Our
Future
Health

Participant and public involvement and engagement

Strategy and progress report

Contents

Foreword

Our Future Health is now the world's largest health research programme of its kind. The number of people who have volunteered to take part in our research programme numbers in the millions. Through taking part in our research programme, our participants are trusting us. This trust is a privilege that everyone who works across Our Future Health respects and does not take for granted.

The responsibility with which we carry that trust is underpinned by our commitment to ensuring that the diversity of our participants' perspectives – and also members of the public – continue to shape our research programme. Meaningful participant and public involvement and engagement (PPIE) sits at the heart of that commitment.

Although this is the first time that we have published a Participant and Public Involvement and Engagement (PPIE) Strategy, the practice of involving and engaging our participants and members of the public has threaded throughout our programme since its inception. This can be seen through the many examples of our PPIE work to date that are shared throughout this document.

But as well as being a retrospective of how participants and the public have been involved in our programme to date, this strategy importantly sets out our commitments for continuing to involve and engage meaningfully in the future. These commitments will see us continuing to:

- Embed public and participant perspectives in Our Future Health's internal structure
- Draw on a wide range of involvement and engagement approaches and practices
- Share what we learn from involving and engaging participants and the public
- Collaborate across the health research ecosystem
- Evaluate our involvement and engagement work

It is as a result of the involvement and engagement of our participants and the public that we are in a strong position to develop Our Future Health in a way that has their interests, perspectives, and wellbeing at its core. We look forward to continuing to invest in our PPIE work to enable this position of strength to be maintained to facilitate and accelerate impactful health research with benefits for all communities across the UK.

Raghib Ali

Dr Raghib Ali
Chief Executive Officer and Chief Medical Officer, Our Future Health

Introduction

1. This Participant and Public Involvement and Engagement (PPIE) strategy sets out **Our Future Health's vision for involving and engaging participants and the public** in the ongoing design and delivery of our research programme. Through illustrative case studies, this document also **reports on our progress with PPIE so far**; and reflects on how we are achieving, and will continue to achieve, that vision in **five key strategic areas**:

    A. Embedding public and participant perspectives in Our Future Health's internal structure
    B. Drawing on a wide range of involvement and engagement approaches and practices
    C. Sharing what we learn from involving and engaging participants and the public
    D. Collaborating across the health research ecosystem
    E. Evaluating our involvement and engagement work

2. Our commitment to involving and engaging the public and participants in our programme is established in our Ethics and Governance Framework. The Framework emphasises that the involvement of the public and participants should be woven into all aspects of our research programme, rather than being siloed or seen as an 'add on' to core work. This document indicates how we are delivering, and will continue to deliver on, the Framework's commitment.

Participant and public involvement and engagement: our vision and aspiration

3. Through committing to the meaningful involvement and engagement of our participants and members of the public in our research programme, our vision is that their opinions, preferences, concerns, hopes, and expectations are considered and reflected in our endeavours.

4. This vision underpins our aspiration for our research programme to reach, and maintain, a gold standard for PPIE, ensuring that our research programme continues to be undertaken with the interests and perspectives of our participants at heart. It is for this reason that we are making the commitments that we have outlined in this strategy.

Benefits for Our Future Health and our participants

5. We have already seen the very positive impact that using PPIE has brought to our programme, as highlighted by the case studies that are shared throughout this document. Genuine, positive change has been realised through the contributions of our participants and members of the public, and we believe our research programme is all the stronger for it. We are therefore committed to supporting and investing in further PPIE in the future through the next steps that are described in this document.

6. Crucially, PPIE is about ensuring that our programme is the best it can be for our participants, and those who become participants in the future. It is their interests that are at the core of our research programme. We are therefore excited to continue to work with our participants and the public to ensure that those interests continue to be reflected in our programme meaningfully, effectively, and ethically.

Context and use

7. This is Our Future Health's first agreed, published document that shares our PPIE strategy. It builds on, and consolidates, what we have already achieved. Throughout, we therefore share both the PPIE progress we have made so far; and the strategic commitments we are relying on to continue to deliver a strong programme of PPIE for our research programme in the future.

The scope of participant and public involvement and engagement

8. PPIE is a group of methodologies that enables and ensures that our participants and members of the public can contribute to planning, developing, and delivering our research programme. Using PPIE helps us to ensure that their opinions, perspectives, expectations, concerns, and hopes can be embedded into our programme and its endeavours. We draw on a range of engagement and involvement methods to achieve this (see paragraphs 19-32), so that our participants and the public can be supported to contribute actively to the design and delivery of our research programme.

