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INTRODUCING A FUTURE-ORIENTED APPROACH TO HEALTH-CARE
TECHNOLOGIES AND WELFARE POLICIES: AN INNOVATIVE ETHICS PROJECT IN
SWEDEN

Hans-Peter de Ruiters, RN, PhD, and Ingela Skärsäter, RN, PhD

Hans-Peter de Ruiters, RN, PhD, is a Professor of Nursing at Minnesota State University, Mankato, and an affiliate faculty member in the University of Minnesota Center for Bioethics. He was a Visiting Professor at Halmstad University in Sweden from May 2017 until April 2019. Ingela Skärsäter, RN, PhD, is a senior Professor at Halmstad University, Sweden. She is co-leader of the EU-projekt of Digga Halland, and was recently Program Director of the Halmstad University profile-area of Health Innovation.

Correspondence about this article should be addressed to Hans-Peter de Ruiters, RN, PhD, at hans-peter.de-ruiter@mnsu.edu

Right Running Head: A Future-Oriented Approach to Health Care Technologies in Sweden

This article is a description of a two-year year program (May 2017–April 2019) intended to introduce new approaches to addressing ethical issues resulting from the introduction of new health-care technologies and welfare policies. In contrast to the traditional retrospective approach in addressing ethical issues after they occur, this program intended to address ethical issues proactively, before they occurred. This future-focused approach is one way to better

keep up with the acceleration of change that society confronts in society. This project introduced innovative approaches in dealing with unintended consequences and ethical issues resulting from the implementation of new health-care technologies and welfare policies in the Halland region of Sweden.

Key words: ethics of technology; innovations; new health technologies; welfare policies;

Digga Halland; HICube

BACKGROUND

Technology is changing at rates never seen before. In his book *The Great Unknown: Seven Journeys to the Frontiers of Science* (2017), Marcus du Sautoy, Chair of the Department of Mathematics at Cambridge University, predicts that in the next century we will see as much change in technology as we have seen in the last 20,000 years. Even though many of these technologies will have significant benefits for humanity and the earth, they will undoubtedly have a shadow side. In *Alone Together: Why We Expect More from Technology and Less from Each Other* (2017), Sherry Turkle, Professor of the Social Studies of Science and Technology at the Massachusetts Institute of Technology, argues that we should not only focus on what technology does for us, but we should also be curious about what it does with us. This sentiment is echoed by Yuval Harari, Professor of History at the Hebrew University of Jerusalem, in his best-selling book *Homo Deus: A Brief History of Tomorrow* (2016). Harari predicts that due to

the fast change in technology, society will be confronted with significant ethical and societal issues, including unwanted effects on humans and society resulting from people being replaced by machines and technology, and increased health and economic disparities both at a regional and a global level.

The ethics of technology is not new area of inquiry; however, what has changed is the length of time we have to address these issues. By the time ethics boards and researchers identify issues arising from individual technologies, many of those technologies will have evolved even further, making any recommendations on how to deal with ethical issues outdated upon arrival. A program in the Halland region of Sweden was intended to introduce future-focused approaches to address more proactively the unintended consequences and ethical issues resulting from the implementation of new health-care technologies and welfare policies, to better keep up with the accelerating changes in society.

THE PROJECT

Goals and Objectives

This two-year project was initiated to explore new methods to address issues that result from the implementation of new health-care technologies and welfare policies in the Halland region of Sweden. The objective of the project was to increase sensitivity to and knowledge of ethical issues in the design and implementation of health-care technologies and welfare policies, with a particular emphasis on the implementation in patients' home environments. Health-care technologies and welfare policies are not neutral. They impact social relationships at all levels of

society and often have unforeseen consequences with ethical implications. It is imperative that researchers in this field understand the ethical issues involved in the design and implementation of technologies, as well as the social relations between and among informants and stakeholders, including patients, family members, health-care providers, health-care institutions, companies, and regulatory bodies.

Specific goals of the project were:

- to increase the level of sensitivity to and knowledge of ethical issues and values among faculty and staff at a Swedish university regarding the design and implementation of health-care technologies and welfare policies.
- to develop ethics modules for use in the university's courses on health innovation and utilization, with particular focus on how to integrate evaluation of ethical issues during the development and implementation phases of new technologies.
- to emphasize to researchers and product developers the importance of understanding ethical issues and values when health technologies and welfare policies are implemented in homes or home-like environments.

