



Welcomed new members/observers

- Jonathan Stewart
- Robin Shapiro, Washington State Health Advocacy Association

To-do review

- Steve reached out to Sarah Kim about issues creating a patient psychological safety survey to measure impact of campaign and get baseline data including need for IRB and how to go about creating patient survey. Sara attended the meeting to discuss.
- Chris Cottingham contacted Caitlin Maloy, UW Health Sciences research librarian to do lit review on patient psychological safety issues below. If any of the workgroup members come across literature on the topics below please send it to Steve for distribution. This is in progress.
- What are the determinants of patient psychological safety?
- What influences patient psychological safety?
- What tools exist to measure patient psychological safety?
- Steve invited Robin Shapiro at HealthadvocateX (formally known as the Washington State Health Advocacy Association WASHAA) to attend our meeting and discussed getting their member feedback and engagement. Robin has joined the group.
- SCCA PFAC feedback was distributed.

Workplan Review

Group

- Workplan was updated to reflect focus on patient psychological safety.
 - Sarah Kim discussed how to measure our campaign to create to encourage patients to engage their healthcare team when risk/safety issues arise.
 - An IRB approval is most likely needed.
 - What to measure is tied to what question we are asking.
 - Questions drive the evaluation, what questions are we asking?
 - What creates barriers to prevent patients from speaking up? Examine dimensions of barrier that impede trust.
 - How much confidence do patients have to speak up?
 - What is needed to make it easier for patients to speak up on safety issues?
 - Need to segment patients to determine if demographics influence speaking up
 - Do patients trust the MD to speak up? Trust is considered an outcome measure.
 - Do we want to know if the patient's perspective on safety mirrors the institution's culture about patient safety?
 - Activation measure?
 - What differentiates activation from psychological safety? Are these different constructs?
 - Discussion on Activation.

The following has been added for clarification outside of meeting content:

Patient activation is defined as having the knowledge, skill, and confidence to manage one's health and health care... Patient engagement, on the other hand, is less well defined, but is often understood to be the activities and interventions that are used to support increased activation in patients and consumers....A growing body of research that quantifies patient activation indicates that it is a significant predictor of most health behaviors, many clinical indicators, and some costly service utilization such as emergency department use and hospitalizations...Source: Taking the Long View: How Well Do Patient Activation Scores Predict Outcomes Four Years Later? Medical Care Research

and Review, Volume: 72 issue: 3, page(s): 324-337. Activation articles attached.

- Look at facilitators and barriers to speaking up. Would you speak up again? What happened after patients speak up? Do interviews with people who spoke up. Some patients are just visitors in the world of healthcare, some are “dual citizens”. The Wounded Storyteller: Body, Illness, and Ethics by Arthur W. Frank
 - Do we have the band width to do a survey and what would we do with the data?
 - Maybe begin with a series of patient interviews.
 - Discussed issues around doing a survey.
 - Will interviewees need to be compensated?
 - Is there an existing tool?
 - Discussion on are we on track to our original workgroup goal?
 - The goal of the group was to provide tools to help patients speak up. We were going to ask 5 organizations if they were interested in a patient education tool to encourage patients to speak up and measure the impact of the tool on the patients who have used it vs. those who haven't.
 - Process measure – did they get the tool, were they able to use it, did they understand it
 - Outcome measure
 - Is there a tool to use?
 - Perhaps we still need to explore what tools are available. Sara offered to reach out to Kathy Mazor EdD, Professor, University of Massachusetts who has done work in patient experience.
 - We are still in a learning mode and need to investigate what and how to measure.
 - Consensus is that data would be valuable in determining what we need to do differently.
- SCCA PFAC feedback was discussed. Thank you Leila for providing this.
 - Group decided to reschedule Jan 1 meeting to Jan 8th.

Next steps

- Sara will reach out to Kathy Mazor EdD, Professor, University of Massachusetts about measuring patient experience and tools to empower patients to speak up.
- Robin and Jonathan will send articles/info on patient activation (see attached and below).
- Continue to research into concepts and tools availability.
- Steve to look for funding.
- Steve to reach out to Martin Hatlie who is doing related work in use of patient tools in improving diagnoses.
- Present the project to your PFAC's in January to get their feedback and discover implementation issues. The goal is to understand what the most effective approach is to empower patients to speak up and determine the key issues of risk/safety to focus on. Is it preferable to have a multitude of tools to narrow the focus? This feedback will help drive the development of the tool in each organization. - Group

Activation information and articles:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1361049/>

<https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2012.1061>

<https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-019-8025-1>

<https://www.the-hospitalist.org/hospitalist/article/126322/patient-activation-measure-tool-helps-patients-avoid-hospital>

Book mentioned by Jonathan:

The Wounded Storyteller: Body, Illness, and Ethics by Arthur W. Frank
<https://press.uchicago.edu/ucp/books/book/chicago/W/bo14674212.html>

Since it was first published in 1995, *The Wounded Storyteller* has occupied a unique place in the body of work on illness. Both the collective portrait of a so-called “remission society” of those who suffer from some type of illness or disability and a cogent analysis of their stories within a larger framework of narrative theory, Arthur W. Frank’s book has reached a large and diverse readership including the ill, medical professionals, and scholars of literary theory.

Drawing on the work of authors such as Oliver Sacks, Anatole Broyard, Norman Cousins, and Audre Lorde, as well as from people he met during the years he spent among different illness groups, Frank recounts a stirring collection of illness stories, ranging from the well-known—Gilda Radner’s battle with ovarian cancer—to the private testimonials of people with cancer, chronic fatigue syndrome, and disabilities. Their stories are more than accounts of personal suffering: they abound with moral choices and point to a social ethic.

In this new edition Frank adds a preface describing the personal and cultural times when the first edition was written. His new afterword extends the book’s argument significantly, writing about storytelling and experience, other modes of illness narration, and a version of hope that is both realistic and aspirational. Reflecting on both his own life during the creation of the first edition and the conclusions of the book itself, Frank reminds us of the power of storytelling as way to understanding our own suffering.