

# **The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer**

Transforming Cancer Services Team for London

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We would like to thank the Mental Health and Cancer Task and Finish 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 Living with and Beyond Cancer Team, within the TCST, for their support and guidance during the past year.

## Executive Summary

The aim of this work by the Transforming Cancer Services Team (TCST) for London, funded and in partnership with Macmillan Cancer Support, was to produce a document with comprehensive recommendations, including both a pathway and service specification, to enable commissioners to improve the commissioning of psychological support services for people affected by cancer pan-London. This piece of work follows on from the [psychological support for people living with cancer guidance document](#) published in 2015<sup>1</sup>. It focuses specifically on what should be best practice in commissioning services for people affected by cancer and those significant to them, who experience emotional and psychological difficulties which impact on access to treatment, recovery and well-being. This includes services across the whole pathway: from diagnosis through acute treatment, living with and beyond cancer and end of life care.

This document:

- Provides a high-level overview of the range and complexity of psychological difficulties that affect the treatment, well-being and recovery of people living with and beyond cancer
- Identifies how services are currently commissioned in London, the gaps in services and where improvements are needed
- Clearly sets out the key components of a psychological support pathway, what excellent services should look like and what could be achieved in practice
- Identifies the key education and training needs for the wider workforce and how they can be addressed
- Outlines next steps, what further consultation is needed and how the recommendations can be implemented and evaluated.

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 who met 6 times between January and December 2017
- 2 successful stakeholder events in [May](#) and [October](#) 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) Psychologists and Psycho-oncologists
- Meaningful service user involvement throughout the process via focus groups, qualitative interviews, participation in stakeholder events and the Task and Finish group

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<sup>1</sup> London Mental Health Strategic Clinical Network and Transforming Cancer Services Team for London (2015) Psychological support for people living with cancer: Commissioning guidance for cancer care in London.  
<http://www.londonscn.nhs.uk/publication/psychological-support-for-people-living-with-cancer>

- An equality and health inequality screening of the psychological support pathway
- Mapping refresh of cancer psychological support services within acute hospitals, Clinical Nurse Specialist (CNS) support, Liaison psychiatry, Information and Support Centres and integrated IAPT services across London.
- National Patient Experience Survey NPES (2016) <https://www.healthylondon.org/our-work/cancer/patient-experience-survey/> and EHNA (Electronic Holistic Needs Assessment) data.
- Modelling of needs based on prevalence data for London (see prevalence workbook [http://www.ncin.org.uk/local\\_cancer\\_intelligence/tcst](http://www.ncin.org.uk/local_cancer_intelligence/tcst))
- Collaboration across other TCST work streams-cancer rehabilitation, primary care (Cancer Care Review 4 point model)
- Consultation with mental health, primary care and end of life care commissioners

Evaluation of the mapping data combined with feedback from a wide range of stakeholders has identified a range of key issues which build upon the ten recommendations made in the 2015 Psychological Support Guidance document<sup>1</sup>.

## **ACCESS TO CARE**

### **1. 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 the area of 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>2</sup>, contribute psychological evidence and insights to quality improvement projects, train and support staff to deliver Level 1 care (for example, effective information giving, compassionate communication and general psychological support) and the recovery package. Additionally, a crucial role for psychologists with cancer expertise, embedded within cancer pathways is addressing end of life psychological issues by facilitating important conversations and decisions with treating clinicians and families.

GPs, primary care professionals and community teams across the whole pathway should be able to easily access the expertise from psycho-oncology teams, thus improving patient experience and outcomes for all those affected by cancer as well as their families and carers.

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<sup>2</sup> NHS England (2011) *National Cancer Peer Review Programme Manual for Cancer Services: Psychological Support Measures*

Mapping of psychological support services within acute trusts and STPs has revealed that there still remains an inequity in service provision with some areas of London and West Essex having limited or no coverage from Psycho-oncology teams.

**2. Information directories need to be regularly updated for each STP area on local resources and online support for people affected by cancer, their carers and families which incorporate their physical, mental health and social care needs**

There are now 28 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. However, the National Cancer Patient Experience Survey (NCPES)<sup>3</sup> continues to highlight a significant proportion of patients and carers reporting not being given information about caring at home, potential side effects of treatment, enough support from health or social care, or information about financial help and benefits.

**3. STPs 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, patients, their carers and families**

Feedback from both stakeholder events emphasised that the patient must be at the centre of the pathway, with support and access based on psychosocial need, not just where the person is on the clinical pathway. Patients and carers must be able to self-refer and not have systemic, bureaucratic obstacles making the process prohibitive.

