



# **‘Delivering excellent Psychosocial support for adults affected by cancer in London: what progress has been made and what still needs to be done?’ 15 May 2019**

## **Event Report**

July 2019

## About Healthy London Partnership

Healthy London Partnership formed in 2015. Our aim is to make London the healthiest global city by working with partners to improve Londoners' health and wellbeing so everyone can live healthier lives.

Our partners are many and include London's NHS in London (Clinical Commissioning Groups, Health Education England, NHS England, NHS Digital, NHS Improvement, trusts and providers), the Greater London Authority, the Mayor of London, Public Health England and London Councils.

All our work is founded on common goals set out in [Better Health for London](#), [NHS Five Year Forward View](#) and the [Devolution Agreement](#).

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## Acknowledgements

The Transforming Cancer Services Team and the Personalised Care for Cancer Team are grateful to all those who participated in the event, including the speakers and facilitators who gave their time, expertise and support which contributed to the smooth running of the event. A special thanks to Lauren Mahon who opened the event with moving and thought-provoking reflections on the emotional and long-term impact of cancer. We would also like to thank Dr Alex King, Consultant Clinical Psychologist and Dr Claire Reeder, Macmillan Principal Clinical Psychologist for their presentations which focused on putting the pathway and guidance into practice locally. Our thanks also go out to all of the patient representatives who attended the pre-event focus group and whose feedback was very constructive and valued in helping us to better understand more about the psychological impact of cancer and what considerations need to be made in developing a patient facing tool for identifying psychosocial needs.

Finally, a huge thanks to the 84 delegates who attended the event and actively participated in the table discussions, providing valuable and honest contributions. There was fantastic energy in the room and many constructive ideas which will be vital for the success of the pathway across London and West Essex.

## 1. Overview

This event was planned to coincide with one year since the publication of the report, funded and in partnership with Macmillan Cancer Support, [\*The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer.\*](#)

Building on previous events held in October and May 2017, the aims of this event were to:

- Provide an overview of progress in the year following the publication of the guidance
- To present the recently developed London Integrated Pathway for Cancer Psychosocial Support
- To detail local implementation of;
  - The guidance report: '*The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer*' in the development of new services
  - London Integrated Pathway for Cancer Psychosocial Support

- To gather feedback on the London Integrated Pathway for Cancer Psychosocial Support from a broad range of stakeholders to inform continued refinement
- To examine psychosocial provision for cancer services across London and West Essex, particularly noting gaps in services and inequalities in access.
- To discuss how the Integrated Pathway can be used going forward to improve service provision, access and reduce inequalities.

## 2. Delegate recruitment and attendance

Following overwhelming interest in the previous events held in May and October 2017, a large venue which could accommodate up to 100 people was arranged. A total of **109** people registered to attend the event and **84** delegates attended on the day.

### 2.1. Delegate recruitment

In order to facilitate broad and constructive discussions in line with the aims of the event, representation was sought from the geographical remit of the Transforming Cancer Services Team:

- North Central London
- North East London
- North West London
- South East London
- South West London
- West Essex
- Pan London

Furthermore, the event sought representation from across the whole cancer pathway and key stakeholders for the event were identified as:

- Commissioners
- Medical staff including GPs, Oncologists, Nurses,
- Allied Health professionals
- Psycho-oncology teams, including Clinical Psychologists/psychotherapists/counsellors/psychiatrists
- Service Users
- Managers (including service, project and programme managers)
- Clinical leads
- Third sector organisations
- Anyone with relevant interest in the pathway
- IAPT (Improving Access to Psychological Therapies) services Pan-London

The event was advertised through a wide variety of channels. Advertising materials were disseminated through local TCST contact lists as well as:

- TCST Living With and Beyond Cancer newsletter
- Healthy London Partnership newsletter
- Healthy London Partnership communications with primary care, commissioners and NHS England
- Healthy London Partnership social media
- TCST twitter account
- Dissemination through relevant groups, e.g. via TCST Psychosocial Steering Group leads, the pan-London Living With and Beyond Cancer Partnership Board, and the pan-London Patient Advisory Group
- Personalised emails via Macmillan Cancer Support to Macmillan GPs
- Personalised emails to Mental Health Clinical Leads

