Patient survey - online appendix

Web information form

Page description:

Page exit logic: Page Logic

IF: Question "Do you want to continue the study?" is one of the following answers ("No, I want

to quit now.") THEN: Jump to page 29 - Thank You!

Sharing patient lifelog data with the primary care team

Investigators' statement

We are asking you to be in a research study. The purpose of this consent form is to give you the information you will need to help you decide whether to be in the study. Please read the form carefully. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When all your questions have been answered, you can decide if you want to be in the study. This process is called "informed consent."

PURPOSE OF THE STUDY

The purpose of the study is to understand how the personally collected health information (i.e. lifelog data) is being, or can be, used in the care offered by medical providers.

STUDY PROCEDURES

During this study, we are going to focus on two common but very different medical problems: (1) obesity/overweight and (2) irritable bowel syndrome (IBS). If you have either one of these conditions (or both), you are eligible to participate in this study. You must also be over 18 years old.

If you choose to participate, we will ask you to fill out some screener questions, which will determine your eligibility to participate in this study. We estimate the screener survey will take approximately 3 minutes to complete. You will not be compensated for completing the screener survey. You will not be compensated if you do not complete the screener questions

or if you are not eligible to participate in the full survey.

If you are eligible, you will be asked to fill out a full survey, which includes questions regarding to your self-tracking behavior and routines, whether and how you shared those self-tracking information to other people and health providers. The full survey might take you approximately 25 minutes.

RISKS, STRESS, OR DISCOMFORT

The risk of this study is minimal. You may experience some stress with being asked about your experience with self-tracking technology. You may also feel that sharing your experience intrudes on your privacy. We discuss these privacy concerns in the *Other Information* section of this consent form.

BENEFITS OF THE STUDY

Although you may not directly benefit from taking part in this research study, the results from this study may improve our understanding of patients' needs and attitudes on sharing self-tracking data, especially with their health providers. This may lead to better designs for future self-tracking technologies such as smartphone applications.

OTHER INFORMATION

Taking part in this study is voluntary. You can end your participation in the study at any time. Your answers are confidential. Your medical provider(s) will not see your answers. We cannot however ensure the confidentiality of any information sent by email. Only designated research members will have access to your personal data, which will be secured using a password-protected computer.

We may want to show portions of this data when we communicate the results of our research. We may share this information at conferences, in university classes, in meetings with companies and individuals with whom we work, and in books or other written forms; if we do so, we will not use any information that can identify you in any reports about this study, such as journal articles or presentations at scientific meetings.

You will be compensated with a \$5 Amazon.com, Starbucks or Target gift card (your choice) after completing the survey. We will need your email in order to send you the gift card. Unless you express interest in participating in future studies, we will delete all stored email addresses after the gift cards have been awarded.

Participant's statement

This study has been explained to me.
Do you want to continue the study? *
Yes, I want to continue the study.
No, I want to quit now.
Screener questions
Page description:
The following screener questions will be used to determine your eligibility to participate in the
full survey. If you are eligible, the system will direct you to the next page to complete the full
survey. You can refuse to answer any of the screener questions for any reason, but please
know that we may not be able to determine your eligibility if we don't have all the information.
You will not be compensated for completing the screener survey. We will not share your
information with anyone who is not a researcher on this study, and if you are not eligible or
don't want to participate in the study, we will not keep any of the information you share by
answering these screener questions.

Page exit logic: Page Logic

IF: (Question "What is your BMI?" #3 is less than "25" AND Question "Have you been diagnosed with irritable bowel syndrome (IBS)?" #4 is one of the following answers ("No"))

THEN: Jump to page 28 - Thank you!

1. What is yo	our gender? *	
O Male		
C Femal	ale	
© Prefer	er not to say	
Other:	r:	

WALIDATION Min = 18 Must be numeric 2. What is your age? *
WALIDATION Must be numeric 3. What is your BMI? * You can calculate your BMI with the BMI calculator
4. Have you been diagnosed with irritable bowel syndrome (IBS)? * C Yes
NoNot sure

Self-tracking history

Page description:

Some people keep a record of information related to their health and wellness. For example, some people record what they eat and how many calories their food contains. Others might keep track of how many steps they walk in a day. Still others record their symptoms or health outcomes, such as weight or bowel movements.

5. Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet? This could also include factors that may be related to your health, such as places to visit. The record could be kept on paper or digitally, such as on a smartphone or your computer.	
© Yes	
No - I have considered but not tried it	
 No - I have never tried it 	
Specific tracking activities	
Page entry logic: This page will show when: Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("Yes")	
Page description: You said that you keep track of some of your health and wellness information. Please tell us which.	
G. I currently track and/or keep a record of (Please check all that apply): * Weight Physical activity (including step count) Bowel movements Stress Abdominal pain Nausea Bloating Lethargy / fatigue Sleep Food intake Heart rate Locations or places visited None of the above Other:	

of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("Yes")
Page description: You indicated you track . We'd like to know more about it.
7. What do you use to track? Please check all that apply.*
A tracking device (e.g., a FitBit, Jawbone, a scale). Which?
☐ A paper diary or journal. Which?
☐ A smartphone app. Which?
☐ An application on a computer or website. Which?
8. Why do you track ? *
Former tracking activity
Page entry logic: This page will show when: Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("Yes")
Page description:

This page will show when: Question "Do you currently keep, or have you ever kept, a record

Page entry logic:

9. I used to track and/or keep a record of this but not anymore (Please check all that apply): *
 Weight Physical activity (including step count) Bowel movements Stress Abdominal pain Nausea Bloating Lethargy / fatigue Sleep Food intake Heart rate Locations or places visited None of the above Other:
Formerly tracked items
Page entry logic: This page will show when: Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("Yes")
Page description: You indicated you used to track. We'd like to know more about it.
10. What did you use to track? Please check all that apply. *
A tracking device (e.g., a FitBit, Jawbone, a scale). Which?
A paper diary or journal. Which?
A smartphone app. Which?
An application on a computer or website. Which?

11. Why did you track?*	
12. Why did you stop tracking?*	
☐ I met my goals ☐ It was not helpful ☐ It helped but it was not worth the effort ☐ I lost or broke the device I used to keep track ☐ Other	of the data
Benefits or Concern for tracking	
Page entry logic: This page will show when: (Question "Do you currently of any of your health or wellness information, such as si #5 is one of the following answers ("Yes") AND (Questi record of (Please check all that apply):" #6 is not one of above") OR Question "I used to track and/or keep a recorded that apply):" #9 is not one of the following answers.	leep, physical activity, weight, or diet?" on "I currently track and/or keep a the following answers ("None of the ord of this but not anymore (Please

Page description:

13. Based on your tracking experience, could you please describe the benefits, if any, you obtained from keeping this record? *
14. What concerns or difficulties did you experience? *
Sharing tracked information
Page entry logic: This page will show when: ((Question "I currently track and/or keep a record of (Please check all that apply):" #6 is not one of the following answers ("None of the above") OR Question "I used to track and/or keep a record of this but not anymore (Please check all that apply):" #9 is not one of the following answers ("None of the above")) AND Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("Yes"))
Page description:

15. Next, we'd like to know if you share or shared your tracked health and wellness data with any of the following groups:

	I never shared with them	They requested to see my data but I declined	I shared with them once	I shared with them a few times per year	I shared with them a few times per month	I shared with them a few times per week	I shared with them on an ongoing basis	N/A
Partner / spouse *	0	O	0	0	0	0	O	0
Immediate family *	0	О	0	0	O	0	О	0
Extended family *	0	O	0	0	0	0	O	О
Close friends *	0	O	0	0	0	0	O	0
Friends *	0	0	0	0	0	0	0	0
Coworkers or classmates	O	O	0	0	0	0	O	0
Teammates	0	0	0	0	0	0	0	0
Personal trainers or coaches *	О	О	О	О	О	О	0	0
Health care providers (such as doctors, nurses, or dietitians) *	С	С	С	С	О	С	С	o
Health insurance provider *	0	О	0	0	0	0	0	С

16. Have you shared your tracked health and wellness data with people other than the groups specified in the previous question? *
C No
C Yes, I also share with:
Sharing experience with Health Care Providers (1/2)
Page entry logic: This page will show when: (Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("Yes") AND Question "Health care providers (such as doctors, nurses, or dietitians)" is one of the following answers ("I shared with them once","I shared with them a few times per year","I shared with them a few times per month","I shared with them a few times per week","I shared with them on an ongoing basis"))
Page description: You indicated you shared data with your Health Care Providers (such as Doctors, Nurses, or Dietitians). Please tell us more.
17. Which health care provider have you shared data with? (Please check all that apply) * Primary care physician Internal medicine physician Gastroenterologist Nurse Medical assistant Dietitian Psychologist Social worker Other

18. What kind of data did you share and who did you share with? *
19. If you did not share any type of data with a health care provider, why not? *

Sharing experience with Health Care Providers (2/2)

Page entry logic:

This page will show when: (Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("Yes") AND Question "Health care providers (such as doctors, nurses, or dietitians)" is one of the following answers ("I shared with them once","I shared with them a few times per year","I shared with them a few times per month","I shared with them a few times per week","I shared with them on an ongoing basis"))

Page description:

You indicated you shared data with your Health Care Providers (such as Doctors, Nurses, or Dietitians). Please tell us more.

