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Older Adults with AMD as Co-Designers of an Assistive Mobile Application

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ABSTRACT

In the UK, 20% of people aged 75 years and over are living with sight loss and age-related macular degeneration (AMD) is the most common cause of sight loss in the UK, impacting nearly 10% of those over 80; regrettably, these figures are expected to increase in coming decades as the population ages (RNIB, 2012). This paper reports on the authors' design activities conducted for the purpose of informing the development of an assistive self-monitoring, ability-reactive technology (SMART) for older adults with AMD. The authors reflect on their experience of adopting and adapting the PICTIVE (Plastic Interface for Collaborative Technology Initiatives through Video Exploration) participatory design approach (Muller, 1992) to support effective design with and for their special needs user group, reflect on participants' views of being part of the process, and discuss the design themes identified via their PD activities.

Keywords: *Age-Related Macular Degeneration (AMD), Mobile Assistive Technology, Older Adults, Participatory Design, User-Centered Design (UCD)*

1. INTRODUCTION

Vision loss is the most serious sensory disability as a consequence of ageing (Coccharella & Andersson, 2000) Age-related macular degeneration (AMD) is the UK's leading cause of severe visual impairment amongst the elderly. It accounts for 16,000 blind/partial sight registrations per year and is the leading cause of blindness among people aged 55 years and older in western countries (Bressler, 2004). As a progressive, degenerative disease of the eye it severely affects the macula which is vital for clear central vision. The progress of the disease is typically slow and peripheral vision is usually retained (Mitchell & Bradley, 2006). In most cases, people with AMD have "dry" AMD where pigment and light detection cells in the retina die off and the person experiences gradual loss of central vision. With some people this can, however, progress to "wet" AMD which can result in rapidly reduced central vision (Klein, et al., 1995): in the UK, "wet" AMD impacts 4.8% of the over 65s and 12.2% of the over 80s (Owen, et al., 2012). AMD significantly limits individuals' independence as a result

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of the increased challenges associated with completion of daily activities (Cahill, et al., 2005) and reduces their quality of life (Mitchell, et al., 2008), with 48% of visually impaired people reported as feeling ‘moderately’ or ‘completely’ cut off from society (RNIB, 2012). Strategies to combat AMD are now focusing on prevention of AMD progression rather than expensive pharmaceutical treatments which are not universally effective. There is evidence that there is a link between dietary factors, AMD risk (Beatty, et al., 2001), and AMD progression (AREDS, 2001).

In other domains – e.g., diabetes (Tsang, et al.,2001) – electronic diet diaries have proven to be successful aids for improving independent living. Various electronic diet diaries are available on mobile platforms – e.g., Health and Diet Manager (Softpedia, 2012) – but comprise visually-intensive UIs which are not adapted to people with visual impairment and have not been used in the specific context of dietary recommendation for AMD risk mitigation and progress retardation. Our ultimate goal is to develop an assistive mobile application (SMART) to support accurate and convenient diet data collection on which basis to then provide customised dietary advice and recommendations in order to help support individuals with AMD to mitigate their ongoing risk and retard the progression of the disease.

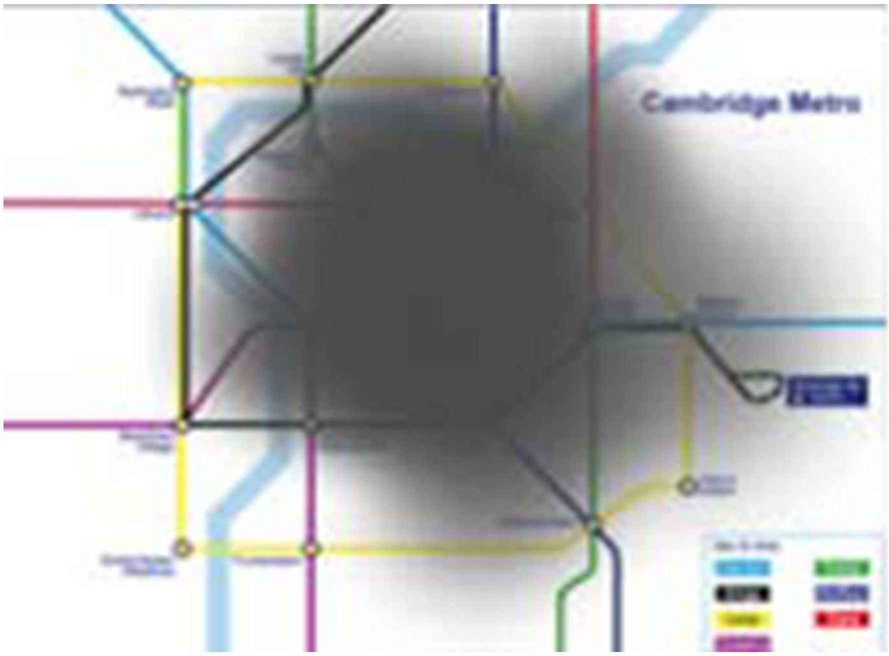
As highlighted by Figure 1, AMD presents a significant challenge in terms of UI design – a challenge which is further complicated by the degenerative nature of the disease. In recognition of this challenge, we are adopting user-centred design (UCD) – in fact, truly participatory design (PD) approaches (Muller, et al., 1993) throughout our research in order to provide participants with an extended sense of being part of the research agenda. Their involvement provides them with a direct mechanism by which to communicate concerns and desires with regard to technology designs, and will hopefully ultimately increase scope for acceptance and impact of the technology once developed. In this paper, we report on our experience of adopting and adapting a PICTIVE (Muller, 1992) participatory design approach to inclusively create paper prototype designs of a self-monitoring, ability-reactive technology (SMART) for users with AMD to support their dietary-based AMD progression retardation over time. We also discuss participants’ reflections on being part of the process and highlight the emergent design themes we identified. Our hope is that, in so doing, we can (a) persuade others that adopting such methods to work directly with special needs users is possible and is useful, and (b) provide some further insight as to how direct involvement of such users might be successfully achieved with relatively easy adaptation and/or accommodation.

