

Accessing patient health records for research:

Thoughts from the UK's PH community

Feedback collected in June 2023

331

Total responses received

RESPONSES FROM PEOPLE WITH PH

Almost half of the respondents (**48%**) were aged 65 or over.

72% described their gender as female.

58% have been diagnosed with PH for more than 3 years.

Sometimes researchers need to access patients' present data and historical data (which might be many years old) to help find ways of diagnosing PH earlier.

75% said they would be happy for their health records to be accessed, without written consent, for this purpose.

89% said they would be happy for this to happen following their death.

Sometimes researchers need to access patients' present and historical data (which might be many years old) to understand how effective a drug treatment is now, or has been historically. The aim may also be to investigate its side effects, or its efficacy over a longer period of time (such as 5-10 years).

77% said they would be happy for their health records to be accessed, without written consent, for this purpose.

89% said they would be happy for this to happen following their death.

Sometimes researchers need to access patients' present data and historical data (which might be many years old) to understand what treatments

are taken at what point, and in what order. By mapping this against disease progression, it can help scientists identify the most effective treatment pathways.

80% said they would be happy for their health records to be accessed, without written consent, for this purpose.

90% said they would be happy for this to happen following their death.

Comments about accessing data without written consent whilst living

"I am happy to have my medical records accessed to further research into PH but would prefer to have knowledge that they are being used and opened to other parties."

"Research benefits everyone and it must pass the review board for ethics so I'm comfortable my rights will be protected."

"I would always want to know who was using my data and for what purpose."

"It depends on what the purpose of the research is. If it's specifically to find out ways of diagnosing PH then I have no issue but often data is not held or used securely and ends up being used for commercial purposes."

“I feel uncomfortable with my records being looked at without me knowing.”

“Research is crucial in order to develop new treatments, so I have no problems with my health records being accessed for this purpose.”

“If my records can help researchers to determine the best ways to eradicate PH and improve the lives of others, go for it! There are some things in my medical records I'd like to keep private, but the majority of my medical history (PH related, and possibly lifestyle related such as alcohol use or my weight/height over time) should be accessible.”

“I would like to help in any way possible for the benefit of future PH patients, assuming data is used correctly and only by those authorised to do so. But I would like to be asked first.”

“Anything that might help PH in the future is a good enough reason in my opinion.”

“Although these type of projects are very important, I still feel that the patient has the right to know that their health record will be used and opt out if they want.”

“Obtaining written consent for every individual study would use up valuable resources and increase the cost of the study. I want research to

go ahead at the most reasonable cost. Provided the data is never going to be used to intrude in people's lives or for marketing purposes, I have no problem with mine being made available to reputable organisations.”

“I have no issue with genuine medical research sponsored by a charity or recognised specialist research body accessing medical records to assist earlier diagnosis or improved treatments.”

“I strongly believe that a person's information should not be used without their informed consent.”

“I want control over who has access to my medical records.”

“I would like the next generation to be free from PH. Happy to contribute my data if that helps.”

“I would not want my information used for possible monetary gain by any large pharmaceutical or other company.”

“Making health records more easily accessible to researchers will be a positive step forward.”

Comments about accessing data after death

“I’m not here to ask so if it helps, that’s fine.”

“I would be delighted if my records could help living sufferers of PH. I’d be of use, at last.”

“Ask permission of any close family surviving. [It would make it] more difficult and slows down the process, but there is information too easily accessible now.”

“I think getting permission for access whether alive or dead needs to be a respectful process. I fear that without protocols, things would be more likely to become lax.”

“I receive so much help and assistance from my specialist centre and from the PHA UK that it feels good to know that I can help others to get an earlier diagnosis even after my death.”

“I would only agree to this if I could give consent prior to death and my next of kin being made aware.”

“Once I’ve passed I believe that the effort and records held by the NHS should be made available for research.”

“I think it would be an intrusion to have access without my consent and on a slippery slope to no protection.”

“It won’t cause me any problems when I am dead!”

“It seems easier somehow to agree to this after death than in life.”

“My family may not want my confidential records used without their knowledge or agreement.”

“Once I have died, my health records are no use to anyone except for research.”

RESPONSES FROM PEOPLE WHO LOVE OR CARE FOR SOMEONE WITH PH

A separate survey was developed for family, friends and carers, and 38 responses were received. We asked how they would feel about their loved one's data being accessed as part of a research study in various scenarios.

18% of the people with PH that respondents said they loved or cared for are aged under 18.

63% of them would describe their loved one's gender as female.

63% said their loved one has been diagnosed with PH for more than three years.

Sometimes researchers need to access patients' present data and historical data (which might be many years old) to help find ways of diagnosing PH earlier.

63% said they would be happy for their loved one's health records to be accessed, without written consent, for this purpose.

83% said they would be happy for this to happen following their death.

Sometimes researchers need to access patients' present and historical data (which might be many years old) to understand how effective a drug treatment is now, or has been historically. The aim may also be to investigate its side effects, or its efficacy over a longer period of time (such as 5-10 years).

79% said they would be happy for their loved one's health records to be accessed, without written consent, for this purpose.

90% said they would be happy for this to happen following their death.

Sometimes researchers need to access patients' present data and historical data (which might be many years old) to understand what treatments are taken at what point, and in what order. By mapping this against disease progression, it can help scientists identify the most effective treatment pathways.

67% said they would be happy for their health records to be accessed, without written consent, for this purpose.

85% said they would be happy for this to happen following their death.

Comments from loved ones about accessing data without written consent whilst the patient is living

“It’s essential for future generations that as much data as possible be made available.”

“I would want the person I care for to have to give specific written permission for accessing any of their data. It would also have to be for specific data, not a blanket permission to access all data.”

“If there was any type of help that would help my wife have a better quality of life I would want to know.”

“I believe they [the patient] would like to be asked first on a need to know basis.”

“All of my daughter’s life her health issues have always been of great interest to all medics who have been involved. If any information can help other people it’s good.”

“My wife is only alive due to advances made in understanding, identifying and treating her illness. She will assist with any research that helps her and others.”

“I feel consent should always be gained before any access of personal data. I would have no objections if asked.”

“I am assuming the research would be carried out with a view of finding something positive regarding to treatment of PH. Therefore I would have no objections.”

“I think this type of information needs written approval whilst they are able to do so.”

“I would either like to be informed you were using my husband’s data or to have gained his consent before accessing his records.”

“My daughter and I have discussed research into PH and I know that she is happy to assist research in any way she can and that she would be happy for her records to be used.”

Comments from loved ones about accessing data when the patient has died

“There seems to be an expectation that if someone dies, then their data is open to all. If the person I care for has expressed a wish for their data to be used, then I would honour that wish. However, permission would have to be given in writing.”

“I would not have his consent although [due to] the fear and despair of this disease he would probably want to do it.”

“It will help for future people.”

“My husband has actually passed away but if accessing his records could help someone else I would be happy for you to do so, it would be nice to be informed though just so you know that he may be helping in some small way even after he has passed.”

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We would like to thank everyone who took the time to share their opinions as part of this research.

All studies involving patients and their kinship must, importantly, gain approval from ethics committees. If the study seeks to access patient data, the ethics of this will be considered as part of this process. Researchers cannot access patient data *'as and when they please'*, so please be reassured it is safe.

The findings of this survey will help inform future ethical approval applications for studies in the field of PH.

If you have any questions about this report, please email office@phauk.org or call **0300 373 5367**