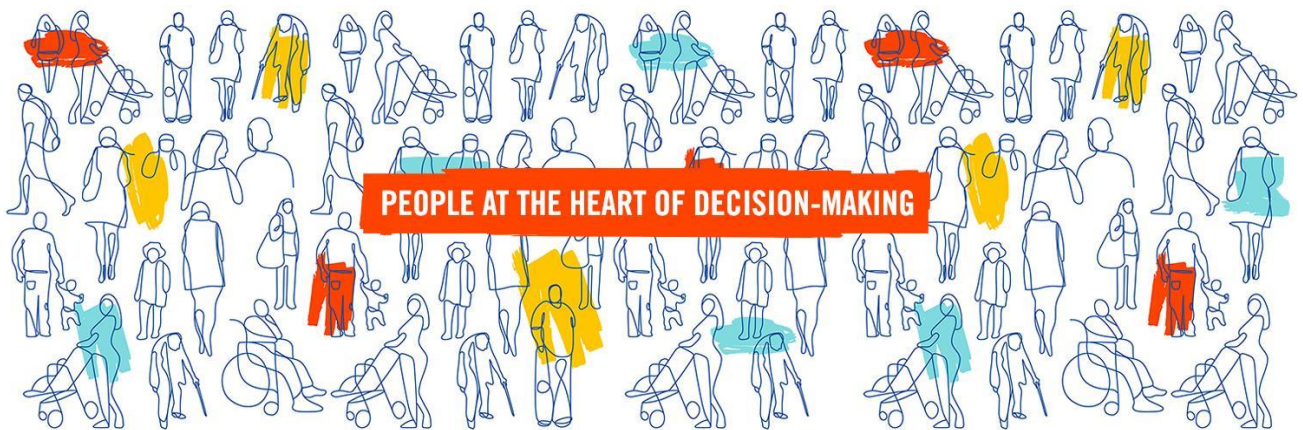




# Deepening UK Biobank participant engagement



**AUTHOR:** Juliet Swann

**CONTACT:** [juliet@involve.org.uk](mailto:juliet@involve.org.uk)

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*“Engaging people must not be seen as an obstacle in the conduct of Biobanking and genetic research. While money and time may seem to be a luxury... it must be weighed against the greater trust such processes imbue in the public and other stakeholders; and the resultant sustainability and social value of research that are realised over the long term.”<sup>1</sup>*

## Executive Summary

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*Is there a problem to fix?*

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Since UK Biobank was established its reputation as a large cohort study allowing research into health conditions, how they develop and their interactions with general wellbeing, and lifestyle choices has seen over 2,000 scientific published papers. While not all participants take part in repeat imaging or enhancement studies, retention is generally high, and the wide consent granted allowing access to NHS and GP medical records means the study data is still updated regularly.

However, increasingly cohort studies, and health and medical research more broadly, undertake more and deeper engagement with participants, patients and the public. This is seen to allow a better understanding of the way these groups weigh up trade-offs and ‘wicked problems’. It gives insights into aspects of health and wellbeing that are softer measures but that add value to the data. It also ensures that consent is indeed ongoing and covers innovations. And it demonstrates trustworthiness.

By taking steps towards deeper participant engagement now, UK Biobank can ‘fix the roof while the sun is shining’. Ensuring participants can take a more active role in the study if they wish will future proof issues around data sharing, innovative data analysis and will shore up participant trust in how their data is collected, accessed and analysed. This will provide a safety net against a number of risks including participant withdrawal; stakeholder criticism of a lack of participant engagement; and possible weakening of UK Biobank’s reputation.

Involve’s recommendations to UK Biobank are founded on an iterative approach to participant engagement. This approach aims to deliver a number of outcomes:

- To provide insights to UK Biobank which will improve internal understanding of participant’s motivations and communication preferences.
- To improve understanding of why some participants participate more actively in enhancements.
- To provide an understanding of how to provide attractive opportunities to move passive participants to playing a more active role.
- To demonstrate that UK Biobank is committed to involving participants in the study as more than just datasets and understands the added value to the research.

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<sup>1</sup> Warriar P, Ho CWL, Bull S et al. Engaging publics in Biobanking and genetic research governance - a literature review towards informing practice in India [version 2; peer review: 1 approved] Wellcome Open Research 2021, 6:5 <https://doi.org/10.12688/wellcomeopenres.16558.2>

- To ensure that UK Biobank meets the highest standards of transparency and openness and thereby demonstrates trustworthiness.

## Introduction

UK Biobank is a world leading cohort study with half a million participants aged between 40 and 69 at the time of recruitment. Recruited between 2006 and 2010, participants answered extensive baseline questionnaires, underwent physicals and provided blood and urine samples. The database is recognised as holding an unprecedented amount of biological and medical data that is available to researchers. That data is supplemented by access to participants' NHS data and their undertaking follow up imaging scans or taking part in enhancement studies.

UK Biobank already engages its half a million participants in a variety of ways, from outward communications to individual and group conversations about a variety of issues, including through outreach events and invitations to take part in enhancement studies. While there is limited concern in the short-term about the relationship with participants and their trust in UK Biobank, events such as the recent controversy over GP Data raise important questions about trust in relation to personal health data and how it is collected, held and used. At the same time, independent reviewers of the recent core renewal application raised concerns about a lack of patient and participant engagement and involvement (PPIE) such as is becoming commonplace in cohort studies. Concerns have also been raised about the continued use of the broad consent that was part of the original recruitment being used to apply new technological analysis. Additionally, UK Biobank's funders are clear that they would like to see UK Biobank exploring deeper participant engagement.

Involve was therefore commissioned to help UK Biobank understand how and where they might change and add to their participant engagement.

## Our approach

To ensure we understood the context in which UK Biobank is operating we undertook a short period of desk research, reviewing the core renewal application, the associated reviewer comments, and several academic papers, as well as considering the wider ecosystem of health, data and technology within which UK Biobank operates.

The next stage of the project was 14 semi structured interviews with UK Biobank staff and stakeholders. These allowed us to map existing engagement activities, gain an understanding of interviewees' concerns and aspirations for UK Biobank, and to start to understand where there might be opportunities for UK Biobank to further develop participant engagement.

We presented the findings from these interviews to a workshop made up of most of the interviewees.

As well as our recommendations, this report includes the analysis of the interviews and a summary of the workshop outputs alongside some guidance in how best to consider whether and how to engage. It also includes some reflections gathered as we worked through the project.

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*Quotes from interviewees and workshop participants are included and formatted like this.*

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We are grateful to all the stakeholders who took the time to participate in this project.

## Findings Summary<sup>2</sup>

The level of commitment to UK Biobank amongst the staff and stakeholders we interviewed was notable, as was the desire to ensure that the participants were engaged and rewarded. Interviewees acknowledged that current engagement is limited to sharing information, with any consultation taking the form of enhancing the dataset rather than developing how UK Biobank operates. Some interviewees commented that there are no processes in place for collating and disseminating incoming feedback from participants, nor does it feel that there is time to learn from participant interactions with one project before moving on to another. This was also indicated by a lack of shared understanding internally about projects and processes – what was happening, when and how that was to be communicated to participants.

There were differing views on whether participants would welcome deeper engagement, as well as how that might happen. Risks of engaging were identified, but risks of not engaging were also highlighted, including that the reputation of UK Biobank could be undermined.

Overall, it was felt that knowing more about participants motivations for taking part in UK Biobank and what they understand about UK Biobank would be advantageous and would improve how success stories are shared, both with participants and the wider public. For some interviewees there was also a clear need to begin to bring participants into governance and decision-making structures as part of future-proofing the study and aligning it with current participant engagement standards.

The workshop demonstrated that being able to discuss and deliberate across UK Biobank teams and with external stakeholders was a useful exercise. It allowed workshop participants to think both practically and imaginatively about the opportunities that could be developed in engaging more with UK Biobank participants. We would suggest that regular cross-departmental meetings to discuss participant engagement and its successes and challenges would be useful as UK Biobank develops the engagement offer.

The suggestions that were discussed at the workshop have formed the basis of our recommendations below. We propose an incremental approach that allows you to move from your current status of predominantly 'informing' participants, to consulting with them and beginning to involve them, with a view to developing a more collaborative relationship, where participants are actively involved in the study and are contributing to robust research outcomes.

To summarise:

- Improving internal comms and processes might help UK Biobank communications with participants
- Current comms activities with participants are working well, but more could be done
- There is room for participants to be brought into governance and decision-making structures.

Additionally, as we progressed through this project a wider reflection on the context in which UK Biobank operates emerged. Much has changed since UK Biobank was first established, in society, in medicine and medical research, in health care and in the way we live our lives. In the same way that UK Biobank embraces new medical technology and potential novel uses of the study data, we

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<sup>2</sup> The full analysis of the interviews and workshop findings can be found at Appendix 1 and 2

would suggest you embrace engaging your participants more in the work of the study and how it is managed. This will mean UK Biobank is seen as up-to-date, state of the art cohort study.

To not take advantage of innovation and attitudinal changes risks data becoming stale, less useful and unattractive to researchers.

## Part 1: Principles of Engagement

There is little point in undertaking participation if:

- Nothing can change, no matter the results of the participation
- Potential participants are uninterested in taking part
- There are insufficient resources (time, money, people) to make the process work properly

You should also ask yourself what level of participation is on offer. Will the process be meaningful to participants?

