



## Department for Digital, Culture, Media and Sport: Consultation on the Centre for Data Ethics and Innovation (CDEI)

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### Response by the Wellcome Trust and Understanding Patient Data (UPD)

3rd September 2018

#### Introduction

Deployed responsibly, new uses of data and new data-driven technologies present exciting opportunities to enhance our lives and benefit society. *AI in the UK*<sup>1</sup> considers the UK well-positioned to develop expertise in the ethics of AI at a global level and if this ambition is to be realised CDEI will need to play a key role.

For the public to be confident in new data uses and data-driven technologies it will be necessary to ensure appropriate governance systems are in place, taking into account a wide range of perspectives and interests. This is an important issue for Wellcome, as building public confidence in responsible uses of data contributes to Wellcome's mission to improve health. Transparency in data uses is so important that Understanding Patient Data (UPD)<sup>2</sup> was set up with the specific aim of supporting conversations about how health and care data is used.

Our response focuses on strategic questions and areas where Wellcome and UPD are best placed to advise, not on operational issues. We are pleased to respond to this consultation and are happy to further discuss the challenges and opportunities of creating trustworthy systems for using data.

#### Summary

- **We consider the creation of CDEI to be a very positive step and support the roles and functions set out in the consultation. However, there must be greater emphasis on CDEI's role as the facilitator of a full discussion and debate on innovation in data uses and new data-driven technologies.**
- **CDEI should embed high-quality public dialogue work as a priority in its work plan. Insights from this kind of engagement will be required for CDEI to establish its societal legitimacy and ensure that the benefits of innovations in data can reach all sectors of society.**
- **CDEI must make both its activities and its recommendations public and use these public outputs to demonstrate its authoritativeness. This transparency will be important for enabling CDEI's outputs and advice to be trustworthy.**
- **CDEI must have enough resource for ongoing engagement, across government, sectors, with the wider public and with all relevant stakeholders, both within the UK and internationally. This will be essential if it is to meet the challenges in its remit.**

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<sup>1</sup> <https://publications.parliament.uk/pa/ld201719/ldselect/ldai/100/100.pdf>

<sup>2</sup> [www.understandingpatientdata.org.uk](http://www.understandingpatientdata.org.uk)

**Recommendation: The proposals for CDEI's roles, objectives and themes are positive but incomplete. CDEI must also facilitate full and proper discussion and debate.**

1. CDEI will hold a unique function by convening business, academia, government, regulators, the public and other stakeholders in anticipating emerging issues around data uses and data-driven technologies. This covers many of the key stewardship functions for data identified in *Data Management and Use*<sup>3</sup> and the key work areas chosen are a sensible starting point.
2. The consultation sets out CDEI's role in analysing and anticipating gaps, and then agreeing and articulating best practice. We suggest there is an additional role between these: to enable discussion and debate on what best practice should be.
3. This model is not without precedent: The Human Genetics Commission fulfilled a similar function, providing advice while not being a regulator. Its work may be instructive to CDEI as it sets up and plans its operations. *The Human Genetics Commission final report*<sup>4</sup> contains good examples on how to advise government, facilitate public debate and work in an open and transparent manner.
4. Issues concerning data use have the potential to be controversial, particularly given the scale of impact that data-driven technologies are having and could have across many sectors. Because of this, it is important that CDEI creates sufficient space to enable different views and values to be aired, explored and discussed. It will need to allow these different perspectives to contribute to and inform its activities, if it is to produce ethically robust guidance to government.

**Recommendation: CDEI should embed high-quality public dialogue work as a priority in its work plan. This needs to be properly resourced, which may require partnerships.**

5. For innovation to flourish, it is very important that CDEI both investigate public views and values on data uses and new data-driven technologies and continue to engage with the wider public over time.
6. Dialogue work must include representatives of civil society, including both those who could be impacted, and those who might influence decisions about, data uses and new data-driven technologies. In order that CDEI's best practice guidance and the advice it develops is fair and equitable, it must ensure it is representative of the UK's diverse population.
7. Embedding public participation can enhance and inform policy. If participation happens early in the decision-making process through an open policy approach the result is a richer range of policy options, and higher credibility and trust.
8. It needs to be clear what people can expect from participation in public engagement, and what purpose and potential influence their participation may have. Involve, who worked with UPD to produce *Data for Public Benefit*<sup>5</sup>, have useful guidance on methods.

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<sup>3</sup> <https://royalsociety.org/~media/policy/projects/data-governance/data-management-governance.pdf>

<sup>4</sup> <http://webarchive.nationalarchives.gov.uk/20121102202223/http://www.hgc.gov.uk/Client/document.asp?DocId=336&CategoryId=7>

<sup>5</sup> <https://www.involve.org.uk/resources/publications/project-reports/data-public-benefit>

9. There is currently little evidence, and more is required, to understand better what people think about uses of data. UPD has worked with the Academy of Medical Sciences on a public dialogue project exploring new technologies that use data in healthcare. This will be published later this year and may be informative for CDEI as it devises its work plan on public engagement<sup>6</sup>.
10. Public dialogue to inform advice and policy is, however, expensive and requires significant time. We suggest CDEI should look to partner with other organisations with public engagement and content expertise to deliver this research.

**Recommendation: CDEI must make both its activities and its recommendations public and use these public outputs to demonstrate its aim to deliver the best possible outcomes to society from uses of data.**

11. CDEI's recommendations to the Government must be made public and it must share its work, including committee and advisory group memberships. Evidence and information about its activities should be accessible to all, in plain English, across different channels and at a level of detail that will be meaningful and understandable to lay publics.
12. In addition to championing and promoting best practice in data use, CDEI must demonstrate its authoritativeness by not being afraid to challenge bad practice where it arises. People want to know how data about them is being used, who has access to it and why, and to be assured that public and societal benefits are not overridden by commercial interests. CDEI has the potential to build public confidence if it ensures these values are central to its work.

**Recommendation: CDEI must have enough resource for ongoing engagement, across government, sectors, with the wider public and all relevant stakeholders.**

13. CDEI will need to build its influence to work successfully cross-sector and cross-government. This will help to create incentives for others to follow its advice. It will need strong, ongoing connections with all stakeholders, including regulators, who can provide the function of redress where necessary.
14. CDEI will need to attract and retain experts who understand many different sectors, both within the UK and internationally. This breadth of knowledge will be essential to identify where sectors might learn from one another, how they are different and where action is needed.
15. Given the strong need for CDEI to function collaboratively and across different sectors, it will need to be adequately resourced to enable these connections and networks to flourish.
16. Wellcome is scoping the development of a potential new priority area looking at the opportunities of new uses of data to improve health for everyone. As part of this, we recognise that it is essential to build public confidence in responsible uses of data and new data-driven technologies. We would be happy to discuss potential ideas, and possible opportunities for collaboration, with CDEI in more detail.

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<sup>6</sup> <https://acmedsci.ac.uk/policy/policy-projects/use-of-patient-data-in-healthcare-and-research>