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Co-Created Personas: Engaging and Empowering Users with Diverse Needs Within the Design Process

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ABSTRACT

Personas are powerful tools for designing technology and envisioning its usage. They are widely used to imagine archetypal users around whom to orient design work. We have been exploring co-created personas as a technique to use in co-design with users who have diverse needs. Our vision was that this would broaden the demographic and liberate co-designers of their personal relationship with a health condition. This paper reports three studies where we investigated using co-created personas with people who had Parkinson's disease, dementia or aphasia. Observational data of co-design sessions were collected and analysed. Findings revealed that the co-created personas encouraged users with diverse needs to engage with co-designing. Importantly, they also afforded additional benefits including empowering users within a more accessible design process. Reflecting on the outcomes from the different user groups, we conclude with a discussion of the potential for co-created personas to be applied more broadly.

KEYWORDS

Co-created personas, co-design, aphasia, dementia, Parkinson's disease, vulnerable users, healthcare, design.

1 INTRODUCTION

The design of health and care technologies has come into focus in the HCI community in recent years, especially with the dramatic rise of chronic health conditions in an increasingly

ageing Western population [17]. For example, there are currently over 46 million people affected by dementia worldwide [18], approximately 10 million people worldwide are living with Parkinson's disease [19], and around a third of all people surviving a stroke will experience some form of aphasia [3].

In parallel, there have been calls to involve target user groups directly in participatory design [5] and co-design [34] of health services and digital technologies to ensure their success and adoption [15, 29, 45]. Co-design techniques have been adopted for involving vulnerable user groups, such as people with dementia [20, 24, 39] and aphasia [13, 33, 43].

This noted, many co-design techniques and methods have limitations for use in situations where the physical, emotional and social factors related to a specific health condition and its symptoms, and the resulting requirements for technology, need to be considered. For example, many co-design techniques were developed with a view to more egalitarian design, without a particular focus on diverse user groups [5]. The design techniques themselves, then, are likely not accessible to users with cognitive, physical and language impairments. Such design paradigms may create problematic power structures between the professional researchers and the co-designers, leading to end-products that might not meet their expectations or requirements. A number of recent projects have broadened the design constituency by committing to co-design with users with diverse needs, such as people with dementia [20, 21, 32], aphasia [13, 33, 43] and older individuals [26]. In this paper, we leverage a classic design tool – the persona – and reconsider its use by encouraging co-designers to co-create personas. In doing this, we aim to broaden the demographic beyond those directly participating and obfuscate the personal relationship between co-designers and their health conditions. This paper contributes to the design process of technologies for people with diverse health conditions (Parkinson's, dementia and aphasia) by:

- Describing our experience of incorporating co-created personas into co-design projects;
- Presenting findings from the usage of co-created personas with diverse user groups; and
- Detailing the substantive affordances of using co-created personas in the design process.

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2 RELATED WORK

Co-Design and Co-Design Methods

Engaging users is an important aspect of design and there are a number of ways to create empathy with their lived experiences [46]. Engaging users in participatory design [5] and co-design [34] in the early stages of a project are well-adopted approaches, especially when designing technology in health and social care contexts [15]. Working with those who engage with the design domain in their lived experience has been shown to be a highly effective strategy of engagement [25], outperforming non-co-designed solutions. Co-design goes beyond simply consulting a user group for their requirements, instead considering them as designers within the process who contribute creatively to design decisions. Projects such as the work of Robinson et al. [32] are exemplars of the efficacy of this design approach. Given the success of co-design in engaging users towards achieving effective outcomes, there has been a growing voice advocating its use in designing technologies [9, 34], particularly in health contexts [15, 43].

A number of techniques have been considered for engaging users in the development of technologies, however, many of these are not accessible to those with the health conditions focused on in this paper (Parkinson's disease, dementia and aphasia). Such techniques are generally abstract, cognitively demanding and require high levels of speech and language proficiency. Recently, design techniques to engage individuals facing challenges to their speech/language [43] or cognitive function [21] have been reported. Adaptions to current techniques have also been shown to offer effective solutions [46]. For example, one might engage a user group in a workshop by utilising drawings, photographs and varying levels of prototype to develop solutions [9], employing experts in engaging with the user group to facilitate the session. Bourazeri and Stumpf [7] describe an typical example of this process in detail (their PERCEPT approach) from scoping and ethics approval, to recruitment and the design process itself.

To develop technology for people with dementia, the KITE project [32] employed workshops, focus groups and developed prototypes. Engagement was facilitated with people with dementia and their carers. The OASIS [21] method used video-prompts to facilitate discussion about a technology, inspired by invisible design concepts [8]. Although working with fictional or low-fidelity prototypes has been shown to be successful with a number of groups, sometimes a strategy is to use higher-fidelity prototypes. With certain user groups – especially people with aphasia – it has been demonstrated that higher fidelity prototypes reduce the amount of abstraction required [13, 13, 33]. Wilson et al. [43] describe

the SWIM (Someone Who Is not Me) technique, which encourages a co-designer to consider someone they know as a 'stand-in' within the design process, thereby broadening the demographic of the co-designer population.

