



# Greater Plains Collaborative

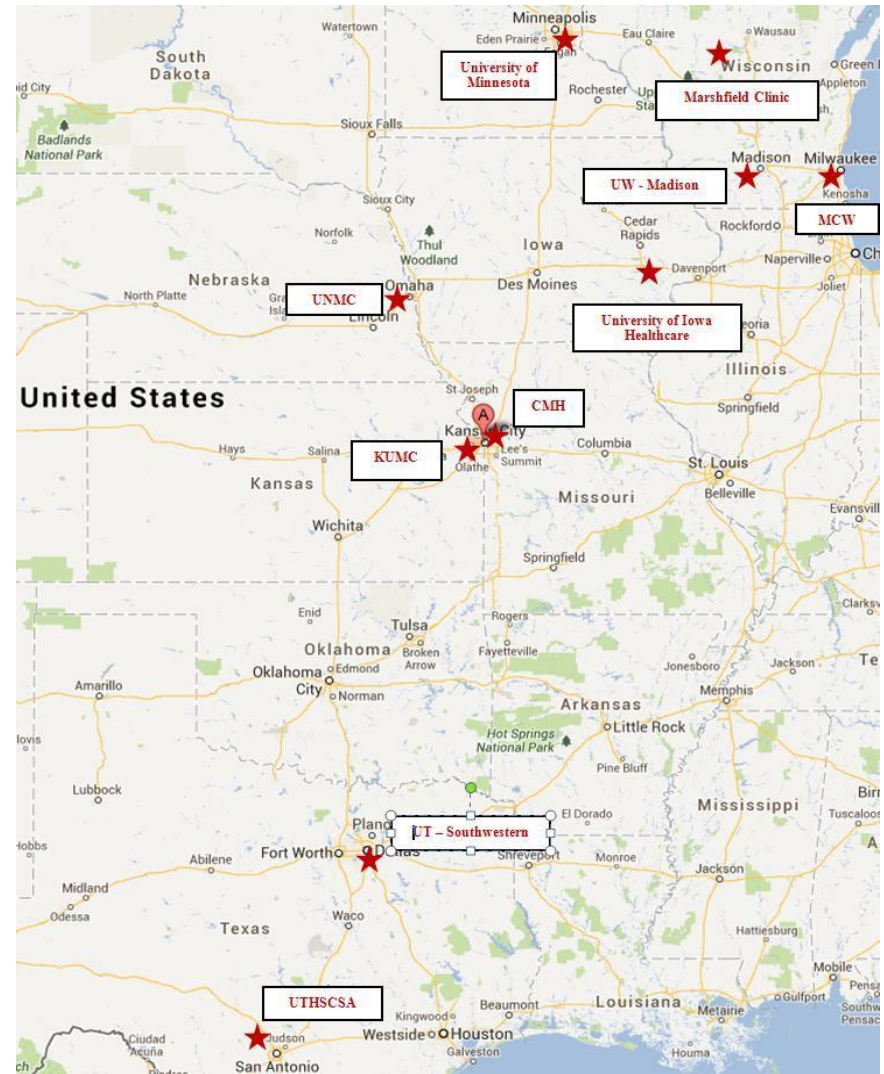
Clinical Data Research Network



# Greater Plains Collaborative (GPC)

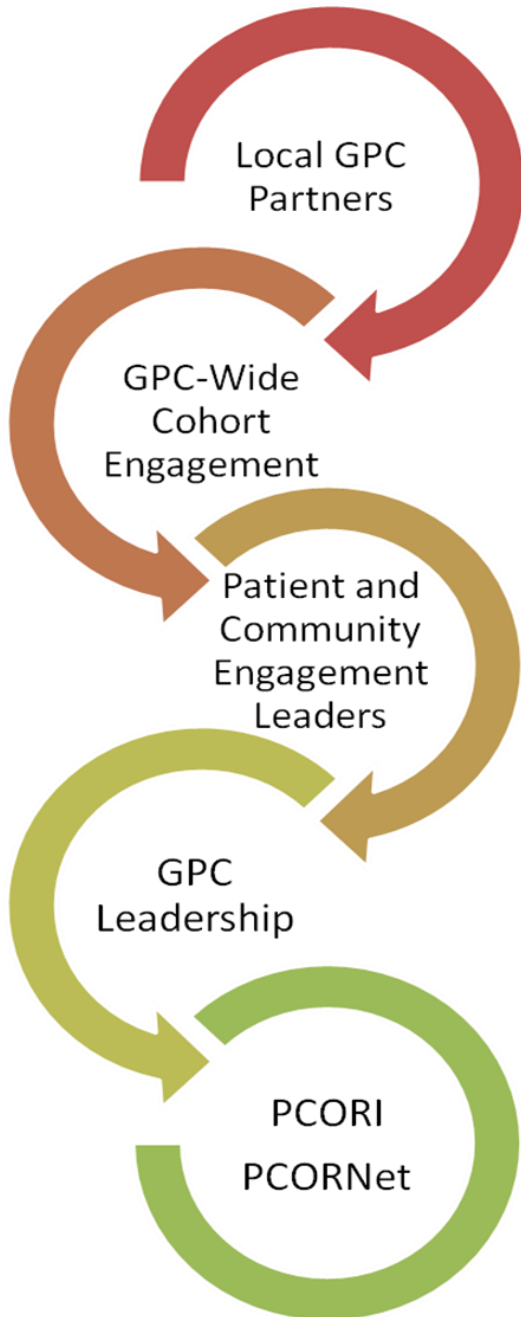
## Disease Cohorts : ALS, Breast Cancer, Weight

- **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

