

#PtEngagement Tools, Tips and Resources

This workbook is a collection of feedback provided through several Twitter threads, starting with #HowNotToDoPtEngagement, and then migrating to #HowToDoPtEngagement. To date, it represents the insights from **74 unique patient partners and advocate organizations** from within and outside Canada. I am deeply indebted to them sharing their thoughts, and for continuing this work.

Canada = 36; USA = 19; England = 8; Unknown = 5; Australia = 2; New Zealand = 1; Ireland = 1; Ghana = 1.

Last edited: Wednesday, March 21, 2018 by @brynphd

A special acknowledgement to @couragesings for starting these two important threads and for sharing numerous resources to facilitate good patient engagement in clinical care and research. In reviewing these comments, please remember their words: "Know there isn't a cookie cutter formula for engaging #pts. Always ask your #pt partners what works best for them."

Contributors:

Twitter Handle	Name	From	Website
@AbsPORU_PEP	Alberta SPOR SUPPORT Unit (PE platform)	Canada	http://www.aihealthsolutions.ca/initiatives-partnerships/spor/patient-engagement-platform/
@alexhaagaard	Alex Haagaard	Canada	https://in-visibleproject.tumblr.com/
@allyc375	Alison Cameron #FBPE	England	https://allywritesblog.wordpress.com
@AmandaBoldersto	Amanda Bolderston	Canada	https://doctoralbraindump.wordpress.com/
@AmandaRossWhite	Amanda Ross-White	Canada	
@amaybee	Alies Maybee	Canada	http://patientthinking.blogspot.ca/
@anetto	Annette McKinnon	Canada	http://yourgoldwatch.blogspot.ca/
@AureliaCotta	Aurelia Cotta	Canada	http://nomatterhowsmall.blogspot.ca/
@BantingJennifer	Jenn Banting	Canada	
@BCampbellDuke	Beth Campbell Duke	Canada	http://campbellduke.com/
@BCSUPPORTUnit	BC SPOR SUPPORT Unit	Canada	http://bcsupportunit.ca/
@BrianDonnaPenn1	Brian & Donna Penner	Canada	
@ChronicallyJess	Jessica Caron	USA	https://www.chronically-jess.com/
@CJadams80	Carl Adams	England	
@clockbirddesign	Clockwork Firebird	England	
@couragesings		Canada	https://www.redbubble.com/people/couragesings
@current_mike		Canada	https://macromichael.com/
@danamlewis	Dana Lewis	USA	
@DeborrahS	Deborah Sherman		
@dianapoulsen		Canada	https://dianapoulsen.wordpress.com/
@drifarrell	Liam Farrell	Ireland	https://drliamfarrell.wordpress.com/home/
@DrMWeiser	Margaret Weiser	Canada	
@esiobhanoneil	Siobhan O'Neil	England	
@fqure	Faisal Qureshi		https://fqure.github.io/
@GailBellissimo	G. Bellissimo	Canada	
@GenCounsNews	Leslie Ordal	Canada	
@GERONursing	Jennifer Baumbusch	Canada	https://nursing.ubc.ca/our-people?c=78.4601809837321
@gilmerHealthLaw	Erin Gilmer	USA	healthasahumanright.wordpress.com/about/
@graceCordovano	Grace Cordovano	USA	https://www.enlighteningresults.com/
@heartSisters	Carolyn Thomas	Canada	https://myheartsisters.org/
@hedy_wald	Hedy Wald	USA	
@HelenKaragio	Helen Karagiozakis	Australia	https://t.co/i85XKB07Di
@hwitteman	Holly Witteman	Canada	hollywitteman.ca
@janoldenburg	Jan Oldenburg	USA	janoldenburg.com
@JessHavens_	Jess Havens	Canada	
@Know_HG	Margaret O'Hara	England	pregnancysicknesssos.co.uk
@kristine_lemo			
@kylierpeacock	Kylie Peacock	Canada	
@leorapinhas	Pinhas Leora		
@lisafieldsms	Lisa Fields		
@maladorphelines	RQMorphelines	Canada	rgmo.org
@maritimespor	Maritime SPOR SUPPORT UNIT	Canada	http://www.spor-maritime-srap.ca/
@MaryOCMack	Mary MACK	USA	https://t.co/q6ViQRSfsw
@miShouldTalk	Amanda C. Itliong	USA	https://t.co/WhQXvrwPIT

@MMaxwellStroud	Max Stroud	USA	http://blog.galenhealthcare.com/2014/06/13/the-work/
@morgan_gleason	Morgan Gleason	USA	https://morgangleason.com/
@MortuaryReport	ace ratcliff	USA	https://www.stayweirdbekind.com/bio
@pacerinnovates	Pacer Innovates	Canada	pacerinnovates.ca
@PatientAdvisors	Patient Advisors	Canada	patientadvisors.ca
@PatientIntv	Heidi Grabenstatter	USA	patientinitiative.org
@patientlibrary	Patient Exp Library	England	https://www.patientlibrary.net
@pattynece	Patty Nece	USA	
@PharmacareFaces	Bill Swan	Canada	https://www.facesofpharmacare.ca/
@RaeofSunshine79	Rachel Martens	Canada	https://coffeandresearch.blogspot.ca/
@researchgirlca		Canada	
@RobynKLaczy	Robyn Laczy	Canada	
@salthorne	Sally Thorne	Canada	https://nursing.ubc.ca/our-people?c=51.2249938994628
@SandraWoodsMtl	Sandra Woods, CIPP/C	Canada	https://www.linkedin.com/in/sandrawoodsmtl/
@savvy_coop	Savvy Coop	USA	savvy.coop
@seastarbatita	Isabel Jordan	Canada	http://modelingchange.blogspot.ca/
@ShariBerman68	Shari Berman	USA	https://lifeaccordingtosomebody.com/
@ShereesePubHlth	ShereeseM, MS/MBA	USA	https://about.me/shereesemaynard
@SKoczkur	Susanna Koczkur	Canada	
@StephEBas	Steph Edusei	England	anewviewconsultancy.com
	https://twitter.com/tanthonyhowell		
@thePatientsSide	Amy Gleason	Canada	http://amygleason.blogspot.ca/
@TheSameMel	Melody Smith	USA	
@TimothyKariotis	TKariotis	Australia	
@tjhockeymom	Tracy Wasylak	Canada	
@trishpaton	Trish Paton		
@TuneInHealth		Canada	
@Unuhinui	Anna M	USA	
@un suicide	Sandra	Canada	un suicide.wikispaces.com
@WellbeingWgtn	Wellbeing Wellington	New Zealand	https://wellbeingwellington.nz/
@yawampoma	Yaw Ampomah	Ghana	https://publichealthconcern.wordpress.com/
@ZakkisMom	Stephanie Middleton	USA	

#PEStrategies TweetChat

This is a summary of the MSSU and NB PIHNCI Network co-hosted #PEStrategies tweetchat out of New Brunswick, Canada on March 20, 2018. To date, it represents:

565 Tweets: 148 Original Tweets; 89 Replies; 328 Retweets; 32 Images and Links

67 Contributors: Canada (AB, BC, NB, ON); USA (CT, ID, MA, MI, NY)

Contributor	Q1: From your perspective, describe #patientengagement in health research. Where are we at right now?
@ABSPORU_PEP	We are at the beginning, but fairly strong beginning, concerning PE in Alberta! Shifting the culture will take some time.)
@couragesings	Yes, culture change moves very slowly! #PEStrategies I wish it could move faster, but that's not how things work :(So many barriers: needs to be taught earlier so this is the norm rather than afterwards (do this work upstream rather than where we are now, working downstream)
@brynphd	I wanted to say infancy, but perhaps more like adolescence? We know it's good, but...but...we like doing things OUR way! In other words, lots of room for growth! It also seems like a lot of loose ends that are starting to find their way to a more cohesive practice, from this perspective. Lots of folks in their own swim lanes that are starting to look and see that there's others with them!
@couragesings	It feels like we're in the infancy of how to do this type of work. Lots to figure out. #PEStrategies
@nicolecbarry	Patient engagement in research is a perspective that is, perhaps, a novel way of thinking/approach for research... https://t.co/gldiB1F26
@QuinlanTurner	PT Engagement (to me) is motivating ptsto take an active role in understanding and managing their care pathways. It involves finding equal footing with their careprovider to drive the best outcomes. We're moving in the right direction but still in infancy
@RobynKlaczv	Patient Engagement in health research stills needs more patient voices and patient control. I echo @brynphd - lots (and lots) of room for growth in this area! :) Getting there.
@CraigMacKie12	My feelings are in line with @brynphd and @couragesings, in Canada especially we're still in the infancy/adolescence phase. It gives grant applications an edge, which means it resembles the Knowledge Translation (KT) of the moment, lots of interest because there's money around, but not necessarily a lot of understanding or sincere effort. A lot of people shoe-horning it into an existing grant application without much planning b/c it may increase the chances of funding.
@brynphd	Agree with this (hence my comment on "adolescence") - it's difficult to properly engage when we only ask because funding partners want to see it...
@erin_michalak	yes, that's a risk, we described this as 'hit and run' engagement in a past publication
@CraigMacKie12	I think one way of addressing this might be by creating a public record of when teams are doing well and when teams are doing poorly (something like "Glass Door" for PE...glass door provides a forum for employees to review companies).
@jhoronjeff	I think professionals are coming around to the value patients bring. So that's Step 1, but there's a lot of work to be done to establish best and equitable practices towards doing so.
@jhoronjeff	I think Step 2-Step ___ is about establishing best practices, eg. understanding methods of engagement, managing scope and expectations, fair compensation, training for professionals & patients, creating resources and toolkits, making it easier for sides to connect
@K_SalemOaks	Step 2: We need to start thinking seriously about how patients are compensated for their time and effort. If pharma really values their input, they to start valuing their time.
@brynphd	I feel like some, when I started, wanted "proof" before incorporating. That's not what we ask, though, of other parts of research, so I've moved away from that to the "how"?
@jhoronjeff	Yeah, part of the reason I grew impatient with academia. We have real problems to solve, let's get to doing it! That said, for the laggards, I think being able to show them it's effective will be important. But that's why at @savvy_coop we work with eager innovators
@abrewi3010	I think we are at a spot were patients are transferring from "volunteers" to their actual role as experts
@brynphd	Agreed! I wonder what made that change happen?
@abrewi3010	I think the movement towards everyone include made #healthcare realize I'm an expert too. Paternalism called is volunteers.
@brynphd	How can we all effectively co-parent this infant into a positive adulthood?
@QuinlanTurner	Continuing to educate and build communities like this one where patients feed off each other to understand the valuable information we each possess and how it can contribute to healthcare
@erin_michalak	I started in PE in mental health research a decade ago, at which time I felt like I was swimming upstream. I now I feel like I'm in a strong flotilla, and it doesn't feel like an upstream battle
@couragesings	We expect people to work in teams with #pts, & yet why aren't #pts incorporated into the education system so this is standard?
@brynphd	It's a really good question! People are brought in as "pretend" patients for med students to work with, and it seems to stop there.
@couragesings	Pretend #pts? Noooooo. Why not real #pts working from the beginning with students?
@_KateEllis_	I think when it comes to #PEStrategies, we've got a mixed bag. Some research teams are way ahead of the curve, some see the value but not sure how to engage, and some are stuck on the model where pt is subject, not partner. I guess we're in a transition period? I think having the incentive of #PEStrategies a necessary component of grant applications can move us into the right directions
@PatientCritical	Having patients as a priority and necessary part of a process means the chance to make connections, spark inspirations & infuse lived experience into research. Probably most important are the connections to explore the world with newly discovered peers.
@PatientCritical	To get anything done, there's a real need to explode #healthliteracy & #patientengagement in the public consciousness.
@K_SalemOaks	I agree with Pl. #Healthliteracy is a frontier that we need to cross. Imagine how much easier #PEStrategies would be if kids grew up knowing as much about where medicines come from as they do about their social media.
Contributor	Q2: Looking back, what has been your BEST experience with #patientengagement to date? What made it work well?
@couragesings	Good #ptengagement experiences have included: *Ensuring my out of pocket expenses are covered; *Being clear at what level of engagement the opportunity is (using the IAP2 spectrum); *Being heard; *I like opportunities where I'm a true collaborative partner - an equal voice at the table & not being used as a token
@RobynKlaczv	Best part is the relationship-building. The people. My team @ABSPORU_PEP We are tight. And working with patients and the public and seeing patient partners develop capacity and grow as research team members. Absolutely, hands down the people.
@ABSPORU_PEP	All of the projects we've been able to co-design with patients. One of our successful projects was the Alberta Depression Priority Setting Project (http://bit.ly/2VcuUqj) - great facilitation, consistent engagement of all members, and the help of Albertans!
@CraigMacKie12	My best experience with PE has been coming into contact with initiatives like #PatientIncluded conferences (https://patientsincluded.org/) There is room for patient & service user reps to actively organize independently and set standards.
@K_SalemOaks	In 30 years in Pharma R&D, my best experience was a couple (he had Peyronie's Disease) and they taught us how to measure, speak up about, and step up to what can be an awkward discussion. They changed our view.
Contributor	Q3: What was your MOST FRUSTRATING experience with #patientengagement? Why?
@abrewi3010	I'm a #chronicpain #rheum patient, to say I'm not engaged is frustrating. Not allowing me to work or contribute is frustrating
@QuinlanTurner	The lack of inclusion of patients by so many providers and organizations who claim to be working towards "better patient outcomes". It amazes me that patients aren't welcome at many of the prominent conferences focused on the diseases we live with
@couragesings	Why I value conferences that truly value #patientsincluded & make it so #pts are meaningfully engaged throughout.
@TO_dpr	When the engagement isn't real - just a check in the box. Could be bc organization doesn't understand how to be real with patients, bc there isn't compensation, or bc I'm not taken seriously. On the flip side, when I do have frustrating experiences, I give honest feedback & offer advice for next time. I can only hope people take this as constructive feedback.
@ABSPORU_PEP	The resistance to change and adapt - resistance to include patients as collaborators and partners in research, not just as participants & consultants. Along with that comes the many barriers - unintentional sometimes, but frustrating nonetheless!
@ProukLaurie	I've gotten to the point that I don't engage with them even they don't do patient engagement well. This is all my time and it's worth more than tokenism.
Contributor	Q4: Looking ahead, what does ideal #patientengagement look like?
@nicolecbarry	Patients as equal partners in patient oriented research!
@TO_dpr	I love working w researchers, companies, organizations & whoever (!), who want to learn about #patientengagement & the values patients think are important to doing it right and properly.
@_KateEllis_	Engaging pts as partners BEFORE the research Q is fully formed, allowing modification to research design based on pt priorities
@H_SalemOaks	So true. Patients should be engaged for the entire process. When you only bring them in later it perpetuates the idea that they are "subjects"
@PatientCritical	Ideals are one thing but the fact that how we paint ideals increase the real world expectations is just as important. For me it's about teaching patients it's alright to disagree & teach them how to do that & forward both the research & patient's role in it
@PatientCritical	Research isn't about obedience it's about forwarding discourse redpectfully. Those #PEStrategies patients need to learn and doing so will make better research possible. Again it's down to building bridges & respect for all #healthcare partners.
@K_SalemOaks	Absolutely. R&D is filled with people who have been trained to wrestle intellectually. They don't mean to be mean - but sometimes it feels pretty tough. We need to help prepare patients to go toe-toe with the OTHER experts at the table
@K_SalemOaks	I was at #patients2018 last week and had a great conv. with a researcher from Brigham and Women's. She said that if patients don't bring their A-game, they don't get asked back. I want to prepare them for that A-game.
@brynphd	On the one hand, I'm with you on prepping folks for their A game...on the other, that comment ruffles me!! (Because not every researcher brings their A-game to a conference!)
@QuinlanTurner	Real partnerships between patients & researchers. No more tokenistic engagement. No more "get a patient name for the grant" - then nothing. #Patientengagement should be diverse and inclusive - we need to further analyze "who really gets to be a patient partner?"
@RobynKlaczv	Patients leading & co-leading research is the norm! #PatientEngagement is not an after thought, but a given. All patients feel appreciated & heard. Patient partners are compensated. Legitimate space for patients to provide ideas for research priorities!
@ABSPORU_PEP	I think a better question is what does #healthcare engagement look like? How is healthcare going to engage patients who are not longer waiting.
@abrewi3010	That PE should "ideally" occur throughout the cycle of research and KT was endorsed in our recent @BCSUPPORTUnit PE workshop too
@erin_michalak	Engagement with the purpose of meaningful and relevant research, not engagement for the sake of engagement
@SamFowlerNB	
Contributor	Q5: What do you see as the biggest barrier for patient partners to engage in research?
@LaureCookNB	I'd like to see more mandates include #PE in policies and practices. Patients should be included at all stages of research, rather than at the start or end of a project.
@K_SalemOaks	Traditional paternalistic attitudes in the upper echelons of pharma. Lack of awareness of opportunities to get involved. Nurturing those who have the will, health, and means to be involved.
@nicolecbarry	I think the barriers are wide-ranging and differ based on the individual - everything from awareness of the opportunity, practical (e.g., transportation, location), financial, emotional
@RobynKlaczv	Plain language. We need to all start speaking in plain, understandable language, esp at meetings. And equally- patient partners often do not know they can get involved in research and how. And POWER dynamics. We need to challenge power dynamics on a daily basis.
@ABSPORU_PEP	We need to ask our patient partners this questions more - difficult to answer on behalf of patient partners. Based on team experience, we find biggest barriers to be: Language, Time, Role, & Tokenistic Engagement.
@PatientCritical	Patients need training in procedure, scope & the dialect of a given team. Patients need to be given contact information & a formal process to request clarification, offer feedback. Patients need to be comfortable, encouraged to explore & settle into a team.
@QuinlanTurner	I think pt knowledge through experience is downplayed because most of us don't have a PhD. I firmly believe pts need to be taken seriously as a legit resource and not just a profit driver. Most pts would do ANYTHING to help our fellow pts. Give us the chance.
@brynphd	For patients? I can't presume the barrier, but like @nicolecbarry said - very individual. Ask them if there's hesitation.