2. BACKGROUND

While impairments (physical and/or sensory) that are associated with ageing (Hawthorn, 2000), and age itself (Heart & Kalderon, 2011), can essentially make technologies much harder to use (Hawthorn, 2000), the biggest limitation of technology use by the elderly is the fact that such technologies are not typically specifically designed to meet older adults’ needs, wants, and capabilities (Czaja, et al., 2006; Klein, et al., 1995; Sayago & Blat, 2010).

A recent study examining the experiences and attitudes of older adults towards technology has found that (a) older adults are highly motivated to learn (or continue to learn) to use technology and (b), consideration of their lifestyles and the role of proposed technology is crucial to the successful design of such technology (Caprani, et al., 2012). To overcome the aforementioned limitations researchers have increasingly involved target users in the design and development of assistive technologies by adopting PD approaches. For instance, Wu *et al.* (2004) adopted PD methods to design and develop an orientation aid – *Orienting Tool* – for amnesics to assist them when they feel lost or disoriented by providing information regarding their whereabouts and intentions. Their experiences (including outcome of the project) demonstrated that PD is a viable approach

Figure 1. Example of how a subway map might be viewed through an eye affected by AMD [generated using www.inclusivedesigntoolkit.com]



for involving special needs users with cognitive impairments in the design of technology. Similarly promising results have been noted by Moffatt *et al*. (2004) who used PD methods to design a daily planner for people with aphasia.

A semi-formalised example of a PD approach is the PICTIVE method – a paper prototyping technique which utilises common office supplies (e.g., coloured paper, pens and Post-It™ notes) to produce paper prototypes of user interface designs (Muller, 1992). It relies on video technology as a means for recording design sessions and, in so doing, makes the 'record-keeping' of the sessions relatively easy. The use of inexpensive, familiar, and easily-manipulated materials to generate paper prototypes of designs encourages everyone on the team to contribute equally and fully and, as such, empowers them to become integral members of the PD group – that is, they became full and active members of the design team for the purpose of hands-on design of technology. This, in turn, creates an informal, friendly atmosphere encouraging the sharing of diverse ideas and insights (Muller, et al., 1993). The tangible outcomes of PICTIVE PD sessions are (a) paper prototype designs for the technology, and (b), as a result of the recorded activities and prototype designs, a rich set of elicited user and associated software requirements.

An example of the successful use of the PICTIVE PD method to design technology *with* a special needs user group is the work by Lumsden *et al.* (2005), who designed a mobile application to assist functionally illiterate adults to cope with literacy-based tasks in their daily lives. They report on how, when tailored to a project's needs, the PICTIVE method can be a valuable tool for design activities involving participants with impairments (or adults with limited literacy skills in their case) (Leung & Lumsden, 2008). This view was also supported by Massimi *et al.* (2007) who used participatory (PICTIVE) activities with older adults to transform an off-the-shelf mobile phone into a specially-designed memory aid. Their experiences, which are consistent with those already mentioned, confirm the potential benefits of engaging older adults (with impairments) in the design and development of technology to support their specific needs.

It isn't only older adults (with impairments) who have the potential to benefit from healthcare-related technology designed using the PICTIVE method. For instance, it has been proposed as a 'candidate method' for the design and development of e-Health applications targeted at young women in an attempt to encourage positive health-based behavioural change based on their specific needs and preferences (Duffett-Leger & Lumsden, 2010).

Despite this, and the significant potential for mobile assistive technology to enhance visually-impaired people's healthcare and independent living, persons with AMD have not traditionally been *directly involved in the design* of technology to support their needs. They have been the focus of a study into handheld GUI-based computer interaction for older adults with AMD which identified that severity of the disease, design efforts and strategies, and contrast sensitivity were important indicators for successful iconic search and manipulation of handheld computers by this user group (Leonardi, et al., 2008). Beyond this, however, research into making technology accessible for the visually impaired has, to date, tended to focus on desktop computers for the visually impaired rather than (mobile) assistive technologies for persons with AMD, who have very specific needs and visual capabilities which degenerate over time.