9. PPIE does not extend to unilateral communications with the public and participants. It is for this reason that this document does not include actions that relate to how we communicate about our programme with our participants or members of the public (e.g., conveying information about our research programme in the media or on social media; or sending invitation letters to potential participants).

The principles that underpin our participant and public involvement and engagement strategy

10. Our strategy is underpinned by nine principles that guide our PPIE work. These principles have been co-developed with our Public Advisory Board (for further information on this Board's role, see paragraph 12).

Principle	**Applying the principle**
1. Involve underserved or underrepresented people	We are committed to supporting a diverse cohort of participants to take part in our research programme. To ensure that we meet this commitment, we will involve and engage people who are underserved in health research (e.g., minoritised communities or younger people).
2. Tailor activities according to who will be involved	Each involvement or engagement project we establish will be bespoke to those people who are being involved, and the issue that is subject to their views and contributions.
3. Rely on trusted actors and trusted spaces	When we seek to engage different groups and communities, we will, as far as possible, rely on the guidance of trusted actors. This might include community leaders, teachers, engagement experts, or faith leaders. We will also endeavour to undertake involvement or engagement activities in trusted spaces where those whom we involve will be comfortable and at ease.
4. Report back to those who have been involved, to form a feedback loop	We will establish mechanisms for those whom we involve being informed about developments that arise from their contributions. This might be through direct communication with

	those individuals (should they wish to receive those communications), or through informing them through more indirect means (e.g., a newsletter or report).
5. Respect the views that arise during involvement and engagement activities	We will treat people who volunteer their time, views, or experience with respect. This includes giving their contributions due consideration and regard. We will ensure that activities are not just a ‘tick box’ exercise and are instead meaningfully factored into the decision-making that supports our programme.
6. Ensure that involvement and engagement does not become burdensome	We will be respectful of people’s time. We will strive to avoid asking people to support us with little notice, or at times that are inconvenient to them (e.g., during working hours). We will also ensure as far as possible that those whom we involve are well briefed on the issues or projects that we work with them on.
7. Involve people in a timely way	We will only involve people if issues are at a stage where their opinions and perspectives can be meaningfully considered.
8. Avoid over-promising	Where promises are made about what the outcomes of involvement or engagement might lead to, they need to be followed-through. Equally, we will communicate clearly with those whom we involve, highlighting that, though we will consider and listen to their views, we will not always be in a position to implement all actions that are recommended.
9. Ensure involvement and engagement activities are accessible	When we involve or engage people, we will – where practicable – provide accessible formats for materials they are invited to consider; and ensure that in-person activities are held in spaces that can accommodate participants’ needs.

11. Across each of these principles, we will also act according to our organisational values, including honesty, transparency, and inclusivity. We see these values as key to us respecting those whom we engage and involve; and as integral to the demonstration of our trustworthiness to our current, and future, participants.

A. Embedding public and participant perspectives in Our Future Health’s internal structures

Progress to date

The role of the Public Advisory Board

12. Our Public Advisory Board is a core part of our governance structure and provides advice and oversight on aspects of Our Future Health’s research programme that have, or could have, an impact on participants’ interests. **We are committed to ensuring that there is public and participant representation in our governance structure** and will continue supporting the Public Advisory Board to the fullest extent possible. An overview of its role is provided in Box 1 below.

Box 1: Overview of Our Future Health's Public Advisory Board

We established the Public Advisory Board in 2021.

The Public Advisory Board's Chair works with the Chairs of Our Future Health's other advisory boards, to ensure that the Public Advisory Board's views and interests are represented across our governance structure.

The Public Advisory Board currently has 17 members, whose backgrounds include teaching, design, IT, computer science, coaching, and marketing. Members also have lived experience as patients or carers, and some are also members of other patient / participant panels. Public Advisory Board members also sit on our other boards (including our Ethics Advisory Board and Scientific Advisory Board) to bring public and participant perspectives to their deliberations.

