



ETHICAL GOVERNANCE FRAMEWORK

Drafted by the Ethical Advisory Group of the UK10K project

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Overview

This document sets out policies and guidelines for the UK10K project that specifically relate to the ethical and regulatory issues with regard to participant involvement.

The objectives of the UK10K project are to apply genome-wide sequencing to existing research collections of (i) patients with specific diseases and (ii) participants in longitudinal cohorts, to establish a long-lasting research resource of general benefit to UK and global genetic research, and to characterize the genetic basis of several specific diseases. This project will draw together samples and information from more than ten studies that are currently running across the UK and other countries. The studies are either longitudinal cohorts or disease-specific studies. In the case of disease-specific studies, patients have given their informed consent for genetic research into the basis of their existing condition.

The UK10K project data will be generated in a research setting, not in a laboratory accredited for clinical diagnostic testing. The data to be generated and the likely yield of genetic variants discovered in each participant are summarised here. Four thousand participants in UK longitudinal cohorts will be sequenced to approximately six-fold coverage of their entire genome (on average), which is an efficient design for capturing population variation, and will identify approximately 3 million variants in every genome. Six thousand patients will have ~95% of their genes sequenced to approximately fifty-fold coverage (on average), which will identify approximately 20 thousand variants in genes in every genome, including hundreds of variants that have never previously been observed in human populations and whose functional impact is not known. Among these novel genetic variants there will be tens of variants in the ~2,500 genes in which specific mutations are already known to cause genetic diseases (as defined by the Online Mendelian Inheritance in Man database), but the vast majority of these novel genetic variants in known disease genes are unlikely to influence disease risk.

The aim of the Ethical Governance Framework is to enable the UK10K project to operate as a federated system. This means that projects can work together under a common ethical framework, which can acknowledge the nuances of particular studies, while still allowing them to be part of a common endeavour. At the same time, we must make sure that there is sufficient harmonisation so that these very different studies can participate in an ethically-coherent project that maximizes the research benefit, while acknowledging the responsibilities and obligations that are owed to research participants.

An important precept is acknowledging and respecting the role of the principal investigator of each collaborating study. In the UK10K project, the principal investigators have a number of responsibilities and obligations, such as obligations of confidentiality. Many of the principal investigators have collected samples from research participants and may have an on-going clinical and/or research relationship

with research participants. This means that they are in a good position to assess what are in the best interests of research participants, in consultation with the participants themselves and others.

The principal investigator and other researchers in UK10K have a custodian role, to ensure the careful and responsible management of the samples and information entrusted to their care by research participants. As part of this role, they have the responsibility to ensure the safekeeping of the sample and data by depositing it in a biobank or research repository, or to have the samples and information destroyed at the end of a project. They have an obligation to operate in conformity with the requirements of their own institution and fulfill all necessary regulatory and ethical requirements. They also have obligations to the UK10K project and other researchers, as well as the funders and the wider research community, to carry out high quality, ethical research. Once samples and information are deposited into a research repository these obligations are transferred to the new custodian, who must ensure that the original obligations to research participants are honoured.

The purpose of this document is to provide a framework for this collaboration and to focus on specific issues that are key to the development and operation of UK10K. To achieve this we have drawn upon the ethical policy documents established by other large-scale genetic consortium projects, including the UK Biobank and the organizing schema of the International Cancer Genome Consortium, as well as upon the precedents established in current research practice.

Policies (*in bold italicized red, in boxes*) are the principles that all project members agree to abide by during the course of the project. **Guidelines** (*in bold blue*) are recommendations that are believed to represent ‘best practice’ at the time of writing. If the guidelines supporting a given policy offer alternative ‘best practice’ possibilities then each collaborating study in UK10K should choose one to follow. For some policies this gives project members a choice over which of the ‘best practice’ options articulated in this document is appropriate for their study. Our intention is that the same policy can be adhered to in a different way using the best practice possibilities outlined in the guidelines. We regard this as ‘living’ document and anticipate that there will be new examples of what is considered ‘best practice’ as these types of studies increase and practice develops.

