

National Statistician's Data Ethics Advisory Committee Minute

Wednesday, 17 February 2021
Meeting held via video conference

Present

Members

Dame Moira Gibb (Chair)
Stephen Balchin
Vanessa Cuthill
Isabel Nisbet
Marion Oswald
Emma Uprichard

UK Statistics Authority

Lily O'Flynn
Daniel Towler
Emma Walker (for item 5)
Karen White (for item 6)

Office for National Statistics

Louisa Blackwell (for item 3)
Gemma Hanson (for item 3)
Nicola Rogers (for item 3)
Dawn Snape (for item 7)

Other

Maria Calem, Home Office (for item 3)
Eveie Shaw, Home Office (for item 3)
Susie Balderston, University of Birmingham (for item 4)
Joanna Long, University of Birmingham (for item 4)
Simon Pemberton, University of Birmingham (for item 4)

Apologies

Rob Bumpstead
Colin Godbold
Simon Whitworth

1. Minutes and matters arising from the previous meeting

- 1.1 The Chair welcomed members to the 23rd meeting of the National Statistician's Data Ethics Advisory Committee (NSDEC).
- 1.2 Members approved the minutes from the previous meeting.
- 1.3 Lily O'Flynn updated the Committee with progress on actions from previous meetings and correspondence. All actions were complete.
- 1.4 The Secretariat informed the Committee that the previously approved minutes had been published on the UK Statistic's Authority Website.

2. Updated terms of reference. NSDEC(21)02.

- 2.1 Lily O'Flynn presented the Committee with an updated Terms of Reference. The updates included a clarification surrounding the process of project considerations via correspondence. This update also proposed a transition to the use of an online collaboration tool to facilitate correspondence reviews of project proposals.
- 2.2 The Committee raised the following points in the discussion that followed:
 - i. The committee recognised the importance of balance between the need to review projects quickly and the importance of considered discussion during meetings. Consideration at a meeting is generally to be preferred to online
 - ii. The online tool should have a prompt function so that the members know when a project is uploaded for consideration.
- 2.3 The Committee approved the updated terms of reference and suggested we try the new online collaboration tool to understand its utility.
- 2.4 **Action: The Secretariat to publish the new Terms of Reference and operationalise the collaboration tool.**

3. Longitudinal cohort study for refugees. NSDEC(21)03

- 3.1 Louisa Blackwell, Nicola Rogers and Gemma Hanson from the ONS presented the next stage of the Vulnerable Persons and Vulnerable Children Resettlement Scheme linkage pilot study that NSDEC reviewed in February 2020. Maria Calem and Eveie Shaw from the Home Office also joined. The linkage study was successful, and the research team proposed to create a longitudinal cohort for refugees using administrative data.
- 3.2 The following points were raised in the discussion:
 - i. The Committee were encouraged that the Home Office Strategic Engagement group were involved with this work to ensure that the relevant stakeholders and representatives of refugee groups were consulted as this work progresses;
 - ii. The Committee felt that it could be useful to make the de-identified longitudinal cohort dataset more widely available to the research community through a secure data access environment, given the new insights that could be gained from this data;
 - iii. The Committee advised that the research team work with the ONS Legal Services team to identify the most appropriate legal gateway that would allow this information to be used safely and securely for research purposes;
 - iv. The Committee advised that additional consideration is given to protocols and requirements for working with data from under 18s that may or may not be accompanied by an adult when reaching the UK, as part of this study;
 - v. The Committee encouraged continuing conversations with counterparts in Scotland and Northern Ireland to scale-up this study to include UK-wide data, as opposed to England and Wales data only; and,
 - vi. The Committee encouraged the ongoing open publication of various phases of this work to ensure transparency. The Committee requested updates from the researchers as this project iterates to ensure that appropriate ethical consideration is given at all stages of this work.
- 3.3 The Committee acknowledged the thoroughness of the application and appreciated the value of the study. The Committee requested to be updated on the progress of the research.

3.4 **Action: ONS and Home Office colleagues to provide the secretariat an updated application with the considerations and suggestions of the Committee.**

4. **Trauma, Social Harm and Health in Criminal Justice Involved Women: The Women's Risk Needs Assessment (WRNA) Validation Research Study. NSDEC(21)04**

4.1 Simon Pemberton at the University of Birmingham presented a project which proposed using linked identifiable MoJ, NHS and DWP data to validate the Women's Risk Needs Assessment tool used by Women's Centres to support women involved in the criminal justice system. The administrative recidivism data will be compared to the output of the risk assessment tool either 6 or 12 months after the risk assessment has been carried out, to understand the tool's validity in identifying risks to these women's long-term outcomes.

