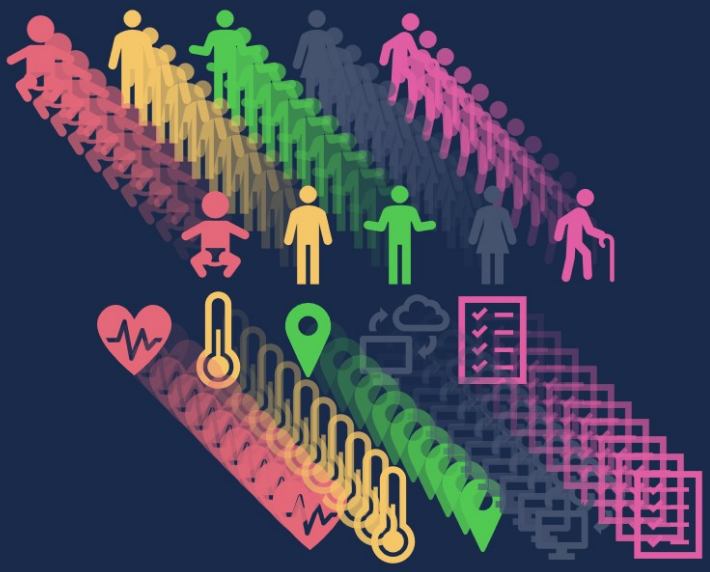
Reconfiguring the citizen-patient through health and care data



3rd & 4th December 2026

Room 4.04, Charteris Land, University of Edinburgh

and Online via MS Teams

FINAL PROGRAMME

THE UNIVERSITY of EDINBURGH
School of Social and Political Science

UK Research and Innovation

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DARE

https://dare.ed.ac.uk

This two-day workshop brings together researchers across Science and Technology Studies, Sociology of Health and Care, Medical Anthropology, Critical Data Studies, and related fields to explore how citizenship and patienthood are being reconfigured together in an era of intense datafication (Ruckenstein & Schüll, 2017) across health and care.

Within digital and data-driven healthcare, there are high expectations that increased computational power, universal connectivity, and – crucially – the availability of extensive data about patients will drive health and care towards a model that is smart, connected, integrated, and dynamic, and therefore more efficient, productive, and personalized. Future visions and emerging articulations of data-driven health and care come with particular expectations of patients in return for these promises, demanding connectedness, data generation, and data-sharing as well as civic contributions in the form of participation in consultations, research, and implementation work. How people become patients, how they live as patients, and what it means to be a patient is changing. At the same time, health and care data are imbricated in myriad technoscientific practices shaping the conditions and possibilities of citizenship, from biometric surveillance in criminal justice and border control to opaque assessments of eligibility and entitlement to state assistance, education, employment, insurance, or credit. Through such data practices, old injustices are retrenched and new ones emerge – met by new patterns of refusal and resistance.

In an era of ever-expanding notions about which data are relevant to health and care and ever-increasing uses of health and care data across other domains, thinking about citizenship and patienthood calls for us to revisit our conceptual toolkit. Almost all data can be health and care data, and health and care data can be used almost anywhere: are 'patient 2.0' (Danholt et al., 2013), the 'digitally-engaged patient'(Lupton, 2013), and the 'patient-consumer'(Mold, 2015) (Schlich & Elder, 2025) still good to think with across systems that are becoming so thoroughly data-saturated? Can the multiplying social relations they engage in, and are engaged by, be adequately characterised in terms of 'biosociality' (Rabinow, 1996), 'datasociality' (Navne & Svendsen, 2022), 'biological citizenship' (Rose & Novas, 2007), 'bio-digital citizenship' (Petersen et al., 2019), or '(digital) health citizenship' (Petrakaki et al., 2021) (Jauho & Helén, 2023)?

This workshop extends and troubles prevailing concepts by attending to how 'actual, potential, troublesome, and impossible citizens' (Rose & Novas, 2007, p. 440) and actual, potential, troublesome, and impossible patients emerge together through contemporary health and care data practices.

Day One

09:30 – 10:00 Arrivals, tea & coffee
10:00 – 10:30 Welcome and introductions
10:30 – 12:00 Panel 1
12:00 – 13:00 Lunch (catered)
13:00 – 14:30 Panel 2
14:30 – 15:00 Tea & coffee break
15:00 – 16:00 Group activity (in-person only)

Panel 1: Who counts?

