



**NICaN Children and Young Peoples Network
Friday 26th March, 2010
Ennis Room, Belfast City Hospital**

In attendance:

Dr Anthony McCarthy (Clinical Lead/Chair)
 Ms Bridget Tourish (NICaN)
 Ms Suzanne Mooney (QUB)
 Mr Richard Hardy (Cancer Centre)
 Ms Liz Osborne (NICFC)
 Ms Julie Duffy (Cancer Centre)
 Ms Gillian Coll (RBHSC)
 Ms Fiona Collinson (RBHSC)
 Ms Cecilia Milburn (Clic Sargent)
 Ms Naomi Spence (RBHSC)
 Ms Barbara Jackson (RBHSC)
 Dr Carole Cairns (RBHSC)
 Ms Lorna Dickson (RBHSC)
 Ms Anne Lappin (NI Children’s Hospice)

Apologies:

Ms Liz Henderson
 Ms Bernie McShane
 Dr Jacqui Harney
 Ms Aiveen Higgins
 Ms Mary Frances McMullin

Item number	Summary of key points / outcomes/ action	Identified Party & date
CYP-0310-01	<p>Welcome and Introductions Dr McCarthy welcomed everyone to the meeting; apologies were noted as recorded above. A special welcome was extended to new members who were attending their first meeting of the group.</p> <p>Minutes and matters arising from meeting 26/6/09 The minutes were agreed as a true and accurate reflection of the meeting. It was noted that the key matters arising would be covered within the agenda for the meeting, however the following updates were noted:</p> <p><u>Membership Update</u></p> <p>Adult Haematologist – Dr Mary Frances McMullin has been confirmed as adult haematologist on the group and has been forwarded relevant documents.</p>	

<p>CYP-0310_02</p>	<p>Primary Care representation – Ms Tourish advised that primary care representation is being sought via the primary care group.</p>	
	<p>Patient and Public Involvement – Ms Tourish advised that work is underway via NICFC and Clic Sargent in relation to securing patient and public involvement on the group and such representatives will be fully supported by the NICaN Patient and Public Involvement Co-ordinator.</p>	
	<p>Action: Ms Tourish to continue liaison with NICFC and Clic Sargent and to keep the group updated on progress.</p>	<p>Ms Tourish Ongoing</p>
	<p>Cancer Services Framework (CSF) Update Ms Tourish provided update and advised that the public consultation has now closed in relation to the CSF. She advised that a number of comments have been received in relation to the children and young people standards and that a response is required to be submitted to the DHSSPS. Discussion followed in relation to some of the comments received.</p>	
	<p>Action: Dr McCarthy/Ms Tourish to meet to produce response to comments received. Group to be consulted if necessary, copy of response to be forwarded to the group</p>	<p>Dr McCarthy/ Ms Tourish</p>
<p>Cancer Patient Pathway System (CAPPs) Ms Tourish advised that she had a discussion with Dr Lisa Ranaghan in relation to the development of an MDM module within CAPPs for children's.</p>		
<p>Action: Dr McCarthy and Ms Tourish to arrange meeting with Dr Ranaghan Ms Sarah Williamson. Group to be kept updated on progress.</p>	<p>Dr McCarthy/ Ms Tourish</p>	
<p>Links with Teenage Cancer Trust (TCT) Dr McCarthy provided update on behalf of ms Henderson. It was noted that Ms Henderson had discussions with Mr Davies (TCT) and that he is keen to establish links with the network group. Mr Davies agreed that it would be useful for himself and a colleague to attend a future meeting of the group to gain an overview of the groups work and the associated challenges and discuss a way forward.</p>		

<p>CYP-0310_03</p>	<p>Action: The group agreed that Mr Davies and colleagues should attend the next network meeting on Friday 25th June, 2010 where an overview of the priorities for the group together with the key challenges should be presented. It was also agreed that an invitation to this meeting should be extended to wider stakeholders to include trust management, commissioners and DHSSPS.</p> <p>Ms Tourish also drew the group’s attention to a forthcoming TCT conference to be held in early June and advised that where funding is available; it would be very useful for some members to attend and feedback to the wider group.</p> <p>Ms Tourish to liaise with Dr McCarthy and Ms Henderson in arranging this meeting, group to be kept updated.</p> <p>Update on baseline assessment Ms Tourish provided update, highlighting that a baseline questionnaire had been circulated to Haematologists and relevant oncologists. She advised that following discussion with Dr Anne Kyle (Chair, NICaN Haematology Group), it has been agreed that its best for the cancer managers at each trust to pull the relevant data from available systems (CAPPs, PAS, Pathology) and then a Haeamtologist from each unit can QA the data and answer the generic questions.</p> <p>Ms Tourish advised that she would remain confident of gaining adequate information.</p> <p>Action: Ms Tourish to continue to progress work on baseline assessment and sub-group to meet once responses has been received to prepare presentation for meeting on 25th June, 2010.</p>	<p>Ms Tourish/ Dr McCarthy Ms Henderson</p> <p>Ms Tourish/ Dr Harney Ongoing</p> <p>Ms Tourish/ Sub-group</p>
<p>CYP-0310_04</p>	<p>Research survey – treatment and care of teenagers and young adults Ms Tourish provided update, highlighting that she had circulated an e-mail to the group requesting that relevant members complete the survey which is being led by Rebecca Birch, PHD student, Leeds University and funded by Cancer research UK.</p> <p>Ms Tourish encouraged members to complete the survey by accessing www.surveycapture.com/survey/tya01.</p>	

<p>CYP-0310_05</p> <p>CYP-0310_06</p> <p>CYP_0310_07 CYP_0310_08</p>	<p>It was noted that contact has been made with Rebecca and it has been agreed that the results of the survey will be shared with the group broken down both by NI results and that of other UK networks.</p> <p>The group agreed that this will be very useful information in obtaining a benchmark of NI services to that of services elsewhere in the UK.</p> <p>Action: Relevant members to complete questionnaire and Ms Tourish to keep group updated on progress.</p> <p>Development of care pathways Dr McCarthy advised that as agreed at the last meeting, work is underway in transferring the early Drafts into the NICaN Pathway template.</p> <p>A copy of one of the pathways was circulated for information.</p> <p>Action: Dr McCarthy and Ms Tourish to populate all pathways into NICaN template for discussion/sign off at next meeting.</p> <p>Clinical trials A list of open paediatric clinical trials had been circulated together with associated accrual rates. Dr McCarthy discussed the open trials with the group. He also highlighted that where a trial is not open in a NI centre, there is a facility to transfer the patient to other UK centres.</p> <p>Dr McCarthy referred to a recent article of interest within the Oncology Times in relation to trials and it was agreed that this article should be circulated to the group for information.</p> <p>DRAFT Annual report and work plan Ms Tourish discussed the draft annual report and work plan for the group, highlighting that the annual report outlines the key achievements of the group and challenges for 10/11.</p> <p>Key priorities for the group for 10/11 were discussed to include scoping of available patient information resources and the establishment of a sub-group to consider survivorship issues for this patient group.</p> <p>Acton: Ms Tourish to finalise documents and circulate to group for final comments/additions.</p>	<p>All</p>
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	<p>Dates for future meetings It was agreed that the next meeting will be held on Friday 25th June, 2010, 1pm, Staff Restaurant, Knockbracken Healthcare Park.</p>	
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