PIPING Piped From Question 17. (Which health care provider have you shared data with? (Please check all that apply)) Did you ask your health care provider to review your data or did your health care provider suggest it? *					
I suggested it He/she suggested it I don't recall who suggested it					
20. What were your expectations for sharing the data with your health care provider? *					
21. Did sharing the data with your health care provider meet those expectations? Why or why don't you think so? *					
22. Did you have any concerns about sharing your data? If so, what? *					

23. What could have made your sharing experience better? *
Sharing experience with Health Insurance Provider (1/2)
Page entry logic: This page will show when: (Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("Yes") AND Question "Health insurance provider" is one of the following answers ("I shared with them once","I shared with them a few times per year","I shared with them a few times per month","I shared with them a few times per week","I shared with them on an ongoing basis"))
Page description: You indicated you shared data with your Health Insurance Provider. Please tell us more.
24. Did you ask your health insurance provider to review your data or did your health insurance provider suggest it? *
C I suggested it.
My health insurance provider suggested it.
C I don't recall who suggested it.

25. What data did you share with your health insurance provider? If you did not share, why not? *
26. What were your expectations for sharing the data with your health insurance provider? *

This page will show when: (Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("Yes") AND Question "Health insurance provider" is one of the following answers ("I shared with them once","I shared with them a few times per year","I shared with them a few times per month","I shared with them a few times per week","I shared with them on an ongoing basis"))

Page description:

You indicated you shared data with your Health Insurance Provider. Please tell us more.

27. Did sharing the data with your health insurance provider meet those expectations? Why or why don't you think so? *
28. Did you have any concerns about sharing your data with health insurance provider? If so, what? *
29. What could have made your sharing experience with your health insurance provider better? *
Potential future sharing with your Health Care Providers

This page will show when: (Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("Yes") AND Question "Health care providers (such as doctors, nurses, or dietitians)" is one of the following answers ("I never shared with them"))

Page description:

We are interested in learning more about your interest and concerns about potential sharing health and wellness related data with your Health Care Provider (such as Doctors, Nurses, or Dietitians).

PIPING Piped From Question 6. (I currently track and/or keep a record of (Please check all that apply):)

You said you track some items. What would you share with your health care provider? *

l would			
never share	I would share this with my health	I want my health care	
this	care provider if they asked.	provider to review this	Unsure

PIPING Piped From Question 9. (I used to track and/or keep a record of this but not anymore (Please check all that apply):)

You said you used to track some items. What would you share with your health care provider?

l would			
never share	I would share this with my health	I want my health care	
this	care provider if they asked.	provider to review this	Unsure

- 30. Would you be willing to keep a record of additional data if your health care provider suggested it? *
 - Yes, absolutely
 - O No, never
 - Maybe. It depends on:

31. If you are willing to share, or currently want to share, with your health care provider, who among your health care providers do you want or don't want to share with? why or why not?
32. If you are willing to share, or currently want to share, with your health care provider, what would you hope to gain from it? *
33. What concerns would you have about sharing with your health care provider? *
34. What might reduce those concerns? *

This page will show when: Question "Health care providers (such as doctors, nurses, or dietitians)" is one of the following answers ("They requested to see my data but I declined")	
Page description: You indicated that your Health Care Provider (such as Doctors, Nurses, or Dietitians) requested to see your data but you declined. We would like to know more.	
35. Who asked you to share and what type of data did they ask you to share? *	
36. Why did they ask you to share? *	
37. Why did you decline? *	
Potential future sharing with your Health Insurance Providers	

This page will show when: (Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("Yes") AND Question "Health insurance provider" is one of the following answers ("I never shared with them"))

Page description:

We are interested in learning more about your interest and concerns about potential sharing health and wellness related data with your health insurance provider.

