

Wessex Data Access Committee: Minutes

Date: Friday 29th August 2025
Time: 13:00-15:00
Location: Virtual via TEAMS (meeting recorded for training and reflection)

Chair: Dr Rachel Chappell
Secretariat: Rebecca Wood

Present:

Rachel Chappell (Chair) RC; Keith Gomes Pinto (NHS Dorset) KGP; Will Jennings (Associate Dean Research & Enterprise, UoS) WJ; Nicholas Fuggle (Associate Professor in Rheumatology, UoS) NMF; Patricia Fuller (Research Fellow, NIHR ARC Wessex) PF; Andy Taylor (DCF) AT; Sam Fortune (DCF) SF; Sandra Hall (DCF) SH; Lindsay Anderson (DCF) LA; Mark Heffernan (Director of Operations, Wessex SDE: Presenter) MH; Rebecca Wood (Minutes) RW.

Apologies: John McBeth, Heather Case, Michael George

	Item
1.	<p>Welcome and Administrative Business</p> <ul style="list-style-type: none"> • Chair welcomed attendees to the Wessex SDE Data Access Committee meeting. • Apologies acknowledged. • No declaration of interest raised. • Previous minutes (Paper A) agreed. • Outstanding actions identified from the previous minutes. • Chair reminded members to provide information to contribute to the DAC Committee presence on the SDE website. • Chair shared a brief reminder of the DAC’s social license.
2.	<p>Study 1: Routes to Diagnosis and Delay to Diagnosis in Neuroendocrine Neoplasia (NEN) and Factors Affecting NEN Incidence and Survival in Wessex SDE Phase 1.</p> <p>MH Presented an overview of the study and shared slides.</p> <p>Study led by researcher from Hampshire Hospitals around endocrine tumour research. The required data sets from NHSE will be pseudonymised at source and brought to the Wessex SDE. This project has no independent funding however the SDE will fund in recognition that:</p> <ul style="list-style-type: none"> • This will be the first researcher from outside of Southampton Hospital to come into the Wessex SDE.

	<ul style="list-style-type: none"> • The SDE will be acknowledged on research papers. <p>Discussion:</p> <ul style="list-style-type: none"> • Importance of output checking and suppression of low-number results with risk of re-identification due to sample size. • The DARF document for this study had blank sections, it is unclear if they were they missed or not applicable to the study. • Inclusion of GMC numbers and implications for clinician privacy. • General support for the study and its alignment with SDE goals. <p>Action1: In future all sections of the DARF will be completed and marked as not applicable or no information available to ensure committee members are aware this has not been missed.</p> <p>Decision: Approved with two recommendations (if the recommendations cannot be met, the study should return to the Wessex DAC):</p> <ol style="list-style-type: none"> 1. Enhanced scrutiny on output checking due to low number suppression. 2. Wider check of identifiable data including a review of relevance of identifiable clinician data (GMC numbers).
<p>3.</p>	<p>Comfort break</p>
<p>4.</p>	<p>Federated Data Platform (FDP)</p> <p>MH shared information on the FDP.</p> <p>The FDP was developed by NHS England in partnership with Palantir, originally known for rapidly deploying the COVID app during the pandemic. The aim of the FDP was to create a unified, standardized clinical data model across NHS trusts. The FDP may become a valuable data source for SDEs, but does not replace the need for SDEs, especially for research and handling complex data types.</p>
<p>5.</p>	<p>SDE Driver Projects</p> <p>MH presented an overview of SDE driver projects, and two studies awarded to the Wessex SDE.</p> <p>SDE driver projects are special initiatives periodically funded by NHS England that go beyond the standard funding received by SDEs. Their purpose is to drive innovation and progress across the network by:</p>

- Proving out new concepts or technologies
- Enabling collaboration between different SDEs
- Integrating new data sources
- Doing something novel that hasn't been done before

In the latest funding round, Wessex SDE was successful in securing two driver projects. Studies related to these projects will come to the DAC.

1. Connect-D (Dementia Driver Phase 2)

Establishing the UK's first federated dementia data system. The objective to create a secure, connected data infrastructure across five NHS SDE's to transform dementia care.

- Service-focussed project with multiple goals
- Driving research and policy through use cases
- Collaboration across multiple stakeholders
- Public and patient involvement is central

2. HPO IBD (Human Phenotype Ontology Driver Project)

Turning clinic letters for IBD patients into life changing insights.

- International collaborations
- AI scans de-identified documents for health signals
- Kick off August 2025 – rollout through 2026
- Empowers decision making

MH presented study updates for projects that have been discussed previously at the Wessex DAC as part of the DAC development discussions.

6. Final Plenary Discussion: Conclusions and Next Steps

- Chair thanked the committee for their attendance and contribution to discussions.
- Chair invited committee members to the SETT Conference on Thursday 16th October at St Marys Stadium everyone will be formally invited shortly if not already.
- Please remember to send apologies: wessexdac@uhs.nhs.uk

7. Close of meeting