



Health eResearch: North England

Engineering scalable health science for patient and public benefit

John Ainsworth

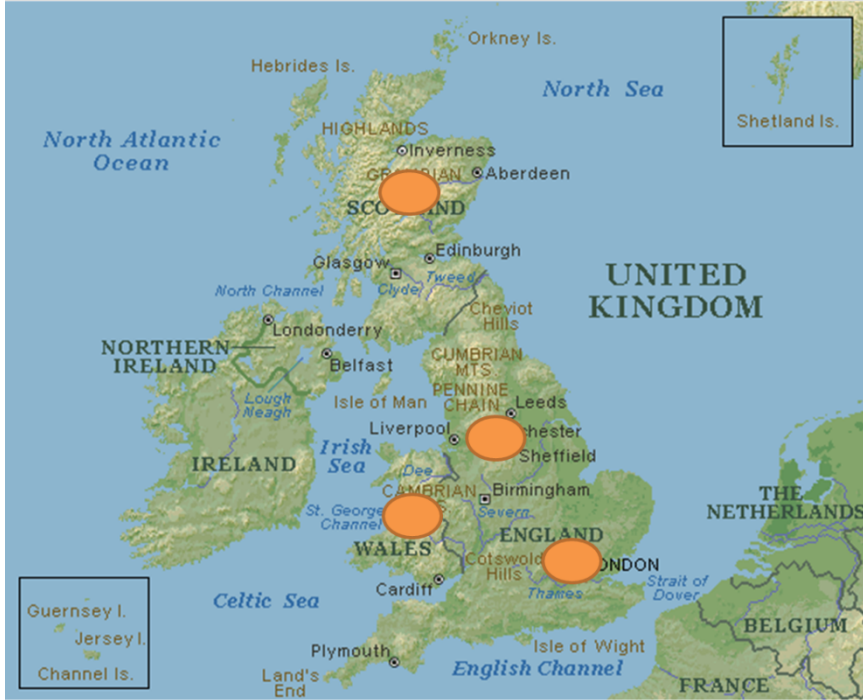
Deputy Director, Health eResearch Centre (North England)

14 May 2013

www.herc.ac.uk



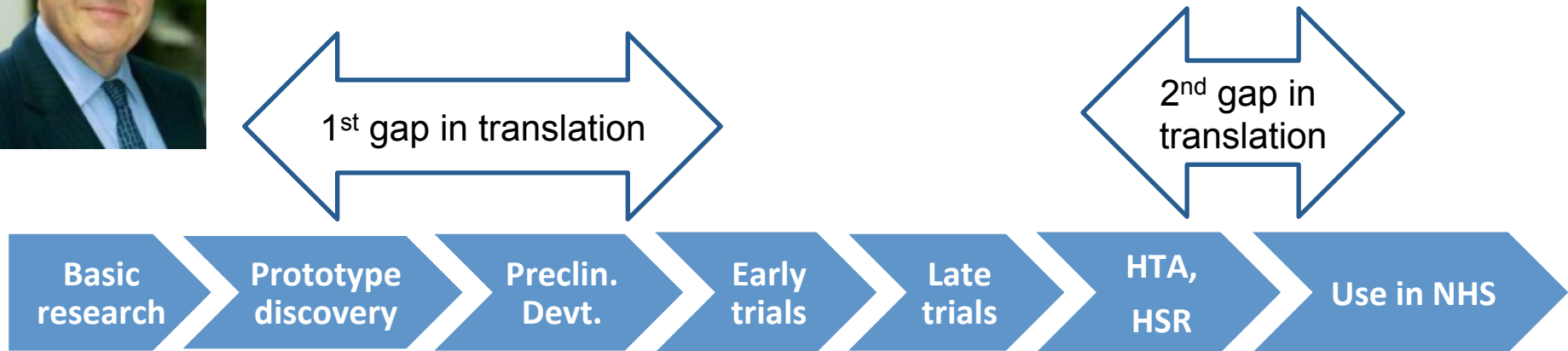
The UK Network of eHealth Informatics Research Centres



£19M investment



Roles of informatics in translational medicine



Bioinformatics

Medicinal informatics

Text mining

Automated experimentation

Trial design & simulation tools

Trial recruitment & data man. tools

Guideline authoring tools

Analysis of linked anonymised clinical datasets

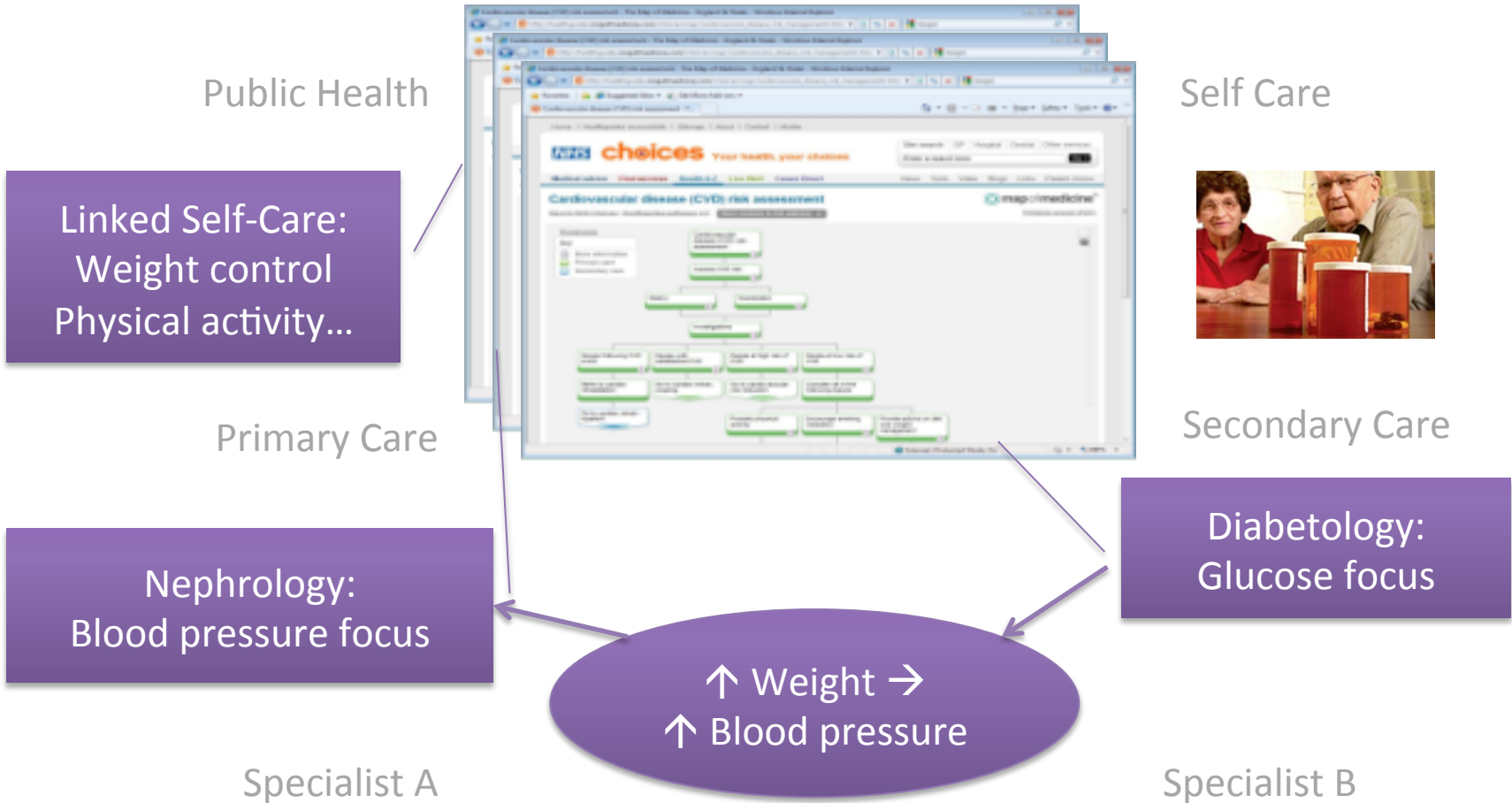
Decision support tools for Drs & pts.

