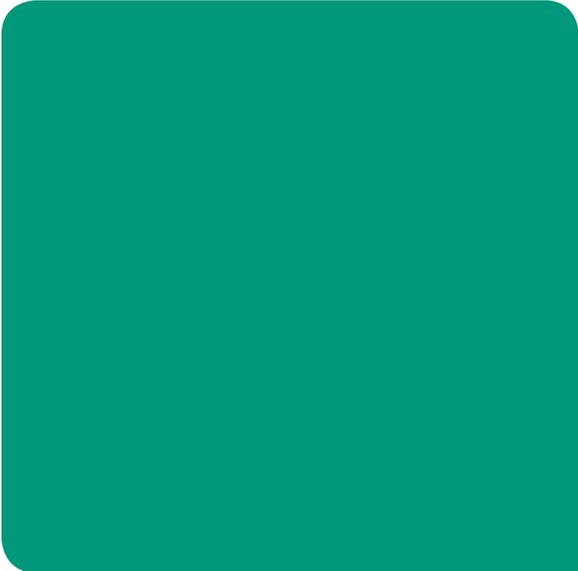


Ethical issues in the use of telecare



Ethical issues in the use of telecare

Jonathan Perry, Stephen Beyer, Jennifer Francis and Pamela Holmes

First published in Great Britain in May 2010
by the Social Care Institute for Excellence

© SCIE 2010
All rights reserved

Written by Jonathan Perry and Stephen Beyer (Welsh Centre for Learning Disabilities), Jennifer Francis
and Pamela Holmes (SCIE)

This report is available online
www.scie.org.uk

Social Care Institute for Excellence
Goldings House
2 Hay's Lane
London SE1 2HB
tel 020 7089 6840
fax 020 7089 6841
textphone 020 7089 6893
www.scie.org.uk

Front cover photograph kindly supplied by Tunstall Healthcare

Acknowledgements	iv
Overview	v
1 Introduction	1
1.1 Defining telecare	1
1.2 Why this report is needed	2
1.3 How this report was developed	3
2 Key concepts and underlying assumptions	4
2.1 Opportunities afforded by telecare	4
2.2 Relating findings to a theoretical model of ethics	4
3 Results	6
4 Policy context	7
5 Pre-installation	9
5.1 Assessment	9
5.1.1 Coordination of assessment	10
5.1.2 Review of needs	11
5.2 Consent	11
5.2.1 Risk, protection and freedom	14
5.3 Risks associated with telecare	16
5.3.1 Perception of telecare	16
5.3.2 Equipment and systems reliability	17
5.3.3 Misuse of equipment	17
5.3.4 Monitoring and response	18
5.4 Sourcing equipment	18
5.4.1 Nature of the UK telecare market	18
5.4.2 Interoperability	20
5.4.3 Impact of personal budgets	20
5.5 Installation	21
6 Post-Installation	23
6.1 Privacy	23
6.2 Social isolation and wellbeing	25
6.3 Fairness in the allocation of resources	27
7 Next steps	30
References	31

Acknowledgements

On behalf of the Social Care Institute for Excellence (SCIE) and the researchers, we would like to express gratitude to members of the project advisory group who have provided enthusiastic and dedicated support and to all who contributed to the fieldwork through the Delphi survey and the focus groups for people who use services.

Special thanks go to our former colleague, David Ellis.

Overview

The ethical issues and means of addressing them in practice, which were identified through work by the WCLD, are presented in two main sections relating to pre- and post-installation of telecare. The main issues raised are summarised below.

Pre-installation

Assessment

- assessment is a prerequisite for needs-based telecare service design
- assessment is critical to achieving the right balance between independence, social wellbeing, privacy and protection
- assessment requires appropriately trained assessors
- telecare must be embedded within the wider care planning process involving joined-up working between organisations
- assessment should be an ongoing process of review.

Consent

- informed consent relates directly to the principle of autonomy
- telecare should not be imposed on people
- gaining informed consent from people with cognitive impairments requires effective presentation of information and judgements of mental capacity
- eccentricity does not imply impaired mental capacity
- the best approach will be individually determined
- judgements of the best interests of people without mental capacity to give informed consent should strive to find the right balance between quality of life outcomes including independence and safety.

Risks associated with telecare

- everyone involved in the commissioning and use of telecare should have realistic expectations of its capability
- problems could arise in any aspect of the telecare service. All possible steps should be taken to avoid problems and careful business continuity planning is needed to cover the possibility of system faults (technical or human)
- quality standards should be set and enforced for all aspects of service provision: installation, equipment, monitoring and response.

Sourcing equipment

- currently, the consumer market for telecare is undeveloped which limits choice and control
- equipment should be sourced to enhance individualisation and best value
- manufacturers and suppliers should be subject to quality standards to improve interoperability of devices
- commissioners should encourage a competitive market in the tendering process.

Installation

- installers need training and education to acquire core competences that will support a person-centred service
- quality standards for the installation process should be established.

Post-installation

Privacy

- as with any direct care service, infringement on privacy needs to be justified
- information generated from telecare services can help service providers determine whether the overall care plan is effective, although this is dependent on data-sharing arrangements
- service providers should be clear about the purpose for which information generated from telecare is being collected
- telecare users and their carers should be informed, prior to installation, about what information will be collected and how it will be used
- the emphasis should be on using information from telecare to drive improvement, and promote people's independence as well as their safety
- data should be securely stored and transferred between agencies using industry good practice standards and agreed joint protocols.

Social isolation and wellbeing

- due to the potentially isolating effect of telecare, it should not be considered as an alternative to direct social care or informal support, unless this is the expressed wish of a person using the service who has full mental capacity
- local commissioning strategies should recognise the potential of telecare for meeting low level needs
- it is important to recognise that a telecare service cannot monitor changes in people's wellbeing with the same sensitivity that other human beings can and this should be reflected in care planning
- telecare should be combined with direct social care and informal support to maximise people's motivation and facilitate carer involvement in supporting social engagement.

Fairness in the allocation of resources

- the case for telecare and telehealth to be funded jointly by the NHS, local authorities and other agencies is made by the wide-ranging outcomes that can be achieved
- manufacturers and telecare providers should work towards greater interoperability of equipment
- if fairness in provision is to be maintained in the context of personal budgets and self-funding, there will be a need to generate high quality information and advice on telecare equipment and installation.

1 Introduction

This report provides a summary of the findings from the work undertaken by the WCLD on behalf of SCIE. It explores the complex ethical issues surrounding the commissioning and provision of telecare and the difficult decisions that professionals may face. Some solutions to these difficulties are also discussed. The aim is to ensure that commissioners and providers of telecare address these issues when developing their procedures and protocols.

The report is therefore aimed at the following audiences:

- social care commissioners
- social care providers
- telecare manufacturers
- telecare providers
- policy makers

People arranging telecare for their own support needs, and the families of those people, may also find this report valuable, as it explores what they might reasonably expect from the professionals providing a telecare service.

1.1 Defining telecare

The main focus of this report is telecare. Telecare has many definitions, but this report uses the term as described in the Department of Health report, *Building telecare in England* (BTiE) (DH, 2005). Telecare is described as:

Equipment [that] is provided to support the individual in their home and tailored to meet their needs. It can be as simple as the basic community alarm service, able to respond in an emergency and provide regular contact by telephone.

One of the defining features of telecare, as it is used in this report, is that it involves remote monitoring. Therefore, as the BTiE document illustrates, telecare can also include detectors or monitors such as for motion or falls and fire and gas that trigger a warning to a response centre. Telecare can also work in a preventative mode, monitoring an individual's health or wellbeing, for instance bed sensors, which can be programmed to record how many times a person leaves their bed during one night.

In its definition of telecare, BTiE also includes technology for monitoring vital signs, such as blood pressure. This is where our report departs from the BTiE document, as *telehealth is not included in our scope*. Instead, telehealth is the intended focus of SCIE's next stage of work on ethics.

There is a further caveat that distinguishes the scope of SCIE's report from the BTiE definition. Although the main focus of our work has been on telecare, our report additionally covers other technology solutions that might be commissioned to support people who use services alongside a telecare package. These additional modalities might include finger print recognition door entry systems as part of an

overall package for home safety and security or reminder systems and prompts to take medication as part of a package to provide dementia support.

SCIE recognises that there is a complicated terminology debate in this field, which is why we have defined quite a specific scope for this report. Nevertheless the ethical issues explored here should not be restricted to the support services our report refers to. With reasonable care, the ethical principles defined here should be applied across the emerging market of technological care solutions.

In summary, the scope of SCIE's report includes:

- a) Telecare, as described by the BTiE document: although excluding telehealth and telemedicine. Examples of telecare include base unit plus pendant, base unit plus fire, flood or carbon monoxide detector and base unit plus epilepsy sensor, or any combination of these. The Department of Health's Whole Systems Demonstrator overview document (DH, 2009a) provides a helpful illustration of available telecare packages.
- b) Other technology solutions, which do not have remote monitoring in themselves but are commonly used alongside a telecare package. Examples include: calendar clocks, personal voice prompts, noise level detectors and finger print recognition door opening systems.

