

PSICOLOGÍA COMUNITARIA INTERNACIONAL:  
APROXIMACIONES A LOS PROBLEMAS SOCIALES  
CONTEMPORÁNEOS VOL. II

INTERNATIONAL COMMUNITY PSYCHOLOGY:  
APPROACHES TO CONTEMPORARY SOCIAL  
PROBLEMS VOL. II

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UNIVERSIDAD IBEROAMERICANA PUEBLA  
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# PSICOLOGÍA COMUNITARIA INTERNACIONAL

APROXIMACIONES A LOS PROBLEMAS  
SOCIALES CONTEMPORÁNEOS  
VOLUMEN II

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## PARTICIPATORY DESIGN FOR FUTURE CARE RELATED TECHNOLOGIES: LESSONS FROM THE SMART DISTRESS MONITOR PROJECT

Alessandro Pratesi<sup>1</sup>  
Judith Sixsmith  
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### ABSTRACT

The impact of care related technology on older people's health and well-being is growing constantly and at a rapid pace. Participatory approaches to the design and development of care related technology have become increasingly common; however, these approaches have often included older people simply as test participants, rather than co-researchers, in the evaluation of developing technologies. This paper presents a participatory project involving older people in the design and development of an intelligent activity/inactivity monitoring system for domestic environments. In order to be successful, the development of such a system must be viewed less as a technological challenge and more as the creation of an integrated *socio-technical system* in which technology is functional to the people and organizations involved.

### COMPENDIO

El impacto de tecnologías relacionadas con la salud y el bienestar de las personas envejecidas está creciendo constantemente y a un ritmo acelerado. En este contexto, enfoques participativos para el diseño y el desarrollo de tecnologías relacionadas con el cuidado de personas envejecidas son cada vez más comunes. Sin embargo, estos enfoques han incluido a menudo a las personas envejecidas simplemente como participantes de pruebas en la evaluación de las nuevas tecnologías. Este trabajo presenta un proyecto participativo que incluye este grupo de personas en el diseño y desarrollo de un sistema de seguimiento de actividad/inactividad inteligente para el espacio doméstico. Para tener éxito, el desarrollo de este sistema debe verse no como un reto tecnológico sino más bien como una

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creación de un sistema socio-técnico integrado, donde la tecnología es funcional para las personas y las organizaciones involucradas.

#### INTERFACING TECHNOLOGY AND AGEING

Rapidly growing ageing populations across the world have led to apocalyptic visions of future care needs in which countries will struggle to deal with the ever increasing cost of health and social care for older people<sup>2</sup> (Martinoni, Sassi, E. & Sartoris, 2009; Vincent, 2006). Population ageing will bring benefits, such as groups of older adults provided with social and emotional capital (Pratesi, 2011), but also a new set of challenges to society, such as ensuring access to health and social care services, housing, welfare, pensions and benefits in other areas (Dunnell, 2008). Rather than framing the ageing population positively in terms of potential resources (Gee & Gutman, 2000; Kinsella & Phillips, 2005) the anticipated increase in the cost of health and social care has cast older people as a social problem and new models of care delivery are sought to relieve pressure on care services (Tinker et al., 1999). It is in this context that technological solutions have increasingly been seen as one of the ways, if not the main way, to reduce the cost of health and social care (Vaarama et al., 2007).

The impact of care related technology on older people's health and well-being is growing constantly and at a rapid pace. Nevertheless, relatively scarce research attention has been given to the progressive permeation of technology in older people's everyday life, their health status, quality of life and well-being. Moreover, research into the role and impact of assistive technology has leaned towards more practical applications (i.e. the implementation of assistive technologies) rather than theoretical understandings of the potential benefits of interfacing technology and the everyday experiential lives of older people. As such, research interest in the topic has tended to be problem-centered, usually relating to specific areas of technology, rather than person-centered (Mollenkopf & Fozard, 2003).

