

Sharing Electronic Medical Records

Shifting the foundations of relationships

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**“Current and emerging challenges of eHealth –
privacy, law, ethics, governance and beyond”**

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Contents

- Medical records what are they for?
- How does that change as we digitalise and share information?
- What fears are expressed
- What ethical obligations do we have?
- How can we fulfil these obligations in a practical way?
- What challenges do we face in introducing shared Electronic Medical Records ?
- How does patient access impact on these issues?

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Medical records what are they for?

- Historical view
 - Aide memoire
 - To support medico legal requirements
 - Unique to the organisation that created them
 - Letters/ communication form the bridges between the digital organisational islands
 - Duplication of information in each organisation where the patient attends (with potential mismatch of crucial data such as medication list)

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Medical records what are they for?

- Future view
 - Resource
 - Communication as alerting mechanism since the resource is shared between clinicians
 - Shared record could be a subset or the whole record
 - Decision support provided the technology
 - Records therefore drive up clinical governance by providing audit feedback effortlessly

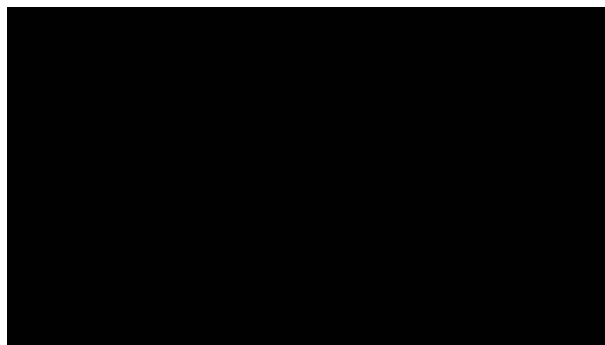
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Perceptions differ of risks/benefits

- Hospital settings have always had shared records within the organisation that crosses multidisciplinary teams and departments
- General Practitioners enjoy a one to one relationship with patients and their records have traditionally been discretely held within the practice
- Public Health Clinicians have outputs of variable quality that is essential if they are to plan commissioning care and manage public health policy effectively

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GP Traditional view



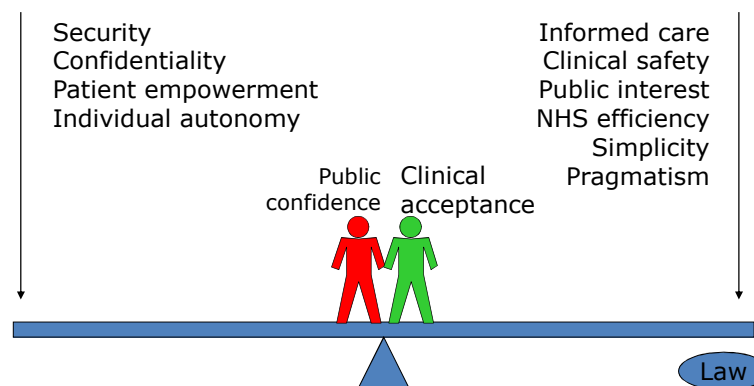
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Ethical Obligations in record sharing

- Gold standard is explicit consent
- Is this
 - Achievable
 - Practical issues
 - How can you consent for all eventualities in the future

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Balancing competing aims



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Ensuring confidentiality and access

- N3 network
- Smartcards/Role Based Access Control (RBAC)
- Legitimate Relationships
- Audit and alerts
- Professional and contractual controls

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Professional and contractual controls

*Clooney and girlfriend Sarah Larson
were injured in road accident*



Clooney hospital punishes staff

Hospital workers in New Jersey have been suspended for allegedly looking at Hollywood star George Clooney's confidential medical records.

The actor was admitted to the Palisades Medical Center last month after breaking a rib in a motorcycle crash.

The 27 staff were suspended for four weeks without pay, for improperly accessing his records.

Mr Clooney, 46, said he had only learnt of the situation this week, and hoped the matter could be resolved.

"We believe this is a harsh penalty and an overreaction," said Jeanne Otersen, a spokeswoman for the Health Professionals and Allied Employees union.

