Consumer Rights to Health Care and Privacy: When is Sharing PHI the Right Thing to Do?

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20 Years of Leadership
A LEGACY OF CARE
2010 RYAN WHITE ALL GRANTEE MEETING AND 13TH ANNUAL CLINICAL CONFERENCE

Disclosure Statement

- Presenter Disclosures
    1. Jane Herwehe, MPH, has no financial interests or relationships to disclose.
    2. Peter Gordon, MD, has no financial interests or relationships to disclose.
    3. Wayne T. Steward, PhD, MPH, has no financial interests or relationships to disclose.

- HRSA Education Committee Disclosures
    1. HRSA Education Committee Staff have no financial interests or relationships to disclose.

- CME Staff Disclosures
    1. Professional Education Services Group Staff have no financial interests or relationships to disclose.

Learning Objectives

- Identify potential uses (benefits) of sharing clinical and surveillance information

- Be able to evaluate risks vs. benefits of sharing protected health information

- Describe approaches used to elicit consumer support in deployment of electronic health information systems

Overview

- Introductions

- Discussion of benefits of sharing patient health information

- Discussion of challenges in sharing patient health information

- Presentation of two successfully-implemented information exchange systems

- Wrap-up

INTRODUCTIONS

SPNS Electronic Networks of Care Initiative

- Goal: To develop and evaluate electronic health information exchanges (HIE) that link providers, public health agencies, and/or patients

- Questions that motivate the work of the Initiative:
  - <u>What</u> is each HIE doing?
  - <u>When</u> are they effective?
  - <u>Where</u> are they effective?
  - <u>With whom</u> are they having an effect?
  - <u>How</u> exactly are they having an effect?
  - Are they <u>cost effective</u>?

SPNS Initiative

- Six demonstration sites
  - Louisiana State University Health Sciences Center, New Orleans, LA (PI: M. Kaiser; Project Director: J. Herwehe)
  - Duke University, Durham, NC (PI: L. Messer)
  - Bronx-Lebanon Hospital Center, New York, NY (PI: T. Kanter)
  - City of Paterson, NJ, Ryan White Division (PI: C. Correa)
  - New York-Presbyterian Hospital, New York, NY (PI: P. Gordon)
  - St. Mary Medical Center Foundation, Long Beach, CA (PI: M Alcouloumre)

SPNS Initiative

- Cross-site evaluation center
  - Center for AIDS Prevention Studies, University of California, San Francisco (PI: J. Myers; Co-PI: W. Steward)

- HRSA-SPNS
  - A. Cajina, F. Malitz, R. Mills, M. Tinsley

SPNS Initiative

- Initiative is entering its 4th and final year

- Each site has implemented a bi-directional electronic health information exchange

- Evaluation includes
  - Quantitative surveys with patients
  - Quantitative surveys and qualitative interviews with users of the systems (e.g., providers)
  - Extraction of de-identified data from the systems

A collaborative project of:
LSU HCSD
DHH – Office of Public Health
Louisiana Public Health Institute

Funded in part by HRSA

Grant #H97HA08476

LaPHIE

- Secure bidirectional information exchange between the LSU public hospital system and the LA Office of Public Health (OPH)

- Purpose: to improve timeliness of disease reporting and access to care and treatment for persons with HIV, syphilis and tuberculosis

Who is targeted by LaPHIE?

- Only persons that OPH considers "not in care" for the targeted conditions.

- Those that have not received test results and are unaware of infection status

- Those that may have received results, but OPH has no laboratory or clinical info indicating monitoring or treatment

- Exposed infants in need of follow up

Disease Alert Component

HIV Special Needs Plans

- A Comprehensive Medicaid Health Plan licensed by NYSDOH

- For HIV Positive Adults and their children up to the age 21 regardless of HIV status

- Members receive Medicaid benefits

- Pharmacy and Dental Carved Out

- HIV Specialists as Primary Care Providers

- Member to PCP Ratio 350:1

- Universal Case Management

- Extensive Care Coordination and Community Collaboration

NewYork-Presbyterian System
SelectHealth

Specialty Network
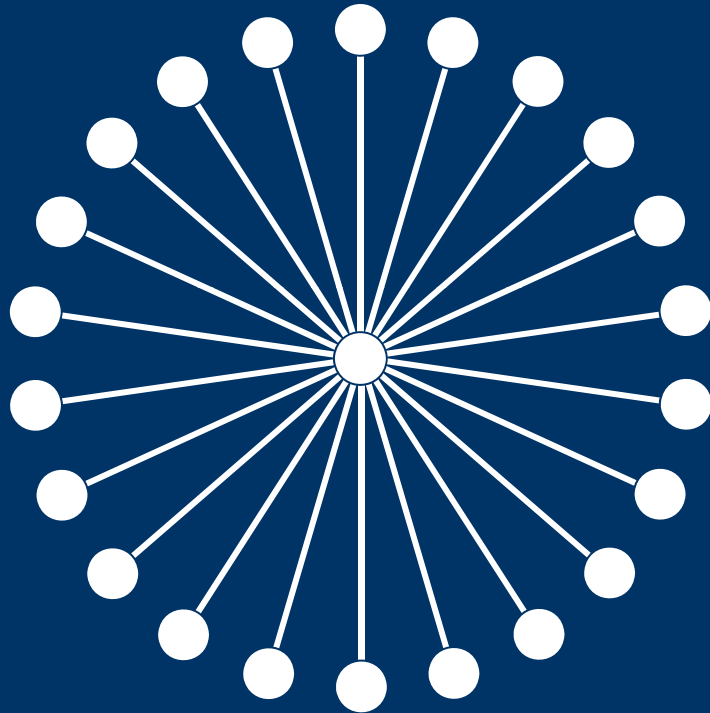
Allergy/Immunology
Anesthesiology
Cardiology
Colon Rectal Surgery
Dermatology
Endocrinology and
    Metabolism
Gastroenterology
General Surgery
Hematology/Oncology
Infectious Disease
Neonatal-Perinatal
    Medicine
Nephrology
Neurology
Neurological Surgery
Oncology
Ophthalmology
Optometry
Orthopaedics
Nephrology
Neurology
Neurological Surgery
Oncology

Ophthalmology
Optometry
Orthopaedics
Otolaryngology
Pediatric Surgery
Physical Medicine &
    Rehabilitation
Plastic Surgery
Podiatry
Pulmonary Medicine
Rheumatology
Thoracic Surgery
Urology
Home Health Care
Durable Medical
    Equipment
Community Based
    Organizations
Transportation
Behavioral Health
HIV Specialty Primary
    Care Providers
OB/GYN
Pediatrics

Member Services: 1-866-469-7774
http://www.nyp.org/selecthealth

SelectHealth   Primary Care Sites

Members (1417) PCP Sites

Top 15 sites as of 4/2010

Care Coordination, PLWH, and Continuity of Care Documents (CCDs)

