

Social media in health research

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Acknowledgements

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- Dr. Lisa Hartling, Department of Pediatrics, University of Alberta
- Ms Michele Hamm, PhD (c) Department of Pediatrics, University of Alberta

Before we get started

- How many of you have personally (not for professional purposes) used or currently use
 - Facebook?
 - Twitter?
 - Wikis?
 - Wrote a blog?
- How about professionally?

Does social media help stem anti-social misfits?

Controversy.

Psychologist believes someone's absence from sites such as Facebook could be a red flag

If you're a Facebook hold-out, or have chosen to abandon the social-media hangout for any number of reasons, be prepared to be labelled a misfit — or worse.

The net has been abuzz this week about a story attributed to the German newsmagazine Der Tagesspiegel in which a psychologist concluded that the slim social-media presence of



James Holmes, left, and Anders Breivik. The accused killers' slim social-media presence was deemed suspicious by a psychologist. TOP: AFP/POOL/RJ SANGOSTIRJ SA NGOSTI/AFP/GETTY IMAGES; BOTTOM: LISE ASERUD/AFP/GETTY IMAGES

they deactivated it because it was full of red flags? Are they hiding something?" asked a Forbes.com writer.

And the dating game tells a similar story.

Slate advice columnist Emily Yoffe told one woman: "I'm fine with people not having a Facebook page if they don't want one. However ... if you're of a certain age and you meet someone who you are about to go to bed with, and that person doesn't have a Facebook page, you may be getting a false name. It could be some kind of red flag."

For the digital generation, that kind of sentiment is understandable, said Queen's University media professor Sidneyeve

Why am I giving this talk?

- co-investigator on a CIHR funded KS grant examining the use of social media in health (Lisa Hartling, PI)
- on a supervisory committee for a PhD student, Ms Michele Hamm, where social media was used as an intervention
- co-I on a recently submitted grant exploring social media in mental health research
- But my research team will tell you –although I have actively embraced social media with a Facebook profile, and Twitter – I was not an early adopter

Objectives

- Define social media
- Describe the role that social media has played and is continuing to play in health research
- Provide some examples of social media
- Describe some potential ways that we can use social media in our work as knowledge utilization researchers/scholars

What is social media?

- a “set of web-based and mobile technologies that allow people to monitor, create, share or manipulate text, audio, photos or video with others” (Canadian Medical Association)
 - Can be multidirectional (ie wikis) or uni-directional (blogs)
- a “decentralized system where participants take care of distribution, deciding collectively which messages to amplify through sharing and recommendation” (The Economist, 2011)
 - The key message here is that participants “participate” rather than being a passive audience, in other words, they are a ‘networked public’
- It is driven by people who are passionate about sharing their messages
- It is really a “living” network – it is constantly adapting and changing

What is social media?

- Represents a significant shift in the way information is developed and shared.
- The past decade has seen a shift from knowledge created and disseminated primarily by individuals to a new approach where all users with access to the Internet can play a participatory role in a more collaborative information sharing system (Meyer and Schroeder, 2009).
- Other terms that are used Web 2.0 (health 2.0, etc) – broadly referring to the next generation of the Web that is a more distinctive medium characterized by user participation/interaction – user-generated content.

What is social media?

- Advances in technology have changed the way we communicate, access information, and share information
- Social media tools can broaden our social connections, provide educational content, provide a venue for research, and facilitate the development of new technology skills
- Social media capitalizes on the free and open access to information
- Mobile social media – essentially social media used on media devices, in comparison to traditional social media running on computers. Mobile social media facilitates a higher location and time sensitivity (wikipedia).

Social media attributes

- Immediate
- Personalization of content
- Presentation
- Participation – collaborative nature

Potential concerns for application in health/health research

- Privacy/confidentiality/ethics
- Cyber-bullying
- Immediate reach – need for excellent judgment

Types of social media

- 1) collaborative projects (wikipedia)
 - 2) blogs
 - 3) content communities (YouTube)
 - 4) social networking sites (e.g., Facebook)
 - 5) virtual gaming or social worlds (e.g., Second Life)
- (Kaplan & Haenlein, 2010)

The use of social media in health: scoping review

- L. Hartling, PI, myself a co-I, funded by CIHR
- Broadly mapping how social media is being used in health care with patients
- This will serve as a main vehicle to guide future systematic reviews
- Research questions:
 - What social media tools are currently being used to improve health outcomes in patient populations
 - For what patient populations and disease conditions are social media tools being used
 - For what purposes are social media tools being used in patient populations (e.g., improve self-care, improve health literacy)
 - What types of research and research designs have been used to examine social media tools in healthcare?
- Plan to submit for review later this fall

