

NICaN TEENAGE AND YOUNG ADULTS NETWORK GROUP

TERMS OF REFERENCE

Date Agreed	Version	Comments/Changes
19/07/2020	1.2	New Chair and social work rep (N.McCay)
21/11/2019	1.1	Addition of patient rep and extended members (N.McCay)

Purpose

The purpose of the Teenage and Young Adults Network Group is to work together to ensure equitable access to high quality, age appropriate treatment and care, and to ensure the best possible experience and outcome for the teenager and young adult’s patient group, with a cancer diagnosis, and their families.

The TYA Network Group will oversee and lead on the development of a regional cancer service which aims (within current resource constraints) to implement the relevant TYA Service Framework for Cancer Prevention, Treatment and Care¹, Standards 31 & 32 and the NICE, Improving Outcomes for Children & Young People with Cancer Guidance².

Scope

Teenagers & Young Adults with a cancer diagnosis are defined, for the purpose of the NICaN TYA Network Group, as any person from the age of 12 years of age up to the eve of the individuals 25th birthday. It is recognised that staff within the TYA service deliver services to different age groups within this TYA category.

In order to ensure high quality person centred care for TYAs with a cancer diagnosis, the NICaN TYA Network Group will:

- Provide steering, oversight and give expertise opinion to assist progress with the implementation of the regionally agreed NI TYA Cancer Service model ;
- Be the authoritative source of expertise and guidance to planners, commissioners and providers of services;

¹ Service Framework for Cancer Prevention, Treatment & Care
http://www.dhsspsni.gov.uk/sqsd_service_frameworks_cancer

² NICE, Improving Outcomes for Children & Young People with Cancer Guidance
<http://guidance.nice.org.uk/CSGCYP>

- Be the provision of clinical opinion on issues relating to TYA cancers for the network;
- Provide co-ordination and ensure consistency across the network for TYA cancer policy, practice guidelines, audit, research and service development.
- Develop clinical pathways and clinical guidelines
- Support the identification of good practice for recommendation and dissemination;
- Determine the strategic direction for the development of TYA cancer services in Northern Ireland;
- Coordination and consistency of policy across NICaN Clinical Reference Groups for the provision of cancer services for TYAs
- Ensure that there is appropriate engagement of stakeholders, including staff, user involvement and commissioners, to ensure services are developed taking these views into account;
- Take into account the role and contribution to services from charitable organisations;
- Ensure compliance with the relevant national cancer standards for TYAs with cancer.

Core Membership

Membership will be by invite to those deemed to have a vested interest in the planning, development and delivery of Teenage & Young Adults Cancer Services in Northern Ireland.

The following core member constituencies were identified as central to lead and implement improvements in Services across Northern Ireland for Teenagers & Young Adults with Cancer.

¹ Service Framework for Cancer Prevention, Treatment & Care
http://www.dhsspsni.gov.uk/sqsd_service_frameworks_cancer

² NICE, Improving Outcomes for Children & Young People with Cancer Guidance
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Role	Constituent Secured
Chair	Dr Aaron Niblock
Lead clinician of Primary Treatment Centre (PTC) (Belfast)	Dr Anthony McCarthy
Belfast Lead TYA nurse for PTC	Renee Reid
Belfast Trust Manager	Joanne Cullen Edel Aughey
Western Lead TYA nurse and/or clinician	Valerie Millar
Western Trust Manager	Bridget Tourish
Northern Lead TYA nurse and/or clinician	Kerrie Sweeney Dr Aaron Niblock
Northern Trust Manager	Pat McClelland
Southern Lead TYA nurse or clinician	Fiona Reddick
Southern Trust Manager	Fiona Reddick
South Eastern Lead TYA or clinician	Lisa Callender/
South Eastern Trust Manager	Mary Jo Thompson
Consultant Haematologist	Dr Sarah Lawless
Consultant Oncologists	Dr Audrey Fenton Dr Rhun Evans
Consultant Paediatricians	Dr Anthony McCarthy Dr Robert Johnston
Paediatric CNS	Katherine Mullan
Lead Social worker for PTC	Kevin O Grady (BHSCT) David Wylie
NICaN Representative	Naomi McCay
PHA nursing Representative	Loretta Gribben
Patient Representative	Caoimhe Wills
Parent Representative	Vacant



Extended members – Macmillan Service improvement leads	Moyra Mills (NHSCT) Caroline Lynas (SET) Caroline Beattie (SHSCT) WHSCT – Vacant BHSCT - Vacant
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Meeting Frequency & Arrangements

The NICaN TYA Network Group will meet twice a year, agreed in advance by the Clinical Lead. All attendance should be recorded.

Venue confirmation will be circulated at the earliest opportunity; papers will be circulated no less than 5 working days before meetings. NICaN will be responsible for the timely distribution of agendas, minutes/notes and papers relating to the work of the NICaN TYA Network Group.

Accountability and Reporting

The NICaN TYA Project Network Group’s authority will come from its credibility. The credibility will be evidenced by the application of the Group and its member’s knowledge and expertise. Individual members will be accountable to their own profession. Core members are responsible for reporting back within their professional group and to ensure adequate consultation and involvement in key areas of work.

The Lead/Chair of the group will be held accountable to the NICaN Board, via a member of the NICaN management team, for the delivery of the agreed work plan. The Lead/Chair will be responsible for reporting to the NICaN Board annually.

Attendance

In order to keep up to date with the progression of the NICaN TYA Network Group it is crucial members attend regularly. If a nominated member fails to attend 2 consecutive meetings contact will be made to establish reason for non-attendance.

NICaN TYA Network Group Support

Naomi McCay