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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

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 Familes
Twitter	2006		Tweets (280 characters)	Hashtags mark interests (#bcsm, #gyncsm, #some, #lcsm, #pallonc)
LinkedIn	2003	Almost 500m	Photos, videos, articles, information, resumes	Professional networking opportunity

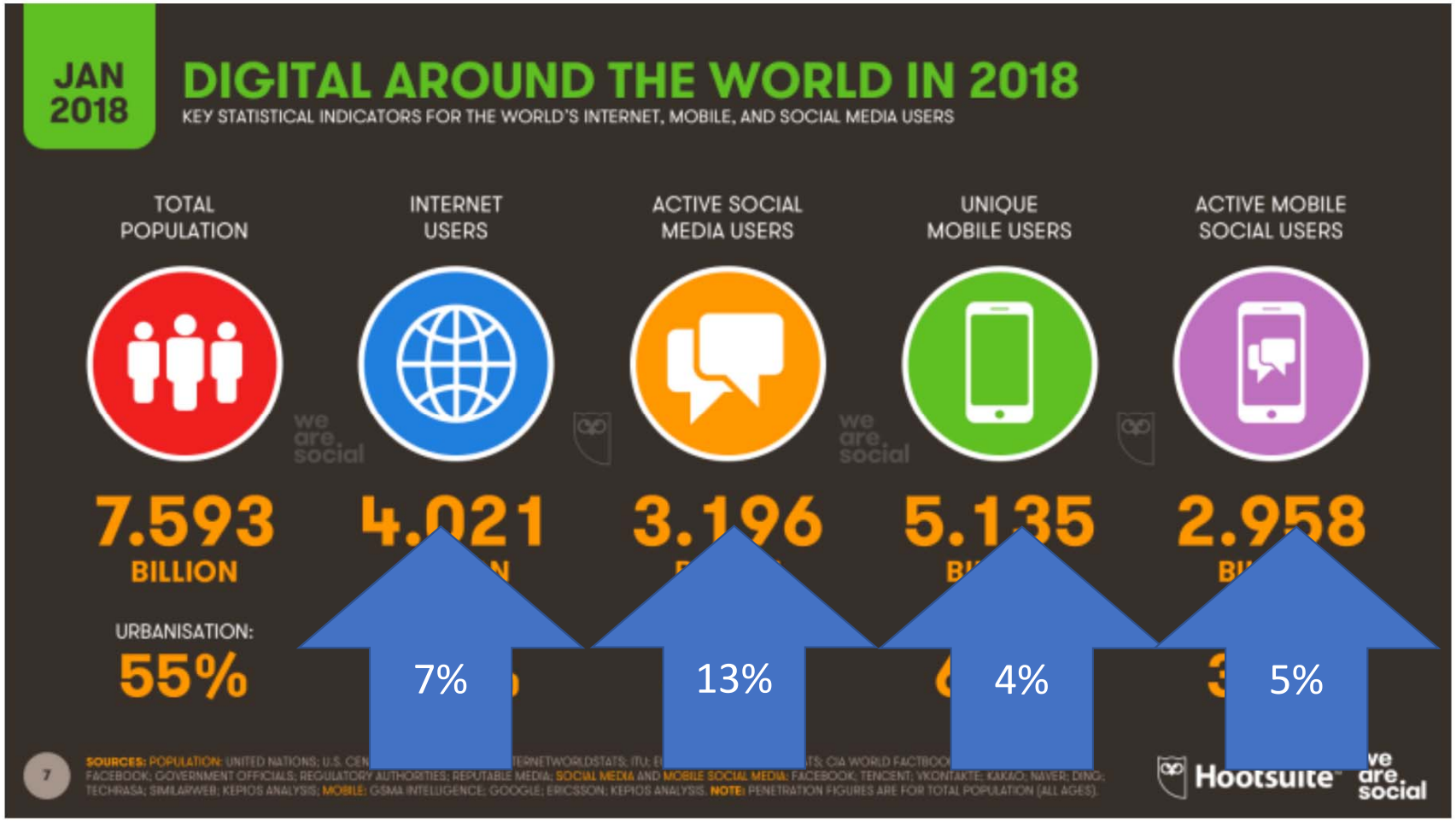
Major Social Media Companies

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	Millenial preferred Entertainment industry predominantly
YouTube	2005		Video, V-logs	Largest video-sharing site in the world (FaceBook making a play)

