

National Statistician's Data Ethics Advisory Committee Minute

Tuesday, 5th July 2022

Boardroom, Drummond Gate, London and via video conference

Present

Members

Dame Moira Gibb (Chair)
Stephen Balchin
Vanessa Cuthill
Colin Godbold
Monica Magadi
Isabel Nisbet
Emma Uprichard

UK Statistics Authority

Lily O'Flynn
Tia-Mae Surtees
Daniel Towler
Simon Whitworth

Office for National Statistics

Jim Newman (for item 2)
Larry Bartleet (for item 3)
Louisa Blackwell (for item 3 and 4)
Helen Moore (for item 3)
Chloe Wright (for item 3)
Nicky Rogers (for item 4)
Alex Lambert (for item 5)
Ian O'Sullivan (for item 5)
Peter Betts (for item 6)
Sofi Nickson (for item 7)
Emma Walker (for item 7)

Apologies

Rob Bumpstead
Marion Oswald

- 1. Minutes and matters arising from the previous meeting**
- 1.1 Members of the Committee approved the minutes from the last meeting in the interim period via correspondence and were subsequently published.
- 1.2 Daniel Towler updated the Committee with progress on actions from the April 2022 meeting, and correspondence in the interim period. All actions were completed or in progress.
- 1.3 Daniel Towler informed the Committee that work was underway to hold a workshop for members later in the year, as agreed in the April meeting.
- 1.4 Members were notified that those members that had sent apologies for the meeting, had sent comments on the projects.

- 2. The ONS Longitudinal Study (LS). NSDEC(22)10.**
- 2.1 Outcome – The NSDEC was not made aware of any specific ethical issues raised during the review of this project by the Independent Group Advising on the Release of Data (IGARD), and agreed that the LS was consistent with the UKSA ethical principles.**
- 2.2 Detail of the project and discussion:**
- 2.3 Jim Newman from the Health Population and Methods Transformation directorate of ONS presented this item. This paper overviewed the activity undertaken to maintain and update the widely used longitudinal research resource. The ONS Longitudinal Study contains linked census and life event data for a 1% sample of the population of England and Wales. The LS started with a sample drawn from the 1971 Census. Data from subsequent censuses, civil registration events and NHS registration events have been linked since 1971. People are included in the sample if they are born on one of four birth dates.
- 2.4 As all NHS Digital data sharing activity requires approval by the Independent Group Advising on the Release of Data (IGARD). A recent IGARD submission covering the sharing of data for LS processing was approved with a number of conditions. One of these is that ‘the LS to be presented in front of the NSDEC.’ It was confirmed to the Committee that there was not a specific ethical issue, identified by IGARD, that NSDEC was asked to provide a view on.
- 2.5 The NSDEC raised the following points within the discussion:
- i. The Committee questioned the rationale for not disclosing the four birth dates. It was confirmed that if the four birth dates were to be disclosed the chances of identification would significantly increase. Maintaining confidentiality of the birth dates makes it significantly less likely that individuals could be identified.
 - ii. The Committee highlighted that, even if the birth dates were to be kept undisclosed, it would still be possible to allow people to opt out of the inclusion of their data within this study. This could be on the understanding that individuals could ask to be withdrawn should they be part of the sample.
 - iii. The Committee mentioned that while efforts are made to make the LS transparent, the NSDEC suggested that being transparent in the privacy notice about the ethical rationale for not requiring explicit consent, rather than just the legal basis, would be very beneficial to consider.
 - iv. The Committee suggested that it would be useful to consult the Information Commissioner’s Office (ICO) on the matter of not sharing the four birth dates.
 - v. The Committee asked whether there had been any technological changes in data linkage over the 50 years the LS has been running that may compromise participants’ identity or have public good implications. The research team confirmed that efforts have been made to keep the procedures as consistent as possible to ensure comparability over time.
 - vi. It was confirmed to the Committee that when data is made available to researchers in the Secure Research Service (SRS), this is strictly de-identified data.
 - vii. The Committee stressed the importance of maintaining the security of the data through robust data access governance safeguards, which NSDEC recognised were currently in place.
- 2.6 The NSDEC agreed that the Longitudinal Study was consistent with the UK Statistics Authority’s ethical principles.

