

Pancreatic Cancer and Community Engagement

A Scoping Review of the Literature



Pancreatic cancer is a burdensome disease with high morbidity and mortality. In 2023, 64,050 individuals are projected to be diagnosed with pancreatic cancer, and 50,550 people will die from the disease.¹ Clinicians must be able to address the clinical, supportive, and palliative needs of patients with pancreatic cancer. It is important that patients with pancreatic cancer are engaged in their care and that their voices are heard as they go through the management for their disease.² Engaging patients and community members in cancer research brings personal experiences and preferences to the attention of researchers who can then be more responsive to the needs of patients with pancreatic cancer.³ To do so, researchers must employ community engagement, defined as the “process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of these people.”^{4,5}

Community engagement allows for patient participation in medical care and higher levels of trust between health care workers, researchers, and the communities they serve.⁶ Community engagement has been found to help mitigate asymmetry (a lack of equality or equivalence) between patient and researchers.⁶ The community engagement approach has been found to help foster people-powered, bidirectional, mutually beneficial efforts that inherently offset power differentials.⁷ By bridging this gap, community-engaged research and interventions in clinical settings can encourage trusting relationships and lead to better health outcomes.⁸ Furthermore, by showing genuine interest in what is important to patients as people rather than research subjects, these approaches can help overcome mistrust in the medical community and contribute to larger community health efforts.⁹

In the cancer setting, community engagement has been used to improve the quality of life in those with disease, reduce disparities in cancer incidence and outcomes, and allow patients to have their voices heard. Community-engaged programs have improved health-related quality of life and emotional-wellbeing of patients with cancer.¹⁰ Engaging stakeholders in the development of community-engaged studies has helped guide research priorities,¹¹ establish research methods,¹² and improve the uptake of research findings.¹³ Community engagement has been suggested as a way of reducing cancer disparities and was successfully implemented to increase the participation of

Inform is the lowest level of the spectrum and is defined as providing the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solution.

minority patients in clinical trials.¹⁴ Culturally sensitive partnerships between academic and community organizations have improved screening among individuals at risk for breast cancer.¹⁵ For these reasons and many others, engaging patients with cancer in research efforts will make research more meaningful and responsive to the communities we hope to serve.

Despite the clear benefits of engaging patients with cancer in community-engaged research, there is a gap in knowledge particularly for patients with pancreatic cancer.^{2,16} This scoping review aims to explore the community-engaged research that has been carried out in the setting of pancreatic cancer.

Methods

This scoping review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews (PRISMA-ScR).¹⁷ The use of scoping review methodology allowed us flexibility to include a variety of publications including commentaries and research studies.

Eligibility Criteria

We included articles that involved patients with pancreatic cancer and used or identified community engagement strategies in their research approach. We defined community-engaged research based on the definition, “a process of inclusive participation that supports mutual respect of values, strategies, and actions for the authentic partnership of people affiliated with or self-identified by geographic proximity, special interest, or similar situations to address issues

affecting the well-being of the community or focus.”¹⁰ There was no requirement regarding the type of study design for inclusion in this review.

Information Sources and Literature Search

We developed the search strategy in conjunction with a research librarian. We searched OVID Medline, Scopus, and Web of Science Core Collection using combinations of the following terms to identify relevant studies: pancreas*, neoplas*, tumor, cancer*, oncolog* metastas*, carcinoma*, adenocarcinoma*, communit*, consumer*, public*, engag*, based*, participat*, involve*, outreach*, CENR*, CER*. There was no exclusion based on publication date. Only articles written in English were included due to the researchers’ abilities. The search was conducted on September 7, 2022.

Selection of Sources of Evidence

Titles and abstracts were screened by 4 investigators; papers with majority agreement were read in full by 4 investigators. A senior author was available for disagreements. The research team used the internet platform “rayyan.ai/reviews” to screen and categorize the abstracts. This platform allows the categorization of each researcher to be blinded to the others.¹⁸

Data Extraction

The following information was extracted from the sources: Author(s), Title, Type of Paper, Year of Publication, Objective, and Main Findings. Each investigator independently reviewed the included papers to determine the level of community engagement. The spectrum of community engagement used was developed by Wieland et al in accordance with the International Association for Public Participation’s Spectrum of Public Participation.¹⁹ This strategy is consistent with that used by Wieland and colleagues. The research team met to discuss this categorization. Evidence that supported the level of community engagement assigned to each source was noted. Disagreements were resolved by discussion of the evidence, ultimately allowing for consensus to be reached by the entire team. Again, a senior author was available for disagreements.