Another approach, probes [14] – the deployment of small packs of artefacts to elicit responses to understand a user group – has been used extensively in design [6]. Probes have demonstrated some degree of success with populations with Parkinson's disease and dementia [20, 39, 40]. Finally, another approach is to undertake longer-term engagement with users by working in their homes [26], of course at the expense of resource.

Personas

Personas have been proposed as fictitious representations of user groups – “hypothetical archetypes” of target users – and their goals, needs and preferences [1, 11]. They are widely used in UX practice and software development, often produced by UX researchers as part of specifying the context of use of a product and then taken forward to create and evaluate design solutions, via ideation, expert reviews or cognitive walkthroughs, especially when participatory design methods are not possible [1, 12, 22].

Many advantages of using personas have been identified [30]. Firstly, *Personas create a strong focus on user-centred design*. They help development teams engage in user-centred activities through broad application of personas in feature specifications, storyboards, design discussions, etc. Personas can be a good way to ensure users are represented when designing and developing technology for healthcare [28, 41, 42], especially when involving users more directly is difficult due to either clinical, ethical or practical reasons. *Personas allow us to extend individual user characteristics into fully realised characters whose attributes can be considered as a whole across a variety of novel situations*. Thus, they bring coherence to a large set of possible design features. *Personas make assumptions about the target users explicit* [30]. They allow development teams to base their design decisions on explicit information about how they assume the product will be used and by whom. *Personas are aimed at a specific user group which is the focus of design* [30]. This helps to distinguish who the product is being aimed at and who it is not. Finally, *Personas support the team to communicate information quickly*. Personas effectively distil complex data such as that derived from ethnographic study of users [4], interviews and observations with users [35] and large-scale online questionnaires [23], using narrative and storytelling to enhance remembering and organising detailed data about users.

A number of efforts have introduced personas into co-design, but have not co-designed them. Examples can be found in the design of digital peer support services where child-personas were adapted to develop health-promoting

services and help young children diagnosed with cancer to transition from intensive care to everyday life [41]. The HealthMap project [42] introduced patient-personas to explore how mobile and Internet-based technologies can support people living with HIV in the self-management of chronic disease. In another participatory service design, young patient-personas with type 1 diabetes were involved in the design of innovative health services [37]. However, there is little work around co-creating personas within the design process. Bourazeri and Stumpf [7] report using co-created personas with people with dementia and Parkinson's disease, while Cabrero et al. [10] considers co-created persona use in designing for people in rural Namibia as a cross-cultural research probe. This work, while important, does not reflect on the usage or efficacy of the persona within the design process. We build upon the discussions of the use of co-created personas in design and offer a detailed investigation of the creation, usage and outcomes of co-designing personas in three design situations with a view to understanding the outcomes and processes of co-creating personas with diverse user groups.

3 THE STUDIES

Working with co-designers, one is limited to the experience in the room. The goal of the three co-created persona activities investigated here was to broaden the demographic of the design teams by creating and bringing new fictional people into the process. Further, from our previous experience working with people with chronic health conditions, we found that it can often be a challenge to directly address people's lived experience of a condition, therefore we wished to abstract from this somewhat. During each of the three studies, we designed personas with the co-designer participants from the outset. The personas were not set in stone – they could flex to fit the needs of the design, and could be changed as the remit of the design became more focused and less 'fuzzy' [34]. We first describe the three co-created persona activities (the "studies") and their user groups, followed by our approach for generating the personas. Then we describe how we analysed the co-design activities and report the findings. All co-designer researchers were **DBS-checked** to work with vulnerable populations and ethical approval was acquired through City, University of London.

Study 1: People with Parkinson's Disease

Study 1 involved people with Parkinson's disease. This is a neurodegenerative disorder that leads to progressive deterioration of motor function, including tremor, stiffness, slowness, impaired balance and, later on, a shuffling gait. The co-designer participants were 5 males and 1 female: Paul, Adam, Brian, Prabhu, Gareth and Sarah, with an average age of 65 (range = 58 - 74), coming from diverse backgrounds, and with an interest in improving their daily living with the use

of technology. (All co-designer participants are referred to by pseudonyms in this paper). Study 1 was undertaken as part of a project to co-design and develop an intelligent toolkit of software, hardware and sensors that will support people living with chronic conditions – the **SCAMPI** (Self-Care Advice, Monitoring, Planning and Intervention) project. This toolkit will allow a person living in their own home, together with their informal carers, to create, change and monitor a quality of life plan. Co-designer participants were recruited through support organisations targeting these groups, such as Alzheimer's Society, Parkinson's UK, and local dementia cafes. Four co-design workshops were conducted over the course of six months, each lasting about three hours and spaced about six weeks apart. For a full description of the co-design activities and the PERCEPT approach to co-create and apply personas with the users during the exploration, design and evaluation steps of the toolkit, see [7].

- Workshop 1: **create initial personas** by exploring the background, technology use, activities and goals of users and co-designer participants.
- Workshop 2: **review and extend personas**; exploring the use of sensors to inform a computational model.
- Workshop 3: **apply personas** through designing the user interface using low-fidelity prototyping.
- Workshop 4: **apply personas** to evaluate the user interface design using an adapted cognitive walk-through.

