Session: Lasting Lessons about Measuring What Matters
Presenters: Stephen Hoy, Alexis Malfesi
Organization: PFCCpartners/Discern Health

Danny van Leeuwen, Health Hats, steps per day, hours playing sax per week
Alexis Malfesi, Discern Health, hours of sleep!
Ellen Schultz, AIR, how long it's been since I last needed my inhaler.
Adriana Rodriguez UCLA Health, Workouts per week
risa hayes, Denver CO, Telligen (QIN-QIO). What is important to me? feeling fit, mobile, healthy.
Rita Goshert, Director Child LIfe program Miller Children's & Women's Hospital Long Beach. Patient and family satisfaction especially with regards to responsiveness of the healthcare team
Hi I am Jan Singer. I am a retiree from MA Health Quality Partners and am now on its Consumer Health Council, Most important to me is am I listened to and is what I say respected.
Melissa Doyle: Beth Israel Deaconess Medical Center, Boston, MA. Running pain free!
Hi! Brittany here from Carson Valley Medical Center in Nevada and meditation and using breathing techniques.
Terri Savino: hello from Middlesex health, Middletown, Connecticut
Deb Jordan Western Maine Health (Mehealth) - a measure that matters most to me is having a partnership with my provider as I prioritize my focus on wellness and prevention.
Bill Adams Being listened to and putting me at the center of my care.
Hi Libby Airhart Lafayette, Louisiana from CFC Syndrome
hello. Ellen Barnett from the Imagine You project training providers to ask What Matters to You and other topics
Danny van Leeuwen: What about community health measurement?
Kim Werkmeister: personalization
Ellen Barnett: ask the patient
Danny van Leeuwen: CommunityHealth
Ellen Schultz: Patients!
Roger Lacoy: Trust
Julia Suvak: Clinical accountability
Janice Singer: inclusion
Julia Suvak: Nurse buy in
Erica Steed: unbias-input
Deb Jordan: Comunication
Risa Hayes: activation
naomi williams: bias
naomi williams: food security
Janice Juvrud: Keep human connection/perspective/experience foremost.
Julia Suvak: Can you define payers
Kim Werkmeister: How do others in the group find ways to compensate PFA members that partner with you? Or as PFA members, in what ways have you been compensated for partnering with health care organizations?
Bill Adams: Patients are often the only people at the table who aren't being paid to be there.

Alexis Malfesi: @ Julia - A Payer is a company that pays for medical services (e.g., insurance companies). Medicare is a payer.

Danny van Leeuwen: We the people are the payers - taxpayers and employees. Insurance companies are brokers

Joe Connell: In some situations, there would be no PFAs at the table if compensation was an expectation.

Erica Steed: And when nothing is done with the data the community/pts lose trust in the system.

Risa Hayes: @Stephen - glad you included this. Itâ€™s important and I love what you put in chat yesterday and just repeated.

naomi williams: people don't care how much you know until they know how much you care. Actions speak much louder than words

naomi williams: how do you translate and make lived experiences valuable to those only looking at numbers?

Roger Lacoy: We need to make sure agencys aren't putting PFCs on the back burner in the name of covid safety.

Ellen Barnett: Stories have a huge impact. What about just saying outloud in the meeting that you are probably the only one not on paid time right then. Just building awareness

Joe Connell: Like the "exnovate" concept!!

Ellen Barnett: Could you comment on your perspective of how PCORI might have shifted the landscape on outcomes that matter.

Jan Lambert: Our Comagine PFAC, in conjunction with the University of Utah and the efforts of Dr. Sara Woolsey, received a PCORI grant to develop a manual to help PFACs engage with researchers for measures development.

Ellen Schultz: @Jan I'd love to learn more about that PCORI grant - will touch base with you offline.

Ellen Barnett: Me too Interested in the idea of a manual for research work.

Janice Juvrud: Have patients and families been asked, conversations had with them to determine what should be measured?

Ellen Barnett: We have been working with folks regarding their own definition of what matters most to them. Then just asking if those items are better as they move through their health care.

Joe Connell: Compassion measures.

Risa Hayes: completely agree!

Marci Romero: Jan Lambert - I also would love to learn more about the grant.

Lindsay Holland: Agreed as well!

Ellen Schultz: An important question someone asked me recently is: "Who are these measures meant to benefit? Who are the actually benefitting?" It feels like such a useful way to start any effort around measurement.

Kim Werkmeister: @Ellen these are GREAT set point questions to be asked when determining measures!

Roger Lacoy: I'm sorry I must leave, thank you all

Bill Adams: Measuring healthcare beyond the patient experience will be important to change. The lowninstitute.org evaluates hospitals not only on their patient outcomes but also their civic leadership and avoidance of overuse. https://lowninstitute.org/projects/lown-institute-hospitals-index/

Joe Connell: Trap: measurement for the sake of data without a clear purpose and utility?

Greg Merritt: Thanks for sharing this Bill-- yes this is how change can happen--- particularly if this has "consequences" or "incentives" to be #1

Alexis Malfesi: @Joe: Great point. "What gets measured gets managed." How do we get there? What gets measured gets managed

Alexis Malfesi: * a little too quick on sending that back :) I think that we get there with what Greg was talking about re: partnership and co-design from the very start

Ellen Schultz: There's more about the dialysis pilot project Stephen mentioned here: https://unckidneycenter.org/research/unc-dialysis-research/goal-directed-dialysis-care/

Greg Merritt: https://press.princeton.edu/books/paperback/9780691191911/the-tyranny-of-metrics Great book on traps... :)

Kim Werkmeister: Fantastic resource @Greg!

Ellen Barnett: Having started with the definition of a measurement - many things that patients care about, don't have measurements that meet the criteria

Jan Lambert: That is why patients need o be involved from the beginning of the measurement process.

Greg Merritt: Or calling it... careful and kind care for all? How might that be measured?

naomi williams: culture change is hard. how do we get the right people to be invested enough to speak up to require change

Greg Merritt: @ellen such great points! Great questions!

Kim Werkmeister: @Naomi good question. I think this goes back to the importance of storytelling. We need to connect to the heart of the people we are trying to engage in changing the culture.

Greg Merritt: Here's another "change" book--- https://jonahberger.com/books/the-catalyst/

Risa Hayes: @Kim - totally agree. And I think our obsession with numbers and measures puts story in the shadows and we need to pull those into the light and make those more important.

Jan Lambert: The recent PCORI conference had a great breakout session on patients partnering with researchers.

Ellen Schultz: This insight from Naomi is sticking with me: â€œpeople don't care how much you know until they know how much you care."

naomi williams: more work to connect storytelling with data measures

Joe Connell: What measurement is and what it is not.

Ellen Barnett: Want to connect with others.

Alexis Malfesi: My reminder - language matters! It's one thing we can all do, in everything that we do.

Bill Adams: Ask why we are measuring what is being measured.

Alexis Malfesi: Would love to connect with anyone - feel free to reach me at amalfesi@discernhealth.com

Deb Jordan: More a reinforcement of what I believe is that we will learn from our patients if we ask and if we listen to what they value and respond

Lindsay Holland: Great presentation! Thank you!

Janice Singer: How to measure things outside of researchers comfort zone

Deb Jordan: Thank you great presentation!

naomi williams: thank you !

Joe Connell: Thanks for the presentation.