Project Initiatives

The project funding paid for a visiting professor with experience in the ethics of health-care technology. This project was multi-faceted and included not only focused work within the academic setting but also in the community with people who work with or are affected by new technologies in real time and space. The key initiatives of the project were:

- working with stakeholders who are exposed to new health-care technologies and/or welfare policies,
- collaborating with developers of new health-care technologies,
- offering presentations and dialogues with academics working in the area of health-care innovation, and
- providing online information and education for the larger community

Working with Stakeholders

Municipal stakeholder workshop. In the Fall of 2017, a workshop was offered for three stakeholder groups (selected elderly community members, builders, and community/home care health providers) to discuss and get input about values and concerns related to the introduction of “smart homes” for the elderly. These homes will be built with surveillance technologies allowing for people to be monitored without caregivers such as family members or professional caregivers having to be physically present. The workshop allowed the stakeholder groups to get an understanding of each other's priorities. For example, the professional caregivers’ priorities included keeping home-based clients safe at home within a restricted budget, while the builders’ priorities focused on building the "home of the future" that responds to the needs of changing community demographics and includes homes in which fragile community members can live safely.

The facilitators included an academic expert in health-care innovation, an architect, and a nurse academic with expertise in the ethics of health-care technology. The experts offered information on current trends in health-care technologies, focusing on home-based surveillance technologies,

and described the benefits of using a democratic development process as proposed by Feenberg (2002). The architect mapped the various views of the stakeholders on large flowsheets that visualized both the priorities and the conflicts; these flowsheets formed the basis for discussion among stakeholders in developing an inclusive approach to the development of smart homes. The primary outcome of the session was to expose the needs and priorities of all three stakeholder groups. This process made visible what a democratic decision-making process looks like in which all groups are heard and in which the understanding of each other's needs forms the basis for collective problem solving. It also offered insight into the complexity of the issues that need addressing, and the benefits of compromise and consensus in order to achieve the best possible home of the future for the elderly.

Working with Developers of Health-Care Technologies

There were several opportunities for technology developers to be exposed to an ethical evaluation of their products. These included four presentations to faculty and developers on the ethics of health-care technologies. Individual consultations included a consultation with developers and researchers of a simulated "smart apartment" within the university. This apartment was equipped with several dozen sensors that allowed for total surveillance of the person in the apartment. The areas of the apartment that have the highest level of risk to the inhabitants, especially the bedroom and bathroom, are also the areas with the most significant privacy concerns, such as personal and sexual behaviors.

The developers were confronted with insights they had not had before, such as:

- Who should have access to the data, especially if it includes information such as sexual behavior?
- Can and should technology be developed in a manner in which specific data points are "ignored" to allow for privacy, and what would this look like?
- What other information is being captured that might be sensitive in the future, and how do we deal with this? How do we deal with future use of data that can have adverse effects on the user and for which no consent is obtained?
- How and where should the data be stored, and who owns the data?

These findings of the consultation allowed the developers to improve and adapt their product in a way that would not only benefit the user, but also give them an “edge” over similar products that were not considering such important issues.

More Stakeholder Involvement: District Conference -

This third initiative was built on the findings of the first two initiatives. It consisted of a program for professional direct care providers in the Halland Region during a HICube conference day.

HICube was launched in 2015 by the European Commission to further develop the health innovation arena in the Halland region by creating collaborations between firms, the academy, research institutes, and public bodies (European Commission, 2019). This conference included home care nurses and aides, public health nurses, community psychologists, social workers, and health-care workers representing the hospitals. A presentation on the ethics of technology (specifically new technologies encountered by this group, such as new documentation programs,

telehealth and communication initiatives, and home-based safety and surveillance technologies) focused on:

- identification of unintended and ethical effects of the new technologies,
- the importance of listening to and understanding the patient's experiences and perspectives,
- how understanding unintended consequences and ethical issues forms the basis of product improvement, and
- strategies for and the importance of communicating this information to health-care administrators and developers of technology.

The audience worked in small groups and responded to a questionnaire that inquired how the introduction of new health technologies had influenced their work. The survey focused less on what technology did “for” them rather focused on what technology did “with” them and their patients. Responses to the questionnaires showed how nurses and other direct caregivers are often aware of issues that result from implementing new health technologies. However, they often do not feel there is a mechanism for making these issues known nor for addressing them.

Working with Academics: Incorporating Ethical Reflection in Doctoral Research

In the initial phase of this project, it became evident that the future researchers and developers of new technologies typically limit their focus on ethics to the research ethics of their studies; students gave little thought to how their work could be used in ways that might be unintended and/or unwanted. Thus, a 6-hour module was added to the research ethics course for doctoral students, to guide them to reflect on their work from an ethical perspective. The module included information on the ethics of technology from several philosophers of technology: Karl Marx,

Jacques Ellul, Albert Borgman, Andrew Feenberg, Lewis Mumford, Neil Postman, and Langdon Winner. Ethical reflection was a new concept for many of the students. By reviewing and understanding different paradigms with which philosophers examined technology and its effects, the students gained insights on how to examine their research.