Other platforms exist

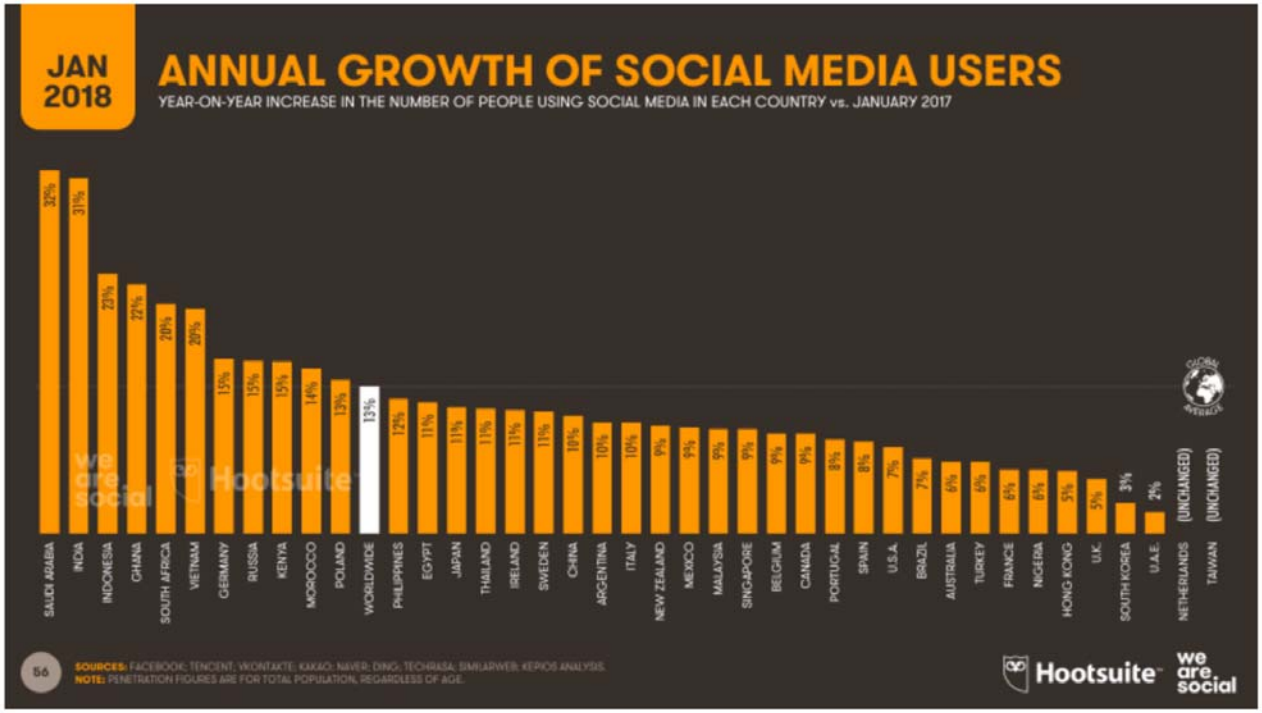
Blogs

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



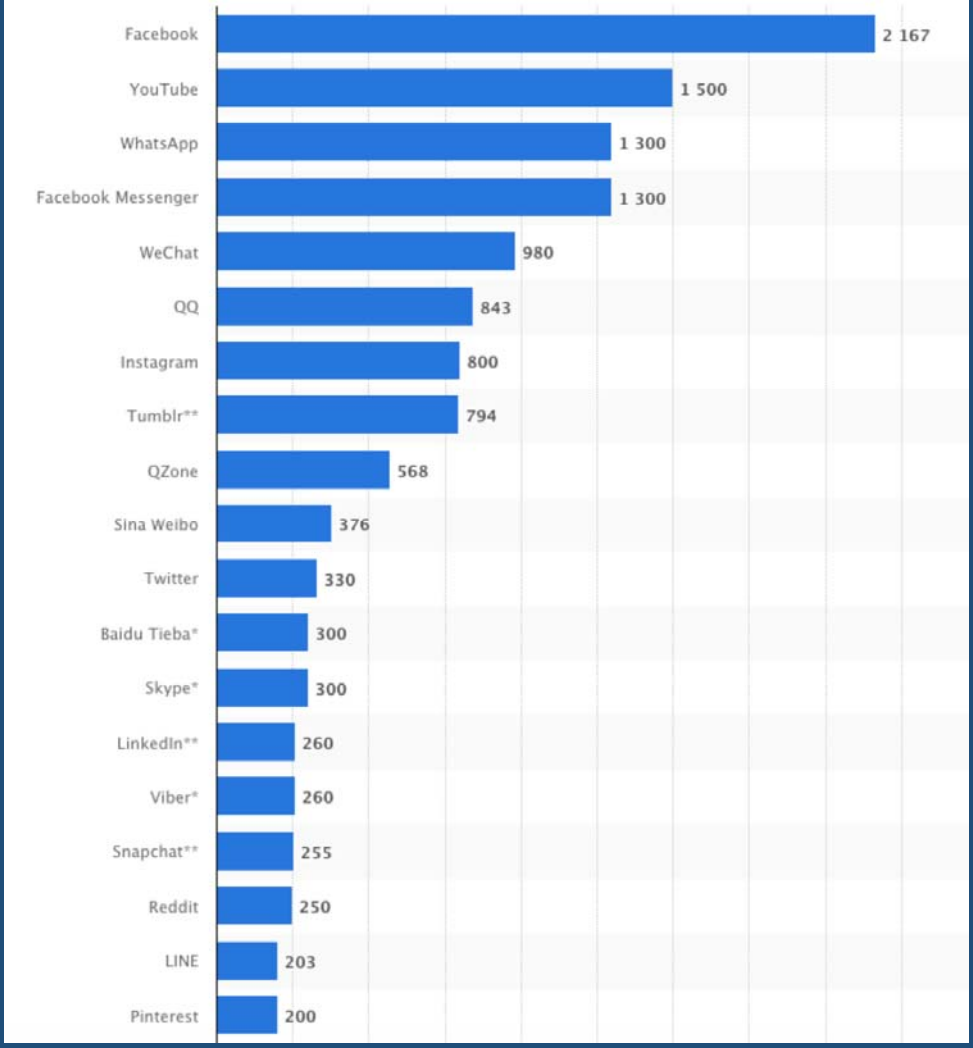
https://www.smartinsights.com/social-media-marketing/social-media-strategy/new-global-social-media-research/

