ICT & Ageing:

Users, Markets and Technologies

4th Report

Good Practice Cases

Deliverable No. 7b

1st tranche of good practice examples

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For more information about the ICT&Ageing study, please visit **www.ict-ageing.eu**.

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1 Introduction

According to the terms of reference, overall 40 examples of good practice concerning the ICT & aging field are to be identified and worked up in the framework of the overall study. This document presents the first tranche of 20 cases as set out in the agreed deliverable plan for 2009. In thematic regard, these concern two core aspects of the study.

A first set of 10 instances illustrates how existing market barriers in the independent living domain are being successfully addressed. These concern:

- particular services that have been successfully mainstreamed in a given national regulatory/market environment;
- innovations on the technology side that have found their way into the market;
- policy approaches that have successfully stimulated market development.

Beyond this, a set of another 10 instances sheds light on existing good practice in addressing ethical issues. These concern:

- approaches adopted by individual projects to address ethical issues throughout the research process;
- useful analyses and guidelines on ethical issues and practice.

The good practice examples concerning market barriers are presented in the following Chapter 2. Subsequently, the good practice examples concerning ethical issues are presented in Chapter 3.

2 Good practice examples addressing market barriers

The following examples have been included in the first tranche of good practice examples:

- **The Veterans Health Administration's CCHT Programme:**
  Care Coordination/Home Telehealth (CCHT) is a national programme operated by the Veterans Health Administration (VHA) in the United States. It was set up to coordinate the care of veterans with chronic conditions and avoid their unnecessary admission to long-term institutional care. With more than 30,000 (mostly elderly) patients being currently served, CCHT is probably the largest and most integrated/mainstreamed example of home telehealth in the US and internationally.
- **TAUNUS BKK Disease Management Programme**:
  TAUNUS BKK, a German public health insurer, has mainstreamed home telehealth solutions within dedicated disease management programmes addressing patients suffering from diabetes or heart insufficiency, many of which are older people. This was enabled through regulatory changes adopted in the context of a national health care reform.
- **National Framework Agreement on Telecare (NFA):**
  The National Framework Agreement on Telecare (NFA) was developed as a public procurement mechanism to support the delivery of telecare policy in the UK. It eliminates the need for local care services to individually undertake their own procurement exercises and more generally aims to contribute to the creation of a competitive market place for telecare for the public sector. This award winning initiative has been rated as very successful, being used by over 80% of local authorities and delivering substantial cost savings.
- **The West Lothian Home Safety Service:**
  The West Lothian authority has launched an innovative programme reshaping existing community services for older people, whereby the introduction of telecare has acted as a catalyst of organisational and cultural change. Further service innovation is currently being explored in the framework of the national Scottish Telecare Strategy.
- **The SOPHIA Telecare Servic**e:
  SOPHIA is a fully up and running service offering that has become available in certain parts of Germany since 2004. The service provides social support to older people living in their own home environment, including the management of age-related risks. The service concept which has developed from a publicly funded pilot project has been successfully mainstreamed by means of an innovative franchise model primarily addressing housing organisations.
- **FASS Tele-assistance:**
  In Spain, the Fundación Andaluza de Servicios Sociales (FASS) has mainstreamed basic telecare in the framework of its legal duty to provide care in the community under the ambit of social legislation enacted at the national policy level. The latter makes explicit reference to tele-assistance as a mean of supporting vulnerable people in living independently in the community.
- **The Dutch Domotics Programme:**
  The Dutch Ministry of Health, Care and Welfare provides subsidies for the mainstreaming of independent living technology in the serviced housing sector. Following the funding of a variety of smart home / telecare technology pilots, public funds have been channelled into the serviced housing domain, with a view to incentvise mainstream deployment of a broad range of relevant technologies.
- **Telecare Business Case Planning Model:**
  The Telecare Learning & Improvement Network in the UK has developed a business

case modelling tool to support social service departments in the development of strategy and business cases for the mainstreaming of telecare. The immediate aim was to support councils in making decisions about how to spend public funds available from a national government programme in an economically sustainable manner.

- **Recommendations for Reimbursement of Home Telehealth and Remote Monitoring:**
  The recommendations on reimbursement of home telehealth and remote monitoring by the American Telemedicine Association provide the most comprehensive analysis of this topic internationally. Although developed in the US and not yet implemented by payers, they nevertheless provide a very useful and instructive analysis of relevance in the European context
- **"WristCare" - A European Success Story:**
  The Vivago "WristCare" system is a commercially available telecare product range developed by a Finnish company (IST) that is now being used in a number of European countries. It represents a significant innovation on traditional social alarm products and is said to the world's first security device that automatically monitors a person's well-being 24 hours a day. The product has received many innovation awards in Finland and internationally. It shows that success in the market requires good understanding and cooperation with health and social services that comprise the core target markets, and that it can take time to break into these markets.

In the following, each of these examples is presented in more detail according to a common reporting structure.

The Veterans Health Administration's CCHT Programme

- mainstreamed home telehealth and care coordination -

Summary

Care Coodination/Home Telehealth (CCHT) is a national programme operated by the Veterans Health Administration (VHA) in the United States. It was set up to coordinate the care of veterans with chronic conditions and avoid their unnecessary admission to long-term institutional care. With more than 30,000 (mostly elderly) patients being currently served, CCHT is probably the largest and most integrated/mainstreamed example of home telehealth in the US and internationally.

Description

CCHT was developed as part of the VHA's efforts to provide non-institutional care (NIC) services to cater for the rising number of elderly veterans with chronic care needs. First introduced in 2003, CCHT is now a routine NIC service that uses home telehealth and disease management technologies in care management as adjuncts to VHA's existing health information technology (HIT) infrastructure.

The main conditions served are diabetes mellitus (48.4%), hypertension (40.3%), congestive heart failure (24.8%) and chronic obstructive pulmonary disease (11.4%), as well as smaller numbers with depression (2.3%) and posttraumatic stress disorder (1.1%). Within the CCHT, care is actively coordinated by a dedicated cadre of care coordinators, usually nurses or social workers who receive specific training in the role. The short (3- to 5-week) training of care coordinators makes it a very flexible approach. Typically an individual care coordinator manages a panel of between 100 and 150 general medical patients or 90 patients with mental health-related conditions. Eligible patients are offered the choice to receive CCHT-based care or other NIC care services and thereafter are free to change if they wish. When a patient is enrolled, the care coordinator selects the appropriate home health technology, gives the required training to the patient and caregiver and, on an ongoing basis, reviews telehealth monitoring data and provides active care or case management.

VHA has established national contracts for commercial-off-the-shelf devices for CCHT, and specific data and technical requirements for the routine exchange of vital signs are standardised in the contracts (e.g. HL-7). A technology algorithm that is based on a patient's needs, the complexity of the disease/condition, and ability to use technology, helps determine which CCHT device is most suitable and cost-effective to use in each case. The most commonly used technologies are messaging/monitoring devices (85%), followed by videotelemonitors (11%) and videophones (4%). Messaging devices present disease management protocols which contain text-based questions for patients to answer and so help assess their health status and disease self-management capabilities. Biometric devices record and monitor vital sign data. Videophones and videotelemonitors support audio-video consultations into the home.

Promoting patient self-management is a fundamental component of the CCHT model and the messaging devices are key to this, helping identify adverse symptoms, knowledge deficits and negative health-related behaviours that can be responded-to before progression to a need for hospital admission or emergency department visit. The objective vital signs data augments this by providing further discriminatory information. Video and telemonitoring data from the home telehealth devices are communicated to the HIT (mainly via ordinary telephone lines) and the HIT platform provides the care coordinators with vital sign and other disease management data from their panel of patients. Each patient is risk-stratified daily according to preset thresholds, with alerts presented if there are any significant changes in the patient's symptoms, knowledge and health factors that may require proactive recognition and management. Care coordinators intervene as necessary (e.g. help patient to self-manage by phone, institute care/case management, and so on) in accordance with such alerts.

The VHA's financial decision support system captures CCHT workload and provides cost data, as well as routine clinical outcome reports. Reductions in hospital admissions (19.7%) and bed day occupancy (25.3%) have been recorded. The cost of CCHT averages $1,600 per annum, and this has been compared with the $13,121 per annum for VHA's home-based primary care service and $77,745 per annum for private nursing home care. Information on patient satisfaction with CCHT-based care is collected from patients every 3 months. Surveys in 2006 and 2007 found a mean satisfaction score of 86%.

Key learning points

- After successful piloting, home telehealth has been implemented into routine care across the organisation, enabled by a comprehensive and systematic approach to the clinical, educational, technology and business processes
- The service replicates, at enterprise level, the potential for cost-savings / cost-avoidance that other pilots have shown, whereby the emphasis is on patient self-management and sharing of responsibility for care between patient and caregiver.

Further information

VHA CCHT website - http://www.carecoordination.va.gov/telehealth/ccht/index.asp

Darkins, A. et al (2008) Care Coordination/Home Telehealth: The systematic implementation of health informatics, home telehealth and disease management to support the care of veteran patients with chronic conditions. Telemedicine and e-Health, December, 2008.

TAUNUS BKK Disease Management Programme

- telehealth as a component of a patient-centred care -

Summary

TAUNUS BKK, a German public health insurer, has mainstreamed home telehealth solutions within dedicated disease management programmes addressing patients suffering from diabetes or heart insufficiency, many of which are older people. This was enabled through regulatory changes adopted in the context of a national health care reform.

Description

The German health care system is characterised by highly decentralised organisational structures in relation to both reimbursement and actual delivery of health care services. Overall, more than 200 public and private health insurers currently exist. The health care reform act from 2000 (GKV-Gesundheitsreformgesetz) enabled German health insurers for the first time to implement dedicated disease management programmes (Integrierte Versogung) by concluding specific contracts with different types of services providers. Subsequently, this right was strengthened by the adoption of further legislation in 2004 (GKV-Modernisierungsgesetz) and 2007 (GKV-Wettbewerbsstärkungsgesetz). As a result, various health insurers have set up disease management programmes in relation to specific patient groups, the general aim being to integrate the various actors along the overall health care chain with a view towards implementing patient-centred service delivery processes cutting across traditional sectoral/occupational boundaries (e.g. between general practioneers, specialists and hospitals).