The Public Advisory Board has advised us on materials, issues, strategies, and approaches, including:

- Initial drafts of our participant information materials at the inception of our programme, which the Board co-developed with us
- Our plans to deliver public / participant deliberative dialogues on feedback and recontact (see paragraph 25)
- The development of plain language guidance for researchers
- The establishment of our Involvement Network (see paragraphs 16-18)
- How researchers' future access to participants' samples can be managed
- Options for how we can be transparent about our relationship with commercial partners

Supporting our Public Advisory Board's development

13. Through asking Public Advisory Board members to complete an annual survey, we are able to reflect on the Board's role in contributing to our research programme; and its future development.

14. In members' most recent responses to this survey, they indicated that we should take action to increase the diversity of the board to include younger people and more people from minoritised groups. We have taken steps to address this through appointing new members.

Next steps

15. We will **continue to monitor the diversity of the Public Advisory Board as current members' tenure ends, and new members are appointed**. Members have also encouraged us to establish a means through which former members of the Public Advisory Board can continue to contribute to the development of our research programme. This steer was one of the driving factors for our establishment of the Our Future Health Involvement Network.

Development of the Our Future Health Involvement Network

Progress to date

16. In February 2025, we established the Our Future Health Involvement Network. This provides an internal structure through which participant and public perspectives can shape our work, affording us the benefit of working with a group of participants and members of the public on an ongoing basis. Prior to establishing the Involvement Network, we worked closely with members of our Public Advisory Board (see above) on the information materials shared with

Involvement Network members. We also met with several of our charity partners to learn from other organisations that have experience of developing their own similar networks. This engagement with our charity partners has been integral to us establishing our network and emphasises further the importance of collaborating with others with respect to our PPIE work (see paragraph 38).

17. Teams across Our Future Health bring different questions and issues to the Involvement Network, and are supported to run activities workshops, surveys, focus groups, and dialogues. Members are invited to indicate if they would like to take part in each activity offered, though we emphasise that not all members can take part in every activity; and that there is no mandatory involvement in the activities offered (i.e., members can volunteer to take part in as much, or as little, as they prefer).

Next steps

18. At the time of writing this strategy, the Involvement Network is being run as a pilot. **Throughout that pilot period, we will evaluate different aspects of its operations and contributions to establish whether the Involvement Network should continue as an embedded part of our programme**. An update to this strategy will be made according to the outcomes of this evaluation.

B. Drawing on a wide range of involvement and engagement approaches and practices

Progress to date

19. ‘Involvement’ and ‘engagement’ cover a broad church of approaches that we currently, and will continue to, draw on to inform our programme and its activities. They include partnering or collaborating with participants and members of the public; involving them in the decisions we are making or policies we are developing; and embedding participants and the public in our governance structure (as with the Public Advisory Board) or working practices (as with the Involvement Network). This section summarises the approaches that we have drawn on to date; and our broad commitments to continuing to use them in the future. Each of the engagement and involvement methods and practices that are highlighted do not, and will not, sit in isolation from each other, but rather comprise an ecosystem of engagement and involvement that underpins our programme.

Community engagement

20. We have a responsibility to ensure that our cohort of participants includes people from a wide range of backgrounds, ethnicities, and ages – as indicated by Principle 1. This is so that our programme can reflect the whole UK population; ensure that the research that we support can incorporate the interests of all communities; and lead to beneficial health discoveries for people from all backgrounds.

21. We address this responsibility head-on through drawing on the expertise and analysis of data scientists to understand the diversity of our cohort, so that we can identify which groups are underrepresented. This analysis is used to develop methodologies for innovative community engagement projects to improve the representativeness of our cohort. Those projects are subject to rigorous evaluation to inform decision-making about what our next steps might be

with respect to the community engagement projects we undertake. Some examples of those projects we have undertaken to date are set out in Boxes 2, 3, and 4 below.

Box 2: Working with the British Muslim Heritage Centre

In November and December 2023, we piloted a mobile appointment centre at the British Muslim Heritage Centre in Whalley Range, Manchester.

In line with Principle 3, we liaised with faith leaders at the Centre to establish how those who worship there could be made aware of the aims of our programme, so that they might consider participating. While we did see an uplift in participants' diversity in this area, it was not sufficient for us to conclude that we could deliver this model at a larger scale.

Since the pilot, we returned to the Centre to speak with – and learn from – people who saw the communications about our research programme but decided not to join. One key message that emerged was that some people who attended the Centre were cautious about joining our programme because they had not heard of us until shortly before our mobile appointment centre arrived.

