National Scale Clinical Information Exchange in the United Kingdom: Lessons for the United States

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MEBI 590
2 Oct 2009
My sabbatical

• 30 April - 1 July in the United Kingdom
• Work funded by Prof Iain Buchan, through UK grant
• Traveled within UK extensively
• Based at the University of Manchester
<table>
<thead>
<tr>
<th>Name</th>
<th>Position and Organization</th>
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</thead>
<tbody>
<tr>
<td>Iain Buchan</td>
<td>Professor Public Health Informatics, NIBHI University of Manchester</td>
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<tr>
<td>John New</td>
<td>Consultant, Endocrinology Royal Salford Hospital</td>
</tr>
<tr>
<td>Mike Bainbridge</td>
<td>Chief Architect NHS Connecting for Health UK Health ICT Champion 2007-8</td>
</tr>
<tr>
<td>John Anderson</td>
<td>Internal medicine and endocrinology Homerton University Hospital Trust, NHS</td>
</tr>
<tr>
<td>Simon Wallace</td>
<td>Physician Executive Cerner Corporation</td>
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</tbody>
</table>
My questions

• How have barriers to health information exchange been addressed in the UK?

• What barriers remain, and why?

• Has the UK succeeded in bringing myriad health care information technologies together to permit information exchange between their electronic medical record systems?

• Have incentives to exchange information been aligned to make this possible?
Overview of today’s talk

Context  Why is information sharing important?
Requirements  What is required for sharing clinical information?
UK experience  How has the UK addressed requirements?
Lessons for the US  What can the US learn from UK experience?
Summary  My summary, your comments
Overview of today’s talk

Context

Why is information sharing important?

Requirements

What is required for sharing clinical information?

UK experience

How has the UK addressed requirements?

Lessons for the US

What can the US learn from UK experience?

Summary

My summary, your comments
Why is clinical information exchange important?

- Absence of clinical information can cause quality and safety problems
- Potential to reduce healthcare costs, increase convenience
United Kingdom compared to the United States

Population

- US: 61,113,205
- UK: 307,212,123

Size

GDP

- UK: 2.23 trillion
- US: 14.29 trillion

Sources:
- Population: CIA World Factbook
- Size: CIA World Factbook
UK healthcare system in one slide

- All citizens have coverage through National Health Service
- Created after WW2; popular, political
- Financing through Secretary of State for Health
- NHS divided into local ‘trusts’; many in each region
  - Primary care trusts. GPs are independent contractors
  - Secondary care trusts are hospitals and specialists
  - Ambulance, home care, other care also in trusts
  - Pharmacy included
  - Some trusts earn more independent ‘Foundation’ status
  - Private care is mostly limited to elective surgery
United Kingdom compared to the United States

Health expenditures per capita

Health expenditure does not necessarily predict performance

Figure 2.6 Performance on level of health (disability-adjusted life expectancy) relative to health expenditure per capita, 191 Member States, 1999

US Deficit

![Graph showing US Deficit Actual and Projected in billions from 2000 to 2019.]

ACTUAL

- $236.2 billion in '00
- Projected deficits from '02 to '08

PROJECTED

- CBO estimate: -$1.85 trillion in '09
- White House estimate: -$1.75 trillion in '09


http://www.washingtonpost.com/wp-dyn/content/graphic/2009/03/21/GR2009032100104.html
Accessed 18 June 2009
Reducing unnecessary health care costs is important to current US administration

"We seem to have as much as $700 billion a year in health care tests and services that are unnecessary, that don't improve health outcomes and that just add to costs both for the federal government and for workers without making anyone healthier..."

...There is no way you can put the nation on a sound fiscal course without wringing inefficiencies out of health care.”

   Peter Orszag, White House budget director

\(^2\)Quoted by David Leonhardt, New York Times, June 9, 2009
Now, in the past month alone, we've done a lot more to advance that goal than we've done in the past decade. We've provided and protected coverage for 11 million children from working families, and for 7 million Americans who've lost their jobs in this downturn. We've made the largest investment in history in preventive care; invested in electronic medical records that will save money, ensure privacy, and save lives; we've launched a new effort to find a cure for cancer in our time. We've also set aside in our budget a health care reserve fund to finance comprehensive reform. I know that more will be required, but this is a significant down payment that's fully paid for; does not add one penny to our deficit. And I look forward to working with Congress and the American people to get this budget passed.
Methods

- 35 interviews
- Review of published and unpublished literature
- Visits to GP surgeries, hospitals, rounds

Limitations

- Only 2 month’s exposure to complex issues spanning decades
- Acquisition bias likely
- Healthcare IT, particularly in the UK, is rapidly evolving and so may be different at time of publication

Most in US know less than I do about UK healthcare IT
What do we mean by data exchange and interoperability?