Synthesis of Results

Common themes among sources were identified as the team met to discuss the included papers and perform data extraction. Subsequently, sources were summarized and grouped by theme as well as their level of community engagement.

Search Results

The search resulted in 1237 articles after removal of duplicates. Screening of abstracts excluded 1201 articles; 36 articles were read in full. Full-text screening excluded 21 additional articles. The remaining 15 articles met inclusion criteria. Our literature search and selection process are outlined in Figure 1.

Characteristics of Studies

Most of the papers in this study were descriptive studies using either survey (n = 2) or qualitative methods (n = 9). Two (n = 2)

The authors found that trusting relationships between providers and patients is key to screening for pancreatic cancer.

studies used social media to study phenomena related to pancreatic cancer. Papers can also be characterized by subject matter. Two (n = 2) papers were commentaries on increasing participation in tissue biobanks using community-engaged methods. Seven (n = 7) of the included studies focused on shared decision-making between patients with pancreatic cancer and their providers. Two (n = 2) papers looked at patient preferences and perceptions of screening tests for pancreatic cancer. One (n = 1) study ascertained the research priorities of those individuals diagnosed with pancreatic cancer.

To understand the depth of community engagement published in the literature, each included article was given a ranking on the International Association for Public Participation’s (IAP2) spectrum of public participation. This method of classifying research based on the spectrum of public participation is in line with previous scoping reviews on community engagement.¹⁹ The spectrum, along with definitions, can be found in Figure 2. Each of the papers included in our review is categorized based on which of the 5 community engagement levels they exemplify and displayed in Table 1.

Level 1. Inform

Inform is the lowest level of the spectrum and is defined as providing the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solution. Five papers fell into this category. One paper in this category evaluated discussions around pancreatic cancer on Twitter to identify topics important to patients with pancreatic cancer and also health care providers.²⁰ Similarly, blogs and online cafes were studied to understand the relationship between the public’s feelings about pancreatic cancer and the factors impacting those emotions.²¹ One commentary paper explored the experience and research potential of the Pancreatic Cancer Action Network (PanCAN) registry, an online registry developed by researchers that patients with pancreatic cancer can participate in if they wish to share their health data.¹⁶ Another group of researchers used surveys to determine whether the amount of information given about a screening test for pancreatic cancer reduces the acceptance of that test.²² Finally, the inform group included a commentary on how to enhance Black patients participation in biobanking. This commentary included a call to action for stakeholders to build collaborative partnerships with faith and civic leaders in the community to solve the problem of Black patients being underrepresented in pancreatic cancer research.²³

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Figure 1. Literature Search and Selection Process

