



Exploring Experiences of Self-Directed Care Budgets: Design Implications for Socio-Technical Interventions

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ABSTRACT

The role of HCI in informal caregivers' lives has been a focus of research for some time. Yet to gain significance in HCI, are the implications of healthcare systems' transformation into a personalised care paradigm, where citizens gain choice and control over the delivery of their care. We provide a first HCI paper to examine self-directed care budgets for disabled citizens, where care funding is controlled by the individual. We explore how digital technology can assist citizens, promoting peer support to create meaningful, personalised healthcare infrastructures. This qualitative study contributes insights from interviews and focus groups with 24 disabled citizens, informal caregivers and healthcare officers, to provide understanding of their experiences and practices. These insights highlight relational care, invisible labour, power struggles with authorities and how citizens seek socio-technical capability. We contribute design implications for self-directed care budgets and HCI research concerned with developing technologies that support this population.

CCS CONCEPTS

• **Human-centered computing** → **User studies; HCI design and evaluation methods; Empirical studies in HCI;**

KEYWORDS

Caregivers, disability, self-directed care budgets, Personal Health Budgets, healthcare

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1 INTRODUCTION

The role of HCI in informal caregivers' lives has been at the centre of HCI research for some time [9, 29, 36]. HCI researchers have examined the daily practices of informal caregivers [9, 54], their relationships with those they care-for and their health authorities

[55], and the ambivalent role that technology can play in supporting and alleviating the daily burdens of care work [1, 4, 66].

HCI has also begun to explore the challenges caregivers face when dealing with a fractured healthcare system [25, 26, 55], finding the responsibility is placed on the caregiver to assemble disjointed services into a cohesive whole. Yet, little work has looked at the implications of healthcare systems' transformation into a personalised care paradigm in Western Countries, where citizens are provided with more choice and control over how their care is delivered [31]. This shift includes initiatives that see citizens managing and directing their own healthcare budgets [14, 32] and the integration of data-driven services by the state to meet objectives more efficiently [21]. While professed as opportunities to increase citizens' empowerment, autonomy, and choice [46], these changes have already sparked concerns among HCI researchers such as the potential negative consequences of offloading care management responsibilities onto caregivers [30, 58]; and the potential harms ensuing from data-driven healthcare service provision whose algorithmic logic may be opaque and in danger of ignoring or replicating existing uneven distributions of benefits, power dynamics and societal biases [48]. Despite this, personalised care and self-directed care budgets are today increasingly adopted in many countries around the globe [20] and to date there are no studies in HCI that have explored the specific challenges informal caregivers and disabled citizens face when accessing and managing their state healthcare budgets and the role HCI could play in this space.

This paper sets out to fill this gap in HCI research by exploring the experiences and practices of those in receipt of self-directed care budgets and their healthcare providers, developing recommendations for the design of digital technology that can support the recipients in this fundamental aspect in their lives and in their interactions with healthcare systems and service providers. More specifically, this paper reports on a UK study to uncover experiences of self-directed care budgets, through engagements with 20 disabled citizens and informal caregivers in receipt of healthcare budgets, and four healthcare authority professionals. Our inquiry focuses on adults with physical disabilities and families caring for children that have physical and intellectual disabilities, both requiring individualised personal and medical care 24 hours a day, seven days a week. Through one-to-one interviews and a novel approach to conduct asynchronous and synchronous focus groups with 17 informal caregivers and disabled citizens, we developed understanding on the conflicts, processes, and labour at play to realise benefits from state healthcare funding.

Our insights expose the complex power relationships between citizens and their healthcare officers, where citizens often find themselves having to “fight” against a scoring system and assessment



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process to gain their healthcare budgets and then work hard to retain autonomy in decision making on how to spend their funding. Having sole responsibility for management and delivery of all aspects of their self-directed care, budget recipients are forced to build personal healthcare infrastructures, seeking out trustworthy advice from peers and support organisations, with healthcare officers providing little support even when aware of the challenges and burdens their service users face.

In the discussion we provide implications for HCI design and research concerned with developing technologies that support citizens in receipt of self-directed care budgets. This includes platforms to support peer-to-peer sharing of peer produced care-related documents, and that promote trustworthy relationships between budget recipients and healthcare officers. We conclude with methodological recommendations for crafting participatory spaces to engage and design with this hard-to-reach population. As a first paper within HCI that examines self-directed care budgets, we contribute insights into the experiences and challenges of accessing and realising benefits from these services. We provide design implications for HCI interventions that can empower budget recipients realising benefits from self-directed budgets and support the development of constructive relations between budget recipients and healthcare officers.

2 RELATED WORK

With the numbers of informal caregivers and disabled citizens managing their own care increasing in global north countries [23, 55], research in this domain has continued to gain importance. HCI have in recent years developed important insights on how the design of technology might alleviate the burdens of caring responsibilities for informal caregivers, who are often family members delivering 24/7 specialised care without training or support [55, 64].

However, little work in HCI has so far focused on how disabled citizens and their family members access personalised state healthcare funding – also known as self-directed care budgets or personal health budgets – to administer and manage their own caregiving, including the staff needed to care for them. Self-directed care budgets are one aspect of a broader move within healthcare, from a transactional to a relational, personalised care paradigm, where the control of care is shifted from the service provider into a partnership with the healthcare recipient. The aim being to improve experience and outcomes through promoting choice and control [20]. This shift is seen as potentially bringing benefits – including enabling informal carer and disabled citizens to gain more flexibility over the day-to-day care delivered in their homes [20, 32]. At the same time, there are scepticisms and concerns that it may merely produce an offloading of caring responsibility onto individual citizens or family members [35, 40, 56, 65]. Thus, adding complexity to the lives of these populations, that are often regarded as underserved [36, 54, 64] and habitually forgotten [25, 67] by healthcare authorities.

Research in HCI has focused on developing in depth understanding on the variety of tasks and challenges experienced by informal home-based caregivers in their everyday lives as they deliver care to close family members [5, 25, 29, 36, 55]. For example, Chen et al. [9] explored how informal caregivers' lives are stressful - involving

a constant interplay and balancing act between the different roles (as family member, caregiver, worker), the visible and invisible tasks they are required to perform daily in order to attend to the medical, physical, and emotional needs of the cared-for. Building on Chen et al., Schurgin et al. [55] discussed the significant complexities and tensions in handling these different tasks, and the requirements, responsibilities and practices involved in managing and coordinating them; with Bratteteig and Eide [5] identifying that such tasks demanded specific skills and knowledge that were often implicit and situated. This range of work has been key to show the nuances at play in informal caregiving work but also to stress the limitation of techno-solutionism [4], when much of the burden of care cannot be understood as simply connected to the daily tasks but also to the social connection and infrastructures at play.

