
#hcsm - March 2, 2014

Sunday March 2, 2014

6:02 [Mark Salke@marksalke](#)

Hi all. I'm Mark from Ann Arbor MI. [#hcsm](#)

6:02 [Mark Ryan@RichmondDoc](#)

Hi! Mark, family doc in [#rva](#), currently on the run from yet another batch of bad weather. Involved in [#MedEd](#) and the [#FMRevolution!](#) [#hcsm](#)

6:02 [Robert Mahoney@mahoneyr](#)

Evening, [#hcsm](#)!

6:03 [T2D Research@T2DRemission](#)

Hmmm. [#Hcsm](#) redefined? Interesting, to say the least.

6:03 [Alan Brewington@abrewi3010](#)

Alan here. On the recovery side of a bug...I hope. Eager to stretch my brain and hopefully learn something. [#hcsm](#)

6:03 [Real Talk Dr. Offutt@RTwithDrOffutt](#)

Laura here. MD, mom, using Some to engage teens abt teenhealth on blogger, twitter, pheed and tumblr. One eye on the Oscars! [#hcsm](#)

6:03 [Bill Wong@BillWongOT](#)

hello everyone. [#hcsm](#) From Monterey Park, CA

- 6:04 [Real Talk Dr. Offutt@RTwithDrOffutt](#)
Tweeps....ur prob watching the oscars, but mute me for an hour.... On hcsn twitter chat.
- 6:04 [HealthSocMed | #hcsn@HealthSocMed](#)
(Some twitter clients/3rd party tools may be a bit slow tonight given other activities on Twitter. Hang in there! [#hcsn](#))
- 6:04 [Jim Rattray@jimrattray](#)
Jim here. Focus is health care marketing, branding, communications & patient engagement [#hcsn](#)
- 6:04 [Alan Brewington@abrewi3010](#)
[@danamlewis](#) thanks! How are you doing? You over the flu?
[#hcsn](#)
- 6:05 [Jennifer Celio@JMCelio](#)
Hi everyone, Jenn from NYC - occupational therapist, adjunct prof and public health aficionado. [#hcsn](#)
- 6:05 [Dana Lewis | #hcsn@danamlewis](#)
[@abrewi3010](#) over the flu (yay), working my way through bronchitis :/ but on the mend! [#hcsn](#)
- 6:05 [T2D Research@T2DRemission](#)
Michael Massing, making sure to spell [#hcsn](#) correctly tonight.

- 6:05 [HealthSocMed | #hcsM@HealthSocMed](#)
Welcome, everyone, to [#hcsM](#)! Special hi to any first-timers joining tonight :), and of course our friendly lurkers. Tweet in anytime!
- 6:05 [Jim Rattray@jimrattray](#)
[@HealthSocMed](#) There's something else happening tonight?
[#hcsM](#)
- 6:06 [HealthSocMed | #hcsM@HealthSocMed](#)
(FYI [#hcsM](#) topics come from you; feel free to submit anytime! Easiest if you DM or [@HealthSocMed](#) w/out hashtag during wk so can track them)
- 6:06 [Dana Lewis | #hcsM@danamlewis](#)
Welcome to [#hcsM](#), all! <--Dana Lewis, [#hcsM](#) moderator, thinker | doer | teacher of health & digital things. Chief Data Producer, [#DIYPS](#).
- 6:06 [Alan Brewington@abrewi3010](#)
[@danamlewis](#) yikes, bronchitis blows! Hope you get over that quickly. Coughing all the time hurts. [#hcsM](#)
- 6:07 [Steven Incontrera@Steven_Paul](#)
Hello [#HCSM](#) universe I'm fresh of of [#HIMSS14](#) and I'm excited to chat.
- 6:07 [Jordan Davidson@JA_Davids](#)
Hi everyone! I'll be lurking/in & out. Working on some materials for endometriosis awareness month, but I love [#hcsM](#) & don't want to miss it.

- 6:07 [Mike Sevilla, MD@drmikesevilla](#)
MT [@danamlewis](#): Welcome to [#hcs](#), all! <--Dana Lewis, [#hcs](#) moderator, thinker | doer | teacher of health & digital things
- 6:08 [Dan Goldman@danielg280](#)
Dan Goldman, lawyer at Mayo Clinic. My UCLA Bruins just tipped off, so I will be splitting my attention tonight... [#hcs](#)
- 6:09 [bacigalupe@bacigalupe](#)
There no Oscars in [#hcs](#) but there no commercials and not losers either.
- 6:09 [Alan Brewington@abrewi3010](#)
[@danamlewis](#) sleep is overrated I believe! Humans only need a couple of hours and a lot of Starbucks :) [#hcs](#)
- 6:09 [Dana Lewis | #hcs@danamlewis](#)
[@abrewi3010](#) despite living in Seattle ;), I think diet coke is the better choice! ;) [#hcs](#)
- 6:10 [Dana Lewis | #hcs@danamlewis](#)
[@T2DRemission](#) thanks! my first & hopefully last experience with it! [#hcs](#) [@abrewi3010](#)
- 6:10 [Steve Sisko@ShimCode](#)
"8 Ways Anyone Can [use [#socialmedia](#) to] Become Public in Under an Hour" (Skip #2 if not a doctor) [ow.ly/u8wZj](#) [#hcs](#)

- 6:10 [T2D Research@T2DRemission](#)
[@bacigalupe](#) Urgh, I get commercials. Do I need to upgrade my [#hcs](#) service? ;^)
- 6:10 [HealthSocMed | #hcs@HealthSocMed](#)
TOPIC 1 - We talked months ago about FDA listening to SM- now they might. What should they listen for? What should pts know about this? [#hcs](#)
- 6:10 [Ann Becker-Schutte@DrBeckerSchutte](#)
MT [@HealthSocMed](#) TOPIC 1 - FDA listening to SM-now they might. What should they listen for? What should pts know about this? [#hcs](#)
- 6:11 [Alan Brewington@abrewi3010](#)
[@danamlewis](#) I forgot, my apologizes to you and diet Coke! :)
[#hcs](#)
- 6:11 [Robert Mahoney@mahoneyr](#)
And hopefully no long boring tearful speeches in [#hcs](#)
[@bacigalupe](#)
- 6:11 [Dana Lewis | #hcs@danamlewis](#)
T1 live at [#hcs](#) - FDA might start listening to SM now. Good or bad thing? What should they listen (&where)? What should pts/consumers know?

- 6:11 [Ronette LealMcCarthy@LealMcCarthy](#)
Will attempt to stay focused tonight but have to admit finding
Twitter [#oscar](#) posts quite amusing. [#hcs](#)m Legal counsel
[@CremationECC](#).
- 6:12 [Ann Becker-Schutte@DrBeckerSchutte](#)
Hi all, I'm Ann, a Kansas City psychologist, advocate for
integration of physical & mental health. [#hcs](#)m
- 6:12 [Ann Becker-Schutte@DrBeckerSchutte](#)
I mean, I guess we could integrate those. RT [@mahoneyr](#) And
hopefully no long boring tearful speeches in [#hcs](#)m
[@bacigalupe](#)
- 6:12 [Lurie Cancer Center@LurieCancer](#)
“[@HealthSocMed](#)-Some twitter clients/3rd party tools may be
slow tonight due to other activities on Twitter. Hang in there!
[#hcs](#)m [#oscar](#)”
- 6:13 [Alan Brewington@abrewi3010](#)
A1 it's got to be a good thing I would assume. Hopefully
patient stories will inspire them to move and innovate quicker
[#hcs](#)m
- 6:13 [Mark Ryan@RichmondDoc](#)
[#hcs](#)m I'd say the FDA's biggest role would likely be to monitor
what PhRMA and industry is saying and watching for
inappropriate recs.
- 6:14 [T2D Research@T2DRemission](#)
Q1 Government listening - i.e., publicly, re: policy - generally a
good thing. [#hcs](#)m

6:14 [Mark Ryan@RichmondDoc](#)
[#hcs](#) it would be interesting if they a,so used it for a forum to both connect with patient concerns/comments, watch for after-market issues

6:14 [T2D Research@T2DRemission](#)
Q1 [#hcs](#) FDA, if memory serves, is the only federal "Administration" created by popular demand.