We recently surveyed advances in the field of mobile assistive technologies for the visually impaired (Hakobyan, et al., 2013), and found evidence of innovation in the field of mobile assistive technology for this user group that has the potential to significantly enhance the quality of life of visually impaired persons via, for instance, improved autonomy and safety. Across the projects surveyed, however, we found little evidence of the *direct* involvement of target users in what was substantively research conducted in the computer science domain. Based on our findings, we argued that the potential and beneficial reach of mobile assistive technologies can only be significantly enhanced if computer scientists, clinicians and *users* work together in a participatory manner for the development of the next generation of mobile assistive technologies. Due to the heterogeneity of individuals' capabilities, both across and within a given visual impairment, the needs and capabilities (and, as such, acceptance of assistive technologies) of the visually impaired will likely vary substantially from user to user, depending on their individual circumstances. This is particularly true for people with AMD, who have very specific visual capabilities which degenerate over time, heightening the importance and significance of including a range of end users directly in the design process.

It would appear that, despite the proven benefits of using PD approaches for the design of technology for special needs user groups, in practice such methods are not being adopted as broadly as they arguably should or at least could be. As noted above, we have illustrated that there is little evidence of such methods being applied to the design of technology for the visually impaired, and specifically for people with AMD. Combining our motivation to address the needs of people with AMD via our SMART application with our desire to include them directly and effectively in the design of the technology, we report here on our experience of adopting and adapting a PICTIVE (Muller, 1992) participatory design approach to inclusively create paper prototype designs of SMART for users with AMD to support their dietary-based AMD progression retardation over time. We anticipate that some developers may be wary of engaging with PD activities with individuals with special needs on account of the perceived complexities associated with accommodating their needs in order to include them in the process. In hope of assuaging such potential concerns, and in trying to demonstrate the positivity of experience that arises out of engaging in PD with special needs users, we focus on our *experience* of adopting and adapting PD methods for our special needs user group rather than the tangible outcomes (in essence, as one might expect, these are prototypic designs and identified user requirements) as the nature of the latter is generally better documented and understood than the former. We also discuss *participants'* reflections on being part of the process and highlight the emergent design themes we identified as a result of an in-depth thematic analysis.

3. ADOPTING THE PD APPROACH

Encouraged by the laudable success of the aforementioned studies where PD approaches have been comprehensively and beneficially adopted for the design of technology for special needs users groups, we decided to adopt the PICTIVE PD method for our own research because its central tenets are (a) the inclusion of end users as equal and valued members of the design team, and (b) the use of common office supplies rather than text documents or computer software (Muller, et al., 1993) as the design medium. We felt these underlying tenets made the method well suited in principle to our user group and, since we anticipated that taking part in design work was a new, and perhaps initially overwhelming, task for our participants, we felt the method had considerable scope to empower (further discussed later in this article) them to feel relaxed and able to contribute to the design work without prior technical expertise or experience.

In the remainder of this paper we reflect on our positive experience of adopting and adapting the PICTIVE PD method for our design activities. Our discussion outlines (a) participants' reflections on their involvement, and (b) the design themes surrounding mutual learning that emerged in our design sessions.

3.1. Participants

Following the design process guidelines for designing for and with special needs user groups established by Leung *et al.* (2008), during the initial stages of our project, we: (1) consulted domain experts (e.g., clinicians, ophthalmologists) from several health organisations to attain an overview of AMD and the risk mitigation associated with dietary choices; (2) established contact with local community support groups for people with AMD and attended several of their meetings to allow us to build relationships necessary to engender their trust and encourage their involvement in the PD stages of our research; and (3) conducted a serious of fieldwork activities that employed an integrated range of UCD methods including focus groups and in-home observational studies with persons with AMD (for detailed information about, and discussion of, our fieldwork activities see (Hakobyan, et al., 2012)) for the purposes of knowledge elicitation. Having acquired a deep and relevant understanding of the needs, difficulties, and viewpoints of individuals with AMD via these activities, we invited 4 already-involved individuals (out of 10 who were involved in our knowledge elicitation phases (Hakobyan, et al., 2012)), comprising 3 with AMD and a carer who also had early stage AMD (see Table 1), who were willing to become integral members of our PD group – that is, they became full and active members of the design team for the purpose of hands-on design of our proposed technology to support their healthcare and independent living needs.

Comprising members of different ages, different stages of visual impairment, and different levels of IT literacy, we believe our design team was largely representative of heterogeneity of the AMD community whilst being ideally sized to encourage active participation (the number of participants in such studies in general and, in particular, in successful previous studies with special needs users (e.g., Massimi, et al., 2007) are typically in this order. Given the potential issues of vulnerability associated with participants' capacity to read documentation associated with the study, in all phases of the study we paid particular attention to valid mechanisms for fully informing them about the work and obtaining their consent to participate. To this end, all documentation (including consent forms) was produced in various font sizes and distributed in advance of each phase of the study so that participants could turn to family/support workers to help them read the material and give them a chance to ask any questions before consenting to participate.

