

Designing technology to support quality of life of people with dementia

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Abstract. Much assistive technology for people with dementia is primarily designed to support security and safety. This paper describes design work carried out for a project called INDEPENDENT which specifically aimed at designing technology to support quality of life. The project involved academic engineers, social scientists and architects, together with representatives of user groups and a manufacturer. The design work was based on a comprehensive user survey in which people with dementia themselves highlighted the factors which affected their quality of life. This data was analysed through a series of multi-disciplinary workshops involving the whole project consortium. The workshops consolidated the data into a wish-list of 11 areas crucial to quality of life that could then be addressed by new designs. Of the total of 69 designs that were considered, 4 were selected for initial design work within the project; a simple music player, a window-on-the-world device for streaming remote images into people's homes and between homes, a conversation prompter, and a device to support sequences of activities. The paper describes progress with these devices, highlighting the iterative and user-led design methodology used.

Keywords: Assistive technology, dementia, quality of life, design methodology

1. Introduction

As the papers in this special issue amply demonstrate there is much potential for assistive technology to support people with dementia, in the same way as it can for any other disability. However there has been some concern expressed about the kinds of technologies that have been developed for people with dementia [9]. It is felt that the major focus has been on trying to improve the safety and security of these clients, and less on maintaining a sense of wellbeing, and this is borne out by the kinds of technologies developed in many studies [3,6,12]. There is also a feeling that some of these developments are more aimed at providing support for carers rather than the person with dementia [8], or to ease the process of service provision. If technol-

ogy can keep an eye on the user and provide an alarm when they do something dangerous, then it takes some of the burden off the carer, and can reduce the level of involvement of professional carers. However there are some notable exceptions to this focus on safety and security, such as the work of Maki [15] on enjoyment of music, and Alm [2] on general reminiscence. Quality of life relies on far more than just being safe and secure, important though these aspects are. It is a difficult concept to pin down but is crucial to the real success of supporting technologies. There is a real need for the development of new technologies that more directly address the aim of trying to improve the quality of life of the person with dementia.

The influence of engineering design on quality of life (QoL) has really come to the fore in recent years, with many studies using QoL measures as part of their evaluation. A number of QoL tools are available for such evaluation work [4], and have taken their place alongside more traditional measures of independence and functional ability [7]. These studies have includ-

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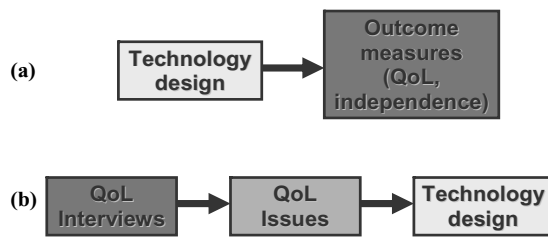


Fig. 1. (a) Traditional use of quality of life measures to assess the impact of new technology, (b) The procedure adopted by the INDEPENDENT project.

ed exploring the impact of assistive technology on the quality of life of people with dementia [5]. The procedure followed with these studies was to use quality of life outcome measures to assess what impact the assistive technology had on the sense of well-being of the user. It is assumed they should have an impact on quality of life, and that it was important to try and measure this to make a judgment about the usefulness of the technology.

This paper concerns a study being run in the UK, known as the INDEPENDENT project, which aims to more directly address the task of configuring technology to improve the quality of life of people with dementia. The study has involved the Universities of Bath, Sheffield and Liverpool, as well as the user organisations Dementia Voice, Northampton Social Services and Sheffcare, and the company Huntleigh Medical. The work has approached the impact of technologies on quality of life in a different way. As stated above the usual approach is to take items of assistive technology that are felt to have an impact on quality of life and carry out a QoL assessment. The approach taken in this study was to reverse this process, and explore with people with dementia the issues which they themselves felt had a major impact on their quality of life, and then to follow a process of design to generate new items of assistive technology that specifically addressed these issues (Fig. 1). The project also had an architectural design element to examine the interaction between the equipment and the space in which it was used within the built environment (e.g. see [16]). This paper however focuses specifically on the engineering design elements of the work, and the way this was grounded in the detailed user assessment studies.