6:14 [Lynnette Hoffman@NomadLynnette](#)
Can Australia improve [#mentalhealth](#) without increasing the budget? [medicalobserver.com.au/news/loose-cha...](#) [#hcs](#)

6:15 [Bill Wong@BillWongOT](#)
[@abrewi3010](#) good point. I also think helping consumers understand common facts and myths. [#hcs](#)

6:15 [Robert Mahoney@mahoneyr](#)
What about the government listening to people who aren't actually talking to them? [@T2DRemission](#) [#hcs](#)

6:15 [Real Talk Dr. Offutt@RTwithDrOffutt](#)
T1 [#hcs](#). Inappropriate marketing claims and safety signals.

6:15 [Mark Ryan@RichmondDoc](#)
Many times, meds are approved with the expectation for continued study and monitoring after release; SocMed could help with monitoring [#hcs](#)

6:15 [Alan Brewington@abrewi3010](#)
A1 the FDA will hopefully get a better idea of market (disease communities) needs. They will hopefully be able to regulate better [#hcs](#)

6:15 [Kati Debelic@Katiissick](#)
Just joined in, Kati here, 24/7 patient [#hcs](#)

6:16 [David Lee Scher, MD@dlschermd](#)
[#hcs](#) If [#pharma](#) is paying to monitor or buy data from SoMe to profit, why shouldn't FDA be permitted do it to monitor safety? [#hcs](#)

6:16 [Dana Lewis | #hcs@danamlewis](#)
(Wondering how they're going to listen; how they're going to staff it... [#hcs](#))

6:17 [Mark Ryan@RichmondDoc](#)
[@mahoneyr](#) I think that FDA skulking in patient communities or fora without making themselves visible would seem pretty sketchy. [#hcs](#)

6:17 [Robert Mahoney@mahoneyr](#)
I'd rather see the FDA participate in [#hcs](#), not just listen to it.

6:17 [T2D Research@T2DRemission](#)
[@mahoneyr](#) Heh. Can only speak for myself. Have been assuming I've been under surveillance for years. Makes public living easier. [#hcs](#)

6:17 [bacigalupe@bacigalupe](#)
Is there any federal agency not monitoring social media?
Important question is: Are they engaging productively? [#hcs](#)

6:17 [Dana Lewis | #hcs@danamlewis](#)
[@mahoneyr](#) how so, though? (re: participating) [#hcs](#)

6:17 [Kati Debelic@Katiissick](#)
[#FDA](#) needs to listen to SM, we are millions with [#mecfs](#) and
no drugs approved. Ampligen was turned down even though
it's working [#hcs](#)

6:17 [Jennifer Celio@JMCelio](#)
T1 - If [@US FDA](#) started "listening", could monitor
conversations about off label use...and devise appropriate
warnings in response. [#hcs](#)

6:17 [Mark Ryan@RichmondDoc](#)
[@danamlewis](#) Seriously. Good luck with screening all of
SocMed for certain key phrases, issues, etc. seems pretty
impossible. [#hcs](#)

6:17 [Alan Brewington@abrewi3010](#)
A1 if the FDA is smart they will staff it will epatients and
advocates. Keep the focus patient centered by doing that
[#hcs](#)

6:17 [Real Talk Dr. Offutt@RTwithDrOffutt](#)
[@danamlewis](#) [#hcs](#). I do think they are woefully
underresourced.

6:18 [Ann Becker-Schutte@DrBeckerSchutte](#)
RT [@abrewi3010](#) A1 if the FDA is smart they will staff it will
epatients and advocates. Keep the focus patient centered by
doing that [#hcs](#)

6:18 [Robert Mahoney@mahoneyr](#)
Agreed. Although I'm not sure what they would possibly gain
from doing that. [@RichmondDoc](#) [#hcs](#)

6:18 [Kati Debelic@Katiissick](#)
RT [@abrewi3010](#) A1 if the FDA is smart they will staff it will
epts and advocates. Keep the focus patient centered by doing
that [#hcs](#) [#hcs](#)

6:18 [OneGrenouille@onegrenouille](#)
T1 - ongrenouille - pt here - question role of e-petitions created
by pt organizations... eg midodrine - did / does that play role
[#hcs](#)

6:18 [T2D Research@T2DRemission](#)
[@RichmondDoc](#) [@mahoneyr](#) That's why I specified publicly. I
wonder, though, if I really object to data mining. [#hcs](#)

6:18 [Mark Salke@marksalke](#)
Yes. Be a participant, bring value. Just like anyone. RT
[@mahoneyr](#): I'd rather see the FDA participate in [#hcs](#), not
just listen to it.

6:19 [Mark Ryan@RichmondDoc](#)
[@danamlewis](#) I suspect they'd listening my monitoring key
accounts and developing some clever automated search tool...
[#hcs](#)

6:19 [Steven Incontrera@Steven_Paul](#)
[@mahoneyr](#) all the big guys ever want to do is listen. Don't
forget the government shutdown all their twitter handles went
dark. [#hcs](#)

6:19 [Mark Ryan@RichmondDoc](#)
(by, not my) [#hcs](#)

6:19 [David Lee Scher, MD@dlschermd](#)
[@mahoneyr](#) "Can't for same reason they don't offer opinions
just facts at conferences. [#hcs](#)

6:19 [Bill Wong@BillWongOT](#)
[@mahoneyr](#) the best they can do is to have reps to participate
in chats like this, I think. [#hcs](#)

6:19 [P. F. Anderson@pfanderson](#)
[@danamlewis](#) Yeah, during the initial [#FDAsm](#) meeting, they
seemed overwhelmed at the idea of scraping [#hcs](#) [#SoMe](#)
for early adverse rxns

6:20 [Steven Incontrera@Steven_Paul](#)
[@dlschermd](#) You are right there [#Pharma](#) is for sure paying
for SoMe user data. [#hcs](#)

6:20 [AnnMarie Walsh@padschicago](#)
RT [@Steven_Paul](#) [@dlschermd](#) You are right there [#Pharma](#)
is for sure paying for SoMe user data. [#hcs](#)

6:20 [P. F. Anderson@pfanderson](#)
[@Katiissick](#) [@abrewi3010](#) There was talk abt creating brief
hashtags for ea med for automated FDA tracking [#hcs](#)

6:20 [Kati Debelic@Katiissick](#)
FDA has been the US agency which has listened the most to
[#mecfs](#) patients. [#hcs](#)

6:21 [T2D Research@T2DRemission](#)
[@abrewi3010](#) Did you get that, FDA? [#hcs](#)

6:21 [Mark Salke@marksalke](#)
[@mahoneyr](#) [@danamlewis](#) Great point, Robert. FDA would
have to invoke a sm policy and empower associates to
participate. [#hcs](#)

6:21 [P. F. Anderson@pfanderson](#)
[@mahoneyr](#) [@RichmondDoc](#) Early warnings on adverse
events, nonstandard uses, etc. [#hcs](#)

6:21 [AnnMarie Walsh@padschicago](#)
RT [@T2DRemission](#) [@abrewi3010](#) Did you get that, FDA?
[#hcs](#)

- 6:21 [Bill Wong@BillWongOT](#)
[@mahoneyr](#) I know we have a regular [#dchat](#) on Wednesdays organized by [@LDorg](#) [#hcs](#)[m](#)
- 6:22 [Mark Salke@marksalke](#)
Good to hear! RT [@Katiissick](#): FDA has been the US agency which has listened the most to [#mecfs](#) patients. [#hcs](#)[m](#)
- 6:22 [Robert Mahoney@mahoneyr](#)
I would be hard for one tweeter to try to represent the whole FDA in [#hcs](#)[m](#) [@BillWongOT](#)
- 6:22 [Kati Debelic@Katiissick](#)
[@DocForeman](#) [@pfanderson](#) [@abrewi3010](#) I think FDA needs to use current HC hashtags and get involved in the discussions [#hcs](#)[m](#)
- 6:22 [Mark Salke@marksalke](#)
Oh it's very possible, Mark. [#hcs](#)[m](#) [@RichmondDoc](#)
[@danamlewis](#)
- 6:23 [Mark Ryan@RichmondDoc](#)
[@pfanderson](#) of course, the automated hashtag tracking only works if people use them; will need to find uses that omit it...
[#hcs](#)[m](#)
- 6:23 [Alan Brewington@abrewi3010](#)
[@RichmondDoc](#) no matter what their role is it should always be based on the idea of patient centered participatory med.
[#hcs](#)[m](#)