PIPING Piped From Question 6. (I currently track and/or keep a record of (Please check all that apply):)

You said you track some items. What would you share with your health insurance provider? *

I would		I want my health	
never	I would share this with my health	insurance provider to	
share this	insurance provider if they asked.	review this	Unsure

PIPING Piped From Question 9. (I used to track and/or keep a record of this but not anymore (Please check all that apply):)

You said you used to track some items. What would you share with your health insurance provider? *

I would never	I would share this with my health	I want my health insurance provider to	
share this	insurance provider if they asked.	review this	Unsure

Show/hide trigger exists.

38. Does your opinion about sharing tracked health and wellness data with your health insurer differ from your opinions about sharing it with your health provider? *

- No, I don't think there is a difference.
- O Yes.

Hidden unless: Question "Does your opinion about sharing tracked health and wellness data with your health insurer differ from your opinions about sharing it with your health provider?" #38 is one of the following answers ("Yes.") 39. Why do you think there is a difference? *
Potontial future charing with your Health Incurence Providers
Potential future sharing with your Health Insurance Providers
Page entry logic: This page will show when: ((Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("Yes") AND Question "Health insurance provider" is one of the following answers ("I never shared with them")) AND Question "Does your opinion about sharing tracked health and wellness data with your health insurer differ from your opinions about sharing it with your health provider?" #38 is one of the following answers ("Yes."))
Page description:
40. Would you be willing to keep a record of additional data if your health insurance provider suggested it? *
 Yes, absolutely
O No, never
C Maybe. It depends on:

41. If you are willing to share, or currently want to share, with your health insurance provider, what would you hope to benefit? *
42. What concerns would you have about sharing with your health insurance provider? *
43. What might reduce those concerns? *
Reasons for declining sharing with Health Insurance Providers
Page entry logic: This page will show when: Question "Health insurance provider" is one of the following answers ("They requested to see my data but I declined")
Page description: You indicated that your health insurance provider requested to see your data but you declined. We would like to know more.

44. What type of data did they ask you to share? *
45. Why did they ask you to share? *
46. Why did you decline? *
General sharing experience

This page will show when: ((((((((Question "Partner / spouse" is one of the following answers ("I shared with them once","I shared with them a few times per year","I shared with them a few times per month","I shared with them a few times per week","I shared with them on an ongoing basis") OR Question "Immediate family" is one of the following answers ("I shared with them once","I shared with them a few times per year","I shared with them a few times per month","I shared with them a few times per week","I shared with them on an ongoing basis")) OR Question "Extended family" is one of the following answers ("I shared with them once","I shared with them a few times per year","I shared with them a few times per month","I shared with them a few times per week","I shared with them on an ongoing basis")) OR Question "Close friends" is one of the following answers ("I shared with them once","I shared with them a few times per year","I shared with them a few times per month","I shared with them a few times per week", "I shared with them on an ongoing basis")) OR Question "Friends" is one of the following answers ("I shared with them once","I shared with them a few times per year","I shared with them a few times per month","I shared with them a few times per week","I shared with them on an ongoing basis")) OR Question "Coworkers or classmates" is one of the following answers ("I shared with them once","I shared with them a few times per year","I shared with them a few times per month","I shared with them a few times per week","I shared with them on an ongoing basis")) OR Question "Teammates" is one of the following answers ("I shared with them once","I shared with them a few times per year","I shared with them a few times per month","I shared with them a few times per week","I shared with them on an ongoing basis")) OR Question "Have you shared your tracked health and wellness data with people other than the groups specified in the previous question?" #16 Option "Yes, I also share with:") OR Question "Personal trainers or coaches" is one of the following answers ("I shared with them once","I shared with them a few times per year","I shared with them a few times per month","I shared with them a few times per week","I shared with them on an ongoing basis")) AND Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("Yes"))

Page description:

You indicated you have shared the data with people such as partners, friends, family, coworkers, coaches, or teammates. Please tell us more about it.

47. What data did you share and with whom? *
48. What were your expectations for sharing? *
49. Did sharing meet those expectations? Why or why not? *
50. Did you have any concerns about sharing your data? If so, what? *

People who have considered tracking

This page will show when: Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("No - I have considered but not tried it")

Page description:
51. You said that you have considered keeping track of some of your health and wellness information. Please tell us which. *
 Weight Physical activity (including step count) Bowel movements Stress Abdominal pain Nausea Bloating Lethargy / fatigue Sleep Food intake Heart rate Locations or places visited None of the above Other:

Items considered tracking

Page entry logic:

This page will show when: Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("No - I have considered but not tried it")

