PARTNERING FOR BETTER HEALTH: BRINGING UTAH'S PATIENT VOICES TO RESEARCH

Summary Report for HealthInsight Engagement Award Initiative Notice, Patient-Centered Outcomes Research Conference (EAIN/PCORI)

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Section 1: Introduction and Project Summary

Patient and stakeholder engagement are critical to the widespread integration of patient-centered outcomes (PCO) and PCO research (PCOR) within the health care system and community. The translation of biomedical research results into clinical practice has been found to take an average of 17 years,[i,ii] and historically outcome measures have been developed based on the perspectives of providers, policy makers and researchers. The Institute of Medicine's "Crossing the Quality Chasm" Report lists patient-centered care as one of the six domains of health care quality[iii] and there is a growing awareness nationally of the importance of patient engagement. The recent paradigm shift from the traditional model of care delivery to a more patient-centric model provides unique opportunities for researchers to both reduce the translational delay and identify measures for PCO and PCOR that are meaningful to patients[iv].

There are several quality improvement efforts underway that aim to enhance outcomes, but even the most successful projects may have limited impact to the setting in which they are implemented. The understanding of the value of PCOR by patients, providers, payers and researchers is still in its infancy in Utah. As of March 2016, there were three Patient-Centered Outcomes Research Institute (PCORI) Tier 1 grantees, four PCORI Tier 2 grantees and one health systems improvement grantee in the state of Utah[v]. While this is a promising start for the Utah community, there remains a need to improve PCO awareness using a community-driven approach. With community involvement, research questions that are important to the Utah community can be identified, and a community resource, such as a network that connects patients and patient advocacy groups with researchers can be established. Together these will enhance the broad awareness of PCO and PCOR in the community and facilitate the development of collaborative research projects to improve PCO.

HealthInsight is a neutral convener and nonprofit community-based organization with offices in Nevada, New Mexico, Oregon and Utah, and whose organizational goals include a focus on empowering patients, families, and the public to take a lead role in their own health and health care. HealthInsight Utah hosts the Utah Partnership for Value-driven Health Care (UPV), which operates under a collaborative, member-driven process and consists of Utah-based payers, providers, purchasers and patients/consumers[vi]. Through the UPV, stakeholder and patient engagement strategies were developed that include the fostering of Utah PCOR capacity at both patient and researcher levels.

In Salt Lake City, HealthInsight invited community stakeholders and organizations to co-design an event that brought together patients, researchers, providers and payers. Partners drawn from the UPV included patient advocacy groups such as Utah Health Policy Project, Salt Lake Interfaith Roundtable, and patient research collaborative, Community Faces of Utah. Other advisors included HealthInsight's Patient and Family Advisory Council, the Center for Clinical and Translation Science Community (CCTS) engagement core at the University of Utah, and Intermountain Healthcare's corporate department of Patient and Clinical Engagement.

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This diverse PCORI Community Stakeholder Subcommittee designed the event with the aim of developing a community network to connect researchers with the community and promote sustainable engagement in PCOR. In addition, we hoped to identify PCOR questions of importance to Utah stakeholders and patients, anticipating that researchers would adopt these as interest areas align.

The group developed the following Aims and Objectives:

Aims

- Aim 1: Disseminate PCO awareness and improve understanding of the value of integrating PCOR in the health care community from the patient, provider, payer and community perspectives.

- Aim 2: Identify and prioritize questions related to PCO for Utah that are important to all stakeholders.

- Aim 3: Share best practices that facilitate patient engagement and increased identification and utilization of PCO.

Long-term Objectives

1. Identify a role for PCOR network (PCORnet) with Utah researchers

2. Create public domain connection site for researchers and patients

3. Obtain PCORI funding for research questions

4. Develop workgroups/guideline development teams for community engagement and research, including the development of a report and/or a roadmap for increasing PCO, PCOR for Utah communities

After receiving the EAIN award, the UPV representatives recognized alignment of this meeting with the Annual Health Services Research (HSR) meeting and planning began alongside this existing event. Representatives of the key stakeholder groups met monthly from September 2015 to March 2016 and co-designed the meeting, developed breakout sessions led by stakeholders and ensured all sessions were co-led with a patient. From the HSR planning arm, traditional research abstracts were requested and patient-centered topics, design and PCOR were stressed. Keynotes and plenaries were co-designed for all participants. Media and communications materials were intended to be in lay-language as much as possible.

On Tuesday March 15, 2016 at the University of Utah's Health Sciences Education Building, 130 community members, patients, researchers, health care providers, students, policymakers and caregivers convened for the 11th Annual HSR Meeting, hosted by Intermountain Healthcare Institute for Health Care Leadership and the University of Utah's CCTS. The title was **Partnering for Better Health: Bringing Utah's Patient Voices to Research**. Event details and full agenda can be found in Appendix A.

