

TEMPLATE RESEARCH PROTOCOL for non-WMO-applicable research

16-12-2024, version 1

Full title of protocol	'Identifying educational needs of health care providers related to		
	mental health care for young adults with cancer'		
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Subsidizing party ⁵	HaDEA		

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Coordinating Investigator		

- Coordinating investigator: Investigator who bears the responsibility for the coordination of investigators operating in the
 various centers participating in multicenter research. Not all multicenter research will have a coordinating investigator.
 There is no requirement to appoint one. A project leader has the responsibility to develop a research protocol and to
 complete the study within the predefined goals.
- 2. Principal investigator: Investigator who has the overall responsibility to comply and to complete the study within the predefined goals.
- Multicenter research: as an alternative you can also state that these are specified in the list with participating centers including principal investigator. This separate document with version date must be uploaded under category I1.
 Sponsor: The party that commissions the organization or performance of the research, for example a pharmaceutical
- 4. Sponsor: The party that commissions the organization or performance of the research, for example a pharmaceutical company, academic hospital, scientific organization or the investigator's employee. A party that provides funding for a study but does not commission it is not regarded as the sponsor, but referred to as a subsidizing party.
- 5. Subsidizing party: A party that provides funding for a study but does not commission it

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List of abbreviations and relevant definitions*

CTA Clinical Trial Agreement

De novo biobank A new data, human material or imaging collection

DMP Data Management Plan

DPIA Data Protection Impact Assessment

DTA Data Transfer Agreement

Exception consent Form Care for data Template, in Dutch: Formulier uitzondering toestemming

GCP Good Clinical Practice

GDPR General Data Protection Regulation in Dutch: Algemene Verordening

Gegevensbescherming

IC Informed Consent

IFU Instruction For Use

MTA Material Transfer Agreement

NWTC Non-WMO Review Committee; in Dutch: Niet WMO Toetsingscommissie

UAVG Dutch Act on Implementation of the General Data Protection Regulation; in

Dutch: Uitvoeringswet Algemene Verordening Gegevensbescherming

WMO Medical Research Involving Human Subjects Act, in Dutch: Wet Medisch-

wetenschappelijk Onderzoek met Mensen

^{*}Please add any new definitions that are used in the research protocol

Summary

Rationale

Cancer is a life-altering event and often has a profound impact on the mental and emotional well-being of those who receive the diagnosis. It may have significant psychosocial consequences, for patients as well as their families. Young adult (YA) cancer survivors are at an increased risk for experiencing mental health issues after cancer treatments, yet many YA cancer survivors might not receive the mental health support they need during their survivorship care.

Objective(s)

The primary objective of this study is to identify educational needs of healthcare professionals (HCPs) related to mental health screening, detection and support of YAs with cancer.

Study type

International cross-sectional survey among HCPs.

Study population

HCPs who are working with YAs with cancer.

Methods

International cross-sectional survey among HCPs.

Burden and risks

No risks. Burden includes the time needed for filling out the survey (10 minutes).

Recruitment and consent

All participants provide written informed consent. All participants can decline the study at any time, without notification of reason(s) for doing so.

1. Introduction and rationale

Cancer is one of the most common diseases in developed societies globally. Cancer affects everyone regardless of age, gender or social status and represents a tremendous burden for people with cancer, families, and societies (EU Cancer Mission). In 2020, 19 million new cancer cases occurred worldwide (Sung et al. 2021) and every year around 3 million people living in the EU are diagnosed with cancer (Bray et al., 2018). The number of cancer survivors is growing every year, with a continuous increase in 5-year survival rates for the most common cancer types in all countries. However, cancer is not only a disease of the elderly as an increase of cancer diagnosis has been identified especially in people under 50 years (Zhao et al. 2023) and in adolescents and young people (AYA). According to De et al. (2021) survival rates among adolescents (A) and young adults (YA) with cancer are improving in the developed countries (Miller et al., 2020). Still, in Europe incidence and mortality vary widely between countries with the highest mortality observed in the Eastern EU countries.

