



## INITIATIVE TO SUPPORT PATIENT INVOLVEMENT IN RESEARCH (INSPIRE)

Community Workshop  
July 18 & 19, 2016  
Seattle, WA

For an immediate response, contact Sarah Lawrence at [lawreso@uw.edu](mailto:lawreso@uw.edu).

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## Acknowledgements

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## Overview

On Monday and Tuesday, July 18 and 19, 2016, the CERTAIN Patient Advisory Network held the Initiative to Support Patient Involvement in Research (INSPIRE) Community Workshop in Seattle. The workshop brought together patients and researchers who are partnering on research studies throughout the Pacific Northwest. The purpose was to advance learning about effective patient-researcher partnerships and to discuss and prioritize gaps in tools, resources and training needed to support patient-researcher partnerships in patient-centered outcomes research (PCOR).

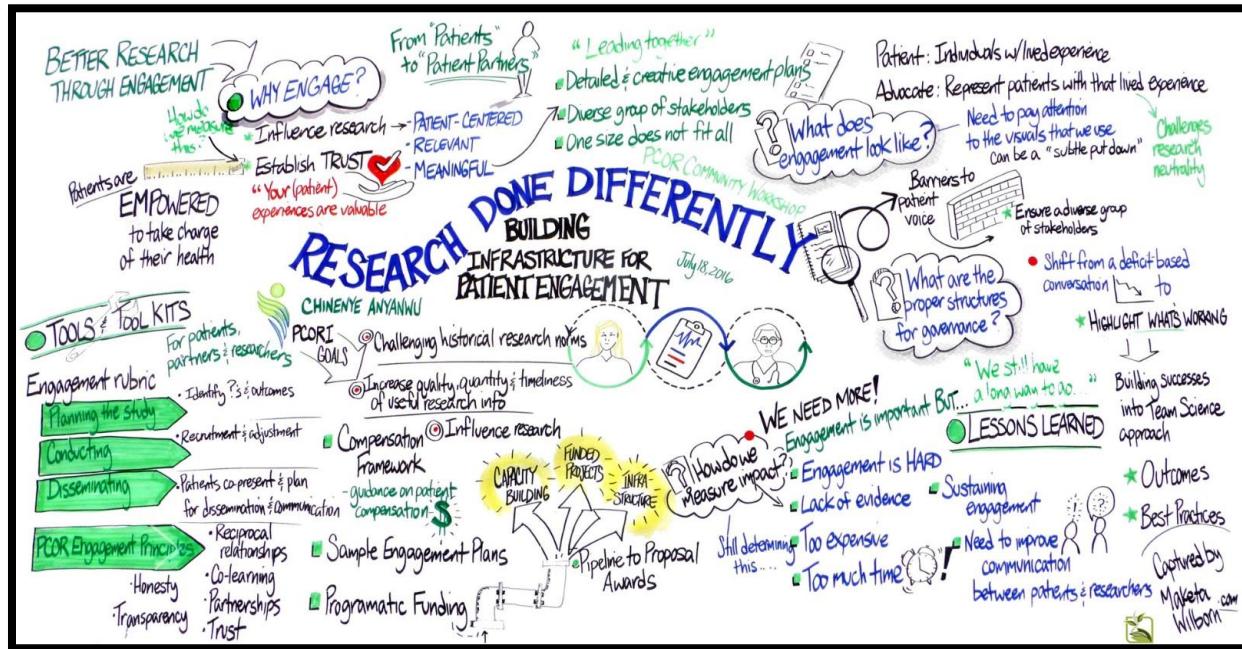
Invitees included patients, caregivers, and clinicians collaborating on Patient-Centered Outcomes Research Institute funded projects; members of the CERTAIN Patient Advisory Network; and scholars from the University of Washington with training in PCOR. In total, 50 participants and speakers from across Washington State, Oregon, Alaska, Wyoming, California, and Maryland attended the 1.5-day workshop. Twenty individuals represented the patient, caregiver or parent perspective, and 30 individuals represented the researcher perspective.

This report presents the four learning sessions in the workshop including the emerging ideas and themes generated from each group discussion. The final illustrations captured through a graphic recorder are included in the session summaries below. These graphic recordings served as the visual framework for the final workshop session which prioritized areas for future work. We conclude with a report on the workshop evaluation and next steps.

# Session I: Research Done Differently: Building Infrastructure for Patient Engagement

Speaker: Chinenye Anyanwu, Engagement Officer

Patient-Centered Outcomes Research Institute (PCORI) (Washington, DC)



The Patient Centered Outcomes Research Institute (PCORI) is an independent research institute established in 2010. It is governed by a 21-member board reflecting all stakeholder perspectives. PCORI's mission is to fund research that helps people make informed healthcare decisions and to improve healthcare delivery and outcomes by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community.

