Justifying Secondary Uses of Health Data under English Privacy Law

Miranda Mourby
30 October 2023

AI + Genomics = Personalised Medicine

Toward Precision Medicine: A New Social Contract?

SUSAN DESMOND-HELLMANN Authors Info & Affiliations

CREDIT: ELISABETH FALL

Earlier this year, Illumina and Life Technologies each announced new products that can sequence a genome for $1000 in a single day (1), which is approximately 3 million times cheaper than the cost during the Human Genome Project back in the early part of the last decade. Furthermore, cloud-based, big-data software companies are capable of using whole- and partial-genome sequencing to automate and operationalize diagnostics in real-life situations with patients. But no one believes that less expensive

'Indeed, it is patients who particularly understand the potential value of a social contract in which patients both contribute personal clinical data and benefit from the knowledge gained through the collaboration'

https://www.science.org/doi/10.1126/scitranslmed.3003473

Technology Drives Reconsideration…

Chapter 16

Ethics and the social contract for genomics in the NHS

Chapter leads
Anneke Lucassen[1] Jonathan Montgomery[2] and Michael Parker[3]

Authors contributed equally
1. Faculty of Medicine, University of Southampton
2. Faculty of Laws, University College London
3. Ethox, Oxford University

'The most important structural implications of the move to **genomic, big data-driven medicine is the requirement for a greater degree of interdependence** between the care and treatment of individual patients on the one hand and the collection and analysis of data relating to the care of very large numbers of other patients…Genomic medicine will require use of patient level information to support better clinical decisions in the future and for others.' Annual Report of the Chief Medical Officer, 2017

Research led by participants: a new social contract for a new kind of research

Effy Vayena[1], Roger Brownsword[2], Sarah Jane Edwards[3], Bastian Greshake[4], Jeffrey P Kahn[5], Navjoyt Ladher[6], Jonathan Montgomery[7], Daniel O'Connor[8], Onora O'Neill[9], Martin P Richards[10], Annette Rid[11], Mark Sheehan[12], Paul Wicks[13], John Tasioulas[14]

Correspondence to Dr Effy Vayena, Institute of Biomedical Ethics, University of Zurich, Pestalozzistrasse 24, Zurich 8032, Switzerland; vayena@ethik.uzh.ch

Abstract

In recent years, there have been prominent calls for a new social contract that accords a more central role to citizens in health research. Typically, this has been understood as citizens and patients having a greater voice and role within the standard research enterprise. Beyond this, however, it is important that the renegotiated contract specifically addresses the oversight of a new, path-breaking approach to health research: participant-led research. In light of the momentum behind participant-led research and its potential to advance health knowledge by challenging and complementing traditional research, it is vital for all stakeholders to work together in securing the conditions that will enable it to flourish.

'Perhaps the most well known case is the amyotrophic lateral sclerosis (ALS) lithium study carried out **on the online platform PatientsLikeMe**. It was initiated by two patients with advanced-stage ALS from Brazil and the USA, both of whom died prior to the completion of the study. One hundred and forty-nine patients with ALS on the platform took lithium in order to test the findings of a small earlier study into its effects on disease progression and symptom alleviation. The PatientsLikeMe ALS study, which was completed over 8 months, was eventually published in Nature Biotechnology. Its finding that lithium had no effect was subsequently confirmed by standard clinical trials.'

Also Resources & Sustainability…

The NHS needs a new social contract

With the NHS celebrating its 75th anniversary, Matthew Taylor reflects on what's needed for it to 'survive and thrive for the next 75 years'.

Matthew Taylor
6 July 2023

While the NHS remains well respected and loved in the UK, there's much to address, a lot of which lies outside the NHS. We need a shared vision of the NHS's next era and a cross-government strategy to support it.

'Finally, we need a new social contract with the public, one in which we offer more and expect more. The 75th anniversary is an opportunity for a national conversation about a more ambitious relationship between NHS and patients. Our own recent research shows the potential of technology in empowering patients to better manage and monitor their own health.' **Matthew Taylor, CEO, NHS Confederation**

The Progressive Policy Think Tank

IPPR North   IPPR Scotland

11/09/2023

Progressive review | Full | IPPR Progressive Review | IPPR

- Anita Bhadani
- Ellie Kearns
- Joseph Evans
- Joshua Emden
- Lucy Mort

The breakdown of the social contract (and what is to be done)

Five years ago, Progressive Review published 'The Social Contract in 21st Century Britain'. In our previous editorial, we opened by stating that "eight years of austerity have left our public services and social safety net in tatters". Today in 2023, in the wake of the pandemic and further public spending cuts, this has only worsened.

