When Novel turns Normal: Social media recruitment in an ever-evolving research landscape



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Learning Objectives

- Gain a basic understanding of current national trends related to internet and social media usage
- Identify and apply strategies for the appropriate use of social media for study recruitment
- Discuss ethical considerations surrounding social media for study recruitment





POLL: DO YOU HAVE PERSONAL EXPERIENCE USING SOCIAL MEDIA FOR STUDY RECRUITMENT?

- Yes
- No





POLL: WHAT STRATEGY DOES YOUR INSTITUTION TAKE ON SOCIAL MEDIA RECRUITMENT?

- Centralized
- Do It Yourself
- Hybrid
- Don't know





Statistics and trends related to internet use and social media



Source: http://www.pewinternet.org/fact-sheet/internet-broadband/







Understanding the 7% of US Adults Who are Not Online

- Seniors are the age group most likely to say they will never go online, citing "too old to learn"
- 14% of adults with less than high school education do not use the internet
- Adults making less than \$30k a year are much less likely to go online
- No significant difference in non-internet use when it comes to gender, race and ethnicity, and community type (rural vs urban)
 - Different from years past

Source: https://www.pewresearch.org/fact-tank/2021/04/02/7-of-americans-dont-use-the-internet-who-are-they/



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% of U.S. adults who say they use at least one social media site

Note: Respondents who did not give an answer are not shown.

Source: Surveys of U.S. adults conducted 2005-2021.

Source: http://www.pewinternet.org/fact-sheet/social-media/



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A Few Key Trends

- YouTube and Facebook remain the most popular, widely used social media platforms across demographic groups
 - Larger percent using YouTube; Facebook leads when it comes to frequency of use
 - YouTube is one of the only major platforms with statistically significant growth in use since 2019 (now at 81%)
- Age gaps most noticeable in Instagram, Snapchat & TikTok
 - Adults < 30 more likely to use and with greater frequency
- Some platforms have more significant demographic differences than others

Source: http://www.pewinternet.org/fact-sheet/social-media/



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POLL: WHAT PERCENTAGE OF ADULTS REPORT USING SOCIAL MEDIA?

- 99%
- 93%
- 89%
- 87%





POLL: OTHER THAN FACEBOOK, WHAT IS THE MOST WIDELY-USED SOCIAL MEDIA PLATFORM?

- Instagram
- YouTube
- Twitter
- Snapchat



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Important Considerations When Choosing Whether And How To Use Social Media Strategies

Pros And Cons To Social Media Use In Research & Recruitment

Access to hard-to-reach populations

Fast data collection

Potentially less burdensome on the participant

Can be cost effective

Easy to utilize partnerships and collaborations

Can engage the population early for research question and formative development and for post-study results sharing •Potential privacy concerns/ethical issues

Challenging channels for institutional offices, which can delay start up

Rapidly changing environment

Certain populations will be excluded if this is the only method

Data quality concerns

Requires significant staff time to successfully engage and monitor

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Social Media Content Types: Organic vs. Paid

ORGANIC

- Social media activity without paid promotion (Free)
- Cost-effective for building
 awareness
- Can be used for partnership and engagement opportunities

BOTH

- Education
- Awareness
- Recruitment

PAID

- Social media activity that involves paid advertising (Not free)
- Created with a specific objective (clicks, brand awareness, etc.)
- Greater potential reach

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Don't forget to join CCTA in a few minutes on Twitter for the Twitter Town Hall discussing clinical trials participation by infants and seniors. Follow along at @CCTAwareness.

> Clinical Trials Awareness Week 2018 **Twitter Chat** hosted by @CCTAwareness May 2 at 12 DM ECT #CTAW20

> > ...

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HOLLINGS CROSS TALK

MUSC Hollings Cancer Center plans to go live.

LUNG CANCER **Advancements in Treament and Prevention**

with special quest Dr. Nichole Tanner Hollings pulmonologist & researcher

JOIN US LIVE Nov. 17 at Noon



1h · 🕥

f) @MUSCHollings

Finding Tomorrow's Cure for Cancer Today!

WED, NOV 17 AT 12 PM

Hollings Cross Talk: Lung Cancer

year old. Let me help! I feel a sense of pride and belonging because of this." —Minneapolis, MN

"Giving us HOPE for the future and if not for some of us, for our families." -Scottsdale, AZ



☆ Interested



In case you missed the article in the Fall 2017 Carolina Tails issue... #petslivesmattertoo



Pets & Smoking: The Deadly Secret Lurking in Your Home - Carolina Tails Magazine

Charleston Animal Society is teaming up with researchers at MUSC to help smokers kick the habit! This alliance for "Project Quit" may seem surprising CAROLINATAILS.ORG





GMEC, Project Count Me In. If you are AA and MEC prease think about this most important





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UF Studies Written by Deaven Hough [?] - January 24 at 2:17 PM - 🔇

Men ages 30 – 80 across the U.S. who have been diagnosed with prostate cancer can play an important role in a national study from the University of Florida. Click the link to visit the study website. Compensation provided.



