Care in the community

S Brown, N Hine[†], A Sixsmith[‡] and P Garner

This paper considers the application of pervasive computing to the provision of care in the community, specifically older frail people living alone in their own homes. The concept of well-being is introduced and developed through the explanation of a conceptual framework that incorporates person, context and experiential factors. The paper reviews how different aspects of well-being might be instrumented within the home of an older person using non-intrusive pervasive sensors and computing devices. The data acquired from these sensors can be used to describe a model of behaviour for each individual. It is proposed that long-term drifts in well-being, that might be early indicators of an underlying physical or psychological condition, can be detected by analysing subtle changes within the behavioural model. The objective of such a system is to provide the stakeholders involved with an intuitive early warning system in order to facilitate appropriate intervention by care providers leading to a reduction in the cost of care to the state and increased quality of life for the individual.

The domain of social care provision in the UK is described in detail, including an analysis of local authority social services referral procedures, and suggestions made as to the role of well-being monitoring for such service providers. Ethical issues have been addressed by explicitly coding choices about sensor types and their usage into the system design tool. System deployment issues are discussed including installation processes, service provision, and functional specification which lead to the key technical challenges that must be overcome for low-cost pervasive systems to become a practical reality across all local authorities in the UK.

1. Introduction

The UK population is ageing. At the time of the 2001 census there were 8.1 million people aged over 65 living in the UK, 3.1 million of them living alone. By 2011 the number of over 65s is projected to reach just under 12 million, and by 2026 over 13 million [1]. The extra workload this will place on health and care services will be compounded by political ambitions aimed at meeting the challenges of rising patient expectations [2]. In addition to this, the Department of Health aims to promote the independence of older people by providing enhanced services from the National Health Service (NHS) and councils to prevent unnecessary hospital admission [3]. As a result we can expect to see a continuing rise in the number of elderly people living at home and requiring good quality health and social care services.

The Department of Health hopes for a substantial change in the uptake of telecare[1] and other electronic assistive technologies to increase independence for older people [4]. Existing telecare solutions currently provide elderly and vulnerable individuals (clients) with the means of raising an alert should assistance be required. Trials have also been conducted with 'smart sensors' which incorporate a degree of intelligence. These second generation systems[2] automatically call a designated carer in the event that the client is incapacitated and unable to raise an alert [5].

The Care in the Community Centre [6] is researching the possibility of developing and deploying third generation telecare systems capable of monitoring long-term activity trends which may indicate a general decline in the 'well-being' of the client. The information provided by a third generation system could be useful to both formal and informal carers and possibly the clients themselves in helping to prevent injuries and improving the client's quality of life.

BT Exact is leading the DTI[3] funded Care in the Community Centre in collaboration with several UK universities. The programme consists of four projects each working towards the common aim of developing

[†] Division of Applied Computing, University of Dundee.
[‡] Department of Primary Care, University of Liverpool.

[1] Telecare — the application of electronic information and communication technologies to support elderly people who live alone.

[2] Telecare solutions can be grouped into three generations — first and second generation systems allow the client to alert the carer if they require immediate assistance. Second generation systems incorporate a degree of intelligence that allows the system to alert the carer if the client is incapacitated. Third generation systems monitor long-term changes in activity trends to assess the well-being of the client and put in place care solutions to prevent incidents from occurring.

[3] DTI — Department of Trade & Industry, the government body that promotes the development of trade and industry within the UK.

and deploying a demonstrator. This paper discusses the concept of well-being and how we might detect changes to it through monitoring common activities within the home. Design, deployment and service issues are also discussed resulting in the identification of a number of key challenges which face the project.

2. The concept of 'well-being'

2.1 The difficulty with defining well-being

While terms such as quality of life (QoL) and well-being are commonly used within academic literature and the health and social care professions, they are concepts that are not easily defined. The following represent just a few attempts:

> '... the individual's achievement of a satisfactory social situation within the limits of perceived physical capacity' [7],
>
> '... possession of resources necessary to the satisfaction of individual needs, wants and desires, participation in activities enabling personal development and self-actualisation and satisfactory comparison between oneself and others' [8],
>
> 'In general terms, quality can be defined as a grade of "goodness". Quality of life in relation to health is a broader concept than personal health status and also takes social well-being ... into account' [9].

