



# ‘Personalised Care for Cancer: Next Steps for London’ 12 February 2020

## Event Report

March 2020

## 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](#).

## Who we are, what we do

The Transforming Cancer Services programme was established in April 2014 to provide strategic leadership, clinical advice, oversight, cohesion and guidance to improve outcomes for patients through a pan-London clinically led, patient-centred collaborative approach.

The Transforming Cancer Services Team (TCST) is part of the Healthy London Partnership. The Healthy London Partnership brings together London's health and care system to deliver changes that are best done "once for London".

Our vision is for all Londoners to have access to world class care before and after a cancer diagnosis. Our mission as a trusted partner, is to drive delivery of world class cancer outcomes through collaboration, commissioning support, clinical leadership, education and engagement.

Our pan-London transformation is responsible for:

- A 'once-for-London' approach to implementing the NHS Long Term Plan
- Providing subject matter expertise, evidence and intelligence for cancer commissioning support
- Working with partners to reduce variation and deliver improved cancer outcomes
- Primary care development and education
- Targeted service improvement in secondary care

**This event was funded by Macmillan Cancer Support**

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call 0808 808 00 00 or visit [macmillan.org.uk](https://www.macmillan.org.uk). To give, fundraise or volunteer call 0300 1000 200 or visit [macmillan.org.uk](https://www.macmillan.org.uk)

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## Acknowledgements

The Transforming Cancer Services Team (TCST) would like to thank Macmillan Cancer Support for enabling four workstreams to support the transformation and improvement in cancer services across London for people who have been affected by cancer. Thank you also for creating the opportunity for the event which was held on Wednesday 12<sup>th</sup> February 2020, Personalised Care for Cancer- Next Steps for London.

TCST's Psychosocial Support, Cancer Rehabilitation, Lymphoedema and workstreams have been led and delivered by Dr Philippa Hyman, Dr Karen Robb and Sophie Lansdowne. The South West London Health & Care Partnership's primary care nursing workstream was led and delivered by Sandra Dyer, Sarah Dewhurst and Yvonne Damanhuri.

The teams have been dedicated to these projects and their inputs have been invaluable over the years to the agenda of personalised care for cancer and for people living with and beyond cancer across London. They have worked in partnership with Macmillan, patient partners, service providers and clinicians across acute, primary care and community services and other third sector organisations with support from commissioners to produce resources and toolkits which have made significant impact and development to people affected by cancer in London.

Vital input and leadership on these four projects has come from Liz Price, the associate director for personalised care for cancer at Transforming Cancer Services team. Her support, strategic direction and commitment to all these four projects over the years has been priceless. Her pioneering dedication to the personalised care for cancer agenda for London has been inspiring. The event on 12<sup>th</sup> February could not have happened without her.

Patient partners have been central to these workstreams. They have shared their personal and sensitive experiences selflessly to push the personalised care agenda forward across London. They have given up their time and energy, given constructive feedback and challenged where necessary to co-design and co-produce resources for people living with and beyond cancer and the Next Steps for London event. A special thanks to Peter Goulding who facilitated the event with strategic oversight of the long-term impact on cancer for all stakeholders. We would also like to thank Daphne Earl, Stewart Block, Bonnie Green, David Jillings and Sarifa Patel for sharing their reflections from a patient's perspective.

The four workstreams were enabled by the pan London Personalised Care for Cancer Partnership Board, the steering groups for each project and the communities of practice in Primary care Nursing and Lymphoedema. A special thank you to all the health care professionals, patient advocates and commissioners who have been part

of these groups and board meetings. A special thank you to Andre Chagwedera, Beth Dahill, Bonnie Green, Daphne Earl, Dr Owen Carter, Dr Sahil Suleman, Joanne Powell, Karen Friett, Kate Ashforth, Maggie Lam, Mary Woods, Steve Tolan and Stewart Block; who have agreed to be champions and featured as “pop up people” at the Next Steps event on 12<sup>th</sup> February.

A huge thank you to TCST colleagues who facilitated STP tables on the day and also to the 107 delegates who attended the event and actively participated in the table discussions, providing valuable and honest contributions to the next steps for London in Personalised Care for Cancer. There was fantastic energy in the room and there were vital actions and succession planning which took place for the success of the TCST Macmillan funded programmes: Psychosocial support, Cancer Rehabilitation and Lymphoedema workstreams and Macmillan’s 2020 ambition to have Primary Care Workforce Leads in each of London’s STP.

## 1. Overview

The Personalised Care for Cancer- Next Steps for London event was planned to help systems across London in their planning process of the Macmillan Psychosocial Support, Cancer Rehabilitation, Lymphoedema and Primary care nursing workstreams as Macmillan funding ends in March 2020.

