Why should I use social media?

5 September 2012

Peter J Gill, BMSc
Honorary Fellow at the Centre for Evidence-Based Medicine
DPhil Candidate in Primary Care Health Sciences, University of Oxford
MSc Candidate in Evidence-Based Health Care, University of Oxford
MD/PhD Program, University of Alberta
Lift up your hands if you have used or currently use the following:

- Facebook?
- Twitter?
- Written a blog?
Objectives

- Explain personal background and involvement in social media
- Define the term ‘social media’ and provide a brief history of the major roles it has played
- Provide examples of the power of social media and describe its growing impact in health care
- Outline my suggestions for how you can take advantage of social media
1. BACKGROUND
Background

- Professional student
  - DPhil / MSc at University of Oxford and MD/PhD at University of Alberta

- Began using Twitter in March 2011
  - No turning back

- Invited to start blogging on trustthevidence.net in August 2011

- Focus on pediatrics, evidence based medicine, primary care and medical education
Publication bias: big problem for children

Peter Gill
Last edited 8th May 2012

A recent study in the journal Pediatrics reported that only 29% of clinical studies in children have been published. This finding reinforces previous studies that there is significant publication bias in paediatric studies. These findings are a cause for serious concern.

What is publication bias? Essentially, it is the selected publication of studies based on the results, such as only publishing studies that demonstrate a drug works while not publishing studies that demonstrate harms.

Publication bias is a serious problem in healthcare and can have a large influence on treatment decisions by only providing limited information. Researchers have demonstrated substantial publication bias in certain areas such as the antidepressant medication reboxetine.

Several initiatives have been spearheaded to help reduce publication bias. The creation of open-access journals have shifted the focus from the importance of the results (as judged by a journal editorial committee) to the methodological rigour by which the study was completed.

But more importantly has been the creation of online trial registries, such as ClinicalTrials.gov launched in 2000. These registries serve as central databases of all the current and on-going clinical studies. Registration is optional, however in 2005 the ICMJE made registration of clinical trials as a pre-requisite of publication. Although this does not represent all journals, it sent a strong message of the importance of registration.

However despite the creation of trial registries, less than half of US based National Institute of Health (i.e. government) funded trials in children were registered on ClinicalTrials.gov. Another important finding was the lack of information included on the registries. One-third of all clinical studies terminated early did not provide any information about why they were stopped. The situation was similar for suspended studies with one quarter not providing information.

Were those studies stopped because of harms? Were the investigators no longer able to recruit children to enroll? Whatever the reason the studies were stopped, this information must be made public.

Registration of all clinical studies involving children must be made mandatory. This is the only way to minimise publication bias and increase the reporting of research. This would create massive industry uproar, but is it ethical to enroll children in a clinical study without having it publicly registered? At a minimum any trial that receives government funded must be registered.

However registration of studies is only one element of the formula. What about the dissemination of the results? Less than 10% of completed studies in children had results posted and publicly available. With the low publication rate, the only way for potential benefits to be realised is for the research to be incorporated into clinical guidelines. These guidelines should not only be evidence based, but also evidence for.

TRUST THE EVIDENCE

Discover the truth behind the research findings that affect everyday healthcare.
2. WHAT IS SOCIAL MEDIA?
What is ‘social media’?

- Social media is a “decentralized system whose participants took care of distribution, deciding collectively which messages to amplify through sharing and recommendation.” The Economist
  - Participants in such a system are a “networked public” rather than an “audience”

- Not a new concept…“Five centuries before Facebook and the Arab spring, social media helped bring about the Reformation.” The Economist
  - Luther’s ’95 Theses on the Power and Efficacy of Indulgences’ spread throughout Christendom within weeks

Source: The Economist. 17/12/2011
Social media in the 21st century

- Major role in ‘Arab Spring’
  - Used to organize and communicate despite attempts at censorship
  - Toppled autocratic regimes

- Growing role in health care
  - 1 in 3 Americans use social media to find medical information
    (Source: Digital Medicine)

- Today social media refers to “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
  - Unidirectional (e.g. blog) and multidirectional (e.g. online forum)

Source: Digital Medicine; Canadian Medical Association.
Key social media tools

- **Facebook**
  - World’s most popular social networking site with >900 million active users
  - Share a variety of information by generally interacting with ‘friends’

