So far away and yet so near?
Ethical considerations in care at a distance

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To the Minister of Health, Welfare and Sport,
Ms E.I. Schippers

Dear Ms Schippers,

The demand for care will increase in the years ahead and yet the number of care professionals will decrease. One way of solving this problem is to use ‘telecare’. Telecare is the generic name for technology that enables remote monitoring or coaching of patients at home, with the aid of a webcam or electronic sensors, for example, which measure patients’ physical functions. This saves time, as it reduces the frequency of visits that care professionals and informal carers need to make. Moreover, telecare can make patients more self-reliant and enhance their social network. Telecare therefore involves a social promise.

In this advisory report the Centre for Ethics and Health (CEG) examines the ethical questions that telecare raises, as care at a distance increasingly replaces direct care. The advisory report therefore examines the conditions that telecare has to meet to make good the aforementioned social promise, also from the ethical point of view.

Telecare will inevitably change the relationships and roles between patients, informal carers and care professionals. Patients and informal carers will most probably carry out more medical/semi-medical activities, whereas professionals will more often take on a coaching role. There need not be any objection to this. Telecare may even enhance the self-management and autonomy of patients and their informal carers. However, it is important not to make excessive demands on patients; not everyone will be capable of always closely following the telecare ‘script’. Moreover, patients may not always
wish to do so because they sometimes consider other values more important than those that apply within the medical regime.

It is also important to organise telecare so that it has an enhancing effect even for patients who are not so self-reliant and media-literate. Furthermore, it is necessary to ensure that telecare arrangements do not add to informal carers’ already excessive workload. The advisory report is a call to manufacturers and care professionals to incorporate these preconditions in the design and embedding of telecare.

At first sight, implementing telecare appears to put pressure on a person’s home life. After all, equipment is installed in the home. However, it turns out that patients tend not to feel their privacy is being infringed, provided they are able to decide for themselves whether or not they wish to cooperate in a given type of telecare and provided they are able to choose when professionals ‘observe them’ through a monitor. The responsibilities and liabilities relating to telecare are as yet not clearly regulated. This is a task for manufacturers, care professionals, patient associations and government.

If the preconditions for telecare that are set out in this advisory report are met, telecare may also be seen as a promise from the ethical point of view.

Yours sincerely,

Rien Meijerink, Pieter Vos,
chair of RVZ general secretary of RVZ
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Executive summary

Care at a distance, also known as ‘telecare’, is a social promise. For example, technology makes it possible to use a compact touch-screen to monitor important physical functions of patients or to provide people suffering from dementia with instructions on preparing food, without a care provider having to be physically present. Telecare could enhance care provided in the home and thereby improve it, make patients more self-reliant, strengthen informal care networks and, last but not least, it could provide a solution to the problem that demand for care is increasing at a time when the number of care professionals in the labour market is decreasing.

Most telecare is currently in the pilot stage and is still supplementary to existing care. This advisory report discusses the realistic scenario in which care at a distance will replace a considerable part of direct care in the home. Whether intentionally or otherwise, in such a case telecare will change care relationships. The relationships between patients, care professionals and informal carers will inevitably be different; informal carers and patients will carry out more medical/semi-medical activities, whereas care professionals will have more of a coaching role. The questions this advisory report poses are:

What ethical questions does care at a distance of this kind raise? Which parties should consider those ethical questions and how should they do so?

The advisory report explores the question in two ways: on the basis of a reference literature study and on the basis of a focus group study. In the focus groups, patients, informal carers and care professionals were asked for their opinions on telecare. This revealed a difference of opinion between younger and older patients. Younger patients feel resistance to telecare because they have no desire to be constantly confronted with their illness at home. They are also concerned about the privacy of their digital medical data. However, they do think that telecare could make care more accessible for them. Older patients in our study had less resistance to telecare, perhaps because they had integrated their illness more in their lives. The advantage they see of telecare is that it enables them to live at home independently for longer. All patients wanted to be able to determine the time of contact themselves; they do not wish to be constantly checked via
a webcam, for example. The informal carers who were interviewed found it a pleasant experience to be able to contact the patient through telecare, as it reduced the frequency of visits they needed to make to check that everything was all right. They also thought it was reassuring that remote professional help was available. However, they were afraid that they would gradually be assigned more responsibilities. Various informal carers thought that care at a distance could never take the place of care provided in person. The spectre of an impersonal call centre was raised. Care professionals who are not yet working with telecare are more hesitant about it. Conversely, the interviewed care professionals who were already working with telecare thought that it made their profession more engaging. Examples they mentioned included that they could be in touch with a patient several times a day and that it was easier to determine if a visit was necessary. They indicated that the **screen-to-screen** contact made the relationship more personal, rather than more impersonal. Care professionals also thought that telecare increased the privacy of patients and possibly that of other members of their household.

On the basis of the reference literature study and the focus groups, the advisory report provides various ethical points for agendas concerning the implementation of telecare.

**Personal contact** is part of proper care. However, telecare need not be an obstacle to personal contact; a webcam also offers **face-to-face** contact with the care provider and can even make care more personal. However, people want to see a trusted and familiar face on the screen. This therefore calls for a permanent telecare nurse instead of a call centre with changing care providers. Moreover, it would be advisable to acknowledge that some necessary types of direct care (wound care but also a comforting arm on a person's shoulder) cannot, in principle, be replaced by telecare.

Telecare can enhance patients' options for **self-management**. Systematically updating their own medical records puts patients in a better position to look after themselves in their own way. However, this assumes that the patient is highly disciplined and meticulous.

Ethically speaking it is important for patients to be able to live the life they choose as far as possible. It is essential not to lose sight of patient **autonomy**. This assumes that the patient is able to consider values and is not automatically subordinated to a medical regime. Cooperation between professional and patient which attests to respect for the patient's individual lifestyle is therefore also one of the criteria that has to be met by care at a distance.

There should be no **division between self-reliant and non-self-reliant** in care. If telecare involves the implicit assumption that users are media-literate and have a good social network, such a division will be reinforced. On the other hand, telecare can also
be arranged so that it supports those who are non-self-reliant and makes them more self-reliant. The latter is preferable from the ethical point of view and it therefore warrants the attention of manufacturers and care professionals.

At first sight, implementing telecare appears to put pressure on a person's home life. After all, equipment is installed in the home. However, it turns out that patients tend not to feel their privacy is being infringed, provided they are able to decide for themselves whether or not they wish to cooperate in a given type of telecare and provided they are able to choose when professionals 'observe them' through a monitor.

However, telecare equipment in the home can lead to increasing medicalisation of private life; some patients would prefer to avoid this. There is also the question of what happens with all the personal measurement data exchanged via the internet. Here, too, it is advisable to actively seek forms of telecare that leave home life intact as far as possible and that keep as much space for freedom of action as possible.

An ethical point is whether users will in due course still be able to choose a form of telecare that they consider pleasant or at least acceptable. For example, with telecare an obvious step might appear to be that family and friends would take over some of the physical care. However, research shows that patients would rather be cared for by a professional than by family members and friends. This effect of telecare would therefore be counter to patients' wishes. Telecare can provide informal carers with support and ease their workload but it can also mean that informal carers find themselves being assigned more care tasks, care tasks which they have not 'chosen' but which they will not readily refuse out of a sense of duty. The freedom of choice of care professionals may also enter into the discussion. Will they still be able to choose what they deem to be proper care, namely care in which the human dimension continues to be part of their work?

Implementing telecare also requires proper consideration of the division of responsibility and liability. It is advisable to guard against patients and informal carers gradually being assigned all kinds of medical/semi-medical responsibilities. It is important for care professionals and informal carers to have clarity about who is responsible for reading out the medical records that patients send. It is also important to clarify who is liable when mistakes are made if equipment malfunctions: the care institution, the user or the supplier?

