12 JUNE 2025 09.00 - 11.00

Panel 65. Designing Worlds, Worlding Design: The Ethics and Politics of Value Creation in Digital Health and Health Data Integration

Convenors:

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Keywords: Design, Digital Health, Ethics, Health Data, Politics, Worlding

Worlding is a conception of practical ethics that calls attention to multiple and contingent ontologies that are shaped by values, and performed or enacted in efforts to impose order. Worlds are ethical and political precisely because they are often associated with efforts to impose a singular order through sanctioned values and practices, but also occasionally coercion or force. In this sense, 'worlds' have been taken up as a way of highlighting modern metaphysics of singularity enacted in 'centres of calculation' often located in the Global North (Latour, 1987; Escobar, 2018; Blaney & Tickner, 2017). For example, McCann et al. (2013) describes how cities link people and infrastructures to global regimes of value and power. Cities are 'worlded' through the imaginaries of policymakers, urban planners, architects, and venture capitalists. Health systems are worlded by physicians' associations, clinical practice guidelines, hospitals, clinics, policymakers, private insurers, and increasingly, Big Tech. Design and governance can also be worlded in different ways. In contemporary terms, design is often associated with Silicon Valley, or the broader modernist impulse to approach all problems solvable through technological means. At the same time, design can be, and often is, worlded differently. Technology governance too, often associated with top-down technocratic interventions, can instead be understood as distributed practices of modified use, non-use, or dis-use, across different worlds that make those objects of governance real in different ways (Briassoulis, 2019).

In this panel we invite papers that examine different worldings of digital health, and the conflicts, contradictions, and contestations that accompany the datafication of health and health care. Contributions may include (but are not limited to): (i) efforts increasingly undertaken by a diverse set of actors (from national governments to corporate entities) to establish or maintain platforms and infrastructures purposed towards extensive health data sharing across borders; (ii) the design of AI systems, and their apparently inexorable (though seldom uncontested) rise in health practice and policy; (iii) the establishment of supranational and international regimes of digital health governance; (iv) the rise of AI nationalism and the securitization of health, and (v) experiments with new modes of accountability, agency, or representativeness that resist the "data oligarchs" of the information age, or move toward new practices of democratic or pluriversal decision-making.

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ID 276 - Borders of digital health – digital bordering practices in healthcare system in Germany

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Cheshta Arora, Vestlandsforsking

Keywords: Digital Health, Migration, Fault lines, Bordering practices

Healthcare systems have always been conjunctions where several economic, political and socio-cultural relations come together on a global, national and local level to draw clear borders for the accessibility of their services. These bordering mechanisms should answer the question of who benefits the services and who does not. In this regard, Healthcare systems not only represent borders (e.g. cultural, social and national), but also function as bordering practices contributing to the controlling and governing border regimes. Considering access to suitable and equitable healthcare a basic human right, these systems fall into a paradox that they often fail to reconcile.

Within this landscape, Digital health in Germany is emerging as an "integrator concept" around which crucial concerns related to health, healthcare, research and innovation, economy and politics converge. Given the advancements in digital technologies, digital health promises to offer simultaneous solutions to the state, the service providers, healthcare workers and patients by improving access to health-related information, offering personalized healthcare, reducing workload, enabling cost-effective delivery of services, improving efficiency and developing integrated welfare services. In addition, digital health in Germany is being promoted as a panacea for several challenges, including providing equitable services to the entire population to address the aforementioned paradox.

While integrating different actors and infrastructures, digital healthcare also coproduces frictions as it redefines the relations between the 'body/citizen' in need of healthcare and the state as a service provider. Based on a critical discourse analysis of the recent acceleration of digital health in Germany and the policies produced and circulated in this context, this paper aims to shed light on the mechanisms of inclusion/exclusion in digital health in Germany.

The paper foregrounds fault lines and bordering practices emerging at the intersection of digital and healthcare services in Germany and how it re-worlds the relationship between healthcare, state, body and the citizen-subject. By adopting 'borders' or 'bordering' as an analytical concept, the paper underscores the need to reevaluate how digital healthcare is redefining relations and matters of care in the contemporary.

