

## TOPIC GUIDE: SHARING PATIENT RECORDS (GERMANY EDITION)

**"MEDICAL RECORD SHARING SHOULD BE WELCOMED AND NOT FEARED"****PUBLISHED: 19 JAN 2018****AUTHOR: ANWAR ODURO-KWARTENG**

Share this Topic Guide:

**INTRODUCTION**

In early 2016, the confidentiality of people's medical records came under the spotlight, when it emerged that Google DeepMind had entered into an agreement to have access to sensitive patient data from three National Health Service (NHS) hospitals in London [Ref: [Telegraph](#)]. One of the organisations involved, the Royal Free hospital trust, insisted that the agreement allows the records to be used to develop a new system which will alert patients that are at risk of acute kidney injuries [Ref: [Telegraph](#)], but many are concerned about the consequences that such medical data sharing will have on the privacy of patient records. Similarly, the ethics of medical data sharing in a digital world were raised in the controversy surrounding the care.data scheme [Ref: [NHS England](#)]. Care.data was proposed by the government as a central database for patient data from all NHS care providers for secondary uses, such as epidemiological research, and public health prediction, but the scheme has since been cancelled due to privacy concerns [Ref: [Guardian](#)]. With the EU unveiling the controversial General Data Protection Regulation (GDPR), it will become harder than ever to share our medical data [Ref: [EUGDPR](#)]. As digital technology embeds itself into daily life ever more deeply, many feel we should re-examine the debate about privacy and medical ethics. Supporters of medical data sharing argue that the potential research gains which access to NHS data could yield far outweigh any potential risks to privacy [Ref: [Financial Times](#)], and claim that it would be wrong to let these concerns get in the way of medical progress. However, critics note that, 'there is a point of principle at stake here about who can or should see our medical records – our most private data.' [Ref: [Telegraph](#)]. Amid the competing arguments, how should we view medical record sharing? Is it a vital tool for the modern age, giving a range of stakeholders the ability to improve patient care? Or does the arrival of big data and tech companies such as Google into the health arena pose a serious threat to privacy?

*For further reading use the menu bar on the right hand side.*

## DEBATE IN CONTEXT

*This section provides a summary of the key issues in the debate, set in the context of recent discussions and the competing positions that have been adopted.*

### Big Data

The UK is the only country in the world which has health data for the lifetime of almost every person in the country since 1948, because of the foundation of a National Health Service [Ref: [CPRD](#)]. Advocates of medical data sharing note that large data sets helped to establish the links between smoking and lung cancer, and also helped to debunk the link between the MMR vaccine and autism [Ref: [New Scientist](#)]. The use of health data is vital in studying genetic information, they argue, as it helps scientists to understand the causes of common diseases in the population as a whole, as well as empowering 'commissioners to ensure the highest standards of care and clinical safety are met' [Ref: [NHS](#)]. The ever-improving potential of technology to gather medical information on a huge scale is one of the reasons that many are excited by the prospect of medical data sharing. For example, Moorfields Eye Hospital in London has recently agreed to give Google's DeepMind one million digital eye scans from patients, in the hope that the computer learning technology will spot early indicators of future sight loss [Ref: [Telegraph](#)]. In addition, responding to the recent decision to abandon the care.data scheme, columnist Polly Toynbee outlines the good that big data can do for health care: 'Data trawls unexpectedly revealed, for instance, that patients taking metformin for type 2 diabetes had less chance of developing cancer. No one knows why, but it opened up a whole new area of cancer research.' [Ref: [Guardian](#)] However, critics point out the potential problems of big data for patient confidentiality. In 2014 it was found that NHS patient data was being sold to companies in industries as diverse as pharmaceuticals and charities, to consultancy firms and universities [Ref: [Evening Standard](#)], and in the same year the NHS were found to have sold 13 years' worth of medical data, covering 47 million patients, to organisations acting on behalf of insurance companies [Ref: [Telegraph](#)]. For privacy activist Phil Booth: 'This is precisely the danger when you create a giant database of highly sensitive information about people – all sorts of other people want to go rifling through it, including the government. There's always another good reason to go digging, but no one thinks of the catastrophic breach of trust this represents.' [Ref: [Guardian](#)]

