



Centrum voor
Ethiek en
Gezondheid

The ethics of e-health. Overarching message of the three CEG reports on e-health

Report on Ethics and Health 2020

The Centre for Ethics and Health

Het Centrum voor Ethiek en Gezondheid signaleert over actuele en beleidsrelevante ethische vraagstukken over gezondheidszorg en biomedisch onderzoek.

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1 Introduction

At the request of the Minister of Health, Welfare and Sport, the Centre for Ethics and Health (CEG) has identified the ethical aspects of three forms of e-health: [1]

- Preventive use of health apps and wearables
- Robotics in long-term care
- Use of sensors in the context of the Social Support Act (*Wet maatschappelijke ondersteuning, Wmo*)

For this, the CEG has prepared three separate reports [2-4] describing the building blocks for a vision of the ethics of e-health. The present document starts by reviewing the main conclusions and lessons from these three reports (§2). This is followed by an ethical perspective on the further development of e-health based on certain key themes (§3). A few examples of how e-health can be used during the COVID-19 crisis have also been included here.

The reports provide an insight into the various aspects that decision-makers need to reflect on in order to promote ethically responsible use of e-health solutions. This includes a wide range of aspects: from keeping an eye on foreseen or unforeseen effects to a broader evaluation of e-health applications while taking also ethical aspects into consideration, and from training to ensuring a greater involvement of the users of the technology. E-health technology is an ongoing experiment that touches upon shared values in healthcare and society. With this overarching message based on the three reports, the CEG is pleased to contribute to the formulation of policy on the further ethical development of e-health.

2 Conclusions and lessons for the e-health triptych

2.1 Health apps and wearables for prevention

The first report deals with health apps and wearables for prevention. In recent years, the government has formulated grand ambitions for the use of e-health, including health apps and wearables. The idea is that people can improve their health or prevent illness based on self-measurement. This can lead to cost savings in healthcare as well as enhance the autonomy and well-being of patients. However, each user will have to weigh up these potential advantages against possible disadvantages such as increased restlessness, an information overdose, and a possibly undesirable decrease in human contact. The use of apps and wearables also gives rise to certain social dilemmas. The government's role as the enthusiastic driving force behind the development of new applications may stand in the way of a critical monitoring of the quality of apps and wearables. Moreover, individual freedom to use apps and wearables may lead to an increased use of collectively funded care. Anxiety caused by the measurements and an overemphasis on health and the possible threats to it could result in this process of medicalisation. Finally, an increase in the use of apps and wearables can give rise to greater health disparities and inequities since not everyone is ready for or capable of self-management.

Therefore, the CEG advocates restraint on the part of the government in encouraging the use of apps and wearables. So far only limited research has been done on the effectiveness of apps. The challenge for the government (including the National Health Care Institute) is to identify the apps and wearables that are actually useful and can replace, improve or make more efficient certain actions or processes within the existing care or prevention services.

If healthcare loses sight of people with lower digital skills and non-users, health disparities may increase and solidarity principles may come under pressure. To avoid the marginalisation of non-users, the government could lay down accessibility and ease of use requirements in the context of the evaluation by scientists and the National Health Care Institute. But despite this, it is inevitable that some people will not be able or willing to use apps and wearables. The government will therefore need to continue to ensure access to non-digital prevention and care. [2]

2.2 Robotics in long-term care

Robotics in long-term care, which is the subject of the second report, is still in its infancy. There are hardly any care robots that can actually offer bedside assistance. Robots for social interaction and cognitive support are still limited in terms of capabilities. Further development and greater research are needed in order to use care robots to improve the quality of long-term care and possibly cope with staff shortages. Moreover, it is essential to continue focusing on practical experiences, particularly the consequences of the use of care robots on important care values. Because taking care of people is more than just performing practical care tasks. It is also about

involvement, caring, dignity, respect, (dealing with) dependency and meaningful contact. Care robots can affect these values both positively and negatively. Robots should not be considered a replacement for human caregivers but an addition to them. The relationship between the caregiver and the care recipient changes with the entry of the care robot into this relationship.

The government would be advised to invest in the further professional development of robotics in care. By considering the use of robots as an experiment rather than as an implementation of a mature product, the government can encourage developers and users to explore and utilise practical experiences to continuously improve these care robots. Furthermore, more research is needed to draw any conclusions about the long-term effects of care robots. The CEG argues that the values introduced by robots in the field of care should be explicitly examined and taken into account in further development efforts. Not the technological possibilities, but the question of whether that technology adds value to care services should be the determining factor. This means, for example, that opportunities for more meaningful contact need to be explored further. Attention should also be paid to training caregivers in the use of care robots and reaching agreements regarding the responsible use of data. Here too, the government has the duty to ensure that care resources are distributed fairly. [3]

2.3 Sensors in the home environment

The third report deals with sensors whose purpose is to enable people with an illness or disability, chronic psychological problems or psychosocial problems to live at home for a longer period of time. Sensor technology can be of added value. But it is not always clear who exactly could benefit from this and who might face problems. This makes it necessary to consider whether the use of this technology is justified. There are questions regarding the protection of the individual, the care relationship and home environment, and social values.