What is needed is a holistic model to explore the changing interrelationships between individuals and their technological care environments incorporating

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<sup>2</sup> Following the WHO definition, old age can be categorized into three main stages: early old age (60-74 years), old age (75-89), and longevity (90+ years). However, the influence of individual factors means that there is no strong relationship between chronological ageing and socio-psychological or biomedical ageing. Researchers are as likely to work with fit active and engaged octogenarians as they are with 60 year olds experiencing chronic ill health, social isolation and depression. Older people as such, cannot be considered a specific, clear-cut and homogeneous group, but rather a heterogeneous mix of people who are often defined by age yet inhabit multiple psycho-social and health related positions.

ethical, social, psychological and emotional perspectives. A paradigm shift based on the social model of inclusion (Abbott, 2007) as opposite to the development of technologies in isolation from people is required. Such a paradigm shift is particularly relevant to community psychology because the active engagement of lay people constitutes a cornerstone of working within community based approaches (Kagan et al., 2011). In particular, the genuine inclusion of older adults in the research and development of new technologies can be effective for both social communities (by ensuring that new technologies fit into the everyday life of older people) and scientific/technological communities (by ensuring that new technology developments are usable, relevant and improve the quality of life of users).

Research on participatory processes suggests that the active engagement of stakeholders in the design and implementation of research can be empowering for participants, while at the same time yielding more valid and effective research findings (Dewar, 2005; Eisma, Dickinson, Goodman, Syme, Tiwari & Newell, 2004; Involve, 2009; Reed, Weiner & Cook, 2004; Ross et al.; 2005; Van den Hove, 2006; Warburton, Bartlett, Carroll, Kending, 2009) as well as technological products/systems which are more accessible and acceptable to them (McCreadie & Tinker, 2005; Melander-Wikman, Ylva & Gard, 2008). Eisma, Dickinson, Goodman, Syme, Tiwari & Newell (2004) suggest that effective participation happens when the role of the research participant is clearly explained; the design process is articulated in plain language; and interactive hands-on elements are used wherever possible as part of the data gathering process. Dewar (2005) identifies key strategic issues that need to be considered if participation is to progress beyond tokenistic involvement (i.e. making only a perfunctory or minimal effort towards the goal of older people's involvement and participation). Beresford (2002) stresses the importance of critical thinking as well as the necessity to promote close and equal partnership with participants and other stakeholders.

The attention in recent years has been on the development of the concepts and technologies of ambient assisted living specifically to support older people to live independently and age-in-place within their homes and communities (Burnholt & Windle, 2001; Gitlin, 2003; Sixsmith and Sixsmith, 2008) and improve their quality of life (DoH, 2004). This has been a product of and supported by recent health and social care policy in the United Kingdom (UK), which has recognised independence and well-being as an achievable goal for older people through improved choice and control over the services they receive (DoH, 2005, 2006). Such a policy drive has emphasised user-friendly technological design and person-centered approaches giving voice and visibility to older people's needs, situations, and wishes (Coleman, 1998; Mollenkopf & Fozard, 2003). Nevertheless, participation of 'end users' has been mostly limited to testing systems in order to

establish their functionality and usability, while older people's life experiences have not been brought to bear on technological developments. Moreover, while several studies have critically reflected on participatory research processes as projects have been completed, fewer have engaged in ongoing reflexive analyses which feed forward into enhanced experiences of participation for older people as the project develops.

In light of the multiple and overlapping issues intertwining strengths and limitations of participatory processes, this paper provides an account of our experience of older people's involvement in the design and development of an intelligent activity monitoring system for use in domestic environments: the *Smart Distress Monitor*.

#### ACTIVITY MONITORING FOR AMBIENT ASSISTED LIVING: THE SMART DISTRESS MONITOR

The Smart Distress Monitor (SDM) is a three-year Technology Strategy Board funded project (2009-2011) which aims to enable older people to age safely and independently at home. The project involves a partnership between an academic institution, a team of technologist and an advisory group of older people, working together on the design and implementation of new ambient assisted living technology. The goal is to develop an intelligent activity/inactivity sensor, based on existing infrared technology to detect and locate vulnerable people when in need of assistance. This will be achieved in real time and without the need for the older person to actively engage with the system. As such, issues of usability are less forefronted in this project and issues of acceptance and impact on quality of life are extremely important.

The novelty of the Smart Distress Monitor lies in its capacity to go beyond simple movement and fall detection by exactly locating the person in the rooms of their home and charting their activity (and periods of inactivity) across and between homes. Hence, the system will recognize if, and where, the person is sitting or lying down; identifies the presence of other people in the house and records movement patterns according to activity/inactivity. The ability to do such accurate movement tracking enables routine behaviours to be detected for each individual system user. The self-learning element of the system allows for deviations from the norm which *might* indicate the presence of a problem to be identified. For example, a person who remains still for a long period in an unusual place of the house, a person who start using the toilet more often than usual, or a person who used to cook her meals and suddenly stops using the kitchen.

