Medical Trust Beyond Clinical Walls

Valorization Workshop Report

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The NWO-funded Societally Responsible Innovation project Medical Trust Beyond Clinical Walls investigates how telecare used as part of a treatment plan for chronic illness transforms the trust relationship between physician and patient. Telecare is defined here technological systems and accompanying services that allow patients to be remotely monitored and provided with information and advice specific to their medical situation in an automated way (e.g., via a web interface).

This report descibes the discussions of a workshop held on 21 February 2013 with Dutch industry and public stakeholders. Two focus groups formed to reflect on the future of telecare and societal trust in telecare. Originally the two groups were meant to focus on telemonitoring and telecoaching, but the discussions ended up being much broader, reflecting on the future of telecare and its public acceptance. These reflections will be used to target the research project and formulate ethical guidelines for trustworthy telecare.

I. First Focus Group

Participants: Lems, Kraemer, Vos, Kruijt, Nap

Broad future trends and transitions

Today we are in transition from a situation where monitoring takes place in the clinic, to one where it takes place outside the clinic. The participants predicted the following broad trends and problems:

- Telecare will be embedded in the social and living environment. It will both monitor and give feedback to people. Alongside this development, in the future the role of the physician will change to that of supervisor of intelligent systems. Specialists will need to have skills related to managing these systems, and also have a generalist's overview.
- Telecare will give people with health problems more autonomy and self-sufficiency, but it will also place pressure on them to adopt the technology and behave in certain ways, and make them responsible not just for their own health, but for their own health *care*. For example, higher insurance premiums could be assessed for those who do not adopt healthier lifestyles or use telecare systems.
- The lack of structural financing of telecare will be a barrier to innovation in this area.
- Coordination problems and conflicts will arise because of different telecare systems used by different institutions or for different health conditions, and could even lead to unsafe situations for patients. (This concern was repeated by the other discussion group.)

Trust and distrust

The group also discussed situations in which patients and society could have either too much or too little trust in telecare, relative to the reasonable (ethical) expectations we have of it.

Participants concluded that society would be wrong to trust telecare if it turned out that:

- People are put under social, financial and institutional pressure to adopt intrusive telemonitoring technologies.
- People use telecare tools for obsessive self-tracking, causing them to become unhappy when the right results are not achieved or through loss of interest in activities previously enjoyed.
- Telecare leads to too much confidence or a falsely positive sense of one's own health.
- People become isolated because care givers and others think they are being monitored and taken care of by the system, and therefore stop visiting them.
- Telecare is too expensive and not fully financed by insurance, and inequality of access arises.
- An integrated approach to the health of the whole patient disappears. Medical problems that only become apparent through direct human observation are not noticed, and the patient might even manipulate the system to hide his/her medical problems (e.g., alcoholism).
- Different aspects of clinical care are split up among different telecare providers and/or systems and become chaotic or conflicting.

Society would be wrong to distrust telecare if it meant that we could not use it to help solve the demographic and institutional challenges currently facing medical care in Europe and elsewhere.

II. Second Focus Group

Participants: Kalf, Haakma, Mooij, Nickel, Voerman

Trust vs. Acceptance

Some participants expressed scepticism about "trust" being the appropriate focus for ethical reflection on telecare. In their field the focus is much more on "acceptance." It is unclear to what extent trust is really a driver of acceptance: perhaps people accept technology for other reasons than trust. Trust may or may not have a big impact on adoption and usage, whereas "acceptance" is a catch-all term for whatever motivations people turn out to have for adopting and using technology. This raises the question whether ethics of telecare should perhaps focus on sound reasons for accepting, rather than trusting, telecare technology and services.

The focus on trust may reflect a different ethical perspective on the reasons behind the decision to use a technology. An approach based on acceptance is more consumer-oriented: reasons for accepting telecare are simply people's individual reasons for wanting their lives to be happy, comfortable and productive: to be able to walk up and down stairs again, go outside, etc. This approach focuses on an ethics of facilitating well-being. An alternative approach emphasizes an ethics of responsibility: by operating in the health care domain, telecare providers and developers adopt certain responsibilities towards patients, such that patients should have good reasons for trusting their telecare providers to meet those responsibilities. Trust and trustworthiness are built on these responsibilities.

Responsibility and the shift from information to coaching

One participant's "nightmare scenario" example involved a coaching environment that urges a patient to go outside for physical exercise (running, say), which, given further details of the patient's general medical condition not incorporated into or managed by the coaching environment, leads to a cardiac arrest. This scenario reveals, according to the participant, that we adopt a certain responsibility when we shift from providing information to coaching: in the first case, we leave the decision-making entirely to the patient, while in the latter case, we infer some advice about what the patient should do.

