Appendix B. Recommended Steps for Implementing the BREATHE2 Program

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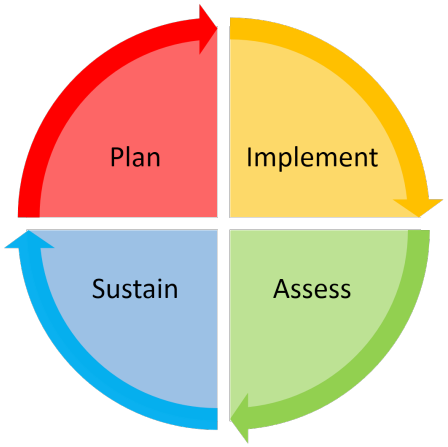
In writing this implementation guide, we adapted a similar approach to that we developed in an earlier PCORI funded project in which we provided general guidance on how to establish a peer support program.[1] We organized our guide to implementing the BREATHE2 program in 4 stages:



1. Plan

The initial planning involves outreach to key stakeholder to seek their perspectives on starting the program and ensure their buy-in. It is important to helpful to seek the endorsement of physicians particularly pulmonologists and other health care professionals, as well as that of relevant administrators within the health care system(s). Keeping these stakeholders well-informed about planned program activities will facilitate future collaboration. In our study, we found that stakeholder buy-in (particularly of the medical providers) was very important for program participants' enrollment and participation in program activities. Moreover, having the support of hospital administrators and medical personnel helped to alleviate logistical and administrative challenges that often arise when planning a new program.

Key decisions to think through at this stage are the scope of the program (e.g. what hospitals and medical facilities it will accept participants from); where it would be embedded (e.g. would the program be part of a hospital's patient education and coordination services, population health or social work division, or embedded in a medical department such as Medicine or Pulmonary division); who would be the leaders accountable for the program, hiring program staff, and budgeting for program expenses; who will serve as Program Coordinator; will the

meetings be held on hospital/health system grounds or in the community (e.g. in our study, we opted for having meetings on hospital campus as both coordinators and peer supporters felt safer to be close to an emergency department and have oxygen outlets in the room).

The choice of the program coordinator is very important as the coordinator plays essential roles in this program (see the sample coordinator job description at end of this guide). It is best to recruit a coordinator who is very familiar with the health care system and available social services, who preferably has worked with elderly patients with chronic illnesses, and who has experience with facilitating group conversations and training in provision of counseling services. In our study, we planned to have a licensed clinical social worker as program coordinator. The coordinator was responsible for the recruitment, training, and supervision of the peer supporters (also called BREATHE Pals). She discussed the programs goals, requirements and expectations with each candidate volunteer and determined their appropriateness to be a BREATHE Pal, in consultation with BREATHE 2 Study PI. The coordinator was responsible for matching BREATHE Pals with program participants, facilitated the group events, offered support services to the BREATHE Pals, and helped study participants who were facing any obstacles preventing them from receiving healthcare and accessing available supportive services.

Examples of the BREATHE2 program materials are provided at the end of this guide. Development of these materials involved an iterative collaborative process that involved researchers, clinicians, and patient/caregiver partners. Our goal was to develop materials that were brief, clear, and easily understandable. In order to facilitate group events and ensure a respectful and welcoming environment in which the BREATHE Pals and participants would feel free to share their experiences, we also developed a set of Rules for Engagement (also provided at end of guide).

2. Implement

Implementation of the peer support program requires trained peer supporters, engaged program participants, meeting location and supplies, a process for matching participants and supporters, and documentation tools.

The BREATHE Pals are nominated by physicians and/or health care providers. They are patients and caregivers who have successfully learned how to manage their COPD and are ready to provide peer support to other program participants. To qualify to become a patient peer supporter in the BREATHE2 program, one must have COPD, be a current non-smoker, and have completed an acute pulmonary rehabilitation program, thus serving as a positive role model. The BREATHE Pals receive special training for this role and complete all the requirements for becoming volunteers at the healthcare site. Peer supporter training topics included listening, empathy, effective communication skills, and general peer support skills, as well as discussion of COPD-specific topics, common questions and challenges with COPD, and local resources available for COPD patients. Peer supporters also receive training on HIPAA and confidentiality. Rules of engagement are also established and revisited periodically to safeguard a confidential, non-judgmental, and respectful environment in which all participants feel free to share their ideas and/or suggestions.

