asks us to account for an individual's beliefs, experiences, and views. Hence, both perspectives ask HCI to consider the individual - leading to more meaningful and inclusive technology design.

With the aim and research paradigm set, the methodologies of AR and PD are next discussed.

3.3. Action Research

An early consideration for this research was the risk that a lack of guiding HCI literature on self-directed care budgets would lead to embarking on an approach that would fail to deliver change. A response from HCI to address this risk is the use of Action Research (AR), as a key characteristic of AR is its iterative approach of performing action, gaining learning, and then planning iterations based on the learnings (Hayes, 2011).

3.3.1. Features of Action Research

AR's set of features is of applicability to this study - it is collaborative, democratic, seeks scholarly knowledge, and sustainable social change (Hayes, 2011).

These features direct researchers to work with participants who are dealing with issues in their lives. Hence, AR focuses on localised problems of importance to the participants. 'Localised' in this context need not be restricted to a geographical nature but to participants that share a context within their lives and hence share a common set of problems. This localisation can form a barrier to generalisability, as any responses to these problems are likely to be highly contextualised. AR does not see this as an issue, instead, it seeks the transferability of outcomes and reliability of research findings (Hayes, 2011). Transferability can be attained by including detailed descriptions of the research, its participants, activities, and engagements. These allow the reader to make a valued judgement on whether the findings are sufficiently appropriate and trustworthy to be applied to the context they are studying (Stringer, 2007, p. 59; Hayes, 2011).

The credibility of the research supports this trustworthiness. Here, AR favours prolonged engagements, where tacit knowledge can be elicited and a deeper relationship built between researcher and participant based on extended conversations over and between engagements (Hayes, 2011). Credibility is delivered through seeking multiple perspectives as a form of triangulation, this was achieved in this study by engaging with individuals in their various roles: unpaid carers, disabled citizens, VCSE organisations, and state healthcare officers. Credibility is furthered by evaluating the 'workability' of responses delivered by the research (Greenwood and Levin, 2007, p. 63), this links the theoretical, scholarly knowledge that has been gained, to action in the field aimed at delivering positive responses to participants' issues.

In addition, AR supports this study's epistemological view of constructivism, that knowledge is not just formed from multiple social constructs but evolves as the researcher's understanding evolves (Stringer, 2007, p. 127), acknowledging the skills and knowledge of both participants and researcher (Greenwood and Levin, 2007, p. 96).

3.3.2. Background of Action Research

AR is credited to Kurt Lewin in the 1940s, who ‘allowed’ researchers to be deeply involved with participants rather than as the traditional remote observer. This involvement formed an alternative to research’s positivist approach when applied to complex societal issues (Lewin, 1946), recognising that social problems are to drive inquiry and that there was a need for practical responses.

Lewin mapped out the iterative stages of AR: a ‘plan’ stage that begins with a general idea, moves to aims and objectives, fact-finding, and a detailed plan; an ‘act’ stage where the plan is executed; and last, the ‘reflect’ stage where the cycle is evaluated and learnings taken. These stages repeated with the learnings from one cycle influencing the next as a “spiral of steps” (Lewin, 1946, p. 38).

These stages were endorsed by Hayes’ foundational HCI paper on AR (2011), illustrated in Figure 4, and applied to this study as follows: i) the plan stage contained tasks concerned with planning and designing the AR cycle, its methods, and configurations of participation; ii) the act stage located the recruitment and engagements with participants, plus any technology build; and iii) the reflect stage located the data analysis.

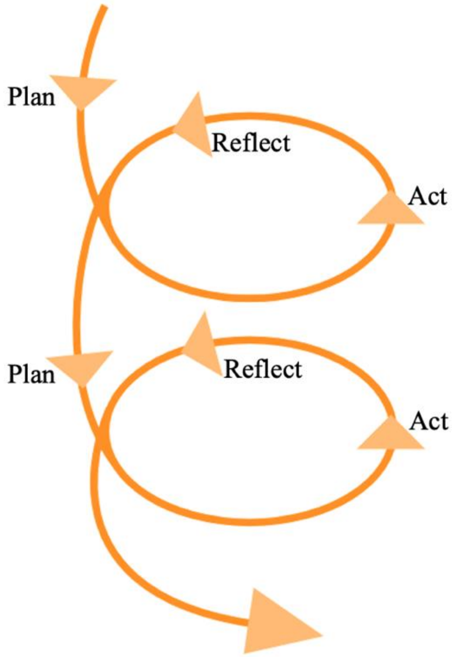

Figure 4: Iterative spiral of Action Research (Hayes, 2012)

3.3.3. Sustainability Demands of Action Research

A caution from Hayes (2011) regards the sustainability of innovation. Research projects are often short-term, dictated by funding cycles that tend to focus on creating novel products rather than attending to questions of sustainability and democratic considerations for the empowerment of participants (Crabtree *et al.*, 2003; Olivier and Wright, 2015; Bødker and Kyng, 2018). It is critical to be reminded that as research projects conclude, the participants remain in place as do their societal issues that AR was to address.

A successful AR project provides for sustainability, embedding innovations as enduring and dependable. As argued by Maria Puig de la Bellacasa, sustainability extends beyond mere availability, it pertains to a "matters of care" approach (2011, p. 89), where technology demands ongoing maintenance and ethical care, ensuring continued relevance and utility (Krüger *et al.*, 2021). This feature is a topic of significant importance in HCI, particularly in relation to healthcare interventions, where outdated or inaccurate guidance could lead to harm.

However, achieving sustainability poses substantial challenges to HCI founded on the typically short-term nature of research, leading to reduced software reliability and a withdrawal of skilled resources and finances (Nicholson *et al.*, 2021). HCI literature offers strategies for addressing these challenges focused on designing sustainable solutions within a community context (Parker, 2013; Marttila, Botero and Saad-Sulonen, 2014; Silberman, 2015; Sun, McLachlan and Naaman, 2017; Poderi and Dittrich, 2018; Shew, 2020; Bettega, Masu and Teli, 2021; Krüger *et al.*, 2021; Nicholson *et al.*, 2021). Key learnings have been to foster community ownership through the community's involvement in the design (Taylor *et al.*, 2013; Nicholson *et al.*, 2021), designing for governance and hence sustainability throughout the design process (Ostrom, 1999; Parker *et al.*, 2012; Marttila, Botero and Saad-Sulonen, 2014; Crivellaro *et al.*, 2019; Harrington, Erete and Piper, 2019; Bettega, Masu and Teli, 2021), and minimising financial demands by using virtual servers (O'Hara, Perry and Lewis, 2003).

Further, HCI studies suggest that the co-creation of a digital commons can facilitate consideration of democratic questions of sustainability, mitigating upfront in the co-design process the ethical implications, complexities, and costs associated with the long-term maintenance of novel computer systems (Ostrom, 1999; Silberman, 2015). Though of note is that the open-source software often used for such endeavours due to its community ethos (Marttila, Botero and Saad-Sulonen, 2014; Teli, Di Fiore and D'Andrea, 2017), cannot be taken to imply that citizens with low technical skills can access all its features (Manuel and Crivellaro, 2020; Hamm *et al.*, 2021).

With AR as one methodology for this study, the methodology of new PD is now described.

3.4. New Participatory Design

New Participatory Design (new PD) (Bødker and Kyng, 2018) is used as a co-existing methodology to AR in this research due to its inherent nature of working with participants, furthered here as a conscious sharing of power between HCI researcher and participant (Harrington, Erete and Piper, 2019). New PD in this context recognises the role of the researcher as one that supports the configuration of participation, to elevate participants as collaborators in the research rather than directing their participation to being solely that of informers (Vines *et al.*, 2013; Bødker and Kyng, 2018; Rajapakse, Brereton and Sitbon, 2021).

This positioning of participants as collaborators gains criticality when researching with a marginalised population, as participatory methods support them to take part in the design of technology that meets their needs (Anuyah, Badillo-Urquiola and Metoyer, 2023), guarding against technology solutionism (Williams, Boyd and Gilbert, 2023).

3.4.1. Origins and Transitions of Participatory Design

Participatory Design (PD) has its origins in Scandinavia in the 1970s and 1980s. The emerging use of technology in the commercial world impacted on the workforce, but that same workforce was granted little or no involvement in its design or in gaining expertise in that technology (Beck, 2002).

As a political research practice, PD addressed these imbalances through training and collaboration with trade union members (Beck, 2002; Vines *et al.*, 2013; Bødker and Kyng, 2018). PD was a means to empower the workforce democratically, partnering their unions with management and academia (Spinuzzi, 2005).

This ‘classic’ PD aimed to include a diverse set of stakeholders in the cooperative design of technology. This was to promote the democracy of end-users in design workshops and other sessions, decentring expertise as all participants were seen as having skills but could also gain skills from others (Bardzell and Bardzell, 2016).

The advantage to the management of PD was that it created technology that was optimised through the leveraging of the end-users’ knowledge, bringing efficiencies and improved system designs (Bødker, 2015). Further, the workforce’s engagement in the design meant they had invested in the technology, easing its adoption into the workplace. These perhaps more capitalist advantages to PD are in contrast to its emancipatory agenda and birth in the labour movement, the approach shifting away from the political to a focus on user-centred design (Bannon and Ehn, 2012).

With the trade unions' influence weakening and technology becoming an everyday artefact (Bødker and Kyng, 2018), PD became seen as a methodology where users no longer partnered in design. Instead, they could be brought in at the start of a software project to elicit requirements, then at the end to review a finished artefact, perhaps as a 'box-ticking exercise' of user involvement (Light, 2010; Williams, Boyd and Gilbert, 2023). This shifted the emphasis of PD to tools, design methods, and facilitation techniques aimed at improving the efficiency of design (Gautam and Tatar, 2020).

3.4.2. A Shift to New Participatory Design

HCI authors have called out for PD to return to the political for over a decade, looking to processes that fostered the infrastructuring of publics around matters of concern (Ehn, 2008; Bossen, Dindler and Iversen, 2010; Le Dantec and DiSalvo, 2013; Bødker, 2015).

Bødker and Kyng's response is contained in their inspirational paper, "Participatory Design that Matters - Facing the Big Issues", which called for a "new PD" (2018, p. 10). New PD formed an attempt to renew PD's original democratic and political aims of supporting power redistribution and conflict negotiation - to challenge hegemonic forces that act upon participants.

The authors viewed HCI as having leveraged PD for the "small issues" of life (Bødker and Kyng, 2018, p. 2), such as designing products and systems that end-users liked to use, rather than those that made major changes to lives and ambitions.

The "big issues" (Bødker and Kyng, 2018, p. 1) are referenced as those issues that are centred not on technology but on the participants' social and political lives beyond the research project. This view responds to the original objectives of PD: to work in partnership with those the technology will impact, to gain knowledge of their implicit and invisible work practices, to produce artefacts or reimagined ways of working cooperatively and iteratively (Spinuzzi, 2005).

Bødker and Kyng set out five elements for this new PD. First, research projects are to address topics where dramatic, negative changes are in progress, this is a call to action for researchers and participants. Second, the participants are to drive the project. Third, researchers are to take up dual roles of researcher and activist, "working for a vision that they believe in, a vision of great importance to them, and of great importance to their partners" (Bødker and

Kyng, 2018, p. 17). Fourth, the core project deliverables are to be sustainable and of high impact - delivered through high technological ambitions. Last, project deliverables are to be safeguarded and maintained through democratic control - this demands an educational agenda for the participants to gain the skills to develop, administer, and maintain the deliverables. This study aligns with these elements in its context of supporting disabled citizens and unpaid carers, by aiming to alleviate their lives of caring within a personalised care paradigm.

However, limitations exist with the new PD approach. The active involvement of participants and the educational agenda demands their time, which can be a scarce resource for marginalised participants (Anuyah, Badillo-Urquiola and Metoyer, 2023). Also, participants may not want to be trained in technology, having other priorities in their lives (Pedersen, 2016). Further, high technological ambitions can be at odds with sustainability, as ‘leading edge' innovations will have minimal supporting infrastructures, and are in contrast to the favoured social, rather than technical, innovations supported by other authors (Björgvinsson, Ehn and Hillgren, 2010; Le Dantec and DiSalvo, 2013; Teli *et al.*, 2020).

With AR and PD set as two methodologies that guide this research, the following section describes how these two methodologies deliver a unified approach for this thesis.

3.5. Unifying Action Research and New Participatory Design

Bødker and Kyng state that new PD is intertwined with AR (2018, p. 25), as the two methodologies share characteristics of collaboration, democracy, seeking scholarly knowledge, and sustainable social change (Hayes, 2011). Indeed, Participatory Action Research (PAR) could be viewed to cover the use of both AR and PD, as PAR is founded on AR but with attention directed to collaborative research with communities and academia aimed at social change (Stillman, 2013). Yet, the five elements described within new PD (Bødker and Kyng, 2018, p. 10) resonated with my positionality to the extent that I selected AR and new PD as the methodologies for this research.

The two methodologies further bring their own affordances that resonate with this thesis. AR is iterative, allowing progressive problem-solving through an iterative approach (Hayes, 2011). New PD focuses on participatory involvement where those with expertise are empowered to contribute to design (Bødker and Kyng, 2018).

The following section describes methods for engaging with a marginalised population of disabled citizens or unpaid carers.

3.6. Research Design

The majority of the participants in this study were disabled citizens or unpaid carers, hence the design of their participation demanded particular care and attention, discussed in the following sections.

3.6.1. Considerations for HCI to Engage with a Marginalised Community

Movements such as disability justice (Charlton, 1998) and health activism in HCI (Parker, 2013; Talhouk *et al.*, 2018) have advocated for research that foregrounds participants' lived experience, positioning them as active co-creators (Karasti and Baker, 2008; Sanders and Stappers, 2008; Björgvinsson, Ehn and Hillgren, 2010, 2012; Harrington, Erete and Piper, 2019).

Collaborative design and collective action with marginalised and underserved populations present challenges for citizens and HCI researchers. The citizens' participation in face-to-face workshops and other group activities is inhibited by the social barriers that led to their isolation, such as the unpredictability of their lives arising from their care priorities and responsibilities (Long *et al.*, 2017). Travelling from their homes to, for example, a university, could be an undertaking of significance - requiring a disabled citizen to use specialist transport, or an unpaid carer to fund a specialist paid carer to backfill their absence from caring. The impacts of this were called out in the study by Long et al., where the authors used interviews, cultural probes, and workshops, finding participation was reduced in the workshops "due to the intensity of their care routines, or decline in their cared-for's health" (2017, p. 1342). These constraints were compounded by COVID-19, as a disabled citizen can have a lowered immune system or breathing issues that result in infection being high risk, so face-to-face engagements and sending cultural probes could not occur during the pandemic.

Another challenge for researchers to engage with a marginalised population is the likely knowledge distance between themselves and the participants (Waycott *et al.*, 2016; Vyas, Durrant and Vines, 2022). Suchman discussed this in her "Making Work Visible" article (1995), discussing that the greater the distance, the simpler the view of others' work becomes. Suchman's discussions were based within a law firm, where those with high professional status perceived the work of those distant and lower in the hierarchy as unskilled, where on close examination it proved otherwise. I see the transferability of this distance to this study's marginalised population, whose duties from afar could be seen as delimited to simplistic, hands-on care. However, the distance can be lessened by working alongside participants long-term and including them in the design of engagements, as practised in this study as respectful design (Rajapakse, Brereton and Sitbon, 2021; Bettega *et al.*, 2022).

HCI has employed varying approaches to working with marginalised and vulnerable groups, such as assets-based design, design justice, and value-sensitive design (Anuyah, Badillo-Urquiola and Metoyer, 2023). I employed “Respectful design” (Rajapakse, Brereton and Sitbon, 2021, p. 1) in this study as it uses mutual learning and empowerment to collaborate on design, delivering benefits by building and maintaining trust through long-term engagements based on respect for the individual participant (Rajapakse, Brereton and Sitbon, 2021). ‘Design’ in this context describes the process of design rather than the outcome of a design process. ‘Respect’ in this sense being at the individual level rather than the societal (Seymour *et al.*, 2022), to allow for the uniqueness of an individual rather than assuming people can be grouped together because of a common characteristic. Rajapakse, Brereton, and Sitbon’s (2021) approach was not to dictate methods for design, but to empower participants to have a voice by considering their constraints of participation. Their study took place with individuals with cognitive or sensory impairments and although their context differs from this study, the aim remains, for participants that have unique requirements and abilities to participate meaningfully in engagements.

HCI literature contains examples of working with populations that require this elevated attention to respectful design. Examples being when researchers met with participants in their homes with one family at a time or at specialist care centres that the participants already attended (Rajapakse, Brereton and Sitbon, 2021). This approach also seen in other literature (Albinali, Goodwin and Intille, 2009; Chen, Ngo and Park, 2013; Ammari and Schoenebeck, 2015; Bosch and Kanis, 2016; Frauenberger, Makhaeva and Spiel, 2016; Hornof *et al.*, 2017; Yamashita *et al.*, 2017; Gui, Chen and Pine, 2018; Li *et al.*, 2018). Cultural probes have been used as in Crabtree et al.’s work (2003), surveys (Schurgin *et al.*, 2021), and working with groups in focus groups and workshops (Kane *et al.*, 2012; Lindsay *et al.*, 2012; Piper *et al.*, 2016; Morrissey *et al.*, 2017; Hodge *et al.*, 2018; Unbehaun *et al.*, 2018).

With the considerations for participation described, the following sections address how these will be accounted for.

3.6.2. Asynchronous Remote Communities

An HCI method that addresses issues of participation is that of Asynchronous Remote Communities (ARC), which leverages online social media communities to examine the posts from participants. The first study involved people with rare diseases (MacLeod *et al.*, 2016), where the authors created and ran a Facebook[5] group for 22 weeks to explore participants' life experiences. Shortcomings included Facebook algorithms controlling whether researcher postings were notified to participants, participants directly posting to the researchers that negated the group participation, and issues with activities that were not understood by participants. Over and above these shortcomings were recommendations to add socialisation activities and to promote familiarisation among participants by recruiting homogenous populations (MacLeod *et al.*, 2016).

ARC has since been used with pregnant participants (Prabhakar *et al.*, 2017), people with HIV (Maestre *et al.*, 2018), young adults to discuss their mental health (Bhattacharya *et al.*, 2019; Meyerhoff *et al.*, 2022), LGBTQ+ communities (Liang *et al.*, 2020; Walker and DeVito, 2020), Black young adults (Harrington and Dillahunt, 2021), and parents and children (Garg, 2021; Michelson *et al.*, 2021).

Authors have extended the method by using community software such as Slack[6] (Bhattacharya *et al.*, 2019), WhatsApp[7] (Lambton-Howard *et al.*, 2019), and purpose-built software (Meyerhoff *et al.*, 2022). Advantages have been discussed, such as participants having time to consider their responses, dominant personalities not being free to override the voices of others, and the flexibility and anonymity that asynchronous engagements deliver (Bhattacharya *et al.*, 2019). Recommendations have been made to be mindful of participants' access to technology and to consider holding activities at regular intervals to promote engagement (Prabhakar *et al.*, 2017; Maestre *et al.*, 2018). Such studies have offered lessons for using ARC and confirmed its viability for stigmatised, remote, or time-constrained populations.

To date, ARC has been delimited to asynchronous sessions, though the incorporation of synchronous has been recommended by HCI practitioners (Maestre *et al.*, 2018; Bhattacharya *et al.*, 2019).

ARC has been discussed as being unable to engage participants in group activities to gain the same level of richness that face-to-face engagements can provide, this is perhaps a reason that

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[5] https://www.facebook.com/

[6] https://slack.com/intl/en-gb/

[7] https://www.whatsapp.com /

ARC studies have been restricted to collecting experiences and co-design at the theoretical level (Harrington and Dillahunt, 2021). AR cycles 1, 2, and 3 in this study describe how ARC was reconfigured and extended through the addition of optional synchronous engagements, novel engagement tools, long-term engagement, long-duration asynchronous sessions, and an educational agenda.

Regardless of the challenges and opportunities in gaining meaningful participation from a marginalised population, tackling healthcare infrastructuring issues at the system level require the assemblage of citizens and the involvement of civic authorities, which the next section addresses.

3.7. Working Together

In this section, the focus shifts to how citizens can assemble to effect change in the context of care and infrastructuring, discussing two types of collaborative actions - coproduction and commoning. The first section describes differing assemblages of citizens with their purposes and styles of governance.

3.7.1. Assembling Citizens for a Common Cause

As discussed in the Literature Review, the shifting of healthcare infrastructuring from a state responsibility onto disabled citizens and their unpaid carers has both benefits and challenges. Whilst personalised care provides disabled citizens with choice and control, there are concerns about the neoliberal offloading of responsibility without adequate support.

For citizens to address injustice at the societal level requires them to come together to form a collective voice. This assemblage aligns with the definition of a ‘public’ from John Dewey: people with a common cause congregating to debate “common concerns” (1927, p. 209). When the debate progresses to taking action such as in this study, Spade (2020, p. 137) expresses these assemblages as ‘movements’, seeing them as spaces where help can be both provided and sought, exposing system failures, learning about the system in context, forming responses, and building solidarity to make social change. Such movements were assembled in AR cycles 1, 2, and 3 - created to debate and to take action, similar to those discussed by HCI practitioners (Le Dantec and DiSalvo, 2013; Vlachokyriakos *et al.*, 2018; Crivellaro *et al.*, 2019).

Spade (2020, p. 142) raises a potential harm here, seeing that neoliberalism relies on “social safety nets” such as movements and publics, rather than state welfare, in that citizen assemblages are formed to create new ways of working to circumvent system failures. These assemblages can then be seen as supporting neoliberalism and its negative outcomes, rather than being in place to fight the state and its deficiencies (Spade, 2020, p. 142). Such outcomes were recognised in Digital Civics, where citizen participation in civics matters was called out as explicitly not for "finding ways of making citizens do it for themselves" (Olivier and Wright, 2015, p. 2). Instead, to turn to the relational, the citizen and their civic working together in coproduction across their differences (Muir and Parker, 2014; Olivier and Wright, 2015).

The challenge is the lack of trust and the unbalanced power dynamic that pervades the relationship between the citizen and their public authorities (Corbett and Le Dantec, 2018a; Bates *et al.*, 2020; Cook, 2021). For example, Harding et al. (2015) reported how citizens felt fear and vulnerability when providing information to their civic authorities, even in less personal matters of highway maintenance.

Of note that it is not just the citizens that demand support, public officers also require support in how to find or establish communities, maintain them, and engage with them (Corbett and Le Dantec, 2018a).

A subtype of movement created in AR cycle 1 was a Community of Action (CoA), which provides autonomy to its members in how the community operates and its aims (Zacklad, 2003). Zacklad established the underlying theoretical framework for a CoA within a similar context to this study - an AR project in healthcare that included unpaid carers. The author defined a CoA as being 'structurally open', the members being able to change the informal social structure of the community, being aware of the goals of the community and the means to achieve them. Zacklad also added to the definition of a CoA as being a community where a body of knowledge is created from the implicit and explicit knowledge of its members. This knowledge is then used to improve an externally provided service and to provide peer support within the CoA.

HCI can support these assemblages by taking direction from them in the design and use of technology. For example, Digital Civics seeks to work with citizens to support them in gaining control over their lives, building communities, and coproducing with their local public authorities (Crivellaro *et al.*, 2014, 2019; Olivier and Wright, 2015; Boehner and DiSalvo, 2016; Vlachokyriakos *et al.*, 2018; Dickinson *et al.*, 2019).

This coproducing forms a shift to the relational in participatory engagements, embedded in mutual learning, long-term relationships, citizen empowerment, and technology (Crivellaro *et al.*, 2014; Muir and Parker, 2014; Corbett and Le Dantec, 2018a, 2019). Also, within Digital

Civics and the broader field of HCI, research can endeavour to create safe design spaces and socio-technical processes "for people to come together, imagine and co-create the 'common good' " (Crivellaro *et al.*, 2019, p. 2).

Once the assemblages are in place, the question is raised of how they can achieve change. The following sections outline two methods: coproduction - where action is taken with the service provider; and commoning - where the service provider is typically excluded.

3.7.2. Coproduction

Addressing the social injustices that place the burden of infrastructuring upon the disabled citizen and unpaid carer demands change at the institutional level, one approach to this being coproduction.

Coproduction as a named concept emerged in the late 1970s, with Ostrom et al. (1997, quoted in Aligica and Boettke, 2011) highlighting a blurring between producer and consumer, and the importance of collaboration to build an effective delivery of service. Ostrom (1996, p. 1073) described coproduction in terms of when "… citizens can play an active role in producing public good and services of consequence to them".

Varying typologies of citizen participation exist, including that of Arnstein's "ladder of participation" (1969), see Figure 5. This illustrates an ascending degree of participation, with coproduction occurring towards the topmost rungs as power is increasingly transferred to the citizen.

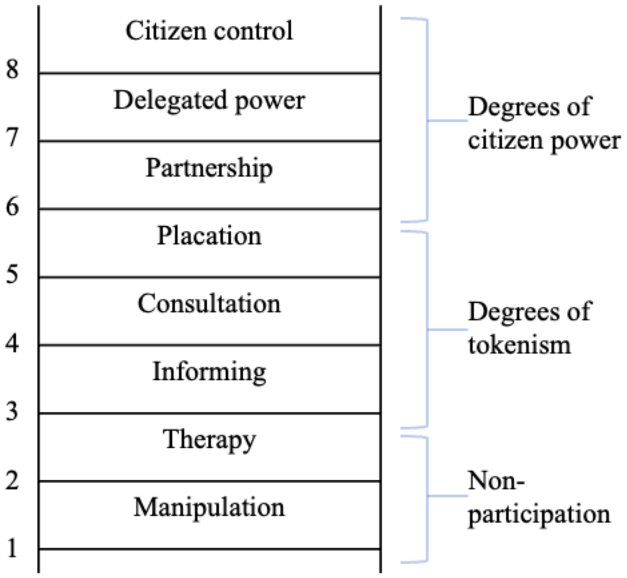

Figure 5: The Ladder of Citizen Participation (Arnstein, 1969)

Arnstein cautioned that coproduction can become a ‘tick box exercise’, undertaken to announce that the public authority has met their goals of including citizens in decision making by simply handing out invitations to meetings. Arnstein described this as “the empty ritual of participation” (1969, p. 216) that maintains the status quo with no relinquishment of power.

A still current issue is the lack of a clear definition. Masterson et al. (2022) found 60 definitions in common use, with coproduction as an umbrella term, ambiguous in use, covering a range of other ‘co’ words such as co-creation and co-design. Without standard definitions, I will use ‘coproduction’ as creating or improving a public service with attendance from citizens that make use of the service and their public authority accountable for that service (Yuan, 2019).

Both citizen and their service provider can gain benefits from coproduction. First, coproduction elevates the role of the frontline workers, recognising that their ongoing interactions with citizens deliver an expertise (Needham, 2008). In the case of healthcare infrastructuring, this could deliver insight to the worker on the invisible care work being performed in homes. Second, the involvement of the citizens can change their stance to being increasingly motivated, involved, and responsible users of the service (Brudney and England, 1983; Leadbeater, 2004; Needham, 2008), based on the move away from a disempowered dependence model or “professional gift model” (Duffy, 1996, pp. 22–23), to one of agency and empowerment. Third, there is the potential for the citizen to become more civically aware with heightened social capital (Ostrom, 1996). Fourth, coproduction can increase ‘allocative efficiency’[8], sensitising the frontline workers and their hierarchy to the needs and desires of citizens (Needham, 2008).

However, an issue in practice with coproduction is that it asks the state to relinquish power to the citizen. This shift in the power dynamic is viewed with scepticism by state staff (Yuan, 2019), who can be reluctant to hand over power to people they regard as unqualified and untrustworthy (Torres, 2007; Holmes, 2011). Ostrom envisaged this - that for coproduction to be successful, especially when it is new to a domain of public service, the motivation of both public officials and citizens becomes critical as there will be a base of “considerable distrust” on both sides (Ostrom, 1996, p. 1081). Though with the potential for coproduction to end

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[8] Allocative efficiency is where production is aligned to consumer preference such that there is a minimum of over or under production.

ongoing “cycles of hostility” (Needham, 2008, p. 223). Ostrom’s recommendation was for the citizen groups to demonstrate enthusiasm, aimed at incentivising the officials, and for both sides to build commitment to each other by encouraging one another to input to debates.

Further, Miller and Stirling (2004, quoted in Needham, 2008) stated that coproduction can be limited by the time and financial pressures on frontline workers and a lack of social capital amongst citizens.

3.7.3. Coproduction in Healthcare

Since the late 1990s, coproduction has been a component of UK healthcare policy as a tool to enhance the provision of public services (Dunston *et al.*, 2009). The approach has been seen as a shift from the transactional, ‘one size fits all’ care service delivery (Needham, 2008; Public Administration Select Committee, 2008), reducing power imbalances and social distances between healthcare providers and recipients of care (Filipe, Renedo and Marston, 2017). This further aligns with the care ethics approach that emphasises the importance of understanding individual needs and values in relationships.

However, Batalden et al. (2016, p. 514) argued that a balance of power and responsibility between the professional and the citizen is “neither possible or desirable”, that the “burden of responsibility” for health errors lies predominantly with the professional, who provides a buffer for when the citizen makes unhealthy choices. The authors expressed concern that citizens would not be able to assimilate and extract the correct healthcare information from all that was available. These views embedded within the medical model.

It can also be difficult and time-consuming for healthcare professionals to engage in coproduction, as specific training is demanded, together with a complex change in the cultural approach to citizens (Boyle and Harris, 2009; Bovaird and Loeffler, 2012; Batalden *et al.*, 2016). These difficulties result in inconsistent use of coproduction, with productivity pressures reverting staff to traditional, transactional methods (Batalden *et al.*, 2016).

Coproduction is an important area of study for HCI as it can potentially improve the usability and accessibility of public services and healthcare technology (Cordella and Paletti, 2017; Yuan, 2019). Additionally, coproduction can help to ensure that such technology is responsive to the needs and preferences of disabled citizens, unpaid carers, and their healthcare providers.

However, with the above challenges for the healthcare state to embark in coproduction with the citizen, issues will likely prevail, forcing the citizens to look to alternative approaches to improve service that do not involve the state - one such alternative being commoning.

3.7.4. Commons and Commoning

Nobel Prize laureate Elinor Ostrom (1999) argued that a physical commons or common-pool resource (CPR), such as a freshwater supply or a fishing area, could be operated sustainably without the intervention of the state or market economics. This challenged a belief of the time that a CPR could not be sustainable because of its inherent over-exploitation - the “tragedy of a commons” (Hardin, 1968). Ostrom argued for design principles that ensured sustainability by the consideration of accountability, visibility, participation, and governance.

These principles have been reused for the design and operation of a digital commons, also known as a wiki, for example, Wikipedia[9] (Marttila, Botero and Saad-Sulonen, 2014). A digital commons in the context of this study shares peer-produced content for community adoption, seen as a response to where resources required by citizens are lacking (Silberman, 2015). As such, a digital commons is based as a collective endeavour within democracy rather than hierarchies, serving as a hub for the distribution of social capital (Teli, 2015; Johnson *et al.*, 2021).

The social process of creating and maintaining a commons is known as commoning (Linebaugh, 2008; Marttila, Botero and Saad-Sulonen, 2014; Baibarac and Petrescu, 2019; Sciannamblo *et al.*, 2021). Commoning both nurtures social collaboration and embeds early in the design process questions of governance that promote sustainability. Hence, commoning is not just about the co-design of the technology, but also about responding to democratic aims through the nurturing of processes that consider how technology is to be governed in the long-term (Harrington, Erete and Piper, 2019).

For commoning to be successful, literature has examined how it needs to be founded in the installed base, account for the transient nature of governance rules and people, and make explicit the transparency of governance (Ostrom, 1999; Marttila and Botero, 2017; Seravalli, 2018; Teli *et al.*, 2020). Further, HCI advocates for the use of open-source software to build a digital commons, seeing the low cost and its inherent community ethos adding to a digital

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[9] https://en.wikipedia.org/

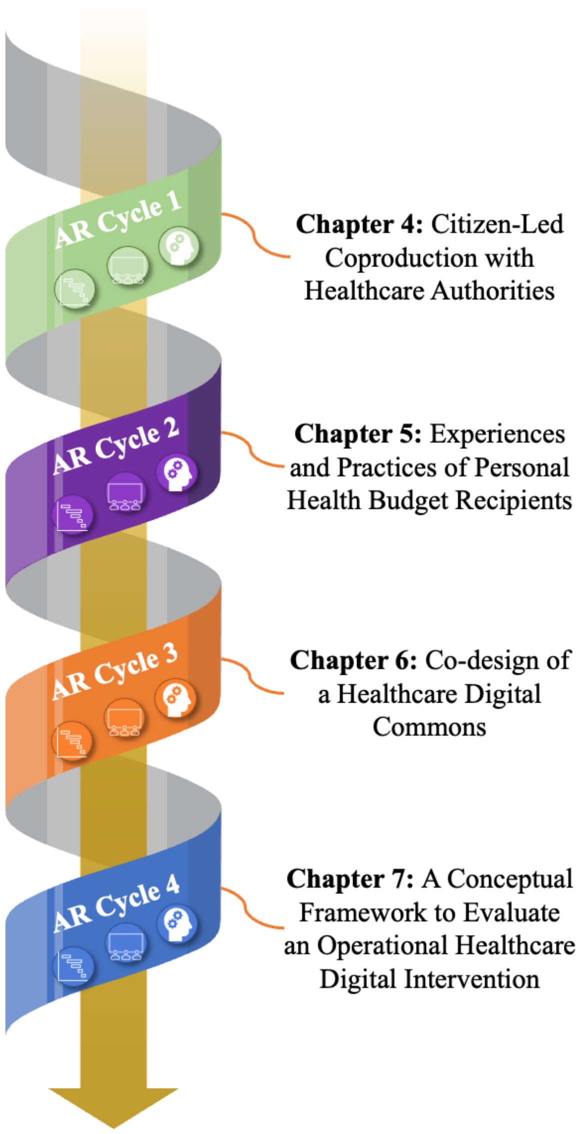
commons’ democratic nature and long-term sustainability (Marttila, Botero and Saad-Sulonen, 2014; Teli, Di Fiore and D’Andrea, 2017; Poderi, 2019; Bettega, Masu and Teli, 2021).

Bettaga, Masu, and Teli (2021) described five tactics that support digital commoning that this study adopted. i) Create design procedures that inspire self-reflection in participants, intentionally moving away from using participants purely as informants. ii) Recognise participants’ requirements and interests to configure their participation more appropriately. iii) Identify participants as groups, as shared activities allow for an easier exploration of digital commoning. iv) Reconsider the use of mainstream tools for designing and exploring alternatives that can better suit the participants. v) Align design technologies to the capabilities of the participants.

With methodologies and methods in place, the remaining sections of this chapter examine the use of AR cycles and topics of data collection, recruitment, data analysis, and ethics.

3.8. Action Research Cycles

Each of the four AR cycles in this study has been aligned to a separate chapter, providing for ease of description. This is illustrated in Figure 6, the diagram based on that from Hayes (Hayes, 2012), reproduced as Figure 4,



Chapter 4: Citizen-Led Coproduction with Healthcare Authorities

Chapter 5: Experiences and Practices of Personal Health Budget Recipients

Chapter 6: Co-design of a Healthcare Digital Commons

Chapter 7: A Conceptual Framework to Evaluate an Operational Healthcare Digital Intervention

Figure 6: The four AR cycles in this study with symbols for plan, act, and reflect

3.8.1. AR Cycle 1 - Coproduction

This first AR cycle began by investigating the infrastructuring challenges in managing PHBs, with a response for the PHB holders to work in coproduction with their healthcare officers.

The plan stage of this AR cycle was used to set aims and objectives - these being for both parties to work together in coproduction to understand and alleviate the issues experienced by PHB holders. The act stage was used for recruitment and engagements, as part of which I facilitated the co-creation of a Community of Action (CoA) with seven parents of children with long-term complex needs based in the North East of England.

An early engagement with the CoA comprised a trial of a method based on but reconfiguring and extending ARC. The engagement was designed to be respectful to this time-pressed community by holding a focus group that was of extended duration, remote, asynchronous /

synchronous, and text-only - in this case using virtual sticky notes. An element of new PD initiated here was to create an educational agenda (Bødker and Kyng, 2018; Bannon, Bardzell and Bødker, 2019) to provide the participants with the skills and experience in the use of such tools - this key to the subsequent AR cycles. The act stage drew to a close with face-to-face and remote meetings between the CoA members and their healthcare officers.

The reflect stage analysed and reflected on the data collected, providing insight into the lives of unpaid carers, their interactions with healthcare authorities, and their expectations from coproduction. Findings illustrated the success of the CoA in providing peer support and the effectiveness of the remote engagement approach that informed the subsequent AR cycles. A perceived failure of coproduction led to a different approach in the following AR cycle to mitigate the social injustices exposed. This new approach bypassed issues of engagement with healthcare officers that the CoA had encountered.

3.8.2. AR Cycle 2 - Experiences and Practices

This second AR cycle was planned to collect additional data on the experiences and practices from a broader set of stakeholders who were at the centre of managing PHBs, and to determine options for ways forward that bypassed the need for healthcare officers.

The act stage of this AR cycle first held interviews with PHB holders that included disabled citizens as well as unpaid carers, but also VCSE staff, and healthcare officers - all from across England. These interviews were followed by a two-week remote focus group that excluded the healthcare officers as part of respectful design. The power dynamic entailing the citizen participants would have felt daunted by the presence of healthcare officers, fearful of their care budgets being cut if their stories were recognised and hence their identities. The focus group was again remote, asynchronous / synchronous, and text-only. However, a different tool was used to that from the first AR cycle, so a survey was undertaken to gather data on the use of this method and tool.

The data collected pointed to the co-creation of a digital commons, this forming the third AR cycle.

3.8.3. AR Cycle 3 - Co-design of a Digital Commons

This AR cycle aimed for the co-design of a healthcare digital commons with the PHB holders and VCSE staff through focus groups and design sessions. Healthcare officers were excluded for the same reasons as in the previous AR cycle.

The plan stage incorporated principles of sustainability from the outset and throughout co-design. This highlighting an ethical imperative of this research of considering the community the technology is targeted at, together with their financial and other resource constraints.

The act stage employed the same core remote method and tool used in AR cycle 2 but repurposed with new tools to elicit requirements, gain feedback on detailed design and prototypes, and discuss governance. These design sessions demanded adding to the educational agenda, as none of the participants, bar one, had any experience in designing technology. Further, I took on the technical design and build, including architectural design, configuration of the servers and network tools, and the construction of the digital commons. The digital commons was deployed in mid-September 2021 following the co-design and technical build.

The reflect stage of the AR cycle comprised analysis of the data collected from the engagement sessions, generating insights of trust, responsibility, and benefits of participation.

3.8.4. AR Cycle 4 - Evaluation of an Operational Healthcare Digital Intervention

This last AR cycle was in place to determine the success or otherwise of the digital commons - in terms of its usefulness and sustainability to its end-users of PHB holders. No appropriate evaluation method was found within HCI literature, hence the plan stage of this fourth AR cycle created a mixed-methods conceptual framework to determine usefulness and sustainability through concepts of usability, usage, sustainability, and caring.

This framework was then applied to MyCareBudget in the act stage. Quantitative data was collected through surveys to ensure that the digital commons was usable as a website. Server and web analytics were captured to provide insights into the numbers and roles of people that were using the digital commons and the functionality that was accessed. Sustainability was assessed through the analysis of maintenance logs. Interviews were held with PHB holders, VCSE staff, and healthcare officers to gain data regarding their use of MyCareBudget.

The reflection stage of this AR cycle analysed the data collected to form insights into the usefulness and caring exhibited by MyCareBudget, leveraging the theory of care ethics. The evaluation found the conceptual framework was of value and that MyCareBudget offered both usefulness and sustainability to its targeted end-users of PHB holders.

3.9. Data Collection

The constructivist stance and hence the focus on the life experiences of participants led to a predominantly qualitative approach to collecting data (Braun and Clarke, 2013, p. 21; Duarte and Baranauskas, 2016). Note that the non-personally identifiable data is freely available at https://doi.org/10.25405/data.ncl.23367383.v1 .

Interviews were selected as a suitable method for exploring understandings and practices (Braun and Clarke, 2013, p. 81). The interviews were designed as semi-structured, supported by an interview guide that provided a list of questions to be covered but also allowed for the interviewee to raise other topics that could be brought into this study. The interviews were one-to-one, so an interviewee would not feel overwhelmed by a panel of interviewers. Additionally, the interviews served as an 'introduction' for the citizen participants prior to them taking part in group engagements, where they could learn about this research and my background, to begin gaining trust and familiarity in the process, aims, and objectives.

I used focus groups as the other core method for collecting qualitative data (Braun and Clarke, 2013, p. 110), with myself as moderator. I needed these to be safe, such that the participants would feel open about discussing personal issues in their lives of caring with myself and with each other. Associated benefits of focus groups would be helpful to the participants, as they can promote learning and empowerment - the isolated lives of the participants meaning they can believe they are alone in their experiences (Braun and Clarke, 2013, p. 111).

Other methods of qualitative engagements were ruled out. I discounted ethnography as though I had immersion in my family home where a PHB was in operation, this would have been difficult to arrange in others' homes - unreasonable when COVID-19 arose. I also ruled out diaries as they demand time to complete, which the citizen participants were unlikely to have, and other cultural probes due to the risk of them carrying COVID-19.

Exceptions to the qualitative approach took place at two points. One to evaluate the method of remote focus groups in AR cycle 2 where I believed a survey was best placed to gain participants' attitudes and feedback on the usability of the method (Müller, Sedley and Ferrall-Nunge, 2014). Second, as part of a mixed-method evaluation of the socio-technical intervention in AR cycle 4, where I employed surveys and other quantitative methods to inquire into characteristics of use, for example, the number of end-users.

3.10. Recruitment

Participants were drawn from those populations close to the management of PHBs in England: PHB holders as disabled citizens, PHB holders as unpaid carers, healthcare officers that dealt with PHB holders or managed PHB policy, and VCSE organisations that supported PHB holders. These groupings of participants are explained below,

- **Disabled citizens** with life-long conditions but without learning disabilities. For example, individuals with spinal injuries, or advanced nerve or muscle wasting conditions that allowed them to manage and administer their PHBs, though not perform their own physical care. Such disabled citizens used their PHBs to pay for personal assistants (PAs) who carry out personal and medical care, household duties, and provided physical support for the administration and technology required for life.
- **Unpaid carers** as parents of their disabled children of any age, supported by a team of paid carers funded through a PHB to deliver personal and medical care. The child will be constrained by their age and learning disability in that they are unaware of administrative and care management tasks. Their parents acting in their best interests and being their voice and signatory in all affairs.
- **Clinical Commissioning Group (CCG) officers** who are employed by the state to oversee the operation of PHBs within NHSE's personalised care policy. Their differing roles, accountabilities, and responsibilities cover the commissioning of PHBs, directing PHBs, administering PHB payments to citizens, and supporting PHB holders and their families. As such, CCG officers can hold roles that either place them on the frontline, engaging daily with citizens to deal with PHBs, or as more management / executive roles that meet citizens less frequently. Note that I also refer to CCG officers as 'healthcare officers' in this study.
- **VCSE staff** who are employed with VCSE organisations that focus on the care and support of citizens with PHBs.

I use the term 'citizen participants' to group unpaid carers and disabled citizens. 'Citizen' is used to emphasise questions of agency and rights to access healthcare, as well as the unpaid care work they perform. In this regard, I align with the Digital Civics' agenda and its emphasis on considering how HCI design concerns expand and change when viewing people as agents of change rather than passive 'users or consumers' (Olivier and Wright, 2015).

Of note is the overlap across the groupings given above. It was not uncommon, for instance, to find that VCSE staff were also unpaid carers in their home lives. Also, all the disabled citizens above acted as unpaid carers for their PHB administration, though I reference them as disabled citizens as I engaged with them in that capacity. Similarly for CCG officers and VCSE staff who I reference as such unless stated otherwise.

Excluded from this study were the following categories of participants,

- **Paid carers**, though they are intimately close at the point of caregiving, they typically have little or no knowledge of the infrastructuring work demanded for a PHB.
- **Clinicians**, as my initial interviews supported HCI literature that discussed how the onus was placed on the citizen to build their personal healthcare infrastructures to deal with clinical healthcare professionals (Chen, Ngo and Park, 2013; Gui and Chen, 2019). However, these professionals were supplementary to running a PHB and so I ruled this cohort outside the scope of this research.
- **NHSE staff**, as I attended an NHSE Academy for Personalised Care in mid-2019, where I built relationships with staff in the NHSE PHB team dedicated to personalised care and PHBs. The NHSE staff explained that they produced healthcare policies for the CCGs but had no power to direct how, or if, they were delivered by the CCGs. Hence, I chose not to recruit them as they were distant from the frontline delivery of PHB service.
- **Unpaid carers managing social care funding**, for example, citizens caring for their aged family members. Most of this type of care is funded through social care in England rather than healthcare, a form of funding with different sets of organisations, policies, and procedures to those of PHBs.

The sampling strategy within these populations was based on non-probability and convenience (Lenarduzzi *et al.*, 2021), with some snowball recruitment (Gobo, 2004), in that I recruited all those that asked to take part. This does imply that the sampling was non-random, as it only included those who were interested in research and had the time - it is unknown how representative of the population the participants were (Gobo, 2004). Further, the categories of participants that were recruited varied with the requirements of each AR cycle as purposive sampling (Gobo, 2004; Lenarduzzi *et al.*, 2021).

In total, 64 people took part in this study though this varied between the four AR cycles, see Table 1. This total number of participants broadly aligns with the 50 that Braun and Clarke (2013, p. 55) see as the upper end of the sample size for a qualitative study. Data saturation was seen in each AR cycle when coding in Thematic Analysis (Braun and Clarke, 2013, p. 55). That is, most of the codes arose from the analysis of the initial interviews, with the number of new or amended codes markedly tapering off from that point. My belief here is that the sample size in each AR cycle was sufficient, supported by HCI qualitative literature in this context of home caregivers where the sample size was typically less than 20 (Chen, Ngo and Park, 2013; Long *et al.*, 2017; Gui, Chen and Pine, 2018).

AR cycle	Sample size across all engagements for an AR cycle
1	23
2	25
3	20
4 - surveys	27
4 - interviews	23

Table 1: Sample size for each AR cycle, noting many participants took part in more than one AR cycle

3.11. Data Analysis

I selected Reflexive Thematic analysis (TA) for the systematic analysis of the qualitative data created by this research project - stated as a useful method for eliciting the “complexities of meaning within a textual data set” (Guest, MacQueen and Namey, 2012, p. 11). Braun and Clarke (2013, p. 45, 2021) further argued for its applicability to studies such as this research for the following reasons: as an acknowledgement that the interpretation of the data would be subjective; that the research questions are aimed at exploring both personal and relational experiences embedded within their wider socio-cultural aspects; and the use of a range of data collection methods.

I examined other analysis techniques, noting that Braun and Clarke (2021) stated it was rare for one method to be the only ideal one for a study. Interpretative Phenomenological Analysis (IPA) was discounted as though similar in some respects to TA, it is more suited to interviews and to research questions that are wholly focused on experiences; this latter point also discounting Grounded Theory (GT) (Braun and Clarke, 2021). Discourse Analysis (DA) was discounted as the research questions were not restricted to the effects or use of language (Braun and Clarke, 2021).

Complete coding was performed to not delimit any topic of interest (Braun and Clarke, 2013, p. 206), with primarily a semantic viewpoint taken.

I followed the process of six recursive steps laid out by Braun and Clarke (2006): 1) familiarisation of the data; 2) generating initial codes; 3) generating themes; 4) reviewing themes; 5) defining and naming themes; and 6) reporting on themes. An example of how these six steps were applied to a transcribed set of interviews is given below,

1) Import a transcribed interview into NVIVO[10], read the data through and create temporary, 'first-thought' codes in NVIVO and attach the relevant data extract to each one. This first-thought coding and the next step were performed as close as possible after the interview so the engagement could be readily recalled.
2) Re-read the data two or three times and create a first full set of codes.
3) There would be a large set of codes by this point, perhaps 20 or more, so these would be arranged into a hierarchy within NVIVO to generate a set of four to six top-level modes.
4) Read through the hierarchy with any changes resulting in codes moving across the hierarchy, the top-level nodes becoming potential themes. Steps 1 to 4 would then be repeated for each new interview, revising the themes, codes, and hierarchy.
5) Import the themes into Microsoft Word, where they would be described, their names refined, and the themes associated to form a narrative.
6) Copy the themes into a report such as a research paper, where a re-writing would occur, revisiting the research questions and original data extracts. This was then reviewed with my supervisors as a further iterative and reflexive process, debating the influence of my positionality on the analysis (Bowman *et al.*, 2023).

3.12. Methodological Limitations and Mitigations

Specific limitations in the use of this study's methodologies are called out within the text of the relevant sections, 3.3 and 3.4, with more general limitations and their mitigations provided here.

AR has limitations that demand attention when performing research, as AR's multiple cycles require long-term involvement of participants and so I took care to encourage participation. Examples were to hand over elements of decision-making to gain the citizens' ownership, use of small financial payments to show I valued their time, feeding back after engagements, and giving regular project updates to indicate I respected them as individuals, not just informants to 'my' research.

The use of PD delivers benefits through the active involvement of participants seeking change, but there are limitations arising from that feature. First, working with citizens to elicit

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[10] https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

their thoughts and feelings can require gaining and maintaining their trust, especially in sensitive settings such as this study. This requires time and effort from the researcher, exacerbated in the context of this study where the citizens were time-poor, and professional healthcare staff would likely have high workloads that can lead to extended intervals between contacts. Additionally, both groups have priorities of interest that might conflict with the research. These factors required careful planning and extended timescales, though my positionality as an unpaid carer mitigated aspects of these when engaging with the citizens. Second, professional participants are likely to have experience in attending workshops, use of whiteboards, sticky notes, and so on - whereas this might not be the case for citizens. Also, neither group may have the expertise to contribute appropriately to technology co-design sessions. I took care to attend to this when planning and attending meetings as part of the educational agenda, supporting participants to 'have their say'.

3.13. Ethics

I used the ethics process of my university[11] from the outset of this study to gain ethical approval - a response of 'low risk' being the result. This in part as no children were participants, no recruitment took part using the NHS, and all participants had full capacity to understand consent. I revisited this ethics process at the start of each subsequent AR cycle, but no material changes arose.

I gained participants' consent by asking recruits to read a Participant Information Sheet and sign a Consent Form, followed by a Debrief Sheet after their engagement - see Appendix B for examples. I printed these for the participants' signatures in face-to-face interviews and meetings, moving to emailing PDFs and Microsoft Forms for remote engagements. Although the Consent Form allowed for stills and videos to be taken, I asked participants to sign a Model Release form when this occurred months or years after their initial consent.

All participants are referred to using pseudonyms. Individual CCGs, VCSE organisations, and NHSE departments are either not named or pseudonyms are used.

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[11] https://www.ncl.ac.uk/research/researchgovernance/ethics/process/

3.14. Chapter Summary

This Methodological Approach chapter provided the rationale for my selection of the research paradigm, the configuration of participation, and the design of this research.

My positionality and principles directed a choice of a research paradigm that would empower the citizen participants of disabled citizens and unpaid carers to use their whole life experiences. These to gain an understanding of their personal feelings and experiences about managing their PHBs and their responses to issues. Hence, a critical realist approach with a constructivist philosophy was adopted, providing an ontological and an epistemological view embedded in the human and individual aspects of values and beliefs. These decisions led this study to collect and analyse personal values and beliefs through qualitative methods of interviews and focus groups.

