

Project Transform: engaging patient advocates to share their perspectives on improving research, treatment and policy

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ABSTRACT

Objective: Incorporating the patient perspective into lung cancer research, policy and treatment is becoming increasingly recognized as important. This project sought to create an engagement partnership with lung cancer patient advocates and to explore their views on transforming lung cancer healthcare systems, treatment and policy to be more patient centered.

Methods: A patient action committee (PAC) of patient advocates living with lung cancer was engaged through group meetings, in-person and phone interviews, and email correspondence. Group meetings (two 1 hour meetings, one 3 hour meeting) served to discuss engagement strategies and project goals, while individual interviews ($n=19$) (30–75 minutes) provided in-depth exploration of individuals' perspectives. Meetings and interviews were recorded to identify priorities for addressing issues within lung cancer research, treatment and policy. PAC members corroborated the results through email and in-person meetings.

Results: PAC members identified three general objectives: (i) for healthcare systems, increasing access to care through accessible, coordinated and affordable care, (ii) for treatment, addressing patient needs in treatment and research through patient education, shared decisions and clinical trials, and (iii) for policy, shining a light on lung cancer through screening policies, public awareness and research funding.

Conclusion: Patient advocates expressed their views that lung cancer is a neglected disease that is not highly prioritized in healthcare systems, treatment approaches and public perceptions. This project represents an integral step in developing an ongoing partnership between researchers and these advocates.

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Introduction

Approximately 430,090 people are living with lung cancer in the USA, and an estimated 221,200 cases were diagnosed in 2015¹. At a 5 year survival rate of 18%, lung cancer is the leading cause of cancer mortality¹. Lung cancer accounted for 10% (\$12.1 billion) of direct medical costs in the USA in 2010². Lung cancer often affects older adults³, minority populations⁴ and those with comorbidities⁵, which further complicates treatment decisions and necessitates individualized decision making.

Treatments for lung cancer include surgery, radiation therapy, chemotherapy, targeted therapies and immunotherapy, based on tumor characteristics and the current condition of the patient⁶. The recent emergence of multiple new treatments has increased the complexity of treatment options and decision making. Patients must consider survival but also symptoms and quality-of-life issues due to both the cancer and treatment side effects^{7,8}.

The value of patient preferences and advocacy in treatment decisions and policy decisions is increasingly being

recognized^{9,10}. Patients often have different perspectives than regulators or payers on issues such as costs of cancer treatment¹¹. From a policy perspective, patients have experiential knowledge on their illness and/or health condition and can provide insights into living with the illness and the impact of technology and treatments¹². From a clinical perspective, involving patients in treatment planning and care improves satisfaction, quality of life and adherence¹³. However, lung cancer patients often do not receive patient-centered care or support^{14,15} and often are not engaged in their care. Furthermore, low levels of concordance between patients and providers on expectations for lung cancer treatment goals and outcomes have been observed¹⁶.

This project was a first step in a collaboration between researchers at Johns Hopkins University and patient advocates at LUNgevity, called Project Transform. LUNgevity is a premier lung cancer patient advocacy organization in the US committed to increasing quality of life and survivorship of patients with lung cancer. A Patient Action Committee (PAC) consisting of lung cancer patient advocates living with this disease was formed in April and May 2016. The objective of