2. Exploring issues important to quality of life

2.1. The user survey

The work started with a series of in-depth interviews with people with dementia, 16 living in their own homes

and a further 10 living in care homes. A diverse range of people were involved with varying levels of dementia other than severe. Interviews were loosely structured to explore areas of importance to the individuals, looking at enjoyable activities, reasons for enjoying, and factors enabling or limiting them, and their impact on the user's sense of well-being. Interviews were transcribed and coded prior to analysis. Carer's and the interviewer's observations were also collected, to generate a rich set of qualitative data. The data were entered into a template that categorised the contextual factors that had an impact on quality of life. These factors covered personal aspects, formal support network, social network, physical environment, and cultural and spiritual environment. Data were entered into the template according to whether they had an enabling or challenging influence. Table 1 illustrates a typical template for the influence of music.

2.2. Converting the user data into a wish list

Having collected and categorised all this data a series of workshops were held involving the whole research team to develop a list of potential technologies based on the issues raised in the qualitative data collected. All members of the team were involved, the social scientists, architects and the engineers, together with the user representatives. The workshops were found to provide a very constructive and creative way of using the data to identify the issues to be tackled. The multi-disciplinary nature of the workshops was a positive factor in ensuring a wide range of perspectives were brought to bear on the deciphering of the data and its interpretation into specific technological areas. This interactive and collaborative approach was felt to be a strong factor in the success of the project. Consensus was reached despite widely differing perspectives, and all involved gained much insight through working closely with disciplines with which they didn't normally engage [14].

Early workshops discussed the data from the interviews to attempt to tease out the emerging themes that positively contributed to the quality of life of people with dementia. A total of 18 themes were developed, some more relevant to those in the earlier stages of dementia which focused on maintaining active participation in life, some more relevant to later stage dementia which focussed more on personal satisfaction such as reminiscence and stimulation. Later workshops attempted to consolidate and prioritise these issues, and finally a voting system was used to enable all the members of the consortium to rank them. In this way wish-

Table 1
Qualitative analysis template relating to musical activities

Personal Aspects	Formal Support Network	Social Network	Physical Environment	Cultural environment
<i>Enabling Aspects</i>				
Music as enjoyable (feeling good, feeling better)	Ensuring exposure to music (carers playing, encouraging PwD to use music player)	Listening to music as a social activity	Church (hymns)	Music and pleasure (feel happy, feel better, feel good)
Listening to own music (on CD/tape, on radio)	Providing access to music in care settings (day and community centres)	Dancing as social activity (engaging in meaningful activity, non-verbal communication)	Social and care spaces (pubs, care settings)	Reminiscence (evoking memories, association with youth, association with emotional memories)
Engaging in musical activities (singing, dancing, making music)		Music in social places (with family and friends, in church)	In the home (background noise, encouraging activities) Using musical equipment	
<i>Challenging Aspects</i>				
Forgetting enjoyment of music	Time and resource demands on carers	Remembering desire for music	Access in social and care settings (physical disabilities)	Opportunities for access to music (dependency on others)
Expressing musical desires (remembering tastes, expressing tastes)	Concentration on physical care tasks	Dependency on others for access to music	Using equipment (forgetting how to use, forgetting the role, forgetting activity music is used for)	Motivation to listen (difficulties with equipment, lack of desire)
Health issues (Hearing difficulties)	Dependency on others for access to music	Initial unwillingness to take part in musical activities	Ownership of necessary equipment	

list was generated of the key areas that the data suggested would have a major positive impact on quality of life. This wish-list is presented in Table 2 together with the scores each issue attracted.

It is interesting to note that up to this point the team rarely involved any discussion of technology. The aim was to tease out the important issues affecting quality of life without any consideration at that stage of whether there were any possibilities for technological intervention. This was felt to be important because it prevented constraining the ideas because of concerns of technical feasibility, etc., and to ensure the process was user-led rather than technology-led. Once the wish-list was generated the team compiled a list of 69 possible items of technology which addressed each of the issues in the wish-list. This list of technologies was not exhaustive and could be much further extended, but it provided a very good basis for the project to move onto its next stage, that of exploring possible useful assistive technologies.

2.3. Technologies to be developed

A further workshop was used to discuss these technologies, and to categorise them and prioritise them according to the perspectives of the team members. From this list a set of four items were selected for actual de-

sign and development work within the project. The multi-disciplinary workshop approach to discussing and guiding the progress of the project has continued into the technological development phase to ensure the designers maintain a broad perspective to their work, and to bring in the observations of the non-engineers.

