Trusted Research Environment

Provided by
Health Informatics Centre
Electronic Medical Data Coverage

Geographic - Tayside And Fife

Population of Scotland

Time Period 1972 - 2016

Health Informatics Centre
Phenotypic Data Available

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)

**Data For Linkage**

- **Parents**
- **Conception**
- **Birth**
- **Early Life**
- **Childhood**
- **Adulthood**
- **Late Life**
- **Death**

**Pre-consented Cohorts**
- **SHARE**: 100+K
- **Generation Scotland**: 20K

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

**Disease Registers**
- TARDIS Respiratory Disease
- SDCRN – Scottish Dementia Network
- SCI Diabetes
- Epilepsy

**Existing Research Studies**

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

**Walker**
48,00 Births (1952-1966)
Data Linkage Across The Generations

Babies
Mothers
Fathers

Walker Dataset
1952 – 66
48,000
Dundee Births

1952
• Cohort participants episodes recorded in dataset

1975 - Births and Neonatal Record

1986 - Acute Hospital Admission Tayside

1980 – Cancer Register

1986 - Laboratory (Biochemistry, Haematology, Immunology, Microbiology)

1984 - Community Prescribing

1990 – Diabetes Records

1994 - Radiology Records

2004 - Community Prescribing (Dispensed)

Health Informatics Centre
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

Group of Interest

Tayside Population

Status:
- Alive

Age:
- >= 65

Condition(s):
- Type 2 Diabetes

Prescribed:
- Insulin > 2yrs & NOT Taking Statins

Matches:
- 570K
- 450K
- 120K
- 70K
- 9210
Data Linkage - Joining the “dots”

Cohort Definition

CHI – Community Health Index

Specialist Biobanks

GoDARTS

GoSHARE

eHEALTH Records

Routine Phenotype Data

Scottish Diabetes Register

Prescribing

Demographic History

Routine Phenotype Data

SMRXX

Specialists Data Types

PACS Data

Genomic

Specialist Biobanks

Prescribed:

• Insulin > 2 yrs

• Not Taking Statins

Age:

• >= 65

Condition(s):

• Type 2 Diabetes

Data Linkage - Joining the “dots”

Health Informatics Centre

CHI – Community Health Index

Health Informatics Centre

dundee.ac.uk/hic
Patient Recruitment to Study Completion

**Identify** → **Contact** → **Track recruitment process**

- **Data entry and Validation** of paper based data
- **Data Linkage** – Enrich study data with routinely collected eRecords study follow-up
- **eForms & Paper Forms** for Surveys and CRFs data capture

**Follow-up**
- **Secure Access for Data Analysis**

**Recruitment**
- Patient Contact and Recruitment

**Health Informatics Centre**

[dundee.ac.uk/hic](dundee.ac.uk/hic)

[University of Dundee](http://www.dundee.ac.uk)
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
Project-specific data entry.
  Adding missing data, e.g. CHI numbers, GP directions/dates to prescribing dataset for individual study cohort.
  Patient paper record review and data entry.
  Entering of study questionnaire results.

Clerical support to studies.
  Processing mail-outs to potential study participants.
  Project paper scanning and shredding, e.g. consent forms.
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

Health Informatics Centre
ISO27001 Certified Trusted Research Environment

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

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

Virtual Windows Clients

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

De-identified Data Extracts

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

NHS Tayside

Data Linkage

Health Informatics Centre