



Digital Curation for the Public's Health: Ethics, Security & Trust

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Digital Curation for the Public's Health

Ethics, Security & Trust

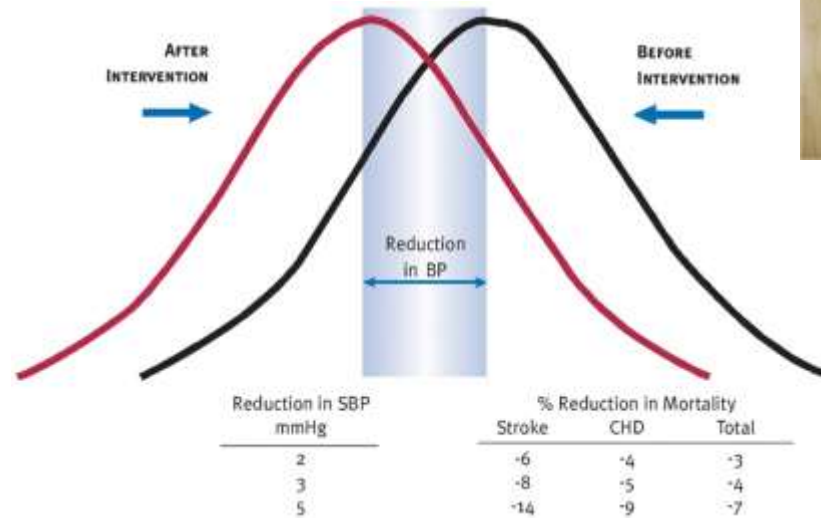
DCC/RIN Research Data Management Forum
"Dealing with Sensitive Data: managing ethics, security and trust"

10th March 2010

Prof. Iain Buchan
University of Manchester

Digital Curation for the Public's Health

- Where does the public's health need digital innovation?
- How can research curators promote this innovation?
 - Ethics
 - Security
 - Trust
- Is a framework required?
 - Social contract
 - Digital & operational infrastructure: e-Lab



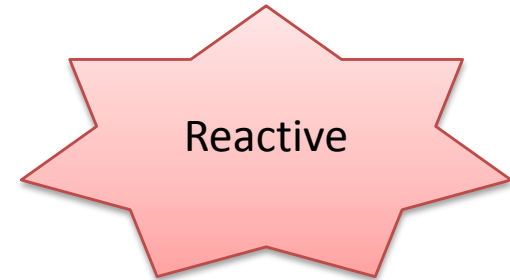
Source: Whelton PK, et al. Primary prevention of hypertension: Clinical and public health advisory from The National High Blood Pressure Education Program. JAMA 2002;288:1882-8.

Public Health Needs for Digital Innovation: I

CITIZEN-LED PREVENTION & EARLY INTERVENTION

Approaches to Healthcare

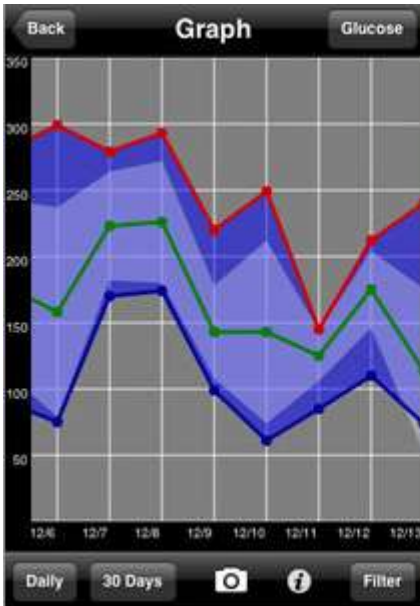
- Clinical model:
 - Rescue the ill
 - Resource \propto illness
 - Specialise to optimise
- Public Health model:
 - Rescue the at-risk
 - Resource \propto disease/risk
 - Generalise to optimise



Healthcare Digital Innovation is Mostly Clinical



- Specialist-driven
- Excellent in niches
- Incremental

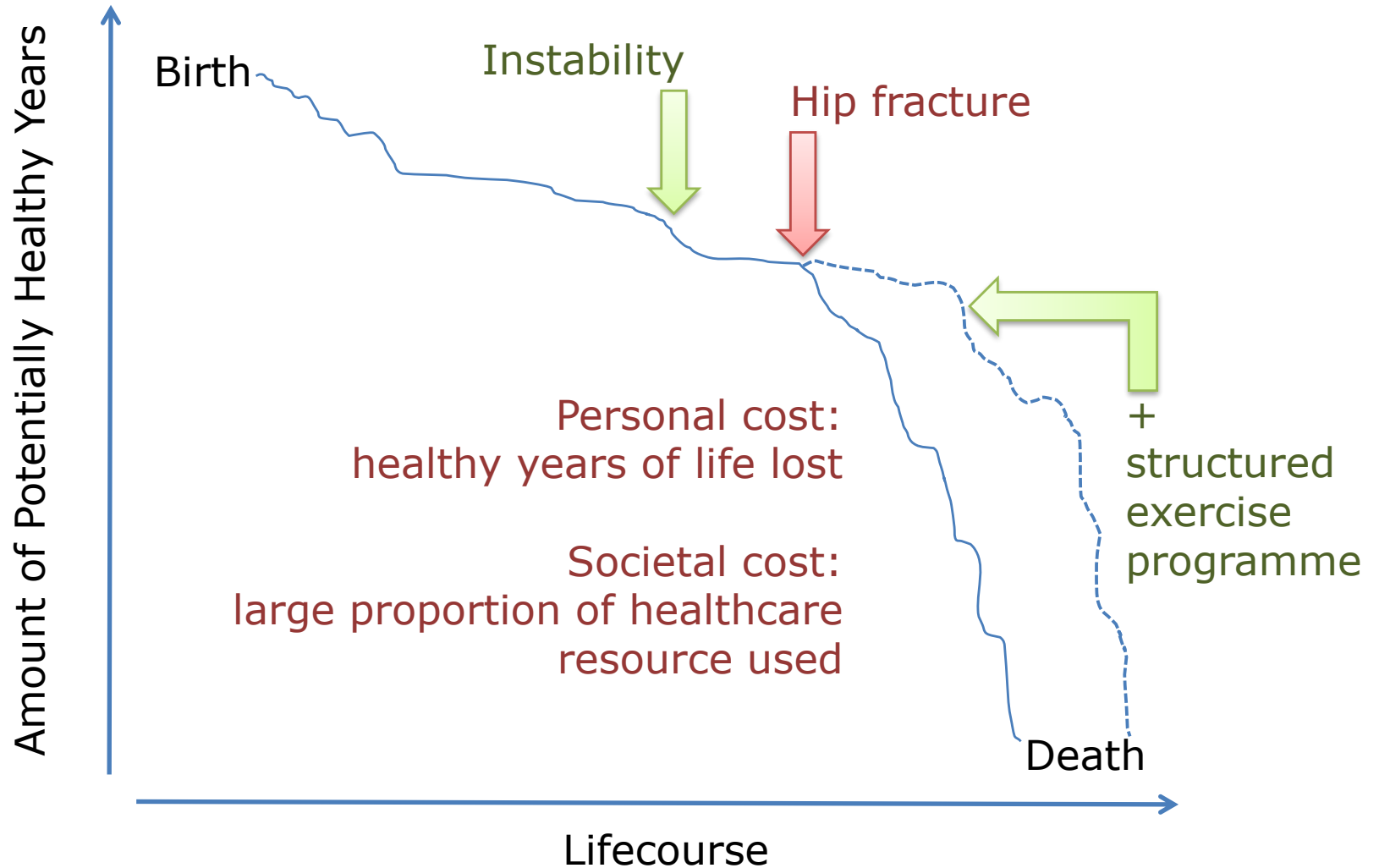


Time	Activity	Value	Unit
7:33 PM	Food	21	grams
7:33 PM	Levemir	21	units
7:33 PM	Light Activity	54	min
7:33 PM	Glucose	114	mg/dL
7:33 PM	Humulin	52	units
7:32 PM	Glucose	158	mg/dL



...while public health technologies may be left to perverse market-forces.

A life-course view of personal health



State-led:
Health Promotion

Citizen-led:
Health & Wellbeing

Manchester Public Health
Development Service



Manchester **NHS**
Primary Care Trust

Know

Act



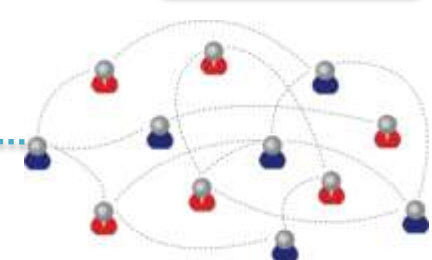
Persuasive Technology

Feel

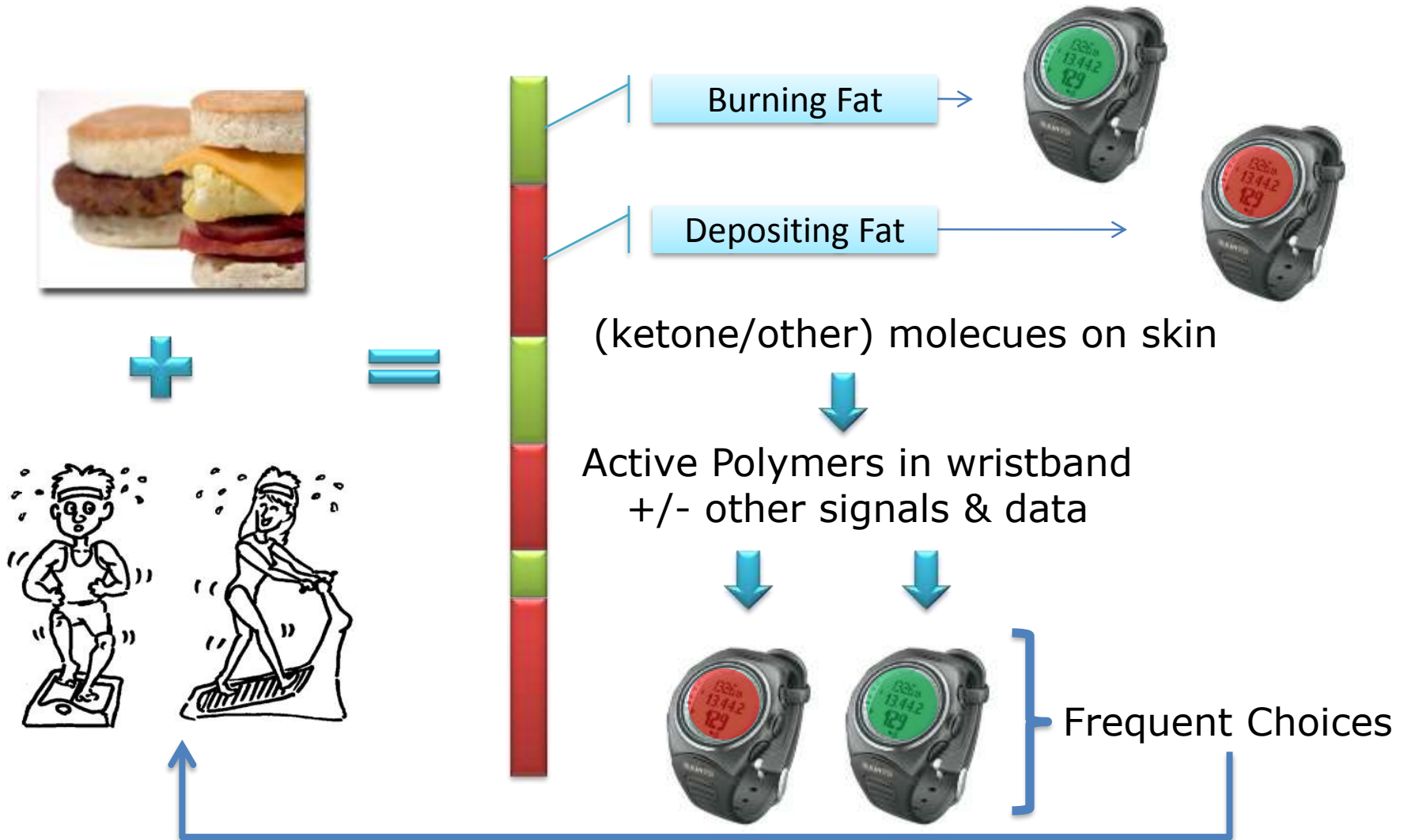
Interact

Social Marketing

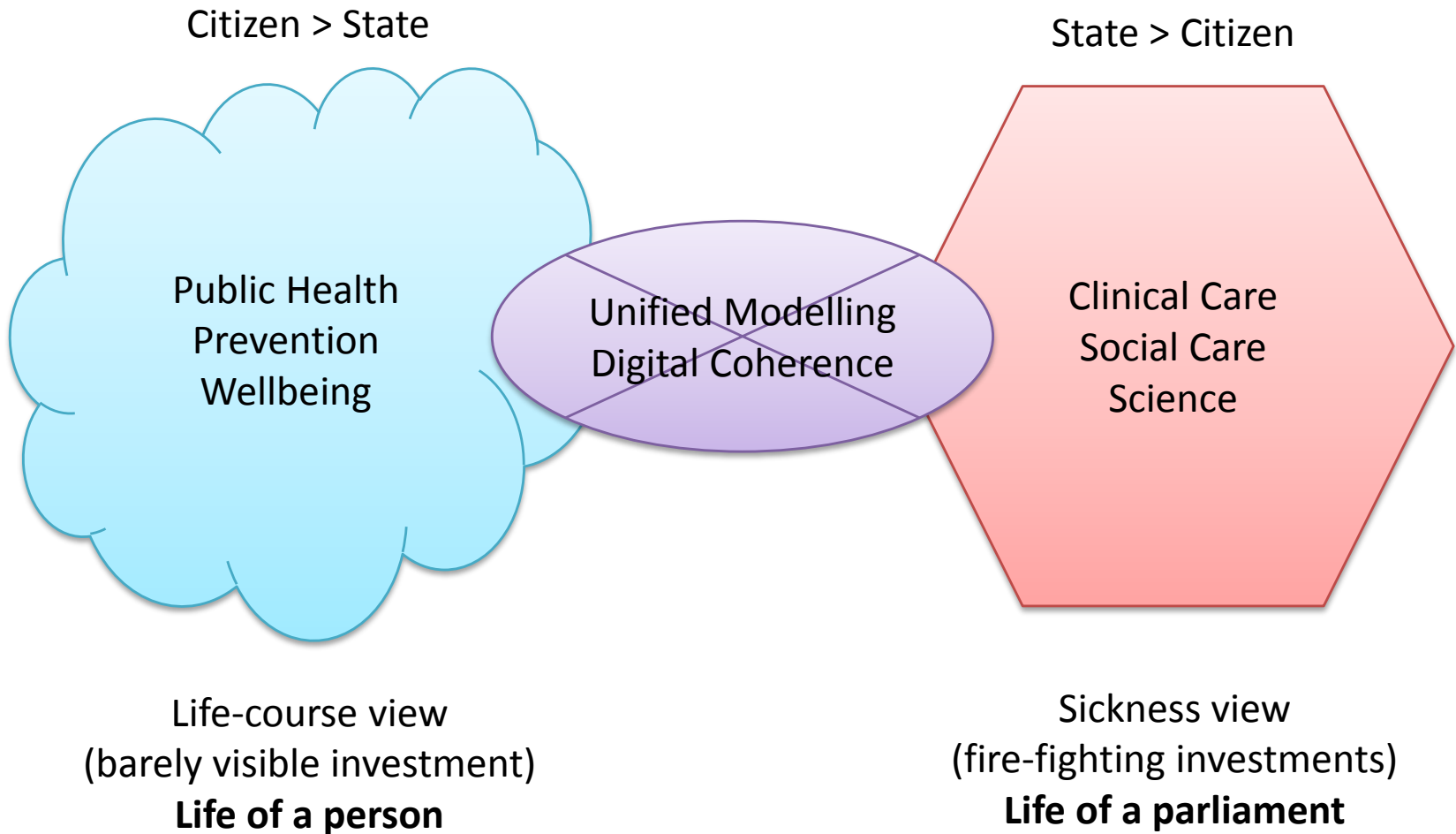
Social Networks

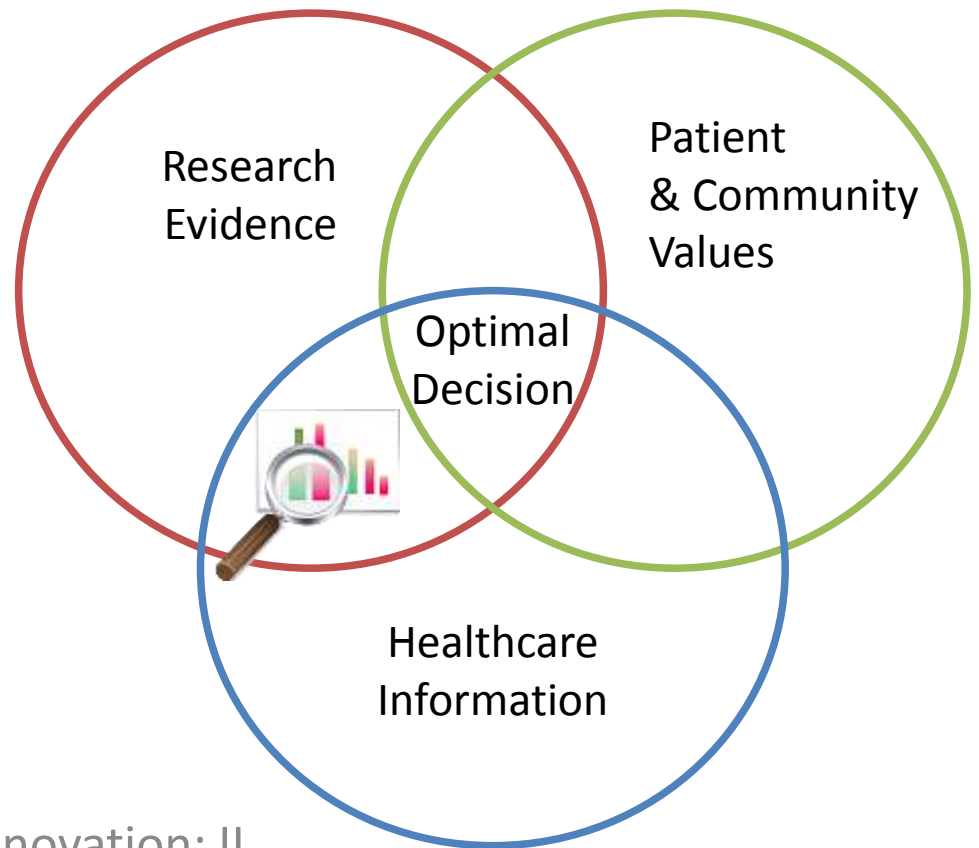


Re-wire the brain to resist over-malnutrition?



