

## National Statistician's Data Ethics Advisory Committee

### Correspondence Minute

Papers reviewed via correspondence between November 2020 and January 2021

**1. Addendum to previous paper: To determine the population-level relative risk of hospitalisation or death that COVID-19 presents to people with different socio-demographic characteristics and co-morbidities. NSDEC (20)12.**

1.1 This paper was submitted by Jonny Tinsley from the ONS Health Analysis and Pandemic Insights Division. The paper presented an addendum to a previous project taken to NSDEC in June 2020. This outlined two developments. First, the paper asked the Committee to approve the linkage of data from the ONS COVID-19 Infection Study (CIS), and also Test and Trace (T&T) data from the Department for Health and Social Care (DHSC), to the main risk factor research. The second considered additional research on long COVID and mental health, which would use the same linked data sources as the main risk factor work.

1.2 The Committee acknowledged the importance of this research and could see the public good that would be gained through greater knowledge of the effects of COVID-19. The Committee raised the following points for the researchers to consider:

- i. The Committee recommend that the researchers continue to assess the ethical implications of this linkage work throughout the project's lifecycle to continue to consider and minimise any potential ethical risks. The Committee request an updated proposal from the research team as this work iterates into new phases.
- ii. The Committee advise that the researchers remain mindful of their obligations under data protection legislation. Namely, the researchers should ensure that the data that is collected and added to the linked dataset as part of this study is proportionate and has a specific research and statistical use. Furthermore, the Committee reminded the researchers about their requirement to destruct the linked data set once it is no longer needed.
- iii. The Committee wanted further assurance about the proportionality of the use of mental health data, which would not be collected with consent as the lawful basis for processing.
- iv. The Committee requested that specific uses of the dataset relating to mental health use the UKSA's ethical framework to assess the ethical risks of their work and seek independent advice from NSDEC where necessary, given the sensitive nature of the data and the potentially vulnerable participants involved.

1.3 The Committee were supportive of the project subject to the points raised in section 1.2 being addressed, clarified and confirmed.

1.4 **Action: Jonny Tinsley to provide responses to the secretariat.**

## 2 **Census 2021, England and Wales: Recommendation on approach to guidance for variations of sex characteristics (VSC)/intersex.**

2.1 This paper was submitted by Michelle Monkman and Andrew Nash from the ONS Public Policy Analysis Division. The paper outlined two potential approaches regarding whether to include guidance on the sex question and/or the gender identity question for individuals that have VSC/ are intersex in the 2021 Census. Therefore, this paper sought ethical advice as to whether advice should be provided to participants answering this question.

2.2 Three separate ethical considerations were explained to aid the Committee in reaching a conclusion. These included:

- i. providing personal information;
- ii. impact on the new gender identity data collected, including potential conflation of sex (VSC/intersex); and,
- iii. gender identity, (trans) data and the quality of data.

2.3 The Committee were supportive of the recommendation to not provide guidance in the Census on the recording of VSC/Intersex and acknowledged the extensive engagement with the relevant communities on this proposal.

2.4 The Committee

- i. Suggested that the researchers provide an explanation of this decision to the stakeholders who had an expectation of guidance being provided, and;
- ii. Asked for clarification why the free text box could only be included in the gender section, and not the sex question.

2.5 The Committee supported the recommendation of no guidance subject to the researchers addressing, or confirming points raised in section 2.4.

2.6 **Action: Michelle Monkman and Andrew Nash to provide responses to the secretariat.**

## 3. **Study to assess the algorithmic feasibility of COVID-19 specific vocal biomarker detection. NSDEC (21)01**

3.1 This paper was submitted by Joe Packham from the Joint Biosecurity Centre (JBC) requesting data ethics advice on a pilot feasibility study. This paper presented a pilot study to assess the algorithmic feasibility of screening for COVID-19 using vocal biomarkers from audio data. The Joint Biosecurity Centre would partner with testing sites to collect audio recordings, linking to COVID-19 test results to reconstruct, validate and refine existing algorithms from academic and commercial parties that screen for COVID-19.

3.2 The importance and potential value of the project was acknowledged by the Committee. The Committee raised the following points as advice for potential consideration and action:

- i. The Committee strongly recommend that the researchers seek consideration from NHS REC to ensure ethical scrutiny is received from a medical perspective.

- ii. It was suggested that the researchers should consider the potential ill health of the participants and thus make the process of testing the algorithm and providing informed consent as straight forward, efficient and easy as possible.
  - iii. The Committee made the point about the issue of exclusion of some people without access to a car and a mobile phone and recommended that project outputs are transparent about any such limitations.
  - iv. In addition, the Committee advised that all forms should be available in more than one language to ensure certain populations are not excluded from this study.
  - v. The Committee wanted further clarification on the process of de-identifying participants and their responses; and,
  - vi. The importance of a public communications strategy was stressed to ensure that the purpose and limitations of this study are clearly communicated to ensure the validity and public acceptability of the project. Furthermore, it must be made clear that study outputs are owned by the academic and statistical community to avoid any politicising of the results.
- 3.3 In response to the feedback, JBC provided evidence of a favourable outcome from NHS REC and updated the Participant Information to accommodate the points raised by the Committee.
- 3.4 The Committee were supportive of this pilot research project and advised that any further operational use or deployment of a related algorithm should go to a medical ethics committee for further ethical scrutiny and consideration.