Cancer is a life-altering event and often has a profound impact on the mental and emotional well-being of those who receive the diagnosis (Zebrack et al., 2015; Kaul et al., 2017; Chang & Lai, 2022). It may have significant psychosocial consequences, as well for their closest ones and families (Caruso et al., 2020). YA cancer survivors are at an increased risk for experiencing mental health issues after cancer treatments, yet many YA cancer survivors might not receive the mental health support they need during their survivorship care. Overall, childhood, adolescent, and young adult cancer survivors were in the Lee et al. (2020) study 57% more likely to develop depression, 29% more likely to develop anxiety, and 56% more likely to develop psychotic disorders in the years following treatment compared to their siblings or healthy members of a control group. Young adults are also at a unique stage in their emotional, cognitive, and social development, which cancer often disrupts (Nass et al. 2015). Furthermore, YAs with cancer and YA cancer survivors can face significant mental health challenges throughout their cancer journey that are different to those faced by children and older adults (Tanner et al. 2023).

People with cancer require mental health support throughout the different phases of their cancer journey (Brandenbarg et al., 2019). However, mental health issues of people with cancer are poorly recognized or even minimized by health care professionals (HCPs) (Fernando et al. 2023), as they often consider mental health symptoms as normal reactions to cancer diagnosis. In addition, HCPs lack skills and resources to recognize early signs of mental health problems and how to intervene (Granek 2019). This results in situations where people with cancer lack appropriate support and treatment for mental health issues, relating to poorer care outcomes and hampering engagement to care (Grassi 2017; Duggan 2021). HCPs need to have adequate skills to provide equal, accessible, high quality, effective yet personcentered cancer care (EU4Health programme 2021-2027, European Commission 2020, Cancer Mission; Eu Beating Cancer Plan 2021). Caring for people affected by cancer, including the family and caregivers, is not limited to specialist units. Therefore, all HCPs need basic competencies related to supportive cancer care with communication abilities to encounter people affected by cancer. Developing and sharing knowledge and skills in specific mental health needs of YAs with cancer would enable HCPs to detect problems earlier, intervene appropriately, liaise effectively with colleagues and provide holistic support to people affected by cancer and therefore lead potentially to overall better health outcomes (Nash, 2020). HCPs have a significant role: they are the gatekeepers who should be able to recognize mental health challenges at early stage (Lazenby, 2015). The under-recognition and associated undertreatment of mental health problems of people affected by cancer remains one of the pressing and urgent issues of relevance to young people with cancer and their caregivers/families. The health care professionals (HCPs) need to have adequate skills to provide equal, accessible, high quality, effective vet person-centered cancer care (EU4Health programme 2021-2027, European Commission 2020, Cancer Mission; EU Beating Cancer Plan 2021). There is body of evidence on the benefits of providing psychosocial cancer care as part of standard care in reducing distress and psychosocial morbidity associated with cancer and in fostering a better quality of life during and after treatment, and eventually in increasing survival (Caruso et al., 2020; Niu et al. 2021).

Counselling, psychoeducation, specific forms of psychotherapy, and pharmacological interventions (Mitchell et al., 2018), different combinations of physical activity and social interventions (Bikomeye et al., 2022; Milton et al., 2022) have been developed for people with cancer to alleviate the psychological maladjustment to cancer and treatment (Caruso et al., 2020). As there are evidence-based treatments available for this group, screening, identification and timely access to evidence-based psychosocial approaches for people with cancer must be provided, both in the hospital and in community settings (Lazenby, 2015; Grassi et al., 2018). Furthermore, it is important to identify patients who are most at risk, inform resource allocation, identify patient and institutional barriers to implementation and justify the delivery of a person-centered model of care (Chang & Lai, 2022).

2. Objective(s)

The overall aim of the MELODIC project is to promote mental health and well-being of young adults with cancer, and their family members by improving screening, early detection, and efficient and person-centered management of mental health needs during the first year after their cancer diagnosis. As a first step in the development of the MELODIC intervention, in this study we will identify the educational needs of HCP in relation to the mental health of YA with cancer.

The primary objective of this study is to identify the educational needs of HCP in relation to mental health screening, detection and support for YA with cancer.