### The ethics of consent

Modern medical ethics emphasises the principle of informed consent, both in research and in clinical practice. The very first point of the Nuremberg Code - a set of [research ethics](#) for [human experimentation](#) - states that: 'The voluntary consent of the human subject is absolutely essential' [Ref: [Nuremberg Code](#)]. However, the care.data scheme came under intense scrutiny from those who argue that the issue of consent had been taken too lightly [Ref: [Telegraph](#)], with similar concerns about whether consent was sought to share patient records with Google [Ref: [New Scientist](#)]. In light of this, New Scientist magazine is quick to praise the potential of technology companies to shed light on important medical trends, but underlines that consent is paramount, because: 'If we are to hand Google et al, ever more data, then we should insist they ask us first, and tell us what they want it for.' [Ref: [New Scientist](#)] Moreover, technology writer Subhajit Basu is critical of the way that Google, together with the NHS, have sought to 'extend the definition of implied consent to fit [their] purpose' [Ref: [Wired](#)], because we must remember that: 'Consent is a key concept in the provision of healthcare – this is true across ethical, legal and practical dimensions.' [Ref: [Wired](#)] But for some supporters of medical data sharing, those who criticise data sharing on this scale are 'consent fetishists' [Ref: [The Times](#)], suggesting that: 'Public health...research will be rendered impossible if individual consent for all secondary uses of health data becomes the norm.' [Ref: [Journal of Epidemiology and Community Health](#)]

## The greater good vs privacy

The contemporary discussion about medical record sharing also encompasses the tension between individual privacy, moral responsibility and the greater good. ‘The widely accepted idea that my right to privacy always trumps your right to the benefits that might accrue from data sharing, needs to be challenged on ethical grounds’ [Ref: [Guardian](#)], according to author and writer Roger Taylor. He argues that it is a moral imperative to pursue medical record sharing, because of the impact it could have on all of our lives. Similarly, one commentator observes that: ‘To be sure, privacy needs protection from rogues of all kinds – but we are at risk of losing balance between benefit and risk’, concluding that: ‘There is dark age thinking in too much fear of data collection.’ [Ref: [Guardian](#)] In fact some in Germany go as far as to call this thinking ‘big-data phobia’ [Ref: [Handelsblatt Global](#)] But opponents remain unconvinced by these arguments, maintaining that: ‘Right now, medical confidentiality is under serious threat’ from patient record sharing, because often these schemes make it difficult for patients to opt out if they wish to [Ref: [Wired](#)]. They accept that there are potential benefits to record sharing, but argue that: ‘While there is much public good that can come from open-source data sets, ultimately you should be in charge of how your personal information is shared and used’ [Ref: [Wired](#)]. So are critics right to worry about issues of privacy and consent with medical record sharing? Or do we have a duty to embrace the potential benefits to us all that technology and data sharing may bring?

## ESSENTIAL READING

*It is crucial for debaters to have read the articles in this section, which provide essential information and arguments for and against the debate motion. Students will be expected to have additional evidence and examples derived from independent research, but they can expect to be criticised if they lack a basic familiarity with the issues raised in the essential reading.*

### Review of health and care data security and consent [↗](#)

Department of Health 6 July 2016

### The lesson from the NHS Care.data row: You can't keep privacy issues private any more [↗](#)

Brian Glick [Computer Weekly](#) 18 February 2014

### Ethics and medical records [↗](#)

BMJ

### What we will collect under care.data [↗](#)

HSCIC

## FOR

### Why the closure of care.data is bad news for the NHS and society [↗](#)

Roger Taylor [Guardian](#) 19 July 2016

### A viable shot at a better NHS has been killed off by privacy paranoia [↗](#)

Polly Toyne [Guardian](#) 7 July 2016

### Share your medical records [↗](#)

Hugo Rifkind [The Times](#) 25 February 2014

### Sharing your data is safe and beneficial [↗](#)

Clare Gerada [The Times](#) 8 February 2014

## AGAINST

### Should the NHS share patient data with Google's DeepMind? [↗](#)

Subhajit Basu **Wired** 11 May 2016

**If Google has nothing to hide about NHS data, why so secretive?** [↗](#)

**New Scientist** 4 May 2016

**Don't mislead us about our NHS records** [↗](#)

Phillip Johnston **Telegraph** 20 January 2014

**Your medical records on sale for a pound** [↗](#)

Phil Booth **Open Democracy** 13 August 2013

## IN DEPTH

**We must urgently clarify data-sharing rules** [↗](#)

Jan-Eric Litton **Nature** 24 January 2017

**Why Google DeepMind wants your medical records** [↗](#)

**BBC News** 19 July 2016

**Response to a Nuffield Council on Bioethics Consultation** [↗](#)

**Progress Educational Trust** 20 January 2014

**Patient records to revolutionise medical research in Britain** [↗](#)

Ian Sample **Guardian** 28 August 2012

## KEY TERMS

*Definitions of key concepts that are crucial for understanding the topic. Students should be familiar with these terms and the different ways in which they are used and interpreted and should be prepared to explain their significance.*

