

INSIGHT Data Trust Advisory Board: Terms of Reference

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1. Introduction to the INSIGHT Data Trust Advisory Board

1.1. The INSIGHT Health Research Data Hub

INSIGHT¹ is one of seven Health Research Data Hubs (previously known as Digital Innovation Hubs)² funded through Health Data Research UK (HDR UK).

The purpose of INSIGHT is to bring together and make available data and advanced analytics to National Health Service (NHS), academic and industry researchers to develop new insights in disease detection, diagnosis, treatment and personalised healthcare. INSIGHT is focused on eye diseases such as age-related macular degeneration and glaucoma, and its application to wider health, including diabetes and dementia.

A particular focus of INSIGHT is to facilitate the use of ophthalmic imaging data to enable discoveries that improve people's lives. A range of ophthalmic imaging types are now in widespread use as standard care within the NHS. The best known of these are retinal photography and optical coherence tomography, but many other types of imaging exist and indeed many functional tests of vision (such as visual field measurement) are also saved as an image.

These images of the structure or function of the eye and visual system already provide valuable information for the diagnosis and monitoring of eye diseases, but it is increasingly recognised that these images also provide important but untapped insights into wider health status. To detect these more subtle changes requires the collection of large numbers of these images and for these images to be linked to appropriate relevant health data from that same individual.

¹ <https://www.hdruk.ac.uk/infrastructure/the-hubs/insight/>

² <https://www.hdruk.ac.uk/infrastructure/the-hubs/>

Depending on the nature of the condition under research, it may be essential to link not only eye data but also general health data. For example, a complex study of a health condition such as dementia may benefit from linkage of diagnoses, observations (such as blood pressure and weight), investigations (such as blood results, heart tracings and systemic imaging). In contrast, the data required for a study of a purely ocular condition may be simply the images themselves and the associated diagnosis.

INSIGHT partners are: University Hospitals Birmingham NHS Foundation Trust; Moorfields Eye Hospital NHS Foundation Trust; University of Birmingham; Google Health UK; Roche and Action Against Age-related Macular Degeneration.

This document describes the Terms of Reference for the INSIGHT Data Trust Advisory Board.

1.2. Role of the INSIGHT Data Trust Advisory Board

The purpose of the INSIGHT Data Trust Advisory Board is to support INSIGHT to make data available to enable research and discoveries that improve people's lives.

The INSIGHT Data Trust Advisory Board will provide oversight and scrutiny on behalf of the INSIGHT Steering Group by:

- Developing and iterating the standard criteria used to assess applications to access the data made available via INSIGHT.

- Assessing and providing recommendations on individual applications to access the data made available by INSIGHT;
- Working with INSIGHT to develop a framework that can be used to separate data access requests that are ‘novel and/or contentious’ and should continue to be reviewed by the INSIGHT Data Trust Advisory Board, from those applications that are sufficiently low-risk and non-contentious that their evaluation and data access recommendation can be appropriately made by the INSIGHT Chief Data Officer (or nominated Deputy) against the standard access criteria.
- Reviewing and providing feedback on the processes, procedures and outcomes associated with the granting or denying of requests for access to data made available via INSIGHT.

The scope of the INSIGHT Data Trust Advisory Board is limited to that of the INSIGHT Health Data Research Hub. Organisations that make data available via INSIGHT may choose to make the same, or similar, data available in other ways and for other purposes.

The role of the INSIGHT Data Trust Advisory Board is expected to evolve over the life of the INSIGHT Health Data Research Hub, which is initially funded through to 31 August 2022.

During the first year of INSIGHT’s operations, the INSIGHT Data Trust Advisory Board will work with the INSIGHT Leadership Team to develop a framework that can be used to establish whether requests to access data made available by INSIGHT can be considered novel and/or contentious. The purpose of the framework, which will be published openly alongside the INSIGHT Data Trust Advisory Board Terms of Reference and the standard criteria, will be to free the INSIGHT Data Trust Advisory Board from providing recommendation on data requests that are equivalent in purpose,

nature or scope of previous requests, and/or can be considered uncontentious. Once introduced, INSIGHT will use this framework to identify data requests that can be considered by INSIGHT, using the standard criteria set out in Section 4, without recommendation from the INSIGHT Data Trust Advisory Board.

