ISCF Accelerating Detection of Disease Challenge

Final Evaluation Report

UKRI

Ipsos

technopolis group

Contents

Acronyms used in the report

ADD – Accelerating Detection of Disease

AISI – Artificial Intelligence Safety Institute

BMI – Body Mass Index

BMJ – British Medical Journal

CRM – Customer Relationship Management

cTRE – certified Trusted Research Environment

DHSC – Department of Health and Social Care

DSIT – Department for Science, Innovation and Technology

FCM – Founding Charity Member

FIM – Founding Industry Member

GFA – Grant Funding Agreement

GP – General Practitioner

HDR UK – Health Data Research UK

HMG – His Majesty's Government

IEQ – Impact Evaluation Question

IM – Industry Member

IMD – Index of Multiple Deprivation

ISO – International Organization for Standardization

ISCF – Industrial Strategy Challenge Fund

M&A – Mergers and Acquisitions

MedTech – Medical Technology

MHRA – Medicines and Healthcare products Regulatory Agency

MRC – Medical Research Council

NDL – National Data Library

NHS – National Health Service

NHSBT – NHS Blood and Transplant

NIHR – National Institute for Health and Care Research

NPL – Non-personalised Letter(s)

OLS – The Office for Life Sciences

OPEX – Operating Expenditure

PEQ – Process Evaluation Question

PPIE – Public and Participant Involvement and Engagement

QEP – Questionnaire and Engagement Platform

R&D – Research and Development

SME – Small and Medium-sized Enterprise

SMS – Short Message Service

ToC – Theory of Change

TRE – Trusted Research Environment

UKRI – UK Research and Innovation

VC – Venture Capital

Executive Summary

Accelerating Detection of Disease Challenge

The Accelerating Detection of Disease (ADD) Challenge ('the Challenge') formed part of the UK Government's Industrial Strategy to drive economic and social benefits through research and innovation. Its core objective was to transform the prevention, early diagnosis, and treatment of chronic diseases by generating and using biological and digital data alongside advanced analytical methods. The Challenge was to establish a world leading research resource by recruiting at least 1.33 million participants by March 2025, with a longer ambition to expand to 5 million. This cohort, designed to be representative of the UK adult population, is recruited and managed by Our Future Health, an independent organisation created specifically for this purpose. Our Future Health intends to track participants' health over time, with consent for linkage to their medical records, making this available as a resource to researchers.

The Challenge received **£79 million** in funding from UK Research and Innovation (UKRI), alongside an additional **£68 million** from the Office for Life Sciences (OLS) via the Department for Science, Innovation and Technology (DSIT). By the end of the Challenge, a further **£131.5 million** in co-funding from industry and charity partners (out of a total **£184.5 million** they committed to provide, contingent on meeting recruitment milestones) was received. After the Challenge ended, the programme has continued under the auspices of OLS and with monitoring from the Medical Research Council (MRC) in UKRI.

Overview of the evaluation

Ipsos and Technopolis were commissioned by UKRI in 2022 to deliver a process and impact evaluation of the Challenge. The evaluation assessed the effectiveness of UKRI and Our Future Health in progressing towards and achieving the Challenge's objectives since its launch in 2019, and provided feedback on programme delivery. This final evaluation report summarises findings across this multi-year study, covering both the impact achieved by the Challenge and Our Future Health, as well as the processes set up for delivery of the Challenge. The data cut-off for this study was 31 March 2025.

Progress to date

The tables below provide a summary of progress against the Challenge outcomes and impact (expected to be met by 2025 or up to 2030 and beyond) and evidence to answer the evaluation questions agreed with UKRI. To ensure this evaluation report assesses the progress of the ADD Challenge consistently, further detail on each of these aspects is provided in the main report and annexes.

Summary of progress against the Challenge Theory of Change

Outcomes and Impact	Progress
Progress against outcomes for 2025 - the end of the ADD Challenge	
▪ **Representative, cohort resource of 1.33 million participants, characterised and consented for recontact**	▪ Our Future Health has successfully met the objective set by the Challenge to recruit over 1.33 million participants. This is a significant achievement given the scale and complexity of recruiting such a large cohort. The resource has, however, not currently met the objective set by the Challenge to be fully representative of the UK population. This can be inferred by comparing the cohort's demographic breakdown with the same breakdown in the 2021 and 2022 Censuses for each country in the UK, which Our Future Health set as a benchmark to report on progress. ▪ Our Future Health has demonstrated a moderate level of progress towards establishing representativeness. To achieve this, it has conducted a variety of studies and community engagement activities. However, the cohort is not representative of the UK population in relation to age, index of multiple deprivation (IMD) and ethnicity. Our Future Health used the Censuses for each UK nation as a practical benchmark to monitor progress (see **Annex 6**: Cohort representativeness data for the full breakdown of targets and deviations). When using this benchmark: ▪ Older age groups are overrepresented, whereas younger age groups are underrepresented. ▪ Participation from individuals from the most deprived areas is underrepresented. The share of participants who live in areas with the highest deprivation is half of what it should be. ▪ Some ethnic groups are underrepresented compared to the target (e.g. Bangladeshi, Pakistani, African and Caribbean ethnic groups.
▪ **Initiation of studies using this resource to** - **validate biomarkers** - **conduct risk stratification / detection / treatment / prevention** - **research novel products and services**	▪ A small but growing number of studies using Our Future Health data have started. 37 studies have been approved by the Access Board, of which 24 are active by March 2025. It is currently too early to assess the outcomes of these studies in terms of validation of biomarkers, risk stratification or the development of novel products and services. Furthermore, protocols to enable recontact and sample access remain under development with two pilot studies enabling recontact planned to commence in 25/26 illustrating Our Future Health's intent to operationalise recontact functionality in practice.
▪ **Health and disease insights available to participants through participant feedback routes**	▪ Our Future Health is still making progress towards developing a research resource which will, in future, be able to drive improvements in population health outcomes. To date, the feedback and recontact systems are still being developed. While point-of-care feedback for cholesterol was previously provided to participants attending a recruitment appointment, this was withdrawn by 31 December 2024 due to initial levels of pressure on primary care and participant concern generated by test results. A wider range of health insights are not yet available to participants, beyond blood pressure and BMI at the initial appointment. It is too early to measure the impact of this activity, both in relation to the value it adds to Our Future Health data and to participants.
▪ **Increased UK participation in global clinical studies through efficient participation recontact routes**	▪ Our Future Health has established itself as one of the largest health research programmes in the world by number of participants. Generally, there has been positive feedback regarding the recruitment journey and the importance of participating in the programme. Our Future Health has reached its UKRI milestone and has recruited over 1.33 million participants, with positive feedback reported on the current recruitment processes. ▪ However, it is too early to assess outcomes and impacts, such as increased UK participation in global clinical studies or improved public perception regarding participating in health research programmes. At present, studies using the resource are

	restricted to data use projects. For example, observational analysis of de-identified cohort data within the Trusted Research Environment (TRE), focused on identifying biomarkers or disease risk. There is currently no participant enrolment into interventional studies or international trial arms. Enabling these studies will require Our Future Health to complete work on participant recontact.
▪ **Increased technical and research capabilities in using large datasets, combining genomic data with multiple different datasets among resource users**	▪ Our Future Health's TRE is operational, with 24 studies active in the TRE by 31 March 2025, with growing researcher engagement (around 900 accounts with 529 registered researchers). Data linkage with NHS England secondary care data is progressing, although primary care linkage remains challenging. Linkages in the devolved nations face delays due to complex governance and approval processes in each nation. Genotyping targets were met within a month of the Challenge's end, with 1.27 million participants genotyped. Our Future Health has ensured that genomic data is regularly made available in the TRE through a series of updates. In addition to this, the TRE also covers data such as participant demographic information, questionnaire data covering personal and household circumstances and lifestyle; secondary care records from the NHS in England; cancer treatment and diagnosis; as well as death registration and mortality data. It currently excludes primary care data and health records data in the devolved administrations. ▪ The TRE offers secure data access and analysis tools. However, the public browser, which will provide prospective users with greater visibility of what they can test or discover using data in the resource, is still pending development. The focus in 2025 has shifted to imputed genetic data.
▪ **New and enhanced research collaborations promoted through shared use of depletable resources**	▪ Our Future Health's TRE supports 24 active studies as of the end of March, indicating growing research engagement. While still early, this demonstrates increasing use of the resource and the potential for new and enhanced research collaborations.
▪ **Resource and its users attract additional non-Government funding and investment**	▪ Our Future Health has secured additional co-funding from industry and charity partners with £154 million committed from Founding Industry Members (FIMs), £12.5 million from a newly signed Industry Member (IM), and £18 million from Founding Charity Members (FCMs), totalling **£184.5 million**. While Our Future Health has reached the 1.33 million participants target, it had to carefully manage its cashflow given uncertainties about post-Challenge funding. This included slowing down recruitment activity, financial re-profiling and finely balancing competing priorities.
▪ **Viable business model developed**	▪ Our Future Health has established a pricing model for researchers to access and analyse data in studies. However, this model is being tested and is subject to price changes. A long-term model for pricing, including for sample access and recontact, is still under development and ongoing negotiations with additional industry, charity and philanthropy partners are still underway. ▪ Our Future Health remains reliant on government funding. As confirmed in the Life Sciences Sector Plan, it has sought and will receive £58 million in 2025/26 and up to £354 million in further government funding to operate between 2026 and 2030.
Progress against outcomes for 2030 and beyond – after the end of the ADD Challenge	

▪ **Identification of novel biomarkers for a range of conditions for a diverse population**
▪ **Discovery of novel research, products and services with potential to change healthcare pathways**
▪ **Our Future Health Cohort becomes a globally recognised resource and is used nationally and internationally for studies**
▪ **Resource and its users attract international investment, and Our Future**
	▪ As no active studies have been completed at the time of the evaluation study and given that these outcomes are expected to emerge by 2030 and beyond, an early assessment of these outcomes needs to consider early, emerging signs of progress:
	  ▪ It is too early to assess whether Our Future Health is contributing to the identification of novel biomarkers, novel research projects and services. These outcomes rely on future research and approved studies taking place. Achieving these outcomes in full will also require Our Future Health to launch recontact studies and research using samples. Current approved studies do set objectives to identify novel biomarkers; however, they currently only analyse data in the TRE. Approved studies so far cover a range of conditions including rare diseases, cardiometabolic disorders, neurological disorders and cancer however results from these studies have not yet emerged.
	  ▪ Our Future Health is already one of the largest and most representative global research programmes. Of the 529 approved researchers in the TRE, 168 (32%) are overseas users with several based in Europe or North America, with further interest demonstrated by prospective users in both the UK and internationally.

Health is a credible and sustainable commercial entity	▪ Our Future Health has attracted initial co-funding from industry and charity partners, however, its long term funding and operating model beyond current government funding is uncertain. The studies undertaken within the resource are not yet mature enough to influence major follow-on investment decisions within each researcher's wider organisation. Of the 15 FIMs, which include several international firms, 8 have begun to conduct their first research project using the resource. However, these are exploratory, use participant data only and are not complete. At this early stage, the research underway has not led to changes to their investment strategies or resource allocations.
Impact beyond 2030 – Health	
▪ **Improvement in population health outcomes through earlier diagnosis and intervention** ▪ **Improved public awareness of risk factors for disease** ▪ **Novel research, products and services inform changes in healthcare pathways and enable new, earlier and tailored treatments**	▪ It is too early to observe any improvement in population health outcomes, which will require additional users of the resource and approved studies to research new methods for early diagnosis and treatment. Initial point-of-care feedback was previously provided on cholesterol and commentaries investigating the efficacy of the cholesterol point of care testing have been published. Blood pressure feedback is provided at the blood collection appointment. However, there is no available data on behaviour change or broader public awareness impact. Several aspects of the resource, such as participant feedback platform and data linkage are still being implemented. It is therefore too early to assess impact, such as initiation of studies, health and disease insights, increased UK participation in global clinical studies and the development of novel research products and services. Modelling future health impacts would need to rely on selection of specific clinical pathways, but the resource is disease agnostic and research using it is not sufficiently advanced to identify priority disease targets.
Impact beyond 2030- Social	
▪ **Enabling a greater proportion of clinical studies to include underrepresented populations and thereby aim to reduce health inequalities experienced by these groups** ▪ **Enhanced technical and research capabilities in dealing with large multi-omics datasets across UK businesses and research organisations** ▪ **Improved public perception of benefits of data sharing and involvement in research**	▪ Given that these outcomes are expected to emerge by 2030 and beyond, an early assessment of them needs to consider early, emerging signs of progress: ▪ It is too early to assess whether clinical studies are including underrepresented populations, as this requires Our Future Health to develop recontact protocols to enable clinical studies to take place. There are, however, some initial positive outcomes which indicate progress can be made towards this. For example, Our Future Health has recruited over 130,000 participants from non-white ethnic backgrounds which is more than any previous resource based in the UK, which demonstrates the higher potential for clinical studies to include under-represented groups. ▪ There are a growing number of users of the TRE including active researchers. The resource provides access to genotyped data and other participant information including secondary healthcare records and questionnaire responses. However, these will not yet be representative of all studies to be undertaken through the resource. ▪ Early participants recruited into Our Future Health have provided positive feedback about their experience, and Our Future Health is making progress towards developing a resource with representation from all demographic groups and communities. ▪ There is further work Our Future Health will need to conduct to understand the impact on public perception. While Our Future Health has established multiple initiatives to engage the public, such as newsletters and a public advisory board, and shares details about how it uses participant data online, assessment of public attitudes is infrequent and measurement of the impact of these methods is limited.

Impact beyond 2030- Economic	
▪ **Economic growth in the UK diagnostics, risk prediction and precision medicine sectors**	▪ It is currently too early to assess the direct impact of the Challenge on investment and economic growth within the broader life sciences sector. While there are observable amounts of investment in the FIMs and FCMs in the UK, it is not yet possible to attribute this to investment in studies or developments that have taken place as a result of Our Future Health. This is a longer term benefit expected from the resource. Studies using Our Future Health resource will need to produce initial results which are promising for enabling further R&D. These results will in turn need to then stimulate follow-on investment within companies.

Key findings for each evaluation question

Evaluation question Key: IEQ – Impact Evaluation Question, PEQ – Process Evaluation Question	Findings of the evaluation
IEQ1: To what extent has the ADD Challenge established a novel R&D resource of 1.33 million participants, which is representative of the UK population?	▪ Our Future Health has successfully recruited over 1.33 million participants, placing it among the largest health research resources internationally, and it has progressed in establishing a novel Research and Development (R&D) resource. This follows some initial delays in recruitment after the resource was established. Recruitment has now picked up and Our Future Health has met a set of funding milestones which UKRI revised in August 2023. ▪ The resource is currently not fully representative of the UK population, when using the benchmark set by Our Future Health to compare participant numbers to breakdowns in the 2021 and 2022 Censuses for each country in the UK (see **Annex 6**: Cohort representativeness data). It has made moderate progress towards establishing representativeness and is more representative than comparable resources such as the UK Biobank, which did not recruit individuals under the age of 40 and recruited a greater share of people than Our Future Health has from a higher socio-economic status. However: ▪ The cohort is not representative of the UK population in relation to age, IMD and ethnicity, with some groups deviating from the UK Censuses target. ▪ Older age groups are overrepresented, whereas younger age groups are underrepresented. ▪ Participation from individuals from the most deprived areas is underrepresented (e.g. those in areas making up the first decile of the IMD – and are therefore the tenth of people in society who live in the areas with the highest deprivation) should make up 10% of the resource's participants however only make up 5%. As a single IMD score is assigned to each area, not accounting for local differences in socioeconomic status, there may be further disparities in who signs up for Our Future Health in each local area, which is not captured by this measure. ▪ Some ethnic groups are underrepresented compared to the target (e.g. Bangladeshi, Pakistani, African and Caribbean ethnic groups). ▪ Within a month of the end of the Challenge, the target of completing 1.35 million genotyping assays (the method used to understand an individual's genetics) was met, covering 1.27 million unique participants. ▪ A total of £278 million in Challenge funding has been released as of March 2025 from UKRI, DSIT, industry and charity partners. Our Future Health has received all Government funding for meeting its revised numerical milestones which were tied to recruitment and genotyping. ▪ Recruitment activities started in large cities with high socio-economic and ethnic diversity. Keeping the current recruitment rate and improving the cohort's demographic, socio-economic and ethnic representativeness has been challenging as recruitment expanded into a greater number of rural areas or areas with lower diversity in England and the devolved nations.

	▪ Reaching the target for both 1.33 million full participants (which is the default definition of "participants" used throughout this report to describe volunteers who have consented to joining Our Future Health, completed the online baseline questionnaire and provided a usable blood sample) and achieving representativeness required Our Future Health to maintain high levels of resources to recruit underrepresented populations. However, the programme has found this challenging as it slowed down recruitment to reduce its expenditure to a level where it could meet recruitment targets with the cash it had available. ▪ There are opportunities to improve the breadth of recruitment, including target populations which remain underrepresented. Our Future Health is running initiatives such as community champion pilots to address these disparities. Maintaining engagement and improving recruitment from under-represented communities will be critical to achieving representation. ▪ Our Future Health has delivered recruitment at scale while maintaining recruitment costs which are in line with or less expensive than other research cohorts, at an average cost per participant of around £132. Where the programme continues to target under-represented harder-to-reach groups, unit costs are likely to rise, therefore maintaining value will depend on the use of targeted, evidence-led incentives and continuous monitoring of costs. ▪ The TRE became operational in June 2023 and is enabling 24 active research studies to take place as at the end of March 2025. ▪ Agreements with NHS England have linked 97% of eligible participants' secondary health records (those records for hospital visits and cancer or death registrations) in England. However, access to primary care data in England (records for General Practitioner – GP – consultations) and all data in the devolved administrations is subject to ongoing approval and legal processes which has resulted in an uncertain timeframe. Users of the resource have expressed how important it is that they can access full healthcare records for both primary and secondary care.
IEQ2: To what extent has the ADD Challenge developed a research resource which drives improvements in population health outcomes through improved risk prediction, early detection, and management of chronic diseases?	▪ Feedback and recontact systems are still under development. Point-of-care feedback on cholesterol was suspended by 31 December 2024 due to initial levels of pressure on primary care and participant concern generated by test results. A non-genetic online feedback platform is planned for pilot testing over 2025. There were early delays in developing these systems due to financial constraints, with no earlier funding assigned to these. Development of these systems will require Our Future Health to consider outstanding ethical and technical challenges, which it has begun to address through research and public deliberation activities. ▪ As of the end of March 2025 there were 24 active research studies and 529 approved researchers on the TRE. Initial findings from these studies which use the resource are yet to emerge as studies are each at an early stage. The cohort's scale and comprehensive data collection mean there is high potential for studies to contribute to population health improvements through biomarker validation and risk stratification. However, it is too soon to assess whether the resource has generated novel research outputs, and subsequent improvements in population health.
IEQ3: To what extent has the ADD Challenge increased public involvement in health research, including underrepresented groups?	▪ Our Future Health has made progress in increasing public involvement in health research, largely due to its status as one of the world's largest health research programmes by total participant numbers. It has also run a series of workshops and deliberation activities with members of the public including those from under-represented groups. However, it is not yet fully representative of the UK population, which remains a concern. Initiatives such as community pilots are underway to address these disparities. Maintaining engagement and improving recruitment from under-represented communities will be critical to achieving representation in line with the 2021 and 2022 UK Censuses. ▪ Participants are generally satisfied with the recruitment journey and recognise the value of taking part in the research programme. However, it is too early to assess outcomes and impacts, such as increased UK participation in global clinical studies or improved public perceptions of participation in health research. ▪ A recontact system is not yet in place, meaning it is currently not possible to assess further involvement of cohort participants in research studies or to monitor the participant response to follow-on studies. Engagement with consented participants is

	currently via quarterly newsletters and reminders via email and latterly Short Message Service texts (SMS) to support completion of the recruitment journey however this communication is not for recontact or invitation to studies but more general communication. ▪ Commencing recruitment in large, diverse areas of England was a sound approach by Our Future Health to 'seed' the cohort and identify what works. Nevertheless, experience from other research cohorts highlights that such recruitment remains complex and challenging, requiring sustained effort and additional strategies beyond initial large-scale engagement. ▪ The cohort has made moderate progress toward representativeness and is more reflective of the UK population than other comparable research resources but is not yet fully representative of the UK population. The Challenge did not achieve its representativeness goal, for several reasons: ▪ Several population sub-groups were harder to reach, engage and involve in research due to cultural and other social factors. While no specific costs were recorded for recruiting underrepresented groups, these are likely to be significantly higher than recruiting participants in an untargeted way. This has implications for Our Future Health in balancing representativeness with cost management, and the organisation will need to make pragmatic decisions about the cost effectiveness of pursuing a representative cohort. ▪ Expansion of recruitment to rural areas and the devolved nations will help Our Future Health towards its geographic and possibly socio-economic diversity targets and towards equity of opportunity for the public to participate, but is less likely to help in increasing the ethnic diversity or younger age participation due to the demographic make-up of these areas.
IEQ4: To what extent has the ADD Challenge driven investment and promoted growth in the UK diagnostics, risk prediction and precision medicine sectors?	▪ The ADD Challenge has not yet resulted in follow-on investment within the UK diagnostics, risk prediction, and precision medicine sectors. While expectations remain positive regarding the resource's potential to attract investment, tangible changes – such as successful study arms or trials –have not yet materialised. This is because approved studies are still at an early stage, and enabling systems such as participant recontact are not yet in place. There are some favourable signals in the wider market for investment. For example, university spin-out equity rose to £1.86bn across 243 deals and now accounts for 17% of total equity investment, and investments in medical technology (MedTech) have grown strongly. However, there are also challenging conditions. UK SME equity fell to £10.8bn while deal volumes dropped more sharply, with the steepest contraction at seed and venture stages. Our Future Health is well positioned to stimulate investment; however these conditions may mean that firms are cautious in investing in the resource until key capabilities are fully in place.
PEQ1: How have UKRI's funding, governance and operational processes affected progress towards the Challenge's objective of establishing a novel resource?	▪ UKRI's funding, governance, and operational processes have enabled the Challenge to make considerable progress in developing a novel resource. UKRI's governance mechanisms were robust and effective overall. However, they were not always fit for purpose during the initial setup and establishment phase. These strengths and limitations in UKRI's processes are set out below: ▪ The Industrial Strategy Challenge Fund (ISCF) funding enabled successful co-investment by industry and charity. Partners committed funding totalling **£184.5 million**, exceeding an initial Challenge target for **£160 million** co-funding. Milestones for releasing committed funding were agreed independently between Our Future Health and its industry and charity funders and exceed the Challenge timelines. UKRI has adapted its engagement with the programme to better align with Our Future Health's overarching governance. However, the reliance by Our Future Health on additional Government funding and an outstanding funding gap to expand the cohort, coupled with costs that have grown significantly, indicates the initial co-funding target as set out in the business case has not been sufficient. ▪ The decision to establish Our Future Health as a charity and a company limited by guarantee has had both positive impacts and constraints on the delivery of the programme. It has provided the organisation with the independence to make strategic decisions and set up its own partnerships. However, this structure also introduced governance complexities, with potential tensions between the company and its sponsors stemming from different timescales, deliverables and reporting expectations agreed with different sponsors. Furthermore, establishing a new entity posed initial operational challenges such as setting up administrative functions. Although an initial hosting agreement with

	Cancer Research UK was signed in January 2020, the initial arrangement was limited to recruiting five employees. Requests to Cancer Research UK were necessary to scale recruitment further and the programme still required dedicated finance, technology and management staff and office space to scale effectively. UKRI has acknowledged the tensions created by the Challenge's delivery model, including the risk of overlap across governance groups, and has begun to engage actively with Our Future Health at all levels to ensure its governance and processes are aligned. ▪ The initial Challenge funding amount of **£79 million** was not sufficient to enable Our Future Health to reach the target of 1.33 million participants, without securing additional Government funding. UKRI initially adopted an upfront grant funding model, which provided liquidity and speed for the early establishment of Our Future Health. However, the lack of stress-testing for core financial assumptions, and insufficient operational support provided to Our Future Health team during the inception of the programme contributed to cost overruns and early delays, impacted key appointments and the setup of core business functions. The focus on recruitment targets affected the depth of UKRI oversight and ability to mitigate programme risks during inception. A transition to a funding-in-arrears model, managed by Innovate UK, later introduced structured financial management linked to milestone achievements. ▪ UKRI's willingness to renegotiate funding timelines and milestones, coupled with its strategic financial management, enabled Our Future Health to meet key revised recruitment and genotyping targets by March 2025. This flexibility helped address earlier delays and allowed for necessary adaptations in response to operational and cost pressures. To ensure it had cash allowing it to continue to operate, Our Future Health needed to request early payments and re-profiling from FIMs and UKRI and renegotiate FIMs' contractual terms.
PEQ2: How have Our Future Health's commercial activities and operational procedures affected progress towards the Challenge's objective of establishing a novel resource?	▪ Our Future Health's commercial activities have allowed it to make progress towards its funding goals and secure a growing number of partners to develop its resource. Operational costs related to recruitment and building core capabilities are, for the most part, being managed effectively. However, it seems unlikely that the programme will be able to operate without additional Government funding in the future. ▪ Several operational procedures have been established to support progress towards Challenge objectives, but a number of frameworks and processes are still under development. Elements still to be completed include the development of legal, ethical, and scientific frameworks for programme delivery, particularly focusing on participant feedback and recontact strategies, as well as sample access for researchers becoming operational. Without these frameworks in place, Our Future Health will be unable to fully utilise the resource and implement activities (such as providing health risk feedback or inviting participants to studies). ▪ A diverse funding model has been developed, bringing in significant industry and charity co-investment commitments of **£184.5 million**. FIMs each committed £10 million and provided expertise to help shape the programme through a role in the Founders Board. Industry members also gain exclusive access to the TRE, which other large companies cannot yet join. No such exclusivity arrangements apply for academic, NHS, Charities or other public health bodies. FCMs negotiated agreements with Our Future Health, aligned to their capacity to contribute and have Founders Board membership. Our Future Health has also developed its tiered pricing strategy for academic and SME users, generating interest in the resource. However, this strategy is subject to change and only some prospective users have visibility of current pricing. While there is interest in the resource, researchers must contact Our Future Health for details on prices. Researchers may have preferred a more open and transparent view of the fees involved. The researcher platform provides researchers with information on the data available within the TRE.
PEQ3: How has Our Future Health's programme design and delivery affected progress towards the Challenge's objective of establishing a novel resource?	▪ Our Future Health has made considerable progress towards establishing a novel resource and has responded well to issues encountered in the initial setup and implementation phases of the programme. This is evidenced by the successful recruitment of 1.33 million participants, the launch of the TRE for a growing number of researchers, and the securing of access to linked secondary healthcare, cancer registrations, and death registration data. The programme has also made effective strategic adjustments during implementation, including adaptable recruitment approaches, the scale-up of community recruitment pathways and piloting.