The theory of care ethics was introduced, emphasising the importance of recognising and addressing power imbalances in caregiving relationships. Care ethics is leveraged here as a lens for understanding the challenges faced by disabled citizens and unpaid carers, and for developing more equitable technologies for healthcare infrastructuring. Both this theory and the critical realist approach are focused on the individual, their beliefs, and their societal relationships.

Methodologies of AR and new PD were selected, this chapter describing their origins and similarities, with AR leading to the four AR cycles employed in this research to understand and form responses to the issues experienced by the citizens as PHB holders. The use of respectful design guided the configuration of participation, leading to the adaption and reconfiguration of ARC as a method for remote group engagement.

This chapter further proposed coproduction and commoning as potential responses to issues of healthcare infrastructuring, stressing the need for transparency and democratic decision-making in governance processes.

The following four chapters each describe an AR cycle. The first AR cycle holding an initial set of engagements with PHB holders, the formation of a Community of Action, and attempts to coproduce with local healthcare authorities.

Chapter 4. Citizen-Led Coproduction with Healthcare Authorities

> *"Nobody has a clue of what type of thing that you've been through, or the impact that it's had on your life"* - Bella, a mother managing a PHB for her son.

4.1. Introduction

This first of four AR cycles was initially motivated by my desire to corroborate my personal experiences of co-managing a PHB for a family member, which surfaced issues in service delivery from the local healthcare authority.

Beginning with an explanation of the operational aspects of Personal Health Budgets (PHBs) in England, this chapter moves on to discuss how participation from a time-poor population was configured, based on data gathered from semi-structured, face-to-face interviews with five PHB holders from across England. The analysis of these interviews allowed for the design of a remote, asynchronous / synchronous, text-only focus group. Participants for this focus group were seven local PHB holders as unpaid carers assembled by this research into a Community of Action (CoA), their aim to support their peers of local families that have children with long-term complex needs. The CoA chose to engage in coproduction with their local CCG officers, where issues on both sides could be voiced, to deliver change for mutual benefit.

The engagements and subsequent analysis in this chapter provide insights into the unpaid carers' lives of caring for their children, their relationships with their CCG officers, and their expectations of coproduction. A preliminary reflection discusses the success of the remote engagement method, this key for the design of the engagements in subsequent AR cycles.

The following sections lay out the aims and the study design for this first AR cycle.

4.2. Aims, Rationale, and Objectives

My personal experience in supporting a family member in managing a PHB highlighted infrastructural issues with the delivery of service from CCGs. When starting this study, I believed these issues were likely to be widespread and could be alleviated and ameliorated by working with CCG officers who were empowered to deliver change within their CCG. The aim of this work was to deliver meaningful change to PHB holders, initially across my local CCGs, but potentially nationwide.

A core objective was to understand the care practices of other citizens that held a PHB so I could establish commonalities. With a set of issues in hand, these could be taken to local CCG officers to be addressed. My initial thoughts were that resolving issues would reduce the number of formal complaints generated by citizens and hence reduce the workload of the authorities - to the mutual benefit and motivation of citizens and state.

Ancillary objectives were to determine how to engage with the citizens and the CCG officers. Holding frequent 'traditional' face-to-face interviews (this was prior to COVID-19) and group meetings in a university meeting room would not align with the time-poor and precarious lives of caring that the citizens lead. Further, meetings with both CCG officers and individual citizens within the unbalanced power dynamic that I had personally experienced would not be conducive to open dialogue. Hence a form of citizen collective would be required, to work in coproduction to establish a positive, working relationship between the PHB holders and their CCG officers, where issues on both sides could be voiced.

Figure 7 illustrates this first AR cycle and its location with the following cycles, where I planned for an initial set of interviews, followed by creating a Community of Action centred on the North East of England to work in coproduction with their CCG officers.

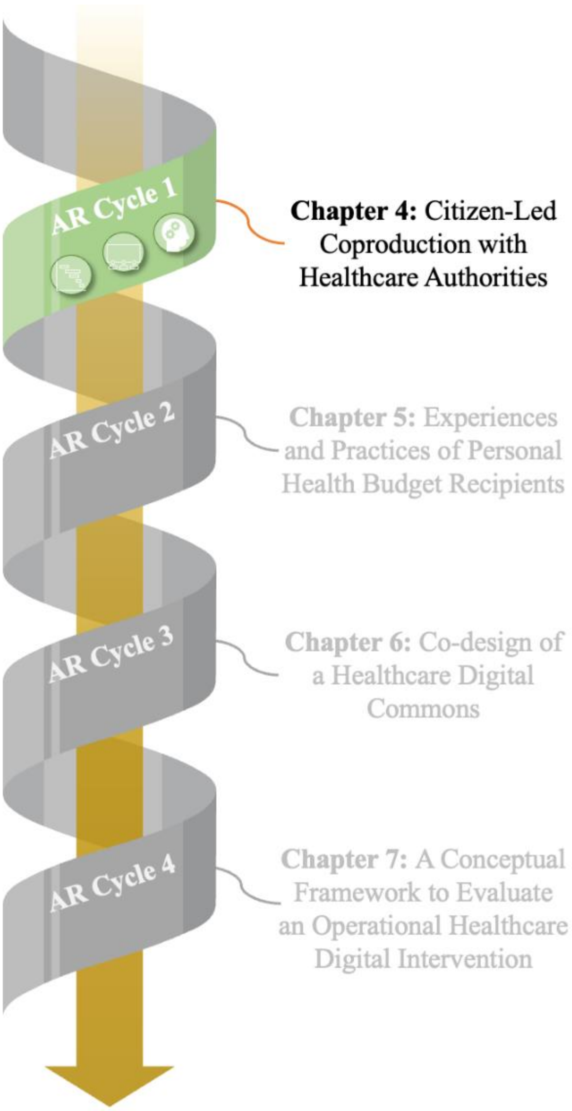

Figure 7: AR cycle 1 (highlighted in colour) and its location within the four AR cycles

The following sections describe the approach for this study - located within the Plan stage of this AR cycle - before moving on to recruitment and engagements within the Act stage.

4.3. Study Design

4.3.1. Approach

The Methodological Approach chapter laid out the use of AR and PD as suited for a qualitative study of the lives of PHB holders. The research design and its configuration of focus groups as data collection points demanded particular attention due to the time-poor and care-dominated lives of the citizens, and the power imbalance with their CCG officers.

4.3.2. Timeline

Figure 8 illustrates the timeline for this first AR cycle and its engagements, showing the Act and Reflect stages extended due to the impact of the COVID-19 pandemic delaying interactions with both citizens and CCG officers.

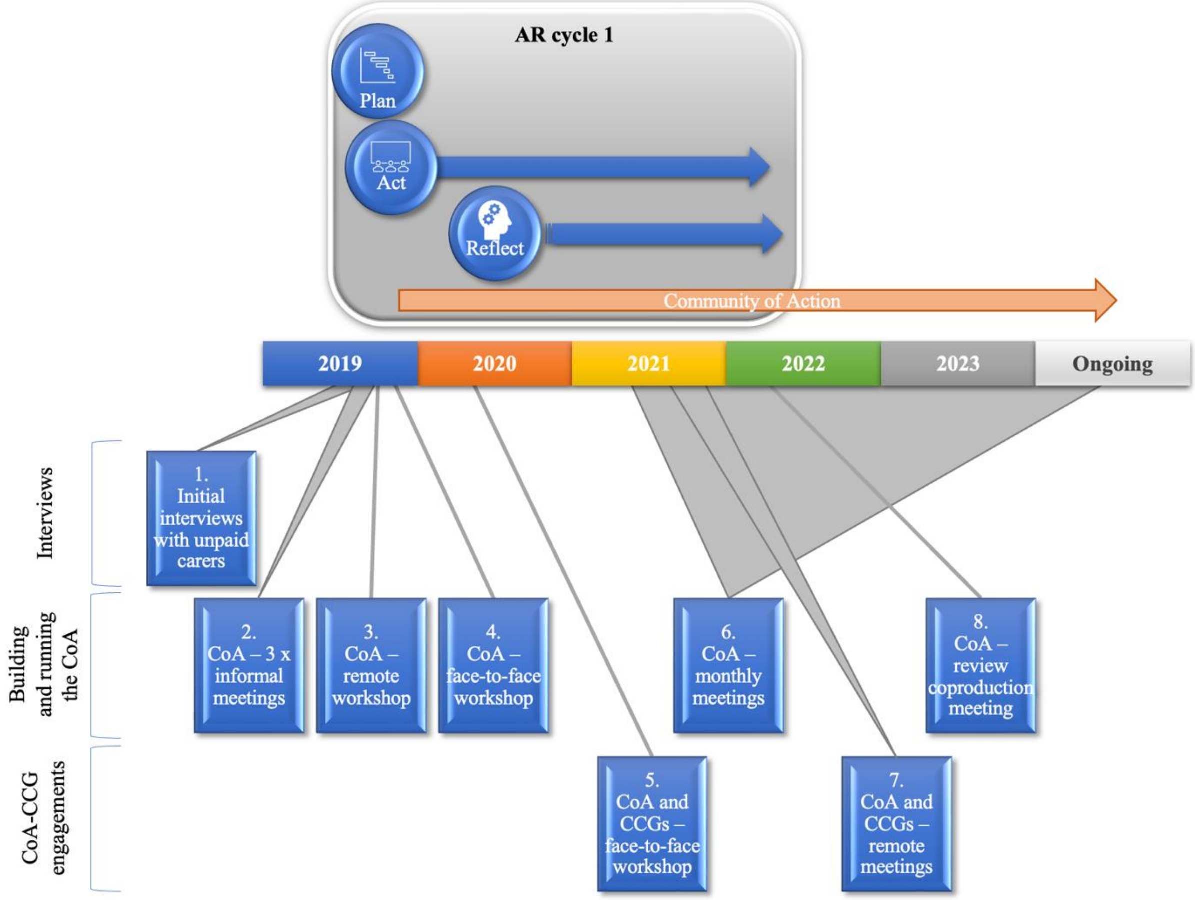

Figure 8: Timeline for AR cycle 1, showing engagements with the CoA members and CCG officers

The following sections provide details on the key engagements and their recruitment.

4.3.3. Initial Interviews

My positionality as an unpaid carer assisting in the management of a PHB provided first-hand experience of the issues and benefits. Establishing these as commonalities beyond my personal experiences required recruiting similar unpaid carers - individuals that received a PHB to fund a team of paid carers to care for their disabled children in the home. A family member was an opportunistic participant, snowball recruitment delivered two more participants, and then two opportunistic participants when I attended an NHSE Academy for Personalised Care. The participants had a total of ten years of experience running a care budget.

One-to-one, face-to-face, semi-structured interviews were held in 2019 with the five participants at a date, time, and location of their choice, noting these took place before COVID-19 - see item 1 in Figure 8. Data collection methods based on group sessions were discounted at this time, as I required more data on the lives of such participants before I could design group interactions.

I prepared an interview guide with the objective of developing an understanding of the participants' lives of caring, but also their attitudes to participating in research - see Appendix C. I felt this latter point to be critical, as I was planning a longitudinal study with participants as a marginalised group, so I required data to configure their participation. Questions used to guide the interviews included "*What is the level of care needed from your family for your child?*" and *"Can you think of any way that research could improve your life or of others similar to you?"*

I took care at the beginning of the interviews to explain the research, my PhD, and my university. Also feeding back findings from the analysis of the engagements - this approach carried forward into the subsequent AR cycles. The interviews were all audio recorded with the participants' consent and transcribed using an agency arranged by my university. The interviews lasted between 30 and 90 minutes, with four hours of interviews recorded.

4.3.4. Forming a Community of Action

My next action was to determine how this research could support the lives of PHB holders in my locality, the North East of England. I emailed the two local participants recruited from the previous interviews, with the ensuing email conversation agreeing that 'something had to be done' about our shared belief that the CCGs were delivering a poor PHB service, agreeing we needed to form a movement to deliver change.

The type of assemblage I felt best suited was a Community of Action (CoA) (Zacklad, 2003), as its members had to be more than informants to this research, my desire being to work with them as empowered collaborators. The analysis from the earlier interviews had shown the citizens felt disempowered by their CCGs, so my approach would be to empower them as a group and as individuals.

As a demonstration of how this research would involve them as collaborators and that the CoA was not to be a research entity but one owned by its members, I handed over responsibility for the CoA's recruitment and meetings to its members. The decision taken by the CoA for recruitment was for a small group of fewer than twelve members and all were to be local parents holding PHBs for their disabled children. The NHSE supported this decision, as through my previous attendance at the NHSE Academy for Personalised Care in 2019, I was in regular contact with staff at the NHSE PHB Team and a VCSE organisation dealing in PHBs. Both the NHSE team and the VCSE organisation had overseen similar CoAs and they recommended keeping the group small and homogenous, as they had witnessed the larger, more diverse groups fragmenting into smaller, single-issue factions.

A decision taken by the CoA members was for all potential recruits to have graduated from the NHSE Academy, as the first few members, who had all attended the Academy, felt it built a foundation of knowledge on PHBs, how to deliver change, and coproduction. The CoA members excluded CCG officers from joining the group, as the power imbalance meant their inclusion would have inhibited the CoA members' openness and freedom of voice.

The CoA and I totalled eight members from seven families, with an early churn of two members (one member left due to the death of her disabled son, and one potential member felt it was *"not for me"*). Likely owing to the CoA members recruiting acquaintances, all had professional backgrounds and all were from a similar demographic, each caring for one or more children with long-term complex needs. At the time of the CoA's formation in 2019, the members had a collective experience of 18 years in running a care budget.

In the three months following the decision to form a CoA, three informal meetings took place as social events to build the CoA (see item 2 in Figure 8), and I created a WhatsApp group for the members. The membership grew with each meeting, though not all the members could attend every meeting, their priorities of caring taking precedence.

The earlier one-to-one interviews exposed the participants' negative experiences with engaging in research. These guided me not to request members' signatures to Consent Forms at this early stage, as I felt it was too formal a process that might deter their participation. Their consent was subsequently obtained following these early meetings when I felt I had gained their trust.

4.3.5. The First Remote Workshop for the Community of Action

The CoA members agreed on the need for more meetings to build relationships within the group and to agree on ways of working. My initial interviews had exposed the complex, unpredictable, enduring lives led by unpaid carers in caring for their children, which would make it challenging to arrange face-to-face meetings. This was evidenced as I did make three attempts at arranging a face-to-face meeting with all the CoA members but each time I had to postpone the meeting as not all could attend.

My recommendation for a two-week remote workshop was accepted, the configuration of the workshop based on HCI's Asynchronous Remote Communities (ARC) method (MacLeod *et al.,* 2016). I extended the method by adding a synchronous component as I felt this would deliver a greater number of responses in a more conversational style.

Tools previously used with the ARC method such as Facebook, WhatsApp, and Slack (MacLeod *et al.*, 2016; Bhattacharya *et al.*, 2019; Lambton-Howard *et al.*, 2019; Meyerhoff *et al.*, 2022) were considered but rejected in favour of a remote method that allowed virtual sticky notes to be placed onto a shared virtual board. I judged this as an easy to follow and engaging method of interaction.

The CoA members declared themselves as technology averse apart from one member, so the key criteria were for a tool without downloads, as one member stated she felt downloads were complicated, and a simple interface that could be used on a smartphone display, as not every member had access to a tablet or personal computer.

I reviewed the tools I could find on the internet, selecting 'vWall'[12]. This tool is browser-based and allows a facilitator to prepare questions in advance and then open a virtual sticky note sharing session, with attendees able to see one another's virtual sticky notes as they are posted. I selected the option to anonymise the postings on the belief this would promote freedom of voice, plus, it allowed a simple link to be emailed to start posting, rather than a need to register and then sign in each time. A free trial of vWall was sufficient for this study, so there were no costs.

I had four objectives for this first workshop (referenced as item 3 in Figure 8). First, to continue building relationships and trust amongst the group; second, to create a shared understanding of issues with PHBs; third, to explore the issues that the CoA members wanted to resolve; and last, to test group engagements using this reconfigured and extended ARC method (MacLeod *et al.*, 2016).

To achieve these objectives, I created a set of six questions that I passed to one of the CoA members for her review, resulting in minor changes to the wording as she felt her edits were more aligned with the language of the CoA members. The first two questions were 'recall' questions (MacLeod *et al.*, 2016) designed to ease the participants into the process by being

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[12] https://vwall.org/

simple elicitations of their own experiences, *"Write a post-it note for each type of difficulty you have experienced when dealing with your CCGs in trying to access / receive a PHB.*" Followed by*, "Once you have had the PHB, are there any difficulties with running it?"* The next three were generative (MacLeod *et al.*, 2017) for the participants to place themselves into the future: *"What things do you think would need to be different for the process of accessing and running a PHB to be better?"; "Write post-its for what we need as a group to make our PHBs a success"; "What might be your top priorities for our first achievements as a group?"* The final question was one of recall to obtain feedback on the workshop process, *"Write post-its for your thoughts on this method".* This interaction method aligned with that of a Future Workshop, where people generate ideas to address social issues through working and becoming empowered as a group (Vidal, 2005).

All the CoA members took part in the workshop, with me acting as facilitator. I posted the questions to the CoA ahead of the event, then opened the workshop and left it accessible for fourteen days. I arranged a 90-minute synchronous session on the third day for the CoA to work together as a group, where I re-posted the questions at 15-minute intervals. The CoA's WhatsApp group was used to confirm the workshop dates, provide instructions as part of the educational agenda for this research, and nudge participants to keep posting notes in the asynchronous sessions.

I had initially proposed to run a synchronous session each evening for ten minutes, but the participants rejected this, as their preference was for a longer, one-off demand of their time. Knowing the questions in advance allowed the participants time to consider their responses and minimise the power imbalance of myself as the facilitator. I arranged to be co-located with one of the participants during the synchronous session, to gain feedback in real-time and detect any issues experienced but not voiced.

The workshop generated a large set of data: 16 virtual sticky notes added in the initial two-day asynchronous session; 87 notes in the 90-minute synchronous session; and 30 notes in the final 12 days of the asynchronous operation - see Figure 9. The postings were crafted, as the CoA members had the time to edit and consider their notes, as seen by the quality of spelling, use of punctuation, and size of the notes (one had 238 words). The software provided an easy route for data collection as no transcription was required, as text from the virtual sticky notes could be downloaded.

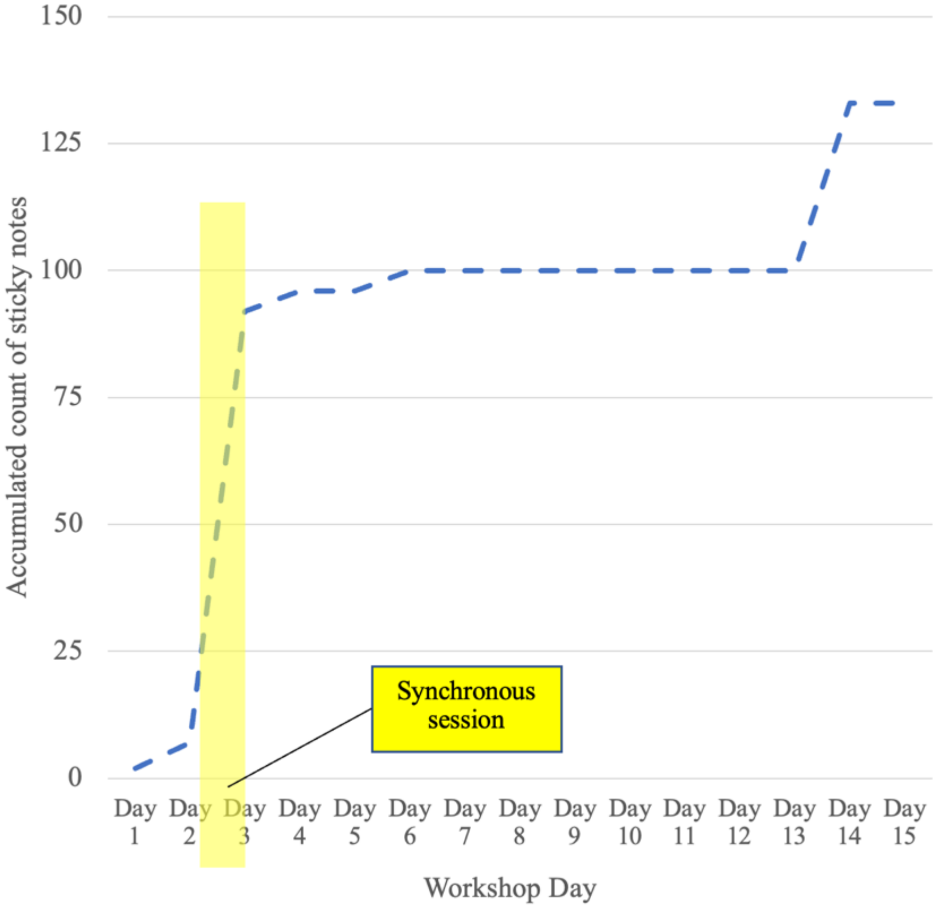
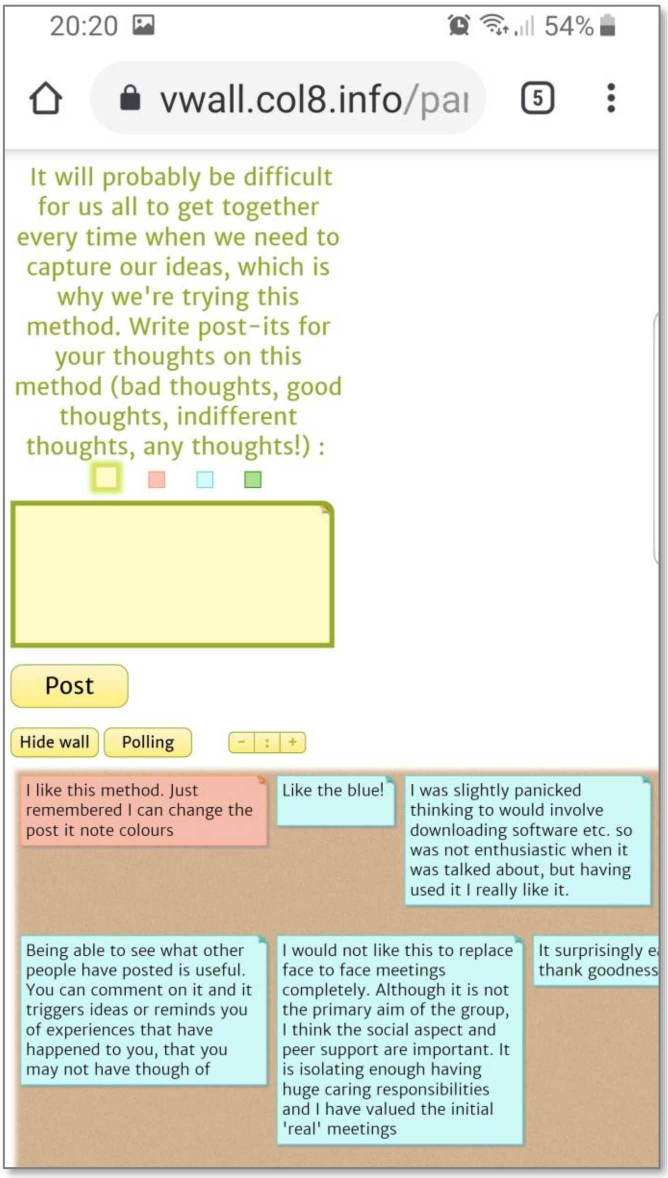


Figure 9: Graph showing the accumulation of virtual sticky notes in the first remote CoA workshop

Figure 10 provides a sample smartphone screenshot of the workshop showing a question and its responses.



It will probably be difficult for us all to get together every time when we need to capture our ideas, which is why we're trying this method. Write post-its for your thoughts on this method (bad thoughts, good thoughts, indifferent thoughts, any thoughts!) :

I like this method. Just remembered I can change the post it note colours

Like the blue!

I was slightly panicked thinking to would involve downloading software etc. so was not enthusiastic when it was talked about, but having used it I really like it.

Being able to see what other people have posted is useful. You can comment on it and it triggers ideas or reminds you of experiences that have happened to you, that you may not have though of

I would not like this to replace face to face meetings completely. Although it is not the primary aim of the group, I think the social aspect and peer support are important. It is isolating enough having huge caring responsibilities and I have valued the initial 'real' meetings

It surprisingly e
thank goodness

Figure 10: Sample smartphone screenshot of the virtual sticky note workshop

4.3.6. Formalising the Community of Action

In conversations with the NHSE PHB team, they had expressed an interest in the CoA as they had no citizen groups in the North of England that focused on PHBs. Arising from this, they offered to fund a facilitator experienced in CoAs and PHBs to run a workshop with the CoA members, the objective being to formalise the CoA by co-creating its aims and values.

The CoA members were keen to take up this offer, perhaps seeing it as a stamp of authority that NHSE had recognised the validity and potential of the group. As such, they committed to attending in person (this was prior to COVID-19). The event is referenced as item 4 in Figure 8.

I formed the structure of the workshop by working with the NHSE facilitator and one CoA member, using Zoom[13] videoconferencing and email. All the CoA members attended the workshop, held at my university, where I took the role of a CoA member rather than facilitator or researcher. The workshop was comprised of whiteboard and sticky note sessions and lasted for five hours including breaks for refreshments. Topics included were: *"A refresh on what coproduction is within personalised care"; "The group's purpose"; "Write sticky notes for what we need as a group to make our PHBs a success"; "What are some of the things that are working well locally".* See Figure 11 for a photograph of a wall at the workshop covered in sticky notes and other papers.

Figure 11: Artefacts from the NHSE-facilitated workshop

I subsequently created a summary of the workshop in the form of a set of slides that I passed around the CoA members to gain their approval. The aim of the group was agreed to be,

> *"Helping families in the North East that have children and young people with complex needs"*

With ways of working to be: *act as a collective; work in coproduction with CCGs to improve experience of PHBs; consider the constraints of the CCGs.*

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[13] https://zoom.us/

Following this face-to-face workshop and now with an agreed aim and ways of working, the CoA members resolved to meet with their CCG officers.

4.3.7. Recruitment and Engagement for the First CoA/CCG Meeting

The CoA members and I co-created the first CoA/CCG meeting's objectives – to build relationships with the CCG officers and start a co-learning process between the two groups aimed at improving the service delivery of PHBs.

However, tension surfaced regarding my seeking consent from the CCG officers to take part in this research when I checked this beforehand with three CoA members. I felt confident in this request, as in all earlier interactions with the members of the CoA, my research had been welcomed with its resources of facilities and time, assisting them in building and operating their CoA. My request for Consent Forms to be handed to the CCG officers was blocked by all three members, though accepting that I explained the research at the outset of the meeting. The CoA members believed that asking for consent would inhibit participation from the CCG officers as they would be aware their words would be documented, so they would either walk out or not take an active part. On inquiring further, the CoA members had experiences of asking to record their personal meetings with CCG officers, resulting in those meetings coming to a premature end when the officers refused to continue. Amelia, a CoA member, stated, *"If they knew we were recording them, they wouldn't come."* Without consent from the CCG officers, I fell back to writing field notes.

Two members of the CoA, who on occasion work with the local CCGs, volunteered to recruit senior CCG officers who in their view held positions of authority that were able to influence the delivery of PHBs. Four weeks' notice of the meeting was given and the email invitation was sent by a CoA member who had previously worked with some of the invitees. This was done to engender trust, rather than the invite originating from me or someone else who was unknown to the CCG officers.

None of the invitees chose to attend or gave reasons for this. Instead, they delegated to CCG junior officers, none of whom had the power to influence the delivery of PHBs at a CCG level, with just one officer dealing with PHBs at a citizen level. This was upsetting to the CoA members, who had invested effort in co-designing the workshop, foreseeing that it would now be a waste of their time. I talked to the group, asking that we proceed with the workshop, arguing that we had an opportunity to deliver change and that this would be our first step, albeit smaller than hoped. The CoA agreed, so the workshop took place - referenced as item 5 in Figure 8.

I was keen to deliver an open design space at this face-to-face CoA and CCG meeting. So with my prompting, the CoA members arranged the meeting room to have small round tables instead of a single rectangular table; additionally arriving well before the CCG officers so they could sit in alternate seating, all to reduce an ‘us and them’ feeling.

Six CCG officers attended. The meeting began with a one-hour presentation by the CoA with topics co-created by the CoA of: *“Coproduction and personalised care within NHS England”; “PHBs”; “Our aims and experiences”.* The presentation was followed by a group discussion of 45 minutes to gain the perspective of the CCG officers, with questions of: “*What matters to you in your job?”; “What are your drivers?”; “How do you view PHBs?”; “How would you change PHBs if you had a magic wand?”*

One week after this workshop, the first COVID-19 lockdown in England came into operation (March 2020), and likely due to the CCG officers focused on the pandemic, the CoA members received no response from all but one of the CCG officers that attended, or their managers. That one CCG officer appeared to take note of the CoA members’ experiences, further meeting with a subset of the CoA on three occasions to improve the service delivery of their individual PHBs.

4.3.8. Recruitment and Engagement for the Second CoA/CCG Meeting

In part because of the impact of the COVID-19 pandemic, the AR cycles became ‘messy’ at this point. AR cycle 2 started later in 2020 - reported in the next chapter. However, in early 2021, AR cycle 1 resumed as the NHSE PHB Team came back to the CoA, seeking the CoA’s assistance in dealing with the CCGs in the North East of England. The NHS team’s interest arose from data they had collected that showed these CCGs displayed a lack of coproduction and low numbers of PHBs.

The CoA members and NHSE staff worked together to book a workshop with a senior CCG executive (one who had declined to attend the previous workshop) and her senior officers that commissioned PHBs across the region. Extended timescales were experienced in arranging this meeting, even with NHSE staff promoting the meeting. For example, delays in responses from the CCGs meant that the meeting, once agreed to take place, took over three months to book a date and time.

The NHSE staff handed over the workshop planning and running to the CoA members, who were still adamant that I was not to seek consent from the CCG officers and NHSE staff to take part in this research.

All the CoA members, five CCG senior executives, and one NHSE staff member attended the workshop held over Microsoft Teams - referenced as item 7 in Figure 8. An updated presentation from the previous CoA/CCG workshop was used, though with the same objectives. I believed the right people attended, with an agreement from all that change was needed. The lead CCG executive committed to organising monthly local meetings and quarterly regional meetings between the CCGs with the CoA. However, we heard nothing more from any of the CCG attendees; I sent two reminder emails to the lead CCG executive, but they were not answered.

4.3.9. Ongoing Meetings with the CoA

The CoA remain together as at the time of writing, holding monthly meetings that began in early 2021 (referenced as item 6 in Figure 8), offering to meet with CCG and NHSE staff whenever they can. Their WhatsApp group is used to offer peer support to one another and to keep everyone updated on public reports related to PHBs and care. Two of these monthly meetings have been held with different senior CCG officers attending, but, again, the CoA members have never received any communications following the meetings.

I arranged for one of these CoA monthly meetings in 2022 to have an agenda item for reviewing coproduction - referenced as item 8 in Figure 8. My objectives were to understand their thoughts on coproduction in the context of the CoA and to reassess whether the CoA should change its stance in dealing with CCGs. I posed questions of *"Is coproduction worth it?", "Could our group have worked better?", "Is coproduction the right approach moving forward?"*, and *"If there were a group of people like us that were starting up a coproduction group, what would you advise them?"* Five out of the seven CoA members attended this monthly meeting. I summarised the feedback gained from those that did not attend, who responded that they agreed with the sentiments expressed and had no additional comments.

4.4. Findings

These findings arose from the unpaid carers' day-to-day caring practices and challenges, supported by insights from the building of the CoA and group engagements. I performed analysis as described in the Methodological Approach chapter, section 3.11, with data excluded from the NHSE staff and CCG officers as I had no consent from these groups.

The opening two themes explore the citizens' experiences of research, first by their reflections on having taken part in previous research in *"Trust and Involvement in Research"*, which allowed me to design the configuration of their participation. The next theme of *"Engaging* *with a Marginalised Community"* reflects on my group engagement method used within this AR cycle to determine its validity for group engagements in the following AR cycles.

The next themes cover the unpaid carers' lives of caring and hopes for the future. *"Seeking Support to Care for My Child*" offers insights into the lives of parents with a disabled child, together with the challenges in managing a PHB. *"(Re)structuring Relations"* progresses onto their relationships with their CCG officers and the final theme of *"Expectations and Failures of Coproduction"* examines the CoA members' views on their coproduction with CCG officers.

Pseudonyms are used throughout. Quotes are anonymous when sourced through sticky notes, both virtual and physical.

4.4.1. Trust and Involvement in Research

These first two themes are in place to gather analysis that would direct how I configured engagements for the remainder of this research, based on the participants' past experiences of research and their lives of caring.

At the start of my engagement process, I asked the participants in the interviews to reflect on their previous experiences with participating in research. This was motivated by my desire to develop research that was collaborative and had the potential to deliver a positive social impact for PHB holders. Their view was that research was a philanthropic method of delivering benefits to their children and their peers, so they would be keen to take part. Amelia, parent to her disabled son in his 20s, said, *"My usual experience with the people I know whose children have complex needs, is that they are quite keen to participate in [research] if they think it's going to help others."* Bella, a parent to her disabled son in his 20s, had been involved with research for over ten years, *"Research is really important to me. Just purely and simply because I want [my] child's life to be better when I'm dead."*

Several participants stressed they would not take part in all types of research. The researchers and the research had to be seen to be rigorous, confidential, relevant, and understandable, with responsibility placed on the researchers to build and maintain trust with their participants. Amelia said, "*You know, people can just set up their own charity and just register, and then you never know how credible they are, or how much training they've had on research, and how much it's going to be confidential."* Bella stated she had to know what the research was to be for, looking back to her past experiences *"There was no real explanation about how important this [research] was, or how relevant it was to my family, or what it would do for* *[my child], or what it would do for other children even, it just didn't really attract me to keep going with it."*

Methods of engagement were also seen as important, with surveys viewed as impersonal and lacking the ability to extract the participants' experiences, or for the participants to question the researcher. Bella said, *"Rather than sitting filling an endless tick-box form in, where you don't know whether you're getting the answers right or wrong or whether they're making any difference. It is much better to have an open conversation."*

On questioning, the participants believed that the researchers they had met did not exhibit care and commitment. The participants wanted to be treated with respect and to feel part of the research process. Sarah, a mother to her disabled son in his early 20s who was blind, epileptic, a wheelchair user, and cognitively impaired. She gave her opinion, *"... because I suspect what [researchers] lack is the human side and actually, they are interested in the results and the result only."* Sarah added, *"You would often fill stuff in and you would almost feel quite excited and be keen to understand what the results of that was. (Laughter) Nothing ever came back."*

Opening a space to understand and critically examine the participants' previous experiences of taking part in research was a fundamental step for me to configure a style of engagement with unpaid carers that was open, collaborative, and communicative. The next theme explores how unpaid carers' lives of caring impacted on the design of engagements for this research.

4.4.2. Engaging with a Marginalised Community

I found the participants as unpaid carers had experienced physical and emotional challenges arising from their priorities of care - the unpredictability, stress, exhaustion of caring, and their lack of time. These are examined in the next theme. I used this knowledge to design the remote engagements for this and the subsequent AR cycles, with this theme gathering the participants' reflections on my methods.

Aligning to the lives of unpaid carers directed me to design a group engagement configuration that avoided fixed start times and travelling, the resulting remote and asynchronous / synchronous events using text input rather than remote video engagements. A few members were initially nervous about using software new to them but found the simplistic interface of the tool an enjoyable way to interact with other members. Virtual sticky notes were written of: *"I was slightly panicked thinking to would involve downloading software etc. so was not enthusiastic when it was talked about, but having used it I really like it"; "I like this method"; "Happy with this approach".*

The CoA members judged this remote, asynchronous / synchronous workshop a success, as they found it conducive to their complex lifestyles, with the option to attend the synchronous session and contribute asynchronously. One member could not attend the optional synchronous session and two others were late, showing the need to allow for the unpredictable life of caring. One virtual sticky note reflected on the latecomers and the no-show, "*We are all short of time and as this evening has proved, life can be very unpredictable. This seems to offer a good solution in that we can add to it later if we cannot make it at the planned time.*"

Another facet of remote asynchronous engagements was that it gave time for participants to reflect and consider responses from others. Face-to-face sessions using sticky notes can give rise to rushed writing due to time pressures, text that is hard to read, limited space for text, and participants not having time to reflect on the notes of others. The virtual sticky notes from this remote session showed the method as a workable option: *"Being able to see what other people have posted is useful. You can comment on it and it triggers ideas or reminds you of experiences that have happened to you, that you may not have thought of"; "I like the ability to leave it open for some time afterwards so you can add to it later if you think of other things"*.

An unexpected but positive feature of remote sessions without video was that participants could be temporarily absent, even in a synchronous session, to attend to their caring duties. This also illustrates a loss in such remote, non-visual engagements - that aspects of engagements can be missed, unless called out by the participants. A participant wrote about her experiences in the synchronous session, *"Oh I did manage to add some [notes] while cooking dinner and entertaining my son"*.

A further benefit was that dominant members could not take over the session, and more reserved members had opportunities to engage. One virtual sticky note explained this: *"If you had ... someone tending to dominate the discussion they could just type away without annoying everyone else. And if someone was not confident about speaking up, this might empower them to do so"*.

The participants were adamant that remote meetings alone would not suffice for their CoA to grow and stay together, being aware of their need for face-to-face social connections, especially with their peers who understood the issues they experienced in caring. One virtual sticky note stating the importance of this, *"I would not like this [remote workshop] to replace face to face meetings completely. Although it is not the primary aim of the group, I think the social aspect and peer support are important"*.

Limitations were experienced with using this software. There was no ability to comment on other people's notes or to flag them as liked/disliked - I detected this as the participants began to position their sticky notes under the notes of others in lieu of this function. Also, the participants could not revisit previous questions, as only one question could be active for posting at a time.

This theme illustrated the success of using the reconfigured and extended ARC method - critical to this group of participants who were time-poor and could not commit to meeting start times. As illustrated in Figure 9, the extension to ARC of a synchronous session showed benefit as it delivered nearly twice the number of notes than all of the asynchronous session.

The following three themes explore the unpaid carers' lives of caring, their relationships with state authorities, and their approach to improving these relationships.

4.4.3. Seeking Support to Care for My Child

This theme surfaces the day-to-day challenges and tensions that the participants experienced as unpaid carers, these related to the enduring care required for their children, supplemented by the burden of managing their PHBs.

Caring for any young child impacts on their carers' sleep, their ability to work in a paid role, and with the wider family. Ordinarily, caregiving for a baby diminishes as the child grows and attains developmental milestones. The unpaid carers in this study explained how they experienced this caregiving as a never-ending demand on them. That while the care changed over time as their child aged, it would never reduce, indeed, it increased as the older child could no longer be lifted or carried, demanding physical devices such as hoists and wheelchairs. Sarah recognised the physical hardships required to care for her child and that her extended family were unable to provide support due to the complex care demanded, *"We tried leaving [our disabled child] with grandparents ... but they couldn't cope with him, they just found him too difficult."* Bella described the complexity of her son's condition and hence the intense levels of work demanded to care for him,

> *"He has multiple comorbidities that go with him because of having cerebral palsy[14]. Bowel impingement[15], which affected his gut motility[16]. He's got a colostomy[17]. He's got a gastrostomy[18] because he doesn't drink enough. He has a learning disability. He's got a visual impairment. He can't sit up. He can't walk. He can't move around in his chair independently. He can't feed himself very well, so he needs somebody feeding him. He has overnight CPAP[19] now.*

The participants expressed a sense of invisibility from their social groups, the state, and especially those in place to directly support them - their CCG officers. This invisibility both distanced and disconnected the unpaid carers from their local services and the state. Amelia said,

> *Even social workers, and politicians, and people in the health service who are really in control of planning services, really have no concept of how difficult the lives are for people in the community when you've got a child with complex health needs.*

Bella added to the breadth of this invisibility by stating, *"Nobody has a clue that type of thing that you've been through or the impact that it's had on your life."*

Despite voicing a lack of support from their CCG officers, the introduction of PHBs from the state has been welcomed. Hence, opening a space to talk about the positive aspects of PHBs was a focus of the first face-to-face CoA workshop. A theme emerged that centred on the positive changes they could see in their child, now that the unpaid carers had control over their children's care, with virtual sticky notes of, *"My child is the happiest and healthiest he*

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[14] A group of lifelong conditions that affect movement and co-ordination.

[15] A partial blockage in the bowel.

[16] A dysfunction in how the gut moves food and waste.

[17] A surgical intervention to divert the gut to a new opening in the abdomen where waste is collected in a disposable bag.

[18] A surgical intervention where a tube is inserted from the abdomen directly into the stomach to deliver food and drink.

[19] Continuous Positive Airway Pressure: a device that delivers pressurised air into a mask over the face.

has ever been since we could choose his care with a PHB"; "My child is cared for at home where she is safe".

This control also allowed the unpaid carers to self-care in terms of sleep and breaks from caring, their team of paid carers offering respite from the continual caring experienced prior to gaining a PHB: *"Having care overnight, so getting sleep"; "Being able to use [the] budget to pay for weekend/evening respite."*

As part of the CoA members' motivation to help their peers, they adopted a philanthropic approach to the CoA's aims, the respite from care that a PHB can deliver now allowed them time to take an active approach to resolve issues. Their lives of hardship reinforced their determination to prevent this from occurring to other families. A virtual sticky note stated, *"We are not advocating for ourselves, we have what we need, we are trying to make things equitable for others and improve quality."*

However, while the PHBs provided the participants with opportunities for choice in their day-to-day caring practices, they also delivered new, unexpected responsibilities and challenges that demanded skills and knowledge to perform. These unsupported tasks transitioned the unpaid carers from a 'customer' of transactional healthcare services to a company owner - in effect running a residential care home. Amelia said in her interview, *"I was his carer, now I'm his care home manager. I want to be his mum"*. The virtual sticky notes from the remote CoA meeting stated, "*So I've been left effectively running a care agency"; "Even for really driven, educated families like us, we're struggling with the implementation"*.

This theme illustrated that all the participants reported the high levels of complex care needed for their children, voicing a societal and institutional lack of understanding and recognition of the challenges, struggles, and demands entailed with their care work. One response to these challenges has been the state's intervention of PHBs, and while offering unpaid carers the opportunities to control their day-to-day caring practices, PHBs have added additional responsibilities and work.

4.4.4. (Re)structuring Relations

This theme offers insights related to the CoA members voicing a desire to reset relations with their CCG officers beyond the 'us and them' and the anticipated challenges that this would pose in practice.

An adversarial relationship with their CCG officers dominated the lives of the participants and as such, was a recurring topic from the one-to-one interviews. A common statement exemplified how their healthcare services were a source of anxiety rather than support, Amelia stated, *"The biggest stress in my life is not caring for my child, it's [the CCG officers]"*.

The stress arose from a power imbalance between the CCG officers and PHB holders, where officers asserted control over the funding provided, how it can be spent, and the governance that surrounds it. Thus, the participants' experiences of their relationship with the CCG officers became imbued with stress and anxiety, while at the same time being entirely reliant on their funding. The power dynamic and resultant fear of losing their healthcare budget were voiced by Bella, *"I think that's the one thing that worries us about [our PHB], is it's just something that you feel like somebody else could come along and say, 'Actually, he doesn't really need that. You're not keeping it.' It's a massive fear."*

The tensions, power dynamic, and complexities within this relationship were evidenced by several CoA members blocking me from seeking consent from the CCG officers to take part in this study. The virtual sticky notes posted in the CoA remote workshop illustrated these tensions, as they demonstrated how years of fighting for their legal right to care funding had diminished the unpaid carers' trust and confidence in their CCG officers. The officers were legally accountable for delivering PHBs but were perceived as operating with disregard to their duties of care and legal obligations, delivering the 'gift' of paid care as transactional and impersonal. Sticky notes were captured of, *"They try and restrict the information they give you to keep you as low cost as possible"; "[CCG] case managers appear to have little understanding of PHBs and when [we] advise them on process, rather than fact check, they assume we are wrong"*.

These frustrations and anger took precedence at the face-to-face meeting between the CoA members and their local CCG officers. I witnessed tensions arising from the CoA members' past experiences as they became forceful in their comments, feeling empowered by belonging to a group rather than as an individual, feeling free to speak 'at' the CCG officers in a direct manner. One CoA member explained to the CCG officers about the poor level of service received, saying, *"The care and support planning was not being done properly at the beginning."* Complaints were stated about how they were treated, *"Every time I email my social worker, I get a telling off."* The legal knowledge held by the CoA was also demonstrated, with accusations of *"What you're [the CCGs officers] doing, starting with an hourly rate, breeches the Care Act."*

My field notes from this first CoA/CCG meeting showed that I felt the CCG officers listened in a passive sense - they answered direct questions rather than engaging in conversations and debate about the PHB service. They did not display any apparent anger, but there was no engagement in the issues voiced by the CoA members. This likely because the officers did not have the seniority to control PHB delivery - as the CCG officers present had been delegated to attend.

At the first remote meeting held between the CoA and executive CCG officers, with NHSE in attendance, the CCG officers were far more engaged, actively listened, and prompted for more information. Talking with the CoA following that meeting, the members were happy with their performance at the meeting and excited about the potential for working together with the CCGs. Amelia stated, *"Well done everyone. I think everyone was very clear and measured. There was some defensiveness [from the CCG officers] that was to be expected, but also some acknowledgement of the issues."* However, no contact was received from the CCG officers following this meeting.

This theme focused on the adversarial relations between the participants and their CCG officers, though constrained because of a lack of voice from the CCG officers as the CoA members had blocked my gaining consent. The participants experienced fear and stress arising from their relations with CCG officers but had become empowered through acting as a CoA.

The theme ended with members' expectations that they could begin to work in coproduction with the officers to counter the social injustices experienced.

4.4.5. Expectations and Failure of Coproduction

The CoA members and I were enthusiastic about the potential benefits for our peers by working in coproduction with the CCG. Our hopes were for coproduction to surface and resolve issues in the delivery of PHBs, but also for a cultural change, to lessen the adversarial relationship between the citizen and their CCG officers. The notion from the CoA members that coproduction was a productive approach to social change arose from their earlier attendances at the NHSE Academy for Personalised Care, where coproduction was lauded for delivering change in healthcare.

However, despite the CoA members' enthusiasm for coproduction, this approach was adopted with caution, as the negative relationship with their CCG officers once again surfaced. The CoA members expressed their awareness that CCG officers would likely reject a call to devolve power to citizens - an essential element of coproduction. Hence, to mitigate against the rejection, the CoA would have to adopt a more informant-like stance at first, nurturing the

CCG officers towards coproduction - a physical sticky note proclaiming, *"We coproduce by stealth"*.

Paradoxically, despite their fear, anxiety and stress, the group was adamant about recovering the relationship by working alongside CCG officers rather than challenging them in an adversarial manner. Physical sticky notes from the face-to-face meeting held to formalise the CoA stated: *"We find out what the CCGs' worries/problems are e.g. their jobs, their budgets"; "Focus on mutual benefits to help them [CCGs] save resources/use resources more effectively"*.

With no visible response following any of the meetings with CCG officers, the CoA members and I felt we had failed in coproduction, frustrated at a lost opportunity to make a difference to the lives of PHB holders. Reflecting on this perceived failure, the members believed that the CCG officers had no sight of the need for coproduction, that they saw the CoA as a group in place only to complain, the distance between the two parties too great for the CCG officers to see the need for action. The stance of the CoA members contradicted the second meeting with CCG officers, when the CoA members felt they were received warmly, but the lack of any responses following that meeting negatively affected the CoA members' view of working with the officers. Irene, parent to her disabled daughter in her early teens, gave her view, "*I think they just see us as a demanding group and just can't stand in our shoes very easily."* Jake, parent to his severely disabled twins, with, "*My gut feeling is that those [CCG officers] present honestly think they're doing a good job and that all that is needed is tinkering around the edges."*

When I asked the CoA members to reflect on coproduction by imagining what advice they would give to any similar CoAs, they understood that coproduction was only viable when both sides wanted to engage. Amelia said, *"If you've got a CCG who are really interested, absolutely go for the coproduction route. If there's no interest coming from them, I would then probably do peer support."*

Members of the CoA had different views on moving forward. The majority, regardless of their perceived failure with coproduction, wanted to continue trying to work alongside their CCGs, seeing that although there would be future failures, benefits could be delivered. However, the frustration and anger of other members turned them away from coproduction, forcing them towards a more activist approach, believing that coproduction was only successful when it originated from the authorities, not the citizen. These contradictory approaches did not appear to give rise to tensions within the CoA, and the different approaches indicated how confident some members felt to challenge their authorities.

Georgia, parent to her disabled daughter in her teens, believed that the CoA should continue to attempt to coproduce, *"... there's value for us somewhere a little bit further upstream in terms of this."* Amelia disagreed, based on the duration the CoA had been trying and failing to engage with CCG officers, saying, *"... it's completely pointless. We've tried for three years, and there's no interest at all from the CCGs ... we would love to [coproduce] but we're banging our heads off a brick wall ... I think we should take a much more aggressive tack."*

The CoA members saw benefits in the group itself, as it provided a forum for them to engage with each other to discuss their issues and hardships. Conversations were seen in the CoA's WhatsApp group where help in care legislation and process was requested and responded to, and also for emotional support. The CoA continued to meet monthly via Zoom, Georgia saying, "*But the really good thing about this group is the peer support."* Amelia with, *"Because I think this group really does have the peer support value."*

Coproduction with their health authorities was seen as a failure by the CoA members, though the benefits of peer support within the group were sufficient for the CoA to see value in continuing to meet on a regular basis.

This set of themes presented data that explored the lives of citizens as unpaid carers and PHB holders, their relationships with their state healthcare authorities, and their experiences of engaging in research.

The next section offers a preliminary reflection and limitations specific to this AR cycle and their impacts on the subsequent AR cycles on these themes, with Chapter 8 as a Discussion chapter for discussions that span the breadth of the study.

4.5. A Preliminary Reflection on Engagements

4.5.1. Group Engagements with a Time-Poor Population

The design and use of a remote, text-based, asynchronous / synchronous workshop were successful in gaining engagement from a time-poor and time-constrained population. The participants appeared keen to engage, expending effort in writing lengthy virtual sticky notes, wary of software new to them but excited when they found they could readily adapt to it.

The synchronous session provoked a significant spike in responses from the participants, showing the value of extending ARC with this feature. This success was a research learning from this AR cycle that was reused in subsequent AR cycles, where the engagement design was refined and expanded to seek a broader range of data.

However, face-to-face engagements did take place for different purposes. Social meetings when building the CoA and throughout its operation were welcomed by the CoA members, albeit none ever had full attendance from all the members due to their pressures of care. The CoA face-to-face meeting and the CoA/CCG meetings were fully attended by the CoA members, both events seen as critical, one-off events that they made all endeavours to attend. This opposed to the research-focused events that they perhaps felt were not essential. This was a learning for this research that this population's physical attendance at an event is possible when they viewed it as key to their lives or their peers - rather than 'just' for that of research.

A further reflection was on my role in the engagements in this first AR cycle. As both a researcher and a member of the CoA, I felt conflicted as to which role I was to assume at the group engagements. My default role was to act as researcher / facilitator, but at the formal CoA meeting with an NHSE facilitator, I attempted to be both researcher and CoA member. This failed, as I was not able to act in both roles simultaneously, so I took the role as a CoA member to offer my experience as input into the workshop. In the reconfigured ARC workshop using virtual sticky notes, I realised after the workshop that the extended duration would have allowed me to take on both roles, and so for the remote workshops in the following AR cycles, I acted as both facilitator and participant.

Lastly, analysis from the first theme showed how some of the participants had felt 'used' and then 'discarded' by previous research that they had taken part in. Although I believe I would have taken action regardless, this provoked me to keep in touch with the participants through regular email updates to allow them to feel engaged with this research.

