

National Statistician's Data Ethics Advisory Committee Minute

Friday, 15 October 2021
Meeting held via video conference

Present

Members

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

UK Statistics Authority

Lily O'Flynn
Daniel Towler
Simon Whitworth

Office for National Statistics

Peter Jones (for item 2)
Meghan Elkin (for item 3)
Rachel Griffiths (for item 3)

Other

Marianne Hester, University of Bristol (for item 3)
Emma Williamson, University of Bristol (for item 3)

Apologies

Emma Uprichard

1. Minutes and matters arising from the previous meeting

- 1.1 The Chair welcomed members to the 26th meeting of the National Statistician's Data Ethics Advisory Committee (NSDEC).
- 1.2 The Committee welcomed Professor Monica Magadi who was recently appointed to the NSDEC. Monica is a Professor of Social Research and Population Health at the University of Hull.
- 1.3 Members approved the minutes from the previous meeting.
- 1.4 Daniel Towler updated the Committee with progress on actions from the June 2021 meeting, and correspondence in the interim period. All actions were completed or in progress.

2. School Covid Infection Survey 2 (SIS2)

- 2.1 Peter Jones, from the Health Analysis and Pandemic Insight directorate, ONS, presented this item. This presentation firstly provided an overview of the changes on the recommissioned Schools Infection Survey for the academic year 2021/22. This project was recently received comments via correspondence where the Committee were asked their opinion on six areas of the project that required

ethical consideration. This presentation provided responses to questions and comments raised by the Committee.

- 2.2 The original SIS study (SIS-1) undertaken for academic year 2020/21 was designed to understand the levels of infection and transmission of COVID-19 in English schools. The study is being redesigned to extend data collection beyond infection and transmission, to further understand the indirect impacts of the pandemic on school children.
- 2.3 The update outlined that the recommissioned SIS will have the following changes:
 - i. The sample will be rebalanced to enable regionally and nationally representative estimates.
 - ii. The linkage of administrative data, which is considered to be a 'crucial evolution of the study' by the Scientific Advisory Group to meet emerging research priorities in schools.
 - iii. The use of PCR testing will be discontinued. Instead, there will be a focus on antibody testing to understand the children's immunity levels, which is an area of relatively low understanding.
 - iv. Staff will no longer be included in the study due to the rollout of the adult vaccination programme.
 - v. The questionnaire will be extended to pupils to gather information on long COVID, mental health and vaccine sentiment.
- 2.4 During the round of correspondence, the Committee were presented with six key changes that required ethical consideration. The NSDEC provided the following responses to the concerns raised during the correspondence consideration of this project, which were addressed during the meeting:
 - i. The Committee requested justifications for the linkage of SIS data to wider administrative data. Pete Jones provided an overview of the linkage purposes, demonstrating the public good for each linkage.
 - ii. The Committee advised that, at the very least, participants should be able to request their tests result, and expectations could be managed in regard to the turnaround times. Pete confirmed that after NSDEC opinion, SIS2 will now share results with participants and ensure expectations are managed on when participants can expect to receive their results.
 - iii. The Committee were asked their opinion on the use of incentives to encourage responses. It was agreed that provided there is equal opportunity to receive this payment, then it is suitable. The NSDEC asked whether schools would continue to receive compensatory payments. It was confirmed that schools would continue to be compensated.
 - iv. The Committee agreed that parental consent would be necessary. Pete updated the Committee by confirming that year 11 pupils, who may be 16, would be included in requiring parental consent.
 - v. In response to the self-completed questionnaires being extended to students aged 11 to 18, the Committee agreed it seems reasonable to hold contact details of 11- to 18-year-old pupils given the parental involvement in providing this information. Additionally, the NSDEC requested information on what would be included in the survey, and if children will be asked questions around their family's opinions. It was confirmed that children would not be asked about their family's views or behaviours in relation to COVID-19 restrictions and health advice.

