



**Our Future Health  
Governance Manual**

10 December 2021

# Our Future Health Governance Manual

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## 1. Introduction

### 1.1 Governance

- 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 17th September 2019. The registered office address is 2 New Bailey, 6 Stanley Street, Salford, Greater Manchester, United Kingdom, M3 5GS. The Articles of Association were last amended on 10th December 2019. Our Future Health is also registered as a charity registered with the Charity Commission for England and Wales (Charity Number 1189681) and OSCR, Scottish Charity Regulator (Charity Number SC050917).
- 1.1.2 Our Future Health Trading Limited is a private limited company (Number 12599493) which is wholly owned by Our Future Health. It was incorporated in England on 13<sup>th</sup> May 2020 and has the same registered office as Our Future Health. The Articles of Association have not been amended since incorporation. The relationship between Our Future Health and Our Future Health Trading Limited is set out in an Intercompany Agreement. Details of the current trustees and directors of both entities 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 Board of Trustees

- 1.2.1 The Board of Trustees of Our Future Health (“Board”) is responsible for the governance and strategy of Our Future Health. The Board currently comprises of 4 trustees, comprising a mix of medical and scientific expertise. The trustees have full legal responsibility for the actions of Our Future Health. The trustees are appointed for a renewable term of 3 years and are the directors of the company for the purposes of the Companies Act 2006. Details of the current trustees and directors can be found in Appendix A.
- 1.2.2 The Board meets at least four times a year. They delegate day to day responsibility for the running of Our Future Health to the Executive Team. The Executive Team of Our Future Health and Our Future Health Trading Limited consists of the Chief Executive Officer and their direct reports, all of whom are employees of Our Future Health.
- 1.2.3 The Board has approved and adopted a Conflicts of Interest Policy.



## 2. **Audit & Risk Committee**

### 2.1 **Purpose**

2.1.1 The purpose of the Audit and Risk Committee (“Committee”) is to provide formal and transparent arrangements for applying financial reporting internal control principles and to 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 by resolution 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 and the following paragraphs will govern the constitution of the Committee:

2.2.2.1 The Committee will comprise at least three members;

2.2.2.2 The Chair of the Charity will not be a member of the Committee;

2.2.2.3 At least one member of the Committee should have recent and relevant financial experience with competence in accounting and/or auditing; and

2.2.2.4 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 one of their number present to chair the meeting.

2.2.4 Appointments to the Committee will be for a period of up to three years, which may be extended by no more than two further periods of up to three 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 one 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, the Chief Executive Officer, the Chief Operating Officer and any 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 four times each year having regard to the Charity'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 the Charity'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, notice of meetings, confirming the venue, time and date together with an agenda and all relevant papers, should normally be circulated to each member of the Committee, to any other person required to attend, and to all other Trustees, at least five working days prior to the date of the meeting.
- 2.4.5 The quorum for meetings of the Committee will be two members.
- 2.4.6 Decisions of the Committee will be made by majority vote. In the event of an equality of 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, and will ascertain, at the beginning of each meeting, the existence of any conflicts of interest and minute them accordingly. Draft minutes of Committee meetings will be circulated promptly to all members of the Committee and, once agreed, to all members of the Board.

2.5.2 The chair of the Committee will report formally to the Board on its proceedings after each meeting on all matters within its duties and responsibilities and will also formally report on how it 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 where action or improvement is needed.

## 2.6 **Duties of the Committee**

2.6.1 The Committee should carry out the duties below for the Charity, Our Future Health Trading Limited (company number 12599493) and the group as a whole, as appropriate.

2.6.2 Financial reporting

2.6.2.1 The Committee will monitor the integrity of the financial statements of the Charity, and any formal announcements relating to the Charity's financial performance, reviewing and reporting to the Board on significant financial reporting issues and judgements contained in them having regard to matters communicated to it 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 period(s);”

(b) The consistency of, and any changes to, significant accounting policies both on a year on year basis and across the charity/group;

(c) The methods used to account for significant or unusual transactions where different approaches are possible;

(d) Whether the Charity 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 the Charity’s financial reports and the context in which statements are made; and
  - (f) All material information presented with the financial statements, such as 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, where to carry out a review prior to Board approval would be 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 the Charity 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 and 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 the Charity’s internal financial reporting and internal control policies and systems, covering all material controls, including financial, operational and compliance controls, and the Charity’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 the charity and strategies in place to mitigate them, reporting to the Board.
- 2.6.5 Compliance, whistleblowing and fraud
- 2.6.5.1 The Committee will:
- (a) Review the adequacy and security of the Charity’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;

