OPTN Ethics Committee
Facilitating Patient Navigation Workgroup
Meeting Summary
August 4, 2020
Conference Call

Amy Friedman, Chair
Andrew Flescher, Vice Chair

Introduction

The Facilitating Patient Navigation Workgroup met via Citrix GoToMeeting teleconference on 08/04/2020 to discuss the following agenda items:

1. Review of discussion and determined criteria
2. Workgroup Discussion

The following is a summary of the Workgroup's discussions.

1. Review of discussion and determined criteria

The Workgroup reviewed the Facilitating Patient Navigation white paper criteria determined in the previous meeting.

Summary of discussion:

The Workgroup Chair discussed the goal of the project as it appears on page 1. There was discussion about the tension between the matters identified in the paper and whether a sentence should be added to the "Goals" section about that tension. A Workgroup member recommended describing why the tension exists. There was discussion about transplant programs being disincentivized from being labeled as "aggressive" and also potentially punished when their outcomes are reviewed.

The Workgroup Vice Chair discussed the balance between utility, patient safety, and equity in regard to the level of information shared with the patient. They noted that various topics may have different thresholds for the amount of information that is appropriate to disclose to the patient. The Workgroup Chair asked to what extent it is appropriate to modify the approach of how the information is shared based on who the patient is. They commented that patients may have different preferences in how much information they receive in order to either be directed toward a solution by their care team or to have access to research to inform their own decision-making. Treating each patient exactly the same is not always correct.

UNOS Staff reviewed the project form's problem statement. The Workgroup Chair commented that they agreed with the problem statement language. UNOS Staff read the project form's proposed solution. The Workgroup Chair asked if the project form will be updated with the document's drafted language. UNOS Staff confirmed that the newly drafted language will be used to update the project form. The project form is what is shared with the Policy Oversight Committee (POC). The Workgroup Vice Chair commented that the first step is to make sure the Workgroup is on board with the project proposal that will be presented to the POC. Then the Workgroup leadership will finalize the language on the project form.

A member commented that they want to work as partners with transplant programs to help them determine ways to best inform patients and thereby improve their outcomes. They commented that health literacy is important and that at a systems level there are multiple factors that affect a patient and their family's ability to understand existing or future data. The Workgroup Chair supported the idea of inviting transplant programs to partner in this initiative and would like to have the theme of partnership as the tone of the white paper. Another member agreed with this sentiment.

The Workgroup Chair asked UNOS Staff to review the other components of the project form. UNOS Staff noted that the original title will continue to display but will not affect the ability for the title to be edited in the final product. UNOS Staff shared that this project would likely go out to public comment in August 2021, requiring that the document be completed by June. The Workgroup Chair agreed that this is a feasible timeline. A member asked when this would be presented to the POC. UNOS Staff answered September, requiring that the project form be finalized by August 28. The Workgroup Chair agreed with this timeline.

The Workgroup Chair asked for an informal vote to approve the direction of the project. The Workgroup Vice Chair shared that they incorporated all comments and suggestions made by the Workgroup members in the white paper outline. They noted that white papers are written by assigning sections to Workgroup members to lead which makes the writing process very collaborative. A member commented that they support the proposal but raised a concern about the burden that will be put on the transplant program staff. They noted that the rate at which practices change will require frequent updates to ensure the data given to patients is most current. The Workgroup Chair commented that the concept of patients receiving up to date information should be included in the white paper. All members present voiced that they support this proposal.

Next steps:

The Workgroup leadership will finalize the project form to prepare for POC review on September 9.

2. Workgroup Discussion

The Workgroup continued planning the white paper and discussing the items brainstormed at the previous meeting.

Summary of discussion:

UNOS Staff shared the criteria brainstormed during the last meeting. The Workgroup Chair commented that they would like to discuss the "psychosocial evaluation" and "insurance and payment" criteria further with Workgroup members that were not present because of their specific expertise and interests. A member agreed that these members' contributions will be valuable and should be included.

The Workgroup Vice Chair questioned the use of the word "consumer" because of the transactional or contractual connotation. They asked the Workgroup for other word choices. Suggestions included "person," "patient," "client," "audience," "stakeholder," "patient supporter," and "patient advocate." The Workgroup Chair noted that "patient" is not always applicable, as the white paper will address multiple stakeholders including patient family members and support personnel. A member commented that using the term "consumer" may be further discussed due to how the patient may make decisions based on insurance and financial constraints but agreed that "patient" may be more appropriate. A member commented that they do not agree with the use of "consumer" when speaking to an individual who is potentially receiving an organ as it does not pay respect to the person providing the gift of an organ which is not a good.

A member asked UNOS Staff about how using language that describes "rights" is perceived by the POC. UNOS Staff responded that the POC is sensitive to absolute terms because they may be read as enforceable policy rather than best practices or guidance.

The Chair asked what should be used as references in the project form. UNOS Staff noted that Ethics project forms do not typically include references. A member stated that references can included in the white paper in addition to any research that is requested and used as supporting materials.

Next steps:

UNOS Staff will schedule a call between Workgroup leadership and members not able to be present for the meeting. UNOS Staff will update the project form with the newly drafted language and send a PDF to the Workgroup leadership for comment.

Upcoming Meetings

- September 1, 2020

Attendance

- **Workgroup Members**
  - Amy Friedman
  - Andrew Flescher
  - Colleen Reed
  - Jill Campbell
  - Jim Sharrock
  - Mahwish Ahmad
  - Stephanie Little
- **HRSA Representatives**
  - Jim Bowman
  - Marilyn Levi
  - Shannon Taitt
- **UNOS Staff**
  - Eric Messick
  - Kiana Stewart
  - Ross Walton