Thank you to our sponsors!
<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
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<tr>
<td>12:00-12:15 pm ET</td>
<td><strong>Welcome &amp; Introductions</strong></td>
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| 12:15-1:30 pm ET   | **Building Teams: Practical approaches to create safe and collaborative environments**  
Facilitators: Rebekah Angove, PhD, Director, Patient Insight Institute; Mary Mukira, Engagement Manager, Patient Insight Institute |
| 1:40-2:50 pm ET    | **Advocates as “citizen scientists”: How to lead community conversations and gather insights**  
Facilitator: Melissa Williams, MPH, Director of Grassroots Advocacy, National Patient Advocate Foundation |
| 2:50-3:00 pm ET    | **Closing Remarks and Day 2 Preview**                                   |
As a result of today’s sessions, we hope you will...

Objectives

Feel motivated to connect with your community and gather insights

Be more thoughtful in how you build and work in teams
Session 1
Building Teams: Practical approaches to create safe and collaborative environments
Rebekah Angove
Patient Insight Institute
@RebekahAngove

Mary Mukira
Patient Insight Institute
@MaryMukira

#PatientInsights23
In this session we will learn how to...

1. Implement best practices on how to best engage patients
2. Create safe team spaces honoring the expertise and lived experiences of others
3. Workshop actionable research engagement approaches
Before Building A Team, What Are We Getting Into?
BUILDING TEAMS

Recruitment

Skills
Experience
Knowledge
Talent

#PatientInsights23
BUILDING TEAMS

Addressing Barriers

- Bias
- Trust
- Managing Expectations
- Power Dynamics

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BUILDING TEAMS

The Hard Conversations

Trust and Trustworthiness

Power Dynamics

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BUILDING TEAMS

The Hard Conversations + Managing Expectations

Trust and Trustworthiness

Power Dynamics

#PatientInsights23
BUILDING TEAMS

• **Respect and Dignity:** Treat all individuals with respect, acknowledging their inherent worth and unique perspectives. Value diverse backgrounds and experiences.

• **Cooperation and Collaboration:** Foster collaboration and partnerships among all stakeholders. Strive towards working together as equals. This includes co-learning and acknowledging the expertise each person brings.

• **Communication & Transparency:** Encourage open, honest, and transparent communication within the team. Members should feel comfortable sharing their ideas, concerns, and feedback. This includes active listening and constructive feedback.

• **Well-Defined Roles:** Clearly define the role of the group as well as the roles and responsibilities of each team member. This reduces confusion and ensures that everyone knows what is expected of them.
• **Trustworthiness**: Ensure that all stakeholders can trust each other as well as the research process, data, and outcomes. Maintain integrity and credibility in research.

• **Conflict Resolution**: Conflicts are inevitable in any team. It’s essential to have a process for resolving disputes and disagreements constructively and to foster a positive, solution-oriented approach to conflict.

• **Impact and Outcomes**: Focus on research that will make a difference in healthcare and the lives of patients. Emphasize patient-centered outcomes and real-world impact. Look to patient communities to guide you.

• **Continuous Improvement**: Encourage a culture of continuous learning and improvement. Teams should regularly evaluate their processes and performance, identifying areas for enhancement and adapting to changing circumstances.
Discuss & then
Let’s Practice!
Your Job:
Discuss the perspectives of different team members in these scenarios and come up with solutions.

Value everyone’s diverse and unique lived experience

Understand and acknowledge the power dynamics in the room/on the team

Managing expectations & commitment to the community is part of handling the hard conversations

Be transparent about all aspects of the project + acknowledge distrust (pt tip: advocate for yourself)

Remember…
SCENARIO 1

As the research project continues, community members in the group want to do more with the final project findings. They want to bring these findings to individuals, community groups and/or legislators to inform and improve the current situation based on the topics addressed by the research.

This is out of project scope, and researchers are hesitant to share too much information on their results too early. It is unknown if the project leaders/organization intend on building on the outcomes of this project, and how.

What do you see as the next steps to resolve this conflict?
• What's going wrong
• What are different team members not seeing
• What are some solutions
SCENARIO 2

- Projects the group advises on vary in topic, but always center around the same target populations.

- A member of the project group asks about participant diversity and how this project may or may not actively contribute to institutional or community-level changes… “are we making a difference to those that need help?”

- How can the group best address concerns and communicate next steps to ensure everyone feels heard and satisfied?
• What's going wrong
• What are different team members not seeing
• What are some solutions
Since more patients and caregivers are being asked to engage in Patient-Centered Outcomes Research (PCOR) as partners and advisors, the Patient Insight Institute patient community identified actionable tips for both researchers and patients/caregivers to ensure this engagement is of maximum benefit and impact to all involved.

**TIPS FOR PATIENTS AND CAREGIVERS:**

1. **REMEMBER: YOU’RE NOT AN IMPOSTER.**
   
   While it may feel uncomfortable to participate in a research project as a non-healthcare or scientific professional, your contributions are invaluable and valued.