2. Social media growth is a worldwide phenomenon



https://www.smartinsights.com/social-media-marketing/social-media-strategy/new-global-social-media-research/

3. Not all platforms are equally used



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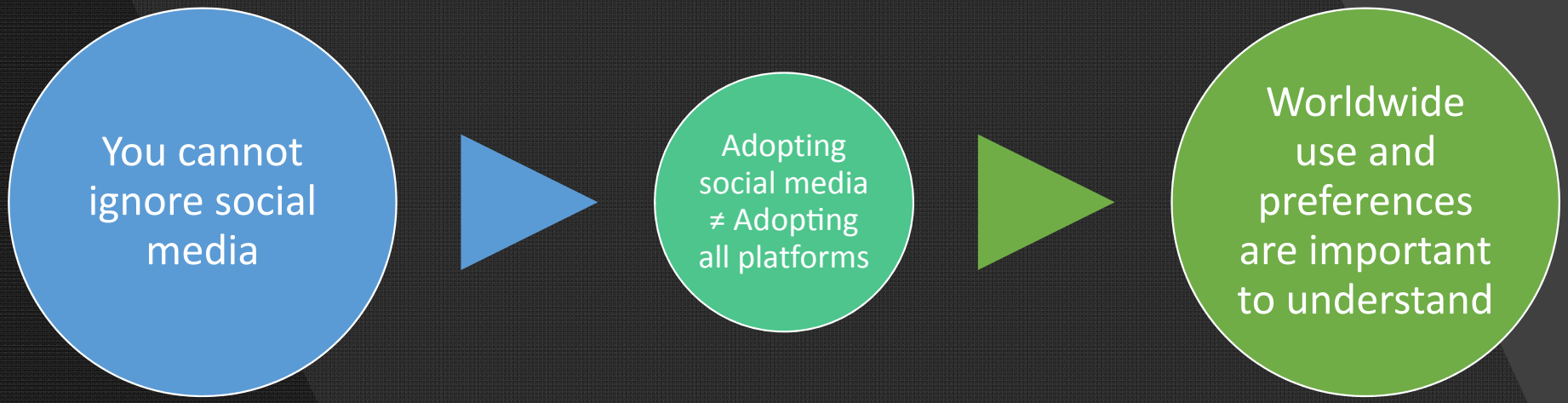
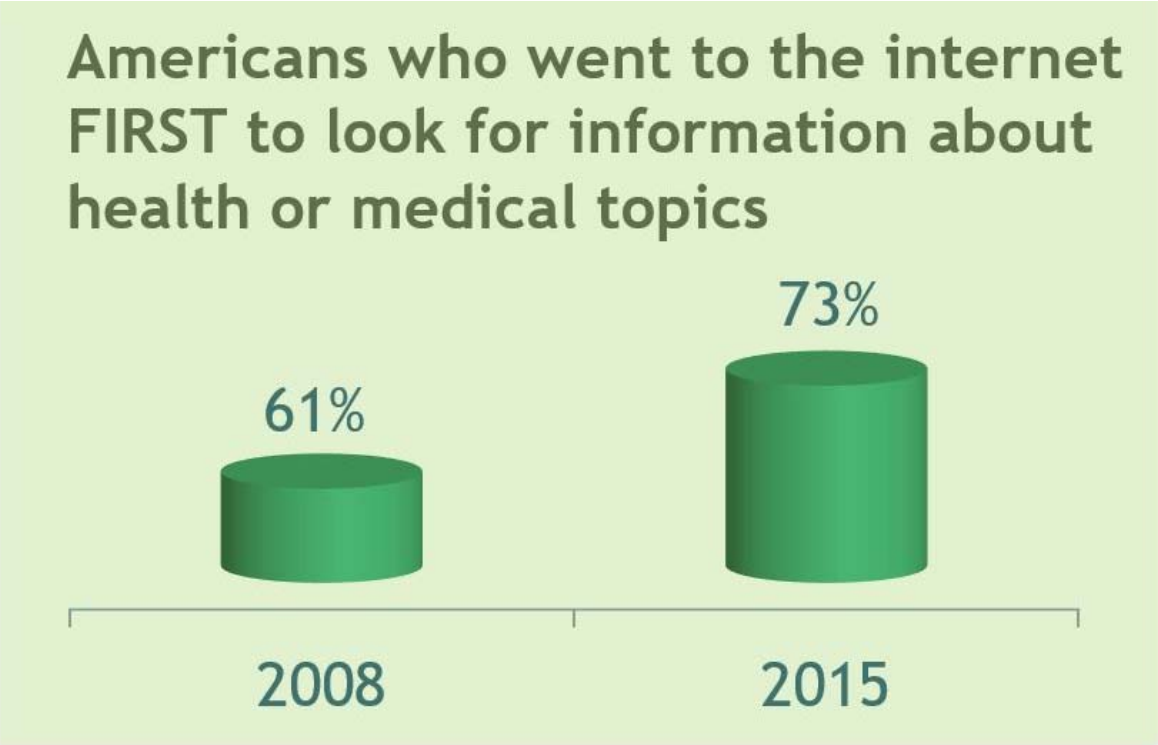
Summary


