

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

### Minutes and Actions

**Tuesday 16<sup>th</sup> October 2018**

10:00-12:00

Meeting Room 6, Trust Headquarters, 3rd Floor, The Christie, Wilmslow Road, Withington, M20 4BX

#### Members present

Name	Role
<b>David Wright (DW)</b>	<b>Clinical Director for TYA Pathway</b>
Amanda Lane (AL)	TYA Lead Nurse, Pennine Acute Hospitals NHS Trust
Anna Mackland (AM)	TYA Occupational Therapist, The Christie NHS Foundation Trust
Charlene Jones (CJ)	TYA Clinical Nurse Specialist, GM and North Cheshire – NW
Leila Hamrong (LH)	Young Voices Representative
Lorraine Wright (LW)	Youth Support Co-ordinator Team Lead, The Christie NHS Foundation Trust
Mel Attack (MA)	User Involvement Manager, GM Cancer
Nicola Chesman (NC)	TYA Physiotherapist, The Christie NHS Foundation Trust
Paul Fleming (PF)	Young Voices Representative
Rachel Allen (RA)	Pathway Manager, GM Cancer
Sarah Burns (SB)	Consultant Haematologist, Manchester University NHS Foundation Trust (MRI)
Tracy Kelly (TK) – arrived 10:45	Macmillan Lead Cancer Nurse, Manchester University NHS Foundation Trust

#### Apologies

Anne Tomlinson	Macmillan Lead Cancer Nurse, Lancashire Teaching Hospitals NHS Foundation Trust (Royal Preston Hospital)
Beverley Meenan	Macmillan Lead Nurse for Cancer and Palliative Care, Stockport NHS Foundation Trust
Carmel Wiseman	East Lancashire Hospitals Trust
Cath Fitzsimmons	Macmillan Lead Cancer Nurse, Salford Royal NHS Foundation Trust
Jackie Brunton	Lead Cancer Nurse, Blackpool Teaching Hospitals NHS

	Foundation Trust
Kate Law	Clinical Nurse Specialist; Community Liaison Team Leader, The Christie NHS Foundation Trust
Kerrie Waterhouse	The Christie NHS Foundation Trust NHS Foundation Trust
Rachel Campsey	Nurse Specialist/Proton Key Worker, The Christie NHS Foundation Trust
Satarupa Choudhuri	Consultant Haematologist, Pennine Acute Hospitals NHS Foundation Trust
Wiebke Appel	Consultant Clinical Oncologist, Lancashire Teaching Hospitals NHS Foundation Trust
Angela Dixon	
Anna Castleton	The Christie NHS Foundation Trust
Chiara Lobetti	CMFT
Debbie Smith	MFT
Geraldine Skailes	LTHTR
Heidi Moertl	CMFT
Ian Welch	MFT
Joanne Barks	BFW Hospitals
Joanne Wilkinson	Lancashire Teaching Hospitals
Katy Kelton	Morecambe Bay Hospitals Trust
Lorraine Keogh	ELHT
Mark Grey	BFW Hospitals
Martin McCabe	University of Manchester
Michael Leahy	The Christie NHS Foundation Trust
Pauline Robinson	Morecambe Bay HT
Richard Brough	Stockport NHS Foundation Trust

## 1. Welcome and introductions

DW welcomed all members. It was highlighted that several members were delayed in traveling to the meeting and a number of apologies had been received.

DW highlighted that in order for the Board to run effectively representation from the majority of designated trusts is required. Board meetings will be rotated across different sites within the region to improve access to the meeting.

