Wessex SECURE DATA ENVIRONMENT | Part of the NHS Research Secure Data Environment Network

Wessex Data Access Committee: Minutes

Date: Friday 28th August 2026
Time: 13:00-15:00
Location: Virtual via TEAMS (meeting recorded for training and reflection)

Chair: Dr Rachel Chappell
Secretariat: Laura Fletcher

Present: Rachel Chappell (Chair) RC; Mark Heffernan (Managing Director, Wessex SDE) MH; Lindsay Anderson (Digital Critical Friend) LA; Michael George (Clinical Digital Research Fellow) MG; Keith Gomes Pinto (NHS Dorset) KGP; Will Jennings (Associate Dean Research & Enterprise) WJ; John McBeth (Professor of Health Data Science) JM ; Patricia Fuller (Research Fellow) PF; Sandra Hall (Digital Critical Friend) SH; Sam Fortune (Digital Critical Friend) ; Andy Taylor (Digital Critical Friend) AT; Lisa Ballard LB; Laura Fletcher (Minutes) LF.

Apologies: Heather Case

	Item
1.	**Welcome and Administrative Business** • Chair welcomed attendees to the Wessex SDE Data Access Committee meeting. • Apologies were noted. • A declaration of interest was noted in relation to one of the studies. It had been raised with the Chair in advance of the meeting, and it was agreed that the member concerned would not participate in the recommendation for that study. • The minutes of the previous meeting (Paper A) were approved. The Chair noted a paper circulated to members regarding the statutory responsibilities and accountability of committees operating within the SDE governance structure. Members were advised that this did not change the operation or remit of the Wessex DAC but clarified that the Committee makes recommendations to the Wessex SDE and the Senior Responsible Owner who have legal accountability for final decisions. It was agreed that the wording used within future Committee minutes would reflect this position.
2.	The Chair presented the SRO review paper following the Committee's consideration of the data intermediary company proposal in June. The review had been undertaken in response to the novelty and complexity of the proposal and questions raised during and following the previous Committee discussions. The review considered the governance arrangements required to support commercial data partnerships whilst maintaining public trust and the Wessex SDE's social licence. **Discussion:** • The Committee reviewed the escalation and review process undertaken with input from relevant SDE and PPIE representatives. Members supported the principle of having a

	transparent route through which concerns arising from DAC consideration could be escalated and reviewed. • The review identified four areas requiring further clarification, including the establishment of a value return framework for commercial partnerships, clarification of the relationships between different Data Access Committees, further consideration of social licence through PPIE, and appropriate governance arrangements for future commercial relationships. • Members discussed the respective roles of the Wessex DAC and data intermediary DAC's. It was clarified that, any proposed use of data accessed through the Wessex SDE would return to the Wessex DAC for consideration as the Wessex SDE governance process retains primacy over access to data held within the Wessex SDE. • Members were advised that the data sharing agreement had not yet been signed and that recommendations from the review would be used to inform this and managed as per usual contract management processes. • The Committee recognised the value of commercial partnerships and data intermediaries and noted that these should operate within governance arrangements that enable the NHS to retain appropriate oversight of the use of data and provide transparency regarding the public benefit and value return to the NHS. This reflected the recommendations contained within the SRO review paper. The Committee agreed that the escalation and review process had been appropriate and supported the recommendations contained within the SRO review. Members noted that the final report would be share with the SRO and Wessex SDE Programme Board **Actions:** 1. The Chair to share report with SRO and Wessex SDE Programme Board. 2. The review recommendations to inform ongoing contractual and governance discussions.
3.	**Study 1: Chronic Pain as a Perioperative Risk Phenotype: Independent Risk Marker or Identifiable Indicator of Biopsychosocial Vulnerability** The Committee considered a study examining whether pre-existing chronic pain is independently associated with poorer outcomes following surgery or whether it acts as an indicator of wider biopsychosocial vulnerability. The study will compare surgical outcomes in patients with and without chronic pain by linking existing postoperative outcome data with Hospital Episode Statistics and information collected through the perioperative assessment questionnaire. **Discussion:** • The Committee noted that the study would use an existing postoperative outcomes dataset held within the Wessex SDE and link this with information relating to hospital admission, readmission, mortality, and self-reported chronic pain. • Members considered the use of information provided through patient reported pre-operative questionnaires. The committee discussed if some patients with complex medical histories may find these questionnaires difficult to complete and there was potential for relevant information to be omitted or not fully captured. • The Committee discussed the importance of data quality, including the completeness and accuracy of information collected and the methods used by researchers to account for