@brynphd	I like what @courageings said (I think?) - PHD is also Personal History with Disease. My PhD taught me how to design a study. Yours has differently but also valuable experience!
@K_SalemOaks	I beg to differ. PhD - People having Disease. You/we are patient scientists. The skills needed to be taken seriously can be learned and practiced. Sometimes, the research team wants to test your resolve - you can pass that test.
@CraigMacKie12	Acronyms and jargon cluster according to the specific research team that you are working with. Different spheres of healthcare have interest in different funding agencies/journals/tests/measures and thus use different terms when the "talking research" starts. I've found it worthwhile to create a list of acronyms and jargon that are specific to your research team, and make this part of an "onboarding" or "new partner" package.
Contributor	Q6: What do you see as the biggest barrier for research teams to meaningfully engage patient partners?
@K_SalemOaks	Traditional paternalistic attitudes in upper levels of pharma. (i.e. lack of incentives) Having the time and people to be able to reach out Lack of creativity based on being regulated Fear" will Health Canada or FDA frown upon it?
@brynphd	From my experience so far - I think it's willingness to do something different. We are inclined to do things that fit within our existing way of thinking. There's a lot of uncomfortable space in doing something new. So people still hesitate.
@AbsPORU_PEP	Researchers often tell us they are challenged by timelines, funding & internal capacity
@RobynKLaczy	PE was never really taught/encouraged to them at their time of education and training. This will change with time. Researchers also are tasked with large check-lists and forms forms forms. Researchers need flexibility concerning timelines & more FREE training.
@erin_michalak	Meaningful engagement requires (often small, but vital) pots of funding to support PE in between operating grants and projects
@SamFowlerNB	Research teams may not know who to engage with or how to connect with them, but patient registries are a great tool to overcome this barrier
@PatientCritical	Money. If you don't budget for a thing, you don't truly care about a thing. Time: If you don't build time into someone's job for a thing, you don't truly care about a thing. #codesign & review. If you don't include patients in building & reviewing...
@PatientCritical	Funding isn't a dirty word. Funding shows you're putting your commitment to patients on the line as a condition of good research.
Contributor	Q7: Last one – wave your magic wand. If you could change ONE thing right now to improve #patientengagement, what wo
@AbsPORU_PEP	More of an uptake - boundary pushers! From both sides - patients and researchers. Hopefully we would have a little more ground to work on and with!
@RobynKLaczy	Wave my wand and power dynamics are replaced by diversity and loud, happy patient voices! :) Honestly, we need more people on board with PE from both patient/public audience and research audience.
@K_SalemOaks	Overcome the fragmentation to demand the education required to succeed. In EU they had EUPATI. In US and Canada - many patient groups, many diseases. No single place to get consistent education. #PEstrategies We hope to change that
@nicolecbarry	For all patient partners to feel as if they are equal partners and that their expertise is valued - this can include things like compensation and being included from the beginning of the research process :)
@QuinlanTurner	Shift the stigma of chronic illness to a source of empowerment. Living with an illness is extremely difficult which is why it's crucial for those that can contribute. Helping one person avoid one pitfall of a disease is worth it. Helping many is amazing
@SamFowlerNB	For patients to feel empowered in the research process
Contributor	Other Comments
@ihoronjeff	The @bmj_latest has a @BMJPatientEd, but I wouldn't say patient run. @S4PM has a journal, but also not patient run. Editors are a start
@TO_dpr	I am a member of a working group with @PFMDwithPatient working on some guidelines. Hopefully when they are public they are "shining stars"
@ihoronjeff	There are lots of things in the works, some around fair compensation, some around methods and procedures. In US @PCORI and @fastercures have led the way in these discussions, but there's still a lot more room for growth. I also work with @OMERACT, good stuff there
@brynphd	Part of the challenge, too, is that we are inclined to want a table of values we can use and point to; but it's really about the conversation and not being anxious about having it!

