Participant Involvement Strategy

2024 - 2027

Summary

This strategy sets out our plans over the next three years to develop an expanded programme of participant involvement for UK Biobank.

Our broad aims are that:

1. Participant involvement is embedded in UK Biobank culture
2. Participant involvement at UK Biobank meets the highest standards
3. Participants and staff are supported to collaborate with each other

We will utilise different involvement methods to facilitate both in-depth discussion and broad engagement, including establishing a Participant Advisory Group and a large pool of Participant Reviewers, involving participants in UK Biobank committees, and conducting participant surveys.

We will deepen the involvement of participants in four areas of our work: Communications, Enhancing our research data, Ethics, and Strategy and governance.

We will evaluate the participant involvement programme to capture how we are meeting our aims, including commissioning an independent evaluation at the end of the three-year period.

Introduction

UK Biobank’s participants are at the heart of our organisation and, in many cases, they know best how we can get things right. Our participants have influenced our work in a range of important ways over the past 20 years. To ensure we continue to operate to the highest standards, we want to take a more strategic and embedded approach to involving participants in our work.

This Participant Involvement Strategy sets out our plans to expand the meaningful involvement of participants in our work and review the impact this is having.

This strategy was produced by UK Biobank participants and staff. Their discussions were informed by contributions from engagement experts and family members of participants, and by learning from the participant involvement activities of other organisations. A full description of our methods and contributors is at Annex A.

About our participants

Our 502,000 participants were aged 40–69 years when they were recruited throughout England, Wales, and Scotland between 2006 and 2010. Many thousands of participants have developed health conditions such as cancer, diabetes, stroke and depression, and around 40,000 have died.

There are slightly more women than men in the study, and participants are somewhat healthier and wealthier than the UK population across the same age range. However, they include large numbers of individuals from a wide range of socio-economic backgrounds. This makes UK Biobank a powerful resource for studying previously unanswered questions about the links between different risk factors and disease.

At the time of recruitment, UK Biobank was representative of the national distribution for different ethnic groups, with 29,000 participants recruited from Black and other ethnic minority groups. UK Biobank is currently the largest research resource in the world of whole genome data on individuals of African and South Asian ancestry, even though these numbers are still relatively small when looking at associations between ethnicity and disease risk.

How we have been involving participants

Since UK Biobank's inception, we have actively sought to understand our participants' views and preferences.

For example, when we began our imaging study in 2014, we assessed the impact of receiving incidental findings by conducting surveys of participants and their GPs, and through workshop discussions with participants who had received incidental findings. This work directly influenced the design of the imaging study. Since then, over 20,000 participants have completed an anonymous feedback form after their imaging visit. Their feedback has led to a range of changes in practice.

Why involve participants?

Research studies that involve patients and the public are more relevant, acceptable and understandable to people taking part, provide a better research experience, and have better communication of results.

We believe involving participants and their families in our work is vital for the success of UK Biobank because it helps ensure that:

- our work remains relevant and acceptable to participants and wider society, so it has a positive impact on people’s lives, and
- we continue to act in a trustworthy manner, so that participants and others feel confident to support and work with UK Biobank in the long-term.

Aims

This Participant Involvement Strategy has three broad aims.

1. Participant involvement is embedded in UK Biobank culture

We will involve participants in a wider range of UK Biobank activities and processes and this will become a normal and expected part of our work.

We will put in place effective internal communication channels to raise awareness of participant involvement at UK Biobank and the value they are bringing, and the support that is available to staff. We will create regular opportunities for senior leaders in the organisation to take part in participant involvement activities. We will develop feedback channels so that participant contributions are considered and acted upon, and we will monitor the impact this is having.

2. Participant involvement at UK Biobank meets the highest standards

To ensure our participant involvement activities are done well and to the highest standards, we will be guided by the following values:

- **Meaningful** – participants are involved when there is genuine scope for influence. Contributions by participants are heard and acted upon by the right people in the organisation. Our participants hear about the difference their views and contributions are making.
- **Respectful** – we show respect for our participants and the contributions that they make. We treat participants as equals and value their feelings and views.
- **Inclusive** – our participant involvement activities are accessible, flexible and varied to ensure a wide range of participants can get involved. We take steps to understand why some participants are not getting involved and work to reduce barriers to participation.
- **Transparent** – we are open about our participant involvement activities, who has and has not been involved, and the impact it has and has not had. This is an important aspect of UK Biobank acting in a trustworthy manner.

