Trusted Research Environment

Provided by
Health Informatics Centre
Electronic Medical Data Coverage

Geographic - Tayside And Fife

Population of Scotland

Time Period 1972 - 2016

20%
A “Lifetime” of Phenotypic Data

Health Care Data

- **Primary Care**: Community Prescribing
- **Secondary Care**: Out Patient Visits, Hospital Admissions, Accident & Emergency, Cancer Register, Psychiatric Episodes.
- **Diagnostics**: Radiology Events, Cardiology & Vascular Labs, Bowel Screening
- **Laboratory**: Biochemistry, Haematology, Immunology, Microbiology, Virology
- **Diabetes Surveillance**: BP, BMI, Smoking Alcohol, Amputations, Ulcers
- **Diabetic Retinal Images**: DRS Retinopathy Image Library (Go DARTS Population)
- **Radiology Images**: MRI, CT, US, X-Ray

Data For Linkage

- **SMR02**: Maternity & Neonate
- **Child Health Pre-School/School**: SIRS/CHSP
- **Register Of Deaths

Parents Conception Birth Early Life Childhood Adulthood Late Life Death

Existing Research Studies

- **Walker**: 48,00 Births (1952-1966)

Research Datasets

- GoDARTS Diabetes – 18K - Case/Controls
- TASC FORCE – 5000 - MRA Volunteers
- POPADAD – 1200 - Diabetes with no CVD
- TRACE RA – 3200 - Rheumatoid Arthritis/UK

Pre-consented Cohorts

- SHARE – 144K+
- Generation Scotland – 20K

Disease Registers

- TARDIS Respiratory Disease
- SDCRN – Scottish Dementia Network
- SCI Diabetes
- Epilepsy
Data Linkage Across The Generations

Walker Dataset
1952 – 66
48,000
Dundee Births

- 1952 – Births and Neonatal Record
- 1986 - Acute Hospital Admission Tayside
- 1986 - Laboratory (Biochemistry, Haematology, Immunology, Microbiology)
- 1990 – Diabetes Records
- 1994 - Radiology Records
- 1994 - Cancer Register
- 2004 - Community Prescribing (Dispensed)

Babies
Mothers
Fathers

Cohort participants episodes recorded in dataset
Study Feasibility Searches
Feasibility Searches (\& Cohort Identification)

Cohort Search Criteria

Inclusion:

✓ Health Board : Tayside
✓ Status : Alive
✓ Conditions : Type 2 Diabetes
✓ Age: >= 65
✓ Prescribed : Insulin > 2yrs

Exclude:

✗ Prescribed: Statins

Status: • Alive
Age: • >= 65
Condition(s): • Type 2 Diabetes
Prescribed: • Insulin > 2yrs & NOT Taking Statins

Matches

570K
450K
120K
70K
9210

Group of Interest
Data Linkage
Research Data Management

Data Repository Management

Data Acquisition

Data Linkage & Extracts

Data Curation

Regular Updates

Customer Relationship Mgt

Enforcing Data Governance

Status:
• Alive

Age:
• >= 65

Condition(s):
• Type 2 Diabetes

Prescribe d:
• Insulin > 2yrs & NOT Taking Statins

Study Feasibility Searches

Accredited Safe Haven

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Cohort Definition

CHI – Community Health Index

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Data Linkage - Joining the “dots”

Specialist Biobanks

eHEALTH Records

Public Records

Research Datasets

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Health Informatics Centre

dundee.ac.uk/hic
Research Data Management Platform (RDMP)
‘Optimizing and Augmenting the Research Data Supply Chain`
Over £1 million invested in a new Research Data Management Platform
And Upgraded Safe Haven Environment
Case Study # 1
β blockers : Their Effect in Managing Chronic Obstructive Pulmonary Disease (COPD)

Setting Tayside, Scotland (2001–2010)
Population 5977 patients aged >50 years with a diagnosis of COPD.

There was a 22% overall reduction in all cause mortality with β blocker use.
Case Study #2: Tamoxifen adherence: Relationship to Mortality in Women with Breast Cancer

More than 400 lives are being lost each year because breast cancer patients fail to take the full course of the drug Tamoxifen due to "intolerable" side-effects.

Patient Contact And Recruitment
Patient Recruitment to Study Completion

Identify → Contact → Track recruitment process

Recruitment

Data entry and Validation of paper based data →

Follow-up

Data Linkage – Enrich study data with routinely collected eRecords study follow-up

eForms & Paper Forms for Surveys and CRFs data capture

Electronic Clinical Data Record

Secure Access for Data Analysis

Health Informatics Centre
Software Development
Applications Tailored To Improve Your Research

- Secure web-hosting and Data Collection
- Electronic Forms Development
  - Study Questionnaires, CRFs
  - Web-based or ePaper
- Bioresource & Disease Registries
- Study Recruitment Management
- Randomisation for Clinical Trials
- Sophisticated Probabilistic Matching
  - Indexing non-medical data
- NHS Network Hosting
Data Entry
Governance Approval
Data Governance

Services Available:
✓ Liaise with National & Local Data Governance
✓ Project Data Governance Audits
✓ Data Governance Advice
✓ Approval Application Vetting
✓ Governance Applications for New Datasets

Clinical Datasets
• Research Datasets
• Case Note Reviews

Governance Approval

Research project specific
de-identified Data extracts

Accredited Safe Haven

Data Informatics Centre
Accredited Safe Haven
Scotland’s Only ISO27001 Certified Trusted Research Environment

Analytics Software Library:
- R
- SAS
- STATA
- SPSS
- MS Office
- Matlab

Virtual Windows Clients

Resilient Infrastructure:
- High-Availability Storage
- Redundant Power
- Daily Backups

Secure Access Controls:
- Firewall
- HTTPS Connection
- Password Protection

Data User Access-from-anywhere:
- 24x7 via Internet

De-identified Data Extracts

NHS Tayside

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