Integrating Patient Voices into Research

Ann Blair Kennedy, DrPH; Mary McCarthy; Jaime Fivecoat; Peggy Wagner, PhD

University of South Carolina School of Medicine Greenville Greenville Health System Health Science Center Patient Engagement Studio

What is the Patient Engagement Studio?

A team that joins the perspectives of patient experts and other stakeholders in health research and innovation.

Building Trust

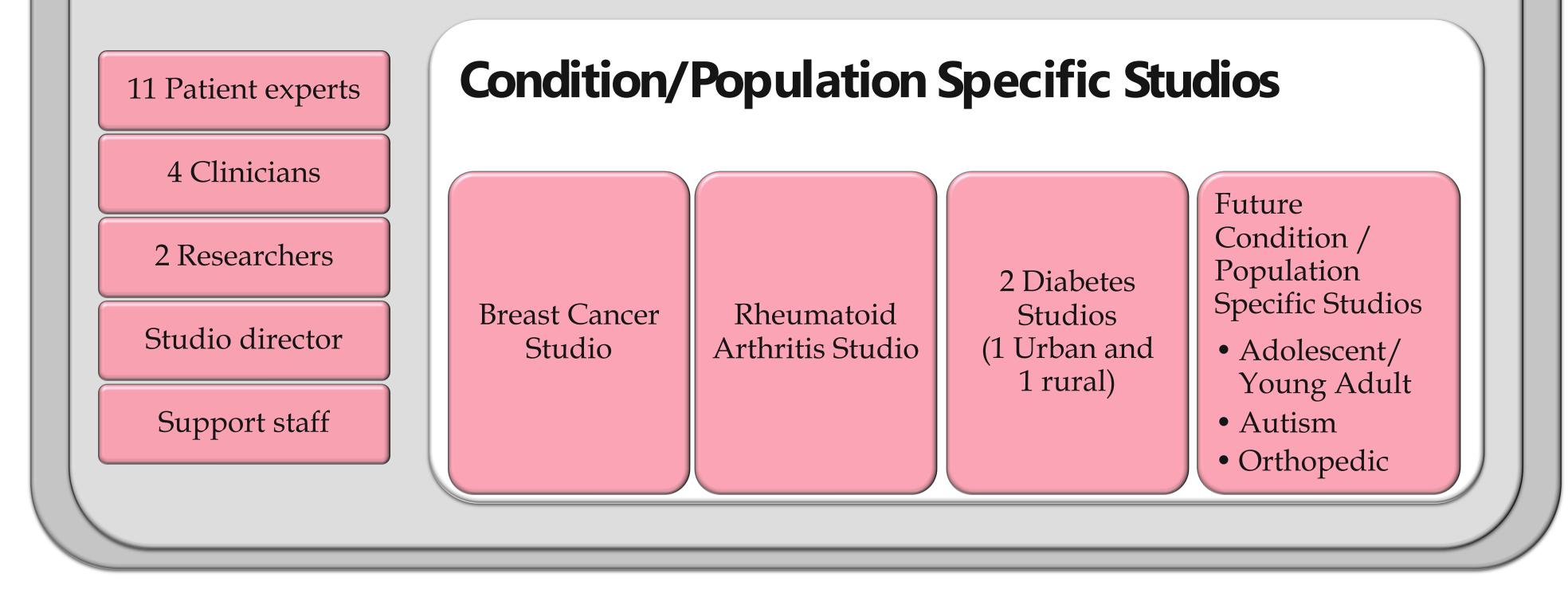
Eliciting feedback

Positive communication

The Message Box

Patient Engagement Studio Steering Committee

The steering committee meets with researchers and clinical experts to develop and clarify effective, patient-based health care approaches. The Steering Committee also coordinates the work of Condition/Population-Specific Studios.





Scan here with HP Reveal for a short video of the patient expert's perspectives

Audience: Participants attending Evaluation '18

1. Researchers are not trained on how to request input from, listen to, and implement suggestions provided by patients experts

Timeline

Reviewed/assisted with 18 projects: from virtual reality interventions for pain and anxiety to data collection for health literacy project. Continued medical education initiatives.

Reviewed 11 projects from to mHealth apps to Stress in families with children with autism. Received PCORI grant. Medical education initiatives

2018

2. Many researchers are unfamiliar with integrating patients experts into research teams as co-investigators 3. Researchers need to be able to build trust with patient experts by mutual respect, positive communication, and eliciting feedback through appropriate questions. Establishes project credibility **Problems?** With lack of training on 2. Anticipates potential how to engage and build controversies trust with patient experts Issue 3. Ensures transparency What? as research collaborators, and accountability scientists limit their 4. Improves relevance to Improving the quality potential funding and patients and the public So and relevance of health publication sources as well 5. Enhances quality of the research as reduce the impact of research their life's work. 6. Increases dissemination **Solutions?** and uptake of findings Researchers should seek training on improving communication with patient experts and work with their healthcare systems and medical schools to create patient engagement panels to integrate patients as co-investigators in research projects.



First meeting of Patient Experts and Researchers.

Reviewed 10 projects in Year 1: From Acupuncture in Cancer-related neuropathy to Telehealth initiatives

2017

Scan here with HP Reveal for a short video framing the researcher perspectives

2016

The Message Box communication tool was created by COMPASS to help researchers engage effectively with policy makers and the public.

The Message Box Workbook can be found at www.Compassscicomm.org/the-message-box-workbook

This poster is enhanced by Augmented Reality delivered by the HP Reveal App Follow Dr.ABK on the app and then scan in the indicated areas for more content



