

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 and *how* it 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 UK Statistics Authority's ethics self-assessment tool. The UKSA's ethics self-assessment tool enables researchers to self-assess the ethics of their research by scoring their research against the UKSA's ethical principles.

The UKSA's ethical principles are:

- 1. Public Good The use of data has clear benefits for users and serves the public good.
- 2. 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 methods and/or 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 Legislation¹, the <u>Human Rights</u> <u>Act 1998</u>, the <u>Statistics and Registration Service Act 2007</u> the common law duty of confidence, and the <u>Equality Act 2010</u>.
- 5. Public Views and Engagement The views of the public are considered in light of the data used and the perceived benefits of the research.
- 6. Transparency The access, use and sharing of data is transparent, and is communicated clearly and accessibly to the public.

¹ "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).



This self-assessment process is designed to provide researchers with an easy-touse framework to consistently review the ethics of their projects. Although the selfassessment is not designed to automatically resolve the ethical issues in individual projects, it is designed to help identify an accurate and consistent estimation of the "ethical risks" of research proposals. Identification of any potential ethical risks should be used to shape discussions that will drive improvements in research proposals and activities. Ensuring that researchers and analysts continuously consider research in light of the UKSA's ethical principles will ensure that the use of data for research and statistical purposes continues to be ethical and for the public good.

How to use the self-assessment

We recommend that self-assessments are conducted as early as possible in the project timeline, as this will help to determine and ensure the most ethically sound route for research. We also advise that you revisit the self-assessment throughout the project lifecycle to ensure that any changes to the proposed project are considered in light of the ethical principles.

Although this framework is presented as a self-assessment, it need not be a process that you complete on your own. It is also important to remember that the self-assessment process is designed to consider the ethics of your particular project – therefore, it is the analysts' responsibility to ensure that the project satisfies all of the relevant legal requirements relating to their project. We therefore recommend that you discuss your research projects and/or self-assessment form with the following (where relevant and appropriate):

- 1. Senior director/manager of your branch/business area/organisation responsible for the research project
- 2. The relevant Information Asset Owner(s)
- 3. Any relevant legal and data protection experts within your organisation
- 4. Where appropriate, any relevant Communications and Media relations teams/individuals

All completed self-assessments should be sent to the UK Statistics Authority's Data Ethics team, at <u>Data.Ethics@statistics.gov.uk</u>. The Data Ethics team is available to review finalised self-assessments and support thinking through mitigations to minimise against identified ethical risks.

To help you navigate through the process we have included a user checklist at the end of this document.

The self-assessment form

The self-assessment form consists of 3 main sections:

- 1. Basic Information
- 2. Weightings for sensitive research areas
- 3. Item drop down selection and justification



Information and guidance for completing each of these sections is provided in the next three sections.

The self-assessment tool calculates the average ethical risk for the research project and provides you, as the researcher, with a suggested course of action based on a risk-based outcome. Whatever the course of action, you should share your completed self-assessment form with the Data Ethics team, at <u>Data.Ethics@statistics.gov.uk</u> before proceeding with the project.

The suggested courses of action are as follows:



1. Basic information

This section consists of five parts: 1) Project title; 2) Project timeline; 3) Project purpose; 4) Research overview; 5) Data sources.

Project title

Please provide the title for your project. Please make sure that the title is indicative of the project.

Project timeline

Please provide some details about your project timeline. This should include key dates such as the start and end date of your project, as well as any dates for dissemination activities (such as project reports and outputs).

Project Purpose

Please provide a short summary of the project's purpose. This should include the following information (where relevant):

- 1. Project partners and/or sponsors
- 2. Research aims and/or research questions



Project overview

Please provide details of how the project will be completed. This should include the following information (where relevant):

- 1. Methods proposed / how data are collected, used, processed, and shared
- 2. The research environment where the project will be completed
- 3. Plans for dissemination of research findings
- 4. Any useful and relevant background information

Data sources

Please provide a list of data sources that this project utilises, along with what type of data this is (i.e. Survey, Admin, Social Media, Web Scraped etc). Please also provide a justification for each of the data sources that explains why this data is requires and how this supports the public good of this work.

