Balancing the protection of privacy against the duty of care in telehealth

Henning Boje Andersen

Professor emeritus

Technical University of Denmark

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Healthcare monitoring: How to balance ethical obligations that push us in opposite directions

PUSH TOWARDS monitoring:

- Most frail citizens living independently want to be looked after

- They will tell us that they want others to check on them – family, friends, care-workers

- Modern ambient and wearable technologies: fairly reliable and inexpensive

Concern in Japan over high number of 'lonely deaths' while living with others

Dementia linked to many instances of people dying at home among family but remaining undiscovered for days

📷 A woman walks through a deserted commercial area in Osaka, Japan. More than 500 people died 'lonely deaths' while living with others in Tokyo and Osaka in 2017-19. Photograph: Buddhika Weerasinghe/Getty Images

90-årig lå hjælpeløs i hjemmet: Avisbuddet kom til hjælp

Igor Sándor var onsdag for første gang på besøg på den avis, han har delt ud i 13 måneder. Og for at fortælle om, hvordan han hjalp en 90-årig kvinde, der lå hjælpeløs på gulvet i sit hjem. Foto: Kim Rune

90-årig kvinde var faldet om og lå hjælpeløs på gulvet, men så kom avisbuddet Igor Sándor til hjælp.

This company taps the Internet of Things to give caregivers of the elderly peace of mind

Howz is an unobtrusive home-monitoring ecosystem that helps

By [The UK's Department For International Trade](#) on March 21, 2017

PEACE OF MIND

A Concierge Medical Practice

Client Login

Peace of Mind In-Home Primary and Senior Care

Remote Monitoring Systems Can Give Caregivers Peace of Mind

'Big Brother' tech at CES will help adult children keep a watchful eye on aging parents from afar

by Christina Ianzito, **AARP**, January 10, 2020

ASSOCIATED PRESS

The CarePredict Tempo Series 3

[En español](#) | When Ryan Herd's 73-year-old father had cancer and other health concerns a few years ago, Herd was worried but knew his dad wasn't likely to tell him about any problems that might arise.

Is privacy really a concern - or is it researchers in search of a problem?

Example: *(study from Skåne: Nymberg et al 2018) Eight categories emerged from the [focus group interviews with 15 patients from three pri-mary health care centers]:*

1. 'E-health – a solution for a non-existing problem?'…
2. 'No experience with e-health',
3. Lack of will, skills, self-trust / mistrust in technology',
4. 'Organizational barriers',
5. 'Wanting and needing to move forward',
6. 'Concerns to be addressed for making e-health a good solution',
7. 'Potential advantages with e-health vs. standard healthcare'
8. 'Need for speed, access and correct comprehensive information'.

PRIVACY or synonyms not mentioned

So, for most frail independently living citizens in need of healthcare attention: privacy not necessarily a burning or even noteworthy problem

