

7.3 CHILDREN AND YOUNG PEOPLE'S CANCER

Introduction

Cancer affects about 24 boys and 21 girls in Northern Ireland each year, with 6 deaths among boys and 5 among girls each year. Some factors associated with a higher risk of cancer in children include some inherited conditions, problems with development in the womb, exposure to infections such as the Epstein-Barr virus and exposure to radiation.

75% of all children with cancer survive at least five years. There is no difference in survival between boys and girls. No improvements in survival have been detected over the last ten years. Leukaemia and brain cancer make up almost 60% of all childhood cancers with survival from leukaemia better (79.5% after five years) than survival from brain cancer (57.4% after five years).

Overarching standard 31:

All children and young people (aged 0-24, to include young people up to the day before their 25th birthday) with cancer should be managed by a multidisciplinary team whose composition reflects the needs of the child or young person at each point in their care journey.

Rationale:

A complex range of services is required for children and young people with cancer involving many disciplines and professional groups and crossing organisational boundaries. Modern cancer care has come to be defined by its delivery through teams of professionals working together (MDTs). A broader definition of these teams has emerged in relation to cancer services for children and young people. The team's composition at any one point in the care journey will vary and should reflect the patient's needs, both disease and age related. Decisions made by the team should be recorded and disseminated to all relevant health professionals.

There are currently a number of gaps in team composition within Northern Ireland. There is currently no funding allocated to the provision of many allied health, social and educational professional services to children, young people and their families living with cancer. Investment is therefore required to improve timely and equitable access for all children and young people with cancer and their families to effective and efficient services to continuously improve outcomes.

Evidence:

National Institute for Health and Clinical Excellence (NICE) (2005) Improving outcomes in children and young people with cancer

<http://guidance.nice.org.uk/CSGCYP>

Department of Health (2000) The NHS Cancer Plan

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009609

American Academy of Paediatrics (2004) Guidelines for Paediatric Cancer Centres. *Paediatrics* 2004; 113 (6): 1833-1835

<http://pediatrics.aappublications.org/cgi/reprint/113/6/1833>

Department of Health (2004) National Service Framework for Children, Young People and Maternity Services

http://www.dh.gov.uk/en/Healthcare/Children/DH_4089111

Responsibility for delivery / implementation			
HSC Board Public Health Agency HSC Trusts Primary care			
Quality Dimension			
Effective, patient centred & efficient Multidisciplinary teams treating children, young people and their families with cancer have sufficient capacity and expertise for early intervention to assist in the effective management of the effects of cancer and its treatment.			
Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
Undertake a baseline mapping of existing MDT composition at each stage of the cancer journey to include capacity	Regional Children's Network	Evidence annual improvement on baseline assessment in line with priorities to be identified by the regional Children & Young People's Network	March 2010 March 2011 March 2012

NOTE: Performance indicators and targets will be reviewed and adjusted as necessary, in the light of the current Budget settlement for 2011/12 to 2013/14.

Overarching standard 32:

All adolescents and young people (aged 14-24, to include young people up to the day before their 25th birthday) with cancer should receive holistic assessment and care that is age appropriate and delivered by team members who are adequately trained in the care of this specific group of patients.

Rationale:

Young people and adolescents with cancer have particular age-specific needs associated with their cancer and the impact it has on them and their family. It is important that those assessing, treating and caring for this group of patients are skilled in the recognition of, and can respond to, their needs. There is currently no provision of training in caring for adolescents and young people with cancer in Northern Ireland.

Young people with cancer are currently being treated in a number of wards and departments depending on the nature of their cancer. It is important to ensure that regardless of the place of care that these young people still receive holistic assessment and care by appropriately trained multidisciplinary team members.

Evidence:

National Institute for Health and Clinical Excellence (NICE) (2005) Improving outcomes in children and young people with cancer

<http://guidance.nice.org.uk/CSGCYP>

Department of Health (2000) The NHS Cancer Plan

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009609

American Academy of Paediatrics (2004) Guidelines for Paediatric Cancer Centres. *Paediatrics* 2004; 113 (6): 1833-1835

<http://pediatrics.aappublications.org/cgi/reprint/113/6/1833>

Responsibility for delivery / implementation

HSC Board

Public Health Agency

HSC Trusts

Primary care

Quality Dimension**Person centred, effective & timely**

Multidisciplinary teams treating children, young people and their families with cancer have sufficient capacity and expertise for early intervention to assist in the effective management of the effects of cancer and its treatment.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
Percentage of staff trained in the assessment, treatment and care of young people with cancer*	Course & department records	Establish baseline Performance level to be determined once baseline established	March 2011
Percentage of young people with cancer who receive holistic assessment by a staff member who is appropriately trained	MDM records	Establish baseline Performance level to be determined once baseline established	March 2011

**Staff working in areas with designated young people's beds.*

NOTE: Performance indicators and targets will be reviewed and adjusted as necessary, in the light of the current Budget settlement for 2011/12 to 2013/14.