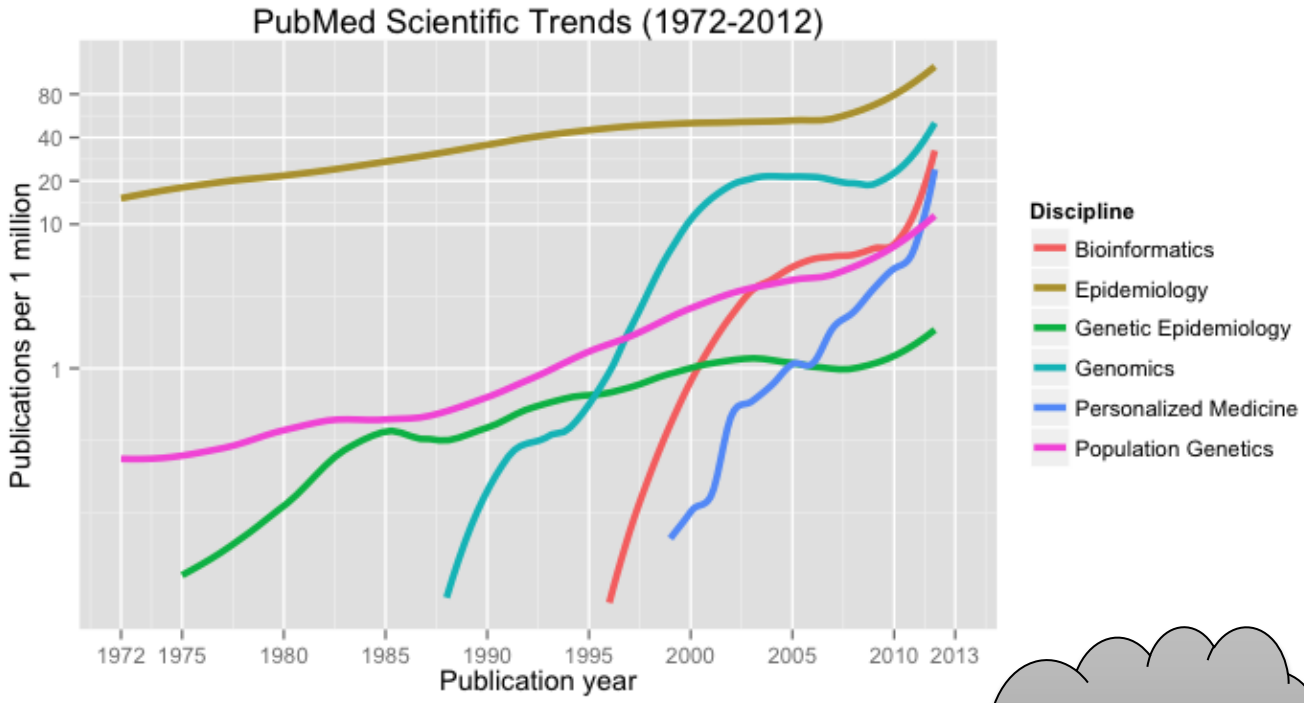
Techniques for Data Linkage and Anonymisation – A Funders View