**4. 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>4</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 CARE**

**5. Integrated care requires a platform where professionals working across acute, primary care and community services, between physical, mental health and social care can collaborate to improve outcomes for patients**

The King’s Fund document *Bringing together physical health and mental health*<sup>5</sup> emphasises that the needs of an individual “are met in a co-ordinated way with medical, social and psychological needs being addressed together”. Therefore, a pan-London board for psychosocial support for adults affected by cancer should be constituted, where key stakeholders (including service users and clinicians) will work together to drive forward

<sup>3</sup> Quality Health Limited (2016) National Patient Experience Survey <http://www.ncpes.co.uk/index.php/reports/2016-reports>

<sup>4</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* <http://endoflifecareambitions.org.uk/>

<sup>5</sup> Kings Fund (2016) *Bringing together physical and mental health: A new frontier for integrated care* <https://www.kingsfund.org.uk/publications/physical-and-mental-health>

improvements in cancer psychosocial support for all Londoners. This will avoid duplication of work, provide opportunities to share learning and best practice develop an integrated approach and serve to address the inequity of provision in psychological support across London.

- 6. The psychosocial needs of the patient and those significant to them must be identified and reviewed at numerous points along the pathway. Within primary care in London, the Cancer Care Review 4 point model<sup>6</sup> needs to be seen as an opportunity to assess psychosocial needs and the emotional impact of cancer, whilst within acute settings person-centred Holistic Needs Assessments (HNAs) and treatment summaries should provide similar opportunities**

Further training for professionals across the pathway regarding physical health and mental health integration would be helpful to ensure that professionals feel confident to identify psychosocial issues affecting their cancer patients. An example of this may be routinely including a question about the impact of consequences of treatment (including physical or social consequences) on their quality of life. Psychological and emotional issues should not be seen as separate from physical health and socio-economic factors.

- 7. All the elements of the Recovery Package must be implemented effectively and seen as useful tools to 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 a GP (or patient) does not receive a treatment summary this needs to be addressed and seen as a likely contributor to increasing patient anxiety and potentially negatively impacting on the ability of Primary Care staff to provide excellent patient care.

In addition to the effective use of the recovery package, there are also small shifts in how professionals work across the pathway that can have a considerable impact on preventing distress and promoting adjustment. A few examples include: focusing on effective communication and good partnership working across the pathway, prompt efficient and reliable appointment and reporting processes, early identification of those who may need extra support, good safety netting and follow-up in primary care and developing a psychologically minded culture across all cancer services emphasising the integration between health and psychological well-being.

## **EDUCATION AND TRAINING**

- 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. This will mean working across acute, primary care and community settings**

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

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<sup>6</sup> Transforming Cancer Services Team for London (2015) *Cancer as a long term condition: A review of Cancer Care Reviews and a proposed model for London* <https://www.myhealth.london.nhs.uk/system/files/Cancer%20Care%20Review.pdf>

to ensure that people with more complex presentations are seen at Levels 3-4, as recommended by NICE guidance<sup>7</sup>, by cancer specialists within community or hospital settings, always with consideration of patient preference. Further consultation on optimising relationships and pathways between primary care, IAPT services and Psycho-oncology teams will form part of phase 2 of this work.

## **9. Psychosocial support for people affected by cancer should be considered 'Everybody's business'**

Over a decade ago an important document was published 'Everybody's Business: Integrated mental health services for older adults'<sup>8</sup>. A key message was that good quality care for older people was 'everybody's business' across the whole system, with person-centred, holistic care offered across physical health, mental health and social care.

A very powerful message from service users at both stakeholder events was that people affected by cancer, their families and carers should be able to expect that all staff with whom they have contact have a basic understanding of their psychosocial needs and those of their carers and to not consider their physical health and psychological needs as separate. In addition that when specialist psychological support is required, the referral process is simple and timely and staff are skilled to respond to their needs.

Education, training and workforce development are key to achieving this including junior staff through to the most senior experienced medical colleagues across acute, primary care and community services.

## **EQUALITY**

### **10. The significant differences in patient experience of cancer care across a number of 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<sup>9</sup>. 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>9</sup>. An initial Equality and Health Inequalities Screening Analysis<sup>10</sup> was completed using the NHS England screening tool within phase 1 of this work. A comprehensive Equalities and Health Inequalities Analysis will be completed in Phase 2 of this work to ensure that the recommendations in this report and service specifications meet the diverse needs of Londoners. As part of phase 2, there will be recommendations regarding what data needs to be captured across the pathway and how to evaluate services with consideration of the nine protected characteristics: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation. It is recommended that a number of other groups often excluded within healthcare should also be considered, for example, the homeless, vulnerable migrants and people affected by severe mental illness.

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<sup>7</sup> National Institute for Health and Care Excellence (2004) *Guidance on Improving Supportive and Palliative Care for Adults with Cancer* <https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005>

<sup>8</sup> Care Services Improvement Partnership and Department of Health (2005) *Everybody's business. Integrated mental health services for older adults: a service development guide* <http://www.wales.nhs.uk/sites3/Documents/439/everybodysbusiness.pdf>

<sup>9</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>10</sup> NHS England (2015) Equality and Health Inequalities Analysis: Refreshed NHS Continuing Healthcare Redress Guidance 2015 <https://www.england.nhs.uk/wp-content/uploads/2015/04/equal-hlth-inequal-anlys.pdf>

## **11. The introduction of the NHS England ‘quality of life metric’ in 2019 provides an opportunity to ensure that psychological and emotional well-being is prioritised across all STPs in London**

Given the impact of physical health consequences of cancer and its treatment, mental health and social factors on quality of life, prioritising cancer rehabilitation and psychosocial support across the pathway will be essential to ensure that quality of life improves for all Londoners affected by cancer.