Use of social media by health care professionals and trainees: a scoping review

- PhD student – Michele Hamm, University of Alberta
 - Questions being addressed:
 - What social media tools are being used in health care professional and trainee populations
 - For what purposes are social media tools being used in health care professional and trainee populations?
 - Currently has a manuscript in review on this topic and she is defending this work on December 10., 2012
 - Given guidelines and policies at the University of Alberta, I am unable to share these findings. Once they are published, I will be TWEET about them.

Key social media approaches: Wikis

- Sometimes called '*collaborative writing applications*'
- Collaborative websites that can be edited by all users
- Can be a central resource of information, yet have an interactive component (some portions can be static/not editable)
- Users are responsible for the direction and content of the wiki website
- Everyone that uses the wiki has the opportunity to contribute to it and/or edit it
- Can be used as a medium for collaboration, as a venue for information sharing with multiple audiences

Key social media approaches: Wikis

- Wikis have appeared in all aspects of healthcare (e.g., anesthesia, dermatology, etc.)
- Recent studies have highlighted how in a given week, 70% of junior physicians used Wikipedia (Heilman et al., 2011)
- Patients use wikis to share their experiences (Wikia Diabetes, 2012) and find information (Heilman et al., 2011)
- Educational institutions are using wikis to educate health care professionals (Varga-Atkins et al., 2010; Kohli et al, 2011)

Key social media approaches: Wikis

- Upcoming research – Archambault, P. et al., (2012). Wikis and collaborative writing applications in health care: A scoping review protocol. *JMIR Res Protoc*, 1(1): e 1).

Example: Wiki as a KT intervention

- Ms Michele Hamm is a PhD student at the University of Alberta (Dr. Lisa Hartling, supervisor, S. Scott committee member)
- Program of work examining the risk of bias in pediatric trials
 - develop a KT intervention (Wiki) to close the gap between research and practice (on Risk of Bias in pediatric trials)
 - Intervention target: Researchers/Trialists
- www.starchildhealth-riskofbias.wikispaces.com
- Intervention – focusses on research methodology education (e.g., blinding, allocation concealment, etc)
- Why a wiki?
 - Flexible formatting
 - Interactive yet can have static content
- Mixed methods results – to be defended December 2012

You are not a member of this wiki. [Join now](#) [Dismiss](#)

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- [Pages and Files](#)
- [Members](#)
- [Manage Wiki](#)

- Home
- Sequence generation
- Allocation concealment

home

[Edit](#) [0](#) [0](#) [57](#) ...

Welcome to the StaR Child Health Risk of Bias Wiki!

What is StaR Child Health?

StaR Child Health stands for Standards for Research in Child Health. This is a group of methodologists, clinicians, and policy-makers who seek to enhance the quality, ethics, and reliability of pediatric clinical research by promoting the use of evidence-based standards. Within StaR Child, there are a number of Standard Development Groups, including one focused on risk of bias.

Example: Wiki as a KT intervention

- Archambault, P. et al., (2010). Healthcare professionals' intention to use wiki-based reminders to promote best practices in trauma care: a survey protocol. *Implementation Science*, 5:45.

