



## **Paving a Pathway to Engage Underserved Populations in Research: From Prioritization to Dissemination**

Final Report Project 20016-PAF

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## **Project Abstract**

In May 2021, Patient Advocate Foundation surveyed 27,541 patients and caregivers to better understand the needs, barriers, and priorities of underserved patients, and increase this group's capacity, comfort and confidence to actively participate in the research ecosystem. The survey yielded 3,109 respondents, 54% stating they had never been contacted to participate in research, and 88.5% stating they would join a research team if training were provided, underscoring the untapped resource of patient expertise. The ensuing survey analysis laid the foundation for a messaging campaign to the patient network and a series of listening sessions.

To ensure we organized this project through the patient and caregiver lens, we initially recruited 10 patients and caregivers to co-develop all aspects of the project. Each partner was grouped into three workgroups: Patient Partners, Patient Workgroup and the Stakeholder Advisory Group. Each member represented various faces of "underserved" persons, with 40% having no experience in research engagement.

We grew each workgroup to host a total of 18 partners, including Research Assistants. Each workgroup member was heavily involved in project activities, including agenda-setting, listening session facilitation, providing direct feedback on messaging and project resources/materials.

This project was conducted virtually, and its activities included: survey dissemination, survey analysis, hosting two listening sessions, distributing seven patient and stakeholder-informed messages to survey respondents and developing a messaging rubric to ensure research and results are accessible, appropriately communicated and relevant.

We are utilizing our findings to provide tools for researchers to better engage underserved populations in their research teams, as equal members.

## Introduction

To better understand and overcome barriers to research engagement, Patient Advocate Foundation surveyed our patient network to fulfil our project objectives of 1) capturing views on research, 2) identifying barriers to research engagement and 3) identifying ways to sustain participation in research opportunities.

The disparity in patient engagement in research is layered. There's the reality of *convenience sampling* as the primary method for recruitment and the interconnectedness of logistical challenges, health literacy gaps, general access barriers and mistrust patients have or feel that must be addressed on a systemic and individual level. Not addressing these realities exacerbates existing disparate health outcomes and deepens patient mistrust of systems, research, and researchers and ultimately does not yield substantive results.

There is an identified need to expand understanding about ways to effectively involve a more diverse group of patients and how that representation affects research projects and engagement contributions. This project is designed to better understand the needs, barriers, and priorities of underserved patients, and increase this group's capacity, comfort and confidence to participate actively in the research ecosystem.

## Team

### Staff

Name	Role
Rebekah Angove	Project Lead
Wyvonia Woods-Harris	Patient co-lead
Monica Grandovic	Patient co-lead
Amy Jeroy	Education Manager
Kate Gallagher	Research and Analytics
Mary Mukira	Engagement Manager

### Advisors

Name, Location	Role	Name, Location	Role
Monica Grandovic, IN	PP	Rebecca Barnes, KY	SAG
Wyvonia Harris, TN	PP	Sue Friedman, FL	SAG
Sarita Battish, PA	PWG	Susan Brown, MD	SAG
Julie Roberts, NC	PWG	Jacqueline Lambert-Davis, AL	SAG
Sa'Brina Davis, NC	PWG	Jessica Jones, IN	SAG
Stephen Christoph, PA	PWG	Jamie Stokley, IN	SAG
Frances Lennane, FL	PWG	Isha Yardi, MD	SAG
Breanna Obando, FL	RSA	Elvira D'Souza, NJ	SAG
Ono Abhulimen, NC	RSA		
Dymon Blango, NC	RSA		

Identify as a patient	67%	Experience with access challenges	33%	Low-income	39%
Identify as a caregiver	44%	Experienced transportation issues*	33%	Racial/ethnic minority	61%
Worked in healthcare	39%	Experience with research **	56%	Disabled	33%

\*issues related to location (rural) or disability

\*\*includes research training, participation, and/or engagement

### Timeline

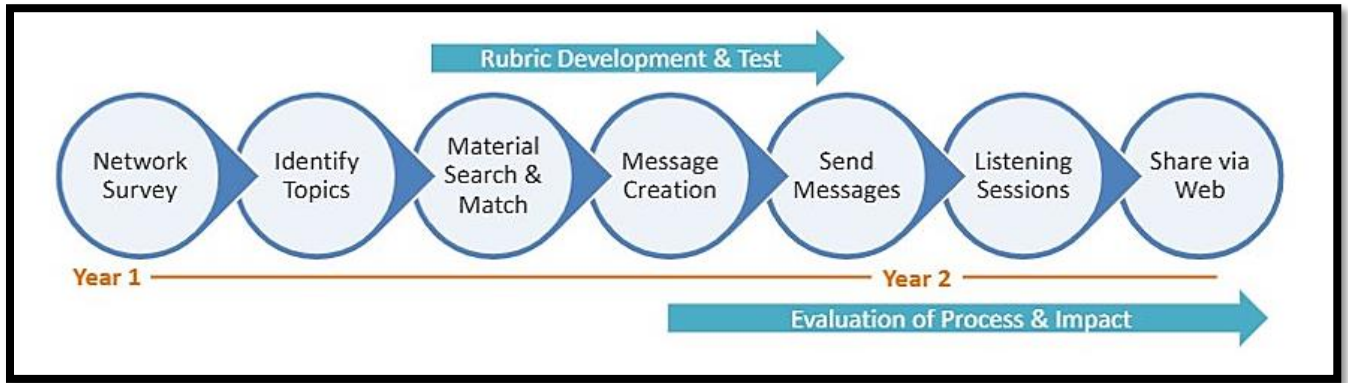


Figure 1 features a concentrated timeline of major project milestones for the 24-month project.