So from the items on the list the project decided to develop prototype devices to address the following four issues.

1. Access to music. It was decided to explore the design of a simple music player that was easy to use by someone with dementia.
2. Social isolation. It was decided to explore the use of remote cameras to transmit images of the outside world into people's living space, and images of carers in their living environment. This aspect was given the label "window-on-the-world".
3. Conversation prompting. It was decided to examine the potential of technology to provide prompts during a conversation. This aspect was to be primarily a feasibility study to see what technologies may have potential.
4. Supporting sequences. Again this aspect was aimed at being a feasibility study to see if simple sequences could be supported through some form of prompting.

Table 2
Wish-list of issues important to quality of life, to provide goals for the technological design work

Theme	Description	Score
1. Oral/personal histories	Promoting reminiscence either when alone or with others	11
2. Social participation	Assisting people with forming new or continuing old relationships with family and friends. Encouraging and assisting with family visits	9
3. Conversational prompting	Supporting the act of conversation with others	7
4. Encouraging use of music	Promoting the enjoyment and use of music, either through playing or listening	7
5. Encouraging community relationships	Promoting relationships, and helping participation with local community	7
6. Supporting sequences of activities	Supporting activities that involve a series of sequential steps	3
7. Exercise and physical activity	Encouraging and supporting people to be physically active	3
8. Encouraging access to nature	Encouraging and assisting with access to outdoor spaces and nature	2
9. Sharing experiences of care and caring	Providing support with physical care tasks to free quality time between carer and PWD	1
10. Creative activities	Supporting people to take part in hobbies, pastimes and creative activities	1
11. Pottering in the home	Promoting participation in minor tasks and household chores	0

3. Development of assistive technology

3.1. Design approach

The design work was primarily carried out at the Bath Institute of Medical Engineering at the University of Bath. The Institute has a long history of applying user-led design approaches to the development of assistive technology [11], and to applying these approaches to design for people with dementia [1,13]. A key issue for assistive technology is that the design has to take into account a complex interface with the user. The Institute has approached these issues through focusing on the user-interface aspects in isolation of the supporting technology, and allowing prototype solutions to the user interface to evolve according to feedback obtained from tests of them. This approach is very effective although it does lead to some ethical problems with people with dementia because the early prototypes may well not be very effective, and this can cause anxiety and distress. For this reason tests are not usually started until a design has become reasonably reliable. Alternative approaches ensure that a lot of early work involves carers of people with dementia in order to use their intimate understanding of the way someone with dementia might react to a piece of equipment. People with dementia only become involved in testing when it is felt that the device has evolved to something fairly mature. Testing of early prototypes has been carried out through contacts identified by the researchers from the Universities of Sheffield and Liverpool, and through the Research Institute for the Care of the Elderly (RICE) in Bath.

3.2. Music player

The importance of music to people's sense of well-being was strongly indicated by the user survey. A

difficulty for people with dementia is accessing music when they want, and to select the kind of music they wish to listen to. Music playing equipment, like many items of domestic electrical equipment, is designed to appeal to young cognitively-able people, where it is felt that incorporating a plethora of controls is a positive selling feature. Unfortunately for many people, and certainly for people with dementia, the complicated interface that such designs present is a strong disincentive to their use. The Institute has previously explored the design of a domestic radio and TV remote control where the control interface was reduced to one button only. It was felt that a similar approach could be used to enable the playing of recorded music.

The initial design looked at a single switch CD player (Fig. 2a, b). The user had to lift the cover to insert the CD and then just turn it on and off through the use of one switch only. The volume could be pre-set by the carer through a control hidden on the back of the device. This instrument was a first attempt at providing a simple-to-use music player, and it was anticipated that it would be a starting point for the iterative development process outlined above.

The device was tested in care home settings in Sheffield and in user's own homes in Liverpool. All the users were in the early stages of dementia. A simple check list was used by the researcher during tests to ensure key aspects were explored, although it was also important to ensure the researcher was sensitive to the inevitable unpredicted responses. Users found the device straightforward to use but several areas were highlighted as needing further attention.

- The manipulation of the CD gave some users problems. Some indeed were not very familiar with this form of recorded music.
- The single on/off switch was not an obvious means of operating the device. Some users pressed the centre of the CD cover for example.



(a)



(b)

Fig. 2. (a) Single switch CD player, (b) Single switch CD player in use.

