

National Statistician's Data Ethics Advisory Committee Minute

Thursday, 2 July 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
Dr Emma Uprichard

UK Statistics Authority

Dr Emily Mason-Apps
Dr Simon Whitworth
Mr Rhys Nadin (for item 9)

Office for National Statistics

Mr Pete Benton (for item 2)
Ms Becky Tinsley (for item 3)
Mr Peter Fullerton (for item 4)
Ms Orlaith Fraser (for item 5)
Mr Brendan Davies (for item 5)

Office for Statistics Regulation

Dr Mary Cowan (for item 8)

Other

Dr Catherine Bromley, Economic and Social Research Council (for item 6)
Professor Peter Elias, University of Warwick (for item 6)
Ms Anne Nierobisch, Economic and Social Research Council (for item 6)
Ms Jemma Gardner, Department for Education (for item 7)
Mr Irfan Mohamed, Department for Education (for item 7)
Ms Lia Sussman, Department for Education (for item 7)

1. Minutes and matters arising from the previous meeting

- 1.1 The Chair welcomed members to the 21st 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 Dame Moira Gibb, informed the Committee that she had recently taken up a role as Regional Convenor for London's Trace, Track, Contain and Enable Programme. Mr Stephen Balchin informed the Committee that he is currently an official at the Department for Health and Social Care, which are a sponsor of some of the projects that would 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. COVID-19 Infection Survey Update

- 2.1 Mr Pete Benton, Director of Population and Public Policy Operations, from the Office for National Statistics (ONS) provided the Committee with an update on the progress of the pilot phase of the COVID-19 Infection Survey, along with an overview of the next phases of the survey which will seek to measure the infection and immunity rates in a UK-wide representative sample.
 - 2.2 Mr Benton informed the Committee that the research team will continue to seek medical ethics approval from the National Research Ethics Service for any amendments to be made to the protocol for future phases of the survey, and would continue to consult the NSDEC on matters related to data ethics.
 - 2.3 The Committee welcomed the update from Mr Benton and the following points were raised in discussion:
 - i. The Committee recommended that the researchers consider the impact of the easing of lockdown on participant recruitment and sample representativeness moving forward;
 - ii. The Committee recommended that the researchers continue to consider the importance of maintaining public trust in the use of data collected as part of this survey; and,
 - iii. The Committee were informed that a de-identified dataset will be made available in the ONS Secure Research Service. This will enable Accredited Researchers to access data under Chapter 5, Part 5 of the Digital Economy Act (2017; DEA) to use the data for projects approved by the Research Accreditation Panel.
 - 2.4 The Committee emphasised the importance of continuing to consider the ethics of future uses of data collected from the COVID-19 Infection Survey, and welcome the opportunity to provide further advice on future phases of this work.
- ## **3. NSDEC Briefing on COVID-19 Surveillance Studies [NSDEC(20)14]**
- 3.1 Ms Becky Tinsley from ONS provided the Committee with an overview of three cross-government surveillance projects that ONS are involved in to look at the prevalence of COVID-19 in care homes, prisons and schools. The Committee were informed that ONS's role varies across the studies, but is limited to providing analytical input into to the design and analysis of the studies. ONS will also have a role in publishing the official statistics from

these studies to ensure that results are published in a timely and transparent manner in line with the Code of Practice for Statistics.

- 3.2 The Committee were informed that the protocols for all three of the studies have been approved by the Public Health England Research Ethics and Governance Group, and that ONS will complete an ethics self-assessment to consider the ethics of their involvement in each of these projects.
- 3.3 The Committee welcomed the update from Ms Tinsley and the following points were raised in discussion:
 - i. The Committee were informed that incentive schemes would not be used for any of the three studies, and recommended that the researchers consider the difference that makes compared to the main COVID-19 Infection Survey;
 - ii. The Committee were informed that the results will be published as official statistics and as analysis in academic journal articles;
 - iii. The Committee recommended that the researchers continue to be mindful of the factors that will affect sample representativeness (for example, children not attending school); and,
 - iv. The Committee were informed that ONS will only have access to de-identified data for analysis.
- 3.4 The Committee welcomed an update on this work at a future meeting.

