

Personal Data on Mobile Phones for Public Health

INFORMED CONSENT

This questionnaire is organised by researchers at Open Lab, which is part of the School of Computing at Newcastle University and the questions are designed for the purpose of academic research.

In this research, we are interested in your perspectives on access to medical and wellbeing data on mobile phones. You are being asked to complete a survey about some imagined scenarios about other people, and provide some background demographic data. We are interested in your views and opinions, based on your background and experience.

Participation is voluntary and you can withdraw from the research at any time. Incomplete responses will be deleted before analysis. Information you provide will be used for academic research. All your data will be treated with full confidentiality and, if published, you will not be identifiable. Electronic data will be stored and transferred using encryption at all times.

Since this questionnaire uses scenarios about personal and wider health problems, you could find it upsetting especially if you know anyone recently affected by medical conditions. If you think you may become upset by completing the survey, then you are advised not to participate.

Anonymous data may be shared with researchers running other research studies at Newcastle University and in other organisations such as universities and research departments. This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of research and cannot be used to contact you. It will not be used to make decisions about services available to you.

After the study is completed, we will analyse the results and submit them for publication (typically a scientific journal or conference). Presentations may also be given at scientific conferences. Only group data will be discussed in the findings, so individuals will not be identified. If you would like to find out more about the study, a summary of the findings can be sent to you when the project is completed later in 2020. If you wish to receive this, please add your email address when prompted.

In case of a publication, the data will be manually checked to assure that any potentially identifying information is removed. The fully anonymous data may then be published together with a report. The original survey data will be removed from the secure online storage by 30 March 2021.

If you have any questions about this research, please contact the researcher [REDACTED] ([REDACTED]) before starting the survey. [REDACTED] is based at Open Lab:

Open Lab
Newcastle University
[REDACTED]

Urban Sciences Building
Newcastle Helix
NE4 5TG



To continue to the survey, you must agree that:

1. I confirm I have read the information above and had the opportunity to consider the information and ask questions, and have had any questions answered satisfactorily.
2. I understand my participation is voluntary and am free to withdraw at any time.
3. I understand data from my participation will be subject to anonymous scientific analysis, publication and anonymous data may be shared with other researchers.
4. I am aged 18 or over, and live in the United Kingdom.

* Required

1. Please indicate your agreement to the above statements and consent before proceeding: *

Mark only one oval.

- ☐ I consent, begin the study
- ☐ I do not consent, I do not wish to participate in the study
Skip to section 11 (Do Not Consent)

Prolific ID

2. If you have reached this questionnaire through Prolific, please enter your Prolific ID here: *

Demographics - About You

3. What is your age? (in years)

4. What is your gender identity? *

Mark only one oval.

- ☐ Woman
- ☐ Man
- ☐ Non-binary
- ☐ Prefer not to say

5. Which of the following best describe your current situation (select as many as necessary)?

Check all that apply.

- ☐ Working full time (30 hours a week or more)
- ☐ Working part time (1-29 hours a week)
- ☐ Retired
- ☐ Unemployed
- ☐ Long term sick or disabled
- ☐ In community or military service
- ☐ Undergraduate student
- ☐ Postgraduate student
- ☐ In full time education (not higher degree)
- ☐ In part time education (not higher degree)
- ☐ Doing housework, looking after children or other persons

6. In the last year, have you done any of the following? *

Please note: if you are visiting this questionnaire using a mobile device, you may need to drag the response options left and right in order to see all available options.

Mark only one oval per row.

	No	Yes, only OFF-line	Yes, only ON-line	Yes, both off- line and on-line	Dont know
Contacted a politician, government or local government official (e.g. your MP or a councillor)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Signed a petition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Deliberately bought certain products for political, ethical or environmental reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Found information that helped you form your opinion on a public issue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wrote a letter, comment, or sent an email or message supporting a social or political cause	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7. How would you describe the place where you usually live? *

Mark only one oval.

