International consumer engagement in guideline development: Surveying patients in 30 countries

Assoc. Prof. Emily Haesler, Curtin University and Australian National University, Australia
Prof. Janet Cuddigan, University of Nebraska Medical Center, United States
Dr Jan Kottner, Charité-Universitätsmedizin Berlin, Germany
Prof. Kerelyn Carville, Curtin University, Perth, Australia
For the Pressure Injury Guideline Governance Group

Background
The International Pressure Injury Clinical Guideline, developed by 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
- 736 respondents identified as a caregiver
- 119 respondents had experienced a pressure injury
- 36 caregivers had also had a pressure injury themselves

Results: How important is information to pressure injury patient consumers?

- Dietary information
- Beds and chairs to use
- How to care for skin
- How to assess skin
- Where to get more information
- Carers know about pressure injuries
- Hospital has a prevention plan
- Risk factors
- How pressure injury happens

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

Implications for guideline developers
More evidence on successful 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