

Genuine partnership and equitable research: Working “*with*” older people for the development of a smart activity monitoring system

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Technological and Methodological Innovation: Working “with” and “for” Older People to Develop a Smart Activity Monitoring System

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ABSTRACT

Recent UK government policy has highlighted the value of user involvement in service development, particularly concerning assistive technologies and their role in providing care. This article illustrates the case of a person-centred, participatory project involving older people in the design, implementation and development of innovative technological solutions to enable older people to live independently and age-in-place within their homes and communities. The research aims and objectives included: the identification of technological, psychological and social needs of older people; the definition of user requirements to inform an activity monitoring system for use in private homes and residential care settings; and the analysis of the ways in which such systems impact on the everyday lives of older adults in different settings.

The innovative aspects of the user-driven, participatory approach illustrated in this paper concern the involvement of older people as co-researchers throughout the research process. This article reports the reflexive accounts which emerged during the project and provides viable and practical pathways to facilitate participatory research in the development of assistive technology for older adults. It provides practical guidelines for future user-driven, participatory research involving older adults in the design, development and implementation of assistive technologies. Our findings show that developing authentic, non-tokenistic research partnerships and including older people’s ideas, motivations and perspectives in the design and development of these types of technology can lead to productive forms of mutual inspiration and technological solutions grounded in the experiences of older people.

Keywords: Innovative assistive technologies, Innovative research partnerships, Smart Activity Monitor, User-driven, Person-centred, Participatory research approaches, Older adults as co-researchers.

Introduction

Too often the phenomenon of population ageing is perceived as a social problem, raising new challenges in terms of health and social care services, housing, welfare, pensions and benefits (Dunnell, 2008), while it can instead be framed in terms of potential resources positive assets, capacities and social and emotional capital (Kinsella and Phillips, 2005; Pratesi, 2011). It is in this context that innovative assistive technologies have increasingly been seen as one of the viable pathways to increase cost-effectiveness, quality and choice in how health and social care services are delivered (Vaarama, Pieper and Sixsmith, 2007). Recent health and social care policy in the UK has recognised independence and well-being as an achievable goal for older people through providing improved choice and control over the services they receive (DoH, 2005, 2006). Such policy encourages research into the development and application of *assistive technology* for supporting and improving the quality of life of older and disabled people. In conducting research with older people, the government encourages the involvement of users in the research process (DoH, 2004) to improve the authenticity and quality of the research.

Literature on participatory processes suggests that the active engagement of stakeholders in the planning, design and implementation of research can be empowering for participants, whilst yielding research findings which are grounded in the experiences of older people (Staley, 2009). Until recently, however, approaches to the design of assistive technology have largely focussed on clinical, legal and technical issues associated with system design (Seelman, 2010). Here, much of the research has primarily been *problem-centred* and based on existing technological solutions which are then adapted to older people's needs (Kruse, 1992; Mollenkopf and Fozard, 2003) rather than *person-centred*, i.e. stemming from older people's lived experiences and progressing towards improving their quality of life. Working in partnership with older people in the design of products to assist them recognises that older people can make a positive contribution to the research and that their experiences provide unique insights.

User-driven approaches have become more common within research *on* older people. However, these often include users simply as test subjects in the evaluation of developing technologies or involve users in tokenistic roles i.e. through only symbolic gestures of inclusion. For example, keeping users informed about the research proposals but not involving them as partners in the decision making process. It can be argued that tokenistic forms of engagement can be worse than no participation at all, amounting to the manipulation of participants, who in effect have little power over the development of the research (Dewar, 2005; Lane, 2005). A more comprehensive person-centred, non-tokenistic and inclusive approach to system development involves users' input throughout the whole research process and in ways which emphasises their power to effect change. The philosophy of person-centred design highlights the importance of including users at each stage of the design process and by ensuring that user requirements are captured and integrated into the product development lifecycle (Rubin, 1994; Shneiderman, 1998). This can be achieved in a variety of ways to involve users such as: an appropriate allocation of function between user and system, iterative design solutions, multi-disciplinary research teams and user advisory boards (Maguire, 2001). Involving users in such ways provides for a better fit between technology and the everyday environment of the user (Salvo, 2009). Person-centred design allows user expectations to be effectively managed, promoting a greater sense of ownership in the process (Preece et al., 1994; Sixsmith, 1999).