	On Reasons to Engage Patients:
@anetto	In the research article point out that there is not enough research to measure the value of patient engagement so we need to do more research.
@BantingJennifer	Look at the tweets as an amazing opportunity to build on the patient and family engagement you know. We would not know #HowNotToDoPtEngagement if we hadn't been a part of a team that knew #HowToDoPtEngagement !
@courageings	#pt & family centred care (PFCC) is a shift in culture; it needs to be embodied in all interactions with #pts, policies & more.
@courageings	A story is a starting point. True #ptengagement means working with #pts in collaboration to make change. We can't do that if we're not at the same table
@DinhTammy	"The lived experience of consumers is just as important as data to drive change" #InnovationinAction
@graceCordova	Asking "Do you have any data or references that engaging patients impacts ROI?"
@GrandmaKim	Death of my son - I would prefer someone reached out - asked,- checked in. Despite being a 'frequent flyer' at our childrens hospital, not one clinic, administration or foundation formally said "we will miss your child"/ "Sorry for your loss" . Additionally as I sit here today sorting all the old papers, reports etc.. I realized that after 17 years on site, alongside employees, contributing to the endless surveys... there is no exit interview, there is no thank you, no recognition pin. There is something fundamentally wrong with a service that does not complete the cycle of feedback, the value of frequent users and the touch base effort to retain 'customer loyalty' while toting "We can only be better together" #PatientEngagement
@MMaxwellStroud	You know the single most disruptive thing that could happen to healthcare? Bring patients to the table - have them identify what would be most helpful and what is most frustrating

Contributor	On Number of Patients Needed for Project:
@BCampbellDuke	The question we always asked in education: Who isn't here? When you have the answer, you need to find out why and then fix it. (Love that we're now writing the 'how to' checklist!)
@courageings	Diversity of #pts is so important! One #pt cannot represent ALL #pts, but can certainly share their own experiences.
@courageings	Find a diversity of voices to learn how best to improve. Ensure #pts have support & orientation to the committee & clear expectations.
@courageings	Or only using the same 'chosen few' #pts again and again.
@courageings	It's so important to have at least 2 #pt partners participating.
@DeborahS	One voice can be scared into silence. One voice can be ignored, marginalized. One voice can't speak for all patients. One voice is the definition of tokenism.
@DeborahS	Have several Pts or PWLE at the table, not one solo voice.
@dianapoulsen	Having only one patient in the board or only one patient who shows up. We need allies.
@graceCordovano	Forgetting to include #carepartners.
@graceCordovano	Include only 1 patient (to check off the box).
@thePatientsSide	Have a patients panel with only one patient in the panel of 4 (don't forget to add #caregivers to the discussion too!)
Contributor	On the Phrases: "We Are ALL Patients" / "I Know Patients Because I'm a Doctor":
@BrianDonnaPenn1	Never ever say "we are all patients" to a patient who has been harmed in Healthcare. It is definitely a #HowNotToDoPtEngagement No no.
@courageings	It's not the same experience for a #pt outside the system living with #chronicillness b/c of privilege that comes with working within the system: knowledge, personal connections, health literacy & more.
@courageings	Again, this is not saying those within system can't be #pts, but is saying equating the experience in an attempt to show 'we're all the same' is hurtful.
@courageings	At a workshop, do a group exercise with the people at your table about a new initiative. Ask everyone to think from the #pt perspective. Doesn't matter if they are not a #pt.
@courageings	Oh, and please use the phrase, "We're all #pts."
@courageings	Saying 'we're all #pts,' can be very hurtful to #pts with chronic illness so it's best to avoid this phrase.
@courageings	During your meeting, forget you have #pt partners on your team; start sharing what you would think...as a #pt.
@courageings	"I know what #pts want. I work in the system as a HCP."
@courageings	Working in system gives privilege, connections, health literacy & more #pts outside system do not have. Why it's so important to partner *with* #pts. Our experiences are quite different.
@graceCordovano	Start your meeting with the decree "We are all patients!"
@miShouldTalk	"I know about patient experience. I'm a doctor and I see patients all day." So, I guess I know all about doctor experience because I see y'all all day?
@TimothyKariotis	Interesting though the use of the term patient, which in some ways seems to be part of a paradigm which perpetuates a power differential between people accessing healthcare and people providing healthcare
@savvy_coop	Doctors bring a necessary perspective to health innovations, but it is a different perspective from that of a patients. We can't improve the #patientexperience if we don't understand it. We need to stop guessing and start asking - patients are savvy!
Contributor	On Involving Caregivers/Care Partners:
@GERONursing	Have an organizational #PatientEngagement committee that doesn't include any patients or family caregivers.
@hedy_wald	Call me, a family #cancer caregiver an "informal" caregiver...nothing "informal" abt what I do 24/7.
@ZakkisMom	"Parents don't know their child's history" - goes on to tell me surgeries my son did NOT have but refuses to change EHR to include the ones and the dates he did have. I know every surgery and cath - all 26 of them, the pressures, the mm, what was done
@Unuhinuii	Talk to the assumed caregiver of the disabled patient as if they weren't there. Instead of like asking your customer directly. "Is she in pain?" Doctors seem confused about the difference between their blind and deaf customers.
Contributor	On Involving Youth:
@BantingJennifer	Engaging only parents in the feedback process limits youth's voice and ability to self advocate and grow to share their diagnosis.
@graceCordovano	Ignore pediatric patients in exam rooms, only addressing their parents/legal guardians. Bonus points for concurrently staring at the #EHR screen.
@morgan_gleason	Talk to my mom instead to me
Contributor	On Patients as Consumers Concept:
@graceCordovano	Patients don't really care about their medical records, their experiences, the details of their insurance. Patients are consumers.