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ID 291 - Making genomic data reusable. The case of the "data collector-analyser".

Quentin Dufour, Aix-Marseille Université; Centre national de la recherche scientifique

Keywords: Data reuse, genomics, health data warehouse, Collecteur-Analyseur de Données, Plan France Médecine Génomique

In 2015, the French government launched the Plan for French Genomic Medicine (PFMG), which aims to integrate genomic diagnostics into the healthcare circuit and stimulate scientific research on the topic. In this context, the PFMG built a specific infrastructure: the data collector-analyser (CAD). Officially created in 2022, the CAD is a health data warehouse whose mission is twofold. On the one hand, to centralize genomic data produced in France (notably by medical biology laboratories and dedicated research projects). On the other hand, promoting data sharing and reuse by making genomic data available to research and healthcare communities.

Grounded in STS and Data Studies, this communication analyses health data reuse policies by focusing on the CAD case. We tackle the following question: what kind of work, and what kind of organisation, are involved in the process that makes genomic data reusable? Our hypothesis is that, to make data available for new users, the CAD needs to directly intervene on and transform genomic data. This transformation occurs at the crossroads of several scientific, ethical, and legal issues.

After outlining the genesis of the CAD, we explore the issues involved in the process of collecting, storing, and making genetic data available. More specifically, we show that there is a major friction between two reuse goals – research and care. This friction affects data characteristics and their ability to circulate among different communities of users.

The communication is based on an ongoing investigation into the political and ethical issues of health data reuse. It relies on qualitative methods (interviews and observations of work situations).

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ID 796 - ‘NeuroCovid’ disease definition: technoscientific and political practices instructing the order of things

Benedetta Muda, Università degli Studi di Milano Statale
Janneke Kuiper, Katholieke Universiteit Leuven
Nicolò Caporale, Fondazione Human Technopole
Emanuele Villa, Fondazione Human Technopole
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Keywords: neurocovid, disease-category, health-data, review, ethnography

The World Health Organisation (WHO) estimated that the Coronavirus Disease 2019 (COVID-19) has caused more than 2 million deaths in the European Region1. Far from having exhausted its course, an increasing amount of clinical evidence associate COVID-19 infection with an elevated risk for neurological and psychiatric complications (i.e. ‘NeuroCovid’) in 33-49% of patients after 6 months from the infection2,3. NeuroCovid is thus de facto emerging as a new disease category whose ontology-in-the-making bears the mark of the political and technoscientific upheavals characterising the current times. Firstly, the latest technoscientific advances in the life sciences are reconfiguring epistemic practices of disease categorisation and investigation, as the spectrum of methods by which researchers find agreement on newly discovered biomedical facts are increasingly converging toward one scale of analysis: the single cell data. In parallel, the European Union is promoting a profound normative restructuring towards supranational health data sharing, through the European Health Data Space (EHDS) Regulation4, fully impacting current governance of data-flows among public and private actors, and thus their power to govern advances across the digital- and the life-sciences.

To investigate these epochal changes as they come to bear on the ‘NeuroCovid’ disease, this paper adopts a two-fold approach: first, a critical review of the literature, from the medical and STS fields alike, will provide insights into the multifaceted, contingent and conflicting disease ontology by posing foundational questions such as: what is NeuroCovid, and who has the power to adjudicate it? How are stakeholders’ lives impacted by the fashion and timing of disease definition? Second, this analysis will be enriched by an ethnographic study conducted within the European Consortium NeuroCOV5, particularly in its Milan-based team of researchers and clinicians, aimed at documenting the state-of-the-art epistemic practices of NeuroCovid disease definition through participant observation and interviews. Leveraging “NeuroCOV” as an invaluable case-study and closely observing key research nodes, from patients’ enrolment phases to single-cell omics data harmonisation, occurring in one of the largest consortiums currently investigating the disease, will further enlighten disease categorisation practices in the current medical field, characterised by thrusts of political reconfiguration and datafication.