	limitations within the underlying data. It was recognised that consideration of these issues formed part of the research methodology. • Members recognised the relevance of the research question and the potential value of improving understanding of the relationship between chronic pain and outcomes following surgery. **Recommendation: Approved**
4.	**Study 2: Identifying Hidden Respiratory Risk and Unmet Care Needs in People with Learning Disabilities: A Comparative Linked Hospital Data Study in Wessex** The Committee considered a study aiming to improve understanding of respiratory health in people with learning disabilities by identifying individuals at higher risk, examining patterns of hospital use and exploring potential gaps in recognition and care. The study will use routinely collected secondary care data held within the Wessex SDE, including Hospital Episode Statistics and the CARDS dataset, to compare respiratory-related outcomes between adults with and without learning disabilities. The work is intended as an initial pilot, with the potential for future linkage with primary care data. **Discussion:** • Members discussed the proposed project timeframe. It was clarified that the Data Access Scheme provides access to the SDE for 12 months, with an expectation that analysis and subsequent dissemination activity would normally be completed within an overall 12–18-month period. • The Committee discussed patient and public involvement and engagement, particularly given that the study includes people with learning disabilities. Members noted the importance of ensuring that this population is appropriately represented and that engagement is accessible and meaningful. The Committee considered this an area that the research team should continue to develop as the study progresses. • Members discussed the quality and consistency of diagnostic coding used to identify people with learning disabilities. Attention was drawn to the potential difficulty of distinguishing between learning disability and neurodivergence within some hospital records and the effect this could have on cohort identification and analysis. • It was clarified that the initial study would use University Hospital Southampton data currently available within the Wessex SDE. Although the applicant is based at Bournemouth University, University Hospitals Dorset data are not included at this stage. Members noted that the work would provide a basis for future regional participation • Members recognised the potential public benefit of the study, particularly in relation to identifying health inequalities, unmet need, and opportunities to improve respiratory care for people with learning disabilities. • The Committee also noted the opportunity to understand data quality and support future improvements in data collection and care. **Recommendation: Approve with Observations** Members agreed that the following points should be shared with the research team for wider consideration:

	• further consideration of PPIE, particularly how people with learning disabilities are meaningfully involved. • the limitations and quality of diagnostic coding used to identify learning disability and distinguish this from neurodivergence; and how learning from identified data-quality limitations could be fed back into future data collection and care pathways.
5.	**Study 3: Mental Health Integrated Data Linkage Wessex (MIND-Link Wessex) – Integrating UHS and HIOW for Addiction and Neurodevelopmental Research** The Committee considered a study seeking to establish a pilot linked mental health data resource bringing together existing University Hospital Southampton datasets with specialist mental health data from Hampshire and Isle of Wight Healthcare NHS Foundation Trust. The initial focus will be on alcohol use disorder, gambling-related harm, and attention deficit hyperactivity disorder (ADHD), alongside associated mental and physical health conditions. The study aims to improve understanding of patient pathways, service use and outcomes and establish a reusable linked data resource to support future mental health research across Wessex. **Discussion:** • The Committee discussed the proposed linkage of acute hospital data with specialist mental health data held within the RiO electronic patient record system. It was noted that the project would initially focus on data mapping, governance arrangements, harmonisation and assessment of data and linkage quality before progressing to further analysis. • Members recognised the potential value of bringing together information currently held separately across acute and specialist mental health services to provide a more complete understanding of patient pathways and healthcare use. • The Committee discussed the sensitive nature of mental health data and the importance of maintaining appropriate safeguards when linking and using these data within the SDE. • Members considered the wider public benefit described within the application. While the potential value of developing the linked resource was recognised, it was noted that the application placed considerable emphasis on research infrastructure and service development. Members felt that the direct benefits for patients and the public, including who may benefit, how they may benefit and how findings would be disseminated, could be articulated more clearly. • It was agreed that this should be provided to the research team as an observation for consideration as the project develops. **Recommendation: Approved with Observations** Members agreed that the research team should further consider and clearly articulate the wider patient and public benefit of the work, including how patients may ultimately benefit and how these benefits would be communicated.
6.	**Study 4: Prostate Progress** The Committee considered the next phase of Prostate Progress, a national prostate cancer research programme using real-world clinical and patient-reported data to improve understanding of prostate cancer, treatment pathways, and outcomes. The proposed work will initially use structured clinical data from University Hospital Southampton, with subsequent phases seeking to

