Wessex Data Access Committee (DAC) Terms of Reference

This document sets out the Terms of Reference for the Wessex Secure Data Environment (SDE) Data Access Committee.

Version history

#	Date	Author	Reviewer	Changes
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2	28/04/25	Jo Stuart (Senior PM)	Rachel Chappell	Amendments to 5.3.2 and addition of version history
3		Rachel Chappel (DAC Chair)		Approval
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1. Purpose

1.1. The Wessex Data Access Committee (the "Committee") is constituted as a decision-making body for the Wessex Secure Data Environment (“SDE”). It reviews applications for access to data within the SDE and makes decisions under the authority delegated to it.

1.2. The Committee ensures that requests align with NHS data governance principles, ethical standards, and public benefit considerations, safeguarding patient privacy while enabling appropriate research and service improvement.

1.3. The Committee may also review and provide advice on SDE policy matters relevant to its remit, where such matters are delegated to it or referred to it by the SRO, Wessex SDE Board, or SDE Operations within their respective authority or delegated competence.

2. Authority and Governance

2.1. The Wessex SDE is an NHS-owned and managed platform that stores and links NHS patient data for research and innovation. It is supported by NHS organisations in the Wessex region, including NHS Dorset and NHS Hampshire & Isle of Wight Integrated Care Boards. As part of the NHS Research SDE Network in England, the Wessex SDE adheres to national technology, governance, and operational standards.

2.2. The SDE operates under a Memorandum of Understanding (MoU) with NHS England and is a key initiative of Dorset Integrated Care Board, Hampshire & Isle of Wight Integrated Care Board, and Wessex Health Partners ("WHP"). These organisations provide strategic sponsorship and oversight through the Wessex SDE Executive Sponsor Group.

2.3. University Hospital Southampton NHS Foundation Trust ("UHS") serves as the Host Organisation for the SDE and the Committee, ensuring governance and regulatory compliance.

2.4. The Wessex SDE Senior Responsible Owner (“SRO”) is accountable for the operation of the SDE and for ensuring that appropriate governance arrangements are in place for access to data.

2.5. The Wessex SDE Board provides oversight, assurance and accountability for the strategic development and operation of the SDE, and reports to the Executive Sponsor Group, in accordance with the SDE’s approved governance arrangements.

2.6. The SRO constitutes the Committee as a decision-making body for data access applications within the scope of these Terms of Reference and the SDE’s approved governance arrangements.

2.7. The Committee is responsible for reviewing data access requests against agreed criteria and for approving, rejecting, deferring or placing conditions on access, in accordance with these Terms of Reference and the SDE's approved policies and processes.

2.8. The Committee operates independently in its consideration of individual data access applications. The SRO, Wessex SDE Board, and SDE Operations may not overturn a Committee decision outside the appeals, review or escalation processes set out in these Terms of Reference.

2.9. The Committee operates in accordance with the Wessex SDE **Core Values** and **Strategic Research Priorities**, ensuring decisions reflect public expectations for responsible and equitable data use while maximising public and patient benefit.

3. Membership

3.1. **Composition**

3.1.1. The Committee comprises a non-voting Chair and ten (10) voting members, representing diverse expertise and lived experience to ensure fair and transparent decision-making:

- **Chair:** Facilitates discussions and ensures effective decision-making but does not vote.
- **Four (4) Public Members:** Represent patient and public perspectives.
- **Six (6) Professional Members:** Cover expertise in clinical practice, patient care, research, data governance, ethics, and law.

3.2. **Observers**

3.2.1. Standing observers are:

- **SDE Operations Representative(s):** Present data access applications, provide operational context to decisions including operational, clinical and engineering expertise, and ensures alignment with SDE governance framework.
- **Secretariat Representative:** Records minutes and ensures procedural compliance.

3.2.2. Observers do not participate in decision-making but may contribute to discussion at the Chair's discretion.

- Additional observers, such as specific study experts or study-related researchers, may be invited when necessary, at the discretion of the Chair.

3.3. **Appointment and Term**

3.3.1. Appointments follow an open and transparent recruitment process overseen by the SRO or a body acting under authority delegated by the SRO**.** Terms are:

- **Public and Professional Members:** one (1) year terms, renewable annually, up to a maximum total term of three (3) consecutive years.
- **Chair:** Three (3) years, with the option to extend for one further three-year term by agreement.

