

Developing a technology 'wish-list' to enhance the quality of life of people with dementia

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A.J. Sixsmith, G. Gibson, R.D. Orpwood, J.M. Torrington, Developing a technology 'wish-list' to enhance the quality of life of people with dementia. Gerontechnology 2006; 6(1):2-19. INDEPENDENT was an inter-disciplinary project to explore the potential of technology and design solutions to enhance the quality of life of people with dementia and to help them to live independently, to empower them without compromising their rights or privacy. This paper describes the user-focused approach and methodology devised within INDEPENDENT to drive the technology development and to ensure that any subsequent devices and systems are grounded within a thorough understanding of the needs, preferences and desires of potential users. A key aim was to take into account the everyday realities within which people with dementia live, and the paper outlines an ecological model of quality of life as a guiding framework involving factors associated with the person, context, everyday activities, personal meanings and well-being. The paper describes the project methods and techniques as a possible model for user-driven research and development for people with dementia and/or other vulnerable groups. This involved a series of related workshops to: explore the problem area; specify a 'wish list' of opportunities where technology interventions could help to improve the quality of life of people with dementia; identify possible technology solutions; prioritise a final set of technologies for development. The paper briefly describes the results of this process in terms of the key dimensions of quality of life and potential design and technology solutions.

Keywords: older people, quality of life, technology, R&D

INDEPENDENT¹ was an inter-disciplinary project to explore the potential of technology and design solutions to enhance the quality of life of people with dementia, to help them to live independently and to empower them without compromising their rights or privacy. The key aim of the project was to engage with users to provide an understanding of quality of life in

dementia and to use these insights to feed into all stages of technology and design development within the project. The project was particularly concerned with developing technologies that could enable people with dementia to participate in activities that are enjoyable and personally meaningful and contribute to a positive sense of well-being.

The main aim of this paper is to describe the novel approach and methodology used during INDEPENDENT to drive the technology development and to ensure that any subsequent devices and systems were grounded within a thorough understanding of the needs, preferences and desires of potential users, taking into account the everyday realities within which they live. The paper has three main objectives:

- (i) To outline a conceptual model for researching quality of life in dementia.
- (ii) To describe and demonstrate the methods and techniques used within INDEPENDENT as a possible model for user-driven research and development for people with dementia and/or other vulnerable groups. This was based on in-depth user research, followed by a series of project workshops aimed at identifying possible technological interventions.
- (iii) To briefly describe the results of this process in terms of the key dimensions of quality of life of people with dementia and a 'wish list' of potential design and technology solutions.

Background

Recent years have seen a rapid growth in research and development in new technologies to improve services and enhance the independence and quality of life of older people. The actual and potential role of new technologies has been widely recognised². A range of applications are being developed or are already in the marketplace, addressing both the direct and indirect support of frail and disabled people³, for example: smart housing, client monitoring, teleconsultation, health and social care assessment, client records and care planning, client support (for instance, emergency response, counselling, giving information), health and social care information systems. Internationally, examples of such research enterprises include the Aware Home residential laboratory at the Georgia Institute of Technology. The goal of the Aware Home initiative is to provide a focus for research and development efforts

to support ageing-in-place, with research taking place on the use of ubiquitous computing systems in the home to meet issues relating to safety, comfort, communication, entertainment and remote management⁴.

However, the specific needs of people with dementia have only been recently addressed and there remains considerable scope for research and development (R&D) for this client group^{3,5}. Much of the R&D effort has focused on the needs of people with physical impairments (in areas such as: mobility, sensory functions, motor control and manipulation), rather than those people with cognitive impairments. For physically impaired people, the underlying basis for technological development and design is to remove the environmental barriers that turn a person's impairment into a disability. In contrast, cognitively impaired people may have impaired abilities to understand their environment, formulate plans, carry out actions, communicate, or remember what they have done or where they are. Thus, the R&D community should consider the needs of people with dementia more specifically, so that the potential of new technologies can be harnessed for a group that is already considerably marginalized within our society.

Some recent research has begun to look at the specific needs of people with dementia. A key driver of R&D in the UK is the Extending Quality of life for Older People (EQUAL) initiative⁶, funded by the Engineering and Physical Sciences Research Council (EPSRC). This has funded projects in several areas: cognition, dementia and learning disabilities, hearing and seeing, design for all, housing and accessibility. Of the 39 EQUAL projects since 1998, five have had a specific focus on people with dementia, examining technological and environmental design solutions to promote independence and enhance quality of life. In the USA, the Everyday Technologies for Alzheimer Care (ETAC) programme has recently been set up⁷ to specifically develop

technologies to enhance the lives of people with dementia and their caregivers. The aim is to detect and compensate for functional decline, help to delay the onset of disablement, provide support to caregivers and postpone the movement to residential care. Five projects have been funded, focusing on using the internet to support caregivers, supporting activities of daily living, using digital television, and monitoring symptoms and activities in people with dementia. A number of projects have also been funded by the European Commission, notably Astridguide.org⁸, which created a guide to technology appropriate to people with dementia across the EU. Another project, ENABLE, aimed to develop and test a number of products in several areas: devices to support memory (time orientation, taking medicines, etc.); devices to provide pleasure and comfort (multimedia programmes), and devices to facilitate communication (pre-programmable telephone).

