Our Future Health

Our Future Health Protocol

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1. Background

1.1. Overall aims

The overarching objective of Our Future Health is to help people live healthier lives for longer through better prevention, earlier detection and improved treatment of diseases. The Our Future Health research programme will speed up the discovery of new methods of early disease detection, and the evaluation of new diagnostic tools, to help identify and treat diseases early when outcomes are usually better.

To achieve these objectives, we will recruit up to 5 million adults from across the UK to create a diverse and inclusive cohort of people who have consented to participate in the research. In addition to being asked for permission to link their personal health data to other health-relevant data, participants will be asked to provide biological samples and complete questionnaires on recruitment; agree to re-contact for ongoing biological sampling and questionnaires and consider taking part in further research studies; and agree to being offered personal health information arising from the research. The specific aims are presented below.

- **Specific Aim 1:** Build a resource linking multiple sources of health and health-relevant information, including genetic data, on millions of people in the UK, to facilitate basic discovery research by academic and commercial researchers on early indicators of disease
- **Specific Aim 2:** Analyse the data in the resource to estimate personal disease risk information for participants, based on genetic and non-genetic information, and offer this estimated personal health information to participants
- **Specific Aim 3:** Re-contact sub-groups of participants generally for additional samples, and additional data collection including linkage to digital data sources
- **Specific Aim 4:** Selectively invite participants to additional studies and trials based on the health-related information we hold about them
- **Specific Aim 5**: Analyse the data in the resource to generate population health insights describing the health of the whole cohort or specific sub-cohorts for the benefit of public good, such as the ability to impact national health policy

Building this large resource with linkage, feedback, health research studies and trials, and population health insights will facilitate a new generation of discovery and translational research that will advance primary prevention (reduce onset of disease in the general population), secondary prevention (earlier detection and intervention of disease to alter/slow progression), and tertiary prevention (reduce impacts of existing disease).

The UK is uniquely placed to deliver this programme. We have an exceptional track record in population research, and many outstanding research groups. Our diverse (ethnically/ socioeconomically) population is willing to take part in research. Our government is committed to levelling up the major inequalities in health outcomes seen across the population. The NHS and our comprehensive disease registration systems provide a mechanism for invitation, recruitment and follow-up at an unprecedented size and scale. In addition, a programme of this scale and nature is made possible by the major advances in digital technologies over the past decade. Furthermore, the proportion of the UK public connected to data and devices (‘digital health’) is substantial and rapidly growing.

The Our Future Health research programme is intended to be both a prospective observational cohort and a platform for future discovery, translational, and population health research studies with consent for return of results, risk-stratification, and re-contact. Our Future Health will build on our national strengths and complement existing prospective cohort resources and translational research efforts in the UK.

1.2. Genesis of Our Future Health

The initial idea to set up a very large cohort in the UK to improve early detection of chronic diseases was first discussed in 2016 with several medical research charities, UK Research and Innovation (UKRI), and leading public health practitioners and academics. The concept was described in the 2017 Life Sciences Industrial Strategy and discussions progressed on possible government funding.

The proposal to establish a 5-million strong volunteer cohort enabling research intended to improve the early detection of chronic diseases was set out in the Accelerating Detection of Disease challenge of the government's Industrial Strategy Challenge Fund (ISCF).

An investment of £79 million was allocated from the ISCF by UK Research and Innovation to test the feasibility of, and establish, the Our Future Health research programme. This was expected to be matched by funding of at least £160 million from industry and charity partners who would work in partnership with Our Future Health to design and deliver the programme. This target has been exceeded by the signature of our funding partners from the life sciences industry and biomedical charity sector.[1]

1.3. Initial planning of Our Future Health

In 2018, a Science Task & Finish Group was convened to make recommendations on the scientific design / scientific protocol of Our Future Health (Successive Chairs: Prof David Hunter; Prof Chris Whitty, Prof Patrick Chinnery). The Science Task & Finish Group concluded its work in early 2020.

An Ethics and Feedback Advisory Group (EFAG) was established in Sept 2019 to provide strategic advice on the development of ethical guidelines and principles for Our Future Health, and to develop an Ethics and Governance Framework to guide its operations (Successive Chairs: Prof Martin Bobrow; Prof Michael Parker). The Framework provides advice to the Board and Executive, and is publicly available for funders, partners, researchers, participants and the general public. Building on the work of EFAG, an Ethics Advisory Board has been established as part of the long-term governance of the cohort and is responsible for monitoring the implementation of the Ethics & Governance Framework, and for reviewing and updating it as appropriate.

An Industry Advisory Group and an NHS Advisory Group were established early on in the development of the programme. A number of other advisory and operational boards were established and further details regarding the governance structure of the programme can be found in section 14.

In Sept 2019, a not-for-profit company was established to run Our Future Health. The company, initially named Early Disease Detection Research Project UK (EDDRP UK), was registered as a

[1] Our Future Health website, 'How we are funded' https://ourfuturehealth.org.uk/about-us/how-we-are-funded/

charity in May 2020. The Executive was established in April-May 2020, and the programme was subsequently renamed from the placeholder EDDRP UK to Our Future Health in 2021.

2. Scientific rationale

2.1. Prospective study design

Prospective observational cohort studies are valuable because these real-world studies facilitate the identification of biomarkers and causative factors that contribute to future disease.[2] Prospective study designs are less prone to bias than case-control study designs.

Existing large prospective studies in the UK and Europe include:

- **UK Biobank:** 500,000 participants, UK[3]
- **Million Women Study:** 1.3 million participants, England and Scotland[4]
- **Whitehall I and II Studies:** 17,500 and 10,000 participants respectively, England[5,6]
- **ALSPAC:** Avon Longitudinal Study of Parents and Children, 14,000 families, England[7]
- **Understanding Society:** The UK Longitudinal Household Study, 40,000 households, UK [8]
- **GLAD Study:** Genetics Links to Anxiety and Depression, n=22,000 to date (aim is 40,000), UK[9]
- **EPIC:** European Prospective Investigation of Cancer and Nutrition, 500,000 participants, UK and 9 countries in Europe[10]
- **Genes and Health:** 67,000 participants (aim is 100,000), UK[11]

There are a number of large or influential prospective studies in the US, including:

- **All of Us** (currently have recruited 873,000 participants; aiming to achieve a final sample size of 1 million, US)[12]
- **Million Veteran Programme** (1 million participants, US)[13]
- **Nurses' Health Study** (275,000 participants, US)[14]
- **Framingham Heart Study** (originally 5,000 participants, US)[15]

Prospective studies with East Asian and Hispanic populations have also been set up, including the following which are collaborations with investigators at Oxford University:

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[2] Manolio et al (*Nature Reviews Genetics,* 2006) Genes, environment and the value of prospective cohort studies.
[3] https://www.ukbiobank.ac.uk/
[4] http://www.millionwomenstudy.org/introduction/
[5] van Rossum et al (*J Epidemiol Community Health*, 2000) Employment grade differences in cause specific mortality. A 25 year follow up of civil servants from the first Whitehall study.
[6] https://academic.oup.com/ije/article/34/2/251/746997
[7] http://www.bristol.ac.uk/alspac/about/
[8] https://www.understandingsociety.ac.uk/
[9] https://gladstudy.org.uk/about/
[10] https://epic.iarc.fr/
[11] https://www.genesandhealth.org/
[12] https://allofus.nih.gov/
[13] https://www.research.va.gov/mvp/
[14] https://www.nurseshealthstudy.org/
[15] https://www.framinghamheartstudy.org/

- **Kadoorie Study** (500,000 participants, China)[16]
- **Mexico City Prospective Study** (150,000 participants, Mexico)[17]

Other listings include the International HundredK+ Cohorts Consortium (IHCC)[18] and the NCI Cohort Consortium[19].

Prospective cohort studies provide important insights into disease aetiology. However, they have not traditionally been designed to provide insights on whether or how these basic discoveries can be translated into actual health benefits for individuals and societies. For this, translational research is needed.

2.2. Translational research

Translational research studies are valuable because they aim to establish whether and how basic discoveries about disease aetiology can be translated into positive outcomes for populations.[20] Translational research has been defined as having four phases (T1-T4):[21]

- T1 involves processes that bring ideas from basic research through early testing in humans
- T2 involves the establishment of effectiveness in humans and clinical guidelines
- T3 primarily focuses on implementation and dissemination research
  Implementation research has been defined as the scientific inquiry into questions concerning implementation—the act of carrying an intention into effect, which in health research can be policies, programmes, or individual practices (collectively called interventions); the intent is to understand what, why, and how interventions work in "real world" settings and to test approaches to improve them[22]
- T4 focuses on outcomes and effectiveness in populations

Recent examples of translational research include multi-centre studies in the UK and around the world to develop and assess the outcomes and effectiveness of COVID19 vaccines.[23]

Another successful international example is the US Electronic Medical Records and Genomics (eMERGE) Network which, since 2007, has brought together medical research institutions and researchers to integrate biorepositories with electronic medical record systems for genomic research and implementation.[24] It also has a focus on social and ethical issues such as privacy, confidentiality, and community engagement.

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[16] https://www.ckbiobank.org/site/
[17] https://www.ctsu.ox.ac.uk/research/prospective-blood-based-study-of-150-000-individuals-in-mexico
[18] www.ihccglobal.org
[19] https://epi.grants.cancer.gov/cohort-consortium
[20] Woolf SH. The Meaning of Translational Research and Why It Matters. JAMA. 2008;299(2):211–213. doi:10.1001/jama.2007.26
[21] Fort, D., Herr, T., Shaw, P., Gutzman, K., & Starren, J. (2017). Mapping the evolving definitions of translational research. Journal of Clinical and Translational Science, 1(1), 60-66. doi:10.1017/cts.2016.10
[22] Peters, Taghreed, Olakunle, Akua, Nhan. Implementation research: what it is and how to do it BMJ 2013; 347:f6753
[23] Sharpe et al (2020) The early landscape of coronavirus disease 2019 vaccine development in the UK and rest of the world
[24] https://www.genome.gov/Funded-Programs-Projects/Electronic-Medical-Records-and-Genomics-Network-eMERGE

Translational research studies can also be embedded within public health programmes at a national scale with prominent UK studies that include:

- A study examining uptake of colorectal cancer screening over three invitation rounds in the NHS Bowel Cancer Screening Programme among individuals aged 60-64yrs (n=62,000)[25]
- A randomised controlled trial (UK Age trial) investigating the effect of mammogram breast screening from age 40 years on breast cancer mortality involving 23 breast screening units across Great Britain (n=161,000)[26]
- A study of the effectiveness of NHS Health Check programme at reducing cardiovascular disease risk among patient aged 40-74 years after one year (n=3,172)[27]

The intent is that Our Future Health research programme will provide a:

(1) **Prospective observational dataset** for basic science / epidemiological, discovery and aetiological research;
(2) **Biosample resource** to enable biomarker discovery, genomics and other omics assays for discovery, pre-clinical and translational research; and
(3) **Translational research and clinical trials platform** comprising a cohort of people who can be re-contacted for translational/implementation research to develop and test new diagnostic technologies, prevention strategies and treatments.

Our ambition is to continue to recruit an ethnically and socioeconomically diverse population. We expand further on this important point in the sample frame section below.

2.3. Samples

The ambition of Our Future Health is to recruit 5 million participants each of whom will provide consent, complete a baseline questionnaire, donate a blood sample and be eligible for linkage to health-related data. The 5 million number will provide a UK prospective cohort in which, with sufficient statistical precision, it will be possible to study:

- Both common and rare phenotypes and diseases
- Subpopulations based on ethnicity, index of multiple deprivation, geography, risk stratification, genotypes, and precursor conditions
- Statistical interactions between genotypes and environmental factors in relation to disease
- Pre-diagnostic/pre-interventional bloods for studies of subpopulations with specific diseases/phenotypes
- Sub-populations based on their disease-specific genotypes or polygenic risk scores
- Populations invited and consented to ancillary studies.

[25] Lo SH, Halloran S, Snowball J, et al Colorectal cancer screening uptake over three biennial invitation rounds in the English bowel cancer screening programme. Gut 2015;64:282-291.
[26] Duffy et al (*Lancet Oncology,* 2020) Effect of mammographic screening from age 40 years on breast cancer mortality (UK Age trial): final results of a randomised, controlled trial.
[27] Artac et al (2013) Effectiveness of a national cardiovascular disease risk assessment program (NHS Health Check): Results after one year.

After describing the sample ambition, the sections that follow provide additional details of the above novel aspects of Our Future Health that are facilitated by the large sample size and the ability to re-contact participants.

2.3.1. Sample ambition

The 5 million participants we aspire to recruit into Our Future Health will be reflective of the UK population according to the most recent census data available. To inform such, we have drawn on 2021/2022 census data of population counts by age, sex, ethnicity, and index of multiple deprivation for England and Wales (2021), Scotland (2022), and Northern Ireland (2021).

Table 1. Sample ambition

Our Future Health Sample Ambition								
Sex >	Female				Male			
Ethnicity >	White	Black	Asian	Mixed/Other	White	Black	Asian	Mixed/Other
Age v								
18–19	53,777	3,829	7,887	4,857	55,937	3,982	8,321	5,119
20–29	315,271	17,695	42,515	23,896	311,381	16,680	41,401	22,979
30–39	346,102	18,819	52,808	23,453	331,548	15,258	45,968	21,563
40–49	324,853	18,766	44,357	17,012	315,509	15,479	43,073	16,625
50–59	385,993	17,240	26,585	11,888	372,458	15,370	25,952	11,841
60–69	319,702	7,820	17,574	6,267	305,820	7,004	16,356	6,170
70–79	273,138	3,270	9,276	3,002	245,331	2,128	7,292	2,712
80–84	85,176	1,396	2,559	750	66,277	997	2,351	635
85+	92,097	1,182	1,984	739	54,079	794	1,611	462
Totals	**2,196,109**	**90,017**	**205,544**	**91,865**	**2,058,341**	**77,693**	**192,325**	**88,107**
%	**43.9%**	**1.8%**	**4.1%**	**1.8%**	**41.2%**	**1.6%**	**3.8%**	**1.8%**

This sample ambition is reflective of the UK population in terms of age, sex, and ethnicity. It will provide large numbers of participants of the primary ethnic minority groups resident in the UK – Indian, Pakistani, Bangladeshi, Chinese, Black African, Black Caribbean, Arab and Mixed – populations that have been underrepresented in health research. Combined with a proportional representation of participants across the nations, this sample will provide for a diverse cohort that will be amenable to a variety of studies that have not been possible in a UK prospective cohort before.

Achieving a sample that is reflective of the UK population is an overarching aim of the Our Future Health programme for both ethical and scientific reasons. Ethically, it is important that we make substantial efforts to make participation in Our Future Health equitable and accessible to people regardless of their socioeconomic position, disability, physical health, mental health, sex, age, and ethnicity. Scientifically, it is important that the participants in Our Future Health are sufficiently diverse to facilitate a range of discovery and translational research the resource is intended to support. Related to this, the concept of "representativeness" has been debated at length in the epidemiologic literature[28,29]. We recognise that our participant sample is unlikely to be fully representative of the UK population in a large range of demographics and risk factors that extend

[28] Nohr, E. A. and J. Olsen (2013). "Commentary: Epidemiologists have debated representativeness for more than 40 years--has the time come to move on?" International Journal of Epidemiology 42(4): 1016-1017.
[29] Schooling, C. M. and H. E. Jones (2014). "Is representativeness the right question?" International Journal of Epidemiology 43(2): 631-632.

beyond those shown in Table 1. However, the important aspects of representativeness and selection biases are specific to any hypothesis being tested and the external population to which an inference is to be made[30]. By ensuring we recruit a diverse population, we will provide a resource that is amenable to a large range of hypotheses and potential inferences to improve the health of the UK population.

2.3.2. Common and rare phenotypes and diseases

The size of this sample will provide the ability to prospectively assess, with strong statistical precision, a wide range of common and rare phenotypes and diseases in a UK population. In addition, it will provide large numbers of prevalent diseases for retrospective, statistically powered case-control and case-cohort studies.

We have estimated incident diagnoses of disease that would accrue in Our Future Health in the initial 2.5-years of follow-up using various population/subpopulation sizes (**Appendix A**), demonstrating the immediacy of the impact that this programme will have on health research.

To interpret the advantages of these estimated incident diagnoses that may accrue in the population that comprises the Our Future Health cohort, we have also calculated minimal detectable odds ratios for aetiologic studies using ranges of case numbers, alpha values (critical p values), and exposure prevalence (**Table 2**). Note that the colour shading of all tables in these sections indicates 0 cases (pure green), 5,000 cases (yellow), and 10,000 or more cases (red), a scale based on aetiologic odds ratios of ~1.5 for mid-range exposure prevalence and mid-range alphas.

[30] Huang, J. Y. (2021). "Representativeness Is Not Representative: Addressing Major Inferential Threats in the UK Biobank and Other Big Data Repositories." Epidemiology 32(2): 189-193.

Table 2. Minimal Detectable Odds Ratios by Case Count, Exposure Prevalence, and Critical p-value

Exposure Prevalence[a]	Critical p-value	Minimum detectable odds ratio, by number of cases[b]						
		500	1,000	2,500	5,000	7,500	10,000	25,000
0.5	0.05	1.28	1.19	1.12	1.08	1.07	1.06	1.04
0.5	0.00005	1.62	1.40	1.24	1.16	1.13	1.11	1.07
0.5	0.00000005	1.89	1.56	1.32	1.22	1.17	1.15	1.09
0.25	0.05	1.31	1.22	1.13	1.09	1.08	1.07	1.04
0.25	0.00005	1.65	1.44	1.26	1.18	1.15	1.13	1.08
0.25	0.00000005	1.90	1.59	1.35	1.24	1.19	1.17	1.10
0.1	0.05	1.45	1.31	1.19	1.13	1.11	1.09	1.06
0.1	0.00005	1.92	1.62	1.38	1.26	1.21	1.18	1.11
0.1	0.00000005	2.25	1.83	1.50	1.35	1.28	1.24	1.15
0.025	0.05	1.88	1.60	1.37	1.26	1.21	1.18	1.11
0.025	0.00005	2.83	2.22	1.74	1.51	1.41	1.35	1.22
0.025	0.00000005	3.53	2.66	1.98	1.67	1.54	1.47	1.29
0.01	0.05	2.43	1.97	1.59	1.41	1.33	1.29	1.18
0.01	0.00005	4.08	3.02	2.19	1.82	1.66	1.56	1.35
0.01	0.00000005	5.35	3.78	2.61	2.09	1.87	1.75	1.46
0.0025	0.05	4.21	3.11	2.25	1.85	1.69	1.59	1.36
0.0025	0.00005	8.60	5.70	3.63	2.75	2.39	2.18	1.72
0.0025	0.00000005	12.32	7.76	4.65	3.38	2.88	2.59	1.95
0.001	0.05	6.80	4.67	3.10	2.41	2.12	1.96	1.59
0.001	0.00005	16.14	9.85	5.67	4.00	3.35	2.98	2.18
0.001	0.00000005	24.59	14.28	7.70	5.20	4.24	3.72	2.59

[a] Exposure prevalence among controls.

[b] Calculated at 80% power assuming 4 controls per case.

A variety of scenarios can be deduced from this flexible table set up. For example, the advantages of having a population of 1 million can be clearly seen for diagnoses such as transient ischaemic attack and ischaemic stroke, irritable bowel syndrome, cholecystitis, tinnitus, diabetic eye disease, uterovaginal prolapse, postmenopausal bleeding, septicaemia, migraine, peripheral neuropathy, dementia, and rosacea, all of which accrue 4,000–6,000 cases in this short term period of follow-up – a threshold that provides strong statistical precision for testing aetiologic hypotheses. An increase to 2 million participants sees many other diagnoses surpass a 4,000-case threshold in this short period of follow-up, including lung and bowel cancers, stroke, non-rheumatic mitral valve disorder, anal fissure, Barrett's oesophagus, blindness, obstructive and reflux uropathy, neuropathic bladder, agranulocytosis, spinal stenosis, rheumatoid arthritis, fibromatosis, polymyalgia rheumatica, chronic sinusitis, sleep apnoea, and pulmonary collapse. The diseases that can be researched with strong statistical precision is obviously increased further as the number of participants and thus case numbers increase. At 5 million participants, many rarer diseases accrue to sufficient numbers to provide for strong statistical precision for a range of hypotheses to be investigated. These tables underscore the benefits of progressing towards and reaching 5 million participants in being able to study both common and rare phenotypes and diseases. They also underscore the unique opportunities that Our Future Health will provide to the world research community.

Another important use of the Our Future Health cohort will be in developing and validating predictive models of health and disease status. This includes polygenic/integrative risk scores and biomarkers, which will be generated and returned to consenting participants as a primary objective of the programme. However, with the rapid growth and development of machine learning methods, in step with advances in computing power, there will be a broad interest in using the cohort to develop new predictive models of different types. The case numbers shown in Appendix A demonstrate the potential of Our Future Health for research into predictive models of health and disease as they provide for high precision for estimates of validation statistics such as sensitivity and specificity (**Table 3**).

Table 3. Margins of Error for Estimates of Sensitivity and Specificity by Case or Control Count.

Sensitivity or Specificity (%)	**Margin of error[a] (%), by number of cases or controls[b]**						
	500	1,000	2,500	5,000	7,500	10,000	25,000
50	4.4	3.1	2.0	1.4	1.1	1.0	0.6
70	4.0	2.8	1.8	1.3	1.0	0.9	0.6
80	3.5	2.5	1.6	1.1	0.9	0.8	0.5
90	2.6	1.9	1.2	0.8	0.7	0.6	0.4
95	1.9	1.4	0.9	0.6	0.5	0.4	0.3

[a] Margin of error is half the width of a 95% confidence interval

[b] Cases for sensitivity; controls for specificity

2.3.3. Subpopulations

We will strive for diversity in our sample by aspiring to reflect the UK population in terms of age, sex, ethnicity, socioeconomic status, and geography. Achieving this aim will deliver a variety of subpopulations of interest each of which will accrue sufficient incident disease as to offer aetiologic and diagnostic insights. Subpopulations may be defined by the participant factors stated above, as well as minor allele frequencies, precursor diseases (e.g. colonic polyps, Barrett's oesophagus), genetic disease risk profiles, and blood group subtypes. These examples of potential subpopulations for study further underscore the benefits of our sample ambition. In terms of ethnic diversity, 5 million participants would be partly comprised of 168,000 Black participants and 398,000 Asian participants, primary ethnic-specific populations of which would include: 141,000 Indian, 104,000 Pakistani, 103,000 Black African, 50,000 Black Caribbean, 39,000 Chinese, and 41,000 Bangladeshi. This will provide a research platform to understand differences in disease risk by ethnicity[31,32,33], providing a levelling-platform with the potential to improve health for all ethnicities in the UK.

[31] Ali, R., et al. (2021). "Life expectancy by ethnic group in England." BMJ 375: e068537.
[32] Maruthappu, M., et al. (2015). "Incidence of prostate and urological cancers in England by ethnic group, 2001-2007: a descriptive study." BMC Cancer 15: 753.
[33] Shirley, M. H., et al. (2014). "Incidence of breast and gynaecological cancers by ethnic group in England, 2001-2007: a descriptive study." BMC Cancer 14: 979.

2.3.4. Statistical interactions

Our Future Health will create new opportunities to investigate how different factors interact to cause disease or alter treatment efficacy. Estimating these interaction effects has previously been challenging; in contrast to the individual effects of specific treatments, environmental factors or genetic variants, estimating interactions requires considerably larger sample sizes[34]. Additional obstacles to the study of interactions include the availability of high-quality and wide-ranging exposure assessments, known temporality of exposures, and ethnically and geographically diverse populations[35].

To examine the potential to estimate gene-environment interactions using the Our Future Health cohort, we have calculated minimum detectable odds ratios under a variety of scenarios. Here we assume a conservative scenario, such as might be found in a pharmacogenetic context, where the environmental exposure is a treatment with a modest effect ($OR_E = 1.25$) and the genetic factor has no effect on the outcome ($OR_G = 1.0$) except in treated individuals. We assume that the minor (risk) allele is dominant. We then estimate the minimum detectable odds ratio for the interaction between the treatment and genotype (OR_{GE}, the effect of the genetic factor in treated individuals) for a range of genotype minor allele frequencies (MAF), treatment prevalence, critical p-values for significance tests, and numbers of cases (**Table 4**).[36] These calculations ignore model misspecification, measurement error and other issues which reduce precision, further underscoring the need for the target sample size of Our Future Health.

[34] Ritz, B. R., et al. (2017). "Lessons Learned from Past Gene-Environment Interaction Successes." American Journal of Epidemiology 186(7): 778-786.
[35] McAllister, K., et al. (2017). "Current Challenges and New Opportunities for Gene-Environment Interaction Studies of Complex Diseases." American Journal of Epidemiology 186(7): 753-761.
[36] Moore, C.M., et al. (2019). “Power and sample size calculations for genetic association studies in the presence of genetic model misspecification.” Human Heredity 84:256-271.

Table 4. Minimal Detectable Interaction Odds Ratios by Case Count, Risk Allele Frequency, Exposure Prevalence, and Critical p-value

Risk allele frequency	Exposure prevalence[a]	Critical p-value	Minimum detectable interaction odds ratio, OR_{GE}, by number of cases[b]			
			2,500	5,000	10,000	25,000
0.25	0.25	0.05	1.30	1.20	1.14	1.09
0.25	0.25	0.00005	1.57	1.38	1.25	1.16
0.25	0.1	0.05	1.44	1.30	1.20	1.12
0.25	0.1	0.00005	1.87	1.56	1.38	1.23
0.25	0.05	0.05	1.64	1.42	1.28	1.17
0.25	0.05	0.00005	2.33	1.83	1.54	1.32
0.1	0.25	0.05	1.38	1.26	1.18	1.11
0.1	0.25	0.00005	1.75	1.49	1.33	1.20
0.1	0.1	0.05	1.57	1.38	1.26	1.16
0.1	0.1	0.00005	2.18	1.74	1.49	1.29
0.1	0.05	0.05	1.84	1.55	1.37	1.22
0.1	0.05	0.00005	2.87	2.12	1.71	1.41
0.05	0.25	0.05	1.53	1.35	1.24	1.15
0.05	0.25	0.00005	2.06	1.68	1.45	1.27
0.05	0.1	0.05	1.81	1.53	1.35	1.21
0.05	0.1	0.00005	2.76	2.06	1.68	1.40
0.05	0.05	0.05	2.22	1.77	1.51	1.30
0.05	0.05	0.00005	4.02	2.67	2.02	1.57
0.01	0.25	0.05	2.39	1.86	1.56	1.33
0.01	0.25	0.00005	4.56	2.91	2.15	1.63
0.01	0.1	0.05	3.40	2.39	1.87	1.49
0.01	0.1	0.00005	9.81	4.59	2.92	1.99
0.01	0.05	0.05	5.50	3.27	2.32	1.72
0.01	0.05	0.00005	63.37	8.97	4.36	2.53

[a] Population prevalence of the exposure.

[b] Calculated at 80% power assuming 4 controls per case.

2.3.5. Pre-diagnostic bloods

The lack of large prospective cohort studies with pre-diagnostic bloods available to researchers has stifled disease interception research[37]. There has been a distinct lack of progression of biomarkers from nested case-control studies to the pre-diagnostic arena for insights on diagnosis and prognosis. The sample size ambition of Our Future Health will reduce pressures of biospecimen retention requirements and enable the possibility of boutique subpopulation research studies using pre-diagnostic blood specimens. Although the Access Board will approve and adopt the rules for biospecimen access, any such study proposal will undoubtedly require

[37] Pepe, M. S., et al. (2001). "Phases of biomarker development for early detection of cancer." Journal of the National Cancer Institute 93(14): 1054-1061.

strong preliminary evidence[38,39] that will form the basis of a conservative selection strategy[40,41] to ensure the resource is used appropriately and preserved for the long term. Nevertheless, Our Future Health has the possibility to be the only large-scale UK prospective cohort study to offer the possibility of access to pre-diagnostic biologic samples for biomarker validation.

Broad assays (-omics) are no longer confined to small sample sets – high throughput efficiencies are enabling the ability to deep phenotype the totality of samples in a given resource[42,43,44,45.] Continued gained efficiencies will likely spur the continued movement to big, layered -omics data and Our Future Health will provide an ideal platform for such cohort-wide deep phenotyping which greatly increases the potential for insights into the determinants and causes of disease.

2.4. Participant questionnaires

Participant questionnaires comprise an essential component of any health-related population study. Through questionnaires, we can elicit important health-related information that is not available, is incomplete, or is potentially incorrect in medical records and other health-related linked data that participants consent to donating to Our Future Health when joining the programme. Questionnaire data is also more rapidly obtainable than many health-related linked data and can complement health-record linkage by obtaining repeated measurements or more detailed self-reports than might be possible via the healthcare system. Examples of questionnaire derived health-related information that can supplement and complement health-related linked data include:

- up-to-date health status, exposures, and outcomes (e.g. general health, current cigarette smoker, mental health)
- long-term health or exposure histories that pre-date electronic medical records (e.g. any surgical procedure before 1990, lifetime cigarette smoking history)
- exposures or outcomes that are either poorly or not captured by electronic medical records (e.g. typical alcohol consumption, recent physical activity, over-the-counter medications, mental health)
- Measures that are not regularly repeated or typically available until later in life in medical records (e.g. body weight, alcohol consumption, anxiety, physical activity)
- Health relevant lifestyle factors and personal characteristics that might be unavailable in medical records (e.g. employment status, marital status, type of housing)

[38] Wentzensen, N. and R. C. Eldridge (2015). "Invited Commentary: Clinical Utility of Prediction Models for Rare Outcomes-The Example of Pancreatic Cancer." American Journal of Epidemiology 182(1): 35-38.
[39] Wentzensen, N. and S. Wacholder (2013). "From differences in means between cases and controls to risk stratification: a business plan for biomarker development." Cancer Discov 3(2): 148-157.
[40] Pepe, M. S., et al. (2008). "Pivotal evaluation of the accuracy of a biomarker used for classification or prediction: standards for study design." Journal of the National Cancer Institute 100(20): 1432-1438.
[41] Pepe, M. S., et al. (2015). "Improving the quality of biomarker discovery research: the right samples and enough of them." Cancer Epidemiology, Biomarkers and Prevention 24(6): 944-950.
[42] He, K. Y., et al. (2017). "Big Data Analytics for Genomic Medicine." Int J Mol Sci 18(2).
[43] Rappaport, S. M. (2012). "Biomarkers intersect with the exposome." Biomarkers 17(6): 483-489.
[44] Siroux, V., et al. (2016). "The exposome concept: a challenge and a potential driver for environmental health research." Eur Respir Rev 25(140): 124-129.
[45] Wild, C. P. (2012). "The exposome: from concept to utility." International Journal of Epidemiology 41(1): 24-32.

Thus, self-report questionnaires significantly contribute to a comprehensive assessment of health, enhancing research insights into how we may improve the nation's health.

Questionnaires also allow us to serve certain populations that would otherwise continue to be misclassified and underrepresented in health research. For example, asking about sexual orientation and gender identity will allow us to ensure we are recruiting a sample representative of all peoples in the UK. This in turn will enable research that supports the provision of a health-care system that serves the needs of all, rather than over-generalising research from nonrepresentative populations.

Delivering regular, repeated questionnaires also facilitates the ongoing involvement of participants – reminding them of the important research programme they have consented to be part of and retaining their interest and attention. We will have the opportunity to further engage participants by using questionnaire responses to formulate feedback and advice that might be of interest and support individual health choices.

In addition to our core participant questionnaire, we will develop a roadmap of future questionnaires built from these principles that underscore the scientific and participant rationales of our programme. These future questionnaires will include general follow-up questionnaires and additional modules focused on specific health-related topics.

2.5. Physical measurements

We will assess physical measurements when participants provide blood samples for those metrics and in locations where this is feasible and cost-effective. Although height and weight are typically accurately self-reported within a population[46], in-person assessment of these metrics provides individual accuracy which is important for a variety of disease risk estimations as well as participant feedback that incorporates such information[47]. Weight is associated with many diseases including cardiovascular disease and cancer. Height can be used to calculate body mass index (BMI) from weight which has greater predictive accuracy for disease, and height also an independent predictor of certain cancers, vascular disease and all-cause mortality.
Capturing height and weight in-person may be extended to measurement of other physical characteristics such as waist circumference[48], bioimpedance[49], blood pressure and hip circumference[50]. Waist circumference is highly correlated with intra-abdominal fat mass while bioimpedance analysis is a non-invasive, low-cost analysis of body composition. Waist circumference and bioimpedance analysis have each been shown to be associated with a higher risk of diabetes and vascular events independently of BMI. Excessive intra-abdominal fat may be more harmful to health than fat elsewhere due to higher release of free fatty acids into the portal bloodstream which lowers the body's sensitivity to insulin, and alters the balance of blood lipids.

[46] Celis-Morales et al (*Genes Nutr*, 2015) How reliable is internet-based self-reported identity, socio-demographic and obesity measures in European adults? https://pubmed.ncbi.nlm.nih.gov/26143178/
[47] Newell et al (*Am J Prev Med*, 2017) The accuracy of self-reported health behaviors and risk factors relating to cancer and cardiovascular disease in the general population 1: A critical review. https://pubmed.ncbi.nlm.nih.gov/10987638/
[48] Ross et al (*Nat Rev Endocrinol*, 2020) Waist circumference as a vital sign in clinical practice: a Consensus Statement from the IAS and ICCR Working Group on Visceral Obesity.
[49] Böhm et al (*Eur J Clin Nut*, 2017) The use of bioelectrical impedance analysis for body composition in epidemiological studies.
[50] Ross et al (*Nat Rev Endocrinol*, 2020) Waist circumference as a vital sign in clinical practice: a Consensus Statement from the IAS and ICCR Working Group on Visceral Obesity.

Elevated blood pressure or hypertension is a well-established cause of coronary heart disease, stroke and several other vascular diseases. In addition, blood pressure accounts for a large proportion of the effects of obesity on health, such that a proper understanding of the effects of obesity is not possible without a proper understanding of the effects of blood pressure.

Thus, each of these baseline physical measurements provide significant contributions to disease risk predictions and have a strong rationale for being included in the Our Future Health research programme.

2.6. Data linkages

Health-related data linkages are a core component of the UK research infrastructure, made possible by routine data collection that can be safely and securely linked to participants. Our Future Health participants consent to data linkages when joining the programme, and their donation of these data provide important additional information on individual and geographic disease-related exposures as well as individual health outcomes. Examples of each of these are shown below:

- Individual disease-related exposures
    - medication prescriptions
    - coronavirus infection
    - surgical implants
    - radiation therapy

- Geographic disease-related exposures
    - particulate matter from combustion and other sources
    - food choices including distance and accessibility
    - meteorological information including flooding and extreme weather
    - geographic deprivation metrics

- Individual health outcomes
    - diagnoses captured in primary care records, secondary care records, and cancer registration databases
    - survival time following a serious diagnosis or clinical intervention
    - date of death including underlying and contributory causes of death

These participant-level geotemporal health-related data will greatly enrich the Our Future Health programme enabling researchers to assess the success of interventions, how and in who new therapies extend survival from acute disease, and how social determinants contribute to heath inequalities. These examples highlight the strong rationale for data linkages in this research programme.

2.7. Biological samples

A broad variety of biological specimen types could theoretically be collected in a given research study, but most prospective cohort studies have decided to collect blood at baseline on all of their participants. This is because it is a minimally invasive, cost-effective, and a participant-accepted

specimen type that can provide systemic insights on an individual's health-related exposures, disease risk, and disease status. For example, blood can provide information on viral exposures, pesticide exposures, polycyclic aromatic hydrocarbon exposure, lipid profile including high density and low-density lipoproteins, genetic susceptibility, DNA adducts, diabetes metrics, circulating tumour DNA (ctDNA), and circulating proteins indicative of disease. These examples of scientific insights that can be derived from blood provide a strong rationale for the collection of this biospecimen from all Our Future Health participants.

From the Our Future Health baseline blood samples, we plan to assess a range of biomarkers for research use purposes, such as cholesterol, triglycerides, high-density lipoprotein, low-density lipoprotein, lipoprotein a, other lipid-associated analytes and HbA1c. Hypercholesterolaemia is a well-established cause of coronary heart disease, stroke and several other vascular diseases providing for a variety of aetiological and translational research studies. HbA1c, meanwhile, provides an estimate of blood glucose (sugar) levels and could help us understand how to build better models with enhanced triaging of risk for diabetes. Vascular diseases and diabetes are major causes of morbidity and mortality in the UK providing a strong rationale for measuring such biomarkers using the baseline blood sample. We may also assess other singular or combined sets of biomarkers such as proteins, metabolites, chemicals, RNAs, and DNAs that have a clear scientific rationale for research use purposes. Note that if we desire to use any biomarker information generated for research purposes for participant health insights, we will submit a Study Protocol amendment for the Research Ethics Committee to consider.

Blood is a highly feasible and cost-effective biospecimen to collect given the facts that phlebotomy services are readily available and deployable, and that high-throughput automated laboratories and biobanks exist for processing and storage. These facts support the selection of blood as the central biological sample that we will collect when a participant joins the programme. However, this does not preclude the collection of additional biological specimen types, and we will continuously monitor the feasibility and cost-effectiveness of such as the programme progresses (this will include exploring the feasibility and potential piloting of novel blood collection methods such as self-collected capillary samples).

3. Research Ethics Committee (REC) approval status and ways of adhering to research ethics guidelines

Core programme documents which are submitted to REC for review and approval include the protocol, participant information sheet, consent forms, proformas and invitation letters. All amendments made to these core documents will be submitted as substantial amendments to REC for approval before use. Supporting programme documentation includes invitations, reminders, videos and posters) and content viewed by participants (e.g. on the website or their dashboards) are also reviewed by REC as and when amendments are made.

The size and pace of development at Our Future Health requires innovative approaches to build a diverse cohort which remains engaged in the programme and is willing to take part in ongoing and additional research. The programme relies on evolving, adapting, and iterating approaches to successfully innovate to meet milestones for recruitment and the programme more widely. Before scaling up any of our solutions, we run tests and pilots on smaller segments of the cohort to generate evidence and learnings, before decisions are made to implement any given solution for

the broader cohort. Alongside ensuring that we adopt solutions that are evidenced to create impact, we use this approach to understand challenges in rolling out new solutions, and to listen to our participants to inform our iterative approach. Our aim is to facilitate the meaningful engagement and involvement of our participants and researchers throughout to ensure that they have an enhanced experience and that their voices can continue to shape the programme.

We have engaged with the REC to navigate ways of working that can facilitate the need for our teams to work iteratively and at pace, through ongoing testing and pilots, to shape the programme to suit the experiences of a diverse and growing cohort of participants. We are committed to ensuring that research ethics requirements can be adhered to whilst enabling Our Future Health to innovate and adapt to the needs of the programme and its cohort.

To ensure robust ethical oversight during rapid iteration, we have developed a 'Boundaries and ways of working within research ethics standards' document (Appendix C) which was approved by REC in 2025 to facilitate user research, PPIE, and experimentation in the design and optimisation of Our Future Health. This document lays out an approach to working with REC to enable activities that fall within stated parameters to take place without specific REC review each time a new activity within the above remit is conducted. Activities are classified as low, medium and high risk. All items deemed to be high risk are submitted to REC for review. Activities assessed as medium or low risk will not be submitted to REC for review but will be assessed and collated internally for ethics review and audit purposes by the ethics team in Our Future Health.

Appendix C currently contains good practice guidelines for user research, PPIE, experimentation and design. The ongoing development of the document in the year ahead will span other areas of Our Future Health and will also include templates with content to facilitate Cohort engagement (see section 7), Feedback of health-related information to participants (see section 8)and Re-contacting participants for further research (see section 9). All items assessed by the Our Future Health ethics team to fall within the parameters laid out in the approved appendix will not be submitted to REC for review.

4. Recruitment

4.1. Overall strategy

As described in our Sample section, our ambition is to recruit up to 5 million people from diverse backgrounds. To achieve this ambition, we plan to engage the public (our potential participants), invite eligible participants by postal, electronic invitations (e.g., SMS/email), attain digital consent to participate in the programme, attain a digital baseline health questionnaire, and attain physical measurements and a blood sample at an in-person appointment.

We will deliver local and national communication activities to make the public aware of the programme, its primary aims and what and how a participant's time, data, and blood sample will be used.

In addition to using postal and electronic methods for invitations, we will also design and deploy in-person settings to promote and facilitate participation in the programme.

Given the primarily digital nature of the programme, we will explore means of participation which reduce barriers to access for those could be digitally excluded.

We will provide flexibility in venues for attaining physical measurements and blood from consented participants, primarily focusing on:

1. Community venues such as pharmacies, mobile units, and 'pop-up' clinics.
2. Partnerships with the NHS to use existing appointments such as blood donations and health care phlebotomy.

Schematic summaries of these recruitment workflows are shown in Figures 1 and 2, in section 4.10.

This primary overarching plan has a strong rationale in that it is flexible, scalable, cost-efficient, and feasible. It was built with the widely used COM-B Model (Capability, Opportunity, Motivation, Behaviour)[51] of human behaviour in mind, which encourages careful consideration of barriers when designing activities relating to behaviour (in this case, becoming a participant of Our Future Health). Our recruitment strategy is also be aligned with the highest ethical principles, as detailed in our Ethics & Governance Framework.

Our recruitment strategy will enable rapid, large-scale recruitment into the programme while simultaneously allowing us to adapt, tailor, and target our methods to ensure inclusion of populations that have been underrepresented in health research. In the following sections, we describe our detailed plans for engagement for recruitment, invitation, consent, baseline questionnaire, and phlebotomy.

4.2. Engagement for recruitment

The goals of engagement for recruitment are to raise awareness of Our Future Health, generate interest in taking part, and to provide opportunities for the public and other stakeholders to share their views.

To recruit a cohort that is reflective of the UK population, specific engagement strategies will be designed, tested and deployed. Engagement strategies will be designed to promote equity, diversity, and inclusion in Our Future Health. We will focus on better understanding and reducing barriers by enabling community collaboration and dialogue, enhancing awareness and relevance, and making participation easier where possible. These engagement strategies will be designed to support our local and region-specific recruitment plans.

4.2.1. Engagement through partnerships

Identifying and building relationships with individuals and organisations who can support participant recruitment to Our Future Health is an essential component of this programme. We will aim to work with partners that can support recruitment by publicising the programme to target audiences through existing networks, and with partners that are able to support our plans to send invitations to people to take part. This will include local opinion formers in public health, large businesses, community organisations, academia and local government.

[51] COM-B Model (Michie et al, 2011) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3096582/

Collaborative engagement with delivery partners – such as pharmacies and supermarkets – has the potential to increase awareness and engagement via well-known organisations that have strong local and national footprints. Recent activities with these sectors, which we will build upon going forwards, have demonstrated the opportunities to co-locate Our Future Health clinics on partner sites thus increasing the visibility of the programme to those going about their normal shopping activities, as well as partners using their existing communication channels to cascade information about Our Future Health. Whilst activities to date have been focussed on supporting recruitment activities, we will pivot these towards supporting cohort engagement with clear new opportunities to partner on activities around disease focussed campaigns and promotion of health/risk prevention (see section 7.3)

To overcome barriers experienced by underrepresented groups, we will aim to develop partnerships with trusted voices and community leaders or representatives, including local public health teams, community groups and those who have strong networks in each area. We will also look to work with well-recognised and trusted brands such as supermarkets, sports organisations and our charity partners which are embedded in communities we are trying to reach.

Engagement strategies will be designed with the support of our Diversity and Inclusion Advisory Board which comprises people with expertise in engaging communities locally and nationally. We will also leverage the expertise of our charity partners and on our Ethics Advisory Board, Scientific Advisory Board and our Public Advisory Board, each of which provide additional expertise of the challenges of engaging and recruiting participants into health research studies from diverse backgrounds across the country in culturally appropriate ways.

To achieve engagement with and maintain ongoing support from a range of partners, we are planning to focus on a combination of:

- Clear, motivating partnership proposals, backed up by credible voices from a range of domains (e.g. science, healthcare, charities, politics, celebrities) and working with existing partners to engage others
- Providing feedback on partners' support in driving recruitment, so they can be credited for their efforts and achievements
- Strong, enduring relationships with leaders in partner organisations, particularly in the charity sector, and ongoing engagement and outreach
- High quality tools, content and campaign resources to make it easy for partners to promote Our Future Health
- Tailored campaigns, co-created with partners to improve impact
- Supporting national, local and digital PR, to provide a positive ongoing context for partners choosing and continuing to help us

4.2.2. Engagement through participants

We will draw on the expertise and networks of our participants, supporting them to share information about Our Future Health with their communities. We launched a Community Champions programme pilot in May 2025, where we contacted a group of our participants to invite them to become a Community Champion in their area. This is a voluntary role that was offered to 125 participants who respond positively to our invitation; and live in areas of the country that have high levels of either ethnic or socioeconomic diversity. We will work with the Champions to establish programmes of activity to encourage information-sharing, discussion, and awareness raising of our research programme. The ultimate aim of the scheme is to improve awareness of our

programme, with a view to increasing participation, particularly amongst diverse groups and communities. The outcomes of the pilot will be drawn on to understand whether Community Champions should become an established part of our broader programme. More details on the pilot can be found in Appendix D.

We have made it simple for participants to generate awareness of the Our Future Health research programme with tools, simple processes and (non-financial) incentives to encourage their families and communities to consider becoming participants.

4.2.3. Publicity campaigns and communications

A comprehensive programme of publicity activities will increase awareness and understanding of Our Future Health among the target population. Publicity campaigns will be designed to increase responses to invitations sent to members of the public and so enable recruitment into the cohort. Activities include advertising, public relations, social media and community-based events that can effectively reach the target population in each area. These activities will aim to increase levels of awareness across the target population as a whole, particularly those groups that we anticipate are less likely to engage and respond. We use a range of messaging, channels and methods of engagement designed to increase motivations to participate in the programme, including:

- Membership bodies/groups – tapping into the scale of organisations that have a strong connection to or presence within our target audiences. These could be place-based or interest-based opportunities, or a combination of the two (e.g. faith organisations)
- Patients as advocates – exploring routes through patient charities/groups to encourage people with diseases to make the case within their communities and families for participation
- Social campaigning – adopting a networking approach to increase reach using social media in particular, drawing on the potential to tap into motivations around specific disease areas with the support of relevant charities
- Influencers – engaging and enlisting the support of high-profile advocates who have reach and influence across target populations, both geographically and digitally.

We will also engage with stakeholders and advocates at the regional and national level. These may be a combination of those within the NHS healthcare system (e.g. clinicians, NHS Health Check commissioners, NHS leadership) and across the broader public health arena e.g. medical charities, local authorities, patient groups and researchers.

4.3. Invitation

4.3.1. Invitation methods

Postal invitations will continue to be utilised as a primary method of recruitment, enhanced by a variety of electronic communication (email, SMS) and wider engagement approaches. A combination of personalised invitation letters (NHS DigiTrials) and non-personalised invitation letters (addressed to households) are used with the intention to reach most of the U.K.'s adult population.
NHS DigiTrials provides unparalleled scale, with the ability to target invitations based on demographic information and will help us build trust with potential participants. The NHS DigiTrials application process includes Section 251 support which will enable NHS DigiTrials – on

our behalf – to randomly select eligible individuals and send named invitations for participation in Our Future Health in England. We will dynamically adjust the number of invites sent to specific population groups based on conversion rates and our ambition to recruit a diverse cohort that is reflective of the UK population. Only one NHS DigiTrials invitation can be sent to a named individual (under current approvals).

Non-personalised letters (NPL) are sent to households across the UK (England, Scotland, Wales and Northern Ireland). Although segmentation by demographics is not possible, invites will be dynamically adjusted within population groups and repeat household invitation is possible. Recruitment clinic locations will be planned to ensure a representative cohort as possible using demographic data to inform planning.

Invitations may also be sent by collaborations with community pharmacy networks or large employers using their existing customer/workforce databases. We are also exploring other ways to send invitations, including potential partnerships with existing cohorts.

In partnership with NHS bodies, invitations to Our Future Health will be sent by email to blood donors by NHSBT, and through existing patient communication systems – which may include post, email and text message – in primary and secondary care. Text messages are attractive because they are inexpensive, already sent in high volume by the NHS, and can include a link to our participant information sheet and consent process that can be accessed via a patient's smartphone or computer prior to a planned appointment. Our Public Advisory Board members and secondary care PPIE work in 2021 revealed that this was an acceptable and viable format, but with the caveat that it needs to come from a known and trusted source.

4.3.2. Feasibility of invitation strategy

The invitation methods described above have high feasibility based on past use of the infrastructure by prior studies.

The largest prior UK example of a successful postal recruitment strategy is UK Biobank. Individuals registered with the NHS were invited by post and able to respond via post, internet, or phone to arrange an appointment at an assessment centre. Consent, questionnaire, baseline measurements, and phlebotomy were all conducted at assessment centres that were specially designed and fitted out for this purpose.

NHS DigiTrials is a similar, more formalised process to invite NHS-registered individuals to research studies, which is already demonstrating success with recruitment to the Randomised Evaluation of COVID-19 Therapy (RECOVERY) trial and the Platform Randomised trial of Interventions against COVID-19 In older people (PRINCIPLE) Trial.[52]

We demonstrated the feasibility of NHSBT email invitations sent to blood donors in joining Our Future Health in a pilot study in 2021. In addition, INTERVAL[53] and COMPARE[54] studies had already successfully demonstrated recruitment of blood donors for research studies that used the first 35 ml of blood that would otherwise be discarded for infection control, while the STRategies to Improve Donor ExperienceS (STRIDES) study[55] also successfully recruited blood donors.

[52] https://digital.nhs.uk/features/nhs-digitrials-already-saving-lives
[53] https://www.intervalstudy.org.uk/
[54] https://www.comparestudy.org.uk/
[55] https://www.strides-study.org.uk/

4.3.3. Invitation development

We took a theory- and evidence-based approach to the development of our invitation content. Specifically, we conducted user research to assess comprehension and acceptability of invitations and used randomised online experiments to identify content that maximises response.

For digital invitations, where possible, we will send a limited number of pre-invitation notifications and invite reminders to optimise response rates. Reminders may be personalised or targeted using the principles referred to in Section 7– Cohort Engagement. This has been validated in the findings from our PPIE work in primary and secondary care and via input from our Public Advisory Board.

We will consider different ways to improve the accessibility of our invitations and joining process for those who have lower digital literacy or limited access to technology.

4.4. Reimbursement

Our Future Health is committed to the principle of equity in participation and widening access as substantially as possible. One such initiative is offering reimbursement to compensate for the time and costs incurred to participate in Our Future Health. We intend reimbursement to reduce practical barriers to participation, increasing response rates in those who may otherwise be less likely to participate.

Participants joining Our Future Health via the community route will be offered reimbursement in the form of a £10 voucher once they have completed all the steps to becoming a full participant. In order to be eligible for reimbursement, participants must register, consent, attend a clinic appointment to donate a blood sample, and complete an on-line questionnaire. Once eligible, participants will be required to claim the £10 voucher within a set period, and to then digitally redeem this voucher from the provider within 28 days.

4.5. Registration

The digital registration form is designed to collect necessary participant information prior to consent:

- Full Name
- Date of Birth
- Contact Information (email, phone, address)
- How did they hear about us (optional)
- User-created password
- Ethnicity information (optional)

This form is hosted on a secure platform and serves as the initial part of the joining process for prospective participants as outlined in section 4.6 (Consent).

The ethnicity data gathered at registration will not be used to identify or analyse individual participants. This data will be used to enhance inclusivity in our recruitment process and to help recruit a diverse cohort of participants, building a resource that better represents groups historically underrepresented in health research. The data gathered at registration will be analysed at an

aggregate level to identify broader trends, not to segment individuals based on protected characteristics. The data gathered at registration will not be available for researchers.

4.6. Consent

The primary method of consent in Our Future Health will be digital. The consent process starts with information provision which comprises the consent form and the participant information sheet, opportunities for potential participants to have their questions answered, and a formal recording that the individual consents to participate in the Our Future Health research programme. Participants register an account with their contact details either before or at the time of consent so we know who the consent belongs to, and so we can contact that person as part of their involvement in the programme.

We designed the consent and participant information sheet in alignment with the principles set out in our Ethics & Governance Framework, namely that valid consent comprises three components: information, comprehension, and voluntariness. For further details, please see the Ethics & Governance Framework[56].

The consent form and participant information sheet were rigorously co-developed with members of the public through focus groups, co-design meetings and multiple rounds of user testing interviews.

We also had input to the first version of the participant information sheet from the Ethics & Feedback Advisory Group as well as other external stakeholders and advisers including national and international experts in consent from academia. The consent form and participant information sheet were approved by the REC and subsequent amendments have been reviewed and approved by the REC.

The consent includes the ability to re-contact participants, so we can invite them to complete additional questionnaires, provide further samples, receive personal feedback and consider invitations to enrol in future studies that will have separate REC-approved study protocols with their own consents and participant information sheets.

We will continue to use our Participant-Reported Experiences Survey to obtain feedback on the ease and acceptability of the consent process, and as part of our evaluation/analytics and insights.

Individuals with queries can call or email the Our Future Health support centre. The support centre is operated by specially trained staff. The main functions of the support centre are to:

- Answer questions about consent procedures and the scope of Our Future Health
- Allow questions from potential participants (and their GPs) to be addressed either by the trained call centre staff or, if not possible, by more senior members of the Our Future Health team
- Administer the questionnaire to visually impaired participants, and those who do not or cannot access the questionnaire via the website/digitally

[56] https://s42615.pcdn.co/wp-content/uploads/Ethics-and-governance-framework-v2.0-April-2021.pdf

We will continue to use insights from our interactions with our participants and the public to iterate the consent and participant information sheet further, if required. We will submit updates to the REC for review and approval prior to deployment.

4.6.1. Loss of capacity in existing participants

In September 2023, Our Future Health came together with the Health Research Authority (HRA) and Genomics England, as well as academics, legal experts, researchers, charities and members of the public, to host a roundtable to explore how we might establish a process for when we are made aware of changes to a participant's capacity. In line with the blog published by the HRA (Blog: Consent, capacity and long-term research - Health Research Authority), we will not routinely monitor participants' capacity over time in our cohort.

However, there are cases in which Our Future Health is being contacted directly by a participant or their family member to inform us of a loss of capacity or an early diagnosis which may lead to future loss of capacity. In these cases, it is important for us to balance the ethical imperative to support inclusive research with the responsibility to protect vulnerable participants from intrusive or interventional research, and Our Future Health is committed to developing a process to support these commitments to its participants.

To inform our approach to us learning about our participants who have lost capacity during their participation in Our Future Health, we are planning a public dialogue to understand societal views and ethical expectations for when we are made aware that a participant may have a loss of capacity. We will use these findings to engage further with ethics, legal, regulatory and policy experts as we develop our operational approach to participant loss of capacity.

4.7. Baseline questionnaire

We have developed a baseline questionnaire to capture health and lifestyle factors that would be difficult or impossible to obtain from data linkages. This questionnaire was developed largely by a core scientific advisory team and was intended to align closely to existing large epidemiological cohorts, such as the UK Biobank. We went through a process of cognitive testing with Our Future Health participants to refine how questions are asked and understood. The baseline questionnaire collects information on demographics, socioeconomics, physical activity, lifestyle exposures, family history, medical history, depression and anxiety, medications, and supplements. It takes, on average, 35 minutes to complete. The initial version of the baseline questionnaire was used in pilots conducted in 2021. Following review of the pilot data and further testing, the questionnaire was expanded slightly on the health and family history sections. The contents of the current questionnaire can be found in Appendix B. Data shows that 92.8% of participants who start the baseline questionnaire complete it.

4.8. Short baseline questionnaire

We will develop a short version of the questionnaire. This will be a shortened list of the already-approved questions from our baseline questionnaire. There will be no additional items or new question types.

The items that comprise the short questionnaire will be selected by:

1. Data reduction approaches
   Where several items have been included to measure the same underlying phenotype, we will identify cardinal items for inclusion in short questionnaire using data reduction approaches.

   We will use pilot data to examine the internal validity (Cronbach alpha) of any related items. We will establish inter-item correlations and perform factor analyses to establish the overall fit, factor scores and item loadings. We will iteratively drop less well performing items and re-evaluate internal validity using Cronbach alpha and factor analyses until we find the minimum number of items that can be used to index the underlying outcome.

2. Stakeholder input
   We will review the results from this data driven approach with stakeholders including our scientific advisory board and participant advisory board. We will collect input from stakeholders on priorities for retention and outcomes or items that do not represent immediate priorities for healthcare research.

3. Testing and piloting
   We will pilot the resultant shorter questionnaire with members of the public to establish whether the time taken to complete meets our length criteria (<10minutes) and to ensure it is being understood and is generally acceptable to participants.

When we have a satisfactory short questionnaire, we will test it against the longer baseline questionnaire to establish whether rates of conversion to full participant (consent + blood sample + questionnaire) are improved. The short form questionnaire may enable a streamlined, in-person, full participant recruitment model to be deployed in the field, if desired or required. Any participants who complete a short core questionnaire will be asked to provide responses to the remaining questions from the primary baseline questionnaire after recruitment.

4.9. Participant-reported experiences

We administer a quantitative survey instrument/questionnaire to assess participant-reported experiences (PREs) to understand key indicators such as satisfaction, attitudes and understanding. The participant-reported experience measure (PREM) survey instrument includes the following measures:

- Satisfaction e.g. with the information provided, website, consent process, questionnaire process, appointment
- Informed choice
- Attitudes/values
- Knowledge/understanding
- Decision
- Communication about the programme to others e.g. family members, friends, GP, other healthcare professional
- Motivation
- Reasons for taking part and completing various elements of the programme
- Reasons for booking blood appointments

See Appendix B for more details of these questions in the survey.

The original PREM questionnaire (v1) was developed in 2021. We collected participant-reported experiences using the PREM during our 2021 pilot phase. We also conducted in-depth interviews with a subset of participants and active/passive decliners to provide complementary rich qualitative insights on their experiences. Minor additions may be made iteratively to ensure we are accurately capturing participant reported experiences during future recruitment activities. We will continue to conduct qualitative interviews and brief quantitative surveys on subsets of PREM questionnaire responders to ensure we complement quantitative findings with a deeper understanding of the participant experience.

4.10. Phlebotomy and physical measurements

We record physical measurements (in community settings) and collect a blood sample from each consented participant. Participants will have a choice in where they donate their blood and undergo a brief physical assessment. Locations may include:

1. Community covering pharmacies, mobile units, and 'pop-up' clinics
2. Existing NHSBT appointments for blood donations for those recruited via NHSBT route
3. At home collection

As general practice, two vials of blood will be drawn from participants. However, up to five vials of blood could be taken for purposes such as quality control or where samples may be unusable. Blood samples will be used to extract DNA and conduct genotyping, as well as conduct baseline assessments of various analytes (as described in section 2.7) and will be sent to our biobank for long-term storage. At all opportunities the blood collection time and date, and time of last significant meal will be collected at the time of blood draw. Physical measurements will also be taken at this time including blood pressure, height, weight, and waist circumference.

4.10.1. Baseline cholesterol assessment

A finger-prick point-of-care-test (POCT) for cholesterol was offered to participants during the first two years of recruitment. The decision taken by the Department of Health and Social Care to switch from using finger-prick cholesterol tests in the new NHS Digital Health Check to a laboratory cholesterol test contributed to the decision to cease baseline POCT cholesterol testing. We also listened to views on our cholesterol testing from GPs and Our Future Health volunteers before deciding to make this change.

Discussions are ongoing to determine whether a replacement cholesterol test will be offered. We are currently exploring alternative ways to measure cholesterol and how to provide that information back to volunteers and we will make a decision in the next few months. Our priority will always be to make sure Our Future Health is as valuable as possible for health researchers to discover new ways to prevent, detect, and treat diseases.

4.10.2. Community routes

We have conducted extensive market research and a viability assessment from which we are confident of being able to conduct phlebotomy and physical measurements outside of the NHS in a cost-efficient manner using pharmacy collaborations, mobile units, or 'pop-up' clinics.

Through a booking system, consented participants are able to book online or by telephone, an appointment location and time for phlebotomy and physical measurements. By establishing Our Future Health community collection sites, we will have greater control over locations, the participant experience and how we manage consent relative to limitations of working solely within the NHS.

We have benefited from information shared by GRAIL which has recently operationalised the Galleri study, and this has allowed us a greater understanding of, for example, cancellation rates, no shows, and other aspects of user behaviour. Based on our research, our approach is to phase the roll out of the venues, with a lower capacity for the first two months of deployment, which will allow us to learn and adapt the service according to behaviour.

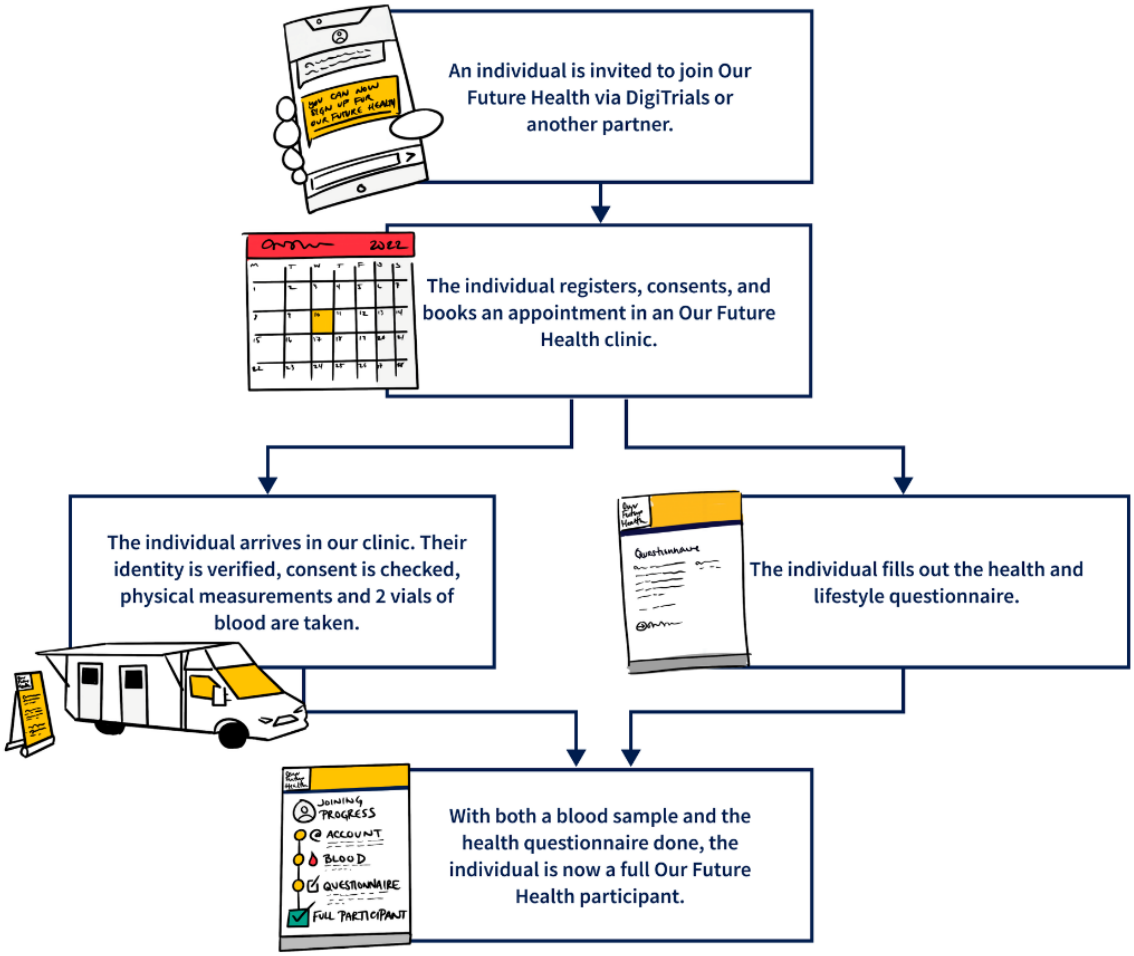

Figure 1. Flowchart of recruitment in community settings

We are also working with community pharmacy groups and the NIHR 'research ready community programme for community pharmacies.' Community pharmacies are an attractive venue with 89% of the UK population being able to access a community pharmacy within a 20-minute walk, with access being greater in areas of highest deprivation. Community pharmacists can also access harder to reach patient populations.

4.10.3. Community walk-in recruitment pilot

We are piloting a new walk-in recruitment model, placing clinics in the heart of diverse communities. Members of the public are first engaged by Our Future Health Connectors—experienced third-party staff skilled in reaching underrepresented groups. Participants can speak with agency staff, ask questions, and begin their digital consent journey by scanning a QR code, enabling them to decide, consent, and donate on the spot. Once consented, they check in and join the queue for a same-day clinic appointment.

The first phase of the pilot, delivered in 2025, validated the model's operational and technical feasibility and gathered early evidence of the ethical feasibility (participants feeling that they have information to make an informed choice about joining the programme) and recruitment efficacy. Feedback indicated many participants would have been less likely to join through other recruitment methods.

Building on these insights, phase two is testing walk-ins against the pre-booking model, with full outsourcing to assess scalability. Third-party staff have undergone comprehensive training in Good Clinical Practice, data protection and confidentiality, ethical framework and informed consent, safeguarding and inclusive engagement, along with a programme-specific orientation.

We have developed a robust event-management framework and standard operating procedures to ensure ethical engagement. Key safeguards include:

1. Preventing participants from feeling compelled or coerced to make immediate decisions, thereby mitigating undue pressure to enrol into the programme.
2. Equipping staff with standardized responses and resources to support informed decision making.

This method of recruitment will be critically important in removing barriers for people who may otherwise find it more challenging to join the programme, particularly those from diverse communities. It will also offer a flexible, scalable approach that could be adapted to other settings.

4.10.4. NHS blood donor route

For the NHS blood donor route, following a donor consenting online to Our Future Health, we are now working with NHSBT to optimise the process by which participants are linked with their future blood samples. The goal is to maximise efficiency and minimise friction for both NHSBT and Our Future Health. A flag is created in the NHSBT system to notify phlebotomists of blood donors who have consented to participate in Our Future Health and wish to provide a blood sample at their next donor appointment. Our Future Health regional leads (senior NHSBT research nurses) will support donor carers in implementing this phlebotomy route in the main phase of the programme.

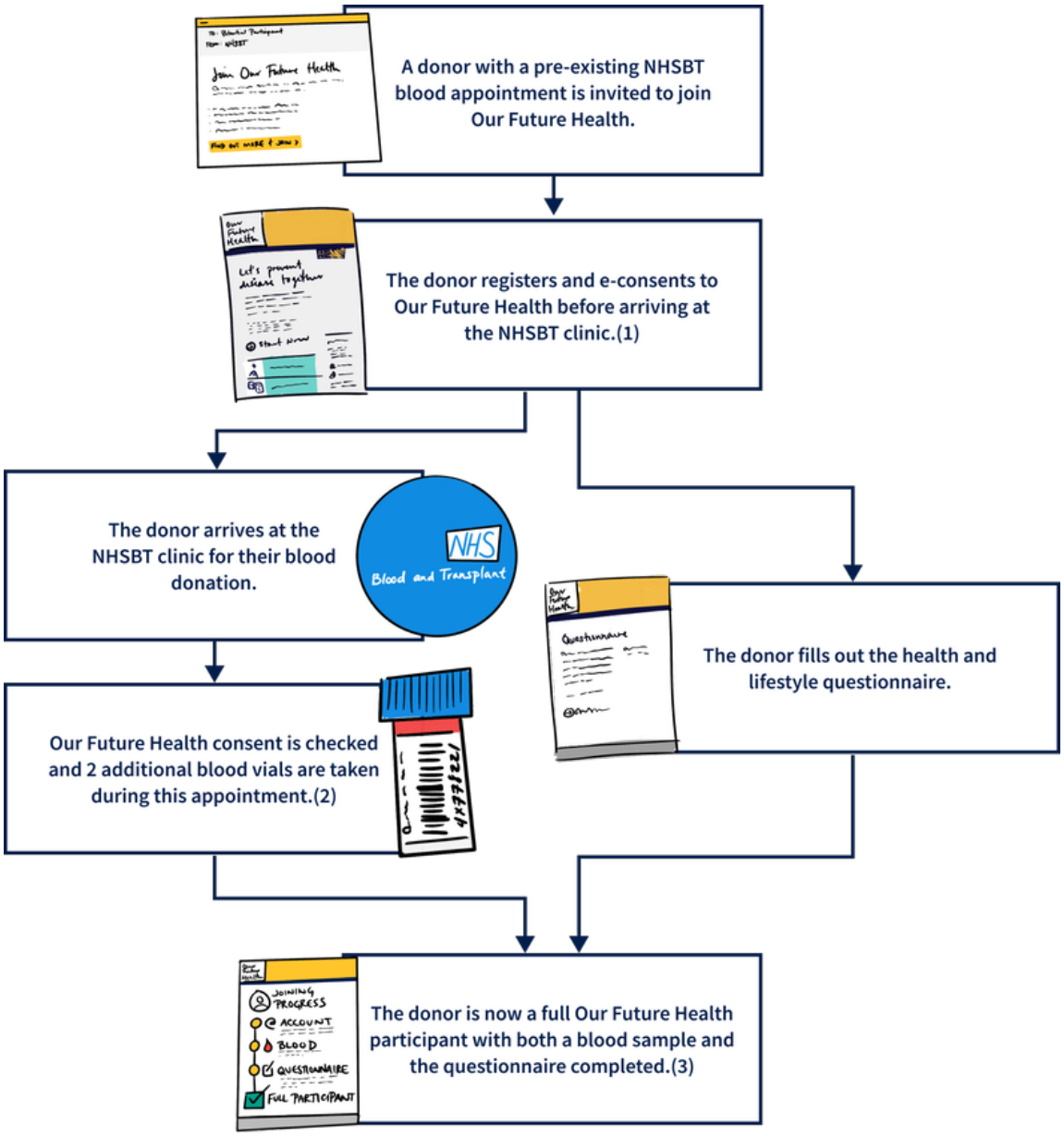

Figure 2. Flowchart of NHSBT recruitment

The participant information materials inform participants that Our Future Health will share specific genetic information about them from their blood sample with NHSBT. This includes red blood cell types, platelet types, HLA subtypes and white blood cell groups. NHSBT will use this information to provide better matched blood and stem-cells for patients. The genetic information will also help NHSBT improve their services. Participants are also informed that Our Future Health will share personal identifiable information about them with NHSBT in order for their genetic information to be linked with their NHSBT donor record.

4.10.5. Home appointment pilots

We are planning to pilot two new blood sample collection models which involve blood collection at home; blood samples will be taken by a phlebotomist at home or via a self-administered home kit (see Appendix G). Our current recruitment approach of booking an appointment may not be

suitable for all participants and there could be prospective participants who wish to take part but aren't able to attend an appointment. The pilots would offer participants who have consented but not attended a clinic appointment an opportunity to donate their blood sample and have their physical measurements taken at home.