3. Study type

3.1.	Study type
	□ Retrospective
	☑ Prospective
	☐ Combination Retrospective/Prospective
3.2.	Single center / Multicenter
	☐ Single center
	☑ Multicenter
3.3	Check all the applicable boxes
	☐ Medical records (re-use of data from healthcare, including AI)
	☐ Case report
	☐ Re-use data from research
	☐ Evaluations of quality of healthcare (retrospective)

☐ Research with additional use of residual material from regular healthcare
☐ Research with re-use of human material from research or existing biobank
☐ De novo biobank
☐ Phase IV research
☐ Healthcare evaluation research (prospective)
☐ Research with medical devices
☐ Research with In Vitro Diagnostic Tests
☑ Other research, describe: survey among HCPs

4. Study population

4.1. Study population

X	Adults (16 years and older)
	Minors (younger than 16 years)
	Incapacitated adults (16 years and older)
	Incapacitated minors (younger than 16 years)

4.2. Population (base)

The target population will include all HCPs (e.g. physicians, nurses, health visitors/community health scientists, psychologists etc.) working in cancer care who are involved in the management of young adults with cancer. The cohort will include a convenience sample of HCPs approached through European and national professional cancer organisations. The participation in the study is entirely voluntary. The focus of the survey are the HCPs in the participating countries of the MELODIC consortium, however, HCPs from other European countries may also participate. We anticipate that at least 200 HCPs will complete the survey.

4.3. Inclusion criteria

In order to be eligible to participate in this study, a subject must meet all of the following criteria:

- HCPs involved in the management of young adults with cancer
- Providing informed consent

4.4. Exclusion criteria

A potential subject who meets any of the following criteria will be excluded from participation in this study:

- Students involved in the management of young adults with cancer

4.5. Sample size calculation

We anticipate that at least 200 HCPs will complete the survey. This will be enough to get an insight in the educational needs of HCPs.

5. Methods

5.1. Research methods

Using a cross-sectional design, we will undertake an international online survey. This single assessment will take approximately 10 minutes. The survey is developed in the English language.

The survey questions focus on the educational needs of HCPs in assessing and managing the mental health needs in YAs with cancer. As there is no already existing validated questionnaire on this topic, the international research consortium developed the survey based on literature, and clinical expertise of the international consortium members.

Expert review & item selection

The initial questions are reviewed by a panel of experts in oncology, psychology, mental health and public health from the consortium. The number of questions should be as few as possible and as many as necessary. The most appropriate questions are selected by consensus, based on their relevance to the research question and their clarity.

Pretesting

The final questions will be refined and simplified to a B2 English level, so that all potential participants will be able to understand all the items. To increase the validity and reliability, a small purposive sample of HCPs from the different countries will test the questionnaire. Feedback will be sought on general impressions of the survey, clarity of wording, biased or problematic questions, logical structure and any potential concerns about navigation or physical completion of the questionnaire. The questionnaire will be adapted as appropriate based on this feedback.

We will enter the survey into Castor Electronic Data Capture (EDC) and distribute it to a small representative sample of HCPs. We will evaluate the usability of the platform (access, layout), and the content of the survey (interpretability of items and consent statement), and the time taken to complete the survey.

5.2. Standard clinical care versus extra for research

5.3. Burden and risks

The burden for HCPs consists of completing the questionnaire.

5.4. Medical device(s) / In vitro diagnostic tests

6. Incidental findings

6.1. Chance of incidental findingsIs there a chance of incidental findings?☐ Yes☒ No

6.2. Procedures

n/a

7. Statistical analysis

7.1 Main study parameters/endpoints

The main study endpoint is to get an insight into the educational needs of HCP involved in the management of young adults with cancer, with regard to:

- Mental health screening among young adults with cancer
- Support of mental health problems of young adults with cancer

7.2 Secondary study parameters/endpoints

n/a

7.3 Other study parameters

n/a

7.4 Analysis

Data will be extracted from Castor EDC and analyzed in IBM SPSS Statistics for Windows (Version 29.0.2.0). Analysis will proceed using summary descriptive statistics, with exploration of between group differences (based on country, profession) analyzed and tested for statistical significance as appropriate by either Students t-tests and Wilcoxon rank-sum tests for continuous variables that are normally or not normally distributed, respectively, or Chi-square tests for categorical variables.

8. Ethical considerations

8.1 Regulation statement

The study will be conducted according to the principles of the Declaration of Helsinki as amended by 75th WMA General Assembly, Helsinki, Finland, Gedragscode Gezondheidsonderzoek 2022 and in accordance with other guidelines, regulations and Acts.

