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Preliminary findings from a UK-wide national survey of public attitudes towards Our Future Health and related factors in 2022: a briefing paper

What did we do?

We conducted a survey of public attitudes towards Our Future Health and other relevant topics with <u>Kantar Public</u> in May-June 2022. A combination of online and telephone approaches was used to conduct the survey. During the survey, respondents viewed (or listened to) a "<u>What joining involves</u>" explainer video, after which they were asked questions about topics including their attitudes towards Our Future Health, and whether they would take part if invited.

Why did we do the survey?

We conducted the survey to understand attitudes towards Our Future Health in different audience segments to inform the programme design and materials; and to get a baseline snapshot about public awareness and attitudes towards Our Future Health to allow tracking of any changes in public awareness and attitudes over time.

Who completed the survey?

The survey was completed by 2,763 people in total, comprising a representative sample of over 1,000 members of the public who were representative of the UK population; plus boosted samples of over 1,500 people from Black ethnic backgrounds, Asian ethnic backgrounds, and people from areas of higher deprivation. This interim summary report is based on the findings from the representative sample of the public who completed the survey.

What did we find?

Willingness to take part

Overall, just over half (52%) of the survey respondents reported they would be willing to take part in Our Future Health. Similarly, 52% reported they would be willing to provide a blood sample solely for Our Future Health; slightly more (61%) reported they would be willing to provide a blood sample for Our Future Health if it was part of a routine blood test. Over half (57%) also reported they would have time to complete an online questionnaire if it took 30 minutes to complete; more (81%) reported they would have time to do the questionnaire if it took 10 minutes to complete.

Perceived benefits of taking part

Over two thirds (69%) respondents agreed that they understood the potential benefits of taking part in Our Future Health. Overall, 79% of respondents agreed that taking part could lead to better ways to detect diseases early; 78% that it could lead to better medical treatments; 76% that it could advance medical research; 73% that it could help other people in the UK; 69% that it could help other people in their community. Just under one third (31%) agreed that taking part could help them personally.

Interest in receiving personal genetic information

When asked about their interest in receiving personal genetic information arising from the research programme, 78% reported they would want to receive personal genetic information about their risk of preventable, serious diseases if they took part in Our Future Health; 65% would want personal genetic information about their risk of serious diseases that are not preventable; and 79% would want personal genetic ancestry information.

Practical barriers to taking part

Just under one in four (23%) respondents stated they don't have time to take part in Our Future Health. Similarly, 23% said that they would find it hard to provide a blood sample on a weekend; while just under a third (32%) said they would find it difficult on a weekday. One in ten (10%) reported that they have a fear of needles that would stop them from providing a blood sample.

Attitudes regarding data storage and access

Overall, half (50%) agreed that they would feel comfortable giving Our Future Health access to their medical records; 53% agreed they would be comfortable with academic researchers having access to their health information; and 41% with pharmaceutical, diagnostic or health technology companies having access to their health information.

Summary and next steps

In summary, we found that the majority of people surveyed understood the benefits of taking part in a health research programme such as Our Future Health, e.g. that taking part has the potential to lead to better ways to detect diseases early, and to help people in the UK and around the world. We also found that a majority of people were interested in receiving personal genetic information, at least based on the minimal information about was provided in the survey. In addition, there were important practical barriers to taking part, including difficulties getting to a blood sampling appointment on a weekday, challenges completing a long (30 minute) questionnaire online, and needle phobias.

These findings are important because they highlight that many people are positive towards research programmes such as Our Future Health, and because they highlight where some people may have some practical barriers and/or areas of concern that might prevent them from taking part. The findings are informing our overall recruitment strategy and planning.

Our next steps include conducting more complex regression analyses to assess associations between willingness to participate in Our Future Health and personal characteristics (e.g. sociodemographics, attitudes, practical barriers). These analyses will be conducted using a larger sample size of 2,763 survey respondents, including boosted samples of people from Black ethnic backgrounds, Asian ethnic backgrounds, and people from areas of higher deprivation. This next phase of analyses will be important for audience segmentation, that is, to inform understanding of how different groups think and feel about Our Future Health. Those findings will then provide vital insights addressing how recruitment and retention materials, processes and approaches might be tailored and targeted to the needs of different groups.

