Leveraging Social Media to Raise Awareness & Build Community

08 June 2017

PCORnet Best Practice Sharing Session
Today’s Presenters

Joseph M. Coe, MPA,
- Patient Advocate & Social Media Manager,
  Global Health Living Foundation/CreakyJoints

Patty McAdams
- Communication Specialist, DCRI
- ADAPTABLE Study Communications Lead
ADAPTABLE is funded through a PCORI Award [ASP-1502-27079] and is a demonstration project conducted through PCORnet®, the National Patient-Centered Clinical Research Network.

The views presented in this presentation are solely the responsibility of the author(s) and do not necessarily represent the views of the other organizations participating in or collaborating with PCORnet® or of the Patient-Centered Outcomes Research Institute (PCORI).
Social Media By The Numbers

ACTIVE MONTHLY USERS

- Facebook: 1,600,000,000
- Twitter: 328,000,000
- Instagram: 600,000,000
Social Media Demographics

Facebook
- 71% of US Adults who access the internet
- 82% of 18 to 29-year-olds online
- 79% of 30 to 49-year-olds online
- 56% of online users ages 65 and up

Twitter
- 32% of 18 to 29-year-olds online
  - Rate basically holds steady until users hit age 50.
- 13% of 50 to 64-year-olds online
- 6% of online users aged 65 and up
Facebook Best Practices for Organic Posts

- **Use an image**: Social Media is a Visual Platform

- **Regularly Post**: Post content that is intriguing to your population. Share other Facebook pages. Provide content that is useful.

- **Create short call-to-actions**: While there is no text limitation, best practices show that concise messages drive more engagement.

- **Consider boosting posts**: Facebook is essentially a pay-to-play platform and paying to boost posts will dramatically increase reach.

- **Use Facebook Live**: Facebook is invested in this function and serves up the video to a large portion of your followers.
Facebook Organic Engagement

Answer this question: What gives my followers value?

Crowdsourced comments created into an image.

Facebook Live with rheumatologists from the Hospital for Special Surgery.
Facebook Advertising 101

- **Page Post Engagement**: Promote your Page posts
- **Page Likes**: Get Page likes to grow your audience and build your brand
- **Clicks to Websites**: Get people to visit your website
- **Website Conversions**: Get people to perform certain actions on your site (requires adding a Facebook pixel to your site)
- **App Installs**: Get people to install your mobile or desktop app
- **App Engagement**: Get people to use your desktop app
- **Event Responses**: Increase attendance at your event
- **Offer Claims**: Create offers for people to redeem in your store
Facebook Targeting

- **Locations:** Target ads to people based on locations (ex: country, state, province, city, congressional district, zip or post code).

- **Gender:** Target ads to women, men or both.

- **Languages:** Target ads to users of certain languages.

- **Detailed Targeting:** Include or exclude people from an audience based on demographics, interests and/or behaviors. Connections. Include or exclude people from your audience based on connections to your pages, apps or events.
Facebook Like Building

A good place to start is to develop a “like building” campaign. You can do this organically but advertising helps expedite the process. You can target people who like similar pages, have certain keywords in their profile, demographic (age, sex, location etc.)

It is important that pages have a good amount of followers and updated content to make Facebook advertising successful.
Examples of Successful Facebook Ads

1. **DID YOU HAVE A FLARE TODAY?**
   - Sign Up for ArthritisPower™
   - Keep track of your symptoms and help advance research.

2. **Keeping Track of Medicine is a Pain.**
   - Track medication with ArthritisPower™
   - Keep track of medicine, alternative treatments, and more with ArthritisPower.
Facebook Advertising 101

- Try different messages for different audiences
- Identify the messages that are driving the most registrations. Optimize by metrics like cost per conversions, clicks, and click-through-rate
- Shift your budget to the best performing ads and create more ads like them
Twitter Engagement

- Be consistent. Tweet throughout the day.

- Find what hashtags are being used to engage your community. (A good tool for healthcare related hashtags is Symplur)

- Create opportunities for engagement (i.e. Twitter Chats)
Twitter Best Practices for Organic Tweets

- Be simple
- Include relevant hashtags (#but #dont #hashtag #every #word)
- Be a meaningful part of a conversation
- Include an image (it does not count toward your character limit.)
#CreakyChats

Monthly #CreakyChats
- Twitter chats include 50-100 participants per chat
- Topics generated to appeal to a broad user base

Partners/Topics include
- @EverydayHealth – lifestyle and arthritis
- @CureArthritis – frequently asked arthritis questions
- @RNSociety – maximizing your doctor visit
- @ACR (#SimpleTasks) – traveling with arthritis
- @SleeptemberOrg – sleep and arthritis
- @USPain – advocacy in 2017
Twitter Advertising

Similar to Facebook, Twitter has a robust platform for ad targeting.