- **Blogging**
  - Online interactive journal or website written by an individual or an organisation
  - Many free services (e.g. blogger.com or wordpress.org)

Source: CMA Future Practice November 2011
Twitter

- Social networking service that allows users to send and read “tweets” or short messages up to 140 characters long
  - Users share information and web links instantly among “followers”

- Individuals can respond to tweets, enabling debate and discussion
  - Message propagation occurs through “retweeting”

- Can send direct confidential messages back and forth

- Hashtags (e.g. #ccsympt12) facilitate indexing, searching and remote conference participation
  - Ask questions via Twitter using #ccsympt12 during presentation remotely

- ‘Push’ vs ‘pull’ information

Source: CMA Future Practice November 2011; BMJ 2011;342:d948
What does Twitter look like?
3. SOCIAL MEDIA IN HEALTH CARE
Frustration with lack of trustworthiness of information

For example, UK Prime Minister David Cameron quoted to say that “someone in this country is twice as likely to die from a heart attack as someone in France.”

Twitter debate revealed selective use of studies, methodological research flaws and planned rebuttal by economist at think-tank

Twitter provides a voice for the few enthusiasts keen to read the 353 pages of draft legislation

Source: BMJ 2011;342:d948
Dark view of medicine

- Unique insight into the minds of leaders in medicine
  - “In sudden bursts of candor, humor, and cynicism, Horton has been tweeting thoughts that don’t often see the light of day.” Larry Husten, Forbes

Richard Horton
@richardhorton1
Welcome to a permanent attack on the present
london

- Describes editorial dispute with authors to publish paper in NEJM and Lancet
  - Evidence of journal manipulation by industry?
When papers get salami sliced and divided between NEJM and us, it gets complicated. And sometimes nasty. And today, even threatening.

Now put to rest a terrible authorship dispute that has blocked an accepted paper for months. Crucial lesson: agree authors before starting.

The mother of all authorship disputes has broken out.

When papers get salami sliced and divided between NEJM and us, it gets complicated. And sometimes nasty. And today, even threatening.

In the saga of our salami sliced paper at NEJM and Lancet, both journals are now saying, it’s us or no go. This is getting silly.

NEJM/Lancet salami story, Part 164: US author writes to report “significant disagreement” among authors. We are told to suspend review...

Authors on both versions of what seems to be largely the same paper with our two journals to gather and resolve their dispute. We wait...

Lancet/NEJM salami latest. From Principal Investigator. “Approval [of the drug in question] has already occurred in the US, yet...

...private insurers are slow to place it on their formulary. A major publication is typically how this occurs in the US, and it is...

important to be in a journal typically recognised by US-based companies. This would include NEJM...Therefore, this publication is critical..

...to [company A's] ability to “market” their product. Lancet, on the other hand, will aid [company Y] quite nicely.”

Source: Larry Huston, Forbes. 27/01/2012
Twitter journal club

- Similar to traditional journal club except on Twitter
  - Started by medical student in Cambridge in 2011
  - Over 2000 followers

- Meets every 2 weeks at 7pm GMT on Sunday evenings
  - Uses the hashtag #TwitJC

- Papers announced on Twitter 2-3 days prior
  - Introductory post published
  - Discussion summary and transcript posted

- Select significant papers that are relevant to a broad audience
  - Anyone can suggest papers

TwitJournalClub @twitjournalclub 29 Apr
MT @jonjhiltonHang on a minute, noticed how few patients actually made it to the study. Just 7% of PCI & only 15% of CABG analysed #twitjc
Expand

Jamie Green @dJamieEGreen 29 Apr
@twitjournalclub #twitjc - is it safe / ethical to randomise such a study?
View conversation

Northern Doctor @northern_doctor 29 Apr
But I also think that if complicated statistical data-manipulation is going to be done, it should be better explained #twitjc
Expand

Jon Hilton @jonjhilton 29 Apr
#twitjc surely that is a massive confounding factor. Might there be some other characteristic being inadvertently represented?
Expand

Truffle, Also Clive @trufflethebendy 29 Apr
Have to agree with @northern_doctor here I think #twitjc
Expand

Northern Doctor @northern_doctor 29 Apr
Definitely a place for observational studies like this one, as long as they’re not over-interpreted! #twitjc
Expand