## 2. Minutes of last meeting 19<sup>th</sup> June 2018

<b>Discussion summary</b>	<p>DW invited Board members to review the minutes of the June meeting and highlight any discrepancies. DW proceeded to offer a summary of the main discussion points from the previous meeting for the benefit of new board members.</p> <p><b><i>NICE guidance for suspected cancer – recognition and referral for TYA patients:</i></b></p> <p>DW reminded board members that earlier in the year there had been some concern around NICE guidance that exists which includes a 48 hour referral. The GM Cancer arena is very much focused on the 62 day pathway. The concern was around how a 48 hour pathway would be monitored. DW updated that he had discussed with Marie Hosey (MH; Lead for Cancer</p>
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	<p>Managers in GM). MH felt that these guidelines sit within primary care as primary guidelines rather than within the TYA service.</p> <p>DW highlighted the need to disseminate this via Sarah Taylor (ST), particularly that monitoring should sit within general practice. DW and ST to discuss further if necessary.</p> <p>DW highlighted that following a previous piece of work undertaken around the 62 day pathway, there were no concerns in terms of performance for the TYA service in Lancashire, South Cumbria, GM or Cheshire.</p> <p><b><i>Proton Beam Therapy:</i></b></p> <p>Prior to the last board, a meeting was held to discuss some of challenges that may exist when the Proton Beam Therapy service for teenagers and young adults is live. Concerns included the geographical spread of incoming patients (from all over the country) and consequential potential for inequity in support offered by The Christie. There is a team in place dedicated to TYA patients which includes occupational therapy and physiotherapy.</p> <p>PF queried whether there was any mental health provision including in the staffing model. DW was unsure whether psych-oncology had increased their pool of staff and this will need exploring. There will be a level of assessment prior to the therapy and it is highly likely that individual needs of young people will be included in that assessment. There will be processes in place between The Christie and the referring Trust to ensure continuity around identification of patient needs. DW spoke of the aim to establish a TYA psychology service which was an ongoing area of focus within the Pathway Board work programme, from family level therapy through to level 4. This is still being worked through and Dr McCabe is taking this forward at present. It is unclear whether the psychologist will focus on TYA Proton Beam Therapy patients. Patients living away from home whilst undergoing treatment at The Christie was discussed and the consequential psychological impact. DW noted that GM is learning from other established sites so will be well-informed of such key issues and how best to overcome them. It was also noted that it will be much easier for patients to seek weekend leave when undergoing treatment in Manchester which would be much more difficult if having treatment in the US.</p> <p><b><i>Palliative care and end of life for TYA patients:</i></b></p> <p>DW updated that this work had not progressed since the last meeting in June. DW needs to meet with Kath McBain (KM) to discuss survivorship issues for young people that are coming out of paediatrics and beyond or those coming out of the TYA service. There is a piece of work that needs to be undertaken. DW is to attend KM's upcoming Pathway Board in November.</p>
<p><b>Actions and responsibility</b></p>	<p>a) <b>DW to write to TYA stakeholders to share the TYA Board position on NICE guidance via (ST) that monitoring of the NICE guidance for suspected cancer for TYA patients should sit within general practice, not the TYA service.</b></p> <p>b) <b>DW to discuss progress around TYA psychology service and whether there will be a focus on Proton Beam Therapy.</b></p> <p>c) <b>DW to attend KM's Pathway Board. RA to contact Fiona Lewis (FL),</b></p>

	<b>Pathway Manager for meeting details.</b>
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### 3. Matters arising

<b>Discussion summary</b>	<p>Future meeting dates have been shared with all Board members.</p> <p>DW reminded the Board that the next meeting will take place in Preston and conference call facilities will be available.</p> <p>RA noted that The Christie's Trust Headquarter meeting room has been booked for the 2019 Board meetings beyond the January date, however owing to the lack of conference call facilities RA will be finding an alternative meeting room.</p>
<b>Actions and responsibility</b>	<p><b>a) RA to ensure conference call facilities are available for future Board meetings given the geographical spread of Board members which is different to other GM Pathway Boards.</b></p>

