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Social Media and the Research Enterprise


On Applications and Practical Utilization

Objectives

- What exactly *is* social media?
- Why should you care about it?
- What can be gained from exploring it?
- How do I do it?

The digital age is upon us!
 Conversations about cancer are going online beyond traditional borders – with or without you
 Social media represents an opportunity to listen, learn, and engage

Take-Home Points






Mechanism by which virtual communities form around shared interests

Evolving technologies aiming to facilitate communication




- One to one
- One to many

What exactly *is* social media?

Major Social Media Companies

Company	Inception	User base	Content	User communities
 Facebook	2004	Almost 2B	Photos, videos, Memes, Articles	Support groups Institutions Organizations Families
 Twitter	2006		Tweets (280 characters)	Hashtags mark interests (#bcs, #gyn, #some, #pallonc)
 LinkedIn	2003	Almost 500m	Photos, videos, articles, information, resumes	Professional networking opportunity

Major Social Media Companies

Company	Inception	User base	Content	User communities
 Doximity		>70% of US physicians	CVs, Licensing information, news articles, blogs	Professional site for physicians Used for rankings
 Snapchat	Mobile-first company		Photos, video snaps	Millennial preferred Entertainment industry predominantly
 YouTube	2005		Video, V-logs	Largest video-sharing site in the world (FaceBook making a play)