3.3.2. A list of current members and their affiliations is maintained in **Appendix A**, updated by the Secretariat.

3.4. **Removal and Replacement**

3.4.1. A member may be removed upon the request of the Chair to the SRO, or a body acting under authority delegated by the SRO**,** for the following reasons:

A. Three (3) consecutive unexcused absences.

B. Breaching confidentiality.

C. Failing to declare conflicts of interest.

D. Conduct that, in the view of the Chairm undermines the Committee's integrity.

3.4.2. The SRO, or a body acting under authority delegated by the SRO, oversees removal and replacement, ensuring due process and compliance with relevant NHS policies.

3.5. **Committee Secretariat**

A designated Secretariat function, reporting to the Chair, shall provide administrative support.

4. Remuneration and Expenses

4.1. **Public Members** receive involvement payments in line with NIHR guidelines, with reimbursement for reasonable expenses.

4.2. **Professional Members** typically participate as part of existing roles without additional compensation. Professional service payments and reimbursable expenses shall be determined in accordance with existing NHS or organisational policies.

4.3. **External Advisors** may receive payments on a case-by-case basis, subject to approval through the SDE's approved financial and governance arrangements.

- All payments and reimbursements shall be administered in accordance with relevant NHS financial regulations and governance standards.

5. Role and Responsibilities

5.1. Committee Role

5.1.1. The Committee will:

A. Review and decide data access requests to the Wessex SDE, taking account of SDE Operations' assessment of feasibility, desirability and operational readiness.

B. Prioritise data access requests where SDE resources are limited.

C. Review and provide recommendations on SDE governance policies and procedures for data management and research delivery.

D. Commission and consider expert, independent advice as needed.

E. Where appropriate, establish working groups or sub-committees within its membership. The Committee shall not delegate decision-making authority to any working group or sub-committee except where expressly permitted by these Terms of Reference.

F. Promote public trust through transparency, good communication, timely publication of decisions and recommendations, and independent audit of its activities where appropriate.

G. Work with counterparts in other organisations to help ensure consistency of decision-making across SDEs

5.1.2. In fulfilling its role, the Committee ensures that all decisions consider:

A. NHS Values as set out in the NHS Constitution[1]

B. Data Access Principles, together with additional information and assessments made as part of the Data Access Process.

C. Ensuring data access requests demonstrate a clear and meaningful public benefit, serve a legitimate public interest

D. Wessex SDE Core Values and Strategic Research Priorities.

E. Ensuring data use is legal, compliant with governance, ethical, and appropriate in line with SDE policies, for example our approval under section 251 of the NHS Act 2006 and its current regulations, the Health Service (Control of Patient Information) Regulations 2002.

5.2. Responsibilities of Members

5.2.1. Members must:

E. Adhere to **Wessex SDE Ways of Working (Appendix D)**.

F. Declare conflicts of interest per the **Conflicts of Interest Policy**.

G. Sign a Confidentiality Agreement before participating.

H. Complete relevant NHS data governance training.

5.3. **Committee Chair**

5.3.1. The Chair is responsible for the effective operation of the Committee, ensuring discussions are well-informed, focused on key issues, and that all members have equitable input. The Chair will:

A. Preside over all Committee meetings, when present, and facilitate discussion as a non-voting member of the Committee.

B. Represent the Committee impartially and independently of the SDE Senior Management Team.

C. Exercise full discretion in defining, managing and mitigating conflicts of interest, in consultation with the Secretariat.

D. Ensure Committee members receive appropriate training and remain updated on evolving policies, with support from the Secretariat.

5.3.2. The Chair may nominate a Deputy Chair from among the Committee's members to act in the Chair's absence. Where a voting member acts as Deputy Chair, they shall chair the meeting as a non-voting member and shall not vote on any item for which they act as Chair.

5.3.3. The appointment of a Deputy Chair shall be recorded in the minutes.

6. Meeting Procedures

6.1. **Frequency and Quorum**

6.1.1. Meetings occur at least monthly, with flexibility based on demand. Meeting dates shall be set by the Chair, supported by the Secretariat.