The project objectives concern the identification of the technological, psychological, functional and social needs of older people; the definition of the requirements for an acceptable activity monitoring system for use in private homes; the exploration of the ways in which such an activity monitoring system impacts on the everyday lives of older people in different settings; the recognition and facilitation of those elements that guarantee that older people are central to the development of the activity monitoring system and are supported to contribute to the user centered, participatory research approach. Hence, although the scope of the SDM project is broader, in this paper we focus on a specific aspect of the research approach, namely the *participatory processes*. As such, this paper is about research processes (concerning the involvement of an Advisory Group of older adults) rather than research methods.

### *Participants in the SDM Advisory Group and their Role*

The design, development and implementation of the SDM system has adopted a user driven, participatory approach to ensure that the needs, perspectives and preferences of older people are taken into account throughout the whole process. Older people's involvement was planned at the research proposal stage via the constitution of an advisory group. An underpinning principle of the participatory approach adopted was to ensure that the participants in the SDM advisory group were clearly informed about their role in the whole research process and that the research was engaging and purposeful for the advisory group, the technologists and the university research team. At the first meeting an informal discussion was held concerning reciprocal roles and tasks, values and responsibilities.

The advisory group comprises six volunteers (three men and three women) with different backgrounds and experiences. Some are still working or about to retire, all are involved in volunteer-based activities and interested in how technology can keep people feeling well and independent for as long as possible. Their age ranges between 65 and 70 and they may be defined as being knowledgeable about general issues of importance to older people but not experts with experiential knowledge of using services/assistive technology.

The role of the members of the advisory group is to input into the research decision-making processes as well as contributing to knowledge production (providing information for the literature review as well as drawing researchers attention to relevant news reports and seminars), recruitment of interviewees and home trial participants, methodological design (commenting on research tools), data collection, analysis and interpretation. Although the participants in the SDM advisory group have been proactively involved throughout the whole research

process, their specific contribution in terms of research participation and analysis has mostly revolved around the aspects we describe in the following section.

#### OLDER PEOPLE'S INVOLVEMENT IN THE ANALYTICAL PROCESS AND IN HOME TRIALS

A thematic analysis of the interviews (both from primary and secondary datasets) was undertaken during the first year involving some of the members of the advisory group, making use of older people's perspectives on technology. This ensured that user perspectives informed the data collection on user requirements from the very outset of the project. In addition, advisory group members took part in workshops organized to discuss data analysis and the translation of user requirements into system specifications. This resulted in a series of use cases which were designed to focus attention on the needs, life situations and events of older people together with the potential and challenges of the infrared activity monitoring system. On the basis of these data, a *User Requirements Report* fully grounded in older people's experience and understandings of technology was produced by the academic team and a prototype system was developed by the team of technologists. As the project progressed, new opportunities for involvement arose and were taken forward by the advisory group. For example, their attendance at conferences and seminars and their input to written reports was facilitated.

Currently, home trials of four to six months duration are being conducted on the prototype system<sup>3</sup>. Advisory group members have evaluated the design of the home trials and made suggestions. An evaluation of the home trials will involve an examination of the practical and psycho-social aspects of the Smart Distress Monitor to establish the capacity, potentialities and acceptability of the system in the home environment. The advisory group of older people continue to be involved in all aspects of the project and they will be asked for their feedback about the home trials and to describe aspects of usability, acceptability and privacy within the home environment. The research team continue to work closely with the team of technologists to ensure that the voices of older people are heard and their views are equitably incorporated into the actual design and implementation of future iterative developments of the system.

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<sup>3</sup> At the time we write this, the research is coming to an end and the activity monitoring system prototype has been installed in four private homes.

STRATEGIES AND PROCEDURES ENSURING THAT OLDER PEOPLE ARE CENTRAL  
TO THE DEVELOPMENT OF "EFFECTIVE" ASSISTIVE TECHNOLOGY

The joint shaping of roles defined at project outset created the conditions for the development of equitable relationships between and across the research team and the advisory group as well as a sense of belonging within the project and shared team work. However, such *belonging* did not characterise the relationship between the *technologists* and the *advisory group*. In particular, the technologists' market-oriented attitude (mainly concerned about producing a marketable system) did create a distance from older people's perspectives, values and motivations (mainly concerned with the needs of older people viewed as a widely heterogeneous group). Sometimes, this translated into two different mind-sets, one inclined towards assertiveness and productivity and the other one inclined towards critical appraisal, negotiation and the consideration of multiple viewpoints, bringing into play concerns with unbalanced power relations. This prompted a discussion on the advisory group members' involvement and empowerment within the project, which have been eventually expanded and facilitated via several formal and informal meetings as well as through individual contacts and conversations over the phone.