Community Based Case Management

Pharmacies

Laboratories

Social Service Agency

Patient 'Centered' Care

Primary Care Site
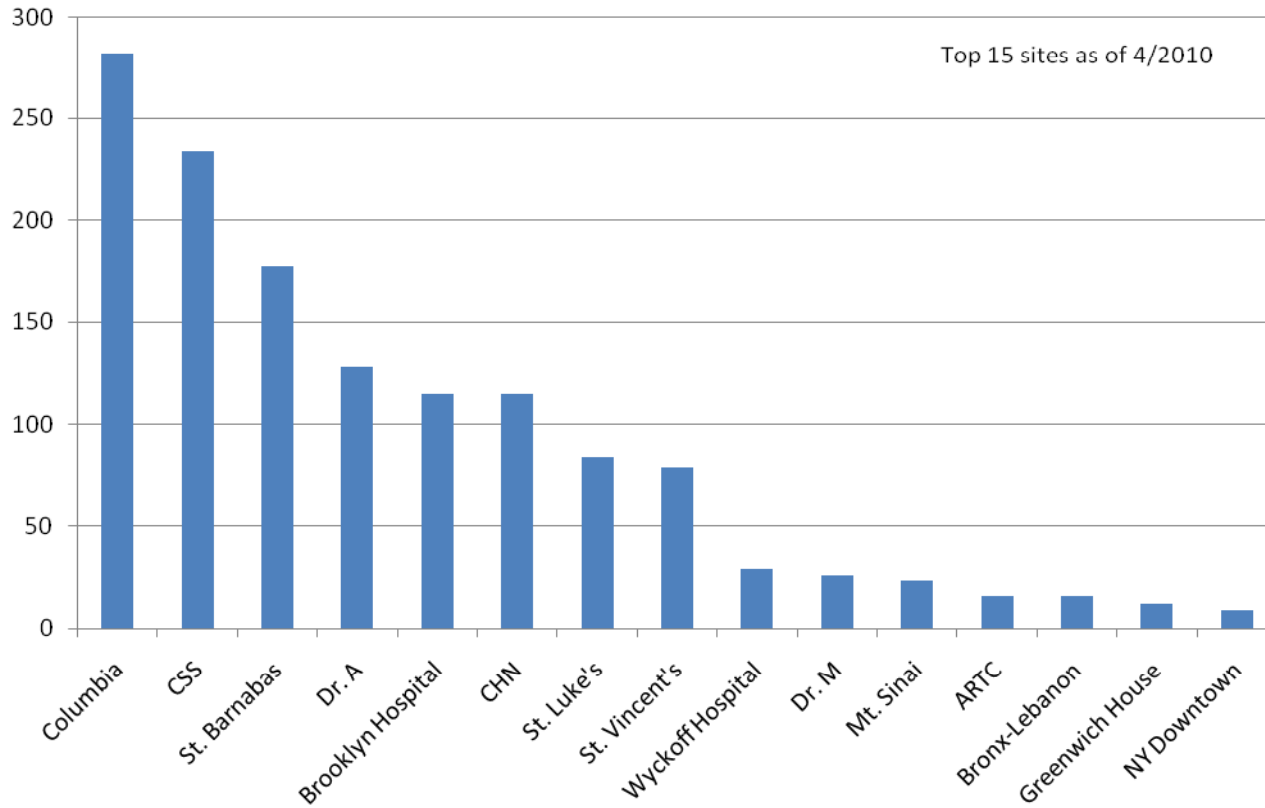
Hospitals
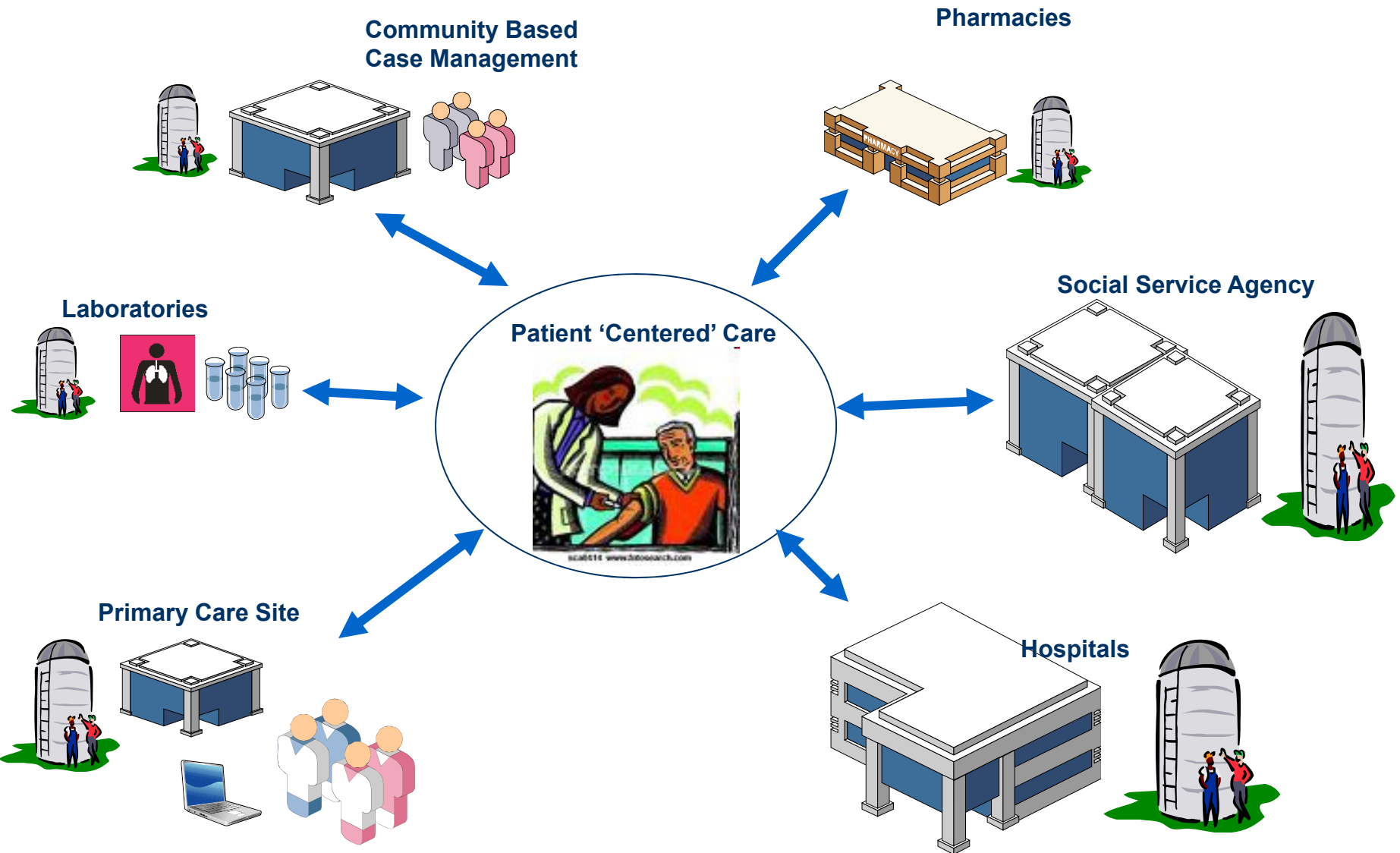
Potential Benefits of Sharing Patient Health Information
(Learning Objective 1)

Questions to Keep in Mind

- Do patients have a right to quality health care? If so, what does this mean?

- What are a patient's rights to privacy in terms of PHI?

- Is it OK to balance a patient's right to privacy with impact on his/her health and the collective wellbeing of individuals and communities?

- How does the current environment around HIV in your community (profile of epidemic, needs, legal climate) affect the balance between right to care and right to privacy?

Potential Benefits of Sharing Patient Health Information

- What are the possible benefits of sharing patient health information?

1. Improved Efficiency of Care

- Reduce duplication of services
  - Cost savings
  - Time savings

- Improve care outcomes
  - Provide the right information to the right clinician at the right time regardless of the venue where the patient receives care

2. Improved Coordination of Care

- Potential to track services received by patient from multiple providers in multiple care settings

- Help reorient the delivery of care around the patient

- Support quality-based reimbursement reform initiatives

3. Improved Facilitation of Care

- Exchange of health information is a cornerstone of patient-centered medical home models (e.g., NCQA Standards and Guidelines, 2005)

- Referrals and tracking can promote linkage to care

- Facilitate the work of patient navigators

- Ease patient burden when navigating health system

4. Enhanced Engagement of Patients

- Facilitate access to health records via patient portals

- User-friendly means of controlling dissemination of health records

- Systems can be used to obtain patient input
  - Self-reported information on symptoms, health conditions, aspects of treatment
  - Patient feedback on care

- Promote "Patient" → "Informed Consumer"

5. Improved Clinical Outcomes

- Better facilitation and better coordination of care may lead to better health outcomes

- Important note: improved health outcomes are a longer range (distal) outcome
  - Ability to effect a change in these outcomes will be influenced by patients' existing health outcomes (at the time a health information exchange system is implemented)

6. Improved Public Health Outcomes

- Facilitate linkages to public health departments, insurance companies, government entities that supply public funding for care
  - Potential to ease reporting requirements

- Enhance decision-making during public health emergencies

- May facilitate access and retention to care

Challenges to Sharing Patient Health Information
(Learning Objective 2)

Potential Challenges to Sharing Patient Health Information

- What are the challenges to sharing patient health information?