6:23 [Mark Salke@marksalke](#)
[@JMCelio](#) [@US_FDA](#) Are people having those convos in sm,
Jennifer? [#hcs](#)

6:23 [Mark Ryan@RichmondDoc](#)
[@pfanderson](#) ...whether that omission be by accident or by
choice. Anyone talking off label would be silly to use the
hashtag. [#hcs](#)

6:23 [Steven Incontrera@Steven_Paul](#)
[@abrewi3010](#) So right those advocates are becoming
[#DigitalHealth](#) Superstars [#hcs](#)

6:23 [Kati Debelic@Katiissick](#)
RT [@abrewi3010](#) [@RichmondDoc](#) no matter what their role is
it should always be based on the idea of pt centered
participatory med. [#hcs](#) [#hcs](#)

6:24 [Jim Rattray@jimrattray](#)
[@abrewi3010](#) [@RichmondDoc](#) if they can help give patients a
stronger voice, it would be a good thing [#hcs](#)

6:24 [AnnMarie Walsh@padschicago](#)
RT [@jimrattray](#) [@abrewi3010](#) [@RichmondDoc](#) if they can help
give patients a stronger voice, it would be a good thing [#hcs](#)

6:24 [P. F. Anderson@pfanderson](#)
[@RichmondDoc](#) You will notice the idea hasn't flown. But it
could. A lot of programming involved, and AI [#hcs](#)

- 6:24 [Mark Salke@marksalke](#)
Hey, US_FDA, I'm available! :) RT [@RTwithDrOffutt](#):
[@danamlewis](#) [#hcs](#)m. I do think they are woefully
underresourced.
- 6:25 [Jennifer Celio@JMCelio](#)
[@marksalke](#) [@US_FDA](#) I couldn't cite specific examples, but
would imagine so, particularly in patient to patient dialogues.
[#hcs](#)m
- 6:25 [Mark Ryan@RichmondDoc](#)
[@padschicago](#) [@jimrattray](#) [@abrewi3010](#) I guess I'm
skeptical. I don't think this is their role, even if I agree with the
premise. [#hcs](#)m
- 6:25 [Kati Debelic@Katiissick](#)
SM reaches out to patients who are left behind by the current
HC system. And there are a whole bunch of us. [#hcs](#)m
- 6:25 [P. F. Anderson@pfanderson](#)
[@RichmondDoc](#) Which is why scraping/tracking wd also have
to use proper names, common misspellings ... [#hcs](#)m
- 6:25 [Alan Brewington@abrewi3010](#)
[@jimrattray](#) [@RichmondDoc](#) I've got to believe if regulatory
function is based around patient centered ideas the market will
follow [#hcs](#)m
- 6:25 [bacigalupe@bacigalupe](#)
Do you imagine a fed employee engaging with folks at 9 PM
on a sunday? T1 [#hcs](#)m

6:26 [Mark Salke@marksalke](#)
Change of paradigm. Yes! RT [@bacigalupe](#): Do you imagine a fed employee engaging with folks at 9 PM on a sunday? T1 [#hcs](#)

6:26 [Mark Ryan@RichmondDoc](#)
Here is the FDA's mission. For better or worse, no mention of enhancing participatory health care. [#hcs](#) fda.gov/aboutfda/whatw...

6:26 [T2D Research@T2DRemission](#)
[@RichmondDoc](#) [@padschicago](#) [@jimrattray](#) [@abrewi3010](#)
Skepticism becomes you. [#hcs](#)

6:27 [Alan Brewington@abrewi3010](#)
[@bacigalupe](#) why not? [#hcs](#)

6:27 [Ann Becker-Schutte@DrBeckerSchutte](#)
MT [@RichmondDoc](#) Here is FDA's mission. For better or worse, no mention of enhancing participatory health care. [#hcs](#) fda.gov/aboutfda/whatw...

6:27 [AnnMarie Walsh@padschicago](#)
RT [@RichmondDoc](#) Here is FDA's mission. For better or worse, no mention of enhancing participatory health care. fda.gov/aboutfda/whatw... [#hcs](#)

- 6:27 [AnnMarie Walsh@padschicago](#)
RT [@RichmondDoc](#) Here is FDA's mission. For better or worse, no mention of enhancing participatory health care. goo.gl/mB5pmp [#hcs](#)
- 6:27 [Mark Ryan@RichmondDoc](#)
In this political climate, I do t see the FDA getting \$ or authority to expand its role further. [#hcs](#) fda.gov/aboutfda/whatw...
- 6:27 [P. F. Anderson@pfanderson](#)
[@Katiissick](#) [@DocForeman](#) [@abrewi3010](#) I suspect there R v good reasons why they R standoffish. Still, individuals in FDA instead of org [#hcs](#)
- 6:27 [Jennifer Chevinsky@jchevinsky](#)
T1 If [@US_FDA](#) looking to honestly & seriously engage w patient populations & advocates- I'm sure many willing to share thoughts! [#hcs](#)
- 6:28 [Ann Becker-Schutte@DrBeckerSchutte](#)
Even if there are practical barriers to engagement now, it makes sense to think about our desired outcomes. [#hcs](#)
- 6:28 [Mark Salke@marksalke](#)
There ya go. Thx, Erin! RT [@ekeeley Moore](#): [@JMCelio](#) [@US_FDA](#) Places like [@smart_patients](#) help to facilitate just that [#hcs](#)
- 6:28 [David Lee Scher, MD@dlschermd](#)
[@Katiissick](#) SoMe is a multidirectional forum for those with a common goal of eliminating barriers to good healthcare. [#hcs](#)

6:28 [OneGrenouille@onegrenouille](#)
[@RichmondDoc](#) [@pfanderson](#) Worry pt advocates use rxes
off label & push to use med as on label for that disorder. I
know of +1 for my dx [#hcs](#)

6:28 [Ann Becker-Schutte@DrBeckerSchutte](#)
MT [@jchevinsky](#) If [@US_FDA](#) looking to honestly & seriously
engage w pts & advocates- I'm sure many willing to share
thoughts! [#hcs](#)

6:28 [T2D Research@T2DRemission](#)
[@bacigalupe](#) FDA? Dunno. White House food-drug policy?
Yup. [#hcs](#)

6:28 [bacigalupe@bacigalupe](#)
[@mahoneyr](#) [@abrewi3010](#) seriously and curiously asking, if it
is happening, it would be good to know [#hcs](#)

6:28 [Kati Debelic@Katiissick](#)
[@jchevinsky](#) [@US_FDA](#) they have engaged with [#mecfs](#) pts
and have proven they have listened, but pharma needs to get
engaged too. [#hcs](#)

6:28 [Ann Becker-Schutte@DrBeckerSchutte](#)
RT [@dlschermd](#) [@Katiissick](#) SoMe is a multidirectional forum
for those with a common goal of eliminating barriers to good
healthcare. [#hcs](#)

6:29 [Ann Becker-Schutte@DrBeckerSchutte](#)
RT [@marksalke](#) There ya go. Thx, Erin! RT [@ekeeley Moore](#):
[@JMCelio](#) [@US_FDA](#) Places like [@smart_patients](#) help to
facilitate just that [#hcs m](#)

6:29 [Jennifer Celio@JMCelio](#)
Thanks for the resource! RT [@ekeeley Moore](#) [@JMCelio](#)
[@marksalke](#) [@US_FDA](#) Places like [@smart_patients](#) help to
facilitate just that [#hcs m](#)