For further information on ethical considerations when using different types of data, see our high-level ethics checklist for <u>third party data</u>, our guidance on <u>location data</u> and our guidance on the use of <u>machine learning techniques</u>.

2. Weightings for sensitive research areas

There are four characteristics (listed below) which help determine the ethical risk of a project, with 'ethical risk' being defined as the perceived likelihood of negative consequences of unethical actions. To measure the differential complexities of various ethical decisions these have been included in the self-assessment as weighted measures. The weights have been reviewed by NSDEC based on its consideration of a large number of projects since 2015.



Data linkage projects

Linking data can lead to useful insights and offers new opportunities for existing datasets. However, as information about a data subject is pulled together from different datasets, the risk of re-identification of the individual increases. Data linkage may be also perceived as profiling, and hence might not be publicly acceptable. This weighting also applies to projects that utilise already linked data.



Special category personal data and processing

Personal data means any information relating to a person who can be identified, directly or indirectly, from the information. This definition provides for a wide range of personal identifiers to constitute personal data, including name, identification number, location data or online identifiers. Sensitive personal data are special categories of personal data as defined in law. These special categories include personal data on racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, genetic data and biometric data (where processed to uniquely identify an individual), data concerning health, and data concerning a person's sex life or sexual orientation. Due to the risk of disclosing the identity of data subjects, along with other personal information, it



is important that researchers put in place additional safeguards. This is mandated by law (<u>Data Protection Act 2018</u>, and the <u>UK General</u> <u>Data Protection Regulation</u>



Patient level health data

There are particular sensitivities when using patient level clinical (health) data for research and statistics. Consideration needs to be given to the public acceptability of using such data and respecting patient confidentiality.



Protected characteristics, and/or those deemed to be at greater risk of disadvantage

Could this research and/or its outcomes relate to individuals based on their protected characteristics? Protected characteristics are defined as age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex and sexual orientation, as per the Equality Act 2010 (legislation.gov.uk).

Examples of groups that may be at greater risk of disadvantage are considered as groups of persons that experience a higher risk of poverty, social exclusion, discrimination and violence, including, but not limited to, ethnic minorities, migrants, people with disabilities and isolated elderly people and children, according to the <u>European</u> Institute for Gender Equality.

See our guidance on considering public views and engagement for research and statistics projects for further information on <u>public</u> <u>acceptability</u>.

Weights have been developed to account for these complexities in the selfassessment process and are applied to the overall self-assessment outcome. As legislation, regulation, and methodology around these areas evolve, these weights will be reviewed. Some weights may be adjusted, and new weight categories may be introduced.

On the self-assessment form:

If any of these characteristics are relevant to your project, please indicate this on the self-assessment form by placing a "1" in the corresponding cell on the form.

If you would like more information about how they impact the self-assessment outcome, then please contact the UKSA Data Ethics team, at <u>Data.Ethics@statistics.gov.uk</u>.

3. Item scoring scales

The scoring scales

In this section, you are asked to assess your project against 22 items grouped against the six UKSA ethical principles. For all of the items, we ask you to respond to each based on a 3-point scale. To do so, each item has a drop-down selection where you are asked to select the most relevant option to your project. These



options are affiliated with a score of 1, 2 or 3. For all items, we also ask you to add a **justification** of your selected rating for each item. To assist you with providing this justification, the form provides prompts on the information that is expected from the justification, based on the selection from the drop-down options.

Where appropriate and justified, some items can be omitted when completing the self-assessment by selecting N/A, but again a justification is required as to why the item is not applicable to your research. The N/A function is only available for some of the items and is illustrated in this guidance as per the N/A diamond to the right of the 3-point scale below.



