text me, message me, email me, PM or DM me, snap me or tweet me… but just don't expose me

Lynette Larkins @ a Glance

Twenty year career in technology leadership and management. Information Security in healthcare since 2003, first at Nationwide Children's Hospital, and now at St. Jude Children's Research Hospital.
- Bachelors in Engineering from the University of Dayton
- MBA from the Ohio State University

435	**197/111/389**	**@lynettelarkins**	**477**	**2**
Facebook Friends	Instagram posts/followers.following	24 tweets, following 234, 22 followers	LinkedIn Connections	Number of tweens at home to assist me with social media

Top 15 Most Popular Social Networking Sites

									MILLIONS
0	200	400	600	800	1 000	1 200	1 400	1 600	1 800

Legend:
- Facebook
- YouTube
- Instagram
- Twitter
- Reddit
- Vine
- Ask.fm
- Tumblr
- Flickr
- Google+
- LinkedIn
- Pinterest
- VK
- ClassMates
- Meetup
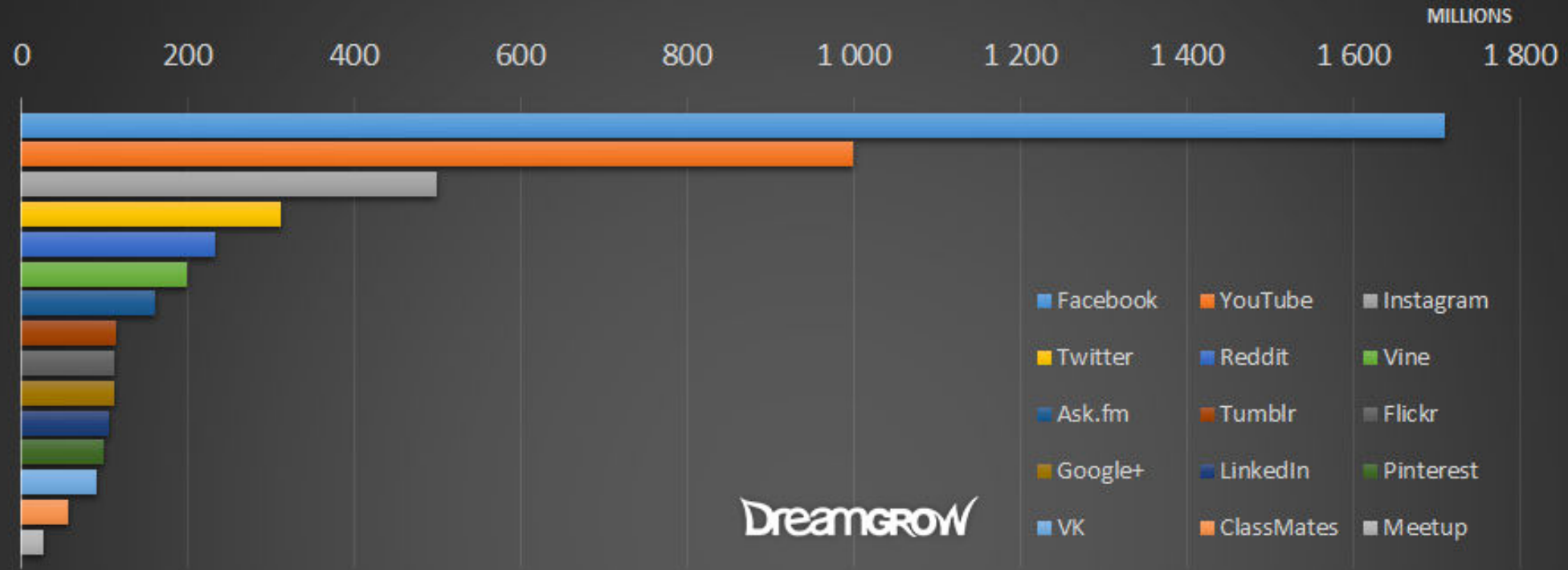
DreamGrow