This document was compiled by the Ethical Advisory Group of the UK10K (EAG) and then went through a process of review. Once a draft was completed by the EAG, it was sent to all principal investigators in the UK10K project and then to external reviewers (see Appendix B). All of these comments were compiled and the EAG met again to review and finalise the document. As this is a living document we anticipate that it will be subject to this process of review, or a similar one, on a number of occasions.

Regulatory Approvals

All research conducted as a part of the UK10K project must be ethically approved and conform to all the legal and regulatory requirements for medical research in the UK and/or in the country where samples have been collected.

The core scientific plan of the UK10K project will have approval from appropriate research ethics committees in accordance with guidance from relevant bodies (such as the UK National Research Ethics Service). All aspects of the project will be carried out in accordance with the necessary legal requirements. In addition, all collaborating projects should also determine whether additional separate ethical (or other) approvals are required for involvement of their study in UK10K.

Under current Wellcome Trust Sanger Institute policy (which is subject to change), where samples of human DNA/RNA are obtained from certain countries within the European Economic Area (EEA)¹, the study will only require ethical approval from the appropriate ethical review body in the country from which the samples originated. If DNA samples are being imported into the Sanger Institute from outside this list of EEA countries¹, the study investigators will need to have local ethical approval from the source country and UK NHS or University research ethics committee approval in order to use these samples. For research using a sample cohort made up from both UK and non-UK sources, investigators may opt to obtain a single UK NHS REC approval that covers both UK and non-UK samples and their use in the project. Documentary evidence of research ethics committee approvals will be stored in a central cache at the Sanger Institute, in its role as sponsoring institute of the UK10K project. The provisions of the Human Tissue Act 2004, such as the requirements that apply to collection, use and storage of samples do not apply to the UK10K project. This is because currently only extracted DNA samples are being used in this project. Extracted DNA does not constitute 'bodily material' nor 'relevant material'² as defined by the Human Tissue Act. In the future, if 'relevant material' is to be used, the UK10K project will consider how to ensure compliance with the Human Tissue Act.

Informed Consent

Participants in the UK10K project will have given their informed consent to genetic research through a process that has been approved by an appropriate research ethics committee (REC).

It is envisaged that the majority of participants in the UK10K project will be UK in origin and have already consented to genetic research. Participants from longitudinal

¹ Austria, Belgium, Cyprus, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Liechtenstein, Luxembourg, Malta, Netherlands, Norway, Portugal, Spain and Sweden.

² Under s. 53 of the Human Tissue Act 2004, "relevant material" means material, other than gametes, which consists of or includes human cells. It does not include (a) embryos outside the human body, or (b) hair and nail from the body of a living person.

cohorts have given broad consent for genetic research; patients have given consent for genetic research into the basis of their existing condition, which may be for disease-specific research.

The prime consideration is whether the existing consents are in accordance with the National Research Ethics Service (NRES) guidelines on informed consent (Appendix A), and/or with the requirements of another relevant jurisdiction in the case of samples sourced from outside the UK, and that they adequately cover the UK10K project plans for:

1. Genetic analyses: the genome-wide sequencing that will be undertaken;
 2. Data management: the deposition of the resulting data under a managed access system, (as outlined in the Data Access section below);
 3. Management and communication of findings of individual clinical significance.
- **When conducting research involving samples collected previously, if existing consents are already in place that will adequately cover UK10K research (as described above), the principal investigator and his or her institution in consultation with the UK10K Ethical Advisory Group may decide that the research should proceed without re-engaging with a research ethics committee.**
 - **If principal investigators are unsure whether the existing consents are sufficient to allow UK10K research, they should consult with the chair of the relevant REC as to whether an amendment to their existing ethical approval and/or re-consent of participants to participate in the UK10K project is required. Both prospective and retrospective consents should be in accordance with the NRES guidelines on informed consent (Appendix A).**
 - **If RECs require the re-consenting of participants, various consent mechanisms could be suggested to the REC. One possibility may be that if participants have already consented for genetic research, a REC might consider that it would be sufficient to communicate with the participant *via* a mechanism for which receipt can be confirmed (e.g. letter by recorded delivery, or verifiable electronic communication) explaining the additional elements of the UK10K study over and above the research previously consented to, and giving an opportunity for the potential participant to opt out of the study. It is desirable to solicit participant feedback on the nature and content of any such proposed communication before implementation to ensure that it is comprehensible and workable.³**