The INSIGHT Leadership Team are also committed to exploring whether the INSIGHT Data Trust Advisory Board could in future be constituted as a 'data trust', whereby the group would take on decision-making authority on behalf of the organisations that make data available via the INSIGHT Health Data Research Hub.

1.3. Legal status of the INSIGHT Data Trust Advisory Board

The INSIGHT Data Trust Advisory Board operates under delegation from the INSIGHT Steering Group. Individual members of the Board shall sign up to a Service Level Agreement that sets out their responsibilities as per this Terms of Reference.

2. Membership of the INSIGHT Data Trust Advisory Board

2.1. Representation

The INSIGHT Data Trust Advisory Board will comprise a Chair and Members representing the public, patients and other stakeholders, as well as INSIGHT, in order to ensure broad representation of the opinions, experiences and perspectives of:

- the public who may be current or future users of the NHS;
- NHS patients with sight-threatening conditions such as age-related macular degeneration and diabetic eye disease;
- charities focused on supporting people with sight-threatening diseases and/or finding solutions to tackle them;
- clinicians and other healthcare professionals;
- NHS organisations experienced in the stewardship of health data and/or involved in setting government policy related to its sharing and use;
- researchers, as users of health data to derive new clinical insights into disease detection, diagnosis and referral;
- health data research institutions and/or regulators;
- organisations that advocate for the responsible use of health data; and
- journalists experienced in covering the use and sharing of health data.

The Chair and Members undertake their roles in an individual capacity, rather than on behalf of their employers or other organisations with whom they are affiliated.

2.2. The responsibilities, qualities and skills required of the Chair and Members

The **Chair** of the INSIGHT Data Trust Advisory Board is responsible for:

- ensuring the INSIGHT Data Trust Advisory Board operates in accordance with its Terms of Reference;
- facilitating the development and iteration of the standard criteria used to assess applications to access the data made available via INSIGHT and overseeing that data requests are considered using it;
- onboarding Members and, where necessary, providing access to materials and appropriate training to enable them to undertake this role;
- chairing quarterly meetings of the INSIGHT Data Trust Advisory Board, where it will assess and provide recommendations on applications to access the data received by INSIGHT;
- managing changes to the Terms of Reference of the INSIGHT Data Trust Advisory Board, its membership and the standard criteria developed by the Board;
- representing the membership of the INSIGHT Data Trust Advisory Board in any discussions with the INSIGHT Leadership Team
- advising the INSIGHT Leadership Team on outputs from its work that are considered relevant to the wider INSIGHT Hub;
- maintaining an inclusive environment where all members of the INSIGHT Data Trust Advisory Board are given the opportunity to play an active role in its decision-making.
- ensuring that the activities of the INSIGHT Data Trust Advisory Board are undertaken as transparently as possible, such as through publication of information and enabling external people, groups and organisations to observe its meetings.

The Chair of the INSIGHT Data Trust Advisory Board is expected to possess the following qualities and skills:

- deep knowledge of science, technology, engineering and/or mathematics, ideally with experience across the NHS, higher education, industry and/or the charitable sector;
- a strong understanding of the opportunities and risks related to the collection, use and sharing of health data (including an understanding of relevant laws, such as the General Data Protection Regulations/Data Protection Act 2018);
- a commitment to supporting the responsible use of data and advanced analytics to develop new insights in disease detection, diagnosis, treatment or personalised healthcare;
- significant leadership experience, such as through holding senior management positions or the delivery of large-scale projects, and an appreciation of relevant governance related practices and processes; and
- strong interpersonal skills and the ability to engage and communicate effectively with others.