- (b) Review the Charity's procedures for detecting fraud;
- (c) Review the Charity'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 the Charity's auditor;
- 2.6.6.2 If an auditor resigns investigate the issues leading to this 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 Assess annually the auditor's independence and objectivity taking into account relevant UK law, regulation, and other professional requirements and the group's relationship with the auditor as a whole, including 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 the Charity (other than in the ordinary course of business) which could adversely affect the auditors independence and objectivity;
- 2.6.6.6 Monitor the auditor's processes for maintaining independence, its compliance with relevant UK law,

regulation, other professional requirements including the guidance on the rotation of audit partner and staff;

2.6.6.7 Assess annually the qualifications, expertise and resources of the auditor and the effectiveness of the audit process, which will include a report from the auditor on their own internal quality procedures;

2.6.6.8 Discuss the audit or the factors that could affect audit quality and review and approve the annual audit plan and ensure that it is consistent with the scope of the audit engagement, having regard to the seniority, expertise and experience of the audit team; and

2.6.6.9 Review the findings of the audit with the auditor. This will include but not be limited to, the following:

(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; and

(e) Levels of errors identified during the audit.

2.6.6.10 The Committee will also review the effectiveness of the audit process, including an assessment of the quality of the audit, the handling of key judgements by the auditor, and 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; and
- 2.7.5 Arrange for periodic reviews of its own performance and, at least annually, review its constitution and terms of reference to ensure it is operating at maximum effectiveness and 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; and
- 2.8.3 Call any employee to be questioned at a meeting of the Committee as and when required.

### 3. **Nomination & Remuneration Committee**

#### 3.1 **Purpose**

3.1.1 The purpose of the Nomination and Remuneration Committee (“Committee”) is to:

3.1.1.1 Establish a formal, rigorous and transparent procedure for the appointment of new Trustees to the Board; and

3.1.1.2 Establish a formal and transparent procedure for developing policy on senior management remuneration.

#### 3.2 **Constitution and membership**

3.2.1 The Committee has been established as a Committee of the Board by resolution of the Board.

3.2.2 The members of the Committee shall be appointed by the Board. The Committee shall comprise at least **three** members, the majority of whom shall be Trustees.

3.2.3 The chair of the Committee shall be appointed by the Board and should be a Trustee. In the absence of the chair of the Committee, the members present shall elect one of their number present to chair the meeting from those who would qualify under these terms of reference to be appointed to that position by the Board. The Chair of the Charity should not chair the Committee when it is dealing with the appointment of a successor to the Chair.

3.2.4 Appointments to the Committee shall be for a period of up to three years, which may be extended for up to two further periods of up to three years, provided the member still meets the criteria for membership of the Committee.

3.2.5 Only members of the Committee have the right to attend Committee meetings. However, other individuals such as the Chief Executive Officer, the Chief Operating Officer and external advisers may be invited to attend for all or part of any meeting, as and when appropriate.

3.2.6 The governance manager shall act as the secretary of the Committee and will ensure that the Committee receives information and papers in a timely manner to enable full and proper consideration to be given to issues.

### 3.3 **Meetings**

- 3.3.1 The Committee will meet at least twice each year and at such other times as the chair of the Committee shall think fit.
- 3.3.2 Meetings of the Committee shall be called by the secretary of the Committee at the request of the chair of the Committee.
- 3.3.3 Unless otherwise agreed by all members of the Committee, notice of meetings, confirming the venue, time and date together with an agenda and all relevant papers, should normally be circulated to each member of the Committee, to any other person required to attend, and (unless it would be inappropriate to do so) to all other Trustees, at least five working days prior to the date of the meeting.
- 3.3.4 The quorum for meetings of the Committee shall be two members, both of whom must be Trustees.
- 3.3.5 Decisions of the Committee will be made by majority vote. In the event of an equality of votes the chair of the Committee will have a second or casting vote.

### 3.4 **Reporting**

- 3.4.1 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 shall minute the proceedings and resolutions of all meetings of the Committee, including recording the names of those present and in attendance. Draft minutes of Committee meetings shall be circulated promptly to all members of the Committee and, once agreed, to all Trustees unless it would be inappropriate to do so.
- 3.4.2 The Committee chair shall report to the Board on its proceedings after each meeting on the nature and content of its discussion, recommendations and action to be taken.
- 3.4.3 The Committee shall make whatever recommendations to the Board that it deems appropriate on an area within its remit where action or improvement is needed, and adequate time should be made available for Board discussion where necessary.

