

Governance Manual

1.	Introduction	3
2.	Audit & Risk Committee	6
3.	Data Protection And Information Security Committee	13
4.	Nomination & Remuneration Committee	16
5.	Access Board	22
6.	Founders Board	26
7.	Implementation Board	31
8.	Technology Task Force	34
9.	Diversity And Inclusion Advisory Board	36
10.	Ethics Advisory Board	40
11.	Public Advisory Board	43
12.	Scientific Advisory Board	45
13.	Technology Advisory Board	47
14.	Working Groups	49
Appendix A		55
Appendix B		56

1. Introduction

1.1 Governance details

- 1.1.1 Our Future Health, a company established to govern the Our Future Health research programme, is a company limited by guarantee (number 12212468), incorporated in England on 17 September 2019. The registered office address is 2 New Bailey, 6 Stanley Street, Salford, Greater Manchester, United Kingdom, M3 5GS. Our Future Health is also registered as a charity with the Charity Commission for England and Wales (charity number 1189681) and OSCR, Scottish Charity Regulator (charity number SC050917). There is currently no requirement to register with the Charity Commission for Northern Ireland. Details of the current Trustees and Directors can be found in Appendix A.
- 1.1.2 Our Future Health Trading Limited is a private limited company (Number 12599493) which was established by and is wholly owned by Our Future Health. It was incorporated in England on 13 May 2020 and has the same registered office as Our Future Health. The relationship between Our Future Health and Our Future Health Trading Limited is set out in an Intercompany Agreement. Details of the current Directors can be found in Appendix A.
- 1.1.3 The Our Future Health research programme is solely governed by Our Future Health.

1.2 Our Future Health Board of Trustees and Directors

- 1.2.1 The Board of Trustees and Directors of Our Future Health ("Board") is responsible for the governance and strategy of Our Future Health. The Board currently comprises of 12 Trustees, comprising a mix of medical, scientific, business, financial, communications and other expertise. The Trustees have full legal responsibility for the actions of Our Future Health. They are appointed for a renewable term of 3 or 4 years and are the Directors of the company for the purposes of the Companies Act 2006. They do not receive any remuneration and are required to declare any external interests that may be, or may be perceived to be, in conflict with their duties to Our Future Health.
- 1.2.2 The Board meets at least 4 times a year. It delegates specific defined responsibilities to its sub-committees (see appendix B regarding financial delegation). The sub-committees report to the Board at each meeting. The Board delegates the day-to-day responsibility for the running of Our Future Health to the Executive Team. The Executive Team consists of the Chief Executive Officer and their direct reports, all

of whom are employees of Our Future Health. The Executive Team is also responsible for managing all operations and logistics of establishing and making the Resource available to researchers. The "Resource" (when used in this document) means:

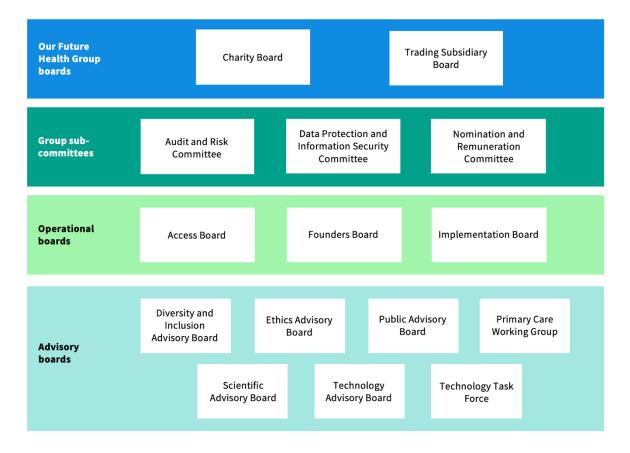
- the data and samples which can be provided via the Our Future Health research programme.
- access to the data and samples via related tools including the Our Future Health Trusted Research Environment.

The Executive Team also reports to the Board at each meeting and others as required.

1.2.3 For the Executive Team to operate effectively, they have established operational and advisory boards to support them in delivering the research programme. The operational boards work with the Executive Team to review and make recommendations to the Board on operational matters. The advisory boards provide additional external expertise into strategic and operational aspects of the research programme either directly via the Executive Team or via the operational boards. A report on the work of each operational and advisory board is presented to the Trustees and Directors at each Board meeting.

1.3 Our Future Health Trading Ltd Board of Directors

1.3.1 The Board of Directors of Our Future Health Trading Ltd is responsible for the governance and strategy of that company. The Directors have full legal responsibility for the actions of Our Future Health Trading Ltd. They are appointed for a renewable term of 3 or 4 years. Those Directors who are not also Trustees or Directors of Our Future Health are offered remuneration for the Board meetings that they attend. All Directors are required to declare any external interests that may be, or may be perceived to be, in conflict with their duties to Our Future Health Trading Ltd.



Our Future Health Governance Structure

2. Audit and Risk Committee

2.1 Purpose

- 2.1.1 The purpose of the Audit and Risk Committee ("Committee") is to:
 - (a) provide formal and transparent arrangements for applying financial reporting internal control principles
 - (b) maintain an appropriate relationship with the Charity's auditors

2.2 Constitution and membership

- 2.2.1 The Committee has been established as a committee of the Board.
- 2.2.2 The members of the Committee will be appointed by the Board, on the recommendation of the Nomination and Remuneration Committee and in consultation with the chair of the Committee. The following paragraphs will govern the constitution of the Committee:
 - (a) The Committee will comprise at least 3 members.
 - (b) The Chair of the Charity will not be a member of the Committee.
 - (c) At least 1 member of the Committee should have recent and relevant financial experience with competence in accounting or auditing.
 - (d) The Committee as a whole must have competence relevant to the health sector.
- 2.2.3 The chair of the Committee will be appointed by the Board, on the recommendation of the Nomination and Remuneration Committee. In the absence of the Chair of the Committee, the members present will select 1 of their number present to chair the meeting.
- 2.2.4 Appointments to the Committee will be for a period of up to 3 years. This may be extended by no more than 2 further periods of up to 3 years, provided the person still meets the criteria for membership of the Committee.
- 2.2.5 The Governance Manager will act as the secretary of the Committee.

2.3 Attendance

- 2.3.1 The Committee will invite a representative of the auditors to attend meetings of the Committee on a regular basis. The Committee should have at least 1 meeting, or part of a meeting, annually with the auditors without management being present.
- 2.3.2 The Committee may request the Chair of the Charity, Our Future Health Executives, and any other relevant senior management to attend meetings of the Committee, either regularly or by invitation, but such invitees have no right of attendance.

2.4 Meetings

- 2.4.1 The Committee will meet at least 4 times each year in accordance with Our Future Health's financial reporting and audit cycle, and at such other times as the chair of the Committee thinks fit.
- 2.4.2 Meetings of the Committee will be arranged to tie in with the publication of Our Future Health's financial statements.
- 2.4.3 Meetings of the Committee will be called by the Governance Manager at the request of the chair of the Committee, or at the request of auditors if they consider it necessary.
- 2.4.4 Unless otherwise agreed by all members of the Committee, members of the Committee and other attendees should get:
 - notice of meetings
 - confirmation of the venue, time, and date
 - an agenda and all relevant papers

This should happen at least 5 working days prior to the date of the meeting.

- 2.4.5 The minimum number of attendees for Committee meetings will be 2 members.
- 2.4.6 Decisions of the Committee will be made by majority vote. If there are equal votes, the chair of the Committee will have a second or casting vote.



2.5 **Reporting**

- 2.5.1 Sufficient time should be allowed after Committee meetings for the Committee to report to the Board on the nature and content of discussion, on recommendations, and on actions to be taken. The Governance Manager will minute the proceedings and resolutions of all meetings of the Committee, including:
 - recording the names of those present and in attendance
 - the existence of any conflicts of interest at the beginning of each meeting

Draft minutes of Committee meetings will be circulated promptly to all members of the Committee and then, once agreed, to all members of the Board.

- 2.5.2 The chair of the Committee will report formally to the Board after each meeting on:
 - (a) all matters that are the Committee's duties and responsibilities
 - (b) how the Committee has discharged its responsibilities.
- 2.5.3 The Committee will make whatever recommendations to the Board that it deems appropriate on an area within its remit.

2.6 **Duties of the Committee**

- 2.6.1 The Committee should carry out the duties below for the Our Future Health group as appropriate.
- 2.6.2 Financial reporting
 - 2.6.2.1 The Committee will monitor the integrity of the financial statements of Our Future Health and any formal announcements relating to Our Future Health's financial performance. They review and report to the Board on significant financial reporting issues and judgements contained in the financial reports including matters communicated by the auditor.
 - 2.6.2.2 In particular, the Committee will review and challenge where necessary:
 - (a) Financial and cash flow forecasts for upcoming financial periods.

