



Session Title: Provider Tools Developed for Patients by Patients

Presenters: Jenna Burke, Randel Horton

Organization: HSAG

Windy Gaston : yes

Renee Petty : Patients

Mary Jones : Staff

Mimi Trinh : Our patients

Tousey Wilson : Family involvement

Jan Lambert : Patient experiences!

Sylvia Bell : Patient and Family voices

Lucilia Prates MA : Patient input.

Teresa Prouty : patients and families

Marie Scherb-Clift : patient caregivers

Margaret Blackwell : In our system the family is most underutilized.

Mark Witsoe : nutrition services

Charlene Setlow : Patients

Susie Becken : patients & family

Caryn Anthony : opportunities for feedback between providers and patients/families

Lindsay Holland to Kim Werkmeister / Cynosure Health(Privately) : Patients

James Sturtevant : Patient experience and suggestions for improvement

Steve Brown : Hearing from patients and clinicians in the field

Sharon Rose : Patients and families Sharon Rose

Deb Jordan to Kim Werkmeister / Cynosure Health(Privately) : realtime feedback from patients and families

Janice Juvrud : Integrating patients in their health care. Family involvement.

Caryn Anthony : more than just filling out a survey

Jacqueline Beaushaw : Listening to patient voices, asking patients what matters to them when it comes to their healthcare.

Caryn Anthony : authentic 2-way communication

James Sturtevant : Active Listening

Kathie Nichols : asking them for their goals and what matters most

Teresa Prouty : creating decision making tools such as ostomy and gtube

Lorna Tirman : Making changes based on patient feedback both verbal and written

Deb Jordan : asking patients what matters most, and listening

Meredith Koob : Using the patient voice in our Learning and Action events for healthcare providers and communities

Marie Scherb-Clift : not pushing problems onto another doctor

Jan Lambert : Seeking patient input from the beginning of any program, rather than getting responses on programs or tools developed by non patient groups.

Teresa Prouty : They need to be included in the beginning not the middle

Lucilia Prates MA : Make sure patients understand that they are the CEOs their bodies and that their voice is the most important.

Kim Werkmeister / Cynosure Health : These are all such important responses!

Janice Juvrud : author of your opening quote please. :)

Kim Werkmeister / Cynosure Health : Janice we will get that for you!

Janice Juvrud : Thank you, so I can google it.

Kim Werkmeister / Cynosure Health : If you have questions for Jenna and Randel, please feel free to type them into the chatbox. We want to be able to get all questions answered!

Janice Juvrud : How were goals and responsibilities determined for the PFAC?

Tousey Wilson : What was the data about achieving the goal of the Alcohol and Depression poster?

Kim Werkmeister / Cynosure Health : Great questions - keep them coming! I will make sure they are all answered at the end of the presentation.

Chrissie Jackura : I really like the opioid list... I have had many surgeries and was just handed the prescription with no options

James Sturtevant : Symptom management for chronic or acute disease.

Tousey Wilson : All care should be provided with palliative care guidelines.

Chrissie Jackura : pain relief and comfort

Caryn Anthony : I have heard wide range of experience that some think its giving up

Jacqueline Beaushaw : Palliative care is a focus on treating the symptoms of disease

Lorna Tirman : treatment with patient priorities at center of care

Deb Jordan : Palliative care is care for those living with a chronic illness focusing on the patients goals and wishes

Janice Juvrud : yes, many believe palliative care is the beginning of the end.

Tousey Wilson : Palliative care starts with asking what matters to the patient and what do they want to do with their precious life and time.

Caryn Anthony : the challenge is also that providers have uneven understanding about when/how palliative care is relevant

Janice Juvrud : Do you think there is a wide range of opinions even among providers?

Sharon Rose : How much are families/caregivers included in training like this for palliative/hospice care?

Stephen Hoy: When asked for the business case for PFCC, I say palliative and hospice care!

Tousey Wilson : Why wouldn't all care givers be doing this?

crystal morse : Can you put the link in chat?

Kim Werkmeister / Cynosure Health : Link to the home health video:
<https://www.youtube.com/watch?v=jh1jOnZ28Ds>. The slides will be available after the session, and the links for all videos are included :)

crystal morse : thank you

Jan Lambert : Impressive what you have accomplished! I am also on a PFAC for a QIN/QIO and have really enjoyed the opportunity to feel we are making valuable suggestions that are sought out and appreciated.

Marie Scherb-Clift : Caregivers are often not aware that Palliative care exists, I attempted my local hospitals monthly palliative care meetings, when the caregiver support group ended. I felt my mother qualified and they never qualified her, she ended up on Hospice for 18 months.

Kim Werkmeister / Cynosure Health : Marie you are right. The more we can educate each other, the better.

Lorna Tirman : helping all employees see waiting and anxiety from care through patients eyes

Tousey Wilson : Palliative care would become available to all patients, currently the few providers are overwhelmed

Mark Witsoe : Nutrition awareness for oncology patients. It is not one size fits all.

Mimi Trinh : 1. Education on advanced care planning... importance of having an advanced directive.

Charlene Setlow : Reading patient's body language as well as verbal.

James Sturtevant : Signage throughout the hospital/clinics from the patient's eyes. What works, what doesn't?

Deb Jordan : Understanding the challenges of accessing the system

Marie Scherb-Clift : Patients express inconsistent care with home health.

Teresa Prouty : families want to partner in their child's care

Sylvia Bell : Ease of access

Julia Slininger to Kim Werkmeister / Cynosure Health(Privately) : Care in the continuum, identifying person-centered goals, and helping them achieve them

Kathie Nichols : shared decision making

Meredith Koob : Being especially inclusive of racial and ethnic minority relevance

Mark Witsoe : The value of digital medical record keeping

Jacqueline Beaushaw : Too many to chose from but maybe getting feedback from patients about how to best make patients aware of services available to them.

Anderson : from a Nursing home perspective education to families for key topics

barbara davis : allow the doctor time to listen to patients talk about health related issues and not give body language that they are in a hurry or uninterested

Janice Juvrud : to support patients, explain the role of family support to the family members who are Designated Care Partners.

Teresa Prouty : reduce the amount of medical lingo used in speaking with families

Janice Juvrud : Yes!

Lorna Tirman : I really enjoyed the specific processes your PFAC worked on! Thank you for sharing

Mimi Trinh : How did you recruit your PFAC members and how many members do you have?

Janice Juvrud : author and quote read at the beginning, please. Thank you

barbara davis : what hospital is this?

barbara davis: s Randel Horton a poet.? There is a famous poet with this name?

Marie Scherb-Clift : some caregivers get a lot from the brief training they receive at the hospital, others walk away wondering who and how to actual perform the injections, catheter changes , because they watch and do not actual experience the treatment task.

Janice Juvrud : "Teach" caregivers how to support providers.

Mark Witsoe : Thank you both!