However, the R&D has largely focused on ensuring safety and security rather than on positively enhancing quality of life³. For example, there has been considerable attention given to safety and security monitoring, location monitoring and systems for automatic device shut-off. Much of the early R&D was technology-driven, often with little attention to real-life problems and situations. More recent work has adopted a needs-led approach to ensure that devices are more usable and relevant to users⁹. The specific focus on quality of life within the EQUAL programme has shifted the emphasis of the research away from overtly health-related and instrumental support to applications that aim to promote social interaction and participation, a more active lifestyle and psychological well-being. However, this area is still weak theoretically. For example, a clear concept or model of quality of life remains elusive, while the relationship between personal and contextual factors, everyday activities and well-being is also problematic¹⁰, es-

pecially in respect to people with dementia. Clinical research within a biomedical paradigm has examined the role of pleasant events in the lives of older people with dementia, particularly in relation to depression and cognitive performance, such as the pleasant events schedule for Alzheimer disease (PES-AD)^{11,12}. However, such work is often a secondary concern within clinical research settings. Moreover, the idea of a 'needs-led' approach has arguably become equated with a 'problem-led' approach, focusing on the so-called 'problems' associated with dementia, such as wandering, agitation and safety and security. The use of technologies may fail to meet the needs of older people generally, and of people with dementia particularly, when such problem-led approaches are undertaken in order to eliminate human forms of care provision. While all these considerations should not be underestimated, the goal of INDEPENDENT was to produce a more radical agenda for developing technologies to positively enhance quality of life.

AN ECOLOGICAL MODEL

The issue of quality of life was the starting point for INDEPENDENT, where in-depth user research was used to provide input into all stages of technology development. The INDEPENDENT project developed an 'ecological' model of quality of life (*Figure 1*) as a framework for guiding the user research^{13,14}. While many models of 'quality of life' have been developed, the ecological approach was particularly suited to the INDEPENDENT project because it focused on practical aspects of everyday activities of the person, highlighting opportunities for technology and design solutions to support these activities. The model draws on the work of researchers such as M. Powell Lawton¹⁵ and T. Kitwood¹⁶. The underlying argument of the model is that the activities that comprise a person's everyday life are shaped by a range of different factors, including attributes of the person (functional ability, cognitive ability, psychological fac-

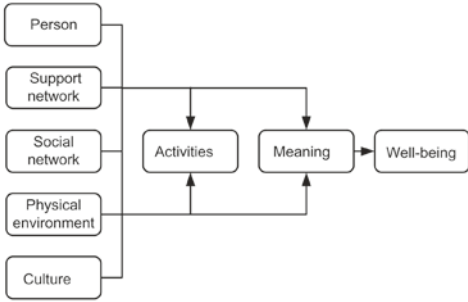


Figure 1. Ecological model of well-being

tors, etc.) and attributes of the immediate (formal support network, social network, physical environment) and wider socio-cultural contexts. These personal and situational factors operate together in a functional, 'ecological' relationship to facilitate or constrain (affordances) a person's activities. The ecological approach is useful in looking at the quality of life of older people, because it highlights the impact and experience of age-related dependency (for instance, cognitive impairment) within its context and allows us to explore how this affects everyday life and well-being. How a person derives meaning from their everyday activities and environment is central to their well-being. Positive well-being is where these factors work together, while conversely apparently minor obstacles in any of them can prevent a positive outcome. Technological and design interventions can potentially play an important part by ameliorating some of the personal and contextual problems faced by a person who is experiencing cognitive decline. The argument here is that a person's well-being will be enhanced if the intervention facilitates activities that are meaningful and valued by the person and takes into account the contextual factors within which the person lives. This can be illustrated by the case of Jack:

Jack was an elderly widower who lived alone. Because of his dementia he was cognitively quite impaired, but was still able to live independently with the support of his sister. He liked to go out and get his sup-

plies from the local shopping centre. However, his trips outside the house became almost non-existent, while the number of visits by other people stopped. Investigation into the case noted that he had problems with his feet that made mobility very difficult, while his sister had become pre-occupied with caring for her sick husband. In this situation, he was unable to buy food and other essentials, while he felt very isolated and lonely.

This brief example illustrates the importance of looking at the underlying factors that contribute to a person's pattern of activity and well-being. Rather than the changes in Jack's cognitive impairment, it was two situational factors that combined together to have a profound impact on his life. Without appropriate intervention there would have been an inevitable breakdown in his ability to live at home independently. Chiropody was a cheap and non-technological solution to his mobility problems, while his need for support to facilitate social participation became an important direction for technological development within the project.

PROJECT METHODOLOGY

The ecological model provided a framework for: (i) carrying out user research in order to develop a theoretical and empirical basis for understanding quality of life amongst people with dementia; (ii) using this knowledge as a resource in a series of workshops to set an agenda for the development of technology and design solutions both within and outside the INDEPENDENT project; and (iii) developing and evaluating technology design interventions with users and carers.

