



# Commissioning guidance for Cancer Psychosocial support

A guide to improving psychologically informed care  
and clinical outcomes for adults affected by cancer  
in London

Transforming Cancer Services Team

February 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 report 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](http://macmillan.org.uk). To give, fundraise or volunteer call 0300 1000 200 or visit [macmillan.org.uk](http://macmillan.org.uk)

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The Transforming Cancer Services Team (TCST) would like to thank Macmillan Cancer Support for enabling this work to be undertaken by funding Dr Philippa Hyman, Macmillan Mental Health Clinical Lead to carry out this project over the past three years. We are delighted that Philippa won Macmillan's 2019 Professionals Award (Excellence in Integration) for this work.

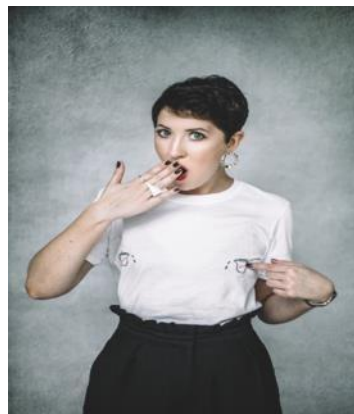
This document is a refresh of the original guidance report published in May 2018 available here: <https://www.healthylondon.org/wp-content/uploads/2018/05/Psychological-support-for-people-affected-by-cancer-May-2018.pdf>

Partnership working with Macmillan, service users, service providers across acute, primary care and community services, other third sector organisations and support from commissioners enabled recommendations to be produced in the original report which has resulted in significant positive developments across London.

We would like to thank the Pan London Psychosocial support and Cancer Steering group who enabled this work to stay on track and provided constructive feedback at all stages of this project. Service users have been central to this work and their time, feedback and challenge has been invaluable. Finally, we would like to thank the Personalised Care for Cancer Team, within the TCST, for their support and guidance during the past year.

## Foreword

### **Lauren Mahon, founder of GIRLvsCANCER, broadcaster and cancer activist.**



When I was diagnosed with breast cancer at age 31 and barely any boobs I thought they were having a laugh. But they weren't. And I did. I have a grade 3 cancerous tumour in my breast which had set up residence without consent and sent my world into a tail spin.

The physical impact of cancer treatment was terrifying but I was in no way prepared for the emotional upheaval I was about to face. As somebody who has always been life and soul of the party I began to feel completely isolated and lonely, no longer able to be the person I know myself to be. I lost my sense of self and my confidence. I didn't look like me or feel like me and I felt a gaping distance between myself and my peers. My priorities and capabilities had changed and my friends just didn't 'get it'.

Luckily for me I had the option of counselling at the Marsden which provided no end of support when I slipped into distress and anxiety. It also put the skills I acquired from my CBT sessions to good use which is something I think should be offered to patients at the point of diagnosis. I hands down would not have handled my cancer treatment without it.

As a young adult dealing with cancer my priorities are different to those raised in the literature provided. Whilst most are preparing you to tell the children, my concern was when can I have a glass of prosecco?! The anxiety around recovery is tough and it's a constant battle to know if what you're doing is right or wrong. I'm always anxious that I'm not doing enough for my body. You read stories in the papers about the latest health trends but it's not clear whether they should be adhered to. It would be great to have clearer direction for recovery - a plan almost.

Diet guides and exercise routines tailored to you so you feel like you're getting somewhere and seeing an improvement. Also knowing what symptoms are sinister and should be taken to your oncology team and what should be handled by your GP - clearer communication between the two. I'm proud to have taken part in this report and wanted to air the issues I feel are sometimes overlooked when examining the big picture. It's these little things that make a big difference to us patients.

**Jonathan Bates, Director of Commissioning Operations SWL Alliance.**

I am delighted that Macmillan Cancer Support has funded and supported the Transforming Cancer Services Team (TCST) to produce a suite of documents focusing on improving the psychosocial support for people affected by cancer in London. The pathway, principles and recommendations in this report, emphasise the importance of keeping the needs of the patient front and centre so that services are responsive and flexible whenever a person affected by cancer needs support. The pathway includes services across the whole pathway from diagnosis, through acute treatment, cancer rehabilitation, living with and beyond cancer and end of life care. The original document published in 2018 has provided a valuable resource and guidance to the model that we are developing in South West London to deliver and improve cancer psychosocial support and reduce unwarranted variations in care across the Sustainability and Transformation Partnership (STP).

Across South West London, we have used the guidance and recommendations to support our development of a whole system model for cancer psychosocial support, with the aim of highlighting the critical role of primary care, Improving Access to Psychological Therapies (IAPT) services, and Psycho-oncology teams in delivering the best clinical outcomes for our patients. No one service alone can deliver all the necessary interventions. We are striving to achieve a more consistent service and equitable access to cancer psychosocial support across SW London and believe that there are significant benefits to patient experience and ultimately to patient outcomes and quality of life.

What the guidance document offers the London cancer system are clear guidelines on how a truly integrated approach can make a difference, including clarity on the referral criteria for both IAPT services and Psycho-oncology teams as well as encouraging service providers to work more collaboratively, sharing expertise and ultimately improving clinical outcomes, patient experience and quality of life for those affected by cancer. There has been considerable stakeholder engagement and the pathway model outlined in this document has been co-designed with the perspective of commissioners, service providers and service users very much in mind.

During 2020/21, the NHS England 'Quality of life' (QoL) metric will be rolled out nationally and for cancer, this will include a focus on psychological well-being. This further provides the impetus for local systems to consider how to better meet the psychosocial needs of people with cancer through improving access and reducing variation.



I welcome the work of the TCST, in partnership with Macmillan Cancer Support, in having engaged with a broad range of stakeholders in arriving at clear recommendations for improving psychosocial support for people affected by cancer across London. The clear message is that we need a whole system approach to addressing inequality and unwarranted variations in care as a priority across London. This report provides the impetus to improve the psychological well-being and quality of life for Londoners affected by cancer.

**Dr Philippa Hyman, Macmillan Mental Health Clinical Lead and Clinical Psychologist, Transforming Cancer Services Team (TCST), London.**



I have worked as a Clinical Psychologist for 20 years. My NHS experience has included working with both children and adults across the life span within health settings, community mental health teams, primary care services, acute hospital services and within both physical health and mental health inpatient wards. I have worked with people affected by long-term conditions, including cancer in both clinical and research capacities. I have also experience of working closely with service users and the third sector and understand how valuable these partnerships can be in improving clinical outcomes. This has enabled me to look at the whole system and the whole pathway. I was delighted to be given the opportunity, funded by and in partnership with Macmillan Cancer Support, to work with the TCST to develop *Commissioning recommendations, pathway and a service specification for psychological Support for Adults with Cancer* which was published in May 2018.

Since the publication of this document, there have been several positive developments across London which have resulted in the development of new psycho-oncology posts and teams which will deliver improved clinical outcomes, patient experience and quality of life. Additionally, the London Integrated Cancer Psychosocial Care Pathway has been localised in several CCGs and STPs in London ensuring that there are clearer referral pathways, better coordinated services, increased collaboration across settings, delivering improved, integrated psychologically informed cancer care.

Ambitious plans by NHS England to improve care and support for people once their treatment ends has led to the new national 'quality of life metric' which will be incorporated into the national cancer dashboard from June 2020. For the first time, there will be a measure which will capture how effective cancer support is and where service improvements may be required. Psychological well-being is a component of

this metric and ensuring that the psychological and emotional needs of people affected by cancer, their families and carers are addressed will be a core component of any quality of life measure. This should be an important driver for real system change in relation to improving cancer psychosocial care across London.

This refreshed guidance document will support commissioners in London to examine their current psychosocial support services for adults affected by cancer, their families and those significant to them. It covers the time from diagnosis, during treatment in acute hospitals, within primary care and across community services through to long-term survivorship and end of life care. Partnership working between commissioners, service providers across the pathway, third sector organisations and service users needs to ensure that we deliver the best possible care for Londoners.

## Executive Summary

Cancer and its treatments have the potential to significantly impact on mental health, physical health and socio-economic status in multiple ways, not least by disrupting relationships, finances and employment. Most people will use a variety of resources to cope including their own inner emotional resources, the guidance of trusted healthcare professionals and external support systems such as family, friends, peer networks and third sector organisations.

But for some people where there may be additional social and psychological adversity, these resources may be insufficient to manage the personal impact of cancer and distress, dysfunction and poor health self-management may follow having a significant impact on the person's quality of life and on the lives of their families and carers. Additionally, psychological obstacles if not addressed, can impact on a person accessing tests, investigations, treatment adherence, engaging with rehabilitation and ultimately impact upon clinical outcomes.

- In the year following diagnosis, around 10% of patients will experience symptoms of anxiety and depression severe enough to warrant intervention by specialist psychological/psychiatric services. Among those who experience recurrence of disease, the prevalence of anxiety and depression rises to 50%. Such difficulties can also be seen in 10-15% of patients with advanced disease<sup>1</sup>
- 58% of people diagnosed feel their emotional needs are not looked after as much as their physical needs<sup>2</sup>
- Cancer patients have a 55% higher risk of suicide than those without cancer<sup>3</sup>
- Even 10 years after treatment, 54% of cancer survivors still suffer from at least one significant psychological issue<sup>4</sup>
- 67% of carers experience anxiety and 42% experience depression. Of these, over three quarters do not receive any support<sup>5</sup>

The experience of cancer and its longer term physical and psychological consequences can also have a significant economic cost.

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<sup>1</sup> National Institute for Health and Care Excellence, *Guidance on Improving Supportive and Palliative Care for Adults with Cancer* (2004). Available here: <https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005>

<sup>2</sup> Macmillan Cancer Support, *Worried sick: the emotional impact of cancer* (2006). Available here: [https://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/impact\\_of\\_cancer\\_english.pdf](https://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/impact_of_cancer_english.pdf)

<sup>3</sup> Calati, R., Di Mattei, V. and Courtet, P, *Risk of suicide mortality among cancer patients: A meta-analysis of observational studies*. (2017) *European Psychiatry*, 41, pp.S290-S291. Available here: <http://www.europsy.net/wp-content/uploads/2017/03/cancersuicide.pdf>

<sup>4</sup> Healthy London Partnership, *Cancer Rehabilitation: a scoping report for London* (2016). Available here: <https://www.healthylondon.org/wp-content/uploads/2017/11/Cancer-rehabilitation-a-scoping-report-for-london.pdf>

<sup>5</sup> Macmillan Cancer Support, *Worried sick: the emotional impact of cancer* (2006). Available here: [https://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/impact\\_of\\_cancer\\_english.pdf](https://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/impact_of_cancer_english.pdf)

- Healthcare costs for people with long-term conditions are 50% higher in people with depression and/or anxiety disorders.
- Psychological therapy reduces physical healthcare costs by an average of 20% (meta-analysis of 91 studies). When data is available on cost of psychological treatment and physical healthcare, savings exceeds costs<sup>6</sup>

The publication of the NHS England 'Long Term Plan' (LTP)<sup>7</sup> outlined how both cancer and mental health are strategic priorities for NHS England. **The London integrated system model for Cancer Psychosocial Care outlined in this guidance document is about ensuring that people affected by cancer experience psychologically informed care at every point along the cancer pathway.**

The underlying principles for cancer psychosocial care aligns with the key themes outlined in the NHS Long Term Plan. These include an emphasis on integration, more joined up/coordinated care, services being more proactive, boosting 'out of hospital care', carers receiving greater recognition and support and a focus on "shared responsibility for health" with support being provided across the whole pathway to help people manage both their physical and mental well-being. The pathway is also an important aspect in delivering the specific goal of the NHS Long Term Plan that every person with cancer should have access to personalised care, including a needs assessment, care plan and health and well-being information and support, by 2021. Furthermore, at the heart of this work has been the NHS Long-Term Plan's goal of more action needed to focus on "reducing health inequalities and addressing unwarranted variation in care".

Additionally, implementing the cancer psychosocial support pathway aligns with the quality of life agenda. The LTP ambition is that "from 2019 we will begin to introduce an innovative quality of life metric...to track and respond to the long-term impact of cancer". Work is underway within the National Cancer programme to develop a 'Quality of Life' metric which will be measured on the National Cancer Dashboard. This will capture whether a patient has had their psychosocial care needs met allowing this vital component of patient experience to be routinely recorded in the national database and used to inform care delivery. The final tool is expected for rollout in 2020.

The aim of this work by the Transforming Cancer Services Team (TCST) for London, funded and in partnership with Macmillan Cancer Support over the last three years, was to produce a document with comprehensive recommendations, including both a

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<sup>6</sup> Layard, R & Clark, D.M, Thrive: *The Power of Evidence-Based Psychological Therapies* (2014).

<sup>7</sup> NHS England, *Long Term Plan* (2019). Available here: <https://www.longtermplan.nhs.uk/>

pathway and service specification, to enable commissioners to improve the commissioning of psychological support services for people affected by cancer pan-London. The guidance document published in May 2018, *The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer*<sup>8</sup>, followed on from the psychological support for people living with cancer guidance document published in 2015<sup>9</sup>.

The 2018 guidance document, which outlined what cancer psychosocial support was already being commissioned, set out the key components of a psychosocial care pathway and provided recommendations for improving care has been impactful in London and has resulted in:

- Significant and ongoing engagement across London between commissioners, service providers (across primary and secondary care), service users and the third sector with the shared goal of improving psychosocial support across the cancer pathway.
- The London Integrated Pathway for Cancer Psychosocial Support (see figure 6) being localised and used as a tool to map local service provision, encourage closer collaboration across local pathways between Improving Access to Psychological Therapies (IAPT) services, Primary care teams and psycho-oncology teams and identify gaps in provision and next steps.
- The commissioning of new psycho-oncology services within the largest STP in London and the development of other posts where gaps had been identified from the original mapping data (November 2017)
- Clear referral criteria being established across the pathway to ensure that those affected by cancer will receive the most appropriate psychosocial support at the right time and in the right place.
- TCST providing bespoke support to STPs in London to address inequity of provision and reduce unwarranted variations in care.

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<sup>8</sup> Healthy London Partnership, *The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer* (2018). Available here: <https://www.healthylondon.org/wp-content/uploads/2018/05/Psychological-support-for-people-affected-by-cancer-May-2018.pdf>

<sup>9</sup> London Strategic Clinical Networks, *Psychological support for people living with cancer Commissioning guidance for cancer care in London* (2015). Available here: <http://www.londonscn.nhs.uk/wp-content/uploads/2015/06/mh-cancer-commissioning-guide-062015.pdf>

- The London Integrated Pathway for Cancer Psychosocial Support being presented both nationally and internationally
- TCST being consulted with both within London and outside of London to share knowledge and expertise regarding how to implement the pathway locally.
- All 5 STPs in London identifying, as part of their responses to the Long Term Plan, that further work is needed to improve cancer psychosocial support in line with access to the high quality personalised care agenda and with consideration of the roll out of the Quality of life (QoL) metric in 2020.

There has been considerable progress in London since the publication of the original guidance document but there is still more work needed. This document is a refreshed and updated version of the 2018 guidance document and focuses on what should be best practice in commissioning the psychosocial care that is required across the healthcare system to deliver optimal clinical outcomes, prevent and address distress, improve patient experience and quality of life for people affected by cancer (patients and those significant to them). This includes services across the whole pathway: from diagnosis, through acute treatment, living with and beyond cancer and end of life care.

This document should be read alongside the:

- Pan-London Mapping of Psycho-oncology Services (2020)
- Business case – Improving psychologically informed cancer care: implementing the London Integrated Cancer Psychosocial Care Pathway and the development of psycho-oncology services (2020)
- Service specification for psycho-oncology services (2020).
  - All of the above are available here:  
<https://www.healthylondon.org/psychosocial-support/>

The document:

- Provides a high-level overview of the range and complexity of psychological factors that affect the treatment, well-being and recovery of people living with and beyond cancer

- Clearly sets out the key components of an integrated cancer psychosocial support system, what excellent services should look like and how this can be achieved in practice
- Outlines next steps and how the recommendations can be implemented across London

Recommendations in this report have been based on a wide range of data and consultation including:

- Key documents and national drivers
- Mental health and Cancer Task and Finish group which met 6 times between January and December 2017 and the Psychosocial support and Cancer Steering group who met bi-monthly from January 2018-December 2019.
- 3 successful stakeholder events in [May](#) and [October 2017](#), and [May 2019](#), with excellent representation across the whole pathway including GPs, primary care workers, secondary care providers, the third sector, service users and commissioners as well as across all STP areas in London.
- A series of meetings between Improving Access to Psychological Therapies (IAPT) and Psycho-oncology leads. Engagement and presentations to the London IAPT Leads Clinical and Strategic Reference Groups (July 2018 and July 2019)
- Meaningful service user involvement throughout the process via focus groups, qualitative interviews, participation in stakeholder events and the steering group
- Consideration of the 2019 TCST Cancer Inequalities toolkit, available here: <https://www.healthylondon.org/resource/cancer-inequalities-toolkit/inequalities-toolkit/>
- National Patient Experience Survey NPES (2018), available here: <https://www.healthylondon.org/our-work/cancer/patient-experience-survey/>
- Modelling of needs based on prevalence data for London – see 2017 prevalence dashboard available here: <https://www.healthylondon.org/resource/2017-cancer-prevalence-dashboard/>
- Alignment with other TCST workstreams e.g. cancer rehabilitation (see 2019 integrated system guidance here: <https://www.healthylondon.org/wp->



[content/uploads/2019/07/A-guide-to-reducing-variation-and-improving-outcomes-in-cancer-rehabilitation-in-London.pdf](https://content/uploads/2019/07/A-guide-to-reducing-variation-and-improving-outcomes-in-cancer-rehabilitation-in-London.pdf)) and other Healthy London Partnership workstreams e.g. Mental Health.

The 12 recommendations made in the 2018 guidance document have been updated following ongoing stakeholder feedback from service providers, service users and commissioners across London, as well as national drivers such as the NHS Long Term Plan<sup>10</sup> and the Personalised Care agenda<sup>11</sup> which had not been launched prior to the last guidance document.

The recommendations have been separated into three broad categories which align with the pathway (see figure 6) i.e. universal, enhanced and specialist support.

## Recommendations

### Universal Support

**1. STPs /System leaders/Commissioners need to take a ‘whole system’ approach to identifying and providing a comprehensive network of psychosocial support, with clear and flexible referral pathways and processes, which are understood by professionals and service users. The London Integrated Cancer Psychosocial Care pathway should be adopted and localised by CCGs and STPs (in the context of developing Integrated Care Systems and Primary Care Networks) to identify gaps in psychosocial support and promote collaborative practice across the pathway.**

Feedback from stakeholders across London, including service providers, commissioners and service users, has shown that the Integrated pathway (see figure 6) is an extremely useful tool and has already been adopted and localised within several CCGs and STPs in London. Focus continues to be on the importance of having the patient at the centre of the pathway, with support and access based on individual psychosocial need, not just where the person is on their cancer pathway.

It is recommended that, where needed, to optimize local delivery and partnership working, that small working groups are established, to map local resources, identify gaps and address these gaps when required. These working groups (including representation from primary care, IAPT, and psycho-oncology teams) will result in better collaborations, sharing of skills and expertise and ultimately better clinical outcomes, patient experience and quality of life for people diagnosed with cancer and those significant to them.

<sup>10</sup> NHS England, *Long Term Plan* (2019). Available here: <https://www.longtermplan.nhs.uk/>

<sup>11</sup> Further details available here: <https://www.england.nhs.uk/personalisedcare/>



## **2. Improving psychologically minded cancer care across the whole pathway will make a significant difference to clinical outcomes, patient experience and quality of life for all Londoners affected by cancer.**

A key message from service users is that people affected by cancer, including their families, carers and those significant to them, should be able to expect all staff with whom they have contact, to have a basic understanding of their psychological needs. This also includes not considering their physical health needs and psychological needs as separate.

Additionally, universal psychologically informed care can be improved with the following simple steps:

- focusing on effective communication and good partnership working between all staff across the whole pathway (for example Holistic Needs Assessments including care plans and Treatment summaries (TS) being shared with patient and GP)
- patients, families and carers being communicated with compassionately by all staff
- high quality, holistic cancer care reviews (CCRs) taking place within primary care (see TCST 4 point model available here: <https://www.healthylondon.org/resource/commissioning-and-delivery-toolkit-for-cancer-as-a-long-term-condition/>)
- prompt efficient and reliable appointment systems and reporting processes in place across the whole pathway
- robust safety netting and follow-up in primary care
- early identification of who may need extra support (e.g. by asking about bereavement and past losses, by having a thorough knowledge of current or past mental health issues, being aware of social isolation and socio-economic deprivation)
- p/rehabilitation services being offered to all
- Supporting self-management across the pathway

## **3. People affected by cancer need to be involved in shared decision-making and be empowered to take control of their own health and psychological well-being wherever possible.**

The Healthy London Partnership document, Steps towards implementing self-care<sup>12</sup>, identified that all five STPs in London have referenced self-care, prevention and

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<sup>12</sup> Healthy London Partnership, *Steps towards implementing self-care: A resource for local commissioners* (2017). Available here: <https://www.healthylondon.org/wp-content/uploads/2017/10/Steps-toward-implementing-self-care-June-2017.pdf>

social prescribing as a means of implementing person and community centred approaches. Patients want to be empowered to make informed choices in managing their own health, wellbeing and care. Shared decision making will require a culture shift to ensure “care planning and self- management is hard-wired into how care is delivered”, especially in relation to how long-term conditions such as cancer are managed<sup>13</sup>. Enablers of self-care involve a focus on patient activation/self-efficacy, improving health literacy and culture change and training within the workforce across the whole pathway.

#### **4. The significant differences in patient experience of cancer care, across several domains for marginalised and disadvantaged groups in London, must be addressed**

Patients from the most deprived areas of London report worse experiences than those from the least deprived in almost all aspects of care and this situation has not significantly improved in London over recent years. Cancer patients from minority ethnic groups have poorer experiences of cancer services than those who identify as white, on almost all aspects of care<sup>14</sup>. It is recommended that those providing psychosocial support use the TCST health inequalities toolkit, which is available here: <https://www.healthylondon.org/resource/cancer-inequalities-toolkit/>. It is further recommended that those providing psychosocial support also consider the Minimum Data Set as set out in the 2019 Integrated Care System Guidance for Cancer Rehabilitation (available here: <https://www.healthylondon.org/wp-content/uploads/2019/07/A-guide-to-reducing-variation-and-improving-outcomes-in-cancer-rehabilitation-in-London.pdf>) and how it can be adapted locally in order to benchmark services and ensure that health equity is considered in relation to access, acceptability and quality of services.

#### **5. The roll-out of the NHS England ‘quality of life’ (QoL) metric in 2020, which explicitly includes psychological well-being, provides a driver to ensure that psychosocial care is prioritised and effectively addressed across all STPs in London (including across Primary Care Networks and Integrated Care Systems)**

Given the impact of the physical health consequences of cancer and its treatment, mental health and social factors on quality of life, prioritising cancer rehabilitation and

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<sup>13</sup> Healthy London Partnership, *Steps towards implementing self-care: A resource for local commissioners* (2017). Available here: <https://www.healthylondon.org/wp-content/uploads/2017/10/Steps-toward-implementing-self-care-June-2017.pdf>

<sup>14</sup> Macmillan Cancer Support (2017) Mind the Gap, Cancer Inequalities in London [https://www.macmillan.org.uk/images/4057%20MAC%20Report%202017\\_tcm9-319858.pdf](https://www.macmillan.org.uk/images/4057%20MAC%20Report%202017_tcm9-319858.pdf)

psychosocial support across the pathway will be essential to ensure that quality of life improves for all Londoners affected by cancer.

