

National Statistician's Data Ethics Advisory

Committee Correspondence Minute

Papers reviewed via correspondence, November 2022.

1. COVID-19 research programme: NHS winter pressures extension NSDEC(22)21.

1.1 Outcome – the Committee supported this work subject to assurances to points outlined in section 1.5 being provided to the Secretariat.

1.2 Detail of the project and discussion:

1.3 The NHS and social care are expected to face more severe pressures than normal this winter because of interacting risks driven by COVID-19 and compounded by the cost-of living crisis. These vulnerabilities will be compounded by a surge in influenza and other viral and bacterial diseases over winter, and existing population vulnerabilities to non-communicable diseases exacerbated by poverty, indoor mixing and/or exposure to cold. ONS was commissioned by the DHSC Chief Scientific Advisor and supported by the Chief Medical Officer to produce statistics that support decision making around NHS winter pressures. This includes understanding the size and location of populations at risk, the consequences for physical and mental health including those with long COVID, and the impact that these compound pressures will have on the NHS and social care services.

1.4 To produce these statistics, data from the 2021 Census will be linked to the GPPR data (the pandemic GP data) via NHS number. Additionally, weights will be created to address linkage failure and make the linked data representative of the 2021 Census population. The weights will be calculated as the inverse of the predicted probability of linking, based on a logistic regression model.

1.5 The NSDEC raised the following points via correspondence:

- i The NSDEC requested appropriate communication to the public on the extension in the scope of the research via the ONS and DHSC websites or other similar websites.
- ii The Committee questioned whether it was realistic for the research findings to influence practice in the field this winter.
- iii The NSDEC questioned whether the outputs would reflect the whole of the UK.
- iv The Committee further questioned whether the outputs would be an estimation of the vulnerable population in each region.
- v The Committee queried whether the project involved the Integrated Care Board.
- vi The NSDEC requested clarity on whether other outputs beyond top level statistics on high-risk subgroups will be produced.
- vii The Committee noted that communication with GPs about the extension of the project will be essential.
- viii The NSDEC advised that the proposed predictive model using Family Resource Survey data needs careful communicating & peer review.

- ix The Committee commented that there may be a possibility that the NHS will face similar challenges in 2023 even when COVID becomes less important, as factors such as cost of living crisis and NHS backlog will still be pressures.
- x The Committee suggested that extending the analysis to other covid risk factors that are currently known.

1.6 The NSDEC acknowledged the public good and importance of the project and provided their support after requesting that assurances to their points be provided to the Secretariat.

1.7 Action – The research team to provide responses and assurances to the Secretariat.

2. Development of a child abuse prevalence questionnaire and safeguarding procedure NSDEC(22)22.

2.1 Outcome – the Committee supported this work subject to assurances to points outlined in section 2.5 being provided to the Secretariat.

2.2 Detail of the project and discussion:

2.3 Child abuse and neglect (CAN) are recognised by the World Health Organisation as a global problem with potentially serious life-long consequences. Measuring the extent and nature is difficult because CAN is usually hidden from view and comes in many forms. Data are key to understanding the prevalence, causes, nature and effects of CAN, yet there is no single data source which measures the current prevalence of child abuse in the UK. In order to estimate the scale and impact of CAN in the UK, valid and reliable measures as well as appropriate safeguarding procedures are necessary. The ONS Centre for Crime and Justice are conducting a feasibility study to determine whether a national survey could provide an effective source of data on the current scale and nature of child abuse.

2.4 The aim of this research is twofold. The first aim is to design two questionnaires to capture the current prevalence of child abuse in the UK, which will be asked of two different participant groups; children aged 11 to 17 years and adults aged 18 to 25 years. The second aim is to devise an appropriate safeguarding procedure for the children aged 11-15 years and then children aged 16-17 years and adults 18-25 years, which successfully contributes to ensuring the participants are safe from significant risk of harm by assessing the current level of risk to the participant and applying the appropriate level of safeguarding. The questionnaire will cover: neglect, physical abuse, emotional abuse, sexual abuse, child exploitation, exposure to domestic violence, and online harms. The questionnaires and safeguarding procedures will be applicable across the 4 devolved nations across the UK.

2.5 The NSDEC raised the following points via correspondence:

- i The Committee requested further clarity on what categories or abuse were in scope of the project.

- ii The Committee suggested that the representativeness of the project's coverage in Northern Ireland be considered.
- iii The NSDEC queried whether the participants interviewed will include those in juvenile detention or prison.
- iv The Committee acknowledged the care taken in the measures outlined to ensure the confidentiality of data identifying individuals. Nevertheless, the NSDEC stressed that universities are at risk of hacking and hostile attack and requested affirmation that the organisers are satisfied with the security measures outlined and if there are contingencies in place.
- v The Committee requested clarification on how the structured distress protocol will work for participants of adult survivor focus groups which are conducted online.

2.6 The NSDEC acknowledged the public good and importance of the project and provided their support after requesting that assurances to their points be provided to the Secretariat. It was also agreed that the NSDEC should be consulted as further phases to this work develop in the future.

2.7 The NSDEC noted that a study of the interplay between ethical oversight of different ethical committees will be useful in the future.

2.8 Action – The research team to provide responses and assurances to the Secretariat and that further phases of the project be brought before NSDEC.

2.9 Action – The Secretariat to develop a study of the interplay between ethical oversight of different ethical committees.