Health Systems Learning from Data: A World First from North England

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Transforming Regional Care
Connected Health Cities & Great North Care Record
Newcastle, 4th November 2016
Learning Health Systems 1662

…any man’s death diminishes me, because I am involved in mankind, and therefore never send to know for whom the bells tolls; it tolls for thee.

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Northern Excess Deaths 1965-2015

Premature (under 75) Mortality in North and South England from 1965 to 2015

Around 2m excess deaths <75y from 1965 to 2015
Life on the tram? Differences in life expectancy across Greater Manchester

Northern Excess Deaths 1965-2015

Premature (under 75) Mortality in North and South England from 1965 to 2015

Around 2m excess deaths <75y from 1965 to 2015

Life expectancy data is based on mortality among those living in the particular ward in 1999-2003. The estimates are not the exact number of years a baby born in the ward could actually expect to live, both because the death rates of the area are likely to change in the future, as is health care provision and because many of those people born in the ward will live elsewhere for at least some part of their lives.

Data Sources: Office for National Statistics experimental ward level life expectancy and health living life expectancy estimates (ONS 2006) linked to selected Greater Manchester Metrolink tram stops. The selection highlights some of the biggest differences between tram stops. We also include information on socio-economic deprivation at ward level from the Index of Multiple Deprivation.

Tram Network: The Metrolink tram network across Greater Manchester includes nearly 100 kilometres of track and 93 stops. In 2015 there were around 33.4 million journeys (Metrolink 2015). The average journey time between tram stops is 2 minutes, but some stops are further apart.
NHS Primary Care: Learning System Legacy

The Inverse Care Law

- The availability of good medical care tends to vary inversely with the need for the population served.

Julian Tudor Hart. The Lancet: Saturday 27 February 1971
UK: 30 years of GPs coding in routine primary care

Making Primary Care Data Analysis-ready

Consider the GP annotation on a diabetes code “DM r/o”

Consider Vioxx MI risk detectable pre-2005 via text not coded data

Bias from different: population samples; clinical IT; coding practices; data cleaning


NEW UNDERSTANDING AND BETTER CARE OF ANAEMIA IN DIABETICS

Re-calculate eGFR (kidney function) from creatinine, age and sex in EHR

DIFFERENT FORMULA PER CREATININE ASSAY

Actionable Analytics: Uncovering Context

**MISSED OPPORTUNITIES DETECTOR**

- Find patients relevant to care pathway
  - e.g. A&E asthma
- Exclude if target inappropriate
  - terminal illness
- Exclude if target achieved
  - Follow-up < 48h
- Identify how care could be improved
  - Rx & social review

**ACTIONABLE INFORMATION**

- Integrated Care Record
  - Salford Resident Population
- BLIZZARD OF DATABASES
  - (Salford: 53 GP offices + 1 Hospital)
- Care Quality Management
- Patients’ Decisions

Actionable information attracts: trust & traction from patients, public and practitioners... and better data quality.

Dashboard Plague

NHS: a decade of dashboards
Business intelligence tools
Provider management led
No theoretical framework
Robust Theoretical Framework is Vital

Task
Action
Audit
Message

ALGORITHM ACCURACY
DATA CREDIBILITY

USABILITY/DESIGN
TEAM DELIVERY

Message
Interaction
Perception
Acceptance

Linear flowchart with nodes labeled:
- Patient
- Co-interventions
- Clinical performance
- Verification
- Data collection
- Data analysis
- Individual patient
- Organisation
- Recipients
- Unintended outcomes

Flowchart links:
- Task to Action
- Action to Audit
- Audit to Message
- Message to Desire
- Desire to Intention
- Intention to Action
- Action to Organisational
- Organisational to Unintended outcomes
- Unintended outcomes to Action Planning
- Action Planning to Co-interventions

Keywords:
- Action Planning
- Clinical performance
- Verification
- Data collection
- Data analysis
Integrating with Clinical Workflows

• Audit & Feedback Theory
• Eye Tracking Experiments
• Field Trials in Salford, UK
• Patients Asking for Safety Alerts
• Now Targeting Antimicrobial Resistance
Patient’s View: Eye Tracking to Understand

In search of a new conversation of healthcare over shared records, brokered by informatics that is context-aware.