"It appears that the basic social contract – by which voters pay in tax to a collective pot and government spends this effectively to provide a safety net and enable people to thrive – is now broken." IPPR

What is the Social Contract?

JOHN RAWLS
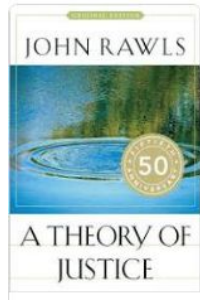
A THEORY OF JUSTICE

3. THE MAIN IDEA OF THE THEORY OF JUSTICE

My aim is to present a conception of justice which generalizes and carries to a higher level of abstraction the familiar theory of the social contract as found, say, in Locke, Rousseau, and Kant.[4] In order to do this we are not to think of the original contract as one to enter a particular society or to set up a particular form of government. Rather, the guiding idea is that the principles of justice for the basic structure of society are the object of the original agreement. They are the principles that free and rational persons concerned to further their own interests would accept in an initial position of equality as defining the fundamental terms of their association. These principles are to regulate all further agreements; they specify the kinds of social cooperation that can be entered into and the forms of government that can be established. This way of regarding the principles of justice I shall call justice as fairness.

Thus we are to imagine that those who engage in social cooperation choose together, in one joint act, the principles which are to assign basic rights and duties and to determine the division of social benefits. Men are to decide in advance how they are to regulate their claims against one another and what is to be the foundation charter of their society. Just as each person must decide by rational

1. There is one original 'social contract' from which subsequent agreements flow.

2. This original contract is based on principles of justice.

3. These principles are summarised as 'justice as fairness.'

Reasonableness in the Social Contract

'Reasonable' foundations for agreement = 1) moral 2) rational. Morality is relational, relying on reciprocity:

'Thus as a model of justification, the original position has two links, one to the moral point of view and the other to the point of view of actual rational individuals. Justification in the original position succeeds if the principles are chosen from a genuinely moral point of view and a rational individual can endorse them…Both links are essential and it is the combination of these two types of rational choice that gives original position arguments their distinctiveness and their power.' (Gaus and Thrasher, p.41)
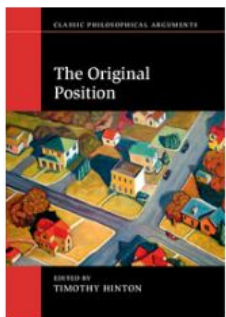
2 - Rational choice and the original position: the (many) models of Rawls and Harsanyi

Published online by Cambridge University Press: **05 December 2015**

By Gerald Gaus and John Thrasher

Edited by Timothy Hinton

Show author details ⌄

Chapter

The Original Position

Reasonableness in the Law

My argument:

The principles of justice we should consider in an English social contract (including for health data) should include the requirements of the European Convention on Human Rights, which have taken on a foundational significance in our implicit constitution.

For health data, Article 8 ECHR provides the necessary principles of justice to make the terms moral as well as rational.

Contribution of the Argument

1) Substantiates reconsideration of the 'social contract.'

2) Defends moral values within 'reasonable expectations of privacy,' not just rational.

3) Challenges trend in English law to construe reasonableness as rational rather than fair (*per* values of dignity and family connection under Article 8 ECHR).

ECHR and English Law

› The 'reasonable person of ordinary sensibilities'

› Clapham Omnibus -> William Prosser -> Naomi Campbell

› UK government restricts Article 8 through 'reasonableness'

› Ergo, privacy rights do not automatically apply, even in healthcare
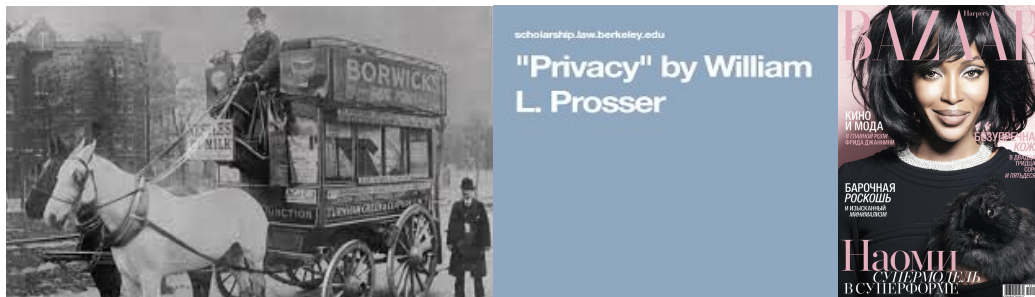
The Queen on the application of W, X, Y, Z v The Secretary of State for Health v The Secretary of State for the Home Department, The British Medical Association