4.5.2. Limitations

A limitation of this first AR cycle was a lack of diversity among the citizen participants. All the participants held a PHB to care for their disabled child and appeared to be of a similar demographic. This demanded redress in the subsequent AR cycle so I could gain an understanding of life experiences from across England and from disabled PHB holders.

The voices of CCG officers were also absent from this first AR cycle, so I planned to meet with CCG officers on a one-to-one basis in the following AR cycles - having checked this with several CoA members who voiced no issues with this approach.

4.6. Chapter Summary

This first AR cycle created a Community of Action recruited from parents of children with long-term complex needs that held a PHB in the North East of England.

Through a series of engagements, more social at first but culminating in a formal workshop with an NHSE-funded facilitator, the CoA members agreed on the aim of supporting their peers. A key objective to achieving this was for the CoA to address the social injustice they experienced through coproduction with their healthcare authorities.

The engagements with the citizen participants in this chapter delivered insights into their lives as parents caring for their children of high and enduring needs, fighting against their CCG officers for their legal entitlement of care funding.

More insights were gained when the CoA met with their authorities with the intent to engage in coproduction. The CoA members felt they failed in achieving this objective and hence the aim of this AR cycle, believing their CCG officers were uninterested in either learning about the issues or working with the CoA to address these issues. Understanding reasons for this failure from the view of the CCG officers remained hidden as the CoA blocked me from gaining consent from the CCG officers - this a facet of the power imbalance and the adversarial relationships. However, as a community, the CoA members continue to provide peer support through sharing knowledge and caring for one another.

The design of the remote engagements with the CoA members was a success as it responded to their intense and precarious lives of caring. The remote, asynchronous / synchronous, text-only workshop allowed them to take part at times that suited them, responding to conversations in a considered manner. The conversations provided a rich dataset that was easily downloadable in textual form for analysis.

The engagements were all designed to counter the participants’ negative prior experiences of engaging in research, where they had been poorly informed about the nature of the research, the researcher, and the outcomes. I had taken care to explain the research, also feeding back findings from the analysis of the engagements - this approach carried forward into the subsequent AR cycles.

The objectives for this AR cycle were met of understanding the citizens’ care practices and how to configure their participation. However, the aim of delivering meaningful change to PHB holders did not have visible success. This led to the second AR cycle, described in the following chapter, which responds to the insights and reflections from this first AR cycle. Specifically, furthering the design of remote engagements and widening the recruitment in terms of region, disabled citizens, CCG officers, and a VCSE organisation - this aimed at addressing the impact of social injustices through an alternate path to coproduction.

Chapter 5. Experiences and Practices of Personal Health Budget Holders

"I worry that families are so nervous about having their Personal Health Budget reduced that they wouldn't come forward with concerns until things hit quite a critical point." - Dana, a CCG officer managing PHBs.

5.1. Introduction

As shown in the previous chapter, the CoA members and I felt a sense of failure, together with frustration and anger, at the lack of engagement from the healthcare authorities. We had high expectations that working in coproduction with our local CCGs would deliver meaningful social change to the region's PHB holders, anticipating that the learnings could be extended nationally. The onset of COVID-19 at this time (March 2020) provided an unwelcome interruption but allowed me time to reflect on ways forward. I was determined to use this research project to make a positive difference through cycles of AR.

The second AR cycle, as detailed in this chapter, set out to further explore the experiences and practices of those in receipt of PHBs, developing recommendations for the design of a digital technology that can support the PHB holders in this fundamental aspect of their lives. This cycle extended on from the first AR cycle with a broader recruitment of participants - from across England, including disabled citizens, CCG officers, and VCSE staff. More specifically, I use this chapter to report on the experiences of those managing PHBs through insights generated from engagements with 20 PHB holders, four CCG officers, and a VCSE organisation. Through one-to-one interviews and advancing my reconfiguration and extension of the ARC method (MacLeod *et al.*, 2016) when conducting remote focus groups with disabled citizens and unpaid carers, I added to my understanding of the conflicts, processes, and work required to realise benefits from PHBs.

The insights follow on from the preceding AR cycle, exposing the complex power relationships between citizens and their CCG officers, where citizens often have to *"fight"* against a scoring system and assessment process to gain their PHBs. Then have to work hard to retain autonomy in spending their funding. Having sole responsibility for the management and delivery of all aspects of their PHB, citizens are forced to perform personal infrastructuring for their healthcare, seeking out trustworthy advice from peers and support organisations. CCG officers providing little support even when aware of the challenges and burdens the PHB holders face.

A preliminary reflection is offered that highlights one aspect of the citizens' infrastructuring, that of the need for each PHB holder to create a set of documentation that enables their management of paid carers and the care they provide. The citizen participants looking to commoning as a design response for them to share such documentation with their peers.

The next section provides the aims and design of this AR cycle, which includes deciding on the nature of a socio-technical intervention for the subsequent AR cycle 3.

5.2. Aims, Rationale, and Objectives

This second AR cycle aimed to lay a foundation for the following AR cycles. This achieved by extending my understanding of the lives of caring gained in the preceding AR cycle, by exploring the barriers, challenges, and benefits met by citizens and their civics when accessing and managing PHBs. The insights gained could then be used to guide the delivery of meaningful support. As such, it forms the second AR cycle, see Figure 12, seeking further information from a wider group of participants that would allow this research to determine a way forward through the use of a socio-technical intervention.

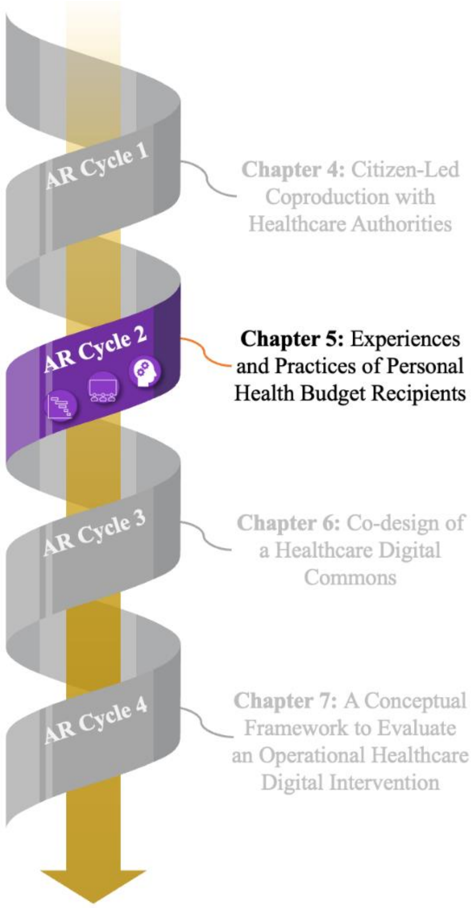

Figure 12: AR cycle 2 (highlighted in colour) and its location within the four AR cycles

A key objective was to ensure equity for the marginalised population in the participatory process such that all participants would have opportunities to engage in shaping ideas and potential responses. This was challenging, as the first AR cycle found the citizen participants to be time-poor due to their caring responsibilities, with precarious and unpredictable lives of caring, meaning they cannot commit to attending synchronous group discussions.

A second objective was to foster spaces where the citizen participants would feel safe to freely express criticisms of their state's services and each other's views. This to promote participants' individual opinions, leveraging their implicit and explicit situated knowledge including, but not limited to, their care practice (Blomberg and Henderson, 1990; Vines *et al.*, 2013; Harrington, Erete and Piper, 2019).

A final objective was to hear the voices of the CCG officers responsible for PHBs, such that a more rounded view can be established, noting a conflict between this objective and the previous objectives arising from the power dynamics in play.

5.3. Study Design

This Study Design section provides detail on how the above aim and objectives were to be achieved, examining the approach, recruitment, and engagements.

5.3.1. Approach

This AR cycle sought to address issues that participants deemed significant, acknowledging the complexity of social issues, conflict, and power relations in such a design process (Bødker and Kyng, 2018). In the context of this study, this demanded I build safe design spaces that attended to the power dynamic between the citizen and their civic authorities (Bates *et al.*, 2020, p. 277).

5.3.2. Recruitment

The participatory research from the first AR cycle generated significant enthusiasm for those involved, who found meaning in the collective process of sharing and understanding common challenges, finding empowerment in the process, and forming a community of peer support. As a result, all the CoA members, bar one, remained involved, as they were motivated to 'do something' about the issues that emerged from this participatory research.

To broaden the scope of this research and to better uncover the processes and actors at play in accessing and managing PHBs, I expanded the recruitment to be from across England, including PHB holders as disabled citizens, unpaid carers, CCG officers, and a VCSE organisation dedicated to PHBs - see section 3.10 for details of these groupings. This was to ensure the data gathered would be more representative of differing perspectives and voices.

I advertised the research opportunity through Facebook pages dedicated to complex health conditions, Twitter hashtags for PHBs and personalised care, and snowballing. In all the recruitment channels, I stated in a neutral fashion my lived experience of running a PHB, this aiming to engender empathy through a shared understanding and hence support for the study.

The recruitment attracted a further 14 citizens from across England, with experience of 15 different CCGs. Four CCG officers were also recruited, noting that two officers were employed in CCGs that managed PHBs to five of the citizen participants. One CCG officer managed a back-office team dealing with PHB payments, one commissioned PHB funding, one a manager for personalised care, and one in a strategic role bringing together health and social care. Two directors were also recruited from a VCSE organisation in England that specialised in supporting citizens in gaining and managing PHBs - one as a disabled citizen, referenced as such in this study, and one referenced as VCSE staff. Table 2 provides information on participant demographics for this AR cycle.

Cohort	Number	Collective care budget experience
Disabled citizens	7	19 years
Unpaid carers	13	27 years
CCG officers	4	20 years
VCSE staff	1	11 years

Table 2: Care experience of AR cycle 2’s participants

5.3.3. Timeline

Figure 13 provides a diagrammatic overview of the timeline for AR cycle 2, the Act stage of this AR cycle locating the interviews with citizens, VCSE staff, and officers, followed by a focus group.

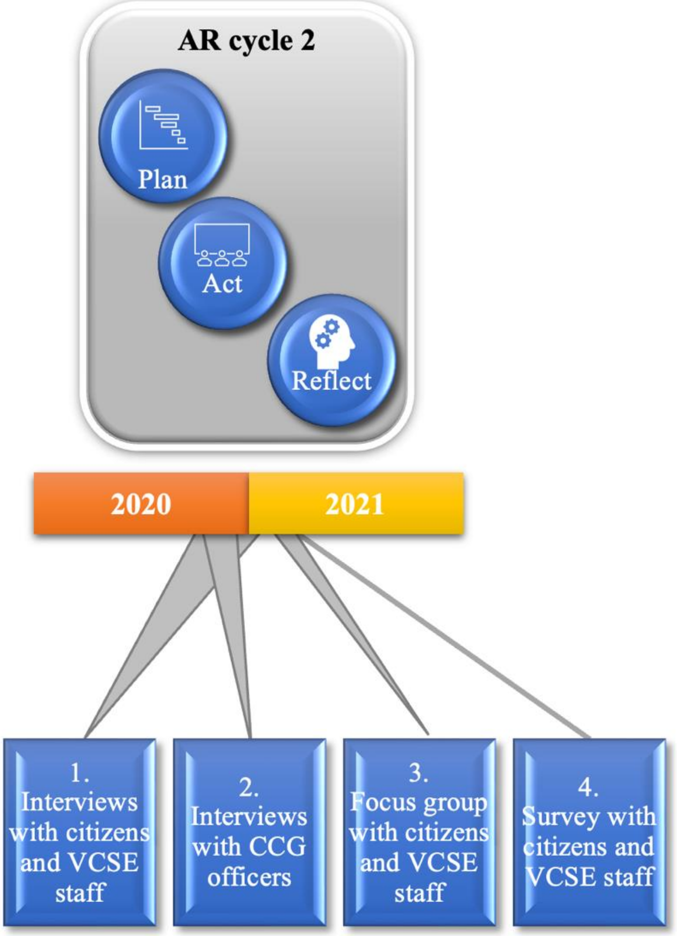

Figure 13: Timeline for AR cycle 2, showing engagements with citizens, VCSE staff, and CCG officers

5.3.4. Engagement Structure

I held three sets of qualitative engagements to understand the practices and institutional relationships surrounding PHBs. First, 20 remote one-to-one semi-structured interviews with the citizen participants and the VCSE organisation. Second, four remote one-to-one semi-structured interviews with CCG officers. Third, a two-week focus group with 15 citizen participants plus one new recruit and the VCSE staff member.

The interviews were designed to gain an end-to-end understanding of the access, benefits, and management work of PHBs. The focus group was designed to enable a peer-to-peer discussion on insights and topics arising from interviews. The design of the group engagement was driven by my direct experience and knowledge as an unpaid carer, and reflections from the group engagement in the first AR cycle.

Interviews with citizen participants and VCSE staff. The interviews were held remotely because of the COVID-19 pandemic, the constraints of the citizen participants' lives, and their geographic spread across England. 20 one-to-one semi-structured interviews with citizens and VCSE staff were held over four months starting in October 2020, with 19 interviews conducted via Zoom videoconferencing and one via telephone. Zoom was chosen as the participants were accustomed to this software due to its widespread use during the pandemic. My personal experience of running a PHB and conversations in the first AR cycle helped formulate open-ended interview questions that began to transition from the inductive approach in the previous AR cycle to a more deductive approach, exploring topics such as identifying the needs for PHBs, experiences of gaining and managing PHBs, relationships between PHB holders and CCG officers, and receiving the support and knowledge needed to manage PHBs. I developed an interview guide to steer the conversations, see Appendix C, with questions that included, *"Can you talk me through the process of gaining and running your PHB?", "Where did you go to get information or support?", "Do you use technology to help with running your PHB?"* I recorded 17 hours of conversation, transcribed using an online service[20].

Interviews with CCG officers. Four, one-to-one, semi-structured interviews with CCG officers were held over four weeks in November and December 2020 using Microsoft Teams[21] videoconferencing, as this software was used across England's state healthcare. The questions used to guide the discussions were similar to that for citizen participants but from the perspective of the CCG officers. I recorded three hours of conversation, transcribed using the same online service as for the citizen participants and VCSE staff.

Focus group with citizen participants and VCSE staff. Following the above interviews, I arranged a long-duration remote focus group in February 2021. CCG officers were excluded from this focus group as several citizen participants and I had felt that the participants' PHBs would be threatened if they criticised the services they received in front of their CCG officers. Their belief was echoed in previous HCI studies that had shown mistrust from the citizens of their civic authorities (Light and Akama, 2012; Corbett and Le Dantec, 2018a; Clarke *et al.*, 2021), the citizen fearful of reprisal, thus inhibiting their input (Harding *et al.*, 2015; Harrington, Erete and Piper, 2019; Bates *et al.*, 2020; Cook, 2021). 20 disabled citizens and unpaid carers took part with the single VCSE staff member, as she was felt to be on the 'same side' as the citizens when her attendance was discussed with two of the citizen participants.

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[20] https://otter.ai/

[21] https://www.microsoft.com/en-gb/microsoft-teams/group-chat-software

I planned the focus group to accommodate for the lives of caring of the attendees, with three half-hour (optional) synchronous sessions embedded within a two-week asynchronous session for participants, see Figure 14. This allowed participants the opportunity to take part without travelling, at times that suited their lives, and also aligned to other studies that found this allowed for more participants, and more time for participants to reflect on the comments of others when compared to face-to-face focus groups (Carla and Mira da Silva, 2013). This engagement method was a continuation from the prior AR cycle based on my reconfiguration and extension of HCI's ARC method (MacLeod *et al.*, 2016).

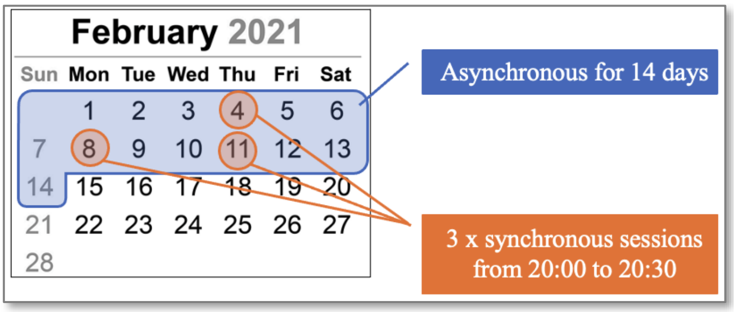

Figure 14: Focus group synchronous and asynchronous sessions

I leveraged data from the earlier interviews in this AR cycle to create the first 'scenario of care' based on an interview quote, to promote discussion and generate ideas. This was posted to the focus group using an interaction style of a bulletin board, see Figure 16, with participants allocated five days to respond to the scenario and discuss it with each other. I then iterated using data from that discussion to construct new scenarios to foster more discussions and help shape ideas. The interview quotes that were used to formulate these scenarios of care included, *"You've got all these roles, responsibilities. No one tells you what they are", "I can get advice, what I need is stuff done*" and *"If I did give this work to someone else, they would have to go through one hell of an education programme before they're able to do it"*. Each scenario was shown to one participant for their review before uploading, resulting in minor changes to the wording. I promoted respect within the focus group with rules I added that inappropriate comments would be removed, any disagreements were to be reasoned, and the request of "*Please be kind to one another*".

This iterative, remote, synchronous / asynchronous, remote method developed for the focus group aimed to: (i) offer a means to bring back to the participants common themes drawn from the qualitative analysis of the earlier one-to-one interviews for collective discussion and reflection; and (ii) support dialogue and connections between topics, discussion, and themes that participants shared over the two weeks.

This style of engagement collected 492 typed comments totalling 24,877 words, plus 1,908 participant interactions such as viewing a question page with its responses; this data excludes my input. Figure 15 provides the number of interactions by hour of day from the citizen participants across the two weeks, illustrating that although the peak (695 interactions) occurred around the synchronous sessions, there was a significant spread across the day and into the night.

Based on the preliminary reflections from the previous AR cycle in section 4.5.1, I decided to act in a hybrid role of facilitator and unpaid carer in this workshop. This allowed me to nudge conversations to develop by adding my personal views and experiences, though the conversations were naturally 'lively' and just required my input to maintain focus on the topics voiced by the participants.

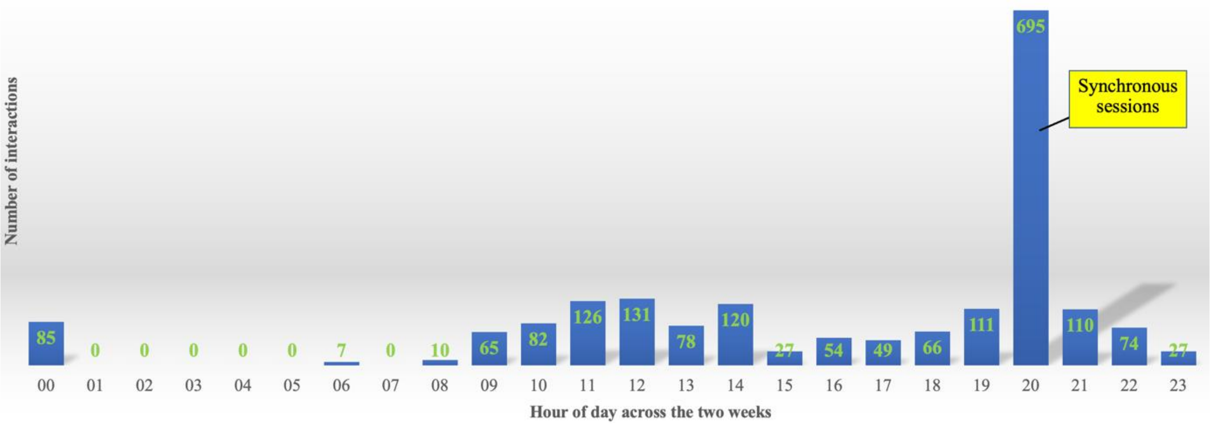

Figure 15: Interactions by hour of day across all synchronous and asynchronous sessions (excluding those of the researcher)

Survey with citizen participants and VCSE staff. Following the above focus group session, I ran a survey to capture participants' reflections on the engagement method. I considered a survey best suited to collect data as the questions were straightforward and I wanted responses to be anonymous, allowing participants to criticise freely. A survey was also zero cost and low-effort compared to interviews and focus groups. The questionnaire comprised six closed questions, see Table 3, plus one open question of *"Use this space to tell me about any problems with using the software, or, features you would have liked to have seen, or, anything else"*. I emailed all the focus group participants with a link to the survey - this was hosted on my university’s Microsoft Forms[22] licence. 10 out of the 21 participants responded (just under a 50% response rate) to the survey, with the open question generating several long responses - one was 184 words.

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[22] https://forms.office.com/

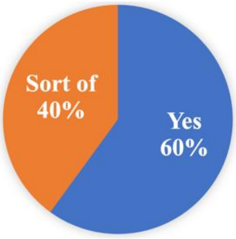
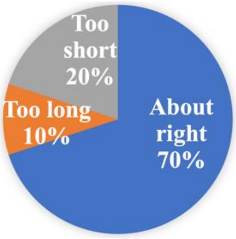
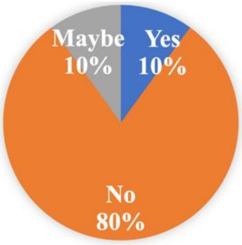
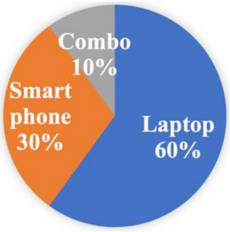
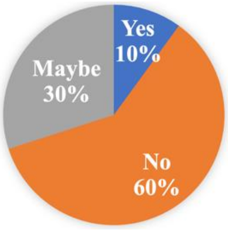
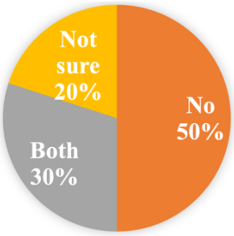
Survey question	Survey responses	Chart of survey responses
Did you find the software easy to use? It's not my software so feel happy to shout at it!	Yes - 6; No - 0; Sort of - 4	
Was 30 minutes for each group session enough time?	About right - 7; Too long - 1; Too short - 2	
Did the whole process just go on for too long?	Yes - 1; No - 8; Maybe - 1	
What type of device did you use to access the software most of the time	Laptop - 6; Smartphone - 3; Other - 0; Combination of the above - 1	
Would you have preferred to have been anonymous?	Yes - 1; No - 6; Maybe - 3	
Would you have preferred to see and talk to each other over Zoom?	Yes - 0; No - 5; Both - 3; Not sure - 2	

Table 3: Closed questions from the survey and their responses

5.3.5. Engagement Tool Selection

I created a set of criteria to select the tool for hosting the above focus group, see Table 4. Note that disabled participants already had the capability to access internet-based software using accessibility tools or their unpaid carers acting as their proxies.

Criteria	Rationale
Remote and allows for asynchronous and synchronous sessions	Provides for the citizen participants' intense and precarious lives of caring
Allow for conversations	A learning from AR cycle 1 where the tool used did not allow for conversations, but participants tried to work around it (by placing virtual sticky notes near one another)
Allow for multiple concurrent conversations	A learning from AR cycle 1 where the tool used did not allow for concurrent conversations, but participants requested this ability
Simplistic user interface	Participants had a range of technical literacy
Suitable for smartphone use	Participants can lack access to laptops and tablets
No large downloads	Older smartphones may not have free capacity
Avoid the need for high bandwidth	Minimise the charge for mobile phone data plans
Minimal or no cost to the researcher	Facilitates re-use for subsequent research
Open-source software	Aligns with the democratic nature of PD-driven research (Poderi, 2019; Bettega, Masu and Teli, 2021)
Downloadable participant responses	Saves time and effort for input into analysis

Table 4: Criteria for selection of an engagement tool for the focus group

I used Google to search for open-source tools but found none that matched all criteria. The criteria of minimal/no cost and open-source blocking most products. Hence, I fell back to leveraging proprietary tools that I could use with no cost, either by restricting usage to a free plan or by contacting the supplier to lean on their corporate responsibility to provide free access.

'Collabito'[23] was chosen as it met the criteria, excepting being open-source. I configured it to operate in a bulletin board style where multiple conversations could take place concurrently with multiple levels of indenting. See Figure 16 for an example from the focus group that illustrates the input and presentation style.

Collabito was a software tool new to all participants, as was the use of a bulletin board. As such, the educational agenda, which was an implicit part of this participatory research, was extended to sensitise participants (Visser *et al.*, 2005) with the first session of *"What did you have for breakfast today?"*, encouraging playful use of emojis, images, and responding to each other's comments.

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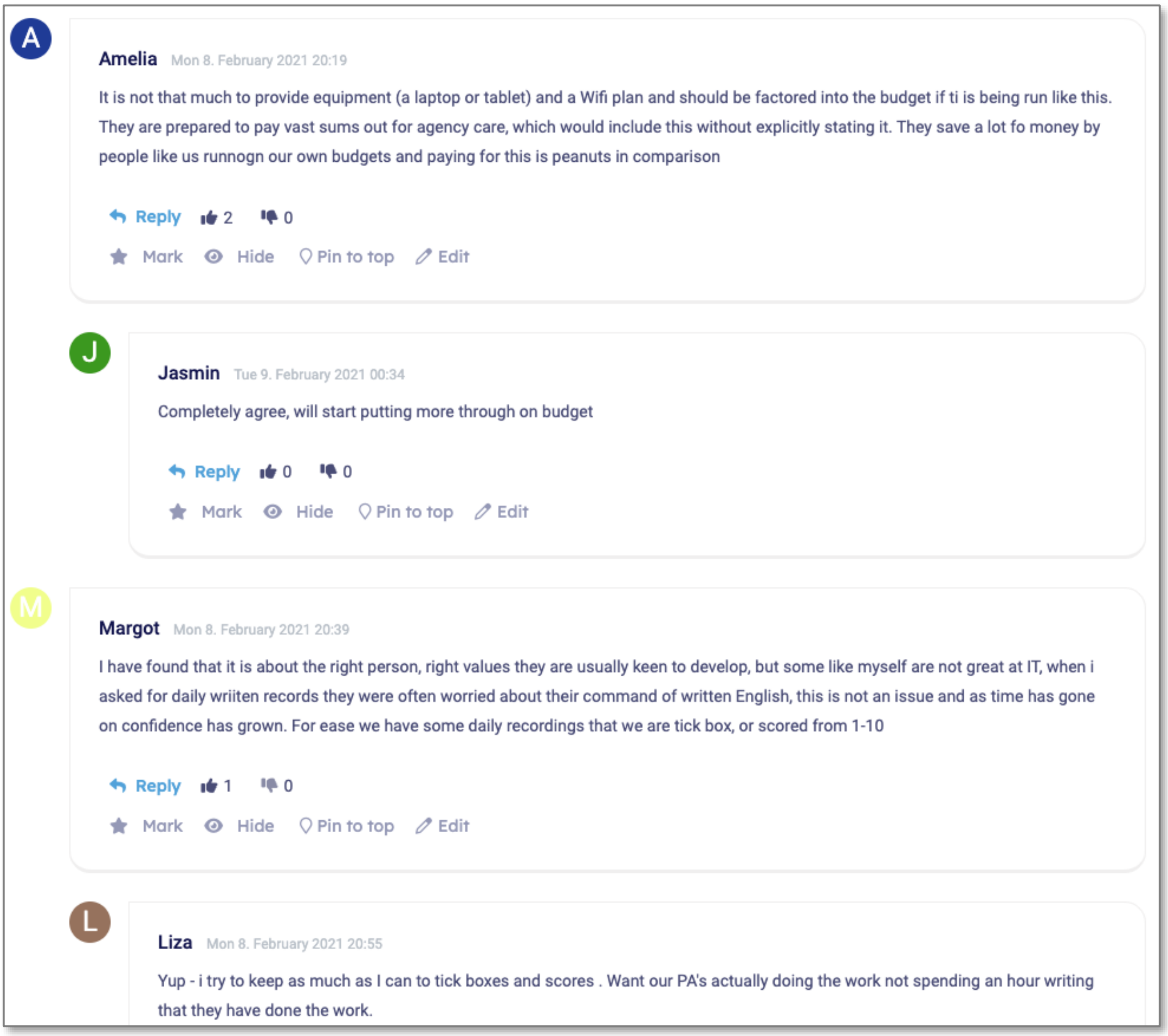
[23] https://www.collabito.com/



Amelia Mon 8. February 2021 20:19

It is not that much to provide equipment (a laptop or tablet) and a Wifi plan and should be factored into the budget if ti is being run like this. They are prepared to pay vast sums out for agency care, which would include this without explicitly stating it. They save a lot fo money by people like us runnogn our own budgets and paying for this is peanuts in comparison

Jasmin Tue 9. February 2021 00:34

Completely agree, will start putting more through on budget

Margot Mon 8. February 2021 20:39

I have found that it is about the right person, right values they are usually keen to develop, but some like myself are not great at IT, when i asked for daily wriiten records they were often worried about their command of written English, this is not an issue and as time has gone on confidence has grown. For ease we have some daily recordings that we are tick box, or scored from 1-10

Liza Mon 8. February 2021 20:55

Yup - i try to keep as much as I can to tick boxes and scores . Want our PA's actually doing the work not spending an hour writing that they have done the work.

Figure 16: Screenshot of a Collabito discussion

5.4. Findings

I present six themes generated from the data analysis sourced from 20 hours of interview recordings, 492 typed comments from the focus group sessions, and the survey responses. The use of reflexive TA was continued as described in the Methodological Approach chapter, section 3.11.

In the first theme, *Gaining Choice and Control with a PHB*, I examine the importance that the citizen participants, VCSE staff, and CCG officers place on personalised, relational care. In *Accessing a PHB*, I look at the process of gaining access to a PHB, surfacing power imbalances at play. *Citizens and the Civic: Navigating the Power Dynamic* illustrates the experiences of citizen participants and CCG officers managing PHBs, uncovering tensions between them. *Experiences of Becoming an Employer* explores how citizen participants must work to operate their PHB, using technology to build capability. The theme of *Personalised*

Needs and Mutual Aid describes how the participants navigated the challenges of managing their PHBs with little assistance, deliberating on how they could share their experience with their peers. The final theme of *Responses to Engagement Methods with a Time-Poor Population* further reflects on my group engagement method to ensure its validity for the following AR cycle.

Pseudonyms are used for all the participants with "(CCG)" and "(VCSE)" suffixed to pseudonyms where the participant is other than a citizen participant. Quotes can be assumed to be taken from the one-to-one interviews, unless stated to be from the focus group.

5.4.1. Gaining Choice and Control with a PHB

This theme extends on from the "*Seeking Support to Care for my Child*" theme in the previous chapter, section 4.4.3, expanding on the unpaid carers' lives of caring, further hearing from the voices of disabled citizens, CCG officers, and VCSE staff.

The unpaid carers and disabled citizens voiced a lack of recognition of their healthcare needs from their CCG officers. These included a deficiency of understanding of the time and effort required for managing their paid carers as employees, but also more nuanced aspects of this work. For example, needing confidence and trust in the skills of paid care staff, the ability to direct the staff, and the need for a personal relationship with staff based on shared values and beliefs. These needs were prominent prior to the implementation of PHBs when CCGs controlled the supply of paid carers through care agencies. All the citizen participants voiced experiences of distress when strangers sent by care agencies would arrive at their homes to deliver personal and intimate care, having no choice or voice as to who delivered this care, their skills, values, and belief systems. Julie, a wheelchair user with a limited range of mobility, recounted struggles with her personal assistants before receiving her PHB,

> *"And there are particular difficulties that I've had. I'm a queer woman, and for example, agencies would often send me homophobes, and they all refused to vet their staff for being rampant homophobes. And ... the CCG would not consider it their problem."*

However, with a PHB in place, the citizen participants gained the choice of interviewing and selecting their paid care staff, aligning personal attributes and values. This relational approach enabled a positive relationship between a PHB holder and their paid carers. Most citizen participants expressed that regardless of issues they had in gaining and running their PHB, they would not give them up, as they would lose these relationships. Bella, parent to her disabled son in his 20s, explained how her PHB provided not just control in selecting paid carers but how she can direct them. These factors provided autonomy to her son's life, extending value to her own, *"... having the ability to take [a] PA on holiday with you, choose where [my son] wants to go and spend time with friends that he wants to be with as well. It's quite life changing, isn't it?"*

The CCG officers all voiced support for PHBs for the benefits and value they delivered. Marina (CCG), who had worked for over 20 years in healthcare and was responsible for all aspects of PHBs in her CCG, believed PHBs were a vehicle that promoted communication and hence relationships between the CCG and PHB holders,

> *"Service users*[24] *really like [a PHB] because it gives them the things that they really need. And they can have that open conversation with [CCG] staff about what's important to them. And they like that they've been heard, I think, is probably the biggest thing."*

This theme reported how citizen participants highlighted the importance of the relational qualities of care work personalised to those requiring care and their unpaid carers. The care work goes beyond a simplistic granting of carer hours, extending into notions of autonomy and control grounded in long-term, supportive, constructive, and positive relationships.

The next theme explores how the citizen participants fight for these values when they are assessed for a PHB, even at the cost of their wellbeing.

5.4.2. Accessing a PHB

Gaining a PHB requires either a discretionary assessment from the citizen's CCG or their use of a manual Decision Support Tool (DST) that drives an assessment process to determine eligibility. The DST segments the needs of the citizen into a set of domains, which are then scored by the CCGs, as described in section 1.7.2. The scoring demands assessors' discretion as there are no rigidly defined criteria, with technology used to record inputs, scores, and decisions, rather than assisting with the decision.

All but one of the citizen participants described how this assessment was distressing, extended months and years past the national guideline of six weeks, and that they had to perform high levels of work to request, monitor, and then raise complaints about poor service. The

---

[24] Service users is the term used by CCGs for citizens using CCG services.

relationships between those requesting a PHB and their assessors became adversarial, characterised by power imbalances that raised barriers to access. The citizen participants recounted the stress generated by the process that involved being judged by a distant panel of CCG officers and healthcare professionals with whom they may never meet. Jessica, a wheelchair user with physical and mental disabilities, described how she felt in an assessment interview, where her CCG officer applied discretion to remove scoreable attributes from her application that Jessica felt were important to be assessed fairly and justly,

> *"I had an awful assessment. I found it really, really traumatic. And the CCG woman went out of her way to make sure that I didn't qualify ... even saying that 'I'm not going to write that down' ... And she had access to my medical record and she'd obviously cherry picked the things that suited her."*

Jessica's CCG rejected her PHB application but she re-applied by raising a formal complaint that was subsequently accepted. This end-to-end process of gaining a PHB took 18 months, leaving her without care during the mental health crisis that triggered the need for her assessment.

When discussing assessments, several of the citizen participants felt there were skills required to score highly enough to qualify for a PHB. These skills went beyond simplistic statements of their needs, demanding the ability to use the language of CCGs and situate that language in government policy. Kayla, a wheelchair user with a limited range of mobility, found the experience from her first application was key when applying for a new, joint PHB with her partner,

> *"And I did it completely differently. Because I knew existentially what my arguments were going to be ... I guess what buttons to push, I knew how to justify what I wanted and why. Because I had that insight into how the system works."*

From the perspectives of the majority of the citizen participants, assessments and access to PHBs were far from a neutral process. Rather, they were permeated with power imbalances and moral judgements that played out in ways such as discretionary scoring. In this regard, two of the CCG officers admitted they were reticent to grant PHBs, as they believed citizens lacked the capabilities to operate them. This was despite state healthcare policy driving CCGs to promote PHBs to achieve citizens' care personalisation, control, and choice. Kelly (CCG) commissioned PHB funding in her CCG and declared herself to be a PHB advocate, however, she did not have trust in the citizen to manage the money and chose to discourage this, saying, *"... and then they don't look after themselves, they [use] it [the PHB funding] to go to Florida* *or whatever else."* Marina (CCG), shared Kelly's beliefs about handing over the budgets to families,

> *"And I think if we had to give them money, to people to manage themselves, it would all go really wrong, really quickly ... And I would worry about giving people big sums of money because they can't manage their money ... the money would disappear."*

The two other CCG officers voiced care and understanding of the needs of applicants and how harmful the assessment process can be. Carla (CCG), who managed a team that administered PHB funding payments in her CCG, equated assessments to 'cutting people' up into the different domains to make them fit the system, *"[If] it is barndoor obvious that that child is [eligible] we will not put the family through a DST, we understand how awful it is to have your child dissected in the domains."*

This theme introduced a manual Decision Support Tool that asked distanced assessors to "*dissect*" candidates into their 'failing' health domains and then score based on level of need. Nearly all the citizen participants found these assessments to be a distressing experience, where they felt powerless as they put forward their case. CCG officers voiced an understanding of the harm the assessment can bring and saw the value in a PHB but were unwilling to grant the control to the citizen that a PHB involved.

The following theme explores citizen participants' experiences once they have gained a PHB, finding the power dynamic continues against them.

5.4.3. Citizens and the Civic: Navigating the Power Dynamic

The promise of autonomy did not appear to materialise in practice. Most of the citizen participants recounted having to *"fight"* to keep their PHBs and to own spending decisions, their CCGs continuing to act as gatekeepers to the citizens' funding.

All the citizen participants found themselves having to seek permission from their CCG officers for any new type of spend, no matter how small, this process on occasion taking months. Amelia, who parented her disabled son in his 20s, had the experience that her CCG initially refused to transfer funds directly to her account, which would have allowed her to spend the money as she needed on training and equipment, instead they paid her carers directly, inhibiting any other type of spend, *"I've really had to fight ... It took me nearly a year after getting the personal health budget to actually get the budget."*

Cases were also reported where a previously agreed PHB was withdrawn by CCG officers. Maria, whose young son is disabled and needs frequent resuscitations, explained how a change in the criteria within the assessment meant the CCG officers ruled her son no longer scored high enough to maintain the PHB, leaving her without support for his caring. *"So we started off qualifying ... that's when we had a PHB. When the framework changed, they disqualified us ... he was then removed from all care services."* Maria subsequently moved her family to a different region in England where she has been told by a friend, correctly, that the CCG would allow her son to gain a PHB.

The CCG officers' attitude that the citizens were not to be trusted with the funding and that the citizens would waste it if not tightly monitored, was familiar to the citizen participants. Their frequent response was that it was the CCGs that were wasting money by constantly referring decisions up and down the CCG management hierarchy. This was seen by the citizen participants as the CCGs holding power, with the citizen participants' desire to gain the funding they are due and then be left to control it. Jasmin, a parent to her disabled daughter in her teens, provided an instance of her CCG micro-managing her PHB, inferring the inefficiencies of the process that she wanted to own, *"They were still wanting me to ask permission to buy a £4.99 first aid kit. And so it went to the [CCG] worker, and then it went to the [CCG] worker's manager to get signed off. And then it got sent back to him."*

The CCGs' ultimate decisional power over the access to and use of PHBs permeated and shaped the power dynamic. The citizen participants learnt to navigate the system with great care - a balancing act between using their legal rights to challenge their CCG, and living with the fear that an angered CCG officer could withdraw their PHB funding. These complex dynamics became apparent when, in the planning of the focus group for this AR cycle, I asked several of the citizen participants about inviting CCG officers, and the participants refused, as they felt this would inhibit open conversation, fearful their identities could be exposed through recounting specific issues, thereby placing their funding at risk. Orla, one of the VCSE directors and a wheelchair user because of a spinal injury, outlined her approach to her CCG, *"So, I am happy of lying under the radar and not drawing too much attention to myself ... I don't contact the CCG if I can help it and I like to stay quiet and not cause a fuss."*

All the CCG officers recognised this unbalanced power dynamic, justifying it in terms of their mandate and duty to ensure both financial and health risks were appropriately managed. Kelly (CCG) provided an example of the need for this oversight and risk management to avoid harm to the child and their parents,

> *... a lot of the parents ... wanted a hot tub. Get it completely and utterly get it. But actually, who's going to lift this child in and out of the hot tub? And where's the risk assessment associated with that?*

Carla (CCG) focused on the risk of losing track of how the funding was being spent and the potential impact on her CCG,

> *"It's not that we want to control it. We just want to make sure that actually when we're sending the money, we know that a) [they've] got enough they want to spend it on and b) half a year down the line the auditor doesn't go 'Oh my god the budget [is out of control]' ... And then it's like all hell lets loose."*

The power dynamic between the citizen participants and their CCGs was compounded by a distance between them. With the power held by the CCG officers, the citizens filtered out negative feedback to reduce the risk of losing their PHB funding. Dana (CCG), who had worked with PHBs for six years in a role aimed at bringing together healthcare and social care, recognised this distance and the fear that lay behind it, *"I worry that families are so nervous about having their Personal Health Budget reduced that they wouldn't come forward with concerns until things hit quite a critical point."*

This reduced communication led the CCG officers to form a false or incomplete view of the citizen and their lives, and vice versa. An example was seen with the running of payroll for their paid carers, Carla (CCG) managed a payroll team that was used by two of the citizen participants. She described her team, *"... what they do [is] excellent. I cannot fault that team, they are over the top in terms of best practice."* Two citizen participants offered an opposing view of that same team, Jasmin saying of them, *"I don't think that they're actually trying to be awkward, but that's how it comes across."* Amelia agreed with Jasmin's view when the topic was raised in the focus group, *"The limited info from that team was not very good and they could not answer queries and also got things wrong, so I stopped asking them."*

In this theme, the citizen participants found that the promised autonomy of a PHB did not materialise. The citizens had to fight to gain control of their budget, the CCG officers seeing this control in terms of managing risk. The distance between the two sides inhibited communication leading to a lack of understanding and constructive dialogue. With little or no support from the CCGs, the next theme examines how the citizens must work to build the capability to operate their PHBs.

5.4.4. Experiences of Becoming an Employer

PHBs offer advantages to CCGs as they allow the potential to move the cost, accountability, and responsibility for the management and administration of care work onto the citizen as the PHB holder. This unpaid infrastructuring work transitioning to become invisible to the CCGs when they no longer perform it, pay for it, or witness it being performed.

Sandra (VCSE), a PHB advocate for over 11 years and a director of the VCSE organisation taking part in this study, provided a summary of the legal information, skills, and work demanded by a new PHB holder,

> *They need to agree with their CCG, the degree of control they will have over who the staff are, and how those staff are going to be employed, and how they're going to be recruited. They'll need good advice about what their legal responsibilities are as an employer, and to agree how any payroll will be run, either by themselves or by another organisation. They'll need to know what hours people will work, for what pay, what training. They'll need to know where any equipment will be bought, and how it will be maintained. What the staff recruitment practice will be and what terms and conditions staff are employed under, what will happen in any emergency or crisis, what will happen if staff don't show up or are sick.*

This list of tasks is appropriate for a company owner or a care home manager, illustrating how the citizen has to 'pay' for the promised autonomy of a PHB by becoming an employer, but without support from their CCG to assist in gaining the capabilities needed.

All the citizen participants used technology in varying ways and of varying willingness to manage being an employer. Technology was seen as both a useful tool and an additional burden on their lives already dominated by care and managing their PHB. Stress arose as the unpaid carers had no fallback but themselves if the technology or processes surrounding care for their child failed, and the disabled citizens had no fallback at all for failures. A focus group discussion responded to a scenario where a tablet could be available to their paid carers that contained all the administrative paperwork needed,

> Amelia: *"Grappling with everything electronically on top of running the care team just feels like 'yet another thing', especially when it inevitably goes wrong."*
>
> Chloe, a parent to her disabled son in his 20s: *"On a tablet would be a good idea as less paperwork, but computer technology is not always reliable (breakdown, files could easily be deleted in the wrong hands)."*

> Orla: *"There's also concerns about security - having all of my info, health records, daily records, PA's details in an app or website - who has access to that and how/where is it stored?"*

The relational aspects of care surfaced once more when several of the citizen participants expressed technology as an inhibitor to relationships and human discretion, factors that they saw as benefits of a PHB. Colin, a wheelchair user owing to Multiple Sclerosis, said in the focus group, *"It's just I also find people need [the] human touch. The [human] interaction is one of the reasons I have or use a PHB."*

The topic of discretion surfaced in the focus group when technology was suggested to take control of planning their staff rota. This was firmly rejected by those that responded, Orla stating, *"Nope. No no no no no. That sounds like an absolute nightmare to me. I just don't think an app deciding the rota would work. You'd lose the human element in decision making."*

This theme described a significant burden of managing and administering their PHBs that had been placed upon the citizen. The citizen participants each used technology to evolve their capabilities but saw technology as a further burden and risk to their lives that could also delimit the human aspects of relationships and discretion.

5.4.5. Personalised Needs and Mutual Aid

This theme describes how a response was conceived by the participants to the lack of support they received when starting with a PHB, discussing the contradiction between taking collective action to meet individualised need.

The focus group began to discuss the documents - that I have termed 'care artefacts' - created by the PHB holders, that are needed for their roles of employer and manager of paid care staff. Care artefacts are documents used to manage the PHB and the paid carers. For example, staff management, payroll, health and safety, and duties of care (see Figure 17); the majority are one-page documents (see Figure 18), but others, including care plans and staff contracts, extend to 20 pages or more. There are two main categories of such documents - those that are read-only such as staff policies, and those that are to be edited to log the care that has taken place.

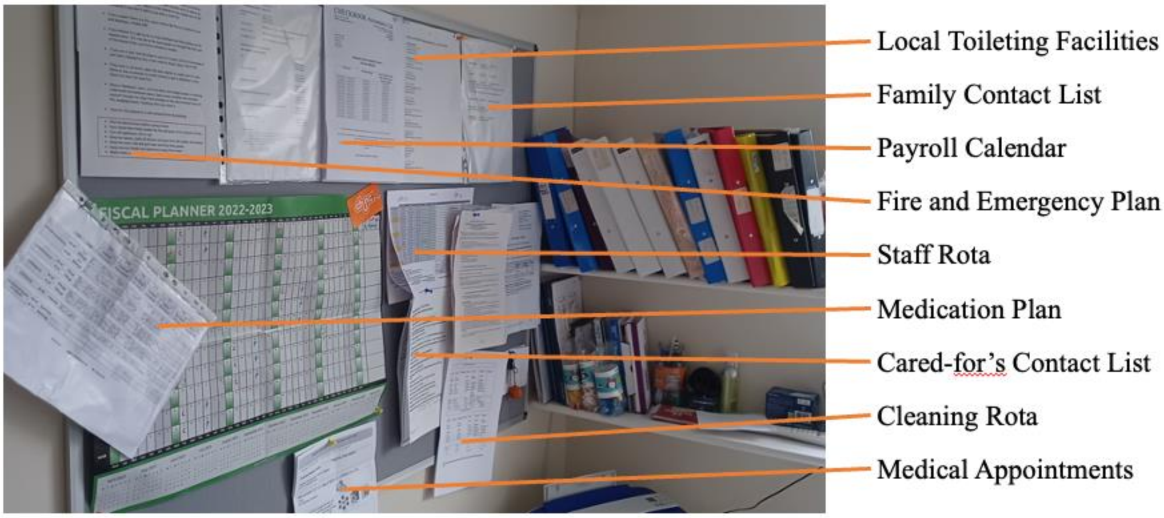
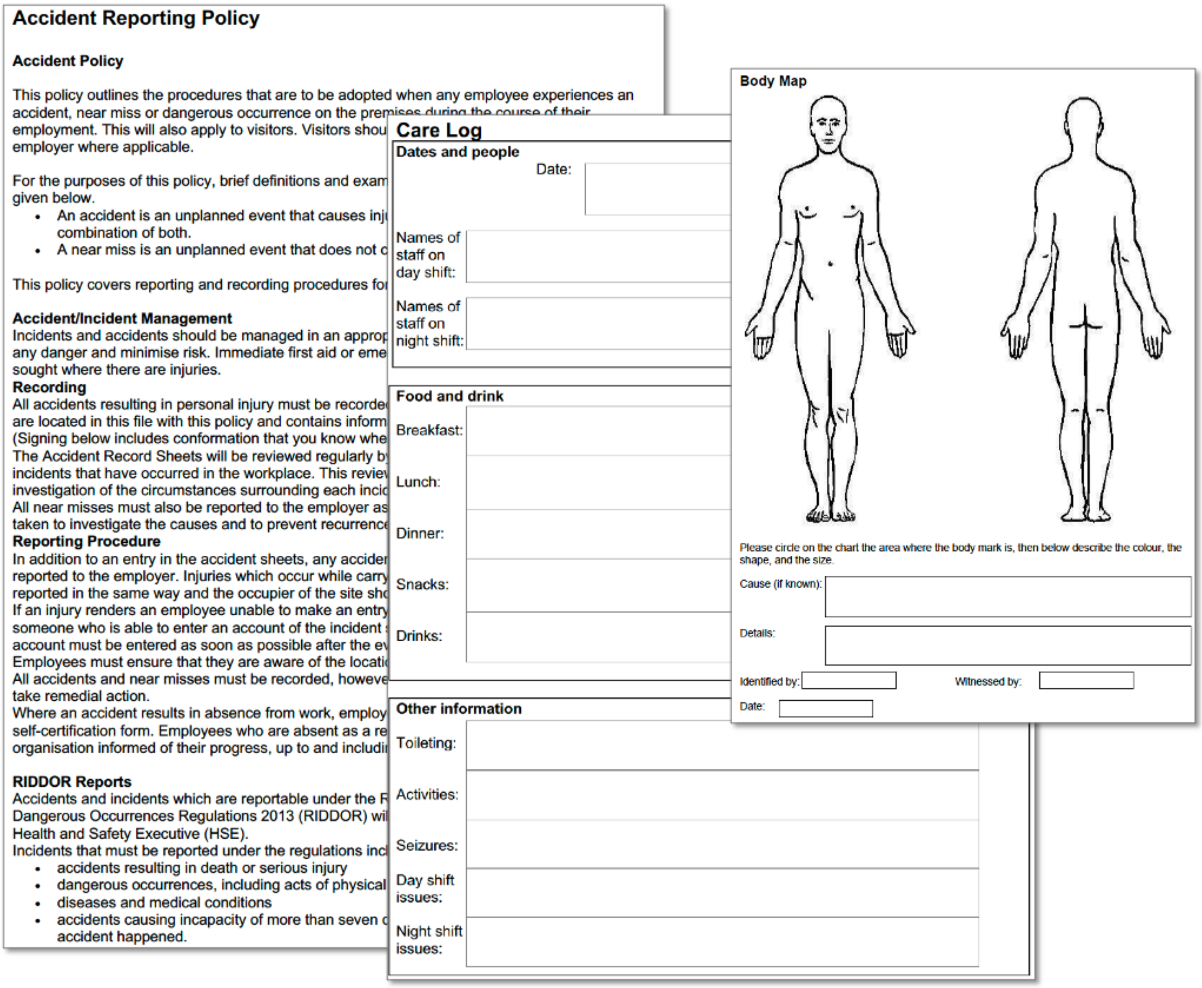


Figure 17: An information board at a disabled child's home for use by paid carers



Accident Reporting Policy

Accident Policy

This policy outlines the procedures that are to be adopted when any employee experiences an
accident, near miss or dangerous occurrence on the premises during the course of their
employment. This will also apply to visitors. Visitors shou
employer where applicable.

For the purposes of this policy, brief definitions and exam
given below.