User research

The approach adopted in the user research was qualitative and exploratory in nature, aiming to understand the complex real-life situations of older people with dementia. In-depth interviews took place with a purposive sample of 26 people with demen-

tia living either in their own homes within the community or within residential care. Fieldwork took place in three study sites: people living in their own homes in Merseyside and the East Midlands, and people living in residential care homes or regularly attending associated day centres in South Yorkshire. These sites were chosen with the assistance of service providers (social services and a residential care provider) who were partners within the INDEPENDENT project, and represented a range of settings in which people with dementia lived. The service partners also assisted in the selection of participants, by identifying and recruiting potential participants from within the client base. The sampling approach emphasised the diversity of participants, both in their personal attributes and in their life context. The only recruitment criterion was that participants had received a diagnosis of dementia, for example from the community mental health service. No particular types of dementia were excluded from the study. At this stage, the research team decided to avoid classifying participants in terms of 'stages' of dementia, although cognitive impairment measurements (such as the Mini-Mental State Exam) were taken. Indeed, it was generally found that an overall 'score' for cognitive impairment did little to characterize the participants' everyday lives. Rather, following the ecological model, the focus was on qualitatively exploring the relationship between personal and situational factors that impacted on a person's activities and well-being. It was an understanding of these relationships that would help the research team to identify opportunities for deploying technologies to support meaningful activities. In the sample of 26 people, 18 were female, and 8 were male. Ages ranged from 62 to 96. Interviews took place with 16 people living in their own homes, and with 10 people living in one of two residential care homes. In addition separate focus groups of formal carers, family carers and volunteers, who were associated with the par-

ticipants from the care homes, were held. Interviews were conducted by interviewers experienced in conducting qualitative research with people with dementia. In addition, two workshops were set up to provide project-specific training and to ensure a common approach amongst the researchers.

The interviews were semi-structured and aimed at exploring the various components of the ecological model: the everyday and enjoyable activities people took part in; reasons why they enjoyed or did not enjoy activities; the factors enabling and constraining the activities; the impact of these activities on the everyday life and well-being of the person. Beyond this, interviews were open-ended in order to explore areas of importance for each participant, and to probe and develop emerging issues during the interviews. Given the wide range of cognitive impairment within the participant group, a key challenge was to derive useful information from everyone involved. Overall level of cognitive impairment was less relevant here than being able to articulate thoughts and communicate effectively in response to exploratory questions by experienced researchers. Informal carers were present in most cases in the community settings, and were invited to contribute to the interview where necessary. In all cases this was at the request of the person with dementia. In one case where the person's communication difficulties were severe, their main carer provided a proxy account. However, a fundamental aim of the project was to elicit the participant's own perspective as far as possible. Carrying out the interviews in the person's own living place in conjunction with carers also allowed observational data to be gathered where relevant, for example, on the layout of the house or the interactions between person and carer, with this information written up in field notes. Interviews lasted between 15 minutes and 1.5 hours, but typically lasted about one hour, and in some cases took place over more than

one visit. Interviews were transcribed and coded prior to data analysis.

An ethical protocol for carrying out the research was drawn up and approved by external research ethics committees. Informed consent was sought from all individuals and was continually reaffirmed throughout the interview¹⁷. Written consent was sought in all cases. All data was anonymised at the point of data collection. Attention was given to ensuring that participants understood the requirements of the study, and were able to retain the information long enough as to make an informed decision to take part. Where individuals were judged to be unable to provide informed consent, proxy interviews with carers were conducted. This occurred in one case.

The interviews provided a rich set of qualitative data representing the views of the person with dementia, their carers and the interviewer's own observations during the interviews. The data were analysed by focusing on each individual activity people mentioned during interviews. Each activity was categorised, described and entered into an analysis template, based on the conceptual model (*Table 1*). The template already provided a basis for a multi-dimensional categorisation of the data (activities, enabling and challenging factors, etc.). Analysis involved populating a template for each activity for a person, with entries comprising brief phrases or summaries relating to key points found within the data. In all cases, the entries made in the templates could be referred back to the original transcripts. Information from other data sources, such as observations and field notes were similarly categorised and included within the same templates. Person-based and contextual factors relating to a person's participation in an activity were identified, with particular attention paid to aspects of each factor that may have enabled or challenged a person's participation in an activity. The possible

personal meanings associated with participation in an activity, and its impact on the person's well-being, were also included in the analysis template. *Table 1* provides an example relating to musical activity. The templates taken together represent a database that can easily be searched and cross referenced to facilitate thematic analysis. Templates across study sites were collated and grouped together into themes based upon the descriptive content of templates, and commonalities between experiences and meanings associated between activities. Reliability in the categorisation of the data was gained by way of discussions within research teams, and between research teams during initial workshops.

Workshops

The user research provided essential in-depth data linking activities to personal and situational enabling and constraining factors. However, the challenge facing the INDEPENDENT project was to use this knowledge to identify and prioritise areas for technology development. To facilitate this, a process for collaborative working was developed within the INDEPENDENT consortium based around project workshops. These workshops were attended by all groups within the project representing medical engineering, architecture and social gerontology, together with representatives from home care and residential care providers, and from industry and user organisations. Rather than working independently on discrete tasks within the project, the aim was to work collaboratively to allow the different research teams to interact and share ideas and knowledge in order to create an informed consensus within the project regarding the directions for research and development.