### 4. Macmillan User Involvement Team update

<b>Discussion summary</b>	<p>MA updated the Board on the work undertaken since the last meeting in June. A flyer has been coproduced and cascaded via LW with an invitation for individuals to get involved in the work of the Pathway Board. Two opportunities were promoted: one was to be a remote member of the Board and one to be a face to face member. The first face to face meet was held on the 19<sup>th</sup> September and PF was recruited. Five young people were present for the first group discussion and the group decided that they would like to be known as the Young Voices Network and 'Young Voices Representatives'. The Young Voices Network are keen to improve engagement going forward by adopting web-ex technology.</p> <p>PF and LH updated the Board on the discussion of the first Young Voices Network. Some of the discussion points included:</p> <ul style="list-style-type: none"> <li>• Pathway Board meeting quoracy</li> <li>• Lack of mental health for TYA and IAMs</li> <li>• An audit of fertility discussion was suggested</li> </ul> <p>DW informed the Board of Birmingham's service which has an audit of 70 questions in place for TYA patients. The advantages and disadvantages of a self-reported questionnaire by way of audit were discussed.</p> <p>It was noted that uptake is better when the audit focuses on a specific area however it was also noted that the creation of several audits is unwieldy.</p> <p>Board members agreed that the Birmingham audit would be a useful tool to explore.</p> <p>DW highlighted that it has been a long time since a broad TYA service audit has been undertaken. It was noted that this would be a big piece of work yet when undertaken previously was completed with a much smaller resource in terms of personnel – the resource available has since increased so it may now be much easier to undertake. Previously it was completed via a postal survey and a 30% response rate was witnessed which is in line with the typical expected response level for such surveys.</p>
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There is potential to push a survey out through Facebook but it was noted that the TYA page doesn't reach everyone, a multi-faceted approach is required.

GM Cancer resource is limited in terms of designing surveys, inputting and analysing data.

IPads would be a useful tool if available in all clinics to genuinely deliver an equitable service.

It was referenced that The Christie Patient Centred Research Group may have ideas that can be explored to tailor a survey to the TYA audience.

The geographical complexities surrounding the TYA service were discussed in terms of roll-out and completion of audits.

GDPR restraints need to be considered.

Fertility and mental health are key factors but 70 questions seems excessive.

A discussion ensued on fertility, specifically from a male perspective, sperm banking. Board members discussed the variation in practice across the trusts in terms of pre- and post-surgery sperm banking. Once current practice is mapped via a survey/audit, the board members referenced the need to take this to the Urology Board for discussion.

The patient representatives expressed a preference of focusing on a survey specifically for mental health and fertility but will discuss with the Young Voices Network and confirm.

Board members agreed that the Birmingham audit would be a useful tool to explore. It was suggested for the professionals to look at the Birmingham audit and take to the Young Voices Network for discussion.

LW suggested for the Young Voices Network to produce a fertility questionnaire as a starting point, which could be taken to the patient-centred research team and in the meantime, DW and other Board members could look at the Birmingham questionnaire alongside this. This could be the focus of the January Board.

RA to look at what exists across other pathways specifically around mental health and fertility.

It was agreed to look at how the issues are covered in the Birmingham questionnaire.

The Bright Light Study was referenced and that the research will be shared in 2019.

Anna Mackland (AM) is an Occupational Therapist within TYA service and sits on the GM Psychology Support and Mental Health Pathway Board which means the TYA Board has a good link for any work stemming out of this from a GM perspective.

AM updated on mental health and updated the TYA Board on discussions held at the September Psychology Pathway Board including, the creation of a directory of psychological support services for GM. AM informed the Board that Pdraig McDonnell (PM) presented to the Cancer Board to seek specific mental health funding for cancer patients with the aim of having set roles