This is a voluntary survey that will collect anonymous data (not related to individual patient care). This study will be submitted for ethical approval by the Erasmus MC Ethics Committee. All data will be captured through Castor Electronic Data Capture Survey platform, which is compliant with European data management practices (GDPR), and all data will be securely stored in Europe.

8.2 Informed consent

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\//ill	tha	cubiacte	ha ac	·kad	for	informa	d consent?
v v III	uic	อนเมษนเอ	טס מס	ハロい	IUI	11111011116	a consent!

- ☑ Yes (Upload Participant Information Letter and Informed Consent)
- □ No, consent already given in previous study (Upload Participant Information Letter and Informed Consent previous study)
- □ No, this research will be performed under the exception consent (Upload form Care for data Template, in Dutch: Formulier uitzondering toestemming)
- ☐ Other (e.g. partly, indirectly) *Please describe the situation.*

8.3 Recruitment and informed consent procedures

Participants will be invited to participate in the survey through general emails and newsletters from our consortium partners, such as the European Cancer Organisation, through consortium

members and promoted through professional social media networks. Together this will reach almost all HCPs working in cancer care in Europe. The survey will be online and anonymous. The survey will be conducted through the Castor platform.

The emails will contain general information about the study, the background of the study and eligibility to participate, as well as a general anonymous link to the survey. Potential participants will be able to read further information about the study and a consent form to participate in the study. Participants will be able to consent to participate after reading the participant information. The survey will be anonymous and participants will only be asked general, non-identifiable demographic variables that are not identifiable, and questions about clinical practice in their region.

Exception consent

n/a

9. Handling and storage of data / images / sound recordings / photos / film recordings

9.1 Data / images / sound recordings / photos / film recordings

Data will be collected in Castor EDC and exported into the Erasmus MC research server for further data analysis. All data will be anonymous. All original data exports, analysis files, analysis script, and data dictionaries will be stored on the research server. A separate DMP describes the management of data for the MELODIC project.

9.2 Privacy protection

This is a voluntary survey that will collect anonymous data (not related to individual patient care). This study will be submitted for ethical approval by the Erasmus MC Ethics Committee. All data will be collected through the Castor Electronic Data Capture Survey platform, which is compliant with European General Data Protection Regulation (GDPR), and the Dutch Act on the Implementation of the General Data Protection Regulation, and all data will be securely stored in Europe.

9.3 Handling and storage of data

All data will be collected through Castor Electronic Data Capture Survey platform and exported into the Erasmus MC research portal for further data analysis. All data will be anonymous. In line with Erasmus MC guidelines, data will be kept 10 years after it is collected.

9.4 Handling and storage of images / sound recordings / photos / film recordings n/a

9.5 Approval of access to data / images / sound recordings / photos / film recordings

10. Handling and storage of human material

•	10.1	Human material No human material is used in this study.		
•	10.2	Check all the boxes which are applicable to the human material origin: ☐ Residual material from regular healthcare ☐ Research (material acquired from a previous study). Add the reference of the study i.e., MEC-number Erasmus MC. ☐ Re-use of human material from existing biobank Describe whether the human material originates from research into the same disease. ☐ Other, please specify		
•	10.3	Handling and storage of human material ☐ Anonymous, i.e. the material can never be traced back to an individual subject ☐ Pseudonymized/Coded ☐ Identifiable		
	10.4	Biobank n/a		
	10.5	Approval of access to human material n/a		
11.	Excl n/a	hange, sharing or transfer of data and/or human material and/or images		
12.	Ame give Sub	endments endments are changes made to the research after a favorable opinion by the NWTC has been en. All amendments must be submitted to the NWTC that gave the favorable opinion. stantial amendments must be approved by the Niet WMO Toetsingscommissie before they can mplemented.		
13.	With	End of study report Within one year after the end of the study a final study report will be submitted with the results of the study, including any publications/abstracts of the study.		
14.	Do y ⊠ Y	elication you have the intention to submit the study results in a manuscript for publication in a journal: es o, <i>please motivate</i>		
		final study report with the results of the study will be submitted no later than three months after end of the study.		

