

DEVELOPMENT AND EVOLUTION OF A LUNG CANCER SUPPORT GROUP TROUBLESHOOTING GUIDE

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BACKGROUND

Research has shown that people diagnosed with lung cancer have greater unmet supportive care, physical and emotional needs compared with those diagnosed with other types of cancer.

In-person support groups can be an important part of meeting emotional needs but research has also shown that for many reasons, including the stigma associated with the disease, those diagnosed prefer lung cancer-specific groups over those that include all types of cancer.

Lung cancer's great symptom and side effect burden and high mortality rate can make lung cancer support groups especially challenging to launch, grow and maintain. As a result, the average number of lung cancer-specific groups in the United States continually hovers around 100, far fewer than are needed to meet the needs of the over 220,000 people diagnosed each year.

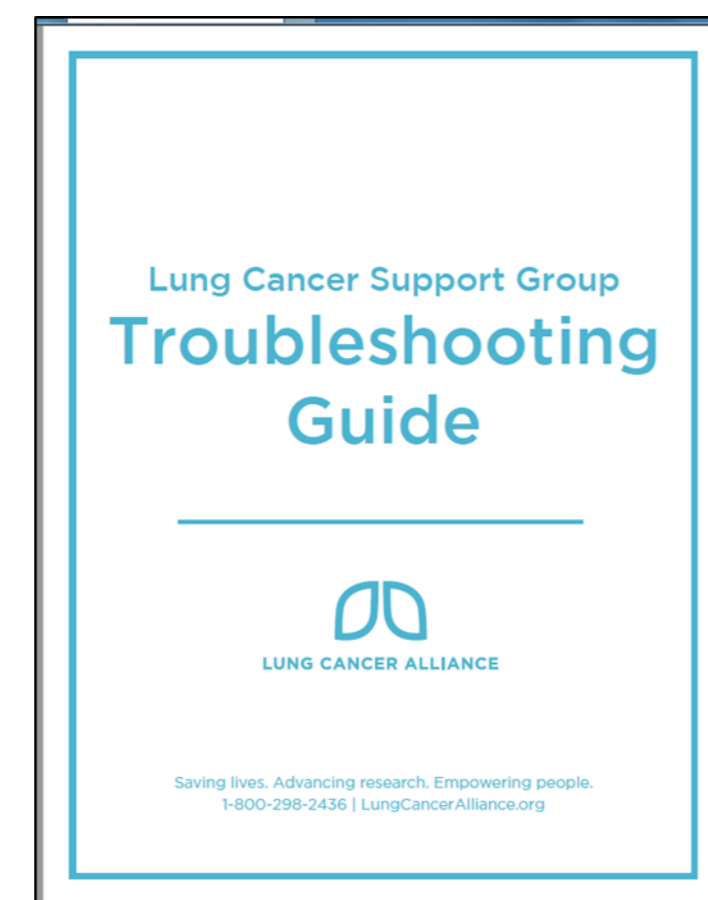
Lung Cancer Alliance (LCA) is dedicated to helping increase the number of available groups and to supporting facilitators make and keep their groups successful. In 2013, LCA surveyed lung cancer support group facilitators in the United States, Australia and the United Kingdom.

The survey identified best practices and, along with the results of an extensive literature review, were incorporated into the *Lung Cancer Support Group Troubleshooting Guide*.

Filled with helpful tips on a wide range of topics, the *Guide* is designed to give facilitators of lung cancer support groups creative ways to solve the most common identified challenges to running lung cancer support groups.

METHODS

To determine the *Guide's* helpfulness, copies were distributed electronically via email or hard copy via mail (according to facilitator preference) to 140 current and former lung cancer support group facilitators across the United States.



Roughly three months later, in January and February 2017, *Guide* recipients received a 14 question online survey via email.

Respondents answered questions related to the helpfulness of the *Guide*, if they had used any of the suggestions contained within and were asked for their ideas to improve the *Guide*.