Page description:	
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52. Why didn't you try to track? (Please check all that apply). *
☐ I thought it might embarrass me ☐ I didn't know how to start ☐ It cost too much money ☐ It took too much time ☐ I didn't see the benefits ☐ I just never got around to it ☐ Other:
53. What, if any, benefits did you hope to get from tracking?*
54. What, if any, concerns did you have about tracking?*
Potential future tracking and sharing

This page will show when: (Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("No - I have considered but not tried it", "No - I have never tried it") OR ((Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("Yes") AND Question "I currently track and/or keep a record of (Please check all that apply):" #6 is one of the following answers ("None of the above")) AND Question "I used to track and/or keep a record of this but not anymore (Please check all that apply):" #9 is one of the following answers ("None of the above")))

Page description:

We are studying the ways that smartphone applications and other tools might help collect health and wellness information, such as your dietary intake, physical activities, symptoms, or mood, for review by your medical team. We'd like to hear you opinions on this.

55. Would you be willing to keep a record of data about your health and wellness if your health care provider requested or suggested it? *
C Yes, absolutely
C No, never
Maybe. It depends on:
56. If you were to track the data, what would you want to gain from sharing it with your health care provider? *

57. If you were to track the data, what concerns would you health care provider? *	u have about sharing it with your
58. What might reduce those concerns? *	

Potential future tracking and sharing

This page will show when: (Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("No - I have considered but not tried it", "No - I have never tried it") OR ((Question "Do you currently keep, or have you ever kept, a record of any of your health or wellness information, such as sleep, physical activity, weight, or diet?" #5 is one of the following answers ("Yes") AND Question "I currently track and/or keep a record of (Please check all that apply):" #6 is one of the following answers ("None of the above")) AND Question "I used to track and/or keep a record of this but not anymore (Please check all that apply):" #9 is one of the following answers ("None of the above")))

Page description:

Next, we'd like to know you opinions about sharing data you collect with your health insurance provider.

Hidden unless: Question "Does your opinion about sharing tracked health and wellness data with your health insurer differ from your opinions about sharing it with your health care provider?" #59 is one of the following answers ("Yes.") 62. If you were to track and share data about your health and wellness with your health insurance provider, how would you hope to benefit? *
Hidden unless: Question "Does your opinion about sharing tracked health and wellness data with your health insurer differ from your opinions about sharing it with your health care provider?" #59 is one of the following answers ("Yes.") 63. If you were to track the data, what concerns, if any, would you have about sharing with your health insurance provider? *
Hidden unless: Question "Does your opinion about sharing tracked health and wellness data with your health insurer differ from your opinions about sharing it with your health care provider?" #59 is one of the following answers ("Yes.") 64. What might reduce those concerns? *

Page description:
 65. Do you own a smartphone like an iPhone, Android or Blackberry? * A smartphone is a mobile phone with more advanced computing capabilities such as web browsing, emailing, photo taking and media playing. Yes No
66. What is your race/ethnicity? (Check all that apply) * White/Caucasian
 67. What is the highest level of education you have completed? * Did not complete high school High School/GED Community College Bachelor's Degree Master's Degree Doctoral (PhD) or Professional Degree (MD, JD)

J

Hidden unless: Question "Are you willing to participate in a future study?" #69 is one of the following answers ("Yes, I would like to participate in both interview and observation study.","Yes, I would like to participate in the interview study only.") Phone: *
MIDIATION %s format expected **LOGIC** Hidden unless: Question "Are you willing to participate in a future study?" #69 is one of the following answers ("Yes, I would like to participate in both interview and observation study.","Yes, I would like to participate in the interview study only.") Email: **
Gift card payment
Page description: To thank you for participating in our study, you are eligible to a \$5 gift card. Please provide your email address and indicate whether you prefer an Amazon gift card, a Starbucks gift card, or a Target gift card. (Unless you express interest in participating in future studies in previous page, your email will be stored separately from your answers above. That means we will not be able to trace your survey answer back to you.)

Gift card type:

- C Amazon.com
- Starbucks
- Target

Thank you!

Page entry logic:

This page will show when: (Question "What is your BMI?" #3 is less than "25" AND Question "Have you been diagnosed with irritable bowel syndrome (IBS)?" #4 is one of the following answers ("No"))

Page description:

Thank you for your time and interest. Unfortunately, your responses indicate that you are not eligible to participate in this study. If you have any questions, please contact [withhold for review]. Please note that we cannot assure the confidentiality of any information sent by email.

Thank You!

Thank you for taking our survey. Your response is very important to us.