Care costs escalate without prevention





Public Health Needs for Digital Innovation: II

DYNAMIC LINKAGE OF RESEARCH INTO PRACTICE AND PRACTICE INTO RESEARCH

Healthcare Problem: **Gaps** in Communication & Organisation

Self Care

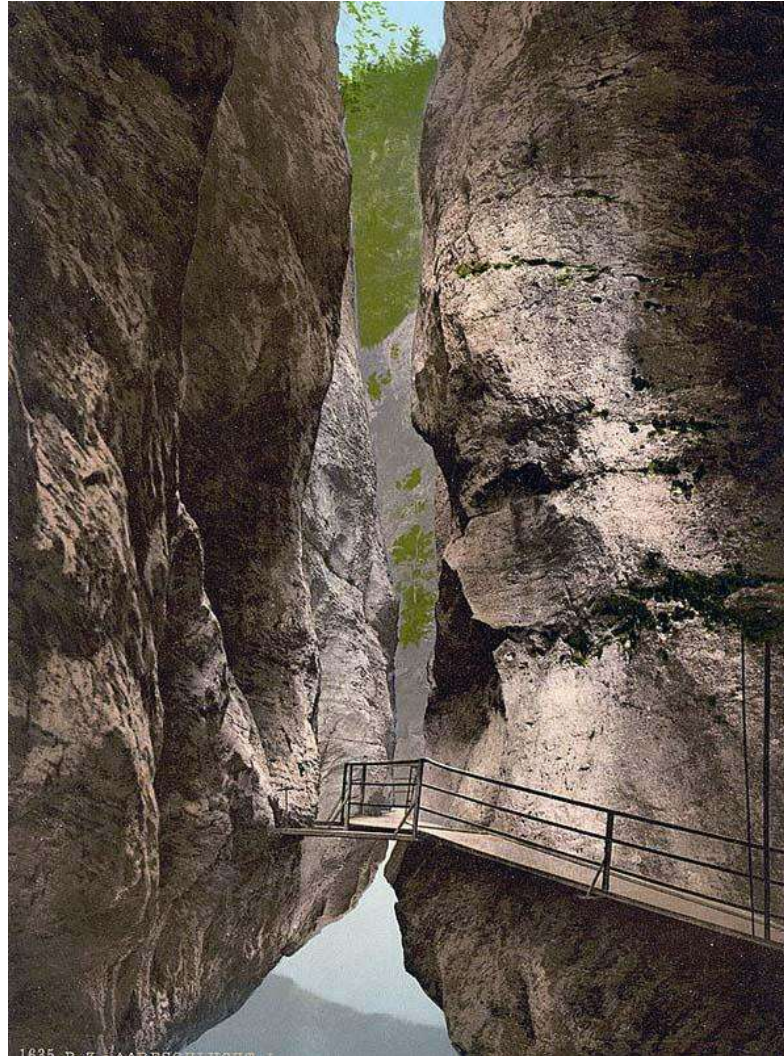
Clinical Care

Primary Care

Secondary Care

Hospital A

Hospital B



Digital Bridges Since 1990s: Integrated Care Pathways (Disease-specific)

Self Care

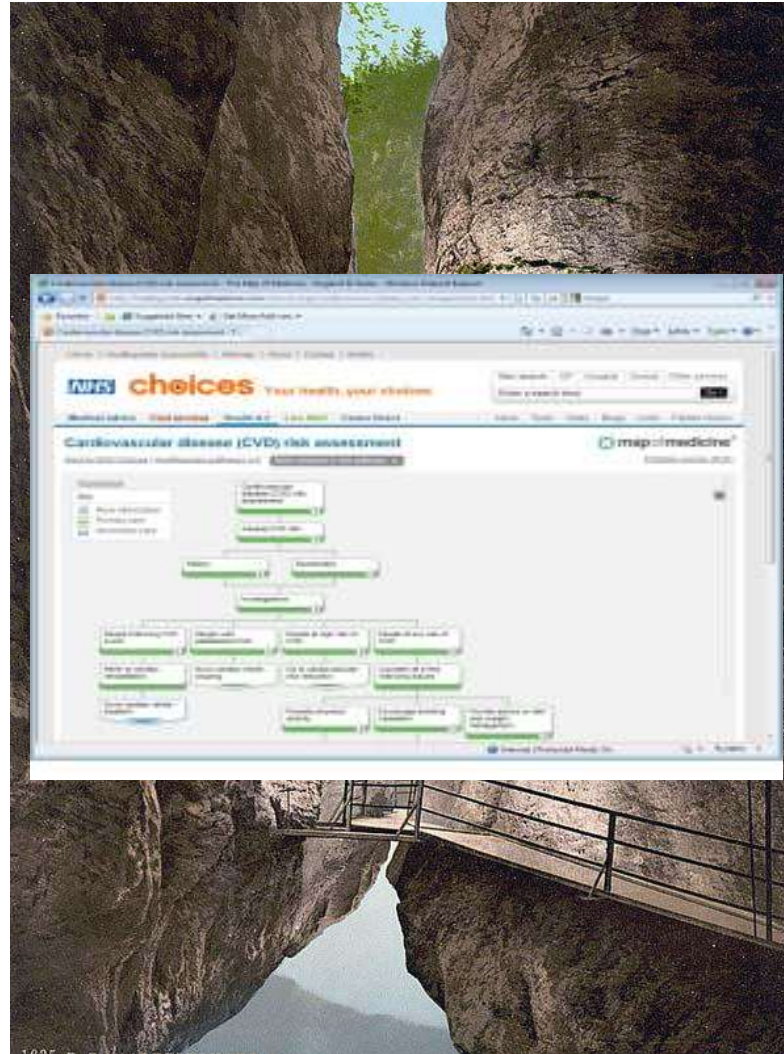
Clinical Care

Primary Care

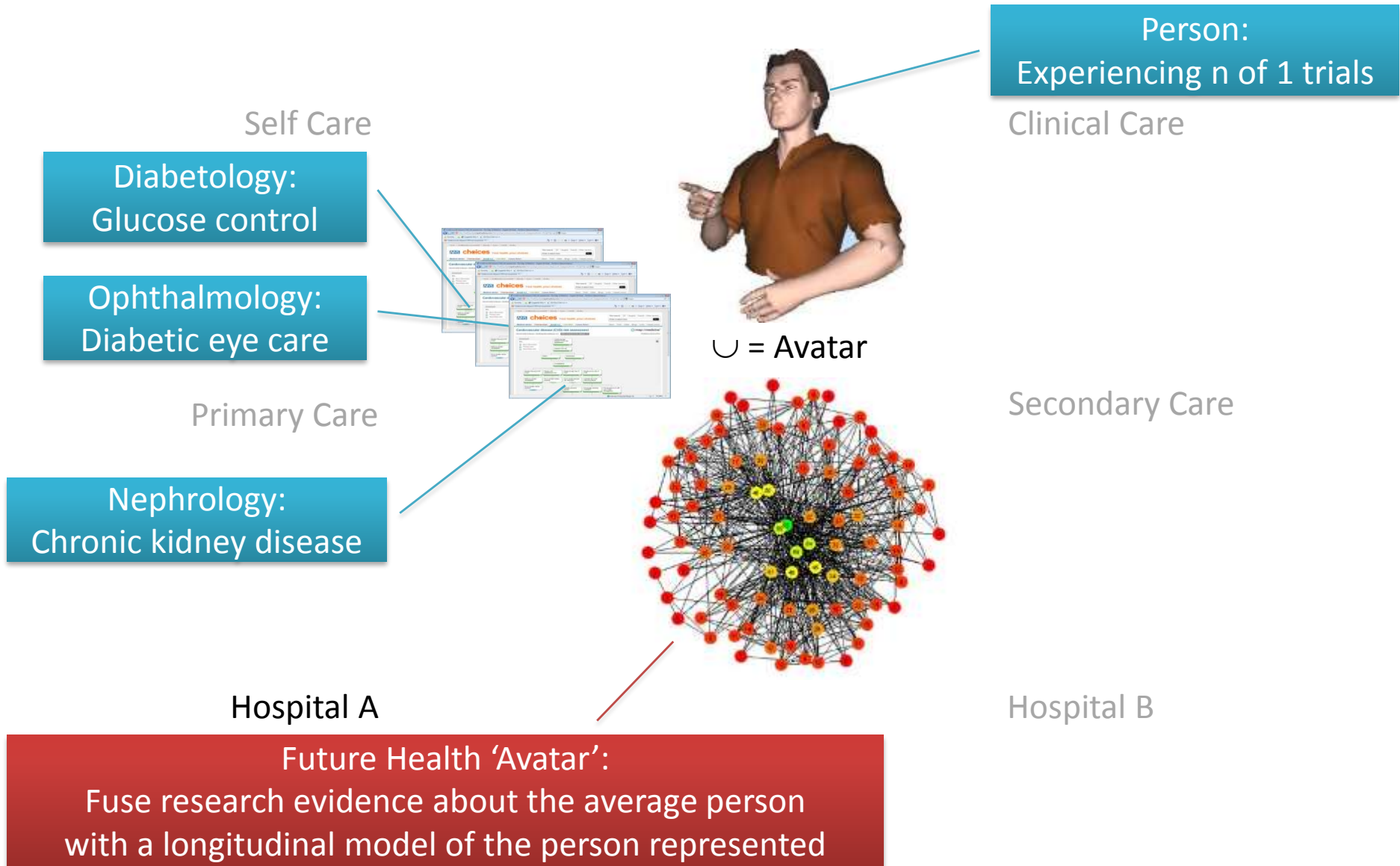
Secondary Care

Hospital A

Hospital B



Missing: Patient & Community
'Big-picture' Across Disease / Specialist Pathways



Person:
Experiencing n of 1 trials

Clinical Care

Self Care

Diabetology:
Glucose control

Ophthalmology:
Diabetic eye care

Primary Care

Nephrology:
Chronic kidney disease

U = Avatar

Secondary Care

Hospital A

Hospital B

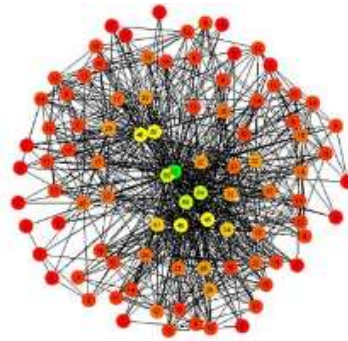
Future Health 'Avatar':
Fuse research evidence about the average person
with a longitudinal model of the person represented

Health Records & Knowledge Bases

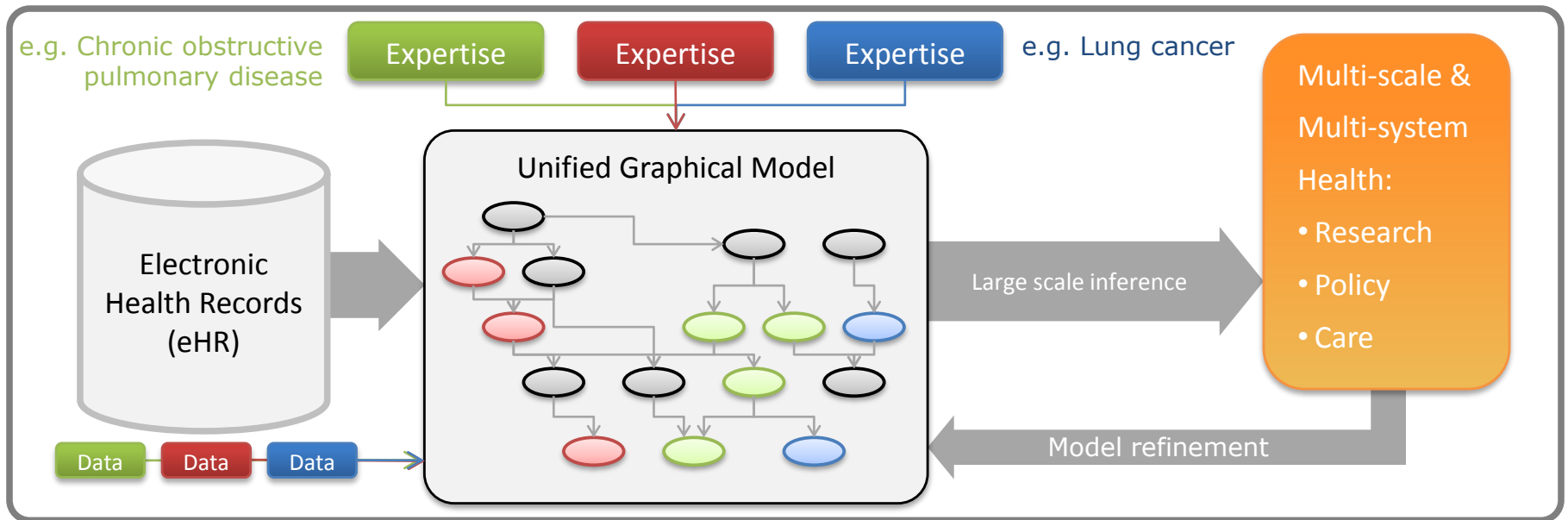
Data-intensive Paradigm -shift

Health Avatars & Dynamic Models

Open Unifying Modelling:
Across mechanisms and contexts



∪ models = Avatar

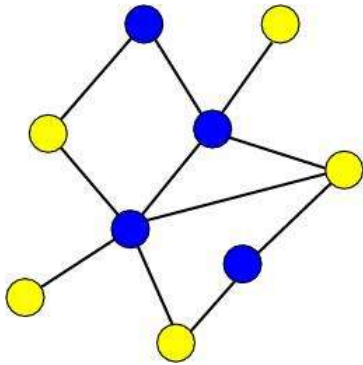


Trans-disciplinary Analysis of Clinical Research Data

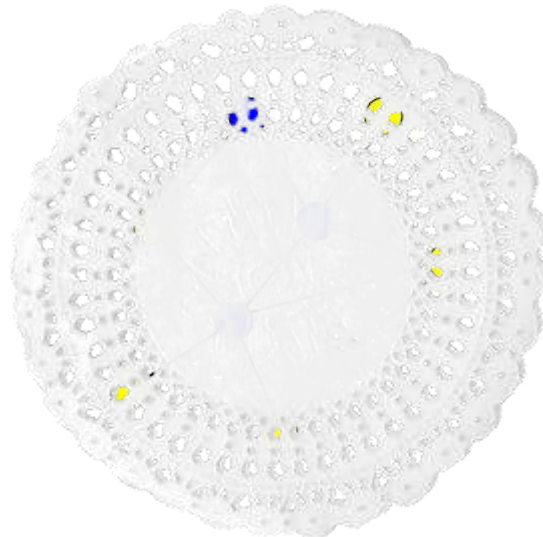
Machine Learning in Epidemiology...

Introducing Health Sciences Signal Paths to Physical Scientists & Engineers

Problem Space



Observation Space



Data Space

	Genotype	100	101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120
Sample1	0101	0000	1000	1000	1010	1010	1010	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000
Sample2	1000	0000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000
Sample3	0101	0000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000
Sample4	0101	0000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000
Sample5	0101	0000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000
Sample6	0101	0000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000
Sample7	0101	0000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000
Sample8	0101	0000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000
Sample9	0101	0000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000
Sample10	0101	0000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000	1000

$$y = b_1x_1 + b_2x_2 + b_3x_3 + c$$

...like resolving an image through a prism through a doyley

Hypothesis-driven Epidemiology: Sieving Associations

Association	Bias	Type	Explanation
$C \rightarrow M$	Cause-effect	Real	Cause-effect
$MI \rightarrow C$	Reverse	Real	Effect-cause
$C \leftarrow ? \rightarrow MI$	Confounding	Real	Effect-effect
$C \not\leftrightarrow MI$	Random error	Spurious	Chance
$C \not\leftrightarrow MI$	Systematic error	Spurious	Bias

C = caffeine, MI = myocardial infarction (heart attack)

Disciplined approach to causal inference, Bradford-Hill:
Criteria (temporality, strength, dose-response,
consistency, plausibility, consideration of alternatives,
open to experiment, specificity, coherence)

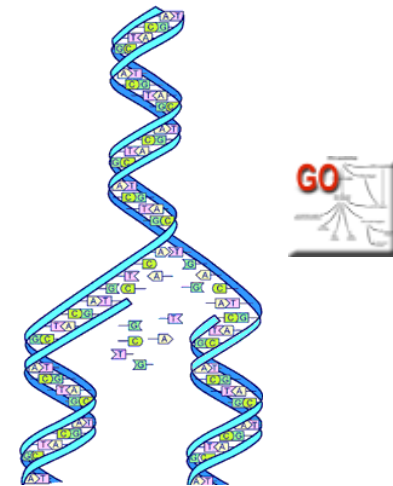


Need to Address Complexity & Scale

Problem 1:
Dwindling hits from tools to
detect independent “causes”



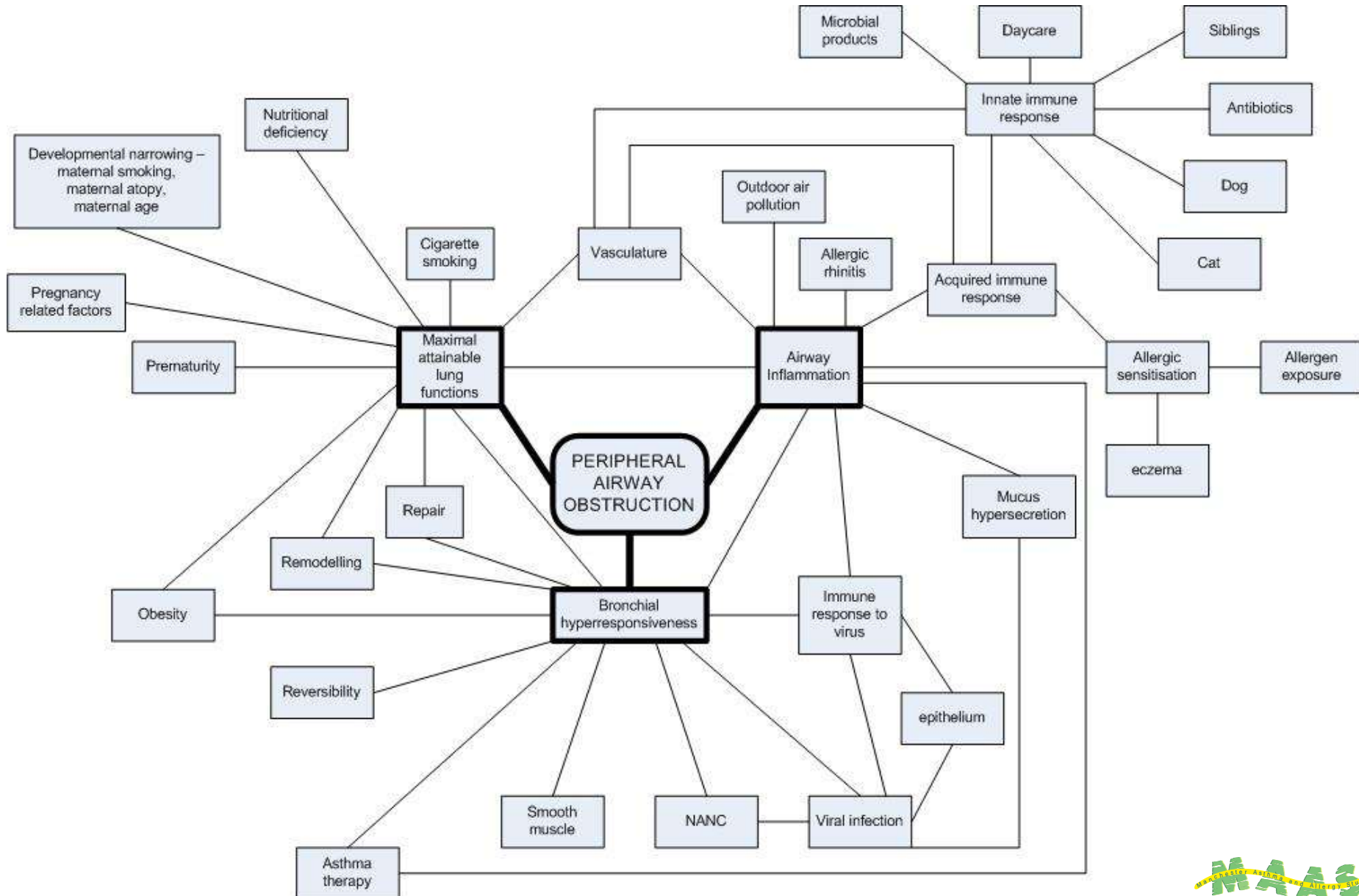
Problem 2:
Knowledge can't be managed
by reading papers any more



The big public health problems
e.g. Type 2 Diabetes
have “complex webs of causes”

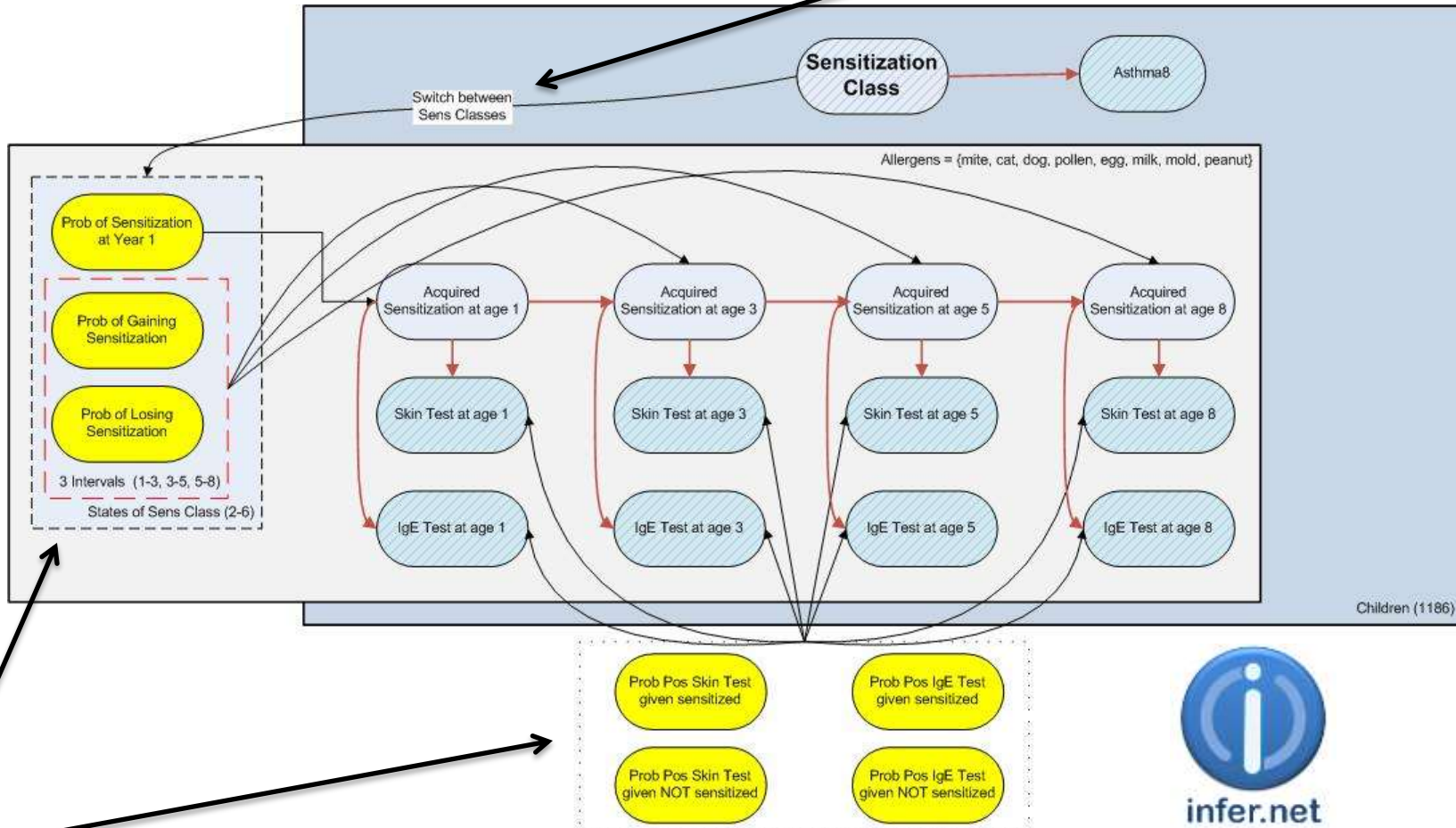
The “data-set” and structure
extend beyond
the study's observations