HTA: health technology assessment
HSR: health services research



Evidence Engine Does Not Scale

Evidence predicts <30% outcomes.
Building usefully complex models of health & care needs a much larger scale of research, 'in the wild'.



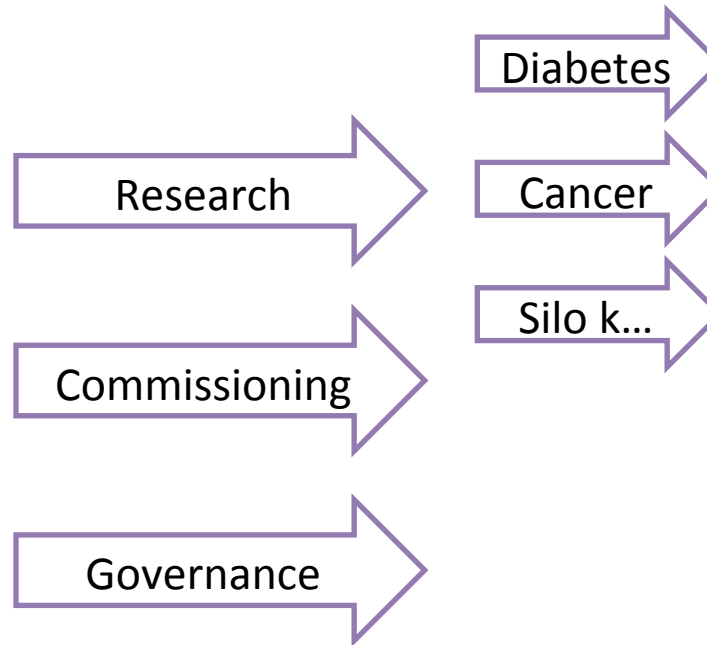


New Evidence from Health Records?

