

Lung Cancer Support Group Implementation and Facilitator's Guide



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Introduction

Lung cancer patients and their families have many psychosocial needs as they deal with the challenges of navigating lung cancer. An opportunity to connect with peers provides invaluable benefits such as reduced isolation, lower stress levels and improved coping skills. There are many different models for support groups, with varying levels of facilitator involvement. When launching a brand-new support group, it is recommended to have a more structured model to reduce attrition and attract new members. **This group should be tailored to the unique and specific needs of those facing lung cancer and program leaders should not attempt to expand the focus to meet the needs of those facing other cancers or other lung diseases.**

The American Lung Association is committed to offering support and resources to those facing lung cancer. The Patient & Caregiver Network (PCN) is a free, nationwide community providing direct access to lung disease management tools, education, and connection to other patients and caregivers. The Lung Association is pleased to present a Nationwide model for lung cancer support groups, a program of the PCN, with the hope that many local markets will be able to expand the support offerings to lung cancer patients in their community and create more support opportunities for PCN members facing lung cancer.

The Implementation Model

Lung cancer support groups are unique and nuanced programs. The model and steps below are intended to guide you through the process of launching the most appropriate lung cancer support group for the patients and caregivers you intend to service in your specific community. American Lung Association Lung Cancer Support Groups may look different from city to city. The idea is not that the entire nation follows one format, but that everyone follows the same steps to determine how to structure their support group. Read on and follow the steps to get a lung cancer support group started!

**Community Assessment ▶ Vision and Goals ▶ Program Set Up ▶
Communications Plan ▶ Evaluation Plan ▶ Launch ▶ Evaluate and Adjust**


Step One: Conduct a Community Assessment

Before launching any new type of programming, it is important to familiarize yourself with existing programs in your community. Questions to ask:

Are there any existing lung cancer support groups in my community?

- If so, where are they located? Who do they aim to serve? How are they structured? Who is in charge?
- What lung cancer support group gaps are there in my community? Are there underserved populations? Locations where many patients live but no programming exists?
- Who are the stakeholders? Are there any lung cancer advocates in my community who could be a partner? Are there physicians or allied health professionals who are trusted or well known in the community? Local businesses who can assist with promotion and funding?

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Pro tip 1: Talk with your lung cancer constituents to learn about their needs and their opinions on community programming.

Pro tip 2: Familiarize yourself with the content on [Lung.org/lung-cancer](https://www.lung.org/lung-cancer) and [Lung.org/stigma](https://www.lung.org/stigma) as part of this Step.

Step Two: Establish a Vision and Goals

After completing the community assessment, you should have a clearer vision of the needs of the lung cancer community. Determine the goal or goals of your program. Use this goal-setting template to guide you:

[Following participation in the Lung Cancer Support Group, participants will](#)

Step Three: Set up your Program

The community assessment from Step One and vision and goal development from Step Two, should clarify what you want your program to look like and if you need to seek any additional funding (see Seeking Financial Support section). Now it is time to solidify the details.

- **Find a venue.** Choose a location(s) with easy parking, near where people live (not necessarily near where they get their care). Choose a place where people *want* to go. A hospital can bring up difficult memories and bad feelings and people may not want to go there in their free time. You may want to consider hosting at local restaurants or coffee shops during low traffic times and asking if they would consider offering a discount or free items to your group. All venues should be smoke-free, comfortable and afford enough privacy for the session. Determine if you will have a virtual component to your program (see the Resource Center for more guidance on establishing a virtual program).
- **Establish a schedule.** It is recommended your group meet monthly to start. You may want to poll your lung cancer constituents to determine the best time for the meeting. Early evening (5 pm) may be a good starting place because it can accommodate those who work and those who do not want to drive when it is dark.
- **Staff the support group.** Consider utilizing LUNG FORCE Heroes and volunteers where appropriate. Identify who will be completing the following tasks:
 - Leading the group
 - Recruiting/communicating with the speakers
 - Securing the venue
 - Developing and executing the communications plan
 - Setting up the venue
 - Conducting the evaluation
 - Communicating with potential and current members. Consider if you want to ask people to register ahead of time. Pro: It helps with planning. Con: It creates a barrier to attendance.

