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# Creating consensus-based practice guidelines with 2000 nurses

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## ABSTRACT

Medical professionals follow evidence-based practice guidelines to achieve effective patient outcomes. Traditionally, to develop guidelines, a small group of experts examine evidence then agree on a set of statements, which are then published in journals. However, more than 7000 primary care journal articles are published monthly. This study examined a different way of drawing up practice guidelines, which involved large numbers of nurses from different countries directly in developing then disseminating the guidelines to speed up acceptance and the implementation of best practice. The results were consensus-based best practice guidelines for the treatment of patients with ostomies, which have received a high level of acceptance and enthusiasm from practitioners in 27 countries.

**Key words:** Ostomy ■ Stoma ■ Developing practice guidelines ■ Consensus building ■ Optimising patient outcomes ■ Quality of life

**T**raditional medical practice has been for clinical research specialists to study an issue and the evidence around it, determine the best practices to reach the desired medical outcome and make recommendations, which are published in journals, for practitioners in the field to follow. However, it is estimated that more than 7000 primary care journal articles are published monthly and that it would take a clinician over 625 hours per month to evaluate these articles (Alper et al, 2004).

MIT professor Edgar H Schein (2013) calls this the 'culture of do and tell'. Best practice guidance 'is nothing if it is not

used' (Patton, 1997), a statement that is reinforced by the many examples of evidence-based medical practice changes that fail to be implemented and therefore do not result in improved patient outcomes (Grol et al, 2005). Evidence suggests involving clinicians in the development of an innovation or proposal of change promotes implementation (Grol et al, 2005).

This research was designed to determine if a more collaborative approach to developing best practice guidelines for stoma care nurses would lead to faster acceptance and implementation and, ultimately, better patient outcomes. The study involved large numbers of nurses directly in the guidelines' development and in the dissemination of this information to speed up acceptance and implementation of the best practices.

According to Ostomy UK, more than 102 000 people in the UK have a stoma. Estimates of the global population of people living with a stoma range from 1 million to 2.5 million. Various studies have reported that as many as 76% of people with a stoma experience leakages (Porrett et al, 2011; Claessens et al, 2015; Maydick-Youngberg, 2017) and that this results in a loss of confidence in their stoma and a significantly decreased quality of life (Richbourg et al, 2007; Welser et al, 2009; Erwin-Toth et al, 2012; Colwell et al, 2017; Maydick-Youngberg, 2017). When surveyed, more than 75% of stoma care nurses reported that they sometimes or often encounter patients who have reduced their participation in hobbies, socialisation, leisure and physical activities because of their stoma and almost 40% of nurse respondents reported having stoma patients who do not leave their homes because of their worry about leakages (based on Delphi surveys carried out during stages 2 and 3 of this project). Evidence shows that, with the right treatment and appliance, patients can resume their normal activities with confidence but clinical practice guidelines for product selection are lacking (Hoeftok et al, 2017).

This project created a global consensus on medical practice guidelines between close to 2000 stoma care nurses, which is designed to significantly increase the quality of life of people with a stoma by using appliances that match their body profile to ensure the best fit and confidence.

## Methods

A modified Delphi process was used for this project, which combined the scientific rigour of the traditional Delphi and RAND Nominal Group Technique (NGT-R), with virtual

