



Patient Privacy: Policy and Practice *Executive Summary*

Health Information Technology and Privacy Survey (HITaPS)

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Introduction:

The Hospital Information Technology and Privacy Survey

In 2007, more than 500 US hospitals participated in the Health Information and Privacy Survey (HITaPS). The survey included general medical and surgical hospitals in 16 different states across the country. Your hospital participated in this study, and in so doing, gave voice to the views many other hospitals like your own. We very much appreciate the time you took to respond to the survey.

HITaPS is a unique resource for health researchers and policy makers. The survey includes information about:

- How hospitals and their privacy officers view patient privacy and HIPAA, including its benefits and drawbacks
- How hospitals are implementing privacy policies to comply with HIPAA
- Who on the hospital staff is developing and implementing HIPAA-compliant privacy policies
- What privacy-related challenges hospitals presently face, and expect to face, in the future

What follows is a summary of the study's preliminary findings in the form of an annotated chart pack. We focused on topics we believe to be of particular interest to health-care professionals who deal with privacy issues on a day-to-day basis. We invite you to share this information with others in your hospital as well as with professional colleagues. We hope that these findings contribute to on-going discussions about how health care providers can best ensure patient privacy and promote high quality health care.



Principal Investigator-- HITaPS was developed by Mark C. Suchman (J.D., Ph.D.), Professor of Sociology, Brown University. Dr. Suchman initiated HITaPS when he was Professor of Sociology at the University of Wisconsin.

Funding for HITaPS was provided by the National Science Foundation (Grant SES-0242033), The Robert Wood Johnson Foundation (Investigator Award #047734), the University of Wisconsin-Madison (Project 040584) and Brown University.

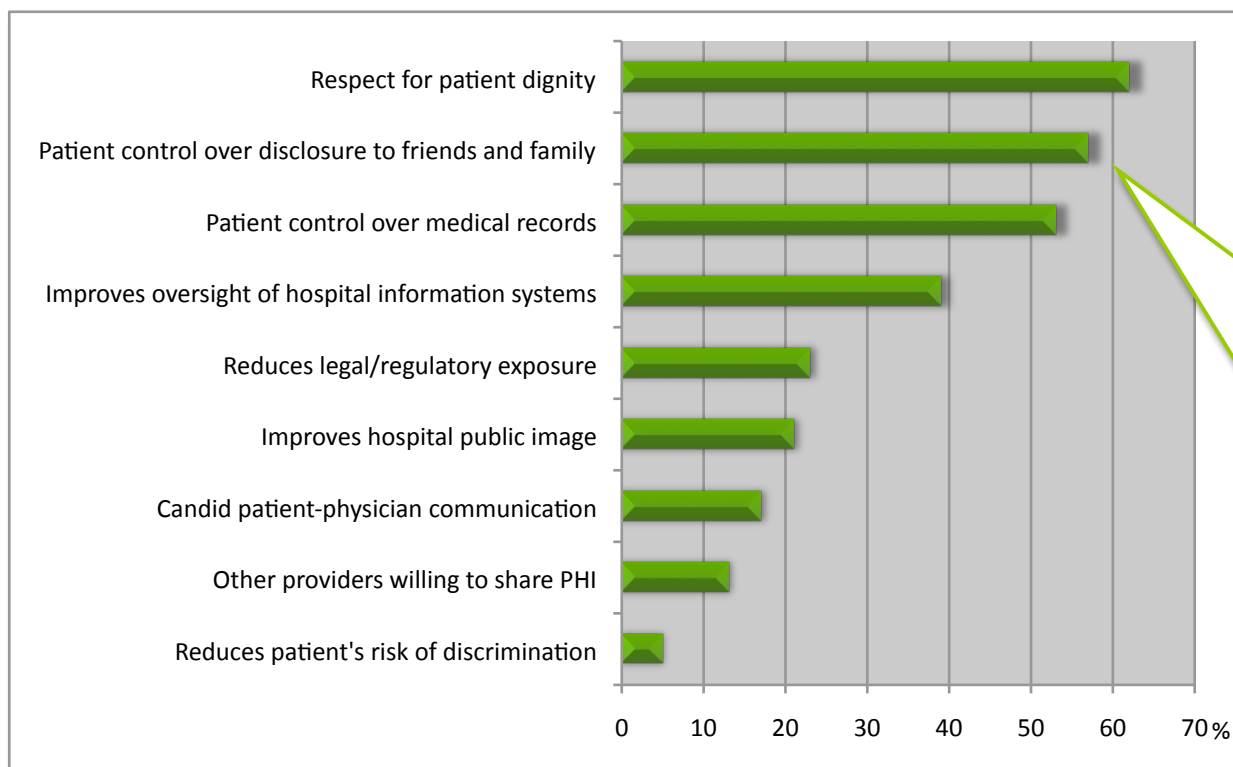
Data Summary: Annotated Chart Pack

Views about patient privacy: Pros and Cons

HIPAA (The Health Insurance Portability and Accountability Act of 1996) includes provisions to protect the privacy of patient medical information. The HIPAA Privacy Rule took effect on April 14, 2003. Before we asked specific questions about HIPAA, however, we wanted to find out how hospitals saw patient privacy, in general. What are its benefits and drawbacks? What are the most significant threats to patient privacy?

Benefits of Privacy

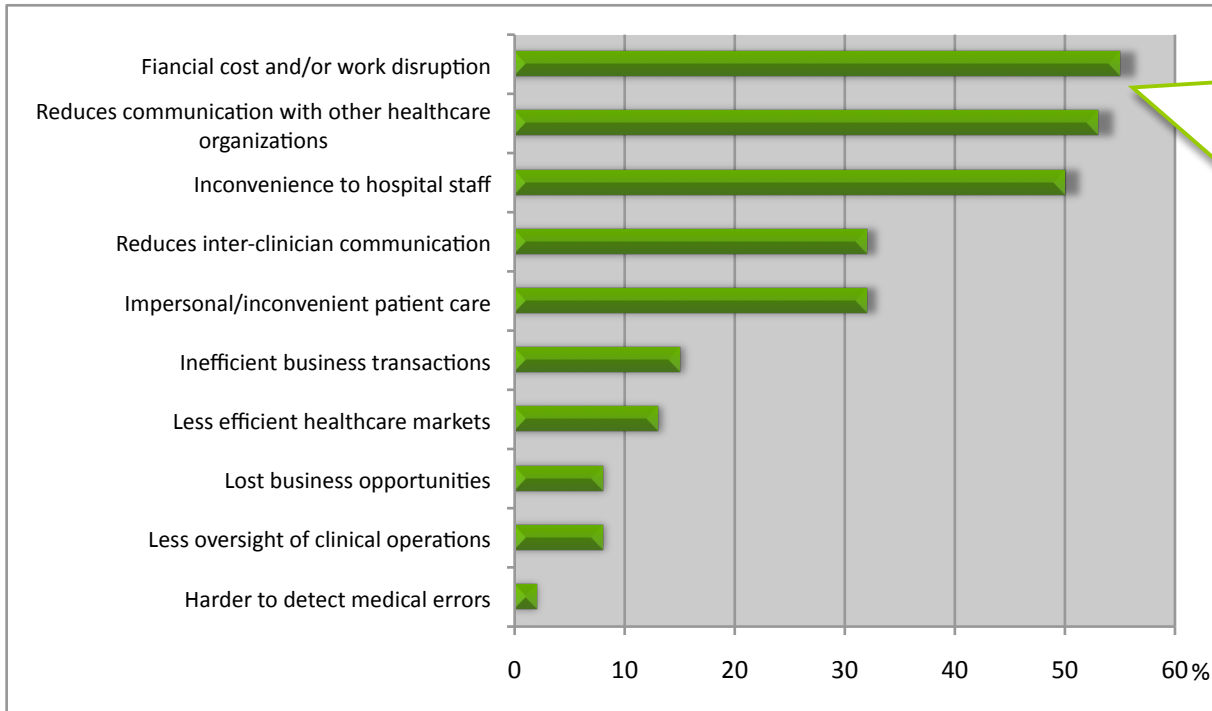
Percent of hospitals saying benefit is in the “top three”



Patients First!
Privacy Officers see privacy policies and practices as benefitting patients, first and foremost. The benefits to hospitals and the health care system are secondary.

Drawbacks of Privacy

Percent of hospitals saying drawback is in the "top three"

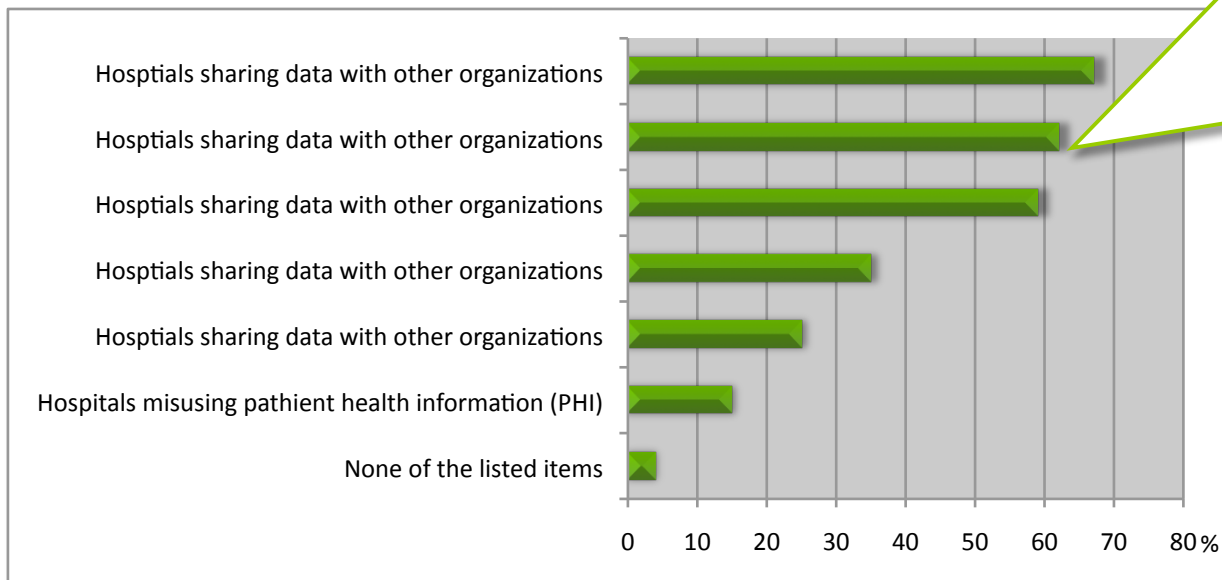


Clinical Challenges.