Challenge #1:
Perceived Legal Barriers

- Perhaps the single most pervasive perceived barrier

- The law that attracts the most attention is the Health Insurance Portability and Accountability Act (HIPAA)

Understanding Perceptions

- As part of cross-site evaluation, conducted 61 key informant interviews across the six demonstration sites
    - Project staff and IT specialists
    - Intended users of the health information exchanged systems

Perceptions of the Law

- Participants described the challenges of having to overcome institutional aversion to sharing data
  - Resistance more pronounced when academic or governmental entities involved

- Process to overcome concerns facilitated by:
  - Drafting, reviewing, re-drafting and approving formal data sharing agreements
  - Negotiating technical agreements among IT staff
  - Use of "off the shelf" products
  - Clarifying HIPAA

What HIPAA Actually Says

- The HIPAA Privacy Rule protects the privacy and security of an individual's health information held by a Covered Entity. 45 CFR sections 160, 164

- Without patient authorization, protected health information (PHI) may be used and disclosed for Treatment, Payment, and Operations (TPO) and certain other uses and disclosures without authorization from the patient.

- Any other use or disclosure of PHI must be authorized by the patient or conform to an exception permitted by HIPAA.

HIPAA-Related Definitions

- **Treatment:** The provision, coordination, or management of health care and related services among health care providers or by a health care provider with a third party, consultation between health care providers regarding a patient, or the referral of a patient from one health care provider to another.

- **Payment:** The activities of health care providers to obtain payment or be reimbursed for their services and of a health plan to obtain premiums, to fulfill their coverage responsibilities and provide benefits under the plan, and to obtain or provide reimbursement for the provision of health care.

HIPAA-Related Definitions

- **Health Care Operations:** Administrative, financial, legal, and quality improvement activities of a covered entity that are necessary to run its business and to support the core functions of treatment and payment.

(HIPAA summary courtesy of JS Kahn, UCSF evaluation team)

HIPAA: Perception vs. Reality

- Note that the perception of HIPAA and the realities of HIPAA may not be the same

- HIPAA regulates the sharing of PHI

- But special patient authorization is not required to share PHI when sharing is related to treatment, payment, or healthcare operations
  - Treatment, payment, and operations are at the core of many health information exchanges

Changing People's Perceptions of HIPAA

- *"The case just really needs to be driven home to them that really you can't use HIPAA to say we can't give you that information because of HIPAA…, HIPAA also provides what's allowed to be shared and under what circumstances it's allowed to be shared. And there seems to be an education issue for a lot of organizations that are providing care but try to use HIPAA in a sense as a weapon to not share data when in actuality they can and they're allowed to. But they always fall back on, 'We can't tell you that because of HIPAA.'"* --Project Director

Challenge #2: Perceived Patient and Provider Resistance

- When the SPNS Initiative was under development, patient and provider attitudes were considered a major barrier to sharing information
  - Carmen & Britten, 1995; McAlearney et al., 2006; Mitchell & Sullivan, 2001; Risdale & Hudd, 1994

- But data from the Initiative suggests that attitudes are evolving

Assessing Patient Beliefs

- Quantitative survey with convenience sample of 550 patients drawn from the six sites

- Patients asked to indicate their willingness to allow personal health information to be shared electronically
    - Responses ran along a 5-point scale
    - 5 = most willing to share
    - 1 = least willing to share

Patient Beliefs
About Sharing Health Information

Bar chart: Willingness to Share Electronically (scale 1 to 5)

- Primary Provider: ~4.3
- Other Clinicians: ~4.1
- Other HC Provider: ~3.9
- Pharmacists: ~3.8
- Non-HIV Specialists: ~3.6
- Non-clinical Staff: ~3.1
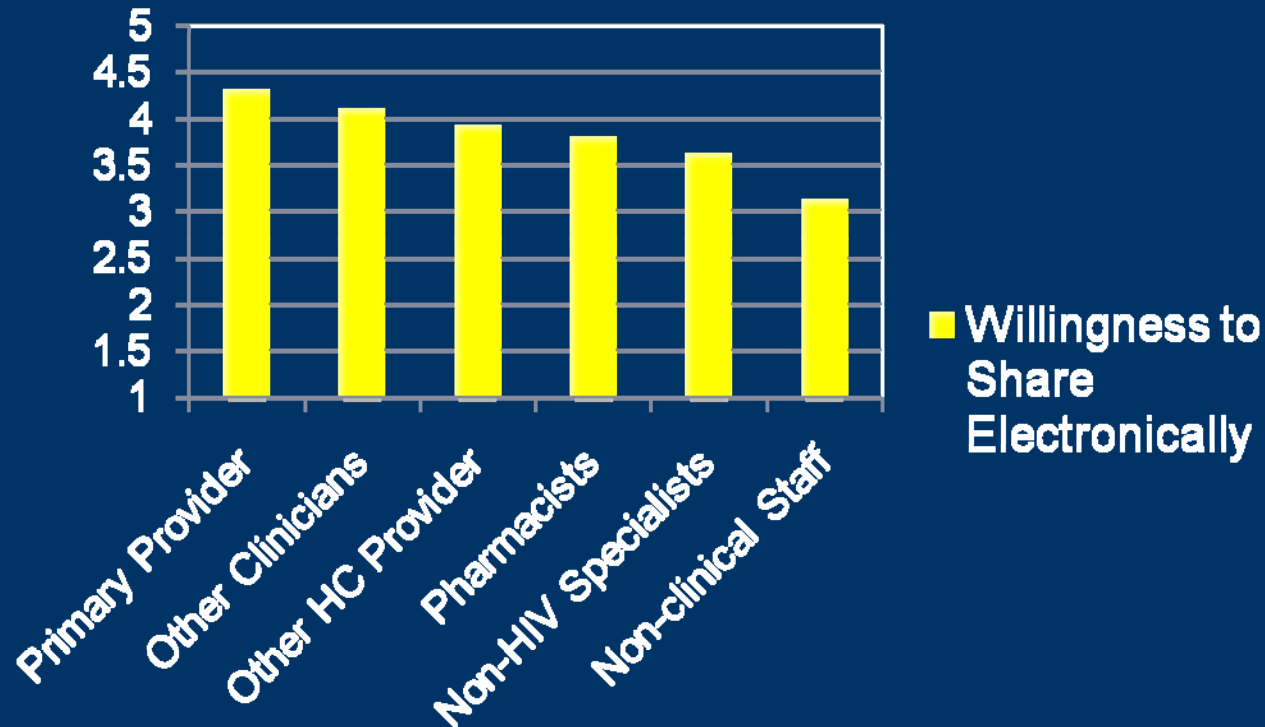
Patient Beliefs
About Sharing Health Information
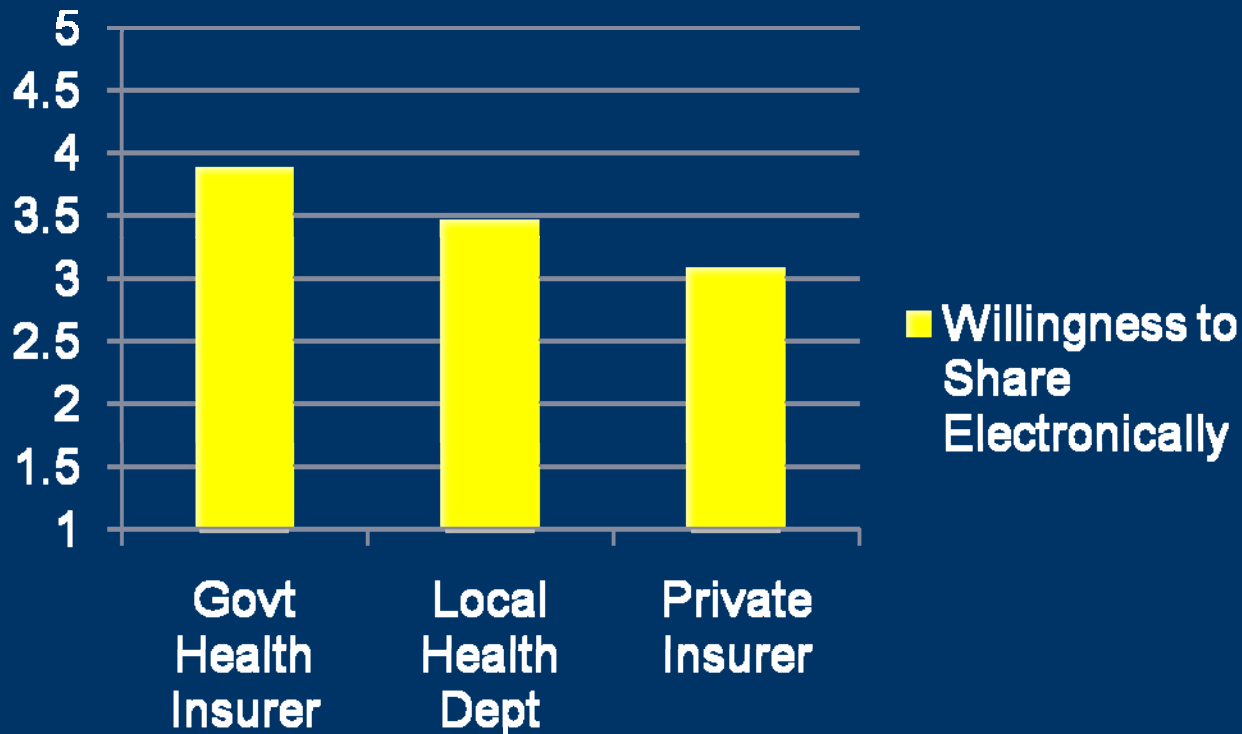
Provider Perceptions of Patient Attitudes

