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# Safety-Netting Research

## Patient Information Sheet – Patient Questionnaire

Summary


- Sometimes we have **symptoms** – such as feeling tired or losing weight – that could have **lots of different causes**.
- The doctor or nurse may advise you to keep an eye on such symptoms for a certain amount of time and come back if they haven't gone away or if they've got worse. This is called **'safety-netting'**.
- Your **surgery is taking part in research** led by Bradford Teaching Hospitals NHS Foundation Trust about safety-netting patients with these sorts of symptoms.
- As part of this, the **surgery is using a tool called the Shared Safety Net Action Plan (SSNAP) to encourage patient involvement in safety-netting.**
- You've been given this information sheet because you or someone you care for may have had these symptoms recently, and you're **invited to complete a questionnaire** to tell the research team about your experiences, which will help them understand how safety-netting works.

## What's involved?

### *Background and purpose of the research*

Safety-netting – in which patients and/or their family members or carers are actively involved in monitoring their symptoms - can help doctors and nurses find out as quickly as possible what's causing symptoms. It can be especially useful for symptoms where the cause is not clear at first, sometimes called 'non-specific symptoms'. But current ways of helping patients with these symptoms may not work well for patients and their families. For example, they might forget or misunderstand what symptoms they're supposed to be monitoring.

The Shared Safety Net Action Plan (SSNAP) has been designed with general practice staff, patients and members of the public to support active monitoring of symptoms (see https://yqsr.org/supporting-impact-tools-and-resources/). SSNAP produces a summary of the safety-netting discussion, which can be printed or sent electronically to patients. It also provides ways for surgeries to follow up with or contact patients.

This research study is assessing how SSNAP is working. It involves adult patients with non-specific symptoms and adult family members or informal carers who are with them when they see a doctor or nurse about those symptoms, as well as surgery staff. Findings will be used to decide whether to run a bigger study across England, which would in turn show whether it's a good idea to offer SSNAP nationally.

### *What does it involve?*

You're invited **to complete a brief online or paper questionnaire about your or your family member's experience of seeing a doctor or nurse from your surgery about non-specific symptoms.** At the beginning of the questionnaire you will be asked to tick some consent questions – this is your agreement to take part- and provide some information about yourself. The link to the questionnaire is https://yqsr.org/questionnaire-intervention/ or, if you've been sent a paper version, you can complete it and return it in the stamped addressed envelope provided.

It's up to you whether to complete the questionnaire. It's ok if you decide not to and it won't affect your or your family member's care in any way. It's also ok not to answer any questions you do not want to.

The information you provide in the questionnaire, which includes information about you such as your age range, sex, ethnicity and whether you have a disability or ongoing health issues, is anonymous. Nobody in your surgery will know whether you completed a questionnaire or not, or what information you gave in the questionnaire. Questionnaires contain an identifier for your surgery, but you cannot be identified from this.

Your responses will also be anonymous to the research team *unless*:

- you'd like to receive an optional £20 shopping voucher as thanks for completing the questionnaire;
- you'd be interested in talking about your experience of safety-netting with a member of the research team at Bradford Teaching Hospitals NHS Foundation Trust in an interview;
- you would like a copy of the study's findings when available.

If you'd like any of those things, there's space in the questionnaire to provide the research team with some contact details (name and address for vouchers and study findings, name and email/telephone number to be contacted about an interview). If you provide this information, the team *will* know who you are but they will not share this with anyone outside the team. It's up to you whether to provide your contact information and it's ok if you decide not to (you can still complete the questionnaire without doing that).

### *What are the possible benefits of taking part?*

Telling us your views could help the NHS and help make sure other patients with non-specific symptoms are offered the right care at the right time. If you complete a questionnaire you'll also be offered an optional £20 shopping voucher as a thank you. We can only offer one voucher per questionnaire.

It's your responsibility to check for impacts on tax and benefits that may arise from receiving this, before deciding whether you wish to accept the voucher. There are some helpful tips here: https://www.nihr.ac.uk/documents/payment-guidance-for-members-of-the-public-considering-involvement-in-research/27372#benefits-advice-service.

