The challenge of healthcare data
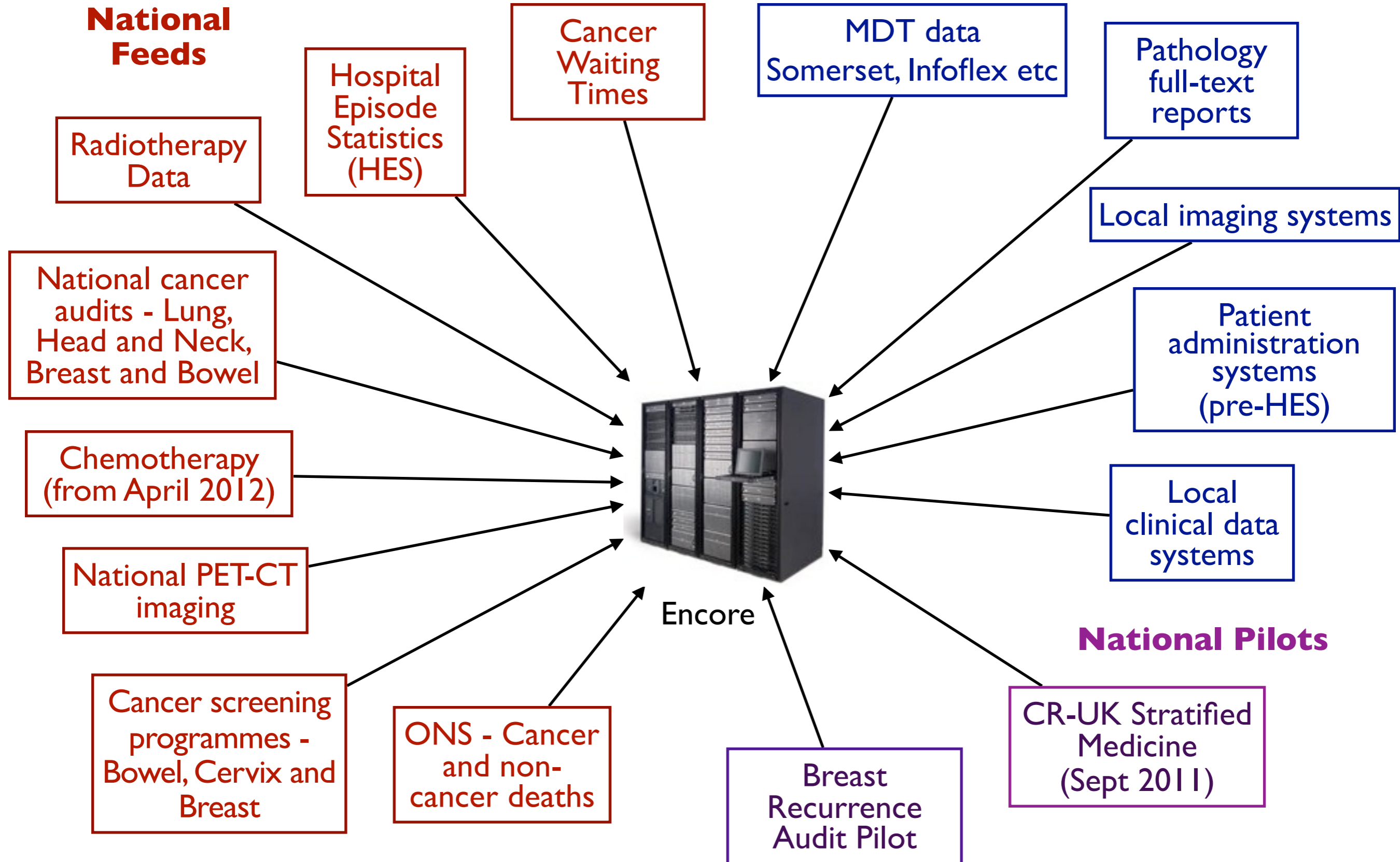
Jem Rashbass
National Cancer Registration