○ No Substantial Judicial Treatment

Court
Court of Appeal (Civil Division)

Judgment Date
14 October 2015

Case No: C1/2014/1780

Court of Appeal (Civil Division)

[2015] EWCA Civ 1034, 2015 WL 5885537

Before: The Master of the Rolls Lord Justice Briggs and Lord Justice Bean

Date: Wednesday 14th October 2015

44. Ms Proops submits that the fact that patients are made aware that the information may be transmitted to the Home Office does not of itself mean that the data are not private or confidential. We disagree. The Supreme Court decision in JR 38 confirms what was said in cases such as Murray that the question whether there is a reasonable expectation of privacy is a broad one which takes account of all the circumstances of the case. We do not see how overseas visitors who, before they are treated in an NHS hospital, are made aware of the fact that, if they incur charges in excess of £1,000 and do not pay them within 3 months, the Information may be passed to the Secretary of State for onward transmission to the Home Office for the stated immigration purpose can have any, still less any *reasonable*, expectation that the Information will not be transmitted in precisely that way. They will, however, have a reasonable expectation of privacy in relation to the Information vis-à-vis anyone else.

[WITHDRAWN]
MEMORANDUM OF UNDERSTANDING

BETWEEN

HEALTH AND SOCIAL CARE INFORMATION CENTRE

AND

THE HOME OFFICE

AND

THE DEPARTMENT OF HEALTH

- Court is the arbiter of what a 'reasonable' person would think

- No accommodation of the 'non-ordinary' attributes or circumstances of marginalised people

- Data-Sharing placed them in a position of vulnerability, and threatened their ability to see their families.

- Court of Appeal gave little consideration to the detail of the Claimants' evidence on impact.

Social Contract for AI?

› Data collection for AI development

› Can introduce novel relationships and secondary uses

› E.g. Royal Free NHS Trust & DeepMind (2015-2017)

› Failure to comply with 'no surprises' principle:

ico.
Information Commissioner's Office

Upholding information rights

Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF
Tel. 0303 123 1113 Fax. 01625 524 510 www.ico.org.uk

Sir David Sloman, Chief Executive
Royal Free NHS Foundation Trust
Pond Street
Hampstead
London
NW3 2QC

3 July 2017

Dear Sir David,

**RFA0627721 – provision of patient data to DeepMind**

I write to confirm that I have concluded my investigation into the above.

In summary, my investigation has determined that the processing of approximately 1.6 million patients' personal data by DeepMind Technologies Limited ('DeepMind') for the purpose of the clinical safety testing of the Streams application did not fully comply with the requirements of the Data Protection Act 1998 (the 'Act').

The processing of patient records by DeepMind significantly differs from what data subjects might reasonably have expected to happen to their data when presenting at the Royal Free for treatment. For example, a patient presenting at accident and emergency within the last five years to receive treatment or a person who engages with radiology services and who has had little or no prior engagement with the Trust would not reasonably expect their data to be accessible to a third party for the testing of a new mobile application, however positive the aims of that application may be.

The mechanisms to inform those patients that their data would be used in the clinical safety testing of the Streams application were inadequate. In short, the evidence presented to date leads me to conclude that data subjects were not adequately informed that the processing was taking place and that as result, the processing was neither fair nor transparent.

Automating Reasonable Expectations?
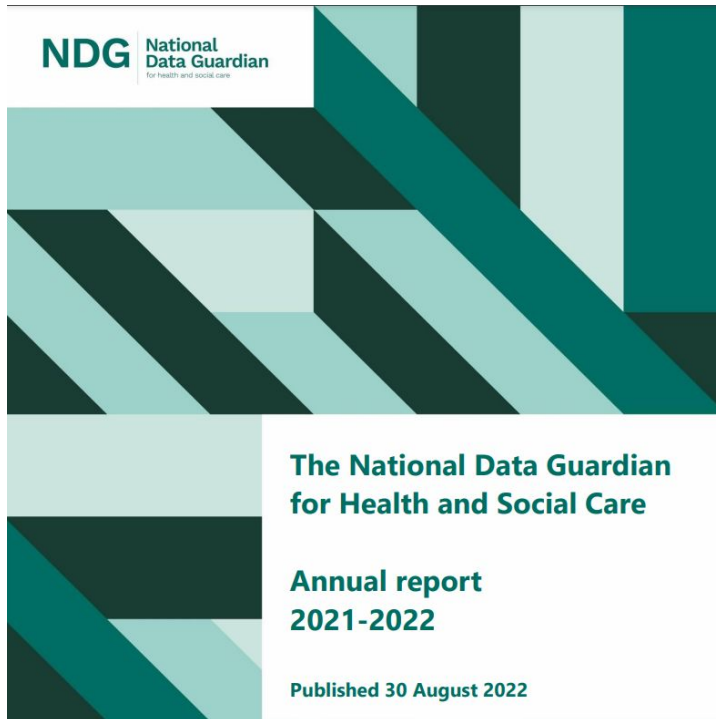
9.3 Reasonable expectations research project