By offering participants an opportunity to donate their blood at home, the pilot aims to validate the feasibility and effectiveness of both home blood collection concepts to understand the demand for these types of appointments and to provide insight into the desirability and uptake compared to prebooked clinic appointments. The pilots will also test the quality of the blood sample obtained by these methods and gain insight to the participant experience of home phlebotomy.

5. Blood sample logistics, processing and genotyping

Each participant blood sample will have a unique barcode label which will be linked in Our Future Health's system to participant ID and personal data. Blood samples will be sent overnight or same-day at ambient temperature and centrifuged within 30 hours at the country-specific processing facility to fractionate the blood. DNA will be extracted from buffy coat before being genotyped using a custom genotype array. Aliquots of plasma, buffy coat and residual DNA will be sent to our ultra-low temperature biobank for long-term storage.

We have designed the blood sample logistics, processing, and genotyping pipeline with flexibilities, redundancies, and integrations throughout. Quality management, quality control and data security is embedded in this pipeline with a variety of security standards and ISOs requiring certification or self-declared conformity. This pipeline will deliver the real-time throughput needs of Our Future Health and will provide quality-checked, called genotype data that will flow back to Our Future Health via a secure transfer mechanism.

We are conducting imputation on the genotyping data to expand the number of genetic markers using the UK Biobank 200k phased WGS product as the reference panel. Imputed genotypes will help us to deliver each of our programme's five specific aims, providing a resource for basic and translational research, as well as the basis for generating integrated risk scores and other genetic information which may be returned to participants. This will enable the programme to be able to offer such information to participants as well part of the ways in which participants can be identified and subsequently invited to join additional studies, each of which will have their own REC approvals and materials.

5.1. Repeat blood samples

There are strong scientific rationales for collecting repeat blood samples. These include the ability to investigate:

- Age-specific biomarker thresholds to improve risk prediction or provide individualised baseline levels
- Age-specific biomarker changes to improve risk prediction or provide for proxy endpoints

- Specific time-windows proximal to disease when the likelihoods of earlier detection and improved intervention are high
- More accurate classification through correction of regression-dilution bias
- Random variation and patterns of variation (e.g. seasonal, menstrual, etc.) of biomarkers in healthy, asymptomatic and symptomatic patients
- Natural history of disease
- Discover biomarkers in a disease course that are predictive of treatment response

We are committed to collecting repeat blood samples to cover this research gap. Repeat blood samples will enhance the resource, broaden scientific opportunities, and help future-proof the scientific utility of the Our Future Health programme by enabling diversity and evolution of the types of blood samples collected.

We will continue to work with all stakeholders – including our participants and all of our boards to design and deliver a programme of repeat blood samples.

6. Data linkage

Linkage to health-related data is a central component of the Our Future Health programme, forming part of the core cohort dataset. We will link to and then receive and store data that is controlled by third parties and provide that data in de-identified form to researchers. Agreeing to link to data held by third parties will be a requirement of joining the programme.

6.1. Initial high priority data linkages

We will apply to the Data Controllers of country-specific central demographic registers to enable confirmation matching of all Our Future Health participants. This will confirm electronic identification of the participant and enable linkage to the first high priority set of data linkages that will include primary care, secondary care, cancer data, and death data.

Demographic registers for the UK include the Personal Demographics Service (PDS; England), the NHS Central Register (NHSCR; Scotland), the Welsh Demographic Service Dataset (WDSD; Wales), and the Health and Social Care Northern Ireland (HSCNI; Northern Ireland). Once a participant has been matched via the relevant country-specific demographic register this will enable Data Controllers to search priority linkage datasets for any records each participant may have and supply those records to Our Future Health via secure means and under appropriate Data Sharing Agreements.

The initial high priority datasets for the Our Future Health programme include:

a. **Primary care data:** General practice data are an essential component of our programme to provide a detailed picture of a participant's health. These data include exposures, phenotypes, diagnoses, and prescriptions/dispensing of medicines.

b. **Secondary care data including hospital admissions:** Secondary care data provide detailed records of hospital outpatient and inpatient visits, surgeries, and procedures that are an essential component of understanding a participant's health status, diagnoses, and progression/regression of disease.
c. **Cancer registration data:** Cancer registration provides almost complete capture of cancer diagnoses in the UK. These datasets provide patient and tumour level information including pathology reports, molecular testing results, treatment records, and hospital activity records.
d. **Death registration data:** Vital status, date of death, underlying cause of death, and contributory causes of death are essential data for any study within the Our Future Health programme.

6.2. Other linked data sets

Once the initial high priority set of data linkages have been completed, we will explore linking to additional health-related datasets such as disease/service specific registries (e.g. cardiac disease, kidney disease, intensive care), coronavirus infection, coronavirus vaccination, imaging (e.g. Diagnostic Imaging Data Set [DID]), costings, pre-cancers (e.g. UK National Barrett's Oesophagus Registry [UKBOR]), maternity (e.g. Maternity Services Data Set [MSDS]), census, education, welfare, employment, environment etc. Examples of data sets that Our Future Health may link to can be found in Appendix H. Our ambition is to build a complete picture of health in our programme to enable comprehensive research studies to be conducted.

7. Cohort engagement

Our Future Health has successfully recruited millions of people into the diverse research cohort. The next phase is active engagement: encouraging all participants to regularly update their health and lifestyle information through, for example, questionnaires, responding to re-contact study invitations, and maintaining a long-term relationship with the programme.

Effective participant engagement – through personalised communication, timely feedback, and relevant health insights – is essential to sustaining an active, responsive cohort. It underpins successful recruitment into follow-up research studies by ensuring participants remain aware, motivated, and ready to respond. Through ongoing engagement, participants can be invited to complete additional questionnaires, consent to new data linkages, or update key information such as health status, contact details, and lifestyle factors. This ensures our dataset remains up to date and scientifically valuable, supporting more targeted and impactful research.

Beyond operational benefits, meaningful engagement helps us demonstrate trustworthiness to our participants, reinforces transparency and accountability, and provides for part of an ethical foundation of Our Future Health. This continued commitment to active participation enables richer, higher-quality data collection over time—maximising the long-term impact and return on public investment.

7.1. Approach to cohort engagement

Our Future Health is investing in a multi-channel participant engagement strategy that will evolve with the cohort. This includes:

- **Personalised digital experiences**, including improving our participant study portal to provide tailored insights and participation opportunities to take part in e.g. clinical trials, or to complete additional questionnaires;
- **Regular communications**, including newsletters, themed health updates, and invitations to contribute to new data collections or research studies that would lead the participant to more information on their participant portal. These communications may be cohort-wise or targeted to a particular sub-group;
- **Technical infrastructure**: including systems that support the management of participant communications, such as tools for segmenting audiences and coordinating when and how invitations are sent.
- **Partnership-led engagement**, working with community, charity, and public sector partners to co-deliver content and opportunities, particularly with underrepresented communities;
- **Inclusive design and communications**, ensuring content is accessible, culturally appropriate and informed by user research;

Participants will be invited to engage with Our Future Health over time in ways that include, but are not limited to: updating health and lifestyle data; participating in new surveys or health assessments; receiving feedback on personal and population-level health insights; and taking part in further research studies.

To enable a unique and meaningful experience for participants, engagement activities may be personalised based on the following information that Our Future Health holds about the participant:

- Previous interactions with Our Future Health, such as opening/interacting with emails, participation in re-contact studies and engaging with participant health feedback
- Participation status, for example having started but not completed a questionnaire, or having consented but not having had a blood sample taken.
- Participants' prior reported interests or motivations for joining Our Future Health.
- Participant evaluations of previous engagement or participation activities, for example participants having reported a positive experience of a re-contact study or health feedback.
- Non-special category demographic data, such as age, index of multiple deprivation or region of residence.
- Health information that a participant would reasonably know about themselves, for example, a health condition that the participant disclosed in the baseline questionnaire or that is documented in their NHS health record.
- Data differences, such as missing data.
- Eligibility for a re-contact study about a condition that the participant may not reasonably know they have / are at risk of, which, with informed consent may be disclosed during the invitation process.
- Eligibility for a re-contact study about a condition that the participant may not reasonably know they have / are at risk of, where the engagement activity could not implicitly or

explicitly inform the participant about the risk. For example, educational content about genetics.

Our Future Health has drafted a document (Appendix C – Boundaries and ways of working within research ethics standards) to set out parameters under which we can deploy engagement activities without specific approval from the REC. We categorise activities by risk and those deemed high-risk will be referred to REC for approval. For example, we will seek approval from the Research Ethics Committee prior to using personalisation based on racial or ethnic origin, religious beliefs, sexual orientation or behaviour.

7.2. Governance and evaluation

All engagement activities will be underpinned by governance processes and subject to ethics and information governance oversight. We will regularly evaluate the effectiveness of engagement approaches, including participant satisfaction and contribution levels, and adapt based on findings. Our engagement strategy has been shaped by participant workshops, co-design sessions, and early pilots. We will continue to embed the participant voice in how we evolve and scale engagement, ensuring that it supports trust, inclusivity, and long-term scientific and public health impact.

7.3. Partnerships to support cohort engagement

Our Future Health will work with carefully selected partners to enhance the overall participant experience and promote sustained engagement with the programme over time. These partnerships are intended to offer participants additional opportunities to connect with the purpose and impact of their involvement, beyond the initial recruitment and sample collection phase.

Such partners may include medical research charities, cultural institutions, employers, public-facing organisations, ambassadors or influencers who have reach through to certain communities and community networks with strong public trust and recognition. These partnerships will be used to share relevant updates on research progress, disseminate accessible educational content about health and science, and recognise the contribution of participants to the advancement of medical research.

All partnership activities will be designed to support the ethical principles of transparency, respect, and reciprocity. They will be developed in a way that ensures participants are not subject to any undue influence, and that engagement remains voluntary, appropriate, and aligned with the purpose of the research.

8. Feedback of health-related information to participants

8.1. Background to issues around feedback

We are in the process of making decisions about whether and how health-related research data are offered to participants. These may include questionnaire-based findings, results from physical measurements, imaging, analysis of biological samples, genetic results, or other individual-level data collected or generated throughout the course of the study, including linked NHS and administrative data.

The return of individual genomic findings continues to raise complex ethical, practical, and regulatory considerations. The debate around returning such results is well-established. In 2013, the American College of Medical Genetics and Genomics (ACMG) recommended returning certain secondary findings from clinical exome or genome sequencing.[57] In 2014, the Clinical Sequencing Exploratory Research (CSER) Consortium and the eMERGE Network in the US similarly advocated for returning clinical genomic findings that meet an actionability threshold, provided the participant has consented and appropriate clinical referral pathways are in place.[58]

More recent guidance from these clinical networks has reinforced this position, while clarifying that researchers are not ethically obliged to actively search for actionable findings. Instead, they should be prepared to return them when discovered within clinical data that meet the requisite standards. The eMERGE Network — a consortium of 10 US healthcare institutions conducting clinical genetic sequencing with results being directly into EHR and provision of requisite clinical decision support – has expanded its approach to include integrated genomic risk assessments as part of their clinical service study — combining monogenic risks, polygenic risk scores, and family history — delivered through structured reports with care recommendations and educational materials. In the context of clinical trials, there is growing support for participants to have meaningful access to their own data, including individual research results. However, for research studies looking to report back health-related insights to their participants — as opposed to clinical programmes looking to report back results and insights from their patients — challenges remain, including regulatory constraints around laboratory certification, ambiguities in data access rights, and the need to ensure equitable interpretation and communication of genomic risk across diverse populations.

In the UK and EU, the return of individual results is also impacted by regulatory frameworks for medical devices and in vitro diagnostics (IVDs), such as the UK Medical Devices Regulations 2002 (as amended) or the EU In Vitro Diagnostic Regulation (IVDR). Where feedback is derived from investigational devices or analytical processes not yet CE- or UKCA-marked for clinical use, appropriate ethical and regulatory safeguards must be in place. This includes ensuring that participants are adequately informed of the investigational nature of findings, that the results are returned only with explicit consent, and that appropriate clinical support or referral mechanisms are available if needed.

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[57] Green, Robert C., et al. "ACMG recommendations for reporting of incidental findings in clinical exome and genome sequencing." Genetics in medicine 15.7 (2013): 565-574.

[58] National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Health Sciences Policy; Committee on the Return of Individual-Specific Research Results Generated in Research Laboratories; Downey AS, Busta ER, Mancher M, et al., editors. Returning Individual Research Results to Participants: Guidance for a New Research Paradigm. Washington (DC): National Academies Press (US); 2018 Jul 10. 1, Introduction.

In addition to these considerations, there are specific scenarios in which returning information to participants becomes essential to the integrity and transparency of the research process. For example, if participants are invited to join a study based on stratification using their health data-such as genetic risk scores, phenotypic characteristics, or linked health records, it may be ethically necessary to return the relevant information used to define their eligibility. In such cases, feedback is not simply a benefit to the participant, but a prerequisite for informed consent.

Transparency about why a participant has been selected demonstrates trustworthiness and strengthens the value proposition of taking part. Furthermore, clear, relevant feedback can enhance the motivation to participate, particularly in studies focused on prevention, early detection, or personal health improvement.

At the scale of Our Future Health, even small increases in follow-up driven by feedback could place pressure on NHS services. Careful planning, forecasting and coordination with NHS stakeholders will be essential to avoid unintended burden. In particular, whole-cohort return of genetic results must be supported by the health system. National oversight is critical to ensure alignment with clinical pathways, appropriate service models, and sustainable delivery through the NHS.

8.2. Rationale for participant feedback

Recognising the regulatory, ethical, and health system complexities, we plan to offer participants the option to receive feedback on their personal health-related results - including lifestyle and genetic findings - where they have chosen to do so and provided consent. We consider feedback to fall into three categories, detailed below.

As a research programme, most feedback will be returned in the context of specific research studies:

1. **Supporting informed re-contact:** In some cases, feedback will be necessary when participants are selected for re-contact based on their health-related information. Returning this feedback ensures transparency about the basis for their invitation and enables informed decision-making about participation.

2. **Generating evidence:** Feedback within research studies will also allow us to generate much-needed empirical evidence on the clinical utility and cost-effectiveness of these approaches including how novel types of risk information are delivered, understood and acted upon. These insights will help inform future healthcare delivery and policy.

Occasionally, feedback will be returned to the whole cohort. We refer to this type of feedback as *health insights.* The rationale for providing health insights to the total cohort is:

3. **Reciprocity:** Some participants may see health insights as a tangible personal benefit of participation, making it a reasonable way of recognising their contribution to the programme.

8.3. Examples of participant feedback

Below are some examples of the types of health insights that can be made available to the whole cohort:

(a) Baseline physical measurements (blood pressure, height, weight, waist circumference). These measurements are not a health check and are not, for now, shared with participants' GP or the NHS. We provide health insights to participants who wish to receive it about their blood pressure, cholesterol (if tested) and heart rate on a paper proforma and/or electronically with signposting to NHS resources, or advice to contact NHS 111, a pharmacist or GP in the rare circumstances where that is necessary (i.e. measurements that warrant medical attention immediately or within days e.g. a very low heart rate). The development and piloting of returning measurements digitally is shown in Appendix E.

(b) Questionnaire insights which may include comparisons to healthy recommendations, comparisons to the population, as well as resources participants may wish to consult.

(c) Disease risk assessments using validated clinical risk calculators, such as QRisk3 or the Leicester Diabetes Score, both of which have been extensively validated and demonstrate high clinical utility.

Feedback of items such as those listed in (b) and (c) above will be submitted to REC for approval prior to implementation.

The following are some examples of feedback that would be returned to a subset of the cohort, as part of a re-contact study:

(a) Being invited to participate in a re-contact study based on their genetic or non-genetic data. Where participants are selected due to specific health-related information (e.g. disease risk, family history, clinic measurements), the invitation process may involve feedback.

(b) Being approached by NHSBT if their genotypes suggest that they have less common minor blood group antigens that are underrepresented among NHSBT blood donors. This may be particularly beneficial for minority groups for whom NHSBT sometimes has difficulty providing optimally matched blood products.

(c) Integrated risk scores that provide disease risk estimates. Integrated risk scores may be returned to participants as part of a performance or service evaluation with the NHS exploring clinical utility, feasibility or cost-effectiveness. These scores could include integrated risk scores for cardiovascular disease,[59] age-related macular degeneration, glaucoma, and type II diabetes.

(d) Other examples include risk predictions based on common genetic variants associated with risk of iron overload or deep venous thrombosis.

(e) Variants that influence the efficacy or side effects of prescription drugs as part of a research study.

Feedback to support or facilitate re-contact studies will be submitted to REC for approval.

[59] Natarajan et al (*Circulation*, 2017) Polygenic Risk Score Identifies Subgroup With Higher Burden of Atherosclerosis and Greater Relative Benefit From Statin Therapy in the Primary Prevention Setting

8.4. Principles for all types of feedback

We have conducted extensive consultation with the public and our participants on the topic of feedback as part of re-contact studies and whole cohort health insights, as well as consultation with our Public, Ethics and Scientific Advisory Boards. Based on their input we have refined our principles for the return of health feedback:

- **Clarity**: There must be an explicit purpose and clear, ethical justification for providing feedback which can be easily explained to participants.
- **Harm minimisation:** due care must be taken to avoid participants' distress or harm – both to participants and their families: for example, through offering support or information where feedback is provided.
- **Informed consent:** Participants should be able to choose whether to receive feedback as part of recruitment to any given re-contact study (i.e., to protect their 'right not to know'), have sufficient time to consider the options, and fully understand that it may mean they will not be able to take part in some studies, as well as understand the implications of participation.
- **Careful communication**: Care must be taken in all communications, both to ensure expectations are managed and studies are not viewed as a source of diagnostic information; and that findings are communicated sensitively, with clear explanations of potential uncertainties.
- **Trust**: The trust that participants have placed in Our Future Health should be protected by treating participants with respect, care, and consideration, managing expectations at all points and being clear about the responsibilities of Our Future Health and independent researchers.

8.4.1. Incidental Findings

Our Future Health is a population cohort study. All data collected, including health measurements and genotyping data from the SNP array, are part of the study design and are therefore not considered "incidental findings." The SNP array is used for defined research purposes such as investigating the genetic basis of disease, generating polygenic and integrated risk scores and other analyses relevant to the study's objectives.

Certain devices may, however, produce indications beyond their primary intended measurement. For example, the blood pressure monitor may display a symbol indicating an irregular heart rhythm. In such cases, Our Future Health considers that it has a responsibility to inform participants of the indication, and to advise that they may wish to consult a healthcare professional. Participants will also be directed to relevant NHS resources for further guidance.

As detailed in this protocol, Our Future Health may offer some participants health-related information, such as digital clinic measurements or integrated risk scores, supported by information and care pathways as part of re-contact studies. This approach ensures that participants receive clear, applicable information within the scope of the study, while avoiding the return of findings that are of uncertain significance, or without appropriate support.

8.5. Operational requirements for participant feedback

In addition to the overarching principles, we have identified specific operational requirements that apply when returning different types of feedback. These ensure feedback is delivered safely, ethically, and in a way that protects both participants and the NHS

8.5.1. Requirements for all types of feedback

1. **Validity and utility:** Personal health information of uncertain clinical validity or utility should only be returned with great caution.
2. **Specific consent:** Feedback must only be provided where participants have given additional, explicit consent to receive it.
3. **Immediate results:** It is good practice to provide direct feedback of simple measurements taken at recruitment (e.g. BMI, blood pressure).
4. **Participant diversity:** Not all participants will value individual feedback in the same way. Feedback should therefore be piloted, evaluated, and refined over time.

8.5.2. Requirements for cohort-wide feedback (health-insights)

1. **NHS impact:** Any cohort-wide return of health information has the potential to increase demand on NHS services, particularly general practice. An impact assessment and evaluation plan should be in place before proceeding.

8.5.3. Requirements for feedback as part of re-contact studies

In some cases, feedback is essential to ensure informed consent when inviting participants to a re-contact study. In such circumstances:

1. **Confirmatory testing:** The study sponsor must provide confirmatory testing using a clinical-grade assay, where required. A clear example of an exception is the situation in which the participant already has a documented diagnosis of a condition using a clinical-grade assay.
2. **Support:** Appropriate counselling and clinical support must be available to participants receiving feedback.
3. **NHS preparedness:** NHS services should be informed and prepared for any increase in demand resulting from health feedback given to participants by virtue of them being invited to take part in a re-contact study, or received during the study itself.

For re-contact studies which are taking place in NHS organisations, the study sponsor must demonstrate how costs to the NHS will be recovered. For example, by completion of the NIHR's interactive Costing Tool (for commercial studies involving the NHS), or the Schedule of Events Cost Attribution Tool (SoECAT) (for non-commercial studies involving the NHS). The attribution of costs for the study would be checked as part of HRA and HCRW Approval in England and Wales, or the NHS/HSC permission process in Scotland and Northern Ireland. Where appropriate, evidence of HRA and HCRW Approval or NHS/HSC permission will need to be provided to Our Future Health in advance of participants being invited to take part in a re-contact study.

NHS organisations not directly involved as research sites may also be affected when feedback is given to participants because of inviting them to take part in a re-contact study. For example, if large numbers of participants visit their GP after receiving health feedback. The potential impact

on the NHS will be considered by Our Future Health for each re-contact study. Researchers applying to do a re-contact study with Our Future Health must specify how the potential impact of the study on NHS services and healthcare professionals has been considered.

8.6. Process for selecting and releasing health insights

The process described in this section applies primarily to cohort-wide feedback (health insights) delivered through the Our Future Health participant digital product. Feedback arising from re-contact studies may or may not be integrated into the participant product. Given the need to support multiple studies in parallel, and the varied nature of those studies, it would not be practical or desirable to require product integration for every return of feedback. Doing so could result in a fragmented participant experience comprising unrelated health insights.

Accordingly, the following process is limited to the governance of cohort-wide health insights. It consists of three phases:

- **Identification and scoping** – A health insight is proposed, and evidence is gathered on how it should be developed and delivered.
- **Design, validation and pilot** – The health insight is designed and tested. Its acceptability, utility, and safety are evaluated through user testing and pilot release to a limited group of participants. User testing will adhere to the limitations set out in the 'Boundaries and ways of working document (Appendix C). Impacts on behaviour, health outcomes, and NHS services are assessed.
- **Cohort-wide release and monitoring** – The validated health insight is made available to all eligible participants who wish to receive it. Ongoing monitoring is undertaken to assess impacts on participant behaviour, health outcomes, and NHS services.

It will be necessary for both the cross-functional teams delivering this work and external stakeholders affected by it to align on the processes and decisions involved; we are in the process of working out how best to do so.

8.6.1. Health insight release decisions

Evaluation during the product development lifecycle will enable teams to assess the acceptability, utility and safety of health insights. Evaluation during product development will encompass a range of qualitative and quantitative methods (e.g. surveys; semi-structured interviews; unmoderated user testing) and will aim to validate our assumptions about how feedback is viewed and used by participants.

8.6.2. Safe cohort-wide distribution

We are committed to evaluating the impacts of newly developed health insights on volunteers' behaviours, patterns of health service use, and health outcomes. Doing so will be important to ensure that the distribution of health insights does not negatively impact the NHS. Such evaluations would be expected to take place in two main ways:

1. *Pilot studies*, in which we limit the allocation of a new health insight to a small number of participants and measure pre-specified outcomes. The goal of a pilot study is to help us

determine whether a specific feedback item is safe, and whether it should be offered to the wider cohort.

2. *Monitoring studies*, in which we distribute a new health insight item to all eligible members of the cohort who wish to receive it and regularly monitor pre-specified outcomes. The goals of a monitoring study are to validate our assumptions about the impacts of widespread health insight distribution, and to help us decide if and when a health insight should be decommissioned.

In either case, measured outcomes will vary depending on the nature of the health insight. For example, outcomes might include engagement (i.e. whether participants clicked on links or content), user behaviours (e.g. completing the next step in an intended user journey; intention to join re-contact study), or health outcomes (e.g. GP appointments made; new diagnoses). The Evaluation and Governance Framework will help us decide what evaluation is necessary for new health insights prior to cohort-scale deployment, according to the risks to participants and the NHS. Delivering on this commitment will require close collaboration with the NHS and we may build partnerships for evaluation.

9. Re-contacting participants for further research

Our Future Health will facilitate a re-contact service to invite selected participants to take part in health research studies and clinical trials. These will be referred to as 're-contact studies'. Re-contact studies will be sponsored by external organisations including academia, NHS, charity or commercial organisations. The rich dataset held by Our Future Health will enable risk-stratified recruitment on a large scale, enabling researchers to undertake precision research in a more efficient and cost-effective way than with traditional approaches.

The provision of re-contact studies is underpinned by an Our Future Health re-contact policy.

9.1. Background on re-contacting participants for further research

We define *re-contact studies* as the recruitment of Our Future Health participants into further research studies led by external sponsors. By contrast, activities such as inviting participants to complete additional questionnaires, provide further samples, consent to further data linkages, or contribute new types of data (e.g. from wearables) are considered *cohort enrichment*.
Most prospective cohorts enable participants to continue contributing to core data collection. However, recruitment into external studies is less common, risk-stratified recruitment is rare, and offering new health information (feedback) as part of an invitation is novel.

For example, although 1% of UK Biobank access applications are to re-contact participants into third-party studies, UK Biobank participants "consented on the understanding that no results would be fed back to them following their assessment visits" and so "care is taken to ensure that re-contact does not represent implicit feedback of which participants are not aware". [60] UK

[60] Conroy et al (2019) The advantages of UK Biobank's open-access strategy for health research.

Biobank further states that "recruitment based on genotype or on phenotype that is not explicitly self-reported by the participant is highly restricted."[61]

There is however some precedent for risk-stratified (recall-by genotype, phenotype or a combination) approaches to re-contact. For example, within East London Genes and Health (ELGH)[62] (e.g., ELGH familial hypercholesterolemia 'genotype-first recall' study[63]), within NIHR BioResource[64] (e.g., the IBD BioResource Protocol[65]), and within Avon Longitudinal Study of Parents and Children (ALSPAC)[66] (e.g., recall-by-genotype study of CHRNA5-A3-B4 genotype[67]).

9.2. Rationale for re-contacting participants

Re-contacting participants for further research is an important step for Our Future Health in supporting the development of new ways to prevent, detect and treat diseases by catalysing participation in UK clinical trials. This forms part of the UK Government's 10 Year Health Plan for England[68] and the Life Sciences Sector Plan[69].

The need to establish studies at the scale required, tracking participants and data over long timeframes, whilst maintaining adequate levels of follow-up, limits all health research sectors in early detection and prevention research. Cohorts of participants with specific genotypes or phenotypes are difficult to scale and are often not available for a range of conditions. Further, gathering the evidence base for a personalised medicine approach is challenging and expensive. Our Future Health is uniquely placed to provide a motivated and research-ready cohort of participants who are representative of the UK adult population. Our rich genotype and phenotype datasets, including linkage to health-related data and health records, will enable the selection of participants for re-contact studies with precision and efficiency. This will allow researchers to better identify what screening tools, diagnostic tests and treatments work best for whom, when and how, without having to recruit at a cost-prohibitive scale.

9.3. Types of re-contact studies

We will support a broad portfolio of re-contact studies, covering prevention, detection and treatment of common and rare health conditions. Re-contact studies could be of any

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[61] UK Biobank's re-contact procedures for third party researchers. https://www.ukbiobank.ac.uk/wp-content/uploads/2018/05/ukb-recontactprocs-14.3.2018-item-5b-2.pdf

[62] Finer et al… & van Heel (2019) Cohort Profile: East London Genes & Health (ELGH), a community-based population genomics and health study in British Bangladeshi and British Pakistani people.

[63] ELGH genotype-first recall to study extreme genetic risk of atherosclerotic cardiovascular disease. http://www.genesandhealth.org/research/research-studies-approved/s00013-genotype-first-recall-study-extreme-genetic-risk-atherosclerotic

[64] https://bioresource.nihr.ac.uk/

[65] https://www.ibdbioresource.nihr.ac.uk/wp-content/uploads/2017/01/protocol-V6.pdf

[66] https://www.bristol.ac.uk/alspac/

[67] Ware, Timpson, Davey Smith, Munafo (2014) A recall-by-genotype study of CHRNA5-A3-B4 genotype, cotinine and smoking topography: study protocol

[68] https://www.gov.uk/government/publications/10-year-health-plan-for-england-fit-for-the-future

[69] https://www.gov.uk/government/publications/life-sciences-sector-plan

methodology, including but not limited to, a questionnaire study, a sample collection study, longitudinal observational study, or a randomised controlled trial (RCT).

However, from an Our Future Health perspective, re-contact studies will be broadly categorised based on the factors upon which participants are selected to be invited to participate. Of particular importance is whether the participant will learn new information about themselves as part of the invitation to a re-contact study, and if they will, the requirement to obtain consent to receive that information (in line with the participants original consent to take part in Our Future Health). To enable clear communication and design the optimal invitation materials and strategy for participants, we will also consider factors such as how easily a participant is likely to be able to understand the new information, the perceived seriousness of the information, the certainty of the new information (e.g., if the new information is a derived risk of a condition, how robust the evidence base is for the risk) and the likelihood of developing the condition (i.e., how high is the risk).

At one end of the spectrum, participants will be selected based on a random sample from the Our Future Health cohort, or on relatively simple criteria known to them and easily understood, such as age, sex, or self-declared lifestyle factor. At the other end of the spectrum, participants could be selected based on information that is unlikely to be known to them and is complex to communicate. This could include being selected using a genetic risk-stratification approach. In addition, the re-contact studies themselves will vary in complexity of design and how complex they are to communicate to participants and the wider public. Table 5 shows the factors which impact on the complexity of communicating a re-contact study to a participant. A re-contact study could involve any combination of factors across the 'Selection criteria', 'Likelihood of awareness' and ''Perceived seriousness' columns.

Table 5. Factors which impact the complexity of communicating a re-contact study to participants

Factors which impact the complexity of communicating a re-contact study to participants		
Selection criteria	**Participant - likelihood of awareness**	**Participant - perceived seriousness**
• Cohort-wide • Random selection • Demographics • By phenotype • By genotype • By combination of phenotype + genotype • By risk score	• Of the factors upon which they were selected • Of the health condition of study • Of their individual risk of the health condition	• Of the health condition of study • Of the intervention(s) being studied

9.4. Our Future Health re-contact study approval

Every re-contact study proposed by an external research organisation will be subject to approval from the Access Board and will require approval from a Research Ethics Committee both for the study and for Our Future Health to send out invitations to participants. Our Future Health will develop templates and boundaries to streamline REC approvals for re-contact study invitations

when the programme is scaling up such studies in the future. Pilots to inform the development and optimisation process for re-contact studies will be carried out (Appendix F).

9.4.1. Method of contact and participant preferences

Re-contact study invitations may be sent using a combination of postal letter, email, SMS text message, participant dashboard notification or other relevant means. Participants in the cohort will be reminded as part of routine communications that they can update their personal contact details in their Our Future Health online account.

We will provide a digital participant dashboard within the participants' Our Future Health account portal that provides details of re-contact studies. Where relevant, consent will be sought to receive new information as part of the invitation to a re-contact study, and consent to be contacted by the external study team about the study. Multiple study opportunities may be available on the digital dashboard.

If a participant does not respond to an initial invitation, we will send an appropriate series of reminder prompts using either postal letter, email, SMS, invitation on the participant portal (or a combination of) or other relevant means. Where the participant is eligible to take part in multiple studies, we will manage outreach appropriately and respectfully according to the notification preferences they have set.

9.4.2. Ethics and regulatory approval for re-contact studies

The Our Future Health Ethics and Governance Framework (EGF) provides guidance on our approach to ensuring the research programme adheres to ethical principles and protects the rights, safety and wellbeing of participants.

There will be a clear division of responsibility between Our Future Health and the external re-contact study sponsor for the development of study materials, obtaining the necessary ethical and regulatory approvals, and providing participant support.

Our Future Health will seek ethical approval from the Cambridge East REC for invitation, relevant consent, and study-specific engagement materials disseminated by Our Future Health.

The external re-contact study sponsor will obtain all necessary ethical and regulatory approvals for the delivery of the study, including approval for the study protocol and informed consent materials for taking part in the study. The external sponsor will be responsible for obtaining informed consent from the participant for taking part in the study. Where health feedback is returned as part of the invitation process, the study sponsor will have additional requirements as detailed in Section 8.5.

We will complete a "green light" readiness check for each re-contact study to ensure all necessary access board, ethical and regulatory approvals are in place prior to sending invitations to participants.

9.4.3. Participant and Public Involvement and Engagement (PPIE) for re-contact studies

PPIE is integral to the Our Future Health programme (see section 13). In the context of re-contact, we have undertaken a deliberative dialogue, and subsequent extensive PPIE and design research on our invitation strategies, with a diverse selection of our participants. These activities have

shaped our approach to inviting participants to re-contact studies – including where new information could be shared as part of those invitations. We will continue to work with participants – including those who advise us as members of our Participant Advisory Board and our Involvement Network – as we offer more re-contact studies to members of the Our Future Health cohort, to ensure that our approach is, and remains, optimal.

We encourage external re-contact study sponsors to embed PPIE into the design and conduct of their study, in line with HRA guidance. We will utilise the PPIE undertaken by the research team to inform the strategy for the re-contact study invitations.

10. Participant communication and withdrawal

Our Future Health may contact participants using a variety of contact methods, e.g. by letter, email, text message. Participants will receive essential communications about their involvement in the programme. These may include, for example, reminders to book appointments, complete questionnaires, invitations to view feedback and receive information about—or invitations to—re-contact studies.

Participants are given the choice if they wish to receive marketing communications, such as newsletters. Participants can opt-out of marketing communications via their Our Future Health account or through unsubscribe links in the marketing materials.

10.1. Participant Withdrawal from programme

At the time of providing consent, participants are informed that they can withdraw from the programme at any time without providing a reason. If a participant chooses to withdraw from Our Future Health, they are given two options:

- "Partial withdrawal"
    - Our Future Health will no longer contact the participant and will delete all identifiable data from the participant record
    - Our Future Health will retain permission to use de-identified information and samples provided previously
    - Our Future Health will unlink external datasets, but will retain historical data in a de-identified form
- "Full withdrawal"
    - Our Future Health will no longer contact the participant
    - Our Future Health will not obtain any further information on the participant and will destroy all data and samples related to this participant (with the exception of existing models or analyses that were created using their de-identified records)*
    - Data and samples for the participant will not be made available for new research projects.**

- It won't be possible to remove their samples or data from any research that started before the withdrawal.

*Participants are told that it is not possible to delete their data or remove their samples from any research that has already started. Such a withdrawal will prevent information about them from contributing to further analyses, but it would not be feasible to remove their data from analyses that had already begun using an existing data release.

** Participants are also told that this may not happen immediately as data is made available to researchers in a series of releases; we anticipate that new releases will be made on a quarterly basis. Their data will not be included in new releases but there could be a period of up to six months (factoring in preparation time) when their data could be included in the current release of the data after withdrawal.

When a participant withdraws, either partially or fully, they will not receive any further communications from Our Future Health. This includes not receiving any feedback or invitations to take part in re-contact studies. When a participant withdraws from Our Future Health, they will remain in any re-contact studies to which they have consented. If they wish to withdraw from any re-contact studies they must request withdrawal directly with the study.

Participants who do not have internet access will contact the Our Future Health support team to request a withdrawal form. Once verified, an approved member of the team will make the required changes in the database and, where appropriate, initiate data deletion and sample destruction.

11. Access process

Keeping our participant data safe is of critical importance to Our Future Health. Our researcher registration, access and accreditation processes work together to help us do this and are underpinned by the principles of the 'Five Safes' framework: safe data, safe projects, safe people, safe settings, safe outputs. This framework has become best practice in data protection whilst fulfilling the demands of open science and transparency.

Researchers apply to the Our Future Health Access Board to access data, samples or to re-contact participants recruited through the research programme. Access Board members include experts, members of the public and participants.

Detailed information about the Access Board, and the access process are kept up to date on the Our Future Health website.

11.1. Key principles guiding development of Access Process

The principles detailed below were developed with public members of our Access Board, the Ethics Advisory Board and the Founders Board and guided the development of the Access Process

1. The access procedures will be as simple as possible, and the decisions will emerge in a timely fashion. The objective is to maximise responsible use of the dataset, not to unduly guard it for the benefit of a restricted user group.
2. The key principles underpinning these access procedures are the granting of data, samples and/or re-contacting of participants i.e. the Our Future Health resource to suitable research projects and to ensure that in this manner, the resource is used extensively, in a responsible and useful way to benefit society as widely as possible.
3. Access to the Resource will be underpinned by the principles of the Five Safes: safe data, safe projects, safe people, safe settings, safe outputs.
4. The Our Future Health Access Board is responsible for access to the data, samples, and participants. All data policies, access policies, and information relating to how the data is managed and accessed has been made publicly available to ensure transparency and disclosure.
5. These access procedures reflect the value of the resource and the undertakings given to the participants when they joined the programme.
6. Our Future Health will continue to interact with participants, researchers, and society in general to maximise engagement and interest throughout the resource's lifetime (which is intended to be some decades) and ensure that the research projects that are taking place as well as the findings that result from those projects are publicised with a view to generating further interest and maintaining the initiative's momentum.
7. Researchers who are granted access to the resource for an approved research project will be required to return their results to Our Future Health and to publish their findings so that other researchers can use and build on this knowledge to further benefit the public interest (public health benefit). Full details will be included in the Our Future Health Publication Policy.
8. In order for a research project to be approved, the researcher will need to demonstrate that their research will provide knowledge, further scientific understanding and that it meets our definition of public health benefit.
9. The process for applying to use the resource has been designed to be efficient but robust. Data and/or samples will be provided in an expeditious manner once projects are awarded and the required documentation has been signed and approved, to enable research to begin in a timely manner.
10. Our Future Health will maintain an up-to-date list of registered researchers and their affiliations. Organisations conducting research studies will ensure compliance with security and information governance accreditations, as determined by Our Future Health over time.

11.2. Safe People

Only trained and registered researchers access the data within a trusted research environment. The researcher registration process checks the credentials and experience of each researcher and ensures they are trained in information governance. Registered researchers are required to agree to the Our Future Health terms of use.

11.3. Safe Projects

11.3.1. Study application process

Registered researchers apply to the Our Future Health Access Board to access data, samples or to re-contact participants recruited through the research programme. The study application process

ensures only health-related research is approved that is in line with the consent participants provided, is for public benefit and is aligned to Our Future Health objectives. Researchers will need to detail the purposes for which they want to use the data which may range from a fairly narrow hypothesis to exploratory studies that may assess a variety of factors. They are approved for a fixed and agreed period of time. Researchers are required to notify us of any changes by submitting an amendment to their approved study.

All applications to use Our Future Health resources for research are held to the same standards by the Access Board. This is the case whether an application is from Our Future Health partners, industry, charity or researchers at universities, government or the NHS.

Compliance with the agreed terms of access is monitored. A process is in place to review, investigate and proportionately deal with non-compliance (for example, by imposing restrictions on future access).

11.3.2. Access Fees

There are fees to access to the Our Future Health resources. The fees that apply will be dependent on the type of organisation(s) involved in the study and will differ between commercial research and non-commercial research (e.g. academics or charities). Lower fees may be offered to, for example, early career researchers or applications from lower- to middle-income countries. The principal aim of this fee is to cover the costs of any sample and/or data retrieval, preparation and analysis required for the particular research use and to help cover the costs of maintaining the resource for future users. It will support the long-term sustainability of the Our Future Health programme. Fees will be reviewed regularly to ensure that researchers from different sectors and with different approved research interests are able to fairly access the data.

In addition, researchers are billed their own cloud computing and storage costs within the Our Future Health Trusted Research Environment (TRE). Given the flexible nature of research, demands on computing resources will differ. This approach allows for more intensive research techniques such as machine learning but leaves the choice to the researcher as to how much to spend.

11.4. Safe Settings

Registered Researchers can only access Our Future Health data in an accredited TRE. TREs offer a highly secure computing environment, where researchers can access and work with de-identified data.

11.4.1. Trusted Research Environments

The success of Our Future Health rests on the research and science that is conducted with the data and the cohort, but this must be balanced with our strict security and confidentiality commitments. The best way to balance these needs is to provide a TRE within which to access de-identified data.

The evolving policy landscape in the UK is moving towards the use of TREs (also known as Secure Data Environments or SDEs) as safe shared spaces for data analytics that prevent the data from leaving. The UK Health Data Research Alliance (representing many major health data organisations in the UK including UK Biobank, the NIHR BioResource, NHS England, UK Health Security Agency,

Genomics England and many key hospitals and charities) "is committed to an approach to data access based primarily around trusted (trustworthy) research environments; with appropriate robust and independent TRE accreditation, monitoring and auditing,"[70] and this commitment is echoed in the UK genomics strategy[71] and the Sudlow Review[72].[7374]

The Our Future Health TRE provides a wide variety of computation and data storage resources as well as analysis tools for clinical, genetic and other data types, to serve the needs of researchers from many disciplines. Each study has a separate allocated workspace within the TRE.

11.5. TRE accreditation process

We have developed a robust accreditation process to ensure that any TRE hosting Our Future Health data meets the necessary standards of data governance and cyber security, as well as operational, privacy and technical requirements. All TREs must successfully complete this process and achieve accreditation before they can receive Our Future Health data. All the same rules and controls apply to any TRE that is accredited to receive Our Future Health data. This includes the rules on researcher registration, Access Board study approval, and the strict controls around what data may be removed from the TRE. Data will only be transferred to an accredited external TRE for the purpose of their approved study for an agreed period of time. All applications for accreditation are reviewed by an independent, third-party assessor. This will make sure that decisions are fair and impartial.

The Our Future Health accreditation process was developed in 2022 with legal, data governance and security experts and in close consultation with others in the wider health research community, including our charity and industry partners; research organisations; government leads in all UK nations; the NHS; the Information Commissioner's Office; our own Public Advisory Board and members of the public. Our Future Health's Technology, Scientific and Ethics Advisory Boards, and a specific Technology Task Force made up of experts from across the life sciences sector, have provided input throughout.

Our Future Health also participated in the Information Commissioner's Office (ICO)'s Regulatory Sandbox, a service that supports organisations which are creating products and services that use personal data in innovative and safe ways. This allowed us to draw on expertise and advice from the ICO.

The process is based on well-established and well-regarded standards and frameworks, such as the Office for National Statistics Five Safes framework, the UK GDPR, and international cyber security standard ISO 27001.

[70] Trusted Research Environments (TRE), A strategy to build public trust and meet changing health data science needs, Health Data Research UK Green Paper, July 2020
[71] Genome UK: the future of healthcare, UK Government Office for Life Sciences, Sep 2020
[72] The Sudlow Review: 'Uniting the UK's Health Data: A Huge Opportunity for Society', November 2024

11.6. Safe Data

All data in the TREs is robustly de-identified to protect the privacy of participants while maintaining its scientific and research value.
Comprehensive data dictionaries and metadata are maintained by Our Future Health and made available for researchers to use. Provenance and traceability of all data items are recorded and made available for researchers.

Wherever possible data is structured and coded using commonly used standards to allow for broadest use of the data, in the public interest.

11.7. Safe Outputs

11.7.1. Statistical Disclosure Control (SDC)

There are strict technical and security controls, as well as operational and governance processes, that determine what research outputs data can leave the TRE. This is to minimise the risk of research outputs data that can identify an individual participant leaving the environment. These include strict data export rules agreed to as part of a legally binding contract and independent checking (auditing) of data exports.

We use a combination of SDC rules and principles. SDC rules provide a clear set of guidelines for researchers, while principles give us the flexibility to respond to new situations.

11.7.2. Airlock

Researchers using Our Future Health's TRE are required to use an 'airlock' to request export of their research outputs. The airlock process facilitates a review of requested research outputs by an Our Future Health airlock manager, ensuring that the export abides by SDC policy. The process will undergo continuous review to ensure we have a process that can scale up appropriately.

11.7.3. Dissemination of results, outputs and publications

Researchers who use Our Future Health are required to disseminate the results of their research as rapidly and widely as possible, subject to ethics and confidentiality considerations. They are encouraged to discuss their research findings with other scientists and the public, and to share relevant data and materials as openly as possible.

Researchers must inform Our Future Health of any upcoming publications or other publishing of research outputs resulting from the use of the resource (for example, published reports and pre-prints). Research outputs are expected to acknowledge Our Future Health participants, and a copy of the final output must be provided along with a summary of findings.

11.7.4. Dissemination and return of results

Researchers are required to provide Our Future Health with a copy of all of the results of their research based on the resource (including any negative findings and relevant supporting data) for incorporation into the TRE.

Researchers who have had access to samples will be required to provide details of the assay techniques used and return the results to the Our Future Health resource within 9 – 36 months of approval.

A limited delay prior to the return of findings to the Our Future Health TRE will be permitted, in order to e.g. enable a paper to be published; a patent to be filed; or other competitive advantage to be pursued. Depending on the research organisation's membership status, an exclusivity period can be agreed for up to 36 months and will require review by the Access Board.

11.8. Our Future Health data access

Our Future Health staff will use the resource for research purposes and for business processes. Below we define each of these activities, provide example use cases, and outline the governance and security requirements that keep participant data safe.

11.8.1. Our Future Health Research Activities

Our Future Health research activities are where the primary motivation is to use participant data to directly generate and disseminate generalisable knowledge to further scientific understanding. Examples include:

- Commissioned/contracted research in which Our Future Health are the lead or a collaborating research entity
- Rare occasions when Our Future Health is conducting a study in which the primary purpose is to generate generalisable knowledge to enhance scientific understanding and publish in a peer reviewed journal, book chapter, or external report

The standard Access Process applies to all such Our Future Health research studies.

11.8.2. Our Future Health Business Processes

Our Future Health business processes are where the primary motivation is to use participant data to support the development, improvement and operational delivery of the Our Future Health programme, including the *enablement* of research activities conducted by third-party research organisations. Examples include, but are not limited to:

- Improving our products and services, for example improving the user experience,
- Supporting the efficient and effective operation of the organisation, for example by producing and sharing key metrics and identifying opportunities for improvement and learning from these
- QA/QC of data / assessment of beta data
- Development of data product pipelines
- Analytics to support, document and assess data products during development and after release
- Testing new methods for internal analysis and to develop or enhance data products
- Comparison of OFH prevalence data to results from other datasets to assess the representativeness of our data, in support of our diversity goals
- Developing new algorithms to generate additional exposure metrics or indicators of population health
- Generating feasibility counts for potential researchers

- Generating summary data for various types of publications to advertise the resource
- Generating population health insights and results to attract new users
- Audit
- Clinical audit to support digital clinical safety investigation or complaint or potential product failure
- Processing data for security purposes
- Processing data for withdrawals
- Development and testing of population health dashboards

Our Future Health business processes will not require approval by the Access Board. However, they may be subject to other internal review and approval processes which will provide data privacy and security assurance, accountability and transparency for audit purposes, as well as to ensure that these business processes remain within scope, as described herein. Business processes can include operational data, non-releasable data, beta data, and new data that has not yet been released for general research use by research users. To conduct these activities, Our Future Health will use appropriate secure environments intended for the relevant purposes. Analyses for business processes will observe the relevant checks and guidance on statistical disclosure control (SDC) prior to releasing any outputs.

11.9. Dissemination of aggregated (non-personal) population health insights

Questionnaire data, clinic measurements and linked health records and administrative data can be analysed for different populations, broken down by various demographic indicators such as age, sex and geographical area, in order to produce aggregated, de-identified, population health insights for surveillance.

Our Future Health may share these insights with public bodies to improve public health and inform policy; participants via news and updates; researchers and the public via scientific and clinical publications; as well as being used in press releases to encourage participation in the programme from potential participants; and share internally to support development and operational delivery of the programme.

Our Future Health plans to develop analytical dashboards generating (aggregated non-personal) population health insights to support population health management by local public health teams, health planners and policy makers who are less likely to have the time and resources necessary to query data in the TRE to help with their local, routine, health planning. The dashboards could include data visualisations such as maps and charts, that can be used by non-technical users such as health planners and policy makers from a variety of backgrounds. The dashboards in this instance might focus on reporting the main causes of mortality and morbidity in the UK: cardiovascular disease, cancer, mental health, diabetes, liver disease, respiratory illness and multiple long-term conditions. In addition, the dashboards will report incidence and prevalence of common risk factors such as smoking rates, alcohol consumption, physical inactivity, hypertension and vaping rates. In the event that we develop these resources we will establish the appropriate governance.

12. Digital data and platform

12.1. Overview

The Our Future Health programme is enabled by a set of digital platforms. These include:

- **Participant platforms**, including our main Our Future Health public web site and systems powering registration, consent, appointment bookings, questionnaires, reminders and emails, support requests, biosample management, associated analytics and business intelligence, personalised health feedback and future systems for invitations to re-contact studies or requests for additional information
- **Data platforms**, including the ingestion, storage and processing of data (questionnaire data, NHS data, genetic data), quality control, linkage to NHS records, processing of withdrawals, creation of data products including de-identified datasets for release to researchers
- **Researcher platforms**, including registration, applying for access, billing, data and systems documentation, emails and communications, our trusted research environment (TRE) and associated data transfers, the airlock for safe data import and export

These platforms are underpinned by comprehensive security controls, monitoring, incident management, backups, management of cloud infrastructure, data governance, quality management and other operational systems and processes.

The remainder of this section will focus on three capabilities that are most relevant to this protocol.

12.2. Consent and participant withdrawal

Participant consent is described above (Section 4.6). From a technical perspective the consent functionality is designed to collect and store the date, time and version of consent.

An operational record will be retained of a participant's previous consent and subsequent withdrawal, for audit purposes, only accessible to very limited technical staff. A secure copy of each research data set is retained by Our Future Health for troubleshooting and archival purposes. The data held within each data set is de-identified and held in secure cloud storage.

12.3. Data linkage

Section 6 above describes the data sets that Our Future Health will be linking with.

- Linking to central NHS data from England happens within an NHS England environment, as part of a pipeline of processes prior to data being loaded into a trusted research environment. Our Future Health provides NHS England with participant information so that the corresponding health records can be identified and provided back to Our Future Health. These records are stored in our data platform separate from direct identifiers, quality assured, curated, and made available for the research purposes in the manner described above.

12.4. Security and resilience

Information security is a key concern for the programme. The Our Future Health baseline for cyber security is the ISO27001 standard, to which we are certified. We also hold Cyber Essentials Plus certification and meet the NHS Data Security and Protection Toolkit standard.
We employ a range of security controls to protect sensitive data. These include preventative controls such as identity and access management for internal users and for external users (i.e. participants, researchers, etc.), secure configuration of our technical systems, cryptography to ensure data is encrypted at rest and in transit and the embedding of security into our application and system development processes.

They also include detective and responsive controls such as our 24/7 Security Operations Centre, our threat team who proactively 'hunt' for signs of malicious activity and our incident response processes.

In relation to participant data, we have further controls such as pseudonymisation to minimise the risk of reidentification.

We not only secure our own organisation but operate a comprehensive third-party security management programme to ensure that our suppliers and third parties are equally diligent in their security.

Finally, we continually assess and assure the effectiveness of our controls, including through independent testing and auditing. Any issues or opportunities for improvement are fed into our continuous improvement plans so that we continually evolve and mature our security.

13. Participant and public involvement and engagement (PPIE)

13.1. Rationale for PPIE

Undertaking PPIE ensures that our participants' – and the public's – opinions, preferences, concerns, hopes, and expectations are considered and reflected in the design and delivery of the programme. This includes helping us to shape:

a) Recruitment pathways that are feasible, relevant, accessible, and inclusive for the UK public
b) Participant-focused policies and procedures
c) Our offers of health-related feedback, health insights, or re-contact studies to our participants
d) The experience of participating in Our Future Health
e) The communication of research findings and discoveries to participants and the public

13.2. PPIE strategy

We are committed to upholding best practice in PPIE through adopting and applying the following nine principles that underpin our PPIE strategy (our strategy is openly accessible on our website):

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.

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

13.3. Our Future Health PPIE structures

Our Involvement Network also allow us to bring PPIE activities to members of our cohort, and the public on an *ad hoc* basis. Our PPIE is further supported by the advice and steers we receive from our Participant Advisory Board, which is an embedded part of our governance structure (see section 14 below).

13.4. Our Future Health Involvement Network

We have established an Involvement Network to facilitate and embed the involvement of participants, and members of the public who are not taking part in our programme, in our PPIE activities, so that their perspectives can shape our work.

13.4.1. Guiding principles for the Our Future Health Involvement Network

When working with the Involvement Network, Our Future Health:

i. Offers members the opportunity to take part in activities in a timely way, and at a stage when their opinions and perspectives can be meaningfully considered.
ii. Reflects on and considers members' contributions, perspectives, and opinions.
iii. Ensures that members who take part in an activity are informed of whether, how, and at what point it is possible to withdraw from any activity; or from the Involvement Network as a whole.
iv. Avoids over-promising, through communicating clearly to members what their contributions might, or might not, lead to.
v. Reports back to those who have been involved, to form a feedback loop.
vi. Ensures that activities are accessible and accommodate people's needs as far as is practicable.

13.4.2. Consenting to take part in the Involvement Network

When members join the Involvement Network, they are asked to read an information leaflet which gives them details about the group and how they will be supported. Once they have read this form, they are invited to sign a consent form. After joining the Involvement Network, members are asked to re-sign the consent form annually. If members are asked to contribute to any publicity about the Involvement Network, they are asked to sign a separate consent form for the use of their quotes, pictures, or video.

13.4.3. Membership

Membership of the Involvement Network is limited initially to people who have taken part, or expressed interest in, previous PPIE with Our Future Health. However, the members of the Involvement Network may grow in time.

13.4.4. Activities

Involvement Network members are offered opportunities to take part in activities to support the design, delivery, and development of the Our Future Health research programme. Activities include workshops, surveys, focus groups, dialogues, and written feedback. Activities may be online or in person.

Members are invited to indicate if they would like to volunteer to take part in each activity offered to them. However, in the information leaflet that members receive when they join the Involvement Network, it is made clear 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).

13.4.5. Confidentiality

Members are asked to sign a confidentiality agreement when joining the Involvement Network, as some of the activities may include information that is not ready to be shared in the public domain at the present time.

13.4.6. Withdrawing from the Involvement Network

The information leaflet that members receive when they join the Involvement Network makes clear that they can withdraw from the group at any time; and do not have to give a reason for doing so. Withdrawing from the Involvement Network does not affect members' participation in the wider Our Future Health research programme.

13.5. Participant Advisory Board

Our Participant Advisory Board (formerly called the 'Public Advisory Board) is a core part of our governance structure (see Section 14) which provides advice and oversight of aspects of our research programme that have, or could have, an impact on participants' interests.

We have an annual review process with our Participant Advisory Board to ensure that we can reflect on whether we are continuing to support this Board optimally.

Participant Advisory Board members whose period of tenure ends are all invited to join our Involvement Network.

13.6. PPIE methodologies

We draw on a range of engagement and involvement methods to ensure that our participants, and members of the public, can shape our programme.

13.6.1. Deliberation and dialogue

We draw on deliberative methods and dialogue approaches to explore participant-focused issues with our participants and members of the public. As appropriate, we commission external agencies to deliver these deliberative dialogues, while working closely with those agencies throughout the duration of the project. This has included us commissioning the delivery of two deliberative dialogues on how we might offer feedback to our participants; and invite them to consider taking part in re-contact studies, respectively.

Where participants and members of the public take part in deliberative or dialogue projects, we endeavour to give them an option of continuing to be involved in our PPIE activities through inviting them to consider joining our Involvement Network.

13.6.2. User-centred research and behavioural science methods

We are committed to ensuring that our programme meets the needs, preferences, and requirements of our participants, and potential future participants. We practise a participant- and public-centred approach through drawing on cross-cutting methods including:

- Focus groups
- Co-design
- Co-creation
- Interviews
- Surveys

This allows us to listen to, and act on, people's thoughts and attitudes with respect to the key components of our programme: participant recruitment; research and data platforms; and feedback, engagement, and re-contact.

13.7. Direct participant involvement in public-facing contexts

We offer opportunities to some participants to contribute to the development of videos, articles, photos, or other media; or appear in such materials. Where these opportunities arise, we only involve participants who have given specific consent to contribute to, or appear, in this way.

Participants are invited to take part in these opportunities in a range of ways, including when they attend their Our Future Health appointments, via email, or when they contact Our Future Health via social media channels and other forms of correspondence. Participants are given a consent form to read and sign before they are involved in any such activities.

14. Governance and compliance

14.1. Governance

The Our Future Health research programme is organisationally complex, receives funding and income through a range of sources and is required to work in partnership with various aspects of the NHS and across all nations of the UK. As such, it is critical that we have an appropriate governance structure that enables the programme to take effective and timely decisions but also provides opportunities for consultation with stakeholders and advisers, which requires us to have agile approaches to programme governance. Given the pace of developments in the genomic, digital, data and analytics areas, the programme must have the flexibility to respond to emerging opportunities and capitalise on innovations and novel research, as well as respond rapidly to new and emergent threats to data security, integrity and participants' wishes.

The programme also requires robust governance to ensure legal compliance, the security of data and privacy of participants, and to meet and exceed the expectations of the participants in order that we create long term relationships with the programme which are built on a bedrock of trust. It is also vital that we build into our plans the ability for participants to have meaningful interactions through the digital interfaces and provide effective support, information and reassurance where required. See **Figure 3**, below:

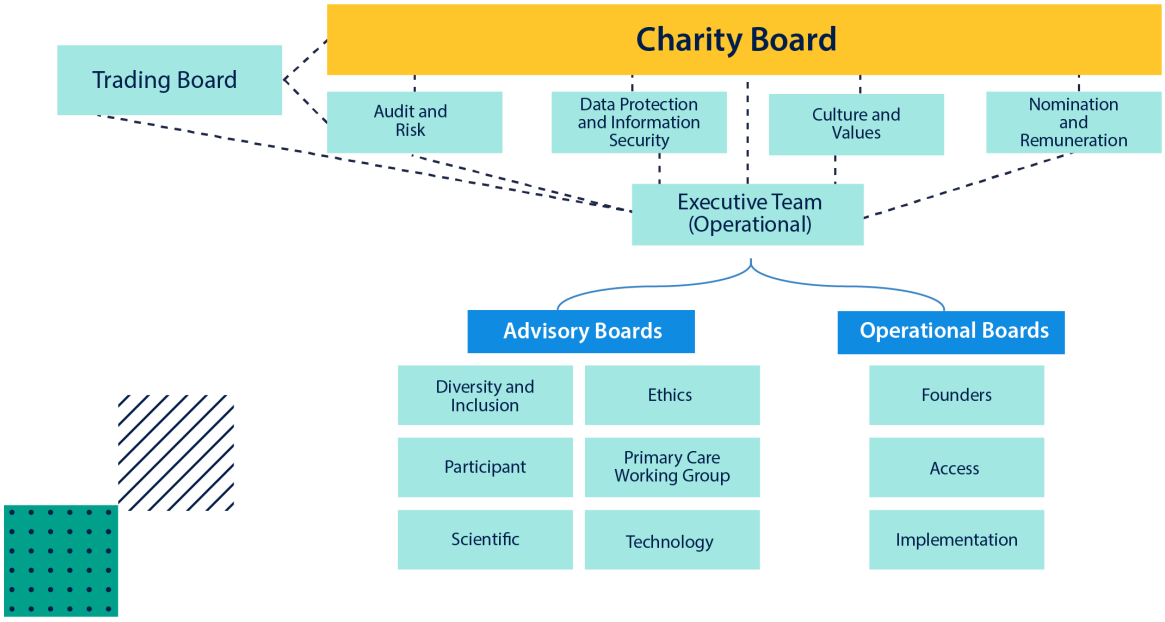

Figure 3. Our Future Health Governance structure

The governance model comprises a number of advisory and operational boards. The function of these groups is to advise the Our Future Health Executive Team and the Our Future Health Board. The Access Board will be responsible for access to data, samples and participants and will report to the main Board. From time to time the programme may also establish task-focussed and time-limited working groups, as required.

To promote coordination there will be some cross membership between the different governance structures, where this is appropriate; for example, the views of the public and participants will be intrinsic to the skills profile of a number of advisory boards and the Access Board.

14.2. Compliance

We are committed to upholding the highest standards of compliance, assurance and continuous improvement. We do this through a programme of quality assurance that includes risk and incident management, third-party assurance, internal and external audit, document control, corrective and preventive action, and organisational improvement.

In addition, we have achieved a number of certifications and accreditations, including ISO 27001, Cyber Essentials Plus, and the NHS Data Security & Protection Toolkit, thereby supporting the organisation's commitment to security, quality, and public trust.

Our
Future
Health

Our Future Health is a company limited by guarantee registered in England and Wales (number 12212468) and a charity registered with the Charity Commission for England and Wales (charity number 1189681) and OSCR, Scottish Charity Regulator (charity number SC050917). Registered office: 2 New Bailey, 6 Stanley Street, Manchester M3 5GS.