Whilst the debate on user-driven or person-centred approaches is not new (Williams and Grant, 1998; Israel et al., 2001; Telford, Boote and Cooper, 2004; O'Connor and Cooper, 2005; Weaver and Cousins, 2007; Sandoval et al., 2012), participatory research *with* older adult communities in the development of *assistive technology* still represents a relatively young field of inquiry. Moreover, while several studies have critically reflected on participatory research processes following their completion, few have engaged in a continuous reflexive analysis to feed forward into enhancing the experiences of participation for older people as the project develops, a research gap highlighted by Fudge, Wolfe and McKeivitt (2007). In their review of studies involving older people as *partners* in the research process (rather than as *research subjects* or informants) Fudge, Wolfe and McKeivitt (2007) highlight the vast potentialities of older adults, as key technology users, to be creative problem-solvers in their own right. However, the authors also identify a number of barriers to involving older people in research, such as socio-cultural barriers, research skills, health conditions and time and financial resources and constraints. Additionally the review identifies only a small number of studies which involve older people at all stages of the research process and little evidence is provided to reflect upon the ways in which older people's proactive involvement in research can be used as a systematic method and applied to future research projects. All this confirms a shortfall in the literature and highlights important research gaps, which require further exploration if we want to fully understand the benefits of and improve participatory research on assistive technology which is purposeful and engaging for older people.

The aims of this article are to highlight the importance of participatory research approaches *with* (rather than *on*) older adults in the field of assistive technologies and provide pathways and practical suggestions which can be applied to future research projects. In doing so, this paper reflects upon the technological, methodological, sociological and psychological challenges of involving users in the design and development of innovative care related technological products. Issues related to the development of trust and reciprocity between all the research partners towards the application of authentic participatory processes will be illustrated and discussed. As a preface to this, the next section will overview existing models of user-centred and participatory processes, with a specific focus on those involve older people.

Models of participatory processes involving older people

Although participatory research with older people can be problematic, complex and difficult to facilitate (Watt, Higgins and Kendrick, 2000) it can bring about positive results for both participant and researcher (Hanley et al., 2003). Involving older people in the design and development of assistive technology can yield a final product which more accurately matches older people's requirements, resulting in more accessible and acceptable technologies (Eisma et al., 2004). However, several key challenges make such involvement a difficult task: the developmental process can be rather obscure and hard to grasp for non-technologists; the concepts underpinning technological development can be difficult to grasp since such concepts are often ground-breaking or represent blue sky thinking; and matching older people's requirements to prospective technological solutions is not straightforward and needs a degree of abstraction and visualisation which goes beyond usual modes of thinking. In addition, many older people struggle to understand what constitutes research and their own role in the process. Taken together, these challenges can make participation of older people in technology projects merely tokenistic.

Eisma et al (2004) suggest that effective participation happens when the role of the research participant is clearly explained, both the design process and the technologies are explained in plain language and interactive hands-on elements are used wherever possible as part of the data gathering process. Fudge, Wolfe and McKeivitt (2007) emphasise that each participatory project is unique, raising important ethical, philosophical and practical challenges which will likely differ from project to project. Their review of projects involving older people in research on assistive technology points to three recent studies (Lacey and MacNamara, 2000; Marquis-Faulkes, McKenna and Newell, 2005; Seale et al., 2002). These studies demonstrate the huge potentiality of older people, as key technology users, to be creative problem-solvers in their own right. More specifically, Marquis-Faulkes, McKenna and Newell (2005) use participative dramatised focus groups with older people to gather user requirements for a fall monitor; Seale et al. (2002) apply a participative focus group methodology to facilitate older people's involvement in the design process of assistive technologies; and Lacey and MacNamara (2000) highlight the importance of iterative changes (recommended by the users themselves) in order to arrive at a final product—a smart mobility aid for older people—which more accurately reflect users' requirements and needs. However, when looking at the scope and the extent of user involvement in the three studies, both Seale et al. (2002) and Marquis-Faulkes, McKenna and Newell (2005) involve participants in only one phase of the research process, and only Lacey and MacNamara (2000) engage older people in all stages of product development from project definition to completion. Moreover, there is little evidence reflecting upon the ways in which older people's involvement in research, as a systematic approach, impacts on the research process and the potential development of innovative technologies.

