Background and aims: Advance care planning (ACP) has the potential to reduce suffering and improve outcomes in serious illness, but its implementation has been limited. A consortium of seven Practice Based Research Networks (PBRNs) in the US and Canada known as Meta-LARC designed a cluster randomized comparative effectiveness trial of two models of ACP in primary care practices.

Methods: Meta-LARC facilitated identification of primary care concerns and topics through collaboration among researchers, PBRN directors, clinicians and patient/family advisors. Over 2 months, we used the PBRNs to quickly assess interest, develop options, assess feasibility, refine ideas and obtain buy-in. Through this iterative process, we identified an existing ACP program to study (the Serious Illness Care Program by Ariadne Labs) and developed a proposal, research protocol and a stakeholder engagement plan.

Results: The trial, agreed to by all seven PBRNs, was funded by the Patient Centered Outcomes Research Institute and began in November 2017. This panel will discuss the key decision steps and drivers for the trial design (Part 1) and the accomplishments to date including engaging stakeholders (Part 2), adapting ACP training for teams (Part 3), obtaining ethics approval in two countries (Part 4), supporting ACP implementation in diverse primary care practices (Part 5) and developing patient-reported measures of goal concordant care (Part 6).

Conclusion: PBRN networks provide an important infrastructure that can facilitate design of a large, complex study of ACP with the potential to influence the spread of ACP in primary care practices in at least two countries.

Background: Patient and family engagement is essential to community-based pragmatic research. After our study of advance care planning (ACP) in primary care was funded, we expanded the proposal and developed a detailed Engagement Plan (EP) to accompany the study protocol.

Methods: We established a cohort of 11 Patient and Family Advisors (PFA) to guide the project; seven associated with participating PBRNs and four unaffiliated at-large PFAs (2 US; 2 Canadian). During project initiation, the joint coordinating center established a working committee to develop an EP using the PCORI template. We surveyed PFAs about goals, solicited feedback from PBRNs and engagement experts, distributed planning assignments, and shared drafts with stakeholders.

Results: The EP was developed based on a quality improvement approach in which monitoring, measuring and improving engagement is the focus. Monitoring engagement includes baseline assessment of needs, quarterly surveys and annual check-ins. Engagement measurement tracks stakeholder inputs and resulting impact on the project and establishes processes to support participant recruitment and retention. PFA-identified goals form QI targets and inform strategies to clarify expectations, forms of participation, and documenting and communicating the impact of PFA contributions. The EP will be updated twice annually.

Conclusion: Creating a formal EP allowed operationalization of our commitment to PFA engagement and integration into multiple aspects of the study. Making the plan a living document allows us to identify challenges, address issues, and document our experience. Approaching engagement as a component of trial design and execution facilitates development of best practices and science around engagement.