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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

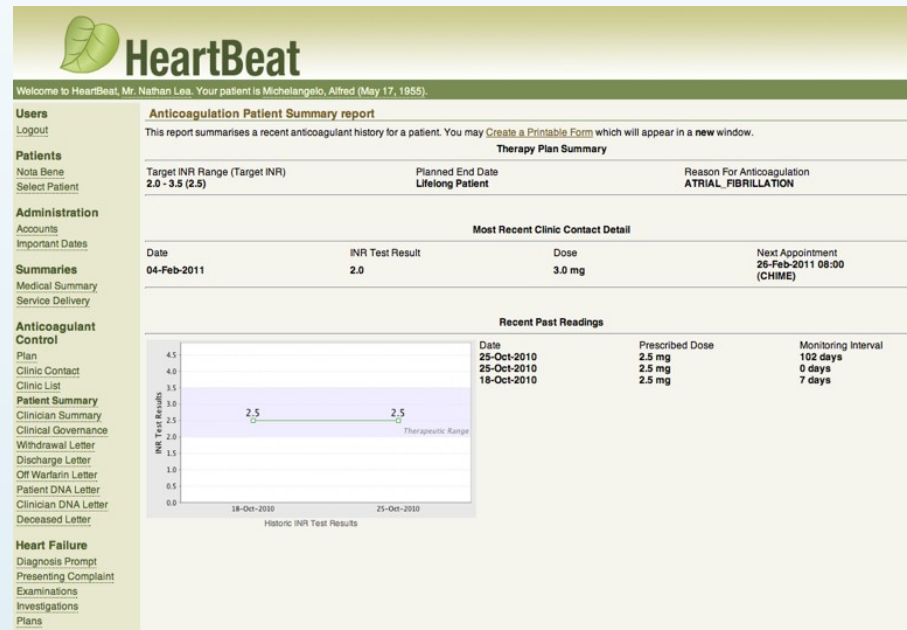
- Introduction
- What is Health Informatics?
- Information to Support Clinical Care
- Chronic Conditions Self Management
- Information to Support Medical Research
- Research and Disease Surveillance
- Health Service Support
- Protecting the Right to Privacy and Duty of Confidentiality
- Concerns
- Complexity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



HeartBeat

Welcome to HeartBeat, Mr. Nathan Lea. Your patient is Michelangelo, Alfred (May 17, 1955).

Users
Logout

Patients
Nota Bene
Select Patient

Administration
Accounts
Important Dates

Summaries
Medical Summary
Service Delivery

Anticoagulant Control
Plan
Clinic Contact
Clinic List
Patient Summary
Clinician Summary
Clinician Governance
Withdrawal Letter
Discharge Letter
Off Warfarin Letter
Patient DNA Letter
Clinician DNA Letter
Deceased Letter

Heart Failure
Diagnosis Prompt
Presenting Complaint
Examinations
Investigations
Plans

Anticoagulation Patient Summary report
This report summarises a recent anticoagulant history for a patient. You may [Create a Printable Form](#) which will appear in a new window.

Therapy Plan Summary

Target INR Range (Target INR)	Planned End Date	Reason For Anticoagulation
2.0 - 3.5 (2.5)	Lifelong Patient	ATRIAL_FIBRILLATION


Most Recent Clinic Contact Detail

Date	INR Test Result	Dose	Next Appointment
04-Feb-2011	2.0	3.0 mg	26-Feb-2011 08:00 (CHIME)

Recent Past Readings

Date	Prescribed Dose	Monitoring Interval
25-Oct-2010	2.5 mg	102 days
25-Oct-2010	2.5 mg	0 days
18-Oct-2010	2.5 mg	7 days

Historic INR Test Results



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** LangaugeGeneration

- 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)