COMPPARE.ORG Study for prostate cancer patients Thank you for your interest in the COMPPARE study....



The MUSC Youth Collaborative offers paid and confidential research opportunities for... See More

...







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Research Study Seeking Participants

South Carolina Clinical & Translational Research Institute ...

Let's get down to business!

IMPLEMENTATION OF SOCIAL MEDIA STRATEGIES

Key To Successful Social Media Strategies: Have A Plan!

- Know your audience
 - Are they online? What social platforms do they use?
- Determine your goals
 - Community education and awareness?
 - Single study? Collection of studies? Long-term promotion/awareness of a lab or study team?
 - Recruitment? Data collection? Online community for participants?
 - Understand your resources
 - Track your success

- Post regularly
- Partner with other large organizations to increase audience
 - Tags, mentions, joint events
 - Provide value don't just ask, but offer
 - Not every post can be an ask- avoid multiple calls to action
 - Provide information, inspiration, and empowerment

Source: Flood-Grady E, Solberg L, Baralt C, Meyer M, Stevens J, Krieger J. Engaging Institutional Stakeholders to Develop and Implement Guidelines for Recruiting Participants in Research Studies Using Social Media: Mixed Methods, Multi-Phase Process/ J Med Internet Res 2021;23(10):e23312. <u>https://www.jmir.org/2021/10/e23312</u>; "The Health Communicator's Guide to Social Media," J. Schindelar, CDC Social Media Team Lead





Key To Successful Social Media Strategies: Create Effective Content!

- Create content that activates your audience
 - Use photos of people
 - Calls to action!
- Be engaging
 - Use language understood and appreciated by your population
 - Give ethically appropriate opportunities for interaction
- Usability
 - Make sure everything is mobile friendly

- Use evidence-based messages
 - Use language that reflects you audience's identities
 - Looking for parents of toddlers for a study on childhood sleep patterns?
 Say so! (keeping sensitivity in mind)
 - Use intrinsic and extrinsic appeals
 - Compensation provided? Free transportation? Potential benefits to participants, the community?

Sources: "The Health Communicator's Guide to Social Media," J. Schindelar, CDC Social Media Team Lead; Flood-Grady E, Hough D, Damiani RE, et al. Communication strategies for designing Facebook advertising campaigns to recruit rural participants to develop healthcare delivery interventions. J Clin Transl Sci. 2020;4(5):398-407. Published 2020 Jan 16. doi:10.1017/cts.2020.5



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Measuring And Tracking Success

Paid advertising campaigns

- Opportunities for systematic data collection and analysis
 - Results, link clicks, impressions, frequency, cost, etc.
- Data breakdown by age and gender
- Evaluate using feasibility query
- Organic content
- Shares, likes, retweets

🖬 🗏 Ads Manager									Search business					
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	Default name - Traffic - Image 4		Active Initial learning complete	T2DM + NAFLD ad set #1 3 active ads	Lowest cost Link Clicks	\$239.00 Lifetime	Jan 22, 2019, 5:04 PM 21 days ago	190 Link Clicks	3,018	4,636	\$0.25 Per Link Click		\$46.78	
	Default name - Traffic - Image 1		Active Initial learning complete	T2DM + NAFLD ad set #1 3 active ads	Lowest cost Link Clicks	\$239.00 Lifetime	Jan 22, 2019, 5:04 PM 21 days ago	963 Link Clicks	6,176	13,404	\$0.12 Per Link Click		\$117.63	
	Default name - Traffic - Image 6		Active Initial learning complete	T2DM + NAFLD ad set #1 3 active ads	Lowest cost Link Clicks	\$239.00 Lifetime	Jan 22, 2019, 5:04 PM 21 days ago	309 Link Clicks	3,191	5,402	\$0.17 Per Link Click		\$52.06	
	Default name - Traffic - Image 3		Inactive	T2DM + NAFLD ad set #1 3 active ads	Lowest cost Link Clicks	\$239.00 Lifetime	Jan 22, 2019, 5:04 PM 21 days ago	13 Link Clicks	272	317	\$0.22 Per Link Click		\$2.85	
			Inactive	T2DM + NAFLD ad set #1 3 active ads	Lowest cost Link Clicks	\$239.00 Lifetime	Jan 22, 2019, 5:04 PM 21 days ago	1 Link Click	61	63	\$0.55 Per Link Click		\$0.55	
	Default name - Traffic - Image 2		Inactive	T2DM + NAFLD ad set #1 3 active ads	Lowest cost Link Clicks	\$239.00 Lifetime	Jan 22, 2019, 5:04 PM 21 days ago	Link Click	38	39	Per Link Click		\$0.36	
· ·	Results from 6 ads 🌖						_	1,476 Link Clicks	7,892 People	23,862 Total	\$0.15 Per Link Click		\$220.23 Total Spent	



