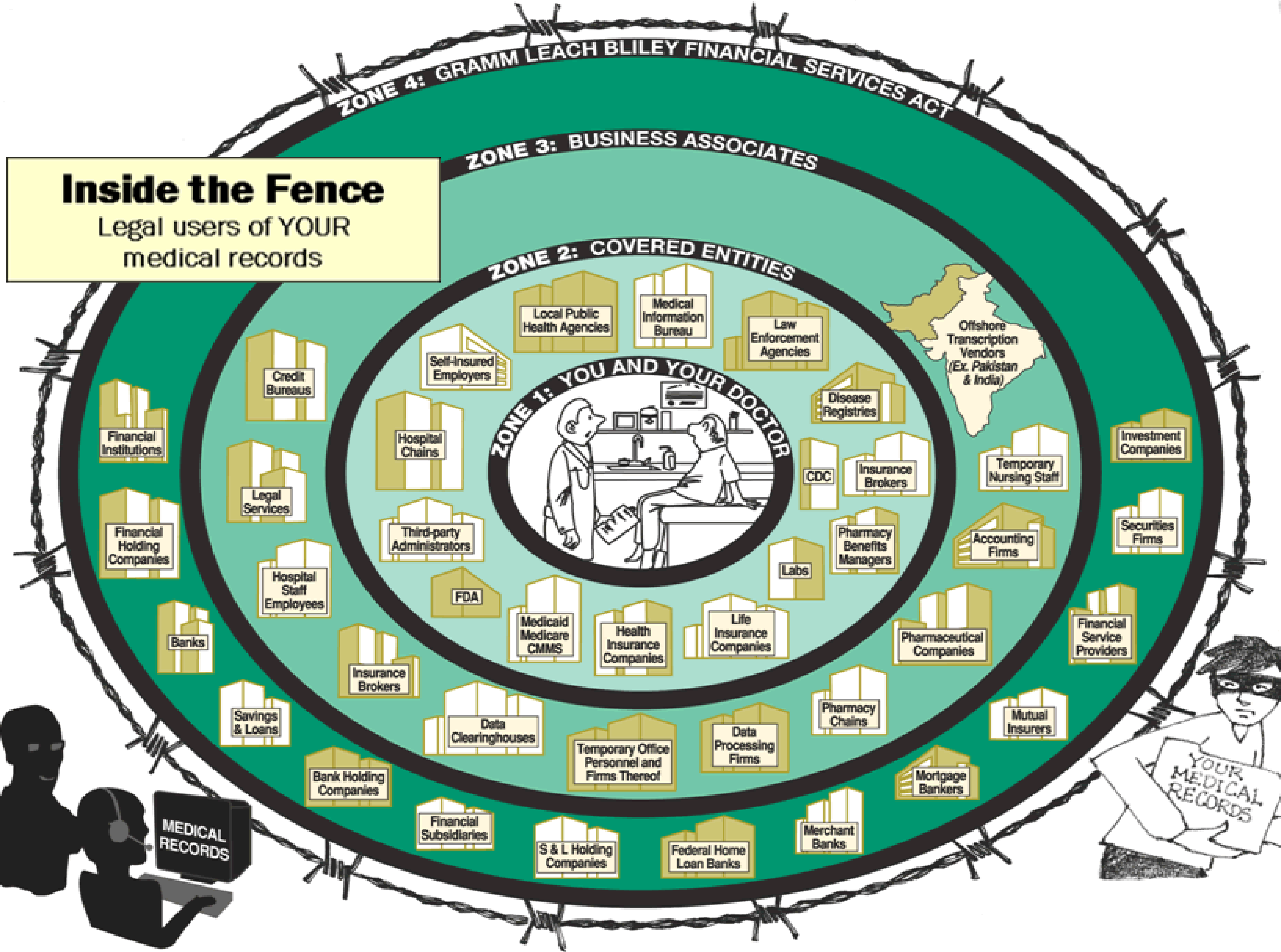
Deregulating Consent

1996	Congress passed HIPAA, but did not pass a federal medical privacy statute, so the Dept. of Health and Human Services (HHS) was required to develop regulations that specified patients’ rights to health privacy.	*“… the Secretary of Health and Human Services shall submit to [Congress]…* ***detailed recommendations on standards with respect to the privacy of individually identifiable health information.”***
2001	President Bush implemented the HHS HIPAA “Privacy Rule” which recognized the “right of consent”.	*“….a covered health care provider* ***must obtain the individual’s consent,*** *in accordance with this section, prior to using or disclosing protected health information to carry out treatment, payment, or health care operations.”*
2002	HHS amended the HIPAA “Privacy Rule”, eliminating the “right of consent”.	*“The* ***consent provisions…are replaced*** *with a new provision…that provides regulatory permission for covered entities to use and disclose protected health information for treatment, payment, healthcare operations.”*

Inside the Fence

Legal users of YOUR medical records



ARRA—historic new privacy rights

- No definition of privacy
- Right of consent not restored

New rights:

- Ban on sales of PHI
- Segmentation
- Audit trails x 3 years
- Breach notice
- Encryption
- Right to restrict disclosures of PHI for payment and HCO if pay out-of-pocket
- Preservation of the therapist-patient privilege

AHRQ: 2009
20 focus groups

- A majority want to “own” their health data, and to decide what goes into and who has access to their medical records (AHRQ p. 6).

- There was near universal agreement in all focus groups that if medical data are to be stored electronically, health care consumers should have some say in how those data are shared and used. (AHRQ p.29)

- A majority believe their medical data is “no one else’s business” and should not be shared without their permission. This belief was expressed not necessarily because they want to prevent some specific use of data but as a matter of principle. (AHRQ p. 18)

- Participants overwhelmingly want to be able to communicate directly with their providers with respect to how their PHI is handled, including with whom it may be shared and for what purposes. Most believe they should automatically be granted the right to correct misinformation (AHRQ p.33)

In fact, in the AHRQ Report they learned there was no support for the establishment of general rules that apply to all health care consumers. Participants thought that health care consumers should be able to exert control over their own health information **individually, rather than collectively**. (AHRQ p. 29)

AHRQ Publication No. 09-0081-EF “Final Report: Consumer Engagement in Developing Electronic Health Information Systems” Prepared by: Westat, (July 2009)

http://healthit.ahrq.gov/portal/server.pt/gateway/PTARGS_0_1248_888520_0_0_18/09-0081-EF.pdf

Guaranteed Data Privacy

1. Adapt/use the National Data Infrastructure Improvement Consortium (NDIIC) open source electronic consent module as the minimum standard for consent tools in PHRs and for all HIT
2. Require the strong privacy protections in 43 CFR Part 2 be extended to cover all personal health information (PHI), wherever it is held.

http://www.ndiic.org/