



2017 Health Services Research Conference

Partnering for Better Health Through Patient and Caregiver Activation



Dr. Ben Brooke, PCORI researcher, and his PCORI patient advisor, Gordon Carmichael, enjoy the poster stroll.

Event Overview

Patients empowered to partner with researchers on topics they value leads to more meaningful scientific results. Researchers ready to listen and walk in tandem with patients and families to learn new ways to advance health brings science to the bedside faster. HealthInsight and Intermountain Healthcare in partnership with community organizations including the Community Faces of Utah, University of Utah Center for Clinical and Translational Science (CCTS), Salt Lake Interfaith Roundtable, Utah Health Policy Project hosted 118 patients, caregivers, health care providers, and researchers to learn from one another and develop opportunities for collaborating on health research projects at the **2017 Health Services Research Conference: Partnering for Better Health through Patient and Caregiver Activation.**

The event combined dynamic speakers and interactive sessions to bring researchers and patients together for cross-collaboration and patient input on study design and outcomes. Event details and full agenda can be found online at: <https://healthinsight.org/partnering-for-better-health>.

Key Learning and Highlights

Keynote presenters Peter Margolis, MD, PhD, Director of Research and Co-Director at Cincinnati Children's Hospital Medical Center and Sam Brown, MD, MS of the University of Utah kicked off the day with demonstrations of the power of patient and family engagement in care innovation. Their talks were followed by breakout sessions, a poster stroll, and ongoing networking opportunities.

Of particular interest was the debut of a series of engagement workshops for researchers on how to deeply partner with communities, developed and hosted by the Community Faces of Utah and the Center for Clinical and Translational Science (CCTS). Researchers learned guidelines for respectful, lasting engagement from active community leaders.



Researchers learn how to actively engage communities in their studies at a new engagement training workshop.

Breakout sessions on current local Utah patient education and engagement health services research fostered dialogue on best practices and next steps for pilot programs. One highlight was a panel including a local patient and family advisory council member, a PCORI patient researcher, and the executive director of a Native American community advocacy group that works on disparities research with local scientists.

The University of Utah CCTS also demonstrated a live research studio in the afternoon. The studio is a structured focus group where selected community members react to proposed research topics, study design, and provide input based on their lived experience to enhance all aspects of the research such as recruitment, intervention implementation, aims and outcomes, or subject retention. The recorded video of this studio can be found at: <https://vimeo.com/211358129/60db140790>.



Community members engage in facilitated discussion during a live Studio Session to provide feedback on potential research topics.

Event Results and Next Steps

This successful event had over 53 likes, shares, and re-tweets on Twitter under the hashtag #PBHutah2017, 15 posters on display including 8 from community organizations such as Alliance Community Services, Best of Africa, Cavalry Baptist Church, Comunidades Unidas, Hispanic Health Care Task Force, National Tongan American Society of Utah, Urban Indian Center, and Community Faces of Utah. The event was designated as a Patient’s Included conference. Of the 118 attendees, 32 percent health care providers, 22 percent were patients and community members, 16 percent caregivers and family, 14 percent researchers, 12 percent policy makers and insurers, 2 percent students and 2 percent others.

We were also fortunate to host 35 Swedish health care providers and researchers attending an exchange retreat to learn about health research and the U.S. health care system. Their attendance augmented the conversation with their international perspective. Overwhelmingly, participants reported in the final evaluation of the day that they would like to become more involved in patient centered outcomes and research through emailed newsletters and by attending future events like this one.



This event fostered energy and excitement to continue pursuing opportunities for patient engagement in research throughout Utah. Next Steps include:

- Continuation and refinement of engagement workshops
- Development of a matchmaking website allowing researchers and communities to search and connect
- Addition of a web-based resources section with a navigation-training toolkit, video recordings of live CCTS studio sessions, Health Services Research Meeting results and additional training materials
- Development of community-oriented engagement seminars to learn to partner with researchers



Patient panelists showcase their expertise and unique perspective on interacting with the health care system in an afternoon panel.

Insights from the Audience: Most Valuable Information Learned

- Complex patient roles call for individual responsibility and collective contributions to medical research
- The unexpected ability and eagerness of researchers to communicate and collaborate
- Improved awareness of resources in the community for patients and caregivers
- Power of patient involvement working in networks and teams
- Seeing how patient perspective can help harness the inherent motivation of patients and caregivers
- Growing need for qualitative methods in patient centered outcomes
- Community engagement means building trust over time, as a committed long term process

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