6.1.2. The Committee may be stood down at the discretion of the Chair, where there is insufficient business to conduct.

6.1.3. A quorum is required for Committee meetings to proceed. A meeting is quorate where five (5) members of the Committee including the Chair or Deputy Chairt, at least one (1) Public Member, and at least one (1) Professional Member are present and eligible to participate in the relevant decision.

6.1.4. An SDE Operations Representative should normally attend to present applications and provide operational advice, but shall not count towards quorum.

6.1.5. Where the Chair determines that a Member has a conflict of interest, the Chair shall determine the appropriate mitigation. Where the Member is excluded from the decision, they shall not vote and shall not count towards quorum for that item.

6.1.6. A Member may vote only if present remotely throughout the relevant agenda item via a stable connection enabling full audio-visual participation. Votes submitted by email or other methods shall not be accepted.

6.1.7. A Member may vote on an agenda item at a meeting only if present throughout the relevant item, whether in person or remotely, via a connection that enables effective participation in the discussion. Votes submitted by email or other written methods shall not be accepted for meeting decisions.

6.2. **Decision-Making**

6.2.1. Each member is entitled to one vote, except for the Chair, who remains non-voting.

6.2.2. Decisions require approval by at least 70% of members present and eligible to vote, rounded up to the nearest whole number.

6.2.3. Meeting agendas are set by the Chair, in consultation with the Secretariat and SDE Operations.

6.2.4. Meeting papers should normally be circulated at least five (5) business days before the meeting. The Chair may agree a shorter circulation period where they are satisfied that members will still have sufficient time to review the papers and participate in an informed discussion.

6.2.5. Each agenda item shall clearly state the nature of the decision required and provide sufficient background information to enable informed deliberation.

6.2.6. Sub-groups may be formed at the discretion of the Chair for specific tasks. Sub-groups shall not have decision-making authority except where expressly permitted by these Terms of Reference.

6.3. **Observer Conduct and Media Attendance**

6.3.1. Observers must:

- Sign a Confidentiality Agreement before participating.
- Refrain from making audio, video, or written recordings of meetings without the express prior consent of the Chair.

6.4. **Extraordinary Meetings**

6.4.1. The Chair may convene an Extraordinary Meeting of the Committee where urgent business requires consideration outside of the Committee's ordinary procedures, including the waiver of any normal notice period for agenda papers and any

requirement to consult with the Committee Secretary or SDE Operations Representative.

6.4.2. The Chair must set out clearly at the beginning of the meeting the reasons for convening the Extraordinary Meeting and these reasons shall be recorded as part of the meetings formal decisions and minutes.

7. Conflict of Interest

7.1. Members must declare interests before appointment and update annually.

7.2. Interests are recorded in a **Register of Interests**, publicly available unless confidentiality is required.

7.3. The Chair, with Secretariat input, determines appropriate conflict mitigation measures.

8. Appeals Process

8.1. Applicants may request a review of a Committee decision within 30 days, providing reasons for the request and any supporting information. Requests for review shall be considered jointly by the Chair and the SRO.

8.2. The Chair and SRO may uphold the Committee's decision or remit the matter back to the Committee for reconsideration. They shall not substitute their own decision for that of the Committee.

8.3. A matter may be remitted where the Chair and SRO consider that there may have been a procedural error, material new information, a material misunderstanding of the application, or another substantive reason why the Committee should reconsider the matter.

8.4. Where the Chair has a conflict of interest or was materially involved in the decision under review, the Deputy Chair shall act in the Chair's place.

8.5. Final outcomes shall be communicated to the applicant within 30 days of receipt of the request for review, unless an extension is agreed and recorded.

9. Accountability and Reporting

9.1. **Accountability**:

9.1.1. The Committee is accountable to the SRO and reports through the Wessex SDE Board, in accordance with the SDE's approved governance arrangements.

9.1.2. The Committee makes decisions on data access requests within its delegated remit and may provide advice to SDE Operations on matters relevant to that remit.

