

Health Data and Health Data Spaces: Actors, Narratives, and Surveillance

Conference, 7-8 June 2023

Call for Papers

Technology has a long tradition as a factor in improving health care and promoting public health. However, the context has evolved considerably, especially under the influence of neoliberalism. Since the beginning of the 21st century, several phenomena have changed regarding the actors involved and the discourses conveyed. The first phenomenon relates to marketing devices and applications for measuring health indicators available to the general public. Specialised companies have started to enter the sector by offering products and services (analytics) to consumers, allowing the emergence of the “quantified self” phenomenon (Lupton, 2016). They have since been joined - and sometimes bought - by big tech companies, thus increasing the potential for collecting and analysing health data. Secondly, private companies and public services have, in turn, become interested in the “quantified self” philosophy from which they can benefit organisationally. They support individual responsibility through a gamification approach, for example, by proposing to use the IoT for occupational health or social security benefits. They use AI systems, mainly developed and managed by private companies. Manipulating people’s choices and health behaviours, devices operationalising the “quantified self” ideology have seen a steep rise (GlobalData, 2022) – particularly due to the recent pandemic – in previously little-considered areas, such as in occupational health or workplace safety programs. Both public and private actors propagate new narratives in the name of data for good.

In this context, the role of individuals regarding their health is multidimensional (Cardullo & Kitchin, 2019). They are invited to become actors empowered to take care of and be responsible for their health, but also in solidarity with society (König, 2017). Consumer empowerment is accompanied by extensive digital surveillance and control. States and public administration are also encouraged to develop the infrastructure conditions (data spaces, security principles) and to offer the legal framework for deploying such health management systems while ensuring their compliance with the fundamental rights of individuals. What are the political and organisational challenges of such a transformation of the health sector for traditional health actors and individuals? What are the legal and organisational consequences of such a health sector transformation for individuals, public health authorities, and public health services? What responses are or could be made by policymakers and public administrations in terms of legislation and organisation of health data governance?

This workshop aims to bring together researchers from different fields (law, information systems, computer science, political science, economics) working on public administration, health, and digitisation. We welcome abstracts on the following topics:

- Data ecosystem
- Digital (data) sovereignty
- Self-tracking tools and nudges

- Femtech
- Individual responsibility and the role of conditionality
- Individual self-determination and empowerment
- Digital solidarity
- Data altruism
- Health data governance
- Health data space
- Health data
- Data ownership
- Individual- and population-level health data (sensitive, health, wellbeing)
- Digital intermediaries in the health sector

Submission & Eligibility

The deadline for the submission of abstracts is **20 February 2023**. The abstract should be up to 750 words and emailed to Messagerie.IDS@unine.ch (please put “Health data” in the subject line). It should articulate:

- the issue or research question to be discussed,
- the data or case study on which the article builds,
- the methodological or critical framework used,
- an indication of the expected findings or conclusions,
- five key references.

The following information must also be included in the abstract (in a single pdf document): A short biography (max. 200 words), the author’s name and affiliation, and the author’s contact details, including email address.

A decision on acceptance of the abstract will be communicated by **8 March 2023**. Authors of accepted abstracts will be requested to submit their draft papers (min. 3000 words) by **15 May**.

Submission is open to all faculty members. Ph.D. candidates, post-docs, and junior faculty, meaning tenure-track faculty who obtained their Ph.D. less than seven years ago, are encouraged to submit.

Organisation

The conference is co-organised by the Swiss Graduate School of Public Administration (IDHEAP, SNF NRP 77 IoT to promote health in the workplace) and the Institut de droit de la santé (IDS, SNF Eccellenza project The Increasing Weight of Regulation: The Role(s) of Law as a Public Health Tool in the Prevention State). It will take place on Wednesday, 7 June 2023, and Thursday, 8 June 2023, at the IDEAP, University of Lausanne, Switzerland.

The conference provides all contributors with an opportunity for debate and an initial round of feedback on the papers. The selected abstracts will be published in the proceedings on the dedicated conference website.

Catering during the event will be covered for accepted contributors who participate in the workshop on location (there is no travel support, but limited funding will be available for those who cannot benefit from institutional financial support).

Organising committee

Prof. Mélanie Levy

Prof. Tobias Mettler

Prof. Sophie Weerts

Cardullo, P., & Kitchin, R. (2019). Smart urbanism and smart citizenship: The neoliberal logic of 'citizen-focused' smart cities in Europe. *Environment and Planning C: Politics and Space*, 37(5), 813-830. doi:10.1177/0263774x18806508

GlobalData. (2022). Global wearable technology market set to surpass \$54 billion in 2023, forecasts GlobalData. Retrieved from <https://www.globaldata.com/media/medical-devices/global-wearable-technology-market-set-to-surpass-54-billion-in-2023/>

König, P. D. (2017). The place of conditionality and individual responsibility in a "data-driven economy". *Big Data & Society*, 4(2), 2053951717742419. doi:10.1177/2053951717742419

Lupton, D. (2016). *The Quantified Self*: Wiley.