4. Data Science Campus Rapid Ethical Review Process for COVID-19 Projects [NSDEC(20)15]

- 4.1 Mr Peter Fullerton from the ONS Data Science Campus (DSC) provided an update on the application of the Rapid Ethical Review process that the DSC developed to consider the ethics of the fast-paced work being undertaken by the Campus to produce aggregate statistics to inform the Government's response to the COVID-19 pandemic.
- 4.2 Mr Fullerton informed the Committee that, to date, 12 COVID-19 projects have been assessed using the Rapid Ethical Review process, and that two of those projects had also been subject to a full ethical self-assessment subsequently. Mr Fullerton explained that the Rapid Ethical Reviews is only used for COVID-19 related projects that need to be conducted at pace to inform Government, and that the DSC will continue to use the full ethical self-assessment process for all other projects.
- 4.3 The Committee welcomed the update on the application of the Rapid Ethical Review process, and the following points were raised in discussion:
 - i. The Committee acknowledged ONS's success in upholding public trust in the use of data to inform the Government's response to COVID-19, and highlighted the importance of continuing to ensure that ONS's uses of data are subject to ethical scrutiny;
 - ii. Mr Fullerton explained that any work that continues beyond the stage required to provide rapid results to inform Government's response to

- COVID-19 will be subject to a full ethical self-assessment, or brought to the Committee for consideration where appropriate ;
- iii. The Committee acknowledged that there may be instances where a critical need to undertake vital analysis at pace and emphasised the importance of continuing to be as transparent as possible;
 - iv. The Committee encouraged Mr Fullerton to continue to consider the ethics of the DSC's uses of data throughout the lifespan of projects relating to the COVID-19 pandemic, especially as the situation evolves.
- 4.5 The Committee thanked Mr Fullerton for providing the update, and offered to provide advice and guidance on DSC projects at future Committee meetings.
- 5. Ethical application of funnelling methodology for prosecution of refusals in the 2021 Census [NSDEC(20)16]**
- 5.1 Ms Orlaith Fraser from ONS presented a method to fairly select "hard-refusal" households for non-compliance follow-up activity as part of the upcoming 2021 Census. Hard-refusal households are those that explicitly state that they do not intend to complete the Census. The method outlined will only be required in the event that the total number of hard-refusals exceeds the operational/resource capacity for follow-up, and aims to ensure that every possible step is taken to ensure that no group is selected unfairly or disproportionately. Ms Fraser informed the Committee that ONS had sought legal advice on the proposed method. Ms Oswald stated that it was not clear in the paper what risks this legal advice had identified.
- 5.2 The Committee approved the method outlined, but recommended that the team consider the following points:
- i. ONS should consider how the follow-up field visits will be conducted if there are any social-distancing restrictions in place at the time of Census, and seek further guidance if this involves changing the proposed methodology;
 - ii. ONS should consider, and learn from, the approaches taken in other countries;
 - iii. ONS should carefully consider the effectiveness and public acceptability of the methods used; and,
 - iv. In order to maintain public trust and understanding of the value of Census, and participation, ONS should ensure that there is clear messaging about exactly how data collected from the Census is held, analysed and shared.
- 6. ESRC Early Life Cohort Pilot Study- proposed sampling and participant recruitment plan [NSDEC(20)17]**
- 6.1 Dr Catherine Bromley from the Economic and Social Research Council (ESRC) and Professor Peter Elias from the University of Warwick presented a proposal for the sampling and recruitment of the ESRC's new Early Life Cohort Pilot Study. The researchers intend to draw the sample from the birth register linked to NHS maternity records. In England and Wales this is held by the Office for National Statistics (ONS). The equivalent agencies in Scotland and Northern Ireland (National Records of Scotland, and the Northern Ireland Statistics and Research Agency) will be approached to establish the feasibility of using these sources.

- 6.2 Dr Bromley and Professor Elias informed the Committee that a full application for the proposed ELC will be submitted to NSDEC by the Scientific Leadership Team (SLT) once appointed. The Committee were therefore asked to provide advice on the proposed approach at this initial stage.
- 6.3 The Committee acknowledged the clear value and utility that a new ELC could offer by generating high quality data to enable policy relevant research. The following points were raised in discussion:
- i. The SLT should be encouraged to consider how recruitment strategies can ensure that hard-to-reach or underrepresented groups are captured within the cohort;
 - ii. The Committee recommended that the sampling and recruitment strategies should make it as easy as possible for potential participants to opt-out at every stage;
 - iii. The Committee were reassured by the work being conducted to explore the public acceptability around the ELC study and the use of the opt-out sampling method;
 - iv. Dr Bromley and Professor Elias informed the Committee that they are continuing to discuss the approach with colleagues in ONS and the Devolved Administrations;
 - v. The research team should establish who will be the data controllers and data processors for data collected as a result of the ELC pilot; and,
 - vi. The researchers informed the Committee that they intend for a de-identified dataset to be made available to researchers in secure research settings such as the ONS Secure Research Service and other secure environments accredited as processors under the Digital Economy Act.