Our Future Health

Appendix A: Estimated number of Incident Diagnoses in Initial 2.5 Follow-up period of Our Future Health

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Appendix A: Estimated Numbers of Incident Diagnoses in Initial 2.5-year Follow-up Period of Our Future Health

Condition	Category	1M	2M	3M	4M	5M
Primary Malignancy – Skin	Cancers	8,050	16,100	24,150	32,200	40,250
Primary Malignancy – Prostate	Cancers	3,620	7,240	10,860	14,480	18,100
Primary Malignancy – Breast	Cancers	3,370	6,740	10,110	13,480	16,850
Primary Malignancy – Lung	Cancers	2,790	5,580	8,370	11,160	13,950
Primary Malignancy – Bowel	Cancers	2,770	5,540	8,310	11,080	13,850
Primary Malignancy – Bladder	Cancers	1,360	2,720	4,080	5,440	6,800
Primary Malignancy – Melanoma	Cancers	1,190	2,380	3,570	4,760	5,950
Non Hodgkins Lymphoma	Cancers	920	1,840	2,760	3,680	4,600
Leukaemia	Cancers	710	1,420	2,130	2,840	3,550
Primary Malignancy – Kidney	Cancers	710	1,420	2,130	2,840	3,550
Primary Malignancy – Oesophageal	Cancers	670	1,340	2,010	2,680	3,350
Primary Malignancy – Pancreas	Cancers	610	1,220	1,830	2,440	3,050
Primary Malignancy – Uterus	Cancers	590	1,180	1,770	2,360	2,950
Primary Malignancy – Oropharyngeal	Cancers	540	1,080	1,620	2,160	2,700
Primary Malignancy – Stomach	Cancers	520	1,040	1,560	2,080	2,600
Primary Malignancy – Ovary	Cancers	500	1,000	1,500	2,000	2,500
Monoclonal Gammopathy of Unknown Significance	Cancers	440	880	1,320	1,760	2,200
Plasma Cell Malignancy	Cancers	430	860	1,290	1,720	2,150
Primary Malignancy – Brain	Cancers	390	780	1,170	1,560	1,950
Myelodysplastic Syndrome	Cancers	330	660	990	1,320	1,650
Primary Malignancy – Liver	Cancers	260	520	780	1,040	1,300
Polycythaemia vera	Cancers	220	440	660	880	1,100
Primary Malignancy – Biliary	Cancers	220	440	660	880	1,100
Primary Malignancy – Mesothelioma	Cancers	190	380	570	760	950
Primary Malignancy – Thyroid	Cancers	130	260	390	520	650
Primary Malignancy – Cervix	Cancers	65	130	195	260	325

Primary Malignancy – Testis	Cancers	60	120	180	240	300
Hypertension	Cardiovascular	49,730	99,460	149,190	198,920	248,650
Atrial Fibrillation	Cardiovascular	13,820	27,640	41,460	55,280	69,100
Stable Angina	Cardiovascular	8,600	17,200	25,800	34,400	43,000
Heart Failure	Cardiovascular	8,580	17,160	25,740	34,320	42,900
Myocardial Infarction	Cardiovascular	7,590	15,180	22,770	30,360	37,950
Transient Ischaemic Attack	Cardiovascular	4,360	8,720	13,080	17,440	21,800
Ischaemic Stroke	Cardiovascular	4,150	8,300	12,450	16,600	20,750
Peripheral Arterial Disease	Cardiovascular	3,920	7,840	11,760	15,680	19,600
Unstable Angina	Cardiovascular	3,750	7,500	11,250	15,000	18,750
Coronary Heart Disease	Cardiovascular	3,580	7,160	10,740	14,320	17,900
Venous thrombolism	Cardiovascular	3,190	6,380	9,570	12,760	15,950
Non-rheumatic Aortic valve disorder	Cardiovascular	3,080	6,160	9,240	12,320	15,400
Pulmonary Embolism	Cardiovascular	3,000	6,000	9,000	12,000	15,000
Multiple valve disorder	Cardiovascular	2,490	4,980	7,470	9,960	12,450
Stroke – not otherwise specified	Cardiovascular	2,420	4,840	7,260	9,680	12,100
Non-rheumatic Mitral valve disorder	Cardiovascular	2,400	4,800	7,200	9,600	12,000
Left Bundle Branch Block	Cardiovascular	2,050	4,100	6,150	8,200	10,250
Right Bundle Branch Block	Cardiovascular	1,980	3,960	5,940	7,920	9,900
Abdominal Aortic Aneurysm	Cardiovascular	1,830	3,660	5,490	7,320	9,150
Raynauds Disease	Cardiovascular	1,770	3,540	5,310	7,080	8,850
Supraventricular Tachycardia	Cardiovascular	1,490	2,980	4,470	5,960	7,450
Atrioventricular Block, first degree	Cardiovascular	1,230	2,460	3,690	4,920	6,150
Intracerebral Haemorrhage	Cardiovascular	930	1,860	2,790	3,720	4,650
Cardiomyopathy – other	Cardiovascular	890	1,780	2,670	3,560	4,450
Pericardial Effusion	Cardiovascular	740	1,480	2,220	2,960	3,700
Secondary Pulmonary Hypertension	Cardiovascular	700	1,400	2,100	2,800	3,500
Rheumatic Valve Disorder	Cardiovascular	680	1,360	2,040	2,720	3,400
Ventricular Tachycardia	Cardiovascular	660	1,320	1,980	2,640	3,300
Primary Pulmonary Hypertension	Cardiovascular	630	1,260	1,890	2,520	3,150
Atrioventricular Block, third degree	Cardiovascular	620	1,240	1,860	2,480	3,100

Dilated cardiomyopathy	Cardiovascular	480	960	1,440	1,920	2,400
Subarachnoid Haemorrhage	Cardiovascular	450	900	1,350	1,800	2,250
Atrioventricular Block, second degree	Cardiovascular	440	880	1,320	1,760	2,200
Sick Sinus Syndrome	Cardiovascular	350	700	1,050	1,400	1,750
Subdural haematoma	Cardiovascular	340	680	1,020	1,360	1,700
Hypertrophic cardiomyopathy	Cardiovascular	130	260	390	520	650
Trifascicular Block	Cardiovascular	110	220	330	440	550
Bifascicular Block	Cardiovascular	90	180	270	360	450
Gastro-oesophageal Reflux Disease	Digestive	21,280	42,560	63,840	85,120	106,400
Diverticular Disease	Digestive	15,440	30,880	46,320	61,760	77,200
Gastritis	Digestive	14,220	28,440	42,660	56,880	71,100
Diaphragmatic Hernia	Digestive	12,670	25,340	38,010	50,680	63,350
Abdominal Hernia	Digestive	11,590	23,180	34,770	46,360	57,950
Oesophageal Ulcer	Digestive	11,410	22,820	34,230	45,640	57,050
Cholelithiasis	Digestive	8,310	16,620	24,930	33,240	41,550
Irritable Bowel Syndrome	Digestive	5,690	11,380	17,070	22,760	28,450
Cholecystitis	Digestive	4,360	8,720	13,080	17,440	21,800
Peptic Ulcer	Digestive	3,640	7,280	10,920	14,560	18,200
Anal Fissure	Digestive	2,570	5,140	7,710	10,280	12,850
Barrett's Oesophagus	Digestive	2,010	4,020	6,030	8,040	10,050
Fatty Liver	Digestive	1,810	3,620	5,430	7,240	9,050
Peritonitis	Digestive	1,790	3,580	5,370	7,160	8,950
Appendicitis	Digestive	1,670	3,340	5,010	6,680	8,350
Pancreatitis	Digestive	1,370	2,740	4,110	5,480	6,850
Cirrhosis	Digestive	1,170	2,340	3,510	4,680	5,850
Alcoholic Liver Disease	Digestive	1,050	2,100	3,150	4,200	5,250
Ulcerative Colitis	Digestive	930	1,860	2,790	3,720	4,650
Liver Failure	Digestive	740	1,480	2,220	2,960	3,700
Anorectal Prolapse	Digestive	680	1,360	2,040	2,720	3,400
Cholangitis	Digestive	650	1,300	1,950	2,600	3,250
Anorectal Fistula	Digestive	610	1,220	1,830	2,440	3,050

Coeliac Disease	Digestive	600	1,200	1,800	2,400	3,000
Portal Hypertension	Digestive	590	1,180	1,770	2,360	2,950
Oesophageal Varices	Digestive	560	1,120	1,680	2,240	2,800
Crohns Disease	Digestive	530	1,060	1,590	2,120	2,650
Volvulus	Digestive	410	820	1,230	1,640	2,050
Angiodysplasia of colon	Digestive	350	700	1,050	1,400	1,750
Autoimmune liver disease	Digestive	150	300	450	600	750
Deafness	Ear	15,010	30,020	45,030	60,040	75,050
Tinnitus	Ear	6,190	12,380	18,570	24,760	30,950
Meniere's Disease	Ear	470	940	1,410	1,880	2,350
Raised Total Cholesterol	Endocrine	36,530	73,060	109,590	146,120	182,650
Raised LDL-C	Endocrine	24,180	48,360	72,540	96,720	120,900
Obesity	Endocrine	16,180	32,360	48,540	64,720	80,900
Type 2 Diabetes Mellitus	Endocrine	13,940	27,880	41,820	55,760	69,700
Raised Triglycerides	Endocrine	13,780	27,560	41,340	55,120	68,900
Low HDL-C	Endocrine	9,740	19,480	29,220	38,960	48,700
Thyroid Disease	Endocrine	7,730	15,460	23,190	30,920	38,650
Diabetes Mellitus – other or not specified	Endocrine	1,030	2,060	3,090	4,120	5,150
Hyperparathyroidism	Endocrine	670	1,340	2,010	2,680	3,350
Polycystic Ovarian Syndrome	Endocrine	370	740	1,110	1,480	1,850
Syndrome of Inappropriate AntiDiuretic Hormone	Endocrine	210	420	630	840	1,050
Type 1 Diabetes Mellitus	Endocrine	100	200	300	400	500
Cataract	Eye	20,500	41,000	61,500	82,000	102,500
Diabetic Eye Disease	Eye	5,700	11,400	17,100	22,800	28,500
Glaucoma	Eye	3,640	7,280	10,920	14,560	18,200
Macular Degeneration	Eye	3,610	7,220	10,830	14,440	18,050
Blindness	Eye	2,030	4,060	6,090	8,120	10,150
Retinal Detachment	Eye	1,080	2,160	3,240	4,320	5,400
Retinal Vascular Occlusion	Eye	940	1,880	2,820	3,760	4,700
Anterior Uveitis	Eye	850	1,700	2,550	3,400	4,250
Ptosis	Eye	810	1,620	2,430	3,240	4,050

Keratitis	Eye	730	1,460	2,190	2,920	3,650
Scleritis	Eye	590	1,180	1,770	2,360	2,950
Erectile Dysfunction	Genitourinary	23,340	46,680	70,020	93,360	116,700
Benign Prostatic Hyperplasia	Genitourinary	9,645	19,290	28,935	38,580	48,225
Acute Kidney Injury	Genitourinary	9,100	18,200	27,300	36,400	45,500
Chronic Kidney Disease	Genitourinary	8,350	16,700	25,050	33,400	41,750
Menorrhagia	Genitourinary	7,780	15,560	23,340	31,120	38,900
Urinary Incontinence	Genitourinary	7,780	15,560	23,340	31,120	38,900
Uterovaginal Prolapse	Genitourinary	5,585	11,170	16,755	22,340	27,925
Postmenopausal Bleeding	Genitourinary	4,055	8,110	12,165	16,220	20,275
Urolithiasis	Genitourinary	3,750	7,500	11,250	15,000	18,750
Obstructive and reflux uropathy	Genitourinary	2,350	4,700	7,050	9,400	11,750
Neuropathic Bladder	Genitourinary	2,330	4,660	6,990	9,320	11,650
Glomerulonephritis	Genitourinary	1,800	3,600	5,400	7,200	9,000
Postcoital Bleeding	Genitourinary	1,580	3,160	4,740	6,320	7,900
Dysmenorrhoea	Genitourinary	1,475	2,950	4,425	5,900	7,375
Endometriosis	Genitourinary	1,250	2,500	3,750	5,000	6,250
End Stage Renal Disease	Genitourinary	950	1,900	2,850	3,800	4,750
Hydrocele	Genitourinary	925	1,850	2,775	3,700	4,625
Endometrial Hyperplasia	Genitourinary	760	1,520	2,280	3,040	3,800
Female Infertility	Genitourinary	730	1,460	2,190	2,920	3,650
Tubulo-interstitial Nephropathy	Genitourinary	700	1,400	2,100	2,800	3,500
Chronic Cystitis	Genitourinary	530	1,060	1,590	2,120	2,650
Male infertility	Genitourinary	250	500	750	1,000	1,250
Anaemia – other	Haem/Imm	13,030	26,060	39,090	52,120	65,150
Iron Deficiency Anaemia	Haem/Imm	9,520	19,040	28,560	38,080	47,600
Agranulocytosis	Haem/Imm	2,230	4,460	6,690	8,920	11,150
Secondary Thrombocytopaenia	Haem/Imm	1,470	2,940	4,410	5,880	7,350
Vitamin B12 deficiency anaemia	Haem/Imm	1,030	2,060	3,090	4,120	5,150
Hypersplenism	Haem/Imm	500	1,000	1,500	2,000	2,500
Aplastic Anaemia	Haem/Imm	490	980	1,470	1,960	2,450

Folate Deficiency Anaemia	Haem/Imm	480	960	1,440	1,920	2,400
Secondary Polycythaemia	Haem/Imm	320	640	960	1,280	1,600
Primary thrombocytopaenia	Haem/Imm	250	500	750	1,000	1,250
Hyposplenism	Haem/Imm	200	400	600	800	1,000
Sarcoidosis	Haem/Imm	200	400	600	800	1,000
Thrombophilia	Haem/Imm	200	400	600	800	1,000
Other haemolytic anaemia	Haem/Imm	110	220	330	440	550
Immunodeficiency	Haem/Imm	90	180	270	360	450
Sickle Cell Trait	Haem/Imm	60	120	180	240	300
Thalassaemia Trait	Haem/Imm	40	80	120	160	200
Bacterial Infection	Infections	24,590	49,180	73,770	98,360	122,950
Infection – Other organisms	Infections	23,180	46,360	69,540	92,720	115,900
Infection – Lower Respiratory Tract	Infections	18,680	37,360	56,040	74,720	93,400
Urinary Tract Infection	Infections	12,360	24,720	37,080	49,440	61,800
Infection – Digestive System	Infections	8,790	17,580	26,370	35,160	43,950
Infection – Skin	Infections	7,040	14,080	21,120	28,160	35,200
Infection – Other organs	Infections	5,370	10,740	16,110	21,480	26,850
Septicaemia	Infections	4,800	9,600	14,400	19,200	24,000
Pelvic Inflammatory Disease	Infections	3,100	6,200	9,300	12,400	15,500
Viral Infection	Infections	3,090	6,180	9,270	12,360	15,450
Fungal Infection	Infections	2,710	5,420	8,130	10,840	13,550
Infection – Ear/Upper Respiratory Tract	Infections	2,460	4,920	7,380	9,840	12,300
Infection – Bone	Infections	860	1,720	2,580	3,440	4,300
Rheumatic Fever	Infections	670	1,340	2,010	2,680	3,350
Infection – Male Genitourinary	Infections	635	1,270	1,905	2,540	3,175
Infection – Anorectal	Infections	540	1,080	1,620	2,160	2,700
Infection – Liver	Infections	500	1,000	1,500	2,000	2,500
Infection – Eye	Infections	350	700	1,050	1,400	1,750
Chronic Hepatitis	Infections	320	640	960	1,280	1,600
Infection – Other Genitourinary	Infections	320	640	960	1,280	1,600
Infection – Other nervous system	Infections	320	640	960	1,280	1,600

Tuberculosis	Infections	310	620	930	1,240	1,550
Parasitic Infection	Infections	220	440	660	880	1,100
Infection – Heart	Infections	150	300	450	600	750
Meningitis	Infections	70	140	210	280	350
Enthesopathy	Musculoskeletal	36,420	72,840	109,260	145,680	182,100
Osteoarthritis	Musculoskeletal	31,380	62,760	94,140	125,520	156,900
Osteoporosis	Musculoskeletal	8,180	16,360	24,540	32,720	40,900
Spondylosis	Musculoskeletal	7,200	14,400	21,600	28,800	36,000
Gout	Musculoskeletal	6,770	13,540	20,310	27,080	33,850
Carpal Tunnel Syndrome	Musculoskeletal	6,490	12,980	19,470	25,960	32,450
Intervertebral Disc Disorder	Musculoskeletal	6,170	12,340	18,510	24,680	30,850
Fracture – Wrist	Musculoskeletal	3,160	6,320	9,480	12,640	15,800
Spinal Stenosis	Musculoskeletal	2,930	5,860	8,790	11,720	14,650
Fracture – Hip	Musculoskeletal	2,840	5,680	8,520	11,360	14,200
Rheumatoid Arthritis	Musculoskeletal	2,650	5,300	7,950	10,600	13,250
Fibromatosis	Musculoskeletal	2,500	5,000	7,500	10,000	12,500
Polymyalgia Rheumatica	Musculoskeletal	2,360	4,720	7,080	9,440	11,800
Scoliosis	Musculoskeletal	1,140	2,280	3,420	4,560	5,700
Collapsed Vertebra	Musculoskeletal	970	1,940	2,910	3,880	4,850
Spondylolisthesis	Musculoskeletal	930	1,860	2,790	3,720	4,650
Giant Cell Arteritis	Musculoskeletal	450	900	1,350	1,800	2,250
Psoriatic Arthritis	Musculoskeletal	420	840	1,260	1,680	2,100
Sjogren Syndrome	Musculoskeletal	240	480	720	960	1,200
Ankylosing Spondylosis	Musculoskeletal	210	420	630	840	1,050
Lupus Erythematosus	Musculoskeletal	210	420	630	840	1,050
Reactive Arthritis	Musculoskeletal	30	60	90	120	150
Migraine	Neurological	5,700	11,400	17,100	22,800	28,500
Peripheral Neuropathy	Neurological	5,510	11,020	16,530	22,040	27,550
Epilepsy	Neurological	1,640	3,280	4,920	6,560	8,200
Chronic Fatigue Syndrome	Neurological	1,600	3,200	4,800	6,400	8,000
Parkinson's Disease	Neurological	1,280	2,560	3,840	5,120	6,400

Diabetic Neuropathy	Neurological	1,260	2,520	3,780	5,040	6,300
Trigeminal Neuralgia	Neurological	1,080	2,160	3,240	4,320	5,400
Bell's Palsy	Neurological	970	1,940	2,910	3,880	4,850
Essential Tremor	Neurological	720	1,440	2,160	2,880	3,600
Autonomic Neuropathy	Neurological	590	1,180	1,770	2,360	2,950
Multiple Sclerosis	Neurological	230	460	690	920	1,150
Motor Neurone Disease	Neurological	170	340	510	680	850
Congenital Septal Defect	Perinatal	290	580	870	1,160	1,450
Depression	Psychiatric	20,000	40,000	60,000	80,000	100,000
Anxiety	Psychiatric	15,610	31,220	46,830	62,440	78,050
Dementia	Psychiatric	5,850	11,700	17,550	23,400	29,250
Alcohol Misuse	Psychiatric	5,740	11,480	17,220	22,960	28,700
Delirium	Psychiatric	1,960	3,920	5,880	7,840	9,800
Substance Misuse	Psychiatric	1,330	2,660	3,990	5,320	6,650
Schizophrenia	Psychiatric	740	1,480	2,220	2,960	3,700
Bipolar Affective Disorder	Psychiatric	620	1,240	1,860	2,480	3,100
Intellectual Disability	Psychiatric	420	840	1,260	1,680	2,100
Personality Disorder	Psychiatric	390	780	1,170	1,560	1,950
Obsessive Compulsive Disorder	Psychiatric	270	540	810	1,080	1,350
Autism	Psychiatric	90	180	270	360	450
Eating Disorders	Psychiatric	60	120	180	240	300
Chronic Obstructive Pulmonary Disease	Respiratory	11,680	23,360	35,040	46,720	58,400
Allergic/chronic Rhinitis	Respiratory	11,130	22,260	33,390	44,520	55,650
Asthma	Respiratory	8,770	17,540	26,310	35,080	43,850
Pleural Effusion	Respiratory	6,610	13,220	19,830	26,440	33,050
Respiratory Failure	Respiratory	4,310	8,620	12,930	17,240	21,550
Chronic Sinusitis	Respiratory	2,740	5,480	8,220	10,960	13,700
Sleep apnoea	Respiratory	2,710	5,420	8,130	10,840	13,550
Pulmonary Collapse	Respiratory	2,470	4,940	7,410	9,880	12,350
Bronchiectasis	Respiratory	1,840	3,680	5,520	7,360	9,200
Aspiration Pneumonitis	Respiratory	1,560	3,120	4,680	6,240	7,800

Nasal Polyps	Respiratory	1,290	2,580	3,870	5,160	6,450
Pulmonary Fibrosis	Respiratory	1,220	2,440	3,660	4,880	6,100
Pleural Plaque	Respiratory	920	1,840	2,760	3,680	4,600
Pneumothorax	Respiratory	800	1,600	2,400	3,200	4,000
Asbestosis	Respiratory	370	740	1,110	1,480	1,850
Hypertrophic Nasal Turbinates	Respiratory	370	740	1,110	1,480	1,850
Dermatitis	Skin	23,300	46,600	69,900	93,200	116,500
Actinic keratosis	Skin	7,760	15,520	23,280	31,040	38,800
Seborrheic Dermatitis	Skin	5,290	10,580	15,870	21,160	26,450
Urticaria	Skin	4,560	9,120	13,680	18,240	22,800
Rosacea	Skin	4,040	8,080	12,120	16,160	20,200
Psoriasis	Skin	3,470	6,940	10,410	13,880	17,350
Acne	Skin	1,850	3,700	5,550	7,400	9,250
Lichen Planus	Skin	1,000	2,000	3,000	4,000	5,000
Pilonidal cyst/sinus	Skin	440	880	1,320	1,760	2,200
Vitiligo	Skin	330	660	990	1,320	1,650
Hidradenitis	Skin	310	620	930	1,240	1,550
Alopecia Areata	Skin	300	600	900	1,200	1,500

Calculations conducted by Ralph Goldacre (University of Oxford) based on Kuan et al (2019) A chronological map of 308 physical and mental health conditions from 4 million individuals in the English National Health Service. The Lancet Digital Health 2019 Vol. 1 Issue 2 Pages e63-e77. Calculations are based on Clinical Practice Research Datalink (CPRD) data using harmonised Read, International Classification of Diseases (tenth revision), and Office of the Population Censuses and Surveys Classification of Interventions and Procedures version 4 codes across primary-care and secondary-care records. Calculations assume a uniform distribution over 5 ten-year age groups (30–79 years) and an equal number of men and women.

Our Future Health

Appendix B: Questionnaire and Ongoing Surveys

V1.0
31 DECEMBER 2025

CONTENTS

BASELINE QUESTIONNAIRE
V2.2 JAN 2024

Key
Section 1 - About you and your household
Section 2 - Work and education
Section 3 - Your lifestyle
Section 4 - Family health history
Section 5 - Your health history

Key

[Anything in square brackets is not shown to participants]
[CAPITAL SQUARE BRACKETS INDICATE VARIABLE NAME (BRACKETED TEXT INDICATES QUESTION SOURCE)]
Text in square boxes indicates help text

About you and your household [SECTION 1]

[SECTION INTRO]

This section is where we gather most of our data.
This is the information that will help researchers make discoveries to improve the health of people in the UK. It will be the largest and most diverse research project that has been done in the UK. We are grateful that you and many others are donating their information to help future generations live in good health for longer.

If you do not wish to answer a question you can select 'Prefer not to answer'.
If you want to see previous questions and change your answers, use the BACK button.
If you have any difficulties with completing this, you can use the HELP button or ask a staff member for assistance.
Remember, if you cannot find an exact answer, please select the closest response.

- Please touch NEXT to continue

(H3) How to complete the questionnaires or get help

- If you do not wish to answer a question you can select 'Prefer not to answer'.
- If you want to see previous questions and change your answers, use the BACK button
- If you have any difficulties with completing this, you can use the Help button on the top right of every page.
- Remember, if you cannot find an exact answer, please select the closest response
- You can complete all the questions for each section now or save your progress and continue at a later time

The HELP button will provide you with some additional information to help you answer each question. If you still need help after reading the information provided, do not hesitate to press the HELP button.

[SEX (ONS 2021)]

What sex were you registered with at birth?
A question about gender identity will follow later in the questionnaire

SELECT 1 from

1	Male
2	Female
3	Intersex
-3	Prefer not to answer

We ask about your sex at birth because it can help researchers make new discoveries about how the sex you were born with affects health and risk of disease. It is also important when processing your biological sample in the lab

[GENDER]

Select the option that best describes your current gender identity

SELECT 1 from

1	Man
2	Woman
3	Gender-fluid
4	Nonbinary/third gender
5	I don’t identify with any option provided
-3	Prefer not to answer

[GENDER_B (OXFORD_EDI)]

Do you identify as trans or do you have a trans history?

SELECT 1 from

1	Yes
0	No
-3	Prefer not to answer

[SEXUAL_ORIENTATION (CENSUS 2021)]

Which of the following best describes your sexual orientation?

SELECT 1 from

1 Straight/heterosexual
2 Gay or lesbian
3 Bisexual
4 Asexual
5 Pansexual
6 Other sexual orientation not listed
-3 Prefer not to answer

This question is voluntary, so you can respond “prefer not to answer” if you prefer
"Straight/Heterosexual" means that you're only attracted to people of the opposite sex
"Gay or Lesbian" means that you're attracted to people of the same sex
"Bisexual" means that you're attracted to more than one sex
"Pansexual" means that you're attracted to people regardless of their sex or gender identity
"Asexual" means that you're not attracted to any sex
We realise we have not listed every sexual orientation. If your sexual orientation is not described by any of these categories, please select the “other sexual orientation not listed” option.

[HEIGHT_M (STRIDES)]

We are now going to ask you to tell us how tall you are.
How would you prefer to enter your height?

SELECT 1 from

1 Feet/inches > **GO TO HT_FT**
2 Centimetres > **GO TO HT CM**
-1 Do not know my height > **GO TO WEIGHT_M**
-3 Prefer not to provide my height **> GO TO WEIGHT_M**

[HT_FT]

What is your height (Without shoes)?
If you don’t know, please provide a best guess

Enter INTEGER
[Require]:
min value 3ft 0in
max value 7ft 11in

[HT_CM]

What is your height (Without shoes)?
If you don’t know, please provide a best guess

Enter INTEGER
[Require]:
min value 90cm
max value 299cm

[WEIGHT_M (STRIDES)]

We are now going to ask you to tell us how much you weigh.
How would you prefer to enter your weight?

SELECT 1 from

1 Stones/pounds > **GO TO WT_ST**
2 Kilograms > **GO TO WT_CM**
-1 Do not know my weight **> GO TO Language**
-3 I do not want to report my weight > **GO TO Language**

[WT_ST (STRIDES)]

What is your weight (Without shoes/heavy clothing)?
If you don't know, please provide a best guess

Enter INTEGER
[Require]
min value 3 stones / 0 pounds
max value 63 stones / 13 pounds

[WT_KG (STRIDES)]

What is your weight (Without shoes/heavy clothing)?
If you don't know, please provide a best guess

Enter INTEGER
[Require]
min value 20kg
max value 400kg

[LANGUAGE (PSE UK)]

What is your main language?

SELECT 1 from

1 English
2 Welsh
3 (Scottish) Gaelic
4 Punjabi
5 Gujarati
6 Bengali
7 Urdu
8 Hindi
9 Cantonese
10 Mandarin
11 Polish
12 Arabic
13 Other (Including British Sign Language)
-3 Prefer not to answer

[ETHNICITY (PSE UK)]

What is your ethnic group? Choose one option that best describes your ethnic group or background?

SELECT 1 from

1 White – English / Welsh / Scottish / Northern Irish / British
2 White – Irish
3 White – Gypsy or Irish Traveller
4 White – Polish
5 Any other white background
6 Mixed – White and Black Caribbean
7 Mixed – White and Black African
8 Mixed – White and Asian
9 Any other mixed multiple ethnic background
10 Asian or Asian British – Indian
11 Asian or Asian British – Pakistani
12 Asian or Asian British – Bangladeshi
13 Chinese
14 Any other Asian/Asian British background
15 Black or Black British – African
16 Black or Black British – Caribbean
17 Any other Black / African / Caribbean background
18 Arab
19 Other
-3 Prefer not to answer

[MARITAL STATUS (CENSUS 2021)]

What is your current legal marital or registered civil partnership status?

SELECT 1 from

1 Never married and never registered a civil partnership > **GO TO D4 (UKB)**
2 Married > **GO TO MARITAL_STATUS_A**
3 In a registered civil partnership > **GO TO MARITAL_STATUS_B**
4 Separated, but still legally married > **GO TO MARITAL_STATUS_A**
5 Separated, but still legally in a civil partnership > **GO TO MARITAL_STATUS_B**
6 Divorced > **GO TO MARITAL_STATUS_C**
7 Formerly in a civil partnership which is now legally dissolved > **GO TO MARITAL_STATUS_D**
8 Widowed > **GO TO MARITAL_STATUS_C**
9 Surviving partner from a registered civil partnership > **GO TO MARITAL_STATUS_D**
10 Other **> GO TO D4 (UKB)**
-3 Prefer not to answer > **GO TO D4 (UKB)**

[MARITAL_STATUS_A (CENSUS 2021]

Who is your legal marriage to?

SELECT 1 from

1 Someone of the opposite gender
2 Someone of the same gender
3 Other
-3 Prefer not to answer

➔ **GO TO D4**

[MARITAL_STATUS_B (CENSUS 2021]

Who is your registered civil partnership to?

SELECT 1 from

1 Someone of the opposite gender
2 Someone of the same gender
3 Other
-3 Prefer not to answer

➔ **GO TO D4**

[MARITAL_STATUS_C (CENSUS 2021]

Who was your legal marriage to?

SELECT 1 from

1 Someone of the opposite gender
2 Someone of the same gender
3 Other
-3 Prefer not to answer

➔ **GO TO D4**

[MARITAL_STATUS_D (CENSUS 2021]

Who was your registered civil partnership to?

SELECT 1 from

1 Someone of the opposite gender
2 Someone of the same gender
3 Other
-3 Prefer not to answer

➔ **GO TO D4**

[D4 (UKB)]

What type of accommodation do you live in?

SELECT one of 7 from

1 A house or bungalow
2 A flat, maisonette or apartment
3 Mobile or temporary structure (i.e. caravan)
4 Sheltered accommodation **> GO TO D5A**
5 Care home **> GO TO D5A**
-7 None of the above

-3 Prefer not to answer

Please select:
-A house or bungalow for any whole, detached, semi-detached or terraced (including end-terrace) house or bungalow.
-A flat, maisonette, or apartment for any purpose-built block of flats or tenement, part of a converted or shared house (including bed-sits) or within a commercial building (for example in an office building, or hotel, or over a shop).
-If none of the options apply, select 'None of the above'.

[D5 (UKB)]

Do you own or rent the accommodation that you live in?

SELECT one of 8 from

1 Own outright (by you or someone in your household)
2 Own with a mortgage
3 Rent - from local authority, local council, housing association, student accommodation
4 Rent - from private landlord or letting agency
5 Pay part rent and part mortgage (shared ownership)
6 Live in accommodation rent free
-7 None of the above
-3 Prefer not to answer

Please select: - Own outright if you or someone in your household owns the accommodation that you live in. - Own with mortgage if you or someone in your household has a mortgage on the accommodation that you live in.

[D5A (UKB)]

Do you have any of the following in your home? (You can select more than one answer)

TOGGLE of 6 choices
[Require >1 response]

1 A gas hob or gas cooker
2 A gas fire that you use regularly in wintertime
3 An open solid fuel fire that you use regularly in wintertime
-7 None of the above **[EXCLUSIVE]**
-1 Do not know [**EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[D5A1 (UKB)]

How is your home mainly heated?

TOGGLE of 6 choices
[Require >1 response]

1 Gas central heating
2 Electric storage heaters
3 Oil (kerosene) central heating

4 Portable gas or paraffin heaters
5 Solid fuel central heating
6 Open fire without central heating
-7 None of the above
-1 Do not know
-3 Prefer not to answer

Select the answer which best describes how your home is mainly heated. If you use more than one type of heating equally, you can choose multiple answers. Solid fuel refers to wood or coal. Regular use is when you use this for most days of the week in the winter time.

[D5B (UKB)]

How many years have you lived at your current address?

Enter INTEGER
[Require ≥ 1, ≤ current age,
Units: years]
OR
-10 Less than a year
OR
-1 Do not know
OR
-3 Prefer not to answer

If you have lived there for less than one year select 'Less than a year'.
If you are unsure, please provide an estimate or select 'Do not know'. If you have lived at your current address at different times, add up the total number of years you lived there. For instance, if you lived at your current address for 3 years, moved overseas for one year and returned to your current address for another 5 years, then you would enter 8 years.

[D7 (UKB)]

Including yourself, how many people are living together in your household? (Include those who usually live in the house such as students living away from home during term, partners in the armed forces or professions such as pilots)

Enter INTEGER
[Require ≥ 1, ≤ 100
Units: people]
OR
-1 Do not know
OR
-3 Prefer not to answer
➔ **IF ANSWER = 1, GO TO D8**

If you live alone, enter 1. Include those who usually live in the house such as students living away from home during term, partners in the armed forces or professions such as pilots.

[D7A (UKB)]

How are the other people who live with you related to you? (You can select more than one answer)

TOGGLE of 9 choices

[Require ≥1 choices]

1 Husband, wife, or partner
2 Son and/or daughter (include step-children)
3 Brother and/or sister
4 Mother and/or father
5 Grandparent
6 Grandchild
7 Other related
8 Other unrelated
-3 Prefer not to answer **[EXCLUSIVE]**

Answer this question considering all the people who you counted in the household in response to the previous question.

[D8 (UKB)]

How many cars or vans are owned, or available for use, by you or members of your household? (Please include company vehicles if available for private use)

SELECT one of 7 from

1 None
2 One
3 Two
4 Three
5 Four or more
-1 Do not know
-3 Prefer not to answer

Do not include motorcycles.

----------END OF SECTION 1 ----------

Work And Education [SECTION 2]

This section is about work and education. Different physical Requirements of us at work can result in different illnesses and issues. Examining and understanding different levels of work and education can also help us examine inequalities which can result in poor health and other social issues. Your work may have changed during the COVID-19 pandemic. Please answer the questions as accurately as you can based on your current situation.

[D9 (UKB)]

Which of the following describes your current situation? (You can select more than one answer)

TOGGLE of 10 choices
[Require ≥1 choices]

1 In paid employment or self-employed
2 Retired **> GO TO D12**
3 Looking after home and/or family
4 Unable to work because of sickness or disability **> GO TO D12**
8 On paid leave (e.g. parental leave, long term sick leave, furlough)
6 Doing unpaid or voluntary work
7 Full or part-time student **> GO TO D12**
9 Unpaid carer **> GO TO D12**
-5 Unemployed **[EXCLUSIVE] > GO TO D12**
-7 None of the above **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

If more than one situation applies, select all that are appropriate.

[D9AA (UKB)]

How many years have you worked in your current role? (If you have more than one job please answer this, and the following questions on work, for your MAIN role only. Looking after home and/or family should be considered as a job/work)

Enter INTEGER
[Require ≥1, ≤ Current age,
Units: years]
OR
-10 Less than a year
OR
-1 Do not know
OR
-3 Prefer not to answer

If you have more than one 'current job' then answer this question for your MAIN job only (ie: the job that you spend most of your time doing).
If you have been with the same employer, but have changed jobs whilst you have worked for them, then only give the number of years that you have been in your current job (not the number of years that you have been employed by the same company).
For instance, if you have worked as mail-room sorter but then been promoted to manager of the mail-room, please give the number of years you have worked as the mail-room manager only.
If you have changed employers, but have had the same job, please give the total number of years that you have worked in that job. For instance, if you have worked as a cleaner for 3 different companies, please give the total number of years working as a cleaner.

[D9A (UKB)]

In a typical WEEK, how many hours do you spend at work? (Do not include hours travelling to and from work)

Enter INTEGER

[Require ≤ 168,
Units: hours]
OR
-1 Do not know
OR
-3 Prefer not to answer

If you have more than one 'current job' then answer this question for your MAIN job only. Please round up or down to the nearest hour.

[D9G (UKB)]

How many times a WEEK do you travel from home to your main work? (count outward journeys only)

Enter INTEGER
[Require ≥0, ≤ 999,
Units: times]
OR
-10 Less than once a week
OR
-1 Do not know
OR
-3 Prefer not to answer

If the number of times varies each week, take an average over the last 4 weeks. If you only work from home please enter 0.

[D9E (UKB)]

What types of transport do you use to get to and from work? (You can select more than one answer)

TOGGLE of 6 choices
[Require ≥1 choices]
1 Car/motor vehicle
2 Walk
3 Public transport
4 Cycle
-7 None of the above **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

If you have more than one 'current job' then answer this question for your MAIN job only. If you use more than one form of transport then select all that apply.

[D9F (UKB)]

About how many miles is it between your home and your work?

Enter INTEGER
[Require ≥0, ≤ 999,
Units: miles]
OR
-10 Less than one mile

OR

-1 Do not know

OR

-3 Prefer not to answer

If you have more than one 'current job' then answer this question for your MAIN job only. If you are unsure, please provide an estimate or select 'Do not know'. If you only work from home please enter 0.

[D9B (UKB)]

Does your work involve walking or standing?

SELECT one of 6 from

1 Never/rarely

2 Sometimes

3 Usually

4 Always

-1 Do not know

-3 Prefer not to answer

If you have more than one 'current job' then answer this question your MAIN job only.

[D9C (UKB)]

Does your work involve heavy manual or very physical work?

SELECT one of 6 from

1 Never/rarely

2 Sometimes

3 Usually

4 Always

-1 Do not know

-3 Prefer not to answer

If you have more than one 'current job' then answer this question for your MAIN job only. Physical work includes work that involves handling of heavy objects and use of heavy tools.

[D9D (UKB)]

Does your work involve shift work?

SELECT one of 6 from

1 Never/rarely **> GO TO D12 (UKB)**

2 Sometimes

3 Usually

4 Always

-1 Do not know

-3 Prefer not to answer

Shift work is a work schedule that falls outside of the normal daytime working hours of 9am-5pm. This may involve working afternoons, evenings or nights or rotating through these kinds of shifts.

[D9DA (UKB)]

Does your work involve night shifts?

SELECT one of 6 from

1 Never/rarely
2 Sometimes
3 Usually
4 Always
-1 Do not know
-3 Prefer not to answer

If you have more than one 'current job' then answer this question for your MAIN job only. Night shifts are a work schedule that involves working through the normal sleeping hours, for instance working through the hours from 12am to 6am.

[D12 (UKB)]

Which of the following qualifications do you have? (You can select more than one)

TOGGLE of 8 choices

[Require ≥1 choices]

1 College or University degree
2 A levels/AS levels/BTEC or equivalent
3 O levels/GCSEs or equivalent
4 CSEs or equivalent
5 NVQ or HND or HNC or equivalent
6 Other professional qualifications e.g., nursing, teaching
-7 None of the above **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

A levels/AS levels and equivalent includes the Higher School Certificate O levels/GCSEs and equivalent includes the School Certificate. If your education was in another country please choose the category(ies) that best fits with your educational qualifications.

[D11 (UKB)]

At what age did you complete your continuous full-time education?
If you stopped your studies with no intention of returning, please give the age at which you stopped even if you began studying again later in life.

Enter age in years

[Require ≥ 5, ≤ current age,

Expect ≤ 40,

Units: years]

OR

0 Still in full time education

OR

-2 Never went to school

OR

-1 Do not know

OR

-3 Prefer not to answer

Please give the age that you completed 'continuous' full time education.
For example, if you stopped your studies when you were 17 years old with the intention that you had completed your studies but then returned to full time studies when you were 24, enter 17.However if you only temporarily stopped your studies at 17 with the intention that you would return to studies (for instance a gap year) and then completed your full time education at 21, enter 21

[D10 (UKB)]

What is the average total income before tax received by your HOUSEHOLD?

SELECT one of 7 from

1 Less than £18,000
2 £18,000 to £30,999
3 £31,000 to £51,999
4 £52,000 to £100,000
5 Greater than £100,000
-1 Do not know
-3 Prefer not to answer

Add up the incomes of everyone in your household for your answer. The information you provide is confidential and won't be shared with any tax authorities.

----------END OF SECTION 2 ----------

Your lifestyle [SECTION 3]

In this section we ask you about your day-to-day physical activity.
This will help our researchers look at how exercise is tied to overall health, but also things like how healthy your bones, lungs, and heart as well as diseases such as type 2 diabetes.
We'll also ask about driving habits, sleep patterns and the use of tobacco, vaping and alcohol if relevant.
Aspects of your lifestyle may have changed during the COVID-19 pandemic. Please answer the questions as accurately as you can based on your current situation.

[WP1 (UKB)]

Thinking about the last 4 weeks, in a typical WEEK, on how many days did you walk for at least 10 minutes at a time?
(Include walking that you do at work, travelling to and from work, and for sport or leisure)

Enter INTEGER
[Require ≥ 0, ≤ 7
Units: days]
OR

-1 Do not know

OR

-2 Unable to walk

OR

-3 Prefer not to answer

[WP1A (UKB)]

Thinking about the last 4 weeks, how many minutes did you usually spend walking on a typical DAY?

Enter INTEGER
[Require ≥ 0, ≤ 1440
Units: minutes]

OR

-1 Do not know

OR

-3 Prefer not to answer

Count the number of minutes that you usually spend walking in one day.
If the time you usually spend walking on each day of the week varies a lot, give an average of the time you spend walking. For instance, if on one day of the week you usually walk for 4 hours but on the other day you walk 2 hours then give the average - that is 3 hours.

[WP2 (UKB)]

Thinking about the last 4 weeks, in a typical WEEK, on how many days did you do 10 minutes or more of moderate physical activities like carrying light loads, cycling at normal pace? (Do not include walking)

Enter INTEGER
[Require ≥ 0, ≤ 7
Units: days]

OR

-1 Do not know

OR

-3 Prefer not to answer

Count the number of days in a week that you do moderate physical activities for at least 10 minutes continuously at a time. Remember to include activities that you do for work, leisure, travel and around the house.

[WP2A (UKB)]

Thinking about the last 4 weeks, how many minutes did you usually spend doing moderate activities on a typical DAY?

Enter INTEGER
[Require ≥ 0, ≤ 1440
Units: minutes]

OR

-1 Do not know

OR

-3 Prefer not to answer

If the time you usually spend doing moderate physical activity on each day of the week varies a lot, give an average of the time you spend doing moderate physical activity.

[WP3 (UKB)]

Thinking about the last 4 weeks, in a typical WEEK, how many days did you do 10 minutes or more of vigorous physical activity?
(These are activities that make you sweat or breathe hard such as fast cycling, aerobics, heavy lifting)

Enter INTEGER
[Require ≥ 0, ≤ 7
Units: days]
OR
-1 Do not know
OR
-3 Prefer not to answer

Count the number of days in a week that you do vigorous physical activities for at least 10 minutes continuously at a time. Remember to include activities that you do for work, leisure, travel and around the house.

[WP3A (UKB)]

Thinking about the last 4 weeks, how many minutes did you usually spend doing vigorous activities on a typical DAY?

Enter INTEGER
[Require ≥ 0, ≤ 1440
Units: minutes]
OR
-1 Do not know
OR
-3 Prefer not to answer

If the time you usually spend doing vigorous physical activity on each day of the week varies a lot, give an average of the time you spend doing vigorous physical activity.

[WP4 (UKB)]

How would you describe your usual walking pace?

SELECT one of 5 from
1 Slow pace
2 Steady average pace
3 Brisk pace
-7 None of the above
-3 Prefer not to answer

Slow pace is defined as less than 3 miles per hour. Steady average pace is defined as between 3-4 miles per hour. Fast pace is defined as more than 4 miles per hour.

[WP4A (UKB)]

At home, during the last 4 weeks, about how many times a DAY do you climb a flight of stairs? (approx. 10 steps)

SELECT one of 8 from

0 None
1 1-5 times a day
2 6-10 times a day
3 11-15 times a day
4 16-20 times a day
5 More than 20 times a day
-1 Do not know
-3 Prefer not to answer

If you are unsure, please provide an estimate or select 'Do not know'.

[WP4AA (UKB)]

In the last 4 weeks, which forms of transport have you used most often to get about? Not including travel to and from work; you can select more than one answer

TOGGLE of 6 choices

[Require ≥1 choices]

1 Car/motor vehicle
2 Walk
3 Public transport
4 Cycle
-7 None of the above **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

Remember not to include journeys to and from work.

[WP4B1 (UKB)]

In the last 4 weeks did you spend any time doing the following? (You can select more than one answer)

TOGGLE of 7 choices

[Require ≥1 choices]

1 Walking for pleasure (not as a means of transport)
2 Other exercises (e.g., swimming, cycling, keep fit, bowling)
3 Strenuous sports
4 Light DIY (e.g., DIY that does not require a lot of physical effort)
5 Heavy DIY (e.g., DIY that requires a lot of physical effort)
-7 None of the above **[EXCLUSIVE] > GO TO WP11**
-3 Prefer not to answer **[EXCLUSIVE] > GO TO WP11**

➔ **If ANSWER = 1 GO TO WP4C1 (UKB)**
➔ **If ANSWER = 2 GO TO WP4C2 (UKB)**
➔ **If ANSWER = 3 GO TO WP4C3 (UKB)**
➔ **If ANSWER = 4 GO TO WP4C4 (UKB)**

➔ **If ANSWER = 5 GO TO WP4C5 (UKB)**

➔ **IF ANSWER INCLUDES MULTIPLE RESPONSES 1-5 SHOW EACH APPLICABLE WP4C1-5 IN ORDER**

Strenuous sports include sports that make you sweat or breathe hard. Heavy DIY includes chopping wood, home or car maintenance, lifting heavy objects or using heavy tools.

[WP4C1 (UKB)]

How many times in the last 4 weeks did you go walking for pleasure?

SELECT one of 8 from 1

1 Once in the last 4 weeks
2 2-3 times in the last 4 weeks
3 Once a week
4 2-3 times a week
5 4-5 times a week
6 Every day
-1 Do not know
-3 Prefer not to answer

If the time you spent walking for pleasure varied, please give an average over the past 4 weeks.

[WP4E1 (UKB)]

Each time you went walking for pleasure, about how long did you spend doing it?

SELECT one of 9 from

1 Less than 15 minutes
2 Between 15 and 30 minutes
3 Between 30 minutes and 1 hour
4 Between 1 hour and 1.5 hours
5 Between 1.5 hours and 2 hours
6 Between 2 and 3 hours
7 Over 3 hours
-1 Do not know
-3 Prefer not to answer

➔ **If WP4B1 ANSWER DID NOT INCLUDE 2 OR 3 OR 4 OR 5 GO TO WP11**

If the time you spent walking for pleasure varied, please give an average over the past 4 weeks.

[WP4C2 (UKB)]

How many times in the last 4 weeks did you do other exercises such as swimming, cycling, keep fit?

SELECT one of 8 from

1 Once in the last 4 weeks
2 2-3 times in the last 4 weeks
3 Once a week
4 2-3 times a week

5 4-5 times a week
6 Every day
-1 Do not know
-3 Prefer not to answer

[WP4E2 (UKB)]

Each time you did other exercises such as swimming, cycling, keep fit, about how long did you spend doing them?

SELECT one of 9 from

1 Less than 15 minutes
2 Between 15 and 30 minutes
3 Between 30 minutes and 1 hour
4 Between 1 hour and 1.5 hours
5 Between 1.5 hours and 2 hours
6 Between 2 and 3 hours
7 Over 3 hours
-1 Do not know
-3 Prefer not to answer

➔ **If WP4B1 ANSWER DID NOT INCLUDE 3 OR 4 OR 5 GO TO WP11**

[WP4C3 (UKB)]

How many times in the last 4 weeks did you do strenuous sports?

SELECT one of 8 from

1 Once in the last 4 weeks
2 2-3 times in the last 4 weeks
3 Once a week
4 2-3 times a week
5 4-5 times a week
6 Every day
-1 Do not know
-3 Prefer not to answer

[WP4E3 (UKB)]

Each time you did strenuous sports, about how long did you spend doing it?

SELECT one of 9 from

1 Less than 15 minutes
2 Between 15 and 30 minutes
3 Between 30 minutes and 1 hour
4 Between 1 hour and 1.5 hours
5 Between 1.5 hours and 2 hours
6 Between 2 and 3 hours
7 Over 3 hours
-1 Do not know

-3 Prefer not to answer

➔ **If WP4B1 ANSWER DID NOT INCLUDE 4 OR 5 GO TO WP11**

[WP4C4 (UKB)]

How many times in the last 4 weeks did you do light DIY?

SELECT one of 8 from

1 Once in the last 4 weeks
2 2-3 times in the last 4 weeks
3 Once a week
4 2-3 times a week
5 4-5 times a week
6 Every day
-1 Do not know
-3 Prefer not to answer

[WP4E4 (UKB)]

Each time you did light DIY, about how long did you spend doing it?

SELECT one of 9 from

1 Less than 15 minutes
2 Between 15 and 30 minutes
3 Between 30 minutes and 1 hour
4 Between 1 hour and 1.5 hours
5 Between 1.5 hours and 2 hours
6 Between 2 and 3 hours
7 Over 3 hours
-1 Do not know
-3 Prefer not to answer

➔ **If WP4B1 ANSWER DID NOT INCLUDE 5 GO TO WP11**

[WP4C5 (UKB)]

How many times in the last 4 weeks did you do heavy DIY?

SELECT one of 8 from

1 Once in the last 4 weeks
2 2-3 times in the last 4 weeks
3 Once a week
4 2-3 times a week
5 4-5 times a week
6 Every day
-1 Do not know
-3 Prefer not to answer

[WP4E5 (UKB)]

Each time you did heavy DIY, about how long did you spend doing it?

SELECT one of 9 from

1 Less than 15 minutes
2 Between 15 and 30 minutes
3 Between 30 minutes and 1 hour
4 Between 1 hour and 1.5 hours
5 Between 1.5 hours and 2 hours
6 Between 2 and 3 hours
7 Over 3 hours
-1 Do not know
-3 Prefer not to answer

[WP11 (UKB)]

How often do you visit friends or family or have them visit you?

SELECT one of 9 from

1 Almost daily
2 2-4 times a week
3 About once a week
4 About once a month
5 Once every few months
6 Never or almost never
7 No friends/family outside household
-1 Do not know
-3 Prefer not to answer

If this varies, please give an average of how often you visit or have had visits in the last year. Include meeting with friends or family in environments outside of the home such as in the park, at a sports field, at a restaurant or pub.

[WP12 (UKB)]

Which of the following do you attend once a week or more often? If this varies, please think about activities in the last year.
(You can select more than one)

TOGGLE of 7 choices

1 Sports club or gym
2 Pub or social club
3 Religious group
4 Adult education class
5 Other group activity
-7 None of the above
-3 Prefer not to answer

You can include online activities.

[WP12A (UKB)]

In a typical DAY in summer, how many hours do you spend outdoors?

Enter INTEGER

OR

-10 Less than an hour a day

OR

-1 Do not know

OR

-3 Prefer not to answer

If the time you spend outdoors in summer varies a lot, give the average time per day. For example, if you spend 1 hour a day on each weekday and 4 hours a day on the weekend, the total hours in a week are 13 (5 + 8), so you spend approximately 2 hours a day.

[WP12B (UKB)]

In a typical DAY in winter, how many hours do you spend outdoors?

Enter INTEGER

OR

-10 Less than an hour a day

OR

-1 Do not know

OR

-3 Prefer not to answer

If the time you spend outdoors in winter varies a lot, give the average time per day. For example, if you spend 1 hour a day on each weekday and 4 hours a day on the weekend, the total hours in a week are 13 (5 + 8), so you spend approximately 2 hours a day.

[WP5 (UKB/NSCH)]

In a typical DAY, how many hours do you usually spend in front of a TV watching TV programs, videos, or playing video games?

Enter INTEGER

OR

-10 Less than an hour a day

OR

-1 Do not know

OR

-3 Prefer not to answer

If the time you spend in front of the TV varies a lot, give the average time for a 24-hour day in the last 4 weeks.

[WP5A (UKB/NSCH)]

In a typical DAY, how many hours do you usually spend with computers, cell phones, handheld video games, and other electronic devices?
(Do not include using a computer at work; put 0 if you do not spend any time doing it)

Enter INTEGER
OR
-10 Less than an hour a day
OR
-1 Do not know
OR
-3 Prefer not to answer

If the time you spend on the computer or other handheld devices varies a lot, give the average time for a 24-hour day in the last 4 weeks. Remember not to include time spent on a computer at work.

[WP7 (UKB)]

In a typical DAY, how many hours do you spend driving?

Enter INTEGER
OR
-10 Less than an hour a day
OR
-1 Do not know
OR
-3 Prefer not to answer

If the time you spend driving varies a lot, give the average time for a 24-hour day in the last 4 weeks.
Include driving a car, bus, motorcycle, boat, truck etc.
Include all the driving that you do as part of work, getting to work or outside of work. If you do not drive, please enter 0.

[SL1 (UKB)]

About how many hours sleep do you get in every 24 hours? (please include naps)

Enter INTEGER
OR
-1 Do not know
OR
-3 Prefer not to answer

If the time you spend sleeping varies a lot, give the average time for a 24 hour day in the last 4 weeks.

[SL1AA (UKB)]

On an average day, how easy do you find getting up in the morning?

SELECT one of 6 from
1 Not easy at all
2 Not very easy
3 Fairly easy

4 Very easy
-1 Do not know
-3 Prefer not to answer

If this varies a lot, answer this question in relation to the last 4 weeks.

[SL1AB (UKB)]

Do you consider yourself to be?

SELECT one of 6 from

1 Definitely a 'morning' person
2 More a 'morning' than 'evening' person
3 More an 'evening' than a 'morning' person
4 Definitely an 'evening' person
-1 Do not know
-3 Prefer not to answer

If this varies a lot, answer this question in relation to the last 4 weeks.

[SL1A (UKB)]

Do you have a nap during the day?

SELECT one of 4 from

1 Never/rarely
2 Sometimes
3 Usually
-3 Prefer not to answer

If this varies a lot, answer this question in relation to the last 4 weeks.

[SL4 (UKB)]

How likely are you to doze off or fall asleep during the daytime when you don't mean to? (e.g. when working, reading or driving)

SELECT one of 5 from

0 Never/rarely
1 Sometimes
2 Often
-1 Do not know
-3 Prefer not to answer

If you are unsure, please provide an estimate or select 'Do not know'.

[SL2 (UKB)]

Do you have trouble falling asleep at night or do you wake up in the middle of the night?

SELECT one of 4 from

1 Never/rarely
2 Sometimes
3 Usually
-3 Prefer not to answer

If this varies a lot, answer this question in relation to the last 4 weeks.

[SL3 (UKB)]

Does your partner or a close relative or friend complain about your snoring?

SELECT one of 4 from

1 Yes
2 No
-1 Do not know
-3 Prefer not to answer

If you are unsure, please provide an estimate or select 'Do not know'.

[TOBACCO_A (CONNECT)]

Have you ever used any of these **tobacco** products, even once?
Select all that apply.

TOGGLE of 8 choices

[Require ≥1 choices]

0 Cigarettes (manufactured or hand-rolled) > **GO TO S3A**
1 Electronic delivery devices that can be vaped, such as e-cigarettes (e.g., UWELL, Vype, Vuse, Vapouriz, WizMix) > **GO TO V2**
2 Cigars, cigarillos, or little filtered cigar (e.g., Montecristo, Romeo Y Julieta, Cohiba, Davidoff, Neos red)
3 Chewing tobacco, snus, snuff, Gutkha**,** or dip (e.g., Skruf, Tulsi, Sikandar, conwood, Al Capone powder)
4 Shisha, hookah or water pipe
5 Tobacco pipe
6 I have **not** used any of these tobacco products **[EXCLUSIVE]** > **GO TO S11**
-3 Prefer not to answer **[EXCLUSIVE]**

IF RESPONSE != 0 OR 1 OR 6 GO TO TOBACCO_B

[S3A (CONNECT/UKB)]

How old were you when you **first** smoked a cigarette?

Enter INTEGER

OR

-1 Do not know

OR

-3 Prefer not to answer

If you do not remember when you had your first cigarette, please enter your best guess.

[S2AA (CONNECT]

On how many occasions have you smoked cigarettes in your life?

SELECT one of 5 from

0 10 or less
1 11-49
2 50-99
3 100 or more
-3 Prefer not to answer
➔ **GO TO TOBACCO_B**

[V2 (NHS3)]

How old were you when you first used an e-cigarette (vaping)?
Enter INTEGER
OR
-1 Do not know
OR
-3 Prefer not to answer

[V3 (NHS3)]

When you used your first e-cigarette (vaping)
SELECT one of 6 from
1 I had never smoked tobacco cigarettes
2 I was a current smoker of tobacco cigarettes and had no plans to quit
3 I was a current smoker of tobacco cigarettes and was planning to quit
4 I was a current smoker of tobacco cigarettes and was planning to reduce smoking
5 I had stopped smoking tobacco cigarettes
-3 Prefer not to answer

[TOBACCO_B (CONNECT)]

Have you ever **regularly** used any of these **tobacco** products?
Select all that apply.
TOGGLE of 8 choices
[Require ≥1 choices]
0 Cigarettes (manufactured or hand-rolled)
1 Electronic delivery devices that can. be vaped, such as e-cigarettes (e.g., UWELL, Vype, Vuse, Vapouriz, WizMix) > **GO TO V4**
2 Cigars, cigarillos, or little filtered cigar (e.g., Montecristo, Romeo Y Julieta, Cohiba, Davidoff, Neos red) > **GO TO S11**
3 Chewing tobacco, snus, snuff, **Gutkha,** or dip (e.g., Skruf, Tulsi, Sikandar, conwood, Al Capone powder) > **GO TO S11**
4 Shisha, hookah or water pipe > **GO TO S11**
5 Tobacco pipe > **GO TO S11**
6 I have **not** used any of these tobacco products **[EXCLUSIVE]** > **GO TO S11**
-3 Prefer not to answer **[EXCLUSIVE] > GO TO S11**

We understand that the meaning of "regular basis" might be different for different people. When you answer this question, please think about what "regular basis" means to you.

[S3B (UKB/CONNECT)]

How old were you when you first started smoking **on a regular basis**?

Enter INTEGER

OR

-1 Do not know

OR

-3 Prefer not to answer

We understand that the meaning of "regular basis" might be different for different people. When you answer this question, please think about what "regular basis" means to you. If you don't know, please give us your best estimate.

[S4(UKB/CONNECT)]

What type of cigarettes have you mainly smoked?

SELECT one from

1 Manufactured cigarette

2 Hand-rolled cigarettes

-7 None of the above

-3 Prefer not to answer

If you smoke both hand-rolled, and manufactured cigarettes select the one that you smoke more of. If you still currently smoke, report the type you smoke most frequently.

[S1 (UKB/CONNECT)]

Do you smoke cigarettes now?

SELECT one of 4 from

1 Yes, every day

2 Yes, some days > **GO TO S4AA (UKB)**

3 Yes, but rarely > **GO TO S4AA (UKB)**

0 No, not at all > **GO TO S4AA (UKB)**

-3 Prefer not to answer > **GO TO S11 (UKB)**

[S1A (CONNECT)]

On the days that you smoke, how many cigarettes do you smoke **per day on average?** Please provide the number of cigarettes, not the number of packs.

Enter INTEGER

OR

-10 Less than one a day

OR

-1 Do not know

➔ **GO TO S5A**

Count the total number of cigarettes (including both hand-rolled and manufactured cigarettes) For hand-rolled cigarettes: - One ounce of tobacco makes about 30 cigarettes. - One gram of tobacco makes about 1 cigarette.

[S4AA (UKB/CONNECT)]

Did you ever smoke cigarettes on **most or all days**?

SELECT one of 3 from

0 No > **GO TO S5A**

1 Yes

-3 Prefer not to answer > **GO TO S5A**

[S8A]

How old were you when you FIRST smoked on most days?

Enter INTEGER

OR

-1 Do not know

OR

-3 Prefer not to answer

[S8 (UKB)]

How old were you when you last smoked on most days?

Enter INTEGER

OR

-1 Do not know

OR

-3 Prefer not to answer

[S4AB (CONNECT)]

On the days that you smoked how many cigarettes did you smoke **per day on average?** Please provide the number of cigarettes, not the number of packs.

Enter INTEGER

OR

-10 Less than one a day

OR

-1 Do not know

[S4AC]

Why did you stop or reduce your smoking?

TOGGLE of 19 choices

[Require ≥1 choices]

1 Advice from a GP/Health professional
2 TV advert for a nicotine replacement product
3 Government TV/radio/Press advert
4 Hearing about a new stop smoking treatment
5 A decision that smoking was too expensive
6 Being faced with smoking restrictions
7 I knew someone else who was stopping
8 Seeing a health warning on a cigarette pack
9 Being contacted by my local NHS Stop Smoking Services
10 Health problems I had at the time
11 A concern about future health problems
12 Attending a local stop smoking activity or event
13 Something said by family/friends/children
14 A significant birthday
15 The coronavirus outbreak
16 Restrictions on where I could smoke
-7 None of the above [**EXCLUSIVE**]
-1 Do not know [**EXCLUSIVE**]
-3 Prefer not to answer [**EXCLUSIVE**]

➔ **GO TO S11**

Count the total number of cigarettes (including both hand-rolled and manufactured cigarettes if both are smoked). For hand-rolled cigarettes:
- One ounce of tobacco makes about 30 cigarettes.
- ONE GRAM OF TOBACCO MAKES ABOUT 1 CIGARETTE.

[S5A (UKB)]

Compared to 10 years ago do you smoke...

SELECT one of 4 from

1 More nowadays?
2 About the same?
3 Less nowadays? **> GO TO S5B (UKB)**
-3 Prefer not to answer

[S9B]

In the time that you have smoked, have you ever stopped for more than 6 months?

SELECT one of 3 from

0 No > **GO TO S11**
1 Yes > **GO TO S10B**
-1 Do not know
-3 Prefer not to answer **> GO TO S11**

[S10B]

When you stopped for more than 6 months, why did you stop?

TOGGLE of 19 choices
[Require ≥1 choices]

1 Advice from a GP/Health professional
2 TV advert for a nicotine replacement product
3 Government TV/radio/Press advert
4 Hearing about a new stop smoking treatment
5 A decision that smoking was too expensive
6 Being faced with smoking restrictions
7 I knew someone else who was stopping
8 Seeing a health warning on a cigarette pack
9 Being contacted by my local NHS Stop Smoking Services
10 Health problems I had at the time
11 A concern about future health problems
12 Attending a local stop smoking activity or event
13 Something said by family/friends/children
14 A significant birthday
15 The coronavirus outbreak
16 Restrictions on where I could smoke
-7 None of the above [**EXCLUSIVE**]
-1 Do not know [**EXCLUSIVE**]
-3 Prefer not to answer [**EXCLUSIVE**]

➔ **GO TO S11**

[S5B (UKB)]

SHOW IF (S5A = 3) OR (S1 > S1A AND S1 != 0 AND S1 != -3)

Why did you reduce your smoking?
(You can select more than one answer)

TOGGLE of 19 choices
[Require ≥1 choices]

1 Advice from a GP/Health professional
2 TV advert for a nicotine replacement product
3 Government TV/radio/Press advert
4 Hearing about a new stop smoking treatment
5 A decision that smoking was too expensive
6 Being faced with smoking restrictions
7 I knew someone else who was stopping
8 Seeing a health warning on a cigarette pack
9 Being contacted by my local NHS Stop Smoking Services
10 Health problems I had at the time
11 A concern about future health problems
12 Attending a local stop smoking activity or event
13 Something said by family/friends/children
14 A significant birthday
15 The coronavirus outbreak

16 Restrictions on where I could smoke
-7 None of the above [**EXCLUSIVE**]
-1 Do not know [**EXCLUSIVE**]
-3 Prefer not to answer [**EXCLUSIVE**]
➔ **GO TO S9**

[S9 (UKB)]

In the time that you smoked, have you ever stopped for more than 6 months?
SELECT one of 4 from
1 Yes > **GO TO S10**
0 No > **IF (S1 == 0 AND S3 != -3) GO TO S10**
ELSE GO TO S11
-1 Do not know > **IF (S1 == 0 AND S3 != -3) GO TO S10**
ELSE GO TO S11
-3 Prefer not to answer > **IF (S1 == 0 AND S3 != -3) GO TO S10**
ELSE GO TO S11

[S10 (TOOLKIT)]

Why did you stop smoking?
(You can select more than one answer) **TOGGLE of 19 choices**
[Require ≥1 choices]
1 Advice from a GP/Health professional
2 TV advert for a nicotine replacement product
3 Government TV/radio/Press advert
4 Hearing about a new stop smoking treatment
5 A decision that smoking was too expensive
6 Being faced with smoking restrictions
7 I knew someone else who was stopping
8 Seeing a health warning on a cigarette pack
9 Being contacted by my local NHS Stop Smoking Services
10 Health problems I had at the time
11 A concern about future health problems
12 Attending a local stop smoking activity or event
13 Something said by family/friends/children
14 A significant birthday
15 The coronavirus outbreak
16 Restrictions on where I could smoke
-7 None of the above [**EXCLUSIVE**]
-1 Do not know [**EXCLUSIVE**]
-3 Prefer not to answer [**EXCLUSIVE**]
➔ **GO TO S11**

[V4 (NHS3)]

How often, on average, did you use e-cigarettes (vaping) during the past 12 months?

SELECT one from 12

1 Never
2 Less than 1 time/mo
3 2-3 times/mo
4 1-2 times /week
5 3-6 times /week
6 1-4 times /day
7 5-14 times /day
8 15-24 times /day
9 25– 34 times /day
10 35 – 44 times /day
11 More than 45 times /day
-3 Prefer not to answer

[V5 (NHS3)]

What type of e-liquids/cartridges do you or did you use in your e-cigarettes?

TOGGLE of 10 choices

[Require ≥1 choices]

1 Fruit/dessert flavour WITHOUT nicotine
2 Fruit/dessert flavour WITH nicotine
3 Menthol flavour WITHOUT nicotine
4 Menthol flavour WITH nicotine
5 Tobacco flavour WITHOUT nicotine
6 Tobacco flavour WITH nicotine
7 Marijuana or THC concentrate
8 Alcohol
9 Other
-3 Prefer not to answer [**EXCLUSIVE**]

[S11V2 (CONNECT)]

In **the past year**, about how often were you around tobacco smoke from other people smoking in your home or at work?

SELECT one of 8 from

1 Every day
2 Most days of the week
3 One day per week
5 One day per month
6 A few days per year
0 Never **> GO TO A1**
-3 Prefer not to answer **> GO TO A1**

[S12 (UKB)]

On days you were around other people's tobacco smoke in **the past year** in your home or work, about how many hours per day were you around it?

SELECT one of 6 from

0 Less than 1 hour per day
1 1 to 2 hours per day
2 3 to 5 hours per day
3 6 to 9 hours per day
4 10 to 15 hours per day
5 More than 15 hours per day
-3 Prefer not to answer

➔ **IF TOBACCO _B = 1 GO TO V2 ELSE GO TO A1**

[A1 (UKB)]

About how often do you drink alcohol?

SELECT one of 7 from

1 Daily or almost daily **> GO TO A3B (UKB)**
2 Three or four times a week **> GO TO A3B (UKB)**
3 Once or twice a week **> GO TO A3B (UKB)**
4 One to three times a month **> GO TO A2B (UKB)**
5 Special occasions only **> GO TO A2B UKB)**
6 Never **> GO TO A1A (UKB)**
-3 Prefer not to answer **> GO TO END SECTION 3**

If this varies a lot, please provide an average considering your intake over the last year

[A1A (UKB)]

Did you previously drink alcohol?

SELECT one of 3 from

1 Yes **> GO TO A7A (UKB)**
0 No > **GO TO END SECTION 3**
-3 Prefer not to answer **> GO TO END SECTION 3**

[A2B (UKB)]

In an average MONTH, how many glasses of RED wine would you drink?
(There are six glasses in an average bottle)

Enter INTEGER

OR

-1 Do not know

OR

-3 Prefer not to answer

Please include sparkling red wine here.

[A2C (UKB)]

In an average MONTH, how many glasses of WHITE wine or champagne would you drink?

(There are six glasses in an average bottle)

Enter INTEGER

OR

-1 Do not know

OR

-3 Prefer not to answer

Please include sparkling white wine, prosecco and rosé here.

[A2E (UKB)]

In an average MONTH, how many pints of beer or cider would you drink?
(Include bitter, lager, stout, ale, Guinness)

Enter INTEGER

OR

-1 Do not know

OR

-3 Prefer not to answer

[A2A (UKB)]

In an average MONTH, how many measures of spirits or liqueurs would you drink?
(there are 25 standard measures in a normal sized bottle; spirits include drinks such as whisky, gin, rum, vodka, brandy)

Enter INTEGER

OR

-1 Do not know

OR

-3 Prefer not to answer

[A2F (UKB)]

In an average MONTH, how many glasses of fortified wine would you drink? (There are 12 glasses in an average bottle) (Fortified wines include drinks such as sherry, port, vermouth)

Enter INTEGER

OR

-1 Do not know

OR

-3 Prefer not to answer

Fortified wines include: Sherry, Port, Vermouth, Muscat,Madeira, Malaga, Tokay, Frontignan, Frontignac.

[A2G (UKB)]

In an average MONTH, how many glasses of other alcoholic drinks (such as alcopops) would you drink?

Enter INTEGER

OR

-1 Do not know

OR

-3 Prefer not to answer

➔ **GO TO A5**

[A3B (UKB)]

In an average WEEK, how many glasses of RED wine would you drink?
(There are six glasses in an average bottle)

Enter INTEGER

OR

-1 Do not know

OR

-3 Prefer not to answer

Please include sparkling red wine here.

[A3C (UKB)]

In an average WEEK, how many glasses of WHITE wine or champagne would you drink?
(There are six glasses in an average bottle)

Enter INTEGER

OR

-1 Do not know

OR

-3 Prefer not to answer

Please include sparkling white wine, prosecco and rosé here.

[A3E (UKB)]

In an average WEEK, how many pints of beer or cider would you drink?
(Include bitter, lager, stout, ale, Guinness)

Enter INTEGER

OR

-1 Do not know

OR

-3 Prefer not to answer

[A3A (UKB)]

In an average WEEK, how many measures of spirits or liqueurs would you drink?
(there are 25 standard measures in a normal sized bottle; spirits include drinks such as whisky, gin, rum, vodka, brandy)

Enter INTEGER

OR

-1 Do not know

OR

-3 Prefer not to answer

For mixed drinks that contain spirits or liqueurs, count one bottle as one measure. There is a question later on alcopops

[A3F (UKB)]

In an average WEEK, how many glasses of fortified wine would you drink?
(There are 12 glasses in an average bottle; Fortified wines include drinks such as sherry, port, vermouth) **Enter INTEGER**

OR

-1 Do not know

OR

-3 Prefer not to answer

Fortified wines include: Sherry, Port, Vermouth, Muscat,Madeira, Malaga, Tokay, Frontignan, Frontignac.

[A3G (UKB)]

In an average WEEK, how many glasses of other alcoholic drinks (such as alcopops) would you drink?

Enter INTEGER

OR

-1 Do not know

OR

-3 Prefer not to answer

[A5 (UKB)]

When you drink alcohol is it usually with meals?

SELECT one of 5 from

1 Yes

0 No

-6 It varies

-1 Do not know

-3 Prefer not to answer

[A6 (UKB)]

Compared to 10 years ago, do you drink?

SELECT one of 5 from

1 More nowadays

2 About the same

3 Less nowadays **> GO TO A7 (UKB)**

-1 Do not know

-3 Prefer not to answer

➔ **GO TO END SECTION 3**

[A7 (TOOLKIT)]

Which of the following, if any, do you think contributed to you reducing the amount you drank?

TOGGLE of 14 choices
[Require ≥1 choices]

1 Advice from a doctor/health worker
2 Government TV/radio/press article
3 A decision drinking was too expensive
4 I knew someone else who was cutting down
5 Health problems I had at the time
6 A concern about future health problems
7 Something said by family/friends/children
8 A significant birthday or event
9 Improve my fitness
10 Help with weight loss
11 Detox (e.g., Dry January)
12 Other reason
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[A7A (TOOLKIT)]

Which of the following, if any, do you think contributed to you stopping drinking alcohol?

TOGGLE of 14 choices
[Require ≥1 choices]

1 Advice from a doctor/health worker
2 Government TV/radio/press article
3 A decision drinking was too expensive
4 Financial reasons I knew someone else who was cutting down
5 Other reason Health problems I had at the time
6 A concern about future health problems
7 Something said by family/friends/children
8 A significant birthday or event
9 Improve my fitness
10 Help with weight loss
11 Detox (e.g., Dry January)
12 Other
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

----------END OF SECTION 3----------

Family health history [SECTION 4]

We ask about your family history because some diseases and health issues can be passed down generations.

In a long-term study like ours, this helps us identify when this is happening, with who and why and helps us work toward solving these issues for future generations.
Now, some questions about you and your family.

[D2 (UKB)]

Where were you born?

SELECT one of 12 from

1 England > **GO TO Y1 (UKB)**
2 Wales > **GO TO Y1 (UKB)**
3 Scotland **> GO TO Y1 (UKB)**
4 Northern Ireland **> GO TO Y1 (UKB)**
5 UK (don't know country) > **GO TO Y1 (UKB)**
6 Republic of Ireland
7 India
8 Pakistan
9 Poland
10 Elsewhere
-1 Do not know **> GO TO Y1 (UKB)**
-3 Prefer not to answer > **GO TO Y1 (UKB)**

[D2A (UKB)]

What year did you first come to live in the United Kingdom?

Enter INTEGER
OR
-1 Do not know
OR
-3 Prefer not to answer

Please give the year that you FIRST came to live in the United Kingdom. Do not count years if you came to holiday or visit friends or family.

[Y1 (UKB)]

Were you adopted as a child?

SELECT one of 4 from

1 Yes
0 No
-1 Do not know
-3 Prefer not to answer

[Y13 (UKB)]

Is your biological father still alive?

SELECT one of 4 from

1 Yes
0 No **> GO TO Y13B (UKB)**

-1 Do not know **> GO TO Y13D (UKB)**
-3 Prefer not to answer **> GO TO Y13D (UKB)**

[Y13A (UKB)]

What is his age now?

Enter INTEGER
[Require > current age, ≤ 122
Units: years]
OR
-1 Do not know
OR
-3 Prefer not to answer

[Y13B (UKB)]

What was his age when he died?

Enter INTEGER
[Require ≥ 10, ≤ 122
Units: years]
OR
-1 Do not know
OR
-3 Prefer not to answer

[Y13D (UKB)]

Has/did your biological father ever suffer from?
You can select more than one answer. We will ask more details for any type of disorder that you select here

TOGGLE
[Require ≥1 choices]
1 Autoimmune disorder **> GO TO AUTO_A_DAD**
2 Blood disorders (Anaemia) **> GO TO BLOOD_A_DAD**
3 Cancer **> GO TO CANC_A_DAD**
4 Digestive system or liver problems **> GO TO DIG_A_DAD**
5 Endocrine, nutritional and metabolic disorders (e.g., diabetes, thyroid disorder, vitamin deficiencies) **> GO TO EN_A_DAD**
6 Eye or visual problems **> GO TO EYE_A_DAD**
7 Fractures, breaks, or joint problems **> GO TO FRAC_A_DAD**
8 Heart or circulatory disease (e.g., high blood pressure or stroke) **> GO TO HEART_A_DAD**
9 Kidney or urinary system disorders **> GO TO KIDN_A_DAD**
10 Lung or respiratory problems **> GO TO LUNG_A_DAD**
11 Mental health conditions (e.g. depression, bipolar disorder) **> GO TO MH_A_DAD**

12 Neurodevelopmental conditions (e.g. Autism spectrum disorder, ADHD) > **GO TO ND_A_DAD**
13 Neurological disorders (things that affect that brain or nervous system) > **GO TO NEU_A_DAD**
14 Reproductive system problems > **GO TO REPRO_A_DAD**
15 Other not listed > **GO TO Y16 (UKB)]**
-7 None of the above> **GO TO 6 (UKB)]**
-1 Do not know **[EXCLUSIVE] > GO TO Y16 (UKB)]**
-3 Prefer not to answer **[EXCLUSIVE] > GO TO Y16 (UKB)]**

Answer this question for blood relations only. If you are not sure if your father suffered from any of the listed illnesses, please select 'Do not know'. If you know your father suffered from certain listed illnesses but are unsure about others, only select the ones you are sure about.

[AUTO_A_DAD]

Has/was your father ever diagnosed with any of the following autoimmune disorders?

TOGGLE
[Require ≥1 choices]

1 Rheumatoid arthritis
2 Lupus
3 Inflammatory Bowel Disease (IBD)
4 Multiple Sclerosis (MS)
5 Graves' disease
6 Guillain-Barre syndrome
7 Psoriasis
8 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[BLOOD_A_DAD]

Has/was your father ever diagnosed with any of the following types of anaemia?

TOGGLE
[Require ≥1 choices]

1 Iron deficiency anaemia
2 Vitamin deficiency anaemia
3 Sickle cell anaemia
4 Aplastic anaemia
5 Thalassaemia
6 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[CANC_A_DAD (CONNECT)]

Which type(s) of cancer specifically was your father diagnosed with?
Please indicate where the cancer originated, even if it spread to other body areas

TOGGLE

[Require ≥1 choices]

1 Anal
2 Bladder
3 Brain
4 Breast
6 Colon/rectal
7 Oesophageal
8 Head and neck (Including cancers of the mouth, sinuses, nose, or throat. Not including brain or skin cancers.)
9 Gastric
10 Kidney
11 Leukaemia (blood and bone marrow)
12 Liver
13 Lung or bronchial
14 Lymphoma
16 Pancreatic
17 Prostate
18 Skin **> GO TO DAD_CANC_B**
19 Stomach
20 Testicular
21 Thyroid
23 Another type of cancer
-1 I know they had cancer, but don't know what type
-7 None of the above **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[CANC_B_DAD (CONNECT)]

What type of skin cancer specifically was your father diagnosed with?

TOGGLE

[Require ≥1 choices]

1 Melanoma
2 Basal cell
3 Squamous cell
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[DIG_A_DAD (CONNECT)]

Has/was your father ever diagnosed with any of the following digestive system or liver problems?

TOGGLE

[Require ≥1 choices]

1 Gastro-oesophageal Acid Reflux (GORD)
2 Barrett's Oesophagus
3 Irritable bowel syndrome
4 Inflammatory Bowel Disease
5 Diverticulitis or Diverticulosis
6 Ulcerative Colitis
7 Crohn's Disease
8 Coeliac Disease (also known as Gluten-Sensitive Enteropathy)
9 Gallstones (Biliary Stones)
10 Fatty liver disease
11 Liver Cirrhosis
12 Hepatitis
13 Pancreatitis
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[EN_A_DAD]

Has/was your father ever diagnosed with the following conditions?

TOGGLE

[Require ≥1 choices]

1 Type 1 diabetes
2 Type 2 diabetes
3 Overactive thyroid
4 Underactive thyroid
5 Cushing syndrome
6 Lactose intolerance
7 Vitamin A deficiency
8 Thiamine deficiency
9 Vitamin D deficiency
10 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[EYE_A_DAD]

Has/was your father ever diagnosed with any of the following eye or visual problems?

TOGGLE

[Require ≥1 choices]

1 Glaucoma
2 Visual impairment including blindness
3 Double vision
4 Night blindness
5 Colour blindness
6 Macular degeneration
7 Cataracts
8 Retinal detachment
9 Diabetic retinopathy
10 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[FRAC_A_DAD]

What type of fractures, breaks, joint or bone problems did your father experience?

TOGGLE

[Require ≥1 choices]

1 Hip fracture
2 Osteoporosis
3 Osteoarthritis (arthritis)
4 Gout
5 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[HEART_A_DAD (CONNECT)]

Has/was your father ever diagnosed with any of the following heart or circulatory diseases?

TOGGLE

[Require ≥1 choices]

1 B-12 Deficiency (Pernicious Anaemia)
2 Coronary Artery/Coronary Heart Disease
3 Congestive Heart Failure
4 High Cholesterol
5 Heart Attack (Myocardial Infarction)
6 Abnormal Heart Rhythm (Arrhythmia)
7 Chest Pain (Angina)
8 Heart Valve Problems
9 High Blood Pressure (Hypertension) [Please do **not** include hypertension during pregnancy.]
10 Blood Clots (Deep Vein Thrombosis, Pulmonary Embolism)

11 Stroke
12 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[KIDN_A_DAD (CONNECT]

Has/was your father ever diagnosed with any of the following kidney or urinary tract problems?

TOGGLE

[Require ≥1 choices]

1 Kidney stones
2 Chronic kidney disease (or chronic kidney failure)
3 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[LUNG_A _DAD (CONNECT)]

Has/was your father ever diagnosed with any of the following lung or respiratory conditions?

