



SWOG DIGITAL ENGAGEMENT
WHERE WE'VE BEEN, WHERE WE ARE ...

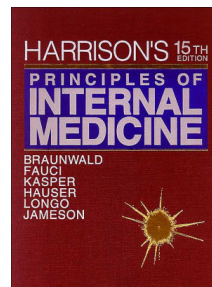
Mark A. Lewis, M.D.
@marklewismd
SWOG Spring Meeting
May 10th, 2023

THE PAST AS PROLOGUE

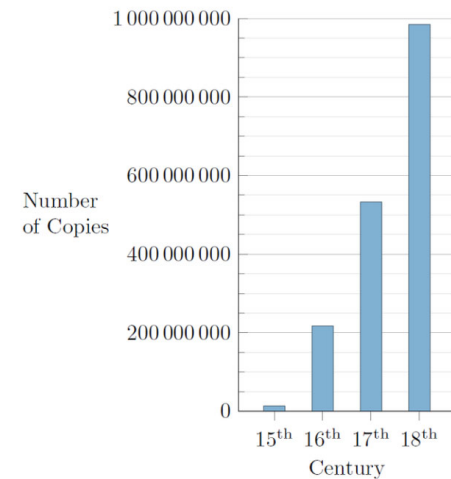
- From the fifteenth century onward, the printed word became the primary vehicle for high-integrity transmission of information

But ...

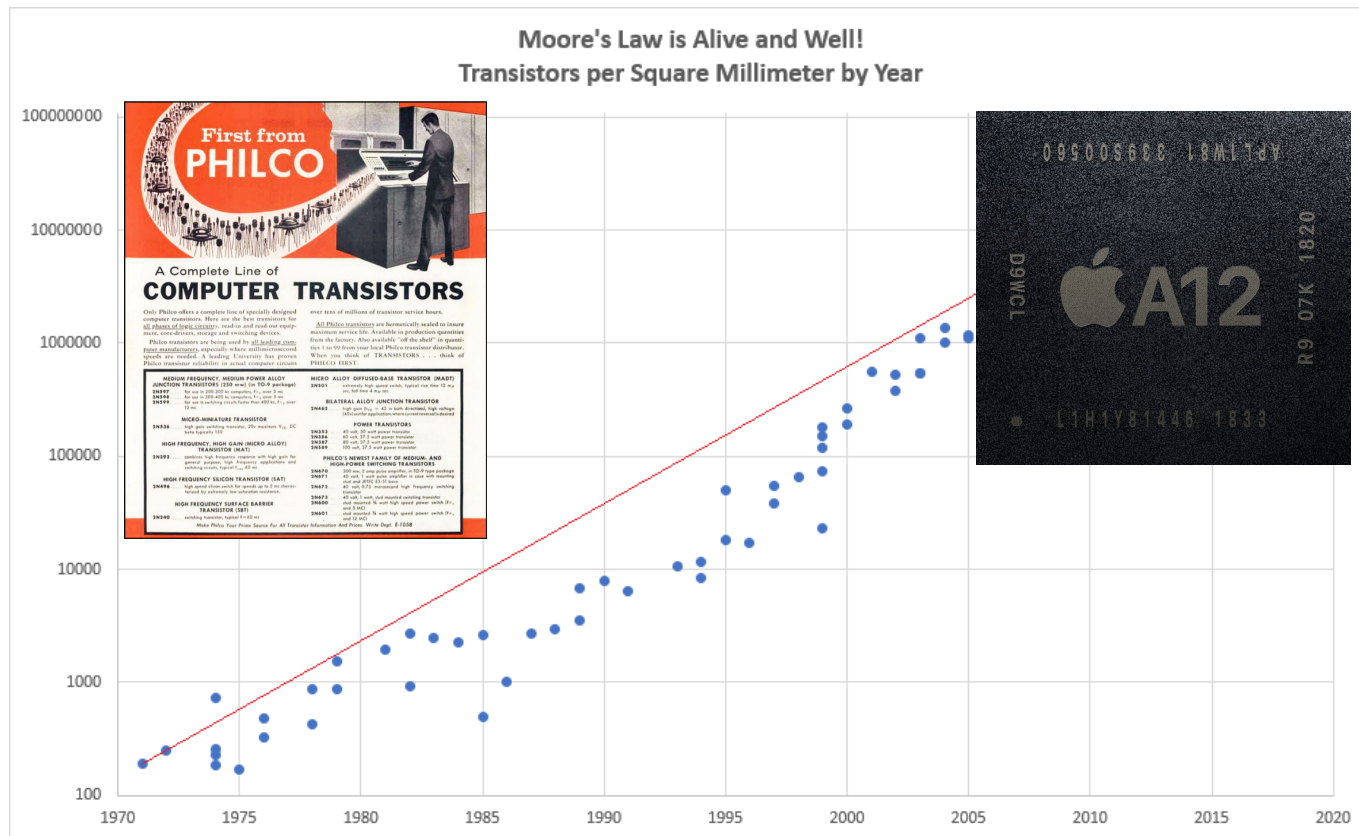
- Means of production were controlled by a select few
- Acquisition of knowledge required substantial resources
- Ink as a medium of programmed obsolescence



