

## Teenagers and Young Adults (TYA) Cancer Pathway Board

### Minutes and Actions

**Tuesday 16<sup>th</sup> July**

14:00-16:00

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

<b>Members in attendance</b>		
<b>Name</b>	<b>Role/organisations</b>	<b>Attendance 2019/20</b>
Alison Armstrong (AA)	Programme Lead, Greater Manchester Cancer	1/2
Angela Dixon (AD)	CLIC Sargent	2/2
Anna Castleton (AC)	The Christie NHS Foundation Trust	2/2
Anna Mackland (AM)	TYA Occupational Therapist, The Christie NHS Foundation Trust	2/2
Charlene Jones (CJ)	TYA Clinical Nurse Specialist, GM and North Cheshire – NW	2/2
David Wright (DW)	TYA Pathway Clinical Director	2/2
Jane Cronin (JC)	User Involvement Manager, Greater Manchester Cancer	1/1
Jessica Jones (JJ)	Blackpool Teaching Hospitals NHS Foundation Trust	1/2
Kirsty Ackland (KA)	TYA Research Nurse, The Christie NHS Foundation Trust	1/1
Lorraine Wright (LW)	Youth Support Co-ordinator Team Lead, The Christie NHS Foundation Trust	2/2
Mark Reed (MR)	Nurse Specialist/Proton Key Worker, The Christie NHS Foundation Trust	2/2
Nicola Chesman (NC)	TYA Physiotherapist, The Christie NHS Foundation Trust	2/2
Paula Daley (PA)	User Involvement Manager, Greater Manchester Cancer	2/2
Pauline Robinson (PR)	Morecambe Bay HT	1/2
Rachel Allen (RA)	Pathway Manager, Greater Manchester Cancer	2/2
Rachel Campsey	Nurse Specialist/Proton Key Worker, The	1/2

(RC)	Christie NHS Foundation Trust	
Sarah Burns (SB)	Consultant Haematologist, Manchester University NHS Foundation Trust (MRI)	2/2
Satarupa Choudhuri (SC)	Consultant Haematologist, Pennine Acute Hospitals NHS Foundation Trust	2/2
Victoria Cooper (VC)	Lead Cancer Nurse, Stockport NHS Foundation Trust	1/1

### Guests in attendance

Name	Role/organisations
Debra Allcock (DA)	Macmillan Programme Manager, Greater Manchester Cancer
Jennifer Cheshire (JC)	Teenage Cancer Trust

### Apologies

Name	Role/organisations	Attendance 2019/20
Amanda Lane (AL)	TYA Lead Nurse, Pennine Acute Hospitals NHS Trust	0/2
Anne Tomlinson (AT)	Macmillan Lead Cancer Nurse, Lancashire Teaching Hospitals NHS Foundation Trust (Royal Preston Hospital)	0/2
Barbara Houghton (BH)	Salford Royal NHS Foundation Trust	0/2
Carmel Wiseman (CW)	East Lancashire Hospitals Trust	0/2
Chiara Lobetti (CL)	CMFT	0/2
Chris Lowe (CLo)	Lancashire Teaching Hospitals NHS Foundation Trust	0/2
Debbie Smith (DS)	MFT	0/2
Geraldine Skales (GS)	LHTR	0/2
Jackie Brunton (JB)	Lead Cancer Nurse, Blackpool Teaching Hospitals NHS Foundation Trust	0/2
Jagdish Adiyodi (JA)	East Lancashire Hospitals NHS Foundation Trust	0/2
Joanne Barks (JB)	BFW Hospitals	0/2
Joanne Wilkinson (JW)	Lancashire Teaching Hospitals	0/2
Jonathan Vickers	Salford Royal NHS Foundation Trust	0/2
Kate Law (KL)	Clinical Nurse Specialist; Community Liaison Team Leader, The Christie NHS Foundation Trust	1/2
Katy Kelton (KK)	Morecambe Bay Hospitals Trust	0/2
Kerrie Waterhouse (KW)	The Christie NHS Foundation Trust	1/2
Leila Hamrang (LH)	Young Voices Representative	1/2
Lorraine Keogh (LK)	ELHT	0/2
Lynnsey Willcox (LW)	University Hospitals of Morecambe Bay NHS Foundation Trust	0/2
Mark Grey (MG)	Consultant Haematologist, Blackpool Teaching Hospitals NHS Foundation Trust	0/2
Martin McCabe (MM)	University of Manchester	1/2

Michael Leahy (ML)	The Christie NHS Foundation Trust	0/2
Richard Brough (RB)	Stockport NHS Foundation Trust	0/2
Simeon Mitton (SM)	MFT (Central)	0/2
Wiebke Appel (WA)	Consultant Clinical Oncologist, Lancashire Teaching Hospitals NHS Foundation Trust	0/2

## 1. Welcome and introductions

DW welcomed all members. Apologies were noted.