Still, a large number of studies show that the elderly are concerned about loss of privacy
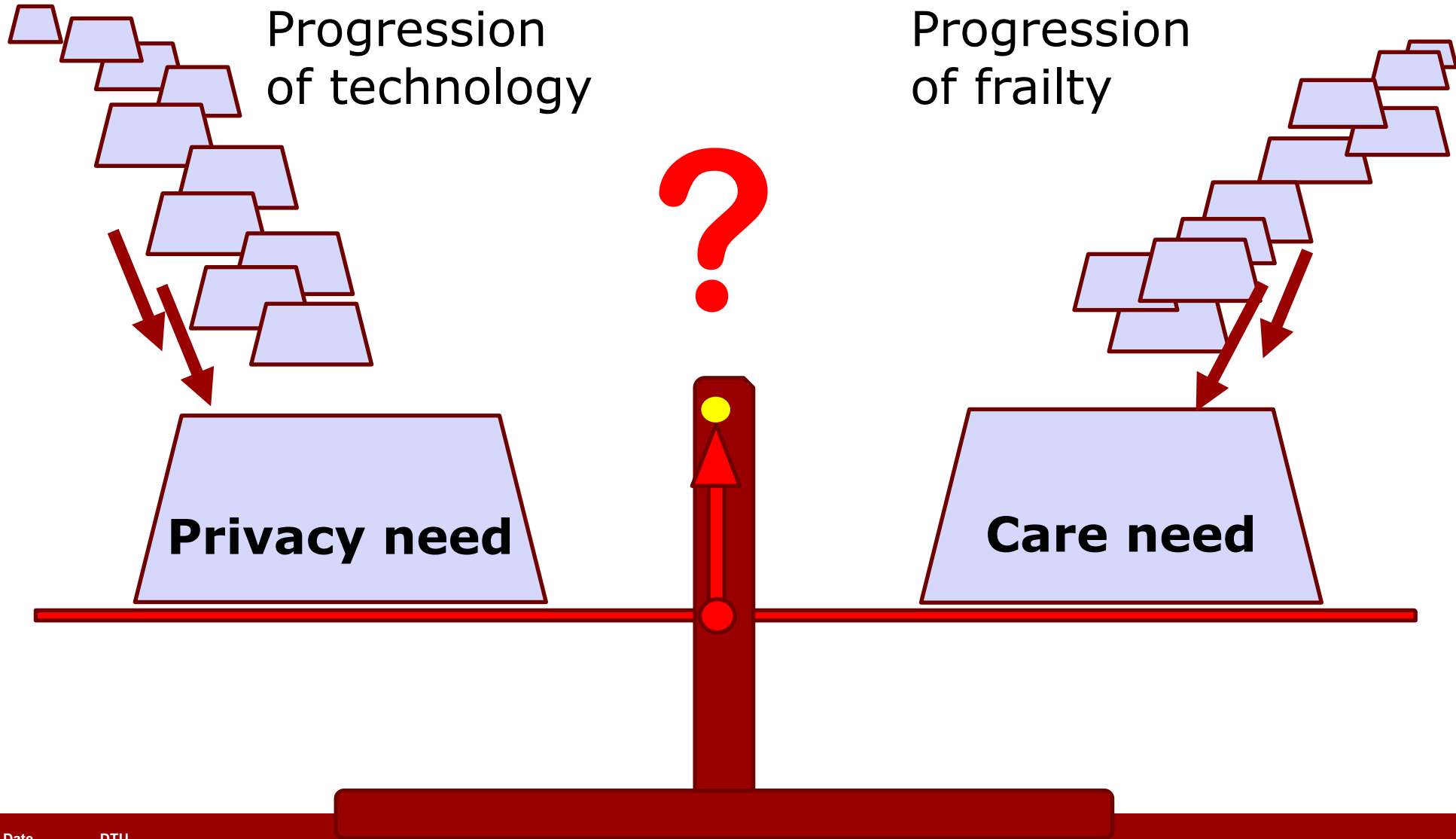
Example quotes

…. seniors want health-related ICT that gives them independence, safety, and security, allows them to socialize and manage their own health, and helps them in their daily activities…. Lack of privacy and safety and stigma are some of the reported barriers

(Vassli & Farshchian, 2017)

… the respondents [21 persons, (mean age: 85) living independently at home] were willing to compromise their privacy if their autonomy and personal integrity were respected and if the benefits of sensor-based monitoring outweighed health-related threats

*(*Ehrari, Ulrich, Andersen 2020)

Progression of technology

Progression of frailty

Privacy need

Care need

What data may caregiver organisations collect from in-home monitoring ?

Sensitive personal data (GDPR)

- Details of racial or ethnic origin.
- Political, religious or philosophical beliefs.
- Trade union affiliation.
- Genetic / biometric data to uniquely identify a natural person.
- Health details.
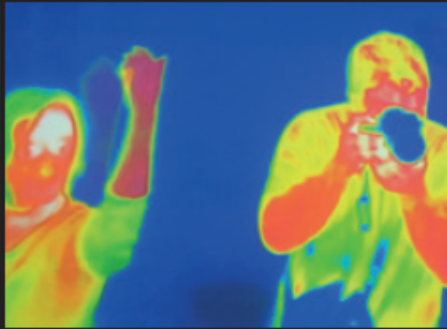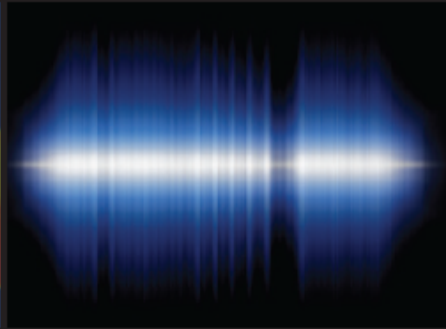- Information about a person's sex life or sexual orientation.
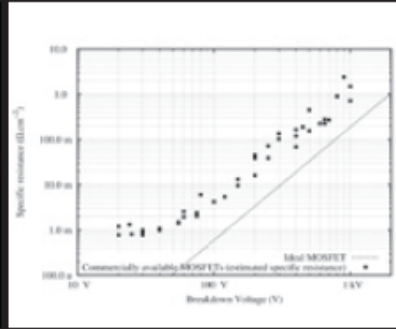
Non-sensitive personal data:

- gender, date of birth, place of birth and postcode.

