# Increasing the Availability and Quality of Human Tissue for Research





The Physicians Committee is a nonprofit health organization that is dedicated in part to developing higher standards for ethical and effective scientific research.

We are looking to engage scientists and educate the public about the importance of human tissue research.

In October 2018 we held a roundtable to launch a multi stakeholder approach to address this issue.

Participants were charged with identifying the challenges of using human tissues in research and to cultivate a strategy to help meet the needs of the basic and translational research communities to increase the availability and quality of human tissues in research.

#### Roundtable Discussion

- Twenty three stakeholders –
  scientists, policy experts, tissue
  providers, federal agencies, and
  NGOs
- Three breakout groups –
   scientific, policy, and education
- Developed a set of recommendations
- Roundtable summary report available on <u>pcrm.org</u>
- Publication is forthcoming



### Key Recommendations

- 1. Increase availability of human tissues though streamlining donation consent forms.
- 2. Educate and improve communication pathways among donors and medical personnel. A better understand of the importance of human tissue research, dispelling negative connotations around "laboratory research".
- 3. Increase opportunities for training and education in the need for, collection of, and value of research tissues for OPOs and hospital staff.

## Key Recommendations

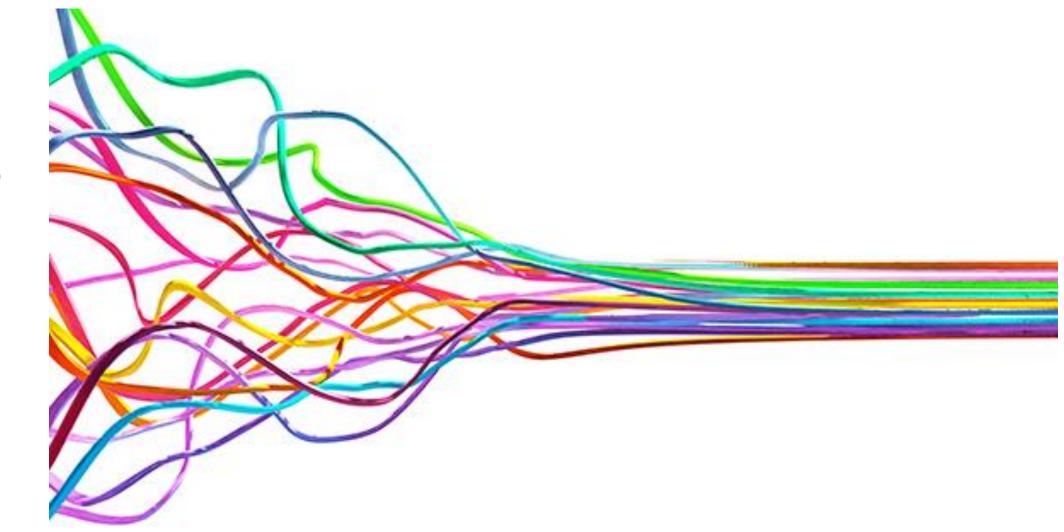
- 4. Metrics are important to assess quality and adequacy of tissues: Standard definitions of quality and minimum quality specifications should be established.
- 5. An overarching priority is the need for standardization of use, language, characterization, cell type, and recovery and procurement practices.
- 6. Prioritize funding for human tissue research and promoting open access data.
- 7. Revise federal agency policies that "prescribe" research or tests using animals as the preferred method.

# Collaborative Approach

Accessibility and quality are two main barriers of using human tissues and cells for scientific advancement.

Frequently, researchers express that they do not have enough tissues to carry out their studies or that the tissues are not of high quality, which hinders their results and reproducibility.

Coordinated effort amongst all principal stakeholders is vital to implement changes.



# We welcome new committee members!

Share your expertise to benefit the human tissue research community

Contact jmccarthy@pcrm.org

#### Discussion Questions

- 1. As an end user, how would you approach standardizing the characterization of human tissues and cells for research applications? In developing quality control measures for each key step recovery, preservation, and performance how do we establish a baseline or a definition of what's "normal", how do we define what's minimally expected for performance specifications, and acceptance criteria for each step? Who should be involved in these types of discussions?
- 2. What would be helpful or necessary to know about patient or donor demographics and medical history while remaining HIPAA compliant?
- 3. How can we create best practices for tissue recovery, preservation, and provision that are universally adopted and facilitate more access for a broad range of users?

#### Discussion Questions

- 4. Should the scientific community as a group pursue a common database that represents normal human tissues and various diseases and pathologies? How would you begin designing a database that can be accessible and searchable to select suitable donor-derived tissue and cell materials? Who would support this? What regulators should be involved?
- 5. What types of policies or resources can be put in place to better support and encourage researchers to use human tissues?