

National Statistician's Data Ethics Advisory Committee Minute

Tuesday, 18th October 2022
Meeting held via video conference

Present

Members

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

UK Statistics Authority

Matt Short
Tia-Mae Surtees
Simon Whitworth

Office for National Statistics

Alex Buckley (for item 2)
Shona Horter (for item 2 and 3)
Amber Jordan (for item 3)
Tara McNeill (for item 4)
Rachel Mullis (for item 4)
Johanna Pollard (for item 4)
Maria Quattri (for item 4)
Chris Shine (for item 4)
Klaudia Rzepnicka (for item 5)
Emma Sharland (for item 5)
Isobel Ward (for item 5)
Jonny Tinsley (for item 6)
Carolyn Watson (for item 6)

Apologies

Marion Oswald
Vanessa Cuthill

1. **Minutes and matters arising from the previous meeting and correspondence**
 - 1.1 Members approved the minutes from the previous meeting and correspondence.
 - 1.2 Tia-Mae Surtees updated the Committee with progress on actions from the July 2022 meeting, and correspondence in the interim period. All actions were completed or in progress.
 - 1.3 **Action – The Secretariat to include a follow-up of the actions from the previous meeting in minutes from the next meeting (Appendix 1).**

2. Qualitative research on the lived experiences of domestic abuse survivors in temporary 'safe' accommodation in England (NSDEC(22)14)

2.1 Alex Buckley and Shona Horter from the Centre for Equalities and Inclusion, ONS, presented this item. This project aims to fill data and evidence gaps on the experiences of domestic abuse survivors in temporary 'safe' accommodation settings, to better understand their journeys and needs. Interventions Alliance have been commissioned by the ONS to carry out in-depth interviews with domestic abuse survivors and the ONS will then thematically analyse results.

2.2 The following points were raised in the discussion that followed:

- I. The public benefit needed to be strengthened to include how the ONS would involve key stakeholders in this research to help ensure the outputs influenced policy in a way that would improve lives.
- II. The Committee were informed that the selected supplier was experienced in trauma informed research design and delivery.
- III. The Committee advised that the ONS develop a policy to set out their approach to disclosure control and archiving for qualitative research outputs. This should be shared with the NSDEC at a future meeting.

2.3 **Action – The research team to work with the secretariat to strengthen the public benefit part of the application in line with NSDEC's comments.**

2.4 **Action – The research team to share interview consent forms and the Secretariat to ensure that these comply with the UK Statistics Authority's ethical principles.**

2.5 **Action – The Secretariat to work with ONS qualitative teams on policies around statistical disclosure controls and data archiving for qualitative projects. This will be shared with NSDEC at a future meeting.**

3. Qualitative research into the lived experiences of asylum-seeking, refugee and migrant young people in the UK (NSDEC(22)15)

3.1 Amber Jordan and Shona Horter from the Centre for Equalities and Inclusion, ONS, presented this item. This project seeks to fill data and evidence gaps on the needs and priorities of young asylum-seekers, refugees and migrants through in-depth interviews on wellbeing and engagement with services, including health, housing, education and leisure.

3.2 The following points were raised in the discussion that followed:

- I. The different groups of young people who would be involved in the research were discussed. The limitations of the sample size in terms of involving different groups were recognised and need to be communicated when results are presented.
- II. It was noted that the interviews were potentially wide ranging, and the research team would need to be focused to be able to draw valid conclusions together.
- III. The importance of safeguards for the peer interviewers was discussed. The research team should check with the supplier's safeguarding policies and share with the Secretariat.
- IV. As with the previous item, the need for an ONS policy setting out their approach to disclosure control and archiving for qualitative research outputs is relevant for this research.