**6. STPs and Alliances should actively signpost people affected by cancer to the Cancer Care Map, and ensure any relevant local online resources, where they exist, are regularly updated in line with the Cancer Care Map. STPs and Alliances should also ensure that all professionals across the pathway, especially community navigators, social prescribers and cancer keyworkers, access the Cancer Care Map, as well as the Cancer Information and Support Centres where needed. Additionally, STPs and Alliances need to ensure that the Cancer Care Map is kept up to date, by notifying of any changes to local services.**

The Cancer Care Map is available here: <https://www.cancercaremap.org/>. The map signposts to services across the UK, including those which focus on emotional support, health and wellbeing and practical concerns. Additionally, there are now 32 Cancer Information and Support Centres identified across London. Information and sign-posting, especially when personalised to the needs and preferences of the individual can have a significant positive impact on reducing anxiety and improving emotional well-being.

Many service users report that they had found out about services themselves and let their health professionals know about them. They identified that information provision and sign-posting, for example to third sector organisations and online support, can have a vital role in enabling people to access support early. This can have a powerful, preventative effect and impact on promoting psychological adjustment. Access to peer support was considered particularly valuable.

*“I found support out there myself. No-one told me. If I’d been directed to stuff earlier, I would have accessed it earlier which would have really helped”.*

## Enhanced Support

**7. To deliver personalised care as outlined in the NHS Long Term Plan, the psychosocial needs of the patient and those significant to them must be identified and reviewed at numerous points along the pathway. Personalised Care (PC) interventions remain important; within primary care in London, the Cancer Care Review 4-point model<sup>15</sup> needs to be seen as an opportunity to assess and record psychosocial needs and the emotional impact of cancer.**

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<sup>15</sup> Healthy London Partnership (2018) *Commissioning and delivery toolkit for cancer as a long-term condition*. Available here: <https://www.healthylondon.org/resource/commissioning-and-delivery-toolkit-for-cancer-as-a-long-term-condition/>

**Within acute settings, person-centred Holistic Needs Assessments (HNAs) and treatment summaries (TS) should provide similar opportunities. Health and Well-being information and Support must also be tailored to the person affected by cancer. If these interventions are delivered effectively this should prevent distress, promote adjustment and improve outcomes for patients.**

Meaningful evaluation should be planned to examine not just output (for example how many holistic needs assessments (HNAs) or cancer care reviews (CCRs) are completed) but actual impact on quality of life, follow up care, patient experience, and emotional well-being. If primary care teams (and patients) do not receive a treatment summary, this needs to be addressed and be seen as:

- a likely contributor to increasing patient anxiety
- having a negative impact on the ability of primary care teams to provide excellent patient care.

2018 eHNA data demonstrated that worry, fear or anxiety is the most reported concern across all age ranges. Interestingly, despite the wide range of psychosocial needs identified by the e-HNA, only 32.8 % of people received a care plan across all cancer types<sup>16</sup>. This indicates that even when needs are assessed and identified, this does not always result in the necessary action and support being offered.

**8. Psycho-oncology teams should take the lead in sharing their clinical expertise, providing training and consultation to all professionals working with people affected by cancer, their families and carers across the whole pathway, including acute, primary care and community settings.**

Clinical Nurse Specialists (CNSs) and Allied Health Professionals (AHPs) play a vital role in delivering a range of effective psychosocial interventions. Ongoing training and supervision from psycho-oncology teams, as indicated in NICE guidance<sup>17</sup>, must be prioritised to support this workforce in delivering the personalised care agenda, to improve staff retention and satisfaction and reduce staff burnout.

Improving Access to Psychological Therapies (IAPT) services for long-term conditions must work closely with psycho-oncology services when developing pathways for cancer to ensure clarity regarding local clinical criteria for referral and allocation and to address workforce education and training needs. Several psycho-

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<sup>16</sup> *Cancer Stats Dashboard*. Available here: <https://cancerstats.ndrs.nhs.uk/user/login>

NB. At the time of publication, the eHNA data provided via the Cancer Stats portal is limited. More detailed data outlined above is provided by the RM Partners Analytics team. For more information, please contact: [rmpartners.info@nhs.net](mailto:rmpartners.info@nhs.net)

<sup>17</sup> National Institute for Health and Care Excellence (2004) *Guidance on Improving Supportive and Palliative Care for Adults with Cancer*. Available here: <https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf773375005>

oncology leads in London have successfully delivered training on working with cancer for the IAPT long-term conditions workforce.

GPs and primary care staff are often the key point of contact for someone with cancer and this is especially the case with the increasing numbers of people living with cancer as a long-term condition or those experiencing the psychological consequences of cancer and its treatment. Psycho-oncology teams have a vital role in sharing expertise to improve the psychologically informed cancer care offered within primary care.

## Specialist Support

### **9. All acute hospitals where cancer is diagnosed and treated should have access to psycho-oncology teams, who are uniquely positioned as cancer specialists with expertise in psychological and mental health.**

Psycho-oncology teams work with a full range and severity of psychological and mental health difficulties associated with cancer. These teams play a vital role in both cancer prehabilitation and rehabilitation in supporting patients to access cancer investigations, treatment and post-treatment care thus improving patient experience and outcomes. They offer highly specialist clinical care for inpatients during medical admission and outpatients, as well as input for families and carers.

Psycho-oncology teams provide highly specialist 'indirect' services including rapid access to complex case consultation, supervision for Level 2 workers, for example, Clinical Nurse Specialists (CNSs) and Allied Health Professionals (AHPs) to fulfil peer review requirements<sup>18</sup>. Peer review requirements are still considered a useful framework by services to ensure high quality service delivery. These teams contribute psychological evidence and insights to quality improvement projects. There is a crucial role for psychologists with cancer expertise, embedded within cancer pathways, in addressing end of life psychological issues by facilitating important conversations and decision making with treating clinicians and families.

There should be access to a range of professional disciplines within psycho-oncology teams. There should be appropriate access to liaison psychiatry (preferably with oncology expertise) for both cancer inpatients and outpatients when needed to ensure an integrated service delivery and the best clinical outcomes. This avoids disjointed and unnecessary referral to already overstretched generic community mental health teams.

GPs, primary care professionals and community teams across the whole pathway should be able to easily access the expertise from psycho-oncology teams, thus

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<sup>18</sup> NHS England (2011) *National Cancer Peer Review Programme Manual for Cancer Services: Psychological Support Measures*

improving patient experience and outcomes for all those affected by cancer as well as their families and carers.

### **10. Acute and Community Palliative care services should include access to psychological specialists capable of delivering a range of interventions including domiciliary visits.**

Recent mapping of psycho-oncology provision across London, including cancer palliative care (available [here](#)), demonstrates that there is significant inequity and unwarranted variations in access to psychological interventions within both acute and community palliative care services. Additionally, there are issues around equity of access to services when they are available. Ability to get to a clinic should not determine whether a person can access a service. Domiciliary visits must be available by psychological specialists when indicated.

Furthermore, bereavement services must be clearly available to enable families and carers to access timely support, irrespective of where their loved one dies. Currently, whether their loved one dies at home, in hospital or within a hospice setting determines what bereavement support services are available. Ambitions for Palliative and End of Life Care<sup>19</sup> recognised the importance of involving, supporting and caring for those important to the dying person by delivering “good bereavement and pre-bereavement care”. Bereavement services are currently not clearly commissioned across London resulting in an inequity of provision, but these services must be considered an essential part of the support system.

## **Integrated Support**

### **11. Integrated cancer psychosocial care requires dedicated leadership and a dedicated platform within the relevant governance structures (STPs/Alliances/Integrated Care Systems/Primary Care Networks). This will drive and facilitate the collaborative work between professionals across acute, primary care and community services and between physical, mental health and social care, which is needed to improve outcomes for patients.**

The King’s Fund document ‘Bringing together physical health and mental health’<sup>20</sup> emphasises that the needs of an individual “are met in a co-ordinated way with medical, social and psychological needs being addressed together”.

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<sup>19</sup> National Palliative and End of Life Care Partnership (2015) *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*. Available here: <http://endoflifecareambitions.org.uk/>

<sup>20</sup> Kings Fund (2016) *Bringing together physical and mental health: A new frontier for integrated care*. Available here: <https://www.kingsfund.org.uk/publications/physical-and-mental-health>



Psycho-oncology leads across trusts should establish a networked group to act as a source of expertise and a conduit for London wide developments. The networked group should have representation at the London Personalised Care for Cancer Board (there is currently psycho-oncology representation on this board but not from a networked group) and consideration should also be made to having a psycho-oncology lead on the London Cancer Transformation and Improvement Board (CTIB). It is also recommended that STPs have a named psycho-oncologist on their cancer boards and on their personalised cancer care boards. Given that screening uptake, engaging in tests and investigations, treatment adherence, prehabilitation and rehabilitation, patient experience and quality of life are all mediated by psychosocial variables, it makes sense for there to be representation from psycho-oncology on a London regional programme board and at STP level.

### Next Steps

Please note that from April 2020, TCST is no longer being funded or commissioned to support the delivery of the recommendations outlined in this report. Therefore, for the momentum to continue across London in improving psychologically informed cancer care, cancer alliances and STPs will need to prioritise this work and take the necessary steps to move this agenda forward. Additionally, where Macmillan Cancer Support fund existing psycho-oncology services, timely work will be needed with commissioners to future proof these services.

### For system leaders/commissioners

System leaders/Commissioners are asked to:

- a) Adopt the proposed London Integrated Cancer Psychosocial Care Pathway.
- b) Localise the pathway by mapping current resources, supporting partnership working and identifying gaps at STP/ICS level.
- c) Where there are no or very limited Psycho-oncology teams, allocate sufficient resource to ensure a Psycho-oncology service is available to deliver the outcomes indicated in the pathway (including closer working partnerships across Primary Care and Improving Access to Psychological Therapies (IAPT) services).
- d) Ensure that the commissioning recommendations outlined in this document are referenced in Sustainability and Transformation Plans (STPs) and that psychosocial support from diagnosis, through treatment, living with and

beyond cancer and end of life care (across the whole pathway including acute, primary care and community services) is reviewed. It will require commissioners to work closely and collaboratively with their provider colleagues and service users and to take a 'whole system' approach.

- e) Ensure that successful integration of physical health and mental health support for those affected by cancer across the pathway can be achieved by overcoming barriers such as separate budgets, payment systems and contracting arrangements.
- f) Consider how cancer psychosocial support can become embedded within the context of system reconfiguration such as Integrated Care Systems and Primary Care Networks.

### For providers

- g) Providers to review their current pathways and service provision in order to work collaboratively with their peers and commissioning colleagues, within integrated care systems, to help achieve the objectives outlined above.
- h) Ensure that they systematically capture a minimum data set that will enable them to complete health equity assessments and service improvements. This data set should also be able to demonstrate outcomes, productivity, challenges of meeting unmet needs and incorporate a wide range of quantitative and qualitative data needed to develop business cases.

### For alliances

- i) Consideration of the governance arrangements at STP and Alliance level to ensure that there is Psycho-oncology representation whenever decisions are being made regarding psychologically informed cancer care and developing and improving cancer psychosocial support.

### For others

- j) The third sector to work with the NHS and social care to ensure that the Cancer Care Map is kept up to date to reflect an accurate view of emotional support service provision on a local level.
- k) The third sector to work with the NHS to help support awareness raising and education on psychological care within the wider workforce.



## Key resources

This guidance report should be considered alongside:

- Pan-London Mapping of Psycho-oncology Services Report (2020) (available here: <https://www.healthylondon.org/psychosocial-support/>)
- Business case - 'Improving psychologically informed cancer care: implementing the London Integrated Cancer Psychosocial Care Pathway and the development of psycho-oncology services' (2020) (available here: <https://www.healthylondon.org/psychosocial-support/>)
- Service specification for psycho-oncology services (2020) (available here: <https://www.healthylondon.org/psychosocial-support/>)
- Health inequalities toolkit (2019) (available here: <https://www.healthylondon.org/resource/cancer-inequalities-toolkit/inequalities-toolkit/>)
- Commissioning guidance for Cancer Rehabilitation (2019) (available here: <https://www.healthylondon.org/wp-content/uploads/2019/07/A-guide-to-reducing-variation-and-improving-outcomes-in-cancer-rehabilitation-in-London.pdf>)
- National Cancer Patient Experience Survey data (2018) (available here: <https://www.healthylondon.org/our-work/cancer/patient-experience-survey/>)
- Cancer prevalence dashboard (2017) (available here: <https://www.healthylondon.org/resource/2017-cancer-prevalence-dashboard/>)
- Commissioning and delivery toolkit for cancer as a long-term condition (2018) (available here: <https://www.healthylondon.org/resource/commissioning-and-delivery-toolkit-for-cancer-as-a-long-term-condition/>)

The recommendations by TCST in this guidance document will support commissioners to understand better how to deliver psychologically informed cancer care in London, to reflect on their current understanding of cancer psychosocial support services, to benchmark their services against best practice and to provide the best available services for their communities.

*“The role of psychological support in oncology is huge as soon as you put it on a par with the physical aspects of medicine....we wouldn't give people chemotherapy without anti-sickness drugs, so why would we treat someone with a disease which clearly has significant psychological impact, without offering psychological support”*

**Dr Matthew Williams, Consultant Clinical Oncologist, Imperial College Healthcare, NHS Trust.**

# 1. Understanding the psychological impact of cancer

## 1.1 Definition and causes

The World Health Organisation (WHO) defined health in its constitution<sup>21</sup> as: “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. Furthermore, “mental health is defined as a state of well-being in which every individual realises his or her own potential, can cope with the stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community”.

Cancer and its treatments have the potential to significantly impact on mental health, physical health and socio-economic status in multiple ways, not least by disrupting relationships, finances and employment. Psychological distress is a common and understandable response to a diagnosis of cancer, acute treatment and living with and beyond cancer. Most people will use a variety of resources to cope including their own inner emotional resources, the guidance of trusted healthcare professionals and external support systems such as family, friends, peer networks and third sector organisations. Increasingly social prescribing and the arts have demonstrated a significant impact on health and well-being too<sup>22</sup>.

However, the impact of cancer and its treatment may at times overwhelm a person’s available resources and significantly affect the person’s quality of life and the lives of their families and carers. In the year following diagnosis, around one in ten patients will experience symptoms of anxiety and depression severe enough to warrant intervention by specialist psychological/psychiatric services.

It is important to consider the psychological factors in cancer more broadly than narrow diagnostic definitions of clinical anxiety and depression. It is essential to consider the psychological factors that affect uptake of screening and investigations, decision-making and adherence to treatment, or those factors that negatively impact trust and relationships with a healthcare team. Furthermore, it matters that there is understanding of the impact of cancer when a person presents with a current or past history of serious mental health difficulties, significant losses, traumas and early adversity. Consideration of the way that psychological obstacles can impact on whether ‘physical’ cancer rehabilitation is successful is also essential in improving patient outcomes and quality of life.

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<sup>21</sup> World Health Organisation (2006) *Constitution of the World Health Organization*. Available here: <http://www.who.int/about/mission/en/>

<sup>22</sup> All-Party Parliamentary Group on Arts, Health and Wellbeing(2017) *Creative Health: The Arts for Health and Wellbeing (Inquiry Report)*. Available here: [http://www.artshealthandwellbeing.org.uk/appg-inquiry/Publications/Creative\\_Health\\_Inquiry\\_Report\\_2017.pdf](http://www.artshealthandwellbeing.org.uk/appg-inquiry/Publications/Creative_Health_Inquiry_Report_2017.pdf)

Psychological difficulties may be caused by a range of contributing factors both cancer and non- cancer related. Figure 1 shows the range of factors that can contribute to psychological distress.

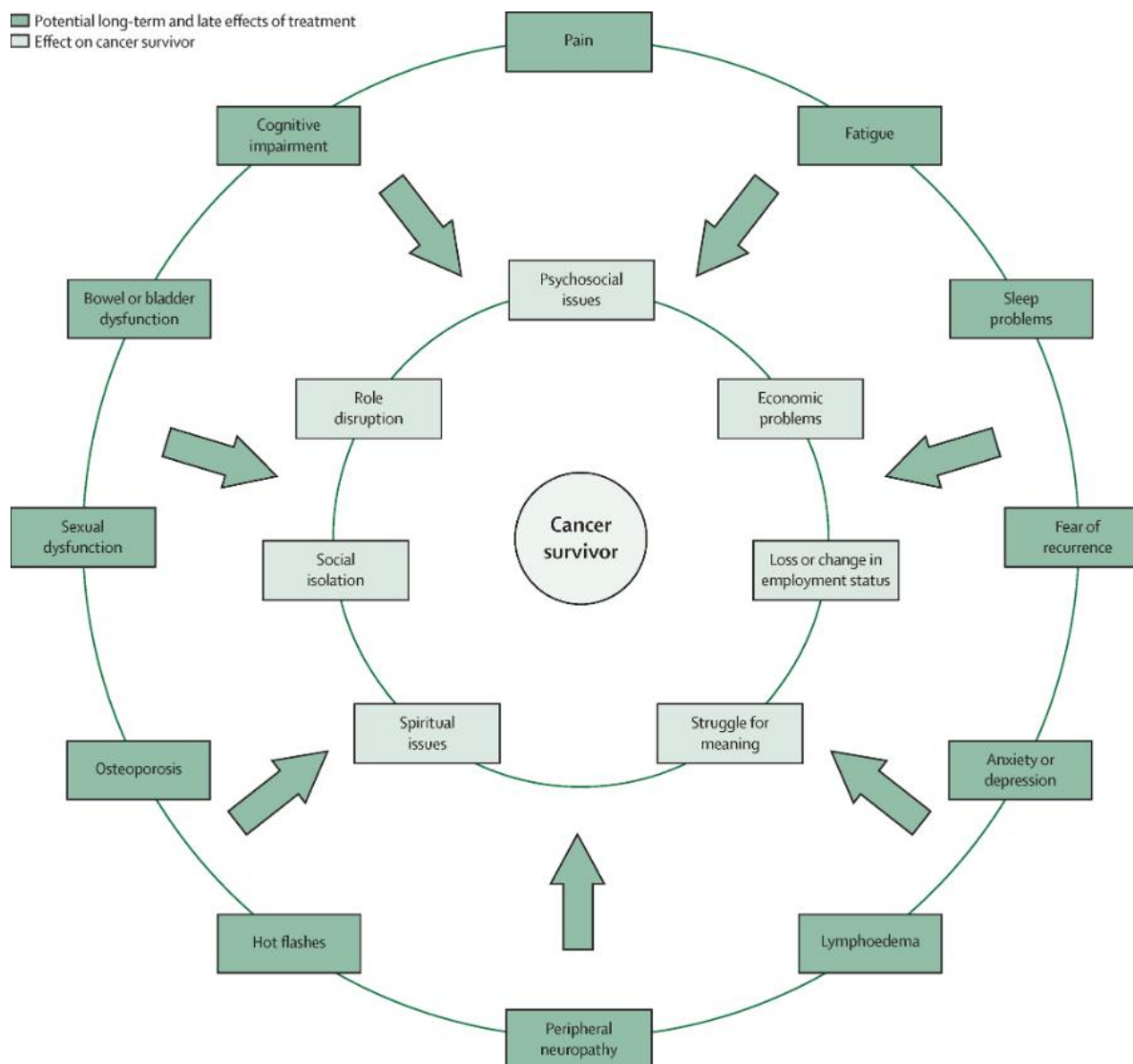


Figure 1: Range of factors that contribute to psychological distress<sup>23</sup>

Psychological difficulties commonly associated with cancer treatment, post-treatment recovery and adjustment include:

- anxiety, including adjustment disorders, generalised anxiety, phobias and panic attacks
- depression ranging from adjustment disorders to severe clinical depression

<sup>23</sup> Jacobs, L.A; Shulman, L (2017) *Follow-up Care of Cancer Survivors: Challenges and Solutions*. The Lancet, 18 (1)

- problems with interpersonal relationships, which may also extend to health and social care professionals
- psychosexual difficulties and body image difficulties
- alcohol and drug-related problems
- personality disorder
- deliberate self-harm
- psychotic illness
- organic brain syndromes (delirium)
- cognitive impairment
- trauma and post traumatic stress disorder

Additionally, the need to identify psychological difficulties affecting families and carers and provide appropriate support, including bereavement work, must be considered alongside the needs of the person with the diagnosis.

## Theoretical assumptions behind the proposed integrated pathway model for London

### *Concept of psychological adjustment to cancer*

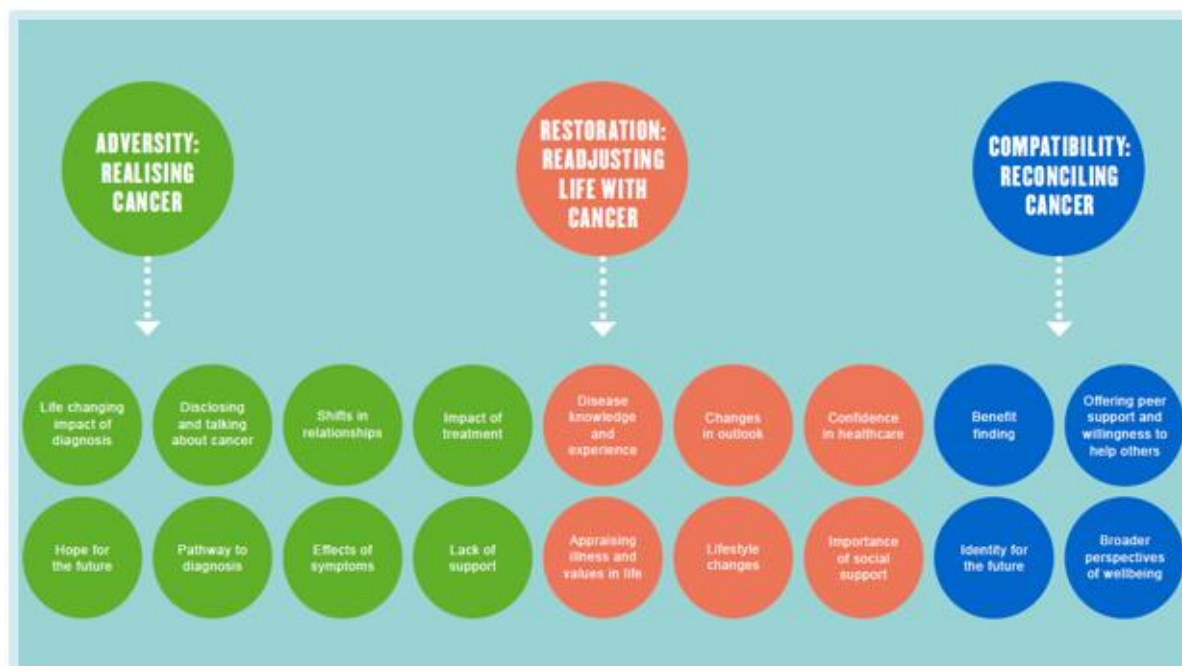
It is important to highlight the theoretical ideas and assumptions that underpin the proposed integrated psychosocial care model for London. The word ‘adjustment’ is commonly used in relation to cancer, but the focus on this concept does not always incorporate the idea that it is an active psychosocial process of change which can include positive as well as negative consequences.