Researchers have proposed more structured and formalised ways of conducting participatory research. For example, Reed, Weiner and Cook (2004) recognize the necessity of

transforming the rhetoric of participatory processes into tangible user-centred processes and outcomes. Their critical reflection draws on three individual research projects in which older people's partnership is analysed in different environments and settings. The extent of users' participation within the three projects varies along a continuum that spans from involving users as data sources to training them as co-researchers. The authors identify the different roles that older people can occupy at each stage of the research process and discuss the possible ways in which these roles can be effectively implemented. The article concludes highlighting the necessity to develop models of participatory research able to subsume both ethical and professional debates on this topic and to identify the practical issues associated with it.

Other scholars have attempted to outline more general frameworks and guidelines to conduct effective participatory work. Such attempts are useful to understand the importance of clarifying roles and degrees of involvement, communicating effectively and recognising different expectations when conducting participatory research (Warbuton et al, 2009). Ross et al. (2006) examine participatory research at a number of levels, including project management and a consumer panel working alongside the research team and influencing the dissemination in local falls prevention strategies. The authors draw out the issues related to the context and method of involvement, and discuss the impact on research quality and local service development in health and social care. Since context and research rationale vary across projects, they suggest that there is no single scheme or model for involvement to recommend as universally valid; nonetheless, they present a tentative model of involvement that proposes links between research context, process and resulting impact and benefits. Here, importance is placed on critically reflecting upon the development of participatory research as learning and changing process rather than the prescriptive application of a set of methods or guidelines. Similarly, Van den Hove (2006) recognises the limits of idealistic conceptions of participatory approaches which do not adequately capture the heterogeneity of different perspectives. The author suggests that research needs to re-situate the notion of negotiation within participatory research, indicating that participatory approaches lie on a continuum between consensus-oriented processes and compromise-oriented negotiations and arguing that, through the explicit recognition of the negotiation dimension, both the quality and the effectiveness of participatory processes can be significantly improved.

Researchers have also emphasized the need to engage in active debate concerning the positive impact of participatory research with older people and the conditions which undermine effective partnership. Dewar (2005) points to the fact that efforts to involve users at all stages of research have not been as effective as they might be, particularly when the involvement concerns older people. The author discusses a set of assumptions that need to be challenged to go beyond tokenistic involvement and identifies key strategic issues that need to be considered in order to promote and enable future effective partnership with older people. Among them, the necessity to adopt a systematic approach to record participatory research processes and outcomes, the ability to maintain a critical stance when undertaking such research and the consideration that participation may not necessarily be a beneficial process for all subjects involved. Beresford (2002) stresses the necessity to consider user involvement in research critically and systematically, taking into account the diversity of approaches that have been developed, and the need to develop equal and reciprocal partnerships between participants and the various stakeholders. Given the multiple challenges involved in the application and development of participatory processes and the need to reflect on field studies, in the following section we provide an account of how these issues have been addressed within the *Smart Distress Monitor* (SDM) project described below.

Innovative assistive technology for independent and safe ageing at home: the Smart Distress Monitor Project

The Smart Distress Monitor was a three-year Technology Strategy Board funded project (2009-2011) designed to develop an “intelligent” activity monitoring system that will support older and/or disabled people’s independence, safety and quality of life by charting their activity/inactivity patterns in their living environments. What makes this system innovative from other activity monitoring systems is the capability to ‘learn’ patterns of behaviour and identify, over a period of time, deviations from the norm. These deviations might indicate the presence of a problem and the necessity to intervene. The innovative aspects of the system consist therefore in its capacity to go beyond mere safety and emergency issues (such as fall detection) by constantly monitoring and recording people’s activity and inactivity within domestic environments. By interpreting activity/inactivity patterns and comparing the persons’ routine behaviours to their unusual ones, the infrared sensor will be able to detect the presence of both *health* problems and *well-being* related issues, which might be indicated by *behavioural* deviations from the norm (such as, for example, not entering the kitchen).