Personas with Parkinson's Developed. We created two personas to represent people with Parkinson's disease, Steven and Pat. In addition, two more personas representing Steven's wife and daughter were added in workshop 3. These can be found in full in the supplementary material. Steven is a male 64 year old, diagnosed with Parkinson's disease when he started having difficulties in buttoning up shirts. Pat is a female 53 year old with Parkinson's disease who works as a chief executive for a public health service, diagnosed when she started having problems with the voice recognition system at work.

Study 2: People with Dementia

This study involved people with dementia which is caused when the brain is damaged, often by Alzheimer's disease or a stroke, and includes cognitive symptoms such as memory loss, difficulties with problem-solving and language issues. The co-designer participants were two males (Colin and George) with dementia with an average age of 75, and their two female carers (Paula and June) with an average age of 60. We conducted four workshops over the course of 6 months, as in Study 1, to co-create the personas. The first workshop was attended by four additional people with dementia and their informal carers, who subsequently dropped out. Colin

and Paula joined at the second workshop, with a separate mini-workshop for them to catch up, replacing Workshop 1.

Personas with Dementia Developed. Three personas were created in total: one primary persona with dementia (Fred) and two personas (Vera, his wife, and Enid, his daughter) from his wider care network. Fred is a male 67 year old retired train driver from Essex with dementia. Vera is a female 62 year old who is Fred's wife. Vera's main goal is to look after Fred and ensure that his daily routine is maintained. Enid is a female 38 year old, Fred and Vera's daughter. These personas can be found in the supplementary material.

Study 3: People with Aphasia

Co-designer participants in study 3 were four people who had mild-moderate aphasia as a result of stroke; two were female and two were male (Elizabeth, Angela, Oscar and Neil) with an age range of 44-68 years (average age 58). They were recruited through connections with a University speech and language department and were chosen on the basis that they had experience of consulting on previous technology projects at the university (involving co-design). They were employed as members of the research team during this process. All co-designer participants were not in work since their stroke. Four co-design workshops were conducted over a six month period in a professional user experience lab at City, University of London. Each workshop lasted 2hrs 30mins, with a 30 min break in the middle. Study 3 was undertaken as part of a project to design a technology that will enable people with aphasia to create and curate digital content – the [INCA Project](#). Throughout the workshops we were designing an iPad app which would enable users with aphasia to engage in creative writing (see [27] for details).

- Workshop 1: **generating initial data for four personas.** The workshop also involved an icebreaker activity where everyone brought artefacts to get to know each other and for the generation of two personas.
- Workshop 2: **reviewing and extending personas;** exploring creative writing processes through generating redacted poems.
- Workshops 3 and 4: **applying the personas** by designing and evaluating an app to enable people with aphasia to engage in creative writing. Prototypes of the app were evaluated individually and within groups with the co-designer participants, and through discussions in the context of the personas.

Personas with Aphasia Developed. Four personas were created in total (full details in the supplementary material). Jimmy is a male 67 year old retired bus driver with aphasia who struggles with speaking and writing. Charlotte is a 56 year old female with aphasia who works in customer

support at a bank and struggles with reading. Annie is a 60 year old with aphasia. She is independent (lives alone), struggles with her reading and writing and would like more confidence in her speech. John is a young stroke survivor (25) who works as a carer and lurks on social media, and struggles with speaking due to his aphasia.

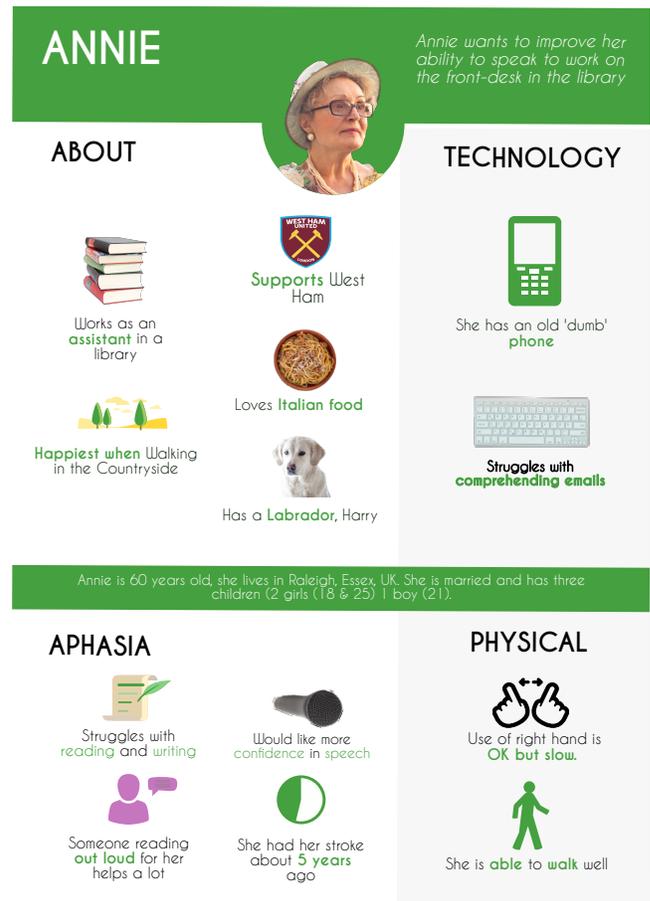


Figure 1: Co-Created Persona, Annie, who was designed with four people with aphasia. The persona was co-designed in terms of both its details, and its aphasia-friendly aesthetic.