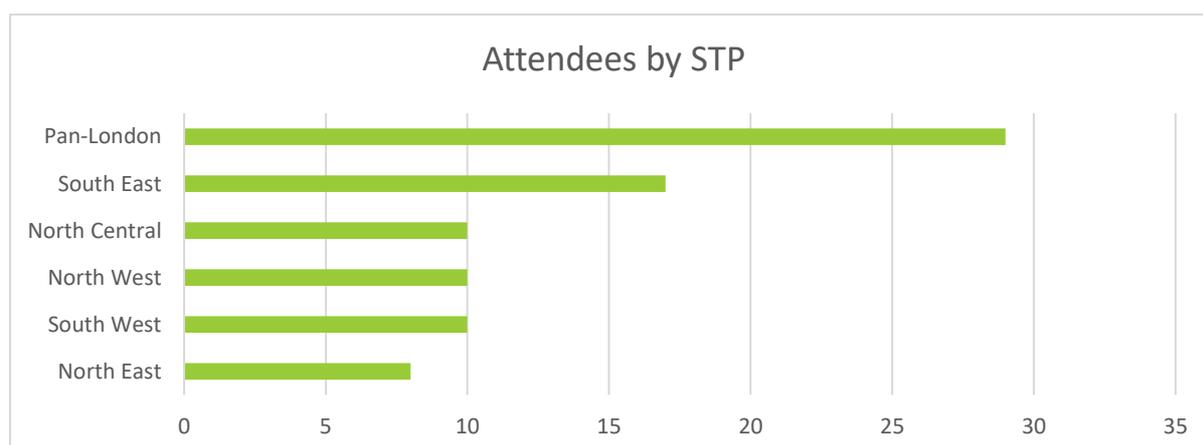
A list of STPs and their CCG remit can be found in Appendix B

## 2.2. Delegate attendance

### List of attendees by STP

The event had representation across all STP areas within TCST's geographical remit, with the exception of West Essex. Whilst 2 of the event registrations were from West Essex, neither of these went on to attend on the day. The breakdown of delegates by STP is provided below and further detail is provided in Appendix A.

Figure 1: Number of event attendees by STP



### List of attendees by job role

Delegates represented a wide-range of professional, service user and carer backgrounds, including mental health professionals, nursing, third sector and a small number of commissioners. The breakdown of delegates by job title is provided below and further detail can be found in Appendix A.

Figure 2: Number of event attendees by job title



### 3. Pre-event service user focus group

Nine patient representatives attended a closed focus group ahead of the event, which ran from 11.30am – 1pm. The group was asked to discuss their experience of psychosocial support in cancer, and to consider what had improved in the last year and what still required attention. The primary themes from the focus group centred on the need to treat cancer as a long-term condition; providing services which could be accessed years after diagnosis, dependent on need as opposed to stage of the pathway. Patient representatives highlighted the long-term impact of cancer and its treatment, and how often it is specialised services which are needed.

Participants were asked to discuss the merits of a patient facing tool, which is being developed as a tool to indicate the level of psychosocial support patients currently need. Feedback from this focus group will inform further development and refinement of the tool, with further consultation and focus groups planned.

### 4. Event Programme

The event programme was split into two parts; the first focused on the work and progress in psychosocial support for adults affected by cancer in London and West Essex, in the year following the publication of the guidance funded and produced in partnership with Macmillan Cancer Support, [\*The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer.\*](#) The second part of the event programme provided time to explore current gaps, inequalities in access and service

provision, and how the London Integrated Pathway for Psychosocial Support can support work to address these.

Further detail of these are provided below and the event programme provided to delegates is provided in Appendix C.

Attendees were seated according to their STP to enable STP level conversations about progress and where the focus now needed to be, the feasibility of implementing the London Integrated Pathway for Psychosocial Support and how this could best be done to improve access and reduce inequalities locally.

#### 4.1 Psychosocial support for adults affected by cancer in London: where have we got to?

The event opened with Dr Philippa Hyman, Macmillan Mental Health Clinical Lead, TCST in conversation with Lauren Mahon, of Girl vs Cancer and from the award winning podcast You, Me and the Big C. The conversation focused on Lauren's experience of cancer, its treatment and its emotional impact, as well as what she found helpful in terms of support.

Philippa subsequently presented an overview of the work of TCST and progress in the year following the publication of the TCST guidance report, [\*The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer\*](#). This included an introduction to the newly developed London Integrated Pathway for Cancer Psychosocial Support.