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- Keeping current and past members engaged with the Lung Association
- Entering constituents into the Lung Association's constituent management system (ROI)

Step Four: Develop a Communications Plan

Write a detailed communications plan featuring activities to be executed before, during and after your program. Below are some points to consider as you develop your communications plan:

- Identify where lung cancer patients are likely to frequent (e.g., care centers, pharmacies, stores, community centers) and place flyers or rack cards where you can (see sample promotional materials in the Resource Center).
- Keep your printed communications short and simple. Work with the American Lung Association's National digital team to determine how you will feature details of your group on the American Lung Association's website, including the support group landing page at Lung.org/lung-cancer-support. Print communications should use the American Lung Association Lung Cancer Support Groups logo (available in the Resource Center) and have:
 - The name of the program
 - A brief description. Be sure to include a note saying all are welcome.
 - Location and time
 - Email and phone number for more information
- Identify champions to help spread the word. This may include LUNG FORCE Heroes, volunteers, health professionals and Lung Association staff.
- Create a marketing budget. Allocate dollars to digital marketing and utilize social media channels to reach your target audience.
- Consider making the first meeting a bigger event where members can learn about the program for the year.
- Decide how you are going to communicate with present and future members about the program.
- Use best practices from other program communications to inform your Lung Cancer Support Group communications plan.
- Consider how you are going to keep members engaged and reach out to those who have been lost to attrition (see the Engagement section for more information).

Step Five: Evaluation Plan

Evaluation is a key component of a successful program. Refer to the goals you set in Step Two when evaluating your support group. You may structure the evaluation any way you want, however it is recommended that you evaluate after each session and the program as a whole. The template of the evaluation form is located in the Resource Center.

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Evaluating the program as a whole may be trickier, as the members may change each time. Identify a handful of “regular” members and ask them if they would consider participating in a brief phone call at the end of the program. Through several brief phone calls with members, you will be able to conduct a qualitative analysis of the program and see if any themes emerge.

Step Six: Launch your Program!

Below are 8 Keys to Success:

1. **Keep it lung cancer specific and stigma free!** This is perhaps the biggest key to success. A lung cancer diagnosis is different from any other cancer diagnosis AND different than any other lung disease diagnosis. Each session should be geared towards those facing lung cancer. Resist the urge to make sessions more universal to garner attendance from people facing other diseases. It compromises the integrity of the program, reduces trust, and will result in an inability to meet the main goal of serving lung cancer patients. Review the assets at [Lung.org/stigma](https://www.lung.org/stigma) for more information.
2. **Make it easy for people to attend!** Lung cancer patients and their families have enough on their plates. If they need to navigate traffic, can't find parking (or must pay for parking), have difficulty locating the venue, or face other barriers, they will be less likely to attend.
3. **Develop a robust promotional plan!** Launching a new program is challenging and it takes a multi-pronged communications approach to be successful. Establish a steady drumbeat of clear communications about a month ahead of launch and on a regular schedule, utilizing internal and external networks and relationships with key stakeholders.
4. **Keep the tone positive and hopeful!** Some support groups aim to serve as an opportunity for patients to spend an hour or so venting about their challenges. While this is a perfectly acceptable model and those facing lung cancer do need to vent about their challenges, it is recommended that you structure your support group as educational and positive, leaving time for networking and sharing at the end (see a sample agenda in the Resource Center).
5. **Bring in dynamic speakers with experts!** This will keep your program exciting and entice people to attend. Your community assessment should help you identify leaders in the field in your community.
6. **Be communicative!** Promote your group, send reminders and be very transparent if there is any change. People are comforted by details and reminders, especially during a time when they might be feeling extra stress.
7. **Don't underestimate the power of food!** Consider providing snacks or discounts on food (if hosting in a non-traditional venue like a restaurant or coffee shop).
8. **Utilize name tags!** This simple practice helps breed familiarity as well as reduce anxiety for cancer patients who might be experiencing “chemo brain” and can't remember names well. It also keeps you from having to spend time introducing people in the beginning of

the session, which can be time consuming and cut into the actual program.