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- **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



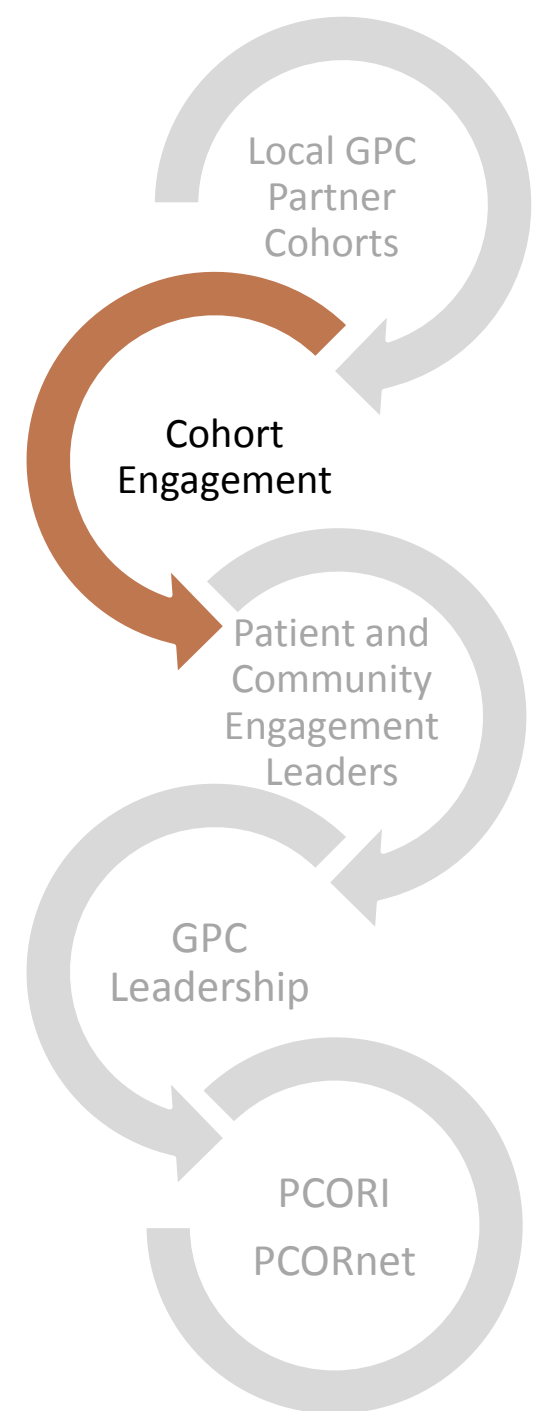
# Local GPC partners

- 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