The TAUNUS BBK was among the first health insurers in Germany to incorporate dedicated telehealth solutions within its disease management programmes. A programme specifically targeting diabetes patients was contractually agreed in spring 2006, relying upon a dedicated diabetes management and decision support system (KADIS®) that is provided by the Gerhardt Katsch Institute for Diabetes as well as a dedicated home telehealth system (Diabetiva®) provided by the German telemedicine provider PHTS Telemedizin. Following to a successful pilot phase, the scheme became available as a regular service offering in 2007. Depending on the respective medical indication, vital parameters such as blood sugar, body weight, blood pressure and an electrocardiogram may be monitored with help of a home care unit on a daily basis. All data captured are automatically fed into a personal health record (MROL). Specialist staff at the monitoring centre are automatically alerted when predefined threshold values are exceeded, and a suitable intervention is initiated after additional manual checking of the incoming data. Should an emergency situation arise, the case is personally handed over to an emergency physician through a direct telephone contact, including relevant information stored in the personal health record. A similar program targeting patients suffering from heart insufficiency has been contractually agreed with the Cardiologic-Platform Hessen (Kardiologie-Plattform Hessen eG) and PHTS Telemedizin in January 2009. Amongst others, it relies upon a dedicated telemonitoring system (Zertiva®) which has been piloted by TAUNUS BKK since 2005 already. Again, vital data are remotely monitored on a daily basis, and interventions are initiated as appropriate. Moreover, patients are regularly interrogated by telephone according to a structured protocol. Also, they receive advice in relation to nutrition, exercises and pharmacotherapy.

Preliminary evaluation activities suggest that the two disease management programmes in general, and the telehealth services in particular have significantly contributed to the improvement of the patients' quality of life in a cost efficient manner. Outcomes suggest for instance that patients with heart insufficiency who participated in the telehealth scheme had to be less frequently treated in a stationary setting. Overall, the number of patients who were referred to a hospital decreased by 42%. For those who needed to be referred to a hospital a decrease of hospital days of 24% was observed. Overall, costs for hospital treatment decreased by 77% according to a recent press release. Similar benefits have been observed in relation to diabetes patients.

Key learning points

- Regulatory changes within the highly decentralised national health system have enabled health insurers to direct funding streams towards telehealth service providers.
- A dedicated policy towards the development of disease management programmes has driven investments in home telehealth solutions.

Further information

„Mit Herz dabei“ – Neue Versorgungsform für chronisch Herzkranke startet in Hessen, BKK Taunus Press Release, 28th January 2009

Gesundheitsökonomische Daten bestätigen Nutzen von Telemedizin, BKK Taunus press release, 4th December 2008

Volker Heuzeroth (2009): My home is my Hospital. „Schwerwiegende Komplikationen zu Hause behandeln“. In Ambient Assisted Living. 2. Deutscher Kongress mit Ausstellung, 27. – 28. Januar in Berlin, Tagungsband, VDE Verlag GmbH, Berlinun Offenabch.

Website of TAUNUS BKK (http://www.taunus-bkk.de) and website of PHTS Telemedizin (http://www.phts.de/phts/)

National Framework Agreement on Telecare (NFA)

- public procurement of telecare equipment and services -

Summary

The National Framework Agreement on Telecare (NFA) was developed as a public procurement mechanism to support the delivery of telecare policy in the UK. It eliminates the need for local care services to individually undertake their own procurement exercises and more generally aims to contribute to the creation of a competitive marketplace for telecare for the public sector. This award winning initiative has been rated as very successful, being used by over 80% of local authorities and delivering substantial cost savings.

Description

Effective public procurement processes are identified as a key requirement in UK telecare policy ('Building Telecare in England'). To support this, the National Health Service (NHS) Purchasing and Supply Agency (PASA) established a specific project management group to deliver the procurement solution and sourcing activity required for telecare. In addition to the standard procurement activities to set up the framework agreement, parallel activities included stakeholder engagement and consultation to develop the evaluation and award criteria (through workshops and focus group with the main intended users - local authority commissioners); and data gathering and research to develop understanding of the marketplace (both the supply/product and customer/demand bases) and benchmark existing practices.

The resultant Telecare National Framework Agreement (NFA) complies with the EU public procurement regulations and provides a sourcing solution that:

- can be used by all public sector/voluntary bodies across the UK, ensuring extensive product/service ranges and geographical coverage
- helps achieve best value and pricing, and create a competitive marketplace for telecare for the public sector
- enables the introduction of innovation and new technology to help achieve policy goals in the health/social care and healthcare industry fields.

Currently there are 13 suppliers included in the agreement, covering the following modalities:

- telecare / community alarms (equipment to assist in reducing accidents and incidents in the home; home activity, lifestyle and environmental monitors; integrated systems for telecare and healthcare; community (social) alarms)
- telehealth/medicine (blood pressure monitoring; blood glucose monitoring; cardiac arrhythmia monitoring; asthma monitors; home personal medical assistant units; integrated health monitors; medication reminder systems).

In addition to telecare equipment, the national framework agreement also includes relevant installation and maintenance services for equipment, and monitoring and response services.

Since its launch in 2006 the following benefits have been reported:

- committed public sector spend and uptake: more then 40 million euro of purchases through the NFA to date; over 80% of local authorities have used it
- savings: cash savings to the public sector of almost 10 million euro, with a further 30 million euro in efficiency savings
- increased choice and flexibility: wide range of participating NFA suppliers and associated sub-contractors and partnering organisations; choice of large range of products/services from 13 suppliers
- support for policy, industry and innovation: has significantly contributed to the Department of Health's telecare/telehealth policy; also has developed a commercial framework for the telecare industry to channel activity and develop a sustainable UK market, which can support the introduction of innovation and new technology.

In recognition of the achievements of the telecare NFA, the NHS PASA telecare project team was awarded the prestigious Chartered Institute of Purchasing and Supply 'Best Public Procurement Project' in 2007.

Key learning points

- This is an example of effective use of public procurement to support telecare/telehealth development, providing both a practical tool and a broader development support in this field.
- This approach combines both care policy and industry policy objectives.

Further information

National Framework Agreement for Telecare. NHS Purchasing and Supply Agency.
http://www.pasa.nhs.uk/PASAWeb/Productsandservices/Telecare/NFA.htm

Building telecare in England.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4115303

The West Lothian Home Safety Service

- telecare as a catalyst of community care service innovation -

Summary

The West Lothian authority has launched an innovative programme reshaping existing community services for older people, whereby the introduction of telecare has acted as a catalyst of organisational and cultural change. Further service innovation is currently being explored in the framework of the national Scottish Telecare Strategy.

Description

As early as 1999, the Council of West Lothian initiated its "Opening Doors for Older People" project which was itself operating under the wider banner of the "Wired West Lothian" initiative. In the framework of this pilot project, packages of technology were installed into approximately 75 homes of older people. In a second phase beginning in May 2002, a successor project enabled the West Lothian Council to upgrade its community alarm service to the "Home Safety Service". Today this service can be applied for by, or on behalf of, anyone who is considered to be vulnerable at home. There is no charge for this service but a working telephone landline is essential. The Home Safety Service team provides a package of technology comprising of a Lifeline unit and a range of sensors protecting the person and their home by means of a 24-hour telephone link to West Lothian Care Line. Sensors provided may include a pendant, flood detectors, smoke detector, movement sensors and an extreme temperature sensor. Needs in relation to the separate components are assessed individually from case to case. Service staff experienced in the use and programming of telecare equipment provide ongoing support in the use of the technology.

Experiences reported at various conferences suggest that the technical implementation of relevant technology applications turned out to be amongst the least complicated tasks. Instead, the bottleneck in providing a 'conveyor belt of care' was the provision, organisation and coordination of the services behind these technologies. Innovation primarily lay in the organisational design, involving professionals, all working for different organisations, but offering one pathway for health and social care. According to information provided at the web site of the West Lothian Community Health and Care Partnership there are currently over 3000 households in West Lothian with telecare equipment installed. Experiences gained so far suggest that service deployment has resulted in improved levels of care and quality of life for elderly people, helping them to stay longer in their own homes, reducing anxiety for families and cutting costs for the public authority.

The current service is being further developed in the framework of a dedicated programme that was launched in August 2006 by the Scottish government. The major aim of this programme is to support the development and enhancement of telecare services in the country. It makes funds for telecare developments available to health and social care partnerships across Scotland through a £16m Development Fund. Based on experiences gained since the staring of the national program, a dedicated policy strategy was adopted in 2008 outlining a policy framework for the further development of telecare in Scotland until the end of 2010. More specifically, this includes an Action Plan detailing the Scottish Government's expectations on further developments from the national Telecare Programme Board and from the 32 local partnerships over this period. In Lothian a dedicated pilot - the NHS Lothian Telecare/Telehealth Pilot - targets 'high service users' within National Health Service (NHS) Lothian to provide early and continuous monitoring of the health and social needs of people with selected long term conditions. The ultimate aim is to reduce the likelihood of acute aggravation of their conditions, and hence reduce the demand for expensive interventions, such as unplanned hospital admissions. It works by adding 'telehealth' solutions to an existing telecare agreement formed between West Lothian Community Health and Care Partnership (now under wider NHS Lothian) and commercial technology suppliers.

Key learning points

- Mainstream implementation of 2nd generation telecare was driven by a strategic vision towards service innovation across existing organisational/occupational boundaries, whereby technology was understood as a useful tool rather than the main driving force behind community care service innovation.
- The further evolution of existing telecare services at the local level is supported both by a dedicated telecare strategy pursued by the Scottish government and by the availability of public funds.

