Greater Plains Collaborative
Clinical Data Research Network
Greater Plains Collaborative (GPC)

Disease Cohorts: ALS, Breast Cancer, Weight

- **KS**: University of Kansas Medical Center (KUMC)
- **MO**: The Children’s Mercy Hospital
- **IA**: University of Iowa Healthcare
- **WI**: University of Wisconsin-Madison, the Medical College of Wisconsin, and Marshfield Clinic
- **MN**: University of Minnesota Academic Health Center
- **NE**: University of Nebraska Medical Center
- **TX**: University of Texas Health Sciences Center at San Antonio and University of Texas Southwestern Medical Center
Patient/Stakeholder Engagement in CDRN Activities

- **Local GPC partners:** Each local partner organization/site will have a group of local patients from each disease cohort.

- **GPC Cohort Engagement:** 2-3 members from across the local sites will work with the GPC-wide research leads for each cohort.

- **Patient and Community Engagement Leaders:** Patient and patient advocate volunteers from across the GPC will work with academic engagement leaders from each site and participate in GPC Community monthly calls.
  - A patient committee will also be established to advise the DROC on data sharing issues from a patient perspective.

- **GPC Leadership:** Volunteers from across the GPC sites will work with the GPC-ALL group and participate in bimonthly conference calls (GPC Global).

- **PCORI/PCORnet:** Volunteers from two GPC sites participate in the PCORnet Community Engagement Task Force.
Patient and Stakeholder Engagement in the GPC
Local GPC partners

• Each local partner organization/site will have a group of local patients from each cohort willing to participate in:
  • Solving local engagement challenges for CER and GPC
  • Idea generation of research interests
  • Vetting GPC and other local research activities germane to their group (ALS, BC, Weight) such as survey review, methods of engagement, remuneration of participants, etc.

• Group size is determined at the local level

• Expect a total of 30-100 patients/stakeholders from across all 10 sites
Cohort Engagement

• 2-3 patients/patient advocates identified at the local level will work with the GPC-wide researcher leads for each cohort (Barohn/Patel; Chrischilles; Hale)
  • Will participate in all cohort specific calls
  • Work at this level will help guide research and protocols that will be executed across all sites
  • Patient/stakeholders will partner with the specific cohort researcher leads to ensure input and direction
• Expect 6-9 patients/stakeholders
Patient and Community Engagement Leaders

- Patient/patient advocate volunteers from across the GPC sites will work with the academic engagement leaders from each local partner site and participate in the monthly calls
  - Support development and refinement of global, GPC-wide engagement approaches
  - Oversee and/or direct communications for recruitment and involvement for all 3 cohorts
  - Review engagement strategies recommended at the cohort level when appropriate
  - Group size is flexible but should include 5-10 patients/stakeholders from multiple GPC sites
- Expect 7-20 patients/stakeholders
GPC Leadership

• Volunteers from across the GPC sites will work with the GPC-all group
  • Participate in bimonthly conference calls (different representatives for the monthly call on cohorts and the monthly call on other “issues” (e.g., community/patient engagement)
  • Identify where other engagement circles should weigh in or be involved as the GPC evolves
  • Serve as a conduit of information from the GPC leadership to the cohort engagement circle or the patient and community engagement circle
  • Two-5 volunteers working closely together are desired