### **SERVICE USER INVOLVEMENT**

## **12. 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>11</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 approaches. Patients want to be empowered to make informed choices in managing their own health, wellbeing and care. The NCPES (2016)<sup>6</sup> identified that only 33.3% of Londoners were given a care plan, thus identifying there is still a long way to go in ensuring that people feel empowered to take control of their health. Shared decision making will require a culture shift to ensure “care planning and self-management is hard-wired into how care is delivered”<sup>11</sup>, 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 across the whole pathway.

People affected by cancer, their families and carer must continue to be meaningfully and actively involved in service co-design to improve psychosocial care for Londoners. Service users were active participants in phase 1 of this work via focus groups, stakeholder events, interviews and involvement on the Transforming Cancer Services Team’s Mental Health and Cancer Task and Finish group meetings. NHS England has produced guidance on patient and public participation in commissioning health and care<sup>12</sup>, with ten key principles of participation including proactively seeking participation from people who experience health inequalities and poor health outcomes which will be an important part of phase 2 of this work.

### **NEXT STEPS**

#### **For commissioners**

- Commissioners to ensure that the commissioning recommendations outlined in this document are referenced in Sustainability and Transformation Plans (STPs) and that psychological 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 pathway’ approach.

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<sup>11</sup> Healthy London Partnership (2017) *Steps towards implementing self-care: A resource for local commissioners.* <https://www.healthylondon.org/wp-content/uploads/2017/10/Steps-toward-implementing-self-care-June-2017.pdf>

<sup>12</sup> NHS England (2017) *Patient and public participation in commissioning health and care statutory guidance for CCGs and NHS England* <https://www.england.nhs.uk/publication/patient-and-public-participation-in-commissioning-health-and-care-statutory-guidance-for-ccgs-and-nhs-england/>

- Further work will be required to 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.

#### ***For providers***

- Providers to review their current pathways and service provision in order to work collaboratively with their peers and commissioning colleagues to help achieve the objectives outlined above.

#### ***For alliances/vanguard***

- The three alliances/vanguards, in conjunction with TCST, to scope the merits and feasibility of developing a pan-London psychosocial cancer programme board. The aims of this board would be to drive forward the implementation of this pathway, provide peer support, disseminate knowledge and skills, share good practice and improve research and development opportunities. Additionally having one pan-London group would ensure equity of services and standards across London.

#### ***For others***

- The third sector to work with the NHS and social care to ensure there is an integrated online service directory including resources and online support that is available to support the emotional needs of people with cancer, preferably at STP level.
- The third sector to work with the NHS to help support awareness raising and education on psychological care within the wider workforce.

#### ***For TCST***

- To present the report at STP Cancer Boards and provide specialist expertise to support local implementation of best practice.
- Phase 2 of this work to include further consultation on details of the service specification, including workforce calculations, and to develop a business case to support the specification.
- Phase 2 of this work to include further consultation to optimise relationships and pathways between primary care, IAPT services and psycho-oncology teams.
- Phase 2 of this work to include a comprehensive health equity assessment to ensure the pathway and associated recommendations fit with the diverse needs of the population of London.
- To work closely with the Healthy London Partnership Communications Team to promote and disseminate the recommendations widely across London and West Essex.
- To continue to work with others e.g Macmillan Cancer Support to promote the recommendations regionally and where appropriate nationally.
- To present the report and specification to relevant areas of commissioning at a regional level, including Primary Care, Mental Health and End of Life Care.

Moving forward, this report should be considered alongside other TCST work streams including developments within primary care such as the Cancer Care Review 4 point model, which provides an opportunity to identify issues that may be impacting on quality of life and emotional well-being using multi-morbidity care planning as per NICE guidance 56.<sup>13</sup>

Additionally, the Cancer rehabilitation scoping report for London<sup>14</sup> has considered the importance of a holistic patient-centred approach encompassing physical, psychological, spiritual and social factors and the importance of psychological support being embedded within cancer prehabilitation and rehabilitation services. The recommendations by TCST outlined in this document provide a compelling narrative for improving the commissioning of services to positively impact on the mental health and quality of life of individuals throughout their cancer journey. We hope it will support commissioners in London to reflect on their current understanding of psychological 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**

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<sup>13</sup> National Institute for Health and Care Excellence (2016) *Multimorbidity: clinical assessment and management* <https://www.nice.org.uk/guidance/ng56/resources/multimorbidity-clinical-assessment-and-management-pdf-1837516654789>

<sup>14</sup> Transforming Cancer Services Team for London (2016) *Cancer Rehabilitation: a scoping report for London* <https://www.healthylondon.org/wp-content/uploads/2017/11/Cancer-rehabilitation-a-scoping-report-for-london.pdf>

## Introduction

**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 18 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 TCST to develop *Commissioning recommendations, pathway and a service specification for psychological Support for Adults with Cancer*.