3.3 **Action – The research team to ensure that any bias introduced to the analysis through the small sample is communicated in research outputs.**

3.4 **Action – The research team to seek information from the research supplier about safeguarding and provide assurances to the Secretariat.**

4. **Experiences of non-household populations (NHPs) who access Improving Access to Psychological Therapies (IAPT) services - beginning with the experiences of prisoners who access IAPT (NSDEC(22)16)**

4.1 Maria Quattri, from the ONS Integrated Data Analysis team presented this item. This project uses the IAPT administrative dataset to explore the experiences of non-household populations (NHPs), beginning with the experiences of prisoners in IAPT, to address data gaps for hard-to-reach groups to improve the inclusivity of data and evidence on these populations.

4.2 The following points were raised in the discussion:

- I. Given some of the data quality issues, the Committee advised the ONS Integrated Data Analysis team carry out a comprehensive data quality assessment to understand the feasibility of this work.
- II. The Committee advised that the implications of any data quality issues on the potential for this work to impact policy should be considered and communicated in the presentation of any outputs.
- III. It was suggested that the ONS should do more to engage other government departments on this work to maximise the potential impact of this research in terms of achieving public good.

4.3 The Committee agreed that the research team should complete the UK Statistics Authority ethics self-assessment tool for the other proposed Non-Household Population groups and send these to the Secretariat for review.

4.4 **Action – The research team to carry out a data quality assessment and provide assurances to the Secretariat about the feasibility of this research.**

4.5 **Action – The research team to complete self-assessments for projects on the other non-household populations and provide these to the Secretariat for review.**

5. **Risk factors associated with self-harm and suicide in adults and children (NSDEC(22)17)**

5.1 Emma Sharland, Isobel Ward and Klaudia Rzepnicka from the Health Analysis and Life Events Division, ONS, presented this item. This project will link 2011 Census to ONS mortality data and Hospital Episode Statistics to identify individuals admitted to hospital as a result of self-harm or those who have died as a result of suicide. It will investigate multiple risk factors and their association with self-harm and suicide, beginning with bereavement.

5.2 It was suggested that the presentation of the results should make clear that the approach to identifying household relationships has limitations and may not capture the complexity of relationships.

5.3 The Committee were happy to advise on the specifics disclosed in the research proposal but were unable to comment on other potential research in this area. The Committee agreed that the research team should return to the Secretariat with self-assessments for the projects on the other risk factors.

5.4 **Action – The research team to complete self-assessments for projects on the other risk factors and provide these to the Secretariat for oversight.**

6. Future plans for the ONS Public Health Data Asset and Longitudinal linkage and analysis of Census data (NSDEC(22)20)

- 6.1 Jonny Tinsley from the Health and Life Events Division, ONS, presented this item. The paper considered the public good and ethical concerns regarding:
- I. Developing the 'Public Health Data Asset' to include Census 2021 data, and for this to be used for the production of new health statistics, beyond the COVID arena.
 - II. The longitudinal linkage of Census 2011 and Census 2021 data to support new statistics.
- 6.2 The NSDEC recommended that projects using the Public Health Data Asset use the UK Statistics Authority's ethics self-assessment tool and that future projects come to the Committee, subject to the risks disclosed within the self-assessment.
- 6.3 Given the sensitivities of some of the health data in the Public Health Data Asset, the secretariat was asked to review projects using a cautious approach.
- 6.4 It was recognised that the Public Health Data Asset is a large scale, dynamic, linked data asset holding a wide variety of sensitive data on many people. The opportunities this presents to produce innovative statistics for the public good were recognised.
- 6.5 The following points were raised in the discussion:
- I. The NSDEC stated the importance of the ONS making sure they took the public along with them as this work progresses and want assurance that the public are aware and supportive of the way in which the ONS is using this data.
 - II. The NSDEC asked for the ONS to present their work on public engagement and public acceptability at the next NSDEC meeting.
 - III. The NSDEC also wanted assurance that the ONS's security policies and procedures are secure enough to ensure this data asset is kept secure. The NSDEC asked for the ONS to present its work in this area at the next NSDEC meeting.
- 6.6 **Action – The Secretariat to ensure that health data projects should come to NSDEC based on the information in the ethics self-assessment tool. The Secretariat are to adopt a cautious approach in reviewing these applications.**
- 6.7 **Action – The ONS to present their work on public engagement and public acceptability at the next NSDEC meeting.**
- 6.8 **Action – The ONS to present how they keep large scale dynamic linked data assets secure at the next NSDEC meeting.**