UK's largest health research programme is coming to the British Muslim Heritage Centre in Manchester – Our Future Health

22. The lessons we learned from our pilot with the British Muslim Heritage Centre were applied to a second Manchester-based pilot, which welcomed potential participants to have a 'chai and chat' about our programme on the Curry Mile (see Box 3). This pilot allowed us to assess whether increasing the visibility of our programme led to an uptick in our programme's inclusion of diverse participants in the local area.

Box 3: Chai and chat on the Curry Mile

In April 2024, we offered a 'chai and chat' on Manchester's Curry Mile, where locals were able to learn more about the programme and ask questions about it in an informal setting, over a cup of tea.

The chai and chat days were arranged in advance of one of Our Future Health's mobile appointment centres opening on the Curry Mile a few days later, so that those who had learned about the programme could follow-up and join if they wished to. We also visited businesses on the Curry Mile so that posters could be put up to share details about the mobile appointment centres and how people could join our programme.

Evaluations of this pilot indicated that our engagement activities on the Curry Mile increased the number of participants from the area who decided to join Our Future Health. In one area of Manchester very near to the Curry Mile, participation rates increased by one third.

People who came for a 'chai and chat', did, however ask us whether they could join our programme and provide a blood sample on the same day – i.e., 'walk in' to one of our appointment centres. We could not accommodate their requests, but we did take this on board for our future planning (see Box 10), in accordance with Principle 5 which requires us to respect the views that arise during involvement and engagement activities.

Manchester’s Curry Mile hosts UK’s largest health research programme – Our Future Health

Next steps

23. **Continuing to develop in-person PPIE activities will be something that we consider further in the future**. This might include, for example, organising participant- and public-focused activities and events across the different regions of the UK. In accordance with Principle 3, we **will also explore further how working with trusted actors might support our engagement with diverse communities**. Ongoing projects in this context are shared in Box 4.

Box 4: Working with trusted actors: Community Champions and Global Community Enablers

In accordance with Principle 3, we are working with trusted actors to engage different communities in our research programme.

In March 2025, we began piloting a Community Champions programme. This programme aims to improve awareness of Our Future Health in diverse communities, with a view to increasing diverse participation. The Community Champions are all Our Future Health participants who work with us to establish programmes of activity to encourage information-sharing, discussion, and awareness-raising of our research programme. We draw on the expertise and networks of our Champions, supporting them to share information about Our Future Health with their communities.

Around the same time, we also began working with Global Community Enablers, a South London-based group that works with members of the Black community. The Global Community Enablers develop events and engagement activities so that information about our programme can be shared with members of their communities.

24. These community engagement projects inform our own programme’s development. However, they may also be instructive for other organisations and researchers working in health contexts. It is for this reason that we are committed to **sharing information about our community engagement projects – and what we learn from them** – with our participants (through our newsletter – in accordance with Principle 5); and with others working in the same research ecosystem (e.g., through the cross-organisational professional engagement network we have established – see Box 11).

Deliberation and dialogue

Progress to date

25. Some aspects of Our Future Health’s design and delivery relate to ethical questions that directly impact participants’ interests. Although we liaise with the Public Advisory Board to address these questions, there are some instances when broader deliberation is required. An example of this is our exploration of how we might offer health feedback to our participants; and also recontact our participants to offer them opportunities to take part in further health research studies. As our research programme had not explored these types of ‘offer’ through

deliberative dialogue, we committed to exploring key questions by using this methodology, as described in Box 5.

Box 5: Deliberative dialogues on feedback and recontact, November 2023-March 2024

In November 2023, we commissioned a series of public and participant deliberative workshops with 100 participants and members of the public to allow us to understand key issues for our Feedback, Engagement and Recontact programme in the early stages of our planning. The issues concerned how we might offer health feedback to our participants; and how we should approach recontacting participants to enable them to take part in further health research studies. Whilst these topics require scientific, ethical, clinical, operational, technical and other inputs, we intentionally chose to begin with PPIE in order to generate principles that would help guide the programme and its activities as it evolves.

We collaborated with two companies with strong experience of running deliberations on issues in health research contexts. While we worked very closely with these companies, it was imperative that dialogue participants should feel that they could contribute openly without feeling 'watched' by the facilitators – which would have been challenging had Our Future Health staff facilitated the dialogues. The dialogues used a combination of online platforms and in-person workshops to facilitate the involvement and engagement of participants on these topics.

