



Department of  
**Health, Social Services  
and Public Safety**

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AN ROINN

**Sláinte, Seirbhísí Sóisialta  
agus Sábháilteachta Poiblí**

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MÁNNYSTRIE O

**Poustie, Resydènter Heisin  
an Fowk Siccar**

## **Palliative and End of Life Care Strategy**

## **Consultation Response Questionnaire**

**December 2009**

## CONSULTATION RESPONSE QUESTIONNAIRE

You can respond to the consultation document by e-mail, letter or fax.

Before you submit your response, please read Appendix 1 about the effect of the Freedom of Information Act 2000 on the confidentiality of responses to public consultation exercises.

Responses should be sent to:

E-mail: [primcaredev@dhsspsni.gov.uk](mailto:primcaredev@dhsspsni.gov.uk)

Written: Primary Care Development Unit  
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Telephone: 028 9052 0248

Text phone: 028 9052 7668

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**Responses must be received no later than 19th February 2010.**

I am responding:    as an individual                      
                              on behalf of an organisation                      
                              (please tick a box)

Name: \_\_\_\_\_  
Job Title: \_\_\_\_\_  
Organisation: \_\_\_\_\_  
Address: \_\_\_\_\_  
\_\_\_\_\_  
Tel: \_\_\_\_\_  
Fax: \_\_\_\_\_  
e-mail: \_\_\_\_\_  
\_\_\_\_\_

## Background

The overall aim of the Strategy is to improve the quality of palliative and end of life care for adults in Northern Ireland irrespective of the nature of the condition they have, or where, or by whom, they are being cared for. The Strategy will provide a source of advice and guidance, primarily to health and social care commissioners and service providers, but also to patients and clients and those who are looking after them. This will ensure that people with palliative and end of life care needs, their families and carers are provided with high quality, consistent and integrated care, irrespective of care setting or condition.

The development of this Strategy has been informed by a range of national and international strategies and developments in palliative and end of life care undertaken by a number of national and international bodies. The Strategy also builds upon a considerable amount of work that has already been undertaken in Northern Ireland, for example, the Northern Ireland Cancer Network (NICaN), through the auspices of its Supportive and Palliative Care network group has developed generic standards for palliative care as well as regional guidelines for best practice care.

The Strategy's outcomes will include:

- A raised awareness and understanding of palliative and end of life care;
- Health and social care professionals enabled to identify individuals who could benefit from palliative or end of life care;
- Increased opportunities for choice for individuals in respect of where they receive palliative and end of life care and ultimately where they die;
- An integrated and co-ordinated whole system approach to palliative and end of life care through the development of care pathways that are responsive to patient needs, irrespective of their condition or care setting;

- A raised awareness of the need for appropriate support arrangements for carers and families.

### Purpose

This questionnaire has been designed to support the consultation process relating to the Palliative and End of Life Care Strategy.

The questionnaire seeks your views on the Palliative and End of Life Care Strategy, and should be read in conjunction with the Draft Strategy document. It is particularly important to know whether the proposed Strategy will improve the quality of palliative and end of life care for adults in Northern Ireland irrespective of condition or care setting.

### The consultation questionnaire

The questionnaire can be completed by an individual health professional, stakeholder or member of the public, or it can be completed on behalf of a group or organisation.

## Content of the Strategy

**Q1. Do you agree that this Strategy adequately reflects the balance between palliative and end of life care?**

Yes  No

If you answered "no" to this question please outline the reasons for your answer.

## Vision for Quality Palliative and End of Life Care

**Q2. Do you agree with the vision for quality palliative and end of life care?**

Yes  No

If you answered "no" to this question please outline the reasons for your answer.

**Q3. Do you agree that the Strategy's recommendations support the implementation of the vision?**

Yes  No

If you answered "no" to this question please outline the reasons for your answer.

**Q4. Do you agree that implementation of the vision will result in improved palliative and end of life care for adults in Northern Ireland?**

Yes  No

If you answered "no" to this question please outline the reasons for your answer.

### Section 3 Developing Quality Palliative and End of Life Care

**Q5. Do you agree that there is a need to raise awareness through promoting and encouraging open discussion about palliative and end of life care?**

Yes  No

If you answered "no" to this question please outline the reasons for your answer.

**Q6. Do you agree that information, education and training should be available for patients, families, carers, volunteers and communities?**

Yes  No

If you answered "no" to this question please outline the reasons for your answer.

**Q7. Do you agree that quality palliative and end of life care is dependent on having compassionate, skilled, knowledgeable and competent staff in all care settings?**

Yes  No

If you answered "no" to this question please outline the reasons for your answer.

**Q8. Do you agree that a programme of research should be developed to inform planning and delivery, drive up quality and improve outcomes in palliative and end of life care?**

Yes  No

If you answered "no" to this question please outline the reasons for your answer.