The workshops resulted in the development of a 'wish list' of areas in which technological planning, design and development could take place. The 'wish list' then contributed towards the identification of particular devices or technological

Technology 'wish-list'

Table 1. A qualitative analysis template relating to musical activities

Influence	Personal aspects	Support network	Social network	Physical environment	Cultural / spiritual environment	Personal meanings & well-being
Enabling	Enjoying music, Listening to own music, Engaging in musical activities	Carers playing music for PwD, Encouraging use of music players, Accessing music in care settings	Listening to music socially, Dancing with others, Being in social places	Listening to music in church, Listening to music in social places, Playing music as background noise in home, Using simple musical equipment	Music part of religious activities	Meanings bringing sense of life to the home, Taking part in activities with other people, Being active in spaces, going to special places
Challenging	Forgetting enjoyment of music, Health difficulties affecting enjoyment, for instance, deafness	Time & resource demands on carers, Dependency on others	Remembering desire for music, Dependency on others, Unwillingness to take part in musical activities	Forgetting how to use equipment, Forgetting the role of equipment, Forgetting activity music is used for, Not owning simple music players	Few opportunities to access music	Well-being, Bringing enjoyment & positive emotions, Making PwD feel happy, Evoking old memories, Evoking emotions

systems to be developed, and in the development of criteria to be used in their design and evaluation. Results of the user research were presented to project partners via these project workshops. Initially, data were used to create a preliminary list of areas in which the development of technologies could be investigated prior to the identification of specific areas for further technology development. The development of the 'wish list' was thus an iterative process, in which areas were reduced from general thematic categories into a series of specific ideas for technologies.

The collaborative working within INDEPENDENT comprised a series of five related workshops, with each workshop representing a specific stage within the development

of the 'wish list'. A general process for the workshops was developed, comprising:

- (i) Resource materials, including qualitative data analysis, case studies, and reports on previous workshops, for use in workshops (These were prepared and circulated prior to the event);
- (ii) An agenda, identifying aims and tasks;
- (iii) Attendance by all members of the various teams within the project;
- (iv) Initial clarification of the aims, and a review of the current position and knowledge, followed by the main workshop activity;
- (v) Materials (for instance, flipcharts, tables and diagrams) produced in the workshops were collected and notes of discussions were taken by a rapporteur;
- (vi) Immediately afterward the workshop,

an account of the event and its outcomes were written up by the rapporteur; (vii) The report was then circulated amongst the group for comments, additions and clarifications, prior to the next workshop; and (viii) Some independent working was often required between workshops to consolidate outcomes and to carry out specific tasks in preparation for subsequent workshops.

The workshops addressed the following aims:

Workshops 1-2, Exploring the area: This involved the presentation of preliminary findings of the user research and discussion of these findings within the group.

Workshops 3-4, Identifying opportunities: This involved using the knowledge base to outline key areas where interventions could help to improve the quality of life of people with dementia.

Between Workshops 4-5, Identifying solutions: This involved the development of ideas in a 'long list' of possible technology solutions.

Workshop 5, Prioritising technology development: This involved sifting through the various potential solutions to identify a final set of technologies for development.

People with dementia and their carers were not directly involved in the workshops. However, qualitative interviews, observations and other consultations took place with these groups concurrently with the workshop methodology, and were conducted by several of the consortium partners. Issues arising from these parallel consultations were regularly fed back into the workshop procedure. Furthermore, people with dementia and carers were directly consulted throughout the design and development of the specific devices identified for technological development. However, the possibility of direct involvement of participants and carers in workshops should not be discounted and will be explored in future research.

RESULTS

Exploring the area

Workshops 1 and 2 took place with the goals of exploring the data from the user research, to discuss the potential implications for design and technology interventions and to highlight possible areas of importance for the future development of the project. The workshop explored the area of quality of life in dementia, in preparation for future work, identifying issues that could be addressed through the use of assistive technologies.

Prior to the workshops, thematic analysis of the data was carried out to develop an initial list of themes relating to quality of life for people with dementia. During the workshops initial and ongoing results were presented by researchers conducting the user research. This was followed by detailed discussion of the results to clarify and better understand the emerging issues, and to ensure inter-coder reliability. As a result of these discussions, and building upon the qualitative data analysis conducted up to this stage, a list of key themes was developed focusing on activities that positively contributed to the quality of life of people with dementia (Table 2). Key themes were identified and agreed based on three factors: the frequency in which issues were highlighted in the data; their importance and relevance to different groups of people with dementia; and their occurrence within the three different study locations.

During discussions of the data, it became clear that people at different stages of dementia had very different needs and experiences, and were likely to have very different requirements for technological interventions. Table 2 also indicates how each theme was rated by consortium partners according to its perceived relevance to those at mild-moderate stages of dementia, and to those at more severe stages. No strict categorisation was used, such as mini-mental state scores¹⁸, as the emphasis was on the functional limitations the per-

Technology 'wish-list'

Table 2. Preliminary areas for technological development in relation to stage of dementia

Themes	Description of theme	Usefulness at stages of dementia	
		Less de-menting	More de-menting
Reminiscence	Reminiscence provided a context & focus for many activities.	yes	yes
Activities of Daily Living (ADLs)	Participation in ADLs was important in building self-esteem and independence	yes	no
Pottering	'Pottering' involved participation in a variety of small tasks, essential to the maintenance of a person's environment	yes	no
Conversation	Conversations refer to social interactions resulting from talking with others	yes	yes
Communication	General difficulties relating to communication resulting from dementia	yes	yes
Social participation	Participating in activities with other people, through a variety of activities or contexts	yes	no
Community participation	Having links with formal and informal community structures. For instance, social capital	yes	yes
Being physically active	Being active, and having opportunities to be active (for instance, taking part in housework activities, or going for a walk)	yes	no
Home location	Environmental cues and perceived problems and benefits of the home environment	yes	yes
Nature	Having opportunities to engage with the natural environment at some level	yes	yes
Music	Cognitive and emotional benefits of music and activities related to music, for instance, dancing	yes	yes
Foods	Food and its role in providing nutrition, and also stimulation and pleasure through taste	no	yes
Relationships	Building strong personal relationships with immediate family, friends and carers	yes	yes
Stimulation, motivation, initiative	The role of stimulation, motivation and initiative within a person's everyday life	no	yes
The outside world	Impact of changing levels of access to the world beyond a person's lived environment	yes	no
Stress reduction	Reducing feelings of carer burden, and associated feelings of stress	yes	no
Memory	Memory related specifically to loss of recall, but was also fundamental to participation in all events	yes	yes
Creative activities	Creative activities provided sources of stimulation for many, but had specific difficulties relating to ability and recall	yes	no