The aim of the event was to support the cancer system across London to begin their actions and succession planning for the Macmillan funded programmes in TCST (psychosocial support, cancer rehabilitation and lymphoedema) and South West London's primary care nursing workstreams. Macmillan and TCST funding for these programmes ends in March 2020.

The four workstreams have clearly set out why the situation needs to be different in cancer care across London. In their guidance documents, reports and resources, they have given strategic oversight to what needs to happen and created opportunities to influence and share learning across London in cancer care and support services. The support from TCST and SWL STP clinical leadership has enabled tools and resources to be developed and implemented locally for each workstream across the region.

These resources have explained that there are more people diagnosed with cancer, more people surviving, but not necessarily living well and 70% of people with cancer have at least one other long-term condition. With each STP in London prioritising at least one of these areas within their work programme for personalised care for cancer; this event aimed to provide the opportunity to come together as five cancer systems to discuss next steps and develop local networks of experts to take this forward after the Macmillan funded projects come to an end in March 2020.

Key resources for these workstreams can be accessed using the links below:

#### Cancer rehabilitation

<https://www.healthylondon.org/wp-content/uploads/2019/07/A-guide-to-reducing-variation-and-improving-outcomes-in-cancer-rehabilitation-in-London.pdf>

#### Lymphoedema

<https://www.healthylondon.org/resource/commissioning-guidance-lymphoedema/>

#### Psychosocial support

<https://www.healthylondon.org/wp-content/uploads/2020/02/Refreshed-February-2020-Guidance-doc-Psychological-support-for-people-affected-by-cancer-.pdf>

#### Primary Care Nursing and cancer

<https://www.swlondon.nhs.uk/ourwork/macmillan-primary-care-nursing-project/>

The above resources have identified and explained what the problems are for people affected by cancer, and this has been described very well through statistics and stories from patients, carers and their families. They have also informed the cancer system of what the benefits are for people having the best possible quality of life after the diagnosis and treatment of cancer. Thus, the Personalised Care for Cancer Next Steps for London event was to support cancer system leaders to work out how they will help people living with and beyond cancer have the best possible quality of life. And to work out how they will go about this from April 2020, without clinical leadership, transformation and improvement support from TCST and SWL STP.

## 2. Delegate recruitment and attendance

There was overwhelming interest and response to the Personalised Care for Cancer: Next Steps for London event, and it was sold out within 72 hours of going live on Eventbrite. To ensure that everyone who needed to be there could be there to influence discussions at the event, special invitations were sent to stakeholders across London and some participants were added to the waiting lists to ensure the event was not oversubscribed. A total of **145** people registered to attend the event, **25 people** were on a waiting list and **107** delegates attended on the day.

### 2.1. Delegate recruitment

To facilitate broad and constructive discussions in line with the aims and objectives 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 key stakeholders across the four workstreams. This included:

- Patient partners
- Commissioners
- Clinicians including GPs and Nurses Allied Health professionals and psychologists
- Managers (including service, project, programme and Macmillan partnership managers)
- Clinical and strategic leaders
- Third sector organisations

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 a good representation across all STP areas. The breakdown of delegates by STP is provided below and further detail is provided in Appendix A.

