

Table 2A. Examples of Engagement Impact

Impact	Examples of Engagement Impact
Relevance of research question	<p>The patient family partners (PFP) highlighted the importance of measuring quality of life and agreed to importance of capturing impact on acute care use.</p>
Study design process and outcomes	<p>During PFP meetings, the partners repeatedly voiced the need for information about COPD, its treatment, and ways to self-manage it. They proposed using groups ‘like this one’ to communicate about these issues and support each other.</p> <p>PFP members provided ongoing and timely feedback about the planned research; this ensured that interventions within the study addressed important issues, remained relevant to people with COPD and were feasible in practice. They provided critical input in setting the goals and aims of the study. They engaged in multiple discussions during regularly held meetings where intervention materials and content were reviewed and edited per group feedback. They also actively participated in the drafting and revising of study recruitment materials.</p>
Study rigor and quality	<p>The Peer mentors/ BREATHE Pals (the peer mentors in the BREATHE2 Study were called ‘BREATHE Pals’, a suggestion from the patient family partners) were very engaged in delivering the peer support activities and we have elicited their feedback on their experience with the program, its implementation, and their recommendation for future improvements. We have also elicited feedback on the same areas from patient and caregiver participants who were randomized to receive the peer support program.</p> <p>Close work with the patient and caregiver co-investigators and the patient and family partners have led to the intervention being tested in this study. For example, for the peer support program Get-Togethers activities, the research team including the patient and caregiver co-investigators developed an initial set of opening questions for each group event and proposed ice breaker activities. The initial plan was drafted as a table by the Intervention Development Workgroup, which includes patient and caregiver co-investigators and researchers. This draft was then reviewed in detail at the study's second joint team bi-annual meeting (which includes researchers, all patient and family partners, and stakeholders). We got further feedback from patient family partners on how to phrase the questions pertaining to patient-caregiver relationship and on specific icebreaker activities that the partners thought was 'worthy' of repeating at multiple sessions. Based on this feedback a final set of opening questions and icebreaker activities were developed</p>
Recruitment	<p>Positive impacts of stakeholder engagement included facilitation of intervention implementation (e.g. finding rooms for Get-Togethers, getting volunteer status for the peer mentors) and recruitment efforts (e.g. creating EPIC reports to aid screening and recruitment activities). All recruitment materials were co-developed with patient partners and stakeholders. Later in study, the patient and family partners proposed creating a video to help with participant recruitment and future engagement in study interventions. The video would bring in the 'patient voices' and will describe goals of the study and its interventions. The partners proposed ideas about the key message for that video which is that “there is hope after COPD diagnosis and one may have good quality of life while living with COPD”. We worked with our Hopkins communications and marketing team and patient and family partners to develop this and used in study recruitment activities with good results.</p>

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<p>Transparency of research process</p>	<p>We had an ongoing robust patient and family engagement process including having a patient and family partners group that meets independently throughout study period and jointly with research team. We also have patient and a caregiver co-investigator on the research study who are very engaged with all research activities</p> <p>The experiential knowledge of partners (including their judgment and values) has been utilized throughout the research process, in a plethora of different ways and at many different levels. Patient and stakeholder perspectives have shaped the informed consent document and how we presented the study to potential participants. Later in study, the patient and family partners proposed creating a video to help with participant recruitment and future engagement in study interventions. The video brought 'patient voices' into the recruitment process. The partners proposed ideas about the key message for that video which is that “there is hope after COPD diagnosis and one may have good quality of life while living with COPD”. We worked with our Hopkins communications and marketing team and patient and family partners to develop this and used in study recruitment activities with good results. Furthermore, the BREATHE Pals (patients and caregivers providing peer support) provided their feedback on areas for future improvement for study intervention.</p>
<p>Adoption of evidence into practice</p>	<p>One unique benefit of patient and broad stakeholder engagement in this study is that it helped create a sense of ‘ownership’ of the program by the partners and stakeholders. This led to more ‘buy in’ and support for the study as it is nearing its end.</p> <p>Patients, caregivers, and stakeholders have been engaged in discussions about mechanisms for sustaining peer support delivery to study participants post end of research period. We have agreed based on discussions with study partners and stakeholders about mechanisms for future peer support to study participants post research period end, to inform participants about a variety of options to receiving peer support. Those include COPD Foundation support line, Better Breathers club groups (these are sponsored by the American Lung Association), and a local support group facilitated by one of the BREATHE Pals with support from one of the study sites (Howard County General Hospital).</p>