

**Health Information Technology and Health Information Exchange Topical Meeting
Research
August 16, 2006**

Key Points

- How can we do rigorous research that is meaningful and is conducted with scientific rigor
- How do we identify other data that may be relevant
- How do we exploiting technology most appropriately
- How do we increase the validity of the data

Vision

- Interoperability is critical
- Buy in from key parties is critical IT Executives, legal counsels, CME CEU, IT patients, payers to improve quality
- Who owns the data
- Who manages the data and reviews the use
- Legal requirements regulatory agency
- Stewardship for the data
- Where does the budget come from to support RHIOs
- Funding for oversight & funding for research
- Informed consent
- Research how to design and implement platform and integrate data
- Structure ability use platform
- Data use when institutional privacy is an issue (scorecards)
- Collaboratives are risk adjusted
- Data should not be used as a stick
- Not marketed QI only
- Use of data
 - What are we defining as research?
 - Benefits? What is the goal?
- Getting research into the practice
 - Evidence based medicine
- Clinical review board clients vs. internal and external review
- Universal consent process you can query my data and contact me about a research project, send me a letter, prescreen
- Broad base from each others interest
- Market research and research that informs knowledge
- Quality improvement
- Managing the data
- Sharing the content
- Library function
- Telephone co. library
- RHIOs parallel to repository what they needed to do
- State level RHIO?

- Clinical work support separate from research concepts
- Support research as a product, cohort level query
- Multi-tiered query for information- distributed
- De-identified standardized condition broadly useable fashion
- Patient level concerns
- Some information in this system compartmentalized health history
- Opt out only
- Error rates
- Determine system purpose in design to facilitate clinical data, quality review and research. It is unlikely to be able to be all things to all people.

Policy Options

- Process or policy for governing the use of data
- IRB
 - Multi-agency IRB
 - Who is on the IRB consider the concerns of the collaborators
 - Specialized IRB
 - Prospective and retrospective re IRB
- Multi-tiered process provider level de-identification
- Transparency and attitude
- Human subjects
 - Define de-identified- MPI is not really de-identified
 - Too rich of a data source
- NIH funding for primary data collection
- Research drive the building of train or on the back end cost will be high

Barriers to HIT Adoption

- Cost
- Changing workflows
- Intervention vs. trials focus
- Cost of repository