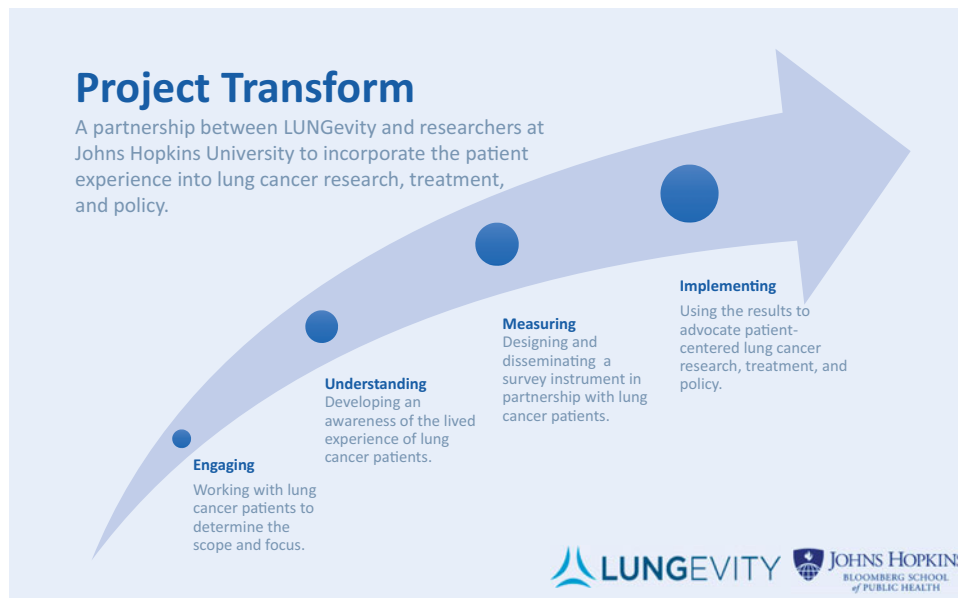


Figure 1. Patient-centered engagement framework. The framework that guides Project Transform consists of four phases: engaging, understanding, measuring and implementing. We report on the process and results of engaging patient advocates living with lung cancer who were part of a patient action committee (PAC).

this paper is to describe meetings and interviews held with PAC members as an initial part of the engagement process. These interviews were held to explore the members' perspectives on transforming lung cancer healthcare systems, treatment approaches and policy to be more patient-centered.

Key points for decision makers

- Highly motivated patient advocates can be an effective group for engagement as they are extremely informed and active in the patient community.
- Effective engagement is an iterative process that should span multiple active interaction points.
- Patient advocates living with lung cancer emphasized that lung cancer is a neglected disease area not highly prioritized within healthcare systems, treatment approaches and public perceptions.

Methods

Engagement process

This initiative is the first step in a process of incorporating the views of people living with lung cancer into lung cancer treatment, research and policy. It uses the principles of patient-centered outcomes research (PCOR) to evaluate questions and outcomes meaningful to patients and to enhance the relevance of research to actual health decisions that patients face¹⁷. This project applied an engagement framework comprising four steps: engaging, understanding, measuring and implementing (Figure 1 and Table 1). These steps are iterative and inform each other. In particular, for a successful engagement project, continuous efforts to encourage engaging and understanding between the project team and patient-partners are needed.

Here, we consider the first step of this framework, engaging, to determine the scope and focus of the project.

Previous work has shown that partnering with patient organizations and engaging patients with cancer according to PCOR standards can be an effective approach¹⁸. Individual interviews are an important part of initial engagement as they connect the project team with participants and can help establish mutual trust and understanding. Furthermore, they can help identify priorities from individuals' perspectives to identify unmet needs and guide further engagement. Step two of the framework, understanding, was previously published¹⁹.

Committee structure

This project was built around two advisory boards, a project management team and a patient advisory committee (PAC). The project management team was composed of three individuals affiliated with Johns Hopkins University, including a physician, a health outcomes researcher and a health economist (J.F.P.B., S.M.D., E.M.J.), and one individual affiliated with LUNgevity (A.F.), the largest lung cancer patient advocacy organization in the USA. The project management team administered the project, including scheduling engagement activities, and analyzed results. Johns Hopkins team members were trained in qualitative methods and had previously conducted patient interviews. The team member affiliated with LUNgevity had extensive experience working with patients with lung cancer.

The PAC was composed of patient advocates living with lung cancer. LUNgevity aided in establishing the PAC through their lung cancer survivor networks. PAC members were invited by LUNgevity to participate in the PAC because they were active in the LUNgevity advocacy community. PAC members voluntarily joined and participated in the PAC. PAC members advised the project management team on strategies to expand Project Transform and next steps. They also reviewed and provided feedback on study materials. The PAC is an evolving group. PAC members participate according to

Table 1. Patient-centered engagement framework with supporting quotes.

