NHS

Data for R&D
PROGRAMME

NENC Secure Data Environment

Dr Alan Bagnall

Data for R&D PROGRAMME

NHS

Mandate for change

Delivering a range of ambitions across life sciences, research, and data-driven innovation

NHS Long Term Plan
January 2019

Saving and Improving Lives
March 2021

Life Sciences Vision
July 2021

Genome UK
March 2022

UP TO £260M FOR NHS-LED HEALTHCARE RESEARCH AND TO EXPAND LIFE SCIENCES MANUFACTURING IN THE UK

A review commissioned by the Secretary of State for Health and Social Care

Better, Broader, Safer: Using Health Data for Research and Analysis

April 2022

Department of Health and Social Care
+ Follow

The new health and care data strategy will drive innovation and improve efficiency, including faster treatment & diagnosis for patients, to tackle the Covid backlog.

The health & care data strategy will give millions of patients

Independent report
Commercial clinical trials in the UK: the Lord O'Shaughnessy review - final report
Updated 26 May 2023

Up to £200 million to boost NHS healthcare data research
March 2022

Goldacre review
April 2022

Data Saves Lives Strategy
June 2022

James O'Shaughnessy's Clinical Trials Review
May 2023

Why do we need SDEs?

ICB as Single Region-Wide Data Controller

Single Process

Single Approval

De-risks Individual data controllers

The NENC R&D Data Repository

- A rich, curated, persistent regional R&D data asset

- Underpinned by Section 251 application allowing legal use of data to flow for research

- Reduced workload and complexity for data controllers

- Ability to develop multi-SDE research programs

Achievements

512

512 Hours given since October 23

14 Public members recruited to date

3 PMs at advocates induction

15 Task and Finish groups

13 In-person meetings

3 Evaluation criteria created

14 PM surveys completed

8 Document reviews

4 SDE Strategy Groups/ Prog Board

PPIE involvement topics and issues covered

PEG
Process and test

PEG
Job descriptions

PEG
TOR

Use Case
Evaluation and testing

CAG
CAG response plan

Public messaging
Dentifiable/de-identifiable

Public messaging
Comms T & F

Design Style
Comms T & F

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Data Access Process

- Initial check by project support service
- Check against exclusion criteria
- Check sponsor organisation (eg no insurance, tobacco companies etc)

Does it meet their assessment criteria

- Application scored against criteria
- Is it in the public interest?
- Report on public members on decision made and their reasons
- If public members say no, project goes to DAC but applicant will not be given access

Data access request received by Project Support Service

From online form on hosted SDE website

Initial check

Public member review

Yes

No

Query

Paperwork prepared by Project Support Service

Project support service prepares reports from public members and data contributor queries for the DAC to consider when making their decision

DAC assessment

Yes

No

Researcher notified and data access register updated (website)

Detail check

Detailed check by project support service to ensure applicant has right approvals, technical and legals in place:

- Ethics
- Meets cyber security standards
- Information governance
- Finance
- Data is available

Data contributor notifications sent

Notification sent to all data contributor

- Email sent
- 14 days to return comments, questions, concerns
- Summary of comments, questions, concerns collated by Project Support Service and will be shared with the DAC so they can consider them when they make their decision

14 day cooling off

Data pipeline status

Building a rich, comprehensive regional dataset initially based on statutory data flows:

Acute

SUS – Inpatient

SUS – Outpatient

SUS – Accident & Emergency

Emergency Care Data Set
Maternity Services Data Set

ePrescribing and Medicines Admin

Diagnostic Imaging Dataset

Cancer Waiting Times

Mental Health and Learning Disabilities

Mental Health Services Data Set (covers Hospital, community, Mental Health Act, PROMS, clinical activity)

IAPT - Improving Access to Psychological Therapies

ePrescribing and Medicines Admin

Community

Community Services Data Set

Ambulance

Ambulance Data Set (also local 999/111 flows)

Primary Care

Local Data Flows

Social Care

Client Level Data Set

Additional

Various local Data Flows

End to End Process Overview

01 INITIAL ENQUIRY

Users access the website for guidance and are directed to the NENC SDE mailbox. An enquiry form is shared to gather some high level detail.

ENQUIRY FORM

02 TRIAGE CALL AND FEASIBILITY FORM

After receipt of the form a call is arranged to gather further detail on the project. This is documented in a feasibility form. he request is assessed against pre-defined feasibility criteria. If no funding is in place the team will signpost the user and provide costings for inclusion in any funding bid.

FEASIBILITY FORM

03 REQUEST OUTCOME

Feedback will be provided to the user with one of the following outcomes: Project Accepted, Project Accepted with Conditions, Project Rejected, or Bespoke Support.

USER VALIDATION

04 PROJECT SUPPORT SERVICE (PSS) DATA ACCESS FORM (DAF)

The user will work with the PSS to complete a full DAF. This will include all the necessary information for the DAC to review the application.

DAC APPLICATION FORM

05 SUBMISSION TO DATA ACCESS COMMITTEE (DAC) AND PATIENT EVALTUATION GROUP (PEG)

The DAF will be submitted to the NENC DAC and then PEG for review and recommendation as to if this should proceed.

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05

DATA ACCESS
AGREEMENT SIGN OFF
Research Organisation and ICB to complete a Data Access agreement, Researcher to complete user access form

06

WORKSPACE MOBILISATION AND DATA ANALYSIS
A dedicated workspace will be created and agreed data will be made available to the researcher for analysis to be carried out

07

PROJECT CLOSURE
The project is completed, outputs are reviewed and shared from the workspace. Data is archived and will be deleted following the retention period.

Piloting of forms and user understanding feedback so far

- Positive user feedback

- Information requested via forms has provided sufficient detail for feasibility exercise

- Details provided on these forms have supported the team to assign projected costs.

- Alignment to NHS E requirements and national Data Access Request Form (DARF)

- Further testing ongoing