The Participant Engagement and Cancer Genome Sequencing (PE-CGS) Network

What will the PE-CGS Network do? The Network is comprised of five Research Centers and one Coordinating Center, each one funded by the National Cancer Institute (NCI).

The overall purpose of the PE-CGS Network is:

- To promote and support direct engagement of cancer patients and post-treatment cancer survivors as participants in cancer research
- To use such approaches for rigorous cancer genome sequencing programs addressing important knowledge gaps in the genomic characterizations of tumors in areas including, but not limited to, the following:
    - Rare cancers or rare cancer subsets
    - Cancers in understudied populations
    - Cancers with high disparities in incidence and/or mortality o Cancers with an early age of onset
    - Highly lethal cancers

Together, the PE-CGS network will engage diverse communities to provide insights into scientific insights that could be applied to development of new cancer therapies, methods of diagnosis, or opportunities for cancer prevention. The network aims to ensure that participants feel respected and empowered to participate in cancer genomics research.

Why is this research needed? Although recent technological advances in genomic sequencing have greatly improved our ability to conduct cancer research, there remain limitations in our understanding of cancer genomics. For example,

- Many of the hundreds of different forms of cancer have not been sufficiently characterized.
- For cancers where molecular characterizations exist, underrepresentation of racial minorities in cancer genomic studies means that questions remain about the generalizability of the data.
- Most current cancer genomics studies lack adequate clinical or epidemiologic data.

Several studies have demonstrated the potential of direct participant engagement to reach and recruit greater numbers of patients with high-priority cancers than is typically possible in clinical settings, particularly individuals from understudied communities.

Is this connected to the Cancer Moonshot Initiative? The PE-CGS Network is part of the NCI's Cancer Moonshot℠ Initiative. The Blue Ribbon Panel convened by the Cancer Moonshot Initiative emphasized reaching minority and underserved populations as a high priority and noted the importance of directly engaging with participants to facilitate participation in research and ensure patients are respected and have access to the research enterprise.

What research is being conducted and who is involved? The five Research Centers and one Coordinating Center will engage with a diverse array of patient populations:

USC PE-GCS: Optimizing Engagement of Hispanic Colorectal Cancer Patients in Cancer Genomic Characterization Studies - This Research Center, led by investigators from the University of Southern California, focuses on optimizing the engagement of Hispanic/Latinos in colorectal cancer (CRC) genomic characterization research studies to promote best practices for engaging these underserved populations and improve overall outcomes for CRC among Hispanic/Latinos.

Count Me In: Partnering with Patients to Define the Clinical and Genomic Landscape of Rare Aggressive Sarcomas in Children and Adults - *The Broad Institute, Massachusetts*

This Research Center will directly engage patients with two rare cancers – osteosarcoma and leiomyosarcoma – as partners in research in order to generate a large database of clinical, genomic, molecular, and patient reported data. This work will accelerate discoveries that drive novel treatment strategies, new clinical trials, and new standards of care, and serve as a model for patient- partnered research in other cancer types and patient communities.

Engagement of American Indians of Southwestern Tribal Nations in Cancer Genome Sequencing - *University of New Mexico Health Sciences Center, New Mexico*
There is a critical underrepresentation of cancers from American Indian patients in national cancer genome databases. The goal of this project is to engage with American Indian communities in order to increase their understanding and participation in precision medicine, molecular characterization of tumors, and cancer research, with the long-term goal of reducing their cancer burden.

OPTimIzing engageMent in discovery of molecular evolution of low grade glioma (OPTIMUM) - The optimal clinical management of low-grade glioma (LGG)—a malignant tumor of the brain diagnosed primarily in young adults remains unknown. Led by investigators at Yale University, Brigham and Women's Hospital, The Jackson Laboratory for Genomic Medicine, The University of Colorado, and Beth Israel Deaconess Medical Center, this project engages a community of 500 LGG patients to develop a comprehensive genomic characterization of the evolution from primary LGG to recurrence.

Washington University Participant Engagement and Cancer Genomic Sequencing Center (WUPE-CGS) – Steered by investigators from Washington University, this project builds a rigorous scientific evidence base for approaches to direct engagement of cancer patients and post-treatment cancer survivors as participants in cancer research. The focus is on rare and understudied cancer populations with significant disparities, including cholangiocarcinoma, multiple myeloma in African Americans, and colorectal cancer in African Americans under age 50

Participant Engagement and Cancer Genome Sequencing (PE-CGS) Coordinating Center - *Ohio State University, Ohio*
The Coordinating Center will facilitate network coordination, collaboration, and support community outreach, and identify best practices in participant engagement and genomics.

Is more information about the Network available? Yes, information about the PE-CGS Network can be found on the following websites:

- The PE-CGS Network Coordinating Center: https://pecgs.org
- NCI: https://www.cancer.gov/research/key-initiatives/moonshot-cancerinitiative/implementation/patient-engagement
- NCI's Epidemiology and Genomics Research Program: https://epi.grants.cancer.gov/events/pecgs/

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