1.2 Why this report is needed

Telecare has great potential to benefit people who use services, improving their confidence and helping them to remain independent in their own homes. By monitoring people's safety, it can also free up the time of friends and family carers who can then spend more time providing social support. It has also been said to reduce the costs of social care provision, allowing the more efficient deployment of direct care staff.

The technology involved in telecare services has been in use for many years for supporting older people, most commonly in the form of pendant alarms. However, more recently there has been increasing interest in both extending and mainstreaming telecare services, following considerable government investment in different parts of the UK (DH and ODPM, 2006). This has meant increasing the range of people who use telecare as well as the sophistication of available equipment. Although these developments bring clear benefits, they also raise new ethical concerns around providing telecare services to vulnerable people, particularly people with cognitive impairments. There are also increasing threats to individual choice and privacy through more extensive use of monitoring. It is essential that professional practice develops in parallel with the expansion of telecare, to ensure the benefits are realised and the risks are managed. SCIE therefore commissioned a study to identify the ethical issues relating to the commissioning and provision of telecare services and most importantly, to highlight the means of addressing those issues in practice.

The study, which was carried out by researchers at the WCLD at Cardiff University, focused mainly on the use of telecare to support adults with a cognitive impairment,

including dementia. The rationale for this is that although any ethical guidance should have universal relevance, it is these groups which are likely to be the most vulnerable to many of the ethical issues identified in the literature.

The overarching aim of this report is to explore the complex ethical issues surrounding the commissioning and provision of telecare services and to focus on ways in which professionals should address those dilemmas in their routine practice and in the development of local protocols.

1.3 How this report was developed

The issues described in this report and suggested practice approaches for addressing them are mainly derived from the Delphi study carried out by the WCLD. The Delphi method is based on a structured process for collecting data and distilling knowledge from a group of experts (Adler and Ziglio, 1996), and in this case it was used to find out the views of a range of telecare experts on the ethical issues associated with expanding and mainstreaming telecare.

Initially a draft questionnaire was developed using the findings from a literature search and a study of the use of assistive technology by people with learning disabilities (Beyer et al, 2008). The questionnaires were also informed by input from the project advisory group and by two focus groups, one comprising people with early stage dementia, and the other, people with learning disabilities.

The questionnaire was emailed to 115 people and 23 responded. The respondents included local authority telecare leads, health representatives, occupational therapists, service providers and commissioners, third sector representatives and academics. A table of the key themes categorised into 'ethical issues' and 'potential solutions' was sent back to the respondents for comment. The results were discussed with the steering group and the two focus groups. This SCIE report summarises the messages from this whole process with specific focus on the Delphi study findings. It is based on a report of the work by the WCLD.

The next section describes the key concepts and underlying assumptions that form the basis for this report and it is followed by the main body which presents the results of the WCLD's work under 'policy context', 'pre-installation' and 'post-installation'.

2 Key concepts and underlying assumptions

2.1 Opportunities afforded by telecare

Although this report focuses on threats to the ethical provision of telecare, it is important to emphasise the considerable opportunities that telecare offers. By monitoring safety, risk and lifestyle and reminding people to eat or self-medicate, telecare could potentially free family carers and professionals' time to spend it in a 'reabling' role or simply providing social support. Telecare can help promote people's confidence and independence and give them greater control within their daily lives. As well as responding to an immediate need (for example, to a call for help following a fall), telecare can work in a preventative mode. Through 'lifestyle monitoring' it can provide early warning of deterioration in wellbeing, so there is great potential for telecare services to contribute to a preventative agenda that aims to reduce the need for acute or residential care.

A recent evaluation of telecare underlined the impact telecare can have on people's lives (Beale et al, 2009). In a large survey, the report concluded that about three-fifths of the respondents felt that their current quality of life was either 'a bit better than it used to be', or 'much better than it used to be' compared with the situation before their telecare service was installed. Another third felt that it was 'about the same.' Less than 5 per cent said that their quality of life was 'worse than it used to be.'

It is therefore in the context of an understanding of the positive contribution telecare can make to the overall support of an individual that the rest of this report discusses the complex ethical issues telecare raises and the ways they should be addressed.

2.2 Relating findings to a theoretical model of ethics

The WCLD researchers adopted an ethical framework to help illustrate the potential problems associated with the use of telecare. The framework comprised of four main principles and throughout this report, references are made to the ways in which the commissioning and provision of telecare can compromise those principles. The framework, originally developed by Beauchamp and Childress (1994), has been widely used in health and social care and it is specifically relevant that it has been used by a number of authors to discuss the ethical issues associated with the use of telecare to support people with dementia (Marshall, 2000; Bjerneby et al, 2004).

The four principles are: autonomy, beneficence, non-maleficence and justice; each of them is described briefly below.

Autonomy: Autonomy refers to the ability of an individual to make choices. It is related to independence and choice in day-to-day activities and which, as citizens, we often take for granted. Where people are reliant on professionals or family carers for the provision of constant support or safety monitoring, the introduction of a telecare service can drastically improve their autonomy. For example, a telecare service could reduce the reliance on other people by providing the assurance of an immediate response in the case of a fall or a fit, and it can also allow an individual to manage

their environment more independently. It is an important principle that telecare, like other interventions or support services, sets out to help maintain or extend people's autonomy of action.

Beneficence: Beneficence is the principle of working for the benefit of the individual. Telecare has the potential to benefit people in a number of ways. It can provide assurance and confidence to individuals about their own safety through the use of emergency alerts and sensors; it can reduce unwanted dependence on professional staff or family carers; and it can increase comfort through environmental sensors and controls. Therefore when assessing the appropriateness of introducing telecare, from an ethical perspective it is important to maximise the potential benefits that the individual might gain.

Non-maleficence: Non-maleficence is the principle of doing no harm. While telecare can clearly be beneficial for a person it also has the potential to expose people to risk. This is a particular dilemma where telecare is introduced to enhance someone's independence. In this case, a care plan might identify the need for sensors that will alert a monitoring centre, or staff within a residential or extra care setting, for example if a person has spent an undue length of time in a chair without moving or has got up in the night and not returned to their bed. In this context a balance has to be achieved between ensuring someone's safety and invading their privacy.

A further way in which a person's dignity could be affected is inherent in the use of a telecare service where the individual is required to wear a pendant or use an environmental control system. In future, relevant technologies may be refined but certainly in the current context, the potentially stigmatising effect of telecare should be recognised and minimised.

Justice: Justice relates to a moral obligation to act on a fair adjudication between conflicting claims, so in this context, 'justice' refers to fairness in access to support services. The principle demands that, in the interests of justice, resources for telecare services should be allocated in a way that balances the needs of the individual with those of the wider community, and seeks not to disadvantage one population group at the expense of another.

3 Results

This part of the report presents the results from the WCLD's work, namely the Delphi process. The process identified ethical issues and means of addressing them that are overlapping and interrelated; to improve clarity and practice relevance they are reported here in two overarching sections. In one section, issues that apply to the *pre-installation* phase are discussed. The principal ethical concern here is that services should be tailored to the individual and that in considering appropriate telecare, the risks of the person coming to harm should be balanced with their right to autonomy.

The next section explores issues relating to *post-installation*. The principal ethical concern here is that information collected from telecare should be collected for a positive purpose and with consent, and that the risks of invading people's privacy should be balanced against telecare helping people be independent; that telecare should not socially isolate people; and that the allocation of funding for telecare be fair and just.

An introductory section first provides an overview of the policy context for telecare ethics.

To summarise, this results section is organised as follows:

Policy context

Pre-installation

- Assessment
- Consent
- Risks associated with telecare
- Sourcing equipment
- Installation

Post-installation

- Privacy
- Social isolation and wellbeing
- Fairness in the allocation of resources

4 Policy context

- *Putting People First* stated that telecare should be viewed as integral, not marginal
- the personalisation agenda suggests that telecare services should be designed around individual need and that an ethical balance between cost and individualisation is desirable
- *Fair Access to Care Services (FACS)* places an emphasis on high priority need at the expense of longer-term prevention including telecare services
- effective joint working is needed between all those involved in telecare delivery
- training strategies for staff underpinning these social care reforms should include telecare.

The personalisation agenda (DH, 2008) may not be compatible with an increasingly financially constrained practice context. From an ethical perspective, opportunities for beneficence might be missed and there is the possibility that harm might be caused if cost considerations take precedence over individualisation in the design and provision of telecare services. The vision for an integrated and responsive care system, set out in *Shaping the future of care together* (HM Government, 2009), has been reiterated in the recent White Paper *Building the national care service* (HM Government, 2010). It makes the case for effective partnerships between local authorities, the housing sector, the voluntary sector and health bodies to deliver effective needs assessments and maximise the 'early intervention' or 'invest to save' potential of telecare.

