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Consent to be a Research Subject

Social Diffusion in Online Media for Reaching Hidden Communities and Underrepresented Groups

Principal Investigator: Vincent Silenzio, MD, MPH

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Introduction

This letter describes a research study that researchers from the University of Rochester are conducting along with our research partners from the Rochester Institute of Technology, and Drexel University. This study is intended to show that online social networks such as Facebook can be used to assess health. We estimate that approximately 900 people will take part in this study. You will be asked to complete a brief survey. This should take up to five minutes. At the end of the survey, you will have the chance to ask up to three of your friends who you think would be eligible and willing to participate.

Payment

You will receive \$15 in online credit at Amazon.com for completing the survey. You can also earn more Amazon.com credit when you refer friends who complete the survey. You can refer up to three Facebook friends. For each one who completes the survey, you will receive an additional \$15 in Amazon.com credit, up to a total of \$60. When added to the \$15 credit you receive for finishing your own survey, you may receive an overall total of between \$15 and \$60 in credit you can use as you please at the Amazon.com store.

Your participation in this survey is completely voluntary. You are free not to participate or to withdraw at any time, for whatever reason without penalty.

Privacy

All the information we receive from you, including your name and any other identifying information, will be strictly confidential. In order to protect your privacy, your individual responses will not be shared with anyone. Only summarized data that is pooled from all participants will be presented at meetings or in any publications. Information regarding your personal identity will not be used, nor would any information be shared that would make it possible for anyone to identify you or your responses.

We are using a secure online connection to minimize any risk to your privacy from unauthorized parties (e.g. computer hackers). While we are taking steps to prevent it from occurring, you should be aware that there is a small possibility that responses could be viewed by unauthorized parties because your responses are being communicated over the web and stored on a web server. There are no other expected risks to you for helping with this study. There are also no expected benefits for you.

Neither your Facebook Friends nor Facebook itself will know that you are taking this particular survey. However, as part of this survey, you will be asked to add the Facebook application LINCS to your Facebook account. This is the generic name we give to any software we use in [our lab](#) to administer surveys on Facebook. That you have added this app will be known to Facebook, and by default, if any of your Facebook friends are asked to add this application, they may see that you have also done so. You may hide even this information from your friends by [following this link](#), though Facebook still knows you have added the LINCS app.

We will keep what we learn about you private, but we may have to share this information with University of Rochester monitors or the Department of Health and Human Services. While they normally protect the privacy of this information, they may not be required to do so by law. Results of the research may be presented at meetings or in publications, but your name will not be used.

By law, we have to get your authorization to use health information we collect from you. We will use your responses to the survey questions, including your age range, gender, and sexual orientation, to conduct the study. This information may be audited to make sure we are following regulations, policies and study plans.

Your Authorization for this study will not expire unless you tell us you want to cancel it. We will keep your responses to the survey questions indefinitely. However your name and other personal information will be discarded as soon as possible after the conclusion of the study, once all participants have received payment. If you cancel your Authorization, you will be removed from the study.

More Information

For more information or questions about this research you may call Dr. Vincent Silenzio at 585.275.6069. If you have questions, concerns or complaints about your rights as a research subject you may contact, anonymously if you wish, a Human Subjects Protec-

tion Specialist at the University of Rochester Research Subjects Review Board, Box 315, 601 Elmwood Avenue, Rochester, NY 14642-8315, Telephone 1-(585) 276-0005. For long-distance you may call toll-free: 1-(877) 449-4441. You may also call these numbers if you cannot reach the research staff or wish to talk to someone else.

Sincerely yours,

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Laboratory of Interactive Networks and Computational Studies (LINCS)

University of Rochester School of Medicine and Dentistry