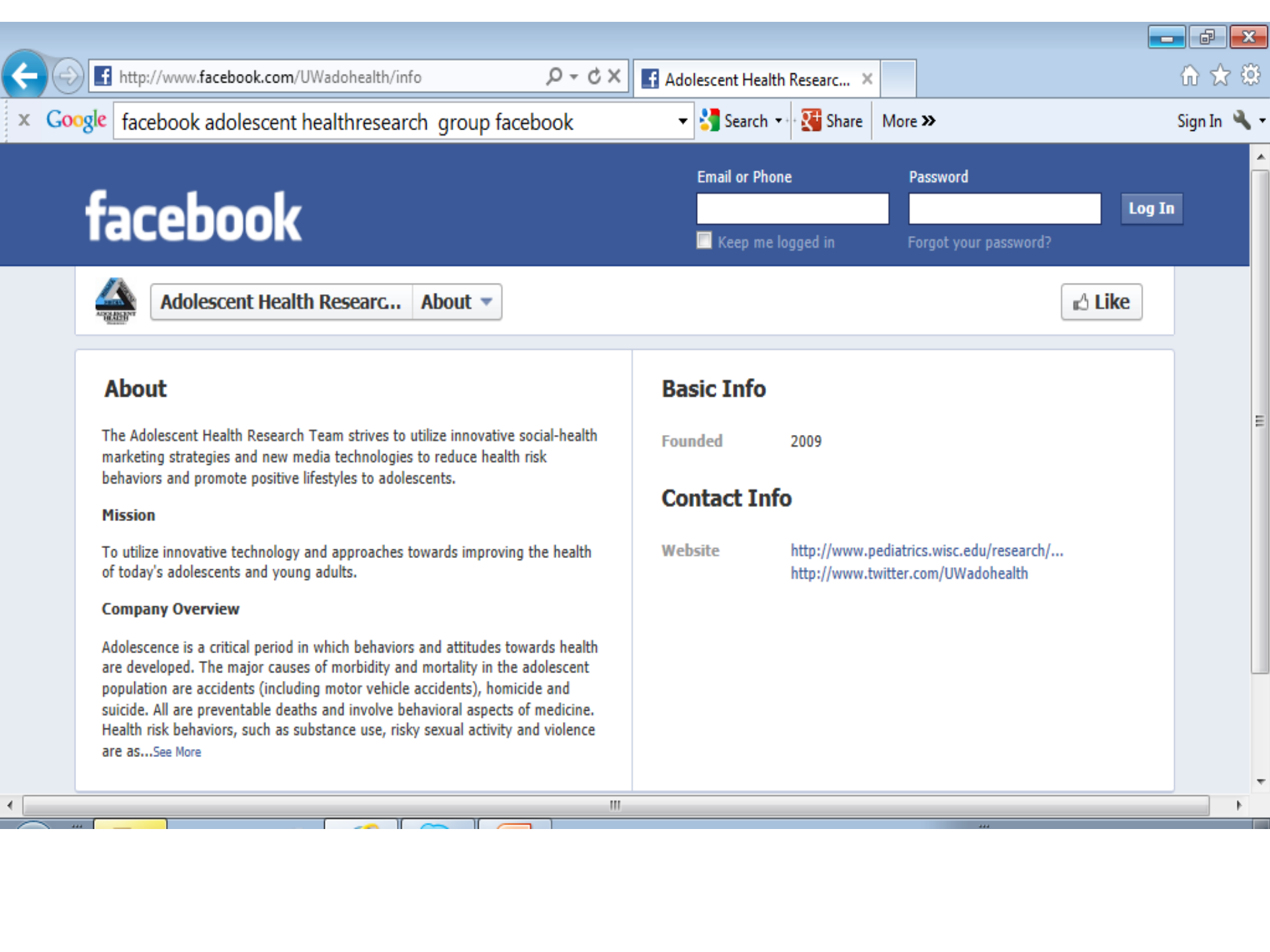
Key social media approaches:

Facebook

- Most popular social networking site with over 1 billion users with approx half of those accessing Facebook each day
- Typically you share information with “friends”
- Individuals, groups, organizations, businesses can have Facebook pages

One example using Facebook

- Adolescent Health Research Team, University of Wisconsin
 - Research centres on adolescents' use of media and technology and how these may impact adolescent health behaviors
 - Facebook – largely a way to engage with multiple users and disseminate findings
 - Also a vehicle for recruitment for research studies



facebook

Email or Phone

Password

Log In

Keep me logged in

[Forgot your password?](#)



Adolescent Health Researc...

About ▾

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About

The Adolescent Health Research Team strives to utilize innovative social-health marketing strategies and new media technologies to reduce health risk behaviors and promote positive lifestyles to adolescents.

Mission

To utilize innovative technology and approaches towards improving the health of today's adolescents and young adults.

Company Overview

Adolescence is a critical period in which behaviors and attitudes towards health are developed. The major causes of morbidity and mortality in the adolescent population are accidents (including motor vehicle accidents), homicide and suicide. All are preventable deaths and involve behavioral aspects of medicine. Health risk behaviors, such as substance use, risky sexual activity and violence are as...[See More](#)

Basic Info

Founded 2009

Contact Info

Website [http://www.pediatrics.wisc.edu/research/...](http://www.pediatrics.wisc.edu/research/)
<http://www.twitter.com/UWadohealth>

