

1 **Determining the core content of a digital survivorship care plan for melanoma** 2 **survivors: A multi-stakeholder Delphi-consensus study**

3
4 Dear Editor, Given the increasing incidence and survival rates of melanoma, survivorship care
5 (SSC) is becoming increasingly important. However, implementation and effectiveness of related
6 survivorship care plans (SCPs, personalised care plans for cancer survivors) are currently
7 suboptimal, and may benefit from tailoring their content to key stakeholders' needs. In addition,
8 a dynamic digital format would enable tailored content to meet the diverse individual needs.
9 Since it remains unclear what elements they consider essential, we conducted a three-round,
10 multi-stakeholder e-Delphi consensus study among melanoma survivors and their healthcare
11 providers (HCPs) with the objective of achieving consensus on the core content of a melanoma
12 SCP.

13
14 Forty-four potential elements were identified from prior in-depth qualitative research on stage-
15 and treatment phase specific melanoma SSC perspectives and needs^{1,2}, and structured according
16 to the main SSC categories: (1) information and education, (2) identification and treatment, (3)
17 oncological follow-up and (4) coordination^{3,4}. Thirty-eight melanoma survivors (stage I-IV) and
18 26 HCPs (dermatologists, internist-oncologists, (oncological) surgeons, nurse specialists, support
19 counsellors and general practitioners) treated or working in one of four regional hospitals in the
20 south-western part of the Netherlands were invited to participate by email. Participants were
21 asked to rate the desirability of including elements using a 5-point Likert scale. Consensus was
22 defined as $\geq 70\%$ rating an element as 'definitely include' or 'definitely exclude'. Equivocal
23 elements were presented again in the next round. We emphasised that the eventual content of the
24 SCP would be adapted to every individual patient's melanoma stage and treatment phase.

25
26 After three rounds, thirty-two survivors (84.2%) and 15 HCPs (57.7%) participated, with
27 respectively 27 (71.1%) and 10 (38.5%) completing all three rounds. Consensus was reached on
28 24 out of 44 elements to be included in a melanoma SCP (Table 1). The majority of agreed
29 elements belonged to category 1 or 3. Most elements in category 2 and 4 remained equivocal.
30 Notably, major differences in opinion between survivors and HCPs were observed, with
31 survivors mainly rating elements concerning improving coordination, and HCPs mainly rating

1 elements related to improving psychosocial care as desirable to be included. No consensus was
2 reached on excluding elements from the SCP.

3
4 The data that support the findings of this study are available from the corresponding author, and
5 will be shared on reasonable request. The need for ethical approval of this study was waived by
6 the medical ethical committee of the Erasmus University Medical Centre after review of the
7 study design (MEC-2019-0558 and MEC-2020-0197).

8
9 The finding that key areas of consensus focused on information and education, and oncological
10 follow-up, underscores the importance of clear, actionable information throughout the entire
11 disease trajectory. This aligns with traditional content and formats of SCPs³. However, our study
12 also suggests the need for expansion of traditional SCP content by providing e.g., comprehensive
13 information about the whole care process, advice on decisions regarding (systemic) therapy, a
14 personal follow-up schedule and elements supporting self-management in detecting recurrences.
15 This is consistent with previous literature emphasising the importance of adequate patient
16 education throughout the treatment process⁵ and on survivor engagement and empowering
17 patients to stimulate self-management in future SCP practices^{3, 6, 7}.

18
19 Notably, elements related to psychosocial support were not deemed crucial for inclusion, while
20 previously stressed as important.^{1, 2} This may indicate that patients do not perceive SCPs as the
21 appropriate platform for this information. Additionally, our study revealed diverging
22 perspectives between melanoma survivors and HCPs, particularly regarding psychosocial
23 support and care coordination. For instance, tools to enhance information transmission were
24 valued highly by survivors but less so by HCPs. This discrepancy echoes previous research
25 demonstrating lower patient satisfaction levels with care coordination compared to HCPs'
26 perceptions⁸. Understanding the reasons behind these differences could provide valuable insights
27 into refining SCP content. Furthermore, differentially weighting of melanoma survivors' and
28 HCPs views should be considered, as SCPs are primarily designed for patients.

29
30 This study had several limitations, including the regional restriction of the participant sample.
31 However, given that melanoma care is organised in similar networks (in which systemic

1 treatment is centralised) across the Netherlands, our findings are likely applicable to other
2 melanoma centres within the country, and potentially internationally if melanoma care is
3 embedded in similar networks.

4
5 In conclusion, the findings highlight the importance of providing adequate information
6 throughout the entire disease trajectory, and personal oncological follow-up supporting self-
7 management. Furthermore, the study underscores the value of understanding and addressing
8 potential divergences in perspectives between survivors and HCPs. By exploring and
9 overcoming these differences and incorporating the consented elements into the design of a
10 melanoma SCP, its implementation and effectiveness in practice can be facilitated, leading to
11 SSC tailored to stakeholders' needs.