Dr Alex King, Psycho-oncology lead at Imperial College Healthcare NHS Trust, then presented on the local implementation of the pathway. This was followed by a presentation by Dr Claire Reeder, Macmillan Principle Clinical Psychologist, who focused on using the TCST guidance report to develop a new cancer psychological service within Lewisham and Greenwich NHS Trust

Delegates were encouraged throughout the afternoon to document their thoughts on progress and work which still needs to be done, via flip charts on the walls around the room.

#### 4.2 Psychosocial support for adults affected by cancer in London: where do we need to go?

The second part of the event programme provided delegates to explore current psychosocial provision in their STP area, particularly thinking about addressing inequalities in access. Delegates were also encouraged to discuss the London Integrated Pathway for Psychosocial Support and how it could be used to support this. Delegates were further asked to record feedback on an evaluation form focused on the pathway, as discussed in the next section (4.2.3).

Delegates were placed in STP groups. They were provided with:

- A map of their STP area
- London Integrated Pathway for Psychosocial Support
- Inequalities data relating to their specific STP (also presented by Dr Niki Lang, Senior Programme Manager at the Healthy London Partnership and TCST)

Delegates were then asked to work together to discuss:

1. Mapping services - what's your knowledge of current cancer psychosocial support services within your STP? How are they working together? Next steps to develop integrated cancer psychosocial care?
2. Health equity - what steps are needed to ensure that we are meeting the needs of the different communities within your STP?

Delegates were asked to provide brief feedback to the group.

#### *4.2.2. London Integrated Pathway for Psychosocial Support feedback*

Delegates were asked to record feedback on an evaluation form focused on the pathway. A total of 31 delegates completed the feedback form for the Integrated Pathway and these were collated after the event. The form asked

*'Do you believe the London Integrated Pathway for Cancer Psychosocial Support will help improve psychosocial support for adults affected by cancer in London?'*

The form also provided space for additional comments to inform the continued development and refinement of the pathway.

- 30 out of 31 delegates 'strongly agreed' or 'agreed' that the pathway will help improve psychosocial support for adults affected by cancer in London, which represents 96.8% of delegate.
- Of these, 61.3% agreed with the statement, and 35.5% strongly agreed.

Some of the comments provided include:



Further detail of feedback received is provided in Appendix D.

## 5. Event evaluation

A total of 42 delegates completed evaluation forms were collated after the event. Questions focused on the content, speakers and presentations, and structure of the day (e.g. if there was adequate time for discussion and networking).

A summary of the findings are provided below:

- 95.2 % of delegates thought the content of the event was either “excellent” or “good” (47.6% rated the content as good, and 47.6% as excellent)
- 97.6 % of delegates thought the quality of speakers was either “excellent” or “good” (47.6% rated the speakers as good, and 50% as excellent)
- Many delegates suggested that the opportunity to work with STP colleagues, to discuss gaps in services, share ideas and explore ways forward, was the most useful element of the event

- Other participants also noted that presentations focused on implementing the pathway and guidance in practice was the most useful aspect of the day
- Many delegates highlighted that it was very helpful to hear an update on progress on the work to date
- A large number of delegates also suggested that 'The patient's voice was very powerful'
- 52.3% of delegates agreed that there was adequate time for discussion, whilst 38.1% of delegates partly agreed.
- 57.7% of delegates agreed that there was adequate time for networking, whilst 34.6% of delegates partly agreed.
- Feedback around the venue was generally very positive, with 97.6% of delegates thought the content of the event was either "excellent" or "good" (35.7% rated the venue as good, and 61.9% as excellent)

Other comments received included:



## 6. Next steps

A key aim of the event was to share progress in terms of impact and implementation following the publication of the guidance report, [\*The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer\*](#) and to examine current STP provision of psychosocial services for those affected by cancer across the whole pathway, identifying gaps and inequalities which need to be addressed. The event programme also provided the opportunity to seek feedback on the TCST London Integrated Pathway for Psychosocial Support.

Bespoke support for implementation of the pathway will continue to be provided at STP level to influence and guide the development of new psych-oncology services where there are gaps and help assure the sustainability of existing services. As part of this, a template business case for psychosocial support is in development and a final draft will be submitted to the Pan London Cancer Commissioning Board in September 2019 for ratification.

Additionally, a mapping refresh of Psycho-oncology services across London will be carried out over the next couple of months, as the most recent mapping took place in November 2017. The re-mapping exercise will play a vital role to ensure that inequity in service provision is addressed, gaps are identified, there is clarity regarding how services are commissioned, and to understand where further support may be needed at STP level.

