Social Media for Patient Advocacy
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Agenda

• Overview of Social Media Tools and Techniques
• 15 min Breakout Session – New and Advanced
• Group Discussion
Advocacy in the Digital World

- Mailings, newsletters not as effective
- New tools, new ways to communicate
- Communication needs to be timely
- Cost effective
Why Social Media?

• Social Media shrinks the world – connections can be instantaneous
• Reach goes beyond the limits of geographic communities
• Learn from others
Advocacy + Social Media = Perfect Match

• Targeted Messaging
• Reach new constituents
• Engage new “Ambassadors”
• Expand reach to new communities
Three Rules for Success

1. “Never post anything you wouldn’t want published on the front page of the NY Times.” Assume everything is ALWAYS PUBLIC
2. Be polite and respectful.
3. Be consistent.
Social Media Tools for Success

1. Twitter
2. Facebook
3. LinkedIn
4. Instagram/Snapchat/Pinterest
Twitter

- Individual messaging
- Open, transparent conversations
- Follow conferences, areas of interest
- Short, concise, rapid fire
- Information sharing
Facebook

- Open and closed groups
- More in depth conversations and discussion
- Robust information creation and sharing
- Biggest area for growth
Linkedin

- Connect with Congress
- Industry representatives
- Showcasing individual skills and involvement with key organizations
Instagram/Snapchat/Pinterest

- Secondary information creation and sharing
- Showcase images from events
- Short form video
- Tag and pin relevant articles to share with larger audience
hashtags

https://www.wired.com/2017/05/oral-history-hashtag/
Hashtags

- #CPAT17
- #Cancer
- #CancerSurvivor
- #ACA
- #AHCA
Hashtags

Public Posts

Write4wellness
3 hours ago - 📞

Heading to #CPAT17! Expecting to learn more about cancer advocacy!

Write4wellness
3 hours ago - 📞

Hello, my friends! I'm a newbie at cancer policy advocacy, and am expecting to absorb tons...See more

Stacey Tinianov @coffeemommy · 50m
Patient Advocacy, Research Advocacy & now Healthcare Policy Advocacy at #CPAT17 Every piece of puzzle still comes down to putting PEOPLE 1st

Lacuna Loft and 1 other follow

Veronika Panagiotou @veronikap88 · 19m
#CPAT17 Here I come! Fighting for healthcare!@CancerAdvocacy @StupidCancer @communityphdpup

Jen Campisano @JCampisano · 37m
Gearing up to speak at #CPAT17. I’m nervous - my story is deeply personal, but remembering these are my ppl & trying to save healthcare is 💪

NCCS @CancerAdvocacy · 39m
We are excited to welcome cancer advocates from all across the country to our annual #CPAT17 Symposium today!

Maria Shriver and 4 others follow

Xenia Rybak @xenianyb · 3h
Heading to D.C. for #cpat17. Excited to learn about #canceradvocacy and #protectourcare and to head to the hill on Tuesday.
#BCSM

Breast Cancer Social Media
#BCSM by the Topics

- Research report
- Major Conferences
  - ASCO
  - ASCO Breast
  - ASBRS
  - SABCS
- Celebrity Effect on Breast Cancer conversations
- Day to Day living
- Finding your new normal
- Getting through surgery
- Dealing with Chemo
- Tips and Tricks for self-care
#BCSM by the Numbers