- Findings from qualitative interviews complemented findings from the patient survey

- *"Regarding electronic mistrust issues….we've kind of progressed over the past 5 or 6 years to using our electronic, internal electronic medical record system a lot more and so patients are very used to seeing people typing. You know as soon as you show up things are going into computers and you know you get your blood pressure taken it goes right into the computer and we print out, like all prescriptions are electronic and we usually are using the computers while we're talking to people so my guess is that some of that's not as much of an issue as it has been in the past."*

--Medical Director

Provider Attitudes About Sharing Information

- *"I think the information that is provided to that agency, and the agency acts in the best interest of the patient, without revealing any information that is not necessary to any people who don't need to know that information, I don't see any ethical concerns there….I don't think – the programs don't define ethics. I think it's the people who are gonna use [the system] – as long as the people know it's exclusively keeping privacy of the patient, going to be used for the betterment of the patient, I think those ethical values are fine, ethics are fine. But I think if you're going to use information in order to distort or damage or do something, then no matter what it is, then it's not ethical. So I think it's – it's not an ethical concern, the program is not. I think it's human beings who will decide how to use that."*   --Medical Provider

Other Challenges

- Providers must learn new systems
  - Provider training is an inevitable part of implementing any new system

- Need for IT experts to implement and maintain electronic systems
  - Financial cost
  - IT experts at different institutions must learn to work together

Balancing Risks Vs. Benefits

- There is no one right answer. But in thinking through the issue for any given system, it is helpful to keep in mind:
    - What does it mean for a patient to have a right to quality health care?
    - What are a patient's rights to privacy in terms of PHI?
    - Is it OK to balance a patient's right to privacy with impact on his/her health and the collective wellbeing of individuals and communities?
    - How does the current environment around HIV in your community (profile of epidemic, needs, legal climate) affect the balance between right to care and right to privacy?

Eliciting Support for Two Electronic Health Information Exchanges (Learning Objective 3)

Fundamental LaPHIE Question

- We identified an electronic solution, we had the technology to electronically share information between public health and health care providers, but should we exchange info for this purpose?

- Understanding stakeholder (consumer and provider) opinion on the proposed use of public health information and mechanism for sharing was

Network Partners and Governance Structure
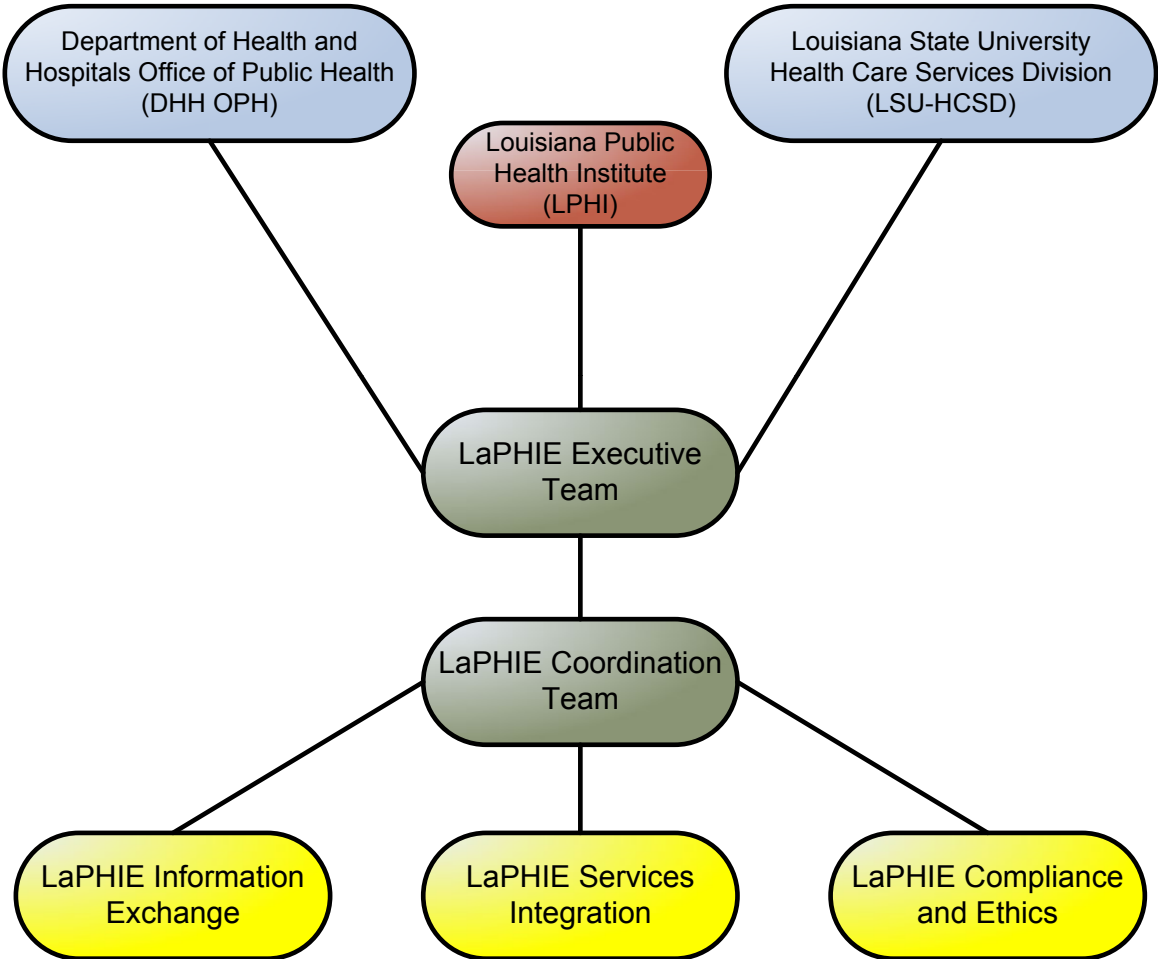
Process

