

INFORMATION LEAFLET FOR FRIENDS AND FAMILY

Hidden Costs of Hospital Discharge: Understanding the costs and outcomes associated with Hospital Discharge from the perspective of people, carers and local authorities

We are conducting a research study to better understand what happens after people are discharged from hospital. We would like to invite you to take part in the research study. If you think you can help us, please read this leaflet to help you decide if you want to take part. You can contact us if you have any questions.

Summary:

We don't currently know enough about how well people, and those who care for them (family and friends), cope after they are discharged from hospital. They may go on to need some extra support, or new equipment. We want to understand more about how well people cope when discharged, and how well their family and friends cope if they are involved with providing support. We will track the support people say they need, the support they actually get, how this is arranged, and how it is paid for.

Who do we want to take part?

Family members and friends of people who have recently been discharged from hospital. We are specifically looking for the friends and family members of people aged 65 years or older, who were recently discharged from hospital.

About the research:

The research is funded by the National Institute for Health and Care Research (NIHR) School for Social Care Research (SSCR) and managed by the University of Birmingham. We want to talk to the family and friends of people who were recently discharged from hospital.

Once we have a good understanding of what happens now, we can look at how things can be improved in the future.

Ethical approval has been granted by the Science, Technology, Engineering and Mathematics Committee at the University of Birmingham (ERN-5102).

What will happen if I take part?

If you would like to take part, you will be asked to fill in a consent form.

A member of the research team (from the University of Birmingham) will then invite you to take part in an interview. The interview will last between 45 minutes and an hour and can take place face-to-face in your own home, online, or over the phone. You will be asked how things went from your perspective (after your family member or friend was discharged from hospital), whether you bought any extra equipment to help your family member or friend, and if things went as planned (as was expected when the person was discharged).

If your family member or friend was discharged from hospital very recently (less than 1-month ago), you will be asked to take part in a similar interview about 4-months after the person you are close to was first discharged from hospital. Once again, this interview will last between 45 minutes and an hour and can take place face-to-face, online, or over the phone.

We will audio record the interviews using an encrypted audio recording device (for both face-to-face and online interviews). A record of what is said in the interviews will be typed-up (transcribed). We will read all of the transcripts to identify important messages and themes.

Do I have to take part?

It is your decision whether you take part. If you have any questions, please ask us.

You can stop being part of the study at any time, without giving a reason. If you want to withdraw, please let us know within two weeks and we will destroy any research data that we have collected from you. After two weeks, it is likely that your data will already have been included in our analysis.

Are there any possible risks?

You may find talking about your experience in the interview upsetting. If this is the case, we will ask if you want to continue with the interview and provide suggestions of organisations which could offer support. If you tell us anything which makes us believe that you or anyone else are at risk of significant harm, we will need to break confidentiality and tell staff from the council who have responsibility for keeping people safe.

If you are unhappy about any aspect of this research, you can contact Professor Hareth Al-Janabi. Email: h.al-janabi@bham.ac.uk Phone: 0121 415 8483.



We hope you will be willing to share your views and experiences with us, so that you can help us to improve services for people in the future.

As a thank you for taking part, we will give you a **£20 shopping voucher** for taking part in the first interview and a **£25 voucher** for taking part in the second interview.

Where can I get more information about taking part?

If you have questions that you would like to ask, or if you would like to take part, please contact:

Dr Stephen Williams

Telephone: 07890 426602

Email: s.j.williams@bham.ac.uk



OR

Dr Philip Kinghorn:

Telephone: 0121 41 47620

Email: p.kinghorn@bham.ac.uk

PART B: How will we use information about you?

We will need to use information from you for this research project.

Here is a summary of the information we will collect:

- If you agree to take part, we will ask you to sign a paper consent form, which will be stored securely at the University of Birmingham for 10 years.
- We will use your name and contact details (which could include email or postal address and phone number) to contact you about the study and to arrange the interviews.
- Audio recordings of the interviews.
- Anonymous transcripts (from the audio recordings).

People will use this information to do the research or to make sure that the research is 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.

The University of Birmingham is responsible for looking after your information. Anonymous transcripts will be shared with people outside of the University of Birmingham research team for the purposes of research, including for future research projects.

We will keep all information about you safe and secure by:

- Securely storing your data including paper consent forms at the University of Birmingham.
- Storing audio recordings on a secure network at the University of Birmingham. Recordings will be deleted from the audio recording device and from the secure University of Birmingham network once they've been transcribed.
- Storing anonymous transcripts (from the audio recordings) on a secure University of Birmingham network for 10 years.

Your data will not be shared outside the UK.

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

We will keep your data for a maximum of 10 years. The study data will then be fully anonymised and securely archived or destroyed.

You can request to stop being part of the study at any time, without giving a reason. If you want to withdraw, please let us know within two weeks and we will delete any research data that we have collected. After two weeks, it is likely that the data will already have been included in our analysis.

You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.



The overall messages and themes will be published in academic journals and shared at meetings and conferences with councils and care providers. We may use direct quotes from the interviews to support and illustrate our research findings, but these will be anonymous.

We will produce guides and other helpful information to make the process easier in the future for people being discharged from hospital.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- by asking one of the research team
- by sending an email to dataprotection@contacts.bham.ac.uk

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.

How will I be informed about the study findings?

At the end of the project, we will add resources and a plain English summary of the research to our project website:

<https://www.birmingham.ac.uk/research/projects/hidden-costs-of-hospital-discharge>

You will be asked by the research team if you are happy to receive a link to the website by email, once resources are added (at the end of the project), or if you would prefer to have the plain English summary sent to you by post.