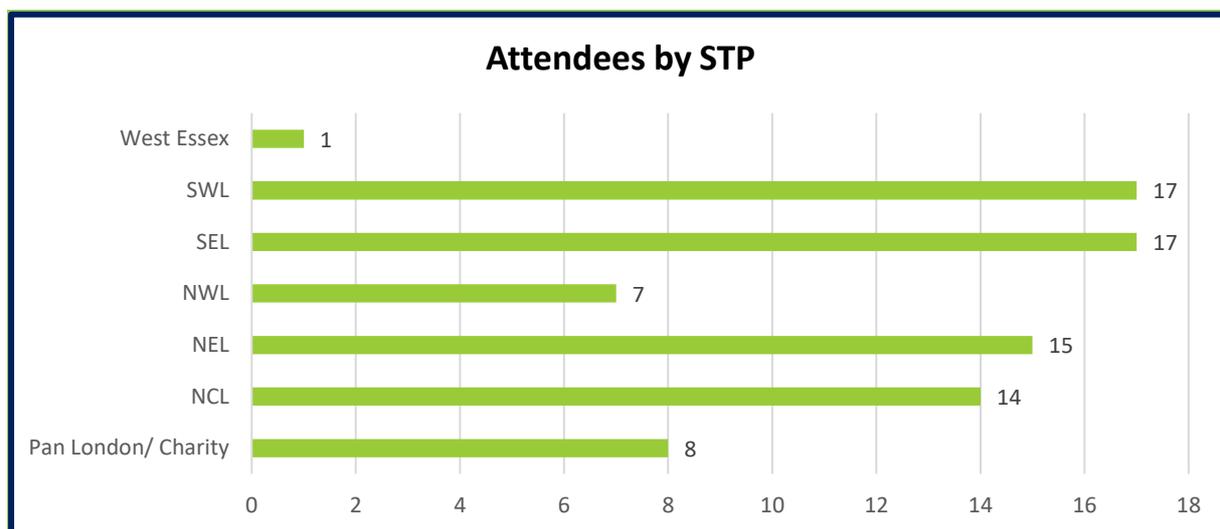


Figure 1: Number of event attendees by STP

### List of attendees by job role

Delegates from each workstream were well represented on the day. There was a good mixture of commissioners/system leaders, professionals from primary and secondary care NHS organisations and patient partners. The breakdown of delegates by job role is provided below and further detail can be found in Appendix A.

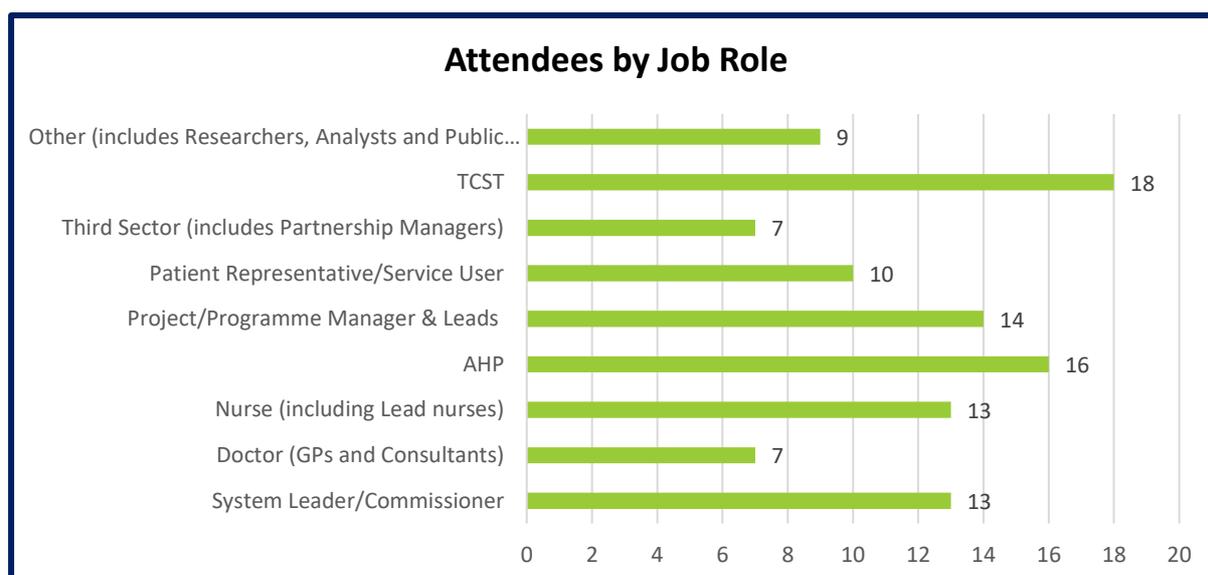


Figure 2: Number of event attendees by job role

### 3. Event Programme

The event programme was split into two parts; the first part focused on the work and progress of the workstreams, including discussion by a group of patients regarding their concerns and 'one wish' for the future of this work. The second part of the event programme provided time for participants to reflect on:

- the current strengths, gaps, opportunities and concerns in access and service provision for people affected by cancer in psychosocial support, cancer rehabilitation, lymphoedema and primary care nursing services in their STP
- how as a cancer system, these strengths and opportunities can be supported, and gaps and concerns be addressed.

A copy of the event programme can be found in Appendix C.

Attendees were seated according to their STP to enable constructive STP level discussions about planning. At each table, there was at least one TCST colleague facilitating discussions.

Each STP table had a localised pack which included:

- Cancer prevalence data for the STP from the TCST prevalence dashboard
- National Cancer Patient Experience Survey data for the STP
- Inequalities data from the TCST Inequalities toolkit
- E-Holistic Needs Assessment data for London
- STP priorities for Personalised Care for Cancer included in Long Term Plans
- Key contacts and resources for the STP

There were also workstream clinical champions for each STP on every table. Champions are people who have agreed to play a supportive role for those working on the continued development of these services and workstreams from March onwards. They are full time clinicians and please note that the champion role is unfunded. The champions are shown in the table below in Figure 3. Further details of STP champions and key contacts can be found in the STP packs.