**For further information, please contact:**

**Dr Philippa Hyman**

**Macmillan Mental Health Clinical Lead and Clinical Psychologist**

**Email: [England.TCSTLondon@nhs.net](mailto:England.TCSTLondon@nhs.net)**

**Team tel nos: 0113 825 1287 or 0113 825 1287**

**Sophie Lansdowne**

**Macmillan Project Manager – Personalised Care for Cancer**

**Email: [sophie.lansdowne@nhs.net](mailto:sophie.lansdowne@nhs.net)**

**Team telephones: 0113 825 1287 or 0113 825 2870**

## Appendix A: Breakdown of Attendees per STP and title

Attendees per STP		
<i>STP</i>	<i>Registrations</i>	<i>No. of attendees on day</i>
North East	10 (8.8%)	8 (9.1%)
North Central	12 (10.6%)	10 (11.4%)
North West	14 (12.4%)	10 (11.4%)
South West	14 (12.4%)	10 (11.4%)
South East	22 (19.5%)	17 (19.5%)
West Essex	2 (1.8%)	0 (0%)
Pan London (including third sector and service users)	39 (34.5%)	33 (37.5%)
<b>Total</b>	<b>113</b>	<b>88</b>

Attendees per job title	
Clinical Psychologist/Psychotherapist	23 (28%)
Service User	14 (17.1%)
Third Sector	12 (14.6%)
TCST	9 (11%)
Programme/Project Lead/Manager/Coordinator	5 (6.1%)
Commissioner	4 (4.9%)
Nurse (including Lead Nurse)	3 (3.7%)
Counsellor (including Senior)	3 (3.7%)

GP	2 (2.4%)
Clinical Lead	2 (2.4%)
Palliative Social Care Worker	2 (2.4%)
Psychiatrist	1 (1.2%)
General Manager (Trust-based)	1 (1.2%)
AHP	1 (1.2%)

## Appendix B: London STP and CCG breakdown

STP	CCGs as part of remit
<b>North Central London</b>	Islington, Camden, Haringey, Enfield, Barnet
<b>North East London</b>	Waltham Forest, Tower Hamlets, Newham, City & Hackney
<b>Barking Havering Redbridge</b>	Barking, Havering, Dagenham and Redbridge
<b>South East London</b>	Greenwich, Lewisham, Lambeth, Southwark, Bromley, Bexley
<b>South West London</b>	Croydon, Merton, Sutton, Richmond, Kingston, Wandsworth, Sutton
<b>North West London</b>	Central London, West London, Brent, Harrow, Hillingdon, Hammersmith & Fulham, Hounslow, Ealing
<b>West Essex (part of Hertfordshire and West Essex STP)</b>	



## Appendix C: Event Programme

### ‘Delivering excellent Psychosocial support for adults affected by cancer in London: what progress has been made and what still needs to be done?’

Wednesday 15<sup>th</sup> May 2019

12.45pm-5pm (registration and lunch from 12.45pm, for 2pm start)

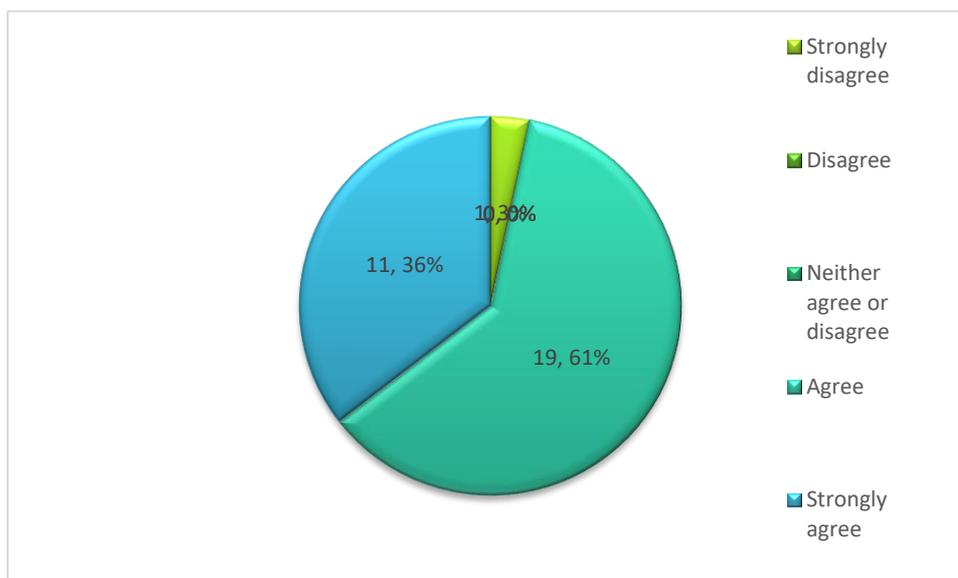
Coin Street Conference Centre, Southbank Suite, 108 Stamford St, South Bank, London SE1 9NH

