Today’s Discussion

• 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.
General Project Assumptions

- 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.
Snapshot of Project Approach

Five Phases

- Identify Key Factors of Meaningful Choice
- Develop Educational Material
- Develop Open Source eConsent Tool
- Pilot Educational Material and eConsent Tool
- Enable Meaningful Choice for Patients

- Analyze and evaluate patient feedback and document project findings
- Finalize open source tool to reuse as appropriate

October 2011  June 2012  June 2012  November 2012  March 2013
Key Factors Identification & Educational Material Development

- Tiered Approach to Key Factors Identification
  - Survey
  - Focus Groups

- Development of Education Material
  - Main video
  - Additional detail videos
Survey Background

- Intended to help identify what patients want to know before making their decision

- Two-page written survey, anonymous

- Rural/Urban of WNY
Survey Findings – High Level

• 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)
Focus Group Background

• 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
Focus Group Findings – High Level

Who

What

Why

How
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.
eConsent Trial Pilot Overview

• **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
Anticipated Project Outputs

• 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
ONC’s eConsent Project Team

- 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