Twitter Handle	On Meeting Times:
@couragesings	Schedule meetings at 7am. Rush hour, what rush hour?
@couragesings	Schedule a focus group to get feedback from parents of kids with illnesses. Run it at 9am during a weekday when your target group is working. Say you tried to engage with parents.
@couragesings	Small things can make the hugest difference for engaging with #pts. If no one shows up for your 9am meeting, ask #pts what time works best for them? Ask how you can support them.
@couragesings	Hold meetings at the times most convenient for your schedule. Bonus points for staying within business hours; #pts will come when YOU want them!
@couragesings	Decide with your #pts upon a mutually agreed time. This may occur outside business hours
@couragesings	Ask your #pts/caregivers what time works best. Hard for those working to take time off to come to meetings during business hours.
@couragesings	Decide collaboratively on a time for meeting. These times might be outside normal work hours to accommodate different schedules.
@couragesings	Try to provide some food if your meeting is over a meal time. Include this in your budget. Ask about any dietary restrictions/allergies.
@GERONursing	Only hold #patientengagement activities between Monday to Friday, 8am to 4pm.
@graceCordovano	Plan extended in-person meetings without consideration for diet needs/restrictions.
@researchgirlca	Only engage patients through boring lunchtime meetings at clinical offices where everyone brings their lunch and you can only get in with a proxy card
@yawampoma	Scheduling meeting with patients at your convenience.
Twitter Handle	On Meeting Location:
@couragesings	Hold meetings in the hospital. Because triggering #PTSD in people seems like fun.
@couragesings	For some #pts, the hospital can make participation difficult. Consider holding meetings in a more neutral location offsite.
@kylierpeacock	Book a full day "team" meeting without consulting first & book that meeting where a patient goes for appointments and has had traumatic events there.
Twitter Handle	On Scheduling and Changes:
@AmandaRossWhit	Send an e-mail cancelling the meeting while the patient is standing in the hallway outside the conference room #toolate
@AureliaCotta	also the one where they ask you ahead of time, but never include you on full information until the last day or so. *sigh*
@couragesings	Ask #pts what would work to notify them about meetings; not all #pts have Outlook calendars.
@couragesings	Send all meeting invites through Outlook. Do not ask #pts if they have an Outlook calendar.
@couragesings	Set location for event in one city, but later change city without highlighting change. Flip coin to guess how many #pts show up.
@couragesings	Working with #pts will mean finding out how to support them. Nothing worse than applying for something only turned down b/c the org couldn't accommodate the health issue
@graceCordovano	Only meeting in-person.
@JessHavens_	When booking appts actually allow time for patients to ask questions - instead of assuming they'll automatically be okay with your goals. "We're running late because the patient before you asked too many questions" should never be a problem I hear
@patientlibrary	Phone up a patients'/service users' group in a panic, saying "Could you send someone to tomorrow's committee meeting? We need a patient rep!"
@StephEBas	Make the engagement materials incomprehensible; don't offer help with transport, child care, other costs; give five days notice (after all they've got nothing better to do)
@TuneInHealth	Give space to the "same players" & forget hard to reach groups exist; Hold consultation meetings b/w 9-5; Tokenize marginalized folks by placing burden of representation on them

Twitter Handle	On Who is Recruited:
@alexhaagaard	Engage only with patients who reinforce your policies, practices & beliefs. Patient engagement that doesn't challenge what you're doing & how you're doing it is meaningless. (And no, you're most definitely not just 'already doing everything right'.)
@courageings	Listen only to #pts who will agree with everything you say.
@DrMWeiser	Invite patients and families to community updates about research and care, but only recruit patients as participants in physician-led studies. Why not ask for patient ideas for research, and offer seed funding
@graceCordovano	Don't post opportunities for engagement openly (like it's a secret society). Ensure only people who "know someone" get involved or recommended.

Twitter Handle	On Terms of References / Starting Involvement:
@BantingJennifer	Don't invite a patient or family to a committee, council or decision making table and not prep everyone around the table as to why we are engaging patient and families in the discussion.
@courageings	Have terms of reference, but please...don't follow them.
@courageings	Co-create terms of reference with #pt partners. Having clear terms of reference & following them helps set expectations.
@DeborahS	A "comfort agreement" can be helpful too. Identify what makes pts feel comfortable/safe and uncomfortable/unsafe at the table, and everyone undertakes to aim for the former, avoid the latter.
@fquire	Solutions I'd propose: 1) Develop a start-up health magna carta; 2) Develop patient recognizable industry mark/logo for startups to adhere to; 3) Educate... err...RE-Educate public on engagement and what's being done to prevent this hash
@maladorphelines	A contract will be signed with all parties in the project...except with patient organizations!
Twitter Handle	On Acknowledgements for Contributions:
@alexhaagaard	Hire abled researchers with long academic CVs, who then 'talk to' patients who will remain uncredited and uncompensated. Lots of your patients have academic as well as lived expertise, but we lack extensive CVs due to our life circumstances. HIRE US.
@courageings	Ya know...I recently spent MY time editing a document. It has been 10 days and not even a thank you.
@gilmerHealthLaw	Forgetting to thank patients for helping get you VC funding. Because as you get richer, they remain poor.
@gilmerHealthLaw	Or send patient a followup letter saying you "looked into it" and proceed to explain in a way that clearly shows you're trying to limit liability rather than make actual changes.
@graceCordovano	Ask for patient insights (to ultimately benefit your organization, platform, product, solution) and never follow-up with the patients who participated to share how their contributions helped.
@maladorphelines	Ask for your input on patient engagement, but put your ideas in a footnote of the report.
@SandraWoodsMTI	Ask a patient for their story, to "raise awareness" of a #RareDisease; post it to your own blog, which includes ads, but don't tell the patient; and don't link to the patient's own advertising-free blog...
Twitter Handle	On Power Dynamics:
@courageings	When doing introductions, ask everyone for their name & what they do for a job. Especially impactful for those #pts unable to work: helps them feel inadequate in a room full of professionals.
@courageings	When doing intro's, choose an icebreaker that gives #pts a chance to be a part of the group & contribute.
@current_mike	Have patient participate. Encourage strong enthusiasm. *Insult them & make them feel inferior to put them in place.* Find productivity. Use personal info. Get great results. *Shut them out as if they're incompetent. Ignore requests for further dialogue.*
@current_mike	Invite patient to participate. Encourage enthusiasm. *Insult them & make them feel inferior to put them in place.* Have them work very hard. Get exciting results. Don't contact them for months/ysr at a time. Ignore their emails and requests for dialogue.
@current_mike	Patient-oriented #research in #MentalHealth is GREAT: It's so easy to #ignore #insult #judge #frame #discredit & get rid of patients, if you feel like it. No one believes a #person with mental illness over academics or doctors.
@current_mike	Prior to 1st meeting I was put in subordinate position by team leader's offensive, inappropriate discussion of body image. Team's #Stigma perpetuated my powerlessness, limited #patient contribution & then covered up initial errant mistakes
@GailBellissimo	If #patients are at the table, it is presumed the group is convened/working on common goals/purpose, please DO NOT start the mtg w/ introductions that include place of work & title.
@GERONursing	The first step of the care quality complaint process is to meet with the person you are complaining about or their direct supervisor (aka people who have power over your care; anxiety trigger). If you don't do this we won't let you escalate the complaint.
@SKoczkur	Engage patients & collect data from lived experience & not support and trusting the findings. Nothing more dismissive to patients. We need #PatientLedResearch to ensure the #PatientVoice is heard & used to implement change.
@Unuhinuii	Interrupt and talk over your patient, diss their symptoms, just showing a sour face while they try to discuss any health issue with you
@yawampoma	Still assuming paternalistic nature discounting that patients are indeed experts in their conditions.
Twitter Handle	On Limiting What Patients Say/Share:
@anetto	If the patient is too frank, or voices unpopular opinions, be sure not to invite them to any more meetings #hownottodoptengagement #selfedit
@courageings	Co-create the agenda *with* #pts. Ask what's important
@current_mike	Engage a patient as a person based on their experience with a condition, but try to detach them from their #personality for the purpose of academic research. Encourage an atmosphere of Us (researchers) vs. Them (patients). Talk behind patients' backs.
@current_mike	My recent experiences in an unnamed study, had me first admit to belief in spiritual experience, then give examples, then kick me out of the study based on my honesty. Science has made great progress with #MentalHealth & #Stigma, but this is really low.
@delia_sinni	"Theres an overwhelming experience of consumers being told 'no' - No, that's not how we do things. No, that's not possible - start your conversations with yes"
@dianapoulsen	Explain to the patient "we don't need horror stories". What story do you need? That time I didn't get a warm hug?
@dianapoulsen	Telling a patient that stories from mothers are more impactful and relatable. Because no one has ever been single.
@dianapoulsen	Completely rewrite their narrative to give them happy ending or take things out of context.
@GailBellissimo	Do not ask us to share our #story as part of a meeting/reason for our being at the table. Our #livedexperience will be conveyed in our contributions.
@heartSisters	When organizations need a patient face for fundraising campaigns, but dictate which part of the patient's actual story must be left out...
@janoldenburg	Have your Patient Council address topics like what fabric and patterns the Patient pajamas should be made from but don't ask their input on any meaningful policy issues
@kristine_lemo	Invalidating the negative experiences of patients (by offering justifications, etc.); expecting patients to figure out the system themselves and assigning blame when they can't
@MaryOCMack	Constantly say "you are your best advocate" but then dislike the patient who advocates. Too bad I missed this chat, but here's one: Get annoyed and angry when patient asks questions about informed consent document for clinical trial.
@tanthonhowell	At a recent conference focused on patients' involvement with industry, we heard the conf organizers provided a free pass (\$2,500+ value) to the patient, but told the patient not to ask questions from the microphone?! Practices like this have to be exposed and removed.
@tjhockeymom	Make sure when you ask patients there opinions- you listen!!
@unsuicide	Set agendas for meetings based on what you want to talk about, not patients. Consult only on issues you feel are important.

