Navigating the Twittersphere: Connecting with Patients & Other Stakeholders in 140 Characters or Less

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Objectives of this presentation

- Demystify Twitter
- Deconstruct a Twitter Chat
- Delineate Engagement Opportunities
Twitter 101

- Social media tool rooted in “micro-blogging,” sharing thoughts in 140 characters or less
- Started in 2006, now a popular way to keep up on both people and events
- 10 years later, over 310,000,000 monthly active users
- Users have handles, designated by @ (e.g., @researchmatters; @POTUS)
Twitter 101…

- Follow topics or create threads using # (#Zika, #patientengagement)
- Twitter can help find suitable hashtags, or you can create your own
- Ancillary tool, Symplur, curates health-care specific hashtags
- Following, liking and retweeting help build your Twitter network
- You don’t have to be on Twitter to use Twitter!
- Great way to follow conferences/events that you can’t attend personally
- Overwhelming universe of content—tools like Tweetdeck can help filter topics
Anatomy of a Twitter Page

Start a new Tweet here:

Search for users (@) or topics (#)

Anytime one of my followers tweets, it shows up in my feed

Reply, retweet, or like someone’s tweet here

This thread would be seen by anyone following the #improvingpatientcare hashtag:
But what can you say in 140 characters?

- Takes practice, but being pithy does get easier

- Like texting, Twitter has its own language—creative use of characters, numbers, spacing, abbreviations

- Use URL shortening tools to post long hyperlinks (bit.ly, buffer.com)

- Pictures/infographics can supplement main message
Twitter Chats Popular for Health-related Topics

- Engaged communities who are motivated to participate based on shared interest in a condition (breast cancer, type 1 diabetes) or subtopic (health IT, HIPAA, healthcare leadership, social determinants)
- Moderated Twitter chats enable rapid exchange of ideas and insights
- Often structured around a set of questions for participants to “discuss” online over the course of an hour
- Sometimes accompanied by a blog or other kickoff article
- Moderators and chat hosts set the tone and keep discourse on track
- A good way to discover people to follow, and gain new followers
- Many recurring weekly chats have led to strong online and offline connections
- Capture discussions via Storify, Paper.li or other content curation platform
Anatomy of a Twitter Chat: #hcldr

#HCLDR is open to anyone and everyone. It’s not just for healthcare executives. If you care about health, the care you or your loved ones receive or any aspect of the healthcare industry – then we consider you a healthcare leader and we hope that you will share your leadership with our community.

- Tuesdays, 5:30-6:30 Pacific / 8:30-9:30 Eastern
- Started in 2012 by two passionate health care people
- Weekly blog by an organizer or guest host to set stage, tee up questions for that week’s discussion
- Attended by 100+ participants every week (patients, clinicians, system leaders, public health)
- Attendees follow the conversation by appending #hcldr to their tweets
Research Engagement: Opportunities via Twitter

- **Interest in a particular condition?**
  - Follow key patient advocates
  - Follow societies or organizations dedicated to the condition
  - Direct message people/organizations with specific questions
  - Tag your posts with the condition’s hashtag to increase visibility

- **Interest in the work of a given researcher, patient, clinician, health care leader?**
  - Following, liking or retreating appeals to a very basic human trait – the desire to be noticed, appreciated
  - Tools like ResearchMatch are also on Twitter
  - Twitter has been used as a direct patient recruitment tool; IRB guidance on use of social media for outreach may vary from site to site

MBC Project → Recruited 2500 patients in 11.5 months
Example: Metastatic Breast Cancer Project

MBC Project: Patients Enrolled, Consented, and Saliva Samples Received

- Registered
- Consented
- Saliva Received

- Facebook and Twitter posts by patients/advocates
- Facebook post by a metastatic breast cancer patient/advocate
- San Antonio Breast Cancer Symposium
- Official Launch With Advocacy Partners
- Soft launch
- In January, we started sending online consents to all registered patients
- In March, we started sending saliva kits to consenting patients
- ASCO

>2500
>1400
>750

MBC Project @MBC_Project · 21h
This is what patient-driven research looks like. Pts sharing info, tumor samples, & saliva
mbcproject.org
Comments & Questions?

#thankyou!