son experienced, their activities and subsequent quality of life. Using this knowledge, categorisations were then based on expertise and knowledge within the project group. For people with milder levels of impairment, areas highlighted as important involved the promotion of functional independence through continued active

participation in the activities of daily life, community and social participation, aiding communication and memory, stress reduction and encouraging physical activity. For people with moderate to severe levels of impairment, the focus changed to more basic areas or to areas involving close personal contact with a single person. There-

Table 3. A theme-context matrix; Personal aspects (*italic*); Formal support aspects (**bolditalic**); Social aspects (*regular*); Physical environment aspects (**bold**); Cultural / spiritual environment aspects (SMALLCAPS)

Activities	Memory	Communication	Behavioural issues	Initiative / motivation	Stress reduction	Enabling activity	Restricting activity	Relationships	Stimulation	Occupations / leisure	Initiative / motivation	Stimulation	Outside world	Lived environments	Safety	Security	STIMULATION	FREEDOM OF CHOICE
Reminiscence	2	2	1	1	1	1	0	1	2	1	1	1	1	1	0	0	2	1
ADLs	2	1	1	2	1	2	1	1	1	1	2	1	1	2	2	1	1	1
Pottering	1	1	1	1	1	1	1	0	1	1	1	2	0	2	1	0	1	1
Conversation	2	2	1	2	1	1	1	2	2	1	1	1	1	1	0	0	1	1
Social participation	2	2	1	2	1	1	1	2	2	1	1	1	2	1	0	1	2	2
Community participation	2	2	1	1	1	2	1	2	2	1	1	1	2	1	1	1	2	2
Physical activity	1	1	1	2	2	1	1	1	1	1	2	1	2	2	2	1	1	2
Being in the home	1	1	1	1	1	1	1	0	1	1	1	1	0	2	1	0	1	1
Nature	0	1	1	1	2	1	1	1	2	1	1	2	2	1	0	0	2	1
Music	1	1	1	1	2	1	1	1	2	2	1	1	1	1	0	0	2	2
Food and eating	1	1	2	2	1	1	1	1	2	1	1	1	1	1	1	0	2	2
Creative activities	1	1	1	2	2	1	1	1	2	1	1	1	1	1	0	0	2	1
	16	16	13	18	16	14	11	13	20	13	14	14	14	16	8	4	19	17

fore, reminiscence, communication and stimulation were particularly relevant. It is important to note that in keeping with the user-led model of research, technological issues were not considered at this stage of the analysis.

Identifying opportunities

The aim for this phase of the work was to create a 'wish-list' of key opportunities for the technology development phase of INDEPENDENT. Workshop 3 built upon the initial explorations of the data, and developed a theme-context matrix, which acted as a systematic method of investigating the relative importance of individual activities, and the main factors affecting each of these activities (Table 3). The theme-context ma-

trix also operationalized the key opportunities identified in previous workshops within the ecological model of well-being. Workshop 4 used the results of this matrix to build the wish list of areas for technology development (Table 4).

A theme-context matrix

This involved identifying what factors impacted on a person's activities, with this knowledge being used to highlight opportunities for the deployment of technologies in order to support facilitating factors and/or ameliorate constraining factors. A key issue here is that the performance of an activity does not just depend on the person factors, but on how these interact with other factors within the person's every-

day life context. To achieve this, a theme-context matrix was developed within the workshops, and subsequently used to rank activities in order to highlight specific areas for technological development.

The thematic list (*Table 2*) was rationalised through discussion and consensus within the workshop to create the theme-context matrix by linking the themes highlighted in the qualitative interviews to the contextual factors within the ecological model of quality of life. For reasons of brevity *Table 2* represents only a summary of the multiple factors influencing each activity area, as follows:

Personal aspects. These relate to the abilities and impairments of the person, and their own subjective experiences of dementia. Memory was a key issue, as most suffered some level of cognitive impairment, usually resulting in short-term memory loss. Memory can influence a person's ability to participate in an activity. However, the memory of actually taking part in an activity also plays a key role in terms of enjoyment. Other personal issues included a person's ability to communicate with others, either verbally, through touch or through expressing emotions. Behavioural issues relate to behaviour around an activity, such as attempting to assist with activities, or signs of aggression or discontent during particular events. Finally, initiative relates to the level of a person's ability to motivate themselves to take action, or to take the initiative rather than relying on others.

Support network. This relates to the formal and informal care networks present around a person, and their role in activities taking place. Stress reduction refers to the role of activities in affecting levels of emotional or physical stress in a person, and also, importantly, the level of stress that may be experienced by informal carers within the context of an activity. Enabling and restricting activities refer to the

role of care networks in either maintaining or restricting access and participation in a particular activity. For example, the provision of a mobile meals service may impact on instrumental ADLs such as cooking, which may be positive but which may also be negative, depending on each individual case.