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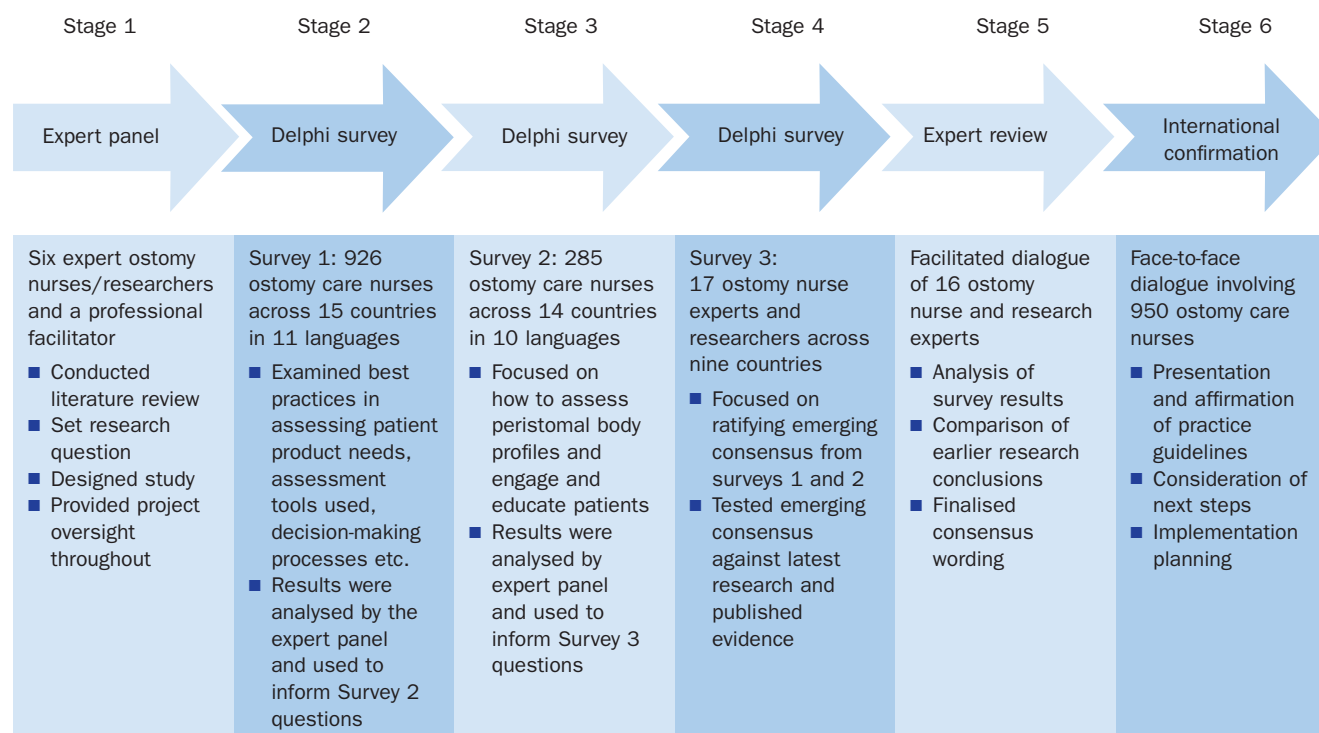


Figure 1. Modified Delphi research methodology

and face-to-face professionally facilitated dialogues. The methodology was designed by an International Association of Facilitators certified professional facilitator, who had received specialised training in evaluative sciences.

The modified Delphi process includes elements of traditional Delphi survey methodology (Dalkey and Helmer, 1963), NGT-R (Murphy et al, 1998) and process facilitation (Schuman, 2001). The hermeneutic approach used in this study includes both the top-down and bottom-up approaches recommended in Grol et al's (2005) theory of change (Grol et al, 2005).

Stage 1 of the process started with a group of international stoma care nurse experts gathering for a combined face-to-face and virtual meeting to determine the study questions, the objectives and to approve the overall study methodology and design. This included an advisory group who led the research study and an expert panel who provided expert advice throughout the research process (Table 1).

A detailed literature review was conducted, which was reviewed by the advisory group and expert panel members at the beginning and periodically throughout the research process, using the Stetler model of research utilisation (Stetler, 2001). An independent facilitator led all group dialogues, using structured group facilitation processes, to ensure outcome-based and balanced conversations were conducted, where all

group members had an equal say in the decision-making and where all ideas were heard and thoughtfully considered. The advisory group continued their interactions through a series of virtual dialogues that occurred at each stage of the research process. Through these discussions they informed the Delphi survey process by contributing to question design, determining survey dissemination methods and interpreting results. The expert panel was consulted at stages 1, 4 and 5 of the process.