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ID 799 - Digital Twins, Digital Dreams: Who Guides the Visions of Tomorrow's Healthcare?

Elisa Elhadj, Katholieke Universiteit Leuven
Maiju Tanninen, Katholieke Universiteit Leuven
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Keywords: digital twins, in silico medicine, imaginaries

The growing prominence of computational simulations and modeling (CM&S) tools in healthcare has, in recent years, attracted significant attention, funding, and, arguably, hype. At the heart of this development is the field of in silico medicine, which leverages these simulations to improve the diagnosis, treatment, and prevention of medical conditions, and is further evolving through so-called digital twins. These advanced models represent human biological systems, including specific processes, cells, bones and organs such as the heart or the liver. Yet, through this emerging technology, we observe a further step in the infusion of engineering logics and automation-related values into healthcare. This incites reflections on what type of healthcare (and world) is being imagined here and by whom?

In this paper, we empirically study the making (and imaginaries) of digital twins in Europe, exploring how the in-silico community envisions the future of medicine and how these visions manifest in their practices, talks, texts and visualisations. We draw on an extensive multi-sited ethnographic study where we engaged in i) an in-depth analysis of the leading Virtual Physiological Human Institute news archive ii) participant observation and interviews at various events, workshops, and meetings of associations, laboratories and projects within the in silico community, iii) document analysis of white papers, reports, policy briefs and academic literature discussing digital twins in medicine, and iv) focus groups within the In Silico World Project.

We demonstrate how digital twins act as a charismatic technology, with the in silico community overlooking their multiplicity, and capitalising on the growing uptake of CM&S in other fields. Building on this, we highlight how the transfer of logics from engineering to healthcare introduces frictions between engineers and clinicians, raising broader considerations about the datafication of health and healthcare. In particular, we discuss how the uncodable elements of medical practice, such as experiences, human senses, and tacit knowledge fall through the models. This reveals an intriguing dynamic of nearness and remoteness, showing how those who play a crucial role in pushing forward certain visions of how healthcare should look and is envisioned, as well as how human bodies should be understood, are, in reality, remote from the actual healthcare practices. This invites reflections on expertise and the 'worlding' of healthcare, highlighting the need for further attention to the socio-ethical implications of digital twins.

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ID 811 - Inside the European Health Data Space Regulation: Following the Trail of Standards and Power

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Keywords: Healthcare, Data Spaces, Power Structure, Innovation, Infrastructure

The Data Strategy unveiled in 2020 by the European Commission (EC) presented data sharing as the cornerstone of economic development for businesses and individuals. Coincidentally, the COVID-19 pandemic showed that the current framework on health data sharing could be burdensome in times of need and highlighted its problems for scientific research and innovation. The following Data Spaces Initiative 2022 combined both approaches: sharing data can be helpful for the economy and, at the same time, reach objectives of public interest. The European Health Data Space (EHDS) text is close to publication. The next step is the development of its technical aspects. The EHDS relies on standards to achieve interoperability of Electronic Health Records systems across Member States and to set up its technical infrastructure for sharing patients' health data to foster research and innovation. The EHDS is not just a legal framework but an act of world-making. It establishes a new order in which health data is governed, standardised and circulated. This paper maps out how the EHDS conceptualises standardisation to achieve the goals above. We propose a taxonomy based on four different layers in which we identify the methods and actors involved in the technical construction of the legislation. In practice, standards are essential in establishing the necessary infrastructure for data sharing and interoperability while serving other non-technical purposes such as data labelling. From a worlding perspective, standards are not merely technical instruments but mechanisms through which specific values and ontologies are enacted. The construction of the EHDS is shaped by the imaginaries of policymakers, regulators, and industry actors who seek to impose a particular order on health data governance. Their construction depends on adopting implementing acts and delegated acts by the EC, which gives it a de facto incommensurate decisional power with only limited institutional safeguards as a recourse. This governance model raises concerns regarding the disproportionate influence of industry players. Based on these findings, this paper follows the power distribution embedded in the EHDS. It explores its implications for privatisation, regulatory balance and stakeholder (such as patients, healthcare providers, researchers and technology companies) interests. Focusing on the socio-technical dimensions of standardisation, our findings contribute to broader discussions on EU data governance and its potential to shape future data spaces.