A core aspect of PCORI-funded research is the direct involvement of and engagement with healthcare stakeholders. The end goal is to generate evidence that directly informs patients, caregivers, and clinicians in decision-making. The goal of engagement is to:

- Influence research to be patient-centered, relevant, and useful
- Establish trust and a sense of legitimacy in research findings
- Encourage successful uptake and use of research results

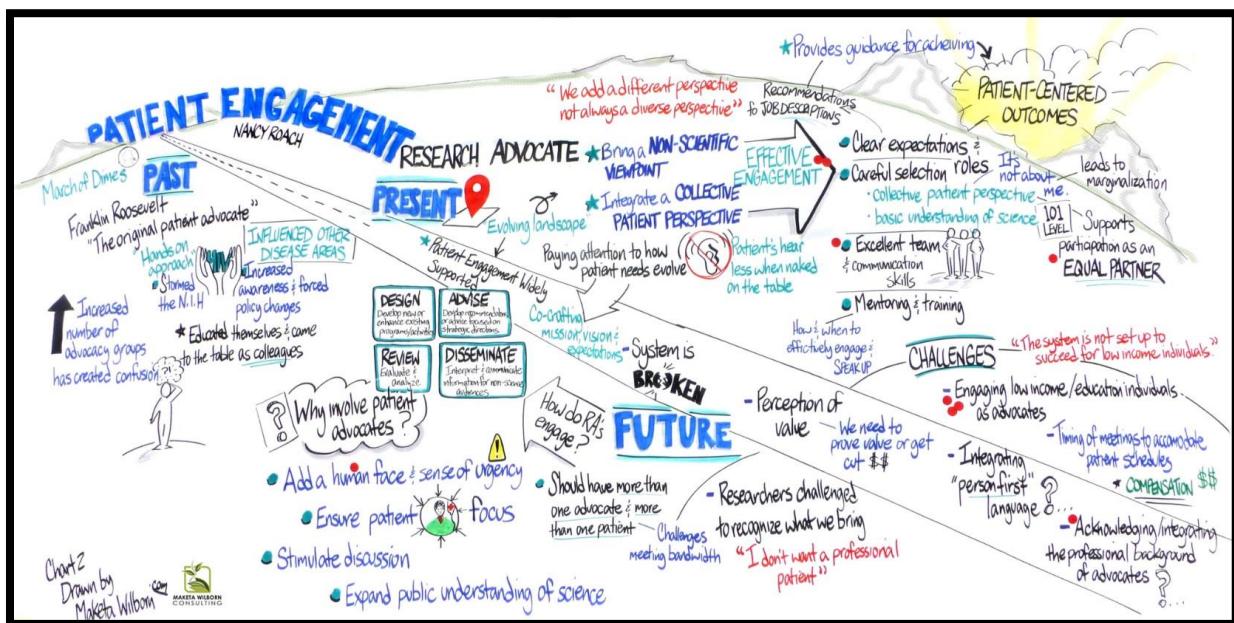
PCORI defines engagement as meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the research process. Engagement plans should be well thought out, creative, and involve a diverse group of stakeholders. PCORI acknowledges that engagement is not one size fits all—it may take many shapes and be tailored to the needs and details of the particular project or program. Further guidance on what PCORI means by engagement can be found on the [PCORI website](#).

PCORI has the following resources and tools to help facilitate engagement in research:

- [Engagement Rubric](#): provides practical guidance to applicants, merit reviewers, awardees, and engagement/program officers on effective engagement in research
- [Compensation Framework](#): application guidance on compensation for Patient Partners
- [Sample engagement plans](#) and promising practices from current funded projects
- Personnel dedicated to supporting engagement in funded projects, serving as a bridge between engagement and science, and identifying additional tools and resources for PCORI development ([Engagement Officers](#), [Patient Engagement Advisory Panel](#), [Ambassadors](#))
- Programmatic, non-research funding aimed at supporting capacity-building and infrastructure development to support and sustain engagement:
  - [Eugene Washington Engagement awards](#)
  - [Pipeline to Proposal awards](#)

## Session II: Patient Engagement: Past, Present, and Future

Speaker: Nancy Roach, Founder & Chair, Board of Directors, Fight Colorectal Cancer (Portland, OR)



### Overview

Nancy Roach is the Founder and Chair of the Board of Directors of [Fight Colorectal Cancer \(CRC\)](#), a community of activists focused on a cure for colorectal cancer. Through her work with Fight CRC, Nancy developed the [Research Advocacy Training and Support \(RATS\) Program](#), one of the first comprehensive research advocate training programs in the nation.

Throughout her career as a research advocate, Nancy has been involved with multiple National Cancer Institute advisory committees, the Clinical Trials Transformation Initiative, the Food and Drug Administration Patient Representative Program, and multiple research projects. As someone with a long track record of championing patient involvement in research, Nancy was invited to give the keynote address at the INSPIRE workshop to provide an overview of how she has seen patient research advocacy

develop and how she would like to see infrastructure and support for research advocacy and patient engagement develop in the coming years.

## The Past

When Franklin D. Roosevelt developed the National Foundation for Infantile Paralysis (today called the March of Dimes) in 1938, he became the first patient advocate. The model of advocacy used at that time was primarily raising money to support research.