- 2.7 **Action – The Secretariat to include security as a topic for the workshop to be held later in the year.**
- 2.8 **Action – The Secretariat to review the NSDEC application form to better capture ethical consent and the ability to opt-out.**
3. **The 2023 Recommendation**
- 3.1 **Outcome – The NSDEC encouraged the team to ensure that the Centre for Applied Data Ethics (CADE) is involved throughout the development of the 2023 Recommendation.**
- 3.2 **Detail of the project and discussion:**
- 3.3 Larry Bartleet, Louisa Blackwell, Chloe Wright and Helen Moore, ONS, were present for this item. The paper was in response to a request by the NSDEC at the April meeting, as a number of projects recently submitted to the NSDEC for review have referenced the Recommendation. It gave an overview of what the recommendation is and what is being done to ensure that the work is ethical.
- 3.4 The 2023 Recommendation has an ambition to provide the best picture of the population including more regular population totals: for example, monthly population totals by age and sex at a local level.
- 3.5 The NSDEC raised the following points within the discussion:
- i. The Committee requested that the briefing on the public consultation is shared with the Centre for Applied Data Ethics.
 - ii. While the potential value of this work was appreciated, the NSDEC stated that there could be significant harm. The Committee stressed that appropriate protections and security controls need to be implemented.
 - iii. The NSDEC presumed that the legal basis for this work would be for research and statistical purposes, and therefore questioned whether research required monthly data.
 - iv. Due to the increasing sensitivity and quantities of data, the Committee recommended that the ONS should ensure that the Five Safes, which is a framework for ensuring the effective use of data, which is confidential or sensitive, is still fit for purpose.
 - v. The NSDEC urged the team to work with CADE to ensure that ethics is covered in any public engagement work.
 - vi. The Committee recommended that CADE are involved to support teams conducting work for the Recommendation.
- 3.6 The Committee appreciated the overview of what the 2023 Recommendation is and would be interested in being kept updated on progress.
- 3.7 **Action - The research team to ensure that CADE is engaged to inform the ethical appropriateness of the 2023 Recommendation.**
4. **2021 Census Data Asset: Proof of Concept. NSDEC(22)06.**
- 4.1 **Outcome – The NSDEC encouraged the team to continue to engage with both CADE and the NSDEC as this project develops.**
- 4.2 **Detail of the project and discussion:**
- 4.3 Nicky Rogers and Louisa Blackwell from the Health Population and Methods Transformation division, ONS, presented this item. Following the presentation that was delivered to the NSDEC in April, the research team returned with a full NSDEC application setting out the 2021 Census Data Asset Proof of Concept.