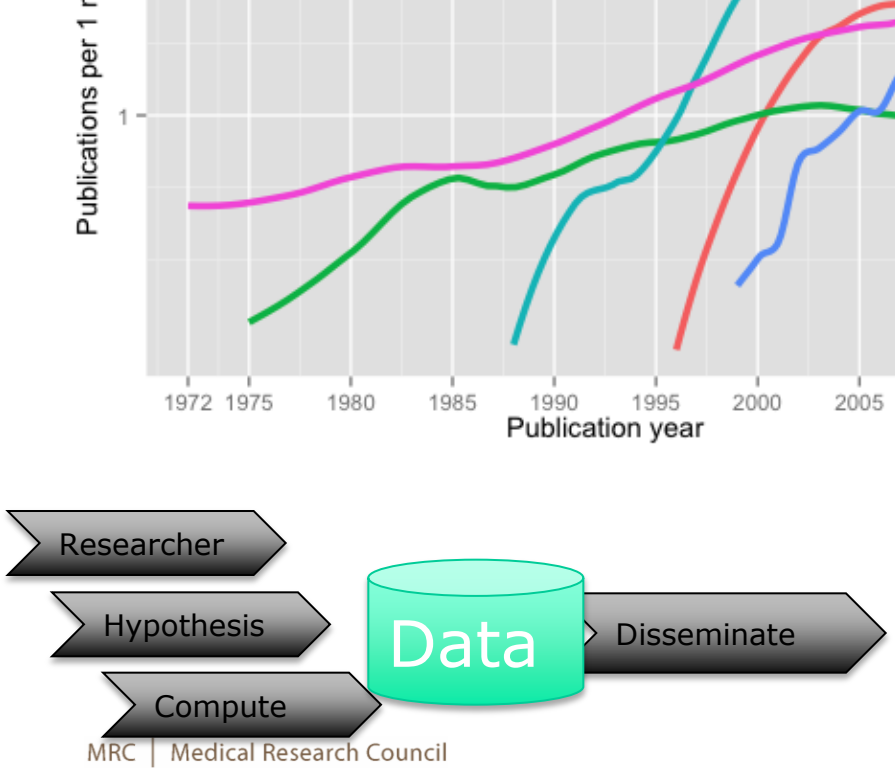
Turing Gateway Meeting 23rd October 2014

