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Information Studies Seminar

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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://humbox.ac.uk/3101/

Introduction

- Senior Research Associate, CHIME
- Medical research projects that use clinical data
- Live system support, deployment and administration
- Part time PhD - information security and shared electronic healthcare records
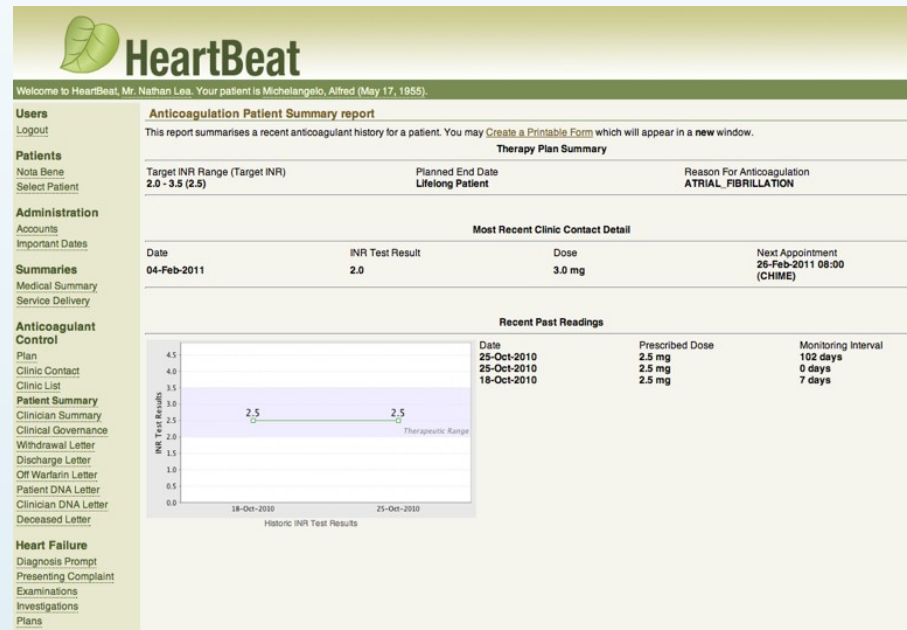
Today's Seminar

- 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

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▼  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  LangaugeGeneration
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- 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)