Jon Hilton @jonjhilton 29 Apr
#twitjc Hang on a minute... Just noticed how few patients actually made it to the study. Just 7% of PCI and only 15% of CABG were analysed
Expand

TwitJournalClub @twitjournalclub 29 Apr
Final point - How much reliance should we put on such non-randomised studies that make use of the available data like ASCERT? #twitjc
Changing world of research

- Academics are losing faith in the system
  - **Peer review** is slow and favors conventionality
  - **Citation counting** is helpful but insufficient and takes years
  - **Journal impact factor** incorrectly used to measure impact of individual article

- More and more research is moving online
  - Articles stored in online **reference browsers** like Mendeley and Zotero (each with >40 million articles)
  - Hallway conversations end up in **blogs**
  - Up to one-third of scholars are on **Twitter**
  - Datasets increasingly **stored** and shared online

Altmetrics

- Tracing the use of this information is called **Altmetrics**
  - "creation and study of new metrics based on the Social Web for analyzing, and informing scholarship."

- Superior to conventional measures of impact
  - Diversity of language provide **complex measurement** of "diverse scholarly ecosystem"
  - Measure **aggregate** impact of research
  - Track impact outside of **white tower**
  - Fast and open
  - Reflect **article** not venue

Article Usage

Total Article Views: 562,700
Aug 30, 2005 (publication date) through Apr 23, 2012

<table>
<thead>
<tr>
<th></th>
<th>HTML Page Views</th>
<th>PDF Downloads</th>
<th>XML Downloads</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>PLoS</td>
<td>399,822</td>
<td>84,413</td>
<td>1,860</td>
<td>486,095</td>
</tr>
<tr>
<td>PMC</td>
<td>66,192</td>
<td>10,413</td>
<td>n.a.</td>
<td>76,605</td>
</tr>
<tr>
<td>Totals</td>
<td>466,014</td>
<td>94,826</td>
<td>1,860</td>
<td>562,700</td>
</tr>
</tbody>
</table>

*Although we update our data on a daily basis, there may be a 48-hour delay before the most recent numbers are available. PMC data is posted on a monthly basis and will be made available once received.*

Citations

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Scopus</td>
<td>738</td>
<td>CrossRef</td>
<td>381</td>
</tr>
<tr>
<td>PMC</td>
<td>134</td>
<td>Pubmed Central</td>
<td>134</td>
</tr>
<tr>
<td>Totals</td>
<td>665</td>
<td>Scopus</td>
<td>738</td>
</tr>
</tbody>
</table>

Social Networks

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>CiteULike</td>
<td>336</td>
<td>Connotea</td>
<td>18</td>
</tr>
<tr>
<td>Facebook</td>
<td>2500</td>
<td>Mendeley</td>
<td>3</td>
</tr>
</tbody>
</table>

What the community is saying

- jeremymcc: "research findings ... simply accurate measures of prevailing bias." Most Published Research Findings Are False bit.ly/bRpWnM
- lanewaylearning: For all you sceptics out there j.mp/lFQndj "Why most Published Research Findings Are False"
- ASSCRStemCells @BCPallab @dfc21 Peer-review science also needs interrogative journalism. Still question scientific findings & hype. tinyurl.com/c94hl6

What the community is saying
4. CAPITALIZING
Why should you use social media?

- Engage patients, researchers, clinicians and consumers by creating **dialogue** and **debate**

- Increase **dissemination** of your educational message and research results immediately

- Restriction of messages to 140 characters forces **brevity**

- **Free** to use, available to everybody

- Network is **horizontal**

- Tide is shifting...
Moving forward

1. **Engage** – To capitalize on social media, people must use social media

2. **Connect** – Link up with others of similar interests and create a community related to your interests

3. **Educate** – Begin disseminating information that YOU find important, either as an individual or as an organization

4. **Impact** – Track and measure the impact of your social media strategy
Conclusion

- Social media is driven by **people** who are passionate about the information they **disseminate** and **share**
  - Living network that is constantly adapting and changing

- Opportunity to create “**networked public**”
  - Engage the **patient**, the **media**, the **researchers**, the **clinicians**, the **consumers**
  - Platform to disseminate high-quality educational material and research worldwide
QUESTIONS?