There is a significant body of evidence that many people affected by cancer feel that their physical health needs are given far more attention than their psychological needs. 58 % of people with cancer feel their emotional needs are not looked after as much as their physical needs.<sup>15</sup> Mental health across all areas of the NHS has not been given the funding or priority it deserves over the years. There will always be competing priorities in an NHS with limited resources and growing demands on its services. However, we cannot ignore that “Mental health problems represent the largest single cause of disability in the UK. The cost to the economy is estimated at £105 billion a year - roughly the cost of the entire NHS”<sup>16</sup>

Identifying psychological and emotional support needs and providing high quality support is essential from diagnosis, through treatment, living with and beyond cancer and end of life care. This document provides recommendations for best practice in psychological support services and identifies the key issues that need to be addressed in London going forward. Our focus on early diagnosis of cancer and survivorship must also recognise that people are therefore living longer with the psychological and emotional consequences of cancer and the treatment received. We cannot neglect this area if we genuinely believe in improving quality of life for those affected by cancer.

Ambitious plans by NHS England to improve care and support for people once their treatment ends has led to the introduction of the new national ‘quality of life metric’ which will be

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<sup>15</sup> Macmillan Cancer Support (2014) *The Rich Picture: People with Cancer*

<http://be.macmillan.org.uk/Downloads/CancerInformation/RichPicture/MAC150691114RPPeoplelivingwithCancer-Interactive.pdf>

<sup>16</sup> NHS England (2016) *The Five Year Forward View for Mental Health* <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>

incorporated into the national cancer dashboard in 2019. Currently there is a pilot phase (2017-1019), with pilot sites at Barts Health NHS Trust and University College London NHS Foundation Trust. For the first time, there will be a measure which will capture how effective cancer support is and where service improvements may be required. 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 document will support commissioners in London to examine their current psychological 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.

## Foreword

Lauren Mahon, Service User



*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.*

**Dr Anthony Cunliffe, Joint National Lead Macmillan GP Adviser, Macmillan GP Adviser London and GP Lead, Transforming Cancer Services Team**



We know that cancer and its treatments can have a significant psychological impact on both the person diagnosed and those significant to them. The majority of people will use a variety of resources to cope including their own inner resilience, external sources of support such as family, friends, peer networks, third sector organisations or online support. But for some people the impact of cancer can be overwhelming, negatively impacting on quality of life and severe enough to warrant intervention by cancer specialists with expertise in the area of psychological and mental health.

I am delighted that Macmillan Cancer Support have funded and supported TCST to produce a pan London psychosocial pathway for people affected by cancer. The pathway, principles and recommendations in this report, emphasise the importance of keeping the needs of the patient at the centre of a pathway of support 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.

Psycho-oncology teams, usually based within acute hospitals, are uniquely positioned as cancer specialists and have a vital role in addressing psychological factors and supporting people to access cancer investigations, treatment, care, rehabilitation and recovery thus improving patient outcomes. They provide specialist psychological care for inpatients during medical admission and outpatients as well as support for families and carers. Additionally they offer a range of 'indirect' services including rapid access to case consultation and training and supervision for Level 2 workers such as Clinical Nurse Specialists and Allied Health Professionals.

The national Improving Access to Psychological Therapies (IAPT) programme began in 2008, to increase the availability of NICE recommended psychological treatments for people with depression and anxiety disorders. IAPT has now expanded to include people with long-term conditions and/ or medically unexplained symptoms. The main conditions that have been focused on to date have been diabetes, chronic obstructive pulmonary disease (COPD), coronary heart disease (CHD) and musculoskeletal problems/chronic pain. Since 2017, cancer is included within the scope of IAPT services. It is now essential that IAPT services work closely with psycho-oncology services when tailoring their cancer pathways for local implementation. This will ensure clarity regarding referral criteria, allocation, and identifying education and training needs for the IAPT workforce and when complex presentations need to be stepped up to cancer specialists.

A key principle underpinning the whole pathway across acute, community and primary care services is preventing distress and promoting adjustment. In simple terms there are small shifts in how we all work that can have a considerable impact on the mental health of those affected by cancer and those significant to them. A few examples include:

- 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 cancer care reviews (CCRs) taking place within primary care
- Prompt efficient and reliable appointment and reporting processes in place across the whole pathway
- Good safety netting and follow-up in primary care
- Identification of who may need extra support early on (e.g by asking about past losses, knowledge of current or past mental health history, social isolation, socio-economic deprivation)
- Developing a psychologically minded culture within primary care and across all cancer services emphasising the integration between physical health and psychological well-being.

Training and education may be needed for healthcare staff across the pathway to support this ambition, so that physical health and mental health are no longer regarded as separate, disconnected elements of healthcare.

There are also compelling economic arguments for addressing the psychological aspects of living with cancer as a long-term condition (LTC). A number of studies have found that:

- Healthcare costs are higher in those with a LTC who also have psychological difficulties such as depression and/or anxiety.
- In relation to spending on psychological therapy versus healthcare costs, savings exceed costs.

