### National Statistician's Data Ethics Advisory Committee Minute

Wednesday, 25<sup>th</sup> January 2023 London and via video conference

### Present

#### Members

Dame Moira Gibb (Chair) Stephen Balchin Rob Bumpstead Vanessa Cuthill Colin Godbold Monica Magadi (present from item 1 to item 4) Isabel Nisbet Emma Uprichard

### **UK Statistics Authority Secretariat**

Natasha Kong Matt Short Simon Whitworth

#### In attendance

Owen Brace, Director of Communications and Digital Publishing, ONS (for item 3) Andy Wall, Chief Security Officer, ONS (for item 4) Joe Moore, Policy Liaison Unit, Central Policy Secretariat, UKSA (for item 5) Jacob Seamons, Policy Liaison Unit, Central Policy Secretariat, UKSA (for item 5) Larry Bartleet, Central Policy Secretariat, UKSA (for item 7) Jo-Anna Hagen, Central Policy Secretariat, UKSA (for item 7) Gary Connell, Department for Education (for item 8) Neide Phillips, Department for Education (for item 8) Helen Boaden (Chair-designate) (observer)

### Absences

None

### 1. Introductions and farewells

- 1.1 The Chair introduced Helen Boaden to the committee. Helen has been appointed by the National Statistician as the National Statistician's Data Ethics Advisory Committee (NSDEC) Chair-designate. Helen was an observer at this meeting.
- 1.2 The Chair also informed the committee that Marion Oswald had notified of her intention to retire from membership of the Committee. The Chair and members of the Committee thanked Marion Oswald for her work as part of NSDEC.

## 2. Minutes and matters arising from the previous meeting and correspondence

- 2.1 Members of the Committee had approved the minutes from the last meeting in the interim period via correspondence. The Committee also approved the minute for the projects that was considered via correspondence in November 2022, which included "COVID-19 research programme: NHS winter pressures extension NSDEC(22)12" and "Development of a child abuse prevalence questionnaire and safeguarding procedure NSDEC(22)13".
- 2.2 Matt Short updated the Committee with progress on actions from the October 2022 meeting, and correspondence in the interim period. All actions were completed or in progress.

### 3. Public awareness and acceptability of linked data assets in the ONS NSDEC(23)01.

- **3.1 Outcome** the Committee supported this work subject to assurances to points outlined in section 3.5 being provided to the Secretariat.
- 3.2 Detail of the presentation and discussion:
- 3.3 Owen Brace, Director of Communications and Digital Publishing from the Office for National Statistics (ONS) presented this item.
- 3.4 The presentation explored the ONS's approach to raise public awareness on the creation of linked administrative data, in particular the findings of recent research regarding public appetite and public awareness of the creation of these linked data assets.
- 3.5 The NSDEC supported this work and appreciated the informative presentation, and raised the following points within the discussion:
  - i. The Committee sought clarity on how the concept of 'administrative data' was articulated in these public engagement efforts, particularly on the boundaries on what can be constituted administrative data.
  - ii. The NSDEC asked about whether the information on these linked data assets is available in formats that are accessible to population sub-groups that have shown lower levels of public trust in recent research and surveys.
  - iii. The Committee noted that data handling by other organisations, including in the private sector, has the potential to influence public perception on the utilisation of data, and ONS should be mindful of that in public communications and engagement efforts.
  - iv. The NSDEC emphasised the importance of ensuring that administrative data used to create linked data assets is accurate in order to maintain public trust.
  - v. The Committee further emphasised the need for clarity when utilising the term "government" in ONS communications and public engagement, as the public perception of what constitutes "government" is wide-ranging and not limited to the ONS, but may include central government and local authorities.

- vi. The Committee suggested that this work will be useful to government analysts, so that these findings can help those working on individual projects trying to ascertain public acceptability.
- vii. The NSDEC asked if there were more efforts to secure engagement of lay people and their involvement in key decision-making panels about the use of administrative data for statistics and research purposes. The Committee requested an update on this work from the secretariat, in particular how feedback from lay people could feed into the work of the NSDEC.
- **3.6** Action Owen Brace to provide the Secretariat with assurances to the points raised in section 3.5.
- **3.7** Action The Secretariat to update the NSDEC on how lay people could feed into NSDEC decision making.