Privacy officers are most concerned about the challenges that privacy poses for clinicians: disruptions to work, impaired communication, and inconvenience.

Threats to Privacy

Percent of hospitals saying threat is in the "top three"



An Inside Job?

Privacy officers are most concerned that hospital *staff* will access or misuse patient data. They are less concerned about threats to privacy from outside the hospital or by the hospital itself. Although asked, no privacy officers expressed concern about outside hackers.

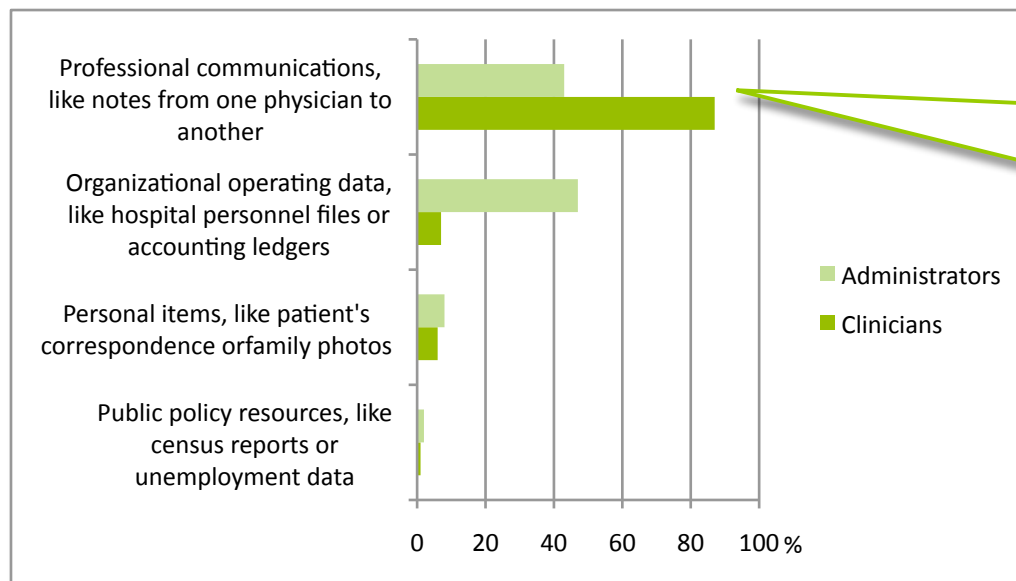
The Future?

The vast majority (81%) of hospital privacy officers expect that the **level of privacy expected from hospitals** will increase in the next ten years. Only 3% believe that the expected level of privacy will decrease, while 17% believe it will remain the same.

Whose data is it, anyway?

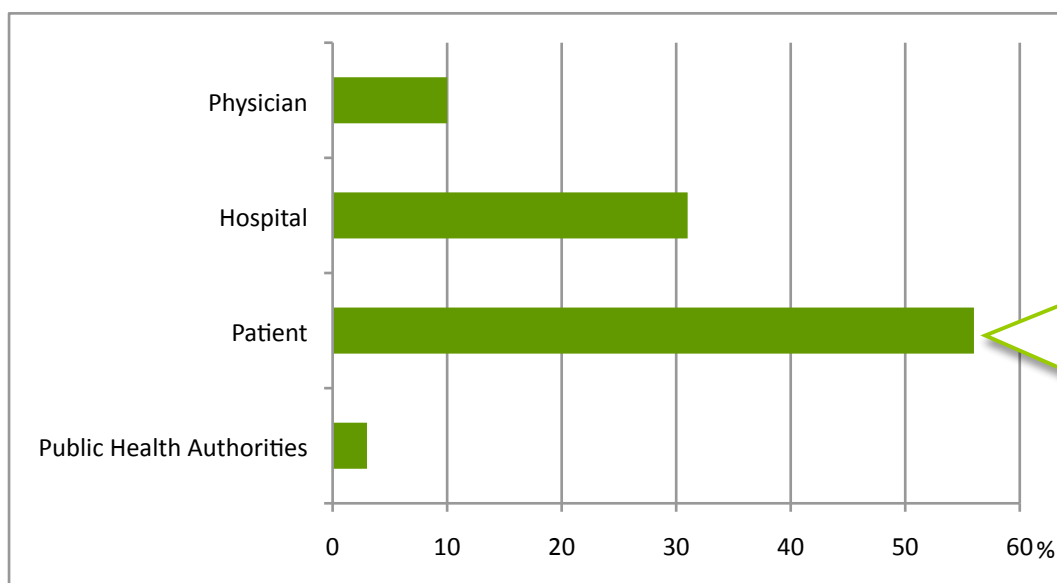
In practice, protecting patient privacy often comes down to protecting medical records. For this reason, we asked privacy officers about how patient records are understood in hospitals.

We asked about the dominant image of patient medical records...



"It's my data...": Almost all clinicians see medical records as professional communications. Many administrators, however, see medical records as organizational data.

We also asked privacy officers who should have the greatest say over patient medical records...



"...But you can visit whenever you want." Even though hospital personnel predominantly view patient medical records as professional notes or organizational files, just over half of all hospital privacy officers believe that patients should have the greatest say over their medical records.

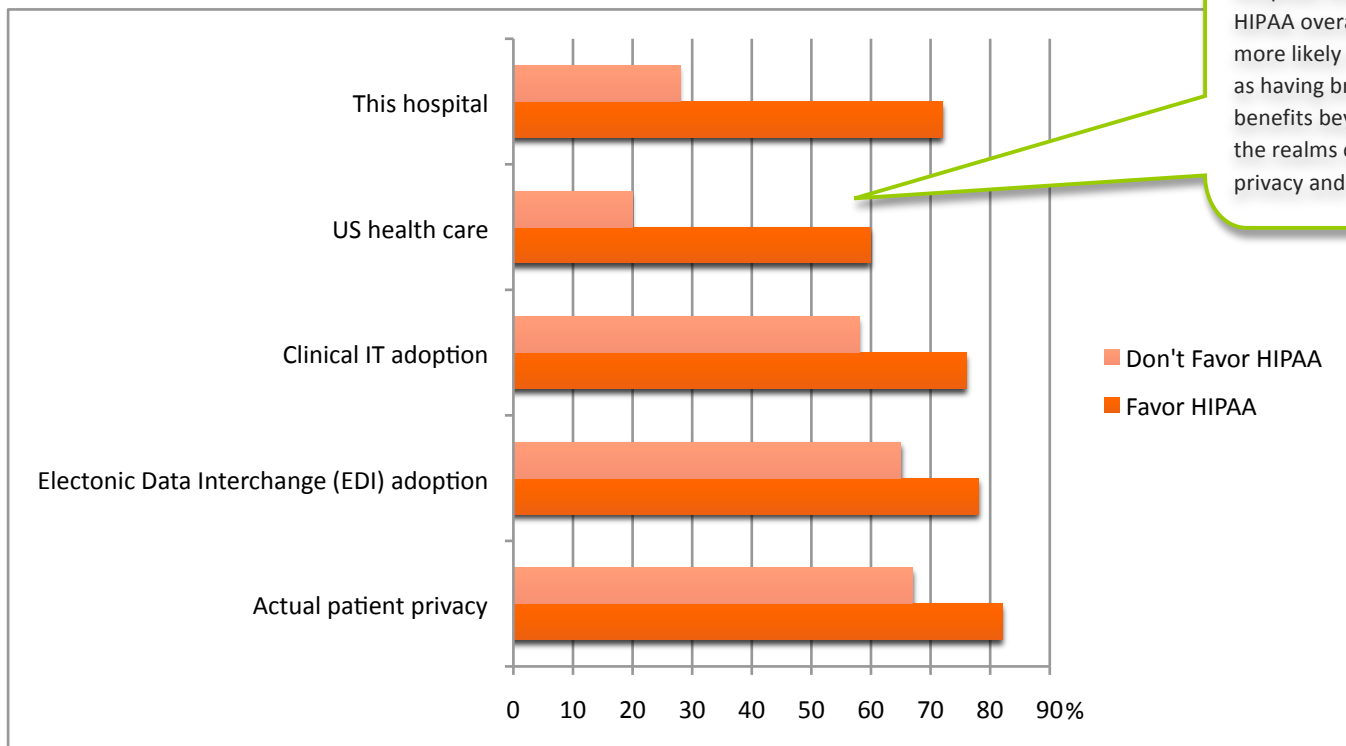
87%
favorable!

HIPAA: What's it good for?

When asked about their **hospitals' overall views of HIPAA**, privacy officers were overwhelmingly positive, with 87% reporting "favorable" or "strongly favorable" views in the hospital, while only 13% reported "unfavorable" or "strongly unfavorable" views.

But views about the benefits of HIPAA vary significantly between those who favor HIPAA and those who do not:

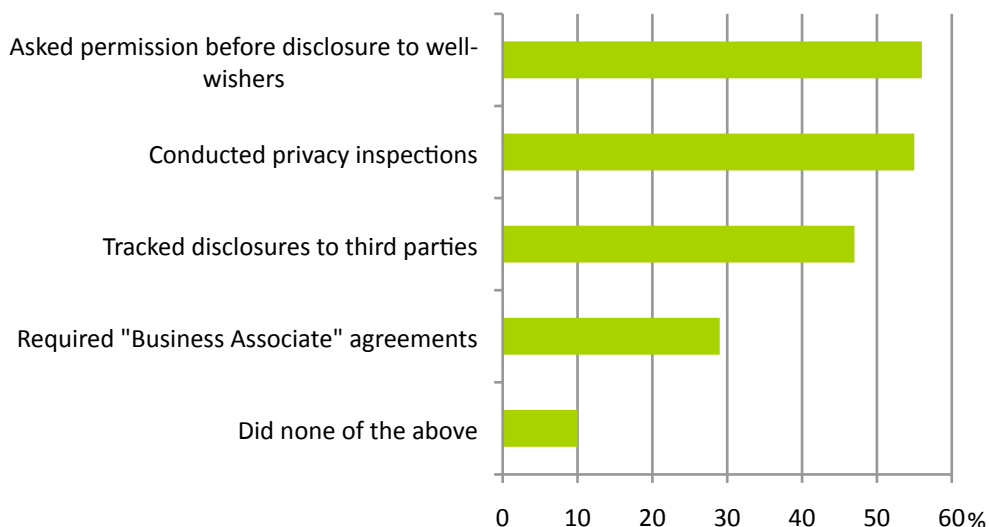
Percent of hospital privacy officers who reported that HIPAA was somewhat or very good for...