³As an exemplar, the South East London Research Ethics Committee 2 have proposed that the participants in the TwinsUK cohort should be sent a verifiable communication informing them of this new project and the implications of whole genome sequence data, giving them the opportunity to opt-out within a four-week time frame. The sample custodians for the TwinsUK cohort have subsequently consulted with their focus group of participants (the twin volunteer opinion panel), who viewed the proposed content of the communication and gave their approval for this process.

Confidentiality

All researchers in the UK10K project have an obligation of confidentiality and must conform to data protection principles to ensure that samples and data are processed lawfully. Appropriate protections will be put in place to safeguard the interests of participants and to ensure data security, such as the replacement of participant's names with a barcode or study number. There is always a possibility that research participants could be indirectly identified from the data generated through the project. Therefore, all researchers in UK10K are under professional obligations to maintain the confidentiality of the samples and data. Those who access the data through a managed access system must sign a form agreeing not to try and identify individuals. If they did try to identify someone, they might well be subject to disciplinary proceedings.

Feedback to Participants

In most cases participants will be able to access the research findings of the UK10K project through the UK10K website (www.uk10k.org) where a lay description of the project, media releases, and publications in peer-reviewed scientific journals can be found. As a general rule, the UK10K study will not feedback to participants their genome sequence data, either as a matter of course or on request by the participant. This is because research data produced by the UK10K project is not of a clinical diagnostic standard. Ten percent of the UK10K project comprises studies of patients with rare genetic diseases, many of whom have specifically consented to have pertinent diagnostic data fed-back to them. These individual research studies have already established robust management pathways for validating potentially diagnostic research data to diagnostic standards prior to reporting back to the patient.

1. Findings of clinical significance

The investigators of the UK10K project have an obligation to establish robust management processes for handling potential clinically significant findings should they arise, but do not have an obligation to search for such findings. Management processes to facilitate this will be agreed and established prior to data generation commencing and must have the approval of the relevant authorities, such as a research ethics committee.

There are many REC-approved precedents within the UK for not feeding back any individual genetic research findings to participants. However, these are typically

situations where the results from the study are expected to have little, or no predictive value to individuals.

A small minority of the genetic variants identified in the UK10K study may be 'clinically significant', which we define as those variants that contribute to the current disease status or alter assessment of the future disease risk of the research participant. Of all the ethical issues raised by the UK10K project, we consider the issue of feedback to participants of genetic research findings of potential clinical significance to represent the most substantive risk of divergence between the existing consents and the National Research Ethics Service (NRES) guidelines on informed consent. Below we expand on the legal and ethical background to this issue and the policies and guidelines we have established for managing this issue.

We distinguish between two classes of clinically significant findings: those that pertain to the disease being researched in each project, which we term '**pertinent findings**' (PFs), and those that relate to other diseases outside of the original research objectives, which we term '**incidental findings**' (IFs). 'Incidental', in this context, means incidental to the original aims of the research study, and are therefore unforeseen at the time that participants give consent. 'Incidental' does not imply that the evidence for disease causality is weaker, or that the associated disease is less severe. Given the nature of the data being generated by the UK10K project, the potential for identifying potential IFs is considerably increased compared to previous genetic research projects. The assessment criteria that apply to PFs and IFs are slightly different, although the management pathways are the same.

There are many REC-approved precedents within the UK for genetic research studies feeding back confirmed clinically significant findings to the patient that pertain to their existing disease status (PFs). Among some of the studies participating in the UK10K project, some patients have explicitly consented to feedback of PFs, and there are pre-existing management pathways for confirming the analytical and clinical validity of research findings relevant to a specific disease and communication of these findings to the patient. We regard that ethically robust feedback to participants of findings that pertain to the current disease status of the participant (Pertinent Findings - PFs) is a desirable benefit of the UK10K project.

We are unaware of any REC-approved precedents within the UK for genetic research studies feeding back confirmed 'incidental findings'.

