

Greater Manchester **Cancer**  
**TYA** Pathway Board

**Pathway Board Meeting**

Minutes

**Meeting time and date:** 30<sup>th</sup> January 2018 – 10:00-12:00hrs

**Venue:** The Christie Palliative treatment centre – (Dept 30) 2nd Floor Seminar room.

**Chair:** David Wright

#	Item																																																				
1	<b>Welcome and apologies</b>																																																				
	<table border="1"> <thead> <tr> <th>In attendance</th> <th>Initial</th> </tr> </thead> <tbody> <tr><td>Rebecca Price</td><td>RP</td></tr> <tr><td>David Wright</td><td>DW</td></tr> <tr><td>Kerrie Waterhouse</td><td>KW</td></tr> <tr><td>Kirsten Oakes</td><td>KO</td></tr> <tr><td>Lorraine Wright</td><td>LW</td></tr> <tr><td>Chris Lowe</td><td>CL</td></tr> <tr><td>Satarupa Choudhuri</td><td>SC</td></tr> <tr><td>Leila Hamrang</td><td>LH</td></tr> <tr><td>Cath Fitzsimons</td><td>CF</td></tr> <tr><td>Pauline Robinson</td><td>PR</td></tr> <tr><td>Kate Law</td><td>KL</td></tr> <tr><td>Charlene Jones</td><td>CJ</td></tr> <tr> <th>Apologies</th> <th></th> </tr> <tr><td>Deborah Sullivan</td><td>DS</td></tr> <tr><td>Anna Castleton</td><td>AC</td></tr> <tr><td>Jackie Brunton</td><td>JB</td></tr> <tr><td>Amanda Lane</td><td>AL</td></tr> <tr><td>Beverley Meenan</td><td>BM</td></tr> <tr><td>Mel Atack</td><td>MA</td></tr> <tr><td>Lisa Stone</td><td>LS</td></tr> <tr><td>Anna Mackland</td><td>AM</td></tr> <tr><td>Tracy Kelly</td><td>TK</td></tr> <tr><td>Anne Tomlinson</td><td>AT</td></tr> <tr><td>Cath Fitzsimmons</td><td>CF</td></tr> <tr><td>Martin McCabe</td><td>MMc</td></tr> </tbody> </table>	In attendance	Initial	Rebecca Price	RP	David Wright	DW	Kerrie Waterhouse	KW	Kirsten Oakes	KO	Lorraine Wright	LW	Chris Lowe	CL	Satarupa Choudhuri	SC	Leila Hamrang	LH	Cath Fitzsimons	CF	Pauline Robinson	PR	Kate Law	KL	Charlene Jones	CJ	Apologies		Deborah Sullivan	DS	Anna Castleton	AC	Jackie Brunton	JB	Amanda Lane	AL	Beverley Meenan	BM	Mel Atack	MA	Lisa Stone	LS	Anna Mackland	AM	Tracy Kelly	TK	Anne Tomlinson	AT	Cath Fitzsimmons	CF	Martin McCabe	MMc
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2	<p><b><u>Pathway Board director introduction / Minutes of the previous meeting</u></b></p> <p>The board accepted the minutes of the 28th November 2017 as correct.</p> <p>DW acknowledged that the low attendance for today's meeting would be due to the meeting clashing with a recovery package meeting being held by GMC.</p>
3	<p><b><u>Pathway Board member responsibilities / ToR (for note)</u></b></p> <p>The completed document was previously circulated to the board for comments prior to the meeting. No comments or amendments were received.</p> <p>This document has now been accepted at correct as ratified at the PWB meeting on 30/01/18.</p>
4	<p><b><u>Proton Beam Therapy - Challenges for the TYA service</u></b></p> <p>This item was deferred to be discussed at the next pathway board meeting.</p>
5	<p><b><u>TYA 2017-18 Work plan</u></b></p> <p>The board talked through each section of the work plan in detail and provided progress updates in all areas.</p> <p><u>62 day performance</u> – No issues raised by the board regarding 62 day performance across the network. The board will continue to track their progress against these targets and raise any issues should they arise.</p> <p><u>Strengthening links with Children's board / Ambulatory Chemotherapy Project-</u> The children's board had yet to meet since the last TYA pathway board was held. Updates to be provided by KL at the next meeting.</p> <p><u>GATEWAY-C –</u> DW has now met with Sarah Taylor (the GP lead for GM Cancer) and filmed a segment for the lymphoma module of the Gateway C project. This is yet to be uploaded on the gateway C website at the time of this pathway board meeting. The board discussed and agreed that there was no need for a dedicated TYA Module, given that Teenage cancer trust already has a similar resource available. DW hopes to be a part of other modules representing the TYA service.</p> <p><u>Educational programme for TYA units-</u> Teenage Cancer Trust and Coventry University have combined to produce a TYA study day that is generic and can be facilitated across the country. The day has several set presentations such as normal teenage development, professional boundaries etc. but can also be regionalised to reflect the region in which it is being delivered. The days are facilitated for free and are free to attend. DW has requested one of these days for the Autumn of 2018 and proposes that this is seen as the education event for the Board. This was supported by the Board. The event would not preclude any other events if someone feels strongly about delivering another education event.</p> <p><u>TYA cancer guidelines-</u> Review of the TYA guidelines published on the GM Cancer website is to be undertaken. The board have agreed to look at disease specific guidelines that detail guidance relating to the TYA patients and ratify that this information is correct. Following the initial review of this information, A separate document is to be considered that amalgamates this information. DW has volunteered to contact his pathway director peers to review each board's guidance in relation to TYA.</p> <p><u>Research trials-</u> DW fed back to the board that he had been in discussions with NHIR supply Trials data on what spectrum of trials are open to TYA patients for teams to look at this information. Having reviewed this report it became apparent that this portfolio would be much too large to routinely send this information out to</p>