Approach to Persona Generation

Persona Creation. In all three studies, we asked the co-designers to co-create personas in workshop 1. During these activities, we asked them to invent another person, similar to themselves in that they had the same impairment, that we might use in the workshops as an extra voice in the design process. At the beginning of each study, the co-designer researchers created scaffolds by listing features that are common in personas, such as name, age, location, family, and hobbies, and other background information. Features oriented around the goals of the design activities were also

included. These included digital content creation and curation, and how people with aphasia might engage with it in Study 3, or the activities that people with dementia and Parkinson’s disease carry out in their everyday lives, and their technology use in Studies 1 and 2.

There were some differences between the approaches employed in the studies, due to the goals and technical backdrop of the designs, and the user groups themselves. As mentioned above, the features of the personas were chosen to fit the goals of the design activities. Studies 1 and 2 followed the PERCEPT (PERrsona-CENTred Participatory Technology) approach [7]. Personas were constructed iteratively, always alternating between bringing out co-designer participants’ lived experiences through a workshop exercise, and then reflecting on and integrating this information into the personas. This had an effect on the number of personas initially created: participants with Parkinson’s disease created two primary personas, whereas participants with dementia created one, and two secondary personas to represent a wider informal care network, mirroring the group composition.

In contrast, the work with people with aphasia utilised the SWIM technique [43] to acquire details about the impairments of the personas. SWIM has been shown to work well with people with aphasia as it is less abstract and concrete discussion is useful with this population. Each co-designer participant worked with a co-designer researcher in a one-on-one session in which they were asked to think about someone that they know in real life, capturing specific details about that person’s aphasia to be used in a persona. Due to the way this was organised, four personas were created (one for each co-designer participant).

Co-designer researchers facilitated discussions between the co-designer participants to invent data for the personas – generally on paper or a whiteboard (for example, see Figure 2). This was achieved by the co-designer researchers asking for specific details about the personas that we deemed important for the design (e.g., “How old do we think Annie is?”). The co-designer participants then discussed these features and were encouraged to think outside of the specific information we requested; they were thus empowered to add new features to the personas. The co-designer researchers tried to ensure that each member of the co-design team had equal weighting in the discussions, which was sometimes facilitated by turn-taking when choosing characteristics of a given persona.

Consensus was reached through discussion of features in relation to other characteristics of the persona and the other personas created. In general, we made sure that all co-designer participants were happy with a given feature and its data before moving on. The number of personas created depended on the requirements of the project. Generally, the

Figure 2: Result of a session working with people with aphasia. Key features – name, age, hobbies – were requested, but freedom was extended to the co-designer participants to contribute other ‘interesting things’.

aim was to capture diversity, while not having so many as to be excessive, making it hard to remember each one.

Refining and Using the Personas. In all studies, the personas were then actively progressed outside of the workshops, becoming more refined in their details and their aesthetic (see supplementary material). After workshop 1, all studies used the personas actively in the workshops, leading to refinements due to perceived shortcomings by the co-designers. Use of the personas was encouraged by reflecting on what the persona might think after discussing each aspect of design or technology with the co-designer participants.

In form, the personas began as hand-written text on paper or whiteboard in the first session, then progressed through various versions developed in a graphics package and printed out for the workshops. The personas were then edited as and when the need arose: we realised that sometimes they were not fit for purpose (e.g., they might miss a key detail about their technology use), so adaptations were made as the sessions progressed, e.g. with a marker pen. The personas were re-introduced briefly to the co-designer participants each time they were used in all three studies, and the co-designer participants could make edits to them before use. Numerous iterations of visual and text design were explored to make them as accessible as possible.

Data Collection and Analysis

All co-design workshops were recorded. This resulted in 18 hours of video data for study 1 (Parkinson’s disease), 15 hours of video data for study 2 (dementia) and 10 hours of audio and video data for study 3 (aphasia). A thematic analysis of these data was undertaken to investigate the co-creation, usage and refinement of the personas.

The analysis began with a bottom-up investigation of headline data from the co-design workshops. We created an initial set of ‘super-codes’ to investigate the data and developed emergent codes when applicable. We applied the emergent codes in detail to a sample of the video data in order to refine the codes. This code-set was then re-applied to the data iteratively to understand its main themes, and whom and to which part of the process each code referred to. Data were coded based on conversational turn and we considered saturation to have occurred when no more codes emerged, which Aldiabat et al. [2] describe as “code saturation”. Codes were not mutually exclusive – that is, super-codes and codes could overlap. For example, while a co-designer was evaluating how well an interaction technique worked (*Evaluation* in the *Design Process* super-code), a persona might be being used as ‘shorthand’ by someone who had trouble remembering (*Shorthand* in the *Affordance* super-code), whilst also being used to critique a specific aspect of a design (*Critiquing* in the *Affordance* super-code). The two first authors applied the codes, creating and discussing them to ensure consistency, and considering differences and commonalities. All data were coded in NVivo by these two main coders.