You cannot ignore social media
Adopting social media ≠ Adopting all platforms
Worldwide use and preferences are important to understand

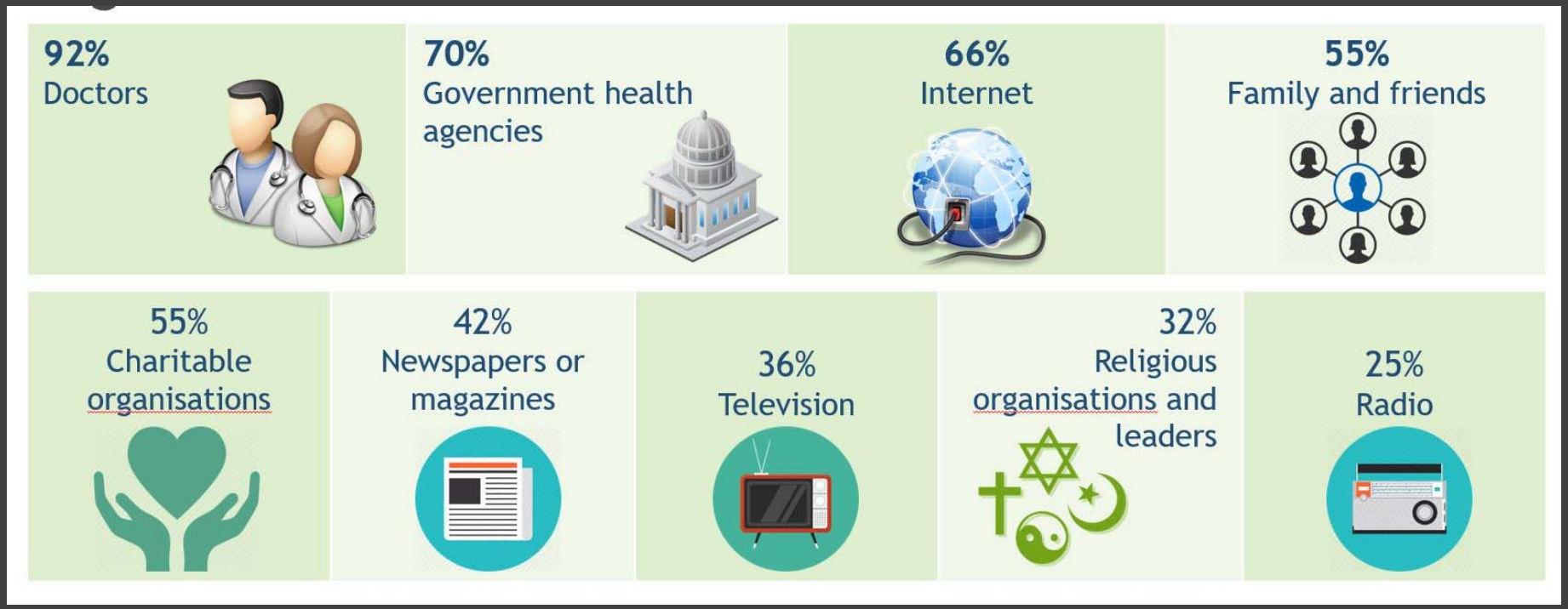
Social media and medicine: Why you should care



Why should you pay attention?

- Public is turning to the internet *first*

Adapted from: https://hints.cancer.gov/_images/infographics/HINTS-TRUST-Infographic-Cancer-Sources_Facebook-Optimized.jpg Accessed March 2017.



Adapted from: https://hints.cancer.gov/_images/infographics/HINTS-TRUST-Infographic-Cancer-Sources_Facebook-Optimized.jpg Accessed March 2017.

Still, the internet is informing *decisions*

Information from social media impacts how
health

40%

Proportion of 18–24 year
health information

90%

ocial Media for

Proporti
healthca

41%

l media impacts their choice of

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

The largest focus group in the world is found on-line

Needs Assessment Using Twitter

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

Method: Tweetchat in partnership with #gyncsm: 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)

