

# Social Media and Infectious Diseases

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## Objectives

- 1) To understand the impact of social media on disease transmission
- 2) To understand social media in the control of infectious diseases
- 3) To advocate for clinician involvement in social media for disease awareness and prevention

### SOCIAL MEDIA EXPLAINED

- Facebook
- Twitter
- LinkedIn
- Instagram
- YouTube
- Pinterest
- Nextdoor
- WhatsApp
- Google+
- Tumblr
- SoundCloud
- Dropbox
- OneDrive
- Box.com
- Google Drive
- Dropbox
- OneDrive
- Box.com
- Google Drive



## Conflict of Interest

### Financial Disclosures

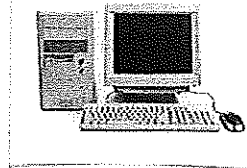
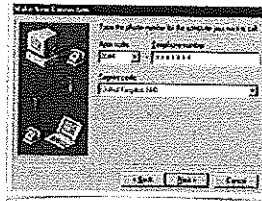
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### Unlabelled/Unapproved Use Disclosures

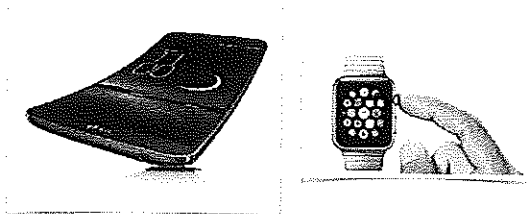
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Other Disclosures - I am an active user of social media

## 16 years ago



## Today



## What is social media?

forms of electronic communication (as Web sites for social networking and microblogging) through which users create online communities to share information, ideas, personal messages, and other content (as videos)

Term first coined in 2004

Merriam-Webster's Dictionary

## The development of social media

Initially emails sent between computers in 1971

Followed by messaging boards in late 70's

Self - created websites in 1994 (Geocities)

Instant messaging in late 90's

Friendster, myspace, and facebook in 2003-2005

[www.onlineschools.org](http://www.onlineschools.org)



Social media are a catalyst for the advancement of everyone's rights. It's where we're reminded that we're all human and all equal. It's where people can find and fight for a cause, global or local, popular or specialized, even when there are hundreds of miles between them.

*Queen Rania of Jordan*

## Why infectious diseases?

Social media links people, and they may be worlds apart or in the next room

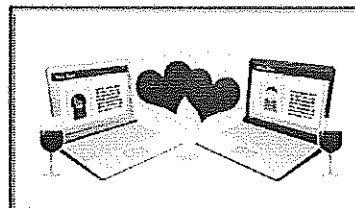
Can be used as a gateway to meet people online and in reality with similar interests

Conversely, can bring together people who would have never met in real life

Everyone can access, in the poorest most remote settings

The data people generate from social media can be correlated to surveillance

## Case 1: The rise of Infectious Diseases



## Online dating

Started virtually around the same time people started connecting online

Connecting people who may have never met before, particularly with sexual interests

The end result is self explanatory...



## First outbreak

Early Syphilis in Southern California in 1990's was fairly rare (41 cases)

All of a sudden an increase in cases described in 2000-2002, particularly in MSM

A significant number of cases had been in HIV(+)

Clinically relevant as syphilis in HIV can be a cause of morbidity (early CNS disease, end organ complications, increase transmission, difficulty in treatment)

Centers for Disease Control and Prevention (CDC). Internet use and early syphilis infection among men who have sex with men—San Francisco, 2000–2002. *MMWR*. 2003;52(10):193–196.

## First outbreak

Epidemiological investigation into cases in 2000

2 men with early syphilis admitted to a number of contacts who met through an AOL chat group

How do you do contact screening through the internet?

1. Klausner, J. D. Tracing a Syphilis Outbreak Through Cyberspace. JAMA 284, 647 (2000)

## First outbreak

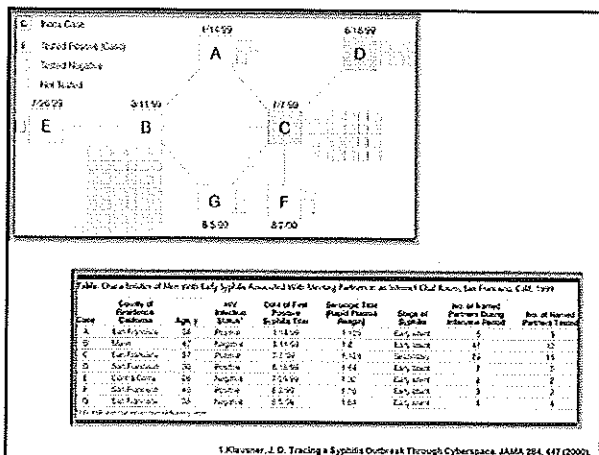
Initially local public health asked for disclosure from ISP, but turned down due to privacy reasons