Implementing HIPAA

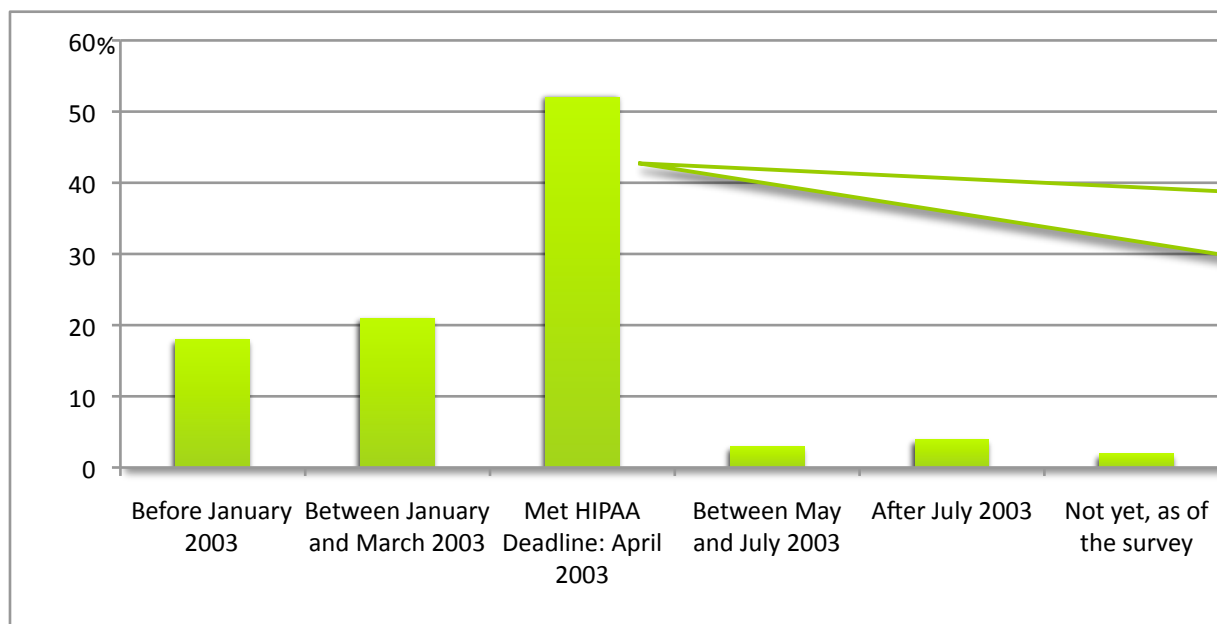
Because concerns about patient privacy pre-dated HIPAA, we asked about whether hospitals engaged in certain privacy-enhancing activities even before HIPAA went into effect.

Pre-HIPAA, Percent of Hospitals That Took Various Precautions...



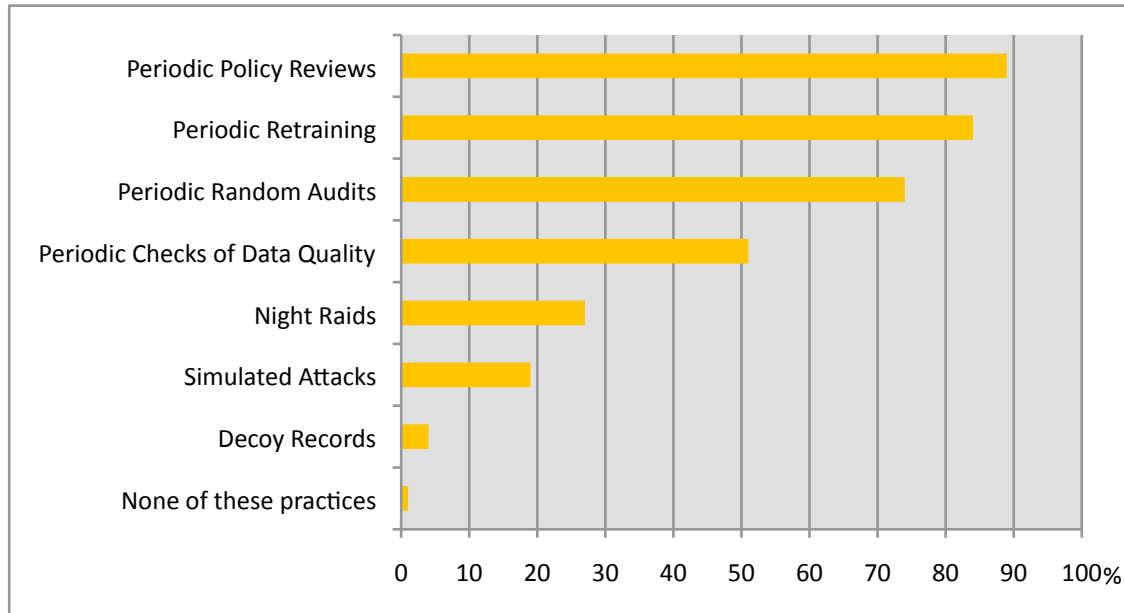
"These new federal health privacy regulations set a national floor of privacy protections that will reassure patients that their medical records are kept confidential. The rules will help to ensure appropriate privacy safeguards are in place as we harness information technologies to improve the quality of care provided to patients." Tommy Thompson, 2003, US Secretary of Health and Human Services

When did hospitals implement policies that complied with HIPAA?

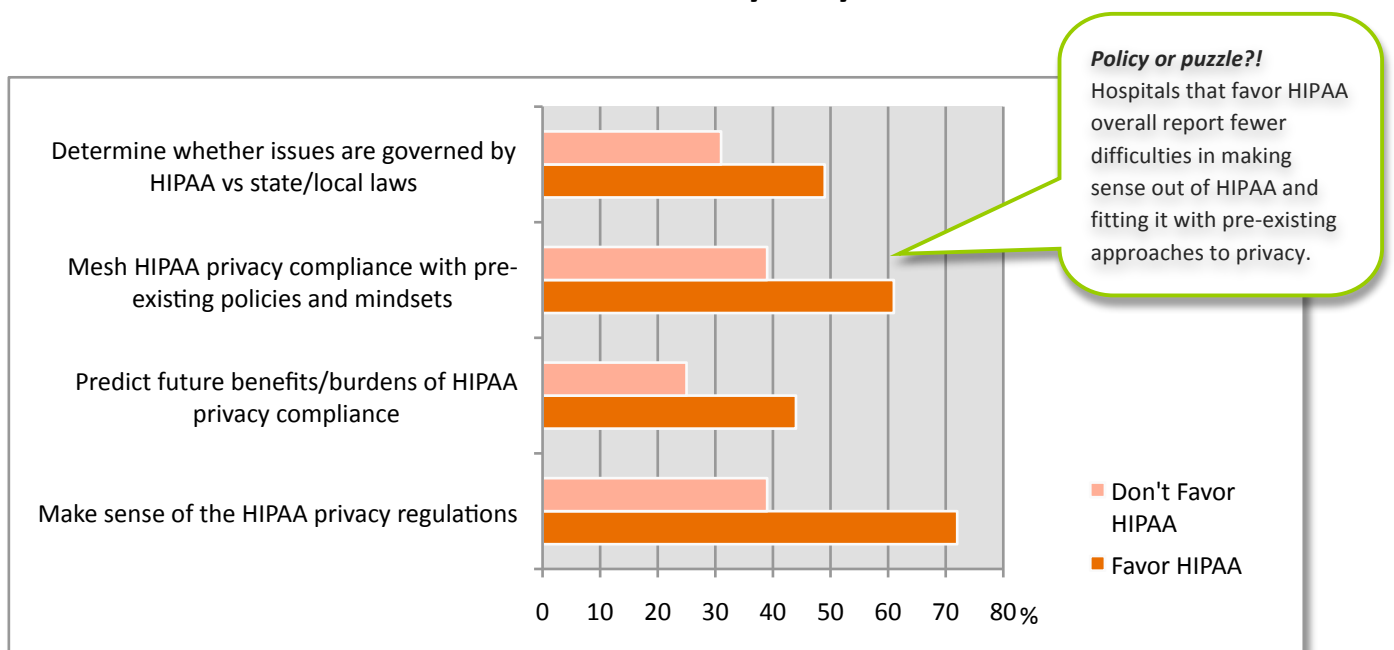


Right on Time. Over 90% of hospitals surveyed met the HIPAA compliance deadline.

Percent of hospitals whose HIPAA practices include...



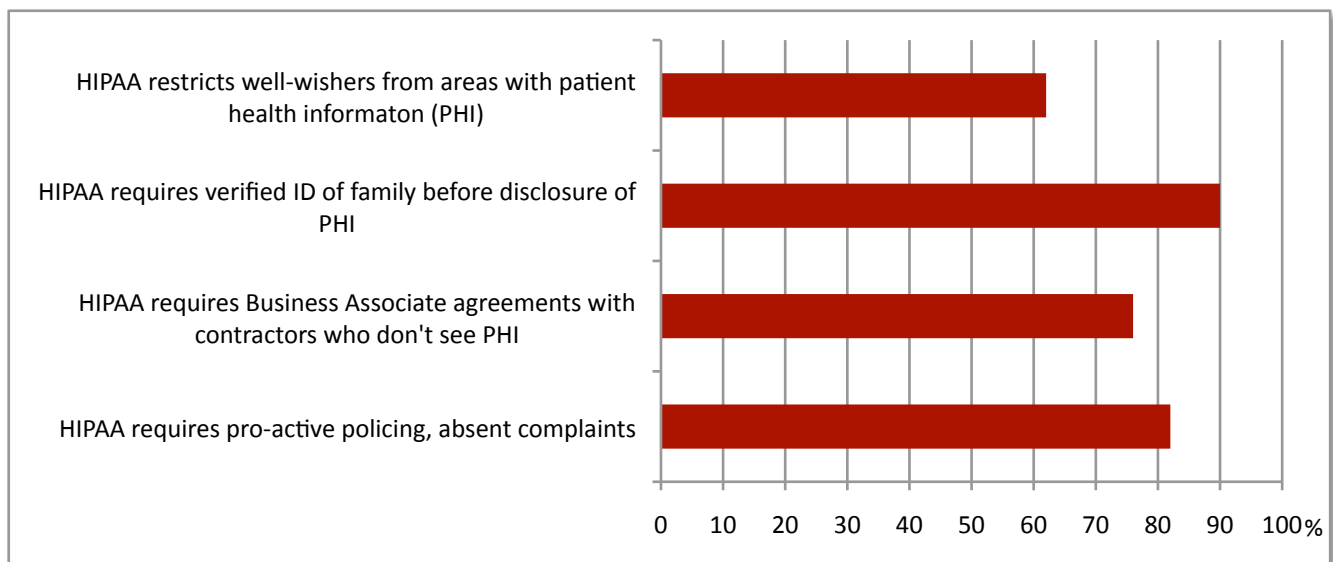
Percent of hospital privacy officers who reported that it was 'somewhat' or 'very easy' to...



