



Care with technology? An ethical framework for telecare

This framework is laid out as a series of questions to be openly considered and debated by older citizens, telecare users, carers, policy makers and professionals. It is not a yes/no checklist, but an aid to decision making. It has been developed following extensive debate and research with older people in England, Spain, Norway and the Netherlands.

1. Who is involved?

Who needs to be consulted, who participates in system design and who decides which needs are going to be met? Telecare should be designed, shaped and trialled through consultation with a broad range of actors. Older people are ready and willing to participate in these processes: it is up to industry, government and providers to facilitate this activity, in collaboration with established networks of older people. Telecare that is produced without appropriate and meaningful consultation and engagement will not meet the needs of older people.

2. What problems can telecare help with? How do other problems fit in or not?

Although telecare can be very useful in an emergency situation, and has other specific roles, it cannot function as a 'solution' for problems associated with advanced ageing. There are needs that it cannot recognise or meet. When telecare is designed to enhance (or can be used for) social support, it seems very popular. More often, though, it is used to monitor older people who remain rather passive and using the system for social contact can be seen as 'misuse'. But telecare systems can be used to promote social relationships that are more horizontal and active, rather than vertical and passive.

3. Use and implementation: who is connected to the telecare system?

The installation of a telecare system opens up questions of privacy and confidentiality, highlighting complex issues about the ownership, use and control of personal information and sensor data. The availability of data raises questions about access to it. Information about an older person's activities in their home, or their feelings about their chronic illness, is powerful. The sharing of such information has the potential to change relationships of care, e.g. between parents and adult offspring or between paid carers and older people. Some developers recommend the use of

telecare to assess or monitor the capacities of older people living alone. It must be made clear to the older person both prior to and at the point of installation that this might happen.

4. How might a telecare device change an older person's home?

The aim of staying at home should be discussed, rather than assumed. Although many older people strongly desire to remain in their own homes as long as possible, this might not be so appealing if 'home' is under scrutiny and is the object of constant monitoring. Telecare systems run the risk of turning homes into 'institutions'. Strong efforts should be made to minimise the disturbance to people's homes, and designers, prescribers and installers must take seriously the objections of older people to such intrusions. Telecare devices may diminish people's sense of security despite their aims to do the opposite: they may make people feel vulnerable and scrutinised.

5. Who will be the active user of the telecare system: the older person and/or others?

Becoming a user of telecare is to take on a new identity and to accept a new network of connections in which older people have a particular (and quite limited) set of roles. There are notable differences in older peoples' experiences of telecare systems where they can maintain physical control (e.g. where they push alarms to request help) and those in which alarms are triggered automatically. The latter lead to more 'false alarms' which create difficult work for teleoperators and others involved in monitoring, and can create unnecessary concerns for older people and their families. Using telecare systems puts older people into new relations both with people they know, and with people they have never met (but may come to know). These changes should be reflected upon and openly discussed with prospective users of telecare.

6. What would happen if the older person's condition deteriorated?

Older people's lives can be subject to rapid change: often telecare is prescribed to very vulnerable people who are on the edge of being unable to manage on their own or who have serious chronic disease, with high support needs. Telecare systems are often installed as a 'last ditch' effort to help people stay 'at home'. The systems themselves, however, tend to be rather static, and unable to adapt to individuals' changing needs. Some devices can be reprogrammed (e.g. bed sensors) but this requires ongoing analysis of how the current arrangements are working. If telecare is not well supported, devices remain unused: either because older people and their families do not understand how to use them, or because the device no longer meets the person's needs. Individuals – both professionals and others – need ongoing support and training about telecare systems so they can use them as effectively as possible.

7. Is it worth the effort?

There is a widespread but simplistic presumption that telecare saves money by reducing demand for residential care and reducing demand on other care services. However, in practice telecare

involves a lot of work for many different groups of people and creates new forms of labour, both for providers and users. It is not necessarily time or cost saving. In most cases, telecare cannot prevent negative incidents: it cannot stop people falling, becoming ill, or getting lost. Its two main functions are to assess need for assistance and/or to enable support. Some telehealth systems require a lot of effort from users, who need to log on daily or weekly to answer difficult questions and report on their health. Given that the telecare system may not prevent negative events, it is important to balance the efforts involved against the benefits of being involved. Prescribing and installing telecare is a complex process and practical questions about costs to individuals and to health services need careful assessment.

8. Difficult decisions and pressures to accept and adopt

Sometimes older people receive telecare as part of trials or pilot studies designed to test the acceptability and workability of particular systems. This is often a positive experience for older people, who enjoy being involved in research. It should also be recognised that trial results are often positive due to the care and attention this stage of development attracts from all concerned. Difficult decisions must then be made at the conclusion of such studies: it is unethical to remove technologies from people who had come to rely on them, without an adequate substitute. Conversely, it is sometimes unclear to older people how they can have telecare removed from their homes. Older people must be able to change their minds about accepting telecare and the telecare itself should be adaptable (open to supplementation/reduction). In some countries, government policies direct local authorities to commission telecare services, which may then be prescribed to individuals who may not benefit. Families may also put pressure on individuals to accept systems they do not actually understand or want.

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