A Graphical Model of Asthma



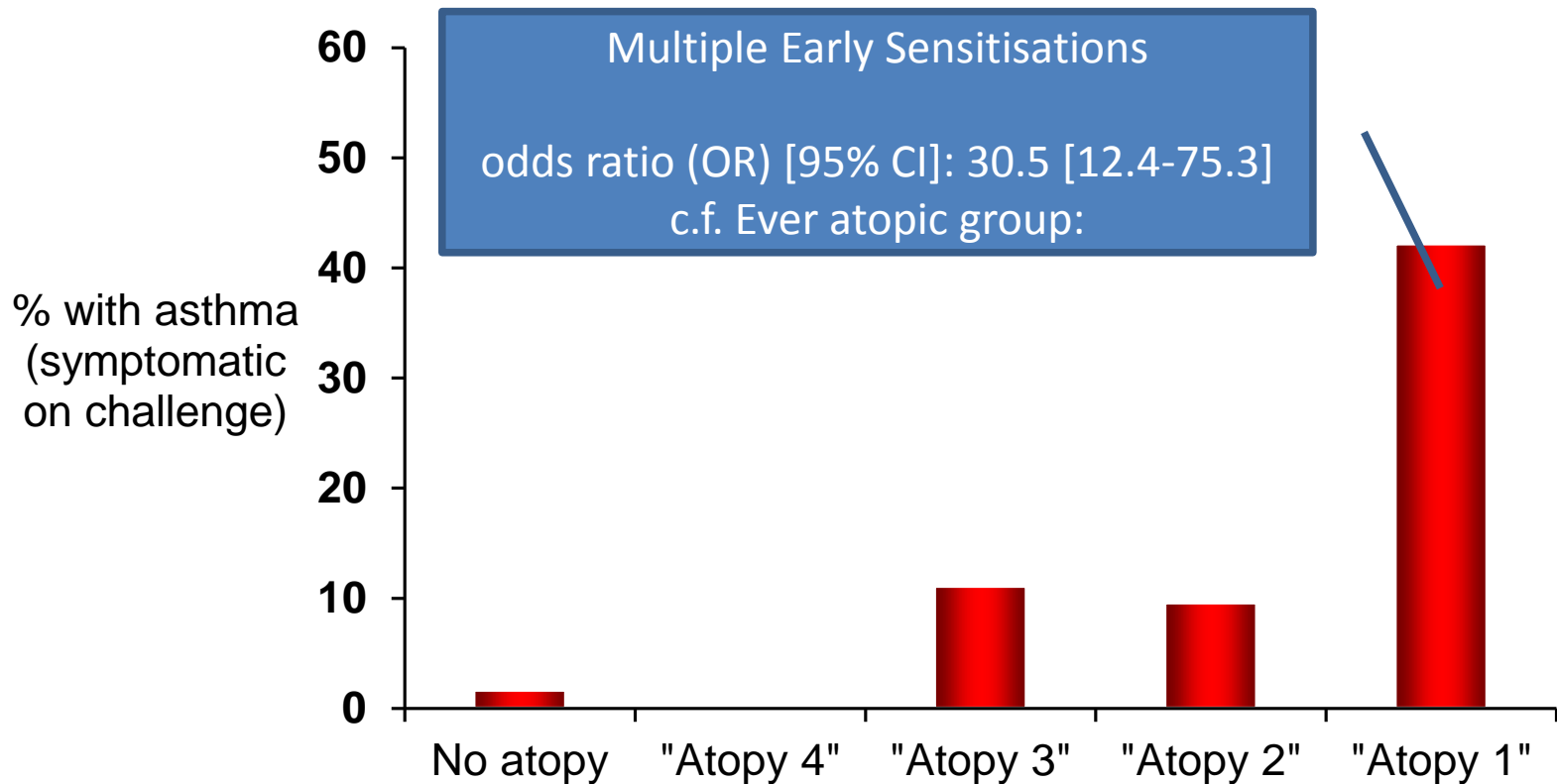
The Atopy Model

Unsupervised Clustering



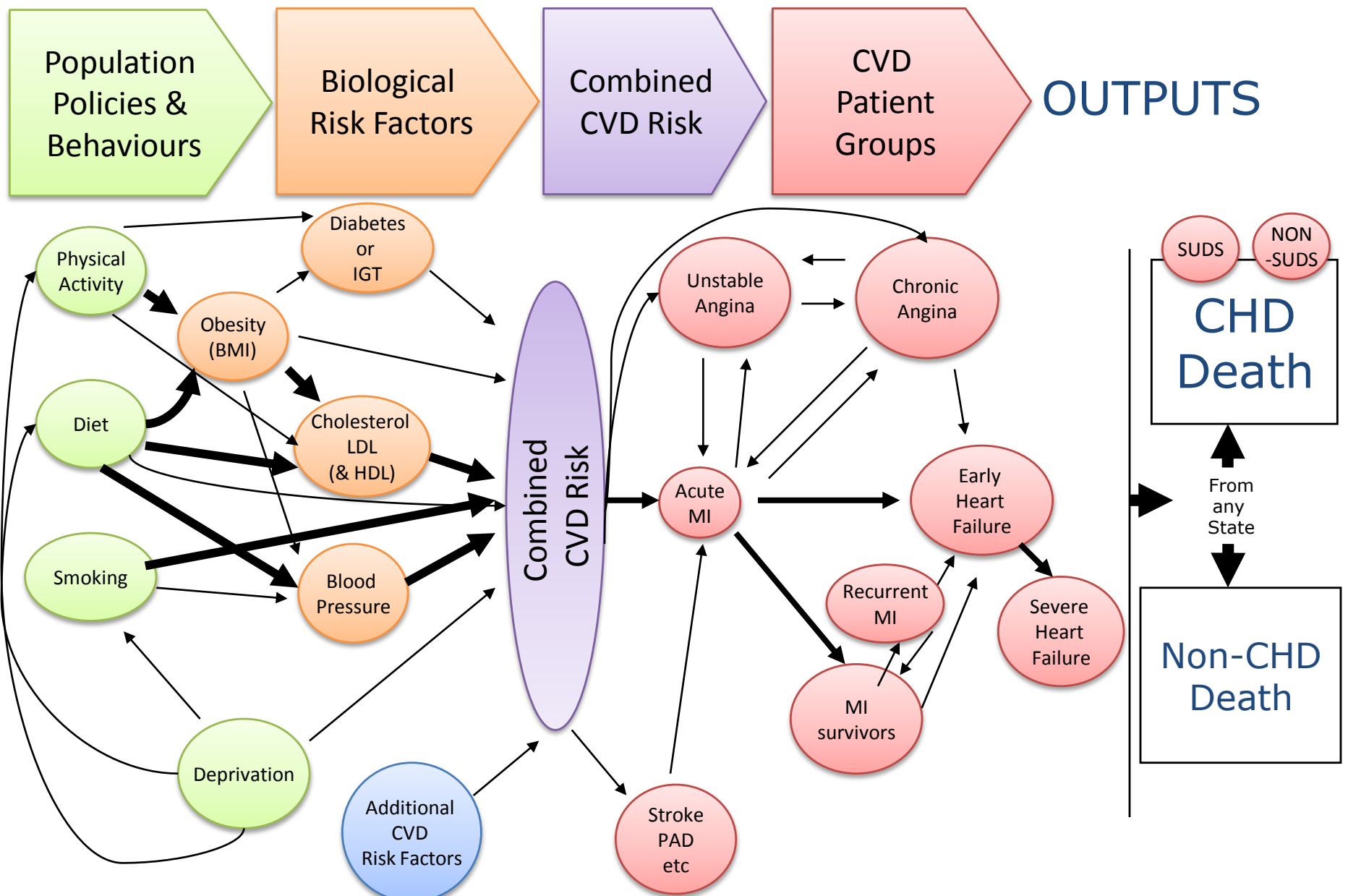
To Infer

Atopy Classes and Asthma




Trans-disciplinary Simulation of Public Health Impacts

Digital Assets → Policy Decisions...



Pulling evidence together into one, realistically-complex model: e.g. MRC IMPACT II

Outputs: Population-based incidence, prevalence; Deaths prevented; Life-Years; Life expectancy; Costs; Cost-effectiveness ratios











 You can now see the interventions which have effect in the selected node. Each intervention has an average Risk reduction for all patients in the selected state and can be changed. You can also use the drop down box to switch between adherence and availability.

[Add Intervention](#) [Add Node](#) [Add Edges](#) [Remove Selected Nodes](#) [Remove Selected Edges](#) [Remove Selected Interventions](#) [Hide Edges to Death States](#)

Risk reduction | Constraints | Transition distributions | Cooling schedule

Gender: Male Female

Lifetime Sub-Distribution Function
Probability of a person of a specific age moving from MI_Survival to ... before all other nodes, within time t.

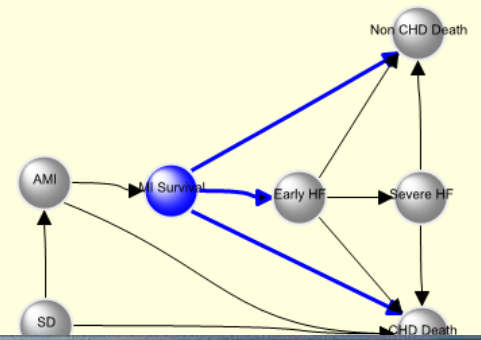
Age	t	EarlyHF	NonCHDDeath	CHDDeath	Weight
20	1	0.01 fitted	0.0233 fitted	0.005 fitted	1.0  
30	1	0.02 fitted	0.052 fitted	0.007 fitted	1.0  
40	1	0.03 fitted	0.061 fitted	0.008 fitted	1.0  
50	1	0.05 fitted	0.07 fitted	0.012 fitted	2.0  
60	1	0.02 fitted	0.001 fitted	0.05 fitted	1.0  

[Add Constraint](#)

Survival Function
Probability of a person of a specific starting age still being in MI_Survival at time t.

[Add Constraint](#)

Node	MI Survival
Description	null
QALY	0



Recombine evidence around probabilistic graphical models of disease & care-services


http://localhost:54561/Editor/ModelEdit/12 - Windows Internet Explorer

http://localhost:54561/Editor/ModelEdit/12

sample normal distribution excel











http://localhost:54561/Editor/ModelEdit/12

2. Model

 You can now see the interventions which have effect in the selected node. Each intervention has an average Risk reduction for all patients in the selected state and can be changed. You can also use the drop down box to switch between adherence and availability.

[Add Intervention](#) [Add Node](#) [Add Edge](#) [Remove Selected Nodes](#) [Remove Selected Edges](#) [Remove Selected Interventions](#) [Hide Edges to Death States](#)

Risk reduction | Transition probabilities

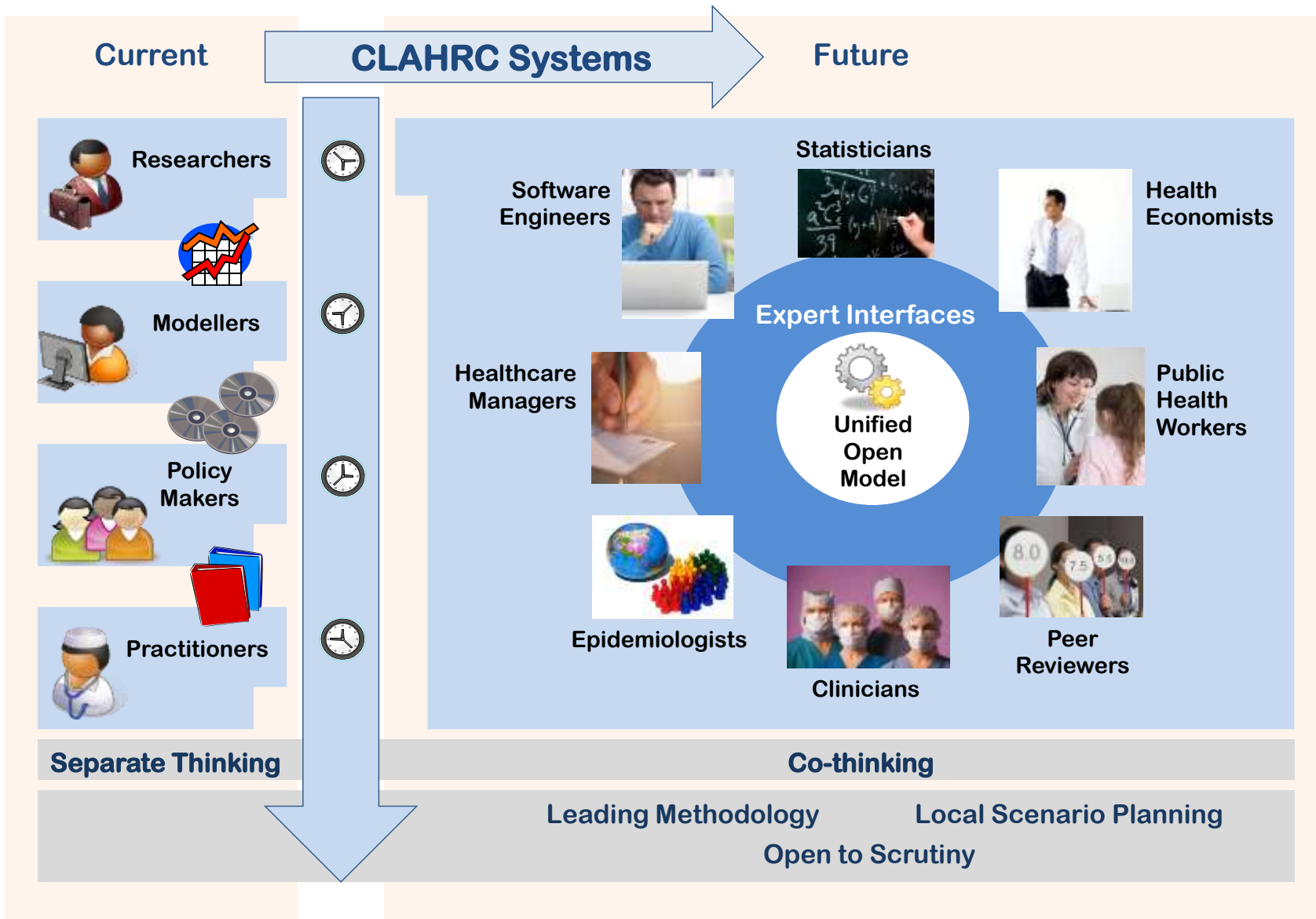
<input checked="" type="checkbox"/> ACEI	78%	 
<input type="checkbox"/> Aspirin	69%	 
♂ 0 - 33 yrs	63%	
♂ 34 - 89 yrs	63%	
♂ 90 - 120 yrs	63%	
♀ 0 - 40 yrs	74%	
♀ 41 - 91 yrs	74%	
♀ 92 - 120 yrs	74%	
<input checked="" type="checkbox"/> Beta blockers	78%	 
<input type="checkbox"/> Rehab	78%	 
♂ 0 - 120 yrs	78%	
♀ 0 - 120 yrs	78%	
<input checked="" type="checkbox"/> Statins	47%	 

```

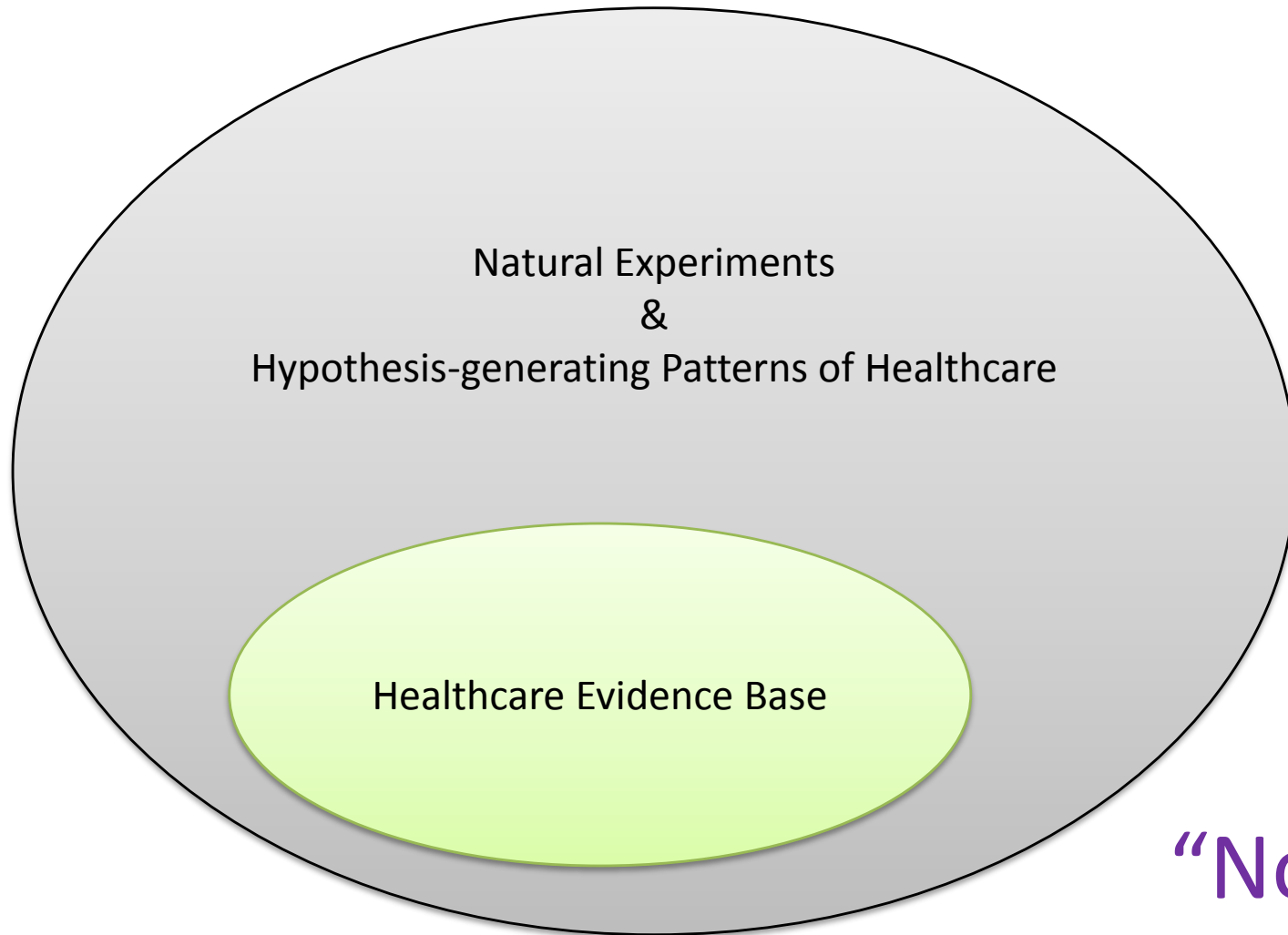
    graph LR
      CA((CA)) --> AMI((AMI))
      CA((CA)) --> CHD_Death((CHD Death))
      AMI((AMI)) --> MI_Survival((MI Survival))
      AMI((AMI)) --> Early_HF((Early HF))
      MI_Survival((MI Survival)) --> Early_HF((Early HF))
      MI_Survival((MI Survival)) --> CHD_Death((CHD Death))
      MI_Survival((MI Survival)) --> Resurgence((Resurgence))
      Early_HF((Early HF)) --> Severe_HF((Severe HF))
      Severe_HF((Severe HF)) --> CHD_Death((CHD Death))
      Severe_HF((Severe HF)) --> Non_CHD_Death((Non-CHD Death))
  
```

Ask 'what if'
invest in statins
vs. smoking cessation
etc.

