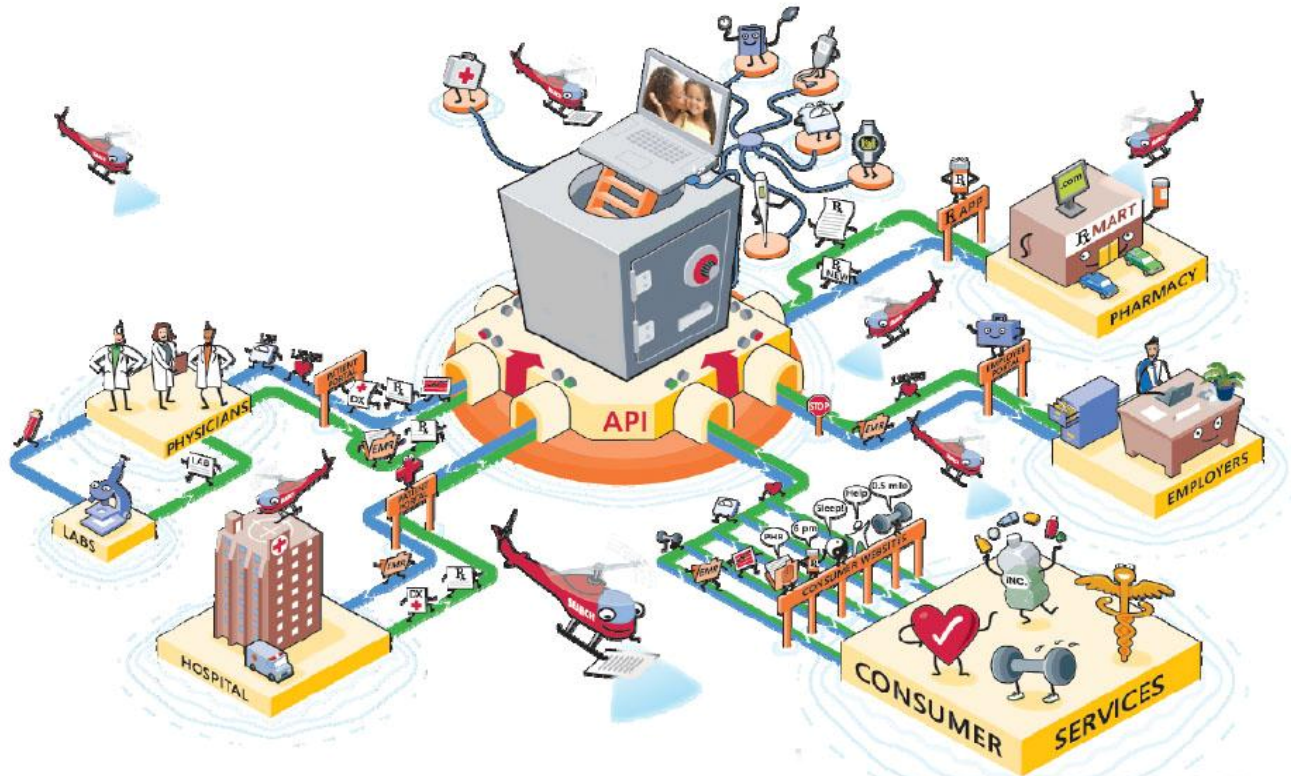


Privacy and Security Factors Affecting PHRs and Consumer Health



The opinions expressed in this presentation are solely my own and do not represent the opinions of either IBM, the HIMSS Security and Privacy Committee or any other organization that I am associated with.

This is not a product plug or position talk for any organization.

My Background

- From the Health Informatics group at IBM Almaden Research Center
 - Information Integration and Analytics
 - Multimodal Analytics
 - Healthcare Standards, Interoperability, and Open Source Software
 - Public Health
 - Healthcare Privacy
 - URL: <http://www.almaden.ibm.com/cs/disciplines/hc/>
- Led the development of
 - [Hippocratic Databases](#)
 - [Exception Management for Health Information Systems](#)
 - [Integration of Health Information from Multiple, Disparate Sources](#)
- Been privileged to
 - Work with a great team of people with deep expertise in healthcare and computing
 - Work with vibrant healthcare associations and standards organizations
- Attended
 - The University of the West Indies – Mona, Jamaica.
 - Imperial College of Science, Technology & Medicine – London, England.

Structure of the Talk

- What are the factors that influence your rights, i.e. privacy rights ?
- What exactly are your rights ?
- What technologies can be used to help me exercise these rights ?
- What does the current healthcare landscape look like?

Caveat:
You may not like what I say.
You may argue with it.
It is up to you to effect change (if necessary)

Factors Influencing Patient Rights

- Business
 - What are things that I have to do to reduce my liability?
 - How do I sell or build trust?
 - What is the business value of owning patient data? to my partners? Contractors?
- Legal
 - What do lawmakers select as the baseline for privacy compliance?
 - What makes a good sound-bite?
- Technology
 - How do technology align with business goals and legal compliance?
- Social
 - What are the attitudes of patients?
 - What do patients know about their rights?
 - What do patients believe about their rights?
 - What do patients do when faced with a privacy decision?

Further Reading:

Tyrone Grandison, Rafae Bhatti. ["Regulatory Compliance and the Correlation to Privacy Protection in Healthcare"](#). International Journal of Computational Models and Algorithms in Medicine. Special Issue on Privacy and Security Issues for Medical Data. March 2010.

What are your Rights

- Notification
 - Patients should receive a notice of a covered entity's privacy practices.
- Authorization and Consent
 - Written authorization is required for impermissible disclosures
- Auditing and Accounting
 - Patients have the right to an accounting of all impermissible disclosures of their personal health information.
- Access
 - Patients have the right, under most circumstances, to access the covered entity's designated record set and to amend information that is inaccurate or incomplete.

With HITECH and ARRA privacy extensions, the definition of covered entities have been extended to include business associates

What Technology can help me?

- Notification
 - HC Business: Workflow-enabled systems with direct mail or email
 - HC Patient:
- Authorization and Consent
 - HC Business: NA
 - HC Patient: NA
- Audit and Accounting
 - HC Business: Reporting tools for access logs
 - HC Patient: Query interfaces to reporting tools
- Access
 - HC Business: Data systems that provide a longitudinal view and control of all your data
 - HC Patient: Portals that allow the viewing and modifying of your data.

Be concerned with companies without the technologies outlined in “HC Business”

The Imperatives of the Current Healthcare Landscape

- Current Legal Frameworks
 - The current Healthcare Reform push
 - Meaningful Use (and EHR certification)
 - HITECH
 -
- Legacy Technology Investment
 - A lot of money currently invested in “stuff” that works
- Planned Obsolescence
 - Current products are designed to decay and be replaced
- Product Retrofitting
 - Can systems designed with a 70s mind be modified with practitioners with a '10s mindset?

Conclusion

- Your behavior affects your rights
- Businesses and lawmakers currently have the greatest impact on your rights
- Compliance to best practices in privacy does not imply you are protected to the level you expect.

More Information

<http://www.almaden.ibm.com/cs/disciplines/iis/>