


UTILIZING SOCIAL MEDIA TO ADVANCE YOUR RESEARCH AGENDA

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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

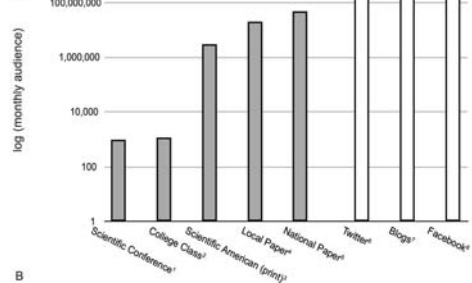
CRITICISMS OF SOCIAL MEDIA

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- Unpublished, non-peer review

Cann, Social Media: A Guide for Researchers, 2011
 Nature Methods 2011;8(4):273
 Winstead, NCI Cancer Bulletin, 2011
 Social Media Guidelines for AACR Conferences



A



B


Bik and Goldstein, PLoS Biology, 2013





RECRUITMENT







PATIENT RECRUITMENT

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


Moreno *et al.*, *Pediatrics*, 2008






PATIENT RECRUITMENT

- Lots of evidence for effectiveness



Kappelman *et al.*, *Clin Gastroenterol Hepatol*, 2014; 12(8): 1315-23.
Randell *et al.*, *Inflamm Bowel Dis*, 2014; 20(3): 541-4.
Herfarth *et al.*, *Inflamm Bowel Dis*, 2014; 20(7): 1194-7.



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)



KNOWLEDGE TRANSLATION



“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

Scanfield *et al.*, Am J Infect Control, 2010



COMMENT



Call for "liberation": a November 2010 rally in Edmonton, Canada, for a multiple-sclerosis treatment.

The rise of people power

Chafe *et al.*, Nature, 2011

Calls in Canada for trials of a contentious treatment for multiple sclerosis illustrate how social media can affect research priorities, say Roger Chafe and his colleagues.

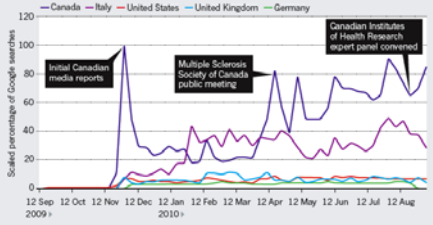


KNOWLEDGE TRANSLATION (PUBLIC)



HOT TOPIC

A measure of the number of Google searches for the term CCSVI (chronic cerebrospinal venous insufficiency) reveals that public interest in Canada soared in just one year.



Chafe et al., Nature, 2011



KNOWLEDGE TRANSLATION (PUBLIC)



- Scientists use:
 - Reports
 - Briefing notes
 - Press releases, news conferences

- Patient groups:
 - Social media

'Clinical Equipoise' vs. 'Facebook Equipoise'!

Chafe et al., Nature, 2011



'FACEBOOK EQUIPOISE'



Research

Research Content	Like Count	Total Comments	Reply Percentage
85	1.09K	91	12

Research Post 1: [Text about research findings]

Research Post 2: [Text about research findings]

Research Post 3: [Text about research findings]

Research Post 4: [Text about research findings]

Research Post 5: [Text about research findings]

Research Post 6: [Text about research findings]

Research Post 7: [Text about research findings]

Research Post 8: [Text about research findings]

Research Post 9: [Text about research findings]

Research Post 10: [Text about research findings]



Current Standings	Category -	Archived
12	What are the after effects of ceasing biologic treatment for CD?	view 8 comments - Other - 8 months ago
12	I propose that the link between Crohn's/UC and other auto-immune diseases be researched more in depth.	view 2 comments - Other - 8 months ago
12	Is there a relationship between Crohn's and chronic acne? Could long term antibiotic use for acne be associated with the development of Crohn's in young adults?	view 8 comments - Other - 8 months ago
12	What is the relationship between IBD and hormones? How do the two impact each other?	view 3 comments - Other - 4 months ago
11	We should compare the prevalence and/or characteristics of IBD between rural versus urban areas to see if urban/rural factors contribute to IBD	view 8 comments - Environment - 8 months ago
11	Are parasites (like hook worms) a safe and effective treatment option for patients with IBD?	view 6 comments - Alternative Therapies - 8 months ago
11	What is the comparative safety and efficacy of natural supplements (vitamin D, fish oil, turmeric) commonly used in IBD versus prescription medications?	view 3 comments - Alternative Therapies - 3 months ago

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



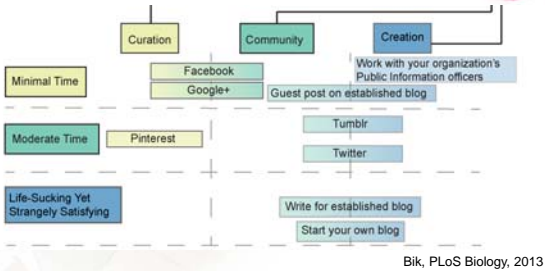
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GETTING INVOLVED



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.
PLoS Biology 2013; 11(4): e1001535