- (b) The consistency of, and any changes to, significant accounting policies both on a year-on-year basis and across the Our Future Health group.
- (c) The methods used to account for significant or unusual transactions where different approaches are possible.
- (d) Whether Our Future Health has followed appropriate accounting standards and made appropriate estimates and judgements, taking into account the views of the auditor.
- (e) The clarity of disclosure in Our Future Health's financial reports and the context in which statements are made.
- (f) All material information presented with the financial statements. This includes the strategic report and the corporate governance statement relating to the audit and to risk management.
- 2.6.2.3 The Committee shall review any other statements requiring Board approval which contain financial information first, provided that such prior review is practicable and consistent with any prompt reporting requirements under any law or regulation.
- 2.6.2.4 Where the Committee is not satisfied with any aspect of the proposed financial reporting by Our Future Health it will report its views to the Board.

2.6.3 Narrative reporting

- 2.6.3.1 Where requested by the Board, the Committee should review the content of the annual report and accounts. They will advise the Board on whether, taken as a whole, it is fair, balanced, and understandable.
- 2.6.4 Internal control and risk assessment systems
 - 2.6.4.1 The Committee will keep under review the adequacy and effectiveness of Our Future Health's internal financial reporting and internal control policies and systems. This will cover:
 - (a) all material controls, including financial, operational and compliance controls

- (b) Our Future Health's procedures for the identification, assessment, management and reporting of risks
- 2.6.4.2 The Committee will review the major existing and emerging risks facing Our Future Health and the strategies which are in place to mitigate them. They will report these to the Board.
- 2.6.5 Compliance, whistleblowing, and fraud

The Committee will:

- 2.6.5.1 Review the adequacy and security of Our Future Health's arrangements for its employees and contractors to raise concerns, in confidence, about possible wrongdoing in financial reporting or other matters. The Committee will ensure that these arrangements allow proportionate and independent investigation of such matters and appropriate follow up action.
- 2.6.5.2 Review Our Future Health's procedures for detecting fraud.
- 2.6.5.3 Review Our Future Health's systems and controls for the prevention of bribery and receive reports on non-compliance.
- 2.6.6 Audit

The Committee will:

- 2.6.6.1 Consider and make recommendations to the Board in relation to the appointment, re-appointment, and removal of Our Future Health's auditor.
- 2.6.6.2 Investigate the issues if an auditor resigns and decide whether any action is required.
- 2.6.6.3 Oversee the relationship with the auditor including (but not limited to):
- (a) Recommendations on their remuneration.
- (b) Approval of their terms of engagement, including any engagement letter issued at the start of each audit and the scope of the audit.

- 2.6.6.4 Annually assess the auditor's independence and objectivity. This will take into account: relevant UK law and regulation other professional requirements - the group's relationship with the auditor as a whole – this includes any threats to the auditor's independence and the safeguards applied to mitigate those threats including the provision of any non-audit services 2.6.6.5 Satisfy itself that there are no relationships (such as family, employment, investment, financial or business) between the auditor and Our Future Health 's (other than in the ordinary course of business) which could adversely affect the auditor's independence and objectivity. 2.6.6.6 Monitor the auditor's processes for: - maintaining independence - its compliance with relevant UK law and regulation - other professional requirements including the guidance on the rotation of audit partner and staff 2.6.6.7 Annually assess the qualifications, expertise and resources of the auditor and the effectiveness of the audit process. This will include a report from the auditor on their own internal quality procedures. 2.6.6.8 Discuss the audit and the factors that could affect audit quality. They will review and approve the annual audit plan and ensure that it's consistent with the scope of the audit engagement, taking into account the seniority, expertise, and experience of the audit team. 2.6.6.9 Review the findings of the audit with the auditor. This will include but not be limited to: (a) A discussion of any major issues which arose during the audit. (b) The auditor's explanation of how risks to audit quality were addressed.
 - (c) Key accounting and audit judgements.
 - (d) The auditor's view of their interactions with senior management.

- (e) Levels of errors identified during the audit.
- 2.6.6.10 The Committee will also review the effectiveness of the audit process. This will include:
 - an assessment of the quality of the audit
 - the handling of key judgements by the auditor
 - the auditor's response to questions from the Committee

2.7 **Other matters**

The Committee will:

- 2.7.1 Have access to sufficient resources in order to carry out its duties.
- 2.7.2 Give due consideration to laws and regulations and any applicable rules, as appropriate.
- 2.7.3 Oversee any investigation of activities which are within its terms of reference.
- 2.7.4 Work and liaise as necessary with all other board committees, taking particular account of the impact of risk management and internal controls being delegated to different committees.
- 2.7.5 Arrange for periodic reviews of its own performance and, at least annually, review its constitution and terms of reference. This is to ensure it's operating at maximum effectiveness. It will recommend any changes it considers necessary to the Board.

2.8 Authority

The Committee is authorised to:

- 2.8.1 Seek any information it requires from any employees in order to perform its duties.
- 2.8.2 Obtain, at the Charity's expense, expert independent legal, accounting, or other professional advice on any matter it believes it necessary to do so.
- 2.8.3 Call any employee to be questioned at a meeting of the Committee as and when required.

3. Data Protection and Information Security Committee

3.1 Purpose

- 3.1.1 The Data Privacy and Information Security Committee brings together expertise across scientific, regulatory, legal, ethical, and technology domains. This is to provide expert advice to the research programme on:
 - (a) the awareness and adoption of data protection technology and on
 - (b) all matters related to the protection and privacy of data, including protecting a participant's privacy and rights
 - (c) In this context, data protection is:
 - (d) the assurance that data is usable and accessible with acceptable performance
 - (e) for authorised purposes only
 - (f) compliant with applicable laws and regulations

As well as the technology associated with data protection, there is also a wider context which is being driven by increasing legislation to keep personal data private.

- 3.1.2 The Committee exists to support the mission of Our Future Health, and not to do security for its own sake. As such, it will seek to help the Board and the executive team, both proactively and reactively, to find an appropriate risk approach. The approach will recognise the difficult balance between:
 - effectively delivering the scale and complexity of Our Future Health's objectives
 - managing the complex risks and vulnerabilities that arise with any large-scale project involving citizen data and complicated technology
- 3.1.3 The Executive Team will decide if it should refer a matter to the Committee for advice or decision., This will be done on a case-by-case basis, taking into account the risks, importance, potential impact, complexity and so on of the matter being considered. The Chief Technology Officer and the Executive Director of Ethics, Compliance

and Governance will consult with the Chair when necessary as to whether a matter should be referred to the Committee.

3.1.4 The Committee has delegated authority from the Board to make decisions that fall within its remit, but will decide if it should instead make a recommendation to the Board. This will be done on a case-bycase basis, taking into account the risks, importance, potential impact, complexity and so on of the matter being considered. The Chair will consult with the Chair of the Board, the Chair of the Audit and Risk Committee, the Chief Technology Officer and the Executive Director of Ethics, Compliance and Governance as they consider necessary as to whether a matter should be referred to the Board. The Committee will also provide advice to the Board and the Executive Team on matters that fall within its remit.

3.2 Membership

- 3.2.1 The Committee will comprise:
 - (a) at least 3 Trustees, at least 1 of whom will also be a member of the Audit and Risk Committee
 - (b) 1 member of the Technology Advisory Board
 - (c) 1 member of the Ethics Advisory Board
 - (d) other members as may be required to provide the breadth and depth of knowledge and experience to enable the Committee to fulfil its role.
- 3.2.2 There should always be a majority of Trustees on the Committee.
- 3.2.3 All members will be appointed by the Board of Trustees and will serve for 3 years. All members will be eligible to serve for a second term of 3 years. Any member appointed by virtue of being a member of another Board will stand down if their membership of that other Board ends.
- 3.2.4 1 of the Trustees, to be chosen by the Board, will chair the Committee. In their absence, another Trustee will chair the meeting.
- 3.2.5 There must be a minimum of 3 people attending the Committee, and at least 1 must be a Trustee. If the majority of members in a meeting are not Trustees, any decisions made will need to be ratified by email after the meeting. For any decision to be ratified, the majority of members voting, regardless of how they vote, will need to be Trustees.

3.3 Frequency of meetings

3.3.1 The board will meet monthly for the first year, unless otherwise agreed. The frequency of meetings will be reviewed at the end of the first year.

3.4 Reporting requirements

- 3.4.1 The Committee is a sub-committee of the Board of Trustees. A written summary of the proceedings of each Committee meeting will be sent to the following meeting of the Board. This, includes any:
 - decisions made
 - recommendations to be considered by the Board
 - advice to be provided to the Board issues that the Committee wants to highlight to or raise with the Board
- 3.4.2 The Chair (or another Trustee member of the Committee) address that summary in the Board meeting if required. In cases of urgency, the Committee should not wait until the following meeting of the Board. The Committee's reports to the Board will highlight any decisions that it has taken, which will be open to review by the Board.
- 3.4.3 The Committee will raise any matter that requires consideration by the Audit and Risk Committee with the Chair of the Audit and Risk Committee within 7 days. This Committee may request a shorter timescale if the matter is more urgent.
- 3.4.4 The Chair of the Committee will meet with the Chair of the Audit and Risk Committee before each Board meeting and otherwise as required, to discuss any issues that need to be raised with the Board and to ensure that an appropriate level of assurance can be provided.