Further information

JIT (Joint improvement team) website about Telecare in Scotland: http://www.jitscotland.org.uk/action-areas/telecare-in-scotland/

West Lothian Community Health and Care Partnership website: http://www.westlothianchcp.org.uk/

Kelly (2005): Touching People's Live with Techology. Presentation at the Silver Economy in Europe Conference on 16th/17th February2055 in Bonn, Germany

Kelly (2008): Bringing Technology and Healthcare Together in the UK. Presentation at the eInclusion Ministerial Conference on 30th Nov. to 2nd Dez. In Vienna, Austria

The SOPHIA Telecare Service

- a telecare deployment model addressing housing organisations -

Summary

SOPHIA is a fully up and running service offering that has become available in certain parts of Germany since 2004. The service provides social support to older people living in their own home environment, including the management of age-related risks. In technological regard, different systems and devices are utilised including an age-friendly telephone set, state-of-the-art alarm service technology including advanced sensoring and activity monitoring, and video telephony utilising the ordinary television set.

Description

The SOPHIA service is being deployed by means of a franchise model primarily addressing housing organisations that are interested in offering value added services to their elderly tenants. Round-the-clock operation of local services centres is at the heart of the SOPHIA service model. These operate in close cooperation with locally available volunteers and professional services such as community care services and handicraft businesses. This approach enables the service centre to organise on-demand support in relation to a wide spectrum of personal needs, e.g. help in daily shopping, small repairs or if a clients simply wants to have a chat. A dedicated not-for-profit foundation – the SOPHIA foundation – has been established in order to recruit and train volunteers who support individual clients. Different service packages are offered:

- A “basic” service package includes 24/7 availability of a service-centre by telephone, a weekly reassurance call initiated by the SOPHIA staff as well as on-demand advice to clients and/or their relatives in relation to formal services that are locally available from other parties. In case of illness, the client is contacted on a daily basis by service centre staff.
- A “security” package includes – in addition to the above services – a personal alarm service utilising an intelligent wrist band and if required various sensors placed in the client’s home (e.g. gas and fire sensors). The Wrist band enables an alarm call to be actively triggered by the client. Response is initiated according to an individually agreed protocol and delivered by external parties, e.g. a family member, a neighbour or the family doctor. Moreover, the intelligent wrist band enables the service centre to actively initiate an intervention on the basis of a 24h activity profile generated through this device.
- A “contact” package enables – in addition to the “basic” service - video telephone contacts to be established via an ordinary TV set with the service centre or any other party (e.g. family members and friends) stored in a personalised video telephone directory. Beyond this an “information button” enables access to dedicated news, e.g. concerning health matters. This package is typically offered to individual clients when specific needs arise, e.g. in case of immobility or absence of any social contacts. As the economic capabilities of many clients who stand to benefit most from the “contact” package tend to be rather confined, support is available from the SOPHIA foundation and Kabel Deutschland, a national cable network provider.

A so called “comfort” package comprising all service components sketched above is available as well. For clients who are eligible to receive support under the statutory long term care insurance scheme, service fees are reimbursable up to an amount of €18.36 per month. A mixed financing model relying on contributions by housing organisations, service fees and partial public reimbursement of service costs enables to keep the financial contribution required to be made by the end users at a manageable level, currently about €35 per month on average depending on the service package actually utilised. The current service scheme has developed from a local pilot project in Northern Bavaria that had been supported by public funds until 2004. In 2005 a regional service organisation – the SOPHIA Franken GmbH & Co. KG – was founded in order to serve the 50 trial participants beyond the immediate trial duration. Today, 850 clients are served in that region. Further regional service organisations operating according to the same model have been set up since then in Berlin, North Rhine Westphalia and South Bavaria. At the end of 2008, about 2000 older clients were served across the country, and concrete plans exist to roll out the service model in further regions.

Key learning points

- A differentiated set of service components addresses a continuum of user needs that had been identified in a demand-driven manner throughout the piloting phase.
- A flexible financing model enables tailoring of a “business case” towards local circumstances and the particular requirements of the actors involved.
- Systematically managed cooperation of professional staff and voluntary supporters at the local level enables provision of personalised support spanning across a spectrum of user needs (e.g. management of personal risks, support in daily living, social interaction)

Further information

SOPHIA website: http://www.sophia-tv.de/

Nunner, G. (2009): Nutzerantizipation und wirtschaftliche Realität im Bereich “betreutes Wohnen Zuhause”, In: Tagungsbeiträge zum 2. Deutschen AAL Kongress mit Asstellung.

Zahneisen, A. (2009): SOPHIA-Best Practice, In: Tagungsbeiträge zum 2. Deutschen AAL Kongress mit Asstellung.

FASS Tele-assistance

- mainstreaming telecare in public social service provision -

Summary

The Fundación Andaluza de Servicios Sociales (FASS) has mainstreamed basic telecare in the framework of its legal duty to provide care in the community under the ambit of social legislation enacted at the national policy level. The latter makes explicit reference to tele-assistance as a means of supporting vulnerable people in living independently in the community.

Description

The Law on the Promotion of Personal Autonomy and Care of Those in Dependent Situations (39/2006) defines and sets the remit of telecare in Spain, commonly known as tele-assistance. This national law makes explicit reference to tele-assistance as a means of responding to emergency situations, insecurity, loneliness or social isolation (Article 22). Accountability for planning and coordinating services provision at the community level - including both non-ICT based services as well as tele-assistance - is legally assigned to 17 Autonomous Regions and two Autonomous Cities.

At an early stage, the government of the Autonomous Region of Andalusia (Junta de Andalucía) has adopted a dedicated policy towards investing in ICT in order to support social service provision. Tele-assistance is provided by the Fundación Andaluza de Servicios Sociales (FASS), a non-profit organisation founded by the regional government which provides a wide range of services in the community including, for instance, long distance transport, day care, respite care and assistive technology provision.

Operation of a number of service centres on a 24 hours / 7 days a week basis is at the heart of the tele-assistance provided by FASS. The core service is primarily directed towards risk management by enabling an alarm to be triggered in an emergency situation with help of state of the art social alarm technology. Clients can at any time and from any location within the home establish a voice connection to the service centre by a wireless pendant and a fixed assistance button installed in the home. In case of an emergency situation, response is organised according to an agreed protocol and on the basis of a personal client record stored at service centre. Around 2.500 calls from clients are received per day, with up to 10% of them classified as emergency calls. The client base is currently growing by nearly 1.000 new users every month. The core service which is currently used by over 95,000 clients throughout Andalusia has been steadily enhanced during the last years through adding further service components:

- additional sensors (e.g. smoke and gas detectors) are placed in the client's home on request if a particular need arises, e.g. in the case of significant physical or mental disability, and a mobile alarm device enabling an emergency call to be triggered from outside the home has been introduced;
- personal reassurance and monitoring calls are actively established by the service centre staff on a case by case basis, e.g. following to a hospital discharge;
- an agreement has been concluded in order to interconnect the national 112 emergency service infrastructure with the FASS tele-assistance service.

The FASS tele-assistance service is currently available at a monthly service fee of €18, whereby various discounts (100%, 80% and 40%) are available, in particular to holders of the so called "Andalucía Junta 65 Card", a smart card issued by the Regional Ministry for Equality and Social Welfare through FASS to citizens aged 65 years and above. A 100% Discount is available to holders of a "gold card" living alone or with only another "gold card" holder as well as to holders of a "green card" who are aged 80 years and above, provided these live on their own. The same discount is available to persons not holding an "Andalucía Junta 65 Card" who live in a dependent situation according to national legislation and who are aged 80 years and above, regardless of their economic ability. Dependent persons aged below 80 years can avail the service for free if their economic capabilities range below 75% of the national Public Income Indicator (IPREM). Furthermore, disabled people aged below 65 years can also access the tele-care service with a discount of 40% regardless of their economic ability.

Key learning points

- The mainstreaming of basic telecare is driven by dedicated social legislation, along with a proactive public investment decision taken at the regional policy level.
- A dedicated policy strategy has been adopted with a view to continuously enhance the basic telecare service infrastructure with further service components in a demand-driven manner.

Further information

FASS Web site: http://www.juntadeandalucia.es/fundaciondeserviciossociales/

ICT & Ageing study country profile: http://www.ict-ageing.eu/?page_id=256

The Dutch Domotics Programme

- subsidising technology deployment in the serviced housing domain -

Summary

The Dutch Ministry of Health, Care and Welfare provides subsidies for the mainstreaming of independent living technology in the serviced housing sector.

Description

A general policy shift has taken place in the Netherlands during the 1990ies towards avoiding traditional forms of residential elderly care, and it is now more than ever a strong desire among older people in the Netherlands for ways that allow them to live in their own home as long as possible. In addition, lack of healthcare and homecare staff has driven a policy debate on suitable ways to maintain current levels of care provision with fewer personnel. Against this general background, the Ministry of Housing, Spatial Planning and the Environment and the Ministry of Health, Welfare and Sport have jointly stimulated the implementation 'domotics' - technology in the home that enables people to continue to live independently for longer – through dedicated funds between 2003 and 2006. Also, the living and care action plan that had been submitted to the Lower House in July 2004 stated that housing corporations would have a responsibility to invest in this technology. Beyond this, the Ministry of Health, Welfare and Sport Studies funded studies on the impacts of domotics specifically geared towards the needs of people demanding a great deal of care such as people suffering from dementia.

Jointly, these policy efforts triggered a large amount of experimental activities concerning the introduction of smart home solutions and ICT enabled service delivery into the homes of older people across the country. Throughout this experimental phase a great deal of experience was gained by the various actor groupings involved, e.g. housing organisations, care services and technology providers. This phase was followed by a dedicated policy effort directed towards mainstreaming domotics in relation to serviced housing stock that was newly to be developed. From 2006 on, a policy and instrument were settled to pay € 2500 – 3000 extra per apartment on smart home technology if this apartment is to be occupied by a person in need of care. Only care organisations and/or housing associations developing serviced housing stock for older persons (serviced accommodation) are allowed to request the allowance.