@WellbeingWgtn	Talking the practice of codesign, lol for this slide: [text on slide]: Co-design is not deciding what we want to do and then co-opting a consumer onto a group; not making changes (to layout/an information leaflet and so on) and then asking consumers to comment; not working with consumers but not listening and acting on their expert advice
Twitter Handle	On Late Requests for Feedback/Participation:
@amaybee	Oh my! I have experienced that a number of times. In part an issue that funders timeframes do not support #patientengagement; in part poor planning and relationship building.
@courageings	Just happened: asked to provide feedback by tomorrow.
@courageings	Ask for feedback a couple days before something is due.
@courageings	Plan ahead in order to allow #pts sufficient time to provide feedback. Ask #pts about timeframe & what's do-able with their schedules.
@courageings	Make all the decisions for your project, invite #pts to look at what you've done for 'feedback' at the end.
@courageings	Send email 430pm on a Friday. Say feedback is needed by Monday morning. Not like #pts have anything else to do over the weekend.
@courageings	Respect our time as #pts. Sending something last minute on a Friday is not considerate of our time.
@heartSisters	Ask a patient for input at your final project meeting (after all substantive decisions have already been made)
@maladorphelines	Bring you in after the project is written and sent in to whom it may concern. And when you see that patient needs are not met in the project...too late to say anything. If you do, you look like a party-spoiler
@researchgirlca	Late to the #HowNotToDoPtEngagement discussion but here's one not mentioned yet I think: ask pt/org for letter of support for grant appl - it's the first time they've heard of the project and you need it back in 48 hours.
@ShariBerman68	When hospital staff presents a new initiative/program to patient advisors after it has been developed asking for feedback (i.e. rubber stamp)
Twitter Handle	On Publication:
@courageings	Conduct #pt oriented research. Submit findings to journals only accessible behind a paywall.
@courageings	If possible, budget to submit to journals with #openaccess or #patientsincluded journals. If not possible, are there other ways to disseminate info to #pts (blogs etc)
@PatientCritical	Pub: A great researcher & patient advocate wrote an insightful article for us about the struggles patients face. Patients: (PAYWALL) Pub: See? Told ya. Struggles. The #meansofproduction are still designed in most of #healthcare to keep patients OUT.
Twitter Handle	On Surveys and Measures:
@courageings	Design surveys about the #ptexp without co-creating them with #pts.
@courageings	Co-create surveys & resources about the #ptexp with #pts/caregivers.
@graceCordovano	Tell patients to eat healthier, exercise more, stop smoking, stop drinking, sleep more, to improve their outcomes without tying changes in behaviors meaningfully to outcomes patients value (lowering A1c vs walking daughter down the aisle).
@miShouldTalk	Survey a chronically ill patient 4 months after a specific procedure to get their feedback. They've had 14 procedures since then, but you're asking about a specific day.
@researchgirlca	Survey rare small patient subpopulation with outcome measures designed for able bodied people. Hint: mowing the lawn isn't a vigorous physical activity example for people with paralysis OR condo-dwellers!
@Unuhinuii	Here, fill in this 30 page paper questionnaire before the visit. What do you mean by accessible formats? Oh and feedback forms are inaccessibly in paper too
Twitter Handle	On Acronyms:
@courageings	Speak in acronyms so #pts don't understand what you're talking about.
@courageings	When setting up committee, make it clear acronyms are to be avoided. Create an environment where anyone can ask clarification if an acronym is used.
Twitter Handle	On Involvement throughout Project:
@AmandaBoldersto	Say "we've been told we need patients on this committee for accreditation" and grimace.
@ChronicallyJless	Be open to the possibility of a future work/research partnership - or even friendship - with your invited patients. After all, we are all passionate individuals looking to contribute to the same cause.
@CJadams80	(Referring to slide seen on Twitter): Don't listen very much to people who experience our services and we do the designing; listen to our service users and go off and do the designing
@courageings	If something is agreed on together with the team, if changes are going to be made, ask the #pts if they are OK with the change.
@courageings	Tell #pt if not satisfied with Patient Care Quality Office, can submit complaint to independent review board. Fail to mention even if review board makes recommendations to health
@courageings	"Yes, we can accommodate the needs of #pts with that health issue in our engagement activities. After all, we are #pt centred." ... "Oh sorry, not *that* issue."
@courageings	#HowToDoPtEngagement? LISTEN to your #pts & *hear* what they are saying.
@courageings	Hold a panel on #pt engagement with no #pts on the panel.
@courageings	Agree on a word to be used in a paper with your team. During editing process, replace that term & see if any #pts will notice.
@courageings	Involve #pts from the beginning of your projects so we can collaborate with you! When all decisions are done ahead of time, it doesn't give us a chance to meaningfully contribute.
@courageings	Remember why your #pt partners are there: to provide the #pt perspective. Seek out their thoughts.
@courageings	Make broad assumptions as to what #pts want: "all #pts want X". Score extra points if not a #pt speaking these 'truths.'
@courageings	Never make assumptions about what #pts want. Work with #pts and *ask* them what's important
@courageings	"We do #ptengagement - we listen to #pt stories to start our meeting. Then we ask the #pts to leave while we continue with *our* agenda."