Data security

One participant argued that data security no longer represents a novel or ethically puzzling issue for responsible telecare development. In this person's view, this issue has already been dealt with extensively. In principle we know what good data security requires (which does not mean, of course, that it is always implemented). However, elsewhere during the workshop, other participants expressed the exact opposite opinion, that data security presents an increasing moral challenge for telecare.

Imperfections in current intramural care and the baseline for ethical evaluation

All participants agreed that responsible telecare should be evaluated with the imperfections of current intramural care in mind: given current practices, launching a telecare system that is *as reliable, as trustworthy, as secure, as transparent* as those intramural practices should be viewed as ethically permissible provided that one accepts current practices as well. This may seem obvious, but the point deserves attention because the comparison may sometimes be hard to make.

We can study and therefore criticize the performance of a telecare system in perhaps much more detail than that of a human doctor. Furthermore, we can regard every aspect of a telecare system as intentional design, or at least design for which the designers are somehow responsible, whereas many

aspects of how human doctors operate may be unintentional or unconscious, even though they may have an impact on the patient's trust.

Finally, there may be cases in which the telecare system acquires additional responsibilities simply because it offers additional services. Hence, an important question to ask when a telecare system adds a functionality that intramural care did not offer is as follows: even though it may not perform function X as well as we might like,is the system acceptable because it is still better than not performing X at all, or is it unacceptable because once you start offering the patient functionality X you also give the patient a reason to expect that X meets a certain minimal standard of competence?

Are there special responsibilities due to the medical nature of telecare?

A core issue underlying much of the discussion, not only during the parallel session but also for the rest of the day, was whether the health care sector has to meet higher standards or has special responsibilities compared to other sectors of business. The aforementioned consumer-oriented perspective suggests not. On this view, the justified demand to be reasonably safe and looked-after in telecare environments, for the patient, is no different than the demand that the consumer be safe in his new car, on his intercontinental flight, or when buying a certain type of meat on a regular basis. Every business has a responsibility to sell products that meet certain standards of health and safety and telemonitoring and telecoaching are no different in this respect.

Others have taken a different approach, on the grounds that (1) the relation between patient and caregiver involves a more substantial dependence of the former on the latter than in a standard consumer-producer relationship and (2) state-sponsored and sanctioned medical care involves certain claims and titles attesting to scientific and medical standards of excellence that citizens are entitled to expect of those who operate within its institutions and carry its titles.

Integration of telecare for different medical conditions and different types of care

Personalization involves tailoring medical advice for a medical condition to the circumstances of living and the personality of the patient. But moreover, it also involves combining medical assessment of multiple conditions and problems that the patient might have into a coherent treatment plan. Current systems are unable to do this. However, some participants argue that we should not only expect future telecare systems to become capable of this and better at it, but also that human doctors will become *worse* at it as the amount of available data increases. Telecare plays a double role in this development: not only to assist us in processing an abundance of medical information, but also as a new way to generate medical data by monitoring patients in unprecedented ways.

In the final plenary session all participants agreed that integration is a much needed, but currently missing, feature in the telecare world. We need integration of platforms for the different conditions that a patient might have. We also need integration of the different types of care that technology can offer: both monitoring and coaching, both somatic and psychotherapeutic forms of care.

During the parallel session, we brainstormed about how this might come to pass. Although one participant stressed the advantages of an integrated platform or infrastructure, others argued that the only way this sort of technology will evolve is bottom-up: small and many different applications start providing isolated functionalities, and slowly companies will add functionalities to them and combine them in new ways. The question is how to make this work in a dependable way within the institutional world of health care.

Demedicalization and health politics

Another core issue of discussion behind many of these questions involves the dynamics of medicalization and demedicalization. According to some, our society has become increasingly medicalized in the past few decades and the only way to make health care financially manageable again is to think of health *care* as the exception and other forms of health policy as the norm and preferred focus for technological innovation. Some participants argued, for example, that we should invest research in manipulating living environments in ways that increase how often people move, go outside, and so on. Thus, a strong focus on *prevention* seems to be on the political agenda.

III. Next Steps

As seen in the above reflections, this workshop yielded substantial insights from a group of industry experts and societal stakeholders in the field of telecare. The preliminary conclusions developed here will be used by the project team in the following steps of the research:

- Describing scenarios for consideration by focus groups, interviews and surveys with telecare users and potential users.
- Formulating ethical guidelines for trustworthy telecare, by comparing these reflections with those of other European telecare research consortia such as EFORTT and SCIE.[1]

We would like to thank all participants in the workshop for their valuable contributions. We invite those with further comments and questions to contact Sander Voerman at s.a.voerman@tue.nl .

[1] EFORTT: Ethical Frameworks for Telecare Technologies for Older People at Home. (2011). Final Report. Available at www.lancs.ac.uk/efortt;

J. Perry, S. Beyer, J. Francis and P. Holmes. (2010). Ethical issues in the use of telecare. Social Care Institute for Excellence. Available at www.scie.org.uk.