	link clinical information with patient-reported outcome measures and explore the use of additional data sources. The project also aims to support future integration of Wessex SDE data within the wider Prostate Progress federated dataset. **Discussion:** • The Committee discussed the proposed use of genomic data and recognised that genomic information can vary in its nature and level of identifiability. Members noted the importance of assessing the specific data requested rather than treating all genomic data in the same way. • The Committee considered genomic data from a social licence perspective, noting that members of the public may regard genomic and other particularly sensitive health information differently from more routinely collected health data. • Members discussed the possibility that analysis of genomic data could identify findings of potential relevance to an individual patient's care. It was clarified that the current regulatory approvals do not permit researchers to re-identify and contact individuals based on research findings. A future amendment to the relevant approvals to address potential re-identification for clinical purposes was noted as planned. • The Committee recognised the potential public benefit of the programme, including its ambition to increase the number of patients contributing data and improve understanding of prostate cancer and patient outcomes. • It was noted that an earlier phase of Prostate Progress had previously been considered by the Committee. Members discussed whether subsequent phases of previously considered studies would always need to return to the DAC, or whether a proportionate approach could be developed for future amendments. It was agreed that this was a useful consideration for the Committee's ongoing work on precedent-setting criteria. • Members discussed whether changes to an existing study should return to the Committee where additional data are introduced. It was suggested that future criteria could distinguish between substantive changes to the research design or significant changes in the nature of the data and more limited amendments involving similar data. **Recommendation: Approved**
7.	**Study 5: Utilisation of Healthcare and Mental Health Services and Exploring Factors Associated with the Development of Cognitive and Mental Ill Health in Survivors of Critical Illness** The Committee considered a study examining the longer-term mental and cognitive health of people who have survived a critical illness. The study aims to use linked health and social care data to identify factors associated with the development or worsening of conditions such as anxiety, depression, post-traumatic stress disorder, and cognitive impairment following critical illness. The research seeks to identify people at greater risk increasing the opportunity for earlier support, and targeted recovery interventions. **Discussion:** • The Committee discussed the proposed linkage of data from acute hospital, mental health, primary care, and local authority services. It was noted that this was the first study considered by the Committee involving the proposed use of local authority social care data,

	and members therefore considered the wider governance and social licence implications in some detail. • It was clarified that the local authority data requested was specific and relevant for the purposes of answering the specified healthcare research question. • Members discussed the sensitivity of social care information and whether members of the public would reasonably expect these data to be linked with health information for research. It was noted that previous public engagement undertaken by the SDE had considered the use of wider data, including social care data, and had identified the importance of clear public benefit and appropriate safeguards. • The Committee recognised the potential benefit of the study, particularly in improving understanding of the mental health and cognitive effects experienced by some patients following intensive care and identifying opportunities for earlier support. • Members noted that social care information can be more subjective than some routinely collected health data and that context may be lost when information is incorporated into a larger linked dataset. The importance of considering this when interpreting the data was highlighted. • The Committee discussed the PPIE undertaken for the study. It was noted that no additional PPIE specific to the study had been completed beyond previous engagement undertaken through the Wessex SDE. Members discussed the importance of meaningful patient and public involvement when considering the social licence for research and noted the value of PPIE being incorporated throughout a study. • Consideration was given to the proposed use of local authority data, with members noting that some types of data may be considered more sensitive by the public. Members felt that further PPIE would provide additional assurance regarding public acceptability of the proposed use and linkage of local authority data. • Members considered whether the study could begin using the health data elements while further PPIE was undertaken in relation to the proposed use of local authority data. **Recommendation: Approval to proceed with Health Data only; Further PPIE Required for Local Authority Data** The Committee recommended that the study could commence using the health data elements of the proposed dataset. Before the proposed local authority data are incorporated, the Committee requested further PPIE to explore public views on the use and linkage of local authority data for this research. The outcome of this work should be brought back to the Committee for further consideration of the local authority data component. **Action:** 3. Further PPIE to be undertaken regarding the proposed use of local authority data, with the outcome returned to the Committee before that element of the study proceeds.
8.	**Study 6: FAIRSTART (Resubmission)** The Committee did not consider Study 6 during the meeting due to time constraints. The FAIRSTART resubmission will be added to the next agenda.

9.	**Precedent and Setting Criteria** Aspects of precedent setting were discussed as part of study 4 deliberations. It was noted that, as the number of studies coming to the Committee increases, there is a need to continue considering how precedent-setting criteria could support a more proportionate and efficient review process.
10.	**Close of meeting** The Chair thanked the Committee for their attendance and contribution to the discussions.