



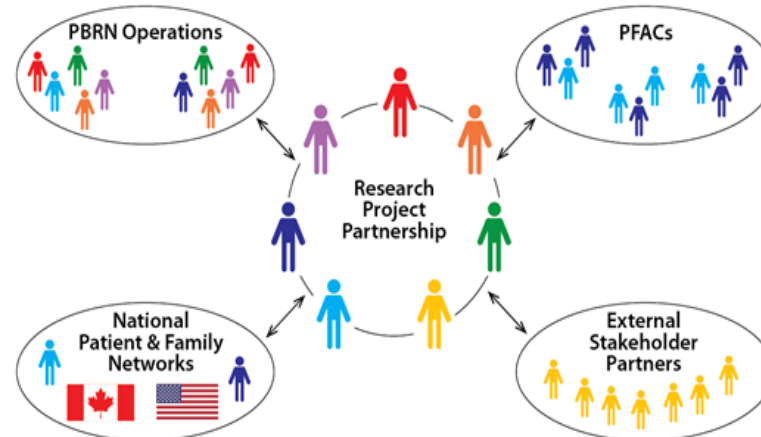
# Effectively Engaging Patient Family Advisers in a Complex Cluster Randomized Trial About Advance Care Planning in Primary Care

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**Background:** Meta-network Learning and Research Center (Meta-LARC) is conducting a cluster randomized trial to improve goal concordant care for primary care patients with serious illness via Advance Care Planning (ACP). This study inherently emphasizes the importance of patients and families actively participating in the planning and execution of ACP because discussing values, preferences and care options is central.

**Methods:** The study team developed a nationally recognized comprehensive engagement plan, including a diverse group of partners in all aspects of the project. This team sought stakeholder input, surveying researchers, clinicians, and Patient Family Advisors (PFAs) in order to develop and come to an agreement on a set of shared goals. The approach to process and outcomes monitoring is designed to support this set of shared goals. Monitoring of engagement and ongoing support are needed to create meaningful and successful interactions, contributions, and overall meeting the personal reasons why each person is participating in the project. Ongoing engagement capacity development and improvement is facilitated using a systematic and formal approach to Continuous Quality Improvement (CQI). In order to measure the efficacy of this engagement plan and capacity for effective engagement, annual qualitative interviews were conducted using a semi-structured interview guide with the PFAs to collect facilitators and barriers, as well as general PFA perception. Between years one and two of the study, 18 interviews ranging from 20-55 minutes were conducted and analyzed for key themes and emerging trends around PFA experience in the study.

“I think that as the project evolves into **implementation and managing the intervention** – the role of the PFAs will obviously evolve along with that...I probably get more than I give because it **really relates to me and my family**. I just really like the project. My feelings are an example of the way a patient gets engaged – when there is a project with added value and applicable to everyday life.” (Interviewee #8)



\*Figures represent types of participants, not the number of members.  
Color Key: dark blue=patients; light blue=families; orange=primary care clinicians; green and purple=primary care staff and administrators; yellow=external stakeholders; red=researchers (Investigators and staff)

## Results:

- PFA feedback about their involvement has been overwhelmingly positive.
- All interviewees expressed satisfaction with their contributions and level of participation.
- PFAs have a comprehensive understanding of their role in the project.
- Good communication was another hallmark, including digital and in person connection.
- PFAs talked about their excitement for future participation in the project.
- An additional finding was the positive impact ACP had on PFAs’ personal lives.

**Conclusion:** This project has demonstrated the importance of PFAs in not only ACP, but primary care research at large. In addition, the methods developed in the engagement plan have been established as effective guidelines for meaningful partnerships and bidirectional communications between researchers, clinicians, patients, and the community.

## Meta-LARC Advance Care Planning Trial [PrimaryCareACP.org](http://PrimaryCareACP.org)

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## Engagement Partner Goals

- ✓ Guide creation of training tools and workflows.
- ✓ Ensure patients and families questions are answered.
- ✓ Guide how SICP is implemented.
- ✓ Help integrate ACP as routine in primary care.