Open Unified Models for Health Policy

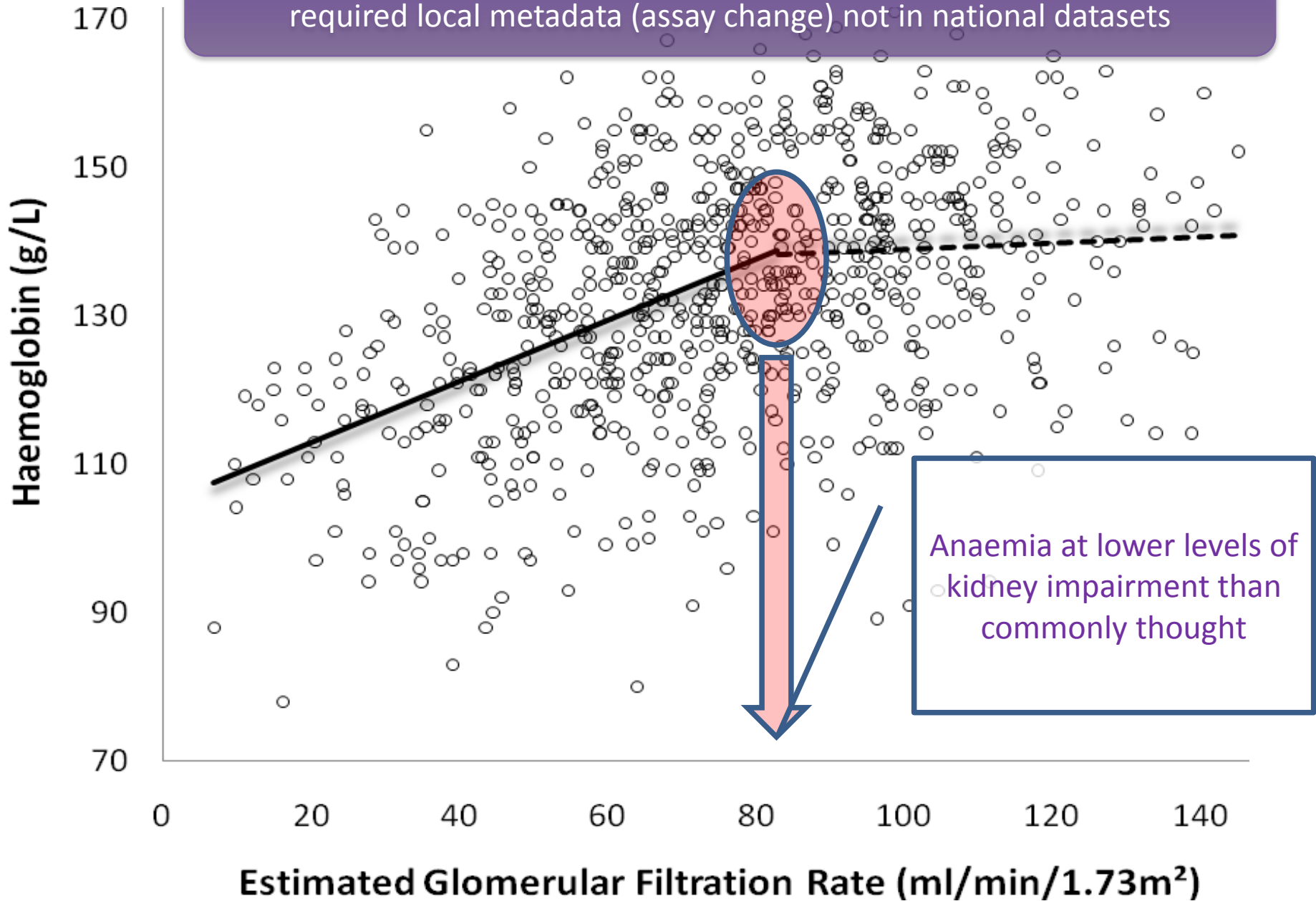


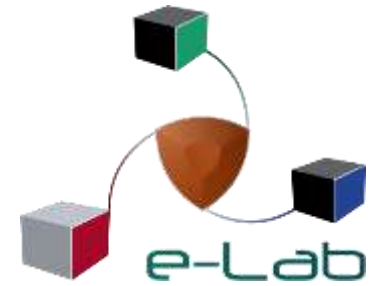
Can models be built from literature?



“Not fully”

Clinical (audit) question leading to scientific finding:
required local metadata (assay change) not in national datasets

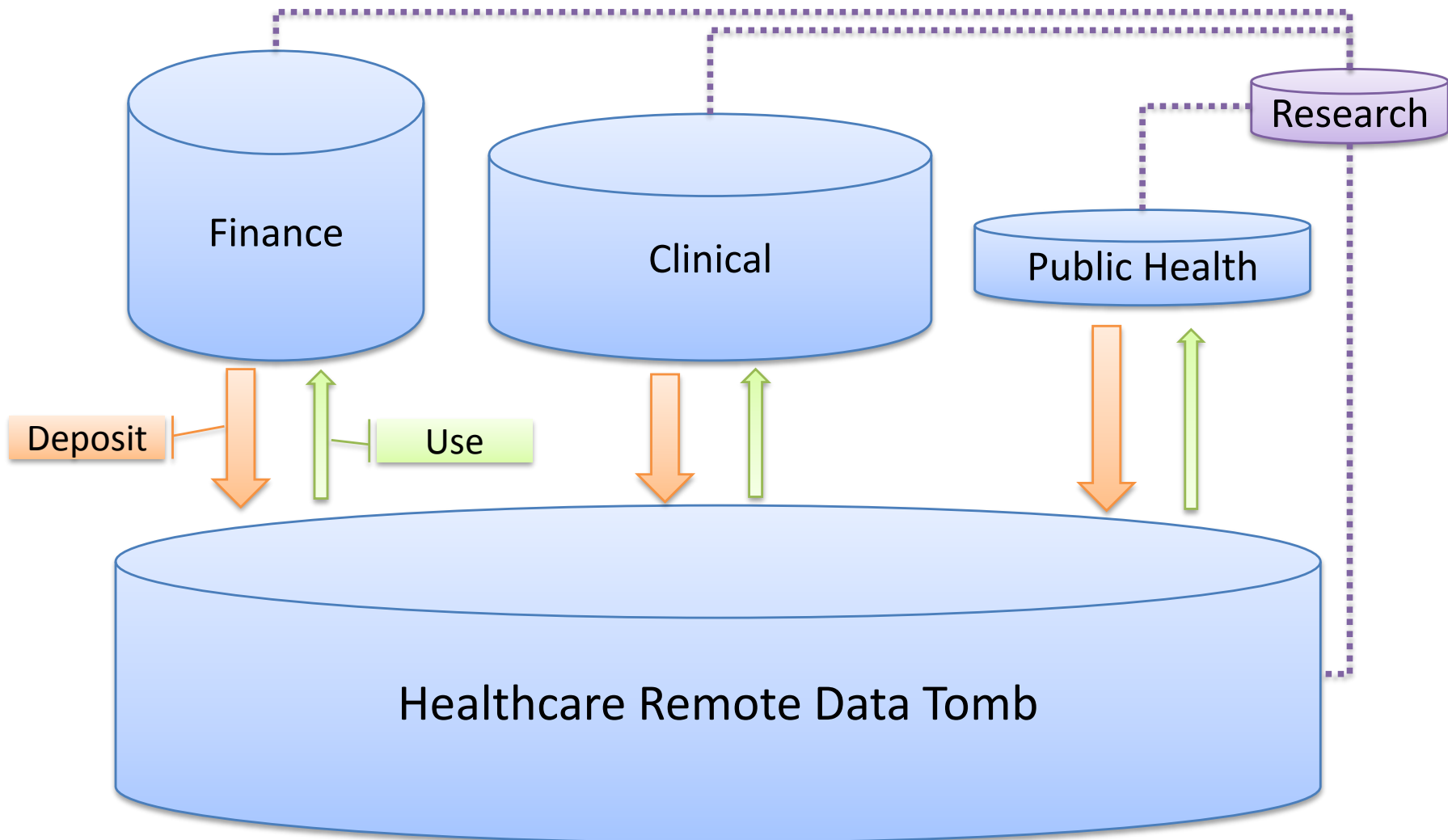




Framework for Digital Research in Healthcare: I

DIGITAL & OPERATIONAL INFRASTRUCTURE: E-LAB

Digital Dust (data deposit > use)



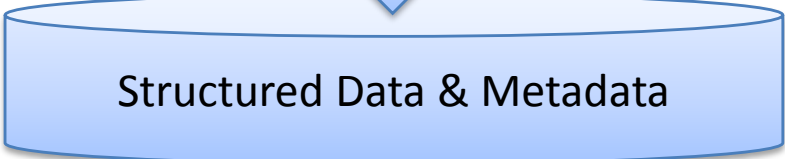
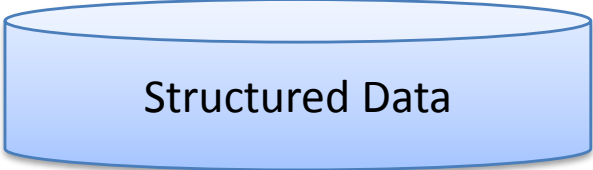
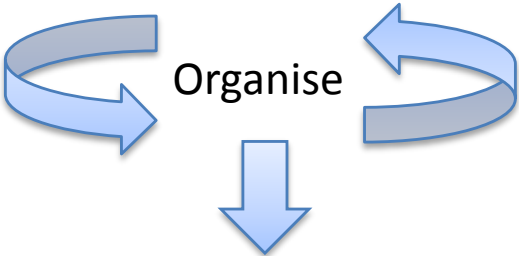
Data supply is not the bottleneck

Methods/Models ↑

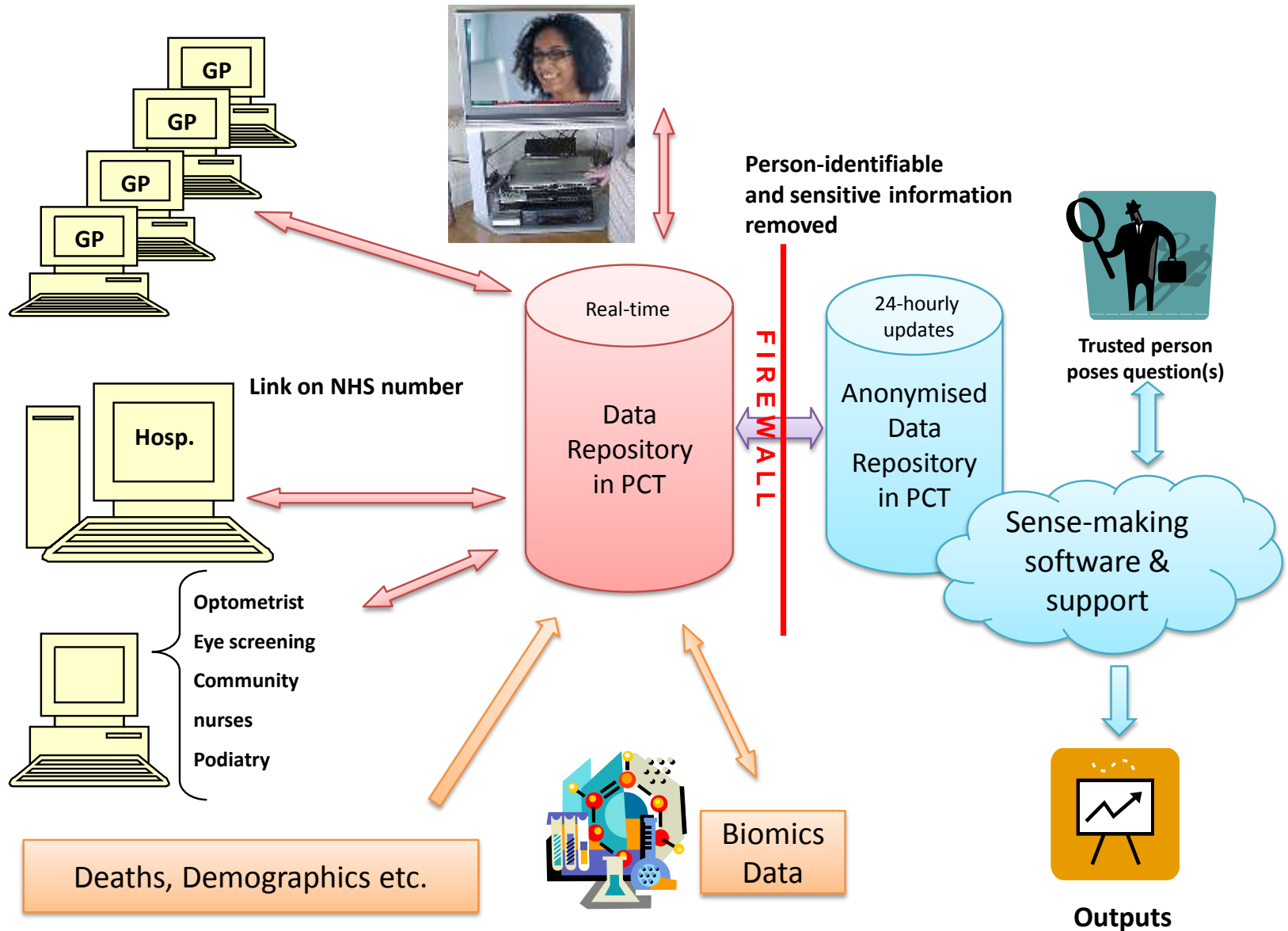


Contextual expertise ↔

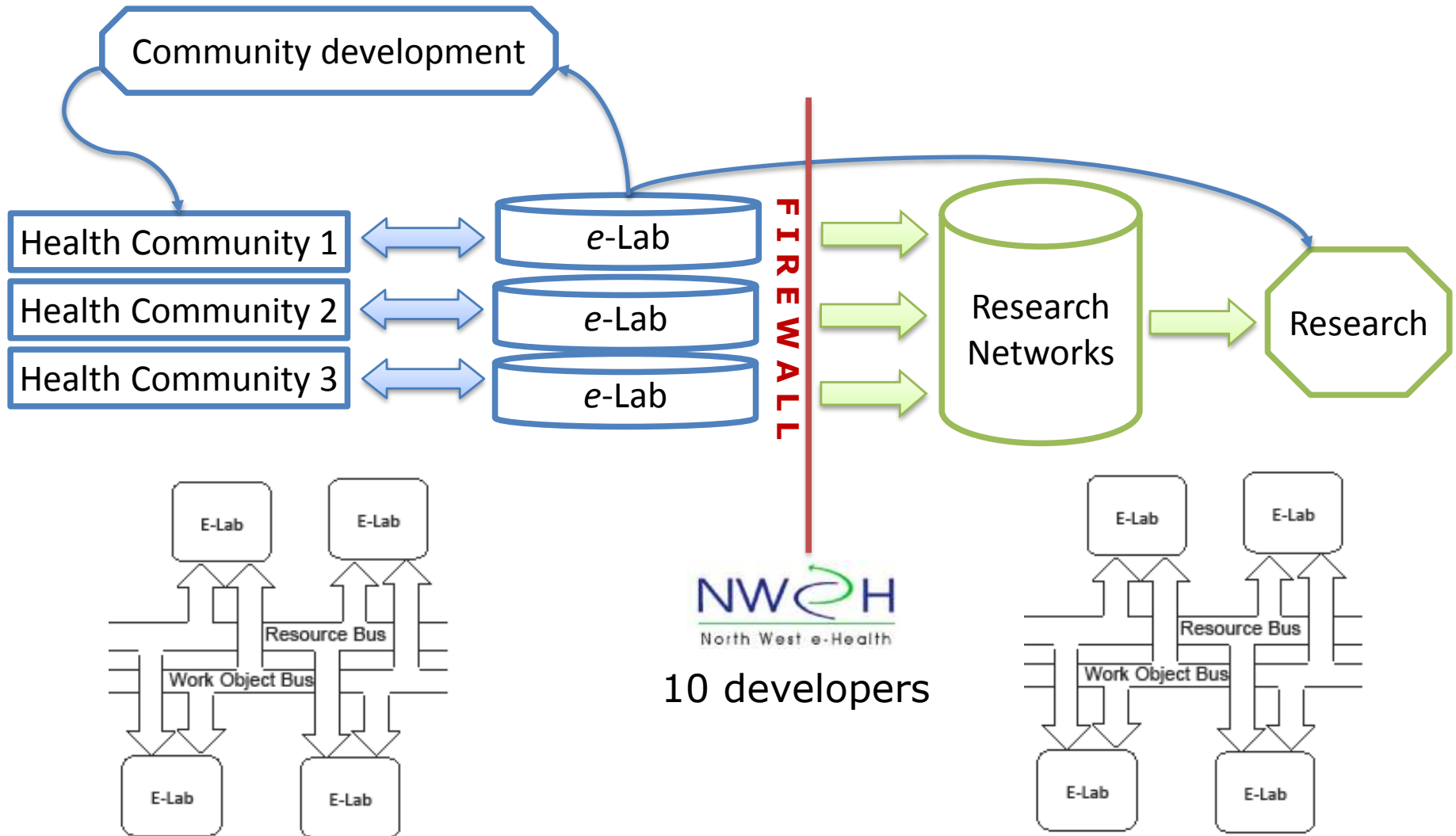
Data ↑↑↑



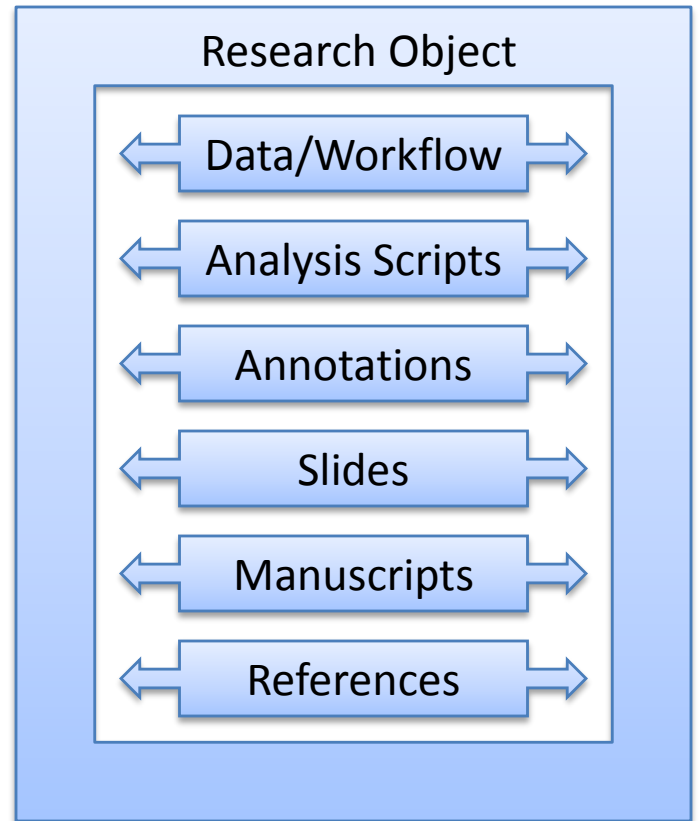
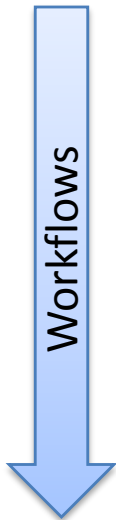
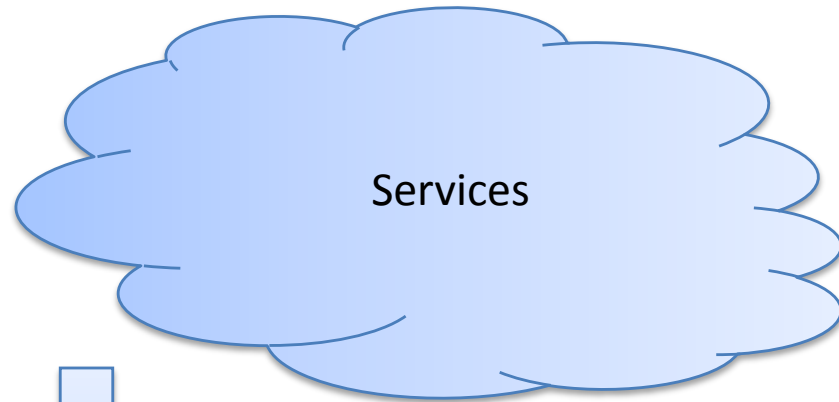
NHS e-Lab: Salford Pilot



Federation: More local use → better quality data

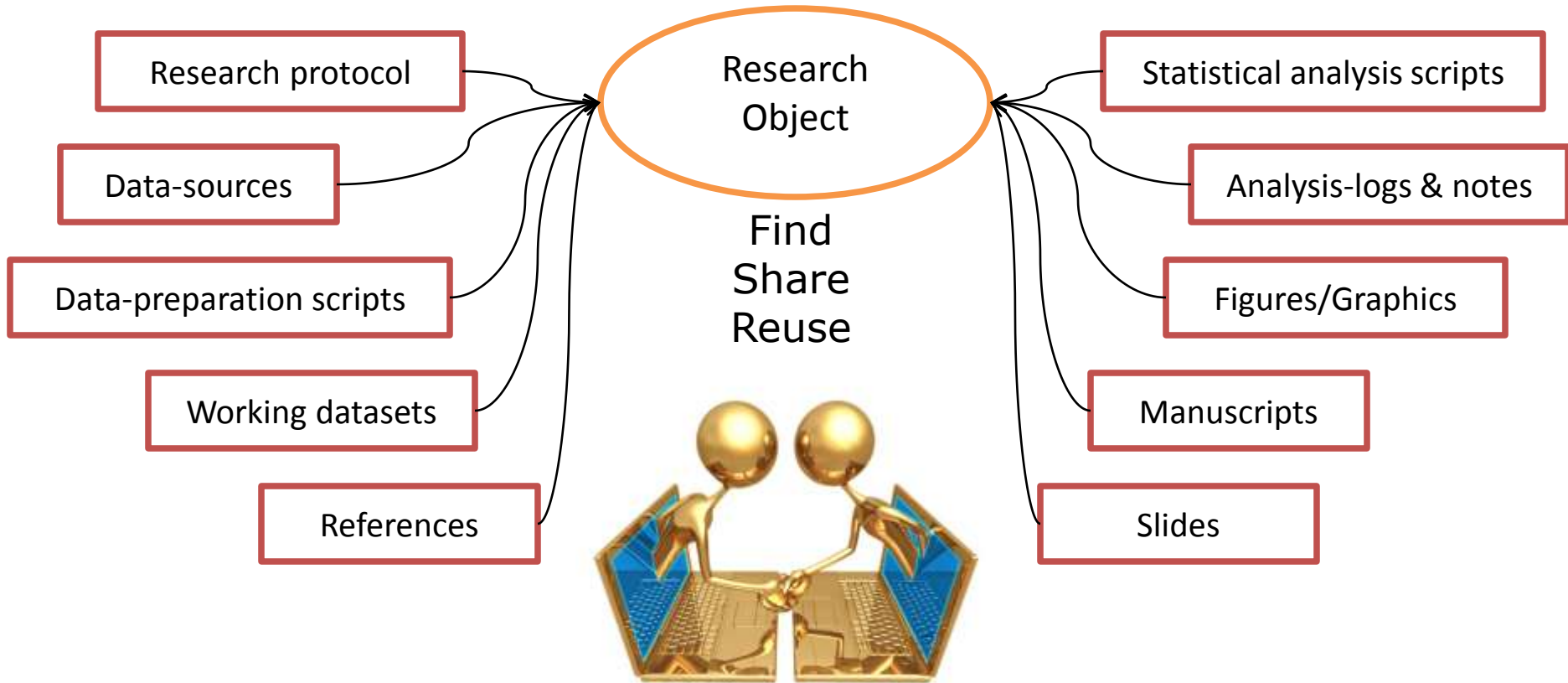


Work/Research Object



Encapsulated → (DAG) discovery?

e-Lab



Socially-stimulating science, in-silico

Prototype NHS e-Lab

settings

Project Details

- Data
- Documents
- Data Exploration
- Notes
- Snapshots
- People
- Help

Project Details

What it life expectancy for wards in Salford

This is to answer the question of life expectancy in Salford with deprivation information for wards



Data

- Life Expectancy
- Life Tables



Documents

- LifeExpectancy.csv



Data Exploration

You have not added any explorations to your project. Add an exploration here.



