



Modify Survey



This survey has at least one response. Only limited changes are allowed on a survey with responses. To fully edit this survey, you must first delete all of the responses, which can be done by clicking [here](#).

End-of-Life Care Research on adults with cancer

[No Title Entered]



1. **Country***
 Please choose your country of residence

2. **Name of Research Unit/Centre:***
 Write the name of your centre or department

3. **Please indicate the physical location of your Unit/Centre.***
 Cancer Centre
 Charity

- District General Hospital
- Hospice
- Primary care
- Teaching hospital
- University campus (not attached to a hospital)
- Other, please describe:



4. Name of Scientific Team Leader:

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5. Professional background of the Scientific Team Leader (tick as many as apply)*

- Anthropology
- Basic sciences
- Epidemiology/Public Health/Policy
- Medicine_GP
- Medicine_Oncology
- Medicine_Palliative medicine
- Medicine_Psychiatry
- Medicine_Other
- Nursing
- Occupational Therapy
- Physiotherapy
- Psychology

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- Social work
- Sociology
- Spiritual care
- Other, please specify



6. Gender*
Of the person completing this form

Male Female

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7. Age*
Of the person completing this form

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Introduction

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Thank you for agreeing to complete this survey. We are going to ask you about the research that is taking place in your department on adults who have cancer and are 'at the end of life' The survey is divided into four sections;

- A. Research completed in the last three years
- B. Current research
- C. Future plans for research
- D. Barriers, needs and priorities for end-of-life cancer care research in Europe

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For this survey, 'End of life care' has been defined as care in the last twelve months of the patient's life.

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A. Completed research on end-of-life care in the last three years

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8. Have you completed research on end-of-life cancer care in the last three years?*

Yes No

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9. Did the research directly involve patients ?*

Yes No

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10. Did the research directly involve family members / relatives ?*

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Yes No

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11. We are interested in getting a clearer picture of the breadth of your research activity completed in the last three years. Please use the table below to indicate the research topics that your unit/centre has worked on (tick as many as apply)

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	Major area	Minor area
Pain	<input type="radio"/>	<input type="radio"/>
Dyspnoea	<input type="radio"/>	<input type="radio"/>
Fatigue & cachexia	<input type="radio"/>	<input type="radio"/>
Cognitive symptoms and delirium	<input type="radio"/>	<input type="radio"/>
Other symptoms	<input type="radio"/>	<input type="radio"/>
Assessment & measurement tools	<input type="radio"/>	<input type="radio"/>
Bereavement	<input type="radio"/>	<input type="radio"/>
Cultural issues	<input type="radio"/>	<input type="radio"/>
Complementary therapies	<input type="radio"/>	<input type="radio"/>
Evaluation of education programmes	<input type="radio"/>	<input type="radio"/>
Ethics	<input type="radio"/>	<input type="radio"/>
Family & care givers	<input type="radio"/>	<input type="radio"/>
Medical sociology	<input type="radio"/>	<input type="radio"/>
Last days of life & quality of death	<input type="radio"/>	<input type="radio"/>
Policy and the organization of services	<input type="radio"/>	<input type="radio"/>
Psychology	<input type="radio"/>	<input type="radio"/>
Communication	<input type="radio"/>	<input type="radio"/>

- Rehabilitation
- Research methodology
- Spiritual care
- Other (please specify below)

 12. Specify other research topics

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13. Please indicate the research methodology*

- Audit & quality control
- Basic research (basic science, laboratory research)
- Clinical trials
- Epidemiology
- Health service research
- Production of guidelines
- Systematic reviews and meta-analysis
- Translational research
- Other, please specify

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14. Please indicate the study design of the clinical trials being completed in your department

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- Randomized controlled trial
- Prospective, non-randomized trial
- Observational study
- Retrospective study
- Cross sectional study
- Qualitative study
- Other, please specify

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↓ 15. Please give us the number of conference abstracts in end of life care from your research group the last three years*
(2006, 2007 and 2008)

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-
-  16. Please give us the number of publications in end of life care in peer-reviewed journals from your research group in the last three years*
 (2006, 2007 and 2008)


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-
-  17. In which journals have you published your work on end-of-life cancer care during the last three years?
 (2006, 2007 and 2008) Please tick all that apply