Millions of unique visitors per month, over the past 3 months
Updated Sept 18, 2016

Source: Statista
*Source: www.dreamgrow.com

Social Media Apps: Mobile Platforms

- Top 10 Social Network Apps worldwide as of April 2016 (based on number of active users)

WhatsApp	1,000,000,000
Messenger (FB)	900,000,000
WeChat	697,000,000
QZone	640,000,000
Instagram	400,000,000
Viber	249,000,000
LINE	215,000,000
SnapChat	200,000,000
YY	122,000,000
BBM	100,000,000

Source: Statista

Social Media use in Clinical Trials

- Twitter
  - @subatomicdoc #CardioOnc #radonc
 - @theNCI National Cancer Institute
  - @US_FDA
  - @Alliance_org

- Facebook
- Blogs

New tools, same rules

- Does social media create a new world, or just new tools?
- You are still responsible for protecting patients and yourself every day
- Your professional reputation is paramount. You are responsible for protecting that professional reputation.

Risks to Consider

- "Trolls"
- "Ragers"
- "Misguided"
- "Unhappy customers"
- "Bots"
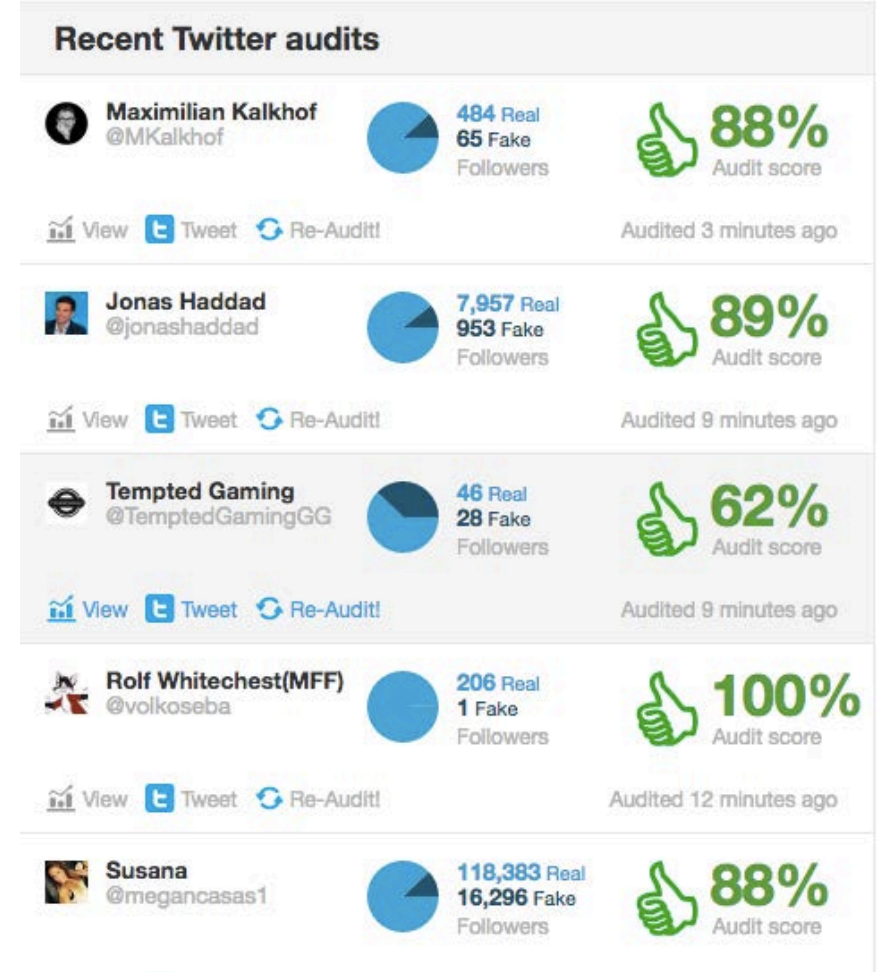
www.twitteraudit.com