Particular attention needs to be paid to the question of how to deal with patients suffering from dementia who in due course no longer remember that they consented to telecare, or those who consented to a form of telecare due to be replaced because the technology has been superseded.
Finally, it would be advisable to **monitor** the actual telecare, to see whether the care meets the ethical conditions. Healthcare providers can be expected to ensure that they treat the care recipient with respect and are mindful of what the social environment of patients is capable of providing. Guidelines on this can be drawn up in consultation with patient associations. Issues concerning privacy and liability should be regulated by legislation. This is a task for government.
1 Care at a distance

1.1 Introduction

The healthcare sector is increasingly paying attention to e-health. E-health is the use of new information and communication technologies, especially internet technology, to support or improve health and healthcare (RVZ 2002). E-health is seen as a promising development because it offers solutions now, at a time when demand for care is increasing – largely as a result of an aging population – and the number of care professionals in the labour market is decreasing.

This advisory report is concerned with a particular type of e-health, namely care at a distance. In care at a distance a patient, or client, literally receives care at a distance by means of a particular type of technology. The patient or client is therefore not at the same location as the care provider. Care at a distance is an interesting subject for an advisory report on account of the ethical questions this type of care provision involves. These ethical questions are already emerging in the field. This was why the Province of Utrecht produced a publication in 2009 on ethics in care at a distance¹. The present advisory report can be seen as a sequel to the Utrecht compilation, but also to the advisory reports published by the CEG in 2004 on homecare technology.

1.2 What is care at a distance?

Care at a distance is care in which the care recipient is not at the same location or in the same room as the care provider; the distance is bridged with the aid of webcams, internet connections, fibre-optic cables and computerised measuring and recording equipment. Existing technologies are therefore given a new application. This type of care is also known as telecare². In this advisory report we use the terms ‘care at a distance’ and ‘telecare’ interchangeably.

¹During the presentation of the compilation Een verkenning van de grenzen. Ethische overwegingen bij zorg op afstand, on 23 September 2009, to state secretary Bussemaker, the Province of Utrecht handed the torch to the CEG. The debate resulted in the CEG publishing an advisory report on ethics and care at a distance.
²See also Pols, Schermer and Willems (2008). Telezorgvisie.
Care at a distance comes in various forms:

- Passive monitoring systems: domotica (homecare technology), GPS tracking

  **GPS tracking**
  
  Elderly people, people in the early stages of dementia, and chronically ill and disabled people are sometimes unwilling or no longer willing to venture outside because they are afraid of falling, becoming unwell or not being able to find their way back home. If they nevertheless wish to go outside, someone always has to accompany them. According to its providers, GPS tracking offers greater freedom of movement to people in need of care because they can go outside without an attendant carer being physically present. A small GPS device can be monitored on a mobile phone or laptop computer. It often has an alarm button too, which enables the person in need of care to warn the attendant carer if something goes wrong. In that case, the attendant carer, usually an informal carer, has to be alert.

- Active monitoring systems: the health buddy, diabetes and heart-failure programmes

  **The health buddy**
  
  The health buddy is a device with a display and four large buttons, and it is connected to an analogue telephone line. It asks the patient daily questions about symptoms, knowledge and behaviour. The patient can answer the questions on the display by pressing one of the four buttons. The health buddy responds to the answers in the form of teaching, confirmation and messages that require action from the patient. The entire process takes a few minutes and can be used at any time of the day. If the answers indicate a worrying pattern, a care professional is notified automatically. Care professionals use the health buddy to communicate with their patients and to provide feedback, such as tips that make it easier for them to deal with their chronic disease.

- Active alarm systems (whereby the user presses a button if something is wrong)

- Care systems: video communication with the aid of webcams but also digital outpatient departments

- Integrated systems for healthcare and social care: PAL4

  **PAL4**
  
  PAL4 stands for Personal Assistant for Life. It is a digital window in the form of a personal internet channel which can be displayed on any equipment that has internet access. This might be a touchscreen, a TV, a telephone or an ordinary computer. PAL4 is for people with a care or welfare question and a meeting place for members of their family for video contact, relaxation and questions concerning care and residential security. It is therefore multifunctional. Participants can use PAL4 to get in touch with each other, nursing staff, volunteers and informal carers. The aim is to provide optimum support for communication between the client, care providers, volunteers and informal carers.
1.3 **When is care at a distance used?**

Care at a distance is currently used for various types of conditions or problems:
- chronic diseases: such as COPD, diabetes, heart failure, risk of thrombosis, renal insufficiency
- fertility disorders (digital outpatient departments)
- cognitive disorders, particularly Alzheimer's disease
- social problems: isolation, lack of mobility.

1.4 **Promises and developments**

Various developments taking place in telecare involve both technological and social promises.

**Technological**

Technology companies are rapidly developing various types of telecare and domotica applications for in the home, such as sensor systems that will make it possible to monitor people in the home situation. A sensor system indicates whether anything unusual is occurring. It works by combining a number of signals, for example whether the bed was slept in and whether the refrigerator has not been opened for a while. The signals go to a system; given a particular result, a care provider or family member is alerted. Another development is support with routine, daily activities. People suffering from dementia can be given instructions that they should get dressed, for example, because they will be picked up half an hour later for a visit to the doctor or that they have to do some shopping, prepare a meal or take medicine (Beyen 2010).

The development of nanotechnology is seen as the big promise for the future. Nano refers to the billionth part of something; a nanometre is a billionth of a metre. Nanotechnology makes it possible to control substances at the molecular level and thereby develop materials with new properties. Experts predict the arrival of a new generation of supercomputers. They expect the rapid emergence of smart environments full of electronic devices that communicate with each other. They envisage clothing with built-in sensors that can monitor the wearer's heart rate and body temperature. Electronic aids of this kind will enable elderly people to continue living at home independently for longer (www.rathenau.nl, www.rivm.nl, Milligan e.a., to be published).

**Social**

The reference literature identifies various promises of telecare (Pols, Schermer and Willems 2008) which we will mention here. These are: (1) quality improvement by intensifying care; (2) more self-management for the patient; (3) ability to care for the aging population and the efficient deployment of a declining number of professionals and (4) the use of telecare to reinforce informal care and care networks. What the likelihood is of these promises materialising is impossible to estimate at the moment.
(1) QUALITY IMPROVEMENT BY INTENSIFYING CARE
Telecare will supposedly enable more intensive care. Many of the pilot projects in the Netherlands are based on this promise. They are primarily concerned with preventing any deterioration and promoting stability in the patient's situation. The medication taken is more closely monitored. More intensive monitoring of patients may avoid or reduce hospital admissions. Care professionals remain responsible and the patient consequently feels more secure. Care at a distance is presented here as supplementary to direct care. Patients see their care provider as often as before, but inform the care provider of the daily, routine measurements that they make themselves and thereby receive de facto more intensive care. The partial replacement of direct care by telecare does not necessarily mean that the promise of better total care will be fulfilled.

(2) MORE SELF-MANAGEMENT FOR THE PATIENT
The promise of self-management means that the patient will have more responsibility for the treatment and care and will also take over activities from the care professional. Patients will also largely determine when they call on the help of professionals. This means that telecare should promote the autonomy, independence and self-reliance of people.

(3) FEWER PROFESSIONALS LOOKING AFTER MORE PATIENTS
Telecare will alleviate the anticipated scarcity of care professionals in the labour market by making the available professionals more productive. This promise is the one most frequently mentioned in research but it is the one that has been crystallized the least. As yet, in pilot projects, telecare appears to create more work for professionals. The time they gain by not travelling is often lost again because the care becomes more intensive.

(4) SOCIAL SELF-RELIANCE
Telecare can make clients more socially independent because it enables them to maintain their social network. This promise is hardly ever explicitly stated but it turns out to be an effect of telecare in practice. The increased self-reliance and self-management resulting from telecare partially translates into more social self-reliance. Informal carers can use telecare too, and this can produce all kinds of benefits: an audio-video connection with a sick parent can be established in much less time than it takes to make a short visit. This type of contact puts patients and informal carers at ease. The internet also enables contact with people in similar situations. This promise approximates Health 2.0, in which information is shared on various topics through online communities and networks are emerging (RVZ 2010, Frissen 2010).