	<p>across GM however was unsuccessful.</p> <p>RA indicated that Improving Access to Psychological Therapy services (IAPT) may have received Transformation Fund investment already via the GMHSCP but agreed to investigate further. RA explained that GM Cancer was in receipt of £10 million Transformation Funding for a series of priority projects. GM Cancer is hoping to secure further Transformation Funding investment in 2019 so this may be something that can be taken forward with the senior team.</p> <p>PM will be presenting to the GM Cancer Board again in the near future.</p> <p>MA explained that earlier diagnosis, 62 day performance and psychological support are the three key priorities from all of the patient representatives that sit on our GM Cancer Pathway Boards, regardless of tumour type.</p> <p>DW highlighted that there are opportunities with the GM Cancer Board – every Clinical Pathway Board will have an opportunity to advocate for mental health as a priority.</p> <p>RA highlighted that the GM mental health transformation programme has already received a significant proportion of Transformation Fund. RA suggested finding out whether any of this is attributed to cancer services.</p> <p>A discussion on Level 2 supervision ensued.</p>
<p><b>Actions and responsibility</b></p>	<ul style="list-style-type: none"> <li>a) <b>RA to look at what exists across other pathways specifically around mental health and fertility.</b></li> <li>b) <b>DW and others to look at the Birmingham questionnaire and specifically how it addresses fertility and mental health. This will be shared with PF and LH.</b></li> <li>c) <b>LW and Young Voices Network to produce a fertility and mental health questionnaire which could be taken to the patient-centred research team for their support. PF and LH may then wish to disseminate electronically to collect feedback from within the TYA Young Voices Network. The final survey will be brought to January Board, focusing on both fertility and mental health.</b></li> <li>d) <b>RA to speak to ML to clarify the TYA representative on the psychology board and ensure future meeting dates have been shared.</b></li> <li>e) <b>RA to find out whether any of the GM mental health transformation investment is attributed to cancer services.</b></li> </ul>

## 5. TYA board review

<p><b>Discussion summary</b></p>	<p>DW updated the Board on the configuration of the GM Cancer Clinical Pathway Boards.</p> <p>DW informed the Board of his Pathway Director review which took place in July 2018 with Dave Shackley (DS) and Susi Penney (SP). DW explained that the Pathway Board are waiting on feedback from this meeting, including the major issues in GM and priorities for the next 12 months. RA explained that a draft paper is in development and will be shared soon.</p> <p>It was noted that RA is new in post and had previously worked as a Project Manager in the GM Population Health team within the GMHSCP. It was noted that RA is managing several GM Cancer pathways in her role as Pathway Manager including, lung, skin, childrens', head and neck cancer</p>
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	<p>and breast, on a temporary basis until a fourth Pathway Manager is recruited.</p> <p>RA described the new GM Cancer team structure and the recent staffing changes.</p>
<b>Actions and responsibility</b>	<b>NA.</b>

## 6. Transformation Fund update

<b>Discussion summary</b>	<p>RA updated the Board on the transformation plans for GM Cancer which are outlined in Paper 3 (shared in advance of the meeting). RA explained that in 2016 GM took control of a £6 billion health and social care budget and in addition to this received £450 million investment for transformation activity. This summer £10 million was assigned to GM Cancer and has been split across a number of priority projects, including:</p> <ul style="list-style-type: none"> <li>• Core infrastructure</li> <li>• Accelerated pathways (for three cancer pathways)</li> <li>• Recovery package/ ERAS</li> <li>• CURE smoking programme</li> <li>• Education</li> <li>• CAN guide</li> <li>• Cancer intelligence</li> <li>• Stratified follow-up</li> </ul> <p>RA noted that recruitment for dedicated programme management to support this work will begin soon.</p> <p>A discussion ensued on pre-hab, ERAS and the recovery package which is being led by Zoe Merchant (ZM) and Dr John Moore (JM). The immediate priorities for the programme will be the lung, upper GI and colorectal pathways and a preliminary workshop is taking place on 29<sup>th</sup> October. DW requested for the invitation to be shared with the Board. RA suggested to invite ZM to the January Board to share the programme plans.</p> <p>It was also suggested for Freya Howle (FH) to join a future Board to share an update on the CURE programme. Jonny Hirst (JH) may also like to attend a future board to update on his work.</p> <p>RA offered to investigate plans for wave 2 of the GM Transformation Fund from the GM Cancer senior team.</p>
<b>Actions and responsibility</b>	<p>a) <b>RA to invite ZM to the January Board</b></p> <p>b) <b>RA to invite FH and JH to a future Board.</b></p> <p>c) <b>RA to share the GM Cancer Prehab and Recovery Programme (29<sup>th</sup> October) invitation with all TYA Board members for their information.</b></p> <p>d) <b>RA offered to investigate plans for wave 2 of the GM Transformation Fund with the GM Cancer senior team.</b></p>

