

# National Statistician's Data Ethics Advisory Committee Minute

Wednesday, 23 October 2024  
via video conference

## Present

### Members

Ms Helen Boaden (Chair)  
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 Stephanie Jacobs, UKSA

### In attendance

Mr Edward Bextor (for item 5)  
Mr Andrew Boyd, University of Bristol (for item 2)  
Ms Esta Clark, National Records of Scotland (for item 3)  
Ms Caroline Ellis, National Records of Scotland (for item 3)  
Dr Onyinye Ezeyi, ONS (for item 4)  
Ms Kerry Miller, ONS (for item 4)  
Ms Izzy Millward, ONS (for item 2)  
Mr Uche Okoro, National Records of Scotland (for item 3)  
Mr Alex Pritchard, National Records of Scotland (for item 3)  
Dr Peter Tammes, ONS (for item 4)  
Dr Emma Turner, University of Bristol (for item 2)  
Mr Sion Ward, ONS (observing, for item 2)

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

1.1 Members of the Committee approved the minutes from the 23 July 2024 meeting, with one amendment requested.

**1.2 ACTION: Mr Nikhil Harsiani to make the amendment to the July 2024 minutes, and recirculate to the Committee for their approval.**

1.3 The Secretariat updated the Committee with progress on actions from the 23 July 2024 meeting. All actions were completed or in progress.

1.4 The Chair informed the Committee that, upon instruction from the National Statistician, minutes for each NSDEC meeting should be sent to the Chair within 10 working days of the meeting, where possible.

- 1.5 Given Ms Nisbet's need to leave the meeting before item 6, the Chair brought forward the discussion about NSDEC membership (item 6) to be covered before item 2 began.
- 1.6 The Chair informed the Committee that, as a result of the [independent review of the UK Statistics Authority \(UKSA\)](#) conducted by Professor Denise Lievesley in early 2024, the National Statistician has instructed a standardised approach to recruitment of new members of his advisory groups (of which NSDEC is one). This approach involves formally advertising on the UKSA website for Committee vacancies, and appointing new members through open and fair competition. The Chair said this is the approach NSDEC will take, and that she and NSDEC Secretariat will shortly meet with the UKSA Head of Secretariat to decide details.
- 1.7 ACTION: The Chair, Mr Nikhil Harsiani and Mr Rhys Nadin to meet with UKSA Secretariat, before the next NSDEC meeting, to confirm methods of NSDEC's upcoming member recruitment.**
- 1.8 The Chair invited the Committee to share their thoughts. In discussion, the Committee raised:
- i. The public appointments system has many lay people linked within. It would be good to use that resource, as new members should comprise not only 'experts'; the Committee should have significant lay representation.
  - ii. That new lay members will need to be interested and be able to cope with the complexity of projects that come to NSDEC.
- 1.9 The Committee discussed from which specialist areas future members should come. They made these points:
- i. That it might be beneficial for NSDEC to, once again, have a member with legal expertise. Also, that someone who has a specialist interest in public acceptability would add value to the Committee.
  - ii. The possibility of having someone who has an academic background in ethics (not just data ethics).
  - iii. The benefits of inducting a member who can relate to the views of young people.
  - iv. The relative importance of recruiting a member who has expertise in the use of artificial intelligence (AI).
- 1.10 The Committee noticed that some NSDEC applications and papers have included esoteric text about, for example, ethics theory. The Committee recommended CADE advise researchers to use straightforward language, where possible, when drafting meeting papers and applications.

## **2. Linking Longitudinal Population Studies to HM Revenue and Customs (HMRC) and Department for Work and Pensions (DWP) (NSDEC(24)31)**

- 2.1 Ms Izzy Millward (from the ONS), Mr Andrew Boyd and Dr Emma Turner (both from the University of Bristol) presented on this item.
- 2.2 Mr Andrew Boyd explained the background of running consented longitudinal studies. He outlined the benefits of the UK Longitudinal Linkage Collaboration (UK LLC). These include enabling studies to move from physically sharing research around the world to a 5-safes approach, allowing researchers to pool diverse study populations, and improves cost efficiency.
- 2.3 The Committee acknowledged the benefits to research equity and public trust in longitudinal studies that UK LLC represents. They were broadly in support of this project.