- Our Future Health has struggled to accurately forecast operational costs. This reflects inflationary pressures and the rapid evolution of delivery models. As the programme matured and infrastructure scaled rapidly, the programme has failed to show economies of scale beyond some improvements to processing of samples. However, recruitment costs remain lower than those observed in UK Biobank and All of Us.

Recommendations

Our Future Health has achieved significant milestones by recruiting a cohort of over 1.33 million participants. This makes it the largest health research cohort of its nature worldwide. Recruitment of the cohort was achieved at a pace faster than initiatives like the UK Biobank, whilst keeping the cost per participant below that of other comparable programmes. Combined with dedicated efforts to build a representative resource, it has high potential to:

- Harness genomic data and health records, develop cutting-edge precision medicine and personalised treatments, alongside enabling accurate risk predictions and screening strategies.
- Facilitate the early and widespread testing of new products, including digital innovations, across diverse clinical and real-world environments within the cohort, attracting investment into the development of novel therapies and interventions.
- Attract attention and financial backing from global pharmaceutical and biotech companies.
- Streamline clinical trial processes with cost-effective, timely, and practical solutions that boost trial numbers in the UK.
- Reduce health inequalities through an increasing number of studies involving underrepresented populations, improving trust and participation in research.
- Boost growth in UK life sciences sector and attracting international investment.

If the programme can achieve these wider ambitions beyond cohort recruitment, it can make significant contributions to Government policy, as well as the UK's population health and economic growth. It is central to the Life Sciences Sector Plan, which aims to position the UK as a global leader in life sciences research and development. It aims to enable additional commercial clinical trials in the UK, an objective underscored in the O'Shaughnessy Review which identified regulatory and practical barriers to conducting trials in the UK. Through the development of novel diagnostics, risk-prediction tools and therapeutics, Our Future Health also has the potential to support strategic shifts in healthcare delivery presented in the NHS 10-Year Plan. The programme also allows researchers to conduct comprehensive linked data analysis using participant data, which supports the ambition set out in the Sudlow Review.

So far, these wider ambitions have not been realised. Our Future Health is still working towards setting up core resources and capabilities to enable its wider ambitions, including systems for participant feedback and recontact. To fully realise the initial intended benefits of the cohort, Our Future Health will also need to make the resource fully representative and establish strategies to maintain engagement from its participants. Since the start of this evaluation, Our Future Health has secured additional Government funding beyond the ADD Challenge, to establish these capabilities and continue recruitment.

Going forward, lessons from this evaluation should be considered by a wide range of stakeholders, to ensure the potential future benefits of the programme are realised in a cost-effective manner:

- **The MRC** will manage the relationship with Our Future Health after the closure of the ADD Challenge and continue to monitor progress, on behalf of UKRI.
- **OLS** is committing funding to Our Future Health from 2025/26 onwards, with £58 million in 2025/26, followed by up to £354 million from 2026/27 to 2029/30 as part of the Life Sciences Sector Plan published in 2025. It will be the main Government sponsor of Our Future Health going forward – this will include commitments of Our Future Health contributing to the Life Sciences Sector Plan.
- **UKRI,** having managed the ADD Challenge through MRC and Innovate UK, should consider lessons from the Challenge to structure future large-scale programmes, including future investments to promote novel health research, cohort studies or large-scale data science activities. This includes the selection of organisations or teams to deliver the programme, stress-testing financial and operational assumptions, setting and adjusting milestones and considering how to support the establishment of enabling functions.
- **Department of Health and Social Care (DHSC) and NHS England**, as responsible owners for health policy and clinical priorities which can be supported through research and development conducted using Our Future Health data. This includes innovation and data priorities set out in the NHS 10 Year Health Plan for England.
- **Wider policymakers and legislators who are responsible for setting the legal and regulatory framework in which Our Future Health operates.** This will include a wide range of stakeholders including members of UK Parliament, central government departments including DHSC, the Department for Science, Innovation and Technology (DSIT), the Home Office, Devolved Administrations and regulators including the Information Commissioner's Office and Health Research Authority. Each should consider lessons on how similar initiatives can be supported by legislative changes or clarifications. For example, through amending provisions for sharing and linking health data, as well as relevant information governance and informed consent provisions.

Recommendations for the above stakeholders are set out below.

Ensuring that the resource supports strategic goals for the NHS and Life Sciences Sector (MRC, OLS and Our Future Health)

Recommendation 1. With Our Future Health now operating under additional commitments and £354 million in funding from the Life Sciences Sector Plan, and an additional £58 million in funding over 2025/26 (which will take public funding up to £559 million by 2030) it is essential that robust monitoring and oversight is in place. **MRC and OLS must ensure that they monitor Our Future Health's development of key aspects of the resource, including data linkage, participant feedback, and clinical trial recontact.**

- Monitoring arrangements should **strike an effective balance between checking progress towards the objectives agreed in the recent business case for post-Challenge Government funding, while also recognising the novel nature of the programme and the need for flexible delivery.** The programme needs to be assessed carefully for progress, while also offering alternative means for reaching the programme's overarching objectives. Innovate UK, for example, set qualitative expectations on diversity and clinical trial readiness to provide greater support and flexibility to Our Future Health in achieving.

  To meet goals set out in the Life Sciences Sector Plan, Our Future Health must develop multiple capabilities, some of which would be global firsts if realised successfully. These include: (i) bringing participant recontact into live service (ii) completing primary care linkage in England and data linkage in the devolved nations (iii) maintaining regular data releases, including imputed genetic data; and (iv) meeting agreed recruitment and representativeness milestones. More discretionary goals, while important to progress, may include the precise mix and timing of recruitment tactics and incentives, given the likely focus on under-represented groups and already contacted individuals, updates to pricing, and the delivery of additional TRE features, imputation, and effective processes for clinical trial recruitment.

- The Founders Board provides an effective space for sponsors to discuss Our Future Health's progress and programme risks. **Our Future Health should maximise the potential benefits of the Founders Board**, using it as a convening group with all programme sponsors to: align expectations across public, charitable and private sector sponsors; ensure members contribute to Our Future Health's advisory boards as well as external advisory groups; inform progress reports and dialogues with OLS and wider Government bodies; and identify opportunities for partnerships across Our Future Health, Government and industry.

  In turn, **MRC should seek to avoid duplication of monitoring and reporting arrangements with other Our Future Health sponsors**. However, MRC should prioritise setting clear milestones in relation to the development of data access and linkage, participant feedback, clinical trial recruitment, genomics/imputation and recontact capabilities. This needs to reflect, in particular, the likely **tensions between developing these core capabilities and pressure to achieve further recruitment milestones** agreed with FIMs. MRC should agree a clear delivery plan with Our Future Health, including critical funding milestones and deadlines for establishing the core resources and capabilities discussed above, as well as a detailed risk management plan which sets out mitigation actions for risks that have significant potential to delay or block delivery.

  Examples of key near-term milestones this plan should consider include 1) developing recontact systems over 2025/26, with a live recontact service in place for up to two pilot studies 2) delivering a first primary care data release into the TRE during 2025/26 (covering at least 70% of eligible participants), with a published quarterly refresh cadence and a roadmap for linkages in the devolved nations and 3) setting a recruitment and representativeness waypoint for 2025/26 to reach at least 1.6 million full participants while

narrowing key gaps (for example, raising coverage of 18–29 year olds, those who live in IMD deciles 1–3 and under-represented ethnic groups by agreed percentage points).

Recommendation 2. Our Future Health has taken suitable steps to conduct **deliberative dialogues with members of the public**, particularly to support initial development of its feedback and recontact strategies, to help unpick contentious issues related to these two core functions of the programme. For instance, deliberative research could be used to understand how and in what format feedback should be provided on disease risks, and under what circumstances participants would be happy for the resource to link primary care data provided by their GP.

Deliberative dialogue could also explore how the resource is used, how it supports research into emerging technologies, and how the public anticipate using novel health technologies or supporting their development, including targeted vaccines, AI-enabled diagnostics, community diagnostics with digital follow-up, and screening programmes which recall people based on genotyping results. This deliberative work should build on, rather than duplicate, the recent Change NHS consultation led by DHSC to hear views, experiences and ideas to inform the 10 Year Health Plan. For instance, the Change NHS consultation did not cover how people want to manage detailed access to their health records in great depth including at what point in time they want to see and act on test results or risk scores.

To support this deliberative research, Our Future Health should expand **its Public Advisory Group into a standing citizens' panel** as an asset in the resource**. A core deliberative consultation team could be setup in partnership with Government, with our future Health as central delivery partner.** Members of this citizen panel should continue to provide in-depth and rapid public feedback on an emergent set of issues.

Through gathering this feedback, Our Future Health and partners across the NHS should develop actionable pathways and materials for the adoption of new technologies, including communications, consent papers and operating guidelines. Each example will be relevant to achieving ambitions in the NHS 10 Year Health Plan for England and Life Sciences Sector Plan.

Recommendation 3. Within the Life Sciences Sector Plan, Government committed further funding to Our Future Health for increasing the size of the cohort to up to 5 million participants with linked primary and secondary care health data, genomic data and biobanked samples. This will be a demanding goal for Our Future Health to achieve:

- Further recruitment, particularly in underrepresented communities will be resource-intensive and is a step-change in what Our Future Health achieved over the course of the Challenge.
- Our Future Health also needs to continue to balance recruitment scale-up alongside setting up core functions for feedback and recontact, which are essential to delivering commercial clinical trials.

  - It will become increasingly challenging to incentivise members of the public, who until now have not responded to communications and invitations, to join.

  - The conversion of joiners into full participants, who have provided consent, completed the baseline questionnaire, and provided a usable blood sample, will remain challenging. Efforts will be required to improve conversion through Our Future Health's recruitment pathway.

To mitigate this, **Our Future Health should prepare a fully costed recruitment strategy within the next financial year and present this to MRC.** This strategy should continue to make full use of Our Future Health's operational, analytics and finance teams to identify **value adding opportunities to improve recruitment and conversion rates at reasonable costs**. It should set out how it intends to meet recruitment targets at pace, within budget and with full representation of the UK population. The strategy should consider:

- **How to adapt recruitment approaches to improve response rates among participants who already started the recruitment journey but have not completed it.** This should address concerns that Our Future Health may either exhaust its potential recruitment pool or face significantly higher unit recruitment costs if it does not engage and convert individuals who have enrolled but not completed the recruitment process. Our Future Health should prioritise and commit resource to progressing the recruitment journey of participants who have consented but not yet progressed to a 'full participant' by attending an appointment and/or completing their baseline questionnaire.

- **How to increase the visibility and value of the resource to those considering joining.** As part of developing its approach to health insights, Our Future Health should promote a **tangible offer to new participants.** This includes: **publicly communicating risk scores** planned for the resource; setting out the speed and format through which risk scores could be shared to participants; **communicating work on how Our Future Health integrates with NHS clinical pathways** such as through offering manageable follow-up appointments for those who need them; and **revisiting wider offers** such as sharing insights on ancestry. Our Future Health will already be used for a service evaluation, led by NHS England, on the feasibility and cost effectiveness of returning integrated risk scores for 5 diseases to participants. The results and emerging benefits in this evaluation should be communicated to relevant stakeholders including participants.

- **Revisit and scale or combine initiatives that were successful during the Challenge, to support reaching 5 million people.** Increasing recruitment will require a step-change in how Our Future Health motivates people to join, while keeping costs within a manageable level. It should confirm which initiatives are most effective with specific joiners and ensure each is scaled-up or targeted to have full impact. Our Future Health's overall recruitment strategy should consider **what initiative enables who to join, for what cost price, and how it supports representativeness of the resource**. This should include offering a range of

benefits to incentivise taking part, such as ancestry insights and recruitment materials in languages widely spoken in the UK, and evaluate the relative improvements in recruitment and conversion versus costs among different socio-demographic groups.

As a further example, Our Future Health's £10 reimbursement towards travel costs for joining contributed to an increase in participants, with a stronger effect for younger adults and people in more deprived areas. Before continuing at scale, Our Future Health should **revisit the reimbursement initiative** and pinpoint who accepts the reimbursement (by IMD decile, age, geography and invitation channel), **the impact and cost implication of different reimbursement amounts** (£5/£10/£15), **how effective different delivery formats are** (for instance, cash vs voucher; digital vs paper) and **which timings for reimbursement work best** (announced at invite vs at booking) through user testing and experimentation. Having considered all this, the coverage of this initiative to relevant sub-groups should be agreed and costed.

Recommendation 4. Our Future Health should expand its partnerships with clinical and R&D leaders in the Department of Health and NHS England, making sure it supports data and digital ambitions in the NHS 10 Year Health Plan for England. Our Future Health has worked effectively with NHS England to access data and consider the impact of participant feedback on clinical pathways. However, more explicit actions can be taken to ensure that data in the resource supports transformation of health service across the UK. In England, this will be to meet goals regarding data and innovation in the 10 Year Health Plan. It will also support similar goals to pivot to prevention and technology-assisted models of care in the devolved nations. For example, the **NHS Scotland Operational Improvement Plan**, **A Healthier Wales** alongside the Public Health Wales Long Term Strategy 2023–35, and **Health and Social Care NI Three-Year Plan 2024–27** along with the Northern Ireland Health-Plan Reset. To support these policies, two example ambitions that should be tested include:

- Becoming the **UK's primary validation platform** for developing and testing new digital health, healthcare AI and remote monitoring technologies, drawing upon its large, linked, multi-modal data. As part of this, alignment across the NHS and regulators including the Medicines and Healthcare Products Regulatory Agency (MHRA) and AI Safety Institute (AISI) should take place to focus research on AI opportunities, regulation and secure use. This can also align with ongoing objectives to position the NHS App as a front-door for digital health applications.

- Developing and validating **early disease detection tools**. Given its scale and access to linked genomic and health records data, Our Future Health is well-placed to develop integrated risk scores, screening algorithms, diagnostics or panel tests targeting specific biomarkers and digital decision support tools. This can be done for a wide range of conditions including cardiovascular conditions, diabetes, cancer, dementia, autoimmune conditions, mental health conditions and rare disease. Our Future Health is beginning to develop risk scores for some priority conditions alongside NHS England. However, it needs to develop its participant

feedback and recontact systems to develop products and tools, and gather real-world pilot evidence on these. Early disease detection tools also require careful integration between Our Future Health, NHS England, GP representatives and patient groups to ensure they are validated and direct patients to suitable care pathways.

- Beyond initial efforts to gather feedback on a small number of diseases, Our Future Health should work with NHS management and clinical leaders to **fully integrate all participant feedback** into relevant clinical pathways. This will require structured review and risk assessment of pathways, including capacity to absorb demand, and entry-points in the pathway for consultation.

Recommendation 5. OLS and Our Future Health should explore wider strategic partnerships to maximise the wider social and economic benefits of the resource. While Our Future Health is condition-agnostic and provides the means for researchers to carry out high-priority work, its potential can be maximised through close coordination with Government sponsors. For example:

- OLS and Our Future Health should continue to explore linkages and collaboration opportunities with major national public bodies responsible for or interested in health data, and national and regional health data initiatives resulting from the Sudlow Review. In particular, any future national system for secure access to whole-population general practice data would offer a wide range of benefits and substantially increase the value of Our Future Health when linked to existing cohort data.

- **Our Future Health should explore appetite with its participants to link non-health data, such as administrative data in the National Data Library with health records.** This would inform research focused on prevention and wider determinants of health. For example, the linkage of additional education and welfare data from additional sources could inform research on how these contribute to research on how living circumstances leads to the development of specific conditions. However, this will require careful conversations with participants on consent to link their health data with additional sources.

- **Research funders including UKRI and National Institute for Health and Care Research (NIHR), as well as clinical research teams across the NHS, should explore opportunities to accelerate and 'crowd in' researcher demand** to real-world health or clinical challenges, through competitions. These are to actively encourage use of Our Future Health, drive interest in the resource, generate case studies for its use, and match demand for it to pressing public sector and health needs.

- **Our Future Health should explore linkages and collaboration opportunities with the recently announced Genomic Population Health Service**, to ensure any participant feedback functions developed aligns and builds on services the new NHS programme offers.

- **Our Future Health should explore the potential for its Community Champions to collaborate with the neighbourhood health teams announced under the 10 Year Health Plan for**

England, to help tackle barriers currently hindering participation of underrepresented groups in Our Future Health.

- **"Our Future Health should promote data access to innovators in Regional Health Innovation Zones**, as announced under the 10 Year Health Plan for England, to allow rapid validation and/or trial recruitment for particularly promising novel interventions & digital health technology products.

Creating conditions for success – clarifying and reviewing the governance and regulatory framework for collecting, accessing and linking health data

In scaling up recruitment, Our Future Health will need to ensure that participants fully understand what they are consenting to and how their data may be used. Maintaining public trust in the resource is crucial, and has to be considered together with regular reviews of the consent process and recruitment materials. Such reviews will have to consider any changes to the wider legal and ethical framework that governs informed consent and ethical recruitment into health research programmes.

Recommendation 6. Delays to data access and linking were common during the delivery of Our Future Health, with primary care records and data in the devolved nations facing delays due to the lack of precedence for such requests, and the legal and regulatory complexity of granting access. In line with recommendations in the Sudlow Review, **DHSC and relevant devolved Government departments should set a UK-wide approach for access processes and data governance that involves health records**. This may for instance involve the creation of unified data access and linkage agreements for significant research and linked data programmes. This framework should harmonise the legal, ethical, and technical requirements for building research data resources such as Our Future Health and allow trusted researchers and analysts more rapid data access and linkage of records. Where needed, such a UK-wide strategy should also recommend guidance on how to implement the recently adopted Data (Use and Access) Bill and provide clarification or recommended legislation on specific issues (such as the specific role of GPs as data controllers under UK GDPR).

Designing future Government programmes

Recommendation 7. UKRI should ensure that similar initiatives delivered by independent bodies set specific operational and monitoring milestones more clearly, and provide more targeted support during the initial establishment phase. The evaluation highlighted the risks and complexity involved in establishing a new independent entity, as well as some limitations in standard UKRI governance and monitoring processes. Along with agreeing milestones on setting up core accounting, legal and technology functions, UKRI should consider options to provide specific assistance, such as providing office space, identifying a host organisation or expert advisor support in specialist areas required to set up a new organisation. This might include sourcing professional services to support from a legal, human resources, financial and operational perspective. UKRI should also consider a wider review of best practice on how to set up and

manage an arm's length body, focusing on promoting trust, allowing operational and scientific flexibility, and maximising transparent reporting.

- Future initiatives should assign funding milestones to **successfully meet a wider range of core delivery objectives** which extend beyond one specific area such as recruitment. While each milestone needs to be achievable, and balanced with other programme goals and avoid them conflicting, this approach will stop future initiatives from de-prioritising key features. For example, Our Future Health delayed the development of its core IT systems and infrastructure, this has delayed the resource in providing health insights or data to researchers, as no funding was explicitly tied to these goals. While it may not have been able to deliver all objectives at once, discussions about prioritising resource could not happen as robustly when objectives focused on recruitment. While other initiatives will be distinct to the ADD Challenge, milestones can be assigned for (1) setting up the organisation, including defining and recruiting against core operational, technical and strategic roles required to deliver the initiative (2) developing key digital platforms (3) developing the commercial model (4) reaching researcher user numbers or (5) successfully acquiring data.

- Early development of a **programme theory of change** should take place when developing future initiatives, and use this as a framework to help inform milestones (e.g. what TRE capabilities need to be in place for researchers to use cohort data effectively, enabling novel research). This should include causal relationships and dependencies between key programme activities, ensuring that funding milestones and targets are consistent with it.

- Where UKRI sets co-funding arrangements for an independent delivery body, **a business strategy for operation beyond initial Government funding should be agreed well before the end of the initial Government funding**. The company limited by guarantee model chosen for Our Future Health was appropriate and enabled sufficient flexibility and leverage of match funding from industry and charities. However, Our Future Health has remained heavily reliant on public funding beyond the ADD Challenge, with additional Government commitments at a 5x multiple of annual operating costs projected in the initial business case. Whilst the resource clearly has substantial potential for leveraging additional support from industry and charities, earlier clarity on the operating model beyond the ADD Challenge, including on how to leverage additional commercial revenue, would have reduced the level of post-ISCF Government funding required.

- For future initiatives of this scale and complexity, especially those involving substantial operational set-up and planning, **UKRI should undertake more robust stress-testing of financial and operational assumptions** informing delivery costs and relevant timelines, both at business case stage and in the initial setup phase of programmes. This should consider key assumptions for reaching programme objectives such as, in the case of the ADD Challenge, the costs, cash requirements and strategic approach to recruitment of under-represented groups.