When social precarity becomes clinically actionable: Housing and financial circumstance in mental health records of children and young people with social work involvement
Cassandra Dawson, University of Cambridge
Tessa Morgan, University of Cambridge

What happens to care that does not become data? Elderly women, healing, and uneven datafication in rural Zimbabwe
Ignatius Gutsa, University of Zimbabwe

Portals of the state: Health workers, ethical labor and the untimeliness of data
Sreya Dutta, Max Planck Institute for Social Anthropology

Panel 2: Making citizens and citizenship

Producing health citizenship: Digital health practices and productive power in Taiwan
Stephen Roberts, University College London
Gabrielle Samuel, King's College London

Reconfiguring the citizen patient through health and care data in Nigeria
Abiola Queen, Oyo State Primary Health Care

Enumerated communities: Embodying quantification and citizenship in birth cohort studies
Sahra Gibbon, University College London
Taylor Riley, University College London
Tatiane Muniz, University College London
Carola Tize, University College London

Day Two

09:45 – 10:15 Arrivals, tea & coffee
10:15 – 10:30 welcome back
10:30 – 12:00 Panel 3
12:00 – 13:00 Lunch (catered)
13:00 – 14:30 Panel 4
14:30 – 15:00 Tea & coffee Break
15:00 – 16:00 Discussion: Shared themes, publication plans
16:00 – 16:30 Summing up, group photo, goodbyes

Panel 3: Trust and responsibility

Responsibilisation and multimorbidity in the digital welfare state
Sara Marie Hebsgaard Offersen, Steno Diabetes Center Aarhus

All alone: Vanishing trust in the stories of data breach victims
Marjo Kolehmainen, University of Turku

Patient 4.0? Interoperability and responsibilisation in Scottish health and care innovation
Nicola Sugden, University of Edinburgh

Panel 4: Refusal and resistance

The American bunker state: Commercial concentrations of people and their health data
Mary Ebeling, Drexel University

Counter-data, counter-conduct: Refusal and the fracturing of health citizenship in pandemic Italy
Domenico Maria Sparaco, University of Siena

Abstracts

When social precarity becomes clinically actionable: Housing and financial circumstance in mental health records of children and young people with social work involvement

Cassandra Dawson, University of Cambridge
Tessa Morgan, University of Cambridge

In response to the rising prevalence of mental health disorders amongst children and young people (CYP), understanding the contribution of social and economic conditions is imperative. The present study investigated clinical case notes sourced from the South London and Maudsley NHS Trust, as part of a wider study examining how mental health professionals conceptualise the needs of young people with a social worker. Using framework analysis, case notes of 23 CYP were analysed to examine how housing and financial circumstances were documented, represented, and responded to within a Child and Adolescent Mental Health Service. Drawing on Brown's (2015) description of vulnerability, the analysis used vulnerability as the conceptual link between housing and financial circumstances and institutional responses, capturing how precarity becomes legible as a claim on services. Three themes were produced: Making Precarity Clinically Visible, which described how housing instability and financial hardship were documented as conditions that produced exposure to harm, with consequences for CYP's mental health; Translating Precarity into Engagement and Responsibility, which described how housing and financial precarity was differentially translated into service engagement and parental responsibility; and Vulnerability as a Conditional Claim to Care, which described how similar housing and financial circumstances produced different outcomes depending on how they were framed and by whom. CYP experiencing precarity were ambiguously positioned: services sometimes supported advocacy, redirected responsibility to another service, or deferred or excluded the CYP from care. This ambiguous positioning echoes broader questions about which citizens services can and cannot accommodate (Rose and Novas, 2007). Overall, more active and consistent responses to housing and financial precarity are needed, ensuring that social and economic circumstances are not merely documented but meaningfully addressed within mental health care for CYP.

What happens to care that does not become data? Elderly women, healing, and uneven datafication in rural Zimbabwe