Previous work by the NDG has explored the concept of reasonable expectations and whether it could offer an appropriate legal basis for the disclosure and use of confidential patient information in specific circumstances. We now want to undertake a research project with the aim of better understanding whether clear expectations can be created regarding uses of data collected in the context of providing health and care – and what actions might be required to create those expectations.

Work and outputs

Together with academic partners and research and insight specialists, we will aim to carry out both qualitative and quantitative investigations. We plan to work in partnership with specific programmes that use data to develop communications products relevant to their work and audiences, and together we will test whether particular methods can practically create and maintain people's expectations.

The National Data Guardian for Health and Social Care

Annual report 2021-2022

Published 30 August 2022

My Argument

› Cannot automate human rights
› OR fairness
› OR a social contract based on fairness

ABSTRACT

In recent years a substantial literature has emerged concerning bias, discrimination, and fairness in AI and machine learning. Connecting this work to existing legal non-discrimination frameworks is essential to create tools and methods that are practically useful across divergent legal regimes. While much work has been undertaken from an American legal perspective, comparatively little has mapped the effects and requirements of EU law. This Article addresses this critical gap between legal, technical, and organisational notions of algorithmic fairness. Through analysis of EU non-discrimination law and jurisprudence of the European Court of Justice (ECJ) and national courts, we identify a critical incompatibility between European notions of discrimination and existing work on algorithmic and automated fairness. A clear gap exists between statistical measures of fairness as embedded in myriad fairness toolkits and governance mechanisms and the context-sensitive, often intuitive and ambiguous discrimination metrics and evidential requirements used by the ECJ; we refer to this approach as "contextual equality."

Thus: we should not rely on

Statistical models of R.E, but allow scope for context-sensitivity, including the particular vulnerabilities, intersecting oppressions or marginalisation of an individual in deciding whether their privacy rights are engaged, or interfered with in a justifiable way.

Who is Marginalised?

- Potentially everyone!

Abstract

Artificial Intelligence (AI) and machine learning algorithms are increasingly used to make important decisions about people. Decisions taken on the basis of socially defined groups can have harmful consequences, creating unequal, discriminatory, and unfair outcomes on the basis of irrelevant or unacceptable differences. Equality and anti-discrimination laws aim to protect against these types of harms.

While issues of AI bias and proxy discrimination are well explored, less focus has been paid to the harms created by profiling based on groups that do not map to or correlate with legally protected groups such as sex or ethnicity. Groups like dog owners, sad teens, video gamers, single parents, gamblers, or the poor are routinely used to allocate resources and make decisions such as which advertisement to show, price to offer, or public service to fund. AI also creates seemingly incomprehensible groups defined by parameters that defy human understanding such as pixels in a picture, clicking behavior, electronic signals, or web traffic. These algorithmic groups feed into important automated decisions, such as loan or job applications, that significantly impact people's lives.

- In *R(W,X,Y,Z)*, the applicants' social and legal marginalisation was clear.
- But in future, we may all be assigned to 'marginal' groups within the algorithmic mechanisms used for automated triage in the NHS.
- Fairness and transparency, with particular regard for our dignity and personal lives, will continue to be important touchstones for secondary uses and require context-sensitivity.
- This may be less rational + efficient, but it is more fair.

Conclusions

1. The English social contract for health data should be underpinned by justice as fairness, which in turn should be informed by Article 8 ECHR.

2. English Courts should take the values inherent within Article 8 ECHR into account when determining its scope.

3. Reliance on statistical models of R.E (and indeed, fairness in general) should be limited and subject to context-sensitive oversight within the NHS.