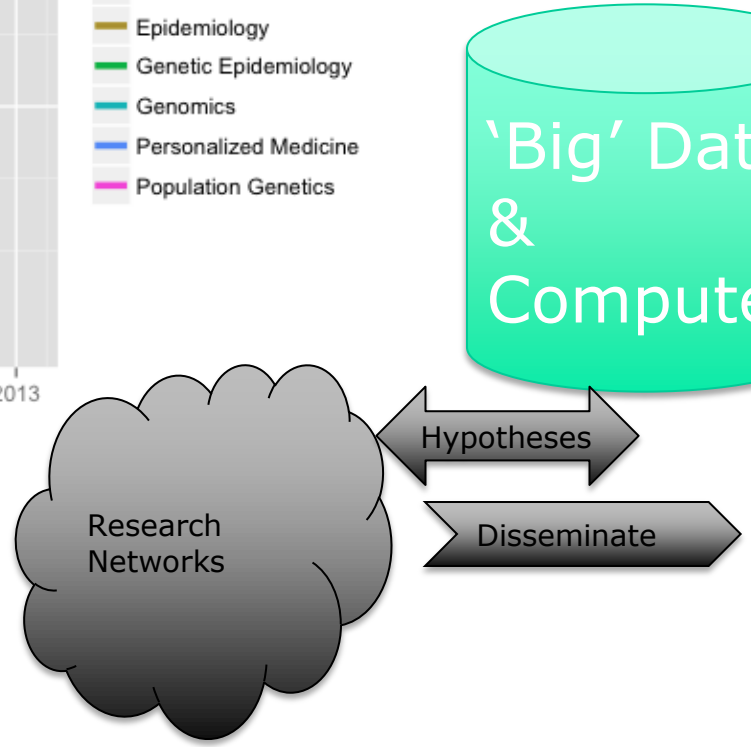
Dr Mark Pitman

MRC | Medical Research Council

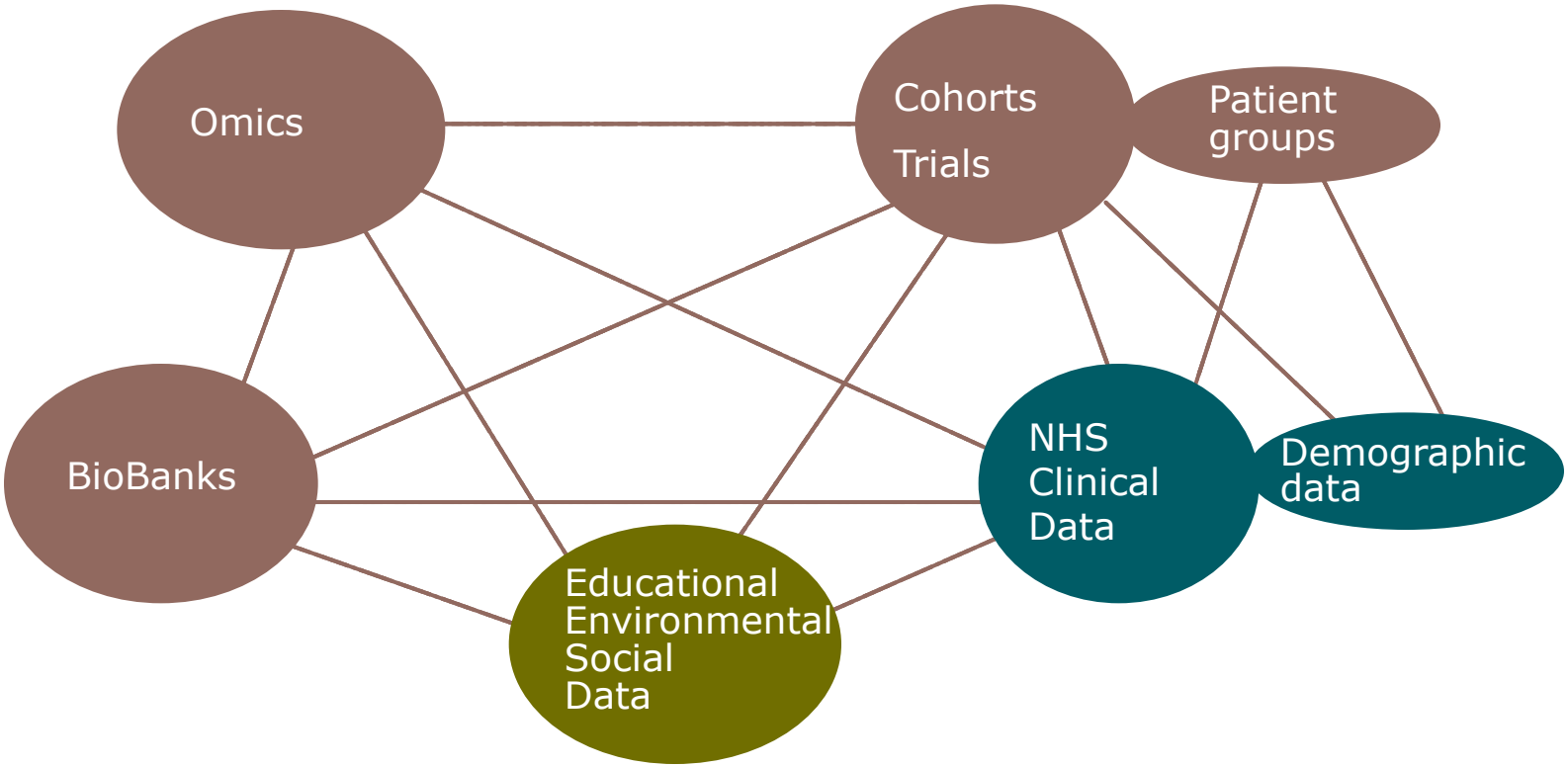
Informatics Tipping Point







Vision of an integrated informatics research landscape



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UK's families put on fraud alert

Two computer discs holding the personal details of all families in the UK with a child under 16 have gone missing.

The chancellor urged people to monitor their bank accounts

Watch Alistair Darling

The Child Benefit data on them includes name, address, date of birth, National Insurance number and, where relevant, bank details of 25 million people.

Chancellor Alistair Darling said there was no evidence the data had gone to criminals - but urged people to monitor bank accounts "for unusual activity".

The Conservatives described the incident as a "catastrophic" failure.

In an emergency statement to MPs, Mr Darling apologised for what he described as an "extremely serious failure on the part of HMRC to protect sensitive personal data entrusted to it in breach of its own guidelines".