Will the exercise focus on:

- Informing those affected (inform);
- Informing those making the decision (consult);
- Change the decision (involve);
- Jointly make the decision (partnership / collaboration);
- Enable others to make decisions and/or take action (delegate).

The table below is adapted from the [International Association for Public Participation](#). It is designed to assist with understanding the level of participation that defines the role of the public in any engagement, and what that means for the organisation offering the opportunity to participate.

Table 1: The spectrum of participation

	<b>Activity</b>	<b>Purpose</b>	<b>Promise to participants</b>
<b>INFORM</b>	To provide the public with balanced and objective information	To inform those with an interest in the outcome (i.e. the public and stakeholder groups)	<ul style="list-style-type: none"> <li>• We will keep you informed</li> <li>• We will provide information openly and transparently</li> <li>• We will not withhold relevant information</li> </ul>
<b>CONSULT</b>	To obtain feedback on analysis, alternatives, proposals and/or decisions	To inform those making the decision or developing proposals	<ul style="list-style-type: none"> <li>• We will keep you informed</li> <li>• We will listen to and acknowledge your concerns and aspirations</li> <li>• We will give serious consideration to your contributions</li> <li>• We will be open to your influence</li> <li>• We will feedback on how your input has influenced the outcome</li> </ul>
<b>INVOLVE</b>	To work directly with participants throughout the policy / decision making process to ensure that their concerns and aspirations are consistently understood and considered	To enable participants to directly influence the decision / options developed	<ul style="list-style-type: none"> <li>• We will keep you informed</li> <li>• We will work with you to ensure that your concerns and aspirations are directly reflected in the outcome / alternatives developed</li> <li>• We will feedback on how your input has influenced the outcome</li> </ul>
<b>COLLABORATE</b>	To partner with participants in each aspect of the decision, including defining the issue, developing alternatives and identifying preferred solutions.	To share the development and decision-making process (as much as possible)	<ul style="list-style-type: none"> <li>• We will look to you for advice and innovation in formulating solutions</li> <li>• We will incorporate your advice and recommendations into decision / implementation to the maximum extent possible</li> </ul>

	<b>Activity</b>	<b>Purpose</b>	<b>Promise to participants</b>
<b>DELEGATE</b>	To place final decision-making in the hands of the participants - to delegate	To hand over the ability to make decisions and / or take action	<ul style="list-style-type: none"><li>• We will implement what you decide</li></ul>



UK Biobank asked Involve to identify ways that engagement with participants in the study could be deepened. Participants are not the only stakeholders that UK Biobank engages with, but this report focuses on this group. That said, the following principles of engagement apply across different stakeholder groups.

## **1.1 Reasons for engaging**

### **The wider context**

Since UK Biobank was established in 2006 the world has changed. Increased globalisation and access to information at the touch of a button or swipe of a smartphone means that we are living in an ever more transactional environment where knowledge is power and ‘what’s in it for me?’ is an ever more common question.

Where these trends are countered is in community-based action and accountability, founded in altruism but supported by transparency and trust and the value of seeing ‘people like me’ taking part.

Some of the broad changes that have occurred since 2006 include that we are living longer; more of us are staying in education for longer (and we are all always learning); financial security is more precarious for some of us; others of us are seeing income maximisation and more than 50% of us own our homes outright, including 94% of the over 65 age group.

We consume media differently and are constantly connected. Streaming and on demand services mean we can access news and entertainment at a time to suit us; we engage with each other across time zones, different platforms and in more immediate and connected ways, including wearable tech. People process information from celebrities and influencers more than newscasters and politicians. Misinformation and disinformation are prevalent. Algorithms mean that we all see information tailored to our interests, narrowing our horizons at the same time as the world becomes more accessible.

More directly associated with UK Biobank, the type of science we do and how we do it has changed; methods of data collection and analysis have changed; the sorts of analysis and processes we can run on medical samples have developed; medicine can test for many more conditions and more diagnoses, treatments and cures are available.

And this was before we experienced a global pandemic that brought home the fragility of life, the value of community, the power of trust, and the contribution data and research make to public health.

Our relationship to those in authority, to each other and our communities, and to knowledge, as well as changing attitudes to altruism, is changing, and this will affect UK Biobank’s relationship to its participants and other stakeholders.

### **Changes within UK Biobank**

Within UK Biobank much has changed, in ways that UK Biobank itself and the participants might not have anticipated.

The relationship with participants and mode of communication has changed. Email is now the usual mode of communication; UK Biobank is active on social media, joining twitter in 2014, and starting a YouTube channel the same year. The Research Analysis Platform allows approved researchers to access and analyse the entire UK Biobank database securely, in the cloud, from anywhere in the world.

Scientific advances have changed the way UK Biobank conducts studies and have given researchers access to significantly more data about participants. Genomic medicine and genome sequencing are an innovation that UK Biobank has embraced, running whole genome sequencing on over 200,000 participants' samples; wrist worn accelerometers were worn by some participants to inform a physical activity study; at home testing kits enabled participants to undertake research about Covid-19 antibodies in their own homes during the pandemic.

The governance of UK Biobank has also changed. The Ethics and Governance Council was superseded by the Ethics Advisory Committee, with a view to better integration with the UK Biobank Board.

## **Increased public and patient involvement and engagement**

Meanwhile participative processes are seeing growth in the health and science sector, as well as in the field of data and public health.

Established in 2004, [Sciencewise](https://sciencewise.org.uk/)<sup>3</sup> is a UKRI funded programme that is the UK Government's exemplar of how to develop robust evidence on public views to inform policy development in areas of scientific and technological innovation. The programme has supported over 70 public dialogue projects including:

- [Exploring public and patient perspectives on the benefits and risks of clinical trials for the Health Research Authority \(HRA\).](#)
- [Understanding public participants' views on consent procedures used by researchers to link patient data with human tissue samples in health research to inform new HRA and Human Tissue Authority \(HTA\) guidance.](#)
- [Hearing public views on the implications of whole genome sequencing for newborn screening for Genomics England and the UK National Screening Committee.](#)

Involve has also been commissioned by the Liverpool Civic Data Co-operative<sup>4</sup> to [understand the role of the public in making decisions about how their data is collected, processed and used in a civic context.](#)

More recently, with funding from the Data Trusts Initiative,<sup>5</sup> The Born in Scotland Data Trust aims to [explore how data trusts might operate in the health research context, specifically in birth cohorts and longitudinal studies that aim to engage participants over their lifetime.](#) (Data trusts are commonly proposed as a mechanism of data stewardship and a model of data governance with the potential to empower individuals and communities by authorising others (broadly referred to as 'data intermediaries') to act on their behalf).

Other cohort studies are also embedding participant engagement, and academic studies as well as anecdotal data suggest that this is beneficial for retention of participants as well as increasing

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<sup>3</sup> <https://sciencewise.org.uk/>

<sup>4</sup> <https://civicdatacooperative.com/>

<sup>5</sup> <https://datatrusts.uk/>

participants' trust in the study. This is also reflected in the findings from [PPIE work in the Bradford Institute for Health Research CARE75 cohort study](#).<sup>6</sup>

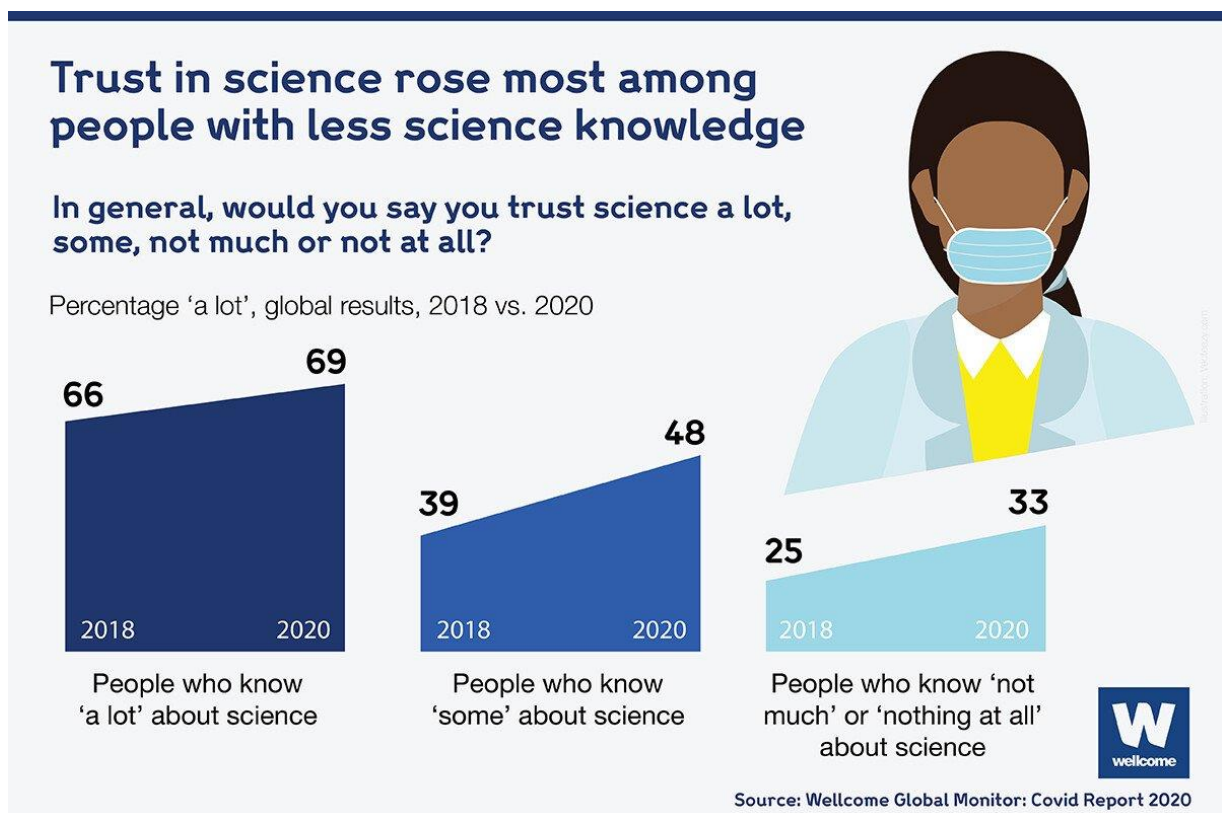
It is increasingly the case that both within and without health and science, deliberative processes are used to involve publics more and more deeply in complex and controversial decisions. The standard tools of learning, discussion and reaching conclusions are being found to allow for informed discourse and a development of understanding necessary trade-offs.