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ETHICS, SOCIAL MEDIA, AND THE IRB

Ethical Considerations

- SM platforms carry inherent privacy and confidentially risks
 - While platform users have "acknowledged and accepted" those risks when deciding to use it, what responsibility do you still have to consider and limit risk factors as it relates to protocol risk-benefit analysis?
- Due to engagement component to SM platforms, there can be opportunity for interaction between study staff and participants or amongst participants
 - Will this jeopardize scientific integrity of the study?
 - Will it jeopardize safety and privacy of the participants/potential participants?
 - What happens if false information about the study is shared?
- The IRB must evaluate constantly changing SM arena and ethical implications, so it helps to be as clear and upfront as possible when outlining a strategy for using those platforms
 - Know what is and is not required to share and provide examples of how you would handle issues that could arise.

Source: "Ethical Considerations in the use of social media," L. Gelinas, Advarra





Steps to Help Navigate the Ethics of Social Media Recruitment



Assess institutional risks and liabilities for social media recruitment

Social Media and the IRB

- By federal regulation, federal guidance, and institutional policy, the IRB reviews recruitment materials for accuracy and to ensure the content presented is not coercive.
- Social media management plan submitted as part of the study/protocol recruitment plan
 - IRB reviews the following:
 - Content of social media recruitment materials, which includes advertising and post content, process for how study teams will communicate with prospective participants
- Ancillary reviews determined by the IRB as needed.



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BUILDING AN INSTITUTIONAL FOUNDATION FOR SUCCESSFUL SOCIAL MEDIA RECRUITMENT: DIY AND CENTRALIZED APPROACHES



- Establish a workflow for any required institutional approvals
- Provide a variety of resources to streamline both content creation and campaign implementation
 - Subject expert consultations
 - MSAs with third party vendors
 - Templates or staff assistance for visuals
 - Institutional possession of potential required certifications and licenses
- Have an easily accessible information hub to house instructions and resources
- Create communication/feedback opportunities for institutional stakeholders



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A "Centralized" Approach



Source: Flood-Grady E, Solberg L, Baralt C, Meyer M, Stevens J, Krieger J. Engaging Institutional Stakeholders to Develop and Implement Guidelines for Recruiting Participants in Research Studies Using Social Media: Mixed Methods, Multi-Phase Process/ J Med Internet Res 2021;23(10):e23312. <u>https://www.jmir.org/2021/10/e23312</u>



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Workshop Activity Scenario

You are part of a research team developing a recruitment plan for a study examining the efficacy of the HPV vaccine for those who receive it as young adults. The study is recruiting males and females ages 18 to 26 who have not yet received the HPV vaccine and have not been previously diagnosed with HPV. Given the target population of your research, your team has decided that incorporating a social media strategy into the recruitment plan will be important. Here is a list of things you are considering:

- The PI asking some colleagues and community partners (not formally affiliated with the study) to share some of the recruitment messages and marketing materials through their own social channels.
- Using ad manager to set up image ads to appear in the feeds of individuals who match the target population
- Doing an Instagram live with past participants to have them answer questions from the research team about their experience being a part of the study.
- Creating a Tik Tok video promoting the concept of taking charge of your own sexual health and inviting them to learn more about preventing HPV by clicking the link in the profile



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Wrap up

- Learning Objectives
 - Gain a basic understanding of current national trends related to internet and social media usage
 - Identify and apply strategies for the appropriate use of social media for study recruitment
 - Discuss ethical considerations surrounding social media for study recruitment
- Reach out
 - Elizabeth (Biz) Flood Grady, PhD: efloodgrady@ufl.edu
 - Tara Pittman, MA: abbottt@musc.edu



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Resources

- <u>Secretary's Advisory Committee on Human Research Protection</u>, or SACHRP: Considerations and Recommendations Concerning Internet and Human Subjects Research Regulations
 - The purpose of this document is to provide a starting point for the development of FAQs and/or Points to Consider regarding the conduct and review of Internet research
 - This includes the Internet as a tool for research and the internet as a venue or locale of research.
 - An important place to start if you are new to using the internet in your research strategies
- PEW Research Center
- <u>CDC Social Media Tools, Guidelines & Best Practices</u>
- <u>Harvard Catalyst guide, "The use of social media in recruitment to</u> research."



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