- Anyone can complain, question, praise or shame you in a very public way

Mitigations

- Have a response plan in place ahead of time
    - Ohio State University Medical Center has a flow chart that shows how and when they teach people to respond to positive or negative postings online
- Institutional governance and support
    - Engage IRB, Media Department, Privacy & Security Offices
    - How do you plan to interact with individuals who post or comment?
    - Who will monitor posts?
    - You must have a mechanism to protect against HIPAA violations and inappropriate posting

Twitter Security Must-Dos

- Use a strong password that is not re-used anywhere else

- Use log-in verification

- Be cautious of suspicious links and make sure you are on twitter.com before entering credentials

Social Media - Passwords

- Easily guessable or crackable passwords most likely will be hacked on Twitter. Just ask...
  - Mark Zuckerberg
  - Khloe Kardashian
  - Katy Perry #hackersgonnahack

- Consider using a Password Management Tool

Login Verification – 2 Factor Authentication

- Twitter and most (all?) social media sites offer this added layer of security. ENABLE IT!!

We've texted you a login verification code.

Please check your phone with number ending in **92** for a six-digit code and enter it in the box below to sign in.

Enter code

Submit

Security

Login verification

○ Don't verify login requests

● Send login verification requests to ▒▒▒▒▒▒▒

After you log in, Twitter will send a SMS message with a code that you'll need to access your account.

○ Send login verification requests to the Twitter app

Approve requests with one tap when you enroll in login verification on Twitter for iPhone or Twitter for Android. Learn more

You will need to generate a temporary password to log in to your Twitter account on other devices and apps. Learn more

Crowdsourcing

- What is it exactly?
  - Obtaining information, input, or funding for a project or task from a large group of people, typically from an online, networked community
- Relevance in clinical trials?
  - Analogous to patient advocates on disease committees
  - Personal genomics companies such as 23andme have surveyed their genotyped 'crowd' to enable many new discoveries in genetics
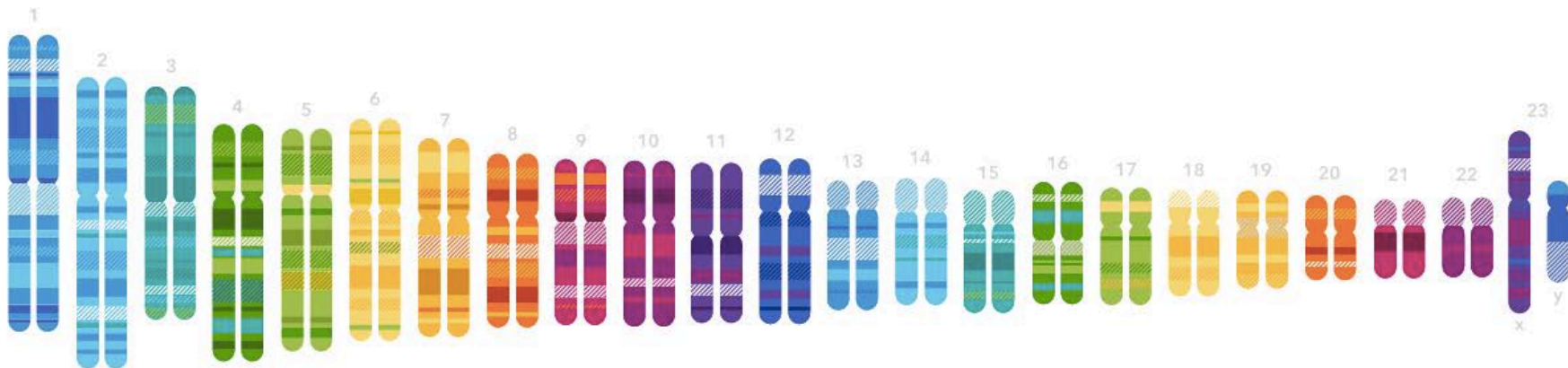
Crowdsourcing ALS Research