DROUGHT of EXPERTISE



TSUNAMI of DATA



BLIZZARD of MODELS/METHODS and LITERATURE

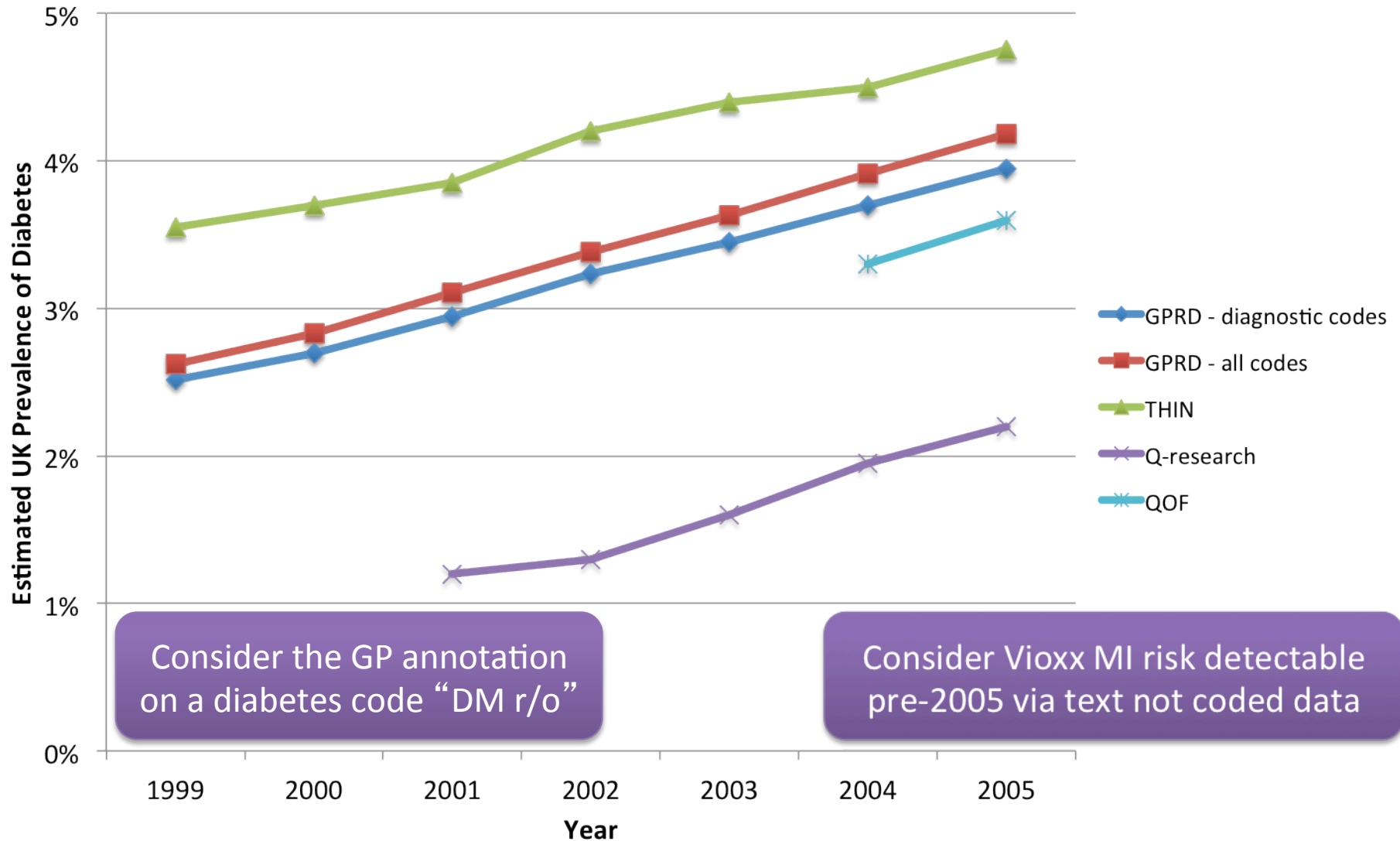


PROLIFERATION of PIPELINES



Little Data to Recalibrate Big Data

UK Diabetes Prevalence from Different Databases





Harnessing Codes for Clinical Trials

Before FARSITE...

select distinct PatientID, GPPracticeCode from Patients where DeathDate is null and PatientID in (select distinct PatientID from Patients where Dob<=1991 and PatientID

Analysts drowning in codes

in (select distinct PatientID from Patients where j.ReadCode in ('.C21.', '.C2A.', '.C2D.', '.C2G2', 'C1021', 'C109.', 'C1094', 'C1095', 'C1097', 'C1099', 'C109D', 'C109F', 'C109G', 'C109H', 'C109J', 'C10F.', 'C10F4', 'C10F5', 'C10F7', 'C10F9', 'C10FD', 'C10FF', 'C10FG', 'C10FH', 'C10FJ', 'L1806', 'X40J5', 'X40J6', 'X40JK', 'XaELQ', 'XaFn7', 'XaFn8', 'XaFn9', 'XaFWI', 'XSETp', 'XU70f', 'XU71F', 'XUKO0', 'XULXc', 'XUPHn', 'XUSbx') and



After FARSITE...

Gender: Any

Ethnicity: Any

Smoker:

 'N/A' (Not Applicable)

 Select:

 Current Smoker

 Ex-Smoker

 Never Smoked

Researchers exploring trial feasibility interactively

Additional Criteria

Include: Has Asthma

AND Asthma

AND Asthma attack diagnosis made less than 12 Months ago

Search for: Diagnoses

Search within term description

Diagnosis made: Less Than

Add with: And, And/Or, And No

Include: Asthma Medications

Exclude: BMI - Overweight

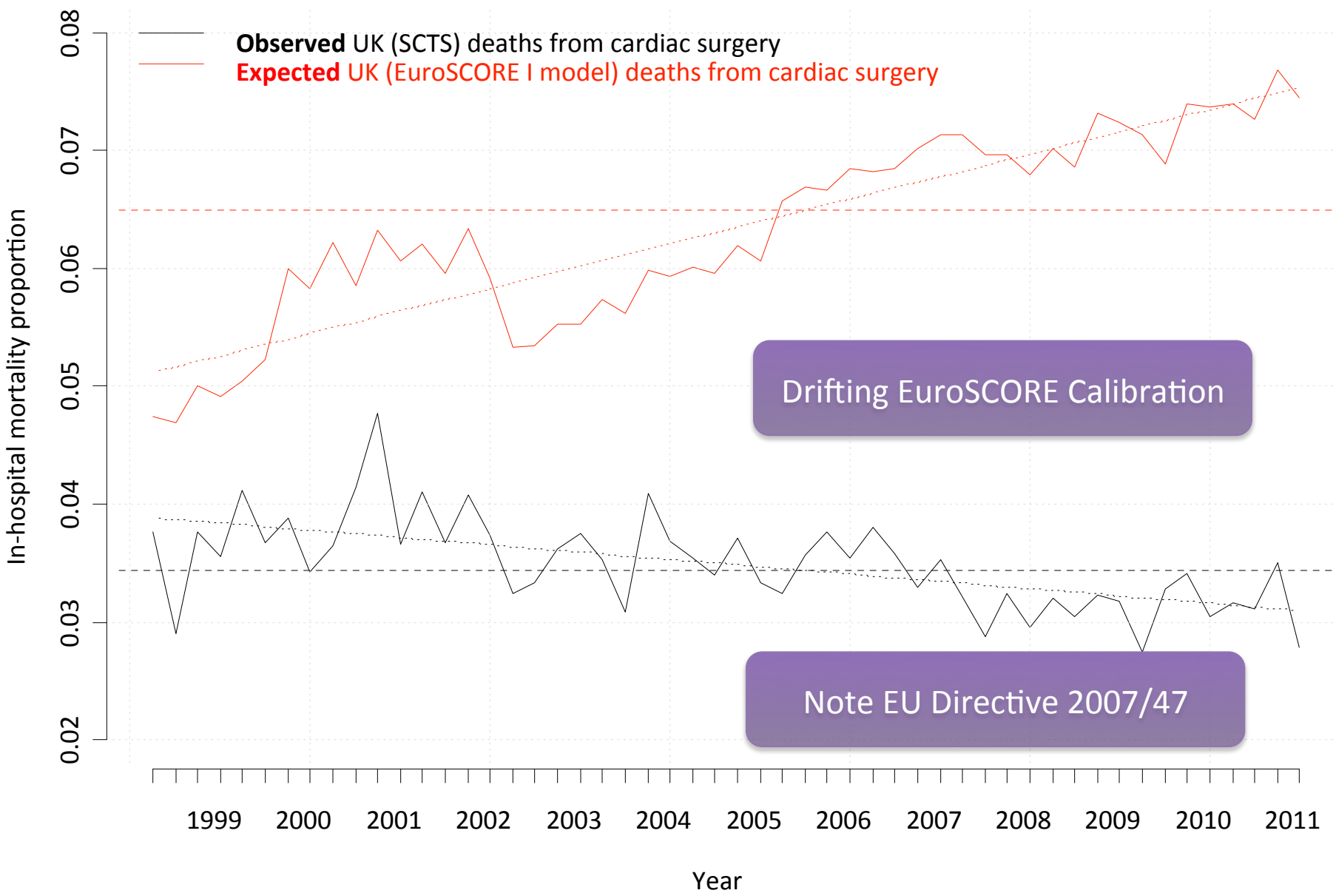
asthma dropdown menu:

- Asthma
- Asthma attack
- Asthma NOS
- Cardiac asthma
- Asthma screening
- Intrinsic asthma
- Asthma confirmed
- Asthma attack NOS
- Asthma unspecified

Reuse this investment...