9.2. **Reporting**:

9.2.1. Meeting minutes, decisions, conditions, and recommendations will be shared with SDE Operations.

9.2.2. Regular updates will be provided to the Wessex SDE Board and SRO.

9.2.3. An annual report will summarise activities and emerging trends.

9.2.4. All reports will use accessible language and include reasons for decisions.

9.3. **Minutes**:

9.3.1. The Secretariat will draft minutes of the Committee and Sub-Committee within five (5) business days and submit them to the Chair for initial approval.

9.3.2. Minutes will summarise discussions and decisions without attributing comments unless explicitly requested.

9.3.3. Conflicts of interest will be recorded.

9.3.4. Members will review and approve draft minutes at the next meeting.

9.3.5. Once ratified, minutes will be published to ensure transparency.

10. Freedom to Speak Up

10.1. Committee members must report governance concerns to the Chair or escalate to the SRO or Wessex SDE Board if necessary. NHS Freedom to Speak Up policies apply.

11. Review of Terms of Reference

11.1. The Terms of Reference are reviewed annually, considering legal, policy, or operational changes. This process will be led by the Chair.

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12. Appendices

Appendix A: Current Committee members and affiliations

Appendix B: Wessex SDE Core Values

Appendix C: Wessex SDE Strategic Research Priorities.

Appendix D: Ways of Working

Appendix A: Current Committee members and affiliations

1. Dr Rachel Chappell, Chair (Southampton Emerging Therapies and Technologies (SETT) Centre Manager)
2. Lindsay Anderson (Digital Critical Friend)
3. Heather Case (Deputy Director of Data and Analytics, NHS Dorset)
4. Sam Fortune (Digital Critical Friend)
5. Prof Nick Francis (Head of School – Primary Care, University of Southampton)
6. Prof Nicholas Fuggle (Associate Professor in Rheumatology, University of Southampton)
7. Dr Patricia Fuller (Research Fellow, NIHR ARC Wessex)
8. Keith Gomes Pinto (Chief Medical Information Officer, NHS Dorset)
9. Sandra Hall (Digital Critical Friend)
10. Will Jennings (Associate Dean Research & Enterprise, University of Southampton)

- Andy Taylor (Digital Critical Friend)

Observers

- Mark Heffernan (Director of Operations, Wessex SDE)
- Michael George, (Medic and Digital Fellow, Wessex SDE)

Appendix B: Wessex SDE Core Values

The SDE core values have been collaboratively developed by the Wessex Public Panel on NHS Data and SDE professionals. These values have been tested with the wider Wessex public and serve to guide the behaviour of the Wessex SDE, setting the standards we aspire to uphold.

1. **Benefits everyone**

   Deliver clear and tangible benefits, shared fairly and inclusively for all communities.

2. **Better together**

   Involve the public through all stages of the SDE, engaging with all communities through clear communication.

3. **Privacy and security first and foremost**

   Strictly controlled access with independently scrutinised safeguards and limits on authorised users.

4. **Open and honest**

   Be clear about how the SDE uses your data and what potential benefits this will bring.

5. **Delivers good value**

   Supports research that delivers measurable improvement to patient outcomes, making the best use of NHS resources.

6. **Respects people's choices**

   Gives you the option to opt out and provides clear information about benefits and risks to inform your decision.

7. **Only positive industry partnerships**

   Build industry partnerships that are collaborative, transparent, accountable, time-bound, and deliver measurable benefits.

8. **Good governance and quality assurance**

   Strong and transparent governance, with independent checks on how the SDE is run and the quality of its data.

Appendix C: Wessex SDE Strategic Research Priorities.

The Wessex public has helped to identify eight strategic priorities for the Wessex SDE. These priorities will help us to prioritise the changes and improvements that the public wants to see as a result of the SDE. They are set out below along with the types of projects and activities that we will prioritise locally to deliver them:

1. **Save the NHS money through prevention and long-term health improvements for everyone**

   Health systems research projects will provide an evidence base for changes to patient pathways and public health activity that deliver more streamlined services, reduce costs and reduce waiting times.

2. **Improve public health, quality of life, and reduce health inequalities**

   Studies that look at impacts on large groups of people (epidemiological studies) will help us to better understand environmental and lifestyle factors, allowing us to provide better public health information and guidance so that people live healthier for longer.

3. **Clear aims, measurable outcomes, and align with Wessex's health needs**

   We already know a lot about the burden of disease in Wessex from our Integrated Care Partnerships (ICPs) and NHS partners. By working collaboratively across the region, we can prioritise projects which will have a direct benefit and impact on local issues.