### The #BCSM Influencers

<table>
<thead>
<tr>
<th>Top 10 by Mentions</th>
<th>Top 10 by Tweets</th>
<th>Top 10 by Impressions</th>
</tr>
</thead>
<tbody>
<tr>
<td>@drattai 18,612</td>
<td>@stales 8,560</td>
<td>@stales 85,890,667</td>
</tr>
<tr>
<td>@stales 12,446</td>
<td>@drattai 7,940</td>
<td>@livestrong 57,817,807</td>
</tr>
<tr>
<td>@jodyms 11,099</td>
<td>@jodyms 5,760</td>
<td>@drattai 55,580,954</td>
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<tr>
<td>@chemobrainfog 5,739</td>
<td>@abhurel 3,265</td>
<td>@jodyms 43,287,544</td>
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<tr>
<td>@xeni 3,747</td>
<td>@chemobrainfog 2,696</td>
<td>@xeni 20,973,035</td>
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<tr>
<td>@regrounding 3,711</td>
<td>@drbeckerschutte 2,686</td>
<td>@talkabouthealth 18,635,028</td>
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<tr>
<td>@abhurel 3,156</td>
<td>@lsthrebunk 2,251</td>
<td>@subatomicdoc 15,258,236</td>
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<td>@danafarber 2,897</td>
<td>@chiqrl13 2,204</td>
<td>@chemobrainfog 14,391,343</td>
</tr>
<tr>
<td>@drbeckerschutte 2,857</td>
<td>@subatomicdoc 1,879</td>
<td>@danafarber 12,730,838</td>
</tr>
<tr>
<td>@ascopost 2,803</td>
<td>@regrounding 1,835</td>
<td>@brodalumab 12,520,907</td>
</tr>
</tbody>
</table>

### The Numbers

- Impressions: 818,684,625
- Tweets: 205,685
- Participants: 24,785
- Avg Tweets/Participant: 11
- Avg Tweets/hour: 8
Healthcare Hashtag Project
symplur.com

Why the Healthcare Hashtag Project?
Discover Where The Healthcare Conversations Are Taking Place
Discover Who To Follow Within Your Specialty Or Disease
Discover What Healthcare Topics Are Trending In Real-Time

The Community by the Numbers
1,104,087,577 Tweets
15,396 Topics
8,054 Hashtags
3,112 Contributors

Tweet Chats
- #MedX
- #BCSM
- #AHealthierNation

Conferences
- #medx
- #AHIMACon15
- #CIMCon15

Diseases
- #Migraine
- #CRPS
- #Lymphoma

Regular
- #FOAMed
- #FFpaciente
- #ZeroSuicide
Conferences & Research
Conference Tweeting

WHY?

HOW?
Why Tweet about Key Events?

- Increase size of audience
- No geographical limits
- No Financial barriers
- Amplify information being presented
- Potential to grow support base
The #sabcs Influencers

Top 10 by Mentions
- @drsteventucker 358
- @chemobraininfo 262
- @aacc 261
- @regrounding 225
- @jodysn 203
- @karunajaggar 168
- @eamoncology 165
- @bcaction 115
- #BRSTKNKactie?2 72
- @jgrakow 70

Top 10 by Tweets
- @regrrounding 323
- @chemobraininfo 274
- @drsteventucker 214
- @eamoncology 209
- @thecancergeek 148
- @bcaction 107
- @karunajaggar 103
- @onclive 79
- @jgrakow 79
- @isthebunk 72

Top 10 by Impressions
- @susangkomen 2,158,268
- @eamoncology 1,587,500
- @drsteventucker 1,301,294
- @bcaction 1,306,269
- @chemobraininfo 1,214,915
- @roche 1,078,850
- @novartis 860,368
- @regrrounding 841,415
- @drseisenberg 531,512
- @oncologytimes 524,200

The Numbers
- 18,894,472 Impressions
- 4,349 Tweets
- 670 Participants
- 36 Avg Tweets/Participant
- 6 Avg Tweets/Participant

#sabcs analytics for time period 12/04/2012 00:00 to 12/08/2012 23:59 (Pacific Time: GMT-07:00) change time period

2012
Social Media For Patient Advocacy

2013

The #sabcs13 Influencers

Top 10 by Mentions

1. @rem3800 102
2. @teamoncology 317
3. @theoncologist 287
4. @jgratkow 247
5. @chemobrainlog 222
6. @jcli_now 183
7. @karunajaggar 165
8. @roche 156
9. @susanglieman 130
10. @ascr 120

Top 10 by Tweets

1. @rem3800 102
2. @teamoncology 317
3. @theoncologist 287
4. @jgratkow 247
5. @chemobrainlog 222
6. @jcli_now 183
7. @karunajaggar 165
8. @roche 156
9. @susanglieman 130
10. @ascr 120

Top 10 by Impressions

1. @rem3800 1,261,260
2. @teamoncology 317
3. @theoncologist 287
4. @jgratkow 247
5. @chemobrainlog 222
6. @jcli_now 183
7. @karunajaggar 165
8. @roche 156
9. @susanglieman 130
10. @ascr 120

The Numbers

2,926,452 Impressions
5,886 Tweets
1,016 Participants
35 Avg. Tweets/Day
6 Avg. Impressions/Day

#sabcs13 analytics for time period 12/12/2013 00:00 to 12/15/2013 00:00 (Pacific Time, GMT-07:00)
HOW?

