

Original Article

Development of a national strategy for palliative care

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ABSTRACT

INTRODUCTION. In 2020, the Danish National Audit Office (Rigsrevisionen) criticised the Danish palliative care (PC) provision. The Board of the Danish Association for Palliative Medicine (DSPaM) recognised an urgent need for a national strategy to improve PC in Denmark. The Board wished to develop a strategy which ensured acceptance and legitimation internationally and within the DSPaM. The aim of this study was to describe the development of the DSPaM 'National strategy of palliative care for patients with life-threatening diseases'.

METHODS. The Cicely Saunders International (CSI) action plan, 'You matter because you are you, an action plan for better palliative care,' seemed applicable because of its extensive, evidence-based content. A thorough translation and cultural adaptation were followed by group discussions and a Delphi process among DSPaM members.

RESULTS. The Delphi process underwent eight editions before the final version was approved by the DSPaM Board in January 2024. A total of 36% of the members participated in the group discussions in January 2022. The response rates were 43% in the first and 62.8% in the second survey, with a final average member agreement of 92.7%. The main differences were that the CSI action plan mentions COVID-19 pandemic and patient empowerment, whereas the Danish strategy document refers to socially vulnerable patients.

CONCLUSIONS. A Danish strategy document for PC was developed through a Delphi process involving the DSPaM members. The Danish strategy document was approved by a large majority of DSPaM members, thus providing a solid ground for a common national strategy for PC in Denmark.

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TRIAL REGISTRATION. Not relevant.

In 2020, the Danish National Audit Office (Rigsrevisionen) criticised the provision of palliative care (PC) in Denmark [1]. In response, the Board of the Danish Association for Palliative Medicine (DSPaM) recognised the

urgent need for developing a national strategy to improve PC.

The DSPaM is a medical scientific association founded in 2001 [2]. Its purpose is to facilitate and optimise PC in Denmark [3, 4]. All physicians with an interest in palliative medicine are welcome to join the association, and by 2022, the DSPaM had 200 members.

Ahead of the DSPaM 20th annual meeting in 2022, the DSPaM Board discussed how the organisation could initiate a process to define new national goals for palliative care in Denmark, recognising the need for a national strategy for PC. The previous 2020 goals were set in 2010 by the DSPaM Board at the time. In 2021, the members of the Board decided to focus on developing a national strategy instead of creating a new set of very specific goals. The Board adopted this strategy to gain both international acceptance and legitimation within the DSPaM.

In 2021, Cicely Saunders International (CSI) published its action plan '*You matter because you are you, an action plan for better palliative care*', which presents challenges and solutions for seven main themes to improve PC in the United Kingdom [5]:

1. Provide PC expertise in places where people are cared for: hospitals, care homes, hospices and at home
2. Make joined-up care a reality
3. Empower patients and carers to have greater choice and control over the things that are important to them
4. Invest in community care services
5. Provide healthcare professionals and careers with high-quality PC training
6. Use outcome measures to embed a system of continuous learning and improvement
7. Fund world-leading research into PC.

As no prior publications provided guidance on developing member-involving, national, strategic PC documents, the DSPaM Board decided to create a process consisting of a translation and cultural adaptation of the CSI action plan involving members; acknowledging that the final result could differ from the CSI document.

Hence, the aim of this study was to describe the process of developing the '*National strategy of palliative care for patients with life-threatening diseases*' of the DSPaM [6].

Methods

The CSI was contacted in October 2021, and permission was granted to use their CSI action plan as a basis for the forthcoming Danish strategy document [5]. The CSI action plan was thoroughly translated and culturally adapted, followed by a group discussion and a modified Delphi process involving DSPaM members [7, 8].