'The items' section below provides guidance for how to consider your response to each of the items.

The average of the rating for all items is a good indicator of the overall ethical risk of the project. However, this could lead to individual high ethical risk scores being averaged out by the results of the rest of the items. To avoid this, we have introduced tolerances.

Tolerances

As mentioned above, to avoid responses that might indicate ethical issues being averaged out of the overall outcome, we have introduced tolerances against each item that is scored. You will therefore notice that when a statement is selected from the drop-down list, this will be highlighted red to indicate the tolerance limit.

For example, the tolerance level for the public good item is set at the middle response, "Potential to achieve public good which requires further exploration". This is because the public good should always be an integral part of the research aims and should be known prior to starting. Without these tolerances, a project could therefore achieve a "Low Risk" outcome, despite there being no clear public good. When these tolerance limits are reached or exceeded, researchers should consider appropriate actions to mitigate the ethical risk. If mitigations are not possible, researchers should also set out a justification as to why. These areas of the self-assessment will then inform a conversation between the research team and the UKSA Data Ethics team to understand whether there are any steps that can be taken to minimise identified risks, and/or whether this issue would benefit from independent scrutiny from the <u>National Statistician's Data Ethics Advisory</u> Committee.

In this guidance, tolerance levels against each item are indicated by a black diamond around the corresponding level on the 3-point scale. In the example below, the tolerance limit is set at 3. This is the most common tolerance level.





The items

In this section, we provide guidance on how to consider your responses to each of the 22 items grouped against the six UKSA ethical principles. We also describe which items have the potential to be omitted where such a response can be clearly justified.





Principle 1 (Public Good): The use of data has clear benefits for users and serves the public good

1. Public benefit



Assessing the public good is, by default, highly subjective. However, when assessing the public good of your research, you should consider the definitions of public good and public interest set out in the <u>Statistics and Registration Service Act 2007</u> and the <u>Research Code of Practice and Accreditation Criteria</u>.

It might also help you to consider:

- i. how beneficial would your research be to society as a whole; and
- ii. whether it is necessary to conduct this research to realise these benefits.

See our guidance on <u>considering and articulating public good</u> in research projects for further information to help you in completing this section.

2. Population coverage



When considering the public benefit of the project, you should assess how many people would be affected. If the study is focused on a small proportion of the population, or a particular group, then:

- i. the research might disproportionally benefit or disadvantage a group;
- ii. the societal impacts of the research might be limited; and
- iii. the risk of breaching confidentiality via re-identification increases.

N/A: Omit this item if the scope of the research is specific to a particular group. However, you should justify why the research is focused on that group, and whether this, or other groups, might be adversely affected by this research.



3. Potential harm Negligible harm to anyone involved, including the public Identified potential harm to anyone involved that can be justified and mitigated against Identified potential harm that cannot be mitigated against

You should consider whether the project could cause any potential negative consequences to the public, and whether these are proportionate to the proposed public benefits of the project. Where appropriate, you should also consider whether the activities involved with conducting the research project could cause potential harm or distress to *any* of the individuals involved, including the research participants, the research team, or the research facilitators.

4. Biases



Identifying and managing bias is essential in research and, to ensure its integrity, it is important that you consider:

- the data sources used and most importantly how these are produced;
- the effect of researcher or observation bias throughout the lifecycle of the project;
- the methods and algorithms employed, their assumptions and constraints; and
- the outcomes of your research and how your research is presented.

It is equally vital that you provide mitigations for any identified bias, as illustrated by the amber and red outcomes, the lack of mitigation would result in the research reaching a tolerance level. As bias could also be identified later in the research process, it is important to keep the self-assessment updated as research projects evolve to reflect any changes.