12 13 **Acknowledgements**

14 We would like to thank all melanoma survivors and HCPs that participated in this study. In
15 addition, we would like to thank Marije Stenstra, melanoma survivor representative, Rick
16 Waalboer-Spuij, dermatologist and Belle de Rooij, specialist in SSC for reviewing the e-Delphi
17 concerning content and language. Furthermore, we would like to thank Julia van den Broek and
18 Esther de Bijl for their contributions to the e-Delphi development

19
20 Nadia C.W. Kamminga,¹ Marlies Wakkee,¹ Inez Swart,¹ Tamar E.C. Nijsten¹ and Marjolein
21 Lugtenberg^{1,2}

22
23 ¹Department of Dermatology, Erasmus MC Cancer Institute, University Medical Center
24 Rotterdam, The Netherlands

25 ²Department Tranzo, Tilburg School of Social and Behavioral Sciences, Tilburg University,
26 Tilburg, The Netherlands

27
28 **Correspondence:** Marjolein Lugtenberg

29 **Email:** m.lugtenberg@erasmusmc.nl

30
31 **ORCID:** NCWK - <https://orcid.org/0000-0002-8386-2540>

1 MW - <https://orcid.org/0000-0001-8578-901X>

2 IS - <https://orcid.org/0000-0002-5225-3363>

3 TECN - <https://orcid.org/0000-0001-9940-2875>

4 ML - <https://orcid.org/0000-0002-4117-2154>

5
6 **Funding sources:** This study was multi-sponsored by Bristol Myers Squibb (BMS), Merck
7 Sharp & Dohme (MSD), Novartis and Pierre Fabre. The sponsors were not involved in the
8 design of the study, data collection, data analysis, manuscript preparation and/or publication
9 decisions.

10 **Conflicts of interest:** None to declare.

11 **Data availability:** The data underlying this article will be shared on reasonable request to the
12 corresponding author.

13 **Ethics statement:** The need for ethical approval of this study was waived by the medical ethical
14 committee of the Erasmus University Medical Centre after review of the study design (MEC-
15 2019-0558 and MEC-2020-0197).

16 17 **References**

- 18 1. Kamminga NCW, van der Veldt AAM, Joosen MCW, de Joode K, Joosse A, Grunhagen
19 DJ, et al. Experiences of resuming life after immunotherapy and associated survivorship care
20 needs: a qualitative study among patients with metastatic melanoma. *Br J Dermatol*. 2022.
- 21 2. Kamminga NCW, Wakkee M, De Bruin RJ, van der Veldt AAM, Joosse A, Reeder SWI,
22 et al. Oncological healthcare providers' perspectives on appropriate melanoma survivorship care:
23 a qualitative focus group study. *BMC Cancer*. 2023;23(1):278.
- 24 3. Hewitt M, Greenfield S, Stovall E. Lost in transition. From cancer patient to cancer
25 survivor. 2005:1-506.
- 26 4. Netherlands HCot. Follow-up in Oncology. Identify objectives, substantiate actions. . The
27 Hague: Health Council of the Netherlands, 2007/2007.
- 28 5. Cartee TV, Alam M, Armbrecht ES, Behera A, Lawrence N, Bordeaux JS, et al. Patient-
29 Centered Outcomes for Skin Cancer Management: Utilization of a Patient Delphi Process to
30 Identify Important Treatment Themes. *Dermatol Surg*. 2019;45(2):246-53.
- 31 6. Vaz-Luis I, Masiero M, Cavaletti G, Cervantes A, Chlebowski RT, Curigliano G, et al.
32 ESMO Expert Consensus Statements on Cancer Survivorship: promoting high-quality
33 survivorship care and research in Europe. *Ann Oncol*. 2022;33(11):1119-33.
- 34 7. van de Poll-Franse LV, Nicolaije KA, Ezendam NP. The impact of cancer survivorship
35 care plans on patient and health care provider outcomes: a current perspective. *Acta Oncol*.
36 2017;56(2):134-8.

- 1 8. Mohr DC, Benzer JK, Vimalananda VG, Singer SJ, Meterko M, McIntosh N, et al.
- 2 Organizational Coordination and Patient Experiences of Specialty Care Integration. *J Gen Intern*
- 3 *Med.* 2019;34(Suppl 1):30-6.
- 4

ACCEPTED MANUSCRIPT

Table 1 Elements reaching consensus / no consensus per main category of SSC

Information and education	C	Personal information incl. (1) melanoma stage, (2) Breslow thickness and (3) treatments. General information about (4) diagnosis; treatment, including (5) schedule with all treatment steps, (6) surgical removal of the melanoma, (7) scans during treatment, (8) sentinel node procedure, (9) (adjuvant) systemic treatments, (10) possible side effects, (11) treatment effectiveness and (12) possible long-term and late effects; (13) decision for (adjuvant) systemic therapy; (14) advice in the decision for (adjuvant) systemic therapy.
	NC	General information about (15) possibility for a second opinion. (16) Tips/information about informing relatives about the disease. (17) Tips/information about informing about the disease at work.
Identification and treatment	C	(18) Overview of where to go in case of various questions and complaints.
	NC	Screening for (19) psychosocial problems, (20) societal problems and (21) physio- and diet related problems. Information about/referral to (22) psychosocial support, (23) peer support, (24) guidance in field of work, (25) financial counselling, (26) insurance guidance, (27) physiotherapy, (28) dietician, (29) psychosocial support for family and caregivers and (30) info about when to have family checked.
Oncological follow-up	C	(31) Personal follow-up schedule. General information about (32) frequency of check-ups and scans incl. (33) explanation; (34) why a scan is needed and what to expect; (35) why the check-ups stop; (36) self-management in detecting recurrences; (37) who to contact in case of changes or suspicion of recurrence; (38) tools for detecting recurrences. (39) Melanoma-specific information about a healthy lifestyle.
	NC	(40) General information about a healthy lifestyle.
Coordination	C	-
	NC	Information about/referral to (41) a care coordinator; (42) hinge consultation; (43) multidisciplinary consultation meetings; (44) tools to improve information transmission between healthcare providers.