New Laws for Clinical Prediction



From G. Hickey & B. Bridgewater



Service-Science Synergy

Enabling the world's largest 'real world' respiratory clinical trial

Clinical Trial:

1 vs. 2 per day dosing → adherence (* deprivation)



Clinical Audit:

Depression vs. readmission

Salford Royal 
NHS Foundation Trust

Public Health:

Recalibrated deprivation score

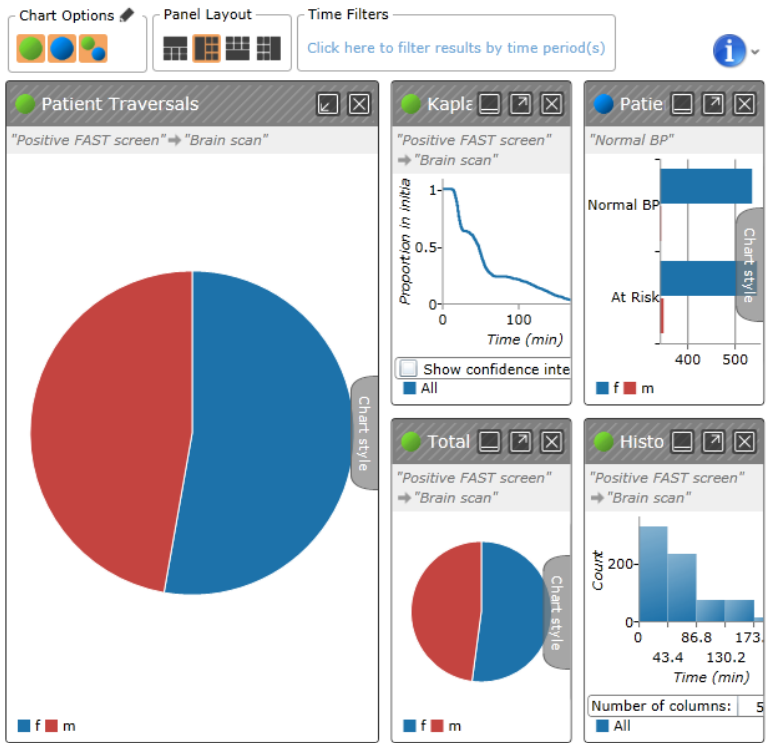
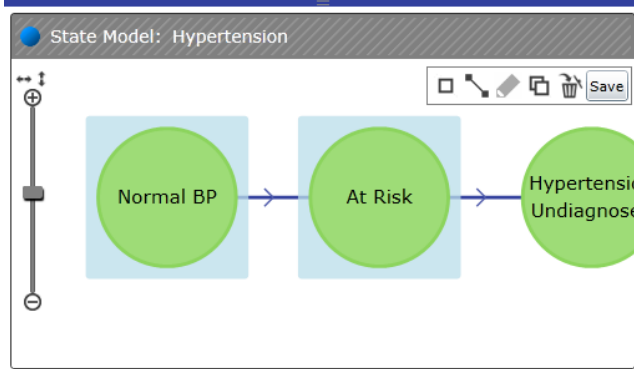
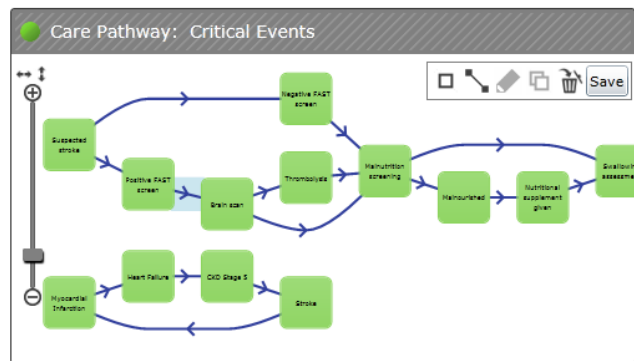


“Users who selected the variables in your basket also selected these variables and these models...”