Putting People First (HM Government, 2007) set out a vision for the future of adult social care, which was shared by central and local government, health and social care and the third sector. Central to this vision is the notion of mainstream telecare services designed around individual need. However, the 'personalisation agenda' under which person-centred planning and self directed support become mainstream, may conflict with the way health and social care services are currently commissioned within budgets that are increasingly competing with other service priorities. This is exacerbated by the increased demands on services associated with an ageing population. Cost efficiency in meeting the increasing demands for care is a high priority for government (HM Treasury, 2004), and there are some expectations that use of telecare and telehealth will contribute to reducing costs (DH, 2009b).

Until now much of the delivery of telecare has been through housing providers and self-purchase. A drive to promote the use of telecare by councils with adult social services responsibilities (CASSRs) will increase local authorities' share of commissioning telecare and put greater demands on current care assessment processes. Social care assessment is underpinned by FACS criteria (DH, 2003, 2010). FACS has been criticised for bias toward high priority need at the expense of prevention, and this emphasis can be seen as compromising the potential of telecare in a preventative mode. The benefits of early intervention at lower levels of need have been recognised in pilot studies such as the Partnerships for Older People Pilots (DH, 2010) and in a recent review of eligibility criteria and its effects (CSCI, 2008). The revised FACS criteria may make it easier to provide individualised telecare earlier through local authorities based on notions of prevention and provide an impetus for more universal access to a continuum of appropriate support funded through a range

of options, including self-funding and investment in voluntary organisations. *Shaping the future of care together* (HM Government, 2009) sets out the government's case for a national system of assessment that is transferable, leading to a more consistent level of state funding of packages. Different options are discussed but the goal is a more transparent notion of how much people will have to pay for support. How these plans play out will have significant implications for telecare and at what stage it is available to people with emerging needs.

There are also potential threats to the four ethical principles that stem from a lack of integrated working across those involved in telecare delivery, such as CASSRs, housing and the NHS. If relevant services are unable to reach agreement over sharing assessments and expertise, pooling resources and planning telecare and telehealth interventions together, then potential users of telecare could experience less effective assessment, a poorer match to equipment, less availability of telecare, and end up in more restrictive environments.

Shaping the future of care together and *Building the national care service* set out government's vision for a more integrated and responsive care system. They put significant emphasis on greater joint working between social services, the NHS and housing providers, promote shared assessments through mechanisms such as the common assessment framework and highlight telecare as a key part of the social care system.

While government policy stresses the need for an individualised approach, there will remain significant autonomy at local authority and primary care trust (PCT) level to implement the new policies. It is here that an ethical balance between cost and individualisation should be delivered. Existing mechanisms such as local strategic partnerships, joint strategic needs assessments (DH, 2007) and local housing strategies should become the vehicles for sharing responsibility for health, social care and wellbeing of local people, and should provide for planning joint approaches to telecare provision.

Training strategies for staff underpinning these social care reforms should include telecare (DH, 2009c), thus setting a challenge for the new national Skills Academy for Social Care. The Foundation for Assistive Technology has put forward proposals for workforce development in the wider area of assistive technology as well as telecare, identifying wide-ranging implications for all those involved in the assessment and delivery chain, and a preference for a national strategic approach (Down and Stead, 2007).

5 Pre-installation

5.1 Assessment

Ethical issues around the assessment process are discussed here on a broad level and then more specifically under 'coordination' and 'review'.

- assessment is a prerequisite for needs-based telecare service design
- assessment is critical to achieving the right balance between independence, social wellbeing, privacy and protection
- assessment requires appropriately trained assessors
- telecare must be embedded within the wider care planning process involving joined-up working between organisations
- assessment should be an ongoing process of review.

Following needs assessment, an assessment for telecare should aim to plan the most appropriate telecare service to balance promotion of independence and social wellbeing on the one hand, and protection and privacy on the other. This can be attained largely by establishing a balance between the needs of individuals and those of carers.

Effective telecare assessment depends on the availability of sufficient numbers of appropriately trained assessors, good coordination between relevant organisations and efficient systems for reviewing needs and agreeing transmission of relevant information into the wider care planning system. There is evidence that in the wider assistive technology workforce, including those working in telecare, few practitioners are competent in assessing the need for and recommending the most effective telecare service (Down and Stead, 2005). The Department of Health guidance for commissioners on personalised care planning for people with long-term conditions (DH, 2009d) is of great relevance to the issue of telecare assessment.

The professionals who carry out such specialist telecare assessments should:

- be appropriately trained and supported, in particular in working with the findings from needs assessments
- be well informed about telecare, the range of options for services and the ability of different kinds of service to meet the needs of different kinds of people who use services
- be able to explain the costs, benefits, risks and any contractual and ethical issues to people who use services and carers
- be confident about using telecare as an integrated intervention within a broader care package
- be able to work in effective partnership with other relevant organisations to ensure an holistic approach to supporting people
- be able to access data from all relevant organisations to inform telecare planning and regular reviews, subject to data-sharing agreements
- keep abreast of new developments in telecare
- understand the preventative potential of telecare services

There is a concern that people using personal budgets may not have access to input from specialist, professional assessors. Personal budget holders are likely to go through a process of self-assessment to identify their care needs without any professional involvement. It is important that they have sufficient information and support so that they are not at a disadvantage in choosing the most appropriate telecare service to meet their needs.

On a broader level, commissioning authorities in England should look at the needs of the whole population via the joint strategic needs assessment.

5.1.1 Coordination of assessment

As well as the involvement of social services in telecare provision, many telecare services are provided via housing or *Supporting people* (Audit Commission, 2005) or through self-funding arrangements. As such, many telecare users will not have had a social care assessment. However, social care services are likely to play an increasingly prominent role as telecare becomes a mainstream service option. Social care assessments determine a person's needs, which is different from the process of identifying services to meet those needs. For example, if a social care assessment identifies that a person is no longer safe to walk more than a few yards from their home and therefore needs to be monitored when they leave the house, a telecare assessment might be conducted to establish the kind of telecare service which would best meet this need. Ideally, individuals should be able to trial equipment without prohibitive cost so that they can evaluate benefits before committing finance. Objective information on people's needs will help with the choice of appropriate equipment.

Full attention should be paid to the views of the person whose needs are being assessed. The individual's views should take precedence even when they are at odds with those of other interested parties, such as family carers and value judgements about a person's lifestyle or behaviours should not be made. That said, the needs of these other parties are legitimate and deserve separate consideration, including through the conduct of carer assessments (DH, 1995). In situations where a person has difficulty articulating their views, or where people lack insight, judgements about their best interests will have to be made. Keeping an eye on costs is also important: there is no point in installing a complex and costly telecare solution if a simpler, effective alternative solution reduces risk or prevents emergencies while maximising independence. Balancing protection and independence is discussed in detail under 'Consent.'

There will be many cases where individuals need healthcare assessments in addition to social care assessments. There is a need for coordination between assessors in these situations so that telecare provision is based on an holistic approach to meeting all the person's needs. This is beginning to be addressed by initiatives like the unified assessment process in Wales (Welsh Assembly Government, 2002) and the single assessment process in England (DH, 2002). When more than one agency is involved in a person's care, initiatives which might facilitate coordinated assessments include: effective use of existing frameworks for joint working (for example local strategic partnerships, local area agreements and the joint strategic needs assessment); joint

commissioning; pooled budgets; joint training programmes around telecare; and shared databases leading to improved communication between relevant agencies.

5.1.2 Review of needs

People's needs fluctuate. This is especially true of those with cognitive impairments such as dementia. Technology which once offered helpful solutions may no longer meet an individual's needs or additional/new needs may have emerged. Telecare has the potential to expose people to risk if it is not reviewed regularly. Despite policy commitment to the importance of regular care plan reviews, the realities of working in social care are such that these are often pushed to the back of the queue by care managers or signed off and handed over to service providers, such as housing providers. Re-assessments might only happen in response to crises or major changes in circumstances and might be carried out by unqualified staff, such as care coordinators. Reviews might even be carried out over the telephone. An additional barrier to regular review can be the costs associated with installation and decommissioning of telecare services, or maintenance costs. Clearly, increased use of automated data, lifestyle monitoring and monitoring centre data on triggered alarms could feed back into the care planning and review processes, subject to data-sharing agreements and the individual's consent. There are particular issues if people have impaired mental capacity, and these are discussed in detail below.

5.2 Consent

- informed consent relates directly to the principle of autonomy
- telecare should not be imposed on people
- gaining informed consent from people with cognitive impairments requires effective presentation of information and judgements of mental capacity
- eccentricity does not imply impaired mental capacity
- the best approach will be individually determined
- judgements of the best interests of people without mental capacity to give informed consent should strive to find the right balance between quality of life outcomes including independence and safety.