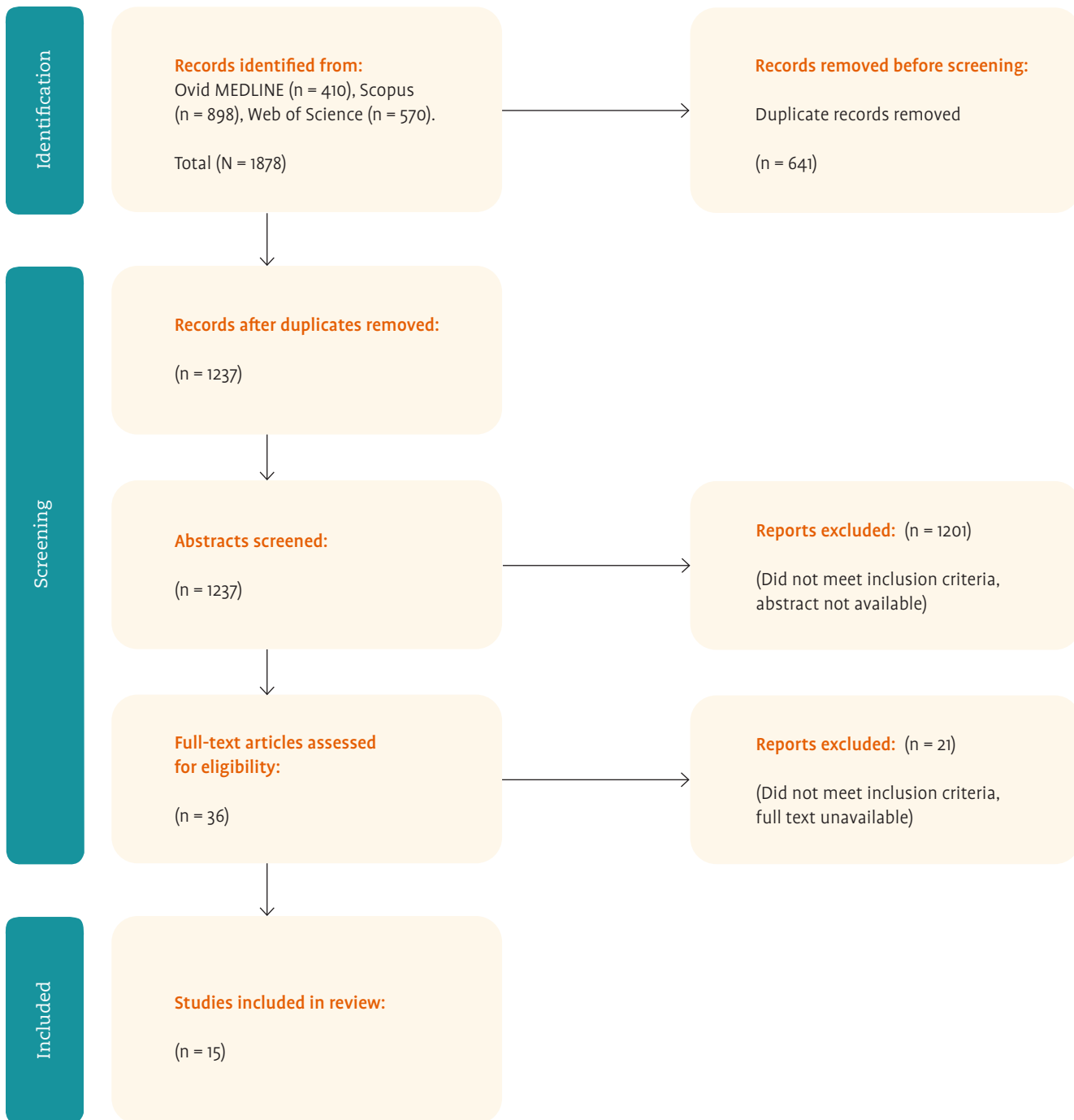



Figure 2. IAP2 Spectrum of Community Engagement²

This tool was designed to assist with the selection of the level of participation that defines the public’s role in any public participation process. The spectrum is used internationally, and it is found in public participation plans around the world.



	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
Public participation goal	To provide the public with balances and objective information to assist them in understanding the problem, alternatives, opportunities, and/or solutions.	To obtain public feedback on analysis, alternatives, and/or decisions. We will keep you informed, listen to, and acknowledge concerns and aspirations, and provide feedback on how.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision, including the development of alternatives and the identification of the preferred solution.	To place final decision-making in the hands of the public.
Promise to the Public	We will keep you informed.	Public input influenced the decision.	We will work with you to ensure your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

IAP2=International Association for Public Participation. Figure used with permission from ©International Association for Public Participation.

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Level 2. Consult

Consult is the next level of public participation and is defined as obtaining public feedback on analysis, alternatives, and/or decisions. Two papers fell into this category. The first was a survey-based study to assess patient experiences and preferences around a fast-track discharge program after surgery for pancreatic cancer.²⁴ The authors noted that almost half of the patients perceived they had not been involved enough in their care or discharge planning. The second study in this category was an article written to study and address disparities in pancreatic cancer research, specifically the challenge of recruiting minority individuals to participate in biobanks.²⁵ The authors indicated they worked with the Pancreatic Cancer Action Network to involve pancreatic cancer survivors and advocates on their community advisory board.

