"Focus on what matters to people, and not on what's the matter with people"

*What do we mean by **human-centered** health innovation? An IHCHI position paper on the semantic disambiguation of a crucial term.*

The Institute for Human-Centered Health Innovation (IHCHI) is a non-profit organization, driven by the purpose of fostering a more human-centered approach to health innovation. IHCHI considers a broad understanding of health, addressing needs that may go beyond the existing healthcare system, including disease prevention and early detection.

But what does "human-centered" actually mean? What distinguishes human-centered health innovation from purely technical or science driven health innovation? A review of the literature, and conversations both within and outside the IHCHI network revealed multiple definitions and dimensions which could be applied.

Of note, some definitions refer to the process of innovation - human-centered because human needs drive the design and development process. Other definitions speak more to the desired impact of the innovation, with the goal to empower individuals to take action towards health outcomes that matter to them.
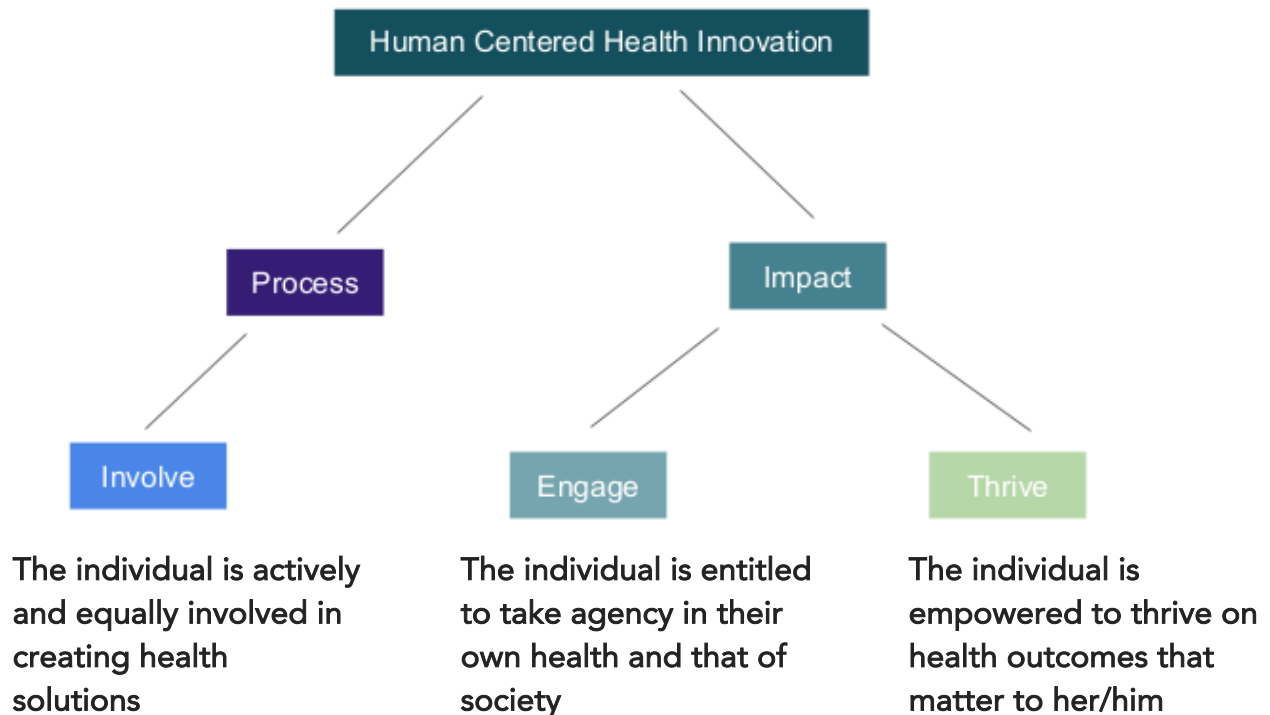
The purpose of this article is to discuss the range of valid perspectives that exist to allow health innovators to consider different ways and levels of human-centeredness in their work as summarized in the chart on the next page.

Ensuring people and their needs drive the innovation process

Let's start with the innovation process. Human-centered design is a well-documented methodology, in which the inclusion of end-users is integral to solution development.[1] Applying human-centered design methodologies increases the chances of solving problems that people really care about, and of accounting for personal preferences, context, priorities and lifestyle in solution design. But frequently, even when the principles of human-centered design are applied, end-users may continue to remain at arms' length. In healthcare, innovators may feel comfortable "ticking the 'patient-centric' box" if patients' feedback is gathered somewhere along the design and development pathway. This is very different from a deeper

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[1] Melles et al., 2021. Innovating health care: key characteristics of human-centered design. International Journal for Quality in Health Care, Volume 33, Issue Supplement_1, January 2021

involvement, up to a sharing of decision-making rights with patients and other end-users (e.g. care providers).