To promote an ethically responsible development and use of sensor technology, the CEG believes that more research is needed into the practical experiences of various target groups. 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.

Sensors can collect, store and share sensitive data. Central or local government authorities and informal care organisations could take responsibility for protecting the autonomy and privacy of the care recipient by laying down agreements and drawing up guidelines for informal caregivers on the use of lifestyle monitoring systems.

Sensor technology is not meant to replace care, but is intended as a specific form of care. The use of technology must benefit both the provided care as well as the care relationship with the informal or formal caregiver. In addition, values other than efficiency, such as involvement and meaningful contact, must also be safeguarded. 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 restraint 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 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. [4]

3 Vision on the ethics of e-health

3.1 Expectations from e-health

Many of the current policy documents are highly optimistic about how e-health technology will solve major social issues, such as an ageing population and staff shortages in care. There are high ambitions in terms of the access to and use of e-health. Apps and wearables are expected to give people more control over their health, robots will help against loneliness, and sensors are meant to help people to live independently at home for longer. In practice, however, we see that these objectives have not yet been realised.

There are different expectations regarding what e-health technology can and cannot do. These expectations, as well as the underlying values and interests, may vary and may sometimes be mutually exclusive: managers want supervision and efficient work processes, nurses want to provide good care to their individual clients, the elderly want social contact and autonomy, and informal caregivers want control and reassurance. What also plays a role are the interests of data companies: they want data. Therefore, different interests and values are at stake for different users, and these cannot always be reconciled with one another. This makes the implementation of technology a complex matter. Technology is not always - and not for everyone - the solution to the same problem. The specific application of technology in practice may also intentionally or unintentionally differ from the purpose for which the application has been developed (moving of the goalposts).

Technology is often seen as a 'quick fix' to social issues. This is clear from the expectations made from the various forms of e-health and also recently from the ambition of launching a coronavirus app on the market within a short space of time. But technology requires a lot of work - by humans - and is not merely a matter of 'rolling out and scaling up'. This means that new technology demands a continuous process of experimentation, learning, evaluation and adaptation. Technology takes shape in the context of use and is influenced by the objectives and values attached by people to the application of the technology.

Meaningful contact in the time of COVID-19

One of the measures to prevent the further spread of the COVID-19 virus is to limit social contacts. Much of our contacts and care services are now being conducted digitally. E-health technology can help in taking over a part of the communication with people in social isolation. Social robots might have been able to fulfil this function if they had been developed and implemented more extensively. Currently, there are hardly any robots that can take the physical tasks off the hands of caregivers, and robots for social interaction and cognitive support have limited capabilities. The report on robotics in long-term care reveals the importance of meaningful contact. This kind of contact is essential for a person's well-being and quality of life. But meaningful contact need not be human contact. People can also connect meaningfully with or via technology. Human contact is also not meaningful per se. However, human contact takes on a different significance when (a part of) the communication occurs via devices.

3.2 Technology push and conflicting interests

E-health technology is often developed by parties outside the care sector. Sometimes these are knowledge organisations, product developers, managers or municipalities that offer a particular innovation or have an interest in it. Economic interests may come into conflict with care values. Apps and sensors are incorporated into consumer products such as smartphones and home appliances. The revenue model of many of the providers of these products consists of collecting and selling data. This raises questions about the social responsibility of providers and the influence exercised by large corporations on healthcare. To safeguard public interests such as the quality, accessibility and availability of care and to ensure that collective funds in the care sector are spent in a responsible manner, it is important that private interests do not prevail.

Since much of e-health technology is still work in progress, it is important to keep room for further development and to continuously evaluate and learn from user experiences in practice. Various models have been developed to involve users in the design process and in the development of innovations (such as via co-design and co-creation) or in taking joint decisions on care. Moreover, inclusive or flexible design can be tailored to more personal requirements or individual users, because a one-size-fits-all model does not work in e-health either. This can help transform the technology push into desirable and effective support via technology.

