Ethical issues in the use of telecare

Key messages

- Telecare offers potential benefits for individual users including safety and independence. It also has the potential to reduce social care costs, allowing the more efficient deployment of direct care staff.

- Telecare has the potential to threaten individual users' privacy, autonomy and control.

- Social care and health professionals need to consider a range of ethical issues when supporting an individual in deciding whether to use telecare. These issues need to be considered before, during and after the installation of a telecare service.

- Commissioners must ensure that people who are self funders or personal budget holders have access to relevant information so they can decide what type of telecare service would best suit their needs.

- Local priorities and commissioning strategies may affect telecare services, including what kind is provided and who receives and pays for it.

- Service providers must have robust systems and agreements for collection, storage and sharing of data.

- Proper support for telecare users will have training implications for practitioners.

- Equipment manufacturers are urged to improve the sophistication of technology to reduce the potentially stigmatising effect of certain types of telecare. They are also urged to improve flexibility in the means of communication between monitoring centres and telecare users.

Introduction

This At a glance briefing examines the ethical issues which local strategies and protocols should reflect and which practitioners should think about when supporting people to use telecare services. The briefing summarises SCIE's *Report 30: Ethical issues in the use of telecare* (Francis and Holmes, 2010), which is based on research commissioned by SCIE from the Welsh Centre for Learning Disabilities.

What is telecare?

Telecare has many definitions and SCIE recognises there is quite a complicated terminology debate in this field. This briefing and the main report use the following description of telecare:

> ' 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. '

(Department of Health, 2005)

SCIE's work on telecare and ethics uses a definition of telecare that includes remote monitoring. According to this definition, telecare can also include detectors or monitors of things like motion, falls, fire and gas, which trigger a warning to a response centre. Telecare can also be used in a preventative way by monitoring an individual's health or wellbeing (for instance, by using bed sensors programmed to

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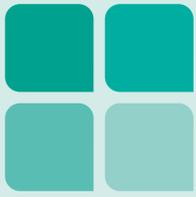
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record how many times a person leaves their bed during one night).

SCIE's work on telecare and ethics also covers other technology solutions which might be commissioned alongside a telecare package. These additional solutions can include fingerprint-recognition door entry systems as part of a home safety and security package, or reminder systems and prompts to take medication as part of a dementia support package.

Despite this complicated terminology debate, the ethical principles discussed here should be applicable across the wider emerging market of technological care solutions.

Context

What is the link between telecare and ethics?

The technology involved in telecare services has been used for many years to support older people, most commonly in the form of pendant alarms. Telecare has great potential to benefit people who use services by improving their confidence and helping them to remain independent in their own homes. By monitoring people's safety, telecare can also free up the time of friends and family carers so they can focus more on providing social support.

In recent years, there has been increasing interest in extending telecare services to more users and there has been considerable government investment in researching and rolling out telecare systems to achieve this.

However, these developments raise ethical concerns around the provision of telecare services, particularly to vulnerable people such as people with cognitive impairments, including dementia. For example, how can practitioners ensure that monitoring people through telecare does not threaten their choice and privacy? How can practitioners support potential users to make decisions about whether to use telecare and what type of service would best meet their needs?

It is important to ensure that professional practice develops in parallel with the expansion of telecare. For this reason, SCIE commissioned the Welsh Centre for Learning Disabilities to undertake a study of the ethical issues in the use of telecare and the ways these ethical concerns can be addressed in practice. Findings from this study form the basis of SCIE's Report 30 (Francis, 2010) and this shorter briefing.

How the ethical issues were identified

Researchers at the Welsh Centre for Learning Disabilities identified the ethical issues in the use of telecare mainly through the 'Delphi' method. The 'Delphi' method is a structured process for collecting data and distilling knowledge from a group of experts. (Adler, 1996)

The experts in this study included local authority telecare leads, occupational therapists, commissioners, providers and third sector representatives. People with learning difficulties and people with dementia were also involved through informing the content of the Delphi questionnaires and in discussions about the findings before they were written up. The Welsh Centre's work also benefited from input by the project advisory group.

The Welsh Centre researchers adopted an 'ethical framework' to illustrate the potential problems associated with the use of telecare. This framework consists of four important principles. SCIE's report refers to the ways in which the commissioning and provision of telecare can compromise these principles.

The four principles are:

- **Autonomy – the ability of an individual to make choices**

    Autonomy is related to the independence and choice in everyday life that is often taken for granted. When people rely on professionals or family carers for their care or for safety monitoring, the introduction of a telecare service can drastically promote or restrict autonomy.

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- **Beneficience – the principle of working for the benefit of the individual**

  Telecare has the potential to benefit people. It can provide assurance and confidence and can reduce unwanted dependence on professional staff or family carers. It can also increase comfort through environmental sensors and controls.

- **Non-maleficence – the principle of doing no harm**

  While telecare can benefit an individual, it also has the potential to expose people to risk. A balance must be achieved between ensuring safety and invading privacy. The potentially stigmatising effect of telecare should be recognised and minimised.