### 4. How ONS are keeping linked data assets safe and secure NSDEC(23)02.

- **4.1 Outcome –** The Committee welcomed the presentation and were reassured by the security measures outlined.
- 4.2 Detail of the presentation and discussion:
- 4.3 Andy Wall, Chief Security Officer from the ONS presented this item. This presentation outlined information security, governance process and security by design used within the ONS to ensure that linked data assets are kept safe and secure.
- 4.4 The Committee welcomed Andy's presentation. The following comments were raised in the discussion that followed:
  - i. The NSDEC commended the thorough presentation which aided their understanding on how ONS protects linked data assets and was assured that these data assets are kept securely.
  - ii. The Committee asked about the security measures in place when data assets are shared with third party organisations. Assurance about the security measures in place provided, including ensuring that third parties have a legitimate use for the data and that sharing of data is limited to only what is strictly necessary for their purposes. The ONS also requests for a third party's information governance practice, supplemented by checkpoints and security working groups for an extra level of assurance.

## 5. What ONS are doing to ensure statistics have impact with policy makers and other stakeholders NSDEC(23)03.

- **5.1 Outcome –** The NSDEC encouraged the Policy Liaison Unit to continue to engage with both CADE and the NSDEC on the points raised in point 5.5.
- 5.2 Detail of the presentation and discussion:
- 5.3 Joe Moore and Jacob Seamons from the Policy Liaison Unit in the UK Statistics Authority (UKSA) presented this item. The presentation detailed how the Policy Liaison Unit functions and acts as a bridge between central

government and the ONS to support policy areas and maximise opportunities for ONS research and statistics.

- 5.4 To understand the needs of policy makers and ensure that policy decisions are informed by the latest evidence and analysis, the Policy Liaison Unit operates flexibly across policy areas and central organisations and has been embedded in key teams. Additionally, some case studies were presented which detailed how the Policy Liaison Unit have successfully promoted ONS data across government, such as the Over 50s Lifestyle Study and Winter Panel Survey, to support statistical analysis.
- 5.5 The Committee raised the following comments in the discussion that followed:
  - i. The NSDEC recommended that the Policy Liaison Unit engage with the UKSA's Centre of Applied Data Ethics (CADE) to ensure the ethical appropriateness of projects that involve new data assets or new data linkages.
  - ii. The Committee welcomed the work that the Policy Liaison Unit is undertaking and suggested that the value of the team's work might usefully be broadened by also connecting the wider research and statistical community to policy makers in Government.
  - iii. The Committee emphasised the importance of appropriate usage of data, emphasising that it should be used for statistical purposes.
  - iv. The Committee raised the importance of the ONS maintaining their visible statistical and professional independence during this work.
- **5.6** Action The Policy Liaison Unit team to ensure they promote the use of CADE's ethical assessment tools to ensure the ethical appropriateness of new data and new data linkages when working with ONS on new statistical outputs.

# 6. Managing access to linked data assets to ensure public good aggregate outputs are produced in ethically appropriate ways NSDEC(23)04.

6.1 This item was deferred to the next NSDEC meeting.

# 7. Evidence to support the National Statistician's recommendation to government in 2023 on the future of population and social statistics NSDEC(23)05.

- **7.1 Outcome** The NSDEC encouraged the team to continue to engage with the NSDEC as this project develops, especially with regards to the planned public consultation.
- 7.2 Detail of the project and discussion:
- 7.3 Larry Bartleet and Jo-Anna Hagen from the Central Policy Secretariat, UK Statistics Authority, presented this item. The paper was in response to a request by the NSDEC at the July 2022 meeting for an update on the evidence behind the "2023 recommendation on the future of population and social statistics in England and Wales".