In Stage 2, the first Delphi survey was created and sent out in 11 languages to stoma care nurses around the world, via regional and nursing association mailing lists. Survey responses were anonymous, which allowed respondents to be confident in sharing their experience and expertise without being concerned they would be identified.

The first Delphi survey collected information that included: each respondent's experience as a stoma care nurse; the factors they consider in assessing patients; if and how they assess stoma patients' quality of life; assessment tools they regularly use; the most common issues and complications they see with their stoma patients; how often they see patients; how they educate stoma patients; and their opinions about optimal best practices in stoma care. In total, 926 responses were received from nurses who provide specialised stoma care in 11 languages. Responses from clinicians who were not nurses or did not provide specialised stoma care were not included in the results or analysis. Another series of virtual dialogues were conducted with the advisory group to analyse the results of the first survey and to develop a follow-up survey.

For stage 3, the second Delphi survey was disseminated in the same manner as the first survey. The second survey, built on the responses from the first survey, was used to confirm the results of the first survey and solicit the opinion of

Table 1. Nationality of advisory group and expert panel members

Advisory group	Canada (facilitator) Denmark (two members, one from Coloplast), Germany, UK, USA
Expert panel	Australia, Belgium, Canada (two), Czechia, Denmark, France (two), Germany, UK (two), USA

### Consensus guidelines—standardising peristomal body profile assessment to enable quick and individualised solutions to improve quality of life

- Contact should be made with stoma patients within 2 weeks of hospital discharge to reassess the patient's body profile and determine which ostomy product type will provide the best security and confidence
- Contact should be made with patients within 2 weeks after a product change or modification to determine the product's efficacy and action should be immediately taken if security is still an issue
- Body profile and peristomal skin health should be assessed at every product change whether a stoma nurse is present or not. Patients should be given tools to help them accurately assess their own peristomal skin health and identify when to seek help
- When a clinician removes or changes a product, they should always assess peristomal skin health, preferably with a validated skin assessment tool
- A patient's peristomal body profile should be assessed regularly using a validated body profile assessment tool and should include the following:
  - Consider the shape of the area around the stoma—is it regular, inward or outward?
  - Is the shape around the stoma uniform or variable?
  - Is the area around the stoma soft or firm?
  - Does the skin around the stoma have superficial creases or deep folds?
  - What is the location of the stoma—above bending line, at bending line, below bending line?
  - What is the position of the stoma opening and the height of the stoma?
- These six steps will help determine the body profile and inform the decision on type of product best suited for that patient (concave, convex or flat). After assessing the patient's peristomal body profile, it will then be up to the clinical judgement of the nurse to determine the best product and accessory combination for that patient. The following should be considered when making that clinical judgement:
  - Patient's health and quality-of-life goals
  - Output type and volume
  - Patient capabilities
  - Patient support
- Product type recommendations should be based on the patient's body profile and skin assessment, preferably using validated tools. Product type should not be made based on provider preference, a set order of product usage (ie start with a flat product and if that doesn't work move to a convex) or through trial and error
- Help patients become more proactive in their own health by understanding how to identify changes to their peristomal body profile and when to seek assistance from a stoma nurse. Engage and educate patients throughout their journey, provide access to tools and education on how to use the tools and help set realistic goals with patients around optimal health and quality of life, throughout their ostomy journey

Figure 2. Final consensus guidelines

respondents on specific best practices in stoma care. The second survey was answered by 285 stoma care nurses in 10 languages. Since all surveys were anonymous, researchers were unable to track if respondents to the second survey had also completed the first survey. Language preference cannot be linked to country of origin, as invitations included links to the survey in all languages, so respondents could choose their language regardless of where they lived.