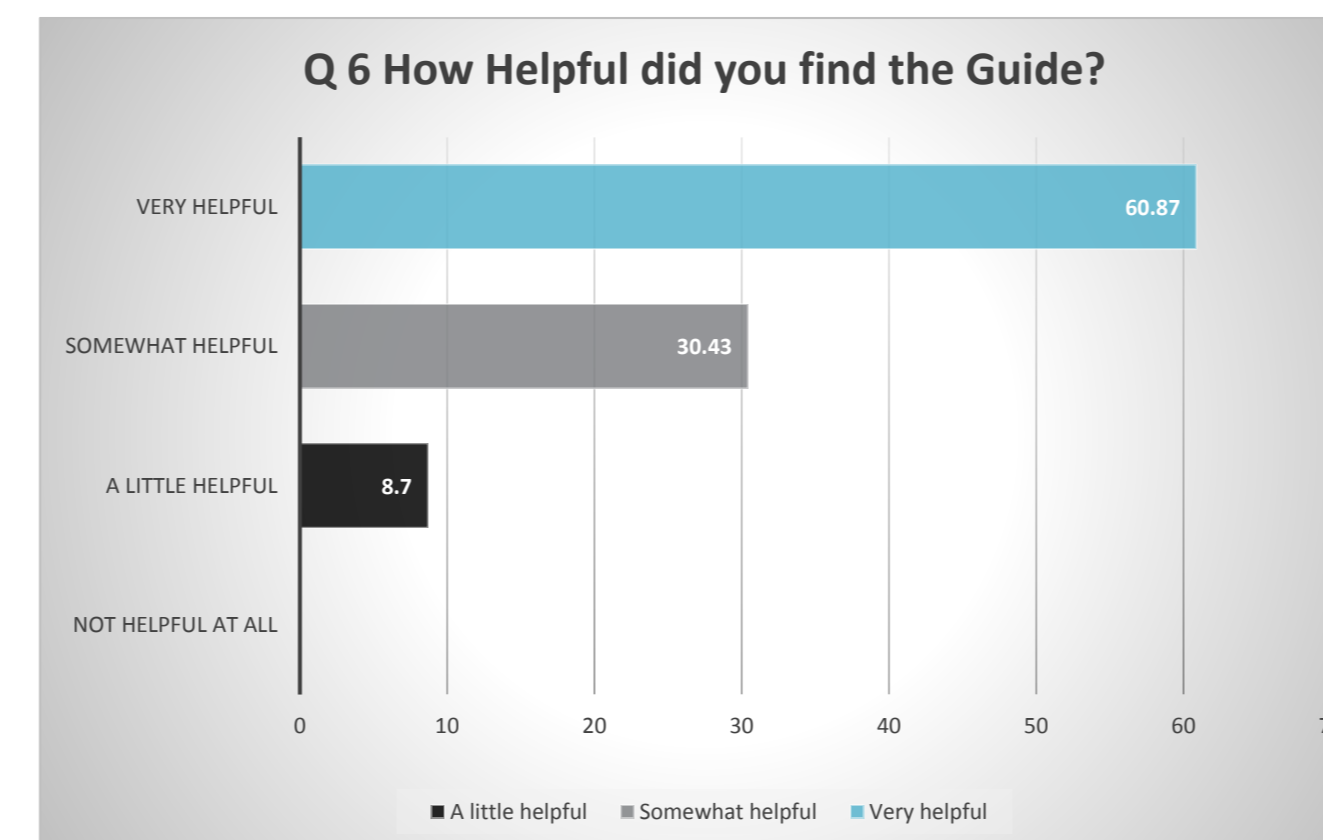
RESPONSE

Thirty (30) facilitators took the survey for an overall response rate of 21%. Five (5) reported they had not received the *Guide* and another 3 indicated they had not read it.

This analysis is of the remaining 22 responses.

RESULTS: HELPFULNESS

Most respondents found the *Guide* helpful.



COMMENTS

This was very relevant to all groups that we do and I forwarded this onto all of my group facilitators.

I think it covered all of the challenges/issues we have faced as a support group. It was well done. I liked the concrete ideas (i.e., how to commemorate the life of a group member).

It truly reinforced what we are doing. There [are] always times I second guess myself and your guide gave me more confidence in what I hope to accomplish.

