Participatory Design:
How to Engage Older Adults in Participatory Design Activities

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ABSTRACT

Ongoing advances in mobile technologies have the potential to improve independence and quality of life of older adults by supporting the delivery of personalised and ubiquitous healthcare solutions. The authors are actively engaged in participatory, user-focused research to create a mobile assistive healthcare-related intervention for persons with age-related macular degeneration (AMD): the authors report here on our participatory research in which participatory design (PD) has been positively adopted and adapted for the design of our mobile assistive technology. The authors discuss their work as a case study in order to outline the practicalities and highlight the benefits of participatory research for the design of technology for (and importantly with) older adults. The authors argue it is largely impossible to achieve informed and effective design and development of healthcare-related technologies without employing participatory approaches, and outline recommendations for engaging in participatory design with older adults (with impairments) based on practical experience.

Keywords: Design Approaches, Inclusive Design, Mobile Technology, Older Adults, Participatory Design

1. INTRODUCTION

The global population of people aged 60 years and older is growing rapidly; it is estimated that the proportion of the world's population over 60 years of age will reach 22% by 2050 (WHO, 2014). The aging population is creating serious healthcare provision challenges given that healthcare expenditure typically increases with age and is predicted to account for an ever increasing proportion of healthcare budgets in the future; adults aged 85 and over consume three times as much healthcare per person as those aged 65-74, and twice as much as those aged 75-84 (Alemayehu and Warner, 2004).

Ongoing advances in mobile technologies are increasing the scope for supporting the delivery of healthcare to older adults within their homes via mobile assistive healthcare technologies. Unfortunately, however, age-related physical and sensory impairments – many of which change or degenerate over time – are

common amongst older adults and present a number of design and ethical challenges in terms of the successful and effective development of such technologies. In addition to these challenges, there are significant barriers for the use of technology by older adults, including counter-intuitive interfaces and the fact that such technologies are not typically specifically designed to meet older adults' needs, wants and capabilities (e.g., Leonardi *et al.*, 2008).

An estimated 40% of information systems projects do not ultimately meet user requirements, and more than 60% of projects go over their estimated budgets due to inadequate user needs analysis; one of the main factors underpinning poor systems development is lack of practical participatory, user-centred design (UCD) knowledge and application within development teams (Johnson *et al.*, 2005). The involvement of stakeholders in software development processes has long been advocated in recognition of the proven higher levels of user acceptance of the resulting technology (e.g., De Rouck *et al.*, 2008; Lacey and MacNamara, 2000). Designers adopting the participatory user-centred philosophy recognise that they are not simply designing for themselves (to their own preferences) or for people with similar abilities and needs, but are instead designing for individuals who are often very different in terms of needs, capabilities, and attitudes (Cheverst *et al.*, 2006). While it could be argued that conventional participatory UCD methods are not always entirely appropriate when designing for a large diversity of users (Stojmenova *et al.*, 2012), or are challenging to apply when engaging individuals with impairments (Connelly *et al.*, 2006), it is nevertheless imperative (to achieve maximal utility, usability, and acceptance) that users' needs, capabilities and wants are given extensive attention when designing technologies for their use.

1.1. Design Approaches to Healthcare Technologies

Healthcare technology designed for patient use has the potential to empower patients to become increasingly engaged in improving their own health and taking on a more active role in their healthcare (Wolpin and Stewart, 2011); assistive healthcare technologies have the potential to enable users to live more independently, to improve users' quality of life, and to better sustain their healthcare. In order to fully realise these benefits, however, such technologies must meet patients' real needs and capabilities effectively and this is best achieved via direct stakeholder involvement throughout the technology design and development process. To understand the extent to which stakeholders, and in particular end users, have participated to date in the design and development of patient-centred healthcare-related technologies, we conducted a review of the literature catalogued in PubMed (which comprises citations for clinical/healthcare literature). We limited our search to focus on research studies that reported healthcare technology for *patients'* use only, and had the design/development of technology rather than its implementation as the primary topic. Our aim was to discover the extent to which participatory methods/tools are being applied in the design and development of technology-based healthcare interventions for patients' use. Only articles that described the development of a healthcare-related application, device or system for patients where the application required user interaction were included in this review. As such, articles that focused on the back-end of the technology (e.g., Li *et al.*, 2008) or required limited input from/interaction with users (e.g., Vervloet *et al.*, 2011) were excluded from this review. In total, 18 articles were reviewed in detail (see Table 1).

