

Privacy Care - study questionnaire

I. Background questions: The aim of first 13 questions is to initially map your daily routine to understand information flows and points of (physical and digital) interaction/no interaction. Please answer them individually. This part would last up to 30 minutes.

Q1. Thinking back across the last week, or a typical week, for each day of the week how many times do you leave your home?

Mon	Tue	Wed	Thu	Fri	Sat	Sun

Q2. Thinking back across the last week, or a typical week, for each day of the week how many hours on average, do you use the Internet?

Mon	Tue	Wed	Thu	Fri	Sat	Sun

Q3. Thinking back over the last week, or a typical week, what kind of activities do you do when you go out on each day of the week?

Mon	Tue	Wed	Thu	Fri	Weekend

Q4. Thinking of the activities in question 3, how often do you feel that your privacy or personal safety is at risk? Can you give examples?

☐ Almost always
 ☐ Often
 ☐ Sometimes
 ☐ Seldom
 ☐ Never

Q5. You might be using the Internet for the following purposes. Tick the appropriate boxes based on the amount of usage.

	Very frequently	Frequently	Occasionally	Rarely	Never
a. Entertainment (movies, music)					
b. Educational					
c. Personal finance (banking, stock trading)					
d. Current events (news, sports, weather)					
e. Travel related (research, reservations)					
f. Product information gathering					
g. Online shopping					
h. Communicating with others (chats/email)					

Q6. Typically, how much personal information (Examples: home address, email address, information about family members, credit card number, financial information, health information, whereabouts) do you think you give away while using the Internet for the following purposes?

	Very much	Quite a bit	Some	Very little	None
a. Entertainment (movies, music)					
b. Educational					
c. Personal finance (banking, stock trading)					
d. Current events (news, sports, weather)					
e. Travel related (research, reservations)					
f. Product information gathering					
g. Online shopping					
h. Communicating with others (chats/email)					

Q7. Who do you see or talk to in person (face-to-face) in a typical week and where? Is there any weekly schedule?

Who	Where
<i>Example: Friends</i>	<i>My house, friend's house, bridge club, AgeUK</i>
<input type="checkbox"/> Friends	
<input type="checkbox"/> Close family members	
<input type="checkbox"/> Doctors / Nurses / Medical staff	
<input type="checkbox"/> Official carers	
<input type="checkbox"/> Distant relatives	
<input type="checkbox"/> Acquaintances/Colleagues	
<input type="checkbox"/> Strangers	

Q8. Who do you see or talk to using Internet (e.g. Email, Gtalk, Facebook messenger, Skype, Whatsapp, Facetime) in a typical week? Is there any weekly schedule?

☐ Friends
 ☐ Close family members
 ☐ Doctors
 ☐ Official carers
☐ Distant relatives
 ☐ Acquaintances
 ☐ Strangers

Q9. Thinking about the amount of time you spend with others, you would like to have:

☐ a lot more contact
 ☐ a little more contact
 ☐ my social activity is about right
☐ a little less contact
 ☐ a lot less contact

Q10. You might be using various methods for communication purposes in the physical or digital world. Tick the appropriate boxes based on the amount of usage.

	Very much	Quite a bit	Some	Very little	None
a. Face-to-face					
b. Letters					
c. Voice calls					
d. Video calls					
e. Text messages/ Chats/Social networking sites					
f. Emails					
g. Others					

Q11. What personal information (Examples: home address, email address, information about family members, credit card number, financial information, health information, whereabouts) do you share with people in the following categories?

Who	Type of Personal Information
Friends	
Close family members	
Doctors / Nurses / Medical staff	
Official carers	
Distant relatives	
Acquaintances/Colleagues	
Strangers	

Q12. What methods do you use most for sharing your personal information with people in the following categories?

Who	Face-to-face	Letters	Voice calls	Video calls	Text messages/ Chats/Social networking sites	Emails
Friends						
Close family members						
Doctors / Nurses / Medical staff						
Official carers						
Distant relatives						
Acquaintances / Colleagues						
Strangers						

Q13. Which new technology, have you found most helpful in your life? Which do you find to be the most annoying?

