

BREAKOUT GROUP DESCRIPTIONS:

Patient Engagement:

The patient engagement group infuses patient voice throughout the GPC. At each engagement circle, patients have the same roles, responsibilities and voting rights as all other members of the team or committee. Patients identify specific data elements of concern to them for best capturing patients' own experiences. The GPC is also addressing mechanisms for engaging patients as participants in research studies.

GPC Patient Engagement Officers currently include:

KUMC: Kim Kimminau, Sarah Schlachter (PMO), Cheryl Jernigan (lead Patient Rep); **CMH:** Kelsey Dean, Laura Fitzmaurice; **UIOWA:** Gary Rosenthal, Brian Gryzlak, Elizabeth Swanton; **WISC:** Betty Kaiser, Gay Thomas, Andrea Maser, Sarah Esmond; **MCRF:** Deb Multerer, Robert Greenlee; **MCW:** Jo Bergholte, Brad Taylor; **UMN:** Michelle Coady, Deb Hendricks; **UNMC:** Deb Meyer, James McClay, Russ Buzalko, Bret Gardner; **UTHSCSA:** Paula Winkler, Alfredo Tirado-Ramos; **UTSW:** Lindsay Cowell, Kate Wilkinson

Institutional Review Board (IRB):

The IRB is responsible for reviewing and approving research involving human subjects. The purpose of the IRB is to ensure that all human subjects research be conducted in accordance with all federal, institutional, and ethical guidelines. IRB approval must be granted before any involvement of human subjects may begin.

GPC IRB members currently include:

KUMC: Steve Fennel (PMO), Kyle Stephens, Jennifer Pennington; **CMH:** Germaine Hughes; **UIOWA:** Michele Countryman, Rachel Bullis; **WISC:** Carol Pech, Nichelle Cobb, Mike Bingham; **MCRF:** Lori Scheller; **MCW:** Connie Byrne; **UMN:** Debbie Dykhuis, Laura Conger; **UNMC:** Gail Paulsen; **UTHSCSA:** Kim Summers, Brandie Otten, Rhonda Oilepo; **UTSW:** Vicki McNamara, Lynn Baker

Cohort Characterization:

The cohorts consist of three patient and researcher work groups for obesity, breast cancer, and ALS. The work groups developed a common understanding of data dictionaries needed for cohort characterization. The teams collaboratively developed surveys for the three cohorts and determined how to ask if eligible patients would be interested in participating in patient centered outcomes research.

GPC Cohorts include: Breast Cancer, ALS, and Height/Weight.

Breast Cancer Cohort members in active and supporting roles currently include:

UIOWA (lead site): Betsy Chrischilles (Lead), Ingrid Lizarraga, Brian Gryslak;

KUMC: Jennifer Klemp, Jamie Wagner, Tamara McMahon (PMO); **WISC:** Amy Trentham-Dietz, Julie McGregor; **MCRF:** Adedayo Onitilo; **MCW:** Joan Neuner; **UMN:** Anne Blaes, Doug Yee, Michelle Coady; **UNMC:** Ann Berger, Shinobu Watanabe-Galloway, Bret Gardner; **UTSW:** Barbara Haley, Phillip Reeder; **UCDAVIS:** Brad Pollock

ALS Cohort members in active and supporting roles currently include:

KUMC (lead site): Rick Barohn (Lead), April McVey, Jeff Statland, Laura Herbelin, John Chen, Mazen Dimachkie;

UIOWA: Andrea Swenson, Heena Olade, Jeri Sieren; **WISC:** Andrew Waclawik; **MCRF:** Rodney Sorenson; **MCW:** Paul Barkhaus, Lynn Wheeler, Jo Bergholte; **UMN:** David Walk, Georgios Manousakis, Gaurav Guliani; **UNMC:** J. Americo, Deborah Heimes; **UTHSCSA:** Ratna Bhavaraju-Sanka, Carlayne Jackson, Pam Kittrell; **UTSW:** Sharon Nations, Nina Gorham, Phillip Reeder, Teresa Bosler, Jaya Trivedi; **UCDAVIS:** Brad Pollock; **OTHER:** Jon Katz, Rachel Richesson, Sally Dwyer, Tina Graber, Valeria Cwic

Height/Weight Cohort members in active and supporting roles currently include:

UTHSCSA (lead site): Daniel Hale (Lead), Alfredo Tirado-Ramos, Alex Bokov, Kimberly Summers, David Rupert, Rhonda Oilepo;

KUMC: Ann Davis, Sarah Schlachter (PMO), Holly Hull, Kimberly Johnson; **CMH:** Sarah Hampl, Laura Fitzmaurice, Rita Fothergill, Shelley Summar; **UIOWA:** Linda Snetselaar, Helena LaRoche, Lena Swander; **WISC:** Alex Adams, Larry Hanrahan; **MCRF:** Ram Pathak; **MCW:** Paul Knudson, Glenn Bushee, Sabrina Uppal; **UMN:** Jayne Fulkerson; **UNMC:** Ghada Soliman, James McClay; **UTSW:** Olga Gupta, Michele Hutchison, Jennifer Cai, Susan Morrison, Teresa Bosler;

GPC Governance Council:

The Governance Council consists of GPC Site PIs and two patient representatives. The Council reviews and approves GPC policies and standard operating procedures (SOPs), new institutional members, partnership relationships with PPRNs and external organizations, budgetary allocation, GPC core activities, and strategies for long-term sustainability. It is advised by three stakeholder committees (the Patient Advisory Council, the Health Systems Advisory Council, and the Clinical and Translational Science Advisory Council), each of which includes one representative from each GPC site. The Governance Council also oversees several central GPC functions related to assessing the suitability of new research opportunities, data queries, analysis and requests, and long-term sustainability of the GPC, including pricing of GPC services. The two core GPC agendas which are overseen by the Governance Council are CDRN data and informatics infrastructures, and collaborator engagement.