Notes

- What it life expectancy for wards in Salford



Snapshots

You have not added any snapshots. You can add a snapshot by browsing your [Data](#) and creating charts and maps.



People

- gary

settings

Data

Project Details

Data

Documents

Data Exploration

Notes

Snapshots

People

Help

Life Expectancy

Show Details

Add a Note...

Add a File...

View data as grid

View data as chart

View data as map

WardCode	WardName	LifeExpectanc	DeprivationSc	IsHighDeprivz	IsHighDeprivz	DiabetesPrev;	CvdPrevalenc	DiabetesPrev;	DiabetesPrev(
00BRFA	Barton	73	3.342892	false	true	8	10	9	7
00BRFB	Blackfriars	70	7.474104	true	true	5	6	6	4
00BRFC	Broughton	70.1	8.241365	false	true	10	15	11	9
00BRFD	Cadishead	72.3	1.498242	true	false	3	4	5	2
00BRFE	Claremont	74	0.4376208	false	false	3	5	4	2
00BRFF	Eccles	73.4	2.245419	false	false	3	4	5	2
00BRFG	Irlam	70.2	0.8358688	false	false	3	3	4	2

🔍 🔄 🗑️

Page 1 of 2 10

View 1 - 10 of 20

settings

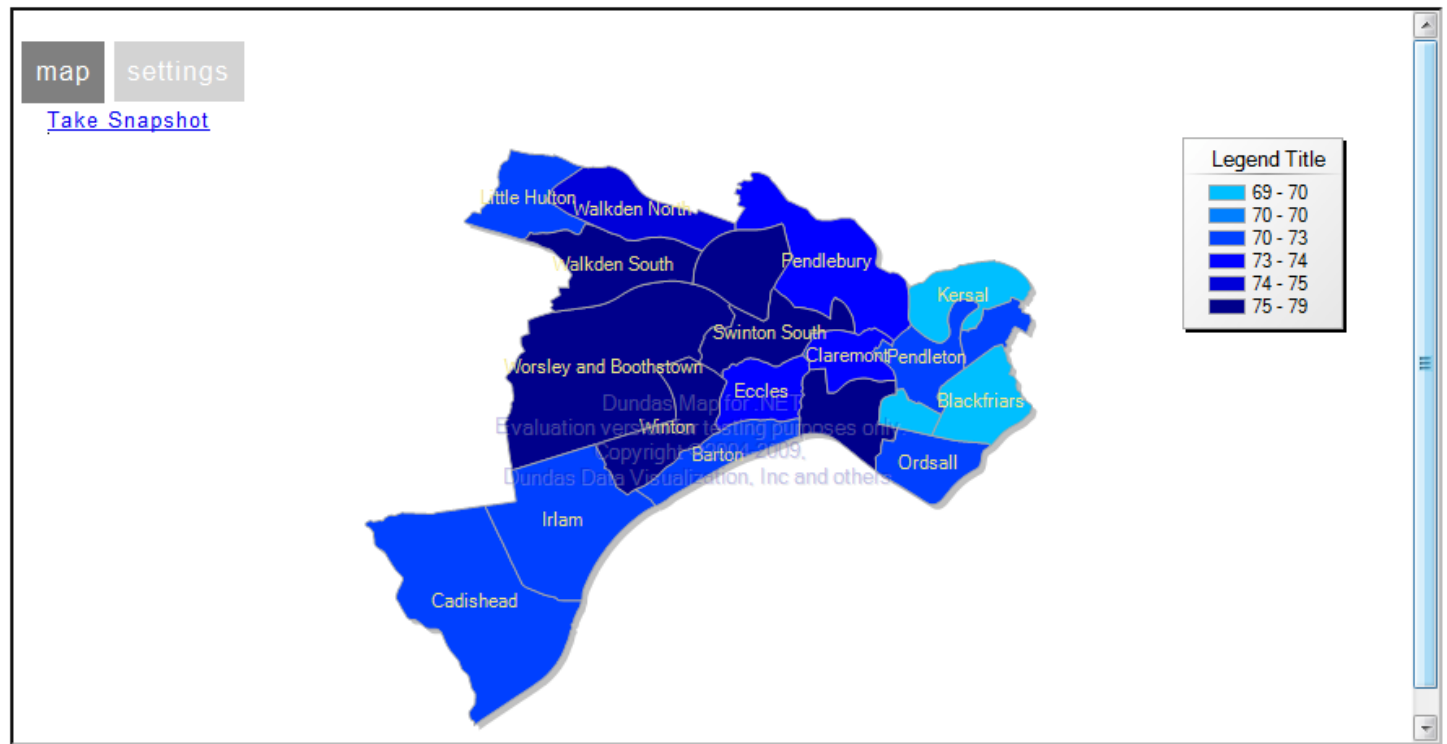
- Project Details
- Data**
- Documents
- Data Exploration
- Notes
- Snapshots
- People
- Help

Data

Life Expectancy

- Show Details
- Add a Note...
- Add a File...

- View data as grid
- View data as chart
- View data as map**



[Next: Merge with visualisation research](#)



Digital Curators Promoting Healthcare Innovation: I

ETHICS

Ethical Principles

- Respect for autonomy
- Beneficence
- Non-maleficence
- Justice

Respect for Autonomy

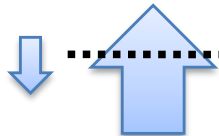
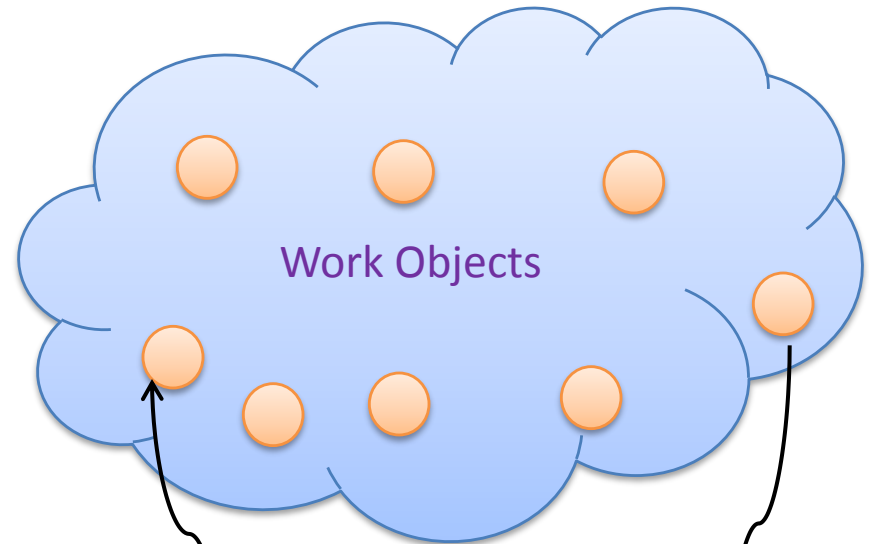
- Patient/subject
 - Consent
 - Opt-in
 - Opt-out
 - Right to participate or not
 - Advocates where appropriate
 - Clinical; carer; guardian; data custodian
- Investigator
 - Access to patients/citizens?

Beneficence

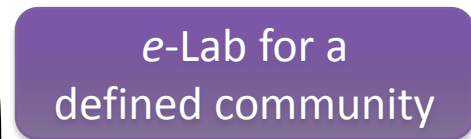
- Duty to deliver good for the data donors
- Under-use is unethical
- Audit the context of use
- Measuring good
 - Research quality
 - Clinical utility
 - Patient/citizen involvement

Unclear Public Good

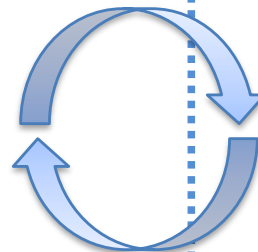
Clear Public Good



De-identify



Local Ownership



Asset Enrichment



Non-maleficence

- Part of NHS & University contracts
- Part of clinical and research information governance protocols
- Not dealt with by restricting access to data

Justice

- Knowing the uses of your health records
- Knowing how your practice is measured
- Fair access to data
- Fair access to methods
- Fair access to models
- Intellectual property protection
- Fair networking opportunities for investigators

Data Curation Example: Obesity e-Lab



The e-Science target:

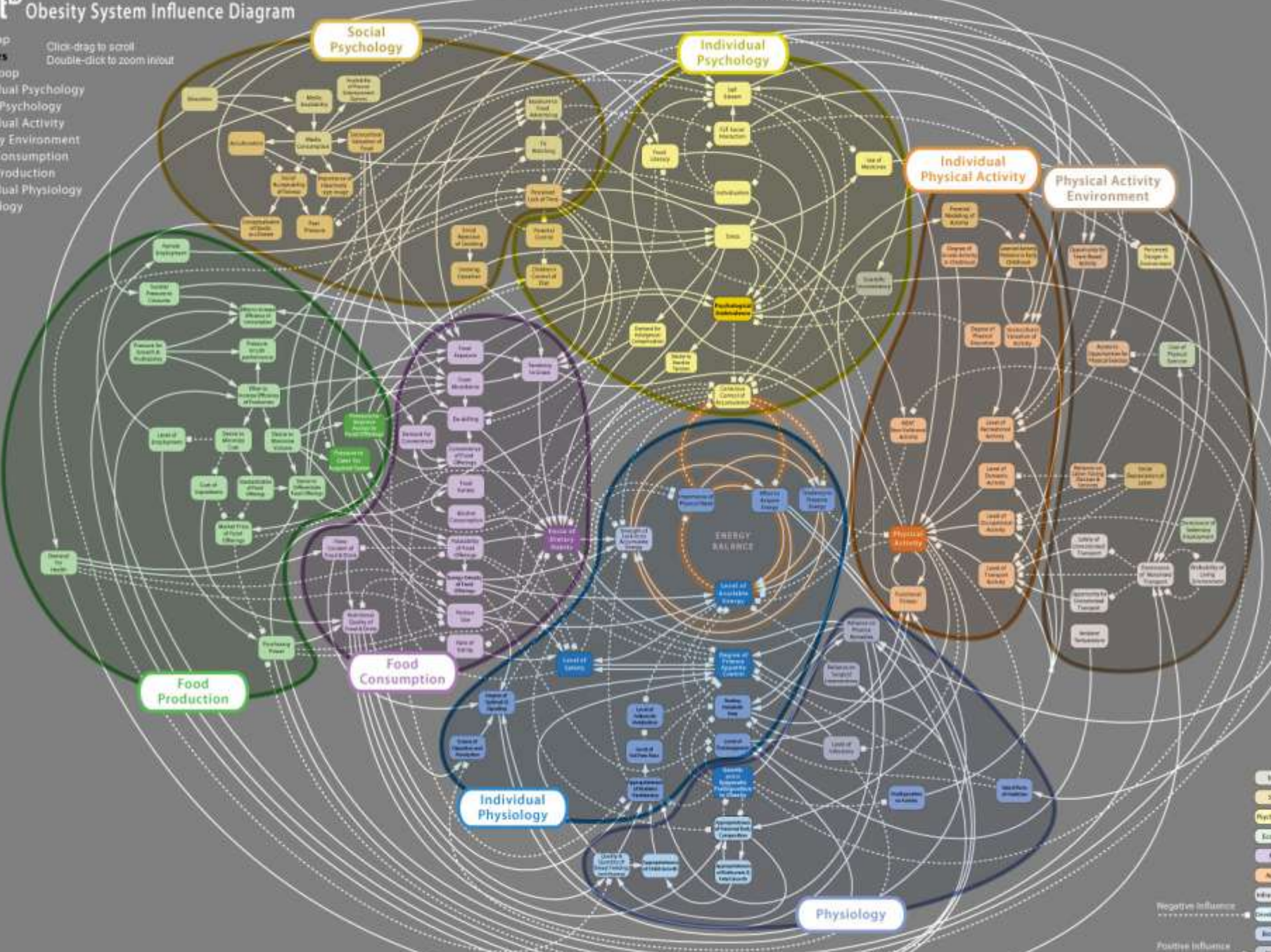
Fragmented understanding of public health problems such as obesity

...data, methods/models and expertise split across disciplines (e.g. Social vs. Biomedical) and settings (e.g. Academia vs. Healthcare)

shift^o Obesity System Influence Diagram

Full Map
Click-drag to scroll
Double-click to zoom in/out

- Core Loop
- Individual Psychology
- Social Psychology
- Individual Activity
- Activity Environment
- Food Consumption
- Food Production
- Individual Physiology
- Physiology



- Social
- Individual Psychology
- Economic
- Food
- Activity
- Individual Physiology
- Biological
- Medical

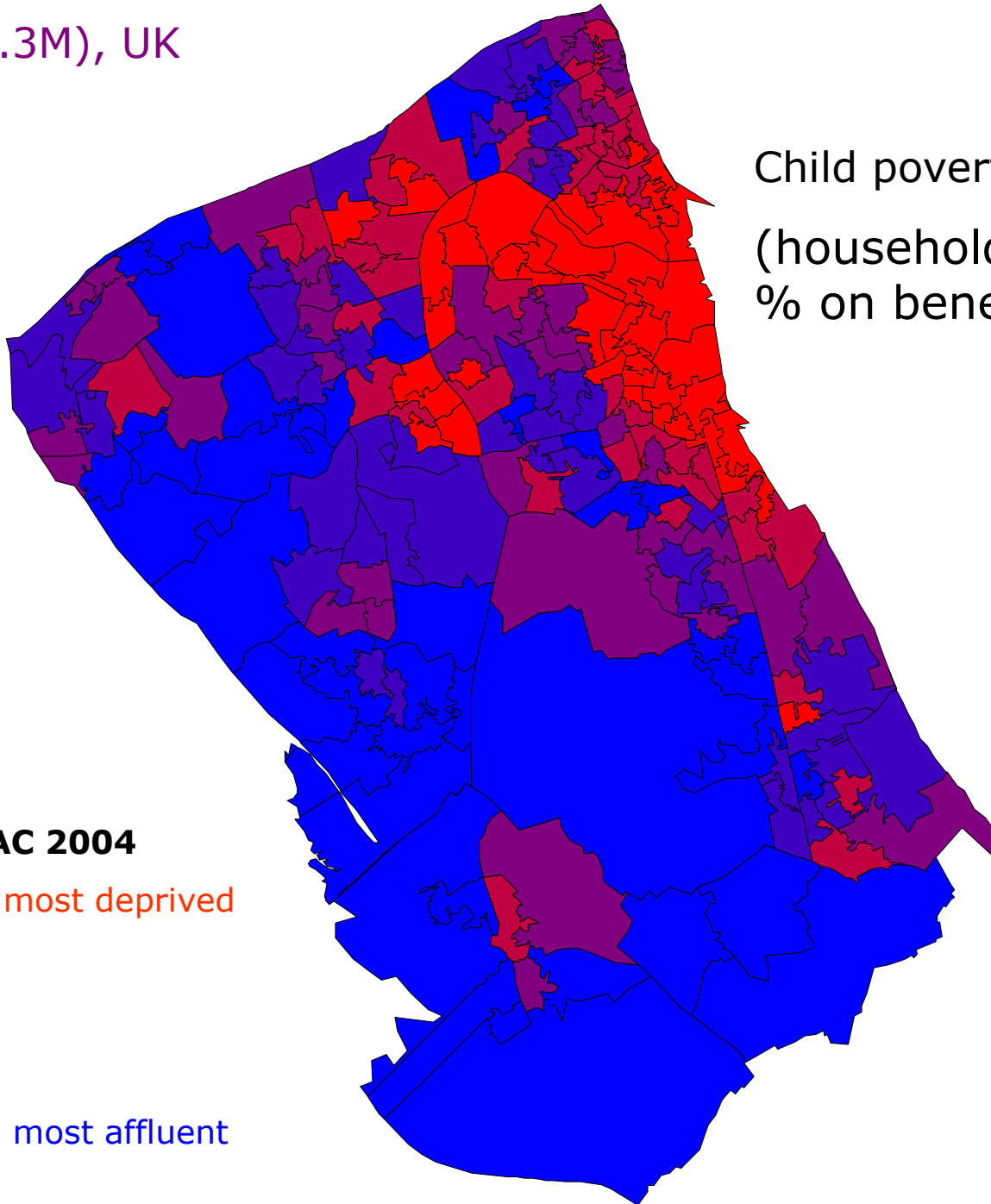
Negative Influence:

Positive Influence:

Wirral (0.3M), UK

Child poverty map

(households with children:
% on benefits in 2001-3)



Fifths of IDAC 2004

Red (light) = most deprived

Red (dark)

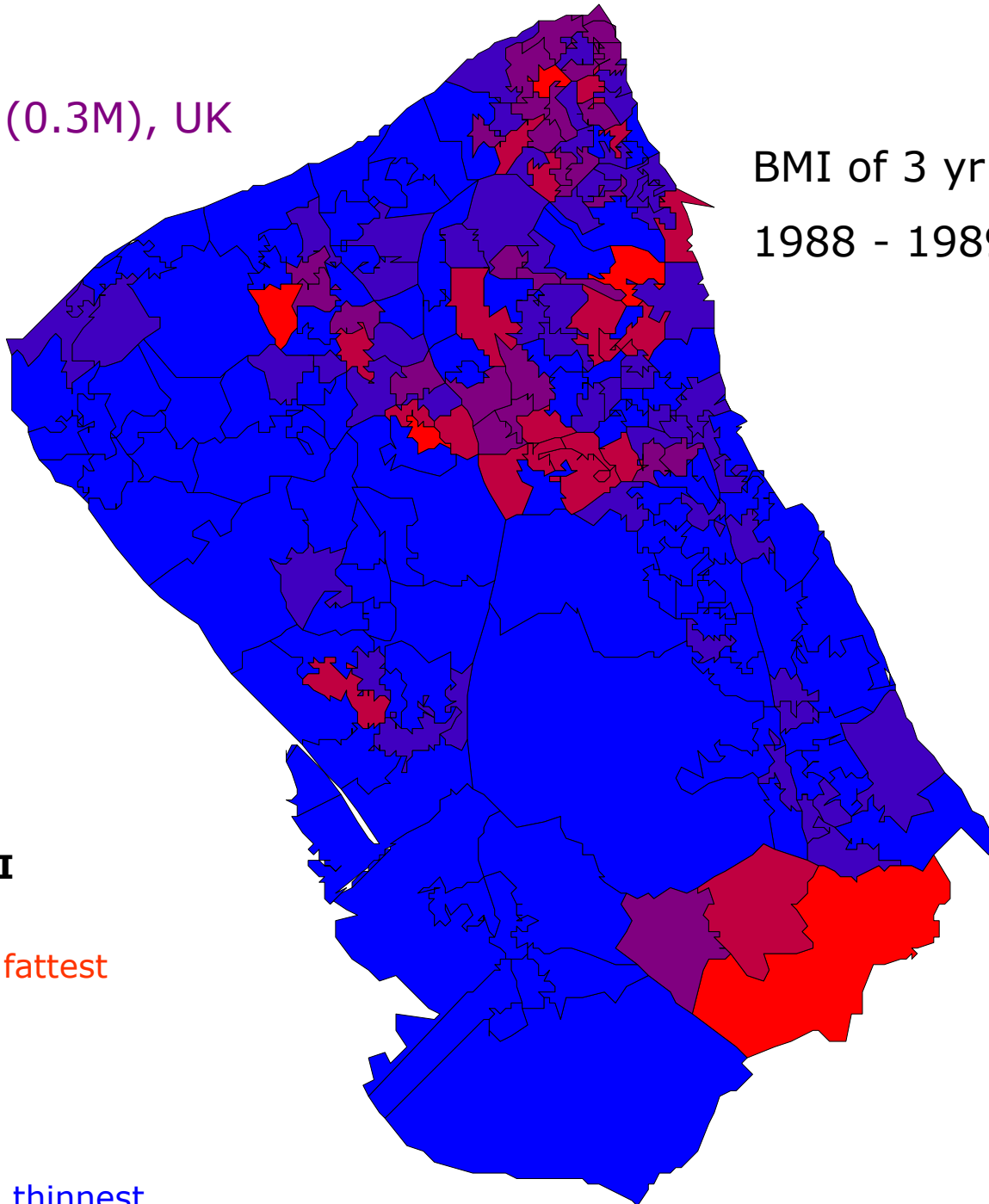
Purple

Blue (dark)