European Output of Printed Books ca. 1450–1800*



THE PACE OF PROGRESS

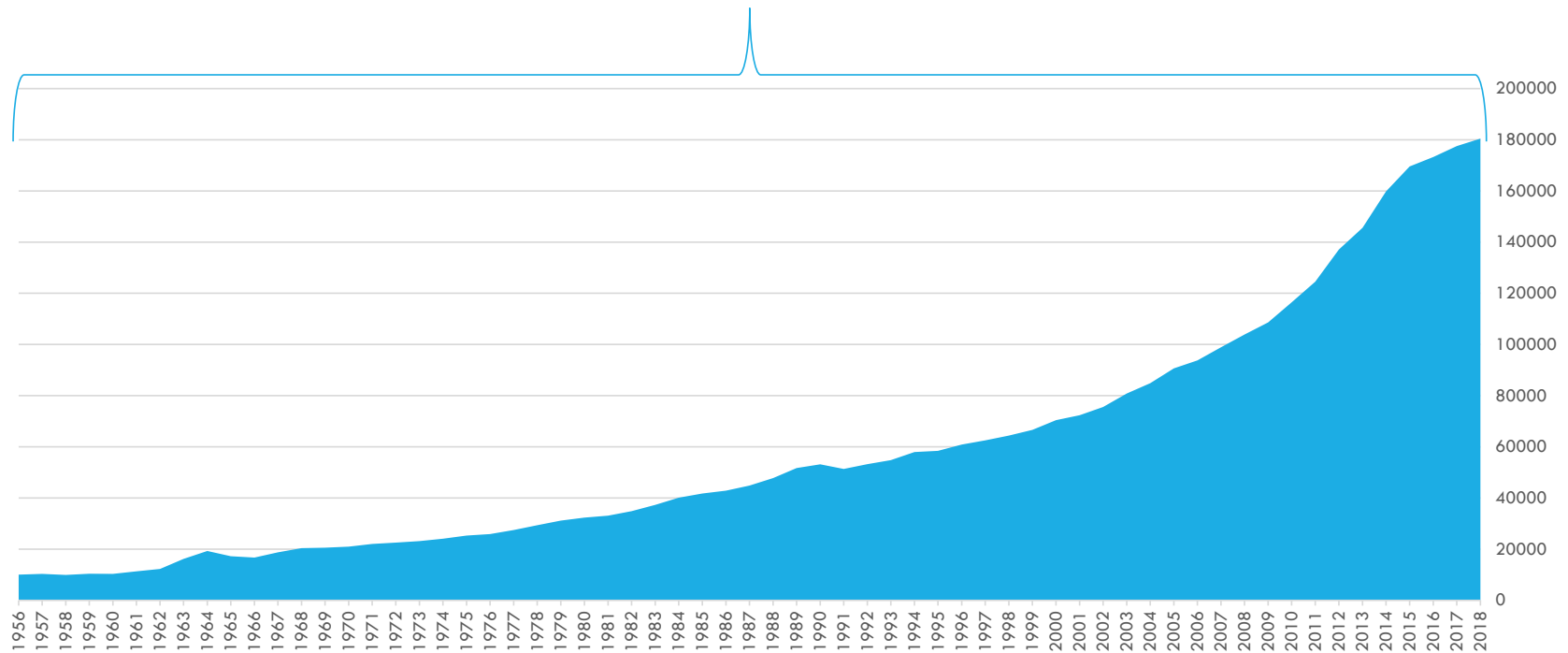


THE LAST DECADE IN HEALTHCARE SOCIAL MEDIA

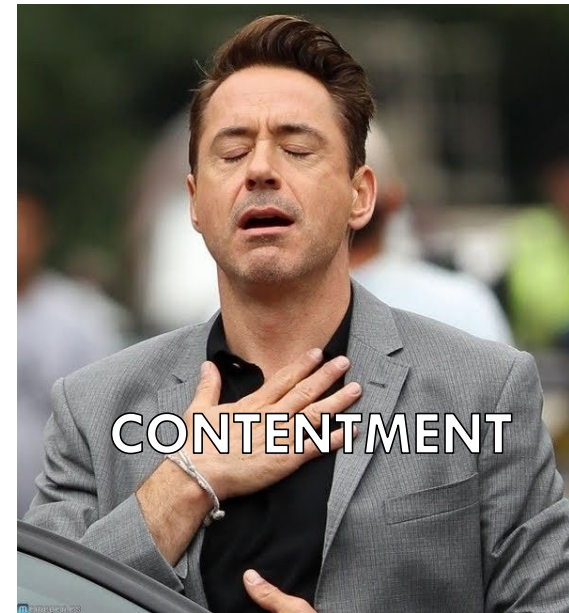


THE RISING TIDE OF INFORMATION

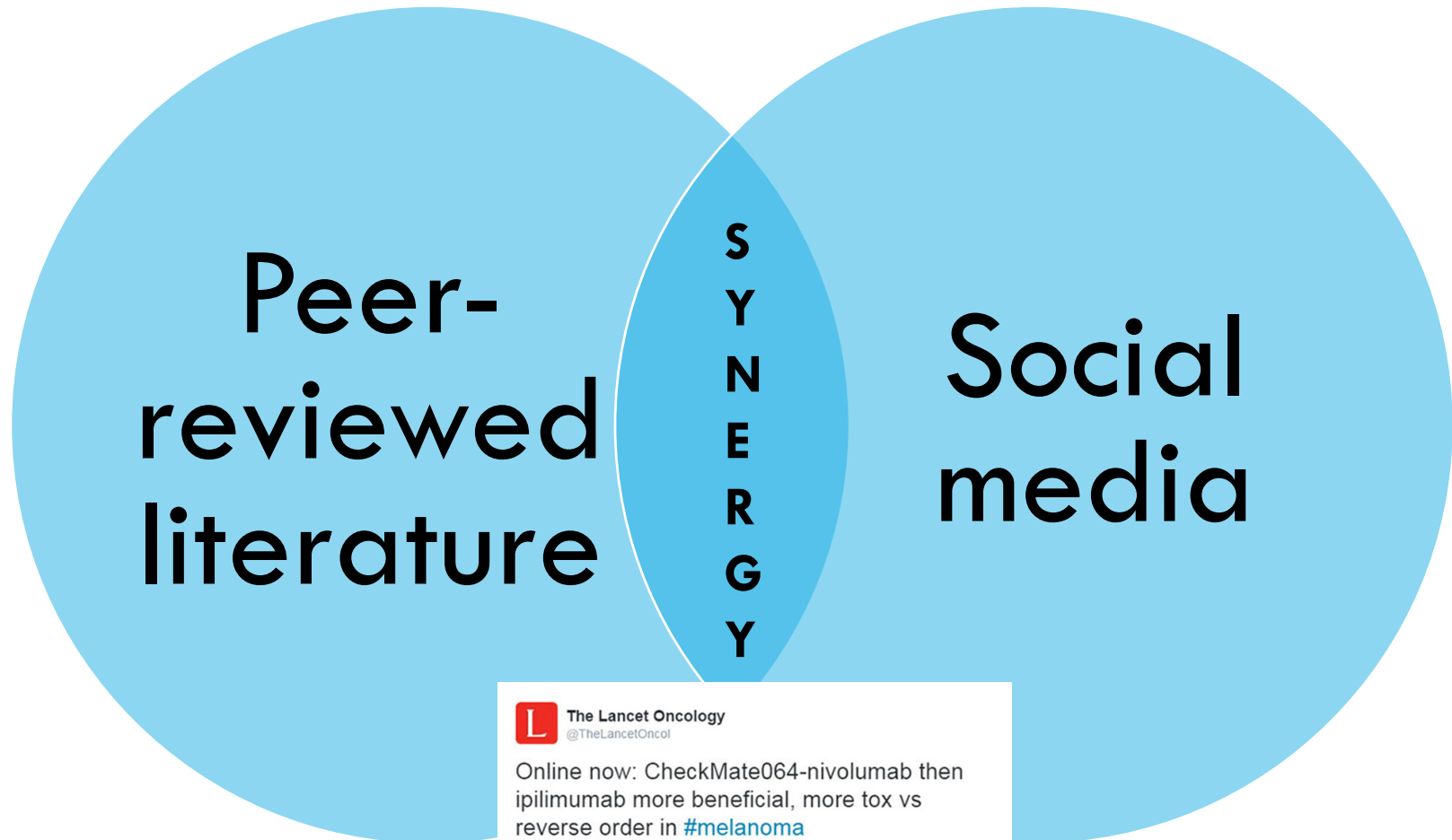
4.6 million cancer-related articles in total!



