



Ensuring the Inclusion of Clinical Research in the Nationwide Health Information Network

An expert meeting held on
May 9, 2006

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Expert meeting: May 9, 2006

■ Sponsors

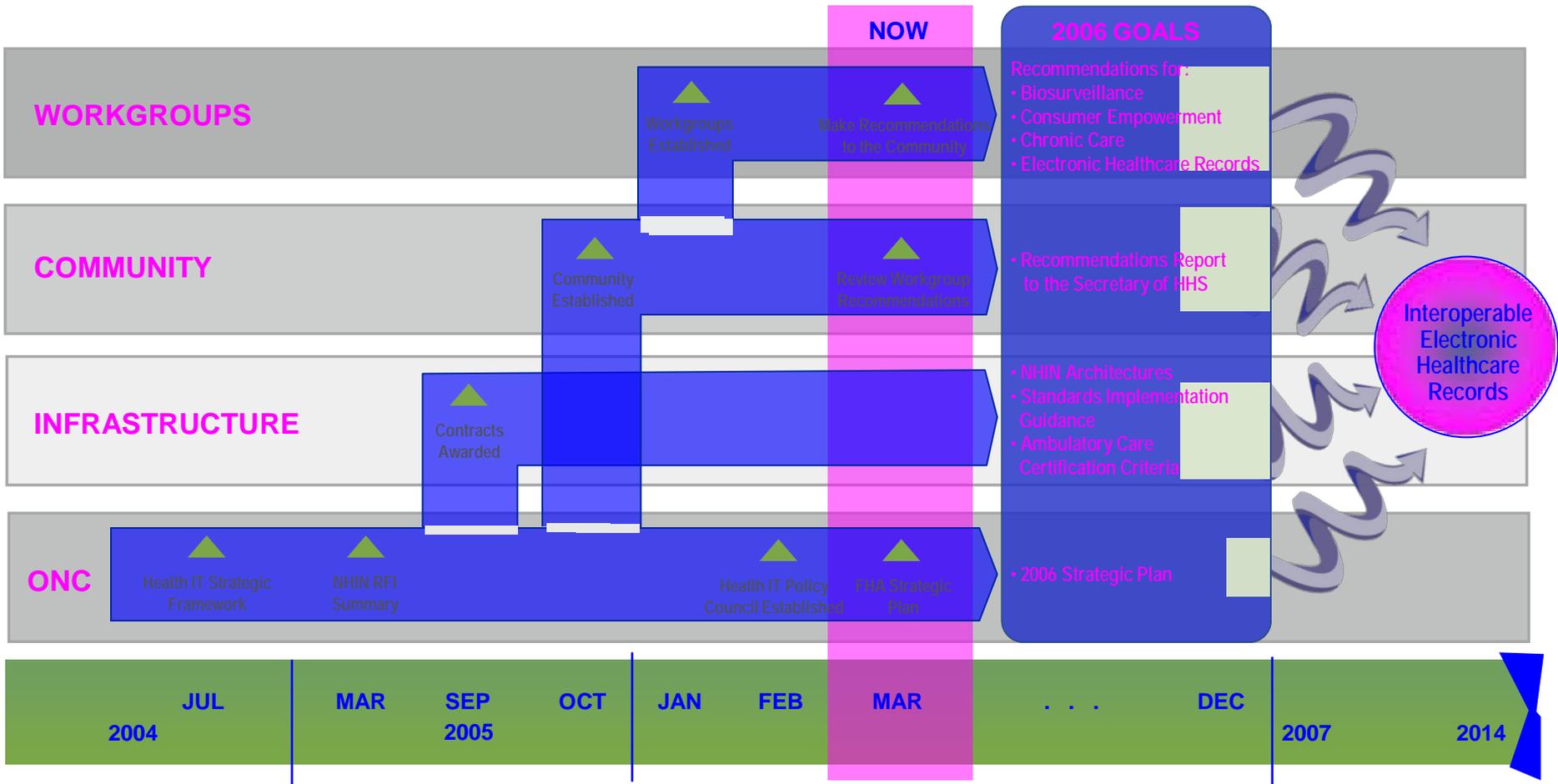
- AHRQ
- NIH's National Center for Research Resources (NCRR)
- FasterCures

■ Attendees

- Clinical researchers
- NHINs and RHIOs
- Patient groups
- For-profit vendors
- Community providers
- Government representatives

Purpose: Start the conversation

Office of the National Coordinator Health IT Roadmap To-Date



Agenda

- Definition of terms
- Panel: State of the art
 - Chris Chute, Mayo Clinic
 - Paul Wallace, Kaiser Permanente
 - Brian Kelly, Accenture NHIN
 - Keith Norris, Drew University
- Identified issues
- Breakout sessions
- Action plan

Developments of the day

Breakout sessions

- Cataloguing the balance sheet
- Health information exchange
- Data capture
- Patients

- Cross-cutting
 - Privacy and security
 - Quality and nature of data
 - Business model

Observations

- Unusual for this combination of folks to talk to each other
- Anticipating how data will change
 - Data abundance
 - Definition of a researcher
 - Human factors and data gathering
 - IRB issues
- Diverse needs, perceptions, readiness to engage
 - Need for a coherent voice

Action plan

- 2 Use Cases
 - Patient accrual
 - Phase IV Post-market Surveillance
- Coherent voice
 - i.e. Connecting for Health public-private collaborative
- Contact
 - Peter Highnam, NCRR/NIH
 - Margaret Anderson, FasterCures

NHIN Public Fora

- **First Nationwide Health Information Network Forum**
 - National Institute of Health's Natcher Conference Center in Bethesda, MD
 - June 28-29, 2006
- **Purpose:** to identify and catalogue the functional requirements for the development of an NHIN
 - Functional requirements are brief, verifiable, declarative statements of what a system must do or actions it must take
- **Process**
 - Specifications of the next phase of NHIN
 - Health Information Technology Standards Panel
 - Certification Commission for Health Information Technology
- http://www.hhs.gov/healthit/NHIN_Forum1.html



<http://healthit.ahrq.gov>

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