### 3.5 **Duties of the Committee**

- 3.5.1 The Committee should carry out the duties below for the Charity, Our Future Health Trading Limited (company number 12599493) and the group as a whole, as appropriate. The Committee shall:

### 3.5.2 Nomination function

- 3.5.2.1 Regularly review the structure, size and composition (including the skills, knowledge, experience and diversity) of the Board and make recommendations to the Board with regard to any changes;
- 3.5.2.2 Ensure plans are in place for orderly succession to Board and senior management positions, and oversee the development of a diverse pipeline for succession, taking into account the challenges and opportunities facing the Charity, and the skills and expertise needed on the Board in future;
- 3.5.2.3 Keep under review the leadership needs of the Charity, both at executive and at board level;
- 3.5.2.4 Keep up to date and fully informed about strategic issues affecting the Charity and the sector in which it operates;
- 3.5.2.5 Be responsible for identifying and nominating for the approval of the Board, candidates to fill Trustee vacancies as and when they arise;
- 3.5.2.6 Before any appointment is made by the Board, evaluate the balance of skills, knowledge, experience and diversity on the Board, and, in the light of 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; and
  - (c) Consider candidates on merit and against objective criteria and with due regard for the benefits of diversity on the Board, including gender, taking care that appointees have enough time available to devote to the position;
- 3.5.2.7 Prior to the appointment of a Trustee, other significant time commitments should be disclosed. The proposed appointee should also be required to disclose any other interests that may result in a conflict of interest;

- 3.5.2.8 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 and involvement outside Board meetings;
- 3.5.2.9 Review the results of the Board performance evaluation process that relate to the composition of the Board and succession planning; and
- 3.5.2.10 Review annually 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:

- 3.5.2.11 Any changes needed to the succession planning process if its periodic assessment indicates the desired outcomes have not been achieved;
  - 3.5.2.12 Suitable candidates for new Trustees and succession for existing Trustees;
  - 3.5.2.13 Membership of the Audit and Risk Committee, and any other board committees as appropriate, in consultation with the chairs of those committees;
  - 3.5.2.14 The re-appointment of any Trustee at the conclusion of their specified term of office having given due regard to their performance and ability to continue to contribute to the Board in the light of the knowledge, skills and experience required; and
  - 3.5.2.15 Any matters relating to the continuation in office of any Trustee at any time.
- 3.5.3 Remuneration function
- 3.5.3.1 Have delegated responsibility for determining the policy for setting remuneration for senior management;
  - 3.5.3.2 Design remuneration policies and practices to support strategy and promote long-term sustainable success, with executive remuneration aligned to the Charity's purposes and values, clearly linked to the successful delivery of the Charity's long-term strategy;

- 3.5.3.3 Ensure that no senior manager will be involved in any decisions as to their own remuneration outcome;
- 3.5.3.4 In determining remuneration policy take into account all other factors which it deems necessary including relevant legal, regulatory requirements and any relevant charity commission guidance. The objective of such policy shall be to attract, retain and motivate executive management of the quality required to run the Charity successfully without paying more than is necessary;
- 3.5.3.5 Review the ongoing appropriateness and relevance of the remuneration policy;
- 3.5.3.6 Within the terms of the agreed policy and in consultation with the Charity chair and/or Chief Executive Officer, as appropriate, determine the total individual remuneration of senior managers; and
- 3.5.3.7 Have full authority to appoint remuneration consultants and to commission or purchase any reports, surveys or information which it deems 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.

### 3.6 **Other matters**

- 3.6.1 The Committee shall:
  - 3.6.1.1 Work and liaise as necessary with all other board committees, ensuring the interaction between committees and the Board is reviewed regularly;
  - 3.6.1.2 Have access to sufficient resources in order to carry out its duties as required;
  - 3.6.1.3 Give due consideration to laws and regulations as appropriate; and
  - 3.6.1.4 Arrange for periodic reviews of its own performance and, at least annually, review its constitution and terms of reference to ensure it is operating at maximum effectiveness and recommend any changes it considers necessary to the Board for approval.

### 3.7 **Authority**

3.7.1 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.

#### 4. **Ethics Advisory Board**

##### 4.1 **Purpose**

4.1.1 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.

4.1.2 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/or NHS sensitivities to public disclosure.

##### 4.2 **Membership**

4.2.1 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.

