

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

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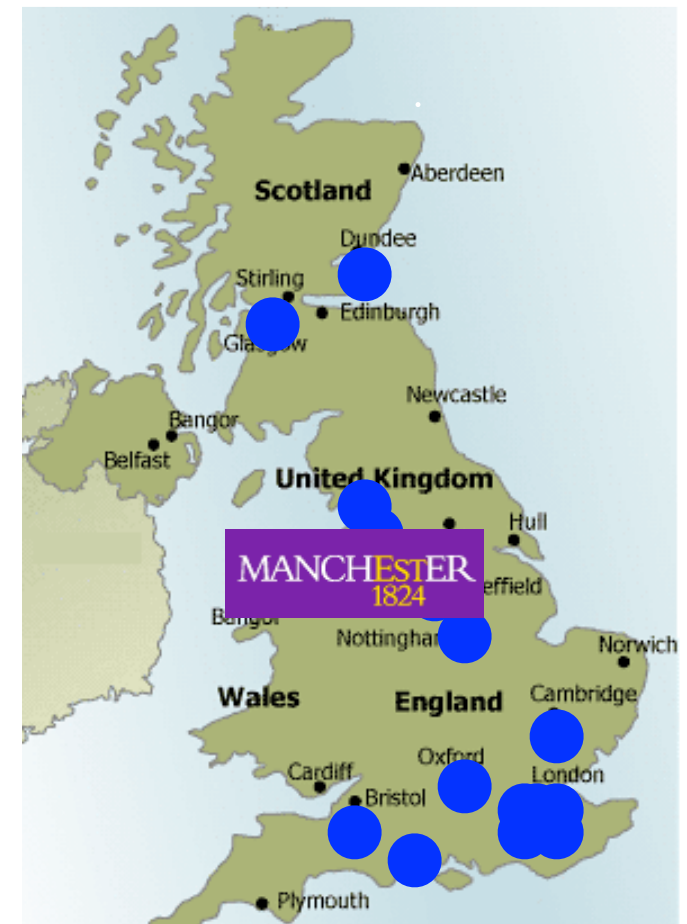
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University of Washington

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



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**Iain Buchan**

Professor Public Health Informatics,  
NIBHI  
University of Manchester

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**John New**

Consultant, Endocrinology  
Royal Salford Hospital

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**Mike Bainbridge**

Chief Architect  
NHS Connecting for Health  
UK Health ICT Champion 2007-8

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**John Anderson**

Internal medicine and endocrinology  
Homerton University Hospital Trust,  
NHS

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**Simon Wallace**

Physician Executive

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# 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

<b>Context</b>	Why is information sharing important?
<b>Requirements</b>	What is required for sharing clinical information?
<b>UK experience</b>	How has the UK addressed requirements?
<b>Lessons for the US</b>	What can the US learn from UK experience?
<b>Summary</b>	My summary, your comments

# Overview of today's talk

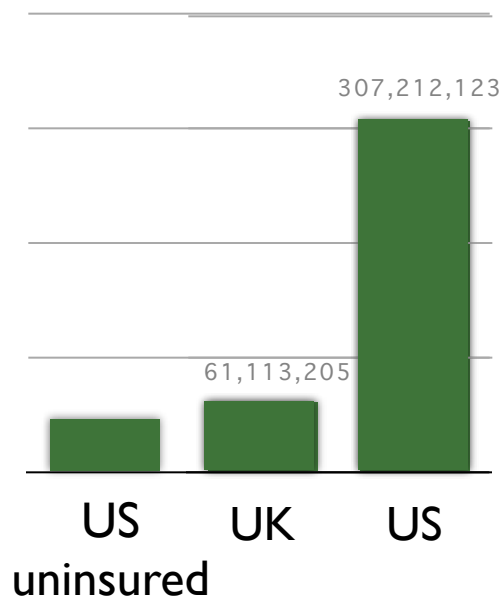
<b>Context</b>	Why is information sharing important?
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# Why is clinical information exchange important?