Principle 2 (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

5. Direct identification



Direct identification means using the published research outcomes to derive the identity of data subjects without the use of additional data sources. Statistical research may require access to datasets with a higher level of granularity and, to produce and publish statistics, researchers might risk breaching the confidentiality of data subjects. You should make sure that adequate statistical disclosure controls are strictly applied to prevent research outcomes being used to directly identify data subjects or attributes identifying population groups.

6. Indirect identification



Indirect identification involves using additional data sources along with research outcomes to derive the identity of data subjects or a set of proxy attributes that can identify individuals or population groups. Although you cannot prepare datasets for every eventuality, you should consider whether the current level of de-identification is proportionate to the datasets being used, and (as much as reasonably possible) if there are any other datasets available which could be used to indirectly identify individuals.



7. Data Security



place to recognised standards that is proportionate to data use/sensitivity Research taking place outside of a recognised secure environment, with proportionate data security precautions taken

Research taking place outside of a recognised secure environment, with some data security requirements still to be considered

Version 3.0

Data security is an essential requirement for any research environment. The level of security required should be proportionate to the data collected, used, processed and curated. Depending on the granularity and sensitivity of data, we must ensure that public data is handled in a secure and responsible manner.

8. Ethical Consent



Informed consent has been obtained from data subjects for all stages of this particular project. Consent has not been obtained from data subjects for this research which can be justified Informed consent has not been obtained from data subjects which cannot be justified

From an ethical point of view, consent should be sought for each data use when collecting, processing, linking and sharing data for each individual project. Their consent should be sought in advance of the project taking place. Consent must be well informed and 'opt-in' rather than 'opt-out'.

As indicated by the middle response provided on the ethics self-assessment tool, there are instances where not seeking informed consent for a specific use of someone's data can be justified. An example of this may be secondary analysis of large administrative datasets, where it would be disproportionate for informed consent for this particular research use to be collected.

In these cases where informed consent for the research project is not sought and can be justified, you should be mindful of how this may impact your consideration of other items on the ethics self-assessment tool. For example, you may be undertaking secondary analysis on a number of administrative datasets. Due to the lack of informed consent for this specific research, you should be clear on the public views and acceptability of the research you are looking to undertake.





If you have secured approval from a data owner to acquire or use a dataset, then you will need to ensure that any further research based on that dataset falls within the context of the original agreement to use this dataset. For further information on ethical considerations when using third-party data, see our <u>high-level ethics checklist</u> focused on this data type.

N/A: There may be situations where permission to access certain data is not required. In such instances, you must still provide a justification, along with necessary evidence, to explain why permission is not required.

Principle 3 (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

10. Validity



Confidence that the methods used, and quality of data will lead to valid conclusions

was previously given

There is limited confidence/it is unsure whether the methods used, and quality of data will lead to valid conclusions Potential that methods used, and quality of data may/will lead to invalid conclusions

In many cases, you might use a dataset without knowing the quality of the data, the methods used to collect, process and visualise the data, and any assumptions made during those processes. All these factors may compromise the validity of the research. You should therefore strive to meet recognised standards of data quality and clearly state any hypotheses and assumptions.



11. Standards



The research organisation has established and tested procedures, and complies with recognised standards There is limited confidence/it is not clear whether the organisation has established and tested procedures, and complies with recognised standards The research organisation does not have established clear procedures or may not comply with recognised standards

Compliance with recognised standards does not only ensure the validity of the research, but also the reproducibility of results. It improves the resilience of the organisation to public scrutiny and is a vital part of building public trust and confidence. Apart for auditable research procedures, researchers should have policies in place to assure the security of the research environment, for example, to manage data breaches.





It is essential that researchers have an updated training portfolio over a broad spectrum of research skills and experience. Documenting these skillsets within the research team enables for more flexible working and ensures continuity and knowledge transfer. Organisationally, this provides assurance that, apart from the technical systems, staff have the required expertise to undertake the research specified.