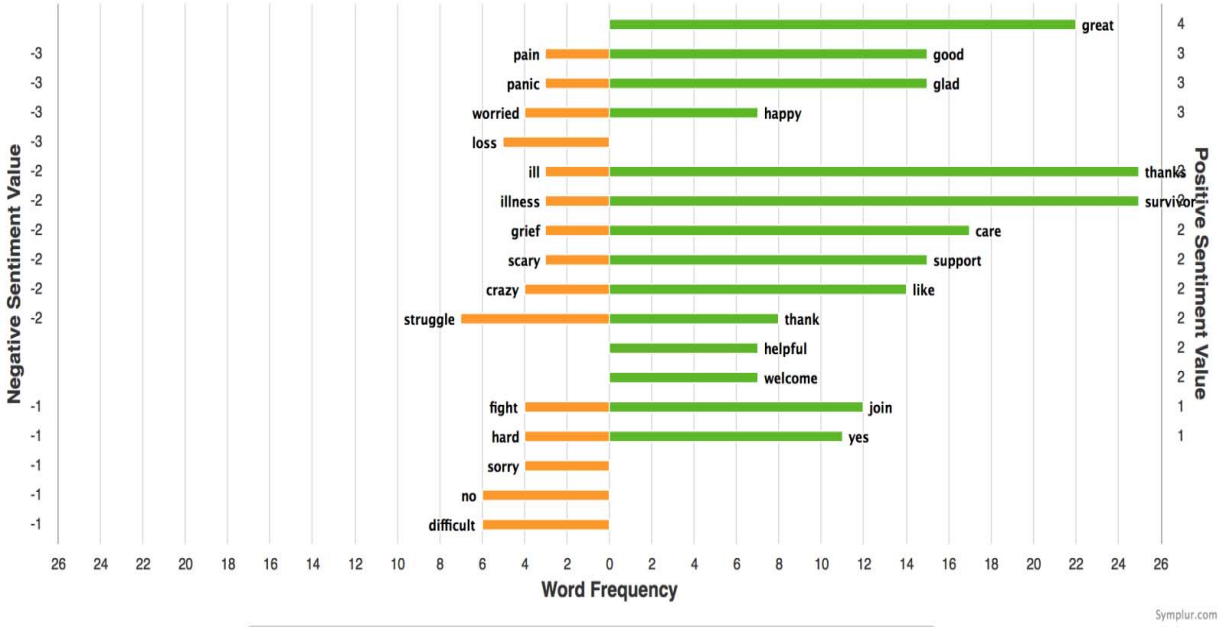
60 added thoughts in the following 24 hours

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/PAR-16-249.html
- R21: Exploratory/Developmental Research grant
  - https://grants.nih.gov/grants/guide/pa-files/PAR-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)

ATAM (Paul and Dredze)

- Alignment Topic Aspect Model = A model of the user's expression of illness and ailment in Tweets
- For each health-related tweet, there is a latent ailment (eg, cancer)
- Each ailment = distribution over words

Ailment	Allergies	Depression	Aches/Pains	Cancer	Obesity	Flu	Dental
Prior Frequency	Allergies 6.4%	Anxiety 5.8%	Back Pain 10.8%	Breast Cancer 8.0%	Diabetes 2.3%	Flu 8.1%	Oral Health 4.6%
General Words	allergies stop eyes allergic	help dont body depression	body head need hurts	cancer pray mom shes	blood doctor high meds	flu "swine flu" "flu shot" dont	meds killers dentist teeth
Symptoms	sneezing cold coughing	pain anxiety stomach	pain aches stomach	pain sad "breast cancer"	pressure "high blood pressure"	fever cold "sore throat"	pain toothache sore
Treatments	medicine benadryl claritin	surgery treatment plastic	massage "hot bath" ibuprofen	surgery hospital "heart surgery"	hospital diet exercise	hospital vaccine medicine	braces surgery antibiotics

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

ATAM (Paul and Dredze)

- ATAM: Treatments more correctly align with an ailment, compared to symptoms

Model	Total	Correct (S)	MRR (S)	Correct (T)	MRR (T)
Discovered Ailments to Articles					
ATAM	12	2	0.33	4	0.51
ATAM+	13	3	0.42	6	0.63
Articles to Discovered Ailments					
ATAM	12	0	0.23	0	0.36
ATAM+	13	1	0.32	5	0.54

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

Risk Factor	Ailments	Correlation ATAM+	Correlation ATAM
Asthma	Allergies	0.241	0.195
Diabetes	Obesity	0.073	0.203
Exercise	All ailments	-0.352	-0.394
Exercise	Exercise	0.140	–
Exercise	Obesity	-0.201	-0.248
Health Care Coverage	All ailments	-0.253	-0.319
Heart attack	Obesity	0.244	0.341
Heart attack	Cancer	0.613	0.291
Obesity	Obesity	0.280	0.203
Obesity	Exercise	-0.267	–
Tobacco use	Cancer	0.648	0.320

Geographic behavioral risk factors

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

- Extracted geographically linked health statistics
  - Able to generate US state in 12% of tweets (n= 196K)
- Generated questions using the Behavioral Risk Factor Surveillance System (CDC, 350K adults, collected in 2009)

Word	Ent.	Most Common Ailments
vomiting	2.19	Flu (23%), Aches (16%), Insomnia (12%)
burn	2.02	Skin (36%), Aches (17%), Headache (2%)
chill	1.95	Headache (28%), Insomnia (18%), Flu (12%)
fever	1.46	Flu (50%), Cold (24%), Infection (11%)
pimples	0.72	Skin (84%), Depression (5%)
fractured	0.69	Physical injuries (82%), Cancer (12%)
toothache	0.61	Dental (83%), Insomnia (9%), Aches (6%)
headache	0.56	Headache (75%), Insomnia (25%)
tumor	0.22	Cancer (96%)
mood	0.20	Depression (96%), Obesity (4%)