- Absence of clinical information can cause quality and safety problems
- Potential to reduce healthcare costs, increase convenience

# United Kingdom compared to the United States

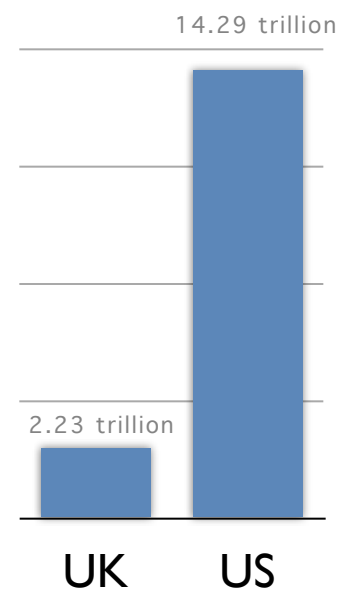
## Population



## Size



## GDP



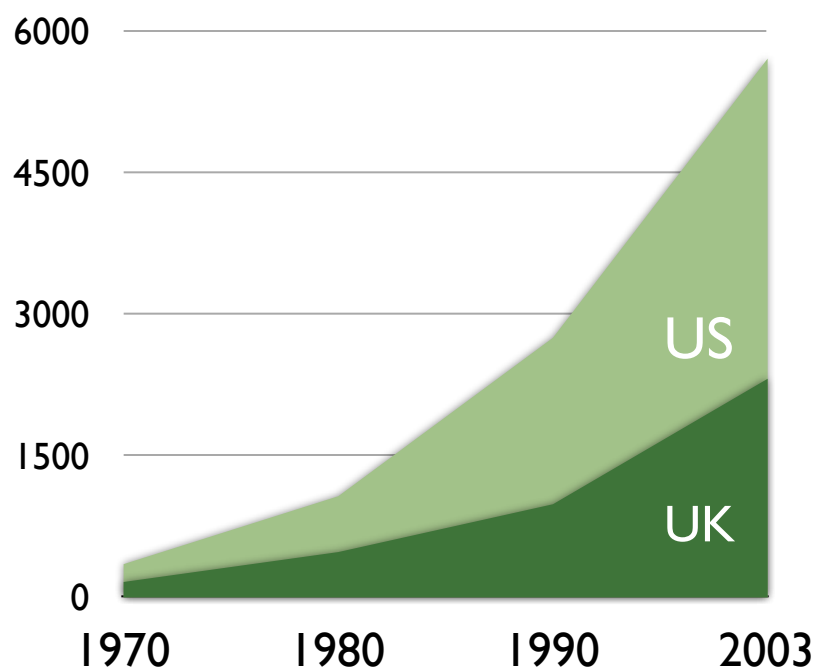


# UK healthcare system in one slide

- 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

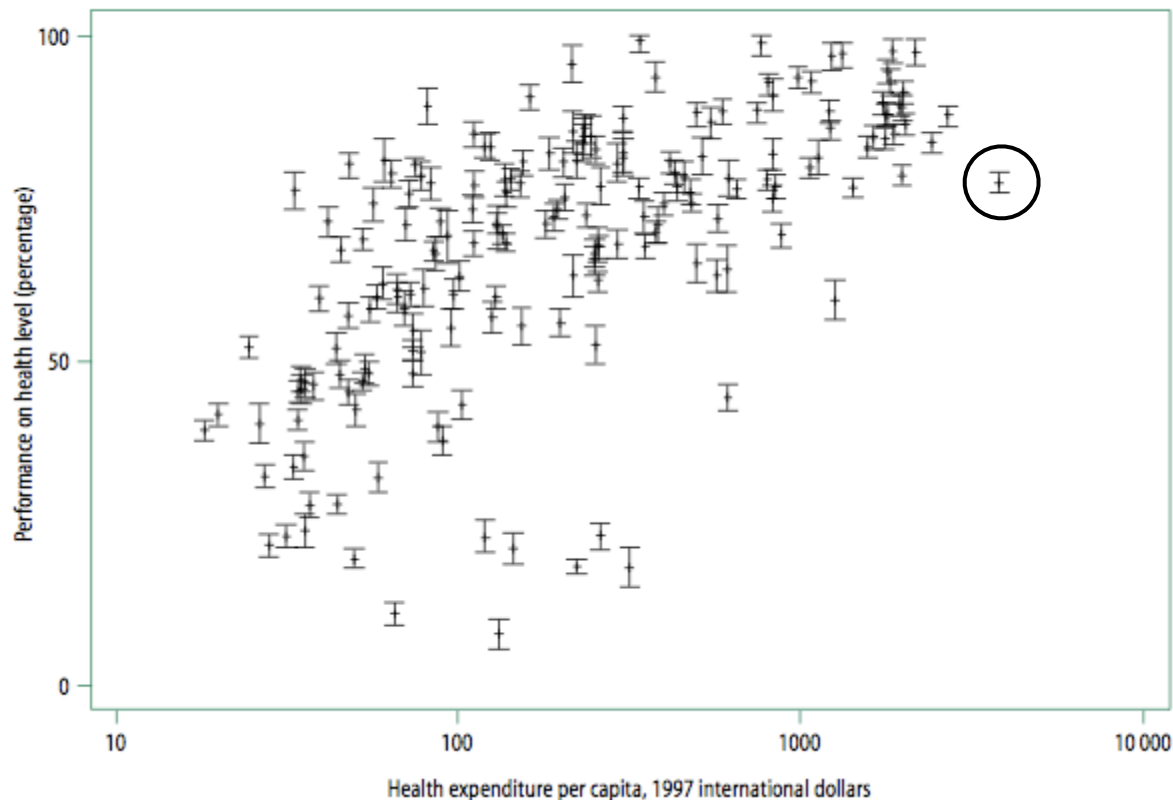
Health expenditures per capita



Source: Kaiser Family Foundation,  
<http://www.kff.org/insurance/snapshot/chcm010307oth.cfm>

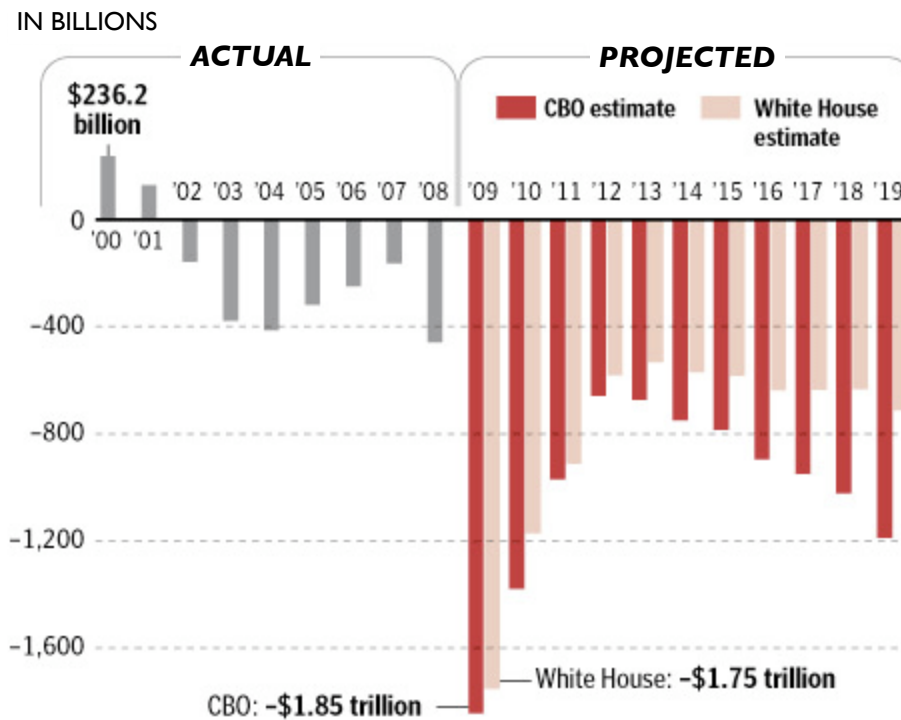
# Health expenditure does not necessarily predict performance

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



Evans DB, Tandon A, Murray CJL, Lauer JA. Comparative efficiency of national health systems: cross national econometric analysis BMJ. 2001 August 11; 323(7308): 307-310.

# US Deficit



SOURCE: CBO, White House Office of Management and Budget | The Washington Post - March 21, 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."<sup>2</sup>

Peter Orszag, White House budget director

<sup>2</sup>Quoted by David Leonhardt, New York Times, June 9, 2009

# Reducing unnecessary health care costs is important to current US administration

Remarks by the President at the Opening of the White House Forum on Health Reform  
The White House  
Office of the Press Secretary  
March 5, 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?