Both this review (as well as our more extensive survey of assistive technology development for the visually impaired (Hakobyan *et al.*, 2013a)) largely reinforced anecdotal observations that the practical application of participatory research (or participatory HCI) for the purpose of software design (especially in the field of assistive healthcare technology) is rarely comprehensively documented or even discussed in detail. Furthermore, it would appear that the tenets of participatory research/participatory HCI are open to considerable

Table 1. Summary of the reviewed technology showing participatory research/UCD methods reported across all 18 papers included in the review

Healthcare Technology	Description	Focus Groups	Interviews	Surveys/ Questionnaires	Observational Studies	Diaries	Participatory Design	Usability Testing
Personal Health Application (PHA) for diabetes (Fonda *et al.*, 2010)	The prototype PHA receives data on major self-management domains, analyses, and provides simple feedback.	✓						✓
Mobilehealth monitoring system (Suh *et al.*, 2012)	A remote monitoring system for monitoring health status of patients with diabetes.							✓
Heart rate monitoring system (Segerståhl, 2009; Segerståhl and Oinas-Kukkonen, 2011)	Heart rate monitoring systems employing a wearable heart rate monitor and web service.		✓			✓		
Mobile phone technology for asthma (Ryan *et al.*, 2005)	A system employing a handheld electronic peak flow meter connected to a mobile phone.							
Cardiac rehabilitation monitoring system (Worringham *et al.*, 2011)	Provides supervised cardiac rehabilitation to patients via a smartphone, ECG and GPS based system.							✓
RemoteLogCam (Güldenpfennig and Fitzpatrick, 2013)	A wearable device to help an individual with cerebral palsy to self-manage hand spasms.		✓					✓
Self-Management of pulmonary rehabilitation (Marshall *et al.*, 2008)	Uses a smartphone to train users to undertake exercise.		✓					
Personalised diabetes telecare (Tsai *et al.*, 2012)	Provides personalized diabetes healthcare services for patients on smart phones			✓				✓
Mobile tool to support lifestyle changes (Jurgensen, 2011)	A tool to help people to take action against obesity and stay motivated for making and maintaining a lifestyle change						✓	
HealthAware (Gao *et al.*, 2009)	A real time system to prevent obesity by enhancing individual daily healthy behaviour							✓
Telehomecare for patients with multiple chronic illnesses (Liddy *et al.*, 2008)	A telehomecare unit collects patient data on vital signs and health information from patients to be accessed by care providers	✓	✓	✓				
Active Lifestyle (Silveira *et al.*, 2013a; Silveira *et al.*, 2012)	An IT-based system for active and healthy aging aiming at improving elderly's balance and strength			✓				✓
VIVOCA (Hawley *et al.*, 2013; Palmer et al., 2010)	A voice-input and voice-output communication aid people with severe speech impairments	✓	✓	✓				✓
Us'em (Markopoulos *et al.*, 2011)	A device for motivating stroke patients to use their impaired arm-hand in daily life activities	✓	✓					✓
AUBADE (Katsis *et al.*, 2006)	Recognizes emotion and allows the user to view the facial animation generated from the estimated emotion state.							✓
HealthGear (Oliver and Flores-Mangas, 2006)	The system monitors the subject's SpO2 and pulse while sleeping and automatically detects sleep apnea events			✓				✓
HealthWeaver Mobile phone application (Klasnja *et al.*, 2010; Klasnja *et al.*, 2009)	Supports cancer patients' unanchored health information management with mobile technology		✓		✓		✓	✓
Interactive robotic device (Tiwari *et al.*, 2011)	A device empowering older patients to engage in self-care (e.g., medication management)		✓		✓		✓	✓

variation in interpretation. For the purpose of the discussion in the remainder of this article, we adopt the relatively broad or traditional definition that participatory research/participatory HCI, as applied to technology development, refers to a democratic approach to technology design that calls for end-user involvement in the design process. In practice, this ideally means the application of methods often referred to under the umbrella term of user centred design (UCD), including focus groups, interviews, surveys/questionnaire, observational studies, diary studies, and usability testing. Distinct from these methods is participatory design (PD) – the most directly participatory of all the UCD methods – in which end users are actively established and empowered as co-designers in the process.