### Survey

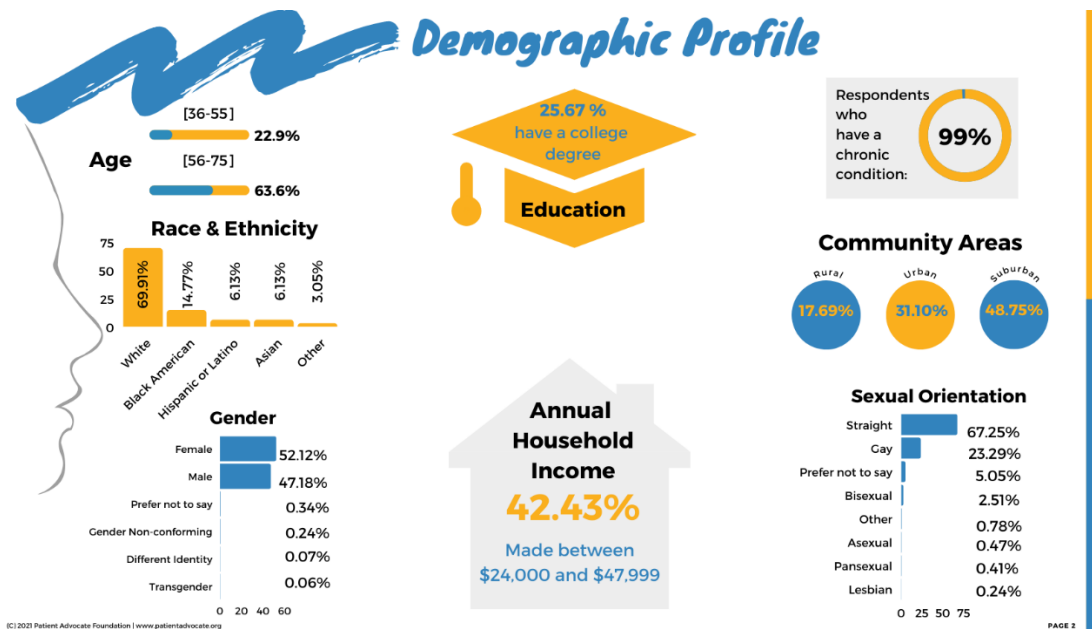


Figure 2 features the demographic profile of survey respondents.

## Overview

The May 2021 survey assesses patient and caregiver priorities and barriers to engagement in the research ecosystem. Ninety-seven percent of those surveyed believe the patient perspective is important in research, yet only 12% have been contacted about serving as a patient partner on a research team and 39% of survey respondents indicated that they would consider participating in research, if they were contacted.

Most survey respondents have a neutral or positive outlook on research and expressed the need for researchers to better understand the challenges that limited-resourced, uninsured, and/or minority patients face.

In analyzing the survey results, we found that the top five barriers to advising on a research team included: 1) project time commitment, 2) time of day, 3) disability or physical limitation, 4) lack of paid compensation and 5) transportation. If engagement barriers were to be addressed, most respondents would consider advising on a research team/ project

## Methods

PAF, along with our patient and caregiver partners, executed the project in two phases. Phase 1 – information gathering, infrastructure and messaging development and phase 2 – enhanced outreach and evaluation. The deliverables in these phases included 1) deploying the survey to previously served clients, 2) distributing targeted email messages to survey respondents on the topics of: *the value of the patient experience*, *addressing research engagement barriers* and *research literacy*, and 3) hosting two unique listening sessions on how to best communicate with patients and which sources patients trust for health information.

In understanding some of the primary barriers to engagement and ensuring workgroup members feel valued and motivated to engage in the project and the portion of our patient network who indicated interested in the progress of the project effectively engage, we employed five engagement methods 1) disseminate Research Insights Survey and use results to inform messaging 2) gather additional insights via email metadata and polling 3) conduct patient-led listening sessions for additional topic specific insights 4) hold regular meetings with workgroup and advisory group members 5) launch patient-informed messaging plan, teach and motivate engagement in research.

To ensure transparency and accessibility of our resources and findings, PAF developed a dynamic project webpage to publish the insights and deliverables of the project. This webpage highlights the patient prioritized research topics, translated research results, and stories from our patient network. It also provides information and links to educational materials, adapted tools and resources, survey results, and Stakeholder Advisory and Patient Workgroup membership and contributions. Placeholders will be created for real-time messaging updates, partnership development, and evaluation results.

