

## **Public participation in health data governance: an imperative raising divide?**

Data's golden age has been acclaimed by the market and various governments, with large amounts of capital being poured into personal genomics companies and state-funded research programmes. They share a similar goal: to harness the power of data by converting it into information that can lead to more efficient decision-making and clinical practice. But the sheer growth of the health-related data shared and traded globally holds both great promise and menace. Big health data can foster scientific advancements with potential to deliver tailor-made treatments and heal millions across the globe. However, inerasable digital footprints left by the use of digital services and apps present (un)foreseeable challenges to people's privacy, dignity and autonomy.

Many argue that by playing an active role in generating, sharing and governing data lay people can contribute to scientific progress and achieve greater control over their data. Grounded in solidaristic concerns with the common good and substantiated by democratic ideals of legitimacy, transparency and accountability, public participation in health data governance has become a new imperative. Yet, in the rush to earn public trust and support for data collection and use, these ideals may be overridden by utilitarian approaches that can transform people's engagement with data into technologies for mass self-quantification and legitimation of top-down agendas.

Delving into the ethical, legal and social implications of public participation in health data governance lends an opportunity to critically reflect about its eminent power to reduce, produce and reinforce inequalities. Who wants to engage with data? To what ends? Through which devices and mechanisms? And, whose voices will be unheeded? Will public participation in data governance contribute to narrow, sustain or widen existing age, gender, able-bodiedness and digital divides? These are the questions this lecture will aim to answer.