NUFFIELD COUNCIL ON BIOETHICS

Response to the Department for Digital, Culture, Media and Sport's consultation on the Centre for Data Ethics and Innovation

September 2018

Introduction

1   The Nuffield Council on Bioethics is an independent organisation that examines and reports on ethical issues arising from developments in biological and medical research that concern the public interest.

2   Our response to this consultation draws on two Council publications: a recently published bioethics briefing note, *Artificial intelligence in healthcare and research* (May 2018) and our earlier, substantive report, *The collection, linking and use of data in biomedical research and health care: ethical issues (2015)*.[1] This report considers current arrangements for governing the use of data and sets out key ethical principles for the design and governance of data initiatives.[2]

3   While our 2015 report focused specifically on biomedical research and health care, the developments in data use that led to the report are of a general nature and are also relevant to fields such as public administration, and the provision of commercial and financial services.

Response

4   We broadly welcome the creation of a Centre for Data Ethics and Innovation, with the aim of ensuring safe and ethical innovation in data and AI. While it is clear that there is the potential for AI to enhance our lives in "powerful and positive ways", this must be considered alongside the potential risks and limitations of AI. There has been considerable government and private investment in AI, and it will be very important for the Centre to promote the responsible and ethical use of AI in line with the public interest as well as with the financial drivers.

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[1] Nuffield Council on Bioethics (2018) *Artificial intelligence in healthcare and research*, available at http://nuffieldbioethics.org/project/briefing-notes/artificial-intelligence-ai-healthcare-research and Nuffield Council on Bioethics (2015) *The collection, linking and use of data in biomedical research and health care: ethical issues*, available at: http://nuffieldbioethics.org/project/biological-health-data.

[2] In our report, we defined 'data initiatives' as involving one more of the following practices: where data is collected or produced in one contact, or for one purpose, are re-used in another context or for another purpose; and/or where data from one source are linked with data from a different source or many different sources.

5 There is a strong public interest in the responsible use of data to support the development of scientific knowledge and innovation, and to improve wellbeing, for example, through improved health advice, treatments, and care.

6 However, in pursuing these important opportunities, attention must be paid to assessing and mitigating the risks that can arise, which may include cyber security threats, unjustified state surveillance, discrimination, or the misuse of data leading to harm for individuals or institutions.

7 One of the most important factors in the use of AI systems is how data are collected and used. The consultation assumes that current data protection regulation is fit-for-purpose to deal with emerging AI applications. In our view, it is important not to assume that laws currently in place for data collection will remain fit-for-purpose in a rapidly evolving context. Furthermore, compliance with the law cannot guarantee that a use of data is morally acceptable and additional, flexible governance measures are likely to be required.

8 Developments in data science and computing have put significant pressure on conventional approaches to information governance, including the approach of seeking consent or anonymising data for use in research. We therefore support the Centre's proposed focus on articulating best practice and guidance. Though legal frameworks such as the Data Protection Act determine how data may be used (and, in certain cases, how it must be used), they are insufficient to determine how they *should* be used or what uses are morally acceptable over time. The Centre should bear this in mind when examining an application of data use, taking into consideration the views of the public.

9 We suggest that a set of morally reasonable expectations about the governance and use of data should be determined in accordance with four principles:

   1. the principle of respect for persons
   2. the principle of respect for established human rights
   3. the principle of participation of those with morally relevant interests
   4. the principle of accounting for decisions

10 Further explanation of these principles, and examples of good practice relevant to data initiatives, can be found in Chapters 5 and 6 of our report.[3]

Engaging closely with citizens, consumers and civil society

11 With the third of these principles in mind, we support the Centre's proposed aim of "engaging closely with citizens, consumers and civil society to understand the broader societal attitudes towards data and AI use and the public values which our governance measures should promote and protect". To help foster trust and cooperation, expectations about how data will be used should be determined

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[3] Nuffield Council on Bioethics (2015) *The collection, linking and use of biomedical research and heath care: ethical issues*, see chapters 5 and 6.

with the participation of people with relevant interests, allowing preferences and interests to be expressed and transformed.

12 With the fourth principle in mind, it is important that account is given of how these interests are respected in decision making. If people's preferences and values are not adequately taken into account, projects that could deliver significant public good may continue to be challenged and fail to secure public confidence.

Independence and transparency

13 In line with this, we agree that the Centre should be independent, informed and operate in a way that is evidence-based, transparent and open in making recommendations to Government.

14 Accordingly, the Centre should make its activities (including Board papers) and recommendations to the Government public at the point that they are delivered to Government to promote credibility and public confidence.