## Results Summary

The survey offered PAF the opportunity to increase patients' awareness of the importance of sharing their experience with other patients and research teams. While 97% of survey respondents believe the patient perspective is important in research, many feel that they have more valuable experience to share with other patients as opposed to researchers. For additional insights, [view the results](#) of the 2021 PAF survey about patient experiences and perspectives related to research and research engagement.

## Email Campaign

### Overview

Throughout the course of this project, our workgroup members collaborated with us on creating seven unique messages to speaking to key topic areas patients stated were relevant to their likelihood to engage in research. These topic areas include the *value of the patient experience*, *addressing barriers*, and *research literacy*. Our workgroup members informed the messages to be culturally relevant, accurately speak to patient needs and the content remain engaging and thoughtful for the audiences.

We remain mindful of the sensitivities and cultural/environmental shifts from the message's initial curation. As such, we continue to seek guidance from and collaborate with our patient and stakeholder groups. Specifically, we remain mindful of the different types of engagement we offer to our larger patient network, to accommodate the survey- identified engagement preferences (i.e. virtual engagement opportunities like direct email polling, online surveys, video/dial-in meetings, compensation offerings, etc., to boost/ engage their research participation). We continued to leverage the feedback of our patient and stakeholder groups, maintaining an informed understanding on how to best craft engagement requests and the structure and content. We used the Mailchimp email delivery system to send messages, appropriately tag individuals based on survey responses and to collect analytics data on the effectiveness of these messages.

For additional insights, please view [Appendix A](#) to review project email messages and [Appendix B](#) for general messaging analytics and polling results.

## Listening Session



It's important to find words that are less stigmatizing because it affects how we see ourselves and others.



## *Overview*

### Listening Session 1

#### *Methods*

Ahead of the listening session, we provided meeting registrants with three documents to review 1) Meeting Agenda ([Appendix C](#)) 2) Terminology to Discuss document ([Appendix D](#)) and 3) Messaging Rubric ([Appendix F](#)). We organized the Listening Session to have two breakout discussion groups to review the terminology document and messaging rubric and regroup in a larger discussion. The first breakout discussion had participants share their thoughts on the messaging rubric by examining, “What is potentially stigmatizing language, topics, or approaches? How can researchers identify these “red flags?” Following that discussion, meeting participants shared their thoughts on the Terminology to Discuss document which included terms often used in health and research spaces. This document helped facilitate conversations around language and how commonly used terms can stigmatize and further bias individuals and impact their care and research engagement experience.

#### *Topics and Results Summary*

For additional insights, [view the results](#) of Listening Session #1 titled “Hear for All,” capturing patient perspectives on biased and stigmatizing language used in research and care settings.

### Listening Session 2

#### *Methods*

Ahead of the listening session, we provided the meeting registrants with the meeting agenda ([Appendix E](#)) and organized the Listening Session to have two breakout discussion groups – the first workshopping a presented social needs scenario and discussing terminology related to it and the second breakout discussion focusing on where and how patients prefer to receive health information.

#### *Topics and Results Summary*

This Listening Session helped orient how patients decipher trusted sources of information and how they prefer to communicate about their health. Most participants shared a common trust amongst receiving information from family, pharmacists, support groups and unbiased online health resources when navigating health information and prefer person to person communication when discussing personal health information. Participants largely shared a preference for hearing from other patients on how they navigate similar experiences and relying on a mix of trade experts (i.e. researchers, clinicians) for informed decision-making and understanding, regarding navigating specific diagnoses or treatments – assuming there’s a reliable sense or builds of trust with those experts.



## Messaging Rubric

In parallel efforts to developing our messaging calendar and content, we captured the input and feedback from our Patient Partners, Patient Workgroup, and Stakeholder Advisors throughout the iterative development process. We used this information to create a standardized approach to ensuring multiple dimensions of patient-centeredness are considered when developing messaging. The resulting rubric can be used to guide researchers through the process of building/assessing messaging to underserved populations. The final rubric ([Appendix F](#)) was then applied to the developed messages and a scoring system created. Patient partners and stakeholder advisors applied the scoring to messages, with each messaging scored by at least two independent reviewers. Discrepancies were discussed and the rubric refined. While final scores of project messages were generally very high, there was positive correlation between rubric score and message engagement (open rates and click rates).

## Impact & Sustainability

- a) Cohort of “underserved” trained and engaged patients ready to support/ engage in CER/PCOR
- b) Understanding of what patients want/ experience
- c) Ongoing sending of campaign as new members are recruited into network
- d) Dissemination of patient preferences related to CER/PCOR engagement

Immediate impact of this project includes increasing members of underserved communities’ exposure to, and knowledge of the research processes, results, and the value of their engagement in the research ecosystem. We also increased our organization’s (and the wider field’s) understanding of this group’s needs, perspectives, priorities, and barriers as related to research and engagement. This was the first steps to normalizing research as part of the conversation around health and increasing trust and confidence in engaging with the research process, results, and/or researchers. This project improved the research literacy among network members and increasing the network’s motivation and willingness to engage across the research process. This also ensures that future outreach is responsive to community needs and resonates with the individuals receiving the messages. We are already seeing an increased demand for research opportunities for engagement from our Patient Network community members.