Brennan’s (2001) model<sup>24</sup> of adjustment describes an active process for the individual where the changes precipitated by cancer “are not always for the worse: sometimes they precipitate ‘healthy personal growth’ in a number of areas”. Consideration needs to be given to the potential impact of cancer both positive and negative on: ideas about the future (goal achievement, aspiration, renewed focus versus pessimism, hopelessness), ideas about the self (self-worth, self-confidence, better self-care versus loss of control), ideas about relationships (separation and dependency versus renewed closeness), ideas about the body (fear, shame versus positive changes in health behaviour), and ideas about the world (existential, loss of faith versus renewed purpose).

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<sup>24</sup> Brennan, J., (2001). *Adjustment to cancer—coping or personal transition?* Psycho-oncology, 10(1), pp.1-18. Available here: <https://pdfs.semanticscholar.org/f049/60a5025562e5b2b49b0896de1f84e9f1443e.pdf>

Figure 2 outlines the 'ARC model'<sup>25</sup> which was a framework built from studies of patients' personal experiences. It encapsulates the adjustment process without pathologizing or medicalising the process. There are three distinct but inter-related categories: Adversity (realising cancer), Restoration (readjusting life with cancer) and Compatibility (reconciling).



**Figure 2: The 'ARC' model**

This model is not a linear model but is a clinically useful conceptualisation of cancer lived experience. It encapsulates key experiences reported by people with cancer which have been synthesised into a framework which has already been used for training of Clinical Nurse Specialists and IAPT colleagues.

The model suggests that whilst some people may navigate cancer with minimal change and 'return to normal', for others there will be substantial shift in their identity and 'mental world', resulting in a 'new normal' that will likely involve both gains and losses. The emphasis on a shift in one's mental world is important in terms of service design and what support can most fit for a person affected by cancer. What is clearly important is avoiding a 'one size fits all' approach to psychosocial support (e.g. everyone must attend a support group), or a person can only be referred to a service if their score is above a cut-off on a specific symptom-focused measure. Drawing on the literature, services should be encouraged to maintain a responsive, flexible,

<sup>25</sup> Le Boutiller, C, Archer, S, Barry, C, King, A, Mansfield, L & Urch (2019), *Conceptual framework for living with and beyond cancer: A systematic review and narrative synthesis*, *Psycho-oncology* 2019; 1-12

person-centred approach to support people affected by cancer and those significant to them.

## 1.2. Prevalence and statistics

**Table 1: London region: number of patients who had a diagnosis of cancer and were alive on 31/12/2017<sup>26</sup>**

	London	England
<b>Persons</b>	231,740 (2634.31 per 100,000)	1,953,645 (35,124.87 per 100,000)
<b>Males</b>	104,651 (1189.62 per 100,000)	882,109 (15,859.56 per 100,000)
<b>Females</b>	127,089 (1444.69 per 100,000)	1,071,536 (19,265.3 per 100,000)

Prevalence figures can be used to estimate numbers of patients requiring a service.

For example, based on London prevalence data:

- “In the year following diagnosis, around one in ten patients will experience symptoms such as anxiety and depression severe enough to warrant intervention by specialist psychological/psychiatric services” 7 (Level 4 interventions).
- “15 % of patients will experience mild to moderate distress at any one time within the first year after diagnosis and are likely to benefit from psychological techniques by trained health professionals or specific psychological interventions” (Level 3 interventions).

It should be noted that these are just two modelling examples of psychological need within one year of a cancer diagnosis. It does not take into account psychological needs at other points along a cancer pathway or the needs of families and carers.

<sup>26</sup> Transforming Cancer Services Team/Public Health England and Macmillan Cancer Support (2019) *Cancer prevalence dashboard 1995-2017 in London*. Available here: <https://www.healthylondon.org/resource/2017-cancer-prevalence-dashboard/>

Table 2 illustrates the number of those living with or after a cancer diagnosis in 2017 per London STP.

**Table 2: Numbers of people living with or a cancer diagnosis in 2017 per STP**

STP	Number of people living with or after cancer diagnosis in 2017 (within the last 21 years)
North Central London	39,094
North East London	43,204
North West London	54,268
South West London	45,901
South East London	49, 273

Table 3 illustrates the numbers affected by at least one psychological issue up to ten years after treatment.

**Table 3: Numbers of adults affected by at least one psychological issue up to 10 years after cancer treatment**

		Numbers of adults with at least one psychological issue
STP	North East London	16,540
	North Central London	14,517
	North West London	20,087
	South West London	16,664
	South East London	18,396
Region	London	86,205

It is essential to consider the needs for people affected by cancer at every stage of the cancer pathway including: needs for those within the first year, those living with and beyond cancer, needs for those living with cancer as a long-term condition/living with treatable but not curable cancer, needs for those with advanced disease/at the end of life and the needs of families and carers. For more details please see the *Business Case - Improving psychologically informed cancer care: implementing the London Integrated Cancer Psychosocial Care Pathway and the development of psycho-oncology services* (2020), available here: <https://www.healthylondon.org/psychosocial-support/>



## 2. Background

### 2.1. National context

Every two minutes someone in England will be told they have cancer. Half of people born since 1960 will be diagnosed with cancer in their lifetime<sup>27</sup>. But now more than half of people receiving a cancer diagnosis will live ten years or more<sup>28</sup>. An ageing population combined with increased survival rates means that the number of people diagnosed and living with cancer will continue to grow rapidly, even with improvements in prevention. In 2015 there were approximately 2.5 million people living with and beyond cancer. This is predicted to increase to 4 million by 2030<sup>29</sup>.

Additionally, 70% of people with cancer are also living with at least one other long-term condition; nationally it is estimated that there are 700,000 people are living with cancer and three or more long-term conditions<sup>30</sup>. The psychological impact of cancer needs to be recognised not only at diagnosis and during acute treatment, but for increasing numbers of people who are now living for many years with the consequences of cancer and its treatment.

There is a recognition that for many people cancer should now be viewed as a long-term condition, a vision which was developed by the Transforming Cancer Services Team for London (TCST) and endorsed by the London Cancer Transformation and Improvement Board (formerly the Cancer Commissioning Board) in December 2015.

Macmillan Cancer Support has produced several valuable documents detailing the impact of cancer and its treatment, how this continues to be a neglected area and addressing the mental health, physical health and psychosocial consequences<sup>31</sup>. One of the most recent publications *Treatable but not curable cancer*<sup>32</sup> reported that

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<sup>27</sup> Independent Cancer Taskforce (2015) *Achieving World-Class Outcomes A Strategy for England 2015-2020*. Available here: [https://www.cancerresearchuk.org/sites/default/files/achieving\\_world-class\\_cancer\\_outcomes\\_-\\_a\\_strategy\\_for\\_england\\_2015-2020.pdf](https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf)

<sup>28</sup> Macmillan Cancer Support (2015) *The burden of cancer and other long-term conditions*. Available here: <https://www.macmillan.org.uk/documents/press/cancerandotherlong-termconditions.pdf>

<sup>29</sup> Macmillan Cancer Support (2019) *Statistics fact sheet*. Available here: [https://www.macmillan.org.uk/\\_images/cancer-statistics-factsheet\\_tcm9-260514.pdf](https://www.macmillan.org.uk/_images/cancer-statistics-factsheet_tcm9-260514.pdf)

<sup>30</sup> Macmillan Cancer Support (2015) *The burden of cancer and other long-term conditions*. Available here: <https://www.macmillan.org.uk/documents/press/cancerandotherlong-termconditions.pdf>

<sup>31</sup> See: Macmillan Cancer Support (2006), *Worried sick: the emotional impact of cancer*. Available here: [https://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/impact\\_of\\_cancer\\_english.pdf](https://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/impact_of_cancer_english.pdf)

Macmillan Cancer Support (2013), *Cured, but at what cost?* Available here:

[https://www.macmillan.org.uk/\\_images/cured-but-at-what-cost-report\\_tcm9-295213.pdf](https://www.macmillan.org.uk/_images/cured-but-at-what-cost-report_tcm9-295213.pdf)

Macmillan Cancer Support (2013), *Throwing light on the consequences of cancer and its treatment*. Available here:

<https://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/throwinglightontheconsequencesofcanceranditstreatment.pdf>

Macmillan Cancer Support (2015), *Rich Picture Series*. Available here: <https://www.macmillan.org.uk/about-us/what-we-do/evidence/research-publications/rich-pictures.html>

Macmillan Cancer Support (2017), *Am I meant to be OK Now?* Available here:

[https://www.macmillan.org.uk/\\_images/LWBC-Report-2017\\_tcm9-317400.pdf](https://www.macmillan.org.uk/_images/LWBC-Report-2017_tcm9-317400.pdf)

<sup>32</sup> Macmillan Cancer Support and NCRAS (2019), *Treatable but not curable cancer*. Available here:

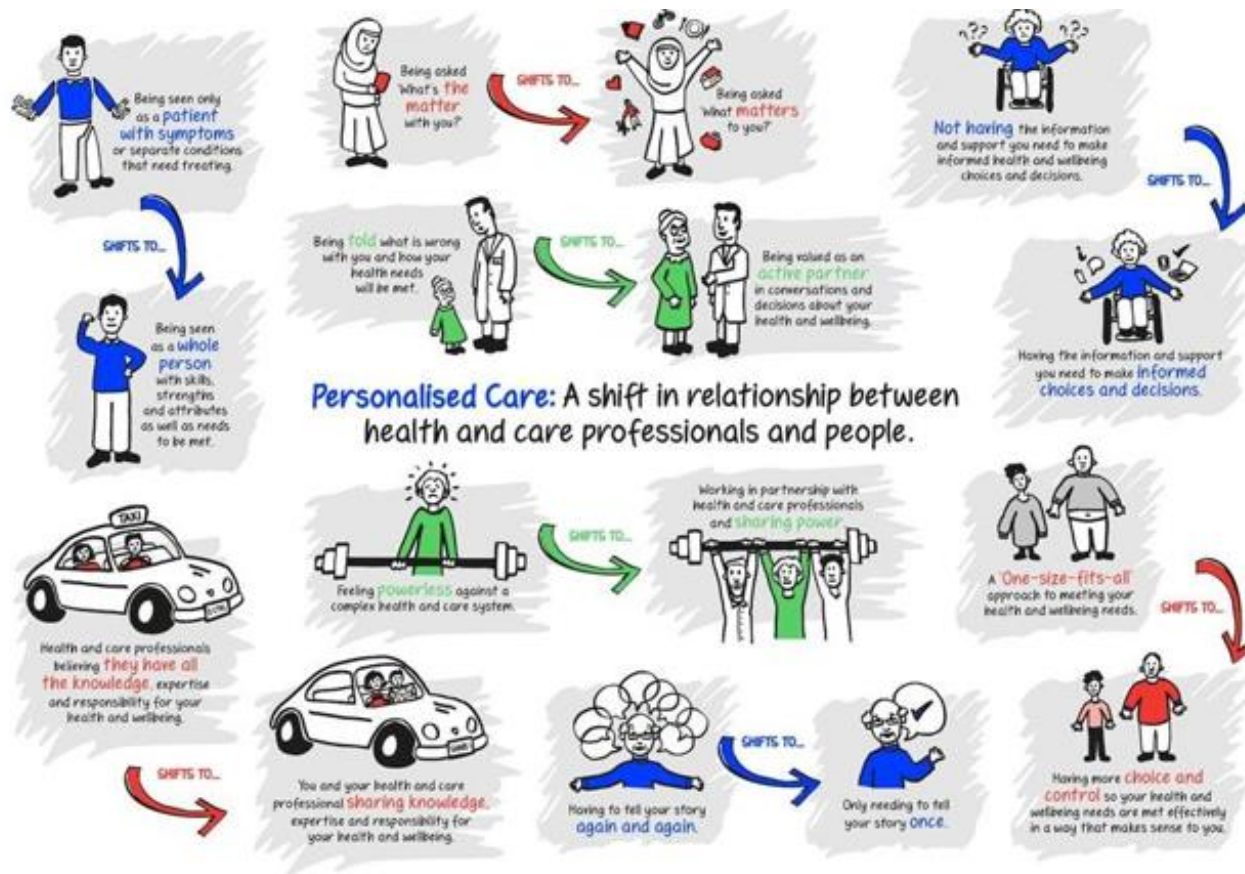
[https://www.macmillan.org.uk/\\_images/tbcn-research-summary\\_tcm9-355791.PDF](https://www.macmillan.org.uk/_images/tbcn-research-summary_tcm9-355791.PDF)

there are at least 136,000 people living with ‘treatable but not curable’ cancer in England, who are more likely to experience worry, fear or anxiety (reported by 58%) due to the unpredictable and uncertain nature of their illness.

Both cancer and mental health are strategic priorities for NHS England, as outlined in the NHS’s Long Term Plan<sup>33</sup>. The proposed integrated pathway model and underlying principles for the delivery of excellent psychosocial support aligns with the Personalised Care Model and the key themes outlined in the NHS Long Term Plan. These include an emphasis on integration, more joined up/coordinated care, services being more proactive, boosting ‘out of hospital care’, carers getting greater recognition and support and a focus on “shared responsibility for health” – support being provided across the whole pathway to help people manage both their physical and mental well-being. The pathway is also an important aspect in delivering the specific goal of the NHS Long Term Plan for every person with cancer should have access to personalised care, including a needs assessment, care plan and health and well-being information and support, by 2021. It also supports the Long Term Plan’s goal of more NHS action needs to focusing on “reducing health inequalities and addressing unwarranted variation in care”. Figure 3 details the personalised care model as outlined by the NHS Long Term Plan.

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<sup>33</sup> NHS England, *Long Term Plan* (2019). Available here: <https://www.longtermplan.nhs.uk/>



This visual is a best practice example by the National Personalised Care team.

Image: Personalised Care Strategic Coproduction Group, 2019

Figure 3: Personalised Care: A shift in relationship between health and care professionals and people

The shift in care as outlined in Figure 3 has the potential to significantly improve clinical outcomes and patient experience for people affected by cancer and would move towards improving psychologically informed practice across the system.

The Five Year Forward View (FYFV)<sup>34</sup> for the NHS also highlighted the importance of shifts in how care is delivered, “the NHS will take decisive steps to break down the barriers in how care is provided between family doctors and hospitals, between physical and mental health, between health and social care”.

The FYFV also noted that long-term health conditions consume 70% of the health service budget.

Following the launch of the National Cancer Survivorship Initiative (NCSI) in 2007<sup>35</sup>, the 2010 NCSI vision<sup>36</sup> and *Living with and beyond cancer: taking action to improve outcomes* (2013)<sup>37</sup>, there is recognition that how well people live, their quality of life, is as important as how long they live for. One of the biggest challenges both nationally and in London is ensuring that improving psychological support for people affected by cancer is given the same attention as support for the physical health difficulties associated with cancer. In recent years, there has been growing recognition of the need to improve the psychological well-being of adults affected by cancer, their families and carers.

A key national driver is the integration of physical health and mental health agenda. Integrated care refers to “the provision of health and care services in such a way that ensures that the various needs of an individual using these services are met in a co-ordinated way, with medical, social and psychological needs being addressed together”.

The King’s Fund report (2016)<sup>38</sup> identifies a number of key messages in order to develop new models of care, including the importance of taking a ‘whole person’ perspective, facilitating skills transfer, supporting a workforce through education with a foundation in physical and mental health, addressing barriers to integration such as

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<sup>34</sup> NHS England (2014), *Five Year Forward View*. Available here: <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

<sup>35</sup> National Cancer Survivorship Initiative (2007) (archived). Available here: <http://webarchive.nationalarchives.gov.uk/20100809103735/http://www.improvement.nhs.uk/cancer/Default.aspx?alias=www.improvement.nhs.uk/cancer/survivorship>

<sup>36</sup> National Cancer Survivorship Vision (2010) (archived). Available here: <http://webarchive.nationalarchives.gov.uk/20100809113601/http://www.improvement.nhs.uk/cancer/LinkClick.aspx?fileticket=4apVUSvGcow%3d&tabid=214>

<sup>37</sup> *Living with and beyond cancer: Taking action to improve outcomes* (March 2013). Available here: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/181054/9333-TSO-2900664-NCSI\\_Report\\_FINAL.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/181054/9333-TSO-2900664-NCSI_Report_FINAL.pdf)

<sup>38</sup> The Kings Fund (2016), *New care models: emerging innovations in governance and organisational form*. Available here:

[https://www.kingsfund.org.uk/sites/default/files/field/field\\_publication\\_file/New\\_care\\_models\\_Kings\\_Fund\\_Oct\\_2016.pdf](https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/New_care_models_Kings_Fund_Oct_2016.pdf)

separate budgets and payment systems by introducing new payment systems and contracting.

The NICE guidance document 'Improving supportive and palliative care for adults with cancer' (2004)<sup>39</sup> remains important in outlining recommendations specific to patient and carer involvement, how psychological services should be arranged, as well as palliative care, rehabilitation services, services for families and carers and workforce development. Although this document has not been refreshed since 2004, the areas addressed in the original document continue to underpin the majority of Psycho-oncology services, especially use of the four levels of psychological assessment and support. Additionally, the national *Cancer Peer Review Programme Manual for Cancer Services: Psychological support measures* (2011)<sup>40</sup> also outlined quality standards, measures, and workforce and service requirements for the delivery of psychological support within hospital settings, which many services continue to use.

The importance of the mental health component of many NICE physical health guidelines for cancer has been identified by the Royal College of Psychiatrists<sup>41</sup>. For example, the NICE guidance for Improving outcomes for people with brain and other CNS tumours<sup>42</sup> emphasises that "psychological assessment and support should be an integral part of the MDT". Additionally, "Neuropsychology and neuropsychiatry services should be adequately resourced to enable the referral of patients who require specialist intervention for cognitive, emotional or behavioural problems". Currently across a wide range of cancer types, NICE recommendations are not being met in relation to psychological support.

Several documents have been published since the original guidance document which have highlighted how essential psychological interventions are across the cancer pathway. For example, Macmillan Cancer Support's report, *prehabilitation for people with cancer*<sup>43</sup> emphasised the vital role psychological interventions, alongside physical exercise and diet, has in improving clinical outcomes, improving resilience

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<sup>39</sup> National Institute for Health and Clinical Excellence (2006), *Improving outcomes for people with brain and other central nervous system tumours*. Available here:

<https://www.nice.org.uk/guidance/csg10/resources/improving-outcomes-for-people-with-brain-and-other-central-nervous-system-tumours-update-27841361437>

<sup>40</sup> National Cancer Action Team (2011), *National Cancer Peer Review Programme: Manual for Cancer Services*. Available here:

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216117/dh\\_12\\_5890.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216117/dh_12_5890.pdf)

<sup>41</sup> Royal College of Psychiatrists (2009), *The Mental Health Content of Physical Health Guidelines*. Available here:

<https://www.rcpsych.ac.uk/pdf/NICE%20and%20SIGN%20mental%20health.pdf>

<sup>42</sup> National Institute for Health and Clinical Excellence (2006), *Improving outcomes for people with brain and other central nervous system tumours*. Available here:

<https://www.nice.org.uk/guidance/csg10/resources/improving-outcomes-for-people-with-brain-and-other-central-nervous-system-tumours-update-27841361437>

<sup>43</sup> Macmillan Cancer Support (2019), *Prehabilitation for people with cancer: principles and guidance for prehabilitation*. Available here: <https://www.macmillan.org.uk/assets/prehabilitation-guidance-for-people-with-cancer.pdf>



to the effects of cancer treatments, enhancing the quality of recovery and quality of life. The recent Anthony Nolan report: *A pathway for post-transplant care*<sup>44</sup> asserted that the psychological needs of patients (and their families) need to be proactively addressed by transplant centres, (influenced by the pathway outlined in this document) with the psychosocial pathway elements of universal, enhanced and specialist support.

In 2008, the NHS Improving Access to Psychological Therapies (IAPT) programme began in England. The programme aimed to implement NICE approved interventions for treating people with anxiety and depression. Initially the programme focused on working age adults but from 2010 was opened to adults of all ages. As there is good evidence that psychological interventions can reduce the cost of physical healthcare<sup>45</sup>, IAPT services have now expanded into providing support for people with long term conditions or medically unexplained symptoms, in what is termed 'Integrated IAPT'. Cancer is now coded as a long-term condition within integrated IAPT services, but has not been a specific area for development as yet. The main focus of interventions remains "to treat the patient's anxiety or depression in the context of their long term condition". There is a comprehensive guidance document, *The Improving Access to Psychological Therapies (IAPT) Pathway for People with Long-term physical health conditions and Medically unexplained symptoms*<sup>46</sup>, which outlines the key principles for implementation. Significant efforts have been made to work closely with IAPT in establishing the cancer psychosocial pathway and referral criteria across the system. Clearer pathways will result in IAPT services receiving more appropriate referrals within the context of cancer.

At a time when early diagnosis and cancer waiting times are being prioritised, it will be essential to ensure that psychosocial support and improved quality of life for all Londoners affected by cancer, is kept high on the agenda. Focusing on extending life needs to be considered within the context of quality of life. The results of the National Cancer Patient Experience Survey (2018)<sup>47</sup> are particularly important in highlighting the key issues that need addressing within acute and community contexts.

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<sup>44</sup> Anthony Nolan (2019), *A pathway for post-transplant care*. Available here:

<https://www.anthonynolan.org/pathway-post-transplant-care>

<sup>45</sup> Chiles, J.A; Lambert, M.J and Hatch, AL (1999) *The impact of Psychological interventions on medical cost offset: A meta-analytic review*. *Clinical Psychology: Science and Practice*, 6(2):204-220. Available here:

<http://psycnet.apa.org/record/1999-03053-005>

<sup>46</sup> NHS England (2018), *The Improving Access to Psychological Therapies (IAPT) pathway for people with long-term physical health conditions and medically unexplained symptoms*. Available here:

<https://www.england.nhs.uk/wp-content/uploads/2018/03/improving-access-to-psychological-therapies-long-term-conditions-pathway.pdf>

<sup>47</sup> Healthy London Partnership (2020), *National Cancer Experience Survey: London*. Available here:

<https://public.tableau.com/profile/transforming.cancer.services.for.london#!/vizhome/NationalCancerPatientExperienceSurvey2018-London/Story1>

NHS England's National Cancer Programme (2016)<sup>48</sup> has several strategic priority areas which may provide an opportunity to drive forward the commissioning of psychological support services:

- A focus on establishing patient experience as on a par with clinical effectiveness and safety
- Future role out of the cancer Quality of Life Metric
- Work on pathway development and integrated care systems (ICSs) which aims to encourage collaborative working across a pathway, and reducing organisational boundaries and obstacles to improve patient outcomes.