Patient involvement in the *conduct* of research, however, did not gain recognition until the 1980s and the rise of AIDS. AIDS activists organized to increase awareness of and to advocate for policy changes. In their “Storm the NIH” event, activists demanded to be involved in setting research agendas and research protocols. AIDS research advocacy began to spread to other areas, perhaps most notably, breast cancer.

## The Present

Today, there are thousands of advocacy groups with a wide range of focus areas including research, policy, support, and awareness. Patient engagement is widely recognized, and advances in communication, notably the internet and social media, has allowed advocates to engage in ways previously not possible.

In the recent past, the field has evolved to identify *research advocacy* as a separate function and focus. The role of research advocates has been given a common definition, including bringing a non-scientific viewpoint to the research process while communicating a collective, rather than an individual, patient perspective. Naming this role was an important step towards patient engagement being taken seriously in the research arena.

Research advocates today assume roles that affect the entire research process (Figure 2), from design of new research projects through dissemination of research results. Research advocates add a human face and sense of urgency to research.

## The Future

As research advocacy continues to evolve as a field, continued work is needed to integrate research advocates into research teams—breaking down barriers between researchers and patients and continuing to incorporate the patient perspective into all aspects of research—and to continue to prove the value of research advocacy to encourage its growth and further integration into research. Formal mentoring and training is also needed for both patients and researchers to ensure the patient perspective is heard and valued throughout the research process. One area for continued focus is modeling other training models such as clinical training where direct observation and mentorship is a key component. Allowing those new to patient engagement or research advocacy to observe someone more experienced provides a unique way to help the individual learn and gain skills.

Figure 2. Research Advocate Roles & Functions



## Group Discussion and Recommendations

Following the presentation, three workshop participants were called on to share their reactions to the presentation from their perspective. A group discussion also raised several key points. These reactions and discussion points are summarized in Table 1 below.

Table 1: Patient Engagement: Past, Present, and Future Key Summaries and Lessons Learned	
<b>Shannon Marsh, Research Advocate</b>	<ul style="list-style-type: none"><li>Mentorship and training are crucial to develop meaningful patient engagement in research</li></ul>
<b>Clarissa Hsu, Researcher</b>	<ul style="list-style-type: none"><li>Integrating and effectively engaging patients is challenging</li><li>Taking lessons from other industries on how they have successfully engaged their stakeholders offers insight into innovative ways to engage stakeholders and design engagement plans</li></ul>
<b>Gail Graham, Patient Partner</b>	<ul style="list-style-type: none"><li>Creating a collegial and welcoming environment helps make research advocates comfortable expressing opinions and contributing to conversations</li><li>To ensure a diverse perspective and viewpoint, it is important for research advocates and Patient Partners to reflect a <i>collective</i> patient experience rather than their individual experiences</li></ul>
<b>Group Discussion: Patient Advocate Training and Research Knowledge</b>	<ul style="list-style-type: none"><li>While both are valuable and needed, there is a key distinction between Patient Partners and patients who inform research<ul style="list-style-type: none"><li>A Patient Partner should be knowledgeable in research concepts and issues and able to talk with the research team on a peer level</li><li>Patients who inform research do not need to have this level of knowledge</li><li>These roles are not interchangeable; engaging each of these roles will yield different results and input</li></ul></li></ul>

Additional discussion centered on:

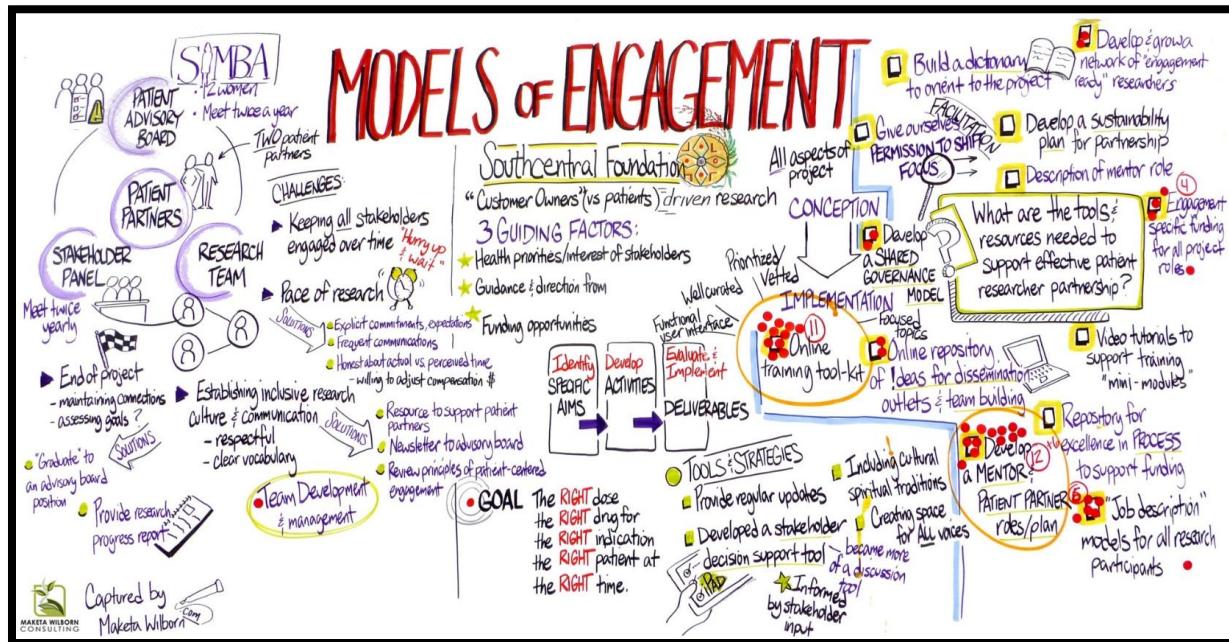
- The importance of engaging patients with diverse perspectives
- Issues around compensating research partners
- The language of patient engagement
- Understanding the type of involvement for the project to ensure individuals with the appropriate skills and experience are engaged
- The importance of demonstrating the value of Patient Partners/research advocates to the patient partners, other research team members, and the broader community
- The importance of mentoring for both patient partners and research teams new to collaborative research