As network membership grows, we will continue to send these developed messages as an introduction to research engagement and PCOR and gather survey and insights about patient experiences and perspectives. We will continue to gain a greater understanding of the nuances of this group’s experiences and priorities, how these change over time and differ between sub-groups within the larger population of underserved individuals. We are already seeing hints of the long-term outcomes anticipated of this project by an increased engagement of underserved patients in CER and other research. This expanded inclusion of underserved patients has the potential to increase the relevance and generalizability of research to this group and improve outcomes.

We are excited by the feedback and enthusiasm of our Patient Network Members to engage in research. Our next challenge is reaching enough researchers to meet the demand of our members. We anticipate that through ongoing surveys, listening sessions, and coaching we30 can keep a substantial number of patients ready and excited to engage once researchers are ready to connect. We are also working on a number of academic partnerships to meet this demand and expand opportunities for patients and researchers to work together.

## **Appendices**

[Appendix A](#) – email messages

[Appendix B](#) – messaging analytics; email polls & results

[Appendix C](#) – listening session 1 agenda

[Appendix D](#) – terminology document from LS 1

[Appendix E](#) – listening session 2 agenda

[Appendix F](#) – final rubric with grading

Appendix A

<b>Estimated Send Date</b>	<b>Topic Area</b>	<b>Audience</b>	<b>Subject</b>
Oct. 5, 21	Value of Patient Experience	Yes, Learn More, Maybe	“How patients change research”
Nov. 12, 21	Value of Patient Experience	Yes, Learn More (A/B testing content)	“Patients are experts too– how you can help advance research”
Jan. 13, 22	Addressing Barriers	Yes, Learn More	“Become a “Research Influencer” in just ten minutes”
Jan. 26, 2022	Listening Session Recruitment	Yes, Learn More, Maybe	Invitation to Listening Session, content and details TBD
Feb. 28, 22	Addressing Barriers	Yes, Learn More, Maybe	“From research subject to team member; how research is changing to include patient perspectives”
Apr. 6, 22	Addressing Barriers	Yes, Learn More	“How can we help? Researchers need your unique experiences.”
April 2022	Listening Session Recruitment	Yes, Learn More, Maybe	Invitation to Listening Session, content and details TBD
May 6, 22	Research Literacy	Yes, Learn More	“Important guide to becoming a “Patient Partner”? What you need to know.”
Jun. 24, 22	Research Literacy	Yes, Learn More, Maybe	“Want to help make a difference in Patients’ lives? Take the first step”

**Topic: Value of Patient Experience**

*Communicate value of patient experience & benefit/impact of participation*

**Subject:** How patients change research

Hi [First name],

I am Dr. Sarita Battish and I am a patient partner. I work alongside Dr. Rebekah Angove and other patient partners, on a project to better understand patient experiences with research.

Having a patient on the research team helps ensure research focuses on what is most important to patients.

Please watch the video below to learn more about how your input can shift the culture of research.



Let your voice be heard!

Dr. Sarita Battish



**Watch this**

Watch this [two-minute video](#) sharing how patient and stakeholder engagement is shifting the culture of research.

Watch this two-minute video sharing how patient and stakeholder engagement is shifting the culture of research: <https://vimeo.com/272646387>

## Topic: Value of Patient Experience

Communicate value of patient experience & benefit/impact of participation

Subject: Patients are experts too– how you can help advance research

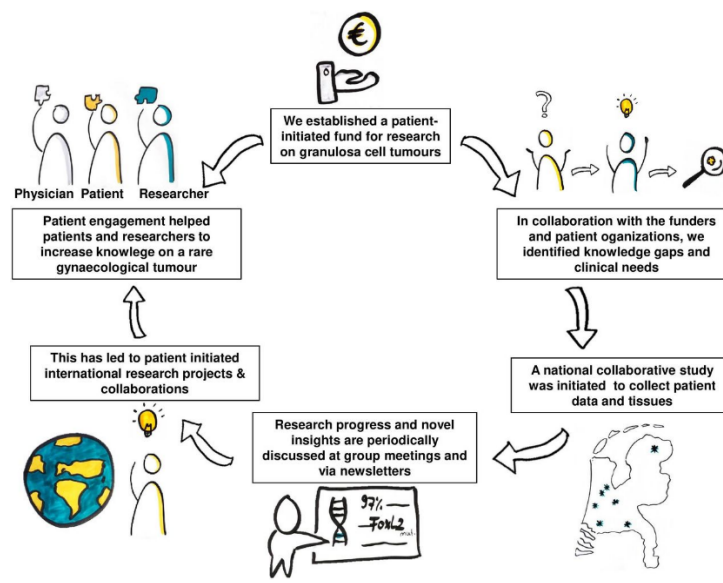
\*combo 1 (photo only)

### Patients are experts too

Do you consider yourself an engaged patient?