Members of the INSIGHT Data Trust Advisory Board are responsible for:

- developing and iterating the standard criteria used to assess applications to access the data made available via INSIGHT;
- assessing and providing recommendations on data requests, through reviewing documentation prior to, and discussion and debate at, quarterly meetings of the INSIGHT Data Trust Advisory Board;
- contributing to changes to the Terms of Reference of the INSIGHT Data Trust Advisory Board, its membership and the standard criteria developed by the Board;

- supporting the Chair to engage in any discussions with the INSIGHT Leadership Team, such as when outputs from its work are considered relevant to the wider INSIGHT Hub;
- helping to maintain an inclusive environment where all members of the INSIGHT Data Trust Advisory Board are given the opportunity to play an active role in its work.

Members of the INSIGHT Data Trust Advisory Board are expected to possess the following qualities and skills:

- a desire to maximise the positive impacts on society of developments in science, technology, engineering and/or mathematics;
- an understanding of the opportunities and risks related to the collection, use and sharing of health data;
- a commitment to supporting the responsible use of data and advanced analytics to develop new insights in disease detection, diagnosis, treatment or personalised healthcare;
- a collaborative attitude and willingness to find common ground with people of different opinions, experiences and perspectives; and
- interpersonal skills and the ability to engage and communicate effectively with others.

2.3. The diversity of Members

Membership of the INSIGHT Data Trust Advisory Board should represent diverse opinions, experiences and perspectives.

The Chair of the INSIGHT Data Trust Advisory Board will also seek to establish and maintain a membership that is diverse across different characteristics, including characteristics protected by the Equality Act 2010 (age, disability, gender reassignment, marriage and civil partnership, pregnancy

and maternity, race, religion or belief, sex, and sexual orientation) and wider characteristics of diversity such as socioeconomic status and educational background.

2.4. Appointment of Members

The initial members of the INSIGHT Data Trust Advisory Board will be appointed by INSIGHT in spring 2020. The initial membership will be appointed through targeted selection based on the following:

- the inclusion of the desired range of opinions, experiences and perspectives described in section 2.1;
- the respective qualities and skills required to undertake the roles of Chair and Member described in section 2.2; and
- the commitment to ensure diversity of members described in section 2.3

There are ten initial Members of the INSIGHT Data Trust Advisory Board. The Chair of the INSIGHT Data Trust Advisory Board can introduce further Member positions if required, although appointment to those positions is subject to the process described below.

Members are initially appointed for a term ending 30 September 2022³. Members may be invited to undertake a further term (and undertake a maximum total of two terms), although their re-appointment is subject to 75% of Members voting affirmatively for it. Members can renounce their position through notification to the Chair of the INSIGHT Data Trust Advisory Board but are encouraged to serve a three-month notice period.

³ In line with Health Data Research UK's funding of the national Health Research Data Hub Programme.

The Chair of the INSIGHT Data Trust Advisory Board will consult with incumbent Members to propose the appointment of a new Member when required. The Chair is committed to maintain: the inclusion of the desired range of opinions, experiences and perspectives described in section 2.1; the qualities and skills required to undertake the role of Member described in section 2.2.; and the commitment to ensure diversity of members described in section 2.3. The Chair will put the appointment of a proposed Member to a vote, where the appointment is subject to 75% of Members voting affirmatively for it.

The Chair of the INSIGHT Data Trust Advisory Board is appointed for a term of three years. The Chair may be invited to undertake a further term (and undertake a maximum total of three terms). The INSIGHT Leadership Team will consult with Members of the INSIGHT Data Trust Advisory Board to propose the appointment of a new Chair when required. The INSIGHT Leadership Team is committed to maintain: the inclusion of the desired range of opinions, experiences and perspectives described in section 2.1.; the qualities and skills required to undertake the role of Chair described in section 2.2.; and the commitment to ensure diversity of members described in section 2.3. The INSIGHT Leadership Team will put the appointment of the proposed Chair to a vote, where the appointment is subject to 75% of Members voting affirmatively for it.