As well as informing the in-progress development of our policies on feedback and recontact, the dialogues – which concluded in March 2024 – also allowed us to forge relationships with the members of the public and Our Future Health participants who took part. All of those who took part who consented to ongoing contact with Our Future Health were subsequently invited to join our Involvement Network; and a small number of dialogue participants have also joined our Public Advisory Board.

26. Using deliberative dialogues to explore issues related to feedback and recontact yielded a rich resource for us to draw on in the establishment of respective policies. In line with Principle 7, the dialogues were developed at a time when decisions about our policies on feedback and recontact had not been made; and the participant-facing tools to deliver feedback or enable recontact had not yet been designed. This meant that the dialogue participants' deliberations had a meaningful impact on our approach and helped us to establish principles to guide our work and ensure that we adopt a participant-centric approach.

27. We also use workshops to support dialogue in a variety of contexts across our research programme. This includes debates and discussions relevant to including minoritised ethnic groups in our research programme (see Box 6); and broader ethico-legal debates that are relevant to the wider health research ecosystem (see Box 7).

Box 6: Workshops with organisations which engage with minoritised ethnic communities

In June 2023, we commissioned a series of workshops with community groups based in Lewisham and Oldham in order to understand how we might best involve members of the Black African, Black Caribbean, Pakistani, and Bangladeshi communities in our programme. The community partners we worked with – Community Connections (Lewisham) and Action

Together (Oldham) – provided key messages that have informed the development of our community engagement programme. They included:

- People's distrust of, and negative experiences of, the healthcare system could be a barrier to people feeling able to join Our Future Health;
- Demonstrating Our Future Health's trustworthiness is key to community members' engagement with the programme, which might be achieved through openness about the programme's processes and aims; and
- Community 'ownership' of the programme is integral.

Box 7: Collaborating with the Health Research Authority on participants' loss of capacity in longitudinal research contexts

In September 2023, we worked with the Health Research Authority and Genomics England to run a scoping workshop on the issue of participant capacity in the context of longitudinal health research (i.e., how research programmes should prepare for participants' loss of capacity – for example, through dementia). The workshop brought together participants and members of the public with experts in law and regulation to lay the groundwork for a potential future programme of work on this issue – potentially including a public dialogue.

Blog: Consent, capacity and long-term research - Health Research Authority (hra.nhs.uk)

Next steps

28. **Using deliberative PPIE methods to explore complex issues will continue to be one of the approaches we consider to support our future work**. In accordance with Principle 7, we will remain cognisant of the fact that such dialogues need to be undertaken in a timely way, to ensure that their outcomes are able to have a genuine influence on the decisions and design of our programme.

User-centred research and behavioural science methods

Progress to date

29. In according with Principle 1, we are committed to ensuring that our programme meets the needs, preferences, and requirements of our participants, and potential future participants from a wide range of backgrounds and experience. We practise a participant and public-centric approach through drawing on methods across user-centred design, quantitative and qualitative behavioural science, and service design methods, so that we can listen to, and act on, people's thoughts and attitudes towards our programme. Box 8 provides definitions of these areas of practice.

Box 8: What is user-centred design and behavioural science?

User-centred design is a practice that allows us to attain an understanding of an issue, and the acceptability or functionality of a solution. It involves observing and understanding people's behaviours, needs, and emotional response. It uses these insights to improve services and experience. At Our Future Health, we use a range of user-centred design methods, including surveys, interviews, usability testing, and card sorting exercises. We carry out these practices according to four key assumptions.

A. Our Future Health is not its participants. Our experience in designing and developing our programme brings bias. It is for this reason that we ensure that working with people outside our programme is built into our design practice.
B. Participant and public perspectives are brought into the design process at each step.
C. Decisions that result from the design process are evidenced.
D. Participant and public perspectives are balanced against the operational realities of the programme.

Behavioural science crosses the boundaries of a range of applied scientific disciplines, including psychology, sociology, anthropology, and economics. It focuses on generating evidence – drawing on research, theory, and frameworks – to understand people's behaviour. Behavioural scientists apply that evidence to solve problems for people and societies, developing interventions that place people and their behaviour at the heart of the design process. At Our Future Health, behavioural science informs the design of our approaches to participant recruitment; feedback, engagement, and recontact; and researcher and data platforms.

Both areas of practice have used, and will continue to use, a range of techniques to support our programme. These include interviews, usability testing, surveys (both qualitative and quantitative), literature reviews, and experimental design.