6:29 [Mark Ryan@RichmondDoc](#)
[@abrewi3010](#) [@jimrattray](#) I can't say FDA is all that focused
on patient-centered ideas. Much of the budget comes from
industry fees. [#hcs m](#)

6:29 [Terry Kind, MD MPH@Kind4Kids](#)
[@meganranney](#) the mention of ad hoc communicators is ripe
for twitter! [papers.ssrn.com/sol3/papers.cf...](#) [@SusannahFox](#)
[@lawrenceswiader](#) [#hcs m](#)

6:29 [Kati Debelic@Katiissick](#)
[@ekeeley Moore](#) absolutely I agree [#hcs m](#)

6:29 [HealthSocMed | #hcs m@HealthSocMed](#)
Moving on to T2 (topic 2) in a few minutes! [#hcs m](#)

6:29 [Bill Wong@BillWongOT](#)
[@bacigalupe](#) they should take the example of [@AOTAInc](#) and
[@AOTAInc](#) PR tonight for [#otalk2us](#). [#hcs m](#)

- 6:29 [bacigalupe@bacigalupe](#)
T1: We also need to remember that less than 10% of population has an account in twitter, and of those majority don't use it. [#hcsn](#)
- 6:30 [Mark Ryan@RichmondDoc](#)
[@onegrenouille](#) [@pfanderson](#) the FDA would prevent companies from promoting off-label; docs and pts can use off label as needed. [#hcsn](#)
- 6:30 [Jim Rattray@jimrattray](#)
[@RichmondDoc](#) [@abrewi3010](#) HHS is a more likely and appropriate agency. [#hcsn](#)
- 6:30 [Kati Debelic@Katiissick](#)
[@RichmondDoc](#) [@abrewi3010](#) [@jimrattray](#) that's a problem bc industry is looking at making money. Cancer, HIV and weight loss. [#hcsn](#)
- 6:31 [OneGrenouille@onegrenouille](#)
[@pfanderson](#) In this case, drug specifically for only one dx due to necessity. Worry knowledge of high off label use could causepull [#hcsn](#)
- 6:31 [Erin Moore@ekeeley Moore](#)
[@RichmondDoc](#) [@T2DRemission](#) So could [#PRO](#) data [#hcsn](#)
- 6:31 [Jim Rattray@jimrattray](#)
[@abrewi3010](#) [@bacigalupe](#) [@mahoneyr](#) Government can do 24/7 ... when it puts its mind to it. [#hcsn](#)

6:31 [Bill Wong@BillWongOT](#)
[@m360health](#) it will take fellow doctors who are brave to educate AND not preach to the choir. [#hcs](#)

6:31 [Alan Brewington@abrewi3010](#)
[@RichmondDoc](#) [@jimratray](#) it should be more patient centered. Industry needs to remember its patients buying products. [#hcs](#)

6:31 [T2D Research@T2DRemission](#)
[@RichmondDoc](#) Thanks for reality check. Not seeing it as exclusionary. OTOH, any attempt to expand their brief always polarizing. [#hcs](#)

6:31 [HealthSocMed | #hcs@HealthSocMed](#)
TOPIC 2 - Is it (ethical? fair? pick your favorite word.) for a patient to live-tweet a HC experience? Why/not? What does it mean to HCPs?

6:32 [Kati Debelic@Katiissick](#)
RT [@BillWongOT](#) [@m360health](#) it will take fellow doctors who are brave to educate AND not preach to the choir. [#hcs](#)
[#hcs](#)

6:32 [Dana Lewis | #hcs@danamlewis](#)
T2 at [#hcs](#) - Is it (ethical? fair? pick a favorite word.) for a patient to live-tweet a HC experience? Why/not? What does it mean to HCPs?

- 6:32 [Mark Ryan@RichmondDoc](#)
[@jimrattray](#) [@abrewi3010](#) Agree--[@HHSGov](#) would seem more likely to be interested in pt-centered care and ideas than the [@US_FDA](#) [#hcs](#)
- 6:32 [OneGrenouille@onegrenouille](#)
[@RichmondDoc](#) [@pfanderson](#) So sorry, was unclear, this drug just now approved for only 1 dx out of med necessity. Worry will be pulled [#hcs](#)
- 6:33 [P. F. Anderson@pfanderson](#)
[@RichmondDoc](#) [@onegrenouille](#) Exactly. Wouldn't want 2C promotion of off-label, but do want to know what off-label uses patients like [#hcs](#)
- 6:33 [Mark Ryan@RichmondDoc](#)
[@abrewi3010](#) [@jimrattray](#) PhRMS does very well by selling sickness and expanding indications for meds. No need to be pt-centered. [#hcs](#)
- 6:33 [Jim Rattray@jimrattray](#)
T2 [@danamlewis](#) Totally fair — and fair game. We should expect it — and engage! [#hcs](#)
- 6:33 [bacigalupe@bacigalupe](#)
[@abrewi3010](#) [@mahoneyr](#) for anything related to health, 9 to 5 has always been an antiqued taken for granted idea [#hcs](#)
- 6:33 [Mark Ryan@RichmondDoc](#)
[@abrewi3010](#) [@jimrattray](#) I think they'll talk a good game and make themselves seem like pt allies, but remember \$ is bottom line [#hcs](#)

- 6:34 [Ann Becker-Schutte@DrBeckerSchutte](#)
A2: I think it's entirely fair. Might detract from therapy. . .but patients/clients own their experience and can share. [#hcs](#)
- 6:34 [Dan Goldman@danielg280](#)
T2: it's their health info, so their right whether to make it public [#hcs](#)
- 6:34 [April Foreman@DocForeman](#)
[@danamlewis](#) As as HCP, the words, "Don't fuck it up" come to mind. [#hcs](#)
- 6:34 [Ann Becker-Schutte@DrBeckerSchutte](#)
Yes. This. RT [@jimrattray](#) T2 [@danamlewis](#) Totally fair — and fair game. We should expect it — and engage! [#hcs](#)
- 6:34 [Amy Steinmann@amyconchetta](#)
[@HealthSocMed](#) even if it's not ethical, fair, how would HCPs prevent it from happening? [#hcs](#)
- 6:34 [Jennifer Chevinsky@jchevinsky](#)
T2 IMO pt should be able to live tweet anything about own experiences; no ethical issue UNLESS tweet about other patients [#bioethx](#) [#hcs](#)
- 6:34 [Mark Salke@marksalke](#)
A2: Why not? Personal choice. I can't imagine a Px I'd wanna share tho. [@katiecouric](#) did a colonoscopy on tv, didn't she? [#hcs](#)

6:34 [Kati Debelic@Katiissick](#)
RT [@DrBeckerSchutte](#) A2: I think it's entirely fair. Might detract from therapy. . .but pts own their experience and can share. [#hcs](#) [#hcs](#)

6:34 [Alan Brewington@abrewi3010](#)
[@RichmondDoc](#) [@jimrattray](#) there is always a need to be patient centered. We are the consumers & only true experts on our bodies [#hcs](#)

6:35 [Ann Becker-Schutte@DrBeckerSchutte](#)
A2: The ethical right to maintain confidentiality is with the HCP--patients can share any of their OWN experience. [#hcs](#)

6:35 [✨Anna✨@smanna750](#)
That is why I started my twitter. To educate people about my disease's. I don't have my phone in hand while they are in the room. [#hcs](#)

6:35 [Jennifer Celio@JMCelio](#)
T2 - Read an article recently about mutual respect btw HCP and pt and use of devices. Both parties benefit from being fully present. [#hcs](#)

6:35 [Dana Lewis | #hcs@danamlewis](#)
(Should pts *tell* the HCPs they are doing it? [#hcs](#))