## 2.2. London context

In London and West Essex, there are expected to be around 387,000 people living with and beyond cancer by 2030<sup>49</sup>. In 2014, both the London Cancer Alliance (LCA)<sup>50</sup> and London Cancer (LC)<sup>51</sup> produced documents with recommendations in relation to mental health psychological support services, including service specifications and referral guidelines. In 2015, the Transforming Cancer Services Team (TCST) for London and London Strategic Clinical Networks jointly published a guidance document entitled 'Psychological support for people living with cancer' 'Commissioning guidance for cancer care in London'<sup>52</sup>. In 2018 the TCST in partnership with Macmillan Cancer Support published '*The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer*', which this document now replaces.

Additionally, the 2019 publication, *Our Vision For London: The next steps on our journey to becoming the healthiest global city*<sup>53</sup>, was produced by the partnership made up of the Greater London Authority, Public Health England, London Councils and the National Health Service (NHS) in London. This publication details a shared

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<sup>48</sup> NHS England (2016) The National Cancer Programme

<sup>49</sup> Transforming Cancer Services Team/Public Health England and Macmillan Cancer Support (2019) *Cancer prevalence dashboard 1995-2017 in London*. Available here: <https://www.healthylondon.org/resource/2017-cancer-prevalence-dashboard/>

<sup>50</sup> London Cancer Alliance (2014), *Mental Health and Psychological Support Service Specification and Referral Guidelines*. Available here: <http://www.londoncanceralliance.nhs.uk/media/100472/lca-mh-ps-service-spec-final-dec-14.pdf>

<sup>51</sup> London Cancer (2014), *Service Specification Psychological Support Services*. Available here: <http://londoncancer.org/media/89175/psychological-service-specification-final-2014june-.pdf>

<sup>52</sup> London Strategic Clinical Networks (2015), *Psychological support for people living with cancer: commissioning guidance for cancer care in London*. Available here: <http://www.londonscn.nhs.uk/wp-content/uploads/2015/06/mh-cancer-commissioning-guide-062015.pdf>

<sup>53</sup> *Our vision for London: next steps on our journey to becoming the healthiest global city*. Available here: <https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2019/10/London-Vision-2019-FULL-VERSION-1.pdf>



ambition to focus on population-based services and to make joint working and integration a reality in London.

### 2.2.1 National Cancer Patient Experience Survey (NCPES) 2018

The most recent NCPES survey demonstrates that although progress has been made in London across several domains, there remain many areas where further improvements are needed<sup>54</sup>. The survey predominantly focuses on people during their acute hospital treatment episode. A range of questions are particularly pertinent in demonstrating the potential impact of communication and quality of information provided on psychological well-being and quality of life. Table 4 below shows a selection of questions that are particularly relevant to experiences of cancer care and future emotional well-being.

**Table 4: National Cancer Patient Experience Survey (NCPES) 2018:**

<b>Patients' experience of written and verbal information</b>	<b>2018 Survey</b>	<b>2018 Survey</b>	<b>2017 Survey comparison</b>
<b>Issue</b>	<b>London percentage</b>	<b>England</b>	<b>London percentage</b>
Q 35 Patient was able to discuss worries or fears with staff during visit (Inpatient)	49%	53%	49% (no change)
Q 41 Patient was able to discuss worries or fears with staff during visit (Day patient/Outpatient)	67%	71%	66% (+1%)
Q 49 Hospital staff gave family or someone close all the information needed to help with care at home.	57%	60%	55% (+2%)
Q 50 Patient definitely given enough support from health or social services during treatment	46%	53%	46% (no change)

<sup>54</sup> Healthy London Partnership (2020), *National Cancer Experience Survey: London*. Available here: <https://www.healthylondon.org/our-work/cancer/patient-experience-survey/>

Q 51 Patient definitely given enough support from health or social services after treatment	41%	45%	42% (-1%)
Q 53 GPs and Practice staff did everything they could to support the patient	55%	59%	56% (-1%)
Q 54 Hospital and community staff always worked well together	56%	61%	56% (no change)
Q 55 Patient given a care plan	32%	35%	32% (no change)

On several questions Londoners score significantly worse, compared to the rest of England. There are groups of patients who report worse experience than others including lesbian, gay bisexual and transgender communities, black and minority ethnic groups, younger patients, those with some types of brain cancer and patients diagnosed through emergency routes.

In relation to preventing distress, promoting adjustment and self-management where clinically appropriate, information and support has the potential to play a key role in maintaining emotional well-being. It is also reasonable to speculate that without appropriate information and support this could have an impact on increased healthcare utilisation.

A full breakdown of the 2018 National Cancer Experience Survey results can be viewed here: <https://www.healthylondon.org/our-work/cancer/patient-experience-survey/>

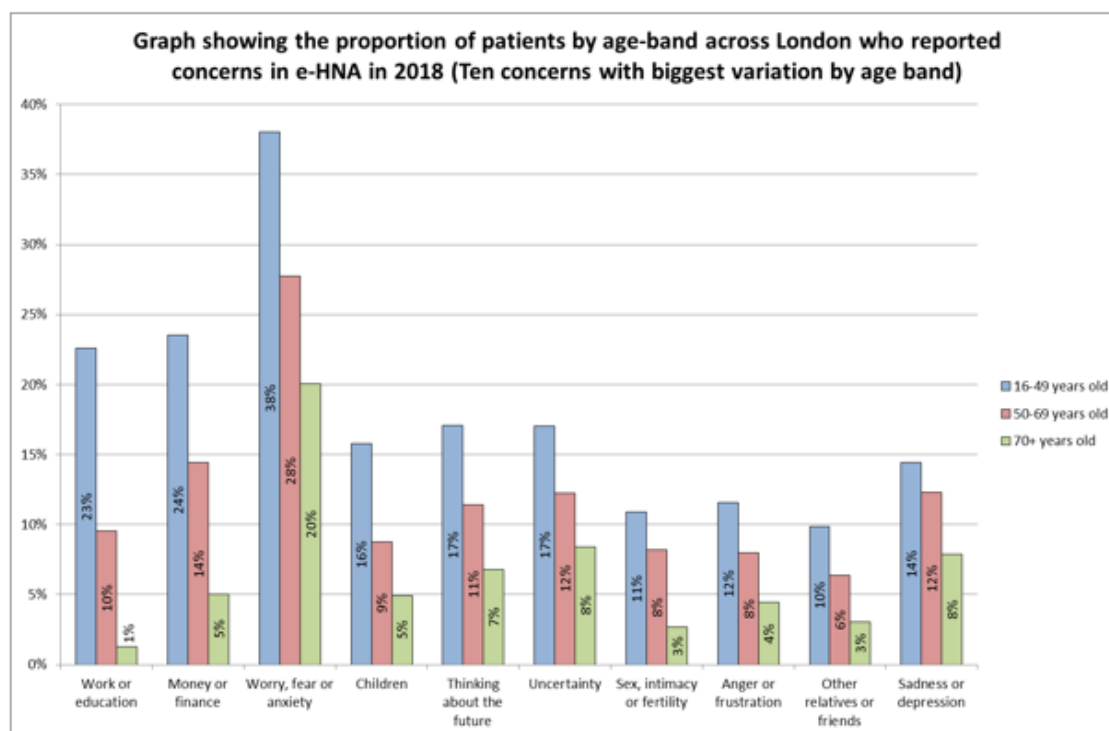
### 2.2.2 Holistic Needs Assessment

Results from London's 2018 E-Holistic needs assessment data support the importance of understanding the interaction between physical health, mental health and social factors. The results show the range of issues impacting on people affected by cancer and the importance of an approach to psychosocial support which encompasses physical health, mental health and social factors, rather than considering separate items in isolation.

Analysis of the 2018 data from the electronic Holistic Needs Assessment (e-HNA) tool in London illustrates that worry, fear or anxiety is the most frequently reported concern for patients, with almost 27% of all patients highlighting it as an issue when

newly diagnosed. Following treatment, this reduces only to 25.1% of all patients receiving an e-HNA<sup>55</sup>.

Whilst this data is limited in terms of the number of London trusts using the e-HNA tool and therefore the number of patients participating, this analysis provides an insight in to the primary concerns patients report both before and following treatment across the year, and therefore the specific support needs for those affected by cancer.



Collated by RM Partners Informatics team

**Figure 4: graph showing the top ten reported e-HNA concerns by age group (2018)**

Interestingly, despite the wide range of psychosocial needs identified by the e-HNA, only 32.8 % of people received a care plan across all cancer types. This indicates how even when needs are assessed and identified, this does not always result in the necessary action and support being offered.

Psycho-oncology teams, as indicated within NICE guidance<sup>56</sup>, need to be in place to deliver the Level 2 training supervision and support on an ongoing basis to ensure the quality of holistic needs assessments and to be available when more specialist

<sup>55</sup> *Cancer Stats Dashboard*. Available here: <https://cancerstats.ndrs.nhs.uk/>.

NB. At the time of publication, the eHNA data provided via the Cancer Stats portal is limited. More detailed data outlined above is provided by the RM Partners Analytics team. For more information, please contact: [mpartners.info@nhs.net](mailto:mpartners.info@nhs.net)

<sup>56</sup> National Palliative and End of Life Care Partnership (2015) *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*. Available here: <http://endoflifecareambitions.org.uk/>

psychological needs are identified, and a person needs to be 'stepped up' for support.

E-HNA data can be broken down by provider Trust, STP and CCG via the Cancer Stats portal which is available here: <https://cancerstats.ndrs.nhs.uk/user/login><sup>57</sup>.

It is clear that although there has been significant progress made in recent years in cancer survival, far less attention has been paid to the psychological consequences of cancer and its treatment. Psychological wellbeing will now have to be prioritised and recognised as having a key impact on quality of life.

### 2.3. Impact on quality of life

It is important to recognise the significant impact that the physical health difficulties associated with cancer and its treatment have on psychological well-being:

- 58 % of people diagnosed feel their emotional needs are not looked after as much as their physical needs<sup>58</sup>
- Even 10 years after treatment 54% of people affected by cancer still suffer from at least one psychological issue<sup>59</sup>
- In the year following diagnosis around one in ten patients will experience symptoms of anxiety and/or depression severe enough to warrant intervention by specialist psychological services. These symptoms are also seen in 10-15 % of patients with advanced disease<sup>60</sup>
- Cancer patients have a 55% higher risk of suicide than those without cancer<sup>61</sup>
- The long-term consequences of cancer include<sup>62</sup>:

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<sup>57</sup> *Cancer Stats Dashboard*. Available here: <https://cancerstats.ndrs.nhs.uk/user/login>

NB. At the time of publication, the eHNA data provided via the Cancer Stats portal is limited. More detailed data outlined above is provided by the RM Partners Analytics team. For more information, please contact: [rmpartners.info@nhs.net](mailto:rmpartners.info@nhs.net)

<sup>58</sup> Macmillan Cancer Support (2015), *Impact Briefs: Psychological and Emotional Support*. Available here: [https://www.macmillan.org.uk/images/Psychological-and-Emotional-Support\\_tcm9-283186.pdf](https://www.macmillan.org.uk/images/Psychological-and-Emotional-Support_tcm9-283186.pdf)

<sup>59</sup> Macmillan Cancer Support (2006), *Worried sick: the emotional impact of cancer*. Available here: [https://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/impact\\_of\\_cancer\\_english.pdf](https://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/impact_of_cancer_english.pdf)

<sup>60</sup> National Institute for Health and Care Excellence (2004) *Guidance on Improving Supportive and Palliative Care for Adults with Cancer*. Available here: <https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf773375005>

<sup>61</sup> Calati, R., Di Mattei, V. and Courtet, P (2017) *Risk of suicide mortality among cancer patients: A meta-analysis of observational studies*. *European Psychiatry*, 41, pp.S290-S291. Available here: <http://www.europsy.net/wp-content/uploads/2017/03/cancersuicide.pdf>

<sup>62</sup> Macmillan Cancer Support (2013) *Cured – but at what cost?* Available here: [https://www.macmillan.org.uk/documents/aboutus/newsroom/consequences\\_of\\_treatment\\_june2013.pdf](https://www.macmillan.org.uk/documents/aboutus/newsroom/consequences_of_treatment_june2013.pdf)

- 500,000 people are facing poor health or disability after treatment for cancer
- 350,000 living with chronic fatigue
- 350,000 experiencing sexual difficulties
- 240,000 reporting mental health difficulties including moderate to severe anxiety, depression and post-traumatic stress disorder
- 200,000 living with moderate to severe pain after treatment
- 150,000 left with urinary problems such as incontinence
- 90,000 with gastro-intestinal problems such as faecal incontinence
- Up to 63,000 people experiencing lymphoedema.

### 2.3.1 Quality of Life Metric

Achieving world class cancer outcomes: A strategy for England 2015-2020<sup>63</sup> made the following recommendation:

**Recommendation 65: NHS England and Public Health England should work with charities, patients and carers to develop a national metric on quality of life by 2017 which would enable better evaluation of long-term quality of life after treatment. PROMs should be rolled out across breast, colorectal and prostate cancer by 2020, with evaluation informing further rollout across other cancer types.**

The NHS Long term plan (LTP)<sup>64</sup> asserted its commitment to the quality of life metric “From 2019, we will begin to introduce an innovative quality of life metric-the first on this scale in the world-to track and respond to the long-term impact of cancer” (Recommendation 3.65, page 61)

As part of the NHS Cancer Dashboard, the new quality of life metric will provide, for the first time, an indication of how well people are living after cancer treatment and not just how long they are alive.

Five pilot sites in England have tested tools including North Central and East London Cancer Alliance (UCLH, Bart’s Health and Royal Free London Trusts). The pilot and evaluation period is running from September 2017 until March 2020.

“One of our key ambitions is to put cancer patient experience front and centre. Everyone is unique, with different views and priorities, so it’s vital that they receive personalised support, this new measure will help ensure local NHS can see where

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<sup>63</sup> NHS England (2015), *Achieving world-class cancer outcomes: a strategy for England 2015 – 2020*. Available here: <https://www.england.nhs.uk/cancer/strategy/achieving-world-class-cancer-outcomes-progress-report-2016-2020/>

<sup>64</sup> NHS England, *Long Term Plan* (2019). Available here: <https://www.longtermplan.nhs.uk/>

things are going well and where improvements can be made.” – NHS England 2017<sup>65</sup>.

Psychological and emotional well-being will have to be prioritised and for the first time is regarded as central to maintaining quality of life with parity to physical health. The roll out of the Quality of Life Metric (QoL) is planned from June 2020 - March 2021.

## 2.4. Economic impact of poor mental health

The impact of mental health difficulties on the individual, their family and loved ones, society, and the wider health and social care system is enormous and well documented. Research by the Kings Fund and the Centre for Mental Health suggests that approximately £1 in every £8 spent on long-term conditions (including cancer) is linked to poor mental health and wellbeing<sup>66</sup>. This is particularly significant as 70% of people living with cancer are also living with at least one other long-term condition<sup>67</sup>. Similarly, international studies suggest that where a physical health concern coexists with a mental health problem, the costs of physical healthcare is increased by 45-75%<sup>68</sup>.

### 2.4.1. Impact of cancer and mental health on healthcare utilisation

Evidence shows that those living with cancer have greater levels of healthcare utilisation compared to populations of the same age and gender. For example, a Nuffield Trust evaluation (2014) showed that 15 months after diagnosis, people with cancer had 60% more A&E attendances, 97% more emergency admissions and 50% more primary care contacts<sup>69</sup>.

Those with cancer and experiencing psychological distress are even more likely to utilise additional healthcare services across the system. For example, several studies<sup>70</sup> found that relative to cancer patients without depression, those with depression:

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<sup>65</sup> NHS England (2017) New quality of life measure for recovering cancer patients (news article). Available here: <https://www.england.nhs.uk/expo/2017/09/12/new-quality-of-life-measure-for-recovering-cancer-patients>

<sup>66</sup> The King's Fund and the Centre for Mental Health (2012), *Long-term conditions and mental health; The cost of co-morbidities*. Available here: <https://www.kingsfund.org.uk/publications/long-term-conditions-and-mental-health>

<sup>67</sup> Jacobsen PB, Jim HS (2008), *Psychosocial interventions for anxiety and depression in adult cancer patients: achievements and challenges* CA Cancer J Clin 58(4):214–230; Fallowfiel L, Ratcliffe D, Jenkins V, Saul J, *Psychiatric morbidity and its recognition by doctors in patients with cancer* (2001), Br J Cancer, 84(8):1011–1015.

<sup>68</sup> The Kings Fund (2012)., *Long-term conditions and mental health: The cost of co-morbidities* Available here: [https://www.kingsfund.org.uk/sites/default/files/field/field\\_publication\\_file/long-term-conditions-mental-health-cost-comorbidities-naylor-feb12.pdf](https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/long-term-conditions-mental-health-cost-comorbidities-naylor-feb12.pdf)

<sup>69</sup> Nuffield Trust (2014) *Use of health and social care by people with cancer*. Available here:

<https://www.nuffieldtrust.org.uk/research/use-of-health-and-social-care-by-people-with-cancer>

<sup>70</sup> Mausbach BT, Irwin SA (2017), *Depression and healthcare service utilization in patients with cancer*. Psychooncology. 26(8):1133-1139; Lo C, Calzavara A, Kurdyak P, et al (2013), *Depression and use of health care services in patients with advanced cancer*. Can Fam Physician, 59(3):e168-e174; Xiaoyun Pan, Usha

- Were twice as likely to have an emergency or urgent care visit
- Incurred 76% more healthcare visits
- Were 81% more likely to be hospitalised
- Twice as likely to experience a 30-day hospital admission
- Had 25% more non-mental health primary care visits
- Incurred 14% higher inpatient expenditure

Depression has also been associated with greater length of hospital stays and psychosocial factors have been found to impact cancer surgery outcomes.

There are also wider socio-economic costs associated with cancer and mental health, particularly as cancer survivors are 37% more likely to be unemployed than people who have never had cancer<sup>71</sup>. These additional costs outlined above are increasingly significant given the expected rise in the number of those receiving a cancer diagnosis.

Evidence suggests that psychological therapy reduces physical healthcare costs by an average of 20% (meta-analysis of 91 studies)<sup>72</sup>. When data is available on cost of psychological treatment and physical healthcare, savings exceeds costs<sup>73</sup>.

Cancer-specific studies show that adequate prevention, detection and treatment for psychological distress for cancer patients is effective in improving quality of life and can result in significant cost reductions in overall cancer care, particularly when integrated within other cancer services<sup>74</sup>. Several studies suggest that cancer patients who access psychosocial services in turn access other healthcare services less and better adhere to treatments and preventative behaviour, leading to better outcomes and quality of life<sup>75</sup>. Furthermore, evidence also suggest that those receiving psychosocial support are more likely to return to work, also reducing the wider costs and impacts of cancer and its treatment<sup>76</sup>.

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Sambamoorthi (2015), *Health care expenditures associated with depression in adults with cancer*, J Community Support Oncol. 13(7): 240–247.

<sup>71</sup> De Boer, A.G.; Taskilla, T.; Ojajarvi, A.; Van Dijk, F.J & Verbeek, J.H (2009), *Cancer Survivors and Unemployment: a meta-analysis and meta-regression*. JAMA 301, 753-762. Available here: <https://www.ncbi.nlm.nih.gov/pubmed/19224752>

<sup>72</sup> Layard, R & Clark, D.M (2014), *Thrive: The Power of Evidence-Based Psychological Therapies*

<sup>73</sup> Layard, R & Clark, D.M (2014), *Thrive: The Power of Evidence-Based Psychological Therapies*

<sup>74</sup> Linda E. Carlson, Barry D. Bult (2004), *Efficacy and medical cost offset of psychosocial interventions in cancer care: Making the case for economic analyses* Psycho-oncology, 13(12):837-49

<sup>75</sup> Mbathio Dieng Anne E. Cust Nadine A. Kasparian Graham J. Mann Rachael L. Morton (2016), *Economic evaluations of psychosocial interventions in cancer: a systematic review*. Psycho-oncology 25(12), 1380-1392

<sup>76</sup> Verdonck-de Leeuw IM, van Bleek WJ, Leemans CR, de Bree R (2013), *Employment and return to work in head and neck cancer survivors* (2010), Oral Oncol. 46:56-60; Tevaarwerk AJ, Lee JW, Sesto ME, Buhr KA, Cleeland CS, Manola J, et al, *Employment outcomes among survivors of common cancers: The Symptom Outcomes and Practice Patterns (SOAPP) study*. J Cancer Surviv, 7:191-202.



Lending further support to the vital role of specialist psychological interventions, the Health Foundation published a report in August 2018<sup>77</sup> which highlighted that patients most able to manage a mental health condition, as well as their physical health conditions:

- experienced **49% fewer emergency admissions** than those who were least able.
- had a **length of stay in hospital 41% shorter** compared to those least able
- **32 % fewer A & E attendances**
- **18 % fewer GP appointments**

There is a significant body of evidence demonstrating that psychologically informed cancer care can have a significant impact not only on the person affected by cancer and those significant to them but also on the wider healthcare system.

### 3. Other key drivers

In developing the pan-London cancer psychosocial care pathway for adults affected by cancer, consideration has been made of the following current drivers:

#### 1. Five year forward view for Mental Health (February 2016)<sup>78</sup>

- Care must be integrated spanning people's physical health, mental health and social care needs.
- "People with long term physical illnesses suffer more complications if they also develop mental health problems, increasing the cost of care by an average of 45 per cent".
- "There is good evidence that dedicated mental health provision as part of an integrated service can substantially reduce these poor outcomes".

#### 2. NHS Five Year Forward View (October 2014)<sup>79</sup>

- Physical and mental health are closely linked-people with severe and prolonged mental illness die on average 15-20 years earlier than other people – one of the greatest health inequalities in England.

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<sup>77</sup> Deeny, Thorlby, R, Steventon, Health Foundation (2018), *A Briefing: Reducing emergency admissions: unlocking the potential of people to better manage their long-term conditions*. Available here:

<https://www.health.org.uk/sites/default/files/Reducing-Emergency-Admissions-long-term-conditions-briefing.pdf>

<sup>78</sup> The Independent Mental Health Taskforce (2016), *Five Year Forward View for Mental Health*. Available here:

<https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>

<sup>79</sup> NHS England (2014), *Five Year Forward View*. Available here: <https://www.england.nhs.uk/publication/nhs-five-year-forward-view/>

### 3. General Practice Forward View (April 2016)<sup>80</sup>

- Describes the importance of enabling self-care and direct access to other services, better use of the talents in the wider workforce, investment in practice nurse development, and the use of social prescribing.

### 4. Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020<sup>81</sup>

- This document outlines six ambitions with clear descriptions of how to achieve the ambitions:
  - Each person being seen as an individual (requires honest conversations, systems for person-centred care, clear expectations, access to social care, helping people take control, integrated care and good end of life care, including bereavement support)
  - Each person gets fair access to care (using existing data, population needs assessment, community partnerships)
  - Maximising comfort and well-being (recognising distress whatever the cause, skilled assessment and symptom management, addressing all forms of distress, specialist palliative care)
  - Care is co-ordinated (requires shared records, clear roles and responsibilities, system wide response)
  - All staff are prepared to care (requires training to provide professional ethos of care, staff support and resilience, knowledge-based judgement)
  - Each community is prepared to help (requires compassionate and resilient communities, public awareness, and practical support)

### 5. NHS England. Commissioning guidance for Rehabilitation (2016)<sup>82</sup>

- “A modern health care system must do more than just stop people dying. It needs to equip them to live their lives, fulfil their maximum potential and optimise their contribution to family life, their community and society as a whole”. This document also outlines the interaction between physical health and mental health and the significant impact one has on the other.