II. Questions related to privacy concerns and mitigation behaviours:

Now that we have talked about some of your routines and experiences, the rest of the questions explore what are your privacy concerns, awareness tendencies and some of the ways in which you deal with them. This part would involve moderated discussions and last up to 1 hour. The following is a preface for the same:

Interviewer: *Privacy is the ability of an individual to control access to themselves or information about themselves. If the person is unable to control it, his privacy could be violated in multiple ways and could make him/her feel very insecure. These violations generally occur in combination with each other during our daily life activities such as using a cash machine, going to the supermarket, visiting the post office, meeting friends or using digital media like a smartphone, laptop, smart watch, home monitoring system, or any other healthcare device.*

*When someone enters your physical personal space against your wishes or awareness, probably making you uncomfortable, it is called **privacy violation in the physical world**. The aim could be to collect your personal information, interact with you (by seeing you or talking to you), or forced intimacy. Examples are eavesdropping, shoulder surfing, stalking or following. See figure 1.*

*When someone tries to (a) access, collect or spread your personal online information, or (b) interact (chat, talk or see) with you over the internet, without your wish or awareness, it is called **privacy violation in the digital world**. Digital devices could collect a lot of your personal data ranging from your locations that you visit, spending habits to health information. It is not trivial to know which of the personal data is being collected at a particular time, who can collect such data, and when this is allowed. See figure 2.*

***** A 10-minute video clipping from the movie: “The Circle (2017)” *****

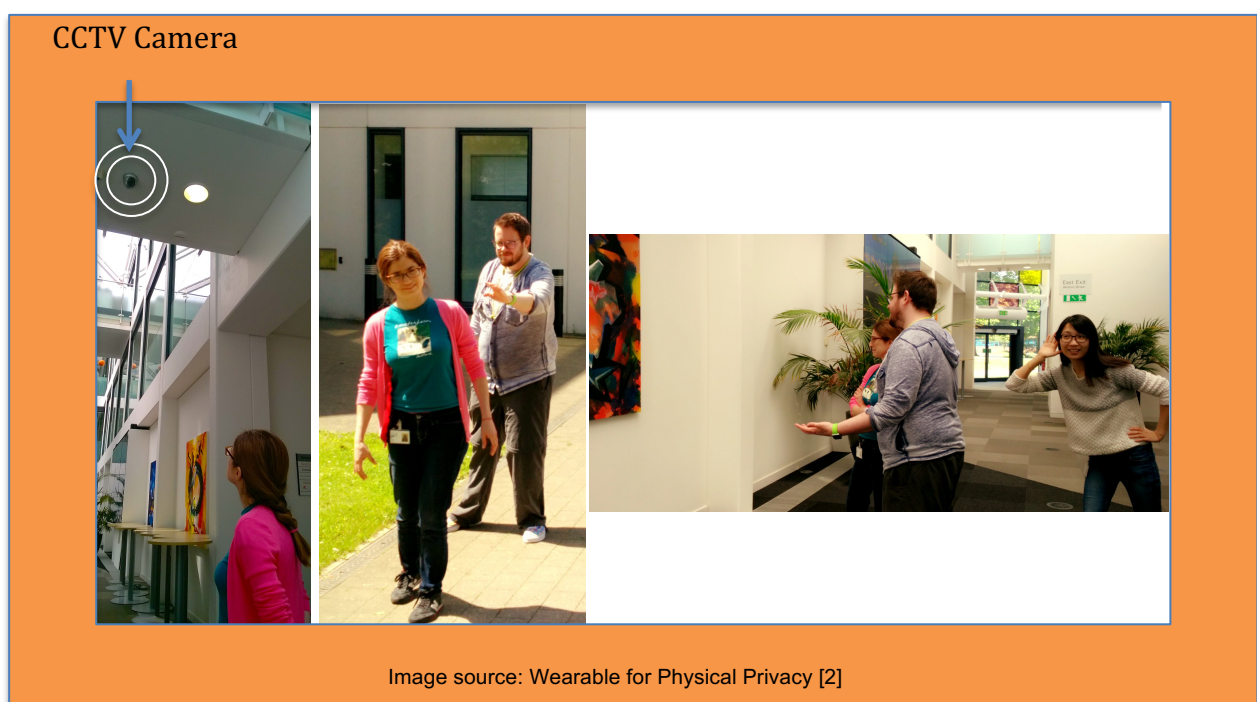


Figure1: Violations in the Physical World



Figure 2: Violations in the Digital World

Q14. How often are you concerned of your overall privacy?

