

Teenagers and Young Adults (TYA) Cancer Pathway Board

Minutes and Actions

Tuesday 16th April 2019

14:00-16:00

Seminar Room, Top Floor Palatine Treatment Centre, Christie Hospital, Wilmslow Road, Withington, Manchester, M20 4BX

Members in attendance

Name	Role/organisations	Attendance 2019/20
David Wright (DW)	TYA Pathway Clinical Director	1/1
Rachel Allen (RA)	Pathway Manager, Greater Manchester Cancer	1/1
Paula Daley (PA)	User Involvement Manager, Greater Manchester Cancer	1/1
Leila Hamrang (LH)	Young Voices Representative	1/1
Safiya El Gindy (SEG)	Young Voices Representative	1/1
Seren Hughes (SH)	Young Voices Representative	1/1
Martin McCabe (MM)	University of Manchester	1/1
Nicola Chesman (NC)	TYA Physiotherapist, The Christie NHS Foundation Trust	1/1
Kate Law (KL)	Clinical Nurse Specialist; Community Liaison Team Leader, The Christie NHS Foundation Trust	1/1
Mark Reed (MR)	Nurse Specialist/Proton Key Worker, The Christie NHS Foundation Trust	1/1
Charlene Jones (CJ)	TYA Clinical Nurse Specialist, GM and North Cheshire – NW	1/1
Angela Dixon (AD)	CLIC Sargent	1/1
Sarah Burns (SB)	Consultant Haematologist, Manchester University NHS Foundation Trust (MRI)	1/1
Satarupa Choudhuri (SC)	Consultant Haematologist, Pennine Acute Hospitals NHS Foundation Trust	1/1
Kerrie Waterhouse (KW)	The Christie NHS Foundation Trust	1/1
Anna Castleton (AC)	The Christie NHS Foundation Trust	1/1

Lorraine Wright (LW)	Youth Support Co-ordinator Team Lead, The Christie NHS Foundation Trust	1/1
Anna Mackland (AM)	TYA Occupational Therapist, The Christie NHS Foundation Trust	1/1

Guests in attendance

Name	Role/organisations
Freya Howle (FK)	CURE Project Manager, Greater Manchester Cancer

Apologies

Name	Role/organisations	Attendance 2019/20
Paul Fleming (PF)	Young Voices Representative	0/1
Michael Leahy (ML)	The Christie NHS Foundation Trust	0/1
Tracy Kelly (TK)	Macmillan Lead Cancer Nurse, Manchester University NHS Foundation Trust	0/1
Anne Tomlinson (AT)	Macmillan Lead Cancer Nurse, Lancashire Teaching Hospitals NHS Foundation Trust (Royal Preston Hospital)	0/1
Beverley Meenan (BM)	Macmillan Lead Nurse for Cancer and Palliative Care, Stockport NHS Foundation Trust	0/1
Jackie Brunton (JB)	Lead Cancer Nurse, Blackpool Teaching Hospitals NHS Foundation Trust	0/1
Helen Ashby (HA) / Claire Liu (CL)	Manchester University NHS Foundation Trust	0/1
(Deputising for Tracy Kelly)		
Joanne Barks (JB)	BFW Hospitals	0/1
Mark Grey (MG)	BFW Hospitals	0/1
Chiara Lobetti (CL)	CMFT	0/1
Heidi Moertl (HM)	CMFT	0/1
Wiebke Appel (WA)	Consultant Clinical Oncologist, Lancashire Teaching Hospitals NHS Foundation Trust	0/1
Carmel Wiseman (CW)	East Lancashire Hospitals Trust	0/1
Lorraine Keogh (LK)	ELHT	0/1
Helen Smith (HS)	Lancashire Teaching Hospitals	0/1
Joanne Wilkinson (JW)	Lancashire Teaching Hospitals	0/1
Geraldine Skailles (GS)	LTHTR	0/1
Debbie Smith (DS)	MFT	0/1
Ian Welch (IW)	MFT	0/1
Katy Kelton (KK)	Morecambe Bay Hospitals Trust	0/1
Pauline Robinson (PR)	Morecambe Bay HT	0/1
Amanda Lane (AL)	TYA Lead Nurse, Pennine Acute Hospitals NHS Trust	0/1
Richard Brough (RB)	Stockport NHS Foundation Trust	0/1

1. Welcome and introductions

DW welcomed all members. It was noted that not all Trusts are represented from across the TYA network. DW highlighted that KW is leaving the TYA service at The Christie.

