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## Economic Commission for Europe

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Item 6 (a) of the provisional agenda

#### **Emerging role of national statistical offices as offices for statistics and data**

#### **Session 1: Emerging data system opportunities and issues**

## **Enabling ethically appropriate uses of data for research and statistics for the public good**

### **Note by the United Kingdom Statistics Authority**

#### *Summary*

This document presents the innovative approach the United Kingdom Statistics Authority has taken to establishing a robust, efficient and transparent ethical governance process to provide the National Statistician with assurance that the uses of data across the United Kingdom's Government Statistical Service are ethically appropriate and for the public good. This includes the development of an ethics self-assessment tool to enable researchers and statisticians to consider the ethics of their work at a relatively early stage in the life course of the project, encouraging a culture of "ethics by design", and the establishment of an independent committee to provide transparent external advice and challenge on the use of data for research and statistical purposes.

This document is presented to the 2019 Conference of European Statisticians seminar on "Emerging role of national statistical offices as offices for statistics and data", session 1 "Emerging data system opportunities and issues" for discussion.



## I. Introduction

1. Advances in technology, skills and legislation are providing national statistical offices (NSOs) with opportunities to access and use data to produce new insights and statistics which can have real value for the country. In maximising the research and statistical uses of these new opportunities it is important that consideration is not just given to what research NSOs can do, but also to what research they should do to ensure that they use data in ethically appropriate ways which are for the public good. High-profile cases from different sectors around the world illustrate that the price of failure on the ethical dimension is likely to mean a loss of trust from the public and data suppliers, greatly restricting the analytical possibilities open to NSOs in the future.

2. This document presents the approach the United Kingdom Statistics Authority has taken to ensuring a robust, efficient and transparent ethical governance process is in place to provide assurance to the National Statistician that the uses of data across the United Kingdom's Government Statistical Service are ethically appropriate and for the public good. This approach plays an important role in enabling the United Kingdom Statistics Authority to mobilise the power of data to help make Britain make better decisions in ways which embrace new ways of working, while maintaining robust ethical standards which are acceptable to key stakeholders, such as the public, data suppliers and the privacy sector.

## II. Description of current work or overview of the topic

3. The Digital Economy Act (2017) (DEA) enables Office for National Statistics (ONS) to approach all government departments, other public authorities, and large and medium-sized businesses, to ask them for data they hold and collect, where ONS needs it to support the production and transformation of the statistics and research we produce. DEA provides a framework to enforce these rights in certain circumstances, as well as setting out the safeguards ONS must adhere to, so for example around confidentiality, proportionality, transparency, collaboration, and the public interest. Providing ONS can document, defend and articulate all of this, then as far as the law is concerned ONS can probably do it. However, just because we "can" do something, does not mean necessarily we "should" do that something.

4. To help us answer the "should" question and keep ONS on the right side of the ethical line, in 2015 the United Kingdom's National Statistician established the National Statistician's Data Ethics Advisory Committee (NSDEC) to provide independent and transparent advice that the collection, access, use and sharing of data, for research and statistical purposes is ethical and for the public good. NSDEC consists of expert members in research ethics, statistical research, data law, data science and data protection who provide expert ethical advice about the ethics of the collection and use of data across the Government Statistical Service. Some of these members represent Government departments but to ensure external perspectives and challenges to the uses of data for research and statistical purposes, the majority are independent members from academic institutions and commercial organisations. A lay member also sits on NSDEC to provide a valuable non-expert perspective to discussions.

5. To provide a framework to enable NSDEC to assess the ethics of research proposals, the United Kingdom Statistics Authority has developed a number of ethical principles which are presented below. These provide a consistent ethical framework to govern the collection and uses of data for research and statistical purposes.

- The use of data has clear benefits for users and serves the public good
- The data subject's identity (whether person or organisation) is protected, information is kept confidential and secure
- The risks and limits of new technologies are considered and there is sufficient human oversight so that methods employed are consistent with recognised standards of integrity and quality
- Data used and methods employed are consistent with legal requirements

- The views of the public are considered in light of the data used and the perceived benefits of the research
  - The access, use and sharing of data is transparent, and is communicated clearly and accessibly to the public. NSDEC is an important enabler in this regard as all research proposals considered by NSDEC and the minutes of each NSDEC meeting are published on the United Kingdom Statistics Authority's website.
6. By using this ethical framework to provide independent advice and challenge about our collection, accessing, use and sharing of data, NSDEC plays an important role ensuring that work of ONS is ethically appropriate and for the public good.