Level	Walker Health Affairs 2005
1	Nonelectronic (mail, telephone)
2	Machine transportable data (ex. fax, PDF)
3	Machine organizable data (e.g. text, HL7)
4	Machine-interpretable data

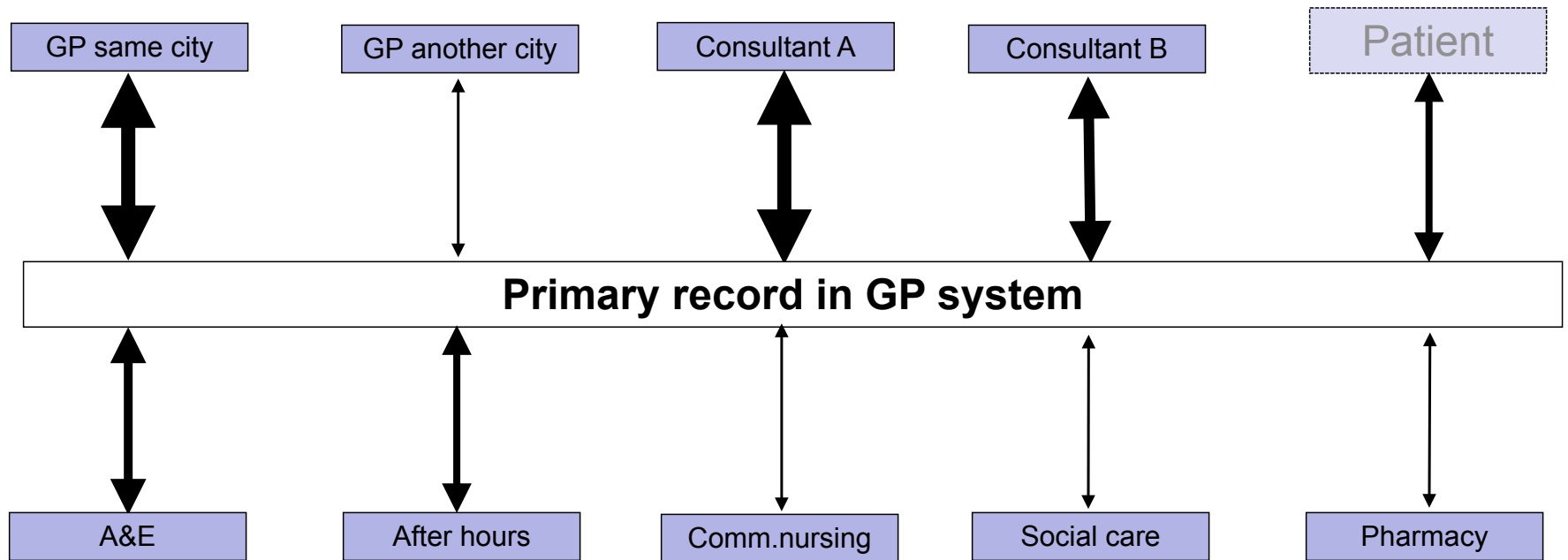
Level	SemanticHealth, EC 2009
0	None
1	Technical and syntactical interoperability
2	Two orthogonal levels of partial semantic interoperability
	2a: unidirectional semantic interoperability 2b: bidirectional semantic interoperability
3	Full semantic interoperability

Walker et al. The value of health care information exchange and interoperability. Health Aff (Millwood). 2005 Jan-Jun;Suppl Web Exclusives:W5-10-W5-18.

Stroetman VN (ed) Semantic Interoperability for Better Health and Safer Healthcare. SemanticHEALTH Report, January 2009.