Disagreements about what HIPAA requires

Hospitals vary in what they think HIPAA requires. This is not unusual in cases where organizations are asked to interpret law and turn it into internal policies. However, in the case of HIPAA, these ambiguities have attracted public attention (see box below).

Percent of hospital privacy officers who reported that HIPAA ‘definitely’ or ‘probably’ required...



In July 2007, the New York Times reported on confusion about HIPAA requirements:

“...accounts from hospital administrators, patient advocates, lawyers, family members, and law enforcement officials offer an anthology of HIPAA misinterpretations, some alarming, some annoying:

¶ Birthday parties in nursing homes in New York and Arizona have been canceled for fear that revealing a resident’s date of birth could be a violation.

¶ Patients were assigned code names in doctor’s waiting rooms — say, “Zebra” for a child in Newton, Mass., or “Elvis” for an adult in Kansas City, Mo. — so they could be summoned without identification.

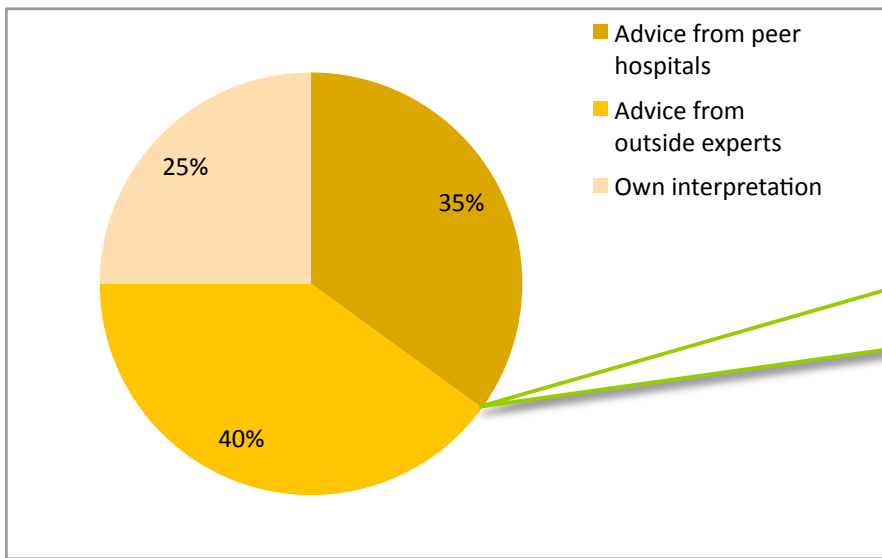
¶ Nurses in an emergency room at St. Elizabeth Health Center in Youngstown, Ohio, refused to telephone parents of ailing students themselves, insisting a friend do it, for fear of passing out confidential information, the hospital’s patient advocate said.”

From “Keeping Patients’ Details Private, Even From Kin” by Jane Gross (7/3/2007)



Where do hospital HIPAA privacy policies come from?

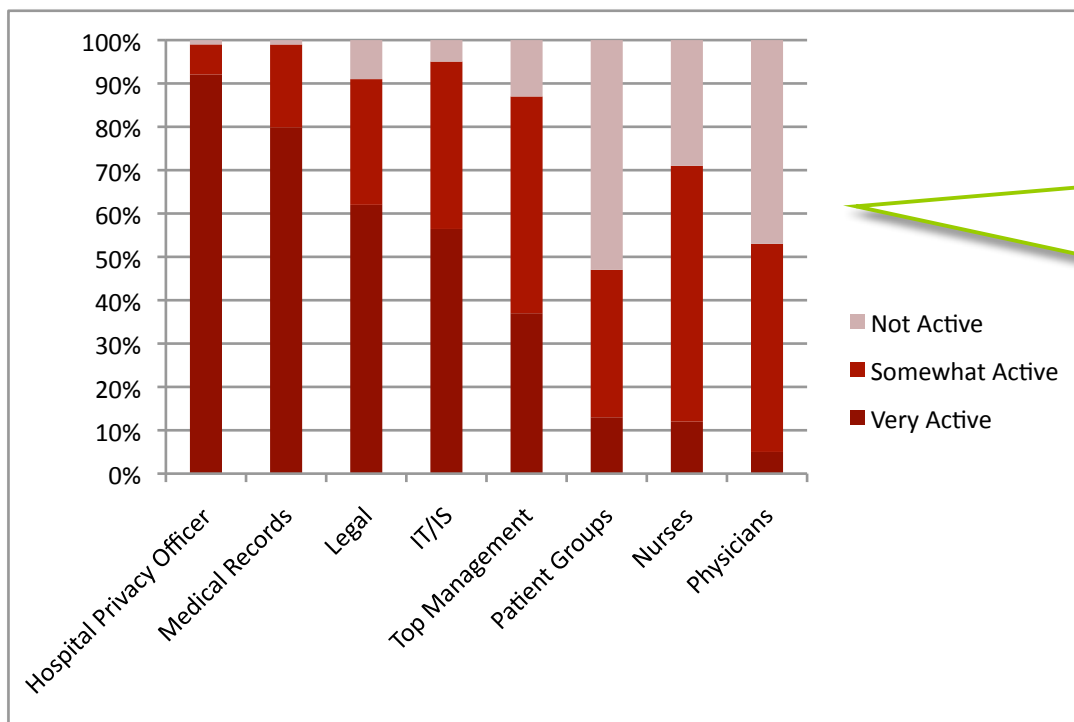
When new laws are passed or regulations imposed, hospitals and other organizations are faced with decisions about how they will respond. We asked about the hospital's overall approach to developing privacy policies as well as who in the hospital and among its constituents was most actively involved in setting privacy policies.



Taking Advice?

Regarding privacy policy development, 75% of hospitals relied most on outside guidance, from peer hospitals or other experts.

The Politics of Hospital Privacy: Who Participates In Policy Development?



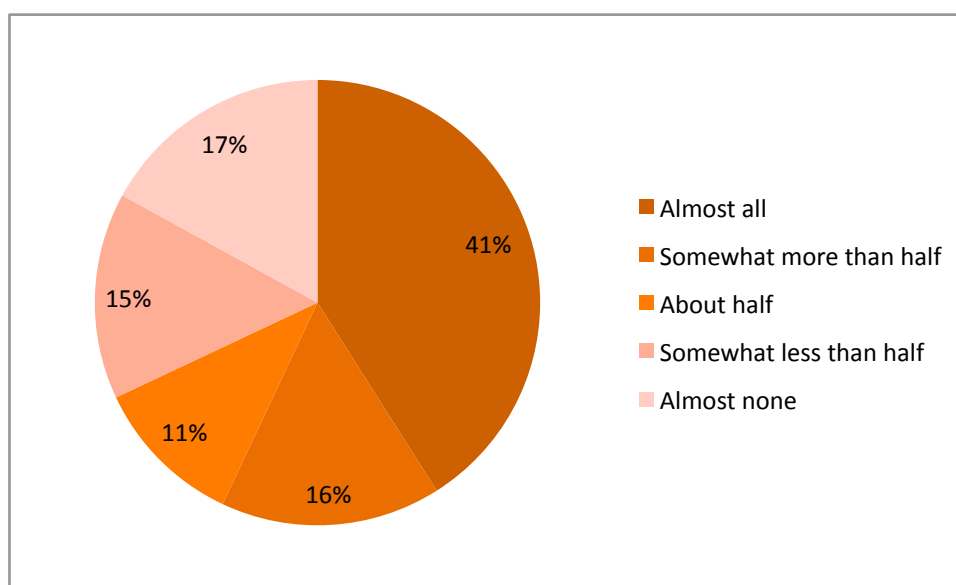
Is There a Doctor in the House?

Clinicians and patient groups are far less active than administrators in HIPAA policy-making.

Who knows HIPAA?

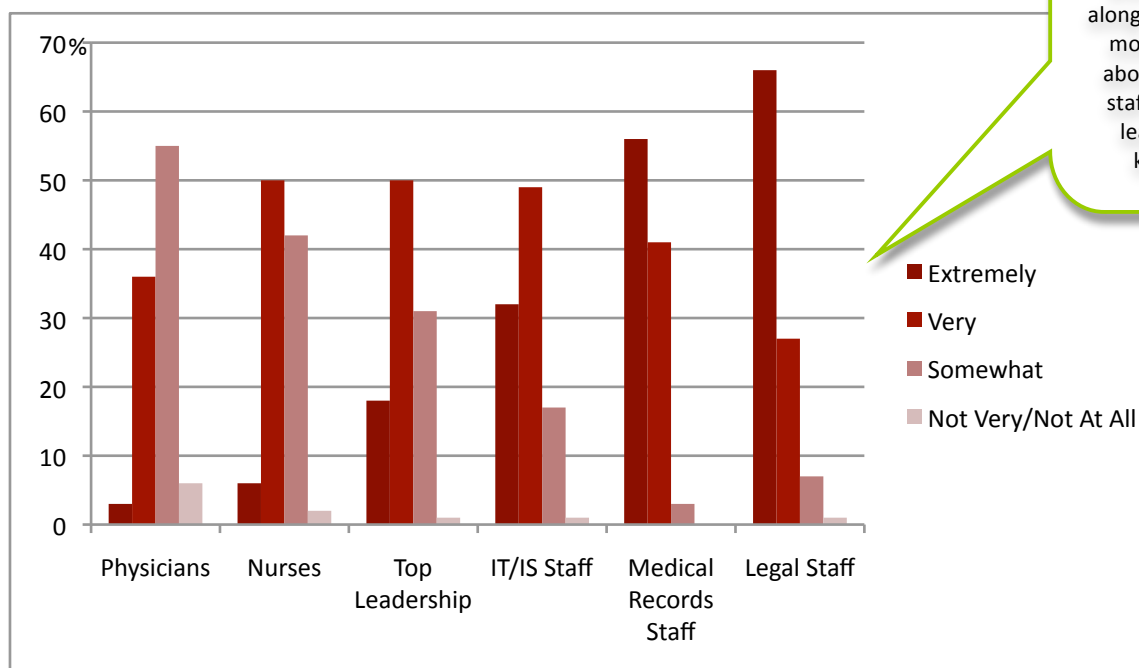
92% of hospitals had a **privacy planning committee**. We wondered how familiar members of that committee were with HIPAA. So we asked privacy officers to tell us what proportion of the privacy committee's members had read the HIPAA text.

