

## Summary

- The Academy welcomes the establishment of the Centre for Data Ethics and Innovation, which has the potential to be a useful overarching hub for consultation and discussion on data-driven technologies such as AI and innovation, working across different sectors.
- There are already a number of data and AI-related bodies. Therefore it is critical that the Centre has a clear, unique remit that addresses an unmet need, and which does not overlap with these other organisations. Otherwise there is a risk that the roles of the different organisations will become blurred, resulting in duplication of efforts and potential confusion of messages.
- Although it is important that the Centre covers a broad range of sectors, individual sectors will have different needs which should be considered in its evidence gathering. For example, it is important to be mindful of the complex environment for use and management of patient data in healthcare, which has its own challenges and associated checks and balances in place.
- Two-way dialogue and engagement with the public must be central to the Centre's strategy and work, particularly in such a rapidly developing and changing field. Trustworthiness and transparency around data-driven technologies will be essential if society is to gain their full benefit.
- It is vital to ensure the independence of the Centre to guarantee that its advice is reliable and credible.

## Introduction

1. The Academy of Medical Sciences promotes advances in medical science, and works to ensure that these are translated into healthcare benefits for society. Our elected Fellowship includes the UK's foremost experts in medical science drawn from a broad and diverse range of research areas.
2. We welcome the opportunity to respond to the Department for Digital, Culture, Media & Sport's consultation on the Centre for Data Ethics and Innovation. This response is based on the views of the Academy's Fellows – many of whom have extensive experience of working with data in medical research and healthcare – and the Academy's previous work on this topic.<sup>1,2,3,4</sup> The Academy is also currently undertaking a policy project on new technologies that use patient data (or 'data-driven' technologies). This will establish principles for how such technologies should be deployed in the health and social care system, based on the findings of a dialogue programme with the public, patients and healthcare professionals.<sup>5</sup>
3. Our response primarily focuses on the role of the Centre with respect to the life sciences sector, which reflects our expertise.

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<sup>1</sup> Academy of Medical Sciences (2006). *Personal data for public good: using health information in medical research*. <https://acmedsci.ac.uk/file-download/34792-Personal.pdf>

<sup>2</sup> Academy of Medical Sciences (2016). *Response to the Department of Health's consultation on the National Data Guardian for Health and Care's Review of Data Security, Consent and Opt-Outs*. <https://acmedsci.ac.uk/file-download/41583-57dfa1b898cb9.pdf>

<sup>3</sup> Academy of Medical Sciences (2017). *Response to the House of Commons Science and Technology Committee inquiry into algorithms in decision-making*. <https://acmedsci.ac.uk/file-download/79291192>

<sup>4</sup> Academy of Medical Sciences (2017). *Response to the House of Lords' Artificial Intelligence Committee call for evidence*. <https://acmedsci.ac.uk/file-download/47067991>

<sup>5</sup> <https://acmedsci.ac.uk/policy/policy-projects/use-of-patient-data-in-healthcare-and-research>