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 pathway approach and we need to address inequality in provision across London and West Essex.

I hope this report will provide the impetus needed for commissioners to drive forward the developments needed to improve the psychological well-being and quality of life for all Londoners at whatever point they are along the cancer pathway.

# 1. Understanding the psychological impact of cancer

## 1.1 Definition and causes

The World Health Organisation (WHO) defined health in its constitution<sup>17</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. The majority of 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>18</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.<sup>7</sup>

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.

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.

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<sup>17</sup> World Health Organisation (2006) *Constitution of the World Health Organization* <http://www.who.int/about/mission/en/>

<sup>18</sup> All-Party Parliamentary Group on Arts, Health and Wellbeing(2017) *Creative Health: The Arts for Health and Wellbeing (Inquiry Report)* [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)

Figure 1 Range of factors that contribute to psychological distress<sup>19</sup>

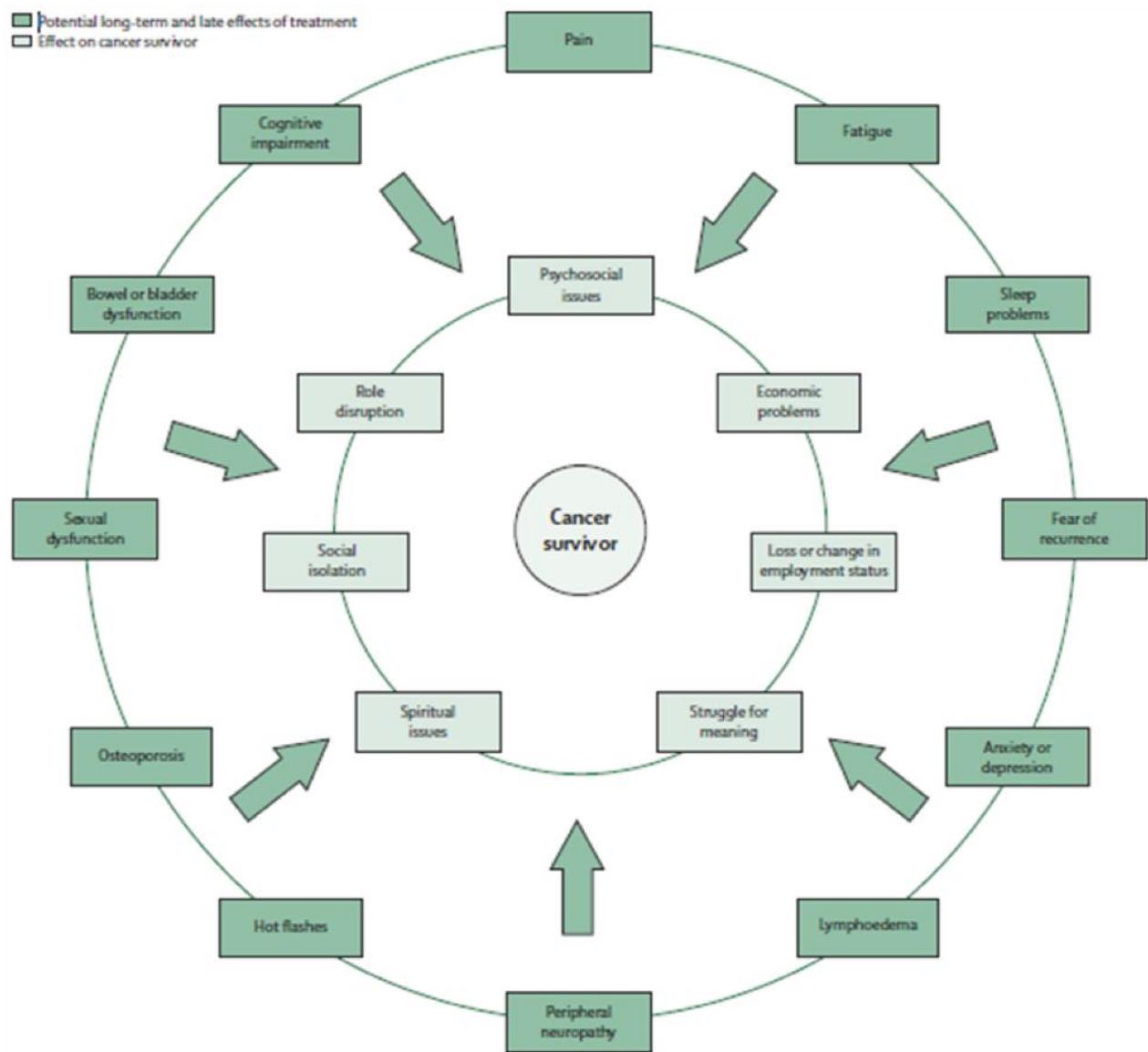


Figure 1: Potential long-term and late effects of treatment and how they affect cancer survivors

Potential long-term and late effects of treatment, any and all of which can affect the personal characteristics of the cancer survivor.

