



**UK Statistics  
Authority**

# **Experience of the National Statistician's Data Ethics Advisory Committee**

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UK Statistics Authority**



## Digital Economy Act 2017

2017 CHAPTER 30

An Act to make provision about electronic communications infrastructure and services; to provide for restricting access to online pornography; to make provision about protection of intellectual property in connection with electronic communications; to make provision about data-sharing; to make provision in connection with section 68 of the Telecommunications Act 1984; to make provision about functions of OFCOM in relation to the BBC; to provide for determination by the BBC of age-related TV licence fee concessions; to make provision about the regulation of direct marketing; to make other provision about OFCOM and its functions; to make provision about internet filters; to make provision about preventing or restricting the use of communication devices in connection with drug dealing offences; to confer power to create an offence of breaching limits on ticket sales; to make provision about the payment of charges to the Information Commissioner; to make provision about payment systems and securities settlement systems; to make provision about qualifications in information technology; and for connected purposes. [27th April 2017]

**B**E IT ENACTED by the Queen's most Excellent Majesty, by and with the advice and consent of the Lords Spiritual and Temporal, and Commons, in this present Parliament assembled, and by the authority of the same, as follows:—

“a legal framework providing the Authority with access to data held by Crown bodies, other public authorities and undertakings (including charities) to support the Authority's statistical functions.”

# Digital Economy Act: Statistics Strand

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- Gives ONS a right of access to data for statistical/research purposes only
- Enable secure data shares with Devolved Administrations to support their statistical needs from devolution
- Protect privacy and security of data; reaffirm rigorous penalties for misuse
- Duty to consult statisticians on changes to data systems
- **Uses of the DEA have to observe appropriate ethical standards**

# Ethical Principles

## Public Good

The use of data has clear benefits for users and serves the public good.



## Confidentiality, data security

The data subject's identity (whether person or organisation) is protected, information is kept confidential and secure, and the issue of consent is considered appropriately.



## Methods and Quality

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.



## Legal Compliance

Data used and methods employed are consistent with legal requirements such as Data Protection Legislation, the Human Rights Act 1998, the Statistics and Registration Service Act 2007 and the common law duty of confidence.



## Public views & engagement

The views of the public are considered in light of the data used and the perceived benefits of the research.



## Transparency

The access, use and sharing of data is **transparent**, and is communicated clearly and accessibly to the public.



# National Statistician's Data Ethics Advisory Committee



- ✓ Majority independent membership ensuring impartial and credible advice
- ✓ External perspectives & challenge to uses of data
- ✓ Supports consistency in ethical decision making across GSS and the wider research community.
- ✓ Independent justification in the face of challenge
- ✓ Greater transparency around how data is shared, linked, and used

# The Self-Assessment



Version 2.1

## National Statistician's Data Ethics Advisory Committee

### Guidelines on using the ethics self-assessment process

#### Introduction

To help maintain public trust and confidence in the use of data for research and statistics it is important that researchers (in ONS, the wider Government Statistical Service, and beyond) whatever their particular discipline (statistics, economics, social research, operational research, other) who use data for statistical, analytical and wider research purposes do not just consider what can be done with the data, methods, expertise and technology available to them. It is equally important that researchers consider what *should* be done. This ethical self-assessment has been developed to provide a framework to help all researchers to think about the ethics of their research.

This guidance is designed to support researchers and statisticians to complete the National Statistician's Data Ethics Advisory Committee's (NSDEC) ethical self-assessment form. NSDEC's ethical self-assessment enables researchers to self-assess the ethics of their research by scoring their research against NSDEC's ethical principles.

#### The NSDEC's ethical principles are:

1. The use of data has clear benefits for users and serves the public good
2. The data subject's identity (whether person or organisation) is protected, information is kept confidential and secure, and the issue of consent is considered appropriately
3. 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
4. Data used and methods employed are consistent with legal requirements such as Data Protection Legislation<sup>1</sup>, the [Human Rights Act 1998](#), the [Statistics and Registration Service Act 2007](#) and the common law duty of confidence
5. The views of the public are considered in light of the data used and the perceived benefits of the research
6. The access, use and sharing of data is transparent, and is communicated clearly and accessibly to the public

<sup>1</sup> "Data Protection Legislation" means the full, applicable data protection framework as set out in the Data Protection Act 2018. This encompasses general processing (including the General Data Protection Regulation and the applied GDPR).

