



# Implementing a Patient-Family Advisor Engagement Structure in a Complex Clinical Trial: Lessons from the Meta-LARC Advance Care Planning (ACP) Study

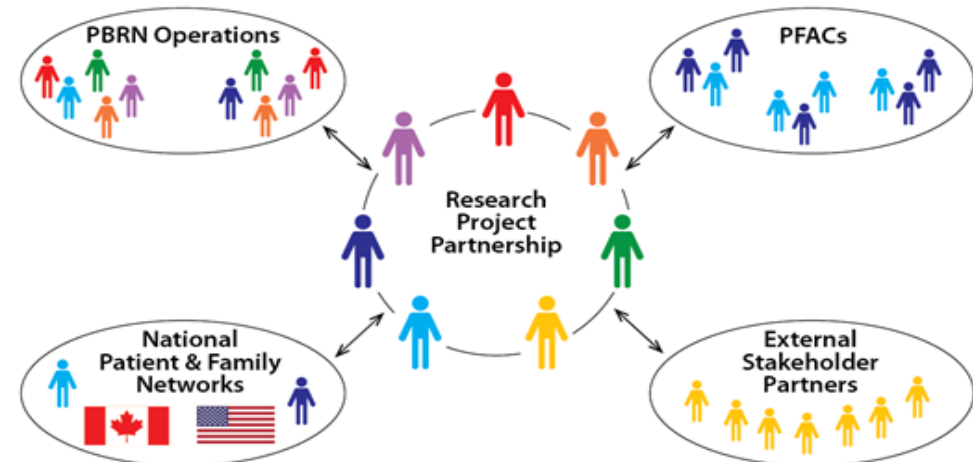
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## Overview

Meta-LARC, a consortium of seven Practice Based Research Networks (PBRNs) in five US states and two Canadian provinces is conducting a cluster randomized trial of two models of ACP for patients with serious illnesses to compare the impact of clinician-focused to team-based ACP in primary care practices. This study emphasizes the importance of patients and families participating in the planning and execution of ACP. Therefore, a strong plan for implementing, evaluating, and improving the ACP Patient Family Advisor (PFA) program was critical.

## Methods

- We created a comprehensive engagement plan that included overall structure, key activity timeline, partner preparation, recruitment and retention, process for monitoring outcomes, seeking input, and surveying stakeholders and PFAs regarding what their goals were.
- Annual impact tracking data reports were used to collect participation rate, type, level, and implementation to monitor engagement outcomes and changes.
- Annual data was reviewed for ongoing engagement capacity development and improvement. This was done through regular surveys of partners via quarterly follow-up meeting experience surveys of the PFAs and research team, supplemented with annual evaluation of PFA involvement tele-interviews.



\*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)





