The theme of the 2013 AMIA Policy Invitational is data-driven, patient-centered care, collaboration, communication and coordination. This meeting will bring together informatics professionals, public policy leaders and patient advocates to generate recommendations to create the policy infrastructure that can enable informatics solutions in support of patient-centered care. This briefing document is designed to introduce all participants to the concepts of patient-centered care, illustrate the challenges to patient-centered care that informatics can solve, and provide a general informatics framework to support a robust dialogue on the topic.

In his Health Affairs blog post from June 2012, James Rickert identified the three hallmarks of patient-centered care: care that engages patients and clinicians in meaningful way under a mantle of shared accountability; care where traditional players remain engaged, including patients, nurses, physicians, insurers and payers, and health care delivery institutions; and care that is designed, organized, and evaluated in a way that focuses on the individual patient’s health concerns and circumstances. This radical shift in focus and priority forces a need for new kinds of data upon which to base care and new information tools to jointly support patient and clinician engagement in the process of health services delivery. Assuring the integrity, security and analyzability of these data and ensuring the availability of advanced informatics solutions that extend the point of care beyond the encounter to the everyday lives of patients requires policies that both capitalize on technological advances and keep up with the shifting mores of clinical care.

Informatics technologies, supported by appropriate policies, enable two key drivers of healthcare innovation: 1) shifting the point of health care from the clinic or hospital bed to wherever the person is – home, school, work, or community; and 2) complementing familiar health care data (lab test, physician orders) with a broad range of patient-generated data, including day-to-day assessment of symptoms or exposures to hazards, self-reported outcomes, passive sensor data, and clinical care responses. This free flow of data makes care truly patient centered, linking the clinic with the person’s life. When patient-centered care is commonly practiced, health care will become more of a daily life process and less of an episodic disruption of the patient’s life.

VISION OF PATIENT-CENTERED CARE

In a world characterized by patient-centered care, clinicians, and patients benefit because each plays an active role in defining health problems, selecting interventions, and evaluating their outcomes. Consider this scenario:

Mary checks in with her online portal, locates the results of lab work ordered by her physician at her last visit, and notes that her cholesterol level remains elevated. Despite counselling from her clinician and careful management of her diet, the result remains abnormal. Ready to try one more round of dietary strategies before
considering a pharmacological approach, Mary tracks her food for two weeks and sets up a consultation with her dietitian. At the consultation the dietitian observes that Mary is eating the right balance of food, and suggest that further diet modifications are unlikely to be effective. Mary plans a follow up visit with her clinician, at which time the clinician recommends new approaches.

The success of patient-centered care relies on a new kind of clinician-patient alliance, full access to clinical data by all parties, an engaged and motivated patient, and the time to negotiate and evaluate plans of action. This vision of the future also relies heavily on a wide range of information technologies that extend the guidance and teaching of clinicians into the everyday experience of the patient and use the power of the technology to bring the everyday experience of the patient into the clinical encounter. Precious resources of clinician expertise and patient time are better used because the point of care becomes a problem solving conversation, not a data collection period.

MAKING THE BUSINESS CASE FOR PATIENT-CENTERED CARE

There is good evidence that patient-centered care—care that is responsive to patients’ needs and goals—is more effective and less costly than care that is organized around the efficiencies of a care-providing institution. Judy Hibbard’s work shows that when care is tailored to the needs and strengths of the individual, it is also less costly and more likely to be effective. Care-providing institutions gain because resources are used more effectively and the risk of uncompensated care diminishes. Payers and, by extension, states and businesses that pay health insurance premiums also gain secondarily from the improved health of employees.

The value of a patient-centered care process depends on the patient and the patient-clinician alliance. Some patients are well equipped to participate in their care; for example, many patients with chronic conditions are well engaged in clinical provider partnerships. Similarly, some patients may be more aware of their reactions or responses to particular therapies (e.g., drug side effects). Still, there are some patients that are unwilling, uninterested or ill equipped to assume an increased role in their care. Thus, when designing policies and tools, we should be mindful of the spectrum of providers and patients and relationships that need to be accommodated.

