

PATIENT SURVEY

Can you please spare 10 minutes to let us know your views about how the NHS should manage your health records in our computer age?

Please only take part in this survey once and only if you are over the age of 18.

We are independent university researchers from Imperial College, London. We are working with Chelsea and Westminster Hospital to research public and patient views about the use of computers to store patient records for healthcare and research. We are asking members of the public in Northwest London to tell us about their ideas. We will use the information to help inform what happens in the future.

This survey is about 'Electronic Health Records'. If created, your electronic health record would store everything about your health and the healthcare you receive from your birth until your death. Electronic health records would bring together in one record all of your separate files, whether stored on paper or a computer, in all of the different locations where you get healthcare. There are many arguments for and against electronic health records and we would like to know your views about this.

The NHS has started making electronic 'Summary Care Records' which you may have heard about. These are summaries about your health (e.g. medications and allergies), rather than complete health records like electronic health records. **We are not asking about Summary Care Records.**

This questionnaire will take about 10 minutes.

All information will be kept confidential and your name will not be recorded. We will not be able to link your responses back to you.

If you would like to learn more about the study, please ask a member of our research team.

Thank you for participating in this study.

Professor Derek Bell and Ms Serena Luchenski

PLEASE COMPLETE THIS SECTION BEFORE YOU FILL IN THE QUESTIONNAIRE:

I confirm that I am **over 18** years of age and that this is the **first time** I am filling in this survey. My participation is voluntary and I may choose not to answer some questions or to stop answering the questionnaire at any point without giving a reason. I confirm that I have read and understood the above information.

Please place an X in the most appropriate box.

Yes, I will participate

No, I do not wish to participate

--	--	--	--

o	p	1
---	---	---

First of all, we'd like to know about your experience.

1. Have you ever worked in a job related to healthcare?

No PLEASE SKIP TO QUESTION 2

Yes

If yes, in which jobs? Please *X* all that apply

Provider (e.g. nurse, doctor, etc.)

Researcher (e.g. NHS, university, public health, etc.)

Another job (e.g. GP receptionist, hospital manager, health charity, pharmacist, etc.)

2. Overall, how satisfied are you with the care you have received in the NHS?

Very satisfied Satisfied Neither satisfied or dissatisfied Dissatisfied Very dissatisfied

3. Have you ever participated in a health research study?

No

Yes

4. Have you ever heard anything about 'electronic health records'?

By 'electronic health records' we mean computer records with complete and detailed health information, as described on the cover page of this survey.

No PLEASE SKIP TO QUESTION 3

Yes

If yes, where have you heard about electronic health records before? Please *X* all that apply

The media (e.g. newspaper, radio, television)

The internet (e.g. Wikipedia, Google)

The NHS (GP, NHS letter, NHS website)

Word of mouth (e.g. friend or relative)

Another source

--	--	--	--	--

Next, we would like to know what you think about *electronic health records* .

5. *If your name and address were present, should these groups have access to your 'Complete record', 'Partial record' or Neither record?*

By '**Complete record**' we mean all of your **detailed** health information (e.g. complete health history)

By '**Partial record**' we mean information will be **limited** to a specific purpose (e.g. prescriptions, allergies, etc.)

	Complete Record	Partial Record	Neither Record
Doctors and nurses (e.g. deciding your treatment)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pharmacists (e.g. giving you medicines)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
GP receptionists (e.g. booking appointments)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ambulance and emergency department staff (e.g. responding to an emergency)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health professionals (e.g. physiotherapists)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You (e.g. reading your own record)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. *If there was a national electronic health records system, would you want your record to be part of it for your own healthcare?*

Yes, complete record

Yes, partial record

No

--	--	--	--	--

7. Now thinking about your 'complete record', should these groups have access to your record with your name and address present, removed or not at all ?

	Name & address Present	Name & address Removed	Not at all
NHS managers (e.g. plan health services)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health policy makers (e.g. check drug safety)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. If there was a national electronic health records system, would you want your record to be part of it for *health services planning and policy*?

Yes, name & address present Yes, name & address removed No

9. Again thinking about your 'complete record', should these groups have access to your record with your name and address present, removed or not at all ?