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Information Governance Challenges

- The workforce is fallible
- How can technology reassure rather than simply threaten patients privacy
- Tendency to overcomplicate
 - Sealing
 - Access controls
- Data Quality
- Liability of “publishing” erroneous information

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Some protections

- Care Record Guarantee
- Ask permission to view records
 - Relevant at point of care rather than hypothetical in advance
- Patients access to the record

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Ethical problems persist

- Secondary use of data
- Does each team member have to request permission on each occasion
- Can the contents be copied/pasted into local records?

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Work with partners

- GMC
- Defence bodies
- Royal Colleges and BMA
- Multi professional groups
 - Guidance documents - Principles

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Examples of key documents with key partners

- MPS jointly written FAQ
<http://www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/faqs/mpsfaqs>
- Principles on permission to View document
<http://www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/aboutscr/documents/principles.pdf>
- RCGP guidance on content of SCR
<http://www.connectingforhealth.nhs.uk/systemsandservices/scr/documents/rcgpscr.pdf>

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Post Ministerial Review

- Change in scope
- Challenges
 - Scotland
 - Child Protection
- Make haste slowly – Harry Cayton 2007 review

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National solution brings its own scrutiny

- Financial
- Political
- Death by boards
- Lack of agility
- Expectations raised and publicised
- External campaigns
- Spin/misrepresentation of facts by media and stakeholders
 - Example of mailshot

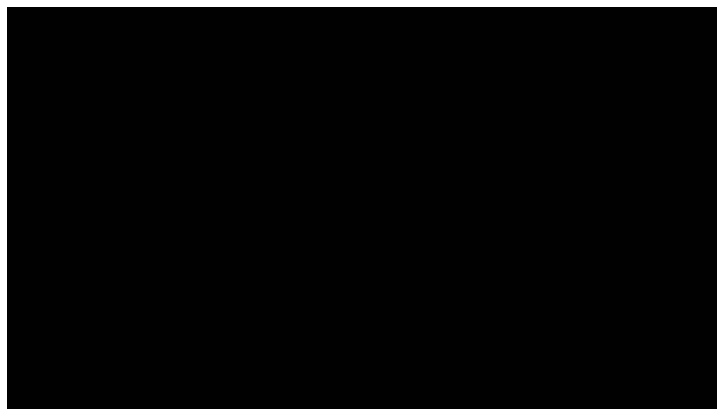
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Drivers for change

- National
 - Operating framework
 - IM&T DES
- Local Business case at regional level
- Practice decision
- Individual GP views
- Patient views

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Transforming opinion



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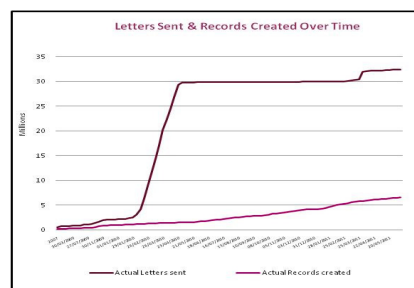
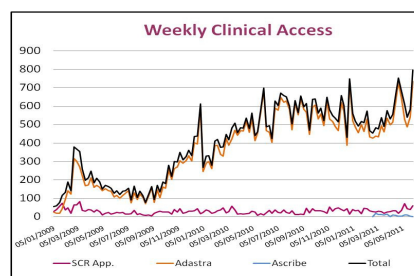
SCR Deployment Progress

Statistic	Value	Weekly Inc.
Patients Contacted	32,428,931	75,622
PCTs which have PIP'd	121	0
Opt Outs*	280,488(1.2%)	279
Practices Live	950	13
Total SCRs Created	6,540,880	94,453
PCTs with Records Created	68	2
PCTs with HealthSpace	11	0
SCR Viewing Sites Business Live	34	0
Total no of SCR clinical accesses**	51,537	796

