SUMMARY OF CONSULTATION RESPONSES
PALLIATIVE CARE BILL

Introduction

The Member in Charge of the Bill lodged the draft proposal on 10 March 2009 along with a statement of reasons explaining why he had not consulted on the proposal.

Prior to this, a draft proposal with the same wording and intention had been lodged and consulted upon by Roseanna Cunningham MSP. However, under rule 9.14.1 of standing orders when she became a Member of the Scottish Government she was no longer able to take forward the proposal. This paper provides a summary of the responses to the consultation exercise conducted by Roseanna Cunningham MSP.

The consultation document accompanying the draft proposal for the Palliative Care Bill was issued on 14 November 2008 and the consultation was due to run until 28 February 2009. This was extended to 9 March 2009 given that the consultation period covered the Christmas and New Year holiday period.

The purpose of the proposal as set in the consultation is as follows:

“The objective of this proposed Bill is to secure access to high-quality palliative care for everyone in Scotland on the basis of need. The proposal aims to secure this by placing local NHS Boards under a statutory obligation to provide that care and set up reporting arrangements so that the quality of care provided can be monitored.”

The consultation document was made available from a link on the Proposals for Members’ Bills web pages on the Scottish Parliament website.

Some 370 copies of the consultation document were issued to organisations, MSPs and MPs. Further copies were posted or e-mailed in response to individual enquiries.

There were 106 responses to the consultation document.

There were 59 from individuals, 23 responses from health professionals nine responses from hospices and charities, five from forums or groups, four responses from church organisations, three responses from societies, and three from local authorities. The breakdown of responses is expressed below in the form of a pie chart.
Respondents to the consultation document were invited to submit their own general comments and/or to answer the six questions contained in it.

**Analysis of Responses**

**General**

As noted above, there were 106 responses to the consultation. Of these responses, 68 expressed support for the proposal, 22 neither opposed nor endorsed the proposal while 16 expressed opposition.
Support for the proposal was strongest amongst individuals and church organisations. It should be noted that most of the individuals responding in favour either had a positive experience of accessing palliative care or they or someone close to them had been unable to access palliative care and as such had endured a painful and degrading end to life.

Those opposed to the proposal were primarily concerned about the cost of the proposal. A number were also concerned about how this proposal would relate to the Scottish Government’s Living and Dying Well strategy. However, it should be noted that in opposing the proposal a number highlighted the good intentions of the proposal and indicated that should sufficient funds be available then there would be merit in the proposal.

Questions

The consultation document posed six questions, these are considered in turn below.

Q1 What are your views on using this definition of palliative care for Scotland in the proposed Bill?

There are various definitions of palliative care, but the following World Health Organisation (WHO) definition is internationally recognised and is proposed for the purposes of the Bill:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual…”

Of the 106 respondents to the consultation, 41 responded to this question. 23 respondents believed that the definition of palliative care in the consultation document was appropriate and comprehensive.

Some, however, felt that there were omissions from the definition. In particular, three respondents felt that there was insufficient consideration of spiritual care within the definition. Three respondents argued that the definition was too focussed on the period immediately before death and there should be more consideration given in the definition to care from the time of diagnosis.

Two respondents felt that there would be benefit in a specific definition for palliative care for children and young people, and another two respondents raised concerns about the definition as regards persons with profound and multiple learning difficulties.
One respondent felt that the definition conflated the term “terminal illness” with something that is curable. Another respondent argued that palliative care can not always relieve suffering and as such it was inappropriate to include that goal within the definition.

Finally, one respondent argued that the definition was too wide, while another expressed concern about what they believed to be a lack of a definition of high quality palliative care.

Overall, however, the majority of respondents believed that the definition was appropriate and comprehensive.

**Q2 What are your views on whether all progressive, life-limiting conditions should lead to an entitlement to palliative care?**

Support for extending the provision of palliative care to all progressive or life limiting conditions was almost universal amongst the respondents. Of the 33 responses to this question, 18 offered unqualified support for this extension. Of the remaining 13, none explicitly opposed the extension.

Six responses expressed support for extending provision, but in so doing, stressed that it should be supplied on the basis of need rather than diagnosis. A further three respondents, while expressing support for the extended provision of palliative care, noted that it would be costly to achieve. Two respondents, in offering support, stressed that it would be necessary in many cases for the additional palliative care need to be met by generalists. One respondent argued that before extending the provision of palliative care, it is necessary to first undertake research to determine what groups of people it should be made available to. Another respondent noted that while in principle this extension of palliative care was desirable it would take a long time to deliver.

The only response questioning the proposal did so on the basis that the respondent felt that in extending the provision of palliative care, it was no longer exclusively about palliative care, but pain relief more generally.

It was clear from the responses that there was strong support for ensuring that persons suffering from all progressive, life limiting conditions should be entitled to receive palliative care.

**Q3 A list of indicators of high-quality palliative care has been provided. What other indicators should be included and why?**

The consultation document lists the following indicators of high-quality care—
• place and cause of death;
• how well pain and other symptoms have been assessed, documented and managed, based on evidence-based clinical recommendation;
• the number dying in their place of choice as suggested in the Advanced Care Plan;
• number of out-of-hours emergency admissions at end of life to all care settings; and
• the stage at which palliative care was made available.

There were 43 responses to this question. Four respondents expressed contentment with the list of indicators in the consultation document and indicated that the list was comprehensive. As asked for in the question, the remaining respondents advocated the inclusion of other indicators.

