Inside a 'Digital Experiment’ - Co-producing Telecare Services for Older People

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Abstract

The problem of the user remains central to information systems research and practice, more so given the importance now given to user-led innovation. Telecare is a much-vaunted example of e-enabled health and social care which, over the past decade or more has received considerable policy attention and investment in Europe and beyond. However, it appears that the technological opportunities offered have not been taken-up in everyday practice and that the engagement of users - service providers and end users - has been identified as a major barrier. This article presents the experience of a European level project that sought to use a form of co-production to engage users in the development of a telecare system for older people. The outcome was a platform with infrastructural properties and a service-orientated architecture better able to support subsequent innovation in use.

Keywords

Digital Experiments; user-centered design; appropriation; co-production; telecare.
1. Introduction

It has recently been claimed that, despite the many years of effort, there is very little
evidence that attempts to promote ‘user-centered design’ have had much practical or
sustainable impact in improving the usability of systems. The ‘basic question’ of, how to
‘match user requirements to technological possibilities’, has yet to have been answered
(Williams et al, original italic, 2005:29). We explore this issue in the context of new
technological possibilities offered by telecare systems as a solution to the remote
monitoring of the health and well-being of vulnerable groups, in particular the growing
ranks of the elderly, a strong demographic trend in most advanced countries (Kinsella and
Wan, 2009). The development of telecare has been dominated by technology-driven
images and paradigms, often appropriated by and rendered subservient to clinical
interests. Such images involve, at best, a 'passive' notion of the user as a 'consumer'
patient/client to be 'satisfied'. Critics, have questioned the threats posed by attempts to
'digitize the body', in particular in relation to the privacy and governance of information,
the nature and form of consent involved in sharing sensitive personal data, and the very
idea that something as quintessentially human as the care of one person for another, can
be delivered in some sense by virtual means (see e.g. Hanson et al, 2009; Webster, 2009).

We consider these issues through the experience of a European level attempt to design
such a platform for the delivery of virtual services to older people – the OLDES (OLDer
people’s E-Services at home) project. Here our role as research partners enabled us to
engage as project ‘insiders’ in an intervention that sought to bring about a more user-centered approach. We argue that this necessarily focuses attention away from the design of artifacts and technologies *per se*, to issues of how and for what purpose new technological resources might be customized and configured to meet the needs and requirements of particular domains of care. We suggest that these issues are most likely to be addressed and resolved through engagement of users in 'design in use' rather than by attempts to increase user participation in a necessarily temporally distant and socially remote 'prior stage' of technology design. We therefore draw upon recent ideas concerning 'digital experiments', user 'appropriation' and 'co-realization' to explore a different model of user engagement - we prefer the term co-production - which we believe is more appropriate for telecare and, more generally, other attempts to e-enable public services (McLoughlin and Wilson, forthcoming).

Our argument is structured as follows. First we briefly review the history of the development of telecare and the problems and issues that have emerged in trying to design systems which will be taken-up by 'users' in the everyday delivery of health and social care. We then outline the notion of 'digital experiments' and associated ideas as an alternative basis for involving users, not only in the design of devices and systems as such, but also in re-thinking the context of their appropriation and use. Finally, we consider the OLDES project and our approach as project partners and participants to nurturing co-production. This involved an attempt to combine action research to develop a co-produced model of a service environment that could be the basis for the procurement and deployment of a telecare platform capable of being shared, re-scaled and re-purposed.
over time. We do not claim that this attempt at co-production was wholly successful. As an 'experiment', the objectives were as open to failure and learning as to the successful achievement of a pre-defined outcome. However, we do argue that our experience helps cast new light on the dynamics and tensions in working in this mode 'on the inside' of technology development projects. It also points to the value of an infrastructural as opposed to ‘applications’ view of the development of e-health systems such as telecare in particular and e-enabled public service delivery in general (McLoughlin and Wilson, forthcoming).

2. Telecare Systems and the Problem of the User in their Development

Telecare is seen by many policy makers as offering potential solutions, not only to the problem of an aging population, but to meeting the health and social care needs of other 'vulnerable' groups such as those with disabilities, people with long term chronic conditions, and members of communities in remote regions. It has been defined as, 'a set of services bringing care directly to the end-user' in or around the home environment, where specific provision is made to cover the risks associated with care being provided outside of a hospital or other setting more directly controlled by care professionals (Barlow et al, 2006). Telecare systems typically seek to provide services which both monitor the safety and security of the home environment, the personal security of the individual being cared for, and the services needed to capture information provided by electronic assistive technologies designed to improve the functionality of the home or to capture personal health and medical information (Barlow et al, 2004, 2006).
In the case of older people, the idea of using technological aids to monitor health and well-being is not so new. For example, an electro-mechanical community alarm bell system terminating in a warden’s quarters was first incorporated into the design of sheltered accommodation built in the South West of England in the late 1940s (Hardey et al, 2009: 7 citing Parry and Thomson, 1993). Of course solutions of this type have long been surpassed by more ‘intelligent’ electronic systems which, as they have become more sophisticated, have moved beyond being emergency and alarm raising devices to support new functionality that allows so-called ‘lifestyle monitoring’ (Hardey et al, 2009). For example, electronic assistive technologies allow the remote capture and transmission of information about the medical condition (e.g. vital signs and other indicators such as sleep patterns and so forth) and well-being (e.g. providing for remote visits to check on the individuals status, automatic reminders to do things such as take medication, alarm systems to detect movement and falls or other mishap etc.) of the older person concerned. Health care and other professionals are able to monitor the status of these systems remotely, whilst older people themselves can be supported in using the information to take more responsibility for their own health and well-being.

