

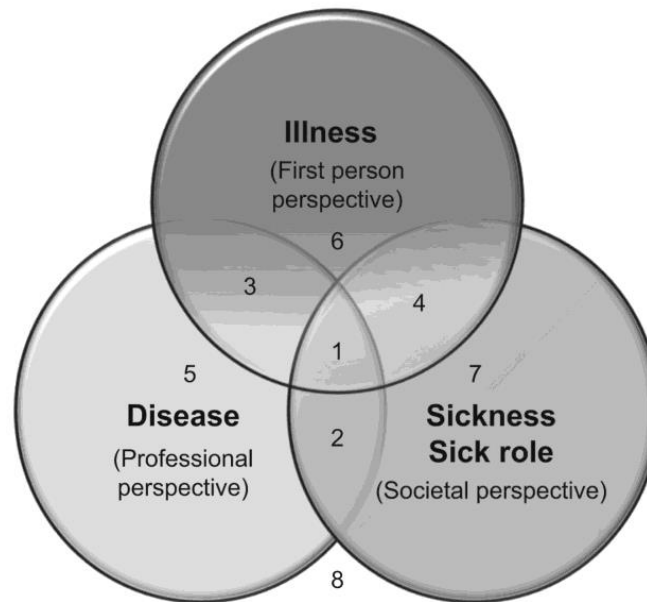
# Health, Technology and Society: The experience of illness and health technologies

## Some definitions:



- Health: as defined by the World Health Organization (WHO), is "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (1948, 2006).
- "The term *disease* broadly refers to any condition that impairs the normal functioning of the body. For this reason, diseases are associated with dysfunctioning of the body's normal homeostatic processes" (Wikipedia: *Disease*)
- "Disease[...] is the pathological process, deviation from a biological norm. Illness is the patient's experience of ill health, sometimes when no disease can be found. Sickness is the role negotiated with society" (Marinker, 1975, cited in Boyd, 2000).
- Disease: a biological problem within an organism ; Illness: the social experience and consequences of living with a disease (Weitz, 2017)

Source: The Routledge Companion to Philosophy of Medicine 2016, p.19.



How medical Technologies shape the experience of illness

- The following typology will be based on Hofmann and Svenaeus (2018).

1. “Technology may create illness by making persons experience their bodies and lives in new ways, e.g., by revealing underlying disease.
2. Technology may alter persons’ conception of themselves and their vulnerability as well as their behaviour by revealing disease risks.
3. Technology can modify already present illness experience in several ways.
4. Technology can shape illness experience by making new phenomena and areas of ordinary life subject to measurement, attention, medical interpretation, and management.
5. Technology influences illness experiences through altering social-cultural norms and values regarding various diagnoses as well as moving experiences from the realm of chance and fate to that of control and responsibility.
6. Technology shapes our experiences of illness through its measures to monitor and measure our health”. (Hofmann and Svenaeus, 2018: 8).

## 1. Revealing Underlying Disease

(Hofmann and Svenaeus, 2018: 3).(images from appledaily.com.hk & knews.cc)

- Technology may create illness by making persons experience their bodies and lives in new ways, e.g., by revealing underlying disease.
- “the incidental finding of a disease during a check-up, a routine test, or a direct-to-consumer test taken for fun. This could for example be a pap smear test to detect cervical cancer “(Forss, 2007).
- “Awareness of diseases, such as hypothyroidism, Diabetes Mellitus, and hypertension has been shown to be associated with poor perceived health “(Jørgensen et al., 2015)

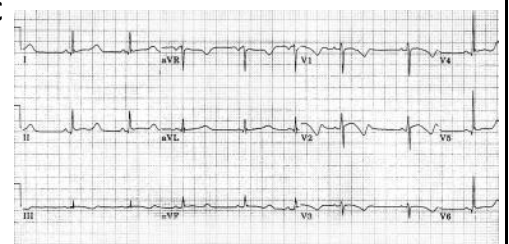
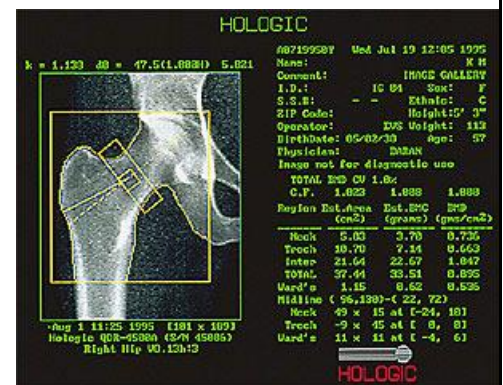


