# Wessex Data Access Committee: Minutes

**Date**: Friday 26th June 2026
**Time**: 13:00-15:00
**Location**: Virtual via TEAMS (meeting recorded for training and reflection)

**Chair**: Dr Rachel Chappell
**Secretariat:** Laura Fletcher

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**Present**: Rachel Chappell (Chair) RC; Mark Heffernan (Managing Director, Wessex SDE) MH; Lindsay Anderson (Digital Critical Friend) LA; Patricia Fuller (Research Fellow) PF; Sam Fortune (Digital Critical Friend) SF; 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; Sandra Hall (Digital Critical Friend) SH; Andy Taylor (Digital Critical Friend) AT; Rebecca Wood (Observer) RW; Laura Fletcher (Minutes) LF.

**Apologies:** Heather Case, Nicholas Fuggle.

| | **Item** |
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| **1.** | **Welcome and Administrative Business**<br><br>• Chair welcomed attendees to the Wessex SDE Data Access Committee meeting.<br>• Apologies noted.<br>• No declarations of interest were raised.<br>• Previous minutes (Paper A) were approved.<br><br>The Chair acknowledged a request for clarification on an application ahead of the Committee meeting. Members agreed that requests for clarification should be submitted to the Chair and Committee Secretariat prior to meetings. This would enable clarification to be provided to an individual (or committee), reduce group emails, ensure that responses were coordinated, and provide learning for future paper preparation. The Committee supported this approach.<br><br>The Chair noted ongoing national alignment of DAC paperwork. In the interim, local improvements could be made to DAC paperwork, including clearer version control of supplementary papers, consistent study titles and reference numbers across all supporting documents, and data flow diagrams. Members welcomed these improvements.<br><br>**Actions:**<br><br>1. Future clarification questions to be submitted to the Chair and Committee Secretariat in advance of meetings.<br>2. The operational team to continue reviewing and standardising DAC paperwork. |

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| **2.** | **Study 1: (Resubmission): REAL DERM**<br><br>The Committee considered the resubmission of the REAL DERM application noting the clarification papers and data flow diagram. REAL DERM is a real-world data validation study for a NICE approved tool used in the diagnosis of skin cancers.<br><br>**Discussion**<br><br>• Members agreed that the additional information significantly improved understanding of the overall scope of the study.<br>• The data flow diagram clearly demonstrated the movement of data throughout the study pathway addressing questions raised at the previous meeting.<br>• Clarification was provided regarding the rationale for inclusion of referral information and how this would support the proposed evaluation.<br>• Members were satisfied that the revised documentation clearly explained the purpose of the dataset and how the information would be processed within the Wessex SDE.<br><br>**Decision: Approved** |
| **3.** | **Study 2: (Resubmission): The Arcturis Real -World Data Network Research Database**<br><br>The Committee considered the resubmission of the Arcturis Real-World Data Network Research Database noting the clarification papers and data flow diagram. The application sought approval for Hampshire Hospitals NHS Foundation Trust data to be hosted within the Wessex SDE to establish a research database for future studies. Arcturus is a commercial data intermediary working with Hampshire Hospitals to curate cancer datasets for research. The company bring additional data expertise and funding to the NHS with the ambition of improving cancer care.<br><br>**Discussion**<br><br>• Members agreed that the additional clarification paper and revised data flow diagram provided significantly greater clarity and addressed the questions raised at the previous meeting.<br>• Members suggested that future applications should include a summary of documentation reviewed during the operational pre-check process to provide additional assurance and context for Committee members.<br>• Clarification was provided noting that Hampshire Hospitals NHS Foundation Trust would remain the Data Controller for the source data, with University Hospital Southampton NHS Foundation Trust acting as Lead Data Controller whilst the data was hosted within the Wessex SDE.<br>• The members noted that Arcturis has independent HRA CAG and REC approval for this study and the HRA recommended that they work with an SDE where possible.<br>• Members were advised that data would be pseudonymised at source and that no identifiable data would be transferred from Hampshire Hospitals NHS Foundation Trust into the Wessex SDE. All outputs would be aggregated and subject to the established SDE disclosure control processes prior to release. |

