

International Pressure Injury Consumer Survey

About this Survey

The book *Prevention and Treatment of Pressure Ulcers/Injuries: Clinical Practice Guideline* is being updated. This book teaches nurses, doctors and other carers about pressure injuries. The book is used across the world in hospitals and clinics.

The EPUAP/NPUAP/PPPIA research team is doing a survey for updating this book. The researchers are from universities around the world, including the Australian National University (ANU). All the researchers are experts in pressure injuries. The contact researchers are:

- Associate Professor Emily Haesler (ANU and Curtin University)
- PD Dr. rer. cur. Jan Kottner (Charité Universitätsmedizin Berlin)
- Professor Janet Cuddigan (University of Nebraska).

Outline of the Project

Pressure injuries are a type of wound. Pressure injuries are also called pressure ulcers, pressure sores, bed sores, bed ulcers or decubitus ulcers. A pressure injury occurs for many reasons but often happen when someone is lying in one position for too long.

We are asking patients and carers what they would like to know about pressure injuries. The answers will be used to update the book and make information sheets for patients around the world. The book will be available on this website in late 2019. We might report the survey results in a research journal. This will be available on the project website, www.internationalguideline.com in late 2019.

What does being involved in the research mean?

We care about the “voice of the patient”. If you or a loved one have had a pressure injury, or have worked to prevent pressure injuries, we are interested in your experience. To be involved you can do a short survey on this website. The survey asks you to share your knowledge, preferences and values. The survey takes about 5 or 10 minutes.

Agreeing to do the survey

You do not have to do this survey (it is voluntary). If you do the survey, your answers are private (confidential). The survey doesn't ask your name. You can complete the survey without us knowing who you are (anonymous). If you do not want to continue the survey at any point, you are welcome to return a blank survey, or throw the survey away.

If you do the survey, you do not have to answer all the questions. After you submit the survey you cannot change or delete your answers. This is because we will not know which survey is yours.

Risks and Benefits

The survey has no personal benefits to you. By answering the survey you will help us to give patients and carers around the world information they want to know about pressure injuries. This might help other people avoid having a pressure injury.

The survey has no risks. You might feel very small discomfort about answering broad questions about your health. If you feel uncomfortable, you can stop taking the survey.



Confidentiality

If you do the survey, your answers are private. The survey doesn't ask your name (anonymous). When we write the results, answers from everyone who did the survey are combined, so no one can tell who you are (confidential).

Privacy Notice

The ANU must comply with the Privacy Act 1988 when it approves a survey. You can read the ANU Privacy Policy at https://policies.anu.edu.au/ppi/document/ANUP_010007.

The policy contains information about how to complain about a breach of an Australian Privacy Principle by ANU, and how ANU will handle the complaint.

Survey Storage

Your answers will be stored on a secure computer in Canberra, Australia for at least 5 years. At the end of the storage period the data will be archived for future research projects. The survey might be repeated next time we update the book, so we might compare them to this survey.

Contact Details

If you need more information or you are concerned about this survey.

If you need more help or information please contact:

- **In Australia, New Zealand and Asia:** Associate Professor Emily Haesler: emily.haesler@anu.edu.au
- **In Europe:** PD Dr. rer. cur. Jan Kottner: Jan.Kottner@charite.de
- **In the Americas:** Professor Janet Cuddigan: jcuddiga@unmc.edu
- **In any country (international call to Canberra, Australia):**
Associate Professor Emily Haesler: +61 2 6244 2946

Ethics Committee clearance

The ethical aspects of this research have been approved by the ANU Human Research Ethics Committee (Protocol 2018/66). If you have problems or complaints about this survey, please contact:

Ethics Manager

The ANU Human Research Ethics Committee
The Australian National University
Telephone in Canberra, Australia: +61 2 6125 3427
Email: Human.Ethics.Officer@anu.edu.au

How to complete the survey

You can do the survey online at <http://internationalguideline.com>

You can complete the survey on paper on the pages that follow and give it back to your health professional. He or she will enter your details online for you.

International Pressure Injury Consumer Survey

1. What country do you live in? _____

2. How old are you?
 - a. Less than 18 years
 - b. 18 to 30 years
 - c. 30 to 50 years
 - d. More than 50 years

3. Have you ever had a pressure injury?
 - a. Yes
 - b. No
 - c. Not sure

- 3a. When did you have a pressure injury?
 - a. Now
 - b. In the past year
 - c. 2 to 5 years ago
 - d. More than 5 years ago

4. Have you been told that you might get a pressure injury? (“at risk”)
 - a. Yes
 - b. No
 - c. Not sure

5. Have you cared for a person with a pressure injury?
 - a. Yes
 - b. No
 - c. Not sure

- 5a. When did the person you cared for have a pressure injury?
 - a. Now
 - b. In the past year
 - c. 2 to 5 years ago
 - d. More than 5 years ago

6. Have you been told that someone you care for might get a pressure injury? (“at risk”)
 - a. Yes
 - b. No
 - c. Not sure

7. What is the biggest problem for you about pressure injuries?

8. The most important goals for me or the person I care for are: (select up to 3)

- a. Stopping any pressure injury from happening
- b. Stopping a large pressure injury from happening
- c. Reducing the size of a pressure injury
- d. Totally healing a pressure injury
- e. Managing pain
- f. Managing other problems from a pressure injury (e.g. ooze, smell)
- g. No goals
- h. Other goal/s

9. The topics in the book are listed below. Please check how important each topic is **for you to know more about** for caring for yourself or someone with a pressure injury.

- a. How a pressure injury happens
- b. What things could increase the chance of getting a pressure injury
- c. My hospital having a plan to stop pressure injuries
- d. My doctors, nurses and carers knowing about pressure injuries
- e. Where to get more information about pressure injuries
- f. What to eat and drink to keep the skin healthy
- g. The type of bed or chair you use
- h. How you lie in a bed or sit in a chair (positioning) and when to move
- i. Caring for skin underneath a cast or brace or medical tubes
- j. How to check your skin is healthy
- k. How to care for the skin to stop a pressure injury happening
- l. Stopping a pressure injury when I can't move myself or the person I care for
- m. How to help a pressure injury heal
- n. Knowing if a pressure injury is healing/when it will heal
- o. What products to put on a pressure injury
- p. Dealing with pain from a pressure injury

10. What questions do you have about pressure injuries?

11. Please tell us a bit about your health and experience with pressure injuries. (optional)