Workstream/ STP	Lymphoedema	Cancer Rehabilitation	Psychosocial Support
<b>NCL</b>	Kay Eaton, Consultant Nurse, Cancer and Supportive Care Clinical Lead for the Lymphoedema Service, University College London Hospitals NHS Foundation Trust	<b>To be confirmed by the NCL Personalised Cancer Care Delivery Group</b>	<b>To be confirmed by the NCL Personalised Cancer Care Delivery Group</b>
<b>NEL</b>	Caitriona O Neill, Director of Community Services and Lymphoedema, Accelerate CIC	Karen Bollard, Clinical Lead Oncology Therapies, Bart's Health NHS Trust	Mark Barrington, Consultant Clinical Psychologist, Barts Health NHS Trust
<b>NWL</b>	Karen Crawley-Jenns, Lymphoedema CNS, London North West University Healthcare NHS Trust	Claire Taylor, Macmillan Nurse Consultant, London North West University Healthcare NHS Trust  Claire O 'Herlihy, Highly Specialist Oncology Occupational Therapist, Royal Free London NHS Foundation Trust	Clare Stevenson, Macmillan Consultant Clinical Psychologist, North West Partnership
<b>SEL</b>	Nancy Jameson, Lymphoedema Lead Specialist Practitioner, Guy's and St Thomas' NHS Foundation Trust	Nic Peat, Clinical Specialist Physiotherapist-Oncology and Neurology, Guy's and St Thomas' NHS Foundation Trust	Sue Smith, Consultant Clinical psychologist, Guy's and St Thomas' NHS Foundation Trust
<b>SWL</b>	Mary Woods, Nurse Consultant Lymphoedema, The Royal Marsden NHS Foundation Trust	Kate Ashforth, Joint Head of Speech and Language Therapy, The Royal Marsden NHS Foundation Trust  Siobhan Cowan-Dickie, Clinical Specialist Physiotherapist, The Royal Marsden NHS Foundation Trust  Carolyn Johnston, Consultant Anaesthetist, St. George's University Hospitals NHS Foundation Trust	Sahil Suleman, Macmillan Consultant Clinical Psychologist, Lead for Macmillan Cancer Psychological Support (CaPS) Team, St George's University Hospitals NHS Foundation Trust

Figure 3: Champions for the TCST workstreams in each STP across London.

### **3.1 Personalised Care for Cancer in London: the story so far.**

The event was opened by words from Macmillan Cancer Support. Emma Tingley, the Macmillan Strategic Partnerships Manager for London. Emma thanked colleagues in the psychosocial, cancer rehabilitation, lymphoedema and primary care nursing workstreams for their progress in cancer services across London so far.

Next Sandra Dryer, Macmillan Primary Care Lead Nurse, SWL STP presented an overview of the Macmillan Primary Care Nursing project and the progress the workstream has made through patient partner involvement and how this led to the development of education resources for primary and community nurses and influencing materials for influencing the content of post-graduate education for nurses and cancer as a long term condition. Throughout the presentation, there were one-minute snap shots made by Bonnie Green, a patient partner; Dr Owen Carter, a Macmillan GP and Joanne Powell, a senior lecturer in general practice nursing at Kingston University and St. Georges' University London on their role and involvement in the primary care nursing project. They also informed delegates at the event about the proudest achievement of the workstream.

Subsequently, Dr Philippa Hyman, Macmillan Mental Health Clinical Lead, TCST presented a background of the Macmillan psycho-social support workstream: Delivering excellent psychosocial support for adults affected by cancer in London. She explained the project timeline from the beginning to date. This involved service user engagement and co-design of a London integrated pathway for cancer psychosocial support with patient partners and stakeholders. Daphne Earl, a patient representative and member of the psycho-social support and cancer steering group gave her one-minute reflection of the workstream. Maggie Lam, Deputy Director of Urgent Care and Cancer at SWL STP and Dr Sahil Suleman, Macmillan Consultant Clinical Psychologist at St George's Hospital gave their thoughts and involvement in the psychosocial support for people affected by cancer project. Philippa briefed the delegates at the event of the recommendations of her project for commissioners and system leaders.

Dr Karen Robb Macmillan Rehabilitation Clinical Lead from TCST, then presented on the Lymphoedema guidance for adults living with and beyond cancer. Karen narrated the journey of the lymphoedema work across London from the beginning. Karen described the patient and public involvement in this workstream and Karen Friett a patient advocate and chief executive of the Lymphoedema Support Network supported the presentation with a one-minute deep dive of the benefit of the TCST Lymphoedema workstream for people affected by cancer. Dr Karen Robb updated delegates about the resources which have been produced and explained that the commissioning guidance for Lymphoedema services for adults living with and beyond cancer is being refreshed by the pan London Community of Practice. Beth

Dahill, Transformation Lead for Planned Care at Barnet CCG echoed the benefits of the Lymphoedema resources and their impact on commissioning a new service in a one-minute reflection of the workstream. Mary Woods, Nurse Consultant Lymphoedema at Royal Marsden Hospital NHS Foundation Trust gave her thoughts and involvement in the pan London Lymphoedema Community of Practice.