Blue (light) = most affluent

Wirral (0.3M), UK

BMI of 3 yr olds
1988 - 1989



Fifths of BMI

SDS BMI fifth

Red (light) = fattest

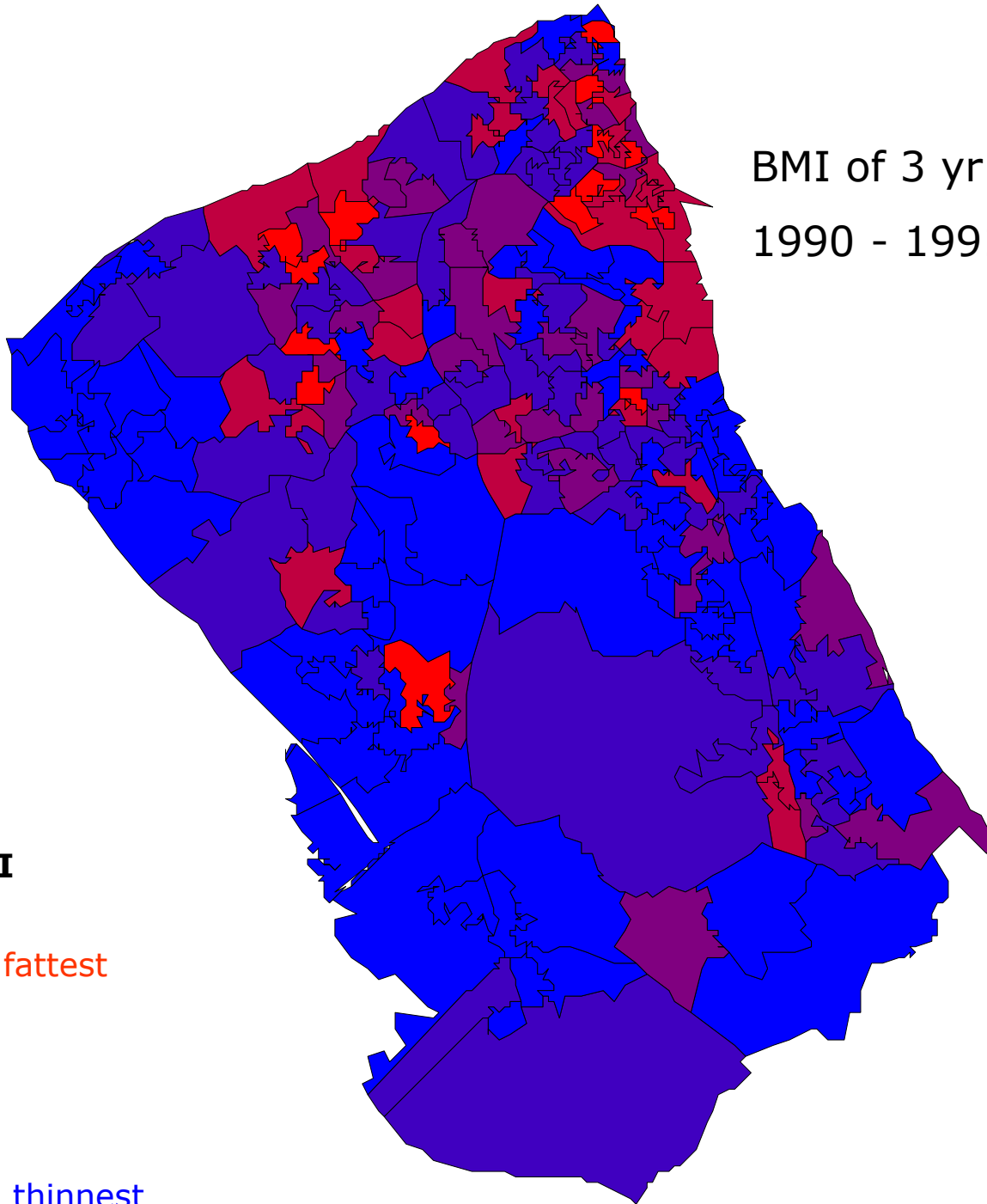
Red (dark)

Purple

Blue (dark)

Blue (light) = thinnest

BMI of 3 yr olds
1990 - 1991



Fifths of BMI

SDS BMI fifth

Red (light) = fattest

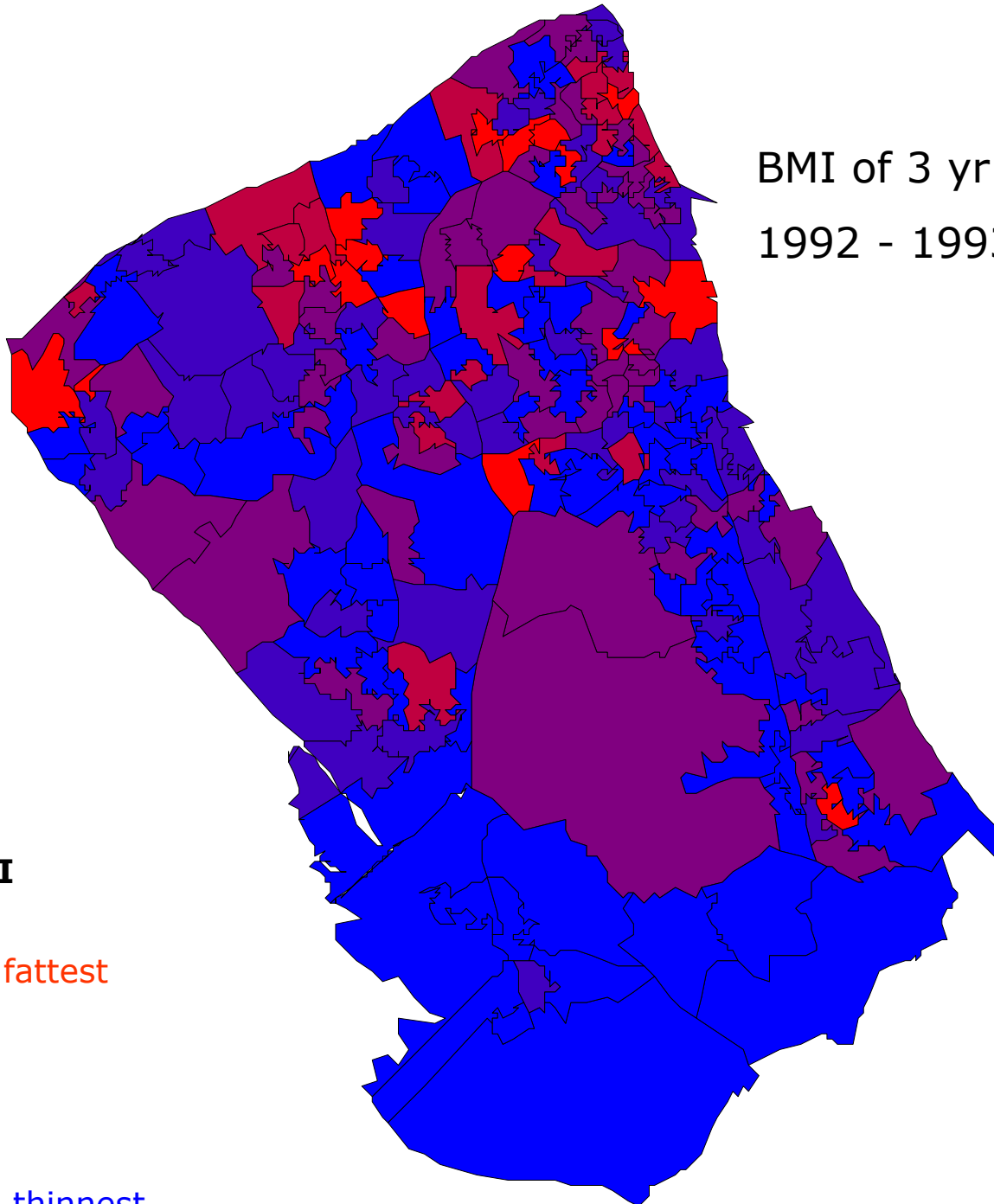
Red (dark)

Purple

Blue (dark)

Blue (light) = thinnest

BMI of 3 yr olds
1992 - 1993



Fifths of BMI

SDS BMI fifth

Red (light) = fattest

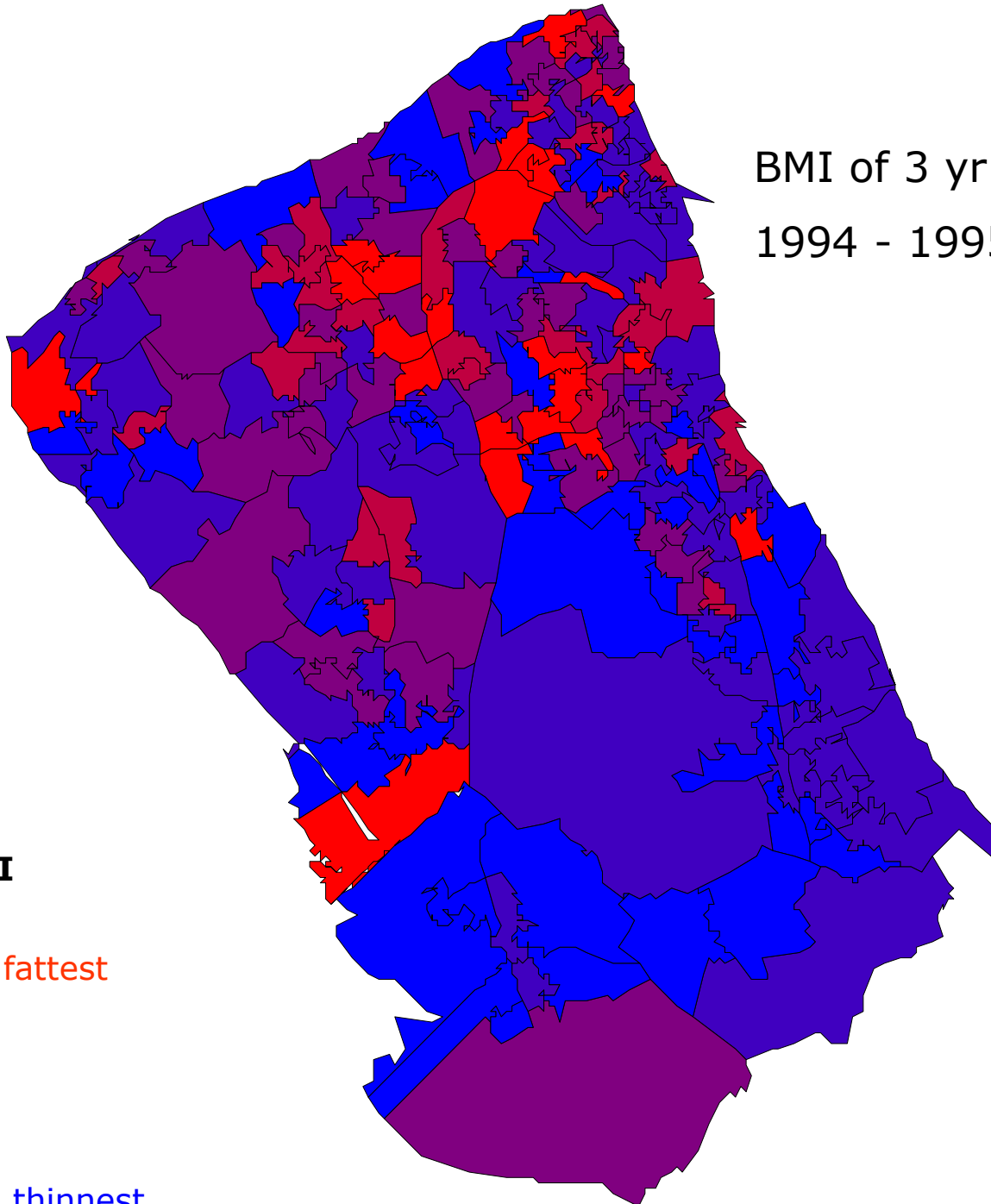
Red (dark)

Purple

Blue (dark)

Blue (light) = thinnest

BMI of 3 yr olds
1994 - 1995



Fifths of BMI

SDS BMI fifth

Red (light) = fattest

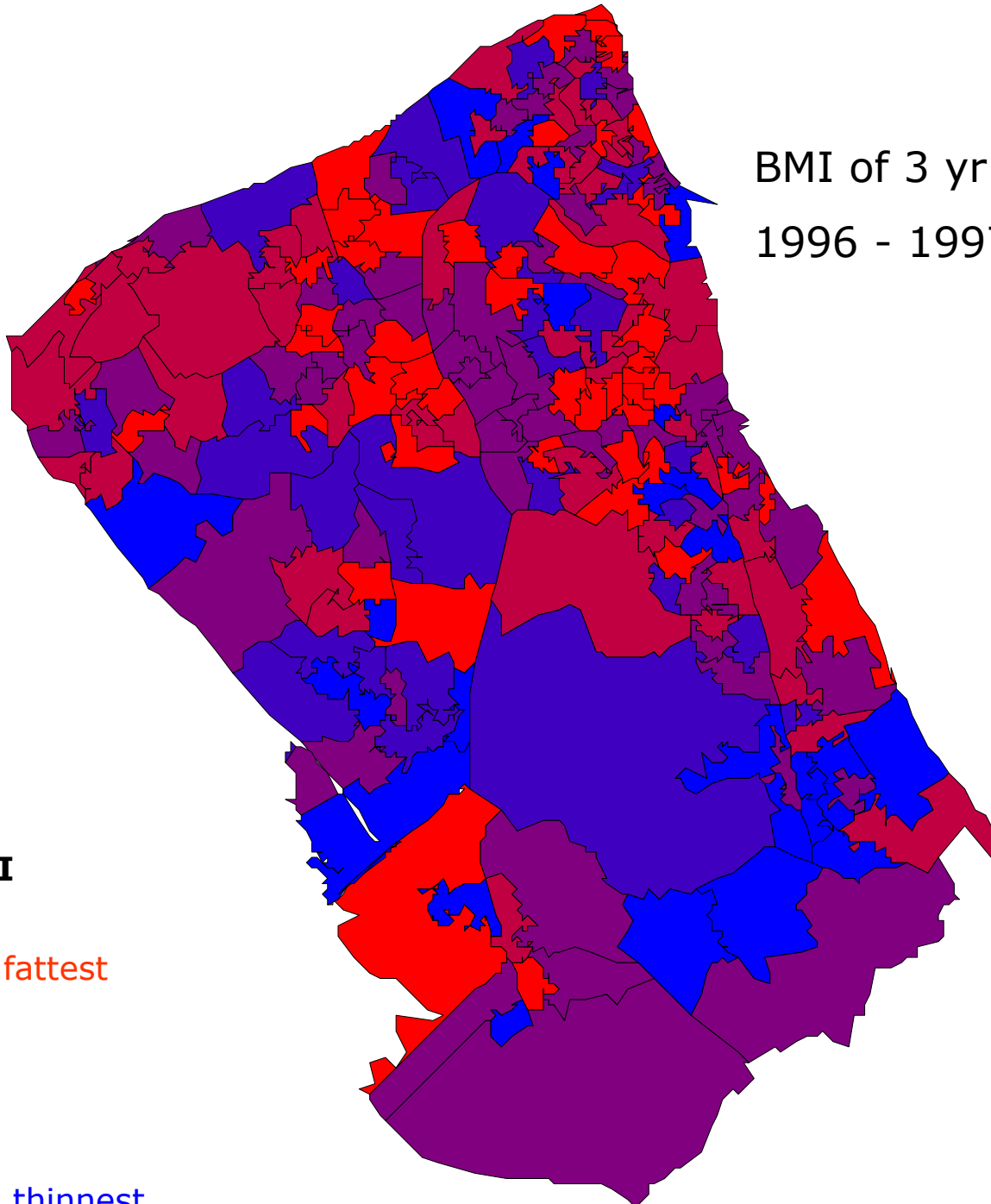
Red (dark)

Purple

Blue (dark)

Blue (light) = thinnest

BMI of 3 yr olds
1996 - 1997



Fifths of BMI

SDS BMI fifth

Red (light) = fattest

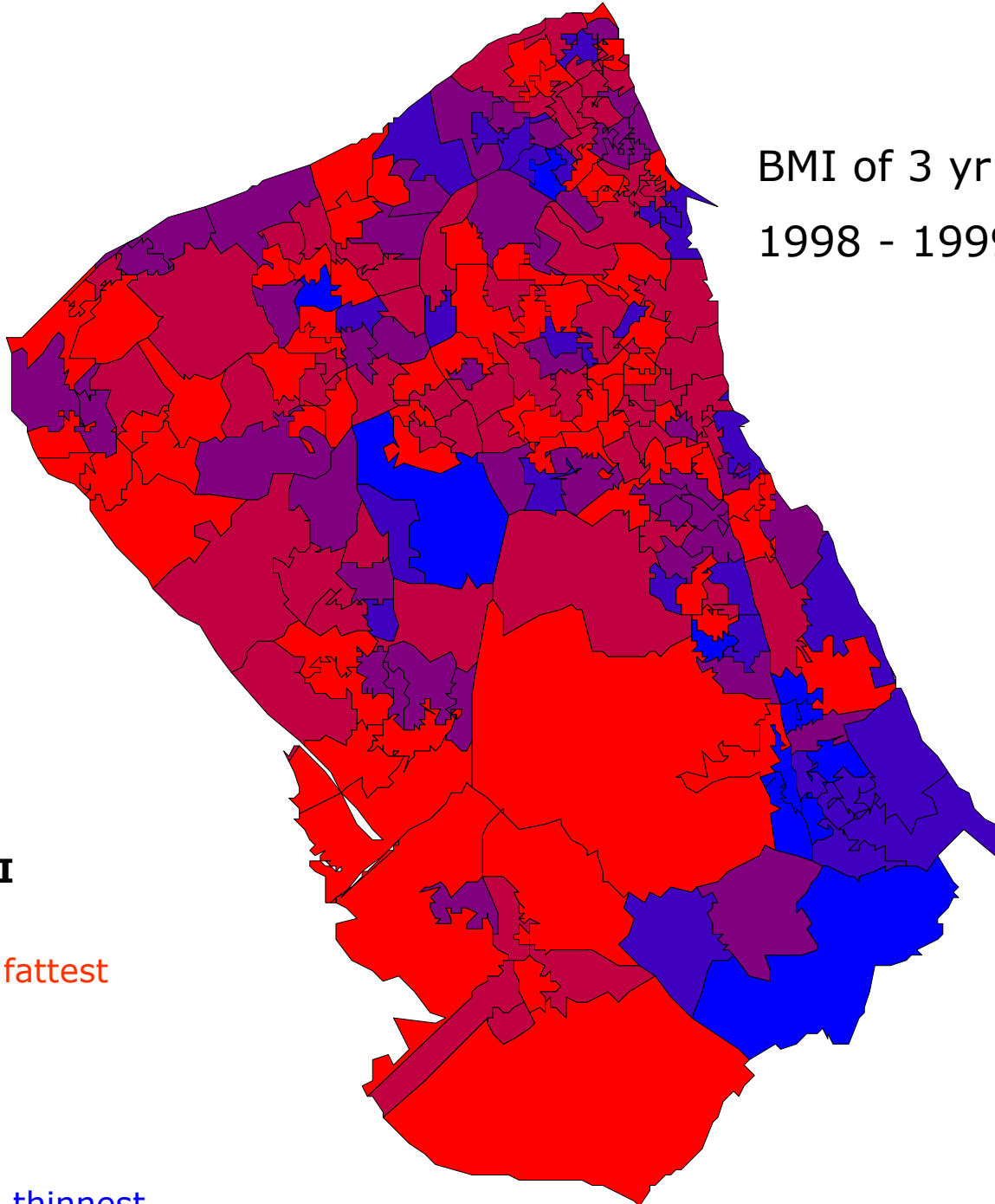
Red (dark)

