

HHS Project: What Works for Consumer Choice in Health Info Sharing?

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The Office of the Chief Privacy Officer within the HHS Office of the National Coordinator for Health IT (ONC) is [seeking a contractor](#) [2] to develop and pilot test innovative ways to give people informed (or “meaningful”) choices about the sharing of their electronic personal health information. CDT Health Privacy Project has [written on the role that individual choice](#) [3] or consent can play in a comprehensive framework of privacy protections governing the sharing of electronic personal health information. We believe that over reliance on consent to protect individual privacy can have the perverse effect of providing weak protections for privacy in practice. Too often, consent forms that are too long or too difficult to understand become the easy gateway to a broad range of information sharing.

But fair information practices (FIPs) have always included provisions for individual choice. The key to providing strong privacy protections for health information sharing is to establish and enforce clear rules on who is able to access the information and for what purposes – and then consider how individuals can have some meaningful choices about how their information is shared within the context of those rules.

When choice is provided, it is critical that it be as informed as possible and manageable by consumers and patients. There is little evidence, however, on what really works for consumers with respect to choices in health information sharing. Consequently, this could be a very important initiative - if it's done well.

This project is likely to attract interest from a number of thought leaders, academics and industry stakeholders who have either published studies or surveys on consent, or who have advocated for various consent models over the years. But I sincerely hope that this project relies less on what has already been published or said about consent – and focuses more on figuring out what works on the ground. Surveys are helpful and capture people’s thoughts and desires about consent – but they rarely if ever get at the question of what actually works in the implementation phase.

The proposal requires the prospective contractors to involve an existing clinical setting, situation or site in which electronic health information is exchanged. The projects must also “rely on the patient population at the clinical partner site” in performing the project – from the development of the informational materials that will be provided to patients, to the design of the user interface, to the pilot testing and evaluation of consent approaches. We hope this means that individual patients will weigh in on what information they want to know before they can make a choice, who is the best “messenger” to educate them about their choices, what is the most effective way to present information and capture patient choice – and we will subsequently learn much more about what makes consent work in the area of electronic health information exchange. Ideally the winning proposal would engage patients of different ages, races, ethnicities, socioeconomic status, so we can understand whether there are differences in among population cohorts that are important to address in future policies and practices.

We look forward to hearing more about this potentially groundbreaking project.

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