Proportion of the HIPAA planning committee that has read the HIPAA text



And everyone else...

How knowledgeable is hospital staff about HIPAA?



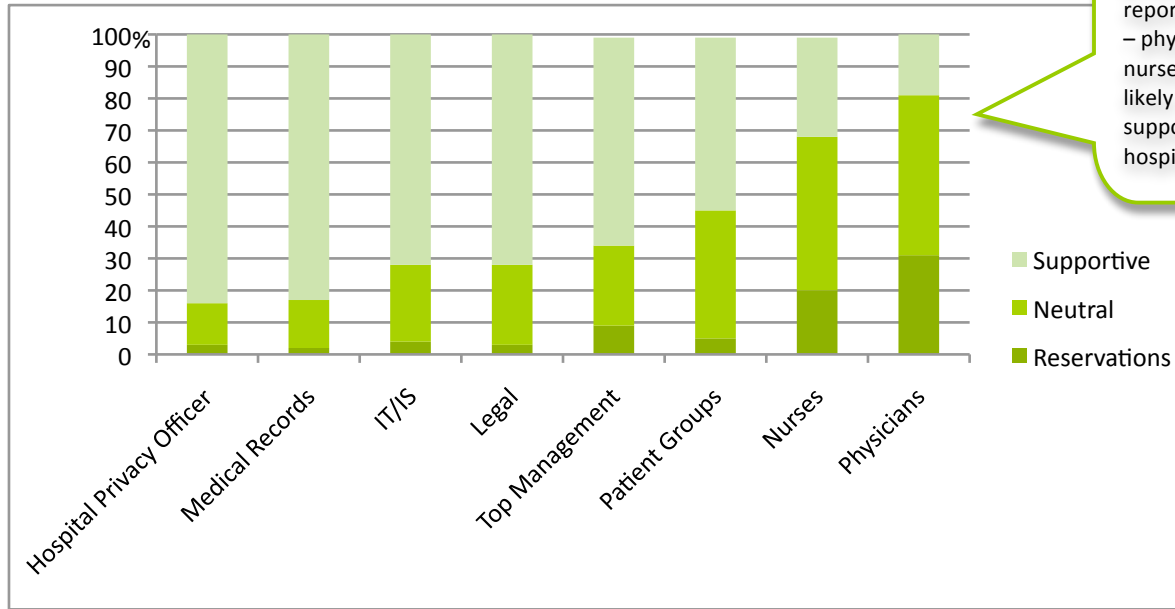
The Knowledge Workers?

Staff who deal with information technology and medical records, along with legal staff, are most knowledgeable about HIPAA. Clinical staff and top hospital leadership are less knowledgeable.

The Politics of Privacy: Support and Resistance

Attitudes: Voices of Support and Reservation

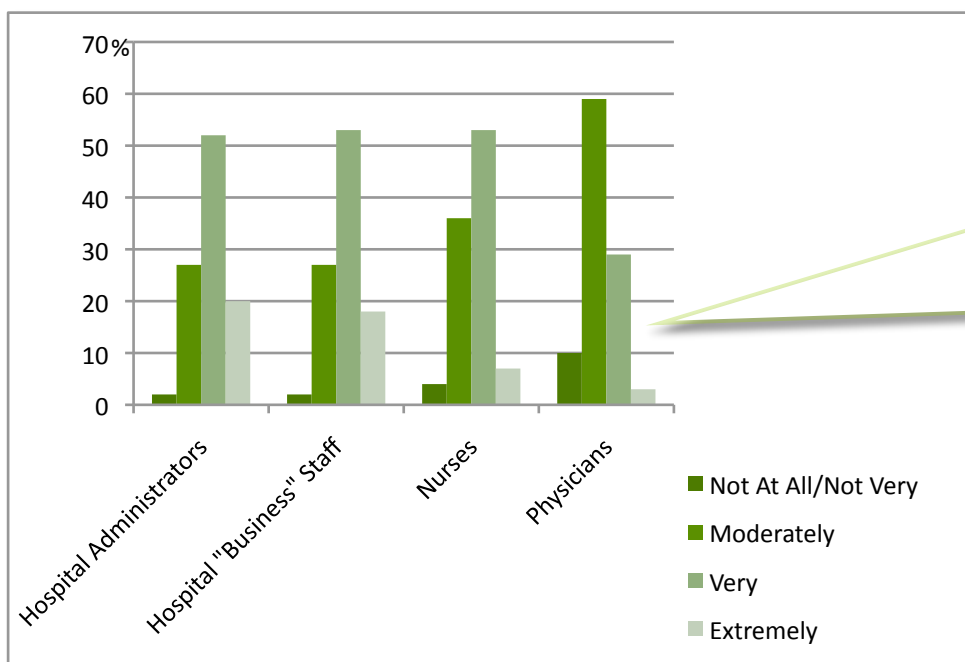
Do groups express support or reservation about tighter privacy policies?



Where you stand depends on where you sit: Hospital privacy officers report that clinicians – physicians and nurses – are least likely to express support for tighter hospital policies.

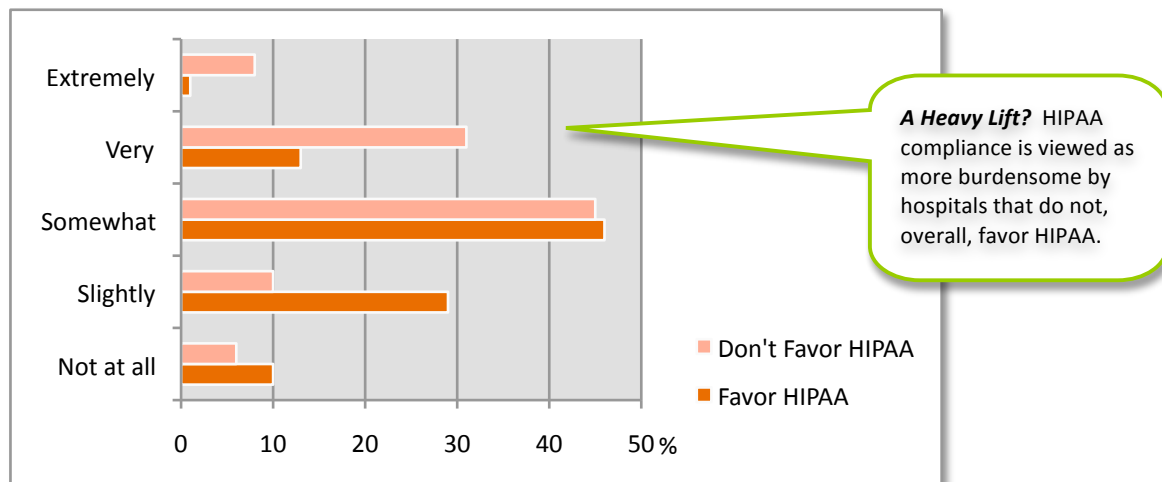
Behavior: Compliance with Privacy Policies

How consistently do members of the following groups follow Hospital Privacy Policies?



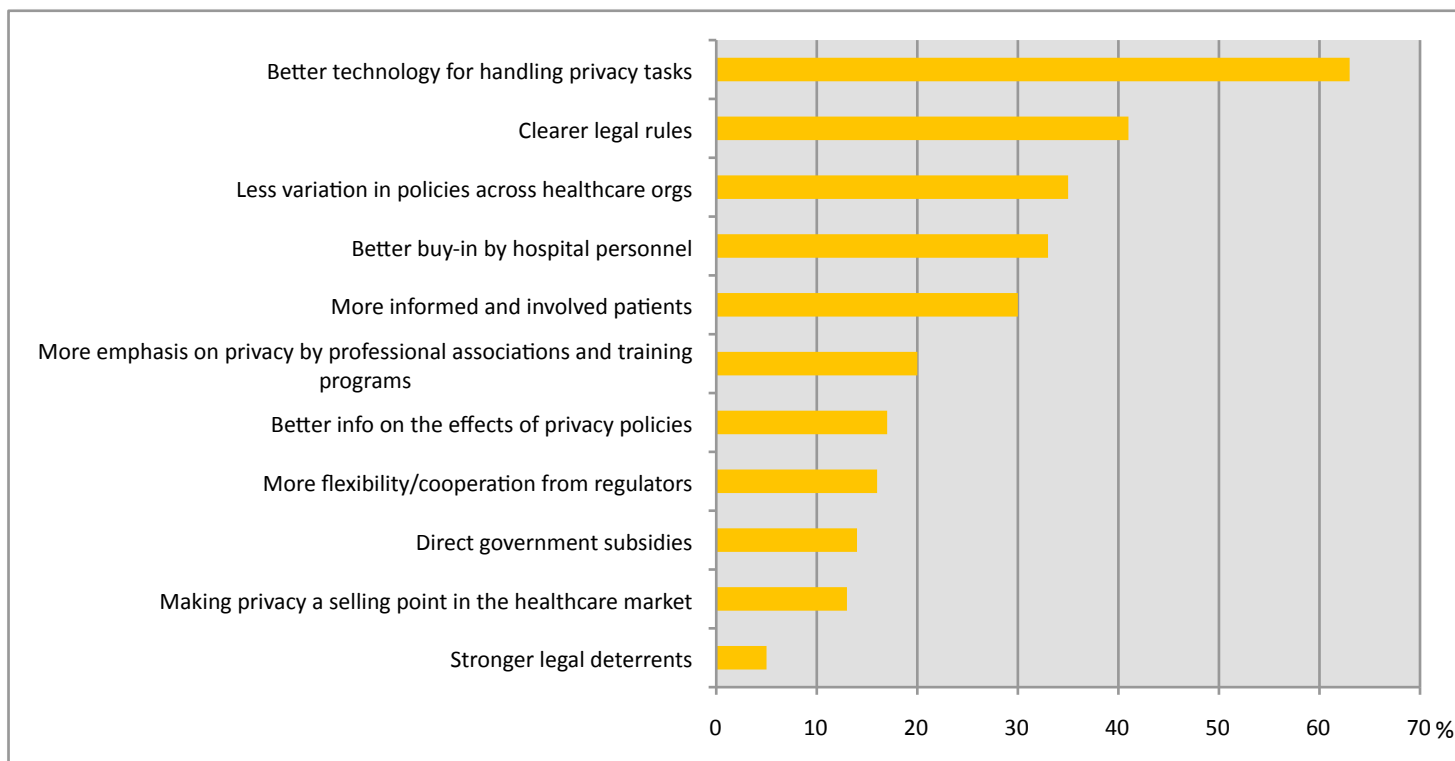
By The Book. Hospital privacy officers report that nurses, hospital administrators and hospital business staff are more likely than physicians to be 'very' or 'extremely' compliant with hospital privacy policies.

