



A private sector perspective on the value of health data governance

“Digital health is the way of the future. We shouldn’t be afraid to collaborate and involve the private sector. Collaboration. Collaboration. Collaboration.” – Shivon Byamukama, Babyl Health Rwanda

The World Health Organization is convinced: "Data sharing maximizes positive health outcomes". And to enable that, health data needs to be well governed to innovate, while protecting individuals. The Health Data Governance Principles created by Transform Health and their partners aim to provide a framework for governments to guide data protection legislation. While governance tends to focus on the public sector, the private sector is often overlooked despite having an outsized role in generating and analysing health data. That’s why the [Digital Connected Care Coalition](#), a private sector coalition of digital health innovators, hosted a panel discussion to bring a private sector perspective on contributing to better health data governance frameworks, welcoming this development as it can actively stimulate public-private partnerships and innovation.

After an introduction to the health data principles by moderator Mathilde Forslund, Jeroen Tas, of Philips, laid out the core challenge: Currently at least half of the world’s population cannot obtain essential health services. To ensure that they do, new technologies have the potential to create access at scale and at affordable cost. By taking an ecosystem approach we can combine the capabilities of the public and private sector to create valuable, lasting solutions. Just as mobile financial services have become readily available throughout the African continent, a similar revolution is needed to make possible the responsible use of health data to benefit patients and strengthen health systems.

With this challenge in mind, the panel outlined why a global health data governance framework was needed in the first place. Shivon Byamukama of Babyl Health Rwanda noted that a global health data governance framework would allow for data protection and stimulate interoperability across jurisdictions. Transparent cross-border standards would enhance equity and build trust: Patients would know that their data will be protected according to international standards. Ruchika Singhal of Medtronic LABS emphasises the importance of standardisation as a catalyst for innovation: The goal of a global health data governance framework is to leverage data to make a difference for patients. We cannot easily achieve that goal and innovate if we cannot pool data to gain new insights. Without standardisation and interoperability, datasets become too fragmented and unusable for innovation.

While the benefits of large, aggregated health datasets are clear, many see an inherent tension between private sector innovation and privacy. Jeroen pointed out that this concern is mitigated if we leverage aggregate data rather than individual identifiable data for innovation. The real challenge is ensuring that those anonymised aggregated datasets are used in a safe and equitable way that ultimately benefits the people from whom the data comes and the population at large. The rise of big tech monopolies and the monetisation of people’s data raised questions about the potential for exploitation of people’s health data. Addressing this, Ruchika drew parallels between health data and natural resources. Much like natural resources, health data is a valuable resource which can be overexploited in ways that harm society. Yet just as environmental regulation exists to mitigate the negative effects of natural resource exploitation, health data need not be exploited if we regulate its use, and instead preserve and grow it. Jeroen argued that unlike natural resources data is not scarce, but rather it is fragmented and can be shared and accumulated indefinitely. Yet just like natural resources, data has value and can be exploited and monopolised for profit. A solution, he suggests, is to federate datasets among different partners, including verification, authorization, and regulation to protect the individual, and use that data to benefit the users



rather than a handful of corporations. A similar approach was taken for instance with payments, with agreements established between different companies, allowing users to pay and withdraw cash anywhere in the world. Thus, to build a federated model, what is needed is a governance framework, the willingness to invest, and to engage all key stakeholders.

The discussion about private sector innovation and solutions raised questions on how health data governance principles can be put into practice. Nicole Spieker of PharmAccess warned of overregulating data out of fear and ultimately missing out on the value of that data for patients. Instead, regulation should focus on creating a framework that allows us to use that value in ways that can improve health outcomes and creates ownership with the individuals to whom the data belongs. Building on that point, Shivon illustrated the need for regulations that spell out the 'dos and don'ts' so that the private sector can operate effectively. To achieve this, Jeroen noted that the private sector can play a key role in supporting health data governance frameworks with transparent cooperation with regulators. He noted that effective and clear regulation can push private sector players in the right direction, while an overbearing or inconsistent regulatory environment can kill innovation.

The DCCC is a coalition of the willing that brings various stakeholders in the digital health space together by building a health ecosystem. Speaking on this ecosystem, Nicole stated that digital innovation will mostly come from the private sector, but has a real opportunity to develop new research, diagnostics, vaccines, and medication tailor made for African citizens and healthcare needs, driving real inclusivity.

Finishing off the discussion, each panellist closed with a powerful take home message:

"Let's not be afraid of the value we can create with this data to make sure people get the healthcare they are entitled to." – Nicole Spieker

"The cumulative benefit for everyone, patient and human welfare should be our guiding star." – Ruchika Singhal

"Utilize this opportunity to leverage data to create the insights that can drive better health for all." – Jeroen Tas

We know the above reflection of our Digital Health Week session reflects the thoughts of the DCCC board members. Although we know the thoughts are aligned with many organizations -like the others endorsing the [Health Data Governance Principles](#)-, it is one part of an important conversation. We look forward to continuing with all stakeholders in the private, public, and social sectors: info@digitalconnectedcarecoalition.com.