Telecare can have a significant impact on an individual's life. As such, it should be the individual who decides whether to use it. One of the most challenging ethical issues in the case of people with cognitive disabilities is that of gaining informed consent. To maximise the chances of gaining informed consent from a person with cognitive disabilities attention has to be paid to the way information is presented. When a person cannot give consent, there is a need for careful consideration of the most appropriate way to make a judgement on their behalf. An ethical approach to making such judgements will strive to achieve a balance between a person's rights to autonomy, independence and the wider duty to safeguard and protect vulnerable people.

The best approach to gaining consent will vary from individual to individual. For example, conveying information to a person with early stage dementia is very different from the approach needed for someone with a moderate learning disability. The person gaining consent must use the most appropriate method for the individual

concerned. If someone makes what might be seen as an unwise decision, it should not be assumed he or she lacks capacity. One of the underlying principles of the Mental Capacity Act 2005 is that 'a person is not to be treated as unable to make a decision merely because he makes an unwise decision'.

Consent relates directly to the moral principle of respect for autonomy which, according to Beauchamp and Childress (1994), has two aspects: (i) non-subjection of autonomous actions to controlling constraints by others; and (ii) respectful treatment in disclosing information, probing for and ensuring understanding and voluntariness, and fostering autonomous decision-making. Consent is a key issue for telecare services for people with a cognitive impairment. If services are poorly implemented they could compromise privacy, cause physical risk and/or increase social isolation. Consequently, telecare should not be imposed on people because of the concerns of others without fully exploring the individual's wishes. Informed consent is an essential early step in the telecare installation process and every effort should be made to gain consent from people with a cognitive impairment.

The Mental Capacity Act in England and Wales and the Adults with Incapacity (Scotland) Act 2000 are the legislative frameworks for handling mental capacity to give consent. The Mental Capacity Act puts forward the following principles relating to decisions about capacity: (i) a person must be assumed to have capacity unless it is established that he [sic] lacks capacity; (ii) a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success; (iii) a person is not to be treated as unable to make a decision merely because he makes an unwise decision; (iv) an act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests; and (v) before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action. Separate tests of capacity are required for different important decisions (for example, a person may have capacity to decide where they want to live, but not to make day-to-day financial decisions relating to their tenancy).

People with a cognitive impairment can have difficulty with many aspects of this informed consent. Information needs to be conveyed in creative ways to maximise comprehension and retention, to help the person weigh up their options and to enable them to convey their decision. When an individual proves not to have the mental capacity to give informed consent, it will be necessary for others to assent on their behalf (that is, to reach agreement through deliberation on what is in the person's best interests). Although it occurs in only a minority of cases, the main ethical issue with assent is that the views of those giving assent take into account what the person may have wished if they had their full faculties, or be biased toward vested interests.

The Mental Capacity Act Code of Practice (DCA, 2007) offers excellent guidance to those working with or caring for adults who may lack capacity to make particular decisions.

Some specifically relevant issues from the Code are summarised in sections (a) to (d) below.

a) Presenting information

Telecare is likely to be unfamiliar to the potential recipient. Explanations of telecare to people with a cognitive impairment should be given face-to-face, be clear and simple. Pictures and photographs might help, although there is only anecdotal evidence that such approaches improve comprehension. DVD presentations showing telecare in use with other people might be a helpful approach as well as trying out the technology in the person's own home or, where practical, in a demonstration facility.

It may be necessary to try a variety of methods of presenting information to ascertain which works best for a person and it may depend on the type of cognitive impairment they have.

Ideally, the content of any means of explanation should be personalised so that it has direct relevance to the person concerned. The ethical implications of the potential telecare system (for example, privacy or risk implications) should always be conveyed clearly. Information should be presented at a pace appropriate for the person concerned. This might require more than one session or materials being left with the person and family. Indeed, seeking consent should not be a one-off activity. It should be regularly reviewed and people should be able to opt out at any point. It will clearly help if the person presenting the information is familiar to, and trusted by, the person receiving it. However, those concerned should not have a vested interest in the telecare being delivered. An independent advocate might satisfy both of these criteria.

There are time and resource implications associated with presenting information in these ways. There may be situations such as hospital discharges where there is insufficient time for personalised information, repeated visits, home trials or presence of independent advocates, although liaising with carers is imperative. Sometimes the pace of installations planned by commissioners, associated with pressure to achieve performance targets, will also militate against the thorough approach to gaining consent advocated here. An ethical approach to telecare provision must balance the potential beneficent outcomes gained by rapid roll-out against the disadvantage of introducing telecare before it is fully understood and accepted by the individual.

b) Ascertaining capacity

The functional test of whether a person can give informed consent is that: (i) they can understand the information given to them; (ii) they can retain the information long enough to be able to make the decision; (iii) they can weigh up the information available to make the decision; and (iv) they can convey their decision, even if it is in a most basic way. Structured 'tests' should be used to establish whether a person has retained the information and understood the potential ramifications of telecare for them. The person conducting these tests should be appropriately trained and competent at communicating with people with a cognitive impairment. In essence,

the person should be asked to explain how they think telecare would work in their situation, and what the consequences of having or not having it might be for them. If they appear not to have understood, alternative ways to facilitate their understanding should be sought before the person is deemed to lack capacity. Organisations such as the Alzheimer's Society, Mencap, Headway and The Stroke Association can play an important role here in helping people and their relatives to understand consent in the context of telecare.

c) Assent

The Mental Capacity Act allows for decisions to be made and actions taken on behalf of individuals who lack capacity if it is deemed to be in their best interests. Ideally, this judgement should be based on information from people like relatives and friends (as personal consultees). If this is not possible, then other people (for example, care staff or an individual's GP) can be consulted (as nominated consultees).

North Lanarkshire Council has produced some good practice guidance on the use of assisted living technology that includes some practical suggestions for situations when people are unable to provide informed consent (North Lanarkshire Council, year unknown).

d) Advance directives

Advance directives are also known as advance wishes, advanced decisions or living wills. They are instructions given by individuals specifying what actions should be taken in the event that they are no longer able to make decisions due to illness or incapacity. Advance directives tend to relate to healthcare. For example, they might include instructions for treatment in particular situations or authorise a specific independent advocate to make decisions on a person's behalf when they are incapacitated. Under the Mental Capacity Act, only advance decisions in respect of *refusal of treatment* are legally binding. Requests for treatment (or any other type of care, including telecare) must be taken into account when assessing best interests for someone who lacks the capacity to make a decision him or herself but are not legally binding. A long-term strategy for telecare might include the idea of gaining consent 'in principle'. This could involve presenting people with potential scenarios when telecare might be appropriate, informing them of the possible advantages and disadvantages from an ethical perspective, and giving them an opportunity to indicate their advance wishes. Guidance on advance care planning for adults affected by a life-limiting condition is a useful resource on the issue of advance wishes (NHS End of Life Care Programme, 2007).

5.2.1 Risk, protection and freedom

The issues of risk, protection and freedom clearly relate to the principles of autonomy and non-maleficence, described as part of the ethical framework at the start of this report. Many features of telecare are designed to reduce risk and to remove the need for a constant staff presence in people's homes. Telecare can enhance independence. However, family and care professionals may overestimate the risk to which a person might be vulnerable, resulting in overprotection. In such cases telecare can restrict an

individual's freedom, inhibit their independence and potentially do harm. An ethical approach to telecare provision must strive to achieve a balance between a person's rights to autonomy, independence and the wider duty to safeguard and protect vulnerable people.

There will be circumstances where restricting a person's liberty would be acceptable if it served a greater purpose, such as keeping the person in the community rather than in hospital or residential care. Where restrictions are involved, this must be based on a good assessment of the person's needs, a care plan, and comply with Mental Capacity Act *Deprivation of liberty safeguards* guidance (Ministry of Justice, 2008).

Consider the following scenario: external doors of a person's house are fitted with exit sensors that alert carers if the person attempts to leave the house. Although the purpose is to protect the person from potential danger if they leave the house unsupported, it can represent a restriction of liberty if the telecare is designed to keep the person at home. A solution should be sought which both protects the person and maximises their freedom to come and go as they please. Although still in the early stages of development and implementation, 'geo-fence' or 'safe zone' technology is a more flexible way of allowing people freedom of movement within safe limits. These limits should be reviewed regularly so that the person always has the maximum freedom possible.

As with 'consent', the Mental Capacity Act *Code of Practice* is a resource that provides guidance on balancing protection and autonomy. Striking the right balance will be achieved via the conduct of effective risk assessments within the wider assessment process. Those conducting assessments should understand the values relevant to people with a cognitive impairment (for example, the importance of autonomy, independence and living a normal life despite cognitive limitations). They should consider the person's chosen way of life, their goals, aspirations, wishes, personal preferences and capacity to make informed decisions. The impact of a person's behaviour on others should also be taken into account although it is important that the needs of the person being assessed should take precedence. The evidence on which the risk assessment is based should be objective rather than anecdotal or assumed. For example, data on the frequency, severity and consequences of incidents should be considered. Multiple sources of data are preferable to a single source as there is less risk of bias. One avenue of data provision could be from existing telecare that can provide a range of data (for example, frequency of triggered alarms). Efforts should be made to interpret this objective data within a data-sharing agreement and robust service level agreement.

