



# PATIENT INSiGHT INSTITUTE

YEAR IN REVIEW



2022

# Message from Insight Leadership



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**E**levating patients' experience and amplifying the patient voice has always been a core value of Patient Advocate Foundation. In October of 2022 PAF established the Patient Insight Institute to expand our capacity and solidify our commitment to generating patient insights and supporting patient engagement in all health care, research, and policy spaces.

Our highly skilled staff work to generate patient-centered evidence through direct collection of patient and caregiver data, as well as the integration of patient and caregiver perspectives into our growing portfolio of programmatic and research projects – giving voice to those who have been historically under-represented in these types of initiatives.

We are proud of our early success as seen through several academic and nonprofit partnerships; secured funding through multiple PCORI Engagement awards, and strong sponsorship support.

We are guided by the patient voice, curating an elite group of patient partners via our [Experts by Experience](#) Advisory Committee as well as through the establishment of two learning communities explored the impact of the COVID-19 pandemic and the ever-evolving landscape of equity and social determinants of health.

In addition to these projects, we also successfully reimaged Patient Congress, as an event built for patients, by the patient community. This event includes multiple tracks focused on centering the patient perspective and is designed to engage patients, researchers and policy makers into impactful conversations around tacking access and affordability issues from multiple stakeholder perspectives.

The Patient Insight Institute continues to learn so much through our patient partners, as their experiences, voices and expertise will continue to shape how we build this community, engage in meaningful partnerships and develop patient-initiated projects. Through impactful research and interdisciplinary collaborations, we will continue our pursuit of a more equitable patient experience. Please join us in looking back on an incredible year of impact and action—and in continuing to build real world evidence that reflects and supports the full patient experience.

**The patient perspective is critical to accelerating changes necessary to improve health and care outcomes.**

# Highlights

**6** Funding opportunities secured for Institute initiatives



Research, Non-Profit and Program Partners

**7**

**29** Scholarships awarded for Insight Congress



Expert by Experience team members

**17**

**3,227** Insight Network Members



In support of PII Initiatives

**\$750K**

## Our Sponsors

**Genentech**  
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# Learning Communities

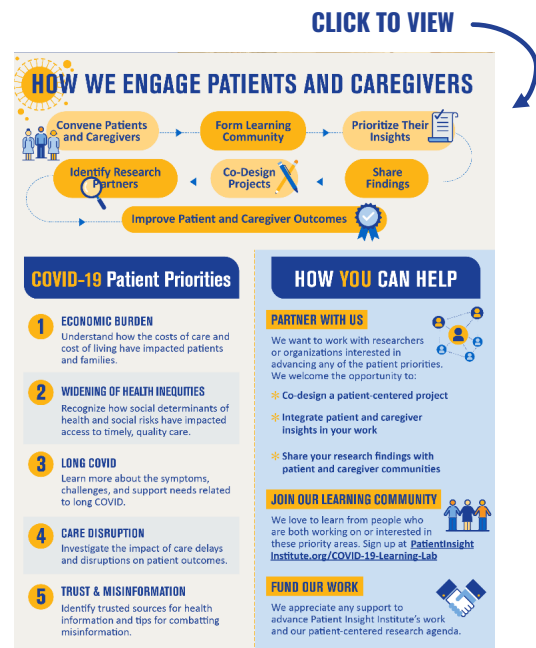
Despite patients' enthusiasm, researchers often find it difficult to recruit and integrate patients into their research, especially those from diverse and/or underserved communities. Created to support our ongoing mission and partner initiatives, these communities are places for patient stakeholders to learn about and share their own perspectives on salient topics as well as provide feedback to researchers and Institute staff on project design and results. They expand researchers' capacity to connect with communities in ways that are culturally responsive, and patient driven. Without the Institute, these formal opportunities for patient inclusion are often too time or resource intensive to be feasible. We created an inclusive team of patient and caregiver stakeholders, that researchers are invited to be part of. The goal of our learning communities is to help ensure that patient voice is included in a way that will not only inform, but also influence health care, policy, and research.



This learning community was developed to explore peoples' healthcare experiences and perspectives during the COVID pandemic and to help inform and advise health services research based on lived experiences as patients or caregiver

The [COVID-19 Learning Community](#)<sup>1</sup> is a group of over 100 patients, caregivers, providers, and researchers working together to create and execute a patient-centered research agenda focused on topics relevant to the COVID-19 Pandemic. Over an 18-month period, community members participated in 4 virtual workshops in addition to 2 independent online training activities. During this time we: Identified patient and caregiver priorities to shape research focused on the COVID-19 pandemic.

