

NHS at 70: THE STORY OF OUR LIVES

Participant Information Sheet

You are being invited to take part in *NHS at 70*, a national programme of work supported by the National Lottery Heritage Fund (NLHF) which aims to preserve NHS heritage and mark its 70th anniversary in 2018 by capturing stories and memorabilia from a diverse range of communities. It is supported by a group of stakeholders including Age UK, the Mental Health Foundation, Rethink Mental Illness, the Stroke Association, the TUC, NHS England and the NHS Confederation. A key part of the project is the creation of a national Digital Archive that will preserve and make publicly accessible the stories and memorabilia contributed by participants. Before you decide, it is important for you to understand why the work is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this.

Who will conduct the research?

The research is being directed by Stephanie Snow, Centre for the History of Science, Technology & Medicine, Simon Building, University of Manchester and will be conducted by a team of researchers.

What is the purpose of the research?

We want to create a more diverse and inclusive history of the NHS than currently exists. The NHS was created in 1948 to provide free and universal access to healthcare and is a key institution of post-war British everyday life. The lived experiences of workers, patients, volunteers and the public encapsulate a unique part of UK post-war social and health history. But the histories of many communities of patients and workers are absent from existing work. By making the history of the NHS more diverse and inclusive we will produce a shared national story about the NHS for everyone that can be taken into the future and benefit national and international audiences.

Why have I been chosen?

Your stories and memories of the NHS will be an important contribution to the Project.

What would I be asked to do if I took part?

If you decide to take part you will be invited to take part in an interview which will last between 1 and 2 hours and be audio-recorded. The interview is an opportunity for you to share your stories and memories of the NHS. The interview is very flexible and you are free to discuss what seem to you to be the most important issues. With your permission, your recorded interview will become part of the Digital Archive where it will be preserved as a permanent resource for use in research, publications, education, lectures, broadcasting and internet. The interviewer may also ask your permission to take your photograph. If you agree then the photograph will also become part of the Digital Archive where it will be

preserved as a permanent resource for use in research, publications, education, lectures, broadcasting and the internet.

What happens to the data collected?

A key part of the project is the creation of a national Digital Archive that will preserve and make publicly accessible the stories and memorabilia contributed by participants. With your permission, your recorded interview will become part of the Digital Archive where it will be preserved as a permanent resource for use in research, publications, education, lectures, broadcasting and the internet. We will never use your information without your consent, and you can tell us how it should be used on the NHS at 70 Recording Agreement which you will complete after your interview has been completed.

You have the following options:

- Use my name: You can tell us to credit you by name when we use your contributions on the website, in print, and in public.
- Use a pseudonym: You can choose to use a pseudonym. The pseudonym will be the name used in the Digital Archive and the name attributed to your contributions on the website, in print, and in public.

Occasionally you may wish to request partial or complete closure of your interview to public access.

Once the interview is completed the interviewer will upload the recording using an encrypted University of Manchester laptop computer to the secure University of Manchester server where it will be accessible only by the research team. If you have chosen to use a pseudonym, we will allocate a unique identifier to your interview and all details of your identity will be kept separately to the audio files and the interview summary.

The project team will summarise the interview and review it to ensure compliance with GDPR requirements before uploading it to the Digital Archive on the NHS at 70 website and we will send you a copy of your interview.

When the project ends in 2020, the website, Digital Archive and all the information that has been contributed by participants will be archived as a permanent record of the project, for use by researchers in the future. All future use of your contributions will adhere to the same access and privacy conditions that you select now.

Your personal data

We are collecting and storing this personal information in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018 which legislate to protect your personal information. The legal basis upon which we are using your personal information is “public interest task” and “for research purposes” if sensitive information is collected. For more information about the way we process your personal information and comply with data protection law please see our privacy notice for research participants:

<http://documents.manchester.ac.uk/display.aspx?DocID=37095>.

The University of Manchester, as Data Controller for this project, takes responsibility for the protection of the personal information that this study is collecting about you. In order to comply with the legal obligations to protect your personal data the University has safeguards in place such as policies and procedures. All researchers are appropriately trained and all interviewers will sign a Confidentiality Agreement to ensure that they protect and respect the confidentiality of interviewees.