teams. Further discussions are to be had around the possibility of recruiting a research nurse to look in to the eligibility criteria for trials that could be available for TYA patients. DW is to speak to Teenage Cancer trust to explore these discussions further.

Clinical standards- Currently there is national work being undertaken by TYA Clinical Reference Group looking at producing a TYA Service Specification. Hopefully there are going to be draft versions of this either towards the end of the year or early 2018. It would be prudent of the board to await the publication of the service specification before defining standards for TYA services across Greater Manchester, Cheshire Lancashire and South Cumbria

Recovery package- The board have agreed to work with their trusts to support the delivery of all aspects of the recovery package by the deadlines set in the GM Cancer Plan. MA, KO and LH have agreed to work with teams to develop the health and wellbeing residential events adding input from a patient's perspective. HNA's are to continue to be completed as standard. Time points for giving the patients End of treatment summaries are to be agreed for each cancer type / treatment episode to ensure TYA patient are being given this information at the most useful points in their treatment journeys.

## 6 **Palliative care / End of life care for TYA's**

KL brought up the issue of inequality within access to palliative care services across the patch. The board discussed the inequalities and variation in service access for TYA palliative / end of life care patients.

The group went on to discuss the need for the children's / TYA palliative care network to assess the numbers of patients needing to access the service. For patients under the age of 18, this information is easily available through accessing the **Service**; however for those patients over 18 this proves to be more difficult. The board agreed that to combat most of the issues discussed, would be for all patients who are 16 or over needs to be accepted into adult services, reducing the likelihood that these patients are lost within the cross over system due to their age.

The board discussed the need to explore this issue further with the help of the boards commissioning lead Gill Barnard.

KL and DW kindly agreed to take this topic to GB, and TIAC to discuss ideas for a possible solution

### Long term consequences of treatment for TYA's

Following on from the above discussion, KL mentioned a related issue that for TYA patients around the lack of support services for TYA patients, who have crossed over into adult care services with little to no support with the aftereffects of treatment following their adolescent cancer episode.

The board agreed that patients are often left with no follow up appointments in place once they have left TYA services and this presents a real issue to those patients who are experiencing late effects of childhood treatment. More specifically the board discussed the struggles childhood brain tumour patients have little to no access to brain and CNS support services in later life.

DW and RP have agreed to discuss these issues with Catherine McBain, the brain and CNS pathway board director to discuss the scope for establishing an aftercare pathway that follows patients into later life, beyond their time within the TYA service.

## **NICE guidance for suspected cancer – Recognition and referral for TYA patients.**

Due to poor attendance, it was decided not to be discussed due to members feeling this needed to be a wider discussion with all pathway board members at the next meeting. DW also stated that there were also some upcoming meetings he will be attending that will be helpful in aiding this discussion at the next meeting. DW informed the board that he had also contacted all GM Cancer pathway board directors to

	<p>establish their thoughts on the management of this issue. Feedback will be given at the next meeting as to the response to this.</p>
7	<p><b><u>User representative update</u></b></p> <p>The board congratulated KO on contribution to the recently published ‘Top research priorities for Teenage and Young Adult Cancer’ project undertaken by the Teenage and Young Adult Cancer Priority Setting Partnership. The project group asked young people who had been diagnosed with cancer between the ages of 13 and 24, their families, friends, partners, carers and healthcare professionals to identify what questions about teenage and young adult cancer they would like to see answered by research. Nearly 300 people replied, submitting 855 questions. The results of which have been published on the Teenage and Young Adult Cancer website.</p> <p><a href="https://www.teenagecancertrust.org/about-us/news/top-research-priorities-teenage-and-young-adult-cancer-identified">https://www.teenagecancertrust.org/about-us/news/top-research-priorities-teenage-and-young-adult-cancer-identified</a></p>
7	<p><b><u>AOB</u></b></p> <p>None noted.</p>
8	<p><b><u>Dates for future meetings</u></b></p> <ul style="list-style-type: none"> <li>- 17th April 2018 - 10:00-12:00hrs – Salford Royal Hospital - Mayo Building (TBC)</li> <li>- 17th July 2018 - Room 231 (2nd Floor) at Preston Business Centre.</li> <li>- 16th October 2018 – Christie THQ meeting room 6</li> <li>- 15th January 2019- Room 231 (2nd Floor) at Preston Business Centre.</li> </ul> <p><b>(WEBex available, please contact Rebecca Price/David Wright if you require this)</b></p>