4 FINDINGS

The main set of codes which arose from analysis of the data can be found in Table 1. These describe the particular themes that we found around the potential affordances of the personas, the alterations made to the personas (and why they were made) along with the various attribution-based data required to pinpoint who contributed each piece of information. Several over-arching themes emerged as a result of this analysis. We will now report and describe these themes and how they relate to our data in the context of our codes - supported by specific quotes from the data.

Broadening of Demographic

A stated aim of using the personas – broadening the demographic (code: *Broaden Demographic*), to beyond those in the workshop – appeared to be successful in study 3 with people with aphasia. Personas were most commonly used to broaden the demographic during activities in which we were discussing elements of the technology, with the personas being used equally in design ideation and evaluation. This is unsurprising because this was their intended purpose. For example, one co-designer with milder aphasia found the app being developed was aimed at someone with more severe aphasia and used ‘Anne’ to consider people with more severe aphasia: “*She would find it very helpful, because she – if she could read out loud it would mean that she could recognise words. It would mean that she could read something but she could not retain in her memory*” (Neil). Discussions around the personas also allowed other co-designers to contribute

potential solutions. When discussing the persona Charlotte, for example, Oscar noted that if she found using word clouds too complex, then pictures could be used: “*Well. You can put some picture in. That would help. Picture will make many words.*”

Once the personas were established, it was clear that sometimes the co-designer researchers, when asking about a particular aspect of the system, did not always need to explicitly ask “*How was this for the persona?*”. After some use, with the persona on the table in front of them, co-designer participants would make use of it without any cueing – clearly becoming more cognisant of the persona, which had become naturally embedded into the session. For example, when Neil was asked how he found arranging the words in the app, he responded: “*I did, but if I couldn’t I would find it difficult.*”

In Study 2, co-designer participants mirrored the composition of their group of people with dementia and their informal carers in the personas. What was unexpected was how they crafted a whole family, developing a tertiary persona of Enid. This broadened the demographic considerably by creating a persona for a user group that was not actually included in the co-design activities. Suggesting, perhaps, that they were not simply responding to the workshop, but reacting to and shaping the process. This was so useful that in Study 1, co-designer researchers gave co-designer participants the personas of Vera and Enid to adapt to their needs, thus creating additional personas that reflected their wider care network and broadening the range of stakeholders.

Empowerment of Co-Designer-Participant

In all studies, we introduced the persona generation activity early to ensure that we could use the personas when making key design decisions. Unknowingly, we allowed our co-designer participants to become more familiar with ‘being designers’, before they were even making design decisions about the system they were co-designing. All studies noted increasing confidence on the part of co-designer participants throughout the introductory creation of the personas, captured in statements coded as *Alteration to Persona*.

In Study 1, co-designer participants were extremely engaged with the co-creation of the personas, given only minimal instructions. Their engagement was accompanied by playfulness and humour, with the co-designer participants working together and drawing on their lived experience to create primary and secondary personas and to flesh them out. For example, when asked how to name one of the personas, Prabhu said – “*Let’s call him Shaking Steven*” referring to 1980s UK pop star Shakin’ Stevens. Gareth also suggested including a “beer fridge” in Steven’s technology as his main activity was to brew his own beer.

In Study 2, co-designer participants were so engaged with the co-creation of the personas, that their informal carers

Super-Code	Code	Definition
Affordance	<i>Affords Strawman</i>	The persona allows someone to critique something they may not feel comfortable with
	<i>Broaden Demographic</i>	The persona is used to encompass a wider set of impairments, perspectives or opinions
	<i>Creates Empathy</i>	The persona allows someone to relate to themselves
	<i>Creates Sympathy</i>	The persona is felt sorry for by someone
	<i>Critiquing</i>	The persona is being used to directly critique an aspect of a system
	<i>Role Change</i> <i>Shorthand</i>	The persona enables someone to more actively become a designer The persona allows for a complex description of something to be referred to quickly
Alteration to Persona	<i>Empowering Details</i>	The alteration to the persona is empowering the persona
	<i>General Details</i>	The alteration to the persona is generic
	<i>Pragmatic Alteration</i>	The alteration is made due to a logical inconsistency in the persona
	<i>Specific to User Group</i>	The alteration made to the persona is specific to the user group
Attribution	<i>"I" Statement</i>	The person is talking about their perspective on something
	<i>Persona Name Statement</i>	The person is talking about a persona's perspective on something
Design Process	<i>Design</i>	The persona facilitates an idea relating to the design of a specific feature
	<i>Evaluation</i>	The persona facilitates a form of usability testing with a system
	<i>Ideation</i>	The persona facilitates an idea relating to a conceptual design idea
Perspective	<i>Said by Co-Designer Participant</i>	The co-designer said it
	<i>Agreed by Co-Designer Participant</i>	It was agreed by the co-designer
	<i>Said by Co-Designer Researcher</i>	The researcher said it

Table 1: Codes created from bottom-up investigation of data.

were pleasantly surprised at how well they could remember the personas' details and characteristics. June (George's informal carer and partner) said – *"I cannot believe that George remembers everything about Fred, you know his condition deteriorates and he can't even remember what he ate yesterday [...] so I cannot believe that he remembers all these things"*.