CHILD BENEFIT HELPLINE
• 0845 302 1444

MPs gasped as Mr Darling told them: "The missing information contains details of all Child Benefit recipients: records for 25 million individuals and 7.25 million families. "

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MoD admits loss of secret files

More than 100 USB memory sticks, some containing secret information, have been lost or stolen from the Ministry of Defence since 2004, it has emerged.

A report said the MoD needed to improve some areas of data protection

The department also admitted that more than 650 laptops had been stolen over the past four years - nearly double the figure previously claimed.

The Liberal Democrats condemned the latest security breaches as evidence of "shocking incompetence".

But the MoD insisted its policies were "generally fit for purpose".

Previously the MoD had confirmed that 347 laptops were stolen between 2004 and 2007.

The Mod said it has no idea on when, where and how the memory sticks were lost.

Defence Secretary Des Browne issued revised figures after "anomalies in the reporting process" were discovered.

The official total is now 658 laptops stolen, with another 89 lost. Just 32 have been recovered.

Issues for use of data in research

- Public trust
  - care.data
- Multiple uses of NHS data – audit, commissioning, research
- Proposed amendments to EU Data Regulation
  - Cohorts would need consent for all studies using their data
- Consultation on safe havens

The Telegraph

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Millions of NHS records sold to insurance firms

Millions of patient records were sold to insurance firms who used it to set their critical illness premiums in a series of 'unacceptable lapses', an independent review finds

Patient medical records in a NHS surgery Photo: Alamy

Sharing your patient record can help researchers save and improve lives

Supported by

Arthritis Research UK · CANCER RESEARCH UK · DIABETES UK · wellcome trust

Safe havens – trustworthy environments

- Provide secure environments for handling data
- Ensure risks of identification are minimised
- Access only to those who meet certain requirements
- Security - technical and professional standards
- Audit data use

SAFE DATA

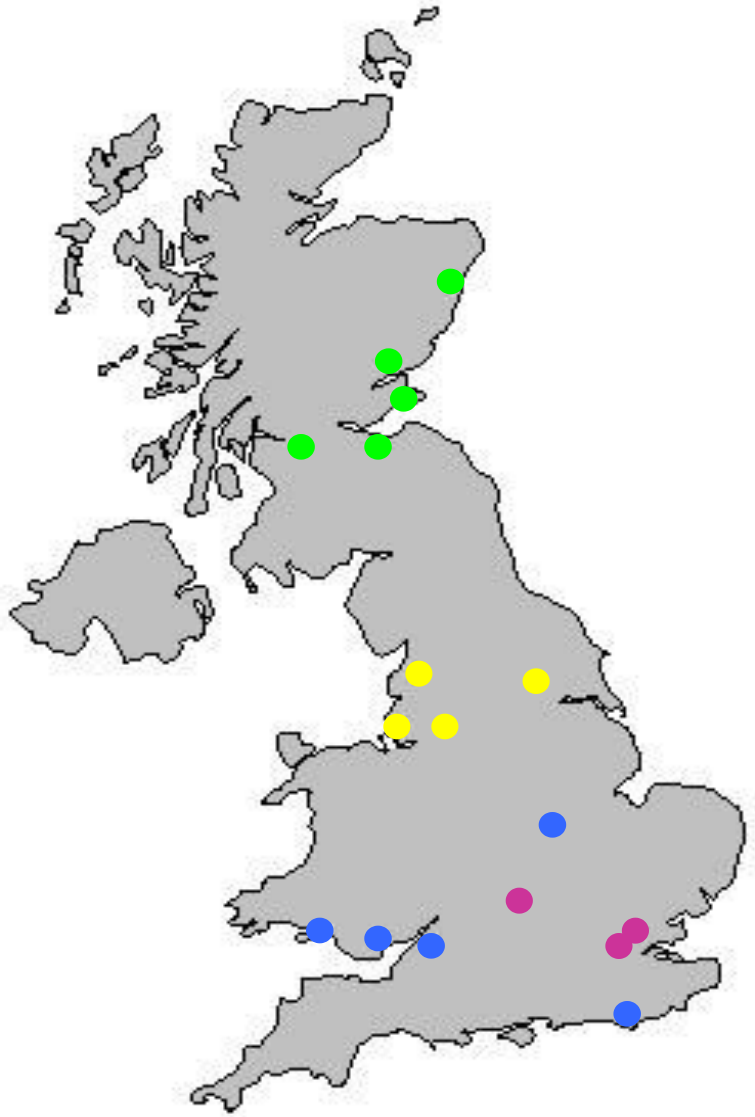
Farr Institute of health informatics research