Telecare can enhance people's independence and freedom by reducing the need for the physical presence of carers. For example, a person with a mild intellectual disability and epilepsy might have a care worker in the house overnight in case they have a seizure. The installation of an epilepsy sensor coupled with an appropriate alert and response system could allow the person to live more independently. Telecare in particular can also enable people with dementia to maintain independence by compensating for disabilities caused by dementia. Examples include the 'smart' oven, combining a degree of automated reading of packet

cooking instructions with appropriate verbal prompts and the use of environmental management technology such as automatic lighting, window closers and temperature control. Telecare can help people with learning disabilities develop their skills. For example, a hi-fi system can be fitted with a device that provides a personalised verbal prompt to reduce the volume if the volume is at a level that might disturb co-residents. Another example is a finger print recognition door opening system that could allow a person who lacked the dexterity to use a door key to enter their home without support from others.

However, there is the potential for telecare to reduce independence by deskilling or disempowering people. For example, gas sensors can be linked to automatic shut-off valves. This can provide a fail-safe system and as such it has great appeal. Nevertheless, such a system might be inappropriate for a person with a poor sense of smell but who is quite capable of taking an appropriate course of action if a gas sensor triggers an auditory alarm. In this case a stand-alone alarm would provide an appropriate degree of protection while allowing independence.

The purpose of technology should not necessarily be to eliminate risk. Rather, in the case of people with impaired mental capacity, the technology should be used to manage and reduce identified risks that otherwise would pose barriers to independence and empowerment. Furthermore, telecare should not generally be used to manage risks that were not previously deemed to be in need of management.

5.3 Risks associated with telecare

- everyone involved in the commissioning and use of telecare should have realistic expectations of its capability
- problems could arise in any aspect of the telecare service. All possible steps should be taken to avoid problems and careful business continuity planning is needed to cover the possibility of system faults (technical or human)
- quality standards should be set and enforced for all aspects of service provision: installation, equipment, monitoring and response.

In addition to the risks faced by vulnerable adults in their everyday lives and the ethical issues associated with protection, there are a number of other risks associated with telecare which can be categorised into four areas: perception of telecare; equipment and systems reliability; misuse of equipment; and monitoring and response. These issues are relevant to both beneficence and non-maleficence.

5.3.1 Perception of telecare

The main concern here is that carers may think telecare exists to replace their role. In fact telecare should be seen as one element of a comprehensive care plan. Similarly, over-reliance on telecare should be avoided and its limitations recognised. For example, 'safe walking' technology can locate someone but it cannot assess their ability to walk safely, cross roads safely and handle other hazards. Telecare should give people the level of freedom or privacy they want while affording them an appropriate degree of protection.

5.3.2 Equipment and systems reliability

Although rare, equipment failure does happen, so to maintain confidence, plans for technology malfunction or system breakdown must be in place and commissioning and procurement procedures should consider reliability. The NHS Purchasing and Supply Agency (PASA) has been replaced with a national procurement partner for UK public services, Buying Solutions (Buying Solutions, 2009). It aims to maximise the value for money obtained by government departments and other public bodies through the procurement and supply of goods and services and it negotiates discounts for the public sector with a number of industry organisations.

Individuals using personal budgets or self-funding to purchase telecare cannot use the services of Buying Solutions, so the provision of good quality, independent advice on products, support and costs will be needed.

Many problems can be avoided by ensuring that good maintenance schedules are in place, including battery changing/charging, sensor testing and replacement, and that there are safeguards to ensure telephone lines maintain efficient function. Where appropriate, portable appliance testing should be undertaken. Clarity is required about lines of responsibility for maintenance, especially in the current context, since personal budgets might complicate the matter.

False alarms are not uncommon with certain types of telecare, so written protocols should detail the action required in the event that they occur. Consideration must also be given to decisions concerning the withdrawal of a telecare service. Protocols agreed by all parties should be incorporated into care plans and service contracts, and should specify what the telecare can and cannot deliver. For example, it should be established that the monitoring centre is able to recognise equipment failure and appropriate arrangements made if they cannot. Contingency plans should include business continuity and resilience arrangements so that monitoring and response services are able to deliver. This would include arrangements for the timely response to messages and alerts and for the event of a monitoring centre going out of business. Such arrangements are not currently compulsory despite a voluntary trade association code of practice, and so commissioners should build such safeguards into contracts.

5.3.3 Misuse of equipment

There should also be contingency plans for the improper use of telecare. By improper use we mean devices being unplugged or pendants not being worn or being worn in places where they do not function. Creative solutions are required, for example, hard wiring of 'always-on' devices and careful location of telecare elements to avoid inadvertent 'switching off' of equipment. This might extend to concealment of devices if the person consents or if they lack capacity and it is in their best interests. Greater use of proactive monitoring could also be advantageous, such as interfaces that allow direct speech between users and monitoring centres. Another issue to be considered is whether people who use services can actively intervene in the system. For example, some users will be able to recognise equipment failure and

take appropriate action themselves. When people lack capacity, systems that do not require active intervention are most likely to prevent harm.

5.3.4 Monitoring and response

The introduction of telecare creates significant reliance on monitoring centres and the responses from monitoring centre staff. This reliance creates its own risks for the user if the system does not perform as expected. A minimum prerequisite is that the equipment can be relied on to send messages and alerts appropriately. The monitoring centre needs sufficient capacity to deal with incoming alerts and operators need to be well trained with sufficient knowledge to fulfil their remit. Subject to data-sharing agreements, they should also have access to up-to-date records about the people who use telecare. Protocols that deal with communications between monitoring centre staff and others need to be clear, effective, linked to the care plan and encompass the needs of the individual.

Monitoring centres should adhere to publicly available service delivery codes of practice, such as the Telecare Services Association Code of Practice and obtain accreditation. Telecare commissioners should also be aware of guidance such as the Telecare Services Association standards and work with organisations that are accredited and adhere to good practice standards. Practitioners and commissioners should pay visits to monitoring centres to see at first hand how they operate.

There are also risks associated with who responds to alerts if roles and responsibilities are unclear. Many telecare services link to local staff, key holders or family members for their response in the first instance. These people need to be available when called and to have a clear idea of their role in relation to each person linked to the telecare system. These should be included in the agreed protocols.

Where informal or unpaid carers are involved in responding to alerts, there are ethical issues to do with the risk of a transfer of responsibility from paid to unpaid care. One option is rigorous vetting procedures in line with Criminal Records Bureau (CRB) and Vetting and Barring Scheme (VBS), but this may be disproportionately bureaucratic in some situations.

5.4 Sourcing equipment

- currently, the consumer market for telecare is undeveloped which limits choice and control
- equipment should be sourced to enhance individualisation and best value
- manufacturers and suppliers should be subject to quality standards to improve interoperability of devices
- commissioners should encourage a competitive market in the tendering process.

5.4.1 Nature of the UK telecare market

There are a number of threats to beneficence, non-maleficence and justice that stem from the way that telecare equipment is currently sourced in the UK. The small number of manufacturers has led to a lack of competition in the market. Many local

authorities have a contractual relationship with particular suppliers or manufacturers that limit their ability to buy other suppliers' equipment. This can be a threat to individualisation and lead to a 'one size fits all' approach to provision. Further, there is a possibility of differences in the range of equipment available to self-purchasers compared with local authority-funded clients, which has an associated threat to justice.

To maximise individualisation, local authorities and others should seek to purchase the best equipment for the person concerned, irrespective of the main provider they are using. Promoting greater flexibility in commissioning to avoid exclusive contracting with one technology provider and to widen provision locally would help in this regard. Manufacturers and telecare suppliers should ideally be selected on criteria such as meeting specified needs, price, reliability, proven track record, conforming to relevant regulations and standards; and support and maintenance. Local authorities should also commit to stimulating wider provision of telecare services by locking into special arrangements with particular suppliers. Local authorities' and PCTs' commissioning strategies should promote the use of a number of suppliers and can do this by considering the needs of the whole population through their work on local strategic partnerships. Joint strategic needs assessments and local housing strategies should be used to promote greater choice and flexibility in telecare provision in the area.

As technology becomes more sophisticated, commissioners and purchasers will require greater assurances over the quality of telecare equipment and of the monitoring and response chain to ensure that users can rely on them and avoid harm due to system failure. This can be assured through contracts and service level agreements. While providers are required to have a European Conformity (CE) certification for some equipment, there may be a role for an industry standards body to provide assurance because formal standards do not currently exist for the technological solutions to social care needs. This is unlike the case for medical devices, which have to conform to rigorous standards laid down by the Medicines and Healthcare products Regulatory Agency (MHRA, 2008).