There is an underlying idea that well-being is in some way about the 'goodness' in someone's life, but beyond this it became apparent that there was no straightforward or agreed definition. The lack of a specific or agreed definition meant that the term presented an immediate problem at the start of the project. It was soon realised that if we were going to develop a system that monitored well-being among frail older people, then some kind of working definition, framework or model would be required.

2.2 A conceptual model of well-being

The aim has been to map out the various domains of well-being and this is provided in Fig 1, which represents a model of well-being drawing on the various literature sources [10—12], as well as results from three focus groups, a workshop with two health care professionals and two face-to-face interviews with older people in receipt of social care services. The focus groups were divided into three sessions — the first two sessions were with professional care providers and managers, each consisting of around 10 participants, the third session being attended by four informal carers. The sessions were semi-structured discussions based on an agenda of issues, including:

- definitions of well-being,
- problems people encounter,
- and positive aspects of life,
- the potential role of monitoring technologies.

This semi-structured approach allowed these issues to be explored in depth, emphasising the perspective of the participants. The interviews and focus groups were tape-recorded. The moderator took notes and a post-session summary was written-up. A thematic analysis was carried out through listening to the recordings in conjunction with field notes.

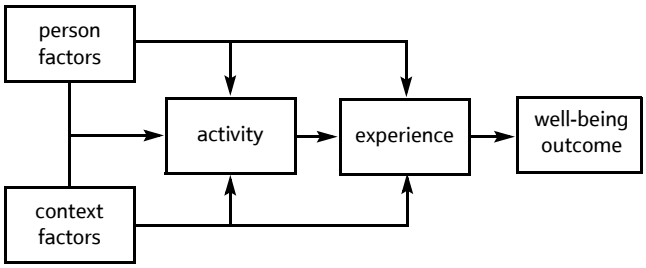


Fig 1 Conceptual model of personal well-being.

While the model is very simple, it provides a robust basis for the project and emphasises a holistic perspective, where the person's abilities, circumstances and experiences contribute to their sense of well-being.

- Person factors

  These refer to the attributes of the person that have a direct bearing on the person's well-being. Key factors include the person's general level of health and fitness, as well as psychological factors that help them to adapt to changes that may occur in later life.

- Context factors

  The context within which a person lives has an important bearing on well-being by either facilitating or constraining the person's goals and actions. These factors include the person's home environment, the social network and social support, neighbourhood, services provided and information.

- Activity

  This refers to what the person actually does within their home, ranging from life-style, activities of daily living through to more positive, life-enhancing activities such as hobbies and social interaction. Recent work on activity monitoring has developed into this area.

- Experience

  This refers to the subjective interpretation by a person of their life situation. It is through this process that a person's life activities become personally meaningful, subjective and idiosyncratic.

- Well-being outcome

  This refers to the person's perceived well-being, e.g. positive or negative affect, life satisfaction. These are internal mental processes that are not amenable to direct monitoring.

3. How to measure changes in well-being

3.1 Identifying target groups

The well-being monitoring system we are developing will not be able to directly monitor changes in person and context factors as a human carer would. Instead the system will rely on monitoring changes in the activities the client performs, which means it is important that we choose activities that are affected by changes in person and context factors.

Our first attempts at identifying these activities proved difficult mainly because of the large number of activities involved. Developing sensor and data analysis solutions for all of these would have proved extremely time consuming and beyond the resources available within the project. The decision was taken to reduce the number of these activities by focusing on a specific client target group (see Table 1).

A number of target groups were identified based on the standards published in the Department of Health National Service Framework for Older People [13]. Adopting this strategy has ensured that the solution we develop will be directly relevant to UK Government policy. Table 1 provides an outline of what the UK Government sees as the key priorities.

The first column in Table 1 describes three general groups given priority under the NSF[4] for Older People. The second column lists sub-groups of these which have been adopted within the project as target groups.

The decision was taken to focus on physically frail[5] older people, and to identify an initial set of activities that could be monitored to identify a change in well-being for this group.