Yes

No



[Click here to enlarge photo](#)

Roze, R. (2020). Figure 1. [image]. <https://ijgc.bmj.com/content/30/12/2012#xref-ref-1-1>

Hi,

Did you know 97% of people believe the patient voice/perspective is important in research, yet only 12% have been approached to share their experiences. Your experiences as a patient and/or caregiver make you an expert; sharing those experiences can impact research and improve the lives of patients and caregivers, everywhere.

We will be sending opportunities for you to collaborate with researchers to fill the knowledge and research gaps. We hope you answer the call to help!

## Topic: Value of Patient Experience

*Communicate value of patient experience & benefit/impact of participation*

**Subject:** Patients are experts too– how you can help advance research

*\*combo 2 (video only)*

### Patients are experts too

*Do you consider yourself an engaged patient?*

Yes

No

Hi,

Did you know 97% of people believe the patient voice/perspective is important in research, yet only 12% have been approached to share their experiences. Your experiences as a patient and/or caregiver make you an expert; sharing those experiences can impact research and improve the lives of patients and caregivers, everywhere.

We will be sending opportunities for you to collaborate with researchers to fill the knowledge and research gaps. We hope you answer the call to help!



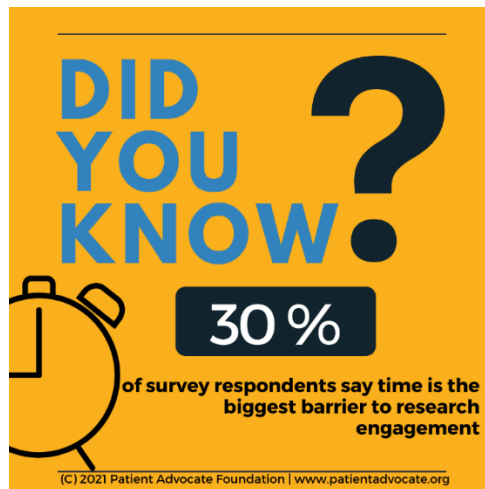
### Watch this

[Watch this two-minute video](#), breaking down how your experiences can profoundly impact research.

**Topic: Addressing Barriers**

*Addressing barriers, challenges or negative perceptions*

**Subject:** Become a “Research Influencer” in just ten minutes



**Share your opinions with researchers!**

Please take [this short survey](#) to help shape priority areas for researchers, on the topic of COVID-19. **You could win an Amazon Gift Card** and your feedback will jointly support patient and caregiver trainings on how to best inform COVID-19 research participation.

(copy and paste into your browser: <https://forms.office.com/r/JNqUBBYtuC>)

Hi,

Short on time? You can still help!

Many people indicated time as being the number one barrier to research engagement. Influencing research or being part of a research team can be manageable.

*Did you know?*

- Taking a survey where you share your experiences can make you a “research influencer.”
- Some research teams need advisors that meet monthly or less.
- Many of these positions include compensation for your time and expertise in the patient experience.

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**TAKE THIS POLL**

After reading this email, if you were approached to participate in scientific research, as a patient partner, how likely are you to engage? (Note: a rating of 1 is 'not at all' a rating to 10 is extremely likely)

**lowest** 1 2 3 4 5 6 7 8 9 10 **highest**

**Topic: Addressing Barriers**

*Addressing barriers, challenges or negative perceptions*

**Subject:** From research subject to team member; how research is changing to include patient perspectives

**TAKE THIS POLL**

How likely are you to affirmatively respond if asked to partner with researchers or inform a research study?

**lowest** 1 2 3 4 5 6 7 8 9 10 **highest**

(Note: A rating of 1 is 'not at all' a rating to 10 is 'extremely likely')

Hi,

Have you heard? Research is changing and currently engaging patients to be equal members of their research team. Researchers in a variety of sciences are learning that they can answer broader, more complex and more meaningful questions by working with teams of patients and other individuals with diverse expertise and perspectives.

Because your experience is valuable to these teams, PAF is working to make the connection between patients and research teams that need a patient or caregiver perspective.



**Watch this**

Watch this video to learn more about how research teams are creating collaborative environments to engage stakeholders and improve research outcomes.

