

REVIEW OF PAEDIATRIC HEALTHCARE SERVICES IN NORTHERN IRELAND (PHASE 1 AND 2):

CONSULTATION RESPONSE QUESTIONNAIRE ON A DRAFT REVIEW OF PAEDIATRIC HEALTHCARE SERVICES PROVIDED IN HOSPITALS AND THE COMMUNITY

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: secondary.care@dhsspsni.gov.uk

Written: Secondary Care Directorate
Room 1, Annexe 1
Castle Buildings
Stormont
Belfast BT4 3SQ

Fax: (028) 905 23302

Responses must be received no later than 31st January 2014

I am responding: as an individual
on behalf of an organisation

(please tick a box)

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Recommendations within the draft Review of Paediatric Healthcare Services Provided in Hospitals and the Community

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

Introduction to Teenage Cancer Trust

Teenage Cancer Trust is the only UK charity dedicated to improving the quality of life and outcomes for the seven young people aged between 13 and 24 diagnosed with cancer every day. We fund and build specialist units in NHS hospitals and provide dedicated staff, bringing young people together so they can be treated by teenage cancer experts in the best place for them.

Through education of young people about the signs of cancer and working with health professionals to improve their knowledge, we work to significantly improve their diagnosis experience. And through our own research and working with our partners in the NHS, across the UK governments, and organisations both nationally and internationally, we strive to improve outcomes for young people.

There are around 2,500 young people diagnosed with cancer each year across the UK. In Northern Ireland approximately 85 new patients in this age group will be diagnosed annually, while approximately the same number again will continue to receive care for cancer or relapse¹. While many of these patients will access either paediatric or adult oncology services at hospitals in Belfast, a minority will also be treated in local hospitals across Northern Ireland. Teenage Cancer Trust is committed to working with all stakeholders to develop a model of care which provides age appropriate support to all young people with cancer throughout the country, highlighting areas of best practice while exploring opportunities to develop the service.

Teenage Cancer Trust's current services in Northern Ireland comprise of a Programme Manager and a Regional Education Executive. The jointly funded Programme Manager is working in partnership with the Health Service and all regional stakeholders to scope and propose the best way of meeting the needs of young cancer patients as well as support the establishment of a teenage and young adult cancer service, while the Regional Education Executive works with schools, colleges and universities to deliver free awareness sessions across Northern Ireland.

Overarching comment

We welcome the opportunity to comment on this consultation, and support the DHSSPS's vision of providing treatment and care of a high standard to all individuals and families across Northern Ireland. We also support the consultation's approach of assessing hospital services alongside those services delivered in the community. Young people with cancer will come into contact with a wide variety of health professionals in a range of settings throughout their cancer journey, and so a coordinated and integrated approach is vital to ensure a positive patient experience and the best possible outcomes.

¹ North West Cancer Intelligence Service (2013)

Our key concerns regarding the review relate to the age range covered by the document (0-18 year olds) and the narrow age band considered to require age appropriate care (16-17 year olds). Existing plans such as the Service Framework for Cancer Prevention, Treatment and Care span children and young people up to age 24, and Teenage Cancer Trust also follow this model by providing services for 13-24 year olds with cancer.

Specialist care delivered in age appropriate settings, in line with NICE Guidance², has been transformational for young people with cancer across the UK. Traditionally treated alongside children or elderly patients at the end of their lives, young people often feel extremely isolated during cancer treatment, some never meeting another young person with cancer. Teenagers and young adults often get some of the rarest forms of cancer and can face ongoing issues relating to survivorship, psychosocial concerns and returning to education or employment post-treatment.

To ensure a high standard of treatment and care for young people with cancer in Northern Ireland it is important to recognise the unique needs of this patient group. These needs should be met by delivering age-appropriate services for all 13-24 year olds in line with current recommendations, commissioning that encompasses a range of services from fertility preservation to self-management of issues such as anxiety and fatigue, and the provision of specialist staff who can communicate effectively with young people. Our jointly funded Programme Manager is currently evaluating the best mechanism for delivering these services across the country.

In order to achieve this, the paediatric review must incorporate and collaborate with all those plans, bodies and guidelines already in place for young people with cancer in Northern Ireland, and continue to work closely with adult hospital and community services.

Specific comments

Recommendation 4:

More clarity is required on how the proposed regional paediatric operational network would work alongside existing networks for young people, such as the NICAN Children and Young People group. We welcome the wide reaching scope of stakeholders who would be part of the regional paediatric operational network, and the DHSSPS's willingness to work closely with the voluntary and community sector. However, we would strongly advocate this network having involvement from similar stakeholders from adult services from the outset in order to foster collaboration and the sharing of best practice, and to ensure effective transition for those patient groups who will access both services.

Recommendation 5:

We welcome the recognition of the importance of age appropriate care throughout the review document; however it is imperative that the specific recommendations of the Service Framework for Cancer Prevention, Treatment and Care (SFCPTC) regarding the necessity of age appropriate care for all 14-24 year olds with cancer are acknowledged and not replaced by this review. The recommendations of the SFCPTC are in line with the NICE Improving Outcomes Guidance for Children and Young People with Cancer, and should be followed for cancer services in contrast to the more narrow recommendations currently set out in the review.

² National Institute for Health and Clinical Excellence (2005), *Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer*

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:

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.

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 at

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