

National Statistician's Data Ethics Advisory Committee Minute

Wednesday, 30 September 2020
Meeting held via video conference

Present

Members

Dame Moira Gibb (Chair)
Mr Stephen Balchin
Mr Rob Bumpstead
Ms Vanessa Cuthill
Mr Colin Godbold
Ms Isabel Nisbet
Ms Marion Oswald

UK Statistics Authority

Ms Lily O'Flynn
Ms Karen White
Dr Simon Whitworth

Office for National Statistics

Mr Peter Jones (for item 2)
Mr Alex Lambert (for item 2)
Mr Pete Betts (for item 6)
Mr Joseph Traynor (for item 6)
Mr Nicholas Stripe (for item 6)

Other

Mr Arfan Iqbal, Scottish Government (for item 4)
Ms Emma Nash, Scottish Government (for item 4)

Apologies

Dr Emma Uprichard

1. Minutes and matters arising from the previous meeting

- 1.1 The Chair welcomed members to the 22nd meeting of the National Statistician's Data Ethics Advisory Committee (NSDEC).
- 1.2 Members approved the minutes from the previous meeting.
- 1.3 Dr Simon Whitworth updated the Committee with progress on actions from previous meetings. All actions were complete or in progress.
- 1.4 Mr Stephen Balchin informed the Committee that he is currently employed by the Department for Health and Social Care which is a partner in a project to be discussed in the meeting. Mr Balchin informed the committee that he was not directly involved in any of the projects that would be discussed.

2. Schools COVID-19 Infection Survey

2.1 Mr Peter Jones and Mr Alex Lambert from the Office for National Statistics (ONS) provided the Committee with an overview of the planned Schools COVID-19 Infection Survey, which aims to assess the role of schools in COVID-19 transmission and understand how transmission within and from school settings can be minimised.

2.3 The Committee raised the following points in discussion that followed:

- i. The Committee recommended that the sharing the positive results with test and trace should feature more prominently in the Participant Information as not isolating is now a criminal offence.
- ii. It is important that the Participant Information is understandable for all children given the wide age range of the children involved and children's concerns about COVID-19. ONS should engage with respected researchers working with children to ensure that the Participant Information is consistent with best practice in this area.
- iii. It needs to be made clearer in the application as to why Year 11 are being excluded from the sample due to it being an exam year, but Year 13 pupils are not being excluded even though that is also an exam year.
- iv. ONS should take steps to ensure that the sample is as inclusive as possible.
- v. ONS should look into the possibility of establishing a reference panel, including representation from academies, that consists of people working in schools to ensure that the research benefits from their expertise and that schools do not become over-burdened by the research.

2.4 **Action: The Committee approved the project subject to Mr Jones addressing the points above.**

3. Centre of Excellence for Data Ethics

3.1 Dr Simon Whitworth presented an overview of plans for the Centre of Excellence for Data Ethics (CEDE) which the UK Statistics Authority are establishing.

3.2 The Committee welcomed this important development and the following points were raised in discussion:

- i. It was suggested that it would be worth considering producing guidance on consent, the use of commercial data and use of predictive models.
- ii. The guidance on vulnerable groups needs to take into consideration that people might not refer to themselves as vulnerable and that vulnerability varies over time.
- iii. The importance of considering law as an important part of ethics was considered. It was suggested that the Reference Panel that was being established to advise on the work of the Centre may benefit from someone with a legal background.

3.3 **Action: The Committee were asked to contact the Secretariat if they were interested in sitting on the Reference Panel and Dr Whitworth was asked to provide updates on the progress of this work to future meetings.**

4. Health and Work Support Pilot and Fair Start Scotland evaluation data linkage project

4.1 Ms Emma Nash from the Scottish Government presented a proposed data linkage project to evaluate Fair Start Scotland (FSS) and the Health and Work Support pilot (HAWS; run in Dundee City and Fife).

4.2 The following points were raised in discussion:

- i. Ms Nash should provide clarity about the legal gateway that was being used to access the data and whether consent was required from participants;
- ii. Ms Nash should provide clarity about extent of the coverage of the control group and justify why this was required; and,
- iii. Ms Nash should provide clarity on whether the health data that will be used includes those people that have opted out of having their health data used for wider purposes.

4.3 Action: Ms Nash to work with the secretariat to address the points raised by the Committee

5. Audit of ethics self-assessment tool and Data Ethics Policy

5.1 Ms Karen White from the Data Governance Legislation and Policy (DGLP) team at the UK Statistics Authority presented the results of an audit of the use of the ethics self-assessment tool amongst researchers accessing data in the ONS Data Access Platform.

5.2 The audit found good use of the ethics self-assessment tool but that it was not clear whether researchers using low sensitivity data (usually aggregate or publicly available data) should use the tool. It was reported that the new ONS data ethics policy now made it clear that the self-assessment tool should be used for all types of data.

5.3 The Committee welcomed the report and encouraged the UK Statistics Authority to continue to ensure that the self-assessment tool was widely used to ensure the ethics of research and statistical production is robustly and efficiently considered.

6. Update and findings from the qualitative research exploring the ethics of asking selected questions on the Crime Survey for England and Wales by online data collection mode

6.1 Mr Pete Betts provided an update on the findings from qualitative research exploring the ethics of asking selected questions on the Crime Survey for England and Wales by an online data collection mode.

6.2 The Committee felt that this work was a valuable piece of work and supported ONS's plans to publish the results of the research.

7. Focus Group with children to explore what matters to their well being

7.1 Ms Karen White from the Data Governance Legislation and Policy (DGLP) team at the UK Statistics Authority presented the results of an audit of previous research approved by NSDEC which involved conducting focus groups with children to explore what matters to their wellbeing.

7.2 The Committee welcomed the reassurance that the compliance review offered in providing evidence that the Committee's advice had been followed in this research.

8. Any other business

8.1 There was no other business.