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<sup>80</sup> NHS England (2016), *General Practice Forward View*. Available here: <https://www.england.nhs.uk/wp-content/uploads/2016/04/gp-fv.pdf>

<sup>81</sup> National Institute for Health and Care Excellence, *Guidance on Improving Supportive and Palliative Care for Adults with Cancer* (2004). Available here: <https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005>

<sup>82</sup> NHS England (2016), *Commissioning guidance for rehabilitation*. Available here: <https://www.england.nhs.uk/wp-content/uploads/2016/04/rehabilitation-comms-guid-16-17.pdf>

## 6. NHS England House of Care-a framework for long term conditions care<sup>83</sup>

- The key principle underpinning the model is that person-centred, coordinated care enables people to make informed decisions that are right for them, and empowers them to self-care for their long-term condition(s) in partnership with health and care professionals.

## 7. Steps towards implementing self-care<sup>84</sup>

- Identified that all 5 STPs in London have referenced self-care, prevention and social prescribing as a means of implementing person and community centred approaches. Patients want to be empowered to make informed choices in managing their own health, wellbeing and care. The NCPES (2018) identified that only 34.5% of Londoners were given a care plan at all, so there is a long way to go in ensuring that people feel empowered to take control of their health. This will require a culture shift to ensure “care planning and self-management is hard-wired into how care is delivered”, especially in relation to how long-term conditions such as cancer are managed. Enablers of self-care involve a focus on Patient activation/self-efficacy, improving health literacy and culture change and training within the workforce.

## 8. NICE guidance 56 (NG56) Multi - morbidity: clinical assessment and management<sup>85</sup>

- This guideline covers optimising care for adults with multi - morbidity (multiple long-term conditions) by reducing treatment burden (polypharmacy and multiple appointments) and unplanned care. It aims to improve quality of life by promoting shared decisions based on what is important to each person in terms of treatments, health priorities, lifestyle and goals. The guideline sets out which people are most likely to benefit from an approach to care that takes account of multi - morbidity, how they can be identified and what the care involves.

## 9. Psychological professions vision for England 2019-24<sup>86</sup>

- To expand access to evidence-based psychological therapies and interventions widely to those who can benefit from them across all areas of health and social care

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<sup>83</sup> NHS England (2017), *House of Care: a framework for long term conditions care*. Available here: <https://www.england.nhs.uk/ourwork/ltc-op-eolc/ltc-eolc/house-of-care/>

<sup>84</sup> Healthy London Partnership (2017), *Steps to implementing self-care*. Available here: <https://www.healthylondon.org/wp-content/uploads/2017/10/Steps-toward-implementing-self-care-June-2017.pdf>

<sup>85</sup> NICE (2016), *Multi-morbidity: clinical assessment and management*. Available here: <https://www.nice.org.uk/guidance/ng56>

<sup>86</sup> NHS England (2019), *Psychological professions vision for England 2019-24*. Available here: <https://www.england.nhs.uk/wp-content/uploads/2019/12/psychological-professions-vision-for-england-2019-24.pdf>

- To innovate, and evaluate innovation, in psychological healthcare
- To increase access to psychological healthcare for those groups that have traditionally had poorer access
- To enable all NHS-commissioned health services to deliver psychologically informed care that increases the wellbeing of service users, carers and families
- To use psychological knowledge more widely to prevent avoidable distress and illness
- To create joined-up professional leadership of the psychological professions
- To enable psychological professionals to work with other health and social care professionals to make the most positive outcomes for service users, carers and families

## 4. Producing the recommendations and pathway

The TCST employed Dr Philippa Hyman in partnership with Macmillan Cancer Support, from January 2017 – March 2020, in partnership and funded by Macmillan to lead this work. Liz Price, Associate Director, Personalised Care for Cancer, supervised the project. Support for Dr Hyman came from the Personalised Care for Cancer Team.

### 4.1. The Steering Group

For phase 1 of this work, a Mental Health and Cancer Task and Finish group was established to oversee the production of the psychosocial care pathway and the commissioning recommendations that were published in May 2018. Membership included representation from the TCST, service users, provider organisations, commissioning, and the third sector. The group met six times from January 2017 to December 2017, with much of the work done virtually. See Appendix A for the membership and terms of reference of the group.

For phase 2, a Psychosocial Support for Cancer Steering Group was established to oversee the whole programme. Membership included representation from the TCST, service users, provider organisations, commissioning, and the third sector. The group met eight times from July 2018 to March 2020. See Appendix B for the membership and terms of reference of the group.

## 4.2. Feedback from three stakeholder events (May and October 2017, May 2019)

[Three stakeholder](#) events were organised to bring together professional representation across the whole pathway including commissioners, GPs and primary and secondary care providers, the third sector, and service users to come together to discuss and agree on a core set of principles to be incorporated into a pathway for London. Each event had extremely good professional and service user and achieved excellent geographical representation across STPs in London.

Several key issues were identified at the stakeholder events which have been considered in the development of the pathway:

- The pathway developed is about improving psychologically informed cancer care
- The patient must be at centre of pathway.
- There is a need for directories of resources/information to be refreshed and updated and to include support groups and resources. *N.B The Cancer Care Map is now available nationally and signposts emotional support, health and wellbeing, practical concerns support and medical services. This is available here: <https://www.cancercaremap.org/>*
- Within primary care there needs to be Level 2, as determined by the 2004 NICE 4 Level model (see Figure 5), support for people with LTCs including cancer, in similar way to the Level 2 support within acute hospital settings.
- Communication is key to the success of any pathway - both verbal and written communication including Cancer Care Reviews, Holistic Needs Assessments and treatment summaries which must be used more effectively, with joined up care planning underpinning the entire pathway.
- Poor communication (including administrative systems and face-to-face) impacts on mental health.
- Importance of patient choice across the pathway -how can we enable people to make choices?
- Pathway must not be linear - there needs to be flexibility and fluidity in recognition of changing needs and complexity (age, tumour type, point on the cancer pathway, social factors) which also relates to an individual's changing personal circumstances over their lifetime.
- Consideration of the needs of the whole family system.
- Team working and collaboration must improve across whole pathway- especially between primary and secondary care.
- Clinical supervision, support and training for CNSs, Practice nurses and GPs (junior and senior staff) is essential.

### 4.3. IAPT and Psycho-oncology meetings

In phase 1 of this work, the aim of these meetings was to bring together clinicians from Improving Access to Psychological Therapies Services (IAPT) and psychologists from acute cancer services to begin a dialogue on how their respective services work, what challenges and dilemmas they face, and understand more about what is clear and more complex in relation to pathways between acute and community services. Since the publication of the original guidance document, a small Task and Finish group was established (membership included GP, IAPT lead, psycho-oncology lead and psychiatrist) to clarify the pathway in relation to:

- referral criteria (inclusion/exclusion criteria)
- when to step up and step down referrals
- how to develop closer collaboration
- the education and training needs across primary care and IAPT services

Additionally, the pathway and referral criteria were presented, received feedback and was endorsed by the IAPT Clinical leads across London in two meetings in July 2018 and July 2019.

### 4.4. Cancer rehabilitation

The recognition of the importance of managing the consequences of cancer has been vital to the cancer rehabilitation agenda both nationally and within London. The *Cancer Rehabilitation scoping report for London*<sup>87</sup> identified the key role cancer rehabilitation services should have in the care of people living with and beyond cancer to optimise quality of life and functioning for patients. These services should address the physical, psychological, spiritual and social aspects of well-being. In April 2019, the TCST published Commissioning Guidance for Cancer Rehabilitation<sup>88</sup> which also highlighted the need for integrated service provision, including the importance of psychological components in both cancer prehabilitation and rehabilitation, as well as excellent case examples of good practice and recommendations for the London cancer system going forward.

Within the Transforming Cancer Services Team, close working relationships have been developed between the cancer rehabilitation and mental health work streams to ensure that cancer rehabilitation and psychosocial support are not treated as separate and disconnected. It is clear that addressing the psychological issues that

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<sup>87</sup> Healthy London Partnership (2017), *Cancer rehabilitation: a scoping report for London*. Available here: <https://www.healthylondon.org/resource/cancer-rehabilitation-scoping-report-london/>

<sup>88</sup> Healthy London Partnership (2019), *Integrated Care System Guidance for Cancer Rehabilitation A guide to reducing variation and improving outcomes in cancer rehabilitation in London*. Available here: <https://www.healthylondon.org/wp-content/uploads/2019/07/A-guide-to-reducing-variation-and-improving-outcomes-in-cancer-rehabilitation-in-London.pdf>

can impact on cancer prehabilitation and rehabilitation is essential for improving patient outcomes.

#### 4.5. Service user perspective

Throughout this project, service user representation has been central to the co-creation of the pathway and recommendations. From representation at the Task and Finish group meetings, to contributions at all regional stakeholder events including a separate focus group with service users prior to the two of these events. Additionally, seven in-depth qualitative interviews have been carried out with service users in their 20s and 30s who were contacted via Trekstock, a third sector organisation supporting young adults with cancer.

A number of key themes were identified through both analysis of the interview transcripts and focus group discussions.

##### 4.5.1 Information and sign-posting

It was recognised by many that there was wide variation across London not only in what support services are available but also in how easy it is to find out about these services. Many people identified that they had found out about services themselves and let their health professionals know about them. Additionally, there was an idea that information provision and sign-posting can have a vital role in enabling people to access support early which can have a really powerful preventative effect and impact on promoting psychological adjustment. Access to peer support was considered particularly valuable.

*“I found support out there myself. No-one told me. If I’d been directed to stuff earlier I would have accessed it earlier which would have really helped”*

*“Somebody should be telling you what services are out there” “There should be a place where all the support is listed”*

*“All the information seems to be focused on older people with cancer, or women with children or you have the Teenage Cancer Trust. It all felt like a different life stage to me. It didn’t fit for me. I found things out because I’m outgoing and on social media. Information needs to fit for young people.”*

##### 4.5.2 Psychological support

The vital role of psychological interventions is consistently identified across the whole pathway. However, there was variation in experiences and access to psychological support. Psychologists with specialist cancer expertise were seen as particularly valuable.



*“I do think psychological support is really important. I feel I’m a positive and resilient person and I still feel I need help, so how do people less resilient cope?”*

*“There’s disconnect between services - in the hospital between physical/medical side and the psychological side.”*

*“In primary care I was seen within an IAPT (Improving Access to Psychological Therapies) service, there was sympathy about cancer but a lack of understanding”*

*“During treatment I was told I could see a psychologist, which was so helpful, but after treatment it doesn’t feel like it’s offered”*

### *Post-treatment support*

There is a wealth of evidence including those outlined in a number of Macmillan publications<sup>89</sup> identifying that for many there is a significant emotional impact on those affected by cancer after treatment ends and contact with the hospital setting finishes or significantly reduces. All service users identified that this stage could feel “like falling off a cliff”.

*“After treatment it was quite difficult to find a reason to leave my front door. The anxiety and depression hit me then”*

*“Contact with the nurse gets less and less at the end of treatment when that’s the time you feel you need more and more reassurance”*

*“I’m unsure where things sit after treatment - when do I go to the GP, when to the hospital, when should I worry. It’s quite scary”*

*“It’s overwhelming, I’m under lots of different people, but there’s no point of contact for me”*

*“I feel like my GP should be involved but isn’t”*

Consistent feedback from service users has identified that currently cancer specialist psychosocial support can be missing much further down the cancer pathway where IAPT services may not be felt to have the cancer knowledge and expertise yet

<sup>89</sup> See: Macmillan Cancer Support (2006), *Worried sick: the emotional impact of cancer*. Available here: [https://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/impact\\_of\\_cancer\\_english.pdf](https://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/impact_of_cancer_english.pdf)

Macmillan Cancer Support (2013), *Cured, but at what cost?* Available here:

[https://www.macmillan.org.uk/\\_images/cured-but-at-what-cost-report\\_tcm9-295213.pdf](https://www.macmillan.org.uk/_images/cured-but-at-what-cost-report_tcm9-295213.pdf)

Macmillan Cancer Support (2013), *Throwing light on the consequences of cancer and its treatment*. Available here:

<https://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/throwinglightontheconsequencesofcanceranditstreatment.pdf>

Macmillan Cancer Support (2015), *Rich Picture Series*. Available here: <https://www.macmillan.org.uk/about-us/what-we-do/evidence/research-publications/rich-pictures.html>

Macmillan Cancer Support (2017), *Am I meant to be OK Now?* Available here:

[https://www.macmillan.org.uk/\\_images/LWBC-Report-2017\\_tcm9-317400.pdf](https://www.macmillan.org.uk/_images/LWBC-Report-2017_tcm9-317400.pdf)

psycho-oncology teams due to constraints on their resources may not be able to offer interventions several years after treatment ends.

*“As a patient I really appreciate the key message about psychological support not being a luxury but a necessity. Likewise, I know that IAPT can’t do it all and specialist support services are also needed. I still have concerns about the time-frames/limits that could be imposed by CCGs on re-accessing services. I didn’t try to access psychological support until after I reached my 5 year “all clear” follow up milestone because that was when I unravelled. It was a battle to access help so long after my diagnosis. I don’t want future patients to struggle if they too have late-onset psychological needs.”*

It will be important for commissioners and providers to assess local needs and service provision for this cohort of patients.

### *Wider implications of cancer and its treatment*

Several people identified the impact of wider factors on mental health such as fertility and social factors such as employment and financial worries. This demonstrates the importance of integrating physical health, mental health and social care in improving psychological well-being and quality of life.

*“There needs to be more support for people with the financial implications of cancer. There’s no safety net financially. You shouldn’t be fighting to keep your home, when you’re facing cancer”*

*“The chat about fertility needs to be more prominent”*

*“Oncologists are fantastic on focusing on cancer but they might not know the finer details of fertility.”*

*“I know women who haven’t had those chats and now after having treatment are being told about fertility”*

## **4.6. Equality and Health Inequality Analysis (EHI) screening**

An initial EHIA screening was completed using the NHS England (2016) screening tool<sup>90</sup>. This enabled the psychological support pathway to be screened across a number of domains to ascertain how this work would benefit one or more of these groups. The nine protected characteristics are as follows:

1. Age
2. Disability
3. Gender reassignment

<sup>90</sup> NHS England (2016), *Inequalities calculation tool*. (archived). Available here: <https://www.england.nhs.uk/about/equality/equality-hub/resources/>

4. Marriage and civil partnership
5. Pregnancy and maternity
6. Race
7. Religion and belief
8. Sex
9. Sexual orientation

NHS England has agreed an additional definition which relates to inclusion health and people with lived experience. Inclusion health has been used to define a number of groups of people who are not usually provided for by healthcare services and covers people who are homeless, rough sleepers, vulnerable migrants, sex workers, Gypsies or Travellers and other multiply excluded people. The definition also covers Female Genital Mutilation (FGM), human trafficking and people in recovery.

Additionally, the Transforming Cancer Services Team (TCST) has produced a toolkit to reduce inequalities in cancer care and outcomes in London and West Essex<sup>91</sup>. The toolkit covers clinical, psycho-social and patient experience dimensions and provides recommendations for all organisations that plan, commission and deliver cancer care for Londoners. It underpins delivery of the three London Cancer Priorities agreed in 2019/20:

- Early detection of cancers including through screening and education activities
- Delivery of the Faster Diagnosis Standard
- Access to personalised care

The toolkit recommendations are based on a comprehensive needs and assets assessment. This includes analysis of published data, evidence of effective interventions (including relevant NICE guidance), consultation with a range of stakeholders, the views of people affected by cancer and insights drawn from these sources.

The toolkit is available here: <https://www.healthylondon.org/resource/cancer-inequalities-toolkit/>

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<sup>91</sup> Healthy London Partnership (2019), *Cancer Inequalities toolkit*. Available here: <https://www.healthylondon.org/resource/cancer-inequalities-toolkit/>

## 5. The London Integrated Cancer Psychosocial Care Pathway for adults affected by cancer

Based on feedback from both stakeholder events and the Task and Finish group it was agreed that the terminology 'Psychosocial care pathway' should be used instead of 'Psychological support pathway'. The term 'psychosocial' captures the importance of considering the broad range of determinants affecting emotional well-being and that there are a range of interventions that are beneficial delivered by a variety of professionals.

The London Integrated Cancer Psychosocial Care Pathway (Figure 6) is based on an adjustment model for cancer i.e. that the majority of those affected by cancer find ways through their experience using their own inner resources, external resources (e.g. supported self-management, third sector support, social prescribing, digital support) and support systems (family, friends, trusted professionals) to adjust to the experience of cancer and will not require specialist psychosocial interventions (levels 3 and 4) but universal support (see figure 5) or for some people enhanced support (level 2). This is an important key message so that adults affected by cancer are not assumed to have a mental health difficulty, for example, by showing distress or worry following a cancer diagnosis.

All care within the pathway should be provided within the framework of the 4 level model recommended by the NICE Supportive and Palliative Care Guidance 2004. This guidance has not been refreshed since 2004 but remains in effect and is a well-recognised framework, understood by service providers, the third sector and commissioners.

**Figure 5: Levels of Psychological Assessment and Support (NICE 2004)<sup>92</sup>**

**Recommended model of professional psychological assessment and support**

Level	Group	Assessment	Intervention
1	All health and social care professionals	Recognition of psychological needs	Effective information giving, compassionate communication and general psychological support
2	Health and social care professionals with additional expertise	Screening for psychological distress	Psychological techniques such as problem solving
3	Trained and accredited professionals	Assessed for psychological distress and diagnosis of some psychopathology	Counselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework
4	Mental health specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy (CBT)

Self help and informal support

<sup>92</sup> National Institute for Health and Care Excellence, *Guidance on Improving Supportive and Palliative Care for Adults with Cancer* (2004). Available here: <https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005>

Although it is recommended that this framework remains and has been useful for developing psycho-oncology services and cancer psychological care, some notes of caution must be offered. The most important considerations for services must be the needs of the local population and the skills mix required to deliver the range of therapeutic offers from each service as well as the leadership skills required.

Additionally, it is acknowledged that for some people, the level 3 and 4 distinction is perceived as hierarchical, suggesting a two-tier system of provision with Level 4 being superior to Level 3. This is not what is intended in this report. Whilst the distinction is made between these two levels no judgement is made with regards to the seniority of posts. These levels are purely a reflection of the most common current make up of teams and what is considered to be the key components of psycho-oncology services.

### 5.1. Description of activity

The below sets out the descriptions of activity for each level, as outlined by the 2004 NICE guidelines<sup>93</sup>. Importantly, these levels highlight that the delivery of psychologically minded care is everyone's business.

Level 1	Responsibilities
All health and social care professionals working with people affected by cancer, their families and carers	Recognition of psychological need
	Look for indications of psychological distress and explicitly ask patients, families and carers about their general well-being. All professionals need to be proactive, asking: "how are you feeling in yourself?"/"what impact is...having on your life?"
	Active listening (asking and listening can be an intervention in itself)
	How is the patient coping? Are they accessing support? Are there difficulties interfering with their life and accessing treatment?
	Contact Psycho-oncology service for advice/consultation if needed
	Signpost to support that patient finds relevant-discuss with them
	Provide general emotional support
	Communicate with compassion, gather relevant information and discuss onward referral where appropriate
	Be aware of Level 2 staff (CNS/AHP) and discuss concerns

<sup>93</sup> National Institute for Health and Care Excellence, *Guidance on Improving Supportive and Palliative Care for Adults with Cancer* (2004). Available here: <https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005>

Level 2	Responsibilities
<ul style="list-style-type: none"> <li>Clinical Nurse Specialists</li> <li>Allied Health Professionals</li> </ul> <p><i>Requires specific Level 2 training and regular supervision by Level 3/4 specialists</i></p>	Meet the person at diagnosis – to build a reliable relationship
	Explore and address the person's information preferences
	Include and involve family and carers
	Screening for distress. Identify and explore relevant vulnerability factors (e.g. learning disability, mental health history, socio-economic adversity) to inform treatment and support plan and liaise with external services to coordinate care when needed
	Guide and coordinate care, including support
	Contribute psychosocial perspective to MDT decisions
	Signpost to internal and third-sector resources, e.g. welfare advice
	Conduct holistic needs assessments (HNAs) at key transitions in a patient-centred manner, to identify significant distress and unmet psychosocial needs
	Offer first-line 'level 2' psychological interventions and support
	Consult with, work jointly with and refer to Level 3/4 psycho-oncology services
Provide relevant guidance and training to level 1 staff.	

Level 3	Responsibilities
<ul style="list-style-type: none"> <li>Psychotherapists</li> <li>Family therapists</li> <li>Counsellors</li> <li>Mental health therapists accredited in a particular modality (e.g. CBT accreditation by BABCP)</li> <li>Social workers with accredited psychotherapeutic training and specialist training in cancer care</li> <li>Mental health nurses with accredited psychotherapeutic training and specialist training in cancer care</li> </ul>	Assess and deliver interventions with complex presentations that include psychosocial factors
	Provide triaging with complex presentations that include psychosocial factors
	Contribute to service developments aimed at delivering the biopsychosocial care delivered by the organisation
	Provide supervision, consultation and training relating to psychosocial factors
	Provide training placements to trainees in their professional discipline to develop the future workforce.



Level 4	Responsibilities
<ul style="list-style-type: none"> <li>• Clinical psychologists</li> <li>• Consultant liaison psychiatrists</li> <li>• Counselling psychologists who:</li> <li>• <i>have substantive mental health training</i></li> <li>• <i>are accredited to deliver interventions across a range of modalities</i></li> <li>• <i>are able to use formal methods to adapt, evaluate and deliver interventions</i></li> </ul> <p>Level 4 professionals have knowledge through training and experience of other mental health services and have completed specialist training (e.g. teaching, supervision and formal courses) with specific reference to cancer care.</p>	assess and intervene with complex presentations that include a combination of physical, social and psychological variables
	able to make differential diagnosis/construct biopsychosocial formulations
	lead the triaging process
	provide supervision/consultation/training relating to severe and enduring mental health issues especially in the context of risk
	lead service developments aimed at enhancing the biopsychosocial care delivered by the organisation
	lead psycho-oncology teams/services
	liaise with and work in combination with other services and agencies (e.g. IAPT, community mental health teams, primary care)
	provide training placements to trainees in their professional discipline to develop the future work force.

## 5.2. Psycho-oncology teams

Psycho-oncology is a multi-disciplinary speciality focusing on the psychological and mental health care of people affected by cancer, carers and families, contributing through direct and indirect care to improving clinical outcomes, patient experience and quality of life.

A range of professionals will be included in (or accessible to) a Psycho-oncology team (level 3 and 4 specialists), reflecting the breadth and complexity of acute cancer activity. A service typically includes Clinical Psychologists, Counsellors, Psychotherapists, Arts Therapists, Counselling psychologists, Liaison Psychiatrists, Psychosexual therapists and Neuropsychologists:

Psycho-oncology teams work clinically with a full range and severity of psychological difficulties that impact on cancer treatment, recovery and adjustment. These may include: anxiety, depression, deliberate self-harm, alcohol and drug-related issues,



mild cognitive impairment, helping people with adjustment issues, decision-making, body image difficulties, problems with interpersonal relationships and relationships with professionals.