Tracking and tracing apps and symptom checkers for COVID-19

The Minister of Health, Welfare and Sport is eager to have an app that can more quickly trace people who have had contact with someone possibly infected with COVID-19. [5] New possibilities are also being explored for doctors to keep in touch with patients remotely and monitor their health. An app that is already in use allows people to report symptoms such as fever and shortness of breath, after which a medical team can contact the patient, if necessary. A symptom checker can help people fulfil their social responsibility towards others. The CEG report on apps and wearables draws attention to the importance of quality and a critical monitoring of the development of new applications. Due to the enormous pressure to produce quick technological solutions to the coronavirus pandemic (techno-solutionism), [6] other important values in care and society are at stake. The criticism regarding the development of coronavirus apps for tracking and tracing is mainly focused on, for example, the lack of data protection [7] and the possible infringement of fundamental rights and freedoms (such as the freedom of association and the rights to safety, health, equal treatment and non-discrimination). Experts [8] have appealed to the government to impose conditions on the use of technologies during the coronavirus crisis: these must be, under all circumstances, temporary, strictly necessary, proportionate, verifiable, transparent and voluntary. [9]

3.3 New roles, different relationships and the man-machine relationship

E-health technology changes social practices and creates new roles for professionals and patients. The use of robots or sensors means that caregivers need to operate an increasing number of devices, be able to deal with sometimes complex ICT systems and handle large quantities of structured or unstructured data. This does not only require new skills - and hence further training and the need to keep abreast of developments - but also a new interpretation of the professional duties and accompanying responsibilities. The arrival of new parties in the sector is also changing the practice of care. With the expansion of the care network, various persons without a medical background are also becoming involved in caregiving activities, sometimes even without certification or training. This includes not just informal caregivers but also, for example, mechanics, data scientists and ICT companies. Health data are also being collected at home by non-healthcare

professionals and this information is being shared with multiple parties, including those outside the care sector. This implies that other values and interests may influence care practices. In addition, the relationships between professionals and hierarchical relationships in the field of care may change, for example, because technology can also be used to supervise the work of professionals (e.g. sensors) or because a different classification of tasks is required (as in the case of robots).

Ethical and legal safeguards, such as informed consent, duty of confidentiality and secrecy of the care relationship, are based on the traditional relationship between caregiver and patient. With the advent of e-health, there may be a shift from this professional care environment to the home environment. The sensitivity of the data implies that explicit agreements need to be made about how the sharing of information for providing good care - including at home by informal caregivers - will be handled in practice. Home and informal care organisations can help in doing this by informing their caregivers on how to handle data and information carefully and by developing guidelines, if necessary. Central or local government authorities can facilitate further research on ways to ensure that important values, such as privacy and autonomy, are also safeguarded within the informal care network.

Besides the change in professional roles, patients are also being asked to actively monitor and manage their own health. Health is therefore increasingly becoming the individual responsibility of citizens. As a result, the treatment relationship between caregivers and patients is also changing. This requires caregivers to assume a more supportive or coaching role or calls for models for taking the care decisions jointly, as well as policies that are aligned with these new roles.

Fears are regularly expressed that technology will soon replace the caregiver. Indeed, in the manufacturing industry, automation and robotics are set to replace human physical labour (assembly lines) or human intelligence (computers) with machines and smart systems. This does not work in the same way in the care sector, because the function of technology is complementary to human care. E-health technology is always combined with care by humans and influences those relationships (blended care). As the Minister of Health, Welfare and Sport has pointed out, 'cold technologies' can contribute to 'warm care'. [10]

Safety, control and monitoring in the time of COVID-19

Quarantine is one of the measures applied during the COVID-19 crisis. Particularly the most vulnerable persons, such as the elderly and those with underlying health problems, may end up trapped in social isolation at home or at the nursing home. Sensors in the home or around vulnerable people can help remotely monitor their movements. Sensors could also be adapted to detect and monitor signs of infection.

But there are also certain disadvantages. Sensors can give a false sense of safety since they may, for example, detect that someone has stopped moving or is having a coughing fit but fail to intervene. For that, an informal or formal caregiver must step in. It is important to keep in mind that lifestyle monitoring is a technical solution for dealing with concerns and doubts in the care of vulnerable people. Caregivers and informal caregivers must be trained to use sensors in an ethically and legally responsible manner.

3.4 Technology as an ongoing experiment

Technology is applied in the context of use, and it is the users who give shape to the technology in practice. For example, the effectiveness and reliability of an app are linked to its purpose and the way users behave, to testing capacity and diagnostics in hospitals and laboratories, and to the importance attached to certain freedoms and values. [11] Even if a device is of high quality and reliable, it may be used incorrectly or in a way it was not intended to be used.

This means that technology is being constantly put to the test, constantly changing, the goal is being constantly adjusted, and therefore the technology is never really complete. Many critics point to the importance of a slow introduction of technology and of treating technology as an experiment rather than as a 'finished product'. It is only during use that the actual effects of the technology and the values it embodies become apparent.

