

Terms of Reference: TVS SDE Programme

Revision history

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| 0.1 | First draft for Board review | KJW |
| 0.2 | Updated | JND |
| 0.3 | Updates for programme phase 2 | KJW, KAV |
| 0.4 | Updates following board members' review March 2023 | KJW |
| 1.0 | Agreed by board members June 23 | |

Purpose of the TVS SDE Programme Board

The purpose of the Programme Board is to set out, oversee and communicate the work of the Thames Valley and Surrey sub-national Secure Data Environment (TVS SDE), which was established in January 2022 by OUH on behalf of the TVS locality. The programme board plays a key role defining the programme scope, tolerances and governance organisation, monitoring threats to benefits realisation, and acting to realise the benefits and communicate them across the stakeholder community.

Aims and responsibilities

The TVS SDE programme will establish a secure data environment for research and development, across its population of 4.3 million people. To ensure its success, a programme board will govern its activities with a strong focus on communications and transparency, risk management and value creation for the NHS.

As part of its governance mandate, the board will set out the programme vision and organisation, providing leadership both internally and externally to foster stakeholder communications and engagement. The board will also oversee blueprint design and delivery of the new capability, working alongside the programme team to ensure delivery in line with the time, cost, and quality expectations set out in the Programme Initiation Document (PID).

One of the key responsibilities of the board is to prioritise benefits realisation and anticipate any risks or issues that may threaten this objective. This requires robust benefits realisation planning and profiles, linked to programme risks and issues log. Risks and issues should be reviewed regularly, with red and red / amber risks scheduled for board discussion. New and emerging risks and issues should be identified promptly, and comprehensive control arrangements should be agreed, via the board and in line with agreed tolerances.

The TVS SDE programme board is responsible for:

1. Strategic oversight: providing strategic oversight of the programme, ensuring that it is aligned with the organisation's goals and objectives.
2. Resource allocation: ensuring that the programme has the necessary resources, including funding, personnel, and technology, to achieve its objectives.

3. Risk management: identifying and managing risks associated with the programme. This includes developing risk management plans, monitoring risks, and taking action to mitigate them as necessary.
4. Stakeholder management: managing stakeholder expectations and communications. This includes identifying stakeholders, understanding their needs, and ensuring that they are engaged and informed throughout the programme.
5. Benefits realisation: ensuring that the benefits of the programme are realised. This includes defining the benefits, tracking progress, and ensuring that the necessary actions are taken to achieve them.
6. Performance monitoring: monitoring the performance of the programme and its individual projects. This includes tracking progress, identifying issues, and taking corrective action as necessary.
7. Governance: establishing and enforcing governance structures and processes to ensure that the programme is managed effectively and efficiently.

Members

Programme Board membership:

| Programme Role | Job title and programme role |
|---|---|
| SRO | Chief Digital and Partnerships Officer, OUH – responsible for overall objectives, benefits realisation |
| NHSE representative | Data for R&D programme Director, NHSE, providing the link to national programme strategy as well as escalation route to NHSE where needed |
| BOB ICS/B lead | Chief Digital and Information Officer, BOB ICS, on behalf of BOB data controllers |
| Frimley Health and Care ICS/B lead | CIO, Frimley Health and Care ICS and Connected Care, on behalf of FHC data controllers |
| Surrey Heartlands ICS/B lead | CIO, Surrey Heartlands ICS on behalf of SH data controllers |
| SRO Thames Valley and Surrey Care Records Partnership | SRO, TVS SCR, supporting strategic alignment between TVS SCR and TVS SDE programmes |
| SCAS lead | Director of Digital, SCAS, providing data controllership representation for the Trust |
| MKUH lead | CTO, MKUH, providing data controllership representation for the Trust |
| GWH lead | CIO, GWH providing data controllership representation for the Trust |
| Health Innovation Oxford & Thames Valley lead | CEO, Health Innovation Oxford, supporting alignment with R&D activities in our region |
| Programme Director | Director, R&D clinical Informatics, OUH, Programme Director, TVS SDE – oversees programme delivery and benefits realisation |