## Trust and trustworthiness

Finally, when considering UK Biobank's relationship with participants (and indeed other stakeholders including GPs and researchers), and the value of good engagement, it is important to understand the role of trust - and not just being trustworthy but **demonstrating trustworthiness**.

The most recent [Wellcome Global Monitor](#)<sup>7</sup> (field work in 2020, publication in 2021), shows that during the pandemic public trust in scientists increased. Globally, those who said they trust scientists 'a lot' rose from 34% in 2018 to 43% by the end of 2020. These increases were highest among those who indicated they know 'some' or 'not much/nothing at all' about science.

Fig 1: Wellcome Global Monitor Report findings on trust in science



The Wellcome Global Monitor suggests that the perceived knowledge of science influences trust in science.

*“As highlighted in the first Wave of the Wellcome Global Monitor, public trust in science and scientists is influenced by a range of factors at individual and country levels. One of the largest of these is the effect of science education, and another is how much people think they know about*

<sup>6</sup> <https://www.bradfordresearch.nhs.uk/care75/care75-ppi/>

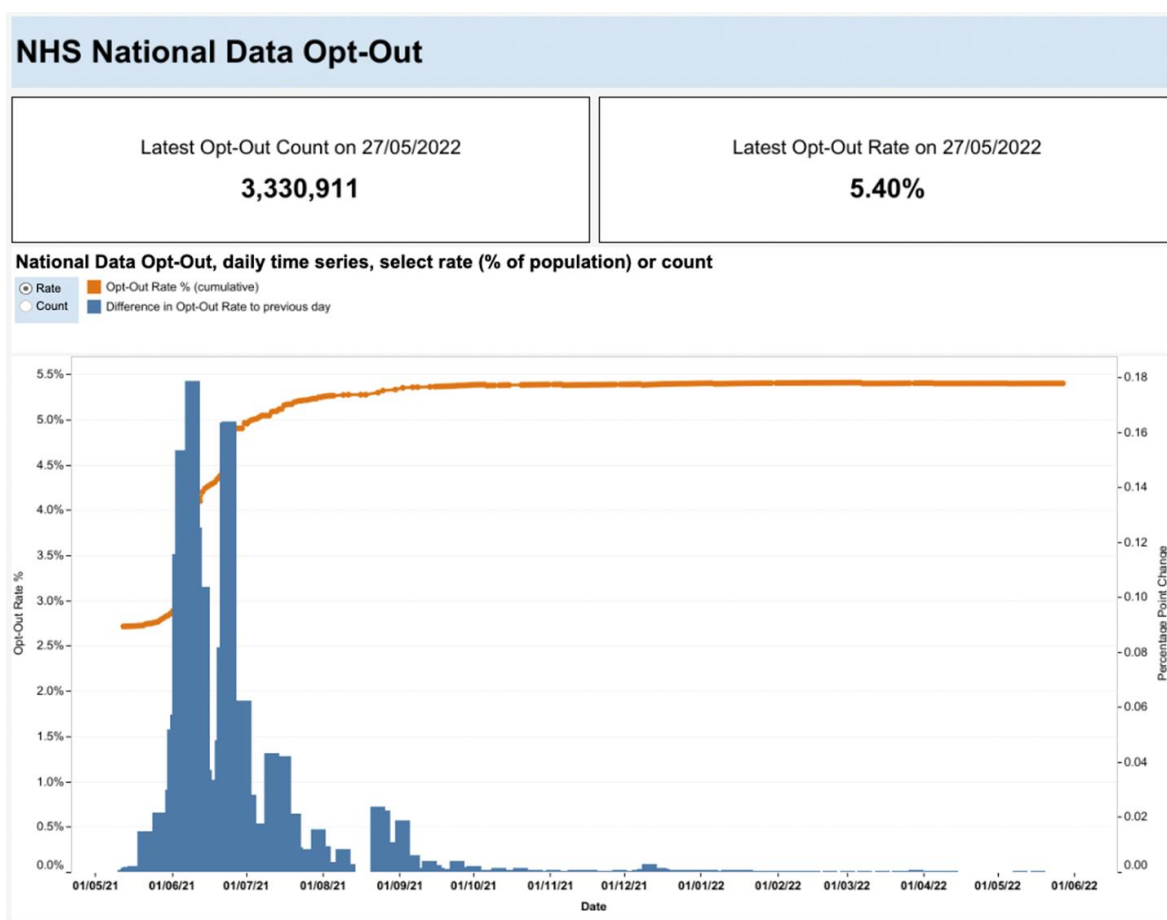
<sup>7</sup> <https://wellcome.org/reports/wellcome-global-monitor-covid-19/2020>

science. In 2020, 63% of people who said they know a lot about science said that they have ‘a lot’ of trust in scientists compared to 37% of those who said ‘not much’ or ‘nothing at all’ about how much they knew about science. Perhaps it is no surprise, then, that **in 2020 trust in scientists rose, possibly as a result of Covid-19 moving the public closer than ever to the work of scientists fighting against the pandemic.**”

Essentially, **the more people understand about science, the more trust they have in scientists.**

We can also see that the reverse is true: May and June 2021 saw a spike in NHS GP data opt out rates amid reports about government proposals to extend the access to GP data sharing.

Fig 2: NHS GP data opt out rates prompted by negative publicity about GDPR



This demonstrates that in the field of data sharing and consent, if trust is lost people will exercise what little power they have and withdraw consent. Information has to be given in a way that can empower the data subject. If people feel that they haven’t been given enough detail or real power, or if they realise how little power they have, it is possible they will stop participating and at worse withdraw consent to the data already held.

Involve would suggest that to avoid this risk, UK Biobank has a role as a transparent actor and communicator to participants about how their data continues to be collected, analysed, and shared, and of the public health benefits that accrue from that data sharing.

We would recommend the work of [Understanding Patient Data](https://understandingpatientdata.org.uk/) in this field.<sup>8</sup>

<sup>8</sup> <https://understandingpatientdata.org.uk/>

## 1.2 The purpose of engaging

Establishing a clear purpose and getting agreement on it is the single most important stage of any engagement process. Indeed, no participatory process should proceed without it.

There are, however, good and bad purposes. A good purpose will be highly focused with clear outputs and outcomes, which are easy for all to understand. A bad purpose will be poorly defined, with unclear outcomes and open to many different interpretations. A measure of a good purpose is its ability to create a commonly shared understanding of the potential impact of the project.

This does not mean that a good purpose must be narrow in its scope. Indeed, many of the best purposes are very broad. The point is that a purpose must be easy to understand and an accurate reflection of what is going to happen. Much of the best participation depends on the participants coming up with their own agenda for change, which is fine, as long as the agenda can then be implemented satisfactorily, and everyone understands what they are part of.

It is essential that all those with an interest or influence over the process are aligned to its purpose. Too often, different purposes exist within the same organisation, sometimes unspoken or assumed, and this only comes to light when the process is underway, which can be both damaging and embarrassing.

### Purpose as reference point

Once established, the agreed purpose can provide a reference point throughout the process. This is especially useful if participants are likely to introduce new subjects during the process, as their relevance to the purpose will determine whether they should be included.

A clear purpose enables the commissioning body to ensure that the right mechanisms are in place to transform the process outputs into outcomes. Clarifying the purpose of a process ensures that any organisation knows what it is getting into and can then check whether participation is appropriate.

A purpose also gives participants the opportunity to make an informed choice about getting involved. Too often we hear complaints of people feeling misled or manipulated. This is often because of miscommunication between the commissioner and participants as to what the process can change.

### Defining the purpose

Defining a clear purpose is not as easy as it sounds. For an organisation to reach a shared understanding requires time, which is almost always in short supply, especially at the start of a process. External circumstances can also affect the purpose and this possibility should be anticipated. For example, the results of forthcoming research or a decision taken by others can both influence the context and the purpose of a participation process. This is a particular risk if the process is not recognised or valued by people more senior than those involved in the detailed design and delivery.