## 2. Update on Integrated Assessment Mapping (IAM) Portal Tool

<p><b>Discussion summary</b></p>	<p>JC demonstrated the <a href="#">IAM Portal Tool</a> via WebEx which has been developed by the Teenage Cancer Trust. The portal contains a TYA specific needs assessment which, once populated by the patient, helps professionals to understand their needs to identify the appropriate support.</p> <p>JC explained that the tool was first implemented in south west England and has been in development for a number of years. It was noted that young people register for an account themselves.</p> <p>JC summarised the 10 domains including items such as physical wellbeing; education and work. The patient can complete the tool at home independently or in a clinical setting. The information collection can be shared with MDT.</p> <p>It was noted that the information available around local services is not restricted by region which is helpful should patients need to access services whilst away from home visiting other parts of the UK.</p> <p>The urgent help button was discussed. The button sign posts patients to support services 24/7 and is monitored by professionals in working hours (rather than 24/7).</p> <p>The MDT management component is a third feature of the portal. DW commented that the use of the feature in the north west is to be debated, specifically how GM integrate. It was noted that all three components do not need to be adopted.</p> <p>JC commented that the database collects basic demographic information, clinical trials, fertility preservation, treatment information, referral information and support. The portal produces outcome summary reports which can be extracted following MDT.</p> <p>There are paper versions for those without internet access. It was noted that in Pennine, patients can be directed to the Maggie's Centre to access PCs there if required.</p> <p>Patients can complete the tool anytime they wish. There is no cost to using the tool.</p>
<p><b>Actions and responsibility</b></p>	<p>a) <b>JC to send some introductory guides to DW/RA for onward dissemination to the Pathway Board.</b></p> <p>a) <b>DW to connect with Joanne D'Arcy and JC to progress implementation of IAMs in GM. It was noted that a separate</b></p>

**discussion is required re: use of the portal in MDT.**

### 3. Minutes of the last meeting 16 04 19

<p><b>Discussion summary</b></p>	<p>DW outlined some of outstanding actions from the previous Pathway Board meeting. DW is still to attend CM's Pathway Board.</p> <p>RA summarised the potential opportunity to access the Transformation Funding Wave 2 via GM Cancer. DW suggested to support the psychological and mental health support application developed by Dr Podraig McDonell, rather than submitting a bespoke TYA psychological and mental health support proposal. DW invited suggestions for other potential transformational proposals from Board members. SC indicated the need for a website to collate specific TYA trial. It was agreed that the issues around TYA clinical trial recruitment and information around research recruitment performance is to be discussed at the next GM Clinical Leaders Forum (expected Autumn 2019).</p> <p><i>[Post meeting note from KA: There is access to clinical trial information nationally via the NIHR website. This is not TYA specific but there is information available for clinicians to see prior to commencing treatment.]</i></p> <p>DW commented that a senior manager has been appointed on a 12 month basis to work across GM to identify and improve pathway delays ensuring that there is equal access of services for patients. This will help to drive 62 day performance across the region.</p> <p>DW spoke of some of the proposed changes to the TYA Cancer Guidelines communicated via the NHS England consultation exercise. The desire for a collective response on behalf of the Pathway Board was discussed. Members are encouraged to email views by COP Wednesday 24<sup>th</sup> July to RA/DW so that a response can be pulled together.</p>
<p><b>Actions and responsibility</b></p>	<p><b>a) Members to email views concerned with TYA Cancer Guidelines NHS England consultation to RA/DW by COP Wednesday 24<sup>th</sup> July so that a collective response can be developed.</b></p>

### 4. Young Voices Network update

<p><b>Discussion summary</b></p>	<p>LW updated on the recent Young Voices Network meeting in which 7 representatives joined. It is envisaged that JC will help to run the group in the future.</p> <p>LW described the meeting agenda which included an item to gather young people's opinions on a blood testing trial, and a TYA prehabilitation service offer. NC presented to the network to gather thoughts on how a more equitable service can be provided to young people. All the Young Voices representatives felt that physical activity advice was something that could/should have been done differently during treatment in terms of the information shared and repeated conversations etc. around physical activity. Offering a variety of exercise/physical opportunities was suggested. NC and LW are to lead a half day event focused on identifying what the ideal prehab/physical activity/lifestyle service should look like.</p>
----------------------------------	--

	<p>It was noted that a new outreach worker is in post at Preston 3 days a week which will help improve equity of service provision.</p> <p>The Young Voices Network discussed the treatment summary templates. All of the Young Voice representative wished they'd had one. Lack of information on the template about mental health was a concern along with female fertility preservation. The network really liked the ability to take the document away with them and were keen for an online copy to be stored somewhere for easy access. The group noted the frustrations around communication between professionals in trust and outside of trust.</p> <p>DW suggested that for TYA treatment summaries, there should be a section on the disease; the treatment received; and then a TYA specific component. It was highlighted that the document needs to be addressed to patient.</p>
<b>Actions and responsibility</b>	<b>a) NC and LW are to lead a half day event focused on identifying what the ideal prehab/physical activity/lifestyle service should look like.</b>

