Understanding Sharing Preferences and Behavior for mHealth Devices

Aarathi Prasad, Jacob Sorber, Timothy Stablein, Denise Anthony and David Kotz

WPES ’12
Mobile health (mHealth)

- Mobile computing technologies for healthcare.

Courtesy: http://sarahcait.blogspot.com/

Courtesy: experientia.com

Courtesy: good.is

Courtesy: seniorcarecenter.com

Courtesy: sana.mit.edu
mHealth architecture

- Patient-centric technologies

Electronic/personal health record (Server)

Sharing partners (Client)

User

Courtesy: http://medicallink.com

Courtesy: http://hhs.state.ne.us

Courtesy: cnet.com

Courtesy: http://ironmantriathlontips.com

Courtesy: http://hhs.state.ne.us
Benefits and privacy

• Users might not use mHealth device if they are not comfortable with collection and sharing
Prior work

- **Focus group, surveys, interviews**
  - Participants were given hypothetical scenarios
  - They had opportunity to collect information, not share
  - They were assumed to have usage experience

- **Stated privacy preferences differ from actual sharing behavior** (Connelly et al., Jensen et al.)
User study

- Participants use a real mHealth device
- They collect their own health information
- They share with real people
User study design - questions

- Was personal or sensed information shared more or less frequently?
- Do sharing decisions differ across types of sharing partners (friends, family, third parties or public)?
- Does sharing behavior change over time?
Participants (n=41)

Sample size

<table>
<thead>
<tr>
<th></th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Students</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
During the study, we continuously collected steps, calories burned and sleep information using the Fitbit.

At the beginning of the study, we collected age, gender, academic major, height, weight, self-reported weekly activity level and health goals, collectively called...
Information collection and sharing

Day: 1 2 3 4 5

Collect data using Fitbit

Sharing data family, friends and others
The participants received mails everyday during the five-day period of the study. From the third day of the study onwards, these mails explained who was receiving their activity information and personal characteristics and what sharing settings they had chosen for each information type for each sharing partner.

The webpage had different views of the same information. The default view was the view for the participant, as shown in Figure 1. There was one view corresponding to each sharing partner. Figure 2 shows the view for “Mom”. On these views, the participant could decide what information she wanted to share with her sharing partner, make changes with the click of a button and observe exactly what her sharing partner will be able to see.

To understand how participants would share their fitness information with third-party organizations and groups, we sent mails to the participants on behalf of 6 different organizations and groups. This mail explained who the group was and why they needed the data; see Figure 12 in 25.
Appendix C. The groups represented college students, research labs, government agencies, engineering companies, wellness institutes and pharmaceutical companies. These requests were sent in random order to the participants during the last three days of the study (three on the third day, one on the fourth and two on the last day). The participants received the mails at the same time, but parties requesting the data were chosen randomly. We did not share the participants’ data with any third-party organizations, but crafted the messages to be believable hoping that the participants would act as if actually sharing.

We logged the participants’ activity on the website to monitor their activity: when they logged in, when they looked at their view or the view of the others with whom they are sharing their data, and when they changed the sharing settings. We conducted interviews at the end of the study, for the questions, see Section C.2 in Appendix C, where we asked the participants several questions: whether they ever took off the device to hide any information, if they ever changed the sharing settings, etc.
Third party and public sharing

Using Fitbit

Third-party requests

Sharing with family, friends, third parties and public
Thanks again for participating in our study. Below is a request for your data sent on behalf of ML_Stude...

A group of students taking a machine-learning class in Harvard University, want access to your Fitbit data for their class project. The table below summarizes what you will be sharing with them based on your current settings.

They have also requested for your email address so that they can contact you if they need more information. This data will be shared with them at 11:59pm tonight.

Do you wish to change this sharing setting? Yes No
**Fitness Study** <fit_study@cs.dartmouth.edu> to me

Thanks again for participating in our study. Don’t forget to review your activity data from yesterday! We hope it helps you achieve your personal fitness goals.

Sharing status:

You have shared 5-minute details of steps, shared 5-minute detail of calories and 5-minute detail of sleep with public. Do you wish to change this setting?  
Yes  No

You have shared 5-minute details of steps, shared 5-minute detail of calories and 5-minute detail of sleep with Mom. Do you wish to change this setting?  
Yes  No

You have shared hourly summary of steps, hourly summary of calories and shared daily summary of sleep with Lifestyle. Do you wish to change this setting?  
Yes  No
## Logging and interviews

<table>
<thead>
<tr>
<th>Day</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Using Fitbit</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sharing data</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Logging website usage</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interview</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Analysis

- Logs
- Interviews
Group sharing score

- Average sharing setting for a group of sharing partners for a day and an information type
- Initial group sharing score - score on 2nd day
- Final group sharing score - score on 5th day
- Scores were normalized $0 \leq \text{score} \leq 1$

