
NHII 03
Consumer Health Track
Group A

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Introduction

◆ Areas

- ❖ Data Interoperability
- ❖ Communication and Information mgt
- ❖ Trustworthy and Relevant Information Resources
- ❖ Specific populations
- ❖ Clinical trials
- ❖ Patient Safety
- ❖ Business and Community Models
- ❖ Demonstration projects
- ❖ Reimbursement
- ❖ Research

◆ Phases

- ❖ Phase 1 1-3 years
- ❖ Phase 2 3-5 years

Data Interoperability

- ◆ Essential for consumer access to important data, health resources and services
- ◆ Recommendations:
 - ❖ Standards development activities should include (and vendors should incorporate) data elements relevant to consumers and patients (phase 1)
 - ❖ HHS should resolve the patient identification issue (phase 2)

Electronic Communication and Data Sharing

- ◆ Improve electronic communication and data sharing among patients, providers, and non-professional care-givers

- ◆ Recommendations:
 - ❖ NLM to fund approaches that further define or improve consumer terminology (phase 1)
 - ❖ Ask FCC and other bodies to promote affordable, available broadband technologies to the home (phase 2)
 - ❖ Define lowest common denominator “platform” for personal access to NHII services as technology evolves (phase 1-2)

Information Management by the Patient/Consumer

- ◆ Encourage and empower the patient/consumer to assume a direct role in managing, sharing, and understanding their personal health information

- ◆ Recommendations:
 - ❖ The NCVHS membership should include a consumer representative (phase 1)
 - ❖ HHS and other stakeholders should support consumer health literacy training (phase 1)
 - ❖ HHS and other stakeholders should support systems that use diverse modalities to address consumers with varying levels of health literacy and cultural/linguistic requirements (phase 2)

Information Management by the Patient/Consumer

- ◆ Recommendations (continued):
 - ❖ HHS should identify metrics to measure progress in the development/ and evaluation of mechanisms for consumer (patient) management of personal health information (phase 1)

Trustworthy Health and Disease Information

- ◆ Methods are needed to assess health and disease information credibility, reliability, and relevance

- ◆ Recommendation:
 - ❖ HHS, working with private sector, should take the lead in identifying feasible ways to measure and promote credibility and reliability of health information resources (phase 1)

Relevant Health Information Resources

- ◆ Effective ways to identify relevant information specific to the needs of a consumer

- ◆ Recommendations:
 - ❖ NLM and Private Sector should improve search tools to enable users with varying needs and profiles to find the most relevant information (phase 1-2)

 - ❖ NLM and Private Sector should provide tools to link personal health record information with relevant information resources based on informatics principles (phase 2)

Specific Populations

- ◆ Target the unmet needs consumers have in areas such as disease management, wellness, and prevention, especially for disabled and underserved populations

- ◆ Recommendation:
 - ❖ HHS sets priorities and metrics to ensure NHII resources target specific high-risk and high-need populations (phase 1-2)

Clinical Trials

- ◆ Improved coordination of clinical trials and clinical care activities

- ◆ Recommendation:
 - ❖ Research investigators and the NIH should improve the recruitment and safe participation of patients in research trials using emerging informatics technologies and standards (i.e. consenting strategies, trial eligibility, adverse event reporting, etc.) (phase 1-2)

Patient Safety

- ◆ Patients need systems that help them know their potential risks and mitigate the risks they identify

- ◆ Recommendation:
 - ❖ Involve patients and patient representatives directly in the development of patient safety initiatives through AHRQ (phase 1)
 - ❖ Funding groups should prioritize initiatives that incorporate the patient directly in the medication management process across settings of care (phase 1)

Business and Community Models

- ◆ Viable business and community models are needed to accelerate the services available to consumers

- ◆ Recommendations:
 - ❖ AHRQ should coordinate scalable systems-level research through cross-organizational RFPs involving Corporate/NSF/NIST/NIH combined funding (phase 1-2)

Demonstration Projects

◆ Recommendations:

- ❖ CMS should expand it's support of operational demonstration projects with patient-centered remote information services (phase 1)
- ❖ AHRQ should sponsor community-based research demonstration projects to educate consumers, patients and professionals about the uses of consumer health technology (phase 1)
 - et* Measure clinical outcomes: e.g. weight loss, cholesterol reduction, hemoglobin A1c reduction, etc.
 - et* Improve adherence re: medication use, preventive health, knowledge about health and disease, scheduled appts, etc.
 - et* Measure adoption promoters and barriers

Reimbursement Model

◆ Recommendation

- ❖ HHS should convene an advisory committee to identify a new reimbursement model that is understandable to all parties, and supports: (phase 2)
 - et* Evidence-based technology-driven care
 - et* Person-centered care
 - et* Wellness and patient education
 - et* Primary care
 - et* Remote monitoring and care

Consolidated Research Agenda

◆ Recommendations:

- ❖ HHS and others who fund community or regional health information networks should encourage an explicit consumer/patient component (phase 1)
- ❖ NIH and cross-organizational initiative to understand patient needs and preferences (phase 1)
- ❖ NIH initiative focusing on improving communication between patients and providers using new modalities and technologies (phase 1-2)

Coordinated Research Agenda

◆ Recommendation:

- ❖ Joint HHS/NSF research initiatives on problems where health care provides a special case of a more generalized issue (i.e. Bayes networks, location-based services, question-answering, information retrieval)
(phase 1-2)