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16. Attachments

☑ Participant information letter and Informed consent document
$\hfill \square$ Care for data Template – Formulier uitzondering toestemming
☑ Questionnaires
□ Data Management Plan
☐ Data Transfer Agreement
☐ Material Transfer Agreement
☐ Clinical Trial (Site) Agreement
☐ Other, <i>please describe</i>

Information letter for research participants

Educational needs in health care providers related to mental health care for young adults with cancer (MELODIC I)

1. Introduction

Dear colleague,

In this information letter we ask you if you would like to participate in this research project. Participation is voluntary. You are receiving this information letter because you are a health care provider working with young adults with cancer.

This letter tells you what the study is about. You can also read what it means for you if you participate in the study. Are you interested? Then read this information letter carefully. When you agree to participate you can thick the box below.

2. General information

This survey study is part of the European MELODIC project involving six European countries: the Netherlands, Finland, Ireland, Portugal, Greece and Estonia. The Medical Ethics Research Committee of the Erasmus University Medical Centre in the Netherlands has reviewed and approved this protocol.

3. What is the purpose of the study?

Young adults with cancer are at increased risk of experiencing mental health symptoms after cancer treatment. However, young adults may not always receive the mental health services they need as part of the care they receive after cancer treatment.

The aim of this study is to identify the educational needs of healthcare providers in relation to the screening, identification and support of mental health symptoms in young adults with cancer.

4. How does the survey work and what does it mean for you?

This survey aims to identify the educational needs of healthcare professionals working with young adults with cancer. Your participation is not mandatory, but if you choose to participate, please complete this questionnaire. We estimate that this will take approximately 10 minutes.

5. What are the advantages and disadvantages of participating in the study?

There are no (direct) benefits to you from taking part in this study. However, your participation may contribute to a better understanding of the training needs of healthcare providers in the mental health care of young adults with cancer. This may help to improve the care of young adults with cancer in the future.

6. If you do not want to participate or want to guit the study

Participation in this study is completely voluntary. Only if you wish to participate will you sign the informed consent form (Appendix B). You can stop completing the questionnaire at any time.

7. What data do we collect?

As part of this survey, we will ask you to complete a one-time questionnaire which will include questions about:

- Some general demographic data (anonymous);
- To what extent you feel skilled in caring for young adults with cancer in the mental health field;
- What the educational needs are of healthcare professionals in addressing the mental health of young adults with cancer.

8. What do we do with your data?

Why do we collect, use and retain your data?

We collect, use and store your responses to the questions of this survey. We will use the results of this survey to develop a training module for healthcare professionals on managing the mental health of young adults with cancer. In addition, we also want to publish the results of the survey.

How do we protect your privacy?

This survey is anonymous, so we cannot trace any data back to an individual. We store the collected data in a secure location within the Erasmus MC to which only the research team has access.

How long do we keep your data?

We keep your research data for 10 years, as required to our national guidelines.

Can you withdraw your consent to the use of your data?

You can stop answering the questionnaire at any time without submission of the questionnaire.

Want to know more about your privacy?

Want to know more about your rights when processing personal data? See: General Data Protection Regulation (GDPR).

9. Will you receive compensation for participating?

We really appreciate your participation in this study. You will not receive any compensation for your participation.

10. Do you have any questions?

If you have any questions about this study, please contact the coordinating researcher, Sid Morsink, s.morsink@erasmusmc.nl.

Appendix A: Participant consent form

Educational needs in health care providers related to mental health care for young adults with cancer (MELODIC I)

I read the information letter. I was also able to ask questions. My questions were sufficiently answered. I had enough time to decide whether to participate.

- I know that participating is voluntary. I know I can stop answering the questionnaire at any time without submission of the questionnaire
- I consent to the collection and use of my anonymous responses to the questionnaire in the manner and for the purposes specified in the information letter.
- I give permission to keep the demographic data and questionnaire responses for 10 years after this study.

I want to participate in this study	Yes □	No □
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Medisch Ethische Toetsings Commissie Erasmus MC

Niet WMO Toetsingscommissie Erasmus MC

Telefoon +31 107033625

Dr. W.H. Oldenmenger

Kamernummer Ae-337

Afdeling: Interne Oncologie

E-mail metc@erasmusmc.nl

Erasmus MC

Ons kenmerk MEC-2024-0812

Datum 6 februari 2025

Niet WMO verklaring		
METC nummer	MEC-2024-0812	
Titel onderzoek	Identifying educational needs of health care providers related to	
	mental health care for young adults with cancer (MELODIC I)	

Geachte heer, mevrouw,

De Niet WMO Toetsingscommissie Erasmus MC heeft het ingediende onderzoek ontvangen op 20-01-2025.