4.2.2 Members of the EAB shall be appointed for a period of two years. Such appointment may then be extended by up to two years at a time by re-invitation and mutual agreement, provided the member continues to meet the criteria for membership of the EAB.

4.2.3 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.

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

##### 4.3 **Meetings**

4.3.1 The EAB will meet three to four times a year as required. Ad hoc meetings can be arranged with the Chair's agreement as needed.

4.3.2 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.

- 4.3.3 The agenda, supporting papers and details of each meeting will be circulated at least five working days in advance.
- 4.3.4 Minutes will be circulated promptly after each meeting and will be agreed at the subsequent EAB meeting.
- 4.3.5 Members will declare any conflicts of interest in accordance with the Our Future Health Conflict of Interest Policy. The secretary or their nominee should ascertain whether any other conflicts exist based on the agenda at the beginning of each meeting and minute them accordingly.

#### 4.4 **Reporting**

- 4.4.1 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 Head 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.

#### 4.5 **Duties of the Board**

The Ethics Advisory Board will:

- 4.5.1 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;
- 4.5.2 Act as a responsive ethics resource, providing timely advice, guidance and recommendations on ethical issues, as requested by the Board and Our Future Health;
- 4.5.3 Provide timely ethical review and advice on policies and documents under development by Our Future Health;
- 4.5.4 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;
- 4.5.5 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.

- 4.5.6 Provide general advice on the interests of research participants and the general public in relation to Our Future Health.

#### 4.6 **Other matters**

- 4.6.1 The EAB will work closely with a number of the other advisory boards and the Access Board.
- 4.6.2 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.
- 4.6.3 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.
- 4.6.4 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.
- 4.6.5 A Deputy Chair will be appointed to the EAB after 12 months to support the Chair in their role.
- 4.6.6 Members will receive a small honorarium and will be reimbursed for all reasonable costs for attending EAB meetings.

## 5. **Founders Board**

### 5.1 **Purpose**

5.1.1 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.

5.1.2 The Founders Board shall be comprised of:

- (a) 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

5.1.3 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, co-ordination, review and agreement of the following activities:

5.1.3.1 establishing and amending, as necessary, the Scientific Protocol for the Resource for data and sample collection, recruitment and serial sampling;

5.1.3.2 monitoring the progress against goals, roadmaps and timelines with respect to the implementation of the Resource;

5.1.3.3 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;

5.1.3.4 creating an accreditation process through which Founding Members will be able to apply for accreditation of their own Trusted Research Environments;

5.1.3.5 the review of and recommendation on the admission of new or additional Founding Members;

- 5.1.3.6 reviewing and advising on the creation and application of any charging model applied by Our Future Health for use of the Resource;
- 5.1.3.7 reviewing and advising on the creation of further Our Future Health policies which directly impact the implementation and usability of the Resource; and
- 5.1.3.8 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.

## 5.2 **Meetings of the Founders Board**

- 5.2.1 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.
- 5.2.2 The Founders Board may convene an extraordinary meeting at the request of a Founding Member or the Executive Team.
- 5.2.3 A minimum quorum of at least seventy five percent (75%) of representatives from Founding Industry Members and at least seventy five percent (75%) of representatives from Founding Member charities and at least one representative from the Executive Team.
- 5.2.4 No later than five (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:
  - 5.2.4.1 updates on development of the Resource, related recruitment/enrolment and progress against (and proposed deviations from) any related plans, timelines and milestones;
  - 5.2.4.2 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;

- 5.2.4.3 minutes and if appropriate metrics from the other governance boards, subject to relevant confidentiality measures;
- 5.2.4.4 Our Future Health's and Our Future Health Trading Limited's budget position versus plan, including expenditure and budgeting;
- 5.2.4.5 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;
- 5.2.4.6 any matters which may require advisory input, remedy or escalation;
- 5.2.4.7 other scientific, strategic or budgetary topics as reasonably requested in advance by the Founders Board.
- 5.2.5 Meeting minutes of the Founders Board shall be recorded and stored in a secure portal for general access by all Founding Members.
- 5.2.6 There shall be one 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):
  - 5.2.6.1 A unanimous vote in favour from all representatives of Founding Industry Members and Founding Charity Members present at the meeting
  - 5.2.6.2 A super majority vote where super majority means at least seventy five percent of the votes cast by representatives from Founding Industry Members present at the meeting and at least seventy five percent of votes cast by representatives from Founding Member charities present at the meeting
  - 5.2.6.3 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)

- 5.2.7 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.
- 5.2.8 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.
- 5.2.9 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.
- 5.2.10 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.
- 5.2.11 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.