COCPIT: Revealing Care Pathways

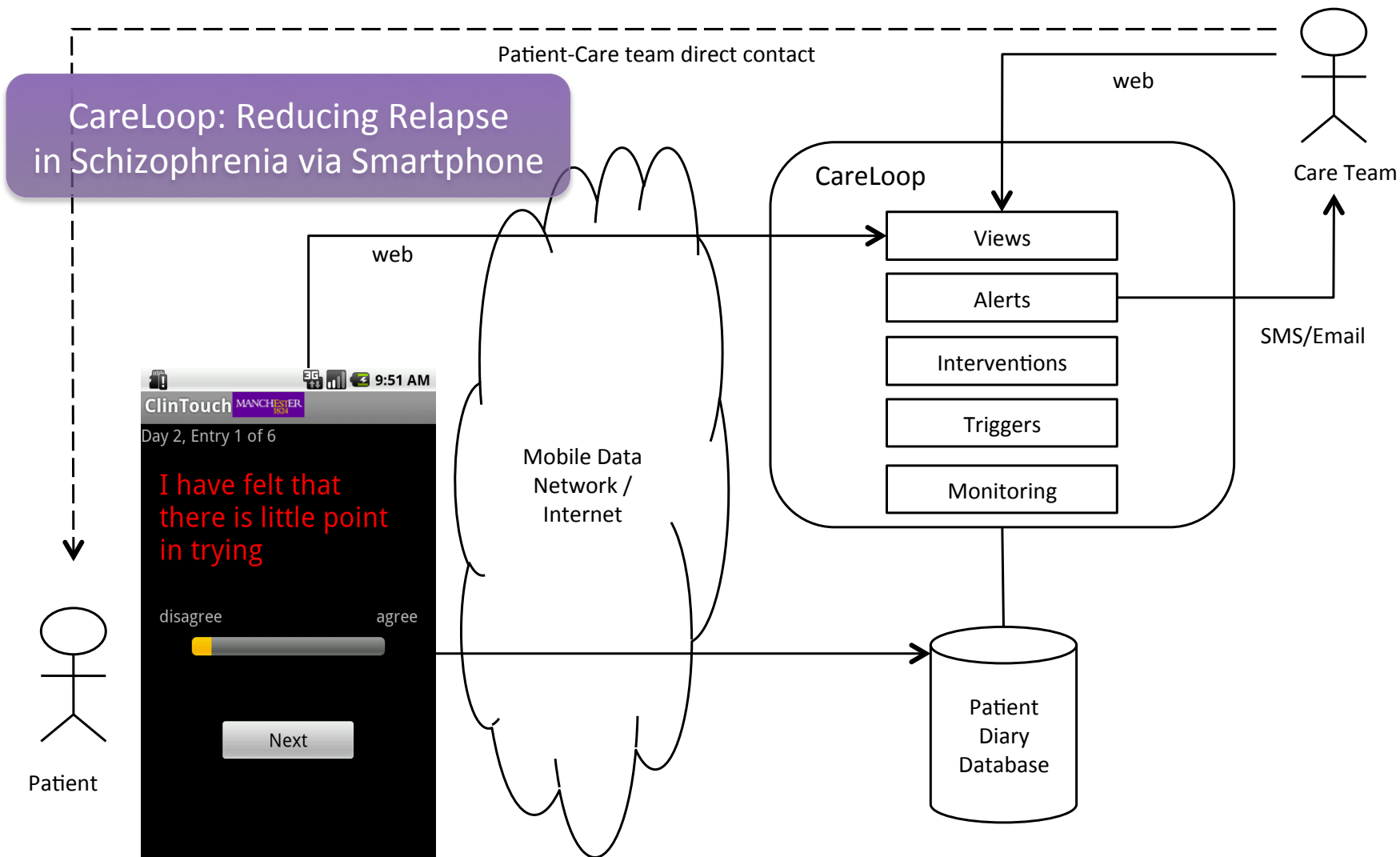
Input: Linked health record data and clinical guidelines



Output: Pictures of observed care contrasted with expected care: helping health professionals to identify missed opportunities for better care and support service improvement