2.4 In discussion, the following points were made:

- i. The research team had shown due consideration to the issues of ongoing consent during studies, and of obtaining public acceptability, in their paper.
- ii. The research team should be commended on their careful approach to public confidence and trust.
- iii. The Committee questioned what proportion of people object to their data being linked in these studies. The research team informed that there is evidence that some data linkages (e.g., health and education) have higher consent rates than economic linkages (i.e., those connected to this application). An example was given for the Avon Longitudinal Study of Parents and Children cohort, which had a ~93% consent rate for health and education linkage, but a consent rate of around 85% for employment, earnings and welfare linkages.
- iv. The Committee wanted reassurance that the commitments made by the team around consent and processing records would be fulfilled. The research team said they would be in line with their initial commitment. They will be transparent in the processes they have taken in the data linkage, and a report will be made publicly available.
- v. The research team are piloting a 'citizen panel', which comprises participants from contributing longitudinal studies and diverse members of the population. These citizens will form a panel to provide a retrospective assessment on whether the projects have delivered the public benefit which were anticipated. The research team hope this pilot, if successful, will drive long-term continuous improvement in how UK LLC assess research applications and how they communicate public benefit.
- vi. The Committee asked for assurance that the funders of this project (for example, the Economic and Social Research Council, ESRC) understand that studies like this have long-term implications, and should not renege on their commitment to the project. The research team confirmed that the funders are investing in UK LLC as a strategic infrastructure asset, which provides some assurance in the long-term support.

2.5 The Committee thanked the research team for their time and work.

### **3. Future of Population Statistics (FoPS) (NSDEC(24)32)**

- 3.1 Ms Caroline Ellis, Mr Uche Okoro, Mr Alex Pritchard and Ms Esta Clark, all from the National Records of Scotland (NRS) presented on this item. This item was sent to NSDEC as an application for ethical review on 1 October 2024. The Committee took great interest in the programme, and invited the FoPS team to discuss ethical risks at this NSDEC meeting.
- 3.2 The research team addressed some of the feedback NSDEC (via correspondence) had for their project. They also outlined the differences between the admin-based population estimates programmes ongoing for England and Wales (grouped), Scotland, and Northern Ireland, respectively.
- 3.3 The research team spoke of their activities to understand public acceptability. They attended a public panel on 1 October 2024. The public panel expressed that for the most part they trusted NRS, generally supported sharing of data and linkage of administrative datasets. The public panel expressed interest in how FoPS related to the decennial census, and how administrative datasets

are being used across the UK. The public panel recommended that NRS clearly communicate the public benefit to their use and linkage of administrative datasets.

- 3.4 From the public panel (see 3.3, above), NRS have adapted their approach by taking on the panel's suggestions about communication and limiting FoPS to census-based questions and income-based questions for the initial phase of their programme.
- 3.5 In their feedback (via correspondence) to NRS' 1 October 2024 application, the Committee raised the issue of how to deal with people who 'don't want to be included' in admin-based estimates. The research team emphasised that admin-based NRS statistics will not and cannot be used to 'target' policy programmes (such as eligibility for benefits) to individuals; the data is used for the production of statistics and research only. They stated that a disadvantage to producing statistics without full population coverage can lead to bias in the results.
- 3.6 NRS works with their suppliers to quality assure privacy notices, and have learnt from Research Data Scotland on public acceptability. On the issue of public confidence, especially when some members of the public do not support the programme, the Committee raised:
  - i. That NRS should consider getting views of the public, not just in the context of acceptability of using one's own data, but also of people in whose interests they are vested (for example, a neighbour or family member). 'Public opinion' and the opinion of individuals with regard to those they are interested in may differ.
  - ii. That there is, indeed, a risk of increased bias in results by 'allowing' some groups not to be included. However, if NRS attempt to circumvent this bias by including said groups anyway, this risks further alienating that community. The FoPS team acknowledged this point, and that a solution to this is currently unclear. The FoPS team will think about how to adapt their user consultation to find public views of this risk.
- 3.7 The research team explained details of their proposed statistical disclosure control (SDC) procedures. Their SDC methods are based on methods adopted by the ONS, Northern Ireland Statistics and Research Agency (NISRA), and NRS during their most recent censuses, respectively. The small cell counts check will be a final check after other SDC methods have been employed. The SDC methods for the Scottish census in 2022 was externally reviewed. The Committee raised:
  - i. That they felt that the SDC approach adequately minimises the risk to disclosure, and that NRS had given due consideration to how to mitigate the risk.
  - ii. That developing technology could allow for people identifying individuals in aggregate estimates of small areas, and that NRS should be agile in their safeguarding to address this. The FoPS team acknowledged this point, and said that they continue to work with topic experts on this.
  - iii. That NRS should understand not just how people use administrative-based estimates they produce, but the means by which they can link these estimates with other data (for instance, commercial data). The FoPS team acknowledged that this issue affects statistics agencies around the world. They confirmed that the SDC methods for the 2022 Scottish census went through a comprehensive sign-off process, and they will apply this to