- An accident is an unplanned event that causes inj
  combination of both.
- A near miss is an unplanned event that does not c

This policy covers reporting and recording procedures fo

Accident/Incident Management
Incidents and accidents should be managed in an approp
any danger and minimise risk. Immediate first aid or eme
sought where there are injuries.
Recording
All accidents resulting in personal injury must be recorde
are located in this file with this policy and contains inform
(Signing below includes conformation that you know whe
The Accident Record Sheets will be reviewed regularly b
incidents that have occurred in the workplace. This revie
investigation of the circumstances surrounding each incid
All near misses must also be reported to the employer as
taken to investigate the causes and to prevent recurrence
Reporting Procedure
In addition to an entry in the accident sheets, any accider
reported to the employer. Injuries which occur while carry
reported in the same way and the occupier of the site sho
If an injury renders an employee unable to make an entry
someone who is able to enter an account of the incident
account must be entered as soon as possible after the ev
Employees must ensure that they are aware of the locati
All accidents and near misses must be recorded, howeve
take remedial action.
Where an accident results in absence from work, employ
self-certification form. Employees who are absent as a re
organisation informed of their progress, up to and includi

RIDDOR Reports
Accidents and incidents which are reportable under the R
Dangerous Occurrences Regulations 2013 (RIDDOR) wi
Health and Safety Executive (HSE).
Incidents that must be reported under the regulations inc

- accidents resulting in death or serious injury
- dangerous occurrences, including acts of physical
- diseases and medical conditions
- accidents causing incapacity of more than seven c
  accident happened.

Care Log

Dates and people

Date:

Names of staff on day shift:

Names of staff on night shift:

Food and drink

Breakfast:

Lunch:

Dinner:

Snacks:

Drinks:

Other information

Toileting:

Activities:

Seizures:

Day shift issues:

Night shift issues:

Body Map

Please circle on the chart the area where the body mark is, then below describe the colour, the shape, and the size.

Cause (if known):

Details:

Identified by: Witnessed by:

Date:

Figure 18: Examples of three care artefacts: an Accident Reporting Policy, a Care Log filled in by paid carers, and a Body Map for marking injuries

All the participants voiced how their CCG officers had tasked them to recruit and manage a care team, but without the support, training, or advice to create the documentation this entailed. To fill this gap, the majority of participants wished they had received support from their peers, ideally through one-to-one conversations with a peer mentor. Orla, a VCSE company director who had sustained a spinal injury in her early twenties, lamented the lack of access to a mentor, *"It would have made a big difference to me to have had anyone else [to] speak to who had a PHB ... My [healthcare authority] didn't offer to put me in touch with anyone."*

In discussions, the citizen participants considered accessing such a mentor as unattainable, so they turned to the internet to seek the care artefacts they needed to perform this management. Kayla, a national disability advocate with a muscle disease, realised that her peers possessed the knowledge on PHBs, the issue was how to access it, *"The knowledge is out there, it's just getting it to the right people in the right way."*

The challenge here was a lack of care artefacts from healthcare authorities, the VCSE sector, commercial organisations, or availability on the internet - requiring each PHB holder to determine the need for every care artefact and then create them without support. Maria gave examples in the focus group of what she needed but lacked, *"There should be risk assessments, training and care plans. I lived in a CCG that had none of this. Absolutely none."* Kayla continued with, *"... I was kind of hoping that I'd be able to find [care artefacts] on the internet ... And that didn't really exist."*

In this way, a few participants began to envisage an online resource for sharing their care artefacts. A discussion that began with a vague idea for a technology that could hold their working documents, moved on to describe what this technology would need to contain, how it could be accessed, and its functionalities. Amelia was the first to raise the concept, saying, *"For me, there should be a piece of technology or a resource somehow, that has all the bits that you need ... and the things to think about when you're setting up [a PHB]."* Zara effectively described a digital common-pool resource (CPR), *"I think open source would be fabulous, the content you put in is what makes it valuable",* Sarah then explicitly called out for a digital commons, "*I would want a ... wiki"*; later suggesting that the wiki would contain care artefacts that could be copied to a local device, stressing the need for the artefacts to be maintained, *"... downloaded from a regularly updated website."*

Sarah's seemingly unremarkable statement triggered a lengthy discussion regarding the meaning of taking collective action to provide care artefacts that needed to be individualised for each person - something they considered to be an apparent contradiction. For example, Amelia considered that, *"... [care artefacts are] to be adapted for your own needs*." So, in discussions, participants envisaged their artefacts could be useful as a starting point for their peers, as something they could individualise. They considered how multiple versions of a single type of care artefact could be offered online, showing the variety of ways they had been individualised by different people. Julie saw this need for different versions of a care artefact, *"I think multiple examples [of each artefact] with the pros and cons of each."*

This call for diverse care artefacts was evidenced in the care artefacts later sourced from participants in the next AR cycle, where 13 types of artefacts had up to four versions that differed in style and content. For example, an 'Accident Log' varied from documents that asked for a wealth of detail for each accident event, to others that recorded a simple list of events.

Thus, in the process of working out how they could respond to the challenges they and their peers faced when running a PHB, considering the practicalities of what it should contain and how it should be delivered, the citizen participants reconsidered the value of sharing multiple versions of care artefacts for people to draw from. Deliberating ideas and options, participants discerned between personalised care and 'individualised' need. In the process, catering for multiplicity didn't seem much of a contradiction but rather a value underpinning their collective action and a nascent design response for a digital commons containing peer-produced care artefacts.

This theme surfaced a form of infrastructuring required to manage and administer a team of paid carers - a set of documents, named care artefacts for this study. With a lack of these documents available from any source, each PHB holder had to create their own, seeing their care artefacts to be of value to their peers once made accessible in a digital CPR.

5.4.6. Responses to Engagement Methods with a Time-Poor Population

Separate from the above themes describing the care work of the citizen participants, an anonymous survey took place at the end of the focus group to elicit responses on the method and tool used for the group engagements.

The majority of the survey respondents welcomed the remote, asynchronous / synchronous design and appreciated the text-only interactions. The selection criteria, see section 5.3.5, that related to devices were pertinent, as three of the respondents used smartphones to take part in the focus group. The software selected, Collabito, also found favour, as all found the tool either easy or *"sort of"* easy to use – see Table 3.

The style in terms of duration and the text-only format also gained approval. The majority of the survey respondents liked both the extended 14-day duration of the focus group and the 30-minute duration of the synchronous group sessions. No respondent preferred a Zoom meeting, one respondent remarking that it avoided social awkwardness, *"With a group that you have never met, I would have been less keen [on video conferencing]."* Another seeing value in the avoidance of technical issues that can hinder synchronous meetings and the ability within asynchronous sessions to avoid caring conflicts, saying, *"I found it an enjoyable experience and probably easier than a face-to-face or Zoom focus group where technical hitches can occur and where commitments at home can mess up the best-laid plans."*

The open question in the survey that asked for their reflections on the engagement method showed more ambiguity. There was a feeling that a video conference would have made the discussions more 'fluid', with one respondent suggesting mixed sessions: where the asynchronous session was anonymous, followed by an optional video conference. Others remarked that the asynchronous session allowed for their priorities of care, where one respondent typed, *"Think [Zoom] would have been more time-consuming but it does make discussion easier. The other advantage [of text-only] was that if I got called away to assist with care it didn't matter."*

The success of this engagement method, and the need from the previous themes for access to care artefacts, are discussed in the following section.

5.5. Preliminary Reflections

Chapter 8 provides a full discussion, with this section offering preliminary reflections specific to this AR cycle and their impacts on subsequent AR cycles.

5.5.1. Responding to the Need for Care Artefacts

In the above Findings section, I explored the struggles experienced by citizens when striving to access PHBs, and how, once gained, citizens take on the role of an employer.

A learning from this AR cycle was that the capabilities needed to access and gain benefit from PHBs included the skills and know-how relating to care and employment law. The capability deficits (Sen, 2005; Calvo *et al.*, 2020) voiced by the majority of the citizen participants in the focus group meant they felt abandoned as health authorities relinquished accountabilities and responsibilities onto them. This is perhaps evidenced by the CCG officers failing to discuss the onerous duties placed on citizens when they become PHB holders or, offering support.

As a response, the citizen participants wished to find ways better to support their peers in their struggle for autonomy, choosing a *"wiki"* to host the care artefacts the participants had developed in isolation. Their decision is significant as the participants recognised the inherent features of a wiki that would support their desire to mentor their peers through technology, envisaging a community-led, accessible platform that allowed for collaboration, information sharing, and user-centred design.

Yet, by acting as a movement to address failures in the state system by creating a digital commons, they were opening risks of unintended consequences for their peers in three ways. First, they were forming "social safety nets" (Spade, 2020, p. 142), in effect supporting neoliberalism and its flaws, rather than demanding their state to remove the social injustice. Second, even though all the citizen participants used technology to assist in the management of caring duties, several voiced concerns regarding risks, including technology failure, data security, costs of staff training, and loss of the *"human touch".* While these risks are often cited in other domain areas of HCI, the impact of technology failure on lives that do not have a failsafe when care becomes unavailable would be extreme. For example, a disabled citizen may not have access to any care at all if technology failed to rota paid carers. Third, I needed to be mindful that exposing citizens' invisible work carried risk, as described by Suchman (Suchman, 1995), for example, that of increasing workers' vulnerability, or their working practices being rationalised, standardised, and enforced onto them.

In summary, creating a digital commons would require careful configuration and study in the next AR cycle to avoid negatively impacting on citizens managing PHBs.

5.5.2. Furthering the Design of Group Engagement Methods

The limitations of the tool utilised in the first AR cycle (vWall) were addressed through the use of a new tool, Collabito, which allowed for multiple, concurrent conversations in the form of a bulletin board. The participants leveraged this functionality, delivering a rich set of data that could easily be downloaded in textual form for analysis - this is an advantage over a face-to-face focus group where concurrent conversations are difficult to record and manage.

The survey to collect participants' reflections of the group engagement found they enjoyed this reconfigured and extended ARC technique, as it aligned with their lifestyles and avoided social awkwardness. The respondents supported the continued use of remote, text-based, long-duration, asynchronous / synchronous focus groups and the Collabito tool, so this was continued into the next AR cycle though broadened for the differing design needs for the co-creation of a digital commons.

Moreover, as in the previous AR cycle, the synchronous sessions evidenced a high entry of comments from the participant when compared to the asynchronous sessions, showing the value of reconfiguring the ARC method with this feature.

Finally, I leveraged my preliminary reflections from the previous AR cycle, see section 4.5.1, taking on a hybrid role of facilitator and participant in the Collabito workshop. The aim was to use my facilitation skills to keep conversations alive and flowing, introduce new scenarios of care, and assist participants where needed. Concurrently, I wanted to use my experience of being an unpaid carer to supplement the conversations, as I felt I could add value here. The experience was conflicting at times as I wanted to avoid actively leading the conversations towards any of my desired outcomes as a researcher, but I still wanted to act as a participant to introduce or emphasise topics that were important to me. However, I felt I succeeded in this hybrid role, the asynchronous nature of the focus groups allowing me time to reflect and hence balance the two roles of facilitator and participant.

5.6. Chapter Summary

This second AR cycle met its aims and objectives of exploring the experiences and practices of PHB holders, a VCSE organisation that supports them, and CCG officers.

Continued use of a reconfigured and extended ARC method delivered enjoyment to the participants and benefits to this research of a rich dataset garnered through an iterative set of care scenarios placed in front of PHB holders and a VCSE organisation. CCG officers were excluded from the focus group to promote the voice of the citizen - data from the officers was collected separately through one-to-one interviews.

Findings showed that as the citizen participants attempted to reap the benefits of personalised care policies in England, the autonomy promised by PHBs was constrained by the additional work, skills, and knowledge demanded of the PHB holder. As well as a lack of support from the citizens' CCGs, the adversarial relationship, unbalanced power dynamic, distance, and the mistrust between CCG officers and PHB holders, further delimited the potential benefits.

The perceived failure of coproduction between the CoA and their CCGs in the first AR cycle now has a possibility of an alternate path to support PHB holders - a digital commons offering peer-produced care artefacts, co-designed with citizens who have the lived experience of operating PHBs. Yet, caution has been stressed regarding the risks associated with unintended consequences that can accompany technology - these demanding attention in the following AR cycle.

Chapter 6. Co-design of a Healthcare Digital Commons

"I can get advice. What I need is stuff done" - Amelia, a mother managing a PHB for her disabled son.

6.1. Introduction

As described in the previous chapter, the second AR cycle surfaced complex power relations. The citizens viewed their CCG officers with fear and anger, witnessing their promised autonomy failing to be realised. The CCG officers believed their actions were derived from a duty to mitigate risks related to citizens' healthcare and public funds. The interviews and focus group also surfaced how citizens, once they gained their PHB, transitioned to become, in effect, the owner of a residential care home, the citizens taking on management roles but without training or support from their healthcare authorities.

In this chapter, 20 out of the 21 citizens and VCSE participants from AR cycle 2 remained as participants to this AR cycle 3, with the aim of co-creating a sustainable digital commons offering peer-produced care artefacts. This as a response to the lack of care artefacts they faced when they first began the personalised healthcare infrastructuring demanded of a PHB.

I configured the co-design process to host safe design spaces that leveraged the whole life skills of participants, whilst attending to questions of values, responsibility, and sustainability in digital innovations and their design. Further employing novel configurations of participatory design methods and tools that I devised to support the need for remote and asynchronous / synchronous group engagements, due to the participants' unpredictable lives arising from their priorities of care.

I show in this chapter how the co-design process and its methods enabled the collective identification of risks and consequences in the design and outcome of a socio-technical intervention, critical for a population with complex healthcare needs. Anticipating ethical implications, complexities, and costs associated with the long-term maintenance of novel computer systems, I describe how the co-creation of a digital commons facilitated consideration of democratic questions of governance, sustainability, risks, and responsibility.

This work shows how participatory methods can configure effective co-creation partnerships and collective action with marginalised populations to support their wider communities, achieved through co-designing a sustainable digital commons that delivered mutual aid. This digital commons has been accessed by over 5,500 people worldwide as of June 2023.

The following sections discuss the aims and study design of this AR cycle before moving on to describe findings.

6.2. Aims, Rationale, and Objectives

The core aim of this AR cycle was to co-create a sustainable digital response to the issues the citizen participants had voiced when they accessed and managed PHBs. This forms the third AR cycle: designing, building, and deploying a digital commons that contains peer-produced care artefacts for use by those in receipt of a PHB, see Figure 19.

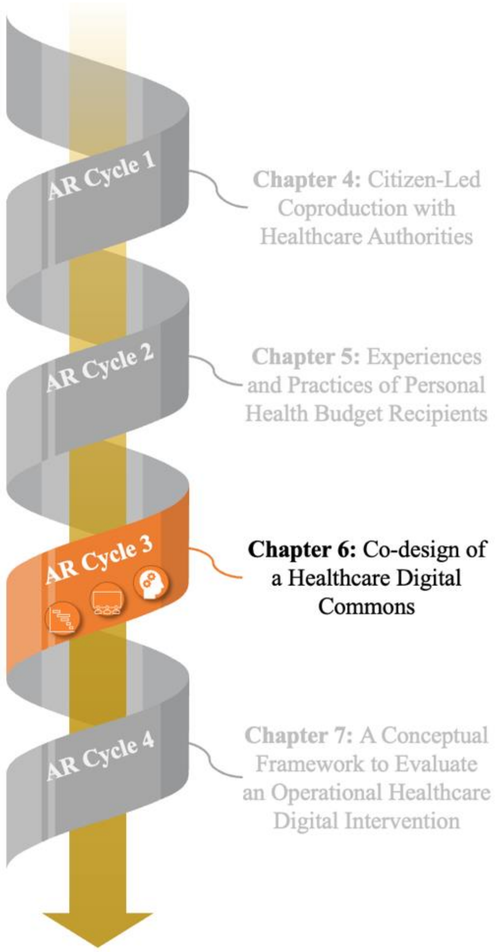


Figure 19: AR cycle 3 (highlighted in colour) and its location within the four AR cycles

The key objective from the preceding chapter of ensuring equity for the citizens in the participatory process was maintained, building on the remote, asynchronous / synchronous, text-only approach used for the previous two AR cycles. A second objective was for the design process to leverage the personal motivation of participants to co-create a response they deemed worthwhile for themselves and their peers, this demanding their long-term engagement. A third objective was to foster safe design spaces, this was achieved as in the previous AR cycle by excluding CCG officers from all group engagements. A final objective was to examine and identify risks and unintended consequences, critical for a population with complex healthcare needs (Chen *et al.*, 2011; Mitchell *et al.*, 2021; Page *et al.*, 2022). This included questions of sustainability of any digital response, demanded due to the ethical considerations of withdrawing any intervention that delivered value to the citizen participants and their peers.

The following section sets out how this aim and its associated objectives were delivered, leveraging new PD (Bødker and Kyng, 2018) and commoning (Linebaugh, 2008; Marttila, Botero and Saad-Sulonen, 2014; Baibarac and Petrescu, 2019; Sciannamblo *et al.*, 2021) to involve the citizen participants in the co-design of a digital commons.

6.3. Study Design

This section describes the process for participants to conceive a response to the issues they voiced in the previous chapter, where I took on the roles of configuring design spaces and performing the technical development.

6.3.1. Approach

The approach was maintained from the previous chapter of adopting new PD and AR, building safe design spaces, and placing participants as collaborators in the research. This needed careful configuration of participation to allow for the novel nature of the co-design and the participants' constraints of caring.

The first aspect of configuration that demanded attention was that I estimated the co-design and build would take about six months, so this was to be a long-term engagement for the participants that would require their continued focus on a single topic. Hence, I needed to design engagements that were contiguous, where possible, to maintain momentum and focus. As a balance, I did not want to turn this research into a burden for the participants, so the co-design tasks had to be straightforward, engaging, and not overly demanding of their time.

Furthermore, extending the work of HCI authors (Chen, Ngo and Park, 2013; Ammari and Schoenebeck, 2015; Bosch and Kanis, 2016), I speculated there would be benefits in including healthcare authorities in the design of a digital commons platform, such as exposing and promoting recognition of the invisible and complex work that running a PHB demands. This surfacing as a facet of justice-oriented interaction design (Dombrowski, Harmon and Fox, 2016). However, this would need to be countered by the power dynamics at play where the citizens voiced both fear and anger at their healthcare officers.

The participants and the intended end-users of the digital commons were a marginalised population, hence I also needed to place questions of ethics, accountability, and sustainability upfront in the co-design process.

Finally, as the participants had suggested the creation of a *"wiki",* a digital common-pool resource (CPR), I selected commoning as the design approach (Marttila, Botero and Saad-Sulonen, 2014; Lyle, Sciannamblo and Teli, 2018). Specifically, I incorporated Ostrom's design principles (Ostrom, 1990) for the sustainable governance of a commons, together with the extension of Ostrom's principles to a digital commons as discussed by De Rosnay and Crosnier (2012), and Bettaga et al.'s (2022) tactics that supported digital commoning.

These commoning processes would provide a platform for unpaid carers and disabled citizens to create, maintain, and consume digitally shared, peer-produced trusted assets (Franquesa and Navarro, 2017), aimed at supporting their capabilities to access and manage care funding.

6.3.2. Recruitment

AR cycle 2 and its participatory research continued to generate enthusiasm for those involved, therefore, all the citizen and VCSE participants, bar one citizen, remained involved with the research in this study's AR cycle 3.

This allowed me to bypass additional recruitment as I judged there would be sufficient participants for this AR cycle, this also provided continuity of participants as they were immersed in the research by this point. The participants comprised citizens from across England, and the two directors of the VCSE organisation from the previous chapter, one referenced in this study as a disabled citizen and one as VCSE staff, see Table 5.

Cohort	Number	Collective care budget experience
Disabled citizens	7	19 years
Unpaid carers	12	25 years
VCSE staff	1	11 years

Table 5: Care experience of AR cycle 3's participants

6.3.3. Engagement Structure

The need to configure participation and the design for commoning directed the shaping of the engagements and the end-to-end participatory design process, shown in Table 6 and discussed below.

Item	Engagement session	Start month, year	Duration	Format	Form of data captured	Quantity of data captured
1	Requirements Elicitation	April 2021	7 days	Focus group	Typed input	29 comments of 1,888 words
2	Categorising Care Artefacts	April 2021	2 days	Drag-and-drop	Spreadsheet	-
3	Rapid prototyping	April 2021	14 days	Clickable prototypes; focus group	Typed input	49 comments of 1,761 words
4	Gathering of Care Artefacts	June 2021	14 days	Email request	Documents	70 care artefacts
5	Commons Governance	July 2021	14 days	2 x Drag-and-drop; focus group	Spreadsheet; typed input	80 comments of 6,525 words
6	Pre-Deployment Checks	July 2021	7 days	Focus group	Typed input	15 comments of 1,304 words
7	Promotion	September 2021	Ongoing	Email request	Twitter	-

Table 6: End-to-end design process

As in the previous AR cycles, I utilised a reconfigured and extended ARC method for the group engagements that comprised remote, long-duration asynchronous sessions, optional synchronous engagements, an educational agenda, longitudinal planning, and novel engagement tools. These, again, were run in bulletin board style, where I took on the roles of facilitator and unpaid carer.

The following expands on each of the six engagement sessions in Table 6, referenced by the ‘item’ number in the first column.

Item 1 - Requirements Elicitation: This session was formed of a seven-day focus group based around a scenario of care, where the participants were asked to reflect on when they first started with their PHB and how an online resource would be best presented,

> *The scenario I would like you to think about is back to when you were starting on the journey to receiving a care budget … If you came across a website that offered you all the templates and policies you needed to start, how would you want to have that website organised to make it easy to use and not overwhelm you?*

This scenario triggered comments that I responded to in a way that placed further, more detailed scenarios of care in front of the participants, eliciting instances of care artefacts in the process. Note that requirements for care artefacts were also sourced from the focus group discussion in the preceding AR cycle.

In total, 181 content and service requirements were recorded, with a sample provided in Appendix H. A decision taken at this point was for a name for the website. I suggested "*MyCareBudget"*[25]*,* which was ratified by the participants. This naming was constrained by the limited availability of low-cost domain names - ongoing costs were a sustainability factor as these would continue to be incurred once my research funding ended.

Item 2 - Categorising Care Artefacts: The previous requirements session identified 70 care artefacts with 19 associated categories, demanding this design session to understand the participants' preferences for their organisation. To achieve this, I created an online drag-and-drop exercise, where each participant worked alone to select each care artefact in turn (the left-hand column in Figure 20) and dragged it over the category (the items in the main section of Figure 20), they believed it best aligned to. This method was simplistic in operation, adding to the educational agenda of the participants by introducing them to new technologies and concepts in a graduated manner, but without formal training sessions that might have been seen as onerous, deterring their participation. The results showed no consensus for any of the categorisations, which led to my decision to use majority rule to decide the categorisation. This method of resolution not raising any concerns with the participants.

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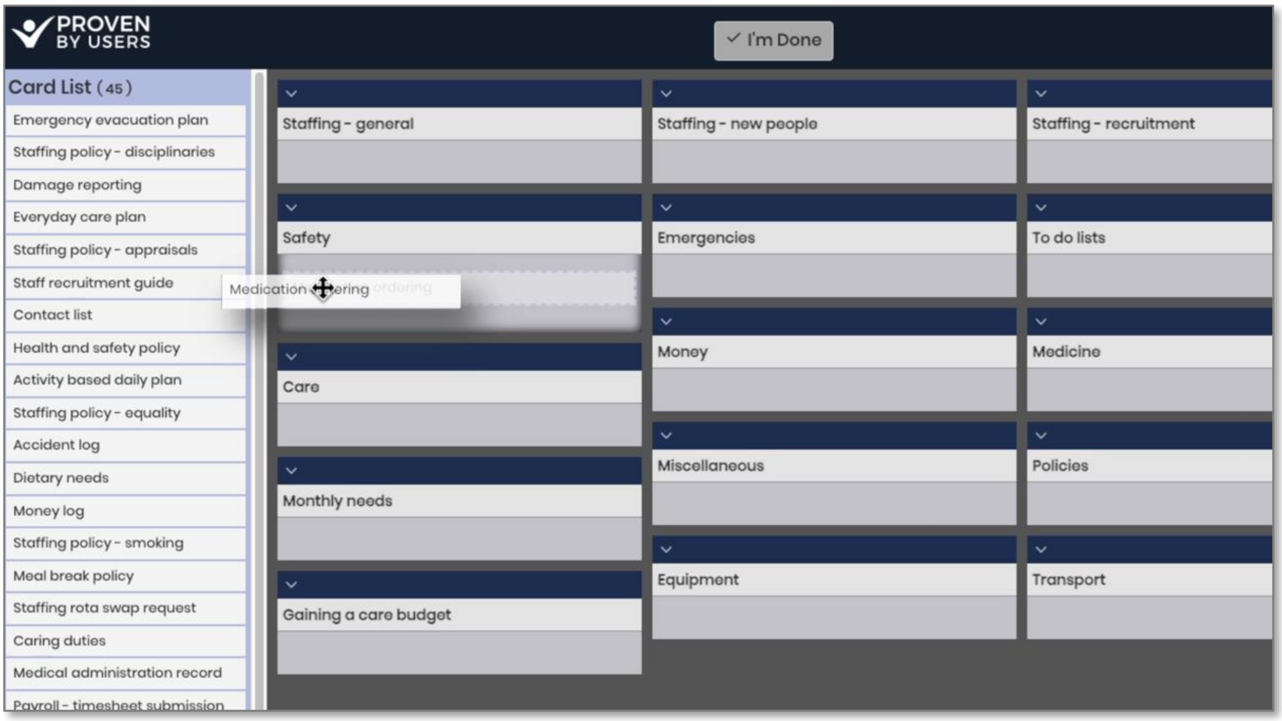
[25] www.MyCareBudget.org



Card List (45)

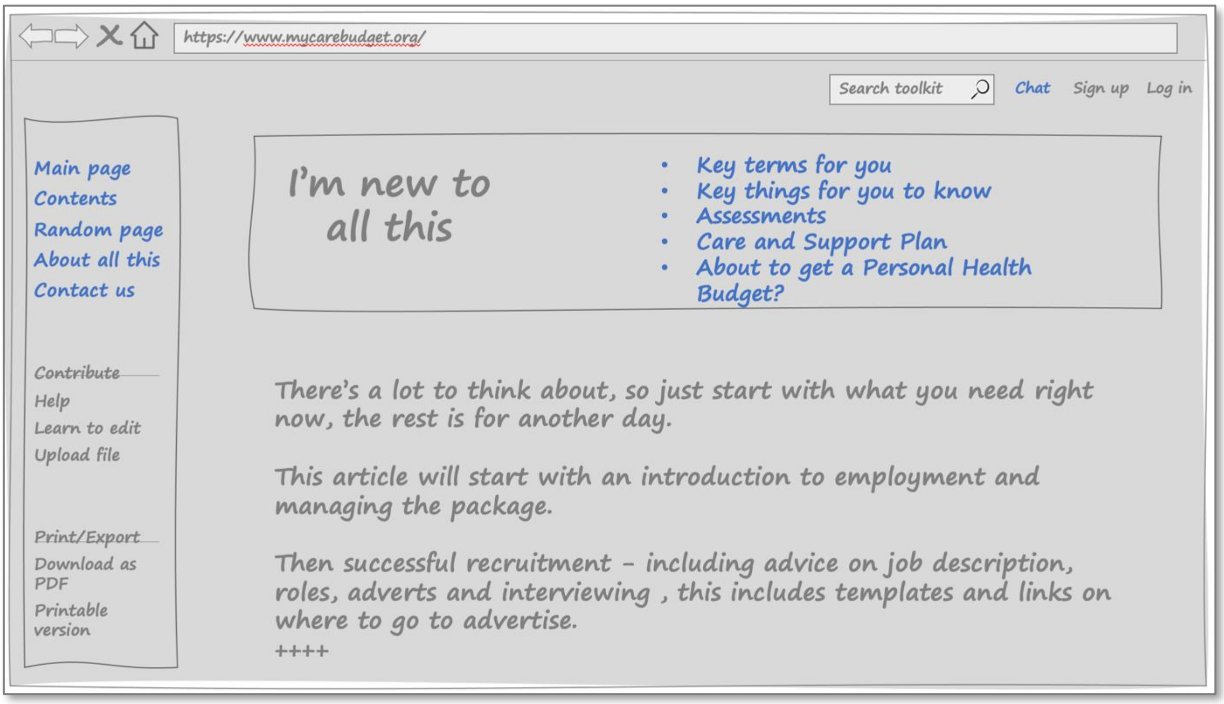
- Emergency evacuation plan
- Staffing policy - disciplinaries
- Damage reporting
- Everyday care plan
- Staffing policy - appraisals
- Staff recruitment guide
- Contact list
- Health and safety policy
- Activity based daily plan
- Staffing policy - equality
- Accident log
- Dietary needs
- Money log
- Staffing policy - smoking
- Meal break policy
- Staffing rota swap request
- Caring duties
- Medical administration record
- Payroll - timesheet submission

Staffing - general
Safety
Care
Monthly needs
Gaining a care budget
Staffing - new people
Emergencies
Money
Miscellaneous
Equipment
Staffing - recruitment
To do lists
Medicine
Policies
Transport

Figure 20: Online drag-and-drop exercise to capture the categorisation of care artefacts

Item 3 - Rapid Prototyping: I first created a clickable text-based prototype of MyCareBudget, see Figure 21, followed one week later by a graphics-based version in response to comments received, see Figure 22. Both minimised the use of straight lines for boxes to give the illusion that they were hastily built i.e., low-fidelity prototypes. This to promote criticism as a low-fidelity prototype would appear as though it had not taken much work to create it, and that the end product is far from ready (Rudd, Stern and Isensee, 1996). To reduce the effort to build the prototypes whilst allowing for feedback on a wide range of features, the prototypes were also 'horizontal' (Budde *et al.*, 1990), in that they contained much of the high-level functionality but little low-level functionality. I asked the participants to provide feedback within a 14-day focus group.

HCI has argued against using rapid prototyping when creating social innovations, taking the view that a fast development will fail to build in the nuances of a community (Hillgren, Seravalli and Emilson, 2011). The risk being that rapid prototyping will be limited to usability issues, whereas 'slow' prototyping will surface process flows and community roles, additionally building teams that add to sustainability (Hillgren, Seravalli and Emilson, 2011). In this research project, these aspects had been covered in earlier AR cycles and the prolonged nature of the co-design, so I deemed the rapid prototyping sufficient to cover usability.



There's a lot to think about, so just start with what you need right now, the rest is for another day.

This article will start with an introduction to employment and managing the package.

Then successful recruitment – including advice on job description, roles, adverts and interviewing , this includes templates and links on where to go to advertise.

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Figure 21: Home page from the text-based prototype

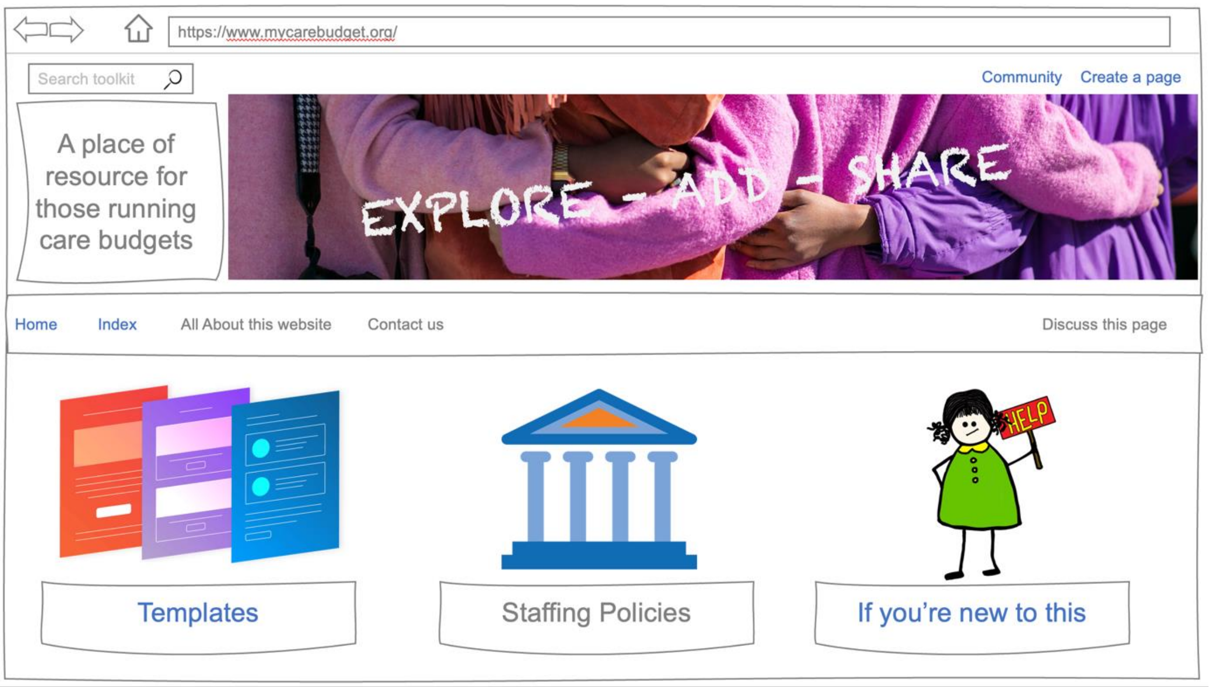

Figure 22: Home page from the graphics-based prototype

Item 4 - Gathering of Care Artefacts: I emailed the participants to request their care artefacts - as digital documents or photographs of handwritten documents, with my assurance these would be anonymised. A list of the care artefacts held on MyCareBudget is provided in Appendix G.

Item 5 - Commons Governance: The purpose of this 14-day session was to define the governance of the digital commons by prompting participants to discuss processes, risks, and mitigations, including conflict resolution, monitoring, and the rights of end-users.

This being a new and abstract topic to participants, they were sensitised (Visser *et al.*, 2005) as part of the educational agenda by using two online drag-and-drop exercises in which the participants worked by themselves over seven days. The first exercise sought to capture end-user roles that I titled *"What can users do?"*, see Figure 23, where end-user actions were given in the left-hand column, to be dragged and dropped over the types of end-users in the main section. The second exercise was purposed to elicit reflection on the graduated sanctions that were to be given to end-users when they used MyCareBudget inappropriately or in error, entitled "*Crime and Punishment"*. Participants were presented with possible end-user actions in the left-hand column of Figure 24, including *"Posting violent or sexual images", "Continued bad behaviour after a warning", "Spelling errors",* and so on - these to be dragged over the sanctions in the main section. I developed these categories independently from the participants, guidance taken from Ostrom's design principles (1990), and operating practices from Wikipedia[26]. The results showed partial consensus and as for the categorisation exercise in Item 2 above, I used majority rule.

Following the two exercises, I arranged a seven-day focus group discussion where I prompted the participants to discuss issues and processes that included conflict resolution, monitoring, and members' rights, and to consider promotion and maintenance beyond the research process. Figure 25 provides a screenshot of this forum originally hosted on MyCareBudget, showing some of the questions posed to the participants, examples being *"What is needed to keep this website safe and useful?"*, *"What type of people would you trust to help run this website?"*, *"What happens when we disagree with one another?"*

An aspect of governance that I presented to the group was whether guest users of MyCareBudget, who had not signed in, could download care artefacts, or that they would need to sign-in first. This sign-in would require an initial registration with MyCareBudget that demanded a confirmed email address. I had to apply majority rule as the group were split, some participants seeing that allowing guests to download would remove a barrier of having to sign in, but registering with an email address would add a sense of value and commitment

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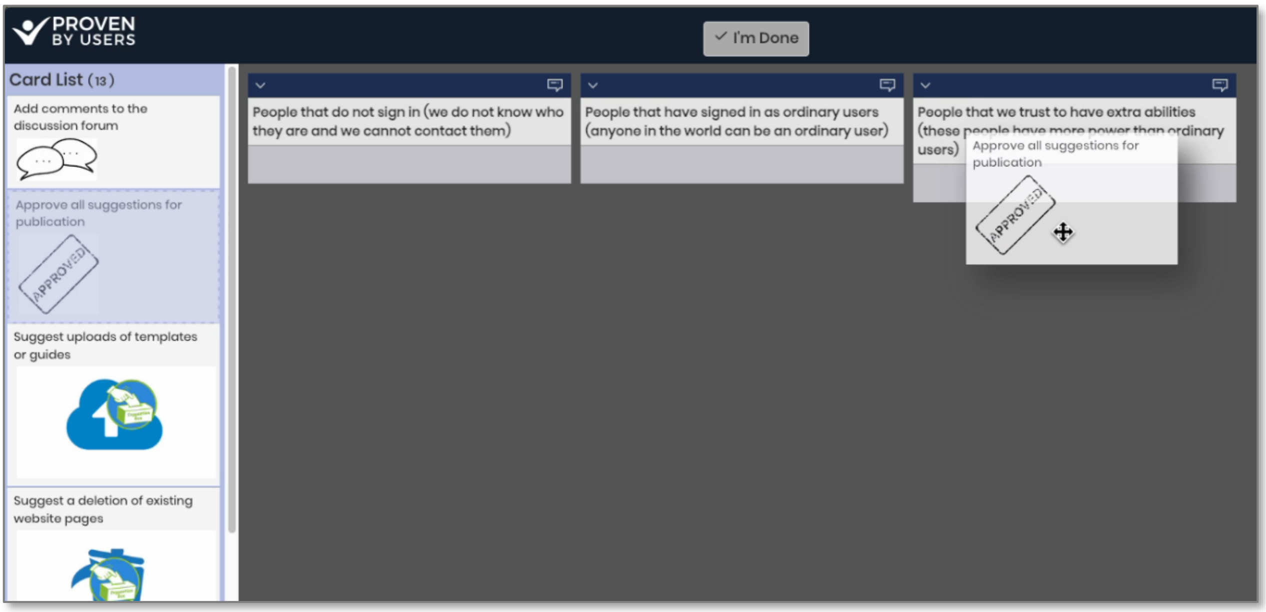
[26] https://en.wikipedia.org/wiki/Wikipedia:User_access_levels

to MyCareBudget. My decision was that they needed to register first, a research motivation for this being that this approach delivered an email address for verifying and contacting end-users. Further decisions were taken that MyCareBudget was to be freely and publicly available.

One aspect of governance I did not debate with the participants was that of licensing, as I felt that after an investigation of options, the use of Creative Commons (CC BY 4.0[27]) was the only reasonable way forward, as this allowed freedom for end-users to download, edit, and share the care artefacts.



Add comments to the discussion forum

Approve all suggestions for publication

Suggest uploads of templates or guides

Suggest a deletion of existing website pages

People that do not sign in (we do not know who they are and we cannot contact them)

People that have signed in as ordinary users (anyone in the world can be an ordinary user)

People that we trust to have extra abilities (these people have more power than ordinary users)

Approve all suggestions for publication

Figure 23: Online drag-and-drop session to capture end-user roles

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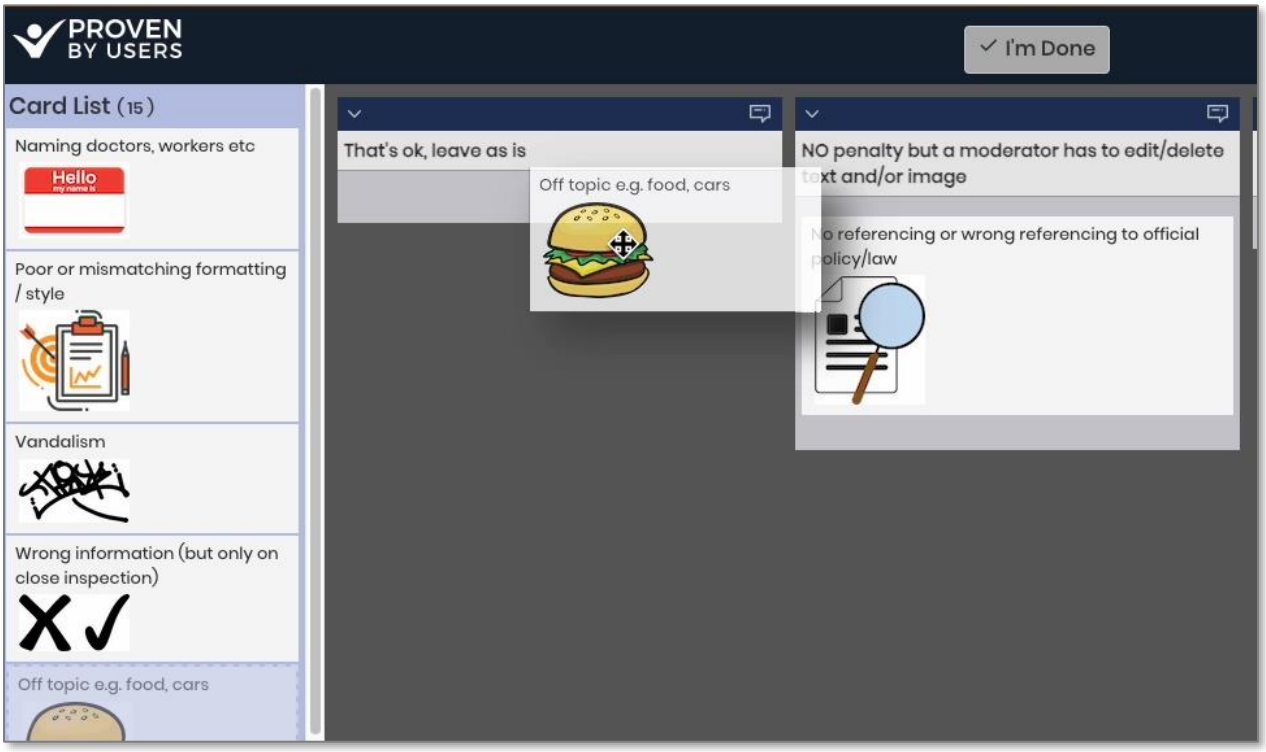
[27] https://creativecommons.org/licenses/by/4.0/



Card List (15)

Naming doctors, workers etc

Poor or mismatching formatting / style

Vandalism

Wrong information (but only on close inspection)

Off topic e.g. food, cars

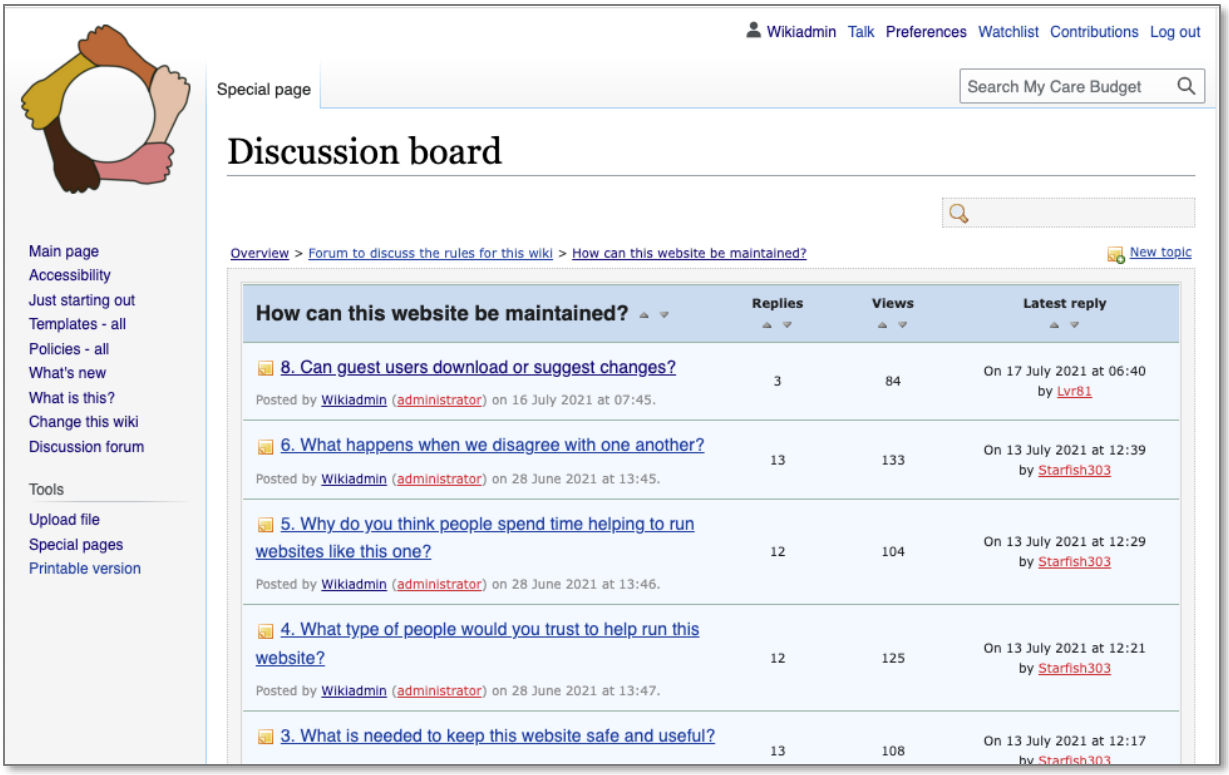
That's ok, leave as is

Off topic e.g. food, cars

NO penalty but a moderator has to edit/delete text and/or image

No referencing or wrong referencing to official policy/law

Figure 24: Online drag-and-drop session to capture end-user sanctions



Discussion board

Overview > Forum to discuss the rules for this wiki > How can this website be maintained?

New topic

How can this website be maintained?	Replies	Views	Latest reply
8. Can guest users download or suggest changes? Posted by Wikiadmin (administrator) on 16 July 2021 at 07:45.	3	84	On 17 July 2021 at 06:40 by Lvr81
6. What happens when we disagree with one another? Posted by Wikiadmin (administrator) on 28 June 2021 at 13:45.	13	133	On 13 July 2021 at 12:39 by Starfish303
5. Why do you think people spend time helping to run websites like this one? Posted by Wikiadmin (administrator) on 28 June 2021 at 13:46.	12	104	On 13 July 2021 at 12:29 by Starfish303
4. What type of people would you trust to help run this website? Posted by Wikiadmin (administrator) on 28 June 2021 at 13:47.	12	125	On 13 July 2021 at 12:21 by Starfish303
3. What is needed to keep this website safe and useful?	13	108	On 13 July 2021 at 12:17 by Starfish303

Figure 25: Governance focus group hosted on MyCareBudget

Item 6 - Pre-Deployment Checks: By this time, MyCareBudget was available online, though not promoted, so I asked the participants to access the website and explore its functionality, content, and appearance. I then hosted a seven-day focus group using MyCareBudget's discussion forum, with a question that asked, *"You have had a look around the website. What do you think? Let me know all your negative points please."* The question specifically asked for their negative comments on MyCareBudget, as by now there was a sense of community in the group, so there was a need to guard against participants being unwilling to criticise the work of one another.

Item 7 - Promotion: Twitter was selected to promote MyCareBudget as there were hashtags linked to personalised care, unpaid carers, and healthcare authorities. I created a Twitter account for the project where I posted tweets highlighting the functionality of MyCareBudget. I also wrote blogs on websites linked to personalised care and PHBs, with a snowballing seen as participants promoted MyCareBudget themselves following a single prompt from myself. Blogs were also written by the participants and by VCSE organisations without my initial knowledge, with further, positive references to MyCareBudget from VCSE organisations and NHSE.

6.3.4. Timeline

Figure 26 provides an overview of the timeline for AR cycle 3, with the Act stage holding all the design engagements. Note that the promotion and operation of MyCareBudget are still ongoing in 2023, but outside of this research.

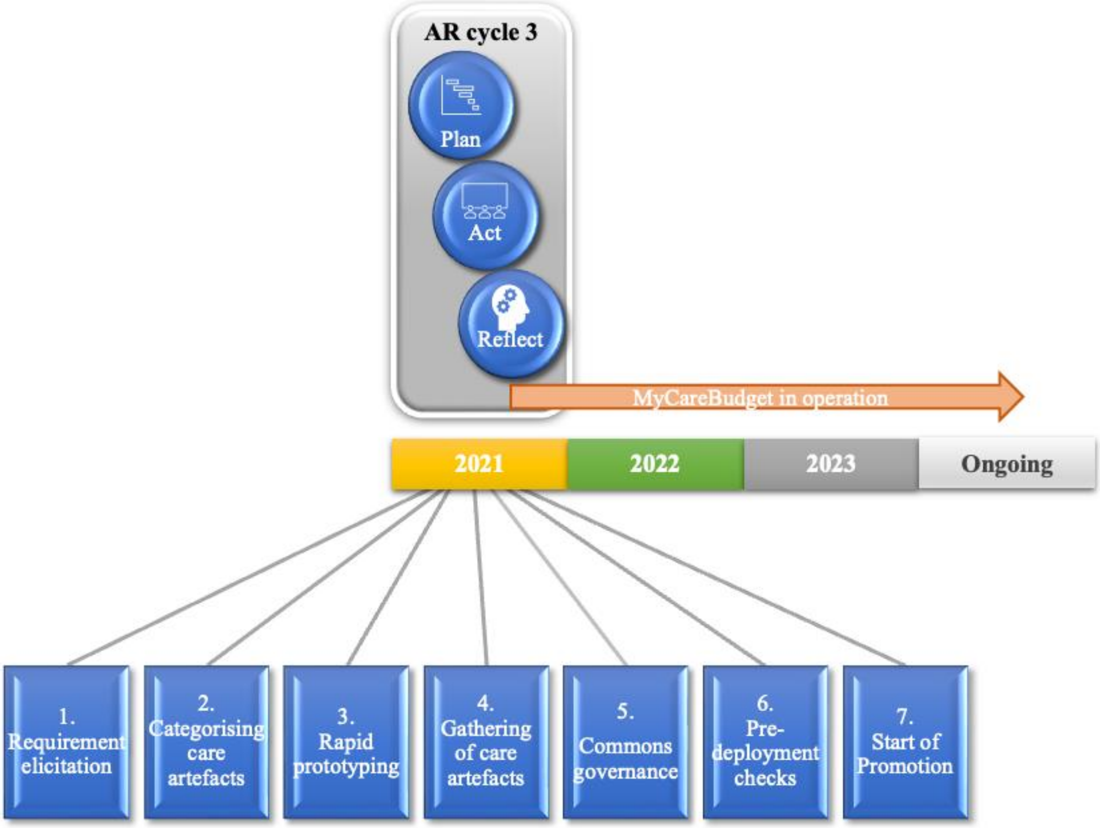


Figure 26: Timeline for AR cycle 3

6.3.5. Engagement Tool Selection

The same criteria as in the previous chapter (section 5.3.5) were applied to select engagement tools. Additional tools were needed as the co-design process demanded different methods to enable the differing forms of engagement, for example, the prototyping and drag-and-drop exercises. Once more, open-source tools were sought, but none matched the criteria, hence a fallback of leveraging proprietary tools that were available free of use.

'Collabito' was used as for the previous AR cycle in bulletin board style, 'ProvenByUsers'[28] for the drag-and-drop sessions, and InVision[29] for building prototypes. With MyCareBudget nearing an operable condition, its embedded discussion forum was used for the final focus groups for the pre-deployment check and governance sessions, allowing comments to be opened for public view, offering transparency to governance.

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[28] www.provenbyusers.com

[29] www.invisionapp.com

6.3.6. Technical Architecture of MyCareBudget

The sustainability of the digital commons was the primary concern with technical choices.

An example was the hosting of servers and domain names. While my university would, by default, have provided these, the transference to external service providers at the close of the research would have meant a loss of gained, online reputation due to a change in domain name. So, I used external organisations from the outset [30]. I also used virtual servers as they can be readily scaled to match traffic demands - this furthering sustainability. Low-cost was also a factor in determining the service providers used for domain names and virtual servers (O'Hara, Perry and Lewis, 2003).

Another example of sustainability was the choice of the software used to build and host the digital commons - open source was selected for its zero cost (Poderi, 2019) and its community ethos (Marttila, Botero and Saad-Sulonen, 2014; Teli, Di Fiore and D'Andrea, 2017). MediaWiki[31] was chosen as it met the criteria and that its use for Wikipedia and thousands of other digital commons has led to an extensive support network, a corpus of research literature, and a familiarity of user interface.

Figure 27 provides an overview of the architectural layers for MyCareBudget, showing the use of open source and free to use services wherever possible (MediaWiki, FileZilla[32], Termius[33]), Content Delivery Network (CloudFlare[34]), commonly-used analytics (Google Analytics[35]), browser-based presentation, and supporting software (Ubuntu[36], MySQL[37], Apache[38]).