In this regard, more recently a discrete number of studies have begun exploring the critical role of healthcare infrastructures and authorities in informal caregivers' work [25, 26, 34, 51] as both a site of design inquiry and intervention. For example, researchers [26, 55] showed how informal caregivers' work is dependent upon their ability to firstly assemble a disjointed healthcare infrastructure into a cohesive, operable whole. Considering healthcare systems' organisational cultures characterised by different services operating within silos, researchers exposed how informal caregivers find themselves having to make connections between visible services to realise benefits from their offerings [25, 51, 55]. In this sense, their effort to create productive and meaningful connections between healthcare services and actors, has been understood as a form of 'infrastructuring' [51], which is often performed by informal caregivers in isolation and that remains unacknowledged and invisible, while demanding time and often entailing distress and financial loss. HCI to date has not examined how caregiving is managed from the perspective of the authorities that commission healthcare services. Literature outside of HCI such as Jones et al. [32] found that infrastructuring needs of caregivers are recognised by the healthcare authorities, who believed that professional guidance is key to supporting caregivers, alongside a cultural shift within the healthcare organisations to recognise the patient perspective. Other work [62] reported how central government funding cuts to healthcare in UK meant that healthcare professionals increasingly are experiencing difficulties performing their work to high standard - due to lacks of appropriate training, awareness of the services they can offer, and time needed to develop relationships with service users.

In HCI literature there is a clear recognition that access to healthcare services plays out in inequitable ways, whereby those lacking knowledge, resources and skills needed, struggle to realise benefits from these services [26, 34, 54]. This capability deficit has pushed HCI researchers to develop effective tools that support informal caregivers' coping and interacting with the healthcare system, primarily focusing on digital artefacts that may provide improvements in communication infrastructures [33, 51], such as Ammari and Schoenebeck [1] who explored peer-to-peer communication on social media to mobilise the resources required for care work. While these efforts appeared to respond to concrete needs, Kaziunas et al. [33] highlighted the precarity of interventions that aim to respond to tensions and power dynamics at play in interactions between informal caregivers and healthcare authorities, whose complexity

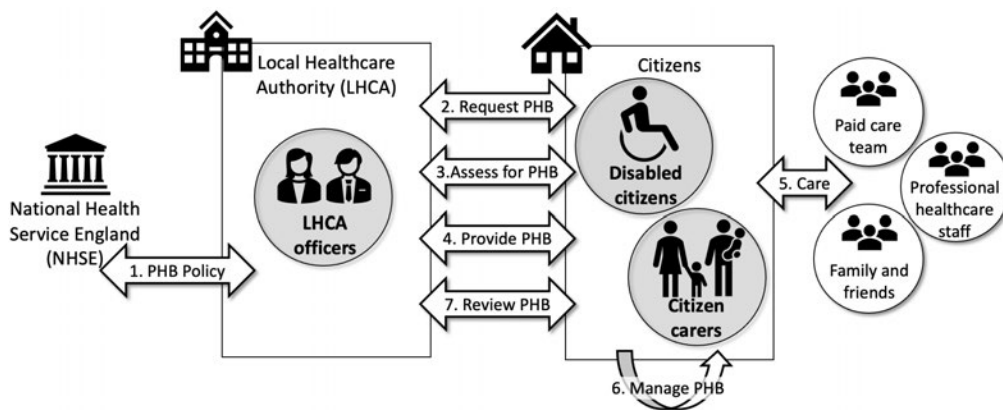


Figure 1: Design to gain and operate a Personal Health Budget in England

cannot be reduced to a novel website or an information sharing app. Adding to this complexity are the implications of uncertain socioeconomic contexts, for example austerity, and the ongoing shift into a personalised care paradigm in the global north. Thus, more research is needed to understand power relations at play between healthcare professionals and service users, and the requirements for appropriate socio-technical infrastructures that support informal caregivers and disabled citizens to successfully access and manage healthcare support and services, within a personalised care paradigm.

With this paper we provide an exploration of the variety of challenges citizens face to successfully access and manage healthcare support and services, specifically in the context of self-directed budgets - a space new to HCI. We contextualise this exploration in the UK, in a case study that explored disabled citizens and caregivers' journeys as they strive to realise benefits from healthcare services, and the interactions between budget recipients and healthcare professionals.

3 CASE STUDY: PERSONAL HEALTH BUDGETS

Self-directed care budgets, also known as Personal Health Budgets (PHBs)¹, have been developed to empower people needing high levels of long-term healthcare support, by granting them control over how they spend their care funding [31]. PHBs have been trialled across countries including United States, UK, Canada, Netherlands, Belgium, Germany, and Australia since the 1990s; with each country using the same guiding principle of empowerment albeit with differing administrative processes [20]. In the UK, PHBs were aimed at populations with complex, long-term conditions; a report published in 2013 [12], stated 150,000 adults over 18 years old had been assessed as needing this form of care in England; a report on children in England from 2016 [49] estimated 118,000 children (between 6 and 16) were also in this care group.

PHBs in England were implemented by the National Health Service (NHS) in the late 2000s. The policy was founded due to

dissatisfaction expressed by disabled citizens on rigid and unreliable care, demands for independent living, and their rights to exercise choice and control [22]. Since then, PHBs have been extensively trialled and today the NHS forecasts that up to 200,000 PHBs will be operational by 2023/2024 [42], seeing PHBs as enabling citizens to “use the money to meet their outcomes in ways and at times that make sense to them” [43]. Yet, while PHBs bestow on citizens a wide range of control of their funds, they also offload responsibility to deliver the care they need onto the recipient when implemented without proper support [32].

