HUMANISING MEDICINE THROUGH SOCIAL MEDIA: PRACTICAL GUIDANCE FOR USING SOCIAL MEDIA IN THE ONCOLOGY PRACTICE

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SOCIAL MEDIA TAKE-HOME POINTS

- The digital age is upon us!
- Conversations about cancer and about stakeholders are going online - with or without you
- Patient-centred care relies on patients
- Social media represents an opportunity to listen, learn, and engage
SOCIAL MEDIA DEFINED

Evolving technologies designed to facilitate ability to communicate

- One-to-one
- One-to-many

Can help in developing online communities with shared interests
FACEBOOK

- www.facebook.com
- Launched in 2004
- Currently over 1.86 billion users
- Share photos, videos, status updates, and content links
- No restriction on type of content
  - Copyright monitoring automated
- User communities: support groups (closed and open), institutions, organisations, non-profits

TWITTER

- www.twitter.com
- Launched in 2006
- Converse in 140 characters (a “tweet”) 
- Follow conversations by using their hashtags
  - #bcsm, #gyncsm, #some, #lcsm, #pallonc

LINKEDIN

- www.linkedin.com
- Launched in 2003
- 467 million+ users
- Site for professional use
- Profiles
  - Individual
  - Companies (including hospitals, professional organisations, schools, etc.)
- Groups

DOXIMITY

- www.doximity.com
- Physician-specific social media site
  - > 60% of US doctors as verified members
- CME credit potential
- User features: secure fax, confidential dialer
- Partnership with Castle-Connolly¹:
  - Top doctors
  - Best hospitals


SNAPCHAT

• A mobile-first company
• Picture/video communication via “snaps”
• Social media channel for millennials and high school age (and younger)
  – Snaps time-out (auto-delete), though possible for viewer to save!
  – Delineates user versus brand content

YOUTUBE

- www.youtube.com
- Launched in 2005
- Acquired by Google in 2006
- Site on which users upload (and watch) videos
- Largest video-sharing site in the world
  - The launch of the Internet star

BLOGS

- A web-based platform for expression of opinions and ideas through journal-type entries
  - Allows for multimedia content and sharing (via hyperlinks)

**HEALTH INFORMATION NATIONAL TRENDS SURVEY (NATIONAL CANCER INSTITUTE HINTS)**

**QUESTION:** How much does the public trust health information from the following sources?

<table>
<thead>
<tr>
<th>Source</th>
<th>Trust Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors</td>
<td>92%</td>
</tr>
<tr>
<td>Government health agencies</td>
<td>70%</td>
</tr>
<tr>
<td>Internet</td>
<td>66%</td>
</tr>
<tr>
<td>Family and friends</td>
<td>55%</td>
</tr>
<tr>
<td>Charitable organisations</td>
<td>55%</td>
</tr>
<tr>
<td>Newspapers or magazines</td>
<td>42%</td>
</tr>
<tr>
<td>Television</td>
<td>36%</td>
</tr>
<tr>
<td>Religious organisations and leaders</td>
<td>32%</td>
</tr>
<tr>
<td>Radio</td>
<td>25%</td>
</tr>
</tbody>
</table>

Adapted from: https://hints.cancer.gov/_images/infographics/HINTS-TRUST-Infographic-Cancer-Sources_Facebook-Optimized.jpg
QUESTION: Where does the public go first for health information?

Americans who went to the internet FIRST to look for information about health or medical topics

- 2008: 61%
- 2015: 73%

Adapted from: https://hints.cancer.gov/_images/infographics/HINTS-TRUST-Infographic-Cancer-Sources_Facebook-Optimized.jpg

DESPITE THIS, DOCTORS ARE STILL SCEPTICAL

Trust in source for cancer or health information

Doctor or healthcare professional

<table>
<thead>
<tr>
<th>Year</th>
<th>Patients (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2002</td>
<td>61.4</td>
</tr>
<tr>
<td>2005</td>
<td>66.8</td>
</tr>
<tr>
<td>2008</td>
<td>68.2</td>
</tr>
</tbody>
</table>

