

Consent Focus Group:

Understanding What Factors Are Most Important To Make Informed Consent Decisions

APP Design Team 2012 Patient Focus Groups
Supporting U.S. Department of Health and Human Services
eConsent Trials Contract # HHSP23320110023WC

OMB Approval: XXXXXXXXXX



Our Goal Today

We want to better **understand what information you need so you can make informed decisions** about providing others access to your health information.

Our Agenda for the Next Hour

15 Minutes: Introduction to Consent and How Health Care Professionals and Health Care Payers might electronically access your Health Care Information

40 Minutes: Group discussion

5 Minutes: Wrap up and thank you

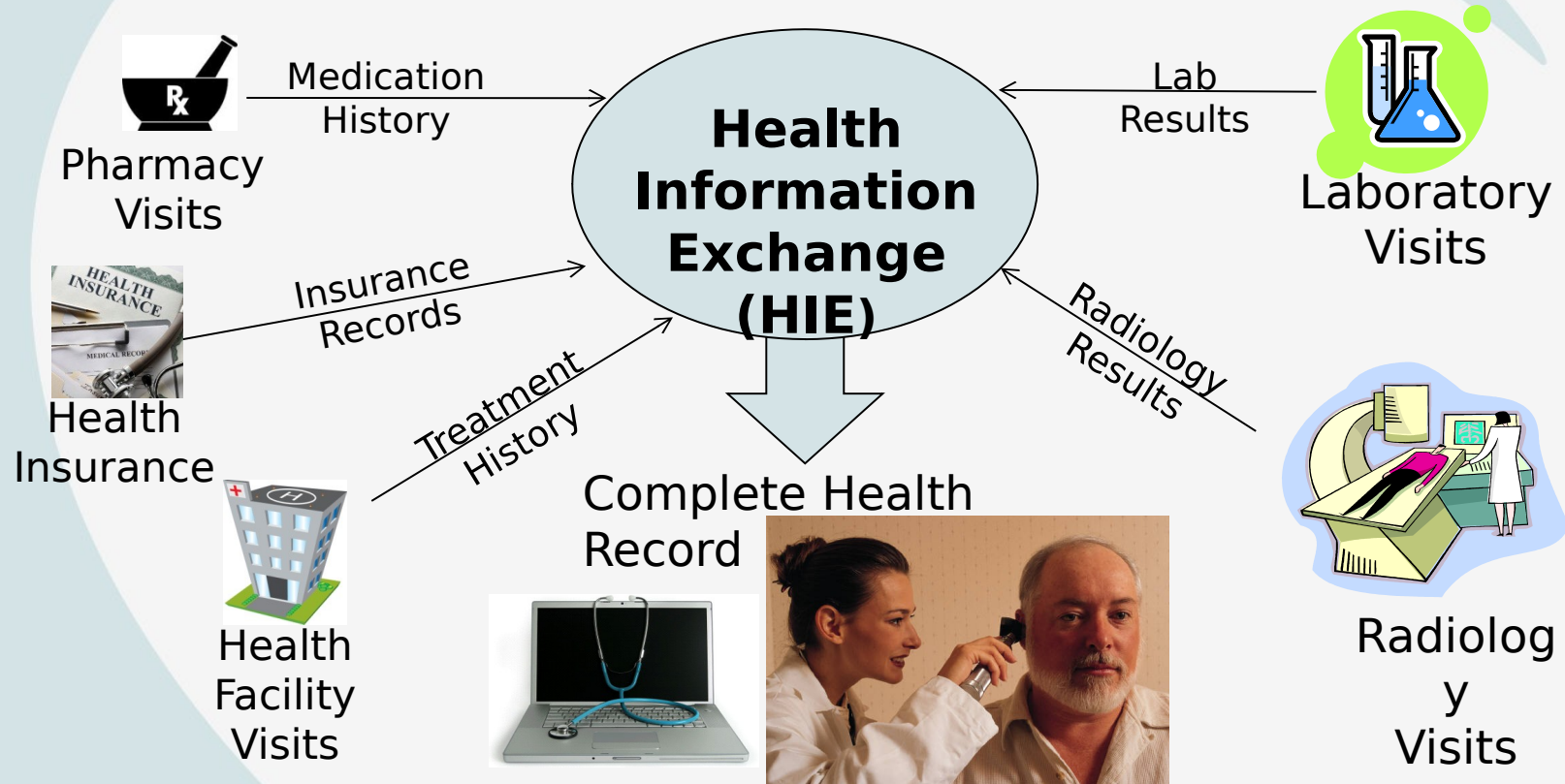
About Us

- U.S. Department of Health and Human Services contracted the APP Design Team **to develop Consent educational materials and technology**
- We are conducting focus groups with New Yorkers (YOU!) to help us identify **what Consent topics are most important to you**
- The results of the focus groups will **help us to develop better Consent educational materials and technology**

FACILITATOR 1
PHOTO AND NAME

FACILITATOR 2
PHOTO AND NAME

How Might My Health Care Information Be Electronically Collected and Accessed?