Increasingly, the spread of high-speed broadband and networked connections is giving rise to ever more fanciful technology-driven ideas such as an, 'internet of things' comprised of ambient systems and smart assistive devices harnessed to the task of providing care to an aging population. For example, a study by the Joseph Rowntree Foundation Centre for Usable Home Technology recently identified a number of
emerging technologies such as 'robopets' and 'clever coffee tables', 'talking' walking frames (that remind people where they are going), set-top boxes so people can consult nurses, doctors and social workers or contact friends and relatives using 3-D video technology, and even special exo-skeleton suits to help infirm people climb stairs (Publicnet Briefing, 2009).

Policy-makers and governments willingly embrace these kinds of ‘futuristic’ and optimistic technology-driven scenarios. The European Commission, for example, views telecare especially in health, as a key part of the Commission’s vision towards an ‘Information Society’ (see Commission of the European Union, 2004, 2005, 2007, 2011). In the UK, a recent government report stated that, 'it is safe to imagine that the pace of technological change that we have seen over the last 20 years will continue, and that by 2030 the kinds of technology that will be available to us will be far beyond anything we know at the moment' and 'those using the care and support system will increasingly expect technology to play a part in helping them decide what care to choose and helping to improve their quality of life' (HM Government 2010: 50). Such ideas have recently been given tangible commitment in the form of an industry and government concordat to develop telecare systems to save 'three million lives by 2015' (Department of Health, 2012; see also www.3millionlives.co.uk). This campaign has as its evidential base what is claimed to be the largest ever Controlled Randomized Trial (CRT) of telecare systems, involving over 6,000 patients and nearly 240 GP practices in three areas of England. The trial revealed that, 'if delivered properly', in the health domain at least, telecare systems, 'can substantially reduce mortality, reduce the need for admissions to hospital, lower the
number of bed days spent in hospital, and reduce the amount of time spent in A&E [Accident and Emergency]' the key to which is, 'to integrate these technologies into the care and services that are delivered' and by, 'putting people at the center and in control' (Department of Health, 2011: 2)

In the case of older people a number of specific benefits, such as reduced need for hospital stays and reduced health care costs, have been identified (see e.g. Kings College, 2004; Colmer, 2007; Inglis et al, 2010) whilst, in general, the technology behind telecare and related assistive technologies is believed to be readily available and proven (Barlow et al, 2006; Colmer, 2007). Despite this, the widespread diffusion of working telecare systems beyond trials and demonstrator projects, has to date proved challenging and problematic (May et al, 2001; Lehoux et al, 2002; May et al, 2005; Barlow et al, 2006; Clark and McGee-Lennon, 2011; Rogers et al, 2011). As a result, innovation in service development remains ‘immature’ (Barlow et al, 2006). One reason for this may be that attempts to engage users in the design and development of systems have been limited (House of Commons, 2005). Indeed, a failure to match 'technological opportunities' to 'user needs' has been identified as a significant barrier to telecare innovations (Barlow, et al, 2006: 399). Similarly, the absence of 'a clear set of users' who have 'expressed a demand' and can 'drive' projects forward in their 'initial' stages, has been identified as a 'fundamental problem' in individual case studies of attempts to introduce telecare into local practice (Barlow, et al, 2006: 402).
In so far as users are considered at all it seems, this tends to be in 'market research' terms as potential 'customers' whose 'satisfaction' as patients with the prospect or actuality of receiving care by virtual means requires assessment. Such studies tend to show positive patient responses to telecare interventions on the part of users. However they, 'often represent highly selected patient groups, and often focus on “hotel” aspects of care rather than important questions of diagnostic confidence and quality of life' (House of Commons, 2005: 399). There are a few examples of attempts to go beyond such conceptions and deploy more human-centred design methods (see e.g. Atack et al, 2004; Brisben et al, 2004; Clemensen et al, 2005; 2007, 2008; Esser and Goosens, 2008; Lie et al, 2006; Pilemalm and Timpka, 2008) and some of these focus specifically on older people (see e.g. Goodman et al, 2002; Kanis et al, 2011). In a notable example, Clark and McGee-Lennon (2011) explore the application of participatory design techniques to identify the barriers to the successful uptake of assisted living technologies and telecare for older people in Scotland. Interestingly, contrary to previous research, their findings point to scepticism on the part of older people and their carers concerning the utility of such technologies in improving their living conditions. In particular, concerns over the privacy and security of the information that might be captured by such systems were highlighted. In addition, there was also unwillingness amongst service providers to change their care practices. Finally, the inflexibility of telecare systems prevented their configuration and customization to suit the specific needs of older people (Clark and McGee-Lennon, 2011:20).
It is against this backcloth that we now turn to the potential that might be offered by
digital experiments to involve users in the development of telecare systems and services.
It is clear that such an approach would need to first, embrace a much broader definition
and scope of 'the user'; involve larger scale and more networked rather than stand-alone
localized projects; pay careful attention to the most appropriate point and means by
which users are engaged in the development process; and offer the means of evaluating
and assessing the differences in outcomes that might arise from adopting telecare. In
particular, it would need to show how users, 'are able to integrate' telecare ‘into their
everyday lives and use it for their own ends' (Rogers et al, 2011: 1078).

3. Digital Experiments and Appropriation

We now frame the OLDES project as a form of ‘digital experiment’ (Williams et al,
2005). Such experiments provide a bounded set of circumstances in which actors on the
supply side and users or representatives of users on the demand side can come together
around a specific technology project in a single organization or ‘close alliance of
organizations’ (Williams et al, 2005: 144). Typically, such projects are not so much
concerned with the ‘creation of new artifacts’ but the ‘effective configuration’ of existing
technologies and their ‘integration’ or ‘appropriation’ by communities of local practice
(Hartswood et al, 2002: 12; Williams et al, 2005). 'Digital Experiments' can therefore be
seen as a further iteration in attempts to address the challenge of how to ‘bridge the gap’
between designers and users but located within a new discourse of ‘appropriation' and
'social learning'.