Warmly,

Mary Mukira



**Topic: Addressing Barriers**

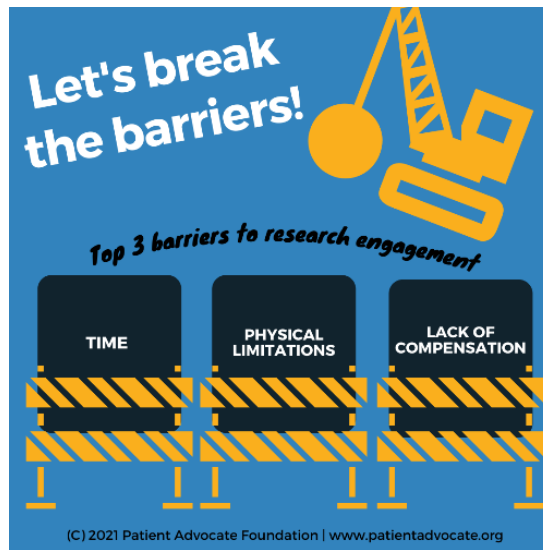
*Addressing barriers, challenges or negative perceptions*

**Subject: How Can We Help? Researchers Need Your Unique Experiences.**

Hi [First Name],

Your input is too valuable to lose! As a research partner, you will help ensure research focuses on what is most important to patients and caregivers.

We know that **time**, **physical limitations**, and **lack of compensation** can be barriers to participating in research projects. Researchers value patient and caregiver experiences and are working to overcome these common barriers.



[Click here to learn more.](#)

**TAKE THIS POLL**

Which of these barriers matter most to you when deciding to participate?

Time

Physical limitations

Lack of compensation

If you have any questions, please feel free to reach out.

Warmly,

Mary Mukira

## Topic: Research Literacy

Research literacy, knowledge, terminology

Subject: “Important guide to becoming a “Patient Partner”? What you need to know.”

Hi [First Name],

Now that you know just how important your voice and leadership is on health sciences research teams, let’s talk about how you can get involved.

Here are three easy ways to get started:

1. Ask how co-collaborators are meeting patients and caregivers where they are.
2. Locate and respond to authentic/trusted patient partner engagement requests.
  - You can do this now by joining our next Listening Session on **Monday, May 23**. [Learn more and register here.](#)
3. Take the short training below to learn more about how patients and communities meaningfully engage in research opportunities.
  - If you want to engage in research now, join our COVID-19 Learning Community! [Learn more here.](#)

The screenshot shows a training guide for PCORI's "Research Fundamentals". At the top left is the "PATIENT INSIGHT INSTITUTE" logo. At the top right is the "COVID-19 LEARNING COMMUNITY" logo. Below these is a "START HERE" button. The main text reads: "Your quick-start guide to PCORI's 'Research Fundamentals,' a comprehensive training package that offers different ways to learn about the health research process and be involved in patient-centered outcomes research." Below this is a navigation section with three numbered boxes: 1. "ENGAGING IN STAKEHOLDER-DRIVEN RESEARCH", 2. "DEVELOPING RESEARCH QUESTIONS", and 3. "RECRUITING AND RETAINING PARTICIPANTS". Each box has a brief description of the module. At the bottom right is the "PAF Patient Advocate Foundation" logo.

## Learn more about engaging in research opportunities

The video player shows two women, Rachel Biblow and Amy Kratchman, sitting on a red couch in front of a large window with a city view. Rachel Biblow is on the left, wearing a blue blazer, and Amy Kratchman is on the right, wearing a patterned top. A large white play button is overlaid on the video. Below the video are the names and titles of the women: Rachel Biblow, MSW, LCSW, Senior Director, Patient and Family Services, Children's Hospital of Philadelphia; and Amy Kratchman, Family Consultant, Children's Hospital of Philadelphia. The video title is "Partnerships in Research at Children's Hospital of Philadelphia" and it has 175 views as of Jun 30, 2017.

[Watch this five minute video](#) on how researchers are engaging patients in research.

**Topic: Research Literacy**

*Research literacy, knowledge, terminology*

**Subject: “Want to help make a difference in Patients’ lives? Take the first step”**



(C) 2021 Patient Advocate Foundation | www.patientadvocate.org

Hi [First Name],

The first step to positively impact patient lives is to join a health sciences research team as a “patient partner.”

So, what does a patient partner do? Essentially, a patient partner is an equal contributing member of a research project team. Patient partners work with their team in co-creating resources, project scope, paper writing/editing and other relevant material support, to improve research outcomes, by leveraging patient and caregiver perspectives.



**Watch this**

[Watch this two-minute video](#), providing insight into the level of input patient partners provide during the research process.