The Chair of the INSIGHT Data Trust Advisory Board will consult with Members to propose the appointment of a Deputy Chair from the membership of the INSIGHT Data Trust Advisory Board. The Chair will put the appointment of the proposed Deputy Chair to a vote, where the appointment is subject to 75% of Members voting affirmatively for it. During ordinary proceedings the Deputy Chair will undertake the same role as Members, but they will deputise in the absence of the Chair and undertake the responsibilities described in section 2.2.

Appointments are only effective if at least two thirds of Members respond and/or vote. Where 75% of membership does not provide an integer, the number will be rounded up if it is n.5 or higher, or rounded down if it is below n.5. For example, in a meeting of ten members eligible to vote, an appointment would require eight people to vote for it affirmatively (as 75% of ten is 7.5), and in a meeting with seven members eligible to vote, an appointment would require five people to vote for it affirmatively (as 75% of seven is 5.25).

2.5. Recompense of Members

Members of the INSIGHT Data Trust Advisory Board will be recompensed by INSIGHT for their contributions made via the INSIGHT Data Trust Advisory Board.

Members will each receive £150.00 for reviewing documentation prior to, and discussing, debating and providing recommendation on data requests at each of the INSIGHT Data Trust Advisory Board's quarterly meetings. Members are recompensed at a rate of £12.50 per hour for other activities they may undertake in their role, such as developing and maintaining the standard criteria used to assess data requests received by INSIGHT, and providing input into the wider decisions, plans and activities of INSIGHT. Members will be recompensed for a maximum of up to three hours required for reviewing access requests prior to each meeting.

Members will be entitled to claim for reimbursement of travel and subsistence costs incurred in undertaking their role.

Recompense of members of the INSIGHT Data Trust Advisory Board, as well as other costs associated with its design, operation and change, are funded by INSIGHT, and administered by the Secretariat of the INSIGHT Data Trust Advisory Board.

2.6. Removal of Members

Members are expected to be committed to their role and the undertaking of the responsibilities described in section 2.2.

The Chair of the INSIGHT Data Trust Advisory Board can propose the removal of a Member if they feel that the Member is failing to undertake these responsibilities. The proposed removal will be put to a vote, and the Member will be removed if 75% of Members vote affirmatively for removal. The decision to remove a Member will be considered final.

Members are not expected to be absent for two or more meetings of the INSIGHT Data Trust Advisory Board within a one year period without reasonable justification. Although attendance in-person is strongly preferred, attendance by teleconferencing is acceptable where in-person attendance is not possible for that Member.

Members of the INSIGHT Data Trust Advisory Board can propose the removal of the Chair if they have grounds for believing that the Chair is failing to undertake the responsibilities described of them in section 2.2. The proposed removal will be put to a vote, and the Chair will be removed if 75% of Members vote affirmatively for removal. The Members' decision will be considered final.

A removal is only effective if at least two thirds of Members respond and/or vote. Where 75% of membership does not provide an integer, the number will be rounded up if it is n.5 or higher, or rounded down if it is below n.5. For example, in a meeting of ten members eligible to vote, a removal would require eight people to vote for it affirmatively (as 75% of ten is 7.5), and in a meeting with seven members eligible to vote, a removal would require five people to vote for it affirmatively (as 75% of seven is 5.25).

3. Members of the INSIGHT Data Trust Advisory Board

The current members of the INSIGHT Data Trust Advisory Board can be found at

<https://www.insight.hdrhub.org/data-trust-advisory-board>

4. The INSIGHT Data Trust Advisory Board standard criteria

The standard criteria used to develop data requests will be developed by the INSIGHT Data Trust Advisory Board in spring 2020, and will be proposed to the INSIGHT Steering Group for approval.