3.5 Other matters

- 3.5.1 Members who are not also Trustees will be eligible to receive compensation for each meeting attended. All members will be entitled to reimbursement for all reasonable costs for attending meetings.
- 3.5.2 All members who hold roles within Our Future Health are required to declare any conflicts of interest in accordance with the Conflict of Interest Policy.
- 3.5.3 All matters considered by the Committee and all the information Our Future Health provides to members, must be considered confidential unless confirmed otherwise.

4. Nomination and Remuneration Committee

4.1 Purpose

- 4.1.1 The purpose of the Nomination and Remuneration Committee ("Committee") is to:
 - (a) establish a formal, rigorous, and transparent procedure for the appointment of new Trustees to the Board
 - (b) establish a formal and transparent procedure for developing policy on senior management remuneration

4.2 Constitution and membership

- 4.2.1 The Committee has been established as a Committee of the Board.
- 4.2.2 The Board will appoint members to the Committee. The Committee shall comprise at least 3 members, the majority of whom shall be Trustees.
- 4.2.3 The chair of the Committee should be a Trustee and appointment by the Board. In the absence of the Chair of the Committee, the members present shall elect 1 of their number present to chair the meeting. Members should choose from those who would qualify under these terms of reference. The Chair of the Charity should not chair the Committee when it is dealing with the appointment of a successor to the Chair.
- 4.2.4 Appointments to the Committee shall be for a period of up to 3 years. Appointment may be extended twice and each extension can be for periods of up to 3 years. Before granting extensions, ensure that the member still meets the criteria for membership of the Committee.
- 4.2.5 Only members of the Committee have the right to attend Committee meetings. However, the Committee can invite other individuals such as the Chief Executive Officer, and external advisers to attend for all or part of any meeting, as and when appropriate.
- 4.2.6 The Governance Manager shall act as the secretary of the Committee. The Governance Manager will ensure that the Committee receives information and papers in a timely manner to enable full and proper consideration to be given to issues.

4.3 Meetings

- 4.3.1 The Committee will meet at least twice each year. The chair of the Committee can approve more meetings if needed .
- 4.3.2 The Governance Manager will organise committee meetings when the chair of the Committee requests it.
- 4.3.3 The Governance Manager will, circulate to each member of the Committee and to any other person required to attend:
 - notice of meetings
 - venue confirmations
 - times
 - date
 - an agenda
 - all relevant papers

This should be done at least 5 working days prior to the date of the meeting.

- 4.3.4 There should be a minimum of 2 members present at every committee meeting. Both members must be Trustees.
- 4.3.5 The Committee will make decisions by majority vote. In the event of an equality of votes the chair of the Committee will have a second or casting vote.

4.4 Reporting

- 4.4.1 The Governance Manager shall minute the proceedings and resolutions of all meetings of the Committee, including recording the names of those in attendance. The Governance Manager will share draft minutes of Committee meetings promptly to all members of the Committee and once agreed, to all Trustees unless it would be inappropriate to do so.
- 4.4.2 The Committee should also allow sufficient time after meetings for the Committee chair to report to the Board on:
 - the nature and content of its discussion
 - recommendations
 - action to be taken
- 4.4.3 The Committee shall make whatever recommendations to the Board that it deems appropriate on an area within its remit. The Committee should allow adequate time for Board discussions where necessary.

4.5 **Duties of the Committee**

4.5.1 The Committee should carry out the following duties for the Charity, Our Future Health Trading Limited and the group as a whole, as appropriate. The Committee shall:

4.5.2 Nomination function

- 4.5.2.1 Regularly review the structure, size, and composition (including the skills, knowledge, experience, and diversity) of the Board and recommend any changes to the Board.
- 4.5.2.2 Ensure plans are in place for orderly and diverse succession to Board and senior management positions The Committee should take into account the challenges and opportunities facing the Charity, and the skills and expertise needed on the Board in future.
- 4.5.2.3 Continuously review the leadership needs of the Charity, both at executive and at board level.
- 4.5.2.4 Keep up to date and fully informed about strategic issues affecting the Charity and the sector in which it operates.
- 4.5.2.5 Be responsible for identifying and nominating candidates for Trustee vacancies for the approval of the Board.
- 4.5.2.6 evaluate the balance of skills, knowledge, experience, and diversity on the Board before appointing candidates to roles,. Then, after this evaluation, prepare a description of the role and capabilities required for a particular appointment. In identifying suitable candidates, the Committee shall (if appropriate):
- (a) Use open advertising or the services of external advisers to facilitate the search.
- (b) Consider candidates from a wide range of backgrounds.
- (c) Consider candidates on merit, against objective criteria and with due regard for the benefits of diversity on the Board, taking care that appointees have enough time available to devote to the position.
- 4.5.2.7 Prior to the appointment of a Trustee, the proposed appointee should disclose any other significant time commitments they have. The proposed appointee is also

required to disclose any other interests that may result in a conflict of interest.

- 4.5.2.8 Ensure that on appointment to the Board, Trustees receive a role description setting out clearly what is expected of them in terms of:
 - time commitment
 - Committee service
 - involvement outside Board meetings.
- 4.5.2.9 Review the results of the Board performance evaluation process that relate to the composition of the Board and succession planning.
- 4.5.2.10 Annually review the time required from Trustees. Performance evaluation should be used to assess whether the Trustees are spending enough time to fulfil their duties.

The Committee shall also make recommendations to the Board concerning:

- (a) Any changes needed to the succession planning process if its periodic assessment indicates the desired outcomes have not been achieved.
- (b) Suitable candidates for new Trustees and succession for existing Trustees.
- (c) Membership of the Audit and Risk Committee, and any other board committees as appropriate, in consultation with the chairs of those committees.
- (d) The re-appointment of any Trustee at the conclusion of their specified term of office. Review their performance and ability to continue to contribute to the Board in the light of the knowledge, skills and experience required.
- (e) Any matters relating to the continuation in office of any Trustee at any time.

4.5.3 Remuneration function

- 4.5.3.1 Have delegated responsibility for determining the policy for setting remuneration for senior management.
- 4.5.3.2 Design remuneration policies and practices to support strategy. Promote long-term sustainable success, with executive remuneration aligned to the Charity's purposes and values. This should be clearly linked to the successful delivery of the Charity's long-term strategy.
- 4.5.3.3 Ensure that no senior manager will be involved in any decisions about their own remuneration outcome.
- 4.5.3.4 In determining the remuneration policy, take into account all other factors deemed necessary. These factors include relevant:
 - legal
 - regulatory requirements
 - charity commission guidance

The objective of such policy shall be to attract, retain and motivate quality executive management to run the Charity successfully without paying more than is necessary.

- 4.5.3.5 Review the ongoing appropriateness and relevance of the remuneration policy.
- 4.5.3.6 Within the terms of the agreed policy and in consultation with the Charity chair or Chief Executive Officer, as appropriate, determine the total individual remuneration of senior managers.
- 4.5.3.7 Have full authority to appoint remuneration consultants and to commission or purchase any reports, surveys, or information necessary at the Charity's expense. However, the Committee should avoid designing pay structures based solely on benchmarking to the market or on the advice of remuneration consultants.

4.6 Other matters

- 4.6.1 The Committee shall:
 - 4.6.1.1 Work and liaise as necessary with all other board committees, ensuring the interaction between committees and the Board is reviewed regularly.

- 4.6.1.2 Have access to sufficient resources in order to carry out its duties as required.
- 4.6.1.3 Give due consideration to laws and regulations as appropriate; and
- 4.6.1.4 Arrange for periodic reviews of its own performance. Review its constitution and terms of reference, at least annually, to ensure it is operating at maximum effectiveness. Recommend any changes it considers necessary to the Board for approval.

4.7 **Authority**

4.7.1 The Committee is authorised by the Board to obtain, at the Charity's expense, outside legal or other professional advice on any matters within its terms of reference.

5. Access Board

5.1 Purpose

5.1.1 The Access Board (AB) will be responsible for the implementation of the access process summarised herein and for overseeing decisions about applications to access data, samples, and participants. Application summaries and decisions will be made public. The overarching objective of the Access Board is to maximise responsible use of the Resource. The Access Board will review applications requesting data or biological samples or seeking permission to approach participants for secondary studies. At all times consideration of the best interests of the participants will be paramount.

5.2 Membership

- 5.2.1 The Access Board will be comprised of sector nominees. Sector nominees should include broad representation from across industry, charities, and academia sectors, and be sufficiently skilled in the field, including ethics expertise, and capable of applying the terms of reference of the Access Board consistently.
- 5.2.2 Access Board representatives must not be from the Founding Members, with the exception of any representative nominated by the Founders Board to sit on the Access Board.
- 5.2.3 The Access Board will establish rules for representation from across the sectors outlined above and voting and quorum requirements to be used at each Access Board meeting, to ensure appropriate voting rights across the sectors.
- 5.2.4 The AB will additionally include members who will:
 - Specifically represent the perspective of the general public and participants, ensuring that perspective is consistently heard and considered in the Board's work.
 - (b) Have sufficient knowledge and understanding of the business of the Board to be able to make constructive contributions to its discussions and to challenge appropriately its positions.