	Name & address Present	Name & address Removed	Not at all
NHS researchers (e.g. healthcare research)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Academic health researchers (e.g. public health research)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health charities (e.g. cancer research)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drug companies (e.g. drug research)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. If there was a national electronic health records system, would you want your record to be part of it for *health research*?

Yes, name & address present Yes, name & address removed No

--	--	--	--

11. If your record was part of a national electronic records system, would you worry about the security of your record?

Yes No

12. Do you think the NHS is presently able to make electronic health records secure?

Yes No

13. How do you feel about the security of electronic health records compared to your current health records ?

Less secure Equally secure More secure

14. Overall, what do you think about the level of possible risks to the security of a national electronic health records system?

Low risks Moderate risks High risks

15. If your record was part of a national electronic records system, would you expect to be asked before your records were accessed for any reason?

	Yes	No
... if your name and address were <u>present</u> ?	<input type="checkbox"/>	<input type="checkbox"/>
... if your name and address were <u>removed</u> ?	<input type="checkbox"/>	<input type="checkbox"/>

16. Overall, are you in favour of the development of a national electronic health records system?

Yes No Undecided

--	--	--	--

People's opinions about electronic health records may depend on how much healthcare they use and why. *Remember we do not have your name or any other details.*

17. Do you have any of the following long term health conditions? *Please X all that apply*

- | | |
|--|--|
| <input type="checkbox"/> No health conditions | <input type="checkbox"/> Alzheimer's disease or other dementia |
| <input type="checkbox"/> High blood pressure | <input type="checkbox"/> Bowel disorder |
| <input type="checkbox"/> Heart disease | <input type="checkbox"/> Epilepsy |
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Problems related to alcohol or drugs |
| <input type="checkbox"/> Chronic bronchitis or emphysema | <input type="checkbox"/> Thyroid condition |
| <input type="checkbox"/> Asthma | <input type="checkbox"/> Urinary incontinence |
| <input type="checkbox"/> Anxiety or depression | <input type="checkbox"/> Sexually transmitted disease |
| <input type="checkbox"/> Back problems and/or arthritis | <input type="checkbox"/> HIV/AIDS |
| <input type="checkbox"/> Fibromyalgia | <input type="checkbox"/> Cataracts |
| <input type="checkbox"/> Migraine headaches | <input type="checkbox"/> Glaucoma |
| <input type="checkbox"/> Effects of stroke | <input type="checkbox"/> Other <input type="text"/> |
| <input type="checkbox"/> Cancer | <input type="checkbox"/> Prefer not to say |

18. Including today, which healthcare services have you used in the past 6 months?

Please X all that apply

- | | |
|---|--|
| <input type="checkbox"/> No healthcare use | <input type="checkbox"/> Hospital - <u>planned overnight visit</u> |
| <input type="checkbox"/> Called an NHS telephone line (e.g. NHS Direct) | <input type="checkbox"/> Hospital - <u>planned day visit</u> |
| <input type="checkbox"/> General Practice (GP) | <input type="checkbox"/> Hospital - <u>outpatients visit</u> |
| <input type="checkbox"/> GP out of hours service | <input type="checkbox"/> Other <input type="text"/> |
| <input type="checkbox"/> A walk-in or out of hours clinic | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Hospital - <u>emergency visit</u> | <input type="checkbox"/> Don't Know |

19. Including today, how many times have you used any healthcare service in the past 6 months?

- | | |
|---|--|
| <input type="checkbox"/> No health care use | <input type="checkbox"/> 10 or more times |
| <input type="checkbox"/> 1-2 times | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> 3-5 times | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> 6-9 times | |

--	--	--	--

People's opinions may also depend on whether they go with someone else to get healthcare. The next two pages are about people that you look after and the healthcare they use.

20. Do you have any dependent children?

- Yes
- No PLEASE SKIP TO QUESTION 23
- Prefer not to say PLEASE SKIP TO QUESTION 23

21. If you answered yes to question 20, to which healthcare services have you accompanied your dependent children in the past 6 months? Please X all that apply

- | | |
|---|--|
| <input type="checkbox"/> Did not need to accompany to any service | <input type="checkbox"/> Hospital - <u>planned overnight visit</u> |
| <input type="checkbox"/> Called an NHS telephone line (e.g. NHS Direct) | <input type="checkbox"/> Hospital - <u>planned day visit</u> |
| <input type="checkbox"/> General Practice (GP) | <input type="checkbox"/> Hospital - <u>outpatients visit</u> |
| <input type="checkbox"/> GP out of hours service | <input type="checkbox"/> Other <input type="text"/> |
| <input type="checkbox"/> A walk-in or out of hours clinic | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Hospital - <u>emergency visit</u> | <input type="checkbox"/> Don't Know |

22. If you answered yes to question 20, how many times have you accompanied your dependent children to any healthcare service in the past 6 months?

