People Centered Health Data Collaboratives: How they work and how they can be improved for global use

Moderator: Mei Lin Fung, Co-Chair, People Centered Internet

How do we harness responsibly the vast amount of health information that has been created and stored by devices but too often is siloed and inaccessible to the scientific community? This session focused on the use of health data collaboratives to make this information accessible to scientists and practitioners, the regulatory issues that need to be considered and/or changed and discusses the promise and pitfalls of the use of personal data.

The initial event on this topic took place as part of the event of the UN Science Summit Sessions on "Key Challenges and Objectives for Digital Cooperation, Governance and Regulation" (Link to recording). The 9th edition of the Science Summit around the 78th United Nations General Assembly (SSUNGA78) took place from 12-29 September 2023. The People Centered Internet (PCI) organized nine sessions in conjunction with the International Science Council from Sept 20-22 to discuss the future of digital in achieving the SDGs. The sessions took a people centered approach; this means to discuss how scientific and digital collaboration can only be advanced through human feedback loops. The People Centered Internet sessions explored the parameters of this approach focusing on specific use cases where this is needed to achieve the SDGs and discussing the recommended enabling policy, regulatory, and financial environments, that are required to support genuinely global scientific collaborations across continents, nations, and themes. Speakers from each panel summarized the most important results in a stocktaking (Link).

Speakers

- Märt Aro, Digital Innovation Advisor to United Nations, European Commission, Estonia, and Lithuania
- Bertrand de la Chapelle, Chief Vision Officer, Datasphere Initiative
- Paul Murphy, Research Fellow, TELUS Corporation, Presentation Slides
- Tamara Singh, Sherpa, Sustainable Finance Development Network
- Kate Wilson, Senior Fellow, People Centered Internet

Further Contributions

Integral Healthcare: combining the local and the global processes in the digital age

- Alessia Maccaro, School of Engineering - University of Warwick – UK
- Maria Laura Ilardo, Research Unit of Philosophy of Science and Human Development – University Campus Bio-Medico – Rome
- Marta Bertolaso, Research Unit of Philosophy of Science and Human Development – University Campus Bio-Medico – Rome

Summary of People Centered Health Data Cooperatives

Prepared by Christine Asjoma, Convenor of the Panel Series "Key Challenges and Objectives for Digital Cooperation, Governance and Regulation"

We need to know that people are doing well, that we are doing well. And how will we know that? That was the topic of this first session. The panel looked at people-centered health data collaborations.

Historical revolutions such as language, writing and printing have each significantly reshaped society. Health is at the heart of the current transformation of our society. Because, as Bertrand de la Chapelle mentioned, health data makes up a significant part of our data landscape. Every single MRI scan generates huge amounts of data. This data needs to be used and still be protected.

A regulatory framework is needed that - like international governmental organizations - can reconcile conflicting objectives and yet - similar to the organizations of the Internet - approach problem-solving efficiently once the objectives are set. This requires a dynamic, iterative regulatory process that adapts to the pace of the Internet. Bertrand de la Chapelle also advocated a move from opt-in to opt-out models for medical data sharing to facilitate research.

Building trust around health data is paramount, added Kate Wilson. She shared her practical experience working in countries such as Ghana, Malawi, and Tanzania. For example, she found that patients were more willing to share their data when the researchers demonstrated their professionalism using tablets.

Märt Aro added examples from the digital pioneer country Estonia. 99% of government services in Estonia are available online. Märt also addressed the role of trust in digital systems, which has been achieved through strict regulations on data access. Estonia was in a difficult situation after the collapse of the USSR. So, there was a great need to implement innovation at that time.

But a concept from one country cannot simply be transferred to another. There are different expectations of data protection in different regions of the world. Building on this argument, Tamara Singh emphasized the importance of hyperlocal context in data management.

Paul Murphy articulated our cross-regional goals: Digital health systems must be holistic, i.e., include the virtual as well as the physical world. They must be ecological, i.e., minimize the digital footprint. And they must be bottom-up, i.e., allow the community to participate in shaping digital policy.

