digitalhealth
REWIRED
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Elizabeth Sapey

Supporting data-driven innovations through secure data environments

University of Birmingham

AI,
DATA AND
ANALYTICS
STAGE

Stage Sponsor: InterSystems Creative data technology

West
Midlands
SECURE DATA
ENVIRONMENT

Part of the
NHS Research Secure Data
Environment Network

NHS

The impact of health inequalities

CHALLENGES

REDUCED LIFE EXPECTANCY

HIGH LEVELS OF POLYPHARMACY

HIGHER RELIANCE ON ACUTE CARE

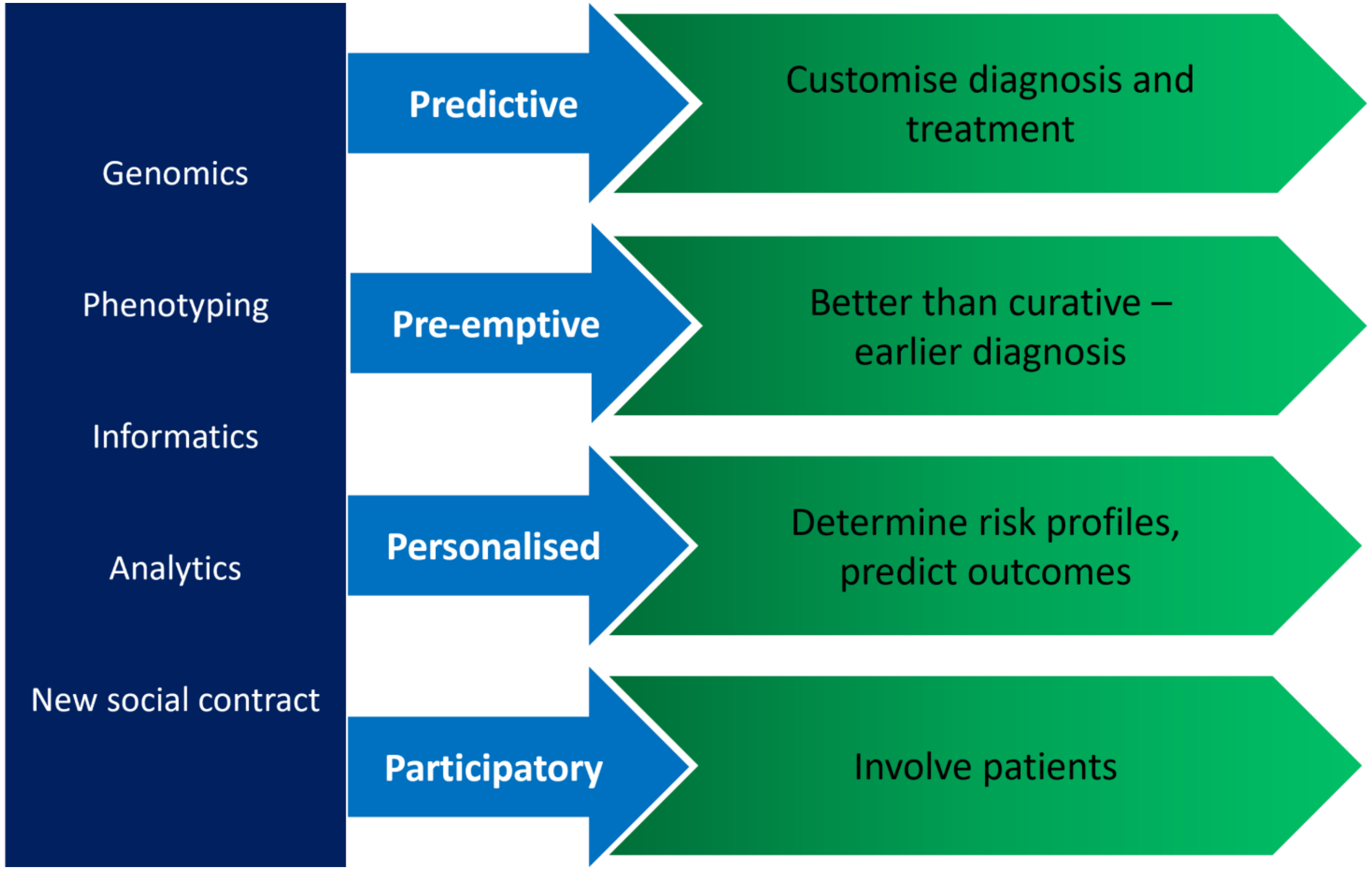
POOR MATERNAL HEALTH OUTCOMES

HIGHER PREVALENCE OF CHRONIC DISEASE

HIGH RATES OF CHILDHOOD ILLNESS

CHALLENGES

"4 P" Medicine approach



Genomics
Phenotyping
Informatics
Analytics
New social contract

Predictive – Customise diagnosis and treatment

Pre-emptive – Better than curative – earlier diagnosis

Personalised – Determine risk profiles, predict outcomes

Participatory – Involve patients

What good looks like

Data silos for research

Twelve SDEs across England

East Midlands SECURE DATA ENVIRONMENT

West Midlands SECURE DATA ENVIRONMENT

Kent, Medway & Sussex SECURE DATA ENVIRONMENT

North West SECURE DATA ENVIRONMENT

Thames Valley & Surrey SECURE DATA ENVIRONMENT

Wessex SECURE DATA ENVIRONMENT

London SECURE DATA ENVIRONMENT

North East and North Cumbria SECURE DATA ENVIRONMENT

East of England SECURE DATA ENVIRONMENT

Connected Yorkshire SECURE DATA ENVIRONMENT

Great Western SECURE DATA ENVIRONMENT

Supporting inclusive research to reduce health inequalities

National SDE: Thematic areas of focus

AI/algorithm development
Testing, training, and validation

Clinical trial activities
Feasibility, recruitment, efficacy, short and long-term trial follow up

Real world studies
Safety, effectiveness, cost effectiveness

Translational research
Discovery and implementation of discovery into practice

Epidemiological studies
Large cohorts for population health research

Health systems research
Evaluation of systems or processes, including operational and applied research

Data use acceptability

Atkin *et al. Research Involvement and Engagement* (2021) 7:40
https://doi.org/10.1186/s40900-021-00281-2

Research Involvement and Engagement

RESEARCH ARTICLE Open Access

Perceptions of anonymised data use and awareness of the NHS data opt-out amongst patients, carers and healthcare staff