Section 2: Process Description

Community Collaboration

After the contract was awarded, the PCORI Community Stakeholder Subcommittee of the UPV met monthly beginning in fall 2015 to develop the framework and agenda for the March 2016 event, including content for breakout sessions and alignment with the HSR organizers.

Members of the event committee were chosen for their experience in accessing and building relationships with diverse members of the Utah community, including an array of patients, caregivers, community members, students and researchers. Five members of this committee committed to facilitating breakout sessions during the March 2016 event. Attendance was excellent for all partners, as well as plenary speakers.

Aims, long-term objectives and outcomes were established prior to the formation of the event steering meetings, allowing monthly meetings to focus on content and creating a model of encouraging dialogue between attendees at the event. HealthInsight led educational training sessions to breakout session facilitators on the Powerful Cycle Model [vii] and how to adapt this model to meet the needs of patients and researchers at the conference by encouraging patient participation, as well as a format that allows for discussion. During discussion on the value of the Powerful Cycle Model, stakeholder leaders were encouraged to identify panel participants and develop three key questions for their sessions.

The Subcommittee was also in charge of ensuring community access to the event, designing and extending engaging invitations, ensuring media coverage of the event, covering transportation, ensuring translation if needed, and making this traditional event accessible and inviting for non-academic attendees. The depth of experience of the community partners in convening their communities greatly assisted in the design of the registration and event materials (see Appendices for copies of media).

Identifying panel participants proved difficult for some of the stakeholder leaders. The group identified a need to increase compensation for patient and community member participants in order to secure their time and focus. The budget was revised to allow for patient and community member panelists to receive $100 each, in addition to planned coverage of parking and transportation costs. Stakeholders were compensated $1,500 each for developing their breakout session, recruiting panelists and participants, and facilitating their session at the event.

Partners demonstrated variability in adapting the Powerful Cycle Model. Some had difficulty developing discussion questions and preferred informative questions for their panelists. Key outcomes of the breakout sessions were to identify research questions, priority health areas and ideas for following-up in the community. These sessions relied on facilitators engaging the audience in dialogue to generate research questions.

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Through detailed collaboration with HSR Meeting organizers, the agenda was crafted to include two keynote addresses for all attendees followed by six, hour-long breakout sessions that each repeated twice throughout the day, and culminated in a plenary panel and wrap-up discussion. Of the six breakout sessions, three were hosted by PCORI Community Stakeholder Subcommittee members and three were led by HSR researchers.

The main lobby of the conference showcased PCORI and health services research posters from the University of Utah. Although invitations had been extended to community organizations to share their PCO-related initiatives, we were not successful in soliciting community-based organizational posters.

Key Successes and Challenges of Working Together	
Successes	**Challenges**
• Broad attendee population of both patients and researchers	• Complexity of communicating guidelines and expectations across six breakout presenters
• Multiple organization involvement led to widespread marketing and media coverage	• Difficult to get researchers and patients to talk to each other
• Diversity in subject matter experts from various community organizations led to a broad spectrum of breakout session topics	• Difficult to get patients into research-focused breakouts and researchers into patient-focused breakouts
• HSR relationships secured globally recognized keynote speaker	• Insufficient amount of coordination between conference organizers due to lack of pre-planned meetings
• HSR's combination of pre-established audience and aligned goals of patient centeredness proved to be the perfect venue to add community member perspectives	• Difficulty in promoting community posters for presentation • Difficulty in getting research content into lay language

The morning plenary session began with a presentation from Dr. Victor Montori, Mayo Clinic Community engagement director. Although it was largely medically focused and not tailored to a lay audience, Dr. Montori was engaging and his discussion of patient-centered shared decision-making tools shared both PCOR-style research and implementation, and told stories of the reasons for this kind of research.

The second keynote address provided a direct report on current PCORI research in Utah addressing childhood asthma management through parental involvement and monitoring. The presentation shared the perspectives and experiences of principal investigator, Dr. Flory Nkoy of the University of Utah, parent advisor Jordan Gaddis, and community pediatrician and research collaborator, Dr. Joseph Johnson. This session both shared direct PCOR outcomes generated in Utah, as well as demonstrated the opportunity of participation. This session was well received and Gaddis' presentation showed patient engagement and benefit to a high level.

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Each breakout note-taker had been coached on what to listen for including health topics of priority to the community, potential research questions and key learnings from the discussion. Each note-taker was also provided a standardized note-taking template and was charged with keeping track of time during each session. These themes and other notes from the sessions are captured in the Appendix B.