Human Centered Health Innovation

Process

Involve
The individual is actively and equally involved in creating health solutions

Impact

Engage
The individual is entitled to take agency in their own health and that of society

Thrive
The individual is empowered to thrive on health outcomes that matter to her/him

Giving a voice to neglected groups of society

Another definition of "human-centered" speaks to the inclusiveness of health innovation - i.e. addressing the needs of *all* humans, including, importantly, those who tend to be neglected in decision making. Consider, for example, those people who "fall between the cracks" because they don't fit neatly into the classifications or processes that underpin our healthcare systems. People with a disease that is difficult to diagnose is one example. Until they have a definitive diagnosis, they are not classified as patients, with possible consequences of lack of insurance, lack of sick pay, and a tendency to be passed from one specialist to another, with no individual taking a lead in their care. The lack of a clearly described collective identity makes it all the more difficult for these patients to make their needs heard and met.

Ensuring that all segments of society have a voice is vital if innovation is to address, and not exacerbate, health inequalities. Challenging as it is, it's important that innovators seek not only the perspective of well-educated and eloquent patients, but also those who are already disposed to inferior health outcomes because of disadvantaged socio-economic circumstances.

There are neglected voices amongst healthcare providers too. For example, nurses have huge potential to contribute to improving our healthcare systems, but rarely have the opportunity to do so, whether due to lack of time, recognition, empowerment or encouragement. In times of crisis, if their work and life conditions become unsustainable, quitting the job they once loved is unfortunately too often the only way out left to them.

Empowering people to engage in their health and that of society

Which healthcare innovations might be considered human-centered in terms of desired impact? One class of human-centered innovations is those that enable and empower people to fully engage in their health, or to actively engage in the health of society. Examples include efforts to help rebalance the power equation in the patient-physician relationship, to support greater personal accountability for health and to facilitate a broader system change designed at strengthening the role of the individual in healthcare - enabled by tools that facilitate access to expert knowledge at the right time.

Rebalancing the patient-physician relationship

There is an increasingly visible movement to rebalance the patient-physician relationship, from the traditional hierarchical relationship where a medical doctor is expected to know best, to one in which patients are respected as sovereign individuals being at any time in charge of their own health. The reality of care providers having less and less time to really know their patients is a contributing factor here, accelerating the need for greater patient involvement in treatment decisions.

Meskó argues that digital health technologies present the perfect opportunity to rethink the patient-doctor relationship, as both medical knowledge and individual health data become far more accessible to all.[2] While access to medical knowledge has traditionally been the privilege of experts in medicine, today the personal doctor need no longer be the single source of information. Through the increased availability of medical information, connection to other patients in virtual communities, and the possibility of seeking alternative points of view from experts on-line, patients have far more agency. That said, the information available, unfiltered as it is, can be overwhelming and misleading. Secondly, by their very essence, digital health solutions generate data for use by the patient which the patient can share with his/her physician - a reversal in roles.

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[2] Meskó et al., 2017. Digital health is a cultural transformation of traditional healthcare.   MHealth. Vol 3, No 9.

What makes this a human-centered endeavor is the aim to enable everybody to choose the role they play in their care team. With this comes the opportunity for the patient to bring their own goals, values, circumstances, and experience right to the forefront of decision-making, the first step in truly personalized care. It also enables the patient to contribute valuable knowledge to their treatment decision, as exemplified by E-patient Dave deBronkhart.[3] And last but not least, there is an increasing body of evidence to suggest that patients who are actively involved in managing their health have better outcomes.[4]

Taking personal accountability for disease prevention

Taking a more active role in one's own health is of course relevant at any time, not only when playing the temporary role of patient. Because human-physician relationships in the context of disease prevention are neither well-established nor reimbursed, one could argue that there is less of a precedent to shift and a greater opportunity to develop individual accountability. Nevertheless, disease prevention in the hands of the individual needs to overcome our tendency to only act on our health when it is demonstrably broken, which is often too late. The challenge of overcoming our deep-rooted bias to prioritize short-term gains over long-term wins should not be underestimated.