“A further example of this would be a genetic test for Huntington’s Disease where a positive result may change the person’s experience of his health significantly despite the disease still being dormant” (Timman et al., 2004) . (Image from: nature.com)



## 2. Revealing Risk of Disease (Hofmann and Svenaeus, 2018: 3).

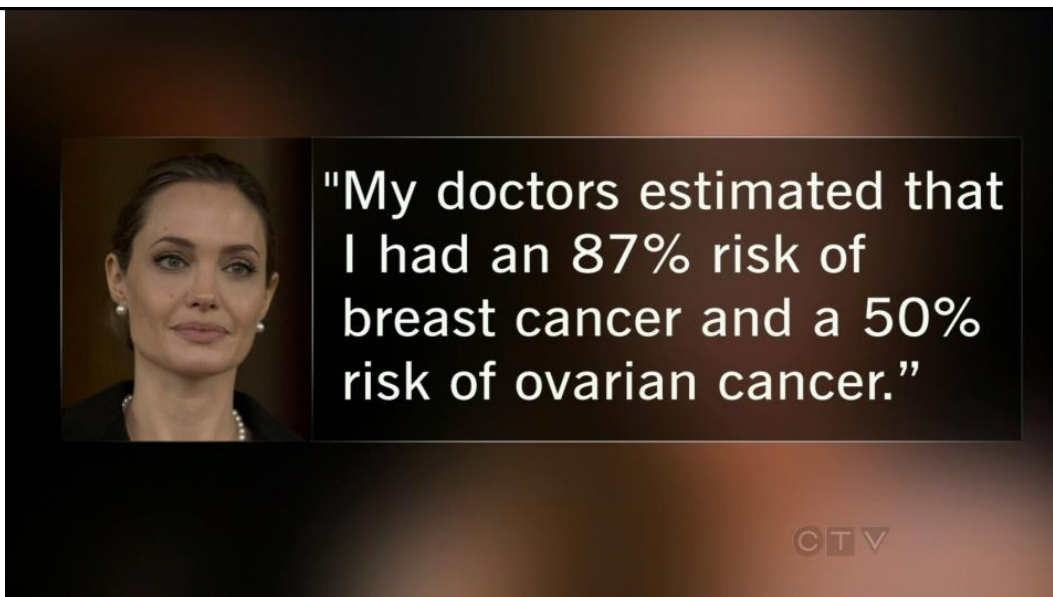
- Technology may alter persons’ conception of themselves and their vulnerability as well as their behaviour by revealing disease risks.
- e.g. The genetic test for Huntington’s Disease
- “Bone density measurements (DXA)... have altered people’s behaviour, experience of anxiety, and feeling of being vulnerable“(Rimes et al., 1999).
- “Long QT Syndrome (LQTS) where ECG and genetic tests have defined and formed the conception of as well as affected people’s experience of risk, vulnerability, and illness” (Hendriks et al., 2008, Andersen et al., 2008).
- (images from breastcancer.org & emedicine.medscape.com)



## Example: Digital Health Technologies such as Social Networking (Barry & Yuill, 2016)



(I shared the news on my facebook post about how AI and CT scan can identify Alzheimer's Disease early )



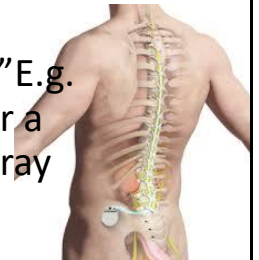
( The American actress, Angelina Jolie, was told that she carries a defected BRCA1 gene. She had a double mastectomy.)

### 3. Affecting Illness Experience (Hofmann and Svenaeus, 2018: 4-5).

- Technology can modify already present illness experience in several ways.
- “blood sugar measurements (HgA1C) alters the experience of (living with) diabetes” (Hilden, 2002, Mol, 2000).
- E.g. Continuous glucose monitoring.
- (image from time.com)



- “Imaging techniques, such as X-ray, Computer Tomography (CT), and Magnetic Resonance Tomography (MRT), have changed our conception of our bodies making us experience them in new ways” E.g. a soccer-player might state that he has some pain in his meniscus or a patient can feel his ‘large intestines a bit bound’ based on seeing X-ray images only” (Nessa and Malterud, 1998).