Ignatius Gutsa, University of Zimbabwe

Health information systems such as Zimbabwe's DHIS2-based reporting architecture translate health events into indicators that determine what becomes visible to health authorities: what gets counted, what gets resourced, and what enters policy. This paper asks what happens to health-sustaining knowledge and labour that cannot be rendered in this form, not because it is hidden, but because the categories through which formal health data is built have no slot for it. Drawing on eleven years of ethnographic engagement in rural Mashonaland East, I examine elderly women whose medico-ethnobotanical knowledge is mobilised across the reproductive and infant-care continuum: herbal treatment for conception difficulties, ante- and postnatal support, assistance with delivery, response to infant illness, and, at the threshold of death, the preparation and burial of children lost to miscarriage, stillbirth, or infancy. These practices are embedded in customary classifications of infancy and death, most visibly in the distinction between suckling and non-suckling infants, which informs burial practice, including Machembere (elderly women) burial. These customary classifications do not map neatly onto the indicator categories of the formal health information system. I argue this constitutes a specific form of uneven datafication: unevenness not only in access to digital infrastructure, but in whose classificatory systems become the ones that count. This has two distinct consequences I treat as analytically separate: it renders these women's labour invisible as health work within planning and policy, and it renders the households and infants they serve invisible as patients within the epidemiological record. Attending to both, I argue, is necessary for understanding how rural health citizenship is constituted at the point where formal data infrastructures end and informal care begins.

Portals of the state: Health workers, ethical labor and the untimeliness of data

Sreya Dutta, Max Planck Institute for Social Anthropology

Multiple government funded health and nutrition schemes, and state appointed health workers who work with beneficiary families across different neighborhoods, shape the experience of state welfare and communal care for millions of Indians. For local health workers their life and personhood is tied to being recognized for a form of ethical labor that sustains state welfare projects. These schemes are being increasingly digitized which demand real-time data collection and entry into different government portals. Health workers, mainly women, rue the lack of proper remuneration and respect as agents who keep the mammoth welfare machinery of the state running. As the state now flexibly accumulates citizen data by mandating they do regular portal entry work for every scheme, health workers consider it not just a burden, but also deeply antithetical to the ethics of working with vulnerable families. This is expressed as how data entry is a mindless, time-taking pursuit, as well as how the act of seeking data can seem untimely in moments of crisis, affecting their relations to their beneficiary families. For health workers the dryness of bureaucratic data collection endeavors is experienced as an affront to lively socialites, temporalities and ethics of care work. The flux of digitization and datafication in welfare work stirs anxiety about increasing technicisation and surveillance and risks bruising health workers affective attachments to their beneficiaries. In this paper, I argue that as data devolves into everyday life through various forms of digitalization processes, it mandates critical scrutiny of the how data affects people's relations to one another. Collection of data, as a form of social encounter, can get caught up and interrupt other kinds of ethical and relational projects. The conflation of data work with welfare work, for instance, in this moment of increasing technicisation of state-citizen services can offer insights.

Producing health citizenship: Digital health practices and productive power in Taiwan

Stephen Roberts, University College London
Gabrielle Samuel, King's College London

This paper examines how citizenship is being reconfigured through digital health practices, drawing on Foucault's concept of productive power as an analytical lens.

Digital health practices, which include self-tracking, data-sharing, and digital participation, do not just reshape how health is managed; they transform the conditions of citizenship itself: what citizens are expected to do, how they are recognised, and how they can participate.

Productive power refers to how power does not just constrain, but brings practices, knowledge, subjectivities, and relations into being. It refers to how power is enacted through everyday practices and technologies to produce new ways of doing, knowing, and being, including new forms of citizenship. As such, productive power offers a useful addition to digital citizenship because it shifts focus from asking whether digital health practices enhance or undermine citizens' duties, recognition, and participation, to asking what kind of citizenship these practices are producing.

Taiwan provides a compelling context for this analysis due to its strong public health institutions, universal health coverage, extensive digital infrastructure, and strong citizen participation. Drawing on an empirical synthesis of three qualitative case studies from Taiwan, we explore how digital health technologies are adopted across diverse health actors. The cases comprise: (1) young disabled people who leverage digital applications to support everyday health and wellbeing; (2) HIV self-tracking apps used by men who have sex with men to monitor sexual behaviours; and (3) community health workers engaged in caregiving and collection of digital data for tuberculosis (TB) management.

Across the three cases, we find that digital health practices generate new health responsibilities, forms of expertise and modes of participation, while repositioning individuals and community actors in relation to institutions, technologies and one another. We conclude that productive power offers a valuable framework for understanding how digital health practices shape contemporary citizenship.

Reconfiguring the citizen patient through health and care data in Nigeria

Abiola Queen, Oyo State Primary Health Care

Across Africa, climate change is intensifying food insecurity, malnutrition and public health inequalities, with women disproportionately experiencing climate-induced nutritional vulnerability.

In Nigeria, governments increasingly integrate environmental, nutritional and health data to anticipate risks, target interventions and strengthen climate adaptation. While these data-driven approaches promise more responsive public health systems, they also raise important questions about how data shape vulnerability, participation and access to care.

