



UNDERSTANDING SOCIETY DATA ACCESS STRATEGY

Contents

1. INTRODUCTION	2
2. OVERVIEW	2
3. DATA ACCESS PRINCIPLES.....	3
Data Custodianship	3
Ethical Considerations.....	3
Commercial Use.....	4
International Access	4
Data Acknowledgement.....	4
Data Security.....	4
4. DATA ACCESS RULES	5
Data Categorisation	5
5. DATA ACCESS PROCEDURES	7
6. UKDS AND ONS APPLICATION REVIEW PROCESS.....	9
Data Linkage.....	9
Other Data Sharing	10
7 ACCESS TO GENOTYPE OR EPIGENETIC DATA	10
8 DATA RETURN POLICY	12

1. INTRODUCTION

This strategy outlines the principles, rules and procedures for accessing *Understanding Society* data, including access to genotype or epigenetic data. An overview of the Study and data access strategy is set out in section 2. Data access principles are in Section 3. Rules and procedures for access to data are set out in Sections 4 and 5. The data categorisation and definitions of impact levels outline restrictions on access in Section 4. The UK Data Service (UKDS) and Office for National Statistics (ONS) application review process in section 6 provides details on how the review process works, who reviews the applications and how access is granted. Access to genotype or epigenetic data and the application review process is in Section 7. This document also outlines the procedures for returning and sharing data in accordance with the data return policy in Section 8.

2. OVERVIEW

- 2.1. *Understanding Society* is an innovative, world-leading longitudinal data resource designed to address the social issues facing 21st Century Britain. The study offers an unprecedented insight into UK households as they respond to regional, national and international change. *Understanding Society* is one of the largest study of its kind in the world and makes a major contribution to the UK's unique and internationally renowned portfolio of longitudinal studies.
- 2.2. All access to and use of *Understanding Society* data, and those of its predecessor the *British Household Panel Study* (BHPS), is governed by the procedures set out in this Data Access Strategy, which seek to be fair, open and transparent. The *Understanding Society* data controller is the University of Essex, and data access is managed by the Understanding Society Scientific Leadership Team (SLT) within the Institute for Social and Economic Research (ISER). The *Understanding Society* Strategic Oversight Board, and Economic and Social Research Council (ESRC) Management Board, will have oversight of the whole process, and review the Strategy and data use on an annual basis.
- 2.3. The aim of the Data Access Strategy is to ensure that the data¹ produced by *Understanding Society* is made as widely available as possible to the research community (nationally and internationally), whilst ensuring that sensitive data and/or data which is or may be disclosive of the identities of participants is secure, maintaining the legal and moral responsibility to the study participants and complying with the undertakings given to them (See [Data Privacy Impact Assessment](#) for more information).
- 2.4. The Strategy identifies a series of mechanisms to provide access to the data collected by *Understanding Society*. These procedures apply to all data collected, not just under the main studies commissioned by the ESRC, but also any co-funded add-on studies or data generated by research using *Understanding Society* data.
- 2.5. Rules and procedures for access to survey and linked data are set out in Sections 4 to 6. Rules and procedures for access to biological samples and genotype data are set out in Section 7.
- 2.6. The Strategy builds on existing agreements developed by the ESRC and UK Data Service (UKDS) for accessing data collected by complex longitudinal surveys. It recognises the importance of developing procedures, protocols and standards to support ethical safeguards surrounding data access and the reuse of data for research purposes.

¹ Unless otherwise specified, the term 'data' when used covers: all information or material gathered during the Study, including text, voice, video; blood; DNA, genotypes derived from these samples; and information arising from linkage to administrative data.