- To ensure meaningful oversight for future initiatives of this nature, UKRI should **explore how programme boards can improve monitoring the operational aspects** during the initial setup phase. For instance, a dedicated business support role could be created for programme boards of similar initiatives. In addition, UKRI might want to stipulate processes for the nominated directors of the company limited by guarantee to be more closely involved with UKRI programme level governance and monitoring.

- Given the complexity of the programme and need for Our Future Health to adjust its strategy and arrangements with funders or suppliers, **future schemes run by UKRI should build in sufficient leeway to contracts to allow programmes to scale-up or -down as required**. Longer or more consistent gateway review timeframes should also be considered to provide assurance to delivery partners when undergoing contractual negotiations.

Recommendation 8. UKRI, as part of future initiatives, should consider either a delivery model that includes an extensive initial seed stage with incubation at a host organisation and access to associated expertise, or – if this route is not taken – a **robust operational and business support offer embedded from inception,** to ensure timely access to expertise and procurement for essential legal and administrative functions. While an initial hosting arrangement was in place for Our Future Health, this did not provide the operational and business support required for the organisation to scale at pace.

- Early involvement of industry enabled FIMs to help shape the direction of Our Future Health at a time when many of the detailed delivery plans were still in development. However, this could have been more closely aligned to expectations set by UKRI through the ADD Challenge business case. **For future initiatives, co-funders' milestones should be aligned and co-developed from the outset - across UKRI, industry and charity sponsors and the delivery body -** to ensure oversight of cash flows, avoid the risk of shortfalls or surplus, and allow flexibility to accommodate forecast variations. In particular, milestone definitions for stages of participant recruitment (e.g., completed questionnaire, blood, linked data) should be harmonised as early as possible once co-funders are convened. Where the delivery body is not yet in place, UKRI should set up-front terms and rules for agreeing milestones.

- **A stronger focus on operational risk** during the setup phase of delivery bodies will be essential when launching future challenges, as demonstrated during the establishment of Our Future Health. **Recruiting experienced senior staff, core operational roles and senior research expertise are critical** to alleviate pressure on the core team and to enable timely development of key operational activities (such as a scalable recruitment strategy) at lower cost.

Recommendation 9. UKRI should ensure that future initiatives prioritise rapid iteration of different recruitment routes during the initial programme phases. Whilst COVID-19 presented significant challenges for early iteration for Our Future Health, future initiatives should apply lessons learned from existing population cohorts and optimise recruitment approaches early

through fast pilot sprints. The recruitment strategy for Our Future Health also evolved significantly over its lifetime, with effective approaches such as targeted reimbursement, Customer Relationship Management (CRM) communication, and community-led pilots being developed and scaled-up. **These should be captured as part of an evidence-based "recruitment playbook" for future activities involving volunteers or research participants.** Programmes should also factor in up-front expertise in clinical trial recruitment, behavioural science, community engagement, operational logistics, communications and marketing, social science and ethnography.

Need for future evaluation of Our Future Health

Recommendation 10. To robustly assess the long term impact of Our Future Health, Government should carry out a follow-on impact and economic evaluation, including an assessment of additional objectives agreed for the 2025-2030 period. This study should, once a sufficient size of completed research studies and users is available, assess progress towards:

- The extent to which the programme has enabled novel research, considering the focus of the research, topic or disease areas and type of study.
- The extent to which such novel research has been translated into novel interventions and projects in diagnostics, risk prediction or personalised medicine and therapeutics.
- The extent to which the programme has enabled novel commercial clinical trials with cohort participants, through the use of a recontact framework.
- The provision of novel health insights to participants through feedback, including whether and how this feedback has resulted in health benefits (such as through behavioural changes and/or earlier detection and treatment).
- Whether adoption of novel interventions and products enabled by Our Future Health has led to population health outcomes and improvements in NHS service delivery.
- Whether Our Future Health has led to increased participation of under-represented groups in health research.
- The economic impacts of Our Future Health, in particular with regards to any follow-on investments made by commercial users of the resource, employment and turnover effects on firms using the resource, as well as any productivity effects following on from population health improvements.

The evaluation should also revisit the programme's Value-for-Money, undertaking a comprehensive Cost-Benefit assessment.

1 Evaluation Rationale, Purpose and Approach

Ipsos and Technopolis were commissioned in 2022 by UKRI to deliver a process and impact evaluation of the ADD Challenge. The evaluation assessed the programme's effectiveness in progressing towards and achieving its objectives and has provided feedback on delivery. The report is based on data available up to 31 March 2025.

The evaluation was delivered in four phases, including 1) a scoping phase in 2022, 2) a baseline assessment in 2023, 3) an interim assessment in 2024 and 4) a final assessment undertaken in 2025.This report summarises findings across the entire study.

1.1 Study objectives

This study assessed the extent to which the Challenge and Our Future Health have progressed towards the objectives set out in the Challenge business case. Assessing public funding provided through the ISCF was in scope for this evaluation.

Additional funding announced under successive Governments through OLS in November 2023 and December 2024, plus revised milestone targets agreed[1] are in scope for the evaluation. Government funding for Our Future Health beyond the duration of the ADD Challenge, such as support committed in the 2025 Life Sciences Sector Plan, is out of scope of this evaluation.

1.2 Impact evaluation

The impact evaluation examined the extent to which the ADD Challenge has progressed towards its core objectives. The key Impact Evaluation Questions (IEQs) it has sought to answer were:

- **IEQ1:** To what extent has the Challenge established a novel Research and Development (R&D) resource of 1.33 million participants, which is representative of the UK population?
- **IEQ2:** To what extent has the Challenge developed a research resource which drives improvements in population health outcomes through improved risk prediction, early detection, and management of chronic diseases?
- **IEQ3:** To what extent has the Challenge increased public involvement in health research, including under-represented groups?
- **IEQ4:** To what extent has the Challenge driven investment and promoted growth in the UK diagnostics, risk prediction and precision medicine sectors?

[1] Such as change in targets to recruit 1.33 million participants and conduct 1.35 million genotyping assays, agreed in January 2025.

1.3 Process evaluation

The process evaluation reviewed the effectiveness of mechanisms (such as governance, programme management arrangements and operating protocols) established to deliver the ADD Challenge's objectives. The key Process Evaluation Questions (PEQs) it has sought to answer are:

- **PEQ1:** How have UKRI's funding, governance and operational processes affected progress towards the Challenge's objective of establishing a novel resource?
- **PEQ2:** How have Our Future Health's commercial activities and operational procedures affected progress towards the Challenge's objective of establishing a novel resource?
- **PEQ3:** How has Our Future Health's programme design and delivery affected progress towards the Challenge's objective of establishing a novel resource?

1.4 Methodology overview

The evaluation employed a theory-based approach, using contribution analysis. This choice of method was informed by several key considerations:

- As some ADD Challenge outcomes will be realised beyond March 2025, with impacts expected to materialise over the very long term, the impact evaluation assessed short- and long term outcomes differently. The evaluation directly assesses whether short term outcomes have materialised by 2025 as expected at the start of the Challenge, and if not what factors contributed to this. The evaluation also considered whether initial conditions are in place for Our Future Health to progress towards its long term outcomes and impacts.
- Impacts were likely to be affected by external factors – these included factors such as COVID-19 and the wider pressures on NHS, which affected access to recruitment routes, but also the wider regulatory framework governing aspects such as data linkage, participant consent and the planned participant recontact feature.

A Theory of Change (ToC), co-developed with UKRI, provided the framework for assessing progress and attributing change. The ToC set out the assumed pathways through which the Challenge is expected to deliver its intended outcomes and impacts, and is presented later under chapter 2 in **Figure 2.1:**.

The following analysis and data collection was undertaken to inform the evaluation:

Document and monitoring information review. The study team undertook a comprehensive review of materials and management information shared by UKRI and Our Future Health. Relevant Materials were shared from the inception of the Challenge up to 31 March 2025 and included:

- The original UKRI business case and delivery plan developed in 2019, alongside updated delivery plans prepared by Our Future Health for UKRI in 2020, 2022, 2023 and 2025.
- Documents analysing the policy and regulatory context for the Challenge.

- Papers for all ADD Challenge Programme Boards held from October 2019 to March 2025, including minutes, updates prepared by UKRI and Our Future Health for discussion at the programme board, and financial updates.
- Risk trackers which the ADD Challenge team updated regularly for Programme Board meetings.
- Our Future Health Grant Funding Agreements (GFAs) and stage gate materials and milestones.
- Our Future Health workstream updates, monitoring report for 2022/23 and quarterly monitoring reports for 2023/24 and 2024/25.
- Briefings, workshop materials and internal documents developed by Our Future Health for its workstreams covering public engagement, recruitment, knowledge generation, and the development of recontact and feedback approaches.
- Recruitment plans, reports on progress in recruitment and the delivery of recruitment initiatives, including recruitment data from the establishment of Our Future Health to 31 March 2025.
- Challenge closure documents.
- Details of studies approved by Our Future Health, provided by its access team.

Interviews. 57 semi-structured interviews were undertaken in support of the evaluation across the baseline, interim and final stages. These took place with a range of representatives from UKRI, Our Future Health, and other key organisations. These interviews discussed progress made by the ADD Challenge and Our Future Health, and explored topics such as governance mechanisms, funding and operational processes, and programme design. Interviews were semi-structured and conducted virtually. Interviews were undertaken with:

- The UKRI Challenge Team, Programme Board and Advisory Group
- Senior officials and teams at Our Future Health, including:
  - Chief Executive Officer
  - Chief Financial officer
  - Executive Director of Science
  - Chief Technology Officer
  - Executive Director of Partnerships
  - Executive Director of Ethics
  - Executive Director of Researcher Data and Product
  - Executive Director of Communications
  - Director for NHS and Health Data Acquisition
  - Director of Delivery
  - Access Board
  - Data Pipeline teams
  - Members of Our Future Health Scientific and Public Advisory Boards

- Founding Industry Members (FIMs) and Founding Charity Members (FCMs) of Our Future Health
- Current users of the resource including academics and staff based out of the FIMs
- Academic researchers who are potential users of the resource, to explore pricing expectations.
- Trade representatives (The Association of the British Pharmaceutical Industry)
- Custodians of linked data (SAIL Databank)
- Public perception organisations (Understanding Patient Data, Association of Medical Research Charities)
- Recruitment partners (Boots, Acacium, NHS Blood and Transplant)
- Regulators
- Research programmes with related experience in accessing and linking participant data (All of Us, China Kadoorie Biobank, NIHR BioResource, 45 and Up, FinnGen, UK Biobank).

Evaluation baseline. An evaluation baseline assessment was undertaken, with particular focus on the knowledge creation and investment outcomes and impacts (see Theory of Change in section 2) This included:

- A separate desk review and in-depth interviews with similar large-scale longitudinal cohort studies. These included: China Kadoorie Biobank, All of Us, FinnGen, 45 and Up, and NIHR BioResource. The rationale and programme objectives, approaches taken to recruitment, data collected, access arrangements and commercial business models were explored.
- Scientometric analysis of the UK Biobank and comparator resources, which analysed the longitudinal trends and characteristics of scientific outputs from each resource. This included peer-reviewed articles, clinical trials, patents and policy documents.
- Analysis of sector growth and investment patterns using Pitchbook, to establish the level and nature of venture capital and equity investments in the UK and United States in relevant markets such as diagnostics, risk prediction and precision medicine.

As the ADD Challenge had not resulted in or led to completed studies or investment by 31 March 2025, it was too early to make meaningful like-for-like comparisons. The first results from a study using Our Future Health data was published in June 2025. A detailed update of the baseline assessment was therefore not undertaken for this study.

1.5 Study Limitations

Given the long term nature of some of the intended benefits of the Challenge, the evaluation focuses on assessing progress towards these outcomes rather than their full realisation. It is

important to note that this report assesses progress up to the data cut-off point (31 March 2025), and that Our Future Health is actively progressing beyond this.

The evaluation carefully considered external factors outside the remit of the Challenge that have affected delivery. This report discusses both those within and those outside the remit of the programme, which have influenced the Challenge's progress. For example, Our Future Health's ability to access health records data depends not only on its own negotiations with external organisations, but also on broader data sharing and legal processes. In Scotland, for instance, discussions are ongoing around the precedent for sharing identifiable patient data, reflecting both the novelty and scale of the programme's ambition. The report also highlights outcomes and impacts that could not be evidenced at the time of drafting and should form the focus of any future evaluation of Our Future Health.

A robust economic evaluation (such as a Cost-Benefit Analysis) was not possible. Whilst the public costs of the programme can be quickly established by combining the ADD Challenge team's administration costs with Government funding to Our Future Health, significant uncertainty remains around how to quantify the benefits of the Challenge. A pilot survey was planned for a contingent valuation with a group of prospective users of the resource. However, given the disease-agnostic nature of the resource and the very early stage of actual adoption and use, results from the pilot would not have been sufficiently robust to inform an economic evaluation. Several other benefits can only be captured by research at a later stage, beyond the timings of this study. This includes potential health and social benefits (again, the feasibility of projecting these impacts was constrained by the disease-agnostic nature of the resource), as well as productivity effects on firms benefitting from results of research enabled by the resource, and associated knowledge spillovers.

1.6 Remainder of the report

The remainder of this report is structured into the following chapters:

- **Chapter 2: Programme overview** provides context and rationale, as well as an overview of the Challenge.
- **Chapter 3: Establishing and sustaining the resource** discusses progress made in developing research infrastructure, access to linked data, the development of a viable business model and pricing strategy, encouraging additional research users to the resource and the securing of funding from government, industry and charity sources.
- **Chapter 4: Recruitment and cohort characteristics** discusses progress made against Challenge recruitment and diversity objectives, effectiveness of recruitment and retention strategies, appropriateness of targets and recruitment channels, development of recruitment and recontact protocols and maintaining public trust.
- **Chapter 5: Improving risk prediction, early detection and intervention** discusses the nature and level of demand for resource use, the nature of studies using the resource, and progress

by Our Future Health or users of the resource in developing new insights and knowledge on disease risk prediction, early detection and intervention. As part of this, the section discusses the development of Polygenic Risk Scores and processes developed for providing feedback to cohort participants.

- **Chapter 6: Additional investment** discusses the resource's progress towards attracting investment and enabling economic growth within the UK diagnostics, risk prediction, and precision medicine sectors.

The following annexes are available at the end of the report and support the study findings:

- **Annex 1** maps each report chapter to the Impact and Process Evaluation Questions it addresses.
- **Annex 2** set outs data sources used for the impact evaluation.
- **Annex 3** sets out data sources used for the process evaluation.
- **Annex 4** sets out the impact and contextual metrics used for the evaluation, with definitions, values and commentary.
- **Annex 5** describes ADD Challenge and Our Future Health governance and delivery structures.
- **Annex 6** presents analysis on Our Future Health cohort representativeness compared to data in the UK Censuses.
- **Annex 7** presents analysis of Our Future Health recruitment pathways, for people who have registered, consented, completed the baseline questionnaire and provided a blood sample.

2 Programme overview

2.1 Strategic context and rationale

Enabling research on early disease detection in the UK, as well as research and development of novel diagnostics and healthcare interventions, has historically been limited by two key factors. Firstly, the extent to which researchers can access and use linked health data. Secondly, the availability of routes for researchers to conduct pilot studies and clinical trials and to recruit willing research participants.

These longstanding challenges were also recognised in major national studies, such as the Sudlow[2] and O'Shaughnessy[3] Reviews, and the recent NHS 10 Year Health Plan for England which aims at shifting the UK health service from reactive to proactive care by enhancing early detection and prevention capabilities[4]. This aligns with broader Government ambitions to improve healthcare outcomes through the use of novel research and technology, including precision medicine, early diagnostic tools, and AI or data-driven innovations.

The idea for a new, large-scale research cohort was first established in 2017. The *Life Sciences: Industrial Strategy* [5] report, published along the 2017 Industrial Strategy[6], presented a new research cohort as an opportunity for the UK to develop a wide range of new technologies and attract investment. The initial business case for the Challenge argued that failure to act would lead to significantly worse health outcomes and higher costs, as healthcare services would remain focused on late-stage disease treatment. Alongside this, the business case suggested setting up a novel research resource rather than expanding an existing resource such as the UK Biobank. Participants of the resource were expected to provide additional consent for recontact, repeat sampling and feedback, which were not a part of the UK Biobank. Additionally, the UK Biobank was undergoing changes to its structure while maintaining and conducting research with its existing cohort, and expansion could have impacted this progress.

The new resource was expected to enable the creation of new knowledge, support the development of novel diagnostics and identify and contact sub-populations at high risk of health conditions. This would ultimately improve early detection rates and patient outcomes. Additionally, such a resource could attract significant investment into the UK's life sciences

[2] The Sudlow Review (Uniting the UK's Health Data: A Huge Opportunity for Society) is available at https://www.hdruk.ac.uk/helping-with-health-data/the-sudlow-review/

[3] The Lord O'Shaughnessy review (Commercial Clinical Trials in the UK) is available at https://www.gov.uk/government/publications/commercial-clinical-trials-in-the-uk-the-lord-oshaughnessy-review/

[4] The NHS 10 Year Health Plan for England is available at https://www.gov.uk/government/publications/10-year-health-plan-for-england-fit-for-the-future

[5] The 2017 Life Sciences Industrial Strategy has been archived at https://www.gov.uk/government/publications/life-sciences-industrial-strategy

[6] The 2017 Industrial Strategy has been archived at https://www.gov.uk/government/publications/industrial-strategy-building-a-britain-fit-for-the-future

sector, drive innovation, and position the UK as a global leader in precision medicine and early disease detection. The business case proposed establishing a large, representative study cohort, linking primary and secondary care health records, and providing secure access to this data for researchers through robust data governance and systems.

2.2 Objectives of the Challenge

The programme was designed to recruit a minimum of 1 million and up to 5 million participants, with FIMs agreeing to separate milestones for a resource of 5 million participants, including incremental targets up to 3 million participants. These individuals would form a new research cohort with the ambition of being world leading in scale and representative of the UK population.

Participants who join the resource agree to provide a blood sample and complete a health and lifestyle questionnaire. They also consent to the linkage of their health records to their genetic data (information about the participant's genes inherited from parents, which indicate risk to certain diseases) and phenotypic data (physical traits influenced by both genetics and the environment). Our Future Health has secured the necessary permissions to:

- Share this data in a de-identified format with approved researchers, and
- Invite participants to take part in future health-related research studies.

Full participants (which is the default definition of "participants" used throughout this report) are those who have consented to join (with health data linkage part of their consent), completed the health and lifestyle questionnaire and provided a usable blood sample.

The key objectives of the Challenge were to achieve:

- Improved risk prediction, early detection and intervention, leading to improved healthcare provision in the NHS
- Development of a large-scale cohort to deliver a unique R&D resource and make the UK a world leader in early diagnosis
- Increased economic growth and new UK investment in early diagnosis technologies
- Increased economic growth and new UK investment in precision medicine
- The development of innovative approaches to health / life sciences sector data sharing, digital connectivity and access to data

If successful, the programme will enable longitudinal studies at a much larger scale than previously possible. This scale will give researchers sufficient statistical power to study both common and less common conditions, while also capturing a more diverse demographic.

Moreover, the Challenge is expected to facilitate greater collaboration and innovation - across the NHS, industry, and academia - and to stimulate additional investment in the UK diagnostics, risk prediction and precision medicine sectors.

The Challenge's intended longer term impacts include the development of new approaches to the early detection and diagnosis of disease. This encompasses risk prediction, biomarker discovery, the application of artificial intelligence to health data, and the development and validation of new diagnostic tools and technologies. Additionally, the Challenge aims to support early healthcare interventions and preventative strategies, enabling the development of earlier and more effective treatments. These outcomes are expected to lead to improvements in population health and the overall quality of healthcare provision within the NHS.

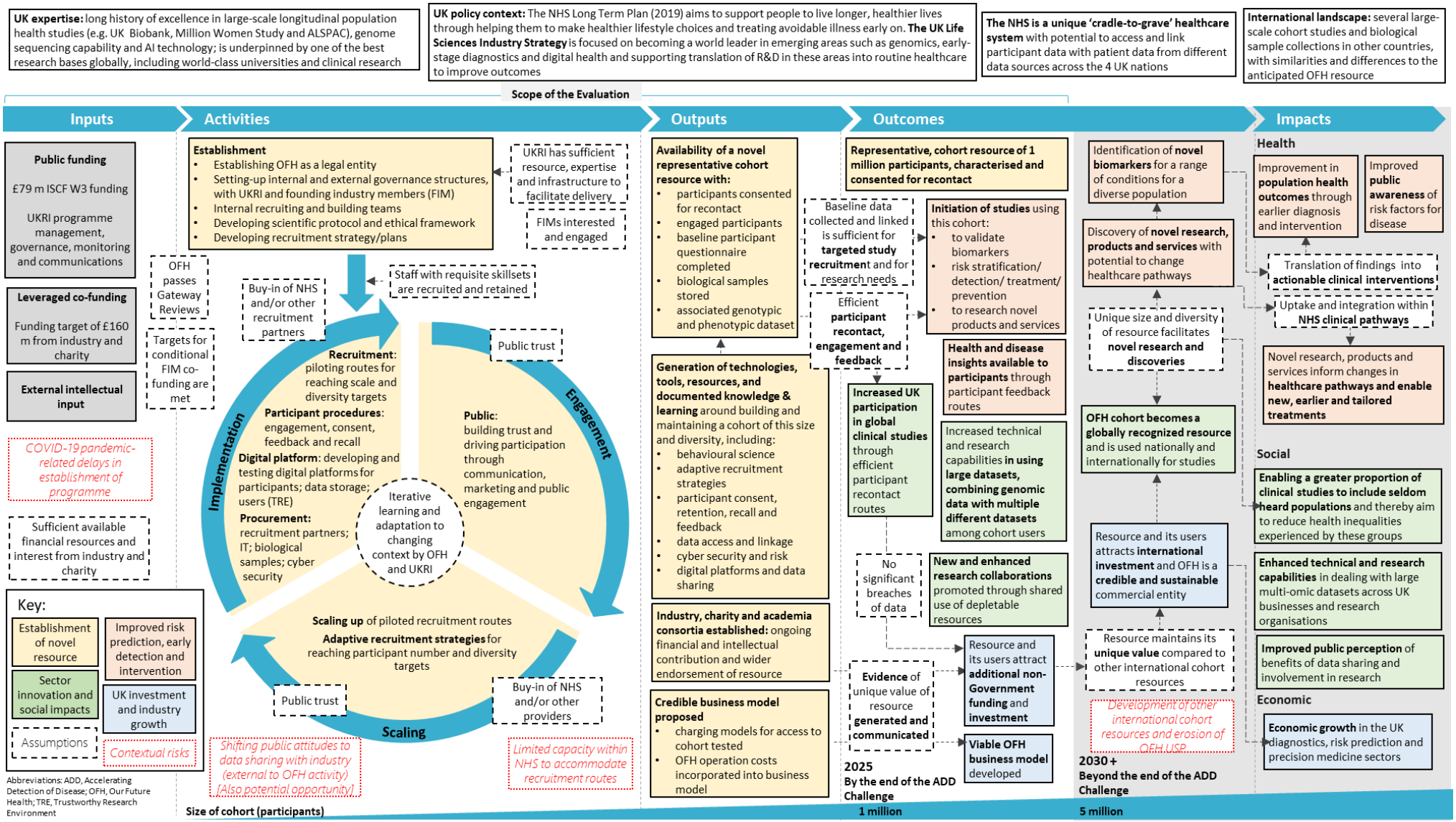
2.3 Theory of Change

The aims and expected impacts of the ADD Challenge have been set out through the theory of change (ToC) diagram below (**Figure 2.1:**). The ToC was developed during the first phase of the evaluation and was approved by the ADD Programme Board in November 2022.