2. Minutes of last meeting 15th January 2019

<p>Discussion summary</p>	<p>DW updated the Board on progress made since the last meeting in January.</p> <p>A request was made to amend the comment in the minutes (section 2) around late effects. The suggested amendment was as follows <i>'It serves a distinct group of patients but not everybody and is medically driven'</i>.</p> <p>DW informed Board members that the level of psychologist support for proton therapy patients was discussed with MM. Those patients aged 18 and above will be picked up by the psych-onc team at The Christie if necessary. Those aged under 16 will be covered through MCRH. Skype interviews with psychologists are offered to those aged 16-18. It was noted that if there is an acute incident that occurs among proton therapy patients aged 16-18, this is currently not built into the TYA Psychologists job plan.</p> <p>Psychological support was highlighted as a priority by members of the Young Voices Network and so needs to remain a key consideration for the Pathway Board to drive. It was noted that psychological support is wider than TYA patients. AC commented that it is hard to build support for proton therapy patients into the existing business case as the requirement is unclear at present in terms of demand.</p> <p>DW is still to meet with KM.</p>
<p>Actions and responsibility</p>	<p>NA.</p>

3. Young Voices Network update

<p>Discussion summary</p>	<p>LW updated on the Young Voices Network meeting which was held on the 3rd April. The main focus of the meeting was the fertility questionnaire and mental health questionnaire. The fertility questionnaire is now ready to be cascaded to gather the views of young people and help verify the effectiveness of fertility services for TYA patients. The questionnaire will be taken to the Way Forward Programme which will involve around 20 young people. The intention is for 10 surveys to be completed at this meeting to sense check the questionnaire. LW will then share the document at the Audit Committee.</p> <p>Ambulatory Care was discussed at the Young Voices Network meeting following concern at the January meeting. A nurse attended the April meeting and was able to respond to concerns and reassure the members.</p> <p>A draft mental health survey was discussed at the Network meeting.</p> <p>SC queried whether the ambulatory care service was in operation for TYA patients. DW responded that it was live for a limited number of treatment regimes. The majority of patients so far have come through the solid tumour pathways. LW commented that informed choice and ability to</p>
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	change one's mind is very important to young people and so it is important that this remains a prevalent agenda in the ambulatory care service.
Actions and responsibility	NA.

4. Feedback from April 2019 TYA Study Day

Discussion summary	It was noted that the Young Voice Network representatives presented at the recent TYA Study Day. The event was very well received with approximately 80 delegates from across the North West.
Actions and responsibility	NA.

5. TYA service audits – update on general ongoing survey

Discussion summary	At the last Pathway Board the consensus was that board members were happy with the Birmingham service evaluation tool. The medium for which the tool is shared and disseminated needs to be agreed. It was noted that the Young Voices Network Facebook page has been hacked and therefore suspended. Many members of the Facebook group have received a text to inform them of the suspended account. It is likely that the page will need to be established again from scratch.
Actions and responsibility	a) The medium for which the Birmingham tool is shared and disseminated across the North West TYA network is to be worked through and agreed.

6. Teenage and Young Adults Cancer Service Specifications

Discussion summary	<p>The TYA Cancer Service Specifications were discussed. The specifications lay out what TYA cancer services should look like from the perspective of principal treatment centres such as The Christie and designated trusts such as MFT. The specifications replace what Peer Review would have been. DW updated that the intention was to discuss the specifications at the January Board but there was little time to do so. DW invited thoughts and comments on any concerns with the specifications. DW commented that there was a consensus (outside of the meeting) that the post/end of treatment agenda requires more work. As it stands, there has been some feedback on this. The latest copy should be released soon. It was noted there have been a few webinar consultation sessions.</p> <p>NC commented that functional/physical effects are not listed in the specifications. NC highlighted that support for physical ability and functional independence should be mentioned alongside the need for social and psychological support. The three aspects are inter-related in holistic care, so suggested the need to highlight this when specifying the support services required for young people.</p>
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Actions and responsibility	NA.

7. Development of psychologist business case

Discussion summary	MM was unable to attend the meeting and so updated outside of the Board meeting. The Business Case is expected to be submitted in May. The business case was built for Christie patients only, not network or external proton referrals. It includes emotional and family support and neurocognitive testing.
Actions and responsibility	NA.