## Section 4 Commissioning Quality Palliative and End of Life Care

<p><b>Q9. Do you agree that a lead commissioner should be identified at regional and local level to ensure that commissioning of palliative and end of life care services is based on qualitative and quantitative population needs?</b></p> <p style="text-align: right;">Yes <input type="checkbox"/>      No <input type="checkbox"/></p>
<p>If you answered "no" to this question please outline the reasons for your answer.</p>

## Section 5 Delivery of Quality Palliative and End of Life Care

<p><b>Q10. Do you agree that every patient identified as having palliative and end of life care needs should have a key professional identified to co-ordinate their care?</b></p> <p style="text-align: right;">Yes <input type="checkbox"/>      No <input type="checkbox"/></p>
<p>If you answered "no" to this question please outline the reasons for your answer.</p>

<p><b>Q11. Do you agree that the potential for having a Managed Clinical Network for palliative and end of life care should be explored?</b></p> <p style="text-align: right;">Yes <input type="checkbox"/>      No <input type="checkbox"/></p>
<p>If you answered "no" to this question please outline the reasons for your answer.</p>

## Section 6 A Care Pathway for Quality Palliative and End of Life Care

<b>Q12. Does the palliative and end of life care pathway provide an appropriate vehicle to deliver quality palliative and end of life care?</b>
Yes <input type="checkbox"/> No <input type="checkbox"/>
If you answered "no" to this question please outline the reasons for your answer.

<b>Q13. Do you agree that the implementation of appropriate tools and triggers, by professionals who are trained and competent to use them, will enable the delivery of quality palliative and end of life care?</b>
Yes <input type="checkbox"/> No <input type="checkbox"/>
If you answered "no" to this question please outline the reasons for your answer.

<b>Q14. Do you agree that specialist palliative care advice and support should be available across all care settings 24/7?</b>
Yes <input type="checkbox"/> No <input type="checkbox"/>
If you answered "no" to this question please outline the reasons for your answer.

<b>Q15. Do you agree that timely holistic assessments led by a multi-disciplinary care team will ensure that changing needs and complexity are recognised, recorded and reviewed?</b>
Yes <input type="checkbox"/> No <input type="checkbox"/>
If you answered "no" to this question please outline the reasons for your answer.

## Exemplars and Case Studies

**Q16. Do you agree that the exemplars and case studies used in this Strategy are helpful to demonstrate quality palliative and end of life care?**

Yes  No

If you answered "no" to this question please outline the reasons for your answer.

## Diagrams

**Q17. Do you agree that the diagrams in this Strategy are helpful in getting their message across?**

Yes  No

If you answered "no" to this question please outline the reasons for your answer.

## Equality Implications

**Q18. Are the policy proposals for the Palliative and End of Life Care Strategy likely to have an adverse impact on equality of opportunity on any of the nine equality groups identified under Section 75 of the Northern Ireland Act 1998?**

Yes  No

Please state the group or groups and provide details of any supporting qualitative or quantitative evidence.

**Q19. Have the needs of the Section 75 categories been fully addressed in the proposals?**

Yes  No

If you answered "no" to this question please outline the reasons for your answer.

**Q20. Is there an opportunity for the policy to better promote equality of opportunity or good relations?**

Yes  No

If you answered yes" to this question please give details as to how.

**Q21. Please use the box below to insert any further comments, recommendations or suggestions you would like to make in relation to the Palliative and End of Life Care Strategy.**

Comments:

**Please return your response questionnaire.  
Responses must be received no later than 19th February 2010.  
Thank you for your comments.**

*Appendix 1*

*FREEDOM OF INFORMATION ACT 2000 – CONFIDENTIALITY OF CONSULTATIONS*

The Department will publish a summary of responses following completion of the consultation process. Your response, and all other responses to the consultation, may be disclosed on request. The Department can only refuse to disclose information in exceptional circumstances. **Before** you submit your response, please read the paragraphs below on the confidentiality of consultations and they will give you guidance on the legal position about any information given by you in response to this consultation.

The Freedom of Information Act gives the public a right of access to any information held by a public authority, namely, the Department in this case. This right of access to information includes information provided in response to a consultation. The Department cannot automatically consider as confidential information supplied to it in response to a consultation. However, it does have the responsibility to decide whether any information provided by you in response to this consultation, including information about your identity should be made public or be treated as confidential.

This means that information provided by you in response to the consultation is unlikely to be treated as confidential, except in very particular circumstances. The Lord Chancellor's Code of Practice on the Freedom of Information Act provides that:

the Department should only accept information from third parties in confidence if it is necessary to obtain that information in connection with the exercise of any of the Department's functions and it would not otherwise be provided

the Department should not agree to hold information received from third parties "in confidence" which is not confidential in nature

acceptance by the Department of confidentiality provisions must be for good reasons, capable of being justified to the Information Commissioner

For further information about confidentiality of responses please contact the Information Commissioner's Office (or see web site at: <http://www.informationcommissioner.gov.uk/>).

*Appendix 2*

Section 75 of the Northern Ireland Act 1998 requires the Department to “have due regard” to the need to promote equality of opportunity between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation; between men and women generally; between persons with a disability and persons without; and between persons with dependants and persons without. The Department is also required to “have regard” to the desirability of promoting good relations between persons of a different religious belief, political opinion or racial group.

In keeping with the above statutory obligations and in accordance with guidance produced by the Equality Commission for Northern Ireland, the Department has carried out a preliminary equality screening exercise to determine if the standards proposed in the Palliative and End of Life Care Strategy are likely to have a significant impact on equality of opportunity and should therefore be subjected to an Equality Impact Assessment (EQIA). The Department has concluded that an EQIA is not appropriate for a number of reasons, for example,,

- The preliminary screening showed no evidence of higher or lower participation or uptake by different groups;
- Interface meetings, and consultations with key stakeholders were already established as a key component in the development of the Palliative and end of Life Care Strategy;
- The Palliative and End of Life Care Strategy appears to promote equality of opportunity and good relations.

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