Consequently, there are high expectations about the social effects of telecare. However, developments are slow. Pilot projects are currently underway at various places in the
Netherlands with telecare applications (Province of Utrecht 2009). Various reports (NIVEL (Netherlands Institute for Health Services Research) 2007/2009, Court of Audit 2009, NICTIZ (National IT Institute for Healthcare) 2009, IGZ (Healthcare Inspectorate) 2009) indicate slow progress in the application of care at a distance. Video communication and telehealth coaching was available on a limited scale in the Netherlands in 2007, mainly in special projects and pilots. Although experiences with video communication and telehealth coaching were mainly positive in 2007, the number of telecare users identified in the 2008 survey had remained the same. Innovations in care are not spreading as quickly as some parties would have hoped. The various reasons for this are mentioned briefly below.

The Court of Audit (2009) observed that there is a lack of innovation incentives in the healthcare system for long-term care. The patient is still not a driving force behind care innovations, whereas users are positive. And healthcare providers see no financial benefit in innovation. A healthcare provider enabled by an innovation to provide the required care in less time cannot keep the payment for the hours saved. Research conducted by NZa (Dutch Healthcare Authority) in 2008 showed that although half the care administration offices have started to pay more attention to innovation, they still give little direction to telecare.

NICTIZ (2009) conducted research that looked at the role of care professionals in care at a distance. The researchers observed that in home care and care of the elderly, ICT and care are like ‘fire and water’. The situation is not much better in care of disabled people; there too, professionals are often hesitant about telecare. In mental healthcare, care professionals are largely convinced of the necessity of ‘e-mental health’. Looked at as a whole, NICTIZ concluded that care professionals are insufficiently involved in the introduction and use of care at a distance.

Technological developments are therefore much further ahead of implementation in care at a distance. Despite the possibilities, care at a distance is mainly applied in – local and temporary - pilots. Nevertheless, anticipated developments in demographics and the labour market, particularly in the care sector, will probably lead to care at a distance being used much more often out of necessity. The likelihood of direct care being replaced by care at a distance will therefore increase.

1.5 Question

More scenarios are possible for telecare from the social point of view. For example, care at a distance can be used to supplement the physical presence of a care provider or to replace that direct contact. In the present advisory report we mainly focus on the scenario in which telecare replaces direct care, as the ethical questions in this realistic scenario are the most pressing. Moreover, we restrict ourselves to ethical questions
concerning the application of care at a distance in the homecare situation. People whose health is deteriorating prefer to stay living at home for as long as possible (Dykstra & Fokkema 2007). They are more familiar with the situation at home and are able to be themselves. Taking this idea as the starting point, we examine the values that play a role when telecare enters the familiar environment.

Our point of departure in this advisory report is the expectation that technological developments will change our lives and way of thinking and that there will be a shift in the standards that apply in the community. Revolutionary developments in medical technology, such as the contraceptive pill and IVF have raised new ethical questions. It is quite conceivable that developments such as e-health and especially care at a distance will also change our opinions on what constitutes proper care.

De politiek der dingen (The politics of things)

“Besides giving things shape, they shape us too. Our lives and communities, our actions and ways of thinking are largely determined by the material world of technology, and thus by things. [...] Political decisions on technology should not only be based on the impact of technology on the environment and health but also on its impact on our understanding and expectations about how our lives and thoughts will be changed by it.” (Bolkestein and Van den Hoven 2009).

The title of this box refers to the book by Bolkestein, Van den Hoven, Van de Poel and Oosterlaken (ed.).

This is about understanding the effect of technology in interaction with its users. Technology has a built-in script for our actions (Mol 2001). The concept of ‘script’ was devised by the French techno-sociologist Madeleine Akrich. Like a script for a play, technologies include instructions on the division of responsibilities and assign positions (roles) to users and other parties who are involved (Akrich 1992/1995, CEG 2004). Looked at in this way, we can also ask the ethical question as to what extent it is good to accept the allocation of roles and responsibilities that a given technological development involves. In other words, it is advisable to give thought to the design of new technologies and the implications of the design for relationships between people and the quality of life (see also Hughes 2004). What do we think of the new behaviour and new relationships that are part of new technology in the care sector?

Technology therefore not only refers to a device but also forms part of a care arrangement. The way in which technology is designed partly determines our role in the relationship to others. In the case of care at a distance, this concerns the roles of patient, care professional and informal carer. It is quite conceivable that patients, care professionals and informal carers will enter into a new relationship with each other as a result of care at a distance; the care relationship will change. Moreover, this also raises the issue of ethically charged concepts such as privacy, control, security, self-determination, appreciation, trust, equality and responsibility.
This leads to the following question in this advisory report:  

*What ethical questions are raised by care at a distance? Which parties should consider those ethical questions and how should they do so?*

In the next chapter we present the opinions on telecare of patients, informal carers and professionals, as they emerged from the reference literature and the focus groups that we organised. Chapter three, the core of this advisory report, discusses the ethical questions and considerations raised by telecare. We conclude in chapter four with a few points for the agendas of policymakers.
So far away and yet so near?
2. Opinions of patients, informal carers and care professionals

The CEG commissioned a focus group study among patients, informal carers and care professionals (Ter Berg and Schothorst 2010). What do they think of telecare? The study's findings were compared with the results of quantitative research.

2.1 Patients' opinions

Differences between generations

The focus groups revealed a difference in opinions on telecare between younger patients and older patients. Younger patients find it difficult to see themselves in the role of a chronically ill person – although they were indeed chronically ill – and they have corresponding difficulty thinking about their lives with all kinds of care applications in the homecare situation, such as a health buddy or an internet connection to a nurse. Their main concern is the creation of a valuable and especially a ‘normal’ life, which would allow studies, work and personal relationships; they are no different in this than young people who were in good health. Looked at properly, ‘being ill’ in their experience is a side issue. They have no desire to be constantly confronted with their illness at home.

Older patients have less resistance to telecare. They say they want to be part of the modern era and the advantage they see of telecare is that it enables them to live at home independently for longer. They believe that telecare can form an important

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3 Focus groups provide an insight into the arguments that people say matter, the issues that concern them and latent sensitivities concerning the subject under discussion. Focus groups should be clearly distinguished from quantitative types of public studies, which are concerned with a representative survey of opinions. This has no place in focus groups. Focus groups are concerned with the occurrence of certain statements and not with the frequency with which the statements are made. In other words they are concerned with gaining an impression of the diversity of opinions that exist in the individual target groups.

The research conducted by Bureau Veldkamp comprised a focus group made up of professionals, two focus groups composed of informal carers (informal carers of people with a chronic mental condition and carers of people with a chronic somatic condition), and two focus groups made up of chronically ill patients (patients aged up to 35 and patients older than 55 years). The respondents were selected through a selection agency. To obtain greater insight into the dynamics of the care network and the experiences of users, interviews were held with three informal carers and their sick partner or parent. They were selected through a pilot project in the Province of Utrecht. Details of the study can be seen on the CEG website: www.ceg.nl.
supplement to face-to-face care. Older patients possibly accept ‘being ill’ more readily; illness is simply part of old age. The norm for elderly people is to continue living independently for as long as possible. It may also be the case that elderly people more readily accept telecare because it makes them feel safe and they see ‘security’ as something which is important to them.