### **Question 1: Do you agree with the proposed role and objectives for the Centre?**

4. We recognise a potential role for the Centre as an overarching hub for discussion and debate, where input can be brought together from across sectors in a transparent, neutral and independent way. The issues relating to data ethics and innovation will be relevant internationally and so we welcome its proposed role to identify global opportunities for collaboration.
5. The scale of the Centre and how it will operate will be key. Both aspects should reflect its objectives. For example, consideration should be given as to whether it will function from a new dedicated space or act as a distributed organisation. It would be helpful to clarify whether the Centre is envisioned as a permanent body or a time-bound entity, and whether it is anticipated that the Centre's recommendations will become enshrined in codes of conduct and/or law.
6. A clear distinction must be made between the role of the new Centre and the many other organisations already working in this area (e.g. the AI Council, Alan Turing Institute and Ada Lovelace Institute). Coordination between these organisations is necessary to avoid duplication of efforts and ensure that the Centre provides a valuable role. For example, it is unclear how the Centre's innovation component will relate to the Alan Turing Institute's aim to foster Government innovation, or how it will align with the horizon scanning function of the Ada Lovelace Institute. Furthermore, the data ethics and governance environment in healthcare is already complex with many different bodies involved in the data pathway, and so this should be considered in any work carried out by the Centre.
7. The Centre's broad remit should be balanced with the understanding that different sectors have different needs; broad recommendations without consideration of the specific challenges in some sectors may have unintended consequences. For example, not all applications of AI are considered equal in terms of usefulness and acceptability, and there may be different views on how data is used for healthcare or medical research compared with commercial advertising purposes. In healthcare, there is already a complex system of checks and balances around access to, and use of, patient data. For example, the Health Research Authority (HRA) carries out ethics approval for all research involving humans, and organisations such as the Independent Group Advising on the Release of Data (IGARD) and the HRA's Confidentiality Advisory Group (CAG) advise on access to NHS data.<sup>6,7,8</sup> In addition, the Medicines and Healthcare products Regulatory Agency (MHRA) regulates healthcare interventions (including data-driven technologies) and so the Centre's recommendations should not replicate any of the systems or processes in place.
8. The Centre should identify ongoing dialogue with the public as a specific objective, to inform its advice and ensure that data and innovation reflect public values.<sup>9,10</sup> This is particularly important in such a rapidly developing field where views will continually evolve and efforts should be made to build trustworthiness wherever possible. While communication is a valuable component of public engagement, without active partnership the outputs will lack credibility with the public.

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<sup>6</sup> [www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/research-ethics-committee-review/](http://www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/research-ethics-committee-review/)

<sup>7</sup> <https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/independent-group-advising-on-the-release-of-data>

<sup>8</sup> [www.hra.nhs.uk/about-us/committees-and-services/confidentiality-advisory-group/](http://www.hra.nhs.uk/about-us/committees-and-services/confidentiality-advisory-group/)

<sup>9</sup> Academy of Medical Sciences (2006). *Personal data for public good: using health information in medical research*. <https://acmedsci.ac.uk/file-download/34792-Personal.pdf>

<sup>10</sup> All-Party Parliamentary Group on Medical Research, Association of the British Pharmaceutical Industry (ABPI), and Genomics England (2014). *Building trust in the use of personal data for medical research*. <https://acmedsci.ac.uk/file-download/36069-535a6150e0c36.pdf>

9. Bringing the public into discussions is critical to ensuring confidence and trustworthiness and giving true credibility to the Centre's advice. Knowledge sharing is also a valuable component so that the public is fully informed of the risks and opportunities of new developments.

**Question 2: How best can the Centre work with other institutions to ensure safe and ethical innovation in the use of data and AI? Which specific organisations or initiatives should it engage with?**

10. As noted above, it is essential that there is clarity on the remit and focus of the Centre, and transparency and openness around how it will work with other organisations in the field as well as key stakeholders, to avoid duplication of efforts and outputs.
11. The Centre should explore the best methods for stakeholder engagement – potentially informed by an advisory body or a council – which should include academia, industry (both large and small companies), public institutions that hold data such as the NHS, regulators and representatives of the public and patients. This could also support the Centre's horizon scanning function and would provide useful insight into new developments and the ethical and legal challenges being faced by those on the front line.
12. Sector-specific bodies should also be consulted for expertise relating to their field. In medical research and health, for example, these organisations might include regulators such as the MHRA and bodies managing health data such as NHS Digital, as well as key expert organisations such as Understanding Patient Data.
13. In addition, the Centre should work with research funders and publishers. Funders are important drivers of data collection and so the Centre can work with them to understand the landscape for data ethics and innovation, as well as to implement its advice. Publishers, too, can play a role in influencing the culture around data ethics and innovation, for example around open access.