3.2 Identifying activities for monitoring physically frail people

An initial set of activities was identified for monitoring changes in the well-being of the target group. The choice of activities was based on ensuring early detection of changes to social contact, physical health and mental health. This initial set of six activities include:

- leaving and returning home,
- visitors,
- preparing food and eating,
- sleeping patterns,
- personal appearance,
- leisure activities.

The first of these activities (leaving and returning home) has been analysed in detail to identify the requirements for the sensors and data analysis algorithms. The first section of Table 2 breaks this activity down into a number of sub-activities each of which must be measured and logged. The logged data is then analysed to look for changes in the activity as listed within the data analysis section. Technical and

[4] NSF — National Service Framework. The NSF for Older People is a document published in 2001 by the Department of Health. It sets new national standards and service models of care across health and social services for all older people, whether they live at home, in residential care or are being looked after in hospital — http://www.dh.gov.uk/

[5] Physically frail — it should be emphasised here that the greatest benefits from well-being monitoring are likely to be gained if the system is deployed before the individual becomes too frail. The time at which this occurs is of course open to interpretation but should ideally rely on the judgement of professionals and formal/informal carers as well as the individual themselves.

Table 1 NSF for older people priorities and standards.

General group	Specific group	NSF Standards
Old age general	Physically frail older people and those with specific physical impairments, who require some level of long-term help and support from health and social care services	Standard 1 — Rooting out age discrimination
		Standard 2 — Person-centred care
		Standard 8 — The promotion of health and active life in old age
Mental health	Dementia	Standard 7 — Mental health in older people
	Depression	
	Other (e.g. anxiety disorders)	
Other NSF priority groups	Stroke	Standard 5 — To reduce the incidence of stroke
	Falls	Standard 6 — To reduce the number of falls

Table 2 Leaving and returning home.

Data logging	• Doorbell used — timestamp • Door knocked — timestamp • Door opened — timestamp • People entering/exiting — number and person type (i.e. client or other) • Door closed — timestamp
Data analysis	• Is the client being picked up by someone? • Is the client returning with someone? • Is the frequency of the client leaving home changing? • Are the time periods the client spends outside of the home changing? • Is the time taken for the client to get in/out of the house changing?
Activity issues	Multiple key holders — the system must be able to deal with situations when key holders other than the client enter the home (e.g. family, friends, home help entering the home when the client is out)
Sensors	• Doorbell use • Door knocking • Door open/shut • Angle at which door is held open • Visitor entering/leaving
Sensor notes: *Beam breakers, pressure mats or focused PIRs[6] could be used to detect when the client is leaving/returning home.* *RFID[7] tagged door keys could be used to distinguish between the client and other keyholders.* *A home-wide generic PIR sensor network is assumed to be in place.*	

ethical issues relating to the activity have been identified, and may be important factors in considering whether the activity is appropriate for a particular client or situation. The final section of Table 2 lists the requirements on the sensors that will be used for monitoring this activity.

3.3 A functional architecture for monitoring activities

A wide variety of systems and equipment already within the home may be possible sources for capturing data. Some of these sensors may be built into existing equipment which can give a better impression of 'what' the person is doing compared to the 'where they are' information that comes from conventional location activity sensors.

The functional overview illustrated in Fig 2 shows a comprehensive view of the primary candidate technical functions of a well-being monitoring system. The functions utilised in any specific instance may be a sub-set of the functions shown, particularly the activity monitors being deployed. The selection of functions may depend on a number of factors including vulnerability of the specific user, care service package, and technology available.

The 'activity monitors' function shown in Fig 2 detects user activity by monitoring the state of sensors or sensor arrays. The sensors may have data processing functionality associated within the monitoring function. The 'interconnection and data paths' function provides the data channel from the activity monitors to the activity interpretation functions; wired and wireless options are indicated. The 'activity interpretation' function provides the interpretation of activity events in order to determine which activities are being performed, the patterns governing those activities, and the deviations from those patterns that could be an indicator of a change in the well-being of the client.

4. System design, deployment and service issues

4.1 Design requirements

The design of the well-being monitoring system will partly depend on how it is to be used within the care domain. Consideration should also be given to contentious issues such as cost, performance, data security and ease of installation. Equally important is ensuring the design takes into account ethical issues such as the privacy of the client.

