**2020 Online KT Conference:**

**Social Media Strategies for Knowledge Translation**

*Social Media in Research: Navigating Ethical Issues*

Luke Gelinas

Originally Recorded on October 28, 2020

YouTube Link: <https://youtu.be/w3aY-_6Jht8>

>> JOANN STARKS: To start things off, we will hear from Dr. Luke Gelinas, of Advarra, a provider of Institutional Review Board IRB and other services.

>> LUKE GELINAS: I am. Hi, everyone, it's great to be here with you all today. I'm really excited about this topic. As Joann said we are going to be discussing ethical and to some extent regulatory issues that arise when using social media in research. I do approach this as someone who is a full time IRB chair and formally trained in ethics so that will probably come through. I'm going to move pretty quick because I have a lot to cover and I want to leave time for discussion later. So, starting off we’re going to focus on social media as it can be used as a recruitment mechanism or recruitment tool. This part of the presentation stems from some work I did a few years back a bunch of colleagues and I at Harvard talking about social media and its potential of a recruitment tool. We were concerned about the fact it was being underutilized, it really wasn’t being utilized. This was back about 2014. We suspected it was due to IRB unfamiliarity with the issues and some ethical uncertainty about what the ethical issues were whether they are new or novel ethical issues that may be challenging.

We thought there were some roadblocks that might be holding up the use of social media in recruitment that we can try to help clear up. I'm happy to share the guidance that resulted from that work.

I want to being with just an observation, which I hope everyone will agree with me on, although it might not be something we are used to thinking. Recruitment challenges in research, I would argue, are really ethical challenges. We know from the empirical literature that rates of under enrollment in research leading to early study termination are high, too high and that leads to a number of ethical concerns, for one, we have a tremendous amount of waste that occurs when studies are began or launched but need to close early due to lack of accrual. You also have participant protection concerns so for the IRB, when we think about risk benefit and whether to approve studies initially. We typically tend to assume the study will produce generalizable and valuable knowledge. That is a lot of what drives the benefit here.

When you have studies that don't actually complete, that under enroll, that are under powered and don't meet the objectives, then the social value they deliver is severely limited or non‑existent. In those cases we’re basically asking participants to enroll in studies and undergo the burdens and risks in research of what turns out to be nothing or turns out to be information of limited value.

I think that is a real ethical concern. There have been some good studies in the past few years to quantify to the extent this which happened. Some of it is striking. The bottom bullet was a study in which the group of researchers clinicaltrials.gov and concluded that studies that closed in 2011 alone over 47,000 subjects participated in underpowered studies. And so, for those 47,000 subjects again it's not clear the risks or burdens they were asked to undertake were justified given these studies didn't meet their end points.

With that background in mind, this is what sparked our initial work on this topic. To what extent could social media help researchers meet recruitment targets and help alleviate some of those ethical concerns that stem from underpowered and early terminated studies?

There is growing body of literature that I am sure you’re aware that social media can in fact be an effective recruitment medium.

Just to give you a quick sense of it Social media has shown to be effective as a recruitment retention mechanism across all sorts of different research studies. I would also note, it’s shown effectiveness as historically vulnerable and underserved and hard to reach populations, there are some real success stories in that regard. That study from 2014 demonstrated that social media can be used as an effective recruitment mechanism to recruit gay Latino couples. Specifically, for young cancer survivors who researchers have historically had trouble tracking longitudinally and continuing to get data from them. Gorman et al showed you can do better if you utilize social media as a way to kind of keep those young cancer survivors engaged and continue to collect data about them.

The last one is a real interesting success story. That is a study from the Mayo clinic published in 2011. Basically, they met their recruitment targets for this rare disease study on spontaneous coronary artery dissection in I think 3 days, so it was an amazingly quick success story when they found they recruited everyone they wanted to in a matter of days using social media as a recruitment tool.

Now I think we have gotten to the point where social media recruitment is ubiquitous and well‑acknowledged as a potentially successful mechanism for recruitment. Ethics and oversight. I think it helps here just to set the stage a little bit. The big question as I suggested earlier when we are thinking about social media and recruitment and aspects of regulatory issues, does social media raise new or novel or in some ways more challenging ethical issues than normal or standard recruitment? The kind of recruitment we are all familiar with.

It can be helpful when trying to think through that question to think about recruitment we are dealing with and distinguish two different types of recruitment. We can start thinking about what we can call passive recruitment. We think of that as distribution of recruitment materials out in the public. So you are placing ads, you are hanging up posters or flyers. You are leaving the research teams contact information on those materials with the hope that members of the public will come into contact with these ads and reach out to the research team to learn more about the study.

