

## Public Trust, Deliberative Engagement and Health Data Projects: Beyond Legal Provisions

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### Abstract

In England, a new scheme for collating and sharing General Practice data has faced resistance from various quarters and has been deferred repeatedly. While insufficient communication and ambiguous safeguards explain the widespread dissatisfaction expressed by the public and experts, we argue how dwindling public trust can be the most damaging variable in this picture—with implications not only for this scheme, but for any future project that aims to mobilise health data for medical research and innovation. We also highlight the indispensability of deliberative public engagement on the values being prioritised in health data initiatives, the significance of securing social licence in addition to legal assurances, and the lessons in it of global pertinence.

### Keywords

trust; health data; public engagement; National Health Service (NHS); GDPR

### Introduction

England's National Health Service (NHS)—one of the few publicly funded, universal healthcare systems in the world—is set to roll-out a new scheme to create a centralised database of patient data extracted from General Practice (GP) records. Given the sensitive nature of the data involved,<sup>1</sup> the announcement of the scheme—General Practice Data for Planning and Research (GPDPR)—in May 2021 has animated fierce debates around the aspirations to use sensitive health information.

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<sup>1</sup> GP data in England is a unique and rich repository with few international comparators—it includes holistic clinical records, both structured and unstructured, going back decades and growing in real time.

Such debates have been explored in Science and Technology Studies (STS) literature, offering a set of approaches that spotlight public deliberation, engagement and consultation, not only for accountable democratic governance but also for better outcomes from innovation initiatives ([Davies 2014](#); [Delgado et al. 2010](#); [Jasanoff 2003a](#); [Selin et al. 2016](#)). We argue in this essay that these outcomes are recursively tied to public trust, since their success relies on broad public uptake and large-scale deployment. Focusing on the GDPR scheme, we highlight the need for securing public trust and the importance of meaningful public engagement<sup>2</sup> against a backdrop of increasing strains on citizens' confidence in data sharing strategies—given recent encounters with various unpopular data collecting and sharing initiatives such as *care.data* ([Carter et al. 2015](#)), the Facebook-Cambridge Analytica and Leave.EU campaign scandal ([Hern 2019](#)) and the NHS Covid-19 Data Store deal with Palantir ([Fitzgerald and Crider 2020](#)). We further argue that unless discussions on the inherent values and tradeoffs within these applications are encouraged and enabled, governments worldwide are likely to continue to run into “a number of practical difficulties, such as confrontation, disruption, boycott, and public distrust” ([Rowe et al. 2005, 332](#)).

### GDPR and the Erosion of Public Trust

From the start, for many, the public announcement of the GDPR scheme seemed rushed, with GPs and medical bodies such as the British Medical Association complaining that there was insufficient information and time. Launched in May 2021, the scheme was expected to go live at the beginning of July. The reasons for this timing are unclear, but initially, patients were given just over a month to opt out from GDPR, with the onus on GPs to notify their patients and to process patient opt-out forms—when they were already swamped with the COVID-19 vaccination programme and pre-COVID backlog. Furthermore, UK-based campaign groups such as medConfidential raised alarm over sharing a centralised database, that included sensitive personal information on sex, ethnicity and sexual orientation, with third parties. The digital rights non-profit entity Foxglove, in partnership with a cluster of advocacy groups, launched legal proceedings against the Department of Health and Social Care, questioning the lawfulness of this new data strategy ([Murgia 2021](#)). These apprehensions were echoed by the opposition Labour party ([Walker 2021](#)).

There was an almost unanimous agreement amongst various stakeholders that NHS Digital—the national IT partner to the health and social care system in England and spearheading GDPR—must clarify who was to get access to this data, under what terms and who would eventually benefit from such access. NHS Digital, however, did not appear to be particularly spirited to mitigate these concerns. Instead, it stipulated a limited timeframe for patients to opt out of this scheme, with hardly any information to allow patients to make an informed choice, fuelling misgivings about the trustworthiness of this exercise.

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<sup>2</sup> For an in-depth understanding of how the categories of ‘engagement’ and ‘consultation’ have been problematised in STS literature, see: Barnett et al. ([2010](#)); Irwin ([2014](#)); Lezaun and Soneryd ([2007](#)); and Thorpe and Gregory ([2010](#)).