There was a considerable number of different indicators proposed. One of the most common indicators proposed, expressed by seven respondents was that the list should include more reference to providing social and emotional care. Another common additional indicator, proposed by five respondents concerned measuring the satisfaction of the patient’s relatives. One respondent argued that there should be consideration of untimely deaths, so as to monitor the use of terminal sedation.

More generally, six respondents questioned the impact of the indicators, suggesting that their effect may be only to increase bureaucracy, while another respondent contended that while the indicators might successfully interact with the definition of palliative care set out by the National Institute for Health and Clinical Excellence, it was unlikely to successfully interact with the World Health Organisation’s definition on which this proposal is based. Another respondent argued that there should be scope within the reporting framework to detail why certain indicators had not been met, as there may be issues outwith the control of the clinicians.

For the most part, respondents did not question the inclusion of the indicators already listed, however, it is clear that there are other indicators, which it might be beneficial to include and the Member will give due consideration of these in considering the development of the proposal.

Q4 What are the funding implications of this proposal? Please provide detailed costings?

Amongst the 26 respondents to this question there was a general feeling that providing the level of palliative care set out in the proposal would be costly, however, none of the respondents were able to provide detailed costings.
Before looking at the ways in which this proposal could lead to an increase in costs, it is interesting to note that two respondents suggested that the proposal would result in cost savings. One suggested that the increased provision of palliative care would mean a reduction in payment of state benefits, while another suggested that ultimately providing more care in the community rather than establishments would result in savings. One other respondent suggested that some costs could be mitigated through effective partnership work with the voluntary sector. Three respondents were unsure of what the impact would be.

The remaining 24 respondents predicted the proposal would generate more costs, but none in response to the question argued against the proposal on these grounds.

Four respondents stressed that palliative care should be an integral part of the health service and not an add on and as such any increased costs should be considered necessary. Another respondent argued that there should be a move away from the interventionist approach currently prevalent in the NHS to a more holistic approach and that the Scottish Government should fund this change.

In terms of where these costs would be, five respondents indicated that the greatest cost would come from the requirement to offer palliative care in the community, enabling people to be cared for and die at home. Other costs highlighted included additional staffing and support to the voluntary sector and training.

**It is clear from the responses to the consultation that implementing the proposal will be costly. However, it is equally clear that for the majority of respondents this additional cost does not mean that the proposal should not be implemented. Indeed for many respondents the provision of palliative care is essential and the benefits of the care outweigh the costs.**

**Q5 What other organisations etc. will be affected by the proposal and in what ways?**

There were 25 responses to this question. The responses set out benefits for certain groups and greater demands on other groups resulting from the implementation of the proposal.

Responses suggested that the group who will benefit most will be the patients. Seven respondents suggested that patients will be the greatest beneficiaries. Among these seven, three also stressed the benefits to the families of the patient. One response also suggested that employers of carers will also benefit as there will be more support for the carers, enabling them to be more productive workers. Another response suggested that extending provision of palliative care
will be of benefit to general practitioners as it will reduce the demands placed on them.

The responses also highlighted organisations and services upon which there will be greater demands should the proposal be implemented. Six respondents emphasised the impact the proposal would have on the voluntary sector and the potential for greater demands to be placed upon it. Among these respondents, two stressed the importance of health boards giving voluntary groups the sufficient support. Three respondents also stressed the impact this would have on care homes in terms of the nature of the service they provide and the demands placed upon them. With the potential for increased care in the community put forward in the proposal, two respondents highlighted the impact this proposal could have on social services. Responses also highlighted the following organisations as groups who may have greater demands placed upon them should the proposal be implemented:

- Education services
- Religious organisations
- Advocacy
- Counselling services
- Care networks

While it is evident that for some this proposal will mean an additional workload and increased demand upon their resources, few respondents in response to this question suggested that these demands would be so significant as to prevent the implementation of the bill. It is clear also that a significant proportion of respondents believe that the primary impact of the proposal would be the benefits it would provide to patients and their families.

Q6 Please provide any other comments on the Bill’s proposal to place a requirement on all Health Boards to provide high-quality palliative care to everyone in need of it?

There were 27 responses to this question. Of these, 13 respondents took the opportunity to welcome the proposal and to stress the importance of providing palliative care as a matter of course rather than as an optional extra. Amongst these 13, four argued that the availability of palliative care was a human right.

Five respondents raised concerns about how this proposal would interact with the Scottish Government’s Living and Dying Well Strategy. However, it was suggested by Sense Scotland that the proposal was complimentary to the Government’s strategy. Indeed, it suggested that in order for the Government’s
strategy to have effect it would be necessary for there to be a statutory obligation, of the kind set out in this proposal, to provide palliative care.

Five respondents also again highlighted the need for substantial resources to implement the proposal.

One respondent questioned whether the provision of ring-fenced money for palliative care might mean that previously curable conditions might instead be treated with palliative care given that funding for diagnostic and curative care would be similarly ring-fenced.

**While some concerns were raised about the financial viability of the proposal, more than half of the respondents took the opportunity afforded by the question to welcome the proposal. Indeed it was stressed by a number of those supporting the bill that what is proposed should be the minimum patients come to expect.**

**Conclusion**

The Member very much welcomes and appreciates the interest that has been demonstrated in his proposal.

The responses to consultation have provided a number of ideas that the member will consider and use to further develop the policy before completing the drafting of the bill. In particular the Member will give further consideration to the list of indicators for high quality care.