In contrast that with what we call active recruitment. This is more targeted recruitment approaches rather than just leave materials out in the public and hope people encounter them and call. This active recruitment occurs when the research team identifies specific individuals or subgroups and actively approaches them with the aim of offering them more information about the study and ultimately enrolling them in research and often this occurs on the basis of the research teams knowledge of certain characteristics that would make the people they reach out to or target, suitable candidates for their trials. So here maybe the classic example is scanning medical records to see which patients at a clinic might be eligible based on their clinical traits as disclosed in those charts and then approaching them for enrollment in a trial.

I think the two different types of recruitment apply across normal non-online recruitment and online recruitment. When you think of either of these forms of recruitment, I would suggest that social media forms of engagement for both of these have strong analogies and more tradition off-line recruitment of the sort we are familiar with.

In many ways posting an ad on Facebook may be similar to placing a poster in a public clinic. Similarly, tweeting out an ad may be similar to hanging a flyer in a public space. You can see the similarities, I hope.

So, targeting in an active sense a member of Facebook page support group for some disease might be similar to approaching someone in a hospital support group or on the basis of their medical records, just as you scan medical records looking for a certain features of a person that might make them eligible for a trial. You may look to Facebook and observe certain behaviors or certain group memberships as a way of identifying which people on Facebook might be eligible and interested in your study.

So, I think that can help. When thinking about social media recruitment, not to be overwhelmed, but to kinda step back and say, in what ways is this similar to recruitment activities that we are already familiar with that will help you get a handle on the ethical issues.

I don't want to suggest that social media recruitment is identical in all regards to non-social media recruitment. What that process can do is help you get acclimated and help you sort out what the actually new or novel or particularly challenging issues are with social media recruitment. In terms of new or novel or unfamiliar or different ethical concerns are the privacy risks.

Social media platforms as we all hopefully know, they themselves carry inherent privacy and confidentiality risks that are going to attach to any recruitment and engagement efforts that take place over them.

So, these platforms typically collect data from our users for marketing purposes. They are basically collecting all the activity this is takes place over these and uses it as marketing for other purposes for different ends.

Another point supported by the empirical literature is that a lot of people using these platforms don't understand how to effectively manage privacy settings. It can be confusing to figure out who you are sharing information with on these platforms. They may further fail to grasp the extent to which the information they share is publicly available.

You probably all know people who share information that maybe they shouldn't on social media. It's not clear they intend to do so rather than they don't have a clear sense of how the privacy settings work. Which is particularly understandable. I'm not sure the last time you looked at Facebook's privacy settings are. It's not straight forward for many people. I think that's particularly concerning when sensitive health information is at stake as it often is in research and research recruitment overture.

So, the word here is just when you engage potential participants on social media because people may not understand the extent to which they communicate or say is going to be publicly available, you might have inadvertent disclosures of protecting sensitive health information which is a significant privacy concern.

So how should we approach these risks and what should we think about them? They are real risks they do warrant our concern. I do think it's possible to be overly paternalistic and too overbearing when we think about these risks. Some people may argue that because of these factors maybe we shouldn't be using social media at all as a recruitment or research tool?

I would argue against this. I think, you know, on the one hand these are risks that have been voluntarily accepted by people when they choose to use the platform. People at least have an opportunity to understand those privacy risks and decide whether they want to accept and join the platform.

I think that these speak against the categorical know or prohibition on using social media as a research recruitment or engagement tool. Especially in light of current events with Cambridge Analytica and all the Facebook and Mark Zuckerberg in the news, I think the public has a pretty good sense that these sites are collecting lots of background data and there are real privacy and confidentiality risks, and it doesn't seem to be deterring members of the public generally using these platforms.

That is an interesting question in itself, but at some point we have to say if the public seems okay with these risks then it may be overbearing for the research communities and IRBs to categorically prohibit the use of social media in recruitment efforts.

I do want to do justice to this objection you may be thinking of. The privacy and confidentiality of these platforms tend to be spelled out, but they are spelled out in highly inaccessible documents. The terms of use of private policies. There is some good empirical evidence indicating one, that these documents are written at a very high level of comprehension. That they are written in legalese essentially. Many people who are not lawyers don't understand half of them. And more importantly too, that very few people actually read them. At the IRB we read them but some days I’m convinced we are the only one who really reads these documents.

It can be difficult for members of the public to really understand the extent of the risks and makes you wonder why the consent to use these platforms is generally informed or whether researchers have additional obligations with respect to privacy risks and confidentiality risks to try to mitigate those risks.

I try to look for a middle road. I think those are legitimate concerns and I think researchers do have more of an obligation at least not to make those risks worse. At least not to amplify them and take steps to mitigate them. What might that look like in practice? If you are a researcher recruiting over these platforms you may have an obligation or at least a best practice to educate individuals a little bit at point of contact about the risk. You might say, hey we are recruiting for this study over Facebook or Instagram or whatever and when you have someone indicate interest on your site, you say there are some privacy concerns with disclosing sensitive information. Would you like to move this discussion offline, give us a call or do this through e‑mail or some other more secure way where privacy risks are less present.