Engagement framework steps	Description	Quote
1. Engaging	Working with lung cancer patients to determine the scope and focus.	<i>"We all have a big goal here to get out there and not only raise awareness, but to help other people through their journey and choose what role lung cancer will have in our lives"</i> [PAC member at return of research results meeting].
2. Understanding	Developing an awareness of the lived experience of lung cancer patients.	<i>"I think especially with lung cancer, you know, if you haven't lived it, it's really hard to understand it. So I think you did capture that great"</i> [PAC member at return of research results meeting].
3. Measuring	Designing and disseminating a survey instrument in partnership with lung cancer patients.	<i>"I feel completely differently about what I'm willing to put up with now that I'm six years out versus when I first started it, and I had great hopes that it was going to make everything better. And that's anecdotal. It will be great to see if you can capture that statistically"</i> [PAC member at return of research results meeting].
4. Implementing	Using the results to advocate patient-centered lung cancer research, treatment, and policy.	<i>"[The Hopkins project team] are advancing the science. We [LUNGeVity] are taking that knowledge and using it to change things. So I think that it goes hand in hand"</i> [Patient advocacy organization representative at return of research results meeting].

their ability, both in terms of time commitment and health status. Members are mostly long-term survivors with chronic stage 3 or 4 lung cancer but vary in disease severity (stages 1–4), years since diagnosis (1–13), histology, and experiences with different aspects of treatment and advocacy. PAC members have been treated for lung cancer at different locations varying from community hospitals to academic centers across the United States. Most PAC members were relatively young compared to the average age of lung cancer patients (under 65 years old). In addition, most PAC members were white and female. The PAC is not a representative sample of patients with lung cancer in the USA but represent informed and motivated patient advocates deeply engaged in the lung cancer advocacy community and knowledgeable about the lung cancer health system.

Priority setting

PAC members were initially engaged through group meetings and individual interviews. At the time of the initial engagement, the PAC consisted of 27 patient advocates living with lung cancer. PAC members were informed about the purpose of the engagement and its potential risks and benefits. After agreeing to join the PAC, PAC members attended a survivorship summit which is hosted annually by LUNGeVity. This summit was also open to other lung cancer survivors and is attended by lung cancer survivors and caregivers from across the United States. At this survivorship meeting, the project team partnered with the PAC members during two initial meetings. These meetings served to introduce the project team, discuss the project and brainstorm objectives. The PAC started identifying areas in which lung cancer treatment, research and policy could be improved from a patient perspective. The two meetings lasted approximately 1 hour. All 27 PAC members and all project team members were present at one of the initial meetings.

The study team developed an interview guide to ask about PAC members' personal experiences, gaps in treatment and the health system, and their priorities for change in lung cancer policy and research. The team conducted 19 semi-structured interviews, five in-person and 14 over the phone,

that each lasted between 30 and 75 minutes. Interviews were held in a private setting (hotel, cancer clinic or at home) with only the project team member(s) and participant present. Three members of the team experienced with conducting interviews (J.F.P.B., S.M.D., E.M.J.) conducted interviews. With the PAC members' permission, the interviews were recorded and transcribed, and the interviewers took detailed field notes.

Each interview started with PAC members sharing their experiences with lung cancer and as patient advocates with LUNGeVity. Interviewers then asked them to address what they thought could be done to improve the experiences of people with lung cancer. Interview guides served to facilitate an open conversation between project members and PAC members and focused on exploring the PAC members' experiences and priorities, as well as the experiences of people they knew¹². Interviews were conducted until all PAC members that had expressed interest were interviewed.

Analysis

Transcripts were reviewed by four team members (J.F.P.B., S.M.D., A.F., E.M.J.) to extract priorities and needs. Transcripts were coded using thematic analysis in Atlas.Ti (Berlin, Germany) to identify recurring priorities on gaps in lung cancer treatment, research and policy. Codes were not identified before data analysis commenced but were identified and adapted as the analysis went on. Each interview was coded by at least two team members. The four project management team members, including the representative of LUNGeVity, met several times to discuss the analysis and reach consensus. The consolidated criteria for reporting qualitative research (COREQ) checklist²⁰ was used to provide an overview of our methods and findings (Table 2).

Drafts of the manuscript were emailed to PAC members for comment. Results were presented to them at a 2 hour in-person meeting to ensure that their views were accurately represented and to ensure PAC member buy-in to strengthen future collaborations. The Institutional Review Board of the Johns Hopkins School of Public Health determined that this project was not human subjects research (IRB 6404) because

Table 2. Application of the consolidated criteria for reporting qualitative research checklist.