The duty of care owed by a researcher towards a research participant regarding the feedback of clinically significant findings is not well established in UK law, although clinicians do have a legal duty of care for their patients. Many of the collaborating studies in UK10K involve principal investigators who may have a dual role as a treating clinician and as a researcher. Within the project, there are different types of principal investigators: non-clinical custodians of population cohorts; clinical custodians of population cohorts; clinical custodians of patient collections from different recruiting physicians; and clinical custodians of patient collections who are themselves recruiting physicians for some or all patients.

There are no national guidelines from the National Research Ethics Service (NRES) regarding the feedback of clinically significant findings in genetic research, other than that during the consent process information should be provided about any procedures for feedback of “*individually significant*” information, and that any such feedback should be explicitly consented to. Consequently, it is not straight-forward to unambiguously establish the standards that ought to be applied when considering the feedback of clinically significant findings from a genetic research study such as the UK10K project. Feedback is only possible if an individual can be identified and it is possible to contact them.

Our understanding of which genetic variants are clinically significant is ever-changing. Moreover, in the context of a project whose explicit objective is to make data available to other researchers, in principle, potential clinically significant findings might be identified through analyses undertaken by non-UK10K researchers accessing the data through managed data access mechanisms, whom we term collectively ‘secondary researchers’. An open commitment to re-evaluate *ad infinitum* genetic data from a research participant to identify clinically significant findings is simply not sustainable.

In the context of a large project comprising many different principal investigators, such as the UK10K project, the role of the project is to develop consensually a framework of principles to achieve consistency and equality of consideration across the project for considering the feedback of clinically significant findings. Therefore, there is not a single approach for discharging this moral duty should it arise as different circumstances may exist for different participant collections and principal investigators.

- **If a principal investigator decides that feedback of findings of clinical significance is appropriate then this must have the consent of the research participant and approval by a research ethics committee. All communications of findings of clinical significance carry a risk of causing unnecessary harm to the research participant and their families. Thus the principal investigator must balance the potential risks and benefits of feeding back clinically significant information and appropriate management pathways must be in place.**
- **If a principal investigator decides that feedback of findings of clinical significance is appropriate, and yet a potential participant has requested no further contact with the research team during the consent process, then the participants ‘right not to know’ should be respected, and their participation should not be disallowed on the grounds that feedback of findings of clinical significance is not possible.**
- **If a principal investigator decides that it is not appropriate to feedback any genetic findings of clinical relevance, this course of action must have research ethics committee approval, and, where possible, and if the participant has**

consented to further contact, then the participant should be contacted and informed that no feedback will occur.

2. Assessment Criteria

Feedback of findings of clinical significance from a research study, whether a pertinent or incidental finding, is only ethically sound if:

- 1. The participant has explicitly consented to the feedback of that specific class of finding (i.e. pertinent and/or incidental findings of specified clinical utility), and has been given an opportunity to exercise their 'right not to know' and yet still participate in the research.*
- 2. The analytical validity of the research finding is established in an independent sample from the patient by a CPA-accredited laboratory.*
- 3. The clinical validity of the research finding must be of equivalent robustness to information fed back from a clinical diagnostic test.*
- 4. Mechanisms exist for the appropriate clinical management of feedback to participants.*

Feedback of PFs will not be applicable to participants who have not been recruited for research on the basis of a specified clinical condition. Therefore for the UK10K project, the feedback of pertinent findings is applicable to disease-focused studies, and not to the cohort studies.

Given the lack of precedents for the feedback of IFs from genetic research and the relative lack of research on the impact of feedback of IFs from genetic research, currently, we regard that it would only be ethical to consider the feedback of IFs of the greatest clinical validity and clinical utility, in other words, where there is an unambiguously predictive relationship between the genotype and disease, and a clinical intervention to mitigate the disease risk is available, and the benefits of that clinical intervention unambiguously outweigh the harms. If a UK10K principal investigator applies for and obtains research ethics committee approval for feedback of IFs, the Ethical Advisory Group will work with the principal investigator (and consult with appropriately qualified experts) to implement this assessment of clinical validity and clinical utility for potential IFs. Given the current lack of precedents and relevant research, we expect that best practice for management of IFs may change, and accordingly this policy will be subject to review.