Of the 18 papers reviewed, 1 paper (6%) reported no use of participatory UCD methods/tools at all, 6 papers (33%) reported the adoption of only 1 method, 6 papers (33%) reported adopting 2 methods, 2 papers (11%) reported use of 3 methods, and 3 papers (17%) reported adopting 4 methods; no project reported using more than 4 of the listed methods, with a maximum of just over half of the available methods being used in any one project. The most commonly adopted method was user testing, followed by interviews, with project teams apparently favouring the less structured and more easily set up methods overall (Vredenburg *et al*., 2002; Gunther *et al*., 2013). It is important to note that the frequency of use of a method does not necessarily reflect its usefulness; methods that are typically ranked highly for practical value can be infrequently used due to cost-benefit trade-offs when selecting participatory UCD methods or due to a lack of knowledge about different UCD methods.

Whilst it is encouraging that user-focused evaluation is being conducted, this is far from a truly participatory UCD-based approach to design in that the users are only being engaged when there is something to test, rather than being democratically included as an integral part of the design process itself. Participatory UCD-methods were used in 8 of the 18 proj-ects for knowledge elicitation, and it is here that researchers often engaged more than one UCD method (e.g., focus groups, interviews, observational studies, etc.). Only 4 of the 18 projects utilised participatory UCD methods during the design phase of their research; this is perhaps the most critical phase in which to engage users in order to return a design which is likely to garner user acceptance, with the relative absence of the use specifically of participatory design methods being especially noteworthy in terms of the degree to which users were being engaged in this part of the process.

In particular in terms of the general lack of design-stage utilisation of participatory UCD methods, our review results corroborate previous findings which indicated that participatory UCD is generally under-utilised in the area of healthcare technology innovation (Searl *et al*., 2010); furthermore, where user participation *is* reported, the experience is not well documented.

A large number of healthcare-related information systems currently fail to achieve expected success due to lack of sufficient involvement of stakeholders during the design process: users are expected to adapt to technological solutions which were intended to increase efficiency, productivity, etc., but which stand little chance of doing so given the processes by which they were developed (Zhang et al., 2005). Although we reviewed the extent to which participatory UCD methods are utilised in the design of technology for the healthcare domain specifically, it should be noted that this under-utilisation of such methods is likely a gross underestimation in terms of its impact on technology use by people with health-related needs because the review hasn't included publications where the focus has been on development of technology for disabilities rather than healthcare.

Despite the above, we are starting to see increased research focus on facilitating, via participatory design (PD), the involvement of special needs users in the design of technologies to maximise their potential for impact and acceptance by such user groups (e.g., Lindsay *et al*., 2012; Leung and Lumsden, 2008). Fisk

et al. (2012) suggest the following key issues to consider when designing user interfaces for older adults:

- Consider older adults' range of abilities and experiences;
- Ensure user goals and expectations match system functionality;
- Consider how best to organise and present information and compatibility issues;
- Provide tools to minimise potential navigation issues; and
- Provide informative documentation for the system including error messages, user manuals and help systems.

Studies in the field of healthcare technology innovation that are advocating the practical use of participatory HCI when developing patient-centred healthcare technology (e.g., Searl *et al.*, 2010; Horsky *et al.*, 2012) indicate that such undertaking does not need to be costly – for example, it can focus on working with target users on paper-based mock-ups and/or conducting interviews (Wolpin and Stewart, 2011). While the potential benefits of engaging older adults (with impairments) in the design and development of technology are widely acknowledged, researchers are calling for a more systematic understanding of the challenges and methodological concessions necessary when engaging with older adults, and general understanding of how such participation is planned and managed (e.g., Lindsay *et al.*, 2012; Vines *et al.*, 2013).

To demonstrate the successful use of low-cost participatory UCD methods, and in an attempt to contribute to such understanding, we reflect below on our positive experience of and describe lessons learned from adopting and adapting a participatory research approach utilising a range of methods, including participatory design itself, to involve our target users in the design and development of a proof-of-concept healthcare diet diary application for older adults with AMD who have very specific needs and capabilities which degenerate over time. Interested readers are referred to (Hakobyan, *et* *al.*, 2013b, Hakobyan, *et al.*, 2014) for specific detail on our methods and findings.