- 6:35 [Real Talk Dr. Offutt@RTwithDrOffutt](#)
T2 [#hcs](#)m. Ethical Ok for patient. Certainly not the other way!
Could be useful to support other pts going thru same
experience .
- 6:35 [April Foreman@DocForeman](#)
[@DrBeckerSchutte](#) As a therapist who had a pt. secretly
broadcast a therapy session...It's "fair" but does affect HC
relationship. [#hcs](#)m
- 6:35 [Mark Salke@marksalke](#)
A2a: Re: HCP identification, tho. Hmm... requiring some new
form of consent, by each? [#hcs](#)m
- 6:36 [Ann Becker-Schutte@DrBeckerSchutte](#)
MT [@RTwithDrOffutt](#) T2 [#hcs](#)m. Ethical Ok for pt. Certainly not
other way! Could be useful to support other pts going thru
same experience .
- 6:36 [Dr. David Tom Cooke@UCD_ChestHealth](#)
[#hcs](#)m T2 unrealistic to not expect patients to engage
experience on twitter as they do for non healthcare
experiences
- 6:36 [April Foreman@DocForeman](#)
[@danamlewis](#) Patients don't have to "tell" but they should, as
the quality of the HC relationship w/ their provider is impt.
[#hcs](#)m
- 6:36 [Alan Brewington@abrewi3010](#)
A2 it is fair. It's a patient experience fully owned by the patient.
[#hcs](#)m

6:36 [ravi nambiar@ravi_nambiar](#)
[@danamlewis](#) [#hcs](#) do not know how providers can deal
with the public, patient engagement is listening, observing and
communicating-not easy

6:36 [Dan Goldman@danielg280](#)
T2: In most circumstances provider could choose not to treat if
it's going to be "broadcast" that way. [#hcs](#)

6:36 [Ann Becker-Schutte@DrBeckerSchutte](#)
[@danamlewis](#) I would hope that my clients felt comfortable
telling me. And I might notice that. . . [#hcs](#)

6:36 [Robert Mahoney@mahoneyr](#)
T2 I'd be worried that HC experience might become more
about engaging one's followers and less about engaging the
HCP's. [#hcs](#)

6:37 [Kati Debelic@Katiissick](#)
T2 usually pts tweet about their medical experience when
things are unacceptable. like waiting for a dr for 3-4 hours.
[#hcs](#)

6:37 [Dan Goldman@danielg280](#)
We face that issue when patients want to video an encounter
to put on youtube. Out Providers can decline [#hcs](#)

6:37 [Jim Rattray@jimrattray](#)
[@danielg280](#) It's already being broadcast. You should expect it. [#hcs](#)

6:37 [Jennifer Celio@JMCelio](#)
T2 - Reaching out as a patient during (often) scary situations can be very comforting, and SM can bridge virtual support systems. [#hcs](#)

6:37 [April Foreman@DocForeman](#)
[@danielg280](#) And the laws about taping and broadcasting w/o consent vary from state to state. [#hcs](#)

6:37 [Ann Becker-Schutte@DrBeckerSchutte](#)
RT [@danielg280](#) We face that issue when patients want to video an encounter to put on youtube. Out Providers can decline [#hcs](#)

6:38 [Ann Becker-Schutte@DrBeckerSchutte](#)
RT [@DocForeman](#) [@danielg280](#) And the laws about taping and broadcasting w/o consent vary from state to state. [#hcs](#)

6:38 [Mark Ryan@RichmondDoc](#)
[@abrewi3010](#) [@jimrattray](#) And I think the [#ePatient](#) community must be constantly on the watch for co-opting from big industry. [#hcs](#)

6:38 [P. F. Anderson@pfanderson](#)
[@jchevinsky](#) Ditto pictures. Especially pictures! [#hcs](#)

- 6:38 [Ann Becker-Schutte@DrBeckerSchutte](#)
RT [@BillWongOT](#) [@danamlewis](#) yes, I think so. It will also help the professionals to know if they follow their patients accidentally. [#hcsn](#)
- 6:38 [Jim Rattray@jimrattray](#)
[@UCD_ChestHealth](#) [@danamlewis](#) Yes, because let's have the discussion IN REAL LIFE first. That's where it truly matters! [#hcsn](#)
- 6:38 [Ann Becker-Schutte@DrBeckerSchutte](#)
MT [@JMCelioReaching](#) out as a patient during (often) scary situations can be very comforting, & SM can bridge virtual support systems. [#hcsn](#)
- 6:38 [Jim Rattray@jimrattray](#)
[@RichmondDoc](#) [@abrewi3010](#) Right on! [#hcsn](#)
- 6:38 [Jennifer Chevinsky@jchevinsky](#)
T2 Can HCPs refuse to treat the 'negative tweeters?' ...don't want to end up on 'cover of twitter' next day [#bioethx](#) [#hcsn](#)
- 6:38 [Ann Becker-Schutte@DrBeckerSchutte](#)
RT [@jimrattray](#) [@UCD_ChestHealth](#) [@danamlewis](#) Yes, because let's have the discussion IN REAL LIFE first. That's where it truly matters! [#hcsn](#)
- 6:39 [Alan Brewington@abrewi3010](#)
A2 I think patients should tell doc that their live tweeting. Only fair that all participates know what is happening. [#hcsn](#)

6:39 [bacigalupe@bacigalupe](#)
Adults or those of privilege always scared of social media use employed by the less powerful (the young, the patient). Get over it [#hcsmt2](#)

6:39 [Mark Ryan@RichmondDoc](#)
[@abrewi3010](#) [@jimrattray](#) Dint get me wrong--I agree w/ you. But PhRMA only cares about \$, and selling as many meds as possible. [#hcsmt2](#)

6:39 [Dan Goldman@danielg280](#)
[@jimrattray](#) Typically you know when video is being taken, so ability to discuss implications [#hcsmt2](#)

6:39 [OneGrenouille@onegrenouille](#)
T2 - as pt blogging hospital exp w/o naming it got response. Complaints didn't. If HCP knew, could better pt care. Cathartic for pt. [#hcsmt2](#)

6:39 [Ann Becker-Schutte@DrBeckerSchutte](#)
RT [@DocForeman](#) Yes. And I think it's imp't to find out WHY a pt. wants to broadcast a HC experience. Desired outcome makes a diff. [#hcsmt2](#)

6:39 [Jim Rattray@jimrattray](#)
[@danielg280](#) One word, one product: Glass! [#hcsmt2](#)

6:40 [P. F. Anderson@pfanderson](#)
[@RichmondDoc](#) [@onegrenouille](#) [@HHSGov](#) Agreed. But if setting up a tracking system, perhaps interagency cooperation wd benefit us all [#hcsmt2](#)

6:40 [Jim Rattray@jimrattray](#)
[@DrBeckerSchutte](#) [@DocForeman](#) Usually because nobody
in real life listens! [#hcs](#)

6:40 [Ann Becker-Schutte@DrBeckerSchutte](#)
MT [@bacigalupe](#) Adults/those of privilege always scared of
social media use employed by less powerful (young, patient).
Get over it [#hcs](#) T2

6:40 [Robert Mahoney@mahoneyr](#)
I don't think neg. tweeting constitutes grounds to fire a patient
but might have to rethink effectiveness of relationship
[@jchevinsky](#) [#hcs](#)

6:40 [Ann Becker-Schutte@DrBeckerSchutte](#)
[@jimrattray](#) [@DocForeman](#) See, that's a mental health bias--
the listening is built in/expected. [#hcs](#)

6:40 [Mark Ryan@RichmondDoc](#)
T2 Patients have a right to share their experiences. I think it
would be kosher, though, to let HCPs know they're doing it.
[#hcs](#)

6:41 [April Foreman@DocForeman](#)
[@DrBeckerSchutte](#) [@bacigalupe](#) My situation was MUCH
more complex than that, and I am very tech comfortable. The
"why" is impt. [#hcs](#)

6:41 [Kati Debelic@Katiissick](#)
[@trackeractivity](#) [@jchevinsky](#) usually good physicians don't get that kind of problem. [#hcs](#)

6:41 [Kati Debelic@Katiissick](#)
[#hcs](#)

6:41 [Jim Rattray@jimrattray](#)
[@RichmondDoc](#) When HCPs listen, the tweets/posts are positive. Negativity comes from being ignored or misunderstood. [#hcs](#)

6:41 [Annette McKinnon@anetto](#)
T2 I would really like to get audio of dr sometimes, but not to broadcast. Would have an effect on conversatiion [#hcs](#)

6:41 [Dan Goldman@danielg280](#)
[@DrBeckerSchutte](#) [@DocForeman](#) True state laws impact taping a convo however most states allow taping a convo if only one party consents [#hcs](#)

6:41 [bacigalupe@bacigalupe](#)
Whenever HCPs think a piece of their power goes away because patients could make them accountable, they ask for restraint and study. [#hcs](#)

6:41 [AnnMarie Walsh@padschicago](#)
I have done limited tweeting during med appointments with PCP. Of the few times I did any tweeting I told him abt it & what I said. [#hcs](#)

6:41 [ravi nambiar@ravi_nambiar](#)
[#hcs](#) my experience is most are understand and communicate timely, then there are those who can be negative and take all your time.