3. DATA ACCESS PRINCIPLES

- 3.1. The procedures and processes that have been applied to provide access to *Understanding Society* data derive from the key principles set out below:
- i. To maximise the impact of the study, the data produced by *Understanding Society* is made as widely available as possible to a range of users;
 - ii. All access to *Understanding Society* data is governed by the procedures set out in the Data Access Strategy, which aim to be fair, open and transparent. The controls applied are proportionate to potential risks and are designed not to create unnecessary barriers to research;
 - iii. *Understanding Society* data (including biological samples) will be available to all bona fide researchers (whether in universities, government departments, charities or commercial companies), for research that can demonstrate public interest and fits within the Study's ethical framework;
 - iv. To maximise access to the survey and related data, datasets are deposited at the UKDS and, for more specialised data, selected data sharing platforms. In order to maintain consistent and up-to-date data on all platforms, wherever possible, data are shared with specialised platforms via UKDS deposits;
 - v. All requests for access to the biological samples collected by *Understanding Society* are managed by the *Understanding Society* SLT and reviewed by the Strategic Oversight Board. Applicants will be expected to bear the cost of processing samples. As a depletable resource, the use of the biological samples will be carefully controlled, in order to optimise the long-term value of the resource;
 - vi. Access to administrative data linked to survey data will be governed by the specific data sharing agreements agreed by the relevant data owner and the University of Essex as Data Controller. In principle, the goal is always to hold such linked data in the UKDS Secure Lab and/or ONS Secure Research Service (SRS) to maximise access to them. Some data owners, however, require their linked data to only be held on other secure platforms for use/onward sharing. In such circumstances, the *Understanding Society* SLT would review such opportunities on a case-by-case basis and agree to them only if the access and review standards match those of the UKDS Secure Lab. In addition, where agreed with data owners, less disclosive versions of key variables will be added to our basic access (End User Licence, EUL) files to widen their access to the research community.

Data Custodianship

- 3.2. The University of Essex is the data controller; however as per the Human Tissue Act² the biological samples cannot be 'owned'. For the biological samples, the *Understanding Society* SLT is the data custodian, responsible for the safekeeping of tissue samples and control of their use, and eventual disposal (if required), all in accordance with legislation and the terms of the consent given by the donor.
- 3.3. Where *Understanding Society* data have been linked to administrative data, the relevant data owner remains the owner of the linked administrative data jointly with the University of Essex.

Ethical Considerations

- 3.4. Access to the data is granted in line with the terms agreed with the study participants. When assessing data access requests by whatever route consideration is given to whether the proposed research is consistent with undertakings given to Study participants when they took part in the study.

² <https://www.hta.gov.uk/policies/human-tissue-act-2004>

- 3.5. *Understanding Society* fully supports the right of study participants to withdraw from its surveys. Withdrawals, however, are not retrospective and such data cannot be removed from data already released.

Commercial Use

- 3.6. Commercial organisations can apply for access to *Understanding Society* data and are subject to the standard procedures. For some data the undertakings given to participants may prohibit commercial access. As per any application commercial organisations will be required to demonstrate the public benefits that are likely to flow from the research use. Applicants must confirm that their use of the data is for research purposes and not for commercial exploitation. No organisation, commercial or otherwise, should be allowed to gain control or ownership over the *Understanding Society* resource.

International Access

- 3.7. International access to *Understanding Society* data is important and unnecessary barriers should not prohibit such research. However, in some instances, procedures for protecting participants' data from disclosure risk may not be effective outside the UK and access may need to be barred. International access to *Understanding Society* data will be determined in accordance with the provisions of the UK Data Protection Act and the GDPR. If agreed by all data owners, Controlled access to the most sensitive, confidential and/or disclosive data held in the UKDS Secure Lab, is provided internationally via reciprocal provision of Safe room remote access within the International Data Access Network (IDAN). Note: Genotype or epigenetic data combined with EUL survey data is only available to researchers whose country of access is deemed to have an [adequate level of data protection](#) as determined by the European Commission.

Data Acknowledgement

- 3.8. It is a requirement of the use of *Understanding Society* data that researchers should acknowledge these sources by means of a study acknowledgement and bibliographic citation. To ensure that such source attributions are captured for bibliographic indexes, citations must appear in footnotes or in the references section of publications. The proposed acknowledgement and current bibliographic citations can be found at: <https://www.understandingsociety.ac.uk/documentation/citation> and in all UKDS web pages for applicable *Understanding Society* Study Numbers (SNS).