De commissie heeft beoordeeld of dit onderzoek binnen de reikwijdte van de Wet medischwetenschappelijk onderzoek met mensen (WMO) valt.

De commissie heeft alleen de WMO-plichtigheid beoordeeld. Er heeft verder geen inhoudelijke toets van het onderzoek plaatsgevonden.

Omdat er geen medisch-wetenschappelijke vraagstelling is en de proefpersonen niet aan een handeling worden onderworpen of een gedragswijze krijgen opgelegd, is de commissie van mening dat het onderzoek niet WMO-plichtig is.

Dit onderzoek mag worden uitgevoerd in het Erasmus MC.

Dit oordeel is gebaseerd op de volgende documenten:

C01Non-WMO-Research-Protocol-MELODIC I 161224	16-12-2024
E1E2. non-WMO PIF MELODIC I 16122024	16-12-2024
F01. Melodic I survey questionnaire	16-12-2024
K6Risicoclassificatie 18-12-2024.pdf	18-12-2024

Als het onderzoek (ook) wordt uitgevoerd in een ander centrum dan het Erasmus MC dient u dit onderzoek daar aan te melden in overeenstemming met de lokale procedure.

Postadres

Postbus 2040 3000 CA Rotterdam

Bezoekadres

Dr. Molewaterplein 40 3015 GD Rotterdam

Contact & route

www.erasmusmc.nl

Voorzitter

Prof.dr. H.J. Metselaar

Het secretariaat is geopend van maandag tot en met vrijdag van 08.30 uur tot 17.00 uur Datum 6 februari 2025



Algemene aandachtspunten

De commissie attendeert u erop dat u er zelf voor verantwoordelijk bent dat uw onderzoek wordt uitgevoerd binnen de kaders van de geldende wet- en regelgeving en het beleid in de instelling waar u werkt. Wij wijzen u in ieder geval op het volgende:

- Voor het opslaan en gebruiken van persoonsgegevens moet gewerkt worden in overeenstemming met de Algemene Verordening Gegevensbescherming (AVG). Voor advies of vragen op het gebied van privacy kunt u terecht bij de PCP (Privacy Contact Persoon) van het Thema of het PKO (Privacy Kennis Organisatie).
- Voordat met de uitvoering van het onderzoek in het Erasmus MC gestart mag worden moet er een datamanagementplan zijn. Voor advies of vragen kunt u terecht bij de data stewards of het Research Support Office.
- Onderzoeksgegevens moeten worden vastgelegd in een gevalideerd data capture systeem. Voor Erasmus MC is dit bij voorkeur Castor en in sommige gevallen LimeSurvey/Gemstracker. Voor advies of vragen kunt u terecht bij het Data Capture Team.

Als de opzet van dit onderzoek inhoudelijk wijzigt, dient u dit als amendement in te dienen bij de Niet WMO Toetsingscommissie voor een nadere beoordeling.

De Niet WMO Toetsingscommissie verzoekt u haar betreffende dit onderzoek op de hoogte te brengen van:

- startdatum (datum inclusie eerste proefpersoon en/of start verzameling gegevens/lichaamsmateriaal/beelden)
- einddatum (laatste visite laatste proefpersoon of laatste verzameling van gegevens/lichaamsmateriaal/beelden)
- publicaties en/of eindrapport

Het besluit verliest zijn geldigheid als de start van de uitvoering niet binnen twee jaar na afgifte van dit besluit plaatsvindt.

Met vriendelijke groet,

namens de Niet WMO Toetsingscommissie Erasmus MC,

Mw.dr. F.M. Spoelstra

Secretaris

Pagina 3/3
Ons kenmerk MEC-2024-0812
Datum 6 februari 2025



To whom it may concern,

The Institutional research review board Erasmus MC (hereafter the Committee) of Rotterdam, The Netherlands, has reviewed the above mentioned research proposal. As a result of this review, the Committee confirms that the rules laid down in the Medical Research Involving Human Subjects Act (also known by its Dutch abbreviation WMO), do not apply to this research proposal.

