



ADMISSION-QUAL: Understanding experiences of hospital care for multiple long-term conditions: a study of patient perspectives

Participant Information Sheet

A recording of this Information Sheet is available to listen to at:
<https://nuvision.ncl.ac.uk/Play/20016>

Invitation

We are a team of researchers from Newcastle University. We are conducting research to find out about the experience of living with, and receiving hospital care for, multiple long-term conditions (that is, two or more health conditions that have lasted for, or are expected to last for, more than a year).

We are inviting you to take part in a research interview. Before you decide if you would like to take part, you will need to understand why the research is being done and what it will involve.

We would be grateful if you could read the following information or, if it is easier, you can listen to a recording which can be found at <https://nuvision.ncl.ac.uk/Play/20016>. If you would like more

information, or if there is anything that is unclear, please contact the study co-ordinator, Sue Bellass (email: Admission.Qual@newcastle.ac.uk; mobile phone: 07827 872728).

The purpose of the study

We are interested in learning about what it's like to live with multiple long-term conditions and your experience of hospital care. We'd like to ask about your health conditions and how your life has changed over time. We would also like to know about your experiences of hospital care – what you thought was good and what could have been better. This will provide useful evidence on how hospital services can be improved for people living with multiple long-term conditions.

Why have I been invited?

You have been invited to take part because you have multiple long-term conditions and have been in hospital within the last 6 months. We are seeking the views of people like you. Taking part in the study is entirely voluntary and your decision to take part will not affect any health or social care or other support you may receive.

What is involved?

A date and time for the interview will be arranged between you and the researcher. You and the researcher will discuss and agree on the best way to conduct the interview (e.g. face-to-face, by telephone, or by video call). If you prefer, we are happy for you to be accompanied by another person during the interview.

The interview is likely to last around 90 minutes. Being interviewed will involve having a conversation with the researcher. We will talk about your experiences of living with multiple long-term conditions,

and of hospital care. The conversation will be recorded on a digital recorder so that there is an exact record.

If you have a face-to-face interview, you will be asked to complete and sign a consent form and will be given a copy of this to keep. If you have a telephone or video interview, the researcher will send you a copy of the consent form in advance for information. At the start of the interview, the researcher will read the form to you and record your responses to the statements. This part of the recording will be kept separate from the interview recording.

Everything discussed during the interview is confidential. Your responses will not be shared with anyone who provides care for you, like your GP or a hospital consultant. However, the researchers have a professional duty of care that they must meet. This means, for example, that the researcher would need to inform someone if you told her that you intended to harm yourself or another person.

You do not have to answer any questions that you do not want to answer. You can also stop the interview at any time. If you change your mind about being part of the study *after* the interview, you can withdraw your information as long as it has not already been analysed. You do not have to give us a reason for changing your mind.

Follow-up research

As part of our research, we will be conducting follow-up interviews with some study participants. This will help us to understand how the experience of living with multiple long-term conditions might change over time. The follow-up period will last for a year and will involve two further interviews. Some study participants may also be invited to record their experiences in other ways, such as through

diaries. Taking part in the follow-up research is also voluntary and we will not ask you to decide whether you want to participate during the first interview. Instead, we will ask for your permission to contact you again.

How will I benefit from being involved in these interviews?

You will not benefit directly. However, you will help us to collect evidence about the experiences of living with and receiving care for multiple long-term conditions. Your views will contribute to a large national research programme that aims to improve knowledge about care for people living with multiple long-term conditions.

What are the risks of taking part in the study?

It is possible that talking about your health or experiences of health services may be upsetting. If you become upset, the researcher will pause the interview and listen to your concerns. The researcher will give you time to decide whether you would like to continue with the interview.

What happens if I lose capacity to make decisions for myself after I've agreed to participate in the study?

If you lose capacity to make decisions you would be withdrawn from the study and no further research would be conducted with you. Information from interviews that had already taken place would be retained and used in the study.

How will you use information about me?

We will need to use information from you for this research project. This information will include your name and contact details. People will use this information to do the research or to

check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so that we can check the results. We will write our reports in such a way that no-one can work out that you took part in the study.

What are my choices about how my information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can I find out more about how my information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by sending an email to the University Data Protection Officer at Newcastle University at rec-man@ncl.ac.uk or
- by ringing us on (0)7827 872728

The recording of the interview will be typed up with all names and identifying features changed so that you personally cannot be recognised. A third party service may be used to type up the recording. In this case, a confidentiality agreement will be in place. We may use quotations in reports to our funders (UK Research and Innovation and the National Institute for Health and Care Research), in presentations or in articles for academic and professional journals. If we do use anything that you have said, it will be made anonymous so that you cannot be identified.

The information you provide will be stored securely at Newcastle University and destroyed 10 years after the study has ended. This allows time to answer any questions that might arise about the way the study was conducted or what it found. However, to make the study more useful to future researchers, we will ask you whether we can keep your anonymised interview transcript for longer and store it indefinitely in a university-managed archive (not your personal details or the audio recording). This is optional. This archive is not open to the general public and is only accessible by researchers.

Newcastle University is the sponsor and data controller for this study. Research records may be looked at to check the accuracy of the research study. The only people at Newcastle University who will have access to information that could identify you will be people who need to audit the data collection process and limited members of the research team.

Who has reviewed the study?

This study has been reviewed and given a favourable opinion by Wales 3 NHS Research Ethics Committee on 16th March 2023, ref. no. 23/WA/0045 and by Newcastle University on 16th May 2023, ref. no. 30877-2022.

What do I do if I have any concerns?

If you have any concerns about the way you have been approached or treated during this study, you can contact the Principal Investigator of the study, Professor Avan Sayer at admissioncollab@newcastle.ac.uk

You can also contact The Patient Advisory and Liaison Service (PALS), which offers confidential advice, support and information on health-related matters.

You can find your nearest PALS office on the NHS website. You can also ask your GP surgery, hospital or phone NHS 111 for details of your nearest PALS.

Thank you for reading this information.



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