I think an important thing for researchers to consider is the extent to which there is or isn't an expectation of privacy. You can distinguish public online spaces versus private ones. The more than online space is private; the more care should be taken by researchers when recruiting from those spaces. Conversely, if you have a completely public open internet space, then less care is warranted.

It could be hard, and you can probably do a whole lecture on how to distinguish public from private online spaces. One example of a public space is typically taken to be Twitter, although even Twitter has some protective aspects to it from the direct message function and when someone wants to disable the public feature on their account on Twitter they can do so.

But a good example of a public internet space or post might be unrestricted tweet. Something that anyone can access, whether or not you have access to Twitter and so on.

Online space, one example might be let's say a patients like me group that requires you to join patients like me and to affirm you have let's say breast cancer or some other condition or a care giver to such a person.

Basically, the more work I think you need do to access a space if you need to create an account, you need to affirm you have certain characteristics, the more private it is. The more private it is the more care should be taken when researchers approach those spaces. I'll talk about that in a moment.

One way for that care to be taken is for researchers to be highly transparent when they enter those private spaces. I don't think researchers should be deceiving or falsifying traits in order to gain access to those private spaces. If there’s a patient support group just for breast cancer survivors, I don’t think researchers who aren't breast cancer survivors should be saying that they are to access those spaces. They shouldn't be lying or deceitful.

More generally, the more sensitive and private these spaces are the more researchers should be proactively disclosing their presence on these spaces. They shouldn't be lurking or creeping around these spaces. They should say hey I'm a part of your group, I’m a researcher, I have such and such a study. Are you interested in learning more?

Another important thing to keep in mind ‑‑ again, the importance of this will increase as the space gets more private. Is there a moderator? Moderators can be helpful for researchers to ascertain the expectations of a group and to get a sense of how the members themselves see the group. Whether they are open and receptive to research advances or not.

This is probably an IRB point to review the terms of use and privacy policy for privacy and confidentiality risks. This falls mostly on sponsors, researchers and IRBs. If you are an investigator working on these platforms you should be familiar with those documents and willing to educate participants on their content as I said earlier.

Finally, here is a really important one. Know the details and the technical specs of the platform you are using.

I want to try to illustrate that in a couple ways. So, I want to ask you a couple things here. Let's imagine a principal investigator who wishes to establish an open Facebook page in the sense that anyone at all whose on Facebook can access this page. It's not invite only, it’s not restricted to certain members. It's open to the entire Facebook community. For recruitment purposes and what they plan to do is instruct potential participants to indicate their interest by posting to the page. I hope you can see what can be problematic about this given what we discussed already. Posts to the page by people will be public to the Facebook community and will be seen by others and that would obviously allow others to infer potentially sensitive information about folks who post to this page, which would be ethically concerning.

There is a solution now. And I think that it's probably obvious to many of you. There is nothing wrong with an open Facebook page, but rather than have folks post to that page to indicate interest, you might have them call or e‑mail or private message the research team. It might be best in many of these cases to disable the post ability for comments on this page or if you are not going to disable them, do a good job of reviewing and moderating them.

Here is another example. This one gets at the know your platform point. Imagine a research team encounters the following tweet. Depression medicine not working. Looking for new options. Hashtag depression hashtag clinical trials. Imagine that the research team is struggling to meet their recruitment goals and they want to contact this person by tweeting that trial information at them. This is a little more ethically subtle. What do you think might be problematic about this?

Again, I think people might differ over this. It's a bit more controversial. Remember, tweets are public. So I would suggest and argue that if you were to tweet trial information back at this person, you are going to call further attention to something many of us might think are ill advised decision on that person's part in the first place, to disclose sensitive health information and doing that amplify this privacy risk.

Controversial because it's possible to reply. This person made a public tweet. They accepted the risk of using Twitter and making that tweet. Why I don't think we have any obligation to mitigate the privacy risks.

Again, this is something people can maybe disagree. But we tend to, at least in the IRB world, try to hold researchers to a higher standard here. The thought is maybe one that is sort of common human decency. If you can minimize the privacy risk moving forward, you should.

I think there is an easy way to do that in this case which would be you might just use Twitter private direct message function as well. That itself may have privacy costs. Some might be a little off put that you direct messaged them. I would suggest in this case it might be a less concerning option than using ‑‑ than sending a public tweet back at them. It's important to know what your platform can and can't do and understand the privacy settings as a researchers and an IRB member and to think of creative ways to move the discussion offline away from the privacy risks, educate folks about the privacy risks or use function of the technology that may mitigate those privacy risks to a certain extent.