Dr Karen Robb also presented on the Integrated Care System Guidance for Cancer Rehabilitation. Stewart Block, a service user and member of the TCST Patient Advisory Group shared his personal experiences and the impact of Cancer Rehabilitation on his quality of life. Karen gave a summary of the progress of the Cancer rehabilitation workstream as well as an explanation of the resources of the projects. This included how she influenced STP plans, better data capture and support the workforce in these services. Kate Ashforth, Joint Head of Speech and Language Therapy, The Royal Marsden NHS Foundation Trust and Steve Tolan, Allied Health Professions Lead, NHS England & NHS Improvement, London Region informed delegates at the event about their role, involvement and the proudest achievement of the workstream to date.

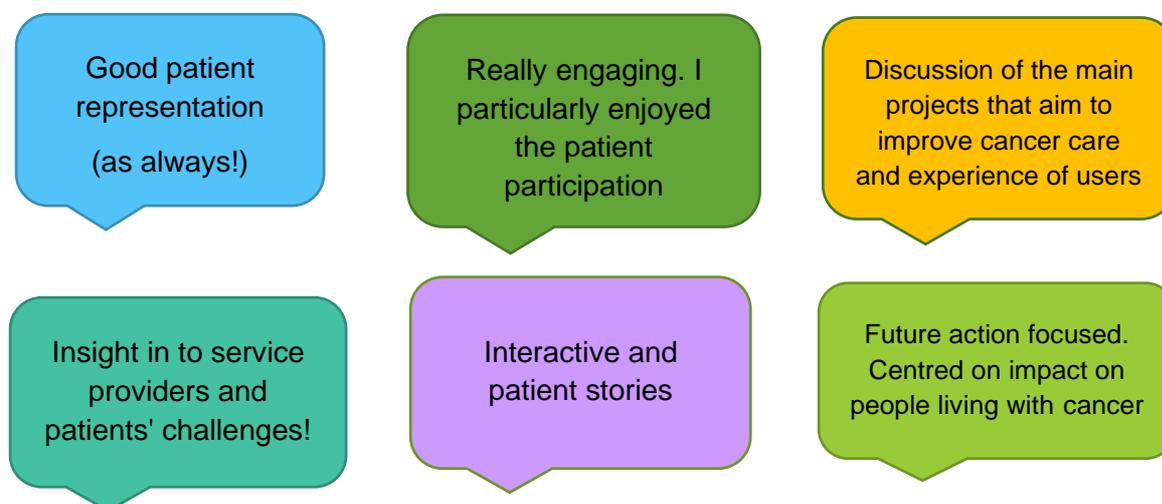
### **3.2 Personalised Care for Cancer in London: what is the future state?**

Liz Price, Associate Director for Personalised Care for Cancer, Transforming Cancer Services Team presented highlights from London STPs' draft responses to the Long-Term Plan for adults affected by cancer in London. Next, Neesa Mangalaparathy from the NHS England Personalised Care for Cancer national programme gave an overview of the personalised care agenda for cancer, highlighting on the national Quality of Life project which commences national roll out in 2020.

### **3.3 Personalised Care for Cancer in London: what do the patients think?**

The next section of the event programme provided an opportunity for the patients to reflect on what they had heard at the event so far and communicate to delegates their perspectives. This exercise was facilitated by Daphne Earl and a discussion was held between Daphne, Bonnie Green, David Jillings, Sarifa Patel and Stewart Block. The patient partners sat on stage whilst the delegates observed and listened to their discussion. The patient partners talked with one another about their personal experiences about receiving care from general practice and community nurses, psychosocial support, cancer rehab and lymphoedema services. They also expressed their hopes for the future regarding the services. The discussion concluded with their individual 'one wish' in terms of all these workstreams and cancer care and support for people affected by cancer from April 2020.

Below are some of the comments from evaluation surveys regarding the patient's voice in the event programme. These were the response when participants were asked "what did you like about the event?"



### 3.4 Personalised Care for Cancer for London: where do we need to go?

The second part of the event programme provided delegates opportunity to discuss their next actions over the short term and succession planning for the four Macmillan funded workstreams. Delegates were encouraged to use the provided STP packs and their learning points from first part of the programme to identify and agree the gaps and opportunities for their own STP. They were also asked to discuss key actions and identify key stakeholders to take on roles to move the psychosocial, lymphoedema, cancer rehab and primary care nursing workstreams forward in their STPs.