FROM A FIREHOSE TO A REFRESHING STREAM



A NON-BINARY APPROACH



 The Lancet Oncology
@TheLancetOncol

Online now: CheckMate064-nivolumab then ipilimumab more beneficial, more tox vs reverse order in [#melanoma](#)
ow.ly/GrCn300Ovt7 [#ASCO16](#)

WHERE THE PATIENTS ARE (AND HAVE BEEN)



**“That’s Where
the Money is...”**

— *Willie Sutton*

HASHTAG ONTOLOGY

Table. Hashtags in the Cancer Tag Ontology

Hashtag	Disease
#adscsm	Adrenal cancer
#ancsm	Anal cancer
#ayacsm	Adolescent and young adult cancer
#bcs	Breast cancer
#blcsm	Bladder cancer
#bt	Brain tumors
#cr	Colorectal cancer
#es	Esophageal cancer
#gyn	Gynecologic cancer
#hn	Head and neck cancer
#hpb	Hepatobiliary cancer
#k	Kidney cancer
#l	Lung cancer
#leu	Leukemia
#lym	Lymphoma
#mel	Melanoma
#mms	Multiple myeloma
#pan	Pancreatic cancer
#p	Prostate cancer
#ped	Pediatric cancer
#sc	Sarcoma
#st	Stomach cancer
#thm	Thymoma & thymic carcinoma
#thy	Thyroid cancer
#ts	Testicular cancer

Breast cancer advocates had started breast cancer social media (#bcs) in 2011

Brain tumor social media (#bt) followed in 2012

Following those organic examples, another 23 hashtags were developed with the following criteria:

- disease-specific
- short, unique, or minimally used on Twitter
- ending in “sm” for “social media” (as a prompt that online use is public)

Attai DJ, Cowher MS, Al-Hamadani M, Schoger JM, Staley AC, Landercasper J. Twitter Social Media is an Effective Tool for Breast Cancer Patient Education and Support: Patient-Reported Outcomes by Survey. *J Med Internet Res.* 2015 Jul 30;17(7):e188.

Katz MS, Anderson PF, Thompson MA, Salmi L, Freeman-Daily J, Utengen A, Dizon DS, Blotner C, Cooke DT, Sparacio D, Staley AC, Fisch MJ, Young C, Attai DJ. Organizing Online Health Content: Developing Hashtag Collections for Healthier Internet-Based People and Communities. *JCO Clin Cancer Inform.* 2019 Jun;3:1-10.

BUT IT'S ALSO WHERE THE ONCOLOGISTS ARE!

- Twitter is currently the dominant digital platform for MDs to engage with one another and the public

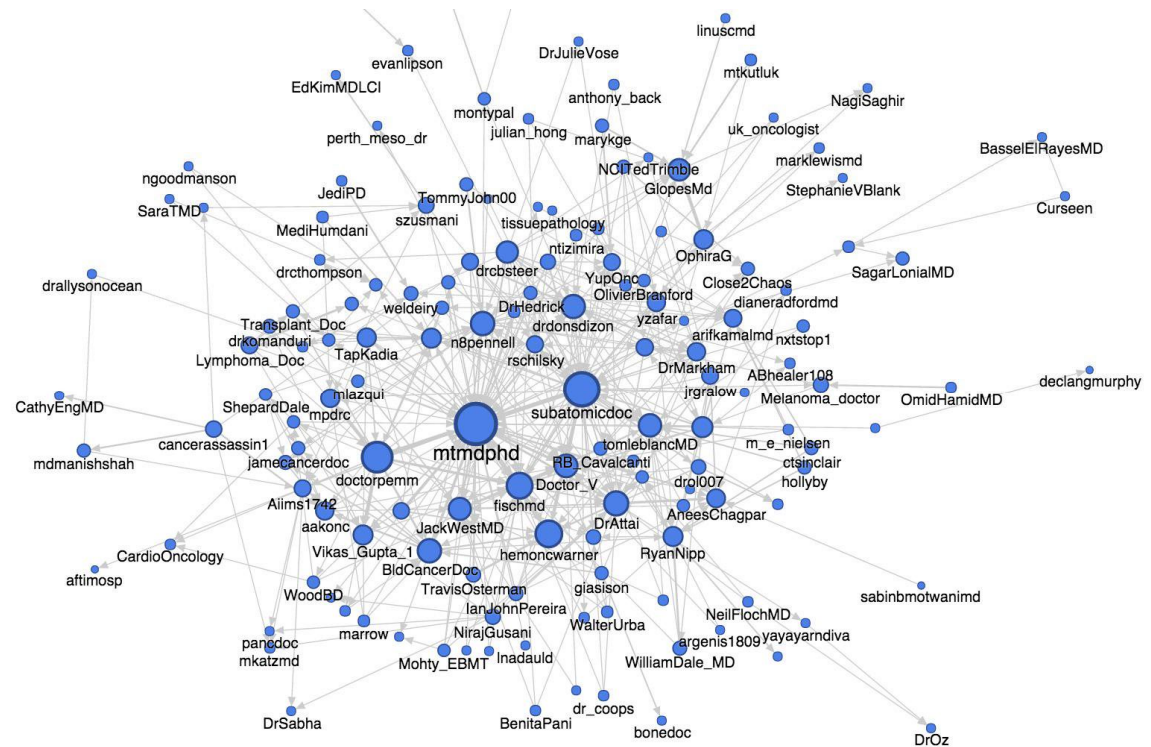
- The 3 C's:

Curation

Contribution

Connection

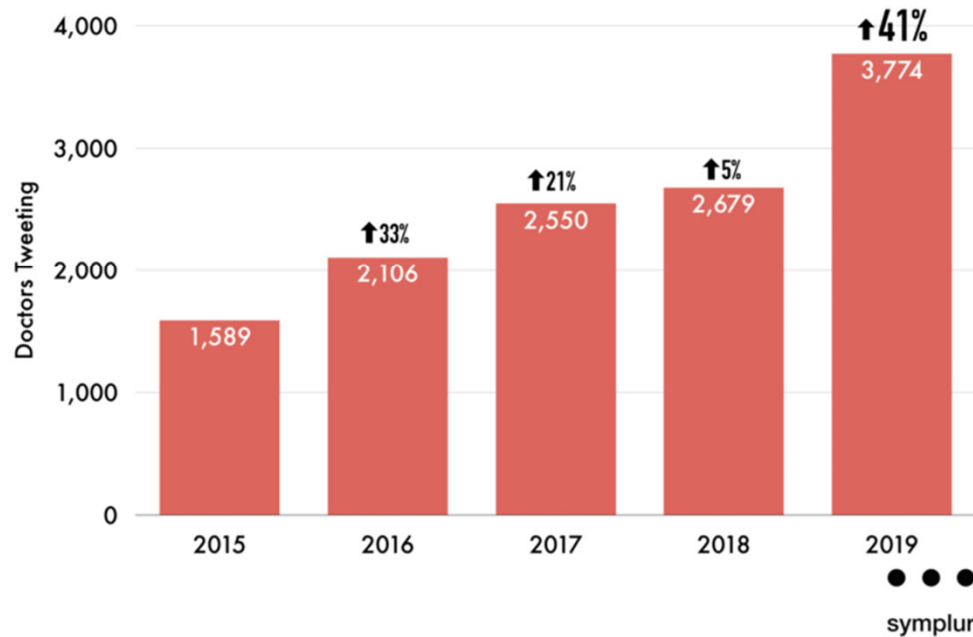
- Virtual conference attendance



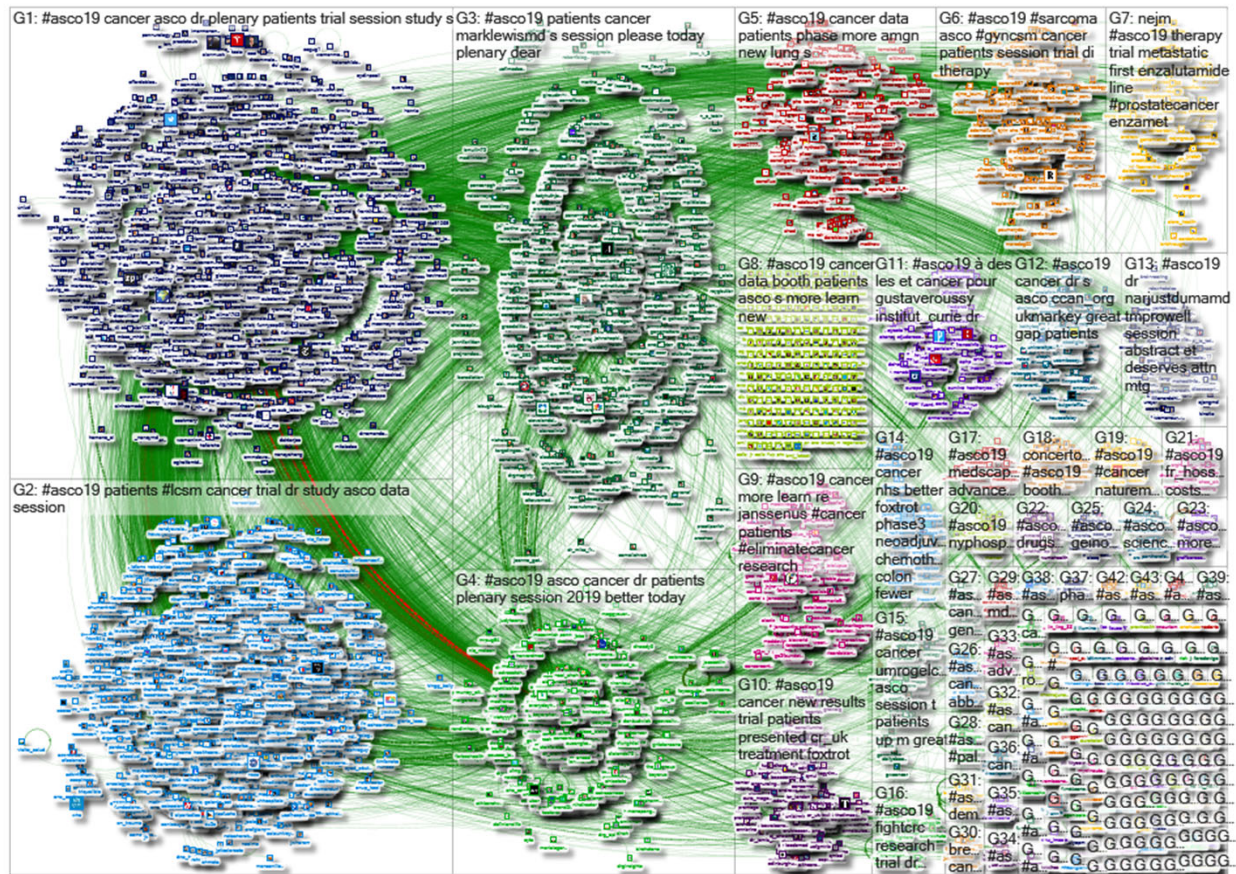
2019: THE INFLECTION POINT OF TWITTER USE AROUND ASCO ANNUAL MEETINGS

Dramatic Growth in Doctor Engagement at ASCO 2019

Unique doctor accounts participating on Twitter during the American Society of Clinical Oncology Annual Meeting.
Data from the Healthcare Social Graph® – Symplur, 2015-2019.



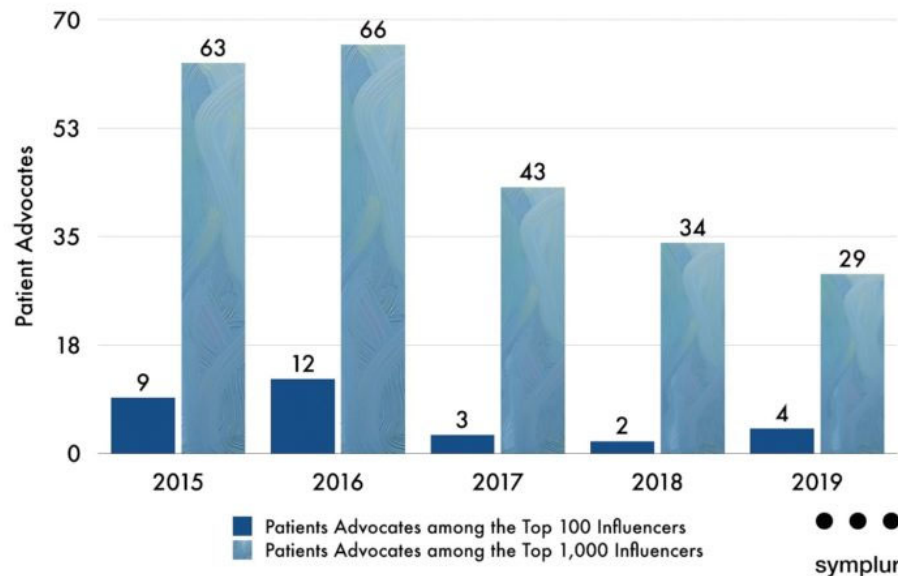
DATA VISUALIZATION?!