- Compliance and Ethics workgroup formed and tasked with a legal and ethics review

- Workgroup accomplishments:
  - Completed inventory/review of all Federal and State legislation
  - Completed consumer focus group discussions and key informant interviews of acceptability
  - Discussed LaPHIE with national experts in confidentiality and biomedical ethics

Two Qualitative Studies

- 16 focus group discussions (FGD)
  - 149 persons in rural (8) and urban (8) Louisiana
  - *broader than LaPHIE, but inclusive of concepts*

- 23 Key informant interviews (KII) of some initial FGD and follow up questions with individuals diagnosed with HIV or STD and matched controls from the Greater New Orleans area *(LaPHIE specific)*

- Findings were used to frame questions and inform legal and ethical discussions on the electronic exchange of healthcare information

FGD and KII Conclusions…

- There was near universal agreement that public health officials and healthcare providers should work together to make sure people obtain their diagnoses and treatment.

- Many view the partnership as a good way for the public to get the help they need, especially if they are out of care, and hard to reach.

- Consumers had preferences about extent of sharing and how information should be protected and communicated.

Outcomes

- Development of position paper supporting LaPHIE
  - Legal analysis related to situations that may occur when public health information is exchanged

- Several Federal and State laws permit collaboration of public health and health care providers for persons with HIV, TB or syphilis

- Documentation of consumer acceptability on sharing of health information supporting project purpose

Conclusions

- State and Federal law (HIPAA) and an ethics review support the mission of LSU and OPH to protect individual/population health and can facilitate electronic information sharing

- Consumers interviewed support intended purpose of LaPHIE and partners should stay true to the project purpose – improve awareness and linkage to care

- Privacy and confidentiality paramount for individuals with stigmatizing conditions and should be protected

Conclusions (cont'd)

- Providers legally required and ethically obligated to protect individual privacy by assuring that all information is shared in the most confidential manner

- Fear of privacy violations should not override legitimate public health objectives or an individual's health

- With over 300 LaPHIE messages issued to date, consumer response received has been positive

Ongoing Evaluation
Post LaPHIE patient interviews

- To date, 9 completed interviews w/ LaPHIE identified patients (Preliminary Qualitative Results)

- Satisfaction with LaPHIE encounter

  6 positive responses to provider handling of LaPHIE message

  3 – no specific comment on recent LaPHIE notice/interaction

- What helped patients come back:

  Reminder calls (3), staff answer questions (2), trust in staff (1), staff allayed fears (2), staff concerned, caring, respectful, knowledgeable (4)

Provider conveyed comments (unsolicited)

- 3 positive – patient glad or appreciative of provider knowing HIV status and linking patient to care

- 1 negative – patient upset, but not specifically with sharing of HIV message, rather with long wait in the ED then having to do medication reconciliation as well as discuss all health issues (inc HIV) rather than the 1 complaint that brought patient to the ED

NewYork-Presbyterian System

SelectHealth

HRSA Special Projects of National Significance
Information Technology Networks of Care Initiative (2007-2011)

My Health Profile: a Member *Continuity of Care Document* (CCD)*

Core Elements of CCD
- CCD Identifying Information
- Patient's Health Status
    - Diagnoses
    - Medications
    - Laboratory results
    - Procedures/Imaging
    - Allergies/adverse reactions
    - Social history/Family history
- Advanced Directives/Life Documents
- Care Documentation

- Practitioners

Offers patients and providers access to key elements of their clinical, psychosocial, and administrative record over a secure, web-based portal.   For more information email pgg2@columbia.edu or call 212-305-3272

PI **-** Peter G. Gordon, MD

Co-PI - Eli Camhi, MSSW
Ron Hesse, Project Coordinator
Suzanne Bakken, RN, DNSc, Evaluator

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https://selecthealth.onfile.com/Member/Show/10008905

Most Visited | Windows Marketplace

NewYork-Presbyterian

NewYork-Presbyterian System
SelectHealth

LogOut | Change Password
Login ID: PeterGordon
[Admin]
Previous Login: 8/12/2009 11:45:36 AM

My Health Profile

Home   Members   Providers   Admin   Business Associates

Member Info (View)
12345A
Temporary Membership
Card
Active
Member Admin
Audit Log
Deactivate Member
New EPin
New Password
Temporary Logins
Upload CCD
Download CCD
Last Modified: 4/22/2009

My Health Profile for Demo Member1

Patient Detail

Name:	Demo Member1	Date of Birth:	01-01-1971
Address:	123 Test St.	Gender:	Male
	New York, NY 10036		

Health Care Providers

Role	Name	Organization	Phone
Case Manager	Iris Gutierrez	Columbia Presbyterian HIV Program	(212) 305-3174
PCP	Gordon, Peter	Columbia Presbyterian Program	(212) 305-3174 (Primary) or (212) 305-2985 (After Hours)
COBRA		Dennelisse Corporation	(212) 265-1480

Problems

Condition	Effective Dates	Condition Status
HIV/CDC AIDS	2/2003	Active
Diabetes Mellitus	5/2005	Active
Depression	1/2006	Active
Hypertension	8/2006	Active
Acute Myocardial Infarction	8/2006	Resolved