- | | |
|---|--|
| <input type="checkbox"/> Did not need to accompany to any service | <input type="checkbox"/> 10 or more times |
| <input type="checkbox"/> 1-2 times | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> 3-5 times | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> 6-9 times | |

--	--	--	--

23. Are you a carer for someone who is ill, frail, elderly or disabled? Please do not count anything that you are employed to do.

- Yes
- No PLEASE SKIP TO QUESTION 26
- Prefer not to say PLEASE SKIP TO QUESTION 26

24. If you answered yes to question 23, to which healthcare services have you accompanied the person(s) you care for in the past 6 months? Please X all that apply

- | | |
|---|--|
| <input type="checkbox"/> Did not need to accompany to any service | <input type="checkbox"/> Hospital - <u>planned overnight visit</u> |
| <input type="checkbox"/> Called an NHS telephone line (e.g. NHS Direct) | <input type="checkbox"/> Hospital - <u>planned day visit</u> |
| <input type="checkbox"/> General Practice (GP) | <input type="checkbox"/> Hospital - <u>outpatients visit</u> |
| <input type="checkbox"/> GP out of hours service | <input type="checkbox"/> Other <input type="text"/> |
| <input type="checkbox"/> A walk-in or out of hours clinic | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Hospital - <u>emergency visit</u> | <input type="checkbox"/> Don't Know |

25. If you answered yes to question 23, how many times have you accompanied the person(s) you care for to any healthcare services in the past 6 months?

- | | |
|---|--|
| <input type="checkbox"/> Did not need to accompany to any service | <input type="checkbox"/> 10 or more times |
| <input type="checkbox"/> 1-2 times | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> 3-5 times | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> 6-9 times | |

--	--	--	--

Finally, we would like to know a bit about you to compare your answers to other people's responses.

<p>26. Are you?</p> <p><input type="checkbox"/> Female</p> <p><input type="checkbox"/> Male</p> <p><input type="checkbox"/> Prefer not to say</p>	<p>27. What year were you born?</p> <p><input type="text"/><input type="text"/><input type="text"/><input type="text"/> e.g. 1965</p>
<p>28. What is your highest level of education?</p> <p><input type="checkbox"/> No academic qualification</p> <p><input type="checkbox"/> Left school at age 16 (e.g. GCSE)</p> <p><input type="checkbox"/> Left school at age 18 (e.g. A-Levels)</p> <p><input type="checkbox"/> Vocational Qualification (e.g. technical college)</p> <p><input type="checkbox"/> Degree</p> <p><input type="checkbox"/> Higher degree</p> <p><input type="checkbox"/> Prefer not to say</p>	<p>29. What is your ethnicity?</p> <p><input type="checkbox"/> Asian/Asian British</p> <p><input type="checkbox"/> Black/African/Caribbean/British Black</p> <p><input type="checkbox"/> Mixed/Multiple ethnic origins</p> <p><input type="checkbox"/> White British</p> <p><input type="checkbox"/> White Non-British</p> <p><input type="checkbox"/> Other ethnic group</p> <p><input type="checkbox"/> Prefer not to say</p>
<p>30. How confident are you using computers?</p> <p><input type="checkbox"/> Very confident</p> <p><input type="checkbox"/> Confident</p> <p><input type="checkbox"/> Fairly confident</p> <p><input type="checkbox"/> Not confident</p> <p><input type="checkbox"/> Prefer not to say</p>	<p>31. Where do you live?</p> <p><input type="checkbox"/> Kensington and Chelsea</p> <p><input type="checkbox"/> Wandsworth</p> <p><input type="checkbox"/> Hammersmith and Fulham</p> <p><input type="checkbox"/> Westminster</p> <p><input type="checkbox"/> Other Borough</p> <p><input type="checkbox"/> Prefer not to say</p>

Thank you for your time
Please hand back your survey to the research team .