TOGGLE

[Require ≥1 choices]

1 Chronic Obstructive pulmonary disease, COPD (including emphysema and chronic bronchitis)
2 Lung fibrosis
3 Bronchiectasis
4 Asthma
5 Hay Fever (Allergic to pollen or Allergic Rhinitis)
6 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[ND_A_DAD]

Has/was your father ever diagnosed with one or more of the following conditions by a professional, even if your father don't have it currently? Please include disorders even if your father did not need treatment for them or if your father did not agree with the diagnosis. Select ALL that apply

TOGGLE

[Require ≥1 choices]

1 Autism spectrum disorder
2 Developmental learning disorders
3 Attention deficit hyperactivity disorder (ADHD)

4 Disorder of intellectual development
5 Developmental motor coordination disorder
6 Developmental speech or language disorders
7 Stereotyped movement disorder
8 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[MH_A_DAD]

Has your father ever been diagnosed with one or more of the following conditions by a professional, even if your father don't have it currently? Please include disorders even if your father did not need treatment for them or if your father did not agree with the diagnosis. Select ALL that apply

TOGGLE

[Require ≥1 choices]

1 Anxiety **> GO TO ANX_B_DAD**
2 Bipolar disorder
3 Body dysmorphia
4 Depression **> GO TO DEP_B_DAD**
6 Post Traumatic Stress Disorder
7 Obsessive Compulsive Disorder
8 Eating disorder **> GO TO EATD_B _DAD**
9 Psychosis
10 Schizophrenia
11 Schizoaffective disorder
12 Personality disorder
13 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[ANX_B_DAD]

Which anxiety disorder(s) specifically was your father diagnosed with in their lifetime?

TOGGLE

[Require ≥1 choices]

1 Generalised anxiety disorder
2 Agoraphobia
3 Social anxiety disorder
4 Panic disorder
5 Panic attacks
6 Specific phobia
7 Other (not listed)
-7 None of the above **[EXCLUSIVE]**

-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[DEP_B_DAD]

Which depressive disorder(s) specifically was your father diagnosed with in their lifetime?

TOGGLE

[Require ≥1 choices]

1 Major Depressive Disorder
2 Perinatal depression
3 Postnatal depression
4 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[EATD_B_DAD]

Which eating disorder(s) specifically was your father diagnosed with in their lifetime?

TOGGLE

[Require ≥1 choices]

1 Anorexia nervosa
2 Atypical anorexia nervosa
3 Bulimia nervosa
4 Binge eating disorder
5 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[NEU_A_DAD]

Has/was your father ever diagnosed with any of the following neurological or brain disorders?

TOGGLE

[Require ≥1 choices]

1 Epilepsy
2 Parkinson's disease
3 Alzheimer's disease/dementia
4 Early onset Alzheimer's disease/dementia
5 Vascular dementia
6 Migraine with aura
7 Migraine without aura
8 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**

-3 Prefer not to answer **[EXCLUSIVE]**

[REPRO_A_DAD (CONNECT)]

Has/was your father ever diagnosed with any of the following conditions?

TOGGLE

[Require ≥1 choices]

3 Enlarged prostate

4 Fibrocystic Breast, or another Benign Breast Disease (such as proliferative Benign Breast Disease or LCIS)

5 Ductal Carcinoma in situ (DCIS)

6 Other (not listed)

-7 None of the above **[EXCLUSIVE]**

-1 Do not know **[EXCLUSIVE]**

-3 Prefer not to answer **[EXCLUSIVE]**

[Y16 (UKB)]

Is your biological mother still alive?

SELECT one of 4 from

1 Yes

0 No **> GO TO Y16B (UKB)**

-1 Do not know **> GO TO Y16D (UKB)**

-3 Prefer not to answer **> GO TO Y16D (UKB)**

[Y16A (UKB)]

What is her age now?

Enter INTEGER

[Require > current age, ≤ 122

Units: years]

OR

-1 Do not know

OR

-3 Prefer not to answer

[Y16B (UKB)]

What was her age when she died?

Enter INTEGER

[Require > current age, ≤ 122

Units: years]

OR

-1 Do not know

OR

-3 Prefer not to answer

[Y16D (UKB)]

Has/did your biological mother ever suffer from? (You can select more than one answer)

TOGGLE

[Require ≥1 choices]

1 Autoimmune disorder **> GO TO AUTO_A_MOM**
2 Blood disorders (Anaemia) **> GO TO BLOOD_A_MOM**
3 Cancer **> GO TO CANC_A_MOM**
4 Digestive system or liver problems **> GO TO DIG_A_MOM**
5 Endocrine, nutritional and metabolic disorders (e.g., diabetes, thyroid disorder, vitamin deficiencies) **> GO TO EN_A_MOM**
6 Eye or visual problems **> GO TO EYE_A_MOM**
7 Fractures, breaks, or joint problems **> GO TO FRAC_A_MOM**
8 Heart or circulatory disease (e.g. high blood pressure or stroke) **> GO TO HEART_A_MOM**
9 Kidney or urinary system disorders **> GO TO KIDN_A_MOM**
10 Lung or respiratory problems **> GO TO LUNG_A_MOM**
11 Mental health conditions (e.g .depression, bipolar disorder) **> GO TO MH_A_MOM**
12 Neurodevelopmental conditions (e.g. Autism spectrum disorder, ADHD) **> GO TO ND_A_MOM**
13 Neurological disorders (things that affect that brain or nervous system) **> GO TO NEU_A_MOM**
14 Reproductive system problems **> GO TO REPRO_A_MOM**
15 Other not listed **> GO TO Y17 (UKB)]**
-7 None of the above **[EXCLUSIVE] > GO TO 7 (UKB)]**
-1 Do not know **[EXCLUSIVE] > GO TO Y17 (UKB)]**
-3 Prefer not to answer **[EXCLUSIVE] > GO TO Y17 (UKB)]**

Answer this question for blood relations only. If you are not sure if your mother suffered from any of the listed illnesses, please select 'Do not know'. If you know your mother suffered from certain listed illnesses but are unsure about others, only select the ones you are sure about.

[AUTO_A_MOM]

Has/was your mother ever diagnosed with any of the following autoimmune disorders?

TOGGLE

[Require ≥1 choices]

1 Rheumatoid arthritis
2 Lupus
3 Inflammatory Bowel Disease (IBD)
4 Multiple Sclerosis (MS)
5 Graves' disease
6 Guillain-Barre syndrome
7 Psoriasis

8 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[BLOOD_A_MOM]

Has/was your mother ever diagnosed with any of the following types of anaemia?

TOGGLE

[Require ≥1 choices]

1 Iron deficiency anaemia
2 Vitamin deficiency anaemia
3 Sickle cell anaemia
4 Aplastic anaemia
5 Thalassaemia
6 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[CANC_A_MOM (CONNECT)]

Which type(s) of cancer specifically was your mother diagnosed with?
Please indicate where the cancer originated, even if it spread to other body areas

TOGGLE

[Require ≥1 choices]

1 Anal
2 Bladder
3 Brain
4 Breast
5 Cervical
6 Colon/rectal
7 Oesophageal
8 Head and neck (Including cancers of the mouth, sinuses, nose, or throat. Not including brain or skin cancers.)
9 Gastric
10 Kidney
11 Leukaemia (blood and bone marrow)
12 Liver
13 Lung or bronchial
14 Lymphoma
15 Ovarian
16 Pancreatic
18 Skin **-> GO TO CANC_B_MOM**
19 Stomach

21 Thyroid
22 Uterine (endometrial)
23 Another type of cancer
-1 I know they had cancer, but don't know what type
-7 None of the above **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[CANC_B_MOM (CONNECT)]

What type of skin cancer specifically was your mother diagnosed with?

TOGGLE

[Require ≥1 choices]

1 Melanoma
2 Basal cell
3 Squamous cell
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[DIG_A_MOM (CONNECT)]

Has/was your mother ever diagnosed with any of the following digestive system problems?

TOGGLE

[Require ≥1 choices]

1 Gastro-oesophageal Acid Reflux (GORD)
2 Barrett's Oesophagus
3 Irritable bowel syndrome
4 Inflammatory Bowel Disease
5 Diverticulitis or Diverticulosis
6 Ulcerative Colitis
7 Crohn's Disease
8 Coeliac Disease (also known as Gluten-Sensitive Enteropathy)
9 Gallstones (Biliary Stones)
10 Fatty liver disease
11 Liver Cirrhosis
12 Hepatitis
13 Pancreatitis
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[EN_A_MOM]

Has/was your mother ever diagnosed with the following conditions?

TOGGLE

[Require ≥1 choices]

1 Type 1 diabetes
2 Type 2 diabetes
3 Overactive thyroid
4 Underactive thyroid
5 Cushing syndrome
6 Lactose intolerance
7 Vitamin A deficiency
8 Thiamine deficiency
9 Vitamin D deficiency
10 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[EYE_A_MOM]

Has/was your mother ever diagnosed with any of the following eye or visual problems?

TOGGLE

[Require ≥1 choices]

1 Glaucoma
2 Visual impairment including blindness
3 Double vision
5 Night blindness
6 Colour blindness
6 Macular degeneration
7 Cataracts
8 Retinal detachment
9 Diabetic retinopathy
10 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[FRAC_A_MOM]

What type of fractures, breaks, joint or bone problems did your mother experience?

TOGGLE

[Require ≥1 choices]

1 Hip fracture
2 Osteoporosis
3 Osteoarthritis (arthritis)
4 Gout
5 Other (not listed)
-7 None of the above **[EXCLUSIVE]**

-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[HEART_A_MOM (CONNECT)]

Has/was your mother ever diagnosed with any of the following heart or circulatory diseases?

TOGGLE

[Require ≥1 choices]

1 B-12 Deficiency (Pernicious Anaemia)
2 Coronary Artery/Coronary Heart Disease
3 Congestive Heart Failure
4 High Cholesterol
5 Heart Attack (Myocardial Infarction)
6 Abnormal Heart Rhythm (Arrhythmia)
7 Chest Pain (Angina)
8 Heart Valve Problems
9 High Blood Pressure (Hypertension) [Please do **not** include hypertension during pregnancy.]
10 Blood Clots (Deep Vein Thrombosis, Pulmonary Embolism)
11 Stroke
12 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[KIDN_A_MOM (CONNECT]

Has/was your mother ever diagnosed with any of the following kidney or urinary tract problems?

TOGGLE

[Require ≥1 choices]

1 Kidney stones
2 Chronic kidney disease (or chronic kidney failure)
3 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[LUNG_A _MOM (CONNECT)]

Has/was your mother ever diagnosed with any of the following lung or respiratory conditions?

TOGGLE

[Require ≥1 choices]

1 Chronic Obstructive pulmonary disease, COPD (including emphysema and chronic bronchitis)
2 Lung fibrosis
3 Bronchiectasis

4 Asthma
5 Hay Fever (Allergic to pollen or Allergic Rhinitis)
6 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[ND_A_MOM]

Has/was your mother ever diagnosed with one or more of the following conditions by a professional, even if they don't have it currently? Please include disorders even if your mother did not need treatment for them or if your mother did not agree with the diagnosis. Select ALL that apply

TOGGLE

[Require ≥1 choices]

1 Autism spectrum disorder
2 Developmental learning disorders
3 Attention deficit hyperactivity disorder (ADHD)
4 Disorder of intellectual development
5 Developmental motor coordination disorder
6 Developmental speech or language disorders
7 Stereotyped movement disorder
8 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 I don't know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[MH_A_MOM]

Has/was your mother ever diagnosed with one or more of the following conditions by a professional, even if they don't have it currently?
Please include disorders even if your mother did not need treatment for them or if your mother did not agree with the diagnosis. Select ALL that apply

TOGGLE

[Require ≥1 choices]

1 Anxiety **> GO TO ANX_B_MOM**
2 Bipolar disorder
3 Body dysmorphia
4 Depression **> GO TO DEP_B_MOM**
5 Premenstrual dysphoric disorder
6 Post Traumatic Stress Disorder
7 Obsessive Compulsive Disorder
8 Eating disorder **> GO TO EATD_B_MOM**
9 Psychosis
10 Schizophrenia

11 Schizoaffective disorder
12 Personality disorder
13 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[ANX_B_MOM]

Which anxiety disorder(s) specifically was your mother diagnosed with in their lifetime?

TOGGLE

[Require ≥1 choices]

1 Generalised anxiety disorder
2 Agoraphobia
3 Social anxiety disorder
4 Panic disorder
5 Panic attacks
6 Specific phobia
7 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[DEP_B_MOM]

Which depressive disorder(s) specifically was your mother diagnosed with in their lifetime?

TOGGLE

[Require ≥1 choices]

1 Major Depressive Disorder
2 Perinatal depression
3 Postnatal depression
4 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[EATD_B_MOM]

Which eating disorder(s) specifically was your mother diagnosed with in their lifetime?

TOGGLE

[Require ≥1 choices]

1 Anorexia nervosa
2 Atypical anorexia nervosa
3 Bulimia nervosa
4 Binge eating disorder

5 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[NEU_A_MOM]

Has/was your mother ever diagnosed with any of the following neurological or brain disorders?

TOGGLE

[Require ≥1 choices]

1 Epilepsy
2 Parkinson's disease
3 Alzheimer's disease/dementia
4 Early onset Alzheimer's disease/dementia
5 Vascular dementia
6 Migraine with aura
7 Migraine without aura
8 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[REPRO_A_MOM (CONNECT)]

Has/was your mother ever diagnosed with any of the following conditions?

TOGGLE

[Require ≥1 choices]

1 Endometriosis
2 Polycystic Ovary Syndrome (PCOS)
4 Fibrocystic Breast, or another Benign Breast Disease (such as proliferative Benign Breast Disease or LCIS)
5 Ductal Carcinoma in situ (DCIS)
6 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 I don't know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[Y17 (UKB)]

How many brothers do you have?
(Please include those who have died, and twin brothers. Do not include half-brothers, stepbrothers or adopted brothers)

Enter INTEGER

[Require ≥ 0, ≤ 25]

OR

-1 Do not know

OR

-3 Prefer not to answer

➔ **IF ANSWER > 0, GO TO Y19**

[Y18 (UKB)]

How many sisters do you have?
(Please include those who have died, and twin sisters. Do not include half-sisters, stepsisters or adopted sisters)

Enter INTEGER

[Require ≥ 0, ≤ 25]

OR

-1 Do not know

OR

-3 Prefer not to answer

➔ **IF Y17 > 0 OR IF ANSWER > 0, GO TO Y19**

➔ **IF (ANSWER = 0 OR -1 OR -3) AND Y17 (ANSWER = 0 OR -1 OR -3), GO TO END SECTION**

[Y19 (UKB)]

Have any of your biological brothers or sisters suffered from any of the following illnesses? Please select all that apply
We will ask more details for any type of disorder that you select here

TOGGLE

[Require ≥1 choices]

1 Autoimmune disorder **> GO TO AUTO_A_SIB**

2 Blood disorders (Anaemia) **> GO TO BLOOD_A**

3 Cancer **> GO TO CANC_A_SIB**

4 Digestive system or liver problems **> GO TO DIG_A_SIB**

5 Endocrine, nutritional and metabolic disorders (e.g., diabetes, thyroid disorder, vitamin deficiencies) **> GO TO EN_A_SIB**

6 Eye or visual problems **> GO TO EYE_A_SIB**

7 Fractures, breaks, or joint problems **> GO TO FRAC_A_SIB**

8 Heart or circulatory disease (e.g. high blood pressure or stroke) **> GO TO HEART_A_SIB**

9 Kidney or urinary system disorders **> GO TO KIDN_A_SIB**

10 Lung or respiratory problems **> GO TO LUNG_A_SIB**

11 Mental health conditions (e.g. depression, bipolar disorder) **> GO TO MH_A_SIB**

12 Neurodevelopmental conditions (e.g., Autism spectrum disorder, ADHD) **-> GO TO ND_A_SIB**

13 Neurological disorders (things that affect that brain or nervous system E.g., Epilepsy) **> GO TO NEU_A_SIB**

14 Reproductive system problems **> GO TO REPRO_A_SIB**

15 Other not listed **> GO TO END SECTION**

-7 None of the above **[EXCLUSIVE] > GO TO END SECTION**
-1 Do not know **[EXCLUSIVE] > GO TO END SECTION**
-3 Prefer not to answer **[EXCLUSIVE] > GO TO END SECTION**

Answer this question for blood relations only.
Include any sisters or brothers who have died. If you are not sure if your sisters or brothers suffered from any of the listed illnesses, please select 'Do not know'.
If more than one sister or brother has suffered from any of the listed illnesses, you only need to select the illness once.

[AUTO_A_SIB]

Has/was your brother or sister ever diagnosed with any of the following autoimmune disorders?

TOGGLE

[Require ≥1 choices]

1 Rheumatoid arthritis
2 Lupus
3 Inflammatory Bowel Disease (IBD)
4 Multiple Sclerosis (MS)
5 Graves' disease
6 Guillain-Barre syndrome
7 Psoriasis
8 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[BLOOD_A_SIB]

Has your brother or sister ever been diagnosed with any of the following types of anaemia?

TOGGLE

[Require ≥1 choices]

1 Iron deficiency anaemia
2 Vitamin deficiency anaemia
3 Sickle cell anaemia
4 Aplastic anaemia
5 Thalassaemia
6 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[CANC_A_SIB (CONNECT)]

Which type(s) of cancer specifically were your brother or sister diagnosed with?
Please indicate where the cancer originated, even if it spread to other body areas

TOGGLE
[Require ≥1 choices]

1 Anal
2 Bladder
3 Brain
4 Breast
5 Cervical
6 Colon/rectal
7 Oesophageal
8 Head and neck (Including cancers of the mouth, sinuses, nose, or throat. Not including brain or skin cancers.)
9 Gastric
10 Kidney
11 Leukaemia (blood and bone marrow)
12 Liver
13 Lung or bronchial
14 Lymphoma
15 Ovarian
16 Pancreatic
17 Prostate
18 Skin > **GO TO CANC_B_SIB**
19 Stomach
20 Testicular
21 Thyroid
22 Uterine (endometrial)
23 Another type of cancer
-1 I know they had cancer, but don't know what type
-7 None of the above **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[CANC_B_SIB (CONNECT)]

What type of skin cancer specifically were your brother or sister diagnosed with?

TOGGLE
[Require ≥1 choices]

1 Melanoma
2 Basal cell
3 Squamous cell
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[DIG_A_SIB (CONNECT)]

Has your brother or sister ever been diagnosed with any of the following digestive system problems?

TOGGLE

[Require ≥1 choices]

1 Gastro-oesophageal Acid Reflux (GORD)
2 Barrett's Oesophagus
3 Irritable bowel syndrome
4 Inflammatory Bowel Disease
5 Diverticulitis or Diverticulosis
6 Ulcerative Colitis
7 Crohn's Disease
8 Coeliac Disease (also known as Gluten-Sensitive Enteropathy)
9 Gallstones (Biliary Stones)
10 Fatty liver disease
11 Liver Cirrhosis
12 Hepatitis
13 Pancreatitis
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[EN_A_SIB]

Has your brother or sister ever been diagnosed with the following conditions?

TOGGLE

[Require ≥1 choices]

1 Type 1 diabetes
2 Type 2 diabetes
3 Overactive thyroid
4 Underactive thyroid
5 Cushing syndrome
6 Lactose intolerance
7 Vitamin A deficiency
8 Thiamine deficiency
9 Vitamin D deficiency
10 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[EYE_A_SIB]

Has your brother or sister ever been diagnosed with any of the following eye or visual problems?

TOGGLE

[Require ≥1 choices]

1 Glaucoma
2 Visual impairment including blindness
3 Double vision
4 Night blindness
5 Colour blindness
6 Macular degeneration
7 Cataracts
8 Retinal detachment
9 Diabetic retinopathy
10 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[FRAC_A_SIB]

What type of fractures, breaks, joint or bone problems have your brother or sister experienced?

TOGGLE

[Require ≥1 choices]

1 Hip fracture
2 Osteoporosis
3 Osteoarthritis (arthritis)
4 Gout
5 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[HEART_A_SIB (CONNECT)]

Has your brother or sister ever been diagnosed with any of the following heart or circulatory diseases?

TOGGLE

[Require ≥1 choices]

1 B-12 Deficiency (Pernicious Anaemia)
2 Coronary Artery/Coronary Heart Disease
3 Congestive Heart Failure
4 High Cholesterol
5 Heart Attack (Myocardial Infarction)
6 Abnormal Heart Rhythm (Arrhythmia)
7 Chest Pain (Angina)
8 Heart Valve Problems
9 High Blood Pressure (Hypertension) [Please do **not** include hypertension during pregnancy.]
10 Blood Clots (Deep Vein Thrombosis, Pulmonary Embolism)

11 Stroke
12 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[KIDN_A_SIB (CONNECT]

Has your brother or sister ever been diagnosed with any of the following kidney or urinary tract problems?

TOGGLE

[Require ≥1 choices]

1 Kidney stones
2 Chronic kidney disease (or chronic kidney failure)
3 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[LUNG_A _SIB (CONNECT)]

Has your brother or sister ever been diagnosed with any of the following lung or respiratory conditions?

TOGGLE

[Require ≥1 choices]

1 Chronic Obstructive pulmonary disease, COPD (including emphysema and chronic bronchitis)
2 Lung fibrosis
3 Bronchiectasis
4 Asthma
5 Hay Fever (Allergic to pollen or Allergic Rhinitis)
6 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[ND_A_SIB]

Has your brother or sister ever been diagnosed with one or more of the following conditions by a professional, even if your brother or sister don't have it currently? Please include disorders even if your brother or sister did not need treatment for them or if your brother or sister did not agree with the diagnosis. Select ALL that apply

TOGGLE

[Require ≥1 choices]

1 Autism spectrum disorder

2 Developmental learning disorders
3 Attention deficit hyperactivity disorder (ADHD)
4 Disorder of intellectual development
5 Developmental motor coordination disorder
6 Developmental speech or language disorders
7 Stereotyped movement disorder
8 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[MH_A_SIB]

Has your brother or sister ever been diagnosed with one or more of the following conditions by a professional, even if your brother or sister don't have it currently? Please include disorders even if your brother or sister did not need treatment for them or if your brother or sister did not agree with the diagnosis. Select ALL that apply

TOGGLE

[Require ≥1 choices]

1 Anxiety **> GO TO ANX_B_SIB**
2 Bipolar disorder
3 Body dysmorphia
4 Depression **> GO TO DEP_B_SIB**
5 Premenstrual dysphoric disorder
6 Post Traumatic Stress Disorder
7 Obsessive Compulsive Disorder
8 Eating disorder **> GO TO EATD_B _SIB**
9 Psychosis
10 Schizophrenia
11 Schizoaffective disorder
12 Personality disorder
13 Other (not listed)
-7 None of the **above [EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[ANX_B_SIB]

Which anxiety disorder(s) specifically has your brother or sister been diagnosed with in their lifetime?

TOGGLE

[Require ≥1 choices]

1 Generalised anxiety disorder
2 Agoraphobia
3 Social anxiety disorder

4 Panic disorder
5 Panic attacks
6 Specific phobia
7 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[DEP_B_SIB]

Which depressive disorder(s) specifically has your brother or sister been diagnosed with in their lifetime?

TOGGLE

[Require ≥1 choices]

1 Major Depressive Disorder
2 Perinatal depression
3 Postnatal depression
4 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[EATD_B_SIB]

Which eating disorder(s) specifically has your brother or sister been diagnosed with in their lifetime?

TOGGLE

[Require ≥1 choices]

1 Anorexia nervosa
2 Atypical anorexia nervosa
3 Bulimia nervosa
4 Binge eating disorder
5 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 I don't know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[NEU_A_SIB]

Has your brother or sister ever been diagnosed with any of the following neurological or brain disorders?

TOGGLE

[Require ≥1 choices]

1 Epilepsy
2 Parkinson's disease

3 Alzheimer's disease/dementia
4 Early onset Alzheimer's disease/dementia
5 Vascular dementia
6 Migraine with aura
7 Migraine without aura
8 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[REPRO_A_SIB (CONNECT)]

Has your brother or sister ever been diagnosed with any of the following conditions?

TOGGLE

[Require ≥1 choices]

1 Endometriosis
2 Polycystic Ovary Syndrome (PCOS)
3 Enlarged prostate
4 Fibrocystic Breast, or another Benign Breast Disease (such as proliferative Benign Breast Disease or LCIS)
5 Ductal Carcinoma in situ (DCIS)
6 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

----------END OF SECTION 4 ----------

Your health history [SECTION 5]

This section includes questions about:

- Your general health and any illnesses you may have had in the past.
- Screening tests that you may have had done.
- Details on your reproductive health, covering areas such as children you have had and puberty.
- Medications you might be taking.
- Your mental wellbeing.
- All the information you give us is treated confidentially. Now some questions about your health.

[H3 (UKB)]

In general, how would you rate your overall health?

SELECT one of 6 from

1 Excellent
2 Good
3 Fair
4 Poor
-1 Do not know
-3 Prefer not to answer

[H4 (UKB)]

Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?

SELECT one of 4 from

1 Yes
0 No **> GO TO H4B**
-1 Do not know
-3 Prefer not to answer

[H4A (UKB)]

Do you receive any of the following? (You can select more than one answer)

TOGGLE of 6 choices

[Require ≥1 choices]

1 Attendance allowance
2 Personal independence payment (previously disability living allowance)
3 Blue badge
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

Only select a response if you personally receive the benefit. Do not include if your spouse or someone in your household receives one of these benefits.

[H4B (UKB)]

Do you use private healthcare?

SELECT one of 6 from

1 Yes, all of the time
2 Yes, most of the time
3 Yes, sometimes
4 No, never
-1 Do not know
-3 Prefer not to answer

If you have access to private healthcare but always use the NHS, select No, never.

[COVID (WT Q)]

Do you think that you have or have had COVID-19?

SELECT one of 6 from

1 Yes, confirmed by a positive test
2 Yes, suspected by a doctor but not tested
3 Yes, my own suspicions
4 No
-1 Do not know
-3 Prefer not to answer

[Y6AB (UKB)]

Do you wear sun protection (e.g., sunscreen lotion, hat) when you spend time outdoors in the summer?

SELECT one of 7 from

1 Never/rarely
2 Sometimes
3 Most of the time
4 Always
5 Do not go out in sunshine
-1 Do not know
-3 Prefer not to answer

If you are unsure, please provide an estimate or select 'Do not know'.

[H7C (UKB)]

Have you had any of the following in the past year?
(You can select more than one answer)

TOGGLE of 8 choices

[Require ≥1 choices]

1 Mouth ulcers
2 Painful gums
3 Bleeding gums
4 Loose teeth
5 Toothache
6 Dentures
-7 None of the above **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[H8 (UKB)]

In the last year have you had any falls?

SELECT one of 4 from

1 No falls
2 Only one fall
3 More than one fall
-3 Prefer not to answer

Do not include falls while playing sport or exercising.

[H9 (UKB)]

Compared with one year ago, has your weight changed?

SELECT one of 5 from

0 No - weigh about the same
2 Yes - gained weight
3 Yes - lost weight
-1 Do not know
-3 Prefer not to answer

[SY2 (UKB)]

In the last year have you ever had wheeze or whistling in the chest?

SELECT one of 4 from

1 Yes
0 No
-1 Do not know
-3 Prefer not to answer

[SY3 (UKB)]

Do you get short of breath walking with people of your own age on level ground?

SELECT one of 4 from

1 Yes
0 No
-1 Do not know
-3 Prefer not to answer

[SY4 (UKB)]

Do you get a pain in either leg on walking?

SELECT one of 4 from

1 Yes
0 No
-1 Do not know
-3 Prefer not to answer

This includes hip, knee, ankle, or muscle pain.

[SY4I (UKB)]

Have you ever had surgery to remove any of the following?

SELECT one of 6 from

0 No
1 Yes, toes
2 Yes, leg below the knee
3 Yes, leg above the knee

-1 Do not know
-3 Prefer not to answer

[SY5 (UKB)]

In the **last month** have you experienced any of the following that **interfered with your usual activities?**

TOGGLE of 10 choices
[Require ≥1 choices]

1 Headache
2 Facial pain
3 Neck or shoulder pain
4 Back pain
5 Stomach or abdominal pain
6 Hip pain
7 Knee pain
9 Premenstrual pain
8 Pain all over the body
-7 None of the above **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[SY6]

Have you ever experienced any of the following that i**nterfered with your usual activities regularly for more than 3 months**?

TOGGLE of 10 choices
[Require ≥1 choices]

1 Headache
2 Facial pain
3 Neck or shoulder pain
4 Back pain
5 Stomach or abdominal pain
6 Hip pain
7 Knee pain
9 Premenstrual pain
8 Pain all over the body
-7 None of the above **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

Think about whether you have ever in your lifetime had a period of three or more consecutive months where you experienced significant pain that made it difficult for you to take part in your usual activities.

[SY1 (UKB)]

Do you ever have any pain or discomfort in your chest?

SELECT one of 4 from

1 Yes **> SY1A**

0 No **> H10 (UKB)**

-1 Do not know **> H10 (UKB)**

-3 Prefer not to answer **> H10 (UKB)**

[SY1A (UKB)]

Do you get this pain or discomfort when you walk at an ordinary pace on the level?

SELECT one of 4 from

1 Yes **> SY1C**

0 No **> SY1B**

-1 Unable to walk on the level **> H10 (UKB)**

-3 Prefer not to answer **> H10 (UKB)**

[SY1B (UKB)]

Do you get this pain or discomfort when you walk uphill or hurry?

SELECT one of 4 from

1 Yes **> GO TO SY1C**

0 No **> GO TO H10 (UKB)**

-1 Unable to walk up hills or to hurry **> GO TO H10 (UKB)**

-3 Prefer not to answer **> GO TO H10 (UKB)**

[SY1C (UKB)]

Does this chest pain go away when you stand still?

SELECT one of 4 from

0 No

-1 Do not know

-3 Prefer not to answer

[H10 (UKB)]

Have you ever had a screening test for bowel (colorectal) cancer?
(Please include tests for blood in the stool/faeces or a colonoscopy or a sigmoidoscopy)

SELECT one of 4 from

1 Yes **> GO TO H10A**

0 No

-1 Do not know

-3 Prefer not to answer

➔ **IF ANSWER is 0, -1 or -3 AND SEX = Female GO TO FH7 (UKB)**

➔ **IF ANSWER is 0, -1 or -3 AND SEX = (Male OR Prefer not to answer) GO TO MH2 (UKB)**

Screening tests for bowel or colorectal cancer include:

- FOBT (faecal occult blood test) - this is when you are given a set of cards and asked to smear a part of your stool on three separate occasions onto the cards and then return the cards to be tested for blood.
- Sigmoidoscopy - a tube is used to examine the lower bowel. This is usually done in a doctor's office without pain relief.
- Colonoscopy - a long tube is used the examine the whole large bowel; you would usually have to drink a large amount of special liquid to prepare the bowel, and you would be given a sedative medication for the procedure.

[H10A (UKB)]

How many years ago was the most recent one of these tests?

Enter INTEGER
[Require ≥ 0, ≤ current age
Units: years]
OR
-10 Less than 1 year ago
OR
-1 Do not know
OR
-3 Prefer not to answer

➔ **IF SEX = Female GO TO FH7 (UKB)**
➔ **IF SEX = (Male OR Prefer not to answer OR Intersex) GO TO MH2 (UKB)**

If you are unsure, please provide an estimate or select 'Do not know'.

[MH2 (UKB)]

Have you ever had a blood test for prostate cancer (prostate specific antigen or PSA test)?

SELECT one of 4 from
1 Yes > **GO TO MH3(UKB)**
0 No **> GO TO MH7 (UKB)**
-1 Do not know **> GO TO MH7 (UKB)**
-3 Prefer not to answer **> GO TO MH7 (UKB)**

If you are unsure, select 'Do not know'.

[MH3 (UKB)]

How many years ago was your last test?

Enter INTEGER
[Require ≥ 0, ≤ current age
Units: years]
OR
-10 Less than a year ago
OR
-1 Do not know
OR
-3 Prefer not to answer

[MH7 (UKB)]

How many biological children have you had?

Enter INTEGER
[Require ≥ 0, ≤ 200]
OR
-1 Do not know
OR
-3 Prefer not to answer

➔ **IF ANSWER = 0 AND SEX = Male GO TO L1 (UKB)**
➔ **IF ANSWER = 0 AND SEX = (Prefer not to answer OR intersex) GO TO FH7 (UKB)**
➔ **IF ANSWER = 1 GO TO FH3D (UKB)**

[FH3C (UKB)MM]

How old were you when you had your FIRST child?

Enter INTEGER
[Require ≥ 8, ≤ current age
Units: years]
OR
-4 Do not remember
OR
-3 Prefer not to answer

[FH3D (UKB)MM]

How old were you when you had your LAST child?

Enter INTEGER
[Require ≥ 8, ≤ current age
Units: years]
OR
-4 Do not remember
OR
-3 Prefer not to answer

➔ **IF SEX = Male GO TO L1 (UKB)**
➔ **IF SEX = (Prefer not to answer OR intersex) GO TO FH7 (UKB)**

[FH7 (UKB)]

Have you ever been for breast cancer screening (a mammogram)?

SELECT one of 4 from
1 Yes **> GO TO FH7A**
0 No **> GO TO FH8**
-1 Do not know **> GO TO FH8**
-3 Prefer not to answer **> GO TO FH8**

[FH7A (UKB)]

How many years ago was your last screen?

Enter INTEGER
[Require ≥ 0, ≤ current age]
OR
-10 Less than 1 year ago
OR
-1 Do not know
OR
-3 Prefer not to answer

If you are unsure, please provide an estimate or select 'Do not know'.

[FH8 (UKB)]

Have you ever had a cervical smear test?

SELECT one of 4 from
1 Yes **> GO TO FH8B**
0 No **> GO TO FH1**
-1 Do not know **> GO TO FH1**
-3 Prefer not to answer **> GO TO FH1**

[FH8B (UKB)]

How many years ago was your last cervical smear test?

Enter INTEGER
[Require ≥ current age]
OR
-10 Less than a year ago
OR
-1 Do not know
OR
-3 Prefer not to answer

If you are unsure, please provide an estimate or select 'Do not know'.

[FH1 (UKB)]

How old were you when your periods started?

Enter INTEGER
[Require ≥ 5, ≤ current age
Units: years]
OR
-1 Do not know
OR
-3 Prefer not to answer

If you are unsure, please provide an estimate or select 'Do not know'.

[FH2 (UKB)]

Have you had your menopause (periods stopped for more than 12 months)?

SELECT one of 5 from

1 Yes **> GO TO FH2A (UKB)**

0 No **> GO TO FH2B (UKB)**

2 Not sure - had a hysterectomy **> GO TO FH3 (UKB)**

3 Not sure - other reason **> GO TO FH2B (UKB)**

-3 Prefer not to answer **> GO TO FH3 (UKB)**

[FH2A (UKB)]

How old were you when you had your last period?

Enter INTEGER

[Require ≥ FH1 integer, ≤ current age]

OR

-1 Do not know

OR

-3 Prefer not to answer

➔ **GO TO FH3**

If you are unsure, please provide an estimate or select 'Do not know'.

[FH2B (UKB)]

How many days since your last menstrual period?

Enter INTEGER

[Require ≥ 0, ≤ 365,

Units: days]

OR

-10 More than one year

OR

-1 Do not know

OR

-3 Prefer not to answer

Please count from the first day of your last menstrual period. If you are unsure, please provide an estimate or select 'Do not know'.

[FH2C (UKB)]

How many days are there usually between your periods? (This is the time from the first day of one period, to the day before the start of the next)

Enter INTEGER

[Require ≥ 7, ≤ 365,

Units: days]

OR

-6 Irregular cycle

OR

-1 Do not know

OR

-3 Prefer not to answer

➔ **GO TO FH3**

[FH3 (UKB)]

How many children have you given birth to?

Enter INTEGER

[Require ≥ 0, ≤ 25,

Units: children]

OR

-3 Prefer not to answer

➔ **IF ANSWER = 0 GO TO FH5 (UKB)**

➔ **IF ANSWER = 1 GO TO FH3D (UKB)**

[FH3C (UKB)]

How old were you when you had your FIRST child?

Enter INTEGER

[Require ≥ 0, ≤ current age,

Units: years]

OR

-4 Do not remember

OR

-3 Prefer not to answer

[FH3D (UKB)]

How old were you when you had your LAST child?

Enter INTEGER

[Require ≥ 8, ≤ current age,

Units: years]

OR

-4 Do not remember

OR

-3 Prefer not to answer

[FH5 (UKB)]

Have you **ever used a medical or implant method of contraception?** Please do not respond about condom, diaphragm or natural family planning.

SELECT one of 4 from

1 Yes **> FH5AA**

0 No **> FH6 (UKB)**

-1 Do not know **> FH6 (UKB)**

-3 Prefer not to answer **> FH6 (UKB)**

[FH5AA]

What have you used for contraception? Please note we are only asking about medication or implant methods of contraception. Please do not respond about condom, diaphragm or natural family planning.

TOGGLE of 10 choices

[Require ≥1 choices]

1 Combined pill **> GO TO FH5A**

2 Injection **> GO TO FH6**

3 IUD (coil) **> GO TO FH6**

4 IUS (hormonal coil) **> GO TO FH6**

5 Progesterone only pill (mini pill) **> GO TO FH5A**

6 Patch **> GO TO FH6**

7 Vaginal ring **> GO TO FH6**

8 Other not listed **> GO TO FH6**

-1 Do not know **[EXCLUSIVE] > GO TO FH6**

-3 Prefer not to answer **[EXCLUSIVE] > GO TO FH6**

[FH5A (UKB)]

About how old were you when you first went on the contraceptive pill?

Enter INTEGER

[Require ≥ 5, ≤ current age]

OR

-1 Do not know

OR

-3 Prefer not to answer

If you are unsure, please provide an estimate or select 'Do not know'.

[FH5B (UKB)]

How old were you when you last used the contraceptive pill?

Enter INTEGER

[Require ≥ FH5A response, ≤ current age]

OR

-1 Do not know

OR

-3 Prefer not to answer

OR

-11 Still taking the pill

If you are currently taking the pill, select ‘Still taking the pill’. If you are unsure, please provide an estimate or select ‘Do not know’.

[FH6 (UKB)]

Have you **ever** used hormone replacement therapy (HRT)?

SELECT one of 4 from

1 Yes > **GO TO FH6A**

0 No **> GO TO FH9**

-1 Do not know **> GO TO FH9**

-3 Prefer not to answer **> GO TO FH9**

[FH6A (UKB)]

How old were you when you first used HRT?

Enter INTEGER

[Require ≥ 16, ≤ current age]

OR

-1 Do not know

OR

-3 Prefer not to answer

If you are unsure, please provide an estimate or select 'Do not know'.

[FH6B (UKB)]

How old were you when you last used HRT?

Enter INTEGER

[Require ≥ FH6A, ≤ current age]

OR

-1 Do not know

OR

-11 Still taking HRT

OR

-3 Prefer not to answer

If you are currently using HRT, select ‘Still taking HRT’.
If you are unsure, please provide an estimate or select ‘Do not know’.

[FH9 (UKB)]

Have you had a hysterectomy (womb removed)?

SELECT one of 4 from

1 Yes

0 No **> GO TO FH10**

-5 Not sure **> GO TO FH10**

-3 Prefer not to answer **> GO TO FH10**

[FH9A (UKB)]

How old were you when you had your hysterectomy?

Enter INTEGER

[Require ≥ 0, ≤ current age]

OR

-1 Do not know

OR

-3 Prefer not to answer

If you are unsure, please provide an estimate or select 'Do not know'.

[FH10 (UKB)]

Have you had BOTH ovaries removed?

SELECT one of 4 from

1 Yes

0 No > **GO TO L1(UKB)**

-5 Not sure **> GO TO L1(UKB)**

-3 Prefer not to answer **> GO TO L1(UKB)**

Only enter 'Yes' if you have had both ovaries removed
If you are unsure of whether both ovaries have been removed, select ‘Do not know’.

[FH10A (UKB)]

How old were you when you had BOTH ovaries removed?

Enter INTEGER

[Require ≥ 0, ≤ current age]

OR

-1 Do not know

OR

-3 Prefer not to answer

[L1 (UKB)]

Have you ever been diagnosed with any of the following by a doctor or other health professional?

TOGGLE

[Require ≥ 1 choices]

1 Autoimmune disorder **> GO TO AUTO_A**

2 Blood disorders (Anaemia) **> GO TO BLOOD_A**

3 Cancer **> GO TO CANC_A**

4 Complications or difficulties in pregnancy or childbirth**> SHOW IF FEMALE; GO TO PREG_A**

5 Digestive system or liver problems **> GO TO DIG_A**

6 Endocrine, nutritional and metabolic disorders (e.g., diabetes, thyroid disorder, vitamin deficiencies) **> GO TO EN_A**

7 Eye or visual problems **> GO TO EYE_A**

8 Fractures, breaks, or joint problems **> GO TO FRAC_A**

9 Heart or circulatory disease (e.g. high blood pressure or stroke) **> GO TO HEART_A**

10 Kidney or urinary system disorders **> GO TO KIDN_A**

11 Lung or respiratory problems **-> GO TO LUNG_A**

12 Mental health conditions (e.g.depression, bipolar disorder) **> GO TO MH_A**
13 Neurodevelopmental conditions (e.g., Autism spectrum disorder, ADHD) **> GO TO ND_A**
14 Neurological disorders (things that affect that brain or nervous system) **> GO TO NEU_A**
15 Reproductive system problems **> GO TO REPRO_A**
16 Other not listed **> GO TO L5DF**
-7 None of the above **> GO TO 5DF**
-1 Do not know **[EXCLUSIVE] > GO TO L5DF**
-3 Prefer not to answer **[EXCLUSIVE] > GO TO L5DF**

If the diagnosis was for cancer, please select cancer. We will ask more about the type of cancer in a subsequent question.

[AUTO_A]

Have you ever been diagnosed with any of the following autoimmune disorders by a doctor or other health professional?

TOGGLE
[Require ≥ 1 choices]

1 Rheumatoid arthritis
2 Lupus
3 Inflammatory Bowel Disease (IBD)
4 Multiple Sclerosis (MS)
5 Graves' disease
6 Guillain-Barre syndrome
7 Psoriasis
8 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[BLOOD_A]

Have you ever been diagnosed with any of the following types of anaemia by a doctor or other health professional?

TOGGLE
[Require ≥ 1 choices]

1 Iron deficiency anaemia
2 Vitamin deficiency anaemia
3 Sickle cell anaemia
4 Aplastic anaemia
5 Thalassaemia
6 Other (not listed)
-7 None of the above **[EXCLUSIVE]**

-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[CANC_A (CONNECT)]

Which type(s) of cancer specifically were you diagnosed with?
Please indicate where the cancer originated, even if it spread to other body areas

TOGGLE

[Require ≥ 1 choices]

1 Anal
2 Bladder
3 Brain
4 Breast
5 Cervical
6 Colon/rectal
7 Oesophageal
8 Head and neck (Including cancers of the mouth, sinuses, nose, or throat. Not including brain or skin cancers.)
9 Gastric
10 Kidney
11 Leukaemia (blood and bone marrow)
12 Liver
13 Lung or bronchial
14 Lymphoma
15 Ovarian
16 Pancreatic
17 Prostate
18 Skin > **GO TO CANC_B**
19 Stomach
20 Testicular
21 Thyroid
22 Uterine (endometrial)
23 Another type of cancer
-1 I know I had cancer, but don't know what type
-7 None of the above **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[CANC_B (CONNECT)]

What type of skin cancer specifically were you diagnosed with?

TOGGLE

[Require ≥ 1 choices]

1 Melanoma
2 Basal cell
3 Squamous cell

-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[PREG_A (CONNECT+ICD)]

What type of complication or difficulties with pregnancy or childbirth have you experienced?

TOGGLE

[Require ≥ 1 choices]

1 Miscarriage (pregnancy loss before 20 weeks)
2 Stillbirth (pregnancy loss after 20 weeks)
3 Live birth and still birth (loss of one or more multiples)
4 Ectopic or tubal pregnancy
5 Trying to get pregnant for more than a year but not getting pregnant during t hat time
6 Hyperemesis gravidarum
7 Gestational diabetes
8 Preterm labour and delivery
9 Complicated labour and delivery
10 Traumatic labour or delivery
11 Pre-eclampsia
12 Eclampsia
13 Gestational hypertension
14 Other not listed
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[DIG_A (CONNECT)]

Have you ever been diagnosed with any of the following digestive system problems by a doctor or other health professional?

TOGGLE

[Require ≥ 1 choices]

1 Gastro-oesophageal Acid Reflux (GORD)
2 Barrett's Oesophagus
3 Irritable bowel syndrome
4 Inflammatory Bowel Disease
5 Diverticulitis or Diverticulosis
6 Ulcerative Colitis
7 Crohn's Disease
8 Coeliac Disease (also known as Gluten-Sensitive Enteropathy)
9 Gallstones (Biliary Stones)
10 Fatty liver disease
11 Liver Cirrhosis

12 Hepatitis
13 Pancreatitis
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[EN_A]

Have you ever been diagnosed with the following conditions by a doctor or health professional?

TOGGLE

[Require ≥ 1 choices]

1 Type 1 diabetes
2 Type 2 diabetes
3 Overactive thyroid
4 Underactive thyroid
5 Cushing syndrome
6 Lactose intolerance
7 Vitamin A deficiency
8 Thiamine deficiency
9 Vitamin D deficiency
10 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[EYE_A]

Have you ever been diagnosed with any of the following eye or visual problems by a doctor or other health professional?

TOGGLE

[Require ≥ 1 choices]

1 Glaucoma
2 Visual impairment including blindness
3 Double vision
4 Night blindness
5 Colour blindness
6 Macular degeneration
7 Cataracts
8 Retinal detachment
9 Diabetic retinopathy
10 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[FRAC_A]

What type of fractures, breaks, joint or bone problems have you experienced?

TOGGLE

[Require ≥ 1 choices]

1 Hip fracture
2 Osteoporosis
3 Osteoarthritis (arthritis)
4 Gout
5 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[HEART_A (CONNECT)]

Have you ever been diagnosed with any of the following heart or circulatory diseases by a doctor or other health professional?

TOGGLE

[Require ≥ 1 choices]

1 B-12 Deficiency (Pernicious Anaemia)
2 Coronary Artery/Coronary Heart Disease
3 Congestive Heart Failure
4 High Cholesterol
5 Heart Attack (Myocardial Infarction)
6 Abnormal Heart Rhythm (Arrhythmia)
7 Chest Pain (Angina)
8 Heart Valve Problems
9 High Blood Pressure (Hypertension) [Please do **not** include hypertension during pregnancy.]
10 Blood Clots (Deep Vein Thrombosis, Pulmonary Embolism)
11 Stroke
12 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[KIDN_A (CONNECT]

Have you ever been diagnosed with any of the following kidney or urinary tract problems by a doctor or other health professional?

TOGGLE

[Require ≥ 1 choices]

1 Kidney stones
2 Chronic kidney disease (or chronic kidney failure)
3 Other (not listed)

-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[LUNG_A (CONNECT)]

Have you ever been diagnosed with any of the following lung or respiratory conditions by a doctor or other health professional?

TOGGLE

[Require ≥ 1 choices]

1 Chronic Obstructive pulmonary disease, COPD (including emphysema and chronic bronchitis)
2 Lung fibrosis
3 Bronchiectasis
4 Asthma
5 Hay Fever (Allergic to pollen or Allergic Rhinitis)
6 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[ND_A]

Have you ever been diagnosed with one or more of the following conditions by a professional, even if you don't have it currently? By professional we mean: any doctor, nurse, or person with specialist training. Please include disorders even if you did not need treatment for them or if you did not agree with the diagnosis. Select ALL that apply

TOGGLE

[Require ≥ 1 choices]

1 Autism spectrum disorder
2 Developmental learning disorders
3 Attention deficit hyperactivity disorder (ADHD)
4 Disorder of intellectual development
5 Developmental motor coordination disorder
6 Developmental speech or language disorders
7 Stereotyped movement disorder
8 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[MH_A]

Have you ever been diagnosed with one or more of the following mental health conditions by a professional, even if you don't have it currently? By professional we mean: any doctor, nurse, or person with specialist training. Please include disorders even if you did not need treatment for them or if you did not agree with the diagnosis. Select ALL that apply

TOGGLE

[Require ≥ 1 choices]

1 Anxiety **> GO TO ANX_B**
2 Bipolar disorder
3 Body dysmorphia
4 Depression **> GO TO DEP_B**
5 Premenstrual dysphoric disorder
6 Post Traumatic Stress Disorder
7 Obsessive Compulsive Disorder
8 Eating disorder **> GO TO EATD_B**
9 Psychosis
10 Schizophrenia
11 Schizoaffective disorder
12 Personality disorder
13 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[ANX_B]

Which anxiety disorder(s) specifically have you been diagnosed with in your lifetime?

TOGGLE

[Require ≥ 1 choices]

1 Generalised anxiety disorder
2 Agoraphobia
3 Social anxiety disorder
4 Panic disorder
5 Panic attacks
6 Specific phobia
7 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[DEP_B]

Which depressive disorder(s) specifically have you been diagnosed with in your lifetime?

TOGGLE

[Require ≥ 1 choices]

1 Major Depressive Disorder
2 Perinatal depression
3 Postnatal depression
4 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**

-3 Prefer not to answer **[EXCLUSIVE]**

[EATD_B]

Which eating disorder(s) specifically have you been diagnosed with in your lifetime?

TOGGLE

[Require ≥ 1 choices]

1 Anorexia nervosa
2 Atypical anorexia nervosa
3 Bulimia nervosa
4 Binge eating disorder
5 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[NEU_A]

Have you ever been diagnosed with any of the following neurological or brain disorders by a doctor or other health professional?

TOGGLE

[Require ≥ 1 choices]

1 Epilepsy
2 Parkinson's disease
3 Alzheimer's disease/dementia
4 Early onset Alzheimer's disease/dementia
5 Vascular dementia
6 Migraine with aura
7 Migraine without aura
8 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[REPRO_A (CONNECT)]

Have you ever been diagnosed with any of the following conditions by a doctor or other health professional?

TOGGLE

[Require ≥ 1 choices]

1 Endometriosis **[validation show if question refers to female]**
2 Polycystic Ovary Syndrome (PCOS) **[validation show if question refers to female]**
3 Enlarged prostate [**validation show if question refers to male]**

4 Fibrocystic Breast, or another Benign Breast Disease (such as proliferative Benign Breast Disease or LCIS)
5 Ductal Carcinoma in situ (DCIS)
6 Other (not listed)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[L5DF]

Do you regularly take medications for any of the following reasons?

TOGGLE

[Require ≥ 1 choices]

1 Autoimmune disorders > **GO TO AUTO_MED_A**
2 Bone health > **GO TO BONE_MED_A**
3 Cancer > **GO TO CANC_MED_A**
4 Diabetic health > **GO TO DIA_MED_A**
5 Digestive problems (including acid reflux and liver problems) > **GO TO DIG_MED_A**
6 Endocrine disorder (e.g., under or over-active thyroid) > **GO TO ENDO_MED_A**
7 Heart or circulatory health (e.g., high blood pressure or stroke) > **GO TO HEART_MED_A**
8 Lung or breathing problems (including asthma) > **GO TO LUNG_MED_A**
9 Medication for mental health conditions and insomnia (e.g., Depression, bipolar disorder) > **GO TO MH_MED_A**
10 Neurological disorders (e.g., Alzheimer's, epilepsy, Parkinson's) **> GO TO NEURO_MED_A**
11 Pain relief **> GO TO PAIN_MED_A**
12 Reproductive or sexual health (including contraception, erectile dysfunction, menopause or hormone medication) **> GO TO REPRO_MED_A**
13 Supplements or nutritional health **> GO TO SUPP_MED_A**
-7 None of the above **> GO TO PHQ_TRIG**
-1 Do not know **[EXCLUSIVE] > GO TO PHQ_TRIG**
-3 Prefer not to answer **[EXCLUSIVE] > GO TO PHQ_TRIG**

By regularly we mean something you take on a fixed schedule, or on most days of the week for the last four weeks. Please also tell us about implants or slow release injections that you have or regularly receive.

[AUTO_MED_A]

Do you regularly take any of the following medication for an autoimmune disorder? (You can select more than one answer)

TOGGLE

[Require ≥ 1 choices]

1 Amino salicylates (5-ASAs, mesalazine)
2 Azathioprine
3 Corticosteroids (e.g., prednisolone)
4 Disease-modifying ani-rheumatic drugs (DMARDs, e.g., methotrexate, leflunomide, hydroxychloroquine, sulfasalazine)
5 Tacrolimus
6 JAK inhibitors
7 Tumour Necrosis Factor (TNF) inhibitors
8 Tocilizumab
9 Rituximab
10 Mycophenolate
11 Cyclosporine
12 Other not listed
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

By regularly we mean something you take on a fixed schedule, or on most days of the week for the last four weeks. If you know you take a medication regularly, but don't recognise these names, please check the packaging. Sometimes the brand names on the packaging will not be the same as the key ingredients.

[BONE_MED_A]

Do you regularly take any of the following medication for bone health? (You can select more than one answer)

TOGGLE

[Require ≥ 1 choices]

1 Bisphosphonates (e.g., alendronic acid, ibandronic acid, risendronic acid, zoledronic acid)
2 Selective oestrogen receptor modulators (SERMs, Raloxifene)
3 Strontium Ranelate
4 Monoclonal antibodies (Denosumab, Romosozumab)
5 Parathyroid hormone (e.g., teriparatide)
6 Vitamin D and/or Calcium supplements
7 Hormone Replacement Therapy (HRT)
8 Testosterone treatment
9 Other not listed
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

By regularly we mean something you take on a fixed schedule, or on most days of the week for the last four weeks. If you know you take a medication regularly, but don't recognise these names, please check the packaging. Sometimes the brand names on the packaging will not be the same as the key ingredients.

[CANC_MED_A]

Are you currently receiving any of the following treatments for cancer? (You can select more than one answer)

TOGGLE

[Require ≥ 1 choices]

1 Chemotherapy
2 Hormone therapy
2 Immunotherapy / Targeted therapy
4 Radiotherapy
5 Other not listed
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[DIA_MED_A]

Do you regularly take any of the following medication for diabetic health? (You can select more than one answer)

TOGGLE

[Require ≥ 1 choices]

1 Acarbose (Glucobay)
2 DPP-4 Inhibitors (Gliptins, e.g., Sitagliptin, Vildagliptin, Saxagliptin, Alogliptin)
3 GLP-1 (incretin memetics, e.g., Exenatide, Liraglutide, Lixisenatide)
4 Insulin
5 Metformin
6 Prandial glucose regulator (e.g., Repaglinide, Nateglinide)
7 SGLT2 inhibitors (e.g., Dapagliflozin, Canagliflozin, Empagliflozin, Ertuglflozin)
8 Statins
9 Sulphonylureas (e.g., Glibenclamide, Gliclazide, Glipizide Tolbutamide)
10 Thiazolidinediones (e.g., Pioglitazone; Actos)
11 Other not listed
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

By regularly we mean something you take on a fixed schedule, or on most days of the week for the last four weeks. If you know you take a medication regularly, but don't recognise these names, please check the packaging. Sometimes the brand names on the packaging will not be the same as the key ingredients.

[DIG_MED_A]

Do you regularly take any of the following medication digestive problems, acid reflux or liver problems? (You can select more than one answer)

TOGGLE

[Require ≥ 1 choices]

1 Proton pump inhibitors (e.g., omeprazole, esomeprazole, lansoprazole, rabeprazole, pantoprazole, dexlansoprazole)
2 Other indigestion medicine (e.g., ranitidine, famotidine, nizatidine, cimetidine)
3 Laxatives (e.g., Dulcolax, Senokat)
4 Aminosalicylates (5-ASAs, mesalazine)
5 Azathioprine
6 Corticosteroids (e.g., prednisolone)
7 Mercaptopurine
8 Methotrexate
9 JAK inhibitors
10 Tumour Necrosis Factor (TNF) inhibitors
11 Pancreatin (e.g., Creon, Pancrex)
12 Other not listed
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

By regularly we mean something you take on a fixed schedule, or on most days of the week for the last four weeks. If you know you take a medication regularly, but don't recognise these names, please check the packaging. Sometimes the brand names on the packaging will not be the same as the key ingredients.

[ENDO_MED_A]

Do you regularly take any of the following medication for endocrine disorders? (You can select more than one answer)

TOGGLE

[Require ≥ 1 choices]

1 Levothyroxine
2 Carbimazole
3 Propylthiouracil
4 Beta Blocker
5 Hydrocortisone
6 Prednisolone
7 Growth hormone
8 Desmopressin
9 Dopamine agonists (cabergoline, bromocriptine)
10 Other not listed
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

By regularly we mean something you take on a fixed schedule, or on most days of the week for the last four weeks. If you know you take a medication regularly, but don't recognise these names, please check the packaging. Sometimes the brand names on the packaging will not be the same as the key ingredients.

[HEART_MED_A]

Do you regularly take any of the following medication for heart or circulatory disorders (You can select more than one answer)

TOGGLE

[Require ≥ 1 choices]

1 Aspirin (low dose)
2 Anticoagulant (blood thinners, e.g., warfarin, Rivaroxaban, dabigatran, apixaban and edoxaban)
3 Antiarrhythmic (e.g., flecainide, digoxin)
4 Calcium channel blocker (e.g., verapamil, diltiazem)
5 Cholesterol lowering medication/statins
6 Blood pressure medication (e.g., enalapril, lisinopril, perindopril, ramipril, candesartan, irbesartan, losartan, valsartan and Olmesartan)
7 Beta blocker (e.g., bisoprolol, atenolol)
8 Diuretic (e.g., Furosemide, Fendroflumethiazide, Amiloride, Bumetanide, Metalozone, Spironolactone)
9 Glyceryl trinitrate (GTN)
10 Nicorandil
11 Anti-platelet (Clopidogrel)
12 Other not listed
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

By regularly we mean something you take on a fixed schedule, or on most days of the week for the last four weeks. If you know you take a medication regularly, but don't recognise these names, please check the packaging. Sometimes the brand names on the packaging will not be the same as the key ingredients.

[LUNG_MED_A]

Do you regularly take any of the following medication? (You can select more than one answer)

TOGGLE

[Require ≥ 1 choices]

1 Asthma reliver inhaler (usually blue)
2 Asthma preventer inhaler (containing steroid medicine)
3 Asthma combination inhaler
4 Anticholinergic inhaler (for COPD or asthma, e.g., Tiotropium or Spiriva)
5 Leukotriene receptor antagonist (LTRAs) tablets (e.g., Montelukast)
6 Tablet bronchodilator (e.g., theophylline)
7 Corticosteroids (e.g., prednisolone)
8 Other not listed
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

By regularly we mean something you take on a fixed schedule, or on most days of the week for the last four weeks. If you know you take a medication regularly, but don't recognise these names, please check the packaging. Sometimes the brand names on the packaging will not be the same as the key ingredients.

[MH_MED_A]

Do you regularly take any of the following medication? (You can select more than one answer)

TOGGLE

[Require ≥ 1 choices]

1 Antidepressant (e.g. fluoxetine, amitriptyline, sertraline, mirtazapine) > **GO TO MH_MED_ANTIDEP**
2 Antipsychotic medication (e.g. haloperidol, amisulpiride, aripiprazole, clozapine) > **GO TO MH_MED_ANTIPSYC**
3 Beta-blocker (e.g., atenolol, bisoprolol, metoprolol, propranolol)
4 Benzodiazepine (e.g., alprazolam, diazepam, halazepam, prazepam, clonazepam, clorazepate)
5 Lithium
6 Sleeping pills (e.g., Antihistamines, melatonin, zopiclone, barbituates)
7 Pregabalin
8 Valproic acid/Sodium valproate
9 Other mood stabilising medication (e.g., Depakote, carbamezapine)
10 Other not listed
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

Please indicate whether you take an antidepressant, even if it is prescribed for a different mental health disorder such as anxiety. By regularly we mean something you take on a fixed schedule, or on most days of the week for the last four weeks. If you know you take a medication regularly, but don't recognise these names, please check the packaging. Sometimes the brand names on the packaging will not be the same as the key ingredients.

[MH_MED_ANTIDEP]

What type of antidepressant medication do you regularly take? (You can select more than one answer)

TOGGLE

[Require ≥ 1 choices]

1 Selective serotonin reuptake inhibitor (SSRI, e.g., Fluoxetine, citalopram, escitalopram, paroxetine, sertraline)
2 Tricyclic a (e.g., amitriptyline, clomipramine)
3 Other (e.g., mirtazapine, venlafaxine, duloxetine)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[MH_MED_ANTIPSYC]

What type of antipsychotic medication do you regularly take? (You can select more than one answer)

TOGGLE

[Require ≥ 1 choices]

1 "Typical" Antipsychotic (e.g., chlorpromazine, haloperidol, promazine sulpride)
2 "Atypical" Antipsychotic (e.g., amisulpiride, Aripiprazole, clozapine, risperidone, olanzapine, quetiapine)
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[NEURO_MED_A]

Do you regularly take any of the following medication? (You can select more than one answer)

TOGGLE

[Require ≥ 1 choices]

1 Anti-epileptic drugs (AEDs, e.g., Sodium valproate, carbamazepine, lamotrigine, levetiracetam, topiramate)
2 Acetylcholinesterase (AChE) inhibitors (e.g., Donepezil, galantamine, rivastigmine)
3 Amantadine
4 Amitriptyline for migraines
5 Catechol-O-methyltransferase (COMT) inhibitors (e.g., entacapone, opicapone)
6 Levodopa (e.g., co-beneldopa, co-careldopa)
7 Dopamine agonists (e.g., pramipexole, ropinirole)
8 Memantine
9 Monoamine oxidase-B inhibitors (e.g., selegiline, rasagiline, safinamide)
10 Pregabalin or Gabapentin
11 Propranolol for migraines
12 Riluzole
13 Triptans
14 Other not listed
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

By regularly we mean something you take on a fixed schedule, or on most days of the week for the last four weeks. If you know you take a medication regularly, but don't recognise these names, please check the packaging. Sometimes the brand names on the packaging will not be the same as the key ingredients.

[PAIN_MED_A (CONNECT/UKB)]

Do you regularly take any of the following medication? (You can select more than one answer)

TOGGLE

[Require ≥ 1 choices]

1 Aspirin
2 Ibuprofen (e.g., Neurofen)
3 Paracetamol
4 Naproxen (e.g., Naprosyn, Stirlescent, Feminax Ultra, Period Pain Reliever, Boots Period Pain Relief)
5 Diclofenac
6 Opioids (e.g., codeine, tramadol, morphine, fentanyl, oxycodone, buprenorphine diamorphine)
7 Oher not listed
-7 None of the Above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

By regularly we mean something you take on a fixed schedule, or on most days of the week for the last four weeks. If you know you take a medication regularly, but don't recognise these names, please check the packaging. Sometimes the brand names on the packaging will not be the same as the key ingredients.

[REPRO_MED_A (NHS)]

Do you regularly take any of the following medication for reproductive or sexual health?

TOGGLE

[Require ≥ 1 choices]

1 Contraceptive medication, coil, implant or patch **> GO TO CONTRA_MED_B**
2 Medication to treat erectile dysfunction (e.g., Sildenafil (Viagra), Tadalafil (Cialis), Vardenafil (Levitra), Avanafil (Spedra))
3 Combined Hormone Replacement Therapy (HRT)
4 Oestrogen-only HRT
5 Oestrogen treatment (Pessary, cream or vaginal ring)
6 Testosterone HRT
7 Oestrogen or testosterone blockers (e.g., clomifene)
8 Other not listed
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

By regularly we mean something you take on a fixed schedule, or on most days of the week for the last four weeks. If you know you take a medication regularly, but don't recognise these names, please check the packaging. Sometimes the brand names on the packaging will not be the same as the key ingredients.

[CONTRA_MED_B (NHS)]

What do you regularly or currently use for contraception? Please note we are only asking about medication or implant methods of contraception. Please do not respond about condom, diaphragm or natural family planning.

TOGGLE

[Require ≥ 1 choices]

1 Combined pill
2 Injection
3 Implant
4 IUD (coil)
5 IUS (hormonal coil)
6 Progesterone only pill (mini pill)
7 Patch
8 Vaginal ring
9 Other not listed
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

[SUPPL_MED_A]

Do you regularly take any of the following supplements? (You can select more than one answer)

TOGGLE

[Require ≥ 1 choices]

1 Vitamin A
2 Vitamin B
3 Vitamin C
4 Vitamin D
5 Vitamin E
6 Folic acid or Folate (Vit B9)
7 Multivitamins +/- minerals
8 Fish oil (including cod liver oil)
9 Glucosamine
10 Calcium
11 Zinc
12 Iron
13 Selenium
14 St John's wort
15 Other not listed
-7 None of the above **[EXCLUSIVE]**
-1 Do not know **[EXCLUSIVE]**
-3 Prefer not to answer **[EXCLUSIVE]**

By regularly we mean something you take on a fixed schedule, or on most days of the week for the last four weeks. If you know you take a supplement regularly, but don't recognise these names, please check the packaging. Sometimes the brand names on the packaging will not be the same as the key ingredients.

[PHQ_TRIG]

We will now ask some questions about whether you have been experiencing symptoms of anxiety or depression in the past two weeks. Would you like to skip these questions?

SELECT 1 of 2

1 Yes

0 No

➔ **IF select Yes, SKIP to end of section 5**

➔ **ELSE [PHQ9_1]**

[PHQ9_1]

Over the last two weeks, how often have you been bothered by any of the following problems: [Little interest or pleasure in doing things

SELECT 1 of 6

1 Not at all

2 Several days

3 More than half the days

4 Nearly every day

-1 Do not know

-3 Prefer not to answer

[PHQ9_2]

Over the last two weeks, how often have you been bothered by any of the following problems: Feeling down, depressed, or hopeless?

SELECT 1 of 6

1 Not at all

2 Several days

3 More than half the days

4 Nearly every day

-1 Do not know

-3 Prefer not to answer

[PHQ9_3]

Over the last two weeks, how often have you been bothered by any of the following problems: Trouble falling or staying asleep, or sleeping too much?

SELECT 1 of 6

1 Not at all

2 Several days

3 More than half the days

4 Nearly every day

-1 Do not know

-3 Prefer not to answer

[PHQ9_4]

Over the last two weeks, how often have you been bothered by any of the following problems: Feeling tired or having little energy?

SELECT 1 of 6

1 Not at all
2 Several days
3 More than half the days
4 Nearly every day
-1 Do not know
-3 Prefer not to answer

[PHQ9_5]

Over the last two weeks, how often have you been bothered by any of the following problems: Poor appetite or overeating?

SELECT 1 of 6

1 Not at all
2 Several days
3 More than half the days
4 Nearly every day
-1 Do not know
-3 Prefer not to answer

[PHQ9_6]

Over the last two weeks, how often have you been bothered by any of the following problems: Feeling bad about yourself – or that you are a failure or have let yourself or your family down?

SELECT 1 of 6

1 Not at all
2 Several days
3 More than half the days
4 Nearly every day
-1 Do not know
-3 Prefer not to answer

[PHQ9_7]

Over the last two weeks, how often have you been bothered by any of the following problems: Trouble concentrating on things, such as reading the newspaper or watching television?

SELECT 1 of 6

1 Not at all
2 Several days
3 More than half the days
4 Nearly every day
-1 Do not know
-3 Prefer not to answer

[PHQ9_8]

Over the last two weeks, how often have you been bothered by any of the following problems: Moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual?

SELECT 1 of 6

1 Not at all
2 Several days
3 More than half the days
4 Nearly every day
-1 Do not know
-3 Prefer not to answer

[PHQ9_9]

Over the last two weeks, how often have you been bothered by any of the following problems: Thoughts that you would be better off dead or of hurting yourself in some way

SELECT 1 of 6

1 Not at all
2 Several days
3 More than half the days
4 Nearly every day
-1 Do not know
-3 Prefer not to answer

More on suicidal thoughts. If you have had thoughts of self-harming or are feeling suicidal contact someone immediately. - See your GP or the out-of-hours GP service. If you have already taken an overdose or cut yourself badly, dial 999.- There are helplines with specially trained volunteers who will listen to you, understand what you are going through, and help you through the immediate crisis.- Contact a friend, family or someone you trust. The Samaritans operate a service 24hours a day, 365 days a year, for people who want to talk in confidence. Call 116123.

[PHQ9_IMPAIR]

[DISPLAY IF ANY PHQ9 > 1)

How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

SELECT 1 of 6

0 Not difficult at all
1 Somewhat difficult
2 Very difficult
3 Extremely difficult
-1 Do not know
-3 Prefer not to answer

[GAD7_1]

Over the last two weeks, how often have you been bothered by any of the following problems: Feeling nervous, anxious or on edge?

SELECT 1 of 6

1 Not at all
2 Several days
3 More than half the days
4 Nearly every day
-1 Do not know
-3 Prefer not to answer

[GAD7_2]

Over the last two weeks, how often have you been bothered by any of the following problems: Not being able to stop or control worrying?

SELECT 1 of 6

1 Not at all
2 Several days
3 More than half the days
4 Nearly every day
-1 Do not know
-3 Prefer not to answer

[GAD7_3]

Over the last two weeks, how often have you been bothered by any of the following problems: Worrying too much about different things?

SELECT 1 of 6

1 Not at all
2 Several days
3 More than half the days
4 Nearly every day
-1 Do not know
-3 Prefer not to answer

[GAD7_4]

Over the last two weeks, how often have you been bothered by any of the following problems: Trouble relaxing?

SELECT 1 of 6

1 Not at all
2 Several days
3 More than half the days
4 Nearly every day
-1 Do not know
-3 Prefer not to answer

[GAD7_5]

Over the last two weeks, how often have you been bothered by any of the following problems: Being so restless that it is hard to sit still?

SELECT 1 of 6

1 Not at all
2 Several days
3 More than half the days
4 Nearly every day
-1 Do not know
-3 Prefer not to answer

[GAD7_6]

Over the last two weeks, how often have you been bothered by any of the following problems: Becoming easily annoyed or irritable?

SELECT 1 of 6

1 Not at all
2 Several days
3 More than half the days
4 Nearly every day
-1 Do not know
-3 Prefer not to answer

[GAD7_7]

Over the last two weeks, how often have you been bothered by any of the following problems: Feeling afraid as if something awful might happen?

SELECT 1 of 6

1 Not at all
2 Several days
3 More than half the days
4 Nearly every day
-1 Do not know
-3 Prefer not to answer

[GAD7_IMPAIR]

[DISPLAY IF ANY GAD7 > 1)

How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

SELECT 1 of 6

0 Not difficult at all
1 Somewhat difficult
2 Very difficult
3 Extremely difficult
-1 Do not know
-3 Prefer not to answer

----------**End of Section 5**----------

Our Future Health Participant Reported Experience Measure

V8 – January 2025

The primary aim of the Participant Reported Experience Measure (PREM) is to evaluate participants' satisfaction with and acceptability of the recruitment and appointment process at Our Future Health. The PREM will provide a key source of quantitative data on acceptability, experience, and barriers to participation, which are key outcome measures in our evaluation of recruitment.