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[30] https://www.ionos.com/ for the domain name and https://www.digitalocean.com/ for virtual servers

[31] www.mediawiki.org

[32] https://filezilla-project.org/

[33] https://termius.com/

[34] https://www.cloudflare.com/en-gb/

[35] https://analytics.google.com/

[36] https://ubuntu.com/

[37] https://www.mysql.com/

[38] https://httpd.apache.org/

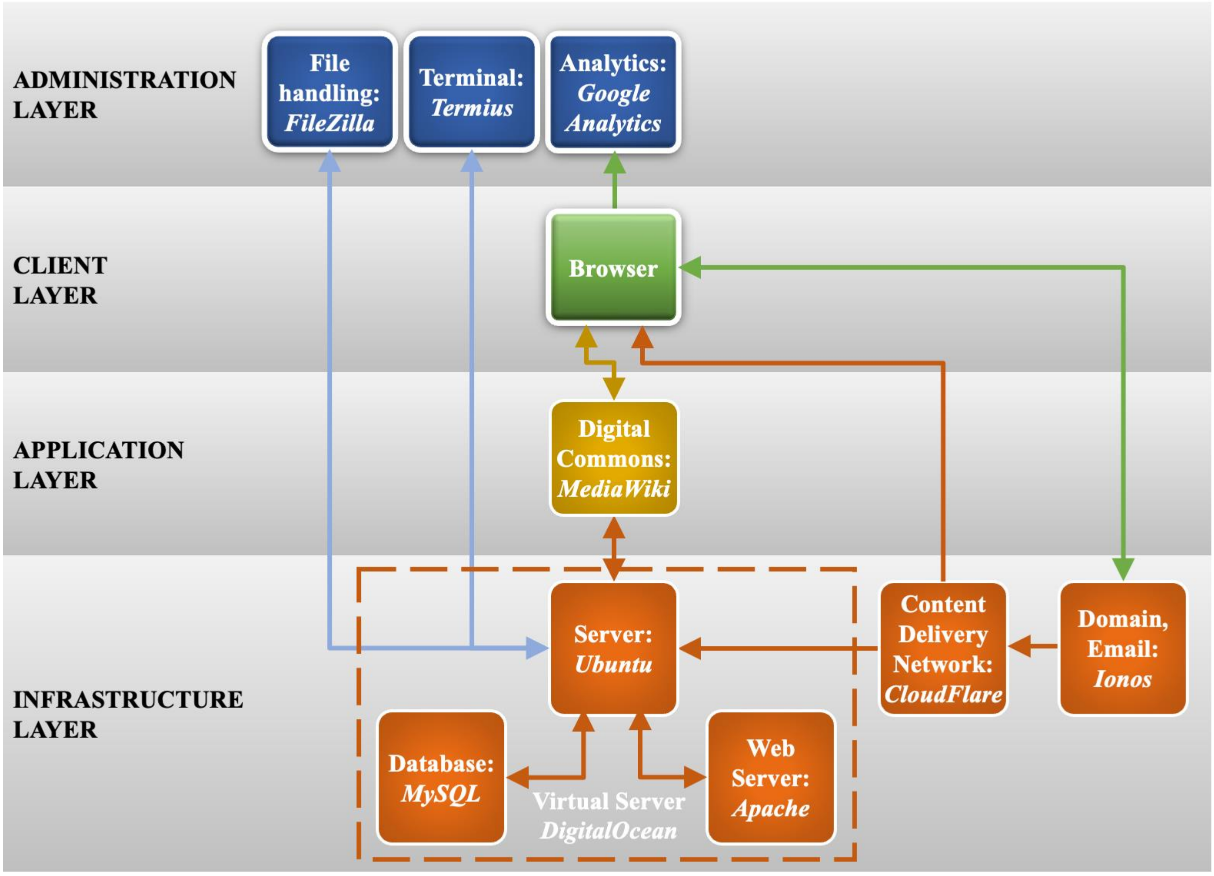

Figure 27: Technical architecture diagram for MyCareBudget

By way of explanation, a browser request to access www.MyCareBudget.org would be directed to 'Ionos', which I configured to redirect to 'CloudFlare' and then to the servers hosting MyCareBudget. As a Content Delivery Network (CDN), I configured Cloudflare both as a firewall and cache, minimising the level of spam attacks and data accesses to the servers. Responses from MediaWiki and CloudFlare were sent directly to the browser.

I took on the development and operational roles for the technical, administrative, and support functions during the research study, as although at least one participant had the skillset demanded, this would have been a significant demand on their time. There was also the potential to hand over the technical design to an external organisation such as a VCSE. However, I chose not to pursue this as I would have likely lost control over methods, architecture, and planning. These elements of control were important for this research as I was constrained by the time limits of a PhD project and the need to incorporate architectural elements that were critical to the research, for example, virtual servers, web-based analytical data collection, and a digital commons.

6.3.7. Analysis

I analysed the 173 textual comments from all the group discussions, see Table 6, using reflexive TA as described in the Methodological Approach chapter, section 3.11. The results are presented in the Findings section below.

The textual comments from the requirements elicitation engagement (item 1 in Table 6) were further analysed using the method of Requirements Engineering and its application to a home care context (McGee-Lennon, 2008). Based on Requirements Engineering principles, this method recognises the complexity within the home context, emphasising principles such as prioritisation, categorisation, and care work. A Requirements Specification (Dix *et al.*, 2003, p. 30) was created in Microsoft Word[39], with each requirement appended with a unique code, title, description, comments, priority, source, and status. I assigned a priority based on the MoSCOW[40] method (Miranda, 2011), though I did not consult the participants on this because of the great number of requirements, 181 in total. Also, I believed that I had the skillset and experience to perform this task, in particular, an awareness of the constraints of project timescales and a judgement of the effort needed to fulfil each requirement.

One requirement that surfaced from several participants was for the online resource to hold individual citizens' versions of care artefacts. I deemed this out of scope, as it required the digital commons to store personal data such as medications and health conditions. Achieving this would have demanded additional effort to build the technical and legal compliance to allow for data protection and an ensuing high level of security. The timescales for this would have been beyond this study. No negative responses were received on notifying the participants of this decision.

6.3.8. A Walkthrough of MyCareBudget

MyCareBudget is a digital CPR built using MediaWiki. Hence, it resembles Wikipedia in presentation, menus, and navigation, as well as compatibility with multiple types of devices,

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[39] https://www.microsoft.com/en-gb/microsoft-365/word

[40] A method that prioritises requirements into categories of "Must have", "Should have", "Could have", "Won't" have

browsers, and operating systems. A further advantage of this similarity to Wikipedia was that it provided a sense of familiarity to end-users.

A difference in use is that Wikipedia's digital articles are typically found by entering search parameters. In contrast, the digital resources on MyCareBudget are discovered by browsing - as a newcomer to PHBs is unlikely to know the care artefacts they require. MyCareBudget's homepage reflects this by providing two browsing options: lists of care artefacts for more experienced PHB holders; and a guided tour for newcomers. After selecting a care artefact, it can be downloaded as a Microsoft Word document, an Adobe PDF[41], or a link to Google Docs[42].

A set of screenshots and accompanying text is given in Appendix F, providing a guided walkthrough of the key elements of MyCareBudget.

6.4. Findings

I generated three themes from the data analysis. The first theme of *Delivering Trustworthy Content* explores participants' considerations of trust. Followed by the theme of *Taking Responsibility* which describes participants' concerns about how the repository could have negative impacts on their peers and its potential misuse by authorities. The final theme of *Benefits of Participatory Design* reflects on how the practice of PD delivered benefits to the participants.

Pseudonyms are used throughout. Quotes from the VCSE staff member are identified with "(VCSE)" suffixed to their pseudonym.

6.4.1. Delivering Trustworthy Content

Within the co-design process, early conversations included considerations and discussions over the viability of a potential resource, issues of trust related to the hosting platform, and the sources of care artefacts, as well as moderation and presentation of advice. Collating and disseminating trustworthy content appeared to be a critical aspect of this work, given the potentially negative consequences that misleading content could have on the care practices of disabled citizens and their unpaid carers.

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[41] https://www.adobe.com/uk/acrobat/pdf-reader.html

[42] https://www.google.co.uk/docs/about/

The participants dismissed social media as a platform through which advice could be disseminated, as they considered social media demanded significant work to validate content for trustworthiness. For example, Jasmin, mother of a young adult demanding 24/7 care, stated*, "I haven't got enough time to deal with social media ... seen as what's posted isn't fact/law."*

Several participants voiced that the artefacts needed to be hosted on an online platform where documents could be stored permanently. This in their view, would provide their peers with opportunities to participate in discussions, as well as edit, correct, and improve artefacts, and, in this way, add value and trust. Colin, a former project manager and now a disability advocate with Multiple Sclerosis, suggested, *"Allow templates to be changeable or added to*", and Amelia, parent to her profoundly disabled son in his 20s, *"... it would be nice if [people] could interact, edit or make suggestions."* In this way, participants began to see their work as a form of a 'living archive' of common-pool resources.

Participants also discussed the sourcing of the care artefacts. They considered their peers as the more trustworthy source of information compared to their local health authorities or other bodies. Individuals typically considered experts in this area, such as staff from state healthcare authorities, were dismissed because of their lack of accurate, situated knowledge on creating care infrastructures at home for a PHB. Margot, a healthcare professional and parent of a severely disabled child, said, *"Families are the best resource. Having and managing a small budget [in an organisation] is very different to employing staff 24/7 [in your home]. There is a vast amount of information that professionals do not know."*

Having settled on PHB holders as those who were to contribute the care artefacts, participants moved on to consider how to maintain trust in such a 'living archive'. This led to considerations on the role of moderation of content and input - the 'commons governance' drag-and-drop activity described above in section 6.3.3 was designed to achieve just this. It appeared clear that all participants wanted to protect MyCareBudget from harmful content, such as the online abuse they had witnessed on the internet. Collectively, they decided that those who spammed or posted hate messages were to be permanently blocked. Forgiveness was granted to those authoring content that included swearing or venting anger at their healthcare service providers. The participants perhaps recognised this frustration in their own lives or wanted the online space to allow for opportunities to discuss broader issues in current healthcare provision. In any case, most participants placed little trust in internet users as a population. For example, Amelia suggested that *"If you did nothing, I think the usual internet idiots would wreck it."* Sandra (VCSE), a director of a VCSE organisation specialising in

PHBs, agreed, seeing moderation as a need, *"I do think that having a moderator to monitor content and a way to check anything new before it is published is going to be necessary."*

As to who would perform the moderation, there was agreement that moderators must be their peers, as they would possess the knowledge to verify content. This was also seen as a way of building a community of peer moderators around the care artefacts. However, this was discussed in an abstract sense, with no participant offering to take part in this activity. Sandra (VCSE) stated, *"[Moderators] need to have good knowledge of Personal Health Budgets, preferably by lived experience of having one."* Erin, mother to a profoundly disabled teenager needing 24/7 care, added, *"Having a democratic moderator system where fellow moderators engage with each other."*

From a user interface perspective, the rapid prototyping design session offered the participants contrasting choices over the look and feel of their website: a simplistic text-based version followed by a graphics-based version. The differing styles promoted a discussion around trust of user interfaces. The graphics-based version was viewed as professional-looking, which they felt denoted commercialisation, implying a financial aim underpinning the website rather than one of care. Participants then discussed that the website should not appear too amateurish, as in the text-based version, as this suggested the website had been built lacking care or knowledge, and hence lose trust. Gabrielle, who parented a disabled adult, expressed a need for a balance between care, professionalism, and commercialism, *"It's got to be slick without feeling commercial."*

Thus, during design sessions, participants explored who or what can be considered trustworthy in terms of resources and moderation, including the role that aesthetics can play in delivering the 'right' message to their communities of peers. The following theme moves forward to examine the responsibilities taken by the participants.

6.4.2. Taking Responsibility

Co-creating MyCareBudget generated significant discussions around the risks and responsibilities of publicly sharing their care artefacts online. This theme identifies such potential unintended consequences and proposals for their mitigation.

Participants perceived MyCareBudget as exposing their invisible work to their CCG officers, seen as a risk to themselves and their peers. The concern was that demonstrating how they manage their PHBs, for example, how they deal with legal and safeguarding needs or personal choices around staff contracts and safety assessments, would offer opportunities for their CCG officers to judge their work. The fear here was that their officers would demand PHB holders to chronicle all aspects of their care, imposing institutional-like procedures onto their private homes and exposing the citizens' private lives to surveillance. Penelope, a wheelchair user of 19 years, stated, *"There is the right to not have extra paperwork. To not turn your home into an institution ... I think the greatest risk is that we create some kind of panopticon in our own homes."*

All participants felt that their PHBs had given them choice and control in how they managed their care, and they did not want to risk relinquishing this back to their authorities. This was broadly connected to the distance between these citizens and their officers that led to both a lack of understanding and dialogue between state healthcare organisations and PHB holders, as well as the power asymmetries at play. This is best encapsulated in Sandra's (VCSE) statement, *"... big organisations suck power back."*

Responsibilities for their peers were expressed as negative unintended consequences arising from MyCareBudget offering dozens of care artefacts, as a citizen considering a PHB might be overwhelmed seeing so many artefacts and hence be dissuaded from taking on a PHB. Participants all expressed a need to be good employers for their paid carers, to adhere to employment and care laws, and to show due diligence towards spending their budgets. Their experience informed them that a PHB comes with a great deal of responsibilities and that newcomers needed to be aware of these, but in a graduated style that would ease their entry into managing PHBs. Jake, parent to twins of school age with severe disabilities, suggested, *"You need to strike a balance. You don't need to be overwhelmed with information, but you need access to all the information because it's important to get it right. Maybe like a reference book to keep on the shelf."* Other participants suggested having a dedicated newcomer's page, Erin, parent to her disabled son in his teens, asked for a "*newbie section",* that acted as a guide to care processes and care artefacts.

Several participants requested disclaimers on the website, making it clear that the artefacts had not been created by legal professionals. This was to mitigate responsibility but also to provide honesty in the artefacts' origin. Amelia also requested a disclaimer on MyCareBudget that provided direction on how to use the artefacts*, "There just needs to be some kind of disclaimer about 'for guidance only'."*

In the commons governance session, the participants believed that maintenance of content would be essential to achieve sustainability. Participants here voiced concern about how the care artefacts could be kept updated with changes such as in employment legislation, though they did not accept responsibility for this activity. Colin stated, *"Things change all the time. [MyCareBudget] needs to be kept updated."*

In response to discussions around sustainability, the two directors of the VCSE organisation who participated in this study offered to take responsibility for both funding and administering MyCareBudget once my research funding ended. Both saw the benefits and authority of MyCareBudget arising from it being designed by PHB holders. Orla, a wheelchair user with tetraplegia for over 20 years due to a spinal injury and one of the VCSE directors, stressed its value as a community-led initiative, *"And we feel that it started off as a user-led project [so it] should stay a user-led project."*

As discussions unfolded, it appeared that the benefits MyCareBudget could deliver would offset these risks, with participants consciously accepting and embracing the responsibility of creating an online repository. Sandra (VCSE) concluded the discussion with, *"It feels like a helpful, informative, useful website is going to outweigh downsides."*

These conversations demonstrated that the participants created MyCareBudget as an expression of their lives of caring and related challenges, extending outwards to their unknown peers in a philanthropic sense, in the main owning the responsibilities that their actions would incur.

6.4.3. Benefits of Participatory Design

During the commons governance session, without my prompting, participants began to reflect on their experiences of co-creating MyCareBudget. In these discussions, they considered how the co-design process enabled them to form a community, feeling the process helped them express and take an activist stance to disseminate knowledge, with a sense of excitement and ownership developing as ideas started to take shape.

Several participants found pleasure in co-creating something that would support those who may consider getting a PHB, Amelia said, *"It just feels like a good thing to do, to help make it easier for people coming after you."* Kayla, a wheelchair user with a limited range of mobility, considered how the co-design process enriched her and the other participants beyond creating something that would benefit society. Her social capital had developed in taking part, also seeing this in other participants, saying, *"This meets our need to feel productive in society and to expand our knowledge and skills. It has therefore developed us as whole people."*

Participants also returned to when they started with a PHB, seeing the value in MyCareBudget, Margot said, *"I love [MyCareBudget]. It would have been so helpful to start with."* Beyond this, several participants stated that reading how other participants managed their PHBs, helped them improve their own management, to articulate and make sense of their implicit knowledge. Here, Erin reflected on how the process was *"... also a way of exercising your brain and knowledge which may otherwise be inaccessible. In the case of this PHB project I feel I'm learning as I contribute."*

These sentiments were not applied to every aspect of the study, as I learnt I had failed to empower every participant by instilling a sense of worth in their achievements. This was highlighted when the participants were prompted to forward the care artefacts they had created. Bella, parent to her disabled son in his 20s, said hers were *"just scraps of paper"* and Chloe, also a parent to her disabled son in his 20s, said that hers were *"not good enough."* I encouraged Bella and Chloe to submit, finding their care artefacts to be content-rich, only requiring a reformatting before being uploaded to MyCareBudget.

A community appeared to form early in the co-design process, surfacing a sense of empowerment as the participants were collectively gaining confidence and developing a socio-technical intervention that could support their peers. Several participants felt strongly about the value of what they were doing as a political act. In this sense, the exclusion of state authorities or officials from the process was considered important, as it enabled their autonomy and reduced dependency on healthcare authorities. In Sandra's (VCSE) words, *"... [we are] part of a collective movement, to be more empowered, and less at the mercy of statutory systems."* Many concurred with Sandra's statement. Jez, an international disability advocate who had sustained a spinal injury in his late teens, also expressed how the process helped them seek and create meaning, purpose, and belief in something beyond themselves, *"Being a part of something bigger than [our]selves and wanting to help others go through a slightly better/easier experience than [we] may have gone through."*

The configuration of the design process and its dialogical approach enabled the above benefits. Participants felt empowered, partly as they felt safe to criticise the healthcare services they had received and the comments from their fellow participants, further able to share insights and expertise arising from their lived experiences of care and their professional careers.

6.5. Chapter Summary

This chapter discussed how I collaborated in Participatory Design with disabled citizens, unpaid carers, and a VCSE organisation to meet this AR cycle's aim of co-creating a sustainable social innovation that supported their personal infrastructuring for PHBs.

The co-design process delivered insights and learnings that met this AR cycle's objectives of: delivering equity in engagements; leveraging the philanthropic nature of the citizen participants to support their peers through a longitudinal study; configuring safe design spaces; and examining potential unintended consequences. CCG officers were excluded from this process to safeguard the citizen participants, their voices sought in the following AR cycle.

Other insights regarded issues of ownership and distribution of responsibility, pointing to the benefits and challenges of the co-design approach and the participants' increased social capital. The insights also contributed novel methods and design processes for HCI to research alongside underserved and marginalised populations, offering co-design implications for a sustainable digital commons that provided for democracy in both its design and as an intervention.

With MyCareBudget in operation, actively promoted, and accessed worldwide, the following chapter and last AR cycle look to assess its usefulness and sustainability to PHB holders, using a novel conceptual framework for its evaluation.

Chapter 7. A Conceptual Framework to Evaluate an Operational Healthcare Digital Intervention

"Why is it a group of personal budget holders, led by one man, has put together an essential practical resource for users, that no authority, charity or organisation has managed and offered for free?" - Colin, a disabled citizen managing a PHB for their own care.

7.1. Introduction

I presented MyCareBudget in the previous chapter, a free to use public digital commons co-designed with citizen and VCSE participants to share peer-produced care artefacts that supported the infrastructuring demanded for a PHB. That chapter discussed the design, development, and deployment of MyCareBudget, with citizen participants collaborating in design decisions and where I took on the technical roles.

With the launch of MyCareBudget in September 2021, this final AR cycle is necessary to determine the value of MyCareBudget as an operational socio-technical intervention. Without this information, it would be unknown whether the co-design with PHB holders had delivered a useful and sustainable resource for their peers.

This chapter begins with laying out the aim of this AR cycle, that of evaluating MyCareBudget. A literature review is presented that draws on HCI work that created evaluation frameworks or applied them to technology. Finding a lack of HCI literature specific to an operational healthcare intervention that attends to its caring aspects, a conceptual evaluation framework was designed for this study of four interrelated concepts. First, establishing the *usability* of operational software, as hard-to-use software would form a barrier to end-users gaining value from it. Second, gaining *usage* data to establish volumes and types of access to the software - as a heavily accessed resource is indicative of its worth. Third, determining the *sustainability* of software based on its historical and anticipated future maintenance. Fourth, as the evaluation is healthcare based, the ability of the software to represent the *caring* of its designers, leveraging the theory of care ethics to provide insights into the caring qualities of attentiveness, responsibility, competence, and responsiveness.

This conceptual framework was applied to MyCareBudget, using quantitative and qualitative data collected from web analytics, server analytics, maintenance logs, two surveys to 27 end-users, and 23 one-to-one, semi-structured interviews with disabled citizens, unpaid carers, CCG officers, and VCSE staff, both as co-designers and those new to this study.

The findings demonstrated that MyCareBudget was useful and sustainable, although MyCareBudget's role as a digital commons for updating content rarely occurred once in operation. The interviews revealed that MyCareBudget complied with the qualities of care ethics - to "care well" in Tronto's terms (2015, p. 5).

The following sections discuss the aims and study design of this fourth and final AR cycle, followed by sections for each of the four dimensions outlined in this introduction.

7.2. Aims, Rationale, and Objectives

With MyCareBudget publicly available, the aim was to evaluate it for usefulness and sustainability to its targeted end-user population of PHB holders. Sustainability could be viewed as a sub-factor that plays a role in determining usefulness, however, the precarious lives of caring of disabled citizens and unpaid carers demanded focus on maintaining any useful intervention. This forms the fourth AR cycle as shown in Figure 28.

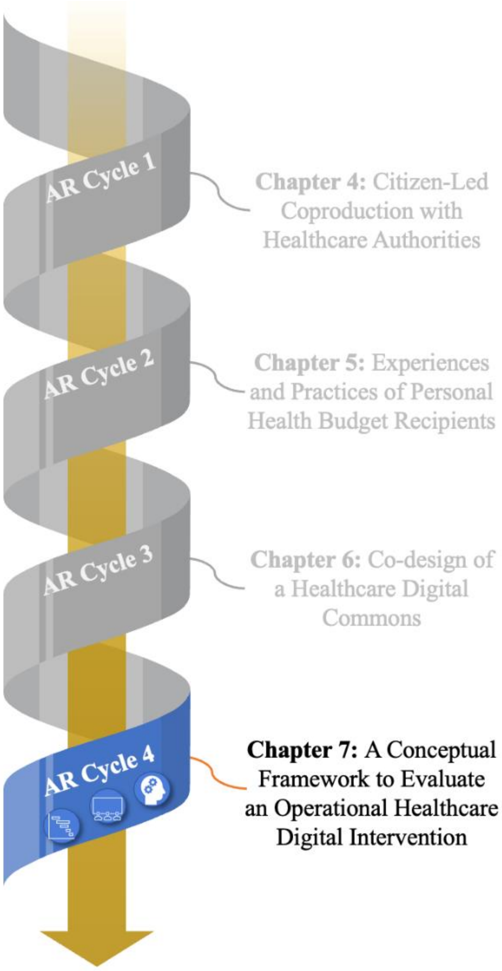

Figure 28: AR cycle 4 (highlighted in colour) and its location within the four AR cycles

The key objectives were to develop and then apply a conceptual framework to determine whether MyCareBudget had been found to be useful by its targeted end-users - citizens in receipt of or on the path to receiving a PHB, and to examine the sustainability of MyCareBudget.

The next section describes the approach to delivering this aim and objectives, first performing a literature review and then developing a mixed methods conceptual framework to assess MyCareBudget.

7.3. Study Design

7.3.1. Approach

The approach to evaluating MyCareBudget was based on previous work in HCI. Initially drawing on literature that assessed generic technology in generic contexts, moving to more specific scenarios of healthcare software interventions and then digital commons once 'in the wild' (Chamberlain *et al.*, 2012).

7.3.2. Related Literature

The assessment of technology as fit for its intended purpose first occurs within the development stage of its lifecycle (Dix *et al.*, 2003, p. 30). Evaluation begins with the technology's development team identifying and correcting problems, ideally extending on to working with a sample of the end-user community where the accessibility factors of functionality and general experience can be assessed (Dix *et al.*, 2003, pp. 35–36; Klasnja, Consolvo and Pratt, 2011; Liebel, Alegroth and Feldt, 2013; Suman and Sahibuddin, 2019). These forms of testing are essential to the integrity of a technological artefact before it is released to its end-users (Dix *et al.*, 2003). This can be critical for healthcare-related interventions where there may be an increased risk of harm (Klasnja, Consolvo and Pratt, 2011; Suman and Sahibuddin, 2019).

Due to technology's broad range, there is unlikely to be a single evaluation process that is ideal for every context. However, McNamara and Kirakowski (2006) argued that any framework for evaluating the success of technology was to be based on three interrelated and overlapping concepts. First, the functionality of the technology was to be evaluated using factors such as its features and sustainability. This latter point is critical as any intervention deemed to be successful fails to continue to be so if it is withdrawn from service (Taylor *et al.*, 2013). Noting that the term 'success' can be problematic as it can typically be taken as meeting a study's objectives as defined by the researcher; however, success can also be where a technology is leveraged for other than its original intent by its end-users (Taylor *et al.*, 2013; Krüger *et al.*, 2021). Second, its usability, as in the interaction between the technology and the end-user, that is, whether the end-user achieved their goal for using the technology. Lastly, experience, as in the end-user's subjective, individual feelings when using the technology (McCarthy and Wright, 2004). There is an implicit sequence here owing to the interrelationships between these three factors - poor usability would lead to a negative user experience, hence usability was to be evaluated first (McNamara and Kirakowski, 2006) and rectified if needed before evaluating onwards.

I acknowledge a range of such frameworks exist, even within healthcare settings (Tomlinson *et al.*, 2013; Lewis and Wyatt, 2014; Stoyanov *et al.*, 2015; Royston, 2017; Zheng *et al.,* 2023), but argue that these can be broadly aligned within the three factors above. For example, Royston (2017) provided six factors that can be aligned with those above from McNamara and Kirakowski,

- Significance: functionality
- Appropriateness: functionality
- Value of information: functionality
- Ease of adoption: usability, experience
- Availability: usability
- Accessibility: usability, functionality, experience.

Another widely used framework is The DeLone and McLean Information Systems Success model (the D&M model) (Delone and McLean, 2003). Although aimed at e-commerce applications, it has also been applied to healthcare (Zheng *et al.*, 2023). This framework comprises six dimensions that again can be aligned with that of McNamara and Kirakowski (2006),

- Systems quality: functionality, usability
- Information quality: functionality
- Service quality: experience
- Usage: usability, experience
- User satisfaction: experience
- Net benefits: functionality.

Lacking from these frameworks is the concept of caring. Within a healthcare context, the concept of caring can be a critical component and hence, a critical component of a healthcare technology's evaluation framework. The theory of care ethics is an appropriate tool for this study with its foundation on activities of caring (1990; Tronto, 1998, 2013, p. 23), that can be leveraged for examining the design and evaluation of technologies in HCI that support caring practices and equitable, responsible relationships (Puig de la Bellacasa, 2011; Light and Akama, 2014, p. 160; Toombs, Bardzell and Bardzell, 2015; Meng, DiSalvo and Zegura, 2019; Key *et al.*, 2021; Tseng *et al.*, 2022). Care ethics can further inform HCI as a lens to the needs and experiences of caregivers and care receivers, their relationships with their healthcare authorities, and the implications of technologies that affect these actors, their practices, and relationships (Toombs, Bardzell and Bardzell, 2015; Toombs *et al.*, 2017; Howard and Irani, 2019; Alam and Houston, 2020; Karusala *et al.*, 2021).

In the context of a digital commons, HCI literature contains studies related to the creation of digital commons for a wide range of purposes (Teli *et al.*, 2015, 2020; Franquesa and Navarro, 2017; Lyle, Sciannamblo and Teli, 2018; Seravalli, 2018; Bettega, Masu and Teli, 2021; Heitlinger *et al.*, 2021; Khatri *et al.*, 2022). However, there are few studies for the evaluation of a digital commons - a challenge being the wide range of their forms, content, platforms, and end-user communities (Roth, Taraborelli and Gilbert, 2008). Of such evaluations for a digital commons, studies were either delimited to the quality of their content (Denning *et al.*, 2005; Costa, Nhampossa and Aparício, 2008) or their use in permanent, formal organisations (Grudin and Poole, 2010; Su and Beaumont, 2010; Crotty, Mostaghimi and Reynolds, 2012), with none found for the context of this research - a publicly available healthcare intervention. Yet, Morell, Salcedo and Berlinguer (2016) have provided a framework to establish the value of a generic digital commons. Although some of the metrics have relevance to this study, such as usage, others, such as monetary value, were either not appropriate or based on commercial analytics that were “impossible to collect or plainly wrong” (2016, p. 39). The authors concluded that alternative indicators of value need to be developed (Morell, Salcedo and Berlinguer, 2016).

Moreover, evaluations for healthcare technologies typically took place over a matter of weeks and thereby omitted data that can arise with longitudinal studies involving diverse populations (Diethei *et al.*, 2020).

In general, previous evaluations of a digital commons were predominantly quantitative, with acknowledged shortcomings. No HCI literature was found that was specific to this study: a publicly available healthcare digital commons. The next section describes my response to this lack by forming a novel conceptual framework drawing on this literature review.

7.3.3. Conceptual Framework for the Evaluation of an Operational Healthcare Intervention

The aim of this conceptual framework was to reflect that of this AR cycle - to assess the usefulness and sustainability of a healthcare digital intervention in the form of software, such as a website, a digital commons, or a smartphone application. The framework could then be applied to MyCareBudget to inform on its success.

Based on previous work that offered usefulness, usability, and user experience as critical factors for an evaluation (McNamara and Kirakowski, 2006), I extended and synthesised these to allow for the healthcare setting. This is delivered through the ability of the digital intervention to act as a proxy for the caring of its co-designers, leveraging the theory of care ethics to determine whether the technology cared well for its intended end-users.

Additionally, HCI literature supports the use of a mixed methods approach for assessments, as this offers triangulation to reduce limitations, thereby increasing the validity of results (Greene, Caracelli and Graham, 1989; Stringer, 2007, p. 141; Greenberg and Buxton, 2008; Palinkas, Mendon and Hamilton, 2019; Rettinger *et al.*, 2020).

The conceptual framework is composed of four overlapping, interrelated dimensions that can be aligned to that of McNamara and Kirakowski (2006) as follows,

- **Usability**: usability, functionality
- **Usage**: functionality, experience
- **Sustainability**: functionality
- **Caring**: functionality, usability, experience

Determine Usability - derived from the usability and functionality factors of McNamara and Kirakowski (2006). Determination of usability can depend on factors such as effectiveness - can end-users achieve their goals, efficiency - the amount of resources demanded to attain their goals, and context of use (Bevan, Carter and Harker, 2015).

Establishing these factors would be a complex task during the development stage when the software was not in active use. However, once operational, the end-users of the technology can be asked for their views on whether they found the technology to be effective and efficient.

This dimension is to be performed first, as if people who accessed a website found it difficult or confusing to use, this negative experience would inhibit them from utilising it as a resource, obscuring further data collection for its evaluation (McNamara and Kirakowski, 2006). Following Determine Usability, the next three dimensions can be completed in parallel or in any sequence.

Determine Usage - based on the functionality and experience factors from McNamara and Kirakowski (2006), as usage of technology will depend on whether its end-users appreciated the services available. Data on the number of people that have used the technology, their return rate, and their roles will provide insight into whether the technology was found to be of value by different cohorts of end-users (Delone and McLean, 2003).

The determination of usage can vary in its data collection points depending on the technology under review. For example, in the case of a digital commons, the volume of content creation and subsequent edits can reflect on its usage and how it is being used (Roth, Taraborelli and Gilbert, 2008).

However, it is to be noted that some technologies, especially those within formal organisations, do not have the choice of use but are the only means available to achieve a task (Delone and McLean, 2003). Hence, it is possible that technology can be used but not valued, which is where the dimensions of usability and caring provide insights into value.

Determine Sustainability - based on the functionality factor from McNamara and Kirakowski (2006) and its components of reliability and durability. Knowledge of the ongoing maintenance resources, including their costs, effort, and skillsets, can be used to establish historical and future sustainability.

Determine Caring - in part based on all the evaluation factors of functionality, usability, and experience from McNamara and Kirakowski (2006), though I see this dimension as novel to an evaluation, required here for the healthcare setting of this framework. This dimension is in place to offer insights into the ability of the software as a proxy to represent the caring of its designers.

The theory of care ethics is leveraged as a lens to provide an understanding into the caring qualities of attentiveness, responsibility, competence, and responsiveness. Based on qualitative data, this counters a wholly quantitative and thereby positivist approach to evaluation that can obscure the human aspect of caring. HCI authors seeing such qualitative assessments as increasing use to marginalised communities (Tseng *et al.*, 2022).

With the four dimensions of the conceptual framework in place, the following sections describe its application to MyCareBudget.

7.4. Application of the Conceptual Framework to MyCareBudget

Gathering mixed methods data to evaluate MyCareBudget began during its technical design, as I built data collection methods for logging both usage and maintenance. Moreover, the methodologies of AR and new PD used in this study are collaborative, hence, the evaluation was also to be a collaborative exercise (Stringer, 2007, p. 141; Hayes, 2011). As such, the voices of PHB holders, co-designers, CCG officers, and VCSE staff all held merit and were to be included in the evaluation.

Of note is that Hayes (2011) stressed that the privilege of the researcher in terms of their knowledge and skills is to be guarded against in evaluation, by the researcher stepping back to take on a role more aligned to that of a facilitator, to avoid dominating the assessment. To achieve this, a definition of success was used based on positive feedback from end-users, rather than aligning with my intended aims of MyCareBudget's co-design.

Figure 29 shows the data collection sources and their application to the four dimensions of the framework.

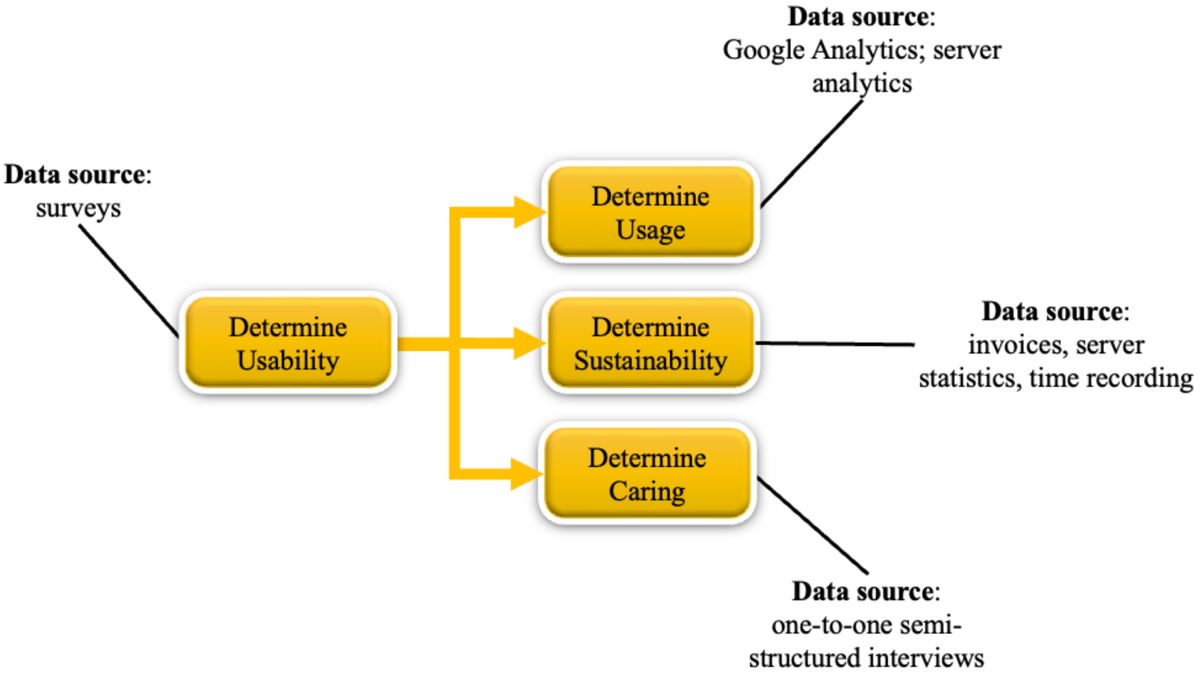

Figure 29: Dimensions and data sources of the conceptual framework as applied to MyCareBudget

Figure 30 provides an overview of the timeline for AR cycle 4 with the four dimensions from the conceptual framework. The extended timeframes for *usage* and *sustainability* allowed for a longitudinal collection of data that increases confidence in the results.

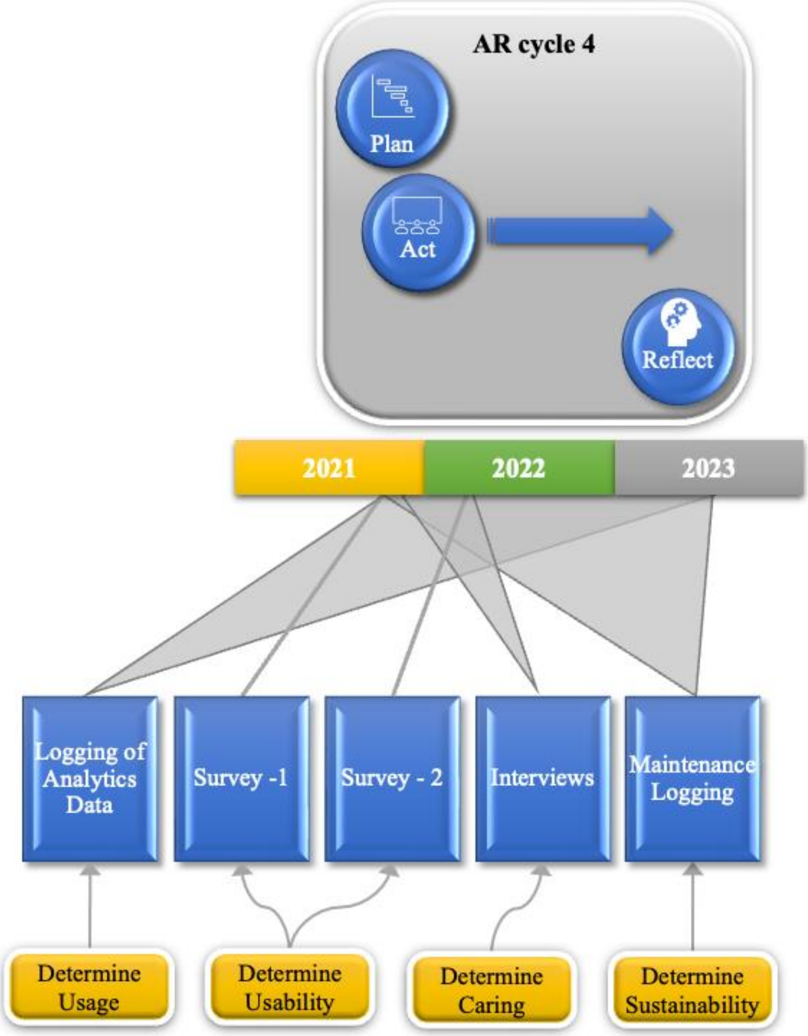

Figure 30: Timeline for AR cycle 4

The following sections are divided into the four dimensions that establish the usability of MyCareBudget through a survey (section 7.5); a quantitative analysis of the usage of MyCareBudget (section 7.6); a discussion on its sustainability (section 7.7); and that establish the caring value of MyCareBudget through interviews (section 7.8).

7.5. Determine Usability

7.5.1. Method for Comparison of Website Usability

A System Usability Scale (SUS) assesses the usability of a website against a scale and then uses the results for comparison against other websites.

An early version of an international standard for usability (ISO 9241-11[43]) was used as the basis for the development of a SUS in the 1990s by Brooke (1996, 2013). This SUS is an end-user questionnaire of ten alternating positive and negative questions, each with a five-part Likert scale ranging from 'Strongly Disagree' to 'Strongly Agree', see Table 7. Brooke (1996, 2013) provides the scoring mechanism, with Bangor, Kortum, and Miller (2008) providing a method to interpret the score based on over 2,300 applications, confirming its suitability and offering improvements to the wording of the survey questions, these used in this study.

SUS questions	
Positive	**Negative**
1. I think that I would like to use this website frequently	2. I found the website unnecessarily complex
3. I thought the website was easy to use	4. I think that I would need the support of a technical person to be able to use this website
5. I found the various parts in this website were well integrated	6. I thought there was too much inconsistency in this website
7. I would imagine that most people would learn to use this website very quickly	8. I found the website very awkward to use
9. I felt very confident using the website	10. I needed to learn a lot of things before I could get going with this website

Table 7: SUS questions from Brooke (1996, 2013), as modified by Bangor, Kortum, and Miller (2008)

I selected Brooke's SUS method (1996, 2013) as the SUS for this study, as Tullis and Stetson (2004) found it was the simplest questionnaire of the four they examined, it addressed the widest range of usability components, and gave the most reliable results. It has been cited

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[43] https://www.iso.org/obp/ui/#iso:std:iso:9241:-11:ed-2:v1:en

thousands of times[44], with literature applying it to similar contexts as for this study: a digital commons (Altanopoulou and Tselios, 2017) and an app for unpaid carers (Rettinger *et al.*, 2020).

Usability was checked twice using the SUS questionnaire. First, shortly after MyCareBudget was publicised in September 2021 to provide early detection of any significant issues that needed resolution. Second, in April 2022 with new participants to capture additional responses.

7.5.2. Determination of Legitimate End-users

When recruitment for usability was first conducted, I looked to contact individuals who had registered with an email on MyCareBudget.

MyCareBudget can be accessed either as a guest end-user, where it can be browsed without signing in (no contact information is stored) or, as a registered end-user that required a confirmed email address that enabled the download of care artefacts. The advantage of this latter strategy for recruitment is that individuals who had registered can be contacted via their email addresses, whereas guest end-users cannot be contacted.

However, an unexpected issue arose soon after MyCareBudget became internet accessible, in that the website was being targeted by high levels of malicious attacks. As an example of the volumes involved, there was an average of just over 40,000 attempts each day by malicious users and software bots attempting to edit MyCareBudget, such volumes not uncommon (statista, 2022). Therefore, distinguishing legitimate end-users became the first step.

The process I created to identify the legitimate end-users was as follows,

- First, extract all the registered end-users with their email addresses from MyCareBudget using an inbuilt MediaWiki function. Based on May 2022 data, 27,504 such end-users were detected.
- Second, remove registered end-users whose email domain name was found on https://www.ipqualityscore.com/ - this website holds data on software bots, fake

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[44] https://scholar.google.co.uk/scholar?hl=en&as_sdt=0%2C5&q=brooke+Sus%3A+a+%E2%80%9Cquick+and+dirty%27usability&btnG=

domain names, and malicious domain names. This left 1,855 end-users from the May 2022 data.

- The third and final step was to examine the website pages visited (using another MediaWiki function) by the remaining end-users, as I found malicious end-users hid their activity by attempting to edit those pages on MyCareBudget that were not frequented by legitimate end-users, for example, the 'General Disclaimer' page. Where the end-user had visited such website pages multiple times and no others, the end-user was excluded. This left 268 end-users.

At each step, the end-users excluded were checked to see if their email addresses were recognisable as valid. For example, the domain names were from the NHS or were recognised as a participant in this research. No such end-users were found, adding trust to this process.

7.5.3. Creating the Usability Survey

I considered a survey best suited to source data for the SUS questionnaire, the reasoning being that the questions were straightforward and that a survey can elicit responses from a greater number of participants than I could interview.

A £50 prize draw was offered as an incentive to complete the questionnaire, with the Newcastle University logo added to emails and the questionnaire to gain trust, along with avoidance of a lengthy questionnaire, and closed questions to encourage completion (Müller, Sedley and Ferrall-Nunge, 2014). The structure and phrasing of the questionnaire were based on Wilson (2007), who recommended stating how the data would be used and to minimise the time needed to complete the questionnaire.

A draft of the questionnaire was tested in two ways (Müller, Sedley and Ferrall-Nunge, 2014) using three co-designers of MyCareBudget from the previous AR cycle: a 'cognitive pre-test' where each question was read and then discussed with one participant, followed by a 'field test' where the survey was tested with two participants. I chose the participants such that they had PHBs or were in the process of gaining a PHB, that their PHBs were used for themselves or their child, and that they accessed the internet via different types of devices - smartphone or laptop. This allowed the questionnaire to be tested from different care perspectives and different technology access methods. The testing revealed several typographical errors, ambiguous terminology, and excessively formal language that were all amended. This testing also provided feedback on timing, enabling potential respondents to know in advance how long the questionnaire would take to complete - less than 10 minutes.

The questionnaire was comprised of questions that formed a Consent Form, the SUS questionnaire, and demographics.

7.5.4. Performing the Usability Survey

Potential participants were contacted by email with a link to a set of pages on MyCareBudget built for the survey, which opened an online questionnaire built using Microsoft Forms. The first email was issued followed by two reminder emails sent after the first and second weeks.

An online method was judged suitable, as it allowed for a high volume of distribution, zero cost, and simplistic data sourcing from a geographically dispersed set of participants (Braun and Clarke, 2013, p. 136; Müller, Sedley and Ferrall-Nunge, 2014).

Basing the survey just on registered end-users gives rise to a coverage error, as this did not survey people who were either unaware of MyCareBudget, or who had found out about MyCareBudget but had not accessed it, or who had accessed it as a guest user. In these cases, I did not possess their contact details, so I could not include these groups. A related constraint with online questionnaires is that they can exclude groups with limited digital access, though this did not detract from this study as I was only targeting those individuals with sufficient digital access to have registered on MyCareBudget.

The survey was run twice, noting the second survey excluded all those selected for the first survey. All the legitimate end-users from section 7.5.2 were invited to take part in the surveys, including all the co-designers from AR cycle 3. 27 individuals responded, just above a 10% response rate. See Table 8, noting that not all respondents supplied data for their care budget experience.

Cohort	**Number of respondents**	**Respondents who were co-designers**	**Collective care budget experience**
Disabled citizens	12	1	>18 years
Unpaid carers	13	4	>24 years
VCSE staff	1	1	11 years
CCG officers	1	-	Not supplied

Table 8: Care experience of respondents to the surveys in AR cycle 4

Braun and Clarke (2013, p. 48) suggested 15 to 50 responses would suffice for a small project, which this survey attained. Further, Tullis and Stetson (2004) found that just 12 respondents would give accurate results for Brooke's SUS method (1996).

A potential issue with this data is whether those responding to the survey had relevancy, in that they could have been completing the questionnaire only for the chance of winning the £50 prize. Though I judge this low risk as those that provided responses to the open question (19 out of the 27 respondents) appeared genuine, as their comments were rich and contextual.

7.5.5. Analysis and Findings from the Usability Survey

Using the algorithm supplied by Brooke (1996), a mean score of 72.6 was produced for MyCareBudget, with a standard deviation of 13, a minimum of 42.5 and a maximum of 97.5. This places MyCareBudget in two categories of 'good' and 'acceptable' (Bangor, Kortum and Miller, 2008) - see Figure 31. Of note is that these terms are a guide to usability rather than a definitive classification (Bangor, Kortum and Miller, 2008) and that the systems used as comparison were not reported as sufficiently granular to score by digital commons or other types of websites.

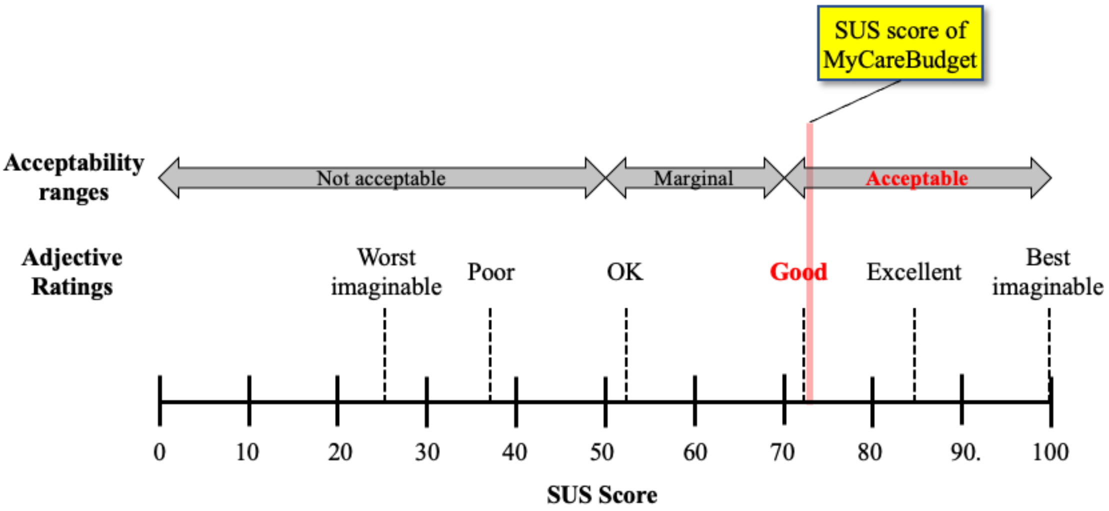

Figure 31: SUS analysis scale (Bangor, Kortum and Miller, 2008) with MyCareBudget's score

There was an association found with the scores of the survey respondents that were co-designers of MyCareBudget. The co-designers who took part averaged a score of 77 with a standard deviation of 6; the remaining scores averaged 71.6 with a standard deviation of 14. The higher and more tightly grouped scores of the co-designers were perhaps influenced by their 'ownership' of MyCareBudget, or perhaps had a greater familiarity with the interface having used it many times. Regardless, even removing their scores still classified MyCareBudget as 'acceptable' (Bangor, Kortum and Miller, 2008).

These results give confidence in this study's use of SUS, which indicated end-users would find the website acceptable to use. Hence, I assumed the usability of the MyCareBudget would not negatively affect their perception of its value.

7.6. Determine Usage

7.6.1. Gathering Usage Data

MyCareBudget's database did not collect data for usage of guest end-users, only those registered with an email address. To collect data for all types of users, I used Google Analytics[45], which uses its own algorithms to determine whether an end-user is legitimate. As of 7 June 2023, Google Analytics showed there had been 5,509 end-users, comprising both guest and registered, of MyCareBudget since its inception, of which 1,100 (20%) returned one or more times. Table 9 provides the top ten countries by number of end-users.

Top ten countries	Number of end-users	Percentage of end-users
UK	4,389	79.7%
US	514	9.3 %
China	222	4.0%
Indonesia	108	2.0%
Ireland	52	0.9%
India	36	0.7%
Netherlands	36	0.7%
Finland	33	0.6%
Belgium	29	0.5%
Sweden	28	0.5%

Table 9: Top ten countries with end-users, sourced from Google Analytics

On examining the domain names of legitimate registered end-users' email addresses gathered in section 7.5.2, there were unintended end-users, and hence unintended usage, outside of the

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[45] A free tool from Google that records webpage visits - https://analytics.google.com/

target group of citizens holding care budgets. Such end-users included staff from the NHS and CCGs (7% of end-users), Local Authorities (2%), VCSEs (3%), and commercial care organisations (3%). Though the true roles of these end-users are unknown, for example, people could have been within the target group of PHB holders but were using their work email address to access MyCareBudget.

On examining the numbers and instances of care artefacts being downloaded, 3,183 in total as of 7 June 2023, it was evident that there was an uneven distribution, see Figure 32.