Figure 1 illustrates the end-to-end process that a citizen in England undertakes to gain a PHB for their own complex, long-term care needs or for that of a family member, founded on National Health Service England (NHSE) having created funded healthcare policies (arrow 1) for commissioning PHBs by Local Healthcare Authorities (LHCAs)². A citizen can request (arrow 2) a PHB from their LHCA officer, which is assessed (arrow 3) based on a discretionary basis by the LHCA, or through use of a Decision Support Tool (DST) [16] that evaluates citizens' need for continuing healthcare across 12 subcategories within physical, mental, behavioural and health, scoring their need from ‘none’ through to ‘severe’ or ‘priority’. A citizen deemed eligible for a PHB (arrow 4) receives this funding without charge, as part of the UK's NHS principle of health services free at the point of delivery [15]. PHB recipients can choose to receive this funding through a ‘direct payment’, where the money is transferred into their bank account for purchasing equipment, services and employing a care team to work alongside their family, friends, and professional healthcare staff (arrow 5), to deliver unified care. The recipients recruit and manage staff, comply with employment law, purchase equipment and account for finances (arrow 6); the potential for outsourcing some of these responsibilities to a third party being rarely offered by LHCAs. Annual reviews (arrow 7) with LHCA officers are performed to ensure the PHB is delivering to agreed needs.

The complexity of this end-to-end process demands support for both the LHCA officers and the PHB recipients to understand policy, law and operational processes, with the PHB recipient taking on

¹The term Personal Health Budgets (PHBs) is used for the remainder of this paper due to it being used in England where this study is situated.

²The term Local Healthcare Authorities (LHCAs) is used in this paper to describe the various civic authorities that can take part in the PHB process.

Table 1: Gender and age within each cohort

| Cohort | Female | Male | Age 30-39 | Age 40-49 | Age 50-59 | Age 60-69 | Age 70-79 |
|--------------------------|--------|------|-----------|-----------|-----------|-----------|-----------|
| Disabled citizens | 4 | 2 | 5 | 1 | - | - | - |
| Citizen carers | 13 | 1 | 5 | 4 | 3 | 1 | 1 |
| LHCA officers | 4 | - | - | 3 | - | 1 | - |

new roles of employer and care home manager, these roles owned by the LHCA officers prior to the introduction of PHBs.

4 APPROACH

The first author is an informal carer for a child with long term complex needs supported by a PHB, thus providing an initial understanding of the topic, experiences of the intensity of care, and existing connections with LHCA officers and citizens operating PHBs. This would allow a novel perspective, provide an appreciation of these citizens' lives that an outsider would find difficult to attain, and guide the design and recruitment of engagements. The positionality of the first author as a PHB recipient was declared in all recruitment, with care taken for this to be neutrally presented.

4.1 Recruitment

Our inquiry focused on uncovering the process and actors at play in accessing and managing PHBs. Thus, we recruited from three distinct groups to ensure the datasets would be representative of the perspectives and voices of disabled citizens managing their own PHBs, informal carers who provide care for their family members, and LHCA officers who play a key role in the decision making process of allocating and reviewing PHBs,

- **Disabled citizens** from England with life-long conditions but without learning disabilities, for example spinal injuries, or advanced nerve or muscle wasting conditions, that allow them to administer their PHBs, though not perform their own care. These disabled citizens use their PHBs to pay for Personal Assistants (PAs) who carry out personal and medical care, household duties, and provide physical support for the technology required to administer life and work.
- **Citizen carers** from England who care for their children with severe to profound physical and learning disabilities, arising from conditions that include autism, cerebral palsy and genetic disorders. The parents, also known as informal caregivers, unpaid carers, or family caregivers, are supported by paid carers who are funded through the 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 as proxies for them, acting in their best interests, being their voice and signatory in all affairs.
- **LHCA officers** recruited for this study are employed by the state in England to oversee the operation of PHBs within NHSE's personalised care policy. Their roles and responsibilities cover the commissioning of PHBs, directing PHBs, managing PHB payments to citizens, and bringing together

healthcare and social care. LHCA officers in England work in partnership with NHSE, independent from other LHCA officers, with responsibility for hospitals, community and mental health services in their locality.

We use the term citizen-participants to group disabled citizens and citizen carers, who together represent those citizens with PHBs used to employ carers. 'Citizen' is used to place focus on questions of agency and rights to access healthcare, as well as the unpaid care work performed by these populations. In this regard we 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' [45].

For the recruitment we used a variety of online channels and snowballing methods, including the use of personal contacts, Twitter feeds with hashtags relating to personalised care, Facebook pages of healthcare charities, PHB advocates and PHB support organisations in England. In all the recruitment channels the first author stated his lived experience of running a PHB, this aimed to engender empathy through a shared understanding and hence support for the study. The recruitment attracted a total of 20 citizen-participant from across England, with experience of 15 different LHCA officers. Four LHCA officers were recruited from the same channels, noting that two officers were employed in authorities that supplied PHBs to five of the citizen-participants. Table 1 provides information on participant demographics, the majority of participants being female, this conforming to studies that examined gender and care [24]. At the start of the engagements, the citizen-participants possessed an average of 2.9 years PHB experience with a standard deviation of 2.3 years; the four LHCA officers had an average of 4.5 years PHB experience with a standard deviation of 1.3 years.

4.2 Engagements

To understand the practices and institutional relationships surrounding PHBs, we held three sets of qualitative engagements - (i) remote one-to-one semi-structured interviews with 19 citizen-participants; (ii) remote one-to-one semi-structured interviews with four LHCA officers; and (iii) a set of focus groups with 16 of the citizen-participants plus one new recruit. The interviews were inductive to gain an end-to-end understanding of access and management of PHBs; the focus group provided a peer-to-peer discussion on insights and topics arising from interviews. The design of the engagements was driven by the direct experience and knowledge of the first author - who is also PHB recipient - and prior engagements with similar populations who were found to be time poor and unable to commit to attending synchronous sessions due to their unpredictable caring commitments and responsibilities.

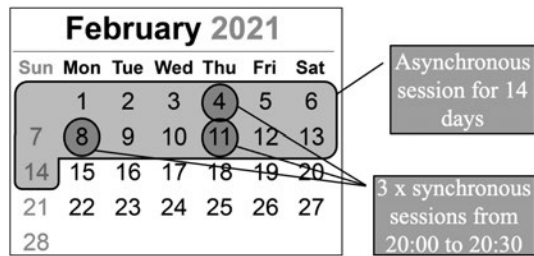


Figure 2: Focus Group synchronous and asynchronous sessions

4.2.1 Interviews with Citizen-Participants and LHCA Officers. The interviews were held remotely, partly due to the COVID-19 pandemic and partly due to the constraints of the citizen-participants' lives. The 19 one-to-one semi-structured interviews with citizens were held from October 2020 to January 2021, 18 interviews were conducted via Zoom videoconferencing and one via telephone. Zoom videoconferencing was chosen as the participants were accustomed to this software due to its widespread use during the pandemic. In interviews, a set of questions was used to guide discussion and exploration of our research questions such as identifying needs for PHBs, experiences of allocating, gaining and managing PHBs, relationships between recipients and LHCAs, and providing or receiving the support and knowledge needed to manage PHBs. The first author's personal experience of running a PHB and prior conversations with other PHB recipients helped formulate open-ended interview questions, for example "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?" We recorded 17 hours of discussion.