Please indicate the above MEC-number in every correspondence on this study.

Yours sincerely,

Secretary of the Institutional research review board Erasmus MC

Educational needs in health care providers related to mental health care for young adults with cancer (MELODIC I)

Questionnaire survey

Section	Issue	#	Item	Responses
Demographics	Location	1	What country do you work in?	[scroll down list with all European countries]
	Profession	2	What is your main clinical professional role?	 Nurse Specialisation: [open] Medical doctor specialisation:[open] Health Visitor/Community Health Scientist Psychologist Social worker Other
	Setting of work	4	Please indicate in which type of institution you work (if more than one sector please select all that apply) *:	 Public cancer centre General public hospital Public university-hospital Private cancer centre General private hospital/medical centre Hybrid public and private funding cancer centre/hospital/medical centre Public Research center Private Research center Other:
	Experience		How many years have you been working in your field?*	 20 years or more 10 to 20 years 5 to 10 years 1 to 5 years < 1 years
	Age		Can you please indicate to which age range you correspond to:	 <25 years 25-34 years 35-44 years 45-54 years 55-64 years >65 years
	Gender		Can you please indicate to which gender you identify yourself*:	 Male Female Non-binary Do not want to disclose

Section I: current practices

I think I can do this

I do this

		Not at all	Not sufficient	More or less	Sufficient	Good	Never	Rarely	Occasionally	Frequently	Always
1.	Do you screen for the presence of distress in young adults with cancer?										
2.	When you screen for distress in young adults with cancer, do you use brief tools such as Distress Thermometer, ESASr etc.?										
3.	When young adults with cancer screen positive for distress, do you perform a comprehensive assessment to identify the sources, nature and extent of distress?										
4.	Do you screen for the presence of anxiety/fear of cancer recurrence in young adults with cancer?										
5.	When you screen for anxiety in young adults with cancer, do you use a validated questionnaire or tool?										
6.	Do you screen for the presence of depression in young adults with cancer?										
7.	When you screen for depression in young adults with cancer, do you use a validated questionnaire or tool?										
8.	Do you discuss mental health in young adults with cancer in your practice?										
9.	Do you discuss healthy lifestyles with young adults with cancer?										
10.	Do you discuss physical activity /exercise with young adults with cancer?										
11.	Do you discuss social activities with young adults with cancer?										
12.	Do you discuss visiting nature (so-called green and blue spaces) with young adults with cancer?										
13.	Do you refer young adults with cancer to mental health professionals, such as psychologists?										

Section II: educational needs in addressing mental health with young adults with cancer

What do you need to improve your skills in addressing mental health in young adults with cancer?

		Definitely not	probably not	maybe	Probably yes	Definitely yes
1.	General theoretical information about mental health in young adults with cancer					
2.	Training in the use of screening tools for mental health problems					
3.	Training in addressing mental health during consultation/ counselling					
4.	Training in addressing social relationships					
5.	Training to learn which mental health problems are typical for patients with cancer					
6.	Training in recognizing early signs of mental health problems					
7.	Training in the use of green and blue spaces to improve mental wellbeing					
8.	Training in the use of physical activity to improve mental wellbeing					
9.	Training in the use of social prescribing					

Could you rank a top 3 of the above-mentioned educational trainings you think would be the most helpful to you?

- General theoretical information about mental health in young adults with cancer
- Training in the use of screening tools for mental health problems
- Training in addressing mental health during consultation/ counselling
- Training in addressing social relationships
- Training to learn which mental health problems are typical for patients with cancer
- Training in recognizing of early signs of mental health problems
- Training in the use of green and blue spaces to improve mental wellbeing
- Training in the use of physical activity to improve mental wellbeing
- Training in the use of social prescribing

How many hours of training do you estimate you need to improve your skills in addressing mental health?

- None
- 1- 4 hours
- 4- 8 hours
- More than 8 hours

How do you prefer to be trained? (multiple answers possible)

- I prefer to be trained with theoretical information I can study
- I prefer to be trained with group discussions
- I prefer to be trained with reflective practice
- I prefer to be trained with problem solving/ problem-based learning
- I prefer to be trained with clinical cases
- I prefer to be trained with colleagues of the same profession
- I prefer to be trained in a multidisciplinary group





Subject: Request for Collaboration in distributing MELODIC Survey

Dear xxx,

I am writing to you on behalf of the MELODIC project, which aims to promote the mental health and wellbeing of young adults (YA) with cancer and their family members/caregivers.