Obtaining consent from the client to install a well-being monitoring system might be a major issue, particularly if they are suffering early symptoms of dementia. Dementia welfare organisations are increasingly emphasising the involvement of the end user, rather than decisions being made for them. With this in mind an informal carer could be involved to provide reassurance or support to the client. Designing a system which meets these requirements is important despite the complexity it introduces, or we risk developing a well-being monitoring solution which is potentially impossible to implement.

4.2 Formal and informal care markets

Formal care is provided by paid care workers who either work for a local authority or a private care agency. In both cases a 'contract' is assumed to exist between the community care provider and client, with the care

[6] PIR (passive infra-red sensor) — detects the motion of anything which is moving and emitting infra-red energy (i.e. humans, pets).

[7] RFID — radio frequency identification.

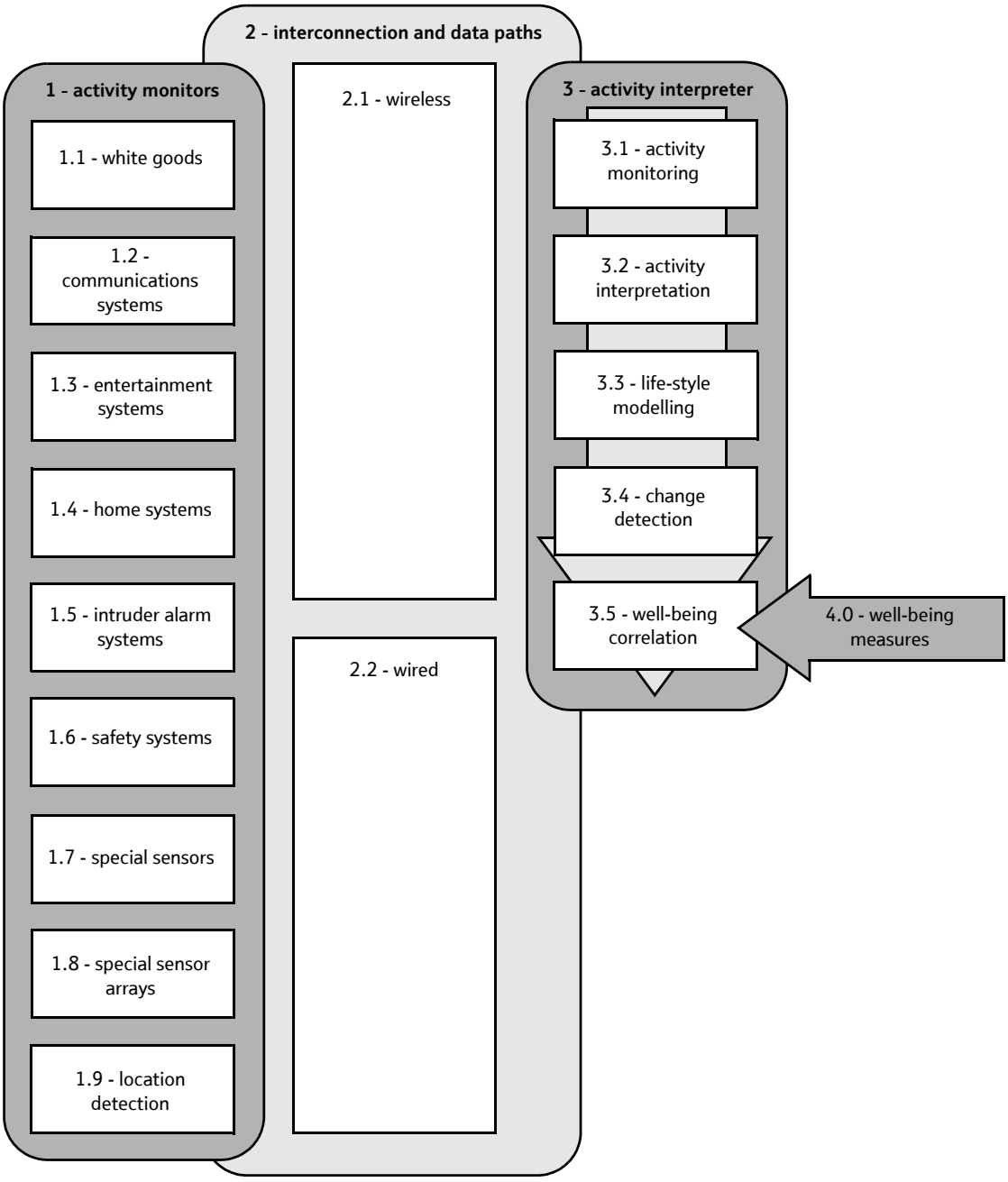


Fig 2 Functional architecture of a well-being monitoring system.

provider expected to adhere to an agreed level of care provision. The largest formal community care providers in the UK are local authorities, each of which provides personal care to older people through referrals into a social services department. During 2000/2001 the budget for local authority personal social services expenditure for older people was £5,899 million. Of this amount £498 million was spent on assessment and care management, and £1,810 million on non-residential provision [14].

