

REVIEW OF PAEDIATRIC HEALTHCARE SERVICES IN NORTHERN IRELAND (PHASE 3):

CONSULTATION RESPONSE QUESTIONNAIRE ON A DRAFT REVIEW OF CHILDREN'S PALLIATIVE AND END-OF-LIFE CARE

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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Hard copy: Donna Magill
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HSC Leadership Centre
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BELFAST BT7 3EN

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Responses must be received no later than 28 March 2014.

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

Name: Dr Sonja McIlfatrick

Job Title: Head of Research

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(please see attached information about AIIHPC)

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Draft Review of Children's Palliative and End-of-Life Care in Northern Ireland

Q1. Does the scope of the information detailed in the review provide a comprehensive assessment of the needs for paediatric palliative and end-of-life care over the next 10 years?

YES: Overall AllHPC would welcome the general direction as outlined within this document. There appears to be little detail about how the recommendations will be implemented. Additional detail will be required for implementation including time lines and line of accountability.

The term 'paediatrics' could be replaced by language capturing care of infants, children and young people.

Q2. Are the enablers for change detailed for these services appropriate or do you feel there are others?

Some are detailed but there are additional enablers required. Further detail around workforce planning and development issues need addressed before workforce could be considered at an 'enabling' level. In terms of Information Technology there are questions around accessibility.

Q.3 Are the 18 recommendations appropriate or do you wish to add or remove any?

Yes: Overall the recommendations as outlined are endorsed, additional important detail on some of the sections wasn't always reflected in the recommendations. As indicated previously there is further specificity required regarding how they will be progressed.

We would support the recommendation for a regional paediatric network with a range of responsibilities for standards of care, development of care pathways, research, and improved co-ordination of care, commissioning and governance. We would also endorse the call to learn from successful initiatives in place in one Trust for regional roll out across NI-e.g. infant mental health and family nurse practitioner initiatives. We welcome the recommendations in relation to key worker and recommendation 9 focusing on the transition to adult services, but suggest there is a need to invest in education and workforce to adequately meet needs of 16-18 year olds in adult care settings. We welcome recommendation 15 regarding education and competency for all staff and note the reference to AllHPC in assisting this development. We support the acknowledged need for workforce planning and possible difficulties in accessing education and development.

Q.4 Taking account of the context and content of this document, are there any other important issues not addressed? YES

If NO please explain

There are other important issues for consideration-the most pressing issue would be workforce planning.

The play needs of children also needs consideration.

Please use space below to address any issues not asked in above questions.

AllHPC is leading on the design and development of an all-Ireland gateway to information and education for palliative care aimed at both public and professional audiences. One major component is aimed at children and young people. This will help meet and support information and education requirements

Equality implications

Q5. Do you think the proposals are likely to have an adverse impact on any of the nine equality groups identified under Section 75 of the Northern Ireland Act 1998? If yes, please state the group or groups and provide comment on how these adverse impacts could be reduced or alleviated in the proposals

Yes No

Response:

- There appears to be a lack of reference to the needs of children with intellectual disabilities or mental health problems.
- It would be helpful if there was a clear link to how the recommendations from the Bamford review integrate with this review.

Q6. Are you aware of any evidence, qualitative or quantitative, that the proposals may have an adverse impact on equality of opportunity or on good relations? If yes, please give details and comment on what you think should be added or removed to alleviate the adverse impact.

Yes No

Response:

Q7. Could the proposals better promote equality of opportunity or good relations? If yes, please give details as to how.

Yes No

Response:

Provide opportunities for linking with other reviews.