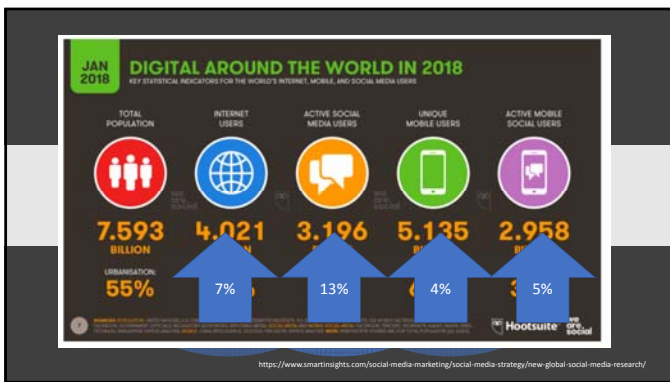
ASCO connection

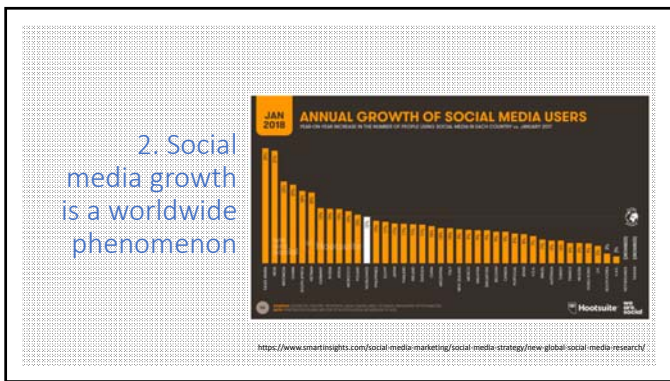
Other platforms exist

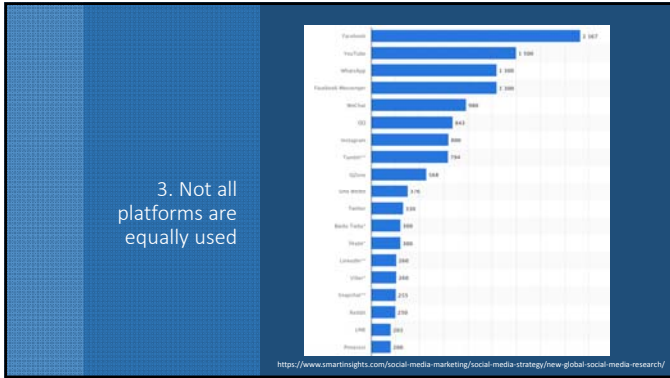
Blogs

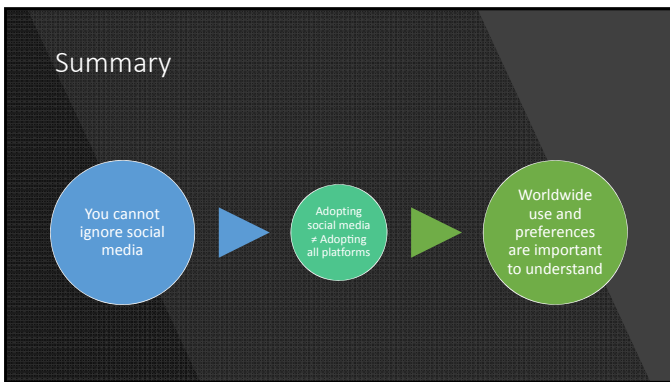
- Everyone as writer
- Unfiltered
- Claims may/may not be verifiable
- Opinions
- Multimedia sharing

KevinMD.com
Social media's leading physician voice

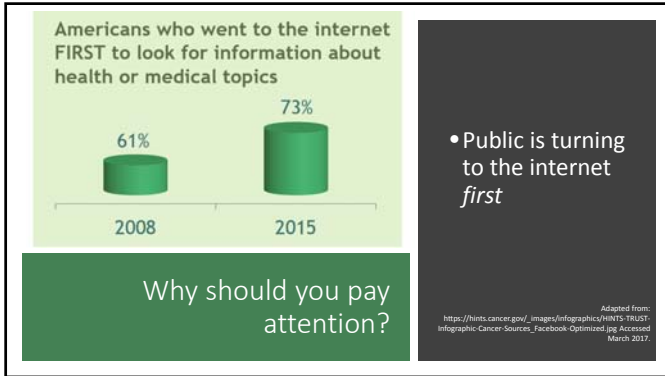


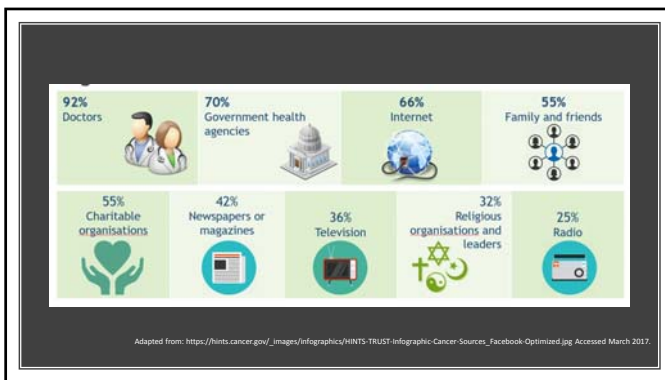


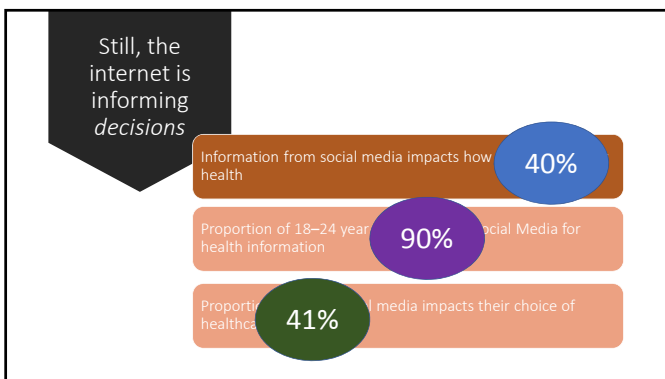




Social media and medicine:
Why you should care








Bottom Line

Two very simple reasons:

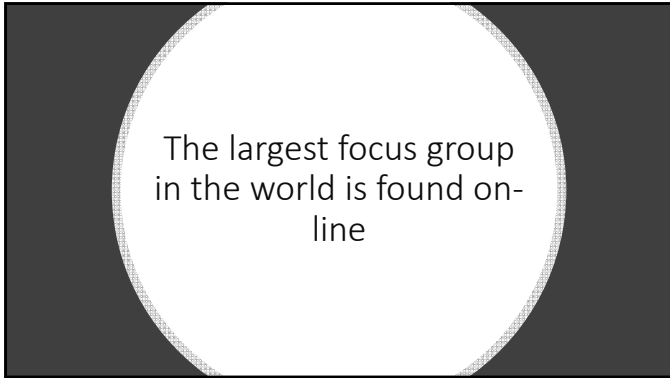
- Your patients are online
- You are online as well (even if you aren't)



Social media and the researcher

Social Media and Research

- Unfiltered look at the cancer experience
- Perspectives not limited by locality
- Communities to inform questions
 - Needs Assessments
 - Background for grant applications
- Advocacy and Fundraising



Needs
Assessment
Using Twitter

Hagan (2018): What are the survivorship needs for women treated for ovarian cancer?

