

Health informatics

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This document is part of a collection of presentations with a focus on the legal and social aspects of electronic publishing. For full details of this and the rest of the collection see the cover sheet at: <http://ucloer.eprints-hosting.org/id/eprint/23/>



Today's seminar

- Introduction
- What is Health Informatics?
- Information to Support Clinical Care
- Chronic Conditions Self Management
- Information to Support Medical Research
- Research and Disease Surveillance
- Health Service Support
- Protecting the Right to Privacy and Duty of Confidentiality
- Concerns
- Complexity
- Research into Information Governance
- Conclusion

What is health informatics?

- Multidisciplinary field
- Improve patient care using available data, presented as information
- Establish good data capture and reuse mechanisms
- Use IT and digital information about patients and their care to support this
- Education and training for professionals

Information to support clinical care

- Design and Deployment of Electronic Healthcare Records (EHR)
- Share information consistently and correctly across care teams
- Example - Heart Failure Clinics based at Whittington Hospital and shared across four PCTs in North London
- Summary Care Record



Chronic conditions and self-management

- Example - diabetes
- Relies on sharing of information with clinicians, blood glucose levels, blood pressure etc.
- Self management essential
- Good practice, healthy lifestyle, self monitoring and management
- Availability and integrity of correct information essential

Information to support medical research

- ▼ **F** CLEF EHR
 - ▼ **F** Demographics
 - ▶ **C** Demographic
 - ▼ **F** LaboratoryResults
 - ▶ **C** Haematology
 - ▶ **C** Electrolytes
 - ▶ **C** Cytology
 - ▶ **C** Histopathology
 - ▼ **F** ImagingStudies
 - ▶ **C** Radiology
 - ▼ **F** OriginalDocuments
 - ▶ **F** LettersandSummaries
 - ▼ **F** Treatments
 - ▶ **C** PrescribedDrug
 - ▶ **C** IVChemotherapy
 - ▶ **C** ChemotherapyProtocol
 - ▶ **C** Procedure
 - ▶ **C** Radiotherapy
 - ▼ **F** Diagnoses
 - ▶ **C** DeathCertificate
 - ▶ **C** CancerDiagnosis
 - ▶ **F** LanguageExtraction
 - ▶ **F** Chronicles
 - ▶ **F** LanguageGeneration

- Information collected at point of care can be shared for research
- This is helped by having a consistent information structure in the EHR, and / or well configured IT resources
- e-Science Initiative
 - Clinical e-Science Framework
 - eDiamond

Research and disease surveillance

- Information to help statistical results and analyses
- Disease surveillance
- ONS and HPA
- Health Informatics expertise - DHICE Initiative
- Support HIV research, data integration and surveillance

Service support

- Improved care guidelines based on availability of more information
- Improved techniques
- Management and Commissioning

Ongoing challenges

- Data provenance
- Shared understanding across more experts
- More information sharing is important, but is it
 - Legal?
 - Ethical?
- Safeguarding individual privacy rights and professional duty of confidentiality?

Protection of privacy and assuring confidentiality

- The individual's right to privacy and professional duty of confidentiality is upheld in UK law
- Anonymity when data is reused is significant
- There are international equivalents
- Guidelines on how to proceed and behave exist (NIGB / NPSA)
- Further safeguards in the form of ethics committees
- ISO standards for information security policy enactment

Complexity – The Times, Letters to the Editor, 20th January 2006

- Over interpretation of legislation
- Misunderstanding of the problem at hand
- Stifled research
- People suffering as a result

Concerns

- There have been concerns over civil liberties
- Fears over unauthorised surveillance
- Doubt over further uses of personal information
- Misuse / misunderstanding of information
- Case of P against Finland at ECHR
- Assurance is essential

Shared EHR and information governance research

- Modelling of analysis of data release and requests for data
- Establishment of available control mechanisms
- Design of a reusable knowledge management formalism like the EHR Archetype - the Security Archetype or Secutype
- Advisory system for data managers

In conclusion

- IT, hardware, software, better networking support more rapid, consistent and complete data sharing in healthcare
- Compelling for clinical care, self management
- Host of further uses, most notably research and service improvement
- Protecting patients rights and professional duty is complex
- There are many guidelines and legal interpretations
- Research is ongoing, and techniques are becoming more sophisticated

DON'T PANIC!
(and thank you)