Applicants are required to describe the planned construction project at some level of detail, e.g. in relation to the number of flats to be built, vulnerable population groups to be targeted and technology components to be installed. Applications are assessed on a case by case basis. In general different types of technology solutions are eligible for funding:

- personal alarm systems, including systems that need to be actively triggered by the client and systems automatically triggering an alarm in case of an emergency as well as dedicated fire alarm systems;
- systems enabling teleconsultations and remote monitoring, including video-based systems requiring a broadband connection and systems enabling remote access to care records by professional staff and/or clients;
- home automation systems directed toward enabling the older person to control the immediate home environment such as automatic door opening systems, intercoms and control systems relating to home appliances;
- systems enabling access to on-demand support in relation to activities of daily living such as meals on wheels and home care as well as social integration;
- IT systems supporting human resource planning, logistics and general administrative functions concerning health/care related service provision;
- assistive devices such as large button panels for people with dexterity problems and large screens for people with visual restrictions.

Expert assessment suggests that in 2006 and 2007 together about 350 projects may have been granted financial support for smart home and related telecare technology. Approximately 250 may have been realized in 2008. On average, each project has been estimated to have involved 90 individual homes.

Key learning points

- Extensive experimentation with smart home / telecare technology was stimulated through public funding.
- Financial support has then been channelled into the serviced housing domain, with a view to incentivise mainstream deployment of both smart home technology and telecare equipment/infrastructure.

Further information

Ministerie van Volksgezondheid, Welzijn en Sport & Ministry of Health, Welfare and Sport: Policy for older persons in the perspective of an ageing population, February 2006

Website of the Netherlands Board for Healthcare Institutions: http://www.bouwcollege.nl

Telecare Business Case Planning Model

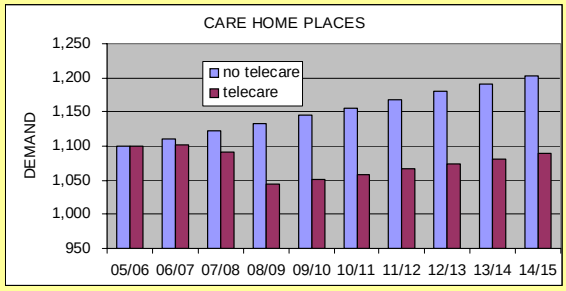
- a practical tool to support local communities in the planning of telecare -

Summary

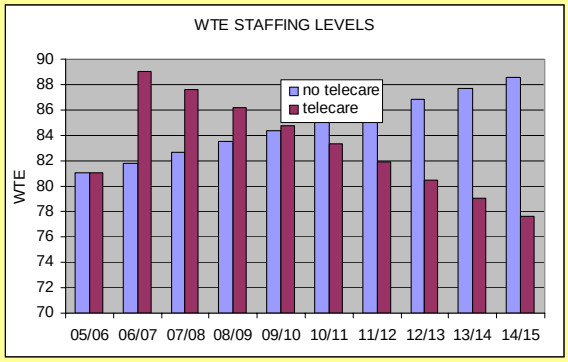
The Telecare Learning & Improvement Network in the UK has developed a business case modelling tool to support social service departments in the development of strategy and business cases for the mainstreaming of telecare. The immediate aim was to support councils in making decisions about how to spend public funds available from a national government programme in an economically sustainable manner.

Description

In the UK, the national government made available £80 million (105 M Euro) for the Preventative Technology Grant over the period 2006-2008. This centrally-funded government scheme provided grants to local authorities in England to invest in care-related technology, especially telecare and also electronic assistive technologies. The funding was for the local authorities but they were expected to work with partners in housing, health, voluntary and independent sectors, as well as service users and carers. The initiative was intended to pump-prime change and the incorporation of telecare in the delivery of mainstream services provided at the community level. A Telecare Implementation Guide and accompanying support materials were developed to give detailed guidance on developing and implementing a telecare service. Active ongoing support was provided through the Telecare Learning & Improvement Network (LIN) of the Care Services Improvement Partnership (CSIP).



Specific emphasis was given to the provision of hands–on support directed towards enabling individual councils to spend funds available from the Preventative Technology Grant in an economically sustainable manner. Together with a manual, two separate - but linked – planning models can be downloaded over the internet. They are intended to enable individual local councils to develop their own business cases for telecare using local data centred on local issues which, in turn, shape the requirement for local telecare development. Also, they are designed to be flexible and straightforward to use and to enable the potential resource and financial consequences of a wide range of assumptions and ideas to be explored in a short period of time.



Using Excel spreadsheets, a dedicated business case modelling tool provides a range of return-on-investment calculations and projections which illustrate individually the changes in cost and infrastructure expected to materialise over time. Some illustrative examples of the type of output that could be produced are provided above. The model also shows that financial gains from telecare are reliant on co-ordinated changes in care practices.

Key learning points

- The national government has taken a focused, centrally-driven effort to kick-start publicly-supported telecare services across the country, whereby a clear focus has been on mainstreaming and sustainability.
- An extensive programme of flanking measures has been put in place, in terms of promotional efforts and provision of support/guidance materials
- A modelling tool specifically focusing on business case planning for telecare by public services provides useful analysis and metrics for identifying and quantifying inputs and outputs, and to illustrate scenarios of development within the care sector.

Further information

Department of Health website with available downloads:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4115303

Telecare performance reports from social care authorities (2008) available at: http://networks.csip.org.uk/IndependentLivingChoices/Telecare/TelecareOutcomes/?

Recommendations for reimbursement of Home Telehealth and Remote Monitoring

- American Telemedicine Association -

Summary

The recommendations on reimbursement of home telehealth and remote monitoring by the American Telemedicine Association provide the most comprehensive analysis of this topic internationally. Although developed in the US and not yet implemented by payers, they nevertheless provide a very useful and instructive analysis that is also of relevance in the European context

Description

The American Telemedicine Association (ATA) 'Federal Policy Recommendations for Home Telehealth and Remote Monitoring' define home telehealth 'visits' as the use of remote devices to allow the patient to communicate and provide medical information, including vital signs, to a health professional via live interactive telecommunications. Remote monitoring may be periodic or continuous and provide one or more objective physiologic data (such as vital signs) or subjective data (such as disease management education assessment, symptom assessment and knowledge assessment) from the patient to a distant location using a capturing device and telecommunications links. Some of the key elements of the reimbursement principles for the service component are as follows:

Policy recommendations for home telehealth visits:

- Any practitioner who would otherwise be entitled to receive payment under Medicare for in-person services delivered in the home should be entitled to be paid for such services if they are provided using appropriate remote monitoring technology. Reimbursement for such services should be subject to the same guidelines stated within the physicians' fee schedule. Such services should be allowed, provided that the service:
    - meets required documentation criteria for an in-person visit;
    - does not substitute for needed in-person care or in-person home services.
- Remote telehealth visits provided by homecare agencies or related organizations should be treated by Medicare similarly to in-home, face-to-face visits for purposes of eligibility and payment. Such services should be allowed provided that the service:
    - is ordered as part of care certified by a physician;
    - meets required documentation criteria for an in-person visit;
    - does not substitute for needed in-person home health services;
    - is considered the equivalent of a visit under criteria developed by the Secretary.

Policy recommendations for remote vital sign monitoring:

- Any individual who would otherwise be entitled to receive coverage under Medicare for in-person encounter-based monitoring services should be entitled to receive such services through the use of remote monitoring. Reimbursement levels for the health care provider monitoring vital signs at a distance should be established using existing resource-based payment methodologies used for in-person monitoring; such services should be subject to the same guidelines developed on the frequency of billing for the in-person encounter-based monitoring service.
- If the remote vital sign monitoring is prescribed and delivered under Medicare as part of approved home care services, the costs of delivering the services, including the costs of the equipment, should be classified as allowable costs and included in the appropriate section of the home health cost report.

Recommendations are also presented for charging/reimbursement for the home telehealth equipment and devices needed to provide such services.

Finally, it is also recommended that support should be provided for self-care technology, either as a covered benefit or through a tax deduction for the cost of the purchase.

Key learning points

- Clear specification of circumstances and rates for home telehealth visits and monitoring
- Shows how 'prescription' and reimbursement of home telehealth and monitoring can be addressed as part of mainstream approaches
- Addresses provision and reimbursement approaches for both medical practitioners and home care agencies.

Further information

Federal Policy Recommendations for Home Telehealth and Remote Monitoring
http://www.americantelemed.org/files/public/policy/Home_Telehealth_Policy_ver3_5.pdf

"WristCare" - A European success story

- IST Vivago system, a commercially successful innovation in telecare -

Summary

The Vivago "WristCare" system is a commercially available telecare product range developed by a Finnish company (IST) that is now being used in a number of European countries. It represents a significant innovation on traditional social alarm products and is said to the world's first security device that automatically monitors a person's well-being 24 hours a day. The product has received many innovation awards in Finland and internationally.

Description

The Vivago "WristCare" system was developed by the Finnish company IST International Security Technology Oy (IST) and is said to be the world's first security device which monitors the user's well being 24 hours a day. There are various models to meet different needs, including versions for home and institutional users. The product is innovative in its integration of both active and passive functionality of social alarms in the same unit.

Implemented in the form of a wristwatch-type device, the Vivago system continuously measures physiological signals, including movement, body temperature, pulse and skin conductivity. The measuring sensors are located within the straps and back plate.

During the first four days of use the system studies the user's normal activity level and well-being, and adapts its function to these. After this, if the WristCare system notices a significant change in the user's activity level or well-being, it automatically sends an alarm after a pre-determined period. There is also a manual alarm that can be triggered when help is needed immediately. As well as providing notification in case of alarm, the system also provides the possibility for ongoing activity monitoring over a longer period. For example, the activity curve transmitted by the Vivago WristCare is used to support care activities associated with the monitoring of sleep/wake rhythms. The wrist unit can also be used as a monitoring solution for users with dementia as well as a security system for care personnel.

The Vivago home system includes a base unit that wirelessly receives the data from the wrist unit and transmits alarms and notifications to the alarm recipient via the telephone network. The alarm can be transmitted as a voice or voice and text message to any telephone - for example to a friend or nurse (through the IST Gateway router) or to a 24-hour call centre. The alarms can be routed to multiple recipients, depending on the time of day. The company also offers its own software application, IST Vista, used for receiving and handling calls at monitoring centres.