### Case study (1): Assistive Technology and Products

- Assistive technology is the application of organized knowledge and skills related to assistive products, including systems and services. Assistive technology is a subset of health technology.
- Assistive products: Any external product (including devices, equipment, instruments or software), especially produced or generally available, the primary purpose of which is to maintain or improve an individual’s functioning and independence, and thereby promote their well-being. Assistive products are also used to prevent impairments and secondary health conditions.
- (From WHO’s Priority Assistive Products List (2016))

- WHO @WHO 24 July 2018 (images from WHO)
- <https://twitter.com/who/status/1021722372880171008>

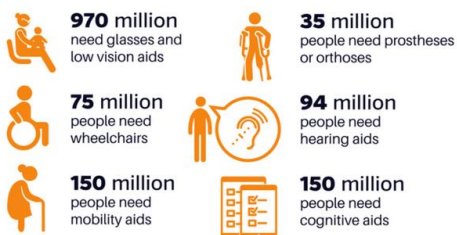
People in need of assistive products:  
1 billion today and 2 billion by 2050



People in need of assistive products:  
1 billion today and 2 billion by 2050



**Today** More than **1 billion** people in the world need assistive technology



but only **1 in 10** have access to the products they need. 

**Why ?**



**By 2030** More than **2 billion** people will need assistive technology

The **GATE** Initiative



From  
WHO 's  
Priority  
Assistive  
Products List  
(2016)

1 Alarm signallers with light/sound/vibration



7 Closed captioning displays



2 Audioplayers with DAISY capability



8 Club foot braces



3 Braille displays (note takers)



9 Communication boards/books/cards



4 Braille writing equipment/brailers



10 Communication software



5 Canes/sticks



11 Crutches, axillary/elbow



6 Chairs for shower/bath/toilet



12 Deafblind communicators



13 Fall detectors



19 Incontinence products, absorbent



14 Gesture to voice technology



20 Keyboard and mouse emulation software



15 Global positioning system (GPS) locators



21 Magnifiers, digital hand-held



16 Hand rails/grab bars



22 Magnifiers, optical



17 Hearing aids (digital) and batteries



23 Orthoses, lower limb



18 Hearing loops/FM systems



24 Orthoses, spinal





25 Orthoses, upper limb



31 Prostheses, lower limb



26 Personal digital assistant (PDA)



32 Ramps, portable



27 Personal emergency alarm systems



33 Recorders



28 Pill organizers



34 Rollators



29 Pressure relief cushions



35 Screen readers



30 Pressure relief mattresses



36 Simplified mobile phones



37 Spectacles; low vision, short distance, long distance, filters and protection



44 Walking frames/walkers



38 Standing frames, adjustable



45 Watches, talking/touching



39 Therapeutic footwear; diabetic, neuropathic, orthopaedic



46 Wheelchairs, manual for active use



40 Time management products



47 Wheelchairs, manual assistant-controlled



41 Travel aids, portable



48 Wheelchairs, manual with postural support



42 Tricycles



49 Wheelchairs, electrically powered



## Case study (2): Gerontechnology

- Gerontechnology: the study of technology and ageing for the improvement of the daily functioning of older people (McCreadie, 2010) (image from medtechboston.medstro.com)



## Gerontechnology products in Hong Kong

- The following images were cropped from Gerontechnology Landscape Report (OHKF, 2017) distributed in Hong Kong Council of Social Service' Gerontech and Innovation Expo cum Summit (16-18 June 2017)

## 4. Technological Medicalization (Hofmann and Svenaeus, 2018: 5-6).



- Technology can shape illness experience by making new phenomena and areas of ordinary life subject to measurement, attention, medical interpretation, and management.
- Medicalization: Process through which a condition or behavior becomes defined as a medical problem requiring a medical solution or through which the definition of an illness is broadened to cover a wider population.
- (image from [neuroethicscanada.files.wordpress.com](http://neuroethicscanada.files.wordpress.com))

