

# Parkland Community Interest in a Population-based Biorepository: Feedback from the Center for the Patient-Centered Outcomes Research (PCOR) Community Advisory Panel

## STATEMENT OF THE PROBLEM

**Population-based biorepositories (biobanks) can accelerate biomedical research** identifying targeted treatments that take into account an individual's genes, environment, and lifestyle. **However, biobanks in the United States have been criticized because they underrepresent vulnerable populations**—racial and ethnic minorities who lack health insurance, experience disproportionate health needs, struggle to access healthcare and other safety-net services, and face environmental and life stressors. **Therefore, it is critically important to build population-based biorepositories that reflect population diversity.**

**Parkland Health and Hospital System and UT Southwestern Medical Center are ideally poised to create a diverse population-based biorepository because the Dallas-Fort Worth Metropolitan Statistical Area (DFW) is one of the**

**fastest growing and most diverse populations in the country.** Implementing and sustaining biorepositories is challenging, both from a financial and stakeholder engagement perspective. We cannot create a strong biorepository infrastructure if we do not understand potential biorepository members' needs and concerns. A robust literature has shown that poor representation of racial and ethnic minorities in biomedical research can be traced to policies that did not systemically engage minorities in research or did not explain the benefits of joining research studies. We must create an infrastructure that reduces obstacles to minority participation in biorepositories. We believe that smart investment in a demographically representative biorepository is the way forward to strong biomedical research that positively impacts the health and healthcare of DFW residents. **This report details findings from the PCOR Community Advisory Panel session in May of 2016.**

## COMMUNITY RECEPTIVITY TO A PARKLAND BIOREPOSITORY

Preliminary exploration of the feasibility of a Parkland-UTSW population-based biorepository included the critical step of engaging potential biorepository participants, Parkland patients, to understand their receptivity and solicit feedback. For this purpose, we invited members of the Center for Patient-Centered Outcomes Research (PCOR) Community Advisory Panel who are current or former Parkland patients to a 2-hour discussion about the purpose of a population-based biorepository.

### Questions posed to the panel:

- ◇ *Who benefits from a Parkland-UT Southwestern biobank and how?*
- ◇ *What are the best ways to monitor the biobank's progress?*
- ◇ *How should biobank news be shared with patients, providers, the community, and DFW leaders?*

## COMMUNITY ADVISORY PANEL

The Community Advisory Panel of the Center for Patient-Centered Outcomes Research (PCOR), funded by the Agency for Healthcare Research and Quality (AHRQ), was established to regularly convene a broad representation of local community members and leaders to provide input on research projects at UT Southwestern. Many of these projects involve patients of the Parkland Health and Hospital System. Panel members have connections to the Parkland system, either as patients, caregivers of patients, or advocates of patients. Members are men and women from diverse socioeconomic, educational, professional, and racial and ethnic backgrounds; the group includes people of African-American, Hispanic, Middle Eastern, and European descent.

## BIOREPOSITORY

**Biorepositories (or biobanks)** are “libraries” where **biospecimens** (blood, saliva, tissue, etc.) are stored and made available for scientists to study for clinical or research purposes. These biospecimens are commonly annotated with information about the patient from whom the biospecimen was taken, including data about their medical conditions and background. There are thousands of biorepositories in the United States, which vary widely by size, the type of biospecimens collected, and purpose.

- *National Cancer Institute*

# Community Advisory Panel Response

## BENEFITS OF BIOBANK MEMBERSHIP

### FINDINGS:

Community Advisory Panel members were intrigued that biobanks might help them learn more about their health (when clinically applicable). They also found it important and motivating that their contribution to research could potentially help their families and community members. Previous studies have shown that providing benefit to one's own racial/ethnic group is a strong motivator for biorepository participation.

## FACILITATE INVITATION AND PARTICIPATION

### FINDINGS:

Discussion centered on how best to create community awareness and participation in the biorepository. Members felt strongly that several invitation methods were needed at the point of healthcare delivery and through community venues. They stressed the need to minimize inconvenience and physical discomfort when procuring specimen samples. This point is also reflected in the research literature. Members were more receptive to the collection of residual samples during usual healthcare than to separate specimen collection.

## BUILD AND MAINTAIN TRUST WITH AN ADVISORY PANEL

### FINDINGS:

Studies have repeatedly shown that lack of community engagement and buy-in can adversely impact research endeavors. Due to the pioneering and personal nature of the biorepository, the Community Advisory Panel and the literature both advise forming an oversight panel to build and maintain trust.

## KEEP MEMBERS APPRISED OF BIOBANK IMPACT

### FINDINGS:

Members of the PCOR community panels, as well as community advisory panels around the country, have emphasized the need to keep the community informed of the impact of the biorepository. When informed, the community is more apt to participate in the biorepository and to positively promote it.

### RECOMMENDATIONS:

- ◆ Creation of a population-based biorepository should be wholly inclusive of community members, regardless of health status, race, or ethnicity.
- ◆ When inviting families to participate, emphasize confidentiality practices and safeguards.
- ◆ Encourage altruism by emphasizing the long-term benefits biobank research can provide to communities.

### RECOMMENDATIONS:

- ◆ Advertise widely: Make use of MyChart, TV monitors in waiting areas, and pamphlets in the larger community (local churches, schools, etc.).
- ◆ Hire a friendly individual to speak to patients about the biorepository as they wait for appointments.
- ◆ Use residual specimens, when possible, or, if necessary, collect additional specimens during a planned collection (e.g., collect additional blood when blood draw is scheduled for other purposes).

### RECOMMENDATIONS:

- ◆ Invite community members who represent the broad racial, ethnic, socio-economic, and socio-cultural diversity of the greater Parkland community to participate in a Biorepository Community Advisory Panel.
- ◆ Structure the panel to convene regularly to provide guidance on how to build community trust and relationships, to advise on community interactions and interests, and to advocate for the communities they represent.

### RECOMMENDATIONS:

- ◆ Routinely inform the Biorepository Community Advisory Panel on biorepository activities and research endeavors.
- ◆ Publish newsletters, emails, and mailers; develop a presence on the web; and participate in health fairs to keep the community abreast of the biorepository, the research yielded, and how it applies to the community.

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