

GUEST EDITORIAL

Co-Production, Co-Education and Person-Centered Healthcare Practice

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“Co-creation and community nurture engagement to invite the public inside, so that they can influence and co-create healthcare, research and community. The public is the sensor that powers influence. They build evidence into practice” (Amy Price 2013) [cf.1].

Introduction

The transition to a system where the public can engage in and teach healthcare as well as do research for themselves is inevitable. It is already happening and individuals who thought about how to meet a need have partnered with researchers to deliver 3D limbs, pancreatic cancer tests, inexpensive microscopes made of paper and brain valves to relieve cranial pressure [1]. A systematic review [2] reports that patient and public involvement (PPI) contributes to salient, pragmatic study design, recruiting benefits, interview quality and a person-centered policy setting. PPI was found to meet cultural challenges, destigmatize mental health, reduce age bias and decrease disease stereotypes. The prerequisites of success were credited to building community through relationship [2].

There is growing pressure to validate PPI by assessing “impact” to make a case for sustainable funding and validation [3]. We can construct methods to build a container or framework for a sustainable intervention, but it is the intervention that will be measured rather than the framework. This is why frameworks that are not tailored to specific use cases may fail as they lack the capacity to match the shared values, needs, cultural expectations or preferences of clinicians, researchers, or patients that use them. Greenhalgh and colleagues suggest that a single, off-

the-shelf framework may be less useful than a menu of evidence-based resources which stakeholders can use to co-design their own frameworks [4]. A relational framework such as Everyone Included [5] can be flexible, tailored to the intervention and can bypass the rigidity of a fixed framework. In this *Guest Editorial* we describe the benefits of using a relational person-centered framework where everyone is included and we report on how this has shaped citizen science, research, healthcare and medical education.

Everyone Included is a set of design and leadership principles co-produced with patients, caregivers, researchers, clinicians and technologists that has been field-tested through a variety of research and implementation projects over the course of seven years [5]. It is also adaptive to the experience of its users and is regularly updated to incorporate what has been learned by others from its use.

Everyone Included in Research, Medicine and Healthcare Conferences

In the Everyone Included model, all parties choose to work as a team and make a way to hear every voice to “provide the stage from which even the hardest and most difficult stories can be told” [6]. When everyone is included and respect is reciprocal, it can be acknowledged that patients have the most recent voice added to the conversation, but true engagement will require meaningful participation from everyone. Diverse expertise where power is shared in

an environment of trust and respect leads to more creative and innovative solutions to healthcare problems [6-8].

The Everyone Included framework was used to develop Stanford Medicine X conferences and was successfully implemented for the Precision Medicine Initiative workshop hosted by former U.S. President Obama at the White house in 2016 [9]. The framework created Patient and Public Partnership guidelines for the initiative that was continued through All of Us [10], the million person DNA National Institutes of Health program under current U.S. President Trump, thus demonstrating robust policy across political diversity. Everyone Included [6] has used this approach to reach 20 million people with 1 billion social media impressions as of 2018 and according to SYMPLUR Signals, the tracking engine for healthcare on social media, even where patients were underrepresented they exerted substantial social media influence [11].

Everyone Included: Computer Based Citizen Science and Education

Astronomers and physicists faced a scientific problem, the researchers knew that humans were superior to machines for classifying information but did not have enough staff for making simple classifications, so they turned to the public for help. The solution became the Citizen Science project Zooniverse [12] which has 1.7 million users where people of all ages and backgrounds participate in real research with over 50 active online citizen science projects. The citizen volunteers were provided with tools and minimal instruction as they worked alongside researchers to analyze images from NASA's Hubble telescope and classify them, thereby assisting scientists in understanding the origin of galaxies [13]. All that was expected from the citizens was that they assist with classification tasks but, even without formal training, they accomplished so much more by working in community.

The citizen scientists were able to progress knowledge of the physical universe, improve automated data analysis and contribute to machine learning through engaging in simple classification tasks. As contributors, volunteers noticed things they could not explain and set out to develop their own hypothesis. The citizens communicated, banded together and discovered a new galaxy [14]. They honed their skills interdependently, not by being spoon fed plain language astronomy, but instead by searching the Internet, combing social media sites and gleaning information from professional astronomers who were willing to help with definitions and theory while showing them, by example, how to critically appraise the information they observed [15]. In another education example, relationship building occurred through the Hole-in-the-Wall Education Limited (HiWEL) project [16], where computers were placed inside selected village walls in rural India and curious, but previously illiterate, children taught themselves and each other to read and acquire mathematics and science skills.