Data Security

- 3.9. ISER, at the University of Essex, has ultimate responsibility for data security, is ISO27001 certified, and requires all Data Processors to also meet this international standard for Information Security Management. The UK Data Archive (UKDA), a service provider for the UKDS, is also ISO27001 compliant and certified. The ONS SRS is accredited to government security standards to hold data up to OFFICIAL SENSITIVE and to make data available for statistical research projects up to OFFICIAL. Data security at ISER is managed by the Information Oversight Committee and at ONS the SRS is managed by the Secure Research Service Security Working Group.

4. DATA ACCESS RULES

- 4.1. Section 4 sets out the framework for providing access to all *Understanding Society* data (with additional information on the specific procedures for accessing biological samples, genotype, epigenetic and related data in Section 7). Access to formally released survey and related data are managed by the UKDS and the ONS SRS. Other repositories are also actively being considered for holding *Understanding Society* data - examples are the Cross National Equivalent File (CNEF), the UKSeRP (University of Swansea) and Secure Anonymised Information Linkage (SAIL). Access to genotype or epigenetic only data are managed by the European Genome/Phenome Archive (EGA), and access to combined genotype or epigenetic and EUL survey data are processed by the *Understanding Society* SLT (see Section 7).
- 4.2. There are three categories of *Understanding Society* data based on the likelihood and potential risk of disclosure. Each have defined access mechanisms:
- The majority of users access data via a standard licence known as an 'End User Licence' (EUL). Their application is authorised directly by the UKDS;
 - Access to more detailed data, which are potentially disclosive of the identities of individuals, households or organisations, is provided via a special licence through the UKDS and/or ONS SRS;
 - For a small number of users access to sensitive, confidential and/or disclosive data is provided via 'Secure Access' through the UKDS³ and/or the ONS SRS. This type of access is only available to persons who are designated as 'ESRC Accredited Researchers' for UKDS or 'Approved Researchers' for ONS SRS⁴.

Data Categorisation

- 4.3. The *Understanding Society* SLT has agreed a set of principles through which the *Understanding Society* data is categorised, reflecting an assessment of the likelihood and potential impact of disclosure. Data that risk the disclosure of information which could identify individuals, households or organisations with which they are associated will require the highest degree of security and management.
- 4.4. *Understanding Society* data falls into one of three categories, which are defined by the likelihood and potential impact of disclosure:
- **Impact Level 1**
Low impact (non-disclosive data, e.g. most survey responses and digital reports of biological assays and direct physical measurements);
- Impact Level 2**
Medium impact (potentially disclosive, e.g. medium level and coarse geographies) and linked genotype or epigenetic data); for non-UK applicants this category is subdivided into two groups, with the less disclosive subdivision (2a) available to international applicants on the same terms as for UK applicants, and the more disclosive subdivision (2b) only available if supported in law, for example in the Data Protection Act, and if additional scrutiny of the application is undertaken. Data classified as 2b is only available to researchers whose country of access is deemed to have an [adequate level of data protection](#) as determined by the

³ <https://ukdataservice.ac.uk/get-data/how-to-access/accesssecurelab/>

⁴ <https://www.ons.gov.uk/aboutus/whatwedo/statistics/requestingstatistics/approvedresearcherscheme>

European Commission. Note that the UKDS catalogue entry for every Understanding Society study identifies the international level restrictions;

- **Impact Level 3**

High impact, e.g. data with the most detailed geographies, and linked individual level administrative data. International access to impact level 3 data is restricted by the UKDS's/ ONS SRS's own access rules, however, such access is allowed if the UKDS/ONS SRS has a legally binding agreement with an international Research Data Centre and the agreement specifically identifies the appropriate *Understanding Society* secure access dataset.

Table 1 provides examples of data included in each category.