Research on health datafication demonstrates that health and care data actively configure citizenship, patienthood and state–citizen relations. Yet little attention has been paid to how the integration of climate, nutrition and health data reconfigures these relationships in climate-vulnerable settings. Existing approaches largely assume that data objectively identify need, overlooking how data infrastructures privilege particular forms of knowledge, construct vulnerability and shape entitlement to intervention.

To address this gap, the paper situates climate adaptation within debates on health datafication, examining how data practices contribute to the production of digital health citizenship, while mobilising data performativity to explain how data enact citizen-patient identities. The analysis draws on an ongoing mixed-methods study undertaken within an Oyo State Government initiative inspired by Sustainable Development Goal 3 (Good Health and Well-being), integrating evidence from 50 purposively selected survey participants and 20 semi-structured interviews, analysed through thematic analysis.

The findings demonstrate that climate, nutrition and health data do more than identify need; they actively constitute the climate-vulnerable citizen-patient by shaping visibility, eligibility and participation. Indigenous knowledge and lived experience simultaneously contest these classifications, revealing vulnerability as socially negotiated rather than simply measured. The paper extends debates on digital health citizenship by demonstrating how climate adaptation reshapes citizen-patient identities through health and care data, advancing more equitable and participatory approaches to public health governance.

Enumerated communities: Embodying quantification and citizenship in birth cohort studies

Sahra Gibbon, University College London
Taylor Riley, University College London
Tatiane Muniz, University College London
Carola Tize, University College London

Lifelong participation in birth cohort studies provides a neglected and underexamined context for examining how quantification and datafication shapes the experience of research participation as a form of citizenship. The expansion of such studies from the 1950's onwards has created vast 'enumerated' populations whose lives have been continuously measured and counted but who are now also an invaluable resource with the expanded technological scope for measuring the 'social' in longitudinal population studies.

This presentation draws on a 4-year Wellcome Trust funded project 'The Biosocial Lives of Birth Cohorts' which uniquely takes the birth cohort as an ethnographic object of inquiry in four national contexts (Brazil, Portugal, UK and the Netherlands). We examine birth cohorts as particular as site of biosocial knowledge-making, where social and relational practices of data collection are central and which implicate specific forms of intergenerational participation. Taking a comparative perspective we examine how the enumerated communities in birth cohorts engage, resist, understand and perceive the quantification of their lives in the context of routine biometric data collection and questionnaires. We outline how in different ways participants accept the scrutiny and enumeration of their bodies informed by a sense of moral duty linked to self-care and as contributing to society. We consider how this form of datafication informs diverse articulations of citizenship, as well as more implicit forms of patienthood shaped by healthism (Gibbon et al 2026) and argue that both are products of contemporary social histories of public health and reflections of inequalities in access to and provision of health resources.

Responsibilisation and multimorbidity in the digital welfare state

Sara Marie Hebsgaard Offersen, Steno Diabetes Center Aarhus

From an interview-based investigation of the potential uses of a health data-sharing platform for patients with chronic illnesses, I explore patients' health data practices and the relation between citizens and the 'common good' of the Danish welfare state and ask: How, why and when do people with complex chronic conditions use digital health tools and access to health data? And how are notions of independence, responsibilisation, empowerment and 'good citizenship' at play when these patients navigate the digital terrain of their health (and when they do not)?

The study explores how Danish citizens with multiple chronic conditions interact with health data and digital health tools in their everyday lives and in interactions with the health care system.

The Danish healthcare system is in the midst of navigating a so-called 'care-crisis' of increasing care needs, system pressure and reduced system capacity. Strategies of managing the crisis include confidence in technological solutions and simultaneously re-organizing the healthcare system with focus on differentiation of care to allocate resources in equitable and sustainable ways. Combined, such strategies imply new levels of responsibilisation of a population who has been accustomed to extensive tax-funded welfare services. Treatment and care are increasingly moving from the clinic to the homes of patients, while patients and their relatives in many cases are expected to be increasingly involved in care decisions and tasks. While these changes may offer empowerment and control, they also demand independence and agency. Digital tools and health data are developed to support this. The analysis of interview data from 25 interviews with patients with multimorbidity explores: 1. the practices surrounding digital health tools and data, 2. the agency implied and derived from digital health, 3. the purposes guiding the use of the tools and data insights, and 4. the contextual conditions shaping digital disease management.

