



The Office of the National Coordinator for  
Health Information Technology



# eConsent Trial Project Overview

**HITPC Meeting  
January 8, 2013**

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**Office of the Chief Privacy Officer**

The Office of the National Coordinator for  
Health Information Technology

- Background, Objectives, & Assumptions
- Snapshot of Project Approach
- Key Factors Identification & Educational Material Development
- Pilot Logistics
- Anticipated Project Outputs
- Questions?

## In a clinical setting...

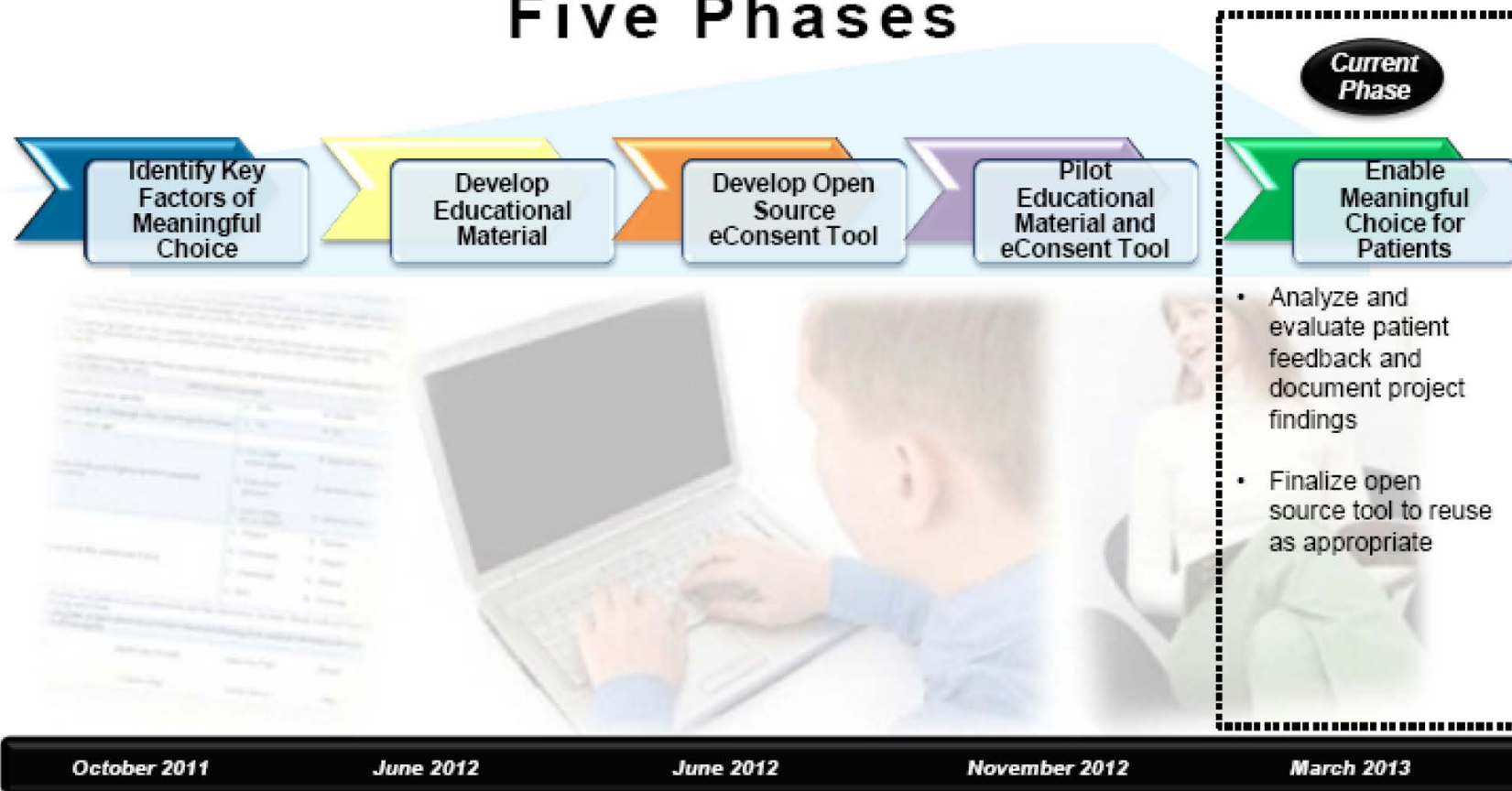
- Design, develop, and pilot innovative ways to:
  - Educate patients about their option to make an individual choice (or patient consent) about whether or not their health care provider can share/access their health information through a health information exchange organization (HIE) (*Meaningful Choice*);
  - Assess patients' knowledge gained and their individual satisfaction with the educational material and associated electronic delivery method; and
  - Electronically capture and record a patient's choice.