Allergies, Adverse Reactions, Alerts

Substance	Reaction	Status
Penicillin	Hives	Active
Codeine	Nausea	Active

Medications

Medication	Filled	Quantity	Days Supplied	Order Date	Ordered By
NORVIR 100 MG SOFTGEL CAP	11/8/2008	30	30	7/7/2008	Gordon, Peter
ALBUTEROL 90 MCG INHALER	10/28/2008	17	25	10/6/2008	Gordon, Peter
FLUTICASONE 50 MCG NASAL SPRAY	10/28/2008	16	25	10/6/2008	Gordon, Peter
REYATAZ 150 MG CAPSULE	10/28/2008	60	30	7/7/2008	Gordon, Peter
TRICOR 145 MG TABLET	10/28/2008	30	30	7/7/2008	Gordon, Peter
TRUVADA TABLET	10/28/2008	30	30	7/7/2008	Gordon, Peter
ZETIA 10 MG TABLET	10/28/2008	30	30	7/7/2008	Gordon, Peter
METFORMIN HCL 850 MG TABLET	10/28/2008	90	30	7/7/2008	Gordon, Peter
ACTOS 15 MG TABLET	10/28/2008	30	30	7/7/2008	Gordon, Peter
LISINOPRIL 40 MG TABLET	10/28/2008	30	30	10/6/2008	Sawo, Dorothy
RANITIDINE 150 MG TABLET	10/28/2008	60	30	10/6/2008	Gordon, Peter
TACTINAL 500 MG TABLET	10/28/2008	100	33	9/29/2008	Gordon, Peter
GLIPIZIDE 10 MG TABLET	10/28/2008	120	30	10/28/2008	Gordon, Peter
ACETASOL HC EAR DROPS	10/26/2008	20	10	10/26/2008	Burnett, Michael
NORVIR 100 MG SOFTGEL CAP	10/15/2008	30	30	7/7/2008	Gordon, Peter
CLOTRIMAZOLE 1% SOLUTION	10/6/2008	30	15	5/19/2008	Weitz, Alan
RANITIDINE 150 MG TABLET	10/6/2008	60	30	10/6/2008	Gordon, Peter
LISINOPRIL 40 MG TABLET	10/6/2008	30	30	10/6/2008	Sawo, Dorothy
TRIAMCINOLONE 0.1% CREAM	10/6/2008	15	8	5/19/2008	Weitz, Alan
ACTOS 15 MG TABLET	10/6/2008	30	30	7/7/2008	Gordon, Peter
METFORMIN HCL 850 MG TABLET	10/6/2008	90	30	7/7/2008	Gordon, Peter
ZETIA 10 MG TABLET	10/6/2008	30	30	7/7/2008	Gordon, Peter
TRUVADA TABLET	10/6/2008	30	30	7/7/2008	Gordon, Peter
TRICOR 145 MG TABLET	10/6/2008	30	30	7/7/2008	Gordon, Peter
REYATAZ 150 MG CAPSULE	10/6/2008	60	30	7/7/2008	Gordon, Peter
GLIPIZIDE 10 MG TABLET	10/6/2008	60	15	7/7/2008	Gordon, Peter
FLUTICASONE 50 MCG NASAL SPRAY	10/6/2008	16	25	10/6/2008	Gordon, Peter
ALBUTEROL 90 MCG INHALER	10/6/2008	17	25	10/6/2008	Gordon, Peter
TACTINAL 500 MG TABLET	9/29/2008	100	33	9/29/2008	Gordon, Peter
OFLOXACIN 0.3% EAR DROPS	9/26/2008	10	10	9/26/2008	00246707
GLIPIZIDE 10 MG TABLET	9/23/2008	60	15	7/7/2008	Gordon, Peter
NORVIR 100 MG SOFTGEL CAP	9/17/2008	30	30	7/7/2008	Gordon, Peter
GLIPIZIDE 10 MG TABLET	9/2/2008	60	15	7/7/2008	Gordon, Peter
REYATAZ 150 MG CAPSULE	9/2/2008	60	30	7/7/2008	Gordon, Peter
TRICOR 145 MG TABLET	9/2/2008	30	30	7/7/2008	Gordon, Peter
TRUVADA TABLET	9/2/2008	30	30	7/7/2008	Gordon, Peter
ZETIA 10 MG TABLET	9/2/2008	30	30	7/7/2008	Gordon, Peter
METFORMIN HCL 850 MG TABLET	9/2/2008	90	30	7/7/2008	Gordon, Peter
ACTOS 15 MG TABLET	9/2/2008	30	30	7/7/2008	Gordon, Peter
LISINOPRIL 40 MG TABLET	9/2/2008	30	30	4/11/2008	Sawo, Dorothy
RANITIDINE 150 MG TABLET	9/2/2008	60	30	4/11/2008	Gordon, Peter

Done

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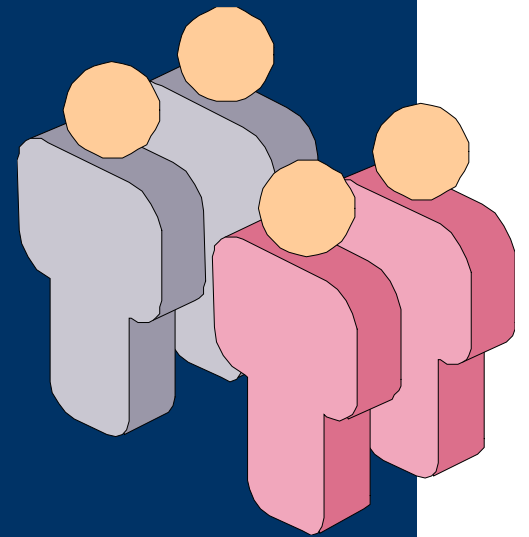
SelectHealth

My Health Profile Implementation

- 2,185 CCDs posted as of August 2010

- 291 patient users have logged in >1129 times

- Each has received an *Internet 101* and *My Health Profile* training session, unique passwords, and emergency access cards

- 102 Clinicians and 52 COBRA Case Managers have logged in > 282 times

HIV Patients' Willingness to Share Personal Health Information Electronically

I am willing to allow my personal health information to be shared with:-- -_____using a secure electronic network.	Strongly Agree or Agree	Neither Agree nor Disagree	Disagree or Strongly Disagree
My primary HIV care provider (e.g., physician, NP, PA)	86%	9%	5%
Other clinicians in the clinic of my primary HIV care provider (e.g. nurses)	78%	10%	12%
Other health care providers (e.g. emergency or hospital personnel)	78%	11%	11%
Non-HIV specialists (e.g. cardiologists, ob/gyn)	72%	9%	19%
Other health care providers (e.g. emergency or hospital personnel)	78%	11%	11%
Pharmacists	63%	22%	15%
HIV support service organizations (e.g., case managers)	74%	14%	12%
Other, non HIV-specific support service organizations (e.g., drug treatment programs, mental health services)	51%	32%	17%
Private health insurers	40%	31%	19%
Government health insurers (Ryan White funding; ADAP; Medicare; Medicaid)	63%	22%	15%
The local health department	53%	29%	18%
Other non-clinical staff in the clinic of my primary HIV care provider (e.g. receptionist/manager)	39%	13%	48%