We will utilise resources produced by other organisations to ensure our participant involvement activities are of a high standard, such as the University Oxford Medical Sciences Division PPIE toolkit and the UK Standards for Public Involvement in health and social care research.

3. Participants and staff are supported to collaborate with each other

We will provide participants with the information and support they need to be able to collaborate with us effectively. Participant contributors will be remunerated appropriately and we will create opportunities for them to get to know and support each other.

We will provide staff with information and training on effective participant involvement, and we will support staff to design and implement involvement projects. We will create opportunities for colleagues to share their experiences, and new staff will have the opportunity to hear from participants as part of their induction.

Methods we will use

We will use a range of involvement methods to ensure we facilitate both in-depth discussion and wide engagement.

We will establish a standing UK Biobank Participant Advisory Group by expanding the group we set up to develop this strategy (see Annex A). The Group will meet regularly to provide participant perspectives and advice on a wide range of issues.

We will also establish a diverse pool of around 100 Participant Reviewers who we will ask for feedback on a range of activities, such as health questionnaires, the devices and measures we plan to use at assessment centres, and the design and content of communication activities.

We will organise workshops and focus groups to gain participant, family and public perspectives on specific topics as required. We will conduct participant surveys on different aspects of our work to give a larger number of participants the opportunity to have input. We will undertake community engagement to understand and address the motivations and barriers to participation in UK Biobank. We will seek to create a small group of participant ambassadors who work in partnership with our communications team.

Areas of focus

We will deepen the involvement of participants in four main areas of our work.

1. Participant involvement in communications

If we communicate with participants well, it leaves them feeling informed, valued and more willing to support UK Biobank in the long-term. It is also important for us to communicate well with other audiences, such as family members who may be supporting a participant to contribute to UK Biobank.

Participants are well placed to advise us on creating content that is appropriate, accessible and engaging. They can also tell us how we can best reach participants, particularly those who have been less engaged since they joined the study.

Actions

1. We will seek the advice of the Participant Advisory Group and the Participant Reviewers pool on the content and design of a wide range of communications materials and activities.

2. We will invite every participant to complete a survey about their communication behaviours and preferences. The findings will inform our communications and project recruitment strategies. We will carry out further participant surveys on different aspects of our work as required.

3. We will support a small group of participants to become UK Biobank ambassadors. Activities might include speaking at our events and meetings, and talking to journalists about their experiences.

2. Participant involvement in enhancing our research data

We continually gather health information about our participants to enhance the UK Biobank database. In recent years, many thousands of participants have taken part in our body imaging project, worn activity monitors, and completed questionnaires about pain, mental health, memory and sleep. We also link to participant records of deaths, hospitalisations, cancers, and primary care.

Seeking the input of participants early on in the development of our enhancement studies has helped ensure our study designs are acceptable, our questionnaires are understandable, and our research centres are accessible and welcoming.

Some participants have been more likely than others to accept our invitations to take part in enhancement studies. We must ensure we understand the motivations and barriers to taking part in our projects and that we don't unintentionally exclude people.

Actions

4. The Participant Advisory Group and the Participant Reviewers pool will advise on the design and implementation of enhancement studies, and help test out the devices and measures we plan to use.

5. We will involve participants and people with a brain health condition, and the people who support and care for them, in the design of the Brain Health Study.

6. We will engage with participants who previously have been less likely to take part in our projects to understand why this is. The findings will help us tailor our recruitment methods and remove barriers to participation.

3. Participant involvement in ethics

Participants have played an important role in discussions about ethical issues that have arisen in the course of UK Biobank's work. For example, we have sought participants' views on whether UK Biobank should be able to access biological samples stored within participants' NHS medical records.

We will deepen the involvement of participants in discussions about the ethics of collecting, storing and sharing their health data. When ethical questions that have broader implications arise, we will seek the views of members of the public to ensure we are keeping pace with societal views and expectations.

Actions

7. Two members of the Participant Advisory Group will be appointed as members of the UK Biobank Ethics Advisory Committee. The full Participant Advisory Group will be consulted on ethical issues when required.