How burdensome is HIPAA privacy compliance?



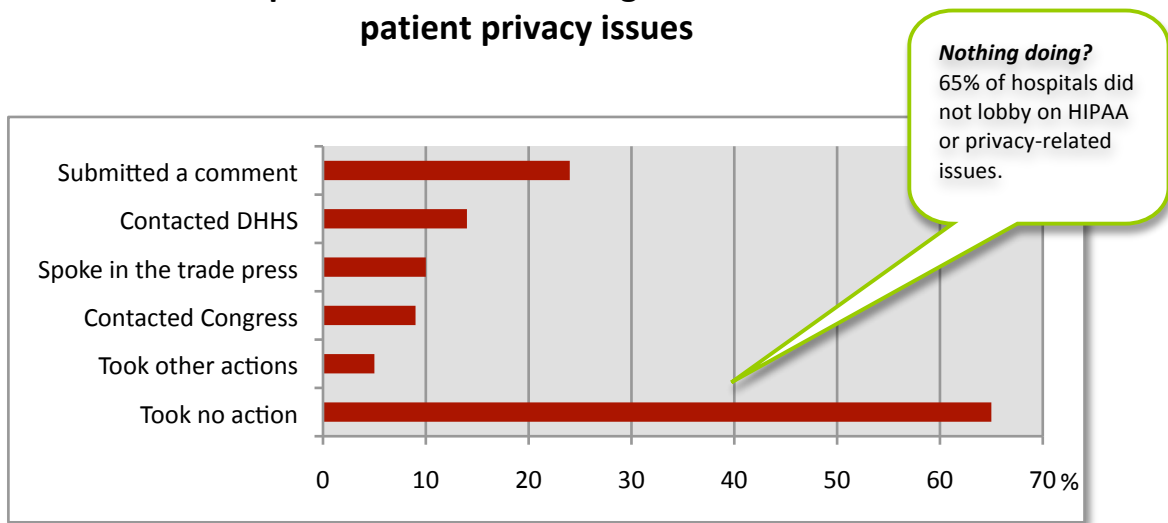
We also asked privacy officers about possible developments that would facilitate improvements in patient privacy.

Percent of privacy officers who named each as a 'Top 3' facilitating developments...



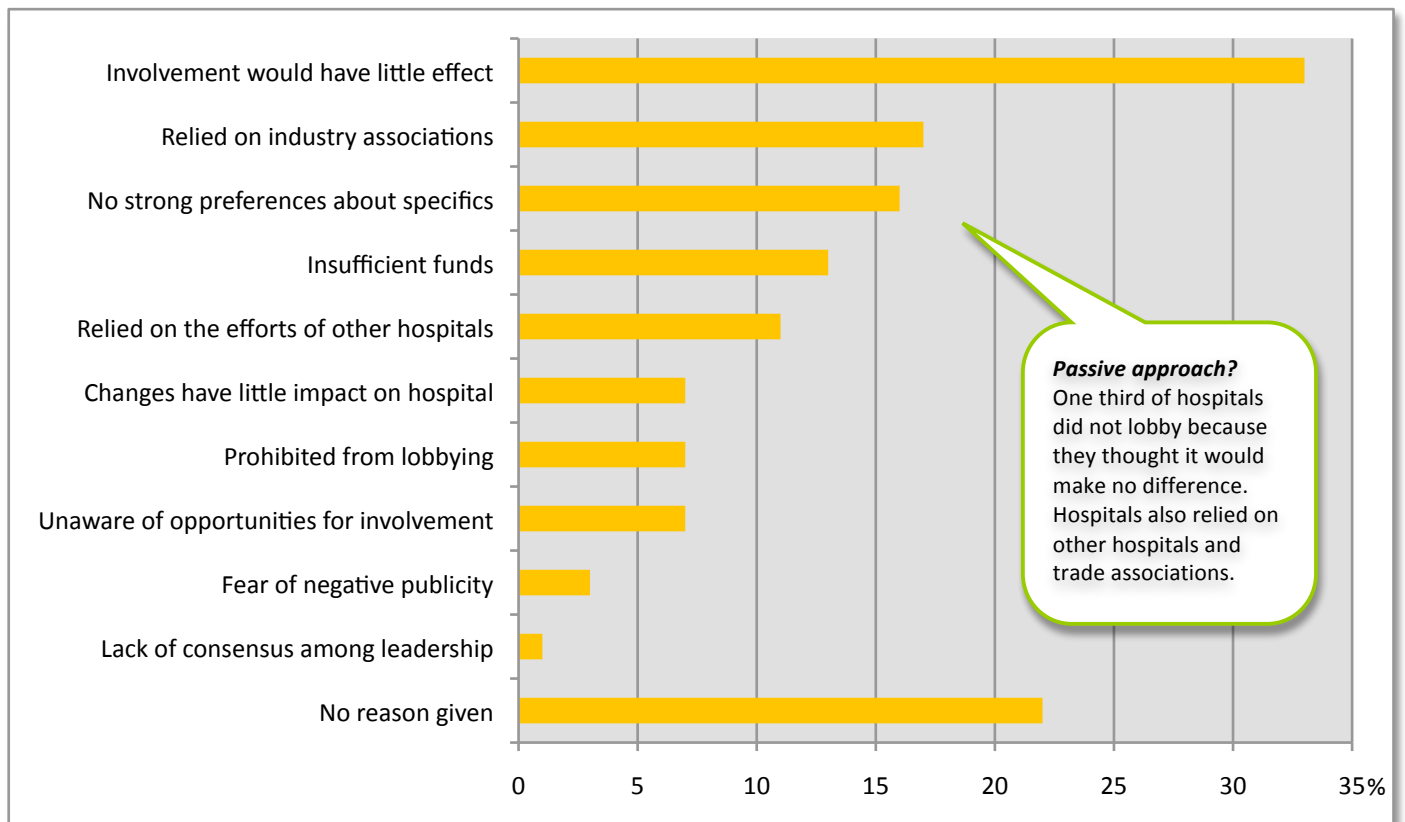
Speaking out...

Percent of hospitals that lobbied the government on HIPAA or patient privacy issues



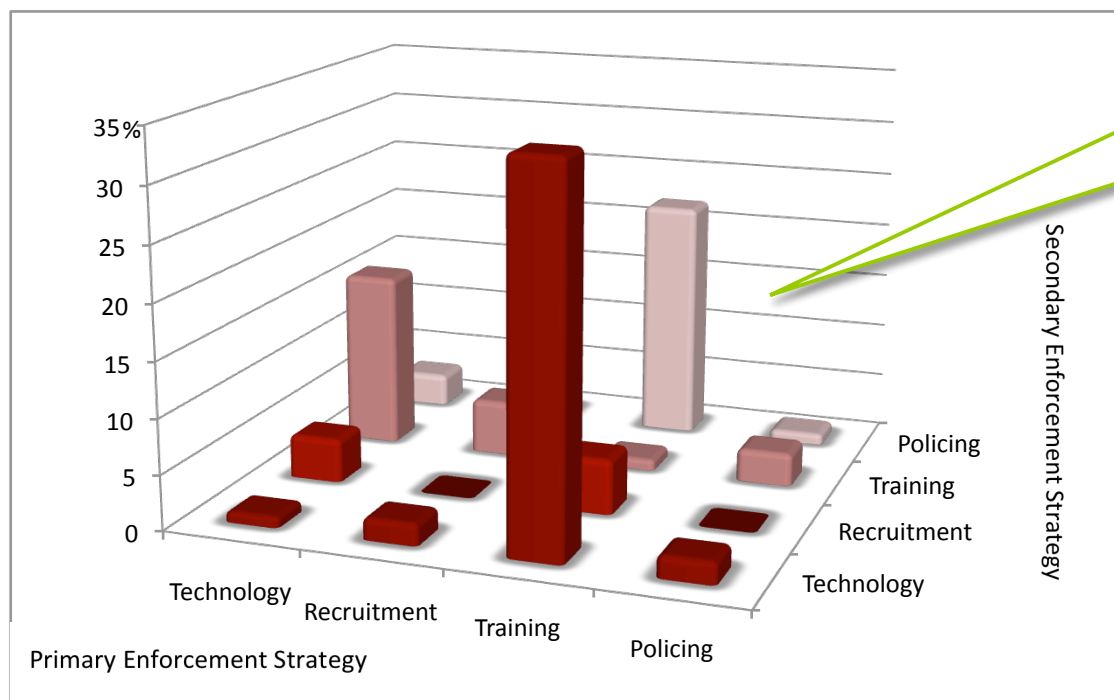
Why Not Lobby?

Percent of hospitals giving each reason for not lobbying around HIPAA-related issues...



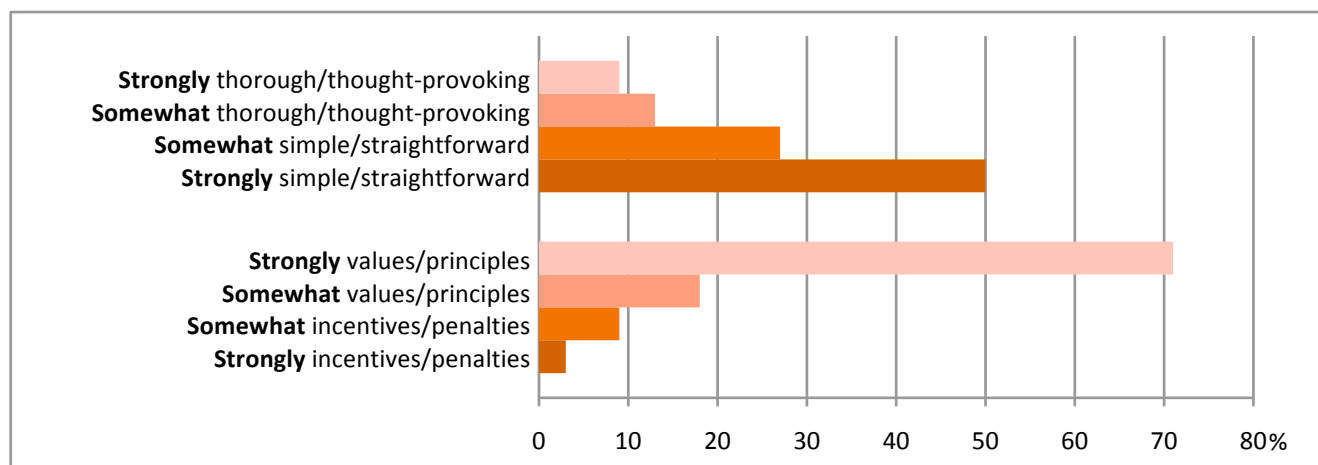
HIPAA Compliance

What strategies do hospitals use to ensure HIPAA compliance?



