

# **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

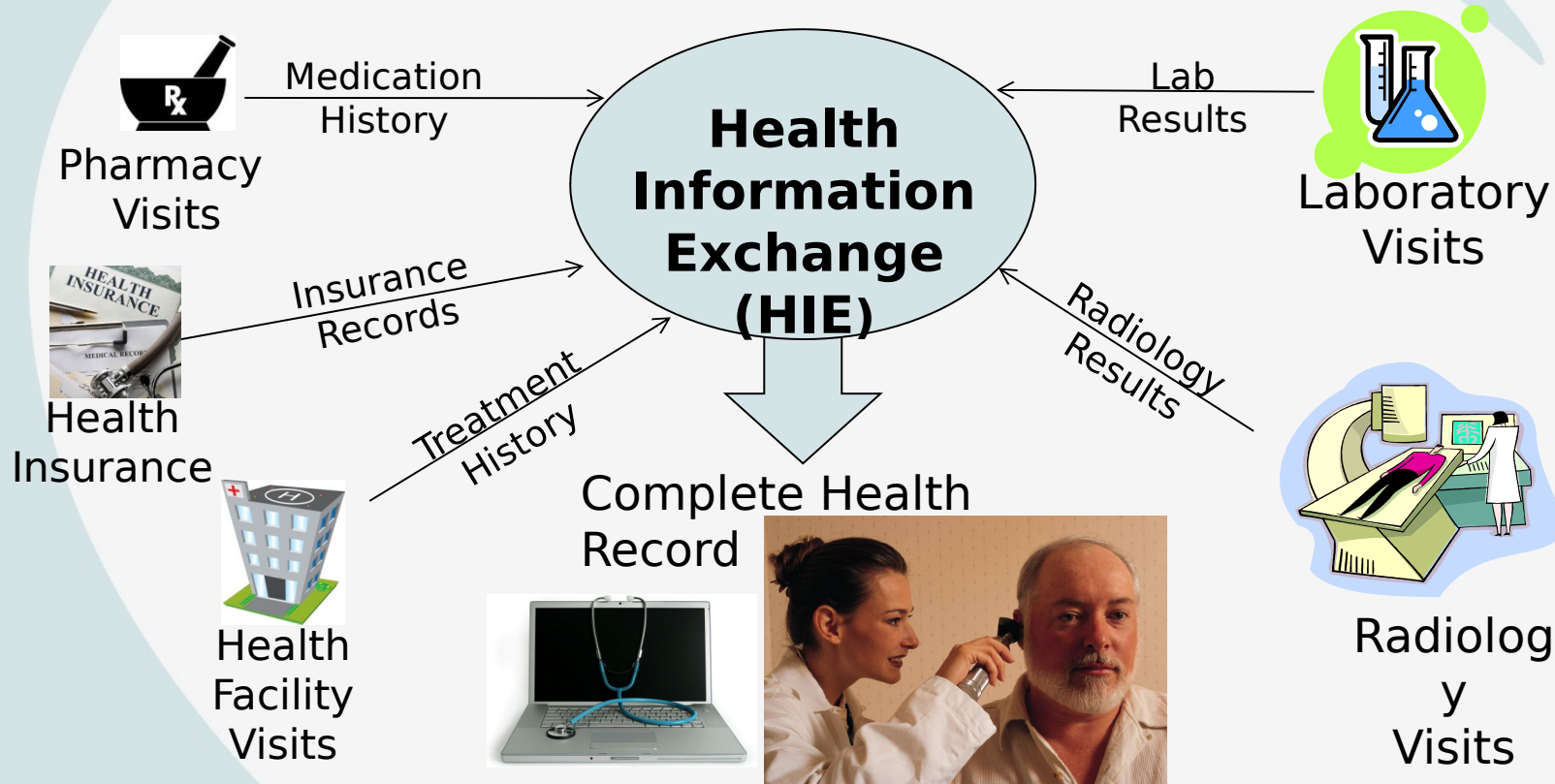
# About Us

- 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 techn**

FACILITATOR 1  
PHOTO AND NAME

FACILITATOR 2  
PHOTO AND NAME

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

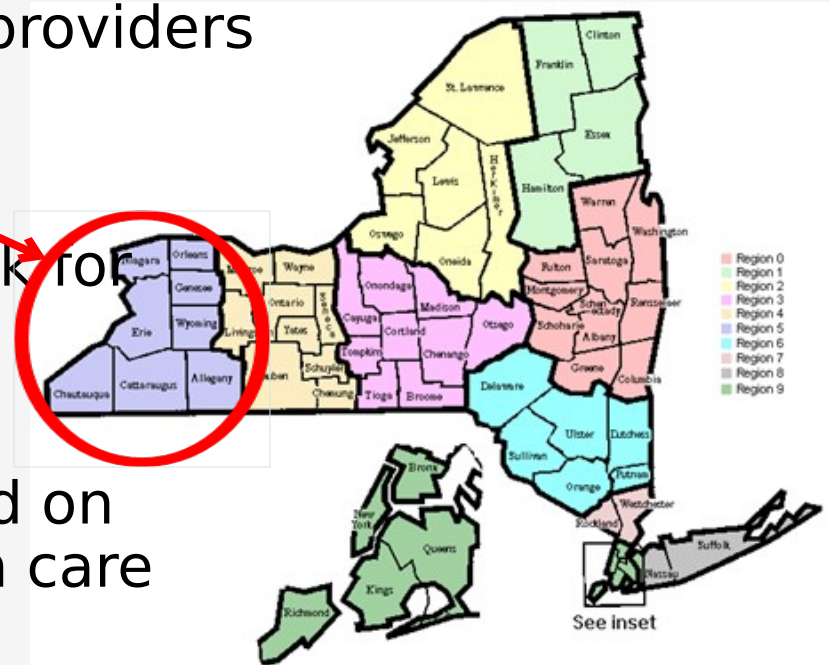


***In most cases within New York, sharing your Health Care Information requires your written consent***

# 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
<ul style="list-style-type: none"> <li>Kaleida Health System</li> </ul>	<ul style="list-style-type: none"> <li>Windsong</li> </ul>	<ul style="list-style-type: none"> <li>Quest</li> </ul>
<ul style="list-style-type: none"> <li>Catholic Health System</li> </ul>	<ul style="list-style-type: none"> <li>Spectrum Radiology</li> </ul>	<ul style="list-style-type: none"> <li>X-Cell Laboratories</li> </ul>
<ul style="list-style-type: none"> <li>ECMC</li> </ul>	<ul style="list-style-type: none"> <li>Southtowns Radiology</li> </ul>	<ul style="list-style-type: none"> <li>Genetic Diagnostic Laboratories</li> </ul>