Method: Tweetchat in partnership with #gynccsm: Re-envisioning ovarian cancer survivorship

Recruitment: Collaboration with partners: OCRFA, SGO, FWC, NOCC

Hagan TL, et al. J Patient Centered Res and Rev 2018. In Press.

Tweetchat
Focus Group
(Hagan,
2018)

T1 A. What does survivorship mean to you? What is it to be an ovarian cancer survivor?
B. Do you use the term survivor? If not, what term do you prefer?

T2 What needs and concerns did you have when you were first diagnosed and treated? How were they addressed? What was lacking?

T3 How was the topic of recurrence addressed with you? Did you find it helpful or not helpful at the time - and now looking back?

T4 A. What issues - physical, emotional or other - currently give you the most difficulty?
B. What are your needs and concerns now? (After recurrence or As you live past diagnosis and initial treatment of ovarian cancer)

T5 What actions have you taken in living past your ovarian cancer diagnosis and treatment? Were you given a Survivorship Care Plan?

Hagan TL, et al. J Patient Centered Res and Rev 2018. In Press.

Survivorship
in Ovarian
Cancer

377 Unique Tweets

43 participants in the 1 hour during
tweetchat (ave 8.6 tweets/person)

60 added thoughts in the following
24 hours

Hagan TL, et al. J Patient Centered Res and Rev 2018. In Press.

Word
Frequency

Hagan TL, et al. J Patient Centered Res and Rev 2018. In Press.

Word
sentiment

Hagan TL, et al. J Patient Centered Res and Rev 2018. In Press.

What did we learn?

- There is a lack of support during transitions
- Physical and emotional needs were unmet by clinicians
- Patients navigated independently
- Survivors want us to be proactive
 - Provide resources
 - Care plans not appropriate for women who face a high recurrence risk
 - Care plans should address needs of women after recurrence

Hagan TL, et al. J Patient Centered Res and Rev 2018. In Press

Social media research opportunities

- R01: Innovative approaches to studying cancer communication in the new media environment
 - <https://grants.nih.gov/grants/guide/pa-files/PA-16-249.html>
- R21: Exploratory/Developmental Research grant
 - <https://grants.nih.gov/grants/guide/pa-files/PA-16-248.html>

Twitter = Big data

Tweets are grounded in an experience:

- User → Specific location, specific time of post
- Tweet → Language, Context
- Typically, tweets are not isolated events

Paul and Dredze: What public health information can be learned from Twitter?

Paul MJ and Dredze M. 5th International Assn for the Advancement of AI Conference on Weblogs and Social Media, July 2011 (Barcelona)

Summary

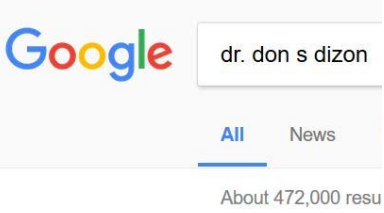
01 Twitter data mining is in its infancy	02 Unique collaborations required	03 Potential to inform Oncology beyond treatment is HUGE	04 Employing <i>public</i> social media data less problematic re: privacy
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To understand it, join it

Getting started on social media





Google dr. don s dizon

All News

About 472,000 results

You are on line... even if you aren't

- Google yourself
- You do not control what information appears
 - nor the order in which they are listed

Protecting your privacy

Adopt Dual Citizenship

- Grow your professional connections
- Maintain online privacy
- Examples:
 - Twitter use for professional activities
 - Facebook as a means to connect personally
- AMA Opinion 9.124: Separation of the personal and professional
- NOTE: All social media posts must be considered public