In stage 4, the results were analysed by the advisory group in a second series of virtual dialogues and a third survey was developed. The third Delphi survey was sent to the advisory group and the international expert panel. Sixteen personalised survey invitations were sent and 14 responses were received.

The questions in the third survey focused on the practice guidance that had emerged from the earlier surveys and facilitated dialogues, narrowed the consensus and tested it against the literature.

Then, for stage 5, all the survey results were summarised and presented to the advisory group and expert panel at a one-day, face-to-face workshop, facilitated by the independent facilitator. The group analysed the consensus process results and refined the wording into best practice guidelines for stoma care nurses designed to ensure optimal quality of life for their stoma patients. The resulting guidelines, the *Consensus Guidelines—Standardising Peristomal Body Profile Assessment to Enable Quick and Individualised Solutions to Improve Quality of Life*, include best practices regarding: frequency of contact with patients; how to assess patients' body profile; the use of validated assessment tools; and how to engage and educate patients and encourage them to be proactive partners in their own care (Figure 2).

The final step in the process—stage 6—was conducted at Ostomy Days 2018 in Copenhagen, where 960 stoma care nurses were presented with and endorsed the best practice guidelines and then engaged in a facilitated dialogue on how to speed acceptance and implementation of the guidelines around the world. An interview matrix facilitation process was used, where every nurse present answered four questions (Box 1), in the language of their choice, in a series of one-to-one and many-to-many conversations. The themes of the conversations were summarised and documented by participants in their language groups then translated and thematically grouped by the facilitators. The results were then presented back to the participants at the close of the Ostomy Days congress and were later provided in writing to participants by the congress organisers.

### Participants

More than 2000 nurses were involved in the consensus building process, covering 20 countries and 16 languages (Table 2), with a combined experience of over 16 million hours of specialised stoma care. An estimated 1200 nurses answered one or more of the Delphi surveys and more than 960 were involved in one or more face-to-face dialogues. Respondents were experienced stoma care nursing professionals, with 75% having more than 10 years of full-time stoma care experience (Figure 3).

### Ethical considerations

Institutional review board approval was provided without qualifiers by Asentral IRB.

All surveys were 100% anonymous with no way for survey responses to be linked to respondents. Demographic information collected focused solely on clinical credentials and type of clinical practice. No individual patient information was collected. The resulting guidelines do not refer to or recommend any products or brands, but instead focus on how to assess patients, identify their body profile requirements and determine the type of product best suited for that patient to provide the highest level of confidence.

**Table 2. Response language in order of prevalence by process stage**

Survey 1 (n=926)	Survey 2 (n=285)	Ostomy Days dialogue (n=960)
English	Dutch	Italian
French	French	Spanish
Japanese	English	German
Dutch	Czech	English
Czech	Japanese	French
Swedish	Swedish	Dutch
Danish	Danish	Russian
Italian	Italian	Portuguese
Norwegian	Norwegian	Danish
German	Finnish	Chinese
Finnish		Korean
		Finnish
		Czech
		Swedish
		Slovak
		Japanese

## Results

The results exceeded the expectations of the advisory group, who reached 100% agreement on the outcomes and reported that the large-scale collaborative process was effective and produced sound, evidence-informed best practice guidelines. All members of the expert panel endorsed the resulting guidelines as well. Participant evaluations at the end of the Ostomy Days congress assessed participants' overall satisfaction with the project process and the results. Participants rated the process and the results very highly, with a mean score of 8.8 on a scale of 1-10 with 10 being the highest satisfaction rating.