<table>
<thead>
<tr>
<th>Level</th>
<th>Walker Health Affairs 2005</th>
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<tbody>
<tr>
<td>1</td>
<td>Nonelectronic (mail, telephone)</td>
</tr>
<tr>
<td>2</td>
<td>Machine transportable data (ex. fax, PDF)</td>
</tr>
<tr>
<td>3</td>
<td>Machine organizable data (e.g. text, HL7)</td>
</tr>
<tr>
<td>4</td>
<td>Machine-interpretable data</td>
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</table>

<table>
<thead>
<tr>
<th>Level</th>
<th>SemanticHealth, EC 2009</th>
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<tr>
<td>0</td>
<td>None</td>
</tr>
<tr>
<td>1</td>
<td>Technical and syntactical interoperability</td>
</tr>
<tr>
<td>2</td>
<td>Two orthogonal levels of partial semantic inoperability</td>
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<tr>
<td>2a</td>
<td>Unidirectional semantic interoperability</td>
</tr>
<tr>
<td>2b</td>
<td>Bidirectional semantic interoperability</td>
</tr>
<tr>
<td>3</td>
<td>Full semantic interoperability</td>
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</table>


Where might clinical information be shared?

Sharing from one location of care to another

Arrow weight indicates frequency of use
End of life care may also benefit from SCR.
Clinical information exchange is one way to reduce healthcare costs

### EXHIBIT 3
**Net Value Of Health Care Information Exchange And Interoperability (HIEI)**

<table>
<thead>
<tr>
<th>Level</th>
<th>Implementation, cumulative years 1–10 ($ billions)</th>
<th>Steady state, annual starting year 11 ($ billions)</th>
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<td><strong>Cost</strong></td>
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<td>Level 3</td>
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<td><strong>Benefit</strong></td>
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<td></td>
<td><strong>Net value</strong></td>
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<td>Level 4</td>
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<td><strong>Benefit</strong></td>
<td><strong>Cost</strong></td>
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<td></td>
</tr>
<tr>
<td></td>
<td><strong>Net value</strong></td>
<td></td>
</tr>
</tbody>
</table>

**SOURCE:** Authors’ analysis.

**NOTES:** For explanation of levels, see text. All results are stated to three significant digits.

Data exchange US today

- In some US communities electronic clinical data exchange between clinics and hospitals
- Within VA, some HMOs, electronic data exchange occurs
- Patient access to their health information is rising: Kaiser, other sites
- Interest in HealthVault, Google Health
- Many US communities exchange information as in my clinic
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For electronic exchange of information to occur

- Sender must have information in electronic form
- Recipient must be able to receive it in electronic form
- Sufficient incentives for exchange must exist for sender and recipient
- There must be a secure medium for exchange
- Legal and ethical environment must exist
Requirements for clinical information exchange

Clinical information exchange

Applications
- NHS Mail
- GP2GP
- GP systems
- Web access
- Repositories
- SCR
- EPS1
- Choose & Book
- PACS

Incentives
- Financial
- Clinical
- Reputation

Foundations
- Infrastructure
- System
- Policy
Overview of today’s talk

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Lessons for the US  What can the US learn from UK experience?
Summary  My summary, your comments
## Foundations

<table>
<thead>
<tr>
<th>Infrastructure</th>
<th>NHS Number</th>
<th>Smartcards</th>
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<tbody>
<tr>
<td>Strong authentication</td>
<td>NHS Net</td>
<td>Currently N3</td>
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<tr>
<td>National health computing application standards</td>
<td>Coding of records</td>
<td>RFA 99 v1.1, GP System of Choice</td>
</tr>
<tr>
<td>National health computing application standards</td>
<td>Unique number for practitioners, practices, facilities</td>
<td>Regional reciprocal access</td>
</tr>
<tr>
<td>Time</td>
<td>This has been developed over several decades</td>
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</table>