**Health IT Policy Committee Individual Choice Recommendations (September 2010) informed project objectives.**

- Gather patients' input and identify what patients feel they require to make an informed decision, including patient evaluation and integration in the pilot design and development process.
- Employ multi-channel approach to accommodate visual/auditory and tactile learners, providing flexibility in delivery of educational material.
- Pilot educational material and eConsent tool at health provider facilities within the *Western New York (WNY) Health Information Exchange (HIE)*, part of an ONC Beacon Community.

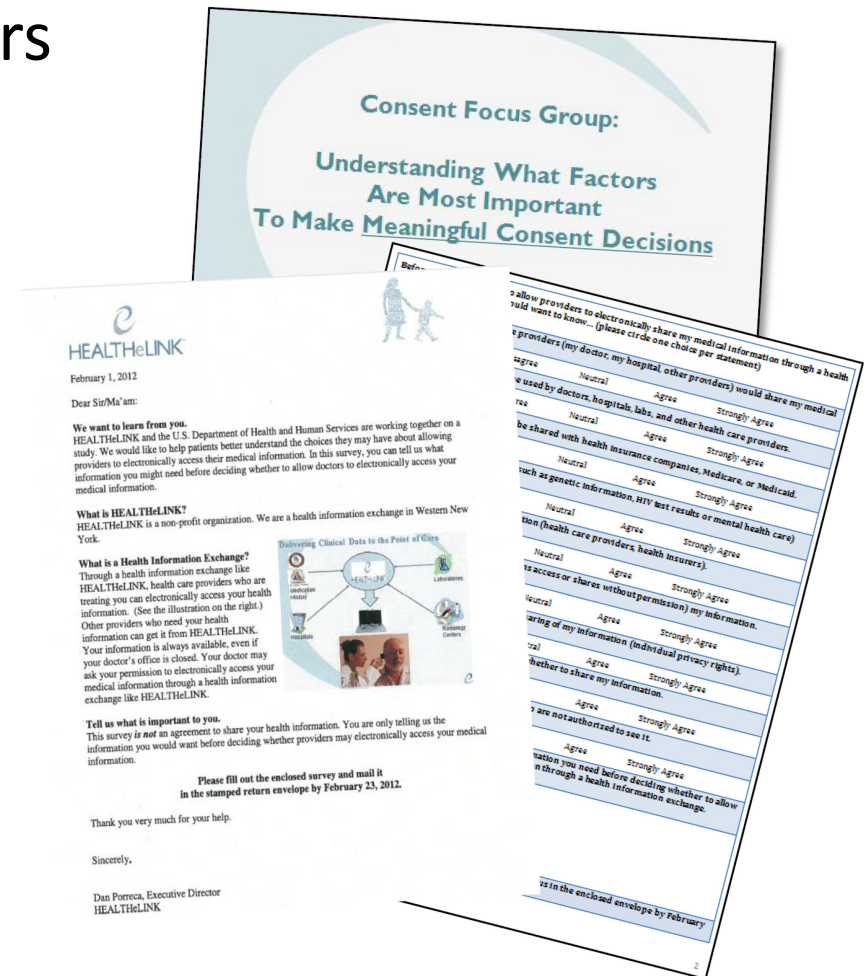
**Project will electronically implement existing patient choice policies.**

## Five Phases



# Key Factors Identification & Educational Material Development

- Tiered Approach to Key Factors Identification
  - Survey
  - Focus Groups
- Development of Education Material
  - Main video
  - Additional detail videos



- Intended to help identify what *patients* want to know before making their decision
- Two-page written survey, anonymous
- Rural/Urban of WNY

Form Approved  
OMB No. 0990-0276  
Exp. Date 07/01/2014

**Survey for Developing Educational Material for Sharing Patient Medical Information**

**What information do you need to decide whether health care providers may electronically share your medical information?**

*As described in our cover letter, doctors and hospitals can electronically share patient health information through HEALTHeLINK, a health information exchange. HEALTHeLINK stores your health information and makes it available to HEALTHeLINK members (health care providers) when they ask for it.*

*We are surveying 2,500 New York residents. Our survey asks about the information you need before deciding whether to allow physicians to share your medical information through a health information exchange like HEALTHeLINK.*

*Your feedback is important. Please return this voluntary and anonymous survey in the stamped return envelope by February 23, 2012.*

**Tell Us About Yourself**

1. Please circle your gender.	A. Male	B. Female
2. Do you speak a language other than English at home?	A. Yes	B. No
3. What is your age?		
4. Please circle your highest level of completed education.	A. Not a high school graduate	D. Associate's degree
	B. High school graduate	E. Bachelor's degree
	C. Some college but no degree	F. Advanced degree
5. Please circle the county you live in.	A. Allegany	E. Genesee
	B. Cattaraugus	F. Niagara
	C. Chautauque	G. Orleans
	D. Erie	H. Wyoming

Please tell us how you prefer to receive information and what information you need. Please circle your responses to the following statements.