No uploads of care artefacts or page edits were submitted direct to MyCareBudget, though 14 disabled citizens and unpaid carers supplied their documents and updates via email to me for upload prior to and in the first two months of operation.

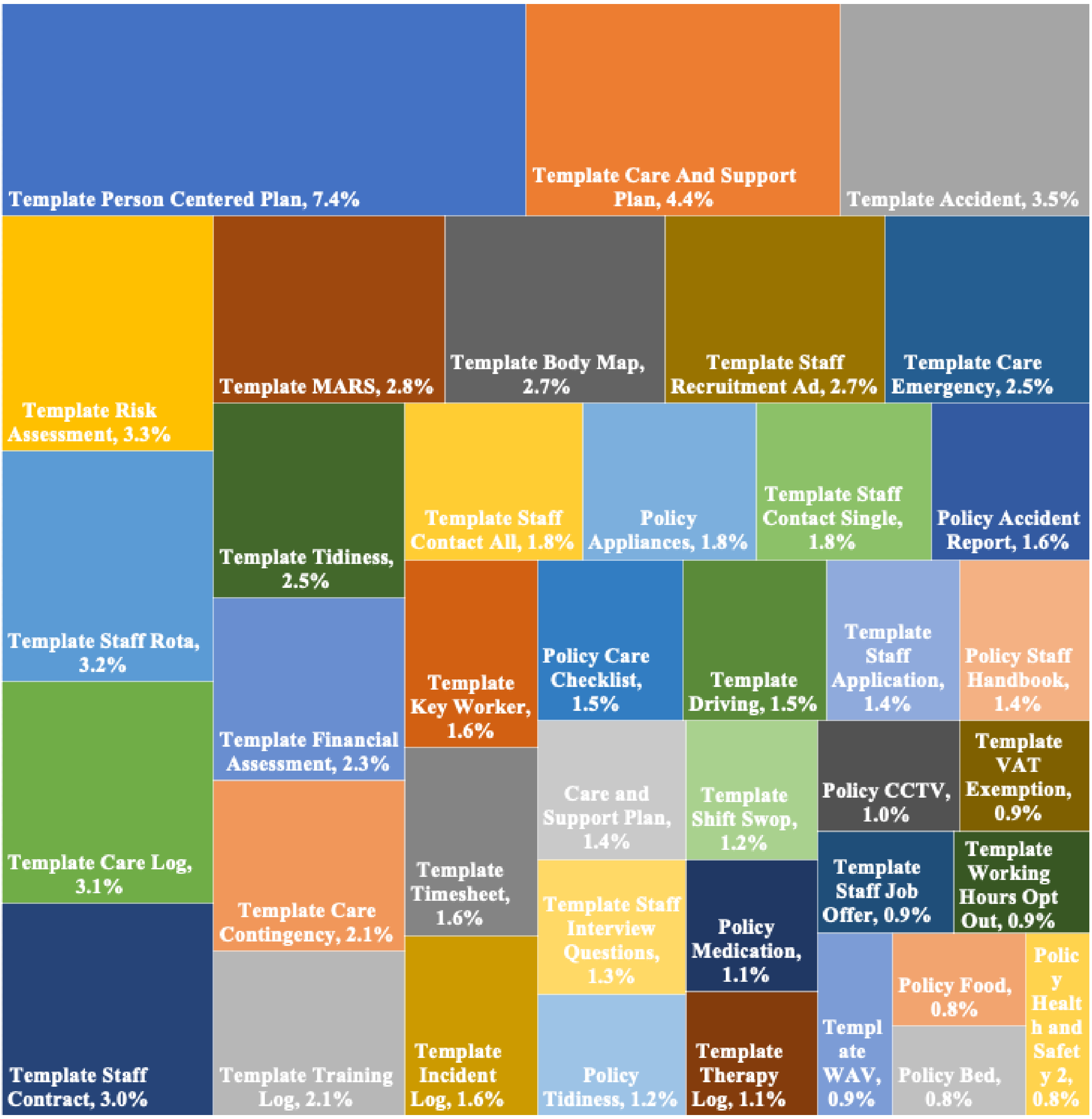

Figure 32: Treemap showing the top 40 downloaded care artefacts as of 7 June 2023

7.6.2. Analysis of Usage Data

This section provides an analysis of five categories of data that relate to the numbers and types of access to MyCareBudget - number of end-users, returning end-users, roles of end-users, use of content, and editing of content. The first three categories are applicable for evaluating generic technologies, with the final two categories more appropriate to a digital commons.

Number of end-users: Section 2.2.5 showed that NHSE stated there were nearly 33,000 people who were the target end-users of MyCareBudget - PHB holders in England. At the time this NHSE data was collected, there were just under 4,400 end-users from the UK that had accessed MyCareBudget - just under 13% of the NHSE total. This must be regarded as the maximum figure due to uncertainty over the roles of the end-users of MyCareBudget. However, even if this figure is viewed with caution, there remains a significant percentage of UK people relative to the PHB population who had accessed MyCareBudget.

Of note is that the usage of MyCareBudget was likely dependent upon placing knowledge of it in front of potential end-users. I found this promotion to be arduous and enduring so I tailed off this work about three months after MyCareBudget became operational in September 2021. My assumption being that an intensive and long-term promotion would have seen the usage of MyCareBudget increase beyond the data presented here.

A distinction here is between the many thousands of end-users (comprising both guest and registered) and the low numbers (268 given in section 7.5.2) who had registered and could download care artefacts. Of note is that one of the co-designers in section 6.4.2 regarded a resource such as MyCareBudget as *"a reference book to keep on the shelf."* Hence a possibility is that a guest end-user will visit MyCareBudget to browse, determine its value, and either not register if they find little value, or register later when they have a need to use the resource.

My conclusion with this data is that MyCareBudget attracted a significant number of end-users.

Returning end-users: The previous section shows that about 20% of end-users returned at least once to MyCareBudget. This is a positive indication that one in five people found value in MyCareBudget sufficient to revisit the resource.

No data is available as to why the remaining 80% did not return, though the possibilities stated above for registering would apply here for revisiting, as would that a single visit may have sufficed. This showing the limitations of the quantitative data collected.

Roles of end-users: In the previous section, the analysis of domain names of registered end-users showed that about 15% were sourced from formal organisations such as the NHS, CCGs, VCSEs, LAs, and commercial care companies. This is a significant percentage of people that are assumed to be using MyCareBudget for other than its intended use of directly supporting peers of the co-designers. I viewed this as a positive outcome - as the resource was either being used by them to recommend onwards to PHB holders, or as a boundary object (Star, 1989; Ackerman, 2000) that would inform them of the infrastructuring work imposed onto PHB holders.

Use of Content: The care artefacts within MyCareBudget have been downloaded thousands of times, but this does not offer insight into why they were downloaded. Though I have assumed here that at least a subset was of use to those end-users that downloaded them. This again illustrating limitations of the quantitative data.

Editing of Content: MyCareBudget is a digital commons in place to share care artefacts but there have been few uploads of content or page edits once MyCareBudget had been operational for a few months. Of these, none were performed directly - all were emailed to me for upload.

I see three possible main reasons for this lack of updates. First, the artefacts presented on MyCareBudget appear to be a comprehensive set, with no apparent gaps and hence there was minimal need to upload additional artefacts. Second, the PHB holders viewed uploading care artefacts as a low priority within their time-pressured lives of caring. Third, this was an indication of the complexity of the open-source software, MediaWiki - as the use of open-source software cannot imply that non-technical citizens have the ability to update it (Manuel and Crivellaro, 2020; Hamm *et al.*, 2021). The skill set demanded impedes accessibility to perform online edits, delimiting the ownership of such public technology by citizens and their communities.

The lack of updates to MyCareBudget extends to its public discussion forum, where little use has been made of this feature, with less than 20 posts to the discussion forum since the release of MyCareBudget.

In summary, I believe the number of people worldwide that have accessed MyCareBudget in the time it has been available, returned to the website, and downloaded care artefacts, is significant. Hence, MyCareBudget has been used, though not in the fullest sense as a digital commons where continual end-user direct updates would have been seen.

7.7. Determine Sustainability

This third dimension within the conceptual framework reflects on the financial cost, availability, maintenance time, and skillset required to keep MyCareBudget operational.

There are no ongoing costs for software due to the use of open-source, with costs for the virtual servers, domain name, and email averaging approximately £22 per month. These costs were originally funded from this PhD research, with the VCSE organisation that participated in this study as co-designers taking over the funding and administering of MyCareBudget from June 2023.

The website has experienced minimal loss of service since it became operational, owing to the use of virtual servers from my choice of a high-availability commercial provider.

MyCareBudget requires less than five minutes a month of my time on average to monitor performance and security, and ensure the content is up to date. Every six months, an additional three hours for maintenance are necessary to ensure that the open-source software versions remain current. However, this maintenance of software versions is a highly technical task, albeit non-specific to MyCareBudget, that blocks the handing over of end-to-end maintenance to citizens or organisations that do not possess these specialist skills. This detracts from the sustainability of interventions such as MyCareBudget, echoing the work of HCI authors that have pointed out that the use of open-source does not imply that all citizens have access to all its functionality (Manuel and Crivellaro, 2020; Hamm *et al.*, 2021).

I see MyCareBudget as being historically sustainable from its record of high availability, low costs, secure funding, and low maintenance effort - albeit the demand for skilled technical resources.

Determining sustainability looking forward is based on the same factors. I do not anticipate change with these factors, with a personal commitment from myself that if the VCSE funding ends, I will seek other funding or self-fund, ensuring MyCareBudget remains operational.

Hence, MyCareBudget has been and is anticipated to be sustainable, though noting the need for skilled technical resources at infrequent times.

7.8. Determine Caring

This fourth dimension within the conceptual framework uses qualitative data from one-to-one, semi-structured interviews with end-users of MyCareBudget of disabled citizens, unpaid carers, CCG officers, and VCSE staff. This data is applied as input towards establishing the value of MyCareBudget by leveraging the theory of care ethics.

The recruitment and engagements for the one-to-one interviews are described in the next section, followed by sections on analysis and findings.

7.8.1. Recruitment and Engagement for One-to-One Interviews

I selected four recruitment channels for the one-to-one, semi-structured interviews, with purposive sampling, criteria being the experience of receiving or supporting PHBs in England and being over-18.

- The first channel comprised all the legitimate registered end-users of MyCareBudget that had used the website in the three months leading up to recruitment. Also included within this channel were all the co-designers of MyCareBudget from the previous AR cycle.
- The second channel was Twitter, using the MyCareBudget Twitter account with recruitment invitations, including hashtags dedicated to personalised care, PHBs, and unpaid carers.
- The third channel was Facebook, posting invitations on pages dedicated to PHBs and unpaid carers.
- The fourth channel was a private NHSE official forum dedicated to healthcare professionals seeking guidance on PHBs. This forum is not publicly available, with my access due to having graduated from the NHSE Academy for Personalised Care.

All but the first channel recruited people that had not previously used MyCareBudget, so these recruits were asked to gain familiarity with the website before the interview.

Table 10 shows the recruitment channels of the 23 people interviewed. No recruitment was gained from Twitter, perhaps because this was the promotional channel for MyCareBudget, so these people were already recruited by the first channel. Table 11 provides a breakdown by cohort.

Cohort	**End-users of MyCareBudget**	**Twitter**	**Facebook**	**NHSE forum**
Disabled citizens	4	-	3	1
Unpaid carers	3	-	4	-
VCSE staff	1	-	-	3
CCG officers	1	-	-	3

Table 10: Interviewee recruitment by channel

Cohort	Total number of interviewees	Interviewees who were co-designers	Collective care budget experience
Disabled citizens	8	3	43 years
Unpaid carers	7	1	44 years
VCSE staff	4	1	41 years
CCG officers	4	-	19 years

Table 11: Care experience of AR cycle 4's interviewees

An interview guide was created that sought participants' views of their use of MyCareBudget, the trust they assigned to it, its impact on their lives, and negative aspects - see Appendix E. Questions included, *"What made you first look at the website?", "The website says that it's built by people with PHBs - is that a good thing or a bad thing?", "Do you see any downsides to this website being available?", "Did you do anything with any of the documents?"*

The interviews for the citizen participants and VCSE staff were held remotely and conducted via Zoom videoconferencing, as the citizen participants were accustomed to this software due to its widespread use during the COVID-19 pandemic. Interviews for the CCG officers were also held remotely but used Microsoft Teams videoconferencing, as this software is used across England's state healthcare. 21 hours of interviews were recorded and transcribed using the same online service as in the previous two AR cycles.

7.8.2. Analysis of the One-to-One Interviews

As in the previous AR cycles, the transcripts from the interviews were analysed using reflexive Thematic Analysis as described in the Methodological Approach chapter, section 3.11.

I generated four themes from the data analysis. The first theme of *Meeting Need* explores how participants found value in the content of MyCareBudget through it being co-designed with PHB holders. *Responsibility of Care* examines responsibility in terms of who should have created the resource of MyCareBudget, with the following theme of *Absolving Responsibility* laying out how the citizen end-users did not take responsibility for maintaining the content of MyCareBudget. A final theme of *Avoiding Harm* reflects on the risks that come with publishing care artefacts.

The leverage of the theory of care ethics is key to this themes, a mapping provided in Table 12.

Care activity	Quality demanded of the quality	Theme
Caring about	Attentiveness	*Meeting Need*
Caring-for	Responsibility	*Responsibility of Care; Absolving Responsibility*
Caregiving	Competence	*Meeting Need*
Care Receiving	Responsiveness	*Avoiding Harm; Absolving Responsibility*
Caring with	-	*Responsibility of Care*

Table 12: Care activity and quality (Fisher and Tronto, 1990; Tronto, 1998, 2013, p. 23) by theme

Pseudonyms for quotes are used throughout, with "(CCG)", "(VCSE)" or "(CO-DESIGNER)" added after a name to give context - the default being a disabled citizen or an unpaid carer that had not been a co-designer.

7.8.3. Meeting Need

The co-designers in the previous AR cycle had identified gaps in their own lives of managing PHBs, assumed those same gaps existed for their peers, and taken responsibility to address them within a publicly available online resource. As such, this theme addresses the care ethics qualities of *attentiveness* and *competence*.

PHB holders new to MyCareBudget responded positively to the resource, finding value for themselves and their peers. Wendy, parent to her disabled daughter in her early 20s, stated, *"I think your idea is phenomenal. I think it's brilliant."* Yasmin, parent to her disabled son in his teens, said, *"It's great. I've been looking at it and downloading bits and pieces."* Lacey, also a parent to a teenage disabled son, commented, *"Having these resources made available to a wider audience would significantly improve the success rate of personal [health] budgets."*

Several of the CCG officers came to realise the responsibilities they had placed on PHB holders through accessing MyCareBudget, it acting as a boundary object for the officers to gain visibility of the lives of PHB holders and the intensity of work demanded to run a PHB. This was new knowledge to the CCG officers, the distance between themselves and PHB holders inhibiting access and communication. Dave (CCG), a frontline CCG worker for PHB holders, remarked, *"It was surprising that there was a lot of information on it."* Hayley (CCG), a CCG manager responsible for personalised care, said, *"Really, really, really helpful for people, not just when they're starting out, but I think even those people who may have been doing it for a long time, but struggle with the detail, and the paperwork."*

Even though appreciated by those end-users new to MyCareBudget, it was not seen by all as a resource they would use in everyday life, or even that they might ever use it - more that it provided a feeling of comfort that such a resource was available. This would be of particular benefit to the citizen participants who felt isolated from their peers, in that they have to work alone to manage their PHBs, with no care artefacts available from their CCGs or the internet. Emily, a wheelchair user with a degenerative condition, commented, *"I was reassured that it was a place that I could visit in the future. To catch up on other things that I don't have much information [on]. At the moment, it was kind of reassuring that it was there."* This remark echoed one from Jake (CO-DESIGNER) in the previous chapter (see section 6.4.2), who viewed MyCareBudget as a reference book that is kept to hand but perhaps rarely accessed.

This feeling of comfort provided by MyCareBudget was amplified by its intimate nature, identified by several citizen participants who were not co-designers, feeling it was 'personal', rather than a large organisation talking 'at' them, this also adding trust. Emily said, *"...it feels more like it's directly speaking to me ... you can feel it. So I didn't need any kind of reassurance that you were legitimate."*

The accuracy of the artefacts was discussed by several participants. This was not applicable to artefacts such as the Body Map but relevant to artefacts such as the Staff Contract or Staff Recruitment Advertisement in terms of their compliance with employment law. The care artefacts were trusted by the citizen participants, as they were sourced from people like themselves who were seen as points of expertise. Emily felt that the authors of the documents on MyCareBudget were her peers, which to her meant they could be trusted, saying *"... from the beginning, I got the impression that the people who wrote all the content, know and knew what they were talking about."* Sandra (VCSE, CO-DESIGNER), director of a VCSE organisation specialising in PHBs, said, *"All of my experience over the last several years is that people highly value the fact that it's coming from people who've done it [held PHBs]."*

The personal nature and accuracy of MyCareBudget was most likely due to it being co-designed by their peers, with participants seeing it as *"coproduction"* or a *"peer support network".* All participants were in favour of this co-design process when asked, seeing benefits of trust and accessibility. Hayley (CCG) said, "*It's a peer support, peer designed network. Gives it the edge for where PHB holders might feel comfortable."*

The citizen participants new to MyCareBudget were aware that most of the care artefacts demanded individualisation once downloaded. Instances were also voiced where artefacts' intended uses were extended from their original intent. An example was the Body Map, a simple outline of a body where paid carers could mark where bruises had been found on the person they were caring for (see Figure 18), this done to safeguard against future occurrences. Geoff, a wheelchair user with motor neuron disease, re-purposed this care artefact to mark where his degenerative condition had diminished his physical capabilities, said, "*I was recording what was going wrong. So for me, it's not just about marks ... it could be used for recording separate physical symptoms as well.*" Zara, a parent caring for her son with complex needs, was re-purposing the Body Map in two ways, one to indicate to new paid carers where to attach medical devices, "*And then I've done another page for the same child with all the [medical] pumps that are attached",* and second, for areas on the body that paid carers needed to pay extra attention to, "*One with injuries on ... because my younger one dislocated his arm three times.*"

The participants validated that MyCareBudget filled the gap intended by its co-designers, meeting the need for care artefacts when managing a PHB. Further, seeing it being designed by those in receipt of a PHB delivered a relevant, trusted, and personal service, as PHB holders as co-designers were considered experts due to their experience of managing their PHBs.

This theme demonstrated MyCareBudget aligned with the care ethics qualities of *attentiveness* and *competence*. *Attentiveness* where the co-designers of MyCareBudget had identified a need for caring for their peers due to an existing lack. *Competence* by the care artefacts from the co-designers successfully meeting that need.

The following theme progresses to insights related to the care ethics quality of *responsibility* by examining who controls the provision of care artefacts.

7.8.4. Responsibility of Care

The co-designers had accepted responsibility for supporting the infrastructuring demands of a PHB by creating MyCareBudget, this theme addressing the participants' thoughts on who should have delivered this resource.

With MyCareBudget in operation, its end-users had the opportunity to reflect on who should have had responsibility for its creation. Questions were raised as to why this study had taken this responsibility, and not the state or VCSEs. Colin (CO-DESIGNER), a wheelchair user with Multiple Sclerosis, said, *"Why is it a group of personal budget holders, led by one man,* *has put together an essential practical resource for users, that no authority, charity or organisation has managed and offered for free?"*

The CCG officers recognised the need for supporting PHB holders that MyCareBudget met but absolved themselves and the wider state (in terms of their CCG and NHSE) from the responsibility of providing for or supporting this need. Reasons offered by the CCG officers were that it would demand too much work, it would be difficult, it was not the responsibility of healthcare authorities, and that the differing CCGs, over 100 at the time of the interviews, each devising their own resource, would create a diverse set of responses. This diversity was seen by one officer as a negative rather than as a potential for creating a resource best suited to their regional needs. Anastasia (CCG), a CCG finance officer dealing with PHBs, said, *"Any government, they'll issue a regulation, but it doesn't tell you how to build [it] ... So all the CCGs are all probably operating in different formats."* Hayley (CCG) said, *"So nothing supports PHB holders, and it can become a bit of a struggle to support PHB holders."* Hayley (CCG) continued with, *"NHS England's role is direction rather than dictation ... Why it's not being picked up, by anyone else? I guess, it's quite a lot of work."*

With the CCG officers stepping back from ownership of this responsibility, it was placed by default upon the citizen. Dave (CCG) said, "*We can create our own but it's more something that we would be expecting people [PHB holders] to be putting in place for themselves as the employer."*

The adversarial relationship between citizen and state also complicated the placement of responsibility. The co-designers had previously stated that they have little trust in their CCG, so if their CCG was to offer such a resource, the citizen would likely transfer that lack of trust to the resource. Ariadne, parent to her disabled son in his 20s who requires constant medical care, who had not taken part in the co-design, said, "*People's experiences of CCG, it's not always a pleasant one. So they might not trust [a CCG] website."*

Indeed, the PHB holder might be the true home for the responsibility of defining care artefacts. Evidenced by the citizen participants individualising the downloaded care artefacts to their own context rather than adapting their context to a standard set of documentation. The issue for citizens undertaking this infrastructuring work was that they were not supported to achieve it, the intensity of the task exacerbated by them being time-poor, and having to create their care artefacts from scratch, without knowing what documents were needed. The likelihood was that the distance between CCG officers and PHB holders had resulted in the officers being unable to appreciate the impact of their lack of support on the PHB holder. Yasmin said, *"And you need that support. And it's just [that the CCGs] dump [on] you."*

With CCGs absolving themselves from providing support and the potential for citizens to not trust resources sourced from CCGs, responsibility for owning the support of PHB holders in the context of care artefacts was accepted by the co-designers - when offered the opportunity by this research project.

This theme addressed the care ethic quality of *responsibility* by examining responsibility in respect of who controls the need for this care. The citizens took ownership of this responsibility in the absence of their state or VCSE organisations - as co-designers of MyCareBudget where they also displayed the care ethic activity of *caring with* as a community.

7.8.5. Absolving Responsibility

This theme examines whether MyCareBudget will remain fit for purpose. As such, this section addresses the care ethics qualities of *responsiveness* and *responsibility.*

Many participants were mindful of changes in law and policy, potentially rendering content out of date. This would impact the sustainability of MyCareBudget - though no participant took responsibility for this maintenance. Colin (CO-DESIGNER) said, *"The problem is continually having to update documentation, things change all the time. The biggest issue isn't knowing, it's keeping up with the knowledge."*

As a public digital commons, MyCareBudget is open to update from anyone, subject to moderation, implicitly placing the responsibility for maintenance on the people that access it. However, this is a responsibility that the co-designers had absolved onto the unknown end-users of MyCareBudget. This becomes an issue for a digital commons in that no individual or group is held responsible for such critical maintenance of content. Indeed, for MyCareBudget, no such updates have been made by end-users, instead, I have taken on this responsibility. One citizen participant did recognise that as a digital commons the responsibility for maintenance falls on its end-users, though she did not personally accept that responsibility. Erin, parent to her disabled son in his teens, stated, *"... it's a wiki. And people are familiar with Wikipedia, the fact that it's continuously changing and coproduced, is a positive, because anything that's kind of really like, unusable or wrong, can be very quickly, remedied."*

MyCareBudget was viewed by PHB holders as maintained, though this was an assumed trust placed on the future end-users of MyCareBudget.

This third theme addressed the care ethic qualities of *responsiveness* and *responsibility*. *Responsiveness* by the end-users of MyCareBudget seeing the need for care artefacts to be maintained. *Responsibility* was not being fulfilled by the co-designers and end-users of MyCareBudget in the context of content maintenance, this falling by default onto me to perform.

7.8.6. Avoiding Harm

This final theme explores potential unintended consequences of MyCareBudget hosting a wide range of care artefacts, thereby addressing the care ethics quality of *responsiveness.*

The perception that documenting care as a proxy for performing caring was seen by several of the participants as a risk that could lead to harm. This was expressed as a warning that documents do not by themselves provide care and can even promote harm if filling in paperwork is seen as the priority. Julie, a wheelchair user with a limited range of mobility, stated *"I know that the worst, most abusive, most dangerous, 'care' I have received was where there's lots of documents. It didn't document the right things."*

An additional risk of harm was seen if too much documentation was implemented into a home. It was mentioned by several participants that most PHB holders will only need a small subset of those hosted on MyCareBudget. Sandra (VCSE, CO-DESIGNER) commented, *"Not everyone will need everything that's on [MyCareBudget]. And in fact, probably no one will need all of it."* One participant was strong that a home was not to be equated to a commercial or public organisation. Giselle, parent to her disabled son in his 30s, relayed a conversation she had with a friend who believed Giselle needed to reduce the number of documents she had, *"And my friend said 'We had to get rid of these'. And she equated a person ... with minimal paperwork."* Giselle continuing with, *"An individual service is not a little big service. You can't scale down a massive organisation and think that the same applies."*

A counter against too much documentation was not enough documentation. It was recognised that there is a balance of power and responsibility with holding a PHB - the choice and control necessitating work to ensure legal liabilities and care of their employed carers. Hayley (CCG), said, *"... you don't want to scare people ... But at the same time, you need people to be aware that actually you need to do certain things. You need to dot the i's and cross the t's."*

This theme provides additional insights into how MyCareBudget addressed the care ethics qualities of *responsiveness*, where the PHB holders that used MyCareBudget felt safe in the interviews to critique MyCareBudget, pointing out risks in its content and how this content could be misused.

7.8.7. Summary of the Determine Caring Dimension

As part of this dimension, the five care ethics qualities of *attentiveness, responsibility, competence, responsiveness*, and the care activity of *caring with* can be summarised to complete the caring assessment of MyCareBudget.

Attentiveness: Citizen participants as co-designers of MyCareBudget demonstrated attentiveness by seeing the need and value in the offering of care artefacts. This was based on their lived experience of gaining a PHB with no support to create the care artefacts they needed.

Responsibility: The co-designers of MyCareBudget demonstrated responsibility accepting the task of co-design, their philanthropy towards their peers motivated them to remain involved with the co-design process that stretched to over six months and included debates over unintended consequences and ensuing responsibilities.

Gaps in responsibility were in moderation and ensuring that the content of MyCareBudget was kept up to date with legislation and policy. The needs were stated in co-design and evaluation, but no co-designer or end-user took responsibility, this defaulting to me.

Competence: As holders of PHBs, the co-designers possessed the lived experience and hence skills of creating and using the care artefacts in their day-to-day lives. Their criticality of care applied both efficiency and efficacy to their care artefacts, delivering competence.

Responsiveness: Responsiveness in the evaluation was found by the end-users seeing the need for the maintenance of the care artefacts and feeling safe in the interviews to critique MyCareBudget.

Caring with: The use of participatory design and engagement methods had been configured to the lives of the participants, enabling an assemblage of disabled citizens, unpaid carers, and a VCSE organisation to co-design MyCareBudget. This co-design demonstrated collective care for their unknown and future peers.

Engster (2005, p. 51) added two factors to the theory of care ethics. This research study and its outcome of MyCareBudget adhered to Engster's first factor of supporting the caregivers, not just the cared-for, and also complied with the second factor of creating programmes of care.

In summary, the co-creation and offering of MyCareBudget respond well to the theory of care ethics - meeting the five qualities of care and those from Engster, albeit with a gap in responsibility that has fallen to me to own. With these findings, MyCareBudget was found to be of value to PHB holders, to "care well" in Tronto's terms (Tronto, 2015, p. 5).

7.9. Chapter Summary

The aim of this AR cycle was attained in that the usefulness and sustainability of MyCareBudget have been ascertained. The core objective of determining this through the creation and application of a conceptual framework was also met, using dimensions of usability, usage, sustainability, and caring.

The findings demonstrated that the website was usable and used, although MyCareBudget's role as a digital commons for updating its content rarely took place once operational - this perhaps due to the content being sufficient for end-users' needs. The findings from the interviews revealed that MyCareBudget's end-users, as disabled citizens, unpaid carers, CCG officers, and VCSE staff, found it cared well, as it complied with the care ethics qualities of *attentiveness, responsibility, competence, responsiveness*, and the care ethics activity of *caring with*.

The mixed methods conceptual framework developed for this AR cycle promoted confidence in its findings due to its triangulation of data, though the limitations of the quantitative data meant that this aspect was not able to deliver fully on its expectations.

With this and the preceding three chapters having covered all four AR cycles, the following Discussion chapter compiles the discussion points to respond to the research questions.

Chapter 8. Discussion

8.1. Introduction

With the four AR cycles now described, this chapter progresses to compile findings to respond to the research questions described in Chapter 1, see Figure 33.

An initial section answers the first research sub-question, synthesising the findings from AR cycles 1 and 2 to describe the challenges and benefits associated with managing a PHB, and the experiences and power dynamic between PHB holders and their CCG officers. This section contributes to the corpus of literature within HCI that focuses on the unpaid carer and the infrastructuring demands placed upon them by their healthcare service providers.

The second research sub-question is then replied to by describing how this study shaped the participation of disabled citizens and unpaid carers. This was by reconfiguring and extending HCI's ARC method to enable the co-design of an operable socio-technical intervention. The conflicts encountered when this study worked alongside impassioned, marginalised communities are then described, along with contributions on how such conflicts can be mitigated. Concluding with reflections on how the power dynamic needs to be addressed in engagements between citizen and state.

A third section responds to the third research sub-question, examining the application of a novel mixed-methods conceptual framework for evaluating MyCareBudget as an operational healthcare digital intervention. The framework is offered as a methodological contribution, with sections discussing the success and limiting factors of MyCareBudget.

The following section answers the main research question by first exploring the outcomes when the CoA attempted to work in coproduction with their healthcare authorities and second, the appropriateness and potential adverse consequences of MyCareBudget. Coproduction is first shown to be an unrewarding task when initiated by citizens onto an unwilling state, and second, this research had, and continues to, support the infrastructuring needs of PHB holders through MyCareBudget. Finally, unintended consequences with MyCareBudget are described, along with the dynamic shifting of responsibilities in the co-design process.

Contributions to academia and non-academia, limitations of this study, and recommendations for future research specific to the research questions are called out within the discussion sections, with a set of overarching recommendations ending this chapter.

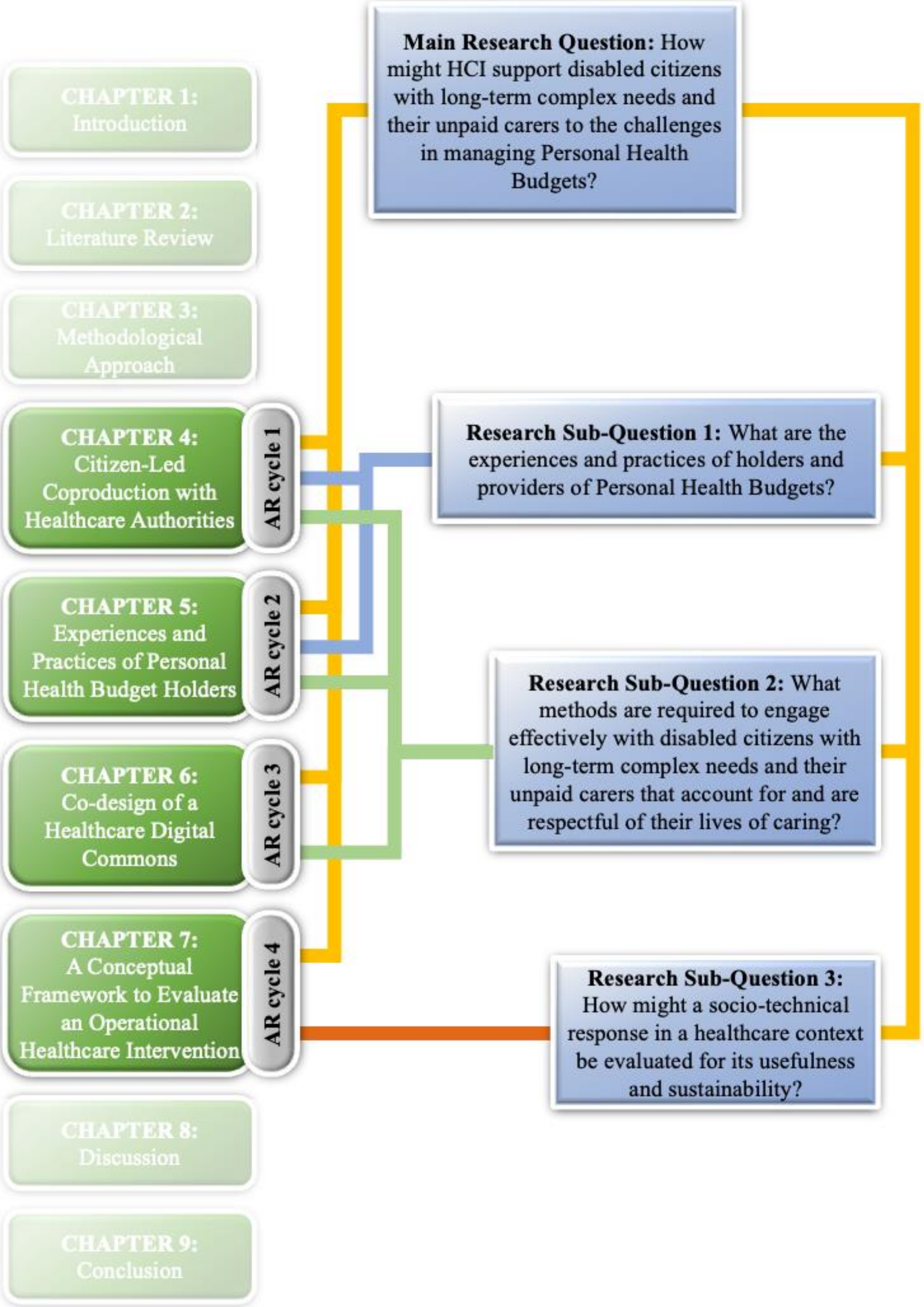

Figure 33: Highlighted mapping of AR cycles, their corresponding chapters and research questions

8.2. Challenges and Opportunities when Infrastructuring for PHBs

This section presents an empirical contribution to HCI and healthcare-related academic fields from researching alongside PHB holders, CCG officers, and a VCSE organisation, as a response to the first research sub-question,

***Research Sub-Question 1**: What are the experiences and practices of holders and providers of Personal Health Budgets?*

Two discussion points are offered below - the experiences associated with managing a PHB and the power dynamic between PHB holders and their healthcare authorities.

8.2.1. Experiences of Managing a PHB

The insights from the engagements in the first two AR cycles underlined the significance and benefits of personalised healthcare that can accommodate for diverse abilities, lifestyles, values, contexts, and needs.

What also became apparent were the capabilities (Sen, 2005) demanded of citizens to make the best use of PHBs to realise their state-promised benefits of choice and control. These capabilities encompassing the skills and resources related to employing teams of paid carers and managing PHB finances. The work and resources demanded to achieve these were found to be non-trivial - creating and managing a micro healthcare system in the home. This was evidenced in that all of this study's citizen participants were articulate and possessed knowledge of care and employment law, supporting authors who have stated that only those with sufficient social capital are likely to gain and sustain a PHB (Beer, Paxman and Morris, 2013; Slasberg *et al.*, 2014; Mladenov, Owens and Cribb, 2015; Owens, Mladenov and Cribb, 2017).

However, the capability deficits (Pedersen, 2016; Calvo *et al.*, 2020) voiced by the majority of the citizen participants meant they felt abandoned when they gained their PHBs, finding that their health authorities relinquished accountabilities and responsibilities onto them without assistance. Such tensions support those discussed by Kaziunas, Klinkman, and Ackerman (2019), where a citizen felt obligated to take on the burdens, duties, and responsibilities demanded for the personal infrastructuring within a neoliberal healthcare regime. This reinforcing a neoliberal privatisation of care and a validation of inequality of access to the benefits of PHBs.

A nuance here is that the infrastructuring referred to in previous HCI studies regarding unpaid carers typically referred to that demanded by citizens to navigate and stitch together a siloed set of healthcare service providers. These organisations are *external* to the citizen and can be viewed as a black box (Gui, Chen and Pine, 2018). This form of infrastructuring was still present and indeed exacerbated when the citizen holds a PHB. However, also present were the *internal* organisational structures required to run a team of paid carers. Here, the PHB holder builds all the organisational aspects and so these were in plain view. Hence, the infrastructuring demands were, to a large extent, within their control, assuming they had the capabilities and resources required, though at the cost of taking on the associated responsibilities.

In summary, although PHBs provided valued benefits to the citizens, the personal infrastructuring demanded led to costs of time and stress arising from the lack of support from their state. This contributing onwards from previous HCI studies (Chen, Ngo and Park, 2013; Bosch and Kanis, 2016; Long *et al.*, 2017; Gui, Chen and Pine, 2018; Tang *et al.*, 2018; Gui and Chen, 2019; Schurgin *et al.*, 2021) and from related academic fields that encompass social policy (Owens, Mladenov and Cribb, 2017) and healthcare (Leonard, 2020; Woodthorpe, 2022).

Additionally, the participants' sense of abandonment was underscored by the power dynamic with their healthcare authorities, discussed in the next section.

8.2.2. Power Dynamic Between PHB Holders and their Authorities

The UK's state legislation and policy dictate that CCG officers are to support and work together with the citizen to realise the benefits of PHBs (Glendinning *et al.*, 2008; Tyson *et al.*, 2009), yet the underlying power dynamic allowed the CCG officers to disregard such directives.

The one-to-one interviews with the CCG officers on the frontline and their managers revealed aspects of the power dynamic at play. The officers believed they were 'doing a good job' - the distance between them and the citizens meaning this was rarely challenged. Other insights showed the officers to be negatively risk averse, likely due to their existence within a medicalised setting (Lewis and Wyatt, 2014).

From a care ethics perspective, the CCG officers are entrusted to *caring with* the citizen - a collective caring formed around justice and equality (Tronto, 1998, 2013, p. 23). In actuality, the officers felt empowered to perform *virtue caring* (Noddings, 2012, p. 53)*,* where the caregiver has little or no interest in reacting to negative feedback from the cared-for, placing responsibility on them to use the care effectively (Owens, Mladenov and Cribb, 2017). This virtue caring perhaps arose from CCG officers envisaging PHBs as being inherently personalised to each citizen and hence needing minimal work to operate. Whereas 'personalised' in this context infers that they have the *ability* to be individualised to a citizen's unique circumstances. The distance between the CCG officers and the PHB holders inhibiting communication that could provide learnings to counter this belief.

The origins and enduring nature of this virtue caring amongst the CCG officers demand future research to understand the positionality of the officers and the underlying causes of the power imbalance. For example, was the virtue caring due to the officers being unwilling to listen to negative feedback or were their budgetary and workload pressures inhibiting their freedom to communicate and *caring with* (Duffy, 2010; Owens, Mladenov and Cribb, 2017; Cottam, 2020)? Such research would aim to nurture coproduction within an understanding of these constraints to the mutual benefit of both citizens and their healthcare authorities.

HCI and related academic fields need to be aware of the systemic challenges experienced in this study. From locating the officers in these black box organisations (Gui, Chen and Pine, 2018) when planning healthcare authority engagements in HCI; to difficulties in gaining access to the officers in healthcare policy research (Jones *et al.*, 2017); dealing with the extended timescales when meeting with the officers; and motivating the officers to join in coproduction (Ostrom, 1996). HCI's use of PD and technology can alleviate some of these issues through methods such as long-term asynchronous engagements and anonymised, online discussion fora.

8.2.3. Section Summary

This discussion section responds to the first research sub-question and so contributes to the work of HCI authors (Chen, Ngo and Park, 2013; Bosch and Kanis, 2016; Long *et al.*, 2017; Gui, Chen and Pine, 2018; Tang *et al.*, 2018; Gui and Chen, 2019; Schurgin *et al.*, 2021) and authors from related academic fields (Jones *et al.*, 2017; Owens, Mladenov and Cribb, 2017; Leonard, 2020; Woodthorpe, 2022) who have examined the lives of unpaid carers and the infrastructuring demanded in their lives of caring. First, by investigating the impact of PHBs on their lives, the additional demands of infrastructuring for PHBs, and the benefits of choice and control. Second, by exploring the power dynamic between the citizen holding a PHB and their healthcare authorities.

The burden of care work, including that demanded for the infrastructuring for PHBs, hinders the participation of disabled citizens and unpaid carers in research, a topic explored in the next section.

8.3. Engaging with Marginalised Populations

A recurring requirement of this study has been the configuration of participation for disabled citizens and unpaid carers that allows for their unremitting lives of caring. As such, this discussion section offers methodological responses to the second research sub-question,

> ***Research Sub-Question 2****: What methods are required to engage effectively with disabled citizens with long-term complex needs and their unpaid carers that account for and are respectful of their lives of caring?*

I offer four aspects for discussion. First, how this study considered the participation of disabled citizens and unpaid carers. Second, how this study has reconfigured and extended the ARC method (MacLeod *et al.*, 2016) to one with the ability to host collaborative processes with the ability to co-design a socio-technical system. Third, the need for HCI to recognise and deal with conflict when working with impassioned, marginalised communities. Fourth, reflections on how this study addressed the power dynamic when engaging with both the citizen and state.

8.3.1. Considerations for Participation with a Marginalised Population

HCI research has foregrounded how PD processes can be predicated and configured with particular populations in mind - typically eloquent, affluent, and from privileged backgrounds (Harrington, Erete and Piper, 2019). Hence, researchers have called for the inclusion of populations from less privileged backgrounds and more specifically, for closer collaborations with disabled populations (Harrington, Erete and Piper, 2019; Spiel *et al.*, 2020). Yet, such authors have noted that when working with these communities, the PD process demands extended time and effort from the researchers to build trust and mitigate for this population's constraints.

Based on these methodological considerations and in line with respectful design (Rajapakse, Brereton and Sitbon, 2021), I configured participation to allow for the lives of disabled citizens and their unpaid carers, with a disability justice approach that delivered access, inclusion, equity, and meaningful participation. This approach leveraged the participants' whole-life expertise to promote their agency (Rankin, Thomas and Joseph, 2020; Erete *et al.*, 2021), whilst attending to their precarious and unpredictable lives of caring and the need for an educational agenda for the co-design of a technology (Bødker and Kyng, 2018; Bannon, Bardzell and Bødker, 2019).

The educational agenda in the context of this study was aimed at providing design and technology skills to the citizen participants - these skills considered as typically owned by professional experts (Bødker and Kyng, 2018). The agenda exposed the citizen participants to unfamiliar designs and technologies, such as online bulletin boards and drag-and-drop activities, and also unfamiliar concepts, for example, the governance required for a digital commons. To achieve this, I configured the participatory process in ways that gradually challenged the participants ‘step-by-step’ over the course of the engagements. This was achieved without ‘formal’ or dedicated training sessions that the participants may have rejected due to the time pressures within their lives. This careful configuration sensitised participants (Visser *et al.*, 2005) to use tools and designs new to them as they gradually gained confidence and proficiency. Thus, besides attending to the “average capability of the group members”, as Bettega, Masu, and Teli (2021, p. 1723) put it, I recommend future work in this space to consider how exposing participants to graduated, appropriate, and planned technical and conceptual challenges can be productive in the course of co-design. This would be of benefit to research and also the citizen, who gains democratic learning and responsible digital citizenship (Bødker and Kyng, 2018; Bettega, Masu and Teli, 2021).

A further topic when engaging with this population was that many of the citizen participants, or their children, were registered as ‘Clinically Extremely Vulnerable’ in England (NHS England, 2021), and hence were at high risk of life-threatening illness due to COVID-19. This risk precluded face-to-face meetings and the sending of cultural probes. With engagement options constrained to remote, I included those with limited digital access by offering one-to-one interviews by telephone and using software for the focus groups that was accessible via low-cost smartphones. HCI researchers wishing to consider similar approaches are to be critically aware of how adopting digital engagement methods can exclude by default. I welcome opportunities for HCI research to broaden the insights generated from this study’s digital-only sessions through face-to-face engagements, to gain the voice of those I could not access online.

Of note is that the co-design and working *with* the participants delivered benefits not just to this research. The citizen participants were vocal in their declarations of pleasure in taking part, finding they had gained social capital, transitioned their implicit knowledge to explicit, and felt part of a community independent from their healthcare authorities. I see the approach of long-term collaboration and an educational agenda as described in new PD (Bødker and Kyng, 2018) to benefit HCI research but also the citizen participants - this to be called out as a benefit of the methodology.

My configuration of participation also played a role as a response to Hill Collins’ emphasis (2000) on engaging with the perspectives of marginalised groups. This was achieved by my attention to the whole life experiences of disabled citizens and unpaid carers. By these means, the citizen participants and I identified gaps in their receipt of care and technology services (Rankin, Thomas and Joseph, 2020; Erete *et al.*, 2021) and co-designed responses (Bettega, Masu and Teli, 2021). Rankin, Thomas, and Joseph (2020) request the HCI researcher to focus critically on intersectionality by reflecting on questions that expose failings in design work. I paid careful attention to these questions, such as who inputs into design and whether they represent the marginalised community being addressed.

A limitation of this research is exposed here in that the citizen participants all possessed a high degree of social capital, for example, being articulate and knowledgeable about care and employment legislation. Future research in this domain is to look to recruit from a broader range of participant demographics, which is assisted by the reduction in COVID-19 infection risk and hence the ability to recruit face-to-face rather than wholly digitally. This broader recruitment could surface citizens not currently accessing PHBs, even though eligible, with HCI leveraging technology to promote accessibility, such as that used for improving access to disability benefit payments in the UK (Watson, Kirkham and Kharrufa, 2020).

In summary, the participants' continued participation in the shaping of this study, their increased social capital, enthusiasm, and rich output generated from the engagements, is clear evidence of the success of the configuration.

8.3.2. Reconfiguring and Extending HCI's ARC Method

As discussed, the time-poor and care-prioritised population of disabled citizens and unpaid carers participating in this study demanded care in configuring group engagements.

The methods I used delivered this care and supported empowering discussion fora leveraging extended duration engagements lasting up to two weeks. These engagements were founded on HCI's ARC method (MacLeod *et al.*, 2016), which avoids short-duration synchronous workshops that impose time constraints that the participants cannot commit to. However, ARC is founded on purely asynchronous sessions and is limited in its ability to engage in group activities and move on from the collection of experiences and theoretical co-design (Harrington and Dillahunt, 2021). This study contributes to HCI and related academic and non-academic fields that research with time-poor populations within healthcare services, with the reconfiguration and extension of ARC by the inclusion of optional synchronous engagements, an educational agenda, the use of novel engagement tools, and the aim of co-creating a functional and sustainable socio-technical intervention. Additionally, I found the synchronous sessions generated far more comments relative to the asynchronous sessions, showing the value of this extension of the ARC method with this feature.

To further mitigate the barriers to participation, I configured the engagements to be entirely typed or mouse-driven, that is, no video meetings. This approach utilised in earlier ARC studies (Prabhakar *et al.*, 2017; Maestre *et al.*, 2018). Most participants received this positively as it removed the social awkwardness that can arise in video calls with new people. Yet, my overriding concerns regarding the participants' time-poor lives meant I missed opportunities for video-based, discursive sessions. These would likely be best located at the end of sets of non-video engagements to act as places of reflection. Future research is to consider an approach of remote, typed, asynchronous / synchronous sessions that are concluded by optional, synchronous video conferencing that elicits discussion and feedback amongst participants.

Further benefits of this text-only format are that of data production and collection. Multiple concurrent conversations are inherently challenging to facilitate and transcribe in face-to-face and videoconferencing focus groups. The use of a bulletin board format, as in this study, provided an ease of managing concurrent conversations that could be downloaded along with metadata such as author, date, and time.

However, an aspect of running 24/7 long-duration focus groups is the constant facilitation required. As the sole researcher in this study, the delivery of this remote process required significant efforts, as I felt responsible to attend as many as I could of the sessions that took place throughout the day, evening, and night. Furthermore, the dialogical nature of the design of the sessions - whereby I would analyse data from ongoing discussions to construct scenarios that would promote supplementary discussions, added additional strain and pressure. Future work in HCI based on this reconfigured and extended ARC method would benefit from considering mitigations to reduce stress on the researcher, for example, by embedding a team of facilitators to share the management of these ongoing, long duration engagements.

A final challenge in the design of the engagements was that I failed to locate open-source design tools that would suitably host the process and align with the needs and constraints of the participants. Therefore, future research could look to develop tools that respond to the needs and requirements of marginalised populations, leveraging open-source software to remove financial barriers and align to a community-driven ethos (Marttila, Botero and Saad-Sulonen, 2014; Teli, Di Fiore and D'Andrea, 2017).

More broadly, I believe future work could validate and transfer this method, configuring it in ways that cater for diverse populations, abilities, and complex lifestyles, to foster meaningful participation. Though noting that tensions and conflicts can arise in such engagements with marginalised populations that the following section addresses.

8.3.3. Conflicts in Participatory Design

The first set of one-to-one interviews in AR cycle 1 illustrated that even with PHBs, disabled citizens and unpaid carers led stressful lives filled with anxiety and high workloads. Thus, for these individuals to assemble in solidarity to work towards social action required a high degree of motivation that I needed to nurture.

Contrary to the normative power dynamic where the researcher owns the engagements (Borning and Muller, 2012), I positioned the CoA to hold control over research actions and decisions that directly affected them, with each member able to veto my research-driven requests as respect for each individual and the collective. This veto was used to block my issuing consent forms for the CCG officers. My stance was to question the reasoning behind this veto, and then not to argue against the CoA but to seek out alternative means of capturing the data, such as in the one-to-one interviews that I later held with CCG officers. Conflicts will occur in such collaborations and I believe it is for the researcher to seek alternative methods that do not contradict the vision of our collaborators. Such conflicts will arise from the new PD element of the researcher having two agendas - that of the research and the "shared vision" with the participants (Bødker and Kyng, 2018, p. 14). These two agendas can operate in harmony to one another's benefit, but also can generate tension as encountered in this study.

HCI has recognised the passion for justice within such communities (Dombrowski, Harmon and Fox, 2016) and has explored ways researchers can navigate community engagements with empathy and care (Wright and McCarthy, 2008). However, HCI also needs to recognise that research is not always the prime motivator for participants. This aligns with Pedersen's call for researchers to be aware that collaborators in research "...often have other and more important concerns than being 'design partners' " (2016, p. 182). As an example, the CoA members were participants in this study, though I found this was secondary to their philanthropic aims of supporting their peers and for justice from their healthcare authorities. The members saw this research as a tool that helped them achieve their objectives, providing resources and legitimacy.

Additionally, HCI has to anticipate that participants can previously have had negative experiences of engaging in research. Findings from AR cycle 1 showed that although participants were eager to take part in research, they demanded indicators of trust and respect. This echoes the work of Harrington, Erete, and Piper (2019), who reported that their participants felt that the academics they had met were self-serving, not vested in the challenges of the communities, and abandoned them once the data collection had been completed. I took care in this study to involve the participants in the ongoing research project through regular communication, additionally providing feedback on the results from design sessions, though balancing this against over-burdening them with emails.

A further point of conflict is that as researchers, we can strive for a professional stance in engagements, but HCI practitioners are to be aware that our collaborators do not have such ‘constraints’ and can act accordingly. The face-to-face meeting between the CoA members and their CCG officers in AR cycle 1 provided the CoA members with an opportunity as a collective to vent their frustration and anger directly at the healthcare officers. Even though the CoA were strong in advance of this meeting that they wanted to work with the officers in coproduction to each other’s benefit. The contribution here for HCI and related academic fields, especially those that involve healthcare services, is that as researchers, we are not to underestimate the depth of frustration that such marginalised groups have endured. HCI’s inclusive design spaces providing participants with opportunities to respond to authorities with a sense of solidarity and empowerment. Whether this hindered the ongoing involvement of the officers in this particular study is unknown, but managing such agonistic design spaces is complex and can take multiple sessions until co-design can commence (Björgvinsson, Ehn and Hillgren, 2012).