Item	
Domain 1: project team and reflexivity	
1. Interviewer/facilitator	J.F.P.B., S.M.D. and E.M.J. conducted interviews
2. Credentials	Clinician (S.M.D.), experienced researchers (S.M.D., J.F.P.B., E.M.J.), lung cancer advocate (A.F.)
3. Occupation	Johns Hopkins researchers (S.M.D., J.F.P.B., E.M.J.) and president of patient advocacy organization (A.F.)
4. Gender	Female (S.M.D., A.F., E.M.J.); male (J.B.)
5. Experience and training	Qualitative methods training and experience (J.F.P.B., S.M.D., E.M.J.); medical training (S.M.D.); experience working with advocacy organizations (A.F.)
6. Relationship established	As president of the patient advocacy organization, A.F. had an established relationship with PAC members; other members of the team met with PAC members during 1 hour in-person meetings to establish the relationship and determine the scope of the project
7. Participant knowledge of the interviewer	Project team introduced their background to PAC members during the 1 hour in-person meetings and before conducting interviews
8. Interviewer characteristics	Project team explained motivation for the study during the 1 hour in-person meetings and before conducting interviews
Domain 2: study design	
9. Methodological orientation	Thematic content analysis
10. Sampling	Purposive sampling of patient advocates living with lung cancer active in the patient advocacy organization
11. Method of approach	Email and face to face
12. Sample size	19 interview participants
13. Non-participation	27 attended the in-person meetings, 19 participated in an interview
14. Setting of data collection	At hotel, at cancer clinic and at home via phone
15. Presence of non-participants	Only researcher(s) and participant were present during interviews
16. Description of sample	Variety of disease severity (stages 1–4), years since diagnosis (1–13), histology, and experience with treatment and advocacy
17. Interview guide	Interview guide was not pilot tested; interview guide provided questions to prompt the interviewer but could be adapted to focus on specific experience to address gaps and evolving priorities and needs
18. Repeat interviews	No repeat interviews were conducted
19. Audio/visual recording	Meetings and interviews were audio recorded
20. Field notes	Interviewer took field notes during interviews
21. Duration	Meetings lasted about 1 hour; interviews lasted 30–75 minutes
22. Data saturation	Conducted interviews until project team felt saturation was reached
23. Transcripts returned	Transcripts were not returned
Domain 3: analysis and findings	
24. Number of data coders	Four data coders (J.F.P.B., S.M.D., A.F., E.M.J.)
25. Description of coding tree	No coding tree was used
26. Derivation of themes	Priorities were derived from the data
27. Software	Atlas.TI (Berlin, Germany)
28. Participant checking	Manuscript was returned to PAC members for comment/correction
29. Quotations presented	Quotations were presented and identified with a participant ID number
30. Data and findings consistent	Presented findings are consistent with data (supported by quotations)
31. Clarity of major themes	Objectives are presented in <i>Results</i> , in Table 3 and in Figure 2
32. Clarity of minor themes	Each objective is supported by three priorities

it sought expert opinions of individuals living with lung cancer.

Declaration of ethical approval

This research was conducted in accordance with the Declaration of Helsinki, and the study protocol was reviewed by the Johns Hopkins Institutional Review Board (IRB 6404).

Results

Engagement results

PAC members endorsed this project's approach to engaging patients as key informants. During the interviews, they expressed excitement about participating in the project: "That sounds good. I'm interested to see how everything turns out. And I'm just happy to be a part of it" [PAC member 15 during individual interview]. Return of the manuscript to PAC members and a 2 hour meeting to return the projects'

results ensured that PAC members' views were presented accurately: "I think you guys did a really brilliant job of capturing the primary issues... and with such simplicity" [PAC member at return of research results meeting].

Priority setting results

PAC members discussed three objectives during the interviews: (i) increasing access to care, (ii) addressing patients' needs in treatment and research, and (iii) shining a light on lung cancer in public policy. Each objective contained three priorities that are summarized in [Figure 2](#). The objectives and priorities are further conceptualized with representative quotes from individual interviews in [Table 3](#).

Priority 1: increasing access to care

The first priority is increasing access to care focused on providing accessible, coordinated and affordable care to improve

patients' experience during treatment and to ensure the best available care delivery to patients of all income and insurance levels, regardless of their geographic location or treatment facility type.

