Panel ABSTRACT

Panel 15: The platformisation of medicine? Digital diagnostics, advanced therapies, and drug repurposing

Organizer: Sarah Wadmann, Anna Brueckner Johansen, Tineke Kleinhout-Vliek, Laura Emdal Navne

Abstract: Western medicine is currently witnessing profound transformations in how disease is diagnosed, enacted and treated. With the advent of precision medicine, new disease categories are emerging and existing classifications redrawn (Navne 2023; Wadmann 2023). Rapid advances in computational power and machine learning are expanding conventional ways of identifying and delineating ill health by capturing datafied signs of disease (Semel, 2022). Meanwhile, the blockbuster era of chemical mass production is giving way to advanced, targeted therapies such as immunotherapy for cancers and gene and cell therapies (McGuire, 2020). Underwriting these developments is the growing importance of platforms for medical research, pharmaceutical R&D and healthcare more broadly. Platforms combine (digital) technology with particular organizational forms (Faulkner-Gurstein & Wyatt 2021). While there are many types of platforms, they share the aim of generating value by occupying a strategic place within a proprietary network. Platformization refers to the strategies pursued to obtain such a location – whether by private or governmental actors (ibid).
Some governments invest heavily in digital infrastructures to brand their nations as research hubs (Tupasela 2021); biotech companies and hospitals strive to develop molecular and data platforms for targeted therapies (Maso et al. 2019; Kleinhout-Vliek et al. 2024); and data-based advances are likewise accelerating the identification of 'old' medicines for 'new' indications (Pushpakom et al., 2019). Situated at the nexus between medical anthropology and science and technology studies, this panel invites papers that offer critical analysis of the processes and implications of attempts at redefining medical diagnostics and treatment through platformization.

SESSION SCHEDULE

17.09.2025 | Slot 1| 4-0-2

Marie-Laure Guilland, Claire Beaudevin, Séverine Louvel: Crafting customized centralization: platformization of genomics in rare diseases in France

Anna Brueckner Johansen: Platformization of payment? Curating value in gene therapy

Michael Morrison: Adaptive manufacturing: Initial thoughts on an emerging manufacturing platform for personalised medicine

Mette N. Svendsen, Laura Emdal Navne: Wayward platformization: genomes as doppelgangers in transnational relations

SESSION PAPERS

Crafting customized centralization: platformization of genomics in rare diseases in France

Marie-Laure Guilland, Claire Beaudevin, Séverine Louvel

This paper discusses the ongoing public platformization (Faulkner-Gurstein & Wyatt 2021) of genomic medicine in France. A government-funded multi-year plan (Plan France Médecine Génomique 2025) has promoted the division of the country's territory into two distinct catchment areas within which whole genome analyses are performed by two distinct, dedicated public centralized platforms. These platforms handle cases in the clinical genetics of rare diseases, oncology, and many more medical specialties.
Based on a collective ethnography of a clinical genetics department, this paper examines the ongoing routinization of genomics within French public hospitals, and how it shapes and is shaped by the changing uses and architectures of these two platforms. Our previous research on the use of genomic technologies in hospital care in oncology pointed to the difficulties of integrating them into already structured professional and socio-technical orders (Beaudevin et al. 2019). In this paper, we address the use of digital technologies in the clinical genetics of rare diseases and how public databases, in-house customized algorithms, so-called "French deeptech" corporate solutions as well as international genomic databases are simultaneously used in evidence generation, the crafting of collegial decision making and the distribution of diagnostic work. Starting in a university hospital, in a molecular board meeting using the above digital resources, we then expand to analyze the various ways in which the novel transversality of genomic work in the French health system is imagined, enacted, reorganized and professionally regulated in relation to these new, public centralized platforms.