- ☐ A big city
- ☐ The suburbs or outskirts of a big city
- ☐ A small city or town
- ☐ A country village
- ☐ A farm or home in the country

8. In what country/region of the UK is that? *

Mark only one oval.

- ☐ Scotland
☐ Northern Ireland
☐ Wales
☐ East Midlands
☐ East England
☐ London
☐ North East
☐ North West
☐ South East
☐ South West
☐ West Midlands
☐ Yorkshire and Humberside
☐ Other UK
☐ I do not live in the UK *Skip to section 12 (Inconsistent Screening Responses)*

Demographics - About Your Use of Technology

We need to identify what all questionnaire respondents can do online to determine how this is different to the wider UK adult population. For each item, please select whether you believe you can or cannot do it - select the best matching answer.

9. Can you do each of the following communication tasks? *

Mark only one oval per row.

	I CAN do this	I CANNOT do this
I can communicate using tools like Email, WhatsApp, FaceTime or Messenger	<input type="radio"/>	<input type="radio"/>
I can post on social media platforms e.g. Facebook or Instagram	<input type="radio"/>	<input type="radio"/>
I can keep my emails and social media accounts safe	<input type="radio"/>	<input type="radio"/>

10. Can you do each of the following handling information/content tasks? *

Mark only one oval per row.

	I CAN do this	I CANNOT do this
I can save information find it again from a different computer, tablet or phone	<input type="radio"/>	<input type="radio"/>
I can use the internet to access entertainment legally e.g. Spotify, Netflix or BBC iPlayer	<input type="radio"/>	<input type="radio"/>
I can check if online information is true or false	<input type="radio"/>	<input type="radio"/>

11. Can you do each of the following transactional tasks? *

Mark only one oval per row.

	I CAN do this	I CANNOT do this
I can buy things online and know how to check if a website is safe	<input type="radio"/>	<input type="radio"/>
I can use the internet for online services e.g Universal Credit or uploading passport forms	<input type="radio"/>	<input type="radio"/>
I can use online banking websites and apps	<input type="radio"/>	<input type="radio"/>

12. Can you do each of the following problem solving tasks? *

Mark only one oval per row.

	I CAN do this	I CANNOT do this
I can use online chat to ask for help with a website or app	<input type="radio"/>	<input type="radio"/>
I can use the internet to find out how to do something online	<input type="radio"/>	<input type="radio"/>

13. Can you do each of the following being safe and legal online tasks? *

Mark only one oval per row.

	I CAN do this	I CANNOT do this
I understand the importance of using, changing and not sharing passwords	<input type="radio"/>	<input type="radio"/>
I can recognise suspicious weblinks	<input type="radio"/>	<input type="radio"/>
I understand how to use privacy settings to control what people see	<input type="radio"/>	<input type="radio"/>

14. Would you describe yourself as a person who is concerned about their health?

Mark only one oval.

	1	2	3	4	5	6	7	
not at all concerned	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	very concerned

15. How do you feel about your use of digital devices (such as computers, smartphones, tablets, etc.)? *

Please indicate in how far you agree with each statement by choosing one answer ...

(Please note: if you are visiting this questionnaire using a mobile device, you may need to drag the response options left and right in order to see all available options.)

Mark only one oval per row.

	1 (disagree)	2	3	4	(agree) 5
I feel confident and relaxed working with digital devices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The harder I work at learning how to use digital devices the more confused I get	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have sometimes thought that I am too old to learn about digital devices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have sometimes thought "digital devices don't like me"	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I always have problems working on digital devices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can usually manage to solve problems with digital devices by myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Demographics - About Privacy

Regarding ORGANISATIONS (institutions, public agencies, or intelligence services), how concerned are you about....

16. ... these organisations monitoring your online communication? *

Mark only one oval.

	1	2	3	4	5	6	7	
Not at all concerned	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Very concerned

17. ... not having insight into what these organisations do with your data? *

Mark only one oval.

	1	2	3	4	5	6	7	
Not at all concerned	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Very concerned

18. ... these organisations collecting and analysing the data that you share on the Internet? *

Mark only one oval.