As part of their STP discussions, delegates were asked:

1. What progress have you made in:
  - Primary care nursing and cancer
  - Psychosocial support and cancer
  - Lymphoedema services
  - Cancer rehabilitation
2. Clinical leadership- Are the clinical leads for these services represented in your STP? How could this be strengthened?
3. TCST recommendations- To discuss and prioritise STP/ICS recommendations in the TCST guidance for Lymphoedema, Cancer Rehabilitation and Psychosocial support

4. Health inequalities- What are your areas of inequality? For example, service gaps, access issues, vulnerable groups etc.
5. Next Steps: What are your next steps in these workstreams?

### 3.5 Personalised Care for Cancer for London- Peer Feedback

Delegates were asked to record feedback on at least two other STPs' priorities and actions. Feedback was recorded by a TCST facilitator on flipchart paper. Peers responded on the actions and succession planning of STPs and shared good practice or any tips they had for the STP.

Some of the comments are provided below:

STP should develop SMART goals and actions to achieve proposals

Focus groups and peer support networks should be set up to achieve the proposals

We have been so fortunate to have such brilliant people involved in the Personalised Care for Cancer Workstream. They have created a brilliant legacy which STPs and Cancer Alliances must build on and sustain.

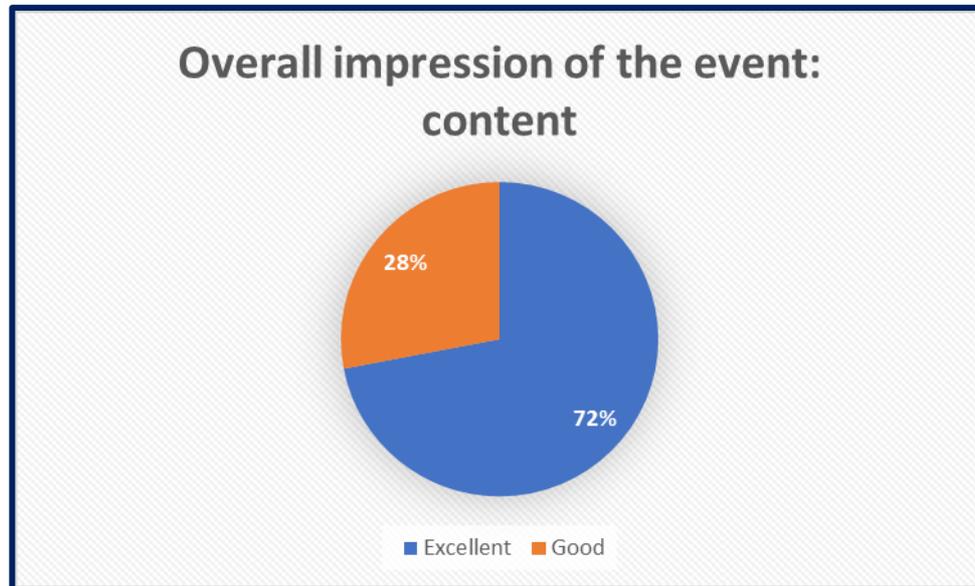
Excellent collaboration, real feel of learning together, with sense of celebrating what's been achieved and looking forward to how to develop things further.

Thank you - also I'm grateful the work happened and hope we can build on this. Relationships are key and who is where and on what board really matters.