Tech & Teach:
Enforcement strategies cluster around technology and training.

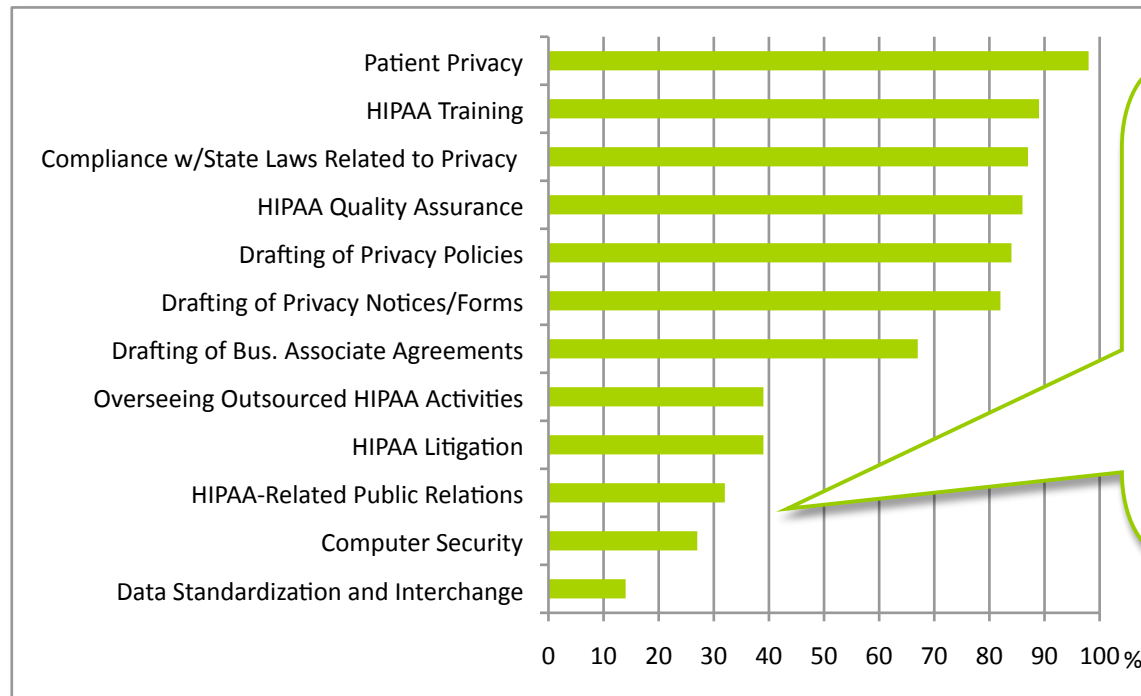
HIPAA Training for Employees: What do hospitals emphasize?



The majority of respondents report that HIPAA training tends strongly towards a focus on **values and principles** over incentives and penalties. In addition, hospitals focus on providing training that is **simple and straightforward** over training that is thorough and thought-provoking.

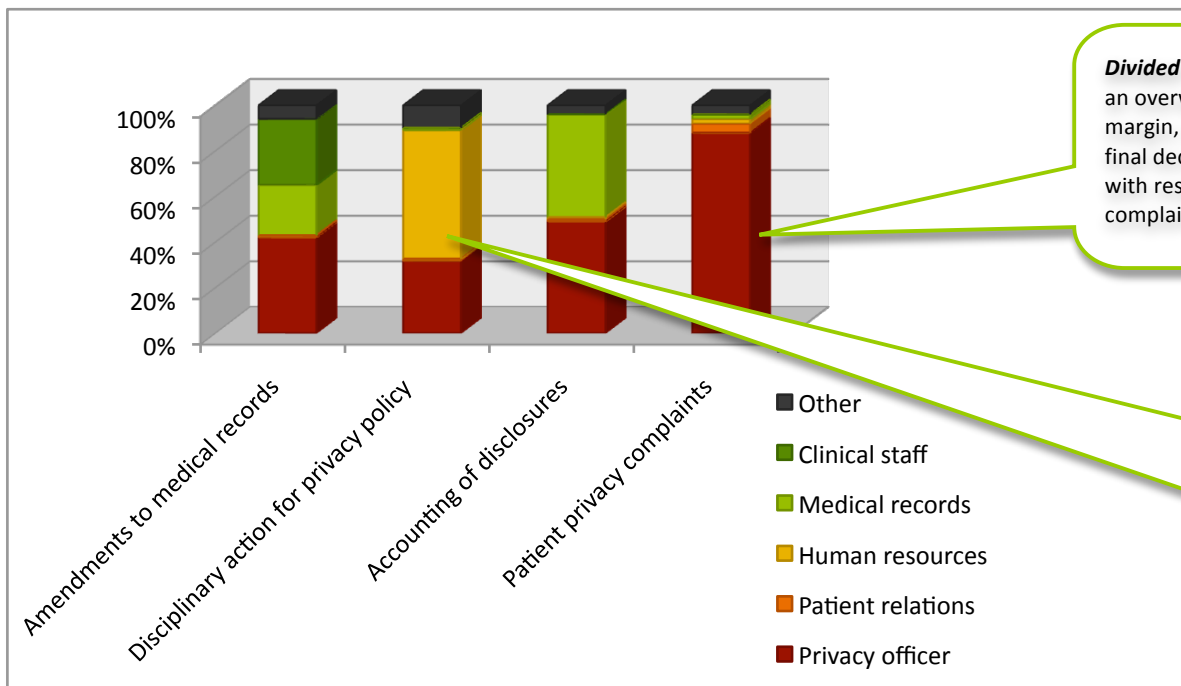
Hospital Privacy Officers: Their Work

Percent of Privacy Officers Responsible For...



What's My Line?
Although HIPAA encompasses three distinct domains – patient privacy, computer security and data standardization – most hospitals assign responsibilities for these tasks to different staff members.

Authority over Privacy-Related Decisions



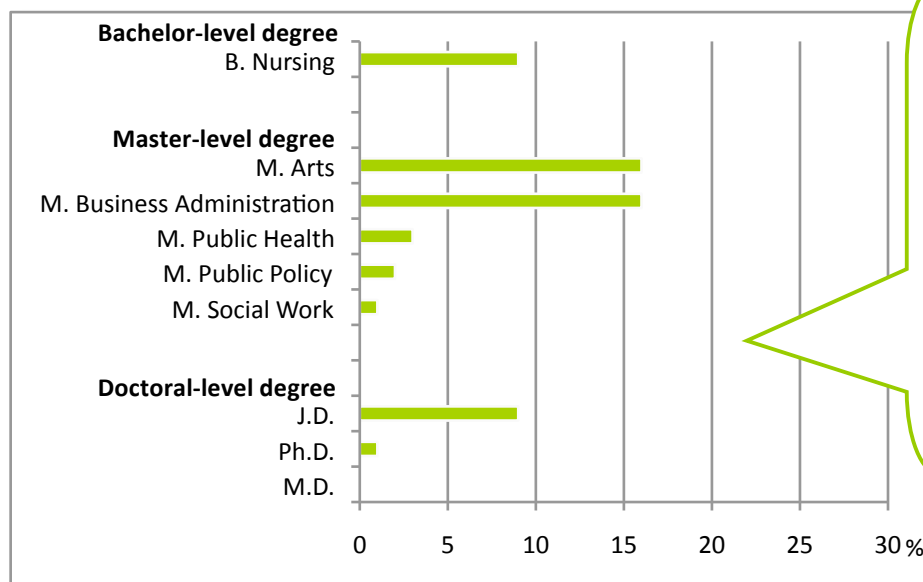
Divided Authority? By an overwhelming margin, the HPO is the final decision-maker with respect to privacy complaints.

But... Human Resources is most often the final decision-maker when it comes to privacy disciplinary actions.

Nonetheless, the vast majority of privacy officers (85%) report that they have “often” or “almost always” have **enough authority to do their jobs.**

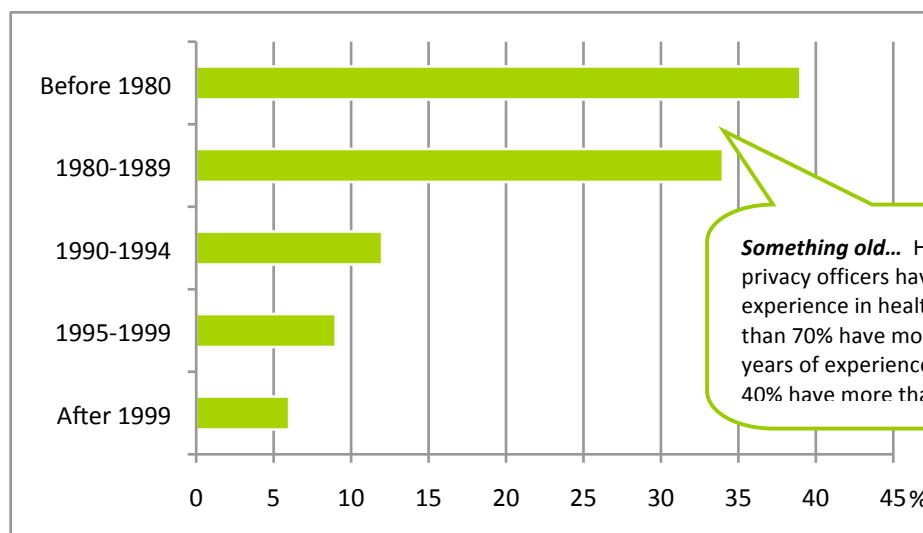
Hospital Privacy Officers: Their Backgrounds

Educational Background of Hospital Privacy Officer



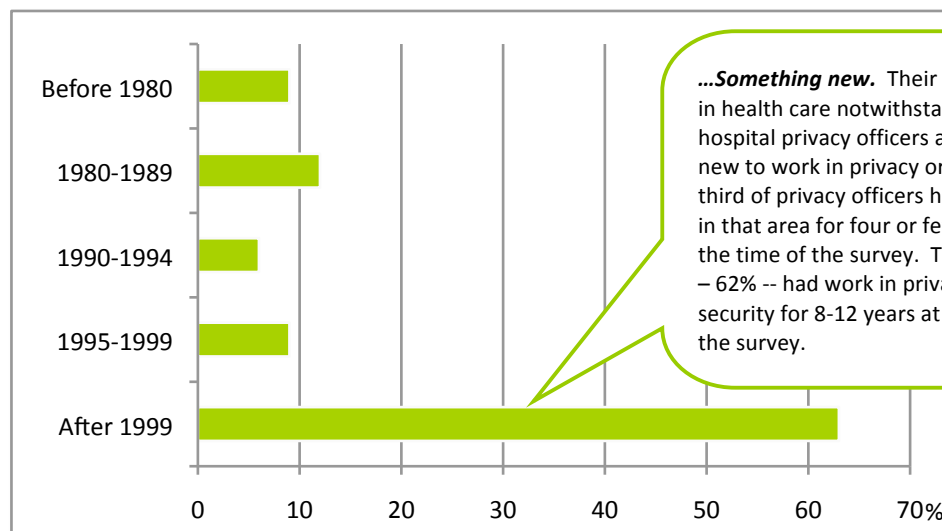
School Days: Hospital privacy officers come from a range of educational backgrounds. Almost half have RHIA or RHIT certification, and 45% have graduate degrees.

