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Appendix A

Additional Materials

E-Mail to potential participants

Subject Line:

Invitation – Media Lab Study on Dealing with Serious Stuff

Body:

Are you or someone in your family dealing with a health or life-threatening condition?

Have you lost a loved one, and are you still coping with bereavement?

Are you dealing with a transition in your life that is causing you extra stress?

We seek participants for a 21-day study centered on an Android application that lets you share your wellness and stories with loved ones. Help us research the use of mobile applications on coping with these issues.

Please email me at joyc@mit.edu for more information.

Warmly,

Joy C. Chen

Affective Computing Group at MIT Media Lab

E-Mail to potential participants, second round.

Subject Line:

Media Lab Study on Dealing with Serious Stuff [up to \$60 for participation]

Body:

Are you or a friend experiencing a particularly serious or difficult period in your life right now?

This can take the form of someone in your families suffering from poor health or a life-threatening condition, bereavement, or it may just be a transition in your life that is causing you extra stress.

We seek participants for a study to better understand how people deal with the serious stuff in their lives and how modern technology is involved.

You (and friends) can help us research the use of mobile applications on coping with these issues. This can be by signing up for an interview and/or using an Android application for up to 21 days.

You can be compensated up to \$60 for your participation.

Please email me at joyc@mit.edu for more information.

Warmly,
Joy C. Chen
Affective Computing Group at MIT Media Lab

Follow up email:

Thank you for your email! I'm pleased to meet you. My name is Joy. Here is some additional information about this study. We will have information sessions on 3/9, 3/11, 3/12 at 4:00 in the Media Lab [rooms TBD]. If you are eligible to participate (see details below), **please RSVP for a session by replying to this email.**

Our Mission:

By making it easier to share our feelings and worries with loved ones, we aim to:

1. Improve day to day feelings of presence and connectedness.
2. Build resilience and cohesion for times when support is critical.

What's involved:

If you would like to help by being a participant, you will be asked to:

1. Attend one of our information sessions.
 - Fill out a questionnaire.
 - Sign consent forms for participation.
2. Chat with me in an individual session.
 - This can be in person or over the phone.
 - You can opt out of this and still participate in the study.
3. Install an app on your Android phone and use it for 21 days.
4. Answer a questionnaire at the end of each week.
5. Have another chat with me at the end.
 - Same conditions as #2

Requirements:

- You are an MIT student
- You own an Android mobile phone
- You are between 18-60 years old

Compensation:

You will be compensated with \$25 at the conclusion of the study, or if you decide to stop at any point, \$1 * days you participated. You will also receive another \$5 at the end of each completed week. If you choose to participate in the interviews at the beginning or end of the study, you will also be compensated \$10 for each. Payment will be at the end of the study.

Lastly, if you are fairly sure you would like to participate, please let me know if you want to schedule an interview time, now, instead of after the info session, so you can have your pick of time slots.

Warmly,

Joy C. Chen

Affective Computing Group at MIT Media Lab

InM Group Introduction

Thank you for coming today to volunteer in the study. Today, I will give you a description of the study, and then ask you to sign some informed consent forms.

My name is Joy. I'm a Masters' student at the MIT Media Lab. My thesis research is in developing technologies for people, specifically those who are dealing with dire situations, such as if someone close to them is suffering from a health or life-threatening situation, or if they are bereaved.

Based on previous research, I've designed an application called InMind. The purpose of this application is to help people keep connected with and moderate communication with their friends and other loved ones. Now, we're running a study to determine how and to what degree InMind can help people manage support and communicate with loved ones.

As part of this study, you will be asked to install and use InMind, as well as invite some of your friends to be a part of your InMind group for three weeks. Whenever your group, including you, reaches a membership of three, the three weeks will begin. From then on, the application will be available on your phone, and you can use it as frequently as you like.

Because this is a research study, there are some things you should know:

1. Everything you do on the application will be saved on the servers here at the Media Lab, and be analyzed as part of the study. For example, we will log when you send messages and who they go to. There is one notable exception. As mentioned on the consent form, for any stories and messages that involve a text body, the text will be encrypted before being pushed to the server, so nobody besides you and the recipient(s) will ever read it.
2. To help me understand your experience, I'd like to interview you twice during the study. The first would be as soon as we can schedule it (if we haven't yet), and the last would be after the conclusion of the study. These can be in person or over the phone. If you would not like to be interviewed for either one, please indicate it on the sheet I'm about to give you.
3. At the end of each week, I will email you a questionnaire for you to fill out.
4. At the end of the study, InMind will stop working, and you'll be asked to remove it from your phone.
5. Also at the end of the study, you will be compensated up to \$60. If you would like to quit the study at any point, for whatever reason, please just let me know. You will be compensated \$1 for each day you were in the study. You will also be paid \$5 for every week of the study you complete, and \$10 for each of the interviews you held with me.

