Electronic Health Records Research in a Health Sector with Multiple Provider Types

Samantha Crossfield
Susan Clamp

Presented by Samantha Crossfield AMBCS, MSc
info@researchone.org
<table>
<thead>
<tr>
<th>Section</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Setting</td>
<td>Clinical care silos</td>
</tr>
<tr>
<td>Issue</td>
<td>Hard-to-access, partial records with costly linkage</td>
</tr>
<tr>
<td>Opportunity</td>
<td>Integrated electronic health records</td>
</tr>
<tr>
<td>Research Aim</td>
<td>Bringing integrated records into research</td>
</tr>
<tr>
<td>Method</td>
<td>Comparative analysis of critical success factors</td>
</tr>
<tr>
<td>Results</td>
<td>Justification of a database protocol with the capacity to enable integrated, cross-organisation type research</td>
</tr>
<tr>
<td>Next Steps</td>
<td>Clinician and researcher engagement</td>
</tr>
</tbody>
</table>
Setting: Multiple Health Care Providers

Example:
A patient with cardiovascular disease receives care from multiple clinicians
Care provision is **tiered and split** across multiple sites in such countries as the UK, Spain, US and China.
Each care provider records patient details in a **health record** that may be **inaccessible to other care providers**.
Issue: Multiple Health Care Patient?

Non-shared records:
Aspects of patient care are separated
Miss timely and relevant information
Duplication of information
Less reliable and therefore depend on patient awareness or telephoning other care providers
Opportunity: Electronic Health Records

- £27 billion incentives for US health professionals
- 76% GPs across Europe in 2008
- 92% Health IT services bring benefits
- 97% UK General Practices used electronic records by 2012

Exemplary Electronic Practice in the UK

<table>
<thead>
<tr>
<th>Service</th>
<th>Technology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Admission, Discharge and Transfer</td>
<td></td>
</tr>
<tr>
<td>Choose and book appointments</td>
<td>Electronic prescribing</td>
</tr>
<tr>
<td>Payment and target monitoring</td>
<td>Electronic referral</td>
</tr>
<tr>
<td>Clinical decision support</td>
<td>Tele-health</td>
</tr>
<tr>
<td>Infectious disease notification</td>
<td>Public health monitors</td>
</tr>
<tr>
<td>Ordering diagnostic tests and pathology result transferral</td>
<td></td>
</tr>
<tr>
<td>Patient demographic sharing</td>
<td></td>
</tr>
</tbody>
</table>

1 Buntin, Burke, Hoaglin et al. 2011  
2 Dobrey, Haesner, Husing et al. 2008  
Opportunity: Electronic Health Records Research

14.5 million emergency department attendances: waiting time correlates with mortality and readmission ¹
Child health records and clinical records: autism does not correlate with the MMR vaccine ²
2.3 million GP records: cardiovascular risk prediction tool - QRisk² ³

¹ Guttmann et al. 2011
² Taylor et al. 1999
³ Hippisley-Cox et al. 2008
Health Care Solution: Integration

- Kaiser Permanente care packages
  - 8 million US patients
- SystmOne centralised health records
  - 26 million UK patients
  - Accessible, accurate, real-time record sharing

3.5 times fewer hospital bed stays \(^1\)

Medicines reconciliation \(^2\)
Records are used more \(^3\)
Patient management across organisations \(^3\)

---

\(^1\) Ham et al. 2003
\(^2\) Moore et al. 2011
\(^3\) Keen & Denby 2009
UK Integrated Healthcare: SystmOne

- Interface designed to facilitate the coding of clinical data
- Information is reliably and centrally captured in non-identifiable code

Asthma causes daytime symptoms most days \( \text{XiNd} \)

Asthma causes daytime symptoms 1 to 2 times per week \( \text{XiINc} \)
SystmOne Coverage

27 million patients
120,000 users
4,800 providers

Including

2000 general practices
1250 district nursing
120 Out of Hours
50 Minor Injuries / A&E

18 million GMS registered
5 million patients
3 million patients
865,000 patients
SystmOne General Practice Coverage

**Care organisations on SystmOne over the previous six years**

- All care providers
- General practices

**GP population per sex and age group**

- Males in England
- Females in England
- Males in SystmOne (GP)
- Females in SystmOne (GP)

**Map of permanent registered GP patients per mid-level super output area**

- Yellow = 0
- Darkest blue > 5,500
SystmOne can bring shared electronic records data to research

- Centralised database with timely, audited access
- Traceable communications between organisations
- Data from multiple care organisations
- Replaces biased, incomplete linkage

Timely and reproducible research
Comprehensive research
Pseudonymisation can replace identifiers