PAC members spoke about inequity in access to treatments and information, particularly with regards to regional disparities: "Living in a small community. If I need some more information, I would have to go to [the nearest big city], which is about 138 miles" [PAC member 11]. They expressed that many patients do not have access to lung cancer specialists: "There's unfortunately not a thoracic oncology specialist here in [city name]" [PAC member 15]. PAC members expressed that some of these patients might not receive adequate care because primary care providers or non-lung-cancer-specialists are not aware of recent advances in lung cancer treatment and diagnosis: "Doctors still will just

fall back to standard of care, chemotherapy, radiation. Stuff that's in some cases 20 years old when there's more effective options" [PAC member 16]. PAC members discussed the need to ensure every individual has access to appropriate care, which – at minimum – included standard of care and genetic testing.

PAC members expressed difficulty with navigating an uncoordinated care system and lack of guidance in navigating treatment starting at diagnosis: "Like you don't know where to begin, it's like you're on an airplane, you're dropped in a foreign country, you don't speak the language" [PAC member 10]. PAC members expressed that care coordination and seeing different types of doctors was confusing: "I mean I didn't see an oncologist for two months. Because I was seeing a pulmonologist. I was seeing a surgeon. So, you know, so it was quite confusing" [PAC member 12]. They expressed that there was little trans-disciplinary coordination and that different parts of treatment felt disjointed and were not properly explained: "There was no nurse navigator ... No one sits down and explains the whole system. You just go from one piece to the other" [PAC member 12]. While PAC members did not express conflict between different aspects of care, they did express that navigating their care, including managing and researching clinical trials, getting regular treatment and scans, getting second opinions and handling insurance issues was a "full-time job" [PAC member 3].

The cost of treatment was described as debilitating regardless of income or insurance status: "Even with insurance now, the deductibles are higher, the out-of-pocket maximums are higher" [PAC member 2]. PAC members had personal experience with or had witnessed others forgoing treatments because of the high cost of care: "And I'm still

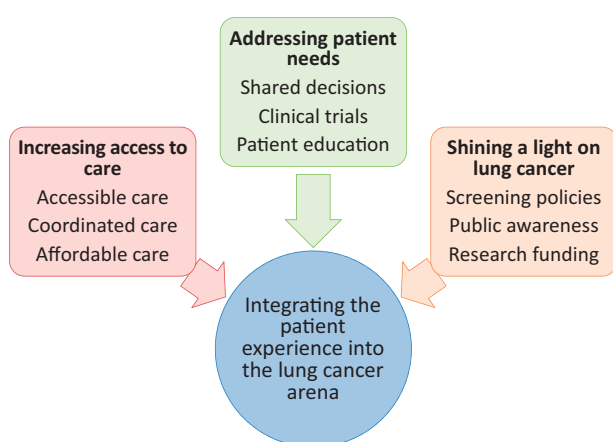


Figure 2. Priorities for addressing gaps in lung cancer research, treatment and policy.

Table 3. Priorities and needs with representative quotes identified by Patient Action Committee members.

Priority	Need	Concept	Quote
Increasing access to care	Accessible care	Care system that provides access to standard of care, genetic testing and specialized treatment regardless of geographic location	"Their primary care providers are sometimes just sending them home not knowing that we have targeted treatment now." [PAC member 7]
	Coordinated care	Care system with available patient navigators, manageable medical records and other resources to coordinate the entire care network	"I developed a shortness of breath... Do I call the radiation oncologist? Do I call my medical oncologist? Do I call my pulmonologist?" [PAC member 9]
	Affordable care	Care system with treatments affordable for patients of all income levels, resources that help pay for care	"Whatever class you enter treatment, you're going to leave the cancer a class lower." [PAC member 2]
Addressing patient needs in treatment and research	Patient empowerment	Patient-centered educational materials with necessary information on the disease and treatment options	"I've been dissatisfied with the delivery of the information. I guess I would like doctors to educate people better when they're coming through this." [PAC member 5]
	Shared decisions	Patient-centered decision making in a patient-provider partnership; the patient's voice is considered in all treatment decisions	"There's a lot of buzz right now... about patients as partners, but I can tell you that I don't feel we're even close to being equal partners yet." [PAC member 14]
	Clinical trials	Patient-centered clinical trials that consider the patient's experience and preferences in all stages of the research process	"My doctor couldn't do [the clinical trial], so I couldn't participate. You make it easier on the patient, you'll get more patients that will participate." [PAC member 10]
Shining a light on lung cancer	Screening policies	Lung cancer screening policies and diagnostic procedures that will ensure early detection and improved treatment outcomes	"Screening for lung cancer has to be out there, just like they do for women for Pap smears, for men for prostate cancer." [PAC member 18]
	Public awareness	Initiatives to increase public awareness of and support for lung cancer, particularly to reduce stigma associated with lung cancer	"I realized that possibly one of the best things that I could do to help other lung cancer patients was to go public about my lung cancer." [PAC member 9]
	Research funding	Policies to increase lung cancer research funding to reflect the morbidity and mortality of the disease	"It's the number two killer in the country. Yet it receives... the lowest amount of funding, and it's been flat-lined for 40 years." [PAC member 17]