## 5. TYA service audits

<b>Discussion summary</b>	<p><b><u>Focus on fertility and mental health</u></b></p> <p>LW summarised that the fertility questions has been through PALS and The Christie audit team. Board members reviewed the survey.</p> <p>DW suggested a couple of amendments:</p> <ul style="list-style-type: none"> <li>• Adding 'skin' into the list of diagnoses</li> <li>• Question 5 – consider changing the phrase 'Diagnostic surgery' as unclear whether a patient would understand this phrase</li> <li>• Section 6 – consider amending the repetitiveness of the question around 'when the conversations took place' and 'Do you think you were asked about fertility at an appropriate time?'</li> </ul> <p>LW noted that the survey has been piloted with 10 young people. The intention is to disseminate the survey from August.</p> <p>Once the fertility questionnaire is rolled-out, the Young Voices Network will begin to address the mental health survey.</p> <p><b><u>Update on general ongoing survey</u></b></p> <p>A draft survey was projected to Board members. RA to share copy of survey with the Pathway Board and respond to RA/DW with requested changes. DW suggested to ratify the survey in October. Dissemination is likely to be via the day unit and TYA/Young Voices Facebook page post the October Pathway Board.</p>
<b>Actions and responsibility</b>	<p><b>a) LW to consider amendments to fertility survey and disseminate from August 2019.</b></p> <p><b>b) RA to share copy of general TYA survey with the Pathway Board. Board members to respond to RA/DW with requested changes. Survey will be ratified at October Board and rolled out.</b></p>

## 6. Update on development of TYA Psychologist Business Case

<b>Discussion summary</b>	MM was unable to attend the meeting and so updated outside of the Board meeting. The business case is progressing.
<b>Actions and responsibility</b>	NA.

## 7. Evaluation of NW Study Day

<b>Discussion summary</b>	<p>The evaluation report from the NW Study Day was shared. 88 delegates attended. Full details can be found in the report here:</p> <div style="text-align: center;">  <p>4. Paper 3_Evaluation of North</p> </div>
<b>Actions and responsibility</b>	NA.

## 8. Lymphoedema

<b>Discussion summary</b>	<p>DA was invited to present on the Macmillan funded Lymphoedema project and a brief overview of the project was explained. In 2015, a Strategic Health Needs Assessment was undertaken by Macmillan. As a result of this exercise. It was evident that there is variation in access and provision for Lymphoedema services across the region. The vision was to have a cost-effective and proactive service across GM and that those affected by Lymphoedema are supported and managed appropriately.</p> <p>DA summarised the objective of the programme to understand the problem, develop ideas for improvements and reduce the variation in access and availability that will be proposed to the GM Network.</p> <p>The programme's model of care is based on prevention/early diagnosis and service provisions. Learning and development is also key as patients need to be aware of the signs and symptoms, and healthcare professionals need to be well informed.</p> <p>DA highlighted that for TYA patients, the only lymphoedema service provision is in Preston, Wales, Leeds and London. The Christie service only see's patients who are over 18 years. It was noted that the provision for 16-18 years is lacking. There was a suggestion for this to be raised at a cancer alliance meeting. DW suggested to feed back through the service specification consultation process.</p>
<b>Actions and responsibility</b>	<b>a) RA to share lymphoedema slides.</b>

## 9. NCEPOD Study of Cancer in Children and Young Adults: On The Right Course

<b>Discussion summary</b>	DW requested comments on the paper shared. A discussion ensued on the report.
<b>Actions and responsibility</b>	NA.

## 10. Prehab workstream for TYA

<b>Discussion summary</b>	<p>NC updated that Kate Collins, Chief Executive of Teenage Cancer Trust is keen to discuss what a prehab offer could look like for TYA patients. A teleconference is to be arranged.</p> <p>DW summarised that to date, the Prehab4Cancer project is focused on three disease groups only. It was noted that ZM is keen to incorporate TYAs where possible and this may be considered for a future implementation wave.</p>
<b>Actions and responsibility</b>	NA.

## 11. AOB

<b>Discussion summary</b>	<p>Morecambe Bay have a newly named TYA nurse locally. Chris Lowe is attending the trust to speak to MDT Co-ordinators to re-energise the service.</p> <p>It was noted that there is a Lancs and South Cumbria Cancer Conference planned for 11 March 2020. The Greater Manchester Cancer Conference is planned for 19-20 November 2019. This will be an opportunity to highlight the great work of the TYA Pathway Board.</p> <p>DW and LW were congratulated for their article published in Cancer Nursing Practice.</p>
<b>Actions and responsibility</b>	NA.

## 12. Date and time of next meeting

<p><b>Tuesday 15<sup>th</sup> October 2019 14:00-16:00</b></p> <p><b>Top Floor Palatine Treatment Centre, Christie Hospital, Wilmslow Road, Withington, Manchester, M20 4BX</b></p> <p><b>Dial-in details to be confirmed.</b></p>
--