### *What are the possible disadvantages and risks of taking part?*

Experiencing non-specific symptoms can be worrying so it's possible that you might feel upset when answering questions about this. You're welcome to stop completing the questionnaire at any time and if you need support for your symptoms, you can contact your surgery. Helplines can be useful too. Depending on what's worrying you, some places where you can get support include:

**The Samaritans**: get in touch at any time to talk about anything that's troubling you. Call 116 12 or email jo@samaritans.org

**Macmillan cancer support line**: if you're worried about cancer, you can call 0808 808 00 00 7 days a week, 8am – 8pm. You can also use the online chat or email at: https://www.macmillan.org.uk/cancer-information-and-support/get-help/macmillan-services

**Age UK advice line**: older people and their families, friends and carers can call 0800 687 1602 from 8am – 7pm for advice and support. There's also a Silver Line helpline, which you can call 24 hours a day, 7 days a week on 0800 470 80 90.

### *Processing participants' data in line with General Data Protection Regulation (GDPR)*

### *How will we use information about you?*

We will need to use information from you for this research project. This information will include your:

- name and postal address if you wish to receive vouchers and study findings;
- name and email address or telephone number if you wish to be contacted about an interview;

- anonymised demographic information about you: whether you are a patient or a family member/carer of a patient; your age range; sex; gender; ethnicity; whether you have a disability; whether you have any ongoing health issues.

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 by:

- Securely storing information collected at Bradford Teaching Hospitals NHS Foundation Trust, where it will remain confidential;
- Your answers to the questionnaire will be downloaded into an Excel spreadsheet, which will be stored in a folder on a secure and regularly backed up Trust server with access restricted to the research team;
- Any contact details you provide to receive a voucher/findings or be contacted about an interview will be transferred to and stored in a separate spreadsheet in the secure, restricted access folder on the Trust server, accessible only to members of the research team;
- We aim to publish our findings in academic journals and present at conferences. You will not be identified in any report/publication and nor will the surgery.

Your personal data will not be stored or shared outside the UK.

### *How will we use information about you after the study ends?*

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 you took part in the study.

We will keep your study data for a maximum of 5 years. The study data will then be fully anonymised and securely archived or destroyed.

### *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.
- 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.

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

You can find out more about how we use your information:

- www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by sending an email to Hannah.Gregson@bthft.nhs.uk or
- by ringing us on 01274 274310

## Further supporting information

### *What if something goes wrong?*

We do not think that being part of this research will have any risks for patients or their families/carers but if you have any concerns, contact a member of research team listed at the end of this information sheet. Alternatively, if you want to talk to someone who's not directly involved in the

study, you can contact the Patient Advice and Liaison Service or PALS at Bradford Teaching Hospitals NHS Foundation Trust, the sponsor for the study, on 01274 364810 (Monday to Friday 9am – 4pm) or email: Patient.experience@bthft.nhs.uk. You can also contact the Trust Data Protection Officer (DPO) on dataprotectionofficer@bthft.nhs.uk or the Information Governance team on Information.Governance@bthft.nhs.uk

### *What will happen if I don't want to carry on with the study?*

You do not have to complete the questionnaire and your care will not be affected by your decision in any way. If you change your mind after completing it we will not be able to delete your responses because questionnaire data will be stored anonymously and so we will not know which are yours.

### *Who is organising and funding this study?*

This study is funded by the National Institute for Health and Social Care Research's (NIHR) Research for Patient Benefit (RfPB) programme (ref. NIHR208819) and is being led by Bradford Teaching Hospitals NHS Foundation Trust, which is the sponsor for the study.

### *How have patients and the public been involved in this study?*

Patients and members of the public were involving in designing and testing SSNAP. During the study, a patient and public group meets regularly to advise on aspects ranging from making sense of information collected, to making sure people hear about the findings.

### *Who has reviewed this study?*

This study has been reviewed by Leeds East Research Ethics Committee, ref. 25/YH/0163, and was approved on 7/10/25. The research design was also reviewed as part of the NIHR funding process.

### *Further information and contact details*

If you have any questions or concerns you can contact:

Lynn McVey (Chief Investigator): Lynn.McVey@bthft.nhs.uk

Hannah Gregson (Research Fellow) Hannah.Gregson@bthft.nhs.uk

Thank you for reading this information sheet.