- vi. The NSDEC also had concerns about an approach which prevents action being taken where a safeguarding issue is identified in a survey response. Pete explained the wellbeing module being used in wave 1 would use the established Strengths and Difficulties Questionnaire (SDQ). Pete informed the Committee that the Department for Education (DfE) use the SDQ and maintain confidentiality of all pupil responses. The use of the SDQ would be reviewed against the ONS Safeguarding Policy, and mental health services will be signposted in information accompanying the questionnaire.
 - vii. It was confirmed that time lags involved with the analysis of survey responses from participating children may impact processes involved with the reporting of potentially identified child safeguarding issues that could arise from survey responses.
- 2.5 In response to the assurances given to the Committee following the comments via correspondence, the following points were raised by the NSDEC during the discussion:
- i. The Committee asked for the rationale to discontinue the PCR testing. Pete informed the Committee that in the last academic year, the use of PCR tests was expensive and added little value as it identified very few positive tests. Pete also confirmed that the linkage of test and trace data would be utilised instead of the PCR tests to provide required data at better value for money.
 - ii. The Committee questioned why the incentivisation of £5 only applies to the questionnaire and not the antibody testing, which could leave students missing out on the incentive if they consent to the testing but not the questionnaire.
 - iii. The NSDEC had concerns about the use of SDQ and the safeguarding concerns with identifying students who may be a cause for concern.
 - iv. The Committee also questioned the relevance of the use of the SDQ and requested assurance as to how this survey fits into the research questions of the SIS.
- 2.6 The NSDEC recognised the clear public good of the study and appreciated Pete's thoroughness of both the correspondence and subsequent discussion.
- 2.7 Action - ONS need to understand and justify the value of asking the mental health questions within the SDQ and take advice from DfE and a children's charity with expertise in this area such as the NSPCC.**
- 3. Research to support the redevelopment of survey questions to estimate the prevalence of domestic abuse. NSDEC(21)14**
- 3.1 Marianne Hester and Emma Williamson from the University of Bristol, and Meghan Elkin and Rachel Griffiths from the Public Policy Analysis Directorate, ONS, presented this item. This research focuses on developing and qualitatively testing a new set of questions to measure the prevalence of domestic abuse in England and Wales. In addition, the research will also further explore the survey mode for asking respondents about their experience of domestic abuse in line with the wider transformation of the Crime Survey for England and Wales (CSEW) self-completion module.
- 3.2 The following points were raised in the discussion:
- i. The Committee asked what the measure for success is for this stage of the research. The researchers confirmed that success would entail the successful transformation of the domestic abuse module within the CSEW.

- ii. The NSDEC stressed the importance of the homogeneity of focus groups, which is required to facilitate free discussion. Even with homogenous groups in relation to demographics, the Committee agreed that it will be important to consider the nature and potential unique experiences within each focus group.
 - iii. The Committee requested assurance on the security of the Zoom platform where online interviews and focus groups would take place. The researchers confirmed that the version of Zoom used for this study is a University of Bristol only platform, and recordings of the interviews and focus groups will only be saved on the secure University server.
 - iv. While no legal gateway is required to collect the data for this project, the Committee requested that the researchers make clear their legal basis to collect and process personal information for this study in study documentation.
- 3.3 The Committee appreciated the application and acknowledged the importance of the research.
- 3.4 Action – Researchers to update the application to cover the legal basis for this research.**
- 4. Overview of data stewardship model for the Integrated Data Service**
- 4.1 Simon Whitworth, from the UK Statistics Authority, presented an overview of the data stewardship model for the Integrated Data Service (IDS), which the ONS is currently developing to improve access to government data for both government and non-government researchers. This presentation outlined the key principles that underpin the data stewardship approach to ensure research projects receive the scrutiny required based on ethical, legal, and public good risks. The new process will automatically generate the risk categories for research projects requesting access to IDS using the information researchers provide through a research project application, thus enabling efficient data stewardship.
- 4.2 The following points were raised in the discussion:
- i. The Committee asked whether the audit safeguard would provide assurance that what is said in the application, is what actually happens in practice;
 - ii. The NSDEC stressed the importance of considering ethics when data is being acquired, processed and linked for use in the service. The Committee appreciated that government departments may have historically faced barriers to share data for research purposes. The NSDEC stressed the importance of ensuring that ethical considerations remain at the forefront of IDS development regardless of the prioritisation of other challenging issues that require work in order to make the IDS successful
 - iii. The Committee recommended that it is made absolutely clear that the personal data made available via the IDS is de-identified at the point of researcher access, and not anonymous. The safeguards that are baked into the IDS model, to ensure re-identification of individuals within the secure environment does not happen, should be clearly explained to stakeholders and the wider public to help build trust in the use of data for research that is for the public good.
- 4.3 The Committee agreed that this looked thorough, comprehensive, well-structured and therefore reassuring that these processes are being established. The NSDEC agreed to providing public support to the importance of data ethics and research stewardship within the development of the IDS.