Breakout sessions were all successful in engaging their audiences, and the intimate breakout settings allowed for discussion of issues and solicitation of topics. However, most researcher attendees attended research-oriented breakouts and most community members and patients attended community-oriented breakouts. The research-led breakout sessions had not been tailored to a lay audience. Fortunately, in some breakouts the discussants were sensitive and translated their results and lingo for a mixed audience. The community led events were accessible to all. Notably, the session led by Community Faces of Utah (CFU) members ensured an open discussion format and allowed community representative leaders from CFU to facilitate the breakout sessions using key questions. They broke into small groups for discussion then reported back to incorporate and capture best ideas. This format allowed for research participants to ask direct questions to community partners. Feedback was positive from all attendees of this session and organizers feel this format should be replicated.

The final plenary included a panel discussion on PCOR experiences from provider, health delivery system and researcher perspectives; we received feedback that there was not an actual patient on this panel. After the panel, breakout session facilitators, using note-taker content, shared summaries, ideas and future direction of their session to the audience. Feedback was positive in this session as we had a glimpse of the content shared throughout the day and were able to formulate some next steps. Although the audience waned at the end of the day, the reported content of breakouts was valuable and spurred discussion. Positive evaluation responses from the attendees show that this was a highly valuable session.

Section 3: Event Metrics

Metrics collected around the event have been important to defining our audience and seeing gaps in what community members have been able to participate. They also demonstrate some awareness of PCOR in our community, significant interest in future participation and qualitative remarks elicit the value of the event for some participants. We were also able to define clinical topics of interest of attendees. Limitations in identification of survey respondents due to constraints with technology effected the interpretation of the impact of the event on PCOR awareness and incomplete return of surveys from all event attendees.

Represented Organizations	
Research and Health Care	**Patient and Community**
ARUP Laboratories	Alliance Community Services
Granger Medical Clinic	Alzheimer's Association

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Represented Organizations	
Health Catalyst	Association for Utah Community Health
HealthInsight	Calvary Baptist Church
Iasis Healthcare	Catholic Community Services
Intermountain Healthcare	Hispanic Health Task Force
PCORI	Interfaith Roundtable
Roseman University	National Tongan American Society
University of Utah	Rare and Undiagnosed Network
Utah Department of Health	Susan G Komen, Utah
Utah Health Information Network	The Cholangiocarcinoma Foundation
Utah Medical Association	Utah Health Policy Project

There were 138 individuals registered for the conference with 130 total in attendance (94%). Please see the charts below for a breakdown on demographics and organizations represented at the conference.
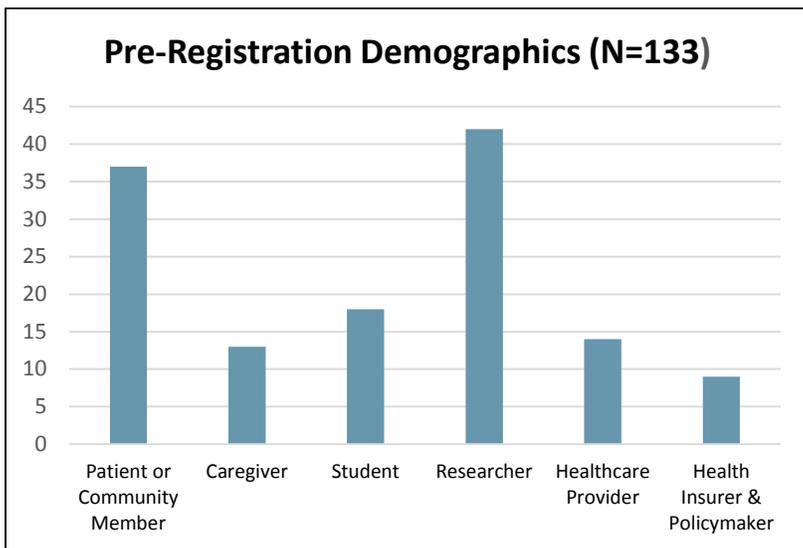

Pre-Survey Data

Upon registration, individuals were asked to complete a pre-survey to assess baseline familiarity with PCOR, current and previous involvement in health-related research in Utah, and likeliness of participating in PCOR in the future as a researcher or patient advisor. As shown in the charts below, the majority of attendees (83%) had some familiarity or were extremely familiar with PCOR prior to attending the conference. The chart on the right displays who was involved, and it is evident that although the research community is experienced in this type of research, patients and community members were still lacking in PCOR awareness.

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Registrants were also asked to write open-ended responses on the pre-survey describing their reason for attending this type of event. Please see the graph below for a selection of responses.

