11th Annual Health Services Research Conference
PARTNERING FOR BETTER HEALTH:
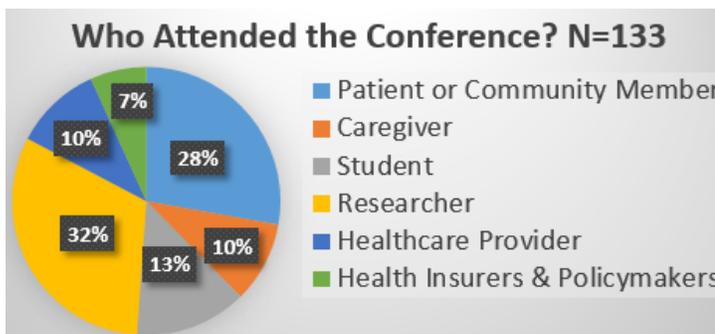### Bringing Utah's Patient Voices to Research

Event Overview

What if *YOUR* story shaped health research? For the first time ever, the Health Services Research (HSR) meeting joined forces with HealthInsight Utah and other community organizations bringing researchers and patients together to promote cross-collaboration and patient input on study design and outcomes. 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 Center for Clinical and Translational Science (CCTS). For the event details and the agenda, visit https://healthinsight.org/partnering-for-better-health.

Josie Stone hosts an interfaith panel on cultural health barriers

Who Attended the Conference? N=133

- Patient or Community Member — 28%
- Caregiver — 10%
- Student — 13%
- Researcher — 32%
- Healthcare Provider — 10%
- Health Insurers & Policymakers — 7%

Keynote speaker Dr. Victor Montori, Mayo Clinic community engagement director, captivated the audience with his dynamic presentation on the need for precision medicine and minimally-disruptive care. He advocated for providers and patients to work better as a team to deliver care that is careful, kind and promotes solidarity in our society. The second address, a research presentation on improving childhood asthma through parent, provider and researcher collaboration, was led by Dr. Flory Nkoy of the University of Utah, parent caregiver Jordan Gaddis and community pediatrician, Dr. Joseph Johnson. Their fascinating experience piloting an asthma e-tracker for children demonstrates the significant care management outcomes that are achievable when parents and researchers work together.

Following the keynote presentations were breakout sessions from research and community perspectives and a poster stroll highlighting current health services and patient centered outcomes (PCO) research. The day culminated with the audience re-grouping for a plenary panel discussion on PCO research experiences from patients, providers and researchers.

Insights from the Audience: What will you do differently after today?

- **Make a goal of involving patients in research design!**
- **Treat education as a conversation.**
- **Help direct the training of community health workers in my organization.**
- **Think more carefully about what 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 Center for Clinical and Translational Science (CCTS) resources more.**
- **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**.

The University of Utah — Center for Clinical and Translational Science, Health Services Research Conference

HealthInsight UTAH

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UHPP Utah Health Policy Project

Salt Lake Interfaith Roundtable

Intermountain Healthcare

Community breakout sessions were hosted by Jason Stevenson of the Utah Health Policy Project, Josie Stone of the Salt Lake Interfaith Roundtable, and Heather Coulter and a team of her community member and researcher volunteers from Community Faces of Utah (see photo at left). These sessions captured health needs and barriers diverse patients face when navigating the health care system in personalized discussions, and ways to collaborate with researchers to overcome these barriers.

Community Faces of Utah experts help bring patients and researchers together.

Event Results

- Of 138 registrants, 130 attended (94%)
- 1,173 slide views & 22 downloads of conference material from http://hsrconference.weebly.com/
- 53 attendees interested in staying involved in PCOR
- Over 70 Twitter mentions, shares, and retweets using the hashtag #PBHutah2016
- 12 posters presentations

Important Themes Identified

- Universally, patients want to be more involved and in control of their health-- patient involvement is key in the iterative research process
- Patients want honest information about the severity of their disease
- Community emphasis on education and health literacy training for patients and providers to improve bi-directional communication and trust
- Need for improved cultural competency and spiritual/dietary support in in-patient settings
- Need for a societal shift to provide individualized care, address community health priorities, and use patient advisors to guide research

Next Steps

Community consensus is to continue pursuing PCOR collaboration opportunities. The 2017 HSR meeting will feature a live studio session to provide consumer feedback to researchers and offer provider workshops on rapid implementation of PCOR in their practices, community partners will develop engagement workshops and guidebooks for researchers and communities, and partners will develop an online platform to connect researches and communities in Utah.

Top 20 Participant-Generated Research Priorities (Based on Frequency)

1. Cancer-- breast, rare cancers (11)
2. Chronic disease prevention, support and pragmatic trials (11)
3. Diabetes and diabetes management (10)
4. Preventive health, education and health literacy (7)
5. Women's health, maternal and infant health (6)
6. Pediatric health and children with special needs (6)
7. Improving patient/provider communication (5)
8. Asthma (4)
9. Health disparities and access (4)
10. Behavioral/mental health (3)
11. End of life care (3)
12. Hypertension, obesity and physical activity (3)
13. Palliative care for all age groups (3)
14. Managing chronic and complex diseases (3)
15. Geriatric health (3)
16. Health information exchange (3)
17. Coordinated care transitions and management (3)
18. Patient engagement and shared decision-making (3)
19. Social determinants of health (2)
20. Adolescent health (2)

How likely is it you will participate in PCO research as a **Patient Advisor**

67%

How likely is it you will participate in PCO research as a **Researcher**

73%

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