Reusable Place-based Health Data Analytics

Salford Lung Study results show COPD patients treated with Relvar® Ellipta® achieve superior reduction in exacerbations compared with ‘usual care’

24 May 2016
Issued: London

Pioneering GSK study provides important new data on the effectiveness of Relvar Ellipta (PF/FV) when used in everyday clinical practice

GlaxoSmithKline plc (LSE: GSK) and Introviva, Inc. (NASDAQ: INVA) today announced

Clinical Audits and Service Planning for the local population

National Proteomics Centre: Stoller Biomarker Discovery
Problem: Big Data & Blunt Evidence


Total Medical Knowledge Base Predicts <30% Outcomes

Zak... 47y; asthma since early childhood; schizophrenia since teenage; overweight; smoker

Primary care team...
Smoking cessation; social support; weight control; work

Respiratory team...
Inhaled steroid adherence

Evidence needed is the union not sum of models

Mental health team...
Antipsychotic medication adherence
Problem: Big Data & Blunt Evidence

Primary care team...
Smoking cessation; social support; weight control

Respiratory team...
Inhaled steroid adherence


Total Medical Knowledge Base Predicts <30% Outcomes
Precision Medicine Approach: Asthma(s)

- Life-course complexity indicates multiple (sub-)diseases
  - Usually starts **young**
  - May **progress**, **remit** or **relapse** over life
- Inconsistent gene-environment interactions indicates multiple (sub-)diseases
  - Variable effects of **genetic polymorphisms**, e.g. CD14
  - Variable **treatment-setting** interactions

CD14 Endotoxin Receptor
- C allele associated
- T allele associated
- No association

50-60% heritability in twin studies but < 2% phenotype explained by current genomics

Learnable Wheeze Groups: Distinctive Biology

Persistent troublesome and late-onset wheeze: poorer lung function; more allergy; distinctive genetic variation

Cross Cohort Team Science

Data & Harmonized Metadata from Cohorts

MRC STELAR Consortium: [www.asthmaelab.org](http://www.asthmaelab.org)

MAAS
SEATON
ASHFORD
ALSPAC
IOW

New US
New Au.

Data Extracts
Modelling
Networking: Ideas, Activities, Results, Meanings

Received Wisdom: Atopic March

• Progression of **allergy**
  Eczema → Asthma → Rhinitis

• Inferred from **population** summary →

• Assumed **causal** link between eczema – asthma & rhinitis

• Clinical response: **target** children with eczema to reduce progression to asthma

*Spergel & Paller, 2003*  
*World Allergy Organization, 2014*
Model-based Machine Learning

Eczema Class
- Probability Eczema Age 1
- Probability Eczema Age 3
- Probability Eczema Age 5
- Probability Eczema Age 8
- Probability Eczema Age 11

Wheeze Class
- Probability Wheeze Age 1
- Probability Wheeze Age 3
- Probability Wheeze Age 5
- Probability Wheeze Age 8
- Probability Wheeze Age 11

Rhinitis Class
- Probability Rhinitis Age 1
- Probability Rhinitis Age 3
- Probability Rhinitis Age 5
- Probability Rhinitis Age 8
- Probability Rhinitis Age 11

Children (n=9801)

Start with a well-reasoned (partial) model, not a 'bucket of data'
Myth Bust and Better Targets Revealed

Model-based machine learning allowing for transitions between skin, lung and nasal allergies over time

MRC STELAR consortium working at scale across MAAS and ALSPACS cohorts

Biology-Behaviour-Environment Interaction

Life course

Developmental genetics

‘Persistent’ genetics

Disease risk environment

Treatment environment

Mechanism knowledge

Missingness

Measurement error

Data

ASTHMA genes

* environments → endotypes

Transient early wheeze
Late-onset wheeze
Persistent troublesome wheeze
Persistent controlled wheeze
Rhythms of Life, Health, Disease and Care

Low-cost ubiquitous technologies capturing digital by-products of the life.

High-cost medical devices (regulated clinical algorithms)

Patterns of disease invisible to infrequent clinical observation

n-of-1 trials

Average patient guidelines

Precision medicine may need data on (sub)disease rhythms to realise its potential

Future? My ‘health avatar’ says no to your care pathway
Complex Frequent Observation/Intervention

- What came first, weighing or weight-loss?

