Building a dynamic functional clinical data warehouse (CDW) for personalised health care - lessons from the Individualised Screening for Diabetic Retinopathy (ISDR) study

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Introduction

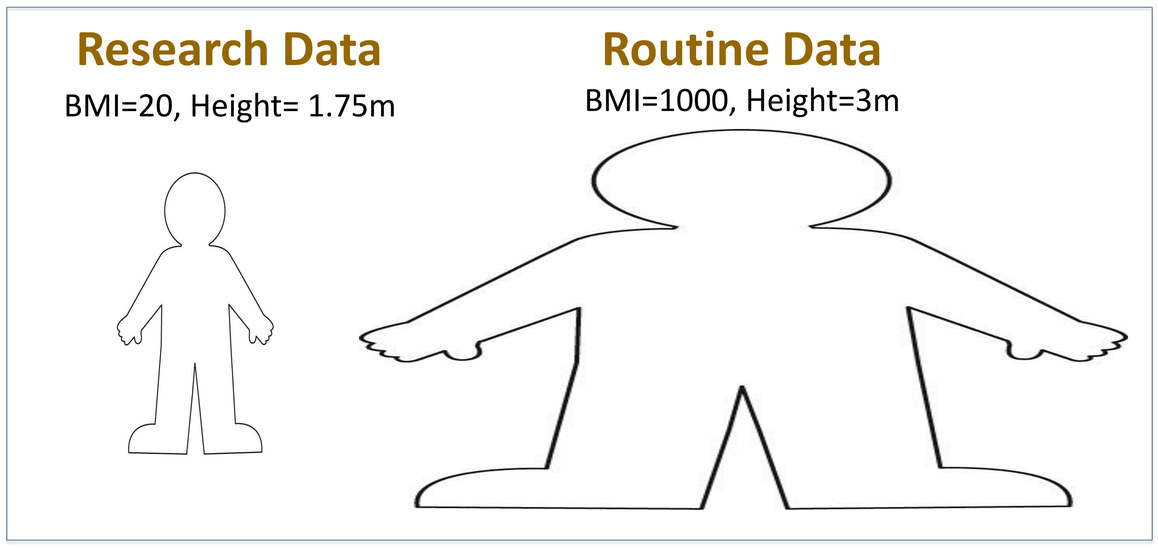
A traditional CDW sits in a research environment and contains static data only

For personalised health care a CDW needs to be

- able to handle large scale routinely collected clinical data
- capable of interacting with live NHS databases

Aim

To develop a routine data management system suitable for the successful implementation of personalised health care in the NHS with clinical data query management, automation and secure data exchange

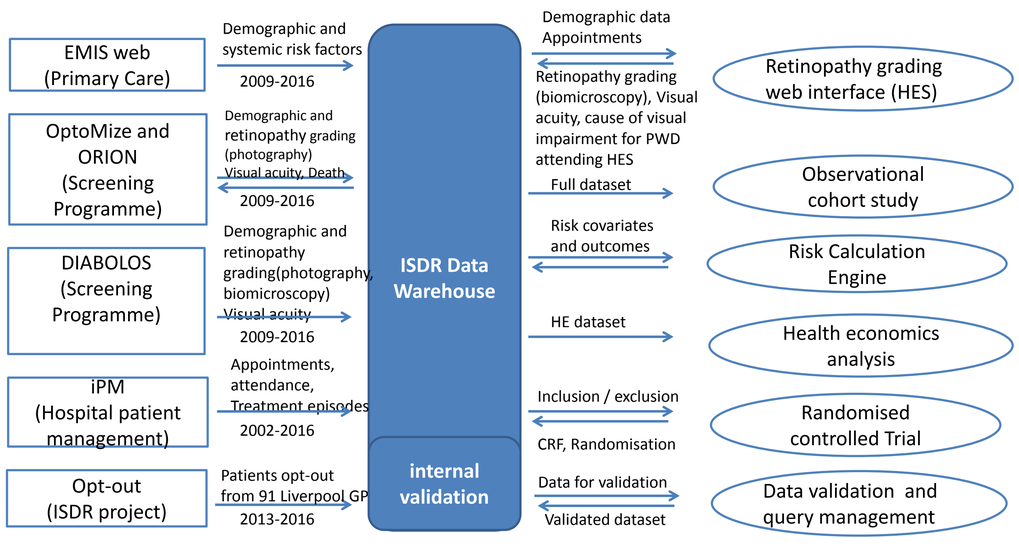


Methods

The ISDR CDW imports and processes routinely collected NHS data from 5 external sources. Key functionalities include:

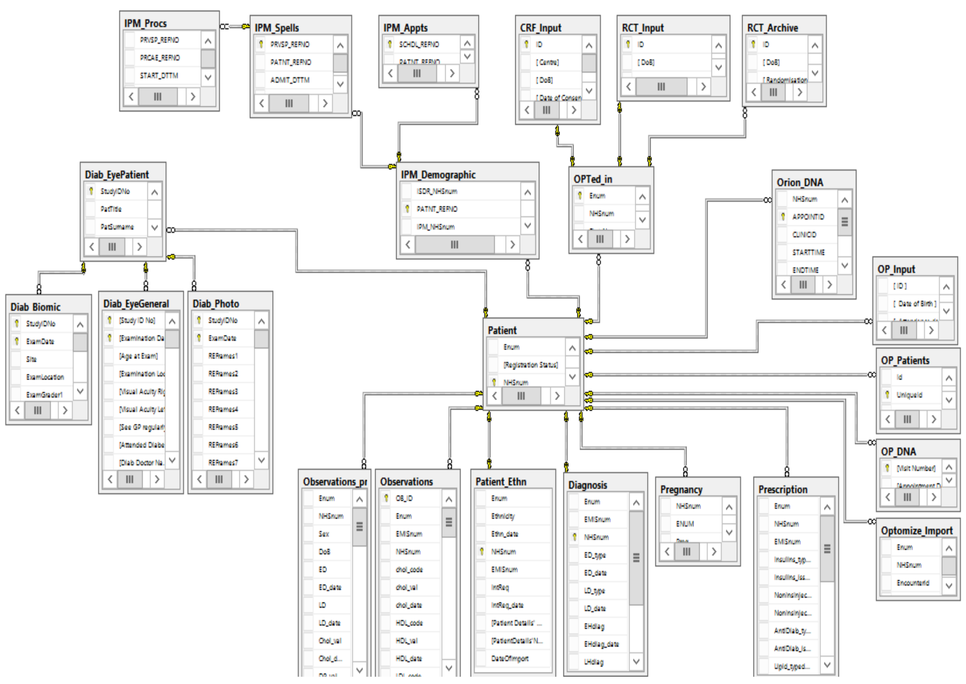
- Stores and links primary and secondary care NHS data from multiple sources
- Data cleaning, validation, query management
- Generate data outputs on demand
- Automated data exchange with multiple platforms
- Supports large scale observational cohort study
- Supports clinical decision making

ISDR Data Warehouse Data Flow



Results

- Data from 2009 on 22,623 patients - 9.08×10^{10} data fields
- 15 data schema specifying input and output data
- Credibility checks + basic cleaning using logic rules and MATLAB
- Import/export on demand using SQL Server Integration Services (SSIS)
- Example output datasets: cohort study, health economics, RCE, RCT, screening programme (daily)



Discussion

Why is it so challenging?

- Complexity of data sources, multiple data sources, inconsistent data quality
- IT Systems introduced without documentation, upgrades
- Multidisciplinary environment (academics, clinicians, technical, external data providers)
- Limited experience in the public sector

Solutions and lessons learnt!

- Performing data sanity checks, set up outlier handling protocols, logic rules and imputation
- Professional procurement of data systems required by the NHS
- Understanding and bridging knowledge gaps requires consistent and extensive communication between data processers, clinicians and key external contacts
- Investment

Conclusions

- Established minimal requirements to set up a clinical data warehouse
- Technical problems solved by bespoke programs and customised database design
- Our approach is generalisable and applicable for clinical care and research in complex chronic diseases and provides a basis for the implementation of personalised health care

Acknowledgements:

This poster presents independent research funded by the NIHR under the Programme Grants for Applied Research programme (RP-DG-1210-12016). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Heath.
The authors wish like to acknowledge invaluable contributions from: Royal Liverpool University Hospital IT team, Liverpool CCG, Diabetic Eye Screening Programme:ISDR Programme administrative team.

EASDec 26th Annual Conference, Manchester, 23-25 June 2016