

# National Statistician's Data Ethics Advisory Committee Minute

Thursday, 17<sup>th</sup> August 2023  
via video conference

## Present

### Members

Helen Boaden (Chair)  
Stephen Balchin  
Colin Godbold  
Monica Magadi  
Emma Uprichard  
Vanessa Cuthill  
Isabel Nisbet

### Secretariat

Simon Whitworth  
Matt Short

### In attendance

Daniel Ayoubkhani, Health Analysis and Pandemic Insight, ONS (for item 1)  
Mike Smith, Health Analysis and Pandemic Insight, ONS (for item 1)  
Vahe Nafilyan, Health Analysis and Pandemic Insight, ONS (for item 1)

### Apologies

Rob Bumpstead

## 1. Investigating the bidirectional relationship between employment and health conditions, treatments and service use (23)18

- 1.1 Daniel Ayoubkhani, Vahe Nafilyan and Mike Smith from Health Analysis and Pandemic Insight, ONS presented this item.
- 1.2 The paper outlined a proposal for research looking at the relationship between employment and health. The proposal included extending the Public Health Data Asset with additional datasets relating to health and labour market status to respond to the three main overarching research questions with refined questions coming in a hierarchy under each over time:
  - i. Is there a relationship between physical and mental health conditions, treatments and service use and labour market characteristics (such as employment status, benefit receipts, income and working hours)?
  - ii. Is there a relationship between changes in labour market characteristics and physical and mental health attributes?
  - iii. Do these relationships vary by demographic and socio-economic factors?

- 1.3 The NSDEC provided initial queries that the research team responded to in this meeting. These following points were raised by the NSDEC. The Committee:
- i. Saw the benefit of the proposed research and the public good that could be achieved through it.
  - ii. Encouraged by the explanation during the presentation of the engagement of other departments beyond the list of sponsors listed in the application and reassured by the governance as outlined in the presentation.
  - iii. Recommend that future applications should consider the sponsors and drivers of research when requesting advice from the NSDEC.
  - iv. Could see that the potential for the radical and ambitious use of the linked data asset, however they requested assurance on how, to ensure sustainability and inclusivity, the ONS would use this data in a transparent way with meaningful public engagement.
  - v. Requested that, with the above in mind, the ONS communications team present to the NSDEC the work they have done in understanding public acceptability for these types of data linkage.
  - vi. Wished to have a discussion with the ONS around the wider considerations involved in the use of linked data on the scale seen in this project.
  - vii. Provided the research team with interim approval for this important research, on the understanding that their comments and requests were addressed. However, for longer-term continuation of this work the NSDEC were keen to receive evidence of public acceptability of data linkage of this type and scale.

**1.4 Action –** The ONS research team to provide NSDEC with responses to the comments and queries in 1.3 and incorporate the changes into a revised version of the project proposal for resubmission to NS-DEC.

**Action –** The secretariat to regularly engage with the research team to ensure the NSDEC are sighted on any ethical issues that arise both during the research and with future use of the data.

**Action –** The secretariat to arrange a discussion with the NSDEC and the ONS regarding the ONS's approach to transparency and public acceptability in the use of linked data.

**Action –** The research team to present to the NSDEC any evidence of public acceptability related to projects of this type.

**Action –** The research team to review the project considering lessons learned, refined questions and public acceptability, and bring this to the NSDEC at a future meeting.