ADVANCE PATIENT AND CAREGIVER ENGAGEMENT VALUES, FUNCTIONS, AND METRICS

Version 2, 30 November 2020

Core values and central practices in ADVANCE engagement:

1. Integrate patient and caregiver voices
   - Develop and maintain sustainable, adaptive mechanisms for patient voices in the research process (e.g., Patient Engagement Panel, patient advisors or study panels, ADVANCE and affiliate practice-based research networks)

2. Elevate patient and caregiver voices
   - 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 to patient and caregiver collaborators
   - Report back to patients and caregivers who provide input to proposals and projects how their feedback was integrated, if their feedback led to any changes or adaptations, and known or anticipated impacts (e.g. improved patient-centeredness of a tool, better aligned outcome measures with patient priorities)

5. Patient and caregiver review of proposals
   - 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. Patient and caregiver-informed recruitment
   - Engage patients and caregivers in the collaborative development of recruitment strategies, materials, and solutions based on study settings, topic areas, and communities/populations of interest
   - Share recruitment strategies 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 common across the OCHIN and ADVANCE networks
  i. Age
  ii. Race and ethnicity
  iii. Sexual orientation and gender identity
  iv. Health conditions, especially chronic conditions
  v. Caregiving
  vi. 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
• Report back to patients and caregivers, project teams, and funders on a regular basis (at least annually)

Figure 1: Patient and caregiver engagement functions and metrics

<table>
<thead>
<tr>
<th>Engage</th>
<th>Educate</th>
<th>Facilitate</th>
<th>Integrate</th>
<th>Participate</th>
<th>Translate</th>
<th>Disseminate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outreach and recruitment</td>
<td>Provide onboarding and research trainings via 1:1s and other formats or venues as needed</td>
<td>Orientation to the group or study, preparation for participation</td>
<td>Adapt engagement structure based on member feedback (primarily from annual 1:1 reviews)</td>
<td>Development of study materials and activities, completion of materials and activities, contribute to interpretation, take part in dissemination planning</td>
<td>Work with other collaborators, partners, and study team members to interpret and frame study findings and project outcomes</td>
<td>Plan dissemination strategy to include academic and community-focused dissemination, collaborate in crafting and sharing messages and content</td>
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<tr>
<td>25 ADVANCE projects</td>
<td>&gt;30 1:1 meetings with PEP members</td>
<td>7 PEP meetings</td>
<td>&gt;30 1:1 meetings with PEP members</td>
<td>3 ADVANCE studies completed in 2020</td>
<td>6 PEP meetings</td>
<td>5 ADVANCE blog posts, monthly dissemination on OCHIN website</td>
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