C. Atkin[1], B. Crosby[2], K. Dunn[3], G. Price[4], E. Marston[5], C. Crawford[6], M. O'Hara[7], C. Morgan[8], M. Levermore[9,10], S. Gallier[11], S. Modhwadia[12], J. Attwood[13], S. Perks[13], A. K. Denniston[14,15,16], G. Gkoutos[17], R. Dormer[18], A. Rosser[19], A. Ignatowicz[20], H. Fanning[21], E. Sapey[22,23,24]* and On behalf of the PIONEER Data Hub[25]

Abstract

Background: England operates a National Data Opt-Out (NDOO) for the secondary use of confidential health data for research and planning. We hypothesised that public awareness and support for the secondary use of health data and the NDOO would vary by participant demography and healthcare experience. We explored patient/public awareness and perceptions of secondary data use, grouping potential researchers into National Health Service (NHS), academia or commercial. We assessed awareness of the NDOO system amongst patients, carers, healthcare staff and the public. We co-developed recommendations to consider when sharing unconsented health data for research.

Methods: A patient and public engagement program, co-created and including patient and public workshops, questionnaires and discussion groups regarding anonymised health data use.

Results: There were 350 participants in total. Central concerns for health data use included unauthorised data re-use, the potential for discrimination and data sharing without patient benefit. 94% of respondents were happy for their data to be used for NHS research, 85% for academic research and 68% by health companies, but less than 50% for non-healthcare companies and opinions varied with demography and participant group.
Questionnaires showed that knowledge of the NDOO was low, with 32% of all respondents, 53% of all NHS staff and 29% of all patients aware of the NDOO.
Recommendations to guide unconsented secondary health data use included that health data use should benefit patients; data sharing decisions should involve patients/public. That data should remain in close proximity to health services with the principles of data minimisation applied. Further, that there should be transparency in secondary health data use, including publicly available lists of projects, summaries and benefits. Finally, organisations involved