The standard criteria are subject to an annual review led by the Chair of the INSIGHT Data Trust Advisory Board. The annual review is informed by:

- feedback from the members of the INSIGHT Data Trust Advisory Board;
- feedback from INSIGHT's Public and Patient Involvement and Engagement (PPIE) strategy;
- feedback from other stakeholders, including people, groups and organisations who have observed meetings of the INSIGHT Data Trust Advisory Board;
- feedback from NHS Data Controllers within the INSIGHT partnership and from the INSIGHT Steering Group;
- feedback from other stakeholders, such as Health Data Research UK; and
- review of relevant changes to legal frameworks, government policy and other developments.
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The Chair also retains the right to propose further reviews of the standard criteria as they feel necessary.

Based on discussion and assessment of this feedback, the Chair will work with the Members of the INSIGHT Data Trust Advisory Board to make suggested changes to the standard criteria, which will be proposed to the INSIGHT Steering Group for approval.

5. How the INSIGHT Data Trust Advisory Board assesses and makes recommendations on data requests

5.1. Procedures

Members of the INSIGHT Data Trust Advisory Board will be notified of the time and date of each quarterly meeting with no less than 30 days' notice. The Chair of the INSIGHT Data Trust Advisory Board will work with the Members to produce an agenda and will compile documentation related to each data access request considered, for review ahead of each meeting with no less than 7 days' notice. The Chair of the INSIGHT Data Trust Advisory Board may also invite people, groups and organisations to observe a meeting of the INSIGHT Data Trust Advisory Board with no less than 7 days' notice.

Meetings of the INSIGHT Data Trust Advisory Board will take place in-person and a secure dial-in facility will be provided for Members unable to attend in person.

Recommendations produced by the INSIGHT Data Trust Advisory Board are only effective when conducted in the presence of the Chair (or the Deputy Chair) and if at least two thirds of Members are in attendance.

Members of the INSIGHT Data Trust Advisory Board are required to declare any potential conflicts of interest they may have in assessing and providing a recommendation on a particular data access request – for example, if they are employed by, or affiliated with, an organisation submitting a request for access to data. Members who have declared a potential conflict of interest will not be able to participate in any discussion or decision related to that request.

The Chair of the INSIGHT Data Trust Advisory Board will work with Members and the Secretariat to make provisions related to the meetings to support Members with disability, accessibility or other needs that may otherwise impact their ability to undertake their role.

The Chair of the INSIGHT Data Trust Advisory Board retains the right to convene Members for extraordinary meetings.

5.2. Assessment and recommendation process

Requests for access to data to the INSIGHT Health Research Data Hub are processed by INSIGHT and then forwarded to the INSIGHT Data Trust Advisory Board by the Secretariat for assessment and recommendation at quarterly meetings. The INSIGHT Data Trust Advisory Board will initially assess and provide recommendation on all data requests successfully processed by INSIGHT, before moving to a subset of requests following the development and introduction of a framework for identifying only novel and/or contentious requests (as described by Section 1.2.).

The role of the Chair is to invite Members to share their views, facilitate deliberation and to build consensus around each request. Based on this, the Chair will put one of the following recommendations to the group for each request:

- 'Recommend access granted'. The data access request meets the standard criteria and members recommend that INSIGHT grants access and use of the data.
- 'Recommend access granted with further conditions'. The data access request meets the standard criteria, although members recommend that further conditions are put in place to allow access and use of the data.

- 'Recommendation deferred pending receipt of additional information or clarification'.
Members were unable to assess whether the data access request meets the standard criteria due to a lack of information or clarity in the information that has been provided.
- 'Recommend access denied'. The data access request does not meet the standard criteria and members recommend that access and use of the data is denied.

If all members agree with the recommendation, it is considered final.

If the membership fails to reach consensus, the Chair of the INSIGHT Data Trust Advisory Board will initiate further discussion between the Members on points of contention and seek to support the Board to consider further conditions that may be applied to the request. The Chair will then put the recommendation to a vote by the members (with the Chair voting last), where the options are: 'Recommend access granted', 'Recommend access granted with further conditions', 'Recommendation deferred pending receipt of additional information or clarification' and 'Recommend access denied'.