Current and Previous Experience in Health Research in Utah

Baseline Familiarity with PCOR
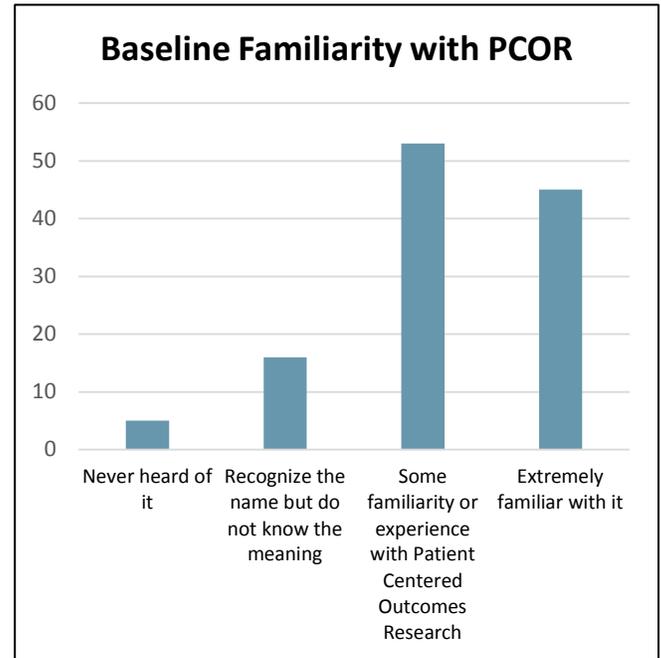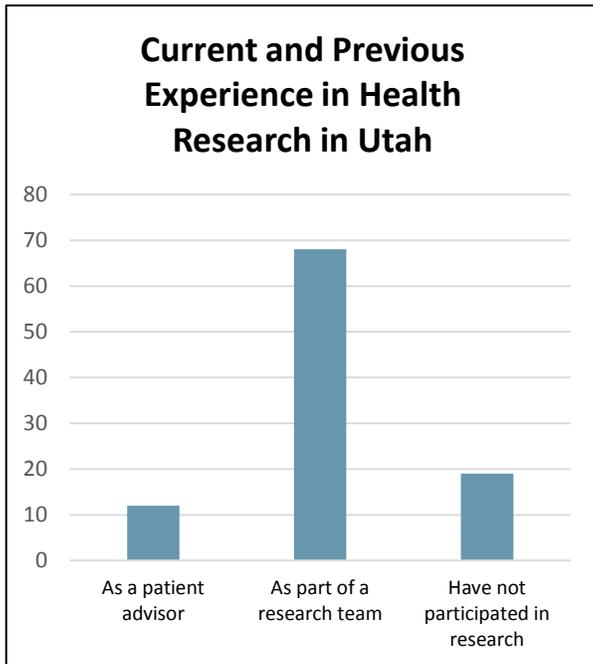
| Why are you attending this event? What makes it special for you? |
|---|
| • I am a parent stakeholder on a PCORI grant |
| • To learn more about PCORI research |
| • To learn more about the Utah PCOR community |
| • Empowering patients, especially the underrepresented, is one my main career goals |
| • Networking opportunity |
| • I am involved with a PCORI grant that is patient centered and have applied to other grants that are patient centered as well |
| • Very interested in health care outcomes for patients and transforming care to be more patient-focused |
| • Interested in getting a better understanding of health services research being conducted locally |
| • Interest in active patient participation in improving health care systems and communication with health care professionals |
| • Relates to our mission to promote value-based care in the Utah Geriatrics Society |
| • To represent physicians, it's an important topic to them and myself |

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Researchers and community organizations were asked to submit posters representing current health research and community health initiatives, 12 posters were selected to be displayed at the conference from researchers. There were no poster submissions from community organizations, possibly because the format was unfamiliar for sharing projects or due to a lack of sufficient advertising efforts within community networks.

Post-Survey Data

Post-survey data were collected from 75 attendees at the event. Parking vouchers and an iPad prize drawing were incentives for participants to return their surveys. Below is a representation of attendees who stayed until the final session. Although researchers were the most represented, community representation remained high, indicating that both populations feel PCOR is an important topic in the community.