- Built patient, caregiver, and researcher skills for working effectively in a research team.
- Learned from researchers about their COVID-19 research and provided ideas on ways they can include patient and caregiver insights.
- Discussed challenges to patient engagement in research development and ways to overcome it.



"I loved being a part of this project! The COVID-19 Learning Community confirmed why researchers ought to engage patients and caregivers throughout the entirety of a project - from ideation to dissemination. The patients and caregivers had so many great ideas to offer and compelling questions to ask of researchers. I'm glad we were able to provide the safe space to have those important conversations and connections."

- *Melissa Williams*

<sup>1</sup> This project was partially funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EASC-COVID-00362).



Patients and caregivers face a variety of challenges in accessing and affording care in addition to a variety of non-medical hardships that come along with a complex or chronic condition. Researchers are busy working on projects that address these social needs related to healthcare, but they need the expertise of patients who have navigated these challenges.

Our Social Need and Equity Learning Community is made up of 15 patients/caregivers that convene 5 times a year with select researchers to discuss social need and equity related research projects and events.



This group provides valuable insights to create, refine, and drive research initiatives. This Learning Community allows patients to share their experiences and advise on various aspects of existing and new projects focused on the intersection of social needs, equity, and healthcare. SIREN is a strong partner in building this learning community of patients, caregivers, and researchers.

#### Activities completed by this group over 2022 include:

- 1 Provided insights on their experience and perceptions of SDOH screening in healthcare
- 2 Gave feedback on interview guide to capture patient feelings about SDOH screening
- 3 Held learning session on Social Care Research
- 4 Advised on SIREN National Research Meeting
- 5 Discussed how patient engagement strategies can strengthen social care research projects
- 6 Reviewed project design of SIREN Patient eNgagement to improve social care (PINNACLE) research project

*\*Activity: Feedback on PAF SDOH focus group guide\**



“Having the opportunity to co-create sincere relationships with the ExE community has not only been personally rewarding, but hearing how the Institute structure has helped repair the level of trust between communities and researchers, helps build that continued expectation of transparency within the culture of research.

- *Mary Mukira*

# Research & Engagement Partnerships

The patient perspective is critical to accelerating change. The Patient Insight Institute provides the expertise and infrastructure to build the capacity for patients, caregivers, communities, researchers, providers, and policymakers to come together in meaningful ways that impact projects and drive change. See more of our featured projects [here](#)



## Equitable Patient Experiences

This two-year project utilizes the Patient Insight Network members to help Institute staff and AHIP understand the various ways providers can address health equity and better serve diverse communities. This 2-year project is just beginning. With a preliminary scan of existing research on consumer preferences for providers, care teams, and office environments that identified domains that will be used to inform our survey and structured inquiry activities in 2023.

This project was motivated by the realization that it can be challenging for consumers to find someone they feel comfortable seeing for care based on information contained in provider directories. This may include difficulty finding a provider that shares their values, identity, language or knowing a provider's unique skills and commitment to diverse communities. Lack of confidence in a provider or network leads to individuals delaying or avoiding care, which further exacerbates healthcare access and outcome disparities.



## Addressing Determinants of Health Together: Pharmacists and Patients Co-Designing PCOR

In partnership with PQA, we developed and executed an in-person "[Addressing SDOH Together](#)" half day workshop in May of 2022. This Patient-led event included a virtual pre-workshop working meeting to build connections and content for the main event, and a virtual post-workshop wrap-up meeting focused on impact and sustainability. To ensure a patient-informed event, monthly meetings were held with patient partners to advise on workshop content, speakers and activities. The event itself included patient panelists and facilitators to bring lived experience to PQA attendees. Gaps in evidence and resources to support pharmacists screening for and addressing SDOH were identified and used to inform future projects and partnerships. This work was funded by aPCORI Engagement Award.



## Bringing Diverse Patient Voices: Serious Illness Care Guide (SICG) Revisions

The primary aim of this collaboration is to revise an evidence-based communication tool, the Serious Illness Conversation Guide, to be more inclusive and accessible with input from diverse patient stakeholders. Researchers, clinicians, patients, and caregivers alike recognize the value of high quality, emotionally supportive serious illness conversations as a facilitator of high-quality care. As such, healthcare systems have placed increased emphasis on implementing educational and quality improvement programs that attempt to ensure that patients have access to conversations about their goals, values, and prognosis ('serious illness conversations') in routine serious illness care. The Patient Insight Institute recruited patients from diverse racial and ethnic backgrounds together to review and revise this critical resource to ensure it resonated with all patient communities. Click [here](#) to see the revised training tool.