2. DESIGNING WITH OLDER ADULTS WITH AGE-RELATED MACULAR DEGENERATION: BEGINNING PARTICIPATION

The most common cause of sight loss in the UK is age-related macular degeneration (AMD); typically affecting people aged 50 and above, it impacts nearly one in ten of those over 80 and accounts for 16,000 blind/partial sight registrations per year (RNIB, 2014). There is evidence that progression of AMD is closely linked to nutritional intake (AREDS 2, 2013). As such, we have worked with individuals with AMD as co-designers in the design and development of a mobile software application intended to promote independent living, enhanced wellbeing, and to hopefully reduce risk of AMD progression based on dietary intake and associated recommendations for people with AMD. At the onset of our project, we consulted domain experts (e.g., optometrists, ophthalmologists) to elicit their expert opinion on how to design our proposed technology such that it can best fit the capabilities of individuals with AMD and, most importantly, on how to engage individuals with AMD directly in the project; interestingly, although we anticipated existing frameworks within ophthalmology for involving AMD users in research projects, we learned that the notion of user participation in research in the field of ophthalmology was very different from the democratised approach we were proposing and realised that part of our challenge would be addressing misconceptions about the nature of participation of members of the AMD community within our research (see below).

We established contact with local community support groups for people with AMD and attended several of their meetings to allow us to immerse ourselves within the community and start getting to know its members. Over a period of 2 months we attended 4 meetings

where we had the opportunity to informally introduce ourselves and our project goals, and to start to learn about our target users' condition and, accordingly, capabilities and limitations from the support network and its members. This allowed us to build a trusted professional relationship with individuals with AMD in an environment in which they were comfortable and to ultimately elicit their voluntary involvement in our research. From consulting domain experts and attending the local community support group meetings it was apparent that the main reason people expressed for being reluctant to participate in research studies was a misconception that laboratory-based research essentially "*used*" people as experimental subjects rather than consulted/involved as experts living with their condition. We quickly realised that, in order to fully benefit from their participation in our research, we would need to address such misconceptions about involvement in our research studies; we needed to convince our participants, in both discussion and action, that we considered them as experts in living with their condition and that our research was entirely aimed at meeting their needs (rather than the other way around); our ultimate success in doing this not only allowed for rewarding and informative focus groups, but it ultimately led to us being able to invite a subset of the focus group participants to take part in the subsequent stages of our project, thus substantially easing the process of finding and recruiting participants for those stages. Results from our participatory work would also suggest that our involvement of participants has drastically altered, in a positive way, their opinion of research and their ability to contribute in a meaningful way to research of benefit to them.

2.1. Focus Groups

Following our community engagement we invited 10 participants to take part in focus groups (conducted in locations familiar and convenient to our participants to overcome potential barriers to participation based on travel concerns and to ensure participants were relaxed in the surroundings) over a period of 4 months; the aim of the sessions was to launch the participatory research and, in so doing, to start learning about and, as such, better understand various aspects of our target users' lives (in particular, how they cope with living with sight loss), to understand their experience with and attitudes towards (mobile) technology, to help us to effectively plan subsequent stages of our research in terms of being sympathetic to our potential participants'/users' abilities and needs, to enable us to determine the context and setting of our future activities, and to allow us to engage potential participants for our participatory design activities. Considering the above, the first focus group sessions were structured to gain insight into participants' views/perceptions on and attitudes towards technological devices per se. Following this, the subsequent focus groups concentrated on participants' coping strategies in terms of living with AMD, the challenges/barriers to day-to-day activities posed by the disease, and their perceived independence and quality of life. The final focus group meetings concentrated on our proposed SMART application – the aim was to elicit participants' opinions on the proposed technology and related high-level needs and wants.