The PREM assesses participants' experiences in 6 modules:

1) Consent process and Information materials
2) Baseline questionnaire
3) Appointment (booking, attending, providing a blood sample, physical measurements)
4) Not starting or completing the questionnaire
5) Not booking or attending an appointment
6) Overall experience

The PREM was revised in 2024 to capture more timely feedback and is now divided into multiple surveys, each triggered by specific events in the recruitment journey.

Participants who complete the questionnaire and appointment will be asked about their experience of completing their questionnaire and online consent, triggered by starting the questionnaire, and their experience of their appointment, triggered by completing an appointment. Participants will all be asked about their overall experience of the programme and motivations for taking part in the last survey that they complete. No participant will receive more than two surveys. Participants who only consent to the programme and take no other actions will only receive one survey asking about their overall experiences and motivations for participating.

Module	Who is shown this module	How will they be shown this module
1) Consent process and information materials	Participants who have completed the questionnaire	Post- Questionnaire survey
2) Baseline Questionnaire	Participants who have completed the questionnaire	Post- Questionnaire survey
3) Appointment (booking, attending, providing a blood	Participants who booked and attended an appointment	Post- Appointment survey

sample, physical measurements)		
4) Not starting or completing the questionnaire	Participants who haven't started or completed the questionnaire	Non-Responder survey
5) Not Booking or attending an appointment	Participants who did not book an appointment	No-Responder survey
6) Overall experience	All participants	In either the 'Post-Questionnaire' or 'Post-Appointment' PREM depending on if the questionnaire is completed before or after the appointment, or in the 'Non-responder' survey if previous participation steps incomplete.

Currently, there are several variations of the PREM participant journey. These are simplified into 3 main journeys:

1. Full participant who completed the questionnaire before their appointment (receives post-questionnaire survey then post appointment survey with the overall experience section).

2. Full participant who completed their appointment before their questionnaire (receives post appointment survey, then post questionnaire survey with the overall experience section).

3. Participants who did not start the questionnaire, book or attend an appointment will receive the 'no activity' survey and will only be shown questions relevant to their journey.

All questions that are shown to participants are shared below. Not all participants will see all questions (see table above).

[Questions about the consent process and information materials]

At the start of Our Future Health, I was told what was going to happen and what to expect

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

The information I was given was easy to understand

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

I had enough information to make an informed choice about whether or not to take part in Our Future Health

- Yes
- Partly
- No
- Didn’t have a choice
- Not sure

Overall, I am satisfied with the information I received before taking part in Our Future Health

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

In the following questions, please choose the options on the scales below that best reflect your experience of signing up to Our Future Health so far.

How **negative** or **positive** did you find the experience of signing up to Our Future Health?

Negative						Positive
1	2	3	4	5	6	7
•	•	•	•	•	•	•

How **straightforward** or **confusing** did you find the experience of signing up to Our Future Health?

Straightforward						Confusing
1	2	3	4	5	6	7
•	•	•	•	•	•	•

How **boring** or **interesting** did you find the experience of signing up to Our Future Health?

Boring						Interesting
1	2	3	4	5	6	7
•	•	•	•	•	•	•

How **easy** or **hard** did you find the experience of signing up to Our Future Health?

Easy 1 •	2 •	3 •	4 •	5 •	6 •	Hard 7 •

How **slow** or **quick** did you find the experience of signing up to Our Future Health?

Slow 1 •	2 •	3 •	4 •	5 •	6 •	Quick 7 •

Do you have any other thoughts or comments about signing up for Our Future Health? If so, please use the space below to share your thoughts:

free text box

[Questions about filling out the baseline questionnaire]

Have you completed the questionnaire?

- I've started it but not finished
- I've completed and submitted it
- I haven't started it yet

In the following questions, please choose the options on the scales below that best reflect your experience of filling out the questionnaire:

How **hard** or **easy** did you find the experience of filling out the questionnaire?

Hard 1 •	2 •	3 •	4 •	5 •	6 •	Easy 7 •

How **short** or **long** did you find the experience of filling out the questionnaire?

Short 1 •	2 •	3 •	4 •	5 •	6 •	Long 7 •

How **confusing** or **straightforward** did you find the experience of filling out the questionnaire?

Confusing 1 •	2 •	3 •	4 •	5 •	6 •	Straightforward 7 •

How **interesting** or **boring** did you find the experience of filling out the questionnaire?

Interesting 1 •	2 •	3 •	4 •	5 •	6 •	Boring 7 •

How **negative** or **positive** did you find the experience of filling out the questionnaire?

Negative 1 •	 2 •	 3 •	 4 •	 5 •	 6 •	Positive 7 •

Do you have any further thoughts or comments about the Our Future Health questionnaire?

free text box

[Questions about booking an appointment]

Did you book an appointment to provide a sample of your blood (at a pharmacy or mobile clinic for example)?

Please answer yes even if you had to cancel or reschedule your appointment

- Yes, I did book an appointment
- No, I did not book an appointment
- I don't know

[Questions about booking and attending an appointment]

Did you attend an appointment to provide a sample of your blood (at a pharmacy or mobile clinic for example)?

- Yes, I did attend an appointment
- No, I did not attend an appointment
- I don't know

I was able to book an appointment at a convenient time

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

I was able to book an appointment at a convenient location

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Overall, I am happy with the process of booking an appointment with Our Future Health

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

I had all the information I needed before attending my appointment

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

The staff member explained what was going to happen at the appointment

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

The staff member(s) made me feel comfortable at my appointment

- Strongly agree
- Agree

- Neither agree nor disagree
- Disagree
- Strongly disagree

Overall, I was satisfied with my experience of the appointment

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Do you have any further thoughts or comments about the process of booking or attending an appointment with Our Future Health? If so, please provide them in the box below.

free text box

[Questions about physical measurements]

During your appointment, did the staff member collect any of the following physical measurements?

	Yes	This measurement was requested, but I did not provide it	No	I don't remember
Height				
Weight				
Waist circumference				
Heart rate				
Blood pressure				

During your appointment, did the staff member write down and give you your measurements for any of the following?

Please select all that apply

- Height

- Weight
- Waist circumference
- Heart rate
- Blood pressure
- None of the above
- I don’t remember

Overall, I was satisfied with the experience of having my physical measurements taken

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Do you have any further thoughts or comments about the process of having your physical measurements taken with Our Future Health? If so, please provide them in the box below.

free text box

[Questions about providing a blood sample]

Did you provide a sample of your blood for the Our Future Health research programme?

- Yes, I did provide a blood sample
- No, I did not provide a blood sample
- I don't know

Can you tell us why you did not provide a sample of your blood?

- I am afraid of needles or donating blood
- I was not able to provide a blood sample on the day for health reasons
- I changed my mind about providing a blood sample on the day
- Staff could not take the sample because they did not have the right equipment
- There were not enough staff available to take my blood sample
- Staff tried, but were unable to take a blood sample on the day
- I don’t remember
- I haven't attended my appointment yet
- Other

In the following questions, please choose the option on the scale that best reflects your experience of providing a sample of your blood for Our Future Health.

How **hard** or **easy** did you find the experience of providing a blood sample?

Hard						Easy
1	2	3	4	5	6	7
•	•	•	•	•	•	•

How **quick** or **slow** did you find the experience of providing a blood sample?

Quick						Slow
1	2	3	4	5	6	7
•	•	•	•	•	•	•

How **confusing** or **straightforward** did you find the experience of providing a blood sample?

Confusing						Straightforward
1	2	3	4	5	6	7
•	•	•	•	•	•	•

How **convenient** or **inconvenient** did you find the experience of providing a blood sample?

Convenient 1 •	2 •	3 •	4 •	5 •	6 •	Inconvenient 7 •

How **negative** or **positive** did you find the experience of providing a blood sample?

Negative 1 •	2 •	3 •	4 •	5 •	6 •	Positive 7 •

Do you have any further thoughts or comments about providing a blood sample for Our Future Health? If so, please provide them in the box below.

free text box

[Post-appointment questions]

Following your Our Future Health appointment, did you contact a health service provider? (For example, your GP, local pharmacy, Accident & Emergency (A&E), or the 111 service)

- Yes
- No
- Other
- I don't remember
- I prefer not to say

[If Yes to Q1]
Which of these health service providers did you contact? (select all that apply)

- GP
- Local pharmacy
- Boots Healthcare
- Accident & Emergency (A&E)
- 111 Service
- Other [please specify]

- I don’t remember
- I prefer not to say

What prompted you to reach out to a health service provider?

- Blood pressure result
- Height and weight measurements
- BMI
- Diabetes risk score
- I don’t remember
- I prefer not to say
- Other [please specify]

[Questions about not booking an appointment]

What is the main reason you did not book an appointment?

- I did not have enough time to book an appointment.
- I could not find a convenient location.
- I could not find a convenient appointment slot.
- I lost interest after consenting.
- I encountered technical issues when trying to book.
- There was no available location that I could reach using public transport.
- There was no convenient parking near an available location.
- I would have had to go out of my way to attend any of the available locations.
- Problems with childcare
- Other (please specify): _____

Please rate how important you find the following factors when considering a clinic location

	Not important at all	**Not very important**	**Neutral**	**Somewhat important**	**Very important**
The clinic is located close to public transport links					
The clinic is near other amenities e.g., shopping areas, restaurants, etc.)					
The clinic has parking nearby					

The clinic has **free** parking nearby					

You may have received up to two reminders to book an appointment. Please tell us how much you agree or disagree with the following statements:

I found these e-mails to be…

	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
Frustrating					
Helpful					
Confusing					
I did not mind receiving these emails					

[if they agreed or strongly agreed the emails were frustrating]

Please tell us why you found the emails to be frustrating (select all that apply)

- There were no new appointments available.
- There were no new clinic locations available.
- They were sent too soon after I joined the programme
- There were too many of them
- The second email was sent too soon after the first
- They gave me no new information
- Other (please specify): _____

[Questions about not attending an appointment]

What is the main reason you did not attend your appointment?

- I did not have enough time to attend my appointment.
- I lost interest after consenting.
- There was no convenient parking near the clinic location.
- Problems with childcare
- I forgot about my appointment
- Something came up
- I made other plans

- Weather
- Other (please specify): _____

[Questions about not starting the questionnaire]

What is the main reason you did not start the health and lifestyle questionnaire?

- I forgot about it
- I did not have enough time to start it
- I was unsure how to access it
- I encountered technical issues while trying to access it
- I did not feel it was relevant to me
- I think it's going to be too long
- Other (please specify)

[Questions about not finishing the questionnaire]

What is the main reason you did not finish the health and lifestyle questionnaire?

- I forgot about it
- I did not have enough time to finish it
- I was unsure how to access it
- I encountered technical issues while trying to access it
- I did not feel it was relevant to me
- I think it's going to be too long
- Other (please specify)

[Questions about the overall experience]

Why did you decide to take part in Our Future Health? Please select all options that apply

- I want to help improve the health of future generations
- I want to help tackle common diseases
- I want to help tackle rare diseases
- I want to help tackle diseases that affect me or my family
- I was offered a £10 voucher in recognition of my time and effort
- I want to help tackle diseases that affect my community
- I am interested in taking part in health research
- I agree with the aims of this research
- I want to receive personal results about my health in the future
- I want to make sure people like me are represented in health research
- Not sure / I don't know

- Other

If you had a question about Our Future health, were you able to get an answer?

- I didn’t have a question
- Yes, my question was answered fully
- Yes, my question was answered partially
- No, I didn’t get an answer

Where did you go to find answers to your questions? Please select all options that apply

- I emailed the Our Future Health support team
- I called the Our Future Health support team
- I read the frequently asked questions on the website
- I read the participant information or consent documents
- I wasn't sure where to go to find answers

In the following questions, please choose the options on the scales below that best reflect your experience taking part in Our Future Health so far.

How **not demanding** or **demanding** did you find the experience of taking part in Our Future Health?

Not demanding 1 •	 2 •	 3 •	 4 •	 5 •	 6 •	Demanding 7 •

How **slow** or **quick** did you find the experience of taking part in Our Future Health?

Slow 1 •	2 •	3 •	4 •	5 •	6 •	Quick 7 •

How **confusing** or **straightforward** did you find the experience of taking part in Our Future Health?

Confusing 1 •	2 •	3 •	4 •	5 •	6 •	Straightforward 7 •

How **boring** or **interesting** did you find the experience of taking part in Our Future Health?

Boring 1 •	2 •	3 •	4 •	5 •	6 •	Interesting 7 •

How **negative** or **positive** did you find the experience of taking part in Our Future Health?

Negative 1 •	2 •	3 •	4 •	5 •	6 •	Positive 7 •

Choose an option on the scale below that best reflects your opinions about Our Future Health.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I think it's a good idea	1 •	2 •	3 •	4 •	5 •
I think it's important	1 •	2 •	3 •	4 •	5 •
I would recommend friends and family take part	1 •	2 •	3 •	4 •	5 •

[Questions about how we might use responses]

Can we use the answers you have provided in the public domain? We will never use your name or anything that would identify you.

- Yes
- No

We would like to invite some people to tell us more about their experiences with Our Future Health to help us improve or publicise the programme. This might include inviting some people to take part in a telephone interview to tell us more about their experiences of Our Future Health. We may use a third-party to arrange and conduct these interviews on our behalf. To do this, we may share your name, the telephone number and email address you gave us when you registered for the third-party agency to contact you. You can read more about our privacy policy here: https://ourfuturehealth.org.uk/privacy/. Do you agree that Our Future Health, or a third party, may contact you in the future to have a conversation with you about how we can improve the programme?

- Yes
- No

Do you agree that Our Future Health may contact you in the future about other projects to publicise the programme

- Yes
- No

PREM Emails

Text of emails to invite participants to complete the PREM survey are shown below.

[Email 1 – Post Questionnaire PREM]

From: Our Future Health
Subject line: Tell us about your experience of the health and lifestyle questionnaire
Preheader: We'd love to hear your feedback

Dear [first name],
We would like to ask you some questions about your experience of the Our Future Health health and lifestyle questionnaire.
Your feedback will help us to make our programme better for others in the future. It should take less than 5 minutes to complete.
[Start the survey]
If you have any further questions, please email support@ourfuturehealth.org.uk or call us on 0808 501 5634 between 9am and 5pm Monday to Friday.
Thank you for supporting the UK's largest health research programme.

[signature]

[Email 2 – Post-Appointment PREM]

From: Our Future Health
Subject line: Tell us about your experience of your appointment with Our Future Health
Preheader: We'd love to hear your feedback

Dear [first name],
We would like to ask you some questions about your experience of your Our Future Health appointment.
Your feedback will help us to make our programme better for others in the future. It should take less than 5 minutes to complete.
[Start the survey]
If you have any further questions, please email support@ourfuturehealth.org.uk or call us on 0808 501 5634 between 9am and 5pm Monday to Friday.

Thank you for supporting the UK's largest health research programme.

[signature]

[Email 3 – Non-Responder PREM]

From: Our Future Health
Subject line: Tell us about your experience of joining Our Future Health
Preheader: Help make Our Future Health better for everyone

You are invited to share your experience of joining Our Future Health by completing a short survey.
We want to understand why some people sign up but don't complete the rest of the process. We understand that life can be busy, and things can change unexpectedly – which is why we'd love to hear more about your experience, so we can improve how we do things.
Your insights are valuable to us, and we appreciate your help in making Our Future Health better for others in the future. It should take less than 5 minutes to complete.
[Start the survey]
If you have any further questions, please email support@ourfuturehealth.org.uk or call us on 0808 501 5634 between 9am and 5pm Monday to Friday.
Thank you for supporting the UK's largest health research programme.
[signature]

Our Future Health

Appendix C: Our Future Health's boundaries and ways of working within research ethics standards

V1.0
14 MAY 2025

User research, PPIE and experimentation in the design and optimisation of Our Future Health

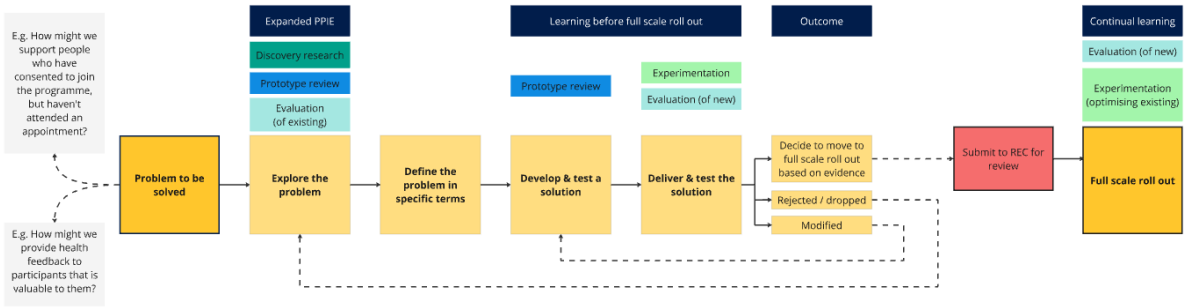
Boundaries for REC approval

Context and background

1. Rapid iteration and testing are critical to our ability to achieve the mission of Our Future Health. Through ongoing research and testing with the public over the last two years, we have facilitated recruitment that has enabled Our Future Health to become the world's largest ever health research programme of its type in an unprecedented timeframe. We now need to use this approach of rapid testing and iteration with Our Future Health participants to build a diverse, highly engaged cohort, who will take part in further research and recontact studies.

2. Figure 1 below reflects the approach we take to building and iterating the design and delivery of our programme (see Appendix 1 for a larger readable version).

Figure 1 – Our Future Health's approach to building and iterating the design and delivery of our programme



NOTE on Fig. 1: The red box 'submit to REC for review' above indicates when we will bring each proposal for full-scale rollout of programme plans and activities to REC for approval. However, there may also be other points during the product development roadmap above, at which we may submit materials and proposals to REC for review, depending on their risk categorisation as expanded below.

3. This process involves a range of research- and involvement-based activities, including:
   - Participant and public involvement and engagement (PPIE)
   - User research and testing
   - Off-platform experimentation, and on-platform experimentation (to optimise what is live, existing or to test new content/design).

   See Appendix 2 for the range of methodologies that may be used.

4. While we focus on those activities in this document, we will always bring amendments to the PIS, consent form, or research protocol to the REC for its approval.

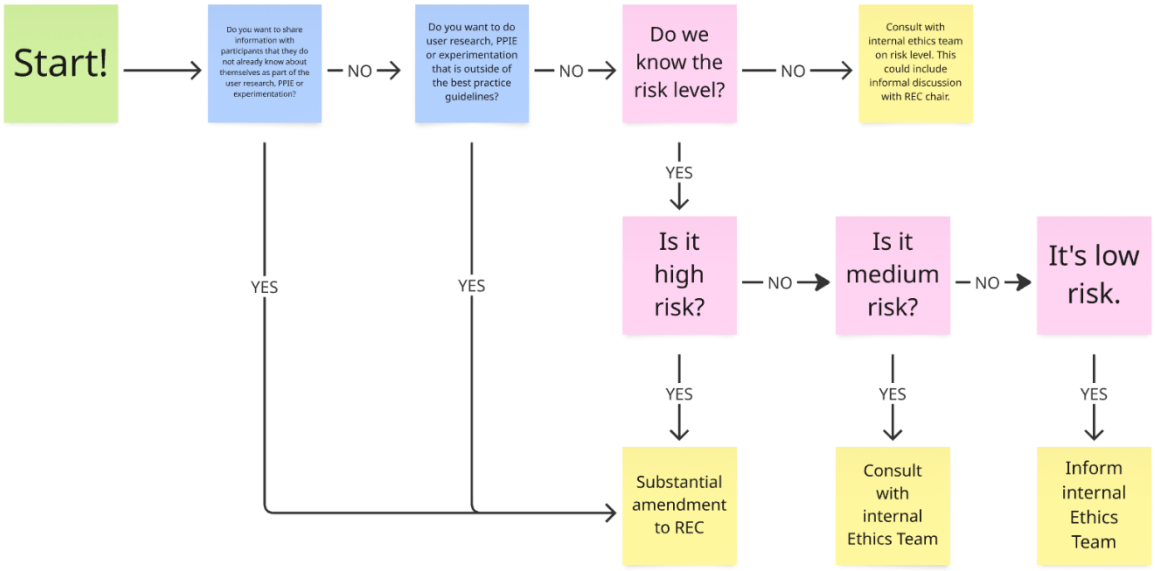
5. In this document, we describe a proposed approach for working with the Research Ethics Committee (REC) to enable this user research, PPIE and experimentation. We (1) outline proposed decision steps which will help Our Future Health determine the REC's involvement for a particular research or involvement activity, (2) describe activities that can be categorised as 'low', 'medium' and 'high' risk to participants or Our Future Health as a programme, and (3) outline guidelines for best practice which all user research, PPIE, experimentation, and design will adhere to (see Appendix 3). We also share the principles that we have set out in our PPIE strategy which will further guide our work that uses PPIE methodologies (see Appendix 4). Those principles were co-created with members of our Public Advisory Board.

6. The contents of this boundaries document sit alongside the REC's 6 January 2025 approval for Our Future Health to establish a pilot Involvement Network as part of its PPIE structure.

The decision steps to take to determine the REC's involvement

7. Figure 2 below outlines a series of decision steps which Our Future Health can take to determine the necessary involvement of REC in the approval of PPIE, user research and experimentation (see Appendix 1 for a larger readable version).

Figure 2: Decision diagram to determine the REC's involvement in the approval of PPIE, user research and experimentation



NOTE on Fig. 2: Though this diagram indicates that teams will inform or consult the internal ethics team for their activities, the ethics team will, where necessary, seek further advice from REC and/or review/escalate the risk category.

Determining risk categories

8. Our Future Health will use the categorisation of the activities below to determine whether user research, PPIE or experimentation should be considered low, medium or high risk to participants or Our Future Health as a programme.

Activities that are low risk

Optimising what is already in use

(Including content / design that has received REC approval previously, or for which approval has been deemed unnecessary). Research, PPIE, or experimentation on:

- visual redesigns of a live user interface (e.g. moving a button) that falls within our best practice guidelines (see here)
- live content redrafting, where the changes do not alter the meaning, intention or understanding of the content or where the content is already in use elsewhere in the programme
- understanding the optimal timing and/or frequency of engagement activities, invitations, reminders or other participant materials
- different mediums of communication. For example, recontact study invitations sent via email versus post
- different variants, where one group is told new information about themselves in a different way that is different to another group

NOTE: We will not always conduct research, PPIE or experimentation to optimise what is already in use.

Sampling approach for user research, PPIE or experimentation

- Non-targeted sampling. For example, testing with, or involving, any available users/participants rather than a specific subgroup
- Sampling based on the area of the UK that someone lives
- Sampling based on participants' engagement status/user behaviour
- Sampling using proxy special category data. For example, inviting participants who attended an Our Future Health clinic in Bradford because we know that Bradford has a large South Asian resident population, and we would like to conduct research with people from a South Asian background

Topic of the user research, PPIE or experimentation

- The development of an invitation strategy and materials
- Designing interventions to maximise recruitment into recontact studies
- The types of health insights that are of most interest to participants
- A hypothetical topic, including topics in the 'high risk' category, e.g. 'if you were to be told your risk of diabetes, how would you like that information to be presented?' *NOTE: research on this topic would not include live experimentation methods.*
- Sharing population health insights as part of research
- Designing engagement activities, including those that would:
    - provide extrinsic value if rolled out. *NOTE: research on this topic would not include live experimentation methods.*

    - target participants who are likely to be less engaged than others in the cohort (no targeted sampling)
    - target participants based on where they live in the UK / within their country
    - target a group of participants eligible for a recontact study (no targeted sampling)
- The development of cohort-wide emails
- Evaluating participants' experience of taking part in Our Future Health or a specific activity
- Talking to carers of those with a condition to inform the design of content/user experience (may be used if a recontact study was being planned on dementia, for example)
- Support functions (e.g. how participants ask Our Future Health questions about a study before joining or raise a complaint)

Activities that are medium risk

Sampling approach for research based on information the individual should know about themselves

- Sampling participants based on health information that they already know about themselves. For example, height as provided at an Our Future Health appointment
- Sampling participants based on data from their NHS health record. Most people will know this data about themselves, but we do not know that they know it for certain. For example, diagnosis of Type 2 diabetes
- Sampling participants based on data differences (such as missing data). For example, participants who have not completed a section of their health and lifestyle questionnaire.
- Sampling based on information that participants have told us as part of previous user research.

Disclosing low risk information

- Telling participants about data differences that they may not be aware of as part of research, for example, missing data
- Showing participants health information that they already know as part of user research / experimentation

Research or involvement where participants or researchers could be put in a potentially vulnerable position

- Researching with or involving participants who could be eligible for a recontact study, but do not know their risk status for the condition of interest (for example, a condition that is more likely to affect women than men)
- Testing or involving participants in developing supporting materials to accompany a recontact study invitation with people who would be eligible for the recontact study (but not disclosing new information to the individual)
- Research that puts researchers / participants in potentially vulnerable situations, for example, an in-person focus group that finishes late in the evening.

Research on targeted content

- User research or experimentation with participants where different content is shown depending on (non-special category) demographic or behavioural characteristics (e.g. age, whether someone completed their health and lifestyle questionnaire or whether they attended a walk-in clinic). See here to see how this would be operationalised.

Research with potential external, health system or reputational impact

- Experimentation with a significant number of individuals that has the potential to have an impact on the reputation of Our Future Health or wider health system. *NOTE*: it is not possible to define 'significant number' as it will vary by study design. For example, an experiment involving 500 people spread across the country is unlikely to have an impact on the wider health system, but if the focus was on individuals living in a particular region of the country the impact could be greater with only 500 individuals.

Design with potentially undue influence

- Research on visual redesign of a live user interface (e.g. moving a button) that falls outside of our best practice design guidelines (see here). For example, where the change highlights an extrinsic motivator for taking part in a recontact study, such as a voucher. *NOTE*: This is considered medium risk as the risk will be dependent on the methodology used. For example, interviews with participants about the redesign would be considered lower risk than live experimentation testing the redesign.

Requests to disclose new information

- Live experimentation which includes asking participants to disclose non-special category demographic or behavioural data (for example, an individual's motivation for joining Our Future Health, how they heard about the programme or the types of recontact studies they would be interested in)

Optimising recontact study invitation strategy and study materials

- Live experimentation on the presentation or ordering of a recontact study invitation strategy (e.g. whether an invitation to a participant to express an interest in a study is opt-in or opt-out, or the number of invitations a participant may receive to an individual study) or study materials content (e.g. invitation, participant information sheet, consent form) and framing (e.g. where motivational emphasis is placed). *NOTE:* all content and invitation strategies will have received prior approval by the REC or for which approval has been deemed unnecessary.

Activities that are high risk

Disclosure of new high-risk information (*NB: this would not be used in PPIE contexts)*

- Sharing information with participants that they do not know about themselves as part of user research / experimentation
- Showing participants data that they know about themselves but combined together to make a risk score as part of research. This includes scores that are publicly available, for example, BMI and the Diabetes Leicester Score, as well as non-publicly available scores, for example integrated risk score or polygenic risk score

Targeted sampling based on special category data

- Experimentation, involvement, or user research where groups are targeted based on special category data

Researching with or involving potentially vulnerable participants

- Researching with or involving people with impaired capacity to consent
- Research where participants are asked to reveal sensitive information about themselves as part of a focus group

Variation to consent model

- Live experimentation of consent models (for example opt in versus opt out consent)

Requests to disclose new special category data

- Live experimentation which includes asking participants to disclose special category data

Appendix 1: Larger, readable versions of Figures 1 and 2

Figure 1 – Our Future Health's approach to building and iterating the design and delivery of our programme

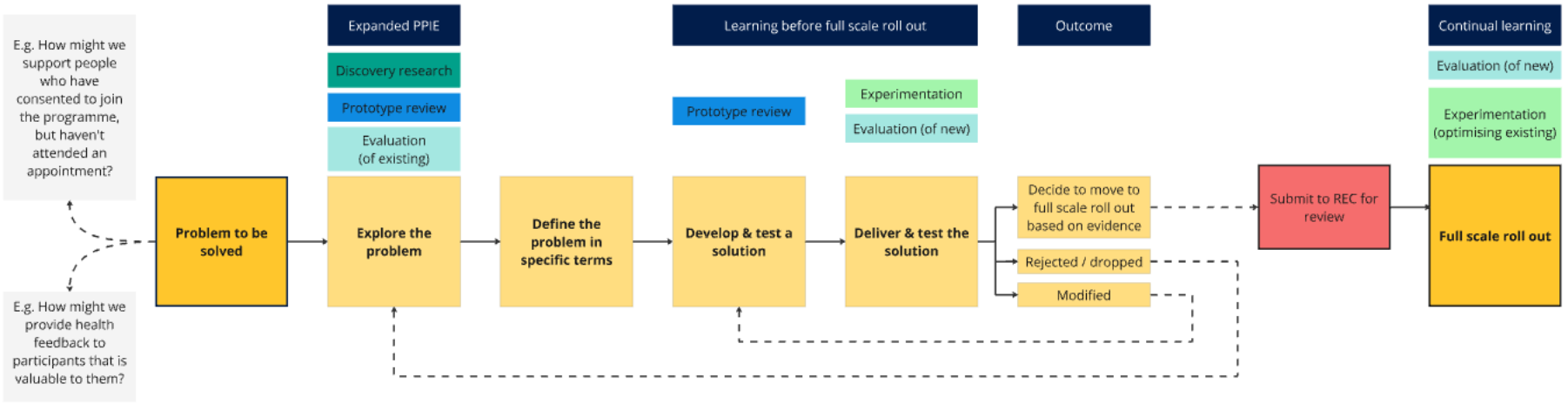
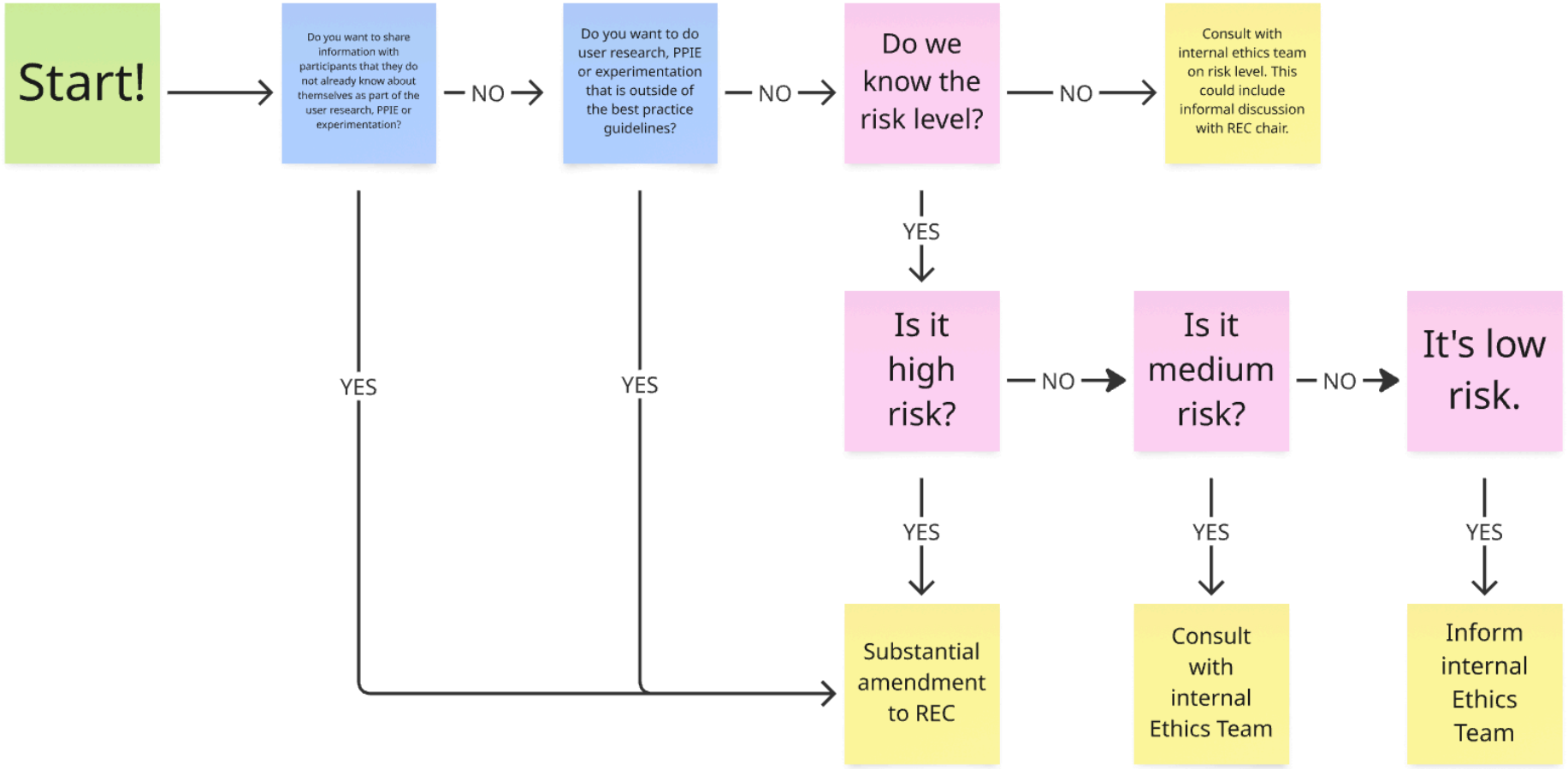


Figure 2: Decision diagram to determine the REC's involvement in the approval of PPIE, user research and experimentation



Appendix 2: PPIE, user research, and experimentation methodologies that these boundaries apply to

Qualitative methodologies

Interviews	Focus groups	Ethnography / field studies
Service walk-throughs	Usability testing	Card sorts
Tree testing	Diary studies	Think-aloud studies
Session recordings	Contextual inquiry	Participatory design / co-design
Deliberative workshops / citizen juries		

Quantitative methodologies

Surveys	Longitudinal studies	Heatmap analysis
Analytics review	Clickstream analysis	Session recordings
Click tracking	Natural experiments	Eye tracking

Off-platform and on-platform experimentation

Randomised controlled trials	A/B testing	Multivariate testing
Quasi-experimental designs	Pre/post testing	Factorial designs

Mixed methods

Process evaluations

Appendix 3: Good practice for user research, PPIE, experimentation and design at Our Future Health

This good practice guideline for user research, PPIE and experimentation have been developed using the **British Psychological Society ethical guidelines** and **Market Research Code of Conduct**.

This good practice is split into:

1. Good practice for user research, PPIE & experimentation
2. Good practice specific to user research & PPIE
3. Good practice specific to experimentation
4. Good practice for design

1. Good practice for user research, PPIE & experimentation

Purpose

- User research and experimentation will be directly connected to, intended to improve, or inform the Our Future Health research programme.
- It will only be done when it is expected to have a meaningful impact or influence decision-making.

Methods & tools

- Researchers suitably trained for the method they are using.
- Access to any raw data for analyses will be restricted to staff users with sufficient and up to date training, and security clearance and access will be regularly reviewed.
- Documentation will be stored for each activity, including research plans, materials, and report of findings.

What happens when the user research, PPIE or experimentation concludes

- Raw data will be retained only for the duration that is necessary.

2. Good practice specific to user research & PPIE

Recruitment

- Potential user research & PPIE participants will not be sampled based on special category data that Our Future Health holds about the individual (i.e. ethnicity, religion), unless the individual has provided that information with the explicit understanding that their data will be used in that way.
- Potential user research & PPIE participants will be told the reason that they have been invited at invitation.

Consent

- User research & PPIE participants will provide informed consent prior to participation.
- As part of the consent process, individuals will be provided with the following information:

  - The purpose of the research, including that the research is for programme improvement rather than scientific discovery
  - The risks and benefits of taking part
  - How long the research is expected to take
  - What individuals will be asked to do
  - The right to stop at any point
  - The right and way to withdraw or provided with an explanation of why it will not be possible to withdraw (for example, it is an anonymous survey).
  - Whether audio, video or screen recording will be used

- Individuals will be given the opportunity or means to ask questions prior to consent.

Participant asks & tasks

- Participants will be informed that they are not being tested as part of the research and that they may skip tasks that they do not understand or feel comfortable with.
- To the best of Our Future Health's ability, research will be arranged at the participants' convenience and access needs will be catered for.

Right to anonymity

- We will only collect identifiable data for the purpose of the research or to facilitate good research practice.
- We will seek explicit permission to collect and share audio, visual or text data that could identify a participant.

Right to withdraw

- Participants will be informed of whether, how and at what point it is possible to withdraw from the user research.
- We will distinguish between withdrawal from Our Future Health and withdrawal from user research.

Benefits & burden

- Where reimbursement is offered, it will be in line with NIHR guidelines.

What happens when the user research concludes

- Participants will be informed about next steps and what will be done with their data.
- Data will be analysed for its intended purpose and findings disseminated internally and externally where appropriate.
- Data will be retained only for the duration that is necessary

3. Good practice specific to experimentation

Robust scientific methods

- All experiments will have well-defined, clear goals and outcomes and will be based on best practice in the field.
- Where possible, experiment participants will be randomly allocated to conditions to minimise the impact of individual characteristics on outcomes.

- Experiments will be informed by prior knowledge, hypotheses (grounded in data or theory), and assumptions, and where needed, discovery and user testing will be conducted prior to the experiment to further understand potential barriers, solutions and user needs, or identify pain points.
- Tests and experiments will be run for a pre-determined and limited time.

Benefits & burden

- No experimentation will be undertaken that might harm participants / prospective participants' wellbeing.
- Participation in an experiment will not result in any undue disadvantage to a participant.

Informed participation

- Where it is possible to do so, participants will be informed of their participation in an experiment.
- Where informing participants that they are taking part in an experiment would influence the outcomes, participants will not be informed, but all due measures will be taken to assess risk and value of the experiment before commencing.

Right to anonymity

- No personally identifiable information will be linked to data collected in experiments seeking to optimise content / design that is existing; data will be anonymised prior to analysis and results will be shown in aggregate.
- Results for experiments of all kinds will be presented in aggregate, and raw data will not be shared outside of the relevant analytic or research team.
- Aggregate results will not be shown if the number of people in an experimental condition is so low as to be potentially identifiable (<10 per condition) or if a small group number could be inferred by calculation (i.e. where a total number of participants is known, and there are only two groups, one which has fewer than 10 participants, we will not report the true size of the larger group).

What happens when the experimentation concludes

- Results from experiments will be shared with the organisation and used to inform decisions about programme direction, operation or change, and help ensure that the changes we implement are effective and aligned with our goals.
- Where participants in one experimental condition are offered something that is of value, for example reimbursement or a personalised health insight, and participants in a control condition are not, participants in the control condition will be retrospectively provided the high value offering provided there were no unexpected or negative outcomes.

4. Good practice for design

The good practice guidelines below are not exhaustive design principles but are guidelines that we will abide by when designing new products or services.

Things that we will not do

- We will not employ dark patterns (see Table 1 below).
- We will not manipulate cognitive biases to drive people and participants toward choices that do not align with their true preferences.
- We will not set false expectations about being a participant or the value participants will gain by taking part through deception or misleading language.
- We will not give more visual importance to monetary or economic drivers (for example, monetary vouchers) than other internal or external motivators.

Things that we will do

- Employ clear content and honest interfaces (transparent design) to create transparent designs.
- User test throughout the design process to identify and eliminate unintentional coercion and improve participant understanding.
- Ensure public and participants' welfare are never endangered by designing toward organisational goals.
- Demonstrate trustworthiness and monitor trust- and understanding-related metrics.

Table 1 – Dark patterns that will not form part of our design

Deceptive pattern	Definition
Comparison prevention	The user struggles to compare products because features and prices are combined in a complex manner, or because essential information is hard to find.
Confirmshaming	The user is emotionally manipulated into doing something that they would not otherwise have done.
Disguised ads	The user mistakenly believes they are clicking on an interface element or native content, but it is actually a disguised advertisement.
Fake scarcity	The user is pressured into completing an action because they are presented with a fake indication of limited supply or popularity.
Fake social proof	The user is misled into believing a product is more popular or credible than it really is, because they were shown fake reviews, testimonials, or activity messages.
Fake urgency	The user is pressured into completing an action because they are presented with a fake time limitation.
Forced action	The user wants to do something, but they are required to do something else undesirable in return.
Hard to cancel	The user finds it easy to sign up or subscribe, but when they want to cancel they find it very hard.
Hidden costs	The user is enticed with a low advertised price. After investing time and effort, they discover unexpected fees and charges when they reach the checkout.
Hidden subscription	The user is unknowingly enrolled in a recurring subscription or payment plan without clear disclosure or their explicit consent.

Nagging	The user tries to do something, but they are persistently interrupted by requests to do something else that may not be in their best interests.
Obstruction	The user is faced with barriers or hurdles, making it hard for them to complete their task or access information.
Pre-selection	The user is presented with a default option to use to influence their decision-making. Preferred options may be highlighted, but alternative options will always be available / clear to the user.
Sneaking	The user is drawn into a final transaction on false pretences, because pertinent information is hidden or delayed from being presented to them.
Trick wording	The user is misled into taking an action, due to the presentation of confusing or misleading language.
Visual interference	The user expects to see information presented in a clear and predictable way on the page, but it is hidden, obscured or disguised.

Appendix 4: PPIE principles as set out in Our Future Health's PPIE strategy

Note to the REC: these principles were co-developed with Our Future Health's Public Advisory Board. They underpin our PPIE strategy, which was finalised earlier this year.

Principle	Applying the principle
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).
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.
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.
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).
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.
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.
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.
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.

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.

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.

Our Future Health

Appendix D: Community Champions

v1.2
15 APRIL2025

Community Champions pilot

Context

1. Community champions programmes bring together members of the public who volunteer to assist an organisation in reaching diverse communities. The participants of such programmes meet regularly and assist the relevant organisation by disseminating materials, organising awareness initiatives, and acting as a consultative body to help improve the organisation and its activities.

2. Our Future Health is planning to pilot its own Community Champions programme, as it is important for us to explore new recruitment methods for groups that are currently underrepresented in our cohort.

3. The aim of our Community Champions pilot is to improve awareness of our programme, with a view to increasing participation, particularly amongst diverse groups and communities. Ultimately, we want to improve the diversity of our cohort and build a resource that reflects the UK population.

4. The Community Champions will all be Our Future Health participants. They will therefore be aware of the programme already and cognisant of what it entails to take part in Our Future Health. As such, they are in a much better position to advocate on behalf of Our Future Health than non-participant members of the public.

5. Over the course of the pilot, our Community Engagement team will work with Community Champions to establish programmes of activity to encourage information-sharing, discussion, and awareness-raising of our research programme. We will draw on the expertise and networks of our Champions, supporting them to share information about Our Future Health with their communities. This eight-month pilot - which we expect to establish in late 2024 - will see us contacting a group of our participants to invite them to become a Community Champion in their area. This will be a voluntary role that will be offered to 250 participants who respond positively to our invitation / register their interest; and live in areas that have high levels of either ethnic or socioeconomic diversity.

6. We have taken this proposal to Our Future Health's Public Advisory Board and Diversity and Inclusion Board, members of which responded positively, and made suggestions to help improve the proposed pilot. Those suggestions have been incorporated into our plans and approach – further details of which are contained in the sections that follow.

Process overview

7. The following steps will be taken to support our Community Champions pilot. More details about each of these steps is set out in the remainder of this document.

Step	Action	Brief outline
1	Initial contact	Our Future Health participants who live in specified areas are contacted via email and invited to register interest in becoming a Community Champion. They may be sent two further reminder emails.
2	Registration of interest	Contacted participants register their interest in becoming a Community Champion through completing an online form on the third-party platform Qualtrics.
3	Assessment of applications	The Community Engagement team assesses participants' responses to the form to establish who will be invited to become a Community Champion.
4	Application outcomes shared with participant	The Community Engagement team contacts participants who have, and have not been, chosen to become a Community Champion.
4a	Unsuccessful applicants	We will share a toolkit as part of our response to unsuccessful applicants. They may like to use this toolkit to share information about our programme through their own networks, but outside the Community Champions pilot.
4b	Successful applicants	Successful applicants will be invited to an induction meeting online, which will explain the programme to applicants, set out expectations and be an opportunity to ask any questions. Members of the Community Engagement team will lead this meeting.
5a	Volunteer Agreement	At the end of the induction, applicants will be sent a Volunteer Agreement via Qualtrics. This document sets out the respective responsibilities for both the Community Champion and for Our Future Health. Champions will be encouraged to read it, sign it, and raise any questions with the Our Future Health team. The Volunteer Agreement will include a link to the Privacy Notice.
5b	Consent form	Successful applicants will also be directed to Qualtrics to complete a consent form. The consent form will include a hyperlink to the Privacy Notice.
5c	New starter form	Successful applicants will also be asked to fill in a new starter form to collate necessary information to facilitate the programme. (e.g. dietary requirements, next of kin details.)
6	Training	All Community Champions will receive training led by our Community Engagement team.

7	Activities begin	Community Champions begin to engage their communities and raise awareness of the Our Future Health programme. They are supported throughout by their designated Coordinator.
8	Activities end	Eight months later, the pilot will end. Community Champions will be informed about how they can continue to support Our Future Health's work.

Invitation process

8. The intended recruitment route for Community Champions is via email. We will email Our Future Health participants who have consented to take part in our programme (i.e., those who have completed their questionnaire and attended their appointment) and invite them to register their interest in becoming a Community Champion. Joining will be completely voluntary, and it will be made clear that it is their decision to choose whether or not to become a Community Champion. If they choose not to, there will be no adverse impact on their involvement in the programme.

9. If other participants learn about the pilot (e.g., through word of mouth, or visiting our website), they will also be able to get in touch with the team to indicate interest in becoming a Community Champion – i.e., we will also consider unsolicited applications.

Invitations according to defined geographic areas

10. We will not be contacting our whole cohort. Rather, we will email participants who live in areas of high ethnic diversity and deprivation to give us the opportunity to involve groups that are currently underrepresented in our cohort. However, the email will not be targeted to participants who have specific demographics. Instead, it will be sent to all consenting participants who live in those areas. We have split those areas into two groups – as indicated below. Those in group 1 will be contacted first. Those in the second group may be contacted only if we do not reach our target of 250 Champions after all reminder emails have been sent to the first group. This may be approximately 4-6 weeks after the first email goes to the first group.

First group of areas	**Second group of areas**
Barking and Dagenham, East London	Birmingham
Beckton, East London	Bolton
Bradford	Burnley
Brent, West London	Bury
Croydon	Manchester
Ealing, West London	Oldham
Harrow, West London	Preston
Hillingdon, West London	Reading
Hounslow, West London	Rochdale
Leicester	Rotherham
Leeds	Sheffield
Luton	Stoke on Trent
Newham, East London	Walsall
Redbridge, East London	Wolverhampton
Slough	
Tower Hamlets, East London	
Watford	

The consent we are relying on to contact potential Community Champions

11. Participants who consent to join Our Future Health agree to receive emails, including news and updates about the programme. All marketing emails include a link to unsubscribe. Therefore, if a participant is not interested in receiving these general updates, they are able to opt out. If they have already done so, they would not receive this email. They can also choose whether or not they wish to register their interest in becoming a Community Champion. If they are not interested, the email can be ignored.

12. We know that participants agree with the aims of Our Future Health and want to improve diversity in health research. There is also a desire from participants to help the programme further after they have consented to take part. By inviting participants to register interest in becoming a Community Champion, we are offering them the opportunity to support Our Future Health and improve the diversity of our cohort.

Data protection considerations

13. This strategy has been approved by Our Future Health's Data Protection team, in the light of a Legitimate Interests Assessment (LIA). The LIA concluded we can rely on legitimate interest (Art.6(1)(f) of the General Protection Data Regulation) as a basis to email participants to invite them to become Community Champions.

The number of emails we will send

14. We will send a maximum of three emails to each participant who lives in one of the designated areas. Those emails will:

    - Let participants know that the application process is open. There are two versions of this email. We will send version 1 to some participants; and version 2 to others. This will allow us to assess which version yields the best response.
    - Share a reminder to apply if they are interested.
    - Make them aware when the application process is closing.

15. The emails will be spaced out over a six-week period, with at least 14 days between emails. We co-designed our email approach with the Our Future Health Public Advisory Board at its 13 July 2024 meeting.

Applications from participants: establishing who will become Community Champions

Participants' online application form

16. Participants who choose to register their interest will be invited to complete an online application form.

17. The purpose of the application form is to collect personal information and assess the interest of individuals who wish to become Community Champions. It includes sections for the applicant's full name, email address, date of birth, ethnicity, postcode, their motivations for becoming a Community Champion, and what they hope to gain from volunteering. The application form will be distributed to participants via an invitation email. It will also be

available on the landing page for the Community Champions pilot when participants log into their Our Future Health account.

Using form data to choose Community Champions

18. The data collected on the application form will allow us to analyse the geographical and demographic diversity of the Community Champion pilot and how we can shape the pilot to their interests and needs.

19. From the applications that we receive, we will be looking to progress applicants who best meet the criteria below:
    a. Come from diverse backgrounds – specifically those from ethnic minority backgrounds which are underrepresented in our cohort and from a younger age group (under 40)
    b. Demonstrate that they have connections with, or work closely with, individuals from underrepresented groups
    c. Have experience of community engagement

20. For those who are not successful in their application to be a Community Champion, we will send them an email informing them that they have not been successful. In that email, we will attach a toolkit which includes ways in which they can share information about the programme is they still wish to do so.

Volunteer agreement

21. The draft volunteer agreement clarifies the roles and responsibilities of Community Champions, setting clear expectations and boundaries to ensure they understand their duties and limitations. It formalises their commitment and accountability, while setting clear expectations about the support that Champions will receive from Our Future Health. The agreement also addresses legal considerations such as confidentiality and data protection, ensures compliance with health and safety, and provides guidelines for ethical codes of conduct. Additionally, it highlights how Community Champions will be supported, supervised, and recognised for their contributions.

22. The development of the volunteer agreement involved several key steps. We began by researching the essential provisions, such as roles, responsibilities, and confidentiality. Then we consulted key stakeholders, including HR and legal, to ensure compliance with regulations. Each provision was reviewed by the appropriate teams, such as data governance for privacy concerns. A continuous back-and-forth process with these stakeholders helped refine each section. Once all feedback was incorporated, we confirmed that each section met the necessary standards and finalised the agreement.

Consent form

23. The consent form is a formal document that allows us to obtain permission from individuals before engaging them in a specific activity, such as providing services, and/or sharing images on social media. It ensures that Community Champions fully understand all aspects of the pilot before committing to the role.

24. Consent forms from participants will be recorded on the third-party platform Qualtrics in the form of a survey, where participants can share their consent preferences. In the event that any

Community Champion would like to withdraw any aspect of their consent, they will need to contact our champions@ourfuturehealth.org.uk email address. They will then be provided with a 'retake survey' link where they would be able to update their preferences. The retake survey link allows us to have the tracked changes from the day of their original consent to when they decide to remove any/all their consent.

25. There will be two types of withdrawal – partial and full. With partial withdrawals, participants' preferences will be updated and, when interacting with them in the future, we will proceed with their updated preferences. With full withdrawals, we will remove all their details from Qualtrics.

New Starter Form

26. The new starter form is a document that collates key information from champions that help facilitate the programme. It collates key information regarding dietary requirements, next of kin information and health considerations that champions would like to share voluntarily (hearing difficulties, sight difficulties, medical conditions, allergies, mental health conditions, medications).
27. The new starter form is filled in via Qualtrics.

Privacy notice

28. To ensure compliance with Article 13 of the UK GDPR, Our Future Health has created a bespoke privacy notice for the Community Champions pilot which covers processing for both successful and unsuccessful applicants.
29. Our reason for creating a bespoke privacy notice for this pilot is that trying to include the legislatively required information in our existing privacy notice would make the latter confusing and complicated to read. We therefore felt that, for the Champions' understanding, and also to support the transparency of this pilot, the optimal approach was to establish a dedicated privacy notice.

30. The privacy notice will be included in any emails the application form and the landing page connected to the Community Champions pilot. If any questions arise, the individual may contact us by emailing champions@ourfuturehealth.org.uk. We will also be carrying out a data privacy impact assessment.

Training Community Champions

31. Our training process is designed to equip Community Champions with the necessary knowledge, skills, and tools to engage their communities effectively and share information about Our Future Health. The training will be delivered internally and structured as follows:
    - **Introduction to Our Future Health**: This session will provide a comprehensive overview of the Community Champions pilot's mission, vision, and objectives. This will equip Champions with the ability to convey a basic introduction to the Our Future Health programme to the communities and community members they engage with.
    - **Events training**: Champions will learn how to plan, organise, and manage community engagement events, from small pop-up stalls to larger community group events. This training will cover logistics, audience engagement, and post-event follow up.
    - **Social media training**: To maximise outreach, this training will focus on how to use social media effectively to promote the programme, engage with communities, and share success stories.

- **Ethics training**: Champions will be introduced to ethical considerations, including informed consent, respect for individuals' autonomy, and maintaining confidentiality. This will also touch on the type of language to use / not use when speaking to people about the programme.
- **Volunteer policy training**: This session will cover relevant policies, including safeguarding, health and safety, lone working, harassment, and discrimination. It will also touch on the code of conduct set out in the Volunteer Agreement, which Community Champions will have signed.

32. The training has been developed through a collaborative approach, drawing on expertise from various departments within Our Future Health, all of whom have expertise of providing training in their respective fields.

Beyond training: providing ongoing support to Community Champions

33. Beyond the initial training sessions, Community Champions will also receive ongoing support through various channels:

- **Dedicated coordinator**: each Champion will be assigned a coordinator who will provide ongoing guidance, answer any questions, and assist with any challenges that may arise. The coordinators will all be members of our Community Engagement team.
- **Regular check-ins**: we will hold monthly check-ins, either virtually or in person, to review progress, discuss upcoming activities, and address any concerns.
- **Access to resources**: champions will have access to a range of resources, including marketing materials, health information, and event planning guides.
- **Further development opportunities**: champions will be offered opportunities for further personal and professional development, such as additional training sessions, workshops, and networking events.
- **Feedback collation**: we will seek regular feedback from Champions to continuously improve our support offerings and ensure that their needs are being met.

Analysis and criteria for taking the pilot forward

34. The following criteria will be used to determine whether we take the pilot forward
    1. That each Champion's engagement endeavours lead to the recruitment of 5 consenting participants in the Our Future Health research programme. That would see us welcoming 1,250 new, consenting participants as a result of this pilot. We will be able to measure the number of consenting participants by tracking individual QR codes on materials shared by Champions. This is by no means an absolute accurate measure but still a good indicator of the success of the pilot.
    2. Achieve a 40% completion rate of champions completing the pilot. This will be measured by registers we keep that track attendance.

Our Future Health

Appendix E: Health Insights - Development and Pilots.

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Our Future Health

CONTENTS

Health Insights Development and Pilots: User research and live pilots for digital health insights

Introduction

This appendix outlines the approach Our Future Health will take to the development and initial evaluation of health-related feedback items.

For each Health Insight under development, Our Future Health will conduct user research and/or pilot evaluations with low volumes of participants. The purpose of these pilots will be to generate learnings that shape the design and delivery of the Health Insight under evaluation, and of the programme more generally.

Usability testing and pilot evaluations for the first item of feedback – the digital delivery of health information that was recorded at volunteers' registration appointment ("clinic measurements") - is expected to commence in 2025.

Clinic measurements

Background

Health-related feedback

Providing health-related feedback to participants is a key aspect of Our Future Health's mission. The return of feedback serves several purposes:

1. **Recruitment into recontact studies:** Providing participants with specific feedback about their health or disease risk that facilitates enrolment into research studies or trials.
2. **Building an evidence base:** Generating empirical evidence on the delivery and outcomes of returning health-related information that is needed to inform healthcare delivery and policy
3. **Value exchange:** Participants may view the opportunity to learn about their health as a personal benefit from taking part.

Feedback strategy

Over the course of the programme, health-related feedback may include lifestyle-based findings, results from physical measurements, analysis of biological samples or genetic results, linked NHS records, or disease risk based on a combination of these sources of data.

Our Future Health recognise the challenges and complexities associated with providing this information to participants. With this in mind, we intend to move towards providing more complex aspects of feedback by first building a robust framework for returning health-related information. The first stage of this strategy is to develop and test the digital return of clinic measurements captured at the appointment. The learnings from this first phase of digital feedback will be used to inform the integration of other sources of health data into feedback, for example from the lifestyle questionnaire or linked records, to provide more detailed and personalised health insights.

This strategy is designed to balance the desire to empower research participants through ownership of their own data as soon as possible with the need to be rooted in the principles of harm minimisation, clarity and accessibility.

Taking a phased approach to the return of health-related information will allow us to:

1. Provide the majority of participants with a digital version of health insights sooner.
2. Enable us to solve the ethical and regulatory challenges of returning health feedback.
3. Ensure that the needs of specific participant groups and edge cases are met, such as those with missing or implausible data.
4. Build secure infrastructure for the delivery of digital health feedback.
5. Reduce the impact on primary or secondary care workloads.
6. Develop a system that is flexible to changes in the programme over time, for example differences in the measures captured at the appointment (POCT cholesterol).
7. Tailor feedback to the nation in which the participant accesses healthcare services.
8. Optimise the participant experience of receiving, accessing and interpreting digital health feedback.

Aims

The aim of the clinic measurements usability tests and live pilot is to ensure that the digital return of clinic measurements and supporting content is usable, easy to understand, and meets the needs of different groups of participants.

Each round of testing will have specific objectives determined by the insights being shown and the participant group invited. These objectives will broadly fall into three areas.

Objective 1 - Technical functionality

Assessment of the systems and platforms through which health insights are created and surfaced to participants.

Example research questions:

- Are participants able to verify their identify before logging in?
- Are participants able to view all health insights?
- Are accurate health insight values being shown?

Objective 2 - Participant experience

Evaluation of participants' attitudes, understanding and value of health insights.

Example research questions:

- What do participants need to know in order to make a decision about viewing health insights?
- What content do participants want to see alongside health insights?
- Does the content meet participants' expectations?

Objective 3 - Participant behaviours

Analysis of average interactions and conversion through the health insights platform.

Example research questions:

- What proportion of participants engage with health insights communications?

- What proportion of participants contact Study Support about health insights?
- Which pieces of content do participants interact with most?

Section 2: Methods

Recruitment of participants

Participants from different user segments will be invited to take part in each round of testing. This will enable specific objectives to be evaluated in a staged approach. Specific groups of participants will be approached for each round of testing to help us better understand the impact of a range of circumstances on participants' experience. These will include e.g. (i) participants with all measurements in normal range; (ii) participants with at least one measurement outside normal range; (iii) participants with missing data (see *Pilot* Schedule, below, for more information). For the time being, we will approach participants with home addresses in England and who attended a study registration appointment in England (as a result of the region-specific proforma). We anticipate needing ~5-20 participants for each round of usability testing, culminating in a small live pilot with ~500 participants.

For usability testing, we will use a partner organisation to schedule interviews and facilitate general research management. Interviews will be conducted by a member of Our Future Health staff. We will never share participant data with the partner organisation, other than whether an interview was completed. The invitation email will ask participant who are interested in taking part in the user research to visit a bespoke registration page on the partner organisation's website to provide their details.

For each round of usability testing, we will identify a cohort of participants who meet pre-defined eligibility criteria based on participation status, data completeness and quality, time since appointment, measurements taken at appointment, and clinical range of results. A randomly selected group of participants who meet this criteria will be sent an email inviting them to take part. Participants will only be emailed once with this invitation.

From these rounds of usability testing, small groups of participants covering a range of data completeness and measurement possibilities will have been taken through the clinic measurements journey in a moderated fashion. The final stage of testing will be a live pilot with a larger group of participants. For the live pilot, participants will be sent an email invite to view and provide feedback on their digital clinic measurements, and will be able to interact with the content in an unmoderated manner before completing a feedback survey.

Participants will only be emailed once with an invitation to one round of the pilot.

Data collection

Data collection methods will vary according to the objectives of each pilot round.

Interviews

For earlier rounds of usability testing, interviews will be used to gather qualitative feedback from participants on their understanding of content, user experience, and overall impressions of health insights. Interviews will use a semi-structured topic guide to direct the questioning and will take

between 30 to 60 minutes to complete. Interviewees will be reimbursed for their time in line with NIHR guidelines.

Transcription and video recordings from the interviews will be stored in Dovetail. Dovetail is software that helps organise user research and feedback. Transcription and video recordings will be retained for as long as Our Future Health require access or until a participant requests their data be deleted. Editing access to the interview recordings and transcriptions in Dovetail is limited to a small number of individuals conducting user research within Our Future Health. Short clips from interviews may be used in insights reports. Viewing of insight reports is restricted to individuals who have been approved to access Dovetail. It will be made clear to participants at the beginning of the interview that clips from the interviews will be shared internally, and that will only be with approved Our Future Health staff.

Surveys

Where quantitative data collection is required, feedback surveys will be used. Surveys may consist of heatmap clicks on content, Likert scale, multiple choice and free text questions and should take no more than a maximum 8-10 minutes to complete. Survey data will be collected anonymously and participants will be reminded not to include any identifiable information in their survey responses.

Analytics

In addition to participant experience data captured through interviews and surveys, analytics captured by the platform will be used to monitor and evaluate participant behaviours. Analytics may include open and click-through rates of emails, clicks on specific content or links, heatmap clicks, and conversion rates. Analytic data will be aggregated for analysis.

Materials

During the testing, participants will be shown their clinic measurements digitally. They will receive an email from Our Future Health with a link to access their measurements. This link will take them to the Our Future Health study site where they will be required to log into their account, and verify access to their email by entering a code sent to them (multi-factor authentication).

Once logged in, participants will see their dashboard, which will include a ‘My tasks’ section featuring a card informing participants that they can now view the measurements taken at their appointment. After clicking on the card, participants will be presented with contextual information about the appointment and the information that they will receive. Participants will be required to confirm that they agree to view the measurements before continuing.

Once agreement is given, participants will be able to see a report of their clinic measurements, including contextual information about the measurements and links to supporting resources.

During testing, participants may additionally be shown other design options for these screens. These designs will not contain any participant data, but will be used as visual stimulus for discussion of participants’ preferences for the design and presentation of information.

Consent

Participants will provide consent prior to taking part in the research. They will be told:

- The purpose of the research, what it involves and what will be done with the findings.
- Who is running the research.
- That the research is voluntary and that they may stop at any time.
- The degree to which their data will be anonymous. All online surveys will be anonymous, online interviews will be audio and video recorded. Recordings will be stored securely and only shared within the organisation.
- If it is possible for data to be deleted and up to when this would be possible.
- How they may ask questions.

For interviews, permission is taken for interviews to be recorded and transcribed for the purpose of synthesising feedback. Participants are informed that recordings and/or transcripts will also be shared with employees within the organisation, for the purpose of learning and improving our products and experiences, and that videos are not shared outside of our organisation. Consent is captured prior to the interview and is repeated for the purpose of the recording.

At the end of the research, we will remind participants that their responses and recordings will be stored for as long as the organisation need to keep the insights, and that if they want to withdraw they should contact either the recruitment agency or the researcher team at Our Future Health. We will seek permission from participants to recontact them to take part in additional user research in the future. After taking part, the digital clinic measurements and supporting pages will be removed and participants will no longer be able to view their health insights.

Pilot schedule

	Participants			Objectives			Content	
	Invite criteria	**Screened characteristics**	**Sample size**	**Technical functionality**	**Participant experience**	**Participant behaviours**	**Insights**	**Supporting information**
Phase 1: Clinic measurements								
Round 1 - Usability	• New full participants • Complete clinic measurement data • Values within healthy ranges • Appointment attended within the last month • Clinic and home address in England	•Demographics •Feelings towards clinic measurements •Satisfaction with appointment experience •Subjective health	5-10	Are we able to generate and return insights based on sensitive data to participants?	Do participants understand the content? Is any content not needed or missing?	Are analytic and engagement metrics being captured as expected?	Clinic measurements	Supporting information adapted from the paper proforma
Round 2 - Usability	• New full participants • Values outside of healthy ranges • Appointment attended within the last month	•Demographics •Feelings towards clinic measurements •Satisfaction with appointment experience •Subjective health	5-10	Are we able to change the presentation of clinic measurements when values are outside of healthy ranges?	How would participants like values to be displayed when they fall outside of healthy ranges?	Does values falling outside of healthy ranges impact engagement with measurements and supporting content?	Clinic measurements	Supporting information adapted from the paper proforma

	• Clinic and home address in England							
Round 3 -Usability	• New full participants • Missing or implausible clinic measurement data • Appointment attended within the last month • Clinic and home address in England	•Demographics •Feelings towards clinic measurements •Satisfaction with appointment experience •Subjective health	5-10	Are we able to change the presentation of clinic measurements when values are missing or implausible?	What information do participants want about missing or implausible values?	How might the exclusion of missing or implausible values impact participant behaviours?	Clinic measurements	Supporting information adapted from the paper proforma
Round 4 - Usability	• Early full participants • Appointment attended more than 6 months ago • Received a cholesterol measurement • Clinic and home address in England	•Demographics •Feelings towards clinic measurements •Satisfaction with appointment experience •Subjective health	5-10	Are we able to change the presentation of clinic measurements when values were not recently collected?	How can we provide value to participants whose measurements were not collected recently?	How do participants interact with clinic measurements when they have not been recently collected?	Clinic measurements	Supporting information adapted from the paper proforma

We may conduct additional rounds of usability testing if we identify other participant groups whose needs we want to evaluate against the content								
Round 5 - Live pilot	• New full participants • Appointment attended within the last month • Clinic and home address in England	•Demographics •Feelings towards clinic measurements •Satisfaction with appointment experience •Subjective health	~500	Are we able to generate and return insights to a subset of new, full participants after they have attended their appointment?	Is the digital clinic measurements report useful to participants?	What proportion of participants open the email and click through to view clinic measurements? What proportion interact with clinic measurements content?	Clinic measurements	Supporting information adapted from the paper proforma
Phase 2: Enhanced insights								
We will submit a future amendment detailing our proposal for piloting enhanced health insights (for example, including derived values and integrated questionnaire data) with participants.								
Phase 3: Disease risk								
We will submit a future amendment detailing our proposal for piloting disease risk feedback with participants.								

Clinic Measurements Recruitment Materials

Email for recruitment to interviews

Subject line: Help us improve Our Future Health
Pre-header: [£XX] voucher for your time and effort

Dear [First name],
We are looking for Our Future Health volunteers like you to speak to our team and share your feedback on receiving health information online.
Your input will help to shape Our Future Health's future digital offer and improve experiences for other participants in the programme.

How it works
The interview will take part on Microsoft Teams, lasting about [XX] minutes. You do not need a Microsoft account to take part. You will need access to a tablet, PC or laptop that has a working camera and microphone.
The interview will be arranged by a partner company called [Partner organisation] and conducted by a member of our team at Our Future Health. We do not share your personal details with [Partner organisation].

[Partner organisation] will contact you if you have been selected to take part. Unfortunately, we won't be able to conduct interviews with everyone who signs up.
If selected, as a thank you for your time and effort, you will receive a £30 voucher for taking part once your interview is complete.

Apply to take part on [partner organisation's] website (enter code XXXX when asked)

Slots are limited, so please sign up soon to share your experience.

Thank you for helping us improve Our Future Health for all our volunteers.

Our Future Health
Let's prevent disease together **Email for recruitment to feedback surveys**
Subject line: Help us improve Our Future Health
Pre-header: Tell us about your experience of receiving clinic measurements

Dear [First name],

We're inviting you to take part in a short survey about receiving clinic measurements online and how Our Future Health gives health information to our volunteers.

How it works
The survey will take around 10 minutes. You may find it easier to complete on a desktop, laptop or tablet than on a phone.

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Click this link to start the survey.

Thank you for helping us improve Our Future Health for all our volunteers.

Our Future Health
Let’s prevent disease together

Notification email

Subject: Your health-related measurements are available to view online

Dear [x],

Thank you for attending your Our Future Health appointment. By taking part, you're supporting new discoveries that will help everyone live longer and healthier lives.

The measurements taken at your appointment are now available to view online. Health-related measurements taken at Our Future Health appointments include:

- height
- weight
- heart rate
- blood pressure

In addition, you may receive information about your heart rhythm.

Sign in to your account to:

- see what measurements were recorded at your appointment
- view useful health information related to your measurements

Sign in and view your measurements

Template topic guide for qualitative research on returning digital clinic measurements to participants

Below we outline a template topic guide for qualitative research with volunteers. It represents a guide to the types of questions that could be asked to volunteers as part of user research and the pilot.

Core themes (explored in every interview)

- Warm up / icebreaker to put interviewee at ease

  E.g. Welcome and introductions, *Tell me a little about yourself*

- Understanding experience of paper proforma

  E.g. *Can you tell me what you thought of the document that was given to you at your appointment that contained your measurements? Did you keep it, share it or show it to anyone?*
  Can you tell me what you liked about that document, and if there were any parts we could improve? After attending your appointment and receiving measurements related to your health, did you do anything differently?

Component themes (only some, or all may be used in user research)

Interviewee may be shown prototype / real data and may be asked to interact with activity as a prompt.

- Understanding usability of accessing digital clinic measurements

  E.g. *What do you understand from this email? How likely might you be to open this email if you received it outside of this call? Where would you click to view your clinic measurements? What might you do next? How do you think you would move on from this screen?*

  Can you tell me about any parts of the process today that were particularly easy or difficult? Are any of the questions you had still unanswered by what you saw today? How could we improve the process you have walked through today?

- Comprehension and acceptability of supporting content

  E.g. *What do you understand [content/topic] to mean? What questions do you have about [topic/content]? What did you like/dislike about the way your measurements were displayed? What was easy to understand / hard to understand? How does receiving digital clinic measurements affect your feelings towards taking part Our Future Health? How would you improve the information you've seen today? What do you expect from Our Future Health in the future?*

- Discovery, acceptability and desirability of future presentation of health insights

E.g., *Can you tell me about a time when you've received information about your health where the experience was positive? what made the experience good? Can you tell me about a time when you had a negative experience learning something about your health? what made the experience bad, and what could have been improved?*

What other health apps do you use? what is it that you like about them? what would you want them to do to improve?

Interviewee may be shown example of an alternative way to present back clinic measurements or an example method of presentation. It will be made clear to interviewees that anything shown is a prototype or an idea being explored as opposed to something that will be available to volunteers in the future.

E.g. *What did you like/dislike about the different options presented?*

Close out and debrief (included in every interview)
Thank volunteer for their time.
Explain next steps if any.
Give opportunity to ask questions.
Refer to Study Support if any new questions arise following the interview.

