CHERRI

Sharing Clinical Recordings for Non-clinical Educational Use

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CHERRI: Common Healthcare Educational Recordings Reusability Infrastructure

www.cherri.mvm.ed.ac.uk



CHERRI

E-Framework

JISC - Information Environment

Repositories - central or communities - JORUM

Requirement for reviewing clinical needs - CHERRI

CRANCS - Clinical Recordings in Academic Non-Clinical Settings

CHERRI Project outputs:

- Questionnaire
- Interviews
- Use cases
- Information framework
- Recommendations

Medicolegal Issues

- Data Protection
- Informed consent required from patient
- Human rights
- Copyright law NHS owns recordings created in a clinical context
- Note © differs in different legal areas (e.g. Scottish ≠ English)



Current Practice

- despite data protection and human rights legislation and guidance, current practice is highly varied
- practitioners aware of relevant legislation and national guidance but did not know how to translate these into the local context
- uncertainty in practice did not only relate to consent; there were often conflicting or unclear issues of ownership and copyright
- the following problems were identified:
 - lack of common process and standards at a local level
 - lack of connection between terms of consent and subsequent use
 - unnecessary duplication in local contexts as a safety measure
 - a pervading culture of risk and uncertainty is leading to both individual and institutional anxiety and loss of utility.

Consent + Licensing

- C+LM licensing will need to be simple and easy to understand
- HIPAA as a starting point
- Also Creative Commons elegant and simple 6 license model (recast in different jurisdictions)
- Two-step process:
 - Consent evaluated, acquired and logged along with recording
 - Consent encoded in licence along with copyrights and licence+recording passed for use
- Licence stays with recording and outlines conditions under which it can be used (compliance dependent)
- Licence can be matched with original patient & consent = audit/provenance trail

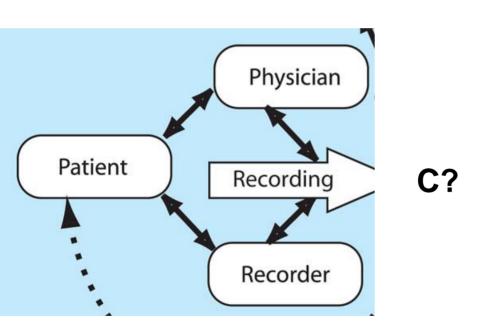


Consent and Licensing

- two principal issues: consent and ownership solutions need to accommodate both of these
- CHERRI has developed a conceptual Consent and Licensing Model (or C+LM) that integrates the two to provide a solution that addresses both the uncertainty and the disconnectedness of current practice
- However: CC problems once granted, use is forever and everywhere
- it is recommended that it follows the same kind of model used by Creative Commons
- provisional discussions about a 'Clinical Commons'



CHERRI Consent + Licensing Model





Recommendations

- That all creators and users of CRANCS should be better educated and supported in the use of such recordings, and that this training and support is normalised as much as possible both for quality assurance and economies of scale purposes.
- That guidance from professional bodies should continue to be regularly updated to take account of changing public and societal attitudes and concerns about use of CRANCS.
- That a common consent and license model for CRANCS is developed and adopted as broadly as possible
- That the licensing model is based on Creative Commons and that this Clinical Commons is set up and run either by CC or a qualified agency



Recommendations

- That all CRANCS are tagged (potentially visibly) with a C+LM mark or icon to indicate its provenance and conditions of use
- That practitioners refuse to use non-C+LM materials because they lack sufficient provenance and guarantee of patients' interests
- That any central repository must adhere to the C+LM before any clinical materials are stored there
- That all relevant agencies have input to and support the development of this common model and that steps are taken to develop the relationship between health services and the tertiary education sector

What next?

How can this be taken forward?

What Edinburgh is planning

Who we are talking to

Role of the/an NHS-HE Forum

What will you do ...?

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