At present, various pilots and living labs are being conducted in the Netherlands, where e-health applications are also being developed and monitored. Unfortunately, many of these experimental spaces are often short-lived. The care organisations that often finance or co-finance these pilots want to recoup their investment quickly by making the technology operational as soon as possible. Moreover, most of the subsidies are aimed at the invention of new technology and short-term evaluations. These experimental spaces should be extended over time, because the goalposts keep moving in practice. Proper evaluation of the effects of a technology requires long-term observation of what users do with it. While scientists and developers have a role to play in this, policymakers and research financiers should also be asked to better emphasise the importance of research on the long-term effects. They can do so by making this kind of research an integral part of e-health subsidies, while setting requirements for the duration and composition of pilots that should focus less on one-off or short-term incentives for new technology.

Moreover, it is crucial to pay attention to the ethical and social effects: in the phase prior to the project (such as when subsidies are granted), in the design (such as value sensitive design and privacy by design), during the development and implementation, and for the ongoing evaluation of the technology. From the ethical perspective, the focus can be placed on the content-related dilemmas described in this document, but it can also be placed on the process. This means paying heed to the purpose of the technology (and being alert to an undesirable shifting of the goalposts), the context of use (including unforeseen effects), involving stakeholders (paying attention to conflicting agendas and people who are less able to look after themselves), and finally, safeguarding the human values that facilitate or encourage good care.

3.5 The importance of values in e-health

Values such as caring, dignity, respect for autonomy, reciprocity and meaningful contact play a key role in good care practices. E-health technology may reinforce or come into conflict with these values. Just as in the case of conventional (face-to-face) care, for e-health too certain considerations must be made and the moral dilemmas must be dealt with. However, ethical and legal issues relating to, for example, autonomy, control and privacy are not exclusive to the use of technology in care and are not necessarily new issues. Moreover, there is no black and white distinction between conventional care and e-health. It is precisely the integration of different forms of care, within a blended care system, that deserves our attention. However, there are certain values and ethical dilemmas that are magnified by technology, adding new dimensions to our understanding of good care. An important factor that makes a difference is that e-health makes remote care possible and that this type of care is increasingly data-driven. This brings with it new tasks and responsibilities as well as new professions and skills, as we have shown previously. The type of issues that require ethical reflection goes increasingly beyond the doctor-patient relationship.

The role of data is crucial in this constellation because other requirements need to be imposed on the interpretation of traditional ethical concepts, i.e. from specific and individual to generic and social. Ethical and legal questions about privacy, consent or control (as well as about data) relate not only to the doctor-patient relationship but calls for attention at the societal level, given that the effects have an impact on larger groups of often vulnerable people. Technology can have harmful effects at the societal level, by leading to discrimination, exclusion, social inequality or increased

health inequalities. E-health can put pressure on shared values such as solidarity, accessibility and quality of care, but with responsible use, it can also reinforce these values. These are the core values in care that call for shared responsibility, alertness and continuous attention.

4 Literature

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Appendix 1 - Composition of the CEG Presidium and Committee

CEG Presidium

- Prof. M. Bussemaker, Chair of the Council for Public Health and Society (*Raad voor Volksgezondheid en Samenleving*)
- Prof. B.J. Kullberg, Chair of the Health Council (*Gezondheidsraad*)
- Prof. M.H.N. Schermer, Professor of Philosophy of Medicine and Social Engineering, Erasmus MC, Rotterdam
- Prof. A.J. Pols, Socrates Professor of Social Theory, Humanism & Materiality, University of Amsterdam and Senior Lecturer and Principal Investigator, Academic Medical Centre, Amsterdam

Composition of the CEG Committee

- The CEG Committee was set up in 2015 to perform the reporting tasks of the CEG.
- Prof. M.H.N. Schermer, Professor of Philosophy of Medicine and Social Engineering, Erasmus MC, Rotterdam, Chair
- Prof. A.J. Pols, Socrates Professor of Social Theory, Humanism & Materiality, University of Amsterdam and Senior Lecturer and Principal Investigator, Academic Medical Centre, Amsterdam, Vice Chair
- Prof. G. A. den Hartogh, Emeritus Professor of Medical Ethics, University of Amsterdam
- Prof. A.C. Hendriks, Professor of Health Law, Leiden University
- Prof. C. Leget, Professor of Ethics of Care, University for Humanistic Studies, Utrecht
- P. Lips, general practitioner and MPhil, National Association of General Practitioners (*Landelijke Huisartsen Vereniging*)
- Dr G.J.M.W. van Thiel, University Lecturer on Medical Ethics, UMC Utrecht
- P.J. Nickel, Senior Lecturer, Department of Philosophy and Ethics, Eindhoven University of Technology
- Dr A.A.E. Wagenaar, Department of Orthopedagogy, University of Amsterdam.

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Draft versions and adoption of the report

CEG Committee

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CEG Presidium

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