Level 3. Involve

Involve is the next level of public participation. It is defined as working directly with the public throughout the process to ensure

that public concerns and aspirations are consistently understood and considered. Six papers fell into this category. All 6 were qualitative studies with a common theme of identifying needs and examining perspectives of patients with pancreatic cancer. Three studies focused on shared decision-making. In the first study, older patients with pancreatic cancer were interviewed about their preferences around shared decision-making and communication.²⁶ Patients preferred decision-making to be divided into more sessions to build trust in their relationship with the oncologist. The authors suggest these findings should be implemented to improve the training of providers. A similar study used qualitative methods to explore patients with pancreatic cancer preferences on shared decision-making and treatment.²⁷ Patients were found to rely more on physician guidance initially whereas in the latter stages of disease, patients wanted to have more control over their health decisions. The third study on shared decision-making sought to identify barriers faced by patients with pancreatic cancer.²⁸ Patients often felt pressured into choosing surgery, confused when clinical opinions differed, and hopeless about the likelihood of survival.

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Table 1. Studies Exhibiting Community Engagement Principles and Their Objectives

AUTHOR (YEAR)	TITLE	TYPE OF PAPER	OBJECTIVE	LEVEL OF COMMUNITY ENGAGEMENT
Behar-Horenstein et al (2020) ²³	Enhancing African American Participation in Biospecimens: A Case in Point for Pancreatic Cancer	Commentary	Survey biobanks and identify disparities in pancreatic biospecimens, provide explanations for disparities, and suggest ways to increase African American participation in organ and biospecimen donation.	Inform
Domenighetti et al (2000) ²²	Does Provision of an Evidence-Based Information Change Public Willingness to Accept Screening Tests?	Randomized, survey-based study	Investigate the willingness of the general population to undergo a screening test for pancreatic cancer based on the quality and the extent of the information provided.	Inform
Grewal et al (2022) ²⁰	Twitter Conversations About Pancreatic Cancer by Health Care Providers and the General Public: Thematic Analysis	Thematic analysis	Evaluate the content of discussions around pancreatic cancer on Twitter and identify subtopics of greatest interest to health care providers and the general public.	Inform
Gupta et al (2021) ¹⁶	Leveraging Patient Reported Outcomes (PROs) in Patients with Pancreatic Cancer: The Pancreatic Cancer Action Network (PanCAN) Online Patient Registry Experience	Retrospective study	Describe the creation, user experience, and research potential of the PanCAN Registry.	Inform
Park et al (2020) ²¹	Understanding the Public's Emotions about Cancer: Analysis of Social Media Data	Retrospective study	Explore the relationship between the public's emotions about pancreatic cancer and factors affecting emotions using social media.	Inform
Larnebratt et al (2018) ²⁴	Information is the Key to Successful Participation for Patients Receiving Surgery for Upper Gastrointestinal Cancer	Cohort study	Identify and explore patient participation among patients who had surgery for liver, bile duct, or pancreatic cancer and followed a fast-track program.	Consult
Permuth et al (2021) ²⁵	The Florida Pancreas Collaborative Next-Generation Biobank: Infrastructure to Reduce Disparities and Improve Survival for a Diverse Cohort of Patients with Pancreatic Cancer	Commentary	Study and address pancreatic cancer disparities by building a robust biobank containing viable tissues, biofluids, images, and data with a racially/ethnically diverse cohort of Floridians with pancreatic cancer.	Consult
Geessink et al (2016) ²⁶	Key Elements of Optimal Treatment Decision-Making for Surgeons and Older Patients with Colorectal or Pancreatic Cancer: A Qualitative Study	Qualitative cohort study	Identify key elements of optimal treatment decision-making for surgeons and older patients with colorectal or pancreatic cancer.	Involve