Participation in health, a key component of our definition of human-centered, is also linked to prevention within the concept of P4 medicine. In addition to participation and prevention, the third and fourth components of P4 medicine are personalization and prediction - both becoming increasingly possible through advances in data science and artificial intelligence. P4 medicine is viewed as having the potential to significantly improve the sustainability of health systems as well as to drive better health outcomes.[5]

Enable individuals to contribute to advances in healthcare, for the benefit of society

The sense of being active rather than passive goes beyond taking personal accountability for one's own health. There is also the sense in which we, as citizens, can play a role in shaping healthcare and a holistic approach to health, for our communities and society as a whole.

Again, if handled correctly, digital health offers various new possibilities here. Our personal data is becoming the lifeblood of healthcare. What if we were to not only help each other

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[3] Dave deBronkart, 2013. How the e-patient community helped save my life. BMJ 2013;346

[4] Hibbard and Greene, 2013. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. Health Aff (Millwood). Feb 2013;32(2):207-14

[5] Flores et al., 2013. P4 medicine: how systems medicine will transform the healthcare sector and society. Personalised Medicine. 2013; 10(6): 565–576

understand the power of our data to advance progress in healthcare but also develop mechanisms so that we can actively choose for what aims it can be used? Much in the same way we are empowered to choose which, if any, charitable aims we wish to donate our hard earned cash - our health data now becoming the new currency.

Re-shaping the healthcare ecosystem

Empowering individuals to actively engage in their health will require the emergence of new players, and for traditional actors to embrace changed roles. To be successful, such change cannot be driven without full consideration of the beliefs, values and priorities of all relevant players - that is, the application of a human-centered lens to all individuals involved in healthcare.

Thrive not survive

Finally, a different, but related, slant on human-centered health innovation is underpinned by the acknowledgement that we humans are more than a set of biological and molecular mechanisms - we are all individuals, with our own history, values, wants and needs. This has been a common thread throughout this discussion. In this context, the ambition of human-centered health innovation is to go beyond absence of disease, and to enable individuals to thrive. Or to put it another way, to focus on what matters to patients, and not on what's the matter with patients. This aligns with the WHO definition of health - "a state of complete physical, mental and social well-being, not merely the absence of disease or infirmity".[6]

Summary

To summarize, there are a number of different ways in which human-centeredness can be considered and addressed when it comes to health innovation - relating to either the approach, the desired outcome, or both. For IHCHI, next steps are to offer the support of our community to accelerate initiatives that fall within the scope of human-centered health innovation as outlined here and in the table on the next page. With a more solid and profound understanding of the different meanings of human-centeredness it will be possible to encompass the right strategies and activities to make health innovation both more viable and sustainable by adapting to the real world needs of the individual.

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[6] Constitution of the World Health Organisation, 2020

	Involve	**Engage**	**Thrive**
	The individual is actively and equally involved in creating health solutions	**The individual is entitled to take agency in their own health and that of society**	**The individual is empowered to thrive on health outcomes that matter to them**
Key aspects	• Deep involvement of end-users in design and development of health innovations • Giving a voice to neglected groups of society • Enabling all players in the health system, e.g. nurses, to drive improvements through innovation	• Rebalancing the patient-physician relationship • P4 medicine - prevention, prediction, personalization and participation • Enabling individuals to take ownership of their health data and choose how they may be employed to advance healthcare for the benefit of society and themselves	• Taking a holistic view of health, that goes beyond the absence of disease • One health: Integrating all the determinants of health beyond the bio-medical: social, behavioral, environmental, etc. • Encouraging approaches that go beyond the current healthcare setting
Examples	• Actively involving all segments of society in creating a vision for a future health system • Supporting people suffering from a long-term condition to join forces to design and develop solutions that make their lives easier • Creating a best practice/ playbook/certificate on how to ensure health innovation is human-centered	• Development of a solution to capture descriptions of symptoms in people's own words - so that symptoms that do not fit neatly into existing boxes are not ignored, and people feel heard by their physician • Create a safe and easy to use platform that encourages and empowers patients to share their experience and help one another	• Defining key metrics to measure the different health states that matter to people on a population level and track how different measures within and beyond the current healthcare setting contribute to their achievement • Investigate different health personas with their specific needs according to age, demography and culture

Author: Gabby Benjamin. Editors: Thomas Brenzikofer, Michael Rebhan
Contributors: Werner Boeing, Stefanie Zechner, Victor Björk, Carsten Danzer, Angelie Pham, TJ Yoon, Fidiana Stan, Lutz Groh, Mina Luetkens, Cornelia Schneider