The diagram summarises how the Challenge is expected to lead to its desired outcomes and impacts. It outlines the pathway from implementation through to long term impact, illustrating the causal relationship between constituent elements. These are structured across several stages: inputs, activities, outputs, medium-term outcomes (2025 - 2030), longer term outcomes (post 2030), and impacts.

The ToC also identifies the underlying assumptions and dependencies within the causal logic chain, as well as the potential risks to the successful delivery at each stage.

Figure 2.1: Theory of Change (ToC)



2.4 Delivery model and funding

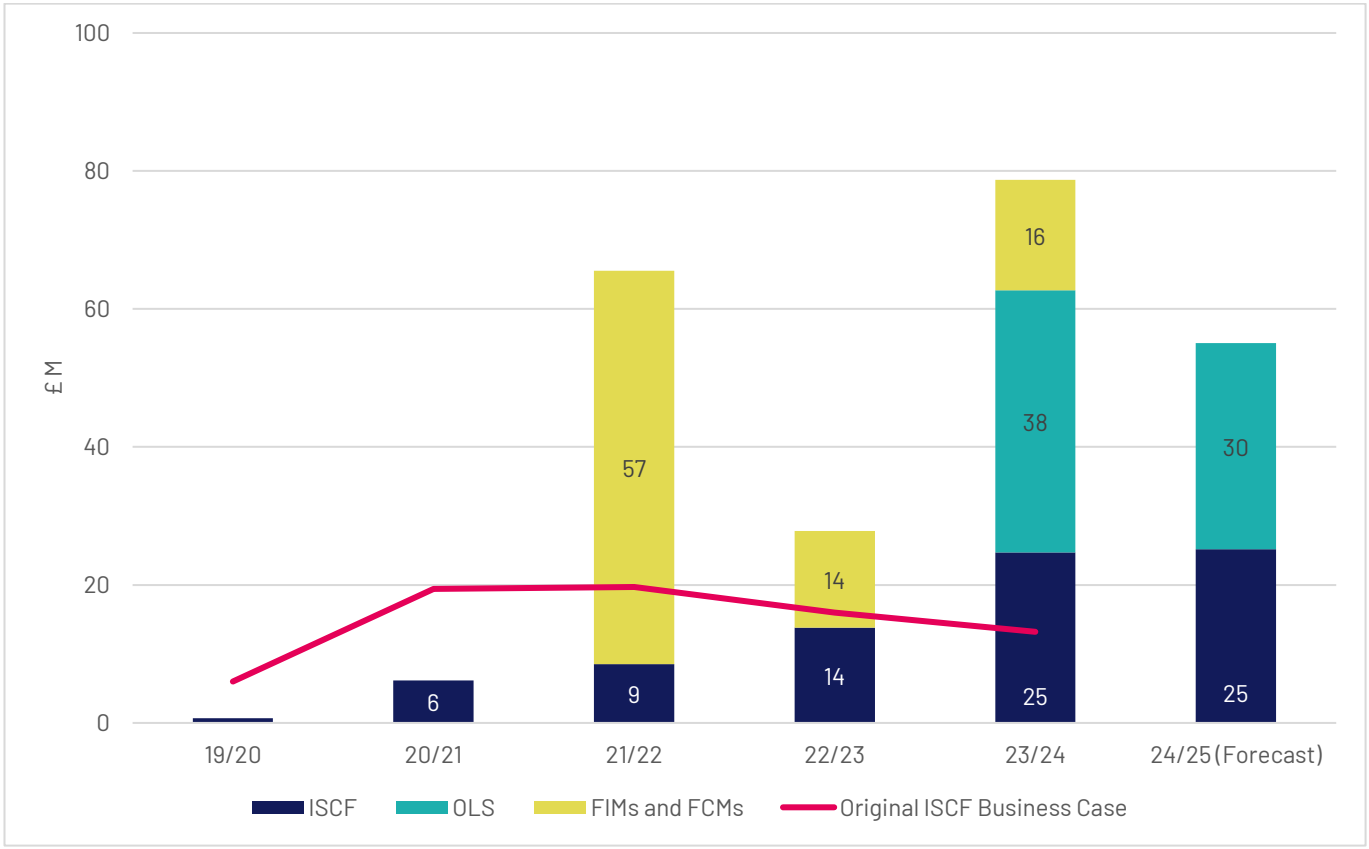
The ADD Challenge was delivered as part of the ISCF, which was established in 2017 to address the big societal challenges facing the UK. The ISCF comprised 23 challenges spanning the four themes of the 2017 Industrial Strategy, including separate programmes addressing the growing incidence of chronic diseases and cancers in ageing populations. Alongside the decision to fund and develop this novel research resource through the ISCF, the ADD business case recommended establishing a private limited company called Our Future Health to deliver the programme. This was to provide greater autonomy and flexibility in securing partners, funding and governance. The private limited company was incorporated in September 2019. Initially, Our Future Health was hosted at an established health research organisation (Cancer Research UK – CRUK) for a short incubation period, before separate office space and infrastructure were rented out. A longer incubation period within an existing organisation was seen as less suitable, as they had the potential to restrict freedom to recruit, limit partnership development, and introduce more complex procedures for spinning out Our Future Health as an independent organisation. Since the end of the ADD Challenge on 31 March 2025, Our Future Health has continued to operate as a private limited company. It is also registered as a charity with the Charity Commission.

Funding for the ADD Challenge included:

- An initial **£79 million** of Government support through ISCF.
- Co-investment commitments from 16 Founding Industry Members (FIM) and Founding Charity Members (FCM) of **£184.5 million** in total, of which **£131.5 million** was realised within the Challenge duration up to 31 March 2025.
- In addition to the **£79 million** ISCF funding, OLS provided further funding of **£51 million** in 2023 and **£16.9 million** in 2024 towards the Challenge, via DSIT funding allocations to UKRI.

Initial funding was provided by the MRC via an up-front grant, this changed to a funding in arrears model under Innovate UK's processes and standard monitoring arrangements. **38Figure 2.2:** overleaf sets out the spending profile against the initial spending plans, as per the business case. The business case projected full recruitment as well as the development of core processes and capabilities delivering a fully functioning resource at a total cost of £239m (of which £79 million Government funding). Actual costs of the ADD Challenge, as of 31st March 2025, were around £278.4 million, with several core processes and capabilities still under development. Projected costs of participant recruitment were significantly below actual costs. Whilst the business case projected a unit cost of recruitment of £58 per participant fully recruited, actual unit costs reached £132 per participant. This was mainly driven by a necessary change in recruitment method away from NHS-based recruitment, given wider pressures on the health system following COVID-19 – overall, £143 million was spent on recruitment up to 31st March 2025, including staffing, logistics and handling, blood collection, and contractor costs.

Figure 2.2: Total Funding Released per year vs initial plans



Source: Analysis of Our Future Health documents. Notes: 1. Forecast figures for 2024/25 are for Government funding only. Actual figures of Government, FIM, IM and FCM funding for 2024/25 are not yet available as Our Future Health has not yet published audited accounts for this period. 2. Government funding amounts include operating expenditure (OPEX) which covers staff, and some overhead costs associated with the ADD Challenge 3. OLS funding committed in 2023/24 was released in two instalments over 2023/24 and 2024/25.

After the end of the ADD Challenge, significant further funding for Our Future Health was announced along the 2025 Life Sciences Sector Plan[7], intended to support recruitment of more participants and the delivery of commercial clinical trials. This post-Challenge funding includes an additional £53 million from FIM and FCM committed investment expected to be realised between 2025 – 2030 and £58 million confirmed funding from OLS for 2025/2026, bringing overall programme funding to about £350 million up to 31st March 2026. A further up to £354 million government funding has been announced for 2026-2029, to enable the resource to continue to recruit up to 5 million participants and include 50,000 of its participants in commercial clinical trials per year by 2030. This will bring total Government funding for its first 10 years to around £743.5 million, close to a tenfold increase of the original Government contribution of £79m. Whilst initial Challenge funding of £79 million leveraged 2.5x (£184.5m) in match-funding, the vast majority of post-Challenge funding for Our Future Health to date is provided through Government.

[7] Life Sciences Sector Plan available at https://www.gov.uk/government/publications/life-sciences-sector-plan

2.5 Progress to date

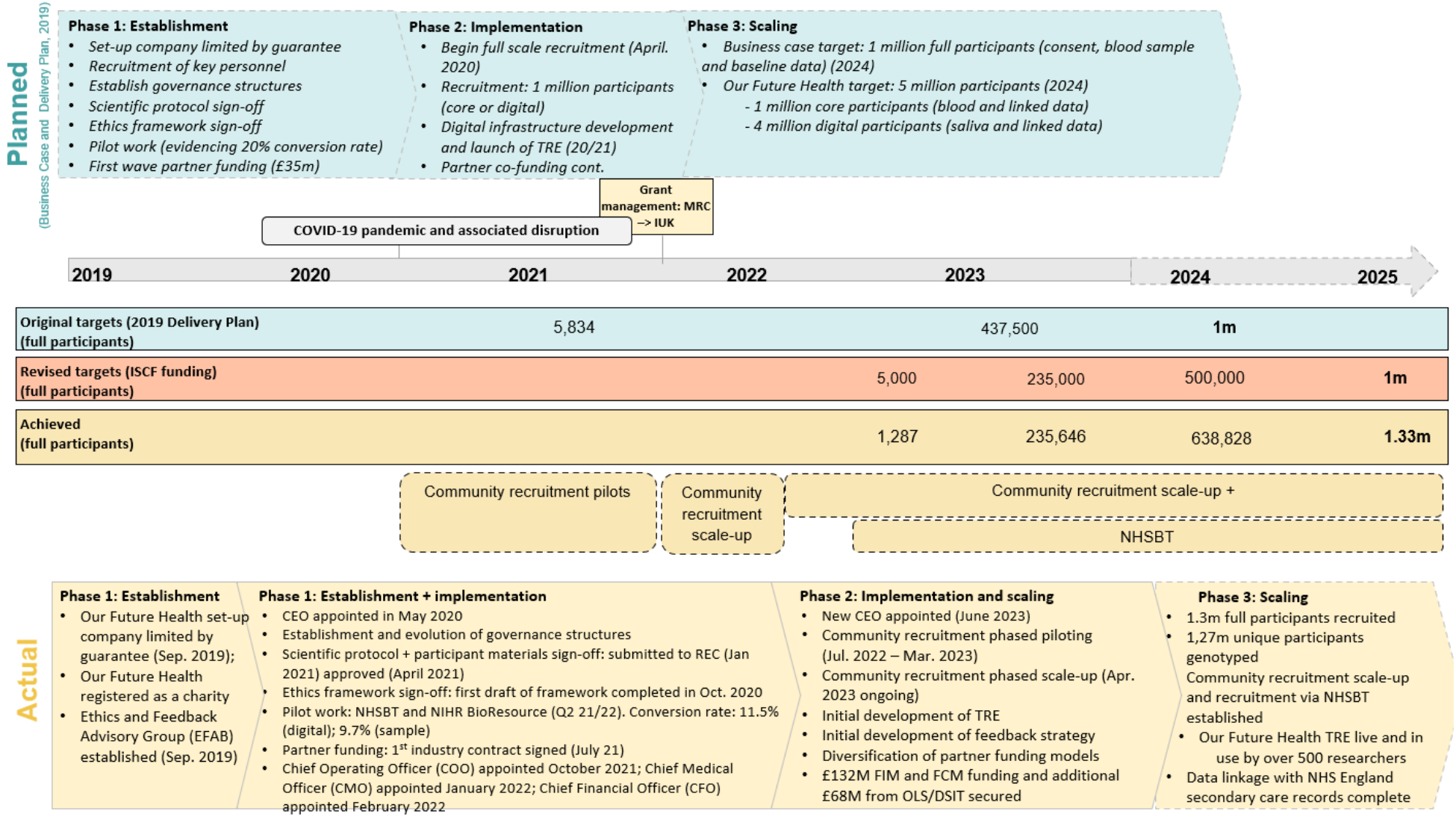
Progress is summarised below against UKRI's original delivery plan, which was structured into three main phases (Establishment, Implementation, Scaling).

- **Phase 1 (Establishment):** As discussed above, Our Future Health was successfully established as an independent legal entity in late 2019. However, it encountered early delays in being operationally ready, establishing core business functions and a permanent location, and appointing key personnel, including the Chief Scientific Officer and Chief Operating Officer. These delays were largely attributable to the COVID-19 pandemic and the pressure this placed on the NHS, as well as a lack of tailored operational support/ a suitable host organisation during initial set-up of Our Future Health. The delivery model described above granted significant flexibility to Our Future Health during this phase, and use of MRC processes allowed funding to be dispersed upfront which gave Our Future Health flexibility and a cash runway. However, the lack of oversight and operational support under these processes also placed greater operational risk with Our Future Health at critical points during set-up, whilst limited operational, administrative and financial expertise was made available to support the set-up of Our Future Health as an independent delivery body. A later funding in arrears approach managed risk more carefully, however associated monitoring was sometimes too focussed on scientific and recruitment aspects of the Challenge – and did not put the required emphasis on the timely setup of core business and operational functions.
- **Phase 2 (Implementation):** Initial recruitment pilots were carried out with NHS Blood and Transplant (NHSBT) and the National Institute for Health and Care Research (NIHR) BioResource. These were planned for 2019 as part of Phase 1 but were delayed until 2021. Gateway reviews to release funding were delayed up to March 2023 to gather evidence of recruitment progress. The Challenge received a no cost extension following the COVID-19 pandemic; this altered the Challenge end from March 2024 to March 2025. Large-scale - community recruitment commenced in October 2022. By July 2023, Our Future Health had recruited just over 236,000 participants. The ISCF funds in this phase were released to enable Our Future Health to develop its digital platform.
- **Phase 3 (Scaling):** As part of full-scale recruitment, non-personalised letters and weekend appointments were introduced by Summer 2023. A revised set of recruitment milestones were agreed in summer 2023 up to the end of the Challenge, superseding the previous funding and milestone arrangements. The availability of additional OLS funds led to further revisions of final milestones and updated delivery plans to increase the resource's diversity and clinical trial readiness. . Our Future Health subsequently met all revised milestones up to

recruiting 1.33 million participants, and met the genotyping target for processing 1.35 million blood samples[8] .

[8] The number of genotype assays conducted is higher than the number of unique participants genotyped. This is as some samples needed to be re-analysed due to a rate of failure experienced with initial assay technology

Figure 2.3: Progress made by the Challenge against revised Challenge milestones and timeline (up to 31 March 2025)



Beyond successful participant recruitment, the programme sought to set up core processes, functions and capabilities required to fully exploit the potential of Our Future Health as a novel large-scale research cohort.

Trusted Research Environment: The TRE became operational in June 2023 and began to facilitate research studies. This compared to initial plans to roll out digital infrastructure, including a secure collaboration environment for researchers, over 2020/21. As of March 2025, **24 studies were active on the TRE**. Researcher interest is growing, with over **900 researcher accounts created and 529 researchers approved**, with many preparing study applications. Alongside secure data access and analysis tools, development of a public data browser is also underway which, once launched, will enable researchers to assess data before submitting applications.

Genotyping: By 31 March 2025, approximately 1,306,000 genotype assays had been run, resulting in approximately 1,270,000 unique participants genotyped. Additional funding has enabled genotyping of up to 350,000 more assays in early 2025, including repeat assays for previously failed samples. Consequently, the overall target for the end of the Challenge was uplifted from covering 1 million participants to 1.35 million assays run. In 2025, the focus on genetic data will shift from genotyping to imputation (filling in gaps in the genetic information by inference using existing datapoints in the assay) to enrich the resource, and to making the resulting data available in the TRE.

Data access and linkage: Our Future Health aimed to access and link NHS records in England over 2020/21. This included primary care, secondary care, cancer registration and death registration data. It would then expand to all four UK nations as data-sharing agreements were concluded. After the TRE went live in 2023, Our Future Health achieved access to secondary care health records, cancer and death registrations in England, with many records already linked to participants. However, access to primary care data is harder to access for research organisations in part due to the different IT systems used by GP practices in England and GP's legal responsibilities as data controllers . Access in the devolved nations has also been delayed, with applications still under review or awaiting legal advice. By 31 March 2025, the **TRE contained data covering 1.6 million people** who consented to take part and completed the baseline health questionnaire. Alongside full participants, this number includes people who have not yet fully completed the recruitment process. Of these 1.6 million participants**, 1.36 million had been linked to an NHS England medical record**. Clinical measurements data (excluding cholesterol) was available on **1.17 million participants.** These measurements include height, weight, waist circumference, blood pressure, and heart rate, significantly enhancing the utility of the dataset for researchers. Of the 1.27 million participants who have had their sample genotyped, **651,031 had genotype data available** in the TRE with the remaining scheduled for staged release.

Our Future Health's achievements in data linkage reflect both significant progress and ongoing challenges. The integration of NHS England secondary care data and the release of clinical measurements data were major milestones demonstrating a commitment to enriching the

resource. However, the inability to access primary care data, due to complexities in how this data is stored and governed, presents a major barrier, in particular for research into early disease development and primary care interventions. In addition, variation in progress across the devolved nations adds further complexity to the data linkage landscape.

Progress in the devolved nations remains mixed. In Scotland, a decision from the Public Benefit and Privacy Panel is still pending. In Wales, a final draft of the tripartite agreement was awaiting signatures. In Northern Ireland, meetings are being scheduled with key personnel to advance data linkage discussions. To support these efforts, Our Future Health has developed a broad stakeholder and partnerships strategy, engaging with government departments, the NHS, and representative bodies (including those for primary care). These partnerships have been productive in facilitating early data access exploring alignment with NHS care pathways. However, given the complexity of the programme, some relationships require careful management, particularly where partners are looking to mitigate perceived risks or assert specific interests.

Participant feedback: Our Future Health planned to pilot feedback in 2019/20 and roll out routine participant feedback through its planned digital platform in FY 2020/21. However, by March 2025, **it has only provided feedback on physical measurements collected in appointments**. While Our Future Health provided cholesterol feedback to participants (via appointment point-of-care testing), this was withdrawn by 31 Dec 2024.

Recontact: Our Future Health planned to establish recontact consent and protocols in 2019/20, begin operational for recontact from 2020/21, and start large-scale recalls of participants from 2022/23. However, by March 2025, **a recontact system is not yet live**. A first **recall-by-genotype pilot is now underway** and broader recontact processes are under development over 2025.

Pricing: Our Future Health has developed a tiered pricing strategy for researchers to access data currently available in the TRE, developed through internal asset valuations, benchmarking exercises and stakeholder engagement. In parallel, a pricing model for recontact services is in development, with detail on how this pricing will be set across organisations or for types of study later in 2025. Pricing for sample access requests has not yet been determined. In response to concerns from SMEs about affordability of access, an Early Adopter scheme for SMEs was launched in November 2024, providing discounted access to the resource. In March 2025 Our Future Health also hosted a dedicated SME community networking event which brought together over 15 SMEs, industry, charity funding partners, UKRI and other health research organisations.

Building and maintaining public trust: Our Future Health implemented initiatives to build and maintain public trust, and ensure the programme aligns with public interest. These efforts are primarily delivered through a Public and Participant Involvement and Engagement (PPIE) strategy. As part of this, a Public Advisory Board was established in 2021, composed of volunteers reflective of key population segments. In addition, Our Future Health held two deliberative dialogues with volunteers and members of the public in early 2024, focused on participant recontact and health

research feedback. In January 2025, the Our Future Health Involvement Network pilot was launched to further incorporate public and participant perspectives into the research programme.

3 Establishing and sustaining the resource

Key findings

- Recruiting 1.33 million full participants into the cohort was a major achievement. However, the focus on recruitment to date meant that the wider research infrastructure needed to fully realise the programme's wider social and economic impacts is still under development.
- The integration of NHS England secondary care data, cancer registrations, death records and the release of clinic measurement data were major milestones in enriching the resource. However, the inability to access primary care data – due to complexities in how this data is made available to organisations – presents a major barrier, particularly for research into early disease development and primary care interventions, which needs to be resolved.
- The funding model has enabled the financial and commercial risk of the programme to be shared between public and private sector sponsors. To manage this risk, the Challenge Programme Board has routinely monitored the financial sustainability of Our Future Health and sought assurances on its funding and financial sustainability. This has included requesting financial plans and clarifications on funding commitments from Our Future Health. The Board has also been able to scrutinise Our Future Health's spending, which includes the exploration of cost-saving measures, while remaining mindful of the potential wider impact on its recruitment progress and funding milestones (see section 2 for an overview of Challenge objectives and milestones).
- Our Future Health has made progress towards developing an operating model to sustain itself as a research service beyond the ADD Challenge funding. This has included an almost tenfold increase of Government support under the Life Sciences Sector Plan, and agreement of additional targets to increase size of the cohort to up to 5 million participants, and recruiting 50,000 participants into commercial clinical trials per year by 2030. Additional commitments by private sector funders have also been made beyond the Challenge duration, however these do not currently match the additional Government commitments.
- UKRI's funding, governance, and operational processes have enabled the Challenge to meet all recruitment milestones in developing a novel resource. While UKRI's governance mechanisms were robust and effective overall, they were not always fit for purpose when monitoring progress during the initial setup and establishment phase. The ISCF funding model has enabled successful co-funding and UKRI has adapted its contact with the programme to better align with Our Future Health's overarching governance. The company

limited by guarantee model has had both positive impacts and constraints on the delivery of the programme.

- After significant initial uncertainty arnd the actual cost of recruitment, Our Future Health has done well to manage recruitment costs. The unit cost for Our Future Health has increased slightly by 4.9%, from £122 per participant in November 2023 to £128 per participant in April 2024, in line with changes to recruitment practices, such as through reimbursement schemes and offering weekend appointments. Whilst unit costs might increase further due to an increased focus on underrepresented and hard to reach groups, cost projections have been robust compared to the initial business case and inception phase of the programme, pointing to a marked improvement in financial planning.
- The initial Challenge funding was, however, not sufficient to enable Our Future Health to reach the UKRI-defined target of 1 million participants by March 2025 (revised to 1.33 million participants and genotyping after additional government funding) or to fully establish key features in the resource such as recontact. Importantly, whilst the business case assumed a government contribution of 33% to deliver the Challenge, actual Government funding represented 57% of successful setup and Challenge recruitment targets.
- UKRI has shown flexibility when it renegotiated the recruitment and genotyping targets that needed to be met to release funding. This has enabled Our Future Health to progress towards its revised programme milestones. The decision to establish Our Future Health as an independent company limited by guarantee enabled it to successfully secure funding from industry and charity sources and liaise with additional government funders such as the OLS. This enabled Our Future Health to engage with a growing range of industry and charity partners .

3.1 How has planning and implementation of the Challenge enabled the successful establishment of the resource?

3.1.1 Government funding of Our Future Health

The ISCF funding model was appropriate for the purpose of addressing market failure and delivering the required support to build a novel research resource. Market failure is common in fields such as health research, and the matched funding model addressed these effectively, while sharing risk with private sector match funders. The funding model also allows companies interested in the resource data to work collaboratively with public and private sector partners. Whilst the risk-sharing model can be seen as an effective model for delivering wider social and economic benefits from health research resources, the initial business case did significantly underestimate the amount of Government funding required to deliver against all objectives of the programme. Cost increased due to three key issues:

- The unique and highly ambitious nature of the programme required a specialist team to oversee set-up of Our Future Health as an organisation. Delays during this phase (set out in section 2 above) such as in appointing key staff and functions contributed to some overspend compared to estimates set out in the business case.