The MELODIC project focuses on improving screening, early detection, and efficient, person-centered management of mental health needs during the first year post-cancer diagnosis.

Specifically, our project will:

- 1. Examine the mental health needs of YAs with cancer and their family members/caregivers.
- 2. Assess the training needs of healthcare professionals (HCPs) and develop an online training program for them.
- 3. Implement an intervention that includes physical activity in natural surroundings (green/blue space) with informational support for YAs with cancer and their family members/caregivers.
- 4. Develop guidance and practical recommendations for HCPs on how to support YAs and their family members/caregivers with mental health needs.

As part of our initial steps, we are conducting a survey to gather valuable insights from HCPs. We believe that your society's involvement in distributing this survey would be instrumental in reaching a broader audience and ensuring the success of our project. We have an approval for the survey from the medical ethical research committee of the Erasmus MC, the Netherlands.

We kindly request your assistance in distributing our survey to your members and affiliates. Your support would greatly contribute to our efforts in enhancing the mental health and wellbeing of YAs with cancer and their families.

Thank you for considering our request. The survey is open from April till end of May 2025. Please feel free to contact me at [Your Email Address] or [Your Phone Number] if you have any questions or require further information.

Yours sincerely,

































Possible message of social media:



Young adults living with cancer are more likely to have mental health challenges during and after treatment. Unfortunately, they often don't get the mental health support they need.

We need your help! Our study aims to uncover the educational needs of healthcare providers to better screen, identify, and support the mental health of young adults living with cancer.

To make a real difference, we're conducting a survey among healthcare professionals like you. Your insights will be invaluable in improving mental health care for these young adults.

Are you:

- A healthcare professional working in cancer care?
- Engaged in the treatment of young adults aged 18-39?
- Able to spare just 10 minutes?

If so, please take part in our survey and help us transform mental health support for young adults living with cancer. Your participation can make a world of difference! Complete our survey here: Castor EDC

































Dissemination Survey

- APRIL: awareness of AYA month
- 1. The above announcement will be sent to all partners of MELODIC project, with the question to disseminate
- 2. ECO:

Various networks: quality of life, survivorship;

Social media channels

IPOS, EONS,

Winette de Graaf – Strong AYA (whether they are interested to distribute the survey)

- 3. EONS: Ask them to make an announcement in their Newsletter and social media channels (@Virpi, is this possible?)
- 4. Announcement via MELODIC LinkedIn page
 - a. Question to all partners to repost it

National strategies

1. Estonia

We can send the announcement to Estonian partners and they will send it further:

- a. Estonian Oncology Nursing Society
- b. Social media channels
- c. Vähikeskused (Siret?)
- 2. Finland

We can send the announcement to Finnish partners and they will send it further

- a. Finnish Oncology Nursing Society Suomen Syöpäsairaanhoitajat
- b. FICANWest Western Finland Cancer Centre
- 3. Greece

We can send the announcement to Greek partners and they will send it further:

- a. Kapa3
- b. Hellenic Health Visitors Association
- c. Social media channels
- 4. Ireland

We can send the announcement to Irish partners and they will send it further:

- a. NCCP National Cancer Control Programme monthly newsletter to all cancer support centres around Ireland
- b. NCCP AYA Cancer Service Network
- c. IPSON Irish Psycho-Social Oncology Network monthly newsletter to members

































5. Netherland

We can send the announcement to:

- a. Repost the MELODIC post
- b. Dutch Oncology Nursing Society
- c. Network of nurse practitioners oncology and palliative care
- d. Psychosocial oncology?? (Sid and Leonieke)
- e. Intranet (Agora) of Erasmus MC Cancer Institute

6. Portugal

The above announcement will be sent to all three major cancer hospitals in Portugal.

































(1) Post | LinkedIn



Are you a healthcare professional working in cancer care?

The new EU-funded project, MELODIC, is conducting a survey to map your learning needs so you can better support the mental health of young adults (aged 18 to 39) living with cancer.

Please take just 10 minutes to complete the survey here.

https://lnkd.in/dpnrWsw2





