**Case example: 55 year old woman, with an incurable but treatable cancer**

*"I had been struggling to cope with the side effects of my punishing cancer treatment and in particular with the impact on my mental health. Aware of my plight my consultant and CNS suggested psychological help which I have been receiving within the hospital setting. I liked the fact that my psychologist understood the system, had access to my notes and understood the procedures I had been through. I felt the psychologist was in the centre of things, part of the MDT (multi-disciplinary team) so it was all joined up. My overall well-being has and continues to improve as a result of my sessions. I consider the support and help that I have been receiving from my psychologist an important and invaluable part of my treatment plan. The difference it has made to me is immeasurable and I really don't know where I would be without it"*

They offer a range of multi-modal interventions which may include the following: Cognitive- behavioural therapy, brief focused psychotherapy, mindfulness, grief/existential therapy, couple/family therapy, systemic interventions, cancer counselling, consultancy to survivorship events, assessment and management of: suicidality and risk, co-morbid alcohol and drug-related problems, personality disorders, deliberate self-harm, psychotic illness, organic brain syndromes, complex co-morbidity. They also provide specialist functions such as neuropsychological assessment and psycho-sexual interventions.

They provide a vital role in:

- Supporting patients to access cancer investigations, treatment, care and rehabilitation thus improving patient outcomes
- Highly specialist clinical care for inpatients during medical admission and outpatients

**Case Example: Access to cancer treatment**

When a patient refused upfront radiotherapy as part of her standard chemotherapy-radiotherapy treatment for cervical cancer, she was referred to the hospital psychology service. On assessment it was revealed that she had been tortured in a South American country in her youth with doctors in attendance. Exposure to the radiotherapy machines and staff had triggered memories of this experience. Urgent PTSD type treatment allowed her to separate the two situations and undergo her radiotherapy on time.

- Psychological support for families and carers
- Highly specialist 'indirect' services including:
- Rapid access to complex case consultation within acute hospital settings
- Supervision and training for level 2 workers (CNSs and AHPs)
- Contribute psychological evidence and insights to quality improvement projects
- Train and support the delivery of Personalised Care Interventions
- Provide consultation and expert advice on cancer and psychological issues to MDT teams and other professionals across the pathway
- Address end of life issues by facilitating important decisions and conversations with treating clinicians and families
- Support those with severe mental illness to receive optimal cancer treatment
- Address the pharmacological interactions that can arise between psychiatric medications and cancer treatments such as chemotherapies.

#### Case example: Support at end of life

A patient had been diagnosed 18 months previously with advanced, highly symptomatic, stage 4 cancer. Through having access to the hospital psychology service she was able to be clear in a psychology session that she was aware of her prognosis, did not want to continue active chemotherapy treatment and would like admission to a hospice. She was then supported to share this information with her CNS and treating doctor. Her hospice admission ensured that her family were involved in her end of life, as well as securing bereavement services for her husband.

### 5.3. Improving Access to Psychological Therapies (IAPT) services

IAPT services provide an important contribution to psychological support within the cancer pathway. They are developing their services to focus on supporting people with long-term conditions (LTC) in what is called 'Integrated' IAPT services. The NHS Long Term Plan not only highlights targets for the increase in access but the importance of a comprehensive offer for long term conditions. These services:

- Focus on providing direct interventions for anxiety and depression in the context of the LTC
- 4 main conditions prioritised so far: Chronic Obstructive pulmonary disease (COPD), Coronary Heart Disease (CHD), Diabetes, Musculoskeletal problems and Chronic Pain
- Cancer is now coded as a LTC within Integrated IAPT services
- Model uses a stepped approach (4 levels) to providing care (e.g. Step 1 being supported self-care and Step 3 providing high intensity CBT for anxiety),

- As Integrated IAPT services consider how they can contribute to the pathway, close liaison with psycho-oncology services will be needed to ensure well-coordinated care planning to deliver excellent clinical outcomes

Psycho-oncology should take the lead to ensure a 'whole system' approach to identifying and providing psychosocial support with clear and flexible referral pathways and processes, which are understood by professionals, patients, their carers and families. Within the pathway there is a clear role for both Psycho-oncology teams and IAPT services, which provide vital support at different points along the pathway.

#### **Case example: demonstrating referral appropriate for IAPT**

*A 35 year old man completed treatment for bowel cancer with a good outcome. He has experienced anxiety and insomnia for many years which was exacerbated by the cancer diagnosis and treatment. He had a few sessions with a specialist cancer psychologist during his treatment with a focus on managing his fears, in particular anticipatory anxiety about chemotherapy sessions. Now a year out of treatment and back at work for 8 months he has been experiencing levels of anxiety and insomnia similar to those that he had prior to his diagnosis. He identifies that these are related to low self confidence in social situations. He says that he still has some worries about his health but he recognises that this is part of a wider pattern of general anxiety. He has been referred to a local IAPT service for ongoing management.*

#### **Case example: demonstrating how psycho-oncology supported the work of IAPT to improve clinical outcomes.**

*A woman in her 40s with a young family, in stable remission but with mobility problems following brain cancer surgery, was referred by her GP to IAPT with concerns about low mood and adjustment. IAPT colleagues sought psycho-oncology advice; with patient consent, they were able to look up her medical records and advised a joint assessment to clarify her needs, preferences and best options. At this meeting, it was jointly agreed that starting with an IAPT Step 2 Psychological wellbeing practitioner (PWP) would be a feasible initial step; she made good use of this input, resulting in measured clinically significant improvement and tangible changes e.g. going to the gym. A year later she remains well in herself and has continued her gym activity.*

Psycho-oncology teams should take the lead across the psychosocial support pathway to ensure they share their clinical expertise, providing training and consultation to all professionals working with people affected by cancer across the whole pathway. This will mean working across acute, primary care and community settings.

There needs to be a 'whole system' approach to identifying and providing psychosocial support with clear and flexible referral pathways and processes, which are understood by professionals, patients, their carers and families. Psycho-oncology teams must be accessible to GPs and primary care, IAPT colleagues, Community Palliative Care Teams and Community Mental Health Teams. This approach will ensure improved patient outcomes, patient experience and quality of life.

#### **5.4. Third sector**

Although the focus of this report has been on NHS commissioned services, it is essential to acknowledge the vital role that third sector organisations provide across the whole cancer pathway. The flexible, person-centred, non-stigmatising, consistent support which is so easily accessible is an essential component of the pathway.

### 5.5. The Pan-London Psychosocial Support Pathway for adults

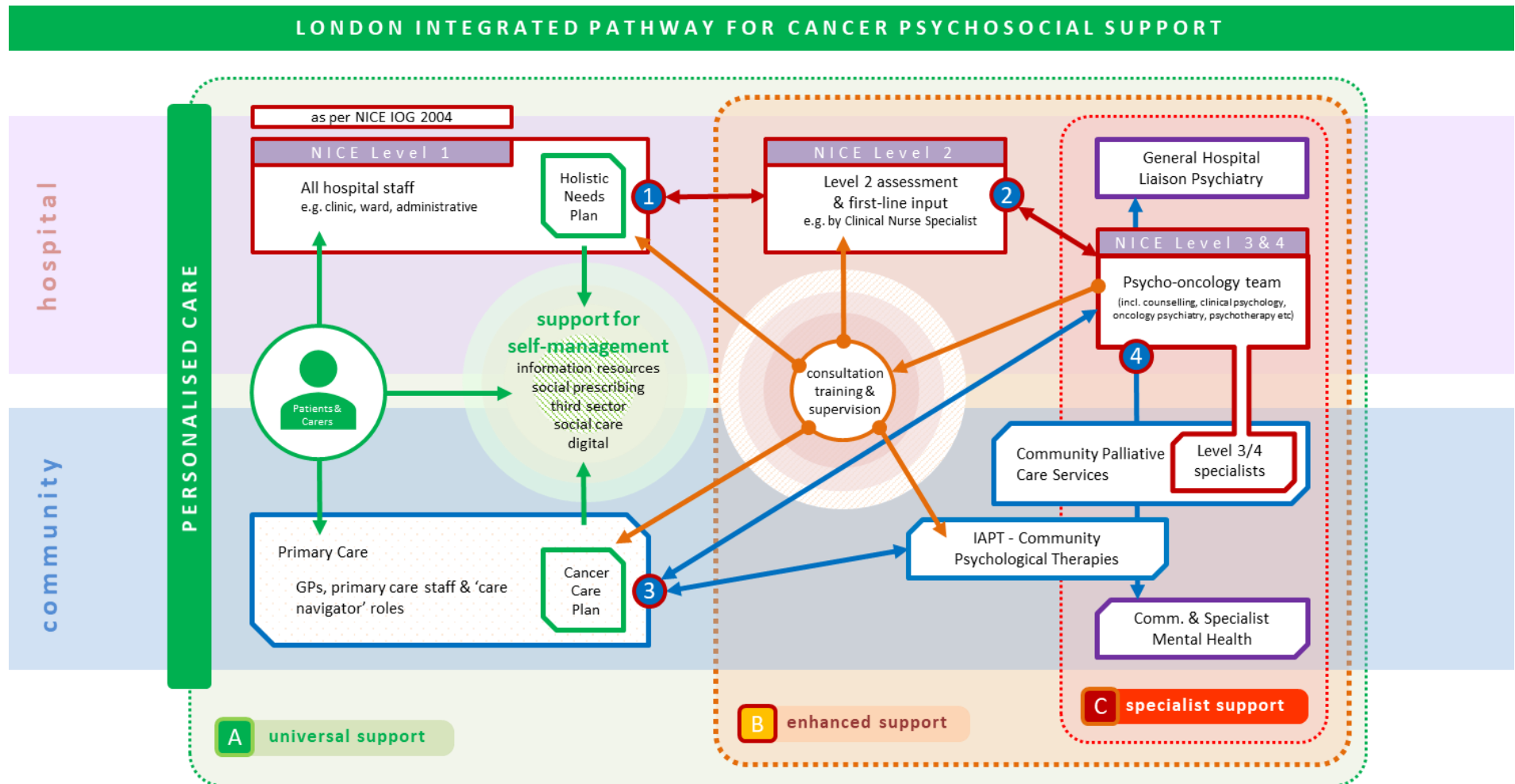


Figure 6: Pan-London Psychosocial Support Pathway for adults

Figure 6 shows the psychosocial support provision across acute, primary care and community contexts.

This model is based on a core set of principles that has been the result of extensive engagement with stakeholders across London, including system leaders/commissioners, GPs, primary and secondary care providers, the third sector, and service users.

### 5.5.1. Key features/benefits of the pathway:

#### **A) Preventing distress and promoting adjustment (part of existing strategies/national priorities)**

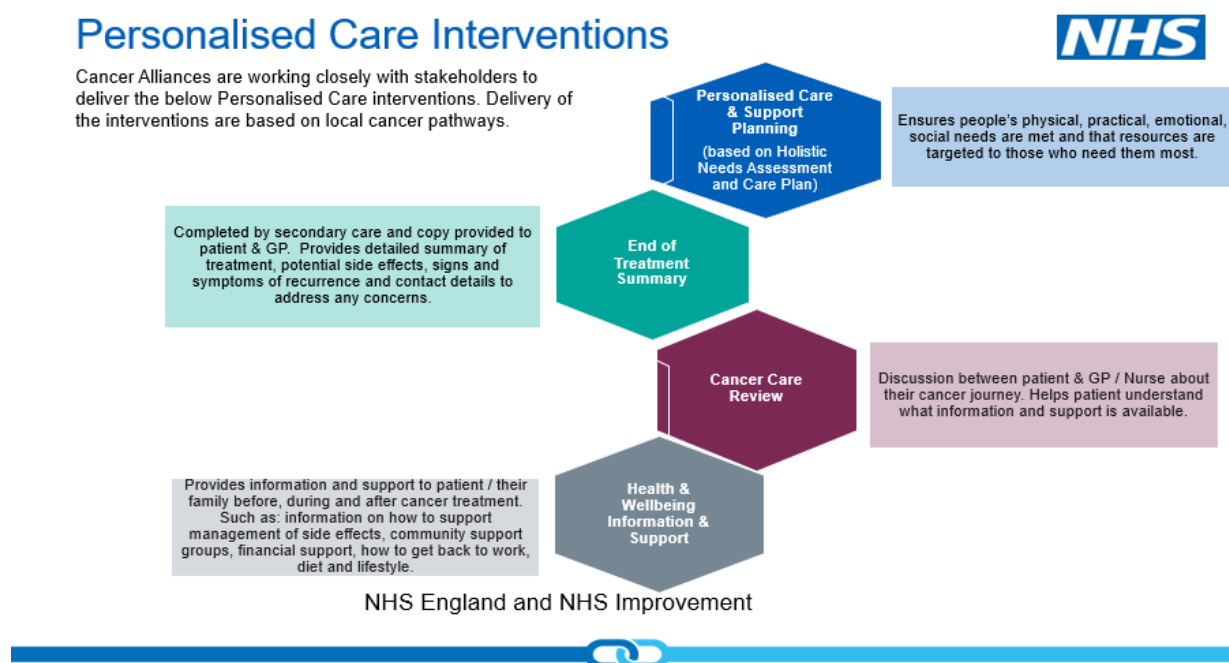
A key principle underpinning the whole pathway, across acute, primary care and community settings is what needs to happen within the existing system to prevent distress and promote adjustment.

Significant positive impact on patients, carers and families with the following simple steps:

- Effective use of Personalised Care interventions (see figure 7) focusing on effective communication and good partnership working between all staff across the whole pathway (for example Holistic Needs Assessments producing helpful care plans and Treatment summaries (TS) being shared with patient and GP), tailored health and well-being support and high quality cancer care reviews (CCRs) taking place within primary care (see TCST 4 point model here: <https://www.healthylondon.org/resource/commissioning-and-delivery-toolkit-for-cancer-as-a-long-term-condition/>)
- patients, families and carers being communicated with compassionately by all staff
- prompt efficient and reliable appointment systems and reporting processes in place across the whole pathway
- robust safety netting and follow-up in primary care
- early identification of who may need extra support (e.g by asking about current or past mental health issues, being aware of social isolation and socio-economic deprivation, recent or previous loss/bereavement, poor previous healthcare experiences)
- supporting a psychologically minded culture within primary and community care and across all cancer services emphasising the integration between physical health and psychological well-being.
- Supporting self-management across the pathway

## Effective use of Personalised Care (PC) Interventions

Figure 7: Personalised Care Interventions (formerly referred to as the Recovery package)

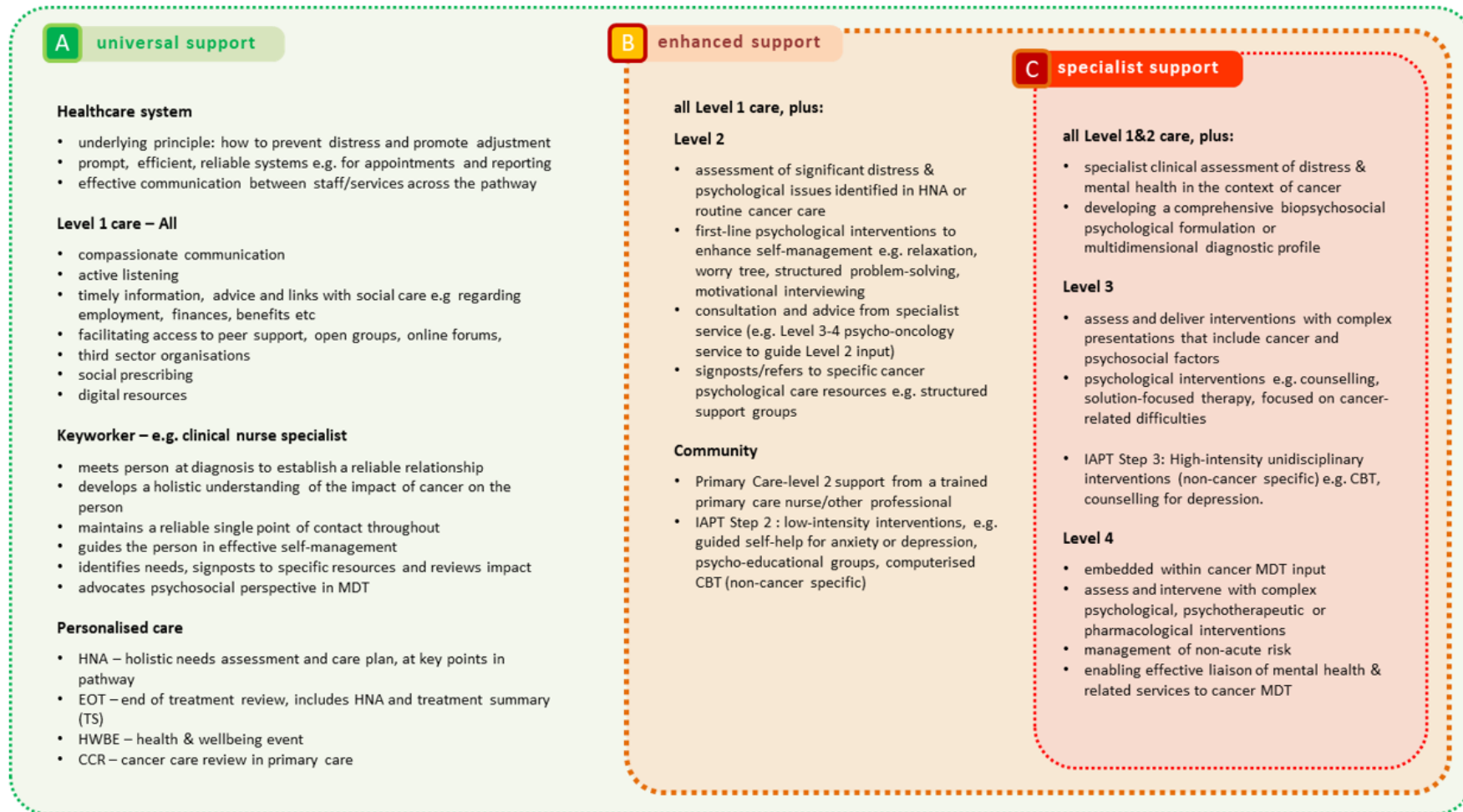


### B) There are three levels of support indicated in this pathway: universal, enhanced and specialist (see figure 8)

- Patients and their families may need different support at different times and may not proceed through universal, enhanced and specialist support in a linear or predictable fashion, so access to services must be flexible.
- All people affected by cancer will have access to universal support, a substantial proportion will require enhanced support episodically or throughout their cancer experience, and a smaller proportion will require specialist support at one or more timepoints. All components of the pathway must be coordinated and working in partnership to deliver excellent psychosocial support.



Figure 8: showing key features of universal, enhanced and specialist support



**C) It is a ‘whole’, integrated pathway for cancer psychosocial care across acute, community and primary care**

- The psycho-oncology team will work with key professionals across the pathway delivering consultation and sharing expertise, education, training and supervision
- Training and education will ensure that physical health and mental health are no longer regarded as separate, disconnected elements of healthcare
- Ultimately this way of working will encourage a “psychologically informed care”, which will improve patient outcomes and experience across acute, primary care and community settings

**D) Psycho-oncology teams, as the specialists in cancer and mental health, should take the lead to ensure a ‘whole system’/integrated approach to identifying and providing psychosocial support with clear and flexible referral pathways and processes, which are understood by professionals, patients, their carers and families**

- Within the pathway there is a clear role for both Psycho-oncology teams and IAPT services, which provide vital support at different points along the pathway
- Further consultation took place in phase 2 to ensure clarity regarding clinical criteria for referral and allocation, to address workforce education and training needs and to ensure that people with more complex presentations are seen by cancer specialists as recommended in NICE guidance.
- Optimising relationships and pathways between primary care, IAPT and psycho-oncology teams formed an important part of phase 2 of this work. The referral criteria outlined below was based on stakeholder feedback and the work of a Task and Finish group which included representation across Primary Care, IAPT lead, Psycho-oncology lead and a psychiatrist.
- Psycho-oncology teams need to ensure that they have the skills mix to ensure excellent delivery of cancer psychosocial care. The recent mapping of psycho-oncology services<sup>94</sup> identified that access to psychiatry remains a challenge with significant variation across London, leading at times to disjointed and uncoordinated care and potentially poorer outcomes for those with cancer and Serious Mental Illness (SMI).

The referral criteria outlined in the boxes below have been developed with widespread engagement and agreement at pan London stakeholder events and

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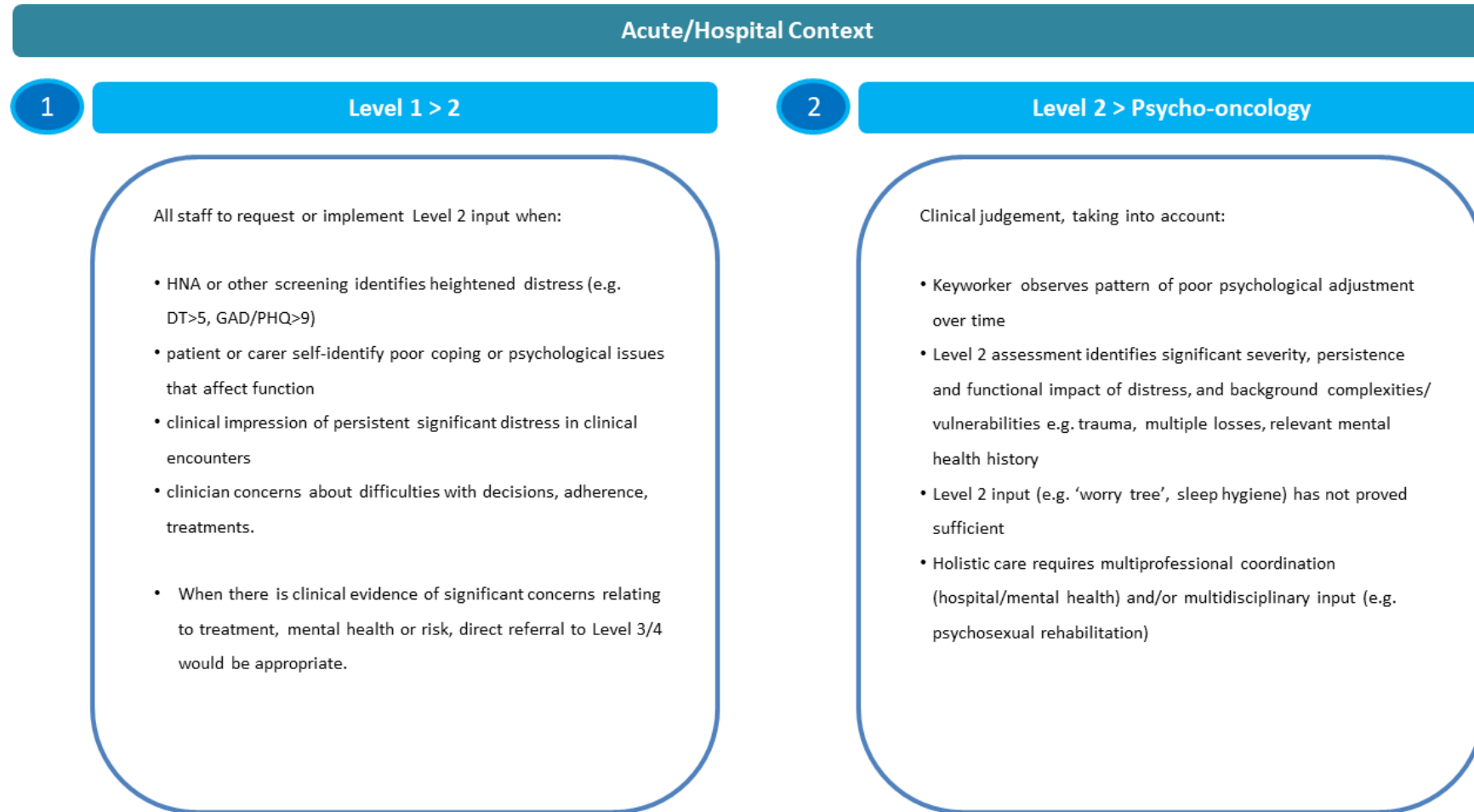
<sup>94</sup> Healthy London Partnership (2020), *Pan-London Mapping of Psycho-oncology Services*. Available here: <https://www.healthy london.org/psychosocial-support/>

within the Task and Finish group. The group had representation across Primary Care, IAPT, Psycho-oncology including a Consultant Clinical Psychologist and a Macmillan Consultant Liaison Psychiatrist.