Translation and cultural adaptation of the Cicely Saunders International action plan

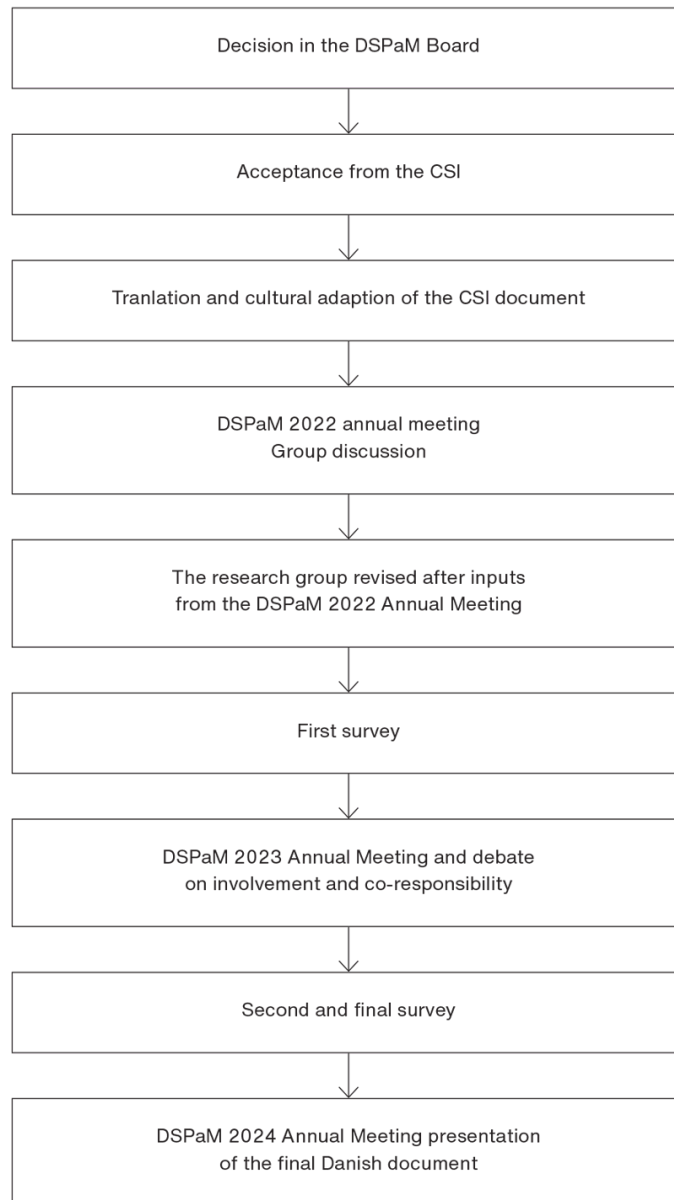
A direct translation of the CSI action plan was done by one of the authors (MKH), followed by a thorough cultural adaptation to the Danish healthcare context and society by five co-authors (EH, MG, JP, MKH, MAN), resulting in the first draft of a Danish Strategy document. This draft was unanimously approved by the DSPaM Board (EH, JP, DLH, HAN, AH, MKH, KM, MG, PS, MAN).

Group discussions at the annual Danish Association for Palliative Medicine meeting

At the annual DSPaM Meeting in January 2022, the first edition of the Danish strategy document was presented to members who then self-organised into smaller discussion groups. All groups were given the opportunity to discuss and document their considerations regarding any content and wording issues.

After the meeting, incoming comments were analysed (**Figure 1**). Three authors (TL, LN, KM) were responsible for making a second draft of the document, which was approved and revised by the authors (TL, KM, MG, MAN, TA, PS). A third edition was circulated to the full DSPaM Board, who were invited to provide comments and suggest revisions, resulting in a fourth edition.

FIGURE 1 The development process of the Danish Association for Palliative Medicine's 'National strategy of palliative care for patients with life-threatening diseases' [6].



CSI = Cicely Saunders International; DSPaM = Danish Assocoation for Palliative Medicine.

The modified Delphi process

For a modified Delphi process among all DSPaM members, the Board defined consensus as 70% agreement in the final survey, consistent with commonly used thresholds in Delphi studies [8]. No limit was decided regarding response rate in the Delphi process. The DSPaM Board also decided that changes could be made right up to the

approval of the final document. This ensured that the final document was as visionary and valuable as possible.