Development of the system and subsequent market penetration took quite a long time. The initial development work began in 1993 and the first generation product was released in 1998. The IST Bodycode® technology underpinning the current product range was first commercially available in 2001. This consists of sensors and algorithms that allow body signals to be monitored and analyzed automatically and continuously.

Development support was provided by the Technical Research Institute of Finland (VTT), which participated in the clinical testing, as well as financial involvement from the financial services group FIM and the Finnish National Fund for Research and Development (SITRA). The company, IST, is now owned by Finnish insurance companies and pension institutions.

Bringing this new kind of product to the market took a long time, although nowadays there seems to be greater awareness and receptivity towards this type of system in target markets such as social care and sheltered housing for older people. WristCare products are now used in Finland, Sweden, Germany, UK, France, Ireland, Spain and Japan. Sales are growing rapidly with already more than 8,000 elderly and over 100 care facilities using the system. In addition to the alarm functionality, the activity monitoring aspects seem to be of increasing interest.

Key technological and other features underpinning its success include its form factor (physical size and shape) and power management, sensing technologies and algorithms, and conceptual fit to needs of purchasing institutions (i.e. market knowledge). Development of care solutions together with professionals within medicine, care and information technology has been a key factor in the success of the product range.

Key learning points

- Correct and reliable technical functioning, and proof of concept, has been central to market penetration and take-up
- Success in the market requires good understanding and cooperation with health and social services that comprise the core target markets; it can take time to break into these markets.

Sources

http://www.istsec.fi/eng/Etuotteet.htm

3 Good practice examples addressing ethical issues

The following examples have been included in the first tranche of good practice examples:

- **The ENABLE Project's Approach to Ethics:**
  The Enabling Technologies for People with Dementia (ENABLE) project investigated whether it is possible to facilitate independent living of people with dementia and to promote their wellbeing through access to enabling technologies. The project gave a deep attention to ethical issues in conducting and reporting on the research, and both the process and outcomes are useful for others to learn from.
- **Ethics of ICT & Ageing: Consulting the Public:**
  Efforts to consult the public on the ethics of ICTs & Ageing have been undertaken in Norway, including a consensus conference in 2000 and also within a new programme of scenario-workshops that commenced in 2008. Results provide guidance for Norwegian policy and practice in this area, and the approaches present useful models for application elsewhere.
- **Perspectives, Principles, Paradigms:**
  The ASTRID guide to using technology within dementia care has provided an important point of reference for ethical practice in this field since its publication in 2000. Using an approach underpinned by the '3 Ps' - perspectives, principles and paradigms - the guide discusses the ethics of technology in dementia care and works through the issues in some illustrative cases.
- **The MINAmI Project's Approach to Ethics:**
  Primarily technology-oriented projects can also take initiative to actively address and reflect on ethical issues that relate to their particular area of expertise. This way, interesting new questions may surface and new approaches to dealing with ethical issues in R&D projects and recommendations for discussion even on societal level are possible.
- **In-home Monitoring of Persons with Dementia:**
  Ethical guidelines often fall short of being sufficiently concrete to provide practical guidance for the research and development setting. An example of a guideline designed for gerontechnology research and development to support persons with Alzheimer's disease and their caregivers shows that the translation of abstract principles to hands-on guidance is possible.
- **The American Telemedicine Association's Guidelines:**
  In an effort to help advance science and to assure the uniform quality of services to patients, the American Telemedicine Association (ATA) has embarked on an effort to establish practice guidelines and technical standards for the field of telemedicine and telehealth. The document "Core Standards for Telemedicine Operations" addresses administrative, clinical and technical standards, whereby ethical issue such as data privacy and informed consent are addressed as far as they concern existing regulative/legal requirements.
- **The Mental Welfare Commission of Scotland's "Safer to Wander?" Document:**
  "Safer to wander?" is a document produced by the Mental Welfare Commission of Scotland on ethical principles and guidance on good practice when considering the use of wandering technologies in support of individuals with dementia who are residents in care homes or hospitals. The technologies in focus include "tagging" and tracking devices that can be used to alert when a person leaves a given area and help locate a person who has gotten lost.
- **The Friendly Rest Room Project's Approach to Ethics:**
  The Friendly Rest Room project was a user-centered research and development project in which prototypes of self-adapting toilets for older users and disabled users

were developed. Because toileting and personal hygiene are deemed sensitive areas of research and the intended user group to be involved was likely to include potentially vulnerable persons, the project gave a deep attention to ethical issues with continual ethical review being conducted throughout the project.

- **North Lanarkshire Council's Best Practice Policy:**
  The best practice guidance document and its appendices drafted by the North Lanarshire Council set out the principles which underpin the Council's policy and guidance on the use of assisted living technology, describe the range of equipment available and provide advice on its use and an assessors' checklist for use of prior to taking up a new device. From the ethical point of view, particularly valuable is the guidance provided for social workers who face technology and care-related decision-making situations with persons from whom it is difficult or practically impossible to obtain an informed consent.
- **The UK Department of Health's Best Practice Guide on 'Risk':**
  The Department of Health in the UK recently prepared a best practice guide on dealing with 'risk' in health and social care, intended for use by everyone who is involved in supporting adults using health and social care within any setting or sector. Although not focusing only on technology-related issues, the guide is nevertheless useful for those considering using ICT-based technologies to reduce perceived 'risk' to vulnerable clients. The purpose of the document is to guide those involved in helping individuals to retain greater control of their lives and to avoid patronising or paternalistic approaches that focus too narrowly on risk reduction.

In the following, each of these examples is presented in more detail according to a common reporting structure.

The ENABLE Project's Approach to Ethics

- deep attention to ethical issues in an RTD project -

Summary

The Enabling Technologies for People with Dementia (ENABLE) project investigated whether it is possible to facilitate independent living of people with dementia and to promote their wellbeing through access to enabling technologies. The project gave a deep attention to ethical issues in conducting and reporting on the research, and both the process and outcomes are useful for others to learn from.

Description

ENABLE was a European RTD project that ran from 2001 to 2004 in Norway, Finland, UK, Ireland and Lithuania. It developed and tested a variety of technologies that could enable people with dementia to live more independently and improve their wellbeing, including specially designed clock/calendars, object locators, automatic lighting, medication reminders, cooker monitors, day planners and easy-to-use telephones.

The fundamental question of whether the research was justified in the first place was addressed. A key factor in support of this was the observed lack of attention until then on technologies oriented towards the needs of and usage by people with dementia themselves, and the consequent lack of availability of useful products. From the ethical point of view of justice, it was felt justified to conduct what was relatively low-risk research with people with dementia and their family carers in order to fill this gap. The ethical principle of justice was also applied in the research - all participants were given the opportunity try the devices and, if they found the experience positive, to keep them free of charge at the end of the trials.

More formally, the proposed research was assessed by local ethics committees before commencement. It was found that structures and approaches varied across countries, as did the nature and depth of consideration of ethical issues by the committees. This is something that may warrant more attention at the EU level. Other challenges to cross-national research in this field were posed by differing requirements and traditions in regard to disclosure of dementia diagnosis to participants.

The ethical principles of beneficence and non-malfeasance were also applied in the assessment of whether the research was justified. Although the products were not expected to directly harm anyone nevertheless their introduction and the research process had the potential to be challenging and disruptive for the participants. This might especially be the case if equipment mal-functioned. In reality, this occurred more often than initially anticipated and is an issue that needs to be given focused consideration and attention in research of this nature. Another issue in a few cases concerned distress to participants when interviewed about quality of life issues and the ethics of whether or not to continue in such cases needs careful attention.

The principle of informed consent was given extensive consideration, which relates especially to the ethical principle of autonomy. Every effort was made to give people with dementia themselves the possibility to consent or not, rather than rely on consent by proxy from family carers. Formally, informed consent was dealt with in each country in conformance with the 'Helsinki Declaration' (World medical Association's Ethical Principles for Medical Research Involving Human Subjects), with reference to local ethics committees as appropriate. Practically, considerable effort was expended to ensure that consent really was 'informed' and freely given, and not because of feelings of being pressured by a health care professional or their carer. Consent was renewed on an ongoing basis during the trials and participants had an open opportunity to withdraw if they wished.

Ethical issues were also addressed in regard to conflicts of interest, for example where the family was keen to test the technologies but the person with dementia was reluctant. Examples of such conflicts were found in all countries, where a tired and exhausted carer saw some possibilities for help but the person being cared for was not very interested to try the product. In such contexts the trial was terminated if the user definitely rejected the product. In one case the carer did not find the product beneficial but the user wished to continue; in that case the trial was continued. In other cases, where the carer was keener than the person cared for, but there was no outright rejection, the trials proceeded on the basis of beneficence for the situation as a whole.

Finally, based on the results and experiences of the trials, the researchers have drawn attention to ethical issues around trial design in this field. It is suggested that randomized controlled trials (RCTs) may not be an appropriate approach, both on methodological grounds and in conformance with the ethical principle of justice.

Key learning points

- Open and informed consent can be achieved with appropriate attention and effort by researchers
- Mal-functioning technology can pose important ethical challenges for research of this nature
- Some ethical issues can be addressed in advance and others will arise during the research process; these need to be openly and fully addressed when they do.

Further information

ENABLE Project (2004) Final Methodology Report. www.enableproject.org; I. Hagen (2007) What is evidence? *in* Challenges for Assistive Technology (G. Enzmendi *et al, eds*) IOS Press pp. 222 - 226.

Ethics of ICT & Ageing: Consulting the Public

- consensus conference and scenario-workshops -

Summary

Efforts to consult the public on the ethics of ICTs & Ageing have been undertaken in Norway, including a consensus conference in 2000 and also within a new programme of scenario-workshops that commenced in 2008. Results provide guidance for Norwegian policy and practice in this area, and the approaches present useful models for application elsewhere.

