Translational research is essential to the success of every cancer center. Increasingly, doctors ask patients to donate tissue to study all aspects of the disease to improve cancer treatment and quality of life. In this process, patients are vital to the success of the cancer center, and therefore are critical stakeholders and partners in the translational research process.

The University of North Carolina (UNC), Lineberger Comprehensive Cancer Center (LCCC) researchers would like to increase the number of patients that donate tissue to support research and value patients who donate. Securing the right tissues at the right time, and processing and storing them properly is essential for research that leads to breakthrough discoveries.

LCCC supports the inclusion of patient advocates in all cancer center research. Therefore, the UNC Breast SPORE patient advocates initiated a program called Patients and Researchers Together (PART) to ensure patients work closely with researchers to drive the best research forward.

The PART-Tissue program aims to develop a process to increase the donation and usage of patient donated tissues. This program is built on significant patient engagement that leads to a bi-directional patient and researcher PARTnership. We believe patients will be more willing to donate tissue if they are informed about the research process, understand the impact research has to improve patient’s lives, and are comfortable as PARTners of LCCC.

Engagement of patient advocates as PARTners

- Create the PART Multi-Stakeholder Committee.
- Create the PART Working Group to identify relevant materials to assist in tissue donation at LCCC.
- Focus on a Lineberger breast cancer tissue collection protocol (LCCCB819).
- Discuss patient, researcher, and clinician/surgeon needs.
- Identify the need for several types of informational materials for patients.
- Develop patient materials with multi-stakeholder involvement.
- Evaluate materials accuracy, readability, understandability, and health literacy.
- Assess current and future needs of LCCC cancer researchers by conducting interviews and a survey.

METHODS

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RESULTS

A process was developed to create and evaluate patient-centered educational materials for patients.

- Future Activities:
  - Operationalize the use of patient materials
  - Assess the materials use and understanding by patients
  - Develop more study specific and topic specific informational materials

Conclusions

A multi-stakeholder working group developed several patient information materials to introduce patients to tissue donation and tissue usage research. The materials were reviewed by a rigorous process with iterative reviews and edits. The reviewers suggested changes to wording, use of pictures and graphics, content and layout. The final “introduction to tissue donation” is available on the PART website (go.unnc.edu/PART) and has been translated into Spanish.