Four, one-to-one semi-structured interviews with LHCA officers were held in November 2020 using Microsoft Teams videoconferencing, as this software is used across England's state healthcare. The initial questions used to guide the discussions were similar to that for citizen-participants but from the perspective of the LHCA officers. We recorded three hours of discussion.

4.2.2 Focus Groups with Citizen-Participants. We arranged a set of remote focus groups in February 2021, where three half-hour synchronous focus groups were embedded within a two-week asynchronous session for 17 citizen-participants, see Figure 2.

A market research online tool (Collabito, <https://www.collabito.com/>) was purposed to host a textual discussion, where participants responded to questions and scenarios posed by the first author, participants then commented on each other's responses, indented in bulletin board style. This bulletin board feature being one reason Collabito was selected, along with its simple user interface and ability to be used across laptops, tablets and smartphones.

A first set of three questions was posed at the start of the asynchronous session, four days before the first synchronous session. A participant quote was shown, followed by a brief 'scenario of care' and then the questions, formed from a qualitative analysis of their one-to-one interviews that had shown unexpected responsibilities and a lack of support to manage their PHB. A sample quote being "And you go from nothing and then the next day . . . you've

got all these roles, responsibilities. No one tells you what they are"; the following scenario of care being "Providing access to experienced people that have been through all of this could be useful to people new to the world of care budgets."; and a sample question of "If you were an experienced PHB holder that offered to talk to newcomers, what are the topics you would want to tell them about?" This method was then iterated, with the second set examining their views on handing control of their PHB to technology, asking, for example, "Why would this be a good thing to do?" and "Why would this be a bad thing to do?" The final set examined views on socio-technical interventions that could support PHB recipients, such as "What would a website have to contain for you to use it?" Each set of questions were placed in front of one participant for their review before uploading, resulting in minor changes to the wording.

This iterative, mixed synchronous/asynchronous methodology we developed for the focus groups aimed to: (i) offer a means to bring back to our citizen-participants common themes drawn from the qualitative analysis of the one-to-one interviews for collective discussion and reflection; and (ii) support dialogue and connections between topics, discussion, and themes that citizen-participants shared over the course of the two weeks. This style of engagement delivered 492 typed comments totalling 24,877 words, plus 1,908 participant interactions such as viewing a question page with its responses. Figure 3 provides the number of interactions by hour of day from the citizen-participants, illustrating that although the peak (695 interactions) occurred around the synchronous sessions, there was a significant spread across the day and also into the night.

4.3 Analysis

Our data corpus comprised of 20 hours of interview recordings, which were transcribed using an online service, and the 492 typed comments collated from the synchronous and asynchronous focus group sessions. These two data sets were imported into NVIVO data analysis software and open coded using Thematic Analysis [6] based on semantic and latent standpoints, inductive for the interviews and then moving to deductive for the focus groups. The first author conducted an initial analysis of the data and generated initial codes and candidate themes. These were then iteratively discussed, reviewed and validated by the other authors, till agreement was reached on final themes, which are presented in the Insights section that follows.

4.4 Ethics

An ethics submission was created prior to starting the study using the authors' university's online ethics process, resulting in an automated low-risk approval. This is considered appropriate, as this study does not include child participants, the adults volunteered to take part in the study and also gave informed consent based on remote participant information sheets using Microsoft Forms.

5 INSIGHTS

We present four themes generated from our analysis. In *Care: Choice and Control* we examine the importance that our citizen-participants and LHCA officers place on personalised, relational care. In *Accessing PHBs*, we look at the process of assessment for a PHB, surfacing power imbalances at play. *Citizens and LHCAs*

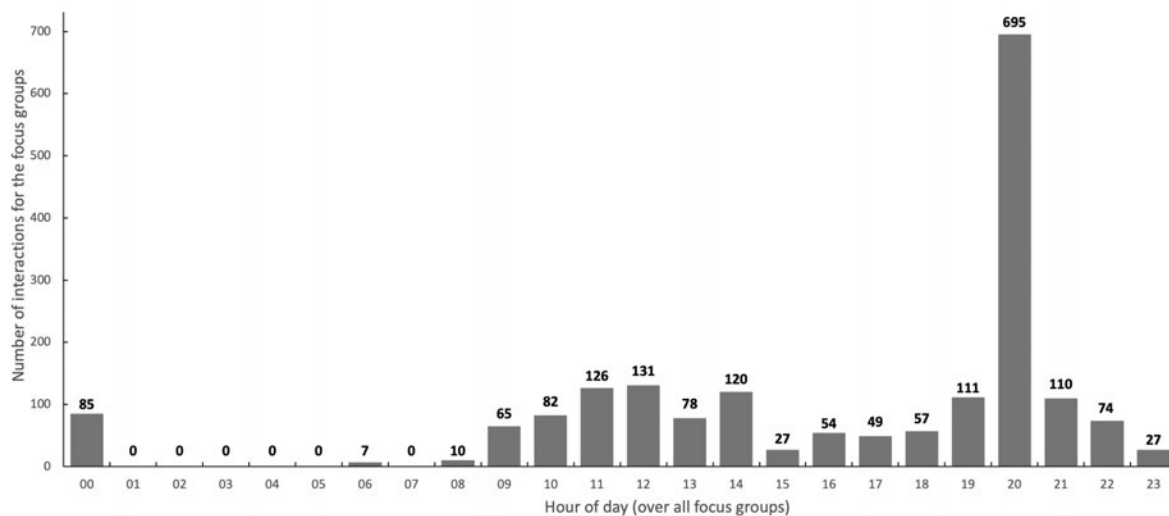


Figure 3: Focus groups' interactions by hour of day across all synchronous and asynchronous sessions

Navigating the Power Dynamics illustrates the experiences of citizen-participants and LHCA officers managing their PHBs, uncovering tensions between recipients and LHCA officers' concerns over autonomy and control, trust and risk management. Finally, in *Experiences of Becoming an Employer*, we explore how citizen-participants must work to operate their PHB, using technology as a means to build capability. Pseudonyms are used for all the participants. Quotes can be assumed to be taken from the one-to-one interviews, unless stated to be from the focus groups.