Targeting best practices

Cover the basics: Select the appropriate location, language and optional device targeting options before selecting additional targeting criteria.

Select one audience targeting type for each campaign: Choose from follower, keyword, behavior, interest or tailored audiences targeting to get meaningful insights into your campaign.

Experiment
ADAPTABLE Study Overview

Three year, pragmatic, patient-engaged study to determine the optimal dose of aspirin (85 mg or 325 mg) for patients with cardiovascular disease

Studying a research question and process — how best to engage patients as partners

First demonstration study of PCORnet®, the National Patient-Centered Clinical Research Network

Funded by PCORI, the Patient-Centered Outcomes Research Institute
Engaging Patients and Partners

- Adaptors Team - patient partners representing each participating network

- Work alongside the study team to provide input at key and critical steps in the research process

- Active in sharing their voice and experiences

- Committed to promoting study awareness, clinical trials, and the role of the patient partner through participating at professional association meetings, videos, blogs, social media, and local events

- Will be integral in disseminating study results and updates to other patients and the community.

Patient partner, Jacqueline, promoting ADAPTABLE at a Women’s Heart Health event
Digital & Social Media Channels

Website: theaspirinstudy.org

Twitter Handle: @ADAPTABLEStudy

Facebook: https://www.facebook.com/ADAPTABLEStudy/

YouTube Channel: https://www.youtube.com/channel/UCDVkzmGpLhr8LP_pOOGP4Tlw
Digital & Social Media Engagement

Why are we engaging?
- Raise awareness for the aspirin question, and the importance of this study in answering it
- Build recognition and support for the overarching goals of PCORnet in terms of involving patients as partners in research and using new methods to conduct more efficient clinical research

Who is our audience?
- ADAPTABLE community including Adaptors (patient partners), clinicians, researchers, operations team members, PCORnet, PCORI, primary-care providers, patient advocates, patient-engagement focused organizations, and the public at large

What is our style?
- Professional, friendly, and informative

What are we sharing?
- News briefs, videos, interviews, Facebook Live events, presentations, events, Adaptor blogs and stories, professional associations relevant news stories
Twitter

ADAPTABLE Study
@ADAPTABLEstudy
A PCORnet Pragmatic Clinical Trial
theaspirinstudy.org
Joined March 2016

TWEETS 423
FOLLOWING 152
FOLLOWERS 368
LIKES 182
MOMENTS 0

Your Tweet activity
Your Tweets earned 2,643 impressions over the last week

May 27
Jun 2
## Twitter Best Practices

- Develop a campaign calendar
- Include rich media: photos, videos, quote cards, hashtags, links
- Perform live tweeting from conferences and events
- Follow key thought leaders and professional associations

### Adaptable Study

**February Campaign Calendar**

<table>
<thead>
<tr>
<th>Day</th>
<th>Tweet</th>
<th>Supporting Materials</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st</td>
<td>@texhn discusses questions answered by ADAPTABLEstudy &amp; how it uses data resources of PCORnetwork: bit.ly/2M9QXjr</td>
<td><a href="https://youtu.be/K06ckPjn484x">https://youtu.be/K06ckPjn484x</a></td>
</tr>
<tr>
<td>2nd</td>
<td>#WearRedDay tomorrow. Learn how ADAPTABLEstudy aims to find the optimal dose of aspirin for patients w/HeartDisease: bit.ly/1nR1Ixe</td>
<td>National Wear Red Day Platform &amp; Partners 2021 (Twitter)</td>
</tr>
<tr>
<td>3rd</td>
<td>What is the optimal dose of aspirin for you? Join @MTRheart &amp; doctors @MidSouthCDRIn for a FB Live discussion: bit.ly/2khwDSy</td>
<td></td>
</tr>
</tbody>
</table>
Twitter General Weekly Schedule

- Aim to post once a day
- Call to action
  - Meet a team member
  - Read an article
  - Watch a video
  - Learn more
  - Follow
  - Share news

<table>
<thead>
<tr>
<th>Suggested ADAPTABLE Twitter Schedule</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Day</strong></td>
</tr>
<tr>
<td>Monday</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Tuesday</td>
</tr>
<tr>
<td>Wednesday</td>
</tr>
<tr>
<td>Thursday</td>
</tr>
<tr>
<td>Friday</td>
</tr>
</tbody>
</table>
Twitter Best Practices

- Avoid jargon
- Include quote cards
- Consider using a pinned tweet
- Provide a social media kit to study team & key stakeholders that includes:
  - Suggested tweets
  - Images and quote cards
Leveraging the ADAPTABLE Community

Create a social media kit to study team & key stakeholders that includes:

- Suggested tweets
- Suggested FB post
- Images
- Quote cards
Measuring Engagement