**Big Data** [↗](#)

**Care.data** [↗](#)

**Epidemiology** [↗](#)

**EU General Data Protection Regulation (GDPR)** [↗](#)

**Hippocratic Oath** [↗](#)

**Informed consent** [↗](#)

**Nuremberg Code** [↗](#)

## BACKGROUNDEERS

*Useful websites and materials that provide a good starting point for research.*

**Stop the privatisation of health data** [↗](#)

John T Wilbanks & Eric J Topol **Nature** 26 July 2016

**Care.data has been scrapped, but your health data could still be shared** [↗](#)

**The Conversation** 12 July 2016

**We need to talk about AI and access to publicly funded data-sets** [↗](#)

Natasha Lomas **Tech Crunch** 9 July 2016

**How the NHS got it so wrong with care.data** [↗](#)

Sarah Knapton **Telegraph** 7 July 2016

**Did Google's NHS patient data deal need ethical approval?** [↗](#)

Hal Hodson **New Scientist** 8 June 2016

**Googles DeepMind shouldn't suck up our NHS records in secret** [↗](#)

Randeep Ramesh **Guardian** 14 May 2016

**Google's NHS deal does not bode well for the future of data sharing** [↗](#)

Neil Lawrence **Guardian** 5 May 2016

**Big-data fear plagues German healthcare** [↗](#)

Maike Telgheder & Grischa Brower-Rabinowitsch **Handelsblatt Global** 24 March 2016

**Why DeepMind wants to bring AI to the NHS** [↗](#)

Michael Rundle **Wired** 25 February 2016

**Smart care: how Google's DeepMind is working with NHS hospitals** [↗](#)

Sarah Boseley & Paul Lewis **Guardian** 24 February 2016

**Medical sharing is vital** [↗](#)

Dr John Parkin **Guardian** 24 January 2014

**Power to the people** [↗](#)

**Nature** 15 January 2014

## ORGANISATIONS

*Links to organisations, campaign groups and official bodies who are referenced within the Topic Guide or which will be of use in providing additional research information.*

**Google Deepmind** [↗](#)

**Med Confidential** [↗](#)

**NHS England** [↗](#)

## IN THE NEWS

*Relevant recent news stories from a variety of sources, which ensure students have an up to date awareness of the state of the debate.*

**Medical records of thousands of patients were handed to US firms connected to tobacco industry** [↗](#)

Laura Donnelly **Telegraph** 15 January 2018

**Apple Health App data being used as evidence in murder trial in Germany** [↗](#)

Stephen Jordan **Digital Trends** 14 January 2018

**AI could have 'immense' benefits for NHS, says tech committee chair** [↗](#)

Jon Sharman **Independent** 11 January 2018

**Pharma "not prepared" for new EU Data Protection Regulation** [↗](#)

Ed Miseta **Clinical Leader** 23 August 2017

**Germany is the first EU Member State to enact new Data Protection Act to align with the GDPR** [↗](#)

**Lexology** 7 July 2017

**Germany planning to 'massively' limit privacy rights** [↗](#)

Ben Knight **Deutsche Welle** 25 November 2016

## AUDIO/VISUAL

This site contains links to websites operated by parties other than Debating Matters. Although we make every effort to ensure links are current, they will sometimes break after Topic Guide publication. If a link does not work, then the publication reference and date should enable you to find an alternate link. If you find a broken link do please send it to the **webmaster** for review.

© 2005-2021 debatingmatters.com: Debating Matters Competition, boi, Unit 208, Cocoa Studios, The Biscuit Factory, Drummond Road, London, SE16 4DG, UK

Tel +44 (0)20 3176 0827 - [dm@theboi.co.uk](mailto:dm@theboi.co.uk) | [admin login](#)