In the first survey of the Delphi process, DSPaM members were asked to decide on the preferred wording to be used consistently throughout the Danish strategy document.

The comments and new ideas from the first survey were collected by two authors (TL, KM), who prepared a fifth edition incorporating comments presented to the co-authors. Once the author group agreed on a sixth edition, it was sent to the DSPaM Board, spawning more changes and resulting in a seventh edition.

In July of 2023, the seventh edition was distributed in a second Delphi survey among DSPaM members. This time, members were given the opportunity to indicate their agreement or disagreement with each of the recommendations. A final document, the eighth edition, was produced by (TL, KM) after these final comments were received and approved by the DSPaM Board.

Comparing the Danish strategy document with the strategy document of Cicely Saunders International

One author (KM) compared the two documents. As they were identical in structure, the content was reviewed section by section, focusing on substantive differences rather than wording, given that the two documents were in Danish and British English.

Trial registration: not relevant.

Results

The development of the Danish DSPaM strategy document underwent eight revisions before the final version was approved by the DSPaM Board in January 2024. A total of 36% (72/200) of the members participated in the group discussions in January 2022, giving feedback on the first version of the document.

The first survey in the modified Delphi study was completed in early 2023. The response rate was 43% (86/200) (31% completed the full survey, while 12% did not answer all the questions).

In the first Delphi survey, the wording 'Basic PC' was tested against 'General PC', 'Primary PC' or 'Other proposals'. 'Basic PC' was chosen in the survey by 60.9%, whereas the other wordings were preferred by 17.4%, 11.6% and 10.1%, respectively. 'Basic PC' is also a defined term used by the Danish Health authorities [9]. Likewise, the wording of 'Life-threatening illness' versus 'Serious illness' was tested. Here, 'Life-threatening illness' received 69.1% and 'Serious illness' 27.9% of the votes.

In the second and final survey, the average agreement with the document was 92.7% (Table 1). By the time of this survey, the DSPaM had 191 members, 62.8% (120/191) of whom completed the survey.

TABLE 1 Level of agreement and suggestions to the Danish strategy document presented by 'Introduction' and 'Themes' of the 120/191 (62.8%) participating members of the Danish Association for Palliative Medicine in the second and final Delphi survey.

	Agreement among participating members, %	Members who made other suggestions, %
<i>Introduction</i>		
Danish strategy document p. 2	89.3	7.8
Danish strategy document p. 3	95.1	4.9
<i>Themes including challenges and solutions in the Danish strategy document</i>		
Theme 1	93.9	5.1
Theme 2	92.8	7.2
Theme 3	96.9	2.1
Theme 4	91.7	7.3
Theme 5	90.6	5.2
Theme 6	91.7	5.2
Theme 7	93.8	2.1

Comparing the Danish strategy document with the CSI action plan, a few differences between the two documents stand out:

Introduction about the need for a plan for PC, the CSI action plan mentions the impact of the COVID-19 pandemic, which is not mentioned in the Danish strategy document.

Theme 1 about providing PC wherever people are living, the Danish strategy document included PC for homeless patients and patients in prisons. These groups were not mentioned in the CSI action plan.

Theme 2 about joined-up care, no major differences between the two documents.

Theme 3 is empowerment. The CSI action plan describes the professionals encouraging and facilitating patients' and carers' self-management of symptoms. In the Danish strategy document, this was described as supporting and involving patients and caregivers.

Theme 4 about investment in community care services, the CSI action plan focused on the challenges related to the fact that hospitals may become overcrowded. The Danish strategy document focused on the challenge of retaining and training qualified professionals in primary health care. Another difference in Theme 4 was that the Danish strategy document included a recommendation for the availability of round-the-clock specialised advice and regular conferences between specialist and basic PC levels, which was placed under Theme 1 in the CSI action plan.

Theme 5 about training in PC, the CSI action plan stated, 'provide healthcare professionals and carers with high-quality PC training', whereas the Danish strategy documents' heading only stated the healthcare professionals. Another essential difference was that the Danish strategy document advocates for a recognised medical specialty, which was not mentioned in the CSI action plan since this was already the case in the United Kingdom.