2.2. In-Home Observational Studies

Emerging from the focus group discussions was a realisation of the true extent of heterogeneity of individuals' capabilities, experiences of living with AMD, and, as a result, the significant differences in their needs in terms of acceptance of assistive technologies. As such, reflecting on this learning, we considered it essential to attain a true sense of 'being there' with representative participants, experiencing their daily life, in an attempt to gain (a) a detailed appreciation of their daily coping strategies and what it is like to live with AMD, and (b) their technological needs so that we could ideally model their daily coping strategies in such a way as to be able to map relevant concepts into the design of our technology. To do this, we conducted a series of

in-home observation sessions over the course of three months. We recruited 4 participants from the focus groups (one male and three female) who were particularly eagerly engaged with the process and willing to participate in this next phase. In recognition of their vulnerable status and for reasons of professional indemnity, participants were strongly advised to invite a third party whom they knew well (e.g., family member, friend, carer, etc.) to be present while the observations were taking place; where participants decided not to have a third party present, they were asked to provide details of a person to contact in case of an emergency. In total, 6 observational sessions were conducted; the number of sessions conducted per participant was determined by availability and also by professional judgment as to whether additional sessions with the given individual would elicit new data (i.e., a judgement as to whether data saturation had been reached); each session lasted no more than an hour. Observations were kept very informal to ensure participants felt at ease: handwritten notes were taken, and the researcher engaged in discussion with each participant as befitted the situation.

2.3. Participatory Design

After having conducted extensive initial participatory knowledge elicitation activities, we adopted the PICTIVE PD method (Muller, 1992) for our UI design activities with people with AMD to create paper prototype designs of a mobile diet diary application to support diet-related disease progression retardation. We choose PICTIVE 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 (e.g., Post-It notes, pens, paper, etc.) rather than text documents or computer software as the design medium (Muller, 1992). Over a period of 5 months, 4 older adults with AMD attended 8 design meetings to directly contribute, in an empowered way, as experts in living with their condition to the design of our mobile application. For the design sessions we opted for a relaxed structure to encourage participants to drive the process rather than being led through it. During the sessions, participants were comfortably seated around a shared design surface on which they worked. All sessions were recorded by a camera (to which participants had consented); the area captured by the camera was delineated in blue tape 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. After each session, the researcher had the opportunity to reflect on the outcomes and observed participant contributions – reflection which was aided by the video record – and this reflection supported effective establishment of the research context/questions for the subsequent sessions. While the PD approach proved successful at encouraging inclusive participant contribution, due accommodations had to be given to the way in which the sessions were conducted, which we have, upon reflection, summarised as recommendations below.

2.3.1 Adapt your Selected Method/Approach for the Specific User Group Requirements

It is essential to consider the participation requirements placed on users, and to tailor PD approaches accordingly. The first session was used to watch an explanatory video on the PD approach and to allow participants to ask questions which successfully relaxed them into the process. This proved to be a very useful and practical approach for introducing the PICTIVE method and illustrating how simple office materials could be utilised to co-design paper prototypes.

Given our users' visual impairments, we eliminated the need for them to read/write during the sessions, leaving those tasks to the researcher under the participants' direction. One-to-one explanations and demonstrations were a prominent part of the sessions; once something was drawn/sketched (i.e., a user interface component) on the shared material, this was passed around the table for participants to be able to see. We had considered the

use of a white/blackboard for demonstration purposes but refrained from using one as we feared this would draw attention to their visual deficiencies rather than assist. 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 accommodation deviates slightly from the core tenet of PICTIVE PD (that is, the development of only a single, shared copy of the prototype), participants truly appreciated this mode of working because it allowed each individual to position the copy at her preferred viewing distance and angle, something which they were not comfortable doing with the large, centralised copy. This also supported personal reflection on the ongoing progress of the design.

We refrained from the use of paper agendas; instead, at the start of each meeting, when we conducted a verbal review of the previous session we also discussed the suggested purpose and objectives for the current session and participants were given freedom to reflexively change the agenda during such discussion. At the end of each session, participants' individual copies of prototypes were collected, refined based on the outcomes of the session as documented via the central copy, and returned, updated, to them in the following session.

2.3.2. Use Metaphors and Pertinent Tangible Objects to Encourage and Support Envisioning of Technology

Older adults may have trouble envisaging technology propositions and so providing examples to 'play' with as desired during design sessions can give them a feel for the technology and current application designs. It was apparent that one of the key challenges in engaging in this design work was to help participants to envisage (mobile) healthcare technologies to support their creative thinking and maximise their involvement and input. A good starting point was a discussion of the advantages of mobile technologies concerning the portability

and anytime/anywhere access of such devices. We further explained 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 the device with multiple applications.