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This discourse seeks to move beyond perceived deficiencies in participative design and related methods of more effectively involving users in the determination of the outcomes of information technology-based innovations. In particular, it is more concerned with fostering 'innovation in-use' by users rather than engaging users through participation in a prior stage of design (Hartswood et al, 2002; Williams et al, 2005). As such digital experiments provide an opportunity to foster 'co-realization'. This involves system developers and others working with users to enable the, 'effective configuration and integration with work practices' of technical artifacts and systems in the context of use (Hartswood et al, 2002: 12). In the form of a demonstrator or trial project for example, such experiments may permit joint learning by designers and users (see e.g. Williams et al, 2005: Trigg et al, 1999; Hartswood et al, 2002). Such experiments can therefore provide a means through which user appropriation in use, rather than user participation in the prior stage of design, might be facilitated and nurtured.

The process of appropriation, involves both ‘innofusion’ (technical innovation by users post-design during diffusion and use) and ‘domestication’ (social learning by users to creatively assimilate technologies), ‘within their local practices, purposes and culture’ (Williams et al, 2005:7). Appropriation work, therefore, involves both, ‘practical efforts to make technology work’ and action to ‘create meanings’ that enable a technology to become integrated into the identity of the individual user and embedded in the culture of the user community as a whole (Williams et al, 2005: 55; 58). In principle, ‘digital experiments’ provide an opportunity for ‘final appropriation’ to take place in an accelerated format as they provide a space ‘within the same configuring constituency’
where, the application can be ‘put together and used within an organized and bounded array of players’ (Williams et al, 2005: 144).

Through their more explicit focus on ‘design in use’, digital experiments might also allow for the development of what has been termed a more pragmatic design discourse of incompleteness and thereby enhanced user engagement. That is, design can be seen as a process that, ‘allows for the pre-specification of a problem, the identification of pre-existing alternatives and the choice of the most optimal solution’ (Garud et al, 2008: 251). Such an approach is dependent upon ‘clear boundaries, stable preferences and fixed goals’ that, inter alia, allow users to clearly specify their requirements and for these unambiguously to be captured and acted upon by designers. However, in circumstances defined by continuous change a quite different approach is needed.

The alternative idea of pragmatic design addresses such situations. It does so by accepting the incompleteness and indeterminacy inherent in the innovation process and the appropriateness of this to situations where the context, goals and purposes of design are subject to multiple interpretations and continuous change. Here the boundaries between designer and user are accepted as blurred. Users engage in design in use. Innovation is a consequence of the evolution of user preferences and needs, which in part, is a consequence of their participation as, ‘the unfolding of the process itself changes the problem’ (Garud et al, 2008: 252). Virtual and digital technologies are of course a major enabler of this kind of ‘fluidity’ whereby, ‘material artifacts and social groups’ are readily ‘associated in a dynamic network’ and where software allows the design and
functionality of any product or service’ to be changed in ‘real-time’. In this way users can, ‘explore their preferences in use’ and different stakeholders can, ‘engage with each other in an emergent fashion’ (Garud et al, 2008: 254).

However, it cannot be assumed that such pragmatic experimentation comes about automatically. In their study of European level digital experiments Williams et al, (2005) noted a tension in the project dynamics in the form of two different ‘modes of design’. On the one hand, there was what they termed the ‘mode of control’. This involved an attempt to, ‘define the expected goal and outcomes of a project in advance’ and ‘to prescribe who would participate in development decisions and the resources used’ (Williams et al, 2005: 168). On the other, was the ‘mode of experimentation’. This exhibited, ‘a greater willingness to change direction and approach in the light of experience’ at the expense of perceived, ‘uncertainty and loss or predictability and control over the direction and outcomes of the project’ (Williams et al, 2005: 168).

Broadly speaking the greater the focus in the examples studied on technical development, the more the mode of control was likely to be emphasized. This meant projects tended to have a narrow focus on technological development and have a clear division of labour between design ‘experts’ and ‘users’. In such projects it was assumed that available technologies could meet user requirements and needs and that the barriers to innovation were by and large non-technical. The engagement of users in the design and development process was useful in so far as it enabled such assumptions to be verified.

In contrast where greater emphasis was given to the experimental mode more, ‘openness
about technical tools and the problems to be addressed’ was evident. In addition, in such projects, a wider range of users – intermediate (e.g. in the OLDES case health and care service providers), proxy (representatives of older people and their kin networks) and final (the older people themselves) were likely to be engaged in the process of experimentation (Williams et al, 2005: 171). Having said this, there was no clear relationship between the mode of design in a project and its ultimate ‘success’. Moreover, an emphasis on experimentation did not obviate the need for project control and coordination. It seemed, therefore, that the dynamics of digital experiments were not clear-cut and likely to involve a tension between the need to produce defined technological deliverables on the one hand, and the possibilities for user-generated innovation through experimentation and learning on the other. If this is the case, how might digital experiments be conducted with a view to maximizing the possibilities for user-generated innovation whilst still delivering viable technical outcomes on the other? In order to consider this question we now turn to the OLDES project itself.

4. OLDES - a Digital Experiment and Space for Co-Production.

The OLDES project was part of the European Union’s Information Society Technologies (IST) Framework 6 Programme (FP6) for Ambient Assisted Living (AAL) for the Aging Society. The project involved a collaboration of local public health and social care providers, system suppliers, and intermediary research organizations and university researchers. It was a three-year project that commenced in January 2007 and concluded, after a short extension, in early 2011. The project proposal set out the aim to offer new technological solutions based on, ‘ambient media-info-com devices, channels and
capacity’, in order to, ‘offer new technological solutions to improve the quality of life of older people’. This was to be based on, ‘Negroponte’s paradigm of a €100 device, giving the guarantee of an affordable system’.

