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MDAnderson
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Making Cancer History®



PROS vs CONS OF SOCIAL MEDIA USE FOR HEALTHCARE PROFESSIONALS

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Disclosure of Conflicts of Interest

- Ishwaria M. Subbiah, MD, MS, has no relevant financial relationships to disclose.



Social Media in Medicine: A Complex Multi-faceted Issue...

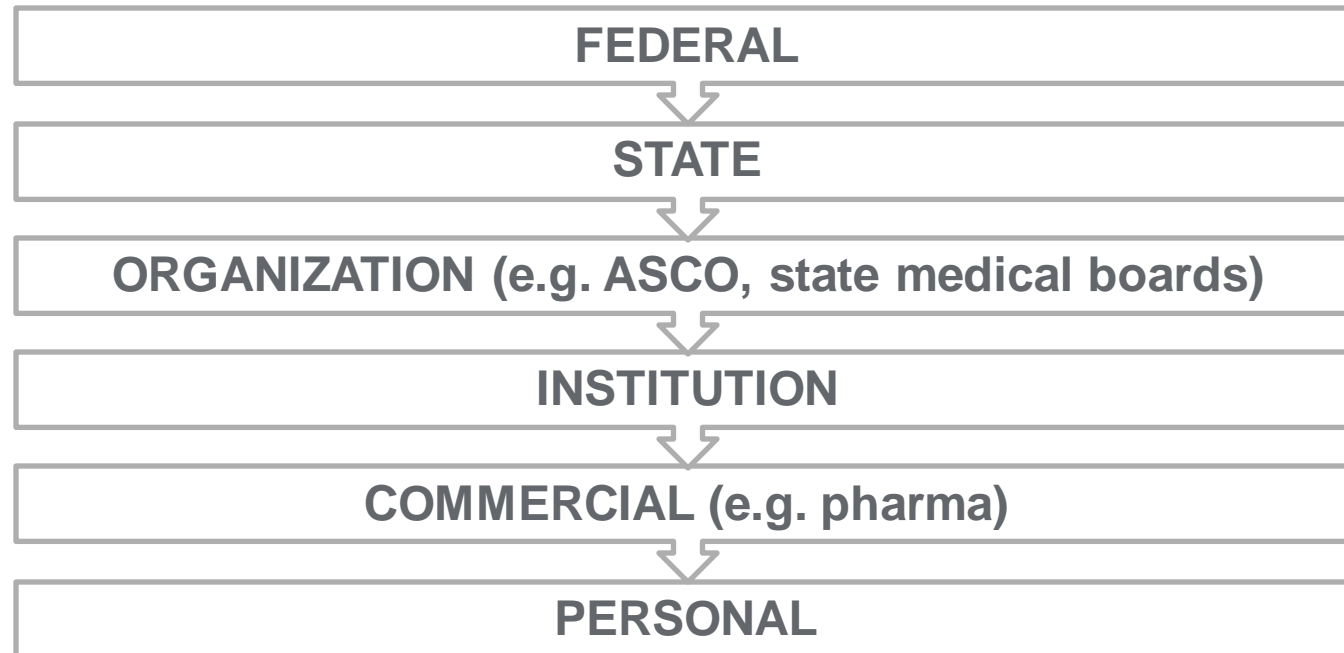
<input type="checkbox"/>	PRIVACY
<input type="checkbox"/>	PATIENT/CLINICIAN SAFETY & SECURITY
<input type="checkbox"/>	PATIENT/CLINICIAN INTERACTIONS
<input type="checkbox"/>	LIABILITY
<input type="checkbox"/>	CLINICIAN RATINGS AND ONLINE REVIEWS
<input type="checkbox"/>	SOCIAL MEDIA AND EMPLOYMENT
<input type="checkbox"/>	...and many more issues.

**Today's Focus: Transcend Boundaries and
Create Opportunities for Patients**



WHO'S THE BOSS:

Levels of Governance of Healthcare-related Interactions on Social Media Platforms



General Rule: Adhere with the Most Restrictive Policy!

HIPAA & OTHER FEDERAL LAWS

STATE LAWS

INSTITUTIONAL/PRACTICE POLICY

ORGANIZATION GUIDELINES



Federal Governance of Social Media

Interactions: “RETROFITTING” LEGISLATION

August 21, 1996

- The Health Insurance Portability and Accountability Act (HIPAA) enacted by the 104th US Congress.

