

# Data: benefits and risks, hopes and fears

25 September  
2021

Camden Citizens  
Charter



# Benefits and hopes

Policy paper

## Data saves lives: reshaping health and social care with data (draft)

The draft strategy sets out ambitious plans to harness the potential of data in health and care, while maintaining the highest standards of privacy and ethics.

From: [Department of Health and Social Care](#)

Published 22 June 2021

Last updated 8 September 2021 — [See all updates](#)



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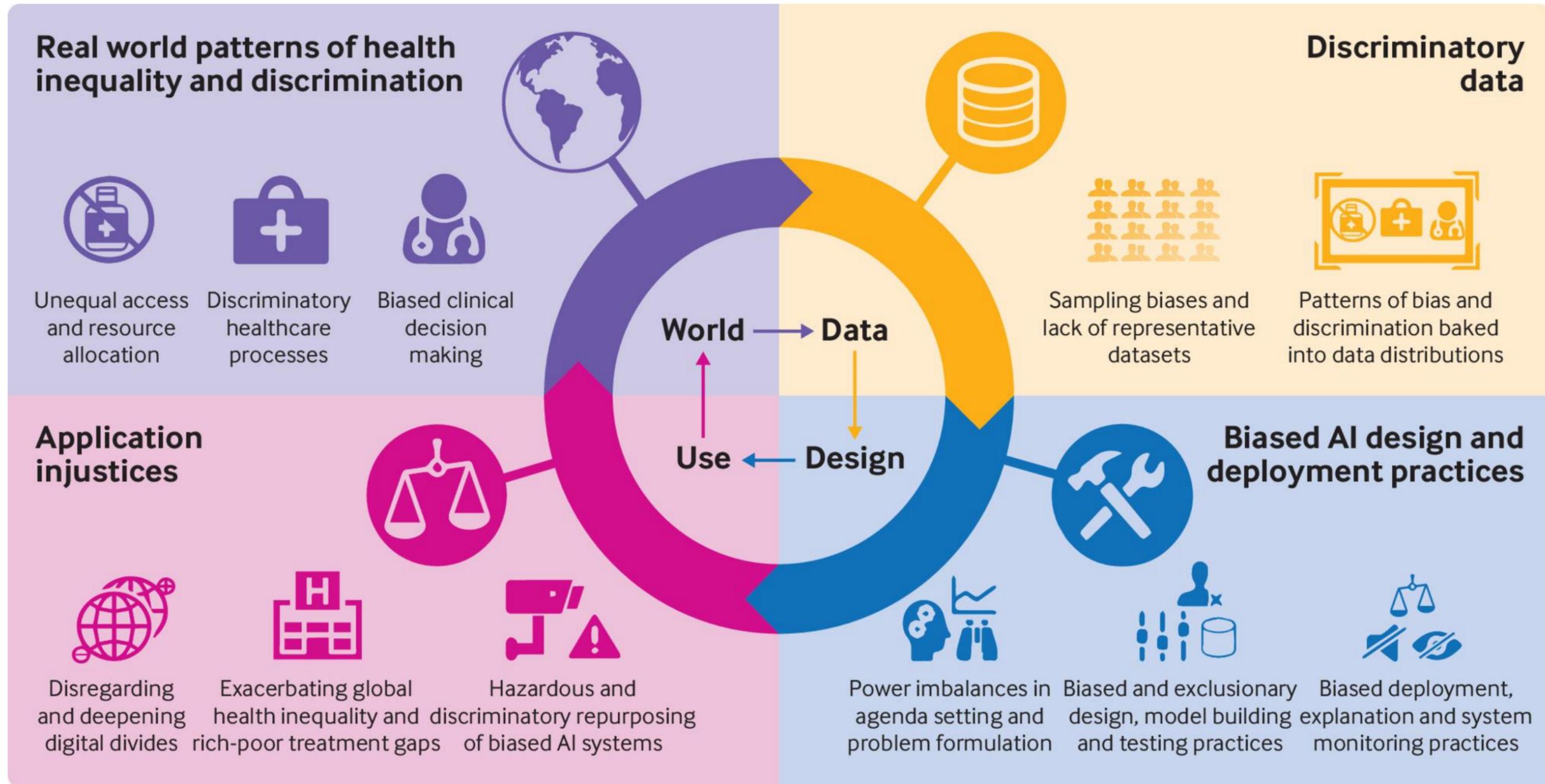
More updates



