A study by Kim et al. reported the results of a survey experiment that examined patient preferences concerning data sharing. In this experiment, patients were randomized to receive 1 of 4 survey instruments, each designed to gauge the patient's willingness to share their personal health information or biospecimens. These surveys included the following: (1) a simple form asking patients to opt-in to sharing their data across 18 different categories, which ranged from demographic information to sexual life to adoption history; (2) a more detailed opt-in form that expanded the 18 categories into 59 different data subtypes; (3) an opt-out version of the simple form; and (4) an opt-out version of the detailed form. For each form, patients could also select if they would like to share their data with their own health care organization, nonprofit organizations, or for-profit organizations.

Some of the key findings from the study by Kim et al. included a willingness among most patients to share most or all of their data with their own health care organization or with other nonprofit institutions. The opt-out versions elicited greater willingness to share compared with the opt-in versions. There were no significant differences observed between the simple or detailed versions of the form.

As the study by Kim et al. and others have observed, data sharing is a potential boon for the health care research enterprise. Increased data sharing can enhance scientific integrity, help to stimulate new hypotheses, and allow the research community to learn more from every data set. The fact that most of the patients in the study by Kim et al. were willing to share much of their data is an encouraging sign. The results in this study are also broadly consistent with a 2018 survey study by Mello et al., which found that clinical trial participants generally felt that the benefits of data sharing outweighed its risks.

Yet, even if most patients say that they are willing to share their data, it is still important to give attention to those patients who decline, even if they are a small minority. Only 46 of 1246 patients (4%) in the study by Kim et al. responded that they did not want to share any of their data. In the 2018 study by Mello et al., only 8% of patients responded that they thought the risks outweighed the benefits of sharing their data. But as the study by Kim et al. found, 77% of patients declined to share at least some of their data, and there was also greater reluctance to share with for-profit entities. This suggests that most patients do indeed want some control in opting in or out of this enterprise and that transparency about who is involved in data sharing agreements will likely be key to promoting trust and maintaining patients' willingness to share their data.

It is also worth considering how much the average patient (or even the specific patients in the study by Kim et al.) knows about the realities of data sharing in health care. This study included a health literacy assessment, which was certainly useful for probing some of this understanding, but even patients who scored high in health literacy may not have been fully aware of how data sharing works and affects them already (for good and ill). As Kim et al. observe, it may be that most patients' apparent willingness to share their health data is due to ignorance about what this entails and the fact that there has not yet been a scandal that is high profile enough to make the risks and harms widely known. Although the story of Henrietta Lacks may have risen to public prominence showing how data or biospecimen sharing intersects with ethical issues around race, consent, and ownership, the experiences of the Havasupai Indian tribe, which showed the possibility of cultural harms, or the 2018 article by Petrow expressing how conflicts of interest at health care institutions can undermine...
trust are not so widely known. But developing ethical data sharing policies and supporting truly informed consent for data sharing practices require that the ethical tensions and potential for harms revealed by these episodes are being effectively communicated to patients and the public.

Thus, future work in this space would do well to focus more on the naysayers. Why are some patients more reluctant to share their data? Do they place a higher value on privacy? Are they more risk averse? Or might there be legitimate grounds for a well-informed patient to object to sharing some or any of their data? If the latter, then it is worth considering that the minority voice may be right in some contexts to say “absolutely not” when asked about their willingness to share data, and, accordingly, it may be incumbent on some health care institutions to ensure that these dissenting voices are heard and respected.

Nevertheless, the takeaways for the research enterprise are broadly encouraging. Most patients seemed to be comfortable sharing some of their health care data for the public good. So long as this willingness or consent to share data is grounded in the patient’s understanding of the history, risks, and benefits of the practice, then the broad support observed in the study by Kim et al seems to be a great sign for the health care community. However, we should not overlook the patients who do not want any of their data shared. Respecting patients and ensuring that data sharing practice is on secure ethical foundations require listening to those who opt out and working to better understand their reasons, experiences, and contexts.

ARTICLE INFORMATION
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