Background

- Why it is important
  - epidemiology of cancer
  - what is cancer registration
- Why it is difficult
  - Very complex data
  - Disparate systems
  - Brown-field site
  - Confidentiality
- Cancer as an exemplar
  - complexity of the data sources
  - movement of patients
  - outcomes
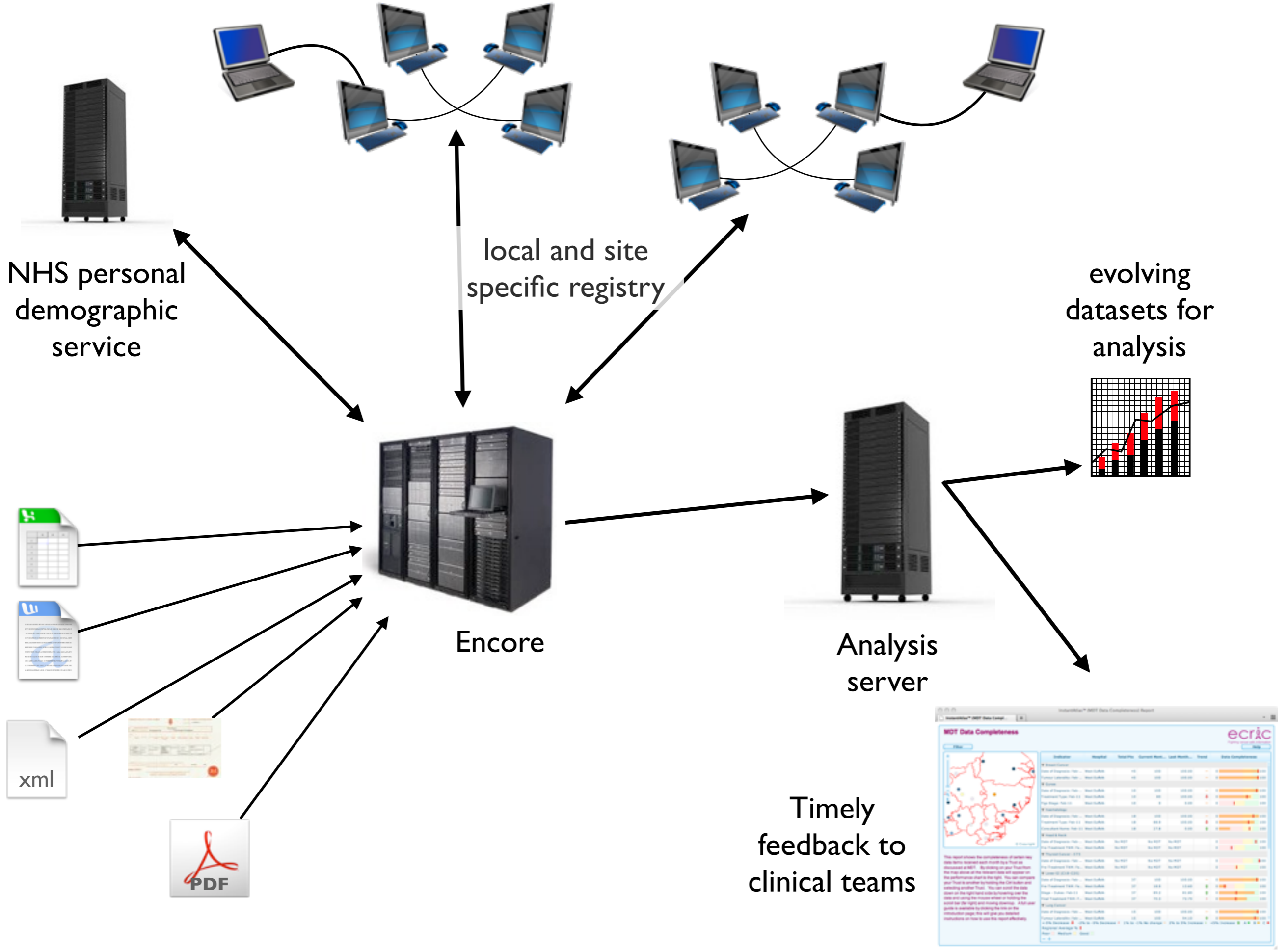 - outliers

Systems and Solutions

- What the systems are really like
    - the real history
    - Standard Government approach
    - data integration and extraction

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Data sources - patient-level data

Local Feeds

National Feeds

Radiotherapy Data

Hospital Episode Statistics (HES)

Cancer Waiting Times

MDT data Somerset, Infoflex etc

Pathology full-text reports

National cancer audits - Lung, Head and Neck, Breast and Bowel

Local imaging systems

Chemotherapy (from April 2012)

Patient administration systems (pre-HES)

National PET-CT imaging

Local clinical data systems

Encore

Cancer screening programmes - Bowel, Cervix and Breast

ONS - Cancer and non-cancer deaths

Breast Recurrence Audit Pilot

National Pilots

CR-UK Stratified Medicine (Sept 2011)

Our approach

- Our approach
  - any data is worth having
  - not about statistics to control for poor data
  - processing scripts
  - mass data importers
  - Ruby - with Oracle back end
- What we have achieved

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NHS personal demographic service

local and site specific registry

evolving datasets for analysis

Encore

Analysis server

Timely feedback to clinical teams

xml

PDF

Patient Pathway analysis

Where next

- Where next?
  - national cancer registration service
  - surveillance
  - full genome analysis
- Job opportunities -
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Using information to improve quality & choice

and so.....

Healthcare data, systems and processes are very complex and very messy.

We are on the verge of creating an integrated dataset and online service that will be unmatched anywhere in the world.

If you like hard problems and challenges - get in touch!

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