Our research has involved developing an understanding of the referral procedure in conjunction with an occupational therapist and senior managers of several social services departments. A focus group discussion was also conducted with social workers from one unitary authority[8] to gain a grass-roots understanding of the procedure.

Figure 3 is a model of the referral procedure common to most social services departments throughout England. The diagram shows how a referral first needs to pass through tough eligibility criteria

[8] Unitary authority — a term used in the UK for local government bodies that form a single tier of administration. The more common alternative to this is a local authority that has a two-tier arrangement where each county has a council and contains multiple districts with councils of their own.

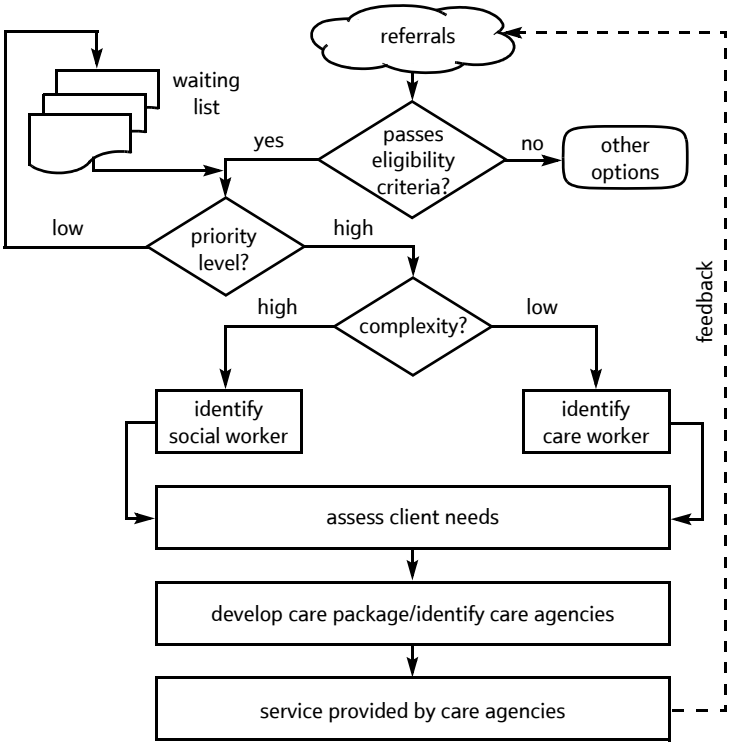


Fig 3 Social services referral process.

before the client is assessed in order to receive the appropriate care package. The diagram shows the care being delivered by a private care agency rather than care workers employed directly by the local authority. This outsourcing approach is becoming more common as local authorities seek to reduce care costs.

Our discussions with social workers revealed a number of issues that exist with the current referral process. These included long waiting lists (sometimes in excess of nine months) and having to spend more time organising the provision of care rather than assessing the client's needs. The main reasons given for this were increasing workloads and a general shortage of in-house and agency care workers.

Social services do keep client records and aim to check-up on the effectiveness of a care package at least every six months. In practice, these follow-up checks are often missed out due to workload pressures, and clients often have to re-enter the referral process at the start when a change to the care package is required.