Referred to a marketing firm, specialized in Internet resources for MSM → Campaign to encourage prevention / testing



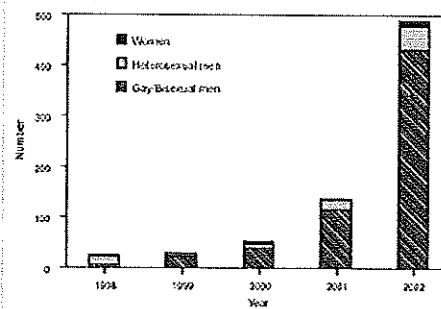
Public health sent messages to at-risk individuals through AOL

1. Klausner, J. D. Tracing a Syphilis Outbreak Through Cyberspace. JAMA 284, 647 (2000)



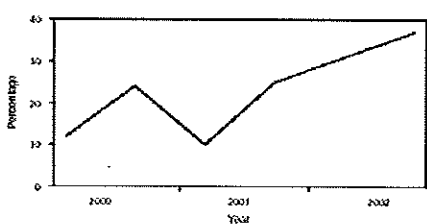
1. Klausner, J. D. Tracing a Syphilis Outbreak Through Cyberspace. JAMA 284, 647 (2000)

FIGURE 1. Number of early\* syphilis cases, by sex, sexual orientation, and year — San Francisco, California, 1998–2002



1. Centers for Disease Control and Prevention (CDC). Internet use and early syphilis infection among men who have sex with men—San Francisco, California, 1998–2002. JAMA 284, 647 (2000)

FIGURE 2. Percentage of persons with early\* syphilis who reported meeting sex partners on the Internet, by year — San Francisco, California, 2000–2002



1. Centers for Disease Control and Prevention (CDC). Internet use and early syphilis infection among men who have sex with men—San Francisco, California, 1998–2002. JAMA 284, 647 (2000)

## High risk internet behaviour

Denver study (n=856) self reports through an STI clinic in 2000

15.8% looked for a partner over the internet, and nearly 2/3 had sex with an internet partner

Those who had internet relationships tended to be male, MSM

Had more previous STD's, more partners, more partners who were known to have HIV

1. McFarlane, M. The Internet as a Newly Emerging Risk Environment for Sexually Transmitted Diseases. JAMA 284, 640 (2000)

## HIV Serosorting

Ecologic study in San Francisco, anecdotal reports of men who had sex with men of the same serostatus

Rates of HIV remained stable

Rates of unprotected intercourse increasing

Rates of those with unknown contacts or seeking HIV testing (due to possible contacts) decreasing

Gonorrhea / Syphilis rates exploded

Are people serosorting based on HIV status using the internet?

1. Truong, M.H. M. et al. Increases in sexually transmitted infections and sexual risk behaviour without a concurrent increase in HIV incidence

## Not just MSM in USA

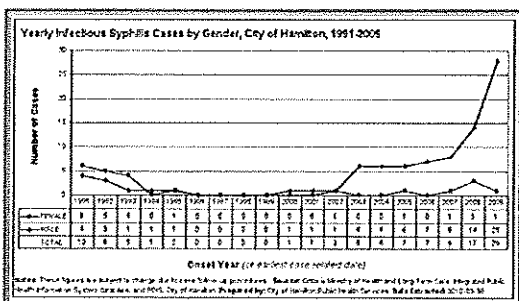
Data from Singapore, heterosexual men

Men who had sexual partners online (n=304) vs. those who had sexual partners via brothels (n=297)

Higher rates of STD's, lower rates of condom use (particularly with oral sex)

1. Wang, M. L., Koh, T. T., Tjahjedi, S., & Govender, M. Men seeking sex online practise riskier sexual behaviours than men frequenting brothels

## Hamilton Data



## The current situation

Online solicitation for sex is becoming much easier with location based apps such as tinder and grinder



People who weren't considered as high risk (middle aged adults) now meeting and engaging in sex online



Injection drug use with sex (chemsex) has created a new outbreak of Hepatitis C linked to social media

54 Dean Street, Chemsex and HIV: a guide for healthcare providers, Dec 2014



Multi-episode notification for HIV infection in high risk men

7% of high risk men have been notified with HIV



Approximately 92% of HIV risk-reducers were high risk men located across London, Manchester & South East England