# 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)**

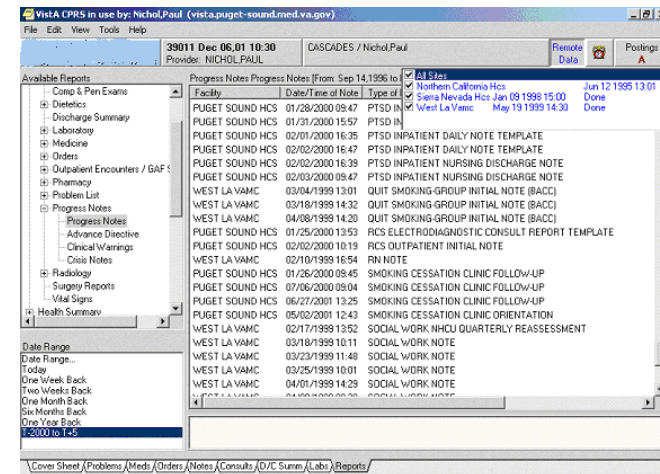
	<b>Implementation, cumulative years 1-10 (\$ billions)</b>	<b>Steady state, annual starting year 11 (\$ billions)</b>
Level 2		
Benefit	141	21.6
Cost	0.0	0.0
Net value	141	21.6
Level 3		
Benefit	286	44.0
Cost	320	20.2
Net value	-34.2	23.9
Level 4		
Benefit	613	94.3
Cost	276	16.5
Net value	337	77.8

**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



# Overview of today's talk

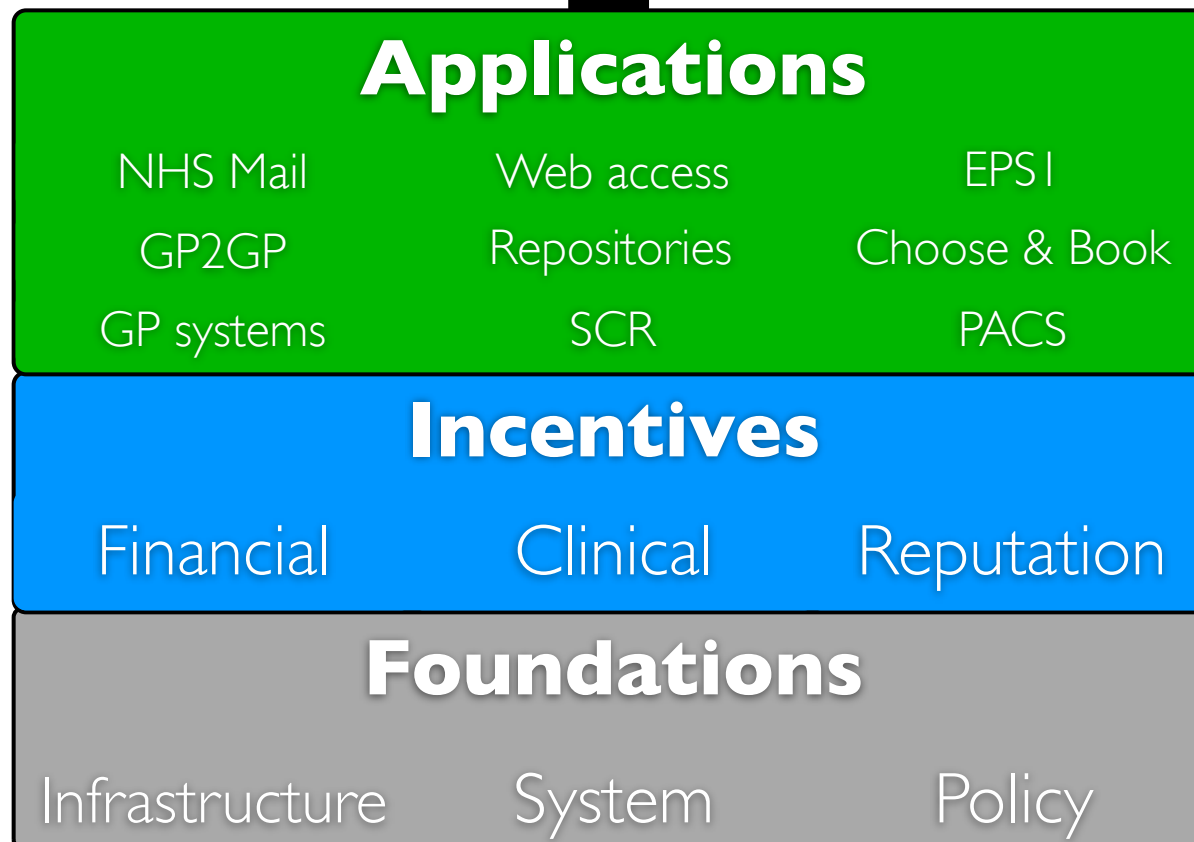
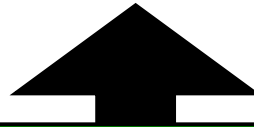
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# For electronic exchange of information to occur