I want to switch gears in the time remaining and talk about online participant communication. We have been talking a lot about recruitment. But this doesn't have to do directly with recruitment. This set of issues I'm about to discuss may be more relevant for studies that have more online presence. I think this is an important topic and one the research community is pretty concerned about. The issue is this. We know that social media is a great tool for facilitating communication between study participants especially.

It's also used to a lesser extent to facilitate communication between the research team and study participants. I think the benefits here, per participant, are sizable. If you talk to patient and participant advocates about social media and the online communities we are a part of, you won't hear them say and testify to how helpful these communities can be. It may provide informational benefit to folks who may be experiencing or may be involved with research for the first time being in a clinical trial can be unfamiliar and daunting and a difficult experience and just having people you can talk to provide factual information one and two, social emotional support can be really helpful for participants.

Just hearing from others experiences in similar situations might help current participants to learn and really to kind of thrive or do much better in their own situation then they may otherwise do. The issue and the reason we talk about this is because there are also risks. These are in some ways unfortunate the emphasis among the research community has been on the risks of public academic literature. There are a lot of people in literature worrying about the extent of which communication among participant enrolled in studies can jeopardize the scientific integrity of the studies they’re enrolled in. You have a list of blinding and participants describing their experiences. There are some bad actors. There are participants out there who intentionally try to unbind themselves, although for understandable reasons.

There are some participants particularly in phase one research who will try to share their experiences in ways that allow others to gain eligibility criteria to gain entrance to phase one studies when they may not be eligible for them. You have worries about misinformation being spread online in these participant support forums.

There is a sort of number of both risk and benefit. I would like to encourage this community to think about these and spend more time thinking them through. I think we need to find a way to mitigate those risks, which I think are genuine in a way that preserves the benefits for participants. A lot of the proposals and literature are heavy handed. We see currently some attempts made to get participants agree not to go on social media and not to discuss their experiences.

We occasionally see in consent documents asking participants not to go online in these communities due to fear on negative effects on science.

Here are some potential strategies for us to discuss. This is the one I just mentioned. I think it's too heavy handed, essentially. So if you ask participants to not use social media at all, there may be a high social media risk where it's appropriate. I would argue it's almost always too heavy handed. It doesn't preserve the benefits and doesn't give the participants chance to connect with others in ways they may need to. It's going to be impossible unless you have someone sweeping the internet at all times to monitor this it doesn't seem feasible.

Another approach would be to actively facilitate and monitor these forums where this information takes place. I think in itself it's okay. I worry it's time intensive and resource intensive. Again, it may not be a feasible strategy ultimately.

Here is an idea that I think needs to be tried. I would love to see sponsors taking the initiative here in trying to find ways to establish forums, perhaps connected with particular studies and encouraging their participants to join those forums facilitating that interactive participant support. And at the same time, this would allow them, assuming they have someone dedicated to overseeing these sites to monitor them for risky communication.

So rather than having someone to search the whole internet to make sure the trial's integrity isn't being put in jeopardy, this sponsor themselves and establish their own spaces here. They can find a nice way to both facilitate the benefits and mitigate the risks. I think this would require savvy. Patients, especially those who are highly sophisticated online, they don't have to join any sponsor or sites or established forum. They can go anywhere they want on the internet. This has to be a collaborative effort and have to be a buy in among patient groups.

Ultimately, this is my last slide. It's really important on this topic to listen to participants. I don't think we have done enough of that. I don't think that researchers have done enough to put themselves in the shoes of the people or participants.

When we think hard about what actually motivates these risky posts? Why are people making them? As I suggested earlier there may be bad actors for the motive of profit and phase one research because they want to make money or just because they don't care about the science. I think it's more often for understandable reasons that aren't ethically concerning. I can completely understand why someone might want to know whether they are receiving a placebo or active product. I can understand why someone would want to know if that is the case for their child. Especially when there are multiple clinical trial opportunities open to someone. Someone has to choose between clinical trial opportunities. They might be thinking, reasonably so, I would like to know if I'm getting a placebo here, because if I am I would like to move onto the next clinical trial. And if it’s someone with a terminal condition where there’s no accepted treatment I think that’s completely understandable motivation, it’s connected to the 2nd point which is that in many of these cases, I feel the motivations are understandable and they are often based on not a less than full appreciation of the importance of certain aspects of the science, but the importance of blinding and why the placebo might be necessary. I think if the research community makes sympathetic attempts to reach out to participants and really stress the extent to which things like blinding and placebo controls and so on are needed to deliver robust knowledge to advance their cures, there is some real dialogue that can happen and needs to happen there.

Finally, if you are someone who is running a trial, I do encourage you to think about this before you start. You should consider your population, you should consider how savvy they are on social media, and you should have a plan going into it either to monitor or to educate or to do both of these things so that you are not sort of running into unforeseen situations. All right? My time is up. I think that is my last slide. Thank you, everyone. I'm happy to field questions offline if any of you have questions on the presentation or would like to keep the discussion going.