Step Seven: Evaluate and Adjust

It is normal to experience growing pains as you try to build and launch a new program. Execute your evaluation plan you established in Step Five. Make changes to your program based on evaluation feedback if necessary. Remember to be patient as you establish yourself as a familiar and reliable entity in the community. High touch programs can take time to build. However, if something clearly is not working or the evaluation points to major problems, be sure to tweak the details of the support group along the way to give it the best chance of succeeding.

Engagement

Engagement between your group members and the Lung Association is a challenging, yet important part of the programmatic experience. It is vital that someone from the American Lung Association enter each attendee's information in the constituent management system called, ROI.

Top Barriers to Attendance (and what to do about it)

1. **Too much “doom and gloom”** ▶ Don't let people talk too much about themselves during a session. Begin the session in an organized way with a clear topic. Leave personal connections and story sharing for the end. Set the tone as upbeat and positive. Encourage them to reflect on how what is being shared is relatable to them (this allows people to share but structures the conversation).
2. **Not relevant to them** ▶ Keep the sessions engaging. Keep topics and the members limited to people facing lung cancer and their loved ones. Bring in speakers at the top of their field. Whenever possible, opt for speakers specializing in lung cancer versus someone who is more of a generalist.
3. **Inconvenient** ▶ Poll your target audience ahead of time to make an informed decision about the venue and time.
4. **Too sick** ▶ Consider offering a virtual component. Unfortunately, the nature of the progression of lung cancer is why it can be difficult to retain members and grow a lung cancer support group. It is not something you can control but by setting the support group up for success in other areas, your group should be able to continue to attract new members and keep your support group going.
5. **Feel Stigmatized** ▶ People facing lung cancer are very sensitive to discussions about tobacco. However, you may have members who need support to quit smoking and could benefit from the robust tobacco cessation programs offered by the American Lung Association. Use your judgment when deciding if and how you discuss tobacco within your support groups. Review the resources available at [Lung.org/stigma](https://www.lung.org/stigma) and address with speakers that they are not to reinforce the stigma that all lung cancer patients are/were smokers.

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Note: Members should be reminded often to consult their physician in all matters relating to their health, and particularly with respect to any symptoms that may require diagnosis or medical attention. The facilitator makes no representations or warranties with respect to any information provided regarding treatment, action, or application of medication. This is important because the American Lung Association or sponsoring organizations will not be liable for any direct, indirect, consequential, special, exemplary, or other damages that arise. Should a participant ask a personal diagnosis or treatment question, advise them to consult a healthcare provider.

Sample Session Ideas

Feel free to be creative with your sessions. Lung cancer research is moving at a rapid pace and lung cancer patients are often interested in learning about new treatments available. Nutrition is another popular topic amongst lung cancer patients, as there is so much information available, but it is difficult to determine what is most salient. Below are some sample session ideas:

1. **January:** Exercise and Lung Cancer (potentially tobacco cessation only if appropriate for the members)
2. **February:** Intimacy and Relationships Post Lung Cancer Diagnosis
3. **March:** Lung Cancer Policy: How to Get Involved in Advocacy
4. **April:** Nutrition and Lung Cancer
5. **May:** Lung Cancer Research Spotlight (choose a lung cancer researcher in your community to discuss their research)
6. **June:** Debrief from the American Society of Clinical Oncology Meeting (ASCO) (a large yearly oncology conference)
7. **July:** Traveling Safely with Lung Cancer
8. **August:** Managing Emotions with a Lung Cancer Diagnosis
9. **September:** Staying Healthy through the Winter with Lung Cancer
10. **October:** Preparing for the Holidays with Lung Cancer
11. **November:** Lung Cancer Awareness Month: What's new and exciting?
12. **December:** Ask Me Anything (AMA) with a Thoracic Oncologist

Additional Ideas:

- Music or Art Therapy Sessions
- Pulmonary Rehab
- Oxygen use
- AMA with different professionals (e.g., oncology social worker, therapist working with oncology patients, lung cancer patient and caregiver, leading physicians in the field)
- Busting Myths and Misconceptions about Lung Cancer
- Stress relief sessions like yoga, meditation, or even learning something new like creative writing or a skill
- Use your community! Check out programming available at local community colleges or other non-profits to get ideas for interesting topics
- Get to know the members! (Encourage people to share not only about their cancer but about other aspects of their life)
- Ask your members for suggestions