## 7. TYA workplan 2018/19

<b>Discussion summary</b>	<p>The TYA workplan was shared with Board members in advance of the meeting. DW proceeded to describe the proposed workstreams.</p> <p><b><i>Ambulatory care:</i></b></p> <p>This service is about to begin at The Christie in a phased approach for TYA patients. This will be based on patient choice. TYA and haematology regimes that would be deemed appropriate have been identified. There still needs to be clarity about the difference between ambulatory care around patients leaving The Christie with a chemotherapy backpack when that would have been had on the ward already as opposed to day case patients.</p> <p>One of the ethos's of TYA cancer support is about peer support – this needs to be considered in relation to ambulatory care. The 1 hour limit was discussed: accommodation has been identified (the same as that being used for families of patients in receipt of Proton Beam Therapy), and so there are factors that still need to be looked at. It was noted that for some patients, ambulatory care will not be appropriate – there needs to be a certain level of self-management and degree of compliance.</p> <p>Patient choice was discussed. DW indicated that in the future it is likely that certain regimes will be available to patients. The vision is for patients to follow an ambulatory setting in the long term however if a patient expressed that they did not want ambulatory care via The Christie, the choice will still be available. It was noted that this regime fits with the 'care closer to home' agenda. There are two things underlying this including quality of care - most TYA patients would much prefer not to, also the financial benefit of freeing up bed space. Patient safeguarding was referenced, particularly in relation to ambulatory care in the patient's home and how clinicians will be liable for any issues that arise.</p> <p>It was noted that the intention is for patient's to complete their first cycle of chemotherapy on the ward so that clinicians can familiarise themselves with individual patients' reactions to treatment in the first instance.</p> <p>A discussion ensued on chemotherapy via cannulation vs a line and the need to consider patient safety and patient choice. DW highlighted that GM are not the first area to implement an ambulatory care service and so The Christie are hopeful that the service will run effectively and efficiently in the region.</p> <p>Board members reiterated that patient choice will remain – patients will not be forced into a particular regime.</p> <p><b><i>Gateway C:</i></b></p> <p>A proportion of GM Cancer's Transformation Fund allocation will be assigned to cancer education across GM. The work will involve all stakeholders across the GM H&amp;SCP (in health &amp; social, voluntary, charitable and community), to create a single agreed educational vision for cancer workforce development and a single service framework for cancer education, as a trailblazer for the</p>
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NHS nationally and supporting the delivery of priority 1 projects.

***Educational programme for TYA units:***

The plan is to run a one day study day on the 9<sup>th</sup> April 2019. The event will be led by the Teenage Cancer Trust and Coventry University. It has a regional focus and is very much an introductory study day. It was noted that some of the Proton Beam Therapy staff may be interested in the event. DW highlighted that this is already an established programme that is delivered around the country. The Coventry University team are leading on the organisation and management of the event. The event is aimed at anybody.

LW spoke of the specific TYA study day led by The Christie. It was agreed that this should be added to the TYA workplan.

***TYA cancer guidelines:***

There are new clinical guidelines for TYA services that are expected to be released by the Children's Teenage and Young Adult Clinical Reference Group. This is an NHS group. These clinical standards should have been released early 2018 however political issues have delayed the release of the standards.

As a region, the Pathway Board needs to see the clinical standards, the Pathway Board needs to review them as a board and accept them as the gold standard. TK queried whether any cancer alliances have been consulted in the development of the guidelines. DW outlined that he was unsure of the inner workings. It was noted that these standards will replace the peer review work which was previously in place as the benchmark of what is to be delivered.

The new workstreams added to the workplan for 2018/19 were discussed, including:

- TYA psychologist
- Mental health assessment - DW explained that the workplan was purposely left blank and will be populated following the Board's discussion. DW invited board members to feed back on what they would like to include here
- Audit of fertility
- Audit of patient experience – DW highlighted that this will be modified following the Boards discussion.
- IAM implementation – DW spoke of the holistic needs assessment (HNA) available online for patients within the TYA service which is accessed via clinicians at The Christie. Behind the tool sits a library of information including local and national services. DW spoke of the Privacy Impact Assessment (PIA) which is currently sat with The Christie Information Governance team. All young people will have access to the tool. A young person can go into the system at any point to reassess themselves. The system also has an alert function to raise critical mental health issues. TK queried what would happen to a patient that is treated as a TYA patient yet meets crisis point when they fall out of the TYA service. DW to follow-up this up with Jen Cheshire to clarify. DW to also clarify login expiration.