Using Twitter to analyze symptoms

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

Twitter to evaluate medication usage

Word	#	Ent.	Most Common Ailments
Pain Relief Medication			
tylenol	1807	1.57	HA (39%), IN (30%), Cold (9%)
ibuprofen	1125	1.54	HA (37%), DN (21%), Aches (17%)
advil	1093	1.08	HA (61%), Cold (6%), DN (5%)
aspirin	885	1.04	HA (69%), IN (10%), Aches (10%)
vicodin	505	1.33	DN (61%), Injuries (11%), HA (10%)
codeine	406	1.94	Cold (25%), DN (19%), HA (17%)
morphine	206	1.17	DN (59%), Infection (22%), Aches (9%)
aleve	183	1.10	HA (62%), IN (15%), DN (14%)
Allergy Medication			
benadryl	871	1.24	Allergies (64%), Skin (13%), IN (12%)
claritin	417	0.54	Allergies (88%), HA (5%)
zyrtec	386	0.49	Allergies (90%)
sudafed	298	1.61	Allergies (39%), Cold (21%), HA (20%)

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

Twitter data limitations

US-centric

Younger

Limitations in

ging

Of over 1.6 million tweets- the investigators only able to use 8% for their work on influenza trends.

necessarily first-person

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

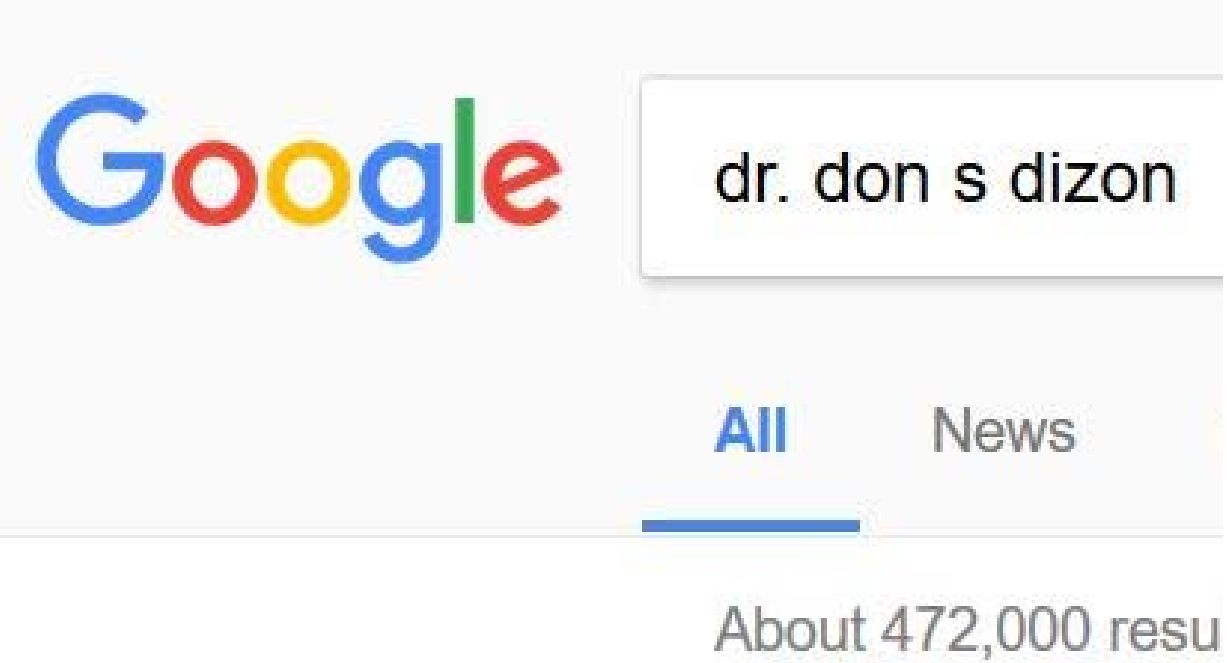
Potential to inform Oncology beyond treatment is HUGE

04

Employing *public* social media data less problematic re: privacy

To understand it, join it

Getting started on social media



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

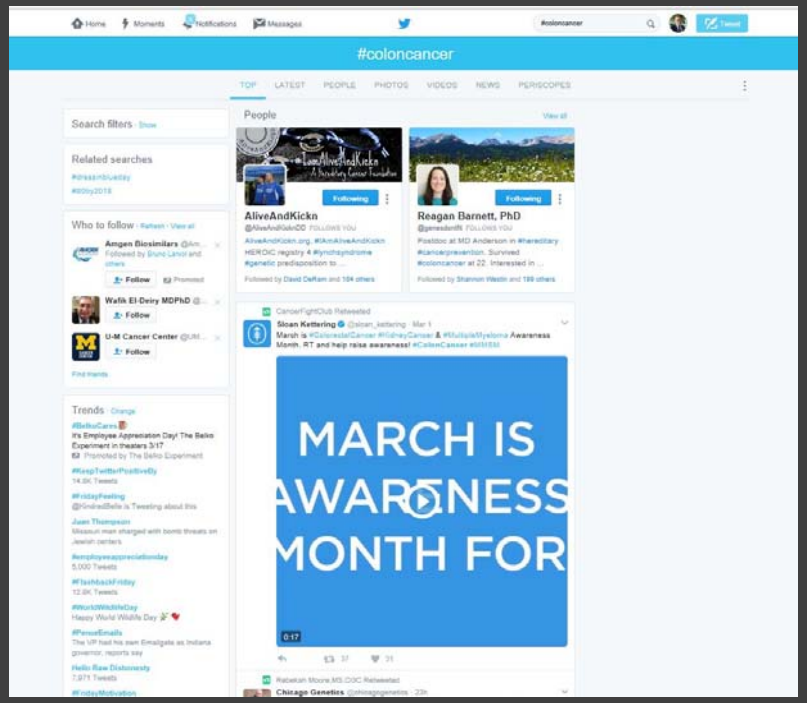
- Sign up using an email
- Pick a username that identifies you professionally