Register the conference hashtag!!

http://www.symplur.com/healthcare-hashtags/

The People Behind Symplur
Howard J Luks, M.D. Audun Utengen, MBA
The Fox Group, LLC
Healthcare Conferences

Healthcare Conferences

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sep 10 2016</td>
<td>AMIA2016</td>
</tr>
<tr>
<td>Sep 10 2016</td>
<td>Stanford Medicine X 2016</td>
</tr>
<tr>
<td>Sep 11 2016</td>
<td>#IAVS2016</td>
</tr>
<tr>
<td>Sep 11 2016</td>
<td>West Midlands CSCP study day 2016</td>
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<tr>
<td>Sep 11 2016</td>
<td>EASD2016</td>
</tr>
<tr>
<td>Sep 11 2016</td>
<td>52nd European Association For The Study Of Diabetes Annual Meeting 2016</td>
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<tr>
<td>Sep 11 2016</td>
<td>#RMIConf16</td>
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<tr>
<td>Sep 11 2016</td>
<td>8th National Motor Neurone Disease Conference</td>
</tr>
<tr>
<td>Sep 11 2016</td>
<td>#MACC16</td>
</tr>
<tr>
<td>Sep 11 2016</td>
<td>North American Congress of Clinical Toxology</td>
</tr>
<tr>
<td>Sep 11 2016</td>
<td>#MayoClinicFL</td>
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<tr>
<td>Sep 11 2016</td>
<td>Twitter Wars at Mayo Clinic in Florida</td>
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<tr>
<td>Sep 12 2016</td>
<td>#CHI2016</td>
</tr>
<tr>
<td>Sep 12 2016</td>
<td>SIM Scientific Conference on Machine Intelligence in Medical Imaging</td>
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<tr>
<td>Sep 12 2016</td>
<td>#DIAGI</td>
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<tr>
<td>Sep 12 2016</td>
<td>DIA Global Labeling Conference 2016</td>
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<tr>
<td>Sep 12 2016</td>
<td>#P4Fest16</td>
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<tr>
<td>Sep 12 2016</td>
<td>Past Present Future of Medicine</td>
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<tr>
<td>Sep 12 2016</td>
<td>#ConcordSun16</td>
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<tr>
<td>Sep 12 2016</td>
<td>ConcordSun</td>
</tr>
<tr>
<td>Sep 12 2016</td>
<td>#TFore16</td>
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<tr>
<td>Sep 12 2016</td>
<td>Transformathon</td>
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<tr>
<td>Sep 12 2016</td>
<td>#HCG2016</td>
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<tr>
<td>Sep 12 2016</td>
<td>Healthcare Executive Group Annual Forum 2016</td>
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<tr>
<td>Sep 12 2016</td>
<td>#PopHealthIT</td>
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<tr>
<td>Sep 12 2016</td>
<td>HIMSS Pop Health Forum 2016</td>
</tr>
<tr>
<td>Sep 12 2016</td>
<td>#DIAGI</td>
</tr>
<tr>
<td>Sep 12 2016</td>
<td>Global Labeling 2016</td>
</tr>
</tbody>
</table>

Trending

1. #IAVS2016
2. #RMIConf16
3. #MACC16
4. #CHI2016
5. #DIAGI
6. #P4Fest16
7. #ConcordSun16
8. #TFore16
9. #HCG2016
10. #PopHealthIT
11. #DIAGI
12. #MayoClinicFL
13. #HIMSSPopHealthForum2016
14. #GlobalLabeling2016

#MayoClinicFL Conference Hashtag

Twitter Wars at Mayo Clinic in Florida

Staff engagement campaign for employees at Mayo Clinic in Florida, September 12-16, 2016. Twitter Wars, a Twitter competition, brings healthy competition and unity, while empowering employees to "get social!"

