

Project Transform: Engaging Patient Advocates to Share their Perspectives on Improving Research, Treatment and Policy

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For which topic were research priorities identified?

lung cancer

In which location was the research priority setting conducted?

North America - USA

Why was it conducted at all?

Incorporating the patient perspective into lung cancer research, policy and treatment is becoming increasingly recognized as important.

What was the objective?

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

What was the outcome?

a list of 9 research topics

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

interview; meeting

How were the priorities for research identified exactly?

Step 1: forming a patient advisory committee (PAC). Step 2: 2 meetings: PAC members identified areas in which lung cancer treatment, research and policy could be improved from a patient perspectives. Step 3: semi-structured interviews with PAC members. Step 4: data processing: thematic analysis of transcripts

Which stakeholders took part?

Patient advocates living with lung cancer. Interviews: 19 participants. Meeting: 19 participants.

How were stakeholders recruited?

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.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of an advisory board. The advisory board was composed of patient advocates living with lung cancer. LUNgevity (the largest lung cancer patient advocacy organization in the USA) 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. Additionally, a project management team was established. 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, and one individual affiliated with LUNgevity.