Description

The Norwegian Board of Technology began to address issues around the ethics of ICTs & Ageing in 2000, prompted by the growth of the elderly population, developments in ICTs, extensive municipal construction of housing for older people, and shortage of health and social care personnel. A consensus conference was organised to address two aspects of ICTs & Ageing – ICTs as a means of communication and the use of ICTs in housing (smart-home technology). The main focus was to examine whether ICT can help elderly people to become independent and support society in taking care of older people and people with dementia in a worthy and humane manner. It was felt that relying solely on the usual approach to policy guidance - consultation of experts – was not sufficient in this field. Such expert milieus are often small, with the same persons often consulted on different matters, so that a limited group may have great influence on social development. In addition, it can be difficult to decide which professional milieus are relevant in interdisciplinary questions. For these reasons it was decided to employ the consensus conference method of technology assessment, where ordinary citizens work their way towards a common, well-considered point of view before technology is put to use. In this way it is a tool for active democracy.

The consensus conference had three objectives: to give unanimous advice on elderly people and ICT to politicians, authorities and other decision-makers; to create a forum for dialogue between experts and non-experts; to contribute to a many-sided and informed public debate on the topic. National and regional newspapers advertised for lay-people interested to attend and 16 of 230 applicants were finally selected, with a view to getting balanced representation by gender, age and place of living, as well as occupation and education. Two preparatory weekend assemblies were held in advance of the conference proper, to familiarise the participants with each other and with the topic in question and also to draw up the questions that the conference was to deal with. A panel of 15 experts was also convened, selected on the basis of the list of questions the lay-people wished to be addressed and their instructions as to what sort of experts they wanted. The consensus conference itself took place over four days, with the first day-and-a-half involving lectures from the experts on the questions they had been given and answering questions from the lay-people. The next day-and-a-half was spent by the lay-people preparing their report, which was presented for experts and audience on the final day. Amongst other things, this allowed the experts to point out any factual mistakes that needed correction.

The overall conclusion from the conference was that there are no real alternatives to using technology - developments cannot be reversed; therefore, there is a need for good regulation. The greatest challenges are ethical - introduction of new technology may reinforce existing problems and dilemmas, at the same time as bringing improvements for each individual in need of care services; clarification of ethical aspects is therefore vital. Technology should not substitute for human care, but should remain only a supplement to existing welfare services; good procedures and guidelines should be formulated, together with technical standards and minimum requirements for implementation and use in welfare services. When technology is chosen, the objectives, function and for which user groups they are intended should be clearly specified by the responsible decision-makers; it should be an absolute that the technology solutions chosen must always be those that are the best ones for the user, given his/her special needs. Equal access should be ensured across all municipalities (given that technology is positive provided certain conditions are met).

Recently the Norwegian Board of Technology has initiated a project on 'e-Health: The Future of Ageing'. This will use scenario workshops in different municipalities, attended by a variety of stakeholders including older people and carers. One of the key emerging recommendations is that health care technology must be used with precaution, as they give rise to challenges related to loneliness, safety and protection of privacy. As regards privacy, in particular, the important principle of proportionality must be applied, so that only information that is really necessary is generated and stored by the technology.

Key learning points

- Consensus conferences are useful to gauge lay-people's opinions and provide policy guidance in this field
- The Norwegian approach and results can provide models and guidance for other countries as well

Further information

ICT for elderly people. Final report from the consensus conference of The Norwegian Board of Technology. 2000 http://www.teknologiradet.no/ICT%20for%20elderly%20people_wNGky.pdf.file.

e-Health: The future of Ageing Project http://www.teknologiradet.no/FullStroy.aspx?m=282

Perspectives, Principles, Paradigms

- ethical guidance from the ASTRID project -

Summary

The ASTRID guide to using technology within dementia care has provided an important point of reference for ethical practice in this field since its publication in 2000. Using an approach underpinned by the '3 Ps' - perspectives, principles and paradigms - the guide discusses the ethics of technology in dementia care and works through the issues in some illustrative cases.

Description

The guide emphasises that ethical practice is not 'recipe knowledge', by which simple, definitive answers can be provided to complex issues and problems. Instead, it is about asking questions that shed light on the various dilemmas that can arise in considering what is appropriate care for people with dementia. Ethical dilemmas and issues arise in dementia care regardless of whether technology is being considered. Sometimes thinking about technology raises new ethical issues; often, however, it just draws attention to ethical issues that have always been there but perhaps not always recognised or dealt with as such. For example, the traditional approaches to dementia care have tended to focus on the problems posed by dementia in terms of the risk to the person with dementia and/or disruption for the carers. As a result, they have often emphasised institutional, pharmaceutical and custodial solutions. In the case of technology, however, there is the added danger that complex issues of risk and safety may be seen as being amenable to instant 'technological fixes' that may be given priority at the expense of a thorough appraisal of the person, the context and the reasons for behaviour that cause risk to the person or others.

It is noted that even if a particular technology is judged to be unethical under particular circumstances this does not necessarily mean that its use is unethical in all circumstances; in other situations the ethical balance may be more favourable. In some cases, indeed, it may be unethical *not* to use technology.

The ASTRID guide elaborates an ethical approach based on the '3 Ps' - perspectives, principles and paradigms. 'Perspectives' involve considering what might be the views of all the people concerned in the proposed intervention and the consequences of not taking an action. The four 'principles' are respect for autonomy, beneficence, non-malfeasance and justice. 'Paradigms' are reference situations against which to evaluate the appropriateness of a particular solution in the case in question.

Autonomy refers especially to consent, and it is argued that many people with dementia are in fact capable of giving informed consent even if this is not a straightforward matter in all cases. This applies for any aspect of dementia care, including implementation of solutions based in technology. In order to give consent the person needs to have the information required, be able to make a decision, and be able to understand the implications of the decision. Better skills in communication with people with dementia are pushing back previously assumed limits. Relevant communication skills include being able to interpret the language of dementia, as well as behaviour and other forms of non-verbal communication. Where the person cannot give consent themselves, consent by proxy may be acceptable but this can sometimes be questionable on ethical grounds, especially where there are important conflicts of interest between the person with dementia and family carers.

One suggested paradigm is to imagine that the situation involved a younger person similarly at risk and examine what would be the likely approach under those circumstances, for example, if it was a younger person with a learning disability. This is a good way to help identify possible 'ageist' attitudes, whereby solutions may be uncritically accepted as being appropriate for older people that would not be accepted in the case of a younger person. This might include the right to take risks (within reason), ensuring that technology does not reduce or replace human contact, and so on.

Overall, the ASTRID analysis concludes that although technology is not a panacea for the challenges of caring for people with dementia, nevertheless using appropriate technology and using technology appropriately can quite often help to effectively meet the needs of the person with dementia and/or their family carers in socially, ethically and economically acceptable ways. An increasing understanding of the experience of people with dementia and their carers is encouraging the emergence of new approaches to care and assistive technologies have an important place in this new range of solutions. These developments are supporting a more positive approach to dementia care where the aims are to improve quality of life; to maintain and, if possible, to increase functional abilities; to prevent and reduce behavioural problems; to avoid chemical and physical restraints; to avoid institutionalisation; and to reduce stress for all concerned.

Key learning points

- Normative ethical 'recipes' are not easy to define - each situation is different and dilemmas are common
- The '3Ps' - perspectives, principles, paradigms - provide a useful approach to ethics of ICTs and dementia
- Comparisons with approaches that might be chosen if the person was younger are useful

Further information

ASTRID: A Guide to Using Technology within Dementia Care. London: Hawker Publications Ltd. 2000

The MINAmI Project's Approach to Ethics

- addressing ethics in the design of ambient assisted living -

Summary

The MINAmi case shows that projects that are primarily technology-oriented can also take initiative to actively address and reflect on ethical issues that relate to their particular area of expertise. In this way, interesting new questions may surface and new approaches to dealing with ethical issues in R&D projects and recommendations for discussion even on societal level are possible.

Description

The project MINAmI (Micro-Nano integrated platform for transverse Ambient Intelligence; FP6 Contract: IST-034690) has analyzed ethical issues that are relevant when designing new technological service systems for the domain of assisted living, and formulated ethical principles and more specific design guidelines and checklists.

In order to deal with the ethical concerns regarding the vision and products of the project and the user evaluations, the project adopted a two-level ethical management structure.

- The project's internal Ethical Committee reviews the user evaluation activities carried out within MINAmi with regard to ethical concerns. The Committee prepares and maintains an ethical guidelines document for the user evaluations and ethical problems that may come up during the project work, and the ethical concerns which arise and their solutions are reported annually.
- An Ethical Advisory Board includes external experts from different fields of ethics. The Board identifies and evaluates broader ethical implications related to the project vision, goal, and products, and published the "Ethical guidelines for mobile-centred Ambient Intelligence".

The project partners consider the identification of ethical concerns and the decision-making regarding solving them to be a shared responsibility of designers and other stakeholders in the design process, such as clients and employers. Utilising mobile-centric ambient intelligence raises not just ethical issues in the specific domains of application and service design but also societal issues, for example, with regard to the role of technology in society. While the project partners admit that these questions cannot be answered within the context of a single project they identify some issues for discussion.

Relating to the MINAmi project's *principle of benefit for the society*, according to which society shall make use of the technology so that it increases the quality of life and does not cause harm to anyone, the project recommends the following issues to be discussed in society:

- Should embedding of tags and sensors in the environment be regulated?
- How informed should people be about AmI systems in their environment? How should they get that information?
- How is the new technology launched in the society? Do we need to educate people, support them in taking ownership of the new technology and to make informed choices?
- Are people allowed to refuse using new technologies?
- In general users should be able to find their own ways to utilise technology. To what extent should the designer anticipate possible (mis)usages?
- In a market economy, commercial entities are quite free to choose their target groups. How can e-Inclusion be ensured in other than public services?
- Do increasing possibilities to monitor health parameters increase the quality of life?
- Can all citizens be provided with equal possibilities to anticipate health hazards?