Types of self-reliance
Future elderly and chronically ill people will probably increasingly embrace values such as independence and self-reliance (Dykstra & Fokkema 2007, RVZ 2008, RVZ 2010). The idea is that the patient personally monitors what has to be done and brings in help when necessary. The study by Pols e.a. indicated that, as yet, people who are chronically ill prefer to leave their illness to be dealt with by ‘those who understand it’; they put safety before self-reliance (Pols, Schermer and Willems 2008). However, the study by Ter Berg and Schothorst (2010) showed that patients have a considerable need for autonomy and personal control. In the quantitative study (Nivel 2008) users of video communication and their informal carers were also asked about safety and self-reliance. Seventy percent of patients indicated that their feeling of safety had increased since they started to use video communication. A third of patients thought that video communication had made them more self-reliant and more independent and that this had made them more capable of continuing to live at home.

Older patients enjoy being more involved in the course of the disease. They consider it useful to be able to forward more details about themselves and like the fact that their use of medicine can be monitored via care at a distance. It is also important to have good people at the other end, people who can be trusted. Younger patients think it is handy that they have an online connection with their specialist, as they are not normally able to arrange an appointment quickly. At the moment, the long waiting period makes them feel compelled to allow complaints to ‘mount up’ before they decide to make an appointment.

“Sometimes you might just have a minor question and with this system you don’t have the problem that you have to wait three months to get an answer from the neurologist.”

We find various types of autonomy in the focus groups, namely individual control and freedom of choice. For older people, being ill becomes an integrated part of their life and telecare is a means of being able to remain independent for longer. In the case of younger people, their illness is on the sidelines and they are mainly concerned with getting access to care quickly.

Determining the contact yourself
Patients want to determine the moment of contact themselves. They say they do not want a nurse checking on them via a webcam, for example. They envisage a situation in
which patients report at given times and that someone only looks to see if anything is wrong at the moment that they fail to report. However, initiatives of this kind already exist in a different form, such as with telephone circles in which people call each other to check that everything is all right.

**Internet and privacy**

Young patients are more inclined to see telecare as a privacy-sensitive issue. After all, telecare is based on the assumption that details are known and are saved. Young people in particular are fairly suspicious about this. Their concerns mainly relate to security. They wonder who has access to telecare data and want to know whether their personal details are saved, thereby creating a data file. Their experience is that internet traffic always leaves traces behind.

2.2 **Informal carers’ opinions**

### From reassurance to more responsibility

It is reassuring for informal carers when remote professional help is available (see also Nivel 2008). They report that this enables them to build in a measure of remoteness for themselves. They feel less burdened if they can also contact the patient with the aid of telecare. Older patients in particular often need several visits a day. Telecare could reduce the frequency:

> "I sometimes drive back and forth several times a day to do things that I could do differently with this. I could easily sort it out for them if they could see me or I could show them how and I wouldn't have to visit."

At the same time, informal carers are afraid they will be assigned more responsibilities. For example, they are afraid that a general practitioner might say they should give an injection to a patient with a certain insulin level. They would like care professionals to retain the responsibility and have no desire to be in a situation in which they are always the ones who have to carry out the further medical actions or have to make estimates.

### The need for involvement

Various informal carers think that care at a distance could never replace *face-to-face* care, i.e. the daily chat that they have with the patient and the visits they make. Informal carers see their involvement as an essential component of looking after someone close to them and they believe it is impossible to establish this type of involvement through care at a distance. The emotional link between the informal carer and the patient is important and difficult to replace; informal carers know their patient extremely well. In their view, certain care cannot be left to third parties. Especially informal carers of mental patients are afraid that care at a distance is impersonal; the term call centre was used on several occasions. Informal carers do not want to see telecare lead to the personal bond becoming a visual bond; they also want to be able to respond physically
to those close to them. However, informal carers see the benefits of telecare for people with certain physical conditions, but they make what they believe to be an important distinction between social contact and real care. Nivel (2008) also concluded that informal carers are generally less positive than the patients themselves about the effects of video communication and telehealth coaching for patients.

**The special position of mental patients**

Informal carers of mental patients say they are extremely afraid of abuse occurring; they have had bad experiences with transferring care to third parties. One case mentioned was that of a patient who handed over his bank pass and the attendant carer subsequently stole money from his bank account. Informal carers are afraid of abuse occurring because they see mental patients as especially susceptible to external influences. Taking these informal carers’ opinions on ‘proper care’ into account might well suggest that they see their own role as indispensable; it is as if they are unable to let go of the patient. These informal carers therefore see the partial replacement of direct care with telecare as taking a distance. A certain type of mental patient, namely those suffering from social anxiety, might experience this distance as pleasant and therefore *de facto* be able to accept more care.

It is especially in mental healthcare that e-mental health is taking off; the sector has developed a range of online interventions\(^4\) (Trimbos-Instituut 2007). E-mental health is the use of information and communication technologies to improve mental healthcare and provides support for members of the public and patients in managing their own health. Demand for e-mental health is increasing; supplies are growing and the reach is increasing.

### 2.3 Care professionals’ opinions

**Experience makes the difference**

It makes a difference whether a care professional is already acquainted with care at a distance or has no experience with it (NICTIZ 2009, Ter Berg and Schothorst 2010). Care professionals who are not yet working with telecare are unable to imagine what it is like and are hesitant about it. They mainly ask whether it changes the character of the care and whether telecare is proper care. Two care professionals:

*I try to imagine myself at the monitor screen. I think that not being able to get hold of patients or simply touch them would take a lot of getting used to.*

*If I’m at the monitor screen, I can’t just put my arm around someone who starts to cry but I can when I’m visiting.*

\(^4\) The disorders here may be completely different from those in the focus groups.
The care professionals who already work with telecare find that it makes their occupation more attractive. The professionals in the focus group clearly see telecare as a supplement to direct care. They think that telecare makes the care better and more intensive and also that telecare can increase efficiency. The benefits of telecare they mention are that they can be briefly in touch with the patient several times a day and that they can more easily determine whether a quick visit to the patient is necessary. Care professionals therefore expect telecare to strengthen the image of their occupation as well as to improve the quality of care.

**A more relaxed kind of contact**

Does telecare result in the loss of warm communication? Opinions differ about this. Some professionals raise objections while other professionals who have had experience with telecare rate contact through the monitor screen as no different from contact in the homecare situation. They indicate that *screen-to-screen* contact makes the relationship more personal rather than more impersonal (see also Pols, to be published). They believe that the monitor screen provides a certain type of intimacy. When professionals carry out all kinds of actions in the patient's home, there is actually no time for a chat and professionals see this as a disadvantage; this was not even mentioned by patients in the focus groups. The on-screen chat takes place in a more relaxed atmosphere; patients experience the pressure of time less.

"Very convivial. Normally you're in the home for an hour but you speak with him less than in just ten minutes of on-screen contact."

**More privacy for the patient**

Care professionals believe that telecare increases patient privacy. When a nurse or carer visits the patient at home, patient privacy is not very evident; sometimes the care provider even has a front-door key. Telecare keeps the professional at a distance and there is therefore less of an infringement of privacy. It can also increase the privacy of a patient's cohabiting partner. In the case of intensive care, partners often more or less lose control of their own household because of the increasing number of visits by medical professionals.

2.4 **Conclusion**

What pros and cons of telecare are mentioned? Patients are generally positive about the possibilities and see the benefits of the freedom of choice and self-reliance that telecare can provide. An important observation was that they want to be in control of the contact via telecare. Professionals are also positive; they think that telecare can increase the profession's status, improve the quality of care and give them more job satisfaction. Informal carers have the most objections, especially informal carers of patients with a mental condition. They believe involvement is of considerable value in
the care relationship and cannot see how involvement can be established through telecare. Moreover, they fear that care professionals might shift more medical activities and responsibilities onto them in the future. They are also concerned about abuse.

The difference in outlook on privacy between young patients and care professionals is interesting. Young patients are concerned about privacy-sensitive aspects of the internet; conversely, care professionals consider that privacy increases with telecare, given the likelihood that fewer professionals will need to visit patients.

