MAY 2017

MEDICAL DATA SHARING

ANWAR ODURO-KWARTENG

DEBATING MATTERS TOPIC GUIDES

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"MEDICAL DATA SHARING IS A THREAT TO OUR PRIVACY"

ABOUT DEBATING MATTERS

Debating Matters because ideas matter. This is the premise of the Institute of Ideas Debating Matters Competition for sixth form students which emphasises substance, not just style, and the importance of taking ideas seriously. Debating Matters presents schools with an innovative and engaging approach to debating, where the real-world debates and a challenging format, including panel judges who engage with the students, appeal to students from a wide range of backgrounds, including schools with a long tradition of debating and those with none.

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CONTENTS

KEY TERMS

Big Data

Care.data

Epidemiology

Hippocratic Oath

Informed Consent

Nuremburg Code

NOTES

Last spring, 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 the Royal Free, Barnet and Chase hospitals [Ref: Telegraph]. The Royal Free trust insists that the agreement will allow 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]. 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 stake holders 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?

Big Data

The UK is the only country in the world which has health data for the life-time 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 England]. 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] 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?

Review of health and care data security and consent
Department of Health 6 July 2016

Ethics and medical records
BMJ

FOR

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

AGAINST

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 Toynbee *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

IN DEPTH

Why Google DeepMind wants your medical records
BBC News 19 July 2016

Patient records to revolutionise medical research in Britain
Ian Sample *Guardian* 28 August 2012

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

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

Together we can get care.data right
Tim Kelsey *NHS England* 2 May 2014

Firms buying NHS data named
Evening Standard 3 April 2014

Privacy activists don't speak for most of us
David Aaronovitch *The Times* 27 March 2014

Privacy concerns over care.data
Andrew Ward *Financial Times* 30 January 2014

Medical sharing is vital
Dr John Parkin *Guardian* 24 January 2014

Power to the people
Nature 15 January 2014

It is sometimes right to worry about security, but data trawls can be useful
Polly Toynbee *Guardian* 23 August 2013

Balancing privacy with the public benefit
Martin Bobrow *Nature* 7 August 2013

Why we still need comprehensive information about populations
Geraldine Barrett & Janet L Peacock *Journal of epidemiology and community health*

IN THE NEWS

NHS data sharing project scrapped
BBC News 6 July 2016

NHS to scrap single database of patients' medical details
Guardian 6 July 2016

Google's DeepMind to analyse one million NHS eye records to detect signs of blindness
Telegraph 5 July 2016

Nearly one million patients could be having confidential data shared against their wishes
Telegraph 5 June 2016

Google given access to London patient records for research
BBC News 3 May 2016

Controversy as Google given access to NHS patient data
Telegraph 3 May 2016

NHS shares medical records of 1.6 million patients with Google as part of data sharing agreement
Independent 3 May 2016

Data sharing would turn the UK in the best clinical laboratory in the world
The Times 21 March 2014

Patient records should not have been sold NHS admits
Telegraph 24 February 2014

Hospital records sold to insurers
Telegraph 23 February 2014

"You're selfish if you don't share you're medical records" says top GP
The Times 8 February 2014

Police will have back door access to health records despite opt-out, says MP
Guardian 6 February 2014

The NHS lost 1.8 million records in a year
Telegraph 29 October 2012

Cameron accused of putting the NHS on sale
Guardian 5 December 2011

ORGANISATIONS

Google Deepmind

Med Confidential

NHS England

Royal Free Hospital

ADVICE FOR
DEBATING MATTERS

FOR STUDENTS

READ EVERYTHING .....
In the Topic Guide and in the news - not just your side of the argument either.

STATISTICS ARE GOOD BUT.....
Your opponents will have their own too. They'll support your points but they aren't a substitute for them.

BE BOLD
Get straight to the point but don't rush into things: make sure you aren't falling back on earlier assertions because interpreting a debate too narrowly might show a lack of understanding or confidence.

DON'T BACK DOWN
Try to take your case to its logical conclusion before trying to seem 'balanced' - your ability to challenge fundamental principles will be rewarded - even if you personally disagree with your arguments.

DON'T PANIC
Never assume you've lost because every question is an opportunity to explain what you know. Don't try to answer every question but don't avoid the tough ones either.

FOR JUDGES

Judges are asked to consider whether students have been brave enough to address the difficult questions asked of them. Clever semantics might demonstrate an acrobatic mind but are also likely to hinder a serious discussion by changing the terms and parameters of the debate itself.

Whilst a team might demonstrate considerable knowledge and familiarity with the topic, evading difficult issues and failing to address the main substance of the debate misses the point of the competition. Judges are therefore encouraged to consider how far students have gone in defending their side of the motion, to what extent students have taken up the more challenging parts of the debate and how far the teams were able to respond to and challenge their opponents.

As one judge remarked *'These are not debates won simply by the rather technical rules of schools competitive debating. The challenge is to dig in to the real issues.'* This assessment seems to grasp the point and is worth bearing in mind when sitting on a judging panel.

FOR TEACHERS

Hoping to start a debating club? Looking for ways to give your debaters more experience? Debaitng Matters have have a wide range of resources to help develop a culture of debate in your school and many more Topic Guides like this one to bring out the best in your students. For these and details of how to enter a team for the Debating Matters Competition visit our website, **www.debatingmatters.com**

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"A COMPLEX WORLD REQUIRES THE CAPACITY TO MARSHALL CHALLENGING IDEAS AND ARGUMENTS"

LORD BOATENG, FORMER BRITISH HIGH COMMISSIONER TO SOUTH AFRICA