Sample Agenda for One Hour Meeting

Meetings should last between one hour and 90 minutes. Below is a sample agenda for a one-hour meeting:

1. Brief welcome and ground rule setting (2 min)
2. Speaker (including questions) (45 min)
3. Evaluation (3 min)

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4. Networking (~10 min based on structure of the session)
5. Announce next month's topic and formally end the session

Seeking Financial Support

You may want to seek additional financial support for your program and/or support for future programs. Here are some points to consider:

- Many local businesses may be interested in sponsoring your event by providing food or goods.
- Get to know the family foundations supporting cancer initiatives in your community. A simple google search can provide helpful intel.
- Look at the sponsors for other cancer events in your community.

Facilitating a Support Group

Below is guidance for how to prepare for and facilitate a support group.

Before the Session

- Develop group touchstones, or ground rules. Since people come and go in support groups, it is helpful if everyone knows the expectations for communication. Having group touchstones is critical because it provides members with a safe comfort zone and builds trust among members. You can create the group touchstones with your group or by presenting them to the group. The latter maybe a valuable option, as it does not take time away from the reason members showed up in the first place. Below are some sample Touchstones:
 - One person talks at a time.
 - All personal information shared in meetings is kept confidential.
 - Meetings begin and end on time.
 - Opinions of members are respected.
 - No one person monopolizes the group's time.
 - No offensive language is used.
 - Cell phones are turned to silent and are not answered in the meeting.
- Create a Meeting Plan Checklist (sample available in the Resource Center) to organize the details that can be easy to forget.
- Confirm details with the speaker. Get the title of the presentation, as well as the speaker's full name, credentials, and brief biography (1-2 sentences only!) for introductions.
- Review the meeting objectives together, and make sure the speaker is clear about aligning the presentation to meet the agreed upon objectives and time allotment. Take this opportunity to remind the speaker of the target audience (many speakers just repurpose presentations from professional meetings which is not ideal) and potential sensitivities (like discussion of tobacco use). **Be firm with speakers about tailoring their presentations to the target audience.**
- Make sure the speaker has the exact location of the meeting and directions, if needed.

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- Print any handouts that need to be copied and prepare any audiovisual equipment for the presentation. Start early with AV set-up, as technology always finds a way of presenting problems!
- Ask whether the speaker prefers to take questions at the end of the presentation or will accept questions throughout.
- Publicize the meeting well in advance.
- Print an agenda and evaluation form and make copies for all (templates available in the Resource Center). Make all documents American Lung Association Lung Cancer Support Groups Branded (customizable documents and logo available in the Resource Center). A longer bio of the speaker can also be included.
- Bring name tags and sign in sheet.

During the Session

- Greet members individually. Saying hello to everyone helps ease any nervous feelings that some may have about attending a support group meeting. Introduce people to each other, especially those members who walk into the room alone. Thank them for attending. Facilitate conversations among members.
- Begin the meeting on time, even if everyone has not arrived. It sends a message to members that they need to arrive on time and validates the efforts of those who do so.
- Open the meeting by welcoming everyone and thank them for attending.
- Make announcements at this time, such as directing members to the nearest restrooms and refreshments. Request that all cell phones be turned off.
- Ask members to sign the attendance form (sample included in the Resource Center). Collect information on the best way to contact them. Let them know you will keep them posted about the next meeting and any changes.
- Briefly review the group touchstones or ground rules.
- Thank any co-sponsors for their donation to the meeting (such as refreshments, handouts, or props).
- Introduce the meeting topic and guest speaker. Use your best facilitation skills to keep the presentation on schedule, and keep members engaged. At the end of the presentation, thank the speaker for their time in preparing the presentation and attending the meeting.
- Guide the discussion to keep on track and to end it on time.
- Pass out the evaluation form.
- End the meeting in a formal way. Some groups close with a ritual, such as practicing deep breathing and/or a relaxation exercise. This is the time to announce the date, topic and guest speaker for the next meeting. It is also the time to thank members for attending the meeting, ask them to complete evaluation forms and **encourage them to join PCN**. You may want to have an iPad ready with the

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PCN sign up to make it easier. Remind them that anyone can join the Patient & Caregiver Network. Signing up for the network is free and will provide direct access to education, support and connection to others also living with lung disease. There is also a PCN flyer available in the Resource Center. Be sure to collect the name tags and evaluations.