12.45	Registration and lunch
14.00	<p><b>Welcome and Introduction</b></p> <p><i>Liz Price, Associate Director Personalised Care for Cancer Team, Transforming Cancer Services Team (TCST)</i></p> <p><i>Dr Philippa Hyman, Macmillan Mental Health Clinical Lead, Transforming Cancer Services Team (TCST)</i></p>
14.10	<p><b>Setting the context for this work</b></p> <p><b><i>Why excellent psychosocial support is vital across the whole cancer pathway?</i></b></p> <p><i>Lauren Mahon (aka girl vs cancer, from the award-winning podcast You, Me and the Big C) in conversation with Philippa Hyman</i></p>
14.30	<p><b>Delivering excellent psychosocial care in London:</b></p> <ol style="list-style-type: none"> <li>1) <b>An overview of progress one year on</b> - <i>Dr Philippa Hyman, Macmillan Mental Health Clinical Lead, TCST</i></li> <li>2) <b>‘From vision and theory, to localised implementation: our progress in West London’</b>- <i>Dr Alex King, Psycho-oncology lead, Imperial College Healthcare NHS Trust.</i></li> <li>3) <b>Implementing the TCST guidance - how we used it to develop a new cancer psychological service within Lewisham and Greenwich NHS Trust</b> - <i>Dr Clare Reeder, Macmillan Principle Clinical Psychologist, Lewisham and Greenwich NHS Trust</i></li> </ol>

15.25	<b>Coffee break</b>
15.45	<p><b>Psychosocial care pathway-what still needs to be done?</b></p> <p><i>Addressing cancer inequalities - Dr Niki Lang, Senior Programme Manager, Prevention Team, Healthy London Partnership</i></p> <p><b>STP groups table discussion (with map of STP area and pathway figure):</b></p> <ol style="list-style-type: none"> <li>1) <i>Any final comments about the pathway figure? (Complete form attached)</i></li> <li>2) <i>Mapping services-what's your knowledge of current cancer psychosocial support services within your STP? How are they working together? Next steps to develop integrated cancer psychosocial care?</i></li> <li>3) <i>Health equity-what steps are needed to ensure that we are meeting the needs of the different communities within your STP?</i></li> </ol>
16.20	<b>Fast feedback from STP areas</b>
16.50	<b>Next steps and closing remarks - Liz Price and Philippa Hyman, TCST</b>
17.00	<b>End</b>

## Appendix D: Collation of responses to Pathway Feedback

1. Do you believe the London Integrated Pathway for Cancer Psychosocial Support will help improve psychosocial support for adults affected by cancer in London? (please tick as appropriate)



- 30 out of 31 delegates ‘strongly agreed’ or ‘agreed’ that the pathway will help improve psychosocial support for adults affected by cancer in London, which represents 96.8% of delegates.
- Of these, 61.3% agreed with the statement, and 35.5% strongly agreed.
- One delegate strongly disagreed with the statement

2. Do you have any final comments about the pathway?

**Themes:**

Useful to speak to managers/commissioners
Need to involve community/religious/spiritual partners
Need greater reference to and integration with the third sector
Need to avoid encouraging limited commissioning, but to enable flexible commissioning of services – patients able to access services later than the 18 month/2 year cut off and for this to be done in a sustainable way
Progress slow
Sustainability important

Need to ensure enough differentiation between IAPT and specialist services and appropriate referral and access
Need to emphasize the social aspects to a greater degree – can be cost effective
Equality and diversity need to be considered to a greater degree
A centrally resourced cancer helpline in a range of language options might be helpful for those needing to access services years after treatment
Integration in to local strategies key to implementation
Coordination between services and education about services key
Staff support, beyond level 2 group supervision and/or Schwartz rounds, key to staff wellbeing, retention and patient care
Need greater inclusion of support services for family members