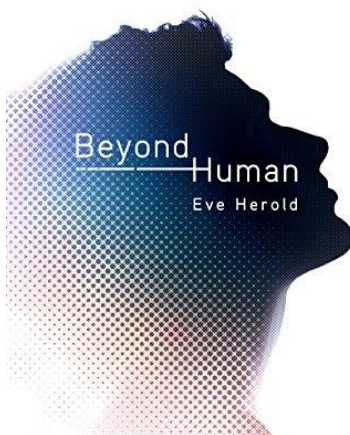
- E.g. the potential medicalization process of contemporary diagnostic psychiatry.
- “A patient who is feeling restless and worried, having difficulties to relax, concentrate, finding focus in life and sleeping at night may change the view on her condition when told that although the doctor cannot find anything physically wrong with her she is probably suffering from an anxiety disorder, which can be treated by cognitive behavioural therapy and SSRI’s [antidepressants]” (Svenaeus, 2013).
- “New mental disorders such as Hoarding Disorder and Disruptive Mood Dysregulation Disorder (listed in DSM-5, 2013) and the widening of diagnostic labels such as depression bipolar disorder, autism, and ADHD are all made possible by way of diagnostic technologies, such as the DSM and ICD manuals”
- Other examples: assistive reproductive technologies redefining the experience of childlessness; the experience of menopause altered by pharmaceutical treatment

- “enhancement technologies, which alter and blur traditional distinctions between natural and artificial, between therapy and enhancement, between health and disease, and between arbitrary events and responsible actions” (Hofmann, 2017).
- (image from [jackfisherbooks.com](http://jackfisherbooks.com))



## Case Study (3): Lifespan extension

How Cutting-Edge Science  
is Extending Our Lives



- “Never before in the history of medicine has mankind faced such hope and peril as those of us poised to embrace the radical medical technologies of today. Beyond Human examines the medical technologies taking shape at the nexus of computing, microelectronics, engineering, nanotechnology, cellular and gene therapies, and robotics. These technologies will dramatically transform our lives and allow us to live for hundreds of years. Yet, with these blessings come complicated practical and ethical issues, some of which we can predict, but many we cannot....

- [It] taps the minds of doctors, scientists, and engineers engaged in developing a host of new technologies while telling the stories of some of the patients courageously testing the radical new treatments about to come into the market. [It] asks the difficult questions of the scientists and bioethicists who seek to ensure that as our bodies and brains become ever more artificial, we hold onto our humanity....

- ...In this new world, will everyone have access to technological miracles, or will we end up living in a world of radical disparities? How will society accommodate life spans that extend into hundreds of years? Will we and our descendants be able to bring about the dream of a future liberated by technology, or will we end up merely serving the machines and devices that keep us healthy, smart, young, and alive?" (from the publisher of the book Beyond Human)



Meet Victor, the future of humanity. He's 250 years old but looks and feels 30.

- **Read the case of Victor in Herold (2016), pp.1-7.**

- “While Victor’s story may sound like science fiction, the technologies extending and enhancing his life are in fact now in development, and some are already being tested in humans. These technologies will radically transform human health and extend our life spans far beyond what most of us have ever dreamed. Many people alive today will be able to take advantage of an array of medical technologies taking shape at the nexus of computing, microelectronics, engineering, gene therapies, cognitive science, nanotechnology, cellular therapies, and robotics. The combination of these technologies is a nascent but rapidly advancing field that many scientists refer to as converging technologies (CTs). Scientists predict that combining the powerful emerging discoveries of today will take medical science, and human life, to an entirely new plateau...”

- “...Rather than predicting the effects of nanotechnology, genetic engineering, and cognitive science in isolation, experts say that one can only glimpse the true potential of these fields by looking at their combined effect. The results of collaboration among various scientific specialists is not only leading to an entirely new multidisciplinary approach to medical research, but creating treatments and cures that are far beyond what we now consider to be on the cutting edge. The possibilities for life extension will soon transform not only individual lives, but society as well. At the same time, the technologies discussed in this book will almost surely introduce ethical quandaries and complications that we are ill prepared to navigate....”