30. The practices of Behavioural Science and UCD have already provided key insights for Our Future Health that have been integral to the development of our research programme. They have enabled us to design our programme in a way that reflects the needs, preferences, and opinions of potential participants in mind. Examples of how these methods have supported our programme to date are provided in Box 9 below.

Box 9: User experience and behavioural science research

Co-design of our participant information sheet, consent form, recruitment materials, and protocol (2020-21)

Co-design sessions involved 120 members of the public. Activities were comprised of:

- 18 focus groups, 10 co-design meetings, and 21 interviews to develop our information sheet, consent form, and other public-facing videos and materials
- Four focus groups, two co-design meetings, and 21 interviews to develop our protocol

User experience research with over 3,000 members of the public (2022)

Fourteen user experience research projects were conducted both by in-house behavioural scientists, and an external provider. The projects allowed the development of our public-facing website, participant information sheet, invitation letters, digital sign-up process, in-person participant appointments, to be informed by public views and opinions. This method also allowed us to explore public attitudes to Our Future Health, and people's desire and preferences for genetic feedback. We continue to draw on user design methods to understand how we can best support our participants, and future participants.

Interviews to understand participants' experiences of taking part in our programme (2022)

We commissioned an external research agency to interview 97 participants who had completed our Participant Reported Experience Measure (PREM) survey. The interviews allowed us to better understand participants' motivations for joining our programme, the extent to which participants understand what taking part in our programme entails, and any points of friction in their participation process.

User research projects to support the development of our programme (2023)
We conducted 19 user research projects and surveyed / interviewed approximately 3,400 people to support the development of our programme's technical products and resources – including our website, how people can join our programme digitally, the invitations that we send for people to join our programme. They also allowed us to understand people's attitudes towards our funding and partnerships – for example, as a result of a public attitudes survey.

Research to understand why some participants do not complete all participation steps (2024)
We worked with an external research company to understand why some people who register for our research programme do not complete all the steps of the participation process (e.g., some participants may complete our questionnaire but may not go onto book an appointment). The research involved 15 participants who took part in qualitative interviews; and 1,335 participants who took place in a quantitative survey. All of those who took part had consented to join Our Future Health but had not booked an appointment. The results have enabled us to learn about why this might be happening, to inform what we can do in mitigation – including through developing a walk-in appointment model (see Box 10 below).

Next steps

31. **We will draw further on behavioural science and user-centred design practices as our research programme continues to develop**. They are practices that will be used across each of the core parts of our programme: participant recruitment; research and data platforms; and feedback, engagement, and recontact. We will also work closely with the research ethics committee that has approved our programme to ensure that the user experience and behavioural science research that we undertake meets regulatory research ethics requirements.

32. We draw on practices such as scientific design, data collection, and evaluation to **assess and evaluate the impact of community engagement projects with diverse community members**. Such evaluation is key to Our Future Health's decision-making with respect to whether pilot approaches should be scaled to become an embedded part of our programme. One of these pilots that is live at the time of writing is described in Box 10 below.

Box 10: Establishing the feasibility of walk-in appointment pilots

In early 2025, we enabled participants in a small number of city locations to join the programme and come to an appointment on the same day, as a 'walk-in' participant. This meant that they could register, consent, and provide samples on the same day – rather than needing to book an appointment in advance.

We decided to implement this approach following our interactions with communities (see Box 3); and following responses to a quantitative survey that explored barriers to participants completing all phases of joining Our Future Health (see Box 9). Our decision was in accordance with the principle that we respect the views that arise during involvement and engagement activities (see Principle 5).

At the time of writing this strategy, we are assessing the feasibility of this pilot, and learning about the impact it may have on our programme if we were to roll it out more widely. Assessing the feasibility of supporting walk-in appointments will allow us to learn how this approach compares with the advance booking model that participants are currently offered; and to establish what our next steps might be in response.

C. Sharing what we learn from involving and engaging participants and the public

Progress to date

Sharing outcomes with the participants and public we involve

33. In accordance with Principle 4, we endeavour to **share the outcomes of involvement activities with those who have contributed to them**. We do this presently through reporting back to the Public Advisory Board with information about what decisions were made in the light of its advice. For our Involvement Network, we have indicated to members that we will share updates with them on the activities they contribute to – however, as highlighted by Principle 8, we do not over-promise about when those updates might be available and are therefore clear with members that such information may not be able to be shared until several months later.