Theme 6 about outcome measures, the CSI action plan mentioned more general outcome measures to improve quality, whereas the Danish strategy document focused on the quality indicators of the national Danish Palliative

Care Database for specialised PC. Furthermore, it was recommended that the database be expanded to include the basic level of care and that paediatric quality indicators be incorporated.

Theme 7 about research, the CSI action plan stated an ambition to be a world leader in PC research, while the Danish strategy document stated an ambition to raise research to a high international level.

Discussion

In this paper, we have described a member-involved process for developing a national strategic document for the future development of PC in Denmark. Through translation, cultural adaptation, group discussions and two Delphi rounds, a new Danish strategy for PC was launched: 'National strategy of PC for patients with life-threatening diseases' [6].

The process was based on a translation of the CSI action plan [5]. CSI's extensive work, expertise, history, and impact were the reasons why we decided to build on an existing document.

Studies have shown that it is difficult to turn strategies into widely shared, impactful documents. For example, the Danish Respiratory Society published a statement in 2015, which was developed by pulmonary medicine and palliative medicine experts about PC, including Advance Care Planning [10-12]. However, in a survey from 2020, while 71% of the Society's members were aware that a statement had been published, only 3% stated that they used it regularly [13]. The DSPaM intended to enhance the strategy's ownership and impact by involving the members in the process. Future dissemination and studies will show if this initiative paid off.

Denmark has traditionally been closely linked to developments in the European Association for Palliative Care and the World Health Organization (WHO). When the DSPaM members were asked in the survey whether to use 'life-threatening' or 'serious illness', a majority of members voted for the traditional 'life-threatening illness', which is in line with the CSI document that follows WHO 2002 [14], and the subsequent Danish Health Authority's recommendations for PC [9]. An argument was made for 'serious illness' as this is used in the International Association for Hospice and Palliative care, the American Thoracic Society and the European Respiratory Society, which in 2020, 2022 and 2023, respectively, launched documents defining PC all using 'severe illness' in the description of the target groups [15-17]. However, the majority of DSPaM members chose to follow the European Association for Palliative Care and WHO tradition.

The difference in focus on COVID-19 in the Introduction may reflect that the CSI action plan was published in 2020 when COVID-19 was a significant concern for many. It probably also reflects the relatively modest involvement of specialised PC in the COVID-19 pandemic efforts in Denmark.

The lack of a Danish focus on patients' and relatives' self-management in Challenge 3 compared to the British version might indicate a professional difference between the two countries, which was not explored in this study. Danish patients are often referred to specialised PC very late in the disease trajectory. The median survival time after affiliation with specialised PC is 34 days [18]. Whether this is decisive for Danish PC, not mentioning self-management and empowerment but rather focusing on the efforts of the health professionals, is an essential topic that should be investigated in the future. Self-management is also a much-debated topic in European healthcare systems [19].

Overall, the Danish strategy document is very similar to the CSI action plan. This may reflect that the Danish PC tradition is founded on the British and international PC tradition. However, it may also be because many elements of the two healthcare systems are quite similar, e.g. co-operation between primary and secondary health care and a rather small private healthcare sector. Furthermore, patients' PC needs are quite universal, and PC needs to develop everywhere globally [20].

The chosen method of member involvement attempted to delegate ownership to DSPaM members throughout the process, and the work was also firmly rooted in the DSPaM Board.

A major strength of the development process was that the British document was used as a starting point, thus building on extensive previous work and experience. A disadvantage of this process is that it may limit the ability to pursue other ideas. A strength of our analysis of the two documents is that they are structured identically. Thus, they can be compared section by section, thereby reducing the need to make syntheses and estimates.

Conclusions

To strengthen and disseminate PC in Denmark, the DSPaM developed a Danish strategy document through a member-involving process of adapting the CSI action plan.

The Danish document was approved by the members of the DSPaM with a large majority, thus providing a solid ground for a national strategy for PC in Denmark.

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