1 Bohensky et al. 2010
SystmOne in Research: Examples

- Born in Bradford
  - 13,000 families: how genetic, environmental and social factors impact health. The project uses Child Health and General Practice data
- Action to Support Practices Implementing Research Evidence
- GATEway to the Clouds
  - Anonymising free text health data
- Improving Prevention of Cardiovascular Events in Primary Care
- Cardiovascular risk in mental health care
- Public health monitoring

John Wright, Born in Bradford
“ResearchOne has the potential to transform medical research by providing low cost methods to monitor the impact of exposures such as air pollution and diet on later health”
<table>
<thead>
<tr>
<th>Data Item</th>
<th>Details</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of birth (MM/YY)</td>
<td>A&amp;E admission / event details</td>
<td>Hospital admission/event details</td>
</tr>
<tr>
<td>Date of death (MM/YY)</td>
<td>Care episodes</td>
<td>Hospital discharge details</td>
</tr>
<tr>
<td>Cause of Death</td>
<td>Care pathways</td>
<td>Medication end details</td>
</tr>
<tr>
<td>Deprivation indices</td>
<td>Care plans</td>
<td>Miscellaneous patient flags</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Child at risk entries</td>
<td>Out-of-hours cases</td>
</tr>
<tr>
<td>Gender</td>
<td>Child health appointments</td>
<td>Pathology results</td>
</tr>
<tr>
<td>Occupation</td>
<td>Child health scheduling suspensions</td>
<td>Recalls</td>
</tr>
<tr>
<td>Rurality indices</td>
<td>Clinical diagnosis entries</td>
<td>Referrals in</td>
</tr>
<tr>
<td>Sector-level postcode</td>
<td>Clinical numeric entries</td>
<td>Referrals out</td>
</tr>
<tr>
<td>Mid-Level Super Output Area</td>
<td>Clinical numeric ranges</td>
<td>Repeat medication</td>
</tr>
<tr>
<td>Clinical Information</td>
<td>Clinical procedure entries</td>
<td>Staff roles</td>
</tr>
<tr>
<td>Acute medication</td>
<td>Consultation data</td>
<td>Vaccinations</td>
</tr>
<tr>
<td>Alert indicators</td>
<td>Contacts</td>
<td>Vaccination consents</td>
</tr>
<tr>
<td>Allergies</td>
<td>Drug sensitivities</td>
<td>Visits</td>
</tr>
<tr>
<td>Appointments</td>
<td>Healthcare provider types</td>
<td>Waiting list entries</td>
</tr>
</tbody>
</table>
Aim: to assess the capacity of the ResearchOne database to support EHR research and to justify its potential benefits to integrated records research using English health data

1. Determined the key features of the established QResearch UK EHR research database\(^1\)
2. Critically reviewed the ResearchOne Database Protocol\(^2\)

\(^1\) Hippisley-Cox et al. 2004; Vinogradova et al. 2012  \(^2\) Crossfield et al. 2012
<table>
<thead>
<tr>
<th>Critical factor</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data consolidation¹</td>
<td>Assist researchers in accessing data from many organisations and so reduce the invasion, time and cost for clinicians and researchers, who must otherwise perform repeated extracts.</td>
</tr>
<tr>
<td>Large cohort of research EHR data¹</td>
<td>Larger sample sizes bring both power and validity to research outcomes, enabling more research questions to be addressed².</td>
</tr>
<tr>
<td>De-identified EHR data¹</td>
<td>Protects privacy and permits research access without a public health mandate or consent, which could not be feasibly and non-invasively acquired for a significantly large cohort³.</td>
</tr>
<tr>
<td>Representative coverage¹</td>
<td>The external validity of a research outcome depends upon it being derived from a representative sample of the population.</td>
</tr>
<tr>
<td>Ethical research practice¹</td>
<td>Success relies upon the database being securely developed and used for ethical purposes.</td>
</tr>
</tbody>
</table>

¹Hippisley-Cox et al. 2004; Vinogradova et al. 2012  
²Cohen, 1992  
³Lowrance, 2003; Wellcome Trust, 2009
Critical Factor: Data Consolidation

- QResearch: Around 5000 General Practices are invited, data is consolidated from over 650 non-integrated organisations
- ResearchOne: Around 5000 health and care organisations are invited, including over 2000 General Practices, over 50 Emergency Departments and over 50 Child Health Units
- ResearchOne: Organisation data is integrated into shared patient records on centralised SystmOne and so no consolidation is required
- QResearch: data is linkable with socio-economic data, English Hospital Episode Statistics (HES), disease registries and death registrations
- ResearchOne: socio-economic data is incorporated, linkable with HES, registry and death registrations

1 Hippisley-Cox et al., 2008; Hippisley-Cox and Stables, 2011  
2 Crossfield et al. 2012
Critical Factor: Large Cohort

- **QResearch**: Over 650 General Practices, around 5000 invited\(^1\)
- **ResearchOne**: around 5000 organisations invited – 26 million centralised patient records
- **ResearchOne**: hosted centrally with the same database capacity as SystmOne\(^2\)
- **ResearchOne**: Potentially large cohort of organisation types and large cohort of multi-shared records data

