NHS e-Lab & NorthWest e-Health

Harnessing health record data for patients and communities

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This Talk

• Problem:
  *Lack of real-world evidence or systematic analysis of healthcare records*

• Solution:
  *Healthcare e-Lab technology & community*

• Deployment:
  *NorthWest e-Health pilots → highly scalable*
Real-world Intelligence Gaps

• 75+% of the evidence (beyond clinical trials) of what happens with treatments ‘in the wild’
• Multiple-condition outcomes
• Early-warning, e.g. obesity
• Capture of tacit knowledge
• Feedback evidence to coding practice
• Realistic ‘what-if’ scenario planning tools
The answer is not a data warehouse

Methods/Models/Applications ↑

Relevant expertise ↔

Data ↑↑↑↑
What might the future of healthcare intelligence look like?

FROM MANAGING KNOWLEDGE TO INTELLIGENT HEALTHCARE SYSTEMS
Digital Bridges Since 1990s: Integrated Care **Pathways (Disease-specific)**

- **Self Care**
- **Clinical Care**
- **Primary Care**
- **Secondary Care**
- **Specialist A**
- **Specialist B**
**Missing**: Patient & Community

‘**Big-picture**’ Across Diseases/Services/Pathways

Self Care

Diabetology: Glucose control

Ophthalmology: Diabetic eye care

Nephrology: Chronic kidney disease

Clinical Care

Primary Care

Specialist A

Specialist B

Future: Realistically complex and dynamic models of individual or community care:
i.e. Mr Smith’s care pathway, not diabetes + eye + kidney care pathways
Large scale inference

Unified Graphical Model

Data-intensive Paradigm -shift

Open Unifying Modelling:
Across mechanisms and contexts

Health Records
& Knowledge Silos

Electronic
Health Records
(eHR)

Health Avatars
& Dynamic Models

Union models = Avatar

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

e.g. Coronary heart disease

e.g. Lung cancer

e.g. Chronic obstructive pulmonary disease
Towards Health Avatar & Digital Health Economies

• Natural experiment capture

• Collective insight capture
tacit knowledge $\rightarrow$ explicit metadata

• Open unified modelling
(not simply multi-scale)

....i.e. not top-down or bottom-up: middle-out
Building a ‘sense-making layer’ on top of NHS care records...

REAL WORLD
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

Depersonalised records

Commissioning Audit Public Health Research

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

- Web browser delivered
- Natural language queries, not battling with clinical codes
- Role based access
- Search for worked examples, not separate data and tools
- Just-in-time training
- Peer-to-peer support and visibility
- Audited (security & credit for contribution)
Disseminating New Models: e.g. Policy Simulator: Probabilistic Graphical Models into Practice

Ask “what if” scenario planning questions

e.g. “what is the likely public health impact of 500k spend on statins vs. smoking cessation”

www.healthimpact.org.uk

Models from research → into NHS practice via e-Lab

Export “Method Object” from research
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.

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.

A currency for “m-Health”
Exploit Heterogeneity

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

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

As much social as technical challenge

... assemble a digital ecosystem of
**data, models and experience**
across molecular, clinical and population worlds

- People with relevant expertise and authorisation
- State-of-the-art algorithms
- Quality assured integrated data

Intelligence
Future transparency of decision support

Usual suppliers

Local Community Integrated Health Record

Usual suppliers

NHS no.

Optometrist Community nurse Podiatrist

Biobanks Local surveys Individual research

ONS vital statistics Local authority socio-economic Public health

Model (re)validation alongside clinical audit

Decision support models

EU Directive 2007/47/EC Software = device
Next: capturing missing signals with patients directly e.g.

- When & why did discordance with treatment happen?
- What was the experience of care leading to discordance?
- What is the self-care contribution?

Read-write patient access to primary care record in Manchester now:

www.htmc.co.uk
Conclusion

• Open Source software available
  http://www.youtube.com/user/NIBHI1

• Pilots are running in NW England

• Scalable community of healthcare intelligence
  – potential for EU cross-border collaboration using same technology