Strategies to communicate about the program to potential participants and ensure a sufficient number participating in program activities can vary according to recruitment setting and patient subgroups. Multiple modalities to communicate about the program are needed. In this study, we used recruitment materials such as flyers, brochures, videos, and letters that were reviewed by patient advocates and study co-investigators to help maximize patient interest. Patient participants and their caregivers were recruited from multiple settings including hospitals and pulmonary and primary care clinics. The research team collaborated with case managers, physicians, and other health care professionals to identify potential candidates. The endorsement of the program by physicians and other health care providers enhanced patient buy-in and participation.

Other important considerations for successful implementation include addressing logistical concerns such as determining the location of the group events, offering parking for peer supporters and study participants, improving accessibility for wheelchair-bound participants and/or participants using oxygen devices, obtaining rooms equipped with oxygen access, and acquiring transportation for low-income participants to and from group events. In our study, we held meetings at midday and offered lunch at meetings, which was highly valued by event participants.

The program coordinator matches participants with BREATHE Pals upon entry into the program based on preset criteria and supporter availability. Priority is first given to matching patients with patient supporters and caregivers with caregiver supporters. Other considerations include oxygen use and gender.

Some level of documentation of program activities will always be needed, such as documentation of when events took place and conversations with participants that require follow-up (e.g. a participant requesting help in accessing particular services). Documentation tools should consider what is feasible to use by the peer supporters and still protect privacy of the participants. In our study, the coordinator used a secure database to document conversation with participants and the peer supporter used brief paper forms that they kept in a secure location and then handed in to the program coordinator.

3. Assess

While proving peer support services, peer supporters received continuing support from the Peer Support Program Coordinator. Peer supporters were encouraged to reach out to the Program Coordinator with queries and observations; conversely, the Peer Support coordinator also reached out to the BREATHE Pals to ask for their perspectives on questions that arose during the course of the intervention. This two-way communication led directly to program adjustments and improvements. In addition, regular sessions were held that brought the

coordinator, key project staff, and all peer supporters together to meet, and discuss challenges, solutions, and insights.

The program coordinator was similarly available to program participants to share feedback.

More formal assessment methods were also integrated into the study. Patients were asked to answer a short standardized survey after participation had ended. Questions were asked about engagement, satisfaction with the services received, and areas for improvement. Longer one-on-one semi-structured interviews were also conducted with a small number of participants and peer supporters for more detailed perspectives.

The feedback received from these assessments provided us with a few key lessons. One point of consensus was the importance of the program coordinator's role. Peer supporters and patients expressed that they were comforted by having someone to turn to as a connection to more specialized healthcare services.

Respondents were very positive about the program and thought that the program duration for participation should extend beyond 6 months. They also would have preferred if the meetings were longer than 90 minutes. Feedback was also provided about the meeting time being challenging for people who had day jobs (especially relevant for caregivers) as the Get-Togethers were usually held around lunchtime on weekdays. This time also posed difficulty for any participants who relied on family members for transportation. Some respondents suggested having multiple meeting times, to provide options for people to be able to attend. Responses from the peer supporters closely echoed that of the patient participants. One observation was that the benefits of peer support seemed to be reciprocal for the supporters as well. They reported feeling engaged and strengthened by the experience, and that they too were learning new things about COPD from the peer group.

4. Sustain

Sustaining the program requires continued buy-in from stakeholders and securing the program coordinator position. Otherwise, expenses of the program consisted of the food and refreshments provided at each meeting, the printing costs of educational materials, and parking fees. Maintaining a large pool of peer supporters is also important. During the course of the study, peer supporters had to drop out of the program or take a break because of their own illnesses. This ended up putting more burden on the remaining peer supporters. Having a broader group of peer supporters on hand would also help with matching new participants to a peer supporter who met all criteria.

