

# **National Statistician's Data Ethics Advisory Committee Minute**

Tuesday, 23 July 2024  
via video conference

## **Present**

### **Members**

Ms Helen Boaden (Chair)  
Professor Sir Ian Diamond, National Statistician (present for item 2)  
Mr Stephen Balchin  
Ms Vanessa Cuthill  
Mr Colin Godbold  
Professor Monica Magadi  
Ms Isabel Nisbet

### **Advisors**

Mr Rhys Nadin, UKSA (also present for item 6)

### **Secretariat**

Dr Pamela Calderon Ambrossen, UKSA  
Mr Nikhil Harsiani, UKSA  
Ms Liv Underwood, UKSA (for item 7)

### **In attendance**

Miss Anita Arif, ONS (for item 3)  
Mr Edward Bextor (for item 6)  
Ms Zara Burman, ONS (for item 3)  
Dr Shona Horter, ONS (for item 4)  
Miss Siannan Kerrigan, ONS (for item 4)  
Ms Tarandeep Sandhar, ONS (observing, for item 1)  
Ms Dawn Snape, ONS (for item 3)  
Dr Daria Tkacz, ONS (for item 4)

## **1. Minute and matters arising from the previous meeting**

- 1.1 Members of the Committee approved the minutes from the 23 April 2024 meeting.
- 1.2 The Secretariat updated the Committee with progress on actions from the 23 April 2024 meeting. All actions were completed or in progress.
- 1.3 The Chair welcomed the National Statistician, Professor Sir Ian Diamond, to the meeting.

## **2. Discussion with the National Statistician, Professor Sir Ian Diamond (NSDEC(24)21)**

- 2.1 The National Statistician (NS) outlined the importance of independent ethics committees, such as the National Statistician's Data Ethics Advisory Committee (NSDEC, or 'the Committee'). The NS said, in some ways, the Office for National Statistics' (ONS) license to operate is on account of NSDEC's work.
- 2.2 The NS recognised that some of the ONS' work is, and will continue to be, sensitive, and that this work should be conducted ethically.
- 2.3 The NS talked of the [independent review of the UK Statistics Authority \(UKSA\)](#) conducted by Professor Denise Lievesley in early 2024. He echoed comments from the review that NSDEC was a positive thing and should be developed.
- 2.4 The NS spoke of the intersectionality between the Committee's work and strong public engagement. He said that effectively communicating to the public about how and why the ONS use public data will encourage more buy-in from the public. He acknowledged that this has not necessarily been a strength of the UKSA in the past.
- 2.5 The NS highlighted the massive potential to public good of data linkage, and that use of linked data will likely keep increasing. Given that, he said the Committee should continue to recognise the importance of ethical principles around linkage.
- 2.6 The Committee members raised the following points in discussion:
  - i. Members commended the ONS' strength in data security, yet, observed that the ONS's efforts in public involvement are sometimes lacking. The NS responded that ONS' public engagement efforts continue to grow. The NS invited the Committee to join an assembly on Thursday, 3 October, 2024, where users will discuss which ONS statistics they find most important.
  - ii. The risks of research involving data are sometimes overlooked in the name of said research being in the 'public good'. The NS acknowledged that this was a challenge that he will think about.
  - iii. While there is much research into the public's opinions of their own data being used, there is a potential lack of knowledge about public attitudes of their fellow citizens' data being used, especially when those citizens opt against certain uses of their data. The NS agreed that there might be a gap in the literature on this.
  - iv. Modelling and artificial intelligence (AI) is now at the point it can be utilised effectively in analysis of populations the size of England, which raises ethical concerns. The NS agreed.
  - v. Certain consent given by the public during the COVID-19 pandemic should be re-assessed. The NS recognised that there has been a willingness to allow, say, data linkage where the dataset(s) relate to COVID-19. He said the public should be engaged about the permissions they give. Still, he highlighted that data linkage is necessary to help achieve the government's goals in, for instance, improving health outcomes of certain groups.
  - vi. There is nervousness of some groups, for example the elderly, of responding to surveys via email or telephone. The NS acknowledged this.
  - vii. The question of what the UKSA's position is regarding the ethical concerns that may arise from linking administrative and survey datasets in place of conducting full censuses. Committee members recommended that

NSDEC consider these concerns and offer their advice. The NS responded that while data linkage between the private and public sectors already happens, this is not ethical grounds in itself for such linkage. He remarked that citizens have a right to see which of their data is being collected, and that citizens should also be able to add information to the record.

- viii. The process by which CADE review ethics self-assessments, and escalate a subset of more complex projects to NSDEC for review, works well and is recognised by research community. Alongside this is the importance of ongoing compliance reviews of NSDEC's recommendations to research projects they review. The NS agreed, and added that ethics reviews of research projects are not blockers to innovative research. Still, the public and the research community should both be clearly communicated about why researchers partaking in ethics review processes serves the interests of all parties.
- 2.7 The NS thanked the Committee for their continued time and effort, and stated again how vital NSDEC is to the work of the UKSA.
- 2.8 The Chair thanked the NS for his joining, and invited him to attend an NSDEC meeting in 2025, which he accepted.
- 2.9 **ACTION:** Secretariat to arrange for the NS to join a 2025 NSDEC meeting.