Post-Survey Demographics (N=75)
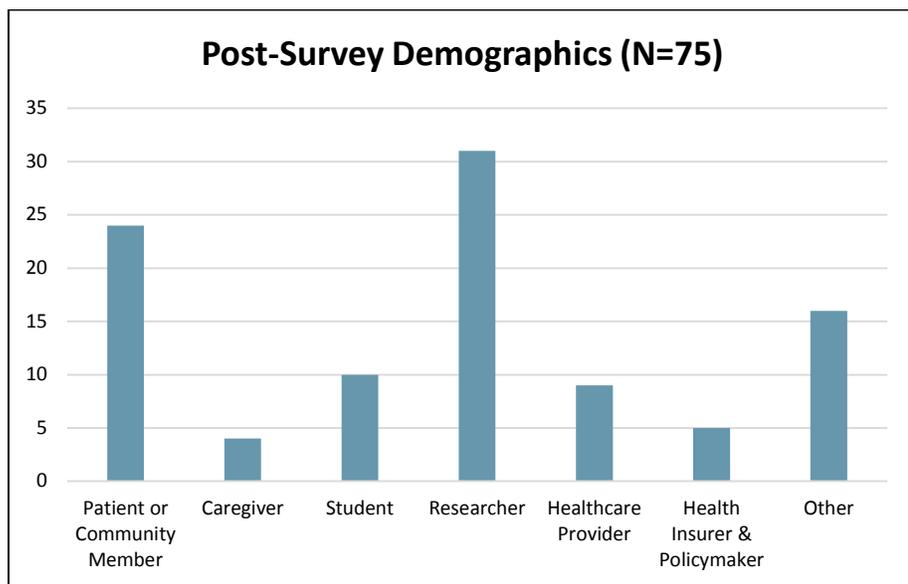
Attendees were surveyed to determine which breakout session they had attended, change in level of familiarity with PCOR after attending and likelihood of participating in research after attending. Although the post-surveys were anonymous and unable to be matched to those who completed pre-surveys, conference organizers were pleased with the overall responses. It was especially satisfying
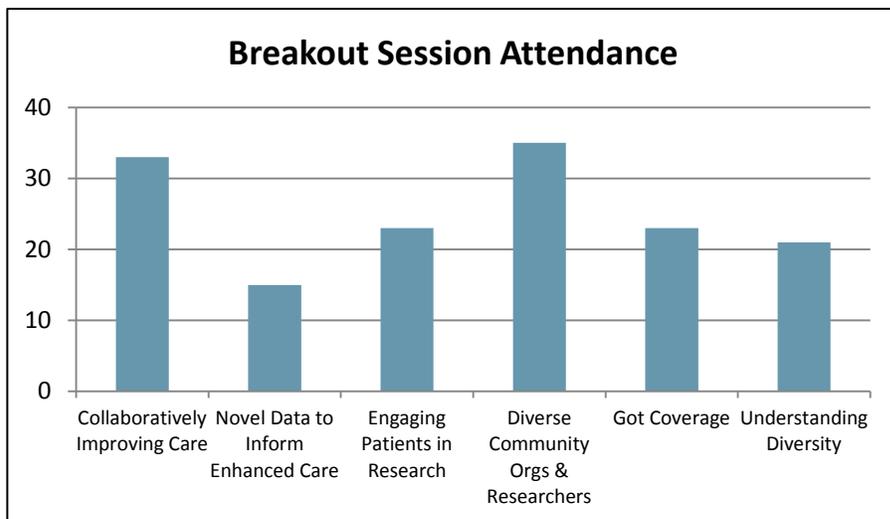
Breakout Session Attendance

to find there was fairly even representation across each breakout session, indicating that breakout topics were pertinent and interesting to attendees of all backgrounds.

The number of attendees that completed the post-event survey who were extremely familiar with PCOR decreased. We speculate that survey respondents were more likely to be non-research attendees as they would be most enticed with the incentives. We also observed campus-based researchers were more likely to come and go from the event as their offices or classrooms were nearby, and we may not have captured their responses. We were thrilled with the interest in participating in PCOR from both patient and researcher sides.