- Graphs show group sharing score averaged across all participants (error bars show standard deviation)
Questions

• Was personal or sensed information shared more or less frequently?
• Do sharing decisions differ across types of sharing partners (friends, family, third parties or public)
• Does sharing behavior change over time?
Analysis: scores for family

Statistically significant: steps more, weight and goals less than others
Questions

• Was personal or sensed information shared more or less frequently?
• Do sharing decisions differ across types of sharing partners (friends, family, third parties or public)
• Does sharing behavior change over time?
Score analysis: family and friends

Statistically significant difference only for weight

- **Traits**
  - Family Sharing Score
  - Friend Sharing Score

- **Weight**
  - Family Sharing Score
  - Friend Sharing Score

- **Goals**
  - Family Sharing Score
  - Friend Sharing Score
Score analysis: family and public

Statistically significant difference more for weight

Sharing scores

Sleep  |  Traits  |  Weight  |  Goals
---|---|---|---
Family Sharing Score
Public Sharing Score
Analysis: public and third parties

Statistically significant difference for major, weight and goals
Questions

• Was personal or sensed information shared more or less frequently?
• Do sharing decisions differ across types of sharing partners (friends, family, third parties or public)
• Does sharing behavior change over time?
Analysis: scores for family

No statistically significant change

Initial Family Sharing Score
Final Family Sharing Score

Sharing scores

Traits
Weight
Goals
Analysis: scores for friends

Most significant change in weight, least for activity

Initial Friends Sharing Score
Final Friends Sharing Score
Analysis: scores for public

Most significant change for traits and weight

Initial Public Sharing Score
Final Public Sharing Score
Post-study interviews

• What information did they share with others?
• How they shared the information and why?
• How they would share other types of information and why?
Information collected

“Bodily functions, [someone] can't really use that against you, whereas .. some medications people don't want other people finding out that they are taking.”

- Amount

“It was a study and it wasn't very long.”

Courtesy: womenandweight.com
Post-study interviews: findings

Information collected

- Sensitivity
  “They can see every step I take, that was just a little weird”

- Utility
  “I think I hid my weight from almost everybody, except for people who actually needed it for medical purposes.”

Courtesy: womenandweight.com
Post-study interviews: Findings

Sharing partners

“With friends who were less active than me, I would have shared less.”

- Feedback

“If I am sharing with my girlfriends, oh they are like you are heavier than me, lighter than me.”

- Negative experiences

“Everything was monitored by the government.”
Female employee got spam about weight loss

Courtesy: cancerinformation.com
Sharing partners

- Relationships

“Friends [...] are not close enough to share everything with them.”

“[My children] don't need to know.”

“With family members or friends who are interested and people doing research I have no problem. It is just third-party companies [that I wouldn't want to have the data].”
Discussion

- Findings

- Recommendations

- Limitations

Courtesy: weee.eu
Findings

• Traits shared less than sensed information

• Information shared more with strangers than family and friends
  “A bunch of researchers looking at the data, I don't care. But I might think twice about some people I know, depending on who they are.”

• Sharing behavior is dynamic
Recommendations

• Provide flexible controls

The participants received mails everyday during the five-day period of the study. From the third day of the study onwards, these mails explained who was receiving their activity information and personal characteristics and what sharing settings they had chosen for each information type for each sharing partner.

The webpage had different views of the same information. The default view was the view for the participant, as shown in Figure 1. There was one view corresponding to each sharing partner. Figure 2 shows the view for "Mom". On these views, the participant could decide what information she wanted to share with her sharing partner, make changes with the click of a button and observe exactly what her sharing partner will be able to see.

To understand how participants would share their fitness information with third-party organizations and groups, we sent mails to the participants on behalf of 6 different organizations and groups. This mail explained who the group was and why they needed the data; see Figure 12 in
Recommendations

- Reduce gap between information and granular controls
Limitations

Our study could have benefited from
- more sensitive mHealth data,
- a bigger sample size,
- better population sampling and
- longer duration
Summary

• Users might not use the device if they are not comfortable with collection and sharing
• User study to understand willingness to share
• Findings
  - secondary information is more sensitive
  - participants shared more with strangers
  - sharing behavior is dynamic
• Recommendations
  - provide flexible privacy controls
Acknowledgements

• Dartmouth TISH group
• Undergraduate interns
  - Alexandra Della Pia
  - Christina Ma
• Funding sources - NSF, HHS
Understanding Sharing Preferences and Behavior for mHealth Devices

Aarathi Prasad, Jacob Sorber, Timothy Stablein, Denise Anthony and David Kotz

WPES ’12

Institute for Security, Technology, and Society (ISTS) at Dartmouth College