The objective, as set out in the project funding proposal, was to develop an easy-to-use low cost computer-based networked entertainment, health and social telecare platform intended to ‘ease the life’ of older people ‘in their homes’. As well as applications in the home, the platform was also intended to enable enhanced communication and information sharing between care agencies. Critically, alongside these objectives, was a commitment to ‘user-centered’ development that, as project publicity material claimed, ‘puts older people at the center and makes their needs the main priority in all developments’. The platform was to be tested at two different ‘pilot’ locations. The first involved a group of over 100 elderly, including around 10 suffering with cardio disease, in Bologna, Italy. The second, a group of 10 diabetic patients in the Czech Republic where mainly medical care services were involved (see Novak et al, 2008). In this article we focus on the larger for complex Bologna experiment which concerned the provision of both health and social care services to older people.

Our intervention in the project was based on a view of ‘digital experiments’ as a potential ‘space’ or ‘occasion’ where the denizens of an actual or prospective community of practice could be brought together to engage with the design and development process in novel ways i.e. what we term a form of co-production (Wilson et al, 2012; Maniatopoulos et al, 2009; McLoughlin et al, 2009). This has some similarities to the idea of ‘co-
realization’. First, what is envisaged is consistent with the idea of a ‘shared situated practice involving users and IT professionals’, that is, ‘grounded in the lived experience of users as they grapple with the problems of applying IT’ (Hartswood et al, 2002: 13). Second, the aim is to avoid the 'design fallacy' (Stewart and Williams, 2005) and to focus on, 'the means by which design emerges and evolves as part of the ongoing struggle' to make a 'particular system work for these particular users, in this particular workplace and at this particular time' (Hartswood et al, 2002:13). Third, the approach is based on the possibilities of 'leveraging' users 'learning by doing'. That is harnessing the knowledge created through user interactions as they, 'cope to some degree with the shortcomings of conventional IT design and development practice, fixing or learning how to work around the deficiencies created through the reliance on a priori design' (Hartswood et al, 2002: 13). Finally, as with co-realization, the aim is to go beyond participatory design in so far as this, despite, 'championing...user expertise and control’, fails to consider the involvement of users, 'at the very point where this becomes most valuable to design, and users have the opportunity to drive the process' (Hartswood et al, 2002: 11).

However, our co-production approach differs from co-realization in two important respects. First, we do not assume that co-realization or co-production can only take place when system developers are taken into the domain of use (e.g. workplace or other user domain) to learn in an ethnomethodological manner from the actual work practices of users as they attempt to render technology of value to them. The idea of a digital experiment involves the creation of another possibility in perhaps a more neutral kind of space - for example one that is pre-competitive and vendor neutral. Here developers and
users can, in principle at least, work together in a facilitated manner during which
effective and useful representations from the lived experiences of users can still be
solicited and articulated through ethnographically informed means (see McLoughlin
2010). The possibilities for co-production are therefore not seen as bounded by the
everyday domain of the user.

Second, co-production assumes that the development challenge involves more than just
exposing developers to an understanding of how discrete systems and artifacts
(‘applications’) are appropriated by users in use. Rather, it is concerned with the
‘cultivation’ (Hanseth and Montiero, 1998; Hanseth, 2002) or ‘nurturing’ of a space where
socio-technical infrastructures to support ongoing and emergent innovation in use can
emerge and evolve. For such ‘nurturing’ to take place, there has to be ongoing agreement
by those involved that, whilst designers and developers are present, they do not have a
privileged position as ‘experts’ and ‘solution providers’. By the same token, the
‘rationality’ of conventional development methodology and systems practice has to be
seen as but one of the ‘rationalities’ admitted to the space. In addition, whilst a co-
production approach involves the fundamental reappraisal of relationships and
boundaries in the design and development process, the differences that exist between
domains of expertise and practice still have to be adhered to. As such, it is accepted as
inevitable that at some points in appropriation, concrete technical work has to be
undertaken. Of course, none of these conditions are pre-determined or given but have to
be brought about and sustained in the context of a live project and all the 'real world'
dynamics that this entails.
As one of the University partners in OLDES, we had responsibility for work packages concerned with user-engagement and its evaluation. In pursuing this role we undertook action research in order to enact, inform and reflect upon our intervention. Our approach here was akin to the 'bricoleuring' and ‘tinkering’ outlined by Badham and Ehn (2000). This involved an explicit commitment to working with the resources, materials and ideas at hand to ‘get things done’ as much as seeking to make interventions based on pre-defined academic frames and principles. In so doing, we were required to gain an in depth understanding of the situated and context specific nature of the project and its settings. To support this, a number of other research methods were drawn upon to inform the project understanding of the context of deployment and use and the roles and views of users, both in the service domain and end users themselves. In addition, as the project progressed, formal attempts were made to evaluate 'end user' reaction to the telecare system prototype once this was eventually ready to pilot. This work took the form of:

- ‘Quick and dirty’ ethnography involving observation and interviews (McLoughlin, 2010) at sites where the OLDES system would be tested. These including both service user and service provider locations such as an existing call-center support service, local hospital (including interviews with representatives of the clinical communities including a GP representative); the Emilia Romagna Health Authority (interviews with representatives responsible for allocating health and social care budgets); Social Services (representatives at the Municipal and District levels) and interviews with the representatives of the health department of the Municipality).
• Focus groups (audio and video recorded) conducted by Italian partners with members of the professional and voluntary care community and representatives of the older people participating in the project.

• OLDES Labs, facilitated by Italian partners, whose participants included 13 – 20 older people already involved in the OLDES project, 1 older person waiting to be included, 3 older people invited directly by potential users, 1 new association representing older people interested in the project, and 3 volunteers from local associations already involved.