CHALLENGES TO PATIENT-CENTERED CARE THAT INFORMATICS CAN SOLVE

It’s easy to envision patient-centered care when the patient is able and willing, the problem solvable, and the care system responsive. In complex care cases, none of these factors may be present. Novel approaches to patient records—such as a participatory care record that not only stores relevant data but also uses dynamic display systems in the moment—can ensure that salient aspects of the patient’s history and his preferences remain visible—even when the patient cannot speak for himself or herself. Here’s the journey of one patient with a chronic, life-threatening illness:

Despite diligent documentation of the thousands of hours spent in a hospital bed, the story of one patient’s needs, wants and experiences can be buried in hundreds of pages of text, impossible for even the most dedicated person to read in time to make critical decisions. A background in technology and a hope that his own experiences would form the basis of good care decisions led Nick to envision an iPad dashboard display to focus the attention of surgeons and clinicians towards the care most consistent with his needs,
expectations and history. This “participatory care record” not only spoke for him when he was unable to speak for himself, it provided a focal point for clinical encounters, displaying patterns and experiences to be shared with his care team, and formed the foundation for a collaborative, patient-centered care process. In his own words: “a participatory health record is best defined by the following statement: show me the same story, at the same time, at the point of care, in context, when and where important medical decisions are made.”

The participatory care record represents a re-formation of the medical record from a static history to a dynamic document that serves not only an archival role, but also a key communication bridge.

CAPTURING INFORMATION AT THE POINT OF HEALTH

Information technology developments enable reaching from the point of health care (provider centric) to the point of health (patient, consumer and caregiver centric). For example, some long-term care providers are beginning to adopt sensor systems that can monitor activities of daily living in places where elder people live. Sensor systems embedded directly into living environments provide enhanced trends of activities of daily living 24/7, monitor walking paths and gait changes over time, and using motion-sensing technology like those found in the Xbox Kinect system, send live moving images of patients in the form of silhouettes to providers when significant changes or falls are detected. Access to this clinical information is sent through a secure, early illness detection system that generates alerts sent to clinicians involved in case management activities. Early illness detection systems have enabled clinicians to recognize changes in health conditions nearly two weeks earlier than traditional forms of assessment requiring physical presence and direct contact. But in order to see approaches like this put into widespread use, we need new information sharing policies to guide balancing the perspectives of patients and providers that address issues such as safety, privacy, unobtrusiveness and liability.

BASIC TENETS OF THE INFORMATICS NEEDED TO SUPPORT PATIENT-CENTERED CARE

Data-driven, patient-centered care relies on information as the foundation for health management. Both health care providers and patients generate and use information. In this model of care, health care providers include the span of formal caregivers including physicians, nurses, social workers, home health aides, and therapy services. Data generated by providers and patients are equally valued. No data source is prioritized; instead, decisions are made based on the triangulation of data sources. No data source is restricted; providers and patients have access to data needed to make decisions. Policies again must guide the balance between the patient’s right to disclose or withhold information with the provider’s need for a comprehensive picture of the patient situation. Policies must also promote the availability of data that promotes patient understanding and engagement.

Informatics solutions to the challenges of patient-centered care must accommodate a wide variety of care providers as well as patients with a wide range of demographic characteristics including those with diverse cultural backgrounds, low literacy, low socioeconomic status, and physical and cognitive disabilities. Thus, when designing policies and tools, we should be mindful of the spectrum of patients and relationships that need to be accommodated. Informatics technology is needed to both facilitate engagement of patients and caregivers and to support patient-centered care. Facilitated engagement requires that patients have greater access to their health information and are able to collect and transmit information for inclusion in a health record. To be truly accessible to patients, patient health information must be represented in a way that promotes patient understanding and use—otherwise
patient information can exacerbate the digital divide, such that those with the least access to technology will have the least access to care.

The specific informatics advances and capabilities to support engagement and patient-centered care include patient identity management, human-computer interaction, data exchange, and data harmonization. Identity management is needed because many engagement technologies will exist in applications outside the electronic health record and cannot be managed only by care providers. Human-computer interaction advances are needed to make data accessible to patients. Data exchange is needed to bring together information collected from the patient and from clinical care; data harmonization is needed to integrate data from these different sources in a meaningful way.