On a personal level, I encountered conflict in engaging with participants within five types of relationships. First, between myself and the citizen participants, exemplified in AR cycle 1 when the CoA blocked me from seeking consent from their healthcare officers. Second, between the citizen participants and their healthcare officers, as in the meeting between the CoA and their CCG officers when the citizens felt empowered to vent their frustrations. Third, when I interviewed the CCG officers, as I felt I had to empathise with their stance against supporting unpaid carers to better elicit their views, even though I felt I was a ‘traitor’ to PHB holders by not arguing against the officers’ views. Fourth, between myself and this research, when I took on the hybrid role of facilitator / participant in the group engagements, finding tension in the facilitator role that ‘steps back’ and the participant role of ‘having my say’. Lastly, in the one-to-one interviews I held with disabled citizens, when I heard episodes of disturbing behaviour they had experienced from their paid carers and CCG staff. As HCI researchers, we may not possess the skills to manage problematic encounters or deal with our emotional wellbeing. Hence, I endorse the recommendations from HCI for training the researcher (Waycott *et al.*, 2015) and organisational support structures (Balaam *et al.*, 2019) to support researchers to deal with conflict, tension, and emotional labour when researching in sensitive settings.

In summary, responding to Bødker and Kyng's call to "address changes that matter" with groups immersed in conflict and tensions (2018, p. 15) will result in challenging and unexpected turns in research. Such tensions are not to be engineered out but accepted as part of Haraway's "staying with the troubles" (2016) as researchers traverse the landscapes encountered when working with impassioned communities.

8.3.4. Towards Dialogical Infrastructures

To allow for the voices of the citizen participants, I chose to exclude CCG officers from the co-design sessions, though this was partly mitigated in AR cycles 2 and 4 where I interviewed the officers one-to-one. This section examines the implications of their exclusion from group engagements, considering ways forward.

In the one-to-one interviews in AR cycle 4, several CCG officers recognised that PHB holders needed support and that the officers were not providing this, as they believed they were not best placed to deliver this due to their lack of knowledge on operating a PHB. They went on to assert their belief that citizens would prefer support from institutions other than the state, due to issues of trust. One officer stated that it was the citizen who was responsible for both identifying the need for and then sourcing this support. I can envisage that the officers voicing these beliefs in a group discussion with the PHB holders would have provoked anger from the citizens and triggered heated debates, detracting from the engagements' purpose of co-design. This supports my exclusion of the CCG officers from these engagements, as this decision progressed my objective of co-design, though at the risk of losing additional insights regarding the power dynamic. HCI practitioners are to be aware of a balance that can be required in the design of participatory engagements with marginalised populations and their authorities. The researcher may have to offset valuable potential learnings against driving the research forward.

A further risk with including the CCG officers in the group discussions was harm to the citizen participants. My insights from the first AR cycle, together with my positionality as an unpaid carer, meant I was aware of the anxiety and stress that the presence of authorities can cause, highlighted when citizens recounted that their PHB funding had been withdrawn by their authorities. My exclusion of the officers attended to risks of harm when conducting work with this marginalised population. The researcher plays a crucial role in the planning and performing of PD with marginalised populations, configuring participation to be safe, open, and inclusive (Björgvinsson, Ehn and Hillgren, 2012; Vines *et al.*, 2013; Bødker and Kyng, 2018; Bates *et al.*, 2020).

The insights from AR cycles 1 and 2 highlighted the distance and friction between CCG officers and citizens seeking to access healthcare support. Both parties lacked understanding of each other’s day-to-day practices, identities, constraints, stressors, and responsibilities. Though noting the CoA members voiced awareness of this lack in their planning for coproduction. This is in line with Suchman’s (1995) insights into organisational cultures within a law firm, the distance inhibiting constructive dialogue, mutual understanding, and cooperation. These insights further echo works in HCI that have explored fractured civic relations (Corbett and Le Dantec, 2019; Crivellaro *et al.*, 2019; Clarke *et al.*, 2021) and chime with Harding et al.’s (2015) recommendation that HCI design is not just to focus on the citizen, but is to accommodate both sides into a safe design space that acknowledges the positions of both parties and the existing mistrust. I believe that including healthcare officers in this study’s co-design would have exposed and promoted recognition of PHB holders’ invisible and complex infrastructuring work. This was evidenced in the subsequent one-to-interviews with the officers in AR cycle 4, where they expressed surprise at the wide range of care artefacts on MyCareBudget that were demanded to manage a PHB.

A response to this challenge is to engage with both parties but to hold design sessions separately, alternating to and fro, the researcher acting as a communication conduit between the two - a method taken by Le Dantec and DiSalvo (2013, p. 249). I did not adopt this here as I had found the extended timeframes in engaging with groups of CCG officers inhibited the use of this approach, instead falling back in AR cycles 2 and 4 to holding one-to-one, unconnected interviews with individuals from the two parties.

Yet, a benefit from their exclusion was that the citizens participants became empowered as they collectively acted to conceive and co-create a response to their voiced issues with infrastructuring their PHBs. This undertaken without their authorities, thereby promoting the citizen’s autonomy and reducing their dependency on their state.

Hence, the need is to establish how HCI and related academic studies can craft design spaces that foster long-term, constructive, and positive relations, noting how the creation of such spaces can expose unequal power dynamics, fear, and deep mistrust - presenting significant risks and challenges to this configuration (Bratteteig and Wagner, 2012; Corbett and Le Dantec, 2021). HCI’s future research endeavours could support the exposure of such complex dynamics through, for example, anonymous data collection and representation initiatives for the safe collection of citizens’ experiences. This can be conceived of as creating design spaces that build on agonism (Björgvinsson, Ehn and Hillgren, 2010, 2012), where citizens’ voices can be safely exposed to recover democratic processes in partnership with their healthcare officers.

8.3.5. Section Summary

This section responded to the second research sub-question, exploring how HCI and related fields of academic research can engage with disabled citizens and unpaid carers. Learnings were driven by insights into the lives of caring of disabled citizens and unpaid carers, conflicts in research, and the power dynamic between this marginalised population and their healthcare authorities.

A reconfigured and extended ARC method was offered as a methodological contribution that was capable of a group co-design of a functional and sustainable digital commons. This capability delivered through the addition of optional synchronous meetings, novel engagement tools, an educational agenda, and long-term engagements.

Of note is that this configuration of participation was undertaken without the CCG officers, which resulted in an ease of design and minimised risk of harm, though at the costs of potential losses of data and learnings for all the participants.

The following section responds to the third research sub-question, which is concerned with the evaluation of the digital commons co-created within this study for value to its targeted population of PHB holders.

8.4. Evaluating an Operational Healthcare Digital Intervention

A research outcome of this study has been MyCareBudget, a digital commons for PHB holders. This section discusses a methodological academic and non-academic contribution as a response to research sub-question 3,

> ***Research Sub-Question 3****: How might a socio-technical response in a healthcare context be evaluated for its usefulness and sustainability?*

I offer four discussion points. First, a reflection on the mixed-methods conceptual framework created within AR cycle 4. Second, a discussion on the success factors of the co-design of MyCareBudget, followed by a third section on its limitations. Finally, a review as to whether a digital commons was an appropriate socio-technical response to the issues experienced by the citizen participants.

8.4.1. Reflecting on the Conceptual Framework for Evaluation

The lack of an HCI methodology to evaluate an operational healthcare digital intervention was identified in the fourth AR cycle. This was required to determine the usefulness and sustainability of MyCareBudget. A conceptual framework was created that was subsequently applied to MyCareBudget, based on four dimensions of usability, usage, sustainability, and caring.

Determine Usability: The method offered by Brooke (1996), for a System Usability Scale (SUS) was a straightforward approach in practice to establishing usability. The SUS results gave a clear view of website usability, based on responses from a survey that did not demand significant time and effort to design, perform, and analyse.

Also, as any website that is difficult to use will cloud the remaining assessments, I see it essential to perform this dimension as the first step, as recommended by HCI authors (McNamara and Kirakowski, 2006).

Determine Usage: The sourcing of quantitative data for this dimension was a simple technical exercise that was gathered from the outset of MyCareBudget's operation. This early consideration was a key element of designing for this dimension of evaluation.

However, this quantitative data had limitations. It was not possible to gain knowledge of why end-users were accessing MyCareBudget, and the data on the number of downloads did not indicate how the downloads were being used.

As a standalone dimension, usage did not offer a clear response to whether MyCareBudget was of value. Yet, this dimension was of use for triangulation to the other dimensions (Greene, Caracelli and Graham, 1989; Palinkas, Mendon and Hamilton, 2019) when based on the assumption that a resource that is accessed and returned to many times is likely to be of merit.

Determine Sustainability: Data collection for this dimension was a straightforward task founded on the creation of maintenance logs from the outset of MyCareBudget, for example, storing invoices and recording time spent on maintenance. The continued availability, low maintenance effort, and low costs demonstrated that MyCareBudget had been sustainable and was anticipated to remain so for the foreseeable future. However, the skilled technical resource required to maintain software versions of open-source is a risk to sustainability, discussed below in section 8.4.3.

Determine Caring: The method of one-to-one interviews was time-consuming, as was the data analysis, however, I felt that the richness of insights was worthy of the time invested.

Leveraging the theory of care ethics was also of benefit with its attention to the activities and relationships of caregiving and care receiving. This qualitative assessment demonstrated that the end-users found value in MyCareBudget, arising from its co-design with PHB holders and its content being sourced from PHB holders.

In summary, the conceptual framework for evaluating MyCareBudget found this online resource offered usefulness and sustainability to PHB holders and others beyond the targeted audience, further providing a rich set of qualitative data. Even with the limitations of the quantitative data, I recommend this mixed methods approach as a contribution to HCI and related academic fields for the assessment of an operational healthcare digital commons and indeed, other types of healthcare-related software interventions. However, as with any novel conceptual framework, this demands iterations in similar contexts for its assessment and refining before its effectiveness and transferability can be validated.

Having reflected on the conceptual framework, the following sections are in place to offer success factors and then limitations of MyCareBudget.

8.4.2. Success Factors for MyCareBudget

The use of MyCareBudget generated positive comments from the one-to-one interviews, voiced by its primary target of PHB holders but also by CCG officers and VCSE staff. I see four key factors that promoted the success of MyCareBudget that align with the four dimensions above of *usability*, *usage*, *sustainability* and *caring*.

Usability was in part provided by leveraging long-established open-source software, MediaWiki. Its use in Wikipedia and across thousands of other wikis and millions of end-users meant the software was generally free from bugs and user interface quirks, further providing a familiarity of user interface. How this software was configured added to this success, in that the structure of MyCareBudget was co-designed with the participants who demanded emphasis on people new to care budgets. This resulted in a categorisation of documents that made sense to newcomers as well as sections more suited to experienced PHB holders.

The *usage* of the content of MyCareBudget derived from it being sourced from PHB holders, because all the content was in active use by their peers and so would be of use to at least a subset of the target population. Yet, the care artefacts still demanded work from a PHB holder to evaluate which care artefacts were relevant to their context and then perform individualisation. I see this provides a saving in effort in comparison to a 'blank sheet of paper' when creating a set of care artefacts for a new PHB holder, at which time even an awareness of the care artefacts required is unknown. Skills and knowledge are required for this task though, which a PHB holder new to care budgets is unlikely to possess.

The call from several citizen participants was for a mentor with lived experience of PHBs to offer one-to-one advice to a new PHB holder - their skills and knowledge deemed to be of high value. The issue is the likely high demand for such a service and the limited resources of PHB holders as a community to provide this. HCI could see this as a potential for Artificial Intelligence (AI) - distinct from the normative service provider-to-citizen model in healthcare (Park *et al.*, 2019), towards a citizen-to-citizen model. I acknowledge the potential harms, ethical issues, biases, mistrust, and regulatory challenges (Whittaker *et al.*, 2018, 2019) but see the potential to alleviate and ameliorate the lives of PHB holders.

Sustainability was a focus from the outset of design. For example, selecting open-source software (Poderi, 2019; Bettega, Masu and Teli, 2021) and virtual servers (O'Hara, Perry and Lewis, 2003). These allowed MyCareBudget to be low-cost and low-effort in operation. In addition, the participation of a VCSE organisation as co-designers led to their commitment to funding and administering MyCareBudget.

This handing over of maintenance responsibilities to a third party was multi-faceted, further surfacing the infrastructuring tasks required to sustain MyCareBudget as an operational technology. This sustainability work spanned administration tasks such as the payment and auditing of invoices related to the virtual servers, email, and domain name, and the regular reviewing of the content within MyCareBudget for applicability with changes to law and policy. Technical tasks included logging and securing access for the virtual servers, email, domain name, and social media accounts; regular monitoring for website performance and security; and the regular updating of software versions. The VCSE staff did not accept these technology tasks due to the high-level of technical skills demanded, though a long-term resolution was agreed for their handing over to the third-party organisation who maintained the VCSE's website.

Lastly, for sustainability and within the configuration of participation, I was conscious of the time-poor nature of the co-designers' lives when I made decisions regarding what could be asked of them to operate MyCareBudget. Hence, I avoided the placement of onerous, long-term tasks on the citizen participants.

Caring was a central theme of this study and the care ethics quality of competence was a success factor for MyCareBudget. Competence is associated with trust (McKnight *et al.*, 2011; Corbett and Le Dantec, 2018b, 2021), a key factor to the first and continuing use of

MyCareBudget. The precarious lives of PHB holders forcing them to be risk averse when accepting information as it could have severe impacts if found to be misleading or false.

I see five aspects of trust that led to the success of MyCareBudget.

First, gaining trust before a website's content is even read can occur by online reputation-building through the use of a trusted brand or a trusted recommendation (Manzini, 2015, p. 175). However, an NHS logo or that of a CCG was rejected by the majority of participants, even by several CCG officers who stated that state authorities have their own agendas that may not align with those of the PHB holders. MyCareBudget is hence offered without branding, reliant on trusted promotion from me, this study's participants, and other VCSE organisations.

Second, once the website has been viewed, Manzini (2015, p. 174) saw trust being generated when system elements were made visible such as the transparency of the organisation behind the website. MyCareBudget achieved this by declaring its co-design with the peers of budget holders as the first message on its home page.

Third, Pink, Lanzeni, and Horst (2018, p. 3) explained trust as a "feeling" in an uncertain world, where trust is gained when the content just "feel[s] right". This was echoed by several of the citizen participants who believed this derived from MyCareBudget being co-designed with their peers.

Fourth, the care artefacts hosted by MyCareBudget aligned with a discussion of trust by Lui, Zhang, and Kim (2023). The authors saw trust being gained when online content was relevant to the consumer's needs and activities, its fitness for use, and where the purveyors of the information were themselves seen as credible. The source of the care artefacts being PHB holders drove the attainment of these drivers of trust.

Fifth, trust was gained due to the layout of MyCareBudget, as its co-designers selected a form of presentation style they preferred, which inferred their peers would too. This style being in a state between 'professional', with its negative notions of commercialisation and power, and 'amateur', which conveyed a lack of knowledge.

I believe the primary reason for the success of MyCareBudget arose from the co-design between citizens holding a PHB budget and academia. This is distinct from the prevalent style of coproduction discussed in literature founded on the interplay between citizens and their service providers.

Of note here is that a subset of the benefits from coproducing with service providers remains. Needham (2008) described the benefits of citizen agency and empowerment; MyCareBudget provides this through the co-designers taking control of their collective knowledge and its dissemination through the formation of a community. Ostrom (1996) also saw a subsequent gain in social capital for the citizen that the co-designers were also vocal in proclaiming. A contribution here is that the benefits of coproduction can be reproduced even when the service providers do not take part.

With the above success factors in place, the following section lays out the limitations of MyCareBudget.

8.4.3. Limitations in Operation for MyCareBudget

Two limitations surround MyCareBudget regarding its operation - challenges in its promotion and the technical skills demanded for its maintenance.

The effort required on my part to continually call out for care artefacts, and indeed, the effort to promote MyCareBudget, far exceeded my planned time. I was new to this activity and even with the experience and skills I have since gained, I could not have dedicated the time and effort required to drive further adoption. This forms a contribution for HCI when delivering an intervention into a community - that the expertise and time to promote that intervention can be onerous and ongoing. This is a similar finding to that from Mamykina et al. (2021), who saw that continual work was demanded to maintain active use of their technology.

The use of open-source software delivered benefits, such as free to use, a breadth and depth of functionality, support for a wide variety of devices and operating systems, and alignment with a community-driven ethos (Marttila, Botero and Saad-Sulonen, 2014; Teli, Di Fiore and D’Andrea, 2017). However, the work to maintain the software to supported versions demanded a high-level of technology skills, albeit these are common across open-source software and not specific to MyCareBudget. Hence, I support the call from HCI to develop open-source software that is more widely accessible to those with low IT skills (Manuel and Crivellaro, 2020), not just in its usage, but also in its maintenance.

8.4.4. Questioning MyCareBudget as an Appropriate Socio-technical Response

An aspect that the conceptual framework was not designed to consider is whether a digital commons was an appropriate socio-technical response to the needs expressed by the citizen participants.

The citizens were clear in their overarching requirements from AR cycles 2 and 3: for an online resource where their care artefacts could be offered to their peers, with the ability for the artefacts to be downloaded, edited, and commented upon. A digital commons aligned to these needs as a common pool resource, promoting social collaboration, governance, and sustainability through commoning (Ostrom, 1990; Linebaugh, 2008; Marttila, Botero and Saad-Sulonen, 2014; Baibarac and Petrescu, 2019; Harrington, Erete and Piper, 2019; Sciannamblo *et al.*, 2021). MyCareBudget has been evaluated to find it provided for these attributes, though the question remains of whether an alternative approach could have been taken.

A path typically taken in HCI is to develop a bespoke website or smartphone application. The application or website can then be customised with the functionality and user interface that meet specific needs. However, this requires a set of development skills that hinders sustainability once in operation, as skilled development resource is needed to perform maintenance and future development (Silberman, 2015). Additionally, creating standard functionality in bespoke software demands a great deal of resources to develop basic services, for example, user identification, security, and adaption to a wide range of devices and operating systems (Lambton-Howard *et al.*, 2020). These factors detract from the use of bespoke development in a resource-constrained PhD project.

I see that commoning techniques could still be used to co-design bespoke software, although the nature of a digital commons lends itself to democratic governance (Marttila, Botero and Saad-Sulonen, 2014; Armouch *et al.*, 2022). A digital commons is inherently flexible and adaptable within a community and typically uses open-source software that is free to use, provides standard functionality, and being based within a community, offers a collaborative model aligned to the democratic and sustainability factors of new PD (Bødker and Kyng, 2018; Poderi, 2019; Bettega, Masu and Teli, 2021).

Hence, I believe a digital commons was the appropriate response to the needs of the citizens in this context.

Yet, regardless of the use of MyCareBudget by thousands of people, there has been little in the way of unsolicited feedback by way of emails, edits, comments, new care artefacts, or changes to existing care artefacts. Hence, MyCareBudget is being used as a read-only, transactional resource. The insights provided one reason, in that several PHB holders saw MyCareBudget as a reference resource that may never be called upon, delivering comfort in it being available at any time. Another possibility was that the care artefacts within MyCareBudget were sufficient for the end-users' needs, so no feedback was required. The contribution here for HCI is that a digital commons can provide value even when used as a read-only resource. Indeed, once a digital common-pool resource such as MyCareBudget has been populated to a usable level, it requires no further additions to remain of use, only maintenance of its content to ensure compliance to its changing environment such as legislation and policies.

8.4.5. Section Summary

This discussion section responded to the third research sub-question by examining the creation and application of a novel conceptual framework for evaluating a healthcare digital commons. The conceptual framework was found to be of use as a mixed-methods evaluation technique, supported through leveraging the theory of care ethics - together finding MyCareBudget to be useful and sustainable. The section closed with discussions on success factors, limiting factors, and the appropriateness of a digital commons in this context.

The following section completes the discussion on the research questions, examining how this study has fared in supporting PHB holders with their personal healthcare infrastructuring.

8.5. Supporting Personal Healthcare Infrastructuring for PHBs

This fourth section discusses empirical contributions to HCI and related academic fields, together with non-academic fields, derived from attempting to work in coproduction with citizens and their local healthcare authorities, then, contributions from examining MyCareBudget as an artefact that delivered insights and dealt with trade-offs (Wobbrock and Kientz, 2016). As such, this section responds to the main research question,

> ***Main Research Question****: How might HCI support disabled citizens with long-term complex needs and their unpaid carers to the challenges in managing Personal Health Budgets?*

Three aspects for discussion follow. First, a discussion on the CoA members' attempts to engage in coproduction with healthcare authorities. Followed by two sections that outline the success of MyCareBudget, the potentially adverse outcomes of MyCareBudget in terms of exposing invisible work, and responsibilities in co-design and delivering sustainability.

8.5.1. Failing in Coproduction but Not in Community Building

The CoA members believed they failed in their quest to work in coproduction with their CCG officers - this to address the social injustice they experienced in the operation of PHBs. All were disappointed that their efforts and high expectations had not materialised in any apparent positive systemic change, as they believed their lived experience to be a rich asset for their CCGs.

The members knew in advance that engaging in coproduction with their CCG officers would not be an easy path, as witnessed by one member's proposed strategy for the CoA of *"We coproduce by stealth"*. Expectations were high as the issues were readily apparent to the CoA and then communicated to the healthcare officers, some of whom were executive staff with the power to initiate organisational change.

The coproduction never materialised in any systemic, tangible form that the CoA members were aware of. Meetings with differing groups of CCG officers were held, but no subsequent meetings ever took place or emails from the CoA responded to by the officers that attended. A possible reason is that the CoA members failed to motivate the officers to make change, this was seen by Ostrom (1996) as key where coproduction has not yet taken place and distrust exists on both sides. Another possibility was that the officers were dominated by high workloads and budget constraints, forcing them to 'fire-fight' the issues that demanded urgent attention (Duffy, 2010; Owens, Mladenov and Cribb, 2017; Cottam, 2020). The officers perhaps viewing the CoA members as successfully dealing with issues related to their PHBs and so were low priority to receive support.

It is challenging to envisage how the CoA members can succeed in coproduction with the ongoing lack of engagement from their CCGs. Individuals from the group continue to raise formal complaints about poor service, advocate for others, and offer to speak with their CCG officers where they can. Further, the intensity of care still dominates their lives, negating options that demand extended time from the members.

Yet, an aspect of coproduction with those authorities that present as a 'black box' (Gui, Chen and Pine, 2018), is that there may be invisibility of any change that has taken place. Following the CoA's first meeting with CCG officers, one officer made positive changes to her relationships with the PHB holders she worked with. However, this was only apparent to the CoA as two members dealt directly with her regarding their PHBs. The possibility exists that the CoA has seeded change in their CCGs that is yet to become visible.

However, the CoA is a success as a community. The group continues to this day, caring-for one another through peer support, sharing knowledge, and providing emotional care. Further offering social opportunities for the members to meet with each other, important to them in their isolated lives, where they can engage with their peers who understand their lives of caring.

8.5.2. The Success of MyCareBudget

With coproduction perceived to have failed in this study's aim to deliver positive, social change, the ensuing two AR cycles conceived of and co-designed a digital commons, MyCareBudget.

MyCareBudget has been assessed to show it supports PHB holders in their specific infrastructuring needs related to care artefacts, demonstrating this work is both critical and valuable to this marginalised population.

However, there are risks of unintended consequences arising from the introduction of a socio-technical intervention. The following two sections discuss these, first in terms of exposing invisible work, then more broadly with respect to dealing with responsibilities in co-design.

8.5.3. Surfacing Invisible Infrastructuring Work

This study exposed gaps in the failings of healthcare systems that within neoliberalism, placed responsibility for caring onto the citizen but without understanding or support from the state. Thus, while this study transformed an individual's responsibility for creating care artefacts into a collective affair and worked to distribute opportunities to access this service, making this work visible became political, and a source of anxiety for the participants.

As an example, a fear expressed by several citizen participants surrounded the exposure of their invisible infrastructuring work in MyCareBudget. That this would result in their CCG officers taking ownership of their care artefacts, imposing formalised documentation processes onto the citizens.

From the perspective of CCG officers, they are based in a large organisation and work alongside other public authorities and staff from commercial companies that operate care homes and care agencies. These are all formal organisations likely to have the resources and the need to document for regulatory, audit, and process purposes. However, as expressed by one citizen participant, a home is not a small version of a large organisation. The risk being that the CCG officers fail to see this nuance and move to enforce a one-size-fits-all set of documentation against the will of the PHB holder. This echoes Suchman's (1995) insights on how exposure of invisible work can lead to increasing workers' vulnerability, with their working practices at risk of becoming rationalised, standardised, and enforced.

The co-designers chose to continue with MyCareBudget, deliberating that the benefits would outweigh the above risks. Future mitigations for the exposure of such invisible work would need to be sourced within safe design spaces populated by both citizens and their authorities

(Star and Strauss, 1999; Sciannamblo *et al.*, 2021). The design spaces allowing the two parties to work together to debate on the ownership and control of care artefacts, the differing scenarios for when each is required, and creating support for their content.

8.5.4. Responsibilities in Research

Additional to the exposure of the invisible infrastructuring work in the previous section, responsibilities for MyCareBudget - its co-design, deployment, promotion, and sustainability - were distributed between me as a researcher, the co-designers, and the unknown future end-users of MyCareBudget.

Responsibility emerged in the co-design as interdependencies within a collective, dynamically shifting between researcher, participants, and future end-users, rather than something assigned to people, or something that someone owns, which is then shared. An example of this was exposed when the participants discussed the moderation of MyCareBudget and keeping its content updated, but responsibilities were not assigned or claimed, these defaulting to me. This view on responsibility contributes on from Jansen et al.'s (2020) healthcare study, which described responsibilities in healthcare as a handing over from one person to another, and Karasti and Baker's work (2008), which described how participants take collective responsibility when their decisions impact on their communities.

Further elements of co-design responsibilities remained with me as the researcher, as I was experienced as a commercial software designer and had access to a research corpus that could shed light on potential pitfalls. Previous studies had asked HCI practitioners to consider the complex roles and relationships of the unpaid carer when designing socio-technical interventions (Schurgin *et al.*, 2021), to pose questions about the nature and outcomes of the engagement, who benefits, and the politics of engagement (Gui and Chen, 2019). Also, for research to avoid the risks of techno-solutionism by engaging with the complexities of social and political contexts of healthcare systems (Kaziunas, Klinkman and Ackerman, 2019). I responded to such calls from HCI authors by working *with* the citizen participants. This co-design achieved more than safeguarding against technologies' potential negative impact, it fostered democratic learning and nurtured responsible digital citizenship (Bødker and Kyng, 2018; Bettega, Masu and Teli, 2021). I endorse HCI literature that asks researchers to take responsibility for the consideration of societal concerns of HCI's innovations, of particular relevance to injustices that centre on racism, sexism, and ableism (Dombrowski, Harmon and Fox, 2016). These injustices demand the inclusion in future research of the populations that the design is meant to benefit, to leverage their situated knowledge to identify, mitigate and, where appropriate, take responsibility.

Yet, this study's Literature Review asked for caution when co-designing a socio-technical intervention external to the state - a potential harm is that such interventions can act as a safety net to the shortcomings of neoliberalism (Spade, 2020, p. 142). While I am confident that MyCareBudget has and will make a positive impact to the lives of disabled citizens and their unpaid carers, I am also aware it addressed immediate needs. That is, it continues the placement of duties onto the citizen (Kaziunas, Klinkman and Ackerman, 2019; Karusala *et al.*, 2023) rather than addressing the more profound systemic issues within the broader landscape of state-provided care in the global north. HCI authors have noted how interventions often speak to issues faced by individual citizens (Gui and Chen, 2019), pointing to the challenges of fostering broader systemic change. Exacerbated when priorities in healthcare are driven by promoting organisational budgets, prioritised above public wellbeing and public value (Gui and Chen, 2019).

Clearly, working towards social justice goals for disabled citizens and unpaid carers demands the transformation of the institutions that deliver such services. Acknowledging the complexity of the power dynamic, I believe a starting place for HCI is to help build Communities of Action, as in this study. This is to build on the work of previous authors that examined the role and actions of such collectives within healthcare (Zacklad, 2003), disability justice, and health activism (Parker, 2013; Talhouk *et al.*, 2018; Metatla *et al.*, 2019; Bennett, Rosner and Taylor, 2020; Sum *et al.*, 2022; Sannon *et al.*, 2023). Then look to craft safe design spaces where healthcare providers and disabled citizens together with their unpaid carers can initiate dialogue, and then work together to reshape healthcare services that deliver benefits and minimise barriers of access.

8.5.5. Section Summary

This last discussion section responded to the main research question - exploring the experiences of the CoA when attempting to work in coproduction and the positive and potential adverse outcomes of MyCareBudget.

By responding to this research question, this study showed, first, that coproduction is a complex and demanding task when initiated by citizens onto a seemingly unwilling civic and second, that this research had and continues to support PHB holders in their specific infrastructuring needs through the co-creation of a sustainable digital commons. Though, noting that even when such an intervention is of sustainable value, there can be unintended consequences in its operation.

The preceding sections in this chapter have formed the discussion points of this study arising from the insights from the four AR cycles, with generic recommendations for future research in the following section.

8.6. Chapter Summary and Recommendations for Future Research

This study has provided HCI and its related academic fields, especially those linked to healthcare services, an understanding of the lives of disabled citizens and their unpaid carers as they undertook infrastructuring to support their PHBs. Further, how these fields and non-academic fields can engage with these citizens as participants, and how building a healthcare socio-technical intervention can respond to the challenges the citizens face. Specific limitations and recommendations for future research have been embedded in the above text of this chapter, with this section calling out two general recommendations.

First, a broader range of recruitment would provide benefits, as the citizen participants in this study demonstrated a commonality of adversarial relationship with their healthcare authorities. Hence, I speculate that only those citizens with such relationships were motivated to respond to recruitment. However, PHBs are a public service for the use to all those eligible, so I believe this is not a limitation of this research. Regardless, future studies are to assess the impact of self-selection on the findings from this study, though acknowledging the potential cost when recruiting from non-associative, seldom heard populations (Thompson and Phillips, 2007).

Second, this study was located in the UK, with its free access to healthcare, but I see transferability based on the global healthcare infrastructuring work of HCI authors (Chen, Ngo and Park, 2013). For example, Gui and Chen (2019) described a similar neoliberal offloading of labour onto citizens in the US, even with that country's markedly different healthcare system to that of the UK's (Gadsby, 2013). This was in part evidenced in this study by a fifth of MyCareBudget's end-user access being from outside of the UK, see Table 9. Future studies within HCI can evidence this transferability by comparing the findings of this study against corresponding populations in countries other than the UK, which have differing healthcare systems but operate within a personalised care paradigm.

The following final chapter concludes by summarising the work within this study, the findings that arose and their responses to the research questions, contributions, future research, and discussions.

Chapter 9. Conclusion

9.1. Summary of Work

At the heart of this study have been disabled citizens in England with long-term complex needs and their unpaid carers, as they respond to the challenges of healthcare infrastructuring demanded by a personalised care paradigm. The aim of this research was to deliver positive, meaningful, and sustainable support to this marginalised population that enhanced their access to the benefits of PHBs.

The Literature Review began by introducing caring as an activity within the context of long-term complex needs, unpaid care work, and the impacts of this work on the unpaid carer. The Review moved onto the concepts of infrastructure and infrastructuring within HCI, and how the unpaid carer has been tasked with infrastructuring in a neoliberal society such as the UK. The chapter ended by introducing disability justice and calls for independent living - responded to by the UK state through a personalised care paradigm and PHBs.

As described in the Methodological Approach chapter, this research is embedded within AR and new PD, with the first of four AR cycles forming a CoA in the North East of England. The CoA was comprised of unpaid carers that held PHBs on behalf of their disabled children, with an objective of the CoA to work in coproduction with their local CCG officers to alleviate the social injustices that surround the personal infrastructuring of PHBs. The CoA was a success in its role as a community of peers but failed to engage in coproduction with CCGs, even after meeting with officers at both frontline and executive levels.

This perceived failure in coproduction motivated the second AR cycle, aimed at examining the experiences and practices of unpaid carers, disabled citizens, VCSE organisations, and CCG officers from across England in regard to PHBs. The unpaid carers and disabled citizens were vocal in their demand for choice and control in their lives of caring but found challenges in the unbalanced power dynamic when dealing with their CCG officers. The citizen participants described the challenges of the infrastructuring demanded for their PHBs and how they wanted to work together with this research to support their peers, deciding to offer their care artefacts free of charge through a digital commons.

The third AR cycle continued on from this decision, co-designing a sustainable and publicly available digital commons of care artefacts sourced from PHB holders. The co-designers were the disabled citizens, unpaid carers, and a VCSE organisation from the second AR cycle, purposefully excluding CCG officers from group engagements to preclude tensions arising from the power dynamic. The design process generated insights into how a commons was to gain trust through its co-design with PHB holders and responsibilities in design, ending with reflections from the citizen participants on the empowerment and sense of community they had gained through taking part in this research.

These first three AR cycles further explored how to perform group engagements with such a time-pressured and care-prioritised population of disabled citizens and unpaid carers. A suitable approach was designed that was founded in HCI's ARC method of remote, asynchronous engagements. This method was reconfigured and extended into one suitable for the co-design of a digital commons by including optional synchronous sessions, novel engagement tools, a long-term engagement, and an educational agenda.

With the digital commons operational, the fourth AR cycle developed a conceptual framework for its evaluation. Employing mixed methods, MyCareBudget was found to have delivered usefulness, evidenced by the number of worldwide end-users, triangulated with a qualitative assessment from the co-designers and end-users of MyCareBudget that included CCG officers. The participants believed this value came from the co-design with PHB holders, moving on to examine ownership of PHB infrastructuring and the conflicts between citizen and their CCG officers. Potential unintended consequences were explored, revealing concerns with the exposure of the PHB holders' invisible infrastructuring work through MyCareBudget and how responsibilities were presented as a dynamic within a collective.

A Discussion chapter followed, composing the findings from the four AR cycles to respond to the main research question and three research sub-questions as described in Chapter 1, see Figure 33.

This chapter concludes this study by synthesising the responses to the research questions, contributions, and future research, ending with a final reflection.

9.2. Responding to the Research Questions

Four research questions directed this study, their intent to provide an understanding of the lives of this marginalised population, the impacts of PHBs on them, and HCI might support them in gaining benefits from PHBs.

9.2.1. Responding to Research Sub-Question 1

The analysis from AR cycles 1 and 2 emphasised the importance and implications of personalised healthcare that allowed for the diverse needs, values, and lifestyles of disabled citizens. However, utilising PHBs required a disabled citizen or their unpaid carer to gain skills and knowledge in managing their paid carers, understanding care and employment law, and “*fighting*” against decisions from their CCGs. Many participants expressed feelings of abandonment arising from the time, effort, and emotional labour incurred when their CCGs transferred infrastructuring responsibilities onto them, highlighting a societal shift toward the neoliberal privatisation of care (Kaziunas, Klinkman and Ackerman, 2019).

A further contribution here leads on from HCI’s work on the infrastructuring required by the unpaid carer to navigate their black box of external healthcare service providers (Gui, Chen and Pine, 2018). PHB holders additionally create and manage their *internal* organisational structures and so these are in plain view, but still demand capabilities, resources, and work.

From the perspective of the CCG officers, the majority believed that these responsibilities of managing a PHB belonged to the PHB holder. The distance between the officers and the PHB holders drove the officers’ belief that they were doing a good job and further concealed the citizen’s invisible infrastructuring work.

From the perspective of the PHB holder, the CCG officers demonstrated *virtue caring* (Noddings, 2012, p. 53), providing PHBs as ‘gifts’ of care (Duffy, 1996) that were to be gratefully received without complaint. This perhaps arose as officers saw PHBs as ‘ready to use’, whereas a PHB’s personalised aspect describes that it has the ability, and so demands work, to be individualised to a citizen’s unique context.

In summary, the above findings respond to this research question by providing an understanding of the experiences and practices of those that hold and provide PHBs in England.

9.2.2. Responding to Research Sub-Question 2

The second research sub-question leveraged findings from the first research sub-question to understand how best to engage with this study’s marginalised population.

Analysis from AR cycle 1 demonstrated that citizen participants led precarious, time-poor, and unpredictable lives of caring. Gaining access to them as a collective for effective group engagements demanded careful and respectful configuration that this research sub-question was in place to answer.

My positionality and principles, as laid out in section 3.2.1, directed me to a disability justice approach, ensuring access, inclusion, equity, respect, and meaningful participation (Karasti and Baker, 2008; Sanders and Stappers, 2008; Björgvinsson, Ehn and Hillgren, 2010, 2012; Harrington, Erete and Piper, 2019). Additionally, as most of the participants had never designed technology or engaged in remote focus groups, an educational agenda (Bødker and

Kyng, 2018; Bannon, Bardzell and Bødker, 2019) was required that would gradually introduce them to unfamiliar concepts and technologies. Special consideration was given to individuals considered Clinically Extremely Vulnerable (NHS England, 2021) due to their risk from COVID-19 infection, so face-to-face meetings had to be avoided. Hence, the configuration moved to remote participation strategies but also with allowance for those with limited digital access through telephones for interviews and zero cost smartphone software for focus groups.

This led to the adaptation of the Asynchronous Remote Communities (ARC) method (MacLeod *et al.*, 2016), reconfigured and extended to better fit the needs and constraints of this research and its participants. This achieved by adding optional synchronous engagements, an educational agenda, longitudinal engagement planning, and novel engagement tools.

Additional benefits of this reconfigured and extended method were that of the synchronous sessions generating many more comments relative to the asynchronous sessions and that the bulletin board text-only format allowed for the facilitation of concurrent conversations and an ease of download.

This configuration of participation was welcomed by the citizen participants, who took pleasure in taking part, gained social capital, and felt part of a movement independent from their healthcare authorities.

However, tensions and conflict occurred between the CoA assembled in AR cycle 1 and their CCG officers. The CoA as a marginalised group felt disempowered by their state, with a constant threat that their care funding could be cut at any time. Their desire for justice transformed into anger in front of their CCG officers as they became empowered as a movement. HCI has recognised this passion (Dombrowski, Harmon and Fox, 2016) and as researchers, we are to consider the impact of how our empowering design spaces can surface anger from the citizen to their state officials. Further, this creation of agonistic design spaces is problematic and can take time and iterations until progress can be made (Björgvinsson, Ehn and Hillgren, 2012).

I feel justified in my decision to exclude CCG officers from the co-design sessions, partly to avoid a distraction to the design process but mainly to safeguard citizen participants from jeopardising their funding. Further, this led to the empowerment of the citizens as they worked independently from their healthcare officers, though this led to a potential loss of opportunities for learnings on both sides.

The above findings respond to the second research sub-question by providing a reconfigured and extended ARC method that was effective in engaging with disabled citizens with long-term complex needs and their unpaid carers in a way that accounted for, and respected, their lives of caring.

9.2.3. Responding to Research Sub-Question 3

The third research sub-question looked to evaluate the digital commons co-created in AR cycle 3 with a mixed methods conceptual framework developed in AR cycle 4, consisting of four dimensions: *usability*, *usage*, *sustainability*, and *caring*.

Determining these four dimensions varied in terms of the effort involved and the validity of the results. Understanding the *usability* of MyCareBudget was found to be a straightforward process that gave a clear result based on a survey that did not demand significant time or effort to design, perform, and analyse. *Usage* was again straightforward based on collecting quantitative data, although issues were found in trusting this data, though it offered value in triangulating with other data from this framework. *Sustainability* was a low-effort reflective exercise, whereas *caring* was high-effort in both collection and analysis, though the data provided a rich set of findings.

This framework was found to be of use as a mixed-methods evaluation, finding MyCareBudget to be a useful and sustainable resource to its intended audience of PHB holders and beyond.

9.2.4. Responding to the Main Research Question

The main research question reflected the aim of the project - to support disabled citizens and their unpaid carers in the management of their PHBs.

The attempt to work in coproduction with the CoA and their healthcare authorities in the North East of England appeared to fail, despite clear communication of issues to executive CCG officers. The CoA members did not appear to motivate the officers, though this could have been tempered by the officers' high workloads and budget constraints. However, despite the coproduction challenges, the CoA has succeeded as a supportive peer community that is still active.

A subsequent endeavour from this research of a digital commons to support the citizens was found to have offered usefulness and sustainability to PHB holders. MyCareBudget is still operational as of the time of writing, gaining new end-users every day, with a novel evaluation framework finding it to be both useful and sustainable. The usefulness arose from the platform being co-designed between the citizen participants and academia, showcasing the benefits of such collaborations, extending to citizen empowerment and gains in social capital. MyCareBudget's sustainability was acquired through this being a fundamental requirement from the start of co-design, with MyCareBudget's funding and administration now owned by the VCSE organisation that took part as co-designers. Yet, the risk of co-designing such an intervention without the state service providers is an implicit support of neoliberalism, as MyCareBudget failed to address the broader systemic issue of the state placing infrastructuring responsibilities onto the citizen without support (Tang *et al.*, 2018; Gui and Chen, 2019; Chatzidakis *et al.*, 2020; Karusala *et al.*, 2023).

In summary, this study has responded to the main research question, providing meaningful and sustainable support to disabled citizens and unpaid carers that hold PHBs.

9.3. Summary of Contributions to Research

The first contribution summarised here is empirical. HCI has previously explored the lives of the unpaid carer as they work to perform the infrastructuring demanded to pull together a siloed set of healthcare systems (Gui, Chen and Pine, 2018; Rajapakse, Brereton and Sitbon, 2018; Chen *et al.*, 2019; Gui and Chen, 2019). This study extended this work by focusing on PHBs - designed for those citizens that demand intense and enduring care as one component of the UK's personalised care paradigm. PHBs were found to provide valued benefits of choice and control to the citizen but at the cost of adding to their infrastructuring resulting in additional work, time, and stress. Moreover, a power imbalance was exposed between the PHB holders and their healthcare authorities, adding to the citizens' stress and allowing the authorities to deliver care as *virtue caring*, where they had no apparent interest in listening to or responding to the issues of the citizen. Lastly, this study included the voices of the disabled citizen that act as their own unpaid carer in terms of managing their PHBs, this not seen in earlier work by HCI on healthcare infrastructuring. Of note is that this empirical contribution extends beyond the field of HCI and into related fields linked to policymaking and healthcare services, and then further still into non-academic areas associated with healthcare.

Second, a methodology leveraged for this research was that of new PD (Bødker and Kyng, 2018), which advocated for the meaningful participation of citizens in research. The use of this methodology here delivered four empirical contributions. First is the need for a graduated educational agenda that introduced and skilled the citizen participants in both technologies and concepts new to them. Second, the recognition and therefore the need to plan for conflicts in research when we work with and strive to empower marginalised communities. The vision of the researcher and that of the community can at times be at odds with one another - HCI's inclusive design spaces providing citizens with a voice to respond to their authorities. Third, that these conflicts and working closely with marginalised communities can impact on the wellbeing of the researcher, demanding training and organisational support structures. Fourth, working with participants can deliver benefits back to them in terms of pleasure, social capital, and feeling part of a community delivering change independent from their authorities.

Third, methodological contributions from two distinct methods. First, a reconfigured and extended ARC method was designed to allow group engagements with participants who cannot commit to workshop start times, where the research goal is the co-creation of a functional socio-technical intervention. This was founded on the ARC method (MacLeod *et al.*, 2016) with a reconfiguration and extension that included optional synchronous engagements, an educational agenda, and novel engagement tools. Second, a mixed-methods conceptual framework for evaluating a healthcare socio-technical intervention. Four dimensions of usability, usage, sustainability, and caring were found to possess varying complexity and confidence. However, their triangulation against one another and the richness of data from the dimension of caring were found to deliver an evaluation framework of benefit. These methods, and therefore the methodological contributions, are applicable not just to the academic disciplines of HCI and beyond but also to non-academic settings involving time-poor populations or that provide care-related health interventions.

Finally, at three points in this study, variations in normative approaches delivered empirical contributions. First, by working outside of the standard process of coproduction where the citizen works with their service provider - instead, working with academia, can continue to deliver the coproduction benefits to the citizen of agency, empowerment, and gains in social capital (Ostrom, 1996; Needham, 2008). Second, that of the ownership of responsibility in delivering interventions, where this shifted dynamically and unconsciously between parties, rather than the more standard view of it being assigned from one to another (Jansen *et al.*, 2020), or shared within a community (Karasti and Baker, 2008). Third, a digital commons need not be a continuing two-way transactional resource - content can be built from the outset without ongoing updates for the resource to remain of use to its community.

9.4. Summary for Future Research

The Discussion chapter offered topics for future research in HCI that are brought together in this section as five key points.

First, challenges and tensions when assembling the citizen and their healthcare authority arose throughout this study. This study did not seek for the two parties to co-deliver in harmony but to gain benefit from working together in an agonistic manner (Björgvinsson, Ehn and Hillgren, 2012). Future research within HCI could look to create Community of Actions (Zacklad, 2003), such as in this study, and then to engage with those officials that hold power to deliver systemic change in the infrastructuring demands of self-directed care budgets, and work together to mitigate risks of unintended consequences. Core challenges called out in this study that demand attention are the extended timescales experienced when engaging with the officers, the need to motivate the officers (Ostrom, 1996), the power dynamic at play, the fear and anger of the citizens, and mistrust on both sides (Ostrom, 1996). The need here is for safe spaces where citizens can voice their needs and issues with service delivery without fear, and indeed the same for the officers. HCI could support this through long-term asynchronous engagement and anonymous data collection to establish a democratic process between citizen and state.

Second, the reconfigured and extended ARC method from this study was found to deliver benefits to the co-design process and to the citizen participants. I see an additional advantage in the inclusion of optional, synchronous video conferencing at the end of asynchronous sessions - this to offer a point of reflection promoted through ease of discussion. An issue that surfaced with this revised ARC method was the time demanded of the researcher - the discursive nature of the sessions and their 24/7 format imposed rapid turnaround of analysis and constant attention. Mitigations could include leveraging a team of facilitators to work in shifts. Finally, future work is to validate this reconfigured and extended ARC method with diverse populations and contexts, and to consider the need for HCI to develop open-source engagement tools that respond to the needs and requirements of marginalised populations and that are widely accessible to those with low IT skills.

Third, the conceptual framework for the evaluation of a healthcare digital commons also demands more trials for its assessment and refining. This is to validate and enhance its effectiveness and transferability, not just delimited to a digital commons, but to a range of healthcare socio-technical interventions.

Fourth, the recruitment and engagements for this study were restricted to digital-only by COVID-19. Subsequent to the pandemic, opportunities exist to recruit and engage face-to-face. This will widen the selection to those with limited digital access, a broader range of intersectionality, and to those with the need for PHBs but who have not yet accessed their benefits. This could extend the potential for such research onwards from examining how to manage the infrastructuring demands of PHBs, to assisting citizens in gaining a PHB. Another cohort for recruitment is those that are satisfied with their PHBs, this is to gain an understanding of their satisfaction that could offer transferability to deliver systemic change.

Finally, the call from participants was for access to a mentor with lived experience of PHBs. HCI could see this as a potential for AI, based on a citizen-to-citizen model, though the risks would demand careful consideration.

9.5. Final Reflections

This study was motivated by a topic of personal concern that came to deliver four core outcomes: contributions to research; the establishment of a local CoA that continues to this day; a group of PHB holders that came together in co-design and gained social capital; and MyCareBudget, a digital commons that has been accessed by over 5,500 people from around the world.

The insights from this study contribute to new PD (Bødker and Kyng, 2018) that advocated for a more activist role for Participatory Design. This is by engaging participants as partners, focused on "the Big Issues" of concern to them (Bødker and Kyng, 2018, p. 2), and for sustained democratic governance of technology through education and meaningful participation. Further contributions are to HCI's knowledge of the lives of disabled citizens and unpaid carers as they manage the infrastructuring demanded to access benefits from their PHBs. Finally, innovative combinations of methods and tools for HCI to collaborate with underserved and marginalised populations, and co-design implications for a sustainable digital commons that provided for democracy in its design and delivery.

This research adds to the body of HCI literature that employs Action Research and Participatory Design to promote social justice for disabled communities, working alongside these citizens in line with the philosophy of "Nothing About Us Without Us".

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Appendix A. Research Engagements

The five tables below list the engagements that took place over the four AR cycles of this research, divided between pre-pandemic and during the pandemic. Note that many participants took part in more than one AR cycle.

Engagements Prior to the COVID-19 Pandemic

AR Cycle 1 Engagements

Engagement	Details
Interviews	Five face-to-face interviews with parents who were unpaid carers of their disabled children
CoA meetings and workshops	Six face-to-face meetings and workshops One remote two-week asynchronous / synchronous focus group with seven unpaid carers of their disabled children
Combined CoA and CCG meetings	One meeting face-to-face with seven unpaid carers of their disabled children and five CCG officers

Table 13: AR cycle 1 engagements prior to the COVID-19 pandemic

Engagements During the COVID-19 Pandemic

All the following engagements were remote.

AR Cycle 1 Engagements

Engagement	Details
CoA meetings	Recurring monthly meetings, still ongoing as of June 2023, with up to seven unpaid carers of their disabled children. Two of the meetings were held with a total of 3 CCG officers
Combined CoA and CCG meeting	One remote meeting with seven unpaid carers of their disabled children, five CCG officers, and one NHSE staff member

Table 14: AR cycle 1 engagements during the COVID-19 pandemic

AR Cycle 2 Engagements

Engagement	Details
Interviews	24 disabled citizens, unpaid carers, VCSE staff, and CCG officers
Focus group	One two-week asynchronous / synchronous focus group with 21 disabled citizens, unpaid carers, and VCSE staff
Survey	10 disabled citizens, unpaid carers, and VCSE staff

Table 15: AR cycle 2 engagements

AR Cycle 3 Engagements

Engagement	Details
Focus groups	Five asynchronous / synchronous focus groups with 20 disabled citizens, unpaid carers, and VCSE staff

Table 16: AR cycle 3 engagements

AR Cycle 4 Engagements

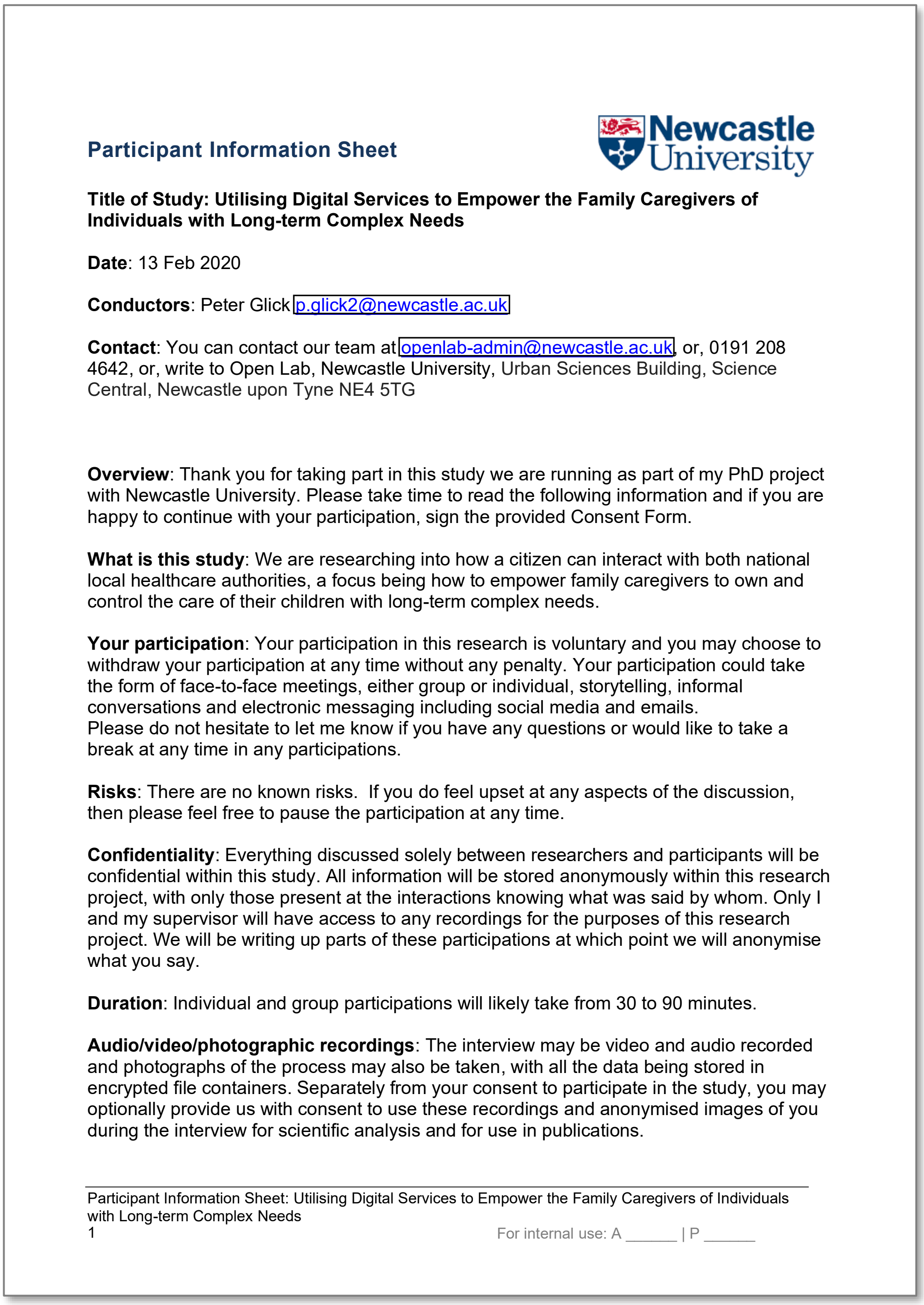
Engagement	Details
Interviews	23 interviews with disabled citizens, unpaid carers, VCSE staff, and CCG officers
Surveys	Two surveys with 27 end-users of MyCareBudget

Table 17; AR cycle 4 engagements

Appendix B. Examples of Consent-related Forms

The following are samples of the ethics forms provided to participants in this study.