MayoClinicFL is a healthcare conference hashtag submitted by @jamie_cassidy
BEFORE THE CONFERENCE

- Generate pre-conference buzz
- Identify key persons not in attendance to follow hashtag
- Prepare a twitter list of people to follow
- Locate twitter handles of scheduled speakers
AT THE CONFERENCE

- Identify source of information in your tweets
- List twitter handles of scheduled speakers
- Post photos at venue in tweets
- When permitted, include photos of slides from sessions
- Watch the hashtag, share what others are tweeting
SHARING RESEARCH FINDINGS

- Find appropriate Facebook groups to share relevant research
- Write an introduction for Facebook posts
- Use twitter to target interested communities. Hashtag it!
DO’S AND DON’T’S FOR SHARING

• Do NOT sensationalize

• Check before sharing what other’s may have posted

• If not using retweet or share feature, give credit

• Distinguish between initial presentation & peer reviewed, published

• Be clear – is it basic science or translational research

• Don’t be afraid to question over-hyped information

• Do your homework
BUILD AND PROTECT YOUR REPUTATION

• Be respectful

• Be social

• Collaborate

• Ask others for input

• Everything you post, is there forever.

• Don’t be hasty with the “enter” button!
Policy/Legislative Advocacy

- Hill Day
- Remote Participation
- Legislative Support
Hill Day: Overview

Hill Days are usually coordinated visits for advocates to meet personally with a member of Congress or their staff to advocate for particular legislation or general support for topics that concern the organizing group.

- Legislative Briefing
- Assigned Teams & Prearranged Appointments
- Background Materials
- Lead Advocate
Hill Day: Before You GO

• BEFORE YOU GO:
  – Follow MCs before visit: https://twitter.com/cspan/lists/members-of-congress?lang=en
  – Identify advocates in the district— even if they aren’t going
  – Recruit colleagues to participate by retweeting
  – Tweet before your visit – make a clear ”ask”
Hill Day: On The Hill

• ON THE HILL:
  – Record any commitments made or concerns expressed
  – Mention and tweet to constituents
  – Take photo with staff
  – THANK THEM!

Thanks to @RepChuck for sharing your relationship to cancer. #RealHopeLS seeing my son grow up Thx for ur support! @AACR @ASCO @AACI_Cancer
Hill Day: After You Visit

• AFTER VISIT:
  – Send TY tweet ASAP
  – Include any “public” statements you can share
  – ALWAYS find something positive to keep the conversation rolling
  – Continue to follow the MC – watch for news on your subject
  – Use Facebook and blogs to summarize event, positions taken
    • Include links to MCs and suggestions for follow up
Hill Day: Targeting Your Message

• TARGETING YOUR MESSAGE:
  – USE HASHTAGS – Choose from among:
    • Be consistent – groups should identify 2-3 tags (ideally short!) and use them
    • #LegislationTag  #DiseaseName  #RelevantCommunity
  – DIRECT YOUR TWEETS:
    • @MemberOfCongress  @GroupName
Remote Participation

• BEFORE HILL DAY:
  – Get briefing materials if possible
  – Follow MCs before visit
  – Identify and follow advocate visiting YOUR representatives
  – Arrange to follow relevant hashtags

• ON HILL DAY:
  – Especially important to watch your representative’s feed
  – Retweet what you can
Remote Participation

- **AFTER VISIT:**
  - Personally contact staffer from initial meetings
  - Continue to follow the MC – watch for news on your subject
  - Tweet again as legislation deadline gets closer
  - Post summaries of event on Facebook and share the posts of others
  - Use the tags identified by the organizers
    - #LegislationTag #DiseaseName #RelevantCommunity
  - Direct your tweets
    - @MemberOfCongress @GroupName
Legislative Support

• **FOLLOW:**
  – Confirm bill number(s) and follow any hashtags
  – Follow on GovTrack.US

• **CONNECT:**
  – Identify and coordinate with like-minded communities
  – Share information quickly with followers using hashtags
  – Updated content keeps people interested
  – ASK for retweets or like/shared on Facebook
  – Explain your positions
Thank You!
Social Media For Patient Advocacy