Participants had been introduced to the concept of our proposed system via participation in the initial focus groups, and were keen to use the design sessions to suggest, as well as learn, alternative means by which the system could increase their independence. At the preliminary stages, suggestions included a 'notes page' to 'store' their 'ideas' and thus support their memory, and any sort of navigational aid – both major challenges to their daily lives as identified during the focus group discussions – as well as e-mail (explained by one participant who owned a computer as a means of sending letters with no stamps required). To introduce an element of tangibility to the design conceptualisation, participants were afforded the opportunity to try out and reflect on related applications on an iPad (we had already limited hardware choice to tablets on the basis of focus group discussion) to help them comprehend how touchscreen technology works, what buttons are and how to navigate from one screen to another (this allowed for deeper consideration than was covered in the focus groups where discussion remained at the level of participants' overall experience of interacting with a mobile device). The iPad was passed around and, in addition to the group discussion, one-to-one explanation about the technology was provided to two participants who had never used a computer before. Participants appeared to find the whole idea of navigation from one screen to another via touch/click incomprehensible. 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.

2.3.3. Use Non-Technical (Accessible) Language and Providing Ample Explanations to Avoid Mismatched Expectations

Simple explanations that reflect participants' mental models allow participants to effectively understand unfamiliar concepts and enhance their contribution.

We focussed on trying to understand participants' perceptions and expectations of not only our proposed application (in terms of eliciting functional requirements), but also of the overall project to avoid any mismatched expectations. We explained to participants: how these design sessions allied with the overall scope of the project – that this was the second (the design) phase of the project and that their contributions to the subsequent development and evaluation phases would also be appreciated/needed; what the subsequent stages would be – i.e., preliminary evaluations of the prototype, development of the back-end, followed by longitudinal field evaluations; and what the overall expected outcome was from the current design phase – i.e., a paper prototype of the UI. We felt this to be essential to mitigate against misunderstandings as a result of mix-matched expectations. For one of sessions the group was joined by a clinical researcher (optometrist and research team member) who contributed to the collaborative design exercise for the session. In addition, she provided general feedback on the design created up to that point, she reviewed the application not just as a diet diary application but also as a low vision tool in general to reiterate

how the design sessions allied with the overall goals of the project, and she discussed how the design findings thus far might usefully be applied more generally for designing with and for older adults with impairments. Participants asked her various questions about the connection between different health conditions, AMD and nutrition, but where equally keen to explain to her, and thereafter evaluate with her, *their* design choices. Throughout the process, the use of accessible, non-technical language by the researcher was of crucial importance when providing explanations and guiding discussions.

2.3.4. Accommodate Comorbidity Issues

Besides their primary impairment, older adults often experience co-morbidities which can impact their participation and so need to be carefully considered in establishing the participatory design protocol; we found that our participants experienced difficulties with hearing and memory, and one participant also had arthritis. To combat memory problems, for instance, each of the subsequent sessions commenced with a summary of the previous session and the researcher identified the session goals and included quick updates (i.e., how far we were in the process and what we had achieved so far) throughout the sessions. As per the practice adopted by Wu *et al.* (2004) when working with individuals with amnesia, when reviewing work from a past session, individual contributions to the design and decision-making process were not identified in an attempt to evaluate past decisions in an unbiased way and reflect the group's work as a collective (as opposed to the contribution of individuals). As part of on-going encouragement given to participants, during and after each session we also outlined the group's achievements and reinforced the value of their contribution and the fact that their healthcare and independent living goals are the driving force behind the design. Further, to combat hearing problems we minimised crosstalk by referring to participants by their names when asking questions such that only one person spoke at

a time. This was also of crucial importance to two of the participants who found conversations that are led or directed via eye contact rather challenging.

2.3.5. Establish a Friendly Atmosphere

Taking part in design work is likely to be a new and, perhaps, initially overwhelming task for older adults. Establishing a friendly atmosphere can help stimulate and encourage individuals' contributions.

3. REFLECTIONS ON PARTICIPATORY RESEARCH

The discussion which follows is grounded upon our observations/experiences and feedback from our participants; it reflects on our practice of conducting participatory research and the technological needs and wants of older adults.