Results of the Delphi surveys also indicated that nurse respondents understood the need for best practice guidance focused on increasing patient outcomes and quality of life. Ninety-five percent of respondents agreed it was part of the stoma care nurse's job to ensure their stoma patients are able to experience an optimal quality of life. However, they observed that the majority of their stoma patients changed

### Box 1. Best practice questions

1. What can we do to ensure peristomal body profiles are always assessed accurately?
2. What can we do to ensure the assessment of the patient's body profile is used to determine the best product type for that patient?
3. What can we do to promote the use of evidence-based practices in stoma care, especially the use of validated assessment tools, like the body profile terminology and the Ostomy Skin Tool?
4. How will you inform your colleagues of these recommendations and teach them in their use when you return home?

their lifestyles and decreased social and physical activities as a result of their stomas (Table 3). When asked why patients decreased socialisation, leisure and physical activities after their stoma, respondents said experiencing leakages in the past as the number one reason (Figure 4) and that having evidence-based, standardised practice guidelines could or would benefit them and their patients. (Figure 5).

The results also support the hypothesis that including large groups of clinicians in the development of practice guidelines leads to faster acceptance, accelerated implementation in patient care regimens and ultimately in better patient outcomes. Close to 2000 nurses from more than 25 countries endorsed the guidelines and developed and committed to implementation action plans to disseminate and promote them among colleagues in their home countries (Figure 6).

The key themes that emerged during the Ostomy Days congress dialogue were:

- Frequent interaction with patients is required and should be anchored in strong, two-way communication (listening to the patient) and patient education on how to conduct their own body profile and skin assessments
- Educate providers and patients on how to assess peristomal body profiles accurately, with an emphasis on continuous assessment to identify changes at an early stage and change treatment and products before complications occur using the practice guidelines developed through this process (Figure 2)
- Use validated assessment tools and continuously evaluate and improve tools and processes to ensure the best possible patient outcomes

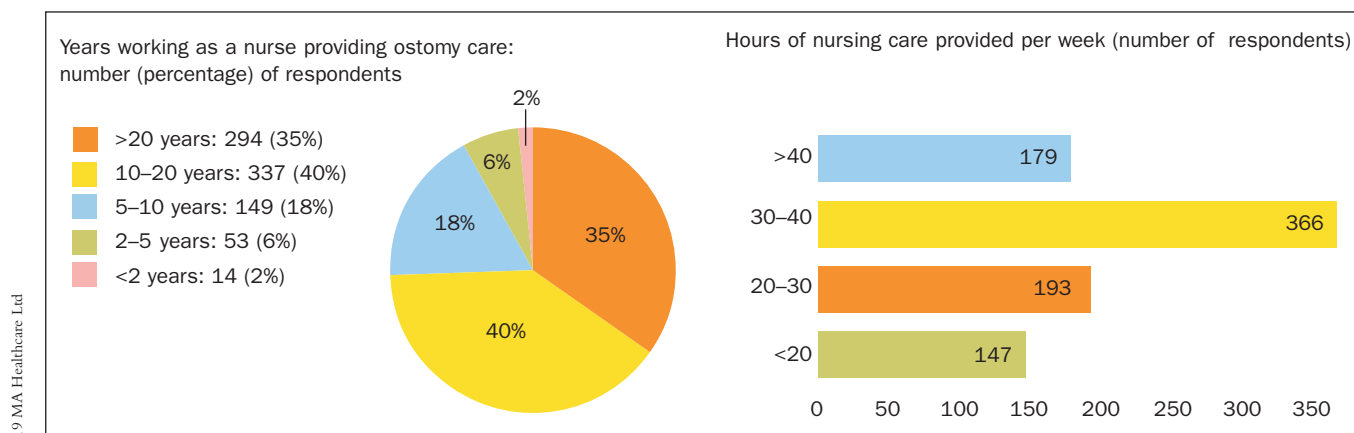


Figure 3. Experience of respondents—years of working and hours of nursing per week



**Table 3. Patient lifestyle changes because of a stoma observed by nurses**

Patients behaviour change	Percentage of nurses who see this sometimes of often in stoma patients
Refuse to leave their homes	40.00%
Only leaving their home for short periods of time	63.16%
Not staying away from home over night	69.12%
Reduced socialisation	76.49%
Decreased physical activity	87.37%
Decreased physical intimacy	80.70%
Significantly reduction in hobbies and social activities	76.14%

- Promote, champion and demonstrate the use and importance of the guidelines with all stoma care providers, by everyone, at all times.