In early June, the government deferred the opt-out deadline until September 2021, to “provide more time to speak with patients, doctors, health charities and others” ([NHS Digital 2021a](#)). Simultaneously, NHS Digital published the latest figures of the National Data Opt-out—a service introduced in 2018 allowing patients to withdraw their data from being used for any purpose beyond their immediate care. These statistics revealed that the opt-out rate had dramatically increased in the run up to the original GDPR opt-out deadline of June 2021. More people registered for the National Data Opt-out in May 2021 (107,429), when plans for GDPR were released, than in the preceding 10 months (72,225) ([ibid. 2021b](#)). Following the public furore around the scheme, this figure escalated to nearly 12-fold (1,275,153) in June 2021, taking the number of opt-outs to more than 3 million—almost 5% of the population ([ibid. 2021c](#)). Such a staggering increase in the number of opt-outs shows that despite the legal cover provided by data protection and the common law of confidentiality ([Taylor and Wilson 2019](#)) and assurances from NHS Digital regarding its governance processes, it did not appear to have secured the ‘social licence’ for GDPR, contingent on people’s perception of this enterprise being in public interest and not solely contributing to commercial profiteering ([Carter et al. 2015](#)).

Such a high level of opt-outs points towards another difficulty that further threatens the prospect of gaining social legitimacy for the use of NHS data in research and planning: as more and more people register for the opt-out, the risk of the resulting database being less representative of the population increases, significantly jeopardising the generalisability of any public health modelling or clinical application developed from it ([Boyd and Crawford 2012](#)). While the granular details and trends of those opting out from GDPR are presently unclear,<sup>3</sup> research has demonstrated that many groups, including older adults, women and minorities are generally under-represented in medical datasets ([Malanga et al. 2018](#); [Rochon et al. 2004](#)). Any move that potentially entrenches this shortcoming could also reinforce the reservations that prompted opt-outs originally, and thus risks perpetuating the cycle of distrust in data-based ventures and their outputs amongst the general public.

In July 2021, the scheme was delayed again, with a commitment that it would not be launched until certain tests have been met ([NHS Digital 2021d](#)). These tests include the option of opting-out of the scheme and have one’s data deleted even after collection has begun and the presence of a ‘Trusted Research Environment’ (TRE)<sup>4</sup> for managing access to sensitive medical data. While these revisions are commendable, it is also crucial that in the time that NHS Digital has bought by delaying GDPR, it also addresses the erosion of public trust, not only because it impacts the uptake of this project and the potential for data to be used in

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<sup>3</sup> It is presently not known, for example, the race, ethnicity, income group or sexual orientation of the individuals that have opted out from the scheme. NHS Digital provides a breakdown by age, gender and geographical location. (See: [NHS Digital 2021e](#)).

<sup>4</sup> While in traditional models of data sharing information is sent to the users/researchers under contract, in a TRE users receive access to the data within a single secure environment. (See: [NHS Digital 2021f](#)).

developing new healthcare applications and research resources, but also because it is likely to affect public confidence in NHS data use more widely ([Data Use Workstream 2021](#)).

### **Deliberative Engagement and Public Benefit**

Public resistance to technoscientific endeavours is rarely the result of an information deficit ([Bucchi and Neresini 2002](#)) or due to lack of formalised knowledge ([Wynne 1989](#)). Nor are public concerns and scepticism lightly-held views that can be alleviated with more information or reassurance ([Irwin and Wynne 1996](#); [Martin and Tait 1992](#)). Instead, public perceptions and reactions are determined by peoples' values and their sense of how science and technology initiatives shape services and institutions, and questions regarding who ultimately benefits from these efforts ([Felt et al. 2007](#); [Smallman 2017](#); [Whitmarsh 2011](#)), leading to calls for greater public participation<sup>5</sup> in decision-making processes ([Jasanoff 2003b](#)). Alongside these calls are also appeals to reckon with the ways in which emerging technologies might reinforce existing structures of inequality and discrimination ([Benjamin 2019](#); [Eubanks 2017](#)), neglect intersectional power relations and struggles ([D'Ignazio and Klein 2020](#)), dilute contextual complexities ([Arora 2016](#)) and engender surveillance for profit maximisation ([Zuboff 2019](#)). As data accumulation, monitoring and exchange accelerate globally, these technologies also offer the potential to serve as further tools to “pathologise and stigmatise” marginalised groups ([Giesecking 2017, 150](#)). Such issues have mobilised recommendations to reimagine data-driven initiatives and associated technological pursuits for more equitable and liberatory ends, more so in a way that is sensitive to competing and multifaceted notions of identity, origins and interests ([Leurs 2017](#); [TallBear 2013](#)).

