OBJECTIVES

• Review the use of social media for research recruitment.

• Discuss the advantages of social media for research dissemination.

• Discuss the perils and pitfalls of using social media for professional and scientific purposes.

SOCIAL MEDIA (DEFINITION)

• Any technology that facilitates communication or collaboration between humans.
MY SOCIAL STREAM

- @ericbenchimol
- @CHEOIBD
- Friends and family
- Organizations (NASPGHAN, AGA, etc)
- Mostly following others (especially tech)
- Prof networking (rolodex)
- Online CV, publications
- Recommendations, diary, gamification
- Education, institution
- youtube.com/user/CHEOibdCentre
- youtube.com/user/theNASPGHAN

CRITICISMS OF SOCIAL MEDIA

- Growth of technology
- Privacy
- Banality
- Loss of authoritative perspective
- Information overload
- Work/life balance
- Accuracy
- Unpublished, non-peer review

Social Media Guidelines for AACR Conferences

Bik and Goldstein, PLoS Biology, 2013
PATIENT RECRUITMENT

• Could be used for:
  – Collection of health information
  – Identify and communicate with potential research subjects
  – Intervention

Moreno et al., Pediatrics, 2008

Randall et al., Inflamm Bowel Dis, 2014; 20(3): 541-4.
Harlath et al., Inflamm Bowel Dis, 2014; 20(7): 1194-7.

• Lots of evidence for effectiveness
RESEARCHER-PATIENT MATCHING

SHIT HAPPENS CAMPAIGN
- Mother of child with Hirschsprung's disease
- Frustration: not enough information after initial surgical treatment
- Starts Blog-Roo's Journey
  http://roosjourney.wordpress.com
- Facebook: >2700 likes, potential reach 260,501
- Twitter: >200 followers, >1000 tweets
- HIRSCHSPRUNG’S ONLINE COMMUNITY!

SHIT HAPPENS AND RESEARCH
- Example: When was your child potty trained?
- Question posted via Mom
- 415 views in 2 days
- 30 responses within hours
- It would take weeks to months to get such a response in real life
PATIENT RECRUITMENT

• Lots of evidence for effectiveness

• Also lots of evidence for concern:
  – Ethics
  – Privacy
  – Selection bias

KNOWLEDGE TRANSLATION

KNOWLEDGE TRANSLATION

• Definition:
  "the exchange, synthesis, and ethically-sound application of knowledge—within a complex set of interactions among researchers and users—to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system."

Canadian Institutes of Health Research (2004)
“It is conceivable that crowdsourcing can be used not only to test and develop health messages but also to distribute messages to targeted populations. In the ideal case, both purposes could be combined in one crowdsourcing application.”

Jonathan DeShazo and Heiko Spallek, Journal of Medical Internet Research (2012)

KNOWLEDGE TRANSLATION (PUBLIC)

- Medical knowledge is being disseminated using social media
- Survey of tweets on antibiotic use:
  - 29.8% on general use
  - 16.2% advice/information
  - 11.6% on effects/negative reactions
  - 10.5% on diagnosis
  - 9.5% on resistance
  - 5.6% misunderstanding/misuse

Scanfeld et al., Am J Infect Control, 2010

The rise of people power

Chafe et al., Nature, 2011
Scientists use:
- Reports
- Briefing notes
- Press releases, news conferences

Patient groups:
- Social media

‘Clinical Equipoise’ vs. ‘Facebook Equipoise’!
IT DOESN’T HAVE TO HURT

GRANT-WRITING KT STRATEGY

• #1 – Establish your social media presence
• Questions to answer:
  - Who is your target audience?
  - How will you engage them and when?
  - What do they need to know?
  - How will your message be packaged?
  - How will your message be delivered to the targeted audience?
  - What do you hope to achieve by sharing your message?

Adapted from: Goering et al., Final report submitted to Ontario Ministry of Health – Research Transfer Training Program, 2003
GRANT-WRITING KT STRATEGY

• #1 – Establish your social media presence
• Questions to answer:
  – Who is your target audience?
  – How will you engage them and when?
  – What do they need to know?
  – How will your message be packaged?
  – How will your message be delivered to the targeted audience?
  – What do you hope to achieve by sharing your message?

Adapted from: Goering et al., Final report submitted to Ontario Ministry of Health – Research Transfer Training Program, 2003

GETTING INVOLVED

TIPS FOR SOCIAL MEDIA

• DON'T friend your patients/families
• For patients: bring the conversation offline
• Diamonds aren’t as forever as your posts
• What is private could be public at any moment
• Say online only what you would say in person
  – What would your mother say?
• Learn your privacy settings
• Google isn’t human – it may be SkyNet
BOTTOM LINE

• Social media is here to stay
• Changing how we collaborate (probably good)
• Being used to recruit (maybe good)
• Influencing science (no choice)

DEVELOP A STRATEGY

REFERENCE

• Social Media: A Guide for Researchers
  http://www.rin.ac.uk/our-work/communicating-and-disseminating-research/social-media-guide-researchers

• Bik and Goldstein. An Introduction to Social Media for Scientists.