## Data for Public Benefit

Balancing the risks and benefits of data sharing

# The 'onward effect' of these divides



Leslie D, Mazumder A, Peppin A, Wolters M K, Hagerty A. Does "AI" stand for augmenting inequality in the era of covid-19 healthcare? *BMJ* 2021; 372 :n304 doi:10.1136/bmj.n304

# What does it all mean?



NHS Digital > ... > Data collections > General Practice Data for Planning and Research

## General Practice Data for Planning and Research (GPDPR)

NHS Digital's daily collection of GP data will support vital health and care planning and research.



An official website of the European Union How do you know? ▾



EN English

Home > Law > Law by topic > Data protection > Data protection in the EU

### Data protection in the EU

The General Data Protection Regulation (GDPR), the Data Protection Law Enforcement Directive and other rules concerning the protection of personal data.

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**77% vs 38%**

Very much in support of the decision to introduce OpenSAFELY and the NHS COVID-19 Data Store and Platform, respectively



**58% to 87%**

In favour of the data sharing initiatives continuing as long as they were valuable



**6%**

Wanted decisions about the future of the data sharing initiatives to be taken by the minister or organisation accountable for the initiative

# Links to supporting documents connected to previous slide

- [NIHR Impact Report 2020-2021 Executive Summary](#)
- [\(Foundations of Fairness - Summary and Analysis.pdf](#)  
[\(understandingpatientdata.org.uk\)](#)
- [The foundations of fairness for NHS health data sharing | Ada Lovelace Institute](#)



## Transparency

What data is being collected

How is it shared?

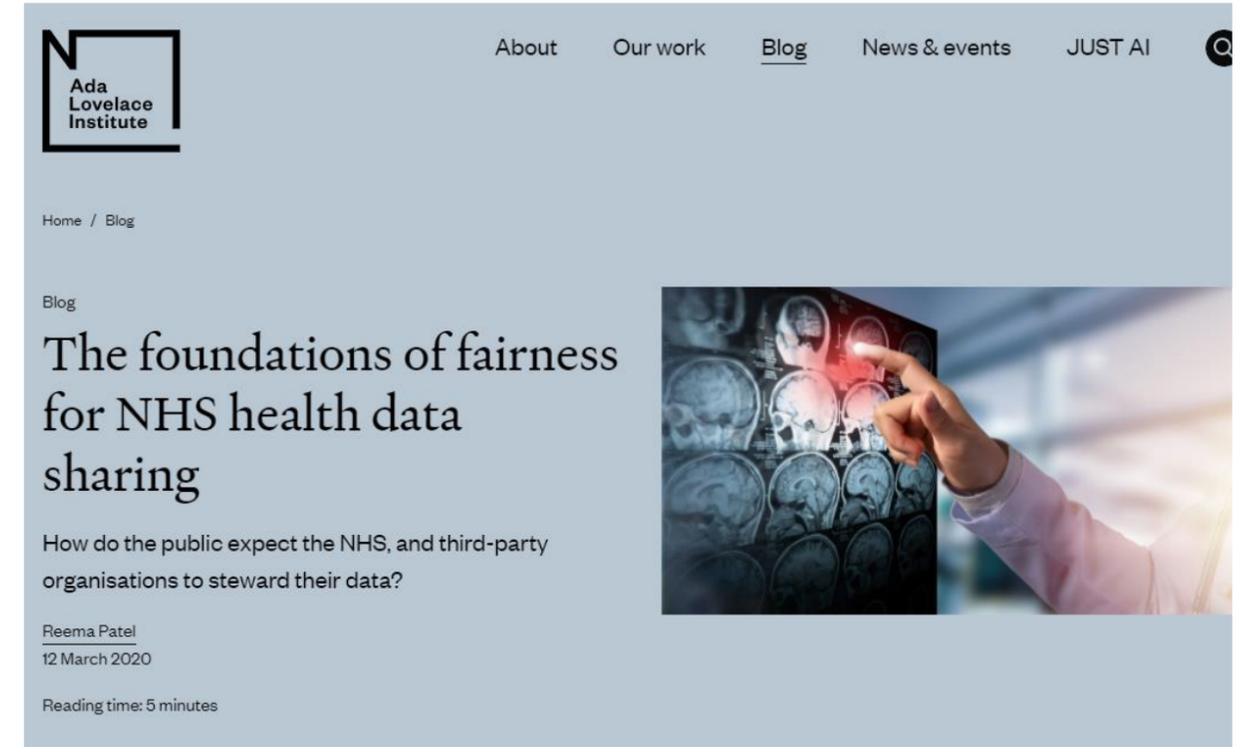
Do I have a choice?