## Appendix B

Date/Time	Campaign	Recipients	Open Rate	Clicks Per Unique Open	Polling/Survey
10/5/2021 @4:30pm ET	Value of Patient Experience "How patients change research"	2173	43.50%	13.70%	N/A
11/12/2021 @2:59pm ET	(V4A-photo only) Value of Patient Experience "Patients are experts too– how you can help advance research"	280	55.90%	7.10%	Do you consider yourself an engaged patient? Yes - 33 votes (97.1%) No - 1 vote (2.9%)
11/12/2021 @2:59pm ET	(V4B-video only)Value of Patient Experience "Patients are experts too– how you can help advance research"	280	57.20%	9.50%	Do you consider yourself an engaged patient? Yes - 30 votes (90.9%) No - 3 votes (9.1%)
1/13/2022 @12:45pm ET	Addressing Barriers "Become a "Research Influencer" in just ten minutes"	1110	54.50%	22.60%	After reading this email, if you were approached to participate in scientific research, as a patient partner, how likely are you to engage? (74 votes) 51.4% - 10 20.3% - 8 8.1% - 9
1/26/22 @5:15pm ET	Engagement Survey - Listening Session #1	2128	16.90%	75% clicks for event registration	N/A
2/28/2022 @6:59pm ET	Addressing Barriers "From research subject to team member; how research is changing to include patient perspectives"	2103	52.20%	3.10%	How likely are you to affirmatively respond if asked to partner with researchers or inform a research study? (254 votes) 47.6% - 10 17.3% - 9 13.4% - 8
4/6/2022 @3:13pm ET	Addressing Barriers "How can we help? Researchers need your unique experiences."	1068		7%	Which of these barriers matter most to you when deciding to participate? (128 votes) Time (42.2%) Lack of compensation (38.3%) Physical limitations (19.5%)
5/6/2022 @9:30am ET	Research Literacy "Important guide to becoming a "Patient Partner"? What you need to know."	1047	45.80%	8.80%	N/A
6/24/2022 @2pm ET	Research Literacy "Want to help make a difference in Patients' lives? Take the first step"	2011	46.80%	6.50%	N/A

# LISTENING SESSION

Researcher Engagement & Communication

Location: Call-In info

Date: February 22, 2022

Time: 5:00 -6:30 PM EST

Facilitator: Mary Mukira

## Agenda:

5:00- 5:10	Welcome <ul style="list-style-type: none"> <li>• <i>Team Introductions</i></li> <li>• <i>Goals of the Meeting</i></li> <li>• <i>Ground Rules of Engagement</i></li> <li>• <i>Gift Card Details</i></li> </ul>	Rebekah
5:10- 5:30	Breakout Session 1 <ul style="list-style-type: none"> <li>• <i>Review: Rubric for Communicating with Patients</i></li> <li>• <i>Discuss: What is potentially stigmatizing language, topics, or approaches? How can researchers identify these “red flags?”</i></li> </ul>	
5:30- 5:45	Regroup and Share	
5:45- 6:05	Breakout Session 2 <ul style="list-style-type: none"> <li>• <i>Review: Terminology document</i></li> <li>• <i>Discuss: What are some acceptable terms that can be used to describe patients who have challenges accessing or affording care?</i></li> </ul>	
6:05- 6:20	Regroup and Share	
6:20- 6:30	Wrap-Up and Evaluation	Rebekah

## Documents:

- Patient Outreach Messaging Rubric
- Terminology Document



## Terminology to Discuss

*Terms used to describe people or populations that are experiencing financial, economic, and/or other hardships that impact their health and care:*

- Limited-Resourced
- Marginalized
- Socially Disadvantaged
- Under-Resourced
- Underserved
- Vulnerable

### **Other related terms:**

#### Social Determinants of Health (SDOH):

The conditions in the environments where people are born, live, learn, work, play, worship, and age which are “shaped by the distribution of money, power and resources, and that affect a wide range of health, functioning, and quality-of-life outcomes and risks.

#### Social Risk Factors:

Specific adverse social conditions that are associated with poor health, like social isolation or housing instability. These social risks have very real impacts on health and health care.

#### Social Needs:

Individual needs that arise from social risks but go beyond social risk factors—they also depend on people’s individual preferences and priorities.

# LISTENING SESSION

Researcher Engagement & Communication

Location: Zoom | Call-In info

Date: May 23, 2022

Time: 5:00 -7:00 PM EST

Facilitator: Mary Mukira

## Agenda:

5:00- 5:10	Welcome <ul style="list-style-type: none"> <li>• <i>Team Introductions</i></li> <li>• <i>Goals of the Meeting</i></li> <li>• <i>Ground Rules of Engagement</i></li> <li>• <i>Gift Card Details</i></li> </ul>	Mary/Rebekah
5:10-5:25	SDOH Level Setting	Rebekah
5:25- 5:55	Breakout Session 1 <ul style="list-style-type: none"> <li>• <i>Review Scenarios</i></li> <li>• <i>Discuss: Social Needs Terminology</i></li> </ul>	Various Facilitators
5:55-6:10	Regroup & Brief Debrief	Mary
6:10- 6:40	Breakout Session 2 <p><i>Discuss:</i></p> <ul style="list-style-type: none"> <li>• <i>Where do you get your health information?</i></li> <li>• <i>Who would you like to hear from when health or research information is being shared via email?</i></li> </ul>	Various Facilitators
6:40-6:55	Regroup & Brief Debrief	Mary
6:55- 7:00	Wrap-Up and Evaluation	Mary/Rebekah