@couragesings	Conduct research about #ptengagement. Interview no #pts.	
@couragesings	Simple: doing research about #ptengagement? Make sure #pts are on your interview list.	
@couragesings	Quoting @AfternoonNapper: "Man, I sure love providing free advice to giant health care companies and not even getting recognition for my contributions!" — said no patient ever	
@couragesings	Have meetings. Don't take minutes. Because guessing about decisions made at a later date can be almost as fun as a scavenger hunt.	
@couragesings	Taking minutes from meetings & indicating what decisions have been made, action items etc is helpful to keep things on track.	
@couragesings	Have meetings. Don't take minutes. Because guessing about decisions made at a later date can be almost as fun as a... https://t.co/PwgSBqf65M	
@current_mike	Hint: Risk is often necessary to find value. I'm the kid in class that always has his arm up & then waving, but the teacher always chooses someone else. Treat me as bad news in #research. Ignore me. Because I'm eager to share?!	
@danamlewis	Dear medical device company that I've never, ever, ever bought products from: stop taking people's emails and subscribing them to your patient newsletters without permission.	
@DeborahS	After the meeting, workshop or conference, when 'the team' is heading out for dinner or whatever, invite the whole team. Remember that includes the Pts/ PWLE.	
@DeborahS	Provide a basic training session for all research partners/steering cttee members and patient co creators on the research methodology being used - why, how it works.	
@dianapoulsen	Explain that women's issues are minority issues.	
@esiobhanoneil	1. Mind already made up; 2. Ears blocked; 3. Mouth open. [To engage patients]: - Open 1&2 and close 3	
@graceCordovano	Don't include #HealthcareExperienceLiteracy in K-12 public school education curricula. Drop patients into healthcare system at some point and hope they figure it out...(oh wait).	
@graceCordovano	Forget to be considerate of cultural or spiritual preferences.	
@graceCordovano	If you have a complaint about your recent hospital stay, please fill out our survey. (We'll get a handle on the results in 4-6 months and still never get back to you.)	
@graceCordovano	"That's what our marketing team is doing."	
@graceCordovano	We are precluded from working with patients. You know, there's real legal/regulatory/compliance issues.	
@graceCordovano	Base your whole "patient engagement" on one interaction as opposed to fostering a collaborative, long-term relationship.	
@graceCordovano	Continue to exclude patients from designing, developing, and delivering medical education.	
@graceCordovano	Create and launch #PtEng "strategies" without any consideration for social determinants of health.	
@graceCordovano	Please do not use #patients as a projection screen.	
@HelenKaragio	Looking at a case study on stakeholder engagement from 2008. Doesn't include patients because it was 'before consumers became a thing.'	
@HelenKaragio	No words. 10 years ago the patient was represented at meetings and workshops by a gnome. Literally a physical gnome statue named VIP (very important patient). I just can't.	
@hwhiteman	I pointed out I have great A1c's, 34 years of experience & I know how to treat a high BG, I'm just sick. R2 asserted, hotly, "Well, I'm a doctor." Cue a knock on the door. R2 left for 5-10 min.	
@Know_HG	What a list of excuses for not involving patients. It would make a great game of #hownottodoptengagement bingo	
@kylierpeacock	Make jokes about seizures after a patient team research member has had 4 traumatic seizures in the last 4 years (NOTE: not funny to joke about seizures).	
@leorapinhas	Hire people with lived experience as peer support workers in MH hosp. Treat them so badly they end up on sick leave	
@maladorphelines	Do not follow these principles in pt engagement: being Direct, Constructive, Continued, Transparent, Respectful	
@maladorphelines	Or tell you that you are just ONE and can't represent ALL and tell you that they are also speaking with OTHERS; makes you wonder why they invited you; makes you wonder about the value of your input.	
@miShouldTalk	Ask me to fundraise for your hospital when your bills are the reason I'm completely broke.	
@miShouldTalk	1. Ask patient to join patient advisory committee 2. Make patient fill out epic application to join 2. Never follow up with them personally (for years) 4. Put them on an email list to receive your volunteer newsletter (but you never let them volunteer)	
@morgan_gleason	Make mistakes in my chart and then say that "the patient must have told us that if it is in the record". I have never been pregnant but this was in my chart and i obviously didn't tell them that!	
@MortuaryReport	gotta love it when you press the leading society on your genetic disease about transparency regarding what they're doing with a million dollar donation and they... yell at you?	
@PatientAdvisors	When a patient partner wants to be more involved in the project, tell them that you can't allow it without going back to the Ethics Review Board and there is not enough time.	
@PatientIntv	Decide research objectives prior to conducting #pt survey. Survey nearly always reflects organizations aims and leaves no room for new patient-driven research directions.	
@PatientIntv	Invite patients and caregivers to participate in layperson grant review, but fail to utilize their insights when making funding decisions.	
@patientlibrary	Get patients involved in a survey/focus group/research study on something that's already been studied to death. Publish a report that adds nothing to the sum of knowledge - just adds to the pile of reports.	
@researchgirlca	Riffing on this one: refuse to give patient a copy of the legal release for surgery form I just signed... while copying it for my file. "You have to make a request in writing to medical records. It's a patient confidentiality thing."	
@salthorne	Rigorous qualitative research is a marvelous tool for bringing a diversified patient perspective into disease discussions. Especially when expert patients are integrated into the study team.	
@savvy_coop	Quoting @PatientWorthy: "Patients don't like to waste their time, make their contribution matter. Don't just do it for the optics," Sheehan advocates for genuine patient engagement	
@TheSameMel	My cat's doc just called to see how she's doing on a new arthritis med. My doc hasn't called me about the DNA test that's been sitting in my patient portal the past week revealing the gender of my unborn baby.	
@un suicide	Similarly, hold conferences & symposia about patient-centred care and patient engagement but majority of speakers aren't patients	
@yawampoma	Fail to recognize the important role patients play in medical education.	

Twitter Handle	On Compensation:
@BCampbellDuke	The 'I'm sorry I couldn't plug your meter because my husband was being moved from ER to cardiac ICU at the time' worked, although I had to listen to a 10 minute speech on how parking fees work and why they're needed. I got the \$25 back, though.
@BrianDonnaPenn1	providing honorariums for Doctors speaking at conferences but patients receive nothing.
@couragesings	Do not cover the out of pocket expenses for #pts.
@couragesings	Fail to include in your budget the costs for #pt engagement. Then say you can't do #pt engagement b/c there's no budget available.
@couragesings	Hold your meeting over lunch. Do not provide any food.
@couragesings	Cover out of pocket expenses for #pts -- things like mileage, childcare etc. Find out from #pts what supports are needed.
@couragesings	Discuss matters of compensation for staff in front of #pts. Helps make us *really* feel like a valued member of the team, especially being the only unpaid member at the table. Have the awareness how uncomfortable this makes the only team member not paid & have this conversation elsewhere.
@couragesings	Pay for expenses & full registration in advance. Follow the principles of #patientsincluded
@couragesings	Cover expenses for #pts - yes, this means meals, too! #pts should not be out of pocket & paying for the privilege to participate.
@couragesings	"Scholarships have been already awarded to #pts. No, our process was not public or transparent. Secrecy is our motto!"
@couragesings	Please - make scholarship info public. Otherwise, scholarships are only distributed to the 'chosen few' #pts while other #pts wonder how to take part in your conference.
@couragesings	Say you offer compensation for your #pt partners. Who knew reimbursing travel costs was considered 'compensation'?
@couragesings	Reimbursement of out of pocket costs = covering expenses, not compensation. Compensation is something given after expenses have been covered, & it may look differently for each #pt.
@couragesings	If there are scholarships available, be transparent about the availability and include public info on how to apply.
@DeborahraHS	Support People With Lived Experience (PWLE) to get to the table; travel expenses, accommodation and honoraria.
@drifarrell	and even if the patients are paid, the docs will be paid far more
@GenCounsNews	ask patients to volunteer their time to give feedback, rather than pay them.
@GilmerHealthLaw	Asking for free advice in exchange for maybe a cup of coffee.
@gilmerHealthLaw	Asking to test your beta product and the "compensation" is getting to test the beta product.
@graceCordovano	Compensate patients? We don't have a budget for that. (When you don't compensate, only the individuals who have the time, means, transportation, childcare, eldercare, etc, will engage. Compensate fairly to include all.)
@HeartSisters	"I can no longer afford to be 'honoured' by any more medical conference invitations" - invite patients to speak at your big event, but withhold any travel/hotel/per diem support
@HeartSisters	When everybody attending the project meeting you finally invite a patient to attend are paid to be there (some you've even flown in and put up in a nice hotel the night before) but you don't offer to pay your patient's parking
@heartSisters	When you finally realize you haven't yet included any actual patient input in the new patient website your ad agency is creating for you, and after that patient spends 90 minutes correcting obvious errors on your site, you give her a \$5 Tim Hortons card
@PatientAdvisors	Announce loudly that all who need transit tokens should follow you up to the 2nd floor
@PatientAdvisors	Of course they could offer patients and caregivers a deep discount if they can induce friends or acquaintances to attend - like a pyramid scheme.
@RaeofSunshine79	A chance to win a \$50 Amazon gift card doesn't pay for my parking and sitter to be here.
@ThePatientsSide	Pay for doctors to speak at conference but do not pay for patients to speak at the conference
@trishpaton	I worked on a project where we had to argue with big city funding body that our small city project had to rethink travel because "city != public transit". They literally told us that wasn't possible. We ended up proposing home visits.
@trishpaton	When asked about support for child care, everyone in the room gives puzzled look and says "why"?
@trishpaton	When working with people who don't have cars, don't check transit routes or provide for taxi chits. Have meetings where it's convenient for you (hospital) and be surprised when they show late, only once, or not at all.
@trishpaton	Spinning off this...make patients ASK about having costs covered, especially in the group, so they can feel on display and like they're imposing.