Our comprehensive review of research and innovation within the field of mobile assistive technology for the visually impaired suggested that, far from older adults being technologically averse as is often the misconception, their lack of technological acceptance is often rooted in the fact that current devices are not designed with special needs or niche older adults in mind; it also indicated that there is considerable scope for positive impact of technology within this user group if designed based on their needs and wants (Hakobyan *et al.*, 2013a). Thus, by adopting a participatory research approach we have elicited the requirements for and democratically designed a prototype of an assistive healthcare technology which we believe accommodates the range of skills, preferences and needs of older users with AMD.

We hope we have clearly illustrated how conducting participatory user-centred design does not need to be a costly undertaking: we have shown how PD can work with target users using common and inexpensive office supplies. Other research has demonstrated that failure to adopt participatory UCD methods can decrease software diffusion and adaptation rates (Wolpin

and Stewart, 2011) and that the estimated cost of fixing an error after product release is 4 to 5 times as much as fixing one uncovered during the design (Pressman, 1992). Together, these findings lend weight to the argument for relatively little upfront expense in return for ultimate cost reduction and increase in acceptance.

We acknowledge arguments that conducting this type of work can present a number of challenges but suggest that our case study shows they are not insurmountable and are worth the effort. Finding and recruiting representative participants can prove difficult, conducting observational studies of vulnerable individuals can raise privacy issues, and engaging individuals with impairments can present logistical difficulties but, as demonstrated by our case study, appropriate engagement with the user community and adaptation (where needed) of participatory user-centred methods can overcome such challenges and yield invaluable results; the tangible results (i.e., our final prototype and elicitation of a comprehensive set of requirements) of our commitment to and wholehearted engagement in participatory research is clear evidence of the significant positive impact of directly involving target users in the design process. The majority of our design findings would certainly not have been uncovered without the direct involvement of target users.

The application of the PICTIVE PD method was a reflective and educational experience for all parties involved, underpinned by the mutual educational nature of the process. Our objective for adopting participatory 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.

The mutual educational nature of the process enabled older adults with AMD to feel relaxed and able to contribute to the design work

without prior technical knowledge or expertise. 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 healthcare technology that will impact their lives. In turn, such technologies, if designed based on comprehensive understanding of users' needs, have the potential to fully empower patients to make informed decisions about their healthcare (Anderson and Funnell, 2010). In terms of our case study, our proposed proof-of-concept diet diary application, which now accurately reflects the requirements of the target users, is expected to assist and empower older adults with AMD to make informed choices about their eye-related healthcare management. In fact, empowerment was one of the 5 principles of truly patient-centred care identified by the International Alliance of Patients Organizations (2013), which indicates that care should be responsive to individual patient preferences, needs, and values. Finally, by being involved in the project participants also gained an opportunity for important socialising (Massimi and Baecker, 2006) – something which can prove problematic for individuals with visual impairment. Since all members of our PD team were involved in all of our participatory UCD methods, a very strong bond formed between the participants and the researcher; 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). 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".

A detailed discussion of the dominant themes – Mutual Learning, Empowerment and Socialising – emerging from thematic analysis of the records of our participatory design activities, and preliminary evaluation of the prototype designed by the PD team, is documented in Hakobyan *et al*. (2014).

We acknowledge, and are still working to overcome, remaining challenges in the closing phases of our research. It is particularly important to give careful consideration to how to 'end' the participatory process: we are cognisant of the potential negative effect that withdrawal of the participatory process may have on individuals who have benefited from a wellbeing perspective as a bi-product of their participation and so propose to consult them directly on how to bring closure to the process in as positive a way as possible. In so doing, we hope to further empower our participants by allowing them to influence the context of the research in this respect. We are now drawing to a close a longitudinal trial of the application with a larger group of end-users for the purpose of validating our app.

We hope we have illustrated how adopting and adapting different methods can minimise challenges with enabling target users to effectively participate in the design and development of technology whilst at the same time maximising the benefit of their input. We hope we have shown that, by taking appropriate steps at the beginning of a participatory research agenda, it is possible to gain the trust and commitment of members of an otherwise reticent population such that they were ultimately a strong driving force behind the success of our design activities. None of the methods adopted were costly, they merely required commitment to the philosophy and a willingness to reflect on and reflexively adapt the methods over the duration of the process; in our case, we feel the commitment has shown to yield reward. Based on our experience, we believe that direct, integrated participation of older adults in the design process for assistive technology to support their needs 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, and, 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.

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