A BRUTAL ATTRITION

Patient Advocates' Share of Voice at ASCO Dropping

Share of publicly self-identifying Patient Advocates among the top 100 and top 1,000 influencers on Twitter during American Society of Clinical Oncology Annual Meetings. Data from the Healthcare Social Graph®.



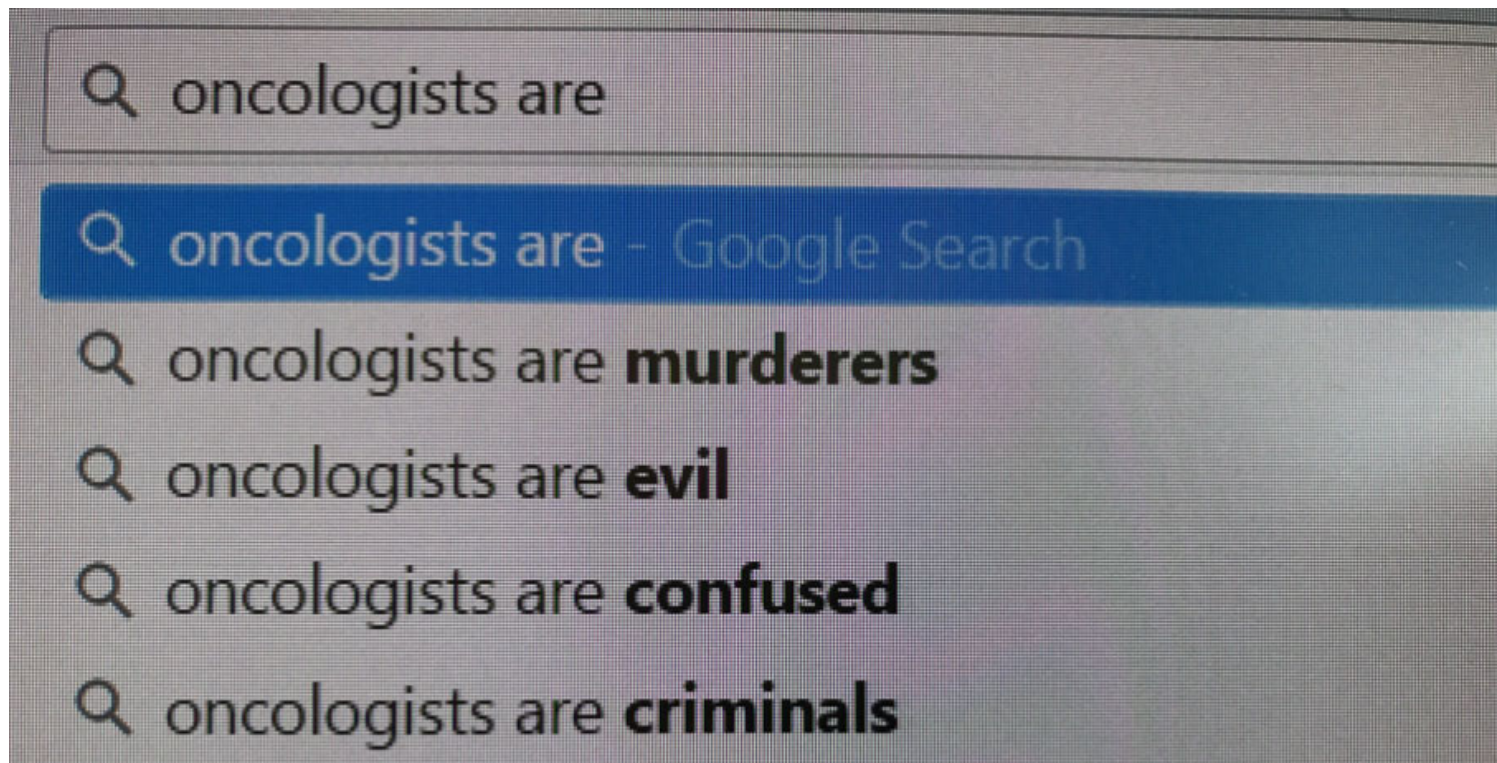
Alicia C. Staley
@stales

Replying to @corrie_painter @symplur and 10 others

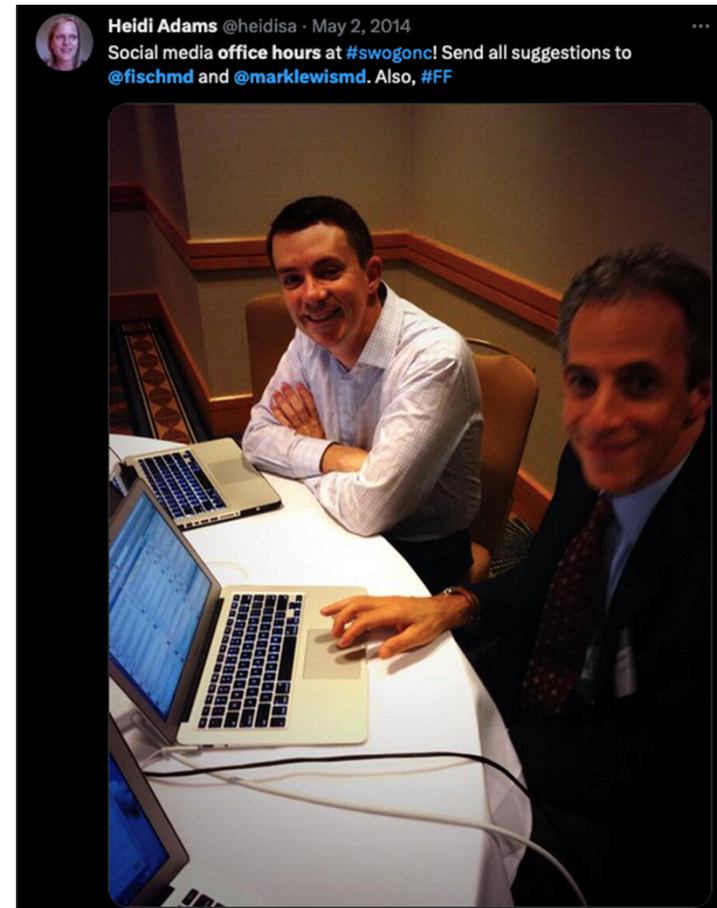
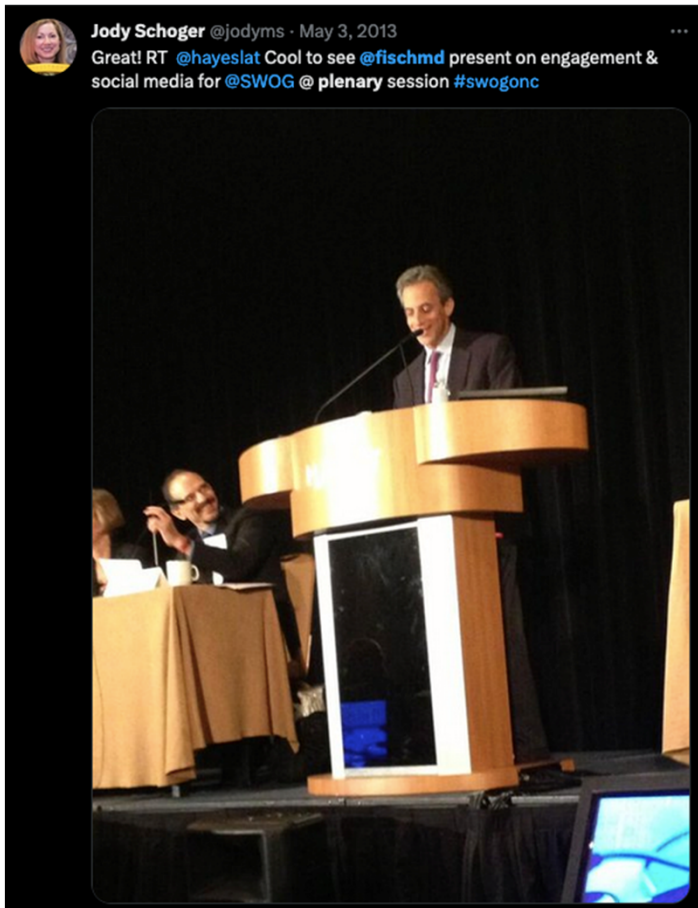
i've been seeing/sensing (but haven't proven via numbers...yet) a very cyclical nature for advocacy via social - when some advocates pass away (@jodyms, @whymommy, @ccchronicles, @regrounding, @AdamsLisa, @JackWhelan, @CultPerfectMoms xoxo) void takes time to fill #bcsm #asco19