6:42 [Howard Luks MD@hjluks](#)
Page edited: Do I Need Meniscus Tear Surgery?
[howardluksm.com/meniscus-tear-...](#) - The meniscus is one of the mor [#hcs](#)

6:42 [P. F. Anderson@pfanderson](#)
[@mahoneyr](#) [@jchevinsky](#) Many would, however. They get nervous. I know of a doc who fired cancer patient for requesting a pain consult [#hcs](#)

6:42 [Kati Debelic@Katiisick](#)
RT [@jimrattray](#) [@RichmondDoc](#) When HCPs listen, the tweets/posts are positive. Negativity comes from being ignored or misunderstood. [#hcs](#) [#hcs](#)

6:42 [Jim Rattray@jimrattray](#)
[@mahoneyr](#) [@danielg280](#) I agree. But Glass will evolve and you will soon not know when someone is wearing it! [#hcs](#)

6:42 [Jennifer Chevinsky@jchevinsky](#)
Agree, but also think unfair if pt takes 2 twitter prior 2 speaking 2 HCP & allowing for chance 2 address issue [@mahoneyr](#)
[#hcs](#) [#bioethx](#)

- 6:42 [Real Talk Dr. Offutt@RTwithDrOffutt](#)
[@mahoneyr](#) [@jchevinsky](#) agreed. Doctors are people with feelings too! [#hcs](#)
- 6:42 [bacigalupe@bacigalupe](#)
As soon as something like GoogleGlass become mainstream, then the change will be driven by the patients using it, not the doctors. [#hcs](#)
- 6:42 [Alan Brewington@abrewi3010](#)
[@RichmondDoc](#) [@jimrattray](#) that's were thee patient earns their fancy title, is it beneficial to a patient or just there to make \$ [#hcs](#)
- 6:43 [AnnMarie Walsh@padschicago](#)
RT [@RTwithDrOffutt](#) [@mahoneyr](#) [@jchevinsky](#) agreed. Doctors are people with feelings too! [#hcs](#)
- 6:43 [P. F. Anderson@pfanderson](#)
[@mahoneyr](#) [@jimrattray](#) [@danielg280](#) Our buses used to have a sign saying no photos allowed on bus. Now everyone has phone out, gave up [#hcs](#)
- 6:43 [Jim Rattray@jimrattray](#)
[@padschicago](#) [@RTwithDrOffutt](#) [@mahoneyr](#) [@jchevinsky](#)
Yes, but they must address their patients' feelings first! [#hcs](#)
- 6:43 [Jennifer Chevinsky@jchevinsky](#)
[@pfanderson](#) [@mahoneyr](#) In hospital setting I thnk it wouldnt be firing as much as sending the resident to see patient instead! [#hcs](#) [#bioethx](#)

6:43 [Robert Mahoney@mahoneyr](#)
(should clarify: I mean pt would be wearing Glass. I hope it goes w/o saying that providers don't wear it) [@jimrattray](#)
[@danielg280](#) [#hcs](#)

6:44 [April Foreman@DocForeman](#)
[@bacigalupe](#) ...everything correctly, and see what you think.
Trusting the pt. and having the pt. trust you is part of good HC.
[#hcs](#)

6:44 [ravi nambiar@ravi_nambiar](#)
[@ravi_nambiar](#) [#hcs](#) i think one on one is best way for
provider to communicate and also for the patient, to reduce
misunderstandings?

6:45 [Robert Mahoney@mahoneyr](#)
Indeed. And that terrifies me. Our technology will no doubt
have outstripped our etiquette at that point. [@jimrattray](#)
[@danielg280](#) [#hcs](#)

6:45 [OneGrenouille@onegrenouille](#)
+1 "[@jimrattray](#) - [@DrBeckerSchutte](#) [@DocForeman](#) Usually
because nobody in real life listens!" Where is
[@HospitalPatient](#) ... [#hcs](#)

6:45 [HealthSocMed | #hcs@HealthSocMed](#)
Good T2 - moving on to T3 shortly! [#hcs](#)

6:45 [Real Talk Dr. Offutt@RTwithDrOffutt](#)
[@jimrattray](#) [@padschicago](#) [@mahoneyr](#) [@jchevinsky](#) [#hcsn](#).
Yes, there must be mutual respect for the care relationship to
be open and effective.

6:45 [P. F. Anderson@pfanderson](#)
[@jchevinsky](#) [@mahoneyr](#) I'm thinking more rural. The
oncologist in this story was only 1 covered by insurance plan.
Captive audience [#hcsn](#)

6:45 [April Foreman@DocForeman](#)
[@RTwithDrOffutt](#) [@mahoneyr](#) [@jchevinsky](#) Yeah. Recording
people w/o their knowledge doesn't build a therapeutic
relationship. [#hcsn](#)

6:45 ✨[Anna](#) ✨[@smanna750](#)
Have never done it, but I think it would be helpful to be able to
tape my convo's w/my Dr's. By the time I get home I forget
things [#hcsn](#)

6:45 [Ann Becker-Schutte@DrBeckerSchutte](#)
RT [@DocForeman](#) Yeah. Recording people w/o their
knowledge doesn't build a therapeutic relationship. [#hcsn](#)

6:45 [HealthSocMed | #hcsn@HealthSocMed](#)
TOPIC 3 - Are online communities same as pt support
groups? What can IRL support groups learn from online
communities & vice versa? [#hcsn](#)

- 6:45 [Ann Becker-Schutte@DrBeckerSchutte](#)
MT [@smanna750](#) I think it would be helpful to be able to tape my convo's w/my Dr's. By the time I get home I forget things [#hcsn](#)
- 6:46 [Kati Debelic@Katiissick](#)
Patients use SM because there is nowhere else to turn. [#hcsn](#)
- 6:46 [Jim Rattray@jimrattray](#)
[@JA_Davids](#) Live tweeting is usually less about helping others and more about seeking attention/venting. [#hcsn](#)
- 6:46 [Mark Ryan@RichmondDoc](#)
[@jchevinsky](#) agree the the nature of the tweet matters. Tweeting educational info? Sharing experiences? Or angry venting? [#hcsn](#)
- 6:46 [Annette McKinnon@anetto](#)
T2 Might not be such an issue if patients had access to records, diagnosis, health goals [#hcsn](#)
- 6:46 [Bill Wong@BillWongOT](#)
[@ravi_nambiar](#) sometimes I will allow my clients' NT roommates (as my clients r autistic and they r assigned some) too in my sessions. [#hcsn](#)
- 6:47 [Robert Mahoney@mahoneyr](#)
Im always surprised how pts will cont to see doctor they have such strong negative feelings about. Maybe no other option. [@jchevinsky](#) [#hcsn](#)