- The implementation phase also required additional funding. This stage focused on setting up recruitment pilots alongside operational set-up and involved changes in recruitment strategy, which contributed to additional costs which the original business case did not account for. Many of the underlying causes were difficult to anticipate (such as COVID-19 increasing pressure on primary care and the NHS more broadly, making recruitment through NHS routes unviable), however, year-on-year cost increases and scenarios, as part of stress testing, could have been anticipated had the core delivery team and organisation been setup sooner.

- As a result of UKRI and funders setting numerical milestones for Our Future Health which prioritised recruitment, there were delays in developing other key aspects of the resource, such as the TRE and the process for participant feedback and recontact. The approach to milestone setting delayed the broader realisation of the value of the resource. While prioritisation was necessary, a more balanced approach between recruitment milestones and milestones on developing core processes and capabilities to enable the wider potential of the cohort would have improved confidence across Government and match funders.

Since Spring 2022, Our Future Health has been successful in raising substantial additional funding from industry and charities, underlining how the co-funding model of the ISCF Challenge helped to reduce risk to Government[9]. Across the ADD Challenge duration, the balanced distribution of funding between the government and private partners demonstrated that the overall financial and commercial risk for the programme were shared across both parties. This risk-sharing model stands out compared to other health research cohorts. For instance, All of Us relies solely on Government funding, and 45 and Up relies on Government funding and access fees. It should however also be noted that significant additional Government funding provided beyond the duration of the Challenge has not leveraged the same support from industry and charities, raising questions about how risks of future delivery and operation are shared between Government and match funders.

UKRI has been flexible in its approach to releasing Challenge funding, by renegotiating the milestones for scaling-up. Following several rounds of additional funding from DSIT and OLS, it has been able to effectively query the progress that Our Future Health is making through the Challenge

[9] At the time of drafting, a slightly greater portion of the total program costs for Our Future Health is funded by the Government (53%) compared to industry and charities (47%). In the original business case, this proportion was different, with 67% of the funding intended to come from industry and charities and a lesser amount of 33% from the Government.

Programme Board and considered the appropriate timing of milestones to best enable Our Future Health to meet recruitment and genotyping objectives and make progress against diversity and other targets by March 2025. This follows on from earlier phases in the Challenge in which Our Future Health encountered difficulties to meet its original delivery timeline. It also reflects previous feedback that the funding model did not give Our Future Health the flexibility to deliver its aims without spending at risk or becoming reliant on external co-funding in such a way that it conflicted with the Challenge's targets and priorities.

Ensuring that the funding model enables Our Future Health to meet its aims within budget was important, so that investors and stakeholders had the required certainty that UKRI funding and co-funding streams will enable programme delivery. The trajectories and revisions to timings were agreed carefully through the ISCF Steering Board over Summer 2023 to recognise the context and complexity within which the Challenge has been delivered. However, the FIM and FCM expectations and payment milestones continued to differ from those originally agreed with UKRI, causing additional administrative overhead for Our Future Health. As part of the initial business case development and through the Our Future Health Founders Board, closer conversations between UKRI and industry may have enabled closer alignment.

Additionally, the Challenge funding model has provided greater flexibility to Our Future Health by enabling it, as an independent body, to seek and raise significant amounts of co-funding. This has included government, industry, and charity funding. The funding model also provides Our Future Health the opportunity to agree further funding arrangements with industry and charities.

The majority of Our Future Health's operating expenditure, just under 80% to date, was allocated to costs for participant recruitment. Whilst recruitment costs were significantly higher than set out in the business case, Our Future Health has maintained relatively low costs compared to similar research resources. Considering Our Future Health's total programme cost, the number of participants recruited, and adjusting for inflation, the cost per participant is moderately lower than UK Biobank and considerably lower than All of Us. However, there is a higher cost associated with measurements and sample collection and processing to a clinically accredited grade, which All of Us does but Our Future Health does not. The UK Biobank cost per participant was approximately £203 (adjusted for inflation) whereas Our Future Health's average recruitment cost per participant was £132. The UK Biobank's cost base reflects multiple appointments and a different set of baseline appointments and sample collections, along with downstream costs for establishing the biobank infrastructure from the outset. UK Biobank's recruitment strategy also followed established NHS routes, which differed to the community route Our Future Health has pursued. The average unit cost for Our Future Health has increased over the programme's life span in line with changes to recruitment practices such as through reimbursement schemes and offering weekend appointments. Unit costs of recruitment have been actively managed throughout by Our Future Health. Activities to improve the response rate in recruitment drives, which is necessary in community outreach initiatives where the response from under-represented communities is

lower, and agreements with partners to implement weekend appointments, will by nature be more resource-intensive.

Each resource has also operated under a different timeframe which affects other non-recruitment costs such as the establishment of IT infrastructure. However, taking all this into consideration Our Future Health is offering value for a resource which has high potential to enable health research and support the life sciences sector. It is likely that the unit cost for recruitment will increase as Our Future Health's programme continues to scale up beyond the 1.33 million participants to date, driven by more costly recruitment of under-represented groups and re-engagement of individuals who have already received invitations but did not sign up. Alongside this, Our Future Health will incur costs for the delivery of additional research services such as provision of feedback, recontact services and clinical trials, as these become available.

3.1.2 Governance and programme management arrangements

UKRI's funding, governance, and operational processes have been suitable for enabling the Challenge to make progress in developing a novel resource. Governance mechanisms overseen through the Challenge Programme Board were robust and effective overall; however, they were not always fit for purpose during the initial setup and establishment phase, particularly in monitoring early-stage progress.

The business case considered several delivery models for the Challenge, including establishing a Research & Technology Organisation overseen by the MRC, incubating the Challenge within an existing organisation, and delivering the programme outside UKRI through DHSC funding. Delivering the Challenge through a company limited by guarantee was decided to be the appropriate delivery vehicle given its independent nature and the ambition to operate access to the resource on a subscription basis going forward.

Our Future Health designed and implemented governance arrangements separate to UKRI's Challenge governance, to review progress and conduct decision making. It adopted a multi-tiered structure to reflect its dual status as both a registered charity and a private company limited by guarantee. This included a Board of Trustees holding legal responsibility, an Executive Team, the Founders Board which funders and partners attend, the Trading Board to take commercial decisions, the Access Board to review applications, sub-committees for audit and risk management, and advisory boards providing external expertise on ethics, public engagement, scientific standards, diversity, and technology.

This model enabled Our Future Health team to operate independently without relying on a host organisation's existing approval processes, to independently negotiate with FIM/FCM, to create roles and recruit staff to them, as well as to take strategic decisions with a higher degree of flexibility.

However, the decision to deliver the Challenge through an independent company limited by guarantee posed some specific governance and delivery issues:

- There was some inherent tension between the chosen delivery model and the ISCF governance and operational arrangements. The delivery model gave Our Future Health substantial flexibility, allowing them to take a more independent stance which created some tensions with the ability of the UKRI Programme Board and Advisory Group to influence the programme, particularly at the start. At the same time, the initial team setting up Our Future Health lacked the required support to put necessary functions in place at speed (such as legal, accounting, operations). As a result, there was sometimes a mismatch of expectations between Our Future Health and UKRI.

- There was a sense that some duplication in governance structures was created across the Our Future Health and UKRI structures, and by implication, reporting commitments Our Future Health had to fulfil vis-à-vis its different funders.

- UKRI's governance mechanisms were robust and effective overall; however they were not always fit for purpose when monitoring progress during the initial setup and establishment phase**.** Additional expertise regarding operational setup might have allowed UKRI to identify and mitigate risks in the setup and establishment phase more effectively. For instance, during 2020 and most of 2021, Programme Board meetings did not consider aspects of operational set-up and filling staff positions as major programme risks. Additional operational expertise on the ADD Programme Board and Advisory Group, for instance covering legal, financial and operational aspects of establishing an independent body, might have helped mitigate risks specific to the setup and establishment of Our Future Health.

- Our Future Health was initially hosted by Cancer Research UK to provide general organisational support. This temporary arrangement ended in early 2021 as Our Future required more comprehensive operational support to effectively scale its operations.

- Some delays also occurred in recruiting key senior roles, such as the Chief Medical Officer, Chief Finance Officer and Chief Operating Officer role which subsequently proved critical in delivering the programme at speed and quality. Earlier recruitment of these critical roles would have alleviated pressure on the core Our Future Health team and helped to develop key operational activities (such as a scalable recruitment strategy in the case of Our Future Health) earlier and at lower cost.

These tensions were, to some extent, inherent to the chosen structure and were not fully resolvable (see also discussion in section 2). Nevertheless, UKRI has taken active steps to increase engagement with Our Future Health counterparts, flexibly adjust funding milestones at various stages throughout Challenge delivery, and maintained a visible presence on Our Future Health governance structures such as the Founders Board.

Post-Challenge public funding will be managed by the MRC within UKRI, and MRC and/or OLS may have their own monitoring requirements. Given the complex funding arrangement for Our Future Health, the MRC should continue to actively manage monitoring arrangements for post-Challenge funding, aligning it to existing oversight and reporting where possible. FIMs and FCMs are aware of the risk that arises from differences in monitoring arrangements among funders and are actively managing it through streamlining Founders Board discussions where possible.

3.1.3 Development of supporting research infrastructure

Building robust research infrastructure is essential for establishing and sustaining the resource, enabling secure researcher access, efficient, scalable data management, and the capacity to accommodate growing participant numbers and data volumes.

Whilst the Challenge recruitment targets have been met, the wider research infrastructure needed to fully realise the programme's wider social and economic impacts is still under development. As of March 2025, **over 900 researchers had created accounts**, with **529 registered users** and **24 active research studies** running within a TRE. The platform is hosted in Azure cloud infrastructure to process, store, quality control, and de-identify participant data. This platform handles multiple data types, including questionnaire, genetic, linked NHS, and clinical measurements data, and supports automated workflows and timely data releases into the TRE. The platform's scalability allows handling of the growing volume of participants and data types, ensuring efficient processing of withdrawals, and maintaining high data security. A 24/7 security operations centre has been established and the programme is compliant with the NHS Data Security and Protection Toolkit.

Several components, such as usability of the TRE and the full functionality of the data browser and secure browser, remain under development, with feedback from early users informing ongoing iterative improvements. Investments have been made to enhance the TRE, including improved ingress and egress for tools, code, and data via an 'airlock' system, and a sandbox environment for prospective users. Additional workflow tools have been identified to integrate into the TRE, and a secure command line interface logging functionality has been implemented. These improvements will increase the usability and relevance of the resource to researchers seeking to carry out data analysis in a secure setting. The data platform and TRE collectively support secure access and data management, with the potential to expand into areas such as recontact studies and participant feedback. The ongoing development of a public-facing data browser will further enhance data discoverability for researchers. Delays to delivering this will make it more challenging for researchers to directly engage with and review data in the resource, which could affect researcher demand. Our Future Health has also sought to agree terms for industry and charity partners to use their own certified TRE (cTRE) to access and analyse participant data. This can provide researchers with more opportunities to use Our Future Health data alongside other in-house datasets or tools. Our Future Health is agreeing terms for cTRE use with data controllers such as NHS England, and needs to cascade these to cTRE owners.

Together, the scalable data platform and secure TRE provide a strong foundation for future growth and expansion. As the cohort size and data volume increase, these systems will be critical for maintaining efficient data management, secure researcher access, and the capacity to support increasingly complex research projects. Continued investment in infrastructure development and enhancement will be essential to fully realise the long term vision of the programme.

Timely achievement of genotyping targets has been managed through partnerships with Illumina and Eurofins, while participant recruitment has been delivered through community partners including Acacium and Boots. It has been necessary to rapidly adjust supplier arrangements during early scale-up, which has helped manage changes in the programme, but also presented a risk to managing relationships with suppliers effectively. To manage uncertainty around funding and recruitment volumes, break clauses were introduced into contracts. Despite these challenges, partners have broadly maintained effective working relationships. The unprecedented nature of what Our Future Health is building limits the pool of available providers and requires highly complex technical briefs and specifications.

3.2 To what degree is the long term sustainability of the resource secured, and what has contributed to this?

3.2.1 Establishment of a viable Our Future Health business model, including additional committed funding from non-government sources and an established access pricing strategy.

The establishment of Our Future Health from scratch and scaling it to a fully independent and staffed organisation with funders was a highly ambitious endeavour. In that context it has made significant progress developing a business model supported by diverse funding streams. However, despite the level of commercial interest and the funding secured from non-government sources, Our Future Health does not yet have a viable business model to operate independently of government funding. This is demonstrated by the significant drop of commercial funding beyond the end of the ADD Challenge, when compared to Government support received to continue operations and recruitment. However, the full value of the cohort data has clearly not yet been realised, suggesting that there is significant potential to increase commercial income in the future.

The decision to establish Our Future Health as a charity and a company limited by guarantee in Phase 1 of the Challenge successfully provided it with the flexibility needed to secure funding from industry and charity sources, while also enabling engagement with government funders such as OLS. This structure allowed Our Future Health to engage with a growing number of industry and charity partners and to clearly articulate the value of the resource to the wider research community.

By highlighting the potential commercial returns, the unique value of the resource, and opportunities to contribute to strategic decision-making via the Founders Board, Our Future Health secured £154 million in funding from FIMs (currently fifteen) and £12.5 million from one IM,

totalling £166.5 million from industry. The creation of an Associated Industry Membership for mid-sized pharmaceutical companies is expected to further diversify income streams. In addition, Our Future Health secured approximately £18 million funding from four FCMs and introduced a Charity Alliance Model to enable smaller charities to participate by pooling financial contributions and engaging collectively. These strategies have proven effective to secure commitments of **£184.5 million** surpassing the original **£160 million** matched funding target.

The future operation of the resource will depend on the nature and extent of user demand, and the completion of features such as participant recontact. The business model to operate Our Future Health beyond the ADD Challenge was still under development at the time of this evaluation – with feedback from interviews suggesting that many current and potential industry and charity funders expecting core functions and capabilities such as imputation and recontact to be developed before further investments are made.

Further revenue streams are being explored. Our Future Health developed a competitive tiered pricing strategy for data access, with the aim of balancing commercial viability with affordability. It has taken efforts to ensure it can test or adjust prices which reflect the uniqueness and value of the resource, while also prioritising accessibility to academic researchers and SMEs. As part of this, prices may adjust regularly as the resource offers greater numbers of participants and datasets. However, it remains uncertain whether all groups of researchers will respond to price rises as each has highly varied requirements. There is also limited public visibility in prices and whether data publicised by Our Future Health will be in the exact format needed for users of the resource.

3.2.2 Promotion of external interest from other potential users of the resource

The Challenge has successfully generated interest among some priority user groups through targeted events, outreach activities and regular updates via the Our Future Health researcher portal. For example, the programme has hosted charity research webinars and a Science and Strategy Day to engage stakeholders. These efforts have contributed to a growing user base, with over **529 researchers** having access to the TRE.

To support groups where pricing is a key concern, particularly SMEs and academic researchers, Our Future Health has waived or discounted access fees. It has also conducted dedicated sessions to engage with SMEs and gather feedback on pricing of the resource. Additionally, the Early Adopter Scheme for academic ambassadors has helped promote the resource to academic communities.

Both the academic scholars Early Adopter scheme and the SME Early Adopter programme have supported product development and helped Our Future Health to improve the user experience of the TRE.

Still, uptake has not yet reached a critical mass where awareness of the resource and its value is spreading organically through research networks. There is also still scope for further promotion of

the resource, beyond the initial engagement events and outreach undertaken. For instance, during Ipsos fieldwork, some researchers affiliated with charities reported not having been contacted or engaged by Our Future Health.

Whilst the resource holds significant potential to attract commercial users, many FIMs have not yet actively used the resource, as they are waiting for additional datasets, such as primary care data, to become available.

3.2.3 Maintaining public trust in the resource

The loss of public trust is a critical risk that could impact the ability to recruit and retain participants and Our Future Health has implemented a number of risk mitigation strategies. The organisation regularly assesses attitudes to data use, through mechanisms such as the Participant Reported Experience Measures, feedback surveys, and ongoing engagement activities. Wider assessment of public attitudes to the use of health data is assessed much less frequently.

UKRI and Our Future Health have both contributed to maintaining public trust. The ADD Challenge team logs risks related to public trust while Our Future Health actively captures public interest and sentiment through survey and engagement strategies. These include the management of a Public Advisory Board, running a public attitudes tracker, and engaging with media. Commitments to transparency, such as publishing plain language summaries via the Health Data Research UK (HDR UK) Gateway, and to cybersecurity through the establishment of a 24/7 Security Operations Centre, demonstrate awareness of risks associated with data breaches and lack of transparency in how participant data is used.

Going forward, Our Future Health must routinely monitor and evaluate its communication strategies, ensuring they remain responsive to rapidly evolving public expectations. It must continue to prioritise the clarity and accessibility of information shared in the public domain, particularly in relation to engagement initiatives across the diverse communities it seeks to recruit from.

4 Recruitment and cohort characteristics

Key findings

- Our Future Health has achieved its 1.33 million full participant target by March 2025. In doing so, it has established a globally significant research cohort. Our Future Health has performed well in implementing a range of recruitment strategies, which have effectively supported the scale up needed to reach this milestone. For example, recruiting across multiple channels, improving the conversion of joiners to full participants (with a current rate of 48%), introducing weekend and walk-in appointments, effective use of CRM tools and piloting initiatives such as reimbursement.
- However, it has not yet achieved full representativeness. In particular, among younger adults, those living in the most deprived areas, and in specific ethnic groups.

4.1 What progress has the Challenge made against its planned impact, as set out in the Theory of Change?

All outcomes in the Challenge's ToC are underpinned by the effective recruitment of cohort participants. Specifically, the ToC outlines that the Challenge should deliver a **representative cohort resource of 1.33 million participants, characterised and consented for recontact.** This outcome, in turn, will enable more clinical studies that include underrepresented groups, aiming to reduce health inequalities.

The scale of this ambition is globally exceptional, and reaching the targeted cohort size within a limited timeframe would have been a challenge for any organisation, particularly one newly established.

By achieving its target of 1.33 million participants by March 2025, Our Future Health has successfully established a globally significant novel and large-scale R&D resource. This achievement makes it one of the largest population studies in the world.

Recruitment for Our Future Health began in Q2 2021/22, and after a period of pilot activities, recruitment ramped up significantly in Q2 2022/23. During the large-scale recruitment, an average of 483,000 participants were recruited per year.

For information[10], the All of Us programme (USA) recruited approximately 121,000 participants per year between 2018 and 2024 resulting in a total enrolment of around 863,000. The UK Biobank recruited approximately 100,000 participants between 2006 and 2010 resulting in a cohort of 500,000 participants.

It is remarkable that Our Future Health has recruited at a rate four to five times faster than these programmes and has registered two to three times more participants. It is however important to point out that the target population and the samples and measurements the All of Us programme and the UK Biobank collect differ from those of Our Future Health and therefore direct comparison should be made with caution.

Representativeness of the cohort has not been fully achieved using the UK Census as a benchmark. Our Future Health set internal operational targets for the socio-demographic breakdowns in the UK Census (age, ethnic groups, socioeconomic backgrounds). These targets assumed that alignment with the Census was impractical and instead assessed the organisation against practical benchmarks for representativeness. While Our Future Health has recruited more individuals than other large cohorts, several key groups remain underrepresented, limiting the extent to which the cohort reflects the diversity of the UK population:

- Age: Young adults (age 18-29) represent 18.7% of the Census but constitute only 7.4% of Our Future Health's cohort.[11]
- Underrepresented ethnic groups: those from Bangladeshi ethnicity represent 0.8% in the Census versus 0.2% in Our Future Health; those from Pakistani ethnicity represent 2.1% in the Census versus 0.6% in Our Future Health, and African, Caribbean and Black other ethnicities represent 3.3% in the Census versus 1.5% in Our Future Health.
- Participants from deprived socioeconomic backgrounds: recruitment from the five most deprived IMD deciles fell below the 10% target for each group: IMD 1, most deprived, (4.9%), 2 (6.3%), 3 (7.6%), 4 (8.6%) and 5 (9.3%). This suggests that the under-representedpopulation resides in the most deprived areas in the UK. As IMD is an area-level measure, these participants may not represent the full socio-economic spectrum within their deciles and may under-represent the most disadvantaged individuals. Triangulation with income, education, or other indicators would help confirm representation and inform strategies to reach underrepresented groups.

[10] Figures are approximate. Based on All of Us recruitment of 850,000 participants from 2018 to 2024 and UK Biobank recruitment of 500,000 participants from 2006 to 2010. See https://researchallofus.org/ and https://www.ukbiobank.ac.uk/enable-your-research/about-our-data/
[11] See Annex 4.

- Gender: Females represent 55.4% of Our Future Health's cohort but 51.7% in the UK population, meaning they are overrepresented, while males represent 44.6% of the Our Future Health cohort but 48.3% in the Census cohort, and so are underrepresented.

Underrepresentation of young adults, specific ethnic groups, and participants from low socioeconomic backgrounds is a well-documented challenge for longitudinal cohort studies.[12,13] Our Future Health sought to address these challenges by launching a range of pilot initiatives and engagement activities aimed at improving cohort representativeness (see below).

To meet Challenge targets to be truly representative, Our Future Health must also recruit participants from across the UK. To date, the vast majority of recruitment has taken place in England, with approximately 1.33 million participants, accounting for 98.2% of the cohort. Recruitment in Scotland began in June 2024, with around 17,000 participants enrolled, accounting for 1.3% of the cohort. Recruitment in Wales started in September 2024, contributing approximately 7,000 participants (0.5%)[14]. Recruitment in Northern Ireland, expected to begin in early 2025, has been delayed and is anticipated to start at the end of 2025.

The systems for participant recontact, ongoing engagement, and feedback are not yet operational, but aspects are expected to be implemented by the end of 2025, such as data access processes, the invitations for participants to enrol in follow-up studies and the internal capabilities for targeted engagement and providing health insights to participants.[15] According to FIMs, these systems will be essential for maintaining long term participation, enabling recontact for follow up studies, and supporting inclusive clinical studies, particularly among underrepresented groups.

Based on available data, we conclude that Our Future Health has **met** one of its recruitment objectives by March 2025, achieving the target of 1.33 million participants, although the other objective of full representativeness was not attained.

4.2 What factors enabled or hindered progress towards the 1.33 million recruitment milestone?

Overall, Our Future Health has performed well in implementing diverse recruitment strategies, which have effectively supported the scale up needed to reach the 1.33 million participant milestone However, financial constraints and delays caused by the COVID-19 pandemic have limited earlier progress. Ongoing challenges include increasing conversion rates and reducing average recruitment costs per participant.

[12] https://www.gov.uk/government/publications/the-report-of-the-commission-on-race-and-ethnic-disparities/health
[13] https://journals.sagepub.com/doi/10.1177/01410768241233109
[14] Recruitment data provided by Our Future Health.
[15] Recontact Draft Roadmap for Capability Development (May 2025) provided by Our Future Health

A key enabler was the use of multiple recruitment channels, including NHS DigiTrials, non-personalised letters and NHS Blood and Transplant (NHSBT). Between October 2022 and July 2023, recruitment activities relied primarily on invitations via NHS DigiTrials. According to Our Future Health, this recruitment channel provided a cost-effective route for recruiting at scale and it represented approximately 80% of total invitations sent by Our Future Health. [16] However, one of the limitations of NHS DigiTrials is that they do not permit repeat invitations. In addition, NHS DigiTrials have limitations in reaching all potential participants as some individuals may have chosen to use the National Data Opt-Out service (approximately 5%[17]), do not update their contact details or do not engage with the health system. For these reasons, in August 2023 Our Future Health introduced invitations via non-personalised letters (NPLs) to households, which are now the main recruitment channel. In addition to NHS DigiTrials and NPLs, Our Future Health also recruits via NHSBT: those that donated blood or platelet were invited to join Our Future Health by email. As of March 2025, these channels supported the distribution of over 47 million recruitment invitations, leading to:

- 3.2 million registered participants.
- 2.3 million consented participants.
- 1.7 million questionnaires submitted.
- 1.33 million participants, representing an approximate 2.8% recruitment rate.

