

CARE CULTURE & DECISION-MAKING INNOVATION COLLABORATIVE :
NAM Working Group on Technologies to Enhance Person, Family, & Community Engagement
January 17, 2019 Meeting Highlights

MEETING FOCUS: Engagement of the health care system leadership, resources, and partnerships for the creation of an equitable health system in which technology enables seamless engagement of patients, families, clinicians, and community resources as partners on behalf of transformative progress in health care.

Motivating questions:

1. Purpose What is the potential for technologies to advance equity and the empowerment of persons, families, and communities in health care?



integration and coordination within health care system we need to build solutions that feature user centered design. Her problems accessing care were the same ones that low income people with low levels of education would face. She strongly suggested framing the discussion to make clear the system has a deficit, not the humans who are using it. (ST)

The role of data standards is critical. Medical forms have extensive duplication, and theoretically it is possible to have a standard form that enables a population. This could be applied to creating a standardized tool to measure SDOH. However, a lack of interoperability between systems means it is not currently feasible. Technologically, it is simple, but a consensus needs to be built, and entities such as the VA have an outside role in catalyzing tech companies to change. (

Afternoon Discussions about Researching Themes:

Current implementation of consent model is fundamentally coercive. The model most familiar to patients if they opt out, they can't use the service (such as Gmail or Facebook). HIPAA functions differently but most patients don't know this they may assume they have to agree to all potential uses of their data or they will deny them service. (JNS)

Addressing patient/consumer protections is an important consideration when talking about consent. For example, the Genetic Information Nondiscrimination Act (GINA) protects genetic data from being used against individuals for health insurance. (



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