13. Human Oversight





The extended use of 'off-the-shelf' software solutions, and the use of code sharing platforms, requires you to be vigilant of assumptions and constraints which may not always be documented. Human oversight is a critical safeguard of any research governance process, requiring an emphasis on the quality of methods used, especially as automated processes become more opaque.

N/A: Omit this item in case of fully **transparent** automated or manual processes with well documented assumptions.

14. New technologies



Established methods and technologies have been tested extensively over long periods, are well documented, and have been subjected to scientific scrutiny. This offers assurance to the public that personal data are handled safely and provides confidence in the quality of research/statistical outputs. New technologies may entail a wider variety of unforeseen risks, from security to methodology, which may not have been discovered. Of course, the research community draws on innovation and should not miss the opportunity to transition to new technologies. Researchers should remain vigilant of the data sources and methods used in their projects and make sure that adequate security arrangements are in place.

If you are using location data or machine learning, see our guidance on ethical considerations in the use of <u>geospatial data</u>, and <u>machine learning</u>.

N/A: Omit this item for small-scale exploratory projects and feasibility studies which are not used to produce any research/statistical outputs.

15. Potential to realise benefits



It may not be enough to state the public benefit of your research project; you also need to make sure that the methods used, and the outcomes derived, can be used to realise the public benefit. Complex statistical outputs, increased number of assumptions, or the level of granularity and geography might not properly inform the public or decision-makers.



Principle 4 (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

16. Established legal gateways and agreements



The access and use of this data are lawful via a legal gateway, or a gateway is not required Don't know, or unsure if the proposed use of data requires a legal gateway Legality has not been confirmed, and/or there has been no formal action to seek legal advice or clearance from the relevant department

Depending on the type of research that you are undertaking, there may be a requirement for data to be acquired, processed, accessed, or disclosed via powers set out in legislation in order for the research to go ahead. We call these powers legal gateways.

If required, it is your responsibility to ensure that you access the data required for your research using appropriate legal gateways and agreements, and for the purpose that these gateways and agreements were intended for. Examples of legal gateways that may facilitate this access include the Accredited Researcher scheme in the <u>Digital Economy Act 2017</u>, the Approved Researcher scheme in the <u>Statistics</u> and <u>Registration Service Act 2007</u>, and <u>Section 251 of the NHS Act</u>.

As identified in the first response in the self-assessment tool, a legal gateway may not be required for data to be accessed and processed. This may be due to the project being a primary survey collection activity, or a case of a data owner accessing data that it already holds (such as ONS analysts using data that ONS already holds).

Please note, however, that legal gateways and data agreements do not exclusively apply to data access and may also apply to other areas of analysis and data sharing, such as data linkage, processing and onwards disclosure. Please consider all aspects of the research that you are undertaking when considering where legal gateways may be applicable. If this is unclear, please get in touch with your organisation's legal support service.

For further information on ethical considerations when using <u>third-party data</u>, see our high-level ethics checklist focused on this data type.





For this item, please consider what legal frameworks are applicable to your research. Examples of commonly applicable legal frameworks for research and statistics include: the Research strand of the Digital Economy Act 2017, UK GDPR, the Human Rights Act 1998 and the Equality Act 2010. Within your scoring justification, where applicable, you should include detail on your <u>lawful basis for processing this data under UK GDPR</u>. *Note, if the lawful basis is consent, this must be reflected in the ethical consent item*.

Working within a developing legal framework entails risks, especially for long-term projects, and as such requires researchers to remain alert to assess the impact of new laws relevant to their project. Due to the trans-national nature of some data and/or research projects, researchers should also consider the need to comply with international legislation when appropriate.

Researchers should consult with legal professionals to ensure the legal compliance of their approach.