- Annals of Internal Medicine
- Annals of Oncology
- Archives of Internal Medicine
- BMC Palliative Care
- British Journal of Cancer (Br J Cancer)
- British Medical Journal (BMJ)
- Cancer Nursing (Cancer Nurs)
- European Journal of Cancer (EJC)
- European Journal of Oncology Nursing (Eur J Oncol Nurs)
- International Journal of Palliative Nursing (Int J Palliat Nurs)
- Journal of Advanced Nursing (J Adv Nurs)
- Journal of the American Medical Association (JAMA)
- Journal of Clinical Oncology (JCO)
- Journal of Hospice and Palliative Nursing (J Hospice Palliat Nurs)
- Journal of Pain and Symptom Management (JPSM)
- Journal of Palliative Care
- Journal of Palliative Medicine
- Lancet

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- Lancet Oncology
- New England Journal of Medicine (NEJM)
- Nursing Research (Nur Res)
- Oncology
- Palliative Medicine (Palliat Med)
- Palliative and Supportive Care
- Progress in Palliative Care
- Support Care in Cancer
- National journals
- Others

 18. Please give us the number of completed doctoral degrees (PhD or equivalent) in your research group in the last three years*
(2006, 2007 and 2008)

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 19. What has prevented you from doing research in end-of-life cancer care? (tick as many as apply)*

- Lack of funding
- Insufficient knowledge and expertise

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- Lack of interest
- Lack of time
- Lack of mentorship
- Lack of technical support
- Lack of infrastructure support
- Lack of personell
- Staff gate keeping
- Low priority
- Clinical issues (the patient population, difficulties in recruiting patients, difficulties in determing prognosis)
- Methodological issues (lack of standardised measurement outcomes, definition of patient population, missing data)
- Ethical issues
- Lack of research training programs
- Lack of senior lecturer posts
- Lack of research network
- Lack of national research agenda
- Other, please specify



20. Would you be able to tell us what have been the main barriers to taking part in end of life care research? Please rank your top three (using numbers 1,2,3, with 1 being the most important barrier)
*

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Rank

Lack of funding

Insufficient knowledge

- and expertise
- Lack of interest
- Lack of time
- Lack of mentorship
- Lack of technical support
- Lack of infrastructure support
- Lack of personell
- Staff gate keeping
- Low priority
- Clinical issues (the patient population, difficulties in recruiting patients, difficulties in determing prognosis)
- Methodological issues (lack of standardised measurement outcomes,definition of patient popul, missing data)
- Ethical issues
- Lack of research training programs
- Lack of senior lecturer posts
- Lack of research network
- Lack of national research agenda
- Other (please specify

below)

 21. Please specify ranked barriers

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 **B. Current research:**

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 22. Are you currently carrying out research on adults with cancer who are at the end of life, i.e. in their last twelve months of life?*

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Yes No


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 23. Are you carrying out research directly involving patients ?*

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Yes No





 24. Are you carrying out research directly involving family members / relatives ?*

 Yes No

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 25. We are interested in getting a clearer picture of the breadth of your current research activity. Please use the table below to indicate the research topics that your unit/centre is currently researching (tick as many as apply)

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	Major area	Minor area
Pain	<input type="radio"/>	<input type="radio"/>
Dyspnoea	<input type="radio"/>	<input type="radio"/>
Fatigue & cachexia	<input type="radio"/>	<input type="radio"/>
Cognitive symptoms and delirium	<input type="radio"/>	<input type="radio"/>
Other symptoms	<input type="radio"/>	<input type="radio"/>
Assessment & measurement tools	<input type="radio"/>	<input type="radio"/>
Bereavement	<input type="radio"/>	<input type="radio"/>
Cultural issues	<input type="radio"/>	<input type="radio"/>
Complementary therapies	<input type="radio"/>	<input type="radio"/>
Evaluation of education programmes	<input type="radio"/>	<input type="radio"/>
Ethics	<input type="radio"/>	<input type="radio"/>
Family & care givers	<input type="radio"/>	<input type="radio"/>
Medical sociology	<input type="radio"/>	<input type="radio"/>
Last days of life & quality of death	<input type="radio"/>	<input type="radio"/>
Policy and the organization of services	<input type="radio"/>	<input type="radio"/>

