

## National Statistician's Data Ethics Advisory Committee

### Correspondence Minute

Papers reviewed via correspondence, June 2021.

1. **An update on phase one of the project 'Investigating the risk factors and inequalities associated with infant mortality'. NSDEC(20)03**
  - 1.1 This paper informed the NSDEC on the progress and minor changes to the wider study protocol for the project investigating the risk factors and inequalities associated with infant mortality, led by the ONS. This informed the Committee that the first phase of this linkage is now being made available in the ONS SRS for wider research use, under the Digital Economy Act.
  - 1.2 The NSDEC were informed that they should expect a more comprehensive update on this project as the ONS looks to include the linkage of further health records to this project in the future.
  - 1.3 The update was acknowledged by the Committee.
2. **Update regarding: Study to assess the algorithmic feasibility of COVID-19 specific vocal biomarker detection. NSDEC(21)01**
  - 2.1 This update paper set out the progress and four minor changes to the wider study protocol of the study to assess the algorithmic feasibility of COVID-19 specific vocal biomarker detection, led by the Joint Biosecurity Centre. This research has moved into Phase B of the research feasibility study that NSDEC reviewed in January, with minor changes to the structure of Phase B of the study set out throughout the paper.
  - 2.2 The Committee were informed that these updates had been approved by NHS REC.
  - 2.3 The following points were raised throughout the discussion:
    - i. The research team confirmed that those aged 16 and over had always been in scope of the study and that there was a discrepancy between the original submissions to NHS REC and NSDEC. It was regarded that, pending advice from internal legal teams, those aged 16 and over would be able to read and understand the participant information and privacy notice to participate in the study and there is therefore little reason to exclude this cohort from the study;
    - ii. When an individual is contacted for their participation in this study via their employer, the Committee stressed the need for clear communication to the employee that participation in this study is not mandatory, and could not affect their employment status. The JBC acknowledged the underlying risk, and committed to taking steps to mitigate issues relating to participation confidentiality to ensure this information is provided clearly and accessibly to prospective participants.
    - iii. The Committee asked for further information on the basis on which Phase A had been determined to be successful, to justify the decision to progress this study to Phase B. The researchers confirmed that Phase A successfully piloted the data collection infrastructure for the study but that there are some challenges with collection of good quality audio data. They are developing a data pre-processing pipeline that goes some way towards addressing this to ensure the required samples are obtained within the study's Phase B;

- iv. The Committee noted that recruitment is proposed to be extended to communication via SMS and telephone and queried how informed consent will be assured in these circumstances. The research team confirmed that a link to all online participant information will be provided to prospective participants to inform the provision of consent to participate, and;
- v. The NSDEC questioned what impact the use of lateral flow tests would have on the validity of results, given the recognised issues with the tests' accuracy. The researchers confirmed that lateral flow tests will only be used if deemed necessary, with PCR tests being the preference due to its reputation as a gold standard COVID-19 testing mechanism. Subsequently, if lateral flow tests are used, this would be considered and communicated within the final analysis.

2.4 The NSDEC appreciated and subsequently acknowledged the updates.