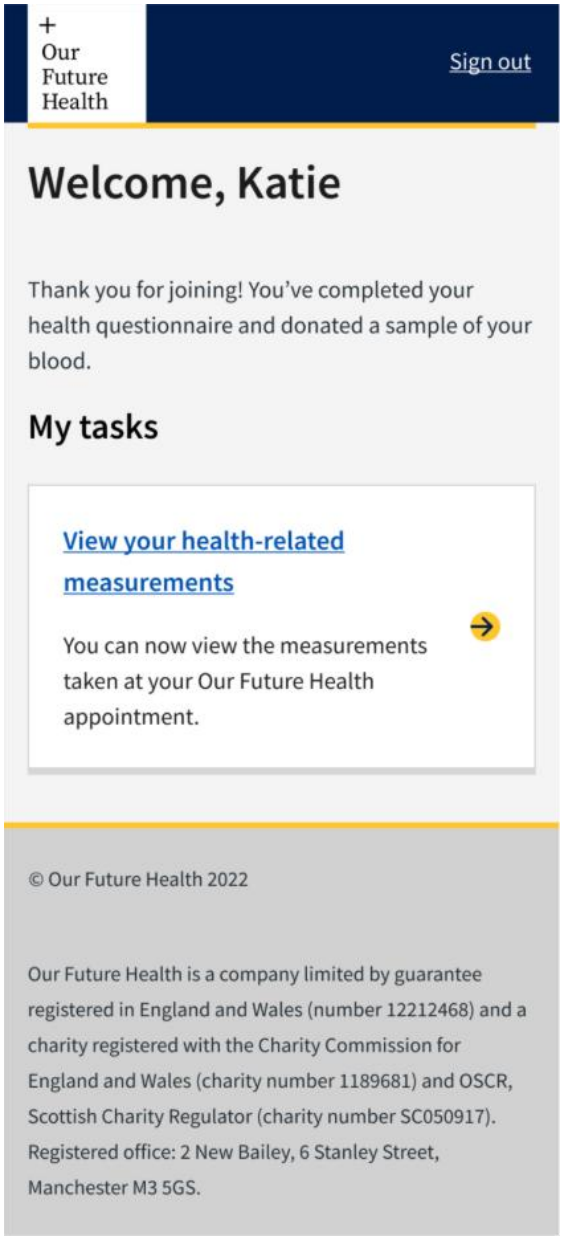
Health Insights Development and Pilots
Clinic Measurements copy

Introduction

This appendix includes all versions of the Clinic Measurements copy that we wish to evaluate with participants in this round of testing. In general, the copy is based on the most recent (REC-approved) version (v8) of the paper proforma. Some minor changes to copy were necessary to enable the *digital* presentation of the information. Some screens are presented twice, to make clear the different iterations of design or text that we wish to test with participants. Please see the explainer text below each screen for more information.

1. Dashboard

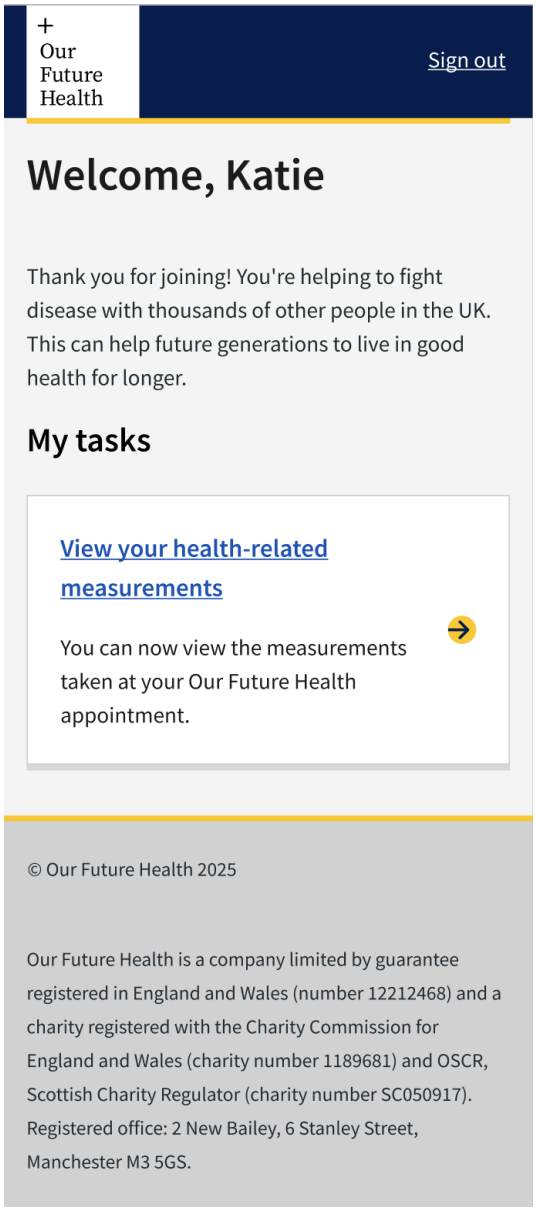
Option A



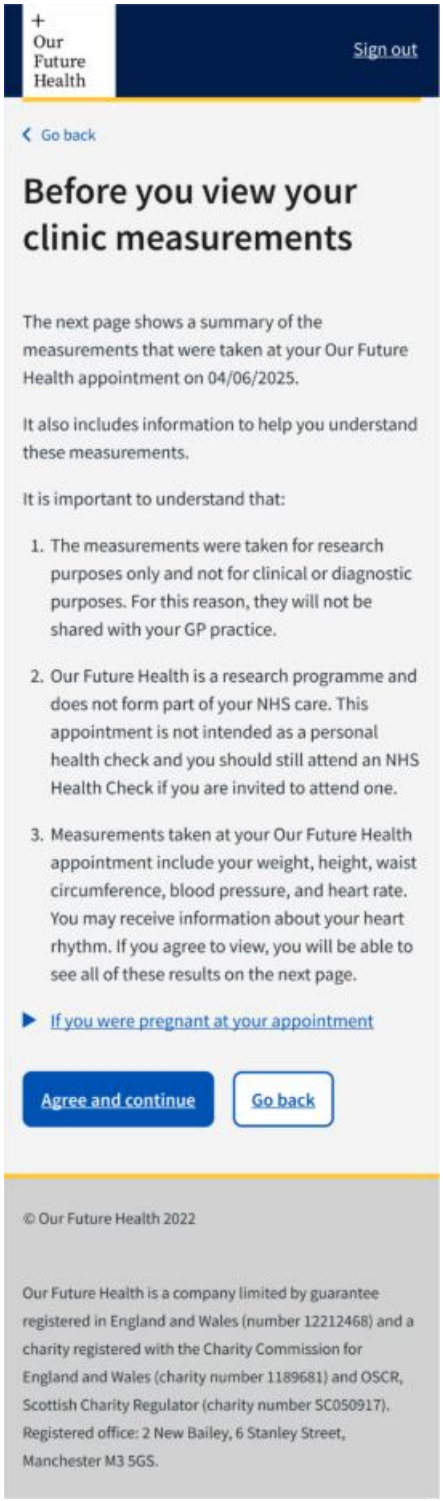
NB: header copy matches the current dashboard screen participants see when they login to their accounts. The “My tasks” section is new.

Option B
As above, but with amended copy, to match the existing participant dashboard:

“Thank you for joining! You're helping to fight disease with thousands of other people in the UK. This can help future generations to live in good health for longer.”



2. Agreement



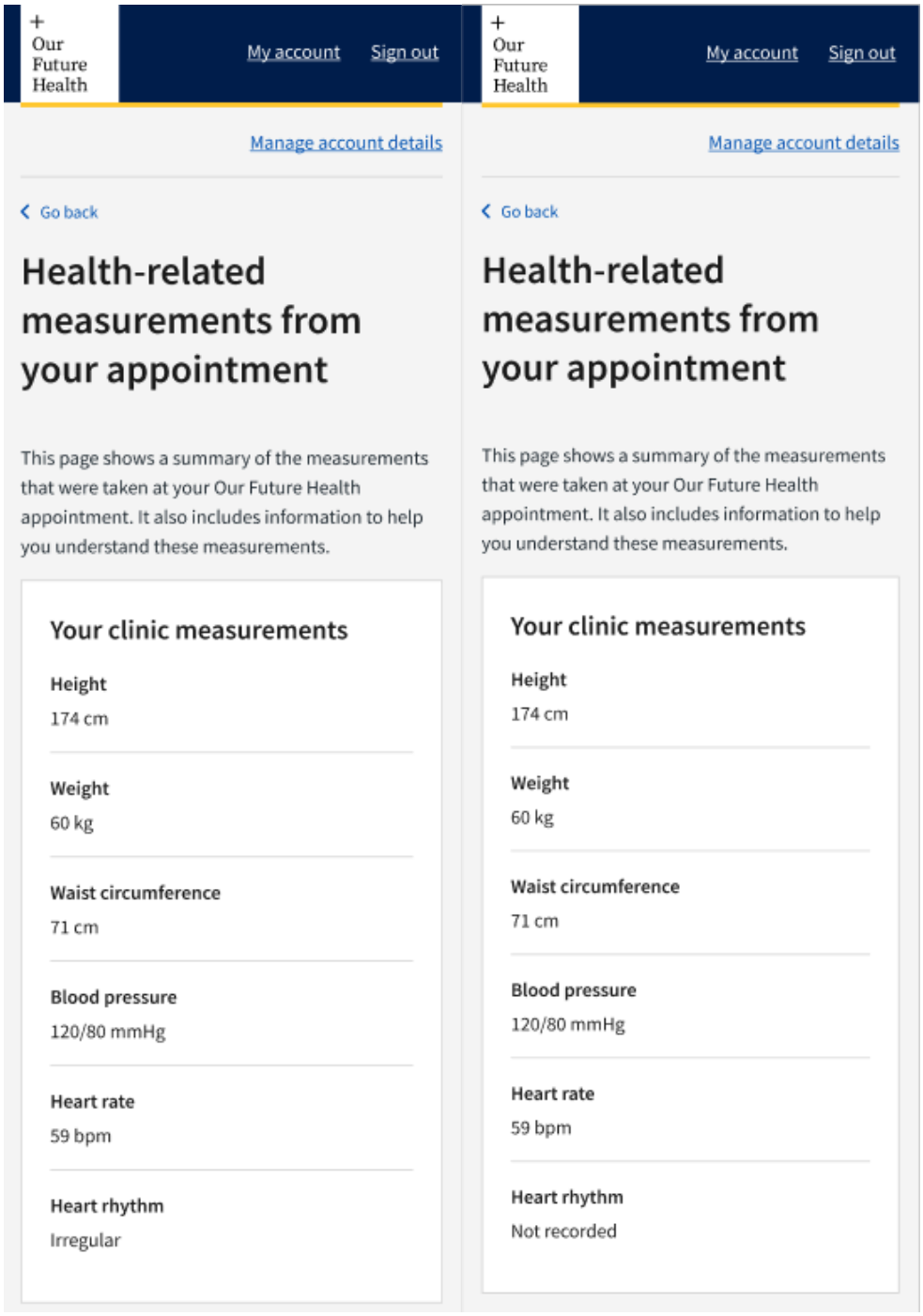
This screen contains some contextual information about participants clinic measurements e.g. the date of their clinic appointment. This screen is shown each time a participant clicks to view their clinic measurements.

Note that we explain that some participants *may* receive information about their heart rhythm in section 3; this is intended to match the behaviour of the "heart rhythm" section of the new REC-approved proforma. If a participant clicks on the "if you were pregnant at your appointment" expander, the following text appears (which matches the REC-approved proforma): "In the 2nd or 3rd trimester of pregnancy, your blood pressure, heart rate, weight and waist circumference will be different than normal. If you have physical measurements taken while pregnant, and they fall outside the healthy ranges advised, it's important to remember that they may be normal for pregnancy and no cause for alarm. If you have any concerns, please discuss them with your midwife/GP."

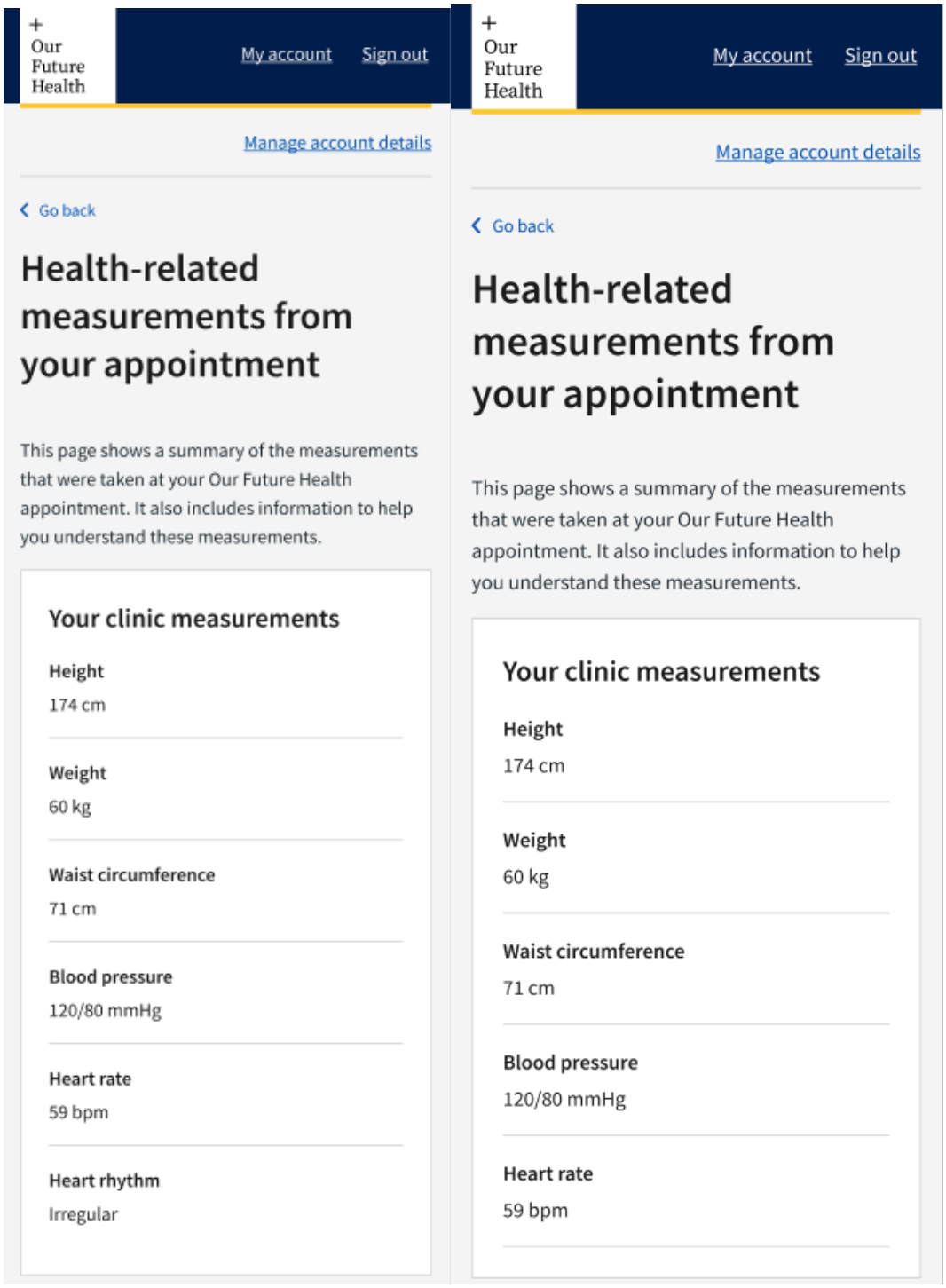
3. Clinic measurements

NB: We want to reproduce the experience of the most recent REC-approved paper proforma, in which heart rhythm is only recorded if irregular. We have designed several ways of doing this digitally, which would be subject to user testing.

Option A: Heart rhythm recorded as "Irregular" vs "Not recorded"



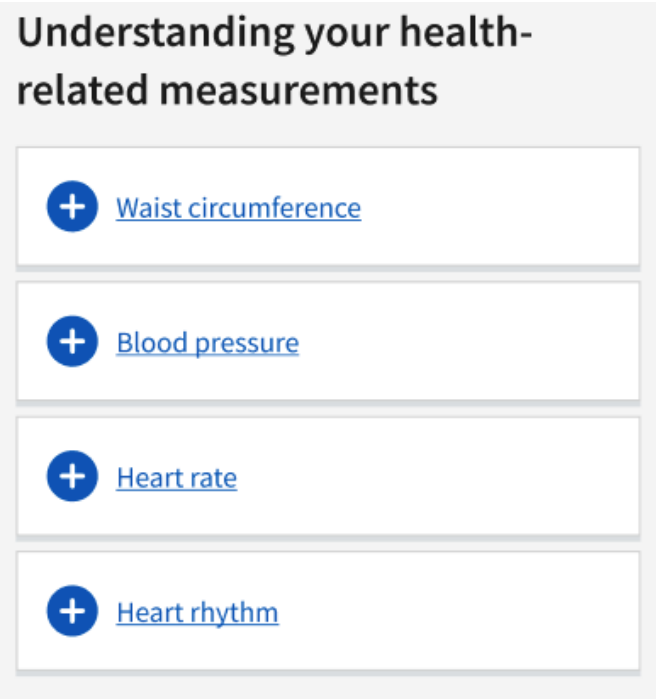
Option B: “Irregular heart rhythm” recorded or absent from data presented to participants



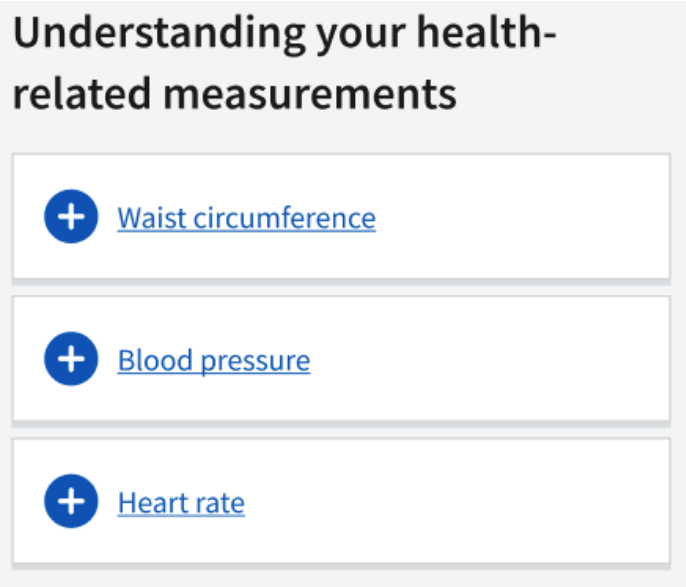
In this instance, we would not report heart rhythm where there was no data recorded (screen on right)

4. Contextual information under expanders

Underneath the clinic measurements pane, we have positioned the contextual information text from the proforma under expanders:

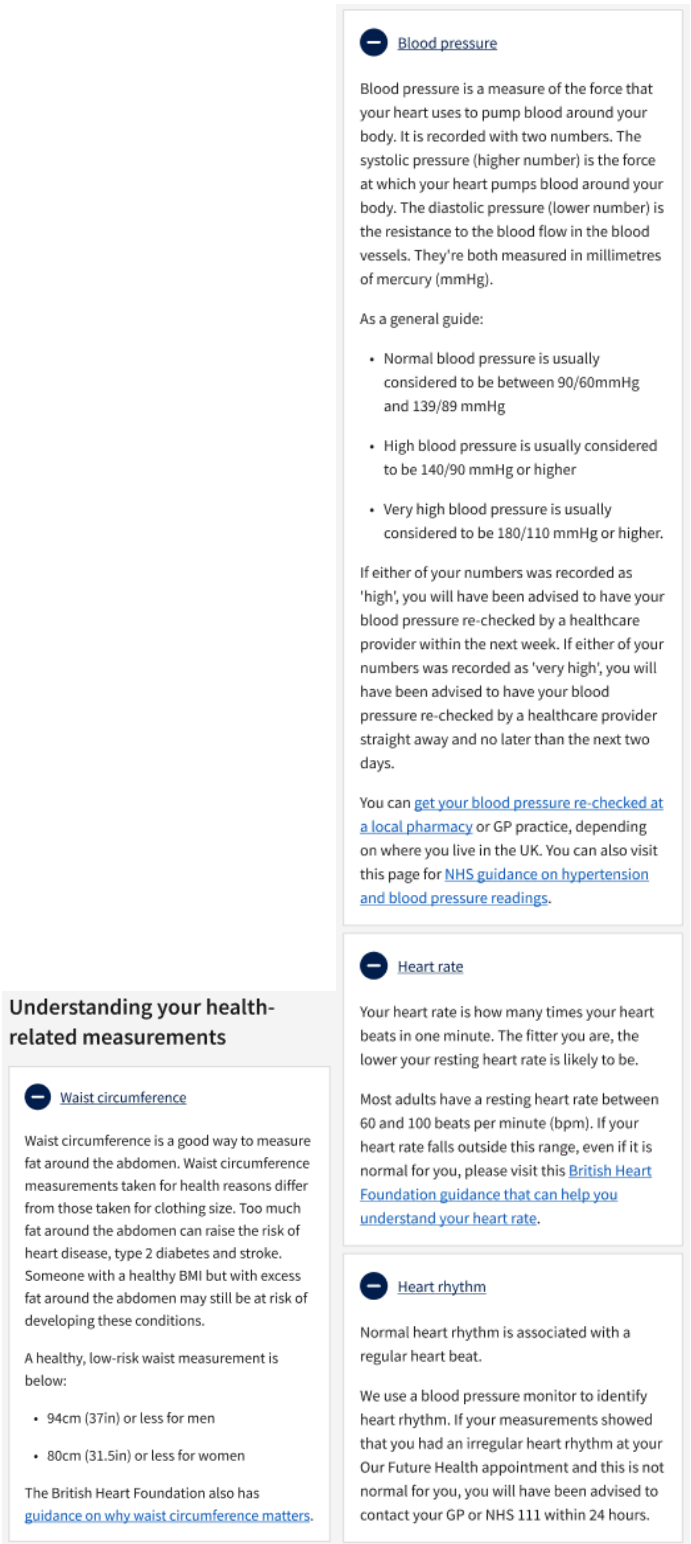


NB: in the design where no heart rhythm information is presented to participants ("option B", above), the expander for Heart rhythm would not show:



Clicking on each expander produces text about each clinic measurement. We have designed several ways of doing this digitally, which would be subject to user testing.

Option A: embedded links



Understanding your health-related measurements

Waist circumference

Waist circumference is a good way to measure fat around the abdomen. Waist circumference measurements taken for health reasons differ from those taken for clothing size. Too much fat around the abdomen can raise the risk of heart disease, type 2 diabetes and stroke. Someone with a healthy BMI but with excess fat around the abdomen may still be at risk of developing these conditions.

A healthy, low-risk waist measurement is below:

- 94cm (37in) or less for men
- 80cm (31.5in) or less for women

The British Heart Foundation also has guidance on why waist circumference matters.

Blood pressure

Blood pressure is a measure of the force that your heart uses to pump blood around your body. It is recorded with two numbers. The systolic pressure (higher number) is the force at which your heart pumps blood around your body. The diastolic pressure (lower number) is the resistance to the blood flow in the blood vessels. They're both measured in millimetres of mercury (mmHg).

As a general guide:

- Normal blood pressure is usually considered to be between 90/60mmHg and 139/89 mmHg
- High blood pressure is usually considered to be 140/90 mmHg or higher
- Very high blood pressure is usually considered to be 180/110 mmHg or higher.

If either of your numbers was recorded as 'high', you will have been advised to have your blood pressure re-checked by a healthcare provider within the next week. If either of your numbers was recorded as 'very high', you will have been advised to have your blood pressure re-checked by a healthcare provider straight away and no later than the next two days.

You can get your blood pressure re-checked at a local pharmacy or GP practice, depending on where you live in the UK. You can also visit this page for NHS guidance on hypertension and blood pressure readings.

Heart rate

Your heart rate is how many times your heart beats in one minute. The fitter you are, the lower your resting heart rate is likely to be.

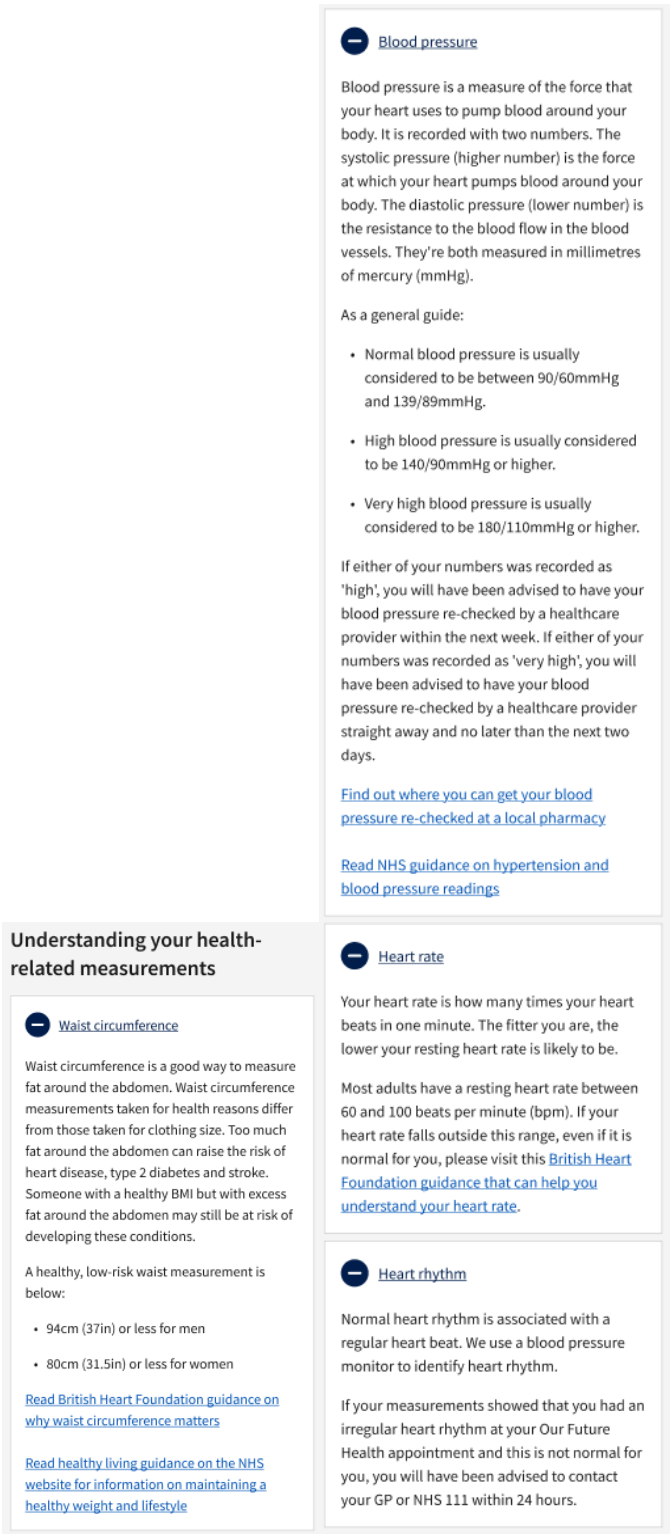
Most adults have a resting heart rate between 60 and 100 beats per minute (bpm). If your heart rate falls outside this range, even if it is normal for you, please visit this British Heart Foundation guidance that can help you understand your heart rate.

Heart rhythm

Normal heart rhythm is associated with a regular heart beat.

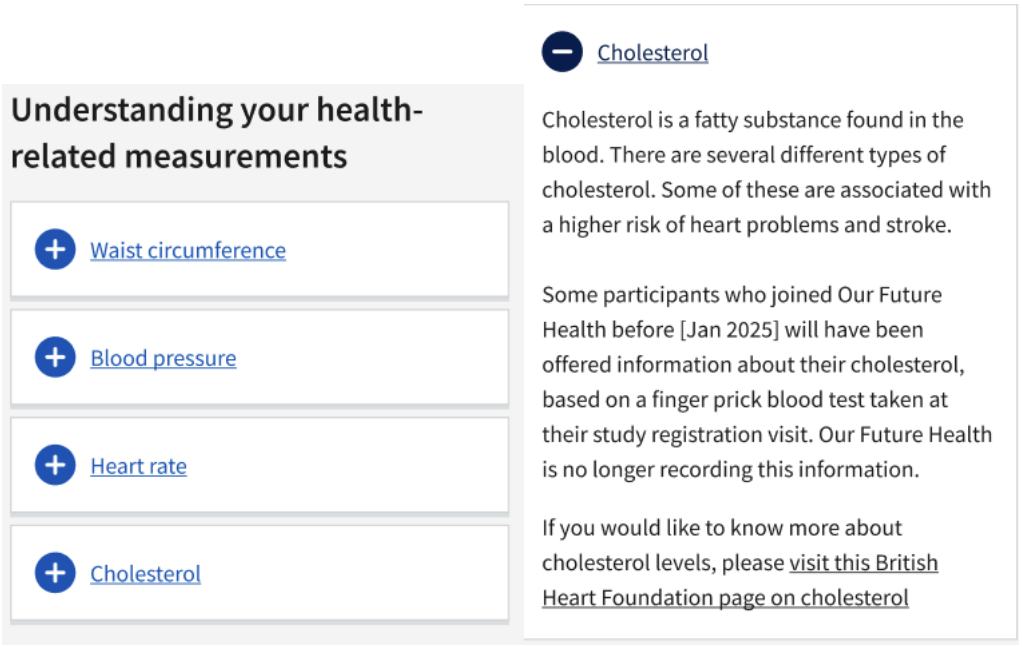
We use a blood pressure monitor to identify heart rhythm. If your measurements showed that you had an irregular heart rhythm at your Our Future Health appointment and this is not normal for you, you will have been advised to contact your GP or NHS 111 within 24 hours.

Option B: links at bottom of expander pane



5. Cholesterol

Participants who joined the study before Jan 2025 will have been offered their Point of Care Testing Cholesterol measurements as part of the proforma. Our Future Health does not plan to give participants who enrolled during this time period their cholesterol results digitally. We wish to trial the addition of some text that explains this:

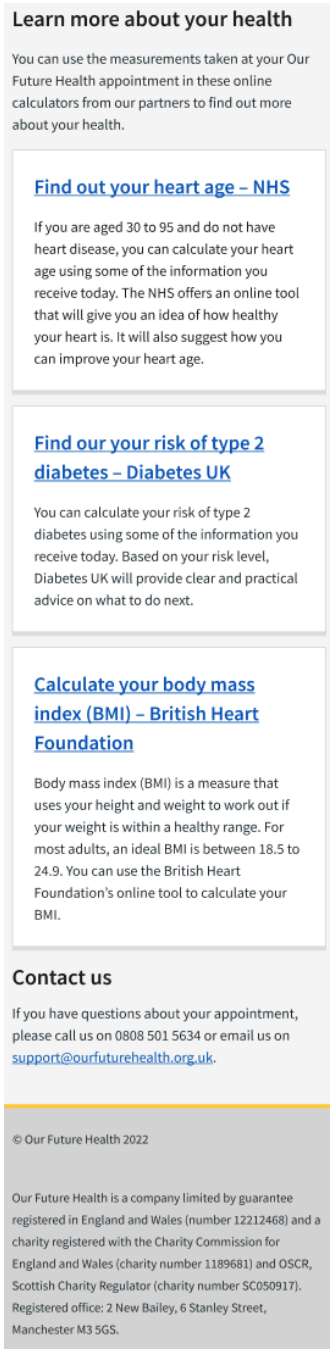


NB: the first and third paragraphs of this copy match the (REC-approved) copy in paper proformas used prior to Jan 2025.

6. “Learn more” - useful links section

We have used copy from the REC-approved paper proforma useful links section to embed information / links to calculators that participants use to find out more about their health. We have designed several ways of doing this digitally, which would be subject to user testing.

Option A: simple title



Option B: limited text

As above, but more limited copy under each heading (as follows):

Learn more about your health

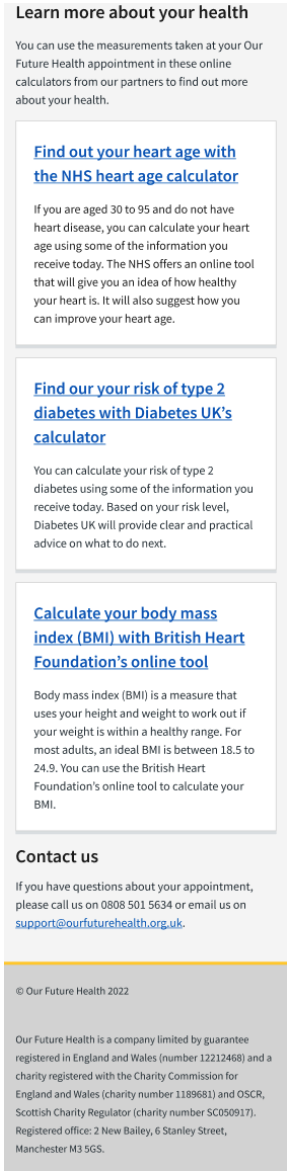
Find out more about your health with the help of online calculators provided by our partners.

Find out your heart age – NHS
If you are aged 30 to 95 and do not have heart disease, you can calculate your heart age using this NHS tool.

Find out your risk of type 2 diabetes – Diabetes UK
You can calculate your risk of type 2 diabetes using some of the information you receive today.

Calculate your body mass index (BMI) – British Heart Foundation
You can use the British Heart Foundation's online tool to calculate your BMI.

Option C: expanded titles



Learnings from Digital Clinic Measurements User Research Phase

Summary of learnings

Between May – July 2025, we conducted participant interviews to evaluate the usability and experience of digital clinic measurements. Approximate 2,000 participants were invited to take part in the interviews via email, representing four user segments: (1) Participants with all measurements in the healthy range, (2) Participants with one or more measurement outside of the healthy range, (3) Participants with one or more measurement missing or implausible, and (4) Participants who attended their appointment more than 6 months ago (early adopters). In total, 21 participants were interviewed. During the recruitment process, participants were screened for demographic characteristics to ensure that participants of all age groups and ethnicities were represented in the interview sample.

Many of the themes that emerged were shared across all four participant segments. We found that participants generally had quite low recall for the content within the proforma, with some having no recollection of receiving a proforma at their appointment at all. Therefore, participants saw value in having a digital record of their clinic measurements. Many participants spoke about using it as a baseline or as something they could refer back to. The agreement screen was unexpected for a number of participants, but was seen as largely acceptable. It was described as T&C's or like an additional consent point. Participants understood that by clicking the button at the bottom of the page that they were agreeing to viewing the measurements taken at the appointment.

Additionally, we found some themes unique to each segment. For example, those with an out of range measurement were more likely to already be familiar with information provided. Those with missing data expected and understood why a measurement may be missing on their report, but still wanted to see information about the measurements that they were missing. For early adopters, many noticed that their cholesterol reading hadn't been included in the report, and all wanted to see their cholesterol measurement in the digital report if it had been taken.

Improving usability

During the interviews, we found that there was a strong consensus between participants who expected to receive access to a digital copy of their measurements soon after the appointment, the timelines on how soon ranged from hours post appointment up to a few weeks. The new email template designed for early adopters aims to reduce any possible confusion by reiterating that the measurements were taken at the time of joining.

Additionally, we identified opportunities to improve the usability of the digital clinic measurements report page. We observed that participants wanted to understand where their measurement fell in relation to the healthy ranges for that measurement, defined by the clinical boundaries. With the previous design, participants were unable to view their measurement at the same time as the details component for that measurement, so were needing to scroll up and down to interpret their measurements against the ranges. The new designs address this by including a chart depicting where measurements sit within the ranges.

Digital Clinic Measurements General Availability Rollout

Aims

Following a successful period of usability testing between May – July 2025, the rollout of digital clinic measurements to all Our Future Health participants, termed 'general availability', will commence in September 2025. We aim to have provided all existing Our Future Health participants with digital access to their clinic measurements by mid-late 2026, in addition to the paper proforma which participants receive during their clinic appointment.

The rollout of digital clinic measurements is expected to take place over several months, in a phased manner that allows for close evaluation of participant behaviours as measurement reports are made available in increasing numbers. Each phase of the rollout will have specific aims that enable the evaluation of key technical, engagement and programme metrics.

Phase 1 – Systems check

First, a small number of participants will be provided with permanent access to their clinic measurements for the first time outside of usability testing. This is intended to be a test of delivering clinic measurements digitally using the tools needed for daily processing and monitoring. This stage is an opportunity to check that all parts of the platform are functioning as expected, and that tracking is in place for the key metrics that will need to be monitored as digital clinic measurements are rolled out in larger numbers.

Phase 2 – Estimate key outcomes

During the second phase, we will begin to send clinic measurements reports to participants in larger batches (~100-1500) to gain early signal of engagement rates (email open, conversion and interaction rates), and participant behaviours (Study Support contact, withdrawals, GP impact). This will enable an estimation of expected impact when the rollout to the whole cohort begins.

Phase 3 – Monitoring and optimisation

In the final phase, clinic measurements will be rolled out to all existing full participants. Broadly, the rollout will begin with participants who joined the programme earlier in recruitment (from 2022) and will progress through the cohort eventually reaching those who have joined the programme more recently. This strategy is designed to provide participants who have been part of the programme for the longest amount of time with digital access to their health-related information as soon as possible. The monitoring of key metrics will be ongoing throughout the duration of the rollout.

Optimisation of the participant experience will be integrated throughout this phase. Examples of this type of testing include AB testing of emails, including subject lines, timing, and content. The aim of these tests is to improve email open and click through rates. We will also run AB tests of the content, design and layout of the clinic measurements report and accompanying pages, with the aim of improving the participant experience of viewing and interacting with the digital reports. During optimisation, participant behaviours and experience will be assessed using analytics and participant feedback surveys.

Methods

Selection of participants

During Phase 1 and 2, we will identify several batches of participants who meet pre-defined criteria. The types of participants represented in these batches will enable us to estimate interaction with the clinic measurements report in different groups. Selection will be based on participation status, data completeness and quality, time since appointment, measurements taken at appointment, and clinical range of results. A randomly selected group of participants who meet the criteria for each batch will be sent the notification email informing them that their measurements are ready to view.

Data collection

Analytics

Analytics captured by the email platform and health insights website will be used to monitor and evaluate participant behaviours throughout the rollout. Email analytics include open rates, click-through rates of emails, and unsubscribes. Website analytics include number of visits, clicks on specific content or links, heatmap clicks, and rates of conversion through log in and agreement pages. Analytic data will be aggregated for analysis and used to evaluate the proportion of participants undertaking certain actions.

Feedback surveys

To complement analytic data, feedback will be captured from participants as they view their clinic measurements, to gain a deeper understanding of their experience. At the bottom of the page, a widget will provide participants with the option to leave their feedback. Participants can elect to complete a short survey of multiple choice and free text questions, which will take around 3-5 minutes to complete. Survey data will be collected anonymously.

Examples of the design of the in-product feedback survey are provided in Clinic Measurements Participant In-Product Feedback.

Rollout schedule

Overview of phases

	Selection criteria	Sample size	Objective	Key metrics	Content version
Phase 1 – Systems test	• Full participants • Complete clinic measurement data • Values within healthy ranges • Clinic and home address in England • Appointment attended within the last year	~50	To "turn on" clinic measurements for a very small group, as a test of providing permanent access to measurements delivered using the tools needed for daily processing and monitoring	• No technical issues • Able to track all email and engagement metrics	Original copy as approved in April 2025 (pg 16)
Phase 2 – Estimate key outcomes	• Full participants • A mix of complete and incomplete clinic measurement data • Values within and outside of healthy ranges • Clinic and home address in England • Appointment attended in 2022 - 2025	~100-5000	To gain early signal of engagement rates (email open, conversion and interaction rates), and participant behaviours (Study Support contact, withdrawals, GP impact)	• Email open rates • Email click-through rates • Email unsubscribe rates • Acceptance screen conversion rates • Feedback survey scores • Study Support contact rates and query content • Withdrawal rates	New copy (pg 35)
Phase 3 – Monitoring and optimisation	• Full participants • Appointment attended in 2022 - 2025	~100,000	To gradually provide access to clinic measurements to all participants in increasing numbers, while monitoring key performance indicators	• Email open rates • Email click-through rates • Email unsubscribe rates • Acceptance screen conversion rates • Feedback survey scores • Study Support contact rates and query content • Withdrawal rates	New copy (pg 35)

Detailed breakdown of Phase 2 – Estimate key outcomes

Number of emails	Selection criteria	Rationale
500	• Joined post-2025	De-risk sending larger numbers through the platform, gauge recent joiner response rates
1500	• Joined in 2024 • Random spread across locations	Estimating important metrics for the biggest group that we will roll out to, early signal of reactions to rolling back
150	• Joined in 2022-2024 • Irregular heart rhythm	Estimates for conversion, impact and acceptability in this group that justify rolling out to high risk groups
150	• Joined in 2022-2024 • Very high cholesterol	Estimates for conversion, impact and acceptability in this group that justify rolling out to high risk groups
150	• Joined in 2022-2024 • Missing or implausible measurements	De-risk data problem areas
1500	• Joined in 2023 • Random spread across locations	Estimating important metrics for some of the earliest joiners, early signal of reactions to rolling back
500	• Joined early in 2022 • Random spread across locations	Estimating important metrics for the most engaged group of participants
500	• Joined early in 2022	A hold out group for segments that we need to revisit or new edges identified through bigger batches

Considerations

Cholesterol

Returning digital clinic measurements to participants who joined the programme before 2025 will also involve providing cholesterol readings that were taken during the appointment. Due to previous concerns with point-of-care cholesterol testing putting a burden on health services, and ultimately the decision to remove point-of-care cholesterol testing from the appointment, the addition of cholesterol to digital clinic measurement reports is being approached with caution. In October 2024, a survey was conducted to assess participant outcomes following a point-of-care cholesterol test, with over 8,000 participants taking part. These results revealed that 20% of participants reported telling their GP about the result of the point-of-care cholesterol test from their Our Future Health appointment, with 11% going on to have a GP appointment about their cholesterol. The majority of those who had a GP appointment had high or very high cholesterol. These findings indicate that the proportion of participants following up with a GP after their appointment was not as great as expected, and that those who did take action had a clinical reason for doing so.

Feedback received from participants during the usability testing for digital clinic measurements conducted between May – July 2025 is also reassuring. Participants had good awareness that the measurements shown were the ones taken previously at their Our Future Health appointment, and had good recollection of their appointment and the measurements taken. The addition of the appointment date at the top of the clinic measurements report also helped to avoid any confusion about when the measurements were taken or whether they may be recent. The wait to receive a digital version of their measurements was largely acceptable to early adopters and these participants felt that this information would always be valuable, no matter how much time had passed since their appointment.

> *"It's a summary of measurements we've taken June 24th. So yeah, so it's just over a year ago." – Participant 1*

> *"I don't think it would ever become unvaluable because for me, I like actually having a record of my past health, being somebody who's had health issues in the past, especially with my Asthma and stuff like that, stuff like this is always very valuable to have because I know being able to go back and refer to something like this down the line and being able to see if it's gotten better or gotten worse or something's changed. It's good to have that time, that, that point in time documented."* – Participant 5

Participants valued having access to their measurements digitally despite their appointment having taken place a long time ago, and talked about them as being a baseline to refer back to. Participants made comparisons between their measurements taken previously and what their measurements might be or are now. In addition, participants expressed a preference for all measurements taken at the appointment to be included in the report, so that they would have a complete record of the data that they provided at the appointment.

> *"I mean, measurements that are taken probably ought to be included really. You know, the more information, the better. You know, as long as it's presented in a, you know, in the right sort of way."* – Participant 1

Based on these insights, the decision has been taken to include cholesterol in digital clinic measurements for those who joined the programme before 2025 and had a point-of-care test at their

appointment. The impact of including cholesterol will be closely monitored during Phase 2 of the rollout, with particular attention given to the rate and nature of queries coming in to Study Support. As part of Phase 2, one batch of invites to view clinic measurements will be sent to 150 participants with very high cholesterol, allowing key outcomes to be evaluated specifically in this group. Additionally, the rollout of digital clinic measurements to larger numbers of participants during Phase 3 will be geographically spread across clinic locations, helping to mitigate any potential impact on GPs in one area if participants do get in contact after receiving their digital report.

Irregular heart rhythm

Irregular heart rhythm has been fed back to participants on the paper proforma since the beginning of recruitment in 2022. However, this data has been only captured in the Clinical Staff App from January 2024. Therefore, participants who had an appointment before January 2024 might have had their heart rhythm returned to them on the proforma, but it will not be on their digital clinic measurements report. For those who did not have an irregular heart rhythm, this experience will be the same as participants who joined since 2024, who are only shown a heart rhythm result on their digital clinic measurements report if the result is irregular.

During the interviews, we also observed low recollection of heart rhythm in participants with irregular readings. This suggests the possibility that some participants who receive an irregular heart rhythm result on their digital clinic measurements report may not already be aware of it. To help understand the impact of this possible discrepancy between the health-information given at the appointment and in the digital report, we will include a batch of 150 participants with irregular heart rhythm during Phase 2, allowing us to monitor participant feedback and queries specifically in this group.

Devolved nations

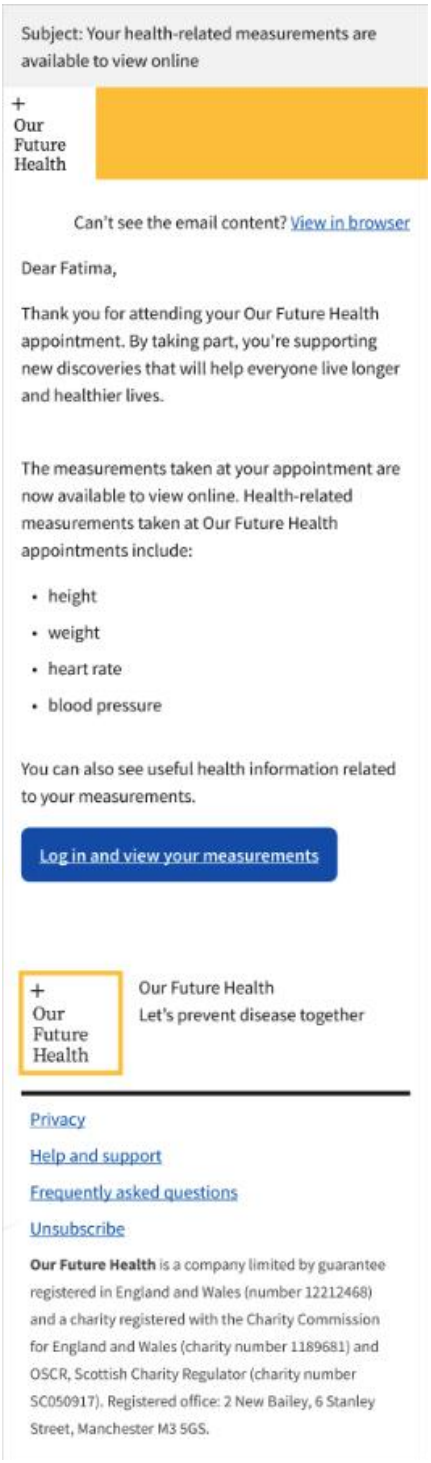
Given the approach of beginning the rollout with participants who joined the programme earliest in the recruitment phase, initially clinic measurements will only be given in a digital format to participants from England. We expect to begin rolling out clinic measurements to participants who joined the programme from Scotland and Wales later in 2026, and have begun developing content to address differences in the experience for those who access health services outside of England.

Clinic Measurements General Availability Copy

This section summarises the content that will be used in General Availability rollout. Commentary on each screen highlights the changes made to screens used in user testing.

1. Email to participants

Option A: general email



Subject: Your health-related measurements are available to view online

+
Our
Future
Health

Can't see the email content? View in browser

Dear Fatima,

Thank you for attending your Our Future Health appointment. By taking part, you're supporting new discoveries that will help everyone live longer and healthier lives.

The measurements taken at your appointment are now available to view online. Health-related measurements taken at Our Future Health appointments include:

- height
- weight
- heart rate
- blood pressure

You can also see useful health information related to your measurements.

Log in and view your measurements

+
Our
Future
Health

Our Future Health
Let's prevent disease together

Privacy
Help and support
Frequently asked questions
Unsubscribe

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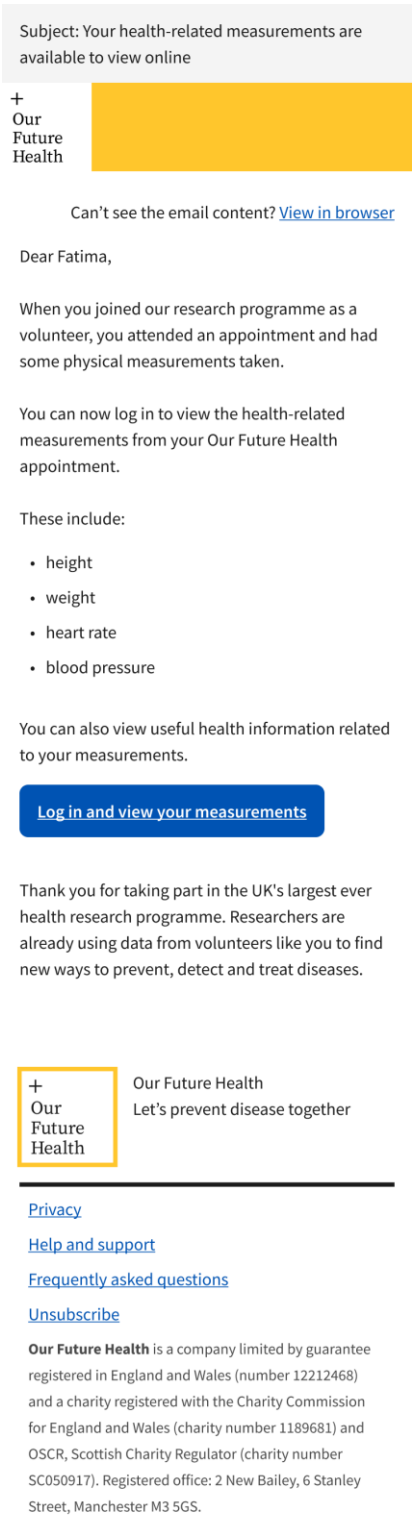
In user testing, participants generally found this information easy to navigate. We simplified the content slightly to reduce friction. NB: as in user testing, the subject line refers to "health-related measurements", rather than "clinic measurements" (as described elsewhere in the protocol) - this choice was made to avoid the insinuation that participants' appointment was clinical in nature.

Option B: email for early adopters.



Subject: Your health-related measurements are available to view online

+ Our Future Health

Can't see the email content? View in browser

Dear Fatima,

When you joined our research programme as a volunteer, you attended an appointment and had some physical measurements taken.

You can now log in to view the health-related measurements from your Our Future Health appointment.

These include:

- height
- weight
- heart rate
- blood pressure

You can also view useful health information related to your measurements.

Log in and view your measurements

Thank you for taking part in the UK's largest ever health research programme. Researchers are already using data from volunteers like you to find new ways to prevent, detect and treat diseases.

+ Our Future Health

Our Future Health
Let's prevent disease together

Privacy
Help and support
Frequently asked questions
Unsubscribe

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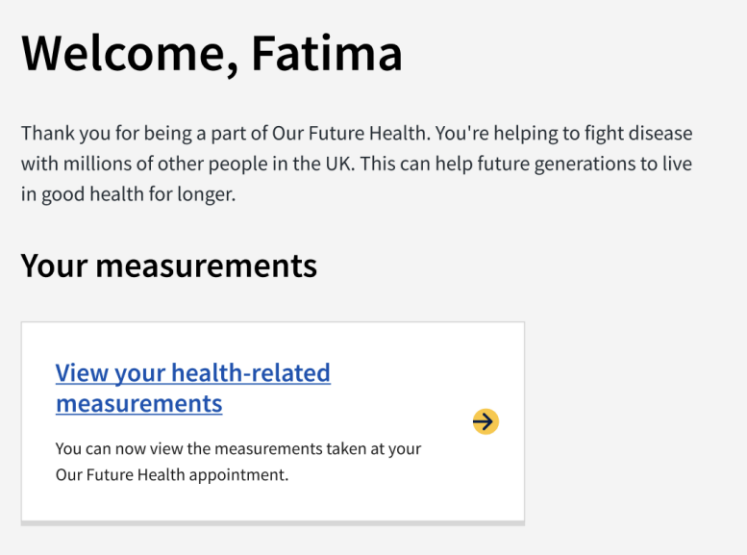
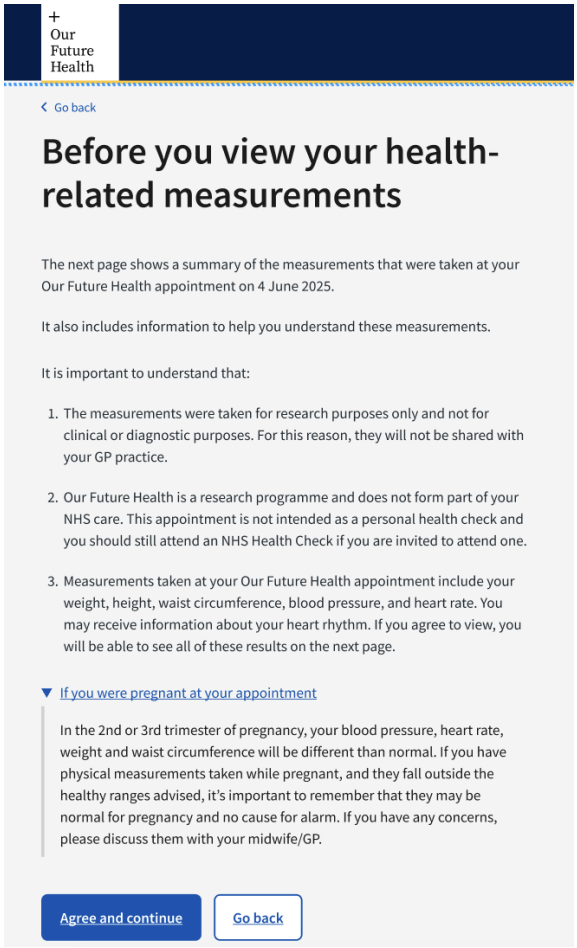
To account for the fact that some participants will have joined the programme some months or years prior to the email arriving, we have amended copy to help provide context for the measurements. Additional copy thanks participants for joining and emphasise that researchers are already using volunteer data to prevent, detect and treat disease. During the initial rollout, this copy will be used for any participants who joined prior to January 2025. In the future, the timeframes in which either email is used may be subject to change.

2. Dashboard



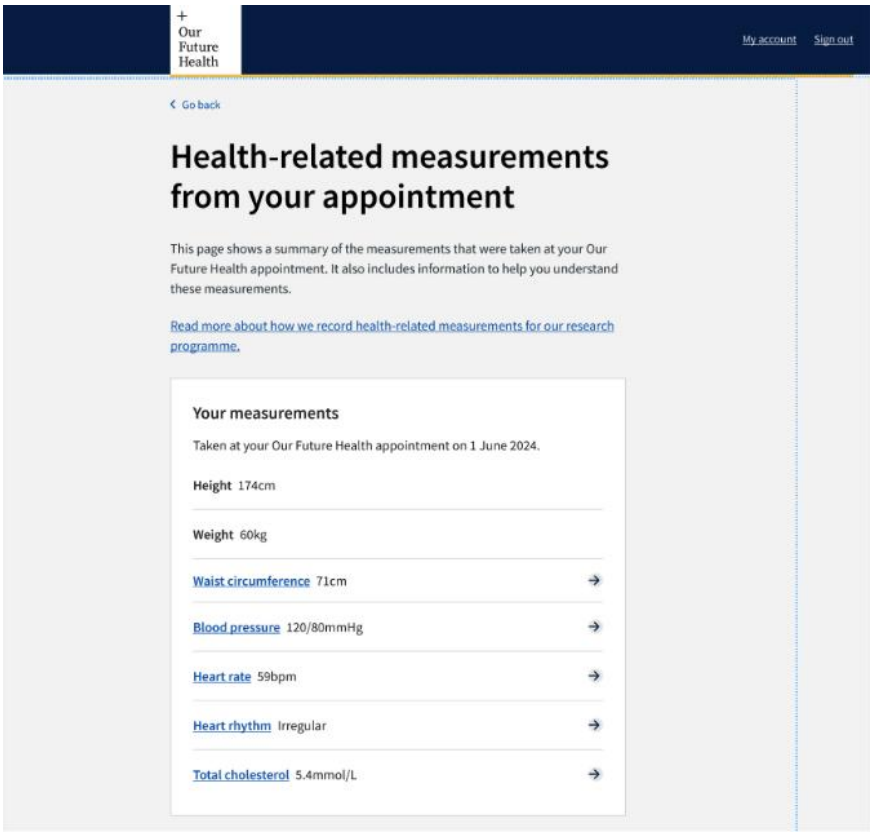
No changes have been made to this page

3 Acceptance



The title has been changed from “clinic measurements“ to ”health-related measurements” for consistency, as suggested.

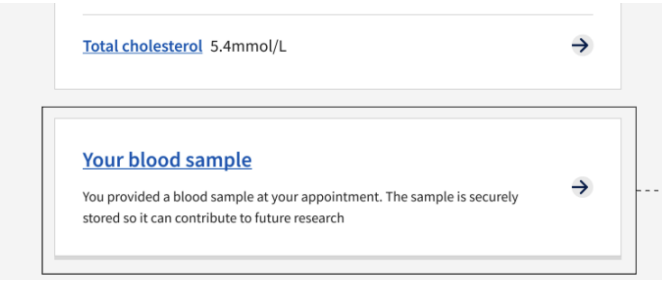
4. Health-related measurements report



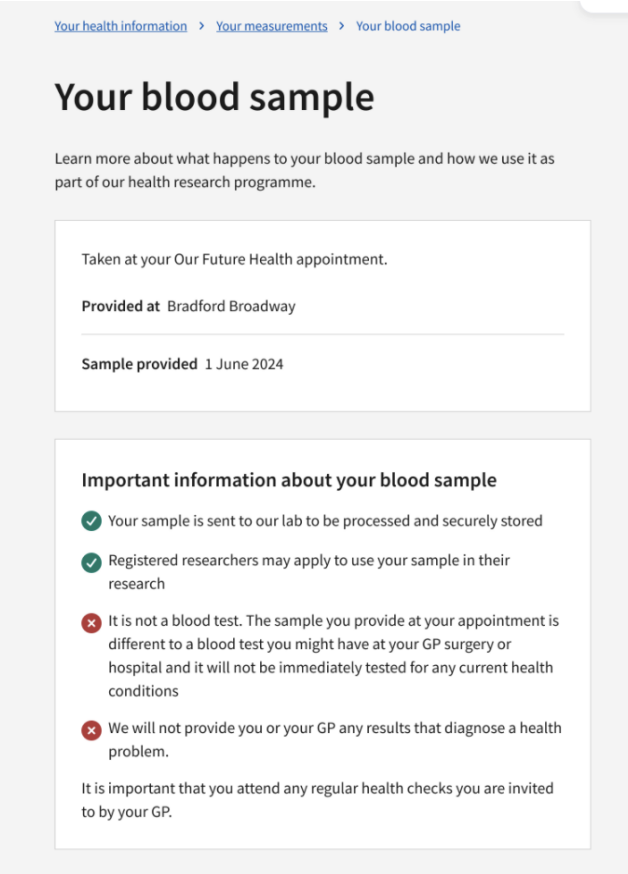
This page now includes a link to an information page that explains more about how measurements were taken (which is included below).

As before, contextual information for each measurement is included in drop-down menus that participants can click on should they wish to know more. We are also exploring hosting this information in additional pages linked from the table.

New addition under the measurements to improve participant understanding around their blood sample and reduce misconceptions about 'blood tests'



Clicking the arrow opens up the following information:



Your health information › Your measurements › Your blood sample

Your blood sample

Learn more about what happens to your blood sample and how we use it as part of our health research programme.

Taken at your Our Future Health appointment.

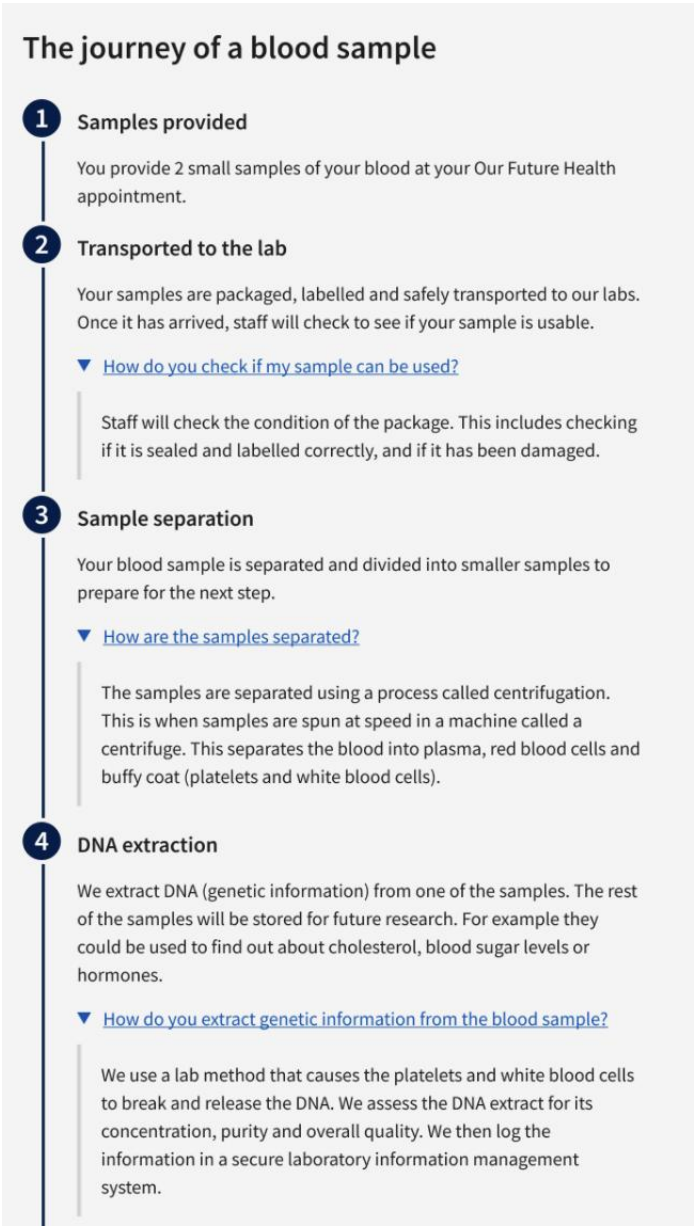
Provided at Bradford Broadway

Sample provided 1 June 2024

Important information about your blood sample

- Your sample is sent to our lab to be processed and securely stored
- Registered researchers may apply to use your sample in their research
- It is not a blood test. The sample you provide at your appointment is different to a blood test you might have at your GP surgery or hospital and it will not be immediately tested for any current health conditions
- We will not provide you or your GP any results that diagnose a health problem.

It is important that you attend any regular health checks you are invited to by your GP.



The journey of a blood sample

1 Samples provided

You provide 2 small samples of your blood at your Our Future Health appointment.

2 Transported to the lab

Your samples are packaged, labelled and safely transported to our labs. Once it has arrived, staff will check to see if your sample is usable.

▼ How do you check if my sample can be used?

> Staff will check the condition of the package. This includes checking if it is sealed and labelled correctly, and if it has been damaged.

3 Sample separation

Your blood sample is separated and divided into smaller samples to prepare for the next step.

▼ How are the samples separated?

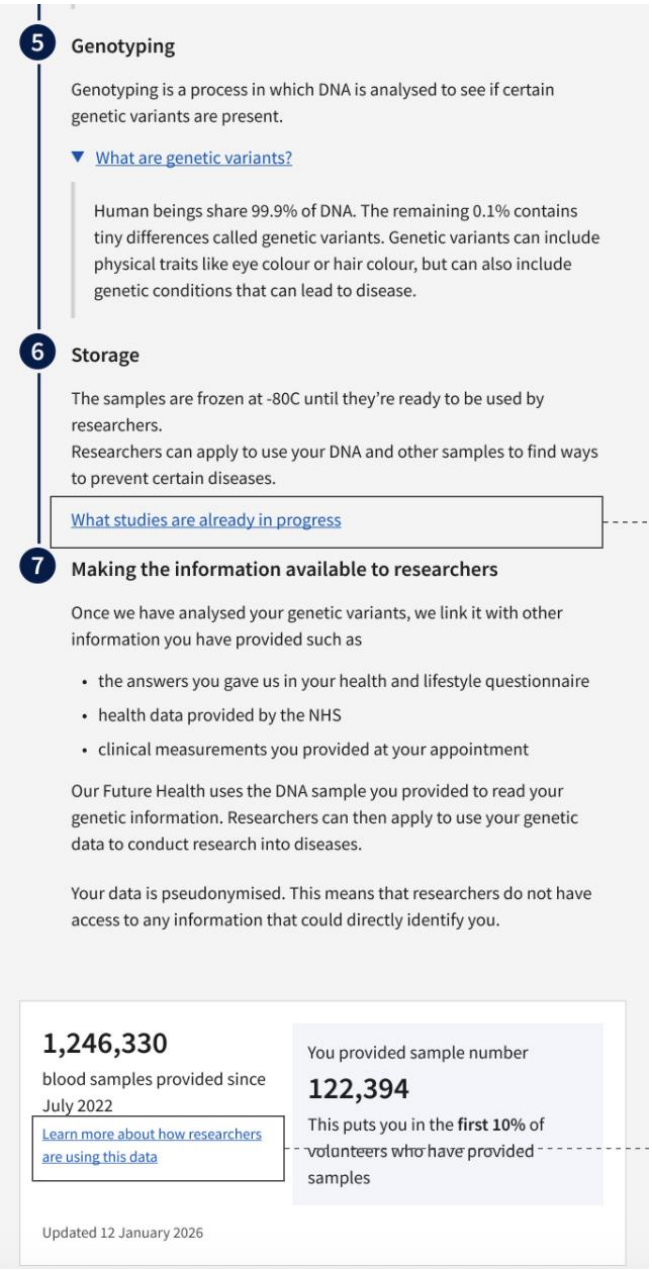
> The samples are separated using a process called centrifugation. This is when samples are spun at speed in a machine called a centrifuge. This separates the blood into plasma, red blood cells and buffy coat (platelets and white blood cells).

4 DNA extraction

We extract DNA (genetic information) from one of the samples. The rest of the samples will be stored for future research. For example they could be used to find out about cholesterol, blood sugar levels or hormones.

▼ How do you extract genetic information from the blood sample?

> We use a lab method that causes the platelets and white blood cells to break and release the DNA. We assess the DNA extract for its concentration, purity and overall quality. We then log the information in a secure laboratory information management system.



'Learn more about how researchers are using this data' opens the following pages and gives links to existing articles:

How researchers use our data

How researchers can use Our Future Health data and what studies are already in progress.

First published study from Our Future Health findings

News

Research at the University of Edinburgh reveals that people living with chronic inflammatory conditions may have almost double the risk of mental health issues

Research in progress

60

approved studies using the Our Future Health data

As of 12 January 2026

Recently updated studies

We publish a summary of every study using Our Future Health data on the Health Data Research UK website.

Helping doctors take the guesswork out of finding the right medicine for high blood pressure, high cholesterol, diabetes, depression, anxiety, and symptoms of menopause
London School of Hygiene and Tropical Medicine — View details

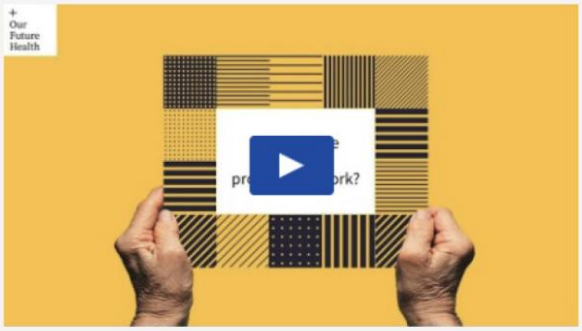
Approaches to understanding what causes life changing disease, and the impact they have on people in the United Kingdom
Thermo Fisher Scientific — View details

Health Risk Prediction and Genetic Insights into Cardiovascular Diseases
Queen Mary University of London — View details

View all studies

Our research mission

How your health information helps researchers prevent, detect and treat diseases.



Meet some of the researchers using Our Future Health data

Improving life for cancer survivors

Professor Krishnan Bhaskaran's research focuses on cancer survivorship. His team are using Our Future Health data to inform the healthcare people get after surviving cancer.

Read more about Professor Bhaskaran's research

Understanding genetic links to depression

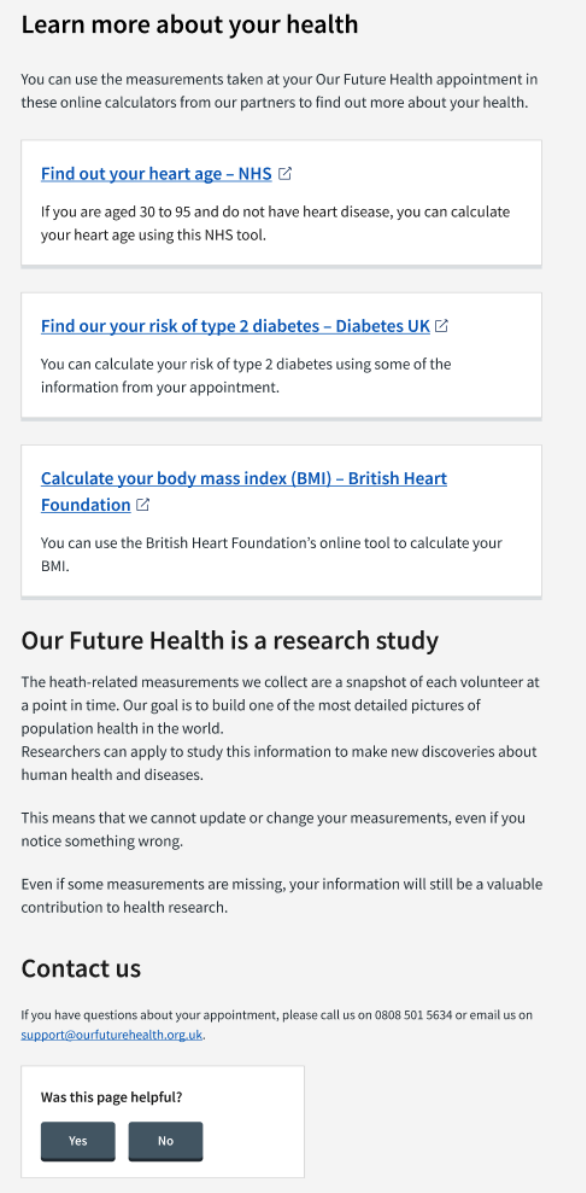
"Depression is currently one of the biggest problems in society" says Professor Cathryn Lewis from King's College London. "My team aims to use genetics to understand why depression happens – and how we can treat it effectively."

Read more about Professor Lewis' research

Investigating lung disease

Lung diseases are the 3rd most common cause of death across the UK. Professor Jennifer Quint is analysing Our Future Health data to explore ways to improve our lung health.

Read more about Professor Quint's research



Learn more about your health

You can use the measurements taken at your Our Future Health appointment in these online calculators from our partners to find out more about your health.

Find out your heart age – NHS

If you are aged 30 to 95 and do not have heart disease, you can calculate your heart age using this NHS tool.

Find our your risk of type 2 diabetes – Diabetes UK

You can calculate your risk of type 2 diabetes using some of the information from your appointment.

Calculate your body mass index (BMI) – British Heart Foundation

You can use the British Heart Foundation's online tool to calculate your BMI.