5.1 Care: Choice and Control

All our citizen-participants have high need of complex care for themselves or for their children. They all recounted how their LHCA appeared to have neglected their needs for both the quantity and quality of care, voicing a societal and institutional lack of understanding and recognition of the challenges, struggles and demands entailed with their extensive care needs. The majority of citizen carers in this study had to abandon their professional careers to fill the significant gaps in care delivered by the LHCA. They all felt that the losses and sacrifices they had to make in their lives were unrecognised by the state or the public, describing how they felt their LHCA ignored their calls for help with caring for their child. Beth is a citizen carer who gave up her career to care for her son, now in his early twenties. Here, she described the complexity of her son's conditions,

He has multiple comorbidities that go with him because of having cerebral palsy. Bowel impingement³, which affected his gut motility⁴. He's got a colostomy⁵. He's got a gastrostomy⁶ because he doesn't drink enough. He has a learning disability ... He's got a visual impairment.

³Bowel impingement: a partial blockage in the bowel.

⁴Gut motility: a dysfunction in how the gut moves food and waste.

⁵Colostomy: a surgical intervention to divert the gut to a new opening in the abdomen where waste is collected in a disposable bag.

⁶Gastrostomy: a surgical intervention where a tube is inserted from the abdomen directly into the stomach to deliver food and drink.

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 CPAP⁷ now.

Beth continued to state, "... nobody has a clue that type of thing that you've been through or the impact that it's had on your life."

Lack of recognition of healthcare needs included a deficiency of understanding of the hours required for care staff support, but also more nuanced aspects of this work; for example, having confidence and trust in the skills of care staff, the ability to direct the staff, and the need for a personal relationship with staff based on shared values and beliefs. This lack of understanding was prominent prior to the implementation of PHBs, when LHCA controlled the provision of paid carers through care agencies. All our citizen-participants voiced experiences of distress when 'strangers' would arrive at their homes to deliver intimate care, having no choice and voice over who delivered care, their skills, values, and belief systems. Joanna, a disabled citizen in her thirties with a limited range of mobility, recounted struggles with her PAs before receiving her PHB, "And there are particular difficulties that I've had. I'm a queer woman, and for example, agencies will often send me homophobes, and they all refuse to vet their staff for being rampant homophobes. And ... the [LHCA] would not consider it their problem."

However, with a PHB in place, disabled citizens and citizen carers have the choice to interview and select care staff, aligning personal attributes and values; this relational approach enabling a positive relationship between carer and the citizen. The majority of the 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. Beth explained how her PHB provided not just control in selecting paid carers, but how she can direct them, the benefits to her son's autonomy extending value to her own life, "... having the ability to take PA on holiday with you,

⁷CPAP, Continuous Positive Airway Pressure: a device that delivers pressurised air into a mask over the face.

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 LHCA officers all voiced support for the use of PHBs for the benefits and value they delivered. Mandy, who initially trained as an Occupational Therapist, had worked at her LHCA for over 20 years and for the last four years had been their lead for personalised care. She was responsible for all aspects of PHBs in her LHCA and believed PHBs were a vehicle that promoted communication and thence relationships between the LHCA and PHB recipients, "So yeah, [healthcare] service users really like it [a PHB] because it gives them the things that they really need. And they can have that open conversation with staff about what's important to them. And they like that they've been heard, I think, is probably the biggest thing."

The citizen-participants highlighted a broad lack of societal and institutional understanding on healthcare needs, and the importance of the relational qualities of care work personalised to those requiring care. The care work goes beyond a simplistic granting of carers' 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 cost to their wellbeing.

5.2 Accessing PHBs

Gaining a PHB requires a discretionary assessment from the citizen's LHCA, optionally based on a manual Decision Support Tool (DST) [16] to prove the need for continuing healthcare, which segments the needs of the citizen into a set of domains that are then scored by the LHCAs. This 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 our citizen-participants described how this assessment was distressing, extended months 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 relationships between those requesting a PHB and their assessors became adversarial, characterised by power imbalances that raised barriers to access. Our citizen-participants who found the process distressing went on to recount the stress generated by the process that involved being judged by a distant 'panel' of people from their LHCA, with whom they may never meet. Janey, a disabled citizen in her twenties with physical and mental disabilities, describes how she felt in an assessment interview where her LHCA officer applied discretion to remove scoreable attributes from her application that Janey felt were important to be assessed fairly and justly,

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

Janey's LHCA rejected her PHB application but then it was accepted after she re-applied by raising a formal complaint, this entire process of gaining a PHB taking 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 that there were skills needed to score enough to qualify for a PHB. These skills went beyond stating their needs, requiring the ability to use the language of the LHCA and situate that language in government policy aligned to evidence of need. Kia is a disabled citizen in her thirties and had the opportunity to revise her assessment when her partner began living with her, finding the experience from her first application was key, "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 majority of the citizen-participants' perspectives, it appeared that assessments and access to continuing healthcare is far from a neutral process. Rather, it is a process imbued with power imbalances and moral judgements that play out in ways such as discretionary scoring. On this regard, two of the LHCA officers we engaged with were open to admit that they were reticent to grant PHBs to recipients, as they believed citizens lacked the capabilities to operate them, despite healthcare policy driving PHBs to achieve citizens' care personalisation, control and choice. Further, none of the LHCA officers demonstrated willingness to train or support the PHB recipients to gain these capabilities. Katya, a LHCA officer with responsibility for allocating funding to PHBs in her LHCA, declared herself to be a PHB advocate, however, she did not voice trust in the citizen to manage the money and chose to discourage this, saying, "... and then they don't look after themselves, they pay for it to go to Florida or whatever else." Another LHCA officer, Mandy, shared Katya'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 LHCA officers we interviewed voiced care, understanding of the needs of applicants, and how harmful the assessment process can be. Cynthia, who managed a team that administered PHB funding payments in her LHCA, 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 non-automated 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 traumatic experience where they felt powerless as they put forward their case; two of the LHCA officers voiced an understanding of the harm this can bring but were then reluctant to reconsider where control should lie in the decision making process or to reassess the support needed to run a PHB. The following theme explores citizen-participants' experiences once they have gained a PHB, finding the power dynamic continues against them.

