

Consent to Participate in the NetHealth Study (Tier 3) (18 years and older)

You are invited to participate in the NetHealth study, a research study on social networks and health. The study is being conducted by Professors David Hachen, Omar Lizardo, Nitesh Chawla and Tijana Milenkovic from the Inter-disciplinary Center for Network Science and Applications (iCeNSA) at the University of Notre Dame, Professors Aaron Striegel and Christian Poellabauer of the Wireless Institute at the University of Notre Dame, and Professor Jessica Payne from the Psychology Department. This study is funded by the National Institutes of Health. We hope to learn more about the formation and evolution of social networks, and how various health related behaviors spread through people's social networks. You were selected to participate in this study because you will be a first year student at Notre Dame. This is a two year study. If you consent to participate in this study, we will ask you to:

1. Install an application of your smart phone, other smart devices such as tablets if you have them, and on your personal computer if you have one. This app will capture information about how you are using the device and whom you are communicating with, *but never any information on the content of your telephone calls, emails, text messages or other forms of communication*. Running this app in the background on a device will not affect the operation of the device or decrease battery life. The information that we will capture will be stored in a secure database and will be restricted to the following items:
 - Communication log data: Date and time of communication event, type of communication (text/voice call/email), incoming or outgoing, duration, identifiers for both sender and receiver. *As noted above, we will capture only instances of communication (to/ from/length) and not the actual content.*
 - Smartphone and smart device status: On/off/charging/idle/active, application and features used (including time/date and location stamp)
 - Physical location including both the location of the smartphone (using cell tower id, router location) and proximate (visible) devices that are nearby the device (via unique Bluetooth device addresses).
2. Configure your phone and personal computer to periodically backup communication log data as described in item #1 from your phone to your personal computer. This information will then be transferred to our secure servers after deleting any information pertaining to the content of text messages.
3. If you have a Fitbit and are enrolled in the study as a Fitbit wearer, we ask that you wear your Fitbit on your wrist while both awake and asleep, and give us access to all data generated by the activity tracker. Data collected from the activity tracker will include physical movement (steps, stairs, distance but not

geographical location) and heart rate that will allow us to measure your calorie burn rates, physical activity levels, and sleep levels and patterns.

4. Complete two (2) online surveys every 3-4 months. These will take 20-30 minutes. One questionnaire will deal with your attitudes, tastes and behaviors, the other with who is in your social network.
5. From time to time, answer short questions that we will push to your smartphone about your tastes, attitudes, moods and activities.
6. "Friend" us on Facebook (there is a unique FB NetHealth Project id) so that we can capture information on who your FB friends are and the posts made by you or to you that appear on your FB news feed. *We will not capture any of the content of your posts or other communication that you make through FB, and we will not use our FB id to make posts or communicate with you.* We will capture information on who made the post, where the post was made, the type of post (e.g., text, picture, link to a website), 'liking' activity, information on who your friends are, the adding and dropping friends, and friend requests.
7. Use an application on your smart phone that we will provide that allows you to record and log various things such as your weight, exercise activity (time and type), food consumed, medications, and how you are feeling.

If you decide to participate in this study you will receive \$20 for signing up, completing this consent form, installing apps on your smart phone, tablet, and computer, and completing two online questionnaires. For each month that you participate in the NetHealth study you will receive up to \$10 for backing up weekly your communication data and using your smart devices with the installed app, and up to \$10 for wearing your Fitbit (if you are enrolled in the study as a Fitbit wearer).

You should be aware of two potential risks associated with participating in this study.

1. Activity tracker skin irritation: While rare, some people experience mild skin irritation resulting from wearing a Fitbit. The irritation is the result of the metal contacts. If you do experience any allergic reaction to the activity tracker during the course of the study, you will be able to withdraw from the study or use another device.
2. Privacy risk: We will be obtaining from your smart devices and online surveys confidential information about you. Therefore we are taking numerous measures to insure the confidentiality of this information, to minimize the privacy risk, and to insure that all data is secure.
 - All potential identifying information such as telephone numbers, e-mail addresses, social network site names, etc. will be (1) encrypted when sent from the phone to our secure servers and (2) anonymized to the greatest extent possible with all participants identified through anonymous numeric identifiers (including all digital IDs such as Facebook name, Twitter handles, e-mail addresses, phone numbers, etc.).

- All data collected through this study will be stored on a secure computer housed at the Notre Dame Center for Research Computing that is only accessible by the principal investigators and their authorized associates.
- At no time will the identity of the participants in this study be revealed.
- You have the right to withdraw from this study at any time and to have all data obtained through your devices destroyed. You also have the right to make your smart phone or other smart device “invisible” at any time, thereby stopping the capture of information while still preserving normal phone functioning. You also have the right to remove the activity tracker at any time.

The major benefit of this study is the valuable information that we will obtain and be able to analyze in order to better understand social networks and how health related behaviors spread through networks. With this information we hope to be able to design better communication systems including wireless systems that will facilitate human interaction within networks and the spread of more healthy behaviors.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential. You may ask at any time to view the data that has been collected through any of your smart devices. Any reporting of results or sharing of data will only be done in an aggregated form (e.g., all Engineering majors) and is subject to all relevant university, state, and federal student privacy regulations.

You the consentor understand that the following conditions apply regarding participation in this study:

1. At any time during or after the study you can request to withdraw from the study. You understand that if you withdraw from the study, the data collected from you through the device will be destroyed if you request that this occur. You also understand that if you withdraw from the study, you will be responsible for returning the activity tracker.
2. The recorded information that is stored in our databases that contains any identifying information will not be broadcast or published in any form without additional consent.
3. Fictitious names or ID numbers will be used in any publications that use the collected data. Data reports and publications will present information only in an aggregated format.
4. All data collected through the devices will be stored on secure computers only accessible by the principal investigators and their authorized associates.
5. All information gathered by the phones will be encrypted during transfer from the phone to our secure database and anonymized to the greatest extent possible while in our databases.
6. You are responsible for the care of your activity tracker (Fitbit).
7. You are responsible for installing our application on your smart devices and insuring that all updates are installed in a timely fashion.

8. You are responsible for periodically backing up communication log data from your smartphone to your personal computer.

Your decision whether or not to participate will not prejudice your future relations with the University of Notre Dame. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without penalty.

If you have any questions or concerns about the research, please feel free to contact , David Hachen (dhachen@nd.edu, 574.631.5745) (co-PI and project manager), Aaron Striegel (striegel@nd.edu, 574.631.6896) (co-PI), Omar Lizardo (omarlizardo@gmail.com, 574.631.1855) (PI), or Christian Poellabauer (cpoellab@nd.edu, 574.631.9131) (co-PI). You can also contact the Office of Research Compliance, 317 Main Building, Notre Dame, Indiana (574.631.1461, compliance@nd.edu) if you have any questions or concerns.

You are making a decision on whether or not to participate. Your signature indicates that you are at least 18 years of age, that you have decided to participate in this study, and that you agree with the information provided above.

Name (Please Print)

Signature

Date

Phone number

Email address

Signature of Investigator

Date