LINEBERGER  
COMPREHENSIVE  
CANCER CENTER

## Early Career Investigator Spotlight: Caitlin Biddell, MSPH, PhD Department of Health Policy & Management

Research Project: Understanding the long-term impacts of financial barriers to care: Patient-informed adaptation of a conceptual framework for adult cancer survivors.

Cancer-related financial hardship is experienced by almost half of cancer survivors in the US and is associated with negative clinical outcomes, including worse patient emotional well-being and heightened risk of mortality.

To explore this relationship, Caitlin conducted virtual, audio-only interviews using an in-depth, semi-structured interview guide initially informed by a conceptual framework of financial barriers to care and then further modified through pilot testing with three patients serving on PAF’s Patient Experience Panel.



“Working with the Patient Insight Institute to conduct a qualitative research study ensured that the work was informed by patients every step of the way – from interview guide development to data collection to dissemination. The research was stronger, made sure that it was responsive to patient priorities and concerns, and I could not have done this within the context of a dissertation without the help and support of the Patient Insight Institute.” - *Caitlin Biddell*

## PATIENT INSIGHT *Congress*

In 2022 we launched our inaugural Patient Insight Congress, an interactive in-person event dedicated to advancing healthcare initiatives informed by the whole patient experience, in November in Washington, DC. Patients and caregivers came together with researchers and health policy professionals to share their insights about the outcomes that matter most to them and what they would like researchers and government officials to address through patient-centered research projects and policy proposals.

The event included panel discussions involving patients and caregivers, pulling from lived experiences to share why the patient perspective is important, as well as insight gathering sessions to identify what matters most to patients, and sessions on elevating patient experiences for actionable policy change. In addition, we hosted a “rapid poster walk” to bring patients and researchers together for a curated session of interactive research poster presentations that allowed attendees to learn more about research happening in their communities and ways that researchers-patients can connect to partner on research design, implementation and dissemination.



# Dissemination Activities

Effective dissemination and communication are vital to ensure that the conducted research has a social, political, or economic impact. Through various platforms, the Insight Institute ensures that the benefits of our collaborative work are passed on to others and that it is put to good use. By increasing the visibility of our research and engagement activities, we strive to drive innovation in ways that patient-centric engagement can drive confidence of the patient voice/perspective in the larger research ecosystem.

## Conferences

### ASCO Quality of Care Symposium.

*Association of patient-reported financial barriers with healthcare utilization among Medicare beneficiaries with a history of cancer.*

**C. Biddell, L. Spees, J. Trogdun, E. Kent, D. Rosenstein, R. Angove, S. Wheeler.**

Chicago, IL | **September 30-October 1, 2022**

### JADPRO Live.

*Experts by experience: Paving a pathway to engage under-represented oncology patients in the research ecosystem.*

**K. Gallagher, A. Richardson, M. Mukira, R. Angove.**

Denver, CO | **October 20-23, 2022**

### PCORI Annual Meeting

*Paving a Pathway to Engage Underserved Populations in Research.*

**M Mukira, K Gallagher, R Angove.**

Washington, DC (Virtual) | **October 26-27, 2022**

### APHA's 2022 Annual Meeting & Expo.

*Experts by experience: building an engaged patient network for research activation.*

**K Gallagher, M Mukira, R Angove.**

Boston, MA | **November 6-9, 2022**

## Speaking Engagements

### American Society of Hematology (ASH) Annual Meeting

*Patient-Centric Goals of Decentralized Clinical Trials (DCT).*

**R Angove.**

New Orleans, LA | **December 10-13, 2022**

### 6th Annual Patient Experience Symposium

*The Patient View: Can Artificial Intelligence Replicate a True Patient Experience*

**R Angove.**

Boston, MA | **September 20, 2022**

### The National Academies of Science-Engineering-Medicine

*Family Caregiving for People with Cancer and Other Serious Illness.*

*Research Challenges and Opportunities; from a patient and caregiver perspective.*

**R Angove.**

Washington, DC | **May 16-17, 2022**



# The Patient Insight Institute at a Glance



## INSIGHTS

- Innovative and Multi-Layered Data Collection Strategy
- Deploy Surveys with Rapid Response
- Gather Experiences and Underrepresented and Under-Resourced Populations
- Facilitate Structured Inquires to Dive Deeper into Specific Topics of Interest
- Synthesize and Translate Findings
- Create Consumable Data and Infographics for Dissemination



## ENGAGEMENTS



- Innovate Engagement Strategy that Exceeds Industry Standard
- Create Safe, Open, Equitable Spaces
- Outreach and Connection to Vulnerable and Medically Underserved Populations
- Provide Trusted and Neutral Facilitation
- Coach Scientific Teams to Optimize Engagement Efforts
- Set Actionable Steps Towards Patient-Centered Change

## Our Process