5.3 Citizens and LHCA's Navigating the Power Dynamics

All our citizen-participants with PHBs found themselves having to seek permission from their LHCA's for any new type of spend, no matter how small; this process on occasion taking months and typically bringing threats of the funding being removed at annual reviews. From the perspectives of our citizens-participants, the promise of autonomy did not seem to materialise in practice, with most of our PHBs recipients recounting having to “fight” to keep their PHBs or to own spending decisions rather than their LHCA's, who in their views continue to act as gatekeepers to the citizens' care funding. Anna's experience of this was that her LHCA initially refused to transfer funds directly to her account, which would have allowed her to spend the money as she needed on carers, 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.”* Myla is a citizen carer in her thirties with two children, her son needs frequent resuscitations and she explained how a change in the criteria within the assessment meant her son no longer scored high enough to maintain the PHB, *“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.”* Myla subsequently moved her family to a different region in England where she has been told by a friend, correctly, that the LHCA would apply their discretion to allow her son to gain a PHB. Jane provided an instance of her LHCA micro-managing her PHB, *“... they were still wanting me to ask permission to buy a £4.99 first aid kit. And so it went to the [LHCA] worker, and then it went to the [LHCA] worker's manager to get signed off. And then it got sent back to him.”*

The LHCA's ultimate decisional power over whether citizens could retain their PHBs, permeated and shaped the power dynamics. The citizen-participants learnt to navigate the system with great care - a balancing act between using their legal rights to challenge the LHCA, and living with the fear that an angered LHCA officer might withdraw their PHB funding. These complex dynamics became apparent when, in the planning of our focus group, we asked our citizen participants about inviting LHCA officers as well, and all refused, as they felt this would inhibit open conversation, fearful their identities might be exposed through recounting specific issues, thereby placing their funding at risk. Olivia is a disabled citizen with a spinal injury following an accident in her twenties, she outlined her approach to relating to her LHCA, *“So, I am happy of flying under the radar and not drawing too much attention to myself ... I don't contact the [LHCA] if I can help it and I like to stay quiet and not cause a fuss.”*

All the LHCA officers recognised this unbalanced power dynamic, but they all justified it in terms of their mandate and duty to ensure both financial and health risks are appropriately managed and mitigated. Katya provided an example of the need for this oversight and risks management as to avoid potential harm to the child and their parents, *“Obviously another thing during the summer holidays, 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?”* Another officer, Cynthia, instead focused on the risk around

money and the potential impact on her LHCA, *“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 dynamics between the citizen-participants and their LHCA's are understood differently by each party, in turn inhibiting the promise and potential for autonomy through a PHB. This appeared to be further compounded by a distance between the citizen and their LHCA. One of the officers, Cynthia, had tried to form a group with PHB recipients so she could better understand their issues with PHBs, but recruiting into the group failed, with citizens reporting they preferred to join communities with experiences related to their specific conditions. With the power held by the LHCA staff, the citizens filter out negative feedback to reduce the risk of losing their PHB funding. Dorothy, a LHCA officer who had worked with PHBs for six years in a role aimed at bringing together health-care and social care, recognised this distance, *“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 adds distance on both sides, leading the LHCA officers to form a false or incomplete view of the citizen and their lives, and vice versa. An example was seen within the running of payroll for their paid carers, one of the LHCA officers, Cynthia, 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.”* The citizen-participants offered an opposing view of that same team, Jane saying of them, *“I don't think that they're actually trying to be awkward, but that's how it comes across, you know. And I think they truly believe that they're doing things right.”* Anna agreed with Jane'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 find that the promised autonomy through a PHB did not materialise, as they had to fight to gain control of their budget, the LHCA 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 LHCA's, the next theme examines how the citizens must work to build capability to operate their PHBs.

5.4 Experiences of Becoming an Employer

PHBs offer advantages to LHCA's as they allow the potential to offload the cost, accountability and responsibility for management and administration of care work onto the unpaid citizens in receipt of the PHBs. The management of care work and care staff becomes invisible work. Samantha, an independent PHB advocate for over 15 years with a professional career in mental health, provided a summary of the legal information, skills and work demanded by a new PHB recipient,

... they need to agree with their [LHCA], 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, thereby illustrating how the citizen has to 'pay' for their promised autonomy by becoming an employer. This new role occurs as they gain their PHB, but without support from their LHCA to assist the citizen in achieving the capabilities needed.

The citizen-participants were asked in the focus group for sources and types of information needed when starting a PHB. The majority recommended seeking those with experience of PHBs, as trust was important to maintain their precarious lives, also describing how their LHCA did not offer help, so they turned to healthcare websites and Facebook groups specific to PHBs and their health conditions, but all found little to help them to build infrastructure. Anna spoke in the focus group about how peers provided useful knowledge, but that trust had to be proven, *"Find other people that have been in a similar situation - they will often give you far more practical information than professionals do. Listen to all the ideas from a few people and evaluate it."* A further focus group discussion on this topic laid out the difficulty in knowing who to trust,

John, who is a working father to twins of school age with severe disabilities: *Or it might just be that the advice some people give is just plain wrong even if given with the best of intentions, always try to go back to the source material instead of relying on opinions.*

Olivia: *OH SO THIS! Even well meaning self-professed advocates give out extremely dodgy advice sometimes - had this recently - never mind those who just think they know best anyway.*

The first author posed a scenario to the focus group of an online repository that held documents and templates - that we have termed 'care artefacts' - created by their peers, that they needed in their new roles of employer and manager. This possibility was seized on by most of the citizen-participants who began to list what these care artefacts could be. Zola, a parent studying for a degree at home whilst caring for her son with complex needs, was excited by the possibility,

I think open source would be fabulous, the content you put in is what makes it valuable. Some of the policy stuff like discipline, health and safety, alcohol at work, equality are pretty standard, so those would be useful, along with those that need to be more personalised like fire, smoking, meal breaks. Record keeping pages like ... medication audits, timesheets, annual leave, supervisions.

