Safe Havens

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“"routine data" is data collected as byproducts of clinical care by the clinician and as an integral part of the process of care.”

Williams JG, BMJ 1995;310;665-666

Secondary data : collected by someone else then used by researcher
What is data linkage?

The process where two or more pieces of information from different sources can be linked together to produce new insights.

- BMI and maternity – insight into child health
- Smoking legislation and reduction in childhood asthma
- Effects of benefits changes on mental health
Collect Data Once, Use It Often

Sources
- Hospitals
- Community Care
- Administrative
- Apps & wearables
- GP
- Social
- Environment
- Cohort Studies

Uses
- Gathering evidence to inform and evaluate health and social care policy, practice and guidelines
- Discovering causes of diseases
- Studying the effectiveness of drugs in real-world populations

Benefits
- Improving public health
- Precision Medicine: The right treatment, the right person, the right time
- Facilitating the development of new drugs, devices and technologies

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Scottish Safe Havens
From birth to death...

Potential data for linkage:
- Health Care Data: Hospital, Primary Care, Laboratory, Imaging, Prescribing
- Social Care Data for older people: Registration of death

Existing collections:
- 1939 register - occupation
- Pre & neo-natal exams
- Health Visitor
- Education
- Scottish Mental Survey 1932 & 1947 - IQ

Growing Up In Scotland:
- Neo-natal & Maternal Databank

Disease Registries for:
- Multiple sclerosis
- Asthma
- Chronic kidney disease
- Parkinsons
- Arthritis

Scottish Longitudinal Study:
- Census – employment, household, chronic illness etc.
- Education
- Hospital episodes
- Vital events – births, deaths and marriages
Join up data for better decisions: Guiding Principles for Data Linkage
http://www.scotland.gov.uk/Publications/2012/11/9015
Cancer Registry
Hospital Admissions
Births & Deaths
Outpatients
Maternal & Birth records
Disease Registries
GP (LES & Keep Well)
Rheumatology
Parkinsons Disease
Prescribing
Population Register
PsyCIS
Weight Management
SERPR – Renal Dialysis
Accident & Emergency / OOHs
Disease Registries
Heart Failure
Passmanns Disease
Outpatients
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Local Datasets
Governance approvals from clinical dataset to research extract

- NHS Clinical dataset
- Safe Haven dataset
- Approved research extract
- Caldicott / LPAC approval
- Data Access Committee / Data Controller approval

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Disclosure

Disclosure occurs when information released reveals the identity or information about a respondent not already in the public domain.

Statistical Disclosure Control

Assessing the risk of disclosure from a potential release and taking measures, if appropriate, to lower that risk by modifying the data, changing the design of the statistic, or a combination of these.

(Office of National Statistics, 2006)
Epidemiology

- Identify patients with specific disease or taking a specific treatment
- Use hospitalisations and death data to build-up clinical histories and investigate outcomes

Support other research methods
- Cross-sectoral linkage
- Act as sampling frame for qualitative studies

Support clinical trials
- Support feasibility studies and patient recruitment
- Passive follow-up of subjects: cheaper, maximises follow-up

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Patterns of AB by eColi sequence on presentation

Outcomes by eColi sequence

Standard Datasets:
• Hospitalisation, Labs, Prescriptions, Death
  eColi sequenced data

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P < 0.05

Sample
Genetics
+ AB
Exposure
+ AMR
+ Medical History
Thank You

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http://www.gla.ac.uk/researchinstitutes/healthwellbeing/research/robertsoncentreforbiostatistics/

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