If 75% of members vote affirmatively for a recommendation, it will come into effect. If no option receives 75% of affirmative votes the recommendation made will be 'Recommend access denied'. Where 75% of membership does not provide an integer, the number will be rounded up if it is n.5 or higher, or rounded down if it is below n.5. For example, in a meeting of nine members eligible to vote, an 'access granted' recommendation would require seven people to vote for it affirmatively (as 75% of nine is 6.75), and in a meeting with seven members eligible to vote, an 'access granted' recommendation would require five people to vote for it affirmatively (as 75% of seven is 5.25).

Members of the INSIGHT Data Trust Advisory Board may log dissenting opinions against recommendations made, which will be recorded in the minutes of the meeting.

The Chair and Secretariat of the INSIGHT Data Trust Advisory Board will communicate the recommendations made at the meetings to the INSIGHT Hub Director. The INSIGHT Hub Director will give due consideration to the recommendations provided by the INSIGHT Data Trust Advisory Board and will provide written communication to the Board, via the Chair prior to the next scheduled INSIGHT Data Trust Advisory Board quarterly meeting, where the final decision is contrary to its recommendation.

5.3. Role of the Secretariat

In the initial period, the role of Secretariat to the INSIGHT Data Trust Advisory Board will be undertaken by staff at the Open Data Institute engaged by AAAMD to support INSIGHT.

The duties of the Secretariat to the INSIGHT Data Trust Advisory Board are to support the Chair and liaise with Members to:

- schedule the quarterly meetings of the INSIGHT Data Trust Advisory Board;
- produce an agenda and documentation related to requests for access to data ahead of each meeting of the INSIGHT Data Trust Advisory Board;
- minute the meetings of the INSIGHT Data Trust Advisory Board and ensure it is undertaking its commitments to transparency;
- recompense members of the INSIGHT Data Trust Advisory Board and reimburse any associated costs; and
- support the Chair of the INSIGHT Data Trust Advisory Board.

- produce a quarterly report of activity and progress, which will inform an annual report to be provided to the INSIGHT Steering Group

The Chair is responsible for overseeing that Members operate in accordance with the Terms of Reference of the INSIGHT Data Trust Advisory Board. This will include assessing whether the conditions required for recommendations at the meetings of the INSIGHT Data Trust Advisory Board to be effective have been met, and monitoring adherence to its other procedures.

5.4. Transparency

The INSIGHT Data Trust Advisory Board is committed to operating as transparently as possible, subject to privacy, commercial sensitivity and national security.

With support from the Secretariat, the Chair of the INSIGHT Data Trust Advisory Board is responsible for:

- maintaining an online presence describing the INSIGHT Data Trust Advisory Board in accessible language, including its purpose, profiles of its members and upcoming meeting dates.
- online publication of the Terms of Reference of the INSIGHT Data Trust Advisory Board. Any changes to the Terms of Reference will be published as a new, dated version, alongside previous versions, with a summary of changes made, no more than 7 days after they have been made. The Terms of Reference are published under an open licence.
- publishing detailed minutes for each meeting of the INSIGHT Data Trust Advisory Board. These include: the standard criteria against which the applications have been assessed; the lay summary of each application; the recommendation of the INSIGHT Data Trust Advisory

Board for each application (as per 5.2); and any dissenting opinions that members have requested to be logged. The minutes are published within 7 days of each meeting of the INSIGHT Data Trust Advisory Board under an open licence.

- running an annual meeting of the INSIGHT Data Trust Advisory Board that is open to the public to attend. Once per year, a quarterly meeting of the INSIGHT Data Trust Advisory Board is made open to interested members of the public, patients and other stakeholders to attend, subject to registration and venue capacity. The location of the annual meetings will vary across the UK.

