

**S**ymptoms and **N**utrition **A**fter **C**ritical **C**are

**Invitation to take part in Research**

**and**

**Participant Information Sheet**

Were you in a critical care unit (ICU or HDU) on a breathing machine?

We would like to invite you to take part in our **SNA** survey.

This involves **completing a survey** once you are at home, asking about:

* your critical care stay
* any after effects or symptoms you may have
* any changes in your eating or weight
* any dietary advice you had or would have liked

Just 25 minutes of your time will help us find out how common these problems are and will help us support future patients better.

If you want more information about this research, please read the next 3 pages.

So, when you are at home, please **complete this survey either:**

* **online** at: [**https://plymouth.onlinesurveys.ac.uk/snacc**](https://plymouth.onlinesurveys.ac.uk/snacc)

*(please type this into the address bar at the top, as a search engine will not find it)*

**OR**

* **over the phone\*** by leaving a message for the researcher, Louise Albrich, on: **07557314013** or snacc@ydh.nhs.uk *(Louise* ***will phone you back*** *to arrange this)*

**OR**

* a **postal survey** is also available on request

Please contact Louise if you have any questions.

Participants will be offered a chance to be entered into a prize draw for a £50 voucher from Marks & Spencers, Waitrose or Sainsbury’s.

This sheet was provided: by post □; in hospital □; at rehabilitation □; at clinic □; by email □

**Summary of the research**

We want to find out how common it is for patients at home to suffer with after effects of being critically ill on ICU, such as reduced appetite and gut symptoms, taste changes, hair loss, weakness and low mood. We would like to see if any of these symptoms link with changes in eating or weight, and whether patients received or wanted nutrition advice.

We are looking for patients 18 years or older, at home or being discharged home, who were on a breathing machine (ventilation) through a throat tube or a tight fitting mask. We cannot include people who are unable to eat or drink anything orally e.g. receiving nutrition only through a tube (nasogastric, percutaneous gastrostomy (PEG), nasojejunal or jejunostomy) or line into your veins (total parenteral nutrition (TPN)).

We have asked hospital critical care teams to give you this ‘research invitation and information sheet’ after ICU discharge or alternatively at any critical care rehabilitation sessions or follow-up clinics.

We ask you to volunteer to complete an online survey at home, which should take you only about 25 minutes to fill in. If you prefer, you can choose to do the survey over the phone with the researcher (Louise Albrich) or we can post you a paper copy which you can fill in and return.

This research is coordinated from Yeovil Hospital, but patients are being invited to take part from hospitals all over the UK. The charity ICU Steps will also email their members that are interested in participating in research.

The study will run over a 6 month period from September 2017.

**Why is this research needed?**

The after effects or symptoms following a severe critical illness impact on daily living and can be long-lasting. This is most common in patients who were on a breathing machine (ventilator or tight mask) for 3days or more. It is thought that some of these symptoms may be associated with dietary intake, but it is unclear how common this is. There is national care guidance on how to support and rehabilitate patients after critical illness, but this does not yet include possible nutritional problems. This survey aims to explore nutrition-related problems and how to better support patients through their journey of recovery.

**What would taking part involve?**

All that is involved is for you to complete the survey at a time that suits you. It will only take 25 minutes of your time.

The survey can be completed online using this link: [**https://plymouth.onlinesurveys.ac.uk/snacc**](https://plymouth.onlinesurveys.ac.uk/snacc).

This online survey can be paused at any time using the ‘Finish later’ button which will save everything entered and send a link to an email you provide. You then use this link to continue the survey later when more it’s convenient.

If you prefer, you can complete the survey over the phone by contacting the researcher (Louise). If you had already started the online survey, just leave your details (in the box below the purple writing), press ‘Finish later’ and type snacc@ydh.nhs.uk as the email address. Louise will then ring you.

Paper copies can also be posted to you to fill in and post back in a stamped addressed envelope.

**What information is asked?**

The survey asks questions about your critical illness, the extent to which you experience a list of symptoms, whether you had any diet advice, your weight through your recovery, and a little about yourself. The questions are either tick box, with a scale or list, or you are asked to type your answer. We advise having any information about your hospital stay and medications to hand before starting the survey. Family members or your critical care team can help provide answers if needed, and the researcher is available by phone to help answer any questions. Remember, the survey can be paused at any point.

**What are the potential benefits?**

Completing this survey may not directly benefit you, but the information will help healthcare professionals support patients with nutritional difficulties better in the future.

You will be offered a chance to enter into a prize draw to win a £50 voucher for Marks and Spencers, Waitrose or Sainsbury’s.

**What if I have any concerns?**

If through completing this survey you identify specific nutrition related problems that need addressing, you can contact the researcher, Louise, who can assist you in seeking help.

For any other concerns please contact the Patient Advice and Liaison Service (PALS) for which we provide details on the next page.

**How will consent be obtained?**

You are asked to confirm your consent online before completing the survey. Involvement in this survey is completely voluntary and you can withdraw participation at any time without the need for a reason, and without your medical or legal rights being affected.

**How will information be kept confidential?**

All information that is shared through this research will be kept confidential. The data collected will be anonymised and no identifiable information will be used in reports or publications. All data will be kept in secure files and be kept for research purposes only. Contact details for initial contact, telephone survey completion or the prize draw will be kept separately to the survey data on a secure study database, not shared with anyone, and will be destroyed after use. The study has been approved by the Health Research Authority and Louise is supported by the National Institute for Health Research.

**How will this research be shared?**

This research will be written up in a report, presented at conferences and submitted for publication in a scientific journal whilst maintaining confidentiality. We will also share the findings with ICUsteps.

**What service user involvement has there been?**

Service users (patients) helped finalise the survey documentation and tested the survey questionnaire.

**Contact details and f**[**urther information:**](http://www.hra-decisiontools.org.uk/consent/content-sheet-support.html#seven)

For more information on the study or to discuss participation or completion of the survey, please contact the researcher:

Louise Albrich, Clinical Research Masters student and Dietetic practitioner

Phone: 07557314013

Email: snacc@ydh.nhs.uk

Post: Dietetics Department, Yeovil District Hospital NHS Foundation Trust, Higher Kingston, Yeovil, Somerset, BA21 4AT

If you have any concerns you need to raise with someone outside the research team, please contact:

The Yeovil Hospital Patient Experience Team on:

Phone: 01935 384706

Email: pals@ydh.nhs.uk

For more information on critical care after-effects and support groups see:

ICUsteps, Kemp House, 152 City Road, London, EC1V 2NX

<http://www.icusteps.org/>

<http://www.nhs.uk/Conditions/intensive-care/Pages/Introduction.aspx#when>

<http://icusteps.org/assets/files/IntensiveCareGuide.pdf>