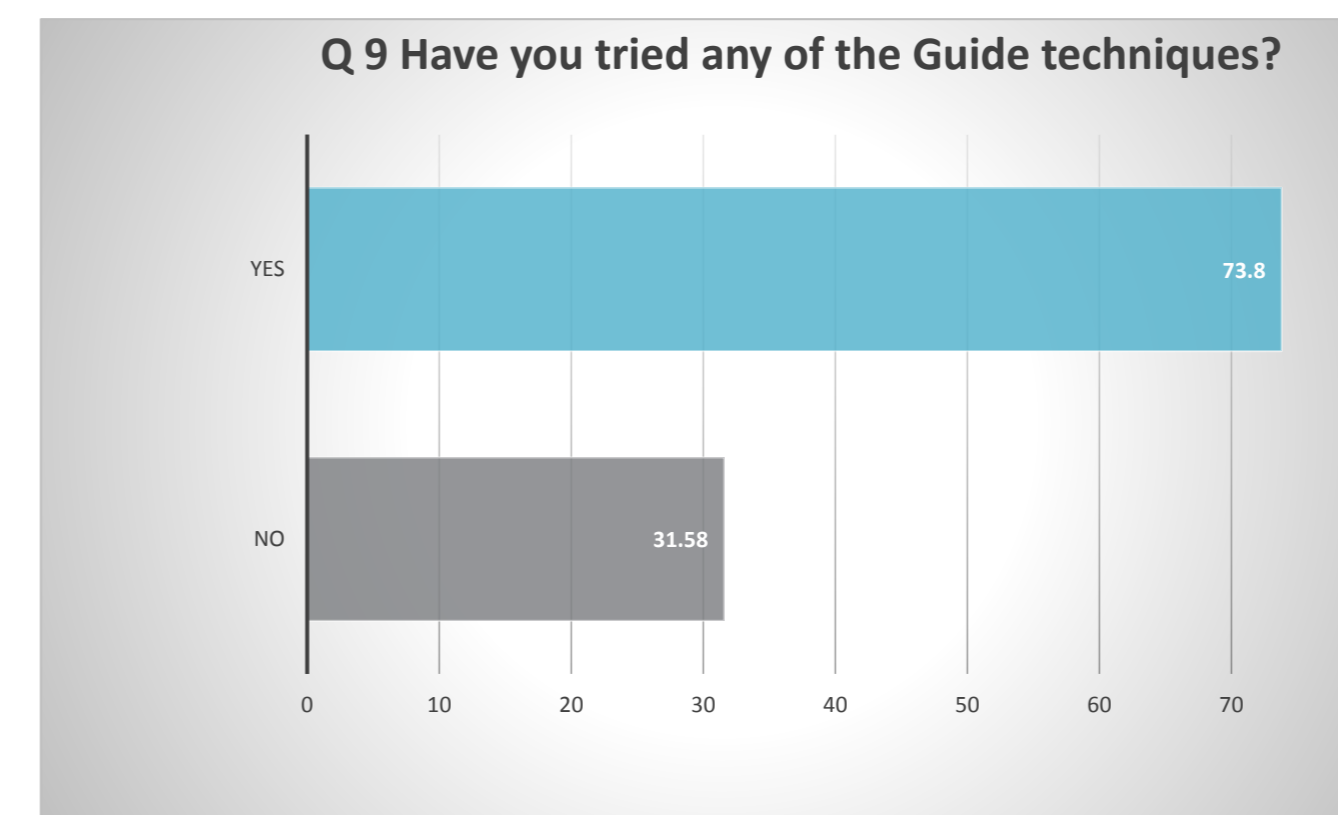
Inviting, easy to use format. I thought the Smart Tips were an especially neat feature.

Smart Tip

If nothing else, bring chocolate. One leader said, "If you have chocolate, they will come!"

RESULTS: USEFULNESS

Most respondents tried at least one of the *Guide* ideas in their group.



COMMENTS

[We are] in the process of developing new member packets--we previously gave out the materials but didn't make up a packet.

We have used the ideas to commemorate a group member's death.

Group rules helped members know the expectations and parameters of the group.

Getting someone who was monopolizing the group to allow someone else to speak...giving the silent ones a voice.

SUGGESTIONS

Additional recommendations around discussion topics.

Condense it. Too many pages with pictures.

OTHER ACTIVITIES

LCA held a small in-person facilitator meeting in June 2017 and queried attendees for adaptations to and new ideas for the *Guide*.

We also revisited existing older very detailed, but currently informal, guidelines for facilitators interested in launching a new group.

NEXT STEPS

From the start, the goal has been to regularly update the *Lung Cancer Support Group Troubleshooting Guide* with additional tips and new ideas.

Based on feedback from the survey, in-person meeting and an updated literature review, the *Guide* will be updated with new best practices and practical information on launching a lung cancer support group as well as creative ways to troubleshoot struggling groups.

CONCLUSION

While focused on lung cancer support groups, the *Guide* does and will provide helpful tips and ideas that can help launch and troubleshoot groups for any type of cancer.

CONTACT

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