It is important that defining the purpose includes clarity about the desired outputs and outcomes. Outcomes are about what you ultimately want to achieve (for example, consensus on building incinerators); outputs are how you will achieve the outcomes (for example, by providing information in leaflets or holding meetings). Making the distinction clear will contribute to defining a robust and useful purpose.

Essentially, in order to evaluate the success of any engagement, you need to identify why you are undertaking it.

Different organisations do engagement for different reasons. As well as any business case for undertaking public (or in this case participant) engagement, which may well be in response to drivers within your operational sector, another key element of establishing your purpose for engaging is to understand which of the drivers you are responding to:

- **Governance** –Increasingly best practice governance is driven not be centralisation and opacity of decision making but rather democratic legitimacy, especially of organisations delivering public benefit, is founded in trust and active citizenship
- **Organisationally** - There are many possible purposes for participation, including to inform about defined activities and seek additional information from your participants, which UK Biobank already does
- **Social cohesion and social justice** –The idea of community has changed and continues to evolve. Public engagement provides space for the development of relationships, ownership and social capital and empowering people
- **Improved services** – By testing services with the people destined to benefit from them, it is possible to create more efficient services that meet real needs and reflect community values
- **Capacity building and learning** – Engagement builds confidence and skills, and helps to create stronger communities
- **Greater ownership** – Building community buy-in to policies, services and service delivery ensures the community understands and supports your decision-making processes
- **New legal and regulatory structures** – And finally, there are increasing legal and regulatory requirements to involve the public. Investing in good quality engagement means you can do this well, as well as being able to anticipate and respond to regulatory changes as they occur.
- **Educate about the wider context** - how data is used, who uses it for what purpose, the benefits it can have and how the data is protected etc
- **Decision making** - To include those who will be impacted by the decision in making the decision
- **Innovation** - Explore issues and come up with new ideas.

Identifying and prioritising these purposes will involve several key steps:

- Liaising internally to clarify what can be changed as a result of the process and what outputs and outcomes are sought
- Liaising externally with those affected by a process to identify people's interests and concerns.

The key questions to help clarify the purposes of the exercise will be:

- What tangible products do you want to have produced during and after the process (outputs)?
- What do you want to have achieved at the end of this process (outcomes)?

And a checking question:

- What will you have to do with the outputs to ensure you achieve the desired outcomes?

## 1.3 Benefits to UK Biobank of engaging

The findings above, including the input from UK Biobank staff and stakeholders allowed us to identify (a non-exhaustive) list of the positive outcomes that could flow from improved participant engagement. These are high level objectives and achieving these results will depend on the quality of the engagement undertaken.

- Increase in participation
- Improved retention
- Higher quality data
- Better understanding of participant perspectives
- More publicly relevant research
- Improved collaboration opportunities
- Reputational boost
- Widening funding pool

Even once you are clear on the purpose of engagement and the benefits that it will bring, it is still necessary to ensure that the engagement is to be effective. The following section covers the basics of good practice in engagement.

## Part 2: A route to engagement

At Involve, while we recognise that public participation is a good thing to do, we believe that the best public engagement, or in this case participant engagement, happens when there is a clear reason to engage; something that can change as a result of that engagement; and that you undertake the engagement at the right time - only once you know these elements can you begin to be clear if IF you could engage , and only then think HOW you might engage.

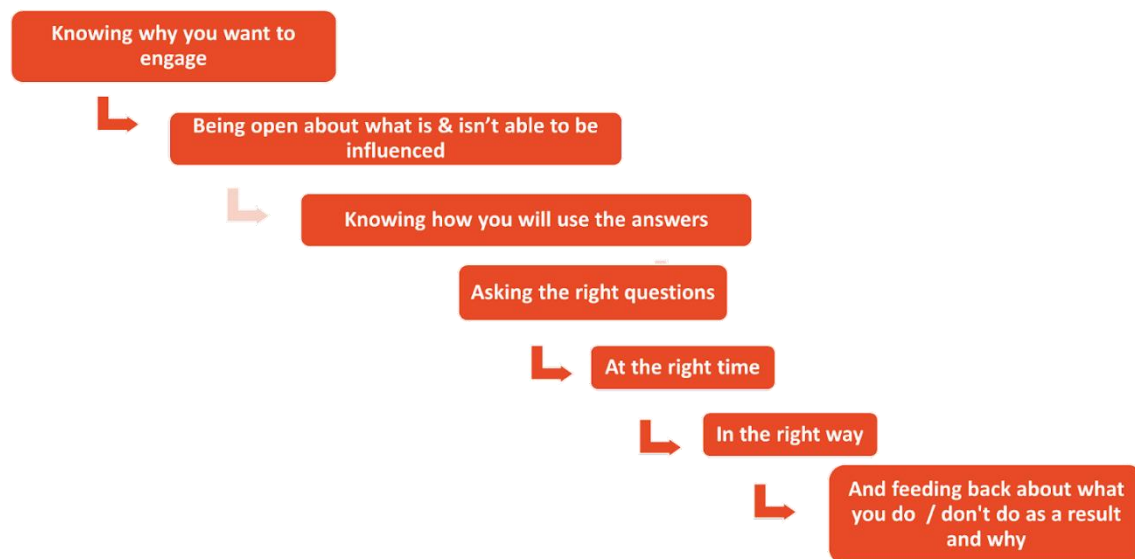
We are not proposing that you try to get a detailed quantitative analysis of the opinions and aspirations of all 500,000 participants. Rather we are proposing that you develop an iterative engagement plan that is intended to move participants beyond being passive recipients of information. Our proposals aim to allow participants to develop a better understanding of the ways of working and outputs of the study, and to provide ways they can interact with both. Our proposals are framed with a view to a more deliberate and deliberative way of working. This will introduce groups of participants to the facts, the dilemmas, the ethical trade-offs and the parameters within which decisions can be taken. It will provide them with the space and the time to talk to each other and with experts to consider how they might answer the difficult questions.

This does not have to be a replacement for existing decision-making structures, but rather a complement that gives those making the hard choices more insight into the attitudes of those who will be impacted by the decisions. It is also, as mentioned, an iterative process, and, as above, we would suggest regular cross-team evaluation points to ensure you are efficiently and effectively meeting your objectives for engagement.

It is also worth remembering that **not engaging is a form of engagement** - participants will make certain assumptions about what you are and are not telling them. It is also important to plan for and undertake engagement to a high standard, ensure it is adequately resourced, and that the process respects equity, diversity and inclusion. Finally, you should have a clear idea of how you will give feedback to participants about their engagement.

The diagram below sets out the steps of developing engagement. It is important to be clear on these elements of your proposed participation before starting out.

Fig 3: The process of developing engagement



To reiterate, before you undertake any participant engagement you consider whether these are things that can change, and that you are clear on what cannot change.

In order to effectively engage, in a way that adds value to both UK Biobank and the participants, it is necessary that:

- The participants can influence, to some degree, the decisions they are being invited to engage on – and that you are clear on what can't change
- The participation will bring in something new
- The participants are interested in being involved
- There are sufficient resources to support the process and ensure it works properly

Understanding what you can offer and why leads to your 'promise to the participants'. This promise helps to frame the subsequent listed necessities.

Developing on the ideas and opportunities discussed at the workshop, below we list some potential reasons we think UK Biobank might engage participants, and importantly, what changes UK Biobank might make as a result of what is heard. We have also included some potential aspects of the study that are not open to change, but that should be communicated to participants as limitations to their influence as part of any engagement.