Myla gave examples in the focus group of what she needed and currently lacks, *"There should be risk assessments, training and care plans. I lived in a [LHCA] that had none of this. Absolutely none."*

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 a further burden on their lives already dominated by care and managing their PHB. This criticality arises as the citizen carers had no fallback but themselves when the processes surrounding care for their child fail, and the disabled citizens had no fallback at all for failures such as carers not arriving for work. Joanna stated in the focus group that she used cloud-based data for sharing, *"... we use Google calendar for shifts and rotas. And the only people who can adjust them are me, although I never do, and the senior [PA]."* A focus group discussion responded to a scenario where a tablet was available to their care staff that contained all the care artefacts needed,

Anna: *Grappling with everything electronically on top of running the care team just feels like 'yet another thing', especially when it inevitably goes wrong.*

Casey: *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).*

Olivia: *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 human relationships and to human discretion, especially as a key reason for a PHB was to gain control over these aspects. Christopher, a disabled citizen in his thirties who is a disabilities advocate, said in the focus group, *"... it's just I also find people need human touch. The 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 automate the shift rota of their care staff. This was firmly rejected by those that responded, Olivia stating, *"Nope. 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 final theme described a significant, invisible, burden placed upon the citizen, that of managing and administering their PHB. The citizen-participants each used technology to evolve their own set of capabilities, recounting a lack of a wide range of care artefacts they need to run their PHBs, though cautious of placing trust in the information that technology can present, seeing technology as a potential further burden to their lives that limits the human aspects of relationships and discretion.

6 DISCUSSION

Drawing from our insights, in this section we provide recommendations for HCI research concerned with developing digital technologies that support informal caregivers and those that manage their own care, to realise benefits from healthcare services within a personalised care paradigm, and more specifically, PHBs. We explore how HCI might foster peer-to-peer support in the context of PHBs;

provide considerations for the design of relational infrastructures in these contexts, vis-à-vis the significant power asymmetries at play between caregivers and their healthcare authorities. Finally, we discuss the effectiveness of the design of our engagement methodology when conducting research with these populations.

6.1 Digital Commons for Peer-to-Peer Support

In our insights we explored the struggles experienced by citizens when striving to access PHBs, and once they gained them, how citizens who manage their care become employers within days. The capabilities needed to access healthcare budgets and in turn manage them successfully, included skills and know-how relating to navigating the healthcare systems, assessing critically the healthcare systems' decision making, as well as care and employment law. The capability deficits [7, 57] voiced by the majority of our citizens-participants in the focus group meant they felt abandoned as health authorities relinquished accountabilities and responsibilities onto them. Yet, they also wished to find ways to better support one another in their struggle to realise their desire for justice and autonomy.

Ammari and Schoenebeck's [1] work on networked empowerment through social media, showed how informal caregivers turn to social media as a platform for support and exchange of experiences and knowledge used to navigate the healthcare systems. However, our insights demonstrated how the use of social media was inhibited, as many of our caregivers feared to speak up publicly about their issues, feeling at risk of losing their funding; this was compounded by their desire to use only trusted resources. Thus, any knowledge sharing platform aiming to provide support and reduce inequities, would need to consider these dynamics. Here, beside possibilities to leverage existing social networks, we look at what 'commoning' processes in Participatory Design [37, 41] could distinctively offer in these contexts. These processes would provide novel platforms for informal caregivers and disabled citizens working together to create, maintain and consume digitally shared, peer produced trusted assets [19], aiming to support their capabilities [41] to access and manage care funding. While this study took place in England, countries around the global north are now offering PHBs - therefore we see potential for transferability of our recommendation for knowledge sharing platforms, which could be designed and tailored in response to the specificities of local employment law, care practices and language.

In this way, HCI researchers could work with informal caregivers and disabled citizens that manage their own care to produce together care artefacts, such as the numerous resources and documents needed to assist not only with funding access, but also with care record keeping, developing care staff policy, and abiding with employment and care law, which so far have gained little attention in HCI. However, particular care and attention would be required from HCI when co-creating digital commons platforms with this population. Indeed, even though all our citizen-participants used technology to assist in the management of caring duties, several voiced concerns regarding risks including those of technology failure, data security, costs of staff training and loss of the "*human touch*". These risks would need to be explored and addressed upfront in any co-design of digital commons process. While these

risks are often cited in other domain areas of HCI, the impact of technology failure in these contexts and on lives that do not have failsafes when care becomes unavailable, would be significantly high.

Furthermore, extending the work of Ammari and Schoenebeck [1] and Chen et al. [9], we posit that including healthcare authorities in the design of digital commons platforms, would also expose and promote recognition of the invisible and complex work that running a PHB demands, as a facet of justice-oriented interaction design [18]. Yet, we should be mindful that exposing caregivers' invisible work carries its own risks as described by Suchman [61], for example that of increasing workers' vulnerability, or their working practices being rationalised, standardised and enforced onto all informal caregivers and disabled citizens managing their own care. As such, any attempt aimed at creating digital commons that exposes their invisible work would require careful configuration and study, to avoid impacting negatively on citizens managing their PHBs.

6.2 Towards Dialogical Infrastructures

Our study exposed a dysfunctional and problematic 'install base' in England's state healthcare systems' infrastructure - where disabled people were "*dissected*" into domains to make them fit within the manual assessment scoring system. This dehumanising process was traumatic for citizens, with one of our healthcare authority participants acknowledging the harm this can cause. While such bureaucratic process might allow for an ease of automation that might afford more efficiency (and therefore less waiting time for those seeking support) - we should be critically aware of the considerable risks and harms that automation could reproduce. Indeed, our insights echo prior work from other disciplines, which highlighted how the digitalisation of administrative processes can facilitate harm encoded in policies and laws [59] and the drastic consequences that careless automation of these can cause [48, 53].

Prior work has been advocating for human interpretation and discretion in the context of service automation based on fairness and morality [59]. Yet, our insights expose how healthcare officers' discretionary work can also enact social biases and produce unjust outcomes, reinforcing unfair preconceptions and serving the power base of the institution rather than that of the citizen. Therefore, future work concerned with advancing social justice through the design of administrative systems in these contexts, should guard against the mere automation of such a dysfunctional install base. Rather, to address the issues of 'street-level bureaucracy' [47] and 'administrative violence' [59], we could look for ways to better understand the dynamics ensuing from the existing knowledge base and develop means to empower citizens through, for example, increased transparency of the assessment process, the provision of tools to hold officials to account when decisions are discretionary biased, and processes to co-create PHB provisions.

