Online patient portals are a powerful way to improve care by giving patients convenient and secure access to their personal health information and promoting therapeutic relationships. But this level of information sharing is in many ways a new frontier for physicians and health systems, and one of the trouble spots involves sharing ethics consultation notes.

An article published in the *AMA Journal of Ethics*® (@JournalofEthics) argues that ethics consultation notes should absolutely be included in patient portals and the EHR. The article—written by Marion Danis, MD, head of the Section on Ethics and Health Policy, and Dominic R. Mangino, postbaccalaureate fellow, in the Department of Bioethics at the Clinical Center of the National Institutes of Health—also lays out how to do this safely and effectively.

### The argument for including notes

One of the benefits of including ethics consultation notes in the EHR and the patient portal is that it can help patients become more familiar with the work of clinical ethics consultants. This could improve patient care, the authors noted, in a couple of ways.

“First, providing patients access to some of their ethics consultation notes through online portals would facilitate patients’ exercise of an existing, but currently underutilized, right to access their health records,” they wrote. “Second, easily accessible and understandable ethics consultation notes might help patients appreciate the ethical concepts that are meant to guide clinical practice.”

### Two decisions to make

The authors suggested that information in the patient portal should, as a rule, match what’s in the EHR—in type and in volume—but they noted there are two questions to answer first.
Does it relate to the patient’s care? As a case in point, hospital policy questions are excluded when no patient is named, but it is less clear whether they should be omitted if they arise in the context of a particular patient’s care.

“Hospitals and consultation services must therefore develop criteria to define when an ethics consultation properly relates to the care of a patient such that it is appropriate for inclusion in the portal,” the authors wrote.

Does it support recommendations? “For example, if a consultation involves discussion of whether to disclose information to a patient or their surrogate decision-maker and disclosure is considered inadvisable, then the note should be omitted from the portal,” the authors wrote. “Consultants could designate the note as ‘hidden’ from patients and require justification for its being viewed by other clinicians, similar to the practices of clinicians documenting psychotherapy notes.”

In some cases, however, it might be appropriate to share only some elements of the consult, such as when the physician asked for guidance in handling inappropriate patient behaviors. In these situations, two versions of the note could be included—a comprehensive note in the EHR and a summary note in the patient portal.

Three follow-up steps to take

When including ethics consultation notes in the patient portal, avoid challenges by taking these three precautionary steps.

Before: Notify patients. Preferably, this would happen in person. “Making patients aware that a consultation has occurred can prevent the possibility of their feeling blindsided, confused, or frustrated, as has occurred after patients discover new, unanticipated information in their clinical notes,” the authors wrote.

During: Address their concerns. While not always feasible, giving patients a heads-up about a consultation can minimize negative reactions by alerting them that an ethics consultation has been requested, describing the nature and purpose of the consultation and giving them a way to contact the ethics consultation service with questions.

After: Allow for change. It “might be advisable for consultants to provide the patient and relevant clinicians opportunities for feedback or discussion of notes and to be prepared to make appropriate corrections,” the authors wrote.

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