All alone: Vanishing trust in the stories of data breach victims

Marjo Kolehmainen, University of Turku

"The worst, and the heaviest part is that we, us victims have been left all alone by authorities. I received a notification from the police that confirmed that the criminal complaint I made has been received. That's all."

Above, an interlocutor who participated in my research on the Finnish psychotherapy center Vastaamo's data hacking incident, voices a common experience: The breach resulted in victims' lack of trust in society, ranging from institutional trust to the ability to rely on their close ones, and from trust in health care to trust in technologies. The breach was thus not only experienced as violence committed by the hacker, but as all-encompassing vanishing trust in society and in communal support. This trust was not necessarily something the victims thought about before the incident; rather, the incident and its aftermath made affectively tangible that something once taken for granted was not there anymore. In this paper, the vanishing trust is analysed from the perspective of relations between citizen-patients and a Nordic welfare state.

This paper proposes that the fact that Finnish society is commonly considered a 'trust-based society' (Pirkkalainen et al. 2022; Jackson et al., 2011), intensified the feelings of loss of trust. The Nordic countries have long traditions in gathering information to population registers, and the establishment of data gathering practices, registers and infrastructures developed alongside the construction of welfare state institutions (Snell et al. 2023). This history is tangible in Finns' willingness to disclose their digital personal data, including mental health related information, which is widely believed to have mainly positive consequences (Kortesoja 2022). In the case of Vastaamo, it could be argued that the most private and confidential information was protected by this very trust (ibid.). Yet when victims sought support from the state – or at least expected it – they felt that the state failed them.

Patient 4.0? Interoperability and responsibilisation in Scottish health and care innovation

Nicola Sugden, University of Edinburgh

As health and care become 'datafied' (Ruckenstein & Schüll, 2017) and new healthcare practices seek to leverage the dual promises of 'big data' and 'personalised care', the role of the patient is changing. Various figures have been called forth to explicate the role of the patient in 21st century health-data ecosystems: the 'digitally-engaged patient' (Lupton, 2013); 'patient 2.0' (Danholt et al., 2013); the 'patient-consumer' (Defibaugh, 2019). Other work has elaborated on the emergence in recent decades of 'data selves' (Lupton, 2020), 'technoselves' (Brierley, 2015), and 'scientific citizens' (Irwin, 2001). I posit a new figuration, 'Patient 4.0', and critically reflect on its entanglement within person-centred health data policy and practice in Scotland.

Since data practices entail particular kinds of subjectivation (Scheel & Ruppert, 2021), it is apt to consider the processes by which such figurations are enacted, the arrangements of power they represent and reinforce, and the practical consequences they entail. Person-centred health data practices promise a 'humanised' (Chute & French, 2019) solution to some of the ethical pitfalls of 'Industry 4.0' principles as applied to healthcare, and a response to some of the problems identified by critical social studies of health, care, and data. But who is the 'person' such policies and practices are 'centred' around? Drawing on an ethnography of health and care innovation in Scotland, I address how this person – 'Patient 4.0' – is imagined to emerge from the current duplicative and multiplicative data ecosystem and from the messy everyday world, and reflect on the impossibilities of disentangling technical elements of 'Industry 4.0' from their neoliberal political-economic origins.

The American bunker state: Commercial concentrations of people and their health data

Mary Ebeling, Drexel University

"If ill-gotten health data is the ""new oil"" fueling Silicon Valley's start-ups seeking to enter into the healthcare tech industry, then the resource-hungry and fossil-fuel burning data centers that proliferate across the U.S. are its bunkers. Following these data centers, that bloom like fungi in dark muck, the Department of Homeland Security (DHS) is surreptitiously spending US$ 1 billion on warehouses that are planned to be converted to detain immigrants, U.S. citizens, and political enemies (Aleaziz 2026). Artificial intelligent (AI) models developed with purloined patient data by tech oligarchs, such as Peter Thiel and Alex Karp (Palantir and Foundry/ImmigrationOS), Elon Musk (xAI and Grok), and Sam Altman (Open AI and ChatGPT) need all three: frictionless private health information, data centers and a police state. This talk critically examines how tech security companies and political actors in the American regime collude to track, criminalize, imprison and punish patients in the United States through their health data.