☐ multiple times a day ☐ daily ☐ weekly ☐ monthly ☐ never

Q15. What are your privacy and safety concerns in the physical world? Do they change when you are with different people or in different circumstances: (1) Inside your home, (2) Outside your home?

Q16. What are your privacy and safety concerns in the digital world? Do they change when you are interacting via Internet with different people or in different circumstances: (1) Inside your home, (2) Outside your home?

Q17. Scenario: Lets suppose that we put sensors in your house to help your GP and carers (family, friends) keep track of your health and wellbeing. The sensors in your bedroom sense your heartbeat and sleeping patterns, those in the kitchen record if you have cooked and eaten your food, and remaining sensors track if you have fallen

anywhere inside the house. All such information is shared in real-time with your GP and immediate family members.

Would you like/dislike to have such a system? Why?

Q18. How often you are able to sense if someone is trying to or is about to violate your privacy and personal safety in the physical world? Any examples?

☐ almost always ☐ quite often ☐ sometimes ☐ rarely ☐ never

Q19. How often you are able to sense if someone is trying to or is about to access, collect or distribute your personal data over the Internet? Any examples?

☐ almost always ☐ quite often ☐ sometimes ☐ rarely ☐ never

Q20. What methods do you use to protect your privacy and safety in the physical world?

a. Do you face any particular challenges?

b. Do you use any assistive devices to help you with that?

Examples: There are many behavioural and technical approaches that people opt to protect their privacy [3]. For e.g.: cover your hand while entering ATM pin, maintain a safe distance from strangers in public places, be alert and watch around, express the feeling of violation verbally or non-verbally, report to authorities via SOS, phone or email, interact with strangers if feeling too private/lonely.

Q21. What methods do you use to protect your privacy and safety in the digital world?

a. Do you face any particular challenges?

b. If you use social networking sites such as Facebook, & WhatsApp, smartphones, laptops or wearable health devices, do you know what their privacy settings are? Can you easily change their privacy settings anytime, anywhere? In general, how much time does it take you to do that?

Examples: There are many behavioural and technical approaches that people opt to protect their privacy [3]. For e.g.: not use Internet, limiting online friends network, giving fake information in online forms, pre-set privacy settings in mobile apps and laptop or change the settings now and then depending upon the context.

Interviewer: *Technology could help in increasing a person's awareness about privacy threats and eventually to avoid or tackle the threats as they are happening.*

Q22. Do you want to be aware/notified of privacy threats with the help of some assistive technological device? Should these notifications be about all or some of such threats in real-time?

a. What kind of information you would like to receive?

b. How often do you want to be notified?

☐ every hour ☐ daily ☐ weekly ☐ monthly ☐ never

c. When do you not want to be notified (for example: when visiting supermarket, visiting friends or during the dinner time)?

References:

- [1] J. Barrett and S. Kirk, "Running focus groups with elderly and disabled elderly participants," *Appl. Ergon.*, vol. 31, no. 6, pp. 621–629, 2000.
- [2] V. Mehta, A. K. Bandara, B. A. Price, and B. Nuseibeh, "Wearables for physical privacy," in *UBICOMP/ISWC '16 ADJUNCT*, HEIDELBERG, GERMANY, 2016, pp. 942–945.
- [3] T. Ahmed, R. Hoyle, K. Connelly, D. Crandall, and A. Kapadia, "Privacy Concerns and Behaviors of People with Visual Impairments," presented at the CHI, 2015, pp. 3523–3532.