The Science (and Art) of Understanding Patient Needs in Health Information Systems

Abstract: Health information systems, such as electronic medical records, are powerful tools that can facilitate management of health organizations and support tasks related to billing, records management, and regulation compliance. However, these systems are designed primarily for clinic-based workflow. As a result, patients living with serious or chronic illnesses are generally unable to manage their day-to-day care work using the current features of these systems.

In this talk, I describe methods used in three distinct projects to elicit the patient perspective to improve health information systems design. By incorporating patient goals, tasks, and preferences, these systems can better support patient information needs and decisions, which serves to complement clinic-based workflow and promote patient-clinician coordination. I articulate the health services and systems design implications of my research findings using patient-centered elicitation methods in three contexts: (1) management of chronic illness; (2) transitions in illness phase during young adult cancer; and (3) detection of cancer symptom emergence in individuals’ Internet search history.