2011<sup>2</sup>

There are more than 100,000 men who use drugs

There is currently no vaccine or drug to prevent HIV infection in high risk men

25% of high risk men have contracted HIV infection

Condoms and PrEP are not enough

A synthetic population of HIV positive and negative men is currently being used for HIV risk-reduction studies with a view to being used in a real world setting at 2017

At Oxford & Westminster Alcohol and Food Bank that will house 1000 men, women and children

54 Dean Street, Chemsex and HIV: a guide for healthcare providers, Dec 2014

## What can we do?

- Positive messaging at point of entry about protection and testing
- Awareness of the risks associated with sexual partners acquired online
- Brazil government recently created fake tinder accounts to educate people interested in online sex during carnival
- Use these apps as modes for research
- Already used as HIV prevention studies
- Should we be labelling similar to cigarettes?

1. Burnett, E. K. et al. Use of the location-based social networking application GRINDER as a recruitment tool for rectal microbicide development

## Summary: Case 1

Social media and sexual partners acquired online have been partly responsible for an resurgence of STI's

As apps become more accessible and sexual practices change, rates may increase, and include non-STI diseases

Positive messaging, testing, and involvement of public health services with these apps is the key

Possibility of research into STI prevention

## Case 2: Social Media in the Control of Infectious Diseases



## The rationale

The internet is a wealth of communication

Infectious disease outbreaks start as a single case then spread

Typically this is reflected as an anecdotal case

How to disseminate this information effectively?

## Promed

Established in 1994 - 40 subscribers

Linked thousands of medical/veterinary/agricultural professionals over the world

Simple email listserv

Signalled the beginnings of infectious disease epidemics

1.Madoff, L. C. ProMED-mail: an early warning system for emerging diseases. Clin Infect Dis. 39, 227-232 (2005).

## Global Public Health Intelligence Network

Public Health Agency of Canada initiative

Instead of asking subscribers to generate content, network monitors news feeds with specific search queries

First described an unusual respiratory illness in China in November 2002 - first description of SARS fed to the World Health Organization

Both ProMed and GPHIN credited with alerting Toronto and coordinating early outbreak response

1.Mylchreest, E. & Weir, L. The Global Public Health Intelligence Network and early warning outbreak detection: a Canadian contribution to

This morning I received this e-mail and then searched your archives and found nothing that pertained to it. Does anyone know anything about this problem?

"Have you heard of an epidemic in Guangzhou? An acquaintance of mine from a teacher's chat room lives there and reports that the hospitals there have been closed and people are dying."

Stephen O. Cunnion, M.D., on ProMED-mail, 10 February 2003

## Another new virus

A new human coronavirus was isolated from a patient with pneumonia by Dr Ali Mohamed Zaki at the Virology Laboratory of Dr Soliman Fakeeh Hospital Jeddah Saudi Arabia.

The virus was isolated from sputum of a male patient aged 60 years old presenting with pneumonia associated with acute renal failure. The virus grows readily on Vero cells and LLC-MQ2 cells producing CPE in the form of rounding and syncytia formation.

[The clinical isolate] was initially tested for influenza virus A, influenza virus B, parainfluenza virus, enterovirus and adenovirus, with negative results. Testing with a pan-coronavirus RT-PCR yielded a band at a molecular weight appropriate for a coronavirus. The virus RNA was tested also in Dr. Ron Fouchier's laboratory in the Netherlands and was confirmed to be a new member of the beta group of coronaviruses, closely related to bat coronaviruses. Further analysis is being carried out in the Netherlands.

The Virology Laboratory at the Dr Fakeeh Hospital will be happy to collaborate with others in studies of this virus.

## Weeks later

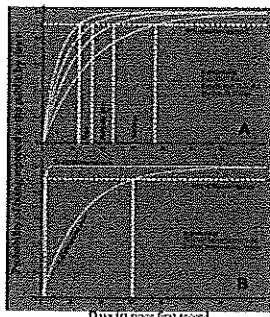
Sequenced the coronavirus and developed serologic assay

MERS coronavirus identified, outbreak currently with 25% mortality, cases found through middle east

International cooperation lead to quick identification and management of the outbreak

Still ongoing - unclear environmental reservoir...

