

International consumer engagement in guideline development:

Surveying patients in 30 countries

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For the Pressure Injury Guideline Governance Group

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Background

Guideline, International Pressure Clinical Injury developed representatives from peak wound care bodies in over 30 countries and led by the US National Pressure Ulcer Advisory Panel, European Pressure Ulcer Advisory Panel and Pan-Pacific Pressure Injury Alliance, is being revised. Consumer engagement is promoted in the guideline development through surveys, patient developers and stakeholder review.

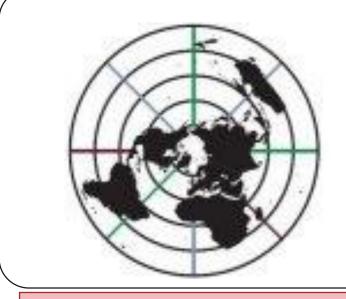
Goal

To promote consumer involvement in guideline development, and to determine consumer priorities for information and resources on pressure injury prevention and treatment.

Methods

- Ethics clearance or waivers from universities and health bodies in Australia, USA and Japan.
- World-wide patient/informal caregiver survey, available in nine languages.
- Survey developed with attention to readability, time to complete and ease to complete.
- Promotion by peak wound care bodies, consumer representative organisations and clinical staff in 30 countries.
- Survey available online since 24 April 2018, open until 30 October 2018.

Results: Consumer engagement (at 3 months)



Responses from 25 countries

Responses from 1177 people

> 37 potential patient developers



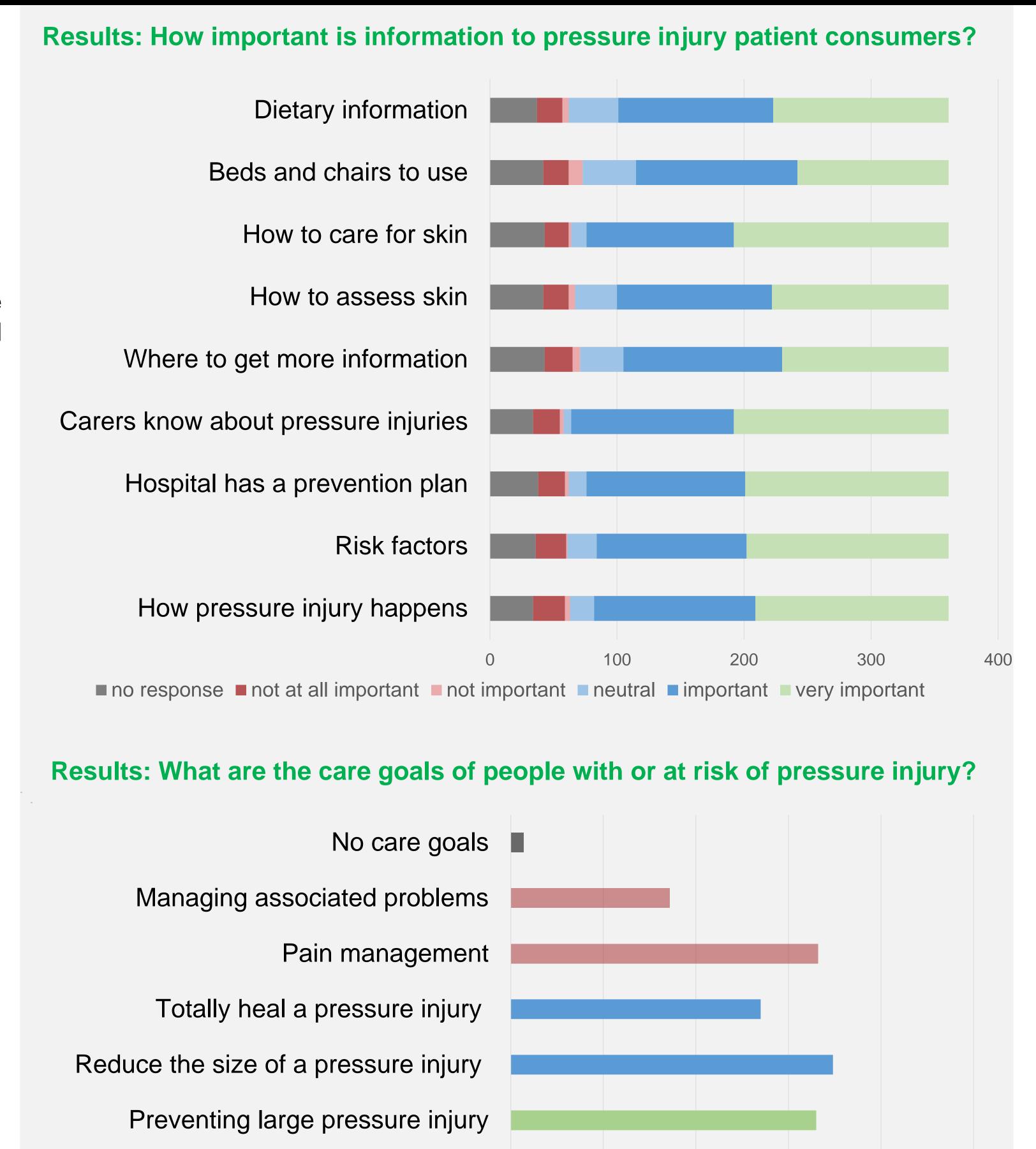
361 respondents identified as a person with or at risk of a pressure injury

119 respondents had experienced a pressure injury



736 respondents identified as a caregiver

36 caregivers had also had a pressure injury themselves



Discussion: Challenges faced in surveying consumers and strategies implemented

Methodological and project challenges

- Determining what information to collect
- Negotiating international ethics requirements
- Coordinating multiple translation teams
- Incorporating data into guideline content

Resource challenges

- Limited budget and staffing
- Limited access to consumers

Survey accessibility challenges

- Simple survey interface design
- Readability
- Web accessibility in different countries

- International project team
- Documented, accessible methodology

Preventing any pressure injury

- Consult with researchers experienced with consumer engagement
- Multiple choice questions and Likert scales for easy, point-&-click responses
- Standardized translation templates
- Utilize 200+ clinician guideline contributors to promote the survey
- Press releases and social media
- Consumer perspectives incorporated into Evidence to Decision framework
- Develop region-specific patient resources

Implications for guideline developers

150

200

250

100

More evidence successful on strategies that promote consumer input into guideline development is needed.

Surveys are a successful strategy to promote consumer engagement and incorporate consumer goals and needs during the stages of guideline development.

The International Pressure Injury Clinical Guideline (3rd edition) will be available November 2019.

http://internationalguideline.com

