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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Responses must be received no later than 28 March 2014.

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

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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
The review is comprehensive review of services and we are not aware of any other information that could be used. The College strongly supports the involvement of children and young people and their parents/carers in service development and redesign with one of the College's key policy priorities focussing on 'Making the NHS better for children and young people'. The RCPCH believes patients and their families are not only beneficiaries of the NHS but also key stakeholders and therefore need to be involved in all areas of planning and service development[i] [ii]. The review demonstrates the participation of children and young people and that their needs and views must be recognised when designing services. The RCPCH has also submitted a response to the consultation on 'Enhancing Healthcare Services For Children and Young People in Northern Ireland' which should be read in conjunction with this submission.
Q2. Are the enablers for change detailed for these services appropriate or do you feel there are others?
The definition used is clear that palliative care for children is not simply provision at the end of life but care focused on improving quality of life for the child and family - will the spectrum of palliative care needs be used for the identification, assessment and care planning for children and families?
Q.3 Are the 18 recommendations appropriate or do you wish to add or remove any? YES/NO
<u>Recommendation 5</u> This recommendation states that each child should have access to 24/7 multidisciplinary community services. Is this realistic for all services (yes for medical and nursing and possibly therapy but this will have significant workforce implications based on the future demand) and what does multidisciplinary mean in this context? <u>Recommendation 12</u> The RCPCH fully endorses a managed clinical network approach to care[iii]. The network model can help to set quality improvement and assurance mechanisms for the whole care pathway for the child. It is important for the network to set a number of outcomes, including patient experience measures, so that these outcomes can be measured over time to show improvement in the quality of service provided and in showing a reduction in unwarranted variation. It is also important to have a dedicated clinical lead for the network. The RCPCH may be able to offer support in developing the network model for palliative care.

Q.4 Taking account of the context and content of this document, are there any other important issues not addressed? YES/NO
There needs to be more emphasis on communication skills training. This is a gap identified by staff in many areas, and is absolutely pivotal to good palliative care. It requires much more than inclusion in a ½ day course. There needs to be explicit mention of advance care planning – again an absolutely key aspect and difficult for many professionals to do with families Are ambulance services included in planning? Technologies and telemedicine will be very important to deliver health services 'remotely' and has already been successfully tried in Scottish paediatrics: http://www.sctt.scot.nhs.uk/programmes/health/paedriatrics/
Please use space below to address any issues not asked in above questions.

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

☐ No ☒

Response:

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:

THANK YOU FOR YOUR COMMENTS.

[i] RCPCH, NHS Confederation, Office for Public Management (2011) Involving children and young people in health services http://www.rcpch.ac.uk/system/files/protected/page/Involving%20CAYP%20in%20Health%20Services.pdf

[ii] RCPCH (2010) Not Just a Phase - a guide to the participation of children and young people in health services http://www.rcpch.ac.uk/system/files/protected/page/RCPCH_Not_Just_a_Phase_0.pdf

[iii] RCPCH, Bringing Networks to Life - An RCPCH guide to implementing Clinical Networks (2012) http://www.rcpch.ac.uk/networks