- ALS Prediction Prize4Life

- Through a crowdsourced competition, 37 groups from around the world—many with no ALS experience —created tools to better predict how the disease would develop

- $50,000 prize awarded to two teams; their algorithm predicted disease progression better than both a baseline model and clinicians using the same data
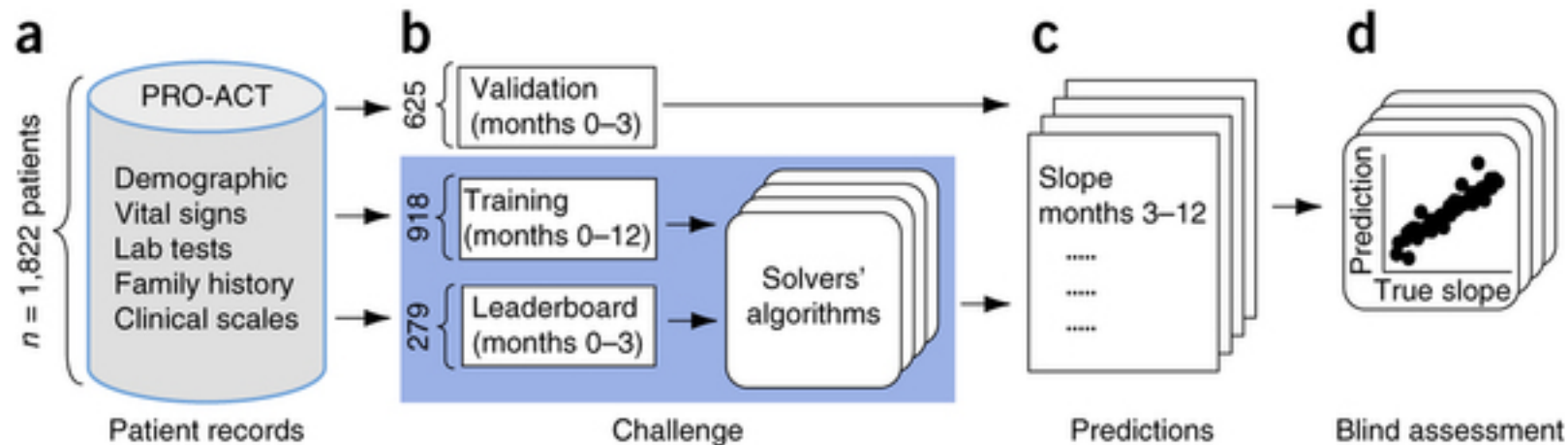
In Summary

1. Social Media outlets are more and more where people turn for information and resources

2. The reluctance on the part of healthcare to engage via social media is understandable, given some of the threats and risks involved such as:
   - Fear of the unknown, loss of control (trolls, bots, and ragers)
   - Each app and site having different security and privacy controls = Complexity
   - Risk of violations of:
     - HIPAA Security or Privacy Rules, State Laws
     - Institutional Policies or Clinical Trial Agreements

3. Proceed carefully, with a cross-functional team approach

Resources

Michael A. Thompson, MD, PhD ,"Social Media in Clinical Trials," 2014 ASCO Educational Book

Natasha Gomer, "Patient Recruitment and Retention via Social is on the Rise" Brandwatch Blog, July 10, 2015

Robert Kuffner et all, "Crowdsourced analysis of clinical trial data to predict amyotrophic lateral sclerosis progression" Nature Biotechnology 33, 51–57 (2015)

Canadian Medical Association, "Social Media and Canadian Physicians: Issues and Rules of Engagement"

Benjamin M. Good, "Crowdsourcing for Bioinformatics" Oxford Univ Press 2013

Statista, "Most famous social network sites worldwide as of Sept 2016" www.statista.com

http://socialmediagovernance.com/policies/ - healthcare social media policy examples

Dominic Chiarelli, "Using Facebook to Improve Recruitment and Retention in Clinical Trials" Quorum Review March 2015

"On the Internet, nobody knows you're a dog."

Thank you

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