7. Investigating vulnerabilities linked to serious youth violence using linked DfE and MoJ data [NSDEC(20)06]

- 7.1 Ms Jemma Gardner from the Department for Education (DfE) presented a revised proposal to use a subset of a linked Ministry of Justice (MoJ) and DfE dataset to explore the relationship between educational/social care factors on serious violence. This linked dataset includes the National Pupil Database (DfE), the Police National Computer (MoJ) and Criminal Courts data (MoJ). This project is being conducted in partnership with MoJ, the Cabinet Office/ Prime Minister's Implementation Unit, the Home Office, and the Office of the Children's Commissioner.
- 7.2 Ms Gardner outlined the changes that the researchers had made to the research proposal in response to the comments provided by the Committee at the previous meeting. These changes included:
- i. Clearly defining the purpose of undertaking this research, outlining clear research aims and potential benefits for informing policy;
 - ii. Clearly outlining the outputs that will result from each stage of this work, and the geographic level at which these would be produced;
 - iii. Explaining in more detail how the use of the linked dataset adheres to the principles of data minimisation and proportionality;

- iv. Providing more information on the safeguards and procedures that will ensure the confidentiality and protection of sensitive and individualised data included in the linked dataset;
- v. Engaging with colleagues in MoJ and the Race Disparity Unit to provide detailed information and plans to mitigate the risks raised from the limitations and potential bias that exist in the data;
- vi. Providing clear assurance that this data will not be used for operational purposes, or to identify individuals or schools; and
- vii. Providing assurance that the results will be clearly communicated to enable appropriate and proportionate interpretation of findings to avoid implying causality.

7.3 Ms Gardner also informed the Committee that the research team had decided to remove the machine learning elements of this work, and confirmed that the researchers would return to the Committee with a revised application if they intend to conduct this analysis at a later date.

7.4 The Committee recommended that the researchers consider the value of approaching an NSDEC (or UKSA) representative to contribute to the Expert Advisory Group being convened to oversee the project moving forward.

7.5 The Committee also asked for clarification on the legal gateway that will govern researchers' access to the DfE/MoJ linked dataset through the ONS Secure Research Service. The Committee recommended the Research Strand of the Digital Economy Act 2017 as an appropriate legal gateway. This legal gateway would ensure that the access to, and use of, such a dataset receives independent scrutiny (from the Research Accreditation Panel) and adheres to appropriate standards of data governance and ethical scrutiny (as agreed by Parliament and stakeholders).

7.6 The Committee agreed that the researchers had addressed the Committee's comments from the 1 April 2020 meeting, and approved the revised application.

8. Analysing the Public Good in NSDEC Applications

8.1 Dr Mary Cowan from the Office for Statistics Regulation (OSR) presented the Committee with an overview of a programme of work that OSR are undertaking to look at how statistics serve the public good. Dr Cowan is leading a project to explore how researchers articulate and conceptualise public good in their applications to the Committee and the Research Accreditation Panel. This work will also help to identify examples of how data is being used to serve the public good, and if there are conceptual differences between the public good of statistics referring to policy needs or the needs of the public.

8.2 The Committee expressed interest in this programme of work, and provided advice on factors that Dr Cowan may want to consider when undertaking this work. The Committee asked that Dr Cowan provide an update on this work at a future meeting.

9. Data Protection and Ethics Compliance

- 9.1 Mr Rhys Nadin from the Data Governance, Legislation and Policy team at the UK Statistics Authority presented this paper. The paper presented a data ethics compliance report following a review of the project “Linking suicide data to Higher Education Student Registry data [NSDEC(18)03]”. This review confirmed that all the recommendations made by the Committee had been satisfactorily implemented.
- 9.2 The paper also presented the objective selection criteria that the team has developed to determine which projects should undergo compliance reviews, along with a compliance review plan for 2020/21.
- 9.3 The Committee thanked Mr Nadin for this paper, and for the reassurance that compliance reviews offer in providing evidence that the advice the Committee give has a real impact in enabling and ensuring ethically appropriate research.
- 9.4 The Committee were supportive of the objective selection criteria that have been developed, and would welcome the opportunity to receive data ethics compliance reports at future meetings.

10. Any other business

- 10.1 There was no other business.