## Lags in reporting?



McAtamney, L., Smith, K., Brownstein, J. S. & Jerns, C. Internet and Free Press Are Associated with Reduced Lags in Global Outbreak Reports

## Google Surveillance

Typically surveillance of influenza-like illness a mixture between clinical and laboratory features

Google used search terms (ex. influenza complications), and made a model based on previous CDC data on influenza-like illness)

Validated against national and regional data

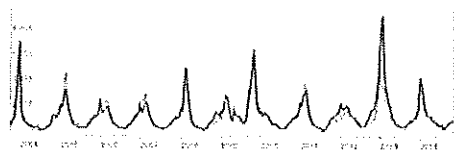
Applied prospectively — picks up influenza-like illness 1-2 weeks before typically surveillance data, r values ~0.5-0.88 with laboratory data

Some faults - ex. when there is local news about influenza/medications it may falsely raise the search rate

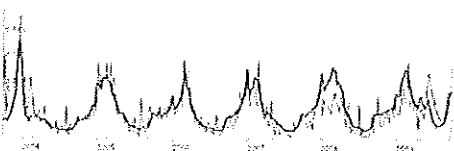
Similar model being applied to dengue

Goldberg, J. et al. Detecting influenza epidemics using search engine query data. Nature 457, 1012-1014 (2009)

## USA Data (Blue = Google, Orange = Public Health)



## Canadian Data

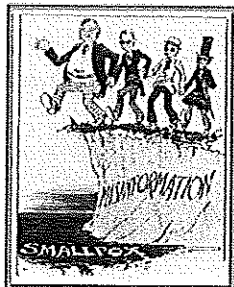


## Case 2: Summary

Social media can lead to early detection and enhanced detection of pathogens, particularly in environments with limited access to "open" internet

User based internet searches also provide a wealth of data that can compliment surveillance systems

## Case 3: Infectious Diseases Advocacy



## Vaccines and social media

Anti-vaccine efforts have been around since the dawn of vaccination

Medical community still managed to mass vaccinate, most of the population

Splinter cells of anti-vaxxers, lead by Jenny McCarthy and Andrew Wakefield's link to autism

The imbalance of internet-based media created by the anti-vaccine effort may be contributing

1. Katz, A. Anti-vaccine activists, Web 2.0, and the postmodern paradigm—an overview of tactics and tropes used online by the anti-vaccine...

## Why social media

Can now link people with similar mindsets without geographical restrictions

Can publish content easily, and skew the balance towards anti vaccine

Tend to view similar content and skew ratings systems

Not enough published by health care providers

Lay person content

1. Wilson, K. & Keelan, J. Social Media and the Empowering of Opponents of Medical Technologies: The Case of Anti-Vaccination. *Journal...*

## Early adopters

Random search of web in 2001 for terms "vaccination" and "immunisation OR immunization" into 7 search engines

Analysis of first 10 sites

43% of sites had anti-vaccine content (100% on google)

"This lovable, extremely alert baby had never produced such a blood-curdling scream as she did at the moment the shot was given ... four hours later, Lee Ann was dead"

"[Is immunisation] really designed for prevention or cure or is it planned for increasing diseases and dependency on treatments and medicines?"

1. Davies, P. Anti-vaccination activists on the world wide web. *Archives of Disease in Childhood* 81, 22-24 (2002).

## YouTube - Vaccine study

Table 1. Ratings and Views of YouTube Videos About Immunization\*

Category of Main Message†	No. of Videos	No. of Views (Median (IQR))	No. (%) Rated	Viewer Rating Mean (SD)‡	No. (%) of Viewer Ratings Positive (n=10)	n = 9
Positive	23	111,823 (55)	46 (20)	3.5 (0.5)	21 (45)	25 (55)
Neutral	43	120,012 (50)	42 (98)	2.4 (0.5)	34 (81)	8 (19)
Anti-vaccine	31	301,827 (250)	20 (65)	1.1 (0.5)	11 (55)	9 (45)
Anti-vaccine	22	808,009 (265)	17 (77)	1.1 (0.2)	14 (82)	3 (18)
False	11	11,042 (24)	3 (27)	1.7 (0.6)	2 (67)	1 (33)
<b>Total</b>	<b>130</b>	<b>1,352,713 (507)</b>	<b>108 (83)</b>	<b>1.9 (0.5)</b>	<b>58 (53)</b>	<b>50 (47)</b>

\*Data were not available for 2 videos in the anti-vaccine category and 1 video in the neutral category.  
†The categories of main messages were defined as follows: positive, pro-vaccination; neutral, neither pro- nor anti-vaccination; anti-vaccine, pro-anti-vaccination; false, anti-vaccination with false information.

