

Developing new models of personal health records: Health 2.0, Second Life and beyond

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Presenters

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Content areas

- 'Traditional' and newer 'non-traditional' developments in the provision of personal health records
- What is 'Health 2.0'? What might it mean for the provision of (personal) health records?
- Second Life, Second Health, Web 3D: Some possible implications for interacting with personal health records

Diversity of Personal Health Record (PHR) 'containers'

- Paper-based:
 - Brennan et al:
 - most common form
 - users develop appropriate strategies for use (Moen & Brennan, 2005)
- Electronic (via PC, mobile device, Smart Card, etc.)
 - Users carry
 - Proprietary or non-proprietary system
 - Example: Health Transaction Network (<http://www.healthtransactionnet.com/>)
- On-line / net access (technology notwithstanding)
 - 3rd party
 - 24/7 access

Some definitions & views of PHR

The personal health record (PHR) is:

- An Internet-based set of tools
- Allows people to access and coordinate their lifelong health information AND make appropriate components available to those who need it.

PHRs offer an integrated and comprehensive view of health information, including information people generate themselves such as symptoms and medication use, information from doctors such as diagnoses and test results, and information from their pharmacies and insurance companies . . .

Some definitions & views of PHR

- Individuals access their PHRs via the Internet, using state-of-the-art security and privacy controls, at any time and from any location.
- Family member, doctors or school nurses, can see portions of a PHR when necessary. Emergency room staff can retrieve vital information from it in a crisis.
- “People can use their PHR as a communications hub: to send email to doctors, transfer information to specialists, receive test results and access on-line self-help tools. PHR connects each of us to the incredible potential of modern health care and gives us control over our own information.”

[The Markle Foundation “Connecting for Health Initiative”, 2003;
<http://www.connectingforhealth.org/>]

Some definitions & views of PHR

- HIMSS defines an electronic Personal Health Record (ePHR) as:
 - A universally accessible, layperson comprehensible, lifelong tool for managing relevant health information, promotion health maintenance and assisting with chronic disease management via an interactive, common data set of electronic health information and e-health tools.
 - The ePHR is owned, managed and shared by the individual or his / her legal proxy(s) and must be secure to protect the privacy and confidentiality of the health information it contains.
 - It is not a legal record unless so defined and is subject of various legal limitations

[<http://www.himss.org/content/files/PHRDefinition071707.pdf>]

Some definitions & views of PHR

AHIMA e-HIM Workgroup definition of PHR

- The personal health record (PHR) is an electronic, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual.
- The PHR is maintained in a secure and private environment with the individual determining rights of access.
- The PHR does not replace the legal record of any provider.
- *The definition of PHR is still evolving in the healthcare community.*

[http://www.ahima.org/emerging_issues/PHR.asp#Definition]

What is Web 2.0?

Web 2.0, refers to a *supposed* second generation of Internet-based services

emphasizing

on-line collaboration

AND

sharing among users

Ref: An introduction to Web 2.0 (The user's voice in the second generation of the WWW)

– Francisco Llaneras Estrada (Nov. 2006)

<http://www.slideshare.net/kikollan/an-introduction-to-web-20-the-user-role/>

What is Web 2.0?

Web 2.0 refers to

- Improved communication & collaboration between people via social-networking technologies
- Improved communication between separate software applications (“mash-ups”) via open Web standards for describing and accessing data, and
- Improved Web interfaces mimicking real-time responsiveness of desktop applications within a browser window.

Ref: Social technologies (aka Web 2.0) for ehealth
– Gunther Eysenbach (after Barreto) (March 2008)
www.webcitation.org/5W9GcYyWN

What is Health 2.0?

- Shreeve:

- Health 2.0 is “all about Patient Empowered (not the misnomer 'Consumer Directed') Healthcare
- whereby patients have the information they need to be able to make rational healthcare decisions”,
- and interoperability of health information will be a crucial determinant of success or failure of the movement.

- O'Grady:

- the most important aspect of using Web 2.0 in health care is the use of social software, which will promote collaboration between patients, their caregivers, and health professionals.

PHRs provided by health care organizations

- UK's NHS Health Space
 - <http://www.healthspace.nhs.uk/>
- Denmark's Health Portal
 - <http://www.sunhed.dk>
- USA/AHIMA myPHR
 - <http://www.myphr.com>
- MyHealtheVet
 - <http://www.myhealth.va.gov>

New Players

- Google Health

- <https://www.google.com/health/p/>
- “Google Health allows you to store & manage all of your health information in one central place.”

- Microsoft HealthVault

- <http://www.healthvault.com/>
- “A HealthVault account helps you collect, store and share information with family members and gives you choice of applications and devices to help manage your fitness, diet and health.”

Moving from healthcare provider to patient as the locus of control

- Whose health record is it?
- Who determines what can be in it?
- Who owns the data and what can be done with it?

Second Life – what is it?

- Second Life[®] is a 3-D virtual world created by its 'Residents'
- 2003 – 'opened' to public
- Current population: >10m Residents worldwide
- Residents retain intellectual property rights in their 'digital' creations.
- Residents can buy, sell and trade with other Residents.

Second Health and other examples of health use of SL

- Second Health

- <http://secondhealth.wordpress.com/>
- <http://www.youtube.com/watch?v=Mp8IyXZAv-U>
- <http://www.youtube.com/watch?v=Hu-QNFLD1mg>

- IBM 3D Virtual Healthcare Island (vHealth)

- http://healthnex.typepad.com/web_log/2008/02/ibm-opens-new-3.html

- miVitals

- <http://www.mivitals.com/>

Some thoughts on 'health records' in SL

- What will a 'health record' mean or look like?
- Will your avatar be your PHR?
- How will SL avatars interact with 'First Life'?
- Who will 'regulate' (if needed) health care and information in SL?
- What are the ethical responsibilities of nurse in SL?

**Availability of updated presentation will be on
the blog:**

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