Post-Survey Familiarity with PCOR
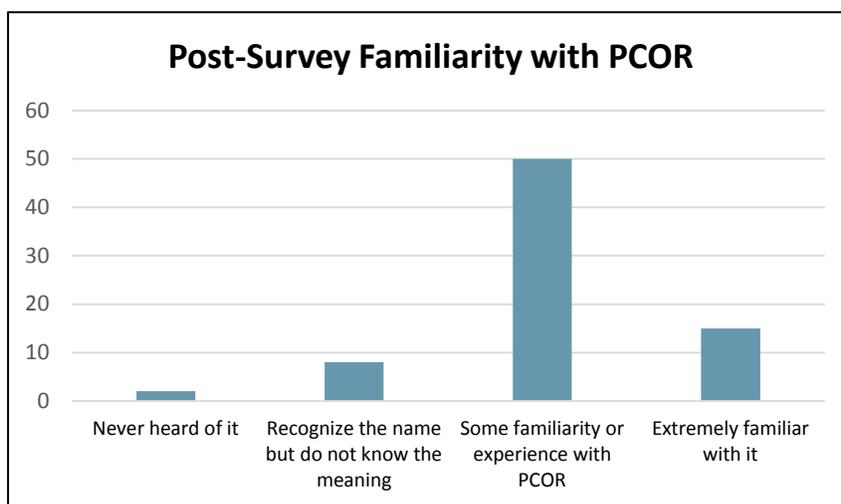
Additionally, 53 attendees expressed interest in staying involved in PCOR opportunities and developments in the community, 15 percent were researchers who wanted to stay in touch with patients interested in being advisors or participants and 66 percent want to continue learning about PCOR in Utah through email and invitations to future meetings regardless of their demographic.
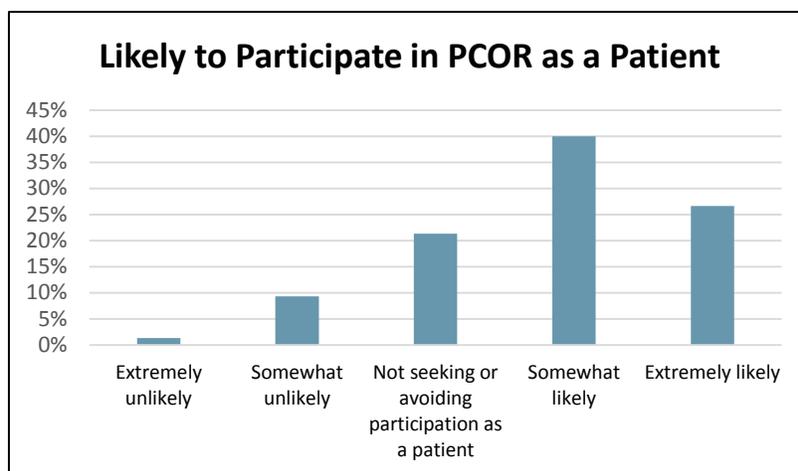
Likely to Participate in PCOR as a Patient

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Likely to Participate in PCOR as a Researcher
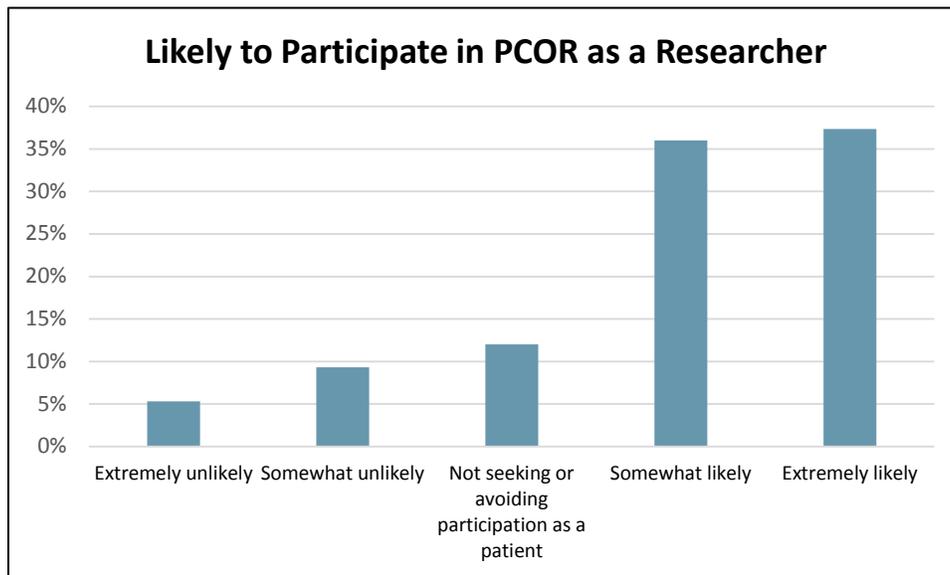
We also collected open-ended responses on what participants will do differently after attending this event. Below are selected responses.

Insights from the Audience: What will you do differently after today's event?
Make a goal of involving patients in research design
Treat education as a conversation
Today's event will help direct the training of community health workers in my organization
Think more carefully what my mom wants before what I think she needs, and make sure she has both
Encourage researchers in the college of nursing to engage in community based/patient centered research
Engage stakeholders earlier, use CCTS resources
Review medications carefully with patients using interpreters
Consider patient outcomes and patient engagement in my study planning and grant applications
Seek out support group for my chronic condition and re-address long-term health plan with my physician

Health priority topics were also collected from breakout sessions to determine what needs are important to the community and should be addressed in future research. Below are the top 20 collected topics, the full list is available in Appendix C.