\(^1\)Vinogradova et al. 2012  \(^2\)Crossfield et al. 2012
Critical Factor: De-identified Records Data

- **QResearch**\(^1\) and **ResearchOne**\(^2\):
  - National ethical and governance approved protocol for de-identification
  - No free text with potential identifiers
  - Partial dates of birth/death – ‘February 1986’
  - Data owners provide consent

- **ResearchOne**:
  - \(k\) anonymisation, \(k = 5\)
  - Patient dissent

\(^1\)Hippisley-Cox et al. 2004  \(^2\)Crossfield et al. 2012
Critical Factor: Representative Coverage

• **QResearch**: 660 General Practices “spread throughout the UK”
• **QResearch**: 96.5% white or unknown ethnic group, ~88% white in the population (2008)
• **ResearchOne**: invited organisations are representative of social, primary and secondary care
• **ResearchOne**: invited organisations represent all Strategic Health Authorities and over 85% Local Authorities
  – SystmOne holds over 300 million years of patient records
  – 13 million patients currently receive care at multiple sites using SystmOne
  – 4.8 billion diagnostic codes recorded on SystmOne
  – 100% rurality indices and ~70% indices of multiple deprivation on SystmOne

---

1Hippisley-Cox et al. 2004; Vinogradova et al. 2012  
2 Crossfield et al. 2012
QResearch and ResearchOne¹:

- Follow ethical and governance-approved protocols
- Aim to enhance General Practice understanding
  - ResearchOne extends this aim across further social, primary and secondary care organisation types
- Reviewed by committees and a national ethics board
- Have a committee to scientifically review research projects
- Not-for-profit

ResearchOne¹:

- Database access is electronically audited
- Data is automatically de-identified before leaving SystmOne

¹Hippisley-Cox and Stables 2011; Crossfield et al. 2012
Almost 1/2 of the patients in England can contribute
Nationally approved de-identification protocol
Data from multiple consenting organisations
Geographic and demographically representative
Ethical framework for supporting timely research
Further Innovation: Beyond the Standard

✓ Cross-organisation type records – ‘child health to geriatric’
  ✓ Supports comprehensive research across care areas
  ✓ Track patients longitudinally across care organisations

✓ Shared, integrated records
  ✓ More comprehensive, with less duplication
  ✓ No costs, bias, inaccuracy and privacy risk from linkage
  ✓ Communications between organisations

✓ Prompt access from centralised records
  ✓ Minimal extraction cost
  ✓ Does not disturb clinical practice
  ✓ Instantaneous electronic audit of consent
  ✓ Timely information on clinical developments

A more comprehensive view of the care sector and care delivery
What is Next for ResearchOne?

✓ Ethical approval
• Organisation participation
  ✓ One-step joining process
  ✓ NHS-accredited security
    – Outcomes fed back
• Outcomes in clinical practice
  – Published results
  – Relevant to multiple organisation types
  – Clinical system improvements
  – Global model
What is Next for ResearchOne?

• Validation
  – Comparison to national statistics
e.g. Vaccinations, diagnoses, demographics
  – Validate existing research

• Innovative research
  – Single or multiple organisation types

<table>
<thead>
<tr>
<th>ResearchOne Programme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Validate existing research – QResearch, GPRD, case studies</td>
</tr>
<tr>
<td>Public health – disease incidence, demographic trends, drug side effects</td>
</tr>
<tr>
<td>Clinical decision support – risk prediction, selecting interventions</td>
</tr>
<tr>
<td>Clinician business intelligence – needs assessment, resource management</td>
</tr>
<tr>
<td>Engagement – embed results in SystmOne, clinician-guided research</td>
</tr>
</tbody>
</table>
What is Next for ResearchOne?

- New research methods
  - Security technology
  - Data mining
  - Natural language programming

Hina et al. 2013. Identification, Classification and Anonymisation of 'Protected Health Information' in real-time medical data for research purposes. The 23rd Meeting of Computational Linguistics in the Netherlands.
Conclusion

• Shared electronic health records are used more and support integrated care delivery
• Shared records research can be more timely, comprehensive, without linkage biases
• The ResearchOne database protocol meets the critical success factors
  – Data consolidation
  – Large cohort – Representative
  – De-identified – Ethical
• The database has capacity for timely provision of integrated, cross-organisation type data
• Global model for integrated health care evolution
‘Take Home Message’

Shared EHR research can focus on an issue rather than an organisation type

The ResearchOne database has the capacity to enable shared records research
‘Take Home Message’

Shared EHR research can focus on an issue rather than an organisation type

Any Questions?

The ResearchOne database has the capacity to enable shared records research