Health apps and wearables - The ethics of e-health part 1

Summary

More and more people are using apps and wearables to monitor their own health. The government sees opportunities for the use of this technology in healthcare for preventive purposes. The idea is that people can improve their health or prevent illness based on self-measurements. This can lead to cost savings in healthcare. Moreover, the possibility of self-management could enhance the patient's sense of autonomy and well-being. However, the increasing supply and use of such apps and wearables also gives rise to certain ethical issues. At the request of the Minister for Medical Care and Sport, the CEG has mapped out these issues.

New health apps and wearables are being launched almost every week but not all of them are of high quality. The government has ambitious plans and applauds the development of apps and wearables. But how can the government welcome this development but also critically monitor it at the same time? If the government recommends apps and wearables at meetings or on websites, this may create the wrong impression that these have already proven their added value.

While it is true that an app that does not work properly need not be harmful - an unresponsive app, for example, is chiefly a source of irritation - situations may arise where people are wrongly reassured by an app. This can lead to health damage. Users may also become unjustifiably alarmed. This is not just detrimental to the well-being of the user, but from a social perspective, it is undesirable that healthy people call on care services because of unwarranted signals from apps or wearables. If this happens, will care still reach the people who need it most?

The challenge for the government is to identify the apps and wearables that are actually useful and to replace, improve or make more efficient an action or a process within the existing care or prevention services. Apps and wearables that allow for a more sensitive tracking of risk factors must be proven to contribute to health improvement. Care providers can put patients who have been wrongly alarmed by measurements on a 'demedicalising' track. For example, they can inform patients about the limitations of apps and wearables and the revenue models behind them. They can also avoid the problem of information overload by helping people use apps and wearables selectively, where only the health indicators that make sense for the health-related goal being striven are monitored.

Many health app providers collect user data for commercial purposes. It is desirable to gain an insight into the revenue model of these providers. User data may be used to create targeted ads and build user profiles. Health insurers may use the user data from apps to segment customers into groups with relatively unhealthy lifestyles or healthy lifestyles. Some apps are particularly targeted at children. A playful app that encourages a healthy lifestyle can be an effective way to combat obesity within this target group. However, it can also lead to stigmatisation and low self-esteem, because of the possibility to compare one's performance with that of classmates or friends. Children will not always be aware of this risk.

The aspect of self-management that can be facilitated by apps and wearables is not feasible or desirable for everyone, since not everyone has the necessary knowledge and skills for this. Apps are often not tailored to people with low digital or health literacy or with a diverse cultural background. For some people, managing their own health can have too great an impact on their quality of life. For example, they may experience it as a burden or feel guilty about adverse health outcomes over which they have no control.

If healthcare does not pay enough attention to 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 requirements relating to accessibility and ease of use in the context of the evaluation by scientists and the National Health Care Institute. It is also a good idea to involve vulnerable user groups during the development phase, as done by Pharos (Dutch Centre of Expertise on Health Disparities). Accessibility could then become part of a quality mark. 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 healthcare. It is also possible to tackle the social causes of an unhealthy lifestyle more effectively through, for example, spatial planning measures and by offering healthy food in schools. An additional advantage is that such measures do not involve any risk of data misuse, as is the case with the use of apps and wearables.