## Session III: Models of Engagement

Speakers:

Karen Wernli, Dianne Johnson, Mary Bush, and Susan Brandzel, SIMBA (Seattle, WA)

Renee Robinson and Adrienne Tveit, Southcentral Foundation (Anchorage, AK)



### Overview

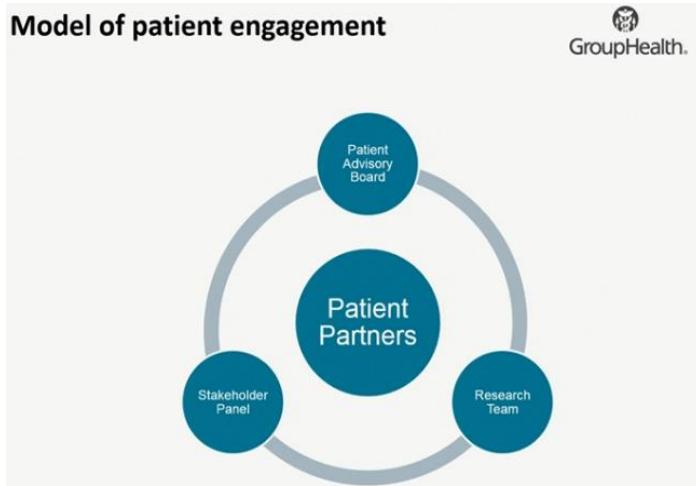
Interviews with Patient Partners and researchers revealed interest in learning from others about different approaches for structuring patient engagement as part of research projects. A panel discussion with two project teams provided an opportunity to learn from different approaches for structuring engagement and served as the basis for discussing tools, resources and trainings needed to support patients and researchers collaborating in research.

### Engagement as Part of a Research Study

Karen Wernli, Dianne Johnson, Mary Bush, and Susan Brandzel provided an overview of patient engagement structured to support the PCORI-funded project Surveillance Imaging Modalities for Breast Cancer Advancement (SIMBA). SIMBA is a study aiming to fill the clinical knowledge gap about how well breast MRI in addition to mammography works compared to mammography alone in women after breast cancer treatment. The project engages patients through three distinct activities (Figure 3).

Figure 3. SIMBA model of patient engagement

### Model of patient engagement



Central to the project are Mary Bush and Dianne Johnson, the Patient Partners who serve as research team members.

A board of Patient Advisors gives the research team the opportunity to engage with a group who represents a broader perspective of women with experience with breast cancer and provide further support to the Patient Partners. The Patient Advisory Board includes 12 women identified through focus groups conducted as part of the study as well as through directed outreach in the community to ensure representation from diverse communities. The group convenes biannually for approximately 3 hours to hear study updates and discuss progress with the research team. Susan, SIMBA project manager, serves as the primary support to Mary and Dianne's involvement with Karen, the project's Principal Investigator. Susan plays an integral role creating cohesion among the full research team while overseeing all aspects of the project.