Using Facebook

- Using Facebook for data collection is not straightforward
 - Technically what you post on Facebook is publicly available, however one can easily run into challenges such as gathering data from friends/networks (people who may not have given permission)
 - Facebook (terms of service) does not allow automated data collection
 - Accessibility challenges have been overcome by asking research participants on Facebook to download their own content and then forwarding this (securely) to the researchers – this is allowed by Facebook
 - **Social media sites often frequently change privacy settings, how profile information is organized as well as software – all of which could significantly alter a research project

Another example using Facebook

- Greene, J et al., (2010) qualitative evaluated the content of communication in Facebook communities dedicated to diabetes.
 - identified the 15 largest Facebook groups, and for each group they downloaded the 15 most recent 'wall posts' and the 15 most recent discussion topics
 - Investigators evaluated the posts, developed a thematic coding scheme and applied codes to the data
 - Results – patients with diabetes, family members and their friends used Facebook to share personal clinical information, to request disease-specific feedback and to receive emotional support.
 - Approximately 2/3 of the posts included unsolicited sharing of management strategies; 13% of the messages provided requested information and 29% of the posts provided emotional support
 - Interestingly, clinically inaccurate recommendations were infrequent, yet associated with promotion of a product or service

Greene, J. (2010). Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. *Journal of General Internal Medicine*, 2(3), 287-292.

Key social media approaches:

Twitter

- Twitter
 - Social networking service that allows users to send and read “tweets” or short messages up to 140 characters long
 - Hashtags are used to facilitate indexing, searching, and participation
 - Individuals can share information and web links instantly among ‘followers’
 - Individuals can respond to tweets, thus encouraging discussion
 - “retweeting” and “tweet-ups”



healthfinder.gov @healthfinder 10 Aug
Doctors recommend that girls and boys get the HPV #vaccines at age 11 or 12. Here's why: 1.usa.gov/rqNiTs
Retweeted by Shannon Scott
Expand

InspireNet @InspireNetBC 13 Aug
RT @mattjodgkinson: @tonythain There's an iPhone app for PLOS Medicine itunes.apple.com/us/app/plos-me... and an iPad app for PLOS itunes.apple.com/gb/app/plos-re...
Retweeted by Shannon Scott
View app Reply Retweet Favorite

Shannon Scott @echoKTresearch 13 Aug
Interesting research! RT @peterjgill Alberta researchers debunk fitness myths bitly.com/R9eMD2 via @UofCMedicine @BradenO'Neill @cebmblog
Expand

CMAJ @CMAJ_News 13 Aug
Physicians must become stronger advocates for health equity, says incoming CMA President Dr. Anna Reid bit.ly/Peq9HS
Retweeted by Shannon Scott

Example of Twitter

- Typical uses: Dissemination of research findings, connecting/engaging with multiple audiences to spread information, research recruitment
- Emerging uses (study trends and accomplish surveillance):
 - Analyzing messages in social media
 - Most twitter messages contain little informational value, however researchers have started to see the value of aggregating millions of messages in terms of providing valuable insights into health concerns
 - Lamos and Cristianini, 2010 – tracked flu rates in the UK and US using Twitter messages
 - Paul & Dredze, 2011 – tracked flu rates in the US with high correlations with CDC data
 - Researchers at the University of Virginia and West Virginia University recently received a grant to analyze Twitter posts on early warning signs of adverse drug reactions (October 2012)

Examples of the power of Twitter in healthcare

- McKee and colleagues (2011) – social media sites allow immediate scrutiny on the NHS reforms in the UK and gave a “voice” to the “voiceless”
- Another high profile example of Twitter was the editorial dispute with authors to publish a paper in either NEJM or the Lancet where Richard Horton offers personal insight (Huston, 2012 published in Forbes)

Lancet Editor Richard Horton Tweets Dark View of Contemporary Medicine

+ Comment now



One brief message at a time, *Lancet* editor Richard Horton is tweeting his dark view of the contemporary medical establishment. If you have any interest at all in peeking behind the curtain to see what

9

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80

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+59,708 views

Felix Baumgartner Unlikely To Cash In On Red Bull Space Jump +46,136 views

Why should we consider using social media in our research?

- Ability to engage with multiple audiences quickly and inexpensively
- Ability to reach and engage with more individuals and organizations in an efficient manner than we could using more conventional – passive – technique
- Increase the dissemination and reach of our research
- Discover new partners, networks for our research through analyzing who is “following” our work, as well as examining the networks of our followers
- Accessibility of our research to the public – social media is available to everyone
- Recruitment
- Also – Twitter forces us to be brief (140 characters) – sometimes, that is a good thing!

Remember.....

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Questions

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