<table>
<thead>
<tr>
<th>Policy</th>
<th>Public discussion of privacy</th>
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<tbody>
<tr>
<td>National policies for protection of privacy</td>
<td>National Information Governance board, Caldicott Guardians</td>
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<tr>
<td>National service frameworks</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>System</th>
<th>GP coordinates care for UK citizens</th>
<th>Strong incentive to use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single payer</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
For the Record: Protecting Electronic Health Information
National Academy Press, Chapter 4, p 86, 1997

Authentication

Authentication is any process of verifying the identity of an entity that is the source of a request or response for information in a computing environment. It is the linchpin for making decisions about appropriate access to health care information, just as it is for controlling legal and financial transactions. Generally, authentication is based on one or more of four criteria:

1. Something that you have (e.g., a lock key, a card, or a token of some sort);
2. Something that you know (e.g., your mother's maiden name, a password, or a personal ID number);
3. Something related to who you are (e.g., your signature, your fingerprint, your retinal or iris pattern, your voiceprint, or your DNA sequence); or
4. Something indicating where you are located (e.g., a terminal connected by hardwired line, a phone number used in a callback scheme, or a network address).
Strong authentication
NHS smartcards

• “Something you have, something you know”

• Combination is better than either one alone

• Builds confidence that you are who you say you are

• Being implemented; in use in practices I visited
NHS Number permits record linking

- Has roots in form taken to Registrar of Marriages, Births and Deaths within 42 days of birth
- Evolved from 1950s to present
- Provides a critical component for safe, efficient clinical information exchange
- In some hospitals used for transmission to other organizations, but not for internal use
The Spine and its role in clinical information exchange

- The Spine is a combination of:
  - National infrastructure
  - A set of transactions
  - Applications that use those transactions, including Choose & Book, Patient Demographic Service, Summary Care Record, GP2GP, and EPS

- It underlies and permits much of the clinical information exchange that occurs in the NHS
Examples of national policy influencing clinical data exchange

• Public discussion of privacy and confidentiality
• National structures to address privacy concerns
  • Caldicott Guardians
  • National Information Governance Board
• National service frameworks for clinical care
National Information Governance Board

- Membership includes representatives of public, medical professional organizations, local government, Council of Caldicot Guardians
## Incentives

<table>
<thead>
<tr>
<th>Incentive</th>
<th>Recipients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital penalized if discharge letters arrive &gt; 48 h</td>
<td>Acute trusts, consultants</td>
</tr>
<tr>
<td>Salary lined to Quality &amp; Outcomes Framework</td>
<td>Used in almost all GP practices</td>
</tr>
<tr>
<td>Practices appear more professional, more likely to meet targets</td>
<td>GPs, consultants</td>
</tr>
<tr>
<td>GP SoC, RFA 99, Common Assurance Process</td>
<td>Suppliers have strong incentive to comply with NHS standards</td>
</tr>
</tbody>
</table>
Financial incentives can change behavior

- Professional and facility fee billing requirements from Centers for Medicare & Medicaid Services in the US have greatly influenced IT systems and their use.

- In US VA, regional director was held accountable through a performance contract, which included incentives equivalent to roughly 10% of the director's salary, for meeting specified quality standards\(^1,2\).


\(^2\) Oliver A. The Veterans Health Administration: An American Success Story? The Milbank Quarterly, Vol. 85, No. 1, 2007 (pp. 5–35).
Strong incentives for compliance with national health IT standards

- National health IT application standards
- GP System of Choice
  - Contract framework
  - RFA 99 v1.1
  - Common Assurance Process for GP systems
Requirements for Accreditation 99 v1.1

Example of requirement that systems NHS pays for conform to set standards for data exchange

Part MI: Messaging and Information Exchange

Contents

Requirements Summary
MI.1 Introduction
MI.2 Overview
MI.3 NHSnet
   3.1 Security
   3.2 Connecting to NHSnet
   3.3 Managed Message Handling Service (MMHS)
   3.4 NHSweb
   3.5 Other WAN Service
MI.4 Electronic Data Interchange (EDI)
   4.1 Security
   4.2 General EDI – Accreditation Status
   4.3 GP-HA Messages
   4.4 Clinical Messages
Annex MI.A.1 References and Specifications
Annex MI.A.2 Contacts
Annex MI.A.3 Useful Web Sites
Requirement for Accreditation

3. The RFA V4 covers:
   - General functionality, based on the RFA Version 3, updated to include data standards and Year 2000 conformance;
   - Electronic Data Interchange (EDI), with revised specifications for GP/HA links including NHS Organ Donor Registration and Cervical Cytology messages, and new requirements for clinical messages for pathology, radiology and discharge summary reports. The EDIFACT standard is specified for all these messages to facilitate integration with the receiving system. The EDI messages have been developed so that they can be sent over the NHS Managed Messaging Handling Service (MMHS), which is based on the X.400 (88) standard. The systems that are accredited must have the capability to connect to NHSnet IP and X.400(88) services, and GPs are encouraged to connect to these services at the earliest opportunity.

