

OCHIN-ADVANCE PATIENT AND CAREGIVER ENGAGEMENT VALUES, FUNCTIONS, AND METRICS

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Core values, central practices, and engagement metrics in OCHIN-ADVANCE:

1. Integrate patient and caregiver experience and expertise
 - Develop and maintain sustainable, adaptive mechanisms for patient and caregiver input, consultation, collaboration, and/or partnership:
 - In the research process (e.g., Patient Engagement Panel, patient advisors or study panels, affiliate practice-based research networks)
 - In network governance and development (e.g., ADVANCE patient investigator, Patient Engagement Panel)
2. Elevate patient and caregiver experience and expertise
 - Support patients and caregivers with baseline and ongoing training and learning resources to strengthen research understanding and input
 - Train and support research project teams and investigators in eliciting, maintaining, and integrating patient and caregiver collaboration and input to research
3. Implement changes
 - Implement patient and caregiver feedback suggested changes or other input to research activities and practices
4. Report impact
 - Document implementations, adaptations, feedback not included
 - Report back to patients and caregivers contributing to proposals, projects, or network related activities
 - How contributions were integrated, including any changes or adaptations
 - Known or anticipated impacts (e.g., improved patient centeredness, priority alignment)
5. Collaborate on proposal development
 - Establish clear expectations and processes to integrate patients and caregivers in proposal development. Key points for involvement in proposal development include describing the topic area or research need, framing of the research question and associated outcomes, engagement and recruitment methods, and community-oriented (non-academic) dissemination.
 - Prioritize patient and caregiver involvement in proposal development as Patient Investigators for projects with higher levels of engagement and recruitment complexity, especially those that include patient-reported or person-centered outcome measures.
6. Collaborate on engagement and recruitment approaches
 - Involve patients and caregivers in engagement and recruitment planning, implementation, evaluation, and learning
 - Consult or collaborate on recruitment materials and approaches as well as data collection tools and methods based on study settings, topic areas, and communities/populations of interest

- Share engagement and recruitment materials and approaches among partners, collaborators, and network members
7. Engage patient and caregiver collaborators with relevant lived experiences
- Maintain and develop diverse PEP membership to provide representation from communities and health experiences across the OCHIN and ADVANCE networks
 - Regional location (northeast, southeast, midwest, northwest, southwest)
 - Age
 - Race and ethnicity
 - Sexual orientation and gender identity
 - Health conditions, especially chronic conditions
 - Caregiving
 - Insurance status
 - Align patient investigator, panelist, and advisor experiences and interests with project topic areas or engagement and recruitment approaches
 - Apply multiple recruitment approaches including peer-to-peer, outreach through member health centers, word of mouth with research partners and collaborators, direct outreach to member or partner patient and caregiver advisory groups
8. Measure engagement together
- Incorporate patient and caregiver feedback in selecting and setting metrics
 - Gather individual feedback and input on patient and caregiver engagement and PEP operations on at least annual basis with priority partners:
 - PEP members
 - Patient investigators (if not on the PEP)
 - Report back on engagement activities and infrastructure to patients and caregivers, project teams, and funders on a regular basis (at least annually)

Figure 1: Patient and caregiver engagement functions and metrics

	Engage	Educate	Facilitate	Integrate	Participate	Translate	Disseminate
Functional activities	Outreach and recruitment	Onboard and train via 1:1s and other formats or venues as needed	Orient to the group or study, prepare for participation <ul style="list-style-type: none"> - Values and norms - Invitations and expectations 	Adapt or develop engagement infrastructure, processes, and approaches based on input	Contribute to proposal development, study planning, materials and activities, interpretation, dissemination	Work with other collaborators, partners, and study team members to interpret and frame study findings and project outcomes	Plan dissemination and communications strategy to include academic and community-focused efforts, collaborate in crafting and sharing messages and content
Metrics	PEP membership Number of projects and engagement roles <ul style="list-style-type: none"> - Proposals - Funded projects - Letters of Support 	Number of trainings <ul style="list-style-type: none"> - Format - Participants - Topic area - Developer 	Number of meetings Asynchronous participation and feedback	Outreach activities (e.g., PEP 1:1s, Learning Forum, PCORI Annual Meeting) Documented recommendations, implemented changes and/or adaptations	Number of projects <ul style="list-style-type: none"> - Research cycle point - Type of contribution (e.g., development, review, co-author) 	Number of meetings Asynchronous participation and feedback Number and format of follow up/report back activities	Number of papers, posters, presentations co-authored Number of non-academic dissemination activities

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