

GoalPlan Study

Participant information sheet



A video-based research study of
care planning for patients with long term conditions

We invite you to take part in a research study.

- Before you decide whether 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. You may want to discuss it with friends and relatives.
- Of course you are free to decide whether or not to take part in this study. If you choose not to take part, this will not affect the care you get from your GP.
- Please ask us if there is anything that is not clear, or if you would like more information. Our contact details are at the bottom of this page.

What is this study about?

A care plan is an agreement between a patient and their doctor which helps them to look after the patient's health from day to day. Most general practices offer care plans to patients who are likely to have an unexpected hospital stay because of their health problems. But care plans don't normally include asking patients what changes they want to make to improve their wellbeing. In this study we will ask GPs to use a simple way of discussing and agreeing these changes or goals with some patients. For example, a patient may want to get out of the house more to meet people, or to take fewer medicines. The research name for this approach is called Goal Attainment Scaling (GAS), and this study will use a short version known as GAS-Light.

Why are we doing this study?

We hope it will help people who have more than one long term health condition to talk to their GP about what is important to them. We plan to compare the progress of people who have a normal care plan with those who have care plans which include specific goals agreed with the patient. We aim to find out:-

- Do patients and GPs like using care plans with specific goals?
- Do GPs need training in goal-setting for care planning?
- How might goal-setting change health outcomes?

How to contact us

If you have any questions about this research, please contact the study researcher or the project lead. Their contact details are provided below:-

- Liz Lenaghan (Researcher),
tel: **01603 591694**,
goalplan.study@nhs.net
- Professor Nick Steel (Project Lead),
Tel: 01603 591161
- n.steel@uea.ac.uk

Why have I been invited?

Your general practice is taking part in this study. You have been invited to take part as the practice has identified you as someone with two or more long-term conditions who would be suitable to have a care plan.

Do I have to take part?

No, it is up to you to decide. If you decide to take part and then change your mind, you can stop at any time. Whether or not you take part, you will still get the usual services from your GP.

What does it involve?

There will be six general practices in this study. The practices will be split into two groups, with three practices in each group. Three practices will be randomly chosen to continue with their usual approach to care plans. The other three practices will use care plans with goals set by the patient and the GP. The general practices will provide some information to the research team about the patients taking part in the study, using details routinely recorded in clinical notes. This information will include a summary of each patient's medical background, conditions, and medication. It will also include any events that occur during the study, such as contact with the practice, hospital visits and admissions.

What will I need to do if I take part?

- **First researcher visit**

If you decide to take part, please return the enclosed **Expression of Interest form**, and a researcher will then contact you and arrange a convenient time to visit you at home, or somewhere of your choosing. They will discuss the project with you, and ask you to sign the consent form. They will use some questionnaires to ask about you and your health. The researcher will contact your GP to tell them you are taking part and an appointment will be made for you with your GP to discuss your care plan. You will either be in the group with a usual care plan, or the group with a care plan that includes goal-setting. The researcher will tell you which group you are in. If you are in the goal-setting group, the researcher will discuss with you how to prepare for your care plan appointment, giving you information about goal-setting and going through the goal-setting form with you. You will need to complete this before your care planning appointment with the GP.

- **Your care plan appointment**

The care plan appointment will be like a routine appointment with the GP, either at your practice or a home visit, if you usually have a home visit from your GP. Travel expenses for attending your practice will be reimbursed. If you are in the goal-setting group, you will use the GAS-Light tool. With your consent, the appointment will be video-recorded (or audio-recorded). This is to help the research team understand what is helping or hindering care plans, and setting goals for care plans. You can stop the recording at any time. Immediately after the care plan appointment, you will be asked to complete a questionnaire about the discussion you had during your care plan appointment.

- **Second researcher visit**

The researcher will also contact you at 6 months to arrange another visit. At this visit the researcher will use questionnaires to ask about your general health.