Where is this headed?
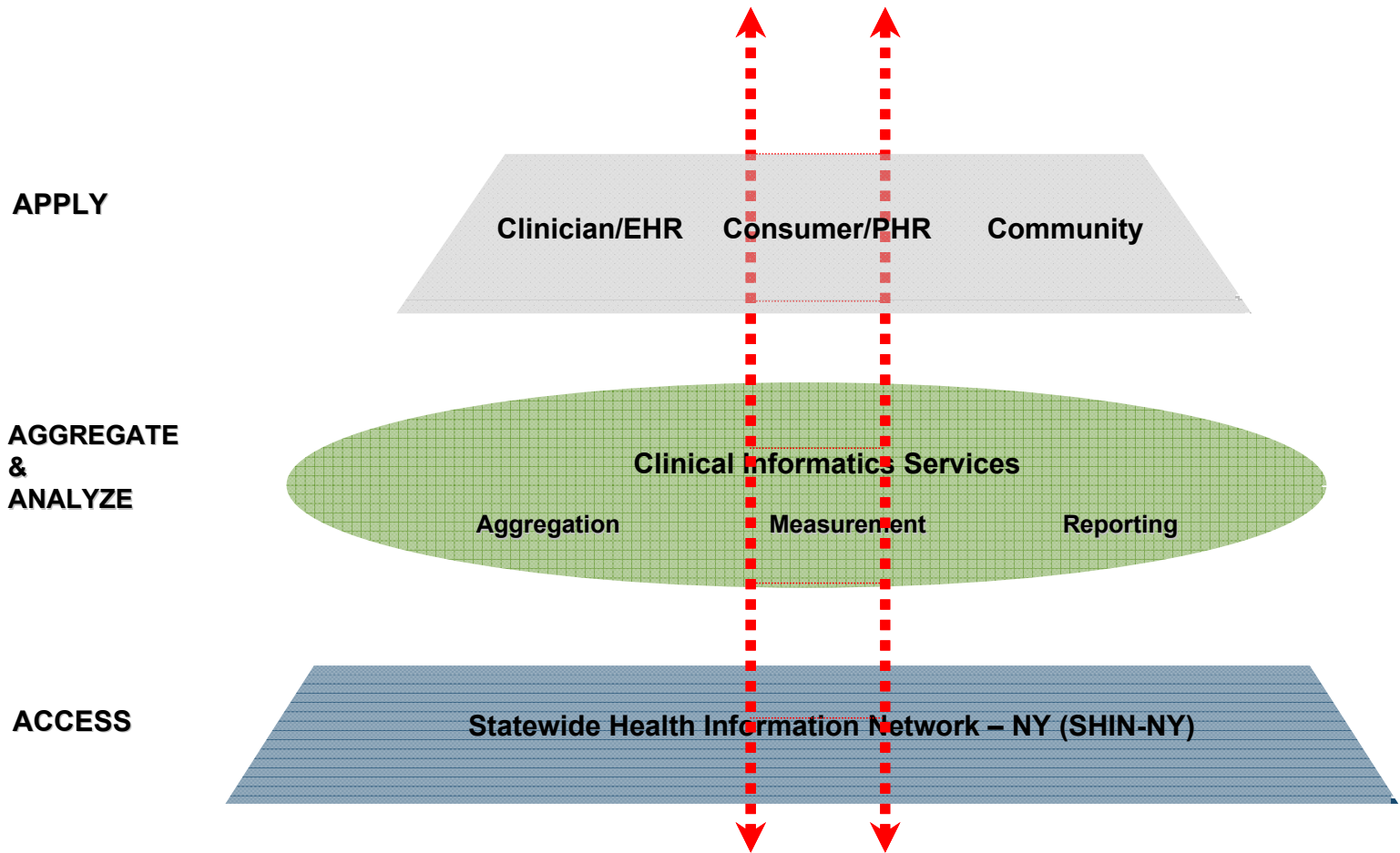

The Nationwide Health Information Network
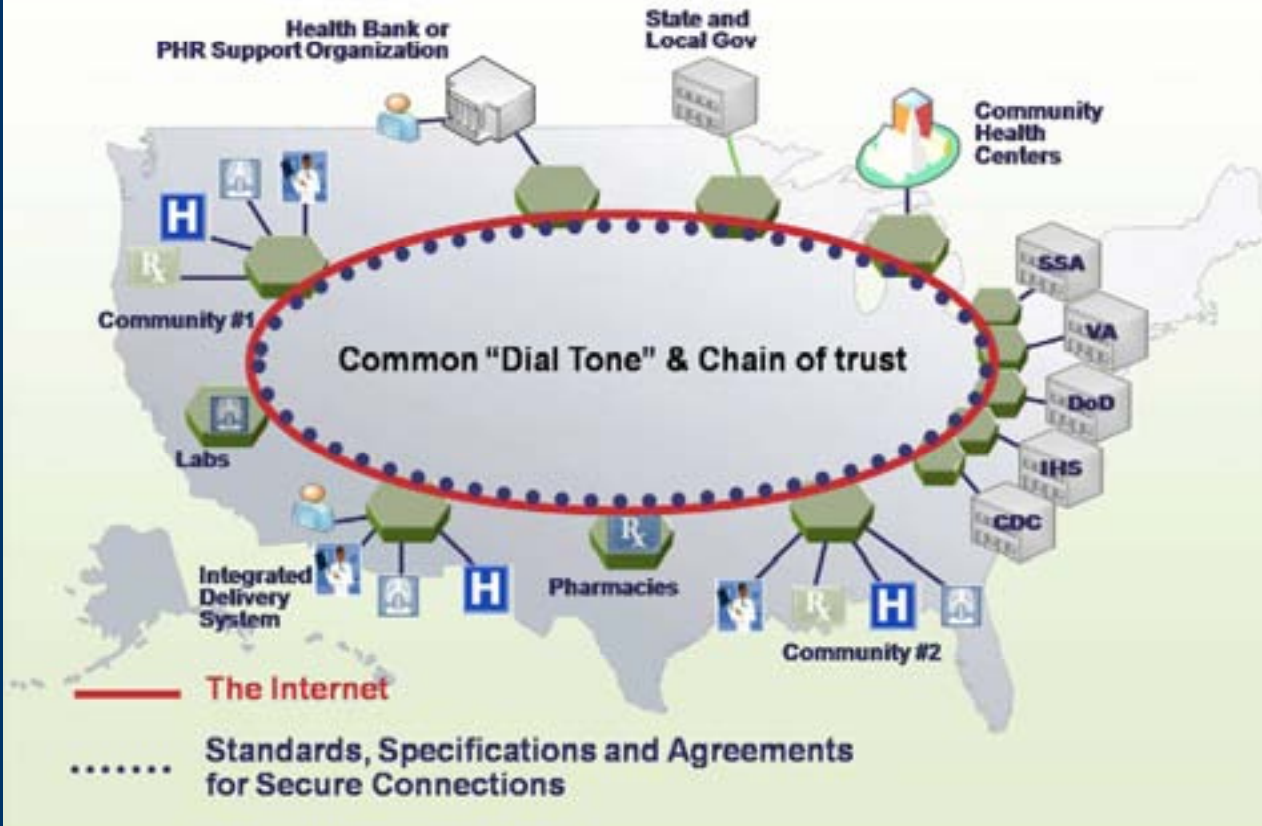
Framework for New York's
Health Information Infrastructure

"Cross-Sectional" Interoperability − People, Data, Systems

APPLY

Clinician/EHR   Consumer/PHR   Community

AGGREGATE & ANALYZE

Clinical Informatics Services

Aggregation   Measurement   Reporting

ACCESS

Statewide Health Information Network – NY (SHIN-NY)

The SHIN-NY

Public Health

CDC

Biosurveillance

Medicaid

Other NYS DOH Databases

Immunization and Child Health

Multiple RHIOs*

SHIN-NY**

NYS DOH UPHN

NYC Health Dept.

Local Health Depts.