4. The RFA Version 4 introduces the concept of mandatory and optional requirements in the field of electronic data exchange. Where a system meets only the mandatory requirements it will be accredited as meeting the RFA standards but that accreditation will be known as RFA(Basic). This level of accreditation is sufficient to fulfil the recommended criteria for reimbursement outlined earlier in this letter.

5. Where a system contains some, or all, of the optional requirements this level of accreditation will be known as RFA(Plus). Where a system has this level of accreditation HAs should be aware that the RFA testing and accreditation can only apply to those clinical messages that are specified in the RFA Version 4 and that have been deemed to be safe and testable by the GP/Provider Links Project. Where an authority is unsure about the status of any clinical message in an accredited computer system the FHS will be able to tell them which clinical messages have passed accreditation tests (see para 3(iv))

March 2003 reminder to PCOs about the reimbursement scheme

Key Messages

- The BMA and the Department of Health have received complaints from practices concerning PCOs which are applying undue pressure to practices to change clinical computer systems.

- Under existing regulations practices are entitled to choose from and be reimbursed for RFA-99 (v1.1 and v1.2) compliant systems. Systems that do not comply with RFA-99 should not be eligible for reimbursement.

- PCOs must not apply local differential reimbursement criteria which favour any particular system supplier.

- While it is sensible and indeed necessary to replace individual practice systems that do not comply with RFA-99, larger scale practice system replacement should not take place until there is greater clarity about emerging national arrangements.

- It is essential that clinical information and patient records should be protected during system migration.
Incentives for information exchange

• Financial
  - GP salary linked to Quality & Outcomes Framework based on encoded data
  - Acute hospital trusts financially penalized if discharge summaries not transmitted to GP in 48 hours

• Clinical
  - Out-of-hours care no longer provided by GP
## Applications

<table>
<thead>
<tr>
<th>Application</th>
<th>Description</th>
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<tbody>
<tr>
<td>Choose &amp; Book</td>
<td>Attachments from GP record</td>
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<tr>
<td>GP systems</td>
<td>Used in almost all GP practices</td>
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<tr>
<td>Summary Care Record</td>
<td>In pilot</td>
</tr>
<tr>
<td><strong>GP2GP</strong></td>
<td>Covers ~ 1/6 of GP patient transfers of care</td>
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<tr>
<td>Regional repositories with web access</td>
<td>Graphnet and others</td>
</tr>
<tr>
<td>PACS</td>
<td>Regional reciprocal access</td>
</tr>
<tr>
<td>NHS Mail</td>
<td>Not broadly used for clinical purposes</td>
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<tr>
<td>EPS1</td>
<td>Paper transmission of barcoded prescription</td>
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<tr>
<td>HealthSpace, EMIS Web, other web portals</td>
<td></td>
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<tr>
<td>Pathology and radiology messaging</td>
<td></td>
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<tr>
<td>Discharge letter messaging</td>
<td>Strong incentive to use</td>
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</tbody>
</table>
EMR use in GP practices widespread

- Most GPs have and use EMRs, for > 15 years

- Nearly all prescriptions entered electronically

- Notes a mixture of encoded and narrative text

- Pathology via interfaces

- As consequence, GPs have substantial informatics expertise
GP2GP

- Transfers encoded and narrative text of patient record from one commercial GP system to another
- At present, used for 500,000 of 3 million (1/6th) GP to GP patient transfers
- Works within systems from same vendor and between systems from different vendors
- Incentives to use: avoid cost manual abstraction and data entry, borne by GP practice staff. Encoded data needed for QOF
Incentives and dependence on foundations for applications used for clinical data exchange