4.2 The following points were raised in the discussion:

- i. The Committee recommended the researchers further engage with data-owning government departments that they hope will contribute to this study to ensure that the data storage, retention and security arrangements proposed by the University of Birmingham meet government-recognised data security requirements;
- ii. The Committee recommend that the researchers also reflect on the physical security of data collected on paper as part of this study, and look at where use and retention of paper copies of sensitive data to be minimised;
- iii. The Committee wished to further understand whether this tool will be used for predictive modelling purposes, which could potentially affect women's ability to access support services. The researchers confirmed that access to services would not be restricted through use of this tool, and agreed to update the project application to reflect this;
- iv. The Committee acknowledged the potential for this project to achieve public benefit, but recommended that the research team reflect on their public engagement strategy to ensure that such public benefits are achieved;
- v. The Committee understands why this initial work is being done for English language speakers only, but encourage the extension of this work to other significant non-English language groups as this work progresses;
- vi. The Committee requested sight of the outcome of the NHS Research Ethics Committee consideration of this work;
- vii. The Committee understand that data must be retained so research can be validated by the wider research community, however recommend that the researchers reflect on whether standard data retention policies apply with this study, given the particular sensitivity of this data; and,
- viii. The Committee suggested a number of amendments be made to the participant information and consent materials to ensure that data storage plans and ability to withdraw consent is clear and transparent to participants.

4.3 Simon Pemberton and the wider research team at the University of Birmingham thanked the UK Statistics Authority Data Ethics team for their assistance and support in bringing this application to NSDEC, noting that the NSDEC process is straightforward and user-friendly.

4.4 The Committee acknowledged the useful nature of the project and supported the project subject to the points in section 4.2 being addressed and other relevant departments being satisfied.

4.5 **Action: The University of Birmingham researchers to work with secretariat to revise application.**

5. Identifying Gaps, Opportunities and Priorities in the Applied Data Ethics Guidance Landscape. NSDEC(21)05.

5.1 Emma Walker from the Centre of Applied Data Ethics within the Data Ethics team at the UK Statistics Authority presented a paper providing an overview of current applied data ethics guidance available to the research and statistical community, and a landscape review to identify the depth and coverage of current guidance. This included an identification of some areas where applied ethics guidance is currently lacking.

5.2 Emma requested the Committee's view on what topics should be prioritised by the Centre for Applied Data Ethics with regards to the publication of applied data ethics guidance. The Committee's advice on potential collaborators that the UKSA's Centre for Applied Data Ethics could pursue was sought also.

5.3 The Committee acknowledged the comprehensiveness of the landscape review and welcomed the development of this work. The Committee strongly supported the idea that guidance will be practically focused. The discussion raised the following points:

- i. Given the regular positive feedback received on NSDEC's public good criteria, the Committee recommended that it would be useful for public good understanding and criteria to be standardised across ethics boards and committees, to assist with researcher understanding. The Committee also recognised that public good is often understood in a UK context, so recommend that some work on international comparisons of public good understanding would be useful to help facilitate comparative international analyses;
- ii. As more work is being undertaken which combines both public and private data, the Committee recommended that additional ethics guidance in the area may be useful;
- iii. Due to the increase in their use and uptake, the research and statistical community would benefit from further ethics guidance on the use of predictive modelling and artificial intelligence; and
- iv. The Committee recommended that work on the intersection of ethical and legal issues would be beneficial.

6. Ethics Compliance Report: Review of Pilot record linkage study: Vulnerable Persons and Vulnerable Children's Resettlement Scheme. NSDEC(21)06.

6.1 Karen White at the Data Protection and Compliance team at the UK Statistics Authority presented this item. This paper presents a data ethics compliance report on the ONS research project Vulnerable Persons and Vulnerable Children's Resettlement Scheme data.

6.2 The report concludes that the research team satisfactorily implemented NSDEC's advice, following the consideration of this application in February 2020.

6.3 The Committee were appreciative of the work that the Data Protection and Compliance team which continued to ensure that the advice of the Committee was being properly considered and operationalised.

7. Inclusive Data Task Force

- 7.1 Dawn Snape provided the Committee with an update on ongoing work that the ONS's Inclusive Data Task Force is undertaking to ensure that ONS improves the inclusivity of the data it collects and statistics it produces.
- 7.2 The Committee welcomed this work as a positive step towards improving inclusivity of groups that are often hidden or hard to reach, in the long term.
- 7.3 The Committee provided Dawn with suggested organisations that the Inclusive Data Task Force may wish to engage with to gain different perspectives to current barriers to inclusion as part of the Task Force's ongoing public consultation. Dawn agreed to facilitate future dialogue between the NSDEC and the Inclusive Data Task Force, and would welcome comments from Committee members via correspondence, throughout the lifespan of the Task Force.

8. Any other business

- 8.1 The Committee welcomed Emma Walker's update on the UK Statistics Authority's launch of the Centre of Applied Data Ethics (CADE). Emma highlighted the upcoming roundtable that CADE will be holding on emerging ethical challenges in research and statistics, for which the Committee's views would be welcomed.
- 8.2 The next meeting will be held on 13 April 2021.