The team presented three challenges they have experienced with engagement along with approaches to handle each based on their experience. The challenges were:

- 1) The pace of research
- 2) Research communication and culture
- 3) Managing research study close-out

Key points made include the following:

- **The pace of research is sporadic.** At times teams rush to get a lot of work done in a short time (e.g., proposal writing, study start-up, manuscript writing, etc.) only to follow with a stretch of time where little changes (e.g., waiting for funding decisions, waiting for data to accrue, waiting for decisions on manuscripts). This makes sustaining relationships challenging. Communicating frequently via newsletters, emails, or phone calls demonstrates partnership, respect, and value of collaboration.
- **There is a lot within the funding cycle that can be mysterious and nebulous to people new to research.** Relationships are formed as a team builds a proposal, but uncertainty exists about future collaboration while waiting for funding decisions. Orienting people to this process is challenging. Being as transparent as possible is important.
- **Expectations and opportunities for involvement may change over time, creating more work than expected for Patient Partners.** Plan the scope of work and expected time commitment early on to ensure balance, but also revisit throughout the project and adjust accordingly. Creating open communication about new project requests and time commitments allows Patient Partners the opportunity to decline if it is too onerous.
- **Research culture and communication can be a barrier to collaboration.** Culture and vocabulary of research teams is not inclusive. How researchers talk about research may be off-putting, especially when it is "work" to a researcher but real-life to a Patient Partner. When you bring patients onto a research team, you shift the dynamic. Create awareness among the research team that words can take on a different interpretation when new people are at the table.
- **Meetings bringing together researchers, clinicians, and people in high level positions can be intimidating,** especially when new collaborations are formed. Creating an environment that is open and welcoming of new perspectives is important. Solutions include:
  - Involving more than one Patient Partner
  - Designating a project manager who facilitates timely communication and coordination with patients
  - Team-building activities outside of scheduled research meetings

- **Facilitate involvement and growth of Patient Partners.** Provide resources (e.g., using social media, how to talk to reporters/media, learning about plain language) that allow development in ways that aren't specific to the research content.
- **The end of the project requires thoughtful planning.** Researchers will continue on with grants that may or may not continue patient partnerships. Patients who wish to stay engaged may or may not have the opportunity to stay involved. There is also an emotional aspect as a relationship comes to a close. Planning for and creating open dialogue around this transition is important.

### Engagement as Part of a Research

#### Institution

Renee Robinson and Adrienne Tveit presented a different perspective. The Southcentral Foundation is an Alaska Native-owned nonprofit healthcare organization serving the Alaska Native and American Indian people living in Anchorage, Matanuska-Susitna Valley, and 55 rural villages in the Anchorage Service Unit. Individuals receiving care at the Southcentral Foundation are referred to as customer-owners, reflecting the stake patients hold in the organization.

The mission of the Southcentral Foundation

is to work together with the Native Community to achieve wellness through health and related services, and this premise extends to research. Engagement is part of the culture and core concepts (Figure 4) at the Southcentral Foundation and infused in research funded by diverse funding agencies, including the National Cancer Institute, PCORI, and Native American Research Centers for Health.

In 2006, Southcentral Foundation established a research department to answer questions important to the customer-owners. Research is driven by the health interests and priorities of Southcentral Foundation stakeholders, including customer-owners, clinicians, organizational leadership, and the Board of Directors.

Among examples of how customer-owners transform research, presenters shared the following lessons learned for supporting involvement:

- **Create opportunities for stakeholder input.** The Southcentral Foundation holds an annual meeting bringing together stakeholders to inform the direction of research. Conducting surveys also facilitates opportunities for obtaining input as needed to support project development.
- **Include a research aim focused on getting input on preferences and needs from the community on the research topic.** The Southcentral Foundation takes an iterative approach to hear from stakeholders, synthesize the information, and feed it back to the stakeholders to ensure it reflects their perspectives accurately.
- **Demonstrate respect for participation and collaboration through regular updates to the community on research progress.** Research updates and findings are provided to both

*Figure 4. Core Concepts developed in collaboration with the Southcentral Foundation customer-owners.*

#### **Southcentral Foundation's Core Concepts**

The Core Concepts are:

W ork together in relationship to learn and grow  
 E ncourage understanding  
 L isten with an open mind  
 L augh and enjoy humor throughout the day  
 N otice the dignity and value of ourselves and others  
 E ngage others with compassion  
 S hare our stories and our hearts  
 S trive to honor and respect ourselves and others

customer-owners participating in research as well as the broader community through articles published in the Anchorage Native News.

- **Recognize that research plans may not align with community needs.** This requires a willingness to adapt to the needs of the community in order to create something that will be usable in practice. The willingness to adapt to community interests and co-develop research facilitates implementation and sustainability of research results.

### Group Discussion and Recommendations

A facilitated discussion followed the presentations. The discussion addressed a number of topics about the culture of research, challenges for ensuring the right information and support is provided at the right time, the importance of communication, and the unique skillset needed to facilitate and build teams.