<b>Actions and responsibility</b>	<p>a) RA to share the study day invitation flyer with the Board once it is available.</p> <p>b) RA to add The Christie TYA Study Day to the TYA workplan.</p> <p>c) Board members to contact RA on what they would like to include in the workplan around mental health assessment.</p> <p>d) RA to modify the workplan following the Boards discussion.</p> <p>e) DW to clarify what would happen to a patient that is treated as a TYA yet meets crisis point when they fall out of the TYA service.</p>
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### 8. GM Cancer Plan

<b>Discussion summary</b>	DW is awaiting feedback from GM Cancer which will be shared with the Board once it is communicated.
<b>Actions and responsibility</b>	a) RA to share outcome of Board and Clinical Director review with Board members, along with specific objectives for 2018/19.

### 9. Palliative care / end of life for TYAs

<b>Discussion summary</b>	DW to meet with KM.
<b>Actions and responsibility</b>	Action listed in section in 2c.

### 10. Upcoming events

<b>Discussion summary</b>	<p>DW highlighted that the GM Cancer Conference is scheduled for 26<sup>th</sup> November.</p> <p>RA explained that organisation of the Conference is being led by The Christie School of Oncology so there may be appear to be a slight disconnect between the GM Cancer team. The Conference capacity has been extended significantly to circa 500 delegates. It was noted that RA has previously shared the event link with the Board for them to register – RA to share again.</p> <p>DW highlighted that a TYA Pathway Board poster will be developed for the conference. A draft will be shared with the Pathway Board in advance. DW suggested to include an overview of the service and work of the Board to date, the Young Voices Network, and an outline of the bereavement work undertaken.</p>
<b>Actions and responsibility</b>	<p>a) RA to re-share the GM Cancer Conference event invitation.</p> <p>b) RA to share poster template with DW.</p>

### 11. AOB

<b>Discussion summary</b>	<p>RA requested for all members present to ensure that they have signed the register. RA explained that Pathway Board attendance will be monitored going forward.</p> <p>It was suggested for the Board Terms of Reference to be reviewed and</p>
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	<p>discussed at the next Pathway Board in January.</p> <p>DW referenced a discussion undertaken by the Board at a previous meeting in relation to the young person's pathway and what should/shouldn't be completed at a local level before patients arrive at The Christie. DW referenced a meeting with MH that when the patient arrives at The Christie, the responsibility is with The Christie. DW highlighted that all designated representatives need to be present to continue the discussion.</p> <p>DW highlighted that MH felt that when patients arrive at The Christie, there are 24 days from the moment that The Christie receive the referral, to the point that the patient starts treatment. It was noted that if some of the pre-work up is completed locally, it increases the chances of the 24 day deadline being met. DW highlighted that this warrants a formal discussion at the January Board. It was recognised that designated trusts believe that the priority is about referring to TYA MDT, completing a notification, and that in essence this ends the designated trust's involvement.</p> <p>TK suggested that this should probably form part of the GM conversations about 62 day pathways and performance and that DW's presence would be valuable as part of the GM discussions.</p> <p>PF thanked the Board for including the patient voice in the discussions. DW highlighted the importance of user involvement</p>
<b>Actions and responsibility</b>	<b>a) DW to re-attend the 62 day pathway/performance meeting.</b>

## 12. AOB

<b>Discussion summary</b>	It was noted that CJ will be embarking on extended leave for 2 months so will miss the next Board.
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## 13. Date and time of next meeting

Tuesday 15 <sup>th</sup> January 10:00-12:00 in Room 231, Preston Business Centre, Watling St Rd, Fulwood, Preston, PR2 8DY
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