The self-assessment consists of 3 main sections for the researcher to complete:

1) Basic information

2) Weightings and sensitive research areas

3) Item scoring scales

**Self-Assessment Form** Version 2.1

**Project Title**

**Project Time line** Please provide some details about your project timeline (e.g. start date, end date, any key dates for dissemination activities)

**Project Summary** Please provide some details about your project (e.g. data sources, how data are collected, used, processed and shared)

**Public Benefit** Please describe the public benefit of undertaking this project

	Weight level	Type 1 if applicable
Is this a data linkage project?	10%	
Does the project involve the use of sensitive personal data (under the DPA and GDPR)?	20%	
Does the project involve the use of patient level health data?	40%	
Does the project include data on children or vulnerable adults?	40%	
<b>Data Sources</b>		
Social media	10%	
Rich media sources	15%	
Metadata or Paradata	5%	
Web scraped data	5%	
Big Data (inc. sensor and mobile data)	5%	

### Result

- Project requires an ethical review before proceeding

Item	Principle	Score	Please type "1" in the appropriate box below to indicate your rating for each question. Please add a comment in the far right column to briefly justify your selection					Score per principle	Please use this section to give a short justification of your selected rating
			1	2	3	4	5		
1	Public benefit							-	Score Justification
	Population coverage								
	Potential harm								
	Biases								
2	Direct identification							-	Score Justification
	Indirect identification								
	Data Security								
	Consent								
	Permitted use of data								
3	Validity							-	Score Justification
	Standards								
	Training								
	Human oversight								
	New technologies								
	Potential to realise benefits								
4	Established legal pathways							-	Score Justification
	Established legal frameworks								
5	Public views							-	Score Justification
	Public engagement								
6	Public access to outcomes							-	Score Justification
	Sharing of methods or tools								
	Data curation and re-use								

# User Support



Version 2.0

## National Statistician's Data Ethics Advisory Committee

### Guidelines on using the ethics self-assessment process

#### Introduction

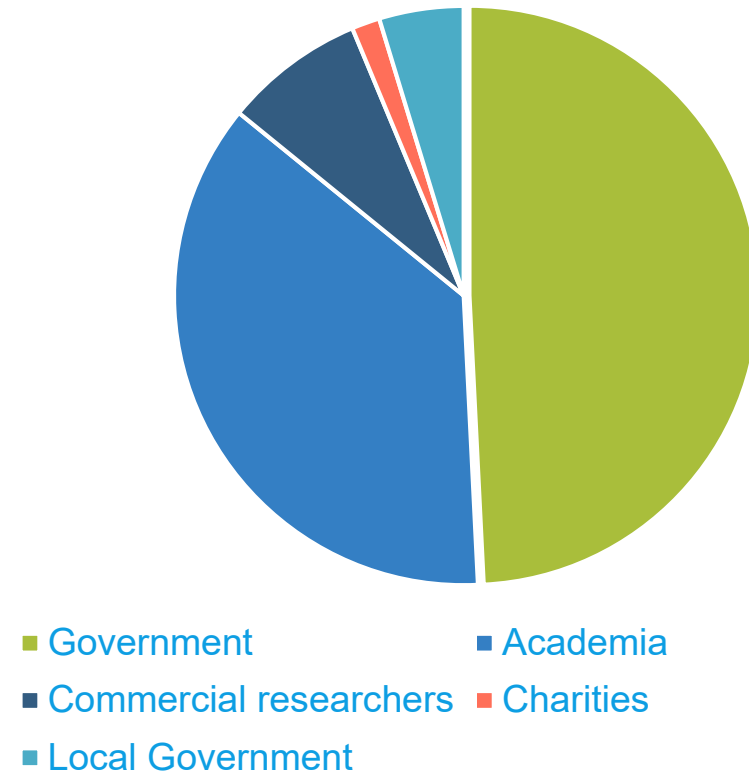
To help maintain public trust and confidence in the use of data for research and statistics it is important that researchers (in ONS, the wider Government Statistical Service, and beyond) whatever their particular discipline (statistics, economics, social research, operational research, other) who use data for statistical, analytical and wider research purposes do not just consider what can be done with the data, methods, expertise and technology available to them. It is equally important that researchers consider what *should* be done. This ethical self-assessment has been developed to provide a framework to help all researchers to think about the ethics of their research.

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# Users

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Users of the UKSA's ethics framework





# Example Projects

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- COVID-19 Infection Survey – COVID-19 tests and antibody in 20,000 households.
- Linkage of Hospital Episodes records with Census data, mortality data and primary care data to determine the level of relative risk of hospitalisation or death from COVID-19
- Environmental and socio-economic impact assessment for siting geological disposal facilities
- Data for children: assessing the impact of family background on the outcomes of children in England

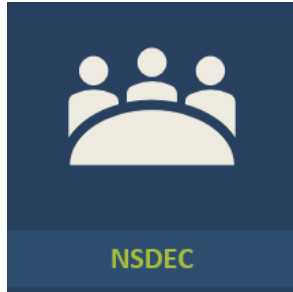
# Strategy

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“To be recognised **world-leaders** in the **practical application** of **data ethics** for statistics and research, with a **centre of excellence** to deliver this.”

# Centre of Excellence for Data Ethics



Continue to develop the **self-assessment tool and guidance** and provide **NSDEC**



**New online ethics training**



**A new ethics user support service .**



**Publish new guidance on cross cutting ethical issues in research and statistics.**



**new collaborations both domestically and internationally.**

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# More information

**Contact:** [nsdec@statistics.gov.uk](mailto:nsdec@statistics.gov.uk)

**Website:** <https://www.statisticsauthority.gov.uk/about-the-authority/committees/nsdec/>