Self-funders and personal budget holders will be at a disadvantage if they do not have access to good information and advice when purchasing telecare. So there is a clear need for arrangements for sourcing telecare to ensure self-funders and personal budget holders gain confidence and competence. Advice must be impartial and there will be a need for independent standards on which personal budget holders can judge the effectiveness of intermediary advisers or brokers. There are currently no national minimum standards for service providers apart from those covered by, for example, the Telecare Services Association Code of Practice, and these standards are not publicly available. While the Care Quality Commission (CQC) has this role for domiciliary care services, it does not extend to telecare services. Therefore there may be a future role either for the CQC or a telecare industry watchdog in relation to overall telecare service delivery standards.

The impact of personal budgets on local markets will need careful monitoring. Personal budgets may be funded from budgets that are already paying for telecare, thus reducing the income for existing telecare providers.

5.4.2 Interoperability

Lack of interoperability of equipment can mean that monitoring centres are limited as to which manufacturers' equipment they can monitor. In extreme circumstances this could lead to people having a telecare service that does not meet their needs.

To provide real choice, greater interoperability between manufacturers of telecare should become standard. This would enable monitoring centres to decode different manufacturers' equipment and manage a flexible network of equipment across a geographical area.

Attempts are being made to achieve greater compatibility between telecare systems. Within healthcare, the Continua Health Alliance is actively campaigning for greater interoperability of equipment (Continua Health Alliance, 2007). As technology and sector standards converge on providing interoperability, the potential for more person-centred solutions will increase.

5.4.3 Impact of personal budgets

The introduction of personal budgets is likely to change the relationship between people who use services, social services, telecare service providers and other relevant agencies. This is due to the new patterns of service purchasing arising from individual commissioning decisions. There are a number of issues that will impact on personal budgets in turn. To receive a personal budget through social services people have to be eligible to receive a service. CASSRs still operate FACS criteria to determine this, and clearly this can potentially lead to inconsistency between areas depending on where the FACS criteria is set. *Shaping the future of care together* (HM Government, 2009) puts forward ideas on how FACS may be adapted to accommodate telecare for people with lower needs and for whom telecare will be a preventative measure, but whether this flexibility is introduced depends on local strategic commissioning decisions.

Another consideration is what prices will be charged to individuals for telecare. Local authorities can reduce costs through bulk purchasing but this does not always benefit the individual purchaser, and the shift to personal budgets is likely to reduce local authority bulk purchasing power and their procurement options. This could lead to greater variety in equipment purchasing decisions and in unit costs.

As one approach, commissioners should consider the services of Buying Solutions, the national procurement partner for UK public services. Unfortunately, neither personal budget holders nor self-funders currently use the Buying Solutions service, so the provision of good quality, independent advice on products, support and costs will be needed.

In lieu of a definitive source of information, websites such as www.atdementia.org.uk or www.telecaremadeeasy.org.uk at the Disability Living Foundation offer information on a wider range of products. Locally, there will be a need for information, advice and advocacy services and brokers who can act in much the same way as independent financial advisers. Local authorities could consider supporting the development of a

diverse service provider marketplace to enable end users to find services to help them source, install and maintain equipment, and have access to trusted assessors able to give independent advice. This should facilitate provision of off-the-shelf, needs-led and affordable solutions. There remains a need for standards to assist in this whole process.

5.5 Installation

- installation can enhance or inhibit autonomy and beneficence
- installers need training and education to acquire core competences that will support a person-centred service
- quality standards for the installation process should be established.

If handled well, installation of a telecare service can enhance autonomy and beneficence, and if handled badly it can reduce the potential for positive outcomes. Installation can involve a number of professionals. Many telecare technicians are experienced with some groups of clients, for example, older people, but not necessarily all client groups who might use telecare. The Foundation for Assistive Technology's workforce development proposal advocates for the training and education of practitioners involved in telecare installation, with core competences that support a person-centred service so that they understand the needs of people with a cognitive impairment and create a better fit between the person and their telecare service (Down and Stead, 2007). Appropriate training will also enable those installing telecare to be confident about communicating with people with a cognitive impairment and help ensure the telecare service can support them more effectively than if a standard approach had been taken.

Until now no formal training scheme for telecare installation technicians has existed, but that is due to change. Agreements with telecare providers could be used to determine the type of personal information that will be shared with their installation staff, if the person has been assessed by a CASSRs and has a care plan. Contracts and service level agreements for installation services should ensure that an ethical approach is employed.

There is a risk of vulnerable people being exposed to unscrupulous or bogus installers or sales people. The new vetting and barring scheme in England could potentially provide a vehicle for ensuring staff involved in the sale and installation of telecare equipment and services are suitable for the work.

Often equipment is installed in a property owned by third parties or which is shared with others. Obtaining permission from landlords will be required, particularly if structural changes are needed to the building. Installation may need a number of phases, with preparatory work being done to bring electricity to the correct points in a house, to modify doors and windows ready for controls or to fit specialist pieces of equipment such as gas equipment or hardwired smoke sensors, before the main telecare equipment can be installed. Clearly this will involve coordination of a number of trades. This must be agreed well in advance to ensure that installation schedules are not disruptive for the client. General agreements on the use and location of equipment should be established between social care, landlords and

organisations involved in equipment design and installation. The Lifetime Homes Standards, currently under revision, provide a useful resource for the design of such interventions (Lifetime Homes, 2009). The Assisted Living Innovation Platform (ALIP) Healthhub project, which is one of nine existing ALIP projects (Technology Strategy Board, 2007), could also be a useful resource.

It can be important to make sure that family members or professionals known to the person using the service are present during installation, especially if the person has communication or cognitive disabilities. This will help to ensure that the installer has all the information they need to position and set up telecare equipment in the best way for the person. Installers should be competent to decide these things in conjunction with the person using the service if the latter has the mental capacity to do so. Installation should take place at an agreed time with a pre-agreed plan of where to site equipment. Costs and users' preferences would have to be balanced in these agreements. If the person is likely to find the installation disruptive (for example, a person with autism and learning disabilities who finds change extremely distressing), then it may be best to schedule the installation when they are not at home. Where people are working there should be flexibility around evening and weekend installations.

Explanation should be given to the person or their family or carer prior to and during installation about how the equipment works. People with cognitive disabilities should have a supporter with them to ensure key operating instructions are taken on board. A system of quality control to include satisfaction surveys should be considered to ensure that installation is, and remains, a positive aspect of the process of telecare use.

6 Post-Installation

There are a number of issues that arise after the telecare service is in operation. They are explored in this section under: privacy, social isolation and wellbeing, and fairness in the allocation of resources.

6.1 Privacy

- as with any direct care service, infringement on privacy needs to be justified
- information generated from telecare services can help service providers determine whether the overall care plan is effective, although this is dependent on data-sharing arrangements
- service providers must be clear about the purpose for which information generated from telecare is being collected
- telecare users and their carers should be informed, prior to installation, about what information will be collected and how it will be used
- the emphasis should be on using information from telecare to drive improvement, and promote people's independence as well as their safety
- data should be securely stored and transferred between agencies using industry good practice standards and agreed joint protocols.

Privacy, which is enshrined in law (Human Rights Act 1998), is clearly recognised as a basic human right and it is as important for people with cognitive disabilities as anyone else. Most people can pick and choose with whom they come into contact and what aspects of their private lives they share. However, it is different for people with cognitive disabilities who usually require health and/or social care support in their own residential settings. It is inevitable that when people receive this kind of support in their own homes there is a trade-off between the help received and some reduction in privacy. Telecare involves a similar trade-off.

Telecare can affect privacy in a number of ways. On the one hand, it can enhance beneficence by giving the individual greater control and reducing the need for their privacy to be compromised by attending professionals or informal carers. On the other hand, telecare has the potential to impact on privacy in maleficent ways, namely due to the extent of information collected by monitoring centres about people and their daily lives.

The range of data that can potentially be collected via telecare equipment and monitoring centres includes:

- information on sensor alerts in people's homes and the reasons for these episodes
- data on people's movements, exit and entry to their homes, and whether they have seizures
- details about people's movements outside of the home, via global positioning systems
- monitoring information on the use of environmental controls in people's homes.

Clearly, collecting information of this type can be beneficial. Sensor alerts can bring neighbours or family members, and sometimes professionals, to assist people in

emergencies. Monitoring trends in alerts or people's patterns of behaviour can help providers and commissioners adjust care plans if it becomes clear that people require more, or different, types of help. However, use of information for those means will depend on an appropriate data-sharing agreement.

Collecting such extensive information about people's daily lives obviously also poses a potential threat to people's privacy. For instance, the information might not be used for the purpose described or agreed with the individual before installation. Second, people's privacy could be threatened by the way information from telecare is stored and whether it is susceptible to theft or misuse. Use of non-UK call centres could compound the problem of data storage as these centres are outside of the jurisdiction of UK/European Union (EU) laws on privacy and data protection. This may become a larger problem as the telecare market becomes more global, particularly in relation to sharing data about people across agencies.