Tables

Table 1. Socio-demographic characteristics

Independent variable	N (%)
Total / overall	1,192 (100%)
Gender	
Female	616 (51.7%)
Male	576 (48.3%)
Identify other way	0 (0.0%)
Age group	
18-24yrs	110 (9.2%)
25-34yrs	230 (19.3%)
35-44yrs	188 (15.8%)
45-54yrs	184 (15.4%)
55-64yrs	189 (15.9%)
65-74yrs	183 (15.4%)
75+yrs	108 (9.1%)
Ethnic group (high-level	
categories)	
White	1030 (86.4%)
Black (all combined)	47 (3.9%)
Asian (all combined)	19 (1.6%)
Mixed/multiple/other	96 (8.1%)
Ethnic group (granular	
categories)	
White British	925 (77.6%)
Any other White background	105 (8.8%)
Black African	32 (2.7%)
Black Caribbean	13 (1.1%)
Any other Black background	2(0, 20/2)
	2 (0.2%)
Indian	9 (0.8%)
Indian Pakistani	
	9 (0.8%)
Pakistani	9 (0.8%) 2 (0.2%)
Pakistani Bangladeshi	9 (0.8%) 2 (0.2%) 1 (0.1%)
Pakistani Bangladeshi Chinese	9 (0.8%) 2 (0.2%) 1 (0.1%) 2 (0.2%)
Pakistani Bangladeshi Chinese Any other Asian background Mixed/Multiple Other	9 (0.8%) 2 (0.2%) 1 (0.1%) 2 (0.2%) 5 (0.4%)
Pakistani Bangladeshi Chinese Any other Asian background Mixed/Multiple Other Education	9 (0.8%) 2 (0.2%) 1 (0.1%) 2 (0.2%) 5 (0.4%) 92 (7.7%)
Pakistani Bangladeshi Chinese Any other Asian background Mixed/Multiple Other Education Less than degree	9 (0.8%) 2 (0.2%) 1 (0.1%) 2 (0.2%) 5 (0.4%) 92 (7.7%)
Pakistani Bangladeshi Chinese Any other Asian background Mixed/Multiple Other Education Less than degree Degree or above	9 (0.8%) 2 (0.2%) 1 (0.1%) 2 (0.2%) 5 (0.4%) 92 (7.7%) 4 (0.3%)
Pakistani Bangladeshi Chinese Any other Asian background Mixed/Multiple Other Education Less than degree Degree or above Missing response	9 (0.8%) 2 (0.2%) 1 (0.1%) 2 (0.2%) 5 (0.4%) 92 (7.7%) 4 (0.3%) 702 (58.9%)
Pakistani Bangladeshi Chinese Any other Asian background Mixed/Multiple Other Education Less than degree Degree or above Missing response Work status	9 (0.8%) 2 (0.2%) 1 (0.1%) 2 (0.2%) 5 (0.4%) 92 (7.7%) 4 (0.3%) 702 (58.9%) 488 (40.9%)
Pakistani Bangladeshi Chinese Any other Asian background Mixed/Multiple Other Education Less than degree Degree or above Missing response	9 (0.8%) 2 (0.2%) 1 (0.1%) 2 (0.2%) 5 (0.4%) 92 (7.7%) 4 (0.3%) 702 (58.9%) 488 (40.9%)

+ Our Future Health

Independent variable	N (%)
Deprivation	
IMD Quintile 1	230 (19.8%)
IMD Quintile 2	234 (20.2%)
IMD Quintile 3	230 (19.8%)
IMD Quintile 4	229 (19.8%)
IMD Quintile 5	236 (20.36%)
Unknown	33 (2.8%)
Religiosity	
Practicing	207 (17.4%)
Not practicing	271 (22.7%)
Not religious	714 (59.9%)
Subjective financial status	
Living comfortably	247 (20.7%)
Doing alright	463 (38.8%)
Just about getting by	289 (24.2%)
Finding it quite difficult	119 (10.0%)
Finding it very difficult	63 (5.3%)