The criteria outlined should be used by referrers to aid decisions of where to refer a patient across the pathway, but it must be acknowledged that clinical judgement should always be front and centre. Where it is unclear which service would be most appropriate, relationships should be developed locally where collaboration and partnership working means that these issues can be resolved swiftly through prompt dialogue.

Commissioners and service providers will also need to consider the increasing numbers of people who are living with treatable but not curable cancer. This cohort often reports psychological needs which may not be met with generalist services, such as IAPT, but their needs could be met by psycho-oncology teams with specialist expertise. However, these services usually have service delivery cut offs, averaging 12-24 months after treatment ends, due to resource constraints.

### 5.5.2. Referral criteria across the pathway



**Figure 9: Referral criteria across the pathway within the acute/hospital context**

## Referral Criteria (ii)

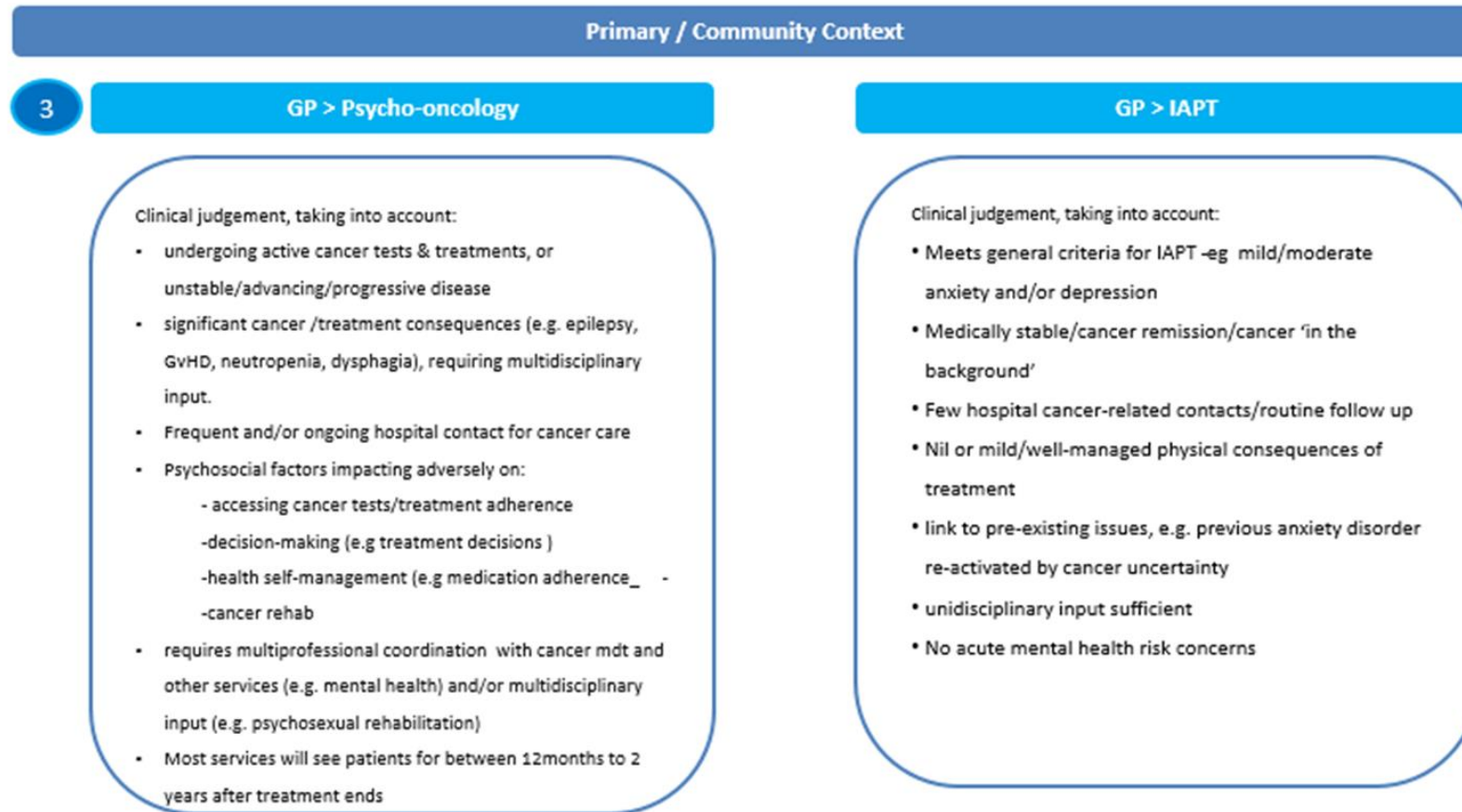


Figure 10: Referral criteria across the pathway within the acute/hospital context

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## Psycho-oncology teams leading service coordination and sharing expertise across the pathway

Psycho-oncology teams will :

- Across the whole pathway, coordinate and collaborate with other enhanced & specialist services (e.g. general hospital liaison psychiatry, community and specialist mental health, palliative care, primary care, IAPT, third-sector providers and others) to ensure the delivery of personalised care with a safe, individualised, comprehensive and clear plan.
- provide consultation, expert advice and training on cancer and psychological issues to a range of professionals across the whole pathway

The aim of this function overall will be to ensure:

- patients are offered all relevant choices
- all people with pre-existing SMI have optimal cancer treatment
- GPs , primary care staff and cancer MDTs are offered clear and reliable advice on how cancer care and mental health / psychological care will be coordinated

**Figure 11: Expanded role of psycho-oncology teams across the pathway**

It is recommended that the London Integrated Cancer Psychosocial Care Pathway is localised, and that agreement can be reached about the best referral pathways, using the guidance outlined above on referral criteria as well as considering the local service provisions, resource allocation and acknowledgement of the role of the third sector in local cancer support provision.

## 6. Key recommendations and next steps

### 6.1. Recommendations

The 12 recommendations made in the 2018 guidance document have been updated following ongoing stakeholder feedback from service providers, service users and commissioners across London, as well as national drivers such as the NHS Long Term Plan and the NHS Comprehensive Model for Personalised Care, which had not been launched prior to publication of the 2018 guidance document.

The recommendations have been separated into three broad categories which align with the pathway (see figure 6) i.e. universal, enhanced and specialist support.

#### Universal Support

**1. STPs /System leaders/Commissioners need to take a ‘whole system’ approach to identifying and providing a comprehensive network of psychosocial support, with clear and flexible referral pathways and processes, which are understood by professionals and service users. The London Integrated Cancer Psychosocial Care pathway should be adopted and localised by CCGs and STPs (in the context of developing Integrated Care Systems and Primary Care Networks) to identify gaps in psychosocial support and promote collaborative practice across the pathway.**

Feedback from stakeholders across London, including service providers, commissioners and service users, has shown that the Integrated pathway (see figure 6) is an extremely useful tool and has already been adopted and localised within several CCGs and STPs in London. Focus continues to be on the importance of having the patient at the centre of the pathway, with support and access based on individual psychosocial need, not just where the person is on their cancer pathway.

It is recommended that, where needed, to optimize local delivery and partnership working, that small working groups are established, to map local resources, identify gaps and address these gaps when required. These working groups (including representation from primary care, IAPT, and psycho-oncology teams) will result in better collaborations, sharing of skills and expertise and ultimately better clinical outcomes, patient experience and quality of life for people diagnosed with cancer and those significant to them.



## **2. Improving psychologically minded cancer care across the whole pathway will make a significant difference to clinical outcomes, patient experience and quality of life for all Londoners affected by cancer.**

A key message from service users is that people affected by cancer, including their families, carers and those significant to them, should be able to expect all staff with whom they have contact, to have a basic understanding of their psychological needs. This also includes not considering their physical health needs and psychological needs as separate.

Additionally, universal psychologically informed care can be improved with the following simple steps:

- focusing on effective communication and good partnership working between all staff across the whole pathway (for example Holistic Needs Assessments including care plans and Treatment summaries (TS) being shared with patient and GP)
- patients, families and carers being communicated with compassionately by all staff
- high quality, holistic cancer care reviews (CCRs) taking place within primary care (see TCST 4 point model available here: <https://www.healthylondon.org/resource/commissioning-and-delivery-toolkit-for-cancer-as-a-long-term-condition/>)
- prompt efficient and reliable appointment systems and reporting processes in place across the whole pathway
- robust safety netting and follow-up in primary care
- early identification of who may need extra support (e.g. by asking about bereavement and past losses, by having a thorough knowledge of current or past mental health issues, being aware of social isolation and socio-economic deprivation)
- p/rehabilitation services being offered to all
- Supporting self-management across the pathway

## **3. People affected by cancer need to be involved in shared decision-making and be empowered to take control of their own health and psychological well-being wherever possible.**

The Healthy London Partnership document, Steps towards implementing self-care<sup>95</sup>, identified that all five STPs in London have referenced self-care, prevention and social prescribing as a means of implementing person and community centred

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<sup>95</sup> Healthy London Partnership, *Steps towards implementing self-care: A resource for local commissioners* (2017). Available here: <https://www.healthylondon.org/wp-content/uploads/2017/10/Steps-toward-implementing-self-care-June-2017.pdf>

approaches. Patients want to be empowered to make informed choices in managing their own health, wellbeing and care. Shared decision making will require a culture shift to ensure “care planning and self- management is hard-wired into how care is delivered”, especially in relation to how long-term conditions such as cancer are managed<sup>96</sup>. Enablers of self-care involve a focus on patient activation/self-efficacy, improving health literacy and culture change and training within the workforce across the whole pathway.

#### **4. The significant differences in patient experience of cancer care, across several domains for marginalised and disadvantaged groups in London, must be addressed**

Patients from the most deprived areas of London report worse experiences than those from the least deprived in almost all aspects of care and this situation has not significantly improved in London over recent years. Cancer patients from minority ethnic groups have poorer experiences of cancer services than those who identify as white, on almost all aspects of care<sup>97</sup>. It is recommended that those providing psychosocial support use the TCST health inequalities toolkit, which is available here: <https://www.healthylondon.org/resource/cancer-inequalities-toolkit/>. It is further recommended that those providing psychosocial support also consider the Minimum Data Set as set out in the 2019 Integrated Care System Guidance for Cancer Rehabilitation (available here: <https://www.healthylondon.org/wp-content/uploads/2019/07/A-guide-to-reducing-variation-and-improving-outcomes-in-cancer-rehabilitation-in-London.pdf>) and how it can be adapted locally in order to benchmark services and ensure that health equity is considered in relation to access, acceptability and quality of services.

#### **5. The roll-out of the NHS England ‘quality of life’ (QoL) metric in 2020, which explicitly includes psychological well-being, provides a driver to ensure that psychosocial care is prioritised and effectively addressed across all STPs in London (including across Primary Care Networks and Integrated Care Systems)**

Given the impact of the physical health consequences of cancer and its treatment, mental health and social factors on quality of life, prioritising cancer rehabilitation and

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<sup>96</sup> Healthy London Partnership, *Steps towards implementing self-care: A resource for local commissioners* (2017). Available here: <https://www.healthylondon.org/wp-content/uploads/2017/10/Steps-toward-implementing-self-care-June-2017.pdf>

<sup>97</sup> Macmillan Cancer Support (2017) Mind the Gap, Cancer Inequalities in London [https://www.macmillan.org.uk/images/4057%20MAC%20Report%202017\\_tcm9-319858.pdf](https://www.macmillan.org.uk/images/4057%20MAC%20Report%202017_tcm9-319858.pdf)

psychosocial support across the pathway will be essential to ensure that quality of life improves for all Londoners affected by cancer.

**6. STPs and Alliances should actively signpost people affected by cancer to the Cancer Care Map, and ensure any relevant local online resources, where they exist, are regularly updated in line with the Cancer Care Map. STPs and Alliances should also ensure that all professionals across the pathway, especially community navigators, social prescribers and cancer keyworkers, access the Cancer Care Map, as well as the Cancer Information and Support Centres where needed. Additionally, STPs and Alliances need to ensure that the Cancer Care Map is kept up to date, by notifying of any changes to local services.**

The Cancer Care Map is available here: <https://www.cancercaremap.org/>. The map signposts to services across the UK, including those which focus on emotional support, health and wellbeing and practical concerns. Additionally, there are now 32 Cancer Information and Support Centres identified across London. Information and sign-posting, especially when personalised to the needs and preferences of the individual can have a significant positive impact on reducing anxiety and improving emotional well-being.

Many service users report that they had found out about services themselves and let their health professionals know about them. They identified that information provision and sign-posting, for example to third sector organisations and online support, can have a vital role in enabling people to access support early. This can have a powerful, preventative effect and impact on promoting psychological adjustment. Access to peer support was considered particularly valuable.

*“I found support out there myself. No-one told me. If I’d been directed to stuff earlier, I would have accessed it earlier which would have really helped”.*

## Enhanced Support

**7. To deliver personalised care as outlined in the NHS Long Term Plan, the psychosocial needs of the patient and those significant to them must be identified and reviewed at numerous points along the pathway. Personalised Care (PC) interventions remain important; within primary care in London, the Cancer Care Review 4-point model<sup>98</sup> needs to be seen as an opportunity to assess and record psychosocial needs and the emotional impact of cancer.**

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<sup>98</sup> Healthy London Partnership (2018) *Commissioning and delivery toolkit for cancer as a long-term condition*. Available here: <https://www.healthylondon.org/resource/commissioning-and-delivery-toolkit-for-cancer-as-a-long-term-condition/>

**Within acute settings, person-centred Holistic Needs Assessments (HNAs) and treatment summaries (TS) should provide similar opportunities. Health and Well-being information and Support must also be tailored to the person affected by cancer. If these interventions are delivered effectively this should prevent distress, promote adjustment and improve outcomes for patients.**

Meaningful evaluation should be planned to examine not just output (for example how many holistic needs assessments (HNAs) or cancer care reviews (CCRs) are completed) but actual impact on quality of life, follow up care, patient experience, and emotional well-being. If primary care teams (and patients) do not receive a treatment summary, this needs to be addressed and be seen as:

- a likely contributor to increasing patient anxiety
- having a negative impact on the ability of primary care teams to provide excellent patient care.

2018 eHNA data demonstrated that worry, fear or anxiety is the most reported concern across all age ranges. Interestingly, despite the wide range of psychosocial needs identified by the e-HNA, only 32.8 % of people received a care plan across all cancer types<sup>99</sup>. This indicates that even when needs are assessed and identified, this does not always result in the necessary action and support being offered.

**8. Psycho-oncology teams should take the lead in sharing their clinical expertise, providing training and consultation to all professionals working with people affected by cancer, their families and carers across the whole pathway, including acute, primary care and community settings.**

Clinical Nurse Specialists (CNSs) and Allied Health Professionals (AHPs) play a vital role in delivering a range of effective psychosocial interventions. Ongoing training and supervision from psycho-oncology teams, as indicated in NICE guidance<sup>100</sup>, must be prioritised to support this workforce in delivering the personalised care agenda, to improve staff retention and satisfaction and reduce staff burnout.

Improving Access to Psychological Therapies (IAPT) services for long-term conditions must work closely with psycho-oncology services when developing pathways for cancer to ensure clarity regarding local clinical criteria for referral and allocation and to address workforce education and training needs. Several psycho-

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<sup>99</sup> *Cancer Stats Dashboard*. Available here: <https://cancerstats.ndrs.nhs.uk/user/login>

NB. At the time of publication, the eHNA data provided via the Cancer Stats portal is limited. More detailed data outlined above is provided by the RM Partners Analytics team. For more information, please contact: [rmpartners.info@nhs.net](mailto:rmpartners.info@nhs.net)

<sup>100</sup> National Institute for Health and Care Excellence (2004) *Guidance on Improving Supportive and Palliative Care for Adults with Cancer*. Available here: <https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf773375005>

oncology leads in London have successfully delivered training on working with cancer for the IAPT long-term conditions workforce.

GPs and primary care staff are often the key point of contact for someone with cancer and this is especially the case with the increasing numbers of people living with cancer as a long-term condition or those experiencing the psychological consequences of cancer and its treatment. Psycho-oncology teams have a vital role in sharing expertise to improve the psychologically informed cancer care offered within primary care.

## Specialist Support

### **9. All acute hospitals where cancer is diagnosed and treated should have access to psycho-oncology teams, who are uniquely positioned as cancer specialists with expertise in psychological and mental health.**

Psycho-oncology teams work with a full range and severity of psychological and mental health difficulties associated with cancer. These teams play a vital role in both cancer prehabilitation and rehabilitation in supporting patients to access cancer investigations, treatment and post-treatment care thus improving patient experience and outcomes. They offer highly specialist clinical care for inpatients during medical admission and outpatients, as well as input for families and carers.

Psycho-oncology teams provide highly specialist 'indirect' services including rapid access to complex case consultation, supervision for Level 2 workers, for example, Clinical Nurse Specialists (CNSs) and Allied Health Professionals (AHPs) to fulfil peer review requirements<sup>101</sup>. Peer review requirements are still considered a useful framework by services to ensure high quality service delivery. These teams contribute psychological evidence and insights to quality improvement projects. There is a crucial role for psychologists with cancer expertise, embedded within cancer pathways, in addressing end of life psychological issues by facilitating important conversations and decision making with treating clinicians and families.

There should be access to a range of professional disciplines within psycho-oncology teams. There should be appropriate access to liaison psychiatry (preferably with oncology expertise) for both cancer inpatients and outpatients when needed to ensure an integrated service delivery and the best clinical outcomes. This avoids disjointed and unnecessary referral to already overstretched generic community mental health teams.

GPs, primary care professionals and community teams across the whole pathway should be able to easily access the expertise from psycho-oncology teams, thus

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<sup>101</sup> NHS England (2011) *National Cancer Peer Review Programme Manual for Cancer Services: Psychological Support Measures*

improving patient experience and outcomes for all those affected by cancer as well as their families and carers.

### **10. Acute and Community Palliative care services should include access to psychological specialists capable of delivering a range of interventions including domiciliary visits.**

Recent mapping of psycho-oncology provision across London, including cancer palliative care (available [here](#)), demonstrates that there is significant inequity and unwarranted variations in access to psychological interventions within both acute and community palliative care services. Additionally, there are issues around equity of access to services when they are available. Ability to get to a clinic should not determine whether a person can access a service. Domiciliary visits must be available by psychological specialists when indicated.

Furthermore, bereavement services must be clearly available to enable families and carers to access timely support, irrespective of where their loved one dies. Currently, whether their loved one dies at home, in hospital or within a hospice setting determines what bereavement support services are available. Ambitions for Palliative and End of Life Care<sup>102</sup> recognised the importance of involving, supporting and caring for those important to the dying person by delivering “good bereavement and pre-bereavement care”. Bereavement services are currently not clearly commissioned across London resulting in an inequity of provision, but these services must be considered an essential part of the support system.

## **Integrated Support**

### **11. Integrated cancer psychosocial care requires dedicated leadership and a dedicated platform within the relevant governance structures (STPs/Alliances/Integrated Care Systems/Primary Care Networks). This will drive and facilitate the collaborative work between professionals across acute, primary care and community services and between physical, mental health and social care, which is needed to improve outcomes for patients.**

The King’s Fund document ‘Bringing together physical health and mental health’<sup>103</sup> emphasises that the needs of an individual “are met in a co-ordinated way with medical, social and psychological needs being addressed together”.

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<sup>102</sup> National Palliative and End of Life Care Partnership (2015) *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*. Available here: <http://endoflifecareambitions.org.uk/>

<sup>103</sup> Kings Fund (2016) *Bringing together physical and mental health: A new frontier for integrated care*. Available here: <https://www.kingsfund.org.uk/publications/physical-and-mental-health>



Psycho-oncology leads across trusts should establish a networked group to act as a source of expertise and a conduit for London wide developments. The networked group should have representation at the London Personalised Care for Cancer Board (there is currently psycho-oncology representation on this board but not from a networked group) and consideration should also be made to having a psycho-oncology lead on the London Cancer Transformation and Improvement Board (CTIB). It is also recommended that STPs have a named psycho-oncologist on their cancer boards and on their personalised cancer care boards. Given that screening uptake, engaging in tests and investigations, treatment adherence, prehabilitation and rehabilitation, patient experience and quality of life are all mediated by psychosocial variables, it makes sense for there to be representation from psycho-oncology on a London regional programme board and at STP level.

## 6.2. Next Steps

Please note that from April 2020, TCST is no longer being funded or commissioned to support the delivery of the recommendations outlined in this report. Therefore, for the momentum to continue across London in improving psychologically informed cancer care, cancer alliances and STPs will need to prioritise this work and take the necessary steps to move this agenda forward. Additionally, where Macmillan Cancer Support fund existing psycho-oncology services, timely work will be needed with commissioners to future proof these services.

### For system leaders/commissioners

System leaders/Commissioners are asked to:

- l) Adopt the proposed London Integrated Cancer Psychosocial Care Pathway.
- m) Localise the pathway by mapping current resources, supporting partnership working and identifying gaps at STP/ICS level.
- n) Where there are no or very limited Psycho-oncology teams, allocate sufficient resource to ensure a Psycho-oncology service is available to deliver the outcomes indicated in the pathway (including closer working partnerships across Primary Care and Improving Access to Psychological Therapies (IAPT) services).
- o) Ensure that the commissioning recommendations outlined in this document are referenced in Sustainability and Transformation Plans (STPs) and that psychosocial support from diagnosis, through treatment, living with and beyond cancer and end of life care (across the whole pathway including



acute, primary care and community services) is reviewed. It will require commissioners to work closely and collaboratively with their provider colleagues and service users and to take a 'whole system' approach.

- p) Ensure that successful integration of physical health and mental health support for those affected by cancer across the pathway can be achieved by overcoming barriers such as separate budgets, payment systems and contracting arrangements.
- q) Consider how cancer psychosocial support can become embedded within the context of system reconfiguration such as Integrated Care Systems and Primary Care Networks.

### For providers

- r) Providers to review their current pathways and service provision in order to work collaboratively with their peers and commissioning colleagues, within integrated care systems, to help achieve the objectives outlined above.
- s) Ensure that they systematically capture a minimum data set that will enable them to complete health equity assessments and service improvements. This data set should also be able to demonstrate outcomes, productivity, challenges of meeting unmet needs and incorporate a wide range of quantitative and qualitative data needed to develop business cases.