## 2.1 Your promise to participants

Table 2: The promise to participants

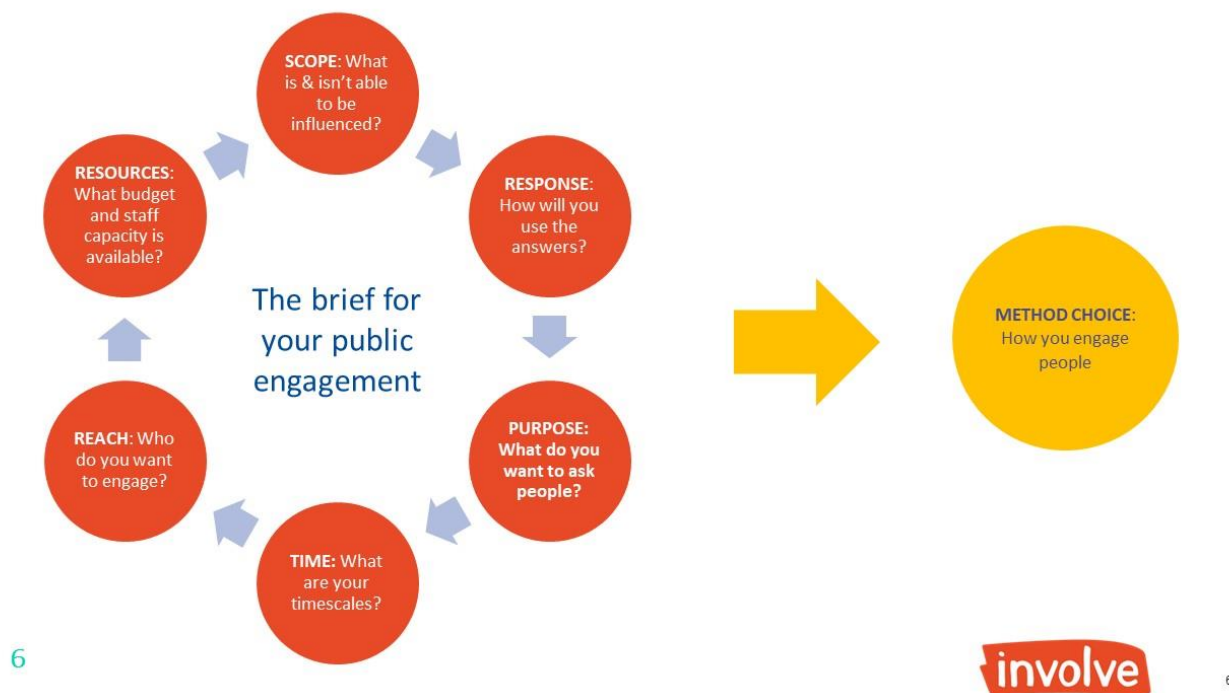
Why do you want to engage?	What can change?	What CANNOT change?	Promise to participants
To improve outgoing communications and enhancement questionnaires	<ul style="list-style-type: none"> <li>The format, frequency, mode, style of the communication</li> </ul>	<ul style="list-style-type: none"> <li>There are financial limits to the mode and frequency of communication – the study must remain cost-effective</li> </ul>	<ul style="list-style-type: none"> <li>We will keep you informed in a way that suits you</li> <li>We will listen to and acknowledge your concerns and aspirations</li> </ul>
To understand participant motivation	<ul style="list-style-type: none"> <li>How participants are invited to take part</li> <li>The methods of participating</li> </ul>	<ul style="list-style-type: none"> <li>Individual feedback is currently not available</li> <li>The topics that are researched (these are decided by researchers)</li> </ul>	<ul style="list-style-type: none"> <li>We will give serious consideration to your contributions</li> <li>We will be open to your influence</li> <li>We will provide feedback on how your input has influenced the outcome</li> <li>We will not withhold relevant information</li> </ul>
To improve the robustness of the data sets by ensuring information is accurate, up-to-date and that participants understand why certain questions are asked in enhancements	<ul style="list-style-type: none"> <li>How much information participants are given about the processing of, access to, and research undertaken with, the data and what it seeks to inform</li> <li>The type of reports participants receive back about how the data is used</li> </ul>	<ul style="list-style-type: none"> <li>The data set cannot be de-anonymised</li> <li>Individual feedback about surveys cannot be offered</li> </ul>	<ul style="list-style-type: none"> <li>We will keep you informed about how your data is collected, stored and accessed</li> <li>We will work with you to ensure that your concerns and aspirations are directly reflected in the outcome / alternatives developed</li> <li>We will provide feedback on how your input has influenced the outcome including of any research you participate in</li> <li>We will not withhold relevant information</li> </ul>
To enhance participant understanding of the study and the public health benefits	<ul style="list-style-type: none"> <li>How research findings are communicated and shared</li> </ul>	<ul style="list-style-type: none"> <li>Research topics and findings are dependent on external researchers</li> </ul>	<ul style="list-style-type: none"> <li>We will keep you informed about the impact of research studies your data has contributed to</li> <li>We will provide information openly</li> </ul>

			<ul style="list-style-type: none"> <li>and transparently</li> <li>We will not withhold relevant information</li> </ul>
To improve participant trust in the governance of the study	<ul style="list-style-type: none"> <li>Decision making and board meetings are more transparent</li> </ul>	<ul style="list-style-type: none"> <li>Legal constraints about responsibility for decisions will have to be respected</li> </ul>	<ul style="list-style-type: none"> <li>We will keep you informed about the governance and decision making processes in UK Biobank</li> <li>We will provide information openly and transparently</li> <li>We will not withhold relevant information</li> </ul>
To lead best practice in participant engagement and demonstrate trustworthiness	<ul style="list-style-type: none"> <li>Decision making and board meetings include participant representation</li> </ul>	<ul style="list-style-type: none"> <li>Legal requirements around governance and charity law will have to be respected</li> </ul>	<ul style="list-style-type: none"> <li>We will look to you for advice and innovation in formulating solutions</li> <li>We will incorporate your advice and recommendations into decision / implementation to the maximum extent possible</li> <li>We will keep you informed about the governance and decision making processes in UK Biobank</li> <li>We will provide information openly and transparently</li> <li>We will not withhold relevant information</li> </ul>
To develop more diverse research	<ul style="list-style-type: none"> <li>Researchers are required / encouraged to undertake participant engagement as part of access to the data set</li> </ul>	<ul style="list-style-type: none"> <li>The cohort is static</li> </ul>	<ul style="list-style-type: none"> <li>We will ensure access to your data includes involving you in the research where possible</li> <li>We will feedback to you openly and transparently about how this is or isn't done</li> <li>We will not withhold relevant information</li> </ul>

## 2.2 Developing methodologies

Once you are clear on your purpose for engaging, what can change as a result of the engaging, and how you are describing that to the participants, you can begin to think about the methodology you might use to deliver that engagement.

Fig 4: Developing the brief for your public engagement



Through the interviews and the workshop, and in the analysis above, we have been able to identify 6 core areas where we sense an appetite for a change in participant / stakeholder engagement at UK Biobank. This table summarises these and introduces some methodologies that could be used.

Table 3: Methodologies

Why do you want to engage?	What method might you use?
To improve outgoing communications and enhancement questionnaires	Surveys or focus groups
To understand participant motivation	Surveys or focus groups
To improve the robustness of the data sets by ensuring information is accurate, up-to-date and that participants understand why certain questions are asked in enhancements	Surveys, focus groups, UX research
To enhance participant understanding of the study and the public health benefits	Focus groups
To improve participant trust in the governance of the study	Participant representatives, panels, shadow committees
To lead best practice in participant engagement and demonstrate trustworthiness	Participant representatives, panels, shadow committees
To develop more diverse research	Conferences, workshops, training

## Part 3: Our recommendations

This section of the report sets out a proposed approach to developing UK Biobank's participant engagement, with a view to moving participants from passive to active members of the cohort.

As mentioned above, we recommend that you undertake internal and stakeholder engagement to ensure shared understanding of scope and purpose. Regular cross-departmental meetings to discuss participant engagement and its successes and challenges will be useful as UK Biobank develops the engagement offer.

At the outset it is inevitable that your already more active participants will be easier to engage. Our proposed approach seeks to leverage that section of the cohort with a view to moving the less active participants to a more engaged status.

### 3.1 Our proposed approach: a cycle of engagement

Given the number of participants in the study, and the variations in their activity, and in their communication preferences we are proposing an approach that starts at a broad level of consultation and progressively moves to more discursive and collaborative possibilities, allowing you to assess after each stage the impact of the engagement and if and how you want to move forward.

#### Stage 1

Our proposal is that you begin your engagement outreach with an easy to complete survey questionnaire about what participants understand about UK Biobank's activities and comms outputs that they receive. We would suggest you send this to all participants, including the postal only members of the cohort. There should be a deadline for responding, and either an incentive for completion (for example a low value shopping voucher), and / or the opportunity to be entered into a draw for a higher value item. Incentivising completion of this supplementary activity that is not directly related to the medical value of the study is good practice in acknowledging the extra time it will take from participants' lives.

If resource allows, we suggest that you create a slightly different survey questionnaire for your more and less active participants. But neither should be more than 8-10 questions long including personal details such as name, email, mobile etc. It may well be this survey leads to your receiving increased non-postal contact methods.

The survey questionnaire should be prefaced with an explanation of the activity and its intended iterations and consequences. Participants should be invited to indicate if they would wish to take part in further consultation and engagement about how UK Biobank operates, or if they wish to self-exclude from this piece of work.

We would suggest you work with [Understanding Patient Data](https://understandingpatientdata.org.uk/)<sup>9</sup> to best understand how to communicate some of UK Biobank's governance, data management and other complex processes.

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<sup>9</sup> <https://understandingpatientdata.org.uk/>

## Stage 2

Immediate actionable changes that are obviously a priority from the survey responses should be delivered upon and communicated to all participants – this shows those who completed the survey that you are serious about change, and those who may not have done so for lack of faith that this was misguided. A further opportunity to get involved in the consultation and engagement programme should be offered at this stage.

Using the survey data, analysis could be undertaken to identify themes and inconsistencies between participants in the cohort. As discussed at the workshop, possible future engagement could empower participants from certain demographic groups to themselves engage with similar participants and ask them questions about engagement and participation rather than it all coming from the UK Biobank staff team.

## Stage 3

In order to further elaborate on how UK Biobank might improve participant communications, those who expressed an interest could be invited to join a day long participatory event to hear more about opportunities for UK Biobank participants to become involved in the operation of UK Biobank, and to discuss what meaningful engagement might look like for them. This could take a number of formats, but one that might be suitable would be to see it as a series of focus groups all happening in one room and with the chance to hear input from each other.

This might be an event that attracts a handful of people and is a way of testing what motivates them and seeing if they have ideas for further outreach. It might be a large-scale event that requires investment and moderation. It could bring together participants alone, it could include other stakeholders and researchers.