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
- 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

<sup>19</sup> Jacobs, L.A; Shulman, L (2017) Follow-up Care of Cancer Survivors: Challenges and Solutions. The Lancet, 18 (1)

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.

### **Concept of psychological adjustment to cancer**

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>20</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).

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

### **Concept of psychological distress and help-seeking behaviour**

It is important to consider the range of factors that influence help-seeking behaviour for psychological distress. Help seeking has been found to relate to a number of factors, including an individual's desire to "maintain their concept of normality or to seek a new normal", "being emotionally literate" (the extent to which someone can evaluate and express their emotional distress), "perceptions of help" including there being limited help available, the limited benefits of help, perceived risks of help (for example stigma) versus benefits of help<sup>21</sup>.

How an individual views psychological distress in the context of cancer will influence help-seeking behaviour. An individual's desire to "attain normality" is critical to understanding why individuals seek, accept or decline help. If a patient perceives distress as a normative reaction to cancer, they will not consider professional intervention as necessary until the distress becomes problematic; interfering with their life to such an extent they require help to restore their life to some form of "normality".

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<sup>20</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>21</sup> Carolan, C.M., Smith, A., Davies, G.R. and Forbat, L. (2017). Seeking, accepting and declining help for emotional distress in cancer: A systematic review and thematic synthesis of qualitative evidence *European journal of cancer care*.

<https://www.ncbi.nlm.nih.gov/pubmed/28597493>

It is important for clinicians to explore a patient's socio-cultural beliefs about mental health, their own appraisal of distress, an individual's beliefs about help-seeking and actively enquire about support available from social networks. This ensures that there is congruence between help offered by health care professionals and help desired by the individual. It also demonstrates why it is essential that a person can easily access help at any point along the cancer pathway as their beliefs about help-seeking may change.

## 1.2 Prevalence and statistics

In London, patients who had a diagnosis of cancer and were alive on 31/12/2015<sup>22</sup> (Data source NCRAS):

- Persons: 209,538 (2415.78 per 100,000)
- Males: 94,316 (2188.55 per 100,000)
- Females: 115,222 (2640.16 per 100,000)

For comparison to England:

- Persons: 1,791,366 (3,269.73 per 100,000)
- Males: 805,944 (2,981.74 per 100,000)
- Females: 985,422 (3,550.17 per 100,000)

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

### *Modelling 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”<sup>7</sup> (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)<sup>7</sup>

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.

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<sup>22</sup> Transforming Cancer Services Team/Public Health England and Macmillan Cancer Support (2017) *Detailed cancer prevalence estimates 1995-2015 in London*

**Table1: Number of cancer patients in London requiring specialist psychological support within 1 year of diagnosis**

Delivery Units	Locality	CCG Code	CCG Name	1 Yr Prevalence (Cases - 2015 Diagnosis)	15% Requiring Level 3 Intervention	10% Requiring Level 4 Intervention	
UCLH Cancer Collaborative	BHR	07L	NHS BARKING AND DAGENHAM CCG	486	73	49	
		08F	NHS HAVERING CCG	982	147	98	
		08N	NHS REDBRIDGE CCG	873	131	87	
	WELC	07T	NHS CITY AND HACKNEY CCG	655	98	66	
		08M	NHS NEWHAM CCG	667	100	67	
		08V	NHS TOWER HAMLETS CCG	472	71	47	
		08W	NHS WALTHAM FOREST CCG	709	106	71	
	NCL	07M	NHS BARNET CCG	1051	158	105	
		07R	NHS CAMDEN CCG	599	90	60	
		07X	NHS ENFIELD CCG	980	147	98	
		08D	NHS HARINGEY CCG	669	100	67	
		08H	NHS ISLINGTON CCG	550	82	55	
	West Essex	07H	NHS WEST ESSEX CCG	1175	176	118	
	RM Partners	NWL	07P	NHS BRENT CCG	894	134	89
			09A	NHS CENTRAL LONDON (WESTMINSTER) CCG	416	62	42
07W			NHS EALING CCG	878	132	88	
08C			NHS HAMMERSMITH AND FULHAM CCG	479	72	48	
08E			NHS HARROW CCG	734	110	73	
08G			NHS HILLINGDON CCG	825	124	83	
07Y			NHS HOUNSLOW CCG	652	98	65	
08Y			NHS WEST LONDON CCG	578	87	58	
SWL		07V	NHS CROYDON CCG	1251	188	125	
		08J	NHS KINGSTON CCG	495	74	50	
		08R	NHS MERTON CCG	602	90	60	
		08P	NHS RICHMOND CCG	693	104	69	

		08T	NHS SUTTON CCG	717	108	72
		08X	NHS WANDSWORTH CCG	835	125	84
South East London	SEL	07N	NHS BEXLEY CCG	922	138	92
		07Q	NHS BROMLEY CCG	1267	190	127
		08A	NHS GREENWICH CCG	757	114	76
		08K	NHS LAMBETH CCG	724	109	72
		08L	NHS LEWISHAM CCG	715	107	72
		08Q	NHS SOUTHWARK CCG	736	110	74
STP Localities		North London		3849	577	385
		East London		4844	727	484
		North West London		5456	818	546
		South East London		5121	768	512
		South West London		4593	689	459
Vanguard/Alliance Geographies		UCLH Cancer Collaborative		9868	1480	987
		RM Partners		10049	1507	1005
		South East London		5121	768	512
<b>TCST Region (includes West Essex)</b>				<b>25038</b>	<b>3756</b>	<b>2504</b>
<b>London Region</b>				<b>23863</b>	<b>3579</b>	<b>2386</b>
Limitation: this will not take into account those who have had a psychological event and have since died.						