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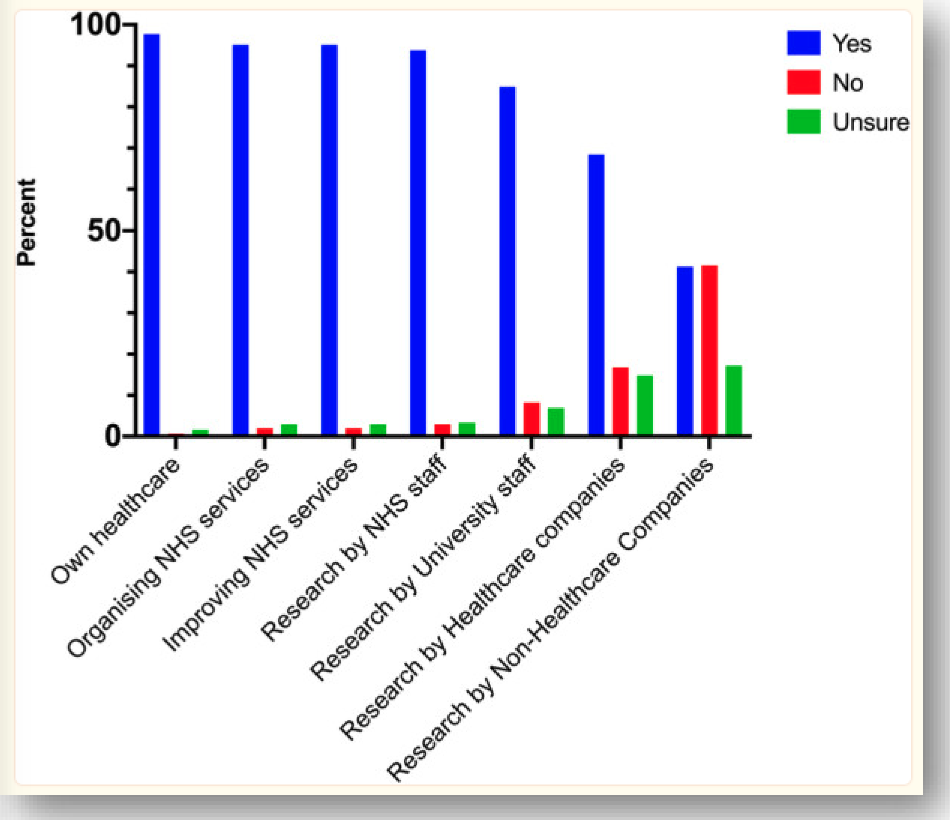
BMC



Acceptability of the use of deidentified health data by purpose

Conclusion

Patients and the public co-developed recommendations for data access activities:

- consider patient benefit
- transparency
- patient/public involvement
- proximity to healthcare services
- benefits to the NHS
- controlled by the NHS
- data minimisation.