After the Session

- Send thank you notes to the speaker, sponsors, and others as appropriate.
- Once you build a rapport with members, you may consider making a plan to contact missing members to check in on them.
- Review the meeting evaluations and use the feedback to make sure that your program is meeting the needs of your members and accomplishing the program goals.
- Add any new members to your ongoing a tracking document and have Lung Association staff enter the data into ROI with the appropriate flags.

Effective Facilitation


Part of being an effective facilitator involves understanding how adults learn best. Consider the following points:

- Members bring valuable life experience that can be beneficial to the trainer and other learners. But sharing can derail a group quickly, so stay vigilant with your facilitation.
- Adults learn by relating new information to past experiences; however, some individuals are resistant to change as they age.
- Adults need to feel that they are in control of their own learning and place value on learning that is important to them.
- Adults want to learn practical, useful, real-world information that they can use immediately and prefer action-oriented learning such as hands-on activities.

A good facilitator...

- Helps the group function as effectively as possible.
- Helps members feel empowered to be active in the group.
- Is interested in the group members and sensitive to their needs.
- Knows that when members feel safe and open, they will exchange ideas, advice and encouragement.
- Is accepting of others and is non-judgmental.
- Is a good, active listener.
- Pays attention to non-verbal cues of group members.
- Displays an optimistic and hopeful attitude, balanced by realism.
- Deals with conflict in an open, honest fashion and works toward resolution.
- Is able to set boundaries.

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Remember to project your voice so that everyone can hear you and stand in a place where everyone can see you!

- Is willing to learn from the group members.
- Is interested in continually improving the support group.
- Takes responsibility for preparing for meetings and works to offer the best possible meetings to members.
- Is accountable to group members and to the American Lung Association.

Verbal Communication Tips

Whether you're making announcements, introducing the speaker or presenting the educational session for the support group meeting, the way you speak is as important as what you say.

Below are tips to use when speaking to the group:

- **Convey and clarify information.** State the essential points, pull together related ideas, summarize and restate often. "What I'm saying is..." "In other Words..." If something the presenter is stating is confusing to you, chances are it is confusing to the members as well. However, the members may not feel comfortable speaking up. The facilitator should notice where there may be confusion and ask the speaker to address it when possible.
- **Listen actively.** Respond to members' comments, reactions and questions in a way that expresses your interest, understanding and support. Active listening means paying close attention to what the speaker is saying and feeling. State back in your own words your understanding of the sender's message (both words and feelings).
- **Relay.** Pass an idea from one member to another, back to the member or to the group. "Anne, how do you feel about John's statement?" "Jim, what do you think that means for you?" "Cheryl, what has your experience been so far?"
- **Read body language.** Take cues from body language to understand messages from members. For example, silence may indicate confusion; tapping fingers may indicate boredom or anger.
- **Ask open-ended questions.** Probing questions are the foundation of adult learning. They encourage individuals to think, to go deeper, to evaluate new information or concepts, to clarify issues and to develop solutions to problems. Use them liberally throughout the meetings. "What made you decide to come to the meeting today?" "What experiences have you had with that?"
- **Reinforce.** Don't forget praise. It's the least expensive, most powerful leadership skill around. People are motivated to keep going when the group's leader or facilitator verbally confirms that they are "right on" or "on the right track."

Non-verbal Communication Tips

Facilitators may be so intent on what they are saying that they neglect their non-verbal communication. But your voice, posture and facial expression send important messages to members, and can set the tone of a meeting. Something

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as simple as smiling and greeting group members with a rousing “Good morning!” tells the group that you are happy to be there.