May 5, 2003

- LinkedIn launched.

February 4, 2004

- Facebook launched.

March 21, 2006

- Twitter launched.



Interpreting HIPAA for the Social Media Era

FIVE MAJOR HIPAA RULES

PRIVACY RULE

SECURITY RULE

TRANSACTIONS AND CODE SETS (TCS) RULE

UNIQUE IDENTIFIERS RULE

ENFORCEMENT RULE – HITECH ACT OF 2009

HIPAA for Professionals <https://www.hhs.gov/hipaa/for-professionals/index.html>



HIPAA PRIVACY RULE: DEFINING WHAT'S PROTECTED

“**Privacy Rule**” - Standards for Privacy of Individually Identifiable Health Information

Establishes **national standards** for the protection of certain health information.

OCR Privacy Rule Summary <https://www.hhs.gov/sites/default/files/privacysummary.pdf>

HIPAA PRIVACY RULE: DEFINING WHAT'S PROTECTED

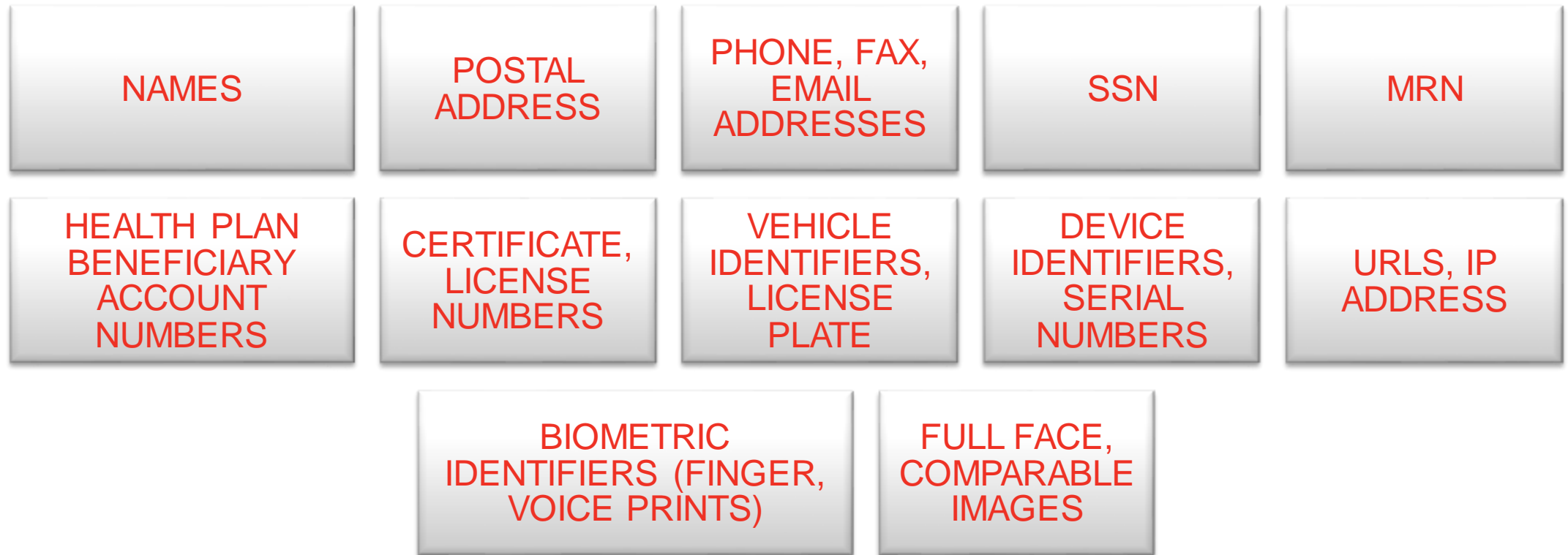
The Privacy Rule protects all "**individually identifiable health information**" held or transmitted by a covered entity, in any form or media, whether electronic, paper, or oral.

The Privacy Rule calls this information "**protected health information (PHI).**"

OCR Privacy Rule Summary <https://www.hhs.gov/sites/default/files/privacysummary.pdf>



HIPAA: DEFINING PROTECTED HEALTH INFORMATION



OCR Privacy Rule Summary <https://www.hhs.gov/sites/default/files/privacysummary.pdf>



EXAMPLES OF HIPAA VIOLATIONS ON SOCIAL MEDIA

**If you've heard about it on the news,
it is likely egregious.**

Commonly Reported Social Media HIPAA Violations

- Images and videos of patients without consent (written).
- Any identifiable information within posts.
- Photographs from a medical facility where PHI is seen (i.e., in background).
- Sharing of identifiable information in private groups.