• Questionnaire surveys administered by Italian partners in telephone or face-to-face interviews with a sample survey of 100 older people aged over 80 (drawn from the district of Bologna where the OLDES system was to be tested) to better understand the needs, life-styles, living conditions and existing care arrangements of elderly people within the municipality.

• A further survey of older people to evaluate user acceptance of the prototype system after it was eventually rolled out.

In addition, we also proposed the deployment of a visualization tool that had been developed iteratively through a number of previous research projects. The tool provided one means by which ethnographic data from studies of the practices of users and the domain of use could be represented. Ultimately, these could inform detailed requirements and technical specifications. The visualizations produced (typically in the form of animated multi-screen power point presentations) could also be effective ‘boundary objects’ that facilitated dialogues, based on the naturalistic language of users, within and
between different stakeholders (Star, 1989; Star and Griesemer, 1989). For example, as an initial point in the process the ‘visualizations’ produced could act, as ‘mirrors’ on, and as ‘windows’ into, a stakeholder’s own and other’s perspectives - particularly useful in multi-agency care service environments where multiple agencies and professional disciplines are typically engaged in delivering a care pathway for a patient or client. The visualizations are intended to be recognizable by users as relevant and realistic in their worlds, provide a basis for them to explore non-technical as well as technological conditions and issues, and provide a starting point for them to adopt and appropriate in the process of internalizing and sharing an emerging set of models, plans and designs.

5. Living inside the OLDES Digital Experiment

Our initial experience of 'living inside’ the OLDES project revealed a number of different perspectives amongst project stakeholders. These presented an immediate challenge to our co-production intervention. Most obviously there was a technical development perspective which had identified an interesting new platform to work with and had a concept of the system framed in exclusively technical terms without any notion of the service environment in which such a system might be deployed, whilst the user need and requirement for such a system was largely assumed. There was also a strong clinical perspective that, whilst declaring a formal commitment to the project at an organizational level, was characterized by deep suspicion and skepticism on the ground. Here general practitioners were concerned with such things as financial incentives and whether the elderly really wanted such virtual services (or as the GP warned, older people were more interested in ‘sex and religion’ than ‘social networking [web sites]’).
As the provisioner and manager of health and care services the perspective of the political leadership of the Municipality of Bologna was also highly significant. The Municipality had for some time viewed telecare as a means of achieving faster delivery of services, stronger relationships between citizens and the city government, and more transparency in the ways local government operated and decision-making could take place. A strategic plan had been developed that focused particularly on older people (Bologna already had the highest percentage -approximately 27%- of people aged over 64 years old in Italy). The Municipality was keen to support the OLDES project since it felt the system could radically increase the numbers of older people who could be accommodated in this emerging system of care. The vulnerable elderly would benefit from remote health monitoring and care through the system as well as the direct contact from existing call center based services. At the same time the range of services could be increased to support not just vulnerable older people but the older population in general - for example by providing entertainment and social networking services. In short, for local policy-makers and politicians, OLDES would provide the basis for an affordable and more efficient means of meeting the needs of an aging populace, whilst providing better quality and more targeted and customized services.

Given these stakeholder positions, an initial starting point for our intervention was the development of a ‘care scenario of the future’. This was intended to 'mirror' stakeholder views and to stimulate discussion of some of the key assumptions that seemed to be driving the project. This visualization used the demonstrator tool to extrapolate from
early depictions by the technology suppliers and developers of the technical architecture of the OLDES platform. The visualization was deliberately provocative. The scenario presented a vision of how a virtual telecare service, targeted at older people living alone with chronic medical conditions, might look and operate. The scenario hypothesized a ‘mock-up’ telecare platform comprised of a variety of sensor and other devices to allow the remote capture and transmission of information from the apartment of an older person. In this ‘virtual apartment’, a TV with the addition of a set-top box provided the older person’s interface with the system. The set was operated by a customized remote control and the older person followed on-screen instructions through a menu-based user interface. TVs were located in the kitchen and the living room of the apartment. Two-way communication between the older person and care providers could also take-place through the interface and be screened on the TV. The status of the systems was monitored remotely by the care-providers. A storyboard was used to depict a ‘typical day’ of an older person living in this telecare environment (Table 1). The storyboard sequence uses two of the demonstrators visual display screens. Screen 1 (Figure 1) presents views and information about the home of the older person - Sra. Verde (SV). One view is a plan of her apartment that indicates activity in the rooms and the passing of time. The remote control is visible to Sra. Verde at all times. Screen 2 (Figure 2) shows the call center application screen of a ‘Care Co-coordinator’ (CC).

**INSERT TABLE 1 AND FIGURES 1 AND 2 ABOUT HERE**

Using this visualization, the question posed for stakeholders was whether such a technology-driven scenario and associated care environment was consistent with the
project’s espoused ‘user-centered’ approach? For example, in this scenario how would consent be given by service users, or those authorized to represent them, to capture, store, process, share and act on the information captured from the apartments? By the same token, how might the roles, rights and responsibilities of the service providers who were to use and share this information to be defined? Further, how might these be governed and by who, in order that they can use the information to provide clinical and social care? How would the privacy of service users be protected and how might adequate protection against ‘data loss’ by service providers and others be ensured? Finally, in what ways might the greater service integration implied by the availability of such information and the sharing of it between care professionals result in more cost-effective and yet citizen-focused services?