### 5.3 **Remediation process**

- 5.3.1 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:
- 5.3.1.1 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;
- 5.3.1.2 provide detailed proposed solutions for discussion including any consequences to the Resource operation; and

5.3.1.3 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.

#### 5.4 **Secretariat**

- 5.4.1 The secretariat will be provided by Our Future Health.
- 5.4.2 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.
- 5.4.3 The secretariat will also provide logistical support, if needed, to progress work undertaken in the period between meetings of the Founders Board.
- 5.4.4 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 / committee for its next meeting.
- 5.4.5 Founders Board members will declare any Conflicts of Interest in accordance with the Our Future Health Conflict of Interest Policy.

## 6. **Implementation Board**

### 6.1 **Purpose**

6.1.1 Our Future Health Board maintains the overall responsibility and decision-making authority for the programme and delegates the day-to-day implementation and management of it to the Our Future Health Executive Team. The Executive Team shall manage all operations and logistics of establishing and making the Resource available to researchers.

6.1.2 The Implementation Board will be a forum for the input into, co-ordination, review and agreement of the following activities:

6.1.2.1 Operational delivery plan to include recruitment planning and processes, sample logistics and handling

6.1.2.2 Conducting the recruitment, consenting and follow-up of cohort participants pursuant to the scientific protocol, including obtaining all necessary informed consents

6.1.2.3 Collecting core cohort data including linked NHS records and wider linkage across government administrative data

6.1.2.4 Return of 'results' to participants and NHS clinical systems

6.1.2.5 Establishing, maintaining, hosting and operating the Our Future Health trusted research environment (TRE) to enable registered researchers to use, access and analyse the core cohort data

6.1.3 The Implementation Board will comprise members of partner organisations who are involved in or support the delivery of the Our Future Health programme. This includes representatives from:

6.1.3.1 UK nations supporting health & social care

6.1.3.2 NHS blood & transplant

6.1.3.3 NHS England (incorporating NHS Digital and NHS-X)

6.1.3.4 NIHR

6.1.3.5 NHS Accelerated Access Collaborative

6.1.3.6 Office for Health Improvement and Disparities

6.1.3.7 Health Data Research UK

- 6.1.3.8 Professional Medical Society & Colleges
- 6.1.3.9 In addition to these members, the Chief Executive Officer and the Chief Operating Officer will also be members and the Board shall be chaired by the Chief Executive Officer. Other members of the Our Future Health Executive Team may be invited to attend as appropriate.
- 6.1.4 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. 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.
- 6.1.5 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:
  - 6.1.5.1 Updates on development of the Resource, related recruitment/enrolment and progress against (and proposed deviations from) any related plans, timelines and milestones. This shall include reporting on matters related to recruitment/enrolment figures (by reference to specific ‘recruited’ criteria, and status (including whether a cohort participant is ‘active’, which means they have not partially or fully withdrawn any consent));
  - 6.1.5.2 Cohort diversity reporting and review;
  - 6.1.5.3 Minutes from the other advisory boards;
  - 6.1.5.4 Our Future Health’s budget position versus plan;
  - 6.1.5.5 Any proposed amendments to the core protocol;
  - 6.1.5.6 Any matters which may require remedy or escalation;
  - 6.1.5.7 Other topics as reasonably requested in advance by the Board.
- 6.1.6 In all situations, the Implementation Board must consider the overall scientific objectives and goals of the Our Future Health programme and the budget it is operating under.
- 6.1.7 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.

- 6.1.8 Meeting minutes of the Implementation Board shall be recorded and stored in a secure portal or Sharepoint for general access by all members.
- 6.1.9 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.
- 6.1.10 The Implementation Board can propose representatives who could be participants at other advisory boards established by Our Future Health in support of the programme.
- 6.1.11 Members will declare any conflicts of interest in accordance with the Our Future Health Conflict of Interest Policy.

## 7. **Access Board**

### 7.1 **Purpose**

7.1.1 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.

### 7.2 **Membership**

7.2.1 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.

7.2.2 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.

7.2.3 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.

### 7.3 **Meetings**

7.3.1 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.

7.3.2 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.

#### 7.4 **Reporting**

7.4.1 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.

#### 7.5 **Duties of the Board**

7.5.1 Specifically, the Access Board will:

7.5.1.1 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.

7.5.1.2 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.

7.5.1.3 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 (i.e. are aimed at improving human health) and are not likely to bring the study into disrepute or stigmatise any of its participants.