Crane GM, et al. Pathology Image-Sharing on Social Media: Recommendations for Protecting Privacy While Motivating Education. *AMA J Ethics*. 2016 Aug 1;18(8):817-25.

WHO FILES THE COMPLAINTS: Entities that Report Social Media Violations

Rare to get reports from patients who themselves are the subjects.

Most common sources:

- Communications Office – monitor institutionally related tweets
- Self-report
- Acquaintances of the employee on social media.

Privacy & Information Security Compliance, Institutional Compliance Program.
University of Texas MD Anderson Cancer Center.



So...are you even more convinced to stay away from social media?

There is hope for effective use....



A MAJORITY OF CLINICIANS USE SOCIAL MEDIA *WITHOUT* ISSUE.

Their strategy: Employ **common sense**
and these standard pearls of wisdom.



PEARL #1: DE-IDENTIFY HEALTH INFORMATION

No restrictions on the use of de-identified health information.

- Neither identifies nor provides a reasonable basis to identify an individual.

2 ways to de-identify:

- A formal determination by a qualified statistician;


or

- The removal of specified identifiers to where the remaining information cannot be used to **re-identify** the individual.

45 CFR 164.502(d), and 164.514(a)-(c)

<https://www.hhs.gov/hipaa/for-professionals/privacy/special-topics/de-identification/index.html>

PEARL #1: DE-IDENTIFY HEALTH INFORMATION

POSTS OF CONCERN	IDENTIFIERS	ALTERNATIVE TO CONSIDER
<p>“Today I saw someone with ...”</p>	<p>Date, Diagnosis (esp. if rare)</p>	<p>Avoid (or be vague about) dates. “I recently saw a case of...”</p>
<p>“...my gameshow host patient with pancreatic cancer is starting chemo but I want to be ready with alternate options if needed...”</p>	<p>Newsworthy circumstances</p>	<p>Avoid details that allow association with recent events. “Any new trials for metastatic pancreatic cancer?”</p>
	<p>Identifying images</p>	<p>WRITTEN CONSENT. Avoid posting full facial images, unique tattoos, or other identifying features without signed consent.</p>

Crane GM, et al. Pathology Image-Sharing on Social Media. AMA J Ethics. 2016 Aug 1;18(8):817-25.



PEARL #1: DE-IDENTIFY HEALTH INFORMATION

POSTS OF CONCERN	IDENTIFIERS	ALTERNATIVE TO CONSIDER
“56 year old female with a new diagnosis of...”	Age	Exclude age for patients > 89 or aggregate ages into “age 90 or older.” Avoid precise ages esp. children. Use approximate ages or ranges for all posts.
“...my patient is moving to the Rice University area and needs a new oncologist...”	Geographic location	Avoid mention of small geographic subdivisions. “My patient is moving to the Houston area...”
“24 year old man with a right arm mass...”	Anatomic site Patient history	If appropriate, consider modifying clinical history. “A woman in her 20s presents with a left thigh mass...”

Crane GM, et al. Pathology Image-Sharing on Social Media. AMA J Ethics. 2016 Aug 1;18(8):817-25.



PEARL #2: RECOGNIZE AN ERROR IMMEDIATELY.

A breach is, generally, an impermissible disclosure of PHI.

EXCEPTIONS: low probability that the PHI has been compromised based on the following factors:

- Nature, extent of the PHI (types of identifiers, likelihood of re-identification)
- The unauthorized person who used (or received) the PHI
- Whether the PHI was actually acquired or viewed; and
- The extent to which the risk to the PHI has been mitigated.

**NOT ALL ERRORS ARE BREACHES.
Contact your privacy officer.**

HIPAA Breach Notification Rule, 45 CFR §§ 164.400-414.
<https://www.hhs.gov/hipaa/for-professionals/breach-notification/index.html>

PEARL #3: WHEN IN DOUBT, OBTAIN PATIENT CONSENT.

Review your practice's media policy.
Obtain necessary consents.