**Question 3: What activities should the Centre undertake? Do you agree with the types of activities proposed?**

14. We broadly agree with the proposed activities and particularly endorse the Centre's role in identifying areas of best practice.
15. All activities that the Centre undertakes must involve and be informed by the public. It should explore the use of AI in the context of public views and benefits to society. The Centre should seek to play a role in reducing inequalities and promote the use of AI in ethical, equitable and societally beneficial ways. It needs to be a champion for a forward-thinking and trusted framework, which has the flexibility to accommodate new opportunities and manage risks as technology and views progress, to ensure that the UK acts as a leader in this field.

**Question 4: Do you agree with the proposed areas and themes for the Centre to focus on? Within these or additional areas, where can the Centre add the most value?**

16. The areas proposed are cross-cutting but also need to be considered in the context of individual sectors. As explained in paragraph 7, the medical research and healthcare sector often has unique requirements and challenges. Therefore the Centre must consider sector-specific implications when giving high-level advice.
17. Our Fellows have highlighted other issues surrounding data including, but not limited to: the audit and integrity of data; Intellectual Property; liability; data privacy; data access; and provenance or context, which may be a key component to discussions around its utility, integrity and reliability.

18. There are many areas where the Centre could focus and so it will need a clear strategy. These should be prioritised along the lines set out in the consultation document: value, rationale and urgency.

**Question 5: What priority projects should the Centre aim to deliver in its first two years, according to the criteria set out above?**

19. We believe that the Centre should focus on a clear number of set outputs. Delivery of these projects should include a framework for 'ways of working' that emphasises how activities will progress the growth and the practical use of AI and data (trying to avoid the risk that ethical issues are considered in isolation or focus is not on topics that do not align with the opportunities/barriers to practical progress).
20. All projects should promote transparency and public understanding and trust in data and AI. To this end, transparency, data integrity, fairness and trustworthiness of data and AI should be prioritised. In addition, the Centre will need to be agile and responsive to address rapid developments in the environment and as an independent body, must be able to manage differences in views across different stakeholders.

**Question 6: Do you agree the Centre should be placed on a statutory footing? What statutory powers does the Centre need?**

21. The Centre's independence is key to its value and credibility. A statutory footing must not compromise this independence and assurances will be needed about how it retains this. Therefore the purpose and advantages, and how this would work in practice, need further clarity. We recognise that a statutory footing will be valuable if it creates a clear line of communication between the Centre and Government and gives legitimacy and credibility to the Centre's advice. However, this should avoid adding extra layers of bureaucracy by establishing unnecessary processes for how advice can be given or implemented which may compromise its effectiveness and/or delay its uptake. Lessons should be drawn from similar 'Centres' where tangible impacts have been made.
22. To guarantee the Centre's sustainability, adequate funding and resourcing will be essential. The source of its funding may affect the perception of its independence and so balanced funding from a variety of sources and sectors may be advisable.

**Question 7: In what ways can the Centre most effectively engage stakeholders, experts and the public? What specific mechanisms and tools should it use to maximise the breadth of input it secures in formulating its actions and advice?**

23. The Centre should look towards other successful established organisations and how this is being tackled internationally, particularly to see how they have built dialogue and trust with the public and their mechanisms of practice. As described throughout, meaningful and ongoing engagement with patients and the public is vital.
24. Engagement of network or membership organisations which can gather expert opinion across a number of experts/key stakeholders, such as learned societies or Academies with large numbers of leading academics, would enable the Centre to target appropriate experts. Expertise should be drawn beyond traditional AI experts including in ethics and social sciences. We suggest a high level of engagement with industry, scientific organisations such as academia and the public.

**Question 8: How should the Centre deliver its recommendations to government? Should the Centre make its activities and recommendations public?**

25. A critical role of this Centre is to demonstrate UK leadership in this area to promote innovation and build public understanding, involvement and trust. Therefore clear and public communication of the Centre's existence, plans, and deliverables should be prioritised, including measures of impact from its advice and updates on progress (e.g. annual reports). However, this should be balanced with the need to avoid unnecessary bureaucracy in how advice and recommendations are delivered.

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