4.4 The NSDEC emphasise the importance of data ethics and research stewardship within the development of the IDS.

5. NSDEC end of year evaluation

5.1 Daniel Towler, from the UK Statistics Authority, presented the end of year evaluation for the Committee. This was informed by a member self-assessment survey to gauge the sentiment of members on the workings of the Committee.

5.2 As a result of the self-assessments, Daniel suggested the following actions, and asked for the Committee's opinions on the proposed changes:

- i. To set a minima time for project consideration at NSDEC meetings and therefore commit to potential flexibility to extend meetings by 30 minutes to allow for busier agendas;
- ii. Continue to explore the potential for further recruitment of members to the Committee in areas of potential expertise gaps;
- iii. To externalise the ethics advice compliance audit function so that the Committee can be assured that their comments and recommendations are being considered by projects that seek NSDEC consideration from outside the ONS;
- iv. To update the NSDEC application form to enable further clarity in applications;
- v. To revert back to email correspondence instead of Confluence for projects that are to be considered outside of the regular meeting schedule, and;
- vi. Look into the possibility of providing options for in-person meetings and/or hybrid meetings in 2022.

5.3 The Committee agreed with the suggested actions.

5.4 Action – The Secretariat to action the suggestions listed in 5.2.

6. Updated NSDEC application. NSDEC(21)15

6.1 Lily O'Flynn and Daniel Towler presented a revised NSDEC application for the Committee to review. The purpose of the update was to streamline the process, which aligns with the focus on improving the service provided to researchers with the launch of the Centre for Applied Data Ethics. These updates also draw on the comments from the NSDEC self-assessment where members agreed that the information received by the Committee could benefit from more clarity.

6.2 Updates to the application form included the following structural changes:

- i. In places, questions were merged and simplified where it was found that application questions were similar or overlapped;
- ii. Some questions were disaggregated to smaller more focussed sub-questions to support researchers in providing the specific detail that the Committee requires; and,
- iii. A question on areas of identified ethical issue that researchers are requesting specific advice on was added to assist the Committee with identifying the areas within a project that researchers require particular support with.

6.3 The Committee appreciated the update to the form and suggested a few minor changes to further clarify to researchers the information that the Committee requires throughout the application.

6.4 Action – Secretariat to make suggested updates to the application form and publish on the UK Statistics Authority website alongside updated guidance once complete.

7. Any other business

7.1 Colin Godbold provided the Committee with an update on the work of the Centre for Applied Data Ethics. The update was provided to keep the Committee informed of how work on the Centre is progressing, including an update on the upcoming pipeline of guidance pieces and confirmation that the Centre is focussing now on evaluating the impact that recently published guidance is having on the research community.

7.2 The quarterly Data Ethics Compliance Review, NSDEC 21(16) was presented to the Committee. This presented a compliance review of ONS and the Economic Statistics Centre of Excellence (ESCoE) collaborative research project 'Management and Expectations Survey (MES) feedback and trial' [NSDEC 19(14)]. The data ethics compliance review confirmed that the research team have taken the advice of the Committee, which has been integrated into the research project appropriately.

7.3 The next meeting will be held on 1 February 2022.