National Statistician's Data Ethics Advisory Committee Correspondence Minute

Papers reviewed via correspondence between April 2020 and June 2020

1. COVID-19 Crime Survey telephone operation [NSDEC(20)10]

- 1.1 This paper was submitted by Mr Joseph Traynor from the ONS Public Policy and Analysis Division. The paper outlined the approach being taken by ONS to continue to collect vital crime statistics while face-to-face survey operations are suspended due to the COVID-19 pandemic. In particular, this paper asked the Committee to focus on the need to retain a single question relating to domestic violence on a telephone operated Crime Survey for England and Wales. The paper outlined the steps taken to mitigate against any potential harm to victims of domestic violence of answering a question on domestic violence over the telephone, and provided assurance that the revised survey would continue to be compliant with ONS safeguarding policies.
- 1.2 In light of face-to-face survey operations being suspended due to the COVID-19 pandemic, the Committee recognised the need for ONS to develop a new approach to enable ONS to continue to produce vital crime statistics.
- 1.3 The Committee was supportive of the proposed approach to conduct data collection via telephone interviewing, and acknowledged the clear consideration that had been given to mitigate any additional ethical risks.
- 1.4 The Committee raised the following points for the researchers to consider:
 - The research team should ensure that respondents are offered the same level of information about available support and advice as would be offered to respondents being interviewed face-to-face;
 - ii. Interviewers must make it clear to respondents that they will not be taking any further action to report any instances of domestic abuse, and will only provide the support information referred to above;
 - iii. The researchers should consider the implications that the domestic abuse question suggests a somewhat narrow definition of domestic abuse; and
 - iv. The researchers should ensure that the estimates derived from this new survey are interpreted with caution due to the potential for bias related to changing the mode of the survey.
- 1.5 The Committee approved this proposal, subject to the researchers addressing, or confirming, the points raised in section 1.4 in a revised paper.
- 1.6 Action: Mr Joseph Traynor provide a revised paper to the secretariat.

- 2. 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]
- 2.1 This paper was submitted by Mr Chris White from the ONS Health and Life Events Division. The paper presented a proposal to link census, mortality, hospital activity and primary care data to provide an understanding of differential risks of COVID-19 related mortality and hospitalisation faced by different sections of the population.
- 2.2 The Committee acknowledged the clear public benefit that would result from conducting analysis to further understand the differential risks of COVID-19 related mortality and hospitalisation faced by different sections of the population.
- 2.3 The Committee approved this proposal, subject to the following points being addressed and approved by the secretariat:
 - The research team should clarify that holding the linked dataset in the ONS Data Access Platform means that access to data will be limited to ONS staff;
 - To ensure transparency, the researchers must provide assurance that the research findings will be published in an open and timely manner on the ONS website;
 - iii. To enable appropriate and proportionate interpretation of any models and results, the researchers must ensure that the limitations of all data sources and analysis are clearly documented within all publications;
 - iv. Publications relating to this study should include clear statements of the steps taken to ensure the confidentiality of patient information and sensitive personal data:
 - v. The researchers must provide assurance that they have considered the public's views;
 - vi. The researchers should clearly outline the scope of this research in terms of the project's proposed geographical coverage, and the criteria for calculating "risk of hospitalisation":
 - vii. The researchers should clarify the relevance of including "religion group" as a variable in the analysis, and provide further justification as to why this variable is in the public interest;
 - viii. The researchers should explain the need to establish individuals' non-emigration status; and,
 - ix. The researchers must clarify how long the data linkage will continue and how long the linked dataset will be retained.
- 2.4 The Committee agreed that approval of this proposal is limited to the duration required to produce the outputs specified within the paper. The Committee recommended that the researchers should seek further ethical guidance if they wish to repeat or expand the scope of this work.
- 2.5 Action: Mr Chris White to provide a revised paper to the secretariat.

3. Mental Health of Children and Young People in England, 2020 [NSDEC(20)13]

- 3.1 This application was submitted by Ms Cher Cartwright from NHS Digital, and Mr Timothy Vizard from the ONS. The application presented a proposal to conduct a survey to assess the mental health and wellbeing of children/young people and their parents during the COVID-19 pandemic.
- 3.2 The proposed survey will involve following up participants who took part in the 2017 Mental Health of Children and Young People Survey in England and who provided permission to be re-contacted to participate in future surveys. The primary aims of this follow up survey are to: measure the mental health and wellbeing of 5 to 22 year olds in England; look at how mental health of children and young people has changed since last interview in 2017; and understand how children and young people have been affected by the COVID-19 pandemic (including the impact of school closures).
- 3.3 The Committee acknowledged the importance and timeliness of this project, and approved the project subject to the following points being addressed and approved by the secretariat:
 - The researchers should clearly outline the relationships between the different organisations involved, and ensure that data controller and data processor roles are clearly specified;
 - ii. The researchers should clarify whether the datasets held by NHS and ONS will be anonymised or pseudonymised;
 - iii. The researchers should outline the purpose for two named academics to have access to the pseudonymised dataset, and provide assurance that there are appropriate safeguards in place to maintain the necessary information security and data governance standards;
 - iv. The researchers should explicitly state that data linkage will not occur when individuals have not provided consent for this;
 - v. Given that data will be collected via online questionnaires, the researchers should consider the risks of excluding vulnerable children and young people, as well as those who experience digital exclusion;
 - vi. The researchers should ensure that questions regarding physical attendance at school are framed to account for school term breaks;
 - vii. The researchers should ensure that all communications provide potential participants with a means to authenticate the purpose of the contact;
 - viii. The researchers should consider the risks to sample representativeness and participant verification that arise from the possibility that participants (especially in the older age group) may no longer be resident at the previous known addresses from the 2017 study; and,
 - ix. The researchers should provide assurance that publications and outputs will comply with relevant standards to ensure transparency.
- 3.4 <u>Action: Ms Cher Cartwright and Mr Timothy Vizard to provide an</u> updated application to the secretariat.