- Psychology
- Communication
- Rehabilitation
- Research methodology
- Spiritual care
- Other (please specify below)

 26. Specify other research topics

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27. Please indicate the research methodology employed in your current research on end-of-life care*

- Audit & quality control
- Basic research (basic science, laboratory research)
- Clinical trials
- Epidemiology
- Health services research
- Production of guidelines
- Systematic reviews and meta-analysis

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Translational research

Other, please specify

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28. Please indicate the study design of the clinical trials currently being carried out in your department as part of research on end-of-life cancer care

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- Randomized controlled trial
- Prospective, non-randomized trial
- Observational study
- Retrospective study
- Cross sectional study
- Qualitative study
- Other, please specify

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↓ 29. Please indicate the discipline of research staff in your unit/centre*

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	Number working full time	Number working part time
Anthropology	<input type="text"/>	<input type="text"/>
Basic sciences	<input type="text"/>	<input type="text"/>
Clinical nutrition	<input type="text"/>	<input type="text"/>
Epidemiology	<input type="text"/>	<input type="text"/>
Health economics	<input type="text"/>	<input type="text"/>
Medicine_GP	<input type="text"/>	<input type="text"/>
Oncology	<input type="text"/>	<input type="text"/>
Palliative medicine	<input type="text"/>	<input type="text"/>
Medicine, other	<input type="text"/>	<input type="text"/>
Nursing	<input type="text"/>	<input type="text"/>
Occupational Therapy	<input type="text"/>	<input type="text"/>
Physiotherapy	<input type="text"/>	<input type="text"/>
Policy	<input type="text"/>	<input type="text"/>
Psychiatry	<input type="text"/>	<input type="text"/>
Psychology	<input type="text"/>	<input type="text"/>
Public Health	<input type="text"/>	<input type="text"/>
Social work	<input type="text"/>	<input type="text"/>
Sociology and other social sciences	<input type="text"/>	<input type="text"/>
Spiritual care	<input type="text"/>	<input type="text"/>
Other (please specify below)	<input type="text"/>	<input type="text"/>

↑ 30. Specify other discipline edit
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↑ 31. Types of Position* edit
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	Total head count
Scientific team leader (professor or other academic position)	<input type="text"/>
Experienced/Senior researcher	<input type="text"/>
Early researcher/post doc	<input type="text"/>
PhD students	<input type="text"/>
Master students	<input type="text"/>
Research manager/administrator	<input type="text"/>
Technical staff	<input type="text"/>
Other (please specify below)	<input type="text"/>

↑ 32. Specify other type of position edit
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↑ 33. How many of your research staff have combined positions with clinical work edit
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Funding

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34. Do you have specific funding for research on end-of-life cancer care in your unit?*

If no, please go directly to Next

Yes No

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35. What type of funding do you have (tick as many as apply)


- Charity
- Government, national
- Government, regional
- International
- Institutional
- Pharmaceutical
- Private
- Scientific awards
- Other, please specify


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 **National collaboration** [edit](#)
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 36. Does your group collaborate with other palliative care research groups in your country ?* [edit](#)
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 Yes No


 37. Are you part of a national network for palliative care research in your country? [edit](#)
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 Yes No

 **International collaboration** [edit](#)
[move](#)

 38. Do you collaborate with palliative care research groups in other countries?* [edit](#)
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[pipe](#)

 Yes No

 39. Please specify the country/countries of your collaborating group(s) [edit](#)
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40. Are there any reasons why your department does not take part in research on end-of-life cancer care? (tick as many as apply)*

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- Lack of funding
- Insufficient knowledge and expertise
- Lack of interest
- Lack of time
- Lack of mentorship
- Lack of technical support
- Lack of infrastructure support
- Lack of personell
- Staff gate keeping
- Low priority
- Clinical issues (the patient population, difficulties in recruiting patients, difficulties in determing prognosis)
- Methodological issues (lack of standardised measurement outcomes, definition of patient population, missing data)
- Ethical issues
- Lack of research training programs
- Lack of senior lecturer posts
- Lack of research network

Lack of national research agenda

Other, please specify



41. Would you be able to tell us which are the main barriers preventing you from taking part in end of life care research? Please rank your top three (using numbers 1,2,3 with 1 being the most important barrier)*