- 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



# Overview of today's talk

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# Foundations

Infrastructure	NHS Number	
	Strong authentication	Smartcards
	NHS Net	Currently N3
	National health computing application standards	RFA 99 v1.1, GP System of Choice
	Coding of records	Part of documentation culture. Read, SNOMED, ICD10
	Unique number for practitioners, practices, facilities	Regional reciprocal access
	<i>Time</i>	This has been developed over several decades
Policy	Public discussion of privacy	
	National policies for protection of privacy	National Information Governance board, Caldicott Guardians
	National service frameworks	
System	GP coordinates care for UK citizens	Strong incentive to use
	Single payer	



# 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

CERTIFIED COPY  of an ENTRY  
Pursuant to the Births and Deaths Registration Act 1953

Registration District Liverpool South

BIRTHS in the Sub-District of Abercromby in the County Borough of L

1	2	3	4	5	6	7	8
Name, if any	Sex	Name and surname of father	Name, surname, and maiden surname of mother	Occupation of father	Signature, description, and residence of informant	When registered	
<u>John</u>	<u>Boy</u>	<u>Alfred</u>	<u>Jennison</u>	<u>General</u>	<u>Jennison</u>	<u>1940</u>	<u>Edwards</u>
			<u>Julia</u>	<u>General</u>	<u>Jennison</u>	<u>1940</u>	<u>Edwards</u>

# 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

Incentive	
Hospital penalized if discharge letters arrive > 48 h	Acute trusts, consultants
Salary lined to Quality & Outcomes Framework	Used in almost all GP practices
Practices appear more professional, more likely to meet targets	GPs, consultants
GP SoC, RFA 99, Common Assurance Process	Suppliers have strong incentive to comply with NHS standards

# 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<sup>1,2</sup>

<sup>1</sup> Kerr EA and Fleming Making performance indicators work: experiences of US Veterans Health Administration BMJ 2007;335:971-973.

<sup>2</sup>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.

## ...mandatory and optional requirements in the field of electronic data exchange.

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))

## Primary care computing

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## March 2003 reminder to PCOs about the reimbursement scheme

Last modified date: 8 February 2007

### 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

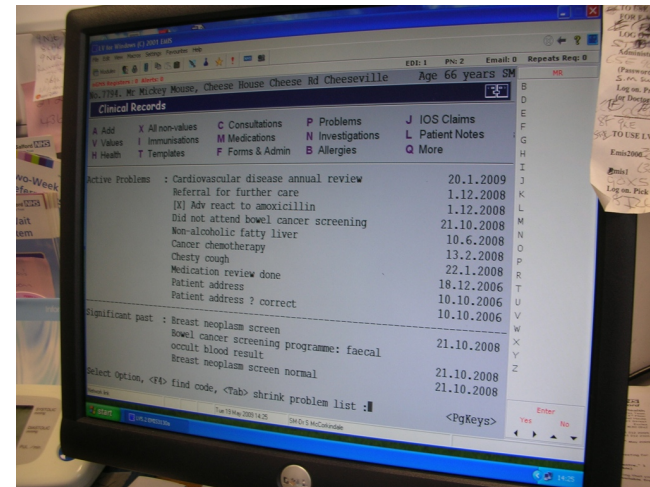
- Financial
  - GP salary linked to Quality & Outcomes Framework based on encoded data
  - Acute hospital trusts financially penalized if discharge summaries not transmitted to GP in 48 hours
- Clinical
  - Out-of-hours care no longer provided by GP

# Applications

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

## 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

Application:	GP2GP	Choose & Book	PACS	Discharge letters	SCR	EPSI	Regional repositories	NHS Mail	Web access
Incentives									
GP	↑↑	→			↑	↑	↑↑	↑	↑
Consultant		→	↑↑↑	↑↑			↑↑↑	↑	↑
A&E					↑↑		↑↑		
Social Care									
Patient	↑↑	↑			↑	↑↑			↑↑
Foundation									
NHS #	•	•	•	•	•	•	•		•
GPSoC/contr.	•	•		•	•	•			
SmartCard	•	•	•		•	•		•	•
Privacy policy	•	•	•	•	•	•	•		•