Purple

Blue (dark)

Blue (light) = thinnest

BMI of 3 yr olds
1998 - 1999



Fifths of BMI

SDS BMI fifth

Red (light) = fattest

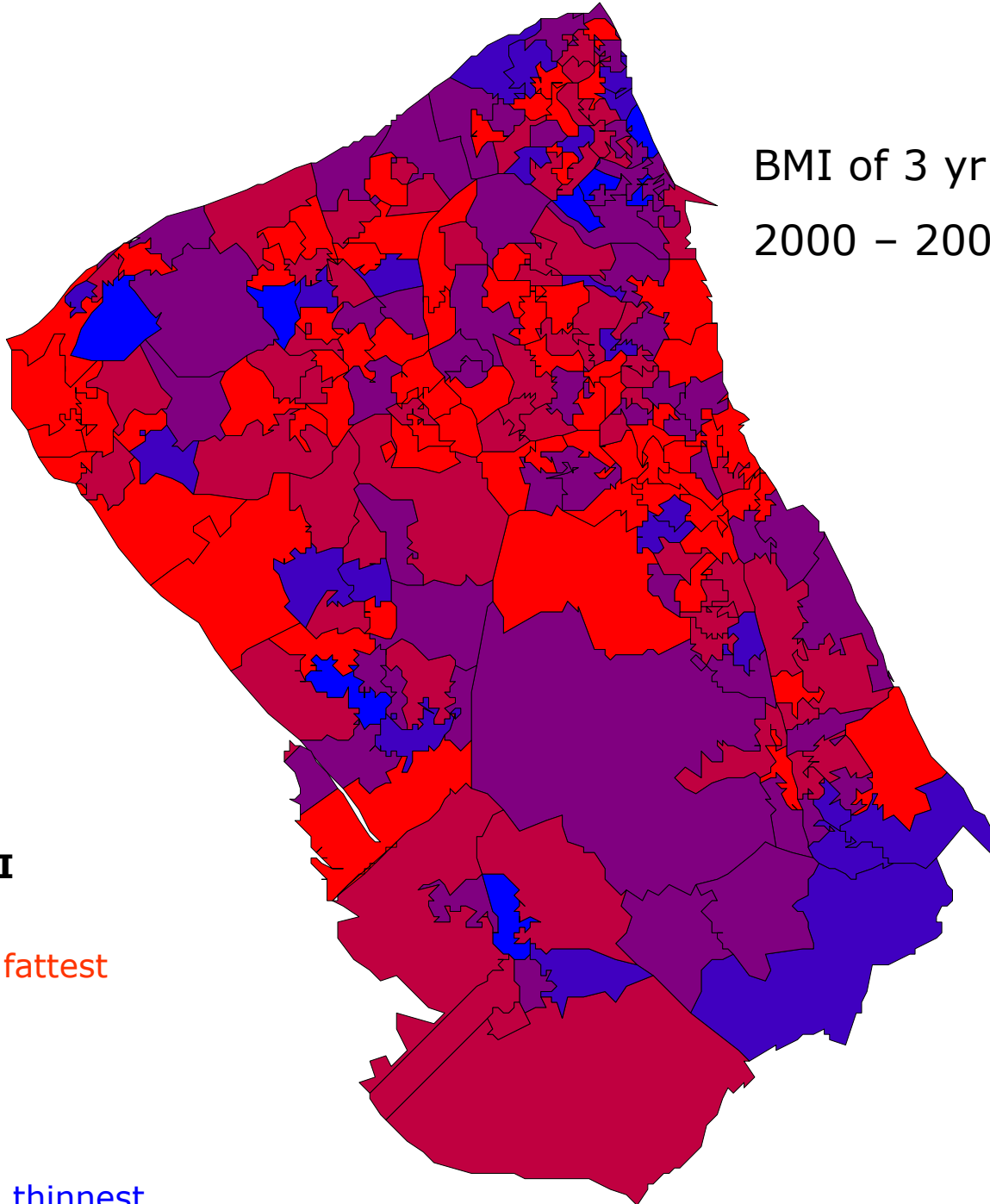
Red (dark)

Purple

Blue (dark)

Blue (light) = thinnest

BMI of 3 yr olds
2000 - 2001



Fifths of BMI

SDS BMI fifth

Red (light) = fattest

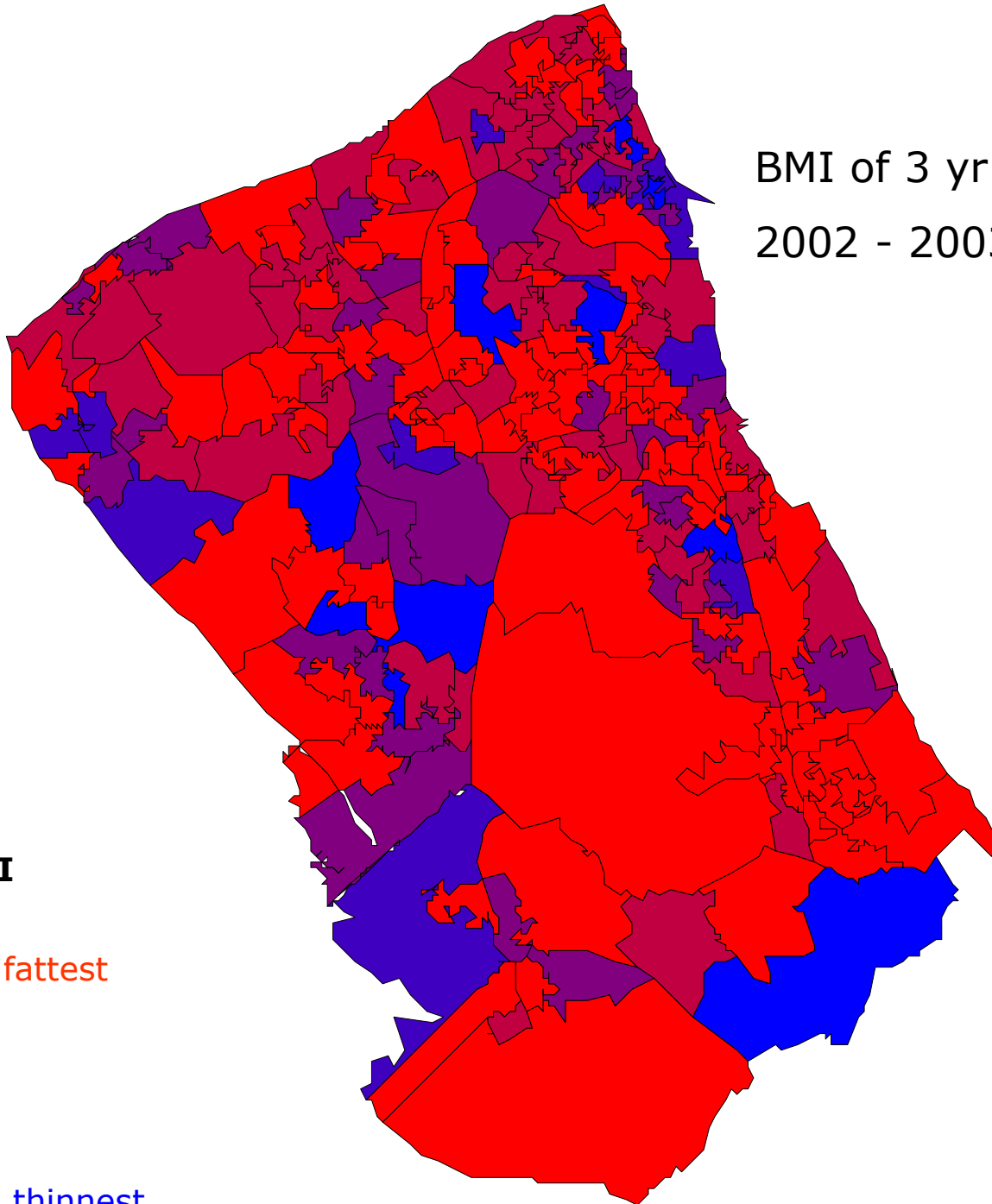
Red (dark)

Purple

Blue (dark)

Blue (light) = thinnest

BMI of 3 yr olds
2002 - 2003



Fifths of BMI

SDS BMI fifth

Red (light) = fattest

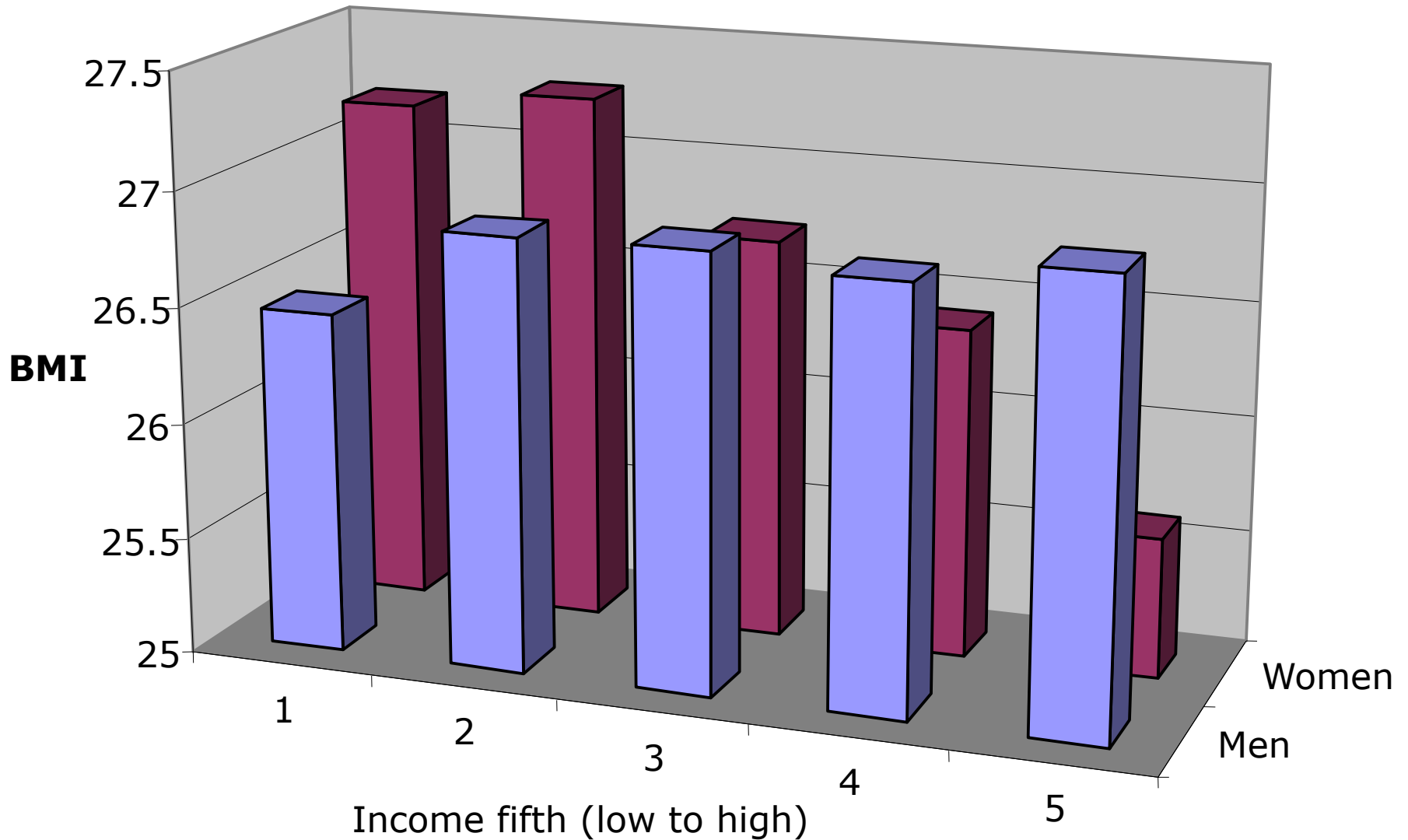
Red (dark)

Purple

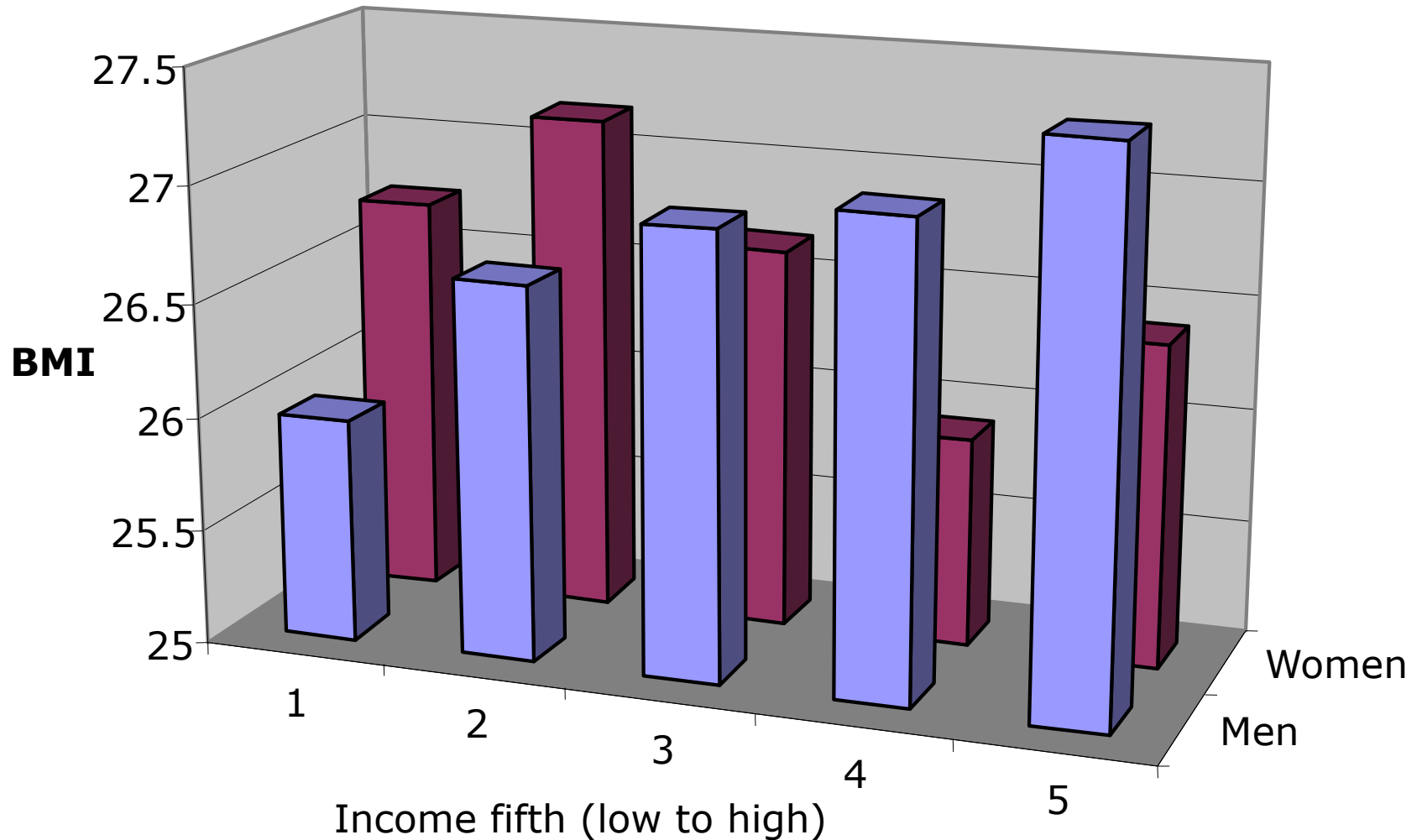
Blue (dark)

Blue (light) = thinnest

Women and not men from low-income households are fatter in England



Women from low-income households and men from high-income households are fatter in Greater Manchester



Beware Discipline Clouds

Social Research:
Data, methods & people

*Previous slides show
social-biomedical signals
about obesity
from under-used datasets*



Biomedical Research:
Data, methods & people

Obesity e-Lab Aim

..to increase the sharing and reuse of
data sources & extracts
and data processing methods
in one in-silico environment ('e-Lab')
shared by social and health researchers

Focus

- Health Surveys for England
 - Large-scale (participants * variables)
 - Annual since early 90s
 - Under-used by NHS who fund it
 - Key barrier: extracting a research-ready subset of data
 - Data archive → playground = e-Lab

Supporting and developing interdisciplinary understanding

Sharing resources – tools, methods, data

First step - sharing of resources

Sharing expertise – discussions and reuse around shared resources

Shared resources provide the basis for discussion

Developing interdisciplinary understanding – language, tacit assumptions, methods

Discussions lead to deeper interdisciplinary understanding

Promoting interdisciplinary working


Understanding of other domains promotes more effective interdisciplinary working





Look inside the **METHOD BOX**. Find and share **datasets**, **methods** and **know-how**. Making **best practice** your practice.

People Methods Data Sources CSV Archives

MethodBox users include NHS Public Health analysts and Department of Health Public Health Observatory analysts, as well as academic social scientists and epidemiologists.


Sarah Thew

 My Profile (edit)
 Logout

Variable cart

Total 0

[Empty cart](#)
[Create CSV Archive](#)

Expertise

Obesity Stata SPSS
Epidemiology Public
Health java Biostatistics
Project Management public
health informatics public
health intelligence

Variables

height useable

Search

People

« previous 1 2 3 next »



Caroline Ridler

No description set
Email: Caroline.Ridler@SEPHO.nhs.uk
Expertise: Not known



Shoalb Sufi

Technical Project Manager at the University of Manchester
Email: shoalbsufi@mygrid.org.uk
Expertise: Project Management | Python | e-laboratories | metadata | java



Sarah Thew

I am a researcher at Manchester University, based at the Medical School.
Email: sarah.thew@manchester.ac.uk
Expertise: Obesity | BMI | Methods | Stata | SPSS | Harmonisation | Epidemiology | Public Health

 Edit



Kuiama Thompson

Health Equity Officer at NHS Salford
Email: Kuiama.Thompson@salford.nhs.uk
Expertise: Public Health | public health informatics | public health intelligence

« previous 1 2 3 next »



Look inside the **METHOD BOX**. Find and share: **datasets**, **methods** and **know-how**. Making **best practice** your practice

Download methods and scripts shared by other Methodbox users

People **Methods** Data Sources CSV Archives

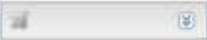


Sarah Thew

My Profile [edit]

Logout

Variable cart



Total: 0

Expertise

Obesity Stata SPSS
Epidemiology Public

Merge Method

Delete Script

Download Method

Script: Derived smoking variable - 2005 HSE

Created at: 24/09/2009 @ 12:16:44 Last used: 07/10/2009 @ 09:31:47

Title: Derived smoking variable - 2005 HSE

File name: smoking2005.txt

Format: text/plain

Description

This is a stata script which combines 5 variables from the 2005 HSE to create a single smoking variable.

Original Uploader



Sarah Thew

Attributions (1)
[edit]

Derived smoking var...

The owner of the script can create links back to other methods and scripts used in the development of this script.



Digital Curators Promoting Healthcare Innovation: II

SECURITY

Major Issues with Clinical Studies

- Bias & generalisability
- >50% over-run
- >30% don't hit recruitment targets
- Unrealistic feasibility assessment
- Consent-management confusion

openCDMS

An Open Source System for:

- multi-centre remote electronic data collection;
- highly configurable security system employing Role Based Access Control;
- fully customisable data set definition including data elements, validation rules and scheduling;
- fully configurable online randomisation with email and SMS text message notification;
- project management reporting including recruitment, completion and UKCRN accrual;
- on-line and off-line data collection;
- flexible query system for identifying eligible trial participants and nested case-control studies;
- designed for compliance with 21 CFR part 11; EMEA GCP; ISO 27001



openCDMS

clinical data management system

openCDMS in use

- PsyGrid study – cohort of 700+ schizophrenics followed from first episode for 18 months
- Running numerous mental health trials
- ADDRESS – Type I+II diabetes 10y cohort study
- DARE – Diabetes cohort (phenotype and genotype)

Investigator-shaped data capture

Outlook - openCDMS Collect - CROOne

File Database Print Advanced Options Help

Status: All

OLK/001001-1

- Baseline - Section A (Core asses
 - Baseline Audit Form (Informa
 - Screening Schedule For Psych
 - Interview and consent inform
 - Personal Details Form - Base
 - Positive and Negative Syndro
 - The Young Mania Scale - Bas
 - Global Assessment of Functi
 - Duration of Untreated Psych
 - Drug Check - Baseline**
- Baseline - Section B
 - Pathways to Care - Collated
 - Premorbid Adjustment Scale
 - Calgary Depression Scale Rec
 - Family History - Baseline
 - Health Questionnaire - EQ-5
 - Side Effect Record - Baseline
 - Antipsychotic Non-Neurolog
- Baseline - Section C
 - Insight Scale - Baseline
 - Adverse Outcomes Detailed C
 - Adverse Outcomes Detailed C
 - Adverse Outcomes Detailed C
 - Adverse Outcomes Detailed C
 - Adverse Outcomes Screening
 - Adverse Outcomes Screening
 - Client Sociodemographic and
 - Time Use Interview Score She
 - Seven-Point Compliance Scal

6 months

12 months

Study termination

Shared

- Treatment Documentation -
- File Note Log - Shared
- Relapse Rating Data Entry Fo
- Treatment Documentation (v

Drug Check - Baseline

Sections 1. General

Other (please specify)

960. Data not known

970. Not applicable

980. Refused to answer

999. Data unable to be captured

Other Drugs not listed above

No

Yes

960. Data not known

970. Not applicable

980. Refused to answer

999. Data unable to be captured

Other drugs

Type of drug	How often have you had them?	Amount (£) per week	Quantity
Meth-amphetamine	3. Frequent user (almost everyday)	100	960. Data not known

New row

You said that you have been using... (summarize the drugs that were identified from the list above), which of these drugs have caused you the most problems or hassles in the last 3 months? Take into consideration the various risk factors associated with the substances the patient is presently using & select the most problematic drugs based on ALL available information.