An analysis of recruitment rates (the proportion of participants relative to the number of invitations) by recruitment channel shows that DigiTrials average recruitment rate since 2022 is 2.9%, peaking in the last quarter of 2023 and first quarter of 2024 at around 7%.[18] NPLs remained relatively stable at around 1.6% recruitment rate since its introduction in 2023. It should be noted that while invitations by NHS DigiTrials are addressed to individuals, invitations via NPLs are addressed to households with one or more eligible participants, and thus NPL response rates calculated per invitation letter is inherently an estimate. The number of total invitations sent via NHSBT by March 2025 was unavailable, but previous reports estimated recruitment rates of 1-2% through this route. Although NHSBT successfully enrolled a substantial number of participants (over 56,000), this represents only 4.2% of the total Our Future Health cohort, suggesting it is unlikely to be a scalable alternative.[19]

It is challenging to compare these recruitment rates with those from other initiatives, as like-for-like comparisons are not possible. For example, recruitment rates via invitation letters were around

[16] As reported by Our Future Health in the 28 February 2024 update to the ADD Programme Board
[17] NHS national data opt-outs: trends and potential consequences for health data research (2024) BJGP Open. Available at: https://doi.org/10.3399/BJGPO.2024.0020
[18] Recruitment data provided by Our Future Health, March 2025
[19] As reported by Our Future Health in the April 2024 update to the ADD Programme Board.

30% in China's Kadoorie Biobank and 19% for Australia's 45 and Up study[20]. However, both the recruitment methods and the target populations differ substantially. In the Kadoorie Biobank, invitation letters were supplemented by door-to-door, community-driven follow-ups, and recruitment took place during early 2000s in China, under different demographic conditions. In the 45 and Up study, the inherent focus on older populations and its relatively smaller scale makes it not directly comparable to Our Future Health, which aims to achieve a representative sample of the UK population, including all adult age groups, at a much larger scale.

Below we provide a breakdown of how each recruitment route contributed to the recruitment of 1.33 million participants:

- 489,845 participants recruited via DigiTrials (36.6% of total participants)
- 505,235 participants recruited via NPLs (37.8% of total participants)
- 56,775 participants recruited via NHSBT (4.2% of total participants)
- 6,227 participants recruited during Community Engagement activities, marketing and other events (0.47% of total participants)

The remaining 278,320 participants (20.8% of the total cohort) are reported by Our Future Health to have joined organically, meaning they were not directly recruited through the above-mentioned recruitment channels. This relatively large proportion may reflect the influence of word of mouth, media coverage, or the broader impact of NPLs, such as prompting discussion within households, families or communities.

Another important enabler of recruitment was the introduction of participant reimbursement in January 2024, a £10 voucher to offset travel costs. Reimbursement was introduced in stages, starting with paper supermarket vouchers piloted in April 2023.[21] Following internal reviews of scalability, digital delivery, ethical considerations, and financial viability, a three-month national pilot (July to October 2023) was launched. The pilot demonstrated a 0.5% increase in recruitment rates (from invitation to full participant), with particularly strong improvements in lower IMD quintiles and among younger age groups.[22] These findings supported a cost-effectiveness assessment, which informed the approval for wider rollout of the reimbursement scheme.[23] Between Q3 2023/24 and Q4 2023/24, the proportion of participants joining the cohort organically increased from approximately 22% in earlier quarters to nearly 30%.[24] Although it's not possible to

[20] 45 and Up Study Collaborators (2008) Cohort Profile: The 45 and Up Study. Int J Epi 37: 941-947
[21] Interviews with Our Future Health
[22] As reported by Our Future Health in January 2024 'Plans for recruiting participants from diverse communities'
[23] Our Future Health participant reimbursement – national pilot review and general rollout
[24] Recruitment data provided by Our Future Health, March 2025

confirm that this increase was only driven by the introduction of reimbursement, it is plausible that reimbursement may have contributed to this.

Since its inception, Our Future Health has undertaken a range of measures to increase the rate of participant conversion – the proportion of individuals who move from registration and consent to becoming full participants (completion of questionnaire and provision of biological sample). To support this, Our Future Health has applied behavioural science approaches, including:

- Regular newsletters to sustain engagement.
- Informing consented participants when recruitment clinics are operating in their local area
- Sending targeted reminders encouraging participants to complete questionnaire and/or book an appointment

In addition, Our Future Health has used data analytics to better understand patterns of participant behaviour, particularly around missed appointments or delayed completions.[25] By piloting different reminder schedules (for example, seven, three or one day(s) in advance of the appointment), Our Future Health has optimised timings that reduce non-attendance and encourage earlier responses. This approach improves overall conversion rates and connects directly to operational and financial considerations. For instance, by aligning reminder timing with contractual cut-off points, Our Future Health enables participants to cancel in time for appointments to be reallocated. This prevents wasted clinic sessions, improves efficiency, and increases availability for others. These actions are being further enabled by the enhancement of CRM capabilities, which allowed for more automated and targeted communications**.** However, these improved CRM features were only introduced late in 2024, meaning they had limited impact on earlier recruitment phases.

Recruitment data suggest these initiatives have had a demonstrable impact on participant conversion rates. There has been a steady increase in the proportion of registered participants who also booked clinic appointments and who became full participants (supporting data available in **Annex 7**: Our Future Health participants by recruitment stage). By contrast, the proportion of registered participants who provided consent, as well as those who submitted questionnaires, have remained relatively stable. This indicates that while engagement strategies have been effective in promoting conversion rates, more tailored interventions may be needed to improve the initial stages of engagement.

Importantly, the proportion of participants progressing through all stages of recruitment to become full participants has increased markedly, from 22% in Q4 of 2022 to 48% in Q4 of 2024/25, with a total across all years of 41% registered participants becoming full participants. This substantial

[25] Interview with Our Future Health, March 2025

improvement suggests that current initiatives are enabling participants to complete every step of the process. However, the data also highlights a major ongoing challenge: 59% of registered participants, approximately 1.9 million people, have not yet advanced to full participation. This gap highlights the importance of refining existing approaches and testing new strategies to further enhance conversion rates. For example:

- Our Future Health could consider the use of targeted incentives aimed at more under-represented groups, as well as providing study materials in languages widely spoken across the UK. These measures would not only improve overall conversion rates but also help to ensure that the cohort maintains its current socio-demographic representativeness.
- By advancing other aspects of Our Future Health, such as participant recontact and provision of health and genetic feedback, participants will begin to perceive tangible benefits from their involvement. This is expected to enhance both recruitment and conversion rates.
- There may also be scope for more innovative participant incentives, such as providing ancestry feedback akin to commercial offers.

Our Future Health reported an average recruitment cost of £132.03 per full participant,[26] which is relatively low compared to other large-scale cohort studies. For example, UK Biobank's cost per participant was approximately £203 (adjusted for inflation) which included a similar lifestyle questionnaire and blood collection albeit along with urine and saliva collections.[27] Nonetheless, recruitment costs remain significant in the context of Our Future Health's broader ambition to recruit up to 5 million participants.

Since 2024, Our Future Health has reprioritised its activities in response to financial constraints, including a strategic decision to slow down recruitment. Going forward, it will remain essential for recruitment strategies to be fully costed when setting out the achievement of a representative resource while also considering the long term sustainability of the recruitment strategy.

4.3 What factors limited the recruitment of underrepresented groups from achieving full representation of the UK population?

Our Future Health has made meaningful progress in recruiting participants from underrepresented groups, with over 130,000 participants identifying as from a non-white ethnic minority background. Despite this, certain socioeconomic groups remain underrepresented, with little change observed since the interim evaluation in March 2024.

[26] As reported by Our Future Health in May 2025 'Recruit costs summary for UKRI'

[27] See page 6; UK Biobank received £66 million to recruit 500,000 participants https://www.ukbiobank.ac.uk/media/errdpizx/ukb-consolidated-accounts-kpmg-signed-14122022.pdf

A significant limitation has been the proportion of registered participants who have not progressed through the full recruitment pathway. To improve conversion from registration to full participation, Our Future Health has tested a range of interventions including behaviourally informed email and SMS reminders. These initiatives had a positive impact in improving conversion rates, particularly among underrepresented ethnic groups.[28] Nevertheless, many participants remain part way through the recruitment 'journey' to become a *full* participant (i.e. consented, provided a usable blood sample, submitted a complete questionnaire and have not withdrawn). In late 2024, improved CRM capabilities were introduced to automate communications and support participant progression, though further improvements are ongoing.[29]

Our Future Health has adopted a 'test and learn' approach to improve inclusion, piloting and evaluating several targeted initiatives. These efforts have been well planned, resourced and used to inform broader recruitment strategies. For example, the Claremont Pilot (London, 2020) involved 16 online focus groups with 120 participants and identified key motivators, such as altruism, alongside barriers including information gaps and distrust in health research.[30]

It is noteworthy that in most cases Our Future Health has not been able to analyse the cost of recruitment through specific diversity-increasing initiatives versus the benefit of recruitment from specific under-represented groups. This information would be an important learning for several stakeholders, as well as allowing Our Future Health to better plan and prioritise future initiatives within the programme, or to provide a well-costed and evidence-based case to funders for possible future targeted funding applications for recruitment of selected under-represented groups.

Two community-based recruitment pilots, the British Muslim Heritage Centre (2023) and Manchester Curry Mile Pilot (2024), used mobile units and local engagement to encourage participation. These pilots ran for approximately 2-4 weeks, achieved moderate improvements in conversion rates, and highlighted that community engagement combined with invitation letters can drive participation. However, they also required substantial resource commitments, limiting their scalability. Instead, the findings informed broader adaptations to recruitment strategies.[31]

A key insight from these recruitment pilots was that booking and attending appointments can be a barrier to recruitment. In response, a pilot of 'walk-in clinics' was conducted in Manchester and London between January and April 2025. Early results indicate improved conversion rates to participants when appointments are not required, although the associated comparative cost per participant and scalability of this approach are still to be assessed. The forthcoming Community

[28] As reported by Our Future Health in May 2025 'Approaches, progress and lessons learnt in recruiting diverse populations and plans to increase/maintain the diversity of the cohort'
[29] As reported by Our Future Health in May 2025 'Approaches, progress and lessons learnt in recruiting diverse populations and plans to increase/maintain the diversity of the cohort'
[30] As reported by Our Future Health 10 June 2020 'Claremont Pilot Qualitative research findings'
[31] As reported by Our Future Health Q4 2023 'Summary of findings from invitation analysis for British Muslim Heritage Centre activities'

Champions programme (scheduled for May 2025) aims to recruit 125 local leaders in areas with high levels of ethnic and socioeconomic diversity to raise awareness and provide local consultation.

Since 2023, Our Future Health has also established strategic partnerships with sports organisations and employers and improve recruitment from underrepresented groups. These include partnerships with the amateur cricket league Last Man Stands, the National Students Esports and the Civil Service Government People Group. In addition, the programme has attended 39 community outreach events between 2023 and 2025, such as World Halal Festival (September 2024, London), Talking Black Womb (May 2024, London) and Bedford Community Engagement (December 2024, Bedford).[32]

These pilots and outreach initiatives reflect a strong commitment to representation and diversity, as outlined in the Challenge's ToC. However, initiatives such as participant reimbursement and community engagement pilots required careful coordination, including ethical approvals and procurement processes, which placed additional demands on Our Future Health's teams.

However, the scale and timing of these initiatives have been insufficient to identify a cost-effective model for reaching under-represented groups. A combination of delays related to the COVID-19 pandemic and the strategic reprioritisation of resources due to financial constraints may have limited Our Future Health's capacity to develop and deliver additional or larger scale pilots at an early stage. As recruitment expands into less populated areas of the UK, maintaining – and improving on – current levels of Census-level representation of ethnic, age and socioeconomic diversity will become increasingly difficult, especially at current cost levels. Additional pilot activities may be needed to explore the nuanced differences across communities whose sociodemographic profiles differ from those in previously targeted areas. Our Future Health will need to account for these differences to develop long term, scalable approaches to effectively engage and recruit under-represented groups across the UK.

[32] As reported by Our Future Health in May 2025 'Approaches, progress and lessons learnt in recruiting diverse populations and plans to increase/maintain the diversity of the cohort'

5 Improving risk prediction, early detection and intervention

Key findings

- Our Future Health has laid strong foundations for conducting research, with the TRE going live in June 2023 and 24 active studies underway. However, it has not yet contributed to population health improvements. This may be achieved in the future through Our Future Health sharing health insights with participants, and researchers developing new interventions using cohort data.
- The planned participant feedback and recontact functions had not been developed by the time of this evaluation, as a result of Our Future Health prioritising recruitment and genotyping milestones. Further progress is now underway, through a first recall-by-genotype pilot and a non-genetic feedback pilot planned for 2025.

5.1 What progress has the Challenge made against its planned impact, as set out in the Theory of Change?

Improving risk prediction, early detection of disease, and health interventions is a key impact outlined in the ToC. This impact is underpinned by the identification of novel biomarkers and the development of new research, products, and services. By March 2025, the Challenge was expected to deliver an **efficient system for participant recontact, engagement and feedback**. This system would enable:

1. Initiation of studies using cohort data.
2. Health and disease insights available to participants.

Since its inception, Our Future Health has undertaken several preliminary activities which informed the ongoing development of an ethical and regulatory framework to establish the approach and

guiding principles to recontact studies.[33] In 2024 it conducted two deliberative dialogues to explore public perspectives on feedback and participant recontact. In addition, Our Future Health has:

- Engaged with other research programmes, researchers, and participants to learn from existing recontact and feedback approaches, understand users' needs and co-design recontact invitations
- Initiated collaboration with the Research Ethics Committee and Ethics Advisory Board to shape the approach to recontact and provision of feedback to participants
- Investigated the regulatory framework for participant feedback by conducting exploratory work and engaging legal and regulatory experts
- Begun feasibility assessments with the sponsor of the first 'recall by genotype' pilot recontact study, which will then submit its application to the Our Future Health Access Board.

Despite these efforts, Our Future Health has not yet implemented a comprehensive system for participant recontact, engagement and feedback although as of 31 March 2025 the platform is in development and not yet in live use. During the interim phase of the evaluation (March 2024), Our Future Health reported plans to deliver participant feedback, and a non-genetic online feedback platform, by the first half of 2025. However, the delivery of these systems has been delayed due to reprioritisation of activities in response to financial constraints. Additionally, Our Future Health noted that developing these systems has proven more complex than anticipated, given the technical, regulatory, and ethical challenges involved. As outlined in Chapter 2 of this report, rising costs and uncertainty about future funding required a reprioritisation of activities, resulting in knock-on effects on the development of systems for participant recontact, engagement and feedback. Although factors such as delays in set-up, staff recruitment, and the launch of pilot programmes may have contributed to these setbacks, funding gaps were likely the primary cause, limiting the resources available for developing and testing these systems.

Based on the available evidence, we conclude that Our Future Health has **not yet established** the systems necessary to fully support the health-related outcomes expected by March 2025, as outlined in the ToC. However, Our Future Health has developed participant-facing health insights (clinical measurements at appointment) and the infrastructure to release these to associated participants.

[33] Offering feedback to participants as part of recontact study invitations: draft ethical and regulatory framework Proposed approach and draft guiding principles. Our Future Health, April 2025

5.2 What factors impeded progress towards establishing recontact, engagement and feedback systems?

Progress in this area was impeded by a combination of early delays and strategic reprioritisation which was necessary to meet recruitment milestones, with feedback and recontact requiring significant additional resource and technical input. Following initial delays in establishing Our Future Health and recruiting key personnel, financial constraints emerged as a major barrier. Our Future Health reported funding uncertainty, which led to the de-prioritisation of several activities, including staff recruitment. This has meant that Our Future Health did not have the staff in place to both accomplish recruitment milestones and infrastructure – which was attached to funding –while also setting up feedback and recontact systems.

In the case of participant recontact, engagement and feedback, the resources required to meet the technical, regulatory, and ethical complexity were not well understood at the outset. This underestimation, combined with the need to redirect resources, delayed progress through to March 2025. However, now that the data set of the cohort has been established, more resource and focus can be shifted towards building the platforms and capabilities required for engagement and providing feedback. Additional funding secured in 2025 is expected to support further development in this area. We provide an update on these developments below:

Health insights

Our Future Health continues to build and develop its Questionnaire and Engagement Platform (QEP), which will be tailored to deliver personal health insights (feedback) to participants. Work is ongoing to identify and evaluate the most effective technical solutions to improve the platform's functionality.

At the interim stage of the evaluation, Our Future Health provided point-of-care feedback for physical measurements (i.e., weight, height, Body Mass Index – BMI, waist circumference), cholesterol and blood pressure to participants at their enrolment appointment. Our Future Health later investigated[34] inaccurate cholesterol readings and phased out its measurement and feedback from January 2025 due to concerns about reputational risks and placing additional burden on primary care services.

A pilot is scheduled for June 2025 to test the delivery of physical measurements (e.g. blood pressure, heart rate and body mass index) digitally. The findings from this pilot will inform the implementation of an automatic digital system to deliver clinic measurement results to new joiners. In 2025/26, Our Future Health also plans to run engagement campaigns with existing participants to

[34] Turnbull I, Ali R. Our Future Health is investigating inaccurate cholesterol readings. BMJ. 2024 Jan 16;384:q104. doi: 10.1136/bmj.q104. PMID: 38228326

support the communication of health feedback, thereby further enhancing public and participant awareness of health benefits of prevention and engaging larger proportion of the population in future health research studies.

Currently, plans for feedback of health insights are limited to non-genetic information. Providing genetic feedback, where this is provided directly to participants and used to predict or manage disease, requires regulatory medical device approval. For this reason, Our Future Health deprioritised earlier efforts to develop Integrated Risk Scores (combining polygenic risk scores with other health and lifestyle information), however it aims to advance development in this area during 2026/27. Our Future Health will be working with NHS England to evaluate the use of polygenic scores and the implications for clinical care pathways. A pilot to deliver disease risk score feedback is also planned. In parallel, Our Future Health is exploring partnerships with professional healthcare organisations and charity partners to assess the impact of health insights on both healthcare systems and participant behaviour. A recently published article by Our Future Health[35] states that Our Future Health intends to become a learning system for the reframing of healthcare toward prevention that can feed into personalised health programmes.

Recontact

The recontact system continues to be developed, building on insights from the first recall by genotype pilot study, which is currently underway and expected to run for approximately one year. Processes for cohort selection and issuing invitations will be developed during the second half of 2025/26. Staff recruitment is also underway to improve resourcing in this area.

Current studies

As of March 2025, **529 researchers** have registered with Our Future Health, and more than **60 study applications** have been submitted for access to the resource. The large majority of approved researchers are from the UK (360), but international researchers have also registered to use the resource (e.g. from United States, Germany, Italy, Switzerland). Most applications originated from researchers in the Early Adopter Programme (which offers one-year free access to the TRE and financial support for computing costs), and the Scholars Ambassador Programme.

A total of **24 research studies** were active in the TRE by March 2025. Most studies are led by academic researchers and FIMs, with some engagement from SMEs. While the lead organisations are primarily UK based, there are a small number from pharmaceutical companies from the US. The majority of studies have planned durations of one to two years.

[35] Cook MB, Sanderson SC, Deanfield JE, Reddington F, Roddam A, Hunter DJ, Ali R. Our Future Health: a unique global resource for discovery and translational research. Nat Med. 2025 Mar;31(3):728-730. doi: 10.1038/s41591-024-03438-0. PMID: 39838119.

The approved studies span nearly **40 disease areas**, including cancer, cardiovascular disease, genetic disorders, diabetes and mental health, demonstrating the disease-agnostic nature of the resource. The portfolio also includes research into rare conditions and broader epidemiological studies. Study types range from focused research (e.g., access to healthcare for under-represented populations) to broader initiatives targeting biomarker discovery, drug target discovery and identification of risk factors. The first study published using Our Future Health data reveals that people living with chronic inflammatory conditions may have almost double the risk of mental health issues.[36]

While early results from research studies[37] have started to emerge, it is too early to assess the real impact of these studies in terms of biomarker validation, risk stratification or the development of novel products and services. In the short to medium-term, public health research may generate insights that inform policy decisions or improve health interventions. Over the medium to long term, findings related to biomarkers and drug targets are expected to feed into the pharmaceutical innovation pipeline, contributing to the development of new diagnostics, prevention, therapies and ultimately improved health outcomes.

[36] Mudra Rakshasa-Loots A, Swiffen D, Steyn C, Marwick KFM, Smith DJ. Affective disorders and chronic inflammatory conditions: analysis of 1.5 million participants in Our Future Health. BMJ Ment Health. 2025 Jun 10;28(1):e301706. doi: 10.1136/bmjment-2025-301706. PMID: 40494639; PMCID: PMC12161381.

[37] For current studies using Our Future Health, see Health Data Research Gateway: https://healthdatagateway.org/en/data-custodian/86

6 Additional Investment

Key findings

- It is too early to assess whether the Challenge has led to demonstrable follow-on investment in companies or led to wider sector growth attributable to use of the resource. Approved data-use studies are still at an early stage. FIMs report they are conducting exploratory analyses but are waiting for additional datasets to be available in the TRE and for operational recontact and sample-access services to be available before committing to larger programmes or changing investment strategy.
- There are favourable signs in the wider market, and this may inform near-term investment decisions. For example, university spin-out equity rose to about £1.86 billion across 243 deals and MedTech investment has been strong. However, in recent years UK SME equity fell to around £10.8 billion in 2024 with sharper declines at seed and venture stages.

6.1 What progress has the Challenge made against its planned impact, as set out in the Theory of Change?

A key outcome outlined the ToC is to generate economic growth in the UK's diagnostics, risk prediction and precision medicine sectors, underpinned by the Our Future Health resource and its users attracting additional investment. By March 2025, the Challenge was expected to have contributed to increased investment, alongside co-funding from industry and charity members, through wider adoption and use of the Our Future Health resource. It also aimed to strengthen the UK's position as a credible destination nation for life sciences investment from overseas.

While there are encouraging trends in overall investment in relevant sectors, it is still too early to draw robust conclusions about the Challenge's direct impact on investment. A comprehensive assessment of investment outcomes will require further time, greater uptake and usage of Our Future Health resource, and causal evidence of follow-on investments decisions made as a result of Our Future Health usage.

Based on available data, we conclude that Our Future Health has **not yet led to any additional investment**, as outlined in the ToC.

6.2 Which factors affected progress and level of additional investment achieved?

This section examines whether Our Future Health or its users have adapted their investment and growth strategies, and how the pharmaceutical and biopharmaceutical R&D sectors have evolved in relation to the Challenge.

As of March 2025, FIMs and FCMs have had limited opportunity to fully engage with the Our Future Health resource and have not yet determined its strategic impact on their target markets. Nevertheless, FIMs and FCMs do acknowledge the resource's strategic potential yet few have made immediate changes to their strategies or investments based solely on access to Our Future Health's data. There is optimism about the value of its genetic data, with organisations seeing potential to support innovation in drug discovery and improve drug trial efficiency, potentially increasing approval success rates.

When asked whether the Challenge had led to organisational changes such as additional employment or new divisions of research, most organisations reported that it was still too early for significant adjustments. In general, roles supporting the initiative and initial studies using Our Future Health data were filled by existing cross-functional teams, rather than through new hires. Some organisations stated that their current research budgets and infrastructure were sufficient to accommodate engagement with the resource and delivery of initial studies.

