Personal Health Record 2 Avatar

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This Talk

• Problem:
  *Data intensity > decision support capacity*

• Solution:
  *Emergent useful complexity of models*

• Deployment:
  *Avatar with credible handling of uncertainty*
Real-world Healthcare Evidence

• Clinical trials usually exclude
  – Women of child bearing age
  – People with multiple conditions
  – People on other medications

• More than two thirds of what will happen to patients when treated is unpredictable with current evidence
Digital Bridges Since 1990s:
Integrated Care **Pathways (Disease-specific)**

Self Care

Primary Care

Clinical Care

Secondary Care

Specialist A

Specialist B
**Primary Care**  
**Secondary Care**  

*Missing:* Patient & Community  
*‘Big-picture’* Across Diseases/Services/Pathways  

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**Self Care**  
**Clinical Care**  
**Primary Care**  
**Secondary Care**  

- **Diabetology:** Glucose control  
- **Ophthalmology:** Diabetic eye care  
- **Nephrology:** Chronic kidney disease  

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**Specialist A**  
**Specialist B**  

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**Future:** Realistically complex and dynamic models of individual or community care:  
i.e. Mr Smith’s care pathway, not diabetes + eye + kidney care pathways
Bottleneck ≠ Data

Methods/Models/Applications ↑

Experts ↔

Data ↑↑↑↑
Mirage of Independent Effects

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
Inconsistent Epidemiology of Asthma

• Breast Feeding
  – Increases the risk (Sears et al, Lancet 2002;360:901-7)
  – Does not matter (Burgess et al, Pediatrics 2006;117:e787-92)

• Cat ownership
  – Good (Hesselmar et al, CEA 1999;29:611-7)
  – Bad (Noertjojo et al, JACI 1999;103:60-65)
  – Does not matter (Rhodes et al, JACI 2001;108:720-5)
Inconsistent Genetic Epidemiology of Asthma

- Linkage replicated in >1 study
- Linkage in 1 study
Putative Polymorphism: CD14

- Pattern recognition receptor - part of receptor complex for endotoxin
- Soluble or membrane bound CD14
- Activation of pathway → IL12 → ↓ allergy
- Maps to 5q32 - region of linkage to asthma
Asthma vs. CD14/-159 genotype

- C allele associated
- T allele associated
- No association
Endotoxin & CD14 inconsistent

- **Endotoxin**: protective in some populations but not others

- **CD14 polymorphisms**: associated with allergic sensitisation in some populations but not others
  - Risk allele different in different populations

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Sengler et al Clin Exp Allergy 2003 33 166 -169
Goa et al : Clin Genetic 1999 56 (2) 164-5
Manchester Asthma and Allergies Study (MAAS): No association between allergic sensitisation and CD14 genotype

Simpson et al, AJRCCM 2006;174:386-92
MAAS: Endotoxin exposure decreases the risk of IgE-mediated sensitisation.

Simpson et al, AJRCCM 2006;174:386-92
CD 14 promoter polymorphism, endotoxin exposure and sensitization

Simpson et al, AJRCCM 2006;174:386-92
At high endotoxin exposure:
T is the risk allele for sensitisation

Simpson et al, AJRCCM 2006;174:386-92
At low endotoxin exposure: C is the risk allele for sensitisation

Simpson et al, AJRCCM 2006;174:386-92
At moderate endotoxin exposure:
No CD14 genotype vs. sensitisation

\[ \text{Ln total endotoxin recovered (EU/m2)} \]

Predicted probability for sensitisation

\[
\begin{array}{cccc}
1.0 & .8 & .6 & .4 \\
CC & CT & TT & 0.0 \\
\end{array}
\]

\[ \text{Simpson et al, AJRCCM 2006;174:386-92} \]
Typical Health Sciences Signal Path

...like squinting at an image through a doyley and prism

Need to blend abstract reasoning, fuzzy evidence and interpretation of results
Machine Learned Epidemiology

• Suspected myth: false division of children into allergic tendency (atopy) or not

• Life-course data: birth cohort of 1,000 children from Manchester with careful measurements

• Potential heresy: unsupervised search for patterns of sensitisation instead of hypothesis
Model: Unsupervised Clustering of Allergic Sensitisation Across Ages
From 2 to 5 Useful Classes of Atopy
Better Prediction of Real-world Outcomes

Admitted at Any Age

First Admitted > 3 Years Old (remove early virus wheeze)
What might a usefully complex healthcare future look like?