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Table 1. (Continued) Studies Exhibiting Community Engagement Principles and Their Objectives				
AUTHOR (YEAR)	TITLE	TYPE OF PAPER	OBJECTIVE	LEVEL OF COMMUNITY ENGAGEMENT
Guo et al (2021) ³⁰	Compounded Trauma: A Qualitative Study of the Challenges for Refugees Living with Advanced Cancer	Qualitative cohort study	Identify the needs and experiences of adult refugees in Jordan with advanced cancer and informal caregivers.	Involve
Lewis et al (2009) ²⁹	Pancreatic Cancer Surveillance Among High-Risk Populations: Knowledge and Intent	Qualitative cohort study	Understand perceptions and intent to screen for pancreatic cancer among those with an increased risk due to a hereditary cancer predisposition syndrome or family history.	Involve
Ibrahim et al (2018) ³¹	'I want to know why and need to be involved in my own care...' A Qualitative Interview Study With Liver, Bile Duct or Pancreatic Cancer Patients About Their Experiences with Involvement in Care	Qualitative cohort study	Explore experiences of involvement among patients who had surgery for upper abdominal tumors and were cared for according to a fast-track care program.	Involve
Schildmann et al (2013) ²⁷	'One also needs a bit of trust in the doctor ...' A Qualitative Interview Study With Pancreatic Cancer Patients About Their Perceptions and Views on Information and Treatment Decision-Making	Qualitative cohort study	Reconstruct perception of patients with pancreatic cancer regarding the disclosure of diagnosis and treatment decision-making, and explore patients' preferences regarding information and treatment decisions and the reasons for their preferences.	Involve
Ziebland et al (2015) ²⁸	Barriers to Shared Decisions in the Most Serious of Cancers: A Qualitative Study of Patients With Pancreatic Cancer Treated in the UK	Qualitative cohort study	Explore patients with pancreatic cancer perceptions of barriers to shared-decision making in a condition in which shared decision making might be difficult.	Involve
Sato et al (2022) ³²	Assessing the Need for a Question Prompt List That Encourages End-of-Life Discussions Between Patients With Advanced Cancer and Their Physicians: A Focus Group Interview Study	Qualitative cohort study	Assess the need for a question prompt list that encourages end-of-life discussions between patients with advanced cancer and their physicians.	Collaborate
Saunders et al (2009) ³³	As the Bell Tolls: A Foundation Study on Pancreatic Cancer Consumer's Research Priorities	Qualitative	Explore the views of people affected by pancreatic cancer about research priorities	Collaborate

PanCAN=Pancreatic Cancer Action Network.

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The other three studies in the involved category also used qualitative methods to involve patients with pancreatic cancer in their research. In the first study, patients at high risk of pancreatic cancer were interviewed about their willingness to undergo cancer screening.²⁹ The authors found that trusting relationships between providers and patients is key to screening for pancreatic cancer. It was suggested that the patient's primary care physicians, along with the oncologist, were involved in this decision. Another study identified the needs and experiences of refugees in Jordan with advanced cancer, such as pancreatic cancer.³⁰ Patients were interviewed to explore the impact of compounded trauma and give a voice to the participants. In the last article in the involve category, patients who went through a fast-track discharge program after surgery for pancreatic cancer were interviewed regarding their experience in hopes of improving the program for patients.³¹

Level 4. Collaborate

Collaborate is the next level of public participation. It is defined as partnering with the public in each aspect of the decision, including developing alternatives and identifying the preferred solution. Two (n = 2) papers fell into this category. Again, both used qualitative methods. The first study was a focus group to assess the need for a question prompt list to guide end-of-life discussions between patients with pancreatic cancer and their providers.³² The patients in the study developed the questions on their own in accordance with their thoughts and values. The authors stated these questions would be used to develop the question prompt list. Lastly, people affected by pancreatic cancer, including patients, caretakers, and advocates were interviewed to ascertain the most important research priorities.³³ The authors investigated the issues that patients with pancreatic cancer and caretakers face to guide how the scientific community may best serve them.

Level 5. Empower

Empower is the highest level of public participation. Empower means placing the final decision-making in the hands of the public. None of the papers in this study reached the empower level of community engagement.

Discussion

Our scoping review demonstrates that community engagement strategies have been used in the setting of pancreatic cancer to some extent. However, we did not find evidence of “deep” community engagement that ultimately leaves decisions in the hands of the research participants. Such a finding provides the opportunity for future research using multiple study designs, including randomized control trials. Community engagement is especially relevant among vulnerable groups that are often not consulted for input, such as individuals with pancreatic cancer who have been diagnosed with a frightening disease with a very low survival rate.³⁴ There is room for deeper, more meaningful community engagement in the setting of pancreatic cancer to allow for the patient's voice to be at the forefront of research studies.²

One common theme revealed in this scoping review was the abundance of “community-based” work without actual evidence of

Historically, research has collected information from communities while rarely giving back to the people we learn from, and often taken without the cultural context from which these communities exist.