If you have questions, suggestions, or any other thoughts, please email, call, or text me at joyc@mit.edu and (510) 565 – 8416. I welcome feedback of any sort at any time!

Please fill out this opening questionnaire as best as you can. We require that you are over 18 and own a compatible Android phone, but beyond that, you will not be excluded from the study based on any of the information you provide.

Basics:

Name: _____

Age: _____

Sex: Male / Female / Other

Academic major: _____

Class Year: _____

Eligibility:

Do you have an android phone? Y (Android OS Version _____), N

Do you have data plan? Y (unlimited / data limit: _____), N

Interview Interest:

Would you like to take part in an opening interview within the next few days (I will schedule this with you) so that you can tell me about your situation and your interests? Y/N

Would you like to take part in a closing interview at the conclusion of the study so that you can tell me about your experience with the application? (You can change your mind at any point, including any time before or during the interview.) Y/N

Other helpful information:

Living situation

- ☐ Dorm (Which one? _____)
- ☐ Independent Living Group (Which one? _____)
- ☐ Off Campus

How often do you talk with close friends?

☐ a few times a day ☐ a few times a week ☐ a few times a month

How often do you talk with family?

☐ a few times a day ☐ a few times a week ☐ a few times a month

How often do you use your smart phone?

☐ all the time, often ☐ a few minutes a day ☐ less, rarely

On a scale of 1 (Never) to 7 (Almost Always), please rate the following statements.

1. I want to talk to my friends when I am troubled. _____
2. I want to talk to family when I am troubled. _____
3. I feel supported by my friends. _____
4. I feel supported by my family. _____
5. I reach out for support when troubled. _____

On the next page, you will see a 10-item perceived stress scale, please fill it out.

Perceived Stress Scale- 10 Item

Instructions: The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate with a check how often you felt or thought a certain way.

1. In the last month, how often have you been upset because of something that happened unexpectedly?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

2. In the last month, how often have you felt that you were unable to control the important things in your life?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

3. In the last month, how often have you felt nervous and "stressed"?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

5. In the last month, how often have you felt that things were going your way?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

7. In the last month, how often have you been able to control irritations in your life?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

8. In the last month, how often have you felt that you were on top of things?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

9. In the last month, how often have you been angered because of things that were outside of

your control?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

This scale can be found in the following articles:

Cohen, S., Kamarck, T., Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24, 385-396.

Cohen, S., & Williamson, G. (1988). Perceived stress in a probability sample of the United States. In S. Spacapan & S. Oskamp (Eds.), *The social psychology of health: Claremont Symposium on applied social psychology*. Newbury Park, CA: Sage.

Upgrade Your Health and Happiness

Updated February 2007

InM Opening Interview Script

High-level research questions to answer:

1. *What are some common social support needs of individuals dealing with illness or bereavement?*
2. *In what ways do their current social interactions satisfy and fail to satisfy those needs?*
3. *How is technology involved?*

Thank you for taking the time to talk with me today.

During this interview, I will ask you a series of questions. Please take as much time as you would like to answer them. I'm here to listen to you, and answer any questions you have. If you don't want to answer any particular question, just say "let's skip this one" and we'll move on. If you want to end our discussion at any point, please just let me know. There is no penalty and there is nothing wrong with doing this.

Lastly, although this study aims to serve those who are dealing with dire situations, not every question in this interview has to feel dire for you. Please feel free to answer as truthfully and thoroughly as you are comfortable.

Do you have any questions before we start?

Part 1: Background

1. [Repeat back some of the information from the opening questionnaire to verify.]
2. Please tell me about your close family and friends. Who are they and how do you interact?
 - a. How often?
3. Who else do you reach out to for guidance or support?
 - a. How often?