1. Kishida, J., Paeri-Garcia, V., Tomlinson, O. & Wilson, K. YouTube as a source of information on immunization: a content analysis. *JAMA* 298

## Twitter Study

Tracked over 300000 tweets during H1N1 epidemic around vaccination

Looked at not only message, but connectness/endorsement between users

Negative messages not only out weighed positive, but were more "contagious"

1. Salathé, M., Vaz, D. Q., Khandelwal, S. & Huzar, D. R. The dynamics of health behavior sentiments on a large online social network. *EPJ Data...*

## Dispelling misinformation



## Toronto Star

Published an article in February around the dangers of the HPV vaccine

Used an unrefined adverse event reporting system as a source of information

Anecdotal cases without any clear association displayed prominently throughout article

Small disclosure at end of article stating there is no evidence of causation of these

## The response

Large scale condemnation by the medical community

Many physicians used web-blogs and twitter to document the fallacy in this argument

To convey the message to other HCW

To convey the message to the general public about the dangers of this type of publication

Back and forth messaging between the Toronto star editors and medical professionals

I'm reading doctor and science writer Ben Goldacre's new book, "I Think You'll Find It's a Bit More Complicated Than That", about the widespread misunderstanding of research and results. For a year now, I've been trying to teach myself about statistics and science so as to find a way through the fog.

*Heather Mallick, Columnist*

"Good god. This is appalling, ignorant, irresponsible journalism, as you well know reporting the raw data from an open adverse event reporting system in that manner, is simply misleading, and an abuse. Where data is made openly accessible we all have a responsibility to reciprocate, and analyse / report on it competently.

You have abused that trust, with a platform so large that you will inflict harm. I'm disgusted and appalled that you'd invoke my name in trying to defend yourselves. The irony is, that while you use bad data to promote fear about vaccines, you miss the real big stories about the flaws in evidence based medicine.

*-Ben Goldacre, over twitter in response to the star article*

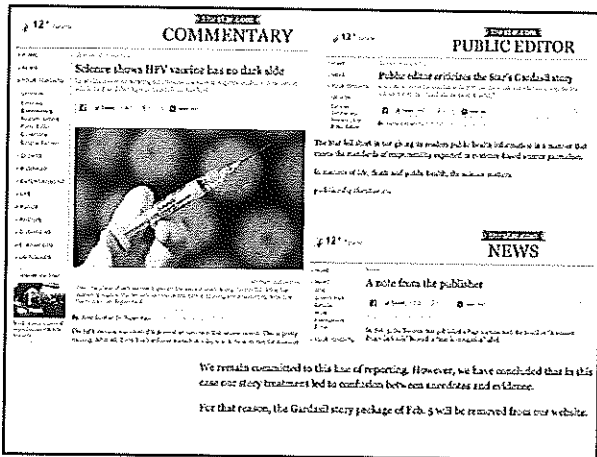
## The end result

Significant distribution over social media

Largely positive vaccine standpoint, particularly as Toronto was dealing with a concurrent measles outbreak

Responses not only local to Toronto, but national and USA health care workers came out to point out flaws in reporting





**Summary: Case 3**

Using the anti-vaccine movement as an example, we see social media being a double edged sword

Lets an unscientific movement gain ground by garnering most of the internet attention

Lets scientists express their opinions freely to make changes into reporting in the media

**Rules of Engagement - CPSO**

1. Assume that all content on the Internet is public and accessible to all.
2. Exercise caution when posting information online that relates to an actual patient, in order to ensure compliance with legal and professional obligations to maintain privacy and confidentiality. Bear in mind that an unnamed patient may still be identified through a range of other information, such as a description of their clinical condition, or area of residence.
3. Refrain from providing clinical advice to specific patients through social media. It is acceptable, however, to use social media to disseminate generic medical or health information for educational or information sharing purposes.
4. Protect their own reputation, the reputation of the profession, and the public trust by not posting content that could be viewed as unprofessional.

**Rules of Engagement - CPSO**

6. Be mindful of their internet presence, and be proactive in removing content posted by themselves or others which may be viewed as unprofessional.
7. Refrain from establishing personal connections with patients or persons closely associated with them online, as this may not allow physicians to maintain appropriate professional boundaries and may compromise physicians' objectivity. It is acceptable to create an online connection with patients for professional purposes only.
8. Refrain from seeking out patient information that may be available online without prior consent.
9. Read, understand, and apply the strictest privacy settings necessary to maintain control over access to their personal information, and social media presence undertaken for personal purposes only.
10. Remember that social media platforms are constantly evolving, and be proactive in considering how professional expectations apply in any given set of circumstances.

