

**NICaN Regional Children and Young People's Group  
Annual Report 2009/10**

**Agreement Cover Sheet**

This annual report has been agreed by:

**Chair of NSSG**

**Name:** Dr Anthony McCarthy  
**Organisation:** Belfast Health and Social Care Trust  
**Signature:**  
**Date agreed**

**Chair of NICaN Board**

**Name:** Mr Hugh McCaughey (Interim Chair)  
**Organisation:** South Eastern Health and Social Care Trust  
**Date agreed**

**NSSG members agreed the report on**

**Date agreed** May, 2010  
**Annual report review date** April 2011

## **1.0 Foreword**

This report related to work undertaken by the NICaN Children and Young Peoples Network during the year 2009/10.

As 2009/10 has been the group's first year in existence, a lot of work has gone into establishing a functional group. I am pleased to say that we now have an enthusiastic group which includes representation from all of the relevant disciplines, patients and carers and from the voluntary sector.

Early in the year the group agreed that, in support of the service framework standards, one of our first tasks should be to undertake a scoping exercise to enable us to identify the current multiple points of entry and pathways experienced by teenagers and young adults aged 16-25. An audit tool has now been developed and agreed by the group and is in the process of being completed. In order to support the audit NI Cancer Fund for Children have also undertaken a piece of qualitative work with their teenagers and young adults to hear directly from them about their experiences of specialist services. It is anticipated that the audit will identify a range of issues relating to communication, staff training, patient information and access to support services and will shape and inform the work programme of the group over the next 2-3 years.

One of the key challenges in 2010/11 will be the successful completion and analysis of the baseline audit which will require the cooperation of a huge number of services across all Trusts.

Currently, the group is being supported within NICaN team with no additional resource. The sheer breadth and complexity of the work that needs to be undertaken means that more dedicated support will be required if the group is to make any significant headway in the short to medium term. The group has commenced discussions with the Teenage Cancer Trust in relation to supporting developments in NI.

***Mr Anthony McCarthy, Chair***

## 2.0 Network Audit

Name of audit project	Dates project has been reviewed	Project Completed?	Dates results of completed projects have been discussed
Baseline review of service provision for teenagers and young adults to identify: treatment points; MDT arrangements for the management of young people; and staff training.	Ongoing	No	To be presented June 2010*

\*Qualitative component presented at regional meeting on 23<sup>rd</sup> October, 2009

## 3.0 Patient and Carer Feedback Involvement

Currently, there is one patient and public representative on the network group. However, further patient and carer involvement is being sought via NI Cancer Fund for Children and Clic Sargent.

NI Cancer Fund for Children has held a number of focus groups with parents and young people to capture an overview of their cancer journey and overall experience. A number of key themes were identified from this piece of work which were presented at the regional group meeting in October, 2009 and will be included as the qualitative component within the overall baseline results.

### A word from the Patient Representative

*My daughter was diagnosed in 2005, aged 15 years old. Because she was over the age of 14 she was classed as an adult and therefore treated in adult wards. While my child got the best treatment from the best consultants in one of the best hospitals, the lack of communication with teenagers had a very negative impact on her healing. I feel that it is vital to the well being of children and young adults with cancer to have the proper facilities and services that they deserve.*

*The NICaN regional children and young peoples network is essential for making the change which will serve to benefit for our children and young people and enable their journey through their illness to be more bearable.*

**Ms Carole Dooley**

**Patient representative**

## **5.0 Key Achievements**

- Agreed terms of reference for the group
- Secured core membership for the group to ensure that all relevant disciplines and stakeholders are represented.
- Reviewed key evidence documents to include Improving Outcomes Guidance and Manual of Cancer Services to inform key priorities for the group
- Established a sub-group to take forward a scoping exercise to identify current care pathways and access to specialist services for teenagers and young adults aged 16 -25 years - baseline audit tool to establish current pathway and access to specialist services for all teenagers and young adults aged 16-25 years old developed and issued.
- Commenced work on the development of care pathways
- Established strengthened links with the Teenage and Young Adults Cancer (TYAC) group with attendance by group members at TYAC events
- Developed an agreed protocol for the treatment of nausea in children receiving radiotherapy
- Identified a clinical trials lead; discussion of open clinical trials is now a rolling agenda item
- Reviewed Cancer Services Framework standards in light of feedback from the consultation process
- Commenced discussions with the Teenage Cancer Trust in relation to supporting developments in Northern Ireland
- Suzanne Mooney (Core Member) was awarded a research fellowship by the N. Ireland Research and Development Office and sponsored by Queens University Belfast, and Belfast Health and Social Care Trust to undertake research with teenagers and young adults with cancer. This

study investigates how hospital service delivery can meet the changing supportive care needs of this patient cohort promoting their well-being in everyday life and will greatly inform the work of the network.