- 4.4 This proof of concept is part of work to create a transformed population and social statistics system. At the heart of this is a system of demographic accounts which seeks to estimate the key components of population and population change. The project seeks to build a 2021 Census Data Asset to provide a prospective longitudinal resource.
- 4.5 Since the presentation in April, the research team outlined some significant developments to the project:
- i. The title of the project has changed from a 'cohort' to being a 'data asset' after the Committee advised that the use of the word cohort could imply that it will be only a sample of the population.
 - ii. The analysis of the data will be via a satellite-based system. Whilst the Census 2021 Data Asset provides a record level representation of the England & Wales population, it is envisaged that there will be satellite cohorts based on samples where the cohort comes from the Data Asset, it is on these cohorts that analysis will take place. On NSDEC advice, the team propose an approach to admin data linkage for the satellite cohort studies, where only the necessary variables are linked to the cohort. The different satellite cohorts will return for ethics consideration in the future.
- 4.6 The NSDEC raised the following points within the discussion:
- i. The Committee recommended that the Information Commissioner's Office (ICO) be consulted, especially on the question as to whether an individual can opt-out of the data asset.
 - ii. NSDEC asked to see the Data Protection Impact Assessment for this work to understand how it will comply with Data Protection Legislation.
 - iii. The Committee requested further information on the lessons learnt from other work which includes the 2011 Health Data Asset and the Refugee Cohort Study. The research team informed the Committee that they had learnt of the importance of not using a one size fits all linkage algorithm; the importance of having a representation of population at risk; and that learning had informed the replenishment strategy for the asset.
 - iv. The Committee encouraged that there be public engagement that solely regards the data asset due to the complex nature of the work. The research team confirmed that there will be a publication that clearly communicates this work to a lay person to make the project more accessible.
 - v. The Committee requested a justification as to why the asset will include the whole census population and not a sample.
 - vi. The research team also confirmed to the Committee that there will be an attempt to include those people who were not captured by the Census.
 - vii. The NSDEC stressed the importance of ensuring that the administrative data used to maintain the asset is of sufficient quality.
 - viii. The NSDEC also recommended that caution be taken in regard to ensuring that linkage of data is as a result of a genuine need, rather than as a result of being able to.
 - ix. The Committee strongly advised that this data asset should have very strong governance and controls to ensure that the work done is secure, non-identifiable and restricted to solely statistical purposes.
 - x. While the research team made clear that this work is not the creation of a population register, the Committee asked that the difference between the Data Asset and a population register be articulated.
- 4.7 The NSDEC supported the statistical merit of the work and appreciated the continued engagement. The Committee strongly encouraged the team to

continue to work with CADE and NSDEC to ensure that ethical practice is at the heart of this work.

4.8 Action – The research team to continue to work with CADE and return to NSDEC as this develops.

5. The ONS Survey Strategy.

5.1 Outcome – the team to engage with CADE to ensure that the importance of ethics and the ethics services provided by the Centre are clearly articulated in the ethics section of the playbook.

5.2 Detail of the project and discussion:

5.3 Alex Lambert, Director for Surveys, and Ian O’Sullivan, ONS presented this item. The ONS has set out a new vision for the future of surveys and that there is a need to work together on surveys more as part of a one ONS ambition for all surveys in the ONS. This presentation informed the NSDEC of this strategy and how ethics are included within it. This included the plan to create a surveys playbook that would include detail on ethics.

5.4 The strategy outlines a plan to complement other sources of data, ensuring that an inclusive picture of society is reflected and being sustainable in the delivery of surveys. The strategy will also encourage more collaboration on surveys across the ONS, putting actions in place to encourage collaboration.

5.5 The NSDEC raised the following points within the discussion:

- i. The NSDEC asked whether one of the four pillars of the strategy should be ethics. It was highlighted that the four pillars represented the major improvement areas required for surveys within ONS; instead, ethical considerations were at the heart of the ‘inclusive by design’ pillar.
- ii. The NSDEC stressed that the consideration of ethics should be a primary consideration for all research and statistics. Therefore, the NSDEC recommended that CADE should be involved to help articulate the ethics section of the playbook to ensure the guidance and services of the Centre are captured.
- iii. The Committee queried whether there will be an agreed approach on collecting informed consent. The NSDEC encouraged the team to conduct work to establish a standard on consent.
- iv. The Committee highlighted the increase in surveys from a variety of sources and the need to consider the impact of this proliferation on the willingness of individuals to give their data.

5.6 Action – CADE to be involved to help construct the ethics section of the playbook.

6. Qualitative research related to redesigning the Crime Survey for England and Wales (CSEW) for mixed mode and longitudinal collection - Screener and Victimisation modules. NSDEC(22)11.

6.1 Outcome – the Committee supported this work subject to assurances to points outlined in section 6.5 being provided to the Secretariat.