4. **Create new knowledge and avoid unnecessary repetition**

   By capturing learning and outcomes from the research projects using the Wessex SDE will we help to embed learning that drives new innovation and research, accelerating system and patient outcome improvements.

5. **Clearly costed, financially sustainable, and delivering value for money**

   The NHS spends a lot of time and money capturing data which is not currently used to its greatest effect. The Wessex SDE will help us to maximise the use and value of this precious data by making available in research ready formats in a single place and enabling national research to consistent standards.

6. **Create financial sustainability for the Wessex SDE to support the NHS in the future**

   The SDE Network is working collaboratively to develop a costing model to ensure that the NHS and patients receive fair value (not just £ but also wider value) from the system. Research to test, train, check and introduce new forms of technology (such as AI) will also help to reduce the burden on the NHS into the future.

7. **Quickly deliver results using existing data and resources**

   Our first priority for Wessex is to map that data that is currently held by NHS and university partners across the region. This will be an ongoing activity which helps us to accelerate

health innovation for real world impact, putting new discoveries into practice in health care settings (also known as ‘translational research’).

8. **A public benefit that would raise awareness of the SDE and build reputation**

   All research projects that want to use the SDE must demonstrate value to the public and NHS. This will be evaluated by the Wessex SDE’s Data Access Committee which will include professional and public members. Guidance on how projects should be evaluated are being developed in collaboration with the public.

Appendix D: Ways of Working

These Ways of Working set out how members of the Wessex Data Access Committee (DAC) agree to work together. They help ensure that everyone, whether professionals or public members, is treated fairly and respectfully, and that the committee's decisions put the public interest first. All members commit to following these guidelines in every meeting.

1. **Valuing All Voices Equally**

   1.1. Every Committee member's views carry equal weight, recognising that lived and learned experience are equally valuable.

   1.2. Members respect and encourage contributions from all, ensuring that Public Members and Professional Members are treated equally.

   1.3. Discussions will support active and equitable participation from everyone, with consideration of diverse perspectives and abilities.

2. **Respectful and Constructive Engagement**

   2.1. Members are expected to communicate respectfully, openly, and constructively, without using exclusionary or dismissive language.

   2.2. All interactions should be courteous, with members challenging ideas respectfully rather than individuals personally.

   2.3. A positive atmosphere, inclusive of all communication styles, is fundamental to the Committee's effectiveness.

3. **Consensus-Focused Decision Making**

   3.1. Members aim to build consensus through open-minded, collaborative discussion, and active listening.

   3.2. Constructive debate is encouraged; entrenched positions should be avoided in favour of achieving solutions everyone can support.

   3.3. Where consensus cannot be reached, members should still respectfully acknowledge differing perspectives to ensure robust decision-making.

4. **Patient, Inclusive, and Deliberate**

   4.1. Discussions will be paced to ensure all members can participate fully, without feeling pressured or hurried.

   4.2. Members should take the necessary time to consider issues carefully and raise questions to fully understand proposals.

4.3. Deliberations will be managed inclusively, accommodating varied abilities and communication needs.

5. **Enabling Constructive Outcomes**

5.1. The Committee's default stance is supportive, aiming to enable valuable research while safeguarding patient privacy and public trust.

5.2. Where applications have shortcomings, the Committee will seek to provide clear, practical guidance to researchers on how proposals can be improved.

5.3. The Committee views its role as facilitating responsible and beneficial research rather than obstructing it.

6. **Public Interest First**

6.1. Decisions will prioritise clear public benefits, aligning with the Wessex SDE Core Values, strategic research priorities, and the provisions of the NHS Constitution.

6.2. Members consistently consider and prioritise protecting patient privacy, ensuring high ethical standards, and responsible data use.

6.3. Public interest underpins every recommendation, maintaining trust and transparency.

7. **Accountability and Behavioural Standards**

7.1. Members are collectively accountable for upholding these ways of working.

7.2. Consistently falling short of these standards may lead to removal from the Committee, as outlined in the Terms of Reference.

7.3. This guidance supports effective collaboration and high standards, promoting a cohesive and productive working environment.