Methodology: First, we map out the legislation to effectively demonstrate where the infrastructural power lies. We will begin by identifying the key actors and institutions involved in drafting, approving and enforcing the legislation. Inspired by legal design, we will bring the relationships between these bodies to light, underlining their interactions and place within and outside the law. Once the legislation and standard-making processes are mapped, we shall analyse how governance creates chokepoints of power. Second, we discuss how this newly established power is reflected and how it ultimately reshapes healthcare. We will focus on two elements, i.e. 1) the impact of new power structures on healthcare delivery and 2) how health data standardisation blurs traditional boundaries.

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ID 816 - Worlding Data Ecosystems for Rare Cancers: Tensions and Values in IDEA4RC

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Keywords: health data ecosystem, worlding, values, tensions, rare cancers, digital health innovations

Values play an important role in the development and maintenance of worlds, as they help shape dominant visions and provide directions on how to bring desired worlds into being (Haraway, 2016; Mol, 2002). Healthcare is a domain where the importance of worlding could hardly be overestimated. This is because digital innovations are increasingly framed as viable solutions to important challenges plaguing this field (Hoeyer, 2024), yet their successful development is shaped by alignments, but also collisions of different worlds and often requires new worlds to emerge. Inherent in worlding are the drawing and redrawing of the emerging world's boundaries, which can have important consequences for how roles and responsibilities, benefits and obligations are distributed. These processes are particularly important in the case of digital health innovations, given the rather opposing attitudes towards borders among the main actors engaged in worlding. Thus, whereas digital innovation developers seek to develop expansive, borderless worlds, medical actors, ranging from clinicians to regulators, engage in worlding by deploying categories, classifications, borders.

This paper therefore examines worlding practices in IDEA4RC, a Horizon Europe-funded project, aiming to develop a European data ecosystem for rare cancers through federated analytical approaches. The development of such ecosystems is driven by the growing value of health data, technological advancements, and EU regulatory frameworks. IDEA4RC brings together over 50 medical researchers, clinicians, data scientists, legal experts, and ethicists. Our role in IDEA4RC involves deploying a longitudinal co-creation approach informed by Responsible Innovation principles. This provided us with access to project documents and enabled us to collect data from 3 co-creation workshops, 30 interviews, and notes from over 200 hours of participant observations of project meetings and validation workshops of IDEA4RC prototypes.

We thematically analyzed how the IDEA4RC contributors mobilized current and anticipated data-related practices, technologies, norms, and values to world this ecosystem. Our findings indicate that in their worlding practices, the IDEA4RC contributors grapple with two main tensions between (1) centralisation and de-centralisation of data governance (e.g. standardized data access application requirements vs. clinical centre-specific requirements) and (2) generalisation and contextualisation of IDEA4RC-mediated practices (e.g. mandating results visualisation options vs. allowing for personal habits and preferences). We argue that these tensions remain unresolved, as the IDEA4RC contributors need to address multiple and often divergent values in the development of this data ecosystem, such as autonomy, solidarity, data altruism, cooperation, competition, effectiveness, convenience. Our findings further indicate that these tensions are rendered more or less pronounced depending on the past, present, and future worlds that the IDEA4RC contributors envision as aligned or in potential collision with the one they are seeking to bring about. Thus, different associations concerning data centralisation or de-centralisation are foregrounded and different ways of conducting research in the IDEA4RC emerging world are envisioned when such data practices are considered as adjacent to worlds marked by the commodification of data and the dominance of a few important players or by altruistic, common-based approaches.