GPC Governance Council members currently include:

KUMC: Russ Waitman, Steve Fennel, Brittany Zschoche; **CMH:** Laura Fitzmaurice; **UIOWA:** Gary Rosenthal; **WISC:** Marc Drezner; **MCRF:** Robert Greenlee; **MCW:** Bradley Taylor; **UMN:** Constantin Aliferis; **UNMC:** James McClay; **UTHSCSA:** Alfredo Tirado-Ramos; **UTSW:** Lindsay Cowell; **IU:** Bill Barnett; **MU:** Jerry Parker; **UCDAVIS:** Brad Pollock

GPC Data Request Oversight Committee (DROC):

The Data Request Oversight Committee (DROC) has been established to review data requests from GPC investigators and external PCORnet investigators. Before any approval, the DROC, which includes patient representation, reviews the purpose of the request, verifies the identity of the requestor, and establishes their authority to request the type of data that they have requested. The DROC also helps to define the requirements, request management processes, and technical means to de-identify the systems and clinicians when desired or when necessary as a further step to protect the confidentiality of the data.

GPC Data Request Oversight Committee (DROC) members currently include:

KUMC: Russ Waitman, Tamara McMahon, Karen Blackwell, Chris Wittkopp, Cheryl Jernigan, Pam Mahoney; **CMH:** Warren Teachout, Laura Fitzmaurice; **UIOWA:** Prakash Nadkarni; **MCW:** Bradley Taylor, Glenn Bushee; **MCRF:** Peggy Peissig, Robert Greenlee, Laurel Verhagen; **UNMC:** Gail Paulsen; **UTHSCSA:** Angela Bos, Alex Bokov, Alfredo Tirado-Ramos; **UTSW:** DuWayne Willett, Teresa Bosler; **UMN:** Michelle Coady; **WISC:** Tom Mish, Umberto Tachinardi

GPC Honest Brokers:

GPC Honest Brokers are individuals identified and authorized by a GPC party to conduct queries on behalf of an affiliate investigator for approved feasibility queries and approved research projects, and to extract information (in the form of either de-identified information or a limited data set) from each GPC party's research repository.

GPC Honest Brokers currently include:

KUMC: Tamara McMahon; **CMH:** Laura Fitzmaurice; **UIOWA:** Prakash Nadkarni; **WISC:** Eneida Mendonca, Tom Mish; **MCRF:** Laurel Verhagen; **MCW:** Glenn Bushee, Kathy Williams; **UMN:** Supreet Kathpalia; **UNMC:** Jim McClay; **UTHSCSA:** Angela Bos; **UTSW:** Susan Morrison, Phillip Reeder

Patient-Powered Research Networks (PPRNs):

Patient Powered Research Networks are networks run by groups of patients and their partners who are focused on one or more specific conditions or communities, and who are interested in sharing health information and participating in research. They are motivated to build an ideal network and play an active role in patient-centered comparative effectiveness research.

American BRCA Outcomes and Utilization of Testing (ABOUT) Network

The ABOUT PPRN is the result of a 10-year collaboration between the leading national nonprofit advocacy organization for individuals and families impacted by hereditary breast and ovarian cancer (HBOC) – Facing Our Risk of Cancer Empowered, Inc. – and a team of researchers at the University of South Florida. These partners – led by patient advocates – have combined their strengths in advocacy, research, and engaging community participation to pursue better information, services, and outcomes for the patient community to which they belong, and to conduct collaborative research that involves patients at every level.

- **Represented by:** Colleen Maguire

Community Engaged Network for All (CENA) / Genetic Alliance

The Community Engaged Network for All (CENA) is a community of patient-led research networks dedicated to empowering individuals, families, and communities to share and learn from their own health information. Each research network is managed through a specific disease advocacy organization (DAO), representing more than 28 rare and common conditions. Together, the CENA DAOs work to engage their communities and build participant-centric research cohorts. Using a web-based tool called Platform for Engaging Everyone Responsibly (PEER), individual participants in CENA share health information, on their own terms, with researchers, organizations, and data analysis platforms of their choosing. They decide how much, with whom, and when to share.

- **Represented by:** Andrea Goodman

DuchenneConnect PPRN

DuchenneConnect is a self-report registry that began collecting data in 2007 as a community resource to facilitate and speed research in Duchenne and Becker muscular dystrophy. The current size of the network is over 3,000 and they estimate adding approximately 50 new registrants a month in Phase II. The fact that DuchenneConnect is a program of an advocacy organization (Parent Project Muscular Dystrophy) has strongly influenced the registry's goals, processes, and governance. Patient and caregiver engagement is at the heart of advocacy organizations and is deeply ingrained in their culture.

- **Represented by:** Ann Lucas

Multiple Sclerosis PPRN

The Multiple Sclerosis PPRN has been developed to advance and accelerate patient-centered research in multiple sclerosis (MS). From its inception, the network has harnessed the power and voice of the community of people living with MS. Its governing board and membership, communications, and research committees are populated by a majority of people with MS, committed to participating in and shaping MS research. The network is continually being enhanced through collaborative ties and diverse stakeholders including leading MS advocacy organizations, clinicians, MS researchers, and other member networks of PCORnet.

- **Represented by:** David Gwynne