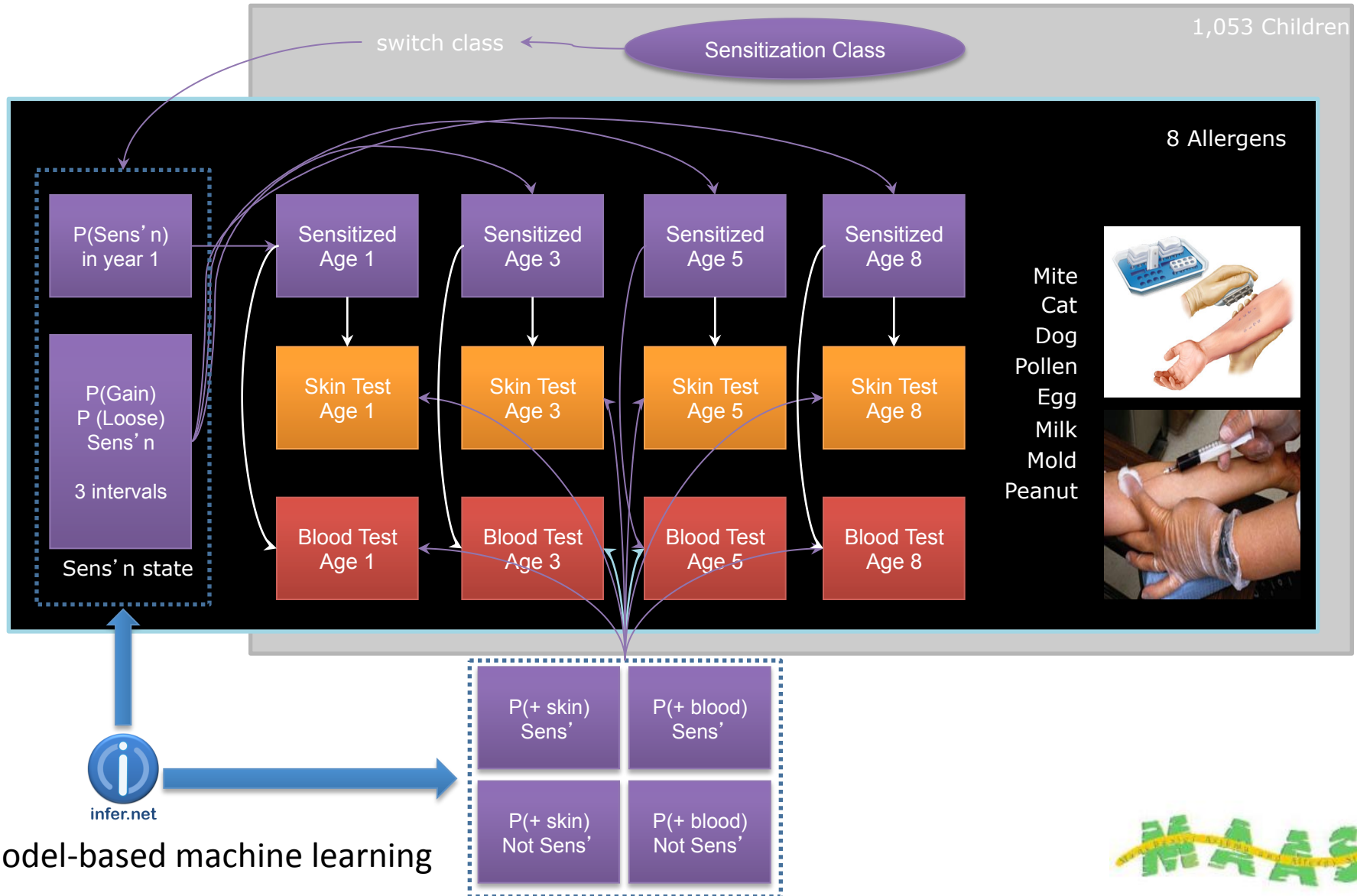


Integrating Patient-reported Data





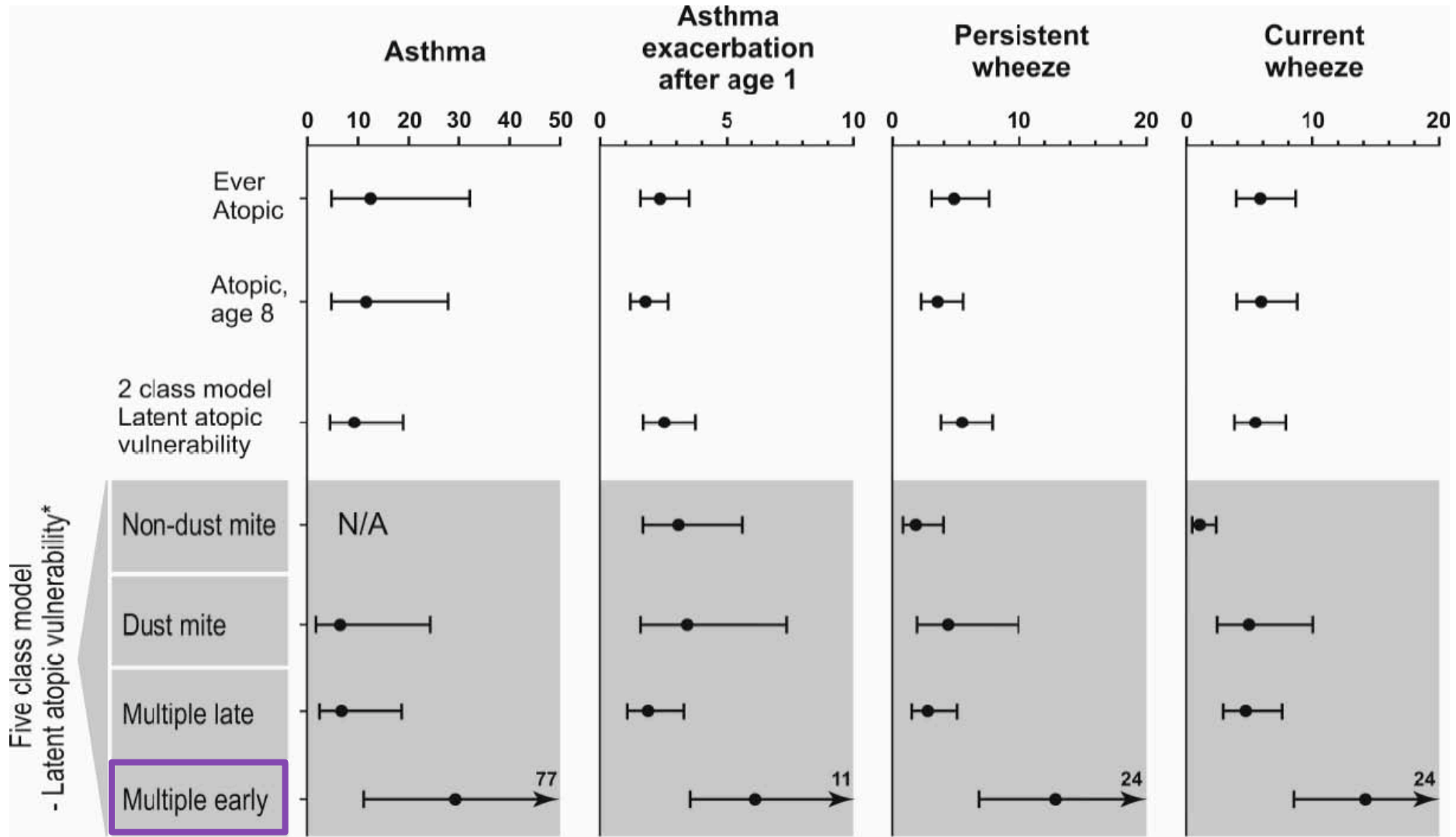
Shaping Hypotheses: Atopy





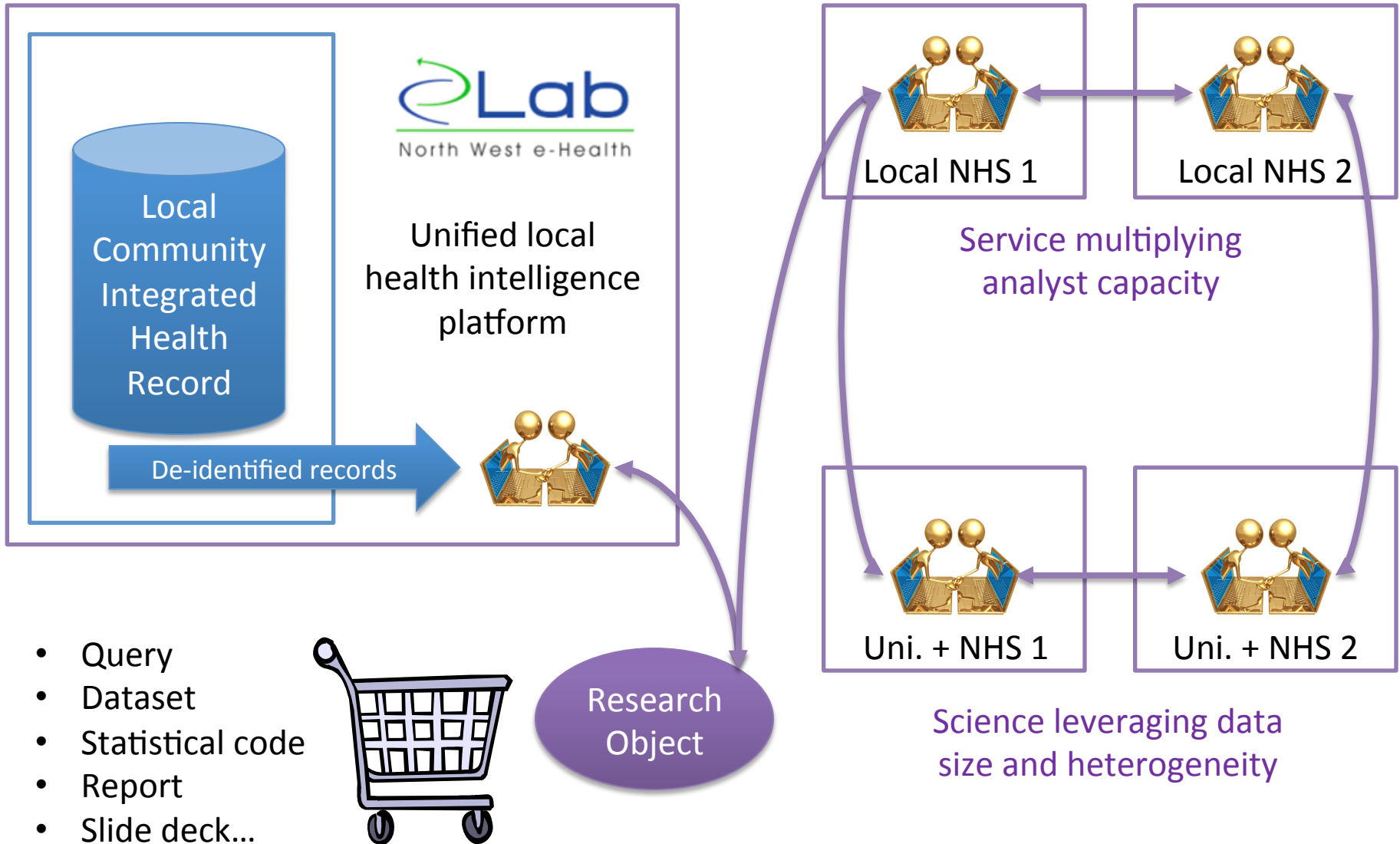
Atopy 'Stratified'