Table 1. PD participants' characteristics

ID	Age	Gender	Experience with Computers	AMD Severity
P1	Mid 60s	Female	Moderate	Dry in one eye
P2	Late 70s	Female	None	Dry/wet in both eyes
P3	Late 80s	Female	None	Dry/wet in both eyes
P4	Late 80s	Female	Some	Dry in one eye

3.2. Study Design

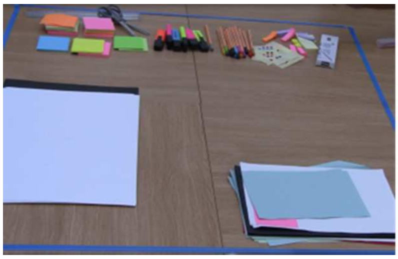
Over a period of 5 months, participants attended 8 design meetings in order to directly contribute, in an empowered way, as experts in living with their condition to the design of our SMART application. Since the PICTIVE PD process advocates that all participants should have equal stake and ownership of the process and the outcome, we opted for a relaxed structure to encourage participants to drive the process rather than being led through it. Although we had originally planned to constrain sessions to approximately 2 hours to avoid fatiguing our members, participants were repeatedly deeply engaged in the process and so were always keen to continue their design work for longer. To this end, we encouraged participants to dictate the length of time they were willing to commit to the session, placing them in control. Consequently, the sessions typically lasted 3-4 hours.

The design sessions took place at the university, in a room chosen for ease of access and good lighting. To remove physical participation barriers associated with commuting, return taxi-based transport was arranged (and funded) between participants' homes and the university. Participants actually commented that they enjoyed conducting this type of work within the university environment. To them, this reinforced the importance of the project and the significance of their contribution; it was regarded as highly motivational and made them feel 'very important' individuals (as is further discussed later in this article).

During the design sessions, participants were comfortably seated around a shared design surface on which they worked (see Figure 2). All sessions were recorded by a camera (to which participants had consented); the area captured by the camera was delineated in blue tape (see Figure 2) on the design surface to ensure all relevant activities took place in view and to allow participants space to work 'off the record' if desired.

In brief, our sessions had the following foci. In session 1, we watched an explanatory video on the PD approach and generally introduced the process. We focussed on understanding participants' perceptions and expectations of our proposed application in order to start eliciting functional requirements. In session 2, participants were first afforded the opportunity to try out relevant applications on an iPhone to help familiarise them with representative technology; we then concentrated on detailed design elements, including colour choice, which led to discussion on the prospect of personalisation and possible ways for recording their dietary intake. In session 3, a considerable amount of time was assigned to icon (design) discussion – in particular, to the advantages of their use and optimal or preferred positioning – followed by a focus on designing the food-recording aspects of the application. In sessions 4 and 5, we identified and prototyped the key screens for the application; a key issue throughout was option/command naming as well as ongoing icon design. During sessions 6 and 7, participants continued to refine the paper prototypes of the user interface created in previous sessions. For the first part of session 6, the group was joined by an optometrist who engaged in the collaborative design exercise to explore motivational design features such as goal setting, virtual rewards, and other playful persuasive

Figure 2. The shared workspace delineated in blue tape



components. We continued with the discussion of suitable colours of maximum contrast for the UI components, and by the end of session 7 completed our paper prototype design. In session 8, participants were presented with an interactive mock-up of the final design in order to identify any shortcomings therein.

3.3. Methodological Concessions/Adaptations

In general, our PD approach proved successful at encouraging creative design thinking and inclusive participant contribution, regardless of level of visual impairment and computer literacy. That said, due accommodations had to be given to the way in which the sessions were conducted to account for (a) participants' individual impairments, and (b) the fact that this was a novel experience for the participants who were trusting us in terms of being with us in our arena rather than in their own comfort zones (in contrast to our knowledge elicitation phase during which we engaged with participants in their domain). Generalisations of the adaptations or methodological concessions we accommodated are outlined below.

- **Adapt Your Selected Method/Approach for the Specific User Group Requirements:** Although, in essence, the PICTIVE PD method was ideal for involving our target users in the design process, we did have to adapt it to accommodate the *specific* needs (capabilities) of our users. We eliminated the need for participants to read/write during the sessions; drawing and writing were, to a large extent, the researcher's undertakings with some assistance from one participant who had very early stage AMD and was rather artistic. We realised very early on in the design process that, to accommodate our participants' visual deficiencies, they would benefit from their own copy of the paper prototype in addition to the one shared at the centre of the work space. Although this deviates slightly from the tenet of PD, participants truly appreciated this because they had to hold the papers reasonably close and at particular angles to be able to see, and some admitted they would be uncomfortable with applying the same viewing technique to the shared document.
- **Use Metaphors and Pertinent Tangible Objects to Encourage and Support Envisioning of Technology:** One of the key challenges for our participants was to envisage (mobile) assistive technologies for the purpose of designing the user interface and determining functional requirements of the application. We found the use of metaphors and pertinent tangible objects of crucial importance in assisting participants to envisage mobile assistive technologies, visualise their design ideas, and encourage creative thinking. For instance, when explaining to participants the difference between a device and its applications, how a device could run various types of applications, and that our proposed diet diary application was one such example, the metaphor of a library with lots of books was

used to illustrate the function of a device with multiple applications. Further, for all design sessions, we provided participants with a tablet device and/or an iPhone to 'play' with as desired to give them a feel for the technology and current application designs.