My paper will delineate the circular connections between the building of AI data centers to concentrate, connect and process health data, held both in disparate government databases and in the private sector, that are used to target patients--both citizens and immigrants alike--as criminals, and the warehouses being bought and converted to detain human beings in Immigration and Customs Enforcement (ICE) concentration camps. American technofascists, since the inauguration of the second Trump administration, have deployed both corruption without consequence and state violence to force the capitulation of medical and research institutions to share health data of their patients, while tracking citizens through their data for purposes other than for their care. The talk will also highlight the various forms of resistance that ordinary people are undertaking to protect each other from the technofascists, including strategies to shut down the concentration camps imprisoning people and the data centers that store their stolen data

Counter-data, counter-conduct: Refusal and the fracturing of health citizenship in pandemic Italy

Domenico Maria Sparaco, University of Siena

Throughout Italy's pandemic waves, the Civil Protection Agency read out each evening the day's tally of cases, recoveries and deaths on national television, colour-coded green, orange and red. This ritual of numbers underwrote the emergency and the decisions of a government presenting itself as technical rather than political. The same figures anchored a rhetoric of ""public health"" mobilised within a healthcare system moving steadily towards privatisation, and helped consolidate the nation around an internal enemy: the ""anti-vaxxer"". From 2021, Italy's Green Pass tied personal identity, via QR code, to vaccination, recovery or a recent negative test, making access to work, transport, education and leisure conditional on documented health status.

Drawing on ethnographic fieldwork conducted in Tuscany between 2022 and 2024 among anti-vaccine and free-vaccine movements, this paper follows what happened when people turned against those numbers. My interlocutors did not stand outside datafication. They socialised around counter-data: handwritten notebooks recording official pronouncements alongside obituaries of people said to have died after vaccination; lists of adverse events circulating on Telegram, whose accumulation was itself offered as proof; alternative readings supplied by dissident clinicians.

On the basis of these counter-data, interlocutors claimed counter-conducts: self-infection to obtain recovery certificates, alternative therapies, withdrawal into networks of trusted practitioners. Other data and other experts were taken as models for a different account of health, and with it a different model of citizenship, grounded in bodily self-determination rather than documented compliance.

I argue that polarisation in data-saturated health systems does not separate those who trust data from those who refuse them, but sets rival practices of counting and certifying against one another. Patienthood and citizenship fractured together, along the same numerical seam.

Data and the Healthcare ‘Revolution’? (DARE)



Dr Catherine Montgomery, Principal Investigator
Catherine is a Senior Lecturer and Chancellor’s Fellow in the Sociology of Biomedicine. She is the PI of the DARE project. With a long-standing interest in the ethnographic study of scientific knowledge production and clinical care, her work has addressed how methods travel in global health research; shifts from standardisation to adaptation in clinical trials; the ways in which patient experience data are mobilised in healthcare; and the changing materialities of care during COVID-19. Her work sits at the intersection of Science & Technology Studies (STS) and medical sociology, and is informed by anthropology and design.



Dr Abby King, Research Fellow
Abby leads DARE's 'Home' work package, exploring the ways in which big data shapes care and biomedical knowledge production in the home. Working at the intersections of Anthropology and Science & Technology Studies, her work has focused on the use of telehealth in the provision of mental health care; the implementation of electronic prescribing technologies in hospital; and the meanings and cultures guiding understandings of 'access to care'.



Dr Max Perry
Max is the lead researcher for DARE’s ‘Policy’ work package. His research focuses on the ways that technological innovation is processed and produced through policy making practices. Specifically, Max is interested in the ways that rhetorical and discursive formations within policy foreclose particular technological futures, whilst opening others. In short, what types of knowing are valorised through the invocation to a 'data driven' healthcare system, and what types of knowing are considered too unstructured or too unscientific to perform clinical knowledge production, and under what conditions are such determinations of value made?



Dr Nicola Sugden
Nicola is the lead researcher for DARE’s ‘Nation’ work package. Trained in the history and philosophy of science and influenced by Science and Technology Studies (STS), she has an overarching interest in the past, present, and future of science, technology, and medicine. Her past work has interrogated childhood and child development, evolution and genetics; psychoanalysis, psychology, and psychiatry; and disability, inclusion, and ethics. She is also interested in theories and practices of science communication and public engagement.



Dr Giorgia Kerr, Research Assistant
Giorgia is a research assistant on the DARE project. Trained in Medical Anthropology and Science and Technology Studies, her principal interest is in the creative and varied ways that we imagine the future of health, care, and medicine, and how we create or mobilise technologies toward those ends. Her past work focussed on how hopeful futures are imagined and created in medical research, with particular interests in genetics and rare disease; open science, data-sharing, and intellectual property law; and the creative problem-solving of everyday medical science.

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