5.3 Meetings

5.3.1 The Access Board supports the Executive Team by developing and operationalising the Resource access process. It should maintain close

working arrangements with the Founders Board, Ethics Advisory Board and other boards as required and can request expertise when required, e.g., from the Scientific Advisory Board. The Access Board will have to ensure that the Resource access process enables timely decisions on all types of applications.

5.3.2 The Access Board shall conduct its activities under strict confidentiality to protect the interests of the applicant. To provide appropriate transparency to the general public, a lay summary is required for each approved application (the wording of which will be agreed between the Access Board and the applicant) and will be made available within the Our Future Health public register of studies, which shall be updated regularly by Our Future Health. Such public register shall not contain or disclose Founding Industry Member's Confidential Information, any Personal Information or other proprietary information including biological target information in an approved study.

5.4 **Reporting**

5.4.1 The Access Board will provide regular reports to the Our Future Health Executive Team and other Our Future Health boards as required including the Founders Board.

5.5 **Duties of the Board**

- 5.5.1 Specifically, the Access Board will:
 - 5.5.1.1 Undertake the review of all applications for studies which require access to the Resource and establish clear policies and procedures for accessing participants' data, samples and for re-contact with the participants themselves consistent with paragraph 7.6 below.
 - 5.5.1.2 Establish a definition of a "depleting" study and an overall depletion framework, along with related examples and principles. This definition and depletion framework will be consistently applied in the Access Board's decision process, taking into account the need to conserve the Resource for the long term and promote maximal value from the Resource.
 - 5.5.1.3 Ensure applications are:
 - (a) In the best interests of, and acceptable to, the participants and consistent with the consent provided.

- (b) Led by registered researchers.
- (c) Ethical and feasible.
- (d) Aligned with the overarching objectives of Our Future Health (are aimed at improving human health, as an example) and are not likely to bring the study into disrepute or stigmatise any of its participants.
- 5.5.1.4 Regularly review the access procedures to ensure they are acceptable to participants and meeting the needs of Our Future Health's user communities.
- 5.5.1.5 Always apply the depletion framework when assessing applications and shall reject applications for any study that may be depleting as per the agreed definition and depletion framework.

5.6 The Access Board has overall responsibility for ensuring that access to, and usage of, the Resource is consistent with:

- 5.6.1 the undertaking given to, and the specific Informed Consent given by the Cohort Participants;
- 5.6.2 (And in compliance with) all laws and regulations including respect for human rights.
- 5.6.3 the conditions placed on Our Future Health in the ethical approval granted by the Health Research Authority.
- 5.6.4 the principles of the Our Future Health research programme to advance early disease diagnosis and detection for the benefit of the public, disease discovery and making innovation available.
- 5.6.5 the Our Future Health Ethics Framework.
- 5.6.6 the Resource Access Process and its objective to facilitate access to the Core Cohort Data, Cohort Participants and Samples and other aspects of the Resource to enable high quality studies. Studies submitted to the Access Board may be broad (such as data mining) or narrow (such as a discrete research question) in their objectives.

5.7 **Other matters**

5.7.1 The Access Board shall conduct its activities under strict confidentiality to protect the interests of the applicant.

- 5.7.2 Members will be entitled to receive compensation for preparing for and attending meetings and to be reimbursed for all reasonable expenses.
- 5.7.3 Members will declare any conflicts of interest in accordance with the Our Future Health Conflict of Interest Policy.

6. Founders Board

6.1 **Purpose**

+ Our Future Health

- 6.1.1 The Founders Board will advise Our Future Health on, and assist Our Future Health with, certain key aspects regarding the development and delivery of the Our Future Health research programme.
- 6.1.2 The Founders Board shall be comprised of:
 - Representatives of Our Future Health and Our Future
 Health Trading Limited including the Chief Executive
 Officer and other Executive Team members.
 - (b) A representative from each Founding Industry Member.
 - (c) A representative from each Founding Member Charity.
 - (d) A representative from UKRI.
- 6.1.3 The Founders Board will be designed to ensure that scientific and public interest expertise is represented and available for assisting the Our Future Health research programme, and will be the forum for advising Our Future Health on and providing the input into, coordination, review, and agreement of the following activities:
 - 6.1.3.1 establishing and amending, as necessary, the Scientific Protocol for the Resource for data and sample collection, recruitment and serial sampling;
 - 6.1.3.2 monitoring the progress against goals, roadmaps and timelines with respect to the implementation of the Resource;
 - 6.1.3.3 ensuring the Access Process under which Registered Researchers who have gained study approval may run Stage 1 Studies and Stage 2 Studies, is conducted as contemplated, and is regularly reviewed to address any updates that may be recommended;
 - 6.1.3.4 creating an accreditation process through which Founding Members will be able to apply for accreditation of their own Trusted Research Environments;
 - 6.1.3.5 the review of and recommendation on the admission of new or additional Founding Members;

- 6.1.3.6 reviewing and advising on the creation and application of any charging model applied by Our Future Health for use of the Resource;
- 6.1.3.7 reviewing and advising on the creation of further Our Future Health policies which directly impact the implementation and usability of the Resource; and
- 6.1.3.8 matters which may require advisory input, remedy, or escalation.

In all situations, decisions of the Founders Board must be undertaken considering the overall scientific objectives and goals of the Our Future Health research programme and the budget it is operating under. All supporting information required by the Founders Board shall be provided by the Executive Team.

6.2 Meetings of the Founders Board

- 6.2.1 Unless otherwise agreed at the Founders Board, the Founders Board shall meet at least monthly or more regularly if required during 2022. Thereafter the Founders Board may decide to reduce the meetings to a quarterly interval.
- 6.2.2 The Founders Board may convene an extraordinary meeting at the request of a Founding Member or the Executive Team.
- 6.2.3 A minimum quorum of at least 75% (75%) of representatives from Founding Industry Members and at least 75% (75%) of representatives from Founding Member charities and at least 1 representative from the Executive Team.
- 6.2.4 No later than 5 (5) Business Days in advance of a scheduled Founders Board meeting, the Founders Board will receive an operational report from the Executive Team which will include details on:
 - updates on development of the Resource, related recruitment and enrolment, and progress against (and proposed deviations from) any related plans, timelines and milestones;
 - (b) cohort diversity reporting and review in line with the then current Scientific Protocol, including target age ranges, eligible populations, ethnic diversity, gender diversity and socioeconomic status;

- minutes and if appropriate metrics from the other governance boards, subject to relevant confidentiality measures;
- (d) Our Future Health's and Our Future Health Trading Limited's budget position versus plan, including expenditure and budgeting;
- status of any proposed studies received by the Access
 Board, subject to appropriate confidentiality restrictions,
 which may benefit from a consortium of Founding
 Members to perform;
- (f) any matters which may require advisory input, remedy or escalation;
- (g) other scientific, strategic or budgetary topics as reasonably requested in advance by the Founders Board.
- 6.2.5 Meeting minutes of the Founders Board shall be recorded and stored in a secure portal for general access by all Founding Members.

There shall be 1 vote for each representative of the Founding Industry Members and Founding Charity Members that are present at the relevant quorate Founders Board meeting. Items being considered by the Founders Board will be voted on and decisions reached subject to the following voting thresholds (dependent on the item):

- (a) A unanimous vote in favour from all representatives of Founding Industry Members and Founding Charity Members present at the meeting
- (b) A super majority vote where super majority means at least 75% of the votes cast by representatives from Founding Industry Members present at the meeting and at least 75% of votes cast by representatives from Founding Member charities present at the meeting
- A simple majority vote (i.e., more than 50%) from both the Founding Industry Members and the Founding Charity Members present at the meeting (along with more than 50% of votes cast by all representatives with voting rights present at the meeting)

- 6.2.6 In the situation where there is a deadlock in the voting, there is a process through which matters can be escalated in an attempt to resolve the issues.
- 6.2.7 The members of the Founders Board will nominate a chairperson who will serve as chairperson of the Founders Board for a period of twelve (12) months, with the chairperson to then rotate between representatives from the Founding Industry Members and Founding Charity Members.
- 6.2.8 Only members of the Founders Board have the right to attend and vote at the Founders Board meetings (except the representatives of Our Future Health and Our Future Health Trading Limited on the Founders Board who have no voting rights). However, other individuals such as members of other Our Future Health advisory boards, alliance or project managers from Founding Industry Members or Founding Charity Members, can be invited to attend as observers for all or part of the meetings.
- 6.2.9 The Founders Board, in consultation with the Executive Team, may choose to establish time-limited working sub-groups who would be charged with specific deliverables. These sub-groups would be established jointly between the Founders Board, relevant members of the Executive Team and/or other relevant experts.
- 6.2.10 Our Future Health through the Executive Team shall provide to the Founders Board all information and documentation necessary for the Founders Board to fulfil and carry out its roles, responsibilities and activities including in relation to matters referred to in this Founders Board section.