**TIPS FOR RESEARCHERS:**

1. **BE TRANSPARENT ABOUT ALL ASPECTS OF THE PROJECT.**
   
   Inform patients about the overall goal and objectives of the research project and how their involvement fits into the bigger picture. Specifically, describe how their participation will be used for research and help manage their expectations by sharing what the research will and will not do.
What’s Next?

• How will you use what you learned today?
  • What can you implement in your current teams?
  • What will you try in your next project team?
  • What do you want to learn more about or dive more deeply into?
BREAK
Session 2. Advocates as “Citizen Scientists”

How to Lead Community Conversations and Gather Insights

Melissa Williams, MPH
Director, Grassroots Advocacy & Partnerships, NPAF
Women’s Suffrage Movement

Civil Rights Movement

Disability Rights Movement

Source: https://www.catawbacountync.gov/news/the-suffrage-centennial-begins/


Source: https://disabilityrights222.wordpress.com/what-is-the-disability-rights-movement/
Social Movement: An organized effort to change laws, policies, or practices by people who do not have the power to effect change through conventional channels... while movements often target the government and seek legislative change, they also challenge institutional policies and practices outside the government, as well as popular beliefs and common behaviors.

Source: https://www.ncbi.nlm.nih.gov/books/NBK268722/
Justin Dart, Jr.
Godfather of the ADA
In this session, you will...

1. Understand the critical role you can play in developing policies by connecting with your communities through conversations and insight gathering.
2. Describe how the principles of community-based participatory research serve as the inspiration for these advocacy actions.
3. Learn how to bring people together to facilitate your own community conversation.
Citizen science relies on people to track progress and collect information (data).

What is Community-Based Participatory Research (CBPR)?

CBPR is a widely accepted collaborative approach to research that works to understand and protect public health by involving all partners in the research process.

It bridges the gap between science and practice through community engagement and social action to increase health equity.

The NIH definition of CBPR emphasizes that community partners are fully involved in each stage of the research, from the study’s conception to its design, analysis and communication of results.

Source: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4042315/

Like citizen science, CBPR relies on people to be fully involved in the research.
What do all of these elements have in common?

**People. More specifically, you.**

We are well-positioned to build a patient-led movement to transform healthcare because of you, and your connections.
POLL:
Have you ever participated in a focus group or listening session?
POLL:
Have you ever facilitated a focus group or listening session?
What are Examples of Insight Gathering

- Listening Sessions
- Community Conversations
- Focus Groups
- Surveys
Why Host a Community Conversation as an Advocacy Action?

- Listen to community concerns and gather stories
- Identify resource gaps
- Can position you as a leader or influencer within your community
Organizing a Community Conversation
Step 1. Identify the topic
What do you want to learn?

- Make a list of the questions you want to ask

- What do you want feedback on? What could help patients and caregivers? What could help your community?

- We have toolkits!
Step 2. Identify your audience
What perspectives are you looking for?

- Things to consider:
  1. NPAF's target audience: Young adults, underserved groups, patients and caregivers
  2. Your spheres of influence: Who do you know that would be interested in a discussion about navigating healthcare?
  3. What's your comfort level?
     a. Are you more comfortable reaching people you know? (Family, friends, co-workers, neighbors, support group, church members)
     b. Are you more comfortable connecting with members of your community?

- Size: No more than 12 people, 8-10 ideal

- It's okay to combine different audiences

#NPAFProTip:
Use our outreach checklist to recruit participants
<table>
<thead>
<tr>
<th>Community Outreach CHECKLIST</th>
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<tbody>
<tr>
<td>For <strong>PATIENTS AND CAREGIVERS</strong>, contact:</td>
</tr>
<tr>
<td>□ Local and online support groups</td>
</tr>
<tr>
<td>□ Doctors' offices / Hospitals</td>
</tr>
<tr>
<td>□ Churches / Places of worship</td>
</tr>
<tr>
<td>□ Local navigators / social workers</td>
</tr>
<tr>
<td>□ Local patient advocacy groups / chapters</td>
</tr>
<tr>
<td>For <strong>LIMITED-RESOURCED POPULATIONS</strong>, contact:</td>
</tr>
<tr>
<td>□ Free clinics / local health departments / community health centers</td>
</tr>
<tr>
<td>□ Public libraries</td>
</tr>
<tr>
<td>□ Food banks</td>
</tr>
<tr>
<td>□ Homeless shelters / women's shelters</td>
</tr>
<tr>
<td>□ First responders</td>
</tr>
<tr>
<td>For <strong>YOUNG ADULTS</strong>, contact:</td>
</tr>
<tr>
<td>□ Colleges and universities (i.e., health centers, student life, student groups)</td>
</tr>
<tr>
<td>□ Youth-focused organizations / Youth development groups (i.e., Young Invincibles)</td>
</tr>
<tr>
<td>□ Small-business owners / Employers</td>
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**NAME:** ___________________________ **EMAIL:** ___________________________

**LOCATION:** ___________________________
Step 3. Work out logistics

- **Date and Time.** Select a meeting time that’s accessible for your participants (take into account work schedules, childcare, etc.)