To further the project understanding of the context of use, a short ethnographic study of the existing call centre based care service and the operators who worked there was conducted. It was anticipated that these 'street-level bureaucrats' (Lipsky, 2010) enjoyed significant discretion in the interpretation and enactment of formal policy that, in principle, might be threatened by the introduction of a telecare system that might 'automate' many of their functions. The study revealed that, whilst their interactions were predominantly telephone-based, front line care workers had developed strong relationships with their clients and that these were familial in nature. The care workers regarded their clients as ‘aunts and uncles’ and the older people were said to see them as ‘nephews and nieces’.
For example, in the call centre we observed a notice board next to the operators’ station with a ‘thank you’ note from one of the older people. This had been sent following a visit from one of the older people who came to visit the centre because she wanted to see the operators who cared for her and where they worked. In a similar example of developing personal relationships there was a photograph of a cat sent by another client.

Such attempts at the humanisation of the virtual links between the cared and the carer are highly suggestive of what is seen as of value in the care relationship by ‘the users’. In a further illustration some of the telecare workers explained how they became more involved with their client’s lives beyond the formal requirements of their roles:

They [the clients of the Centre] have real problems and we are not able to solve them. Their house may be leaking from the rain and they cannot close the windows or they may have some other difficulty. We can call friends and neighbors or relatives. These may not be emergencies, and we are not the emergency service, but sometimes we do get involved in critical situations. For example, I had an appointment with an 85-year-old lady who has enormous problems. She did not respond to the phone call for a long time. Eventually she answered and said that she was on the floor unable to get up. We called her neighbor who is also an old lady who checked but could not move here. So we had to call the emergency services. (Source: Work package1 Usage Models)

Similarly, in another example:

Our discussions with the older people are not limited to the script and to protocols for monitoring their health status. We are, for example, collecting their recipes for publication (Source: Call Centre Operator interview, Work package1 Usage Models)

In a further illustration of how the telecare operators practice went beyond the formally prescribed, we also observed that in executing their roles, the operators had occasion to contact GPs where there was thought to be a medical or health issue with one of their clients. However, the basis of this relationship was informal and whilst most of the GPs
appeared to recognize this relationship there was no formal agreement covering the joint
responsibilities of the two services. A similar situation appeared to exist in the case of the
social workers with whom the operators interacted. In both instances, the interactions
between the operators and the health and social services appeared to take place only when
occasioned by an event arising through a telephone contact with one of the older people.
In the context of a lack of formalization of the relationship, the operators reported that
they felt ‘empowered’ by being able to mobilize these services to assist old people in
times of difficulty e.g. during periods of hot weather.

Such observations prompted interesting consideration in terms of the nature of the service
environment. One question, for example, was the extent to which roles and relationships
of the tele-accompany service needed to be re-thought on the basis of clearer and more
formal collaboration and partnership with the other public service agencies involved.
Similar questions were also evident in relation to the definition of new care pathways by
health care and social service agencies, and at the service commissioning and resourcing
levels where procedures and processes would need to be developed to act upon and
deploy the aggregated information about care patterns and needs that, potentially at least,
could be produced by the broader deployment of the OLDES platform beyond the project
itself. In terms of co-production this presented an opportunity for experimentation and
prompted the development of a model of the architecture of a possible service
environment using the visualization tool (see Figure 3). The model, inter alia, provided a
clearer conception of the service management and governance frameworks that would be
required. At the same time, new concepts such as those of the ‘provisioning’ and
'permissioning' of services to enable access and share information as well, as controlling the access of users and service providers to services, could be articulated. The model also provided an initial representation of how the main sections of the OLDES Network in the clinical, social care and public service commissioning domains could engage within the service environment. All of this challenged the stakeholders to reshape and renegotiate their relationships, as well as their practice.

INSERT FIGURE 3 ABOUT HERE

However, as the project progressed it proved difficult to get stakeholder engagement with these issues. Technological issues and problems continued to dominate the agenda. A prototype platform was developed ‘Alpha’ (see Table 2) which was to be used in usability assessments with the older people participating in the project. Its specification reflected the designer’s assumptions about the user’s needs and requirements.

INSERT TABLE 2 ABOUT HERE

However, getting the Alpha prototype to work as intended proved particularly problematic. In particular, there were difficulties with the supply and reliability of core hardware technologies that failed to operate as specified. The INK computer supplied experienced overheating and other problems and an upgraded replacement machine displayed further faults. Eventually it was decided to source replacement computers from another supplier whilst the original supplier worked on solving the problems with its
During these delays the opportunity was again taken to spend more time developing user-generated data on needs and preferences. Previously the project had not had direct contact with older people and was obliged to communicate with them (e.g. through the focus group activity) through their voluntary sector representatives. However, the first round of questionnaire and focus group work, conducted under the aegis of the Social Centre and the Parish in which the prototype systems were to be rolled out, provided new access to potential final users. This round of activity provided some useful insights for the priorities of the design of the system over and above the assumptions made by the designers. More significantly, it maintained contact and engagement with the user community at a critical point when the failure to produce a working prototype threatened to undermine commitment and support. It also had the indirect effect of establishing a more effective working relationship with the end user community and in particular the care networks constituted by voluntary organizations in the Parish and the older people themselves.

By the end of the funded phase of the project, the technology problems had been sufficiently resolved for a Beta Prototype to be built. The platform was still plagued by technical problems but judged sufficiently stable to be rolled out. At this stage the system was installed into the homes of the final users participating in the project, although around 10% of the installed systems continued to experience technical difficulties. Interactions with users continued to develop as well. These now took the form of
‘OLDES Lab’ events. These were occasions at which OLDES users or potential users were brought together around some issue of interest or value for discussions, presentations and exercises. The focus of the first ‘lab’, for example, was to build relationships with users, seek their opinions about possible OLDES media content (healthcare) and to update potential users about the state of the project. A second ‘lab’ built on the success of the first one with an enlarged number of older people participating. This event included a dialogue with an expert geriatrist and the older people over lifestyle options and choices to promote health and well-being in older age.