Social network. A person's social network is commonly based around informal carers and family networks and plays an important part in access to and experience of activities. Relationships refer to the importance of personal, emotional and practical relationships between the person and others in determining access to activities. Stimulation refers to the importance of social networks, within the context of an activity, in providing encouragement, stimulation and interest. Finally, occupation refers to the range of leisure pursuits available to a person via their social support networks.

Physical environment. The physical environment often has an important role in gaining access to enjoyable activities. Initiation, motivation and stimulation refer to the role of the environment in providing stimuli to which a person may respond, or in encouraging a person to be active. The outside world and lived environments refer to the role of space and place in a person's life, and the activities they enjoy. The outdoors or, simply, places away from the home have important influences in activities taking place in these spaces. Similarly, key aspects of the home environment, such as notions of familiarity and comfort, may also influence a person's experience of activities. Finally, issues of a person's safety and security within space are of importance in understanding many activities.

Socio-cultural environment. This refers to the broader aspects of society and culture that may impact on the person's everyday life, including provision of information and

Table 4. Wish items for technology development

Wish item		Description of opportunity	Score
#	Name		
1	Oral / personal histories	Promoting reminiscence via activities or devices	11
2	Social participation	Assisting people with forming new or continuing old relationships with friends and family	9
3	Conversation prompting	Supporting the act of conversation with others, for instance, reminding a person of previous statements	7
4	Encouraging use of music	Promoting the enjoyment and use of music, either as a specific activity or through passive enjoyment	7
5	Encouraging community relationships	Promoting activity and relationships with or within the local community	7
6	Supporting sequence of activities	Supporting activities of daily living involving sequences of actions	3
7	Exercise / physical activity	Encouraging people to be physically active through physical forms of activity (for instance, walking)	3
8	Encouraging access to outdoor space	Encouraging and assisting with access to outdoor space. Assisting with orientation in outdoor space	2
9	Sharing experiences of care and caring	Providing social support to carers, providing support with physical care tasks or creating opportunities for emotional care	1
10	Encouraging creative activities	Supporting and encouraging people to take part in hobbies, pastimes and creative activities	1
11	Pottering in the home	Promoting participation in small household tasks within the home and/or garden	0

availability of opportunities for self-expression. Cultural and spiritual activities can provide important sources of stimulation. For example, painting has been shown to be a creative activity with many beneficial impacts for people with dementia^{19,20}. Freedom of choice refers to the tacit rules that exist within society about appropriate behaviour, personal responsibility and risk that may constrain opportunities for participation by people with dementia.

Within the matrix, each cell was scored by the workshop participants to reflect the significance of the context factors on the various activity themes. A score of 2 was given where there was a high level of significance. Where some significance was assumed, a score of 1 was given. A score of 0 indicated no relevance. For example, within the context of the linked theme/activity of conversation, personal issues including memory, and social sup-

port issues relating to stimulation may be of importance, whereas environmental issues such as safety and security may be of less significance and scored appropriately. Workshop participants completed this task individually with an overall theme-context matrix being collated using modal values.

The value of this was to highlight how different factors and groups of factors can have an impact on the everyday lives of people with dementia. The provision of activities that stimulate and engage people can have powerful effects for people with dementia, particularly when mobilised in the context of shared and other social activities. Linked to stimulation is motivation and initiative, providing opportunities that encourage people to engage with others and their wider surroundings, and ameliorate problems of social withdrawal. While important in many contexts of the everyday lives of people with dementia, and

with some exceptions such as in activities of daily living and physical activity, issues surrounding safety and security appeared to have a relatively minor role in activities promoting enjoyment.

The 'wish-list'

A fourth workshop was convened to discuss the theme-content matrix in more detail and to use this to create the 'wish-list' (Table 4). The task at this stage was to identify a list of key areas where potential technological interventions could promote quality of life, a process that involved all project members building on the user knowledge base and previous analyses or workshops.

Key themes highlighted in previous workshops were the starting point, while scores in the theme context matrix were also used to both determine the relative importance of individual activities (for instance, listening to music), and the importance of particular contextual factors that impact on individual activities (for instance, stimulation). The workshop required considerable creative thinking on the part of the participants to compile an initial list of suggestions for 'opportunities' for interventions to support activities. Items in the list were rated based on a consensus about the perceived relevance as meaningful activities for people with dementia and the potential for technological intervention (considering the enabling and constraining factors). Data from the user research was used to provide supporting evidence about these items and to develop a general picture of the various underlying factors. In some cases it was determined that while an issue was important for quality of life, technological interventions may only have a limited role. After this, each of the items was discussed within the workshop, with the purpose of identifying items possessing similar characteristics which therefore could be combined within a single item. As a final result of this process, a second list was discussed and scored in order of

perceived importance, providing the final 'wish list' of opportunities for technology development (Table 4).

Identifying solutions

The 'wish list' was used as the basis for a specification that informed the design and integration of the technologies project. The aim here was to create a long list of possible technological interventions to support the activities in the 'wish list'. This was done through the use of standard brain-storming techniques. Design staff from the Bath Institute of Medical Engineering (BIME) were provided with general descriptions of the 11 areas of the list over two 90-minute sessions. They were then asked to verbally suggest possible technologies through which the requirements listed could be achieved. Staff were all experienced medical engineering designers familiar with brain-storming approaches, where ideas are never criticised, and where one idea can build on another. A facilitator who had been involved in the previous workshops noted all the ideas mentioned, and prompted the group when ideas ran dry, or moved onto the next item in the list. Brain-storming can be a very creative process with a group used to working with each other. Other members of the INDEPENDENT consortium also submitted ideas for possible technologies to add to the list. From the original 11 areas highlighted in Table 4, project partners from BIME highlighted 69 specific ideas for individual design technologies.

