PRiSM: Specialist Palliative Care's Role in Cancer Survivorship Model

Developing European consensus recommendations on the role of specialist palliative care in cancer survivorship to inform a model of care.

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Amy Taylor, Andrew Davies
School of Medicine, Trinity College Dublin
Our Lady's Hospice & Care Services, Dublin
Email: tayloram@tcd.ie

Harold's Cross
Blackrock
Wicklow
Respite Rehabilitation Reassurance

Background

Specialist palliative care services (SPCS) provide holistic care for individuals with health-related suffering and those close to them. Historically this included patients with advanced cancer, however, many on anticancer treatment or deemed in remission or "cured" also have significant unmet needs, including poor symptom control, but do not typically access SPCS. It is broadly accepted that cancer survivorship begins at the time of diagnosis and continues throughout life, so all these individuals are classed as "cancer survivors".

Aims and objectives

The aim of this study is to develop European expert consensus about the role of specialist palliative care (SPC) for people who have / had cancer, especially those who do not typically access SPCS, where expert groups are professional and non-professional experts in SPC and oncology (ONC).

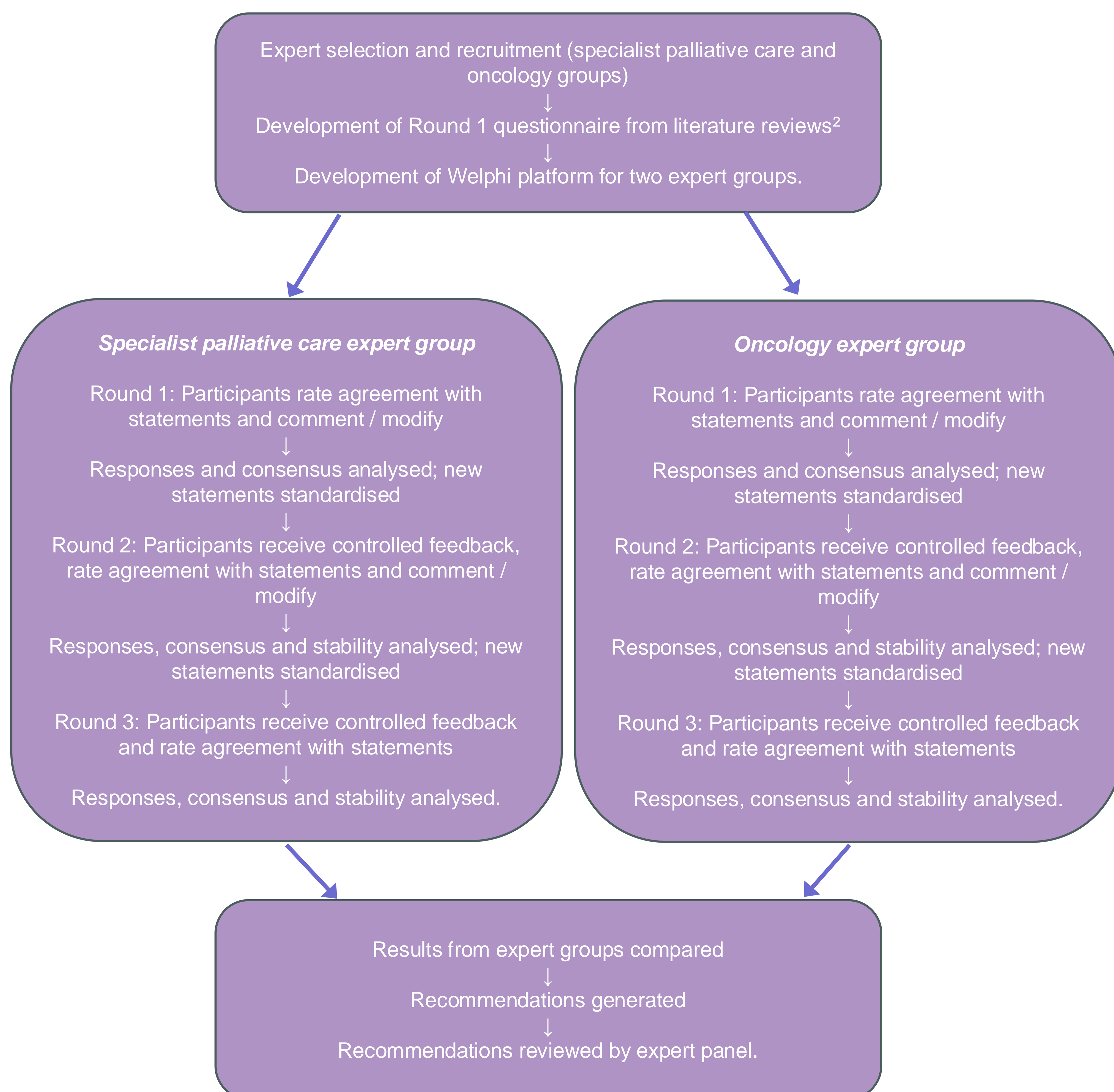
The objectives are:

- To develop expert consensus on the core functions of SPCS.
- To develop expert consensus on who should be described as "cancer survivors".
- To develop expert consensus on categories of individuals with cancer or a history of a cancer diagnosis.
- To develop expert consensus on the role of SPC for categories of individuals with cancer or a history of a cancer diagnosis.
- To identify the barriers to increasing the scope of provision of specialist palliative care services for individuals with cancer or a history of a cancer diagnosis.