- **If meeting virtually:** Decide on platform (Zoom, Google Meet, Microsoft Teams)*

- **If meeting in-person:** Consider space. Meeting rooms in libraries, churches. Ask if a local business may help donate food (baked goods, sandwiches)

- **Send meeting invitation via email**
  - Include date, time, length of meeting
  - Share purpose of community conversation: *Hear about your experiences navigating healthcare*
  - If virtual, include link to meeting
  - Give heads up about turning on cameras
Facilitating a Community Conversation
Facilitate (verb): To make (an action or process) easy or easier.
The Start

- **Introductions**
  - Introduce yourself, explain your role and purpose for the focus group.
  - Participant introductions aren’t necessary, but may help to break the ice.

- **Set ground rules**
  - Consider a community agreement.
  - Urge participants to raise their hand to speak (in-person or virtual).

“**My name is Melissa and I’m a volunteer with National Patient Advocate Foundation. I’ve asked you to participate in this community conversation because I want to hear your perspectives about navigating healthcare. I have some questions that I will be asking, and I’ll be jotting down notes as you are talking. There are no wrong answers. The goal today is to have a conversation. Your feedback will be used by National Patient Advocate Foundation to help build policy proposals that will improve your experiences with healthcare.”**
Community Agreement

1. Keep it confidential
2. Be present as fully as possible
3. Balance between listening and talking
4. Respect differences, be open to new concepts and ideas
5. Take a break if you need one
The Start

- Seating arrangement, if in-person
  - Arrange seats in a circle or sit in a roundtable
  - As the facilitator, mimic the behaviors of the participants. If they are seated, you should be seated as well.

- If virtual, invite participants to turn on their cameras, so you can see real-time reactions
Facilitating Tips

- Keep pen and paper with you to jot down notes
- Maintain eye contact when possible
- After you ask a question, pause and gauge reactions. Repeat question or ask it in a different way if you think people are confused.
- Ask open-ended questions. “Did you have a good day?” vs. “How was your day?”
- Use words or phrases like “Describe” or “Explain” or “Tell Me More”
Facilitating Tips

- Follow the conversation – it’s okay to ask questions that aren’t reflected on your questions list.
- Let all participants have an opportunity to answer a question. “What other thoughts do people have?”
- Assure participants – there are no wrong answers.
- It’s your job to listen, not teach.
- Remember you’re an advocate, not a researcher.
## Facilitating Tips: Possible Scenarios

<table>
<thead>
<tr>
<th>Scenario</th>
<th>What You Do</th>
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<tr>
<td>Too quiet / non-responsive</td>
<td>Use the silence. It's okay if people need a moment to reflect on the question. Try rephrasing question, or asking an easier one. You can offer your own perspective to jumpstart the conversation (i.e., “I've been frustrated with...” or “I really with my doctor would ...”)</td>
</tr>
<tr>
<td>Too rowdy</td>
<td>Remind participants of community agreement (raising hands to speak, not interrupting one another).</td>
</tr>
<tr>
<td>Off-topic / side-tracked</td>
<td>Acknowledge the shift, paraphrase, but bring it back to the original topic.</td>
</tr>
<tr>
<td>One person speaks more than others</td>
<td>“Are there others who agree or disagree? Let’s hear some other perspectives.” Let the person know that you appreciate their feedback and offer to reach out after the meeting to learn more.</td>
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<tr>
<td>Emotions are high</td>
<td>Acknowledge emotions. Allow for a pause.</td>
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The End

- Honor the time allotted
- Thank everyone for their time and participation
- Share information about NPAF, PAF and Needs Navigation
Critical Next Steps: Insights to Action Feedback Loop

1. Brainstorm actions you can do that address raised concerns
2. Synthesize what you heard
3. Share insights with NPAF
Why is this action so important?

What’s the impact?
The Outcome: A Heat Map

Source: https://www.tableau.com/blog/how-vulnerable-are-health-care-systems-rural-recreation-communities
The insights you gather will help:

- Identify resource gaps
- Draft policy proposals
- Hone our messaging to advance Needs Navigation

Positions you as a community leader. It shows that you can:

- Organize
- Convene
- Listen
- Address problems
WHAT? Become a citizen scientist and gather insights of patients/caregivers by hosting your own community conversation.

So WHAT? Everyone understands the experiences of patients/caregivers, and we identify solutions to fix the resource gaps.

Now WHAT? Let us know you’re interested in hosting a community conversation, so we can help you build capacity to make it happen.
POLL:
How motivated do you feel to facilitate your own community conversation or listening session?
Let’s Hear From You!
Share your reflections with us
What’s Next?

• We will send all participants links to slide decks and meeting recordings by end of week

• Registration will open for our in-person Patient Insight Congress next week. Scholarship applications will open January 2024.

• Join us tomorrow!
Tomorrow

Day 2: Thursday, October 19, 2023

12:00-12:10 pm ET
Welcome & Welcome Back

12:10-1:30 pm ET
Translating data into stories: How to make research understandable for nonscientific (lay) audiences
Facilitator: Kathleen Gallagher, MPH, VP of Health Services, Data Management, Patient Advocate Foundation

1:30-1:45 pm ET
Patient Insight Congress 2024 Preview

1:45-2:00 pm ET
Closing Remarks