- **Justice – the moral obligation to act on a fair adjudication between conflicting claims**

  In the interests of justice, resources for telecare services should be allocated so as to balance the needs of the individual with those of the wider community.

Practice points for an ethical approach to telecare

The main ethical concerns identified by the Welsh Centre's work can be divided into two groups: ethical concerns relating to the pre-installation phase and ethical concerns relating to the post-installation phase.

- **Pre-installation phase**

  The principal ethical concern during the pre-installation phase is that services should be tailored to the individual and that when considering appropriate telecare the risks of the person coming to harm should be balanced against their right to autonomy.

- **Post-installation phase**

  The main ethical concern during the post-installation phase is that telecare information should be collected for a positive purpose and

with the consent of the person concerned. The risks of invading individual privacy should be balanced against independence. Telecare should not isolate people socially and the allocation of funding for telecare should be fair and just.

The points below give an overview of the ethical issues which are covered in greater detail in the main SCIE report.

Pre-installation

Assessment

- Assessment is a pre-requisite for needs-based telecare service design.
- Assessment is critical to achieving the right balance between independence, social wellbeing, privacy and protection.
- Assessment for telecare requires appropriately trained assessors.
- Telecare must be embedded in the wider care-planning process and involve joined-up working between organisations.
- Assessment of need and assessment for telecare should be regularly reviewed.

Consent to use telecare

- 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 judgement of mental capacity.
- In seeking to gain consent, it should not be assumed that eccentricity in an individual implies impaired mental capacity.
- The best approach to gaining consent should be determined on an individual basis.
- When judging the best interests of people without mental capacity to give informed consent, practitioners should strive to find the right balance between quality of life outcomes, including independence, and safety.

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Risks associated with telecare

- Everyone involved in the commissioning and use of telecare should have realistic expectations of its capabilities and should understand its limitations.

- Problems can arise in any aspect of telecare services. 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 including installation, equipment, monitoring and response.

Sourcing equipment

- Currently, the consumer market for telecare is undeveloped and this 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 how effectively different devices operate together.

- Commissioners should encourage a competitive market in the tendering process.

Installation

- Installation can either enhance or inhibit autonomy and beneficence, depending on how it is carried out.

- Installers need training and education to acquire the core competencies necessary to support a person-centred service for people with cognitive impairments.

- Quality standards need to be established for the installation process.

Post-installation

Privacy

- As in all direct care services, any infringement on privacy needs to be justified.

- Information generated from telecare services can help service providers determine whether the overall care plan is effective. However, this is dependent on data-sharing arrangements.

- Service providers must be clear about the purpose of collecting information generated from telecare.

- Telecare users and their carers should be informed 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 to 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

- Telecare has a potentially isolating effect. It must not be considered as an alternative to direct social care or informal support, unless this is the expressed wish of the person using the service with 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 a person's wellbeing as sensitively as 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 to facilitate carers' support of social engagement.

Fairness in the allocation of resources

- The wide range of outcomes that telecare and telehealth can achieve supports the argument for joint funding by the NHS, local authorities and other agencies.

- Manufacturers and telecare providers should work towards greater interoperability of equipment.
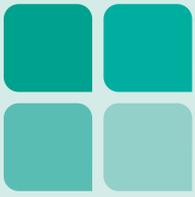
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- In order to maintain fairness of provision in the context of personal budgets and self funding, high-quality information and advice on telecare equipment and installation are needed.

Balancing the tension between policy and practice

Many of the practice points summarised above fall within the remit of individual practitioners. We recognise that the work of individual practitioners is often constrained by broader strategic decisions and national priorities.

However, this situation is not limited to telecare commissioning and provision. Practitioners are well accustomed to balancing the conflict between meeting policy aspirations and dealing with the realities of frontline practice.

A number of policy initiatives highlight the importance of telecare to an integrated and responsive service designed around individual need. However, with significant autonomy at local authority and primary care trust (PCT) level, the current tight economic climate may drive local commissioners to make choices which limit telecare provision and the preventative support it offers.

Individuals' access to levels of telecare will vary according to local strategies. Policies such as Fair Access to Care Services (FACS) may bias provision towards high priority need at the expense of preventative services. Additional factors such as a lack of integrated working between health and local authorities, disagreements over responsibility for assessments and the reluctance of services to pool resources can challenge staff at a local level.

Despite these tensions, practitioners must adhere to ethical principles when considering telecare to ensure that individual users are well served by the technological solutions offered.

Next steps

SCIE's work in this area has also highlighted the need to address the ethical issues relating to the growing industry of telehealth. SCIE hopes to examine the ethical issues concerning telehealth in a subsequent project. Developments in this work will be reported on SCIE's website.

Early consultations with colleagues in the field suggest that, while there are some similarities with telecare, there are also ethical implications specifically pertinent to telehealth. These different ethical implications reflect: the distinct needs profiles of users of the different technologies; the particular requirements that telehealth makes of the person using the service; and the vastly higher costs of telehealth compared to those of telecare.

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