paying for [my past treatment]. The medications, they're not cheap" [PAC member 11]. PAC members discussed the need for affordable care for patients of all income and insurance levels and the need for better resources to support patients in need of financial aid.

Priority 2: addressing patient needs in treatment and research

The second priority is addressing patient needs in treatment, and research focused on increasing patient education, shared decisions and patient-friendly clinical trials in order to increase patient activation and encourage research participation. PAC members discussed a need for patient-centered educational materials to aid in a patient-provider partnership in treatment decision making, including the decision to participate in clinical trials that are designed with the patient experience in mind.

PAC members discussed issues with patient education and acknowledged that many patients were not educated on their disease and treatment options: "I think education is still a big gap. But not only that, access to education" [PAC member 2]. They experienced a lack of lay-language information sources and education initiatives from healthcare providers. PAC members self-educated on the internet and through patient networks. PAC members believed that better-educated patients advocated for themselves, received better care and had better health outcomes.

Our PAC members were actively involved in their treatment decisions and many had very involved physician-patient partnerships: "I make my decisions [based on] the recommendations from my care team" [PAC member 13]. In addition, PAC members expressed that they wished to be equal partners in decisions surrounding their treatment. However, our PAC members expressed that their situations were rare and that many patients with lung cancer were not involved in decisions regarding their treatment.

PAC members described the way research is conducted as research-oriented and not patient-oriented: "For researchers, clinical trials are experiments... For patients, clinical trials are hope" [PAC member 9]. Many PAC members had experience with clinical trials. Some PAC members expressed difficulties with learning about trials or keeping up with the newest research: "What's lacking is a navigator who can help people source clinical trials" [PAC member 9]. Some PAC members also expressed frustration with affording clinical trials: "A lot of people are under the impression that clinical trials are free, they are not free, you get the drug for free, everything else, your insurance or you have to pick up" [PAC member 14].

PAC members were frustrated with the lack of patient-centeredness and inflexible nature in clinical trials: "[My oncologist] says, 'We can try it [a clinical trial], but I have to be honest with you. It won't be as flexible. You won't have the control going through some of the trials that you have with me'" [PAC member 19]. PAC members criticized the limited number of locations at which trials were offered and the inclusion/exclusion criteria based on disease history or other health conditions: "I didn't even have to have the infection,

just the act of testing for it would disqualify me from the trial... I don't understand why they have to have such strict guidelines" [PAC member 3]. Some PAC member described that certain issues with clinical trial enrollment could be avoided if patients were more involved in trial design: "Some of what we can do about this is to help educate people about what the exclusion criteria are about and some of it we could be to help get patients more involved earlier in the clinical trial process to help those designing the trials understand that you could modify criteria" [PAC member 9].

Priority 3: shining a light on lung cancer

The third priority is shining a light on lung cancer focused on promoting screening policies, public knowledge and research funding in order to increase early detection, understanding about lung cancer and scientific knowledge. PAC members discussed an overarching need for heightened public awareness of lung cancer to raise public support for patients with lung cancer and reduce stigma to address these issues to improve diagnostic and treatment outcomes.

Multiple PAC members relayed their diagnosis stories and believed routine screening would have altered their prognosis: "If a CT scan had been part of that physical, there's a chance I could have two lungs" [PAC member 1]. PAC members were optimistic about recent screening policies but discussed the need for broader eligibility criteria. Furthermore, PAC members discussed the risks associated with radiation exposure and false positives and expressed the desire for lung cancer screening to become safer and more accurate.

PAC members were involved in increasing the awareness of lung cancer, ranging from personal outreach to blogging, public speaking appearances and media appearances. They believed it was important to discuss the experiences of patients with lung cancer to increase awareness and decrease stigma. PAC members compared the public support given to other cancers with the support provided to lung cancer:

"While I'm totally sympathetic to other cancers, we just really need a voice, and it needs to be lung cancer specific. It is the number one cancer killer, and it has unique problems and situations" [PAC member 7].

