

## Consultation on the new Centre for Data Ethics and Innovation

### [Response from use MY data](#)

August 2018

#### **Introductory Note**

Whilst the consultation has been issued by the Department for Digital, Culture, Media and Sport (DCMS), much of the work of use MY data has been focused on health data. Our response will largely, though not exclusively, focus on health data.

As the consultation states, “Advances in how data is used, and the technologies that lie behind it, are transforming the world as we know it.”. We would equally point out that the potential for the better uses of data, within an open and transparent framework, and with the knowledge of patients and the public, must be a key goal, and one which use MY data members would support.

It was encouraging to see a very clear recognition in the consultation that “the Centre will set out the measures needed to build trust” in this growing area. We would see this as the critical point. Advances are unlikely to be held back by lack of data, or technology, but rather by the loss of public support.

#### **“Clear rules and structures”**

We would strongly support this concept. Clarity would be needed as to how these rules and structures would initially be defined, and in particular what levels of patient and public involvement would be involved in the creation of these. Additionally, we would expect all such rules and structures to be published, clearly, openly and in a lay-accessible manner. This would ensure the public could question and challenge in an informed manner. We would emphasise the benefits of such challenges – this is not something to be feared but must be addressed openly and honestly.

More details about patient/public involvement in the ongoing oversight is needed.

**“...unfamiliar economic and ethical issues...”**

You rightly state the need for governance to be in place to address these new challenges as they emerge. It is not clear how the public/patient voice will be part of this process.

### **The need for a Centre**

As the consultation states, “The Centre will not, itself, regulate the use of data and AI - its role will be to help ensure that those who govern and regulate the use of data across sectors do so effectively.”

There needs to be more clarity about the beneficial role that a Centre could play. Developments in the areas of data and AI are, and will be, rapid, dynamic and (largely) locally (or specialty) driven. This environment does not seem entirely comfortable with the centre-led philosophy described in the consultation. The document would benefit from more detail in this area as to the practical role of the centre, how it would be an enabler and not just an overhead.

**“The Centre will operate by drawing on evidence and insights from across regulators, academia, the public and business”**

The consultation makes it clear that the Centre is being established as a body which will advise government, becoming “the authoritative source of advice to government”.

If this is to be the case, the Centre will need to have the confidence of a wide range of stakeholders, with the public being the uppermost of those. Given the competitive nature of developments in AI (whether this is through academia-led or industry-led), it is unlikely that the Centre will achieve singularity of opinion or recommendation. Given this, how will the Centre communicate these differences in views in its stated role as the “authoritative source of advice to government”? Will the Centre be expected to arbitrate in the formation of its advice, or will it take its own view? And if the latter is the case, the need for a clear and open governance framework (to show how these

decisions are being arrived at) is critically important. As is the role of the patient/public in this.....

**“Understanding the public’s views, and acting on them, will be at the heart of the Centre’s work, as well as responding to and seeking to shape the international debate”**

We would support the positioning of the public at the centre of this work. We would ask that further detail be added as to how this might be achieved. The document states that there will be extensive consultation. What plans are in place in this regard?

**“..place it on a statutory footing”**

Unclear how this would achieve the stated benefits of strengthening the independent status of the centre. Where would the centre fit in relation to other initiatives, such as the Ada Lovelace Institute the National Data Guardian, etc.

**Where are the controls and safeguards?**

It is not entirely clear what level of public scrutiny will the Centre operate under. If the Centre Director is accountable to Secretary of State for Digital, how will the independence of the Centre be assured?

We would encourage the move towards Board Meetings being made public. As a minimum the papers and minutes should be published. The Centre might also want to consider whether a larger event/conference might be used at some point as part of its transparency and inclusion processes.

**“The role of the Centre is to advise on how we address any gaps in regulation, rather than to set and enforce any new regulations itself”**

With which organisation does the role of enforcement lie? What happens to the “few businesses having unprecedented power to influence behaviours and shape our society”? How will the Centre improve this area?

## **Areas of Activity**

The proposed areas of activity seem well argued and described. In particular the topic around ownership and intellectual property will require extensive public dialogue as to the risks, benefits and implications.

The Centre has already committed to the development of data sharing frameworks. How will the implementation of these be driven, and who is responsible for the oversight of delivery (or non-delivery)?

## **Governance**

We would support the composition of the Board as highlighted, to include relevant expertise in data science, ethics, law, economics, regulation, public communication, as well as moral or religious thinkers. We would ask how different interest groups would be involved, particularly those whose voices are not easily heard. We would emphasise the need for a strong public voice.

## **Summary**

Whilst this response is short, we hope that the comments from use MY data are helpful. As we said at the start of this response, advances are unlikely to be held back by lack of data, or technology, but rather by the loss of public support.

We thank you for the opportunity to feed into the consultation process and hope that use MY data members will be able to play a part in the successful development of the Centre.

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## About use MY data

use MY data is a movement of patients, carers and relatives

use MY data supports and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.

use MY data endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care for all.

use MY data aims to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service improvement and in research, aimed at improving patient decision making, treatment and experience.

### Our vision:

Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

### What we do

- ❖ We promote the benefits of sharing and using data to improve patient outcomes with sensible safeguards against misuse.
- ❖ We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.
- ❖ We provide learning resources for patient advocates on patient data issues, including:
  - hosting workshops for patients and the public, focussing on topics related to patient data
  - a library of resources of data security, consent
  - narratives from individuals about how collecting, storing and using data can help patients.
- ❖ We advocate public policy that supports the effective use of patient data within appropriate frameworks of consent, security and privacy, and with the aim of providing benefit to patients and their health care services.

## Who we are and how we are run

**use MY data** consists of Members who are patient advocates – either patients, carers or families’ representatives.

We also have Associate Members who work for patient organisations, charities, research institutions, public sector and commercial organisations. Our Associate Members are united by an interest in sharing healthcare data to improve patient outcomes under appropriate levels of consent, security and privacy.

**use MY data** is overseen/steered by a small Coordinating Group, which comprises use MY data members.

**use MY data** is supported by the Secretariat, which comprises a Coordinator and Expert Data Adviser. Details of funders can be found at <http://www.usemydata.org/funders.shtml>

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