

ABSTRACT: 2016 ELAM Institutional Action Project Symposium

Project Title: Promoting a Breast Cancer Outcomes Research Integrated Network

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Background, Challenge or Opportunity: The Greater Plains Collaborative (GPC) is a new network of 12 medical centers in 9 states launched in April, 2014 as part of PCORNet: the Patient-Centered Outcomes Research Institute (PCORI) “network of networks” that includes health care data for over 75 million persons cared for in 130 US health care delivery systems. The purpose of PCORNet is to conduct patient-centered outcomes research including pragmatic comparative effectiveness trials. A number of PCORNet sites are associated with the 60 plus National Cancer Institute (NCI)-funded cancer centers. This affords an opportunity for PCORNet to complement the population-focused research agendas of NCI cancer centers. The GPC network is unique in its integration of standardized cancer tumor registries with electronic medical record data in its distributed data network. During Phase 1, the GPC established governance, IRB reliance, and data sharing agreements and demonstrated ability to select, survey, and characterize a cohort of breast cancer patients from across the network. In October, 2015 with GPC Phase 2 awarded, the GPC was given the opportunity to demonstrate a sustainable breast cancer research agenda.

Purpose/Objectives: To promote a breast cancer research agenda within the Greater Plains Collaborative (GPC) by integrating access to three national resources: NCI Cancer Centers, PCORNet, and Clinical and Translational Science Award Program Hubs

Methods/Approach:

- Evaluation of the Phase 1 pilot: Present findings to GPC leadership including recommendations for improvement.
- Stakeholder Engagement: Cancer Center Directors, patients, breast cancer researchers, informatics specialists, NCI and PCORI sponsors
- Virtual Team Building: Invite new members. Build trust through communication tools and collaborative publication policies, manage work through twice a month webinar check-ins and asynchronous document postings and emails, monitor progress through milestones and tracking, and enhance team visibility through frequent reports to the GPC Global Committee.
- Collaborative Paper Writing: Develop an efficient review process and distribute a well-documented linked survey-EMR-tumor registry database to paper-writing teams. Award small grants for analysis.

Outcomes and Evaluation Strategy: By evaluating the Phase 1 pilot, needed improvements to network processes and data quality were presented to decision-makers and scheduled for resolution. The GPC breast cancer interest group expanded to 58 members and 12 medical centers. Funds were secured from a contract amendment and pilot grants and discounted data analysis was made available from affiliated Cancer Centers. Twelve collaborative paper-writing teams were formed and supplied with data. A speaking engagement for the PCORI Executive Director was arranged for the annual meeting of the Association of American Cancer Institutes. Collaboration was launched with the PCORNet hereditary breast and ovarian cancer patient network. Expected longer term outcomes include grants, presentations, publications, and expansion of this model to other cancer types and other networks.

PROMOTING A BREAST CANCER OUTCOMES RESEARCH INTEGRATED NETWORK

BACKGROUND/OPPORTUNITY

PCORNet: the Patient-Centered Outcomes Research Institute (PCORI) “network of networks”:

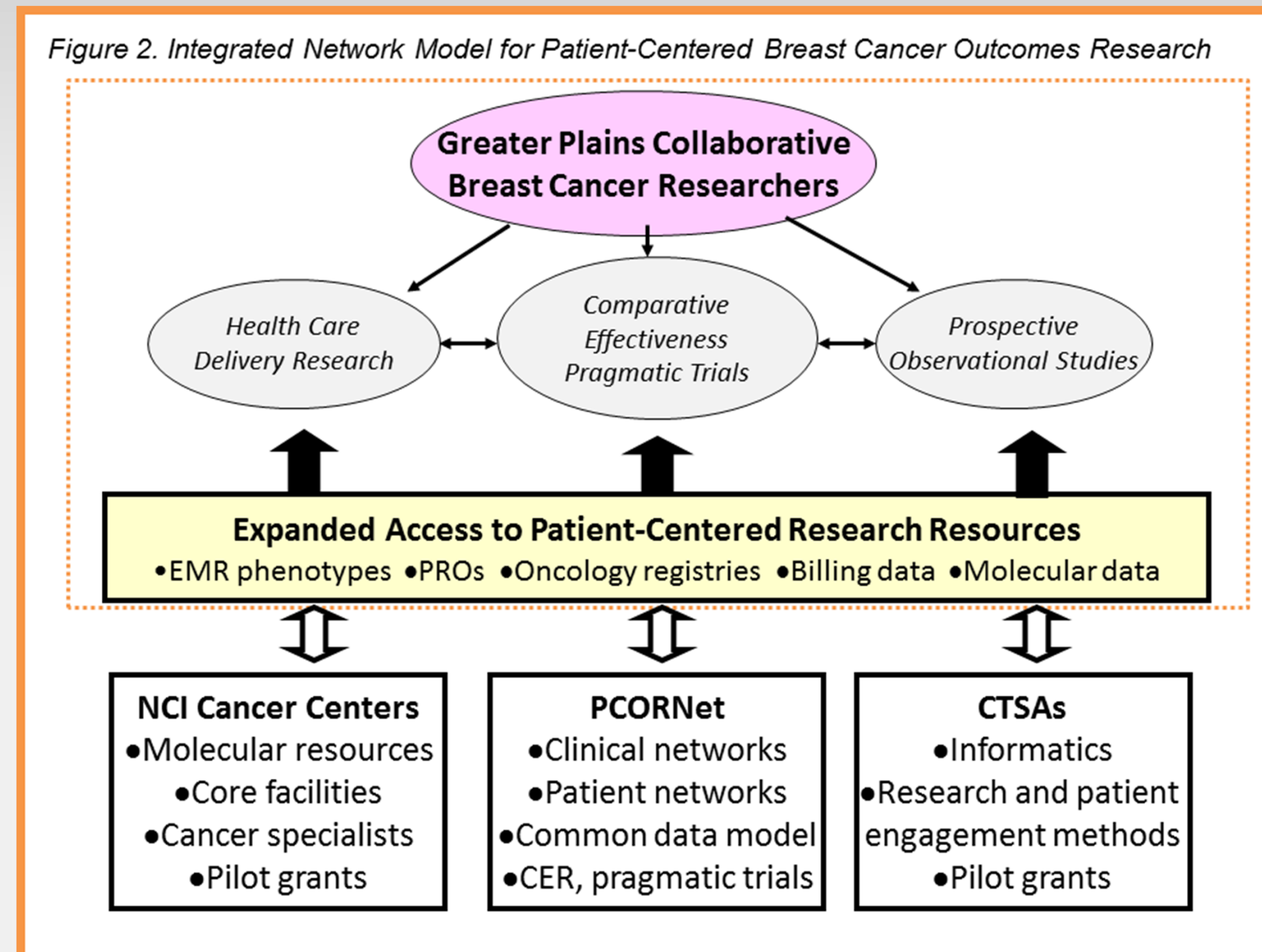
- Includes health care data for over 75 million persons cared for in 130 US health care delivery systems
- Many PCORnet sites are associated with the 60 plus National Cancer Institute (NCI)-funded cancer centers
- Opportunity for PCORNet to complement the research agendas of NCI cancer centers