6.2 Detail of the project and discussion:

6.3 Peter Betts from the Methodology and Quality directorate, ONS presented this item. As part of the Crime Survey for England and Wales (CSEW) Transformation programme, this project aims to improve the wording, order, routing and looping

of questions to produce accurate estimates of crime prevalence and incidence in accordance with data requirements. One of the research aims is to ensure the CSEW questionnaire collects accurate data from victims who have been exposed to multiple or repeat victimisation.

- 6.4 To explore how the CSEW should be redesigned, qualitative research will be conducted to understand how respondents typically engage with the survey. Participants will be asked about their experiences of crime and how they would potentially prefer to be asked about those experiences in the survey. This includes topics such as property crimes and fraud and some sensitive topics such as violence, threats, and sexual assault.
- 6.5 The NSDEC raised the following points within the discussion:
- i. The Committee urged the research team to ensure that the sample size is sufficient to capture difference in ranges of victims due to the varying nature of people's experiences.
 - ii. The Committee queried how the security of recordings of the remote interviews would be ensured, and how identifiability from the recordings will be limited.
 - iii. The NSDEC stressed that all data used to organise interview arrangements should be deleted upon completion of the project.
 - iv. The Committee questioned whether the victim support organisations, who will be used to recruit participants, have been involved in the planning of the research.
 - v. The NSDEC recommended that the results be made available in a transparent manner.
 - vi. The Committee questioned whether interviews would be made available in Welsh, and agreed that at the least, the Crime Survey itself should be made available in Welsh.
 - vii. The NSDEC noted the quota sample for crime types and enquired whether there will be a similar quota for interview modes.

6.6 Action – The research team to provide the Secretariat with assurances to the points raised in section 6.5

7. Harmonisation.

7.1 Outcome – the Committee requested to be kept updated on the work of the harmonised standards.

7.2 Detail of the project and discussion:

7.3 Emma Walker and Sofi Nickson from the Government Statistical Service Harmonisation team, based within the Public Policy Analysis directorate of ONS, presented this item. The presentation overviewed harmonisation and what the current workplan is, this includes detail on what the priority areas/topics are. The team provided an overview of key ethical aspects of harmonisation, which are linked to the ethical principles.

7.4 Harmonisation seeks to improve the consistency, comparability and coherence of data and statistics. Harmonised standards set out how to collect and report statistics to ensure comparability across different data collections in the Government Statistical Service.

7.5 The NSDEC raised the following points within the discussion:

- i. The Committee asked what was being done to try and ensure maximum buy-in for the standards. The team informed the Committee that they had a multi-

faceted approach to ensure buy-in which included a champions network, presenting across governmental departments and contacting research teams who used a non-harmonised approach to understand why they did not use the harmonised standards.

- ii. The NSDEC stated the importance of being clear about what the best terminology is when referring to certain characteristics, as many people may not know what terminology is acceptable, as well as understandable.
 - iii. The NSDEC mentioned that it would be useful to share examples of good questions, so that researchers can be aware of best practice.
 - iv. Conversely, it was suggested that case studies of bad practice, and the subsequent problems that occurred as a result would be useful to encourage uptake of the harmonised standards.
- 7.6 The Committee appreciated the informative presentation and agreed that it would be interested to be updated on progress on developing and embedding these harmonised standards across the UK.

8. Any Other Business.

- 8.1 The Committee was informed that due to resourcing pressures, a data ethics compliance review was not completed in time for this meeting. The data protection team, UKSA, will endeavour to provide a paper either via correspondence or provide two papers at the next meeting. The Committee agreed that receiving this via correspondence would be preferable.
- 8.2 The NSDEC agreed that it may be useful to trial a more flexible approach to organising future NSDEC meeting dates. It was agreed to canvas for dates a couple months in advance of the next meeting.
- 8.3 The Secretariat also confirmed that along with agreeing a date for the next meeting, options for a date will also be provided for the workshop in due course.
- 8.4 Therefore, the next meeting will be held in October 2022.