Internet

<table>
<thead>
<tr>
<th>Year</th>
<th>Patients (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2002</td>
<td>23.4</td>
</tr>
<tr>
<td>2005</td>
<td>18.5</td>
</tr>
<tr>
<td>2008</td>
<td>18.9</td>
</tr>
</tbody>
</table>

PATIENT INVOLVEMENT IN SOCIAL MEDIA

40% of consumers say information from social media impacts how they deal with their health¹

90% of 18-24 year olds trust health information shared on social media²

41% say social media can affect their choice of healthcare provider³

WHY SHOULD YOU CARE ABOUT SOCIAL MEDIA?

Two very simple reasons:

- Your patients are online
- You are online as well (even if you aren’t)
WHY SHOULD YOU CARE ABOUT SOCIAL MEDIA?

Do your own Google search and see how frequently your name comes up!

- Information is *unfiltered*: you have no direct control over what comes up and at what rank...
- BUT! Digital engagement gives you the opportunity to contribute and potentially reorder what information filters to the top of search engines
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The digital footprint
- Online record of who you are and what you do online
- Tracked by your IP address, name, institution

But whose footprint is it??
- Yourself
- Your institution
- Organisations to which you belong
- Feedback from others
- Impostors?
- ALL OF THE ABOVE

IP, Internet protocol.
MANAGING YOUR ONLINE PRESENCE: THE “FOUR Ds”

Discovery  Definition

Dissemination  Defence

DISCOVERY: FIND YOUR DIGITAL FOOTPRINT

• Google search your name and see what comes up
Find out: What is Internet saying about you?

- Online search on your name
- Search name + affiliations (practice, institution, city)
- Also look on specific websites:
  - Healthcare rating systems
  - Society websites
  - Patient-related websites
  - Content-sharing sites
CONTROLLING GOOGLE: DEFINITION

- Disseminate information in order to control what patients and peers learn about you:
  - GOAL: the information found first is the information you want found
  - Reality: very difficult to delete information from the web
    - “Once it’s out there, it’s out there”

- HOW?
  - Sign up for professional sites
  - Publish your CV in multiple places
  - Get involved in social media
Engagement = larger online presence

Remember: assume you cannot remove content once posted; observe before participation

- Copies live on a server somewhere

Choose a medium that you are comfortable with

Each platform has its own language and etiquette
### DEFENCE: ACTIVE ENGAGEMENT, PROFESSIONALLY

<table>
<thead>
<tr>
<th>TWITTER</th>
<th>FACEBOOK</th>
<th>INSTAGRAM</th>
<th>SNAPCHAT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tweets</td>
<td>Pages</td>
<td>Pictures/video</td>
<td>Snaps</td>
</tr>
<tr>
<td>RT: Retweet</td>
<td>Multimedia capability to communicate via posts</td>
<td>Grams allow for posting of visual content with commentary</td>
<td>Static or video, but not permanent</td>
</tr>
<tr>
<td>MT: Modified</td>
<td>Allows for Likes</td>
<td>Allows for Likes</td>
<td>Streaks: ongoing conversation, captured within a 24-hour period without breaking</td>
</tr>
<tr>
<td>HT: Hat-tip</td>
<td>Encourages conversations</td>
<td>Comment feed availability</td>
<td>Accounts can be closed or open</td>
</tr>
<tr>
<td>Conversation tracking via hashtags</td>
<td>Restricted or public pages</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
PHYSICIAN INVOLVEMENT: WAYS WE INTERACT

• Inform others about new outcomes:
  – Comment on medical literature
  – Personal commentary at live meetings

• Better inform patients and the public:
  – Identify reliable resources
  – Add voice to ongoing conversations and debates
  – Debunk unfounded treatments

• Advocate special interests:
  – Clinical trials
  – Research initiatives
DUAL CITIZENSHIP

• Aim to leverage professional connections while maintaining privacy in other settings
• Example:
  – Use Twitter exclusively for professional means
  – Use Facebook exclusively for personal means
• Separation is supported by the American Medical Association (Opinion 9.124)\(^1\)
• IMPORTANT POINT: all social media posts should be considered public

PERSONAL VERSUS PROFESSIONAL

- Clearly define a separation between work and personal life
- Conflicts of interests should be clearly disclosed
- Avoid using institutional graphics or logos
- “Friending” or “following” patients is controversial, and policies will vary
CAN/SHOULD YOU HAVE DUAL IDENTITIES??