Table 1: Examples of data included at different impact levels

<i>Impact level</i>	<i>Data included</i>
Impact Level 1 (EUL)	Content of main interview survey, with some restriction on degree of disaggregation of categories, for example of occupation, industry, country of birth. Top coding of income variables. Region is lowest level of geography.
Impact Level 2a (Special Licence, available to non-UK users)	<p>Main interview survey data with detailed classifications - full occupation, industry, country of birth classifications, month as well as year of birth, no top coding of income.</p> <p>Main interview survey data with intermediate geographies e.g. local authority district, parliamentary constituency, travel to work area.</p> <p>Genotype or epigenetic data without linkage to survey data.</p>
Impact Level 2b (Special Licence, available to eligible non-UK users with additional scrutiny over 2a data)	Main interview survey data with neighbourhood spatial data, e.g. Lower Layer Super Output Area (LSOA), Census Area Statistics Wards; or with organisation identifiers, e.g. school identifier codes or linked genotype or epigenetic data combined with EUL survey data
Impact Level 3 (Secure Data Service)	<p>Full dates of birth and grid reference geographical data.</p> <p>Administrative data linked at individual level (e.g. education data).</p>

Table 2 below shows how different combinations of data at impact level 2a and/or 2b would be classified under this proposal.

Table 2: Classification of Special Licence data combinations

	Main interview survey data with detailed classifications	Intermediate level spatial data	Neighbourhood spatial data
Main interview survey data with detailed classifications (2a alone)			
Intermediate level spatial data (2a alone)	Impact Level 2b		

Neighbourhood spatial data (2b alone)	Impact Level 2b	Impact Level 2b	
Organisation identifier (e.g. school codes) (2b alone)	Impact Level 3 (but see note in 4.6)	Impact Level 2b	Impact Level 3 (but see note in 4.6)

4.5. Note when combining genetic or epigenetic data with survey data, it is only possible to use variables that are in the EUL version of the survey data. However if it is possible to derive an EUL version of a special licence variable such derived variables can be combined with genetics and epigenetics data, subject to disclosive considerations.

4.6. In general, projects are limited to a maximum of three ‘special licence’ datasets due to the increased risk of disclosure through small intersections. It is generally not allowable to mix census level Special Licence neighbourhood geographies for different years, for example, LSOA 2001 and LSOA 2011 or MSOA 2011 and MSOA 2021. This is to prevent the risk of the identification of small geographical areas due to boundary changes. This is, however, judged on a case-by-case basis as, for example, some neighbourhood and / or intermediate level geography datasets are geographically wholly contained within another more detailed geography, and therefore there is no increase in disclosure risk. It should be noted that the combination of Special Licence datasets identified in Table 2 as Impact Level 3 are not currently practicable, however, ISER is working with the UKDS to address the issue.

5. DATA ACCESS PROCEDURES

5.1. *Understanding Society* data is made available for researchers to undertake their analysis by identifying and requesting data from the UKDS⁵ or the ONS SRS.

5.2. The UKDS and the ONS SRS provide the interface with researchers and review applications to ensure they comply with this strategy and their own specified data security requirements. If researchers cannot meet these their applications are rejected at this stage⁶.

5.3. Each Impact Level of data has its own access mechanisms. The majority of users will apply to use Impact Level 1 data End User Licence (EUL). Their application is authorised directly by the UKDS. Access to more detailed data, classified as Impact Level 2, is provided via a special licence. This level of access is authorised directly by the UKDS or ONS SRS after consultation with the *Understanding Society* SLT. Access to Impact Level 3 (sensitive, confidential and/or disclosive data) is provided via ‘Secure Access’ through the UKDS and/or ONS SRS for ‘approved researchers’. Such applications are reviewed and approved by the *Understanding Society* SLT, and if appropriate the data owner of any linked administrative data.

5.4. *Understanding Society* biological data that are not disclosive (measurements such as height and weight, blood pressure and analytes derived from the blood samples) are covered by standard access procedures. Access to biological samples, epigenetic and genotype data is regulated by the *Understanding Society* SLT as detailed in Section 7.