Approximate Year Hospital Privacy Officer Entered Healthcare Field



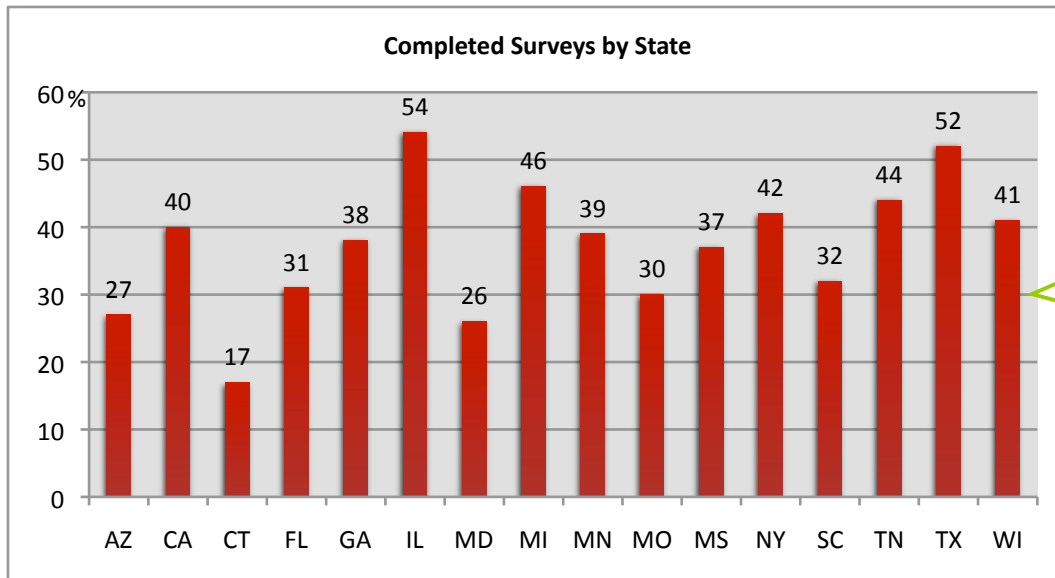
Something old... Hospital privacy officers have a lot of experience in health care. More than 70% have more than 20 years of experience and almost 40% have more than 30 years.

Approximate Year Hospital Privacy Officer Entered Privacy/Security

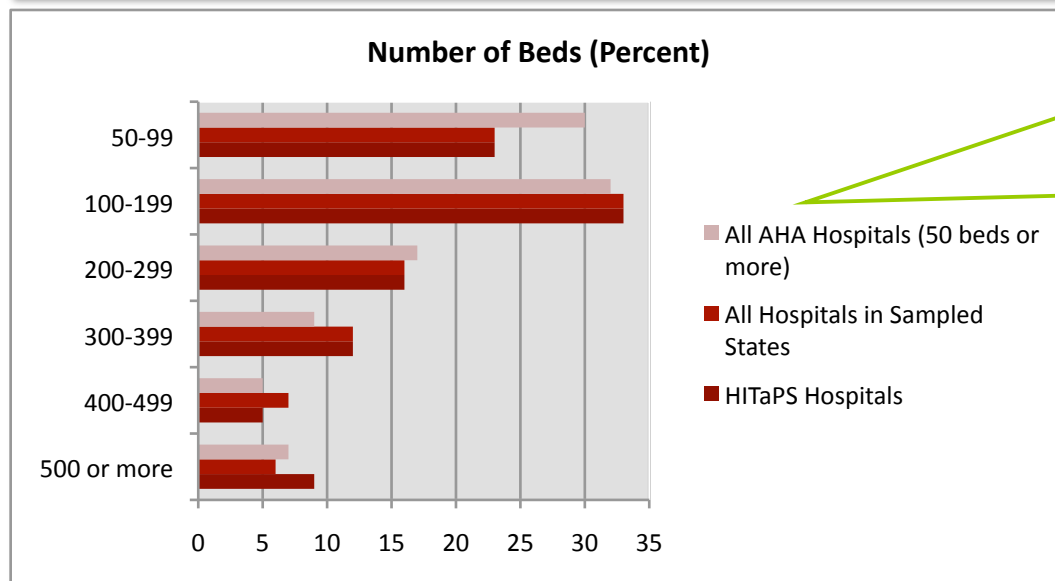


...Something new. Their experience in health care notwithstanding, many hospital privacy officers are relatively new to work in privacy or security. A third of privacy officers had worked in that area for four or fewer years at the time of the survey. The majority -- 62% -- had work in privacy or security for 8-12 years at the time of the survey.

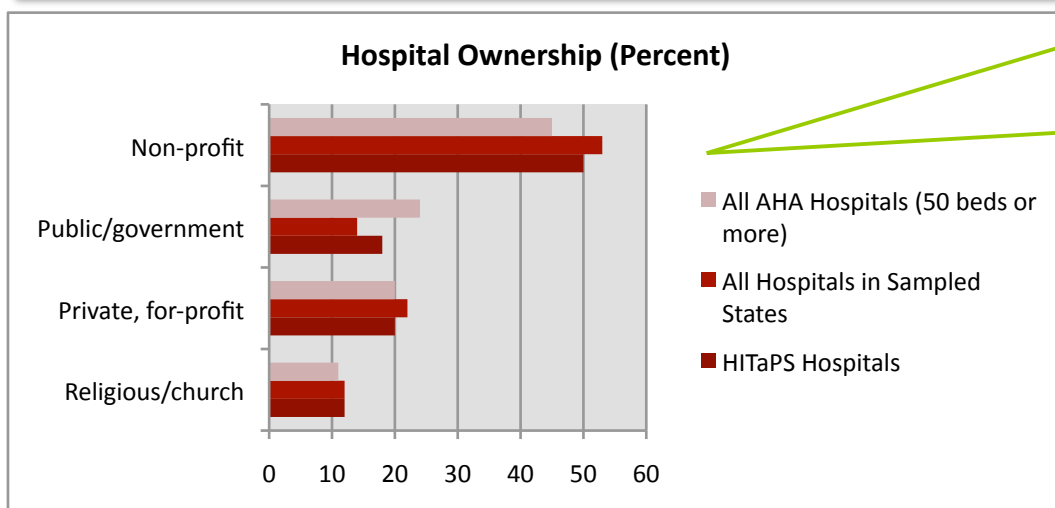
About the Hospitals...



Geography:
Hospitals from around the US were included in the study.



Hospital size:
The sample captures the full range of hospitals—from small community hospitals to large research hospitals.



Ownership Type: The sample captures the variety of ownership arrangements, with non-profit hospitals most prevalent.

The Hospital Information Technology and Privacy Survey

Survey Background

In 2007, a team of researchers at the University of Wisconsin conducted the Hospital Information Technology and Privacy Survey (HITaPS), designed to gather data on clinical IT adoption and HIPAA compliance from a stratified random sample of approximately 600 hospitals located in 16 states across the country. Each participating hospital was asked to complete two distinct survey modules: the first directed to the hospital's HIPAA Privacy Officer, and the second directed to the Chief Information Officer. Survey respondents provided information on organizational policies and practices in their respective areas of responsibility, as well as general information on their hospital's mission, structure, work culture, and market environment.

HITaPS hospitals were randomly sampled from the universe of all civilian, general medical and surgical hospitals, with 50 beds or more, as listed in the American Hospital Association's 2004 Annual Survey. The sample was stratified by state and by Federal Circuit Court jurisdiction, in order to capture variation in market conditions and legal environments. The sample design encompassed two states in each of eight Federal Circuit Court jurisdictions, with states being paired across Circuits on the basis of socio-economic similarity. The surveyed states were: Arizona, California, Connecticut, Florida, Georgia, Illinois, Maryland, Michigan, Minnesota, Missouri, Mississippi, New York, South Carolina, Tennessee, Texas, and Wisconsin.

The HITaPS survey was fielded between February and December of 2007, with the majority of respondents receiving and completing the survey between June and August of that year. Respondents were recruited by telephone, and those who agreed to participate were then given password-protected access to the HITaPS questionnaire, which was administered electronically via a secure web-site. To minimize non-response bias, participants received multiple rounds of e-mail and telephone follow-ups. In all, approximately 1000 Privacy Officers were contacted for participation in the survey; of these, 596 agreed to participate, and 534 eventually completed the full questionnaire.

Principal Investigator Background

Mark C. Suchman is Professor of Sociology at Brown University. He holds a J.D. from Yale Law School (1989) and a Ph.D. in Sociology from Stanford University (1994). His research centers on the legal environment of organizational activity, with a particular focus on the impact of law on entrepreneurship and technological change. His current work examines the legal and policy challenges that American hospitals face in implementing new clinical information technologies. Dr. Suchman has also written on organizational legitimacy, on the role of law firms in Silicon Valley, on the impact of changing professional structures on corporate litigation ethics, and on social science approaches to the study of contracts.

Research Team

The HITaPS research team includes: Susanne Monahan, Associate Professor of Sociology at Montana State University; Todd Arthur Bridges, Crystal Adams, and Miriam Plavin, graduate students in Sociology at Brown University; and Carolyn Siegel, Keilani Groszyk, Scott Geller, Prachi Jalan, and Sofia Quesada, Brown University undergraduates.

Acknowledgements

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