In most cases within New York, sharing your Health Care Information requires your written consent

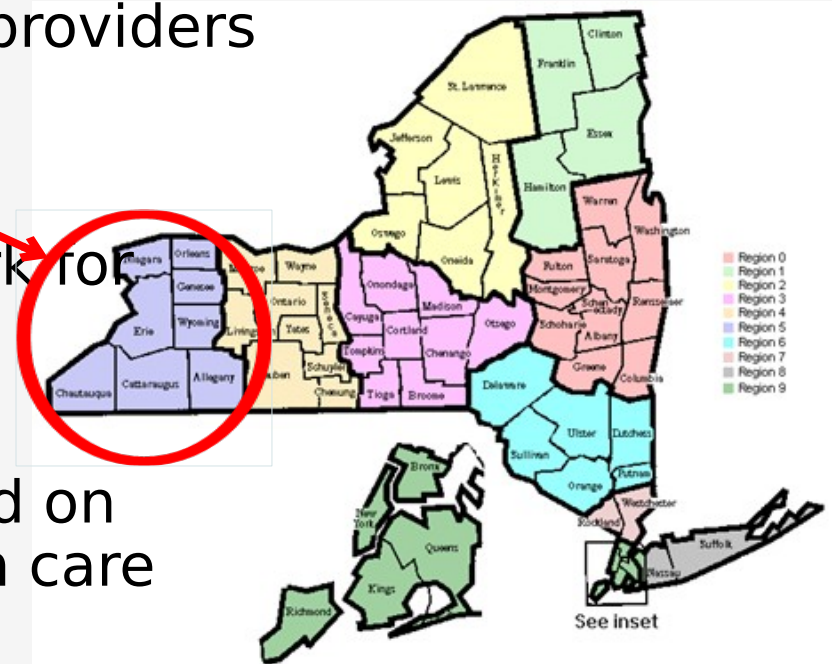
Who is My Health Information Exchange?

HEALTHeLINK is the **H**ealth **I**nformation **E**xchange (HIE) for Western New York

- Collaborates with health care providers in Western New York

- Provides a safe, secure network for exchange of data

- Non-Profit organization focused on improving the quality of health care



In this Area, Health Information Exchange Participants Include:

Hospitals	Radiology Centers	Labs
• Kaleida Health System	• Windsong	• Quest
• Catholic Health System	• Spectrum Radiology	• X-Cell Laboratories
• ECMC	• Southtowns Radiology	• Genetic Diagnostic Laboratories
• Roswell Park Cancer Institute	• Buffalo MRI	
• Niagara Falls Memorial	• Diagnostic Imaging	
• WCA (Jamestown)		
• Mt. Saint Mary's		
• United Memorial Medical Center		
• Upper Allegheny Health System (Olean)		
• Brooks Memorial		

New participants are added each month



What Parts of My Health Care Information Might Be Electronically Accessible?

- Diagnosis
- Health history
- Laboratory tests
- Radiology reports and images
- Medication history
- May include Sensitive Personal Health Information such as:
 - Alcohol or drug abuse problems
 - Genetic diseases or tests
 - HIV/AIDS
 - Mental health conditions
 - Birth control and abortion
 - Sexually transmitted infections



Legal Considerations

- Storing, transmitting and accessing patient Health Care Information is subject to specific requirements and guidelines:

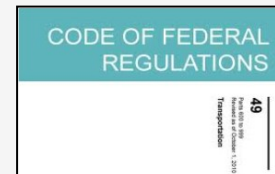
- Statutes



- Laws



- Regulations



- Policies



... at the Federal, State, and Local levels

Consent is a very complex topic!

Who Might Have Access to My Health Care Information?

- Health Care Providers, Health Insurance Payer Case Managers, and Health Insurance Payer Disease Management Nurses may access your information:

➤ IF you have given permission and they are directly involved in your care,

OR

➤ In the event of a medical emergency, unless you have specifically denied medical emergency access.

Important Note: The only Health Care Payer personnel that can see your Health Care Information through HEALTHeLINK are Case Managers and Disease Management Nurses.

What are My Health Care Information Sharing Consent Options?

- **Yes:** I give consent for all Participants who are involved in my care to access ALL of my electronic health information through HEALTHeLINK.
- **Yes/Except:** I give consent for all Participants who are involved in my care to access ALL of my electronic health information through HEALTHeLINK EXCEPT the following Participants (Participants Name/Address to be listed by patient).
- **No/Except:** I deny consent for all Participants who are involved in my care to access my electronic health information through HEALTHeLINK for any purpose, EXCEPT *in a medical emergency*.
- **No/Never:** I deny consent for all Participants who are involved in my care to access my electronic health information through HEALTHeLINK for any purpose

Focus Group Discussion



Placeholder graphic

THANK YOU FOR YOUR TIME!

Your support *TODAY* will help us build
better educational material and
technology
to enable informed consent decisions
TOMORROW



BACKUP SLIDES



References - Acronyms

Acronym	Definition
ECMC	Erie County Medical Center
HIE	Health Information Exchange
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
MRI	Magnetic Resonance Imaging
WCA	Women's Christian Association (Hospital in Jamestown, NY)



References - Links to Additional Information

For additional information on the following topics, please refer to the links provided:

- General Information on Federal Laws, Regulations, and Guidance Related to Health Information
 - http://healthit.hhs.gov/portal/server.pt/community/healthit_hhs_gov_regulations_and_guidance/1496
 - <http://www.healthit.gov/patients-families/protecting-your-privacy-security>
- Health Insurance Portability and Accountability Act (HIPAA) of 1996
 - <http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/index.html>
- Health Information Technology for Economic and Clinical Health (HITECH) Notice of Proposed Rule
 - <http://www.hhs.gov/ocr/privacy/hipaa/administrative/enforcementrule/hitech-enforcementifr.html>



References - Links to Additional Information

For additional information on the following topics, please refer to the links provided:

- New York State Statutes/Policies Related to Personal Health Information
 - http://www.health.ny.gov/technology/statewide_policy_guidance.htm
 - http://www.nyehealth.org/images/files/File_Repository16/heal5/PrivSec_PPs_V2.pdf
- HEALTHeLINK Information and Policies
 - <http://wnyhealthelink.com/>
 - http://wnyhealthelink.com/files/HEALTHeLINK_Policies_09-16-11_v1.pdf