6.3 **Remediation process**

- 6.3.1 If the development of the Resource and/or related recruitment/enrolment are materially behind schedule, and/or if progress is not consistent with (or deadlines may be or are missed for) related plans, timelines, and milestones the Executive Team shall:
 - 6.3.1.1 provide full details of and reasons for the issue which has triggered the remediation process as soon as possible to the Founders Board, including convening an extraordinary meeting of the Founders Board where required;
 - 6.3.1.2 provide detailed proposed solutions for discussion including any consequences to the Resource operation; and

6.3.1.3 the Founders Board shall discuss the matter at a meeting and agree next steps and potential solutions including any update to the planned timelines and goals, taking into account scientific quality and the overall goals of the Our Future Health research programme.

6.4 Secretariat

- 6.4.1 The secretariat will be provided by Our Future Health.
- 6.4.2 The secretariat is responsible for ensuring that the board receives relevant information and papers in a timely manner to enable full and proper consideration to be given to issues.
- 6.4.3 The secretariat will also provide logistical support, if needed, to progress work undertaken in the period between meetings of the Founders Board.
- 6.4.4 The secretariat shall minute the meetings of the Founders Board, including recording the names of those present and in attendance.Once approved by the chairperson, minutes shall be distributed to the relevant board or committee for its next meeting.
- 6.4.5 Founders Board members will declare any Conflicts of Interest in accordance with the Our Future Health Conflict of Interest Policy.

7. Implementation Board

7.1 Purpose

- 7.1.1 The Implementation Board is a strategic group aimed at providing Our Future Health with advice and challenge in order to deliver the programme in the most effective way.
- 7.1.2 The Implementation Board will be a forum for the input into, coordination, review, and agreement of the following aspects of the programme:
 - (a) Assisting in the recruitment of participants through NHS services including NHSBT, primary care, secondary care, community pharmacy, community diagnostic hubs, and screening services.
 - (b) Linkage of participant data to NHS records and wider linkage across government administrative data
 - (c) Feedback of individual health-related findings to participants including both what is fed back to participants and its impact on NHS clinical services and systems including primary care, secondary care, community pharmacy and screening services. The objective is to ensure that the utility of feedback to participants is maximised while minimising any unwarranted impact on clinical services, especially primary care. At all times, consideration of the best interests of the participants will be paramount.
- 7.1.3 The Board will ensure that the implications of the program for the NHS are always taken into account i.e. that healthcare professionals are properly prepared, well-informed and not overburdened as a result of the programme and that there is appropriate engagement within relevant NHS professionals and structures throughout the lifetime of the cohort.

7.2 Membership

- 7.2.1 The Implementation Board will comprise members of partner organisations who are involved in or support the delivery of the Our Future Health programme. This may include representatives from:
 - UK nations supporting health & social care
 - NHS blood & transplant

+ Our Future Health

- NHS England (incorporating NHS Digital and NHS-X)
- NHS Wales
- NHS Scotland
- HSC Northern Ireland
- NIHR
- NHS Accelerated Access Collaborative
- Office for Health Improvement and Disparities
- Health Data Research UK
- Professional Medical Society & Colleges representing primary care, secondary care, community pharmacy and screening services including the Royal Colleges of Physicians, Royal College of General Practitioners, The Royal Pharmaceutical Society and BMA

Those from other organisations with relevant expertise in feedback of individual health results including academia and industry.

- 7.2.2 In addition to these members, the Chief Executive Officer and the Chief Medical Officer will also be members and the Board shall be chaired by the Chief Medical Officer. Other members of the Our Future Health Executive Team may be invited to attend as appropriate.
- 7.2.3 Members will declare any conflicts of interest in accordance with the Our Future Health Conflict of Interest Policy.

7.3 Meetings

The Implementation Board shall meet at least quarterly or more regularly if required. At each quarterly meeting, the Board will receive an operational report which will include at a minimum the following matters:

- Minutes from the other advisory boards
- 7.3.1 Meeting minutes of the Implementation Board shall be recorded and stored in a secure portal or SharePoint for general access by all members.

7.4 Other

- 7.4.1 In all situations, the Implementation Board must consider the overall scientific objectives and goals of the Our Future Health programme.
- 7.4.2 Following initial review and alignment with the core materials described above, should the Our Future Health programme materially

change, the Implementation Board would be asked to consider and report upon the impact of such changes.

- 7.4.3 Our Future Health shall provide to the Implementation Board all information and documentation necessary for the Implementation Board to fulfil and carry out its roles, responsibilities, and activities.
- 7.4.4 The Implementation Board can propose representatives who could be participants at other advisory boards established by Our Future Health in support of the programme.
- 7.4.5 Members of the group are acting purely as representatives of their organisations, and any necessary approvals and regulatory steps will still need to be followed.

8. Technology Task Force

8.1.1 Purpose

- 8.1.1.1 The Technology Task Force (TTF) is established by the Executive Team and shall report to that team through the Chief Technology Officer. The TTF will help with development of the Our Future Health Trusted Research Environment (TRE) specification and the accreditation process for 3rd party TREs. Additionally, the TTF will ensure that the programme is able to achieve its goals by contributing to discussion in relation to the design and delivery of the TRE platform and data tools, data security and data flows required to support the project, considering the changing data and technology landscape in the UK and internationally.
- 8.1.1.2 The TTF provides a direct route for Founding Members (charity and industry) to contribute to discussion which will influence the technology solutions for the programme.

8.1.2 Membership

- 8.1.2.1 Membership of the Technology Task Force will comprise Founding Industry Members and Founding Charity Members who have signed a partnership agreement. These entities may nominate appropriately qualified personnel to attend meetings of the Technology Task Force based on the agenda rather than having a fixed standing member, so as to facilitate robust and detailed discussions on a range of topics that will vary over time.
- 8.1.2.2 The Technology Task Force may nominate up to 2 representatives (1 representative from Founding Industry Members and 1 representative from Founding Member charities) to attend the Technology Advisory Board to represent the Technology Task Force.
- 8.1.2.3 The Chair of the Technology Task Force will be selected by the Technology Task Force and approved by Our Future Health, such approval shall not be unreasonably withheld.

8.1.3 Secretariat

8.1.3.1 The secretariat will be provided by Our Future Health.

- 8.1.3.2 The secretariat is responsible for ensuring that the task force receives relevant information and papers in a timely manner to enable full and proper consideration to be given to issues.
- 8.1.3.3 The secretariat will also provide logistical support, if needed, to progress work undertaken in the period between meetings of the Technology Task Force.
- 8.1.3.4 The secretariat shall minute the meetings of the Technology Task Force, including recording the names of those present and in attendance. Once approved by the chairperson, minutes shall be distributed to the relevant board or committee for its next meeting.

8.1.4 **Other matters**

8.1.4.1 The Technology Task Force shall operate for the defined period set out in the FIM contract, at which time all its activities and responsibilities shall pass to Our Future Health's Chief Technology Officer. The Founders' Board may, if it deems necessary, reconstitute a further technology task force at a later stage for 1 or all of the following reasons:

- To focus on technical issues relating to the Resource

- To focus on the activities contemplated under this Agreement

- In support of Our Future Health's Chief Technology Officer.

- 8.1.4.2 The Technology Task Force shall have access to sufficient resources in order to carry out its duties, including access to the Secretariat for assistance as required.
- 8.1.4.3 Representatives on the Technology Task Force will declare any conflicts of interest prior to a meeting and recuse themselves from discussions as necessary.

9. Diversity and Inclusion Advisory Board

9.1 Purpose

- 9.1.1 Our Future Health is committed to building a research programme that truly reflects the UK population, so that we can identify differences in how diseases begin and progress in people from different backgrounds. The purpose of the Diversity & Inclusion Advisory Board (DAB) is to advise and provide strategic support to the Our Future Health research programme regarding involvement, engagement, recruitment, and retention of communities who are often under-represented in health research, including Black, Asian, and other minority ethnic groups, and people from lower socioeconomic backgrounds.
- 9.1.2 The DAB will provide expert advice to Our Future Health on equality, equity, diversity, and inclusion in relation to issues including participant recruitment, retention, and engagement with and evaluation of the programme.
- 9.1.3 The DAB will advise the Our Future Health Executive Team, and, where appropriate, the Board of Trustees via the Executive Team.

9.2 Membership

- 9.2.1 Members of the DAB will represent groups that possess experience and networks in communities that are classified as under-represented.
 Members will have extensive experience of influencing and motivating communities to engage in both national and local strategic projects.
- 9.2.2 The DAB will comprise members drawn from the following groups:

Community engagement leaders and workers

Individuals who have led or worked on community engagement projects for harder-to-reach audiences – their experience does not have to be specifically health related and it will be important that they can provide tactical advice on national engagement strategies.

Public health, social & health care

Individuals with experience working with patients from diverse backgrounds in the public health or health care contexts, including from organisations with similar objectives in engaging harder-to-reach groups.

Communications, PR, and media

Individuals from communications, PR or media backgrounds with experience of engaging with harder-to-reach groups – health experience is not essential, but they will understand how to deliver successful targeted campaigns.

Academic research

Experienced and respected research leaders who have a professional background that includes targeting of under-represented groups in health research.

Faith leaders

National-level faith leaders with significant influence across their communities – experience in working with third parties as a conduit to under-represented communities would also be desirable.