The Greater Plains Collaborative (GPC) (Figure 1) is a PCORNet network:

- Unique in its integration of standardized cancer tumor registries with electronic medical record (EMR) data in its distributed data network
- During Phase 1, the GPC established governance, IRB reliance, and data sharing agreements and demonstrated ability to select, survey, and characterize a cohort of breast cancer patients from across the network
- In October, 2015 with GPC Phase 2 awarded, the GPC was given the opportunity to demonstrate a sustainable breast cancer research agenda

PURPOSE

To promote a breast cancer research agenda within the Greater Plains Collaborative by integrating access to three national resources: NCI Cancer Centers, PCORNet, and Clinical and Translational Science Award Program Hubs (Figure 2)



METHODS/APPROACH

Evaluate the Phase 1 pilot

- Present findings to GPC leadership including recommendations for improvement

Stakeholder Engagement

- Cancer Center Directors, patients, breast cancer researchers, informatics specialists, NCI and PCORI sponsors

Virtual Team Building

- Invite new members
- Build trust through communication tools and collaborative publication policies
- Manage work with twice a month webinars and asynchronous document postings
- Monitor progress through milestones and tracking
- Enhance team visibility through frequent reports to GPC Global Committee

Collaborative Paper Writing

- Test the concept of “writing teams” for generating collaborations and managing overlap
- Distribute a well-documented database to all paper-writing teams
- Provide small grants for analyst time & discounts from Cancer Center Biostatistics Cores

OUTCOMES & EVALUATION STRATEGY

- By evaluating the Phase 1 pilot, needed improvements to network processes and data quality were presented to GPC decision-makers and scheduled for resolution
 - By attention to virtual team building, 12 collaborative writing teams submitted proposals to write papers together
 - Visibility for breast cancer research in the GPC was increased by presentations to the GPC and PCORI leadership and to NCI Cancer Center Directors
 - See Table 1 for short-term metrics and results
- Expected longer term outcomes** include national presentations, published papers, funded grants, and expansion of this model collaboration to include other cancer types and other networks

Table 1. Metrics and Results

Metric	Result
Number of members involved	58 people, 12 institutions
Publication policies established	November 2015
Findings of Phase 1 pilot evaluation presented to GPC leadership	January 2016. Recommended improvements were prioritized and added to GPC web-based software project management and bug/issue tracking system
Publications Committee recruited	March 2016
Collaborative writing teams approved	12 Topics include aspects of decision-making (7 papers) and survivorship (5 papers)
Linked dataset distributed to writing teams	March 2016
Presentations to GPC leadership	GPC Principal Investigators, PCORI Project Officer, PCORI Executive Director
Support secured from CTSAs and Cancer Centers	Pilot grant, discounts on data analysis by biostatistics cores, prep-for-research queries by informatics cores
Participation of patient communities	Launched collaboration with hereditary breast and ovarian cancer patient network
Engagement of NCI Cancer Centers	Presentation to Association of American Cancer Institutes scheduled (July 2016)

NEXT STEPS

Continue twice-monthly webinars, submit abstracts to San Antonio Breast Cancer Symposium, collaborate with the hereditary breast and ovarian cancer patient network to develop PCORNet designation as a Cancer Cross-Cutting Research Group, conduct preparatory-to-research database queries & pilot studies, submit PCORI Letter of Intent November 2016

Figure 1. Greater Plains Collaborative Member Institutions