- **Voice.** Strive for a friendly tone that communicates patience, cooperation, flexibility and a willingness to hear questions and comments. If your tone of voice is impatient or reprimanding, it may spark resistance and resentment from the members.
- **Facial expression.** People “listen to your face,” so smile! If your face shows enthusiasm and openness, your group members will most likely respond with interest and involvement.
- **Acknowledge.** Use non-verbal cues such as a nod of your head, eye contact and attentive facial expressions to let the members know that you have heard them. This encourages them to continue.
- **Eye contact.** Maintain eye contact to connect with your group. Make sure you are making eye contact with all members, and not talking to one side of the room or group of people more than the other.
- **Posture.** A relaxed, confident posture sets a positive tone. Passive posture gives the impression that what you have to say isn't important or credible. Rigid or domineering posture creates tension.
- **Gestures.** Avoid fidgeting and closed gestures, such as a clenched fist, that express nervousness, defensiveness or hostility.

Addressing Challenging Behaviors

Support group meetings usually go quite smoothly, but any group facilitator is likely to encounter some challenging behaviors among members. The difficulties that a person confronts when coping with lung cancer may affect his or her attitude or behavior. The group needs the facilitator's consistent, positive leadership as an anchor to support and guide the group through difficult situations. Here are some tips on handling problems that facilitators may encounter with group members:

- Don't allow yourself to be drawn into controversy with any group member. Be aware that a vulnerable person may interpret your words as embarrassing, intimidating or argumentative. Choose your words carefully, particularly in front of the group.
- Ask yourself these questions: How does this person's concern relate to other common concerns? What information can I give that would benefit the individual and the group as a whole?
- Use the group to give different reactions to a specific problem or issue. When individuals realize that they are not alone in confronting a problem, they often feel supported and empowered to take action.
- Use humor to relieve tension, open up communication, and allow group members to connect with you and each other. Keep it positive—avoid any humor that might be interpreted as a “put down.” Avoid telling any joke that may offend someone, even slightly.
- Help problem members stay involved and feel supported by the group. You may want to give them a special role, such as summarizing for the group during the sessions.

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- If a member is being difficult, try to help identify their underlying problem. It may be different from what the member is saying.
- Walk the room. Standing next to “sidebar” talkers helps quiet them down. Standing near a shy member and quietly asking, “What do you think, Harriet?” may help them participate.

Managing Questions from Group Members

- Try to anticipate tough questions that may come up about the meeting topic. Keep your answers brief. Don't spend too much time addressing the concerns of one individual or you will lose the attention of the whole group.
- Utilize attendee input, draw from their expertise to help answer questions within the group. If you don't know an answer to a question, say so. Offer to find the information or ask the whole group if they know the answer. If you try to make up an answer, you risk losing your credibility.

Accessing the Resource Center

We've created a Resource Center to help your meetings run smoothly and effectively. Included in the resource center are:

- Feel Better and Holiday Cards
- Facilitator and Member Recruitment Materials (Postcard, Flyers, Rack Cards)
- Partner Recruitment Flyer
- Zoom Meeting Directions
- Sample Marketing Copy and Social Graphics
- Meeting Agenda and Attendance Forms
- New Member Form
- Customizable Weekly Announcement
- Meeting Preparation Checklist
- Evaluation Form
- PCN One Pager
- American Lung Association Lung Cancer Support Group Logo

To access the **Lung Cancer Support Group Facilitator Resource Center** please email a request to LungCancerSupportGroups@Lung.org.

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Getting Started Checklist

Complete this checklist before you get started with your program:

- Read the entire Implementation and Facilitator Guide
- Conducted a community assessment
- Established vision and goals
- Found a venue
- Set a schedule
- Staffed the program
- Wrote a communications plan for before, during and after the program
- Created an evaluation plan
- Reviewed the training webinar in the Resource Center
- Reviewed the assets in the Resource Center
- Created an engagement plan
- Reviewed the content on [Lung.org/lung-cancer](https://www.lung.org/lung-cancer) and [Lung.org/stigma](https://www.lung.org/stigma)

Conclusion

The information provided in this guide is intended to provide a framework for establishing a lung cancer support group. However, as a health leader in your community, you bring your own expertise and judgement to each program. It is important to be nimble and learn from each session and to regularly ask for feedback from your members. It can be challenging to start a new lung cancer program. You may start small, but with thoughtfulness and effort, you can grow your program over time as you build trust in the community.