- **Use Non-Technical (Accessible) Language:** The use of accessible, non-technical language by the researcher was of crucial importance when providing explanations and guiding discussions. Simple explanations that reflected participants' mental models (combined with the ability to experiment on touchscreen phones and tablets) allowed participants to effectively understand unfamiliar concepts and enhance their contribution. For instance, participants found the whole idea of navigation from one screen to another via touch/click incomprehensible to begin with. We explained it with a comparison to a book and its content page: we illustrated with a book how the content page could be viewed as a 'menu' structure from where buttons/options link to particular 'pages' of the application – similar to how chapter names (with corresponding page numbers) in the content page of a book support look-up of the corresponding book sections – noting that on a device a touch/click would take the 'reader' to the actual page as opposed to having to physically turning pages of a book. Following this, the same concept was illustrated on paper with Post-It™ notes as buttons, with the advantage that this medium of explanation (unlike the actual technology itself) allowed participants to 'see' all pages laid out in front of them and 'envisage' how 'touch' can change screens. Participants were frequently reminded that they should ask questions for further explanation whenever necessary.
- **Accommodate Comorbidity Issues:** In addition to their visual deficiencies, people with AMD often have other age-related impairments. Thus, to encourage participants' involvement and maximise their contribution to the design work, we needed to not only compensate for visual deficiencies but to also accommodate comorbidity issues. Our participants experienced difficulties with hearing, memory, and one participant also had arthritis. To combat memory problems, for instance, (a) each session commenced with a summary of the previous session and (b) we included quick updates (i.e., how far we were in the process and what we had achieved so far) throughout each session to recap the group's achievements.
- **Establish a Friendly Atmosphere:** Taking part in design work is likely to be a new and, perhaps, initially overwhelming task for most older adults. We found that establishing a friendly atmosphere helped stimulate and encourage individuals' contributions. We developed a trusted and professional relationship between the researcher and our participants, which we feel was a strong contributing factor to participants' motivation and determination to 'try their best'. This was made possible by the pre-PD knowledge elicitation phases already discussed (Hakobyan, et al., 2012).

4. PARTICIPANTS' REFLECTIONS

While taking part in PD sessions was a novel experience for all of our participants, the practice of conducting PICTIVE PD with older adults with AMD was also novel from our perspective. We feel that the process was a success in terms of (a) the tangible outcome of the sessions (i.e., the final prototype designed by the team and rich set of elicited requirements determined via the prototype and associated discussions), and (b) the extent of participants' involvement in and contribution to the process as 'experts' living with their condition. Whilst *we* found the overall process extremely valuable and illuminating, we were also keen to assess whether our chosen method was the right choice for our target users from *their* perspective. To understand how they felt about it, we conducted a very informal one-to-one interview with 3 of our participants (unfortunately, our fourth participant could not take part due to ill health). Interviews were conducted at participants' homes at their request, and occurred 3 months after the final PD session to encourage participants to comment with the benefit of reflection and hindsight about their experiences.

All interviews were recorded and, subsequently, transcribed. All data collected was qualitative, and was thereafter subjected to analysis using Braun and Clarke's (2006) technique for thematic analysis to enable us to identify patterns of meaning across the dataset and afford a representation of participants' experiences and perceptions of taking part in the PD sessions.

To conduct the thematic analysis we first familiarised ourselves with the data by carefully reading the transcripts. Following this, a second reading was conducted to summarise preliminary topics that identified important features within short segments of data. Individual data extracts were then labelled or coded with a descriptive word or phrase summarising key points. These codes/labels were then sorted and combined into coherent groups that identified broader patterns of meaning. It is important to note that, for the purpose of analysing the interview transcripts, we refrained from explicitly naming individual themes due to our relatively small dataset; instead, we engaged in an interpretive analysis of the data extracts in terms of participants' experiences of taking part in the PD sessions, their views about the manner in which the sessions were conducted (including session aims, the design space and pace of work), and their opinions about the final prototype design. In so doing, we hoped to summarise what aspects they found interesting, valuable, confusing, challenging, etc., and to identify how similar sessions could be improved in the future. Overall, all participants very much enjoyed the design meetings. One participant's somewhat moving feedback aptly exemplifies and summarises all 3 participants' views on the design sessions:

It has given me an interest in what the blindness has done to me. So from those sessions it's a bit like seeing it rise from the ashes. It brought me a life, and for that I am grateful for, and, indeed, the friends that I made. It was fun, not only was it educational, it was fun! I looked forward, so it gave me an outlook of life really. It gave me something back that losing my sight had pinched away from me!

In terms of the meeting space, participants enjoyed traveling to the university; they found the table set-up really 'useful' and appreciated the opportunity to 'pass things' around. One participant suggested a smaller room with more windows could have been more suitable. All participants were astounded to learn how simple office supplies such as coloured paper, Post-It™ notes, and pens could be used to design 'technology'. All commented on their initial surprise to see those on the table, and to 'see' in subsequent meetings how those were brought together to develop and form the whole concept of the design. As one participant noted:

It came all together so wonderful, like a good play, brilliant, good plot, excellent!