Participant Information Sheet



Participant Information Sheet

Newcastle University

Title of Study: Utilising Digital Services to Empower the Family Caregivers of Individuals with Long-term Complex Needs

Date: 13 Feb 2020

Conductors: Peter Glick p.glick2@newcastle.ac.uk

Contact: You can contact our team at openlab-admin@newcastle.ac.uk, or, 0191 208 4642, or, write to Open Lab, Newcastle University, Urban Sciences Building, Science Central, Newcastle upon Tyne NE4 5TG

Overview: Thank you for taking part in this study we are running as part of my PhD project with Newcastle University. Please take time to read the following information and if you are happy to continue with your participation, sign the provided Consent Form.

What is this study: We are researching into how a citizen can interact with both national local healthcare authorities, a focus being how to empower family caregivers to own and control the care of their children with long-term complex needs.

Your participation: Your participation in this research is voluntary and you may choose to withdraw your participation at any time without any penalty. Your participation could take the form of face-to-face meetings, either group or individual, storytelling, informal conversations and electronic messaging including social media and emails.
Please do not hesitate to let me know if you have any questions or would like to take a break at any time in any participations.

Risks: There are no known risks. If you do feel upset at any aspects of the discussion, then please feel free to pause the participation at any time.

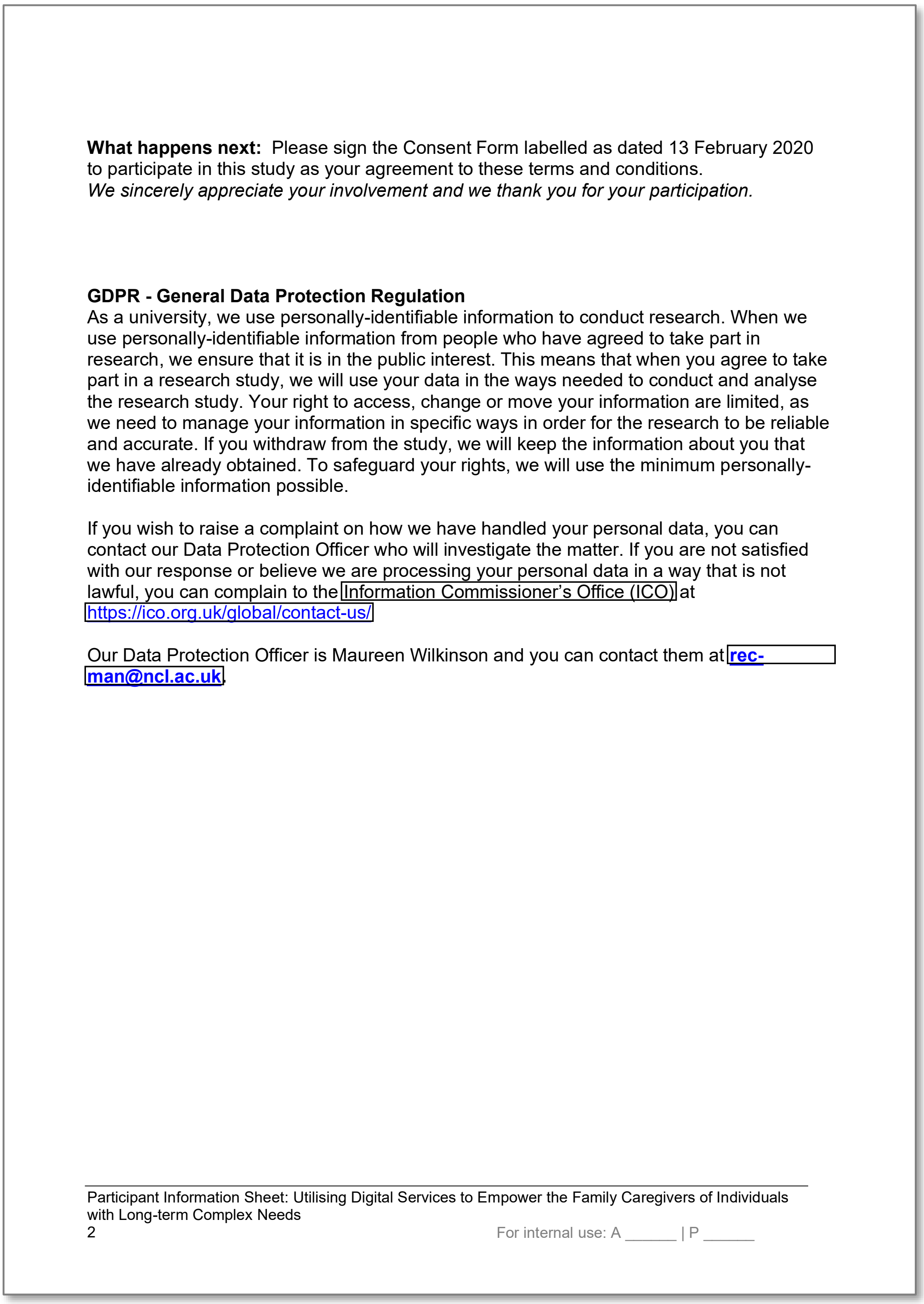
Confidentiality: Everything discussed solely between researchers and participants will be confidential within this study. All information will be stored anonymously within this research project, with only those present at the interactions knowing what was said by whom. Only I and my supervisor will have access to any recordings for the purposes of this research project. We will be writing up parts of these participations at which point we will anonymise what you say.

Duration: Individual and group participations will likely take from 30 to 90 minutes.

Audio/video/photographic recordings: The interview may be video and audio recorded and photographs of the process may also be taken, with all the data being stored in encrypted file containers. Separately from your consent to participate in the study, you may optionally provide us with consent to use these recordings and anonymised images of you during the interview for scientific analysis and for use in publications.

Participant Information Sheet: Utilising Digital Services to Empower the Family Caregivers of Individuals with Long-term Complex Needs
1 For internal use: A ______ | P ______

Figure 34: Example of a Participant Information Sheet used in this study - Page 1 of 2



What happens next: Please sign the Consent Form labelled as dated 13 February 2020 to participate in this study as your agreement to these terms and conditions.
We sincerely appreciate your involvement and we thank you for your participation.

GDPR - General Data Protection Regulation

As a university, we use personally-identifiable information to conduct research. When we use personally-identifiable information from people who have agreed to take part in research, we ensure that it is in the public interest. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Your right to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

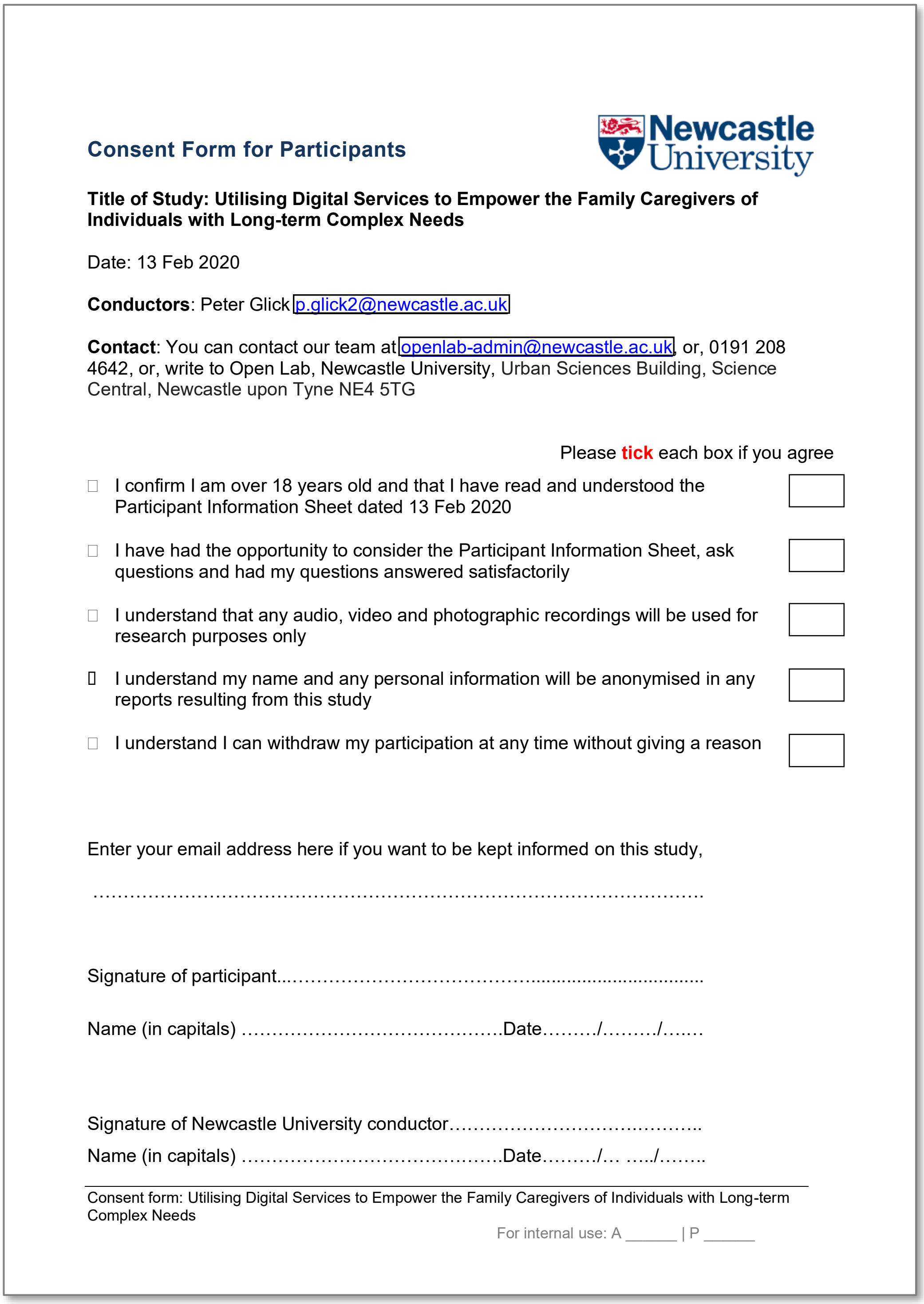
If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful, you can complain to the Information Commissioner's Office (ICO) at https://ico.org.uk/global/contact-us/

Our Data Protection Officer is Maureen Wilkinson and you can contact them at **rec-man@ncl.ac.uk**.

Participant Information Sheet: Utilising Digital Services to Empower the Family Caregivers of Individuals with Long-term Complex Needs
2 For internal use: A ______ | P ______

Figure 35: Example of a Participant Information Sheet used in this study - Page 2 of 2

Consent Form



Newcastle University

Consent Form for Participants

Title of Study: Utilising Digital Services to Empower the Family Caregivers of Individuals with Long-term Complex Needs

Date: 13 Feb 2020

Conductors: Peter Glick p.glick2@newcastle.ac.uk

Contact: You can contact our team at openlab-admin@newcastle.ac.uk, or, 0191 208 4642, or, write to Open Lab, Newcastle University, Urban Sciences Building, Science Central, Newcastle upon Tyne NE4 5TG

Please **tick** each box if you agree

- ☐ I confirm I am over 18 years old and that I have read and understood the Participant Information Sheet dated 13 Feb 2020 ☐
- ☐ I have had the opportunity to consider the Participant Information Sheet, ask questions and had my questions answered satisfactorily ☐
- ☐ I understand that any audio, video and photographic recordings will be used for research purposes only ☐
- ☐ I understand my name and any personal information will be anonymised in any reports resulting from this study ☐
- ☐ I understand I can withdraw my participation at any time without giving a reason ☐

Enter your email address here if you want to be kept informed on this study,

………………………………………………………………………………………

Signature of participant..……………………………………..................................

Name (in capitals) ……………………………………Date………/………/…….

Signature of Newcastle University conductor…………………………….………..

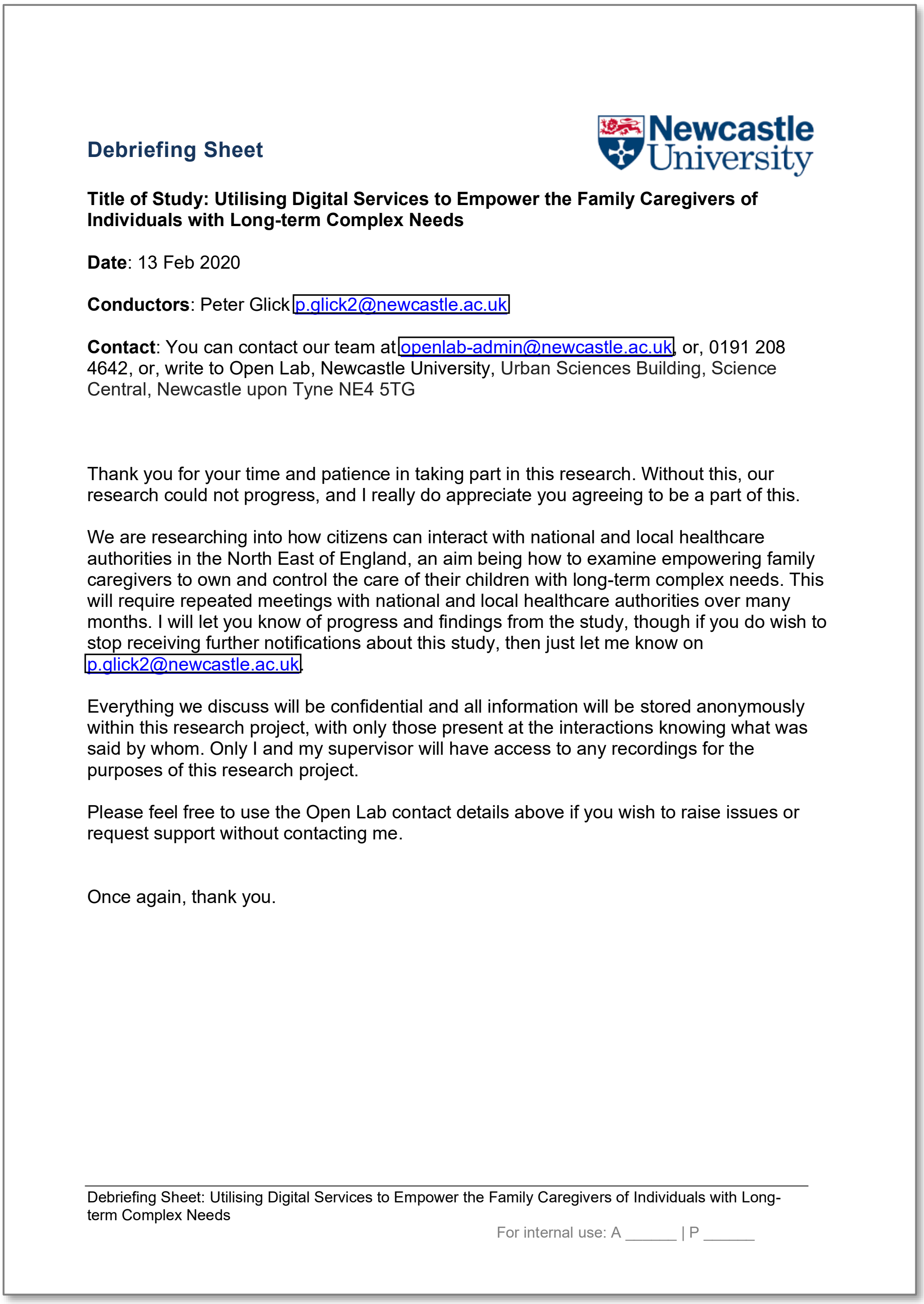
Name (in capitals) ……………………………………Date………/… …../……..

Consent form: Utilising Digital Services to Empower the Family Caregivers of Individuals with Long-term Complex Needs

For internal use: A ______ | P ______

Figure 36: Example of a Consent Form used in this study

Debrief Sheet



Debriefing Sheet

Newcastle University

Title of Study: Utilising Digital Services to Empower the Family Caregivers of Individuals with Long-term Complex Needs

Date: 13 Feb 2020

Conductors: Peter Glick p.glick2@newcastle.ac.uk

Contact: You can contact our team at openlab-admin@newcastle.ac.uk, or, 0191 208 4642, or, write to Open Lab, Newcastle University, Urban Sciences Building, Science Central, Newcastle upon Tyne NE4 5TG

Thank you for your time and patience in taking part in this research. Without this, our research could not progress, and I really do appreciate you agreeing to be a part of this.

We are researching into how citizens can interact with national and local healthcare authorities in the North East of England, an aim being how to examine empowering family caregivers to own and control the care of their children with long-term complex needs. This will require repeated meetings with national and local healthcare authorities over many months. I will let you know of progress and findings from the study, though if you do wish to stop receiving further notifications about this study, then just let me know on p.glick2@newcastle.ac.uk.

Everything we discuss will be confidential and all information will be stored anonymously within this research project, with only those present at the interactions knowing what was said by whom. Only I and my supervisor will have access to any recordings for the purposes of this research project.

Please feel free to use the Open Lab contact details above if you wish to raise issues or request support without contacting me.

Once again, thank you.

Debriefing Sheet: Utilising Digital Services to Empower the Family Caregivers of Individuals with Long-term Complex Needs

For internal use: A ______ | P ______

Figure 37: Example of a Debrief Sheet used in this study

Appendix C. AR Cycle 1 Interview Guide

The text below was used for the AR cycle 1 interview guide.

Initiation

Topic	Detail
Opener	Thank them for joining in this research Tell them I will be recording this - a transcript can be provided Provide my background
My research	It is based on what people say, not testing people to gather test results. It's about what you think and feel Looking into what is out there in existing research and why you are not involved in research

Your family

Tell me about your family	I'm asking as you were very likely living in a world other people will not understand, so it's my job to try and do that What year was your child born? Does your child have a medical diagnosis? Brothers, sisters? What is the level of care needed from the family for your child?
Talk about a standard day - about the time and the stress	Also mental state not just time constraints - emotional distress, diminished quality of life, social restriction, and isolation Your health? How many hours of spare time did you have? How much sleep did you get? When did this start, end, peak, now?

<u>Your thoughts on research</u>

Have you ever been involved in research around your child and your family life?	Have you ever been asked and declined? If you took part, • What format - survey, interview, focus group? • Positive experience? • Do you know what happened in the end? • Would you do it again? • Did you feel valued? • Would you recommend others to take part?
Are you involved in research in any way?	Professionally, voluntary work? Would you ever decline regardless of the research? Would you be happy to be involved given time?
If you were to have been approached, what would have been your response?	
Others they know	Do you know of anyone with a similar role of being a caregiver of someone with highly complex and demanding needs that has been asked to take part in research?
Think back to a time when looking after your child was especially intense	How about if you received an email from a person or organisation asking you to take part from a person or organisation you trusted or had heard of? Would it matter how much time they wanted from you? How about if it was an interview like this, or a focus group (explain) or an online survey? How about if you had to travel to a meeting - locally: What would encourage you take part - money, refreshments, doing your bit?

Thinking about how you can be accessed to take part in research	Would you be ok if you were approached at an out-patient health visit with your child? How about when your child was at school?
Thinking about other ways you could be approached,	For example, Facebook, WhatsApp, other social media; get togethers, friends. How about online such as video conferences?
How should the invite (flyer) be worded?	Official, chatty?
Can you think of any way that research could improve your life or of others similar to you?	
So when you look at families without a child of complex needs, what do they have that you don't?	This is what research may give you
What your thoughts are about research itself?	Would you ever think about starting research yourself? How about the idea of you doing the research - perhaps with someone like me

Summation

That's about it but it would help this whole process if we could look back and understand how you felt about this process	Have we missed anything? How could we make it better? Was it hard or difficult? Was it distressing in any way? Was it different to what you expected?

Appendix D. AR Cycle 2 Interview Guide

The text below was used for the AR cycle 2 interview guide.

Initiation

Topic	**Detail**
Opening conversation to set aims, objectives, expectations, next steps	Thank them for joining in this research Tell them I will be recording this - a transcript can be provided Provide my background Provide overview of this research
Demographic questions	In what region of England do you use your healthcare? How long have you had a PHB? Who is it for (child, other family member, themselves)? Do you receive the PHB funding directly, through healthcare bodies (LAs or CCGs) or through a third-party?

General PHB

What do you like about your PHB?	Control - choice of carers You run or own your own life now? Examples please
What do you dislike about your PHB?	The overheads - ask what they are
If you could change anything about your PHB, what would it be?	
Do you feel you have had to give up anything to have a PHB?	

Do you feel that you have taken on roles and responsibilities that were a surprise to you?	What is the effect on your life of these new roles and responsibilities? Such as learning, time, responsibilities, tasks (hiring, firing)
Do you feel that these new roles and responsibilities should be yours?	If not - who should be taking on these roles and responsibilities?

<u>Gaining a PHB</u>

Can you talk me through the process of gaining and running your PHB?	Did you know what you had to do? Did you know what it would be like to run a PHB? Did you have anywhere to go to, to get advice (friends, authorities, online)? What would have helped you at this stage, for example, hearing from those that are running PHBs?
How do you feel you were treated in the process of gaining a PHB?	Do you think it is fair or unfair, for example were you forced into having PHB, or, did you have to fight to get one? Were you supported in the process? Was it a struggle to get a PHB?
Where did you go to get information or support?	Official websites, charity websites, social media, friends
Hindsight - what would you have done differently?	
What advice would you give to anyone going for a PHB?	

Running a PHB

How do you feel you are treated in the process of running a PHB?	Do you think it is fair or unfair? Are you supported? Do you feel you have control over your PHB?
Can you seek alternatives to the medical solutions with your PHB?	Healthcare is thought of as medication, equipment, physiotherapy What about play, alternative therapies? Are you allowed to use your PHB for anything that you consider helps or do you feel some might be blocked?
What do you need to do to run your PHB?	Managing paid carers, employment paperwork, logging medication, payroll, audit, accountancy, shopping 'One offs': creating policies and procedures 'Ongoing': staff rota, diary, care logs, medicine records, payroll, pensions, staff start/end times, sickness/holiday logs Keeping records - paper and digital: GDPR? Staffing: interviews, disciplinaries, rules and regulations Buying equipment - and maintaining it Audit
How much time do you think you spend doing all this work?	At beginning and now For you to deal with the local healthcare authorities Do you resent this time you spend?
Who is performing all this work to run the PHB?	Your paid carers or the unpaid carers? A third-party? Is the work split between people?
What support do you receive?	Do you pay organisations to run aspects of your PHB such as payroll, receiving the funding? From healthcare authorities, charities?

	What is this support for: running aspects of the PHB? Advice? How about from family or friends?

Technology questions (if time)

Do you use technology to help with running your PHB?	Laptops, tablets, smartphones? Software? Have you built your own technology?
What do you use this technology for? And why?	Monitoring, communicating, diaries, accounting? To give you more of your life back To make caring more efficient / better governed To open up new opportunities for caring – for example sharing PHBs
What tech would you like to have?	Diaries for medication, shift handovers Web cams, spreadsheets for rotas, accounting For you to join up with others in their situation Checking on paid carers - start/finish times, activities while on shift Anything about places where people feel comfortable taking their children, that has facilities Pooling PHBs for days out / specialist wheelchairs / houses / carers / training
What tech do you feel comfortable with?	For example, smartphones, WhatsApp, email
What are your concerns about using technology?	Time to manage it, time to learn it, privacy issues, losing data, cost, fragility, support desks

Summing up

Revisit aims, objectives, expectations, next steps	Next steps are for me to talk to more people like yourself and then I'd like to invite you to a focus group • To meet up with a few other people in your situation so we can talk through common themes - should be in the next few weeks • And where we can look at what we could do to support people with these common themes There is an Amazon voucher for participating in each of these sessions - can I send the first one to your email address we have been using? • Will do this at the end of all these interviews and first focus group Can you pass me onto anyone? Thank you

Appendix E. AR Cycle 4 Interview Guide

The text below was used for the AR cycle 4 interview guide.

Initiation

Topic	Detail
Opening conversation to set aims, objectives, expectations, next steps	Thank them for joining in this research Tell them I will be recording this - a transcript can be provided Provide my background Provide overview of this research
Demographic questions	In what region of England do you use your healthcare? How long have you had a PHB? Who is it for (child, other family member, themselves)? Do you receive the PHB funding directly, through healthcare bodies (LAs or CCGs) or through a third-party?

General questions about the website itself

Website questions	We're not looking for compliments for the website, though any are gratefully received! We need to know what you thought and if that is bad - then that is really, really helpful to us
What triggered first use? And then subsequent uses?	Have you looked at the website? What made you first look at the website? What would make you look at the website? Was it anything to do with who or how you heard about it? Did you return to the website and if so, what made you do this? Is a once only website or would you go back to it and why? What led you to the website? Why did you bother to go there?
Was the technology seen as yet another burden	Do you welcome websites like this, or, is it yet another website you have to visit? Do you find the time for such websites or is just another item on an

	ever growing to-do list? Any thoughts on how we could deliver this information to you in a way that you could accept into your life? What would it take for your CCG to adopt the documents and use them? Would they? Do they see this as their role? Great idea, but no resource to do it? How would they promote it? Did you have any concerns when accessing the website, maybe privacy?
Were there too many downloads - information overload?	There's a lot of documents on the website - was it overwhelming? Did it take a bit of time to work out how to work your way around the website? Do you feel there might be useful things in there you haven't discovered?
Accessibility	Any difficulties in accessing and using the website, for example interface, speed? Any accessibility issues (size of lettering, font, images)?
What made the content trusted (referral source, peer-produced)?	The website says that it's built by people with PHBs - is that a good thing or a bad thing? Good as in peer-produced so they have that lived experience? Bad as in amateur so the information could be wrong? Bad as in not sustainable - could vanish tomorrow? Or break more often? There are all sorts of disclaimers on the website - do you take any real notice of them? Do you ever read this sort of thing? What would make you trust the information more? Did you read the privacy data pages / Terms and Conditions on the website?
Governance needs?	Are you concerned about who runs the website? For example, if you had a complaint would you believe it would be dealt with? Would you think differently if it had an NHS logo, or a well-known

	charity logo? The website says that it's built by people with PHBs - is that a good thing or a bad thing and why?
Was the website used as a search engine, or, was it browsed?	Can you remember how you looked through the website - did you use the search box at all?
Did you browse and find documents that you didn't realise you needed? Did just browsing create knowledge and change behaviour?	Did you look through for a particular document you were interested in, or did you just browse to see what was there? Did you find documents that made you think that you needed them? Have you, or will you be, using more documents because of the website? Is that a good or a bad thing, that is, even more paperwork?
Did you talk about it with other people? Do you know what they did with the website?	Did you talk to anyone about the website? What sort of people - family, friends, healthcare professionals? What did you say about it? Do you know if they looked at it?
What would make you offer any of your documents to be shared?	Would ever add your own documents into the website? What are your reasons for that answer? If you wanted to - would you try doing it yourself or just email them in. What are your reasons for that answer? If you handed over documents, were you worried that they would contain personal data?
What did you feel was missing - documents / functionality?	What was missing in terms of documents? Did you expect the website to do things it didn't offer?
Did you use the links to other sites?	There's a page on there of links to other websites - did you use any of them? Would you ever use this page as a go-to set of links?
What would make you use the discussion forum?	There's a discussion forum on there too - what would make you ever visit it or add to it? Or do you use Facebook and other social media for this sort of connection?

Did it make things worse in anyway?	Did using the website make you feel you were not doing all you should be doing? As in you felt you should be doing more than you are? Is that a bad feeling but good knowledge?

General questions about how you used the contents of the website

Did the website foster any connections, communities? Were they trusted?	Did you meet new people through discussing the website or through Twitter, Facebook and so on?
Did the website change your behaviour (did you see documents that provoked change)?	Have you changed anything with how you run your budget due to the website and its contents - ‘no’ is ok! Do you intend to change, such as using more documents? Or different documents? Was the volume of documents a surprise to you?
Any downsides to this resource?	Do you see any downsides to this website being available? If they need prompting then, • Do you think it allows CCGs to carry on not supporting us, as we are supporting ourselves now? • Perhaps the CCG will take this on, enforce use of documents, standardise documents?? Do you think it gives even more paperwork in your life - sometimes ignorance is bliss
Does the website change attitude towards CCGs?	Who do you think should be supplying all this paperwork? Should the CCGs be offering this? Why don’t the CCGs offer this? Not being angsty, just looking for reasons
Unintended usage and users?	A really general question now - what did you do with the website? I’m asking because I thought people would use it in a certain way - but I might be wrong Has it made you think about how you operate your budget? Has it changed how you feel you have been treated by CCGs / LAs /

	paid care staff / family / friends?
The digital divide	We're speaking now because you were able to access the website Do you know people that could not? Why? Any ideas for how things could change, so they could make use of the resources on the website?

For those that registered/downloaded

Privacy	Did you worry about supplying an email address? If you registered, you had to use an email address - any privacy concerns / did this worry you?
Did you use any of the downloads?	Did you download any documents? Did you do anything with any of the documents? Download and not use (that's fine, I know how busy lives can be running a PHB)? Edit and use them? Use them as is? Pass them onto to anyone - who (don't worry, they are meant to be passed on)? Did you print off any documents - mainly black and white to save money - do you have a colour printer? PDF/Word/Google - what did you use? Issues?

For those that did not download

What stopped you downloading?	What stopped you? Nothing there you didn't already have, nothing matched what you needed, no time Maybe later? Too much there - overload?

For those that took part in the design

Was your voice heard?	Reflect on the co-design process, I am not asking you to remember anything you said a year ago! But looking at the website, does it contain features that you agree with, or maybe even recognise? Or it nothing like you thought it would be?
Ownership?	So if the website (and it does not) had your name as an author on the front page, would you feel comfortable with the ownership aspects of that (forgetting privacy for this)

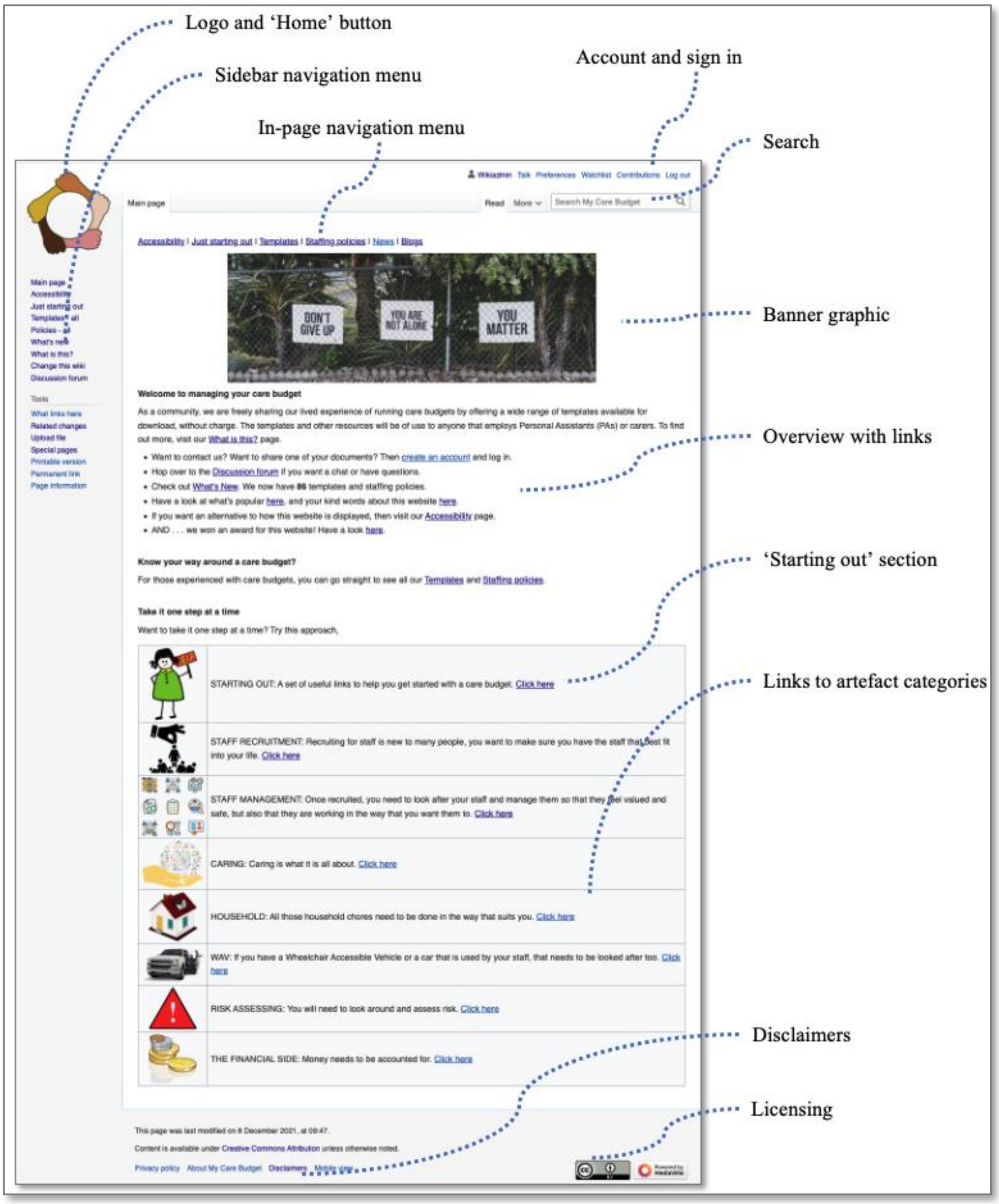
Summing up

Revisit aims, objectives, expectations, next steps	Next steps are for me to talk to more people like yourself so I can understand more about the website's usefulness and how it could be used by a wider range of people I'll keep the website going - it won't stop as the research stops - in fact, a VCSE will take it over There is an Amazon voucher for participating in each of these sessions - can I send this to your email address we have been using? I will keep in touch with how the research is going - just email me back to tell me if you're not interested Thank you

Appendix F. Walkthrough of MyCareBudget

This appendix section provides a guided overview of MyCareBudget as of May 2022. This version of MyCareBudget is similar to that launched in September 2021, with changes limited to an increase in the number of care artefacts, an expanded section of useful links, and additional pages to cover items such as statistics, latest updates, and blogs.

The landing page is shown in Figure 38, annotated to show the main components.



Welcome to managing your care budget

As a community, we are freely sharing our lived experience of running care budgets by offering a wide range of templates available for download, without charge. The templates and other resources will be of use to anyone that employs Personal Assistants (PAs) or carers. To find out more, visit our What is this? page.

- Want to contact us? Want to share one of your documents? Then create an account and log in.
- Hop over to the Discussion forum if you want a chat or have questions.
- Check out What's New. We now have **86** templates and staffing policies.
- Have a look at what's popular here, and your kind words about this website here.
- If you want an alternative to how this website is displayed, then visit our Accessibility page.
- AND . . . we won an award for this website! Have a look here.

Know your way around a care budget?

For those experienced with care budgets, you can go straight to see all our Templates and Staffing policies.

Take it one step at a time

Want to take it one step at a time? Try this approach,

STARTING OUT: A set of useful links to help you get started with a care budget. Click here

STAFF RECRUITMENT: Recruiting for staff is new to many people, you want to make sure you have the staff that best fit into your life. Click here

STAFF MANAGEMENT: Once recruited, you need to look after your staff and manage them so that they feel valued and safe, but also that they are working in the way that you want them to. Click here

CARING: Caring is what it is all about. Click here

HOUSEHOLD: All those household chores need to be done in the way that suits you. Click here

WAV: If you have a Wheelchair Accessible Vehicle or a car that is used by your staff, that needs to be looked after too. Click here

RISK ASSESSING: You will need to look around and assess risk. Click here

THE FINANCIAL SIDE: Money needs to be accounted for. Click here

This page was last modified on 8 December 2021, at 09:47.

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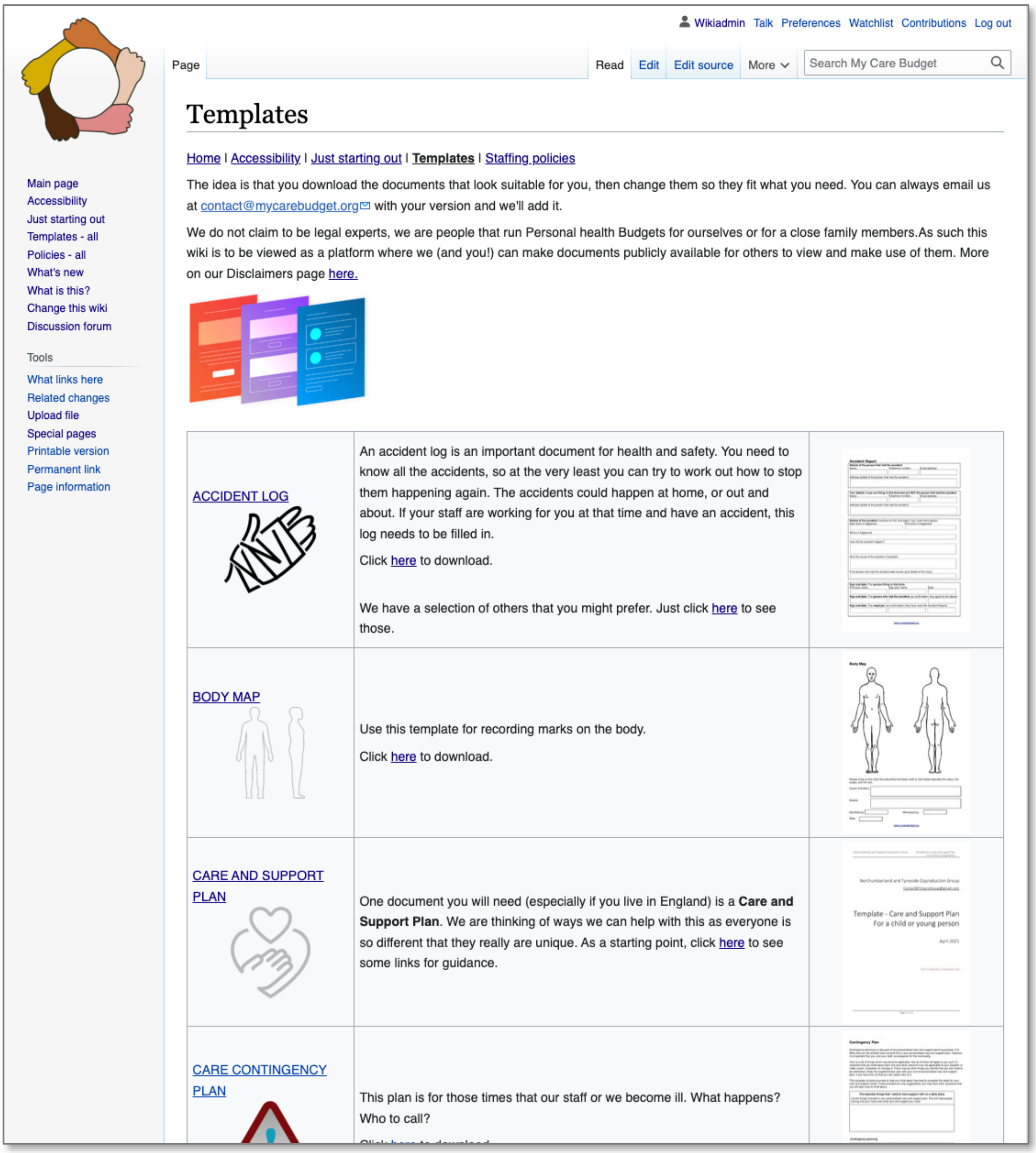
Figure 38: Landing page of MyCareBudget

Categorisation of care artefacts is differentiated between those people new to PHBs and those more experienced. Experienced end-users can navigate to a list of policies or a list of templates (see Figure 39 for an example). Newcomers are guided through a category list (see Figure 40) with the Staff Recruitment category organised as a timeline of recruitment to what artefacts are needed at what point in the process (see Figure 41).



Templates

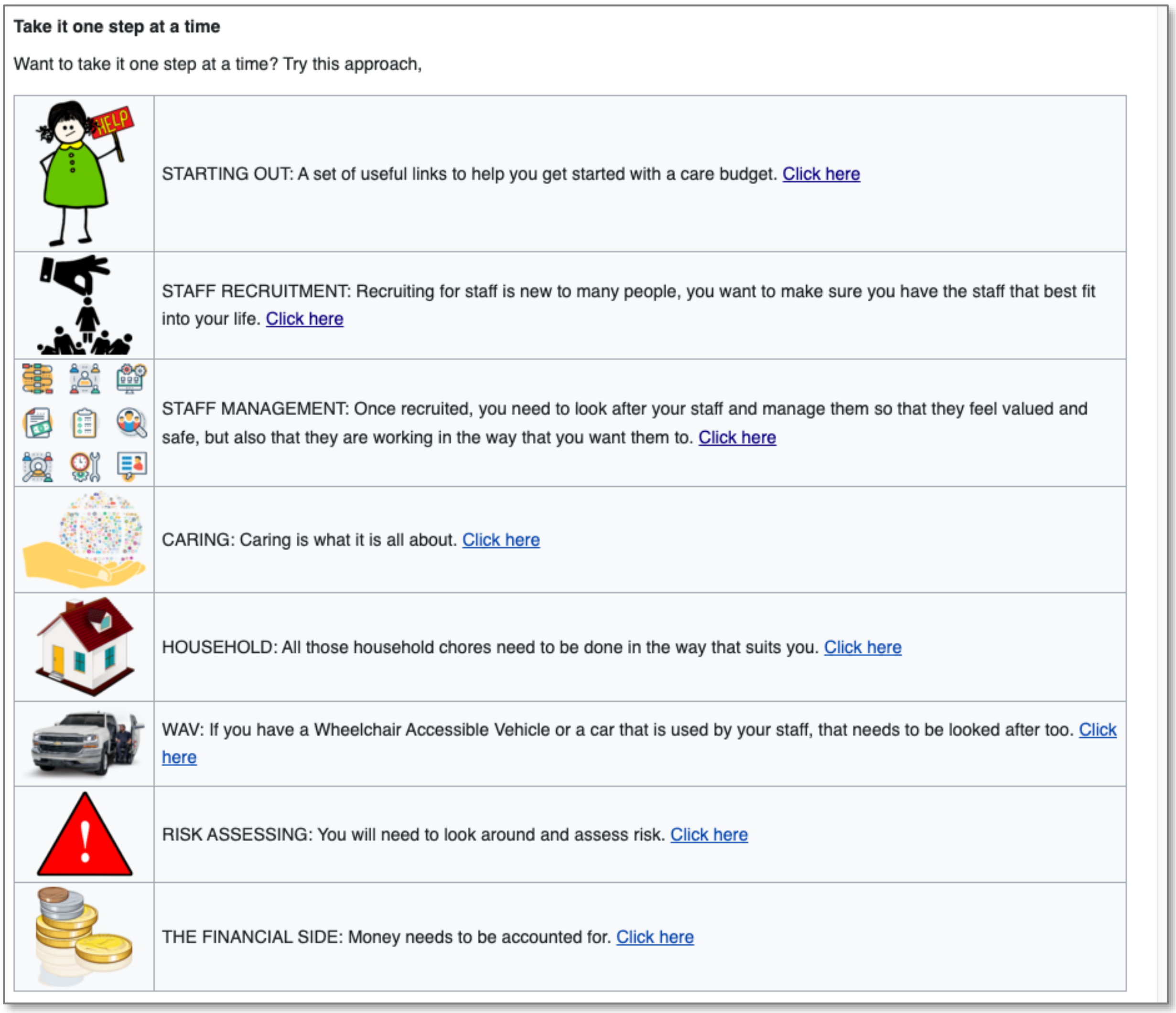
Home | Accessibility | Just starting out | **Templates** | Staffing policies

The idea is that you download the documents that look suitable for you, then change them so they fit what you need. You can always email us at contact@mycarebudget.org with your version and we'll add it.

We do not claim to be legal experts, we are people that run Personal health Budgets for ourselves or for a close family members.As such this wiki is to be viewed as a platform where we (and you!) can make documents publicly available for others to view and make use of them. More on our Disclaimers page here.

ACCIDENT LOG	An accident log is an important document for health and safety. You need to know all the accidents, so at the very least you can try to work out how to stop them happening again. The accidents could happen at home, or out and about. If your staff are working for you at that time and have an accident, this log needs to be filled in. Click here to download. We have a selection of others that you might prefer. Just click here to see those.	
BODY MAP	Use this template for recording marks on the body. Click here to download.	
CARE AND SUPPORT PLAN	One document you will need (especially if you live in England) is a **Care and Support Plan**. We are thinking of ways we can help with this as everyone is so different that they really are unique. As a starting point, click here to see some links for guidance.	
CARE CONTINGENCY PLAN	This plan is for those times that our staff or we become ill. What happens? Who to call?	

Figure 39: List of templates on MyCareBudget for use by experienced PHB holders



Take it one step at a time

Want to take it one step at a time? Try this approach,

STARTING OUT: A set of useful links to help you get started with a care budget. Click here

STAFF RECRUITMENT: Recruiting for staff is new to many people, you want to make sure you have the staff that best fit into your life. Click here

STAFF MANAGEMENT: Once recruited, you need to look after your staff and manage them so that they feel valued and safe, but also that they are working in the way that you want them to. Click here

CARING: Caring is what it is all about. Click here

HOUSEHOLD: All those household chores need to be done in the way that suits you. Click here

WAV: If you have a Wheelchair Accessible Vehicle or a car that is used by your staff, that needs to be looked after too. Click here

RISK ASSESSING: You will need to look around and assess risk. Click here

THE FINANCIAL SIDE: Money needs to be accounted for. Click here

Figure 40: List of categories on MyCareBudget for newcomers to PHBs

STEP 1 - Advertise for someone		
STAFF RECRUITMENT ADVERTISEMENT	This will need to be personalised to meet what you need. Click here to download. We have a selection of others that you might prefer. Just click here to see those.	
STEP 2 - Send them a form to fill in		
STAFF APPLICATION FORM	An application form for someone applying to be a PA. Click here to download.	
STEP 3 - Time to interview them		
STAFF INTERVIEW QUESTIONS	It is useful to have a set of questions ready to interview a potential staff member. This set is just to start you off. Click here to download.	
STEP 4 - Offer them the job		
STAFF JOB OFFER	Found someone you want to employ? This letter will tell them that! Click here to download.	

Figure 41: Staff recruitment on MyCareBudget

Appendix G. List of Care Artefacts

The following list of care artefacts was sourced from MyCareBudget as of June 2023.

Templates

These are accessible on MyCareBudget at https://mycarebudget.org/mediawiki/index.php/Templates). Multiple versions of the same care artefact are not listed.

Accident Log
Body Map
Care and Support Plan
Care Contingency Plan
Care Emergency Sheet
Care Log
Daily Cash Sheet
Driving Capability
Financial Assessment
Incident Log
Key Worker Directive
Learning Log
Medical Administration Record (MAR)
Medical Record
Person Centred Plan
Risk Assessment
Shift Swop
Staff Application
Staff Contact All
Staff Contact Single
Staff Interview Questions
Staff Job Offer
Staff Leave Calculator
Staff Recruitment Advertisement
Staff Rota
Staff Working Hours Opt Out
Therapy Log
Tidiness To Do
Timesheet
Training Log
VAT Exemption
(WAV) Maintenance Log

Policies

These are accessible on MyCareBudget at https://mycarebudget.org/mediawiki/index.php/Staffing_policies. Multiple versions of the same care artefact are not listed.

Accident Report
Appliances
Bruises
Care Checklist
Closed Circuit Television Guide
Closed Circuit Television Policy
Fire
Food
Food Reheating
GDPR
Going To Bed
Health and Safety
Heating
House
Medication
Petty Cash
Positive Communication
Risk Alcohol
Risk Bathing
Risk Vomiting
Risk Wheelchair Accessible Vehicle (WAV)
Rota
Rubbish
Security
Staff Handbook
Staff Holiday
Tidiness
WAV Accident
WAV Loading

Appendix H. Sample of the Requirements Specification Document

The following is a sample from the 181 requirements contained within the Requirements Specification produced within AR cycle 3.

FUNCTIONAL REQUIREMENTS[46]

Care Artefacts

Id	Title	Description	Comments	Priority	Source	Status
CO12	Medical Admin Record	Cannot physically sign if online	Daily and weekly to do lists	Must	AR cycle 1 focus group	Complete
CO13	Medication ordering, stocktake		Daily and weekly to do lists	Must	AR cycle 1 focus group	Complete
CO14	Contact list	For placing on a notice board	Template	Must	AR cycle 2 session 1	Complete
CO15	Troubleshooting	For placing on a notice board	Template	Must	AR cycle 2 session 1	Complete
CO16	National guidance on PHBs	As local diverges from national	Guide	Should	AR cycle 2 session 1	Complete
CO17	Health and Safety		Policy	Must	AR cycle 1 focus group	Complete

Table 18: Sample of functional requirements

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[46] A requirement that specifies what a system is in place to accomplish.

NON- FUNCTIONAL REQUIREMENTS[47]

User Access Control

Id	Title	Description	Comments	Priority	Source	Status
NU11	Security such that end-users have to login	Ability to change password, forgotten password	Can change email without data loss	Must	AR cycle 2 session 5	Complete
NU13	A guest function - no sign in	Documents can be viewed but not accessed		Must	AR cycle 2 session 5	Complete
NU16	Moderators	Notify moderators of all adds or updates		Must	AR cycle 2 session 5	Complete
NU17	Moderation	Automatically block and report offensive language		Should	AR cycle 2 session 5	Complete

Table 19: Sample of non-functional requirements

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[47] A requirement that specifies how a system will operate, such as performance, security, scalability.