Social media tenets for the clinician

Be Thoughtful	Posts represent you and your institution
Be Transparent	Disclose your conflicts of interest
Be Clear	Speak for yourself (vs. speaking on behalf of your institution)
Be Smart	Don't post anything that you might regret later
Maintain Boundaries	Don't friend or follow your own patients

Patient confidentiality: protect at all times


There are no HIPAA compliant social media spaces

Professionals have been sanctioned for social media activity

- 2017: 70% of US state boards have disciplined providers
- Major breaches: misinformation, breach of confidentiality, inappropriate communication with patients

If communication with a patient on social media: all disclosures should be initiated by that patient.

Greysen S, et al. JAMA. 2012;307:1141-2; Greysen S, et al. Ann Intern Med. 2013;158:124-30.



- 1 Get involved
- 2 Engage often
- 3 Always identify yourself
- 4 Protect patient confidentiality and privacy
- 5 Contextualise your activities



- 6 Avoid impropriety
- 7 Give credit where credit is due
- 8 Professionalism is critical
- 9 Separate personal from professional
- 10 Be aware of your institutional guidelines

Getting started

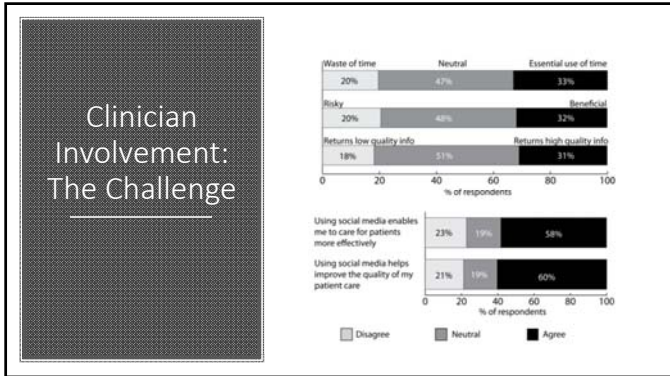
- Try out multiple sites**
 - Sign up using an email
 - Pick a username that identifies you professionally
- Lurk awhile.**
 - Find subjects of interest (hashtags)
 - Follow people you find interesting (@drdonsdizon)
- When comfortable, join.**
 - **Do not post when inebriated, exhausted, or infuriated.**

Hashtags
Marks subject matter on many platforms

Have I convinced you?

Clinician Involvement: The challenge

McGowan BS, Wasko M, Vartabedian BS, Miller RS, Freiherr DD, Abdolrasulnia M. J Med Internet Res 2012; 14:e117



Twitter Use Among Academic Oncologists?

Barriers:

- No value
- Waste of time
- No academic merit
- Huge risk for ???reward
- Work, work, work

How do we engage our peers?

Provide evidence that it will be of *professional benefit*?

Foster altruism

Engage reciprocally

Nurture collectivism

K. Roffi, M. Hansen, D. Jackson, D. Elliott. J Med Int Res 2016; PMAC 4933801

The Collaboration
for Outcomes
Using Social Media
in Oncology



Who is
COSMO?

EAST	<ul style="list-style-type: none"> • Don Dizon (Providence) • Matt Katz, Jennifer Kesselheim (Boston)
WEST	<ul style="list-style-type: none"> • Deanna Attai (Los Angeles) • Mina Sedrak (Duarate)
SOUTH	<ul style="list-style-type: none"> • Michael Fisch (Houston) • David Graham (Raleigh) • MJ Markham (Gainesville)
CENTRAL	<ul style="list-style-type: none"> • Mike Thompson (Racine, WI) • Patricia Anderson (Ann Arbor) • Nathan Pennell (Cleveland)

What is
COSMO?

- Clinical collaboration
- Define best practices
- Conduct outcomes research
- Empiric research on social media engagement to:

In summary

- Social media has changed the patient-provider interaction
- Patients want our voices on line
- Capacity for change is huge
- In an era of “fake news”, we can point towards reliable sources
- Social media = Big data
 - Learn what’s important from folks impacted
 - Re-learn how to talk to patients
 - Inform your research
 - Generate new questions

Questions?

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Thank you for having me