In general people see telecare as a good supplement to existing care and also believe it is necessary to ensure care continues to be affordable. At the same time, people find it difficult to imagine that telecare will entirely replace direct care.
3. **Ethical questions in the case of more care at a distance**

3.1 **Is it just a question of getting used to it or is more involved?**

What will replacing *face-to-face* care with care at a distance mean in practice? Perhaps we could envisage it by comparing the situation with internet banking. Internet banking was introduced gradually and at some point became commonplace. It was initially a nice alternative for whiz kids: an optional new, modern way of settling banking business. Later it gradually became more normal; the frequency of ordinary bank statements decreased and people received fewer transfer forms. Now some people receive hardly any statements on paper and conduct all their financial transactions on the internet. Anyone who wants to revert to paper bank statements has to pay extra. In short, the old method has become unattractive and is increasingly giving way to the new method. The new method is not the norm. Will the same happen with care at a distance? Will care providers gradually switch to a new way of working? Will care provision become less tangible and visible, as with banking? Will telecare become increasingly less of an alternative and more the norm? And would there be any objections if that were to happen? The aim of this chapter is to delineate and classify the ethical questions and considerations in care at a distance.

A shift to care at a distance as a replacement of *face-to-face* care is indeed anticipated. At a time when demand for care is growing and costs are increasing but, simultaneously, fewer care providers and resources are available, patients will be given more individual control and responsibility, and can expect care professionals to be present less often and to have less personal contact (physical touch) with them. This raises the question as to the extent to which such developments can continue. At the moment, people can still opt for care at a distance but it will increasingly replace *face-to-face* care and the option will no longer exist. The key question in this chapter therefore concerns the ethical characteristics that care at a distance needs to have to make it an acceptable replacement for existing *face-to-face* care.

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5 See also the coalition agreement of 30 September 2010: “stimuleren zelfmanagement cliënt” (encouraging client self-management).
3.2 Ethical questions and considerations

Telecare changes the care relationship. What are the ethical implications of this?

MORE COOPERATION
From the ethical point of view, technological developments that enable care at a distance and promote the self-management of patients or clients give rise to tensions. Self-management (interpreted as providing as much personal control as possible over the care of your own health) assumes autonomy, i.e. freedom to take decisions affecting the organisation of your own life. At the same time, self-management calls on an individual's personal responsibility for healthy behaviour, personal care and compliance with the therapy. The requirement of personal responsibility is inseparable from the need to control and fairly apportion the cost of care.

With this, and certainly in the present policy context, 'self-management' invokes two conflicting ideals. On the one hand, self-management is based on the ideal of autonomous, free individuals who organise their own healthcare. On the other hand, self-management assumes that the patient will comply with the instructions of care providers; the patient has to feel bound by the instructions. Self-management therefore means not only self-reliance but may also require the patient to obediently comply with a medical regime (Schermer 2009/2010).

How should we envisage this self-management in practice? Care at a distance provides several possibilities for systematically updating medical records. This requires discipline and meticulousness from patients and the people around them (informal carers). It also leads to verification; monitoring is necessary owing to the possible serious consequences of failing to comply with the therapy. Care at a distance implies self-management and that involves self-reliance but also the opposite, namely external control. Will a nurse use a device to chide patients who fail to comply with the health regulations?

According to Schermer (2010), it is important to find a reasonable balance between the responsibility of patients to attend to their own health and, on the other hand, the freedom they have to integrate medical instructions and lifestyle rules in their daily lives, in their own way. It is advisable for patients with a chronic disease to maintain control of how they organise their lives. This requires proper coordination between patients and care professionals, with the professional taking into account the health-related values, opinions and priorities of the patient, rather than simply requiring measurement data and behaviour. Cooperation between a professional and a patient that displays respect for a patient's individual lifestyle is one of the criteria that care at a distance should meet, if it is to be an acceptable alternative to existing care.
A FAMILIAR FACE IN A TRUSTED ENVIRONMENT

Implementing care at a distance results in a different care relationship and the way we organise that relationship is extremely important. It is crucial that patients are not constantly faced with different professionals in a sort of call-centre setting. People who are designated for contact via a monitor screen want to see a familiar, trusted face. The choice for organising care at a distance is therefore ethically charged. Will patients be confronted with an efficiently operating call centre, with changing care providers who possibly live miles away or are we going to organise telecare to make it as personal and familiar as possible, so that patients are assigned a permanent telecare nurse who can also provide the direct care? The latter is preferable from the ethical point of view, as personal contact appears to result in better care.

Erosion of face-to-face care?

Another question concerns whether all care lends itself to being provided in the form of telecare. Telecare can be used for diagnostics, prescribing medication or lifestyle rules, measuring and monitoring disease parameters and symptoms to avoid admissions to hospital, increasing safety, giving instructions and providing psychological and social support (Schermer 2010, Milligan e.a., to be published). Using telecare to provide emotional support appears to be quite feasible, as does doing exercises while watching short films on the internet. A great deal of care can therefore be provided in the form of telecare. Obviously, some care cannot be provided remotely, such as washing a person or cleaning a wound.

Telecare users are afraid that technology will be deployed to the detriment of human contact (Pols 2009). This fear is confirmed by the focus groups that were established for this advisory report. Personal contact must not disappear. However, a webcam also offers personal, face-to-face contact with a care provider but via a monitor screen. Nevertheless, patients are interested in webcams (Pols, to be published).

Various studies have shown that care providers - nurses and those providing care – are attached to the human contact that takes place in existing, direct face-to-face care. It is precisely the interhuman contact that makes them appreciate the work (CEG 2009, Province of Utrecht 2009, NICTIZ 2009). They believe that reducing or removing this aspect would be to the detriment of their work.

Care professionals who already work with telecare are more inclined to see the advantages of telecare. Telecare enables them to be in touch with the patient several times a day and it provides them with a basis for determining whether someone should visit the patient. They say the on-screen contact they have with patients is more relaxed. A home visit is always subject to fixed times; there is often no time for a brief chat. As far as personal contact with patients is concerned, telecare changes the role of professionals less than they had originally expected.
Patients and care professionals alike consider personal contact important. However, telecare need not be an obstacle to personal contact; it can even make the care more personal. The question revolves around determining the types of care that lend themselves to telecare arrangements and those that never could or should be replaced by telecare. Besides establishing financial, human resources or practical criteria (a computer can't wash a patient), it would be advisable to establish quality criteria too. Are informal carers capable of carrying out certain medical activities they are assigned as well as professionals? Is it conceivable that patients who just need to feel someone's arm on their shoulder will have to go without that care because telecare creates a situation in which professionals and informal carers increasingly use on-screen contact and are less often physically in the neighbourhood?

**Does care at a distance help with self-management?**

**SELF-CARE**

One of the promises of telecare is that it will increase the patients' independence and ability to care for themselves (Pols et al. 2008, Schermer 2010). Within the scope of this, Schermer (2010) distinguishes between three types of self-management.

1. The patient is assigned various practical tasks and, in this sense, becomes an extension of the doctor or nurse. This is self-management but not necessarily autonomy. The patient's self-management is enhanced but not the patient's autonomy. The patient's own opinions play no role in this.

2. Patients learn disease management in an almost professional way. They understand the significance of measurement data, are able to interpret them and act accordingly. Patients become 'proto-professionals'. Here too, the patient's own outlook is not actually strengthened.

3. Patients are enabled and encouraged to find their own way of dealing with the disease in their lives. They can enhance their relevant medical knowledge, understanding and practical skills. Patients can make their own choices to improve the general quality of life, although the choices may not always be the most advisable from the medical point of view. The individual values of the patient are central. In this situation, the relationship to the care professional is one of cooperation and agreement.