7.5.1.4 Regularly review the access procedures to ensure they are acceptable to participants and meeting the needs of Our Future Health's user communities.

7.5.1.5 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.

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

7.6.1 the undertaking given to and the specific Informed Consent given by the Cohort Participants;

7.6.2 (and in compliance with) all laws and regulations including respect for human rights;

7.6.3 the conditions placed on Our Future Health in the ethical approval granted by the Health Research Authority;

7.6.4 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;

7.6.5 the Our Future Health Ethics Framework; and

7.6.6 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.

7.7 **Other matters**

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

7.7.2 Members will receive a small honorarium and will be reimbursed for all reasonable costs for attending meetings.

7.7.3 Members will declare any conflicts of interest in accordance with the Our Future Health Conflict of Interest Policy.

## 8. **Scientific Advisory Board**

### 8.1 **Purpose**

8.1.1 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.

8.1.2 Specifically, the SAB will provide advice on:

8.1.2.1 The scientific priorities for the research programme

8.1.2.2 Key aspects of Resource design and delivery including measurements and sample analyses

8.1.2.3 How best to maximise scientific utility and impact, given the resources available

8.1.2.4 Identify and prioritise enhancements to the Resource that will improve utility and impact

8.1.2.5 Identify scientific issues that require detailed evaluation by time-limited expert subgroups and to advise on the membership and remit of such

8.1.2.6 Areas where Our Future Health has made/is making a significant scientific contribution to the field

8.1.3 As required, the SAB will delegate specific 'deep-dive' tasks (e.g. questionnaire or microarray design) to ad hoc working groups.

### 8.2 **Expertise**

8.2.1 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/genomics; primary care; social/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).

### 8.3 **Method of working and frequency of meetings**

8.3.1 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.

8.4 **Other matters**

- 8.4.1 Members will receive a small honorarium and will be reimbursed for all reasonable costs for attending meetings.
- 8.4.2 Members will declare any conflicts of interest in accordance with the Our Future Health Conflict of Interest Policy.

## 9. **Technology Advisory Board**

### 9.1 **Purpose**

9.1.1 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.

9.1.2 Specifically, the TAB will cover:

9.1.2.1 Privacy-preserving, anonymisation and de-identification technologies; data ethics

9.1.2.2 Cybersecurity and cyber resilience

9.1.2.3 The architecture and scalability of the Our Future Health technology platform

9.1.2.4 Systems engineering and software development

9.1.2.5 Integrating and linking clinical data drawn from NHS and other healthcare data systems

9.1.2.6 Health data and genomics analytics, including the application of artificial intelligence, machine learning and federated techniques

9.1.2.7 Data standards and best practice in the representation, access and sharing of health data consistent with the fair (findable, accessible, interoperable, and reusable) principles

9.1.2.8 Accessibility of the systems to a diverse audience

9.1.2.9 Growth and scaling of Our Future Health systems; working across technology suppliers and partners

9.1.3 The TAB will collaborate with other governing bodies where appropriate and if required it will set up working groups to address specific issues.

### 9.2 **Proposed membership**

9.2.1 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/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.

9.3 **Method of working and frequency of meetings**

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

9.4 **Other matters**

9.4.1 Members will receive a small honorarium and will be reimbursed all reasonable costs for attending TAB meetings.

9.4.2 Members will declare any conflicts of interest in accordance with the Our Future Health Conflict of Interest Policy.

## 10. **Public Advisory Board**

### 10.1 **Purpose**

10.1.1 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.

### 10.2 **Responsibilities**

10.2.1 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:

10.2.1.1 Participant recruitment strategies

10.2.1.2 Community and public engagement initiatives

10.2.1.3 Proposed amendments to the project that directly affect participants or public perceptions of the research programme

10.2.1.4 Submitted consultation proposals from Our Future Health teams

10.2.1.5 Feedback on public- and participant-facing materials as required

10.2.1.6 Advice regarding feedback of information to participants

10.2.1.7 Advice on governance arrangements and issues of public trust

### 10.3 **Membership**

10.3.1 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.

10.3.2 Membership will be voluntary but will for a period of 12 months.

#### 10.4 **Method of working and frequency of meetings**

10.4.1 The chair of the Public Advisory Board will be the public engagement and involvement lead for the first 12 months, after which members will elect the chair and additional roles for the group. Elected representatives will hold their role for 12 months unless they wish to step down.