However the purpose is clarified, it would be planned and facilitated in order to allow all participants to feel they were able to input into the conversation with the necessary understanding of how UK Biobank operates and what more it might do to engage participants.

Depending on size, discussions at the event could be themed around topics that UK Biobank wanted to hear from participants about – whether that be enhancement questionnaires or how to communicate research outputs. Or participants could be tasked with answering an over-arching question, for example: how could UK Biobank better include participants in our operations and communications?

Participants may also be asked to deliberate and decide on a set of ‘rules of engagement’. Per Warrier P, Ho CWL, Bull S et al.<sup>10</sup> – “Rules of engagement can be understood as a means of formalising participants’ and researchers’ values, experiences and beliefs within the governance of Biobanking and genetic research and its conduct.”

This discussion event would also serve to identify those participants who were willing to undertake ongoing engagement. This could be:

- As more regular sounding boards for feedback on comms
- Sounding boards for feedback on enhancement questionnaires
- Panel members for contributing to a specific activity

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<sup>10</sup> Warrier P, Ho CWL, Bull S et al. Engaging publics in Biobanking and genetic research governance - a literature review towards informing practice in India [version 2; peer review: 1 approved] Wellcome Open Research 2021, 6:5 <https://doi.org/10.12688/wellcomeopenres.16558.2>

- Panel members to comment around a specific health condition
- Panel members to contribute to operational decision making.

## Stage 4

Participants would be informed of the changes made as a result of the participatory event. The panel(s) would be established and the terms of reference and membership communicated to participants.

## Stage 5

The panel(s) would report back to participants and would seek to refresh membership on a regular basis.

## Stage 6

Participants would be re-surveyed. This cyclical approach allows for feedback loops to keep operating and for the active participant base to be refreshed as the work of their fellow participants is seen to deliver change.

## Additional elements of the cycle of engagement

1. As mentioned, a full analysis of the cohort and their responses to the survey questions would be a useful way to identify demographic themes, whether by location, age group or another factor
2. As the cycle continues, it will be possible, and indeed desirable to bring in members of participants families, carers, and health providers such as GPs. The iterative approach means that participants themselves can begin to communicate with these stakeholders. The groups can then be brought together to develop new possible engagement activities to bring UK Biobank to a wider audience.
3. Researchers should be encouraged to access those who indicate they are willing to pursue deeper involvement, and proposals for participant engagement should be part of any application to use the resource, possibly with assessing input from a suitable participant panel.
4. The panel could choose to introduce sub-committees of the panel to examine specific work areas (in discussion with the appropriate UK Biobank decision making structures).

### **3.2 The participant panel**

Through the engagement cycle approach, it is expected that there will be sufficient interest to populate a panel that is reasonably representative of UK Biobank participants. If this is not possible, we would suggest a pilot panel and ensure that it was active in promoting its work to participants so they could see the value of engaging in future iterations. We would also suggest that once the panel is established, especially if there is seen to be value in establishing sub-committees, that membership of the panel is extended to family members and carers.

## What would the panel do and how?

The role of the panel should be decided between participants and UK Biobank. UK Biobank should identify where a panel could add value, applying the principles outlined above. UK Biobank should also be clear on the purpose and scope of the panel.

Participants at the participative event would then discuss UK Biobank proposals and determine how best they could contribute, and what resources they would need to take forward a participant panel. They could be presented with alternative models from other cohort studies, other health and social care environments, and other external examples.

## Possible methodologies

There are a number of ways that a participants' panel, or equivalent co-production / collaborative approach could be adopted.

1. Participants could be invited to join existing panels: the Board; the Ethics Committee; the Access Committee, as representatives of the cohort. This role, akin to that of a 'staff rep' would involve the participant liaising with other participants and the UK Biobank governance team to integrate participant opinion and aspirations into the decision-making process.
2. UK Biobank could identify specific governance decisions or research access requests that they considered would benefit from participant input – this could be used in a number of scenarios: to test acceptability of new approaches; to see how participants viewed difficult trade-offs; to present 'wicked problems' and receive participant views.
3. An annual participants' panel could offer reflections of the work of UK Biobank over the past year, and discuss concerns, aspirations and opportunities for the coming year.
4. A participant panel of a representative group of participants could be established and provided with the appropriate administrative support. This panel would be tasked with providing participant input, as a representative group, to whichever committees it was aligned to. They would meet prior to any committee meetings and their input would be considered alongside other papers. They would receive feedback on how their input had been used and this would be shared with the wider cohort.
5. A similarly resourced participant panel could be given more of a 'shadowing' role, with access to the same documents as the committee(s) they were shadowing. Their decisions would be published alongside the decisions of the committees themselves. Where inconsistencies in decision making arose, there would be an agreed process for deliberation and feedback as to the ultimate choice.
6. In a more 'delegating' structure, the recommendations of the participant panel could be required to be implemented by the appropriate committee, unless there were exceptional reasons not to, or reasons outside UK Biobank's control (eg legal). The existing committees would actively report to, seek feedback from and implement recommendations from the panel(s).
7. A participant panel could be given the authority to review access requests (with support and expert advice) or could be tasked with developing research priorities.

Methods 1-5 see participants as an additional resource to aid in decision making, but UK Biobank's chosen committee members retain decision making authority. The final methods place the participant panel in a position of authority and expects their decisions to be implemented.

Alternatively, these panels could be composed of participants but also family members and carers of participants, other stakeholders, and / or the general public. Or UK Biobank could establish

regular dialogues between these groups to ensure they were challenging each other across the different levels of interest in UK Biobank.

We would strongly recommend that UK Biobank reflect on the work of the [NICE Public Involvement Expert Panel](#),<sup>11</sup> in considering the remit for any participant panel.

## Conclusion

This report does not represent the only or exhaustive ways that UK Biobank could deepen participant engagement. We would suggest ongoing dialogue with stakeholders and participants is the only way to determine what sorts and levels of engagement will best deliver for UK Biobank. This should be considered both in terms of your existing objectives, and also to future proof the study and its approach to engagement.

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<sup>11</sup> <https://www.nice.org.uk/about/nice-communities/nice-and-the-public/public-involvement/public-involvement-programme-expert-panel>



# Appendix 1: Findings

## The interviews

Overall, we heard that the UK Biobank staff team is busy, dedicated and enthusiastic and want to do their jobs as well as possible. This is not only in order to benefit UK Biobank, which they see as a resource to be proud of, but also to ensure the research it facilitates is beneficial. Equally the team are intent that the participants, whose altruism they all feel a responsibility to honour and have a sense of respect for, sense this appreciation.

## Current engagement

Current engagement at UK Biobank is overwhelmingly one-way communications to participants. We heard that UK Biobank undertakes a range of outgoing communications: an annual newsletter; events for participants; enhancement questionnaires; invitations to attend repeat imaging visits. And UK Biobank maintains a website and social media presence, with a repository of the research enabled by UK Biobank available online, as well as a password protected participant website.

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*“Biobank’s engagement is on updating and communicating.”*

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*“Participant engagement is focused on informing the participants.”*

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And UK Biobank pivoted well during lockdown - the Participant Resource Centre (PRC) (formerly based at Cardiff University) moved to remote working efficiently and effectively; the local meetings were transitioned to online webinars.

That said, we also heard that internal communications can be less than perfect (as with most organisations of size), and that this means there is not always a shared awareness of activities. It can also mean that communications with participants are not as efficient or as effective as they could be.

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*“Every new study is taken as a brand-new adventure without reflecting on what went well or badly from the previous one - everything is moving very quickly.”*

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We also heard that although UK Biobank runs successful webinars and responds well to individual participant concerns and queries, these responses, and questions raised in the webinars are not necessarily collated, analysed, or circulated more widely to all participants.

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*“Unless participants reach out, they are not informed about what is going on.”*

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Table 1 summarises what we heard about existing engagement activity.

Table 1: Existing engagement at UK Biobank

Engagement activity	Purpose	Level of engagement
Website, social media	Public facing information plus participant updates	Inform
Annual newsletter	Informing participants about UK Biobank activities	Inform
Events / webinars	Informing attendees about particular topics	Inform
Individual queries	To ensure participants proactive needs and concerns are addressed	Inform
Enhancement questionnaires	To add data to the resource	Consult / Inform
Requests to attend repeat imaging scans	To update and add data to the resource	Consult / Inform
Imaging visit surveys	To understand participants' experience and develop the 'offer' / customer experience	Consult
Focus groups	To understand participants awareness of and comfort with broad consent (specifically in relation to the human tissue authority)	Involve

Moving away from what is practically happening, we heard from some interviewees that they were surprised that UK Biobank did not do more to actively engage with participants. However, others were very clear that the original request and agreement with participants was broad consent, minimal contact, and there were clear guidelines on how research access requests would be met, and to review that now was unnecessary and possibly harmful to the study.

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*“Participants were recruited on the premise that the participants wouldn't be asked to engage beyond their basic responsibilities.”*

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We also came to understand that as a data driven study it can be hard to think about qualitative research as providing robust recommendations, and we hope that this report and recommendations can allay some of those concerns.

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*“Other cohorts are required to do this but with half a million people where is the representation?”*

*“The scientific premise is that nothing is valid unless there are huge numbers – UK Biobank need to understand the value to talk to small groups of people.”*

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We also heard a lot about participant feedback - in the sense of relaying medical information resulting from participants’ imaging scans. We heard that this is a complex and oft discussed matter, and opinions were varied and often in direct contradiction with each other. Therefore, at this time we are not including recommendations about this kind of direct medical feedback.