Our Future Health is a research study

The heath-related measurements we collect are a snapshot of each volunteer at a point in time. Our goal is to build one of the most detailed pictures of population health in the world.
Researchers can apply to study this information to make new discoveries about human health and diseases.

This means that we cannot update or change your measurements, even if you notice something wrong.

Even if some measurements are missing, your information will still be a valuable contribution to health research.

Contact us

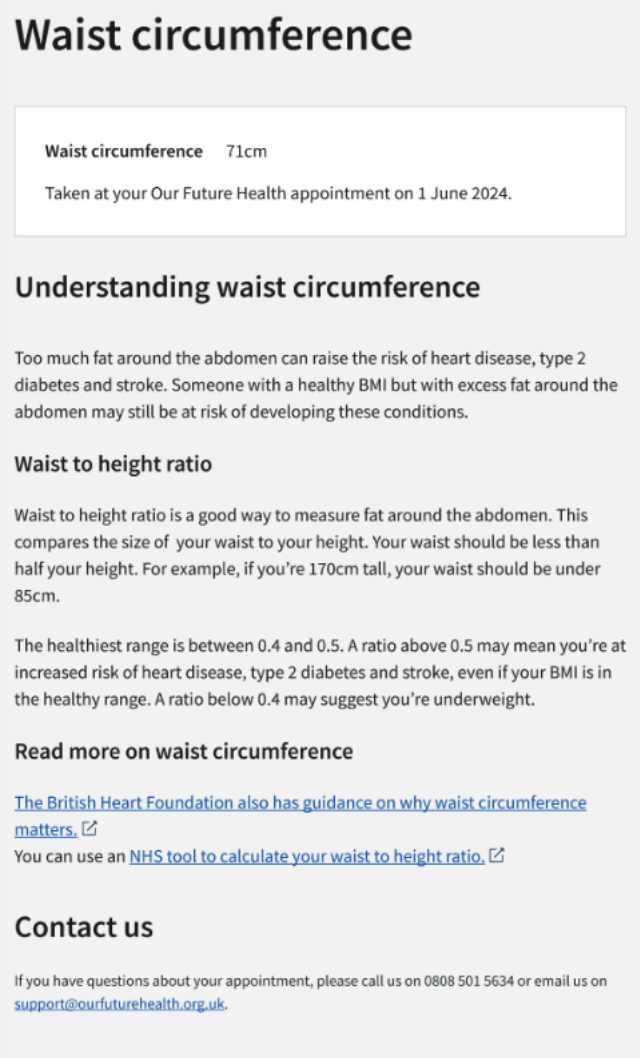
If you have questions about your appointment, please call us on 0808 501 5634 or email us on support@ourfuturehealth.org.uk.

Was this page helpful?

Yes No

As before, we have included links to external calculators from the paper proforma. This section of the report now includes copy reminding participants that health-related measurements were taken for research purposes, and cannot be changed.

5. Waist circumference



Waist circumference

Waist circumference 71cm

Taken at your Our Future Health appointment on 1 June 2024.

Understanding waist circumference

Too much fat around the abdomen can raise the risk of heart disease, type 2 diabetes and stroke. Someone with a healthy BMI but with excess fat around the abdomen may still be at risk of developing these conditions.

Waist to height ratio

Waist to height ratio is a good way to measure fat around the abdomen. This compares the size of your waist to your height. Your waist should be less than half your height. For example, if you're 170cm tall, your waist should be under 85cm.

The healthiest range is between 0.4 and 0.5. A ratio above 0.5 may mean you're at increased risk of heart disease, type 2 diabetes and stroke, even if your BMI is in the healthy range. A ratio below 0.4 may suggest you're underweight.

Read more on waist circumference

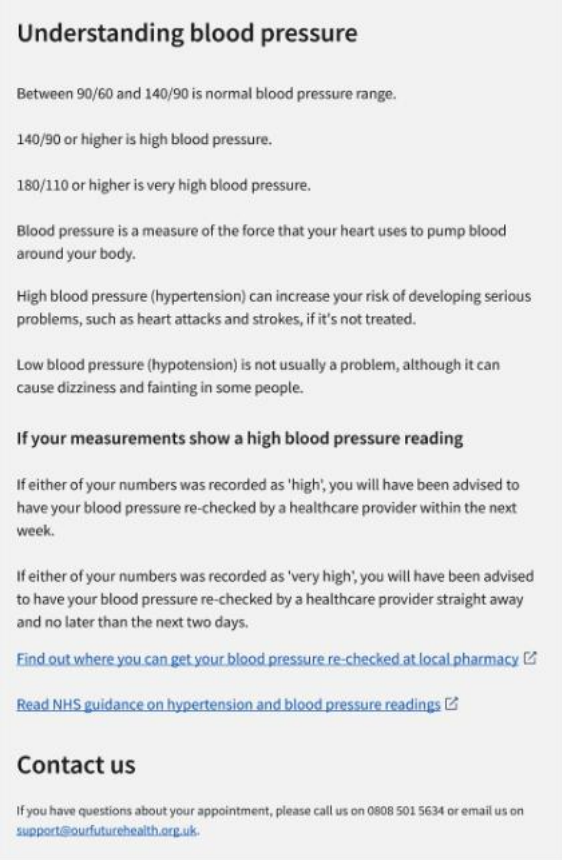
The British Heart Foundation also has guidance on why waist circumference matters.
You can use an NHS tool to calculate your waist to height ratio.

Contact us

If you have questions about your appointment, please call us on 0808 501 5634 or email us on support@ourfuturehealth.org.uk.

Waist circumference copy matches updates to the paper proforma (v8.2).

6. Blood pressure



Understanding blood pressure

Between 90/60 and 140/90 is normal blood pressure range.

140/90 or higher is high blood pressure.

180/110 or higher is very high blood pressure.

Blood pressure is a measure of the force that your heart uses to pump blood around your body.

High blood pressure (hypertension) can increase your risk of developing serious problems, such as heart attacks and strokes, if it's not treated.

Low blood pressure (hypotension) is not usually a problem, although it can cause dizziness and fainting in some people.

If your measurements show a high blood pressure reading

If either of your numbers was recorded as 'high', you will have been advised to have your blood pressure re-checked by a healthcare provider within the next week.

If either of your numbers was recorded as 'very high', you will have been advised to have your blood pressure re-checked by a healthcare provider straight away and no later than the next two days.

Find out where you can get your blood pressure re-checked at local pharmacy

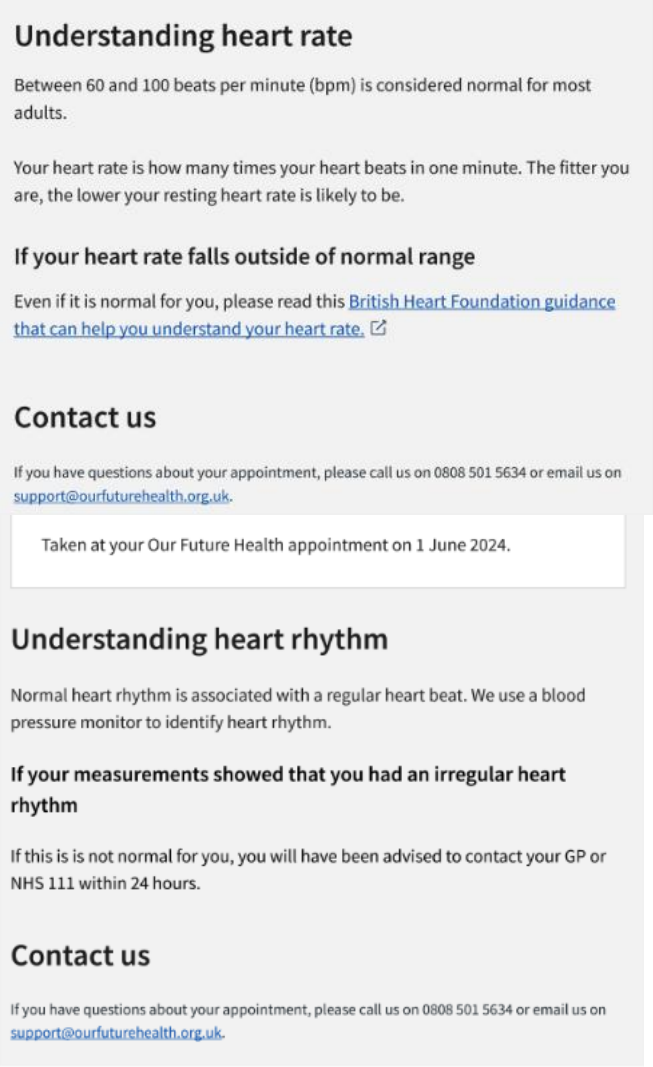
Read NHS guidance on hypertension and blood pressure readings

Contact us

If you have questions about your appointment, please call us on 0808 501 5634 or email us on support@ourfuturehealth.org.uk.

Contextual information about blood pressure has been rearranged and simplified for clarity.

7. Heart rate



Understanding heart rate

Between 60 and 100 beats per minute (bpm) is considered normal for most adults.

Your heart rate is how many times your heart beats in one minute. The fitter you are, the lower your resting heart rate is likely to be.

If your heart rate falls outside of normal range

Even if it is normal for you, please read this British Heart Foundation guidance that can help you understand your heart rate.

Contact us

If you have questions about your appointment, please call us on 0808 501 5634 or email us on support@ourfuturehealth.org.uk.

Taken at your Our Future Health appointment on 1 June 2024.

Understanding heart rhythm

Normal heart rhythm is associated with a regular heart beat. We use a blood pressure monitor to identify heart rhythm.

If your measurements showed that you had an irregular heart rhythm

If this is is not normal for you, you will have been advised to contact your GP or NHS 111 within 24 hours.

Contact us

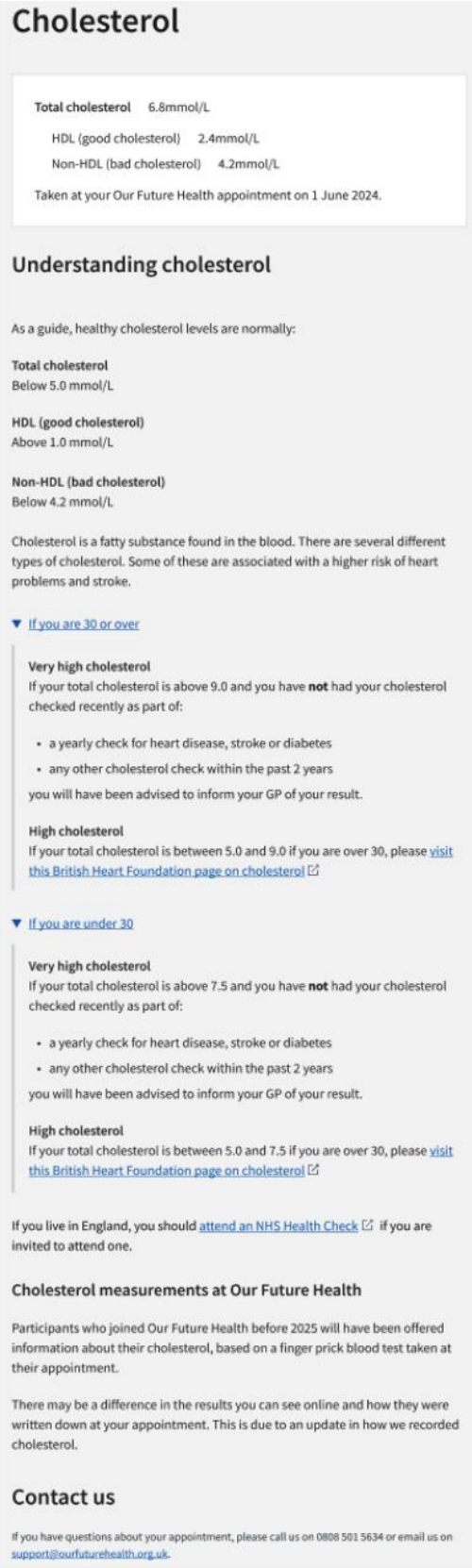
If you have questions about your appointment, please call us on 0808 501 5634 or email us on support@ourfuturehealth.org.uk.

As above, contextual information about heart rate has been rearranged and simplified for clarity

8. Heart rhythm

As above, contextual information about heart rhythm has been rearranged and simplified for clarity.

9. Cholesterol



Cholesterol

Total cholesterol 6.8mmol/L

HDL (good cholesterol) 2.4mmol/L

Non-HDL (bad cholesterol) 4.2mmol/L

Taken at your Our Future Health appointment on 1 June 2024.

Understanding cholesterol

As a guide, healthy cholesterol levels are normally:

Total cholesterol
Below 5.0 mmol/L

HDL (good cholesterol)
Above 1.0 mmol/L

Non-HDL (bad cholesterol)
Below 4.2 mmol/L

Cholesterol is a fatty substance found in the blood. There are several different types of cholesterol. Some of these are associated with a higher risk of heart problems and stroke.

▼ If you are 30 or over

Very high cholesterol
If your total cholesterol is above 9.0 and you have **not** had your cholesterol checked recently as part of:

- a yearly check for heart disease, stroke or diabetes
- any other cholesterol check within the past 2 years

you will have been advised to inform your GP of your result.

High cholesterol
If your total cholesterol is between 5.0 and 9.0 if you are over 30, please visit this British Heart Foundation page on cholesterol

▼ If you are under 30

Very high cholesterol
If your total cholesterol is above 7.5 and you have **not** had your cholesterol checked recently as part of:

- a yearly check for heart disease, stroke or diabetes
- any other cholesterol check within the past 2 years

you will have been advised to inform your GP of your result.

High cholesterol
If your total cholesterol is between 5.0 and 7.5 if you are over 30, please visit this British Heart Foundation page on cholesterol

If you live in England, you should attend an NHS Health Check if you are invited to attend one.

Cholesterol measurements at Our Future Health

Participants who joined Our Future Health before 2025 will have been offered information about their cholesterol, based on a finger prick blood test taken at their appointment.

There may be a difference in the results you can see online and how they were written down at your appointment. This is due to an update in how we recorded cholesterol.

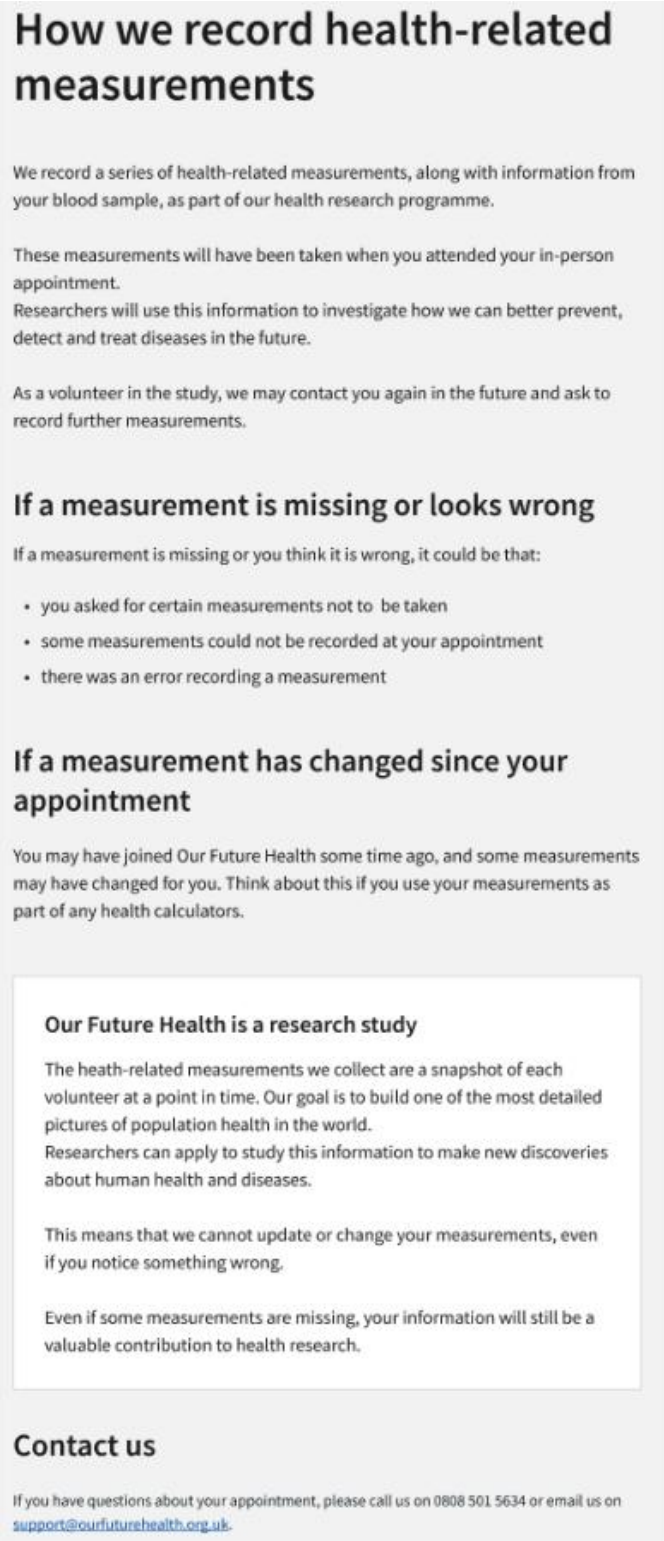
Contact us

If you have questions about your appointment, please call us on 0808 501 5634 or email us on support@ourfuturehealth.org.uk.

As above, contextual information about cholesterol has been rearranged and simplified. Age-specific ranges and suggested actions are now presented under drop-down menus for clarity. We have added a line reminding participants to attend their NHS health check if invited to do so.

NB: the way cholesterol was reported to participants changed over time; as it will be very difficult to determine which version of cholesterol participants were offered, we have decided to streamline how cholesterol is reported digitally for all participants. We have added a disclaimer explaining why some participants may not receive a digital copy of some measurements (e.g. triglycerides).

10. Information page



How we record health-related measurements

We record a series of health-related measurements, along with information from your blood sample, as part of our health research programme.

These measurements will have been taken when you attended your in-person appointment.
Researchers will use this information to investigate how we can better prevent, detect and treat diseases in the future.

As a volunteer in the study, we may contact you again in the future and ask to record further measurements.

If a measurement is missing or looks wrong

If a measurement is missing or you think it is wrong, it could be that:

- you asked for certain measurements not to be taken
- some measurements could not be recorded at your appointment
- there was an error recording a measurement

If a measurement has changed since your appointment

You may have joined Our Future Health some time ago, and some measurements may have changed for you. Think about this if you use your measurements as part of any health calculators.

Our Future Health is a research study

The heath-related measurements we collect are a snapshot of each volunteer at a point in time. Our goal is to build one of the most detailed pictures of population health in the world.
Researchers can apply to study this information to make new discoveries about human health and diseases.

This means that we cannot update or change your measurements, even if you notice something wrong.

Even if some measurements are missing, your information will still be a valuable contribution to health research.

Contact us

If you have questions about your appointment, please call us on 0808 501 5634 or email us on support@ourfuturehealth.org.uk.

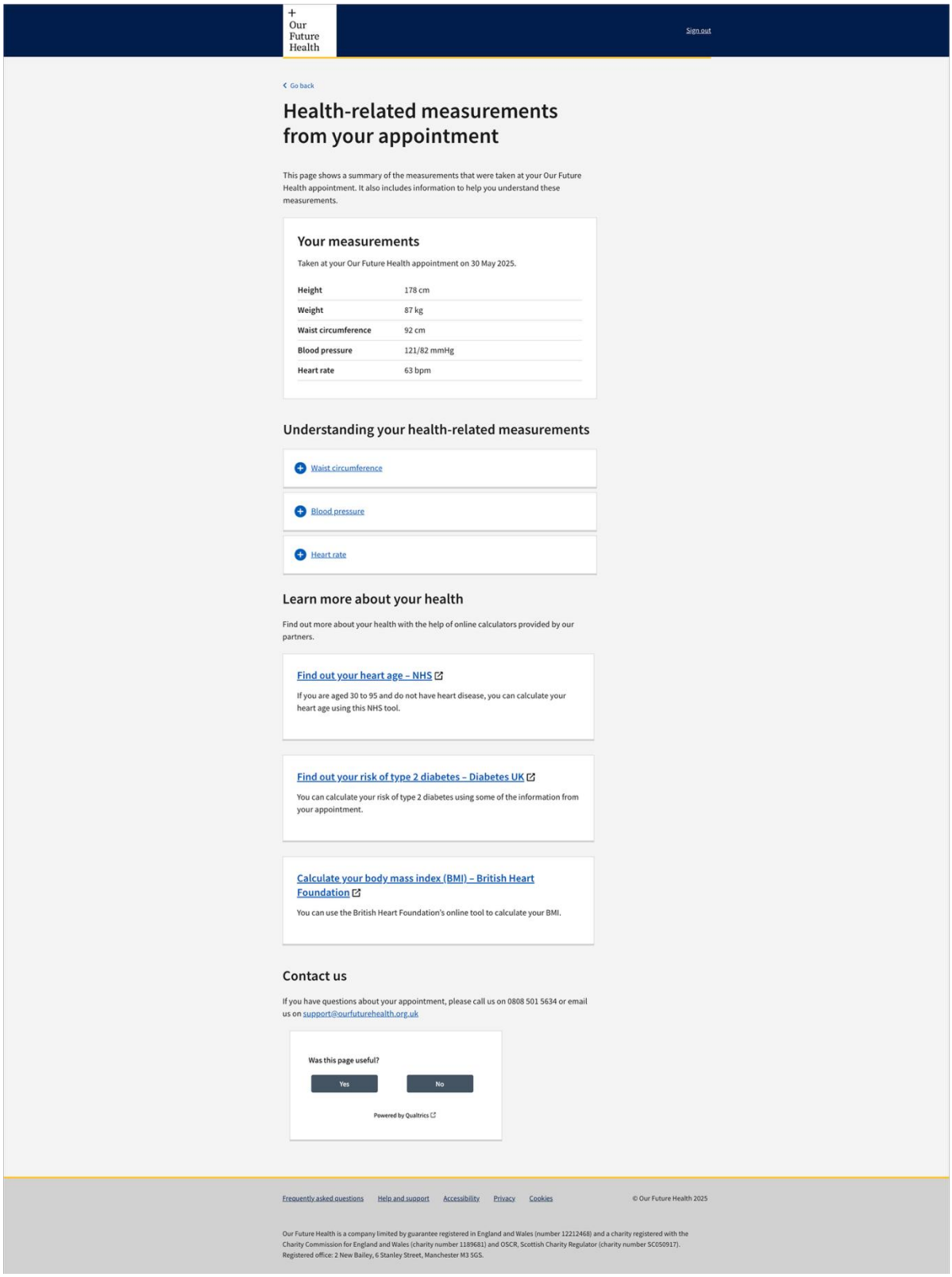
As described above, we decided to include some additional information for participants explaining how we record health-related measurements. This includes e.g. an explanation for why some participants may have missing measurements, and a reminder that Our Future Health is a research programme / that information cannot be changed.

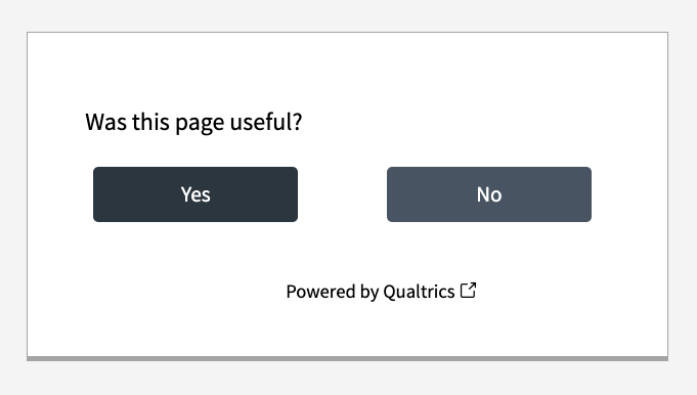
Digital Clinic Measurements Participant Feedback
In-product survey design and content

As part of the health insights platform, participants will have the option to provide feedback via an embedded widget that will appear at the bottom of the page. Data will be collected anonymously, with questions designed to evaluate participants' experience, constituting a low-risk activity under the boundaries for user research previously approved by the REC.

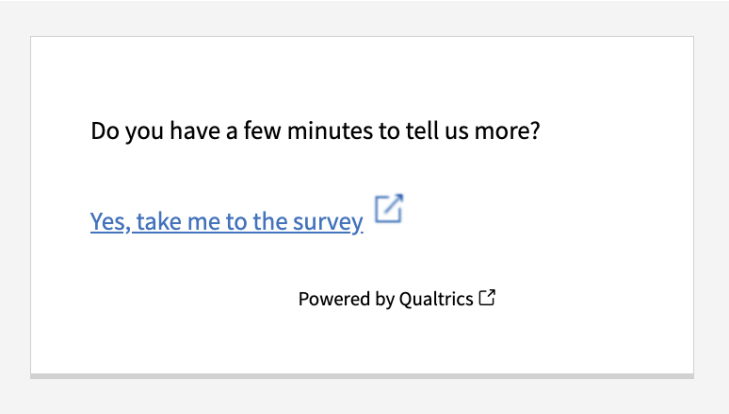
If clicked on, the widget will expand to reveal user experience questions that allow participants to rate the health insights report in key areas. Those who indicate that they have time to provide more feedback will be shown additional survey questions designed to capture their experience of viewing the report and attitudes towards receiving it. The content of these questions will be adapted over time as the content of the clinic measurements pages evolve.

1. The feedback button will appear at the bottom/side of the page

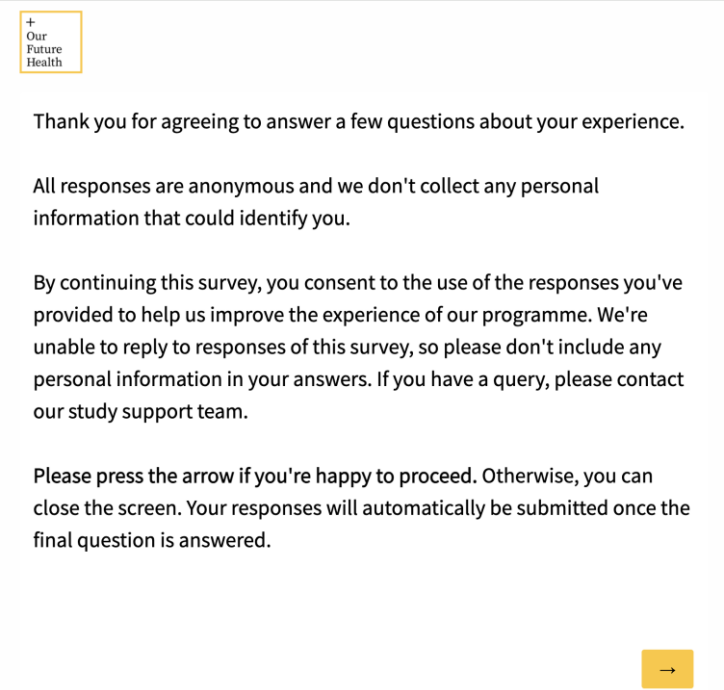




2. Participants can indicate if they have time to answer additional survey questions



3. If participants click the link, the full survey will open in a new window

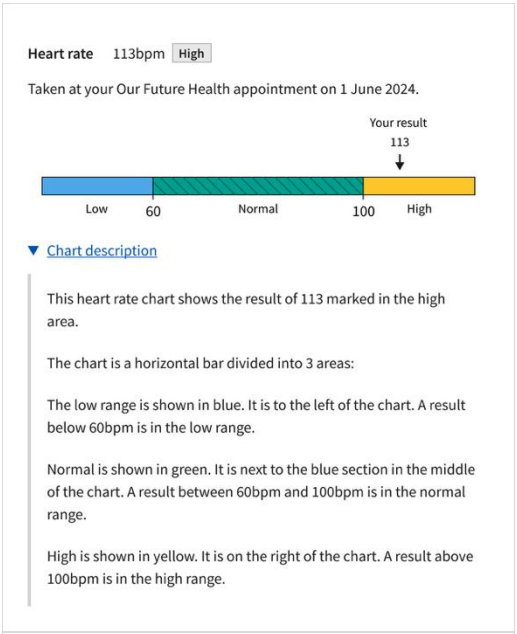


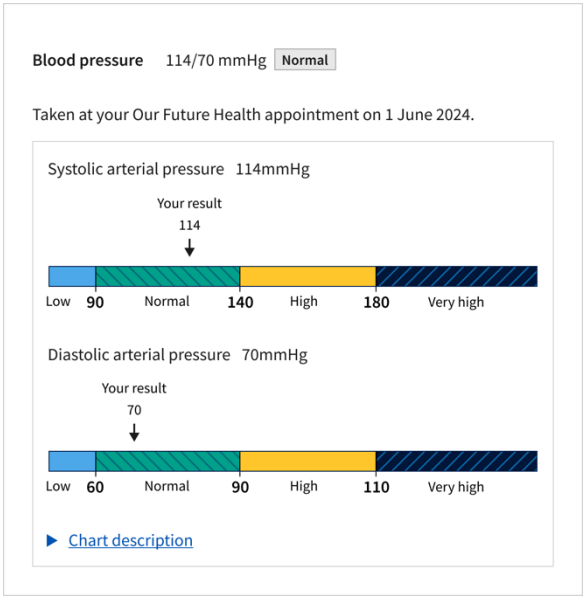
Digital Clinic Measurements Optimisation
Examples of content for AB testing

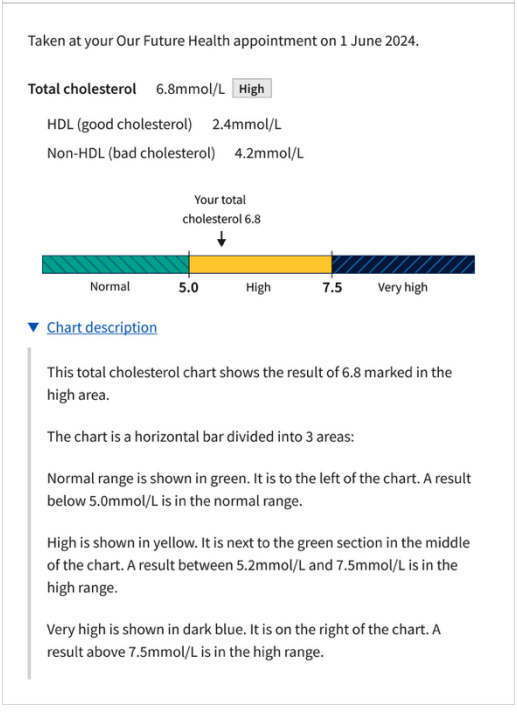
Example 1: Visualisation of measurements alongside text

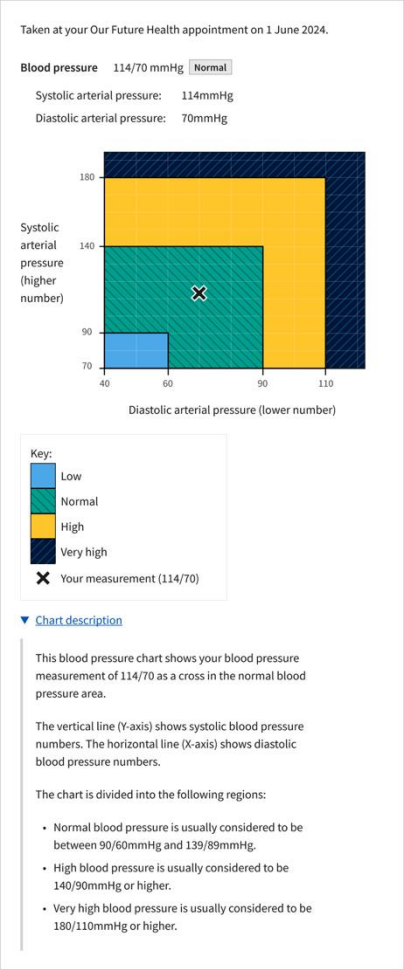
During the research we found participants struggling to compare their own measurement to the ranges shown within expanders below. We also showed prototypes of graphical visualisations at the end of user testing which received positive feedback from participants in improving their interpretation of where a measurement is within the ranges. The below examples show the standard bar chart format for heart rate, blood pressure and cholesterol, which we anticipate using in AB testing as part of the General Availability rollout.

- We are also looking to test a graphical visualisation of blood pressure, as shown below. This visualisation aligns with the NHS's 'Check your blood pressure' online tool.



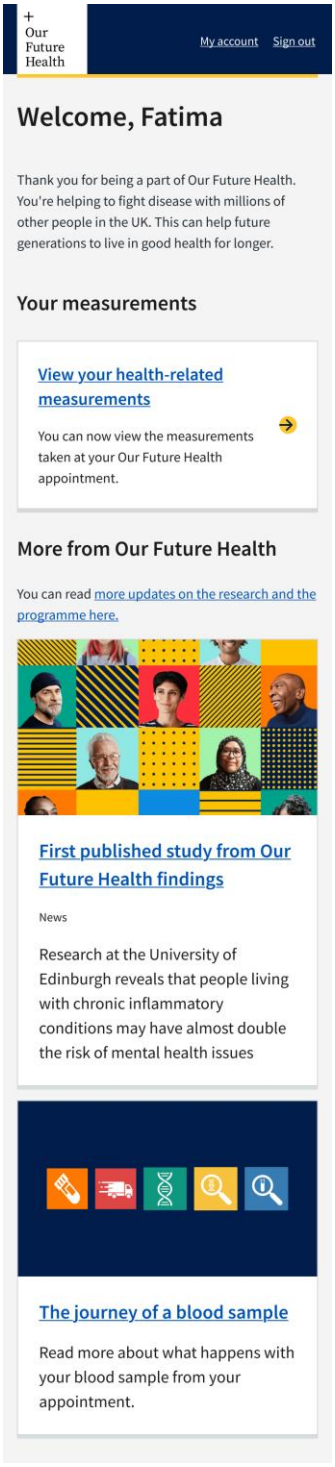






Example 2: Linking to content provided elsewhere

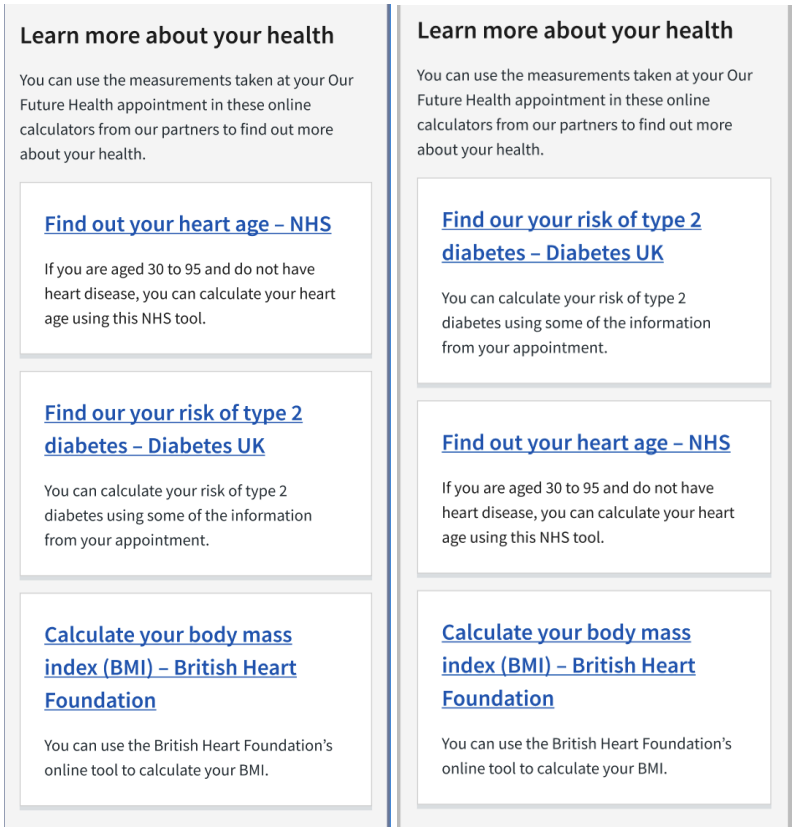
During user research, participants questioned where their 'blood test results are' and similarly participants wanted to be kept up to date with progress on the research and so we want to test linking to existing content, currently available on the public site, on the dashboard when participants log in to view their measurements. We would also like to explore adding new relevant information such as the journey of a blood sample.



Example 3: Showing relevant content to the participant

Changing the order that content is displayed:

Participants mentioned wanting to see content that feels relevant to them, i.e. a participant mentioned the Diabetes UK link being more relevant and useful for them as they have a family history of diabetes. An example of this is shown below where the Diabetes UK link is placed higher.



Showing relevant context-specific content:
Similarly participants wanted the information to be relevant to them, i.e. if they're under 30, they did not want to see the heart age calculator (as it is only relevant for those over 30). We would then hide the heart age calculator link. Another pertinent example is cholesterol; as the range cutoffs for total cholesterol are age-dependent, we would tailor content for participants according to age, as shown below.

Understanding cholesterol

As a guide, healthy cholesterol levels are normally:

Total cholesterol
Below 5.0 mmol/L

HDL (good cholesterol)
Above 1.0 mmol/L

Non-HDL (bad cholesterol)
Below 4.2 mmol/L

Cholesterol is a fatty substance found in the blood. There are several different types of cholesterol. Some of these are associated with a higher risk of heart problems and stroke.

Very high cholesterol
If your total cholesterol is above 7.5 and you have not had your cholesterol checked recently as part of:

- a yearly check for heart disease, stroke or diabetes
- any other cholesterol check within the past 2 years

you will have been advised to inform your GP of your result.

High cholesterol
If your total cholesterol is between 5.0 and 7.5, please visit this British Heart Foundation page on cholesterol

If you live in England, you should attend an NHS Health Check if you are invited to attend one.

Cholesterol measurements at Our Future Health

Participants who joined Our Future Health before 2025 will have been offered information about their cholesterol, based on a finger prick blood test taken at their appointment.

There may be a difference in the results you can see online and how they were written down at your appointment. This is due to an update in how we recorded cholesterol.

[End of document]

Our Future Health

Appendix F: Re-contact Development and Optimisation

V1.0
13 October 2025

Our Future Health

CONTENTS

Re-contact development:
Learning from our first re-contact studies

Introduction

A core aspect of recruitment into Our Future Health is the ability to re-contact participants to invite them to take part in health research studies and clinical trials, led by external organisations including academia, NHS, charity or commercial organisations. In some cases, invitations to participate in a re-contact study will be based on specific phenotypic and/or genetic criteria, such as demographic information, physical measurements, symptoms, diagnoses or lifestyle factors self-reported in the questionnaire, linked health record data, or risk of specific diseases. Invitations to re-contact studies may, therefore, be a mechanism through which participants are informed of new health-related information about themselves, and may include studies for which the participant is considered at risk of developing a condition but has not developed it yet. The ability to re-contact participants on a stratified basis is key to enabling the translational research that is at the heart of Our Future Health's mission. This appendix outlines the approach that Our Future Health will take to the development and optimisation of these activities.

Re-contact pilots

Our Future Health plans to open up to an initial round of applications for re-contact studies from external researchers in 2026. In order to meet this milestone, we plan to run one or more studies in 2025-2026, with a focus on developing and optimising capabilities needed to facilitate re-contact research ("re-contact pilots"). The studies that comprise the re-contact pilots are expected to be selected to allow us to gather learnings across a range of areas. Specifically, we aim to include studies that differ in:

- Selection criteria
- Awareness and ease of understanding of information about a health condition, individual risk, or intervention
- Perceived seriousness of the information
- Likelihood of developing the condition
- Type of study or intervention.

While many of the capabilities that enable re-contact studies will be common across these areas, differences in these factors will require distinct invitation strategies, approaches and technical capabilities. A primary focus of the pilots will be to generate learnings that support the development of participant materials, invitation experiences, technical capabilities and flow of data fitting for each type of re-contact study. We intend to begin with piloting studies in which participants are selected for invite on the basis of self-disclosed phenotypic information and increase in complexity to studies in which participants are selected on the basis of unknown genetic information or risk, or invited to take part in a study of a more involved intervention. This strategy will allow Our Future Health to build the foundational capabilities required to begin delivering re-contact studies as efficiently as possible, while carefully considering the differing needs of participants and researchers for more sensitive re-contact requests.

Pilot objectives

The purpose of piloting various forms of re-contact studies is to generate learnings that drive the direction of the re-contact service that benefits participants and researchers. As such, for each pilot, objectives will be set across three areas:

Feasibility

Evaluation of the systems and platforms necessary to deliver a re-contact service.

Example research questions:

- Can Our Future Health identify and select cohorts of eligible participants by phenotype?
- Can Our Future Health identify and select cohorts of eligible participants by genotype?
- Can Our Future Health facilitate initial recruitment into a study?

Participant desirability

Developing an experience that is positive for participants.

Example research questions:

- What information do participants need to decide whether to take part in a study?
- How do participants want to be invited to re-contact studies?
- How can Our Future Health tailor study invites to meet the needs of participants from diverse backgrounds?
- What type of choices do participants want over the re-contact invites that they receive?

Viability

Determining whether re-contact services are sustainable and scalable.

Example research questions:

- Do researchers find the re-contact process usable and efficient?
- What is the recruitment rate for different types of re-contact studies?
- Can Our Future Health recruit participants from rare disease cohorts?
- Can Our Future Health recruit participants from a range of geographical locations?
- How long does it take Our Future Health to recruit into re-contact studies?
- What is the cost of recruitment into re-contact studies?

Summary of learnings on re-contact

In addition to a deliberative dialogue and other Participant and Public Involvement and Engagement activities, we have also conducted quantitative research with participants to capture their attitudes and preferences for re-contact studies.

Participant awareness of and interest in research offered through Our Future Health

Among 61 surveyed Our Future Health participants, 85% were aware that Our Future Health may invite volunteers to take part in further health research studies, and 71% reported that they are very likely to take part. Participants reported a desire to be matched to studies which they likely qualify for based on health information they've already shared, and all reported participants believed that Our Future Health should prioritise research focussed on improving early detection. When hearing about a new opportunity, the most important things to know were:

- Locations of where I can take part
- How much time and effort is involved
- What are the benefits of taking part
- When the research is happening
- The risks of taking part
- What discoveries the research could lead to.

For the majority of participants, it was important that the research that they are invited to is related to a health problem that they or their family are more likely to be impacted by.

What factors are most important participants when deciding whether to take part in re-contact research?

To capture participant preferences, 41 participants of Our Future Health completed an exercise called 'card sort task', in which they categorised different types of re-contact research according to the aspects that were important to them. The benefits most frequently categorised as being important were "I can learn more about my health by taking part", "A sense of contributing to something that will make a difference to the health of future generation", "Receiving genetic risk of a health problem or condition", and "Accessing a basic version of data". The benefits categorised as being least important were "Access to a community of others through taking part", and "Receiving wearables to wear".

In terms of participation types, research that involved surveys or having physical measurements were categories viewed as most acceptable for participants to be involved in, whether or not there was a benefit. Some types of research were categorised as things that participants would be more likely to do if they received a benefit, including multiple visits to a clinic, taking part in an intervention, or collecting their own samples at home. For 17% - 27% of participants, there were some types of research that they report that they would never do, whether or not there was a benefit, include taking time off work, taking a daily drug to prevent a common disease, or staying overnight in a research centre. Overall, participants expect that the biggest barrier to their future participation may be 'they do not have the time to take part'.

Re-contact pilot selection criteria

The aim of the re-contact pilot study selection process was to select a suitable first pilot study to enable us to develop our core re-contact service capabilities. In July 2025 we opened a call for pilot study proposals to Our Future Health founding industry members, founding charity members, and researchers known to Our Future Health. Proposals were invited for studies that met the following criteria:

- Participants are selected by variables known to them (e.g., information provided in the Our Future Health questionnaire or measured at their Our Future Health appointment).
- Aim to successfully recruit a minimum of 100 participants from the Our Future Health cohort.
- High engagement potential for participants (e.g. low participant burden / high participant value).
- The study will be ready to invite the first participant 2-3 months after selection by Our Future Health.
- Study sponsor / team must be available to work closely with Our Future Health for the 2-3 months post selection on topics such as: cohort selection; Our Future Health Access Board and regulatory approvals; invitation; conversion.
- New health information will not be given to participants as part of the study invitation.
- Must be a research study that is testing rigorous research hypotheses, as opposed to primarily recruiting participants to enter them into a clinical care pathway.
- Sponsor and collaborators must be free of conflicts of interest with a clear governance and ownership structure.

Five pilot study proposals were submitted: one from a commercial sponsor and four from non-commercial sponsors. We conducted a feasibility assessment on each study to ensure it was possible to select eligible participants from the Our Future Health cohort, and in sufficient numbers. Each proposal underwent an expertise assessment within Our Future Health by teams in the following areas:

- Ethics
- Science
- Commercial
- Engagement
- Regulatory

To assist with completing the expertise assessment, we met with all but one* sponsor/study team to discuss their proposal further (*one study did not meet the criteria of being ready to invite the first participant within 2-3 months of selection).

The findings of the expertise and feasibility assessments were put forward to the Our Future Health Executive for selection of one pilot study. The Executive decision included a range of factors, including strategic and operational considerations, wider opportunities afforded by the study, and feasibility within current timelines.
We invited the sponsor/study team of the successfully selected pilot study to submit a full application to the Our Future Health Access Board in accordance with our Access Process Standard Operating Procedure (SOP).

Research plans for Pilot 1: Recall by phenotype

The first re-contact pilot study delivered through Our Future Health will invite participants who experience common digestive symptoms to take part in a research programme called Heartburn Health. The key aspects of the pilot as they relate to the participant recruitment journey are below, full details are available by reasonable request to Our Future Health:

- Invitations to take part will be sent via Our Future Health to participants who are likely to be eligible (see below)
- Eligibility will be determined using participation status, age, sex and self-reported health information including diagnoses and medication use (obtained from the Our Future Health questionnaire). Additionally, geographical location will be used related to the recruiting areas of the programme
- Invitations will outline to participants why they are receiving the invite and key details about the research programme
- Participants will be able to log into their Our Future Health account to view more information about the study, and if they wish to, click-through to the Research Programme's website to complete a screening questionnaire to assess their eligibility for the research programme and access the participant information sheet (PIS)

An initial pilot of recruitment into this programme is anticipated to run between late 2025 – March 2026, with the possibility of recruitment continuing into 2026 following a successful pilot phase.

As the first re-contact invitation sent through Our Future Health to join an externally-sponsored research programme, this pilot will be designed to enable learnings that shape the development of cohort selection, re-contact invitations, technical capabilities, and participant experience for recall by known phenotype studies. As part of this pilot, a range of user research, experimentation and analytic activities will take place to gather qualitative and quantitative evidence for the effectiveness and impact of different elements of the recruitment journey.

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Summary of testing and learning activities for Re-contact Pilot 1: Recall by phenotype

Activity	Aim	Example research questions	Estimated sample size	Key metrics
User research – Interviews and prototype testing of the re-contact invitation journey with participants *Status: Completed (under approved REC principles and boundaries for user research)*	Gather participant feedback on the usability and experience of a recontact study recruitment journey	• What do participants understand about what they are being invited to and why? • How does the invitation and information shared meet the known needs of participants? • What pain points, if any, are experienced in navigating and interacting with the journey? • How acceptable do participants view the experience and choices Our Future Health offers in response to a re-contact invitation?	10	• Qualitative data from interviews
Technical systems check	To run a small number of participants through the invitation journey, as a live check of the systems used for daily processing and monitoring of invites after comprehensive internal end-to-end testing.	• Can we select participants who meet eligibility criteria to take part in Heartburn Health? • Do we observe any technical issues with the recruitment journey? • Are all email and engagement metrics tracking as expected?	10-50	• System performance indicators • Email open rates • Email click-through rates
Analysis – Rollout to a small group of participants	To gain early estimates of engagement rates (email open, conversion and interaction rates), and participant behaviours (Study Support contact, withdrawals, GP impact)	• What response rates do we see for re-contact invites? • What conversion rates do we see for participants who visit the study page? • What proportion of invited participants get in contact with questions?	200-500	• Email open rates • Email click-through rates • Re-contact participation rates Study support questions

Analysis – Effect of email reminders	Evaluate the impact of sending email reminders following invites	• What proportion of invited participants respond following an email reminder? • How many email reminders is an optimal balance between response rate and email fatigue? Note: we will be sending maximum of three	~15,000 based on current operational estimate	• Email open rates • Email click-through rates • Re-contact participation rates • Study support questions
Experiment – Test of preference for invitation channel	Assess differences in response rates to re-contact invitations for a research programme sent by letter and email	• Are there differences in response rates to re-contact invitations sent by email or letter? • Are there differences in the characteristics of participants who respond to invitations sent by email or letter? • What is the cost per interested participant for re-contact invitations sent by email and letter?	~15,000 based on current operational estimate	• Email open rates • Email click-through rates • Re-contact participation rates • Study support questions
User research – Participant feedback on the re-contact experience (surveys and interviews)	Understand participants experience of taking part, or reasons for not taking part	• What are the main reasons that participants decide not to take part in re-contact? • Where in the recruitment journey do participants make the decision not to take part? • How do participants rate the experience being invited to a re-contact study?	~15,000 based on current operational estimate	• Quantitative and quantitative feedback data from surveys and interviews

Supporting activities happening during the pilot

Activity	Aim	Example research questions	Estimated sample size	Key metrics
Analysis – Call to Action for participants to update their contact details, as part of the quarterly newsletter	Assess participant response to a request to update their contact details in a cohort-wide newsletter	• What proportion of participants respond to an ask to update contact details? • What is the incidence rate of data errors when participants update their details? • What subject lines encourage higher open and click through rates for emails asking participants to update their details?	*All participants who receive newsletters*	• Email open rates • Email click-through rates • Rates of editing details • Study support questions
Analysis - Communications designed to prepare participants for re-contact invites	Assess participant engagement with topic-focussed communications on the subject of heartburn / re-contact studies	• What proportion of participants open and interact with "warm up" emails on the topic of re-contact or upcoming studies?	*All participants who receive newsletters*	• Email open rates • Email click-through rates • Email unsubscribe rates
Experiment – Test of the impact of receiving digital clinic measurements before re-contact invite	Assess whether receiving a health insight (digital clinic measurements) before a re-contact invite impacts response rates	• Are participants who receive a health insight more likely to open a re-contact invite email? • Does receiving a health insight before a re-contact email invite increase recruitment rates?	~1000, with scope to expand in line with the digital clinic measurements rollout	• Email open rates • Email click-through rates • Re-contact participation rates • Study support questions

Selection of participants

Participants who meet the eligibility criteria for a re-contact study will be selected for invitations to take part in user research, invitations to the research study, and invitations to provide feedback on the experience.

Data collection

Interviews

Interviews will be used during the design process to gather qualitative feedback from participants on their understanding of content, usability, and overall experience of receiving a re-contact invitation. Interviews will use a semi-structured topic guide to direct the questioning and will take between 30 to 60 minutes to complete. Interviewees will be reimbursed for their time in line with NIHR guidelines. Details of the good practice guidelines that are applied for user research are outlined in 'Protocol Appendix M: Our Future Health's boundaries and ways of working within research ethics standards'.

Surveys

Where quantitative data collection is required, surveys will be used. Surveys may consist of single choice, multiple choice, heatmap clicks on content, Likert scale, and free text questions and should take no more than 8-10 minutes to complete. Survey data will be collected anonymously and participants will be reminded not to include any identifiable information in their survey responses. For this reason, some high-level demographic questions may be included in surveys, to enable analysis of responses by key characteristics and to assess whether respondents represent the cohort. Details of the good practice guidelines that are applied for user research are outlined in 'Protocol Appendix M: Our Future Health's boundaries and ways of working within research ethics standards'.

Analytics

In addition to participant experience data captured through interviews and surveys, analytics captured by the platform will be used to monitor and evaluate participant behaviours. Analytics may include open and click-through rates of emails, clicks on specific content or links, heatmap clicks, and conversion rates. Analytic data will be aggregated for analysis.

Future areas for learning

The first re-contact pilot will allow Our Future Health to begin generating learnings on participant needs, response rates, and methods of invitation for re-contact studies. These learnings are essential for shaping the direction of the re-contact programme for studies involving recall by known phenotype. Further user research and pilots will follow, in order to generate similar learnings for other types of invitation mechanism, for example recall by genotype, or study type, such as recruitment into clinical trials. Additionally, learnings generated from this pilot may not directly translate to participants outside of the eligibility criteria for this study, for example those in other age groups or living in other parts of the UK. Hence, it will be important for us to address these gaps in future re-contact studies.

Gathering participant feedback

As part of the re-contact pilots, we will provide participants with the ability to share feedback throughout the recruitment journey. This direct feedback will be focussed on two areas: 1) Reasons for deciding not to take part, and 2) General feedback about the re-contact experience.

Qualitative data will be collected through short, anonymous surveys hosted on Qualtrics. The survey questions will be designed to capture participants' attitudes and experience, constituting a low-risk activity under the boundaries for user research previously approved by the REC. Participants will be able to skip all questions. The content of these questions will be adapted throughout the re-contact pilots as changes are made to the selection process and recruitment experience.

Interviews may also be conducted with a subset of participants, to complement quantitative data with deeper qualitative insights on the re-contact experience.

Reasons for deciding not to take part

At various stages during the recruitment journey, participants will have the ability to indicate that they have decided not to take part in the re-contact study. Those that do so will have the option to provide feedback on the reasons for this decision via a multiple choice questions, including options such as "I am not interested in being part of this research", "I need more information before I make a decision about taking part", "I have concerns about taking part", "I am not sure that I am right for this study", and "I am already taking part in this research".

Insights from this survey will help to shape understanding of why, and where in the journey, participants are opting not to take part in specific re-contact studies. For example, they will help to identify whether optimisation should focus on participant materials, selection criteria, or Participants will be able to access this survey via the study page, and through email invitations and reminders for the study.

Re-contact experience surveys

Those invited to take part in re-contact studies may be contacted following the invite with the opportunity to provide feedback on the experience. This survey will ask questions to assess participants' understanding of the invite, the factors that influenced their decision to take part or not take part, whether they had any unanswered questions, and their attitudes towards future re-contact requests. Those who do report taking part in the study will also be asked about their understanding of the role of Our Future Health and the study team, and their experience of participating in the research.

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Appendix G: Home Appointments Pilot

V1.0 12 December 2025

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Introduction

Our Future Health is exploring ways to enhance its participant recruitment approaches, with the aim of continuing to drive forward the research programme's diversity, inclusivity, and accessibility.

At present, when participants join Our Future Health, they are required to attend an appointment to donate a blood sample and for physical measurements to be taken. We know that some of our participants find attending these appointments difficult due to accessibility of the clinic location, accessing appointments during standard working hours, or caring responsibilities. This means that, for some participants, they face barriers to taking part fully in the Our Future Health research programme. This could mean that, in the future, Our Future Health could only offer limited health feedback to those participants; or fewer opportunities to take part in additional research studies. It is therefore important that we seek to remove any barriers that those participants might face to becoming full participants of Our Future Health.

Through a phase of discovery work into new recruitment methods, offering home appointments was identified as a potential option for participants facing such barriers. By bringing the blood collection and physical measurement process directly to participants, we hope that we can reduce issues linked to mobility, time constraints, or caring duties. This would help ensure that more participants can engage fully with Our Future Health and be offered the same opportunities for health feedback and research involvement.

Objective

The purpose of the home appointments pilot is to generate learnings that demonstrate and test the feasibility, participant desirability, and viability of home appointments, particularly to identify demographic groups for whom home appointments would most of greatest benefit.

Rationale

Recruitment efforts and initiatives within Our Future Health have been very successful so far for recruiting participants in large numbers, the likes of which are unprecedented for health programmes globally. To reach our achieved milestones in terms of participant recruitment, we have primarily relied on an approach of setting up appointment clinics and then sending letters to prospective participants. These letters invite individuals to book an appointment at a clinic, which they would have to travel to.

This approach, however, may not work for everyone. A big factor that determines whether a participant will attend the appointment is their ability to travel to the clinic location. As noted from previous survey results with participants, a predominant factor for participants not attending their appointment is the lack of a convenient, accessible location with available parking. Participants may also live in remote locations, where a clinic is neither nearby nor easily accessible. In addition, we have already sent invitations to the vast majority of areas in the country (especially in England), meaning that we may reach a point of saturation with our current approach. Alternative approaches, such as walk-in clinics, have been piloted to drive recruitment for groups that may face barriers to participations in our current model.

Home appointments are another such example of an alternative approach, particularly for participants who have consented to participate but have not completed their appointment. Participants may not have attended their appointment because they face mobility or accessibility barriers, despite having the motivation to attend. These barriers may include not being able to access an appointment during 'working hours', mobility factors that limit how far people can travel and clinics being situated in inaccessible locations without parking or public transport links. We view offering home appointments as a method for alleviating these barriers.

Our learning objectives relate to the specific risks and opportunities that arise from offering home appointments on a large scale, which is why it is necessary to first conduct a pilot study with a smaller cohort of participants.

What do we want to know

Proof of concept: we envisage that home appointments will facilitate participants who are engaged but who have not yet attended an appointment with our current recruitment approach. This is why home appointments will be offered in this pilot only to participants who have consented but have not attended their appointment. In this sense, home appointments are seen as a 'second chance' for participants who have previously faced barriers to attending their appointment. We hope to learn if, in this group of participants, home appointments is a viable and effective option for helping them to participate fully in our program. We will analyse the utilisation of available appointments and gauge how desirable home appointments are for participants.

In addition to this, it is important to use the pilot as an opportunity to learn about logistical and organisational challenges with delivering home appointments before we scale the approach up to more participants. This will include analysis of the success and costs of delivering home appointments, whether we are able to safely and quickly deliver blood samples for genotyping and whether participant uptake is high enough to justify the costs (including whether appointment cancellation is kept to a low level from both the supplier and participant side). Our ability to deliver blood samples will be contingent on the locations of participants' homes and how far they are from the clinic where the blood samples are delivered. It will be important for us to understand the kinds of locations that would be more (or less) challenging for us to successfully administer blood samples in.

Value: we hypothesise that home appointments will be especially useful for participants who live in more remote parts of the country which have not historically been near an Our Future Health mobile clinic or Boots clinic. The drawback with our usual clinic approach has been that we are limited to opening clinics in areas that are populated enough to justify their cost and utilise appointments. Home appointments could offer a potential means for sampling participants who we otherwise would not have been able to reach with our current recruitment methods. Hence, we want to understand from this pilot the locations where home appointments would be most valuable for participants.

There is a risk however that home appointments is not adopted by enough participants regardless of their location or circumstances, and as scaling up this service is not financially or operationally viable. This pilot will help us to understand if and where home appointments can be deployed in the future.

Who does it work for: A key focus for Our Future Health is to recruit a diverse representative cohort of participants from across the UK, especially to include those who have historically been

underrepresented in health research. There are known accessibility and mobility barriers to our current model of offering appointments, and these barriers may disproportionately affect these underrepresented groups (e.g. younger people, ethnic minorities, deprived populations, people with disabilities) and others. We will then use this pilot to conduct a subgroup analysis on uptake and success of home appointments within these groups. This will help identify which groups have a greater preference for and uptake of home appointments if this offer is scaled up.

Sample quality: an important consideration for home phlebotomy is that the environment for taking a blood sample marks a deviation from our current approach. A health professional will collect the sample as they would in one of our appointment clinics. However, there is a risk that differences in the method by which samples are obtained can create a lack of parity in the data between home phlebotomy participants and our other participants. In particular, home phlebotomy may result in higher rates of lower quality blood samples due to longer or more inconsistent transport/storage. Rather than a centralised location such as an appointment clinic, blood samples will have to be stored and transported from several home locations around the country. As blood samples will be in storage and transit for longer than they would be in our current pathway, there is a higher chance that they become haemolysed. This is where the red blood cells in the sample burst, rendering them unable to sequenced. Haemolysis can occur when samples are shaken too much or if there is too long a delay before the sample is sequenced. There may also be factors that affect the quality of blood samples due to samples not having been taken in a sterile, controlled clinical environment (such as a clinic). We will use this pilot to compare the proportion of usable, genotyped blood samples from home appointments as compared with samples taken in the clinic.

Experience and desirability: It is important to understand the participant experience of home appointments. This would include the entire process, from appointment booking to the delivery of the appointment itself. We should understand, before any decision to scale up home appointments, whether there is a risk that it is experienced negatively by participants. Such negative experiences could cause reputational damage to Our Future Health, especially given the level of trust that participants would be granting to Our Future Health by allowing someone into their home to collect a blood sample and take physical measurements. We will conduct qualitative interviews and surveys with participants to understand why they decided to book a home appointment and to learn about their experience during the appointment. We would also like to conduct user research with participants who decided not to book a home appointment, in case there are perceived barriers or issues with the approach that we are not currently aware of.

We will be working with a new supplier to deliver home appointments, which will require constant evaluation about our organisational and logistical processes to improve outcomes if we decide to scale up this recruitment method in the future. For example, we might find that a sizeable proportion of participants face issues during their appointment that prompt them to withdraw. Any kinds of urgent issues such as this will need to be identified and rectified quickly. Our ability to monitor appointments will be important to trial as part of this pilot so that any issues when scaled up (given the higher impact of any such issues due to larger exposure to participants) can be appropriately identified.

Guided by the results of this pilot, we may expand to offer home appointments to more participants in other cities who have currently consented but not booked their appointment (with current estimates putting this number at 257,072 participants across the UK). We may tailor our approach to certain subgroups (e.g. younger people, ethnic minorities) if analysis shows that some subgroups have a significantly greater preference/uptake for home appointments. We would not scale up this approach, however, if this pilot shows low uptake across all/most demographics and low

appointment utilisation. We will also not scale up this approach if we find low parity of genetic/sample data with other participants. We do not envision currently offering home appointments to participants who have not already consented.

Pilot Design

Participation in this home appointments pilot will be for Our Future Health participants who have already consented but have not completed their appointment. Participants will be ineligible if they have an active appointment booking. Participants will also not eligible if Our Future Health does not currently have a provided mobile number for them, as mobile numbers are required for our clinical supplier (Heim Health) to deliver appointments and send updates to participants about their appointment.

We will be recruiting participants in six cities across England: Leeds, Bristol, Birmingham, London (in the Wimbledon area), Newcastle and Sheffield. We plan to send home appointment invites to around 70,000 participants across these six cities, aiming to confirm home appointments for around 5,000 full participants during this pilot. These six cities have been chosen to allow us to recruit higher numbers of people from underrepresented groups, namely ethnic minority, younger people and deprived populations. Across these cities, we estimate that we can invite around 45,000 eligible participants who are under 40, around 11,000 participants from an ethnic minority group and around 24,000 participants from the most deprived IMD quintile. We will use this pilot to compare uptake of home appointments amongst these communities.

Our key research questions for this pilot are:

- Are home appointments adopted by consented participants as a means of attending appointments at least as much as the current appointment clinics on offer?
- Are home appointments uitilised more than appointment clinics within any given underrepresented demographic group (under 40s, ethnic minorities, deprived populations)?
- Do blood samples administered, transported and sequenced via home phlebotomy maintain a sample quality that is consistent with those obtained within the clinic setting?
- Are we able to identify common issues and barriers reported by participants that contribute to a negative experience with home appointments?
- Can we maintain participant trust throughout the home appointments process, such that appointments are successfully delivered?

Invitations will be sent via email using the Iterable platform, which we currently use for sending other participant communications. Participant IDs will be sampled using information (appointment status, demographics) on the analytics platform and are converted into Iterable IDs. No identifying information will be taken outside of the analytics platform outside of these IDs. The first invites will be sent during January 2026, 21 days in advance of the first appointment. The last invites and appointments will both be before the end of March 2026. We plan to work with Heim Health as the clinical supplier and partner for delivering home appointments.

For participants in two cities (Newcastle and Sheffield), we will invite participants who are within a 5 to 10 mile radius of a previous mobile clinic in the city centre which is no longer operational. This will be henceforth referred to as the **Proof of Concept Group.** This group comprises of around 22,000 participants who will be invited. In this group, we will focus on assessing the participant

experience and our logistical capabilities, measuring appointment utilisation and uptake among different demographic groups.

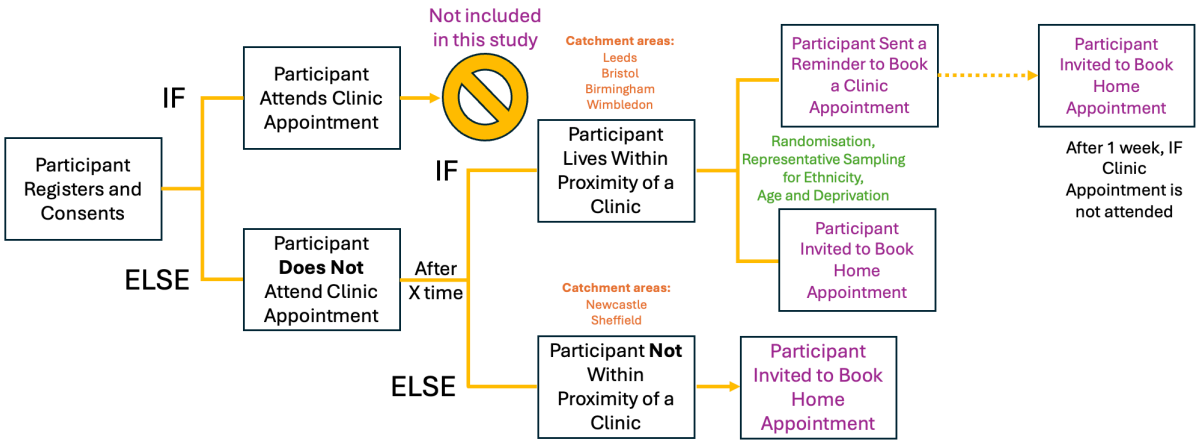
For participants in four of these cities (Leeds, Bristol, Birmingham, London), we will be inviting participants who are within a 5 to 10 mile radius (2.5 miles for London in the Wimbledon) of a currently operational Boots clinic. This will be henceforth referred to as the **Comparison Group.** This group comprises of around 47,000 participants who will be invited (including around 24,000 under 40 participants).

For participants in the Comparison Group, we will conduct a waitlist-controlled comparison. Participants in this group will be randomised into one of two conditions, with representative sampling within each group for ethnicity, age and deprivation:

a. Participants in one condition will be invited to book a home appointment
b. Participants in the other condition will be sent a reminder to book an appointment at the nearby clinic. If the participants have not booked a clinic appointment within one week, they will be invited to book a home appointment.

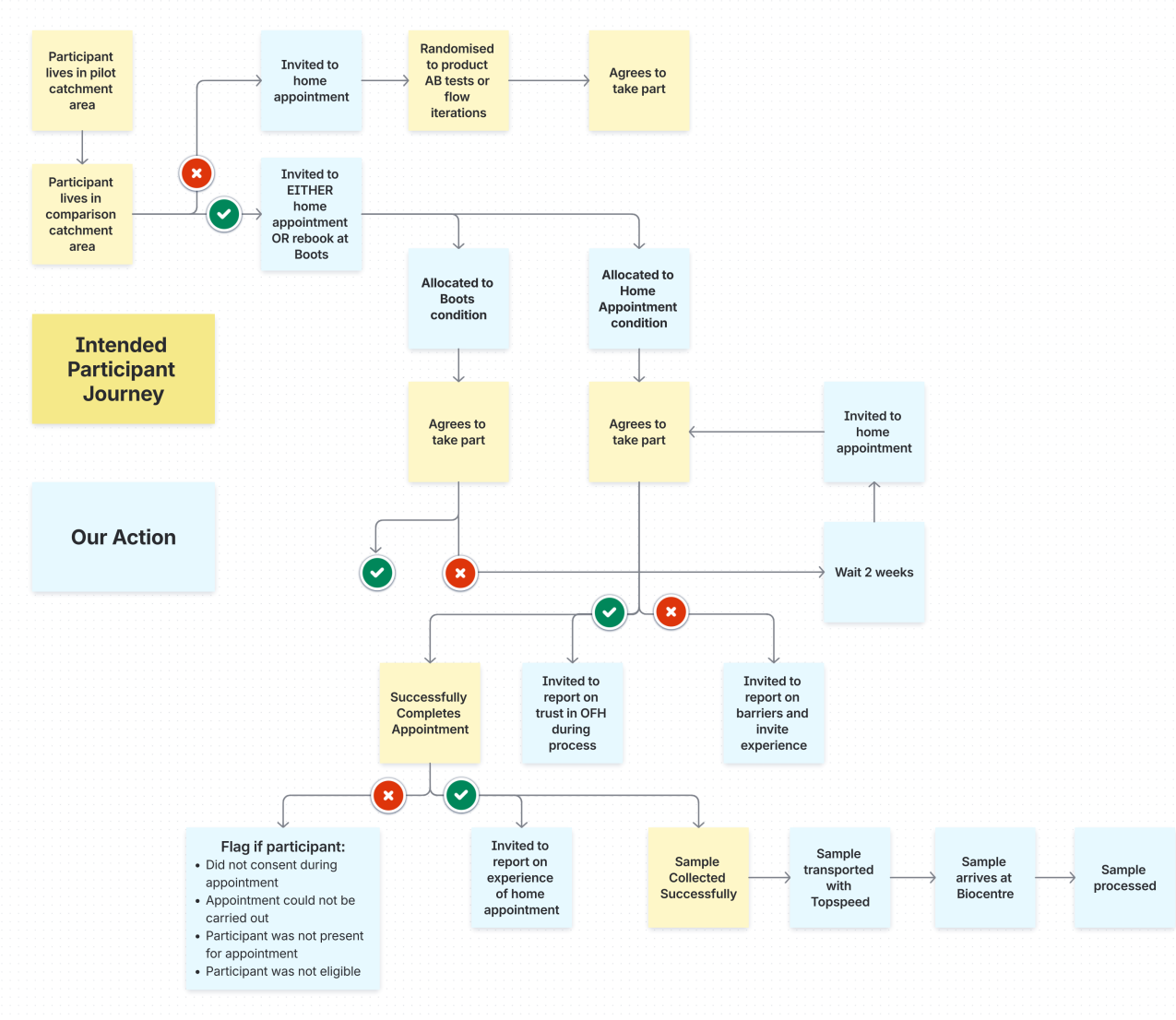
We will compare uptake of home appointments and Boots pre-book clinic appointment between these two groups of 23,500 participants each. As per our power analysis of a one-tailed two-sample proportion test (i.e. testing for non-inferiority that home appointment is not preferred less than Boots clinics), a sample size of at least 16,000 is statistically powered to detect a difference in uptake between groups of at least 1.5%.

Below is a summary diagram of the study conditions and criteria in this study:



We conduct this comparison in order to test our assumption that home appointments alleviate certain mobility or accessibility barriers to clinic appointment attendance. If participants are just as likely to book an appointment when reminded to do so at a nearby appointment clinic, it would not be worth the financial cost that home appointments incur to implement it in locations where we already have a nearby clinic in operation. As well as comparing the uptake (proportion of invited participants who book an appointment), we will also compare sample quality between home appointments and clinic appointment.