In sum, the broad conceptual approach adopted within OLDES shifted somewhat during the period of the project. The shift had two main elements. First, a move from a provider oriented view of technology and service design and provision in which users figured through ‘proxy’ mechanisms to one in which the users themselves, under the aegis and with the support of representative organisations, engaged more directly in the design and development processes. Second, a move from an applications oriented view of the OLDES environment as a set of well defined services provided by the conventional bureaucratic mechanisms of public service delivery, to a more federal approach in which services from various sources are brokered and intermediated to users and even by users themselves. These shifts took place against a background of, and as a response to, a number of disruptive factors through the life of the project. Principle among these was the delay in delivery and the initially unreliable performance of the OLDES set top box/personal computer. However, it is also fair to say that developing technology based services for a cohort of vulnerable older people in the context of a multi-agency, public
and voluntary sector environment, such as that provided by the Municipality of Bologna, is inherently complex and challenging. The story of the project was, therefore, one of continuing reevaluation, learning and adaptation for all concerned.

6. Discussion: Beyond Participative Design in Telecare?

‘Digital experiments’ have been proposed as a means of moving beyond the limitations of ‘participative design’, in particular the problem of the ‘design fallacy’ (Stewart and Williams, 2005). However, despite their potential for ‘accelerated appropriation’ in practice Williams and his colleagues found, ‘virtually no instances of systematic organized end-user involvement’ in the examples of digital experiments that they studied (Williams et al, 2005: 174). In trying to account for this they pointed to a number of factors that might offer some explanation. These included the smallness of the sample, the projects and their duration; the use of cheaper and easier proxy options to represent the end-user in the project (more likely where the mode of control was to the fore); the well-documented difficulties of involving the end-user in design because of perceived skill and knowledge gaps and a tendency to defer to experts; and problems, in commercial settings at least, of sharing knowledge gained from users amongst technology suppliers (Williams et al, 2005: 174).

However, we would suggest the OLDES project went some way to overcome at least some of these problems and issues, or at least point to how they might be more appropriately addressed in future projects, and thereby point to possibilities beyond the
limitations of participatory design. First, OLDES was a single project involving an intervention strategy to nurture, not just evaluate, a user-centered approach. As such, the aim was to find alternatives to the user being engaged as a ‘passive’ actor and ‘object’ of the project and to develop resources to assist them to become ‘systems builders/intermediaries in their own right’ (Williams et al, 2005: 175). Second, the purpose of the intervention was not just to engage users directly in the task of designing the OLDES platform, but also to nurture a process of co-production intended to develop scenarios of the service environment in which appropriation could take place. In turn, this would provide the basis for a more informed guidance and detailed specification of requirements based on user’s own projections of the possible future service orientated architectures underpinning such an environment. Third, in order to do this, the technological development process was seen as one concerned, not with the design of a technological application, but rather with the provision of an organizational and information infrastructure that would be both informed by and supportive of the emergence of such service environments.

We can give this final and fundamental point some illustration by considering the implications and lessons of the OLDES project for the future development of initiatives to provide telecare services. Firstly, one of the issues that has bedeviled the deployment of telecare systems is that they have been developed as essentially stand alone systems, necessarily targeted at particular groups or client profiles in order to make them appear concrete or feasible, and at the same time to provide symbols of success to project sponsors and funders. In such projects, where the mode of control dominates, this focus
tends to be maintained and there is little consideration of the need to identify common resources and functions that might support subsequent design in use by users. This, we suggest, threatens the longer-term sustainability of project outcomes. This is because the return on investment and the social, human and community benefits of telecare platforms can only be realized through the network externalities of sharing within the overall care sector and with the wider civic, social and economic spheres. The ‘business case’ for telecare systems is inevitably undermined if their viability rests on a pattern of diffusion of ‘shrink wrapped’ products and systems alone, and neither is this case assisted by the search for 'gold standard' assessments of the benefits of such products based on the medical preference for randomly controlled trials (House of Commons, 2005).

Moreover, as should be clear, the issue is more than one of the technological evolution of telecare systems. It also involves nurturing the emergence and maintenance of appropriately managed and governed domains within the networks of care such systems are intended to support. A particular issue here is the essential transparency of infrastructures, that is, by definition they are intended have internal workings that are invisible (Bowker and Starr, 1996). However, users in health and care settings need to be able to trust and be confident in the resource and the purposes to which it is being put in the sharing of information about them between clinicians, social workers and potentially many others. Governance, in this sense, cannot be 'built into' a networked system and forgotten about in the way that users of social networking are inclined to do. This is all the more necessary in the context of health and social care services where changes in social need and demand can result in policy shifts (for example the current trend towards
personal budgets and self-directed care) that require a re-purposing of information systems and networks.

7. Conclusion

Telecare systems and e-health and social care in general, are now a major area of investment in information systems in many nations. Whilst we have focused on the consequences of an aging demographic and the possibilities for the virtual care of older people, the potential applications of these technologies extend far beyond this domain. However, these developments provide yet another illustration of the designer/user problem in information systems research and practice. In the case of telecare, it appears that the technological opportunities offered have to date not been taken-up in everyday practice. The engagement of users, though identified as a major barrier, remains problematic. We have presented the experience of a European level project that involved an intervention to bring about a more user-centered approach from within. The lessons from this ‘insider’ experience support arguments for a renewed focus on design in use rather than the engagement of users in prior design. However, in order to accomplish this, we have argued that an infrastructural rather than applications view is needed. In the context of the OLDES project experience, this meant an attempt to co-produce a service rather than provider orientated environment for the telecare of older people into which technological resources might subsequently be deployed and developed. Despite many practical problems and issues, the outcome was a system platform and a service orientated architecture with infrastructural and federable properties that, in principle at least, were better able to support subsequent innovation in use and adapt to political and
policy change. We would encourage future research in this area to similarly reject a framing of the research question as one of how best to engage users in the design of telecare systems and artifact. Rather, this should be re-cast as one of how infrastructures can be nurtured to support the co-production of service environments within which such systems and artifacts might be better appropriated by their users.