- **£19m** funding in MRC coordinated 10 funders call to fund four health informatics research centres (eHIRCS)
  - Manchester, UCL, Dundee, Swansea – 24 universities, 2 MRC Units

Aim of the HIRCs

  - Analyse & link health records with research data and other datasets
  - Build capacity in data linkage and health informatics research

- Additional **£20m** capital to create distributed virtual institute across the four eHIRCs - Farr Institute of Health Informatics Research
  - Joint strategy across Farr Sites
  - Digital infrastructure and safe environments to share data
  - Physical co-location of academics and NHS



The Farr Institute of Health Informatics Research

Farr London

UCL, LSHTM, Queen Mary, Public Health England

Farr Scotland

Dundee, Glasgow, Edinburgh, St Andrews, Aberdeen, Strathclyde, MRC HGU, NHS NSS

Farr CIPHER

Swansea, Bristol, Cardiff, Exeter, Leicester, Sussex, NWIS, Public Health Wales

Farr @ HeRC N8

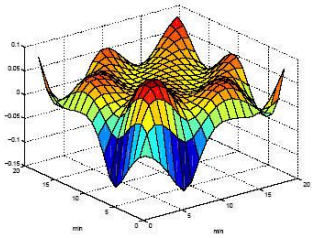
Manchester, York, Lancaster, Liverpool, Sheffield, AHSNs

Medical Bioinformatics call

Aims:

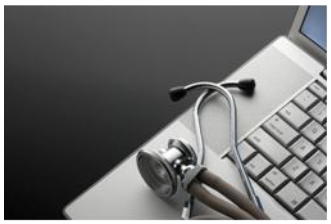
- Integration between genomics, complex phenotypes, and clinical data
- New infrastructure, tools, increased coordination and sharing capabilities
- Support career opportunities for computational scientists, technologists

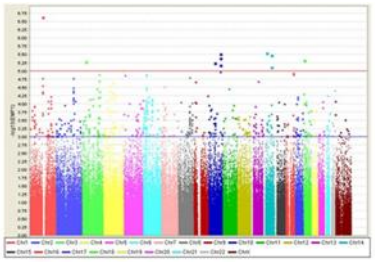
- **£39m** capital and resource - 6 awards
- MRC/UVRI Uganda Research Unit
- UCL (incl. EMBL - Francis Crick Institute, EBI)
- University of Leeds
- University of Oxford
- University of Warwick (incl. Swansea, Cardiff)
- Imperial College



Other MRC data research investments

- Population and patient cohorts and clinical trials
  - Over 2.2m people in the UK participate in population cohort studies
- High throughout science – omics, imaging, Phenome centre
- Stratified medicine
- UK Dementia Platform – integral informatics component
- Clinical Research Infrastructure call
- £24m Genomics England Data Centre





The landscape of health informatics to support research

UK Health Informatics Research Network

Network outward facing - engaging the wider research and stakeholder communities

Each workstream is co-chaired by Farr and an expert outside the Farr

Workstreams

- Methodology
- Best practice in governance
- Public engagement
- Capacity building
- Partnership building – NHS, industry
- Cohort study linkage development
- Communication

Anticipated impact of informatics investments

- UK leadership
- Transformational science at scale
- Greater interoperability through use of standards
- Integration of heterogeneous data
- New partnerships – academic, NHS and industry
- Increase UK skill base
- Economic growth
- Public and patient advocacy