Participants found the short summaries at the beginning of each session beneficial for understanding the aim of each session and felt at ease asking questions whenever necessary. Similarly, they found it 'easy' to contribute to both the discussions during the meetings and the actual paper design. This was essentially due to the group's dynamics, positive atmosphere where everybody was interested in what others had to say and no one was 'dominant' (thus no one felt 'threatened'), and because the meetings were not tightly structured. Participants formed strong bonds, and hoped to remain friends after the completion of the project.

Further, because participants did not feel 'stressed' (both during and after the meetings), and no 'home-work' was involved, they actually came away from the sessions thinking about issues discussed (on two occasions, following a design session, participants were self-motivated to phone the researcher to discuss solutions to a problem encountered during the session).

Participants commented that the activities during the design sessions stimulated their learning, and that the PICTIVE PD sessions were a good way to learn about technology. Participants were 'surprised' to 'learn' and 'enjoy' something they previously did not understand.

Participants felt a sense of pride and ownership of the final prototype design. At one point, one of the participants was questioning the researcher's opinion on *'their'* design. They identified that their opinions were taken on board and manifested in the final design. Completing the design sessions was a major achievement for all participants; they felt privileged to have been asked to participate. One participant explained:

All my children were very impressed. I was baffling with science! You have asked me to do this, because you can clearly see something in me that the project could benefit from, I felt very privileged, really!

All participants expressed disappointment that the design sessions drew to a close and, remarkably, could not really offer any significant suggestions for improvements. They would have been happy to have continued with the process. They were all anxious to see "*their*" prototype implemented and put to practical use.

Overall, participants' post-process feedback emphasised that participating in the project had heightened their perceptions of independence; they felt that they were effectively contributing to society (and their community) by being able to apply 'unrelated' skills (essentially their wealth of experience and knowledge) to the development of an assistive technology from which future generations could benefit.

4.1. Researchers' Reflections

From our perspective, we found it enlightening to work with older adults with AMD – to work collectively to achieve a common goal with different generations, with different life experiences and yet largely a lack of IT experience, and different levels of impairment was thoroughly rewarding. While rewarding, however, the experience was not without its challenges. Above all, it was emotional for the researcher to empathise with their difficulties in terms of living with their impairment and to listen to their life stories, both happy and sad; thereafter, it was sometimes difficult to find subtle ways to divert conversation back to the task to retain a work focus. Secondly, due to the age differences between the researcher and participants (the researcher is a *lot* younger than the participants) the researcher occasionally found it awkward trying to 'teach' participants who had a great wealth of life experiences and knowledge in other domains; she also found it challenging at times to try and place herself in the shoes of the participants in terms of technological knowledge, in order to start building their understanding from the 'roots'. Nevertheless, participants' willingness to learn and support themselves was a key motivational factor for the researcher. Further, the reassurance that the proposed solution was going to be beneficial to the participants (and others to which it could be generalised) was an incentive and great source of motivation and perseverance for the researcher; it was, in fact, of fundamental importance in overcoming imminent challenges on the way.

5. EMERGENT THEMES

As noted, application of the PICTIVE PD method was a reflective and educational experience for all parties involved. The video-recordings from the sessions themselves were also transcribed and returned a rich set of data from which some distinct themes emerged as result of in-depth thematic analysis. In addition to the procedure outlined for analysing the interview transcripts, on account of the fact we had a far greater data set from the series of design sessions on which to base our analysis, we explicitly identified, defined and named themes by sorting and combining relevant codes (see Table 2 for an example of how codes were applied to data extracts from the PD transcripts).

Table 2. Examples of data extracts with codes applied

Data Extracts	Coded As
It's a brilliant idea, because if we, and the likes of us, can learn it, you know, it's marvellous, it keeps your brain active, it stimulates its cells. You might do it for keeping track of food but it will also keep your brain cells alive.	1. Stimulates learning 2. Keeps brain active
The idea that I can be on computer – I would love it! It would make me feel intelligent again, it's so embarrassing with this condition so I don't go out and this would be wonderful. And now that my daughter goes to university, I can go on Facebook and keep in touch that way.	1. Improves self-esteem 2. Prospect of being connected/keeping in touch
We could enter our name, so when you switch it on it says: "Good Morning [name]". This way it's more personal, it's a motivational thing. I would think then at least someone is thinking about me. It makes me feel happy, it sounds nice!	1. Importance of personalising 2. Motivational factor 3. Combatting loneliness/isolation

Following this, the data extracts (including relevant codes) were reviewed by rereading the data extracts for each identified theme to ensure that (a) they formed a coherent pattern within each theme, and (b) to ensure the validity of identified themes in relation to the entire data set. The final phase of analysis involved analysing key aspects each theme captured to determine their scope and focus and this resulted in an informative name for each theme; Figure 3 is an example of a final stage thematic map of initial themes and sub-themes/codes (codes and themes are embedded in rounded rectangle and oval shapes, respectively) demonstrating how different data codes are allied and how they could simultaneously correspond to several themes (e.g., the data code 'Praise and encouragement' fits both into the 'Mutual Learning' and 'Empowerment' themes). It is important to note that individual data extracts were at times associated with multiple codes (as illustrated in Table 2), and individual codes were reapplied to different data extracts only when the conveyed message of both extracts were almost identical (although in Figure 3 some of the codes have a degree of similarity, they are not combined under an umbrella term to preserve key features of each data extract).