| Programme Role | Job title and programme role |
|---|--|
| Finance and commercial lead | CFO, OUH – provides financial oversight, advice and assurance |
| Lead architect | Professor of Software Engineering, University of Oxford – provides expert data science and architectural advice and assurance |
| Digital services, cybersecurity lead | Director of Digital Services, OUH – provides expert advice on digital aspects of the programme and ensures alignment with relevant services within OUH as the host trust |
| Research information governance, ethics lead | Head of IG, OUH and / or Caldicott Guardian, OUH – provides expert advice and assurance on data protection and ethical governance matters |
| Lay stakeholders | Providing the patients and public perspective on decision making, as well as a link into the Community of Practice. Members will be appointed via a formal process. |
| PPIE lead | Director, Community Involvement and workforce innovation, Oxford AHSN – providing a professional PPIE perspective, linking to and support the lay members and Community of Practice and working to maximise alignment in comms with the public across the wider region |
| Stakeholder Engagement lead | TVS SDE communications and stakeholder engagement lead, providing expertise and assurance around comms with patients, public, health care professionals and customers / consumers |
| University of Oxford Medical Sciences Division representative | Deputy Head of Division / BRC Director and the Associate Head of Division (Digital and Information), providing the academic research perspective |
| Programme Manager | Senior Programme Manager, R&D clinical informatics, OUH, responsible for day-to-day programme management and coordination |
| Secretariat | Programme Support Manager, R&D clinical informatics, OUH, responsible for meeting arrangements, invitations, papers and Minutes |

The meeting shall be quorate when at least seven members are present, including the chair (or deputy chair), the three ICS/Bs and three NHS Trusts named above. This is a decision-making board; decisions will be made if quorate.

Observers may be invited to attend the meeting when appropriate. Such attendees are not counted as part of the quorum.

Sub committees

The Data Access Committee (DAC) will be responsible for assessing research proposals, and assigning a risk rating to any that are approved. Depending on the risk rating assigned, they may also be responsible for the approval of any requests made during the delivery of an approved programme that have a bearing on data access or disclosure. They will agree guidelines and policy for data management, export, and publication.

The Development Committee will make recommendations regarding the strategic development of infrastructure, services, and relationships with research organisations, technology providers, and funding bodies. The committee will have a particular focus upon the recovery of costs, the realisation of benefits, and the sustainability of the SDE as part of a health research ecosystem.

These committees will include appropriate representation from healthcare professionals and from patients and the public within the region. The DAC will require expertise in research ethics, data governance, and healthcare innovation. The Development Committee will require expertise in data science, intellectual property, and the practical and financial aspects of research delivery.

Programme team

Core programme functions:

| Function | Remit |
|-----------------|---|
| Management Team | <p>The management team will include a chief operating officer and the leads of five operating areas or functions. This team will be responsible for the day-to-day running of the SDE, including the approval of in-project requests for research programmes with a low risk rating, where the authority for approval has been delegated by the DAC.</p> <p>The team will escalate matters to the DAC and to the board where appropriate.</p> |
| Service Team | <p>The service team will act as a single point of contact for research organisations and research users, responding to user requests, coordinating the work, and ensuring complete and accurate records are maintained. The team will maintain a knowledge base, with additional information on data assets and services, and provide reports on service delivery to other teams, to management, and to the board.</p> <p>The service team is responsible also for IT service management, including support (incident, problem, change, release, and configuration) and delivery (service levels, availability, capacity, business continuity, and financials). Within the team, designated</p> |