- “...With a multitude of technological blessings come complicated practical and ethical issues, some of which we can predict, but many we cannot. Artificial organs and other critical body parts, neural implants to enhance the brain, nanorobots that can cure disease and reverse ageing, and direct interfaces between our bodies and machines will dramatically improve human health, but they also mean that the line between “human” and “machine” will become progressively more blurry.” (Herold, 2016, pp.8-9).

## 5. Technology and the social-cultural roles of diagnoses (Hofmann and Svenaeus, 2018: 6-7).

- Technology influences illness experiences through altering social-cultural norms and values regarding various diagnoses as well as moving experiences from the realm of chance and fate to that of control and responsibility
- E.g. “Technology affects the (professional) prestige of diseases and specialties” (Album et al., 2017, Album and Westin, 2008).
- E.g. myocardial infarction versus fibromyalgia



(image from: pinterest.com & athersys.com)



- “Genetic tests have moved obesity from being a moral disease (weakness of the will) to a genetic disease, and bariatric surgery has made it a surgical or metabolic disease – altering both its status, prestige, and stigma.
- Yet an example is how social media technology strongly has influenced the **social construction** of inflammatory bowel disease [e.g. Crohn's disease] (Frohlich, 2016, Franklen's emphasis).”
- “prenatal ultrasound altering conceptions of one's own body, pregnancy, and being expecting (including moral dilemmas of abortion)” (Verbeek, 2008). (image from mayoclinic.org)





## The Social Construction of Inflammatory Bowel Disease Using Social Media Technologies (Frohlich, 2016)

- “Many people with inflammatory bowel disease (IBD) sometimes lacking adequate face-to-face sources of support, turn to online communities to meet others with the disease. These online communities are places of support and education, but through the use of social media communication technologies, people with IBD are redefining what it means to live with the disease....:
  - the refiguring of the body is beautiful;
  - inflammatory bowel disease is serious and deadly;
  - inflammatory bowel disease is humorous;
  - the disease makes one stronger;
  - and the disease is invisible, but needs to be made visible” (Frohlich, 2016: abstract). **[Franklen: the above partially applies to IBS irritable bowel syndrome too]**



## 6. Medical technologies and the focus on health

(Hofmann and Svenaeus, 2018: 7-8).

- Technology shapes our experiences of illness through its measures to monitor and measure our health.
- “New mobile apps and a range of wearables mediate the conception of bodily activity, sleep, nutrition, digestion, etc. through measurements of bodily functions and make these and other ordinary human experiences subject to medical attention”
- also a case of **medicalization** (healthization) by way of technology
- Example: Digital Health Technologies such as Telemedicine and Self-care monitoring packages (or personal health technologies) (Barry & Yuill, 2016)

## References

- Boyd, K. M. (2000). "Disease, illness, sickness, health, healing and wholeness: exploring some elusive concepts", *Journal of Medical Ethics*, 26, 1. pp.9-17.
- Frohlich DO (2016). "The Social Construction of Inflammatory Bowel Disease Using Social Media Technologies", *Health Commun*, 31(11):1412-20.
- Herold, E. (2016). *Beyond Human: How Cutting-Edge Science is Extending our lives*. St. Martin's Press.
- Hofmann, B. & Svenaeus, F. (2018). "How medical technologies shape the experience of illness", *Life Sciences, Society and Policy*, 14, 3, total 11 pages.
- Laing, R. D. (1967). *The Politics of Experience*. NY: Ballantine.

- Lee, S., Chiu, M., Tsang, A., Chui, H., and Kleinmand, A. (2006). Stigmatizing experience and structural discrimination associated with the treatment of schizophrenia in Hong Kong. *Social Science & Medicine* (62), pp. 1685–1696.
- McCreadie, C. (2010). "Technology and Older People". Pp.607-617 in Dannefer, D. & Phillipson, C. (eds.) *The SAGE Handbook of Social Gerontology*. London: Sage.
- Oliver, M. & Barnes, C. (2012). *The New Politics of Disablement, 2<sup>nd</sup> edition*. Basingstoke: Palgrave.
- Szasz, T.S. (1974). *The Myth of Mental Illness: Foundations of a Theory of Personal Conduct*. NY: Harper & Row.
- WHO (2006). *Basic Documents*, Forty-fifth edition, Supplement, October 2006. Geneva: World Health Organization
- WHO (2016). *Priority Assistive Products List*. Geneva: World Health Organization