Challenges in Medical Patients’ Data Management: a comparative analysis (United States, United Kingdom, France and Quebec – Canada)

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Introduction

• Cooperation in the framework of professional Master degrees of the Universities of Marne-la-Vallée and Compiègne.

• Interdisciplinary approach about information-communication and quality management (with a constructivist vision).

• Methodology: mainly qualitative, documentation analysis and interviews.
1 – Specificity of Medical Patients’ Data (1/2)

• 1 - Medical patients’ data :
  sensitive (critical),
  personal with strong concerns of confidentiality (privacy).

• 2 - Different levels of storage and management.
  (For example in France, the compartmentalization between State and Sickness Insurance)
3 - Restricting legislation:

- “Health Insurance Portability and Accountability Act” (HIPAA) in USA.
- “Commission Nationale de l’Informatique et des Libertés” (CNIL) in France + European directives.
- “Commission d’Accès à l’Information” in Québec (Compostelle).
• Needs of data management at 3 levels:
  – macro (States),
  – meso (hospitals),
  – micro (doctors and patients).
2 – Different responses within specific national contexts (2/5)

• In USA:
  – issues of different legislations between Federate States and Federal Government levels.
  – The NHIN (National Health Information Network) project.
  – Data Management in HMO (Health Maintenance Organizations) such as Kaizer Permanent.
Office of the National Coordinator for Health Information Technology (ONC)

- Request for Information (RFI) on National Health Information Network (NHIN)

- ... As the nation embarks on the widespread deployment of EHRs, a variety of concomitant challenges and barriers must be addressed. One of these is interoperability, or the ability to exchange patient health information among clinicians and other authorized entities in real time and under stringent security, privacy and other protections ...
2 – Different responses within specific national contexts (3/5)

• In UK:
  – The new project of Electronic Health Record (EHR) of the National Health Service (NHS) in the specific programme « Connecting for Health » with a strong task force in national project management articulated in five regional clusters (North East, North West, West Midlands, Eastern, Southern, London)

• now with some problems.
• What is the EHR?
  – *The Electronic Health Record (EHR) is a new computer-based system adopted by the NHS organisations in Wirral. It stores your health records 'electronically', which allows doctors and other health professionals to access up-to-date information about you and your health...*
2 – Different responses in specific national contexts (4/5)

• In France, 3 different projects:
  – **1 Réseau Santé Social**: a technological network for transferring paying back data (electronic sheets: “feuilles de soins électroniques” which correspond to the main French specificity -since 1927- in paying by acts)
  – **2 SNIIR-AM**: “Système d’Information Inter Régimes de l’Assurance Maladie” one of the most important datawarehouses in the world.
2 – Different responses in specific national contexts (5/5)

• **3 DMP**: The “Dossier Médical Personnel” in France with great ambitions with limited means now in limited experimentations by industrial consortiums (private).
• DMP et autres dossiers médicaux 09-03-2006
  – Le DMP concerne la coordination des soins entre tous les professionnels de santé, de ville ou d’établissement de soins, médecins traitants ou spécialistes et professionnels de santé non-médecins. Il a vocation à être complémentaire aux dossiers médicaux informatisés qui existent déjà. Il facilitera les échanges entre ces dossiers, sous le contrôle du patient.
If different responses exist, finally the challenges tackled are roughly the same:

- Data **property**.
- Data **access** and management of access authorizations.
- The good level of **data storage** and data management; even at the regional level.
The challenges:

- The issue of shared medical secrecy / privacy.
- Doctor’s collective responsibility / individual responsibility.
All these challenges converge to a central one:

to solve the problem of the **compartmentalization**

and the main response is:

by the **interoperability** of the different levels
Conclusion (1/2)

• The challenges of Medical Data Management need responses which take into account:
  – the complexity of the management, and
  – the contradiction between the traditional opposite levels:
    » individual / collective,
    » public / private
    » centralized/shared
• Health organizations are organizations which **strongly** highlight our society challenges about:
  – Information management,
  – Knowledge,
  – Services.
Thank you very much for your attention

Questions?