



Engaging Patients, Investigators, and Stakeholders for the Whole Community

Leveraging the Patient Resource Group to support inclusive Strategies, Engagement, Recruitment, and Dissemination of Results

Adam Anicich, MBA

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Patient Engagement

What is *Patient Engagement* and Why do we need it?

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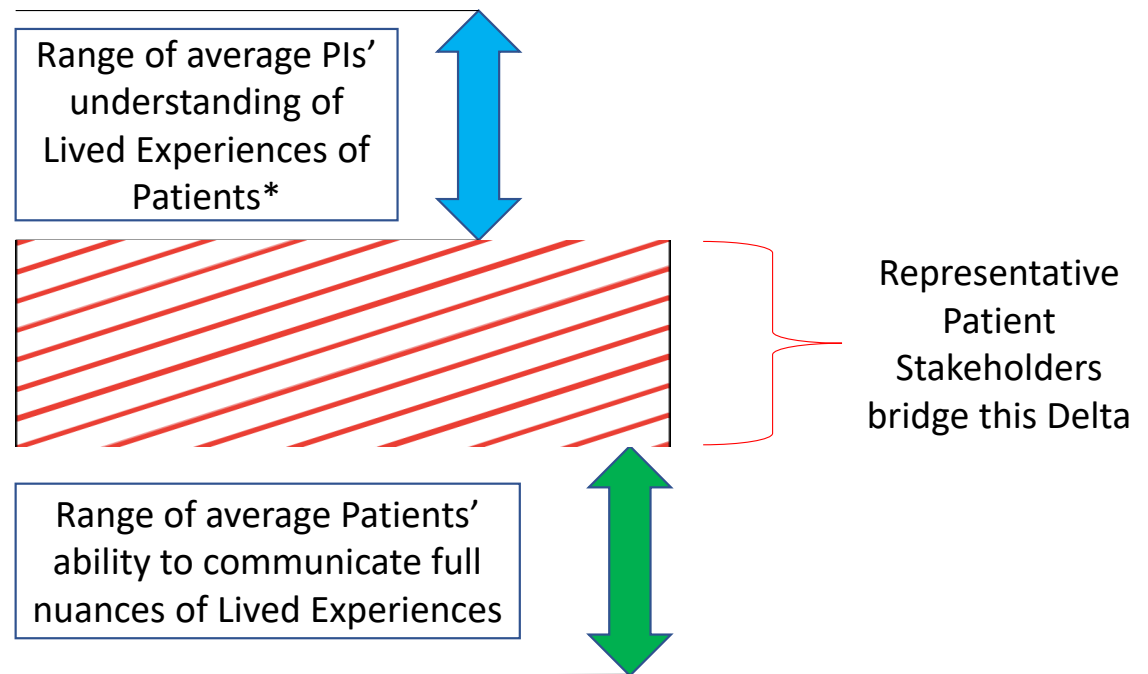


What is a PRG?

- Advisory group able to support various aspects of engagement in the research lifecycle
 - Study design
 - Engagement Materials and Strategies
 - Recruitment and Advertisement
 - Dissemination of Findings/Impact of Research
- Partner in Research Development
 - “Community-connected” consultant who can provide level-headed, external advice
 - Able to share best practices from across various research organizations they are affiliated with
- Based on the Nurse Navigator concept

Why?

- Why do we need patient input?
- Can't the PIs control for the variables across different groups?



* Particularly of Patients from disadvantaged populations



What does a PRG Do?

- Consult with PIs
 - Study strategy and grant support, letters of support
 - Recruitment and engagement strategies
 - Provide expertise in targeting specific populations
 - Help focus relevancy of studies/trials on target population
- Discuss Participation with Potential Participants
 - Develop materials and strategies to recruit participants
 - Explain the benefits of participation in research
- Engage External Groups
 - Support stakeholder buy-in (Organizational, Agency, or University, etc)
 - Develop and cultivate external advocacy
 - Disseminate results and communicate impact

Composition of PMC3 PRG



- Veterans, Active Duty Military, Caregivers, and Family Members
- Diverse ethnic, gender, age, war-time era, and ailment backgrounds
- Experienced in health research and communications
- Capable of supporting PIs at **ANY** stage of research
- Think ***Strategically***
 - Does the member add value to some aspect of the PRG?
 - How is the member connected to the community?
 - Can they help inform stakeholder engagement prior to IRB approval?
 - Does the member have unique insight or skill relating to the research focus?