Key learning points

- A technology-oriented project can provide new insights and approaches to addressing ethical issues in the research and development processes
- A two-level ethical management structure in the project can help ensure that both the vision and the products of the project and the work conducted in the project are ethically appropriate

Further information

Ikonen, Veikko, Kaasinen, Eija Niemelä, Marketta and Leikas, Jaana. Ethical Guidelines for Mobile-Centric Ambient Intelligence, Version 1.2, October 31th, 2008. http://www.fp6-minami.org/uploads/media/MINAmI_EthicalGuidelinesforAmI_v12.pdf

Ikonen, Veikko, Kaasinen, Eija (2008). "Ethical Assessment in the Design of Ambient Assisted Living" Dagstuhl Seminar Proceedings 07462, Assisted Living Systems - Models, Architectures and Engineering Approaches. http://drops.dagstuhl.de/opus/volltexte/2008/1462

http://www.fp6-minami.org/index.php?id=1

In-home Monitoring of Persons with Dementia

- ethical guidelines for technology R&D -

Summary

Ethical guidelines often fall short of being sufficiently concrete to provide practical guidance for the research and development setting. This case provides an example of a guideline designed for gerontechnology research and development to support persons with Alzheimer's disease and their caregivers that shows that the translation of abstract principles to hands-on guidance is possible.

Description

The "Ethical principles and guidelines for gerontechnology research & development for persons with Alzheimer's disease and their caregivers" (Mahoney et. al 2007) offers an ethical model with related guidelines for attaining a humanistic and ethical approach to technology research. More specifically, the guidelines address the development of in-home monitoring equipment for persons with Alzheimer's disease. An ethical model for technology development, according to the proposed framework, needs to be more concrete than many research and development guidelines to date have tended to be. Additionally, the authors of the model suggest that "[f]rom the inception of a project designed to yield as much promise as real-time residential monitoring for Alzheimer's disease, an ethical framework is essential to guide the direction of research as well as the hoped-for applications of the technology." (Ibid.)

The proposed ethical model (originally from Purito) is anchored in (a) humanistic concerns, (b) research needs and (c) technology offerings. The model is used to concretize the different levels of ethical concerns that are present in a given technology research and development setting, especially in the case when the intended beneficiaries include older people with dementia. Humanistic concerns, such as those of respect for persons with conditions warranting residential monitoring; autonomy; quality of life; and respect for family caregivers and family relationships form the core priority in the model. They are concerns relating to our common humanity. Research needs and concerns – specified in the principles of proportionality and privacy and confidentiality – guide considerations regarding the role of the investigators in technology research. Finally, technology offerings, or promises and concerns in societal context, deal with the ethical considerations related to the investigator's role within the larger societal context. Justice and distributional fairness, for example, require that investigators craft research protocols with the goal of developing home monitoring devices or systems that will help meet the needs of all people who might benefit from them. Safety issues are addressed through critical observations with regard to how researchers often view the promise of technological innovation as a positive improvement in the environment and quality of life for older adults. Using examples, the authors attempt to point out that new technologies in the homes of older people may bring both positive and negative implications. In this way, the Internet, for example, may bring about virtual mobility to home-bound persons, but the issues of risks to safety (phishing, scams, financial exploitation) are significant and need to be addressed.

The model is completed with a set of guidelines which are based on more abstract ethical principles but translated into practical action guides, almost like checklists. Engineers, for example, are used to working with checklists and it can be assumed that this format of ethical guidance will therefore be very accessible for developers. For example, instead of theorizing about the concept of justice and distributional fairness, the authors translate this principle into the following action guides:

- Provide equity of participation in testing and use of new technologies.
- Conduct small pilot feasibility studies initially rather than large scale RCTs to reduce economic waste from buying expensive technologies that do not work in your setting.
- Disclose all sources of commercial and public research funding.
- Make transparent any commercial or other influences that might bias the findings.
- Aim to develop devices and systems affordable to all who can benefit from them.

Key learning points

- The guidelines address the entire lifecycle of a research project and they can be applied from the inception until the completion of a technology research and development endeavour
- The translation of abstract principles into a kind of checklist has the potential to be acceptable for engineers who are used to working with checklists

Further information

Mahoney, Diane F. & al. (2007). "In-home monitoring of persons with dementia: Ethical guidelines for technology research and development." Alzheimer's & Dementia 3: 217-226.

The American Telemedicine Association's Guidelines

- Core standards for telemedicine operations -

Summary

In an effort to help advance science and to assure the uniform quality of services to patients, the American Telemedicine Association (ATA) has embarked on an effort to establish practice guidelines and technical standards for the field of telemedicine and telehealth. The document "Core Standards for Telemedicine Operations" addresses administrative, clinical and technical standards, whereby ethical issue such as data privacy and informed consent are addressed as far as they concern existing regulative/legal requirements.

Description

The standards provided in the "Core Standards for Telemedicine Operations" cover the fundamental requirements to be followed in providing remote medical services, interactive patient encounters, and other electronic communications between patients and practitioners for the purposes of health care delivery. The standards address a wide target group within the health care sector as they apply to individual practitioners, group practices, health care systems, and other providers of health related services for the purposes of health care delivery. The standards were developed by panels consisting of experts from the field and other strategic stakeholders. They serve as an operational reference and an educational tool to aid in providing appropriate care for patients. Embedded in the standards are a number of requirements originating from the realm of ethics. For example, the document states that organizations providing services via telehealth are required to have policies and procedures in place to govern all administrative functions that responsibly include and address aspects of telehealth with regard to – among others – privacy and confidentiality, ownership of patient records, patient rights and responsibilities, and network security. Furthermore, organizations are reminded of their obligations to:

- ensure compliance with relevant legislation, regulations, and accreditation requirements for supporting patient/client decision-making and consent, including protection of patient health information;
- have mechanisms in place for assuring that patients are aware of their rights and responsibilities with respect to accessing health care via telehealth technologies, including the process for communicating complaints; and
- integrate telehealth into the existing operational procedures for obtaining consent for treatment from patients and provide a mechanism for additional informed consent when required for invasive procedures.

Additionally, the technical standards require the organizations providing telehealth to have policies and procedures in place to comply with local legislated and regulatory rules for protection of patient health information and to ensure the physical security of telehealth equipment and the electronic security of data. Having presented the fundamental requirements for telemedicine operations in the core standards, the ATA will continue developing further guidelines to address specific clinical practices. Other available ATA guidelines include the following:

- Practice Guidelines for Teledermatology (December 2007). These guidelines, generated by special working group of experts in dermatology, technology and telemedicine in cooperation with staff from the National Institutes of Standards and Technology are designed to aid in the development and practice of coherent, effective, safe and sustainable teledermatology practices.
- Telehealth Practice Recommendations for Diabetic Retinopathy (May 2004). These guidelines, prepared by the American Telemedicine Association, Ocular Telehealth Special Interest Group, and the National Institutes of Standards and Technology Working Group include a roadmap of technical standards, clinical guidelines and administrative procedures.
- Clinical Guidelines for Telepathology (May 1999). Prepared by ATA's Special Interest Group on Telepathology. The concepts discussed in this document is applicable to all three types of telepathology; static (store and forward), dynamic (synchronous), and hybrid (static-dynamic) implementations.

Standards of the ATA are developed in special interest groups and reviewed in a formalized process. The composition of each standard-setting work group is comprised of representation from clinical, industry, government and other potentially affected parties with volunteers recruited broadly from the ATA membership as well as from individuals and organizations outside of ATA. The review process of the standards under development consists of a minimum of 9 review steps, including a possibility for the public to comment on draft documents via the organization's homepage.

Key learning points

- Ethical guidance need not necessarily be provided in a document on its own but can also be embedded in more general standards documents with an administrative, clinical or technical focus
- Standards development in a multidisciplinary and multi-interest special interest group and a rigorous review process as has been adopted by the ATA in which both expert and public comments are part of the process are likely to produce widely accepted standards for a practice.

Further information

The American Telemedicine Association (ATA). (2007.) Core Standards for Telemedicine Operations.

http://www.americantelemed.org/i4a/pages/index.cfm?pageID=3311

Safer to Wander?

- good practice checklist for those considering use of wandering technologies for persons with dementia -

Summary

"Safer to wander?" is a document produced by the Mental Welfare Commission of Scotland on ethical principles and guidance on good practice when considering the use of wandering technologies in support of individuals with dementia who are residents in care homes or hospitals. The technologies in focus include "tagging" and tracking devices that can be used to alert when a person leaves a given area and help locate a person who has gotten lost.

Description

Overall the Mental Welfare Commission can be said to have adopted a positive view of the potential of new technologies in caring for people with dementia. According to the Commission, technology can be a valuable tool which has the potential to help people to maintain their independence and enhance their freedom. Where new technology can provide assistance without unduly restricting or increasing the risks that an individual may face, its use is to be welcomed.

Because it has been recognized that wandering is (often) an activity that has meaning for individuals with dementia and it constitutes a positive experience with physical and psychological benefits, there is a need to focus on how individuals can continue to walk freely and safely without unnecessary restraints.

The document points out that restraints are still a common way to deal with wandering. In order to prevent their residents from getting lost, many care establishments lock doors or use barriers such as keypads or handle arrangements that require skills to open. Not only do these arrangements prevent the free movement of those who are at risk of wandering but also of all the other residents.

To help determine those cases in which wandering technologies can be appropriate, the Commission has provided both general principles and a checklist. The overall principles guiding the consideration of using new technologies highlight, for example, among others the recommendations that

- the intervention must provide a benefit that cannot otherwise be achieved;
- the intervention must be the least restrictive in relation to the person's freedom in order to achieve the desired benefit;
- the past and present wishes of the person must be taken into account;
- the views of relevant others should be taken into account; and
- the intervention should encourage the person to use existing skills and develop new ones.

The checklist requires those considering the use of wandering technologies to reflect on the possible use of the technology from various points of view including those of the causes of the individual's behaviour; risks to the individual; alternatives to technology; ethical implications of the system; the views of the individual, relatives, care team etc.; and the legal implications.

Additionally the checklist provides requirements in relation to the individual care plan which needs to be amended with a specific plan if a new technology is adopted.