- The time delay between pressing the button and the music being played caused some concerns. The delay was in the order of 10 seconds and was clearly affecting the user's sense of cause and effect. They weren't sure they had operated the device properly because of the delay before anything happened.
- The device was not felt to look like something that would play music.
- Mounting the switch and the CD lid on top of a horizontal box made them less visible.

The problem of the time delay and the difficulty in manipulating CDs led the designers to develop a solid state version, like an MP3 player, which provided

instant music on pressing a switch. In addition the concerns about the overall appearance of the device led a pictorial questionnaire to be developed to explore with users the kind of image they associated with a device that played music.

The next prototype was a basic solid-state player with one piece of recorded music that could be accessed simply by pressing a large button (6 cm square) on the front (Fig. 3). The button included a picture of someone playing an instrument and was illuminated when the device was turned on. The unit was housed in a box with a sloping top to improve visibility. Tests showed this was much easier to use, but that further issues required attention.



Fig. 3. Solid-state music player with single button.

- The single button was flat on the top surface of the music player, and it was not obvious that it was something to press.
- The illumination from the button was not strong enough for use in brightly lit rooms and conservatories.
- It was also felt that the image on the button did not convey “music” simply enough.
- It was also noted that some users were confused about what they had to press, and would try pressing the two loudspeaker grills at the back of the device.

A further test with the grills covered simply by pieces of papers showed that hiding the speaker grills made the operation more obvious. The large button was re-designed to stand proud of the surface of the player to make it clearer that it was something to interact with rather than just being decoration. It was also provided with much brighter illumination. Subsequent tests showed that these changes were very effective.

The actual illustration on the switch was a key indication to the user that it would initiate music if pressed, and a separate picture questionnaire was used with the volunteers with dementia to see what kind of image clearly indicated “music” to them. The questionnaire has provided some interesting results, and somewhat surprisingly people with dementia associate musical note symbols strongly with the idea of music. The other much recognised symbol was a musician playing an instrument. This round of design changes was felt to have achieved a satisfactory device for a very simple one-tune player.

However the aim of the work was to enable a choice of music, so as to reflect the social importance of music, and the likely need for users to want to hear music that reflected their mood, or indeed changed their mood, or fitted in with the social situation. A brain storming session was held to look at various ways of enabling choice with as few buttons as possible. The two main categories of design were those that incorporated a series of buttons, each of which would initiate a different tune or series of tunes, and a device which would just use one action to cycle through a preset series of pieces of music. Several other ideas were explored that monitored the user’s behaviour with the aim of reflecting this through the music played. It was felt that designs using a series of buttons could be confusing to the user, and so work to date has focussed on designs using a single button and music cycling. Although one button can be used to cycle through a series of tunes there is still a need for turning the device on and off. Having separate controls was felt to be confusing, particularly given the experience we had found with the pressing of speaker grills. It was felt some totally different action could be used to turn the device on and off, particularly if that action was an intuitive one. An initial design used a lid over the single button. Opening the lid turned the device on and vice versa. To enable the user to still see the music icon on the button, the lid was made transparent. It also opened only a limited amount to encourage a shutting action on completion of listening (Fig. 4). This device is currently under test.

The development work to date on the music player has been described in detail to outline the iterative approach that has been followed, and also to highlight

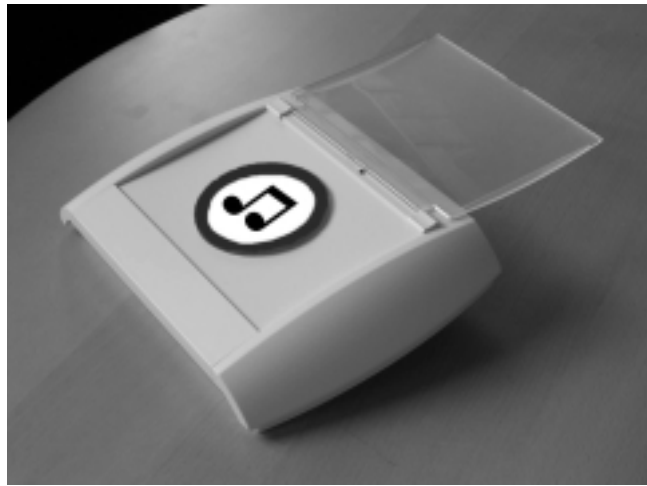


Fig. 4. Music player with cyclic selection and on/off lid.

the kind of issues that have to be dealt with when designing equipment for people with dementia. It is often the case that design issues highlighted by the test seem obvious in retrospect but they are not at all clear when the design is initially carried out. For example the speakers had been placed prominently on the first solid-state music player to try and convey the function of the device as a music player, but in practice this was found to cause confusion because users interpreted the speaker grills as buttons to press. In addition some requirements are very counter-intuitive. This has been our experience with a number of design projects for people with dementia, and underlines even more the importance of engaging very closely with users if new designs are to be effective.