Notable points include the following:

- **Research is a different paradigm.** The culture of seeking grants and competing for research proposals is not a natural environment for collaboration.
- **Research 101 may best be timed with research activities** such as training in Institutional Review Board (IRB) practices and terminology as the initial IRB application is being developed). Providing a lot of information up front can be overwhelming, so think about what information to distill at what point in the process (including refreshers).
- **Research involves a lot of “hurry up and wait” for funding, data, and analysis.** Communicate regularly with Patient Partners to check in and let them know where current research activities stand, even if there is no new information to communicate. Proactive communication demonstrates respect and partnership.
- **Feedback on how input is informing research activities is critical.** Similarly, feeding research results back to study participants is also important to respect their contributions.
- **Patient Partners are an important bridge between research teams and patient groups.** They translate patient experience to researchers and the research process to patients.
- **Team dynamics are important.** Finding people who can represent a diverse perspective but also work well on a team is important across all perspectives. Conflict management, communication, and facilitation skills are important for the individual leading engagement.
- **Patient representation on *all* committees, not just patient/stakeholder advisory groups, is important for governance.**
- **Patients provide the expertise of an individual or community living with a health condition.** **What they advocate for is also personal.** Recognize that there might be emotional and stressful points in their or their loved ones' health journeys. In addition, recognize that triggers may exist through meeting locations (e.g., if held at a hospital where care was received), anniversary dates of treatments or other health-related milestones, or discussions about diagnosis or treatment that bring back memories. Strive to create a group dynamic that offers the ability to shift focus deliberatively to allow space for patients to have time to share personal experiences.
- **Newsletters provide an opportunity to connect with research team members and stakeholders** and don't have to focus solely on study updates. Personal stories about the team or stakeholders keep people engaged as well.

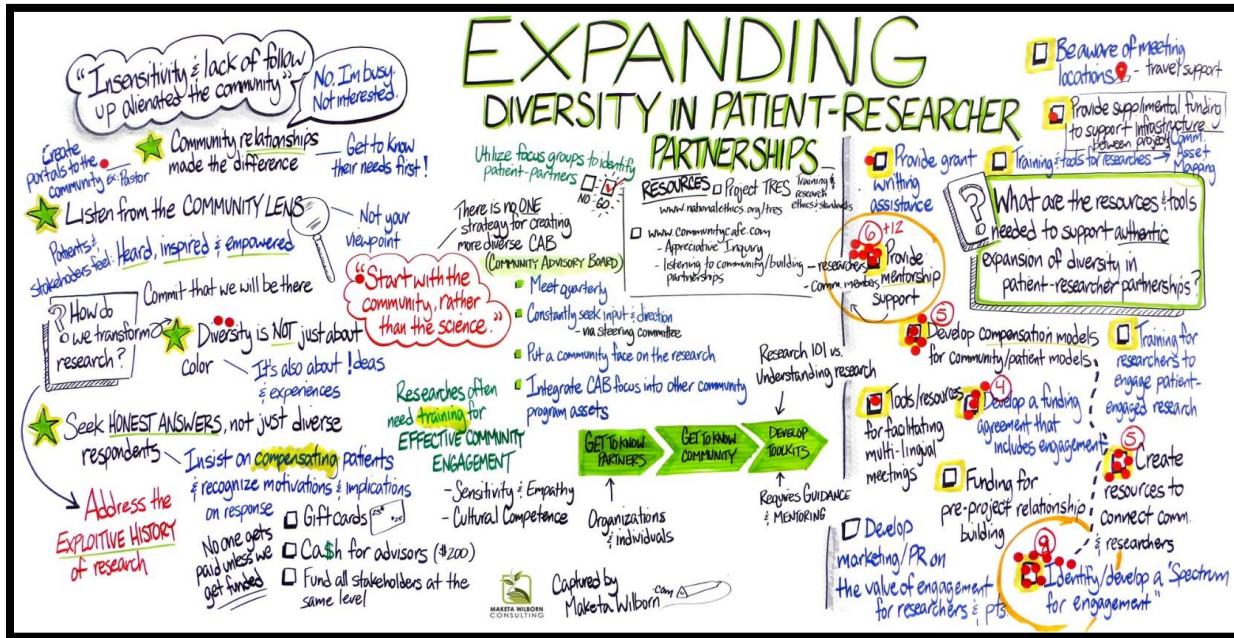
## Recommendations for Moving Models of Engagement Forward

Small group discussions were focused on distilling information learned from the presentations and group discussion into actionable recommendations for advancing models of engagement. The following recommendations, reflected in the visual recording above, served as the basis for prioritization. The bolded recommendations indicate designation as high priority by the group at the conclusion of the workshop.

- **Create a peer-to-peer mentoring program for researchers to learn engagement.**
- **Create a peer-to-peer mentoring program for patients to about research partnerships.**
- **Create an online platform for sharing templates used by research teams:**
  - Share governance models for engagement
  - Job descriptions
  - Roles and expectations
    - Specify to the type of involvement
  - Develop a repository for examples of team-building exercise (e.g., newsletter topics, lunch meetings, etc.)
- **Create a tool kit/Research 101; how a researcher can speak to a Patient Partner (when the data point is a person at the table); a video that shows the steps in process to inform roles/responsibility.**
- Build a dictionary to orient everyone to the project (acronyms, terms, etc.)
- Build a sustainability plan for the partnership, including the project close-out.
- Create opportunities for researchers to learn how to engage patients (e.g., CME, include in didactic training, conference, etc.)
- Create a repository of dissemination outlets outside peer review journals.
- Create a template for research teams to share who is who on the team and the levels of training and expertise each person brings, including engagement work.
- Engage Patient Partners early in the research development process, not after funding starts.
- Share your story. Ensure everyone at the table—researcher, clinician, patient, etc.—shares how they came to the project and area of research. It personalizes the commitment to the team and study.

