

CAG (Confidentiality Advisory Group) update on PPIE (Participant and Public Involvement and Engagement) and Opt-Out Activities (Feb 2023)

Our Future Health plans to recruit 5 million people. As part of pilot activities we sought approval for the issue of invitations via Digitrials in March 2022. Given the initial success of this, we applied to extend to 12 million invites in November 2022.

The success of the invitation process to date has led to a final application for amendment to issue a letter to all adults in England (circa 45m). The attached application for this amendment sets out the success to date and reiterates that this application seeks no change to any aspect of the process previously approved, but simply requests ability to use that process to send invitations across all geographic areas of England.

This document provides an update on key aspects of that process focused on public involvement and co design and on the ability for individuals to opt out of receiving an invitation.

Public engagement, baseline data collection and participant feedback

Summary of PPIE and Engagement Activities 2020 –2022

Alongside careful analysis of the recruitment data from the participants who signed up over the last 7 months, in 2020-2022, Our Future Health involved over 3,600 members of the public in the design and development of the major public-facing materials, as well as in other aspects of the programme design.

The activities summarised in [Table 1](#) were conducted both by our internal Behavioural Science team and through external agencies who specialise in either user experience research (Bunnyfoot) or behaviour change in the health care and health research sectors (Claremont).

All projects involved members of the public and included representation from the following segments: early adopters (health), early adopters (civic minded), early majority, sceptics, lower income, South Asian ethnic background, and Black ethnic background.

In addition, we have successfully appointed and trained 22 members of the public to join our advisory boards and working groups (Public Advisory Board, Secondary Care Working Group, Primary Care Working Group, Ethics Advisory Board, Technology Advisory Board, and Access Board), with a further list of over 40 volunteers we can consult for future user testing and PPIE activities. To support members of the public in taking on these roles we have developed a PPIE training package for new public representatives.

As [Table 1](#) highlights this work has been essential to ensuring that Our Future Health developed:

- a co-designed and REC (Research Ethics Committee) approved PIS (Participant Information Sheet) and consent form (one member of the public attended the REC meeting alongside a member of Our Future Health Staff),
- co-designed explainer videos for Our Future Health (YouTube), and
- a Public Engagement Strategy (Claremont 2021)

For example, work undertaken on user experience included a survey to gauge public attitudes to Our Future Health. 2,767 people completed the survey which, amongst other things, confirmed that the general public have a high interest in receiving personalised genetic information:

- 77% of participants wished to receive risk information of disease which is preventable or treatable,
- 65% wanted non-treatable risk information and

- 77% would want ancestry information. These insights are being used to support our developing feedback programme.

Most recently Kantar reported on participant experience based on 97 telephone interviews with participants who had registered, provided consent and booked/attended an appointment for biological samples and measurements to provide us with further insight and enable any refinement to the process as required. Overall, participants were satisfied with their experience of the Our Future Health programme and were pleased they had taken part. Satisfaction arose from the belief that they were helping others, from their positive experience during the appointment, and the results they received (or expected to receive) from the appointment.

Table 1. Summary of the public engagement activities

Year	Output	Activity	Number	Engaged Group	
2020-21	Scientific Protocol	Focus Groups	4	Public	
			2	NHS Primary Care	
		Co-design Meetings	2	Public	
		Interviews	21	Public	
			12	Charities and cohort studies	
	Participant Information Sheet; Consent form & public-facing videos	Focus Groups	18	Public	
		Co-design meetings	10	Public	
		Interviews	21	Public	
	<u>Insights Gathering:</u>				
	Role of industry in health research	Interviews	21	Public	
	Recruitment methods	Focus Groups	4	Public	
	Public motivations and health feedback preferences	Focus Groups	3	Public	
	Research recruitment in hospitals	Focus Groups	3	Public	
Interviews		4	health care professionals		
2021-22	<u>User Experience Research</u>				
	Public attitudes to Our Future Health	Survey	2767	Public	
	Participant experience of an appointment	Interviews	12	Public	
	Participant desire and preferences for genetic feedback	Qualitative depth interviews	10	Public	
	<u>Improving participant sign-up</u>				
	Round 1	Interviews	12	Public	
	Round 2	Interviews	5	Public	
	Public website re-design: usability testing	User-tests	351	Public	
E-consent flow	Interviews	31	Public		
2023	Participant experience research	Telephone interviews	97	Participant	

Opt-Out Campaigns

As part of the initial application, Our Future Health committed to running overt local media opt-out campaigns one month before the issue of invitations in each geographic area. Operated in partnership with the NHS Digital team, a range of media including print and radio adverts highlighted that the NHS would issue letters on our behalf in their area, and offer the opportunity for anyone who did not wish to receive an invitation to opt-out by either calling NHS Digital (now NHS England) or by logging on to a web page operated on behalf of Our Future Health by NHS Digital (now NHS England). The collated data is then used by NHS Digital to remove those individuals from any mailouts of invitations to join Our Future Health.

To date, Our Future Health has issued invitations in the following geographic regions, with opt-out campaigns running during the months shown.

The opt-out campaigns are planned on a rolling basis and are scheduled 4 weeks prior to invitation letters being issued and in-person appointment venues opening in each given geographical area. At the in-person appointment venues, participants donate a blood sample donation and their physical measurements.

Geographic region	Dates of opt out campaigns	Details of campaign (social media = Meta, LinkedIn and Twitter for four weeks)
Bradford	July 2022	Social media: Adverts on 3 channels for 4 weeks Radio: adverts on one radio station. Press: six insertions across two papers.
Leeds and Huddersfield	July 2022	Social media: Adverts on 3 channels for 4 weeks Radio: Adverts on two stations. Press: seven insertions across four titles.
Birmingham	July 2022	Social media: Adverts on 3 channels for 4 weeks Metro Birmingham (press): three insertions, three weeks. Radio: adverts on two stations.
Greater London	September 2022	Social media: Adverts on 3 channels for 4 weeks Capital Radio: adverts for 4 weeks Metro London: five insertions.
Greater Manchester	October 2022	Social media: Adverts on 3 channels for 4 weeks Print: four insertions across two titles. Radio: 192 spots on Capital Manchester.
East and West Midlands	December 2022	Social media: Adverts on 3 channels for 4 weeks Radio: two weeks on two stations. Press: eight insertions across four titles.
South-east coast of England	February 2023	Social media: Adverts on 3 channels for 4 weeks Radio: three stations, adverts running for two weeks each. Press: ten insertions across five titles.
Cambridgeshire and Peterborough	February 2023	Social media: Adverts on 3 channels for 4 weeks Radio: Adverts across seven stations over 4 weeks. Press: 16 insertions across eight titles.
Berkshire and Guildford	March 2023 (planned)	Social media, ten press insertions, regular adverts across two radio stations and digital audio subscription services.
Somerset (partial)	March 2023 (planned)	Social media, ten press insertions, regular adverts across three radio stations.
North-west England	March 2023 (planned)	Social media, 20 press insertions, regular adverts on six radio stations.
Sheffield	March 2023 (planned)	Social media, two insertions in the Sheffield Star, 96 spots on Hallam FM.