	1	2	3	4	5	6	7	
Not at all concerned	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Very concerned

Regarding OTHER PEOPLE, how concerned are you about...

19. ... other people getting information about you without your consent? *

Mark only one oval.

	1	2	3	4	5	6	7	
Not at all concerned	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Very concerned

20. ... other people finding information about you online? *

Mark only one oval.

	1	2	3	4	5	6	7	
Not at all concerned	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Very concerned

21. ... other people search information spying on you on the Internet? *

Mark only one oval.

	1	2	3	4	5	6	7	
Not at all concerned	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Very concerned

22. ... other people spreading information about you without your knowledge? *

Mark only one oval.

	1	2	3	4	5	6	7	
Not at all concerned	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Very concerned

23. ... other people sharing information about you (e.g. photos, address, contact information, ...) with other people without your consent? *

Mark only one oval.

	1	2	3	4	5	6	7	
Not at all concerned	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Very concerned

24. ... other people publishing information about you (e.g. photos, address, contact information, ...) on the Internet? *

Mark only one oval.

	1	2	3	4	5	6	7	
Not at all concerned	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Very concerned

25. ... people on the Internet not being who they claim to be? *

Mark only one oval.

	1	2	3	4	5	6	7	
Not at all concerned	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Very concerned

26. ... an unknown person claiming to be you on the Internet? *

Mark only one oval.

	1	2	3	4	5	6	7	
Not at all concerned	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Very concerned

27. ... someone misusing your identity on the Internet? *

Mark only one oval.

	1	2	3	4	5	6	7	
Not at all concerned	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Very concerned

Scenario Questions

We will ask you about three scenarios concerning personal data on OTHER PEOPLE's phones. In your responses, please make sure that you DO NOT include any specific information about yourself or others (such as actual names and places from real events).

Scenario 1 - Heart Palpitations

In this scenario, imagine someone else (let's call them Joe) arrives in a UK hospital's accident and emergency (A&E) department with heart palpitations. Joe is an adult. He is conscious and coherent. He has a smartphone and a linked digital sensing device worn on the wrist which measures and logs his heart rate, exercise patterns and location.

Note: Joe is not in a critical condition.

28. What reasons might Joe have for not wanting the NHS to access the phone and/or the data? Please take a little time to write as many different reasons as you can think of. *

29. Why might Joe think the data would not be valid for heart palpitation diagnosis, treatment and/or recovery? Again, try to write as many reasons as possible. *

30. Is validity different for Joe's own heart palpitation treatment and treatment for other people, and why do you think that? *

31. For this scenario, please indicate in how far you agree or disagree with each of the following statements: *

Mark only one oval per row.

	1 (disagree)	2	3	4	(agree) 5
Data on the phone is valid for use in Joe's diagnosis, treatment and/or recovery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Data on the phone will assist Joe's diagnosis, treatment and/or recovery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Data on the phone will assist other people's treatment and/or recovery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If Joe is unconscious or unable to give fully informed consent for some other reason, the NHS should be able to access data on the phone without consent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If Joe is fully informed but refuses permission, the NHS should be able to access data on the phone without consent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is Joe's duty to share all data on the phone in this scenario	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

32. Is there anything else you would like to comment on, such as what data is/is not relevant, or why data may be valid/invalid or useful/useless, or whether a slight change to the scenario would significantly alter your answers?

Scenario 2 - Meningitis

Thinking of a different scenario... Joe arrives in a UK hospital's accident and emergency (A&E) department and Joe is found to have an infectious disease like Meningitis. The medical authorities urgently want to identify and find all potential recent human contacts.
Note: Meningitis is inflammation of the lining around the brain and spinal cord. Although it is only mildly to moderately contagious, it can be very serious and needs to be treated promptly.

33. What reasons might Joe have for not wanting the NHS to access the phone and/or the data? Please take a little time to write as many different reasons as you can think of. *

34. Why might Joe think the data would not be valid for meningitis diagnosis, treatment and/or recovery? Again, try to write as many reasons as possible. *

35. Is validity different for Joe's own meningitis treatment and treatment for other people, and why do you think that? *

36. For this scenario, please indicate in how far you agree or disagree with each of the following statements: *

Mark only one oval per row.

