



Centrum voor  
Ethiek en  
Gezondheid

## Sensors in the home environment – The ethics of e-health part 3

### Summary

This report concerns sensors whose purpose is to enable people with an illness or disability, chronic psychological problems or psychosocial problems to live at home for longer. Currently, such sensors are primarily used for elderly people with incipient dementia. At the request of the Minister of Health, Welfare and Sport, the Centre for Ethics and Health (CEG) is identifying the ethical issues related to these sensors. In two other reports, the CEG has discussed the ethics of two other forms of e-health: health apps and wearables and the use of robotics in long-term care.

Sensor technology can be of added value. A smart home environment can provide support in daily living activities. Passive alarm systems, that send out a signal if something is or appears to be wrong, can provide a sense of control or safety. Lifestyle monitoring sensors can be used by informal or formal caregivers to detect any deviations in living patterns. The potential is clear and the expectations are high: people can stay longer in their familiar surroundings, which improves their overall quality of life and well-being and helps relieve the burden on informal caregivers. However, sensor technology also gives rise to various ethical issues relating to the protection of the individual, the care relationship and the home environment and social values.

### Ethical issues

It is not always clear what the purpose of sensor technology is or who exactly benefits from it. This makes it necessary to consider whether the use of this technology is justified. How can a balance be found between facilitating a safe and independent life for residents in their home environment, while taking into account the needs and care burden of informal or formal caregivers?

Sensor technology for monitoring and supervision may limit autonomy of residents, but can at the same time reduce the need for more drastic alternatives, such as physical restrictions. Respect for the vulnerable individual's personal life and interventions to make such a life possible need to be weighed against one another. The basic principle should be to give as much control as possible to the resident, especially if this person is still sufficiently independent and capable of informed consent.

Informed consent is a legal requirement if a formal caregiver uses technological means. But informal caregivers may also install sensor technology independently, which the vulnerable individual may not always be aware of. How can proper moral and legal agreements be made about this?

Monitoring and supervision applications involve both a restrictive and non-restrictive element. Monitoring sensors used by a formal caregiver can be labelled as involuntary care, to which the Care and Compulsion Act (*Wet zorg en dwang, Wzd*) applies. In case of sensors placed in the home environment, both spatial and informational privacy may be at stake. In connection with respect for privacy, the question that arises is: who has access to the data and for what purpose are the data used?

The use of sensors for lifestyle monitoring may influence the care relationship. After all, the number of contact moments as well as the measurable data become a component of the relationship. Does the data become more important than the resident's personal experience?

One's own home has a special significance as a place of safety and familiarity. Technological solutions should not ignore the needs and preferences of older or vulnerable people. What is more, the context within which these needs are formulated and the impact the sensors have on the daily lives of the people being monitored are also of great importance.

Equal access, inclusiveness and the fight against growing health disparities (whether or not reinforced by the use of technology) are important focus areas for policymaking, because these have an impact on the just distribution of care. To what extent are the sensors accessible and affordable for the people who need or want to use them?

### Lessons for the future

An important factor that makes a difference is that, compared to regular, face-to-face care, e-health makes remote care possible and this type of care is increasingly data-driven. This places different demands on users and policymakers. To encourage the ethically responsible development and use of sensor technology, the CEG lists the following points requiring special attention.

### Research on long-term effects needed

More research must be carried out into the practical experiences of different target groups. Current research on sensor technology covers a relatively short period of time and pilots and living labs are also often short-lived. The government is therefore advised to invest not only in designing new technology or improving existing systems, but also in thorough long-term research on the impact of sensor technology. It is important to involve both ethical and socio-scientific expertise in this research. In this way, attention can be focused on the context of use and the possibly conflicting interests of the users of sensors, especially since some of them are people who are less able to stand up for themselves.

### Protection of privacy and autonomy of the care recipient

Sensors can collect, store and share sensitive data. This gives rise to questions about how the data are protected, who has access to the data and with whom the data are shared. Informal carers sometimes deploy sensor technology without the consent or even the knowledge of the vulnerable person. Privacy is protected under the Constitution and within various international treaties. The GDPR (*Algemene Verordening Gegevensbescherming, AVG*) sets out the safeguards for the protection of privacy and the processing of sensitive information. There are no specific laws and legislation on the use of monitoring sensors by informal caregivers. However, the standards of due care imply that informal caregivers must respect the autonomy and privacy of those they care for as much as possible. Central or local government authorities and informal care organisations can take responsibility for this by laying down the agreements explicitly and drawing up guidelines for informal caregivers on the use of lifestyle monitoring systems.

### Focus on the care relationship and the home environment

Sensor technology is not meant to replace care, but is intended as a specific form of care. Policymakers can ensure that the use of technology benefits the care and the care relationship with the informal or formal caregiver and that values other than efficiency (such as involvement and meaningful contact) also continue to be safeguarded.

### Careful weighing of values and exercising restraint

The use of sensors for monitoring and supervision requires a very careful weighing of values: the value of living at home for longer must be weighed against the needs and capacities of informal caregivers and the wishes of the individual concerned. It is important for both informal or formal caregivers to exercise as much restraint as possible when applying lifestyle monitoring practices and pay due regard to the principles of subsidiarity and proportionality. This means that, where possible, preference should be given to achieving the same objective using less privacy-invasive measures or less high-tech solutions. Professional and informal care organisations can encourage discussions on how these values can be weighed up against one another and develop the guidelines for this. The government can supervise the development of and compliance with the guidelines for the responsible use of data and sensors in the home environment.