5.5. Access arrangements for each category of data assigned by the *Understanding Society* SLT are enforced by the UKDS and/or ONS SRS. Penalties for misuse of data under each category are detailed

⁵ The current released version of *Understanding Society* data is supplied to users by default, however, archived older versions can be provided by making a special request to the UKDS.

⁶ <https://ukdataservice.ac.uk/app/uploads/cd171-researchdatahandling.pdf>

in the UKDS Breaches Penalties Policy⁷ or ONS Research Data Access: Compliance and Breaches Policy.

⁷ http://ukdataservice.ac.uk/media/176861/UKDA142_SDS_SecurityBreaches_public.pdf

6. UKDS AND ONS APPLICATION REVIEW PROCESS

- 6.1. Requests to access data are made to the UKDS or the ONS SRS. The UKDS or ONS SRS check applications to ensure that they comply with this strategy and that the applicant(s) satisfy the security and best practice guidelines in force. If not, then they will liaise with the applicant(s) either to help modify their application as appropriate or, if this is not possible, to reject the application.
- 6.2. Applications for requesting access to Impact Level 2 or 3 data will be forwarded to the *Understanding Society* SLT by the UKDS or ONS SRS. The *Understanding Society* SLT will determine whether the proposal meets the criteria set out below (see 6.3 below). For international access to data classified as impact level 2b, or other applications considered sensitive, an internal *Understanding Society* SLT sub-group will review the applications. The internal group, consisting of at least three experienced *Understanding Society* SLT members, will independently assess the application against the rules laid down in this document. Where there is not a consensus the *Understanding Society* Director will make the final decision.
- 6.3. Applications for data are considered by the *Understanding Society* SLT within 10 working days. Applications are assessed using the following criteria, and in the light of the impact levels outlined above:
 - 1) Has the application been submitted by bona fide researchers who can demonstrate public interest?
 - 2) Does the application violate (or potentially violate) any of the ethical permissions granted to the study or any undertakings given to the participants or their guardians?
 - 3) Does the application run the risk of producing information that may allow individual participants to be identified?
 - 4) Does the application run a significant risk of upsetting or alienating study members or of reducing their willingness to remain as active participants in *Understanding Society* based research?
 - 5) Does the application address topics that fall within the acknowledged remit of the *Understanding Society* project, as understood by participants?
 - 6) Does the application demonstrate that ESRC policy regarding deposit of data will be adhered to?
- 6.4. If access is granted, the decision is communicated to the UKDS or ONS SRS and data will be made available through them under a Special Licence/Secure Access agreement as appropriate.
- 6.5. The *Understanding Society* Executive Team (ET) will review decisions in the case of appeals received from potential users. If the *Understanding Society* ET is content with the decisions made it will explain the reasons to the complainant with reference to the published categorisation principles in this strategy. A further appeal may be made to the *Understanding Society* Strategic Oversight Board.

Data Linkage

- 6.6. Where appropriate approvals have been obtained, from participants and data owners, *Understanding Society* data may be linked to administrative data (e.g. school and hospital records). Data linkage will be carried out in secure conditions to ensure that the owners of the administrative data cannot link data collected in the survey to the name and address of the person concerned. Therefore any application to link *Understanding Society* data will be classified as Impact Level 3.
- 6.7. Access procedures for researchers wishing to link the data at individual, organisation and area level will be governed by the conditions of access set out in this Strategy. Where the data owner is not the University of Essex, approval will be required from the data owner before any decision is made

by the *Understanding Society* SLT on whether to grant access. The University of Essex recognises that Intellectual Property Rights in relation to some data linked to the Study from other sources, such as administrative data from a government department, will remain with the organisation which supplies it and cannot be transferred to the University of Essex.