- 9.2.3 The DAB will additionally include at least 1 member who will:
 - Specifically represent the perspective of the general public and participants, ensuring that that perspective is consistently heard and considered in the Board's work.
 - (b) Have sufficient knowledge and understanding of the business of the Board to be able to make constructive contributions to its discussions and to challenge appropriately its positions.
- 9.2.4 Members will either be directly invited to be a part of the DAB or will respond to a national-level advertisement. In the latter case, members will be selected via an assessment process comprising a written application and panel interview. Efforts will be made to create a board that includes people from a broad range of backgrounds and communities.
- 9.2.5 The secretariat will be provided by Our Future Health.

9.3 Meetings

- 9.3.1 The DAB will begin by meeting quarterly, with the ongoing meeting frequency to be determined by the Chair, in consultation with the Secretariat, and based on Our Future Health requirements.
- 9.3.2 Unless otherwise agreed, notice of each meeting date and time, venue confirmation, agenda of items to be discussed, and any supporting

papers, will be forwarded to each member of the Board no less than 5 working days before the date of the meeting.

- 9.3.3 The Chair will assume responsibility for determining the frequency, timing, and agenda for the meetings, with support from the Secretariat and a nominated Our Future Health Leadership Team representative.
- 9.3.4 The Chair (or representative) will be responsible for liaison with the Our Future Health Leadership Team and others as required.
- 9.3.5 The Chair will ensure that equal and proper consideration is given to issues arising and may be asked to communicate with other DAB members on behalf of Our Future Health in the period between meetings. The Chair will also be part of the Chairs Group, enabling networking with other Our Future Health advisory groups.
- 9.3.6 The Secretariat will ensure that DAB members receive relevant prereads and papers in a timely manner, to enable sufficient time for full and proper consideration before the meeting. The Secretariat will also provide logistical support, if needed, to progress work undertaken by and on behalf of the DAB in the period between meetings.
- 9.3.7 The Secretariat will be responsible for minuting the meetings, including recording the names of those present and in attendance. Once approved by the Chair, minutes will be distributed to the DAB members before the next meeting.

9.4 **Reporting**

9.4.1 The Our Future Health Executive Team will receive the minutes of meetings.

9.5 **Duties of the Board**

- 9.5.1 The DAB will advise on:
 - 9.5.1.1 Aspects of programme design and delivery that relate to engaging, recruiting, and retaining under-represented groups.
 - 9.5.1.2 How to maximise diversity of the cohort and ability to recruit and retain under-represented groups, given the resources available.
 - 9.5.1.3 Addressing motivators and barriers to taking part in health research among under-represented groups.

- 9.5.1.4 Facilitating communication, awareness building and networking with key community, academic, religious, and professional organisations and groups aligned to the aims of Our Future Health.
- 9.5.1.5 Evaluating the programme to identify and prioritise enhancements that will further improve diversity and ability to reach under-represented groups over time.

9.6 **Other matters**

- 9.6.1 Membership will be for 1 year in the first instance.
- 9.6.2 Members will serve for renewable terms of 2 years.
- 9.6.3 The Chair will be appointed by the Board from among their number, to serve for no more than 2 years. No Chair will serve for more than 4 consecutive years.
- 9.6.4 A written report on the work of the Board will be presented at each quarterly Charity Board meeting.
- 9.6.5 These terms of reference will be reviewed at least once every 2 years.
- 9.6.6 The DAB will additionally include at least 1 member who will:
 - Specifically represent the perspective of the general public and participants, ensuring that that perspective is consistently heard and considered in the Board's work.
 - (b) Have sufficient knowledge and understanding of the business of the Board to be able to make constructive contributions to its discussions and to challenge appropriately its positions.
- 9.6.7 The DAB will have access to sufficient resources to carry out its duties, including access to assistance for the Chair as required. Members may be invited to take part in external consultation activities at the discretion of Our Future Health, depending on availability and relevant expertise or interests.
- 9.6.8 Members will be entitled to receive compensation for preparing for and attending meetings and to be reimbursed for all reasonable expenses.
- 9.6.9 Members will declare any conflicts of interest in accordance with the Our Future Health Conflict of Interest Policy.

10. Ethics Advisory Board

10.1 Purpose

- 10.1.1 The Ethics Advisory Board (EAB) will monitor the development of the Our Future Health programme and respond to ethical issues that arise, including those related to data privacy, security, and regulatory compliance. It will set its own agenda in consultation with the Executive and the Board.
- 10.1.2 It will seek to develop and establish its ways of working and reporting in the public interest, with an appropriate level of openness to public scrutiny and a focus on public trust. It will work with Our Future Health to create a culture of transparency, whilst taking into account commercial and NHS sensitivities to public disclosure.

10.2 Membership

- 10.2.1 Members of the EAB are invited based on their personal expertise and to contribute to the combined balance of expertise needed to advise the programme.
- 10.2.2 The EAB will additionally include at least 1 member who will:
 - Specifically represent the perspective of the general public and participants, ensuring that that perspective is consistently heard and considered in the Board's work.
 - (b) Have sufficient knowledge and understanding of the business of the Board to be able to make constructive contributions to its discussions and to challenge appropriately its positions.
- 10.2.3 Members of the EAB shall be appointed for a period of 2 years. Such appointment may then be extended by up to 2 years at a time by reinvitation and mutual agreement, provided the member continues to meet the criteria for membership of the EAB.
- 10.2.4 The members of the EAB will appoint a Chair from among their number. The Chair will serve for 24 months, which can be renewed by the members of the EAB for a second and final term.
- 10.2.5 In addition to core members, others may be invited to attend as appropriate according to the agenda in order to bring additional expertise and experience to the group as needed.

10.2.6 The secretariat for the EAB will be provided by Our Future Health.

10.3 Meetings

- 10.3.1 The EAB will meet at least 3 times a year. Ad hoc meetings can be arranged with the Chair's agreement as needed.
- 10.3.2 Advice may be also sought from the EAB in correspondence where a view is needed, and it is not practical to schedule a meeting in time.
- 10.3.3 The agenda, supporting papers and details of each meeting will be circulated at least 5 working days in advance.
- 10.3.4 Minutes will be circulated promptly after each meeting and will be agreed at the subsequent EAB meeting.
- 10.3.5 Members will declare any conflicts of interest in accordance with the Our Future Health Conflict of Interest Policy. The Governance Manager will ascertain whether any other conflicts exist based on the agenda at the beginning of each meeting and minute them accordingly.

10.4 **Reporting**

10.4.1 The EAB will report formally to the Board of Trustees on its activities after each meeting via a written summary; the Chair of the EAB will report to the Board in person twice a year. Working with the Our Future Health Executive Director of Ethics, Compliance & Governance and the Our Future Health Executive, the EAB will keep the Board informed about relevant developments in the public and professional discussion of ethical issues affecting the programme.

10.5 **Duties of the Board**

The Ethics Advisory Board will:

- 10.5.1 Identify, respond to, define, and examine relevant ethical issues to inform the success and ethical delivery of the Our Future Health programme in the public interest, including consideration of the interests of participants.
- 10.5.2 Act as a responsive ethics resource, providing timely advice, guidance, and recommendations on ethical issues, as requested by the Board and Our Future Health.
- 10.5.3 Provide timely ethical review and advice on policies and documents under development by Our Future Health.

- 10.5.4 Carry out a timely review of the ethical aspects of the pilot phase of the programme and taking this into consideration, make recommendations to the Board for the ethical conduct of the main phase of the initiative.
- 10.5.5 Ensure that the programme is informed and guided by the Our Future Health Ethics and Governance Framework and periodically review the framework document, so it remains up to date.
- 10.5.6 Provide general advice on the interests of research participants and the general public in relation to Our Future Health.

10.6 **Other matters**

- 10.6.1 The EAB will work closely with the other advisory boards and the Access Board.
- 10.6.2 The Our Future Health Governance Manager will work closely with the chairs of all advisory boards and relevant Our Future Health team leads to ensure appropriate connections are made between issues raised at the groups. This will allow other Boards to refer issues to the EAB for consideration as needed; the EAB Chair can refer issues to other advisory boards for consideration in the same way.
- 10.6.3 The EAB shall review its own performance and these terms of reference annually to ensure it is operating at maximum effectiveness and recommend any changes it considers necessary to the Board for approval.
- 10.6.4 EAB members shall refer to the Our Future Health communications team if they are asked to talk about Our Future Health publicly or are approached by the media about the programme.
- 10.6.5 A Deputy Chair will be appointed to the EAB after 12 months to support the Chair in their role.
- 10.6.6 Members will be entitled to receive compensation for preparing for and attending meetings and to be reimbursed for all reasonable expenses.

11. Public Advisory Board

11.1 Purpose

11.1.1 To provide public oversight and an ongoing consultation resource for the design and delivery of, and production of new materials for, the Our Future Health research programme. The Public Advisory Board will act as an intermediary between the relevant Our Future Health governance boards and the public voice.

11.2 **Responsibilities**

- 11.2.1 Members will already be familiar with the aims of the project due to prior involvement and co-design work. Therefore, its members will not represent a true objective public insight. Rather, the group will be convened with the purpose to provide ongoing consultation and oversight of the project. The Public Advisory Board will provide advice and guidance for the following areas:
 - Participant recruitment strategies
 - Community and public engagement initiatives
 - Proposed amendments to the project that directly affect participants or public perceptions of the research programme.
 - Submitted consultation proposals from Our Future Health teams.
 - Feedback on public- and participant-facing materials as required.
 - Advice regarding feedback of information to participants.
 - Advice on governance arrangements and issues of public trust.