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[1] Aboumatar HJ, Kirley E, Lynch T, Bone L, Joo JH, Forte J, Holzmueller C. A Roadmap for Establishing Peer Support Programs in Research and the Real World. Baltimore: Johns Hopkins University; 2018. This project was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (2463-JHU). Special acknowledgment to all project team, partners, and advisors for their valuable inputs into the development of this Roadmap. Accessed at https://www.hopkinsmedicine.org/armstrong_institute/peer_support_roadmap/ on Jan 31, 2020

Get-Together Rules of Engagement

The Rules of Engagement (referred to as 'group agreement') were revisited periodically and posted in the meeting room. Those included:

- What is said in the group stays in the group
- We listen to, support, and learn from each other
- Everybody's opinion is important
- When someone is talking, we allow the person to complete what they are saying before we speak
- There are no right or wrong questions
- We will reduce distractions (cell phones, computers, IPads, notebooks are not permitted- necessary calls may be made outside the room)
- We will start and end on time.

Job Description for the BREATHE Peer Support Program Coordinator

Credentials: Master's Degree in Social Work with LCSW-C

Skills required: Strong counseling, excellent communication, strong collaboration and strong program development skills

Role: The social worker will provide guidance and support to the Peer mentors (BREATHE pals) and Peer support program participants, and will coordinate the BREATHE Peer Support Program activities and monitor its progress.

Recruitment, Selection, Training of Volunteers

The *BREATHE Peer Support Program Coordinator* is responsible for the recruitment, training, and guidance of peer mentor volunteers (also called BREATHE Pals) following the BREATHE2 Study protocol. She will discuss the programs goals, requirements and expectations with each possible volunteer and determine in consultation with BREATHE 2 Study PI their appropriateness to be a mentor. If they are selected to be a volunteer then she will refer them to volunteer services to be started on other hospital volunteer requirements. The *BREATHE Peer Support Program Coordinator* is responsible for making sure all of the peer mentor volunteers are up to date with all the volunteer services and BREATHE Peer Support Program requirements.

The coordinator will help deliver the peer mentor training program. The training program will incorporate interactive training on listening skills and will cover the role and boundaries of the BREATHE Pals activities. It will also cover handling of any emergency situations in the mentoring process.

Mentor Matches

The coordinator is responsible for matching Breathe Pals with study participants. She will provide appropriate information to the mentor to help them address the issues the participant has identified. She will enter data documenting the matching process for future tracking in a redcap database. She will coordinate all aspects of daily management of the program.

Coordination and Facilitation of Get Together (group per support) events

The coordinator will organize and facilitate Get Together events at Johns Hopkins Bayview and HCGH following the BREATHE2 Study protocol. She will collect feedback surveys and other attendance information at the end of each event and debrief on these as needed with Study PI.

Follow Up and Guidance

The coordinator is responsible for providing counseling, guidance and follow up to all peer mentors throughout their study period. To that end, she will hold regular meetings for the peer mentors (and as needed one on one conversation) to discuss their experiences with peer support and get any questions answered. Meeting location will be at Hopkins Bayview and HCGH.

The coordinator will ensure quality of provided peer support services by regular monitoring and eliciting feedback from both the peer mentors and matched program participants. She will contact the mentors after their initial contact with the participant and discuss the interaction. She will also contact the participants to check on their experience with the peer support service. The coordinator will also facilitate access of study participants who need additional treatment or support services to appropriate resources within the health system.

Data Collection and Reports

The coordinator is responsible for reporting and updating all data associated with the peer support program.

Collaboration within study site

The Peer Support Program coordinator will reach out to other healthcare professionals at Johns Hopkins Bayview and HCGH, and communicate about the BREATHE Peer Support program and what it has to offer to COPD patients and their families.