8. We will carry out further in-depth discussions with participants and members of the public, as appropriate, to explore their views on ethical issues relevant to UK Biobank's work.

4. Participant involvement in strategy and governance

For participant involvement to be meaningful, there must be the potential for real influence. To ensure that happens, we will give participants more opportunities to contribute to organisational strategy and governance.

Involving participants in organisational decision making will help ensure decisions are more understandable, relevant and acceptable to participants. Participants have a particular interest in contributing to discussions about researcher access to the UK Biobank resource.

Actions

9. The Access Committee will consult the Ethics Advisory Committee, which will have participant members, and the Participant Advisory Group, about relevant issues that arise in relation to data or sample access applications.

10. We will involve participants in the development of new organisational strategies and long-term plans.

11. All other UK Biobank decision-making and advisory committees, including the Executive Management Team and UK Biobank Board, will be able to consult the Participant Advisory Group on any issues.

Impact and evaluation

The UK Standards for Public Involvement in health and social care research set out the need to assess "the changes, benefits and learning gained from the insights and experiences of patients, carers and the public".

We will use the Public Involvement in Research Impact Toolkit (PIRIT) developed by the Marie Curie Research Centre and the Wales Cancer Research Centre to guide our impact and evaluation activities.

We will undertake each year an internal evaluation of the participant involvement programme to capture how we are meeting our broader aims and actions. We will commission an independent evaluation of the impact of UK Biobank's participant involvement strategy at the end of the three-year period of this strategy.

Plans for the future

Building on the actions and learning of this strategy, we will produce a refreshed strategy for 2027-2030 when we will consider again our approach to participant and public involvement and engagement.

Annex A. Method and contributors

The process of developing this strategy involved a range of people and activities.

The engagement consultancy Thinks Insight and Strategy was enlisted to facilitate and report on the activities of a Participant Advisory Group and two evidence gathering meetings.

Participant Advisory Group

This group of nine participants steered the process, considered evidence, and co-designed the strategy. The members represented a balance across age, sex, educational attainment, and geographical location. Members were not as ethnically diverse as we would have liked, which we will remedy in future participant advisory groups. The group met for three hours four times between October 2023 and February 2024. Members also attended meetings of the staff working group, and the Annual Scientific Conference in December 2023.

Working Group of UK Biobank staff

The members of the staff working group advised on organisational need and how participant involvement can be embedded in our work processes. Individuals from the following teams were represented: Communications, Health Data, Study Administration, Imaging Study, Legal, and Executive Management. Five meetings took place between July 2023 and February 2024. Some members attended meetings of the Participant Advisory Group.

Joint meeting

A final, joint meeting of the Participant Advisory Group and the Staff Working Group took place in Stockport on 22 February 2024 to agree the content of the strategy.

Evidence gathering

The discussions of the two groups were informed by:

- Workshop with engagement experts (virtual, 23 November 2023) – this meeting brought together 15 engagement experts from other organisations to gather examples of best practice and evidence of impact. Organisations represented included: Academy of Medical Sciences, Wellcome, All of Us (NIH), Genomics England, Our Future Health, Understanding Patient Data, Vocal, Avon Longitudinal Study of Parents and Children, Nuffield Council on Bioethics, Sciencewise, Ada Lovelace Institute and NIHR.
- Focus group with family members of UK Biobank (Newcastle, 4 December 2023) – a group of six family members of UK Biobank participants provided their views on their potential future role in the organisation and how UK Biobank can best engage and involve them.
- Examples of practice – during their meetings, the groups discussed participant involvement with representatives of the Avon Longitudinal Study of Parents and Children and the Genomics England Participant Panel.
- UK Biobank Scientific Conference (London, 13 December) – two members of the Participant Advisory Panel talked to researchers during the conference breaks to gather researchers' views on participant involvement at UK Biobank.
- Desk research – a summary of previous participant engagement and involvement activities at UK Biobank was developed to learn from past experience.

Peer review

Towards the end of the process, the strategy was reviewed by three experts:

- Nicola Perrin, Chief Executive of the Association of Medical Research Charities and UK Biobank Trustee.
- Jillian Hastings Ward, immediate past Chair of the Genomics England Participants Panel.
- Karriem Watson, Chief Engagement Officer, All of Us Research Program at the National Institutes of Health, US.