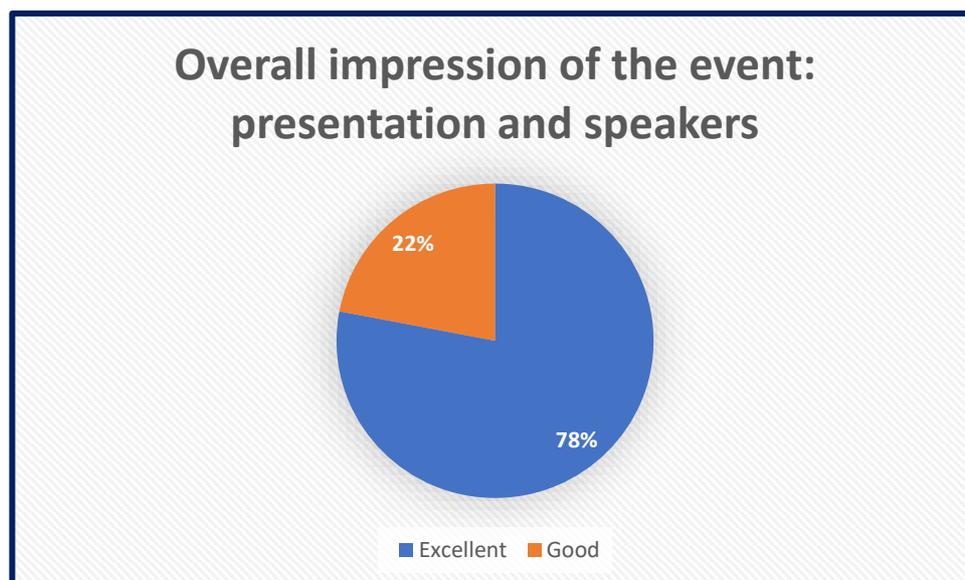
## 4. Event evaluation

A total of 65 delegates (61%) completed evaluation forms after the event, either hard copy or electronically. Questions focused on the content, speakers and presentations, and structure of the day (e.g. if there was adequate time for table discussion).

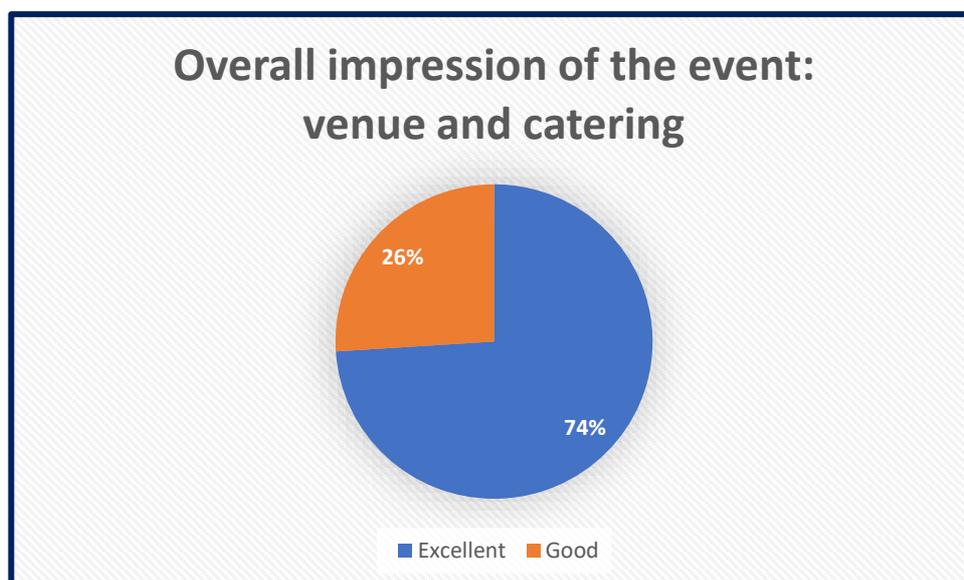
A summary of the findings is provided in the pie charts below:



- 100% of delegates thought the content of the event was either “excellent” or “good” (72% rated the content as excellent, and 28% as good)



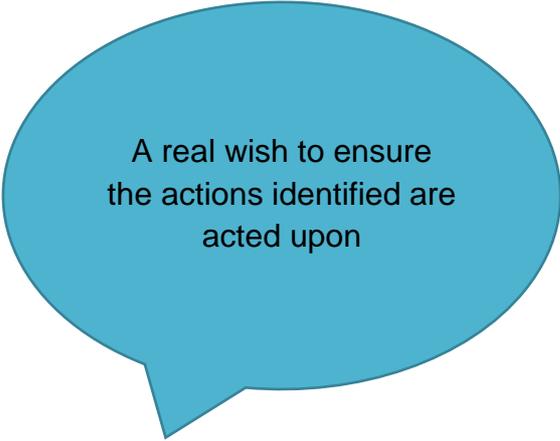
- 100% of delegates thought the quality of speakers and presentations was either “excellent” or “good” (78% rated the content as excellent, and 22% as good)



- 100% of delegates thought the venue and catering of the event was either “excellent” or “good” (74% rated the content as excellent, and 26% as good)
- 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 comments received included:

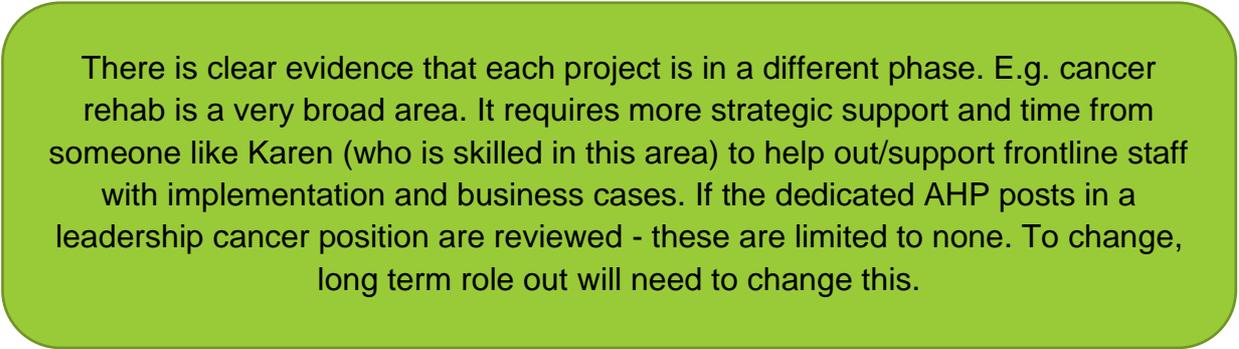




A real wish to ensure the actions identified are acted upon



A lot of good work is person dependent and the loss of this team will leave a gap in driving this forward.



There is clear evidence that each project is in a different phase. E.g. cancer rehab is a very broad area. It requires more strategic support and time from someone like Karen (who is skilled in this area) to help out/support frontline staff with implementation and business cases. If the dedicated AHP posts in a leadership cancer position are reviewed - these are limited to none. To change, long term role out will need to change this.



Thank you - also I'm grateful the work happened and hope we can build on this. Relationships are key and who is the where and on what board



High level of enthusiasm and engagement of all involved

## 6. Next steps

A key aim of the Personalised Care for Cancer Next Steps for London event was to support systems to work out how they will help people living with and beyond cancer have the best possible quality of life in London and to work out how they will go about this from April 2020, without clinical leadership, transformation and improvement support from TCST.

As previously mentioned, each STP was given a pack with their local data to support table discussions. An update to these STP packs has been created based on the findings from the Personalised Care for Cancer-Next Steps for London event.

STP summary resource packs can be found using the links below:

NCL STP pack

<https://www.healthylondon.org/wp-content/uploads/2020/03/NCL-STP-Pack.pdf>

NEL STP pack

<https://www.healthylondon.org/wp-content/uploads/2020/03/NEL-STP-Pack-version-0.1.pdf>

NWL STP pack

<https://www.healthylondon.org/wp-content/uploads/2020/03/NWL-STP-Pack-version-0.1.pdf>

SEL STP pack

<https://www.healthylondon.org/wp-content/uploads/2020/03/SEL-STP-version-0.1.pdf>

SWL STP pack

<https://www.healthylondon.org/wp-content/uploads/2020/03/SWL-STP-Pack- update-v0.2.pdf>

## Appendix A: Breakdown of attendees per STP and job role

Attendees per STP and Job role										
Job Role/STP	System Leader/ Commissioner	GP/ Consultant	Nurse	AHP	Project/ Programme Manager & Lead	Third Sector	Service User/Patient Representative/Carer	TCST	Other	Total
NCL	3	3	2	2	2	1	2	0	0	14
NEL	3	1	2	4	3	1	1	0	1	15
NWL	1	0	3	1	0	1	1	0	1	7
SEL	3	2	2	6	4	0	1	0	0	17
SWL	2	1	4	3	4	1	1	0	2	18
West Essex	0	0	0	0	1	0	0	0	0	1
Pan London	3	0	0	2	1	1	3	18	0	35
<b>Total</b>	<b>16</b>	<b>7</b>	<b>13</b>	<b>18</b>	<b>16</b>	<b>5</b>	<b>10</b>	<b>18</b>	<b>4</b>	<b>107</b>

## 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, 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 CCG (part of Hertfordshire and West Essex STP)</b>	

## Appendix C: Event Programme



### Personalised Care for Cancer: Next Steps for London Event

Date:	Wednesday, 12 <sup>th</sup> February 2020
Time	0900 – 1330
Venue:	Coin Street Neighbourhood Centre, 108 Stamford Street, London SE1 9NH
Facilitator:	Peter Goulding, Chair Pan London Patient Advisory Group

Time	Item
09:00-09:30	Arrival and Registration
09:30-09:40	Welcome & introduction
09:40-09:45	Words from Macmillan
09:45-10:25	The journey so far
10:35-10:50	The future state
10:50-11:10	The patient's voice
11:10-11:30	Coffee break
11:30-12:30	Group exercise: STP reflections and action planning
12:30-13:00	Peer feedback
13:00-13:20	Plenary discussion
13:20-13:30	Final remarks/Next steps



**Healthy London  
Partnership**

**For further information, please contact:**

**Transforming Cancer Services Team**

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

**You can access all the resources and get more information from the HLP website using the link below:**

**<https://www.healthylondon.org/>**