10.4.2 The Public Advisory Board will meet four times a year, or as required (for example if a submitted proposal needs immediate consultation). Members will work closely with the public engagement and involvement lead and will produce a written response to all proposals submitted to the group within 7 working days.

10.4.3 Members will sign a confidentiality agreement document and all meetings may be recorded for internal purposes only. It may be possible for members of Our Future Health team to be an 'observer' at one of the meetings (with prior agreement).

10.4.4 Members may also be asked to be a public representative on additional governance boards within Our Future Health, such as the Scientific Advisory Board and members will be asked to express an interest for the role. Membership on additional governance boards will be in addition to the requirements of the Public Advisory Board and members will be reimbursed in accordance with our honorarium policy.

10.4.5 As Our Future Health grows and recruits participants into the programme, the Public Advisory Board will become the public and participant advisory Board. Further details of this transition will be circulated to members in advance of any changes and will be approved internally before members are asked to join.

#### 10.5 **Working principles**

10.5.1 Members will agree to:

10.5.1.1 Make every effort to attend all meetings and come prepared to ask questions and contribute fully

10.5.1.2 Give apologies in advance if unable to attend for any reason

10.5.1.3 Respect the views of other members of the group, even if they disagree

10.5.1.4 Respect the confidentiality of any material shared

10.6 **Other matters**

- 10.6.1 Members will receive a small honorarium and will be reimbursed for all reasonable costs for attending meetings.
- 10.6.2 Members will declare any conflicts of interest in accordance with the Our Future Health Conflict of Interest Policy.

## 11. Diversity and Inclusion Advisory Board

### 11.1 Purpose

- 11.1.1 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.
- 11.1.2 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.
- 11.1.3 The DAB will advise the Our Future Health Leadership Team, and where appropriate the Our Future Health Board of Trustees via the Our Future Health Leadership Team or the Our Future Health Executive Team.

### 11.2 Membership

- 11.2.1 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.
- 11.2.2 The DAB will comprise 20-25 members drawn from the following groups:

#### **Community engagement leaders and workers**

Individuals who have led and/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

11.2.3 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.

11.2.4 The secretariat will be provided by Our Future Health.

## **11.3 Meetings**

11.3.1 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.

11.3.2 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.

11.3.3 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.

11.3.4 The Chair (or representative) will be responsible for liaison with the Our Future Health Leadership Team and others as required.

11.3.5 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.

11.3.6 The Secretariat will ensure that DAB members receive relevant pre-reads 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/on behalf of the DAB in the period between meetings.

11.3.7 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.

#### 11.4 **Reporting**

11.4.1 The Our Future Health Leadership and Executive Teams will receive the minutes of meetings, as well as a short verbal report from the Leadership Team representative shortly after the meeting.

#### 11.5 **Duties of the Board**

11.5.1 Specifically, the DAB will advise on:

11.5.1.1 aspects of programme design and delivery that relate to engaging, recruiting and retaining under-represented groups;

11.5.1.2 how to maximise diversity of the cohort and ability to recruit and retain under-represented groups, given the resources available;

11.5.1.3 addressing motivators and barriers to taking part in health research among under-represented groups;

11.5.1.4 facilitating communication, awareness building and networking with key community, academic, religious, and professional organisations and groups aligned to the aims of Our Future Health;

11.5.1.5 evaluating the programme to identify and prioritise enhancements that will further improve diversity and ability to reach under-represented groups over time.

#### 11.6 **Other matters**

- 11.6.1 Membership will be for one year in the first instance.
- 11.6.2 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.
- 11.6.3 Members will receive a small honorarium and will be reimbursed for all reasonable costs for attending meetings.
- 11.6.4 Members will declare any conflicts of interest in accordance with the Our Future Health Conflict of Interest Policy.

## 12. Working Groups

In addition to the main advisory boards, there will be a number of working groups/task forces which are established by the Executive Team to address key issues. Charters for these groups are included here.

### 12.1 Technology Task Force

#### 12.1.1 Purpose

12.1.1.1 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.

12.1.1.2 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.

#### 12.1.2 Membership

12.1.2.1 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.

12.1.2.2 The Technology Task Force may nominate up to two (2) representatives (one (1) representative from Founding Industry Members and one (1) representative from Founding Member charities) to attend the Technology Advisory Board to represent the Technology Task Force.

12.1.2.3 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.

12.1.3 Secretariat

12.1.3.1 The secretariat will be provided by Our Future Health.

12.1.3.2 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.

12.1.3.3 The secretariat will also provide logistical support, if needed, to progress work undertaken in the period between meetings of the Technology Task Force.

