Participant Information Sheet

4-Actions Care Planning in Primary Care

You are invited to take part in a research study. To help you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us 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.

What is the purpose of the study?

Asking people to tell professionals about what matters to them is very important in health care. It is a central part of planning care and shared decision-making with people and their families. People with long-term health problems or serious illness often lack an updated plan for complications or changes in health and care. Planning ahead helps people get better care and avoid treatments they do not want or that may have poor outcomes for them. In Scotland we call doing this “Anticipatory Care Planning” (ACP). We are working with GP surgeries in four health boards in Scotland to help them improve how they carry out Anticipatory Care Planning. As part of the study we are asking a small number of people who have had an ACP conversation to tell us about their experiences.

Why have I been invited to take part?

There are two reasons why you may have been invited. One reason is that you may have recently had an Anticipatory Care Planning conversation with someone from your GP surgery which is taking part in the study. A small number of people who had a care planning conversation in the six months before the project started are also being invited.

Do I have to take part?

No, it is up to you to decide whether or not you want to take part. If you prefer not to take part, you do not have to give a reason. The people providing your care will not be upset and your treatment will not be affected in any way. If you decide to take part but change your mind later, you can withdraw from the study at any time without giving a reason. Deciding not to take part or withdrawing from the study will not affect the healthcare that you receive, or your legal rights.

What will happen if I take part?

If you are interested in helping with the study, a project researcher will contact you to discuss what is involved, and to answer any questions you may have.

Two things will happen. The first is an interview with you and, if you wish, a family member or friend who helps and supports you. After around 4-6 months, the researcher will contact you again about a second short interview to find out what has happened since the first interview.

The first interview can be in your own home or a place of your choice. You can also have an interview by phone. If you need to travel to take part in an interview, your expenses will be refunded.

If you agree, the interview will be recorded using an audio recorder and typed up so that we can be sure that we remember and understand what you say correctly. You can listen to the recording, or read the transcript if you wish.

If there is someone who helps and supports you (a relative or a good friend), we may ask your permission to approach them to take part in an interview for the study either separately or at the same time as you. We will not speak to anyone about you without your consent. Your GP will be informed that you are taking part in the study. This is for their records and will not affect any care you receive.

Follow up interview

About 4-6 months after your first interview we will ask to talk with you on the phone to help us understand what impact the ACP conversation has had on your care. We will talk with you and anyone else you want take part. This interview will be shorter, taking 15-30 minutes. It will be recorded and typed up like the first interview.

What are the possible disadvantages and risks of taking part?

The interviews will take up some of your time, but we don't think there are any risks to you.

What are the possible benefits of taking part?

We cannot promise the study will help you personally, but some people do find it helpful to talk to someone about their experiences. Once the study is finished, we will discuss and share our findings with health and social care staff and managers to help improve the way anticipatory care planning is done in Scotland and other parts of the UK.

Will my participation in the study be kept confidential?

All the information we collect during the research will be kept confidential. There are strict laws which safeguard your privacy at every stage.

We will ask for your permission to use health information about you and from your Key Information Summary that is part of your GP record for this research project.

This information will only include details about your health problems and any anticipatory care planning you have. We will use this information to do the research.

People who do not need to know who you are will not be able to see your name or contact details. We will use a code number to identify you instead.

We will keep all information about you safe and secure at all times. Once we have finished the study, we will keep some of the data we have analysed so we can check the results. We will write our reports in a way that no-one will know that you took part in the study.

What happens if something "sensitive" comes up?

What you say in the interview is kept confidential by the research team but you may say something that the researcher thinks should be shared with another professional or service or that the researcher believes they have a legal obligation to report. If you do say something like this then after the interview has ended the researcher may talk to you about the benefits of sharing this information. The researcher may also ask for advice from other people in the research team while keeping your confidentiality as far as possible.

What are your choices about how your 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 and will it use for this research unless you (or someone who you have asked to speak for you) ask us to have it removed.

If you agree to take part in this study, you may be asked if your interview transcripts can be kept securely and used in future research.

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 using the contact information at the end of this document or by contacting the project's Data Protection Officer, Dr Rena Gertz by email at DPO@ed.ac.uk.

How will we look after your data?

When we do an interview with you in person or by phone, if you agree, we will record it using a digital audio recorder that "encrypts" the recording so it can't be heard without the password. The recording will be transcribed by one of the researchers or by a transcriber working for a company that has been approved by the University of Edinburgh and NHS research management. Once the interview has been transcribed it will be checked by a researcher and then "anonymised:" This means that all information that could directly or indirectly identify you will be removed from it. The recording will be deleted and the anonymised copy of the transcript will be stored at the University of Edinburgh on a password-protected computer for up to seven years.

In order to manage your participation in the research, we will store the following information about you on a different password-protected computer at the University of Edinburgh: your name and contact details. If we interview you because you are a health professional, we will record your job title. You will be able to request a copy of all data we hold about you at any time.

What will happen to the results of the research study?

We will offer everyone who takes part in the study a short summary of our findings and we will also publish our findings in medical and other academic journals for teaching and training health and social care staff. We will also write a report for Marie Curie, which is funding this study. You will not be identifiable in any of these reports.

Who is organising and funding the study?

Dr Kirsty Boyd (a retired NHS consultant) is leading the study with colleagues from the NHS and the University of Edinburgh. Dr Bruce Mason and Dr Anne Canny, the study researchers, will carry out the interviews. The study is funded by Marie Curie.

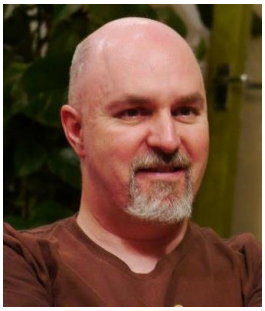
Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. This study has been reviewed and approved by the SE Scotland Research Ethics Committee. NHS management approval has also been given.

What happens now?

One of the study researchers will contact you during normal working hours a day or two after you receive this information. You can let the researcher know then if you are interested in taking part and ask any questions you may have. In the meantime please feel free to discuss this information with your family, friends, GP or nurse.

If you have any further questions about the study, please contact:



Dr Bruce Mason, Project Researcher,
The University of Edinburgh, Teviot Place, Doorway 3,
Edinburgh, EH8 9AG
Phone: 0131 650 9237
Email: Bruce.Mason@ed.ac.uk

If you would like to discuss this study with someone independent of the study, please contact:

Dr Karen Fairhurst, General Practitioner.
Phone: 0131 650 9495 or email: karen.fairhurst@ed.ac.uk

If you wish to make a complaint about the study, please contact:

Patient Experience Team, NHS Lothian
2nd Floor, Waverley Gate
2-4 Waterloo Place
Edinburgh, EH1 3EG
Phone: 0131 536 3370

Email: feedback@nhslothian.scot.nhs.uk