- 7.4 In 2014, the Government set out its ambition that "censuses after 2021 will be conducted using other sources of data and providing more timely statistical information." In the 2018 Census White Paper "Help Shape our Future", the ONS committed to delivering recommendations on the future of social and population statistics including census arrangements in November 2023. To provide evidence for the recommendations, the ONS has for several years been conducting research into the viability of using primarily administrative sources to produce estimates about the population, its characteristics and housing. This is referred to as the 2023 Recommendations.
- 7.5 The item detailed an overview of the work that the Social Statistics Transformation Analysis & Research team has delivered to date and how ethics have been considered in generating an evidence base that will inform this recommendation. The item highlighted the ethical risks and mitigations that have been considered throughout this process, in four main categories:
  - i. Public understanding, acceptability and consent around the use of administrative data for statistical purposes;
  - ii. The collection of certain topics as administrative data;
  - iii. Managing the security and privacy risks associated with working with administrative records on a large scale; and
  - iv. Understanding the user needs for social and population statistics, and how they can be met.
- 7.6 The next stage of the project involves a 12-week public consultation in order to test the proposals with a wide audience of interested parties. The outcome of this consultation will inform the nature of the recommendations.
- 7.7 The NSDEC raised the following points in discussion:
  - i. The Committee appreciated the overview of what the 2023 Recommendation is and would be interested in being kept updated on its progress.
  - ii. The NSDEC requested further details on the planned public consultation to test ONS's proposals, especially with regards to the consultation's audience, the questions that will be asked in the consultation, how the consultation will be undertaken and how conclusions from the consultation will be reached.
- **7.8** Action The 2023 Recommendations team to provide the NSDEC with further details on the planned public consultation, especially regarding the audience of the consultation and the materials presented to them.
- **7.9** Action The 2023 Recommendations team to keep the NSDEC informed of the progress of the 2023 Recommendations as it develops.

# 8. Request to extend Education and Child Health Insights from Linked Data (ECHILD) Dataset NSDEC(23)06.

- 8.1 **Outcome –** The NSDEC requested further detail and clarity on the points outlined in section 8.6 in a revised application and provide this to the Secretariat.
- 8.2 Detail of the project and discussion:

- 8.3 Neide Phillips and Gary Connell from the Department of Education presented this item. This paper set out a request to the NSDEC to extend the ECHILD dataset and include additional health datasets that are linked to Hospital Episodes Statistics Data (HES) by NHS Digital.
- 8.4 The ECHILD project is a partnership between Department for Education, University College London, NHS Digital and Department of Health and Social Care, aimed at improving the lives of vulnerable children. It does that by linking de-identified health and education data to better understand how education affects children's health and how health affect children's education.
- 8.5 The aim of this extension is to identify the drivers of health inequalities and enable better understanding of the relationship between children with disabilities and their health and educational outcomes. The extended ECHILD dataset will facilitate research that will inform policymakers about the associations between education risk factors and health outcomes.
- 8.6 The NSDEC appreciated the public good and need for this work, and raised the following points:
  - i. The Committee requested further details on the list of research projects that will be undertaken using the extended ECHILD dataset, including their specific research aims, the expected outcomes of these research projects and their expected public benefit.
  - ii. The NSDEC wanted clarity on the current ECHILD dataset, such as its variables and the limitations of the current ECHILD dataset.
  - iii. The Committee also requested further clarity on the value the extension is going to add to the research community in terms of what can be achieved using this data that cannot be achieved using existing data that is available.
- **8.7** Action The research team to provide assurance on the points raised in section 8.6 and send this to NSDEC via the secretariat so that final advice can be provided on the proposed approach.

### 9. Any Other Business

- 9.1 The NSDEC discussed the data ethics compliance review of "Parental separation and educational inequality: Any evidence for growing disadvantage or 'diverging destinies' across three recent cohorts? NSDEC(20)07". This project is part of the CRITEVENTS (Critical Life Events and the Dynamics of Inequality: Risk, Vulnerability, and Cumulative Disadvantage) research project, funded by the European Union's Horizon 2020 research and innovation programme and led by Professor Thomas Leopold of the University of Cologne.
- 9.2 This review confirmed that the research team had taken the advice of the Committee and implemented all the Committee's comments.
- 9.3 The Committee thanked the UKSA's Data Governance, Legislation and Policy team for these reviews and said they provided good assurance that the advice of the Committee was being followed.

- 9.4 Committee members paid tribute to Dame Moira Gibb for her contribution and leadership as chair of NSDEC. Dame Moira thanked her fellow committee members and praised the support executive colleagues provided to her and the committee.
- 9.5 The dates of the next NSDEC meetings for 2023 will be decided on via correspondence and will be uploaded on the UKSA website shortly.