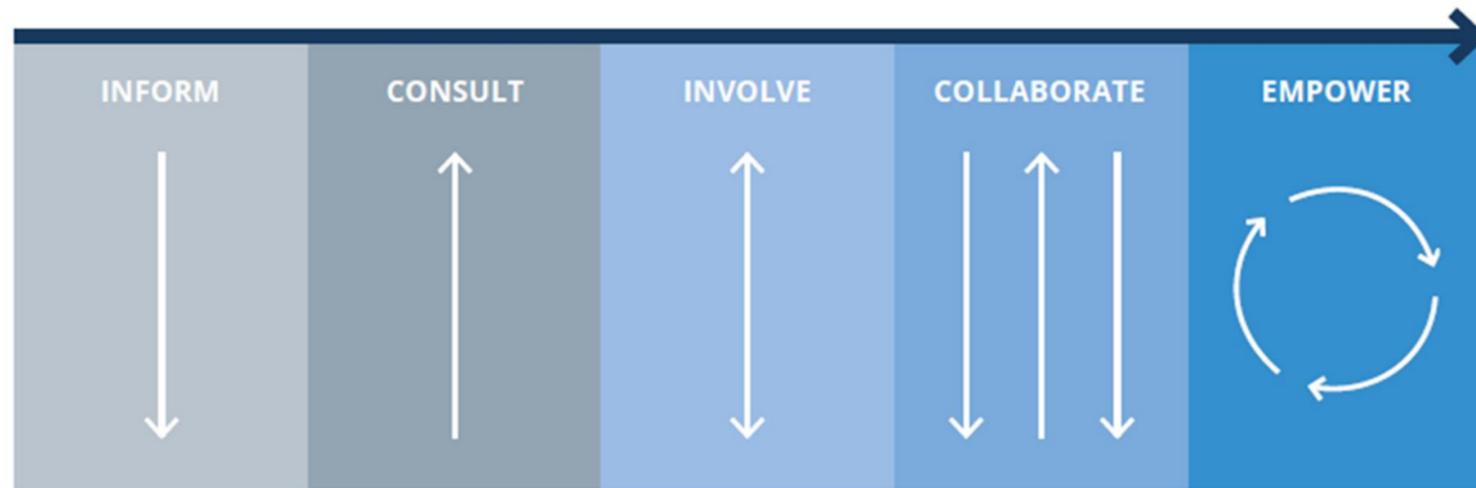
## Partnerships

Who has access to the data?

Who decides who can use the data?



**A spectrum of public participation (see Annex 2)**



At the left hand side of this spectrum people are informed about decisions, at the other, people are meaningfully engaged in the decision-making process.



@AdaLovelaceInst  
@ThinkSpeakMavis

