Overarching Meeting Discussion Questions

1. What is the evolving role of policies for biomedical and health informatics relating to patient-centered care, collaboration, communication, and coordination?

2. What are the public policy issues and challenges related to the integration of multiple sources of clinical, health, environmental, and genomic data?

3. How do existing and emerging social challenges, such as the digital divide, income inequity, and health care accessibility highlight the need for policies that support informatics solutions?

4. What are some best practices for engaging patients and consumers in the governance of data and informatics for patient-centered care?

5. Do we have the right policies in place for data use and reuse?

6. What policies are needed to support and enable informatics innovations that will speed the development and optimize the utility of multiple disease- and specialty-specific registries and other research tools?

7. Can public policy accelerate the integration of informatics in our health profession’s education and training processes?

8. With the growing emphasis on and acceptance of individuals’ roles in their health and health care, what future socio-technical challenges will we face? What is the role of informatics in addressing these challenges?

9. How can we increase the usefulness and acceptance of consumer-generated and mediated data, participatory research through the development of policies that support data stewardship?

10. What policies (financing, data regulation, accountability) influence the ability of a healthcare team to use informatics support for deliver patient-centered care?
**Breakout Sessions Discussion Questions**

**Facilitated Discussions/Breakout Session 1: Data use, reuse, stewardship and governance in a patient-centered care model**

1. What policies should be put in place or refined that help make these technologies available financially and define a shared accountability model?
2. What policies are needed to address challenges for generation of and access to the data needed for patient-centered care?
3. Where does the financial responsibility lie for making access to these technologies/ who is going to provide patients with the tech they need in order to make these data available?
4. What is the patient’s responsibility for using these data to improve their healthcare?
   - Access to technology (kind of like getting electricity to rural areas)
   - How much of this is a public issue; how much a private issue?
5. What incentives could be created to facilitate or foster the use of data for patient-centered care?

**Facilitated Discussions/Breakout Session 2: New models of HIT, sharing and management (logistics of data sharing and accessibility)**

1. New models of HIT - how to engage populations so as not to enhance the digital divide
2. How do we keep current approaches to meeting the needs of special populations from becoming barriers to future innovations?
3. How to prepare the workforce for this change (having patients participate)?
4. What is the relevance of current provider competencies with these new models of care?
5. What is the role of patients in governance?
6. What changes in stewardship strategy are needed?
7. What new models for informatics and data sharing can we develop to engage populations so as not to enhance the digital divide?
8. What policies are needed to systematically engage individuals from special populations getting involved in the development of HIT-related solutions?
9. Minority populations are very reluctant to be genotyped – what implications does that have for healthcare?
10. How can we be sure that policies don’t exacerbate stereotypical thinking and reinforce implicit bias in system design? (Example – multiple co-morbidity issues – as a subgroup, they have additional challenges)
11. Can policies shape the attention/awareness of special populations? (i.e. People with disabilities, social and cultural differences, health literacy challenges, etc.)
Facilitated Discussions/Breakout Session 3: Policy and research imperatives

1. How would you prioritize the policy and research imperatives?
2. Whose priorities should be used to set them?
3. What privacy policies need to be modified or enacted to ensure data acceptability for patient-centered care?
4. What do we know about the issue around potential mismatches between current privacy policies and potential mismatches?
5. Large Group Discussion: Where Do We Go from Here?
   - Identify common themes and potential levers to advance the discussions
   - Formulate key messages for policymakers
   - Propose next steps and action items for stakeholders