- 6:47 [Jennifer Chevinsky@jchevinsky](#)
T3 Online vs IRL pt support groups: ..Not 'the same' ...but maybe a cousin? [#hcs](#)
- 6:47 [Jim Rattray@jimrattray](#)
T3 [@HealthSocMed](#) They are the NEW support group! Crowdsourcing healthcare ideas is hot and hip! [#hcs](#)
- 6:47 [bacigalupe@bacigalupe](#)
Online patients communities are sustainable if they are real communities. That we know a lot about. [#hcs](#)
- 6:47 [Ann Becker-Schutte@DrBeckerSchutte](#)
MT [@HealthSocMed](#) T3 Are online communities same as pt support groups? What can IRL support groups learn from online com & vice versa? [#hcs](#)
- 6:47 [AnnMarie Walsh@padschicago](#)
I think in online groups people tend to be more honest and open with each other. IRL groups many are afraid to be judged. [#hcs](#)
- 6:48 [bacigalupe@bacigalupe](#)
An online patient community is always real, doesn't matter if most interactions are virtual. [#hcs](#)
- 6:48 [Annette McKinnon@anetto](#)
T3 Some online communities are for profit or for pharma so not really patient support groups [#hcs](#)

6:48 [Jim Rattray@jimrattray](#)
[@padschicago](#) Creating a hybrid between online/IRL is the
sweet spot! [#hcs](#)

6:48 [Jennifer Chevinsky@jchevinsky](#)
T3 more flexible/'attendable' online... but more sense of
privacy IRL [#bioethx](#) [#hcs](#)

6:48 [Bill Wong@BillWongOT](#)
[@danamlewis](#) I think virtually they are similar. Online though,
can be a lot more convenient. [#hcs](#)

6:48 [Mark Ryan@RichmondDoc](#)
[@jchevinsky](#) Physicians can terminate a Dr/Pt relationship for
any reason, so long as done properly and w/o abandoning the
pt. [#hcs](#)

6:48 [Real Talk Dr. Offutt@RTwithDrOffutt](#)
T3 [#hcs](#). Like a ven diagram... There certainly is overlap.
Especially true in remote areas or hard to access people with
same issues live.

6:49 [Ann Becker-Schutte@DrBeckerSchutte](#)
If pt centered/led. RT [@bacigalupe](#) An online patient
community is always real, doesn't matter if most interactions
are virtual. [#hcs](#)

6:49 [Jim Rattray@jimrattray](#)
[@BillWongOT](#) [@danamlewis](#) Online, nobody is excluded.
[#hcs](#)

- 6:49 [AnnMarie Walsh@padschicago](#)
RT [@jimrattray](#) [@padschicago](#) Creating a hybrid between online/IRL is the sweet spot! [#hcs](#)
- 6:49 [April Foreman@DocForeman](#)
[@RichmondDoc](#) [@jchevinsky](#) I think there's no one right answer. If ur going to share ur HC experience w/o telling your HCP have reason. [#hcs](#)
- 6:49 [Mike Charboneau@mcharboneau](#)
T3 - I think online communities are a way to learn from someone's past exp to help u with your present. IRL support grps = here n now [#hcs](#)
- 6:49 [Bill Wong@BillWongOT](#)
[@jimrattray](#) [@padschicago](#) great idea! That can be the case in my upcoming work with the autistic college students I work with. [#hcs](#)
- 6:49 [Dana Lewis | #hcs@danamlewis](#)
[@jimrattray](#) depends - have seen some ppl *feel* excluded from pt online community. [#hcs](#) [@BillWongOT](#)
- 6:49 [Alan Brewington@abrewi3010](#)
A3 I believe online communities r the same as pt support groups. Just cause we are not in same space doesn't mean support is diff [#hcs](#)

- 6:49 [Kati Debelic@Katiissick](#)
T3 online communities are great for patients that are housebound or bedbound and where sensory overload is a problem [#hcsn](#)
- 6:49 [OneGrenouille@onegrenouille](#)
[@RichmondDoc](#) [@jchevinsky](#) as Pt - agree - but experience very different amongst HCPs. I cannot even get to discuss with some HCPs. [#hcsn](#)
- 6:50 [Robert Mahoney@mahoneyr](#)
T3 as we continue to replace human interaction with technology, we will probably come to see them as identical. [@HealthSocMed](#) [#hcsn](#)
- 6:50 [Jim Rattray@jimrattray](#)
[@BillWongOT](#) [@padschicago](#) Bill, I'd love to talk about that offline. [#hcsn](#)
- 6:50 [Dan Goldman@danielg280](#)
Online support groups have the ability to archive past experiences/threads. Can be helpful to see how others handled a condition [#hcsn](#)
- 6:50 [Ann Becker-Schutte@DrBeckerSchutte](#)
Requires deliberate, consistent, inclusion. RT [@danamlewis](#)
Depends - have seen some ppl *feel* excluded from pt online community. [#hcsn](#)

6:50 [Jennifer Chevinsky@jchevinsky](#)
[@mahoneyr](#) Have seen this too! Mayb dont want hassle of finding another? Hope not simply low expectations of HCPs in general [#hcs](#)

6:50 [Ann Becker-Schutte@DrBeckerSchutte](#)
MT [@danielg280](#) Online support groups have the ability to archive past threads. Can be helpful to see how others handled a condition [#hcs](#)

6:51 [OneGrenouille@onegrenouille](#)
[@jimrattray](#) [@BillWongOT](#) [@danamlewis](#) bullies on online communities too... [#hcs](#)

6:51 [Dana Lewis | #hcs@danamlewis](#)
[@DrBeckerSchutte](#) depends - if it's an informal community, it's easy for ppl to feel excluded. Unfortunate, but true. [#hcs](#)

6:51 [Mark Ryan@RichmondDoc](#)
[@onegrenouille](#) [@jchevinsky](#) and in that case, it seems fair to ask what the public exposure will gain; what is the end goal? [#hcs](#)

6:51 [Bill Wong@BillWongOT](#)
[@Katiissick](#) and also socially too. I gained a lot of confidence when I know people from online first before meeting them offline. [#hcs](#)

6:51 [P. F. Anderson@pfanderson](#)
[@HealthSocMed](#) I wouldn't say they are the same, but there are certainly overlapping features! Thinking of venn diagrams w/ 80% overlap [#hcs](#)

6:51 [AnnMarie Walsh@padschicago](#)
RT [@danamlewis](#) [@DrBeckerSchutte](#) depends - if it's an informal community, it's easy for ppl to feel excluded. Unfortunate, but true. [#hcs](#)

6:51 [Ann Becker-Schutte@DrBeckerSchutte](#)
RT [@danamlewis](#) depends - if it's an informal community, it's easy for ppl to feel excluded. Unfortunate, but true. [#hcs](#)

6:51 [Dana Lewis | #hcs@danamlewis](#)
[@DrBeckerSchutte](#) (different when it's a specified, structured/identified online community or forum [#hcs](#))

6:51 [Jim Rattray@jimrattray](#)
[@onegrenouille](#) [@BillWongOT](#) [@danamlewis](#) Agreed. Policing online is the greatest challenge. But strong communities police themselves. [#hcs](#)

6:51 [bacigalupe@bacigalupe](#)
What do patients appreciate in an online patient community? Knowing you are not alone and not the only one. No HCP can give you that. [#hcs](#)

6:51 [Annette McKinnon@anetto](#)
[@mahoneyr](#) Maybe some have gone and tried to find a better dr with worse luck [#hcs](#)

- 6:51 [Alan Brewington@abrewi3010](#)
A3 online communities need to realize u can't get support 24/7 though. People need breaks away from computer/phone.
[#hcsn](#)
- 6:52 [Robert Mahoney@mahoneyr](#)
Or maybe some people have a baseline level of dissatisfaction that must always be met. [@jchevinsky](#) [#hcsn](#)
- 6:52 [Ann Becker-Schutte@DrBeckerSchutte](#)
RT [@jimrattray](#) Agreed. Policing online is the greatest challenge. But strong communities police themselves. [#hcsn](#)
- 6:53 ✨[Anna](#) ✨ [@smanna750](#)
It seems easier to vent on SM 2 people u don't know. I feel like not burdening ppl that 1) don't understand 2) want to "fix you" IRL [#hcsn](#)
- 6:53 [Bill Wong@BillWongOT](#)
[@jimrattray](#) [@onegrenouille](#) [@danamlewis](#) true... like what we do here at [#hcsn](#) and other professional Twitter chats.
- 6:53 [Ann Becker-Schutte@DrBeckerSchutte](#)
RT [@bacigalupe](#) The strength of good communities online (citing my research) is that the virtual distance is not opposite to the local [#hcsn](#)
- 6:53 [Ann Becker-Schutte@DrBeckerSchutte](#)
MT [@smanna750](#) It seems easier to vent on SM 2 people u don't know. Not burdening ppl that 1) don't understand 2) want to "fix you" IRL [#hcsn](#)