The full flowchart that visualises the participant journey can be viewed below:



We now summarise the steps in the participant journey:

1.
    a. If the participant lives in a 'Proof of Concept' location (Newcastle or Sheffield), they are sent an email invite to book a home appointment.
        i. If the participant does not book an appointment within one week, they are sent an email reminder.
    b. If the participant lives in a Comparison Location (Leeds, Bristol, Birmingham, London), they are randomised to receive an invitation to book either a Boots clinic appointment or a home appointment. **We will compare relative uptake between these randomised conditions.**
        i. In both randomised groups, participants are sent a respective reminder with 3-5 days if they have not booked an appointment within that time.
        ii. For participants who initially received a Boots appointment invite, if they have not booked an appointment within one week, they instead receive an invite to book a home appointment. Participants will only be able to book

one appointment of any type.

2. A group of participants who do not book a home appointment after being offered one will be invited to a qualitative interview to understand barriers to booking home appointments.

3. A participant will be flagged in the analytics data if any of the following happens during the appointment:
    a. Participant does not consent during the appointment
    b. Participant is found not to be eligible for a blood sample
    c. Participant is not present at home for their appointment
    d. Contextual/other factors prevent the appointment from being delivered successfully

4. For participants who complete their appointment, if they have a negative experience (or if the appointment is not delivered successfully), they will be invited for a qualitative interview.

We will assess participant experience in two ways:

1. By adding questions to our existing Participant Reported Experience Measure (PREM) survey that is sent to all participants following their appointment. We will add a question to the start of the survey to ask if the participant's appointment was in their home. If participants respond "Yes" to this question, we will ask participants why home appointments were seen as desirable to them and about their general experience during their appointment.
2. Qualitative interviews (including video and / or audio recording) will be conducted to understand the participant experience of home appointments. Both participants who attended a home appointment and those who were invited but chose not to book a home appointment will be recruited as part of these interviews. Such work will measure trust that participants had in Our Future Health during the home appointment process (from invitation to post-appointment), as well as capturing barriers and issues with the participant experience during the appointment process. This qualitative work will be conducted in line with the FER User Research DPIA and our user research boundaries.

Our key measures for analysis will be as follows:

Comparison Measures (between home appointments and appointment clinics)

- Uptake (proportion of invitations that result in appointment bookings), both at an aggregate level and within subgroups (e.g. under 40s, ethnic minorities, participants in locations within the most deprived IMD quintile).
- Percentage of booked appointments that are successfully attended and completed
- Cost per appointment and per participant
- Percentage of samples that are usable and genotyped

- Percentage of appointments that are cancelled (either by the supplier or by the participant), both before the appointment and during the appointment, and/or are not attended by the participant (e.g. if the participant is not at home)

Home appointment experience and feasibility measures

- Percentage of samples delivered to the lab within a 30-hour window
- Length of appointments
- Percentage of participants who reported having trust in Our Future Health during the home appointments process (survey/interview measure)
- Percentage of participants who report a positive experience during their home appointment (survey/interview measure)
- Percentage of home appointment participants who contact study support

Our main analysis will be comparing our experience/feasibility measures to thresholds defined in our success criteria and conducting non-inferiority tests on the comparison measures (i.e. to determine whether home appointments perform at least equivalently to our pre-booked appointment clinics on the key measures listed above, which would be considered as successful for home appointments).

Data used for analysis will be stored on our Analytics platform using our existing appointment model and can only be accessed securely by Our Future Health analysts. For sampling, we will use sociodemographic data (sex, ethnicity, age, IMD quintile) to ensure that, across participants, we have a representative sample. We will also use information on the elapsed time since participants had provided consent for the programme to look at whether home appointments are more/less effective for participants who have been recruited into the programme recently. We will control for past appointment status in our analyses (e.g. whether participants previously made a booking or a cancellation), but these will not be used for sampling or inclusion criteria.

Booking a Home Appointment

The home appointments pilot is intended to help facilitate those participants who have already consented to take part in our programme to book an appointment. We will already hold the personal information needed (name, date of birth, phone number, address, postcode) to invite eligible participants to the pilot.

We plan to invite participants via email to start with and will consider a letter of invitation should the response rate to the email be lower than anticipated. We will also we take into consideration the number of letters a participant has be sent in the past. Invitations and reminder correspondence is included in the 'supporting documents' section of this appendix.

If a participant is interested in booking a home appointment, they will be directed to

- Log in to their Our Future Health account
- A new card available on participant's dashboard signposting home appointments
- read a summary of information about what to expect at their home appointment, and if happy, to then proceed to the Heim Health site

- check their personal details are correct
- leave the Our Future Health study site and be transferred into Heim Health's booking application
- book a home appointment on the Heim Health booking application

Participants will be able to view available appointment slots (2 hour windows) in their area over the next few weeks. Once the participant picks their desired appointment slot, they will visit a confirmation page and receive a booking confirmation text and email.

This will include:

- their booked (2 hour) time slot and the date of the appointment
- how to reschedule or get support (i.e. cancel their appointment)
- confirmation that the appointment will take place in their home
- information on what to expect during the appointment, and how best to prepare for the appointment. Please note, some of this information may be provided by Heim Health, however we have also prepared a set of FAQs that includes information to support participants to prepare for their home appointment.

If, for any reason, participants need to reschedule their appointment, they can do so by clicking the URL link in their booking confirmation text.

If, for any reason, participants want to cancel their appointment, the instruction for participants would be to contact Heim Health's operational support team. As we suspect some participants might call Our Future Health's study support team, we will put in place plans to integrate these procedures.

Heim Health respects all cultural and religious preferences, including for example, participant requests for female-only practitioners. In line with the Equality Act 2010 and CQC Regulations 9 and 10, they will make every reasonable effort to accommodate such requests when told in advance of the appointment. Participants can indicate their preference via a gender filter in the booking platform or through support channels. This is securely recorded and used to route bookings to female practitioners in the relevant area.

Standard procedure will be followed to confirm a persons' identity at their home appointment. Participants will be asked to confirm their name and date of birth, and these will be verified against internal records. During the appointment, the health practitioner will measure and record physical measurements (height, waist, weight, heart rate, heart rhythm, blood pressure) and collect a venepuncture blood sample (2 vials of blood). These measures and sample collection are outlined in the protocol (V6.1). The health practitioner will provide the participant with their written measurements on a proforma, and participants will be offered reimbursement in the form of a £10 voucher.

Training

Heim Health is the third-party organisation responsible for delivering the home appointments. Heim Health bring expertise in conducting in-person clinical care in people's homes and will provide qualified staff with a minimum of 6 months experience conducting phlebotomy.

Heim Health staff will be trained on the research programme by Our Future Health. The training provided by Our Future Health will cover the importance of informed consent before each physical measure is performed, ensuring that participants understand that their home appointment is not a health check, and making clear that no diagnostic tests will be run on their blood sample because it is taken for research purposes only. In addition, this training will emphasise the importance of maintaining the privacy of the participant and protecting the participants' data.

Participant and practitioner safety

Heim Health staff will gauge the environment upon arrival and confirm that it is an appropriate setting for a home appointment (e.g. appropriate lighting, sufficient space, the presence of any infection risk). While they can adapt to diverse home environments, if they recognise factors that create a safety risk then they will pause or rearrange the visit. This will be logged appropriately.

In order to protect the health, wellbeing, and rights of participants who decide to have their appointments at home, Heim Health staff will follow their standard operating procedures for safeguarding. These procedures include the provision of dedicated safeguarding training for all staff, clear processes for escalating internally and to relevant authorities any safeguarding concerns, and instruction on record-keeping and confidentiality. These policies cover both adults at risk and children as, although Heim Health do not provide services for children under the age of 18, staff may visit homes with children present.

Heim Health staff will also take precautionary steps to mitigate any risks to practitioners from working alone, in line with their standard Lone Working Policy.

Adverse incidents

In the event of an adverse event, Heim Health staff will follow their standard Incident Management and Reporting Protocol. All practitioners are trained to respond with general first aid and/ or to escalate medical attention if a participant were to become unwell during phlebotomy. They will use the same thresholds in operation at other Our Future Health appointments to determine when a blood pressure reading indicates that a participant should seek urgent medical attention.

Should the participant themselves have any concerns regarding the conduct of their appointment, whether it is in progress or has been completed, they will be able to contact Our Future Health's Study Support team directly via phone or email.

Data protection

To facilitate the appointment booking and rescheduling, the following participant information will be used by Heim Health; name, address, postcode, telephone number and email address. Heim Health are accredited in ISO2001/2022 and cyber essentials. Heim Health keep records for a 5-year period and where participant IDs have been created but there is no action required, this information is deleted after 30 days.

Traceability of samples collected

Once the home appointment is completed, the samples will be placed in a labelled package and scanned at the participant's home. Heim Health staff will then transport the packaged samples to a

central location where a courier (this courier is already used by Our Future Health) will receive the samples. The samples will be scanned and transported to the central laboratory, where they will be scanned again on arrival. This process ensures an audit trail of the samples collected for the home appointment pilot.

Home appointment supporting documents

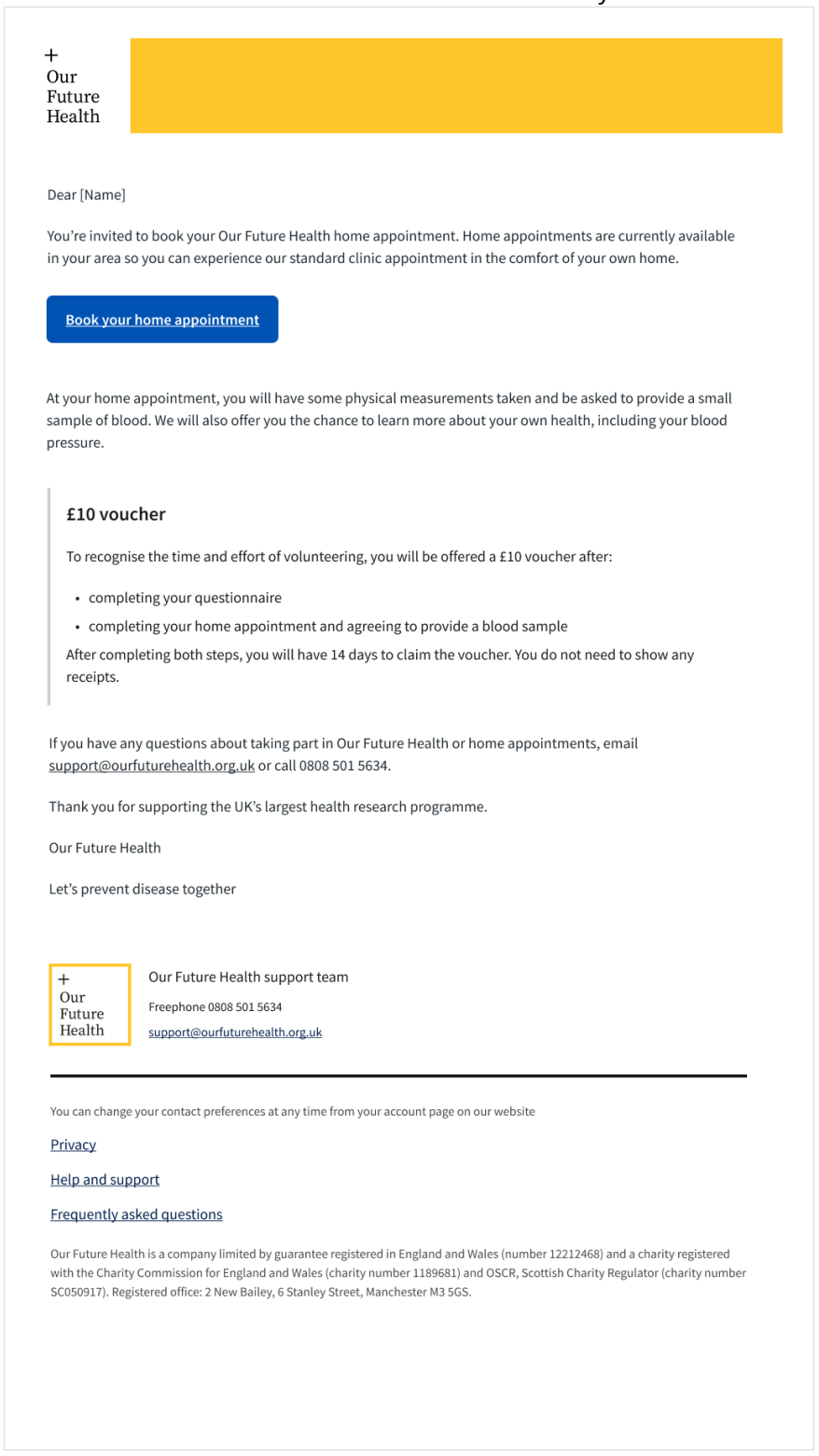
The documents described in the table below are submitted for REC approval. Please note that the content included below may be updated with minor changes depending upon finalising operational aspects of delivering home appointments. We anticipate these minor changes to be non-substantive.

	Document title	**Version and date**	**Description**
1	Email home appointment invitation and reminders	V1.0 12 DEC 2025	The email will be sent to eligible participants inviting them to book a home appointment. The email will be sent to eligible participants reminding them that they can book a home appointment.
2	Email clinic appointment invitation and reminders	V1.0 12 DEC 2025	The email will be sent to participants, inviting them to attend a clinic appointment in their area
3	Email home appointment invitation following clinic appointment invite	V1.0 12 DEC 2025	The email will be sent to participants who have been previously sent a clinic appointment invitation but have not taken action to make a clinic appointment.
4	Letter template home appointment	V1.0 12 DEC 2025	The letter template will be sent to invite participants to book a home appointment
5	Letter template Clinic appointment letter	V1.0 12 DEC 2025	The letter template will be sent to invite participants to book a clinic appointment in their area
6	Home appointment FAQs	V1.0 12 DEC 2025	These FAQs are intended to help participants prepare for home appointments. Some may be included on our website, and some will be used as resources for responses for our Study Support. The FAQs are not an exhaustive list and are likely to be updated as the pilot is implemented.

Document 1 Email home appointment invitation and reminders V1.0 12 DEC 2025

Invitation to book a home appointment

From: Our Future Health
Subject line: You're invited to book an Our Future Health home appointment
Pre-header: Learn more about your own health at home



Dear [Name]

You're invited to book your Our Future Health home appointment. Home appointments are currently available in your area so you can experience our standard clinic appointment in the comfort of your own home.

Book your home appointment

At your home appointment, you will have some physical measurements taken and be asked to provide a small sample of blood. We will also offer you the chance to learn more about your own health, including your blood pressure.

£10 voucher

To recognise the time and effort of volunteering, you will be offered a £10 voucher after:

- completing your questionnaire
- completing your home appointment and agreeing to provide a blood sample

After completing both steps, you will have 14 days to claim the voucher. You do not need to show any receipts.

If you have any questions about taking part in Our Future Health or home appointments, email support@ourfuturehealth.org.uk or call 0808 501 5634.

Thank you for supporting the UK's largest health research programme.

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support@ourfuturehealth.org.uk

You can change your contact preferences at any time from your account page on our website

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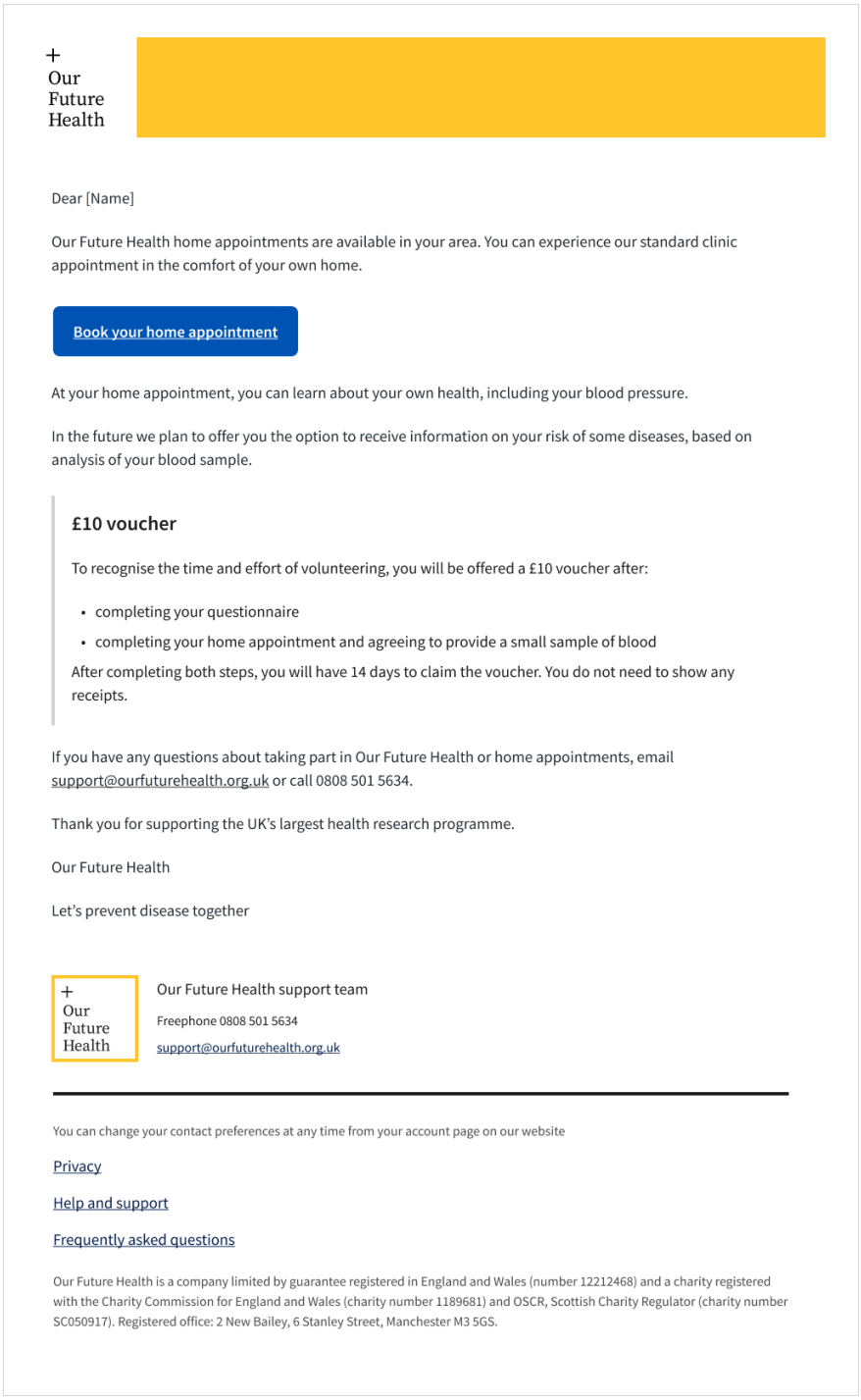
Our Future Health is a company limited by guarantee registered in England and Wales (number 12212468) and a charity registered with the Charity Commission for England and Wales (charity number 1189681) and OSCR, Scottish Charity Regulator (charity number SC050917). Registered office: 2 New Bailey, 6 Stanley Street, Manchester M3 5GS.

Home appointment reminder email

From: Our Future Health
Subject line: Our Future Health home appointments are available in your area
Pre-header: Book your home appointment today



Dear [Name]

Our Future Health home appointments are available in your area. You can experience our standard clinic appointment in the comfort of your own home.

Book your home appointment

At your home appointment, you can learn about your own health, including your blood pressure.

In the future we plan to offer you the option to receive information on your risk of some diseases, based on analysis of your blood sample.

£10 voucher

To recognise the time and effort of volunteering, you will be offered a £10 voucher after:

- completing your questionnaire
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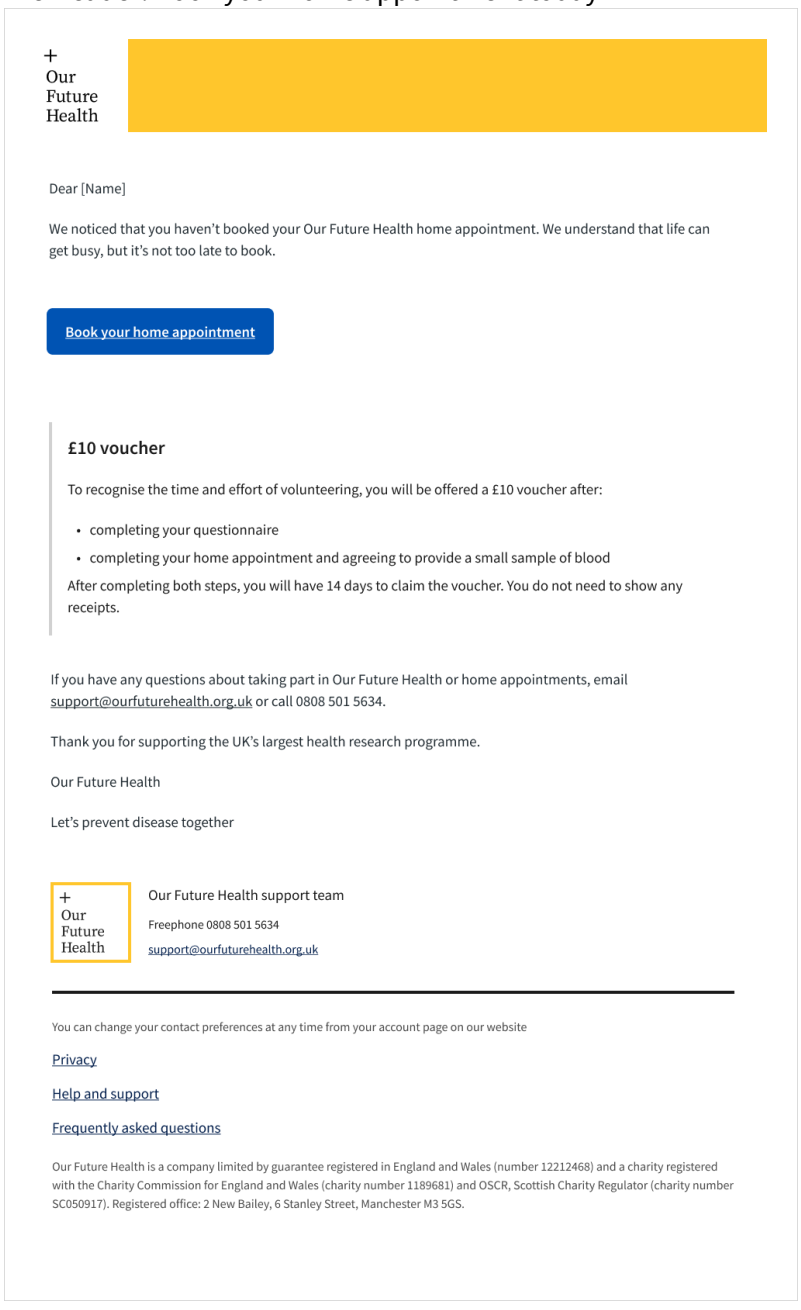
Second home appointment reminder email

From: Our Future Health
Subject line: Our Future Health home appointments are available in your area
Pre-header: Book your home appointment today



Our Future Health

Dear [Name]

We noticed that you haven't booked your Our Future Health home appointment. We understand that life can get busy, but it's not too late to book.

Book your home appointment

£10 voucher

To recognise the time and effort of volunteering, you will be offered a £10 voucher after:

- completing your questionnaire
- completing your home appointment and agreeing to provide a small sample of blood

After completing both steps, you will have 14 days to claim the voucher. You do not need to show any receipts.

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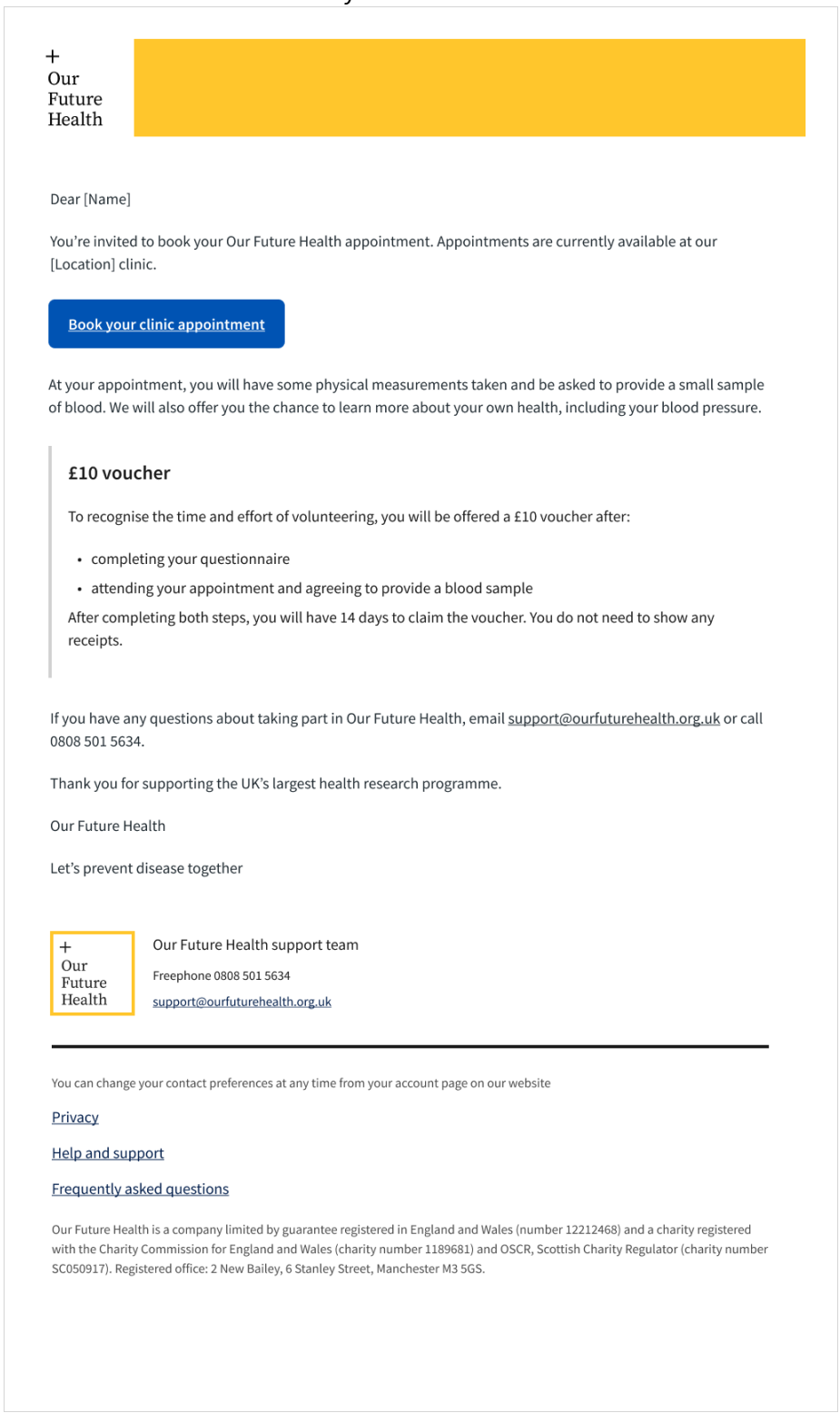
Document 2 Email clinic appointment invitation and reminders V1.0 12 DEC 2025

Clinic appointment invitation

From: Our Future Health
Subject line: Book your Our Future Health appointment at [Location]
Pre-header: Learn more about your own health



Our Future Health

Dear [Name]

You're invited to book your Our Future Health appointment. Appointments are currently available at our [Location] clinic.

Book your clinic appointment

At your appointment, you will have some physical measurements taken and be asked to provide a small sample of blood. We will also offer you the chance to learn more about your own health, including your blood pressure.

£10 voucher

To recognise the time and effort of volunteering, you will be offered a £10 voucher after:

- completing your questionnaire
- attending your appointment and agreeing to provide a blood sample

After completing both steps, you will have 14 days to claim the voucher. You do not need to show any receipts.

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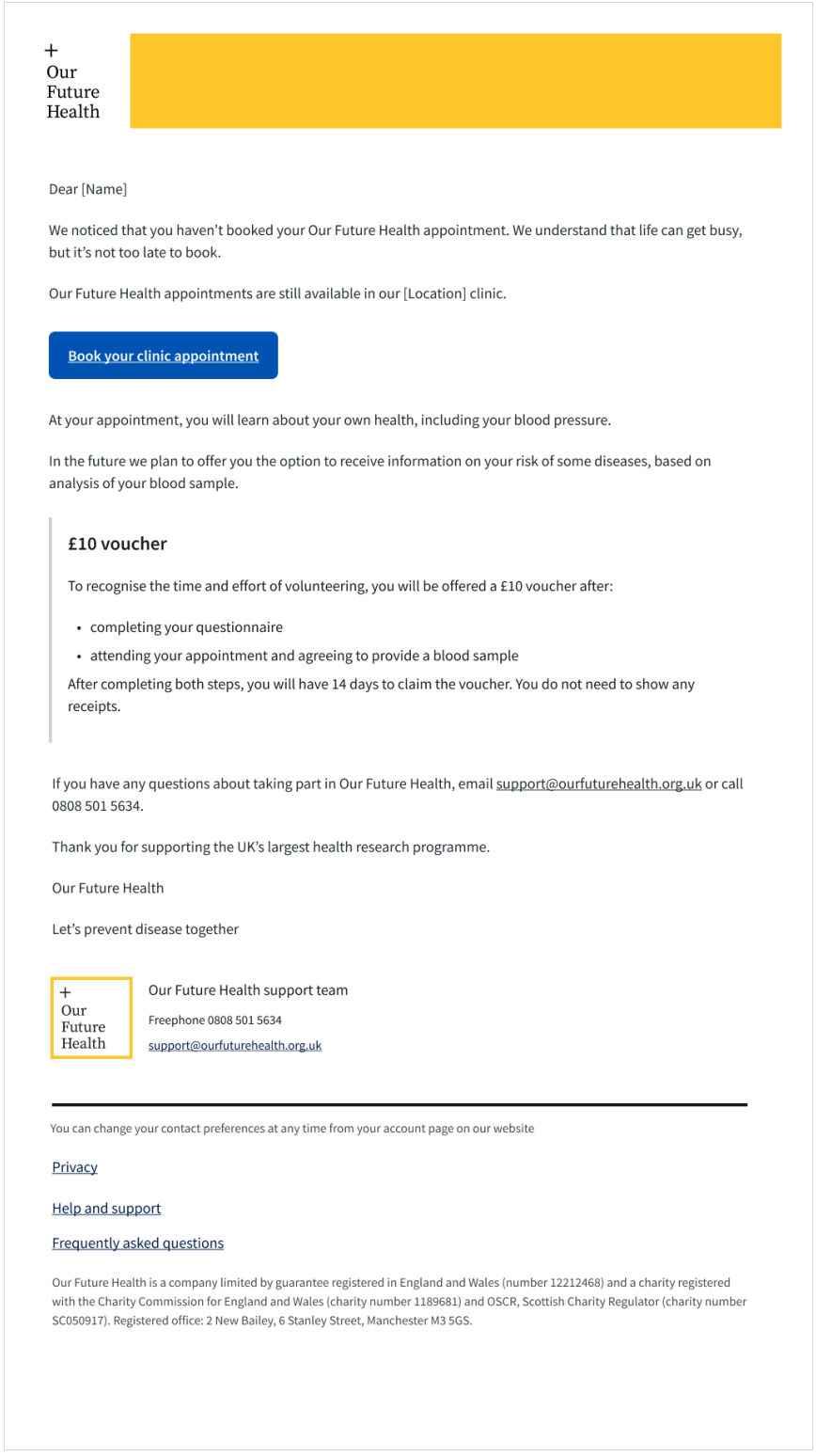
Clinic appointment reminder email

From: Our Future Health
Subject line: Our [Location] clinic has appointments available
Pre-header: Book your clinic appointment today



Dear [Name]

We noticed that you haven't booked your Our Future Health appointment. We understand that life can get busy, but it's not too late to book.

Our Future Health appointments are still available in our [Location] clinic.

Book your clinic appointment

At your appointment, you will learn about your own health, including your blood pressure.

In the future we plan to offer you the option to receive information on your risk of some diseases, based on analysis of your blood sample.

£10 voucher

To recognise the time and effort of volunteering, you will be offered a £10 voucher after:

- completing your questionnaire
- attending your appointment and agreeing to provide a blood sample

After completing both steps, you will have 14 days to claim the voucher. You do not need to show any receipts.

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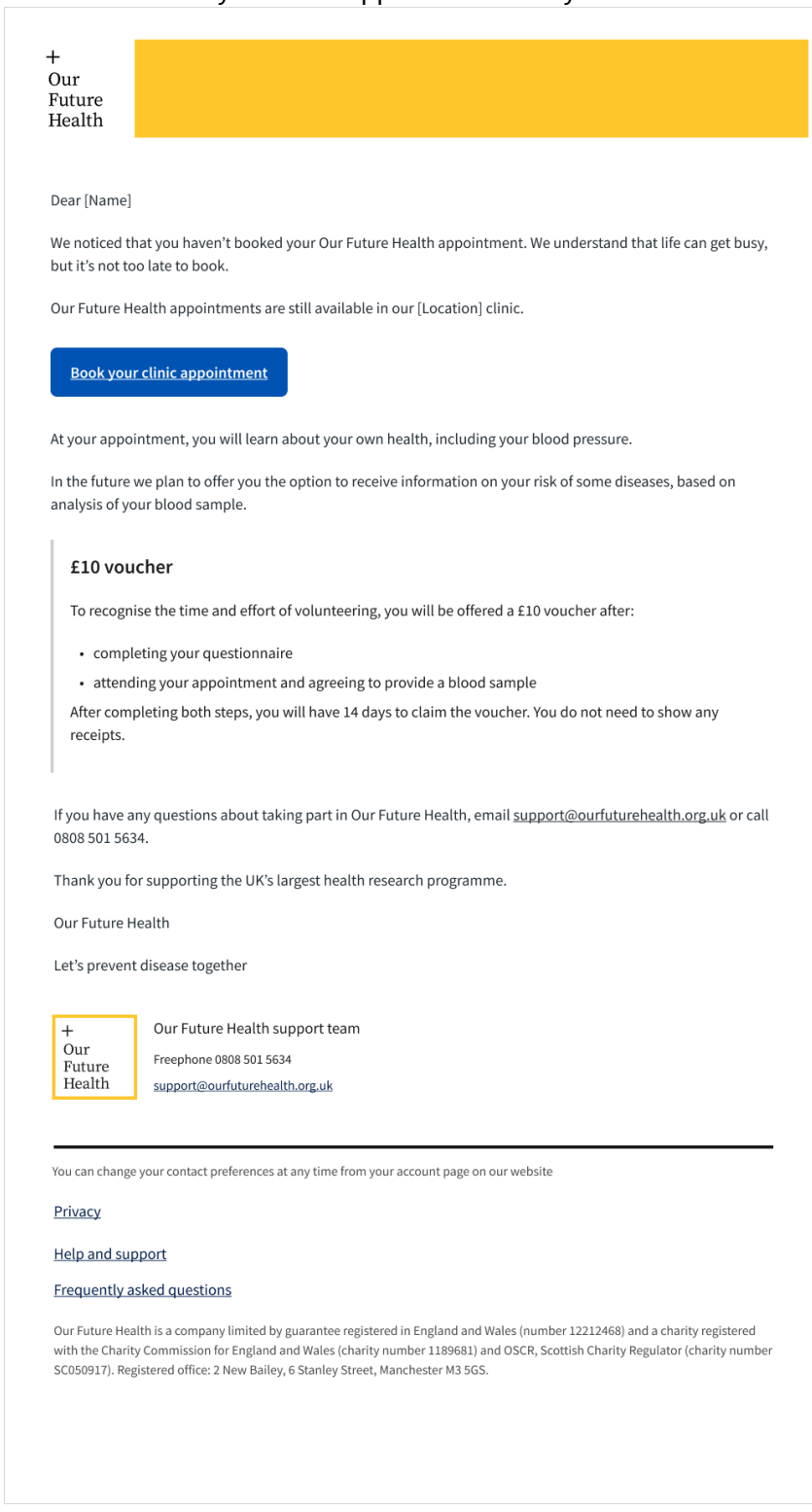
Second appointment reminder email

From: Our Future Health
Subject line: Our [Location] clinic has appointments available
Pre-header: Book your clinic appointment today



Dear [Name]

We noticed that you haven't booked your Our Future Health appointment. We understand that life can get busy, but it's not too late to book.

Our Future Health appointments are still available in our [Location] clinic.

Book your clinic appointment

At your appointment, you will learn about your own health, including your blood pressure.

In the future we plan to offer you the option to receive information on your risk of some diseases, based on analysis of your blood sample.

£10 voucher

To recognise the time and effort of volunteering, you will be offered a £10 voucher after:

- completing your questionnaire
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After completing both steps, you will have 14 days to claim the voucher. You do not need to show any receipts.

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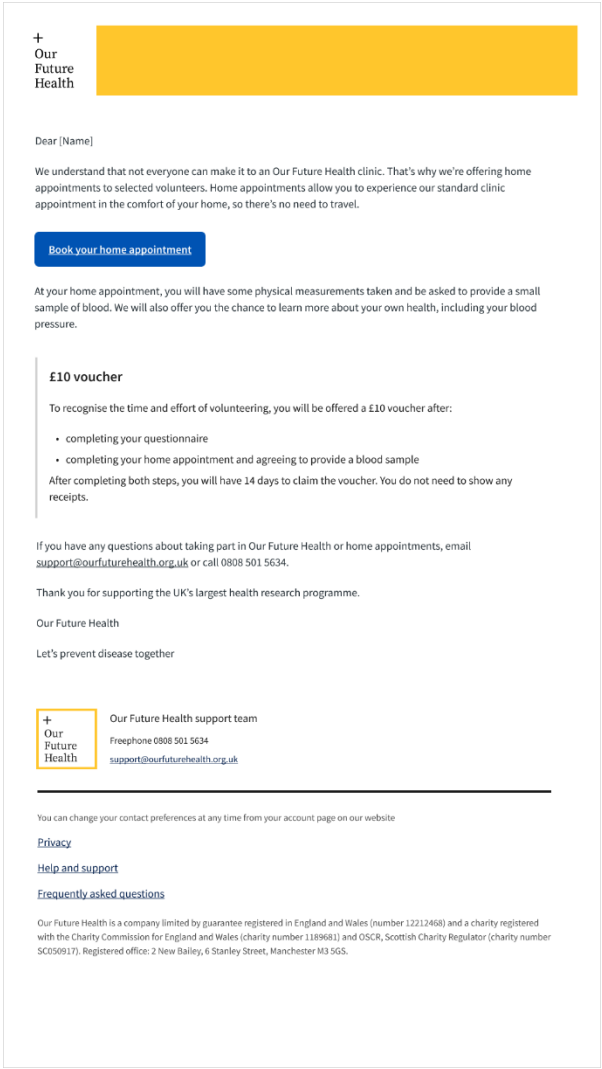
Document 3 – Email home appointment invitation following clinic appointment invite V1.0 12 DEC 2025

From: Our Future Health
Subject line: You're invited to book an Our Future Health home appointment
Pre-header: Learn more about your own health at home



Our Future Health

Dear [Name]

We understand that not everyone can make it to an Our Future Health clinic. That's why we're offering home appointments to selected volunteers. Home appointments allow you to experience our standard clinic appointment in the comfort of your home, so there's no need to travel.

Book your home appointment

At your home appointment, you will have some physical measurements taken and be asked to provide a small sample of blood. We will also offer you the chance to learn more about your own health, including your blood pressure.

£10 voucher

To recognise the time and effort of volunteering, you will be offered a £10 voucher after:

- completing your questionnaire
- completing your home appointment and agreeing to provide a blood sample

After completing both steps, you will have 14 days to claim the voucher. You do not need to show any receipts.

If you have any questions about taking part in Our Future Health or home appointments, email support@ourfuturehealth.org.uk or call 0808 501 5634.

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<u>Document 4</u> Letter invitation template – home appointment V1.0 12 DEC 2025

Dear [Name]

Book an Our Future Health home appointment
We are offering home appointments to people in your area. It means you can experience our standard clinic appointment in the comfort of your own home.
At your home appointment, you will have some physical measurements taken and be asked to provide a small sample of blood. We will also offer you the chance to learn more about your own health, including your blood pressure.
In the future, we plan to offer you the option to receive information on your risk of some diseases, based on analysis of your blood sample.
How to book your home appointment
Log into your Our Future Health account by scanning the QR code or following the link below.
Scan this QR code to book your appointment
Or visit [insert url]
£10 voucher
To recognise the time and effort of volunteering, you will be offered a £10 voucher after:

- completing your home appointment and agreeing to provide a blood sample
- completing your questionnaire

After completing both steps, you will have 14 days to claim the voucher. You do not need to show any receipts.
If you have any questions about taking part in Our Future Health or home appointments, email support@ourfuturehealth.org.uk or call 0808 501 5634.
Thank you. Let's prevent disease together.
[Insert Raghib Ali and John Bell Signatures]

<u>Document 5</u> Letter invitation template – clinic appointment V1.0 12 DEC 2025

Dear [Name]

Book an Our Future Health appointment in your area
You can book an appointment today at our clinic in [location].
At your appointment, you will have some physical measurements taken and be asked to provide a small sample of blood. We will also offer you the chance to learn more about your own health, including your blood pressure.
In the future, we plan to offer you the option to receive information on your risk of some diseases, based on analysis of your blood sample.
How to book your clinic appointment
Log into your Our Future Health account by scanning the QR code or following the link below.
Scan this QR code to book your appointment
Or visit [insert url]
£10 voucher
To recognise the time and effort of volunteering, you will be offered a £10 voucher after:

- completing your appointment and agreeing to provide a blood sample
- completing your questionnaire

After completing both steps, you will have 14 days to claim the voucher. You do not need to show any receipts.

If you have any questions about taking part in Our Future Health or your appointment, email support@ourfuturehealth.org.uk or call 0808 501 5634.

Thank you. Let's prevent disease together.

[Insert Raghib and John Bell Signatures]

<u>Document 6</u> Home appointment FAQs V1.0 12 DEC 2025

When will Our Future Health start offering home appointments?

In early 2026 Our Future Health will begin a trial of a limited number of home appointments in particular areas. This trial will help us to learn more about whether this is a service that we should roll-out more widely in future.

I heard you are starting home appointments, can I book one?

We are trialling home appointments with a small number of existing participants who have signed up but not attended an appointment. At this point, we are only running a small trial of this operation, only participants who have been specifically invited are able to book home appointments.

How many home appointments will you be providing?

Up to 5,000 home appointments will be made available during this trial phase.

I have been invited to book a home appointment, how do I book one?

Home appointments will be delivered on our behalf by Heim Health. Your invitation will have a link to the Heim Health app. On this app you will be able to select a two-hour time window that you would like your appointment to take place in, then a one-hour time slot will be confirmed by 5pm the day before your appointment.

Do I need to have finished my questionnaire before I book a home appointment?

No. If you have been invited to take part in our home appointment pilot, you can proceed to book your appointment whether you have finished your questionnaire yet or not.

What happens at a home appointment?

The home appointments will be very similar to an Our Future Health clinic-based appointment. A trained healthcare professional will visit a participant's home at the time they have booked and take a blood sample and some measurements, exactly as they would in a clinic setting.

How long will the appointment take?

We estimate that these appointments will take around 30 minutes to complete.

Will I get a voucher after completing a home appointment?

Yes, participants who complete a home appointment and their questionnaire will be eligible for a voucher, the same as they would after a clinic appointment.

Why are you doing home appointments?

We are trialling home appointments to see if this helps people who may find it difficult or inconvenient to visit a clinic to join Our Future Health. We hope that this delivers an accessible way for people to take part, particular those who may be under-represented in health research.

Will home appointments roll out further?

This trial will help us to learn whether home appointments might be something that we should roll-out more widely in future. We will communicate with our participants if we decide to offer home appointments more widely to Our Future Health participants.

How will you keep staff members safe in other people's homes?

Heim Health, the organisation that will be delivering the home appointments, has an extensive Lone Worker Policy. This policy provides guidelines that will support trained healthcare professionals to safely deliver home appointments for Our Future Health. These guidelines include risk assessments, precautions and escalation procedures.

Have the staff members doing the appointment passed any safety requirements?

Heim Health, the organisation that will be delivering the home appointments, ensures that all trained healthcare professionals have a DBS check, Fit and Proper Persons check, all relevant skills compliance and ensure that they are fully trained on Heim Health's extensive safeguarding policy.

Can I choose if I have a male or female deliver my home appointment?

Yes, you can select if you would like the appointment to be delivered by a male or female, or if you have no preference.

My appointment is running late/they have not arrived yet, what can I do?

We would recommend using the chat function on the Heim Health app and they will be able to investigate this for you.

Who will be delivering the appointments?

We have appointed Heim Health to deliver these appointments, Home - Heim. They are experienced in delivering home appointments with trained healthcare professionals.

Can I have a clinic appointment instead?

Yes. You are still able to book a clinic appointment by logging in to your Our Future Health account.

Why are you only doing this now/ why wasn't I offered this years ago?

At this point in our programme, we have the resources in place to deliver a trial for home appointments. We believe that this is a good time for our programme to commit to delivering this trial in the best possible way.

Why can't I choose to have a home appointment?

We are trialling home appointments with a small number of existing participants who have signed up but not attended an appointment. At this point, where we are running a small trial of this operation, only participants who have been specifically invited are able to book home appointments. However, this trial will help us to understand whether this is something we should roll-out more widely in future to allow more people to have a home appointment.

How should I prepare for a home appointment?

To ensure that your appointment is safe and successful for you and the trained healthcare professional, please ensure there is a clean, tidy, well lit, private space in your home for the

appointment to take place in. Pets should be secured in a separate room throughout the appointment to support infection control and staff safety.

Children must be supervised by another responsible adult during the appointment. They may remain in the room if they are properly supervised and do not interfere with the appointment or equipment. If supervision is inadequate or the environment becomes unsafe, the appointment will pause until appropriate supervision is in place.

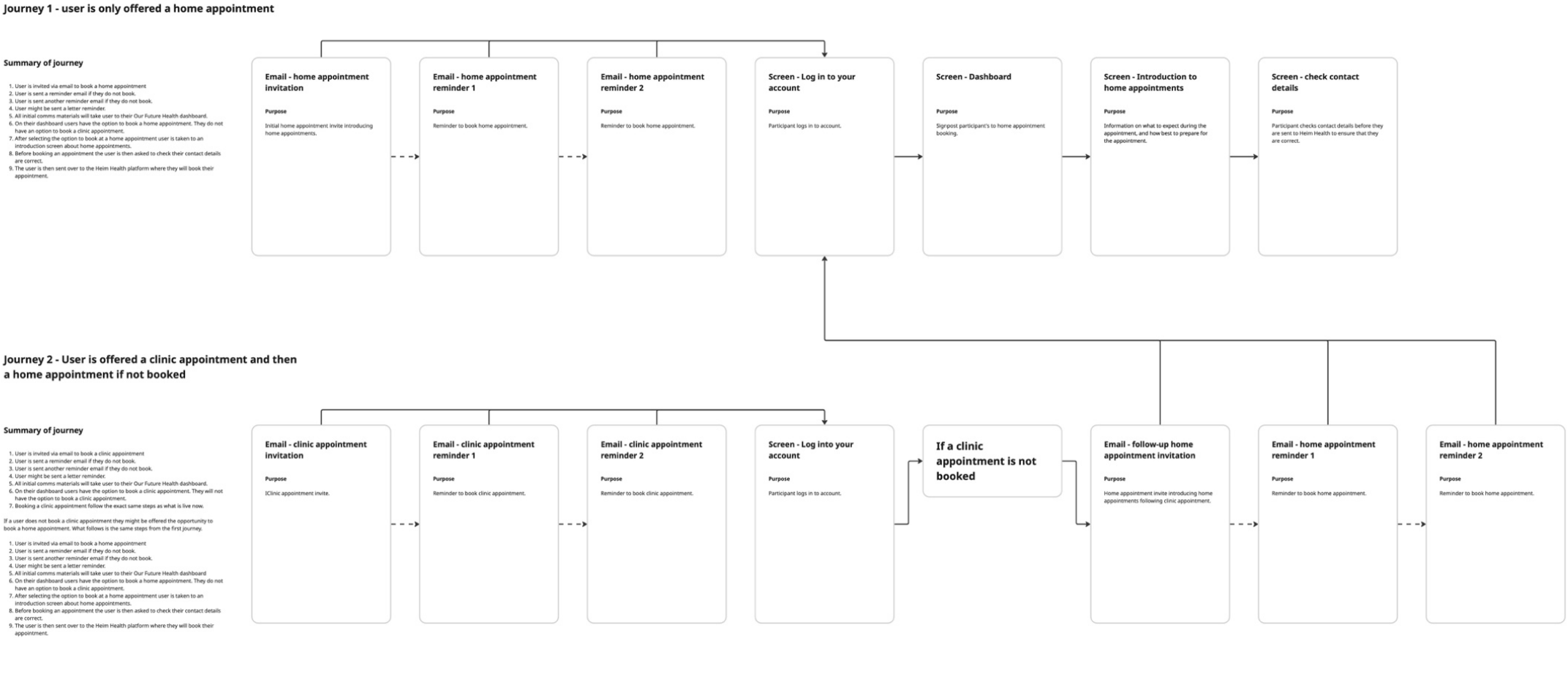
Can my children be present during the appointment?

Children must be supervised by another responsible adult during the appointment. They may remain in the room if they are properly supervised and do not interfere with the appointment or equipment. If supervision is inadequate or the environment becomes unsafe, the appointment will pause until appropriate supervision is in place.

What personal information will Heim health need from me?

Heim Health, who will be delivering home appointments on our behalf, will need participants' name, address, date of birth, email address and mobile phone number to schedule their appointment and deliver and necessary updates about the appointment.

For information only: Participant journey flow



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Our Future Health

Appendix H: Examples of data sets Our Future Health may link to

v1.0

31 DECEMBER 2025

Examples of health-related datasets that Our Future Health may link with, by nation

ENGLAND

Dataset	Description
Adult Psychiatric Morbidity Survey (APMS)	Provides data on the prevalence of both treated and untreated psychiatric disorder in the English adult population (aged 16 and over).
Adult Social Care Client Level Dataset	The Adult Social Care Client Level Data Set (ASCCLDS) collects Adult Social Care activity on requests, reviews, assessments and services at a client level from local authorities in England
Alcohol Dependency Dataset	The Alcohol Dependence dataset is required to monitor the impact and clinical outcomes of alcohol dependence treatment services, as well as the impact on reducing health inequalities. It will also contribute to the evaluation of the programme and drive future policy decisions in terms of further roll out.
Breast and Cosmetic Implant Registry (BCIR)	A data set containing details of individuals who have had breast implant procedures in England, by both NHS and private providers.
Cancer Registration Data (Cohort based studies only)	The Cancer Registration data set contains records of cancer registrations, including the registration date and place, but also information about type of cancer or its site. Records are provided to NHS England by Public Health England, to enable up-to-date data on cancer registrations in cohort data disseminations for which submission of a patient participation list will be required.
Cancer Waiting Times (CWT) data set	The national Cancer Waiting Times (CWT) system allows NHS providers to record data derived from patient care activity. This data can be used to monitor cancer waiting times targets or plan service improvements. As a patient moves through the stages of their treatment pathway data on referrals, treatments and diagnosis are derived from care records locally (decisions on how to collect these data from local systems are made locally).
Civil Registrations of Death	Details of all registered deaths in England and Wales since 1993, as provided by the Office for National Statistics (ONS). It contains details of the registration and basic demographics of the deceased person. This data set may be used in cohort data disseminations, in which case submission of a patient participation list will be required.
Community Services Data Set	A patient-level data set providing information about publicly funded community services for children, young people and adults. These services can include health centres, schools, mental health trusts, and health visiting services.
COVID-19 Electronic Prescribing and Medicines Administration (ePMA) in Secondary Care	Collection of data between 2019 and 2023 sourced from hospital ePMA systems relating to medicines prescribed and administered to patients, to support the response to the COVID-19 pandemic.
COVID-19 Ethnic Category Data Set	NHS England has created this small stand-alone data set by combining GDPPR ethnic category with the latest available ethnicity data in HES to increase coverage in ethnic category data.
COVID-19 General Practice Extraction Service (GPES) Data for Pandemic Planning and Research (GDPPR)	To support the response to the coronavirus outbreak, NHS England has been asked to establish a central collection of GP patient data for COVID-19 purposes for the duration of the coronavirus emergency period.

COVID-19 Hospitalisation in England Surveillance System (CHESS) – also known as Severe Acute Respiratory Infection (SARI-Watch) surveillance system	Data from the United Kingdom Health Security Agency relating to COVID-19 testing, surveillance and hospitalisation, from the SGSS and SARI Watch systems.
COVID-19 Second Generation Surveillance System (SGSS)	Demographic and diagnostic information concerning antigen test reports for COVID-19, in England only. This data set currently includes the first positive results from Pillar 1 (swab testing in PHE and NHS hospital labs).
COVID-19 UK Non-hospital Antigen Testing Results (Pillar 2)	Data related to the second Pillar of the Government's testing programme. It is a collection on antigen swab COVID-19 testing, conducted via drive-through test centres, mobile testing units, satellite test centres, home testing and care home testing.
COVID-19 Vaccination Adverse Reactions	Records relating to patients who have had any adverse reaction to a COVID-19 vaccination, which occur within the first 15 minutes after administration of the vaccine. Scope covers any adverse reactions that occur within the first 15 minutes after administration of the vaccine for vaccination events in England, or events from devolved administrations where this information was subsequently passed to England.
COVID-19 Vaccination Status	Recording individual vaccination events, details of the patients and batch information on the vaccine for anyone vaccinated within England, or those vaccinated in a devolved administration where this information was passed to England.
Demographics (Cohort based studies only)	Demographics data set is derived from the Personal Demographics Service (PDS) for secondary (non-clinical) uses. It includes records of all patients registered with primary care in the NHS in England, Wales and Isle of Man in or after 2004, as well as patients who have utilised the NHS via secondary care in England (only) or patients who, since April 2015, have paid the Immigration Health Surcharge. The Demographics data set is used in cohort data disseminations for which submission of a patient participation list will be required.
Diagnostic Imaging Data Set	Data on NHS-funded diagnostic imaging tests, such as MRI scans and x-rays, extracted from NHS providers' radiological information systems.
Emergency Care Data Set (ECDS)	The data set containing details of all A&E attendances at NHS hospitals in England, including minor injury units and NHS walk-in centres, as well as 24 hour and consultant-led emergency departments. The ECDS will eventually replace the Hospital Episodes Statistics: Accident and Emergency (HES A&E) data set.
General Practice Workforce Data	This quarterly record-level data set includes details about individuals, practices and work being undertaken by GPs, nurses, direct patient care and admin/non-clinical staff working in general practice in England such as job role and hours worked.
Hospital Episode Statistics	HES data is available from four data sets, that is, Hospital Episode Statistics Admitted Patient Care (HES APC), Hospital Episode Statistics Critical Care (HES Critical Care), Hospital Episode Statistics Outpatients (HES OP), and Hospital Episode Statistics Accident and Emergency (HES A&E). For emergency care data from 1 April 2020, the Emergency Care Data Set (ECDS) should be requested.

Improving Access to Psychological Therapies (IAPT)	A patient-level, secondary-uses data set, which provides nationally consistent and comparable person-based information about people referred to IAPT services for depression and anxiety. It contains information extracted or derived from local information systems within NHS commissioned services across England. NHS England national mental health team recently announced a new name for IAPT services: NHS Talking Therapies.
Maternity Services Data Set	A patient-level data set that captures information about activity carried out by maternity services, relating to a mother and baby(s).
Medicines Dispensed in Primary Care (NHSBSA)	A data set containing records of medicines dispensed in primary care settings, such as general practice, community clinics, dentists and nursing services.
Mental Health data (MHSDS)	Includes data about adults in receipt of NHS funded specialist, secondary mental health or learning disability services.
Mental Health of Children and Young People (MHCYP)	This survey series provides England's best source of data on trends in child mental health. The latest survey, conducted in 2017, with a 3 year follow up survey in July 2020, is now available to request from DARS.
National Diabetes Audit	One of the largest annual clinical audits in the world. It measures the effectiveness of diabetes healthcare against NICE Clinical Guidelines and NICE Quality Standards in England and Wales, for both primary and secondary care.
NDRS Cancer Consolidated Data Set	This is a new product which consolidates three NDRS data sets; National Cancer Registrations, Cancer Pathways and Rapid Cancer Registrations.
NDRS Cancer Registration (pre-1995)	This data set contains information about patients diagnosed with a registerable tumour in the calendar years 1985 to 1994. It is very limited and applicants wishing to process this data must first discuss their requirements with the NDRS team to confirm whether the data set can be used for their request.
NDRS Lung Cancer Data Audit (LUCADA)	This audit looks at the care delivered during referral, diagnosis, treatment and outcomes for people diagnosed with lung cancer and mesothelioma.
NDRS National Cancer Diagnosis Audit (NCDA)	This data set contains information from clinical audits carried out at specific points in time, focusing on the diagnostic pathway for patients diagnosed with cancer.
NDRS National Cancer Patient Experience Survey (CPES)	CPES was commissioned by NHS England to collect information via a survey directly from patients with a primary diagnosis of cancer about their experiences. The survey aims to collect information from patients about their experience of the cancer journey from their initial GP visit prior to diagnosis, through diagnosis and treatment and to the ongoing management of their cancer
NDRS National Lung Cancer Audit (NLCA)	This audit data set follows on from the LUCADA data, beginning in 2015.
NDRS National Radiotherapy Data Set (RTDS)	This data set contains information about patients diagnosed with cancer in the calendar year 1995 onwards, with radiotherapy treatment details available from 1 April 2009 onwards.
NDRS Quality of Life of Cancer Survivors in England: (Breast, Colorectal, Prostate, Non-Hodgkin's Lymphoma)	This data set is from a pilot of Patient Reported Outcome Measures (PROMs) data collected in 2011-12, based on a questionnaire distributed to a representative sample of patients with four different tumour types.

NDRS Quality of Life of Colorectal Cancer Survivors in England: Patient Reported Outcome Measures Survey (PROMS)	This data set contains responses to a questionnaire distributed to colorectal cancer patients in January 2013, with over 34,000 responses collected.
NDRS Somatic Molecular Data Set	This data set begins in 2016 and is ongoing. It contains somatic molecular testing data collected directly from molecular diagnostics laboratories in England. The data covers tests for genetic mutations occurring only in the tumour. Data is received from molecular diagnostic laboratories in England. The data set includes information about the number, type and date of tests for each gene tested.
NDRS Systemic Anti-Cancer Therapy data set (SACT)	This data set contains information about patients treated with chemotherapy from April 2012 onward (data prior to July 2014 has some completeness issues). It contains clinical details about anti-cancer therapies and includes information such as the date when a decision to treat was made, treatment cycle dates, and treatment regimen outcome.
Personal Social Services – Adult Social Care Survey (ASCS)	An annual national survey, conducted by Councils with Adult Social Services Responsibilities (CASSRs), gathering information from a sample of services users; aged 18 and over; in receipt of long-term support services funded or managed by social services.
Personal Social Services – Survey of Adult Carers in England (SACE)	A biennial survey, conducted by Councils with Adult Social Services Responsibilities (CASSRs), collecting information from and about adult carers, caring for a person aged 18 or over, who have been assessed or reviewed by social services (or where the cared-for person has received respite or another form of carer support).

SCOTLAND

Dataset	Description
Brain Health Data Pilot	The University of Edinburgh and Public Health Scotland are developing a Brain Health Data Pilot (often BHDP) that links brain scans with other health data collected by NHS Scotland. The combined data makes it easier for researchers to study dementia and other diseases affecting the brain.
COVID19 in Pregnancy in Scotland (COPS)	The COPS study is a sub study to Early Pandemic Evaluation and Enhanced Surveillance of COVID-19 (EAVE II) The cohort includes all pregnant women who could have potentially been exposed to SARS-2-CoV (from March 2020) or COVID-19 vaccination.
COVID-19 Tests	Contains the results of all PCR / Antigen Tests / LFTs reported to Public Health Scotland by NHS Scotland and UK Government Regional Testing Laboratories and home testing kits
General Acute Inpatient and Day Case - Scottish Morbidity Record (SMR01)	The General / Acute and Inpatient Day Case dataset (SMR01) collects episode level data on hospital inpatient and day case discharges from acute specialities from hospitals in Scotland.
GP Out of Hours	NHS Boards provide Primary Care OOH services for patients when their registered GP Practice is closed.
Hospital Electronic Prescribing and Medicines Administration System (HEPMA)	The HEPMA data resource captures and compiles information on all medicines prescribed within the ward/hospital covered by the system; this includes medicine name, formulation, strength, dose, route, and frequency of administration, and dates and times of prescribing. In addition, the HEPMA dataset also captures information on medicines administration, including dates and time of administration.
Maternity Inpatient and Day Case - Scottish Morbidity Record (SMR02)	The Maternity Inpatient and Day Case dataset (SMR02) collects episode level data every time a mother goes in for an obstetric event (this can be an antenatal, delivery or postnatal episode).
Mental Health Inpatient and Day Case - Scottish Morbidity Record (SMR04)	The Mental Health Inpatient and Day Case dataset (SMR04) collects episode level data on patients who are receiving care at psychiatric hospitals at the point of both admission and discharge.
National Records of Scotland (NRS) - Deaths Data	All registrations to the National Records of Scotland of deaths. Please note that cause of death information for the previous year is provisional and is only finalised in August of the subsequent year.
Outpatient Appointments and Attendances - Scottish Morbidity Record (SMR00)	The Outpatients (SMR00) dataset collects episode level data from patients on new and follow up appointments at outpatient clinics in all specialities (except A&E and Genito-Urinary Medicine).
Prescribing Information System (PIS)	The Prescribing Information System (PIS) is the definitive data source for all prescribing relating to all medicines and their costs that are prescribed and dispensed in the community in Scotland.
RAPID (Hospital Stay Level Data)	The Rapid Preliminary Inpatient Data (RAPID) dataset contains the underlying admissions data which is used by System Watch. It enables access to the hospital admissions data submitted in its unprocessed state e.g. it does not contain predictions.

Scotland Accident and Emergency	This dataset includes data items from the national A&E DataMart, the Community Health Index (CHI) database and derived chronic conditions items based on linked hospital admissions data
Scottish Cancer Registry (SMR06)	Public Health Scotland is responsible for the collection of information on Scottish residents when they are diagnosed with malignant (and some benign) tumours.
Scottish Covid-19 Vaccination Data	This dataset contains COVID-19 Vaccination events in Scotland since December 2020. This includes information such as eligibility cohort, date of vaccination, and vaccination product.
Scottish Medical Imaging (SMI) Research Dataset	Contains pseudo-anonymised and linkable clinical imaging data from the National Picture Archiving and Communication System (NPACS).
SICSAG Daily (Scottish Intensive Care Audit Group)	The Scottish Intensive Care Society Audit Group (SICSAG) has maintained a national database of patients admitted to adult general Intensive Care Units (ICU) in Scotland since 1995. Each line relates to a day of stay in critical care.
SICSAG Episodes (Scottish Intensive Care Audit Group)	The Scottish Intensive Care Society Audit Group (SICSAG) has maintained a national database of patients admitted to adult general Intensive Care Units (ICU) in Scotland since 1995. Each line relates to an ‘episode of care’ in critical care
Unscheduled Care Data Mart	The data mart links data from (NHS 24, Scottish Ambulance Service, Out of Hours Primary Care, Emergency Department, Acute, Mental Health and Deaths) to show a Continuous Unscheduled Care Pathway (CUP) for records with a valid CHI number.
Vaccinations	The Vaccinations dataset began in December 2020 with the collection of COVID-19 vaccinations data from the Turas Vaccine Management Tool (VMT) and GPIT systems. It has since begun collecting vaccination data (as recorded in VMT) for: cholera herpes zoster (shingles) flu pertussis pneumococcal typhoid fever hepatitis A Respiratory syncytial virus infection

WALES

Dataset	Description
Annual District Death Extract (ADDE)	Register of all deaths relating to Welsh residents, including those that died out of Wales.
Antiviral Dataset (AVDS)	The Antiviral Dataset contains details of Antiviral and Monoclonal Antibody drugs prescribed to patients to treat Covid-19
Asymptomatic COVID19 in Education Cohort (ACEC)	At the start of the 2020/2021 academic year some education providers established in-house testing facilities.These specialised sites were created in response to the sharp increase in asymptomatic COVID-19 infection rates among the student population.
Bowel Screening Wales (SBSW)	NHS Screening Services - Bowel Screening Data. The aim of the bowel screening programme is to identify cancer early when treatment is more likely to be successful and also remove precancerous growths.
Breast Test Wales (SBTW)	Screening Services - Breast Screening Data. The aim of the breast screening programme is to reduce mortality from breast cancer. Women aged 50 to 70 who are resident in Wales, and registered with a General Practitioner, are invited for a mammogram.
Cancer Network Information System (CNIS / CANISC)	Cancer Network Information System includes multidisciplinary team diagnosis, proposed treatments, and a system-generated summary of the patient's cancer record.
Care Home Dataset (CARE)	This database contains residential and geographical information data about care homes in Wales.
Cervical Screening Wales (SCSW)	Screening Services - Cervical Screening Data. The cervical screening programme has 3 main aims: Reduce the number of cases of cervical cancer (incidence), deaths from cervical cancer (mortality), and the effects of cancer or cancer treatments on health
Covid Lateral Flow Test (CVLF) - Static	Dataset no longer updated after 29/02/2024. The test for people without coronavirus symptoms is called a rapid lateral flow test. Rapid lateral flow tests help to find cases in people who may have no symptoms but are still infectious and can give the virus to others.
Covid Vaccination Dataset (CVVD)	This dataset covers all patients and vaccinations administered or planned for Covid-19, in or funded by the NHS.
COVID-19 Test Results (PATD)	Test results for COVID-19 tests. Details tests, outcomes, and some clinically relevant patient information about COVID-19 Tests in Wales.
COVID-19 Test Trace and Protect (CTTP) - Static	This dataset details the Covid-19 Test Trace and Protect programme implemented across various parts of the UK. Dataset is no longer updated after 31/05/2024.
Critical Care Dataset (CCDS)	Contains a critical care specific fields giving greater granularity for patients under critical care.
Diabetic Eye Screening Wales (DESW)	Diabetic Eye Screening Wales (DESW) is an all Wales service designed to detect sight threatening diabetic retinopathy at an early stage before visual loss occurs, ensuring early treatment and preventing loss of vision in 70-90% of people with sight threat
Emergency Department Dataset (EDDS)	Attendance and clinical information for all Accident and Emergency attendances.
Maternity Indicators Dataset (MIDS)	The Maternity Indicators Data Set captures data relating to the woman at initial assessment and to mother and baby (or babies) for all births. This relates to initial assessment and birth activity undertaken in Wales only.

Outpatient Database for Wales (OPDW)	Attendance information for all hospital outpatient appointments.
Outpatient Database for Wales (OPDW)	Attendance information for all hospital outpatient appointments.
Outpatient Referral (OPRD)	Data on Outpatient referrals from primary care.
Outpatient Referral (OPRD)	Data on Outpatient referrals from primary care.
Patient Episode Dataset for Wales (PEDW)	The database contains all inpatient and day case activity undertaken in NHS Wales plus data on Welsh residents treated in English Trusts.
Radiotherapy Dataset (RTDS)	The Radiotherapy Data Set (RTDS) allows for the routine collection of clinically and managerially relevant ACTIVITY data from Radiotherapy facilities, in order to commission or monitor Radiotherapy Services in an evidence-based manner.
Radiotherapy Dataset (RTDS)	The Radiotherapy Data Set (RTDS) allows for the routine collection of clinically and managerially relevant ACTIVITY data from Radiotherapy facilities, in order to commission or monitor Radiotherapy Services in an evidence-based manner.
SAIL Dementia e-Cohort (SDEC)	This dataset is a population-based electronic cohort containing health-related information on people with and without diagnosed dementia. It was developed by applying coding algorithms to linked routinely-collected datasets.
Systemic Anti-Cancer Therapy Dataset (SACT)	Dataset includes all patients receiving systemic anti-cancer therapies in or funded by the NHS. This includes adult and paediatric cancer patients receiving systemic anti-cancer treatment, in acute inpatient, day-case and outpatient settings.
UK Cystic Fibrosis Registry (CYFI)	The UK Cystic Fibrosis Registry is a national, secure, centralized database sponsored and managed by the Cystic Fibrosis Trust, with UK National Health Service (NHS) research ethics approval and consent from each person for whom data are collected.
Welsh Cancer Intelligence and Surveillance Unit (WCSU)	The Welsh Cancer Intelligence & Surveillance Unit (WCISU) is the National Cancer Registry for Wales and its primary role is to record, store and report on all incidence of cancer for the resident population of Wales wherever they are treated.
Welsh Demographic Service Dataset (WDSD)	Register of all individuals registered with a Welsh GP, includes individuals anonymised address and practice history.
Welsh Longitudinal General Practice Dataset (WLGP) - Welsh Primary Care	Attendance and clinical information for all general practice interactions: includes patients symptoms, investigations, diagnoses, prescribed medication and referrals to tertiary care.
Welsh Results Reports Service (WRRS)	The Welsh Results Reporting Service (WRRS) allows health care professionals across Wales to access laboratory results for pathology requests and any other associated results across all health boards in Wales, wherever they had their test taken.

N IRELAND

Dataset	Description
Enhanced Prescribing Database	This is a record of primary care prescriptions that are submitted by community pharmacies in Northern Ireland to the Business Service Organisation for payment.
Patient Medical Card Registration (NI)	Record of patients registered with a GP practice in Northern Ireland. The data is sourced from the National Health Application and Infrastructure Services (NHAIS) system and includes information relating to a patient's age, gender, postcode & GP practice.
SARS-CoV-2 viral sequencing data (COG-UK data) - Lineage/Variant Data - NI	Data containing COVID-19 lineages and mutations.
COVID-19 Vaccination	Details of completed (processed) COVID-19 vaccinations
NICOLA (Northern Ireland Cohort for the Longitudinal study of Ageing)	The NICOLA (Northern Ireland Cohort for the Longitudinal Study of Ageing) is a large-scale research project aimed at understanding the social, economic, and health factors that influence aging in Northern Ireland. The study follows a diverse group of older adults over time, collecting detailed data on their physical health, cognitive function, lifestyle, and socio-economic conditions.
Northern Ireland Biobank (NIB)	Northern Ireland Biobank was established in 2010 to collect, store and distribute human samples for translational research and is primarily funded by the Northern Ireland Health and Social Care Research & Development Division of the Public Health Agency.
Rural-Urban classification for CPRD Aurum	The measures available for patient (England only) and practice postcode are: 2011 England and Wales Rural-Urban classification; 2015 Northern Ireland Rural-Urban classification; 2016 Scottish Rural-Urban classification.

Geographical Datasets

Annual averages of NO2 and PM2.5

Greenness/green space

Noise pollution

Access to Heathy Assets and Hazards (Retail, Health Services, Air Quality, Greenspace)

Energy Performance Certificates

CORE GEO (Deprivation, Population density, Urban/Rural classification