Prioritising

A fifth workshop was held to select specific technologies for development within INDEPENDENT. Prior to the workshop, the list of 69 ideas was distributed to the project partners. During this workshop, consortium partners re-categorised the various technologies into generic categories, such as simple interfaces, cognitive prostheses, etc. Partners then voted on each of these groupings, to provide a priority list of the different categories of technology ac-

Table 5. Criteria for prioritisation of technologies

Domain	Criterion	Description
Exploitation	Commercial viability	Does the technology appear to have potential as a commercial product or service?
	Intellectual property	Does the system or device meet or break intellectual property rights or copyright of other devices/patents?
	Ethical issues	Does the technology present any ethical problems?
	Route to market	Are there clear directions for the eventual exploitation of the technology?
	Costs / benefits	Is the technology likely to have financial benefits?
Practical implementation	Spatial implications	What are the impacts of installation and use of the device within the environments where they are present?
	Usability	Are there any design issues which affect people's ability to use the device?
	Setting	Are there any contextual factors that impact on the way the device is used?
	Product accessibility	Are there any design features that may potentially restrict access or operation?
Quality of life	Enhancement of well-being	Does the device have positive impacts on a person's sense of well-being?
	Enhancement of independence	Does the device have positive impacts upon a person's functional and emotional independence, either self-perceived or perceived by others?
	Enhancement of social participation	Does the device have positive impacts on a person's ability to engage with other people?
Scientific	Academic credibility	Is the development of the device methodologically and theoretically sound?
	Originality	Is the device new, or does it make a new or innovative contribution?

cording to their perceived impact on quality of life. It was decided that an example technology from the four top items in the priority list would then be the subject of technological development within the INDEPENDENT project.

To aid the choice of these technologies a set of specific guidance criteria was developed during the workshop. These criteria reflected the range of multi-disciplinary expertise present within the project consortium, and are summarised in Table 5. They were based on the experience of consortium partners in consulting and working with people with dementia and/or on their expertise in design and technology. A user perspective was provided

by Dementia Voice, a UK-based dementia welfare and advocacy organisation. Where possible, items were rated based on evidence of data collected during qualitative interviews. Particular emphasis was placed on the potential of the technologies for enhancing quality of life.

Following workshop 5 the engineering team again used brain-storming techniques to explore example technologies within the short-listed top four categories. As a result a shortlist of 11 prioritised proposals for technological development was created (Table 6).

The limitations of the INDEPENDENT project meant that it would only be feasible to carry out a limited amount of technology development work. Indeed, one of

Technology 'wish-list'

Table 6. Proposals for Technological Development

Title	Description	Wish list item (Table 4)
Simple music player	A music player using CDs or other media, modified or designed so that only a single button (or less) is required to operate it	2, 4, 10
Intuitive interface to a music player	Developing an intuitive interface to pre-existing or custom-built music player (for instance, developing a suitable interface for a digital music player)	4, 10
Intuitive jukebox	Juke box using a user interface similar to that described above but interfacing to a large capacity CD changer rather than digital storage	2,4, 10
Connected picture frame	A picture frame containing an LCD display showing pictures and/or short video clips in rotation	1
Family camera	A web camera placed in a communal area of a family member's home, which would allow a person with dementia to see their family more often via a TV or other display	2, 5, 9
Window on the world	Webcam-based system providing a view of a communal space such as the surrounding area (i.e. north, south, east and west), or a personally meaningful place	1, 2, 5, 8
Steerable public-space camera	Webcam-based system with a camera on the roof of a care-home, with the direction of the camera being controlled by residents from a viewing station in the day room	5, 8
Photo phone	Picture frame with a built-in speaker phone, which would allow a person with dementia to contact the person(s) depicted without needing to use a conventional telephone	2, 6
Conversational memory aid: Voice recognition	A device which transcribes a conversation using voice recognition software and displaying it so that a user can look back on a conversation and remind themselves what they were saying	2, 3
Conversational memory aid: Audio	A discrete device to record the last few moments of a conversation and play it back as an aide memoire to the user	2, 3
Sequencing aid	A device to assist a person with dementia in completing everyday tasks by providing instructions at each stage of a particular task	6, 7, 11

the aims of this stage of the project was to develop a 'roadmap' for technology development for people with dementia outside the confines of INDEPENDENT. In this context, four technologies were finally identified for development within INDEPENDENT.

Simple music player. This should be a relatively simple device to enable someone with dementia to select and play music they like through a player that looks like a typical music playing device, but which uses very simple controls such as a single button to operate it. Design issues arise re-

lating to the media to be selected to play music (older media such as vinyl records and cassettes, newer media such as CDs, or digital media such as MP3 files), and to the aesthetics and appearance of the device (How can its appearance communicate its function as a music player, based on the experience of potential users? Should its appearance be similar to contemporary players, or to music players from previous eras? etc.).