## 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>23</sup>. But now more than half of people receiving a cancer diagnosis will live ten years or more<sup>24</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. There are currently approximately 2.5 million survivors of cancer increasing to 3 million, the projected increase by 2030.

The number of people living more than 5 years from the initial diagnosis is predicted to more than double between 2010 and 2030. 70% of people with cancer are also living with at least one other long-term condition and nationally it is estimated that there are 700,000 people are living with cancer and three or more long-term conditions<sup>22</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 Commissioning Board in December 2015.<sup>6</sup>

Macmillan Cancer Support has produced a number of 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. *Worried sick: the emotional impact of cancer* (2006)<sup>25</sup>, *Cured-but at what cost?* (2013)<sup>26</sup>, *Throwing light on the consequences of cancer and its treatment* (2013)<sup>27</sup>, *Rich Picture Series* (2015)<sup>15</sup>, and *Am I meant to be OK Now?* (2017)<sup>28</sup>.

Both cancer and mental health are strategic priorities for NHS England. The Five Year Forward View (FYFV)<sup>29</sup> for the NHS 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>30</sup>, the 2010 NCSI vision<sup>31</sup> and *Living with and beyond cancer: taking action to improve outcomes* (2013)<sup>32</sup>,

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<sup>23</sup> Independent Cancer Taskforce (2015) *Achieving World-Class Outcomes A Strategy for England 2015-2020* [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>24</sup> Macmillan Cancer Support (2015) *The burden of cancer and other long-term conditions* <https://www.macmillan.org.uk/documents/press/cancerandotherlong-termconditions.pdf>

<sup>25</sup> Macmillan Cancer Support (2006) *Worried sick: the emotional impact of cancer* [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>26</sup> Macmillan Cancer Support (2013) *Cured-but at what cost?* [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)

<sup>27</sup> Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment* <https://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/throwinglightontheconsequencesofcancerandits-treatment.pdf>

<sup>28</sup> Macmillan Cancer Support (2017) *Am I meant to be OK Now?* <https://www.macmillan.org.uk/assets/lwbc-report-2017.pdf>

<sup>29</sup> NHS England (2014) *Five Year Forward View* <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

<sup>30</sup> National Cancer Survivorship Initiative (2007) (archived) <http://webarchive.nationalarchives.gov.uk/20100809103735/http://www.improvement.nhs.uk/cancer/Default.aspx?alias=www.improvement.nhs.uk/cancer/survivorship>

<sup>31</sup> National Cancer Survivorship Vision (2010) (archived) <http://webarchive.nationalarchives.gov.uk/20100809113601/http://www.improvement.nhs.uk/cancer/LinkClick.aspx?fileticket=4apVUSvGcow%3d&tabid=214>

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>5</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 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>7</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. National Cancer Peer Review Programme Manual for Cancer Services: Psychological support measures (2011)<sup>2</sup> also outlined quality standards, measures, and workforce and service requirements for the delivery of psychological support within hospital settings.

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>33</sup>. For example the NICE guidance for Improving outcomes for people with brain and other CNS tumours<sup>34</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.

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 mainly 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>35</sup>, IAPT services have now expanded

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<sup>32</sup> Living with and beyond cancer: Taking action to improve outcomes (March 2013)

[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>33</sup> Royal College of Psychiatrists (2009) The Mental Health Content of Physical Health Guidelines, <https://www.rcpsych.ac.uk/pdf/NICE%20and%20SIGN%20mental%20health.pdf>

<sup>34</sup> National Institute for Health and Clinical Excellence (2006), Improving outcomes for people with brain and other central nervous system tumours <https://www.nice.org.uk/guidance/csg10/resources/improving-outcomes-for-people-with-brain-and-other-central-nervous-system-tumours-update-27841361437>

<sup>35</sup> Chiles, J.A.; Lambert, M.J and Hatch, A.L (1999) The impact of Psychological interventions on medical cost offset: A meta-analytic review. *Clinical Psychology: Science and Practice*, 6(2):204-220 <http://psycnet.apa.org/record/1999-03053-005>

into providing support for people with long term conditions or medically unexplained symptoms, in what is termed 'Integrated IAPT'.

Integrated IAPT services started to treat people with long-term conditions in January 2017, with 22 wave 1 early implementer sites across England (including Hillingdon and Richmond), focusing mainly on diabetes, coronary heart disease (CHD), chronic obstructive pulmonary disease (COPD) medically unexplained symptoms and pain. Further funding has now been released for wave 2 of integrated IAPT with 15 new sites nationally. 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". Future developments in supporting those affected by cancer within IAPT services will require clarification regarding referral criteria and allocation as well as the training needs for the IAPT workforce.