8. Overview and update of the Greater Manchester Cancer CURE Project

Discussion summary	<p>FH presented an overview of the CURE project which has been designed to deliver a comprehensive tobacco addiction treatment service for acute care trusts. Funding was provided by GMHSCP for Phase 1 implementation at Wythenshawe Hospital, and rollout will benefit from Transformation Funding across GM, led by Greater Manchester Cancer. A similar model in Canada has demonstrated that comprehensive secondary care treatment of tobacco addiction delivers immediate and highly significant reductions in admission rates and mortality.</p> <p>CURE aims to use the unique teachable moment of a hospital admission to improve rates of smoking cessation during and immediately following hospital visits. Specific eLearning modules for CURE were developed as it was recognised that across the board experience and confidence in treating tobacco addiction or simply giving Very Brief Advice (VBA) would be extremely varied, and the success of CURE depends of the ability of staff to speak to and treat patients effectively.</p> <p>An overarching aspect of the success of CURE is the promotion and realisation of completely Smokefree hospital grounds, supporting smokers in their quest to stop smoking and protect patients, public and staff from second hand smoke.</p> <p>AC queried the level of engagement with the service so far in terms of the initial pilot.</p> <p>DW queried how many patients the CURE model would reach in each hospital based on the investment. Transformation Funding through GM Cancer will 'pump prime' trusts, covering costs associated with implementation in each of the Trusts for one year, after which Trusts are expected to pick up the costs themselves.</p> <p>Pharma costs were discussed. FH outlined that budget arrangements are different in each Trust.</p>
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	<p>There was a query around marijuana smokers and vapers and whether the CURE project reaches these individuals. The treatment options are for nicotine replacement (vaping is not a standard treatment option). The specialist CURE team in each trust will discuss all of the patient's treatment options with the patients.</p> <p>Contraindications of prescribed drugs were discussed.</p> <p>Responsibility for referrals sits with the health professional admitting the patient.</p>
Actions and responsibility	<p>a) RA to share the video with all members.</p> <p>b) The group requested further information on the treatment pathway and the medications that will be offered, specifically the contraindications of Varenicline. FH will provide RA with this information to share with the group.</p> <p>c) FH to consider young people input into any marketing/promotional materials produced for CURE so that it is age appropriate.</p>

9. Prehab workstream for TYA

Discussion summary	<p>NC updated on progress made around the scoping of a prehabilitation service for TYA patients at The Christie. NC, AM and ZM met recently. NC highlighted that there is less evidence in existence for prehabilitation in teenagers and young adults than in other pathways/population groups. Nonetheless, NC spoke of the need for structured exercise interventions for young people. Evidence indicates that young people in general are not exercising in line with the recommended guidelines.</p> <p>Those young people that NC is made aware of at The Christie will receive exercise advice and guidance. It was noted that there is no systematic model implemented at The Christie and so there is variation within the TYA service at present. Systematic opportunities to exercise are not in existence at The Christie.</p> <p>It was suggested that the Young Voices Network may like to get involved in developing a service offer for TYA patients.</p> <p>There was a suggestion to raise the profile of the need to exercise as a starting point.</p> <p>Pockets of exercise programmes exist through GM Active, however patients need to be well enough to attend.</p> <p>There was a suggestion to consider a specific group of TYA patients to target efforts towards initially such as transplant patients.</p> <p>DW mental health</p>
Actions and responsibility	<p>a) NC to attend the next Young Voices Network in July to speak to representatives about a systematic exercise/physical activity offer for TYA patients.</p>

10. Site specific treatment summaries

Discussion summary	<p>TYA treatment summaries exists so some of the elements for discussion are around who completes them; is there a way of making them electronic so that they self-populate and certain fields can be tailored. There is a likeness to many of the templates shared. DW invited thoughts from delegates around the templates shared in advance of the meeting.</p> <p>AC spoke of recent discussions that have taken place around potentially changing the way that TYA patients are how these patients are discussed. This may involve bringing the patients through the TYA MDT again at the end of treatment so that TYA specific issues are captured and patients can be signposted to other services that are required at that point, linking them into appropriate late effects services.</p>
Actions and responsibility	<ul style="list-style-type: none"> a) RA to share the TYA specific treatment summary template and proton therapy document produced by Ed at The Christie. b) LW to share the TYA specific treatment summary with the Young Voices Network. c) Treatment summaries to be listed on the July Pathway Board meeting agenda.

11. Update on Integrated Assessment Mapping (IAM) Portal Tool

Discussion summary	<p>The Integrated Assessment Mapping (IAM) Portal Tool is being taken forward. All patients within the North West TYA network will have access to this tool, not just Christie patients.</p> <p>It was suggested for an overview of this tool to be shared at the next Pathway Board.</p>
Actions and responsibility	<ul style="list-style-type: none"> a) Integrated Assessment Mapping (IAM) Portal Tool to be presented at the next Pathway Board in July.

12. AOB

Discussion summary	<p>DW updated on the transitioning meeting which took place on 1st April with consultants working within the paediatric pathways. This touches on wider work around children who become teenagers that then need follow-up care. A further meeting will take place in May, taking over the psycho-social MDT and allow input from a wider group of professionals.</p> <p>In terms of the late effects service the first starting point of this work is to improve the end of treatment discussion/paperwork. Whilst a late effects service is in existence, it caters very much for a specific patient population in the main part, brain tumour patients who have had radiotherapy are well served but gaps remain for other patient groups so we need to evaluate where those gaps are. If the late effects service was expanded, where are gaps</p>
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Actions and responsibility	NA.
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13. Date and time of next meeting

Tuesday 16th July 14:00-16:00

Top Floor Palatine Treatment Centre, Christie Hospital, Wilmslow Road, Withington, Manchester, M20 4BX

Dial-in details to be confirmed.