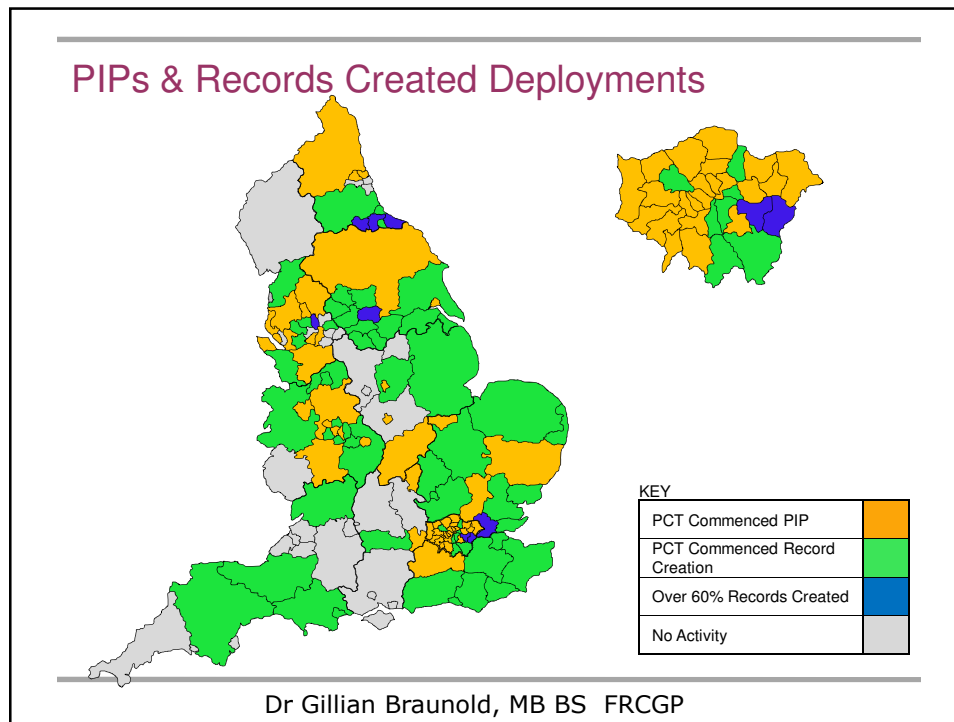
*Opt out figure reported only for those practices that have submitted data on opt out figures

**Total no of SCR Clinical Accesses is up to and including the 05-Jun-2011

% GP Practices with SCR Compliant Clinical Systems				
Supplier	Practices		Supplier Estate Deployed	
	No.	%	Sites	%
EMIS LV	3,278	39.49%	300	9.15%
In Practice Systems (InPS)	1,482	17.86%	258	17.41%
CSC/TPP	1,461	17.60%	349	23.89%
ISOFT Synergy	398	4.80%	43	10.80%



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Evaluation lessons 1

- Consent Model: review the original 'hybrid' consent model for the SCR, which is seen by many as overly complex,
- Benefits Realisation: ensure that 'benefits realisation' work is more balanced, considering the interplay between benefits and dis-benefits.
- Scope: consider developing a tighter definition of the SCR (the information it contains and what it will be used for);
- Programme Management: reflect on the distinction between project management and programme management, consider shifting to a more flexible and adaptive approach to change;

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UCL 2nd evaluation

- Final report covering May 08 to Feb 10 published
- Qualitative studies of encounters, interviews and dataset of anonymised encounters out of hours
- Evaluation at early stage of the programme
- Overall characteristic was scale and complexity
- When benefits occurred they were subtle, hard to articulate, and difficult to isolate from other aspects
- Highlights positive adoption of SCR in Out of Hours settings
- During evaluation usage in A&E low

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How does patient access to records change the situation?

- Fundamentally records move to being a resource
- Fears of clinicians
 - Accuracy and workload if challenged
 - The need to illuminate and explain the records and consequent workload
 - Protecting patients from the uncertainties we shoulder on their behalf

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How does patient access to records change the situation?

- Change in the relationship
- Patient access to information leads to control
- Partnership between patients and clinicians in management of care
- Resultant change in dynamic of service delivery
- Protection or paternalism?

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Legal Issues

- Data Protection act
 - Check for 3rd party information
 - Check that patient doesn't come to harm by seeing records
- How practical is that when records are shared
- Who has editorial control
- How are errors addressed

END

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