Table 2. Behavioural and psychological characteristics

Independent variable	N (%)
Total / overall	1,192 (100%)
Blood donation (and other prosocial behaviours)	
Have you ever done any of the following?	
Donated blood	422 (35.4%)
Donated to charity	975 (81.8%)
Volunteered	631 (52.9%)
Organ donor	511 (42.9%)
Prior participation in health research	
Before today, have you ever taken part in any of the following types of health research studies?	
A clinical trial, that is a scientific study conducted to find	125 (10.5%)
better ways to prevent, screen for, diagnose or treat disease	
A focus group about health , that is a small group of individuals selected to contribute towards research by taking part in an open discussion about a health-related topic	33 (2.8%)
A survey about health, that is a questionnaire completed to help contribute to health research	377 (31.6%)
Technology ownership	
Which of these things do you own or have access to at home?	
A smartphone	1094 (91.8%)
A laptop or desktop computer (e.g. PC or Mac)	991 (83.1%)
A smart TV (a TV that connects directly to the internet)	772 (64.8%)
A tablet (e.g. iPad, Kindle Fire or Google Nexus)	762 (64.0%)
A landline phone	679 (57.0%)
A streaming media player device (e.g. Chromecast, Apple TV, Now TV box, Amazon Fire stick)	433 (36.3%)
A games console	417 (35.0%)
Wearable technology (e.g. a smartwatch or Fitbit/another fitness tracker)	339 (28.4%)
A mobile phone that is not a smartphone	132 (11.1%)
Digital proficiency (each item has 5-point scale; N (%) indicates 'very confident / fairly confident'	
How confident do you feel	
Registering with online banking	668 (86.0%)
Completing a form or application online	1071 (89.8%)
Looking up health information online	1061 (89.0%)
Booking a medical appointment with your GP online	871 (73.1%)
Downloading an app on a smartphone or tablet	1015 (85.2%)

Interest in science	
How interested are you in science?	
Very interested	287 (24.1%)
Quite interested	535 (44.9%)
Neither interested nor not interested	243 (20.4%)
Not very interested	85 (7.1%)
Not at all interested	37 (3.1%)
Combined:	
Not interested (not at all / not very / neither)	365 (30.6%)
Quite interested	535 (44.9%)
Very interested	287 (24.1%)
Have you ever had a genetic test?	
Yes	116 (9.7%)
No	1029 (86.3%)
Don't know	39 (3.3%)
Prefer not to say	8 (0.7%)
If yes, did you have the genetic test through	
The NHS or private healthcare	63 (5.3%)
An ancestry-ONLY genetic testing company (e.g. Ancestry)	39 (3.3%)
An ancestry AND health genetic testing company (e.g.	18 (1.5%)
23andMe)	
A health-ONLY genetic testing company (e.g. Color)	4 (0.3%)
Other	1 (0.1%)

Table 3. Trust

N=1,192	Mean (SD), [median], range 0-10
On a scale of 0-10, where 0 is not at all, and 10 is completely, how much do you trust each of the following?	
Medical researchers in universities	7.1 (1.9), [7]
The National Health Service (NHS)	7.0 (2.0), [7]
Medical charities	6.0 (2.1), [6]
Pharmaceutical companies	4.9 (2.3), [5]
Government	3.5 (2.5), [3]
On a scale of 0-10, where 0 is not at all, and 10 is completely, how much do you trust most people?	6.0 (2.0), [7]

Table 4. Willingness to take part overall

52% of survey respondents said they would take part in Our Future Health

N=1,192	
Based on what you now know about the Our Future Health	
programme, would you take part in it if you were invited to?	
Yes definitely	195 (16.4%)
Yes probably	430 (36.1%)
Not sure / it depends	190 (15.9%)
No, probably not	272 (22.8%)
No, definitely not	105 (8.8%)
Based on what you now know about the Our Future Health	
programme, would you take part in it if you were invited to?	
Yes definitely / yes probably	625 (52.4%)
Not sure / it depends	190 (15.9%)
No, probably not / No, definitely not	377 (31.6%)
Based on what you now know about the Our Future Health	
programme, would you take part in it if you were invited to?	
Yes definitely / yes probably	625 (52.4%)
Not sure / it depends / No, probably not / No, definitely not	567 (47.6%)

Table 5. Capability (would have time) to do online questionnaire

57% of survey respondents said they would have time to complete a 30-min online questionnaire

N=1,192	Agree / Strongly agree	Disagree / Strongly disagree
I would have time to complete a health and lifestyle questionnaire online if it took 10 minutes to complete	962 (80.7%)	76 (6.4%)
I would have time to complete a health and lifestyle questionnaire online if it took 30 minutes to complete	683 (57.3%)	230 (19.3%)