11.3 Membership

- 11.3.1 Members will be recruited from a pool of 24 individuals who have previously taken part in co-design groups. Membership of the previous co-design groups were selected based on specific criteria to ensure diverse representation across the groups; therefore, members of the Public Advisory Board will be representative in terms of gender, age, ethnicity, and geographical location in the UK.
- 11.3.2 Membership will be for a period of 12 months, which can be renewed for 2 further periods of 12 months.
- 11.3.3 The PPIE members of the other advisory boards will also be members of the Board.

- 11.3.4 A written report on the work of the Board will be presented at each quarterly Charity Board meeting.
- 11.3.5 These terms of reference will be reviewed at least once every 2 years.

11.4 Method of working and frequency of meetings

- 11.4.1 The PAB members will elect the chair, initially for 12 months, which can be renewed.
- 11.4.2 The PAB will meet at least 4 times a year.
- 11.4.3 Members will sign a confidentiality agreement document and all meetings may be recorded for minuting purposes only.

11.5 Working principles

- 11.5.1 Members will agree to:
 - 11.5.1.1 Make every effort to attend all meetings and come prepared to ask questions and contribute fully.
 - 11.5.1.2 Give apologies in advance if unable to attend for any reason.
 - 11.5.1.3 Respect the views of other members of the group, even if they disagree.
 - 11.5.1.4 Respect the confidentiality of any material shared.

11.6 **Other matters**

- 11.6.1 Members will be entitled to receive compensation for preparing for and attending meetings and to be reimbursed for all reasonable expenses.
- 11.6.2 Members will declare any conflicts of interest in accordance with the Our Future Health Conflict of Interest Policy.

12. Scientific Advisory Board

12.1 Purpose

- 12.1.1 The Scientific Advisory Board (SAB) will provide advice to the Our Future Health Executive Team to ensure that the programme is able to achieve its goals in a scientifically rigorous and robust way, considering the changing landscape of population health research in the UK and new scientific opportunities as they arise.
- 12.1.2 Specifically, the SAB will provide advice on:
 - 12.1.2.1 The scientific priorities for the research programme
 - 12.1.2.2 Key aspects of Resource design and delivery including measurements and sample analyses
 - 12.1.2.3 How best to maximise scientific utility and impact, given the resources available
 - 12.1.2.4 Identify and prioritise enhancements to the Resource that will improve utility and impact
 - 12.1.2.5 Identify scientific issues that require detailed evaluation by time-limited expert subgroups and to advise on the membership and remit of such
 - 12.1.2.6 Areas where Our Future Health has made, or is making a significant scientific contribution to the field
- 12.1.3 As required, the SAB will delegate specific 'deep-dive' tasks (e.g. questionnaire or microarray design) to ad hoc working groups.

12.2 Expertise

- 12.2.1 There will be a need for broad expertise covering the following key areas: public health; longitudinal population studies; biosample processing, analysis and biobanking; population genetics and genomics; primary care; social and behavioural science; wearables and remote monitoring; statistics and study design; visualisation and analysis of large complex datasets; data linkage (both health and other administrative data).
- 12.2.2 The SAB will additionally include members who will:

- 12.2.2.1 Specifically represent the perspective of the general public and participants, ensuring that that perspective is consistently heard and considered in the Board's work.
- 12.2.2.2 Have sufficient knowledge and understanding of the business of the Board to be able to make constructive contributions to its discussions and to challenge appropriately its positions.
- 12.2.3 Members will serve for renewable terms of 2 years.
- 12.2.4 The first Chair will be appointed by Our Future Health to serve for no more than 2 years. Subsequent Chairs, who can include the first Chair, will be appointed by the Board from among their number, to serve for no more than 2 years. No Chair will serve for more than 4 consecutive years.
- 12.2.5 A written report on the work of the Board will be presented at each quarterly Charity Board meeting.
- 12.2.6 These terms of reference will be reviewed at least once every 2 years.

12.3 Method of working and frequency of meetings

12.3.1 The SAB will meet quarterly and possibly more frequently in the early years of the study. It is envisaged that members will also be called upon between meetings to provide advice on specific scientific issues as they emerge.

12.4 **Other matters**

- 12.4.1 Members will be entitled to receive compensation for preparing for and attending meetings and to be reimbursed for all reasonable expenses.
- 12.4.2 Members will declare any conflicts of interest in accordance with the Our Future Health Conflict of Interest Policy.

13. Technology Advisory Board

13.1 Purpose

- 13.1.1 The Technology Advisory Board (TAB) provides insights into the main platform technology solutions and decisions. This Board will comprise experts and technical leaders who can provide advice on the key decisions related to the main platform and digital interfaces to ensure long-term sustainability, anticipate change, and deliver value to the project.
- 13.1.2 Specifically, the TAB will cover:
 - 13.1.2.1 Privacy-preserving, anonymisation and deidentification technologies; data ethics
 - 13.1.2.2 Cybersecurity and cyber resilience
 - 13.1.2.3 The architecture and scalability of the Our Future Health technology platform
 - 13.1.2.4 Systems engineering and software development
 - 13.1.2.5 Integrating and linking clinical data drawn from NHS and other healthcare data systems
 - 13.1.2.6 Health data and genomics analytics, including the application of artificial intelligence, machine learning and federated techniques
 - 13.1.2.7 Data standards and best practice in the representation, access and sharing of health data consistent with the fair (findable, accessible, interoperable, and reusable) principles
 - 13.1.2.8 Accessibility of the systems to a diverse audience
 - 13.1.2.9 Growth and scaling of Our Future Health systems; working across technology suppliers and partners
- 13.1.3 The TAB will collaborate with other governing bodies where appropriate and if required it will set up working groups to address specific issues.

13.2 Membership

- 13.2.1 The following key competencies will be represented: expertise in personal data and data ethics; cybersecurity; data infrastructure and engineering including scaling of cloud systems and the storage and processing of large volumes of health data; software engineering; experience of NHS and health data across the UK system; clinical data standards; accessibility; application of AI and ML to health data; data analytics; data processing for genomics; growth and scaling of large-scale platforms; commercial and strategic issues working with it and technology suppliers.
- 13.2.2 The TAB will additionally include at least 1 member who will:
 - Specifially represent the perspective of the general public and participants, ensuring that that perspective is consistently heard and considered in the Board's work.
 - (b) Have sufficient knowledge and understanding of the business of the Board to be able to make constructive contributions to its discussions and to challenge appropriately its positions.
- 13.2.3 Members will serve for renewable terms of 2 years.
- 13.2.4 The Chair will be appointed by the Board from among their number, to serve for no more than 2 years. No Chair will serve for more than 4 consecutive years.
- 13.2.5 A written report on the work of the Board will be presented at each quarterly Charity Board meeting.
- 13.2.6 These terms of reference will be reviewed at least once every 2 years.

13.3 Method of working and frequency of meetings

13.3.1 The TAB will meet quarterly. It is envisaged that members will also be called upon between meetings to provide advice on specific technology issues as they emerge.

13.4 **Other matters**

- 13.4.1 Members will be entitled to receive compensation for preparing for and attending meetings and to be reimbursed for all reasonable expenses.
- 13.4.2 Members will declare any conflicts of interest in accordance with the Our Future Health Conflict of Interest Policy.

14. Working Groups

14.1 In addition to the main advisory boards, there will be a number of working groups established by the Executive Team to address key issues.

14.2 Primary Care Working Group

- 14.2.1 Purpose
 - 14.2.1.1 Our Future Health will be the UK's largest ever health research programme, designed to enable the discovery and testing of more effective approaches to prevention, earlier detection and treatment of diseases. It will collect and link multiple sources of health and health-relevant information, including genetic data, across a cohort of 5 million people that truly reflects the UK population. This will create a world-leading resource for academic and commercial researchers to undertake discovery research on early indicators of disease, plus the opportunity to recontact participants on a risk-stratified basis for secondary studies.
 - 14.2.1.2 Since large-scale recruitment of the cohort will be conducted in primary care, effective collaboration with Our Future Health will be integral to the success of the Resource. If appropriate consent is received, clinical data from physical measurements and genomic analyses may be shared with participants directly by the study or via primary care. In either case, the challenges of delivering complex information on clinical risk (e.g., using polygenic risk scores) in community settings must be understood and any impacts to citizens and local healthcare systems mitigated.
 - 14.2.1.3 Our Future Health Primary Care Working Group is the new name for Our Future Health Clinical Liaison Group.