Top 20 Participant-Generated Research Priorities (Based on Frequency)
Cancer-- breast, rare cancers (11)
Chronic disease prevention, support and pragmatic trials (11)

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Top 20 Participant-Generated Research Priorities (Based on Frequency)
Diabetes and diabetes management (10)
Preventive health, education and health literacy (7)
Women's health, maternal and infant health (6)
Pediatric health and children with special needs (6)
Improving patient/provider communication (5)
Asthma (4)
Health disparities and access (4)
Behavioral/mental health (3)
End of life care (3)
Hypertension, obesity and physical activity (3)
Palliative care for all age groups (3)
Managing chronic and complex diseases (3)
Geriatric health (3)
Health information exchange (3)
Coordinated care transitions and management (3)
Patient engagement and shared decision-making (3)
Social determinants of health (2)
Adolescent health (2)

Posters

Researchers and community organizations were asked to submit posters representing current health research and community health initiatives - 12 posters from researchers were selected to be displayed at the conference. There were no poster submissions from community organizations, possibly because the format was unfamiliar for sharing projects or due to a lack of sufficient advertising efforts within community networks.

Media and Marketing

The PCORI Community Stakeholder Subcommittee desired public coverage of the event that included highlights of the PCOR research being done in Utah and improved awareness of this opportunity to forward better community health.

Marketing efforts prior to the conference were advertised on social media networks including Facebook, Twitter, and organization email list serves and newsletters. Over 70 Twitter mentions, shares and retweets were posted using the Twitter hashtag #PBHutah2016.

Media coverage included a news article in the Deseret News by Daphne Chen entitled, Patient-first Approach Leads to New Tool for Asthma, as well as a TV story by Heather Simonsen on KSL NEWS featuring parent advisors on a PCORI research team who are collaborating with researchers to improve asthma monitoring in children. The news article and TV clip can be found in Appendix D. In the weeks following the conference there were 1,173 slide views and 22 downloads from the 14 slide decks uploaded to the conference website, and a community event report that was disseminated to all attendees and organizations involved. This report can be found in Appendix E.

Section 4: Outcomes

The event, as well as the stakeholder engagement process in developing the meeting, has produced ideas, topics and suggestions for improved processes. Notes taken from all sessions (see Appendix B) were compiled and then reviewed with the stakeholder facilitators individually as well as in a de-brief meeting following the event. Outcomes include prioritized themes from the steering committee and general feedback on the event from our planning group. This content informs our next steps as a sub-committee.

Breakout Session Summaries, Key Points and Takeaways

Key Themes and Outcomes from the Breakout Sessions
• Meet communities face to face; relationship building takes time
• Bi-directional partnerships work, find the value to the community first as you build, develop the research question with them before you apply for the grant
• Develop research questions and plan interventions together, and develop research protocols together
• A community that partners with the researcher changes
• Researchers change their perspectives as they become more flexible and ensure the community needs are met
• There is larger impact when we involve community, we involve their families and friends, children
• Time and funding are barriers to this work, how do we work with that?
• Budget for translation in this work
• Cultural differences in general for all cultures and communities need to be addressed, acknowledged, more thank language it is culture that has to translate

Key Themes and Outcomes from the Breakout Sessions
• Importance of patients meeting and having support from patients with the same issues and social support. Expectations of care can improve when less advantaged patients hear from peers about what they can expect from the medical system.
• Is there a co-existence of spiritual and cultural factors in health care and is it recognized? (Question from the audience and suggestion that this is a difficult area)
• Community health workers are an opportunity to impact these areas
• Spiritual leaders are powerful allies to health messages
• Use a community board as an idea generator
• Advertise the CCTS "studio" approach for researchers and patients to have facilitated assistance to develop research ideas, materials, media, etc.
• Consider steps around: How do I engage stakeholders? How do I determine patient centered outcomes? How do I work long term on this? We need a "How to"
• Outcomes need to be relevant to the folks you are researching- must give value back to them

General feedback on the event

Event Feedback from Stakeholders
• Hard to get to the building we chose for the community
• Need better times for stakeholder, community attendees
• No patient was included in the final panel
• Dry run was helpful
• Liked the opening talk, engaged all sectors, inspiring
• Work to ensure lay-friendly language in all sessions and description
• Faith-topics are untapped
• We need to piggy back on existing priority topics from other well-funded or well-positioned groups (Utah Hospital Association focus on obesity, prevention, community benefit work of Intermountain re opioid safety, pre-diabetes and support for behavioral wellness)

Section 5: Next Steps

The next steps for this coalition include reaching out for continued support through PCORI EAIN, integration of ideas into planning for the next HSR meeting, and integration of anticipated work into upcoming grant applications with the CCTS with explicit interest in developing both research and community groups to engage meaningfully with one another. At the HSR, we will have more community presenters speak to their

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experiences and successes as partners in research. Additionally, we will recruit one to two additional communities to participate in planning, and communities will be sought for their alignment and interest in generating health topics. Finally, website development will start with framing a profile application for community groups and researchers, and developing the architecture for the page. We anticipate future funding and hope for a go-live with the website in the next year.