Important new risk group for asthma discovered





Social Machine of Health eResearch



Scalable
Healthcare QI

Linked Self-care

Scalable
Epidemiology

Clinical Trials

Endotype
Discovery



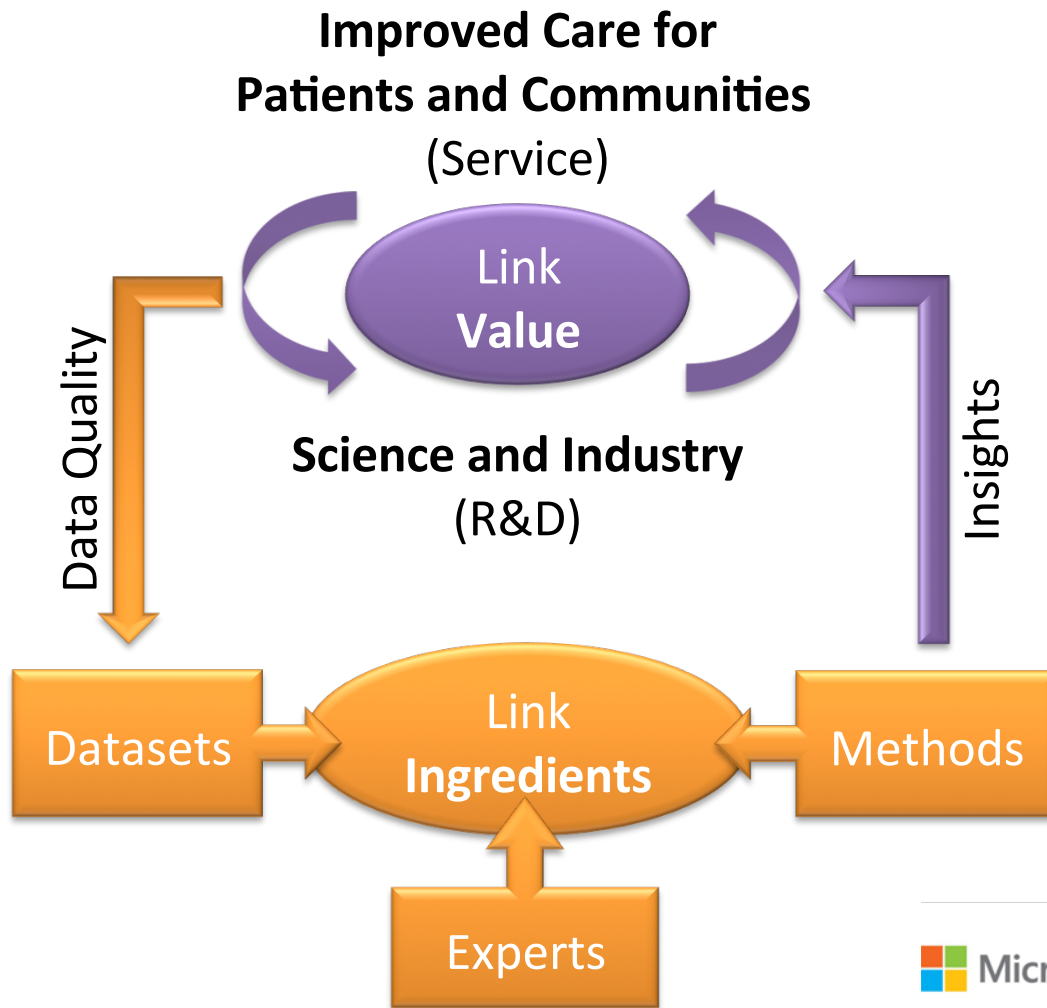
Informatics
Training

Engineering
& Methods Science

Patient & Public
Involvement



Health eResearch Centre: N. England



Success = Informatics releasing patient and public benefit from health records at scale



Our Collective Vision

“To harness health data for patient and public benefit by setting the international standard for the safe and secure use of electronic patient records and other population-based datasets for research purposes”



Why a Network?

- **The Gap in Today's environment**
 - Today we lack a full longitudinal view of the patient because the data are distributed across entire health and social care ecosystems
 - Research activity fragmented
 - The need for a Multi-disciplinary and multi-partner strategic approach
 - The need to compete internationally at scale
- **Our approach**
 - Collaborative and Inclusive
 - Link with key players eg EBI, CPRD, UK Biobank
 - Proportionate governance and Public Engagement to promote privacy and confidentiality
 - Harness high performance computing to support patient care
 - Collect data once use often for quality care, health care system decision making and research
 - Be ambitious!