One useful way of engaging the advisory group members concerned the location and atmosphere generated during meetings. These were held variously at the university, at researchers' and members' homes and even in informal places such as pubs, bars and restaurants. Unsurprisingly, meetings in homes and other informal places tended to emphasise the social nature of the group while getting the work done. Informal, social meetings were very important in promoting strong and effective working relationships. Involvement in research projects means and implies far more than working relationships. Intensive joint work promotes strong interpersonal relationships, which in turn need to be encouraged and cultivated through the development and appreciation of the research participants' skills in an accepting, equal and learning environment. This constant work of informal "getting in touch" was crucial for both advisory group members and researchers as it enabled to constructively critique working practices. It was through such constant process of renegotiation of the roles of each and every participant and through the acknowledgment of their importance and value that the notion of participatory approach to the design and development of care related technology was successfully set into action.

Numerous practical matters can facilitate or hinder the successful involvement of older people in the research process: their general health conditions, their means of transportation, their families, their jobs, their medical consultations, their grandchildren, and, last but not least, their often busy/hectic social lives.

However, several facilitative strategies can help minimize the obstacles and maximize older people's participation and empowerment within the research process. The first facilitative strategy involves tailoring the participatory process to each participant's financial, social and psychological resources and constraints. Organizing forms of car sharing, finding the best location for the meeting, arranging suitable date and time with everybody, taking into account the multiple and different needs and roles of older people (such as participating in cultural and recreational activities, caring for grandchildren, engaging in voluntary work and dealing with unexpected problems) are all examples of the first facilitative strategy. The second strategy involves conducting the constant, meticulous work of "keeping in touch" with each and every member and caring about their personal stories, beyond the research context. The shared attention and participation of the group in a critical family event involving one of the advisory group members is an example of this second point. The third strategy involves acknowledging and highlighting the importance of their contribution to the research process based on the underlying principle that "no one is indispensable, but we are all necessary". The fourth strategy entails being aware of any psychological problems, transportation issues, communication difficulties, sensory/cognitive impairments (e.g. visual impairments which can be accommodated with large font) or health related/disability issues that might represent an obstacle also for something as simple as a meeting attendance. Here, ensuring accessibility to buildings, easy car parking, toilets, and other facilities is very important.

Such practical matters can have a significant impact on older people's attendance at meetings and propensity to remain engaged in the project. Action to address and compensate for these matters can be taken from the outset, for example, through sending friendly reminders a few days before the meeting, contacting the older participants via phone and checking if everything is fine with them, making sure that all the information concerning the day, time and location of the meeting as well as the instructions to get there are provided so as to minimize any unnecessary concern, guaranteeing to the participants a nice and warm welcome (which may include providing them with tea/coffee and biscuits or a catering service) and, last but not least, reminding them about the importance of their individual and collective role, according to the above mentioned principle that no one is indispensable, but everybody is necessary for the attainment of authentic and successful participatory processes.

## USEFUL LESSONS LEARNED

Useful lessons learned from the SDM project and recommendations for other researchers planning to do research with older people to assess the acceptability, usability and effectiveness of new care related technologies include:

1. The need to be crystal clear, at each stage of the research, about the benefits the older people/participants can get from their involvement in the research and to ensure that their consensual, proactive and informed participation lasts throughout the research project. This must be coupled with the necessity to be crystal clear about the participants' role. While this may seem obvious, it is important that, as researchers, we are clear about our thoughts and views in relation to the ethical issues involved at any stage of the research project. The need for honesty, respect and a genuine informed participation is clear. In acknowledging the interpersonal skills of the researcher as an influencing factor, serious consideration of the ethical responsibility this entails is paramount.
2. The need to develop and refine strategies to maximize older people's participation and involvement in research while protecting their right to withdraw at any stage of the research. Researchers need to possess not only intellectual and methodological skills, but also good social and communication skills, and they need to be flexible and able to constantly adjust the research protocol to the participants' necessities and requirements.
3. The need to send prompt, inclusive feedback and continuous up-to-date information to older people/participants to ensure that their "felt/perceived" sense of participation/belonging is meaningful and purposeful. The quarterly reports and any working documents must be concise, easy to understand and available both electronically and in hardcopy. There are occasions where the members of the advisory group seem to be put off by the notion of being in a research project revolving around new technologies because they lack confidence and fear that it is going to be difficult to understand or to take part in the technicalities and/or technology jargon.
4. The need to develop and cultivate informal relationships between the researcher(s) and the older people based upon trust, esteem and reciprocity. These kinds of relationships have been developed through informal methods of communication such as postcards, greeting messages and telephone conversations. Informal meetings have also taken place in cafes, restaurants, pubs and other public spaces, but also the researcher's home and the older people's homes. This requires a constant effort and engagement of the researchers to sustain both the 'practical' and 'emotional' involvement of the participants throughout the project.



These recommendations point to the necessity to take into account and integrate social, psychological and emotional aspects of participation in a research project. Including the older people's perspectives, motivations and thoughts helps to determine and overcome the challenges not only in making technology an acceptable and workable instrument for them, but also in getting access to participants in an appropriate, equitable and inclusive way. Effective involvement of older people in research on care related technologies is crucial if we want to achieve successful research objectives and end products. Failing to address this central aspect can have detrimental impacts not only on the research outcomes but also on the future value of the technology itself.

## CONCLUSIONS

This paper describes our contextual experience of doing participatory research in relation to the development of an activity monitoring system: the Smart Distress Monitor. Developing participatory approaches to research on new technology is key to the successful achievement of the research aims, objectives and goals. This is particularly true for research revolving around ambient assisted living technologies which can be inappropriately developed as *technological* rather than *human/social* solutions to complex health and social care problems. Involving older people in advisory roles places their experiences, motivations and perspectives as central to the design and research process.

While several studies have critically reflected on participatory research processes as projects have been completed (*ex-post*), fewer have engaged in reflexive accounts on older people's experiences of participation in real-time, as the research project develops (*ex-ante*). The reflexive account overviewed in this article was conducted mid-way through the research, enabling all partners to meet the challenges identified and work together towards more productive partnerships and more successful outcomes at project end. As such, the learning gained here contributes to the emerging debate on *participatory processes*.

Older people's participation and involvement in the research must be viewed as a positive, proactive, *dynamic process* that is ongoing throughout the different stages of the project rather than a *routine practice* aimed simply at their tokenistic presence every few months. Regular meetings involving the *physical co-presence* of the research team and the older people are very important because they serve to renew and revitalise the partnership, feelings of inclusion and a sense of belonging to a common project in ways that mere phone calls or email messages cannot guarantee. Constant, exhaustive updates on the research progress and the description of the next steps must be provided, making sure that the older people/

participants are constantly aware of the issues at stake and agree with the methods to proceed. Both the *practical* and *emotional* involvement of the participants must be fed and cultivated throughout the research project, without ignoring the possibility that problematic power relations (in our case: between the team of technologists and the advisory group members) may arise.

Care related technologies can create and expand opportunities for older people's empowerment, safety, independence and well-being. Nevertheless, they also involve important ethical issues concerning intimacy, privacy, power, control as well as the necessity to reflect on the psychological, emotional, social and cultural perspectives of all social actors involved. Only by involving older people in the design and development processes of care related technologies can we attain productive and successful kinds of mutual inspiration between lay people and technologists. Effective inclusion of older people's perspectives, motivations and thoughts can be crucial in making care-related technologies more acceptable, usable and practical for them, but also in achieving successfully research aims and objectives. In order to be successful, the development of an activity/inactivity monitoring system must be viewed less as a technological challenge and more as the creation of an integrated *socio-technical system* in which technology is meaningful and purposeful for all the people and organizations involved. In other words, the implementation of these technologies must be conducted in ways which are fully participatory and inclusive for older people to ensure that the systems are designed both "for" and "with" them.

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En este libro presentamos los trabajos que realizaron los psicólogos y psicólogas comunitarios en diferentes países. Estos se presentaron en la Tercera Conferencia Internacional de Psicología Comunitaria celebrada en junio del 2010 en Puebla, México. Los artículos incluidos están en los formatos de presentación oral, simposio internacional, panel temático, cartel y sesiones innovadoras.

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VOLUMEN II

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