Engagement rate: 2.5% (# of engagements divided by total # of impressions)

Handle of FDA (166K followers)

Noting Dr. Califf’s title and his support of the aspirin-dose question

Video embedded in tweet
Top Tweet Topics

Engagement rate: 3.9%

ADAPTABLE Study
@ADAPTABLEstudy

#ADAPTABLEstudy partner @RealCruzHenry w/ @nyccdrn says patients can transform #ClinResearch for future generations: bit.ly/2pZ9C0w

Engagement rate: 1.9%

ADAPTABLE Study
@ADAPTABLEstudy

Patient partner Jacqueline helps spread awareness abt @PCORI #ADAPTABLEstudy #ClinResearch & women's #HeartHealth @WomenHeartOrg @UCLA_CTSI
Top Tweet Topics

Engagement rate: 2.0%

ICYMI: @PCORI-funded @PCORnetwork-demo #ADAPTABLEstudy aims to find cheaper ways to research medicine bit.ly/2o8KSFm @bswhealth

“So not only are we researching aspirin doses, we’re researching the research methods.”

Peter A. McCullough, MD, MPH | Adaptable Study Site PI & Cardiologist | Baylor University Medical Center at Dallas

Engagement rate: 1.3%

#ADAPTABLEstudy is a @PCORI funded @PCORnetwork demo study that focuses on outcomes that matter most to people @RealCruzHenry @bsilberg
Facebook

- Building a community
- Platform to host live events
- Establish “rules of engagement”
  - ADAPTABLE example will be posted on PCORnet Commons
- Channels linked - Tweets automatically post on FB page
Facebook LIVE Events

- Partnership with Health in Our Hands, AHA, DCRI, Duke Heart Center, REACHnet & Mid-South CDRN
- Promotion through the ADAPTABLE Community, PCORnet, PCORI, DCRI, and AHA
- 20-minute, moderated live Q&A featuring ADAPTABLE leadership and participant

Join our LIVE broadcast from #AHA2016 to discuss a study that seeks to understand what the optimal dose of aspirin is for patients with heart disease. Ask a question in the comments!

6,399 Views
Facebook LIVE: Celebrating Heart Month

ADAPTABLE Study: ADAPTABLE Aspirin Dose

Celebrate Heart Month with patients and study lessons about aspirin dosing and heart disease.

American Heart Association shared ADAPTABLE Study's live video.

13 February at 11:38

ADAPTABLE Study now LIVE on Facebook for HeartMonth. Join the discussion about heartdisease & aspirin dosing: bit.ly/2kfm37g

Show Attachment
Facebook LIVE Tips

- Advanced promotion
  - Reason for broadcast
  - Who will be involved
  - Call to action—bring your questions
  - Broadcast day and time
  - Provide event link

- Partner with a professional association to boost awareness

- Go live when you have a strong Wi-Fi connection

- Check audio connection; reduce room noise

Let us know that you are coming to our next live FB event: bit.ly/2kfm37g. We want to hear from you about #heartdisease & #PCOR.

ClinicalTrials.gov: NCT02697916
Facebook LIVE Tips

- Moderator, study leader, and patient representative
- Script with pre-planned questions
- Opportunity for users to be part of the conversation by commenting and asking questions
  - Say hello to commenters by name; respond to their comments live
- Don’t make your broadcasts too short
  - Recommended time: 10–20 minutes
- General comment:
  - Encourage discussion with doctor
  - Direct users to study website for more information
Institutional Review Board (IRB) Review

Proactively engage the IRB in your efforts to ensure that you are operating within the ethical boundaries of your institution.

Follow guidance from Health & Human Services


Provide training of patient representatives as study spokespeople

- Focus on the study & why it’s important
- Focus on role of the patient partner in clinical research
- Avoid using language that positively promotes the study treatment or intervention
- Avoid using language that confers individual risk or benefit from participating
Key Points

- Develop social media guidelines to outline your social media channels, their purpose, audience, and content types.

- Proactively engage the IRB in your efforts to ensure that you are operating within the ethical boundaries of patient engagement.

- Social media is a visual medium—be sure to share visually stimulating images or graphics.

- Stay away from jargon and use language that is accessible.

- Keep it short and sweet—communicate your message in two or three sentences.

- Leverage partnerships, study team members and patient representatives as spokespeople.

- Take risks! Clever or witty posts are excellent at engaging audiences.
Resources & Contacts

- www.symplur.com
- www.canva.com
- arthritispower.creakyjoints.org
- Jcoe@ghlf.org
- theaspirinstudy.org
- margaret.mcadams@duke.edu
Continue the Conversation on the PCORnet Commons

Join us on the PCORnet Commons to ask more questions or share your own tips for social media.


Note you must be registered to add comments to the Forum. You can register for an account at: http://pcornetcommons.org/registration/