



# End of Life Care: Are You Ready?

## Event Overview

On Monday April 4, 2016, more than 120 community members, health care providers, insurers, policymakers, patients and caregivers convened for the first ever End of Life Care Summit held at the University Park Marriott Hotel in Salt Lake City, Utah. This innovative conference was packed with interactive presentations, discussions, and panels that addressed advance care planning issues in Utah and encouraged community member input on planning conversations, policy change, and fostering alliances between patients and providers to improve patient satisfaction and documentation processes. Event details and presentations can be found at: <http://healthinsight.org/eol-summit#details>.



**Community stakeholders discuss advanced care planning in Utah**

## Highlights

Keynote speaker, Dr. Steven Pantilat of the University of San Francisco captivated the audience in his dynamic presentation on the effectiveness of palliative care in hospital settings and during end of life and how to improve patient-provider communication.

Following his presentation were two panels, one comprised of unique patient, provider, policymaker, payor, and caregiver voices and the other a vibrant mix of cultural and interfaith perspectives. Each panel revealed an array of experiences, successes, and challenges in managing Advance Care Planning, discussed solutions to streamline existing barriers, and addressed communication styles and preferences unique to diverse cultures.

The interfaith panel, facilitated by Josie Stone of the Salt Lake Interfaith Roundtable (<http://www.interfaithroundtable.org/>) also unpacked the complex relationship different communities have with health care providers and loved ones when planning for end of life care. Afternoon breakout sessions geared toward training providers and families to have end of life care conversations and providing a framework of community initiatives focused on advance care planning around the state.

The Conversation Project, led by Kathleen Pitcher Tobey of the Cambia Health Foundation, coached attendees through an interactive toolkit on how to talk to family members and loved ones about preferences during end of life care. The toolkit is free and downloadable at: <http://theconversationproject.org/>. The Serious Illness Conversation Guide, led by Dr. Anna Beck of Huntsman Cancer Institute, aims to train providers how to conduct productive, meaningful end of life care conversations with patients that lead to fulfillment of a patient's personal preferences, accurate documentation and address patient fears and concerns in a positive way. The community updates in advance care planning session highlighted a Provider Order for Life Sustaining Treatment (POLST) pilot project through collaboration between the Utah Health Information Network and Avalon Nursing Homes; an ethnodrama from the caregiver perspective by Dr. Jackie Eaton of the University of Utah; a research study investigating the burden caregivers face and ways to support them by Christie North of the University of Utah; and a summary of the national POLST and policy perspective by Dr. David Fedor of Intermountain Healthcare.



**The Interfaith Panel discussed how different religions and cultures handle death and end of life wishes differently.**



# End of Life Care: Are You Ready?

## Key Learning and Outcomes

Throughout the day, insights were shared and explored by the community regarding advance care planning issues and barriers faced by patients, families and providers. Below are a few key points from those discussions:

<ul style="list-style-type: none"><li>• End of Life agreements are too complex and clinical for patients, especially those from low socioeconomic populations.</li><li>• Confusion persists around what patients actually need for documenting end of life care wishes; e.g. differences between a secure trust, living will and advance directives.</li><li>• Patients are frustrated when providers beat around the bush- they want to know their diagnosis is terminal, even if it's a hard conversation to have.</li></ul>	<ul style="list-style-type: none"><li>• Talking about and preparing for death is taboo in many cultures, it helps when providers already know a patient's story and culture.</li><li>• Each culture has different people who make decisions (Hindu= blood relatives, not spouse), providers must navigate these issues carefully during EOL conversations.</li><li>• There is room for education in faith congregations and cultural community centers to increase end of life awareness.</li></ul>
--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Overall, the community felt there should be an emphasis on education and training for spiritual leaders, providers and community members on how to broach delicate end of life topics. Other priorities were to reform payment structures so providers can be compensated for taking time to discuss end of life care, implement a working electronic health record that is accessible across health systems, develop more comprehensive language support for non-native English speakers and continue building caregiver support networks.

## Evaluation Analysis and Next Steps

Of the 120 attendees, the majority were health care professionals including licensed social workers, clergy, insurance representatives, government workers and health care improvement personnel. When asked how familiar the audience was with The Conversation Project, Serious Illness Conversation Guide, and other conversation toolkits, 41.8 percent responded that although they may have heard of them, these tools had not been sought out or used in their life. Thirty-four percent never knew such tools existed, whereas 23 percent used tools like these to guide their or their patients' end of life care preferences. Interestingly, 84 percent of attendees said they want to use these toolkits in their life.

A little more than half (51%) of the attendees said they had some informal end of life care conversations and just needed to document their preferences, and about 60 percent had some familiarity with or were experienced using advance care planning documents. In the future, we hope to incorporate more training on where to find, how to use and how to upload appropriate end of life documents. Sixty-two percent of attendees were satisfied with the content of this conference and 67 percent said they would attend another, so next steps include sustaining end of life education in the community and making this an annual community conference.

## THANK YOU!

This successful event was co-designed and supported by the Utah Department of Health, Intermountain Healthcare, the Utah Commission on Aging, Utah Health Information Network, Huntsman Cancer Institute, Regence BlueCross BlueShield, the University of Utah and the Cambia Health Foundation.