Several FIMs and FCMs also noted that initial studies using the data would have to be completed before any investment decisions could be made; stating that determining a return on investment remains challenging. The inherently complex and unpredictable nature of pharmaceutical R&D (especially for rare conditions) adds to this uncertainty. While the resource offers new opportunities, the timeline and likelihood of commercial impact are not yet clear, and organisations remain cautious about making strategic changes at this stage.

This is against a wider context of a robust UK pharmaceutical sector with strong R&D commitment, In 2022, R&D expenditure in the sector reached £9.0 billion, accounting for 18% of all UK business R&D. The UK also retains the second-highest health R&D budget allocation as a percentage of GDP globally[38]. Recent mergers and acquisitions, including Johnson & Johnson's $14.6 billion acquisition of Intra-Cellular Therapies[39] and Assura's $635.2 million purchase of NorthWest Healthcare Properties[40], demonstrate continued strategic consolidations within the industry. Strengthening the growth of the sector further there are significant government changes with the recent Life Sciences Sector Plan which announced several commitments. This includes streamlining trial setup and regulation, supporting manufacturing with a £520 million fund, and improving access to the NHS through a new procurement process.

This positions Our Future Health as highly relevant, aligning with the sectors growth and long term investment priorities. However, broader challenges persist which may dampen investment

[38] https://www.gov.uk/government/publications/life-sciences-sector-data-2024/life-sciences-competitiveness-indicators-2024-summary
[39] https://www.jnj.com/media-center/press-releases/johnson-johnson-closes-landmark-intra-cellular-therapies-acquisition-to-solidify-neuroscience-leadership
[40] https://www.assuraplc.com/media-centre/acquisition-of-uk-private-hospital-portfolio

climate. Regulatory costs are rising[41], competition from generics is tightening margins, and there has been a recent decline in pharmaceutical imports and foreign direct investment in life sciences, which may slow growth in the short term[42]. In this context, the Challenge's role in advancing precision medicine and diagnostics becomes more important, helping to sustain the UK's global competitiveness in life sciences.

There are some challenging signals in the market, with UK SME equity falling slightly to £10.8bn in 2024[43] while deal volumes dropped more sharply. However, within the health and life sciences sector there are some mixed signals with medical technologies investment growing strongly.

Looking ahead, the UK pharmaceutical sector is expected to evolve, driven by advancements in AI-driven drug discovery and strategic partnerships (such as Recursion Pharmaceuticals' $712 million acquisition of Exscientia[44]). Interviews with FIMs and FCMs highlighted AI as a promising application area for the Our Future Health resource. This is reinforced by recent government and Wellcome Trust (£600 million[45]) investments for a new national health data research service, which aims to enhance access to NHS data and further emphasises the importance of streamlined data availability for researchers.

[41] https://cps.org.uk/research/the-future-of-regulation/
[42] https://www.gov.uk/government/publications/life-sciences-sector-data-2024/life-sciences-competitiveness-indicators-2024-summary
[43] https://www.british-business-bank.co.uk/about/research-and-publications/small-business-equity-tracker-2024
[44] https://www.europeanpharmaceuticalreview.com/article/245077/ma-outlook-for-pharma-in-2025/
[45] https://wellcome.org/news/national-data-service-will-simplify-access-health-data-research

Annex 1: Mapping of chapters to evaluation questions

The following table presents how evidence in evaluation findings from Chapters 3 to 6 map across to the study Impact Evaluation Questions (IEQs) and Process Evaluation Questions (PEQs):

Chapter 3: Establishing and sustaining the resource	**IEQ1** ▪ Government funding and the funding model adopted ▪ Whether collected and linked data is sufficient for targeted study recruitment and for research needs. ▪ Whether Our Future Health has made suitable progress in developing a viable business model. **PEQ1** ▪ Costs delivering the ADD Challenge at Challenge end to prior costings in the Challenge business case. ▪ How effectively UKRI and Our Future Health have adjusted governance arrangements to changing circumstances and incorporated learning to improve programme delivery. Governance arrangements that have proven effective, and areas for Improvement. ▪ How appropriate and effective UKRI management, monitoring and communication arrangements are for supporting programme delivery. ▪ The feasibility of funding scenarios Our Future Health has explored, such as securing additional co-funding, generating revenue through data access fees, and developing future operational models. ▪ Appropriateness of the milestone objectives chosen to release funding.

	▪ Progress Our Future Health has made in developing a future operating model and funding scenarios, and how feasible these are within the context of its current funding arrangements. **PEQ2** ▪ Securing funding from non-government sources, developing an access pricing strategy, and ensuring long term financial sustainability. ▪ Our Future Health's effectiveness in leveraging co-funding, engaging with commercial partners, and developing pricing and commercial plans. ▪ How effectively has Our Future Health promoted external interest from other potential users of the resource, including through progress in developing a pricing strategy with appropriate pricing structures for each user group **PEQ3** ▪ How effectively planning and implementation of the Challenge has enabled successful establishment of the resource. ▪ How effectively Our Future Health has secured access to routinely updated linked data and what value it provides, including approaches to stakeholder and supplier management to broker access to data. ▪ How effective the digital platform and TRE is for researchers.

Chapter 4: Recruitment and cohort characteristics	**IEQ1** ▪ Up-to-date tools and resources developed to improve recruitment and participation, including among underrepresented groups **IEQ3** ▪ Our Future Health's community recruitment efforts, focusing on engagement strategies, partnerships with community organisations, and the effectiveness of these initiatives in reaching and recruiting participants from diverse communities ▪ Pilots and initiatives to increase the diversity of the resource, undertaken by Our Future Health. This will assess the effectiveness of these initiatives in increasing participation from under-represented groups and their contribution to building a more diverse and inclusive research cohort **PEQ3** ▪ Programme management and learning approaches undertaken by Our Future Health to improve recruitment ▪ Processes for monitoring recruitment and participant coverage ▪ Progress, success and challenges in carrying out public monitoring, engagement and deliberation work to monitor and maintain public trust, including how Our Future Health monitors public trust. Manage risks around public trust and buy-in

Chapter 5: Improving risk prediction, early detection and intervention	**IEQ2** ▪ How and whether the nature of research enabled through the resource is novel compared to other research resources ▪ Whether data that Our Future Health collects from participants is enabling, or will enable, users of the resource to meet their research requirements ▪ The nature of participant feedback provided, whether the feedback is novel, and progress in developing and piloting the participant feedback platform to consider how participants respond to feedback. ▪ The nature of additional research conducted by Our Future Health related to clinical risk, and the potential for these to influence healthcare practices and policy (for instance, risks due to cholesterol levels and the work undertaken to develop Integrated Risk Scores) ▪ The extent to which stakeholders have adopted and used knowledge Our Future Health has developed **PEQ3** ▪ The development and management of stakeholder relationships, for instance with NHS organisations regarding onward referral to services
Chapter 6: Additional Investment	**IEQ4** ▪ Factors that are influencing or that will influence the ADD Challenge's success in attracting investment, including market conditions and the maturity of the studies and resource

Annex 2: Data sources for impact evaluation

The impact evaluation aims to assess the extent to which the ADD Challenge has met its objectives. Key questions, relevant elements in the Theory of Change and methods are set out in the table below:

Impact evaluation question	Hypothesis	Method and data sources
IEQ1: To what extent has the ADD Challenge established a novel R&D resource of 1.33 million participants which is representative of the UK population?	Challenge funding has enabled Our Future Health to recruit 1.33 million participants, and establish a novel research infrastructure containing data of these participants	▪ Stakeholder interviews: – Our Future Health Data Acquisition and Pipeline teams – Our Future Health Chief Financial Officer – Our Future Health access team ▪ Management Information review – % of UKRI funding (**£79 million**) invoiced (actual spending profile against plan) + proportion of OLS(DSIT) funding – Recruitment, retention and recontact metrics provided in quarterly monitoring and Programme Board updates – Recruitment, retention and recontact metrics provided in quarterly monitoring and Programme Board updates – Number of high priority datasets linked and accessible – Number of studies which have applied to Our Future Health – Number of studies approved by Our Future Health – Number of approved studies and users split by home country and organisation type ▪ Review of data on participants provided by Our Future Health, split by gender, IMD quintile and age group

	The Challenge has enabled the development of innovative technologies, tools, resources to build and maintain the cohort	▪ Document review of materials and reports prepared by Our Future Health covering recruitment pilots. ▪ Stakeholder interviews: – Our Future Health Executive Director of Researcher Data and Product
IEQ2: To what extent has the ADD Challenge developed a research resource which drives improvements in population health outcomes through improved risk prediction, early detection, and management of chronic diseases?	The Challenge has initiated larger-scale UK study arms for biomarker validation, risk stratification detection / treatment / prevention and has increased the UK's participation in relevant global studies	▪ Stakeholder interviews: – Our Future Health Executive Directors of Science and of Ethics, and Leads for developing recontact strategies – FIMs and FCMs – Users of the resource ▪ Management Information review: – Number of studies which have applied to Our Future Health – Number of studies approved by Our Future Health – Number of approved study users split by home country and organisation type – Abstracts for studies being undertaken
	Challenge funding has enabled creation of new knowledge in risk prediction, early detection, and management of chronic diseases	▪ Stakeholder interviews: – Our Future Health Executive Director of Science – FIMs and FCMs – Users of the resource ▪ Document review of materials related to Our Future Health research and uptake of learnings ▪ Management Information review – Number of studies which have applied to Our Future Health – Number of studies approved by Our Future Health

		– Number of approved studies split by home country and organisation type
	Challenge funding has provided participants with novel health and disease insights through participant feedback routes	▪ Stakeholder interviews: – Our Future Health Executive Director of Science and team Leads covering recontact, health insights and risk scores. ▪ Document review of materials covering planning, public consultation and development of health insights, participant feedback and recontact processes.
	Challenge funding has contributed to the development of novel products and services with potential to change healthcare pathways	▪ Stakeholder interviews: – Our Future Health Executive Director of Science – FIMs and FCMs – Users of the resource ▪ Management Information review: – Number of studies which have applied to Our Future Health – Number of studies approved by Our Future Health – Number of approved studies and users split by home country and organisation type – Abstracts for studies being undertaken

IEQ3: To what extent has the ADD Challenge increased public involvement in health research, including under-represented groups?	The Challenge has increased the participation of under-represented groups in UK arms of studies on biomarker validation, risk stratification/detection/ treatment /prevention	▪ Document review of reports produced by Our Future Health on recruitment pilots and initiatives, and lessons identified from these. ▪ Review of data on participants provided by Our Future Health, split by gender, IMD quintile and age group.
IEQ4: To what extent has the ADD Challenge driven investment and promoted growth in the UK diagnostics, risk prediction and precision medicine sectors?	The Challenge has leveraged additional investment into firms using the resource, including foreign direct investment	▪ Stakeholder interviews: – FIMs and FCMs It is not possible to fully review investment as the resource and its users have not attracted additional investment at this stage. Analysis focuses on feedback from funders of the resource which expect to attract investment, as well as an assessment of contextual factors in the markets for diagnostics, risk prediction and precision medicine.

Annex 3: Data sources for process evaluation

The process evaluation aims to review the efficiency and effectiveness of processes established to deliver the ADD Challenge objectives. Key questions, sub-questions and methods are set out in the table below:

Process evaluation question	Sub-question	Method and data sources
PEQ1: How have UKRI's funding, governance and operational processes affected progress towards the Challenge's objective of establishing a novel resource?	How appropriate is the ISCF funding model in addressing market failure? To what extent is the level of funding sufficient for the establishment and implementation phase?	▪ Stakeholder interviews: – Our Future Health Chief Financial Officer – Our Future Health Chief Business Officer ▪ Document Review ▪ Management Information Review – Proportion of funding invoiced
	How feasible is the matched funding model in terms of life sciences and charitable sector need, interest, level of risk, and resources?	▪ Stakeholder interviews: – Our Future Health Chief Financial Officer ▪ Document Review ▪ Management Information review – Number of FIMs and FCMs – Amount of match funding committed and secured

	How effectively do governance mechanisms help to identify and mitigate major programme risks?	▪ Evaluation team review of updates from the UKRI ADD Challenge Team based on baseline and interim findings and recommendations.
	To what extent do UKRI governance bodies represent relevant government and academic stakeholder views and have sufficient skills/experience to advise on programme delivery?	
	To what extent do UKRI governance mechanisms complement Our Future Health governance mechanisms, in ensuring effective delivery of the Challenge?	
	How suitable is a company limited by guarantee as a delivery vehicle for the Challenge?	
	How appropriate and effective are UKRI management, monitoring and communication for supporting programme delivery?	
	To what extent was sufficient time and flexibility embedded in UKRI programme management for iterative learning and adaptation?	

PEQ2: How have Our Future Health's commercial activities and operational procedures affected progress towards the Challenge's objective of establishing a novel resource?	How effectively has Our Future Health leveraged co-funding and maintained the interest and engagement of partners?	▪ Stakeholder interviews: – Our Future Health Chief Financial Officer – Our Future Health Chief Business Officer – FIMs and FCMs ▪ Management Information review – Number of FIMs and FCMs – Amount of match funding committed and secured
	How effectively has Our Future Health promoted external interest from other potential users of the resource?	▪ Stakeholder interviews: ▪ Executive Director of Researcher Data and Product ▪ Document Review of materials setting out Early Adopter schemes
	How appropriate and effective are Our Future Health's legal, procedural, ethical, and scientific frameworks, and structures for programme delivery? How efficiently were these developed and/or embedded?	▪ Stakeholder interviews: – Our Future Health Executive Director of Science and team Leads covering recontact, health insights and risk scores. ▪ Document review of materials covering planning, public consultation and development of health insights, participant feedback and recontact processes.
	How suitable is a company limited by guarantee for continuing the success of the resource beyond the lifetime of the Challenge?	▪ Stakeholder interviews: – Our Future Health Executive Team ▪ Document review of materials involving sustainability and transition plans for the resource, and comparative analyses of alternative organisational models.

PEQ3: How has Our Future Health's programme design and delivery affected progress towards the Challenge's objective of establishing a novel resource?	How effectively has Our Future Health built public trust?	▪ Stakeholder interviews: – Our Future Health Executive Team ▪ Document Review of materials developed by Our Future Health to consult the public and gather views on their willingness to participate in the programme.
	To what extent does the programme align with public interest and need?	
	How effectively has Our Future Health communicated data use, sharing and linkage plans with the public? How acceptable are these plans to the public?	
	How effectively has Our Future Health gained buy-in from key provider and supplier stakeholders?	
	How efficiently has Our Future Health procured necessary services?	▪ Stakeholder interviews: – Our Future Health Chief Technology Officer – Our Future Health Leads for health insights and recontact ▪ Document review of monitoring materials setting out management of labs, IT and infrastructure
	How effective is the digital platform and TRE for researchers?	▪ Stakeholder interviews: – Our Future Health Data Acquisition and Pipeline teams – Our Future Health Executive Director of Researcher Data and Product ▪ Management Information review – Number of active TRE users

Annex 4: Impact and contextual metrics used in the evaluation

Type of metric	Category	Metric	Outcomes
Impact	Establishment of novel R&D resource	% of UKRI funding (**£79 million**) invoiced (actual spending profile against plan)	**100%** of funding has been invoiced **(£79 million** plus £67.9 million from DSIT)
Impact	Establishment of novel R&D resource	# of Our Future Health employees	**270** employees at end of March 2025.
Impact	Establishment of novel R&D resource	Dates for key milestones achieved	Under the revised GFA the following milestones were met: July 2023: Milestone 1 achieved. Recruitment target of 235,000, Our Future Health achieved **235,646.** September 2023: Milestone 2 achieved. Recruitment target of 310,000, Our Future Health achieved **318,101.** December 2023: Milestone 3 achieved. Recruitment target of 429,000, Our Future Health achieved **468,000**. Genotyping target of 150,00, Our Future Health achieved **260,000**. March 2024: Milestone 4 achieved. Recruitment target of 574,000, Our Future Health achieved **639,144.** Genotyping target of 350,000, Our Future Health achieved **429,000**. June 2024: Milestone 5 achieved. Recruitment target of 709,000, Our Future Health achieved **726,509**. Genotyping target of 500,000, Our Future Health achieved **521,000**. September 2024: Milestone 6 achieved. Recruitment target of 887,000, Our Future Health achieved **~1,000,000**. Genotyping target of 650,000, Our Future Health achieved **~900,000**.

			Genotyping up to Milestone 6 was measuring number of participants genotyped, updated Milestones 7 & 8 were measuring number of genotyping assays run (to cover samples needing to be re-run alongside new participants). December 2024: Milestone 7 achieved. Recruitment target of 1,088,000, Our Future Health achieved **1,145,000**. Genotyping target of 800,000, Our Future Health achieved **1,090,000**. March 2025: Milestone 8 achieved. Recruitment target of 1,300,000, Our Future Health achieved **1,336,634**. Genotyping target of 1,000,000, Our Future Health achieved **1,350,000** (one month later).
Impact	Establishment of novel R&D resource	No. of high priority datasets (as defined by Our Future Health) linked and accessible	Depending on how each individual dataset is defined (as, for example, there are multiple NHS datasets available) at least **5** are accessible through the TRE: • NHS England secondary care records (Admitted Patient Care, Accident and Emergency, Outpatients) • Death registration data • Cancer registry and pathway data • Clinical Measurements Data • Genotyped Data (using SNP, not yet imputed) This currently does not include primary care records in all UK nations, and secondary care records in Scotland, Wales and Northern Ireland.
Impact	Establishment of novel R&D resource	Progress in recruiting participants through recruitment channels, and in encouraging people to complete the full recruitment journey	At Challenge end, the following progress had been made at each stage in the recruitment journey: – Just over 47 million people had been sent invitations. – 3.2 million people have registered for Our Future Health. – Of these, 2.3 million people have provided consent to participate.

			– Of these, 1.7 million people have completed the online baseline questionnaire. – Of these, 1.33 million people are full participants, defined as someone who has consented to joining, completed the online baseline questionnaire and provided a usable blood sample. From Q4 2022 to Q1 2025, the rate of conversion from people registering to becoming full participants improved from 22% to 48%. Our Future Health has reported that full participants joined through the following channels: – DigiTrials 489,845 (36.6% of full participants) – Non-personalised letters 505,235 (37.8%); – NHS Blood and Transplant 56,775 (4.2%); – Community engagement and marketing 6,227 (0.47%) – Organic 278,320 (20.8%)
Impact	Establishment of novel R&D resource	Retention and recontact metrics: - Response rate of consented participants approached to participate to interventional and observational studies, by gender, IMD quintile, age bracket and ethnicity - # of cohort participants with associated genotypic and phenotypic dataset, by gender, IMD quintile, age bracket and ethnicity - Retention rate: proportion of participants asked for repeat biological sample/repeat questionnaires who are still engaging after 12 months/24 months, by gender, IMD quintile, age bracket and ethnicity	Systems for retention and recontact are not yet in place, meaning it is not possible to calculate response rates for studies or retention rates after 12/24 months. 651,031 participants in total have genotypic data which can be accessed in the TRE. Public data releases by Our Future Health do not yet break this into IMD, age bracket and ethnicity. 1,169,699 participants in total have phenotypic (clinical measurements) data which can be accessed in the TRE. Public data releases by Our Future Health do not yet break this into IMD, age bracket and ethnicity.

		- proportion of participants opting-in to receive genetic feedback - % participants that have been provided with feedback	Systems for feedback are not fully in place. All participants already receive phenotypic (clinical measurement) feedback at the point of care, which prior to 31 December 2024 included cholesterol feedback.
Impact	Establishment of novel R&D resource	Participant satisfaction: Any measures of participant satisfaction and willingness to participate (as carried out by Our Future Health), including demographic comparison	Quantitative measures of participant satisfaction were not collected systematically at the study cut-off.
Impact	Establishment of novel R&D resource	Our Future Health public perceptions polling/ analytics	Public perceptions are not collected systematically at a frequency aligning with the evaluation window; no quantitative update is therefore available.
Impact	Sector innovation and social impacts	Publications / material from Our Future Health teams contributing to new knowledge – disseminating process learning on recruiting and maintaining cohort	There were **2** external publications by Our Future Health by the cut-off, both published to the British Medical Journal (BMJ). These cover the cohort profile and initial research on cholesterol readings. – Cohort profile – Commentary of cholesterol-related measurement by Our Future Health
Impact	Sector innovation and social impacts	# of documents/reports produced by Our Future Health on lessons identified, review of approaches, guides on policies/tools	The majority of internal lessons reports, reviews and guidance are not in the public domain. A count of documents produced is therefore not representative. As a qualitative summary, Our Future Health has published certain documents in the public domain. This includes its survey of public attitudes in 2022, its operating protocol, and ethics materials.

Impact	Sector innovation and social impacts	# of participants consenting to receive genetic feedback: proportion of participants agreeing to receive genetic feedback	A single figure is not reportable. Our Future Health is still developing a layered model for providing feedback (based on the condition or type of feedback). Operational design of this model is still ongoing.
Impact	Sector innovation and social impacts	# of recruited participants with completed questionnaire & one good (usable) blood sample, by recruitment channel, gender, IMD quintile, age bracket and ethnicity	Across each stage in the recruitment journey at Challenge end: – 1.7 million people have completed questionnaires. – Just over 1.33 million people are full participants and have therefore consented for their data to be linked, provided a blood sample and completed the questionnaire. A breakdown of this group is provided in **Annex 6**.
Impact	Sector innovation and social impacts	Any measures of participant satisfaction and willingness to participate (as carried out by Our Future Health), including demographic comparison	Quantitative measures of participant satisfaction were not collected systematically at the study cut-off.
Impact	UK investment and industry growth	# of FIM, FCM and SME subscriptions to Our Future Health Platform	There are **15** FIM, **1** IM and **4** FCM subscriptions at cut-off. Counts or details of specific SMEs which have registered with Our Future Health were not available at Challenge end. At this point in time, no SME had begun an active study in the TRE.
Impact	UK investment and industry growth	£ of match funding committed by FIMs and FCMs, % of matched funding target (**£160 million**) and industry / charity investment split	**£184.5 million** committed (115% of target) split as **£154 million** for FIMs, **£12.5 million** for IMs and **£18 million** for FCMs.
Impact	UK investment and industry growth	% of / £ match funding secured – and % of this tied to recruitment targets	Our Future Health received **£131.5 million** in funding released. Contractual splits and linkages to recruitment milestones are commercially sensitive and not reported.
Impact	UK investment and industry growth	£ Commercial revenue generated by Our Future Health subscriptions /	Beyond the above match funding amounts, commercial revenue routes for Our Future Health are under development. Detailed revenue projections are commercially sensitive and subject to change.