Personal data that in combination can identify a person:

- Name & surname. Email. Location data. Home address. IP address ….

Video sensor (RGB)	Depth sensor	Thermal sensor	Audio sensor	Wearable sensor (smart watch)
Perceives the world in visible light	Measures distance	Measures temperature	Evaluates interactions and perceives sounds	Measures vital signs and motion
Object recognition, person detection, complex behaviour understanding	Pose estimation, gait analysis	Fever detection, respiratory rate monitoring	Speech recognition, speaker detection	Heart rate, sleep, and step tracking

Martinez-Martin et al Lancet Digit Health 2021

Kind of data a caregiver organisations may collect via in-home monitoring

	Health data	Daily living / lifestyle data
Legal / regulatory	GDPR	GDPR and "t.b.d."
Ethical principles	What we owe each other: protection against unwanted access and exposure	

Ethical issues in using ambient intelligence in health-care settings

Nicole Martinez-Martin, Zelun Luo, Amit Kaushal, Ehsan Adeli, Albert Haque, Sara S Kelly, Sarah Wieten, Mildred K Cho, David Magnus, Li Fei-Fei, Kevin Schulman, Arnold Milstein

Ambient intelligence is increasingly finding applications in health-care settings, such as helping to ensure clinician and patient safety by monitoring staff compliance with clinical best practices or relieving staff of burdensome documentation tasks. Ambient intelligence involves using contactless sensors and contact-based wearable devices embedded in health-care settings to collect data (eg, imaging data of physical spaces, audio data, or body temperature), coupled with machine learning algorithms to efficiently and effectively interpret these data. Despite the promise of ambient intelligence to improve quality of care, the continuous collection of large amounts of sensor data in health-care settings presents ethical challenges, particularly in terms of privacy, data management, bias and fairness, and informed consent. Navigating these ethical issues is crucial not only for the success of individual uses, but for acceptance of the field as a whole.

EDITORIALS

Health apps are designed to track and share

We must advocate for greater scrutiny, regulation, and accountability

Quinn Grundy,[1] Lindsay Jibb,[2] Elsie Amoako,[3] Geoffrey Fang[2]

[1] Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Toronto, ON, Canada

[2] Hospital for Sick Children (SickKids), Toronto, ON, Canada

[3] Mommy Monitor, Toronto, ON, Canada

Correspondence to: Q Grundy
quinn.grundy@utoronto.ca
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Mobile health apps have generated substantial investment and enthusiasm for their potential to personalise interventions using real time user data. However, user data are not only invaluable for creating engaging and effective apps. Health apps are just one source of user data that is collected, transmitted to third parties, then aggregated to create detailed impressions about users and people such as them. These sources of big data are commercialised, often as consumer insights or algorithms, and used to deliver microtargeted adverts, influence political behaviours, or make decisions about health

users expect from health apps: users rated health apps with adverts or tracking more negatively.[4] Tangari and colleagues found that only 4% of health apps actually transmitted data; however, they measured data transmission for only 180 seconds while automatically running the app,[4] finding a much lower prevalence of data sharing than recent small, in-depth analyses, which fully explored apps' functions.[5 8]

Data protection

May 2021 marked the third anniversary of the General

A staged Risk Governance Model

A staged Risk Governance Model

Risk Governance: how to identify, assess, manage and communicate risks; how risks are dealt with; protocol for decisions on risk tradeoffs …; who is accountable

Risk Management: Ensure resources, capabilities and services

Risk and Benefits Assessment: What shall users expect? What can go wrong?

Risk Agreement / Informed Consent: protocol for the informed consent proces.

Tack/Tak/Takk/Kiitos !

Kysymyksiä / Any Questions ?

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