Which isn’t to say that we think it is a matter that participants could not or should not be included in discussing. Should this area be open to revision, we would suggest that changes to existing are discussed with participants.

The recommendations we make do provide a structure within which this could happen, should UK Biobank decide to do so in the future.

## Future engagement

We also heard lots of ideas and suggestions for how UK Biobank might:

- improve outgoing communications (with participants and the wider public)
- engage more proactively with participants
- better understand the motivations of participants
- set participation standards
- deliver improved public health benefits
- increase understanding of what UK Biobank does.

These ideas were generally considered quite strategically as being not only of immediate benefit to UK Biobank through enabling people to do their jobs better, but as a way to enhance its attractiveness to researchers and funders. Additionally, it was felt they might improve participant and public understanding of cohort studies and the public health benefits that the research can enable.

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*“Because of Biobank’s international relevance, this could become a case study for public involvement in the medical research sector - lead the way for others to do that.”*

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Table 2: Ideas for future engagement from interviews

Engagement activity	Purpose	Level of engagement
Survey participants for feedback on comms outputs	Outgoing comms with participants could be improved by surveying them to get their feedback on what they currently receive  Outgoing comms in general could be improved	Consult / Involve

	<p>Informed participants could be used in public facing comms</p> <p>Methodical ways of recording participants concerns and feedback could improve communications and project development</p>	
<p>Survey participants about their reasons for taking part in enhancements and repeat imaging studies</p>	<p>Enhancements and repeat imaging uptake could be improved if participants motivations were better understood – by collecting feedback on why participants do and don't respond</p> <p>Results of enhancements could be improved if participants had a greater understanding of the rationale of the project</p> <p>If participants understood more about UK Biobank this could prevent some of the dropouts</p> <p>Improve participants' own health outcomes by understanding what studies using UK Biobank data have shown.</p>	<p>Consult / Involve</p>
<p>Panel of participants to test ideas on enhancements &amp; updates on UK Biobank activities</p>	<p>Engagement might identify symptoms which researchers aren't aware of, lifestyle issues that might have a bearing on the findings.</p>	<p>Collaborate</p>
<p>Panel of participants offering prioritisation</p>	<p>Help understand participants' priorities, their ethical trade-offs, and where they draw the line.</p>	<p>Collaborate</p>
<p>Setting research priorities in consultation with participants</p>	<p>Identifying more socially relevant research outcomes.</p>	<p>Collaborate</p>
<p>Participant representation on existing committees / board or a strategic oversight committee made up of participants</p>	<p>Allow more confidence in knowing when risks can be taken.</p> <p>Shore up the reputation of UK Biobank as increasingly cohort studies do have a lot more participant engagement and public panels.</p> <p>Set a standard for cohort studies globally.</p> <p>Allow UK Biobank to not just say it is trustworthy – but demonstrate</p>	<p>Collaborate</p>

	trustworthiness.	
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Concerns about change also came through, with identified risks including possible withdrawals from the study if participants were worried about new research or technological developments.

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*“There has been no pressure from the participants to change things – UK Biobank would need to demonstrate that more good than harm will be done.”*

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However, other interviewees felt that not embracing change was complacent and risked withdrawals precisely because participants were not told what was happening to their data. Rather it was suggested that improved engagement could prevent withdrawals and increase the numbers of participants completing questionnaires and other enhancements. It was also felt that increased transparency would increase trust and credibility, helping to prevent reputational risks if a decision was found to be controversial.

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*“People have chosen to spend their time to do this, so they have a right to choose to be more involved”*

*“If you engage them and take them on the journey, this risk (of withdrawal) decreases also because the participants joined for altruistic reasons as they are already trusting of Biobank so there is room for building on this trust.”*

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Finally, we heard that the risks of not engaging include damaging UK Biobank’s standing in the international community.

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*“(UK Biobank has) no insight into the possibilities that come with moving with the time and therefore risk losing credibility.”*

*“UK Biobank are way below the gold standard of participant engagement.”*

*“Without better engagement, there is a risk that UK Biobank might become less than gold standard.”*

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All this information was taken to the workshop for discussion. In preparing for the workshop, we went back to some of our preliminary desk research which had helped us understand the context in which UK Biobank is operating.

## **The workshop**

The objectives for the workshop were to:

- Set the context of society, medicine and data and explore where UK Biobank sits within this
- Share findings of interviews
- Support workshop participants to understand the role that participant involvement might play for UK Biobank
- Begin to develop and prioritise reasons for participant involvement and engagement.

## **Opportunities**

Opportunities were themed in a few key areas:

- Improving participant activity
- Understanding how comms are received
- Improving the questionnaire design
- Engaging as a data trust - ie explicit engagement around new uses of data, new linkages etc
- Demonstrating trustworthiness

## Opportunities

Workshop attendees were tasked with breaking down one or two of the opportunities they had identified and thinking about:

1. The purpose of UK Biobank undertaking engagement in this area and what that might look like
2. The outcome for UK Biobank of that engagement
3. The resource implications (only one of the two groups found time for this output)

Table 5: Opportunities, purpose and outcomes for UK Biobank as identified in the workshop groups

Opportunity	Purpose	Outcome for UK Biobank	Resource Implications
<b>Moving participants from passive to active</b> - collecting new data and collating with existing data to develop better insights about participants including why they do or don't take part in enhancements	<ul style="list-style-type: none"> <li>• Increased participation / improving robustness of study through active status</li> <li>• Improving GP relationships</li> <li>• Enabling participant advocacy</li> </ul>	<ul style="list-style-type: none"> <li>• More and better data</li> <li>• More attractive to researchers</li> <li>• Wider interest in science and cohort studies</li> <li>• Improved diversity</li> <li>• Better participant understanding (and understanding of participants)</li> <li>• Potentially a stronger participant voice</li> </ul>	
<b>Leveraging the very engaged</b> - empowering engaged participants to act as public representatives both outward facing and with other participants	<ul style="list-style-type: none"> <li>• To support the movement of participants from passive to active - eg by identifying active participants who may be able to speak to participants like them who are more passive</li> </ul>	<ul style="list-style-type: none"> <li>• Better inclusivity</li> <li>• Better understanding of self-exclusion</li> <li>• Better understanding of reasons for participation</li> </ul>	
<b>Comms analysis</b> - a survey to	<ul style="list-style-type: none"> <li>• Formalising some existing</li> </ul>	<ul style="list-style-type: none"> <li>• Better engagement with outgoing</li> </ul>	

<p>understand how current outgoing comms is being received plus assessing incoming information and whether and how to disseminate that more widely to participants</p>	<p>activities and improving dissemination</p> <ul style="list-style-type: none"> <li>• Solving problems for the whole cohort rather than just individuals</li> </ul>	<p>comms</p> <ul style="list-style-type: none"> <li>• Participants sense of involvement improved</li> <li>• Enabling targeted comms, eg to specific health interests , which could link to public health outcomes</li> </ul>	
<p><b>Survey participants</b> - about reasons for taking part in enhancements (and potentially also about their reception of comms per above)</p>	<ul style="list-style-type: none"> <li>• Improve participants' journey</li> <li>• Show participants that you are listening to them - give something back</li> <li>• Make participants feel engaged</li> <li>• Communicate to them how things have changed based on their feedback (previously and now)</li> </ul>	<ul style="list-style-type: none"> <li>• Provide a better service</li> <li>• Increased participation in enhancements</li> <li>• Making activities more accessible</li> <li>• Targeting and supporting specific groups</li> </ul>	<ul style="list-style-type: none"> <li>• Cost saving in the long run so might cost more initially</li> <li>• Internal person with experience</li> <li>• Time - to set up survey</li> <li>• Ad hoc external consultant</li> <li>• Different comms platforms</li> </ul>
<p><b>Panel of participants</b> - to test ideas on enhancements / to improve participant representation on ethics committee</p>	<ul style="list-style-type: none"> <li>• Panel to feed in to early steps of enhancement studies - seeking input and advice, especially on practicalities</li> <li>• Helping ethics committee account for participants views</li> <li>• Could be early consultation or more ad hoc</li> </ul>	<ul style="list-style-type: none"> <li>• Make sure that enhancements are feasible and acceptable for participants</li> <li>• Streamlines processes</li> <li>• Improves trust</li> </ul>	<ul style="list-style-type: none"> <li>• Needs to be resourced properly like other areas of UK Biobank</li> <li>• A team to contact / select participants and a designated spokesperson</li> <li>• Maintaining and keeping in touch with panel</li> </ul>





## Interviewees and workshop participants

Name	Job Title	I/view	W/shop
Anneke Lucassen	Chair of UK Biobank Ethics Advisory Committee	Y	N
Ben Ullman	Sanctuary Counsel – PR consultancy	Y	Y
Catherine Moody	Head of Population Health UKRI MRC	Y	Y
Fenella Starkey	Senior research facilitator in epidemiology UK Biobank	Y	N
Huma Baig	UK Biobank communications team	Y	Y
Isobel Tandy	Study Admin team UK Biobank	Y	N
Jenny Mills	UK Biobank communications team	Y	Y
Jo Holliday	Health Data Group Lead UK Biobank	Y	Y
Jon Scattergood	UK Biobank Participant Resource Centre lead	Y	Y
Maggie Gregory	UK Biobank Participant Resource Centre Manager	Y	Y
Martin Bobrow	Access Sub Committee Chair UK Biobank	Y	N
Naomi Allen	Chief Scientist UK Biobank	Y	Y
Nicola Doherty	Head of Study Admin UK Biobank	Y	Y
Nicola Perrin	CEO AMRC	Y	Y
Rachel Knowles	MRC	Y	Y
Rory Collins	UK Biobank CEO and PI	Y	Y
Sean Dunn	PRC	Y	Y

## Workshop presentation



UK Biobank  
Workshop Presentatic

## Appendix 2: Revisiting the participation spectrum with ideas for UK Biobank

The table below offers a summary of some of the ideas discussed across the project and allocates them to a level in the participation spectrum. This is presented as a prompt for internal discussion as to how UK Biobank might develop its engagement offer to participants – which we would then suggest integrating into the cycle of engagement described at [Part 3](#).