Integral Healthcare: combining the local and the global processes in the digital age

Alessia Maccaro (School of Engineering - University of Warwick – UK), Maria Laura Ilardo (Research Unit of Philosophy of Science and Human Development – University Campus Bio-Medico – Rome), Marta Bertolaso (Research Unit of Philosophy of Science and Human Development – University Campus Bio-Medico – Rome)

The digital transformation is radically revolutionizing multiple sectors, although its impact on human health and global well-being and effectiveness can vary significantly depending on the specific context in which it is deployed. This context includes social, cultural, economic, political, and environmental factors. The interaction and adaptation of the digital technology to the environment plays a pivotal role in shaping the outcomes and consequences of technological innovations. Recognizing and navigating this dynamic interplay is crucial for harnessing the full potential of digital technology while mitigating unintended consequences to gather a relational epistemology (Bertolaso, Capone and Rodriguez-Lluesma, 2022).

Moreover, as digital technologies once integrated into people's daily life can have both positive and negative impacts on society, therefore a focus on accurate risk assessment and active human involvement is crucial to ensure responsible and safe development and use of digital technologies. Risk assessment is essential for identifying and mitigating these negative effects, while involving people in decision-making ensures needs of different individuals and communities are considered, preventing discrimination or inadvertent exclusion, and/or privacy violations.

The digital innovation particularly involves the healthcare field, and impacts on the efficiency, accessibility and quality of services provided to people. It is well known that advanced tools such as the Internet of Things (IoT), 5G, Telemedicine and Artificial Intelligence (AI) are increasingly being used in biomedicine to improve diagnosis, treatment, and patient outcomes. In particular, in digital health it is important to keep the futuristic hypotheses of an overcoming of the human being at bay is far away to be reached, therefore it is particularly important to emphasize the importance of human involvement, i.e. the "human-centric approach" (Bertolaso and Rocchi, 2020; Beneduce and Bertolaso, 2022), and the interplay between individuals and their societal context in optimizing health services and improving the management of patient care.

In particular, the use of emerging digital and telehealth platforms that respond to the needs of the served populations, e.g., facilitating remote consultations and home-based monitoring, thereby empowering individuals, and their families to manage their health. Utilizing technology effectively becomes essential in supporting healthcare providers and recipients, enabling adaptable community-based care. This, known as Primary Health Care, becomes a global strategic priority (Hanson, K. Et al., 2022). This active involvement of individuals and communities in leveraging digital innovations is instrumental in advancing global health coverage.

The engagement of communities in the digital transformation means paying attention to the specific individual needs and also of the plurality of different cultures: in order to achieve an effective involvement of people in the progress process it is essential to approximate local perspectives and individual sensibilities that must be introduced to the new gradually and not forcing the threshold of acceptability. This does not mean fall into a relativistic perspective but work for a negotiation among the peculiarity of local context and the universalization of shared perspectives (Maccaro, A. et al., 2022 and Maccaro, A. 2019).

The integration of global (the community) and local (the individual) perspectives help to better understand the networks of dynamic (complex) relationships (i.e., interactions), between the various components, considering contexts, biographical and cultural influences, and environmental dimensions. The ethical counterpart of this integrative approach focuses on the patients' needs, rights and well-being, considering both individual and collective (Bertolaso, 2022b).

In a globalized and rapidly changing world, characterized by highly complex problems to be faced, a unique solution (ontologically speaking: a simple, monocausal solution) would certainly be reductive and unable to represent the individual specificities and therefore not sufficient to solve the problem (Bertolaso, 2022a). When faced with complex problems, it is necessary to consider a wider range of ideas and strategies and examine the multiple factors at play, to achieve a global effective solution. Moreover, solutions that were effective in the past may no longer be suited to current challenges, and solutions that work effectively in a specific context may not work as well when applied to another context. Stressing the importance (i) of being flexible and willing to constantly examine new approaches, and (ii) of "modeling multiscale and context-dependent dynamics to create common solutions that can be implemented at different levels" (Fung, M.L. et al., 2023), means developing an integrated approach

that can intervene also in the risk analysis and risk mitigation practices where the individual and cultural perspective (i.e., historical narratives, personal stories, societal dynamics) are welcomed in a risk assessment together with new technologies and digital solutions.

Intervention strategies involve understanding systemic dynamics by identifying complex interactions (Bertolaso, 2022b) through modeling and simulation to predict risk situations.

Addressing potential risk thus requires an integrated approach that combines the power of digital devices with human experience and judgment. In this regard, we emphasize the need to rethink decisional algorithms for risk assessment at both individual and collective levels.

Such algorithms, considered in this way (collective and individual), could help in supporting the technological sustainability and healthcare policies development at a global level.

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