## Year One



13 Active PFAs

# Results

## Year Two

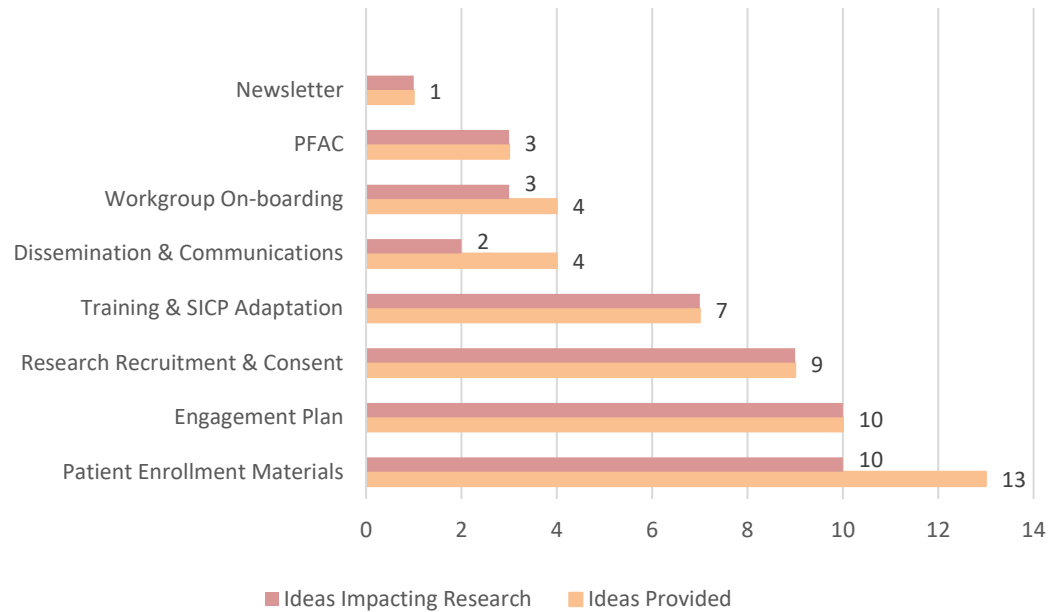


12 Active PFAs

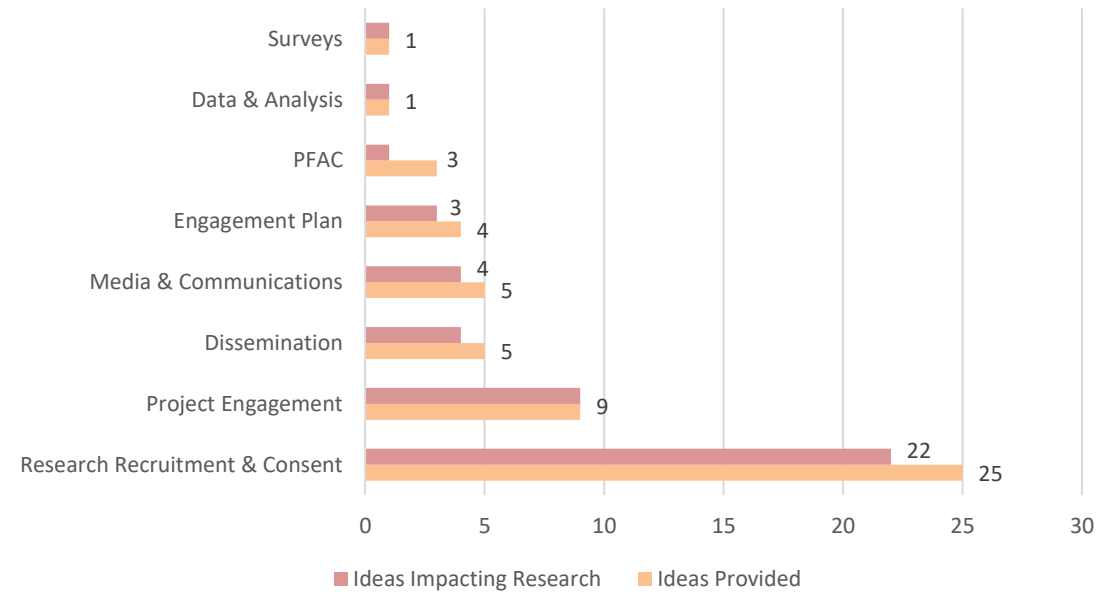
**Ideas Provided: 51 Ideas Impacting Research: 45 Impact: 88%**

**Ideas Provided: 55 Ideas Impacting Research: 47 Impact: 86%**

Year One Ideas Generated by PFAs



Year Two Ideas Generated by PFAs



Number of PFA Activities	Number of Meetings with PFAs & Researchers	Number of Meeting Hours
57	73	111.25

Number of PFA Activities	Number of Meetings with PFAs & Researchers	Number of Meeting Hours
63	43	46



## Engagement Lessons Learned

<b>Job Descriptions and Involvement</b>	Role descriptions and scope should be articulated and shared with potential PFAs before the project starts.  Key opportunities for early input, are deemed critical and valuable.
<b>Preparation for Role Change</b>	As part of the job description and initial orientation of the PFAs, planning for change in type and frequency of engagement activities is important.
<b>Separating PFA Meetings from Research Project Partner Meetings</b>	Having two groups allows for more space for feedback and discussion and ultimately improved recommendations and outcomes.
<b>Field Involvement</b>	PFAs were not heavily involved in the clinic training process, however, they felt it would be very valuable to have the patient perspective during training. Further, PFAs expressed an interest in engaging in the field more.

### Conclusion

Between years one and two of the project PFA engagement and contribution was significant and made a positive impact on the project. As the project evolved, the type and amount of engagement also adapted. These changes allowed for PFAs and researchers to identify key learning outcomes that could inform future engagement plans for complex research studies.

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

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## Summary of Ideas and Recommendations

Year One	Sequence of events provided to patient after referral Provide understanding of scope of study and its importance What is important to tell patients when introducing the project Define opt-out options and compensation on materials Include PFA video testimonials to provide patient perspective in SICP training materials Include clinician time for reflection in SICP training
Year Two	Use PFAs to provide local context and experience to recruitment Provide understanding of scope of study and its importance What is important to tell patients when introducing the project Define opt-out options and compensation on materials Document reasons for declined participation and data management Include PFA tested language in recruitment and survey scripts

### Implications

PFA engagement in research requires:

- Skill development through expert consultation and coaching.
- Comprehensive planning including processes and outcomes.
- Defined roles and responsibilities.
- Flexibility to adjust to study phases.

These components require:

- A significant amount of time and effort.
- Continued development and cultivation on the part of PFAs and researchers.

**The potential for engagement to improve research through collaboration can be increased as projects share strategies and lessons.**