<ul style="list-style-type: none"> <li>Roswell Park Cancer Institute</li> </ul>	<ul style="list-style-type: none"> <li>Buffalo MRI</li> </ul>	
<ul style="list-style-type: none"> <li>Niagara Falls Memorial</li> </ul>	<ul style="list-style-type: none"> <li>Diagnostic Imaging</li> </ul>	
<ul style="list-style-type: none"> <li>WCA (Jamestown)</li> </ul>		
<ul style="list-style-type: none"> <li>Mt. Saint Mary's</li> </ul>		
<ul style="list-style-type: none"> <li>United Memorial Medical Center</li> </ul>		
<ul style="list-style-type: none"> <li>Upper Allegheny Health System (Olean)</li> </ul>		
<ul style="list-style-type: none"> <li>Brooks Memorial</li> </ul>		

*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:

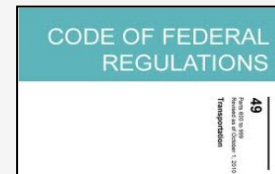
- Statutes



- 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

<b>Acronym</b>	<b>Definition</b>
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://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.health.ny.gov/technology/statewide_policy_guidance.htm)
  - [http://www.nyehealth.org/images/files/File\\_Repository16/heal5/PrivSec\\_PPs\\_V2.pdf](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](http://wnyhealthelink.com/files/HEALTHeLINK_Policies_09-16-11_v1.pdf)