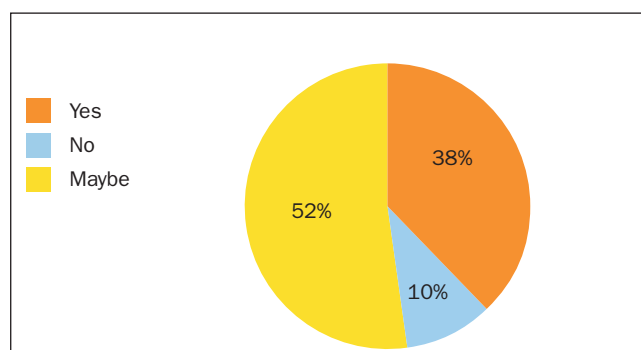
### Conclusions

The results of this study demonstrate the applicability of popular, scientific, decision-making and implementation science theories to the development of medical practice guidelines that lead to better patient outcomes. It supports the idea that evidence-based best medical practice guidance can be developed using large-scale consensus processes, and that the inclusive approach of the process leads to accelerated implementation and results in improvements in patient outcomes.

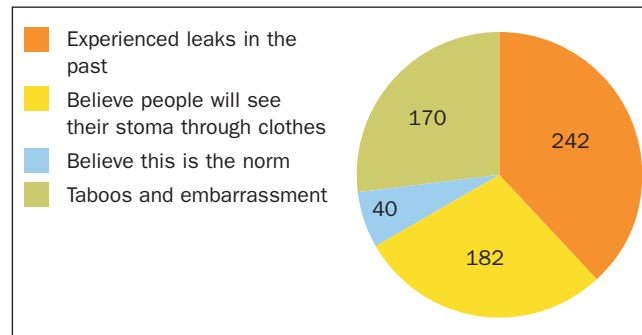
The research also provided practice guidelines designed to lead to better outcomes and quality of life for patients with a stoma. The guidelines are being championed by more than 2000 stoma care nurses in 25 countries and are leading to changes in care regimens for thousands of stoma patients around the world. Further research is recommended into the long-term effects of the practice guidelines on patient quality of life.

Replication of the large-scale consensus process used in this research is also recommended for the development of other types of medical practice guidelines. This would further demonstrate the effectiveness of a collaborative approach on the speed of acceptance and adoption of the best practices and ultimately on patient outcomes. **BJN**

*Declaration of interest: Coloplast A/S funded the study. The research question, project oversight and resulting consensus-based*



**Figure 5. Would evidence-based guidelines be beneficial?**



**Figure 4. Why do patients decrease social, leisure and physical activities? (number of respondents)**

*practice guidelines were created by the advisory group and expert panel, independent of the sponsor. Coloplast products were not mentioned in the surveys nor in the communications with participants. The advisory board members and the authors of this paper have no conflict of interest to declare in the research, results or publication of the findings*

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### KEY POINTS

- Popular decision-making and implementation science theories can be applied to the development of medical practice guidelines
- Consensus-based best practice guidelines for the treatment of ostomy patients have received a high level of acceptance and enthusiasm from clinicians across 27 countries
- Involving large numbers of nurses in the development of clinical practice guidelines can lead to evidence-based and experience-based best practices that lead to better patient outcomes
- Involving front-line healthcare staff in the development of practice guidelines leads to faster acceptance and implementation



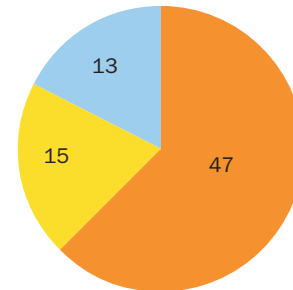
Numbers in chart = number of times that a recommendation was made by a group

**Figure 6A. How to inform colleagues**

How will you inform your colleagues of these recommendations and teach them in their use when you return home?

