Advance care planning is more important today than ever. Many people in the U.S. nearing the end of life are not physically or mentally able to make decisions about their medical care, including 70 percent of older adults who require treatment decisions, up to 69 percent of nursing home residents, and approximately 40 percent of adult medical inpatients. The COVID-19 epidemic has also brought advance care planning into the forefront. Patients who had not previously considered advance care planning are seeing the effects of this terrible disease and want to make sure their decisions are followed if they end up contracting it and do not do well. Additionally, with the move to value-based medicine being led by CMS, providers are incentivized to get advance care plans created for their patient population.

The options for representing advance care planning documents in FHIR are currently somewhat limited. One of the only options is to provide a PDF of the document as a Document attachment to the patient. The Consent resource team had originally intended to fold in advance care planning as a type of consent, but in their research had concluded that advance care planning was too complex to include there. Now that advance care planning as a topic has been moved to the patient empowerment team, there is an opportunity to explore some possibilities and try to design the best solution for representing advance care planning documents in FHIR.

Advance care plans can be made more useful by capturing metadata when the plans are created. The idea is that some of the information associated with the plan is pulled out and used to annotate the document (and provided via FHIR calls when an advance care plan is retrieved). The Consent team already captures some of this for data sharing consents, so the concept is similar to the original approach.

Metadata helps all the participants in a patient’s care. Bringing out end of life choices into metadata makes it more likely that patients will only receive the care they want. It also helps inform the decisions made by providers and proxies at end of life. Additionally, capturing metadata is good for payers, as it helps keep costs down by making it more likely that treatment that is not desired will not be provided to the patient. Using metadata to annotate the PDF document also allows us to capture nuance that may not be found in the document itself. These documents are often mostly about what decisions have been made and not the reasoning behind those decisions. Patient motivations and goals are often much more useful to providers and proxies as they make decisions at end of life.

Capturing this metadata also creates opportunities for emergent behaviors and innovation. PDFs, especially those that can vary as widely as advance care plans, are quite difficult to decompose into data points. Bringing these data out into metadata allows algorithmic behaviors to be used to process them.

There are, of course, some challenges with metadata collection. If the original advance care planning source is a PDF (such as an advance care plan created outside of the medical context with an attorney), then the PDF will need to be indexed before it reaches the system of record so that the metadata will be available. If a standardized form is being used (such as Five Wishes or other standardized advance care planning forms), it may be possible to extract some of this metadata automatically. If tooling is used to create the advance care planning documentation, these tools often gather the metadata first as a source for the eventual document, and could easily provide that data along with the completed form to the system of record.