Impact	UK investment and industry growth	£ of investment into firms using the resource / implied valuation of firms Growth in £ turnover and employment of firms using the resource £ of investments into firms not using the resource / implied valuation of firms Growth in £ turnover and employment of similar firms not using the resource	Based on feedback to the evaluation team, firms using Our Future Health are currently carrying out exploratory analysis within their existing teams. There have therefore not yet been turnover, headcount and investment changes within firms which is attributable to using Our Future Health. Sector context is available in Chapter 6 of the report.
Impact	UK investment and industry growth	Pricing/ subscription model; marks of esteem	While pricing and subscription arrangements for Our Future Health, as a whole, are under development, qualitative progress has been made: – A tiered pricing model for data access is available to researchers on enquiry. Pricing may adjust as datasets and usage expand. – A SME Early Adopter scheme has been launched.
Impact	UK investment and industry growth	Increase in R&D spending by Our Future Health cohort users Increase in R&D employment by Our Future Health cohort users UK GVA (£/year) growth £ Foreign Direct investments made into Our Future Health cohort users	Based on feedback to the evaluation team, firms using Our Future Health are currently carrying out exploratory analysis within their existing teams. There have therefore not yet been turnover, headcount and investment changes within firms which is attributable to using Our Future Health.
Impact	Improved prediction, early detection and intervention	Usage statistics of the Our Future Health resource, including: number and nature (national vs. international) of access requests; details on project focus	There are **24** active studies in the TRE. There are **529** registered / approved research accounts. Of these, **168 (32%)** are researchers from overseas. Examples of topics in approved studies are biomarker and polygenic risk score development, disease-association and early target discovery. This spans conditions including cardiometabolic disease, cancer, neurological disorders, rare disease, mental health and autoimmune / inflammatory conditions. Analyses are

			using de-identified questionnaire data, secondary care records, clinic measurements and genotyping data.
Impact	Improved prediction, early detection and intervention	Details on active studies in the resource that include target product profiles; and associated studies/ trials # studies that have applied to access the resource which aim to develop new products and services	There are **no** studies which include target product profiles. Active studies in the resource are mostly focused on early discovery / association, which will precede product development. For example: identifying associations between diseases and genomic variants or environmental risk factors; identifying drug targets; developing risk stratifiers; identifying biomarkers to support screening; and building pharmacogenomic predictors.
Impact	Improved prediction, early detection and intervention	#Clinical studies associated with Our Future Health, broken down by size and number of Our Future Health participants recruited, focus area (prediction, early detection or intervention), clinical phase, disease area, product type, commercial/academic lead sponsor, location of lead and year	There were **no** clinical studies at the evaluation cut-off.
Impact	Improved prediction, early detection and intervention	Detail of research data use for each study	Study-level records are available via the HDR UK Gateway and the Our Future Health researcher portal, including lay summaries, objectives, approvals and the specific data fields used. As at 31 March 2025, studies accessed the following de-identified data within the TRE: – Baseline questionnaire and demographics – Clinic measurements – NHS England secondary care and cancer records – Death registrations – Imputed genomic data

			At present, studies are using the TRE to run observational, data-use studies. For example, one team is building integrated cardiovascular risk scores by combining clinic measurements (blood pressure, BMI), baseline questionnaire data and imputed genomic data scores, then validating these risk scores against linked hospital and mortality outcomes across age, deprivation and ethnic groups. Another study is using genomic data to identify variations in how participants respond to medicines (for instance, CYP genes) by associating the genetic variants with health outcomes in secondary care and cancer records.
Impact	Improved prediction, early detection and intervention	# and % of studies that initiated novel collaboration	Novel collaboration on projects is not identifiable at this stage as no external studies had been published by the study cut-off. The HDR UK Gateway, which Our Future Health uses to publish approved studies, lists only the project's lead investigator. Based on interview feedback, FIMs and FCMs expressed early interest in collaborating with various external organisations, including academic institutions for disease-specific expertise, technology providers to enhance TRE functionality and data analysis tools, and other companies to secure funding and expertise for large-scale studies and advance research in specific disease areas. .
Impact	Improved prediction, early detection and intervention	# of publications associated with research using Our Future Health, broken down by focus area (prediction, early detection or intervention), disease area, product type, lead author and their institutional affiliation and location.	There were **no publications** associated with research using Our Future Health at the study cut-off. One report was in progress and was published in June 2025, which investigated associations between autoimmune conditions and participants' mental health.
Impact	Improved prediction, early	Field weighted citation impact of these publications	At the evaluation cut-off, no publication is available (with the first publication in June 2025) so a field-weighted citation impact is not

	detection and intervention		meaningful. This can be calculated once there is a sufficient body of outputs. For example, after 12–24 months has passed.
Contextual	Establishment of novel R&D resource	Recruitment progress made by international and national comparator programmes, including process metrics (recruitment invitations sent, individuals registered for recruitment, individuals consented for recruitment Response rate of consented participants by gender, IMD quintile (or similar), age bracket and ethnicity	Comparator cohorts have not published or shared like-for-like, channel-level process metrics such as invitations, registrations and consent. A direct comparison of these metrics is not possible. We therefore report headline cohort sizes: All of Us (USA): 718,000 participants at baseline stage of study (Oct 2023) with 5–10% conversion at large health centres published). There are now 867,000 participants. FinnGen (Finland): 500,000 participants at baseline stage of study which is unchanged. China Kadoorie Biobank (China): 512,891 participants at baseline with an invitation-letter response of approximately 30%. The number of participants has remained consistent. 45 and Up (Australia): 267,000 participants at baseline with an invitation-letter response of approximately 19% and higher response in follow-ups with more intensive prompting. The number of participants has remained consistent. NIHR BioResource (UK): 250,000 volunteers across rare / common disease and healthy cohorts. Expansion to children/young people has been planned, but at present the number of volunteers has remained consistent.
Contextual	Improved prediction, early	Clinical studies and publications associated with comparator programmes, broken down by	At Challenge end, there are **0** peer reviewed publications and **0** clinical trials or target product profiles attributable to Our Future

	detection and intervention	size and number of participants recruited from comparator, clinical phase, by focus area (prediction, early detection or intervention)	Health. It has published **2** BMJ commentary articles and a small number of process and learning documents in the public domain. There are **24** active studies in the TRE which are expected to result in publications. Given Our Future Health is at a relatively early stage in enabling studies, this evaluation did not update information collected on comparator programmes since the baseline study in 2023. The following metrics were identified at Baseline using the Dimensions database: All of Us (US): 239 peer-reviewed articles; 10 patent families; 29 policy documents FinnGen (Finland): 634 peer-reviewed articles; 10 patent families; 4 policy documents China Kadoorie Biobank (China): 401 peer-reviewed articles 45 and Up (Australia, NSW): 565 peer-reviewed articles NIHR BioResource (UK): 575 peer-reviewed articles; 27 policy documents
Contextual	UK investment and industry growth	£ of investment into firms in relevant sectors, broken down by technology focus, location and development status.	It is too early to compare contextual data on investments with firm-level investment into companies using Our Future Health, given no companies have yet completed a study in the resource. Meaningful comparison requires wider uptake of the resource by companies and time to pass for follow-on investment to materialise. There has been substantial activity in relevant markets: Founding Industry Members invested around £180bn across the UK/US since 2020. The UK saw landmark deals such as The Binding Site (£2.2bn, M&A), AviadoBio (£80 million, early-stage venture capital - VC) and

			Pulmocide (£116 million, later-stage VC). Investment into UK precision medicine reached about £596 million (2020–2023), targeted therapeutics about £3.49bn (anchored by strong M&A), and diagnostics/healthcare/AI about £371 million, with peaks in 2021–2022 and a dip in 2023. However, at the same time, the SME funding environment has been tight, with softer VC / public markets, fewer but larger later-stage deals, and a marked fall in precision medicine investment in 2023, implying that SME uptake of Our Future Health and any attributable follow-on investment may lag initial research use. These figures provide sectoral context only and are not attributable to Our Future Health at the study cut-off.

Annex 5: UKRI and Our Future Health governance and delivery processes

UKRI Challenge governance

The UKRI CEO holds overall responsibility for the ISCF and reports directly back to Ministers, who remain the ultimate decision makers on setting the strategic direction. The CEO approves the appointment of the Challenge Director and recommends Advisory Group chairs.

The ISCF Steering Board is accountable to the UKRI CEO and is responsible for the delivery of the portfolio of ISCF Challenges, including the ISCF ADD Challenge. Its key functions include:

- Making strategic decisions across ISCF Challenges and advising the UKRI CEO on scaling funding up or down according to performance of Challenges;
- Appointing the ADD Challenge Director and Chairs of Advisory Boards; and
- Overseeing the ISCF ADD Challenge management team via the ISCF Programme Manager.

The ISCF ADD Programme Board previously met monthly until February 2024 and has met every 6 weeks up to January 2025 and every 3 months thereafter. It is chaired by the ADD Challenge's Senior Responsible Officer, who is accountable for ensuring that the Challenge meets its objectives and realises expected benefits. According to the Terms of Reference, the Programme Board reviews and advises on critical risks and issues, and supports or recommends actions to the ADD Challenge Director, the ISCF Steering Board and UKRI, on matters relating to delivery, strategy, and assurance. Its functions include overseeing Challenge progress; signing off key deliverables, including evaluation deliverables; approving significant changes to planned budget, time, and scope; and escalating key decisions.

The ADD Challenge Director is accountable to the ISCF Steering Board. They lead the Challenge and articulate its vision, overseeing delivery milestones, and establishing risk management processes. The Director regularly attends Programme Board meetings, contributes to key decision making, and represents the Challenge at high-profile events, meetings and the ISCF Steering Board. They also engage senior stakeholder across academia, industry, and government. The ADD Deputy Challenge Director has stepped up as acting Challenge Director since October 2022.

The ISCF ADD Advisory Group provides independent expert advice to the ADD Challenge Team on the direction and progress of the Challenge towards its objectives. The Group also identifies opportunities to increase the value and impact. The ADD Advisory Group (distinct from the Our Future Health Scientific Advisory Board) operates on behalf of the Challenge, directly advising UKRI and the Challenge Director on any matter relevant to the Challenge.

The ADD Challenge Team supports the Challenge Director by managing roadmap milestones, delivery plans, data, and evidence collection, risk management, and analysis. It ensures regular reporting to the ISCF Steering Board and other bodies such as the Advisory Group and Portfolio Support Office. The team is accountable for delivery and financial management, drawing on evaluation and monitoring expertise across UKRI.

Our Future Health governance

Our Future Health was established as an independent company limited by guarantee and as a registered charity, in accordance with the delivery model set out in the approved UKRI business case. Its governance structures operate at three key levels:

- Group Boards and Group Sub-committees;
- Operational Boards; and
- Advisory Boards.

As a charity registered with both the Charity Commission for England and Wales and the Office of the Scottish Charity Regulator, and as a private company limited by guarantee, it has both Trustee and Executive Board functionalities. Governance structures are aligned with the Charity Governance Code.

The Board of Trustees is responsible for the charity's governance and strategic oversight and holds full legal accountability. Trustees serve as company Directors under the Companies Act 2006. They act voluntarily and are not remunerated. The Board of Trustees also oversees Our Future Health Trading Limited, a trading subsidiary established to carry out activities in support of the charity's objectives. This includes entering into funding agreements with Industry partners, licensing access rights, and agreeing to translational research projects with external partners.

The Executive Team (comprising the Chief Executive Officer and direct reports) holds delegated authority for day-to-day operations. Additional responsibilities are delegated to Sub-Committees – such as the Audit & Risk Sub-Committee of the Board of Trustees, which retain accountability for their respective domains.

The Operational and Advisory Boards support the Executive Team in delivering the research programme:

- Operational Boards collaborate with the Executive Team to review and make recommendations to the Board of Trustees or Trading Board as required,
- Advisory Boards provide expert external advice on strategic and operational aspects, either through the Executive Team or via the Operational Boards.

The remits of the Operational Boards are as follows:

The **Access Board** is responsible for access to Our Future Health data including linked data, samples, and participants for research;

The **Founders Board** brings together the FIMs, UKRI and FCMs who are / will be co-funding the Our Future Health programme;

The **Implementation Board** oversees decisions which will impact the delivery and implementation of the Our Future Health programme.

The remits of the Advisory Boards are as follows:

The **Ethics Advisory Board** monitors the development of Our Future Health to make sure it meets the high ethical and governance standards across all its activities;

The **Public Advisory Board** comprises members of the general public and study participants, to advise on various aspects of Our Future Health's work;

The **Scientific Advisory Board** is responsible for making sure that all Our Future Health research meets the highest ethical and scientific standards;

The **Diversity & Inclusion Advisory Board** supports Our Future Health's aim to recruit participants from a diverse range of backgrounds;

The **Technology Advisory Board** supports Our Future Health platform technology solutions and decisions.

Our Future Health refreshed its delivery plan for the ADD Challenge following an iterative review by the ADD Challenge Team during summer 2023. The updated plan, comprising ten overall work packages, was presented to and agreed by the Programme Board in September 2023. The delivery plan was revised again after additional OLS (DSIT) funding become available from October 2023 and underwent a third revision in January 2025 after further OLS funding became available for the period October 2024 – March 2025.

Previously, monthly updates on programme progress were provided by Our Future Health to the UKRI ADD Programme Board and in monitoring documents. Since July 2023, these updates have been submitted quarterly to the monitoring service provider and ADD Challenge Team, with brief updates on participant recruitment to the ADD Programme Board remaining monthly.

Annex 6: Cohort representativeness data

Number of full participants compared to the 2021 and 2022 UK census figures

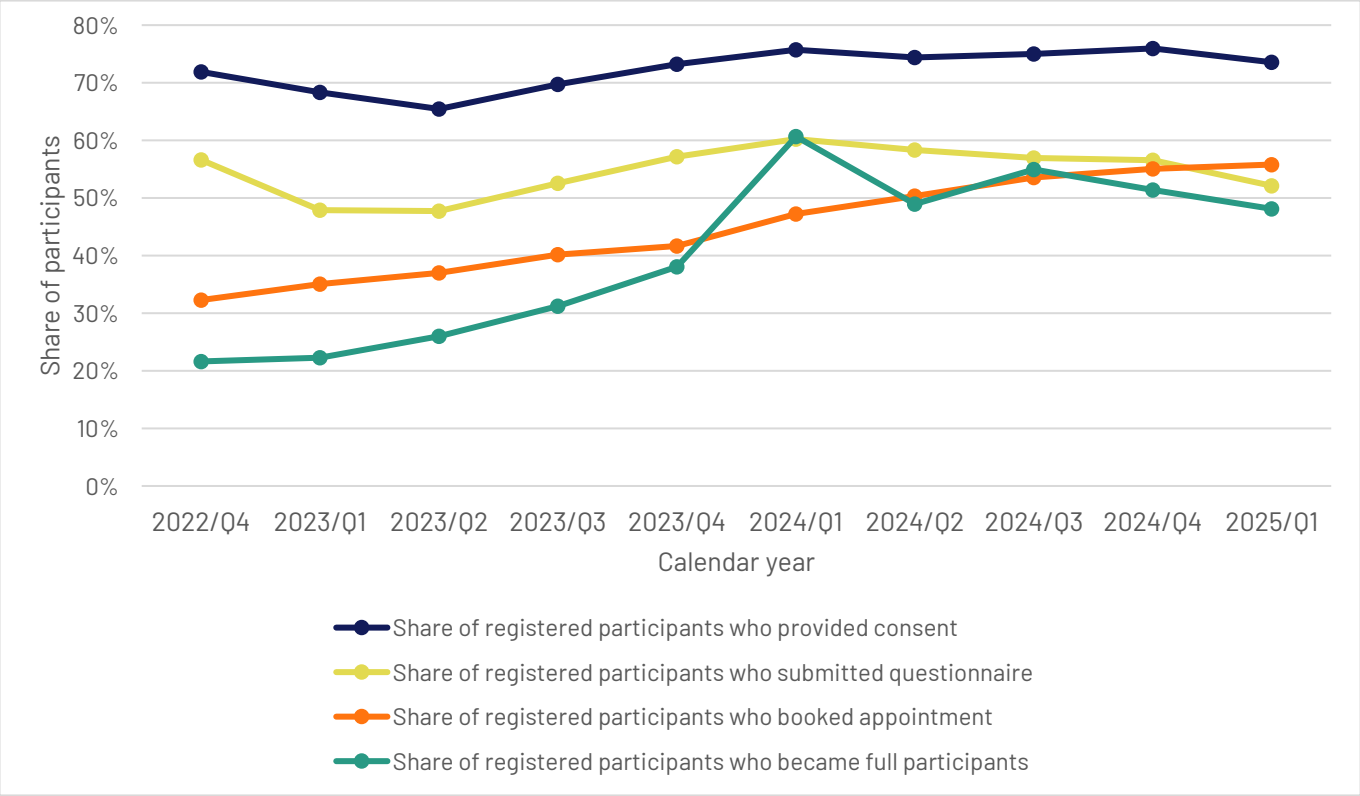
UK Census (combined)		Share of UK population	Share of Our Future Health full participants (n = 1,333,542)	Comparison
Gender	Females	51.7%	55.4%	3.7% greater than Census
	Males	48.3%	44.6%	3.7% lower than Census
Age group	18-29	18.7%	7.4%	11.3% lower than Census
	30–39	17.1%	13.4%	3.7% lower than Census
	40–49	15.9%	15.2%	0.7% lower than Census
	50–59	17.4%	21.2%	3.8% greater than Census
	60–69	13.7%	24.9%	11.2% greater than Census
	70+	17.2%	17.9%	0.7% greater than Census
IMD deciles	1 (most deprived)	10.0%	4.9%	5.1% lower than target
	2	10.0%	6.3%	3.7% lower than target
	3	10.0%	7.6%	2.4% lower than target
	4	10.0%	8.6%	1.4% lower than target
	5	10.0%	9.3%	0.7% lower than target
	6	10.0%	10.5%	0.5% greater than target
	7	10.0%	11.6%	1.6% greater than target
	8	10.0%	12.4%	2.4% greater than target
	9	10.0%	13.4%	3.4% greater than target
	10 (least deprived)	10.0%	15.4%	5.4% greater than target
Ethnicity	White-British	77.7%	81.9%	4.2% greater than Census
	White-Other	7.4%	8.3%	0.9% greater than Census
	Asian-Bangladeshi	0.8%	0.2%	0.6% lower than Census
	Asian-Indian	2.8%	2.5%	0.3% lower than Census
	Asian-Pakistani	2.1%	0.6%	1.5% lower than Census
	Asian-Other	2.2%	1.7%	0.5% lower than Census
	Black-African	2.0%	0.9%	1.1% lower than Census
	Black-Caribbean	1.0%	0.4%	0.6% lower than Census
	Black-Other	0.3%	0.2%	0.1% lower than Census
	Mixed/Other	3.7%	3.0%	0.7% lower than Census

Source: Analysis of Our Future Health data Note: 1. Data provided comes from a slightly different cut-off at the end of March 2025, hence the total count of participants is not 1,336,634 as presented elsewhere in the report.

Annex 7: Our Future Health participants by recruitment stage

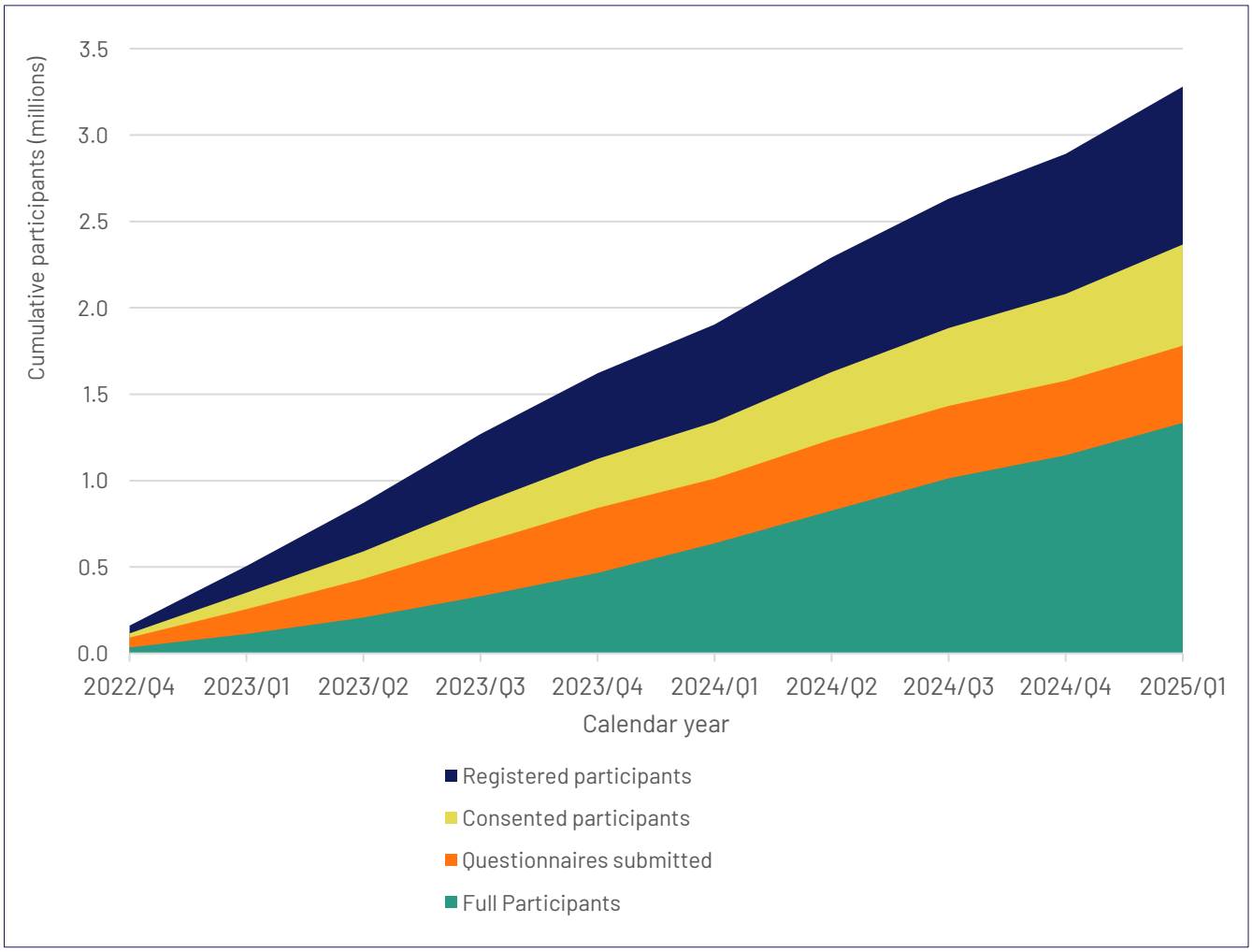
Annex 7 includes graphs presenting the number of participants at each stage in Our Future Health's recruitment pathways. This includes the proportion as well as cumulative numbers of participants at each stage (registration, consent, questionnaire, appointment/blood sample) over time. Analysis is based on summary recruitment data provided by Our Future Health since its establishment.

Share of participants by recruitment stages



Source: Analysis of Our Future Health data Note: 1. Data from 2021 Q3-Q4, and 2022 Q1-Q3 has not been presented as there is no underlying breakdown on the recruitment journey

Cumulative participants by recruitment stages



Source: Analysis of Our Future Health data Note: 1. Data from 2021 Q3-Q4, and 2022 Q1-Q3 has not been presented as there is no underlying breakdown on the recruitment journey

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Ipsos' standards and accreditations provide our clients with the peace of mind that they can always depend on us to deliver reliable, sustainable findings. Our focus on quality and continuous improvement means we have embedded a "right first time" approach throughout our organisation.

ISO 20252

This is the international specific standard for market, opinion and social research, including insights and data analytics. Ipsos UK was the first company in the world to gain this accreditation.

Market Research Society (MRS) Company Partnership

By being an MRS Company Partner, Ipsos UK endorse and support the core MRS brand values of professionalism, research excellence and business effectiveness, and commit to comply with the MRS Code of Conduct throughout the organisation & we were the first company to sign our organisation up to the requirements & self-regulation of the MRS Code; more than 350 companies have followed our lead.

ISO 9001

International general company standard with a focus on continual improvement through quality management systems. In 1994 we became one of the early adopters of the ISO 9001 business standard.

ISO 27001

International standard for information security designed to ensure the selection of adequate and proportionate security controls. Ipsos UK was the first research company in the UK to be awarded this in August 2008.

The UK General Data Protection Regulation (UK GDPR) and the UK Data Protection Act 2018 (DPA)

Ipsos UK is required to comply with the UK General Data Protection Regulation (GDPR) and the UK Data Protection Act (DPA). These cover the processing of personal data and the protection of privacy.

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