### III. Issues and challenges

7. One of the challenges in this work has been to balance the need for a robust ethical governance process with the need, common to all NSOs, to produce fast paced high quality research and statistics that informs timely policy decisions. To ensure that projects that are ethically appropriate can proceed at pace, without having to be delayed by the need to go to a formal ethical review at NSDEC, and to drive a cultural change within the organisation which encourages researchers to take more responsibility for the ethics of their research, the United Kingdom Statistics Authority has developed an ethical self-assessment tool. This provides a consistent framework, based on NSDEC's ethical principles, to enable researchers to self-assess the ethics of their research.

8. The tool asks researchers to score their research against different components of NSDEC's ethical principles, at the research design phase. Researchers consider each principle on a Likert type scale which provides the necessary granularity in the ethical assessment to reflect that ethical decisions are not binary. The tool provides the researcher with an overall ethical risk score for their project and helps them to identify areas where they could potentially do things differently to reduce the ethical risks of their work. NSDEC has oversight of this process, as all ethics self-assessments are reported to the Committee. Those projects that are considered more ethically risky are taken for formal review at the committee to enable such projects to benefit from the independent ethical advice and assurance that NSDEC can offer.

9. The collection, use and sharing of data for the production of research and statistics producing aggregate outputs is widely considered to be a benign use of data. This can sometimes lead to a reluctance amongst researchers and statisticians to prioritise the act of considering the ethics of their work. This challenge has been tackled by a series of communications across the statistical community from senior leaders about the importance of robustly considering whether we "should" do something to ensure that our work is acceptable to the public and other stakeholders. These communications have made clear that we rely on this acceptability to enable us to achieve our strategic objective of mobilising the power of data in to help make Britain make better decision. These communications have used real life examples from different sectors to stress that organisational survival is determined just as much by whether an organisation "can" lawfully do something as by whether it "should" do something.

10. To empower researchers to appropriately self-assess the ethics of their work the United Kingdom Statistics Authority has committed resources to provide expert support and training to guide researchers through the ethics self-assessment framework and apply it to their work. This approach to engaging with the research community has been successful and since the development of the ethical principles, in 2015 over 80 projects from across the Government Statistical Service, academia and the commercial sector have been considered against NSDEC's ethical principles. This has included a wide range of data linkage projects, surveys, and new data collection methods such as collecting data through web scraping and from social media.

11. The independent advice and challenge from NSDEC, about the use of data for research and statistical purposes, has provided valuable input into shaping strategy of ONS towards how it communicates the work of the organisation and engages with the public about the

collection and use of data for research and statistical purposes. This has included taking steps to clearly communicate the public good of research and statistics in a way which goes beyond just describing the statistical improvements that research will potentially enable, to also communicate the potential public benefits that these statistics will inform.

12. NSDEC has also encouraged ONS to work transparently throughout the research and statistical production process so that the public can see how data is being used and what decisions the use of this data is informing and engage with the public to ensure that our uses of data are public acceptability. To help with this transparency all research proposals discussed by NSDEC, along with the minutes from each meeting, are published on the United Kingdom's Statistics Authority's website. This helps to show that ONS is not just accessing and using all sorts of data sources just because it is possible, but that independent advice has been sought on weighing up the public interest and ethical arguments about our uses of data. This has played a key role in helping to maintain excellent reputation of ONS for collecting, using and sharing data in ethically appropriate ways amongst key stakeholders such as data suppliers, privacy groups and the research community.

13. In recent times there has been a significant increase in interest in data ethics amongst the United Kingdom's academic and Government research communities. Much of this work has focused on the theory of data ethics and has fallen short of actually making applied decisions about the ethics of the use of data in real-life research projects. The United Kingdom Statistics Authority's work developing an applied ethical framework which researchers can use to consider the ethics of their research, along with a place for researchers to get credible independent advice against the framework, has therefore made a valuable contribution to the United Kingdom's data ethics landscape, and has enabled the Authority to be seen as a thought leader in this space. The valuable contribution this work has made to the wider data ethics landscape can be seen from the increasing number of non-government organisations from the academic and commercial sectors that have used the ethical self-assessment tool and have taken research projects to NSDEC.

#### **IV. Conclusions and recommendations**

14. The robust and transparent consideration of the ethics of the use of data for research and statistical purposes is a key part of enabling NSOs to mobilise the power of data for research and statistics for the public good. Developing a principle based ethical framework underpinned by processes that enable the framework to be applied in a consistent and timely fashion, supported by training and guidance, has proved to be a successful way of encouraging ethically appropriate research in the context of the United Kingdom.

15. In order to position NSOs as trusted data users and data stewards, it is important that NSOs can transparently show that they take ethics seriously. Failing to do this will mean a loss of trust from the public and data suppliers, greatly restricting the analytical possibilities open to NSOs in the future.

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