Lurk awhile.

- Find subjects of interest (hashtags)
- Follow people you find interesting (@drdonsdizon)

When comfortable, join.

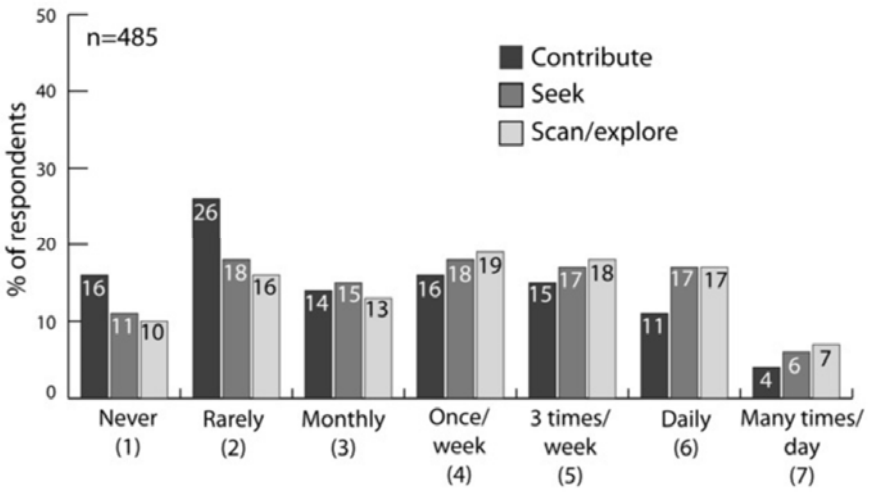
- **Do not post when inebriated, exhausted, or infuriated**.

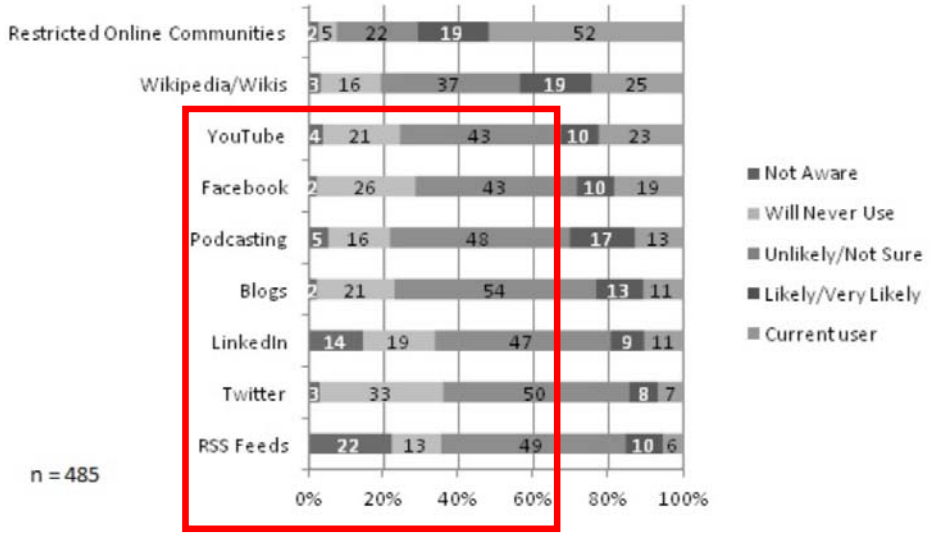


Hashtags

Marks subject matter on many platforms

Have I convinced you?