Excessive work loads often prevent the social worker from monitoring the progress of the client and providing more proactive care provision. When viewed together with the process shown in Fig 3 it is not easy to see how well-being monitoring could reduce this workload. In fact it is more likely to have the opposite effect by identifying clients with unmet needs which social services may then be obliged to meet.

In addition to the formal care market (i.e. social services and private care agencies) there also exists an informal care market made up of volunteer carers such as family members, friends and charity workers. The 2001 Census for England and Wales identified approximately 5.2 million informal carers defined as people who '... provide unpaid care to individuals suffering from either long-term physical or mental ill-health or disability, or problems related to old age' [15].

More recent studies indicate that the number of informal carers has now risen to 5.7 million, and that one half of these carers look after someone who is aged over 75 [16].

High levels of working hours are creating issues within informal care which are similar to those being experienced within formal care. UK Government statistics show that 1.7 million informal carers provide more than 20 hours of care per week, and that almost 1 million provide more than 50 hours care per week [16]. In addition to this it is not uncommon for informal carers to also have a part or full-time job.

The implications of well-being monitoring for the formal and informal care markets are considerable. We believe well-being monitoring would result in an overall cost reduction in caring for older people, while maintaining or improving the quality of care provided. However, it is also true to say that if such a system became generally available, then the work of looking

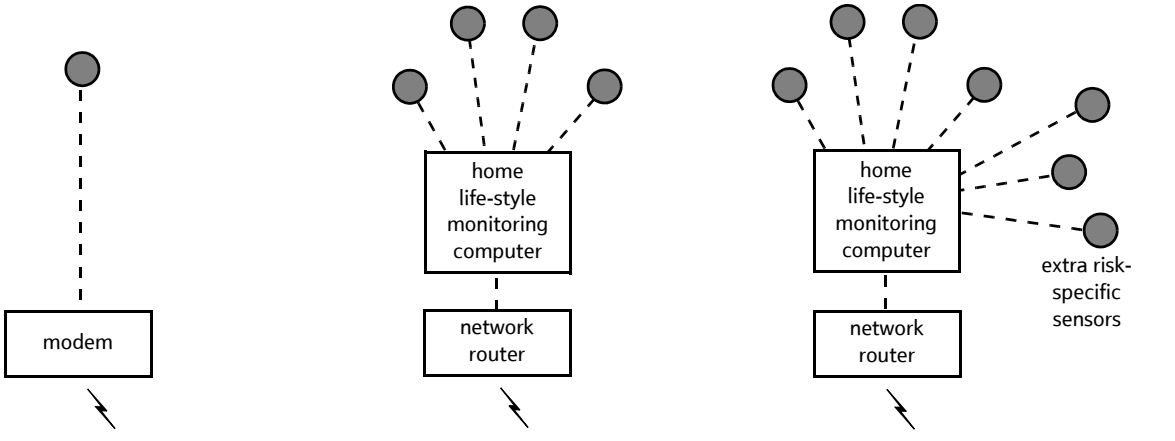
after older people would shift more towards the community and the informal care market. This may require Governments to look at increasing funding towards community-based care while expecting to see savings in other areas of health such as hospitals. Perhaps the greatest challenge will be to convince most local authorities to take on a more proactive role regarding care in the community when their resources are already overstretched.

4.3 Configuring and installing a well-being monitoring system

As discussed previously, our sense of well-being is based on person factors, context factors, personal experiences and activities, with changes in well-being affecting the way in which we perform certain activities. This suggests that the pattern of things which change our level of well-being, and the way in which we exhibit that change, is quite unique. Our aim is to build a system that can learn to understand this 'uniqueness', but it might be possible to give the system a helping hand at the start by instructing it to look for a particular pattern or change in pattern of specific activities. These instructions could be based on information gathered from the client, carers, friends and family. The information could also significantly affect the type and quantity of sensors that are installed. In many cases it may be possible to put the client into one of three broad categories — low risk, at risk or specified risk. Figure 4 describes these categories in more detail and illustrates the different deployment configurations that apply.