12.1.3.4 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 / committee for its next meeting.

12.1.4 Other matters

12.1.4.1 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.

12.1.4.2 Representatives on the Technology Task Force will declare any conflicts of interest prior to a meeting and recuse themselves from discussions as necessary.

12.2 **Primary Care Working Group**

12.2.1 Purpose

12.2.1.1 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 re-

contact participants on a risk-stratified basis for secondary studies.

12.2.1.2 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.

12.2.1.3 Our Future Health Primary Care Working Group is the new name for Our Future Health Clinical Liaison Group.

## 12.2.2 Responsibilities

12.2.2.1 To provide advice and guidance on design and implementation of the study protocol in all four 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

(c) 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)

12.2.2.2 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.

12.2.2.3 Our Future Health is the legal entity established to administer the research platform.

12.2.3 Secretariat

12.2.3.1 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/on behalf of the Group in the period between meetings.

12.2.4 Frequency and duration of meetings

12.2.4.1 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 two hours in duration with timings to be indicated in the agenda.

12.2.5 Other matters

12.2.5.1 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 and/or interest. Members will be reimbursed for meeting attendance plus travel expenses where applicable. The level of reimbursement will be reviewed in line with the duration of meetings. Members will declare any Conflicts of Interest in accordance with guidance outlined in the Code of Conduct for Our Future Health.

12.3 **Secondary Care Working Group**

12.3.1 Purpose

12.3.1.1 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 re-contact participants on a risk-stratified basis for secondary studies.

12.3.1.2 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.

### 12.3.2 Responsibilities

12.3.2.1 To provide advice and guidance on potential secondary care recruitment routes in conjunction with the secondary care discovery group.

12.3.2.2 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.

12.3.2.3 To collaborate on secondary care main study plans and pilots (should they take place).

12.3.2.4 To advise on future plans for recruitment via Biomedical Research Centres (BRCs).

12.3.2.5 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).

12.3.2.6 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.

### 12.3.3 Secretariat

- 12.3.3.1 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.
- 12.3.3.2 The Chair will also provide logistical support, if needed, to progress work undertaken by/on behalf of the Group in the period between meetings.
- 12.3.4 Frequency and duration of meetings
  - 12.3.4.1 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 two hours in duration with timings to be indicated in the agenda.
- 12.3.5 Other matters
  - 12.3.5.1 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.
  - 12.3.5.2 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 and/or interest.
  - 12.3.5.3 Members will be reimbursed at a rate of £100 per meeting attendance plus travel expenses where applicable. The level of reimbursement will be reviewed in line with the duration of meetings.
  - 12.3.5.4 Members will declare any Conflicts of Interest in accordance with guidance outlined in the Code of Conduct for Our Future Health.

## **Appendix A**

### **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).

The directors (also known as trustees) are: Professor Sir John Bell; Professor Fiona Watt; Dr Sir Harpal Singh Kumar; and Dr Tim Peakman.

Our Future Health operates the foundation model of governance whereby the only members of Our Future Health are the directors from time to time. This governance model is common in the charity sector.

### **Our Future Health Trading Limited**

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

Its directors are: Professor Sir John Bell; Professor Fiona Watt; Dr Sir Harpal Singh Kumar; and Dr Andrew Roddam.

## **Appendix B**

### **Draft ToR for Data Privacy & Information Security Board/Committee**

#### **13. Data Privacy & Information Security Board/Committee**

##### **13.1 Purpose**

The Data Privacy & Information Security Board brings together expertise across scientific, regulatory, legal, ethical, and technology domains to provide expert advice to the research programme on the awareness and adoption of data protection technology and on all matters related to the protection and privacy of data including protecting a participant's privacy / rights.

In this context, data protection is defined as the assurance that data is usable and accessible for authorized purposes only, with acceptable performance and in compliance 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.

##### **13.2 Proposed membership**

The committee will be made up of representatives from the other Advisory Boards to reflect the breadth of expertise required for this group. Additionally, this board will be strengthened through additional members with particular expertise in data privacy & governance, legal, data security and data trust.

##### **13.3 Method of working and frequency of meetings**

13.3.1 The board will meet quarterly. It is envisaged that members will also be called upon between meetings to provide advice on any urgent or emerging issues as they emerge.

##### **13.4 Other matters**

13.4.1 Members will receive a small honorarium and will be reimbursed all reasonable costs for attending meetings.

13.4.2 Members will declare any conflicts of interest in accordance with the Our Future Health Conflict of Interest Policy.