MEDIA AUTHORIZATION AND RELEASE

I hereby consent to having my photograph taken, and I hereby give The University of Texas MD Anderson Cancer Center (“MD Anderson”) permission to capture my name, likeness, image and/or voice in photographic, audio, audiovisual, digital or any other form of medium (the “Media Materials”). Furthermore, I hereby authorize MD Anderson and its affiliates (e.g., MD Anderson Services Corp. and MD Anderson Physician Network) to use the Media Materials for any purpose (including any and all business, educational, professional, or fund raising activities).

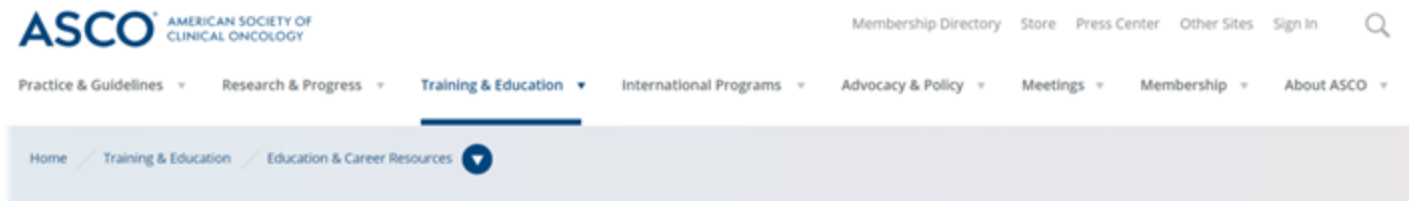
PEARL #4: ENGAGE YOUR COMMUNICATIONS AND LEGAL OFFICES.

Explore resources within your practice network.

- Most hospital systems, practice networks, cancer centers, and universities have communications offices and legal services.

Take social media training through institution or organization (e.g., AMA, ASCO).

- Consider refresher courses to stay up to date with HIPAA social media rules.



Social Media Resources

ASCO Social Media Resources.

<https://www.asco.org/training-education/education-career-resources/social-media-resources>



PEARL #5: VIEW REGULATIONS AS PROTECTIONS, NOT BARRIERS

- Thousands of clinicians engage on social media while **following the regulations** in place for **patient safety and their own protection.**



PEARL #6: USE RESTRAINT - EQ OVER IQ

- Participation in social media is a constant exercise of your **Emotional Intelligence**.
- Your posts enter the public domain.

STRATEGIES FOR EFFECTIVE SOCIAL MEDIA USE IN HEALTHCARE

PEARL #1: DE-IDENTIFY HEALTH INFORMATION

PEARL #2: RECOGNIZE AN ERROR IMMEDIATELY.

PEARL #3: WHEN IN DOUBT, OBTAIN PATIENT CONSENT.

PEARL #4: ENGAGE YOUR COMMUNICATIONS AND LEGAL OFFICES.

PEARL #5: VIEW REGULATIONS AS PROTECTIONS, NOT BARRIERS.

PEARL #6: USE RESTRAINT - EQ OVER IQ.



EXAMPLES OF EFFECTIVE SOCIAL MEDIA USE IN ONCOLOGY

Clinicians who make a difference...

Creating opportunities for our patients: Clinical Trials

Alliance for Clinical Trials in Oncology
@ALLIANCE_org Following

New Trial! Dan P. Zandberg MD @UPMCHillmanCC leads a new @ALLIANCE_org trial (A091802) to see how well avelumab and cetuximab work in treating patients with skin cancer that has spread in the body. Learn more: bit.ly/AllianceA091802 #skincancer #NCI #NCTN#CancerResearch

8:40 AM - 28 May 2019

NRG Oncology
@NRGonc Following

Recently Activated: NRG-LU005 #LungCancer (LS-SCLC): Chemoradiation vs Chemoradiation + Atezolizumab. To learn more, visit the protocol page on @TheCTSU ctsu.org (login req'd). @KHigginsMD @WinshipAtEmory and Dr. Alice Ross @MayoClinic @ALLIANCE_org are co-PIs.