### For alliances

- t) Consideration of the governance arrangements at STP and Alliance level to ensure that there is Psycho-oncology representation whenever decisions are being made regarding psychologically informed cancer care and developing and improving cancer psychosocial support.

### For others

- u) The third sector to work with the NHS and social care to ensure that the Cancer Care Map is kept up to date to reflect an accurate view of emotional support service provision on a local level.
- v) The third sector to work with the NHS to help support awareness raising and education on psychological care within the wider workforce.

## List of Acronyms

<b>Acronym</b>	<b>Term</b>
AHP	Allied Health Professional
CTIB	Cancer Transformation and Improvement Board
CCG	Clinical Commissioning Group
CCR	Cancer Care Review
CHD	Coronary Heart Disease
CNS	Clinical Nurse Specialist (cancer)
COPD	Chronic Obstructive Pulmonary Disease
EHIA	Equality and Health Inequalities Analysis
EHNA	Electronic Holistic Needs Assessment
HLP	Healthy London Partnership
HNA	Holistic Needs Assessment
HWB I&S	Health and Wellbeing Event Information and Support
IAPT	Improving Access to Psychological Therapies
ICS	Integrated Care System
ISC	Information and Support Centre
LTC	Long term condition
LTP	NHS Long Term Plan
LWBC	Living with and beyond cancer
MDT	Multidisciplinary Team
NCPES	Cancer patient experience survey
NCRAS	National Cancer Registration and Analysis Service
NCSI	National Cancer Survivorship Initiative
NICE	National Institute for Health and Care Excellence
PCN	Primary Care Network
QoL	Quality of Life
RP	Recovery Package
STP	Sustainability & Transformation Partnership
T&F	Task and Finish group
TCST	Transforming Cancer Services Team for London
TS	Treatment Summary

## Glossary

### Adjustment

Brennan's (2001) model<sup>104</sup> of adjustment describes an active process for the individual where the changes precipitated by cancer "are not always for the worse: sometimes they precipitate 'healthy personal growth' in a number of areas".

### Alliance

Cancer Alliances were established in 2016. They are a way to bring together local senior clinical and managerial leaders representing the whole cancer patient pathway across a specific geography. From April 2020, there will be four cancer alliances in London: North Central London, North East London, South East London, RM Partners (covering North West London and South West London).

### Allied Health Professional

Allied health encompasses a broad group of health professionals who use scientific principles and evidence-based practice for the diagnosis, evaluation and treatment of acute and chronic diseases; promote disease prevention and wellness for optimum health, and apply administration and management skills to support health care systems in a variety of settings<sup>105</sup>. In a cancer setting the most used professionals include physiotherapists, occupational therapists, dietitians and speech and language therapists.

### Cancer Rehabilitation

There are four recognised stages of cancer rehabilitation, which illustrate how rehabilitation spans the entire treatment pathway contributing to a range of positive outcomes. These are:

- 1) Preventative: reducing impact of expected disabilities and improving coping strategies
- 2) Restorative: returning an individual to pre-morbid levels of function
- 3) Supportive: in the presence of persistent disease and need for treatment, rehabilitation is aimed at limiting functional loss and providing support
- 4) Palliative: prevents further loss of function, measures are put in place to eliminate or reduce complications and to provide symptom management<sup>106</sup>.

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<sup>104</sup> Brennan, J (2001). Adjustment to cancer—coping or personal transition? .*Psycho-oncology*, 10(1), pp.1-18. <https://pdfs.semanticscholar.org/f049/60a5025562e5b2b49b0896de1f84e9f1443e.pdf>

<sup>105</sup> Association of Schools of Allied Health Professionals (2018), *Definition Of Allied Health*. Available here: <http://www.asahp.org/what-is/>

<sup>106</sup> Dietz, J.H (1980), *Adaptive rehabilitation in cancer*. *Postgraduate Medicine*, 68 (1): 145-153.

## Cancer Care Review

Is a discussion between a patient and their GP or practice nurse about their cancer. It usually takes place within six months of their cancer diagnosis. It helps the person affected by cancer understand what information and support is available to them in their local area, open up about their cancer experience and enable supported self-management<sup>107</sup>.

## Clinical Nurse Specialist

Registered nurses, who have graduate level nursing preparation and who would usually be expected to be prepared at Masters level. They are clinical experts in evidence based nursing practice within a specialty area. The specialty may be focused on a population (e.g. young people), type of care (e.g. palliative care), type of problem (e.g. lymphoedema), type of treatment (e.g. chemotherapy) or tumour type (e.g. lung cancer)<sup>108</sup>.

## Equality and Health Inequalities Analysis

Ensures that NHS England can demonstrate compliance, with statutory duties on reducing health inequalities. All tools and resources for this can be found here: <https://www.england.nhs.uk/about/equality/equality-hub/resources/>

## Electronic Holistic Needs Assessment

Allows a Holistic Needs Assessment (HNA) to be completed electronically<sup>109</sup>.

## Health

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity<sup>110</sup>.

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<sup>107</sup> Macmillan Cancer Support (2018), *The Recovery Package*. Available here: <https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package#297615>

<sup>108</sup> National Cancer Action Team (2010), *Quality in Nursing Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist*. Available here: <https://www.macmillan.org.uk/documents/aboutus/commissioners/excellenceincancercarethecontributionoftheclinicalnursespecialist.pdf>

<sup>109</sup> Macmillan Cancer Support (2018), *The Recovery Package*. Available here: <https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package#297615>

<sup>110</sup> World Health Organisation (2008), *Glossary of terms used*. Available here: <http://www.who.int/hia/about/glos/en/index1.html>

## Health seeking behaviour

Health seeking behaviour has been defined as any action undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy<sup>111</sup>.

## Holistic Needs Assessment

An HNA is a simple questionnaire that is completed by a person affected by cancer. It allows them to highlight the most important issues to them at that time, and this should inform the development of a care and support plan with their nurse or key worker. The questionnaire can be completed on paper, or electronically<sup>112</sup> and may be repeated several times within a period of care (eg at the start of cancer treatment and at the end of a phase of cancer treatment).

## Health and Wellbeing Information & Support

Information and Support can be offered in a range of ways such as education events, clinic appointments and information and support centres. The offer may be delivered by the NHS, local authority or third sector services. The purpose is to prepare the person for the transition to supported self-management. For people affected by cancer, the offer should include advice on the relevant consequences of treatment and the recognition of issues, as well as details of who to contact. It should also provide information and support about work and finance, healthy lifestyles and physical activity<sup>113</sup>. Families and carers should be encouraged to participate so that their needs are met too.

## Improving Access to Psychological Therapies

Improving Access to Psychological Therapies (IAPT) is an NHS programme rolling out services across England offering interventions approved by the National Institute of Health and Clinical Excellence (NICE) for treating people with depression and anxiety disorders<sup>114</sup>.

## Information and Support Centre

Is a space providing free confidential information and support for anyone affected by cancer. May be within a hospital facility or in the community and is often provided by the third sector.

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<sup>111</sup> Olenja J (2013), *Health seeking behavior in context* (Editorial). *East Afr Med J*.13(2):61–62

<sup>112</sup> Macmillan Cancer Support (2018), *The Recovery Package*. Available here: <https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package#297615>

<sup>113</sup> Macmillan Cancer Support (2018), *The Recovery Package*. Available here: <https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package#297615>

<sup>114</sup> NHS Digital (2017), *Improving Access to Psychological Therapies (IAPT)*. Available here: <http://content.digital.nhs.uk/article/4972/Improving-Access-to-Psychological-Therapies-IAPT>

## Integrated Care

Integrated care is an organising principle for care delivery with the aim of achieving improved patient care through better coordination of services provided. Integration is the combined set of methods, processes and models that seek to bring about this improved coordination of care<sup>115</sup>. Integration can be between physical and mental health, acute and community care or health and social care.

### Integrated Care System

In an integrated care system, NHS organisations, in partnership with local councils and others, take collective responsibility for managing resources, delivering NHS standards, and improving the health of the population they serve. There are currently 14 Integrated Care Systems nationally, which grew out of Sustainability and Transformation Partnerships set up in 2016.

### Long term condition

Long-term conditions or chronic diseases are conditions for which there is currently no cure, and which are managed with drugs and other treatment, for example: cancer, diabetes, chronic obstructive pulmonary disease, arthritis and hypertension<sup>116</sup>.

### Living with and beyond cancer

Looks at the whole patient pathway from start of diagnosis to surviving and living with cancer as a long term condition. Personalised care interventions within the living with and beyond pathway include: holistic needs assessments, care plans, treatment summaries, health and wellbeing information & support, cancer care reviews.

### Macmillan Badged

Badging refers to a post that through mutual agreement has either (a) previously been funded by Macmillan or (b) been adopted by Macmillan. More information can be found through the Macmillan website: [www.macmillan.org.uk](http://www.macmillan.org.uk)

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<sup>115</sup> Shaw s, Rosen R and Rumbold B (2011), *What is integrated care? An overview of integrated care in the NHS*, Nuffield Trust, UK. Available here: <https://www.nuffieldtrust.org.uk/files/2017-01/what-is-integrated-care-report-web-final.pdf>

<sup>116</sup> Kings Fund (2018), *Long-term conditions and multi-morbidity*. Available from: from <https://www.kingsfund.org.uk/projects/time-think-differently/trends-disease-and-disability-long-term-conditions-multi-morbidity>

## Multidisciplinary Team

A multidisciplinary team is a group of health and care workers who are members of different disciplines (professions e.g. Psychiatrists, Social Workers, etc.), each providing specific services to the patient<sup>117</sup>.

## Mental Health

Mental health is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community<sup>118</sup>.

## Mental health problems

Mental health problems affect around one in four people in any given year. They range from common problems, such as depression and anxiety, to rarer problems such as schizophrenia and bipolar disorder<sup>119</sup>.

## NHS Long Term Plan

The NHS Long Term Plan<sup>120</sup> was published in 2019 and sets out the priorities for the NHS in the following ten years. The Long Term Plan focuses on providing personalised care, high quality lifesaving treatment and care for patients and their families, as well as reducing pressure on NHS staff and investing in exciting new technologies.

## Prehabilitation

Prehabilitation is typically viewed as the beginning of the continuum of rehabilitation and occurs from the time of diagnosis to the point of receiving treatment for their cancer. The aim is to optimise patients' health, reduce the incidence and the severity of current and future impairments resulting from cancer treatment<sup>121</sup>.

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<sup>117</sup> Health Service Executive V2 (2017), *Multi-disciplinary team*. Available here:

<https://www.england.nhs.uk/wp-content/uploads/2020/01/multi-disciplinary-team-streamlining-guidance.pdf>

[https://www.hse.ie/eng/services/list/4/Mental\\_Health\\_Services/dsc/communityservices/Multidisciplinaryteam.html](https://www.hse.ie/eng/services/list/4/Mental_Health_Services/dsc/communityservices/Multidisciplinaryteam.html)

<sup>118</sup> World Health Organisation (2014), *Mental health: a state of well-being*. Available from:

[http://www.who.int/features/factfiles/mental\\_health/en/](http://www.who.int/features/factfiles/mental_health/en/)

<sup>119</sup> Mind (2017), *What are mental health problems?* Available here:

<https://www.mind.org.uk/information-support/types-of-mental-health-problems/mental-health-problems-introduction/#.WmcEm9J-qUk>

<sup>120</sup> NHS England, *Long Term Plan* (2019). Available here: <https://www.longtermplan.nhs.uk/>

<sup>121</sup> Leong, K. J. and Chapman, M. A. S. (2017), *Current data about the benefit of prehabilitation for colorectal cancer patients undergoing surgery are not sufficient to alter the NHS cancer waiting targets*. *Colorectal Dis*, 19: 522–524. doi:10.1111/codi.13723



## Primary Care Network

A primary care network consists of groups of general practices working together with a range of local providers, including across primary care, community services, social care and the voluntary sector, to offer more personalised, coordinated health and social care to their local populations. Networks would normally be based around natural local communities typically serving populations of at least 30,000 and not tending to exceed 50,000. Primary Care Networks began to be established in 2018/2019 with the aim of all being set up by June 2019<sup>122</sup>.

## Psychological Distress

A general term for the end result of factors (psychogenic pain, internal conflicts and external stress) that prevent a person from self-actualisation and connecting with significant others<sup>123</sup>.

## Psychosocial Support Services

Psychosocial support can include mental health counselling, education, spiritual support, group support, and many other such services. These services are usually provided by mental health professionals, such as psychologists, social workers, counsellors, specialized nurses, clergy, pastoral counsellors, and others. These professionals might also refer you or your family to other sources if they identify other needs<sup>124</sup>.

## Psycho-oncology

Psycho-oncology is a specialty that addresses the psychological factors in cancer that impact on access to treatment, recovery and well-being. Psycho-oncology examines the psychosocial needs of the patient and his or her family.

## Quality of Life (health related)

A combination of a person's physical, mental and social well-being. Not merely the absence of disease<sup>125</sup>.

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<sup>122</sup> NHS England (2019), *NHS Operational Planning and Contracting Guidance 2019/20*. Available here: <https://www.england.nhs.uk/wp-content/uploads/2018/12/nhs-operational-planning-and-contracting-guidance.pdf>

<sup>123</sup> Segen's Medical Dictionary "psychological distress.". Available here: <https://medical-dictionary.thefreedictionary.com/psychological+distress>

<sup>124</sup> American Cancer Society (2018) *Understanding Psychosocial Support Services*. Available here: [//www.cancer.org/treatment/treatments-and-side-effects/emotional-side-effects/understanding-psychosocial-support-services.html](https://www.cancer.org/treatment/treatments-and-side-effects/emotional-side-effects/understanding-psychosocial-support-services.html)

<sup>125</sup> National Institute for Health and Care Excellence (2018), *Glossary*. Available here: <https://www.nice.org.uk/Glossary?letter=H>

## **Personalised Care (PC) interventions (formerly known as the Recovery package)**

Personalised Care interventions are a series of key interventions which, when delivered together, can greatly improve outcomes for people living with and beyond cancer.

These include<sup>126</sup>:

- Holistic needs assessment (HNA), including a care plan
- Treatment summary
- Cancer Care Reviews (CCR) (conducted in primary care)
- Health and wellbeing information and support

### **Service User**

Generally 'service user' means anyone who is a patient or other user of health and / or social services<sup>127</sup>.

### **Shared Decision Making**

A key component of patient- centred health care. It is a process in which clinicians and patients work together to make decisions and select tests, treatments and care plans based on clinical evidence that balances risks and expected outcomes with patient preferences and values<sup>128</sup>.

### **Treatment Summary**

A Treatment Summary is a document (or record) completed by secondary care professionals, usually the multi-disciplinary team (MDT) after a significant phase of a patient's cancer treatment. It describes the treatment, potential side effects, and signs and symptoms of recurrence. It is designed to be shared with the person living with cancer and their primary care team.

The Treatment Summary aims to inform the GP and other primary care professionals of actions that need to be taken and who to contact with any questions or concerns for longer term management. The person affected by cancer also receives a copy to improve their understanding and to know if there is anything to look out for during their recovery<sup>129</sup>.

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<sup>126</sup> Macmillan Cancer Support (2018), *The Recovery Package*. Available here: <https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package#297615>

<sup>127</sup> University of Leeds (2018) *Service User & Carer Involvement*. Available here: <http://www.leeds.ac.uk/involvement/pages/about/about2.htm>

<sup>128</sup> National Learning Consortium (2013), *Shared Decision Making Factsheet*. Available from: [https://www.healthit.gov/sites/default/files/nlc\\_shared\\_decision\\_making\\_fact\\_sheet.pdf](https://www.healthit.gov/sites/default/files/nlc_shared_decision_making_fact_sheet.pdf)

<sup>129</sup> Macmillan Cancer Support (2018), *The Recovery Package*. Available here: <https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package#297615>

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- <sup>8</sup> Healthy London Partnership, *The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer* (2018). Available here: <https://www.healthylondon.org/wp-content/uploads/2018/05/Psychological-support-for-people-affected-by-cancer-May-2018.pdf>
- <sup>9</sup> London Strategic Clinical Networks, *Psychological support for people living with cancer Commissioning guidance for cancer care in London* (2015). Available here: <http://www.londonscn.nhs.uk/wp-content/uploads/2015/06/mh-cancer-commissioning-guide-062015.pdf>
- <sup>10</sup> NHS England, *Long Term Plan* (2019). Available here: <https://www.longtermplan.nhs.uk/>
- <sup>11</sup> Further details available here: <https://www.england.nhs.uk/personalisedcare/>
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- <sup>13</sup> Healthy London Partnership, *Steps towards implementing self-care: A resource for local commissioners* (2017). Available here: <https://www.healthylondon.org/wp-content/uploads/2017/10/Steps-toward-implementing-self-care-June-2017.pdf>
- <sup>14</sup> Macmillan Cancer Support (2017) *Mind the Gap, Cancer Inequalities in London* [https://www.macmillan.org.uk/images/4057%20MAC%20Report%202017\\_tcm9-319858.pdf](https://www.macmillan.org.uk/images/4057%20MAC%20Report%202017_tcm9-319858.pdf)

<sup>15</sup> Healthy London Partnership (2018) *Commissioning and delivery toolkit for cancer as a long-term condition*. Available here: <https://www.healthylondon.org/resource/commissioning-and-delivery-toolkit-for-cancer-as-a-long-term-condition/>

<sup>16</sup> *Cancer Stats Dashboard*. Available here: <https://cancerstats.ndrs.nhs.uk/user/login>

NB. At the time of publication, the eHNA data provided via the Cancer Stats portal is limited. More detailed data outlined above is provided by the RM Partners Analytics team. For more information, please contact: [rmpartners.info@nhs.net](mailto:rmpartners.info@nhs.net)

<sup>17</sup> National Institute for Health and Care Excellence (2004) *Guidance on Improving Supportive and Palliative Care for Adults with Cancer*. Available here: <https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf773375005>

<sup>18</sup> NHS England (2011) *National Cancer Peer Review Programme Manual for Cancer Services: Psychological Support Measures*

<sup>19</sup> National Palliative and End of Life Care Partnership (2015) *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*. Available here: <http://endoflifecareambitions.org.uk/>

<sup>20</sup> Kings Fund (2016) *Bringing together physical and mental health: A new frontier for integrated care*. Available here: <https://www.kingsfund.org.uk/publications/physical-and-mental-health>

<sup>21</sup> World Health Organisation (2006) *Constitution of the World Health Organization*. Available here: <http://www.who.int/about/mission/en/>

<sup>22</sup> All-Party Parliamentary Group on Arts, Health and Wellbeing(2017) *Creative Health: The Arts for Health and Wellbeing (Inquiry Report)*. Available here: [http://www.artshealthandwellbeing.org.uk/appg-inquiry/Publications/Creative\\_Health\\_Inquiry\\_Report\\_2017.pdf](http://www.artshealthandwellbeing.org.uk/appg-inquiry/Publications/Creative_Health_Inquiry_Report_2017.pdf)

<sup>23</sup> Jacobs, L.A; Shulman, L (2017) *Follow-up Care of Cancer Survivors: Challenges and Solutions*. The Lancet, 18 (1)

<sup>24</sup> Brennan, J., (2001). *Adjustment to cancer—coping or personal transition?*. *Psycho-oncology*, 10(1), pp.1-18. Available here: <https://pdfs.semanticscholar.org/f049/60a5025562e5b2b49b0896de1f84e9f1443e.pdf>

<sup>25</sup> Le Boutiller,C, Archer, S, Barry, C, King, A, Mansfield, L & Urch (2019), *Conceptual framework for living with and beyond cancer: A systematic review and narrative synthesis*, *Psycho-oncology* 2019; 1-12

<sup>26</sup> Transforming Cancer Services Team/Public Health England and Macmillan Cancer Support (2019) *Cancer prevalence dashboard 1995-2017 in London*. Available here: <https://www.healthylondon.org/resource/2017-cancer-prevalence-dashboard/>

<sup>27</sup> Independent Cancer Taskforce (2015) *Achieving World-Class Outcomes A Strategy for England 2015-2020*. Available here: [https://www.cancerresearchuk.org/sites/default/files/achieving\\_world-class\\_cancer\\_outcomes\\_-\\_a\\_strategy\\_for\\_england\\_2015-2020.pdf](https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf)

<sup>28</sup> Macmillan Cancer Support (2015) *The burden of cancer and other long-term conditions*. Available here: <https://www.macmillan.org.uk/documents/press/cancerandotherlong-termconditions.pdf>

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- <sup>30</sup> Macmillan Cancer Support (2015) *The burden of cancer and other long-term conditions*. Available here: <https://www.macmillan.org.uk/documents/press/cancerandotherlong-termconditions.pdf>
- <sup>31</sup> See: Macmillan Cancer Support (2006), *Worried sick: the emotional impact of cancer*. Available here: [https://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/impact\\_of\\_cancer\\_english.pdf](https://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/impact_of_cancer_english.pdf)
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<sup>51</sup> NHS England (2016) *The National Cancer Programme*

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## Appendix A: Mental Health and Cancer Task and Finish group

Name	Role	Organisation
Liz Price	Senior Strategy Lead, LWBC (Chair)	TCST
Daphne Earl	User representative	TCST
Mark Barrington	Chair, Psychological expert reference group	London Cancer
Alex King	Member, Mental Health and Psychological Support pathway group	Royal Marsden Partners
Afsana Safa / Martin Shelly	GP Advisor	TCST
Kathy Burn	CBT Therapist/CNS	St Christopher's Hospice
Ruth Weiner	Clinical psychologist	Newham Talking Therapies (IAPT)
Mary Docherty	Clinical Fellow	London MH Programme
Nikki Cannon	Senior Development Manager	Macmillan Cancer Support
Sahil Suleman	Macmillan Consultant Clinical Psychologist and Lead for Macmillan Cancer Psychological Support (CaPS) Team, Phoenix Centre	St George's University Hospitals NHS Foundation Trust:

## Appendix B: Psychosocial Support for Cancer Steering Group

Name	Role	Organisation
Philippa Hyman	Macmillan Mental Health Clinical Lead	TCST
Mark Barrington	Consultant Clinical Psychologist	Barts Health NHS Trust
Vanessa Brown	Senior Project Manager	RM Partners
Daphne Earl	User representative	Patient Representative
Jackie Ganley	Head of Service - Improving Access to Psychological Therapies (IAPT)	SLAM
Alison Hill	Lead Cancer Nurse	ULCH
Jill Anderson	Senior Commissioner	Merton & Wandsworth CCGs
Alex King	Consultant Clinical Psychologist	Imperial College
Liz Price	Associate Director	TCST
Karen Robb	Macmillan Rehabilitation Clinical Lead	TCST
Susan Hennessey	Lead Clinical psychologist in end of life care	Barts Health (Tower Hamlets CHS)
Sarah Hart		Patient Representative
Sinead Cope	Centre Head West London	Maggies Centre
Sue Smith	Consultant Clinical Psychologist	GSTT
Emma Tingley	Strategic Partnerships Manager – London	Macmillan
Nicola Weaver	GP	GP Practice
Jemima Reynolds	Health Programmes & Engagement	Trekstock
Sophie Lansdowne	Macmillan Project Manager: Personalised Care for Cancer	TCST
Yvonne Damanhuri	Administrator	TCST



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