7. Any Other Business

- 7.1 The NSDEC discussed the data ethics compliance review of the *Schools Infection Survey 2* and *Research on homeless mortality among St Mungo's clients*. These reviews confirmed that the research team had taken the advice of the Committee and implemented all the Committee's comments.
- 7.2 The Committee thanked the UKSA/ONS's Data Governance, Legislation and Policy team for these reviews and said they gave good assurance that the advice of the Committee was being followed.

- 7.3 The Committee raised that common ethical questions are shared across individual projects that they currently advise on, and emphasised the benefit of addressing these questions together and from a strategic level.
- 7.4 It was suggested that it was important that, for public good to be achieved, statistics need to have impact and inform policy in a way which has a positive impact in people's lives. The committee commented that it is not always clear to them how the ONS ensure that this happens. To learn more about this, the NSDEC requested that as part of the next committee meeting to provide scrutiny and assurance, the ONS provide presentations on public engagement, public acceptability, data security and the public good, and the steps the ONS take to ensure their research and statistics have policy impact for the public good.
- 7.5 The Committee discussed dates for the planned workshop, which will be incorporated into the next NSDEC meeting, and the Committee's request for the above presentations. It was agreed that this will be held in the new year. Options for dates will be provided in due course.
- 7.6 **Action – The ONS to present to the NSDEC the steps they take to ensure their statistics have policy impact.**
- 7.7 **Action – The Secretariat to investigate how strategic questions can be made visible to and addressed by the NSDEC.**

Appendix 1 – Action Log (July NSDEC meeting and correspondence)

NSDEC 5th July:

Project	Action	Complete?	Notes
ONS Longitudinal Study	The Secretariat to include security as a topic for the workshop to be held later in the year.	Yes	A presentation will be delivered by the Security team on how ONS maintain the security of data, to give the Committee assurance on the security measures we have in place.
ONS Longitudinal Study	The Secretariat to review the NSDEC application form to better capture ethical consent and the ability to opt-out.	Yes	Has been discussed within the team and will be implemented in the application form.
The 2023 Recommendation	The research team to ensure that CADE (Centre for Applied Data Ethics) is engaged to inform the ethical appropriateness of the 2023 Recommendation.	Ongoing	CADE has been provided with a list of projects attached to the 2023 recommendation and are working with the research team to ensure ethical compliance across all areas.
2021 Census Data Asset: Proof of Concept	The research team to continue to work with CADE and return to NSDEC as this develops.	Ongoing	CADE are regularly meeting with the research team to develop this work.
ONS Survey Strategy	CADE to be involved to help construct the ethics section of the playbook.	Yes	CADE have provided content on data ethics to be included in the Surveys Playbook.
Qualitative research related to redesigning the Crime Survey for England and Wales (CSEW) for mixed mode and longitudinal collection - Screener and Victimization modules	The research team to provide the Secretariat with assurances to the points raised in section 6.5.	Yes	Responses and assurances received from the research team.
Harmonisation	No actions.	-	-

NSDEC Correspondence 26th July:

Project	Action	Complete?	Notes
Research to support the development of survey questions on gang-related crime and gang membership for the Crime Survey for England and Wales (CSEW)	The research team to provide responses and assurances to the Secretariat and share materials for the interviews once available.	Yes	Responses and assurances received from the research team.
Cognitive Testing of Survey Questions to Estimate the Historic Prevalence of Child Abuse.	The research team to provide responses and assurances to the Secretariat.	Yes	Responses and assurances received from the research team.