Part 2: Social Support Needs and Communication Topics

1. What is the situation that motivated you to want to participate in this study?
 - a. [empathize as appropriate]
 - b. Please tell me about some of the stressors in your life.
2. [Ask this for each distinct group of people they talk to.] When you talk with [subset of people], what are some topics you most appreciate discussing?
 - a. With what frequency do these topics come up?
 - b. Are there any topics that fail to get communicated, and why?
3. To what degree are you aware of how your friends and family are feeling on any given day?
 - a. To what degree do you think they are aware of how you are?
 - b. If you currently communicate this information, how do you do it, and how often?
 - c. What value do you think this knowledge might have for you or your loved ones, if any?

Part 3: Meeting Needs

1. How do you contact people when you feel like you need support?
 - a. Did it work?
 - b. Why?

Part 4: Technology

1. How comfortable are you with technology, in general?
2. Does technology currently play a role in your support network?
3. What do you use, in the course of an average week?

Part 5: Motivation and Expectations

1. Why did you decide you were interested in participating in this study?
2. What do you hope to get out of this experience?
3. Any final thoughts/questions?

InM - Weekly Questionnaire

During the previous week, how has your health been?

	Very good
	Fairly good
	Neutral
	Fairly bad
	Very bad

During the previous one week, how would you rate your stress level?

	5 (highest stress level)
	4
	3
	2
	1 (lowest stress level)

How was your experience with InMind this week?

What did you feel about the status sharing capability of InMind? When was it useful/not useful, confusing, or frustrating?

What did you feel about the story telling capability of InMind? When was it useful/not useful, confusing, or frustrating?

Is there anything you wish you could do through InMind but could not?

If you have any further comments or questions, please call or email me!

On the following pages you will be asked questions about your experiences regarding communication with your group using InMind.

There are no right or wrong answers; we are interested in your personal opinions and experiences. Do not think about questions for a long time, but try to rely on your first reaction.

Some questions ask you about the experiences of the other members in your group. We are interested in your view on their feelings and experiences, so it is no problem if you are not sure about this. Just try to give the answer that you think is most suitable.

ABC-questionnaire 60-item

Let “the medium” be the InMind application, “contact” be any interaction through InM, and “other” be any/all members of your group.

On a scale of 1 (Strongly Disagree) to 7 (Strongly Agree), please rate the following statements.

If there are potentially different values for different members of your group, feel free to use the extra columns. Otherwise, we will assume the first value applies to the group as a whole. Please inform the questionnaire administrator if you need more columns.

- | | | | |
|---|-------|-------|-------|
| 1. I feel obliged to contact the other. | _____ | _____ | _____ |
| 2. After a contact the other keeps thinking about me for a long time. | _____ | _____ | _____ |
| 3. I find it difficult to infer from a contact how the other is doing. | _____ | _____ | _____ |
| 4. I feel that the contacts with the other take a lot of time. | _____ | _____ | _____ |
| 5. The contacts keep the other informed about important events in my life. | _____ | _____ | _____ |
| 7. The other finds it difficult to stay in touch with me through this medium. | _____ | _____ | _____ |
| 9. If I contact the other, I expect him/her to respond. | _____ | _____ | _____ |
| 10. The other experiences the contacts as an invasion of his/her privacy. | _____ | _____ | _____ |
| 11. The other knows what I feel during a contact. | _____ | _____ | _____ |
| 12. The other can easily avoid a contact if s/he wants to. | _____ | _____ | _____ |

13. The contacts keep me informed about important events in the other's life.	_____	_____	_____
14. I find it easy to keep to myself those things that I don't want to share.	_____	_____	_____
15. I expect the other to contact me regularly.	_____	_____	_____
16. The other hardly invests energy in the contacts.	_____	_____	_____
17. During the day I regularly think back to a contact with the other.	_____	_____	_____
20. This medium helps me to keep contact with the other.	_____	_____	_____
21. The other is disappointed if I don't contact him/her for a long time.	_____	_____	_____
22. I find it difficult to share experiences with the other through this medium.	_____	_____	_____
24. Through our contacts, the other learns more about me than I would like him/her to know.	_____	_____	_____
26. The contacts make me feel involved in the other's life.	_____	_____	_____
27. The other could do some more effort to contact me.	_____	_____	_____
28. Because of the contacts the other can identify with me.	_____	_____	_____
29. If the other contacts me, I feel that I should respond.	_____	_____	_____
30. Aside from our contacts, the other hardly thinks about me.	_____	_____	_____
32. The other expects me to contact him/her regularly.	_____	_____	_____
34. Aside from our contacts, I hardly think about the other	_____	_____	_____
35. The other finds it easy to keep to him/herself those things that s/he doesn't want to share.	_____	_____	_____