6:54 [Jennifer Chevinsky@jchevinsky](#)
[@RichmondDoc](#) There are AMA guidelines/suggestions on
this: [ama-assn.org/ama/pub/physic...](#) and [ama-assn.org/ama/
pub/physic...](#) [#bioethx](#) [#hcs](#)

6:54 [Mark Ryan@RichmondDoc](#)
Ducking out a bit early. Thanks as always for the community
and the lively discussion. Have a great week, all! [#hcs](#)

6:54 [Robert Mahoney@mahoneyr](#)
Could be true. But when I find I can't do any better, I usually
stop complaining. [@anetto](#) [#hcs](#)

6:54 [Ann Becker-Schutte@DrBeckerSchutte](#)
RT [@BillWongOT](#) and also socially too. I gained a lot of
confidence when I know people from online first before
meeting them offline. [#hcs](#)

6:55 [bacigalupe@bacigalupe](#)
Synthesis of what I heard from patients in virtual network: Just
because I click on a keyboard doesn't mean I'm not feeling the
words [#hcs](#)

6:55 [HealthSocMed | #hcs@HealthSocMed](#)
Time flies on Sunday nights! Time to wrap up tonight's [#hcs](#)
chat. Last thoughts for the week ahead, everyone?

- 6:55 [Jennifer Chevinsky@jchevinsky](#)
[@RichmondDoc](#) [@onegrenouille](#) Tru- brings Qs of tweeting for catharsis or for patient advocacy... probably fair amount of both going on [#hcs](#)
- 6:55 [Dana Lewis | #hcs](#)
Wrapping up tonight's [#hcs](#) chat - last thoughts, everyone?
- 6:55 [T2D Research@T2DRemission](#)
[@mahoneyr](#) [@HealthSocMed](#) In one Asimov novel, distant, technological communication is so much the norm people get queasy in same room. [#hcs](#)
- 6:55 [Ann Becker-Schutte@DrBeckerSchutte](#)
MT [@ElinSilveous](#) Bummed to have missed [#HCSM](#) chat. Would love to have included my research on [#online](#) health/ social communities. [#web25](#)
- 6:56 [Annette McKinnon@anetto](#)
[@smanna750](#) I'd really rather not vent to the whole world on SoMe. It's like a time bomb. Can come back years later [#hcs](#)
- 6:56 [Ann Becker-Schutte@DrBeckerSchutte](#)
RT [@jchevinsky](#) Tru- brings Qs of tweeting for catharsis or for patient advocacy... probably fair amount of both going on [#hcs](#)
- 6:56 [P. F. Anderson@pfanderson](#)
[@mahoneyr](#) [@anetto](#) But you are nice guy, relatively healthy. Folk w/ chronic illness often scared, in pain, less patient, need to vent [#hcs](#)

6:56 [harriseve@harriseve](#)
Anybody doing this? MT [@jimrattray](#): Online support groups have the ability to archive; to see how others handled a condition [#hcs](#)

6:56 [Ann Becker-Schutte@DrBeckerSchutte](#)
[@jchevinsky](#) [@RichmondDoc](#) [@onegrenouille](#) Both catharsis & advocacy have value, in appropriate spaces. [#hcs](#)

6:56 [Kati Debelic@Katiissick](#)
Social media should be embraced by HC professionals. It's a good thing. Let the pts have a voice. [#hcs](#)

6:56 [Ann Becker-Schutte@DrBeckerSchutte](#)
[@jchevinsky](#) [@RichmondDoc](#) [@onegrenouille](#) But research shows that venting w/o action for change isn't emotionally helpful. [#hcs](#)

6:57 [OneGrenouille@onegrenouille](#)
[@jchevinsky](#) [@RichmondDoc](#) I think it is combined sometimes catharsis and advocacy, sometimes no way to separate out - for me [#hcs](#)

6:57 [Real Talk Dr. Offutt@RTwithDrOffutt](#)
[@HealthSocMed](#) great chat again. Love the endless ways hcs can be applied to help patients and improve their care. [#inspirational](#). [#hcs](#)

6:57 [Ann Becker-Schutte@DrBeckerSchutte](#)
[@harriseve](#) [@jimrattray](#) [#BCSM](#) does, I'd guess [#dsma](#) does,
[#gynscsm](#) does, probably [#lscsm](#)--to name a few. [#hscsm](#)

6:57 [Robert Mahoney@mahoneyr](#)
As HCP I still feel more comfortable with pts blogging after the
encounter than tweeting it during it; guess I can adjust if
needed. [#hscsm](#)

6:57 [P. F. Anderson@pfanderson](#)
[@DrBeckerSchutte](#) [@jchevinsky](#) [@RichmondDoc](#)
[@onegrenouille](#) Maybe, but most of us do it, when we feel bad
enough [#hscsm](#)

6:58 [Ann Becker-Schutte@DrBeckerSchutte](#)
RT [@pfanderson](#) But you are nice guy, relatively healthy. Folk
w/ chronic illness often scared, in pain, less patient, need to
vent [#hscsm](#)

6:58 [Kati Debelic@Katiissick](#)
RT [@jimrattray](#) RT [@bacigalupe](#): Burgeoning research on
online patient communities, important to start learning from it.
[#hscsm](#) [#hscsm](#)

6:58 [Elin Silveous@ElinSilveous](#)
[@giasison](#) LOVE your new profile photos Gia! It's been
awhile. :) [#HCSM](#)

6:58 [harriseve@harriseve](#)
Do it! [@ElinSilveous](#): missed [#HCSM](#) chat. Would love 2have
included my research on [#online](#) health/mutual support/social
communities. [#web25](#)

6:59 [Ess@Dazzlindiva](#)
Online communities are great! Some pt can't always physically make it support groups. TOPIC 3 [#hcsn](#)

6:59 [Dana Lewis | #hcsn@danamlewis](#)
[@abrewi3010](#) hehe agreed (have a 10k in 3 weeks and a half marathon in 3 months to train for!) and thanks! [#hcsn](#)

6:59 [AnnMarie Walsh@padschicago](#)
[@DrBeckerSchutte](#) [@pfanderson](#) Oh yes! Venting abt pain is exactly what I am about to do! LOL [#hcsn](#)

6:59 [Alan Brewington@abrewi3010](#)
“[@JA_Davids](#): [@abrewi3010](#) so true! also time differences make it hard to provide support in real time.” [#hcsn](#)

6:59 [OneGrenouille@onegrenouille](#)
Thank you for chat all, great thoughts [#hcsn](#)

6:59 [Robert Mahoney@mahoneyr](#)
That's true. We all have lower thresholds when we're unwell.
[@pfanderson](#) [@anetto](#) [#hcsn](#)

6:59 [Jennifer Chevinsky@jchevinsky](#)
[@DrBeckerSchutte](#) [@RichmondDoc](#) [@onegrenouille](#) Tru-difficulty= defining when/how is appropriate. HCP shaming prob not 2 beneficial [#hcsn](#)

6:59 [AnnMarie Walsh@padschicago](#)
RT [@abrewi3010](#) Thanks [@danamlewis](#) for another great chat
& I hope the bronchitis leaves quickly. You need to run
marathons, not sick! [#hcsn](#)

7:00 [HealthSocMed | #hcsn@HealthSocMed](#)
That's a wrap on another awesome [#hcsn](#) chat! Thanks, all!
See you again next Sunday at 8pm CT - and remember to DM
or [@HealthSocMed](#) topics!

Writer: [Dana Lewis](#)

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