12:22 PM - 29 May 2019

SWOG Cancer Research Network
@SWOG Following

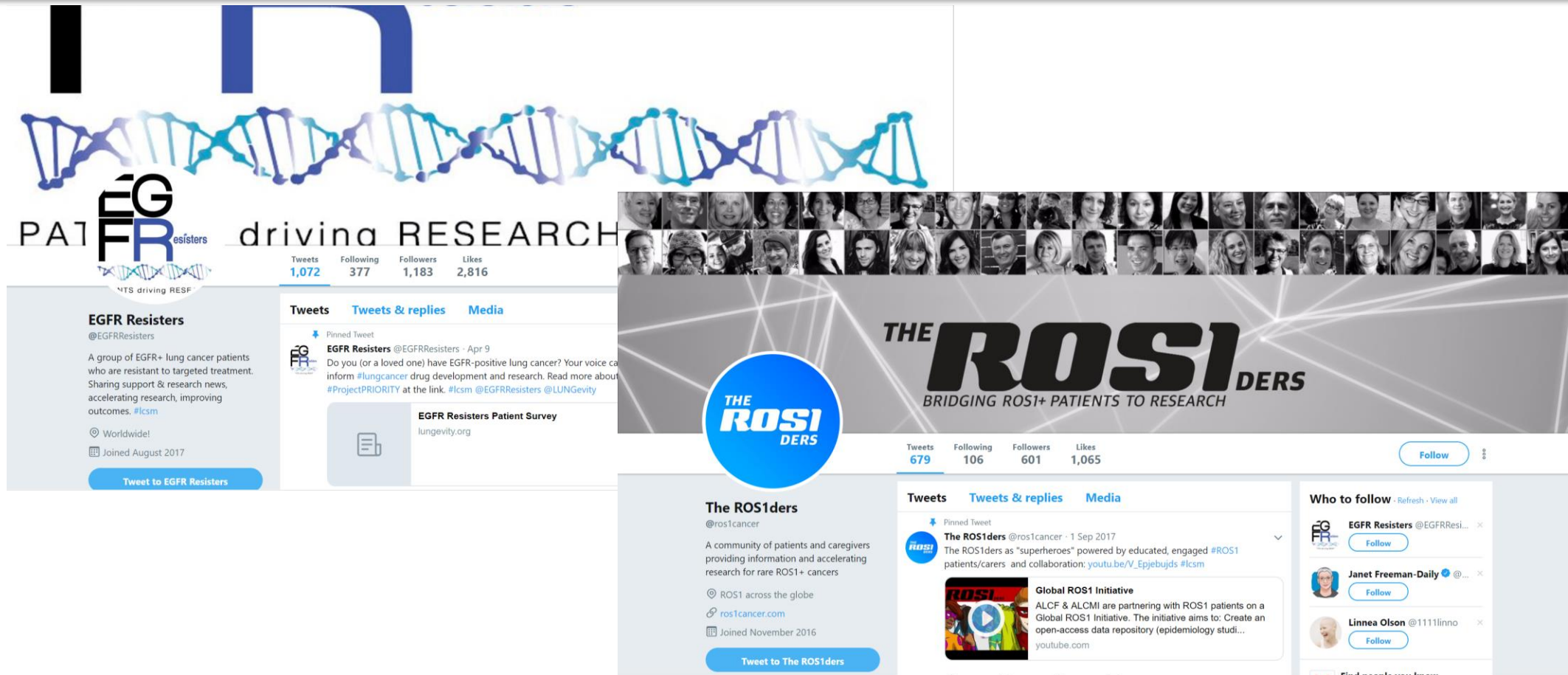
Easy way to find an @theNCI trial from @SWOG @ALLIANCE_org @eaonc @NRGonc @COGorg - all members of the National Clinical Trials Network, the oldest and largest publicly funded cancer research network. We run over 100+ trials at a time on all major cancer types. @NCICancerTrials

NCICancerTrials @NCICancerTrials
You can search for an NCI-supported cancer clinical trial using this form: #NCIwordstoknow cancer.gov/about-cancer/t...
Show this thread

11:18 AM - 28 May 2019

9 Retweets 18 Likes

Creating opportunities for our patients: Bringing together rare cancers and rare aberrations.



The image displays two social media profiles side-by-side. The left profile is for 'EGFR Resisters' (@EGFRResisters), featuring a DNA double helix graphic and a bio that describes a group of lung cancer patients resistant to targeted treatment. The right profile is for 'The ROS1ders' (@ros1cancer), featuring a grid of patient portraits and a bio that describes a community for rare ROS1+ cancers. Both profiles show tweet activity and engagement metrics.