Defined steps:

1. The PCORI Community Stakeholder Subcommittee will co-develop the content and structure of the 2017 HSR Annual Meeting with Dr. Lucy Savitz. We will ensure PCORI researchers are highlighted, engage patient presenters on their experiences and continue to ensure the meeting is inviting to community stakeholders through lay-language in our materials. We will advertise to our partner stakeholders. We will align our operations be a patients-included approved meeting.

2. The Utah Center for Clinical and Translational Science (CCTS) will hold a live Community/Patient Engagement Studio as part of the 2017 HSR conference to demonstrate their capacity to support PCOR collaboration. The studio is an ongoing resource supported by the CCTS. Studios provide a structured setting for researchers to enhance their research projects through learning from community experts, and offer an efficient way for researchers to gain community input or perspective on a project from the informed consent process, appropriate incentives and recruitment materials, methods to engage participants, retaining participation in research, sharing results with communities, or culturally appropriate recruitment and materials. The CCTS recruits consultants that are experts in their community's culture, literacy levels, translation needs, history and past experiences with research. They also support a stipend and food for the consultants. We will live tape the Studio experience for future reference and sharing of the engagement opportunity provided.

3. Pending funding support, which is being solicited from multiple sources, the CFU in partnership with the CCTS, will develop two workshops for presentation with companion guidebooks for reference and future engagement. One workshop will be researcher focused and occur at the 2017 HSR meeting. The other will occur in community settings in 2018 and will develop community organizational skills to partner in meaningful research. They will each be four-hour interactive, hands-on workshops co-developed with the CFU communities.

    a. Each event will include a workbook for participant design of their future engagement. The community engagement workshops will have two presentations in order to refine the product real-time. The focus will be practical, "how-to" guidance for researchers to collaborate with communities (particularly diverse communities) on community-based participatory research

projects, and involving communities and community members in other types of projects on the spectrum of community/patient involvement. CFU and CCTS will use a collaborative model with their community leads to develop all material and will use iterative approaches and significant consumer input into all activities.

b. Topics will include making initial contact, first meetings with individuals, holding meetings with a group, collaborative development of a research project, collaborating on a researcher-initiated research project and throughout the life of a project, addressing challenges, including payment and power equity.

c. For community members/patients potential topics include basics on research designs and methods, human subjects' protections, identifying community needs and interests, questions to ask when researchers approach you about a project and/or collaboration, and negotiating a collaborative research project.

4. To facilitate collaboration between interested, trained communities and researchers we will launch a user-friendly on-line "match-making" platform built with stakeholder and community input. The site will connect researchers and communities according to health topic and promote patient and community engagement in PCOR. We will seek input at the 2017 HSR meeting from researchers and community groups and launch late in the initial year. Resources and researchers contacts will be sourced from partners including the Health System Innovation and Research (HSIR) program located within the University of Utah Health Care System, attendees of the annual HSR Meeting, and members of the Community Outreach and Collaboration Core (COCC) of the CCTS. These partners have extensive relationships with researchers throughout Utah and are committed to spreading awareness and value of PCOR/PCO. Community groups who participate in the community engagement workshops will be able to solicit researcher information and filter through health topics on this website to connect with appropriate researchers who meet the needs of their community. HealthInsight and its Patient and Family Advisory Council will engage existing community and patient groups to participate with the site as appropriate. We will not list individuals but will maintain organizational contacts to avoid privacy concern issues. We will evaluate the use and success of the site over the second year.

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[i] Morris ZS, Wooding S, and Grant J. "The answer is 17 years, what is the question: understanding time lags in translational research." *J R Soc Med.* 2011 Dec;104(12):510-20.

[ii] Westfall, J. M., Mold, J., & Fagnan, L. (2007). "Practice-based research – 'Blue Highways' on the NIH roadmap." *JAMA*, 297(4), p. 403

[iii] Committee on Quality of Health Care in America. Institute of Medicine. "Crossing the Quality Chasm: A New Health System for the 21st Century." *The National Academies Press.* 2001.

[iv] Godlee F. "Outcomes that matter to patients." *BMJ* 2012, 344:e318

[v] PCORI Research and Results. <http://www.pcori.org/research-results?combine=&tag=All&state=All&area=All&research=All&program=All&page=7&order=field_award_state&sort=asc>, Accessed March 17, 2015.

[vi] http://healthinsight.org/utah-partnership-for-value-driven-healthcare

[vii] Dennis Wagner., Krista Pedley. Spectacular Communications: Improving our National Message in Schools and Colleges of Pharmacy and Utilizing it in our Local Settings to Generate Leadership, Action, and Results." Health Resources and Services Administration Department of Health and Human Services. , p. 36.