5:44 PM · Jun 7, 2019 · Twitter for iPhone


SEARCH ENGINE OPTIMIZATION?



THE LAST DECADE IN SWOG SOCIAL MEDIA



LEADING BY EXAMPLE

SWOG  Leading cancer research. Together.

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The Front Line

An update on SWOG's approach to studying rare cancers


Among the specific aims we laid out in the NCTN grant application we submitted earlier this year is the following: To work with a variety of NCTN partners to reduce barriers to participation in clinical trials involving rare cancers.

I want to update you on our efforts regarding this very serious issue. Specifically, SWOG is taking the following three approaches to achieve our goals on this front:

- Leading and contributing treatment sub-studies to NCTN master protocols, which commonly include a range of rare molecular subtypes of solid tumors.*
We are already engaged here by heading the planned multi-group squamous cell lung cancer master protocol, and we are also planning to contribute arms to the NCI's histology nonspecific and GI master protocol initiatives, as they develop.
- Building on our success in opening rare disease studies in areas covered by SWOG's disease committees.*
We have a number of such studies already open or under development:
 - S0805 in patients with Philadelphia chromosome positive and/or Bcr-Abl positive acute lymphoblastic leukemia
 - S1106 for patients older than 65 years of age who have previously untreated mantle cell lymphoma
 - S1107 in papillary renal cell carcinoma
 - S1108 in peripheral T-cell non-Hodgkin lymphoma

The Front Line

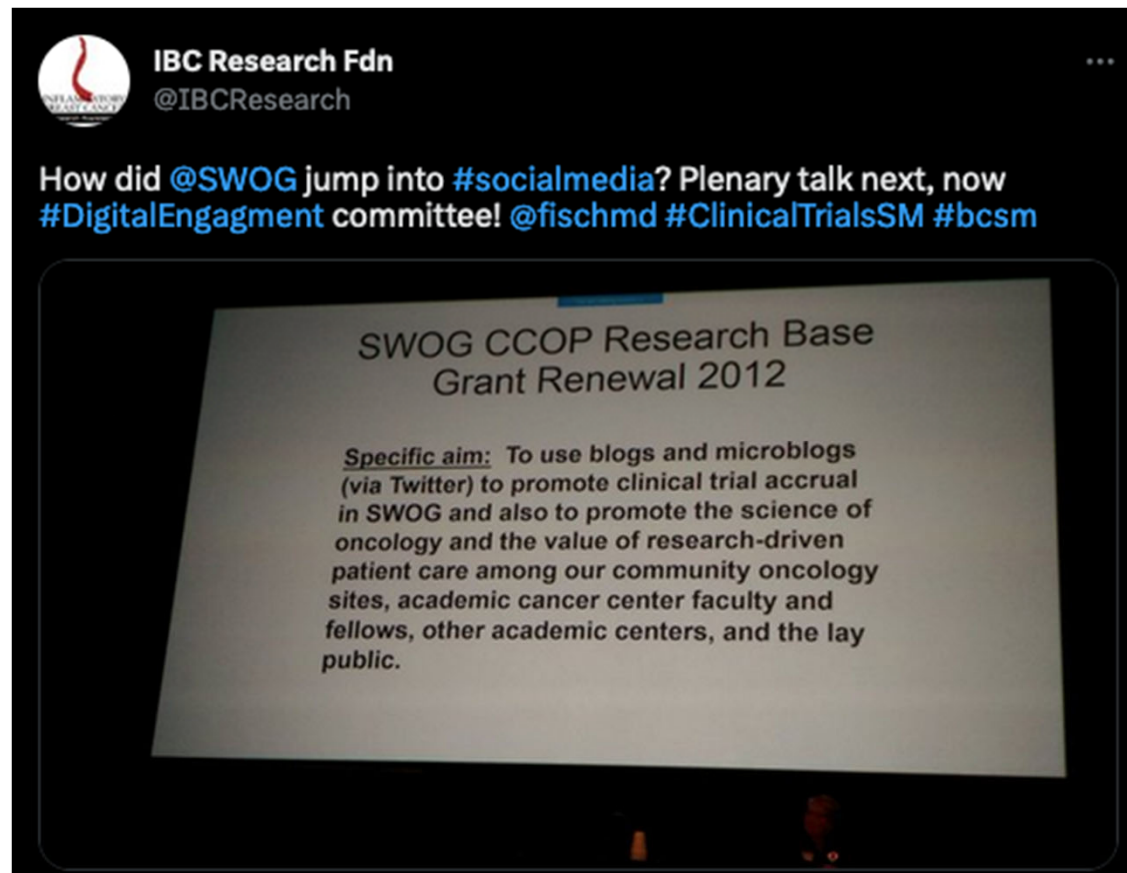
Charles D. Blanke, MD
SWOG Chair



[ABOUT](#)

- ▶ [Accrual Core Team Exemplifies Collaboration in NCI Trials](#)
- ▶ [New Research Requires New Resources. SWOG is on the Move.](#)
- ▶ [New Era of Patient Advocacy at SWOG](#)
 - ▶ [The Hope Foundation Funds Great Ideas. What's Yours?](#)
- ▶ [The NCTN: Mission Control for Biden's Moonshot](#)
- ▶ [The Vision for Our New Website: Keep It Simple, Make It Useful, Do It Quickly.](#)
- ▶ [SWOG's Annum of Diamond Dazzle](#)
- ▶ [Finding New Roles for Top Talent](#)

PROMOTING CLINICAL TRIALS!