Being based on ‘thermal images’—which means that neither the persons nor their specific activity can be identified—the system ensures a complete respect of privacy. However, at the same time, the system will provide an innovative and much richer source of data than existing home monitoring systems relying on sensors such as door switches and conventional movement detectors. Thus, for example, the system will also have the ability to detect if there are other people in the house, to define the exact location of the person(s) within a specific room and to recognize if the person is sitting or lying down. Moreover, users will not have to personally wear or activate the system, which will increase its reliability and efficacy. With regard to its look and design, it will be similar to a smoke detector (in size and appearance), which will reduce the risk of potential stigmatisation connected to the use of assistive technologies.

The design, development and implementation of the activity monitoring system has adopted a person centred, participatory approach to ensure that the needs, perspectives and preferences of older adults were taken into account throughout the process. The Smart Distress Monitor project has been conducted in partnership between a UK academic institution, represented by a research team of sociologists, an industrial partner, represented by a team of engineers, and an advisory group of older people, whose role was to provide systematic input into the research design and development, including data collection, analysis and dissemination. The advisory group was composed of six older adults from different cultural, social and occupational backgrounds and with varying levels of technological and gerontological knowledge (see table 1).

The advisory group of older people shared a number of common objectives with the academic and technical partners:

- To identify the technological, psychological and social needs and preferences of older people;
- To define the user requirements for an activity monitoring system for use in private homes and residential care settings;
- To explore the ways in which an activity monitoring system impacts on the everyday lives of older people in different settings;
- To ensure that older people are central to the development of the monitoring system and are positioned to advise the progress of the research.

Table 1: Characteristics of the Advisory Group participants

Participant Number	Age	Gender	Occupation	Motivation and Knowledge
001	70	M	Ex-army officer	Present and past involvement in other medical and community projects. Extremely motivated and interested in care related technologies, also because of his (precarious) health conditions. No knowledge of care related technologies.
002	68	F	Retired occupational therapist	Highly knowledgeable of ageing process and older adults related issues. Not informed (but interested) about care related technologies.
003	65	M	Semi-retired engineer	Highly knowledgeable of communication technology. Less informed (but interested) about care related technologies. Experiential knowledge of care (caring for his mother-in-law).
004	66	M	Former civil servant	No previous knowledge of technology and older adults related issues. Interested in the issues of privacy and the policy implications of care related technologies.
005	60	F	Academic	Academic and experiential knowledge of care and older adults related issues. No knowledge of (old and new) care related technologies.
006	67	F	City Council research and planning officer (older people)	Highly knowledgeable and engaged with the issues of healthy ageing and quality of life of older adults in urban contexts. Less informed about care related technologies.

Innovation of research methods and approaches: a user-driven ongoing process

The innovative methodological approach of the SDM project involved a number of different research tools and methods:

- Extensive literature reviews on relevant areas of study (including: ageing and ageism, gerontology, gerontechnology, assistive technologies, telecare, participatory processes, behavioural symptoms of diseases, etc.);
- Secondary analysis of existing datasets from previous studies on ageing and technology;
- Face-to-face, in-depth interviews with older people who live alone at home;
- Telephone interviews with professional stakeholders and healthcare professionals;
- Focus groups with older people and their formal and informal carers;
- Workshops and quarterly meetings with the members of the advisory group;
- Home trials of 4 to 6 months duration conducted on the prototype system;
- Face-to-face interviews with home trial participants and their informal carers;
- Home trial participants' diaries.

The first phase of data collection yielded a considerable amount of qualitative data and resulted in the development of a series of use case scenarios which were designed to focus attention on the needs, motivations and perspectives of older people together with the potentialities and challenges of ambient assisted living technology. On the basis of these qualitative data, a *User Requirements Report* fully grounded in older people's experience of the activity monitoring technology has been produced and a *prototype infrared activity monitoring system* has been developed by the team of technologists.

At the time when this article was written, home trials and evaluation had been undertaken to establish the capacity, potentialities and acceptability of the activity monitoring system within domestic settings. Equipment had been installed in four private homes for approximately four to six months. Data on the person's activity within the house were collected via a number of infrared sensors and analysed by the team of technologists. During the period of the home trials, pre- and post-home trial interviews with participants and their informal carers were conducted and participants were asked to keep a diary. The purpose of the diary was to provide a place for them to record information about their daily living activities. The information provided was then used to help improve the system and its response to events taking place in the home.