**Three themes emerged**

- 1. Teach and educate colleagues
  - Everyone. Doctors, patients, ward nurses, homecare etc
  - Teach always—at meetings, associations, when having coffee with colleagues etc
- 2. Create training materials
  - In all forms and formats to help colleagues understand and embrace the recommendations
- 3. Promote, champion and demonstrate the use and importance of the recommendations
  - Create champions in each community/hospital/association
  - Promote the standard of care through multiple channels (eg social media)
  - Demonstrate how to use the recommendations and how they increase patient outcomes

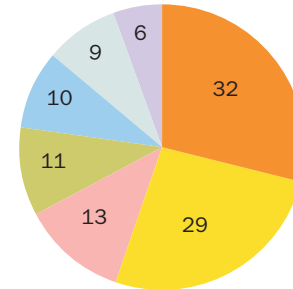


**Figure 6B. How to promote evidence-based practices**

What can we do to promote the use of evidence-based practices in stoma care, especially the use of validated assessment tools, like the body profile terminology and the Ostomy Skin Tool?

**Seven themes emerged**

- 1. Practical, simple tools, with visuals that promote standardized terminology
- 2. Continuing education—mentoring, train the trainer, seminars, nursing schools etc
- 3. Develop and use validated tools, that are evaluated and approved in all countries
- 4. Create and distribute materials in multiple forms, brochures, web-based, videos, YouTube, etc
- 5. Evaluate tool usage, continuously evaluate tools to ensure evidence-based and relevant
- 6. Spread the word at congresses and other venues to all health professionals, not just stoma care nurses
- 7. Assess patients both pre- and postoperatively, using standardised tools, protocols and terminology

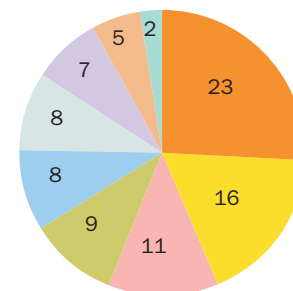


**Figure 6C. Accurately assessing peristomal body profiles**

What can we do to ensure peristomal body profiles are always assessed accurately?

**Nine themes emerged**

- 1. Educate about and publicise the body profile terminology
- 2. Conduct personalised face-to-face patient assessments
- 3. Use consistent language
- 4. Develop/use visual tools
- 5. Educate about available tools and how to use them
- 6. Encourage and help patients to self-assess their body profile
- 7. Standardise documentation
- 8. Use validated assessment tools
- 9. Document practical case studies and use them to educate



**Figure 6D. Using peristomal body profile to determine best product type**

What can we do to ensure the assessment of the patient's body profile is used to determine the best product type for that patient?

**Six themes emerged**

- 1. Ongoing and frequent patient assessments (in all positions), communication and training
- 2. Clinician training
- 3. Create and use a decisional tool to help assess a patient's body profile and determine the right product type to maximise security and confidence
- 4. Provide and promote a standardised process for use by all ostomy care nurses
- 5. Evaluate and validate all tools and processes
- 6. Conduct and publish studies and research to continuously improve tools and processes and validate all evidence-based practices

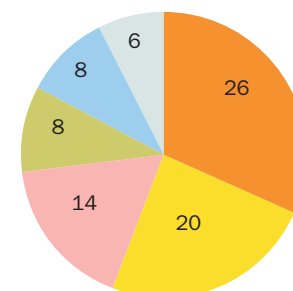


Figure 6. Ostomy Days congress consensus results



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## CPD reflective questions

- What do you see as the main strengths and weaknesses of this type of consensus-based process in the development of medical practice guidelines?
- In what areas of your organisation or professional practice do you see this type of consensus-based process being well received and effective, and why?
- If you were given the opportunity to contribute to the development of medical practice guidelines using a process such as the one described in this article, what factors would you consider in determining whether or not you would participate?