## Appendix F

Message #	Assigned Messages to Review	Must Have Total Score (Patient Reviewed)	Nice to Have Total Score (Patient Reviewed)	Avoid Total Score (Patient Reviewed)	Open Rate	
Message 1	<b>Value of Patient Experience:</b> How patients change research	67%	63%	0%	44%	
Message 2	<b>Value of Patient Experience:</b> Patients are experts too— how you can help advance research	79%	92%	0%	Photo Only: 55.9%	Video Only: 57.2%
Message 3	<b>Addressing Barriers:</b> Become a “Research Influencer” in just ten minutes	79%	77%	0%	54.50%	
Message 4	<b>Addressing Barriers:</b> From research subject to team member; how research is changing to include patient perspectives	75%	75%	0%	52.20%	
Message 5	<b>Addressing Barriers:</b> How can we help? Researchers need your unique experiences	92%	77%	0%	50.50%	
Message 6	<b>Research Literacy:</b> Important guide to becoming a “Patient Partner”? What you need to know	75%	73%	0%	45.80%	
Message 7	<b>Research Literacy:</b> Want to help make a difference in Patients’ lives? Take the first step	100%	100%	0%	46.80%	





## Patient Outreach Messaging Rubric

*As part of our efforts to create effective and engaging email messages for our Patient Network, we captured established best practices<sup>1</sup> as well as the ongoing guidance provided by our patient and stakeholder advisors as we worked through the development process. This resulted in a rubric (below) that can be used to guide the development of future messaging to patient stakeholders and community members.*

<b>Must Haves</b> <i>All messages must...</i>	<b>Description</b>	<b>Scoring</b> [2] Does this well [0] does not do this
Lead with value to patient or impact of participation	Clearly state “Why” their participation in valuable, what value this brings to patients or the patient community, and/or the impact of their participation.	
Include a clear and measurable call-to-action or objective	Clearly state what the patient is being asked to do. Avoid “insider” terms. Use plain language.	
Include clear detail on time and/or commitment required	Directly reference the time and/or commitment required. For surveys, state the estimated time or number of questions.	
Briefly introduce yourself as the sender.	Share who you are, what role you have, and what organization you represent to begin to build role-based trust (fellow patient, CBO, etc.), organizational recognition, and a personal relationship.	
Be written in accessible language at an appropriate level (avoid jargon, 8 <sup>th</sup> grade reading level, etc.)	Write in clear, concise, and simple language. Use terms that most 8 <sup>th</sup> graders would understand. Use readability tools and ask patient community members to review before sending.	
Use person-centered language	People are more than their condition, disability, or social identity. Always use person-centered to show you respect the unique qualities and strengths of every individual.	
<b>Nice to Have</b> <i>All messages should try to...</i>	<b>Description</b>	<b>Scoring</b> [2] Does this well [1] needs improvement [0] does not do this
Be personalized or targeted in some way (community, identity, condition, experience, etc.)	The more personalized the better, your audience should know why you are reaching out to them in particular. Connect based on shared experiences (not labels).	
Build a relationship. Stay engaged.	Build rapport with a series of messages. Communicate at each step of the project. Follow-up with results even if they did not participate to encourage future engagement (ex: “Here are the results of the last survey we sent,” or “Thanks to the 4 patients that agreed to be on our advisory group.”).	
Include a <u>relevant</u> image or infographic	Avoid stock photos where possible. Ensure any photos or infographics enhance the message and don’t distract from it.	



## Patient Outreach Messaging Rubric

Include an interesting or relevant resources/link	Try including a resource, link, or attachment for patients that may want to learn more. Don't try to cram everything into the body of the message.	
Promote bidirectional communication, feedback, and/or engagement.	Try to find ways to make your audience feel like an active participant in a conversation, talk with them not at them. For example, invite them to respond back with any questions or assess the quality of your messages with an embedded poll.	
Increase diversity of responses by targeted distribution and strategic partnerships	The best strategy to increase diversity of responses is to target groups by filtered by demographic or factor of interest (ex: if you need more male respondents, try sending reminders to just males). You can also rely on a trusted partner to outreach to their community of patients on your behalf (for example, a breast cancer project trying to reach more African American women might partner with African American Breast Cancer Alliance).	
<b>Avoid</b> <i>Messages should never...</i>	<b>Description</b>	<b>Scoring</b> [-3] Message includes this potential red flag
<u>Avoid</u> including PHI or information that can indicate a sensitive condition or diagnosis	Do not include diagnosis information or other PHI that may be sensitive. For example, if you are sending a message to a group of patients that you know are HIV positive, don't call out their diagnosis in the subject of body of the email.	
<u>Avoid</u> potentially stigmatizing language, topics, or approaches. <i>When in doubt, ask the community.</i>	Avoid referring to patients based on their identity, demographics, social or economic status, or other potentially stigmatizing characteristics. For example, underserved, marginalized, and disabled can all be stigmatizing terms.	

<sup>1</sup> <https://elgl.org/best-practices-for-effective-messaging-during-the-coronavirus-crisis/>; <https://stec.univ-ovidius.ro/html/anale/RO/2016/2016-II-full/s4/4.pdf>; <https://journals.sagepub.com/doi/pdf/10.1177/1524839918809009>