The monitoring of a specific individual will involve a selection from within the possible set of sensors depending on their perceived or demonstrated vulnerabilities and risks. Individuals who are causing concern may agree to a simple monitoring package, whereas individuals that have experienced serious episodes such as falling or wandering from their homes may agree to a more comprehensive package of sensors. At all stages of the negotiation, deployment and use of these systems, the preferences of the users in the selection of appropriate sensors and algorithms should be taken into account, and a secure and ethical framework for the handling of the sensor data should be devised.

The process used for installing a well-being monitoring system will also have a major effect on its design. For example, installation by a trained technician would mean the sensors could be relatively dumb requiring the technician to manually register them on the network. This may result in lower design and hardware costs but higher installation costs. However, if the system is to be installed by an untrained person such as the carer, or perhaps even the client, then we may need to make it self-configurable, which would have the opposite effect. It is impossible at this stage to estimate what the true hardware and installation costs would be but the view taken within the project is that in most cases practical issues such as attaching the sensors to walls will require a trained technician. In view of this we believe the simpler low cost hardware design is the most sensible option.



low risk client
- single sensors detecting person-specific activity
- activity logged by service centre
- activity compared to expected profile
- deviation from expected activity triggers an alert to preferred carer

at risk client
- generic sensor array detects activity in the home
- activity logged by life-style monitoring computer
- life-style model built up over time
- deviation from expected activity is classified as an alarm or an alert and is passed to preferred carer

client with specified risk
- generic sensor array supplements with additional sensors specific to the identified risk
- activity logged by life-style monitoring computer
- life-style model built up over time
- deviation from expected activity is classified as an alarm or an alert and is passed to preferred carer

Fig 4 Technology deployment model.

4.4 Monitoring clients and responding to changes in their well-being

Assuming a well-being monitoring system were installed within a client's home as described in section 4.3, we would need to put in place protocols for monitoring and responding to changes in the well-being of that client.

The information provided by the well-being monitoring system may provide the carer with an overall indication of positive or negative changes in well-being, or it may provide an indication of changes in specific activities, which affect the well-being of the client. Formal care organisations such as social services and private care agencies could access this information through a PC connected to the server. Other more intuitive interfaces such as the 'digital family portrait'[9] developed by researchers at the Georgia Institute of Technology may be more appropriate for some informal carers. Whatever interface is used it is important that the system provides information which is acceptable to the client and useful to the carer. Therefore both clients and carers should be involved in helping design the monitoring interface and response protocols.

In the event that the system should indicate the possibility of a significant change in the well-being of the client, the carer could use this information to make a more timely and effective response. Depending on the amount of information the carer is given they may be able to initiate a discussion on a specific issue which may be worrying the client.

The well-being data that is collected may also be useful to other stakeholders such as GPs (general practitioners) and hospitals in the event that the client requires treatment for a medical condition. Provided the necessary security and privacy systems are put in place the well-being data could be appended to the client's own electronic patient record within the NCRS (National Care Record System) currently being developed by the NHS. Combining health and social care data in this way would fit in with the Department of Health's long term plan of making the NCRS a health and social record.

A final point to bear in mind is that well-being monitoring is not designed to alert the carer to emergency situations, but to highlight changes in activity which may indicate a change in the well-being of the client. Given this fact, it is reasonable to assume that the system would be used in conjunction with a first or second generation community alarm system operated in the usual way.

[9] Digital family portrait — a simple display set into the frame of a photograph which changes in some way to reflect the health or well-being of the person within the photograph. This concept was first developed at Georgia Institute of Technology.

5. Conclusions and key technical challenges

We have described how this work is leading the development of a third generation telecare system capable of monitoring changes in the well-being of elderly clients at home. The aim of the system is to help carers deal with increasing workloads while maintaining or improving the level of care received by the client. We have discussed how the system will be designed to work on a network of non-intrusive sensors monitoring specific activities. The process of instrumenting these activities takes into account cost, ethics, performance, ease of installation and technical feasibility. Where possible, use will be made of existing sensors such as smoke alarms and security alarms. The system will be intelligent enough to learn about the client and the activities they perform, but will also be matched to the client through an assessment procedure. It is expected that a trained technician will install the system.

