Situating participatory health platforms – Erik Johnston - Arizona State University

A major challenge to any health research or practical health application is that the diversity of communities, inequity of health conditions, and disparity of opportunities prevent a one size fits all approaches. Therefore, it becomes critical for to promote broad access for policymakers, administrators, intermediaries, and patients to information-rich, interactive environments where choices can modeled, simulated, visualized, and studied. I am interested in participatory action research where health related decisions are made within the context of participatory health platforms that incorporate a diverse set of stakeholders in the deliberation, design, and delivery of health care. In particular, I am interested in the following research themes.

> *Theme 1: Whole system deliberation and design of participatory health platforms*
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> *Theme 2: Empowering patients to make evidence based decisions regarding value*
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> *Theme 3: Evolving the very conception of health in a networked age*

Theme 1: Whole system deliberation and design of participatory health platforms

Research typically tries to understanding specific relationships between two factors, but struggles to understand whole systems, especially social and administrative systems. One goal of any system is to insure that care and information must be integrated into all services, creating a seamless, personalized experience for patients, providers, and communities. We are interested in a means to not only confront but also take advantage of the unfathomable volume of data now being generated from the individual to the systemic level. These approaches can range from being too abundant to hardly in existence. In the former case, we face the challenge of leveraging large quantities of information under severe time and resource constraints. In the latter case, limited or incomplete information has to be used to make decisions on ambiguous solution spaces.

In the past few years, the Arizona State University (ASU) School of Public Affairs and Center for Policy Informatics has been involved with two high profile challenge platforms with a public intent. The first, a university-wide challenge platform called 10,000 Solutions. This platform solicits input from the ASU community to identify solutions to eight broad challenges, ranging from education and technology, to community development and others. The platform is similar to the U.S. General Service Administration's *Challenge.gov,* a participatory platform that incorporates user contributions to cultivate solutions to challenges in the areas of science, economy, security, and personal wellbeing. ASU's second challenge platform with a public intent is a collaboration working with the White House Office of Science & Technology Policy to design a national policy proposal competition in response to their Startup America Policy Challenge. Through a network of schools and organizations, The Policy Challenge asks students, faculty, practitioners, and the general public to propose innovative, viable, and actionable plans for administrative change to be implemented at the U.S. Dept. of Education, Energy, and Health & Human Services that will break down barriers to entrepreneurship and best enable the use of new technologies in education, clean energy, and healthcare, respectively. These two platforms complement each other though distinct choices that highlight important design tensions, broad participation vs. informed

participants, general vs. specific challenges, same vs. different groups proposing challenges and solutions, and different prizes to motivate participation: a monetary prize vs. the attention of people with influence. Because of their growing importance and potential application to innovative health solutions, it is critical to develop the scientific principles underlying challenges platforms.

Theme 2: Empowering patients to make evidence based decisions regarding value

How individuals frame and make choices regarding health is an increasingly active research space. It is not just the nature of information that is changing, but also advances in communication and computational technologies enable new opportunities. Rather than trying to independently dealing with public problems, governments and health care providers are able to empower its community and patients to address their own challenges. Crowdsourcing and bottom-up, emergent, problem-solving approaches are desirable as the public have a greater opportunity of taking charge of their own problems, share narratives of treatment plans, and arriving at personally relevant solutions. Designing platforms and mobilizing patient and local provider input can be used effectively to solve local problems and foster sustainable collaborative relationships. New data-driven approaches like participatory innovation, challenges platforms, and personalized communities like patientslikeme highlight the changing ecosystems of health and healthcare delivery.

Theme 3: Evolving the very conception of health in a networked age

The health of a community is more than just the aggregated levels of health of the members of the community. More and more health phenomenon is seen to exhibit externalities and network effects. By understanding these dynamics, our approach to policy design changes as well. For instance, to eradicate a disease like polio or others where immunizations are central to the treatment approach, a broad application and full suppression is necessary for long-term effectiveness. Similarly, for the Affordable Health Care act to work, a threshold amount of the population must have health insurance that will trigger certain tipping points of effectiveness. Similarly, while we have known a major factor in smoking behavior is peer effects, social effects are appearing in exercise behaviors, obesity, and even marriage status. Environmental effects, economic conditions, and other system wide factors also hint that a community view of health would be useful. The collective nature of health therefore suggests new possibilities for how health is measured, designed, and administered.

Health decisions are also unique in that they are challenges challenge with socially important consequences while ultimately being fundamentally intimate decisions at the individual and family level. This tension between the personal choices and collective challenges creates unique dynamics to health decision at the individual, provider, policy and governance levels that are difficult to understand and more difficult to govern. Adding to the complexity of the challenge is the changing roles in health care system as information technologies empower personalized health decisions. Research about health systems, training future health professionals to be fluent in health and informatics, and innovative approaches to governance in this unique context will be the next frontier of research in health policy informatics.