Methods

A European Delphi process was undertaken via the online platform Welphi[1]. Recruitment involved purposive sampling of professional and non-professional SPC and ONC experts through international/national organisations and patient advocacy groups, forming two separate groups. Figure 1 outlines the steps. Consensus was pre-defined as >=75%, Spearman's Rank Order Correlation determined stability, and the Chi-square goodness of fit test identified differences between group outcomes.

Figure 1: Flow chart showing PRiSM e-Delphi process



Results

Eighty-six SPC experts representing nineteen countries/regions and various disciplines entered the study, and 80 completed all three rounds. Fifty-four ONC experts representing seventeen countries/regions entered the study, and 49 completed the process. Outcomes were achieved for 166 statements. Stable consensus between the final rounds was achieved for 93 statements for both groups, an additional 14 in the SPC group, and 9 more in the ONC group about the core functions of SPCS (Figure 2), the application of "cancer survivors" (Figure 3), categories of individuals who have/had cancer, and the extended role of SPCS for groups of individuals who have/had cancer (Tables 1 and 2). The groups differed significantly in 13 statements that reached consensus in only one group, including perspectives on the type of service and current SPC skills.

Consensus statements

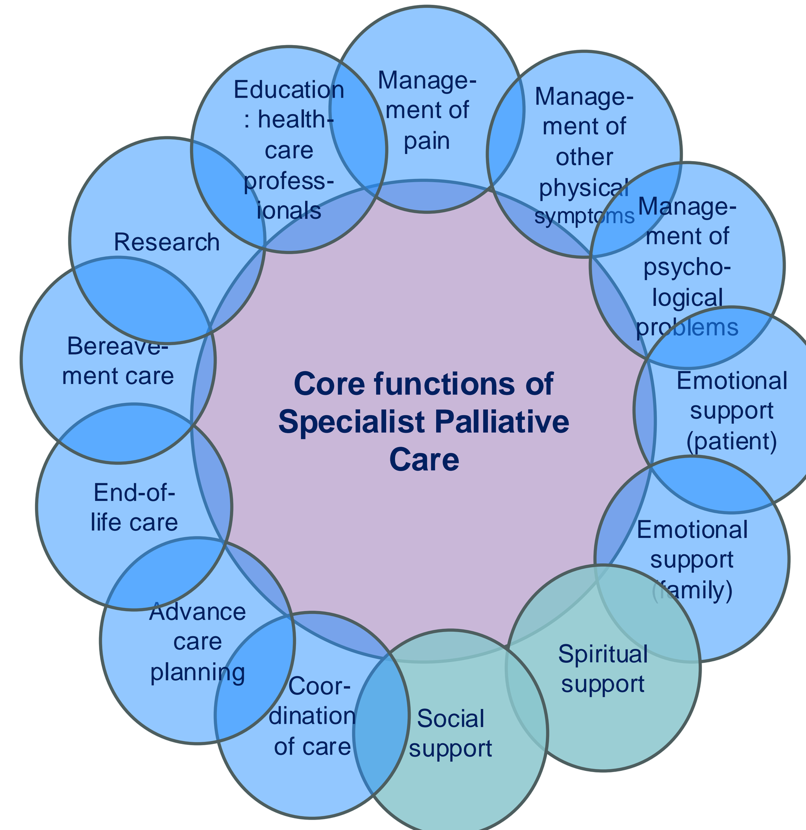


Figure 2: Consensus-based core functions of SPCS. Key: Blue circles = consensus reached in both SPC and ONC groups; green circles = consensus reached in SPC group only.