My subjective assessment

<table>
<thead>
<tr>
<th>Application</th>
<th>GP2GP</th>
<th>Choose &amp; Book</th>
<th>PACS</th>
<th>Discharge letters</th>
<th>SCR</th>
<th>EPS1</th>
<th>Regional repositories</th>
<th>NHS Mail</th>
<th>Web access</th>
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↑ Number of arrows indicates incentive for stakeholder to use; horizontal arrow indicates little incentive to use
● Dot indicates application depends on foundation shown at left
# Current status of clinical information sharing in the UK

<table>
<thead>
<tr>
<th>Status</th>
<th>GP2GP</th>
<th>Choose &amp; Book</th>
<th>PACS</th>
<th>Discharge letters</th>
<th>SCR</th>
<th>EPS1</th>
<th>Regional repositories</th>
<th>NHS Mail</th>
<th>Web access</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>500,000 uses (1/6 pt transfers), 74% practices using.</td>
<td>15 million bookings; 33,000/day(^2)</td>
<td>127 PACS systems, 27 Trusts(^1)</td>
<td>Broad use</td>
<td>Pilot, with 258,000 SCRs on Spine(^2)</td>
<td>190 million prescriptions, 78% GP practices using(^2)</td>
<td>2(?) regions</td>
<td>983,152 messages are sent/received daily(^2)</td>
<td>?</td>
</tr>
</tbody>
</table>

\(^1\)Kathy Mason, Programme Director, Mainstreaming IM&T. PACS Benefits PACS Board Meeting, 27 November 2008  
\(^2\)http://www.connectingforhealth.nhs.uk/newsroom/statistics/deployment  

There are ~7,100 GP practices in England. Source: from 2 above, 5544/0.78,
Other models for clinical information exchange

- Patient carries information
- Patient controls information and grants access
Where might clinical information be shared?

Sharing from one location of care to another

GP2GP = transfer of entire encoded record
SCR = Summary Care Record
Arrow weight indicates frequency of use
End of life care may also benefit from SCR.
Large national health IT initiatives in the United Kingdom

<table>
<thead>
<tr>
<th>Initiative</th>
<th>Years</th>
<th>Sample accomplishments</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS Information Management Group</td>
<td>1992-?</td>
<td>NHS Number, other infrastructure</td>
</tr>
<tr>
<td>NHS Information Authority</td>
<td>1999-2004</td>
<td>NHS Net, NHS Number for Babies, NHS Mail, ECDL</td>
</tr>
<tr>
<td>National Program for Information Technology</td>
<td>2002 - Present</td>
<td>NHS Net 3 (N3), NHS Number adoption, applications</td>
</tr>
</tbody>
</table>

“If I live in Bradford and fall ill in Birmingham then I want the doctor treating me to have access to the information he needs to treat me.”

Observations on current clinical information exchange

- Though foundation and some applications are in place, this is recent and not all are nationally available
- Potential exists for much larger scale information exchange
- Less information flows to/from hospital and consultative care
- Reduction of 55% of repeat x-rays attributable to PACS (year 1 data) (range 30%-99%)\(^1\)

\(^1\)Kathy Mason, Programme Director, Mainstreaming IM&T. PACS Benefits PACS Board Meeting, 27 November 2008
My answers to my questions

• How have barriers to health information exchanged been addressed in the UK?

  With a foundation of policy, infrastructure, systems and applications developed over decades, and with strong use of incentives

• What barriers remain, and why?

  Much information from acute care remains on paper. Hospital workflows have not changed as much as in primary care.

• Has the UK succeeded in bringing myriad health care information technologies together to permit information exchange between their electronic medical record systems?

  By setting a national framework and requiring suppliers to conform to it, there are many suppliers participating. Use of suppliers is evolving.

• Have incentives to exchange information been aligned to make this possible?

  Financial, clinical, and reputational incentives have been aligned to support clinical information exchange.
Summary

• The UK has made enormous progress toward permit clinical information exchange.

• Features most impressive to me are use of incentives, RFA and GPSoC, creating a national infrastructure, and broad use of EMRs in primary care, and scope of IT programs.

• There is early evidence that clinical information exchange has reduced costs; great potential exists for more cost reduction, increased safety, and greater patient involvement.

• The UK course has been difficult, open, and creative.

• US policy makers should learn from this experience. “There are no easy answers,” but it is easier if we learn from each other.
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Questions and Discussion

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Send email to request slides, bibliography and manuscript draft when available.