IBC Research Fdn
@IBCResearch

How did @SWOG jump into #socialmedia? Plenary talk next, now #DigitalEngagment committee! @fischmd #ClinicalTrialsSM #bcsm

SWOG CCOP Research Base
Grant Renewal 2012

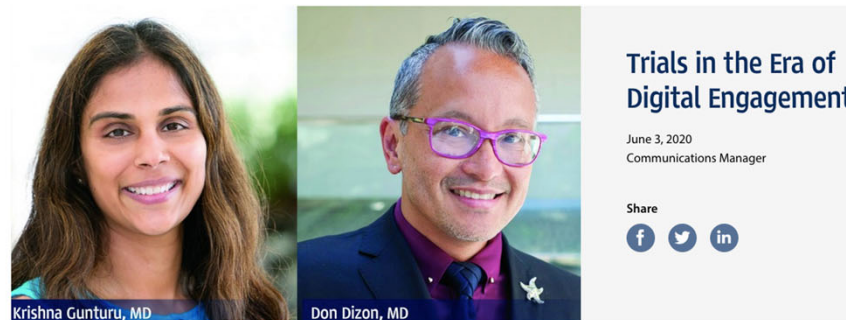
Specific aim: To use blogs and microblogs (via Twitter) to promote clinical trial accrual in SWOG and also to promote the science of oncology and the value of research-driven patient care among our community oncology sites, academic cancer center faculty and fellows, other academic centers, and the lay public.

PASSING THE BATON

When SWOG started our social media working group back in 2012, we stood alone. No other group in the NCTN had such an assembly. Only two of us – SWOG and the Alliance – were on Twitter. And ASCO had just put out its first practical guidance to oncologists about the responsible use of that type of communication.

SWOG's Drs. Don Dizon and Mike Fisch were two of the authors on that guidance. In fact, Mike was co-chair of the SWOG social media working group, with Dr. Mark Lewis, and gave a plenary talk on social media at the SWOG spring 2013 meeting. In 2015, the social media working group became the digital engagement committee – now a full research support committee with an expanded scope. The digital engagement committee not only supports and tests the use of social media in clinical trials. It supports and tests the use of all digital tools – including text messaging, web and smartphone apps, wearable devices, online videos, and more – to improve trials and to improve communication with members and the public.





- **Is it time to ask study volunteers to sign a code of conduct?** This may help prevent disclosure of data during trial conduct and analysis, thus ensure the integrity of clinical trial data. A code, or confidentiality disclosure agreement, could also help patients by specifying that they maintain access to their own trial data.

- **Should social media be a required activity of a clinical researcher?** The authors note that social media is an important way for researchers to directly engage with patients by sharing information, dispelling myths, and highlighting critical trials through direct digital conversation. To help, SWOG is creating social media toolkits to accompany new trials. The aim is to give study leaders access to IRB-approved information – text and graphics – that can be used in Twitter and Facebook posts as soon as their study opens.

- **Is there an appropriate scope of IRB review related to social media use?** SWOG members point out that there are no rules for what kinds of social content requires IRB approval, and when and how. It's also not clear what constitutes "active" and "passive" social media recruitment under National Institutes of Health social media guidance.

- **How should sponsors collaborate with stakeholders on social media activities?** Specifically, the SWOG team believes that patient advocates can play a critical role in public engagement in cancer trials. Advocates currently run a slew of Facebook and Twitter support groups for nearly every cancer type, and are often at the table when cancer trials are conceived and developed. Should trial sponsors do more to encourage patient advocate participation in social media?

RUNNING OUR OWN TRIAL

SWOG Launches on Facebook

March 24, 2017

SWOG Chair

SWOG's Facebook Group Gets an Upgrade

February 9, 2018

Group Chair

The SWOG Grand Facebook Experiment Ends

December 21, 2018

Group Chair

YOU CAN'T KEEP A GOOD TRIALIST DOWN!

Apparently not all of my ideas are brilliant. Nor are they all fully successful. Digital Engagement Committee Chair Dr. Don Dizon says it best: Our private Facebook group was akin to a clinical trial. There was the intriguing hypothesis: If we create a Facebook page just for SWOG Cancer Research Network members, could we spark cross-disciplinary talk about our trials?

The answer, 21 months after launch, is no – or at least not enough to make a clinically significant difference. And so, the Facebook group, SWOG Oncology, will shut down at the end of the month. In the end, it was a negative trial.

Yet I consider the project to represent a good learning experience.

Led by our digital engagement committee and funded by a grant from The Hope Foundation for Cancer Research, the project offered a novel solution to a long-standing SWOG problem – insufficiently connecting our members. How can a prevention investigator talk with a breast committee member? How can clinical research associates engage with investigators, and patient advocates with pharmacists? Aside from opportunities arising at our semi-annual live meetings, it's easy to get stuck in our silos.

Attracting members wasn't a problem. We had nearly 300 in the SWOG Oncology Facebook group. And it wasn't as if people didn't post. They did. They shared fun conference photos, provocative journal articles, press releases, grant opportunities, blog posts.

But we couldn't seem to get conversations started about our SWOG trials – sharing success stories, giving advice on challenges, talking about the latest science or trial designs. And we didn't have diverse, consistent member participation – a key success metric for the pilot.

IF AT FIRST YOU DON'T SUCCEED ...

A few benefits have still sprung from all this. Digital engagement members can focus more on Twitter, the SWOG platform that is a slam-dunk success with more than 5,500 followers. They also know SWOG needs a cross-platform social media strategy, which they're working on.