↑ 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

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

<sup>1</sup>Kathy Mason, Programme Director, Mainstreaming IM&T. PACS Benefits PACS Board Meeting, 27 November 2008

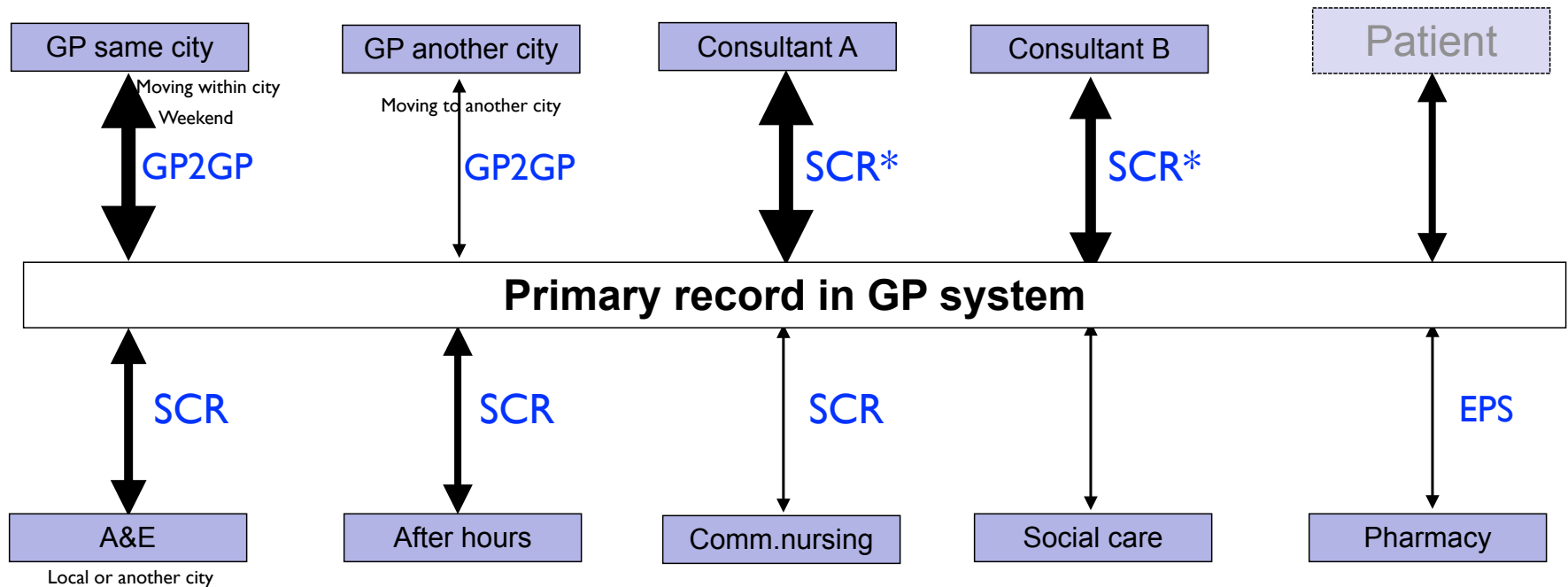
<sup>2</sup><http://www.connectingforhealth.nhs.uk/newsroom/statistics/deployment> Accessed 6/29/09

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

Initiative	Years	Sample accomplishments
NHS Information Management Group	1992-?	NHS Number, other infrastructure
NHS Information Authority	1999-2004	NHS Net, NHS Number for Babies, NHS Mail, ECDL
National Program for Information Technology	2002 - Present	NHS Net 3 (N3), NHS Number adoption, applications

*"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."*<sup>2</sup>

(2) Tony Blair in: NHS Confederation. The NHS Care Records Service (Briefing 105). London: NHS Confederation; 2004. Citation from Greenhalgh T, Stramer K, Bratan T, Byrne E, Russell J, Mohammad Y, Wood G, Hinder S. Summary Care Record Early Adopter programme: An independent evaluation by University College London. London: University College London; 2008.

# 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%)<sup>1</sup>

<sup>1</sup>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.



## Special thanks

- My family
- Professor Iain Buchan
- Charlotte Hooson-Sykes and Amanda Lamb
- eHealth Plus team
- My patients and colleagues in the US



# Questions and Discussion

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