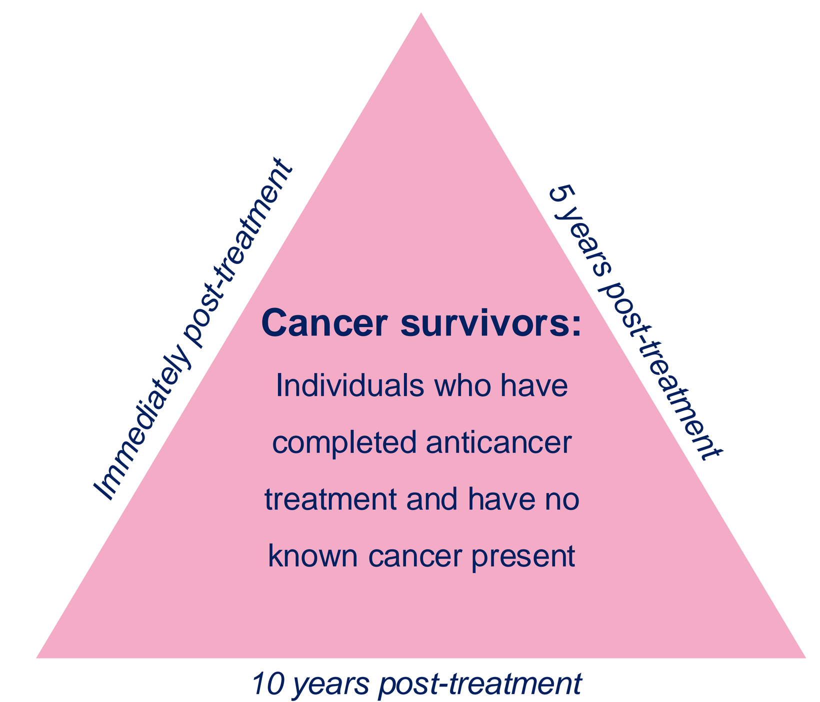


Figure 3: Consensus statements on who should be defined as "cancer survivors".

Extended role of specialist palliative care

Table 1: Consensus statements on the extended role of SPCS for individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease.

Statement reaching consensus	% SPC group	% ONC group
Expert group agrees that SPCS should have a role in supporting the following components of care:		
Management of pain	76%	81%
Expert group disagrees that SPCS should have a role in supporting the following components of care:		
Prevention of second cancers	89%	87%
Surveillance for recurrence or second cancers	88%	90%
Managing financial problems ("financial toxicity")	79%	68%
Expert group agrees that SPCS generally have the knowledge and skills to support the following components of care:		
Management of pain	88%	92%
Management of other physical symptoms / problems	86%	84%
Management of psychological distress	83%	81%
Supporting caregivers	78%	69%
Expert group disagrees that SPCS generally have the knowledge and skills to support the following components of care:		
Prevention of second cancers	90%	92%
Surveillance for recurrence or second cancers	86%	88%
Managing financial problems ("financial toxicity")	76%	47%
Expert group agrees that the following are barriers to extending the input of SPCS to this group:		
Financial resources	82%	71%
Human resources	90%	81%
Time resources	85%	85%
Lack of relevant education and training	81%	62%
Misperceptions about the nature of palliative care	76%	75%
Type of service:		
Expert group agrees that:		
A dedicated multidisciplinary specialist team is required	89%	87%
Expert group disagrees that:		
SPCS should not contribute to this team	80%	83%
SPCS should lead this team	76%	80%

Key: SPC = specialist palliative care expert group; ONC = oncology expert group; SPCS = specialist palliative care services; unshaded box = consensus reached in both expert groups; shaded box = consensus reached in SPC but a majority insufficient to reach consensus in ONC.

Table 2: Consensus statements on the extended role of SPCS for individuals with stable advanced / metastatic disease.

Statement reaching consensus	% SPC group	% ONC group
Expert group agrees that SPCS should have a role in supporting the following components of care:		
Surveillance of physical symptoms / problems	91%	84%
Surveillance of psychological distress	92%	84%
Management of pain	100%	100%
Management of other physical symptoms / problems	100%	96%
Management of psychological distress	100%	98%
Support for cultural, spiritual and religious needs	87%	75%
Supporting caregivers	91%	87%
Advance care planning	98%	98%
Expert group agrees that SPCS generally have the knowledge and skills to support the following components of care:		
Surveillance of physical symptoms / problems	95%	89%
Surveillance of psychological distress	95%	94%
Management of pain	99%	100%
Management of other physical symptoms / problems	99%	98%
Management of psychological distress	98%	94%
Support for cultural, spiritual and religious needs	78%	65%
Supporting caregivers	88%	85%
Care coordination between specialists and primary care providers	81%	81%
Advance care planning	94%	100%
Expert group disagrees that SPCS generally have the knowledge and skills to support the following components of care:		
Prevention of second cancers	77%	74%
Expert group agrees that the following are barriers to extending the input of SPCS to this group:		
Financial resources	86%	90%
Human resources	91%	100%
Time resources	90%	94%
Misperceptions about the nature of palliative care	87%	86%
Type of service:		
Expert group agrees that:		
A dedicated multidisciplinary specialist team is required	89%	94%
SPCS should be a core member of this team i.e. routinely involved in care	83%	85%
SPCS should be an extended member of this team i.e. support with relevant problems / issues	79%	83%
Expert group disagrees that:		
SPCS should not contribute to this team	98%	98%

Conclusions

This study has developed consensus statements on the role of SPCS in cancer survivorship by determining the perspectives of European professional and non- professional experts in SPC and ONC. It is the first study clarifying expert opinion in this area, and also highlights key areas of contention within and between these groups. Results will be developed further by an expert panel to inform a new care model.

Funding

Dr Amy Taylor was awarded a European Cancer Community Foundation Rising Star Grant for this research.

References

1. Welphi. Welphi: the survey app to build consensus [Internet]. Lisbon: Decision eyes; 2024. [updated 2024; cited 2024 Aug 12]. Available from: https://www.welphi.com/en/Home.html
2. Taylor A, Davies A. The role of specialist palliative care in individuals "living beyond cancer": a narrative review of the literature. Support Care Cancer. 2024;32(7):414.