In Study 3 there was a brief reluctance and a sense of minor confusion when making decisions about the personas. Many of the responses initially defining features of the personas were posed as questions. For example, Elizabeth would initially begin phrasing the details about the personas as questions. For example, when choosing Charlotte's name: *"Charlotte?"*. This suggested that – perhaps – the co-designer participants with aphasia were not particularly confident in their role as designers. This lack of confidence faded within the first session, and she – and the rest of the co-designer participants – became more assertive in stating and debating the decisions that they made. After two sessions, the co-designer participants showed affection to the process and showed no reservation about recommending adjustments to the app or the personas. For example, Elizabeth showed how she began to enjoy the process as it continued, and reflected on the process positively: *"It's like funny. Because we change the name into old instead of younger. Maybe we change male to female. [...] We create the persona. To help the people have stroke. With aphasia. And can help them to communicate by using technology"*.

Enhanced Ease of Communication

Utilising the personas as a means for communication (code: *Shorthand*) was a major theme that emerged from the analysis of the data in study 3. It was apparent that, throughout the process, the personas allowed the co-designer participants with aphasia to optimise their use of language rather than having to use extensive language to articulate a particular thought. The *Shorthand* code often coincided with the *Persona Name Statement* code, indicating that the persona worked as a useful way of summarising information quickly. This also aided co-designer participants in making recommendations about how the aesthetic of the personas could be changed to make them more suitable for use by people with aphasia. The personas were designed with lots of graphics and very simple textual descriptions.

The co-designer participants would, for example, sometimes gesture towards a particular part of the physical persona to convey some information about what they were explaining. The persona was most commonly used as a quick method to refer to an impairment to consider what could or could not be done by a person. For example, Annie's persona states that she struggles with reading and writing, but finds that reading out loud helps her a lot. This allowed one of the co-designer participants (Neil) to quickly articulate how others might utilise the application differently by referring to the visual persona – *"if she could read out loud [...] she could recognise words"*.

In Study 2, co-designer participants referred to specific technology that the persona was using to emphasise some

symptoms of their impairment. For example, George tried to highlight the difficulty of keeping a diary with his thoughts by saying – “I think Fred should use the dragon natural speaking, I think it will help him to keep a diary with his goals [...] and activities. I am using it [...] I record my thoughts and then I listen back to them so I can remember them”. We noted the same approach in Study 1. Co-designer participants suggested that integrating voice recognition into the smart home toolkit would help them to set up their life plan more easily. Adam said – “Pat has a voice recognition system both at work and home, maybe it does really help her. It would help us too”.

Further, we noted that the persona was also used in this ‘shorthand’ way to generate ideas adjacent to the main feedback that we were getting on the app in study 3, or indeed to create completely new design possibilities (ideating). After using the creative writing app, one co-designer quickly referred to the Jimmy persona in order to share the idea of creating an application which is able to assist with the generation of music, instead of creative writing – “Can use... but maybe we change with music? [instead of words] ... Yeah?” (Elizabeth). This allowed the co-designer to lower the burden of explaining the – quite complex – concept of how this may be applied to the music domain, by referring to the app in the context of Jimmy’s passion for music through the shared understanding that we were discussing Jimmy.

Different Critiquing Styles

In Study 1, co-designer participants did not explicitly use the personas to critique (code: *Critiquing*) specific features of the smart home toolkit. Instead they referred to themselves and their personal opinions to evaluate the new technology. For example, when asked to evaluate the new technology, Adam said – “I can see how this smart home technology could help people with dementia but it is not for me, I do not have any cognitive impairment, maybe in a few years time”, whereas Sarah said – “I live by myself and maybe one day in the future it would be useful to have a means of sensing, if I have had a fall, I know there are buttons you can press but if you are not conscious and cannot press the button it would be good to have something that monitors you are not moving for a while”. Essentially, instead of referring to the persona (*Persona Name Statement* code), this user group much preferred to discuss their problems – mostly using the “I” *Statement* (code). We noted that co-designer participants with Parkinson’s disease were uncertain about the new smart home toolkit: they believed that it would be more useful to a person with a cognitive impairment, as they were themselves very independent and active.

In Study 2, however, this was different. Co-designer participants critiqued and evaluated the smart home toolkit through the personas. When asked to comment on how easy it was to set up a new life plan using the toolkit, George

said – “The life plan should be jointly created by Fred and Vera. I would expect Fred would need Vera’s help for that” and “Fred might have some problems with spelling, will the toolkit recognise words that are not properly written?”.