Acknowledgements

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Munich: Profil


Table 1: Story Board of day in the life of an older person with the OLDES platform

<table>
<thead>
<tr>
<th>Time</th>
<th>Event/Activity (Tele-care function)</th>
</tr>
</thead>
<tbody>
<tr>
<td>06.00</td>
<td>Room temperature and activity is being monitored in 2 rooms. (Data transfer every 15 minutes which also serves as an “idle channel, equipment functioning” signal). Signora Verdi (SV) wakes up.</td>
</tr>
<tr>
<td>08.30</td>
<td>SV (gets up (activity sensor records), steps on scales (data transfer).</td>
</tr>
<tr>
<td>09.00</td>
<td>SV goes to kitchen (Monitor movement between rooms).</td>
</tr>
<tr>
<td>09.15</td>
<td>SV Turns on TV with remote control (Switch on a channel). (Switch on. Home page with the top-level options displayed)</td>
</tr>
<tr>
<td></td>
<td>SV uses remote control to select radio channel from favourites</td>
</tr>
<tr>
<td></td>
<td>SV listens to radio.</td>
</tr>
<tr>
<td>09.30</td>
<td>‘Reminder: do your exercises’ (on-screen message displayed)</td>
</tr>
<tr>
<td></td>
<td>SV Sees on-screen message screen/sound but does not respond.</td>
</tr>
<tr>
<td>09.35</td>
<td>‘Reminder: do your exercises’ (on-screen message displayed)</td>
</tr>
<tr>
<td></td>
<td>SV accepts by pushing ‘OK’ on remote control.</td>
</tr>
<tr>
<td></td>
<td>(Apply pedometer dumbbell with accelerometer and Bluetooth)</td>
</tr>
</tbody>
</table>
| 09.35 – 10.05 | SV performs light exercise routine  
‘Well Done’ (on-screen message displayed)                                                                                     |
|       | Time Passes                                                                                                                                                           |
| 11.00 | VOIP call from Tele-care operator                                                                                                                                     |
|       | Ringing                                                                                                                                                              |
| 11.15 | SV speaks with Tele-care operator                                                                                                                                      |
|       | ‘Look at Diary’ (on-screen message displayed)                                                                                                                        |
| 11.20 | SV uses remote control to grant Tele-care operator permission to view diary                                                                                              |
| Noon  | (remote clinical data collection schedule)                                                                                                                           |
|       | (Measurement sequence)                                                                                                                                                  |
|       | Tele-care operator reminds SV of school concert this afternoon and sets system reminder.                                                                               |
| 12.15 | SV closes connection with Tele-care operator                                                                                                                          |
|       | Time passes                                                                                                                                                           |
| 15.00 | ‘Concert Reminder’ (on-screen message displayed)                                                                                                                      |
| 15.30 | Children singing                                                                                                                                                    |
|       | Switch off                                                                                                                                                            |
| 18.00 | ‘Medication Reminder’ (on-screen message displayed on close)                                                                                                          |
Room temperature and activity continues to be monitored in 2 rooms. *(Data transfer every 15 minutes which also serves as an “idle channel, equipment functioning” signal).*

Source: OLDES Project Deliverable
Table 2: Prototype Alpha functionalities:

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Low Cost computer-based system</strong></td>
<td>The elderly persons are provided with a low cost computer based system (the INK computer) that works as the access point for OLDES functionalities and services. The computer is connected as a set top box to a classic television set that displays all the information provided by the platform by a simplified graphical user interface (GUI).</td>
</tr>
<tr>
<td><strong>Adapted graphical user interface</strong></td>
<td>The graphical user interface is especially designed to meet elderly person usability requirements. An easy to use remote control is used to select options and access content.</td>
</tr>
<tr>
<td><strong>Tele-health monitoring system</strong></td>
<td>The elderly persons are provided with communicant Bluetooth medical devices. The INK set top computer installed in elderly person houses automatically collects the data measured by these devices and sends them to a central repository in a secured way.</td>
</tr>
<tr>
<td><strong>Entertainment system</strong></td>
<td>Through their INK computer, the elderly persons are able to access entertainment services provided by <em>Tele-accompany</em>: Audio/video content: The elderly persons are able to access audio and video content. Discussion groups: Using an adapted handset connected to the INK, the elderly persons are able to actively participate in discussion groups with an animator helping to create reactions and discussions. Voice-over-IP calls: The elderly persons can easily call their relatives (using a classic PC connected to the internet) and friends connected to OLDES system using their INK and their handset.</td>
</tr>
<tr>
<td><strong>Automated Health Decision Support System</strong></td>
<td>The data stored in the central repository are automatically analyzed by two different intelligent tools. The first one is based on fuzzy logic and the second one is based on a Support Vector Machine. These tools may generate a warning or an alarm if an abnormal situation about health or social condition of the patient is detected.</td>
</tr>
<tr>
<td><strong>Web portal</strong></td>
<td>Prototype alpha integrates a web portal which provides interfaces for: System administrators GPs and professionals Discussion groups animators <em>Tele-accompany</em> members</td>
</tr>
</tbody>
</table>

Source: OLDES Work Package 3: Prototype Alpha and Network Implementation
Figure 1: Sre. Verdi’s TV Screen in Her Apartment

My Health Screen:

- Daily Exercise and Activity
- Medication
- Measurements
Figure 2 Tele-care Operators Computer Screen
FIGURE 3 High-level representation of a possible OLDES service environment