Participatory processes and/or user-driven approaches tend to include users (in this case, older people) simply as 'test subjects' in the afterwards evaluation of already developed technologies. The innovation of our more inclusive person-centred approach is the involvement of older people throughout the entire research process. To provide a sense of agency and equality in the research process, the members of the advisory group were considered as co-researchers from the outset. As part of this participatory approach, older people have been actively involved in determining their level of participation and their role as co-researchers. All members of the advisory group agreed to review documents, relevant articles and provide input into the decision-making process. In addition, some expressed their desire to be involved in the data collection aspects of the research, creating the opportunity for advisory group members to be directly involved in interviewing other older people and the potential to capture experiences which might not otherwise have emerged.

During the first year of the project, the members of the advisory group who opted for a more active involvement in the research process were provided with the necessary skills for interviewing and co-conducting focus groups via training workshops facilitated by the academic research team. The training workshop, together with guidelines on how to conduct semi-structured, in-depth interviews, provided advisory group members with the basic skills necessary to interview other older people within the community and to attend focus groups as co-researchers. Although co-researchers felt that the training was stimulating and empowering, only three members of the advisory group felt that they had the necessary skills and confidence to be actively involved in data collection and analysis. The benefits (and/or the faults) of the participatory process were evidenced in the constant communication and interaction between the academic team and the advisory group of co-researchers undertaken throughout the project.

From the outset, the members of the advisory group were provided with a broad range of possible forms of communication. This included: quarterly meetings with the research partners; face-to-face, e-mail and telephone contacts; circulation and distribution of project related reports, minutes and documents; and information related to assistive technology, academic papers and journal articles, conference proceedings, seminars and outputs from other relevant events. These forms of communication were consolidated throughout the research and represented the primary means for transferring and sharing information between the academic team and the advisory group of older people. The members of the advisory group were encouraged to express and share their thoughts, feelings and opinions on events, meetings,

research progress, status reports, latest news on assistive technologies, relevant websites, forthcoming conferences, articles, and to provide the academic team with regular feedback.

This approach facilitated the development of a continuous two-way dialogue between the research team and the advisory group of older people, a constant flow of information that was capitalised upon by the research team to reshape the scope of the research and refine its tools and methods. This process was enlightening for the research team, revealing issues that would not otherwise have emerged, as the advisory group members were drawing upon their own lived experiences. Their involvement provided crucial and critical insight on the potential impact of home monitoring technology on people's habits, behaviours and feelings, on people's sense of privacy, autonomy, safety and independence and finally on issues concerning personal identity, sense of belonging, the ageing process and symbolic meanings of home.

In light of this continuous input, elements of both the sociological research process and the technological development have been re-shaped or amended and the advisory group members reported that they have felt empowered, more knowledgeable about activity monitoring technology and provided with the platform to have their voices heard and valued. However, the user-driven, participatory approach we adopted also presented some challenges, the management of which was not always successful. Efforts to address such challenges are described in the next section.

Charting the paths towards authentic participatory research

Participatory research is a continuous interactive process that must be constantly renewed and renegotiated. Undertaking participatory research requires the academic team to consider the requirements of all partners, co-researchers and stakeholders while at the same time maintaining high standards of research. This often requires working with each partner individually to re-assert the benefits of undertaking participatory approach. Indeed, some of the main challenges we encountered in this project have been maintaining high levels of collaboration, motivation and enthusiasm of the co-researchers while simultaneously facilitating the dialogue between the different instances of the advisory group of older people (co-researchers) and the team of technologists.

Terms of reference were agreed with all the research partners when the research started. This stipulated the purpose and structure of the advisory group and described what would be expected from the group members in terms of their role and how it could change. The academic research team felt it was important not to place unfair expectations on the advisory group members and thus their expected contribution was not specified, leaving it up to the individual themselves to make decisions on the extent to which they wished to be involved in the project. For example, the members of the advisory group were expected to attend quarterly project meetings, where possible, but no numbers were placed on how many they should attend or how they were expected to be involved. Moreover, according to the terms of reference, they were expected to review and provide feedback on project documentation, without specifying how many or the type of documents they would be expected to review.