14.2.2 Responsibilities

14.2.2.1 To provide advice and guidance on design and implementation of the study protocol in all 4 nations of the UK, particularly in relation to recruitment in primary care and the feedback of clinical (including genomic) data:

- (a) To give insights on procedures and policies in primary care and make best use of routinely stored information.
- (b) To help maximise the utility of feedback to participants (e.g., improved risk stratification of cardiovascular disease using polygenic risk scores) and minimise any unwarranted impact on clinical services, especially primary care.
- To mediate between Our Future Health and organisations representing the interests of primary care, e.g., the Royal College of General Practitioners (RCGP), the British Medical Association (BMA)
- 14.2.2.2 The Primary Care Working Group has been assembled to assist the Executive Team in addressing the issues described in the remit. Its function will be time-limited (initially to 2 years) and task-focused, with meeting agendas agreed prior to circulation by Executive Team and Board.
- 14.2.2.3 Our Future Health is the legal entity established to administer the research platform.

14.2.3 Secretariat

14.2.3.1 The Chair shall act as the secretary of the Primary Care Working Group and is responsible for ensuring that it receives relevant information and papers in a timely manner to enable full and proper consideration to be given to issues. The Chair will also provide logistical support, if needed, to progress work undertaken by, or on behalf of the Group in the period between meetings.

14.2.4 Frequency and duration of meetings

14.2.4.1 The Primary Care Working Group will meet approximately monthly in the first instance with ongoing frequency of meetings to be determined by the Chair, in consultation with the Executive Team. Meetings will normally be less than 2 hours in duration with timings to be indicated in the agenda.

14.2.5 Other matters

- 14.2.5.1 The Primary Care Working Group shall have access to sufficient resources in order to carry out its duties, including access to the Chair for assistance as required. Members of the Primary Care Working Group may be invited to join other advisory or operational groups in the Our Future Health research programme, depending on relevant expertise or interest.
- 14.2.5.2 Members will be entitled to receive compensation for preparing for and attending meetings and to be reimbursed for all reasonable expenses.
- 14.2.5.3 Members will declare any Conflicts of Interest in accordance with guidance outlined in the Code of Conduct for Our Future Health.
- 14.2.5.4 Membership will include individuals who will:
- Specifically represent the perspective of the general public and participants, ensuring that that perspective is consistently heard and considered in the Group's work.
- (b) Have sufficient knowledge and understanding of the business of the Group to be able to make constructive contributions to its discussions and to challenge appropriately its positions.

14.3 Secondary Care Working Group

14.3.1 Purpose

- 14.3.1.1 Our Future Health will be the UK's largest ever health research programme, designed to enable the discovery and testing of more effective approaches to prevention, earlier detection, and treatment of diseases. It will collect and link multiple sources of health and health-relevant information, including genetic data, across a cohort of 5 million people that truly reflects the UK population. This will create a world-leading resource for academic and commercial researchers to undertake discovery research on early indicators of disease, plus the opportunity to recontact participants on a risk-stratified basis for secondary studies.
- 14.3.1.2 Secondary care settings offer the opportunity for ease in recruitment pathways in an environment that is well equipped to assisting with research. Effective collaboration with clinicians and academics working in secondary care research will be crucial, ensuring maximal benefit to Our Future Health, while safeguarding against undue negative impact on care delivery.

14.3.2 Responsibilities

- 14.3.2.1 To provide advice and guidance on potential secondary care recruitment routes in conjunction with the secondary care discovery group.
- 14.3.2.2 To advise on the acceptability, translatability and scalability of recruitment pathways developed by our collaborators, including (but not limited to) Leeds Teaching Hospitals and NHS Scotland.
- 14.3.2.3 To collaborate on secondary care main study plans and pilots (should they take place).
- 14.3.2.4 To advise on future plans for recruitment via Biomedical Research Centres (BRCs).
- 14.3.2.5 To mediate between Our Future Health and organisations representing the interests of secondary care, e.g., the Royal College of Physicians (RCP), the British Medical Association (BMA).

14.3.2.6 The Secondary Care Working Group has been assembled to assist the Executive Team in addressing the issues described in the remit. Its function will be time-limited (initially to 1 year) and task-focused, with meeting agendas agreed prior to circulation by Executive Team and Board.

14.3.3 Secretariat

- 14.3.3.1 The Chair shall act as the secretary of the Secondary Care Working Group (with support from the Our Future Health Business Operations team) and is responsible for ensuring that it receives relevant information and papers in a timely manner to enable full and proper consideration to be given to issues.
- 14.3.3.2 The Chair will also provide logistical support, if needed, to progress work undertaken by, or on behalf of the Group in the period between meetings.

14.3.4 Frequency and duration of meetings

14.3.4.1 The Secondary Care Working Group will meet approximately monthly in the first instance with ongoing frequency of meetings to be determined by the Chair, in consultation with the Executive Team. Meetings will normally be less than 2 hours in duration with timings to be indicated in the agenda.

14.3.5 **Other matters**

- 14.3.5.1 The Secondary Care Working Group shall have access to sufficient resources to carry out its duties, including access to the Chair for assistance as required.
- 14.3.5.2 Members of the Secondary Care Working Group may be invited to join other advisory or operational groups in the Our Future Health research programme, depending on relevant expertise or interest.
- 14.3.5.3 Members will be entitled to receive compensation for preparing for and attending meetings and to be reimbursed for all reasonable expenses.
- 14.3.5.4 Members will declare any Conflicts of Interest in accordance with guidance outlined in the Code of Conduct for Our Future Health.

- 14.3.5.5 Membership will include individuals who will:
- (a) Specifically represent the perspective of the general public and participants, ensuring that that perspective is consistently heard and considered in the Group's work.
- (b) Have sufficient knowledge and understanding of the business of the Group to be able to make constructive contributions to its discussions and to challenge appropriately its positions.

Appendix A

Trustees and Directors

Our Future Health

Our Future Health is a company limited by guarantee (company number 12212468). It is registered as a charity with the Charity Commission for England and Wales (charity number 1189681) and with OSCR, the Scottish Charity Regulator (charity number SC050917).

Its Trustees and Directors are: John Bell – Chair Mary Calam Peter Chambre (also a Director of Our Future Health Trading Limited) John Deanfield Adrian Hennah Harpal Kumar (also the Chair of Our Future Health Trading Limited) Kemal Malik Ciaran Martin Sally Osman Tim Peakman Richard Sexton Fiona Watt Guy Woolley

Our Future Health Trading Limited

Our Future Health Trading Limited (company number 12599493) is a company limited by shares, its sole shareholder being Our Future Health.

Its Directors are: Harpal Kumar (also a Trustee of the Charity) - Chair Gillian Cannon Peter Chambre (also a Trustee of the Charity) Cristina Ortega Duran Andrew Richards Raghib Ali (also the CEO of the Charity) Simon Sturge

Appendix **B**

Delegation of Authority (financial)

Our Future Health operates a framework that is approved by the Board [Delegation of Authority] which documents the approvals spend limits that apply for the ordering of goods and services and subsequent approval of individual invoices. Spend limits and the required approvals vary considering whether the spend is within the approved budget or whether the activity is a new requirement, and this is summarised in the table below:

Total value	Approval for spend in the agreed Budget	Approval for spend outside of the agreed Budget
Over £10m	Board	Board
Over £2m	A&R Committee	Board
Up to £2m	CEO and either CFO or COO (A&R Committee informed)	A&R Committee
Up to £1m	CEO and either CFO or COO	CEO and either CFO or COO (A&R Committee informed)
Up to £500k	Relevant Exec Committee member and CFO or COO	CEO and either CFO or COO
Up to £250k1	Relevant Exec Committee member	Relevant Exec Committee member and CFO or COO
Up to and including £50k	Relevant budget holder	Relevant Exec Committee member

For the clarification of doubt, contract value estimates to be applied to this table are **inclusive of VAT** if applicable and should be calculated for the **lifetime of the contract** to which the organisation will be contractually committed. Contractual options can be excluded, but if so, a formal assessment of any subsequent extension will need to be completed in good time to ensure that options to switch to other

¹ Internal discussions between the leadership team to discuss potential suppliers and their quotes or submissions is encouraged but not formally required under the policy

providers are practical and we do not informally become obliged to extend the initial arrangement. Provisional approval should be obtained from the relevant person in the table above, as soon as indicative costs are known and understood, and certainly before any formal tender, discussions or negotiations have commenced with potential suppliers. Formal approvals can then follow once quotes are available and a recommendation of the preferred supplier is available.

Expenditure is deemed outside of Budget if 1 of the following applies:

- The expenditure is for a new activity that was not in scope at the time of the budget;
- The expenditure is for an approved activity, but the likely cost:
 - Is more than anticipated at the time of the budget by at least the higher of £50k or 10% of the budgeted spend;
 - Will require the removal of other budgeted activity to help manage spend within overall approved budgets.

The same thresholds and principles apply to contract variations that involve a material change to the services being provided part-way through, although the value considered would be the remaining life of the contract rather than the total contract value. The only exception to this rule is where contracts were originally agreed with suppliers under the PCR 2015 regulations. For these arrangements, contract variations should be minimised, and a risk assessment should be completed (in conjunction with the CFO) to ensure that the changes are unlikely to be trigger a challenge from any of the original bidders.

NOTE: separating orders in order to avoid the procurement thresholds or financial authority is forbidden.

The prior approval of the Chief Financial Officer (CFO) is required before entering into any contract which lasts, or has the potential to last, for more than 3 years.