Key learning points

- Because individuals with dementia are particularly vulnerable, not in a good position to defend their rights and at risk of getting lost (and being hurt) if left without adequate care, it is important that those who make decisions about their well-being are well aware of the ethical dimensions that are at play, for example, in using wandering technologies. Documents such as "Safer to Wander?" can contribute to the necessary awareness raising.
- *"The use of technology, including wandering technology, in care homes and hospitals is not in itself a good or a bad thing. Where technology is used, this should be as a tailored and appropriate response to the identified risks faced by an individual. How technology is applied can make the difference between providing restrictive and inflexible care, or a freedom enhancing setting." (Mental Welfare Commission for Scotland, 2007)*

Further information

The Mental Welfare Commission for Scotland. (2007). Safer to Wander? Principles and guidance on good practice when considering the use of wandering technologies for people with dementia and related disorders.

http://www.mwcscot.org.uk/web/FILES/Publications/Safe_to_Wander.pdf

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The Friendly Rest Room Project's Approach to Ethics

- continuous ethical review as a learning experience for project staff -

Summary

The Friendly Rest Room project was a user-centred research and development project in which prototypes of self-adapting toilets for older users and disabled users were developed. Because toileting and personal hygiene are deemed sensitive areas of research and the intended user group to be involved was likely to include potentially vulnerable persons, the project gave a deep attention to ethical issues with continual ethical review being conducted throughout the project.

Description

The consortium subcontracted two ethical peer reviewers for the entire duration of the project to perform what can be called continuous ethical review. Taking into account that the project staff consisted of designers, engineers and social scientists, who were likely to have variying degrees of exposure to ethical issues in their work, the concept designed for the ethical review was based on a strong action-research component. Everyone in the project was to have a chance to learn something new about the ethical aspects of their work.

The goal was to create an appropriate ethical foundation for the project, enhance trust-building and improve the interaction between researchers and users. The work focused on the user needs and requirement eliciting parts of the work as ethical dimensions in these areas of the project work were most likely to be visible. The ethical reviewers were integrated into the daily work processes relating to planning and implementing user requirements elicitation, in particular in iterative prototype evaluation.

The ethical review work took a form that can be classed as normative, guidance-related and empirical. Normative work consisted of identification of ethical issues in the test and research design – designing a common approach; raising awareness to ethical dimensions of development work; comparison of existing guideline documents and their relevance to the project; providing feedback to the sites and the consortium; and reporting. The guidance work involved close cooperation with the project team to find ways of removing taboo effects of the potentially embarrassing topic of research and test situations. Developing a gradual process for informed consent for the purposes of the project formed another aspect of the guidance work. Finally, empirical work was performed in the forms of participant observation, feedback interviews and focus group with users, to find out how the various ethical aspects from respecting autonomy and dignity to protecting privacy were implemented in practice. The findings were reported back to the consortium.

In practice, the ethical reviewers helped identify ethical issues inherent in the project's design but also as new problems emerged in the course of the work, guided the planning of the process for obtaining informed consent and processes for protecting privacy of users (including producing information materials for the users), observed the user tests, and drafted reports on ethics for the project deliverables. Some *ad hoc* guidance was provided when project workers were encountered with ethical issues they did not feel comfortable solving on their own.

Users were continuously interviewed throughout the test cycles of the project in order to monitor how they perceived their participation. The feedback was overwhelmingly positive, many users mentioned having enjoyed themselves and felt well as participants. At the end of the project, the project staff evaluated the ethical review. The action-research element appeared to have worked well as many staff members reported having learned something new abou the ethical aspects of their own work in the process. The results of the evaluation suggest that the ethical review performed in the FRR project was considered useful and helpful; in particular learning the process for obtaining informed consent and ensuring continuously the validity of consent were seen as a necessity that would become an enduring practice in future work.

Key learning points

- A process-oriented approach to ethical review in a technology project, a kind of ethical coaching, can contribute to professionals' and practitioners' increased awareness of ethical aspects in their own work
- A continuous effort in ethical review has the advantage that ethical issues can be addressed as they emerge in a project.

Further information

www.fortec.tuwien.ac.at/frr

Rauhala, M. & Wagner, I. (2005). "Ethical Review – A Continuous Process in an Assistive Technology Project." In: A. Pruski & H. Knops (Eds.). Assistive Technology: From Virtuality to Reality. Assistive Technology Research Series 16, Amsterdam: IOS Press, pp. 31-35.

North Lanarkshire Council's Best Practice Policy

- guidance for use of assisted living technology –

Summary

The best practice guidance document and its appendices drafted by the North Lanarshire Council set out the principles which underpin the Council's policy and guidance on the use of assisted living technology, describe the range of equipment available and provide advice on its use and an assessors' checklist for use of prior to taking up a new device. From the ethical point of view, particularly valuable is the guidance provided for social workers who face technology and care-related decision-making situations with persons from whom it is difficult or practically impossible to obtain an informed consent.

Description

The assisted living technologies used in supporting the independent living of older people in North Lanarkshire (at the time of the publication of the guidelines in July 2003) include door contact switches, pressure mats on the floor, temperature extreme monitors, infrared beams, and fall detectors. Used as stand-alone equiment or as enhancements to the local alert service, assisted living technologies have the potential to both improve a person's safety and well-being and to be intrusive. The document addresses risks of the new technologies to dignity, privacy and human rights in general and describes ways to address the ethical issues in a hands-on manner. For example, the practical approach is illustrated in the listing of relevant questions for assessors to answer before using assisted living technology. These include:

- Who will benefit from the use of the Assisted Living Technology? E.g. the person, their carer, the service provider.
- Has a full assessment been completed and risks identified?
- Is the technology being considered to fill a skill gap?
- Is safety more important than privacy?
- What is the risk? How likely is it to happen?
- What would technology do to reduce the actual risk?
- What are the limitations of the technology?
- Is technology the best option to reduce the risk to a reasonable level? Is it really needed?

The document draws special attention to the notion of informed consent with regard to potentially intrusive technologies and addresses the fact that some persons may be unable to consent. In such a case, other safeguards need to be in place. In case an individual is unable to consent, the assessor should consider the following:

- Is there a legitimate need to use Assisted Living Technology due to the level of risk?
- Is this the least restrictive intervention possible at this time?
- Are the wishes of the adult being considered in the broader sense e.g. has the person previously expressed a wish to stay at home but cannot do so safely without this equipment.
- Whenever possible the consent of the person should be sought.
- Where possible, the element of control should be with the person.

All decisions made on behalf of the adult with impaired capacity must:

- Benefit the adult
- Take account of the adult's wishes, if these can be ascertained.
- Take account of the views of relevant others, as far as it is reasonable and practicable to do so.
- Restrict the adult's freedom as little as possible while still achieving the desired benefit.
- Encourage the adult to use existing skills or develop new skills.

Key learning points

- Ethical issues can be highligted for practitioners in a hands-on manner, addressing key issues in a variety of ways, using checklists, questions, and examples
- Informed consent is a central element of a good practice in technology provision for older people and requires thorough guidance and attention.

Further information

www.atdementia.org.uk/content_files/files/Accessing_Assisted_Living_Technology_protocol.pdf

The UK Department of Health's Best Practice Guide

- Independence, Choice and Risk – Good practice for dealing with risk in the domain of social care -

Summary

The Department of Health in the UK recently prepared a best practice guide on dealing with 'risk' in health and social care, intended for use by everyone who is involved in supporting adults using health and social care within any setting or sector. Although not focusing only on technology-related issues, the guide is nevertheless useful for those considering using ICT-based technologies to reduce perceived 'risk' to vulnerable clients. The purpose of the document is to guide those involved in helping individuals to retain greater control of their lives and to avoid patronising or paternalistic approaches that focus too narrowly on risk reduction.

Description

People perceive risk differently, including people using health and social care services, practitioners, family carers and others working in support of individuals. As this can be difficult for practitioners and confusing for the individual and their carers, the Department of Health in the UK recently provided a best practice guide for the use of everyone involved in supporting adults using health and social care within any setting, whether community or residential, in the public, independent or voluntary sectors. It is intended to guide those involved in helping individuals - including older adults with dementia - to retain greater control of their lives.

The best practice guidance aims to:

- outline a common set of principles that people and their organisations are encouraged to use as the basis for supporting people in making decisions about their own lives and managing any risk in relation to those choices;
- support the principle of empowerment through managing choice and risk transparently in order to enable a fair appraisal of the decision process, if required;
- provide a common approach to risk as the basis for working practices, and encourage practitioners and organisations to embed this guidance into their policies, their agreements with other agencies, and their own cultures and working practices; and
- highlight how to balance necessary levels of protection and preserve reasonable levels of choice and control, in order to help people achieve their potential without their safety being compromised.

The governing principle behind a good approach to choice and risk is that people have the right to live their lives to the full as long as that does not stop others from doing the same. Fear of supporting people to take reasonable risks in their daily lives can prevent them from doing the things that most people take for granted. The consequence of an action and the likelihood of any harm from it need to be considered. By taking account of the benefits in terms of independence, well-being and choice, it should be possible for a person to have a support plan which enables them to manage identified risks and to live their lives in ways which best suit them. Appropriate risk management and safeguarding measures need to be put into place when the risks from supporting a person to do what they want suggest there is a danger of abuse, either of themselves or others.

A supported decision tool – consisting of 21 questions to help the assessment of the person's decision-making situation - was designed to guide and record the discussion when a person's choices involve an element of risk. It is expected to be particularly helpful to a person with complex needs or if someone wants to undertake activities that appear particularly risky. One application area described in the guide deals with dementia and assistive technology.

Key learning points

- A common approach to dealing with risk is helpful in multidisciplinary problem solving; although multidisciplinary working is very effective in ensuring that a person is supported in a seamless way, dilemmas arise when practitioners from different disciplines cannot agree about the best support arrangement; a commonly agreed-upon process needs to be in place to avoid an unnecessary delay in service provision
- Even if support is in place something may go wrong and someone may need to accept responsibility; careful documentation provided by the supported decision tool is critical in order to protect the person in making their own choices as well as the position of the local authority and other providers of care.

Further information

http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Managementofrisk/DH_079297

Department of Health (May 2007). Independence, Choice and Risk: a Guide to Best Practice in Supported Decision Making. Available at:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074773