<https://www.swog.org/news-events/news/2018/12/21/swog-grand-facebook-experiment-ends>

AGILITY IS A MUST

VISUAL CAPITALIST DATASTREAM

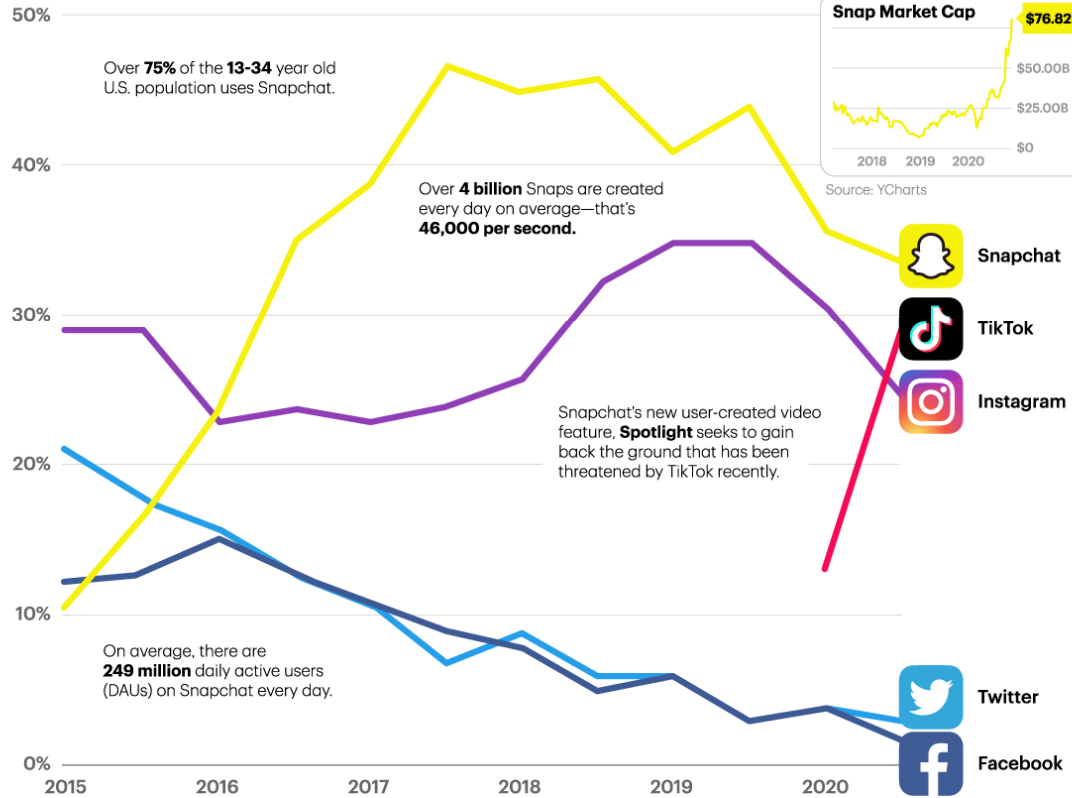
Snapchat Ranks #1 Among U.S. Teens



Snapchat has edged above Instagram in recent years and has emerged as the most popular social media app for U.S. teens.



Percentage of respondents selecting each as their favorite social platform



Over **75%** of the **13-34** year old U.S. population uses Snapchat.

Over **4 billion** Snaps are created every day on average—that's **46,000 per second**.

Snapchat's new user-created video feature, **Spotlight** seeks to gain back the ground that has been threatened by TikTok recently.

On average, there are **249 million** daily active users (DAUs) on Snapchat every day.



Source: YCharts

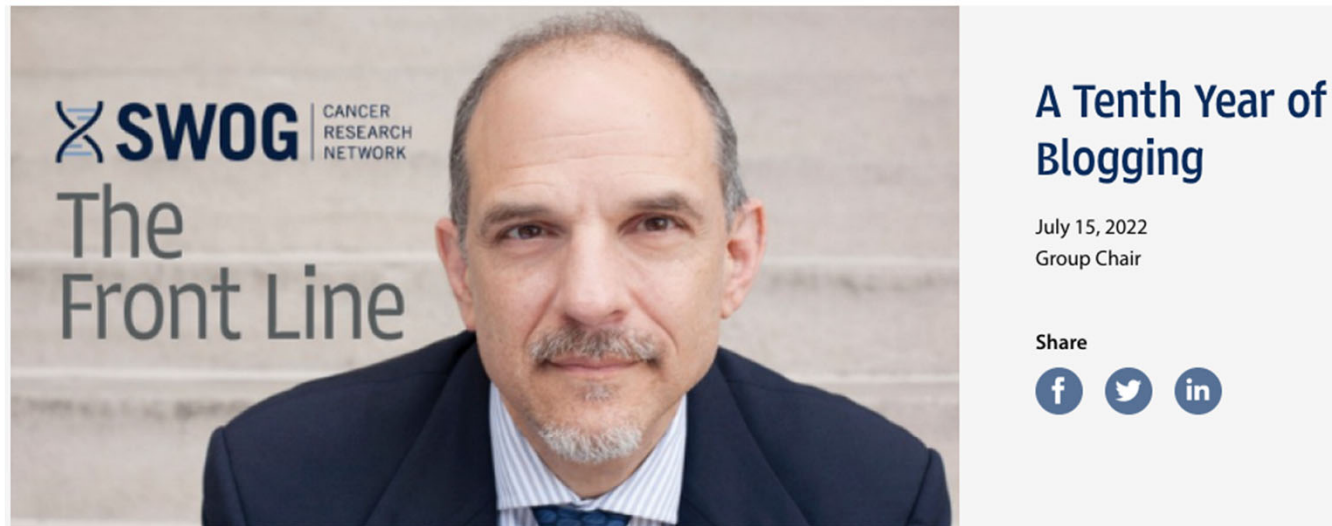


Snap's stock is up **200%** in 2020. Their impressive run had them edge ahead of Twitter by market capitalization.

Source: Piper Sandler



ADAPTING TO THE TIMES



Next week I start my tenth year of writing Front Lines. I stole the idea of a weekly communication tool from a mentor, Dr. George Sledge. In my opinion, Dr. Sledge was one of the most effective presidents ASCO has seen, partly, if not largely, because he liked to communicate with the ASCO membership.

We sent out the first of these posts on July 19, 2013, a few months after the start of my tenure as SWOG group chair. That first message was titled "An update on SWOG's approach to studying rare cancers."

WHAT'S NOW/NEXT?

- Wearables, VR, & telehealth/oncology at home
- ChatGPT and OpenAI
- **FLUX**

TRUE NORTH

TABLE 3. The Four Principles to Consider for Social Media Use: Embrace, Adapt, Insights, and Innovate

Principle	Description
<i>Embrace</i> social media as a mindset	Take a disciplined approach to planning
	Establish goals based on trust and transparency, not just return on investment
	Focus on being accessible and relevant
<i>Adapt</i> internal operations	Shift from silos to network
	Revamp processes to be relevant at the point of need
Turn social network conversations into <i>insights</i>	Don't just talk and listen, analyze and integrate
	Sift through the noise of social data
<i>Innovate</i>	Establish enterprise social media
	Create a forum to turn listening into innovation
	Collaborate across the industry

Gunturu KS, Dizon DS, Johnson J, Mercurio AM, Mason G, Sparks DB, Lawton W, Klemp JR. Clinical Trials in the Era of Digital Engagement: A SWOG Call to Action. JCO Clin Cancer Inform. 2020 Mar;4:254-258.