Other Data Sharing

- 6.8. For very specialised datasets, other repositories are also actively being considered for holding *Understanding Society* data - examples are the Cross National Equivalent File (CNEF), the UKSeRP (University of Swansea) and Secure Anonymised Information Linkage (SAIL). Access to genotype or epigenetic only data are managed by the European Genome/Phenome Archive (EGA), and access to combined genotype or epigenetic and EUL survey data are scrutinised by the *Understanding Society* SLT (See Section 7).
- 6.9. Access to data not formally released, e.g. pre-release versions, is wholly managed within ISER by the *Understanding Society* SLT following fully defined processes. The default impact level for all datasets distributed through this mechanism is 2b (see section 4 for impact level definitions).
- 6.10. In all cases where other data sharing platforms or approaches are adopted, at a minimum, they will be required to follow the standards and requirements established by UKDA and described above.

7 ACCESS TO GENOTYPE OR EPIGENETIC DATA

- 7.1. *Understanding Society* has a significant biological component, including direct measures like blood pressure and the collection of biological samples, including, with participants' consent, the extraction of deoxyribonucleic acid (DNA) samples. .
- 7.2. Section 7 describes the process of gaining access to 'Omics' products from this sample collection, specifically data from a genome wide scan and the results of methylation analysis of the DNA samples. More information is available on the [Understanding Society website](#). Access to genotype and methylation only data are managed by European Genome/Phenome Archive (EGA)⁸, and access to genotype and methylation data linked with EUL survey data are scrutinised by the *Understanding Society* SLT.
- 7.3. The principles guiding access to *Understanding Society* genotype and methylation data are those of the overall study. There are a small number of variations set out in the paragraphs below.
- 7.4. The data should be available to researchers consistent with the undertakings agreed with participants. Communications with study participants for the collection of biological samples from which this data derives can be found in the Wave 2 Nurse section of the [Understanding Society website](#) fieldwork documents.
- 7.5. Given the nature of the undertakings given to participants, the data are not available for commercial research purposes. 'Commercial research' means any research that has, as its primary purpose, the development of products or procedures that may be sold or offered for profit or commercial advantage. Any application from a commercial organisation rather than a charity or not-for-profit would be subject to scrutiny by the *Understanding Society* SLT to ensure that there was a demonstrable public benefit arising from the proposed research.

⁸ <https://ega-archive.org/studies/EGAS00001001232>

- 7.6. Genotype and methylation only data are considered Impact Level 2a for risk of disclosure, while genotype and methylation data combined with other data are considered Impact Level 2b. Where an application relates to genome wide scan data, with the addition of an age band variable but with no other data from the survey, applications should be made to the Wellcome Trust Sanger Institute (WTSI) Data Access Committee (DAC). The same applies for methylation data from the EPIC array. The WTSI DAC has been given delegated responsibility for considering such applications within the framework agreed with the former *Understanding Society* Data Access Committee. If the WTSI has any concerns about an application, it will be referred to the *Understanding Society* SLT. Once an application is approved, the WTSI DAC will authorise applicants so they can download the dataset from the EGA.
- 7.7. For genotype and methylation only data (level 2a), the Wellcome Trust Sanger Institute (WTSI) Data Access Committee (DAC) would grant access to non-UK users providing they meet all the criteria and terms and conditions and provided that the disclosure risk can be managed in a manner equivalent to that for UK based researchers. Genotype or epigenetic data combined with EUL survey data applications would be considered by the *Understanding Society* SLT from researchers whose country of access is deemed to have an [adequate level of data protection](#) as determined by the European Commission.
- 7.8. For disclosure risk and / or quality control reasons a number of cases have been removed from the genome wide scan data files before depositing/sharing. These include those cases where genetic and reported gender or parentage (where both child-parent have provided DNA) results do not match.
- 7.9. Applications for genome wide scan data and/or methylation data linked to EUL survey data should use the application form on the [Understanding Society website](#). This includes the terms and conditions to which the applicant must agree. Applicants are asked to specify the nature of the proposed research and all data to be used in the project. The *Understanding Society* SLT will evaluate the application on the basis of:
- the disclosure risk associated with the application;
 - advice from the relevant experts where necessary, and;
 - an assessment of whether the applications meet the criteria set out in section 6.3.
- 7.10. An internal *Understanding Society* SLT group, consisting of at least three experienced *Understanding Society* SLT members, will review the applications against the rules laid down in this document. Where there is not a consensus the *Understanding Society* Director will make the final decision.
- 7.11. The evaluation of the proposal will be made by the *Understanding Society* SLT within a maximum of 30 days of its submission, but usually much quicker. The *Understanding Society* SLT will inform the applicant of the decision in writing and aim to deliver the data within 30 days except in exceptional circumstances.
- 7.12. Where the request involves a combination of genotype and/or methylation data with EUL survey data, the dataset will be supplied by ISER. This will include the smallest viable subset of survey data to minimise disclosure risk, and depending on the research question, applicants can request the full genome and/or methylation scans or list the *Single Nucleotide Polymorphism* (SNPs) required. As noted in 4.5 above, genetic or epigenetic data can only be combined with survey data classified as EUL. However, if it is possible to derive an EUL version of a special licence variable, such derived variables can be combined with genetics and epigenetics data, subject to disclosive considerations.