	Activity	Purpose	Promise to participants	Possibilities for UK Biobank
<b>INFORM</b>	To provide the public with balanced and objective information	To inform those with an interest in the outcome (i.e. the public and stakeholder groups)	<ul style="list-style-type: none"> <li>We will keep you informed</li> <li>We will provide information openly and transparently</li> <li>We will not withhold relevant information</li> </ul>	<ul style="list-style-type: none"> <li>Biobank could ensure all existing comms have at least two formats and see if this changes the open or response rates (A/B testing).</li> <li>In addition to existing comms, Biobank could develop a suite of outgoing comms and a range of methods for participants to find out more about the work of the project.</li> <li>Biobank could consider summaries of research papers in order to provide accessible documentation of the research outputs.</li> <li>Biobank could be more transparent about who is accessing the data and how this is approved.</li> <li>Biobank could be more transparent about the extent of the consent given at the outset and the variety of data that is added to the</li> </ul>

	Activity	Purpose	Promise to participants	Possibilities for UK Biobank
				collection.
<b>CONSULT</b>	To obtain feedback on analysis, alternatives, proposals and/or decisions	To inform those making the decision or developing proposals	<ul style="list-style-type: none"> <li>• We will keep you informed</li> <li>• We will listen to and acknowledge your concerns and aspirations</li> <li>• We will give serious consideration to your contributions</li> <li>• We will be open to your influence</li> <li>• We will feedback on how your input has influenced the outcome</li> </ul>	<ul style="list-style-type: none"> <li>• Biobank could ask participants what they value about the comms and what would improve them for participants - including frequency, topics, etc and use this to change how they communicate (if appropriate)</li> <li>• Biobank could ask participants why they take part in imaging / questionnaires and use that info to help shape future comms</li> <li>• Biobank could share future plans and ask for participants' concerns and their aspirations for the future of Biobank.</li> <li>• Biobank would have to know what could change and feedback to participants both about changes and about why change hadn't happened.</li> <li>• Biobank could test hypotheses with participants around the extent of the consent that participants think they have given - with a transparent</li> </ul>

	Activity	Purpose	Promise to participants	Possibilities for UK Biobank
				<p>set of proposed additional data collection points and seeking participant views on whether Biobank can and should collect that data and how Biobank should make that data available and to whom - and what it should tell participants about the research the data enables</p> <ul style="list-style-type: none"> <li>• Given the developments in understanding the results of the studies etc, Biobank could consult participants on changes to the feedback rules. This would require understanding the trade offs and there would need to be clarity on what could change if participants did indeed see value in individual feedback. (So could, and arguably should, move to the level of involve).</li> <li>• Biobank could ask participants if providing feedback to participants about the results of research undertaken with identifiable data (eg imaging) is something they would value</li> <li>• Biobank could work with participants to develop a toolkit for researchers to use that could</li> </ul>

	Activity	Purpose	Promise to participants	Possibilities for UK Biobank
				identify which areas of research should include participant engagement as part of the proposal's access to Biobank.
<b>INVOLVE</b>	To work directly with participants throughout the policy / decision making process to ensure that their concerns and aspirations are consistently understood and considered	To enable participants to directly influence the decision / options developed	<ul style="list-style-type: none"> <li>• We will keep you informed</li> <li>• We will work with you to ensure that your concerns and aspirations are directly reflected in the outcome / alternatives developed</li> <li>• We will feedback on how your input has influenced the outcome</li> </ul>	<ul style="list-style-type: none"> <li>• Biobank could engage with participants about how their data is used and what participants are told both about why the research is being done, the outcomes of the research, and how participants can use the research in their own lives (not individual feedback, but an acknowledgement of eg Biobank data shows heavy drinking is bad, here are resources about that).</li> <li>• Biobank could invite feedback about the above and use it to inform future research studies. IE - before you use our data you should provide a participant information leaflet that explains why you want to know if they don't like avocado</li> <li>• Participants could work with Biobank to identify possible research questions? This is picked up below, but at the involve level it</li> </ul>

	Activity	Purpose	Promise to participants	Possibilities for UK Biobank
				would be more on looking at additional or revised questions, where as in collaborate it's looking at research areas, and larger research questions
<b>COLLABORATE</b>	To partner with participants in each aspect of the decision, including defining the issue, developing alternatives and identifying preferred solutions.	To share the development and decision-making process (as much as possible)	<ul style="list-style-type: none"> <li>We will look to you for advice and innovation in formulating solutions</li> <li>We will incorporate your advice and recommendations into decision / implementation to the maximum extent possible</li> </ul>	<ul style="list-style-type: none"> <li>Biobank could recruit lay members to the board and Ethics committee - these could be drawn from the participant cohort or the general public or both</li> <li>Biobank could invite participants to test research proposals and suggest additions - eg, why are you asking if I like avocado when in fact I love avocado but am intolerant so cannot eat it.</li> <li>Biobank could invite participants to prioritise research areas - with those identified by participants being fast tracked or otherwise prioritised</li> <li>Biobank could offer participants the chance to deliberate about the implications of Biobank research on public health outcomes, participants health outcomes, the children and grandchildren of participants</li> </ul>

	<b>Activity</b>	<b>Purpose</b>	<b>Promise to participants</b>	<b>Possibilities for UK Biobank</b>
<b>DELEGATE</b>	To place final decision-making in the hands of the participants - to delegate	To hand over the ability to make decisions and / or take action	<ul style="list-style-type: none"> <li>We will implement what you decide</li> </ul>	<ul style="list-style-type: none"> <li>Biobank could invite a representative group of participants to form mini publics that sit alongside the board; access committee; ethics committee and offer a participant voice in these structures. The existing committees would actively report to, seek feedback from and implement recommendations from the panel(s) eg NICE public panel.</li> </ul>



# Appendix 3: About Involve

## 01. Who we are

We're the UK's leading public participation charity, on a mission to put people at the heart of decision-making.

We're a small but passionate team focused on giving people more power over the decisions that affect their lives. We want to build a stronger democracy that works for everyone – that gives people real power to bring about change in their lives, communities and beyond.

Involve was founded in 2003 to “to create a new focus for thinking and action on the links between new forms of public participation and existing democratic institutions”. We've been promoting and practising participatory and deliberative decision-making ever since. We have worked with governments, parliaments, civil society organisations, academics and the public across the UK and internationally to put people at the heart of decision-making.

We believe that decision-making in the UK needs to be more:

- **Open** - so that people can understand, influence and hold decision-makers to account for the actions and inactions of their governments;
- **Participatory** - so that people have the freedom, support and opportunity to shape their communities and influence the decisions that affect their lives; and,
- **Deliberative** - so that people can exchange and acknowledge different perspectives, understand conflict and find common ground, and build a shared vision for society.

## 02. What we do

We demonstrate how citizens can help solve our biggest challenges.

Democracy isn't working as it should. Decision-makers are struggling to get things done. The public are frustrated that the system isn't working for them. And everywhere people are feeling divided, distrustful and powerless.

Our work seeks to create:

1. **New innovations** - to demonstrate better ways of doing democracy;
2. **New institutions** - to put people at the heart of decision-making;
3. **New norms** - to make democracy more open, participatory and deliberative.

We approach this in three ways:

1. **We set the agenda** - by developing a vision of a democracy that puts people at the heart of decision-making;
2. **We build coalitions** - by mobilising and partnering with broad, unexpected and powerful networks of allies; and,
3. **We make it happen** - by developing and supporting world-class participatory and deliberative processes.

Our recent projects have included:

- **The Citizens' Assembly on Social Care** - the first deliberative process commissioned by UK Parliament;
- **The Citizens' Assembly for Northern Ireland** - the first citizens' assembly to take place in Northern Ireland;
- **MH:2K** - a youth-led approach that has engaged over 3,400 young people in tackling mental ill-health.

Find out more about our work: [www.involve.org.uk/our-work/](http://www.involve.org.uk/our-work/)

## Our values

- **Collaboration** – because change comes when broad coalitions of people work towards a common vision.
- **Equality** – because everyone in society has an equal right to be listened to and participate in decisions that affect their lives. No one should be held back by societal divisions or prejudice.
- **Purpose** – because participation must have an impact. We reject tokenistic or ineffectual engagement.