Next steps

Sharing and disseminating the outcomes of involvement and engagement within Our Future Health

34. Our research programme requires a wide range of expertise – many of which are technically focused and support the efficient management of the very large health research programme that we are developing. Most staff members do not have direct experience of PPIE. But it is PPIE that might eventually feed into the work that they undertake. **Efforts are therefore being made – and will continue to be made – to share the work, insights, and outcomes of PPIE activities across Our Future Health's teams**. Recently, this has included sharing emerging messages from our deliberative dialogues on feedback and recontact with all staff at Our Future Health; and presenting in-depth findings to teams working on feedback and recontact.

Presenting our engagement and involvement work in public fora

35. The news pages of our website share key findings and initiatives that we are developing in the context of engagement and involvement. **We will endeavour to continue using our website to communicate about our engagement and involvement work to our participants, and also other stakeholders**.

36. We also present our approach at events and conferences to contribute to good practice discussions in this context. **Opportunities to share and present our PPIE work at appropriate external events will be continued to be sought throughout the duration of our**

research programme. This will build on the presentations on our engagement and involvement work to date – including at the World Congress of Bioethics, and the Festival of Genomics.

D. Collaborating across the health research ecosystem

Progress to date and next steps

37. Our Future Health sits within an ecosystem of research initiatives and organisations both in the UK, and overseas. It is only through collaborating throughout the ecosystem that optimum progress can be made with respect to health research practices. **We will therefore continue to share what we learn from our PPIE work**. We do this through sharing stories on our website, but also through communicating with, and learning from, other programmes and health research initiatives working in similar contexts. We recognise that working in siloed ways will not enable PPIE in health research to thrive. **We will therefore aim to ensure that the outcomes of our own PPIE work can be shared to inform other organisations working in health research and biobanking contexts**.

Collaborating with other organisations and researchers working in longitudinal research contexts

38. Many of the issues and questions that we address through PPIE reflect similar questions that other organisations that work in biobanking and longitudinal health research contexts are also addressing. We have therefore established a network with others who involve and engage participants and the public in other organisations, as highlighted in Box 11 below.

Box 11: Establishing a professional biobanking and genomics involvement and engagement network

Our Future Health led the development of an informal network between professionals that lead on PPIE at our own organisation, UK Biobank, and Genomics England.

Members of the network meet every two months to discuss the PPIE activities that are being undertaken by each organisation; to share learnings and experience of any challenges or issues; and to discuss good practice examples that are emerging in each organisation's context.

This informal network will continue to meet at its current cadence, or more frequently as the need arises. Membership can also be extended to other practitioners working in this context.

Benefiting from the advice of our charity partners

39. As noted above (see paragraph 16), the advice of other organisations – in particular our charity partners – was integral to the development of our own Involvement Network. **We will therefore continue to draw on the expertise of other organisations as appropriate. This includes working with charities that are Our Future Health partners, which also rely on PPIE methods to support and shape their areas of work**.

Potential PPIE support for researchers

40. In the future, our programme is highly likely to see an increase in applications from researchers who wish to access participants' deidentified data; or recontact our participants to offer them

an opportunity to take part in additional research studies. At the time of writing this strategy, we do not have a clear indication on the degree to which researchers may request our advice or support on their use of PPIE methodologies to underpin their own studies with Our Future Health participants or participants' data or samples. **We will monitor any communications from external researchers to gauge whether we should consider developing a PPIE support function for them in the future.**

E. Evaluating our involvement and engagement work

Next steps

41. We will continue to learn how to engage and involve the public and participants optimally. To support this learning process, **the PPIE projects that we undertake will each be subject to review and evaluation**. Where possible, we will involve the public or participants who took part in those projects to contribute to these evaluations.

42. In addition to reviewing the individual projects that might arise in the light of this strategy, **we will also keep this strategy under review** and, where needed, create an updated version to reflect any changes that are required. However, it is anticipated that the principles that underpin this strategy will remain a bedrock for our approach to involvement and engagement during the lifespan of our programme.

43. Evaluation is important not just so that we can learn from those projects and embed what we learn into future projects; it is also an appropriate mechanism through which we can assess the extent to which the time of those whom we have involved and engaged, and the resources we invested in that involvement and engagement, led to outcomes that benefited the programme, our stakeholders and, most importantly, our participants.