The question concerns the type of autonomy we envisage in self-management: should we opt for autonomy in the sense of living your life as you see fit (3), or autonomy in the sense of personally carrying out medical activities (1 and 2)? From the ethical point of view, the third type of autonomy is preferable because the guiding factor is the person, rather than the system.
SOCIAL SELF-RELIANCE
Telecare could not only contribute to self-management and self-reliance but also to patients’ social self-reliance, as telecare enables them to get in touch with people in similar situations and family members (Pols e.a. 2008, Frissen 2010, RVZ 2010).

Most care of elderly people is provided by the family network, which will become ever more important as professionals increasingly provide care at a distance. People without a social network of this kind could face problems. It therefore makes a difference whether elderly people have a social network and what type of social network it is. There are differences such as those between elderly people with a partner and those without, between whether parents are divorced or not, between elderly people who have children and those without, and whether the children of elderly people live close by or far away (Stuijbergen e.a. 2008). Autonomy comes in many forms and grades (Feinberg 1986). People are not all equally capable of taking control of their disease and organising a network of informal carers around them. It may well be the case that care at a distance is mainly suitable for particular types of people, namely those who are not afraid to use equipment, who are independent and enterprising in life and who have a social network.

People who fail to organise informal care and a social network would be better off in a nursing home. The division between self-reliant and non-self-reliant has long existed. The question is whether we aim to increase the division by opting for telecare for self-reliant people or whether we aim to reduce the division by conversely opting for telecare that provides support for people who are non-self-reliant. The latter could be achieved by making telecare user-friendly and especially by deploying it for establishing and maintaining contacts. Telecare of this kind could facilitate the contact of patients and informal carers with people in similar situations. It turns out that users find contacts of this kind very enriching.

Privacy issues? Whose and how?
Privacy or rather ‘infringement of privacy’ is cited as an important ethical argument against the increasing implementation of care at a distance. It may well be that ethicists in particular foresee problems with this, as many patients put safety before privacy. Nevertheless, we examine below the situations that involve privacy issues and what may make those situations problematic.

Privacy refers to the home life of people. Unlike in public life, in home life people have extensive scope for freedom of action. The protection of home life - the indoor world at ‘home’ – is a major benefit; this is where people arrange their own lives in security and freedom as they see fit. Implementing care at a distance puts pressure on the division between home life and public life. If it is possible to ‘look’ inside from outside using webcams and sensors, the partition between public life and home life becomes, as it
were, porous. People are watched in their own homes; the 'outdoor world' interferes with the 'indoor world'.

In the case of care at a distance we can divide privacy into various 'domains': privacy in private life (the home domain), privacy in family life, and privacy in internet use.

PRIVACY IN PRIVATE LIFE
Privacy in private life refers to the privacy or security of the domestic domain. This privacy is affected when a camera 'outside' focuses on the inside. Patients may experience permanent camera surveillance as a form of surveillance that really infringes on their privacy. Nevertheless, this may sometimes be necessary, in the case of dementia for example. To experience privacy, it is important that patients or those close to them can decide whether or not they wish to cooperate in a particular arrangement (Ter Berg and Schothorst 2010). Patients may consent to being observed as long as they can choose when. They remain in charge of their own home.

In addition, telecare can enable people to become increasingly aware of their medical situation. The appearance of all kinds of medical equipment in the homecare situation will lead to increasing medicalisation of private life (Rathenau Instituut 2009). Because people are more aware of each other's health, pressure may also increase from the social environment. This may also restrict people's privacy, at least when they also experience the pressure from their surroundings as pressure.

In the case of dementia, people in the immediate vicinity often have control of the organisation of the patient's daily life and considerations concerning privacy are perhaps different. Resident informal carers of patients who are suffering slight symptoms of dementia bear a heavy burden and the situation of these attendant carers could be eased somewhat by passive monitoring systems. However, in that case the choice should lie with them: how much of their privacy are they willing to relinquish to create more space in other areas? Attention should also be paid to the privacy of people suffering from dementia. Further examination of how this ought to be done is required; ethically speaking, it is a major challenge to take into account the wishes of people who are becoming increasingly unable to give informed consent. An ethical complication with the types of monitoring systems concerned here (such as the Unattended Autonomous Surveillance system) is that they are invisible. Records of data on the situation at home are kept inconspicuously. This need not be a bad thing; systems of this kind often give patients and their attendant carers a feeling of security without immediately disturbing the domestic domain, as the system is not noticed. However, the fact that people have no problem with it does not mean that there is no ethical problem. For example, what happens with the data records that are kept inconspicuously?
PRIVACY IN THE FAMILY DOMAIN

Screen-to-screen contact is sometimes less threatening or intrusive than nurses who make home visits. Sometimes there are daily visits from numerous care professionals. The person in need of care is unable to leave the home if a visit from another care provider is expected. Moreover, the rhythm of life in the home is determined by the appointment diaries of care professionals. This is experienced as disruptive not only by people in need of care but also by family members and informal carers; after all, their private life is affected too. These complaints may well say more about the way care is organised at present than it does about the desirability of telecare.

PRIVACY AND INTERNET USE

Some types of care at a distance involve using the internet. Patients can get in touch with a nurse, but – in the case of PAL4 for example – they use the same system for making social contacts. Not everyone is aware of the possibilities and hazards of using the internet. A considerable level of media-literacy is required to be able to determine what information to place on the internet and to control who can read or view it, whether the data entered will be collected and traceable to individuals and who will be able to access the data. People who use the internet must be capable of indicating their own limits. People are not all equally capable of this.

Care at a distance will increasingly penetrate our home life. Will we put up with any resulting infringement of our security and space for freedom of action in the home domain? Or should we actively seek forms of telecare that leave home life intact as far as possible and keep as much space for freedom of action as possible? From the ethical point of view it would be advisable to raise this question and put it to the relevant groups (manufacturers, users and care providers), and assign them the task of determining what characteristics the appropriate forms of telecare might have.

Are patients, informal carers and professionals free to opt for telecare?

This advisory report is based on the assumption that care at a distance will increasingly replace face-to-face care. An ethically sensitive point is whether ‘fine tuning’ will continue to be possible, with regard to the type of care at a distance that a person considers desirable or at least acceptable, for example. With internet banking we saw how the old method gradually became unattractive and cleared the way for the new method. Practically unnoticed, internet banking has become the standard; it is questionable whether members of the public consciously opted for this. As prospective users and informal carers, will we be free to choose between various forms of telecare? And, in the event of care at a distance increasingly becoming the norm, will we be able to choose between care at a distance and direct care?
PATIENTS' WISHES AND FREEDOM OF CHOICE
If telecare replaces direct care, the importance of a supporting social network will increase and the possibility of having a professional ‘at the bedside’ will decrease. Research shows that older patients feel less good about receiving instrumental support (such as physical care) from family members and friends; they prefer to receive care from a professional, or in any case a person with whom they have more of a professional relationship (Merz 2009, Stuifbergen, Dykstra & Van Delden 2009, Ter Berg and Schothorst 2010). Will patients be able to opt in practice for a situation in which they are not too reliant on a family member and, nevertheless, still able to live independently? It is conceivable that the general adoption of telecare might result in family and friends increasingly providing physical care. This is contrary to the wishes of patients, who prefer not to receive physical care from those close to them. This effect of introducing telecare may therefore also be ethically objectionable.

WISHES AND FREEDOM OF CHOICE OF INFORMAL CARERS
Telecare can provide informal carers with support and ease their workload, when equipment is able to monitor people in the early stages of dementia for example. Telecare via a webcam or a digital outpatient department is also often reassuring for informal carers, especially if they look after patients with a physical condition; as mentioned, informal carers who look after patients with mental problems are hesitant about this type of telecare. However, replacing direct care with telecare may involve asking more of informal carers. Informal carers may not look forward to this prospect, especially if they have to carry out medical activities too (Ter Berg and Schothorst 2010). Informal carers are known to sometimes find it difficult to be mindful of their own limits. The interests of the person in need of care are a major concern for them. If telecare results in even more care becoming the task of informal carers, they will probably oblige, even if they would prefer not to and even if they do so at the expense of their own health. Therefore, the difficulties informal carers experience may not manifest as problems in the care system. However, from the ethical point of view, any such overburdening of informal carers as a result of telecare would be a bad thing.