- An additional monthly weighing is associated with an extra 1kg weight lost over the course of a year

- Recent weight loss encourages subsequent measurement: a person who has recently lost 1kg is twice as likely to reweigh on a given day compared with someone who has remained the same weight

Complex Frequent Observation/Intervention

- What came first, weighing or weight-loss?

App + Drug → Clinical Workflow Trial

Aim: To Reduce Relapse in Schizophrenia via Smartphone
Drug + behaviour (information * psychological endotype) = outcome

Informatics enabled observation

Informatics intervention

Generic:
• Self-measurement
• Symptom awareness
• Clinical workflow integration
• Self-efficacy / autonomy
• Alert-fatigue avoidance

From J. Ainsworth & S. Lewis
Civic AND Clinical Analytics

2. Detection of geolocation visited

3. Geolocations visited

6. Type of places and activities recognition

5. Places visited

4. Identification of places visited

1. Raw GPS data

7. Out-of-home activities

Smartphone GPS data infer social functioning in patients with schizophrenia

Civic Health Data Analytics

Involved Citizens
Problem Owners
Data Managers
Public Health Analysts
Care Service Analysts
Statisticians
Informaticians
Social Scientists
Health Economists
Health Service Researchers
Communications Experts

Farr Institute & NIHR Centres
Spin-in/out Laboratory
SME
Global Corp.

Insights
Service Planning and Policy

Which services and how?

www.connectedhealthcities.org

Better decision support tools for paramedics: Recognise ‘stroke mimics’

1. Pre-hospital phase

2. Acute hospital phase

3. Transfer to local hospital

4. Discharge and rehabilitation

Faster, more accurate triage and improve access to neurosurgery when needed

Enhanced workflows e.g. medication vs. BP reviews to prevent another stroke
Stroke Prevention: Civic Extension

• **Smartwatch** detects atrial fibrillation over a week, otherwise missed by a GP in a 10 minute consultation: then supports anticoagulant medication.

• Smart **electricity meter** data alert rehab team to a change in daily living patterns and trigger outreach.

• Subsidised **public transport** after cardiovascular risk screening makes it cheaper to walk/tram than take the car to work: increased physical activity sustained where exercise prescriptions fail.
Diameter of Trust

NOT SCALABLE
Excellence provider benchmarking e.g. strokeaudit.org but no learning across disease areas and not integrated with clinical workflows

National/Large Population Audits/Registers/Monitoring

Large enough for economy of scale
Small enough for a conversation with the citizenry about data sharing

Actionable information for health system optimisation

SCALABLE
Payer evidence, quality management, public health intelligence and research share data, infrastructure and expertise

GMCA
PIONEERING DATA SERVICE TO CONNECT GREATER MANCHESTER TO IMPROVED SERVICES
Trust in Predictive Analytics

Academia rewards publishing papers on the same topic every 10 years or so

Law sees algorithms as medical devices (EU Directive 2007/47)

Industry has no trusted third-party lab for validating algorithms/models

EuroScore prediction

Observed death rate

Calibration drift: Typical of many published models

Analytic Federation: Spread the Load

Commons of Metadata and Information Governance (Clinical & Research)

System 1 → System 2 → System 3 → System 4

Analytic Objects

Research Safe Haven

Encrypted (SHA1 & AES256); Certified (ISO 27001)

Identified Records

De-identified Records

Study Protocol / Assessment

Routine Randomisation

Study Recruit

Clinical Care

Clinical Care

Researcher

Patient

Clinician

Linkable Data Providers

RAPID REPLICATION
- Study/audit protocol
- Codes for the data
- Statistical scripts
- Results in progress
- Report
- Slides etc.


My Health Data Ecosystem

My Health, My Data: Where are the most predictive data?
Civic Imperative

“Learning Healthcare Systems” are an illusion if restricted to provider organisations.

Health(care) can’t be optimised outside the civic context of health.

@profbuchan
#DataSavesLives
Connected Health Cities: World First

• Data sharing benefits > risks: public ownership

• Data/technology pull-through from problem-solving

• Care quality, research and commissioning: one analytic

North England: Data works for citizens
Elsewhere: Citizens work for data

@profbuchan
#DataSavesLives