Our Five Major Outcome Areas

- ***Health science***
- ***Methodology and engineering***
- ***Capacity building***
- ***Public engagement and governance***
- ***Industrial innovation***



Our Ten Key Activities



1. Collaborative Leadership.
2. Research collaboration
3. Public engagement.
4. Governance.
5. Methods development.
6. Harmonisation (IT/datasets)
7. Internationalisation
8. Industrial Partnerships
9. Training/ Capacity Building
10. Communications

To deliver impact nationally and internationally



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Governance



Key Recommendations

- **Explain to patients and the public how the personal information they collect could be used in de-identified form for research**
- **Information governance specialists should work together to establish a community of practice**
- **Accredited safe havens**



The Information Governance Review



Published 26th April, 2013



Public Engagement Workstream

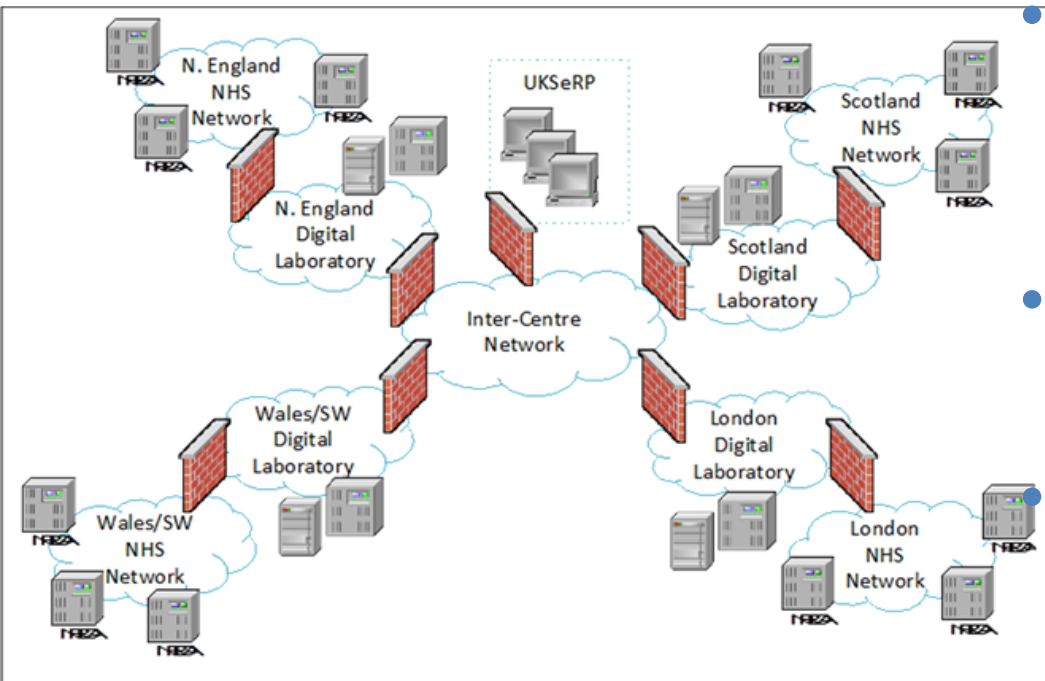
Aims

- To **synthesise existing evidence on citizens attitudes** towards sharing personal data for research.
- To **generate new evidence** on the acceptability of different levels of data sharing under varying conditions.
- To **link** the public engagement activities into the development of policy, governance and the science.

Judith Stephenson (UCLP),
Cynthia McNerney (Wales)
Mary Tulley (Manchester)
Claudia Pagliari/Sarah
Cunningham-Burley
(Scotland)



UK Digital eInfrastructure



- Digital infrastructure for collaborative analysis across the Centres
- Research on a larger scale.
- Shared data handling and statistical computing facilities
- Expand to involve an increasing number of new academic and NHS partners.

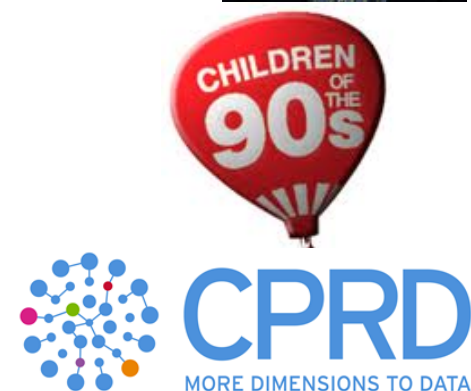




Enabling Datasets



- Enable a larger scale of scientific discovery
- Create a databank of data sources from the UK and internationally.
- Support data acquisition, integration and analysis,
- A single metadata portal for the UK Network.
- Adding value to an increasing number of deeply phenotyped populations, researched seamlessly across the UK.
- NICOR (UCL); ALSPAC (Swansea)





Industry Collaboration

Open innovation programme

- Within a defined governance framework
- Protects patient privacy
- Acceptable to the NHS
- Delivers public and patient benefit





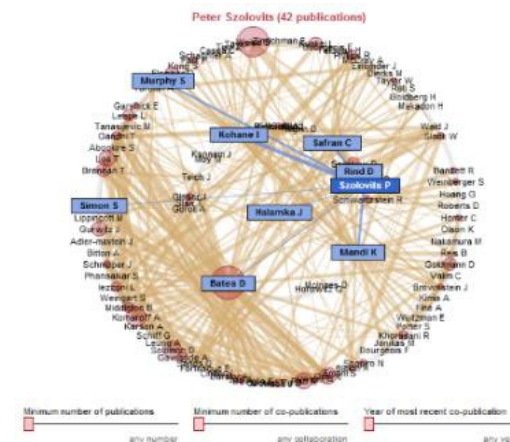
Communications

- Website / inventory of datasets
- Seminars/workshops
- Industry showcases
- Research networking and expertise mining software tool (Harvard Catalyst)

- Annual Conferences

- August 2013 St Andrews
- July 2014 Manchester
- July 2015 Wales
- July 2016 London

- International Advisory Board





A big thank you to our funders

welcometrust

Arthritis
Research UK



NHS
*National Institute for
Health Research*

NISCHR
Iefydliad Cenedlaethol ar gyfer Ymchwil Gofal | National Institute
for Social Care and Health Research



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