Health Equity Group



The Health Equity Group (HEG) was developed to:

- 1) Reduce bias in health research,
- 2) Ensure that historically disadvantaged populations (including those stemming from race, gender, LGBTQ identification, and socioeconomic status (SES)) are appropriately represented in health research studies, grants, trials, and funding, and
- 3) Help eliminate barriers to high-quality healthcare in minority communities, and
- 4) Advise on minority-related issues.

What *value* does a diverse population of community stakeholders bring to your research?

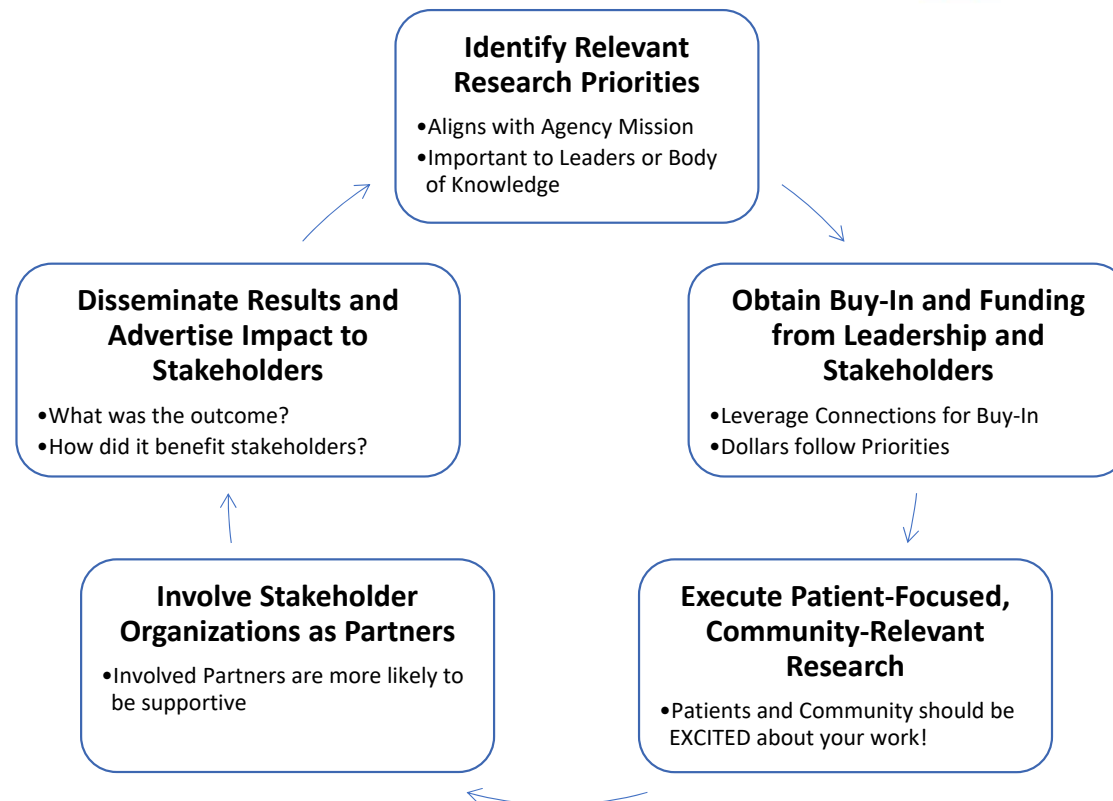
PRG in Action



- External Discussions
 - Grant makers and decision makers
- Review Application Materials
 - Provide thoughts and considerations for study
 - Provide letters of support
- Contribute to Study Designs
 - Walk through with PIs
 - Provide background on Veteran Characteristics not traditionally reported
- Review Websites and Surveys
 - Click-through of proposed collection tools and sites
 - Provide feedback and clean-up of materials

***A representative PRG
can help you better calibrate
your research
with the Communities
you are seeking to help.***

Funding Sustainability Benefits





Questions?