Sleeping tablets or sedatives? (like valium or normison)

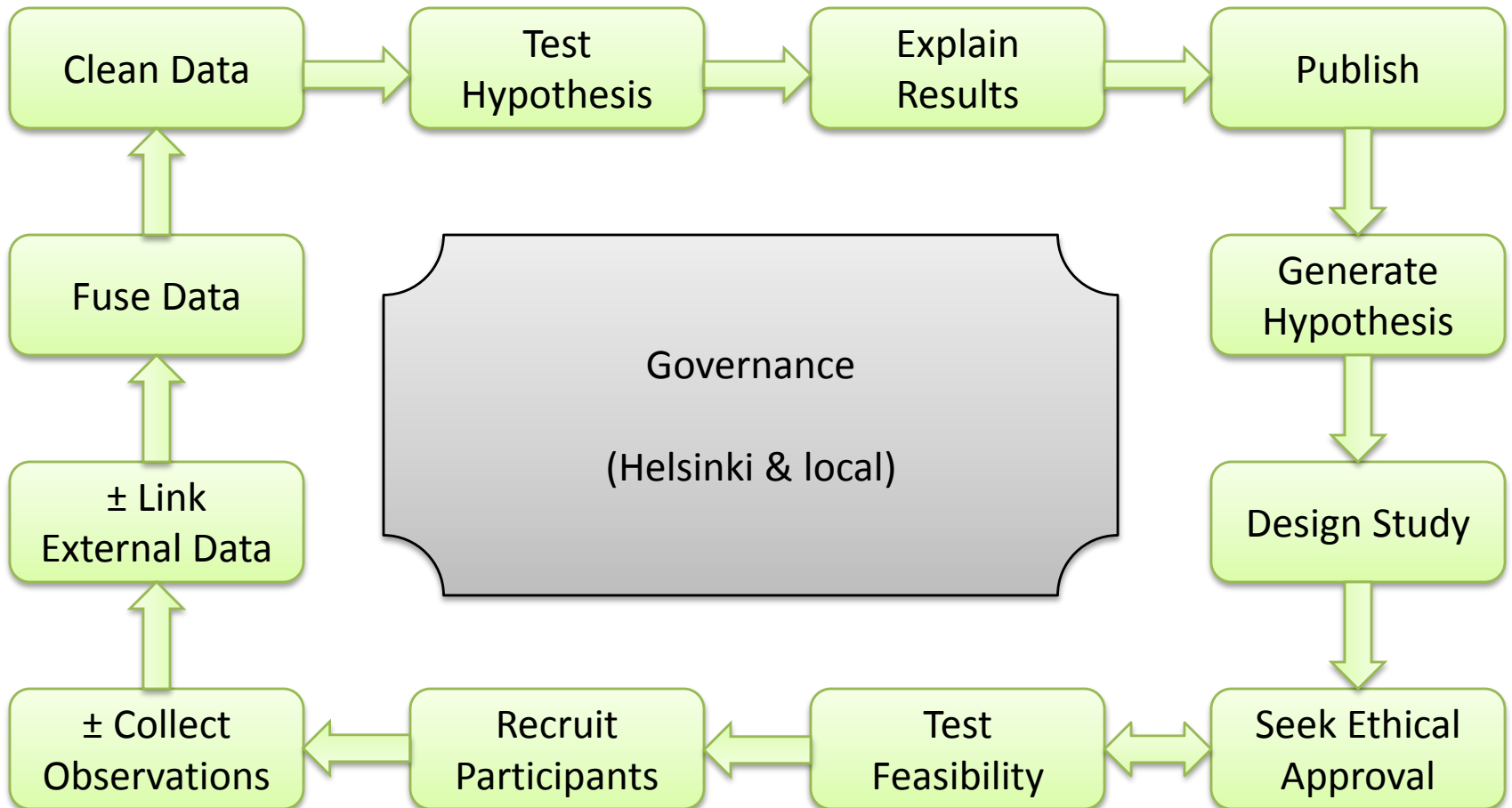
Marijuana, cannabis, or hash?

Drugs you sniff, like petrol/glue?

Drugs like LSD?

Speed, ecstasy, crack or cocaine?

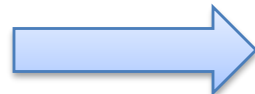
Heroin, morphine or methadone?





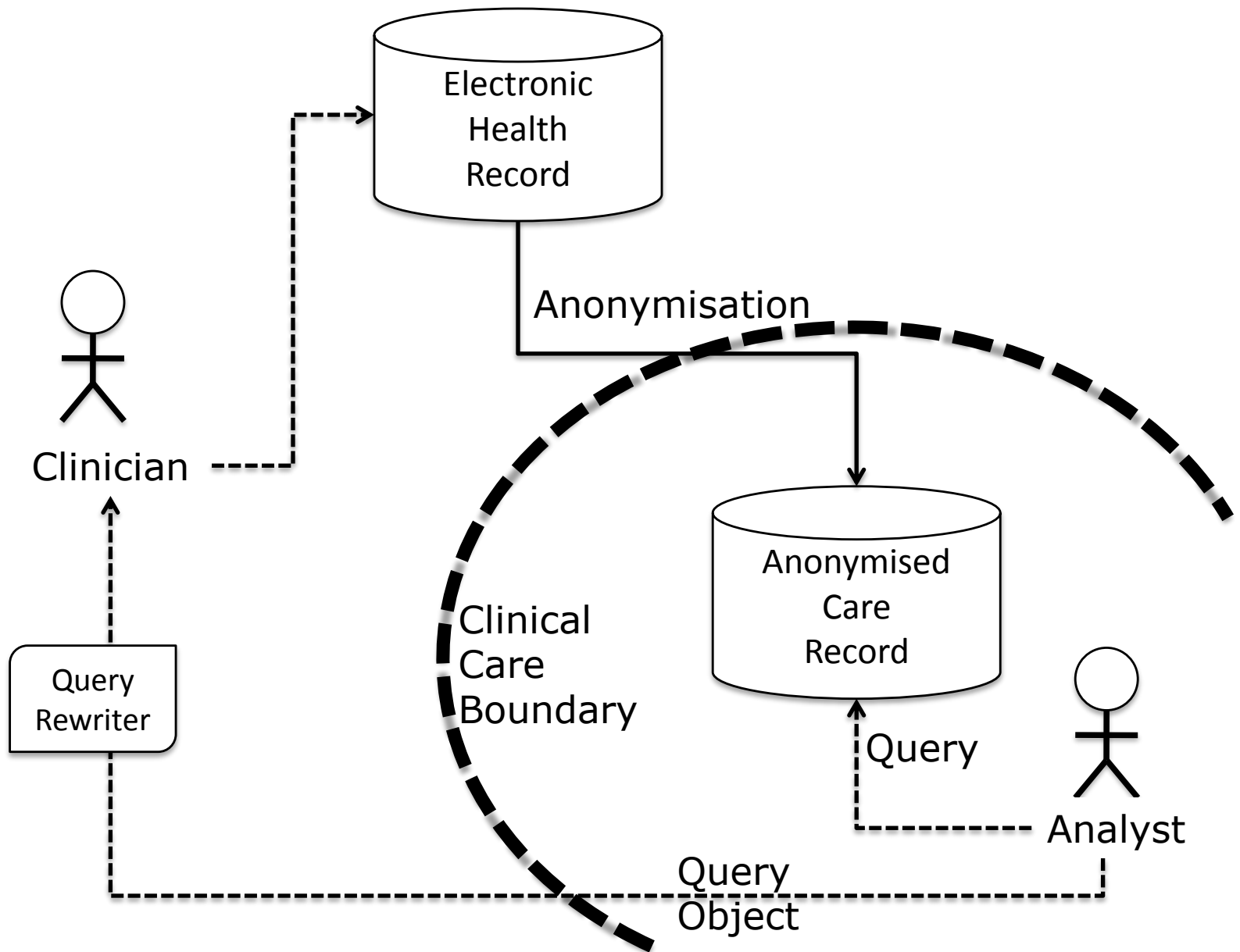
Making sense of local healthcare

Managing clinical studies



+ community





Consent-for-consent

...is the consent to

search an individual's health record

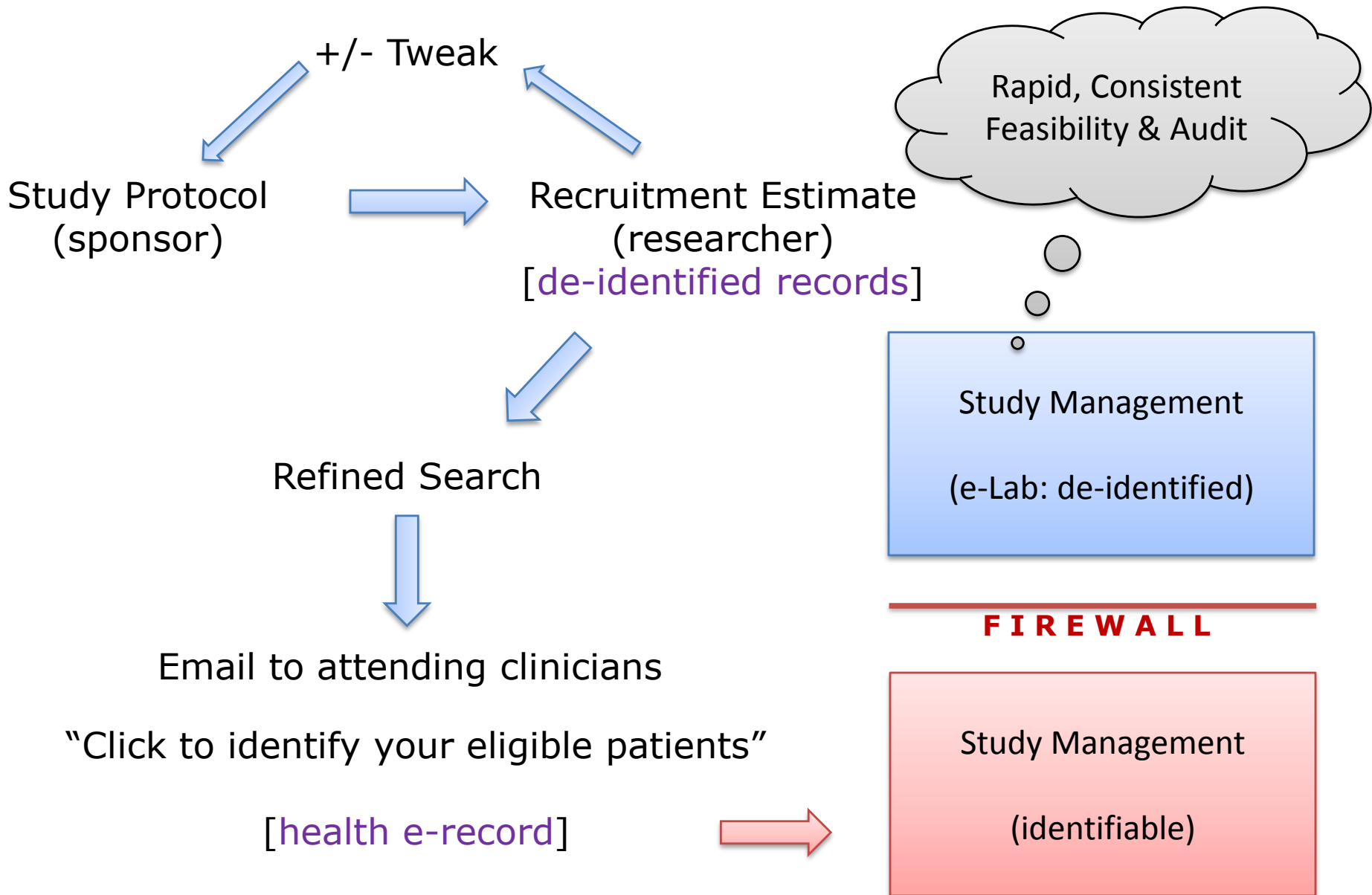
to determine whether or not

they should be invited

to take part in a clinical study.

FARSITE

Feasibility **A**ssessment
and **R**ecruitment **S**ystem
for **I**mproving
Trial **E**fficiency



Realistic Recruitment Estimates

Patient Search

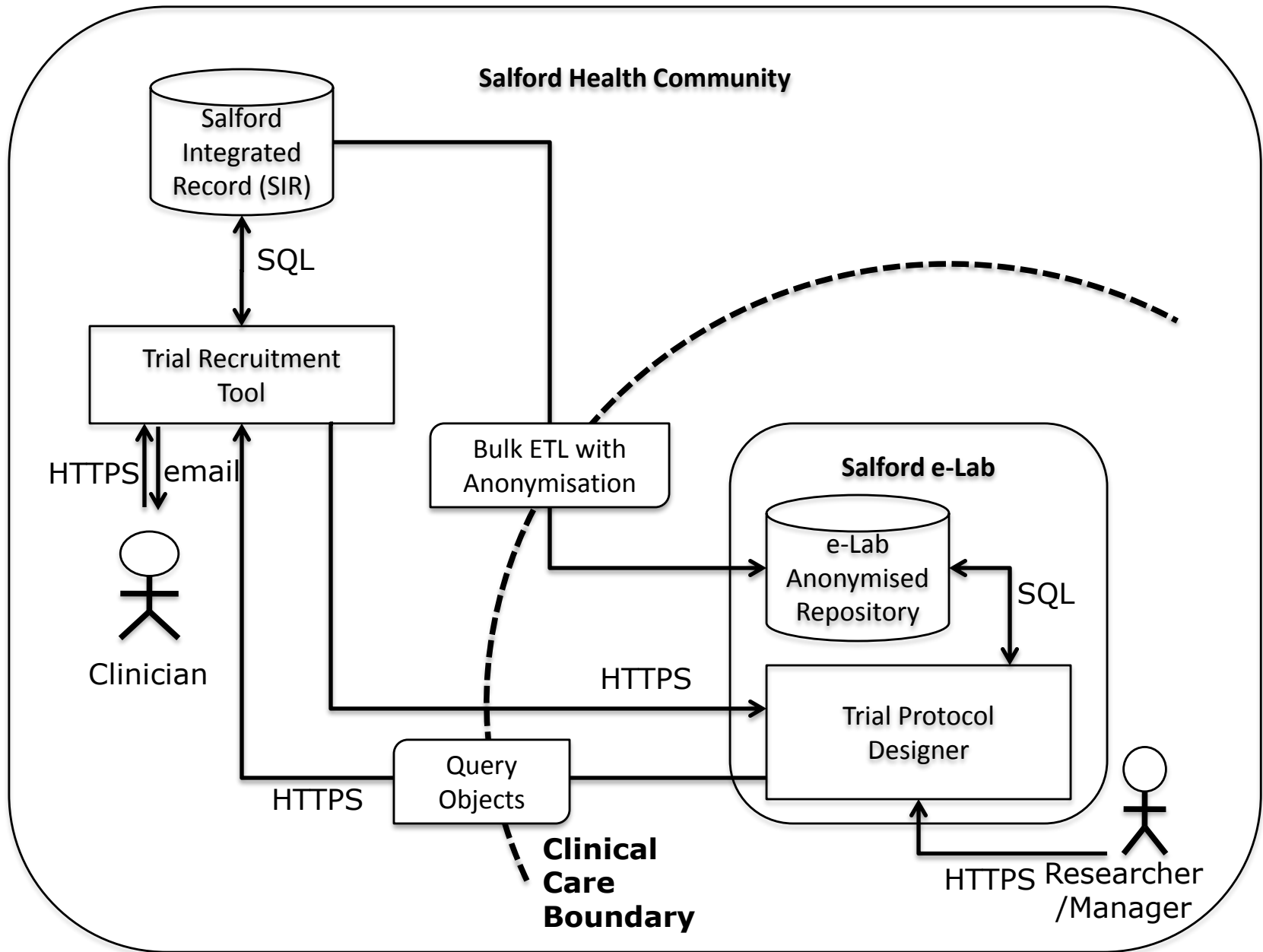
How to search: [\(more...\)](#)

Match all conditions Match any condition

Hba1c	less than	100	Add Remove
BMI	greater than	12.4	Add Remove
Sex	is	Male	Add Remove
Year of Birth	greater than	1970	Add Remove

Search

Clear





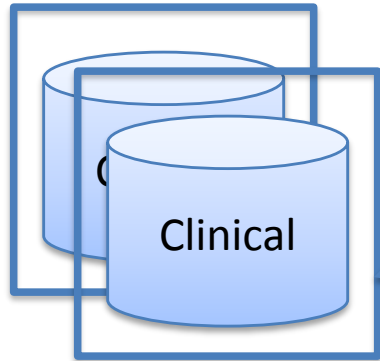
Digital Curators Promoting Healthcare Innovation: III

TRUST

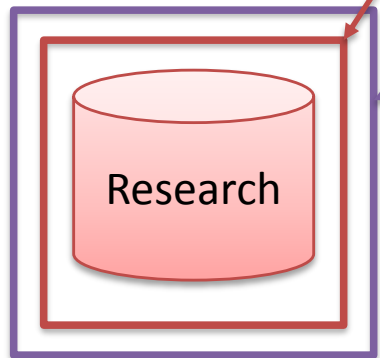
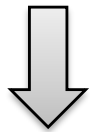
Trust & Benefit in Research across Health Records

Now

Database-centred



x Health Agencies



x Research Agencies

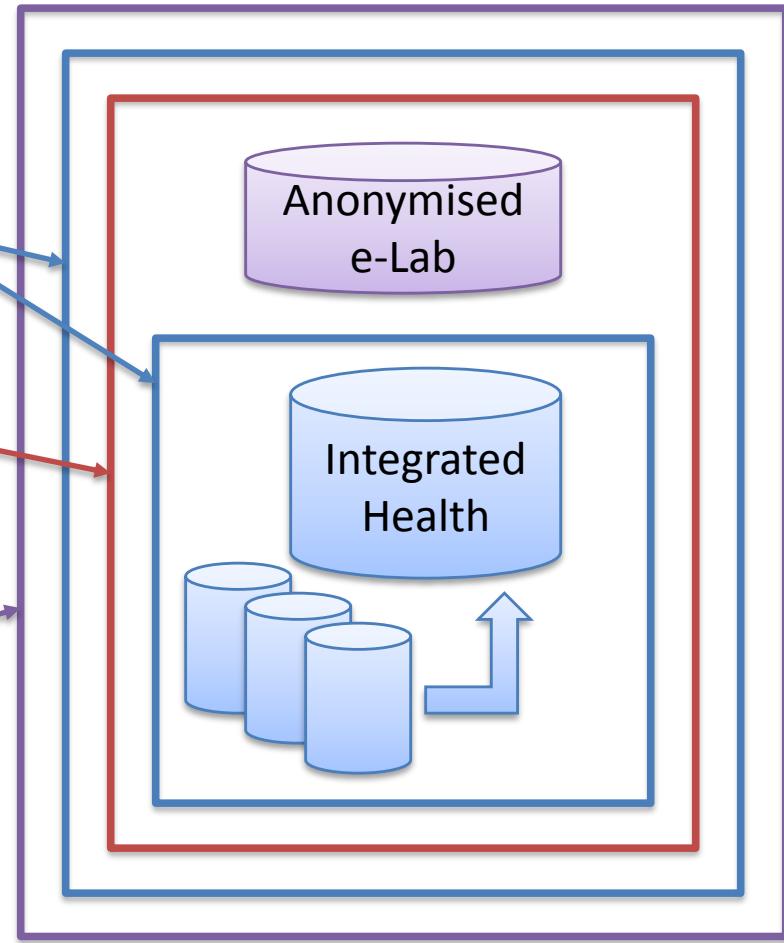
Clinical Information Governance

Research Governance

Ethical Oversight

Future?

e-Lab: Community-centred



x Health Communities

Public Involvement

- Patient / Citizen Scientist
- Social network \leftrightarrow investigator
- Early & mobile signals beyond clinical reach
- Relevant outcomes



Framework for Digital Research in Healthcare: II

SOCIAL CONTRACT

Digital Curation for the Public's Health: What is the Social Contract?

- UK has much already in place in the laws and governance across NHS, higher education and allied public services
- Law, standards, regulations and some infrastructure work nationally
- Trust and capacity-building to provide the best data and analyses works locally ← more attention

Open Unifying e-Lab

∪(open models)

∪

Easy computation

=

∪

Abstract reasoning
and motivation of
domain experts

More complete insights

More reusable evidence

Better management across diseases

Earlier intervention

Greater citizen involvement