

Relevant Core Values and Recommendations from Tiger Team August 19 letter:

- Patients should not be surprised to learn what happens to their health information.
- The provider-patient relationship is the foundation for trust in health information exchange.
- Providers are responsible for ensuring the privacy and security of patient information but may delegate functions to business associates if done in a trustworthy manner.

NEW core value: Transparency about information exchange practices is a necessary component of establishing credibility with patients. In achieving greater openness and transparency for patients, we need to balance the need to give patients complete information on how their information is shared while at the same time providing information in a form that is manageable for patients to read and understand.

Consistent with these core values and previous recommendations, we have the following additional recommendations:

1. Providers are responsible for being open and transparent with their patients about how their data is exchanged. This involves providing the Notice of Privacy Practices required by HIPAA (subject to the additional recommendations below), but providers also should be encouraged to discuss information exchange practices with patients, particularly where there is a new significant development such as "indirect exchange" through a business associate that triggers consent per our previous recommendations (such as an HIO) or when the provider's EMR is shared with an OHCA (see further recommendations below).
2. With respect to the HIPAA Notice of Privacy Practices (the "NPP"):
  - a. Providers should provide a layered notice - a short, 1-2 page summary of information sharing policies and activities should be required. This "summary notice" should indicate how to obtain more information.
  - b. A more detailed notice for interested patients should also be readily available.
  - c. The notice should not only be in plain English but should be written at the reading level of average patient and presented in compliance with applicable laws with respect to language and disability.
  - d. The notice should ideally cover current and anticipated exchange activities in lieu of merely describing what the law permits.
3. Where there is "indirect exchange" through a business associate that triggers consent per our previous recommendations, or where the provider shares information as part of an OHCA, providers' notice to patients should be separate from the HIPAA NPP. Such notice should also be layered.
  - a. With respect to "indirect exchange models" that trigger consent (per previous recommendations):
    - i. All patients should receive a brief summary description of the indirect exchange model, including the name(s) of the organization(s) with legal responsibility for managing the indirect exchange model.
    - ii. Per previous recommendations, notice of the provider's intent to

participate in “indirect exchange” should take place before the patient’s record leaves the control of the provider.

iii. Patients must have an ability to obtain more detailed written information about the indirect exchange model. Such information must include a description of the circumstances under which others may access the patient’s information, other participants in the model, and uses of the patient’s information. Providers may provide this directly to patients or rely upon the exchange to provide the information (i.e., providers should use materials provided by the exchange or may direct patients to the exchange for more information).

b. With respect to OHCAs,

i. All patients should receive summary information, including that the provider shares patient information through an OHCA and the name of the OHCA (or how it is held out to the public).

ii. Such information should ideally be provided to patients before the provider makes his/her record information available through the OHCA, or as soon as practicable thereafter.

iii. As with models of indirect exchange, patients should have an ability to obtain more detailed written information about an OHCA, such as additional information about provider entities who are part of the OHCA. The provider may provide this information to patients directly or rely on the OHCA.

Example of summary notices:

We send an electronic copy of your medical record to the state health Information organization, which makes your data available to other healthcare professionals.

We also use a gateway for electronic submission of prescriptions, which keeps a copy of your medications profile. If you want to learn more details about how we perform electronic exchange of data, you may request a copy of our Detailed Information Exchange Description, which can also be found at this web-site: <http://...>

We are part of IntegratedHealthSystems, which has a shared electronic medical record system that allows the other clinicians and hospitals of IntegratedHealthSystems to have access to your record to ensure that your treatment is informed by the best available information.

4. ONC should require federally funded HIOs to develop and implement public education plans.