There are three broad approaches to collecting and storing information that should be taken to protect an individual's privacy:

1. It should be made explicit in the care planning and subsequent review processes exactly what information will be collected, for what purposes, how it will be stored and with whom it will be shared. Where explanatory material is used to explain these issues to telecare users, or potential users, it should be available in a range of accessible formats. Where capacity allows, people who use services should give formal, signed consent about the collection and use of information about them and this consent should be reviewed on an ongoing basis.
2. Access to people's data should be on a 'need to know' basis and systems should offer different levels of access to telecare-generated data. Data should be securely stored and where data-sharing agreements exist (see below), transferred between agencies using appropriate industry good practice standards including encryption and password protection where appropriate. Details that would identify individuals should not be included in reports for service monitoring or performance review, with information on people being aggregated and anonymised for this public purpose.
3. Agencies involved in commissioning and providing telecare should have agreed protocols for storage, access, use and sharing of information. This would form the basis for informing potential telecare users about how information will be collected and used. Regular audits of adherence to data collection and sharing protocols by participating agencies would help to ensure that agreements were being adhered to. International standards for personal data security do exist and could serve as a basis for appropriate guidance on which local protocols could be based.

The fundamental point is that in commissioning and providing telecare, the aim should be to maximise the beneficial, and reduce any maleficent, aspects of the service. To ensure its beneficial effect the emphasis should be on transparent and agreed use of information to drive improvement and to promote people's independence and safety.

6.2 Social isolation and wellbeing

- due to the potentially isolating effect of telecare, it should not be considered as an alternative to direct social care or informal support, unless this is the expressed wish of a person using the service who has full mental capacity
- local commissioning strategies should recognise the potential of telecare for meeting low level needs
- it is important to recognise that a telecare service cannot monitor changes in people's wellbeing with the same sensitivity that other human beings can and this should be reflected in care planning
- telecare should be combined with direct social care and informal support to maximise people's motivation and facilitate carer involvement in supporting social engagement.

People are social beings and in general, social interaction is an important part of being a member of society. Ideally everyone would be able to engage with their family and friends however much or little they wish, but the likelihood of being able to do so is often limited when people's independence has been reduced through illness or disability. In these circumstances, when people are being supported by or are receiving direct care, professionals often represent a welcome source of human contact. For people using direct services who have little or no family or friendships, the social contact provided by care workers, for instance, can be of paramount importance. There is some concern that the introduction of a telecare service might reduce the assessed need for support from care staff and result in people who use services becoming socially isolated.

The FACS framework, introduced in 2003 and revised in 2010, has concentrated the minds of commissioners on priorities for care. FACS sets out four levels of need: low, moderate, substantial and critical, and councils decide at which level they will fund care, with people whose needs fall below those levels receiving no publicly funded services. In recent years, financial pressures have encouraged local councils to shift their focus towards groups with the highest need, and in 2008/09 72 per cent of councils set their criteria at 'substantial' or 'critical'. There has also been a marked reduction in the number of councils who would support people with 'moderate' (26 per cent of councils) and 'low' needs (two per cent of councils).

In this context, there is a concern that maintaining people's social contact may not represent a priority for investment of limited public funds. For example, if a less resource-intensive telecare service could be commissioned to monitor people's safety, make a daily contact call or remind them to eat, or take their medication, it is conceivable that supplementary 'face-to-face' services would not also be commissioned. However, if the importance of social contact is not considered during care planning, it is possible that the resulting isolation could have a negative impact on the person using the service's mental health, exacerbating any cognitive problems already present. This could ultimately lead to a decline in the individual's condition and increase in their needs, resulting in admission to more intensive and expensive forms of residential or hospital care.

A further potential threat to people's wellbeing from the use of a telecare service comes from the fact that the technology cannot identify changes in people's overall wellbeing with the sensitivity that human beings can. Although the use of lifestyle monitoring through telecare can assist in identifying changes in people's circumstances, it should be used in the context of a person-centred plan that includes, where needed, direct social care support and some level of human contact for monitoring changes in people's wellbeing.

The Delphi feedback, which informs this report, also suggests that an unintended consequence of telecare services is the dilemma encountered by some people who use services that, while still physically able to go out into the local community, they fear moving away from the assurance of their safety monitoring systems. This could lead to reduced physical mobility and social contact, which is counter-productive and should clearly be avoided. Exploring mobile telecare solutions may assist in freeing people from the perceived 'tie' to their home-based monitoring systems.

Although some potential negative impacts have been described here, it has also been suggested that telecare services could have a positive impact on wellbeing and people's social interaction. Respondents in the Delphi process claimed that telecare can also improve the amount and quality of social interaction experienced by users by freeing up family and other carers from basic safety and other monitoring roles to spend more of their time with the individual, in conversation and shared activity. Commissioners should consider using telecare to monitor and provide alerts around safety and to promote independence in a plan with a view to freeing informal carers' time to encourage social inclusion and engagement. Furthermore, telecare safety and monitoring could free up care workers' time, allowing their visits to encompass rehabilitation, or excursions to enhance people's social engagement, although in reality it is far more likely to reduce commissioned visit times in duration and in frequency.

There are two broad approaches that should be taken to protect people's wellbeing and to promote their social inclusion:

1. As a core principle, telecare should be introduced to a person and planned with their needs and wishes in the area of social interaction in mind. Telecare should not be considered as an alternative to direct social care support, unless this is the wish of a person who uses services who has full mental capacity. It should be part of an overall package that may include the maintenance of important social connections.
2. If telecare is being used to enhance independence and reduce reliance on paid professionals or informal carers, care plans should pay attention to means of maintaining social interaction. These could include befriending schemes, the use of volunteers for supporting social activities and work with appropriate community groups.

In summary, telecare should be combined with direct social care and informal support to maximise people's motivation and encourage their reablement, where this is appropriate. Telecare safety monitoring should be used to facilitate meaningful carer involvement and develop the individual's social engagement.

6.3 Fairness in the allocation of resources

- the case for telecare and telehealth to be funded jointly by the NHS, local authorities and other agencies is made by the wide-ranging outcomes that can be achieved
- manufacturers and telecare providers should work towards greater interoperability of equipment
- if fairness in provision is to be maintained in the context of personal budgets and self-funding, there will be a need to generate high quality information and advice on telecare equipment and installation.

The introduction of telecare can impact on one subgroup of the population differently to another, thereby threatening the principle of justice. An ethical and just approach would be to develop a fair and equitable allocation of resources for telecare across all potential users of telecare. However, the Delphi process identified a number of variables that threaten fairness and consistency in the allocation of telecare. They include local charging policies, local funding arrangements, access to information about telecare and user needs and characteristics.

For people in receipt of telecare via their local authority, differences in charging policies and the application of FACS criteria can lead to people having different chances of accessing telecare according to the local authority area in which they live. For instance, some local authorities will charge for a community alarm service element of a telecare service and not for enhanced equipment, while some charge community alarm service clients but not telecare clients using sensor and environmental control equipment. In fact, BTiE clarifies that where telecare equipment is provided by a local authority for assisting with nursing at home or daily living, it should be provided free of charge, although a charge may be made for the service elements (revenue) of telecare and this will be subject to local FACS policies. The BTiE document also explains that a charge can be made for both equipment and service elements where there exists a local strategy to provide telecare as a preventative service. In these cases the FACS means test will be used to establish whether the local authority or the individual is liable for the charges. Although the BTiE document provides welcome clarity about the funding arrangements, it is possible to see how people's access to levels of telecare will vary according to local strategies and as with other social care provision, the chances of having their service publicly funded depend on the application of FACS criteria in their local authority.

Another variable affecting people's opportunities for accessing telecare is the amount of information they have about the available options. In the context of tightened eligibility criteria and the personalisation agenda, there will be increasing numbers of self-funders and people commissioning their own services via personal budgets. Put simply, if people arranging their own care and support do not know about telecare they cannot commission it. In this way information about the possibilities telecare offers acts as a gatekeeper to the commissioning and use of the service, especially among self-funders and personal budget holders.

In addition to the need for consistent, high quality information to inform people's decisions in matching telecare to their needs, there is a concern about the impact

on the costs of telecare in the context of personal budgets. The main worry is that if local authorities do not account for more modern support options, like telecare, in their resource allocation systems then telecare will either be completely beyond the means of personal budget holders or those individuals will have to make compromises in terms of the services they can afford to commission.

Another drawback that was associated with personal budgets was the lack of 'buying power' people would command. Some Delphi respondents pointed out that while traditional, centralised assessment and telecare commissioning can be criticised for not empowering the individual, it has at least provided the opportunity for less expensive bulk purchasing of telecare equipment by local authorities and others. Personal purchasing of telecare reduces the opportunities for economies of scale, with an overall increase in the cost of telecare for individual purchasers. However, personal budget holders can obtain a telecare service through their local authority, housing association or third sector provider, who can use the service of Buying Solutions.

