

Using social media for recruitment in cancer prevention and control survey-based research (SMFR Study) 2018-20247

60-day notice comments

Docket ID: CDC-2018-0083

Comment 1:

In our ever-changing world technology is constantly providing new opportunities to improve the world of tomorrow. Utilizing social media in such a way that the CDC proposes will have profound benefits to the research of cancer. I think that this is a great idea and would like to address a few concerns. 1. I do believe this type of process will be effective in gathering data, especially from Gen X and the Millennial age groups. Social media is a huge part of their daily lives and I am sure they will reach their target sample size of 1,000 surveys. To add to this, it would reduce the administrative burden of conducting surveys in previous manners while also allowing the data to be handled completely electronically, saving time and valuable resources. 2. To ensure accuracy, I would urge the CDC to develop or implore a type of verification process as another user submitted. Also, the CDC assumes that the person completing the survey is being honest and is indeed the person that the ads are being targeted towards. It would be beneficial to ensure that these assumptions are correct, if possible. 3. One thing I did not see in the proposal is how the CDC plans to protect the data of the users they are targeting since the ads will be "targeted toward users who like, visit, or search for terms related to cancer and genetic testing". What is being done with the information of these user's search and like history to protect them from hackers?

Response:

Thank you very much for your comment. We appreciate your support for our study. In regards to ages of social media platform users, while we agree that members of Gen X and Millennials are avid social media users, the Pew Center estimates that 64% of those aged 50 to 64, and 37% of Americans over age 65 are social media users. Facebook especially is used by a majority of Americans across a wide range of age groups¹. In regards to verification, we will be verifying IP addresses to ensure that respondents only take the survey once. However, we will not be verifying responses to individual questions. Verification of medical tests, like cancer screening or genetic testing, would require use of medical records, which can be difficult to obtain and present a different challenge to ensure patient privacy. In addition, since we will be comparing our responses to those from a self-reported survey (the National Health Interview Survey), we expect the level of error associated with response to be similar across surveys. In regards to protection, CDC will only be using readily available tools for advertising placement currently offered by social media and internet companies. We will not be saving or collecting any information about those who are shown ads, or why they were shown a particular ad. No data collected by CDC will be from the users social media profile. The platform that will collect survey responses if a user clicks on an ad will have significant safeguards to ensure that their data is protected. In addition, the study itself has obtained a certificate of confidentiality to ensure that responses are kept as confidential and private as possible.

Comment 2:

Thank you for your consideration of our perspective. Analyses of social media use and online recruitment is very timely. Great work in prioritizing this assessment. This projects proposal brought five considerations to mind. I ask that you review these for any opportunities in your current actions: 1) Verification of subjects, just like verification of users in social media, is not to be taken lightly. Because some social media platforms continue to lack concern or regard for user verification, I would advise that you have a system to verify patients for any clinical components of study. Additionally, I would ask that behavioral and social science research questions consider no verification, just as would be done of sampling in various online recruitment currently conducted within the research industry. 2) There has been literature I have come across that hints and/or specifies at online user recruitment for analytics for various research, whether it be imaging, lab or other skilled interpretation. This use of online recruitment is obviously of concern for data integrity, and I ask the CDC to consider this as well when evaluating the entire issue. 3) Recruitment for these studies should be done under

third parties, if possible, so as not to skew recruited patients aware of the project goals. 4) A second consideration to minimize bias would be to open a second sample of under age 40 patients. 5) Comparison data using NCI pools would be of great use, and I suggest partnering for stronger comparative analytics. Thank you for your consideration. Excellent work! Julie Babyar, RN MPH

Response:

Thanks you very much for your comments. We appreciate your support of our research project. Unfortunately, we will not be able to verify clinical services or medical tests that are asked about in the survey (namely cancer screening tests and cancer treatments received). Obtaining this kind of information would require access to medical records, which can be difficult to obtain and present different challenges to ensure patient privacy. We are working with our partners to ensure data integrity. We are verifying IP addresses to ensure that respondents only participate in the study once and do not generate duplicate data. In addition, we are working with the National Opinion Research Center in this data collection activity and they have considerable experience collecting data through online methods. We will be comparing the prevalence of cancer screening tests and other data points of interest to those obtained by the National Health Interview Survey to understand the extent of bias associated with online data collection with social media based recruitment. In regards to age eligibility, all our surveys will allow anyone over age 18 to participate; however, they will only be asked questions of relevance to their age group. For example, women under 40 should not be regularly screened for breast cancer, and will therefore not be asked about their breast cancer screening practices. As previously mentioned we will be comparing our data to those collected by the National Center for Health Statistics.

Comment 3:

CDC will be introducing a new method of survey taking by using social media such as Facebook, Twitter, and Google Ads as a platform. The survey will be about collecting data about cancer prevention. The purpose of this survey is to reduce the use of paper and collect data efficiently from different generation. The survey will be targeting the general population, cancer survivors and those one at high risk. The idea of this proposal will be an effective way for data collection as the current generation uses social media on a daily basis. In addition, doing the survey online, especially using social media, will be a good way to reduce paper and will be beneficial for the environment. However, there might be an issue collecting data from older generation who don't use social media as the younger generation. I would advise the CDC to come up with more effective way of collecting data for geriatric population. One recommendation I would give to CDC to collect data from the geriatric population is give initiatives to administrators such as Nursing Homes to have someone in person to assist them filling out electronic survey.

Response:

Thank you for your comment. We appreciate your support for our study. Questions of age often come up when discussions of social media arise. You are correct that younger generations are more likely to use social media than older generations, however, that gap is starting to shrink. It's estimated that 37% of adults over 65% use social media¹. We agree that our recruitment methods is more likely to leave out older adults. We plan to compare our results, both demographically and in terms of cancer-related outcomes, to data collected from the National Health Interview Survey, a household survey of Americans. These results will provide a clear indication of how much age-related bias there is in studies using social media and the internet for recruitment.

Comment 4:

The idea of using social media as a preventative tool to combat cancer is absolutely fantastic. Nowadays social media is used globally and often is part of our daily routine. According to the Pew Research Center 69% of American adults use some type of social media and 74% of Facebook users report using this media platform daily. In addition, social media is already being used in healthcare in a variety of ways. In particular, social media is used to share information and educate the public on topics like health hazards, information on new technology, flu shots, pre and post operative care information, etc. Social media is also used in the healthcare

setting to compare and improve the quality of services given to the patients. Healthcare organizations are able to differentiate themselves by taking a look at their competitors social media involvement and following the feedback provided by social media interactions. According to the University of Scranton, social media is also used in healthcare to train medical personnel, provide live updates during procedures, and communicate in times of crisis. Therefore what the CDC is currently proposing is just another step in the evolution of healthcare and social media. Because social media is able to reach so many people, this proposal has the potential to save many lives.

Response:

Thank you very much for your comment. We are very appreciative of your support for our work.

Comment 5:

As a student who has had the opportunity to research this proposed rule and the background about the usage of social media in the recruitment of patients, I think it is important to offer my support for such a measure. The opportunities that social media offers people who are dealing with breast cancer in particular in terms of the information that can be gained about the disease through this measure makes it a worthwhile endeavor. The epidemic that is breast cancer in society today needs to be addressed and this would be one potentially significant step in the right direction. Thank you

Response:

Thank you very much for your comment. We are very appreciative of your support for our work.

References:

1. Pew Research Center for Internet and Technology. Social media use in 2018. March 2018.
<<http://www.pewinternet.org/2018/03/01/social-media-use-in-2018/>>