Twitter Handle	On Conference Fees:
@allyc375	Should have been heading for Jonkoping this week as I had an abstract accepted to speak the @qulturum conference. I was going to self fund but they would not budge on allowing me to attend other days unless I paid a fee. Not going for #patientsincluded status clearly.
@anetto	When you're invited to do a presentation to a group, and no one tells you that everyone else will be using slides.
@BrianDonnaPenn	Guest speaker Doc at a conference stated he hates patient stories. Said he was all about the stats... When I asked if he had an ego problem, he didn't know what to say. I assumed the answer was yes!!
@courageings	Run a conference on the #ptexp. Make #pts pay to attend.
@courageings	Follow the principles of #patientsincluded for conferences to ensure #pts are meaningfully engaged.
@courageings	#QF18 walks the talk of #patientsincluded: reg/travel scholarships for *20* #pts(!), #pts on Steering Committee, Live-streaming and more!
@courageings	Say your conference is #patientsincluded because a couple of #pts attended. Fail to mention they paid out of their own pockets, were not included in the planning or supported in any way.
@courageings	Ensure only #pts with \$\$ or social privilege/connections attend your event: *Offer scholarship for registration; *Encourage fundraising to cover all other expenses. (travel/meals/accommodation)
@courageings	Announce the importance of #pts for your event. Make sure the fee prohibits them from attending.
@courageings	*Budget for full scholarships; *Follow principles of #patientsincluded conferences
@courageings	Run a #patientsincluded conference. Make sure the livestream is accessible...to those who pay a fee.
@courageings	A #patientsincluded conference doesn't charge for livestream access.
@courageings	When asked if conference is #patientsincluded, inform #pts they are welcome to submit abstracts & pay for the privilege to speak. And no, there is no funding for travel expenses.
@courageings	Only inviting #pts to speak does not make a conference #patientsincluded. Specific criteria needs to be met
@GilmerHealthLaw	My favorite part about this list of speakers is that none of them are patients. Love when execs talk "patient-centered care" without patients in the room. I mean what could patients possibly know about it?
@miShouldTalk	Invite patients to your medical conference. Don't even let them have the free pen or a printed program.
@pattynece	Make patients pay for the entire conference for privilege to speak for an hour.
Twitter Handle	On Conference Scheduling:
@courageings	#patientsincluded conferences have specific criteria. A couple of #pts in the audience will not fulfil this criteria.
@DeborahS	Put a patient's name on the agenda at a symposium to "tell their personal story. Forget to ask them in advance. When they refuse to do it, act like they're letting everyone down.
@lisafieldsms	Once at a Conference #patientsincluded patient panel began 7:00 AM. So Early very poor Attendance.
Twitter Handle	On Conference Acknowledgments:
@heartSisters	When all speakers on your conference panel have their names/bio printed in the program, except for the patient whose space is just left blank
@pacerinnovates	Here's another. When everyone's conference badge has their title and institution on 2 lines below the name and your two lines read 'nothing' 'nothing'

Twitter Handle	Comment
@clockbirddesign	Patient Portals that don't link to other GP/practice sites, take three forms of ID that have to be presented at practice IN PERSON to access, and password sent to you via letter. Prescription renewal only available by portal.
@couragesings	Or any piece of tech, really, assuming all #pts have access.
@couragesings	Offer guest wifi at your organizations. Ensure the network is locked. Do not provide a password for #pts to access.
@couragesings	Put all the materials needed to fully engage as a #pt partner on your intranet. Do not give #pts a way to access these materials.
@couragesings	Simple: provide the password for your #pt partners to access the wifi.
@couragesings	Ensure materials are accessible to your #pt partners.
@gilmerHealthLaw	Startups aren't exempt from #HowNotToDoPtEngagement. I've been used by so many businesses who want to "pick my brain" that have gone on to be successful, meanwhile I'm over here struggling to get by. There are better ways to engage patients.
@graceCordovano	Measure success of digital #PtEng initiatives by number of clicks.
@graceCordovano	Continue to develop digital solutions to improve patient engagement that adds to physician or caregiver administrative/electronic burden.
@graceCordovano	Launch solutions that are only available to those in possession of an iPhone (sorry, it had to be said.)
@graceCordovano	Our organization prides itself on patient engagement. We have a patient portal.
@graceCordovano	Have drs, attendings, residents, RNs, NPs, PTs, social workers, case managers, housekeeping, spiritual chaplains, food/bev/TV/phone staff, transport, discharge planners, etc visit admitted pts. Skip medical records depart staff.
@graceCordovano	Make it a 3 ring circus for patients to get copies of their medical records. Charge (ridiculously) for records. Use fax machines & US postal service. Meanwhile, deidentify same records & sell them w/o patients' knowledge
@miShouldTalk	Say on your website all over the place how much you care about patient engagement and the patient experience, but don't list any way for patients to contact you about this or the names of anyone who works on these issues.
@savvy_coop	We love working with #digitalhealth startups. They get #uxdesign and need to optimize for patient, but many have never talked to an elusive patient before, and/or need some help understanding why healthcare/patients behave differently from other markets.
@savvy_coop	Oftentimes #digitalhealth #startups are eager to engage. We help them understand how to work with patients, what fair patient compensation should be, and of course, help them actually connect with patients. We love helping them do it well from the start.
@seastarbatita	Make the bandwidth so bad it's actually useless for patients & families waiting for appointments.
@ShereesePubHlth	Designing systems for stockholders, not stakeholders & then expecting patients to support its use