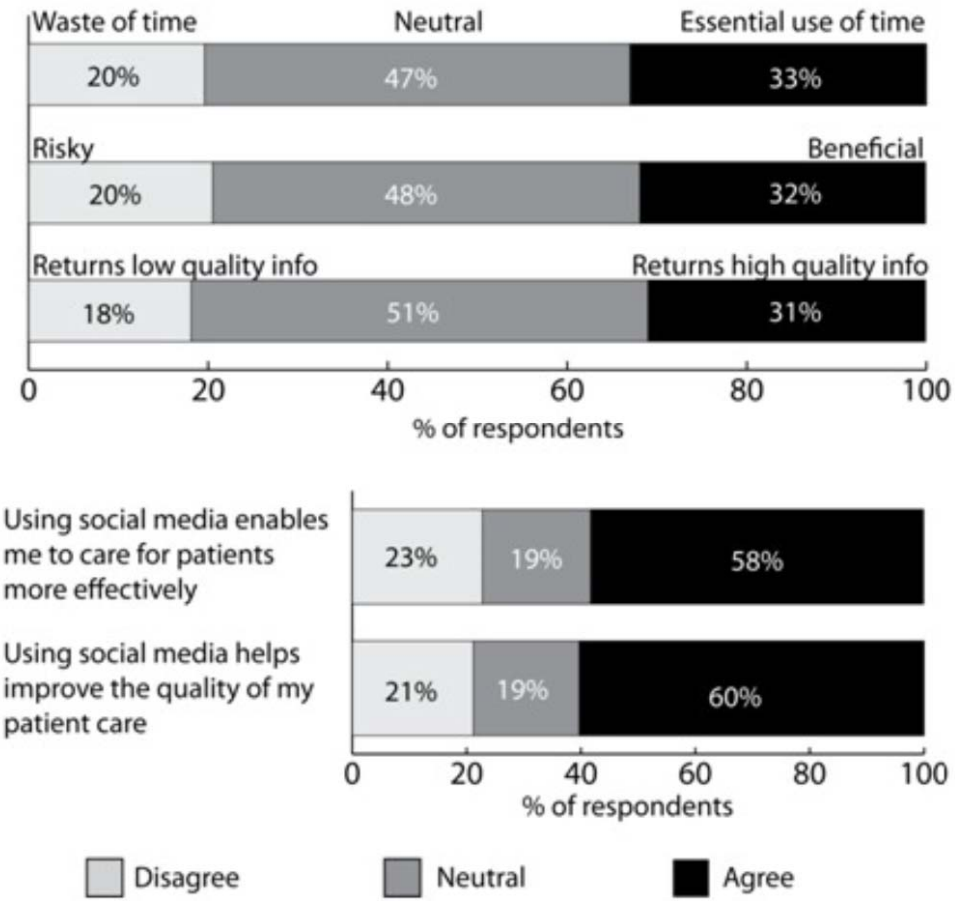




Clinician Involvement: The challenge

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

Clinician Involvement: The Challenge



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 Rolls, M Hansen, D Jackson, D Elliott. J Med Int Res 2016; PMC 4933801

The Collaboration for Outcomes Using Social Media in Oncology

This Photo by Unknown Author is licensed under CC BY-SA

Who is COSMO?

EAST

- Don Dizon (Providence)
- Matt Katz, Jennifer Kesselheim (Boston)

WEST

- Deanna Attai (Los Angeles)
- Mina Sedrak (Duarte)

SOUTH

- Michael Fisch (Houston)
- David Graham (Raleigh)
- MJ Markham (Gainesville)

CENTRAL

- Mike Thompson (Racine, WI)
- Patricia Anderson (Ann Arbor)
- Nathan Pennell (Cleveland)

What is COSMO?

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

What has COSMO done

Promoted hashtags for online use

- Katz MS, Utengen A, Anderson PF, Thompson MA, Attai DJ, Johnston C, Dizon DS. Disease-Specific Hashtags for Online Communication About Cancer Care. JAMA Oncol. 2016 Mar;2(3):392-4. PMID: 26539640

Crafted Reviews for oncologists and hematologists

- Attai DJ, Anderson PF, Fisch MJ, Graham DL, Katz MS, Kesselheim J, Markham MJ, Pennell NA, Sedrak MS, Thompson MA, Utengen A, Dizon DS; Collaboration for Outcomes on Social Media in Oncology (COSMO). Risks and benefits of Twitter use by hematologists/oncologists in the era of digital medicine. Semin Hematol. 2017 Oct;54(4):198-204. PMID: 29153081
- Thompson MA, Ahlstrom J, Dizon DS, Gad Y, Matthews G, Luks HJ, Schorr A. Twitter 101 and beyond: introduction to social media platforms available to practicing hematologist/oncologists. Semin Hematol. 2017 Oct;54(4):177-183. PMID: 29153077
- Sedrak MS, Dizon DS, Anderson PF, Fisch MJ, Graham DL, Katz MS, Kesselheim JC, Miller RS, Thompson MA, Utengen A, Attai DJ; Collaboration for Outcomes on Social Media in Oncology (COSMO). The emerging role of professional social media use in oncology. Future Oncol. 2017 Jun;13(15):1281-1285. PMID: 28589770
- Attai DJ, Sedrak MS, Katz MS, Thompson MA, Anderson PF, Kesselheim JC, Fisch MJ, Graham DL, Utengen A, Johnston C, Miller RS, Dizon DS; Collaboration for Outcomes on Social Media in Oncology (COSMO). Social media in cancer care: highlights, challenges & opportunities. Future Oncol. 2016 Jul;12(13):1549-52. PMID: 27025657

What has COSMO done

Qualitative Research

- TL Hagan, K Nauth-Shelley, MA Thompson, DJ Attai, MS Katz, D Graham, D Sparacio, C Lizaso, A Utengen, DS Dizon. The needs of women treated for ovarian cancer: Results from a #Gyncsm Twitter chat. J Patient-Centered Res and Rev 2017

Stay Tuned!

@-cosmoproject

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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Twitter: @drdonsdizon

Thank you for having me