You have a number of rights under data protection law regarding your personal information. If you would like to know more about your different rights, please consult our privacy notice for research - <http://documents.manchester.ac.uk/display.aspx?DocID=37095> - and if you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, University of Manchester, Oxford Road, M13 9PL. at the University and we will guide you through the process of exercising your rights. You also have a right to complain to the [Information Commissioner's Office](#), Tel 0303 123 1113.

What about documents, images and objects?

Some of you may have kept interesting documents, images and objects about the NHS and the Project team would be very grateful if you were willing to share these with them. We will arrange to scan them or take a photograph and upload these digital files on to the website. We will never use your documents, images or objects without your consent, and you can tell us how it should be used.

You have the following options:

- Use my name: You can tell us to credit you by name when we use your contributions on the website, in print, and in public.
- Use a pseudonym: You can choose to use a pseudonym. The pseudonym will be the name used in the Digital Archive and the name attributed to your contributions on the website, in print, and in public.

How is confidentiality maintained?

All interviewers will sign a Confidentiality Agreement to ensure that they protect and respect the confidentiality of interviewees. All data from the research will be stored on the University of Manchester secure server and be accessible only to the Project team. If you have chosen to use a pseudonym, all identifying data will be kept separately to the audio files and summaries. At the end of this project in 2020 all future use of your contributions will adhere to the same access and privacy conditions that you select now.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a Participation Agreement before the interview and a Recording Agreement after the interview. If you decide to take part you are still free to withdraw from the interview at any time without giving a reason and without detriment to yourself.

You will be free to withdraw from the research, even after the interview has finished up until the project finishes in 2020. If you decide to do this then the digital file and any material relating to your interview, eg.summaries/transcripts/photographs will be deleted from the Digital Archive. If your contribution has already been used in any way on the website you can contact us and we will remove it from the website.

Will I be paid for participating in the research?

There will be no payment for participating in the research.

What is the duration of the research?

The interview will last for between 1 and 2 hours. If you get tired during the process you can ask to stop and take a break, continue on another date or terminate the interview completely.

Where will the research be conducted?

Interviews will be conducted at a time and place convenient to you. This could be in a place like a community centre or a library or in your own home if you prefer.

Will the outcomes of the research be published?

The outcomes of the research will be published on the website and used in research, publications, education, lectures, broadcasting and the internet. We will never use your information without your consent, and you can tell us how it should be used on the Recording Agreement.

In order to help prevent any inappropriate reuse or manipulation, whole digital interviews and edited extracts will be made available through the Creative Commons licence, 'Attribution Non-Commercial No Derivatives' (referred to as CC BY-NC-ND), and will be attributed to you/ your pseudonym and it cannot be used for commercial purposes.

What if I disclose any information about harm to patients?

If any disclosure about harm to patients is made during interviews then the interviewer will have a duty to raise the issue with the appropriate stakeholder and discuss whether the disclosure requires a formal concern to be raised with the appropriate NHS body or professional regulator.

What if I have a complaint about a health service or healthcare professional?

We want you to share your stories, and we know they won't all be positive. But this research is run from the University of Manchester and is supported by the Heritage Lottery Fund. It is not part of the NHS and our team members are not employed by the NHS. We are not able to deal with complaints relating to NHS services or healthcare professionals. You can find information on how to make a complaint with the NHS [through this link](#).

Who has reviewed the research project?

The research has been reviewed by the University of Manchester Research Ethics Committee.

Who can I contact if I have any questions?

It is highly unlikely that anything should go wrong during your involvement in this research. If however you have any questions or concerns in the first instance you should contact the Project Director, Stephanie Snow: stephanie.snow@manchester.ac.uk – 0161 275 0560.

If you wish to make a formal complaint about the conduct of the research you can contact a Research Governance and Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 275 2674 or 275 8093

This Project Has Been Approved by the University of Manchester's Research Ethics Committee UREC4