3.3. Window-on-the-world

Anecdotal observations have shown how much people play the TV and radio in their homes to provide a sense of engagement with the outside world and the rest of society. Further observations in care homes have also shown how popular are images relayed over CCTV cameras. In one home which had a networked TV system with the main terrestrial channels available together with the image from a camera in the foyer of the home (to see visitors), it was the internal camera which was often found to be the one residents were watching. It is also clear that people experience a good sense of social interaction through remote communications [10]. It was felt that these observations could suggest a means of reducing people's sense of social isolation through streaming remote images into their homes.

Initial work explored the impact of simply relaying images from outside the user's living space. All the tests on these devices to date have been carried out in care homes or day centres with people in the early to moderate stages of dementia. Tests were carried out by setting up the camera at a remote location and providing its image on a TV which could be viewed by several residents (Fig. 5). An initial concern was whether the users would recognise the image as having meaning over and above just watching the television. It was clear that even the moderate dementia users recognised the image as being different to the TV. It was very noticeable how almost hypnotic the remote images became. People could not help but watch the screen even if very little was happening. However as soon as something did happen, particularly if it involved other people, the users clearly gained much enjoyment and would comment amongst themselves about the behaviour of the person on the screen. In a couple of tests the images were left on whilst the researcher went through the picture questionnaire mentioned above, but kept an eye on the resident's behaviour. Even though they were no longer aware that they were being monitored the residents themselves kept an eye on the screen and became very animated when something happened.

The technology for these tests was extremely simple, just a remote camera with an RF link to a receiver plugged into the TV, but enabled some very interesting observations of user behaviour. The RF linkage limited the system's range to around 30 m, but for images in the environs of the living space this was quite adequate. The size of the screen did not appear to be important from these tests.



Fig. 5. Window-on-the-world basic set-up.

It was clear that many volunteers really enjoyed watching other people. However this varied between users. Tests in which the camera was placed in the garden to illustrate wildlife and plants also raised interest, with comments about how good it would be to be able to watch birdlife. A questionnaire was used to ask residents about their reactions to the system, and it was clear that being able to choose the image had merit. Two systems of making choices are currently under test; a remote control unit (like a TV remote) with two buttons to illustrate the images to be selected, and a touch screen with smaller images that could be chosen.

This work is about to be extended to look at the way that such relayed images can be used to provide a virtual presence in the home of the carer. Again the technology is very simple, just a pair of cameras streaming images over the internet between the home of the person with dementia and the carer, using a screen in each home. The more challenging aspect is the interface between the user and the system. For the person with dementia they require some means of remotely “knocking on the door” of their relative to request “coming in”. For the carer they need a means of “allowing” the person with dementia into their home, and a means for saying “time to go now” (Fig. 6). Current work is exploring representations of these issues of social etiquette. As with the music player there is a need for various input controls which are as intuitive as possible. The initial success of the lifting-lid approach for the music player suggests that having a pair of doors that can be “opened up” to turn on the window-on-the-world might be worth exploring.

3.4. Conversation prompting

The conversation prompter used a further technique for iteratively exploring the way users interacted with prototype devices. It was not at all clear at the outset of the work what kind of design approach might work best. Simply repeating the last few words spoken would be the easiest action to do, but providing key words from what had just been said, or indicating the subject being talked about might be more effective. Both these last two approaches would require forms of natural language processing, and are certainly far from straightforward. A way of exploring possible approaches without developing all the technology, but enabling user interfaces to be explored is a technique known as Wizard-of-Oz testing. In this technique the researchers themselves act in a manner which emulates the behaviour of the technology. In the case of the conversation prompter this meant the researcher sitting in another room with a microphone link to the conversation taking place. The person with dementia is provided with a “help me” button, and if this is pressed the researcher can speak to them via a loudspeaker. This technique allows the researcher to provide a response as though they were the new piece of equipment. In this way a lot of important and interesting variables can be explored very flexibly without developing any technology that was particularly complicated.