While dialogue and collaboration are necessary requirements for any co-design process, our insights show distance and friction between citizens seeking to access healthcare support and their healthcare officers, both sides lacking understanding of each other's day-to-day practices, identities, constraints, stressors, and responsibilities. This inhibits constructive dialogue, mutual understanding, and cooperation, whilst propagating mistrust and an antagonistic,

unequal, power dynamic. Our insights echo works in HCI that explored these fractured civic relations [10, 11, 13] and chime with Harding et al.'s [27] recommendation that HCI design should not just focus on the citizen, but has to accommodate both sides into a safe design space that acknowledges the positions of both parties and existing mistrust. Therefore we ask what kind of digital infrastructures and social application of Artificial Intelligence within healthcare [48] would help address issues relating to trust and the risk of harm, and deliver benefits to both the state and its citizens? In other words, how can we move to craft spaces for the co-design of infrastructures that foster constructive and positive relations? Yet, creating spaces to expose the existing unequal power dynamics, fear, and deep mistrust also presents significant risks and challenges, considering in particular the healthcare officers' voiced belief they are performing well, and the fear experienced by caregivers of any negative retribution from their complaints. Finding inspiration in endeavours including data feminism and its attention to analysis of power [17], we believe HCI's research endeavour could support exposure of such complex dynamics through, for example, anonymous data collection and representation initiatives to safely collate caregivers' experiences aiming to call for recognition and acknowledgement. This data collection and representation processes might be conceived of as creating design spaces that build on agonism [2, 3], where caregivers' voices can be safely exposed with a view to recover democratic processes in partnership with their healthcare officers. The data arising from this partnership would be large - given the size of the output from this study's focus group - such that we envisage the need for HCI to consider a digital platform to both facilitate this collection, and then utilise machine learning to report on recurring issues for subsequent co-design through neutral understanding.

6.3 A Responsive Socio-technical Design Methodology

In the spirit of critical disability studies and their banner "*nothing about us without us*" [8], we wanted to foster participatory spaces to uncover challenges associated with access to healthcare services and consider together, potential responses. We have done so by feeding back to the group of citizens, the insights gathered through one-to-one interviews and each focus group session, for the purpose of collective discussion, dialogue, and critique. This was done in a way that would incrementally shape our qualitative research journey by building on prior data. As such, our methodological approach aligned with Participatory Action Research (PAR) and its iterative cycles [28].

At the start of the study, we were aware that engaging with informal caregivers and those that manage their own care presents significant challenges, as reported in prior literature [52, 60]. Furthermore, the first author's direct experience of informal care work, meant that we were familiar with caregivers' practical constraints, associated, for example, with attending workshops. Thus, prior to the start of the study, the first author held extensive discussions with citizen-participants to consider how best to configure the study to enable equitable participation and maximum flexibility. Our participatory engagement, purposing an existing commercial

market research application to perform academic research, combined asynchronous participation with a PAR approach where participants' data was analysed and delivered back to them. Extending HCI work on Asynchronous Remote Communities [38, 39, 50], our approach resulted in an extended set of focus groups over two weeks comprised of three synchronous sessions and an always-active asynchronous session. This interleaving of synchronous and asynchronous was used by our citizen participants throughout the day and into the night; the technology and methodology playing a critical role in allowing remote engagements, access through differing device types, minimal set-up, and a freedom for participants to engage around their unpredictable lives of care, allowing them to attend a focus group without adding to their burdens of time-pressure. The topics raised within the focus groups were participatory, as analysis of the outputs from a preceding set of questions were input to the next set and reviewed with a participant beforehand.

Our approach delivered a rich set of data from a focus group of time-poor participants who could not commit to long-duration synchronous meetings due to their priority of care. Thus, we recommend this approach to all HCI researchers wishing to engage meaningfully with this hard-to-reach population, in line with the disability activism stance and as a fruitful way to co-design future digital interventions. Yet, while the approach was successful in enabling the co-production of relevant data, it also placed considerable demands on the researcher, in terms of planning carefully scaffolded sessions that offered ease of use and seamless progression between PAR iterations; for rapid analysis within each PAR iteration; and for facilitating the 24/7 asynchronous session to ensure availability of both the researcher and the technology. Further, our citizen-participants, or their children, are registered as 'Clinically Extremely Vulnerable' in England [44], so are at high risk of serious illness due to COVID-19 - this precluded face-to-face meetings and sending cultural probes. With engagement options constrained to remote, we took care to include those with limited digital access by offering interviews by telephone, and using software accessible via smartphones for the focus group. However, HCI researchers wishing to consider similar approaches should also be critically aware of how adopting digital engagement methods exclude by default; our next step will be to further our insights generated from our online sessions through face-to-face engagements, when COVID-19 allows, to gain the voice of those we could not access online.

6.4 Limitations

Our citizen-participants demonstrated a commonality of adversarial relationship with their healthcare authorities, hence we speculate that only those citizens with such relationships responded to our recruitment. Further work should consider larger scale engagements with these populations to gain further insights, as well as to assess the impact of self selection bias, though acknowledging the potential cost in recruiting from non-associative, hard-to-reach populations [63].

The first author's positionality (neither declared as negative or positive) provided motivation for this work and enabled the study to begin with a direct experience of PHBs. This appeared to have assisted in the recruitment and engagements with citizen-participants by easing the building of rapport and trust. On the other

hand, the first author's positionality as a service user may well have inhibited recruitment of healthcare authorities, though we found this did not inhibit conversations. Whilst recruiting healthcare officers is acknowledged in the literature as a challenging task [32], future research might consider attending official LHCA fora and projects to increase recruitment.

7 CONCLUSION

This study explored the experiences and practices of disabled citizens, informal caregivers and state healthcare officers, as they access and manage PHBs, attempting to reap the benefits of novel personalised care policies in England. We found PHBs can provide the relational, skilled and intensive care needed, however, the autonomy promised by PHBs is constrained by additional work, skills and knowledge that managing these budgets places on the recipient, as well as lack of support and the uneven power dynamics and mistrust at play between healthcare officers and budget recipients.

While our case was contextualised in England, our insights and recommendation for HCI design are relevant to other contexts in the global north, where personalised care policies in the form of PHBs are applied. In particular we recommend that future work explores the distresses and burdens that arise from citizens managing their budgets, by extending peer-to-peer support from social media messaging, onwards to practical support through sharing of peer-produced care-related documents. This sharing of practices should be inclusive of both citizen and healthcare authorities, thereby exposing the invisible care work. We acknowledge the difficulties in crafting the safe design spaces necessary amidst the conflict and tensions between citizen and civic, this being a challenge as HCI commits to Participatory Design's democratic considerations, though in part mitigated by our methodological suggestions.

The digital transformation of healthcare presents considerable risk in this domain. Attempting to automate decisioning that is already embedded in ambiguity, personal relationships, and the negative aspects of discretion, is liable to maintain or deepen the existing distance, inequity, unfairness and injustices. Participation from both sides is essential, where HCI can continue to deploy its recent history on delivering social justice within the citizen-civic space.

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