WISHES AND FREEDOM OF CHOICE OF PROFESSIONALS
Patients like to maintain personal relationships with relatives and friends; they like to engage professionals for physical care. However, professionals think the personal relationship with the patient is an important factor in their work. A question arises as to whether more telecare will be an issue in the freedom of choice of professionals. Will they still be able to choose what they deem to be proper care, namely care in which the human dimension continues to be part of their work? It was argued in section 3.2.2 that care professionals can also build up a personal relationship via a webcam but whether all care professionals would do this successfully is an open question.
The result of certain types of telecare may be that particular groups of patients feel they are at its mercy, that some informal carers are overburdened and that groups of care professionals feel their work ethos is being harmed. Ethically speaking it is important to have sufficient alternative forms of telecare on hand for these people or to ensure other types of care remain available, if telecare is not an option. Can we expect action from patients, informal carers and professionals if they feel their freedom of choice is under threat from certain forms of telecare? Are solutions conceivable that leave scope for care other than telecare, such as allowing patients to purchase the care they feel suits them (personal budget) or allowing them to save throughout life to hire private care during old age?

**More responsibility and liability for patient and informal carer?**

The implementation of telecare will inevitably mean that patients and those close to them will have to carry out more medical activities. Telecare assumes more self-management and therefore changes the care relationship between the professional and care recipient. This also has consequences for the apportionment of responsibilities and liabilities. What shifts will take place and will they be acceptable from the ethical point of view?

Telecare places the care professional more in the role of a coach. Consequently, informal carers become more like semi-care providers, and may not look forward to such a prospect. They would probably prefer care professionals to retain the responsibility for the patient and do not wish to be the ones who have to carry out increasingly more medical actions (Ter Berg and Schothorst 2010).

There is another question for care professionals: if a patient's medical records are forwarded, what is the responsibility of the person who reads the data? Could patients be given a false sense of security because they incorrectly assume that care professionals will immediately read the data patients forward to them? Details are available of telecare projects in which care professionals have an extremely busy time processing and responding to ‘false positives’. Given their responsibility, they cannot ignore these messages. However, in such cases telecare creates a lot of unnecessary work, whereas the intention is to make the care professional's work more efficient.

Another point is the quality of homecare technology and the consequences of using the equipment incorrectly. Who is actually liable if a device becomes defective, the care institution, the patient or the supplier? Little attention has been paid to this subject. It will in any case be necessary to clearly delineate where the responsibilities between the various parties should lie, while also ensuring that proper arrangements about liability have been made.
In short, more care at a distance leads to a different care relationship and to a transfer of tasks between the care provider, informal carer and patient. Responsibilities and liabilities will rest on different shoulders, such as those of the already heavily burdened informal carers. There is also a risk that the quality of care will not be adequately guaranteed. After all, informal carers and patients have not always had sufficient training to carry out certain medical activities themselves. Specific legislation may be required to regulate the responsibilities and liabilities concerning the forwarding of data, the transfer of tasks to informal carers and problems associated with defective, inadequate or incorrectly used homecare technology.

**How to deal with consent in relation to new technological developments?**

During the course of a disease such as dementia, the legal competence of patients may diminish. This raises the question as to how to deal with patients who no longer remember having consented to telecare. Although patients may have previously consented to telecare, new technological developments or advanced insights into telecare may mean that the consent is no longer appropriate. It is also conceivable that a patient could indicate in a lucid moment that he/she does not want to receive any kind of telecare whatsoever. In such cases, it is up to the team and the family to assess whether it is in the interest of the patient to continue with telecare and, if so, in what form. The central ethical consideration should be whether the technology is still being used in the interest of the patient.

**How will the actual telecare be monitored?**

If we assume scenarios in which telecare will replace existing types of direct care, it is important for the telecare to meet certain quality requirements. Apart from technical reliability, deploying technology of this kind must also be ethically accountable. We have mentioned examples of this in this section, such as equality in the relationship between the care recipient and care provider (the patient or those close to the patient retain control), taking into account the social network of people, agreements about privacy, responsibility and liability, and taking into account the capacity and workload of informal carers. Any such ethical use of the technology should be anchored in quality requirements.

Some of these ethical guarantees can be regulated by guidelines, others require more specific regulations. Issues concerning privacy and liability should be regulated by law, insofar as this is not already the case. This is therefore a task for government. Healthcare providers and relevant professional groups should take into account the right relationship between care recipient and care provider and the social circumstances of patients. Guidelines on this can be drawn up in consultation with patient associations. And, although organising social safety nets around a patient may be more the domain of municipal authorities, care providers could play the role of mediator in this. In any case,
it is important for care providers not only to consider the patient as an individual but also as a person in a social network. Moreover, it is important to pay extra attention to the responsibilities and workload of informal carers. District and municipal support centres for informal carers already exist; municipal authorities could expand this task.

3.3 Conclusion

Unlike with internet banking, which concerns an administrative action, telecare touches on vulnerable human relationships. Implementing telecare on a large scale will bring about major and mostly beneficial changes for all the parties concerned. Telecare can provide better quality care because it can make the care more timely, accessible and personal.

Transferring care tasks to the social environment is the largest change that telecare will bring about. Patients will probably have to depend primarily on their social network for certain care tasks and informal carers will be confronted with an increase in their workload. Telecare therefore has consequences for the environment of patients.

The starting point for this advisory report is the scenario that telecare will be increasingly deployed. If telecare is to be an acceptable replacement for direct care, it will have to meet a number of criteria. Firstly, patients, or those close to them, must be able to retain control over when and to what extent there is contact with a care provider. Patients therefore determine when and to what extent the world of care enters their domestic environment. Adopting this approach safeguards privacy in personal life and freedom of choice. This turns care providers into a sort of coach; they assist the patient when necessary. Good telecare promotes patient autonomy, in the sense that the telecare enables patients to live their lives more as they see fit. It would even be possible to use passive surveillance systems in a system of this kind. This is not only because patients can give their consent to this (for instance because the system enables them to continue living at home for longer) but also because such systems can be designed to only display data once a given threshold value has been reached. In this sense, they cannot be compared with permanent camera surveillance.

Secondly, the patient’s social environment has to be organised for telecare. If more care tasks are transferred to the patient’s social environment, it will be necessary to pay more attention to the social network of people. Care professionals can help with organising the individual strengths of the patient’s social network. Failing this, the municipal authorities will have to organise a safety net.

Thirdly, with increasing implementation of telecare, more attention will have to be paid to responsibilities and liabilities. This should be organised properly from the legal perspective but this is not enough in itself. For example, it will also be necessary to
examine whether informal carers are capable of carrying out their task. This assumes focused attention on the balance between the capabilities and workload of the social environment of patients.

Fourthly, telecare must be extremely user-friendly, so that users (patients, informal carers and professionals) who are also not so familiar with computers can get used to it quickly. Any failure to pay attention to user-friendliness will lead to telecare reinforcing the division between self-reliant and non-self-reliant.

Finally, it is especially important in the case of telecare to have a good relationship of trust between patient and care professional. The deployment of a permanent team of well-trained professionals can provide a basis of this kind.
4. Points for policy agenda

Telecare can bring about a change in the quality of care, make patients more autonomous and socially independent, and help care professionals work efficiently. Telecare therefore definitely holds out a promise. However, for telecare to keep this promise, the division of roles and responsibilities to which the technology also gives shape must be properly regulated. This applies especially if telecare is to replace rather than supplement direct care. The following is therefore important for policymakers:

1. Telecare may enhance the autonomy of patients, not only because patients are able to carry out more care activities independently but also because telecare enables them to organise their lives more as they see fit. However, some forms of telecare are conceivable that result in a medical regime being imposed on patients more than was the case in the past. It would be advisable to ensure that cooperation between professionals and patients is such that the patient's own lifestyle is respected. This protects the patient's autonomy.