Initial tests with this equipment found, as expected, that the most helpful response was to remind the talker about the kind of topic they were just talking about. However simply repeating the last few words did seem to help, and this approach was taken a little further

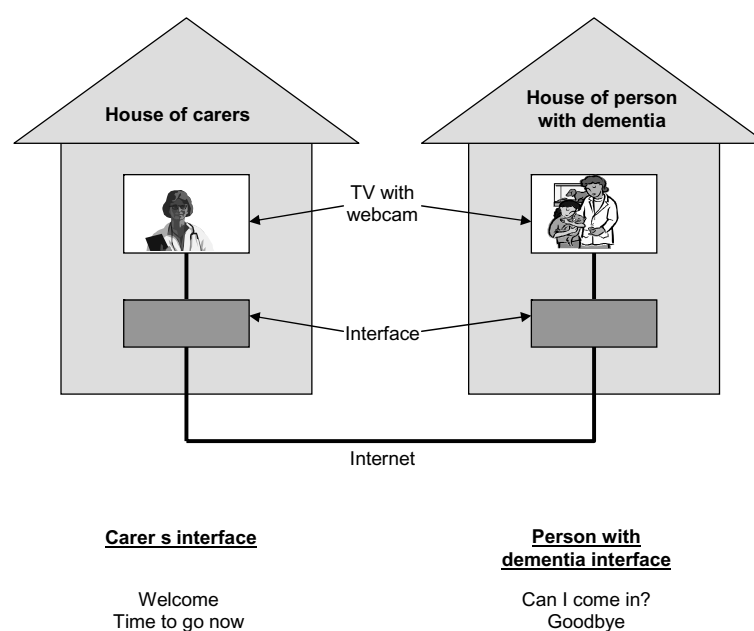


Fig. 6. Diagram of house-to-house video streaming with "social etiquette" interfaces.

through a simple tape loop to provide a recording of the last few seconds. However, such a straightforward recording did not take into account the inevitable decision period during which the talker realised they had lost their train of thought, and had decided to press the help-me button. The tape loop, unless it was unacceptably long, just relayed the murmurs and background sounds during this decision period. Consequently a solid state recorder was designed that incorporated a variable delay so that it would just replay the last few words uttered, and ignored the more silent decision period. This approach is looking promising and is currently being developed further.

3.5. Sequence support

Many tasks involve a chain or sequence of events that cause much difficulty for people with poor working memory such as those with dementia. These difficulties can often lead to withdrawal from engaging in such activities because of their experiences of repeated failure. The project carried out some feasibility work to look at the kinds of prompts that might be effective to support sequences of activities such as preparing a meal, making a cup of tea, cleaning teeth, etc. It is again planned to use Wizard-of-Oz techniques to explore possible useful approaches by remotely providing verbal prompts. Initial work has involved focus group discussions with personal carers to explore how they

feel different approaches might work. A clear issue highlighted by these discussions is that the ability of people with dementia to carry out tasks varies enormously depending on the level of their dementia. Any prompting device would have to take this into account. The way in which a task is broken into do-able chunks would have to start with quite broad chunks for the less cognitively impaired, and then further refine them into smaller steps as the user's ability deteriorated. The two main supporting activities that the technology will have to provide are firstly for a prompt and advice about the current step, and then secondly a detection of when that step has been completed so that the next step can be provided. Current work is looking at a range of possible approaches.

4. Conclusions

The project has used several innovative approaches to exploring this complicated area of technological development.

- Approaching the impact of assistive technology on quality of life through starting with a comprehensive survey of people with dementia to tease out the issues which they identified as being important to their well being.

- A multi-disciplinary workshop approach to using this rich set of data to home-in on a wish-list of desirable aims, and a set of possible technological solutions to achieve them (Table 2).
- An iterative user-led approach to design, involving people with dementia to comment on the new devices and guide their further development.

Although only a small set of the technologies identified were able to be explored within the INDEPENDENT project, it has provided much material for other design teams to use as a basis for their own work. It is hoped that once the design work is nearing completion, and formal evaluations are carried out, good evidence will be provided that the approach followed can lead to assistive technologies that have a major impact on the quality of life of this important group of people.

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