At the beginning of the project, it became apparent that the team of technologists were not necessarily enthusiastic, not with the same level of intensity at least, to involve the advisory group of older people in each and every stage of the project. On the other hand, the members of the advisory group, were eager to be involved in different levels of participation, i.e. attending meetings, reviewing documentation, engaging in data collection and analysis, etc., and thus flexible terms of reference provided a basic framework in terms of role expectations whilst allowing the individual themselves to determine and shape their level of involvement in the

research. There is a fine line between ensuring that older people make a positive contribution whilst sustaining that effort over the course of the research.

A further important issue regarded the different work ethos, cultures and practices of the research partners involved. Whereas the academic research team had a consolidated tradition of conducting participatory research and a solid and grounded understanding of the ways in which participatory research must be conducted and who it should benefit, for the technology partners, the concept of participatory research was relatively unknown and alien to their traditional ways of thinking and working. As a consequence, they were unfamiliar with the dynamics involved in participatory research, such as challenging hierarchical power relationships, adopting a flexible, iterative approach to the design process and presenting complex information to a lay audience. In such a context, the academic research team was required to adopt a 'bridging' role to mediate between partners and ensure an authentic participatory process, which means emphasising the importance of participation as a 'democratic' form of inquiry and grounding the research outputs in the experiential perspectives of older people themselves.

Upon reflection, more work could have been done across the partnership to develop mutual understandings of the benefits of involving older people in research and the conditions that need to be provided to ensure that their voices are heard. Early collaborative workshops could have been undertaken with the advisory group and the team of technologists aimed at facilitating exchange of knowledge and relationship-building. These workshops would have provided a platform for both older people and technical experts to present their experiences, discuss their expectations from the project and engage in exercises to establish closer relationships. Moreover, there was an implicit expectation from the academic team that the team of engineers would have adopted the philosophy of person-centred research as the project developed. Training sessions could have been held with the project partners on the theoretical, ethical and practical aspects of person-centred, participatory research. This would have provided the research partners with a more realistic and pragmatic understanding of the principles of participatory research.

Whilst the two partnerships taken separately—between the academic team and the advisory group of older people, on one hand, and between the academic team and the technology team, on the other—worked relatively well, engaging all three partners in the research process has been more challenging. Only a limited number of all the quarterly meetings that took place during the research included the presence of all three partner teams. Here, geographical distance played a role in preventing the opportunity to discuss the research progress and share ideas in real time. Whilst the academic team and the advisory group were both located in the North-West, the technology team was located in Central England. This geographical distance represented an obstacle to physical face-to-face meetings between all research partners. As a result, there was little opportunity for common discussion and interaction across the academic, technical and advisory group and the development of an effective feedback process was not always easy to facilitate.

One concern of the academic team related to how the partners viewed their roles within the project and if those perspectives were effectively understood and used to shape the project. A key component of participatory research is including, acknowledging and making productive use of the inputs of all participants. As the project developed, the comments and suggestions of the advisory group were incorporated into the research, with the expectation that the final outcome will be reflective of their experiences, values and needs. Here, there needs to be a recognition and clear communication of the trade-off, between the technical capabilities of the system (i.e. what *cannot* be designed) and the need to incorporate the user requirements of the system (i.e. what *can* be designed). This is as much about the users understanding the technical

capabilities and limitations, as the need to ensure that user requirements are translated into the system design. Failure to consider this may well result in tokenistic and disingenuous participation and a system that is divorced from the everyday lives of older people. Our experiences so far suggest there are a number of mediation and facilitating skills that the social scientist is required to apply to facilitate successful partnership-working:

- *Active listening*: Listening and understanding the experiences, concerns and different expectations of partners regarding how the partnership is working and using this to bring about positive change.
- *Shared dialogue*: Ensuring that channels of communication are opened up across all partners and that information is communicated to each member.
- *Critical self-awareness*: Ability to reflect critically on our own role within person-centred research approaches is important for facilitating change and maintaining flexibility within such approaches.
- *Conflict resolution*: Partnerships can be fractious and mediation is often required to successfully resolve conflicts and tensions (or simply misinterpretations) when they arise.

