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
THE *PACE* OF PROGRESS
THE LAST DECADE IN HEALTHCARE SOCIAL MEDIA

Unprofessional → Helpful → Practically mandatory
THE RISING TIDE OF INFORMATION

4.6 million cancer-related articles in total!
FROM A FIREHOSE TO A REFRESHING STREAM

INFORMATION

CONTENTMENT
A NON-BINARY APPROACH

Peer-reviewed literature

SYNERGY

Social media

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
Breast cancer advocates had started breast cancer social media (♯bcsm) in 2011

Brain tumor social media (♯btsm) 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)


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 @symplr 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?

oncologists are

oncologists are murderers

oncologists are evil

oncologists are confused

oncologists are criminals
THE LAST DECADE IN SWOG SOCIAL MEDIA
LEADING BY EXAMPLE

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:

1. 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.

2. 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
PROMOTING CLINICAL TRIALS!

IBC Research Fdn
@IBCResearch

How did @SWOG jump into #socialmedia? Plenary talk next, now
#DigitalEngagement 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

The SWOG Grand Facebook Experiment Ends
December 21, 2018
Group Chair

SWOG's Facebook Group Gets an Upgrade
February 9, 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.
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.

AGILITY IS A MUST

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.

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

Source: Piper Sandler

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

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