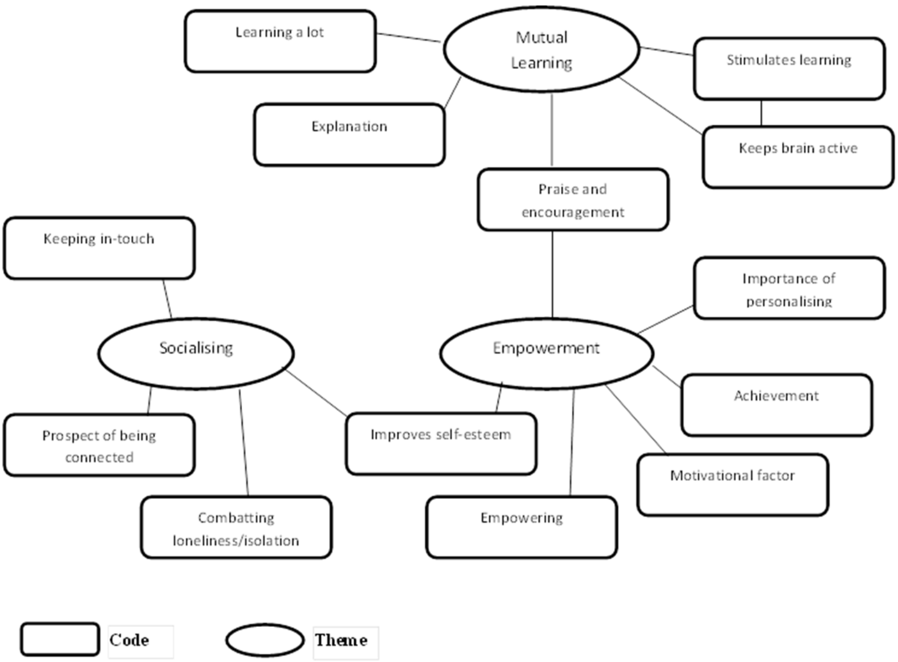
5.1. Mutual Learning

The dominant theme to emerge from our activities was certainly the mutual educational nature of the process. Our objective for adopting UCD – and, in particular, participatory design – approaches was to learn about the needs of users with AMD, to appreciate the implications of designing for this user group and to understand how these can encourage (or hinder) technology use. Despite their personal challenges, our participants invested considerable time and effort in learning new skills; equally importantly, they taught us a great deal about their needs, experiences and expectations. In addition to the exchange of knowledge between the participants and the researcher, participants taught each other and delighted in each other's progress.

Participants agreed to go to each other's houses and support one another in using computers/tablet PCs; in fact, two participants were considering purchasing tablets similar to the ones they tested during the PD sessions. One also agreed to help another participant 'operate' her mobile phone and socialise more (a subtheme discussed above).

The office supplies used within the PICTIVE method eased the process of learning about technology. Participants commented:

Figure 3. Initial thematic map of emergent themes and codes



This method was great! I was picking up young [researcher's] brain, I wouldn't have been interested otherwise" and "Coming from nothing, then enjoying something I did not understand earlier, to yearn for some more, then that speaks for itself!

The extent of the progress participants had made regarding learning technology since participating in the project was illustrated when one of the least computer literate participants (P3 – see Table 1) suggested to 'ask Google' when the team failed to find a suitable name for a command.

Throughout the process, participants were keen to learn as much as possible, including pushing themselves to understand concepts that were not a necessity for successful participation in the process. An excellent example of this curiosity arose when participants asked for a comprehensive explanation of processes surrounding recording their dietary intake and receiving recommendations/advice: participants were keen to learn where 'all that information' would 'go' (i.e., be stored), who would have access to it, and where the recommendations would come from. A brief and appropriate-level explanation about databases was provided to the participants, and we demonstrated how to search for an item within a sample existing diet diary application available on an iPad. One participant commented:

I am learning a lot from this program. It's like doing 'A' levels.

In addition to learning about technology, participants were concerned about the current/existing lack of nutritional guidance and appropriate support available to people with AMD. From the PD sessions, participants also learned a great deal about 'healthy lifestyle'. During the individual interviews, two participants declared that they had improved their diet since taking part in the project. This is a fantastic example of behavioural change as a side-effect of design participation.

Finally, as already mentioned, *we* learned a great deal about the needs, attitudes and perceptions of users with AMD, and older adults in general. Mutual learning throughout all stages was fundamental for the endurance and success of the project; we were reassured about participants' willingness to learn from and contribute to the PD sessions. Their positive interaction with computers (for those participants who owned computers) demonstrated that older adults (with AMD) could and would use technology if the potential benefits of such use are easily understood and appreciated.

In the following sections, we discuss two further subthemes that emerged as a consequence of participants' desire and willingness to learn.