Although not all the participatory interactions between the three research partners have been as successful and productive as we hoped, what we learned from this original and unique collaboration between an industrial partner, an academic team of sociologists and an advisory group of older people is useful for other projects adopting person-centred approaches to the development of assistive technology. In the following section some suggestions are provided for future user-driven research and strategies on how to develop and implement innovative and more inclusive participatory research approaches are discussed.

Involving older people in the development of Innovative Assistive Technology: suggested action points

Involving older people in the research is a complex and difficult process to manage. Providing older participants with freedom and choice within the research process requires effective monitoring and constant negotiation. Enabling choice requires giving older people the opportunities to be (actively) engaged in the research in a variety of ways. In the project here described, much attention was paid to ensuring a meaningful and sustainable engagement. As an academic research team, we have been confronted with the need to ensure that the level of motivation and involvement of older participants could be maintained throughout the research process. Yet, this is difficult to achieve as it is not based on any fixed and clear-cut rules and requires a process of continuous negotiation and reflective analyses. The following action points outline how older people's involvement in the research was approached and constitute guidelines for future user-driven, participatory research:

- *Early relationship-building*: Developing closer and more informal relationships with the members of the advisory group beyond the research context was fundamental in cultivating a genuine partnership between the research team and the older people's advisory group based upon respect, esteem and trust and valuing the contributions of each individual. This equality and reciprocity allowed us to challenge the traditional researcher-subject hierarchical relationship that often exists, so that the participants could feel a sense of freedom, openness and empowerment in the research process.

- *Ongoing relationship-building*: Relationships between the various project participants have been developed via a number of different means, such as face-to-face quarterly meetings, participation in care related technology events/seminars/conferences, and other informal interactions between the researcher and the members of the advisory group, including: conversations concerning personal life events; working lunches; greeting messages and postcards for major holidays, festivals and observances; and sharing interests, ideas and concerns within and outside the research context.
- *Clear and multiple forms of two-way communication*: The prevalent form of communication with the members of the advisory group was via e-mail or telephone, or a combination of the two. Researchers need to be flexible and able to opt for the form of communication that best accommodates the research partners. This is important for communicating everyday information. For example, initial attempts to communicate only via e-mail prevented one of the older co-researchers from receiving information when their internet malfunctioned.
- *Transparent and constant flow of information*: Up-to-date information about the progress of the research needs to circulate regularly (at least every two weeks) to ensure that the members of the advisory group feel a part of the research process, whilst not too often that participants experience information overload and disengage from the research process. Significant amounts of time were spent by the academic team ensuring that clear forms of communication and feedback mechanisms were developed and adjusted to the changing needs and phases of the research.
- *Tailored and accessible information*: Information which is transmitted across the different research partners should be easily interpretable. Specialist/scientific jargon cannot always be avoided, particularly in the area of innovation technology. However, this should not undermine the ability of co-researchers to understand complex information. For example, both the academic and the technology team were encouraged to provide lay summaries of the technical aspects of the Smart Distress Monitor project (for fear that they would be misunderstood). Nonetheless, a number of co-researchers in the advisory group enjoyed reviewing academic journal articles in the areas of assistive technology and gerontology and demonstrated high levels of enthusiasm to understand the functional aspects of the SDM system.
- *Flexible research process*: Contrary to common belief, older people have often quite hectic, busy, mutable and unpredictable lives, for example, when acting as family carers, attending healthcare appointments etc. The successful attendance at meetings for the advisory group of older people was influenced by their specific individual and familial circumstances at the time. This aspect recognises people as emotional beings and that emotional responses to participation need to be considered and managed (Hochschild, 1979). Any academic team involved in participatory research projects should adopt a flexible approach to accommodate the feelings, needs and motivations of the co-researchers.
- *Flexible research partners*: Undertaking person-centred research also raises contradictions when involving diverse research partners: academics, older people and a team of technologists. Emerging findings may not be consistent with the original hypotheses or satisfy the different expectations of the different research partners. This (normal) process of adjustment and negotiation can be more complex and difficult to attain within funded research or research which involves research teams who have different and often competing research orientations (for example, the market-oriented

nature of the industrial partner's approach to the research was quite obvious and explicit). However, being aware of and managing the different expectations of the various stakeholders is important for ensuring their engagement as the project progresses and the complete respect of ethical issues at stake.