The strategy adopted for monitoring well-being has led to a number of key requirements. Firstly, it is important we understand the care domain in order that we develop a system that can be implemented successfully. The system design must be flexible to allow the building of bespoke systems based on different client needs and environments. Powerful software algorithms will be required if we are to identify patterns in the huge volume of data that is likely to be generated. Sensors will generally need to be low cost, powered by batteries which can last for several months and fit into many different environments. Secure data storage and transmission protocols will be required. It may also be necessary to develop an assessment tool for use by the carer in order that bespoke well-being monitoring systems can be designed.

The technical challenges faced by the teams designing the sensors, networks and intelligent software systems are considerable. In some cases what is being asked of the technology may not be practical or feasible, which could mean the need to identify alternative activities for monitoring, or accept higher costs or lower per-formance. The key technical challenges facing us focus mainly on developing low-cost low-power sensors, and software which is intelligent enough to spot slight changes in activity trends represented by thousands of individual sensor firings.

Acknowledgements

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Steve Brown joined BT at Adastral Park in 1985 where he spent several years researching and developing novel packaging techniques for advanced optical devices. During the mid 1990s his work changed significantly and he began researching new applications for the home environment requiring broadband communications. During this time he led BT's involvement in a EURESCOM-funded project called HINE (Heterogeneous In-House Networking Environment) which explored the in-house networking requirements for several applications based around entertainment, safety, security and home automation.

During the last two years he has been managing a DTI-funded project aimed at developing a next generation telecare service designed to monitor changes in the well-being of older people. He holds a BSc(Hons) from the Open University.

Nick Hine has a BSc in Electronic Telecommunications Engineering (Hull University, 1982) an MSc in Biomedical Engineering (Katholieke Universiteit Leuven, Belgium, 1993) and a PhD in Applied Computing (University of Dundee 2001). After a period in industry, he began a vocational training course for disabled adults leading to IT-based employment in mainstream commerce and industry. This took place within a Europe-wide research study into the impact of becoming disabled on a person's life. He moved to Belgium in 1989 for 3 years and conducted research into the usage and usability of broadband telecommunications system by disabled people. Moving to Dundee in 1992, he focused on the use of telecommunications technology by non-speaking people, and the related issues for motor impaired people and deaf people, including the use of mobile technologies for multimedia-based communication. This research has also been applied to the domain of collaborative and distance education. Recent research grants have been secured to conduct research into the requirements for technology by older and disabled people, based on measured life-style, and the influence that this technology can have on quality of life. He was a founder member of the ETSI Technical Committee on human factors for people with special needs, and participated in 5 ETSI research projects.

Dr Andrew Sixsmith is a lecturer in social gerontology in the Department of Primary Care at the University of Liverpool. He has been a member of several national and international committees related to ageing, notably, the British Society of Gerontology Executive Committee and the EU's DGXII's COST-A5 Committee on Ageing and Technology. He has been director of a wide range of research projects, with a particular emphasis on service evaluation and assessment of need and quality of life of older people. His current interests focus on new technologies to facilitate the delivery of community health and welfare services. He has teaching responsibilities for teaching gerontology and health services on undergraduate and masters level courses within Liverpool University and was the UK co-ordinator of the EU-funded Socrates intensive programme on Gerontechnology. He has published widely on health and social care provision and the development of new technologies.

Paul Garner is head of BT's Pervasive ICT Research Centre, responsible for understanding how the rapid growth in intelligent digital communicating devices will impact businesses in the future, along with prototyping novel solutions with the aim of accelerating them into the market-place. A chartered physicist with a BSc in Applied Physics and an MSc in Laser Physics, he has produced many papers in the field of telecommunications applications. Until 2003, he was responsible for managing BT's telemedicine trials, which included the design and implementation of the UK's first major user trial to monitor the life-style of older people, in collaboration with Anchor Trust. He was a member of the UK DTI Foresight Task Force on Healthcare 2020 and a founding member of the UK virtual outreach project, setting up a telemedicine trial at the Royal Free Hospital. He is currently manager of the DTI-backed Care in the Community Virtual Research Centre and, in February 2004, was appointed as an advisor to a European Telecommunications Standards Institute (ETSI) specialist task force on Telecare standards.