2. From the ethical point of view, personal telecare would be the preferred choice. Therefore, encourage searches for technologies and arrangements that put patients in touch with permanent care providers and avoid anonymous call centres. This protects the human dimension of care.

3. It is important for the patient to retain as much control as possible over the time of contact with the care provider. This protects the patient's privacy.

4. Telecare sets new requirements for the patient's social network; in the event of the network being incapable of meeting the requirements, the introduction of telecare will mean a deterioration vis-à-vis direct care. It is therefore important for each patient's social network to be properly delineated and organised for telecare before switching to telecare.

5. Encourage manufacturers to develop techniques that are also user-friendly for people who are not so familiar with computers. This will prevent any further division between self-reliant and non-self-reliant.
6. There is currently no clear and fair division of responsibilities and liabilities between manufacturers of telecare equipment, care providers, care users and informal carers. It is important to conclude well-defined agreements about this.

7. Seek ways to prevent telecare resulting in any additional, hidden overburdening of informal carers.

8. In many cases telecare will include the digital exchange of privacy-sensitive information and users will not always be prepared for it. It would be advisable to protect this information against misuse.

9. An obvious step would appear to be to deploy telecare for the care of people suffering from dementia and patients who are unable to give informed consent, i.e. patients who are therefore no longer capable of making a well-considered decision on the deployment of telecare. It would be advisable to consider the ethical arguments for and against any such imposition of telecare.

10. It would be advisable to monitor the actual telecare, to see whether the care meets the ethical conditions. Healthcare providers should show respect in their relationship with the care recipient and be mindful of what the social environment of patients is capable of providing. Guidelines on this can be drawn up in consultation with patient associations. Issues concerning privacy and liability should be regulated by legislation. This is a task for government.


Appendix 1

Composition of the Council for Public Health and Health Care (Raad voor de Volksgezondheid en Zorg: RVZ)

The work of the CEG/RVZ comes under the responsibility of the RVZ. The monitoring report *So far away and yet so near? Ethical considerations in care at a distance* was adopted by the RVZ in its meeting of 21 October 2010.

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**MEMBERS**
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Professor D.L. Willems

**GENERAL SECRETARY**
P. Vos
Composition of the Forum of the Centre for Ethics and Health (CEG/RVZ)

The Forum was set up in order to provide support for the CEG/RVZ’s monitoring task.

MEMBERS

- Dr. H.J.J.M. Berden, doctor and business administrator, member of Board of Management of St. Elisabeth Hospital, Tilburg
- Dr. M. Boenink, university lecturer on philosophy and ethics of biomedical technology, University of Twente, Enschede
- Professor D.P. Engberts, professor of ethics and law in health care, LUMC, Leiden
- Professor G. Glas, psychiatrist and professor occupying an endowed chair in orthodox reformed philosophy, Leiden University and Zwolse Poort, Zwolle
- Dr. M. van den Hoven, university lecturer on ethics, Ethics Institute, Utrecht
- Dr. J.C.M. Lavrijsen, nursing home physician, researcher and head of the Nursing Home Physician advanced programme, UMCN, Nijmegen
- Dr. A.C. Molewijk, programme manager Ethics Consultation, VUMC, Amsterdam
- Dr. D.P. den Os, represents the views of informal care and care of the elderly, Leiden
- Dr. J. Pols, researcher into care of the elderly/psychiatry/medical technology, AMC/UvA, Amsterdam
- Dr. A. Pool, nurse and psychologist, Krimpen aan den IJssel
- F.H. Stegehuis, care service manager, Menzis Zorg en Inkomen, Zwolle
- E. Ph. M. Otjens, represents the views of the patient, Utrecht

FROM THE RVZ

- Professor D.L. Willems, professor of medical ethics, AMC, Amsterdam, member of the RVZ and president of the Forum
- Professor D.D.M. Braat, professor of obstetrics and gynaecology, UMCN, Nijmegen, also vice-president of the RVZ and vice-president of the Forum
- Dr. A.J. Struijs, senior adviser and project coordinator, CEG/RVZ
- Dr. I. Doorten, senior adviser, CEG/RVZ
- L. Romein, project secretary, CEG/RVZ
Appendix 2

Preparations for the monitoring report

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– A.M. Mulder, Actiz
– Prof. M.J. van den Hoven, Delft University of Technology

Debate on ethics and care at a distance by the Province of Utrecht
During the presentation of the compilation Een verkenning van de grenzen. Ethische overwegingen bij zorg op afstand, on 23 September 2009, to state secretary Bussemaker, the Province of Utrecht handed the torch to the CEG. The debate resulted in the CEG publishing an advisory report on ethics and care at a distance.
Other consultations and adoption of the monitoring report

Draft texts discussed in:

CEG FORUM
Discussion memorandum: 26 November 2009
Progress report: 28 January 2010
Draft monitoring report: 23 March, 3 June, 21 September and a written round, 14 October 2010

RVZ ADVISORY GROUP
Plan of action: 7 December 2009
Draft monitoring report: 7 June, 30 August 2010

RVZ COUNCIL MEETING
Plan of action: 17 December 2009
Draft monitoring report: 17 June, 16 September 2010
Adoption of monitoring report: 21 October 2010

RESEARCH
Appendix 3

CEG publications

Monitoring reports

MONITORING REPORTS ETHICS AND HEALTH

2010:
Council for Public Health and Health Care
– So far away and yet so near? Ethical considerations in care at a distance

2009:
Council for Public Health and Health Care
– Dilemmas of nurses and carers
– Ethical considerations in healthcare-related TV Programmes
Health Council
– He who pays the piper calls the tune? On funding and the development of medical knowledge
– Care for the unborn child. Ethical and legal aspects of fetal therapy

2008:
Council for Public Health and Health Care
– Dilemmas on the doorstep. Reading early warning signs and intervention by professionals in parenting situations
– Farewell to non-commitment. Decision systems for organ donation from an ethical viewpoint

2007:
Council for Public Health and Health Care
– Appropriate evidence. Ethical questions concerning the use of evidence in health care policy
– Financial stimulation of organ donors
– Economisation of health care and professional ethics
So far away and yet so near?

Health Council
- Considerations pertaining to neonatal life termination

2006:
Health Council
- Should blood donors be tested for Variant Creutzfeldt-Jacob disease?
Health Council/Council for Public Health and Health Care
- Confidence in responsible care? The effects of performance indicators and moral issues associated with their use

2005:
Health Council
- Embryonic stem cells without moral pain?
- Ethical aspects of cost-utility analysis
- Now with extra bacterial Food products with health claims
Health Council/Council for Public Health and Health Care
- Tracking down threats to health: screening in GP practice
Council for Public Health and Health Care
- Health care professional and police informant?
- Ethics in health-care institutions and in the education of care professionals

2004:
Health Council
- Fertility insurance: medical and non-medical reasons
- Terminal sedation
- Pesticides, cosmetics, paints: the protection of test subjects in exposure studies
- Advanced homecare technology: moral questions concerning an ethical ideal
Council for Public Health and Health Care
- Intermezzo
- Advanced homecare technology: moral questions concerning a new healthcare practice
- Informal care, cost control and personal responsibility
- Increasing economic component of healthcare and how this affects professional ethics

2003:
Council for Public Health and Health Care
Demanding behaviour and aggression from care clients
- Pressure and informal coercion in care
- Cultural identity and self-determination for care clients of ethnic minority groups
- Self-determination and individual responsibility of people with mental handicaps

**Health Council**
- Activities with gametes and embryos
- Screening of neonates for congenital metabolic disease
- Medicines for children
- Engineering people

These publications may be obtained by e-mailing info@ceg.nl or may be downloaded at www.ceg.nl.