Diagnostic Centers

Patient Centric

SHIN-NY**

Home Health Care and Telemedicine

Patients' Personal Health Records

Pharmacies and PBMs

Managed Care

Physicians Offices and Clinics

Hospitals, Nursing Homes, IDNs, etc

*RHIOs = Policy
**SHIN-NY = Technology

New York State's Vision

NYCLIX Data Elements by Member
As of February 2010

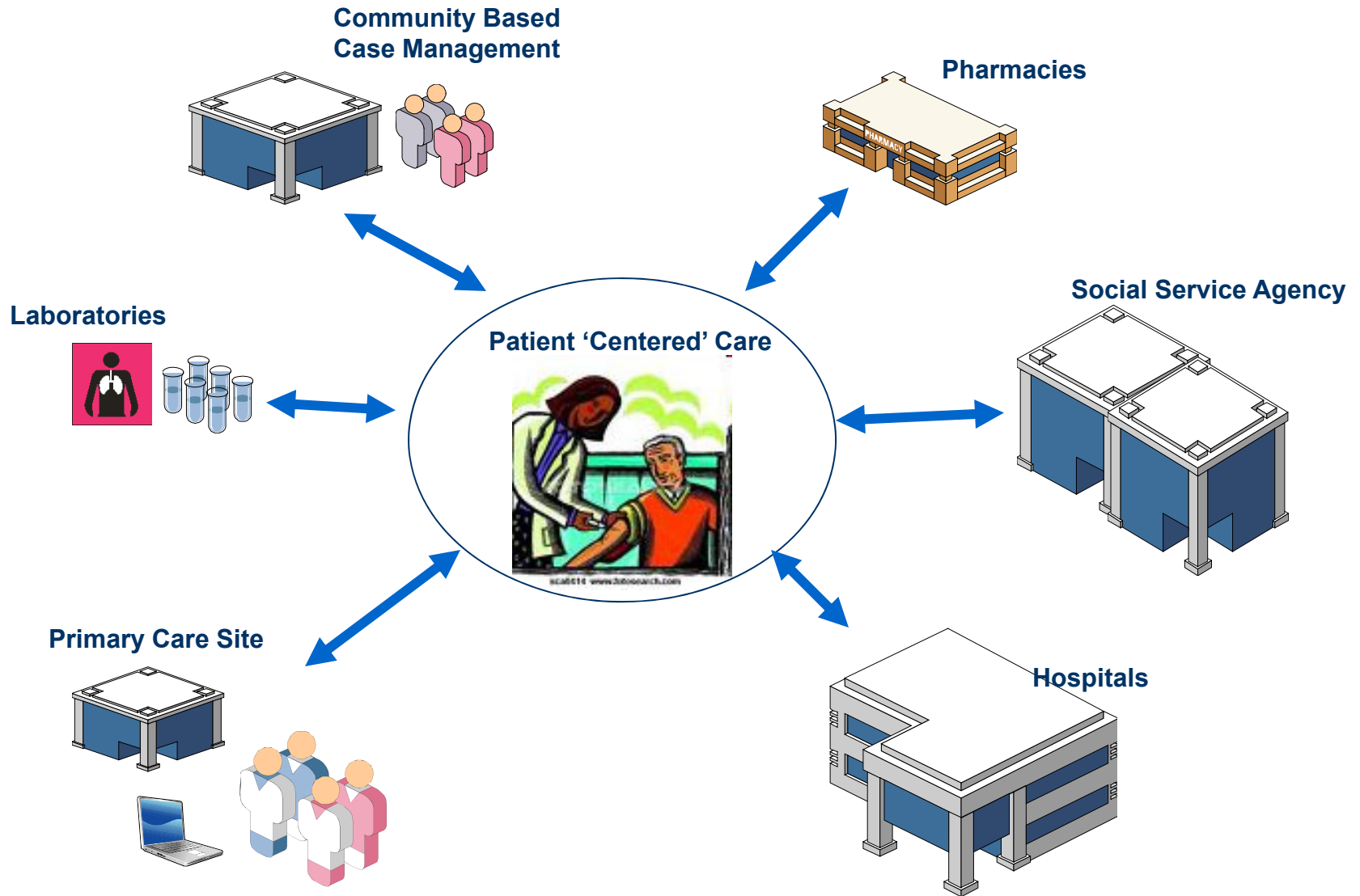| Data Elements	CHP-BI	CHP-SLR	IFH	NYU	MSMC	SVMC	SIUH	SUNY	VNSNY
Registration	✓	✓	✓	✓	✓	✓	✓	✓	✓
Allergies				✓		✓	✓	✓	✓
Diagnoses	✓	✓	✓	✓	✓	✓	✓	✓	✓
Procedures	✓	✓	✓	✓		✓	✓	✓	✓
Laboratory	✓	✓		✓	✓	✓	✓	✓	✓
Radiology	✓	✓		✓	✓	✓	✓	✓	✓
Pathology	✓	✓		✓	✓	✓	✓	✓	
Cardiology			✓	✓	✓	✓	✓		
Endoscopy	✓	✓		✓			✓		
Medications									✓
EKG Reports							✓		
Discharge Summaries				✓					
Immunizations			✓						
Vital Signs	✓			✓			✓		
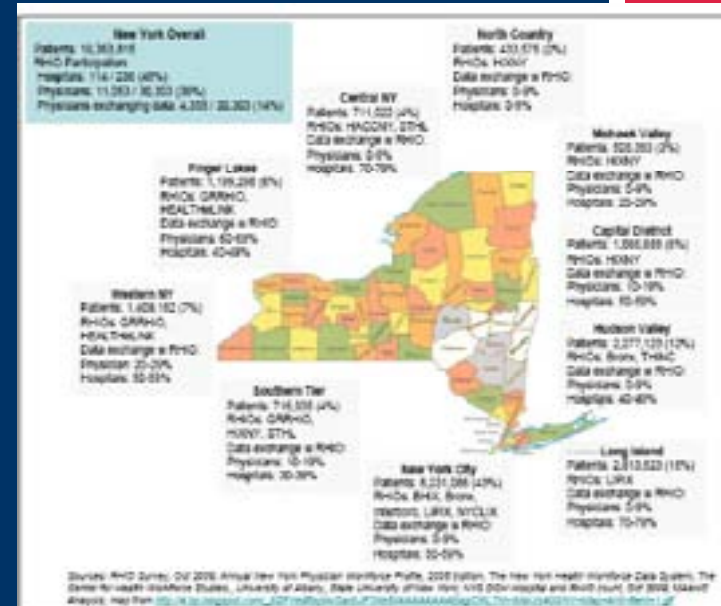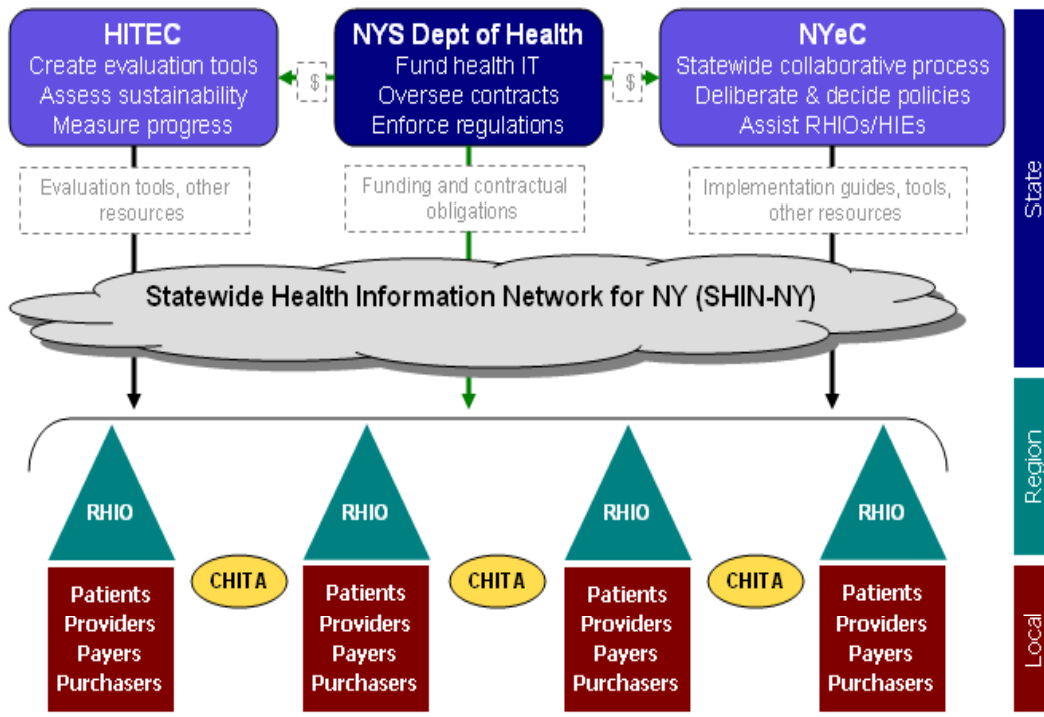
NYS RHIO Consent – basic principals

- If a patient grants consent to participate, they have a right to prohibit provider organizations of their choice to access their PHI

- The patient consent permits provider organization access to PHI for treatment, quality improvement and disease management

- The patient consent permits health plans, employers and other third parties access to PHI for quality improvement and disease management

- Provider organization can then access all PHI, including sensitive information from all providers participating in interoperable HIE

- Patient is informed about all participating providers in the RHIO and how updates to the participant list can be obtained

- Patient gives consent at the provider organization level and allows access to patient's PHI by all authorized individuals in the organization to the extent needed

- Uses are limited to treatment, quality improvement and disease management

- Any New Yorker has the right to not participate in interoperable HIE enabled by the RHIO

Care Coordination, PLWH, and Continuity of Care Documents (CCDs)

Community Based Case Management

Pharmacies

Social Service Agency

Laboratories

Patient 'Centered' Care

Primary Care Site

Hospitals

Balancing Risks vs. Benefits

- Electronic Health Information Exchanges can successfully balance patients' right to quality health care and patients' right to privacy of medical information.

- Where is the right balance in your community?