In this context, NHS Digital must build on the UK's experience of public engagement, through programmes like ScienceWise,<sup>6</sup> to undertake deliberative engagement in the context of GDPR, with the aim of aligning institutional visions of public interest with the range of public views. For instance, the National Data Guardian recently explored notions of ‘public benefit’ ([Hopkins Van Mil 2021](#)) finding (amongst other things) that the public had certain expectations about any use of health and social care data: Transparency—not just for methods and procedures, but also about the value estimated in data use; appropriate safeguards for sensitive datasets—including protection from data manipulation for profit motives; and demonstrating that benefits accrue equitably across all sections of the population—especially for those whose may be disproportionately (under)represented in health datasets. These expectations reveal that a genuine attempt at engaging the public on how ‘public benefit’ might be diversely interpreted can help rebuild consensus around how NHS resources should be used and shared.

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<sup>5</sup> The composition and lineations of public participation have also been interpreted as contested practices in STS scholarship (see: Goodwin [1998](#); Irwin [2001](#); and Wynne [2007](#)).

<sup>6</sup> Sciencewise is a public engagement programme in the UK which assists policy makers to develop socially informed policy (see: [Sciencewise n.d.](#)).

NHS Digital should also pay attention to the issues raised through lobbying and media discourse by various stakeholders<sup>7</sup> regarding GDPR – from the privacy concerns of GPs and professional bodies to the wider equity issues raised by NGOs and provide citizens and civil society actors the opportunity to deliberate and determine how data sharing takes place, to have a say in how the NHS itself might be shaped by data-driven technologies, as well as to influence who should be involved in developing them. Such deliberation must also involve reflection on how public values are incorporated in the ideation and execution of data projects, how they will be scrutinised and the conditions under which ‘benefit’ itself can be re-evaluated ([Stirling 2008](#)). While there is also a need to communicate the safeguards already in place for data sharing, the parameters for screening prospective recipients of patient data and how the desirability of potential use-cases is weighed,<sup>8</sup> NHS Digital must be clear that the essence of engagement practices goes beyond legal reassurances. Unless citizens are invited into a negotiation about what amounts to the ‘public benefit’ of medical data infrastructures, the tradeoffs they are prepared to make for its sake and then offered straightforward means to exercise their choice (such as, of opting out), trust in the legitimacy of this project—and ultimately its ability to meet its potential promise—will not be restored. And as such, the manner in which the implementation of GDPR unfolds in England will serve as an instructive case study for other countries that aspire to open up health datasets for broader use.

## Conclusion

The pandemic has shown us how indispensable data is for understanding disease epidemiology, timely identification of vulnerable groups, finding effective treatments and rolling-out vaccines. It has also demonstrated how dwindling public trust can hamper meaningful adoption of critical data-driven technologies, as evident in the failure of digital contact tracing apps to be deployed at scale in many countries. It is therefore necessary to ensure that public health decisions, even in fast moving situations, are characterised by a commitment to engagement that builds trust with the wider population from the ground up. Failure to do so will not only limit the data resource base of GDPR to have any meaningful impact for research, but it will also jeopardise the acceptability of valuable data-based initiatives in the future. NHS Digital must now venture to understand and address the dissatisfaction of both experts and concerned publics through deliberative public engagement, aiming to build consensus on what ‘public benefit’ and the future of the NHS looks like. While it is important to have robust legal mechanisms for responsible management and sharing of data, what is equally indispensable is the need to build collaborative agreement on how, if at all, data should be used and for what ends.

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<sup>7</sup> Such as General Practitioners, MPs, privacy campaigners, legal firms and patient groups (see: Crouch [2021](#); and Marsh [2021](#)).

<sup>8</sup> These are reflected in the records of Data Access Request Service (DARS) Release Register and the responsibilities and processes of the Independent Group Advising on the Release of Data (IGARD)—all compiled and shared on NHS Digital’s web pages.

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