- **Second care plan appointment**

If you are in the group that has a care plan with goal-setting, you will have another appointment with your GP to discuss the goals you agreed and any progress against these. This will take place approximately 6 months after the initial care plan appointment. This will either be at the practice, or a home visit if needed. Again, travel expenses for attending your practice will be covered. With your consent, this appointment will also be video- or audio-recorded.

- **Focus Group**

If you are in the group that has a care plan with goal-setting, we may invite you to take part in a focus group meeting, up to a year after your initial care plan consultation. Separate information will be sent to you about this.

What are the advantages of taking part?

- We cannot guarantee that you will benefit from taking part in the study.
- If you are in the group that has a care plan with goal-setting, you may feel more involved, and may benefit from discussing your health care needs with your GP.
- You are helping us to find out how to improve health care services.

What are the disadvantages of taking part?

- You may be disappointed if you are not in the group that has a care plan with goal-setting.
- Goals you set may be difficult to achieve.
- Some people may feel uncomfortable about being recorded.

Will my involvement be confidential?

Yes, the researchers will maintain confidentiality, and will ensure that information gathered during the study is stored in accordance with the 1998 Data Protection Act. Electronic data, including the video and audio recordings, will be stored on secure servers and will be password protected. Paper information will be locked in filing cabinets in locked offices, and will only be accessible to authorised persons. Information will be kept for 15 years after the study finishes. You will not be identifiable in any publications.

Will I receive anything for being in this study?

There is no payment for participants.

What if there is a problem?

If you want to withdraw from the study, you can do so at any time without giving a reason. Information collected can be erased before it is analysed by the research team, and cannot be erased once it has been used in the project analysis. If you have a complaint about the study or how you have been treated, please contact your general practice or the research team in the first instance. If you wish to speak to someone not directly involved in this study, please contact the research sponsor's

representative at NHS South Norfolk Clinical Commissioning Group, tel: 01603 257009, email: snccg.RandDoffice@nhs.net'.

What will happen to the results of the research study?

The results will be used to help improve services and develop training. We will write up results for the study's funding body and for publications and conferences, as well as for the general public. At the end of the project we will send you a summary of our results. Full results will be available on the GoalPlan website at www.uea.ac.uk/medicine/goalplan.

Additional ways that my recording(s) may be used

As well as using the video- or audio-recording(s) within the GoalPlan study, we will ask you whether you agree to the recording(s) being used for additional purposes. These are optional.

- [Use of clips in presentations about the GoalPlan study](#)

If you consent to this option, clips from the video- or audio-recording(s) may be used in presentations about the GoalPlan study to professional audiences of researchers, health and social care staff, and trainees. Video and audio clips can often help to put across the findings of research in a much clearer way than when using words only.

- [Use of recordings and transcriptions for future research](#)

The video- and audio-recordings produced as part of the GoalPlan study, and transcriptions from those recordings, are a valuable source of information. If you consent to this option other professional researchers in the field of health and social care will be able to study your recordings and transcripts for future research about health-related communication.

- [Use of recordings and transcriptions for teaching](#)

If you consent to this option, the video- and audio-recordings, and transcriptions from those recordings, may be used in teaching. This would include communication skills training with health and social care staff, trainees, and researchers.

Who is organising and funding the research?

The research is funded by the National Institute for Health Research (NIHR) Research for Patient Benefit programme <http://www.nihr.ac.uk/funding/research-for-patient-benefit.htm>. The study's quality is assured by the NIHR's team of scientific experts. The study has been reviewed and approved by the Leicester South Research Ethics Committee (Ref: 16/EM/0411). Patient and public representatives have been involved at all stages of the development and review process. The research is sponsored by NHS South Norfolk Clinical Commissioning Group.

What do I do next?

If you are interested in taking part, please return the enclosed **Expression of Interest form** using the pre-paid envelope, or call the research team on the number given on the front page.

Thank you for taking time to read this information about the GoalPlan study.