PACE
Proactive Anticipatory Care Evaluation

Patient Information Sheet

A large-print version of this sheet is available on request.

Invitation to take part in a research study

We would like you to take part in a research study. To help you to decide if you would like to take part, we have written this information sheet. It should explain why the research is being done, what you will be asked to do, and why we would like you to take part. Please take your time to read the information. You can talk with your friends or family about it if you like.

What is this study about?

We are trying to find out how the new service you have been invited to or just visited has helped improve your overall health and wellbeing; compared to how you have been cared for until now. Your answers will help in the improvement of this service.

Why have I been invited to take part?

We would like you to take part in this study because you have recently been invited to attend an appointment at the new service at the Jean Bishop integrated care centre or at you care home by your GP. Your GP has identified you as being eligible for this study.

What will happen if I take part?

If you take part in the study, you will be asked to sign a consent form. You will be asked to complete a short questionnaire at the first meeting either at the Jean Bean Integrated Centre or at the care home you live in. Someone from the research team will help you fill in the questionnaire. If you are unable to complete the questionnaire at the first meeting, another date and time convenient for you will be set. It will take you about 45minutes to complete the questionnaire. Someone from the research team will contact you to ask if you are happy to complete a shorter version of the questionnaire in 2-4 weeks and in 10-14weeks time.

We would like you to answer the questions as honestly as you can and there are no right or wrong answers. You will be asked if you would like to nominate a family member or carer to help fill in the questionnaire for you. There is a separate consent form (consultee form) to be completed by the nominated person, please ask for a copy of this.

What else will happen if I take part?

Some people taking part will be asked if they would like to take part in an interview with a researcher if they are affected by any of the following; chronic breathlessness, unintentional weight loss or use of medicine for pain and possible side effects. The interview can be held on the same day you complete the questionnaire or at a different time and place if it is easier for you.

If you take part, a member of the research team will do the interview and it will last around 45 minutes. Each topic will have a slightly different focus but will involve questions around your experience of one of topics listed above. It will also involve your opinion on caring experience, management of care, communication with health professionals, information and support needs, and the impact or potential concerns around these issues.

Do I have to take part?

No. It is up to you to decide if you would like to take part. If you decide not to take part, this will be noted and you will not be asked again. You will also continue to receive care and support from your GP practice or any health professional as usual. If you were to take part, you can still change your mind and stop taking part at any time without giving any reason.

What are the possible benefits of taking part in the study?

It is unlikely that there will be any direct personal benefit for you taking part. However, the information that you will give us will help decide if your overall health and wellbeing has improved by using this new service and give us ways to improve this service in the future.

Are there potential risks of taking part?

There is no significant risk in taking part, other than the time the study will take. However if you have any worries, you can talk about them with the research team or your GP. We would like to stress that taking part is up to you and you can stop taking part at any time without reason.

Will my involvement be confidential?

Yes. All the information we collect will be kept confidential, to fit with the General Data Protection Regulation (GDPR) 2018. The University of Hull is the sponsor for this study based in the United Kingdom. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Hull will keep identifiable information about you for 10 years after the study has finished.

Your rights to access change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information at https://www.hyms.ac.uk/research/research-centres-and-groups/wolfson/pace or by contacting PACE@hyms.ac.uk.

The GP Practice will collect information from you and your medical records for this research study in accordance with our instructions.

The GP practice will use your name, NHS number and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from the University of Hull and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Your GP Practice will pass these details to University of Hull along with the information collected from you and your medical records. The only people in the University of Hull who will have access to information that identifies you will be people who need to contact you to collect data/information or audit the data collection process. The people who analyse the

information will not be able to identify you and will not be able to find out your name, NHS number or contact details.

The research team from the University of Hull will keep identifiable information about you from this study for 10 years after the study has finished.

Expenses

You will be provided with prepaid envelopes, if needed, to return any documents to the research team. There will be no other costs to you.

What will happen to the results of the research study?

The results from this study will be written as a report for the NHS Hull clinical commissioning group (NHS Hull CCG). The results will be written up into journals, presented at conferences and public engagement events. If you would like to receive a summary of the study result, please inform someone from the research team. All personal details will be anonymised in all publications and public documents.

If I find it necessary to make a complaint, who should I contact?

If you have any concerns, questions or complaints about this research, you can contact Dr [redacted] at [redacted]. Dr [redacted] is based at University of Hull but is independent of the research team.

How can I get involved in the study?

Thanks you for taking the time to read this information sheet. **If you would like to know more, please contact the research team using the details below:**

Project Lead)

Telephone: (01482) [redacted]

Email: PACE@hyms.ac.uk