**6. I would prefer to learn about my provider's electronic sharing of my medical information through... (circle all that apply)**

Brochure	Health Care Provider	Video/YouTube	E-mail
Internet	Website/Blog	Mobile Device	Other

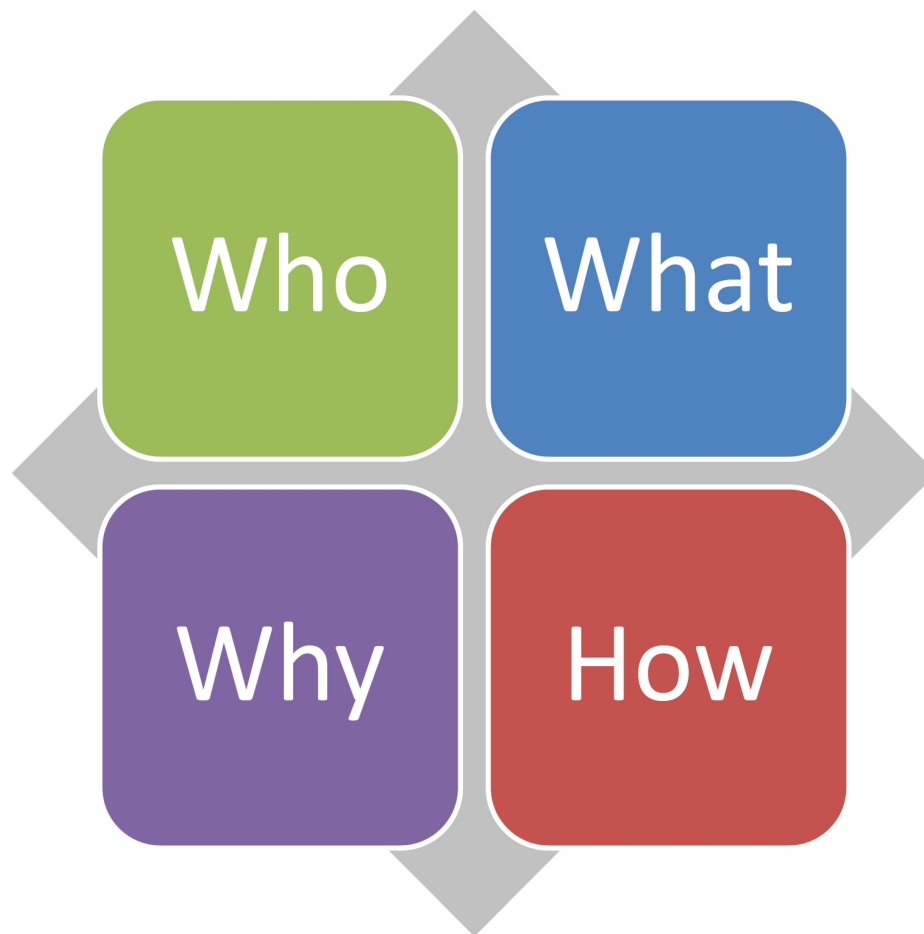
According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0990-0276. The time required to complete this information collection is estimated to average five minutes per response, including the time to review instructions, and complete and review the information collection. If you have comments concerning the accuracy of this time estimate(s) or suggestions for improving this form, please write to: U.S. Department of Health & Human Services, 040001064, 300 Independence Ave., S.W., Suite 2224, Washington D.C. 20201. Attention: PRA Reports Clearance Officer.

- Interested in knowing how people accessing their health information will use it
- Concerned with misuse of information, privacy, and how information is secured
- Want to know if...
  - Information will be shared with health insurance companies
  - Sensitive health information will be shared
  - They can change the status of their consent decision
- Prefer to receive education from their providers
- Provided free text responses (30% of respondents)



- Eight focus groups to “deep-dive” topic areas to focus and refine educational material development
- Survey analysis used to develop prioritized list of topics for focus group exploration
- General educational material served as foundation of participants’ knowledge