### **3. Research to Assist in the Development of a New Ethnic Group Harmonised Standard (NSDEC(24)22)**

- 3.1 Ms Zara Burman, Ms Anita Arif and Ms Dawn Snape from the ONS presented on this item.
- 3.2 The research team informed that their methods for this project had been signed off by both internal and external assurance board.
- 3.3 The Committee raised in discussion:
  - i. The question of how much additional breakdowns in the ethnicity standard drive policy. The research team acknowledged this, and added that harmonisation reduces burdens for users when comparing survey data.
  - ii. The kind of approach researchers took when engaging with members of the public. The research team explained how they have engaged with around 4300 members of the public, and what kinds of groups they represent.
  - iii. There is a need to consider if there is an 'upper limit' to the number of response options on a survey question. The research team have conducted a literature review to explore this, and have found a lack of significant evidence. They will test the length of the list of options by asking members of the public in the next round of public engagement, which they have already started in earnest.
  - iv. The risks around comparability over time of making different ethnic groups identifiable on surveys. The research team conducted a quantitative study in 2023 to map comparability of the Census question to an early version of the new standard, and they found a comparability of over 90%. They plan to do another quantitative study in the near future.
- 3.4 The Committee opined that the public good for this project was generally well-justified.
- 3.5 The Committee also raised in discussion:

- i. It is important to protect individuals' identities who identify in relatively small ethnic groups. The research team said they are considering this.
  - ii. Opinions certain ethnic groups might be affected by both the exclusion and inclusion of other ethnic groups in the harmonised standard. The research team commented that individuals will still have an open text response option in the new standard.
  - iii. A person's ethnicity can often be an important component in how they perceive themselves. Therefore, the ONS should be careful in how they position and communicate ethnic group options in the new standard. The research team noted the Inclusive Data Taskforce's (IDTF) support for a harmonised standard. The research team acknowledged the 'trade-off' between methodological preferences and how users see themselves, and that they should monitor how this changes this over time.
- 3.6 The Committee commended the research team on their important work, and thanked them for their joining the meeting.

#### **4. Lived experiences of Roma people (NSDEC(24)23)**

- 4.1 Dr Shona Horter, Ms Siannan Kerrigan and Dr Daria Tkacz from the ONS presented on this item. They summarised their project's methods to the Committee and gave an overview of what they intended to discuss in the meeting.
- 4.2 The Committee praised the project given its importance and topical nature.
- 4.3 The research team stated their plan is to include Wales, as well as England, in their research.
- 4.4 The Committee raised in discussion:
  - i. The question of how current affairs that involve Roma people impacts, if at all, the research team's approach. The research team said that they do take current events into consideration; for example, they now plan to engage with the Roma community in Leeds. The team have also worked with the Department for Health and Social Care (DHSC) to further understand how Roma peoples engage with healthcare and social services.
  - ii. Experiences of Roma peoples in England and Wales may differ, and should be treated as such.
  - iii. The importance of the ONS not bringing assumptions of 'traditional' family roles to their communications with Roma people.
- 4.5 The Committee suggested that safeguards given to Roma participants, or additional safeguards, should also be extended to the peer researchers in the project. The research team agreed that there are potentially long-term vulnerabilities to peer researchers after the project's conclusion. To mitigate this, the researchers will work with Civil Society Organisations (CSO) who will support both the participants and peer researchers after interviews. Also, the research team will employ the CSO's branding, instead of ONS branding, on safeguarding materials to alleviate any strong 'government presence', which the research team believes will help interviewees and interviewers feel more comfortable.
- 4.6 The Committee recommended that the project's risk assessment should be drafted with the involvement of people in the Roma community. The research team confirmed that they have been meeting, and will continue to meet, with representatives from the CSOs, members from the Roma community and

academics who work on studies of Roma people. They said they will soon meet with these stakeholders and will gain input from them on the ethical risks of their proposed research.