• PROS:
  – Allows for a private versus public persona
  – Minimises risk to patients, and others can contact you in a personal environment
  – “Being myself” versus “Being a doctor”

• CONS:
  – “Robs” patients of the opportunity to see their clinicians as humans
    • The professional identity as constituted by the personal identity
  – Operationally impossible
    • Web searches can quickly connect the two

ACKNOWLEDGE THAT SOCIAL MEDIA IS INHERENTLY PUBLIC, NO MATTER WHAT THE FORUM

AREA OF RISK: PATIENT CONFIDENTIALITY

There are no HIPAA compliant social media

Physicians have been sanctioned for social media activity

Any contact with patients should be initiated by them

HIPAA, Health Insurance Portability and Accountability Act.
AREA OF RISK: CLINICAL RESEARCH

• Social media is an intriguing way to publicise/recruit for studies, BUT:
  – It is considered as an advertisement
  – It requires IRB review (US Office of Inspector General determination)
  – Only limited information can be given ClinicalTrials.gov benchmark
• Always remember: patient confidentiality is paramount

IRB, institutional review board.
As of 2012, 71% of US state boards had held disciplinary proceedings for inappropriate social media activity\(^1\)
- 56% led to restriction, suspension, or revocation of licence

Activities agreed to be problematic include:\(^1,^2\)
- Misinformation on website, including board certification or outcomes
- Patient confidentiality
- Inappropriate communication with patients

A doctor living in far eastern Oklahoma was disciplined Thursday for prescribing violations and using Skype to treat patients under his care.

Dr. of Park Hill, was using the online service to treat patients with mental health issues. The doctor claimed he thought Skype was a suitable communication system for the practice of telemedicine, records show.

Skype is a relatively new technology that allows users to communicate over the Internet using a webcam, microphone or a text message.

Medical board documents show that Skype is not approved as a telemedicine communication system.

In March, a representative of the Oklahoma Health Care Authority alleged that was “practicing telemedicine via Skype on SoonerCare members and prescribing (controlled dangerous drugs) without ever seeing the patients in person for an initial evaluation,” according to a June 14 complaint filed by a medical board investigator.

Dr. [REDACTED] was fired from the hospital last year and reprimanded by the state medical board last week. The hospital took away her privileges to work in the emergency room for posting information online about a trauma patient.

The posting did not include the patient’s name, but she wrote enough that others in the community could identify the patient, according to a board filing. [REDACTED], who did not return calls for comment yesterday, also was fined $500.
Get involved
Engage often
Always identify yourself
Protect patient confidentiality and privacy
Contextualise your activities

Avoid impropriety
Give credit where credit is due
Professionalism is critical
Separate personal from professional
Be aware of your institutional guidelines

GETTING STARTED

You need an email address
• If part of a larger institution, check institutional policies for ability to use work email for account setup
• Institutions may require that social media accounts are subject to monitoring

Establish a unique identifier
• User name in most platforms

Pick your forum and start lurking
• Follow specific people
• Follow conversations by #hashtag
CONCLUSIONS

- We are in a digital era of communication
- Social media cannot be ignored
- To learn: explore
- Protect your identity
- Engage to increase your visibility
- Always remember that your reputation is at stake

So, come on in... The water is just fine!
I BELIEVE INTERACTING WITH PATIENTS ON SOCIAL MEDIA IS GOOD THING.

A. Completely agree
B. Agree with reservations
C. Disagree somewhat
D. Absolutely disagree
QUESTIONS?

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