In Study 3, after the co-designer participants with aphasia had given their own views about an aspect of a prototype, they also used the personas effectively to critique the prototype from the persona’s perspective. The *Critiquing* code was commonly used in tandem with *Persona Name Statement* and was generally *Said by Co-Designer Participant*. For example, when we asked Elizabeth how someone with more severe issues speaking (Charlotte) would get on with using the creative writing app, she was optimistic: “er... She can read slow... If you have patience you can read it again and again. Yeah?”. The personas were also used to critique the app: “If John for example, say he has had his stroke recently, he would be very limited in what he could say or produce. So, it would be very good for him” (Neil). The personas were also used by the co-designer participants to engage in *Ideation* about features that the app might have in the future. For example, when thinking of John – a persona with more severe aphasia – using the app for creating creative writing, Neil noted his solution for overcoming his barriers: “I do reading in church. When I want to prepare it...If I don’t prepare it is not very clear. When I read it, I started putting lines between each phrase. So that I don’t run the words into each other, but also to slow me down”. These ideas and solutions often came un-cued due to the co-designer participants ruminating on how the persona would ‘get on with’ something.

We also saw a more nuanced use of the personas in the data from study 3: there was evidence that the personas were used as straw men (code: *Affords Strawman*). As the co-designer participants were discussing the app, it became evident that some aspects of the design were challenging. For example, likely due to tiredness, one co-designer participant clearly had issues with the number of words he had to read and it took him several minutes to complete a few actions. He explained this using the Jimmy persona and it is evident that this allowed him to feel more confident in critiquing an aspect of system to those who were responsible for its implementation, without explicitly stating that he found it challenging: “So if you cut it down, have Jimmy make his lyrics together...When I saw the thing...It is too much. Too many words for...”.

Further, in Study 1, co-designer participants had problems completing their profile using interactive mock-ups due to their tremor. Paul tried to explain why it was taking him so long to write his name: – “I think that the text box is very small and the buttons too close to each other. Steven will have a problem to complete his profile quickly due to his tremor”.

Attachment to the Persona

Co-designer participants showed a degree of attachment to the personas. Commonly, they generated, or changed, features of the personas which protected them or ‘saved’ them from their current situations. It was therefore occasionally challenging to address some of the more emotionally complex aspects of a condition. For example, when working in Study 3 with people with aphasia, it was challenging to generate an ‘independent’ persona who lived alone. The *Creates Sympathy* code was commonly linked to co-designer participants adding details to persona’s *General Details*. One instance of this was where a co-designer participant showed sympathy for the Charlotte persona: he could not bear to see Charlotte live alone, “*one thing, when you talk about Charlotte...They said that she was living alone. I can’t understand why...How anyone who has got a stroke, you know. You always need to have someone. So, I don’t understand that*” (Oscar). Later, he also used his life experience to contextualise this, “*She is 74, my friend. She fell off the bed and she lives alone. 74. And she was laying on the floor and nobody could help her.*”

We also observed that the co-designer participants in Study 3 sometime showed empathy towards the personas (code: *Creates Empathy*), as the personas enabled them to reflect on their own situation – or indeed the situation that they were in soon after their stroke, before they began recuperative therapy. Neil, for example, used his own experience, combined with persona John’s description to make a design assessment: “*If he had a stroke 2 years ago he would be able to... Let me go back... My speech after my stroke... I couldn’t get the word out. So, I suspect that he would be the same [using the app].*”

In both Studies 1 and 2, co-designer participants empowered their personas and decided to include only subtle cues about the conditions and their effects. Even more so than Steven and Pat, Fred appears to be carrying on as usual as much as possible, trying to maintain the activities that he enjoys. However, during discussions in the workshop, it came to light that in real life the challenges of living with dementia are numerous, for example: “*I find it quite difficult to manage money – can’t be trusted not to spend all of it – so I can’t take a credit card to [a local DIY] shop anymore*” (George).

Another finding was that co-designer participants in Study 1 added even more technology to Pat’s persona, making her an *extreme persona* [16, 44] relatively untypical, possibly to explore the boundaries of the new smart home toolkit. They also extended the personas with unanticipated facets, introducing aspects that we did not initially consider. For example, they pointed out that mental attitude towards living with the disease helps a lot in keeping up with the daily activities – Prabhu said that “*Your personality plays an important role in helping you cope with your condition*”.

Creation of Aspirational Personas

Partially related to the attachment noted previously, and indeed for other reasons relating to the fun of having boundless options to explore, many of the co-created personas were quite aspirational. They often had characteristics which people with a given impairment might not have. For example, in Study 3, most of the personas had jobs, and the coding suggests that almost all of these features were contributed by the co-designer participants (code: *said by the co-designer*). Sadly, this is not the current reality for people with aphasia. For example, Annie – who has problems with reading and writing – works at a library, which is not impossible, but makes for a somewhat atypical persona.