- 4.7 The research team spoke about how they will check the alignment of the supplier's safeguarding policy with the ONS' policy. If there are differences, the research team will ask the supplier to update their policy. In addition, the supplier will support peer researchers throughout the project's process, and peer researchers will receive safeguarding training from the ONS which will be based on the 'Recognise, Report, Refer, Record' principles. The researchers confirmed that the participants' information sheet will make clear that confidentiality may need to be broken if risk of harm is identified.
- i. The Committee lauded these activities from a policy perspective; however, recommended more specificity in, for example, the guidance for peer researchers on how to identify and deal with scenarios where there is a risk of trafficking. The research team said they will request this be a part of the training delivered to peer researchers. Also, the peer researchers and participants will have access to a list of relevant support organisations specific to their respective localities.
  - ii. The research team informed the Committee that they have built in time within the project for training peer researchers and iterating their approach so that they can assure the quality of all peer researchers.
- 4.8 The Committee raised further points for discussion:
- i. The question of what the research team have learnt from ethical issues raised in their previous similar research of Gypsy and Traveller communities, or other similar studies the ONS has done. The research team responded that they are including young people in the present Roma study because of feedback from their Gypsy and Traveller study. The researchers informed that they will be applying lessons they have learnt on who is considered the 'gatekeeper' of a young research participant and how to facilitate young people to share more critical views about their educational experience.
  - ii. The importance of including young people in the study who might have been excluded from traditional education. Therefore, the Committee emphasised to the research team not to rely solely on schools for participant recruitment.
- 4.9 The research team sought guidance on the protocols for storing participants' consent forms.
- 4.10 **ACTION:** Mr Rhys Nadin (ONS) will support the research team, outside of the NSDEC meeting, on how to correctly handle and store consent forms.
- 4.11 The Committee commended the research team's innovative and socially relevant work, and wished them luck.

## **5. NSDEC operations considerations (NSDEC(24)24, NSDEC(24)25, NSDEC(24)26)**

- 5.1 The Chair welcomed the Committee to voice their opinions about the replenishment of NSDEC members (NSDEC(24)24).
- 5.2 The Committee discussed the following points:

- i. Members served on the Committee since its inception noted that, while it was not their intention to leave, they recommend their being replaced within a year.
  - ii. Any future members should be inducted via a fair and open recruitment process. For recruitment of new lay members, there should be open advertisements.
  - iii. The importance of inducting new members with knowledge of medical ethics, social media, and artificial intelligence (AI), respectively.
  - iv. The working patterns of people will affect who can be recruited to the Committee. For example, if the Committee seek working people as new members, they may only be available in evenings for meetings.
  - v. There might be benefit in seeking new members that have expertise in the ethics of linked data and survey response rates, respectively.
- 5.3 **ACTION:** Secretariat will conduct a 'deep dive' of previous NSDEC members to find which knowledge bases the Committee could benefit from. Secretariat will present their 'deep dive' to the Committee at a future meeting.
- 5.4 **ACTION:** Mr Nikhil Harsiani to find out details of the Statistical Assembly (discussed in 2.6.i, above), and communicate this to the Committee.
- 5.5 The Committee discussed how NSDEC meetings should logistically be conducted in future (NSDEC(24)25).
- 5.6 The Committee raised the following points:
- i. There are benefits of meeting in person, especially if new members are recruited. The financial cost of meeting in person once every 12 or 18 months can be justified.
  - ii. Recruitment of new members should, ideally, not just be of people who are based in London.
- 5.7 The Committee agreed that a 'hybrid approach' should be adopted for NSDEC, where most meetings are conducted 'online' but once every 12 or 18 months, the Committee meet in-person at a UKSA office location.
- 5.8 The Committee reviewed elements of the Terms of Reference (ToR) (NSDEC(24)26).
- 5.9 The Committee agreed that the quorum does not need changing.
- 5.10 Around the roles and responsibilities of NSDEC, the Committee discussed:
- i. The ToR may need updating to reflect that it is not necessarily the role of the Committee to ensure research teams are complying with their respective local data security protocols. The ToR should include that when projects come to the Committee for review, the Committee assume the researchers' compliance with data security procedures.
  - ii. The possibility of NSDEC conducting a review, annually, into public perception of use of publicly-held data. This would inform the Committee on how well-justified the 'public views' component of project applications to NSDEC are.

## 6. Data Ethics Compliance Reviews Update (NSDEC(24)27)

- 6.1 Mr Rhys Nadin from the UKSA presented on this item. Mr Nadin explained the reasons for not having presented a Data Ethics Compliance Review in 2024 so far. This was largely due to lack of resourcing in the Centre for Applied Data Ethics (CADE) team. However, this team recently gained a team member, and recruitment for new resource will happen in the next few months.
- 6.2 Mr Nadin introduced Mr Edward Bextor (UKSA), who will take forward these compliance reviews for NSDEC.
- 6.3 The Committee broadly supported the resumption of compliance reviews, and noted their importance to the running of an effective NSDEC.
- 6.4 **ACTION:** Mr Rhys Nadin and Mr Edward Bextor to present a Data Ethics Compliance Review at the next NSDEC meeting (October 2024).

## 7. Any other business (AOB)

- 7.1 Dr Pamela Calderon Ambrossen informed the Committee about work CADE is doing. This involves updating the [UKSA's ethics self-assessment tool](#), engaging with organisations such as ADRUK, and developing publicly-available guidance for researchers on the process of applying to NSDEC (via correspondence and/or in a meeting).
- 7.2 The Chair thanked the Committee for their time and work.
- 7.3 The Committee will next meet on 23 October, 2024.