7.13. Whether a researcher accesses the genome wide or methylation scan data alone via EGA or in combination with survey data, there will be a non-negotiable requirement to supply the *Understanding Society* SLT with three outputs:

- any new scientific data (e.g. genotypes, new variables or polygenetic scores) created in the project. These will be shared with the wider scientific community, increasing the value of the resource;
- notification of all publications using the data;
- any incidental information on genetic variants identified during the research project that could potentially meet three criteria⁹:
 - a. scientific validity (the genotyping is of adequate quality);
 - b. clinical significance (the disease or condition caused by the genetic variant is potentially serious), and;
 - c. potential benefit, i.e. a valid approach exists to prevent or cure the condition/ disease of concern and that early knowledge of the genetic risk to which an individual is exposed could enhance the efficacy of that prevention/cure.

Please note researchers are not being asked to investigate clinically relevant findings, but to report them if they are identified during the course of their research.

7.14. *Understanding Society* has no current plans to share incidental clinically significant findings with respondents. Indeed the informed consent given by respondents, in keeping with most other studies, specifies that ‘*no personal test results from my DNA will be given to me*’. However, there are discussions within the ethical and scientific communities about what constitutes best practice in this respect, and advice may change in the future making it a requirement to report genetic findings to study participants if they satisfy the above criteria. *Understanding Society*, in common with other studies, has therefore decided to collect information on potentially relevant findings from research groups using the DNA data. It should be emphasised, however, that under no circumstances should researchers attempt to contact participants about potentially clinically relevant findings; this would be done, if there was a change in policy, by the *Understanding Society* study team after retrospectively agreeing new consents with participants or after alternative ethically approved processes were agreed.

7.15 With participants’ consent, *Understanding Society* kept some biological samples for future unspecified use. Researchers wishing to use these samples will be expected to bear the full cost of processing them. As a depletable resource, the use of the biological samples will be carefully controlled by the Study’s Strategic Oversight Board, in order to optimise the long-term value of the resource. The principles and process for reviewing applications for biological samples is set out in our tissue bank protocol (link to be added). Researchers wishing to use the samples should contact the *Understanding Society* Director in the first instance.

8 DATA RETURN POLICY

8.1. It is a requirement of the UKDS licence, and UKRI funding, that any researcher who is approved for access to *Understanding Society* data and in the process of undertaking their research generates new data, for the new data and associated metadata to be offered for deposit to a standard agreed with the UKDS, or via the SLT for genetic and epigenetic data. Deposit of analysed data will be the responsibility of researchers and penalties may be incurred for failure to adhere to the agreed policy.

⁹ Knoppers BM, Joly Y, Simard J, Durocher F. The emergence of an ethical duty to disclose genetic research results: international perspectives. *Eur J Hum Genet* 2006;14(11):1170-8

- 8.2. More broadly, the *Understanding Society* SLT encourages all data users to share code they employ to create value added variables with other users – to encourage open science and improve the utility of the data for the wider research community - via the [Understanding Society website](#).