| Function | Remit |
|------------------------------|--|
| | account or relationship managers may be allocated to particular research organisations or research programmes. |
| Technical Team | <p>The technical team will take responsibility for the development and maintenance of the data infrastructure, the implementation of new data points, and the delivery of data and compute resources within the SDE. They will support the service team in assessing data specifications, answering technical questions, and reviewing material for import or export.</p> <p>A combination of skills will be required, in both development and operations. Expertise in platform management, information security, and data engineering will be essential. Access to subject matter experts will also be required, whether these are designated members of the team or colleagues within the participating NHS trusts and partner organisations.</p> |
| Commercials and Finance Team | <p>The commercials and finance team will work to ensure that research programmes are provided with accurate estimates of the costs associated with data provision and analysis both at the proposal stage, and as the research proceeds.</p> <p>They will ensure that costs are recovered, and work with the service and technical teams to ensure that efficient use is made of SDE resources. They will support the SDE management, the board, and the development committee in planning, decision-making, negotiating, and contracting activities.</p> |
| Governance and PPIE Team | <p>The governance and PPIE team will support the SDE management team and the DAC in establishing guidelines, assessing proposals, and reviewing requests. They will take responsibility for data sharing agreements, data protection impact assessments, and data processing notices; they will provide expert governance input into data incidents and near misses, and work with the technical team on the implementation of governance controls. They will ensure that agreements with research organisations and users provide the assurance that is needed to complement these controls.</p> <p>The team will:</p> <ul style="list-style-type: none"> - liaise with research organisations, research ethics committees, NHS England, and the HRA, to ensure that operations are consistent with the approvals granted; - handle subject access and freedom of information requests; |

| Function | Remit |
|---------------------------------------|--|
| | <ul style="list-style-type: none"> - work with engagement initiatives across the region and nationally to help build communities of interest and practice around the SDE programme. |
| Comms and stakeholder management Team | <p>The communications and stakeholder management team maintains a collection of online resources and printed documentation to support engagement. They will work with research organisations to ensure:</p> <ul style="list-style-type: none"> - information about the programme and how to opt out are distributed in line with policy and governance approvals; - information regarding research programmes is provided in a sufficiently detailed and accessible form; - insights, designs, and results are shared wherever possible; and - that the benefits of the SDE programme are fully realised. <p>A transparent account of decision-making and data processing activity within the SDE is not only a legal requirement but also an essential prerequisite for trust and engagement. It is important that the participating NHS organisations, the healthcare professionals who work for them, and the patients and public across the region are able to satisfy themselves that data is being used in a way that is consistent with their expectations.</p> |

Accountabilities

The board is accountable to the Digital Oversight Committee within OUH.

The board is also responsible for providing regular and ad hoc updates to the national SDE Programme Board. Programme board members are accountable for updating their respective organisations on the activity of this board.

Review

The board shall review this ToR annually, and if there is a major change in the programme.

Ways of working

The Programme Board shall meet every six to eight weeks, either in person or via videoconference. Where appropriate, subgroups may be convened to complete discrete work packages and report back.

In practical terms, methods of working will mean:

- The meeting will be chaired by the SRO or Programme Director
- The meeting shall be quorate as long seven members are present, including the chair or deputy chair
- Where members cannot attend the meeting, they should inform the chair, and arrange for a suitably empowered deputy to attend.
- Observers, including other programme staff, may join the meeting from time to time and in agreement with the chair
- Agenda items for discussion will be defined by the members based on a standard agenda template, plus any matters arising
- Any meeting papers shall be distributed electronically at least three working days before the meeting.
- A note of major decisions and actions will be made at each meeting. Meeting minutes will not be published in the public domain as they may contain confidential and / or commercial material.
- The secretariat function shall be fulfilled by the OUH R&D clinical informatics team (SL)

In practical terms, sharing information and resources will mean:

- Papers will be shared over email and / or MS Teams
- Printed copies are not secure
- Where appropriate, members (and observers) will be asked to sign a confidentiality agreement or NDA to protect confidential and / or commercially sensitive information.

Appendix One – Programme organisation