Research findings from the UK10K project will not be of the same standard as clinical diagnostic tests. For example, sample tracking in a research setting is not infallible, which raises the very real risk of causing harm by feeding back information to the wrong person. It is not ethically sound to feedback research findings without having established the analytical validity (accuracy of the genotype in the participant) and clinical validity (the accuracy of the genotype in identifying or predicting a particular clinical condition) of the research finding.

- Assuring that a research finding is of the same quality of information as provided by a clinical diagnostic test, requires that the analytical validity and the clinical validity of the finding can be confirmed to the same standards as are applied to clinical diagnostic testing.
- Assuring that a research finding is of the same analytical validity as provided by a clinical diagnostic test is best accomplished by confirmatory testing of an independent sample that has been handled, stored and tested in a laboratory that has been accredited by Clinical Pathology Accreditation Ltd (CPA-accredited). Such an independent sample may require obtaining a fresh sample from the participant, or using a previously taken sample that has been handled exclusively within a CPA-accredited environment, allied with relevant research and clinical expertise of the disease.
- Prior to analysis by the CPA-accredited laboratory it is desirable for the researcher to verify the findings in an independent experiment so as to minimize unnecessary workload for CPA-accredited laboratories.
- Assuring that a research finding in a participant is clinically valid requires that variants of the same type in the same gene have been unambiguously identified as being pathogenic in a peer-reviewed journal. This assessment of clinical validity is best undertaken by those whose professional duty is to make such judgements, typically in a clinical diagnostic laboratory setting.
- Participation in research should not be necessarily precluded if a participant is not contactable, due to the obligation to make best use of a research donation by the participant. However, inclusion of such a participant may rule out establishing the analytical validity of a research finding and/or feeding back findings of clinical significance if it is not possible to contact them.

3. Management Pathways

UK10K researchers who identify a research finding of potential clinical significance should attempt to identify whether the participant comes from a study in which at least some participants have consented for feedback for the appropriate clinically significant finding (i.e. PF or IF) before contacting the relevant principal investigator, through the UK10K Management Committee, if necessary.

It is the responsibility of the UK10K project management to ensure that a research finding of potential clinical significance (PF or IF) in a research participant identified by UK10K researchers is passed on to the appropriate principal investigator.

If a REC has approved the feedback of clinically significant findings (PFs and/or IFs) and the patient has consented to the feedback of those findings and the assessment criteria have been met, it is the responsibility of the principal

investigator to feedback clinically significant findings according to the REC-approved management pathway, which may differ between studies. This is only possible if participants can be identified and they can be contacted.

Secondary researchers who, having accessed UK10K data through managed data access mechanisms, may identify a research finding of potential clinical significance in a research participant might attempt to contact the relevant principal investigator directly. The name and contact details of the principal investigator for a specified study collection will be made available to facilitate this. If it is not possible to contact the principal investigator directly, a secondary researcher might choose to contact other UK10K project members or the independent Data Access Committee. The UK10K project member or the Data Access Committee member should pass on the information to the relevant principal investigator, via the UK10K Management Committee if necessary.

Data Access

The UK10K project consortium is committed to the principle of maximizing research access to data and will ensure rapid data release via a managed data access system.

The investigators of the UK10K project are committed to the principles of rapid data release to the scientific community and this is supported by the Wellcome Trust that funds the project. The UK10K project considers that the maximal benefit from research will be accrued when data generated by the project is made as accessible as possible to the research community, while protecting the interests of participants with regard to their privacy and confidentiality, and the scope of the research to which they have consented.

The level of detail of data generated on each participant in the UK10K project is such that it will be unique to each participant and thus if linked to other non-anonymised genetic data could potentially be used to identify the participant, which raises important participant privacy protection issues. We note that because the data on each participant is never associated with their name, but only with a unique study number, identification by a third party is only possible if extra information for a participant were to be available, for example, if additional genetic data associated with the participant's name had been generated. Over the past three years, robust and secure database infrastructure has been established, both in the EU and in the US, to store and make available to the research community such potentially identifiable genetic data on research participants. Previous large-scale genetic research studies, for example the Wellcome Trust Case Control Consortium, have generated genome-wide genetic data that is similarly identifiable and have used this established infrastructure to share genetic data securely with hundreds of researchers worldwide.