5.1.1. Socialisation

By being involved in the project, participants also gained an opportunity for socialising (a valuable component in the general wellbeing of the elderly, especially elderly who are often otherwise isolated as a consequence of disability, in particular AMD, which can be a very isolating disease (Stanford, et al., 2009; Wong, et al., 2004). Since all members of our PD team were involved in all of our preceding UCD methods, a very strong bond formed between the participants and the researcher. Since the sessions were not tightly structured, there was opportunity for participants to occasionally engage in social conversation. Although these practices certainly resulted in slow progress at times, this proved necessary to encourage and motivate participants. Interestingly, whenever the conversation deviated onto a social topic, one of the participants (as opposed to the researcher) was always first to prompt the team to return to the task and keep working!

Additionally, after every PD session, the team (including the researcher) went to the university's coffee shop for a hot drink with snacks. This presented a great opportunity for participants to discuss matters outside the project scope (i.e., family, health, travel) and further cement their friendships, including that with the researcher. Participants' post-process feedback emphasised the importance of their bond with all team members; they considered this friendship as a key factor in their motivation. It is worth noting that, on no occasion did any of the participants reschedule, cancel or miss a PD session, with the exception of one member who was unable to attend the last meeting due to ill health.

One participant, who was very keen to participate in the project but was initially sceptical about working with others in a team, made the following comment:

After 12 years, I have met people, and made good, firm friends [...], I was encouraged to speak and say what I felt [...], I really miss the sessions now, it had brought a hope for me!

Finally, participants indicated that they could better relate to and feel part of a much younger and technologically-advanced generation (due to the researcher's age and profession) as a result of being part of the process. We believe this relationship was the fundamental source of motivation and determination for participants to 'try their best' – as one participant encouraged others during one of the design sessions:

None of us want to let [researcher] down, so when we start this we will keep on going, we got to prove it. We are the pioneers.

5.1.2. Empowerment

As already noted, by adopting a PICTIVE PD method we hoped to empower older adults with AMD – to make them feel relaxed and able to contribute to the design work without prior technical knowledge or expertise. This was an inspiring and encouraging experience for our participants, who were proud of being part of a research team. In fact, to them this enhanced their social status. For instance, one participant proudly explained:

My building's manager was very impressed; she had someone in her complex who was going to the university.

This experience changed our participants' outlook of life, stimulating strong desire to aim higher at this stage in their lives. Two participants expressed regrets in not obtaining university degrees, and mentioned that they would have considered an Open University degree if they had met the researcher some years ago.

Participants spoke highly of their involvement and the prototype design:

It was a unique experience, I am most grateful for it. […] I am very proud that someone could benefit from it.

For three of the participants, taking part in the project was a unique opportunity to contribute to and influence something important/beneficial and, as such, take charge of their lives since losing their sight.

Like those who have used PICTIVE for other healthcare-related technology design, we firmly believe that the PICTIVE PD method can be a valuable tool (if adapted to the needs of a given project) for design activities involving users from different backgrounds with different impairments (not just people with AMD) by empowering them to fully participate in the design of a technology that will impact their lives.

From an ethical perspective, our experience and participants' reflections suggest that we have been successful in removing barriers to participation, including individuals in research that has the potential to impact them directly, and in achieving beneficence – both in terms of the deliverable and the wellbeing-related bi-products of participation (which, we should note, we will continue to support via ongoing research activities and contact with the participants). We hope that our observations are of value to others faced with the challenge of designing technology for special needs user groups.

6. CONCLUSION AND FUTURE WORK

This work, whilst representing the design stages of an ongoing research agenda, elicited valuable qualitative and previously unstudied information about the attitudes, needs, wants and capabilities of individuals with AMD as they relate to assistive technology and successful methods for its design. Based on our experience, we believe that direct, integrated participation of older adults with visual impairments (i.e., AMD) in the design process for assistive technology to support their needs (a) is essential in terms of teaching us about the potential positive impact that assistive technological solutions may have on their healthcare, independence and quality of life, (b) by virtue of a deeper and more valid understanding of their needs, has the potential for significant influence on the success of technological development in terms of technology acceptance and ultimate impact, and (c) is eminently possible via easily implemented methodological adaptations and accommodations. From our perspective, working so closely with older adults with advanced disabilities, although sometimes challenging, has been highly rewarding and exciting. Our experience, combined with our participants' feedback, indicates that our tailored PICTIVE PD method was a valuable tool for involving users with AMD in design activities, and for encouraging them to act as fully empowered co-designers. The result, in tangible form, is that we now have clear prototype designs for our SMART application together with a rich set of elicited user- and software-related requirements that we are confident represents the needs and preferences of our target users.

As part of our ongoing research activities, we have arranged meetings with people with AMD who have had no prior involvement in the design process in order to evaluate the design prototype. Upon successful completion of this phase (and any re-design that is identified necessary) we will commence development, to include the UI itself as well as the back-end which will involve the creation of an appropriate food ontology and the development of a rule engine that will combine information from the ontology with data from user profiles and dietary recordings from users to generate individualised recommendations to empower ageing people with AMD to make informed dietary choices.

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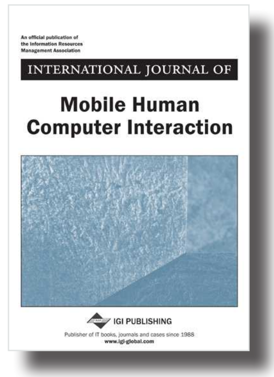

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