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| | • The committee explored safeguards and ongoing engagement, including updates on future research outputs and involvement of PPIE/comms teams. It was noted that Arcturis have offered to provide updates to the SDE on the use of the data.<br>• The Chair confirmed that all data sharing agreements, contracts, legal and commercial agreements will all be put in place post DAC following usual process.<br>• Committee discussed and agreed that this was an appropriate place for discussion of the use of Wessex SDE infrastructure for studies that have their own HRA approvals.<br>• Members highlighted the importance of maintaining transparency, public confidence, and clear public benefit where NHS data is used to support commercially sponsored research.<br>• It was recognised that hosting the research within the Wessex SDE would provide greater oversight of data curation, analytical methodology and disclosure controls than if undertaken elsewhere under the existing approvals.<br><br>**Decision: Approved by majority vote**<br><br>**Action:**<br><br>3, Future DAC applications should include a summary of governance documentation reviewed during the operational pre-check process, where appropriate. |
| **4.** | **Study 3: FOCUS**<br><br>The Committee considered the FOCUS-NHS (Framework for monitoring and improving Clinical Use of biosimilars across the NHS) application, which seeks approval to establish the initial data infrastructure within the Wessex SDE to support future research into Multiple Sclerosis and neuroinflammatory diseases. The study will securely transfer routine Multiple Sclerosis clinical data from Cambridge University Hospitals NHS Foundation Trust into the Wessex SDE. There will be no external data linkage or multi-site data flows at this stage.<br><br>**Discussion**<br><br>• Members were advised that approximately 3,000 patient records would be transferred during the first phase of the project, of which around 1,800 patients had already provided consent. The remaining records would be included under the Wessex SDE's existing CAG and Research Ethics approvals.<br>• It was confirmed that identifiable data would be received by Wessex SDE where it will be processed and pseudonymised before being made available to the named research team in a separate SDE workspace.<br>• Members discussed the phased approach to onboarding participating organisations and noted that approval at this stage related only to data originating from Cambridge University Hospitals. Future phases would be managed separately as additional organisations joined the register.<br>• The Committee was satisfied that the proposed governance arrangements, consent model, and data handling processes were appropriate for the scope of the application. |

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| | • Members welcomed the opportunity for Wessex SDE to host a national research resource and recognised the potential benefits this could provide for future Multiple Sclerosis research.<br><br>**Decision: Approved** |
| **5.** | **Study 4: FAIRSTART**<br><br>The Committee considered the FAIRSTART (Framework for Analysing Integrated Records to Support healthy Transitions and Reduce inequalities) application, which seeks approval to establish a linked maternal-child research dataset within the Wessex SDE. The study will link maternity records from University Hospital Southampton NHS Foundation Trust with child health records held by Hampshire and Isle of Wight Healthcare NHS Foundation Trust to investigate how pregnancy and early-life factors influence children's long-term health outcomes. The research aims to improve early identification of risk and support preventative interventions to reduce health inequalities.<br><br>**Discussion**<br><br>• Members received an overview of the proposed data linkage between UHS maternity data and the Hampshire and Isle of Wight Child Health Information System.<br>• It was explained that the current application relates solely to the linkage of these NHS datasets within the Wessex SDE.<br>• Members discussed the anticipated public benefit of creating a linked maternal and child dataset to support research into factors influencing pregnancy, birth, and childhood outcomes. Clarification was provided that, whilst there is a future ambition to incorporate additional datasets, including Southampton City Council data, this does not form part of the current application and would require separate approvals before any further linkage could take place.<br><br>**Decision: Approved** |
| **6.** | **Study 5: SUNDAE**<br><br>The Committee considered the Southampton DXA and Bone Health Study (SUNDAE) application, which seeks approval to establish a longitudinal bone health research dataset within the Wessex SDE. The proposed study will recruit patients attending DXA scanning services at University Hospital Southampton and link DXA findings with routinely collected clinical information and patient-reported data to support future research into osteoporosis, fracture risk, and bone health. The application relates to the initial build phase of the research dataset.<br><br>**Discussion**<br><br>• Clarification was provided regarding the proposed data linkage, research methodology and the use of routinely collected NHS data within the Secure Data Environment.<br>• Members discussed the proportionality of the requested data and were satisfied that the information requested was appropriate to meet the study objectives. |

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| | • The Committee noted that the research would link routinely collected clinical information, DXA findings and patient-reported data to improve understanding of osteoporosis, fracture risk, and bone health, supporting future musculoskeletal research.<br>• It was confirmed that all data would remain within the Wessex SDE throughout the study and that disclosure controls would continue to apply to all outputs prior to release.<br>• The Committee agreed that the application demonstrated a clear public benefit and that the proposed governance arrangements were appropriate.<br><br>**Decision: Approved** |
| **7.** | **Precedent and Setting Criteria**<br><br>The Chair reminded members of the previous Precedent Setting Paper and invited reflection on the studies presented today to consider whether there were any emerging themes to support future decision-making. The Chair noted that, as the Committee has become more experienced, it is well placed to consider precedent principles. Whilst no changes were proposed at this stage, members agreed this may be a useful approach to consider as application volumes increase.<br><br>**Discussion**<br><br>• Members suggested that applications involving commercial organisations should continue to receive detailed scrutiny, recognising that these are likely to attract greater public interest and require careful consideration of public benefit.<br>• The Committee noted that applications which introduce new governance arrangements or represent a novel use of data should continue to be reviewed in full before any precedent is established.<br>• Members recognised that many future applications are likely to follow similar patterns, particularly pathway studies and research using established datasets. It was suggested that identifying similarities between applications could help streamline future Committee discussions whilst maintaining appropriate governance oversight.<br>• It was agreed that a short discussion on precedent setting would be included at the end of future meetings to support the continued development of the Committee's approach. |
| **8.** | **Close of meeting**<br><br>The Chair thanked the Committee for their attendance and contribution to the discussions. |