- | | | | |
|---|-------|-------|-------|
| 36. I know what the other feels during a contact. | _____ | _____ | _____ |
| 37. Because of the contacts the other knows how I am doing. | _____ | _____ | _____ |
| 38. I hardly invest energy in the contacts. | _____ | _____ | _____ |
| 39. The contacts make the other feel involved in my life. | _____ | _____ | _____ |
| 40. The other feels obliged to contact me. | _____ | _____ | _____ |
| 41. I am disappointed if the other doesn't contact me for a long time. | _____ | _____ | _____ |
| 43. The other finds it difficult to share experiences with me through this medium. | _____ | _____ | _____ |
| 45. After a contact I keep thinking about the other for a long time. | _____ | _____ | _____ |
| 46. The other feels that the contacts with me take a lot of time. | _____ | _____ | _____ |
| 47. I find it difficult to stay in touch with the other through this medium. | _____ | _____ | _____ |
| 48. Through our contacts, I learn more about the other than s/he would like me to know. | _____ | _____ | _____ |
| 49. Because of the contacts I can identify with the other. | _____ | _____ | _____ |
| 50. If I contact the other, s/he feels that s/he should respond. | _____ | _____ | _____ |
| 51. If the other contacts me, s/he expects me to respond. | _____ | _____ | _____ |
| 53. I experience the contacts as an invasion of my privacy. | _____ | _____ | _____ |
| 54. The other finds it difficult to infer from a contact how I am doing. | _____ | _____ | _____ |
| 56. During the day the other regularly thinks back to a contact with me. | _____ | _____ | _____ |

57. I could do some more effort to contact the other. _____
58. I can easily avoid a contact if I want to. _____
59. Because of the contacts I know how the other is doing. _____
60. This medium helps the other to keep contact with me. _____

InM Closing Interview Script

High level research questions to answer:

1. *How did InM fit into their existing support network and methods?*
2. *What were the perceived costs and benefits of integrating InM into daily life?*

Thank you for taking the time to talk with me today.

During this interview, I will ask you a series of questions. If you don't want to answer any particular question, just say "let's skip this one" and we'll move on. If you want to end our discussion at any point, please just let me know.

Do you have any questions? Let's begin.

Part 1: Background

1. [Repeat back some of the information from the weekly questionnaires to verify and give them a chance to reflect.]
2. Thinking back on the last three weeks:
 - a. What was your experience with InMind?
 - b. What were some good experiences you had with InMind?
 - c. What were some bad experiences or annoyances you faced?

Part 2: Social Support Needs and Communication Topics

1. How have the stressors in your life changed since the beginning of the study?
2. What were some of the topics that were helpful to discuss over InMind?

Part 3: Meeting Needs

1. Did you use InMind when you needed support to contact someone?
 - a. If you are comfortable sharing, what were the general circumstances, and how did InMind help or hurt?

Part 4: Technology

1. [If not answered in opening interview.] What tools do you normally use to communicate and what is your experience with them? (Texting, email, calendar, video chat, phone calls, etc)
2. Did InMind change the way you used other technologies in your social support network?
 - a. [Ask about individual technologies if mentioned.]

Part 5: Motivation and Expectations

1. How was your experience in this study, overall?
2. Any final thoughts/questions?

System Usability Scale

© Digital Equipment Corporation, 1986.

	Strongly disagree						Strongly agree
1. I think that I would like to use this system frequently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	1	2	3	4	5		
2. I found the system unnecessarily complex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	1	2	3	4	5		
3. I thought the system was easy to use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	1	2	3	4	5		
4. I think that I would need the support of a technical person to be able to use this system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	1	2	3	4	5		
5. I found the various functions in this system were well integrated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	1	2	3	4	5		
6. I thought there was too much inconsistency in this system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	1	2	3	4	5		
7. I would imagine that most people would learn to use this system very quickly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	1	2	3	4	5		
8. I found the system very cumbersome to use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	1	2	3	4	5		
9. I felt very confident using the system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	1	2	3	4	5		
10. I needed to learn a lot of things before I could get going with this system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	1	2	3	4	5		