Principle 5 (Public Views and Engagement): The views of the public are considered in light of the data used and the perceived benefits of the research See our guidance on considering <u>public views and engagement</u> for research and statistics projects when completing this section

18. Public views



The public is widely supportive of the project aim and method There is limited support of the project aim and methods from the public The public's views of the project aims, and method are negative or unknown

Research does not happen in isolation, so the wider environment in which researchers operate should always be taken into account. This does not mean that the public's views must be sought for every project, as this would be disproportionately time and resource consuming, but an overall awareness of public acceptability must be considered. Information from engagement events for similar



projects, government initiatives, public polls and literature reviews are reasonable alternatives to large public consultations or focus and expert groups.





Securing public engagement is one strategy for facilitating research projects. This could include engagement with the public or specialist/interest groups. Although there are several approaches to public engagement, it is most effective to maintain regular engagement throughout the life cycle of the project. A project might be acceptable at the design phase but may warrant further engagement at a later stage, e.g. when producing outputs.

N/A: Omit this item when no public engagement is required and can be clearly justified (e.g. for the production of statistics as part of statutory responsibilities; or if the same, or a very similar, research project has already completed public consultation or public acceptability testing)

Principle 6 (Transparency): The access, use and sharing of data is transparent, and is communicated clearly and accessibly to the public

20. Public access to outcomes



The use of data produced by the public offers an exciting opportunity to the statistical community but comes with a responsibility to be transparent to the public in the way we use their data. It is imperative that we share the research outcomes with the public and ensure that they remain openly accessible. This transparency principle is enshrined in the <u>Code of Practice for Statistics</u> and <u>Research Code of Practice and Accreditation Criteria</u>, and is also set out in the UK Research and Innovation's <u>Open Access Policy</u>.





tools are, or will be, made widely available to the public

21. Sharing of methods and tools

methods and tools will be available to the public

tools are not, or will not be, made widely available to the public, or will only be shared internally

place

In parallel with research outcomes, researchers often develop new methods and tools to enable future research to be more effective. Where appropriate, it is good practice for researchers to make these new methods and tools available for others to use, as this enables wider research impact and innovation throughout the research community.

N/A: There are some cases where researchers may not be able to share these tools and methods:

Firstly, when reverse engineering the tools or method could compromise the confidentiality of the statistical outputs produced; and

Secondly, when there is a legal agreement in place that prevents us from doing so, for example tools and methods are produced in partnership with a third party which retains intellectual property rights.

In these instances, this item can be omitted.

22. Data curation and re-use

available for re-use

research community

by the wider



You should select an appropriate retention period for the data to ensure that your research can be reproduced and validated. Due to the significant costs and burden involved with re-acquiring and preparing data, we encourage you to re-use raw and linked datasets when possible. You should remain vigilant of the sensitivity of identifiable datasets to be retained when selecting retention periods and data re-use.

known/unclear

N/A: Omit this item when data sharing agreements or original consent does not allow re-use of the dataset.



Training and Support

The Data Ethics team is your main point of contact for ethical queries, and can also help to facilitate further discussions and offer general assistance to researchers by providing advice on the self-assessments.

To support colleagues across the Government Statistical Service (GSS) and wider research community, we can also provide ethics training on request.

For more information, please contact us at <u>Data.Ethics@statistics.gov.uk</u>.

User Checklist

This checklist is to help highlight the key steps you should take when using the selfassessment form to evaluate the ethics of your project. It also highlights some of the key people or business areas that you may wish to discuss your self-assessment/ project with in order to ensure the legality of your project.

-] Made the appropriate checks that the use of data is legal
- Completed the Basic Information section
- Completed the Weightings for Sensitive Research Areas section
- Completed the Item drop down selection and justifications section
 - Shared self-assessment with appropriate colleagues to receive feedback

Shared self-assessment with the Data Ethics team for feedback (this is an essential step, regardless of your self-assessment outcome).

Please send completed self-assessment forms to <u>Data.Ethics@statistics.gov.uk</u> for feedback before commencing your project. Please note that the completed self-assessments submitted to the UK Statistics Authority may be subject to a compliance review audit.