- *Resource allocation:* The realisation of a successful and authentic participatory research project can be limited by resource constraints. Budget and time constraints all limit the extent to which relationship building, reflection and negotiation can be achieved. Resources should be adequately assessed and evaluated from the outset and built into the development of the research proposal.
- *Real-time evaluation:* It is important to evaluate the participatory process in real time and as the work is ongoing in order to identify and resolve any conflict, concern and challenge as they arise. In addition, identifying and documenting the positive benefits of engagement can assist in identifying those elements of participatory work that need to be retained.

Sustaining older people's involvement in research needs to be considered beyond the end of the project. Working towards an agreed *exit strategy* for older people constitutes a thoughtful and sensitive way of gradual separation. This might include keeping participants updated on post-project developments, offering opportunities for attending or presenting at conferences and workshops, co-authoring publications and being actively involved in proposal development and new research projects. In the research presented here, the advisory group of older people opted to maintain contact with the academic team and to provide input into further research. 'Keeping in touch' is an important way to acknowledge and express gratitude for their commitment and contributions.

Concluding remarks: a successful innovative research approach?

The development and promotion of innovative (and effective) research partnerships require highly developed mediation and facilitating skills and critical reflection throughout the entire research process. This involves documenting the benefits of user-centred, participatory research process as well as their challenges, problems and pitfalls. This also requires being able to respond and adjust our research strategies 'in real time,' as the project progresses. This article describes our contextual experience of 'doing' participatory research, engaging older people in the design, implementation and development of Innovative Assistive Technology (a Smart Activity Monitoring system). It provides practical guidelines for future user-driven, participatory research involving older adults in the design, development and implementation of assistive technologies.

While current literature on older people's participation in research is growing, this tends to happen *after* a project closure so that learning rarely feeds forward into more productive partnerships. The reflective accounts presented in this article were conducted *mid-way* through the research, enabling all research partners to meet the challenges identified and work together towards timely adjustments as the project progressed and more successful outcomes at project end. As such, the discussion and the suggestions here provided contribute to the emerging debate on both innovative participatory research methods and the development of innovative assistive technologies.

Investing in research with older people requires high levels of flexibility and adaptability when negotiating significant methodological challenges and reflecting upon older people's real participation in the research. This latter becomes even more complex and difficult when there are other partners and funding bodies involved in the process. Developing mutual understanding

of the motivations involved in participatory research and translating these motivations amongst all project partners is crucial to achieving effective results. This is important if participatory research is to be conducted *alongside* older people (producing empowering outcomes) rather than *on* them (producing potentially exploitative outcomes). In order to be effective and ethically appropriate, the research process must be inclusive, purposeful and productive for *all* the research partners.

The social scientist cannot gain insights on older people's perspectives without developing authentic research partnerships that may be beneficial to all social actors involved, no matter how difficult and complex negotiating and maintaining such partnerships are. Participatory research is a constant, endless, fluid process which must be reflected upon throughout and beyond the timescales of the research in order to improve practice. Engaging older people as equal partners in the research and making their voices heard as part of the process is a practice which requires the management of competing interests but it is a practice that needs to be pursued if we want to achieve *authentically* successful research outcomes.

As highlighted by several reviews of user involvement (Fudge, Wolfe and McKeivitt, 2007; Oliver et al., 2004; Boote, Telford and Cooper, 2002) more case studies and examples are needed on constant reflexive analyses which feed forward into enhanced experiences of research partnership as the project develops and which evaluate the benefits of person-centred approaches in terms of research process and outcome, rather than merely those for the research participants and partners. Our contribution shows that non-tokenistic inclusion of older adults in the design and development of new care related technologies can be effective for both the older adult communities, by ensuring that such technologies fit into the everyday life of older people and they are accessible, functional and aim to improve their independence and quality of life. It is only by involving older people as co-researchers in the design and development of new assistive technologies that we can attain successful research outcomes and creative forms of reciprocal inspiration; an inspiration, we hope, that can be reflected in the design of future research.

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