Creating opportunities for our patients: Engage in immediate conversation on recent publications

A REAL-TIME PEER REVIEW

Eric Topol @EricTopol · May 2

We need much better ways to predict response to anti-PD1 [#cancer immunotherapy](#). Mismatch-repair deficiency is one of the ways [science.sciencemag.org/content/364/64...](https://www.sciencemag.org/content/364/64...) by @GeneCollector @sloan_kettering and collaborators @sciencemagazine

genetic diversity of tumors with mismatch repair deficiency influence anti-PD-1 immunotherapy response

Anirban Maitra @Aimms1742

Replying to @EricTopol @GeneCollector and 2 others

A comparable study just got published in [@Annals_Oncology](#)
Cc: [@FAndreMD](#) [@ldiaz1](#) [@JackieHechtman](#) [@xrtGenomics](#)

Tumor mutational burden is predictive of response to immunotherapy
AbstractBackground. Microsatellite instability (MSI) is a biomarker for response to immune checkpoint inhibitors (ICPIs). PD-1 inhibitors in metastatic colorectal cancer.
academic.oup.com

5:49 PM - 2 May 2019

David Gandara @drgandara · May 24

Meso clearly needs better therapeutic options but surprised that approval of this technique is based on admittedly impressive OS from a single arm Phase II trial-FDA Approves NovoTTF-100LTM System + Chemotherapy for Malignant Pleural Mesothelioma

FDA Approves the NovoTTF-100LTM System in Combination with Pemetrexed for Malignant Pleural Mesothelioma
Novocure (NVCR) today announced that the U.S. Food and Drug Administration (FDA) has approved the NovoTTF-100L System in combination with pemetrexed for the treatment of malignant pleural mesothelioma.
finance.yahoo.com

Nathan A. Pennell MD, PhD @n8pennell · May 25

Agree that is odd, not sure I would use this based on a single arm trial. Maybe because it was a device and not a drug the bar was lower?

Melina Marmarelis @MMarmarelis

Replying to @n8pennell @drgandara

Yes, it was approved under a humanitarian device exemption (for rare diseases) so not the same track as other drugs (or even devices). You only have to show safety not efficacy hence the single arm trial approval.

Jackie Finally metastatic express #pemb

8:39 AM - 25 May 2019

Suresh Ramalingam @RamalingamMD · May 25

As I understand it is a device, not a drug; approval standards are very different!

Vamsi Velcheti, MD @VamsiVelcheti

TTF device now FDA approved for Mesothelioma based on a single arm trial w/ 18 mo mOS w/predominantly epitheloid type... am I missing something here ? where is the randomized trial @FDAOncology #LCSM twitter.com/Medscape/statu...

Dr. Antonio Calles @Tony_Calles

Following

Replying to @RamalingamMD

Making believe patients they could live longer (so far unproven), with no other clinically relevant outcome for patients reported so far, with an increased risk or dermatitis. Not sure this is the kind of advances mesothelioma patients really need.

6:53 AM - 25 May 2019

2 Retweets 17 Likes

Creating opportunities for our patients: Community among clinicians.

CELEBRATE MILESTONES!

Neli Ulrich, PhD @NeliUlrich

And finally it's final!!! 1656 pages showcasing the amazing trajectory of @huntsmancancer @UUtah over the past 5 years! Go fly!!!! @neerajaiims @UofUHealth @UofUResearch @neerajaiims @TomVarghese Jr @MikeGoodMD @Will_Dere @DebzNewz @__glh @GarridoLagunaMD @SiwenONC #HClproud

Ishwaria Subbiah, MD MS @IshwariaMD · Sep 30

Twitter-verse! 🎉 It actually happened! My grant was funded! THANK YOU THANK YOU to the @AmericanCancer Society for my Clinician Scientist Development Grant! 🎉 Bc when #SupportiveCare & phase I teams partner up, it's a win for patients! #Endcancer #hpm #hpc

MD Anderson Cancer Center and 9 others

Lecia Sequist, MD, MPH @LeciaSequist

I am overwhelmed to share that I am now Professor of Medicine @harvardmed Thank you amazing mentors Tom Lynch, Daniel Haber, Jeff Engelman, Alice Shaw, @dhjutsw1 @RamalingamMD Heather Wakelee and others. And especially to @TomSequist who always believed in me, even when I didn't

9:37 AM · 4 May 2019 from Boston, MA

48 Retweets · 750 Likes

Tatiana Prowell, MD @tmprowell · May 4

Replying to @LeciaSequist @harvardmed and 3 others @LeciaSequist, a very sincere congrats! Well-earned!!! 🎉🎉

Amy Comander MD @DrAmyComander · May 4

Replying to @LeciaSequist @harvardmed and 3 others Congratulations!!!