FoPS. They are committed to communicating to the public about which protections apply to their data, both in aggregated and disaggregated forms.

- 3.8 The NRS team stated that the approach they detailed in their application for ethical review was comprehensive, and will likely take until the end of 2026 to implement. Compared to the approach in their application, they will likely make two changes going forward:
- i. They will narrow the scope of which census questions they will include to 4 questions; and
  - ii. They will introduce additional datasets.
- 3.9 NRS have committed to laying a general report before the Scottish Parliament by the end of 2024 which will contain lessons learnt, for example regarding response rates, from Scotland's census in 2022.
- 3.10 The Committee agreed that FoPS' scope should be limited to the same questions of the 2022 Scottish census. They recommended that NRS align, as far as possible, with the outputs of admin-based estimates that the ONS and NISRA publish, to increase comparability. This will also help understand demographic makeup of the UK as a whole.
- 3.11 NSDEC confirmed that NRS can state to their data suppliers that FoPS has undergone ethical review.
- 3.12 The Committee thanked the FoPS team for their work and time.

#### **4. International migrants' utilisation of NHS services (NSDEC(24)33)**

- 4.1 Dr Onyinye Ezeyi, Dr Peter Tammes and Ms Kerry Miller from the ONS presented on this item. A similar project went to NSDEC in 2019 (NSDEC(19)02), but this project did not use Home Office data, whereas the extant project does. The 2019 application was of a feasibility study.
- 4.2 The research team explained the impetus for this work, and gave details of which datasets they seek to access and link. They explained that they will be working with data linkage experts in the ONS to ensure quality, and if it is found that the project's linkage is not of sufficient quality, the analysis will not be published. This research is proposed as a one-off analysis of 2023 and 2024 data as a starting point, with a view to be fed in into the ONS' wider longitudinal population dataset (LPD).
- 4.3 The research team acknowledged the main ethical risks they have identified: the risk of gaps in data, the use of sensitive and personal information, and the potential impacts to vulnerable groups. The Committee agreed that these are risks, and the project as a whole is highly sensitive.
- 4.4 The Committee expressed support for the research team's goals and agreed the public should understand how migrants access healthcare services in this country. However, as some issues involving migration tend to be highly sensitive, and migrant communities can be the subject of suspicion and even attack, the Committee did not feel the ethical risks were sufficiently mitigated in the current proposal. The ethical risks in particular are:
- i. That there was not sufficient information about how the final study would be communicated to the public and what measures would be in place to preserve the integrity of the research. In response, the research team said they intended to work closely with the ONS' Media Relations Office (MRO) who would communicate the limitations of the

research and monitor articles which quote the research. There is a precedent for the UKSA 'stepping in' when their statistics are significantly misused, and the research team stated that this mechanism could be applied here, if necessary.

