

2020 Online KT Conference: Innovative KT Strategies That Work

Hosted by AIR's Center on KTDRR
October 26, 28, and 30, 2020

Center on
**KNOWLEDGE TRANSLATION FOR
DISABILITY & REHABILITATION RESEARCH**

at American Institutes for Research ■



Social Media and Human Participants Research

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Social media as a recruitment mechanism

Recruitment challenges are ethical challenges



- Rates of underenrollment and early study termination are perennially high, leading to waste and participant protection concerns.
- Williams et al., 2015: As of 2013, 12% of all trials on clinicaltrials.gov were terminated early, 57% of those ended early due to insufficient accrual.
- Carlisle et al., 2015: Of all trials registered as closed on clinicaltrials.gov in 2011, over 47,000 subjects participated in underpowered studies.

Empirical background



- An ever-growing body of literature is evaluating social media's effectiveness as recruitment medium across a variety of different contexts.

Empirical background



> For example:

- HIV vaccine trials (Sitar et al., 2009)
- Occipital nerve studies (Goadsby et al., 2013)
- Pediatric cancer research (Akard et al., 2015)
- Depression prevention (Morgan et al., 2013)
- Smoking cessation (Frandsen et al., 2014; Heffner et al., 2013)

> Also among historically hard-to-reach populations

- Gay Latino couples (Martinez et al., 2014)
- Young cancer survivors (Gorman et al., 2014)
- Low-incidence diseases (e.g., spontaneous coronary artery dissection; Tweet et al., 2011)



Ethics and oversight

Two types of recruitment



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- **Passive:** distributing recruitment materials (ads, posters, flyers) with the aim of attracting potential participants to contact the research team for enrollment.
- **Active:** approaching and interacting with specific individuals with the aim of enrolling them in research, usually on the basis of knowledge of characteristics that would make them suitable candidates for particular trials.

Does social media recruitment raise new ethical issues?



- Both passive and active forms of social media engagement have analogies in more traditional off-line recruitment.
 - Posting an ad on Facebook (passive) similar to placing a poster in clinic; tweeting out an ad similar to hanging flyer in a public space.
 - Actively approaching a member of a Facebook patient support group for disease x (active) similar to approaching an in-person hospital support group.

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 - Platforms typically collect data from users and sell it to third parties for marketing purposes.
 - Many people do not understand how to effectively manage privacy settings and fail to grasp when or the extent to which information they share over social media will be publicly available (Boyd, 2010; Madden et al., 2013).
 - Particularly concerning when sensitive health information is at stake.

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 - People have an opportunity to understand the risks (primarily by reading the platform’s “terms of use”) and decide whether to accept.
 - Speaks against a categorical prohibition on using social media as a research recruitment or engagement tool..

Objection



- But we know that people don't read Terms of Use or Privacy Policies!
- It can be difficult for members of the public to really understand the extent of the risks.
- Is consent for social media usage/posts genuinely informed, in the sense that matters ethically?

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 - And perhaps move interactions offline.

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 - The more work to access (create account, etc.), the more private.
 - Importance of transparency in private spaces → Proactive disclosure of research aims/activities.

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 - Review Terms of Use/Privacy Policy for privacy and confidentiality risks. Disclose to participants.

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 - Is there an expectation of privacy? Public versus private online spaces.
 - Is there a moderator?
 - Review Terms of Use/Privacy Policy for privacy and confidentiality risks. Disclose to participants.
 - Know your platform!

Example 1



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- What is problematic about this?
- Posts to the page by interested individuals will be public and thus seen by others, allowing potentially sensitive health information to be inferred about them.

Solution: Instruct interested individuals to call or email or private message the research team.

Example 2



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 - What is problematic about this?
 - Tweets are public. Tweeting trial information at this person calls further attention to what may have been an ill-advised decision to disclose sensitive health information, thereby amplifying the privacy risks. Solution: Use Twitter’s (private) direct message function instead.

Online participant communication



- Social media can facilitate postenrollment communication between research team and study participants as well as among study participants themselves.

Online participant communication



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➤ ***Benefits***

Online participant communication



- Social media can facilitate postenrollment communication between research team and study participants as well as among study participants themselves.

- ***Benefits***
 - Informational, social-emotional benefits for participants
 - Sharing lived experiences and learning from others in similar situations

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 - Jeopardize scientific integrity of study
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- **Risks**
 - Jeopardize scientific integrity of study
 - Risk of unblinding when participants describe experiences
 - Undermine understanding and ongoing informed consent of other participants
 - When participants post false/misleading information

Online participant communication



- Can the risks be mitigated in a way that preserves the benefits of online community for participants?
 - Research community in need of thoughtful and innovative approaches to this problem
 - Some tentative suggestions

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> Potential strategies

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- Ask participants to agree not to use social media during trial participation or not discuss their participation online.

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 - Does it preserve benefits? Is it too heavy-handed, given participant benefits?

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- Ask participants to agree not to use social media during trial participation or not discuss their participation online.
 - Perhaps most justifiable for active patient populations and advocacy groups, rare diseases (= higher social media risk studies).
 - Does it preserve benefits? Is it too heavy-handed, given participant benefits?
 - Enforcement is nearly impossible.

Online participant communication



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- Ask participants to agree not to use social media during trial participation or not discuss their participation online.
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- Actively facilitate and monitor?
 - Researchers may scrape the internet or known public forums for pertinent discussions and intervene as needed.
 - Time-intensive

Online participant communication



> Potential strategies

- Ask participants to agree not to use social media during trial participation or not discuss their participation online.
- Actively facilitate and monitor?
- Might sponsors/sites establish forums connected with the study as a way of both facilitating participant support and monitoring for risky communications?

Online participant communication



> Potential strategies

- Ask participants to agree not to use social media during trial participation or not discuss their participation online.
- Actively facilitate and monitor?
- Might sponsors/sites establish forums connected with the study as a way of both facilitating participant support and monitoring for risky communications?
 - May require some savvy to be adopted by patient groups.

Online participant communication



> Listen to participants.

- What motivates risky posts? Why are people making them?

> Educate participants about the risks.

- Generally and as part of consent process.

> Tailor monitoring plan to situation.

- Higher social media risk trial requires a greater level of monitoring.

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Thank you!

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