## Session IV: Expanding Diversity in Patient-Researcher Partnerships

Speakers: Daniel Mullins and Gail Graham, PATIENTS Program (Baltimore, MD); Linda Ko, Fred Hutchinson Cancer Research Center (Seattle, WA)



### Overview

A dominant theme coming from previous INSPIRE work included thinking about how to engage a broad range of people and perspectives as partners. A panel discussion with two engagement programs provided an opportunity to learn from different approaches for including community partners in research with the intention of increasing diversity. It also served as the basis for discussing tools, resources and trainings needed to support patients and researchers collaborating in research.

Daniel Mullins and Gail Graham discussed [PATIENTS](#), a program through the University of Maryland (Baltimore, MD) that partners with patients and care providers to answer questions about the best treatment options to improve health and quality of life. PATIENTS engages people from all communities, especially those from underserved and minority populations, in every step of the patient-centered outcomes research (PCOR) process. Linda Ko of the Fred Hutchinson Cancer Research Center (Seattle, WA) discussed Together We STRIDE, a community-academic partnership in Washington's Yakima Valley, which centers on an active and engaged community advisory board (CAB) composed of community organization members with vested interest in community health.

The three presenters offered insights into how to approach increasing diversity in patient-researcher partnerships and offered key recommendations, outlined below.

- **Develop and maintain relationships beyond the research needs.** Developing meaningful relationships with the community requires engaging with the community beyond the one-time or time-bound research project needs. Researchers gain legitimacy if they are open to discussing and supporting what is not explicitly on their research agenda.

Both panelist teams approach this by structuring their research programs with a scientific arm, which moves forward research projects and engages the community in individual projects, and an infrastructure arm, which offers support to the community in meeting their needs outside of research. Examples of this included building capacity and providing training for community organizations to develop and submit their own funding applications and providing support for community health events.

This model of engagement is admittedly more time- and resource-intensive and requires researchers to step outside their own research agendas, but Daniel Mullins suggested that community engagement or patient-researcher partnerships should be treated like any other relationships in life. By that definition, to be engaged means to make a commitment to a long-term partnership, for better or worse. In that spirit, maintaining a relationship between points of research engagement, or focusing on topics or initiatives that don't necessarily move a researcher's agenda forward, is important to making community members feel like true and valued partners. When community members feel heard and researchers are willing to work with them to address their broader issues, they will find the time to engage and participate in research. On the other hand, when they feel like researchers are just checking boxes, they will become angry and non-responsive.

- **Share results of engagement with the community!** This seems simple but is often forgotten. In the same way that engaging outside of research needs is important, researchers should share results with the community to build trust and legitimacy. This is an important and often overlooked point to consider. Ensuring dissemination to the community is accounted for when developing budgets and staffing plans for research projects is also important.
- **Diversity isn't (just) about color.** While diversity is often about demographic characteristics (e.g., race, ethnicity, gender, sexual orientation, etc.), just as importantly, it is also about different experiences and ideas. There are many voices that you could bring to the table based on many different criteria from demographic characteristics to types and experiences of a certain disease (e.g., more or less advanced disease, different treatment experiences, etc.) to other personal characteristics. Think critically about what constitutes diversity in your community and for your research.
- **Seek honest answers, not just diverse responses.** As research funders increasingly require patient engagement and outreach to diverse patient populations, diversity can become a checklist to work through without a thoughtful approach behind it. Keep in mind that the ultimate goal of PCOR is providing patients with relevant information. Diversity is about what is important to individual patients, their preferences for treatment, and what they hope to achieve and avoid with the healthcare they receive. Engagement in research that strives to provide this information to patients should look to providing diversity in responses and experiences important to the community, rather than simply checking boxes to ensure a diverse population.
- **There is no one way to engage the community.** Think about the best ways to approach the community you want to engage. You often learn this through engaging with the community outside of your research needs. Build your relationships with the community first, before making research asks. In the spirit of developing a true relationship with your community, think creatively about how you can support the community beyond your specific research needs with funds, time, or other resources.

- **Recognize the power of the community.** Community members who engage with you bring multi-faceted backgrounds, skills, and experiences to the table that extend well beyond their healthcare experiences. Get to know your partners and think about how you can integrate them into all aspects of the project. A partner who likes to write, for example, could help you think through research results dissemination plans beyond typical academic journals and write layperson-focused articles and blog posts sharing results. Furthermore, think about how you can help the community build capacity for owning parts of your research, or even driving forward their own research agenda.

Linda Ko and Together We STRIDE accomplish this by dedicating 15-30 minutes of every Community Advisory Board meeting to a research topic, such as human subjects research protections, so that the community is gaining research skills that allow them to be more informed partners in research. Daniel Mullins and Gail Graham's PATIENTS program focuses on this by offering support and expertise to community organizations developing funding proposals. PATIENTS program staff assists closely for the first submission, and the community organization takes the lead on subsequent proposals.