Table 6. Willingness to give a blood sample

52% of survey respondents said they would be willing to provide a blood sample solely for Our Future Health

N=1,192	Agree / Strongly agree	Disagree / Strongly disagree
I would be willing to provide a blood sample to the Our Future Health research programme if it was part of a routine blood test	731 (61.3%)	268 (22.5%%)
I would be willing to go and give a blood sample solely for the Our Future Health research programme	618 (51.9%)	355 (29.8%)

Table 7. Interest in receiving personal genetic information

78% of survey respondents said they would want to receive personal genetic information about their risk of preventable, serious diseases if they took part in Our Future Health

N=1,192	Agree / Strongly agree	Disagree / Strongly disagree
If you did take part in Our Future Health, would you want to receive personal GENETIC information about your		
Risk of serious diseases which ARE preventable or treatable (e.g. type 2 diabetes, heart disease)	930 (78.0%)	176 (14.8%)
Risk of serious diseases which are NOT preventable or treatable (e.g. some types of dementia)	772 (64.8%)	300 (25.2%)
Ancestry (where your relatives and ancestors likely came from and lived a long time ago)	946 (79.4%)	173 (14.5%)

Table 8. Positive attitudes: perceived benefits of taking part

79% agreed that taking part could lead to better ways to detect diseases early; 78% that it could lead to medical research; 76% that it could advance medical research; 73% that it could help other people in the UK; 69% that it could help other people in the world; and 65% that it could help other people in their community.

N=1,192	Agree / Strongly agree
Understanding of benefits	
How much do you agree or disagree that	
The potential benefits of taking part in the Our Future Health research programme are clear to me	837 (70.2%)
Benefit for others	
How much do you agree or disagree with the following statements? I feel that taking part in the Our Future	
Health research programme could	
Lead to better ways to detect diseases early	940 (78.9%)
Lead to better medical treatments	921 (77.7%)
Advance medical research	901 (75.6%)
Help other people in the UK	874 (73.3%)
Help other people in the world	826 (69.3%)
Help other people in my community	775 (65.0%)
Make sure people like me are represented in health research	735 (61.7%)

31% agreed that taking part could help them personally

(N=1,192)	Agree / Strongly agree
Personal benefit	
How much do you agree or disagree with the following statements? I feel that taking part in the Our Future Health research programme could	
Help my family/friends	588 (49.3%)
Help me personally	369 (31.1%)

Table 9. Practical barriers to taking part: time, travel and needle phobias

23% agreed that they don't have time to take part in Our Future Health; 32% said they would find it difficult to provide blood on a weekday; 23% that they would find it hard on a weekend; and 10% that they have a fear of needles that would stop them from providing a blood sample.

N=1,192	Agree / Strongly agree	Disagree / Strongly disagree
Overall time barrier		
I don't have time to take part in the Our Future Health	274 (23.0%)	559 (46.9%)
research programme		
Barriers to giving a blood sample		
I would find it difficult to get to a hospital or mobile unit to	377 (31.6%)	514 (43.1%)
provide a blood sample during a weekday		
I would find it difficult to get to a hospital or mobile unit to	277 (23.2%)	605 (50.8%)
provide a blood sample on the weekend		
I have a fear of needles which would stop me from providing	113 (9.5%)	931 (78.1%)
a blood sample		

Table 10. Attitudinal barriers to taking part: concerns about data

N=1,192	Agree / Strongly agree	Disagree / Strongly disagree
Our Future Health & data storage		
I would feel comfortable giving the Our Future Health research programme access to my medical records	592 (49.7%)	312 (26.2%)
I would feel comfortable with how the Our Future Health research programme would use my personal health information	587 (49.2%)	299 (25.1%)
I would feel comfortable sharing my health information with the Our Future Health research programme	554 (46.5%)	380 (31.9%)
I would feel comfortable about my personal health information being stored in a large database	534 (44.8%)	379 (31.8%)
Others & data access		
I would be comfortable with academic researchers having access to my health information	630 (52.9%)	302 (25.3%)
I would be comfortable with pharmaceutical, diagnostic or health technology companies having access to my health information	485 (40.7%)	422 (35.4%)

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