The Chair of the INSIGHT Data Trust Advisory Board may also invite people, groups and organisations to observe meetings of the INSIGHT Data Trust Advisory Board as they deem appropriate. This is expected to include representatives from regulators, research institutions and other HDRUK Health Research Data Hubs. Representatives of INSIGHT partner organisations are also able to observe meetings of the INSIGHT Data Trust Advisory Board.

People, groups and organisations that have submitted a data access request for review are not able to observe meetings of the INSIGHT Data Trust Advisory Board where their data requests will be assessed.

Any queries related to the operation of the INSIGHT Data Trust Advisory Board can be raised by contacting enquiries@insight.hdrhub.org

5.5. Confidentiality

Members of the INSIGHT Data Trust Advisory Board - as well as other stakeholders, such as the Secretariat and people, groups and organisations that have observed its meetings, and attendees of

public meetings - are not permitted to share information related to the data requests they have assessed and provided a recommendation on, or observed, until the minutes for the meeting in question have been published.

Members may share information that is contained within publicly available minutes, but are not permitted to share other confidential information they may acquire in undertaking their role, such as that related to organisations that have submitted data requests.

5.6. Raising concerns

Members of the INSIGHT Data Trust Advisory Board - as well as other stakeholders, such as the Secretariat and people, groups and organisations that have observed its meetings - are encouraged to raise any concerns they may have related to the operations of the INSIGHT Data Trust Advisory Board with the Chair. The Chair of the INSIGHT Data Trust Advisory Board will inform and work with the Co-Chairs of the INSIGHT Steering Group to respond to any such concerns, and to put in place any steps as may be necessary.

The INSIGHT Steering Group has ultimate responsibility for all activities being undertaken by INSIGHT and may intervene if they deem necessary for the safety, security and reputable-standing of the data access assessment process.

Where members or other stakeholders are concerned about potential misconduct or wrongdoing, they can raise their concerns to the Co-Chairs of the INSIGHT Steering Group.

6. Changes to the Terms of Reference of the INSIGHT Data Trust Advisory Board

The initial Terms of Reference of the INSIGHT Data Trust Advisory Board were developed by INSIGHT with support from the Open Data Institute.

The Terms of Reference are subject to an annual review led by the Chair of the INSIGHT Data Trust Advisory Board. The annual review is informed by:

- feedback from the members of the INSIGHT Data Trust Advisory Board;
- feedback from INSIGHT's Public and Patient Involvement and Engagement (PPIE) strategy;
- feedback from other stakeholders, including people, groups and organisations who have observed meetings of the INSIGHT Data Trust Advisory Board;
- feedback from NHS Data Controllers within the INSIGHT partnership and from the INSIGHT Steering Group;
- feedback from other stakeholders, such as Health Data Research UK; and
- review of relevant changes to legal frameworks, government policy and other developments.

The Chair also retains the right to propose further reviews of the Terms of Reference as they feel necessary.

Based on discussion and assessment of this feedback, the Chair will work with Members of the INSIGHT Data Trust Advisory Board to make suggested amendments to the Terms of Reference. These suggested amendments will be circulated for review and accepted through consensus among Members, prior to proposal to the INSIGHT Steering Group for approval. Failure to achieve consensus will result in the proposed amendments being rejected.

7. Dissolution of the INSIGHT Data Trust Advisory Board

The operation of the INSIGHT Data Trust Advisory Board is contingent upon the existence and funding of INSIGHT. It is therefore expected to operate to at least 30 September 2022. INSIGHT partners would expect to continue to operate the INSIGHT Data Trust Advisory Board if INSIGHT was to prove sustainable beyond this duration, subject to review by the INSIGHT Steering Group.

In case of the dissolution of INSIGHT, dissolution of the INSIGHT Data Trust Advisory Board will be overseen by the Co-Chairs of the INSIGHT Steering Group. The Co-Chairs would also ensure that any documentation related to the INSIGHT Data Trust Advisory Board - including its online presence, the versions of its Terms of Reference and the minutes for each of its meetings - are archived for appropriate future use.