The data access mechanisms adopted by the UK10K project utilise the established database infrastructure described above. The details of the data access mechanisms are contained in the UK10K Data Sharing Policy document but the salient points with regard to the ethical issues are summarized here. All sequence data will be submitted to the European Genome-Phenome Archive (EGA), which is a secure database established by the European Bioinformatics Institute for the sharing of data with the research community. Access to the data in this database will be managed with oversight from a Data Access Committee. A Data Access Committee independent of the UK10K investigators will oversee the approval process for UK10K data in a fair and consistent manner. This Data Access Committee will only approve applications from an appropriately qualified researcher who signs a legally-binding Data Access Agreement in which they commit to:

- a) use the data only for research purposes;*
- b) protect data confidentiality;*
- c) provide appropriate data security;*
- d) not attempt to identify individual participants from whom data were obtained;*
- e) not redistribute the data or any subset or derivative that could be used to identify the research participant.*

In addition to the sequence data on the participants, for the data to be useful to the research community, genotype-linked phenotypic data may also be made available through the EGA. Access to phenotype data will be overseen by the same Data Access Committee that oversees the sequence data. It is anticipated that the Data Access Committee that was established by the Wellcome Trust to provide oversight for access to Wellcome Trust Case Control Consortium data will also be used to provide oversight of access to UK10K data.

Withdrawal

Research participants must be informed that they are free to discontinue their involvement in the UK10K study at any time. Upon withdrawal, no new information will be collected, no further analyses of existing information will be performed within the UK10K project and existing information will be destroyed. However, it will not be possible to remove data or destroy it once it has been downloaded by other researchers through the European Genome-Phenome Archive (EGA).

The UK10K project is committed to sharing data with the research community and will deposit data with the EGA repository to achieve this. This means that it is impossible to guarantee the complete withdrawal of individual data from all researchers who have accessed the data through the data-sharing repository. We consider that the benefits resulting from sharing data outweigh the risks associated

with being unable to give an absolute commitment to destroy all data generated upon withdrawal. We are aware of several precedents where other studies based on retrospective consents that have adopted the same or similar data access mechanisms have sought and obtained REC approval for this revised interpretation of the action taken on withdrawal, (for example the WTCCC2 project).

- **If this definition of withdrawal is not contained in existing consents, then research ethics committee approval should be sought for the action that will be taken when a participant withdraws from the project.**

Appendices

Appendix A: NRES guidelines for informed consent for genetic studies

These guidelines are taken from the NRES publication “Information Sheets and Consent Forms. Guidance for Researchers and Reviewers”, version 3.2 May 2007.

Documents should explain clearly:

- the background and purpose of the genetic study;
- what samples are required and what analyses are planned;
- whether there could be any results of individual significance to the participant and whether it is planned/possible to make feedback available to the participant;
- any implications, e.g. inherited risk, reproductive decisions, insurance status, etc, should be explained, together with what counselling support would be given. It may be necessary to refer the participant for re-testing by genetic services outside the study. The participant must retain the right to choose whether to access this information. If there will be no reliable information of individual significance, this should be explained;
- whether samples are to be kept for future analyses in conjunction with the planned project and whether later feedback could be available (consented);
- that if samples and information are to be retained, the same information as for other biological samples should be given;
- that if there may be later genetic studies then either additional consent will be sought from the participants or the study will be presented to an ethics committee for consideration. Feedback possibilities must again be considered;
- that if there is any likelihood of commercial significance, the participants would not benefit financially;
- the arrangements, if any, for transfer of samples outside of the UK.

Appendix B: Membership of Ethical Advisory Group

This document was prepared by the Ethical Advisory Group of the UK10K project and was sent to all principal investigators of the UK10K project for comments. It was then sent to external reviewers. As this is a living document we anticipate that this process of formulation and review will continue.

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This document does not represent the views of the external reviewers.