

My Data Choices

Evaluation of Effective Consent Strategies for Patients with Behavioral Health Conditions



Individual control of sensitive health information is a matter of great concern to patients, practitioners, insurers and policymakers. Federal and state law generally supports consent approaches that allow patients to share all or none of their health data. However, research demonstrates that patients prefer more detailed control of their personal data sharing.

The U.S. Office of the National Coordinator for Health Information Technology (ONC) recommends that “patients should have a greater degree of choice to determine, at a granular [more detailed] level, which

personal health information should be shared with whom, and for what purpose.” Individuals differ in identifying and defining the types and categories of health data they consider to be “sensitive.” In particular, little is known about data sharing preferences of patients with behavioral health conditions (BHCs).

This study is designed to **educate patients about health information sharing, including the pros and cons of restricting access to their information for care and for research.** Our research will also explore the technical feasibility of supporting patient-driven, consent-based data access and inform stakeholders about the clinical, ethical, policy and regulatory implications of broader consent choices.

Students will join a multidisciplinary team of researchers and students at the Arizona State University, the Mayo Clinic and local behavioral health centers. The research team has expertise in clinical informatics, medicine, ethics, law and statistics, to participate in some of the following activities:

Aim 1: Elicit patient, legal guardian and provider perspectives on more detailed data control through surveys, interviews and focus groups.

Aim 2: Develop *MyChoice*, an electronic informed consent management tool in English and Spanish, that supports multiple consent options. Design and incorporate multimedia educational material to help patients intelligently exercise detailed data sharing.

Aim 3: Pilot *MyChoice*, compare consent strategies and explore the ethical, clinical, policy, and regulatory implications of detailed data control choices. Recruit 270 adult patients/legal guardians diagnosed with BHCs, including serious mental illness. Compare the consent process and outcomes using the My Choice electronic consent tool when the consenter is OR is not a member of the patient’s care team. Summarize and disseminate the ethical, clinical, policy, and regulatory implications of designing and deploying detailed data sharing choices for individuals with BHCs.

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