Platformization of payment? Curating value in gene therapy

Anna Brueckner Johansen

The pharmaceutical sector is seeing a change from blockbuster medicines to targeted therapies for small patient populations. As this change often comes with unprecedentedly high prices and uncertainty about treatment effects, a central concern becomes determining the therapies' value – clinically as well as financially. When the first gene therapy to treat an inherited disease, Luxturna, entered the Danish market, public and private negotiators overcame these challenges by settling on an outcome-based payment agreement, implying that clinical and economic concerns are thoroughly integrated: the amount to be paid for Luxturna depends on the outcome measures obtained. In other words, the benefit or deterioration of the patient's condition, as documented in patient consultations, has a direct bearing on the public medicine expenses. Based on extensive fieldwork in 2022-2023, in which I followed the clinical implementation of Luxturna, I explore how the value of this gene therapy is negotiated and settled through the novel payment model and what this entails. Analytically, I trace the data infrastructure that forms to make the payment model work in practice, connecting payers, industry, healthcare professionals and patients treated with Luxturna. As part of a wider platformization of public services (Faulkner-Gurstein and Wyatt 2023), the payment model has implications beyond the merely technical aspects: it redistributes tasks, roles and power as it calls for particular forms of data curation and provides for certain conceptions of treatment value – conceptions that might not correspond with patients' experience.

Adaptive manufacturing: Initial thoughts on an emerging manufacturing platform for personalised medicine

Michael Morrison

Adaptive manufacturing builds on the increasing technological capacity for digital sensors to record and monitor activities and to use this data, mediated by fully or partly automated algorithmic systems, to influence the activities of the very material systems being monitored. In manufacturing, this means 'real time feedback loops' that monitor and adjust manufacturing processes in response to the characteristics of the manufacturing processes themselves. Currently, attempts are underway to apply adaptive manufacturing to the manufacturing of autologous cell therapies, especially 'CAR-T' cell therapies for blood cancer. In this paper, I will use existing work on platformization in healthcare to critically assess this emerging infrastructure. Adaptive cell therapy manufacturing clearly has some platform elements; it relies on an infrastructure of digital data collection, processed by proprietary algorithms, to collect data from multiple production runs and 'optimise' each new manufacturing run based on the biological characteristics of the patient's own blood cells, which are also the starting material for manufacturing. However, adaptive manufacturing also makes reciprocal connections between the virtual and biological in ways that are, arguably, more direct than the material consequences produced other digital platforms. Adaptive manufacturing can also support distributed production of advanced therapies, enabling 'local' production at clinical sites rather than centralised industrial sites, which adds another dimension to consider when thinking about the political economy of platforms. I will then use this case to reflect on the utility, and potential limits, of platformisation as a conceptual tool to critically understand adaptive manufacturing in cell therapy.

Wayward platformization: genomes as doppelgangers in transnational relations

Mette N. Svendsen, Laura Emdal Navne

Initiatives to generate, store, use, and reuse large amounts of genomes and other health data from individuals are crucial to the establishment of platforms in transnational data

economies. Based on ethnography from a Danish precision medicine initiative to improve diagnosis and treatment for patients with diabetes, we follow the involved stakeholders' efforts to create a platform that can bring together particular actors while blocking off others. In the Danish diabetes project, the patients' genomes were depicted as at risk of leaving the platform and wandering off to—or being held hostage by—the Chinese sequenzing company Beijing Genomics Institute. To unfold the various stakeholders' ideas about the agency of genomes, we employ the notion of the doppelganger and explore how genomes as doppelgangers of the Danish patients were depicted and discussed by the Danish press, the involved clinicians and researchers, and the patients themselves. We show that the fear of genomic doppelgangers acting on their own, unmoored from the embodied people they represent, highlight wayward platformization. While the literature on platformization has focused on the platform as an organizational model for creating entrances for levering assets, we discuss how platformization also entails setting up boundaries and resisting a foreign body's control in a high-tension geopolitical climate. The geopolitical tensions surrounding the Danish diabetes project pushes us to consider how platformization involves constituting an outside to 'contain' its value-making practices.