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	Rank
Lack of funding	<input type="text"/>
Insufficient knowledge and expertise	<input type="text"/>
Lack of interest	<input type="text"/>
Lack of time	<input type="text"/>
Lack of mentorship	<input type="text"/>
Lack of technical support	<input type="text"/>
Lack of infrastructure support	<input type="text"/>
Lack of personell	<input type="text"/>
Staff gate keeping	<input type="text"/>
Low priority	<input type="text"/>
Clinical issues (the patient population, difficulties in recruiting patients, difficulties in determing prognosis)	<input type="text"/>
Methodological issues (lack of standardised measurement outcomes, definition of	<input type="text"/>

patient population,
missing data)

Ethical issues


Lack of research
training programs

Lack of senior lecturer
posts

Lack of research
network

Lack of national
research agenda

Other (please specify
below)

 42. Specify other ranked barrier

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 **C. Future plans.**

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 43. Are you planning to do research on end-of-life cancer care in the next 2-3 years?*

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Yes No

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 44. Are you only going to continue with your current research activities (no new plans)?*
 If yes, please go directly to Next



Yes No

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 45. Will the research directly involve patients ?




Yes No

[edit](#)
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 46. Will the research directly involve family members / relatives ?


Yes No


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 47. We are interested in getting a picture of your plans for end-of-life care research in the next years.
 Please use the table below to indicate the research topics that your Unit / Centre is planning to study (tick as many as apply).
 It is not possible to deselect

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	Major area	Minor area
Pain	<input type="radio"/>	<input type="radio"/>
Dyspnoea	<input type="radio"/>	<input type="radio"/>
Fatigue & cachexia	<input type="radio"/>	<input type="radio"/>
Cognitive symptoms and delirium	<input type="radio"/>	<input type="radio"/>
Other symptoms	<input type="radio"/>	<input type="radio"/>
Assessment &		

- measurement tools
- Bereavement
- Cultural issues
- Complementary therapies
- Evaluation of education programmes
- Ethics
- Family & care givers
- Medical sociology
- Last days of life & quality of death
- Policy and the organization of services
- Psychology
- Communication
- Rehabilitation
- Research methodology
- Spiritual care
- Other (please specify below)

 48. Specify other research topics

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49. Please indicate the research methodology

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- Audit & quality control
- Basic research (basic science, laboratory research)
- Clinical trials
- Epidemiology
- Health services research
- Production of guidelines
- Systematic reviews and meta-analysis
- Translational research
- Other, please specify

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50. Please indicate the planned study design of the clinical trials

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- Randomized controlled trial
- Prospective, non-randomized trial
- Observational study
- Retrospective study

- Cross sectional study
- Qualitative study
- Other, please specify

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↓ 51. What prevents you from doing research in end of life care in the near future (tick as many as apply)?

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- Lack of funding
- Insufficient knowledge and expertise
- Lack of interest
- Lack of time
- Lack of mentorship
- Lack of technical support
- Lack of infrastructure support
- Lack of personell
- Staff gate keeping
- Low priority
- Clinical issues (the patient population, difficulties in recruiting patients, difficulties in determing prognosis)
- Methodological issues (lack of standardised measurement outcomes, definition of patient population, missing data)

- Ethical issues
- Lack of research training programs
- Lack of senior lecturer posts
- Lack of research network
- Lack of national research agenda
- Other, please specify



52. Prioritize what barriers you would have changed. Rank 3 barriers (using numbers 1, 2 and 3, with 1 being the most important barrier)

	Rank
Lack of funding	<input style="width: 40px; height: 20px;" type="text"/>
Insufficient knowledge and expertise	<input style="width: 40px; height: 20px;" type="text"/>
Lack of interest	<input style="width: 40px; height: 20px;" type="text"/>
Lack of time	<input style="width: 40px; height: 20px;" type="text"/>
Lack of mentorship	<input style="width: 40px; height: 20px;" type="text"/>
Lack of technical support	<input style="width: 40px; height: 20px;" type="text"/>
Lack of infrastructure support	<input style="width: 40px; height: 20px;" type="text"/>
Lack of personell	<input style="width: 40px; height: 20px;" type="text"/>
Staff gate keeping	<input style="width: 40px; height: 20px;" type="text"/>
Low priority	<input style="width: 40px; height: 20px;" type="text"/>
Clinical issues (the patient population, difficulties in recruiting	<input style="width: 40px; height: 20px;" type="text"/>

