



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

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AN tSúil

**Sláinte, Seirbhísí Sóisialta
agus Sábháilteacht an Daibhí**

OFIS AN tSúil

**Domestic, Residential Health
and Public Safety**

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:

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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

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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 think 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

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?

Yes No

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

Section 5 Delivery of Quality Palliative and End of Life Care

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?

Yes No

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

Q11. Do you agree that the potential for having a Managed Clinical Network for palliative and end of life care should be explored?

Yes No

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

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

Q12. Does the palliative and end of life care pathway provide an appropriate vehicle to deliver quality palliative and end of life care?

Yes No

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

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?

Yes No

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

Q14. Do you agree that specialist palliative care advice and support should be available across all care settings 24/7?

Yes No

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

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?

Yes No

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

If you answered “yes” to this question 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. Please see comments in response to Q21.

Q21. Please use the space 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.

The Institute of Public Health in Ireland is an all-island body which aims to improve health in Ireland, by working to combat health inequalities and influence public policies in favour of health. The Institute promotes co-operation in research, training, information and policy in order to contribute to policies which tackle inequalities in health.

Key Points

IPH strongly supports the concept of a strategy to address Palliative and End of Life Care.

We acknowledge the importance of a strategy in this area and agree with the broad direction and vision of the strategy. This is witnessed by our affirmative responses in the accompanying questionnaire. However we wish to make the following key points which if addressed will serve to strengthen the strategy. Where the key points relate to sections of the strategy these have been identified.

Key Point A. Section 1 – Introduction

The Institute acknowledges and welcomes references to the work of the Irish Hospice Foundation (referred to as the Irish Hospice Association) (P14) and the Health Service Executive and wishes to encourage the DHSSPS to engage fully with colleagues in the Republic of Ireland prior to publishing the final strategy document. It is essential that both jurisdictions exploit the potential of shared learning in approaches to palliative care. In this context the Institute of Public Health wishes to draw the DHSSPS's attention to the establishment of an "All-island Institute of Hospice and Palliative Care". This Institute will address important research questions and provide evidence and advice for pathways to more effective policy and practice. It could make a significant contribution to the research and development programme outlined in paragraph 3.18 and 3.19. Currently it is in a development phase but if it has been successfully established prior to the publication of this strategy it should be referred to therein.

Key Point B. Section 2 – Background

The Institute agrees with the sentiment that 'Palliative and end of life care is increasingly recognised as a public health issue'.

However as currently expressed this is very vague. Clarification is required as to what is meant by this statement. This can then serve as useful guidance to the approach that needs to be adopted

if palliative care is to be treated as a public health issue. This is particularly important as palliative care is an area of medicine where the paradigm of the health professional ‘knowing what is best’ and the concept of them ‘doing’ to the client/patient is particularly strong. Hence the need to articulate what is entailed in this approach. The Ottawa Charter with its 5 principles of – building healthy public policy, creating supportive environments, strengthening community action, developing personal skills and reorienting health services is useful in that it changes a construct of ‘doing to’ others to ‘doing with’ others.

Key Point C. Section 2 – Background

Policy Context 2.10

The Institute welcomes the aim to promote equity of care in standards for palliative care (P21) and the reference to a regional approach to enhance equity in the commissioning and delivery of care (P37) but we are concerned with these minimal references to this issue.

The Institute is concerned that an analysis of existing inequalities by social groups, by geography, by patient groups or by disease is not contained within this report. Without such an analysis and without a prioritisation of this issue we are concerned that a situation where services are disproportionately ‘needed’ in areas of social deprivation and disproportionately ‘present’ in areas of affluence will not be adequately addressed.

We recommend that the issue of equity in the provision of palliative care receives a greater priority and becomes a more substantial component of the strategy.

Key Point D. Section 3 – Developing quality and end of life care

Shifting public perception about death and dying and achieving a more positive orientation of this phase in ‘life’ is a challenging task. Traditionally there are many taboos associated with death and dying and while this section acknowledges taboos (3.4) the strategy would be stronger if it acknowledged the extent of the challenge in addressing issue. There are many strategies and areas where awareness raising and education can take place. These include public awareness initiatives, education for health professionals and school based programmes. This strategy document refers to public awareness and health professional education but makes no reference to school based programmes. IPH recommends a section emphasising the importance of addressing this area within the school curriculum in both formal structured programmes of study and through informal opportunities when there are births or deaths in the home

environment. This points the way to the need for Cross Departmental Cooperation to deliver on the vision articulated in the strategy. In this specific case the cooperation of the Department of Education is required. They will need to consider curriculum content and ensure teachers are adequately trained to deliver this type of education.

The issue of education and training for health and social care students is critical. The exemplars provided are helpful however a frequent criticism levelled at education for these sectors, particularly for medical students, is that it is deficient in communication skills training. The importance of skills in this area, such as the ability to initiate difficult conversations, cannot be underestimated and assessment of these skills should be a fundamental part of the training programme.

Key Point E. Section 5 – Delivery of Quality Palliative & End of Life Care

The Institute welcomes many of the initiatives proposed in this section eg the provision of a key worker/case manager and exploring the potential for a Managed Clinical Network but it is concerned that the emphasis placed on methods to obtain these outcomes is not sufficient. To state that (5.20) ‘palliative care has been recognised as particularly suitable for a managed clinical network approach... and requires good communication and cooperation’ simply does not do justice to the scale of this task.

The Institute is also concerned that references to costs and economic aspects of the strategy are vague (5.20). In the absence of economic quantification of aspects of the strategy there is a risk of raising expectation and not having economic capacity to deliver. This could result in a significant erosion of goodwill towards, and enthusiasm, for the strategy.

Key Point F. Health Impact Assessment and Palliative & End of Life Care Strategy for Northern Ireland

Health Impact Assessment is defined as a combination of procedures, methods and tools by which a policy programme or project may be judged as to its potential effects on the health of a population and the distribution of these effects within the population. It is designed to inform and influence decision-making and to reduce inequalities.

The Institute recommends that DHSSPS conduct a HIA on the Palliative and End of Life Care Strategy.

The Department has recently participated in an HIA on the Mental Health & Wellbeing Promotion Strategy. This HIA has been acknowledged by the Department as playing a valuable role in

helping to strengthen this strategy. IPH believes that a similar exercise for the Palliative & End of Life Care Strategy will result in similarly positive outcomes.

We also believe that this shows leadership and sets a good example to other Government Departments whose policies would benefit from the HIA process.

Contact details

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**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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December 2009