HEALTH DATA AND ITS PRACTICES

Explorations in Popular, Professional, and Participatory Contexts

About the Conference

The conference theme addresses "health data" in a general sense and seeks to assemble a variety of insights into different practices and contexts. Health data and medical technologies today not only characterise professional settings such as hospitals or doctor's offices, they have gained increasing popularity in different kinds of media and are central to questions of participation in healthcare. In addition, the abundance of health related data, as well as the technologies for creating, storing, processing and circulating them are part of manifold medical, mundane, or media practices. We organise this conference in order to explore in more detail the role of data and technologies in popular, professional, and participatory health practices.

Popular contexts, for instance, denote health-related data practices that are publicly and openly performed, e.g. on social media platforms. Professional contexts pertain to the collection and processing of health data by health-care experts. Participatory contexts point to the increasing co-creation of health data by experts and laypersons. Of course, these three contexts overlap empirically, yet they all have their specific characteristics that should be taken into account.

Health data, more often than not, is data multiple (to paraphrase Mol 2002a). It inhabits different categories, counting either as body data, medical data, 'activity' data, 'wellness' data, fitness data, mental health data, or care related data. The different categories and meanings come into existence by divergent practices and settings that range from direct talks and actions between a doctor and a patient and something written down on a sheet of paper to machine-generated data, like medical imaging, and self-tracked vital signs produced through wearable sensors and shared on social media. This elicits the more fundamental question, how health data is being produced, circulated and interpreted and which relationships and uses develop between health and body, app and device, health data and other data in different social configurations. The conference seeks to highlight the transformations of health data, its production, processing and circulation in popular, professional and participatory contexts from a praxeological perspective. This poses questions of how popular, professional and participatory data practices co-evolve, how they differ and how they tap into each other.

Popular health data is often collected by wearable sensors and circulated through apps and digital platforms. Such sensor data raises

epistemic and ontological questions of how health is known and enacted. They are touted to create novel contextual insights into health by providing digital biomarkers and phenotypes (Jain et al. 2015; Birk and Samuel 2020). A popular claim surrounding 'born-digital' (Rogers 2013) online and sensor data is that they may provide novel context for predicting, diagnosing, monitoring, or managing one's health and medical conditions. How context is accomplished through sensor data, and how it participates in the construction of biomedically viable knowledge are longstanding pertinent questions (Asdal and Moser 2012; Dourish 2004; Seaver 2015) that gain relevance as the ecosystem of biomedical data, and hence biomedical ways of thinking about health and sickness keep expanding (Sharon and Lucivero 2019).

Professional health data is often produced in specific situations like hospital wards or laboratories, where the professionals (doctors and nurses) have power over the interpretation of the data. The choice between different mediating artifacts or a differently organized body data collection changes the practice of professional telemedicine, too (Nicolini 2011). In these cases, the health data itself (e.g. electrocardiograms) is rarely transformed - but often enacted in multiple ways (Mol 2002a). Moreover, in medical settings like the hospital, health data is often not assessed as sufficient for decision making by clinical practitioners but related with the patient's social, lifestyle and other data. Which data the professionals choose is part of the collective practices constructed by the social fields in a specific setting and is likely to change from location to location (Risor 2017). Participatory health data concerns co-productive data across the lay-professional divide. For instance, it concerns how sensor data is being circulated, and with whom, through what media, how cooperation through and around sensor data is accomplished and reconfigured (or not), and how sensor data and biomedical knowledge are co-produced. In the participatory use and design of digital health technologies, it is important to focus specifically on older people. Research shows that the concrete lifeworlds and everyday practices of older people are often not sufficiently taken into account when designing technology, and that cultural images of age and aging are not sufficiently reflected (Wanka/Gallistl 2021). Furthermore, it is important to ask about the opportunities and challenges of digital health technologies in the shared use of older people with their relatives and professional caregivers. In this context, for example, monitoring systems in the home or the use of digital platforms and apps in caring communities can be examined.

The conference organisers invite contributions from medical sociology and anthropology, science and technology studies, media studies, and organization studies with the aim to foster an interdisciplinary and international exchange.