In Study 2, Fred and Vera, representing people with dementia and their informal carers, also appeared to be *aspirational* personas [31], with the participants trusting that technology will be able to facilitate more desirable experiences instead of day-to-day goals and activities. A pleasant surprise was the facets the co-designer participants chose to include in these personas. Idealistic features were generated, such as those for Enid, who is married to a rich husband and lives in Miami, is very social, enjoys shopping, socialising and horse riding. The persona was also empowered through her role organising galas to fund-raise and increase awareness for Alzheimer’s disease, making her an advocate to some degree. Even Vera’s goals and activities highlight what she would want to do, instead of what she actually does day-to-day. For example, during discussions in the workshop it came to light that in real life the challenges of living with dementia are numerous, for example: “*I am bad with money, which is a bit annoying. My daughter comes down and she is brilliant looking after my finance affairs*” (Colin).

In Study 3, we found that logical consistencies in the personas were often whittled out within the design process. The analysis suggests that most of these amendments, coded as *Pragmatic Alterations*, came from the co-designer researchers. For example, when considering Jimmy’s hobbies it became evident that it would be challenging for him to still sing in a rhythm and blues band due to his limited verbal output. One co-designer researcher therefore concluded – “*Maybe he used to sing in a rhythm and blues band...but now he sings in a choir instead...*”. However, in contrast, in Study 1 the co-designer participants decided to alter their personas and gave them more ‘realistic’ characteristics; Paul suggested that “*We should include grooming for professional appearance to Pat’s activities as she is a Chief Executive for a public health sector*”. Sarah also suggested that they should include shaving and dressing to Steven’s activities – “*He was diagnosed when he was having difficulties in buttoning up shirts at work, so he may need help with shaving and dressing in general*”.

5 DISCUSSION AND REFLECTIONS

For the most part, we found the personas to be powerful tools for engaging users with diverse needs in the co-design process. The co-created personas were a highly effective way of broadening the participant pool. The co-designer participants in all three studies engaged with the personas in diverse but effective ways. We found that doing the initial scoping of the personas with the SWIM technique allowed for the capture of realistic impairments as they were based on real people, then the addition of features enabled the co-designer participants to be more invested and focused on the process as they exhibited *ownership of the design materials*.

We believe that the act of creating the personas was a very effective tool for ‘ramping’ the designers into the process of ‘being a designer’. A fundamental tension in the design process is co-designer participants – who are not designers or technologists by profession – feel reserved making decisions about the design of technology. Our approach addresses this tension of co-design by using persona co-creation as an introductory activity, in which people are drawn into the design process gradually, therefore have more confidence when making decisions about technology. Further, a benefit of co-creating personas in the design process, as opposed to simply using them, might be that we better remember things that we are actively engaged in. Our data seemed to suggest a fast learning process and good memory retention of the persona’s features. Steffens et al. [36] describes this concept in a review of the concept of ‘learning by doing’, noting that (with some exceptions) enactment, as opposed to observing, improves ones ability to recognise specific actions. And indeed, leads to superior free recall of items. They provide a quote from [38], who illustrate this point effectively: “*I need to drive to remember a route. I will remember nothing as a passenger*”.

The minor variations in the method between the studies were mostly indicative of the variations in the user groups and the technologies, however, some variations have offered insight into what works and what does not. In Studies 1 and 2, breaking up the persona creation into smaller parts while focusing on specific facets and drawing on the co-designer participants’ lived experiences worked particularly well. In Study 3, we utilised the SWIM [43] approach to generate the personas by asking specific questions about a real person that the co-designer participant knew. This meant that the initial personas had more information about their impairments and likely resulted in less idealised features for these personas as the starting point was a ‘real person’.

One of the initial expectations of utilising co-created personas was that, by working directly with the people with the impairments/conditions to create the personas, they would

be in some way more realistic. Inspired by the – often unrealistic – personas which represent people with impairments, we felt that the personas themselves could be a viable ‘output’ of the work, and that they could be appropriated by others. However, we would say that we had mixed results here. While some of the personas are realistic, others appear somewhat idealised. Over the course of the projects, this arose due to the co-designer participants’ sympathy and empathy with the persona’s situation. On reflection, this might be indicative of the bond between the co-designer participants and the personas. As a ‘coping strategy’, some of these features were steered by co-designer participants, and were mostly kept in check by the co-designer researchers and other co-designer participants alike. Although we note a potential tension here, we reflect on the early discussions of persona by [30], who note: that it is challenging to “*have every statement in our Personas generated from or related to user data or observation*”. This noted, further work might explore how processes might play a more formative role in guiding more realistic, usable personas in such co-design processes.

6 CONCLUSION

In this paper we have considered the co-creation of personas with three groups of users with diverse needs and detailed how we have utilised them into our co-design work. We believe that our work on the co-creation of personas with users has:

- broadened the demographic beyond a small team of co-designers to include people with diverse health needs;
- fostered empathy, sympathy and memorability within the co-design process;
- offered ‘ramping’ into the design process of being a designer for non-designers; and
- enabled ease of communication through a visual prop, and a way by which users might more effectively criticise designs by using the persona as proxy.

We believe the use of personas as described in this paper might offer new opportunities to engage under-represented and diverse groups of users in the design process, with powerful scope for expansion.

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