PAC members believed a lack of awareness and compassion for lung cancer survivors largely stemmed from the stigma associated with smoking. They believed that if this stigma could be reduced, funding for lung cancer research would increase and health outcomes for patients with lung cancer would improve.

PAC members perceived funding for lung cancer research as too low, especially considering its high mortality rate. They described that, compared with other cancers, lung cancer did not receive sufficient funding, and many attributed this to stigma: "It makes me angry that we aren't receiving the research dollars we should because of the stigma" [PAC member 16]. PAC members believed that lack of funding caused fewer medical breakthroughs and poorer health outcomes. PAC members expressed the need for more research funding, and some were actively involved in advocating for lung cancer funding.

Discussion

We successfully engaged patient advocates living with lung cancer to serve as key informants on our PAC and identify areas where lung cancer treatment, research and policy can be improved from the patient perspective. For healthcare systems, patient advocates' priorities were accessible care, coordinated care and affordable care. For treatment, patient advocates emphasized patient-centeredness in patient education, shared decisions and clinical trials. For policy, key priorities were increasing attention for lung cancer through screening policies, public awareness and research funding. While this project describes key gaps in the lung cancer system, these themes should be studied in more detail to ensure that interventions to address these issues can be appropriately designed.

Our PAC members were highly informed, motivated and engaged patients who were actively involved in treatment decisions and the patient advocacy community. This made the engagement process easier as PAC members were used to sharing their stories and opinions. In addition, PAC members were informed about the state of lung cancer treatment, research and policy, and upcoming developments in those areas. By engaging highly activated patients, we were able to learn about their personal stories as well as get informed opinions on priorities for actions to improve the patient experience in lung cancer.

This project had both strengths and limitations. First, we received only the perspectives of patient advocates who survived lung cancer (often beyond their estimated life expectancy). Engaging family members of deceased individuals could have provided us with a proxy for the perspective of patients for whom treatment might not have been as successful and whose experiences might therefore have been very different. Second, the interview guide was developed without input from PAC members because of time and resource constraints. Since the interview guide was designed to encourage PAC members to elaborate on their experiences, we believe the interviews were still patient-centered. Third, this project explored priorities for incorporating the patient experience as identified by highly activated patient advocates and their experiences might not reflect those of the average, less engaged patient. Future efforts will attempt to target patients that are less engaged in patient advocacy organizations to ensure that their perspectives are captured.

The engagement activities not only served as agenda-setting but also familiarized the researchers and the PAC members with each other and was a key first step in building a strong long-term collaboration between the project team, the lung cancer advocacy organization and PAC members. Through the first two steps in our engagement framework, engaging and understanding, a rapport was established between the project team and PAC members that has facilitated further collaboration. Following the presentation of the results of this project, PAC members and the project team have remained engaged to conceptualize, develop and implement next steps in Project Transform. For future projects, an advisory board composed of stakeholders in industry,

medicine and policy will be formed to serve alongside the PAC in order to help provide additional content expertise.

To ensure that the project has an impact, the project team intends to keep disseminating the results through the peer-reviewed literature, meetings at professional organizations, meetings with patient-advocacy organizations and patients, regulatory agencies and other avenues. The project described in this paper is an ongoing engagement process that does not have a set end date, rather the project's long-term goal is to improve mortality, morbidity and quality of life for people with lung cancer.

Conclusion

Engaging patients living with lung cancer is an essential step in integrating their experiences into lung cancer research, treatments and policy. This engagement identified multiple issues that need to be addressed to make the lung cancer patient's voice heard in these areas. In the long term, efforts are needed that focus on creating patient engagement strategies and stakeholder relationships that can inform decision making within the lung cancer community. As this partnership evolves, we will continue to engage patients and collect qualitative data to evaluate and communicate patients' priorities and preferences for lung cancer treatments and identify patient-centered solutions.

Transparency

Declaration of funding

This work was supported by LUNGevery (with funding from Celgene). The funder had no influence on the design of the project, data collection, analysis, interpretation or writing of the report.

Declaration of financial/other relationships

J.F.P.B., E.M.J., A.F. and S.M.D. have disclosed that they have no significant relationships with or financial interests in any commercial companies related to this study or article.

CMRO peer reviewers on this manuscript have no relevant financial or other relationships to disclose.

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