	1 (disagree)	2	3	4	(agree) 5
Data on the phone is valid for use in Joe's diagnosis, treatment and/or recovery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Data on the phone will assist Joe's diagnosis, treatment and/or recovery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Data on the phone will assist other people's treatment and/or recovery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If Joe is unconscious or unable to give fully informed consent for some other reason, the NHS should be able to access data on the phone without consent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If Joe is fully informed but refuses permission, the NHS should be able to access data on the phone without consent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is Joe's duty to share all data on the phone in this scenario	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

37. Is there anything else you would like to comment on, such as what data is/is not relevant, or why data may be valid/invalid or useful/useless, or whether a slight change to the scenario would significantly alter your answers?

Scenario 3 - Influenza Pandemic

Thinking of a different scenario... Joe arrives in a UK hospital's accident and emergency (A&E) department and Joe is found to have been infected by influenza during a worldwide influenza pandemic. The medical authorities urgently want to identify and find all potential recent human contacts.

38. What reasons might Joe have for not wanting the NHS to access the phone and/or the data? Please take a little time to write as many different reasons as you can think of. *

39. Why might Joe think the data would not be valid for influenza diagnosis, treatment and/or recovery in a pandemic situation? Again, try to write as many reasons as possible. *

40. Is validity different for Joe's own influenza treatment and treatment for other people, and why do you think that? *

41. For this scenario, please indicate in how far you agree or disagree with each of the following statements: *

Mark only one oval per row.

	1 (disagree)	2	3	4	(agree) 5
Data on the phone is valid for use in Joe's diagnosis, treatment and/or recovery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Data on the phone will assist Joe's diagnosis, treatment and/or recovery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Data on the phone will assist other people's treatment and/or recovery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If Joe is unconscious or unable to give fully informed consent for some other reason, the NHS should be able to access data on the phone without consent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If Joe is fully informed but refuses permission, the NHS should be able to access data on the phone without consent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is Joe's duty to share all data on the phone in this scenario	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

42. Is there anything else you would like to comment on, such as what data is/is not relevant, or why data may be valid/invalid or useful/useless, or whether a slight change to the scenario would significantly alter your answers?

Coronavirus and Lockdown Situation

The three scenarios are now complete. Now we would like to ask you to reflect on the situation with coronavirus and the resulting lockdown.
If you have any concerns about your mental health or would like further support, please visit www.nhs.uk/coronavirus or call the Samaritans on 116 123.

43. Do you personally know anyone who had Covid-19 (coronavirus)? *

Mark only one oval.

- ☐ Yes, diagnosed and recovered
- ☐ Yes, diagnosed and still ill
- ☐ Not formally diagnosed but suspected
- ☐ No

44. What data on people's phones might be useful to the NHS during corona virus and lockdown? *

45. What would you think if the NHS were able to obtain data from everyone's phones in a certain geographical area of the UK, without requesting consent? *

46. Please indicate in how far you agree or disagree with each of the following statements: *

Mark only one oval per row.

	1 (disagree)	2	3	4	(agree) 5
I am now more concerned about disease prevention	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would now be more willing to share private information for the purpose of controlling the spread of highly contagious diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I think that information that can be gathered from private smartphones can be helpful in controlling the spread of highly contagious diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am worried that information gathered from private digital devices for the purpose of controlling the spread of contagious diseases may be misused	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Skip to section 13 (End of Survey)

Do Not Consent

Sorry, you did not consent to the survey's conditions.

Inconsistent Screening Responses

Sorry, this survey is only for adults aged 18 or over who live in the United Kingdom.

End of Survey

Please complete the following two steps to record your survey response and receive your reward:

1) Visit this Completion URL to complete your submission on Prolific:

2) And, click 'Submit' on this page to record your response.

If you do not complete the second step, we will not receive your data and will be unable to reward you.

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