Window on the world. The window on the world combines two ideas by using web camera-based technologies to provide remote images within the user's home, in

order to enhance engagement with the family and with the wider community. The work will explore the ability of such technologies to provide a sense of presence within the home of the user's family, with all the interface issues and privacy issues explored. The same generic technology will also be explored from the point of view of bringing the outside world into the home, for example, through the use of remote community-based cameras.

Conversation prompter. When the user loses his or her train of thought the device would prompt, through replaying the last few seconds of a user's speech, or through providing keywords, or topics. The prompter will be under the control of the user, and may be embodied in various forms, including possible transportable or wearable devices. Aesthetics and usability are key issues that will shape the success of this device, as will its acceptability to users.

Sequence assisting device. The device would break simple tasks into separate, clearly defined and easily understandable stages, and prompt the user to enact each stage in turn. The research will assess different techniques for detecting when one stage has been completed and the next needs to be cued. Further work will involve the most suitable interface for providing prompts, for instance, visual prompts via a screen, or audio prompts.

The decision to further develop these four prototypes represented the end of this phase of the project. However, the subsequent development work was carried out in conjunction with further consultation with people with dementia and their carers. This helped to build up a deeper knowledge base relating to the potential use of the devices. The ecological framework was extremely useful in highlighting the 'real-life' scenarios within which the devices would be used and, in particular, ensuring that devices were sufficiently con-

text sensitive. For example, data on the environmental and social contexts in which people interact with music was used to inform the development of the music playing device (reported in depth by Sixsmith and Gibson²¹).

The criteria summarised in Table 5 were used to select the four technologies, together with considerations of practical feasibility. For example, of the four technologies, the simple music player was felt to be fairly straightforward and achievable within the project, whereas the sequence support device was felt to be very open-ended and much more challenging.

CONCLUSIONS

At the time of writing, work on the four development projects listed above is continuing, and will be reported in forthcoming papers. As with much of this project, prototype development took place with full consultation with people with dementia, with devices being tailored according to the needs and preferences of end users. This includes consultations with potential users and their carers to gauge reactions and acceptability of such devices, and to clarify issues surrounding their use. These investigations include the use of 'Wizard of Oz' techniques to assess user acceptance of potential design approaches, and of user-led iterative approaches to engineering design.

One of the goals of INDEPENDENT was to contribute towards the development of systematic methodologies for user-driven research and development with people with dementia. This paper presented the process and techniques used in the project as a possible model for work in this area and provides a useful alternative to technology-driven approaches. The use of an integrated theoretical, methodological and design framework such as the one used in INDEPENDENT is very demanding in terms of time and resources. However, the approach ensured that all members of the multidisciplinary project team possessed

a common understanding of the problem area and had a framework in which a variety of different perspectives could be integrated effectively. The approach promoted communication between engineers, designers, architects, gerontologists and dementia researchers, allowing engineers and designers to ask questions of researchers based upon the needs of people with dementia, while allowing the researchers the opportunity to shape the technology and design process. This ensured that technology development took place in a manner that was derived from the experiences and needs of people with dementia, rather than being technology driven²². Opportunities for technological interventions were identified and those specified on the basis of research with people with dementia and devices were developed from a sound theoretical understanding of their needs, preferences and wishes.

The impetus for developing the 'wish list' approach was the absence of well-established frameworks that supported the interdisciplinary and user-driven aspirations of the INDEPENDENT project. However, the project team recognises that the approach and methodologies outlined in this paper are still open to refinement and development. One issue to consider is the development of procedures that will ensure that any 'wish list' is based on valid and replicable results. The process adopted in INDEPENDENT was largely qualitative in approach, where the identification of technology opportunities and the specification of the 'wish list' were inductive and exploratory in nature. The user research was the basis for stimulating ideas and discussion within the systematic framework provided by the workshops. This exploratory approach by definition is not open to conventional measures of methodological rigour (as in statistical methodology). However, it is important that the approach is systematic and, in this context, ideas about rigour or 'authenticity' in qualitative methodology may be appropriate²³.

Nevertheless, the possibility of developing more quantitative systematic procedures within the more general framework outlined here also needs to be considered. For example, would quantitative evidence about agreement on how cases were categorized, rated, and so on add weight to the conclusions of the research process? Another issue focuses on the particular target group, that is people with dementia, and a key challenge is to develop methodologies that will truly represent the perspective of people with severe dementia. The 'ecological' framework is generally applicable, but the specific methods for gaining the perspectives of people with severe cognitive impairments remain problematic. To some extent the INDEPENDENT project avoided this problem by addressing people with milder levels of impairment. However, future work will require more inventive and sensitive approaches to user participation if the potential of technological interventions is to be made available to a wider group.

A key outcome of INDEPENDENT was to provide an agenda for research and development in the form of the technology 'wish-list'. INDEPENDENT took the position that technological development can be beneficial to quality of life beyond the current focus on safety and security. Also, while issues such as a person's functional and cognitive deficits are of considerable importance, quality of life encompasses a much broader sphere of influence within a person's everyday life. By using a methodological tool such as the theme-context matrix used in this study, the importance of issues beyond an interaction at the level of the person was highlighted. Technologies could be implemented that interact with other domains, such as the spatial and architectural environments of a person's home and immediate geographical area. The social network and support environments have potential to make important contributions towards a person's individual quality of life and again technology could

be implemented that would facilitate these kinds of relationships. Research in these areas would build upon and go beyond

work conducted within INDEPENDENT, and represents an important subject for future study.

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