ENVISIONING USEFUL COMPLEXITY
Large scale inference

Unified Graphical Model

Data-intensive Paradigm shift

Open Unifying Modelling: Across mechanisms and contexts

Health Avatars & Dynamic Models

∪ models = Avatar

Health Records & Knowledge Silos

Multi-scale & Multi-system Health:
• Research
• Policy
• Care

Data-intensive Paradigm shift

Expertise

Unified Graphical Model

Health e-Records

Large scale inference

Model refinement

e.g. Coronary heart disease

e.g. Chronic obstructive pulmonary disease

Data-intensive Paradigm shift

Data-intensive Paradigm shift

Data-intensive Paradigm shift
Building a ‘sense-making layer’ on top of NHS care records...

REAL WORLD STEPS
Anaemia at lower levels of kidney impairment than commonly thought

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

Anaemia at lower levels of kidney impairment than commonly thought
NHS e-Lab

Turning “tombs” of data into useful intelligence

Usual suppliers

Local Community Integrated Health Record

NHS no.

Optometrist
Community nurse
Podiatrist

Biobanks
Local surveys
Individual research

ONS vital statistics
Local authority socio-economic
Public health

Hosp.

Commissioning
Audit
Public Health
Research

“unified sense-making”
Data queries: From this...

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...to this
Prevalence of high HBA1C values for diabetics

Investigation into diabetes in Salford

Data
- High HBA1C Prevalence
- Normalised HBA1C by Patient
- Repository

Documents
- Diabetes ruleset 14.0 as PDF

Data Exploration
- HBA1C
- example Cube

Notes
- Info about data
- Prevalence of high HBA1C values for diabetics
- This is the QOF ruleset

Snapshots
- HBA1C by ward Mean HBA1C values by ward Map
- Normalised HBA1C by Patient High HBA1C Map

People
- gary
- dammers
- gmoulton
Mean HBA1C values by ward

Legend Title
- 6.63 - 6.81
- 6.81 - 6.97
- 6.97 - 7.09
- 7.09 - 7.12
- 7.12 - 7.40

Value
Mean: 7.106
Sample Size: 16
e-Lab

Research/Work Object

Find
Share
Reuse

Research protocol
Data-sources
Data-preparation scripts
Working datasets
References

Statistical analysis scripts
Analysis-logs & notes
Figures/Graphics
Manuscripts
Slides

Socially-stimulating science & service, in-silico
Any data sharing is context-specific.

Localities only share the data items relevant to the work, packaged into a work object that is checked by a local officer before being shared – all subsequent work on the object is audited and visible to the originator.

Local Community Integrated Health Record

Depersonalised records

Shared Work object

Collaboration with other trusted e-Labs: say over supra-district audit
“Borrowing Strength” along Service Buses

Federation of e-Lab communities shares work or method objects without remote data warehousing.

Strength is borrowed and costs reduced by pooling expertise.
Exploit Heterogeneity

• Incorporating more information about differences between centres increases the estimated effects of interventions from meta-analysis of observational studies

• Federation of e-Labs could generate extremely useful healthcare intelligence at scale

Future transparency of decision support

Usual suppliers

Local Community Integrated Health Record

Usual suppliers:
- GP
- Community nurse
- Podiatrist
- Optometrist
- Hosp.
- ONS vital statistics
- Local authority socio-economic
- Public health
- Biobanks
- Local surveys
- Individual research

NHS no.

Model (re)validation alongside clinical audit

Revised records

EU Directive 2007/47/EC
Software = device
Personal Health Record

• EU target: 20% citizens on-line healthcare records access by 2015

• Guided care: partial information

• Patient co-producer: full information
PHR: ‘Access’ Approach

- Citizen rights & responsibilities
- Primary care example: over 75% of patients keep accessing records
- Place for health information exchange beyond clinical encounter
PHR: ‘Asset’ Approach

- Citizen choice and market development
- Emerging business models:
  - Non-profit to increase healthcare efficiency
  - For-profit to open markets e.g. pharmacy-citizen
Digital Replication of Broken Record?

• Tsunami of data
• Flood of models
• Drought of decision-support
Central Question

“How can information enable the co-production of healthcare in the patient-clinician-algorithm triangle, and across social networks?”
Health Records & Knowledge Silos

Open Unifying Modelling: Across mechanisms and contexts

Data-intensive Paradigm shift

Health Avatars & Dynamic Models

Health Records & Knowledge Silos

Expertise

Expertise

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Unified Graphical Model

Data-intensive Paradigm-shift

Multi-scale & Multi-system Health:
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