Everyone Included in Medical Education

Patients can become instructors who teach patient care in medical schools and summer pre-medical science programs. One such program launched by the Stanford Anesthesia, Informatics and Media (AIM) Lab is the Science, Technology and Medicine Program, (SASI) [17] a two-week, interactive session for high school and undergraduate students interested in pursuing a career in the healthcare field. Patients, medical professionals and industry experts are invited to share their experiences, allowing students to gain new and unique perspectives on healthcare. By encouraging open discussions, emphasizing collaboration and building trust among everyone, the Stanford Science, Technology and Medicine Program is promoting a new generation of leaders that value teamwork, empathy and shared decision-making. For example, Hugo Campos [18], a cardiac patient shared his story with the students, including how his condition affected his daily life, how he took control of his treatment process and advocated for data agency. He shared how future medical professionals can make the healthcare system better-suited for everyone's needs. His engaging and compelling story emphasized to students that medicine should not be a fragmented system, but a cohesive team effort that involves everyone.

“In order for any healthcare system to be successful at truly serving the community, it must be a synergistic combination of professionals, patients and the public” (Ujwal Srivastava, 2019, program alumni).

Medical education does not just go one way. On the contrary, patients, researchers, clinicians, medical students, industry and policymakers joined in a massive open online classroom to learn about “partnering with patients in medical research, where everyone included principles were shared and where learners and instructors gained perspectives they could apply to their own work” [19].

A Framework to Transcend Cultures and Research Designs

The Everyone Included relational framework works beyond first world countries. For example, in India, communities, researchers and clinicians have mobilized with an Everyone Included perspective to make life better for the local people [20]. In one online community, medical students, patients, consultants, medical doctors and patients work together to provide free expert advice and medical help for clinicians and their patients in rural India [21]. They learn and model compassion by partnering with patients and they have worked together to improve emergency medical transport, vaccinations, feminine hygiene, pre- and post-natal care and to reduce female feticide [22]. Medical students from other countries join this initiative too through the partnership of The User

Driven Health Care Network and The BMJ Case Reports elective program where the students write up practical papers on topics such as giving an intramuscular injection correctly [23] and share how students can learn about research by jointly reviewing an academic paper [24].

Everyone Included a Future Perspective on Data Agency

Might we use an Everyone Included framework to resolve a worldwide crisis, the personal health data problem? There are tensions around who owns health data, where the agency is positioned and how to construct the best ways to keep data safe, secure and accessible [25]. Rules alone are not working as they were built for a system that has outgrown them. Data are power and like a seed that contains the future within its core. More data analysis has been made possible in the last ten years than in all the previous generations combined. This has generated tensions between initial intentions and unforeseen consequences. For example, the FAIR Data Principles [26] propose that research data should be Findable, Accessible, Interoperable and Reusable, but nothing has prepared us for the use and misuse of personal data [25]. Even when research begins as ethically approved and safe in the researcher's toolkit, data can later be sold to a third party in exchange for analytical services [25], enabling machines to identify disease states from a picture [27], classify your level of intelligence and identify a demographic profile in four "likes" or less [28]. Recently, Facebook has advocated for the use and re-use of user's health information through the linking of their electronic health records to their Facebook profile and social media records [29]. End users have little input in the life of the data they produce, but, with Everyone Included, we could reshape the way data is used so the power can be focused and harm is minimized.

Conclusion

Although PPI and co-production is an emergent practice, self-management and self-care initiatives in healthcare have reduced costs and increased quality of life. For example, patients remotely manage complex conditions such as diabetes, anti-coagulation therapies, home kidney dialysis, tube feeding, pain pumps, thyroid care and asthma. These interventions are potentially lethal when used incorrectly and yet results show patients and the public are competent partners with clinicians in their own healthcare [30]. We suggest that the Everyone Included Framework might change the face of healthcare by providing flexibility, relational boundaries, acceptance, curiosity and the insatiable desire to reframe healthcare to meet the needs of the people who use it.

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