

Parent Consent to Participate in the NetHealth Study (Tiers 1 & 2)
(under 18 years old)

Your son or daughter has been 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 and your child assents (by signing a document similar to this one), we will ask your child to do the following:

1. Install an application of their smart phone, other smart devices such as tablets if they have them, and on their personal computer if they have one. This app will capture information about how they are using the device and whom they are communicating with, *but never any information on the content of their 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 their phone and personal computer to periodically backup communication log data as described in item #1 from their phone to their personal computer. This information will then be transferred to our secure servers after deleting any information pertaining to the content of text messages.
3. Wear a Fitbit Charge HR activity tracker (<https://www.fitbit.com/chargehr>) on their wrist while both awake and asleep, and give us access to all data generated by the activity tracker. We will provide this device to your child at no cost. 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 their 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 their 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 their smartphone about their 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 their FB friends are and the posts made by them or to them that appear on their FB news feed. *We will not capture any of the content of their posts or other communication that they make through FB, and we will not use their FB id to make posts or communicate with them.* 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 their smart phone that we will provide that allows them to record and log various things such as your weight, exercise activity (time and type), food consumed, medications, and how they are feeling.

If you decide to allow your child to participate in this study your child will receive \$50 for signing up, completing this consent form, installing apps on their smart phone, tablet, and computer, completing two online questionnaires prior to arriving at Notre Dame, and agreeing to wear the activity tracker while both awake and asleep. For each month that they participate in the NetHealth study they will receive \$35 for backing up weekly your communication data and using their smart devices with the installed app. They will also receive \$5 for completing each online survey. Towards the end of September we will ask your child to refer up to two of their friends to be in the NetHealth study. They will receive \$5 for each referral that signs up to be in the NetHealth study.

You should be aware of two potential risks associated with your child's participation in this study.

1. Activity tracker skin irritation: While rare, some people experience mild skin irritation resulting from wearing the Fitbit Charge HR. The irritation is the result of the metal contacts. *If your child has any known metal allergies they should notify us via email (nethealth@nd.edu) and we will assess whether they can participate in the study.* If your child does experience any allergic reaction to the activity tracker during the course of the study, they will be able to withdraw from the study or use another device.
2. Privacy risk: We will be obtaining from their smart devices and online surveys confidential information about your child. 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.
- Your child has the right to withdraw from this study at any time and to have all data obtained through your devices destroyed. They also have the right to make their smart phone or other smart device “invisible” at any time, thereby stopping the capture of information while still preserving normal phone functioning. They 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 your child will remain confidential. Your child 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 parent or guardian of the invited student understand that the following conditions apply regarding their participation in this study::

1. At any time during or after the study your child can request to withdraw from the study. You understand that if they withdraw from the study, the data collected from them through the device will be destroyed if your child requests that this occur. You also understand that if they withdraw from the study, they 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. Your child is responsible for the care of the activity tracker that we will supply and for returning it to us at the end of the study.
7. Your child is responsible for installing our application on their smart devices and insuring that all updates are installed in a timely fashion.
8. Your child is responsible for periodically backing up communication log data from their smartphone to their personal computer.

Your decision whether or not to allow your child to participate will not prejudice you or your child's future relations with the University of Notre Dame. If you decide to allow your child to participate, your child is free to withdraw their assent 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 allow you child to participate in the NetHealth study. Your signature indicates that you have decided to allow your child participate in this study, and that you agree with the information provided above.

Name (Please Print)

Signature

Date

Child's name

Phone number

Email address

Signature of Investigator

Date