Governance and ethics

Co-produced protocol

NHS
Health Research Authority

IRAS application: research database with overarching ethical approvals

Home › About us › Committees and services ›

Confidentiality Advisory Group

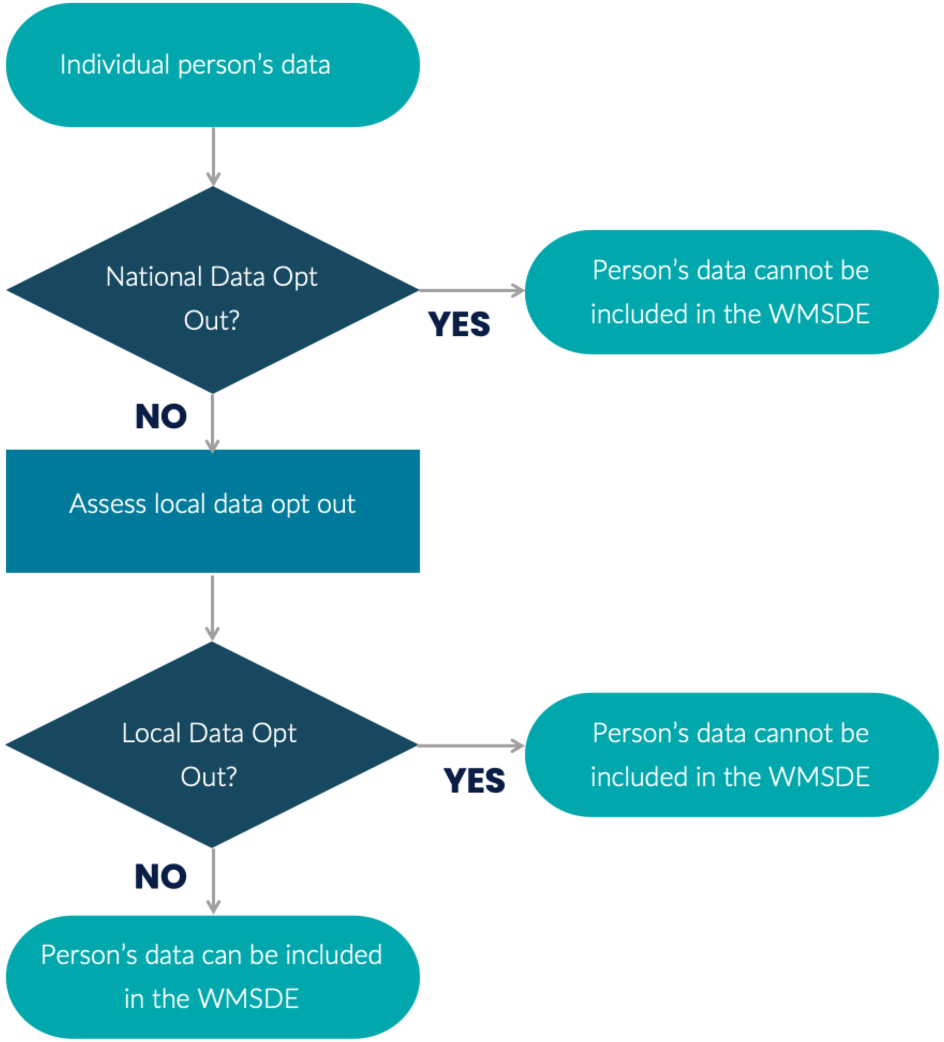
All activities of data preparation for research at local site and SDE

Data Trust Committee

All data sharing decisions are overseen by our patient and public oversight group, called the **Data Trust Committee (DTC)**

- **80%** of the DTC must **support application for access to be granted**
- **40%** BAME representation on the committee
- **17 to >75** age range
- includes people with physical disabilities, people with mental ill-health, carers and people with multiple long-term conditions

National and local opt out



Individual person's data

National Data Opt Out?

YES

Person's data cannot be included in the WMSDE

NO

Assess local data opt out

Local Data Opt Out?

YES

Person's data cannot be included in the WMSDE

NO

Person's data can be included in the WMSDE

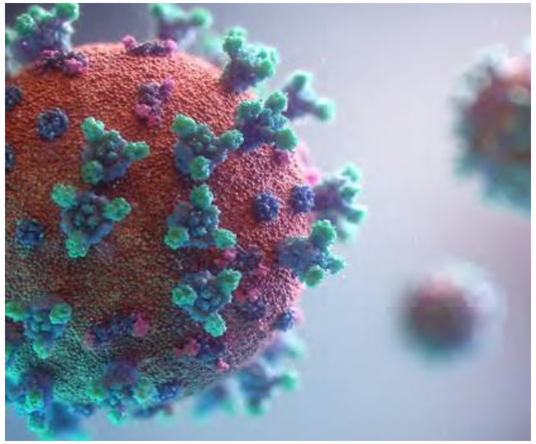
Tested process

PIONEER Health Data Research Hub

- West Midlands SDE processes based on PIONEER, the HDR UK Hub
- Patient and public support for > 90 data requests since 2020
- DTC model developed in PIONEER and now used in other centres across the UK

- In PIONEER, data safely accessed by > 350 analysts across the world
- Data licensing agreements with > 30 organisations
- Worked with SME, large industry, academic, public and charitable sector as well as NHS organisations

- PIONEER work has led to > 24 publications
- Supported > £35M funding awards



- Changed care pathways and improved choices and outcomes for people
- Worked with NHS organisations across the country
- Trained NHS staff to use data to improve care