The gulf between the needs and characteristics of potential telecare users and the state of available technology is also a source of potential inequality. For instance, people with certain sensory impairments or whose first language is not English do not have the same opportunity as others to benefit from telecare. There is a need for greater flexibility in languages and means of communication that messaging, prompting, information leaflets, maintenance instructions and monitoring centres are able to offer so that telecare can be seen as a mainstream support option and not restricted in its potential by people's needs or characteristics.

The Delphi respondents also pointed out that access to telecare is made unequal when local authorities prioritise the provision of the service based on the characteristics of particular groups, such as new clients or clients with particular disabilities. Respondents also suggested that local authorities prioritise telecare to situations where outcomes (normally 'service' outcomes) are measurable, such as to people whose overall care package costs could potentially be reduced.

The issues described so far in this section impact on equity at an individual level. However, the way telecare is funded impacts on equity, arguably at a system level. As with other social care support, local authority investment in telecare services could potentially achieve resource benefits for the health sector including reduced hospital admissions and earlier hospital discharge. It would seem to make more sense and be a better reflection of the reality that benefits achieved in one sector can be attributed to investment made by another, if telecare were funded jointly across for example, health, social care and housing. This would require local joint commissioning agreements for telecare services between local authorities and PCTs and although issues around responsibility and liability would need to be resolved, better integrated working would help to achieve equity in the funding of and benefits derived from telecare.

There are five broad approaches to promoting equity in the provision of telecare services:

1. Telecare should be seen as a mainstream option for all people with needs and should not be restricted to any particular groups. To maintain justice and fairness in access to the service, there is a need for greater flexibility in the languages that all aspects of telecare are able to offer, and appropriate outputs for people who have hearing or visual impairments.
2. If fairness in provision is to be maintained in the context of personal budgets and tightened eligibility criteria, there is a need for high quality information and advice on telecare equipment and installation, independent of manufacturers and telecare service providers. This should enable self-funders and personal budget holders who opt for telecare support to balance safety with independence and control and to purchase appropriate telecare services to meet their needs.
3. Manufacturers and telecare providers should work towards greater interoperability of equipment so that as much choice over telecare elements and packages are available to the people who need them, wherever they live.
4. Telecare must be fully costed so that personal budgets reflect the real cost of telecare provision.
5. Nationally, there should be an emphasis on competitive pricing and interoperability of equipment. As personal budgets and their use for telecare become more common, personal budget holders would benefit from having access to centrally negotiated purchase price agreements.

7 Next steps

As our introduction explains, the focus of our work to date has been on telecare; although this report also covers other technology solutions, commonly used alongside a telecare package. It has become clear during this project that there is an additional need to address the ethical issues relating to the growing industry of telehealth and therefore SCIE is looking to examine the ethical issues relating to telehealth in a subsequent project. It has also become clear during early consultations with colleagues in the field that although there are some similarities with telecare, there will be ethical implications distinct to telehealth. These differences have been explained to us by reasons including: the distinct needs profiles of users of the different technologies, the particular requirements that telehealth makes of the person who uses services and the vastly higher costs of telehealth compared with telecare.

Developments that SCIE makes in the area of telehealth ethics will be reported on our website at www.scie.org.uk

References

- Adler, M. and Ziglio, E. (1996) *Gazing into the oracle*, London: Jessica Kingsley Publishers.
- Audit Commission (2005) *Supporting people*, Wetherby: Audit Commission Publications.
- Beale, S., Sanderson, D. Senior and Kruger, J. (2009) *Evaluation of the Telecare Development Programme: Final report*, York: Health Economics Consortium.
- Beauchamp, T.L. and Childress, J.F. (1994) *Principles of biomedical ethics*, Oxford: Oxford University Press.
- Beyer, S., Meek, A., Kilsby, M. and Perry, J. (2008) 'Outcomes of the TATE Project for people with learning disabilities and staff', *Journal of Assistive Technologies*, vol 2, pp 57–65.
- Bjorneby, S., Topo, P., Cahill, S., Begley, E., Jones, K., Hagen, I., Macijauskiene, J. and Holthe, T. (2004) 'Ethical considerations in the ENABLE Project', *Dementia*, vol 3, no 3, pp 297–312.
- Buying Solutions (2009) *About Buying Solutions* (www.buyingsolutions.gov.uk/aboutus/).
- Continua Health Alliance (2007) 'The virtues of interoperability: the provider's perspective', July Newsletter (www.continuaalliance.org/news-and-media/newsletter/july-2007.html).
- CSCI (Commission for Social Care Inspection) (2008) *CSCI review of eligibility criteria for social care*, London: The Stationery Office.
- DCA (Department for Constitutional Affairs) (2007) *The Mental Capacity Act Code of Practice*, London: The Stationery Office.
- DH (Department of Health) (1995) *Carers (Recognition and Services) Act 1995*, London: HMSO.
- DH (2002) *The single assessment process: Guidance for local implementation*, Local Authority Circular, London: DH.
- DH (2003) *Fair Access to Care Services: Guidance on eligibility criteria for adult social care*, London: The Stationery Office [superseded in 2010].
- DH (2005) *Building telecare in England*, London: The Stationery Office.
- DH (2007) *Joint strategic needs assessments (guidance)*, London: The Stationery Office.
- DH (2008) *An introduction to personalisation*, London: The Stationery Office.
- DH (2009a) *Whole systems demonstrators: An overview of telecare and telehealth* (www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_100947.pdf).
- DH (2009b) *Use of resources in adult social care: A guide for local authorities*, London: The Stationery Office.
- DH (2009c) *Working to put people first: The strategy for the adult social care workforce in England*, London: The Stationery Office.
- DH (2009d) *Supporting people with long-term conditions: Commissioning personalised care planning – A guide for commissioners*, London: The Stationery Office.
- DH (2010) *National evaluation of Partnerships for Older People projects: Final report*, London: The Stationery Office.
- DH and ODPM (Office of the Deputy Prime Minister) (2005) *Preventative technology grant 2006–07 to 2007–08*, LAC (2006)5, London: The Stationery Office.

- Down, K. and Stead, A. (2007) *Assistive technology workforce development: Report summary*, London: Foundation for Assistive Technology.
- HM Government (2007) *Putting People First: A shared vision and commitment to the transformation of adult social care*, London: The Stationery Office.
- HM Government (2009) *Shaping the future of care together*, London: The Stationery Office.
- HM Government (2010) *Building the national care service*, London: The Stationery Office.
- HM Treasury (2004) *Releasing resources to the front line: Independent review of public sector efficiency*, London: The Stationery Office.
- Lifetime Homes (2009) *Consultation on proposed revisions to the Lifetime Homes criteria* (www.lifetimehomes.org.uk/data/files/consultation/lifetimehomesconsultation_2009_10.pdf).
- Marshall, M. (ed) (2000) *ASTRID: A guide to using technology within dementia care*, London: Hawker Publications.
- MHRA (Medicines and Healthcare products Regulatory Agency) (2008) *Medicines and medical devices regulation: What you need to know*, London: MHRA.
- Ministry of Justice (2008) *Mental Capacity Act 2005: Deprivation of liberty safeguards – Code of Practice to supplement the main Mental Capacity Act 2005 Code of Practice*, London: The Stationery Office.
- NHS End of Life Care Programme (2007) *Advance care planning: A guide for all health and social care staff* (www.endoflifecareforadults.nhs.uk/eolc/files/F2023-Notts_Uni_ACP_guide_for_staff_Aug2007.pdf).
- North Lanarkshire Council (year unknown) *Principles and good practice guidance: Use of assisted living technology* (www.atdementia.org.uk/content_files/files/Accessing_Assisted_Living_Technology_protocol.pdf).
- Technology Strategy Board (2007) *Assisted Living Innovation Platform* (www.innovateuk.org/_assets/pdf/other-publications/assisted%20living%20innovation%20platform%20overview.pdf).
- Welsh Assembly Government (2002) *Creating a unified and fair system for assessing and managing care*, Cardiff: Welsh Assembly Government.

Ethical issues in the use of telecare

This report provides a summary of the findings from the work undertaken by the Welsh Centre for Learning Disabilities on behalf of SCIE. It explores the complex ethical issues surrounding the commissioning and provision of telecare and the difficult decisions that professionals may face. Some solutions to these difficulties are also discussed. The aim is to ensure that commissioners and providers of telecare address these issues when developing their procedures and protocols.

This publication is available in an alternative format on request.

Social Care
Institute for Excellence
Goldings House
2 Hay's Lane
London SE1 2HB

tel 020 7089 6840
fax 020 7089 6841
textphone 020 7089 6893
www.scie.org.uk
Registered charity no. 1092778
Company registration no. 4289790