Research and analysis

15 With respect to the proposed activity "commission and bring together research and analysis into the ethical and economic uses of data and AI", we suggest this could also include:

- Research into the potential harms associated with uses of data, as well as their benefits. This research should be sustained as available data and data technologies evolve, maintaining vigilance for new harms that may emerge. (See annex 1 for the 'confidentiality funnel', which shows how many of the harms of data misuse may go undetected, even – paradoxically – by the victims).[4] Appropriate research that challenges current policy orientations should be particularly encouraged in order to identify and test the robustness of institutional assumptions.
- A review of the appropriateness of public-private partnerships to secure public benefit from the research use of public data (e.g. NHS information).

Further comments

16 While responsible collection and use of data will be fundamental to enable safe and ethical innovation of AI, data is just one component of many issues. In our briefing note we identified numerous social and ethical issues arising from potential uses of AI in the context of healthcare and research, some of which are included in the proposed areas of work for the centre.[5] These include the

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[4] Nuffield Council on Bioethics (2015) *The collection, linking and use of biomedical research and heath care: ethical issues*, see p. 40.
[5] Nuffield Council on Bioethics (2018) *Artificial intelligence in healthcare and research*.
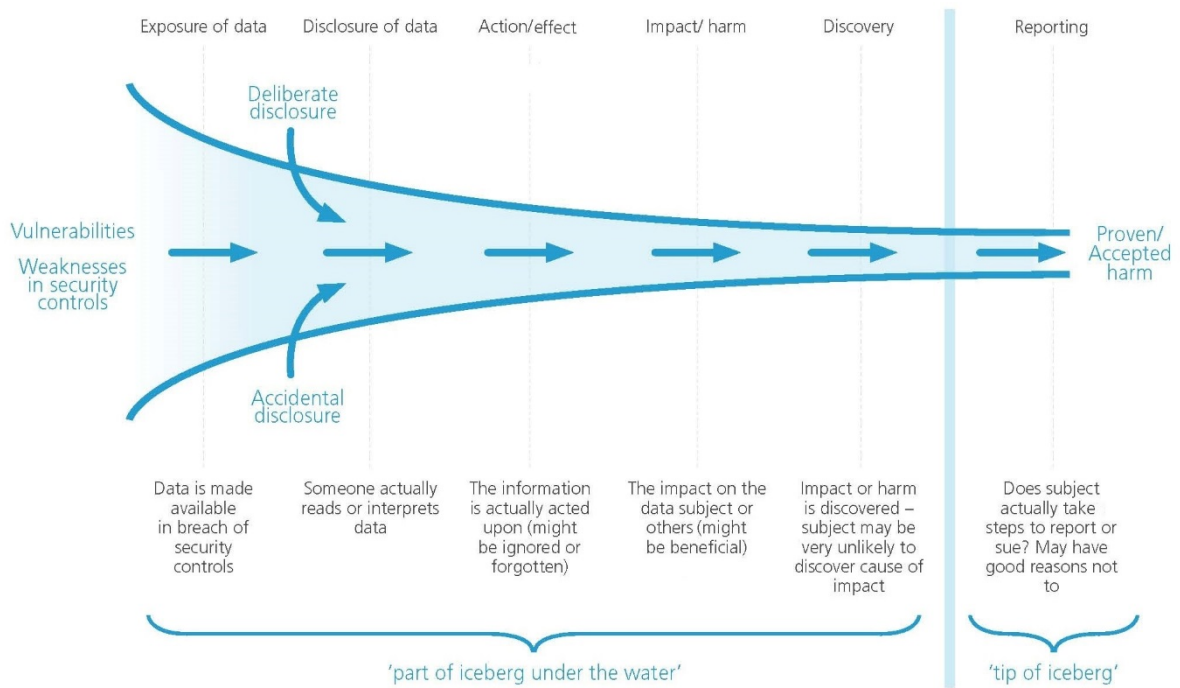
potential for AI to make errors; transparency in the underlying logic of AI; accountability for decisions made by AI; data bias, fairness and equity; trust; effects on people's sense of dignity and social isolation in care situations; effects of the roles and skills requirements of professionals; and the potential for AI to be used for malicious purposes.

17 The Nuffield Council has been involved in the establishment of the Ada Lovelace Institute, an independent research and deliberative body whose mission is to ensure data and artificial intelligence work for people and society. In thinking about the responsible governance of innovation, there is a need to take account of the sort of research and reflection into the social and ethical implications of AI and data use that the Ada Lovelace Institute proposes to carry out and to benefit from complementary initiatives.

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Annex 1. The confidentiality funnel

Exposure of data	Disclosure of data	Action/effect	Impact/ harm	Discovery	Reporting
Data is made available in breach of security controls	Someone actually reads or interprets data	The information is actually acted upon (might be ignored or forgotten)	The impact on the data subject or others (might be beneficial)	Impact or harm is discovered – subject may be very unlikely to discover cause of impact	Does subject actually take steps to report or sue? May have good reasons not to

'part of iceberg under the water'   'tip of iceberg'

Research into the direct harm arising from the misuse of data is vital, because many harms can go undetected, as shown in the figure above.