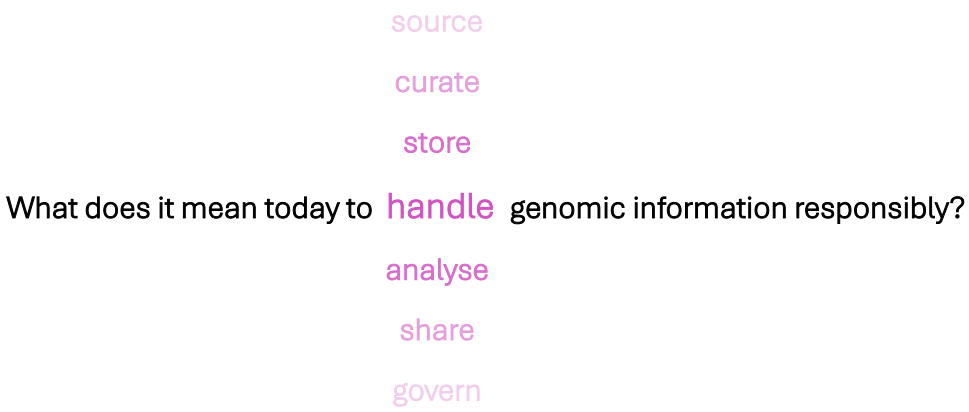
Call for Contributions

Closing Date: **10 July 2026**

Submissions: Please submit your response via **this form**.



Introduction

The Nuffield Council on Bioethics (NCOB) is inviting responses to a call for contributions on what it means today to handle genomic information responsibly. By ‘handle’ we mean to include any interactions with genomic information (and related omics or health information) across its lifecycle and in settings such as healthcare and genetic counselling, clinical and discovery research, and data infrastructure and governance.

We are especially interested in how current technological and social changes are shaping the abilities and obligations involved in handling genomic information responsibly, focusing on:

- The increasing use of artificial intelligence (AI) in genomic medicine and research
- The growing impact of commercial services and public-private partnerships
- The social context and emerging social practices around genomic information

We are running this call as part of our work leading the Network for Ethical Futures in Genomics (NEFG). NEFG is a UK-wide, cross-sector initiative that aims to strengthen collaboration and co-develop guidance for the genomics community. The initiative is jointly funded by Genomics England, UK Biobank, Our Future Health, and the Wellcome Sanger Institute. Responses will inform NEFG’s first report.

Who Can Respond

Responses from all sectors and disciplines speaking to any dimension of the lead question are welcome. You may handle genomic information yourself—e.g., in clinical or research settings—or think about its policy, regulatory, or social implications. Please try to be as specific as possible in your response, drawing on concrete examples and experiences from your setting or across settings.

You do not need to be part of NEFG to contribute, though we would be glad if you considered joining. If you would like to sign up or learn more, please get in touch with NCOB's Genomics Network Manager, Andreas Bruns (abruns@nuffieldbioethics.org).

How We Will Use Responses

Responses will inform NEFG's first report by helping us identify key themes, cross-sector issues, and guiding considerations for organisations, policymakers, and regulators. Responses will not be published in full or shared with any third parties. Contributors will only be named in an acknowledgement section of the report with their agreement. All contributors will be invited to review a draft of the report prior to publication. Responses will be stored securely and deleted one year after the report is published.

Submission Guidelines

Please write your submission in response to the questions below. You do not need to respond to all questions—partial responses focusing on some of the questions are welcome. Submissions should be made via **this form**.

There is a limit of 4,000 characters including spaces per question. You will be asked to submit the names and affiliations of all co-authors, as well as an email address for correspondence. You will also be asked to indicate whether you would be happy to be acknowledged as a contributor in the final report.

If you need to make a submission via email, or if you have any questions, please contact us (abruns@nuffieldbioethics.org).

Please submit your response by **10 July 2026**.

Questions

1. How are emerging AI and other data-driven technologies changing what the responsible handling of genomic information requires in practice? *You may wish to consider:*
    - Specific use cases of AI in your setting, and the opportunities and risks associated with applying AI models to genomic information.
    - How emerging technologies such as AI are affecting abilities or obligations to handle genomic information responsibly across settings or sectors.
    - Where the use of AI and other data-driven technologies exposes gaps in existing governance, guidance, or regulation related to genomic information, and what would be needed to address these gaps.
2. What do responsible public-private partnerships involving genomic information look like, and where do you see current tensions between public interests and commercial incentives (e.g. open data versus commercial licensing)? *You may wish to consider:*
    - Specific examples of constructive public-private partnerships and the measures or partnership models that enable them.

- What commercial services (e.g. direct-to-consumer testing, cloud computing, or data analytics services) affect your or others' abilities or obligations to handle genomic information responsibly, and how.
- Where you see gaps in current governance, regulation, or guidance regarding commercial services and public-private partnerships, and what would be needed to address these gaps.

3. How are current social factors (e.g. persisting health inequalities, misinformation, public expectations and scrutiny) shaping what it means to handle genomic information responsibly? *You may wish to consider:*
    - Your experience of what patients, research participants, or the wider public expect to happen with their genomic information, and where gaps exist between expectations and reality.
    - How the normalisation of genetic and genomic testing in mainstream medicine is affecting your or others' abilities or obligations to handle genomic information responsibly.
    - What specific changes to practice, policy, or regulation could help address systemic issues such as data bias or health inequalities.
4. How are responsibilities affected when genomic information is handled by multiple actors across settings and purposes? *You may wish to consider:*
    - Where you see your own responsibilities starting and ending across the data lifecycle (if you work directly with genomic information), and where you depend on others to be able to meet them.
    - Whether there are gaps where no individual or organisation appears clearly responsible (or accountable) for how genomic information is handled, and what would be needed to fill these responsibility gaps.
    - How responsibilities are affected when genomic information is accessed, shared, or reused across borders, and which minimum standards should 'travel with the data'.
5. What governance arrangements best support the responsible handling of genomic information (e.g. ethics and access reviews, public involvement, specific standards or regulation), and how? *You may wish to consider:*
    - Positive examples (UK or international) of practices, policies, guidance, standards, or regulatory approaches that support the responsible handling of genomic information and clear sharing of responsibilities across settings.
    - Where you think current UK policies, standards, or regulations fall short, and what specific changes would be needed (e.g., in relation to AI-enabled analysis or commercial use).
    - What would be required to establish a coherent UK-wide approach to the responsible handling of genomic information that is also fit for cross-border data access and exchange.