Lucy Kalanithi @rocketgirlrmd · May 4

Replying to @LeciaSequist @harvardmed and 3 others ★★★★★

george demetri @DrSarcoma · May 4

Replying to @LeciaSequist @harvardmed and 3 others Huge congrats, Lecia!!!

Daniel Stover, MD @StoverLab · May 4

Replying to @LeciaSequist @harvardmed and 3 others Congratulations Lecia!

Ashley Love Sumrall, MD, FACP @AshleySumrallMD

ASCO_LDP is concluding today. We're so grateful for this opportunity for mentorship & growth! #ASCO_LDP18 #ASCO_LDP @ASCO #ASCO19 #ASCOLCI



12:53 PM · 30 May 2019 from Chicago, IL

Stephanie Graff, MD, FACP @DrSGraff · 19h

Replying to @AshleySumrallMD @ASCO and 9 others Congrats #asco_ldp Class of 2018-19!! You are off to great places!

Neelima Denduluri @ndenduluri1 · 19h

Replying to @AshleySumrallMD @ASCO and 9 others Congratulations!!!!

Yousuf Zafar, MD MHS @yzafar · 21h

Replying to @AshleySumrallMD @ASCO and 9 others Congrats to you, @ShaalanBeg, Carey Anders, and others!

Rod Rocconi @rodrocconi · 15h

Replying to @AshleySumrallMD @ShannonWestin and 10 others congrats on a great year!!

Charu Aggarwal, MD @CharuAggarwalMD · 21h

Replying to @AshleySumrallMD @ASCO and 9 others Congratulations everyone! Excited to begin this journey (tomorrow)! #ASCO19

Ashley Love Sumrall, MD, FACP @AshleySumrallMD · 21h

Thrilled for you!! 🎉

Neeraj Agarwal @neerajags

So glad to be done with the first phase. Looking forward to all the work and excitement of @theNCI site visit under the most passionate and inspiring leader @NeliUlrich, the director of @huntsmancancer @UUtah

Sumanta Pal @sumypal

Amazing. So great to see my friend & colleague @neerajaiims making such a difference at both a national level in #prostatecancer & at an institutional level in growing @huntsmancancer

Creating opportunities for our patients through close community among clinicians.

Toni Choueiri, MD
@DrChoueiri

Following

Positions open for GU medical oncologists @DanaFarber . If interested, email me a letter of intent and your CV. Ad below. #LankCenter



11:32 AM - 29 May

H. Jack West, MD
@JackWestMD

For those at #ASCO19, I'm happy to connect w/folks who want to learn a new opportunity at @cityofhope, who growing our service for remote expert consults & telemedicine. Innovative work. GI onc, melanoma expertise esp welcome. Let's talk.

H. Jack West, MD @JackWestMD

Our @cityofhope remote consult/telemedicine service is growing & needs more good people. If you're an onc considering a career shift into something novel, this is an innovative team & great place. Learn more here: bit.ly/COHDirES1...

Show this thread

6:46 PM - 30 May 2019

Vivek Subbiah, MD Retweeted

Vivek Subbiah, MD @VivekSubbiah · 4 Jun 2018
★☆☆ Star sighting ! What happens when you meet the star @JTrentMDPhD himself #trentselfie @breelynwikly @GlopesMd @SylvesterCancer ! #ASCO18 #sarcoma



Peter WT Pisters, MD @ppisters · May 21

Congratulations to the Texas Legislature and @joanhuffman @RepJohnZerwas on passing legislation raising the legal sale age for tobacco to 21. This monumental legislation will have a profound impact for Texans and future generations' health: bit.ly/2HH6bVJ #endcancer



21 77

Dr. Razelle Kurzrock Retweeted



WIN Consortium @WIN_Consortium · May 23
Be sure to attend the #winsympo2019 keynote lecture on 'Innovation in Clinical Trials: WINTHER trial', where Razelle Kurzrock, M.D., will discuss the recently published results of the prominent WINTHER trial. ow.ly/g45v50ubxf1 @Dr_R_Kurzrock



4 36