- **Respect is key.** Underlying all of these recommendations is the vital concept of respect for community members and partners. Engaging outside of research shows community members that you respect their time and experiences and value their input. Making efforts to understand a community's needs and challenges, and offering support for addressing them, illustrates a respect for the community that will go far beyond your ability to compensate community members for individual engagement activities.

### Recommendations for Increasing Diversity in Patient-Researcher Partnerships

Small group discussions at each table were focused on distilling information learned from the presentations and group discussion into actionable recommendations for increasing diversity. The following recommendations, reflected in the visual recording, served as the basis for prioritization. The bolded recommendations indicate designation as high priority by the group at the conclusion of the workshop.

- **Assist partners with grant writing from their perspective, so they can go after their own funding and share ownership in the research process.**
- **Develop a peer-to-peer mentorship program for both patient/community partners and researchers.**
- **Develop models of compensation so that partners are compensated fairly and equitably across activities.**
- **Provide supplemental funding to sustain the infrastructure between research projects.**
- **Create resources to connect the community and researchers.**  
**Identify/develop a “spectrum of engagement.”**
  - Be aware of meeting locations. Bring participation to the community.
  - Offer travel support so that participation is not a burden for participants.
  - Explore how PCORI's Patient-Powered Research Networks (PPRNs) can be leveraged to expand the diversity of patient-researcher partnerships.
  - Fund pre-engagement activities to allow researchers to forge relationships within the community before making a research ask.

- Help researchers identify ways to stay connected with hard-to-reach patients.
- Obtain funder and institutional buy-in on the importance of providing food at meetings and small compensatory items to recognize community participation.
- Develop trainings for researchers on engaging the community.
- Develop marketing materials on the value of engagement for researchers and patients.

## Workshop Evaluation and Next Steps

At the end of the workshop, we asked participants to complete an evaluation. Twenty-one participants responded (42% response rate). A summary of the evaluation is as follows:

- Among respondents, we heard the following key reasons for attending the workshop:
  - The opportunity to connect with others actively involved in research partnerships
  - Gaining insight into how their projects could better engage patients
- Evaluations reflected a successful meeting for most attendees, with 96% of those responding ranking meeting sessions and the meeting as a whole as “Excellent” or “Very Good” on a 5-point scale (Excellent, Very Good, Average, Below Average, and Poor)
- An important goal of the workshop was to begin to build connections among the community of patients and researchers involved in partnerships in the Pacific Northwest region, and we were pleased to see that nearly 90% of respondents made connections to people they may partner with in the future.

The final stages of INSPIRE work over the next 6 months includes developing out a web portal for easy access to existing tools and resources that support some of these needs. The INSPIRE team also plans to convene an advisory committee to explore developing a mentorship-focused conference or program for future deployment.

## Appendix A: INSPIRE Community Workshop Agenda

Monday, July 18, 2016	
<b>1pm</b>	<b>Welcome and Introductions</b> <i>Danielle Lavallee, INSPIRE Project Lead</i>
<b>1:20pm</b>	<b>Workshop Purpose and Goals, INSPIRE Project Overview</b> <i>Danielle Lavallee</i>
<b>2pm</b>	<b>Research Done Differently: Building Infrastructure for Patient Engagement</b> <i>Chinenye Anyanwu; Engagement Officer, Patient-Centered Outcomes Research Institute (PCORI)</i>
<b>3pm</b>	<b>Patient Engagement: Past, Present, and Future</b> <i>Nancy Roach; Founder and Chair, Board of Directors, Fight Colorectal Cancer</i>
<b>4:45pm</b>	<b>Setting the Stage for Day 2</b> <i>Danielle Lavallee</i>
Tuesday, July 19, 2016	
<b>8am</b>	<b>Welcome and Framework for the Day</b> <i>Danielle Lavallee</i>
<b>8:30am</b>	<b>Panel Presentations and Group Discussion: Models of Engagement</b> <i>Karen Wernli, Dianne Johnson, Mary Bush, and Susan Brandzel, SIMBA (Seattle, WA) Renee Robinson and Adrienne Tveit, Southcentral Foundation (Anchorage, AK)</i>
<b>10:15am</b>	<b>Panel Presentations and Group Discussion: Expanding Diversity in Patient-Researcher Partnerships</b> <i>Linda Ko, Fred Hutchinson Cancer Research Center (Seattle, WA) Daniel Mullins and Gail Graham, PATIENTS Program (Baltimore, MD)</i>
<b>1:15pm</b>	<b>PCORI Eugene Washington Engagement Awards Program and Opportunities for Engagement</b> <i>Lia Hotchkiss, PCORI Eugene Washington Engagement Awards Program Director</i>
<b>1:30pm</b>	<b>Prioritizing Next Steps</b> <i>Danielle Lavallee and Maketa Wilborn</i>
<b>2:45pm</b>	<b>Closing</b> <i>Danielle Lavallee</i>