I'm Ready To Make My  
Consent Decision  
2 minutes

Consent Decision Overview  
3 minutes

HIEs and HEALTHeLINK  
2 minutes

Why Give Access  
2 minutes

What Can Be Accessed?  
2 minutes

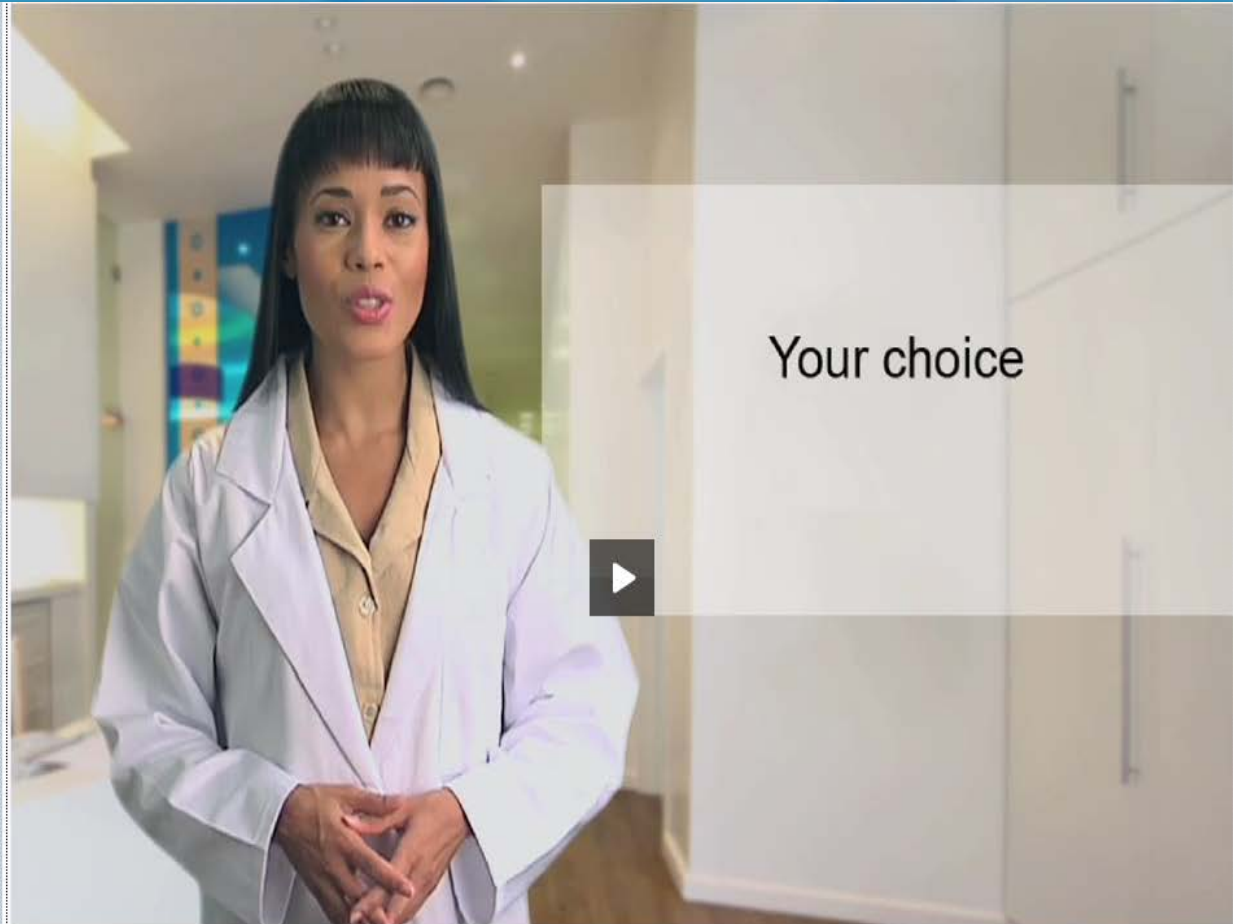
Who Can Access?  
4 minutes

Is My Information Secure?  
7 minutes

Can I Change My Mind?  
20 seconds

More Consent Decision Info  
Less than 1 minute

Instructions



This is about your choice to allow your health care providers to access your health information through a Health Information Exchange (or "HIE" for short) for medical treatment and related services.

- **When:** Launched on October 22, 2012
- **Where:** Four health care provider facilities
- **What:** Patients have option to use tablet computer to
  - View educational material
  - Electronically make a consent decision
  - Take anonymous survey
- **Post Pilot Activities**
  - Conduct debrief with pilot site personnel
  - Analyze data collected during pilot
  - Prepare final eConsent report



- Identification of effective and innovative resources and examples that help ensure:
  - Any choices patients make with respect to sharing their health information are indeed, meaningful.
  - Patients understand the consequences of their choice.
  - Patients better understand their choice regarding whether and when their health care provider can share their health information electronically, including sharing it with a health information exchange organization.
- Project Timeline: October 2011 – March 2013

- eConsent team consists of five teaming partners
  - Subject matter experts on privacy, Health Insurance Portability and Accountability Act (HIPAA), and Institutional Review Board (IRB)/Paperwork Reduction Act (PRA), among other topics
  - Health Information Exchange (HIE)/Regional Health Information Organization (RHIO)
  - Educational video/visual design
  - Software/application development