## **6.0 Key Challenges for 2010/2011**

Key challenges for the year ahead will be the successful completion of the baseline audit to ensure that adequate information is made available to inform future priorities and service improvements.

The network does not currently have a dedicated clinical network co-ordinator and ensuring ongoing support will be instrumental to the outputs of the group.

It is anticipated that the future work plan of the group will be informed by the outcome of the baseline audit. However, a number of defined tasks have already been identified for completion during 2010/11. These include:

- Completion of a best practice care pathway for children
- Completion of a best practice care pathway for teenagers and young adults
- The agreement of a radiotherapy referral protocol
- Development of a C&YPs MDM module within CaPPs (subject to resource)
- Review of current follow up mechanisms to include long term effects.

## **7.0 Work Plan 2010/11**

See below.

For further information on the NICaN regional children and young people group, please follow this link:

[www.cancerni.net/org/childrenandyoungpeoplegroup](http://www.cancerni.net/org/childrenandyoungpeoplegroup)

Area	Ref	Task(s)	Lead	Timescale
<b>1. Service planning &amp; delivery</b>	1.1	Continue to undertake review of group membership to ensure all relevant disciplines are represented on the Network to enable effective functioning of the group.	Clinical Lead/Coordinator	Ongoing
	1.2	Monitor attendance at regional group meetings by professional organisation	Clinical Lead	Ongoing
	1.3	Complete scoping exercise to identify current care pathways and identify associated service improvements	Clinical Lead/Coordinator	Ongoing
	1.4	Work with commissioners, providers and TCT to develop an action plan to address the identified service improvements	Clinical Lead/Coordinator	Ongoing
	1.5	Explore the implementation of a CAPPs MDM module for children and young people	Clinical Lead/Coordinator	Dec 2010
	1.6	Complete the development of regionally agreed integrated care pathways across the Children, teenage and young adults service (initial focus on children)	Clinical Lead/Coordinator	Mar 2011
	1.7	Develop a radiotherapy referral protocol	Radiotherapy sub-group	Dec 2010
<b>2. Service improvement &amp; redesign</b>	2.1	Continue links with the Teenage and Young Adults with Cancer (TYAC) group and undertake a review of available resources	Clinical lead	Ongoing
	2.2	Undertake a mapping of current patient information resources for Children, Teenagers and Young Adults across the patient pathway.	Sub Group	December 2010

	<b>2.3</b>	Explore current mechanisms of follow up to include survivorship and late effect issues in line with other national projects and Improving Outcomes Guidance.	Survivorship sub-group	December 2010
<b>3. Governance &amp; audit</b>	<b>3.1</b>	Share outcomes of baseline assessment / mapping exercise & agree actions to include identification of further audits	Regional group	Annually
<b>4. Education &amp; workforce development</b>	<b>4.1</b>	Attendance at the Advanced Communication Skills training by at least two members of each Children & Young People's Team	Clinical lead	Ongoing * subject to funding
<b>5. Research &amp; development</b>	<b>5.1</b>	Circulate list of open clinical trials and associated trials accrual	Coordinator	Monthly
	<b>5.2</b>	Review clinical trial accrual by MDT and provide remedial action plan if required	Clinical Trials Lead	Annually
	<b>5.3</b>	Support research work being led by Ms Mooney.	All	Ongoing
<b>6. Annual report &amp; work plan</b>	<b>6.1</b>	Agree an annual work plan to be signed by the Chair and Clinical Lead	Chair/Clinical Lead	Annually
	<b>6.2</b>	Produce an annual report detailing the work of the Children and Young peoples Regional group	Chair/Clinical Lead	Annually