- ii. That the results of this research may deter certain groups from accessing public service, particularly healthcare services. The research team appreciated this risk, yet emphasised that their analysis may illuminate existent inequalities in access to services, and assist in the monitoring of such inequalities.
  - iii. That the proposed consultation of migrant representative groups is not yet broad or thorough enough. The research team acknowledged the current limitations in their consultation, and they may work with third sector organisations to expand the migrant groups they can reach.
- 4.5 The Committee recommended that the research team continue to demonstrate the public good of this project.
- 4.6 The Committee recommended that the current project title should be altered to more faithfully represent that the research proposes to link healthcare datasets beyond just from the NHS.
- 4.7 ACTION: The research team will change the project title to more accurately reflect the project's aims.**
- 4.8 The Committee reminded the research team that the data should be used only for statistical or research purposes.
- 4.9 Mr Stephen Balchin, who works in the Department of Health and Social Care (DHSC), confirmed that he has not seen this research other than in the capacity of NSDEC, and that this research is not within his remit per his work at DHSC.
- 4.10 The Committee questioned the validity of the claim that this research could better enable NHS services in their allocation of resources. This is, partly, because some local NHS services already have good stratified understanding of the populations they serve.
- 4.11 ACTION: The Committee requested that the research team submit a revised application for ethical review to NSDEC (via correspondence) which addresses the feedback made in this meeting.**
- 4.12 The Committee commended the research team for their work, and are looking forward to seeing a redrafted ethics application.

## **5. Data Ethics Self-Assessment Compliance Checks (NSDEC(24)34)**

- 5.1 Mr Edward Bextor presented this report. This item was originally intended for presentation at the 23 July 2024 meeting, but was postponed to this meeting.
- 5.2 Mr Bextor ran through the methodology employed to conduct compliance checks against each UKSA ethical principle and sub-principles. Mr Bextor selected four projects' ethics self-assessments, and assessed how compliant each project was with their respective justifications against the principles. This compliance check is different to previous reviews, which assessed compliance of projects against NSDEC recommendations.
- 5.3 Mr Bextor informed that a key finding of his report was that projects often do not re-engage with the Centre for Applied Data Ethics (CADE) when there is a change in their research methodology. While these did not seem to be significant changes, Mr Bextor still recommended that projects update CADE regularly.

- 5.4 Mr Bextor also recommended that CADE advise research teams to update them if the timeline of their project changes. This is to ensure that a project remains in the public good if their outputs are, for example, significantly delayed.
- 5.5 The Committee recognised the importance of the compliance checks and were supportive of the work. They raised the following points in discussion:
- i. That, in addition to checking the projects are compliant with the recommendations CADE make, it might be prudent to review if projects' outcomes (and the putative public benefits) were in line with what they proposed in their ethics self-assessments. Mr Bextor responded that his compliance check did review, to some extent, the benefits to project outcomes upon receiving ethical advice from CADE; however, acknowledged there is value in conducting further review.
  - ii. Recommendations made by CADE and/or NSDEC might result in research teams having to put resource into making changes to their work. The Committee suggested an exercise whereby research teams feed back which CADE and/or NSDEC recommendations added value to their project outcomes, and which may have placed unnecessary additional burden on teams.

**5.6 ACTION: Mr Bextor and Mr Rhys Nadin to come back to NSDEC with a report into how NSDEC's recommendations have influenced project outcomes.**

5.7 The Committee thanked Mr Bextor for his time and work.

## **6. Any other business (AOB)**

- 6.1 Mr Nikhil Harsiani informed the Committee about work CADE is doing. This involves updating the [UKSA's ethics self-assessment tool](#), presenting to international statistical agencies, and engaging directly with trusted research environments (TREs) and researchers at national-level events.
- 6.2 Mr Rhys Nadin introduced Ms Stephanie Jacobs, who was appointed Head of Data Ethics and Research Accreditation at the UKSA.
- 6.3 ACTION: NSDEC Secretariat to ensure all NSDEC members are invited to the UK Statistics Assembly of 22 January 2025.**
- 6.4 The Chair thanked the Committee for their time and contributions.
- 6.5 The Committee will next meet on 23 January, 2025.