Push and Pull Models to Manage Patient Consent and Licensing of Multimedia Resources in Digital Repositories for Case-Based Reasoning

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Virtual patients – What are they?

Virtual patients

- interactive computer simulations of real-life clinical scenarios
- case-based reusable learning objects
- often contain a wide range of multimedia content recorded in a medical context
eViP repository – What have we achieved?

- A freely-accessible repository of 340 virtual patients (VPs)
- The VPs are available in a repository under the creative commons license "Attribution-NonCommercial-ShareAlike" (CC BY-NC-SA).
- VPs, including their multimedia material, have been mainly repurposed from VPs contributed by project partners.

Available in ANSI/MedBiquitous Virtual Patient (MVP) format

http://www.virtualpatients.eu/referatory
Technical infrastructure for patient consent exchange

• Why do we have to reveal *personal data* to the students?
  – Anonymity difficult to preserve
  – Image pre-selection bias
  – Progress in data analysis

• Current state
  – Written consents in paper-based folders stored locally
  – Consent not directly linked to the relevant image
  – No way of tracking down images once they left the virtual patient system

• Are we dealing with this problem alone?
  – CHERRI Project
  – OER Project

• What is our focus?
  – Virtual patients
  – Technical infrastructure

Ref: Gary T. Marx: 7 types of identity knowledge

*macroprolactinoma*
Consent status exchange protocols

a) PUSH Model

1. storeConsent
2. storeExportContactDetails
3a. withdrawConsent
3b. withdrawConsent
4. broadcast- Withdrawal- Message
5. confirmWithdrawal

Network of Virtual Patient Systems

Virtual Patient System 2

Local Consent Repository

Virtual Patient System 1

b) PULL Model

1. storeConsent
2., 4., ..., getConsentStatus
3. withdrawConsent

Central Consent Status Repository

Virtual Patient System 1

Virtual Patient System 2

patient

patient
Checklist for implementation

- Storage of metadata for each individual media file
- Storage contact data for the withdrawal procedure
- MVP package export with warning about sensitive material and request to provide contact e-mail
- Withdrawal button in administration panel
- Implementation of the messaging in the exchange protocol
How secure is it?

• The proposed protocol is based on trust and does not give formal guarantee of multimedia withdrawal.
• Export of sensitive data only to trusted partners – e.g. members of an educational alliance or consortium.
• VP systems which do not confirm the withdrawal message will be blocked from access to new multimedia.
• The patient should be informed that the withdrawal request will be followed with due diligence in all possible cases, but that there are situations in which it will not be possible to withdraw all instances of the resource (e.g. in the case of printed materials).

Ref: Helen Nissenbaum, „Securing Trust Online: Wisdom or Oxymoron”, Boston University Law Review June 2001 Volume 81, No.3 635-664
Perspectives and challenges

• This model is currently in implementation in some of the virtual patient systems

• Problems with the current metadata schemes
  – ANSI/MEDBIQ VP.10.1-2010?
  – Learning Object Metadata (LOM)?
  – MEDBIQ Healthcare Learning Object Metadata?
References


5. Williams J, Hardy S, Quentin-Baxter M. Proposing a Consent Commons in Open Education. Balancing the desire for openness with the rights of people to refuse or withdraw from participation. In: Open ED 2010 Proceedings; 2010 Sep 15; Barcelona, Spain.