- patients, difficulties in determining prognosis)
- Methodological issues (lack of standardised measurement outcomes, definition of patient population, missing data)
- Ethical issues
- Lack of research training programs
- Lack of senior lecturer posts
- Lack of research network
- Lack of national research agenda
- Other (please specify below)

↑ 53. Please specify other ranked barriers

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↓ **D. Barriers, needs and priorities for end-of-life cancer care research in Europe**

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**Barriers:**[edit](#)[move](#)

54. In general, what do you think prevents professionals from doing research in end-of-life care in Europe?*

Tick as many as apply

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- Lack of funding
- Insufficient knowledge and expertise
- Lack of interest
- Lack of time
- Lack of mentorship
- Lack of technical support
- Lack of infrastructure support
- Lack of personell
- Staff gate keeping
- Low priority
- Clinical issues (the patient population, difficulties in recruiting patients, difficulties in determing prognosis)
- Methodological issues (lack of standardised measurement outcomes, definition of patient population, missing data)
- Ethical issues
- Lack of research training programs
- Lack of senior lecturer posts
- Lack of research network
- Lack of national research agenda

Other, please specify



55. In general, what do you think are the main barriers to taking part in end-of-life care research? Please rank your top three (using number 1,2,3 with 1 being the most important barrier) *

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	Rank
Lack of funding	<input type="text"/>
Insufficient knowledge and expertise	<input type="text"/>
Lack of interest	<input type="text"/>
Lack of time	<input type="text"/>
Lack of mentorship	<input type="text"/>
Lack of technical support	<input type="text"/>
Lack of infrastructure support	<input type="text"/>
Lack of personell	<input type="text"/>
Staff gate keeping	<input type="text"/>
Low priority	<input type="text"/>
Clinical issues (the patient population: Difficulties in recruiting patients, difficulties in determing prognosis)	<input type="text"/>
Methodological issues (lack of standardised measurement outcomes, definition of patient population, missing data)	<input type="text"/>

- Ethical issues
- Lack of research training programs
- Lack of senior lecturer posts
- Lack of research network
- Lack of national research agenda
- Other (please specify below)



56. Specify other ranked barriers

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Priorities:

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57. What do you see as priorities for the field concerning future research on adults with cancer in their last year of life. *
Please tick all that apply

- Pain
- Dyspnoea
- Fatigue & cachexia
- Cognitive symptoms and delirium
- Other symptoms
- Assessment & measurement tools
- Bereavement

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- Cultural issues
- Complementary therapies
- Evaluation of education programmes
- Ethics
- Family & care givers
- Medical sociology
- Last days of life & quality of death
- Policy and the organization of services
- Psychology
- Communication
- Rehabilitation
- Research methodology
- Spiritual care
- Other, please specify



58. Please rank what you see as the top 3 research topics, in order of research priority (using numbers 1,2 and 3 with 1 being the most important barriers).*


	Priority
Pain	<input style="width: 40px; height: 20px;" type="text"/>
Dyspnoea	<input style="width: 40px; height: 20px;" type="text"/>
Fatigue & cachexia	<input style="width: 40px; height: 20px;" type="text"/>
Cognitive symptoms and delirium	<input style="width: 40px; height: 20px;" type="text"/>
Other symptoms	<input style="width: 40px; height: 20px;" type="text"/>

- Assessment & measurement tools
- Bereavement
- Cultural issues
- Complementary therapies
- Evaluation of education programmes
- Ethics
- Family & care givers
- Medical sociology
- Last days of life & quality of death
- Policy and the organization of services
- Psychology
- Communication
- Rehabilitation
- Research methodology
- Spiritual care
- Others (please specify below)

 59. Specify other research topics

Country specific questions



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 60. Does your country have a national strategy for end of life care research?*
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Yes No


 61. Is there a national collaboration between palliative care research groups in your country ?
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[pipe](#)

Yes No Don't know


 62. Is there a formalized national network for palliative care research groups in your country?
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Yes No Don't know

 Thank you very much for your time and effort !
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