“community engagement,” as defined in this study and by the Spectrum of Public Participation. In medical literature, there is an abundance of information stemming from work done in the community. Still, these studies often lack aspects of the bidirectional, collaborative nature of community-engaged work where the research teams take direction and learn from the community being studied. Several studies assessed during the initial stage of this scoping review highlighted work done within a community hospital setting but with little other involvement of patients. For example, 2 papers provided a thorough retrospective study of postoperative outcomes after surgical resection of pancreatic cancer in community-based academic hospitals.^{35,36} Although such studies can provide researchers with valuable clinical information (ie, length of hospital stay, operative blood loss, and potential intraoperative or postoperative complications like an anastomotic leak), they do not consider the experiences and values of patients regarding their operative course. One could argue that this information can eventually inform the patient community, but additional steps must be taken to involve the community being studied for this to be considered true community engagement. Our findings echo those of other systematic reviews on similar topics that have found few studies achieve high levels of community engagement.³⁴

Similarly, several retrospective studies identified the characteristics of patients with pancreatic cancer without actively engaging with them or learning from their lived experiences.³⁷ Retrospective chart reviews that examine trends in cancer treatment and barriers to care can also provide valuable information to inform providers and contribute to public health efforts. However, these studies do not contain individual perspectives from community members. Further steps should be taken to involve and empower communities of patients with cancer to make a sustainable impact on the community in the future. For example, researchers could share their findings with patients with pancreatic cancer to learn about their reactions and opinions. This action would allow patients to be involved in the research and foster bidirectional learning experiences. Taking a more community-engaged approach could provide researchers with the information needed to meet the needs of the community rather than examining it from afar.


The framework of community-engaged research developed by the International Association for Public Participation's Spectrum of Public Participation places the ultimate community influence at the “empower” level. Just because the community can make the final decision does not necessarily equate to a standard of community engagement. As Graeme Stuart wrote in a blog post, “a decision

could be made by the community through a process that requires little interaction or engagement (eg, a referendum).³⁸ An additional limitation of this discussion on the empower level is the effect of improper implementation of an empower-based research study. This can potentially leave communities stranded if they do not have the resources or capacity to support the project or understand the decision. The empower level must still be created using the 7 core principles of community engagement to truly be community centered.⁵ However, the focus of our discussion will focus on opportunities to engage the community more meaningfully, allowing researchers to advocate for the community's specific needs, and promote community-engaged research studies in the realm of pancreatic cancer research.

Even though our review did not demonstrate evidence of any published studies incorporating the “empower” standard of community engagement, a few research articles we sorted within the “collaborate” level describe the outcomes of instances when the public helped guide research questions for funding priority.^{32,33} These studies elaborate on the collaborative nature of qualitative research and use of focus groups in multiple stages of the program, allowing the community to have a say in the research that goes on within the context of their environment. Creating community-engaged research allows the focus to transition to a bi-directionality approach and gain insight into a particular cultural context. Historically, research has collected information from communities while rarely giving back to the people we learn from, and often taken without the cultural context from which these communities exist. Research on the higher end of the public participation spectrum has the power to uncover results that are more meaningful within both the scientific and public contexts while also having the potential to diversify participants by increasing trust between these communities.

The “empower” level of community engagement can be viewed similarly to civic government elections. In this analogy, voters are the community members who can decide for themselves whom to vote for and ultimately become the elected official. The candidates running for the position in question aim to build trust with the community they wish to serve. This trust is commonly accomplished by going into the community, building relationships with trusted members, and advocating for the needs of specific groups of people. This example of democracy describes enlisting power to the people to elect someone who can listen and respond to the needs and desires of their community. This process can also be demonstrated within research, the standard that the empower level aims to utilize. For example, Saunders et al. involved the pancreatic cancer community by exploring the research priorities of those affected by the disease.³³ If the authors had shown that these research priorities were funded and pursued as a direct result of their engagement process, that would constitute “empower” level of community engagement.

There are many challenges to engaging community members in pancreatic cancer research. Researchers must forge and maintain meaningful relationships with members of the community. Such an endeavor can be both logistically and practically challenging. Additionally, studies have found that high-quality community engagement sometimes requires adaptations to research protocols making them less rigorous.³⁹ Another study found that lack of funds and power struggles between stakeholders were the main barriers to community

engagement.⁴⁰ Patients with pancreatic cancer may want to participate in research but are limited by their physical or mental health. It is essential that researchers work to overcome the barriers to community engagement to empower the groups they set out to study. Engaging the community in research will ensure equitable and meaningful improvements to health and quality of life among patients with pancreatic cancer. 

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