The educational module is rooted in the Johari Window model used in psychology to examine the blind spots in people's thinking (Luft & Ingham, 1961). This approach was useful in giving future researchers a framework with which they can examine possible unintended or unwanted effects of their research. Being aware of and transparent about these issues is crucial to giving society insight into what they should be vigilant about, and also to allowing developers the chance to address these issues. Students were encouraged to consider adding a section in their dissertations discussing possible ethical consequences of their work, just as they discuss the limitations of their study. Feedback about the module was predominantly positive, and students commented on how they examined their research in a way they had not done previously. The module is now permanently included in the doctoral curriculum.

As a result of this work a trans-Atlantic research study was initiated which examines how the ethical effects of research are addressed in the current research literature and getting a better understanding of strategies to educate doctoral students on how to evaluate their research proactively for unintended consequences and ethical effects (Nygren & de Ruiter, 2019).

Community Education

In the Spring of 2019, an online educational intervention aimed to target 15,000 health-care workers in the Halland region of Sweden as part of a European Community-granted initiative called *Digga Halland* (European Union, 2019). *Digga Halland* was an extension of and built on the HICube initiative described above; its purpose was to help promote new technology and digitalization democratically and ethically. A survey was distributed using both qualitative and quantitative research questions seeking health-care workers' perspectives about the implementation of new technologies and digitization. As part of *Digga Halland*, an 8-module educational intervention was developed that aimed to increase general knowledge and awareness surrounding the digitalization of health care. One of the modules discusses the ethical implications and possible unintended effects of implementing new technologies and digitalization.

In the video that is part of the ethics module, the leaders of our innovative ethics project discuss ethical issues as they relate to caregivers and the public of Halland, and offer paradigms identified in the earlier stages of the project on how to respond proactively to the unintended consequences and ethical implications of new health-care technologies. An essential message in the module is the importance of moving away from dichotomous thinking, to understanding the complexities and being curious about the changes that accompany new technologies and digitalization. An objective of the module is to help develop thinking that considers the identification of ethical issues as an asset to further development, rather than the conventional view that critiquing technology is synonymous with being a Luddite.

PROJECT OUTCOMES

This project allowed us to implement new concepts and ideas about how to address the unintended consequences and ethical implications of new health-care technologies. Often, examining ethical issues occurs in hindsight or when issues arise. This project gave insight into what a proactive approach can look like in real life. It emphasized the importance of involving stakeholders, especially those whose voices are often not heard, such as direct caregivers and the target populations for the new technologies. It showed how democratic inquiry is not only possible, but also empowers those most affected by the unintended effects of new technologies.

Another important outcome of this project was the shift from considering the act of examining ethical issues to be a barrier to technological advancement, to seeing it as an essential part of further development. The earlier and more clearly the developers of new technologies can understand the potential ethical issues, the sooner they can seek solutions to those issues, thus avoiding unnecessary harm, pain, and suffering, and setting themselves apart from their competitors. Finally, this project is reframing the way ethics is incorporated into doctoral education by expanding discernment beyond research ethics to a thorough analysis of the ethical effects of research and/or product development.

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References

du Sautoy, M. (2017). *The great unknown: Seven journeys to the frontiers of science*. Penguin Publishing Group.

European Commission. (2019). *HICube – health innovation area - Internal Market, Industry, Entrepreneurship and SMEs - European Commission*. [online] Available at: <https://ec.europa.eu/growth/tools-databases/regional-innovation-monitor/support-measure/hicube-%E2%80%93-health-innovation-area> [Accessed 5 Nov. 2019].

European Union (2019). [online] alfresco.vgregion.se. Available at: https://alfresco.vgregion.se/alfresco/service/vgr/storage/node/content/workspace/SpacesS_tore/d9bbc011-9dc6-4223-96a1-7179caeee40e/Ans%c3%b6kan%20Digga%20Halland%202018-00007.pdf?a=false&guest=true [In Swe.][Accessed 5 Nov. 2019].

Feenberg, A. (2002). *Transforming technology: A critical theory*. US: Oxford University Press.

Harari, Y. N. (2016). *Homo Deus: A brief history of tomorrow*. Random House.

Luft, J., & Ingham, H. (1961). The johari window. *Human Relations Training News*, 5(1), 6-7.

Nygren, J. & de Ruiter, H.P. (2019). *Examining the Ethical Implications of Healthcare Technology Described in US and Swedish PhD Dissertations: A Scoping Review Protocol*. [online] JMIR Research Protocols Preprints. Available at: <https://preprints.jmir.org/preprint/14157> [Accessed 5 Nov. 2019].

Turkle, S. (2017). *Alone together: Why we expect more from technology and less from each other*. UK: Hachette.

PULL QUOTES

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