At a time when early diagnosis and cancer waiting times are being prioritised it will be essential to also 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 has to be considered within the context of quality of life. The results of the National Cancer Patient Experience Survey (2016) are particularly important in highlighting the key issues that need addressing within acute and community contexts.

NHS England's National Cancer Programme (2016)<sup>36</sup> has a number of strategic priority areas which may provide an opportunity to drive forward the commissioning of psychological support services. Firstly, a focus on establishing patient experience as on a par with clinical effectiveness and safety, secondly the future roll out of the cancer Quality of Life Metric, and finally 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>5</sup>. In 2014, both the London Cancer Alliance (LCA)<sup>37</sup> and London Cancer (LC)<sup>38</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 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>1</sup>.

There were ten key recommendations made in this document:

1. Timely access to commissioned support should be available for the whole cancer pathway. Throughout the pathway people with cancer should be actively informed of the potential need for psychological support and given guidance on access and availability.
2. Individuals should have access to a range of emotional and psychological support according to need.

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<sup>36</sup> NHS England (2016) The National Cancer Programme,

<sup>37</sup> London Cancer Alliance (2014) Mental Health and Psychological Support Service Specification and Referral Guidelines, <http://www.londoncanceralliance.nhs.uk/media/100472/lca-mh-ps-service-spec-final-dec-14.pdf>

<sup>38</sup> London Cancer 2014 Service Specification Psychological Support Services, <http://londoncancer.org/media/89175/psychological-service-specification-final-2014june-.pdf>

3. Psychological support should be available to families and carers.
4. All health and social care staff involved in cancer care should have education, training and supervision that enables them to identify emotional problems and provide psychological support at an appropriate level.
5. Commissioners should ensure that Information and Support Centres (ISCs) are available at all acute trusts.
6. All people living with cancer should be offered a Holistic Needs Assessment with care planning at key points along the pathway.
7. Community provision for emotional and psychological support should be supported and developed.
8. Specific groups should be proactively supported. For example: men, people with severe and enduring mental illness, those who do not speak English as a first language, people with learning disabilities, older people etc
9. Psychology services providing support to cancer centres should be located on-site.
10. Co-production with people affected by cancer and their carers should be integral to service development.

What was clear was that this guidance document had only begun the process of identifying the key issues. There was recognition that the commissioning and provision of psychological support remains uncoordinated. The pathway is unclear, from diagnosis of cancer through to living with cancer as a long term condition and end of life care. Service level quality and productivity standards have not been agreed for London.

In response to this, Macmillan funded and have partnered with the Transforming Cancer Services Team to develop a pan London end-to-end psychological care pathway and service specification. A preliminary psychological care pathway was presented at two events in May and October 2017 to obtain feedback from key stakeholders including service users, service providers, the third sector and commissioners on the key ideas and principles which should be incorporated into the final pathway.

### ***National Cancer Patient Experience Survey (NCPES) 2016<sup>3</sup>***

The most recent NCPES survey demonstrates that although progress has been made in London across a number of domains, there remain many areas where further improvements are needed. The survey predominantly focuses on people during their acute hospital treatment episode. A number 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. The table below shows a selection of questions that are particularly relevant to experiences of cancer care and future emotional well-being.

**Table 2 National Cancer Patient Experience Survey (NCPES) 2016**

<b>Patients' experience of written and verbal information</b>	<b>2016 Survey</b>	<b>2016 Survey</b>
<b>Issue</b>	<b>London percentage</b>	<b>England</b>

Q. 15 Patient definitely told about any side effects of treatment that could affect them in the future	52.4%	54.7%
Q 22 Being given information by staff about how to get financial help or benefits	54.3%	56.8%
Q 35 Patient was able to discuss worries or fears with staff during visit (Inpatient)	50.6 %	52.2%
Q 41 Patient was able to discuss worries or fears with staff during visit (Day patient/Outpatient)	66.2%	71.1%
Q 49 Hospital staff gave family or someone close all the information needed to help with care at home.	55.7%	58.2%
Q 50 Patient definitely given enough support from health or social services during treatment	44.3 %	54.1%
Q 51 Patient definitely given enough support from health or social services after treatment	37.6%	45.7%
Q 53 GPs and Practice staff did everything they could to support the patient	56.6%	62.2%
Q 54 Hospital and community staff always worked well together	54.7%	62.1%
Q 55 Patient given a care plan	33.3%	33.3%

On a number of 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.<sup>23</sup>

A recent publication by Macmillan Cancer Support<sup>9</sup>, focusing on cancer inequalities in London, analysed the NCPES 2016 data. Key findings included that those from the most deprived areas of London report worse experiences than those from the least deprived areas in almost all aspects of care. Additionally, minority ethnic cancer patients reported poorer experiences of cancer services than those who identify as white, on nearly all aspects of care.

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.

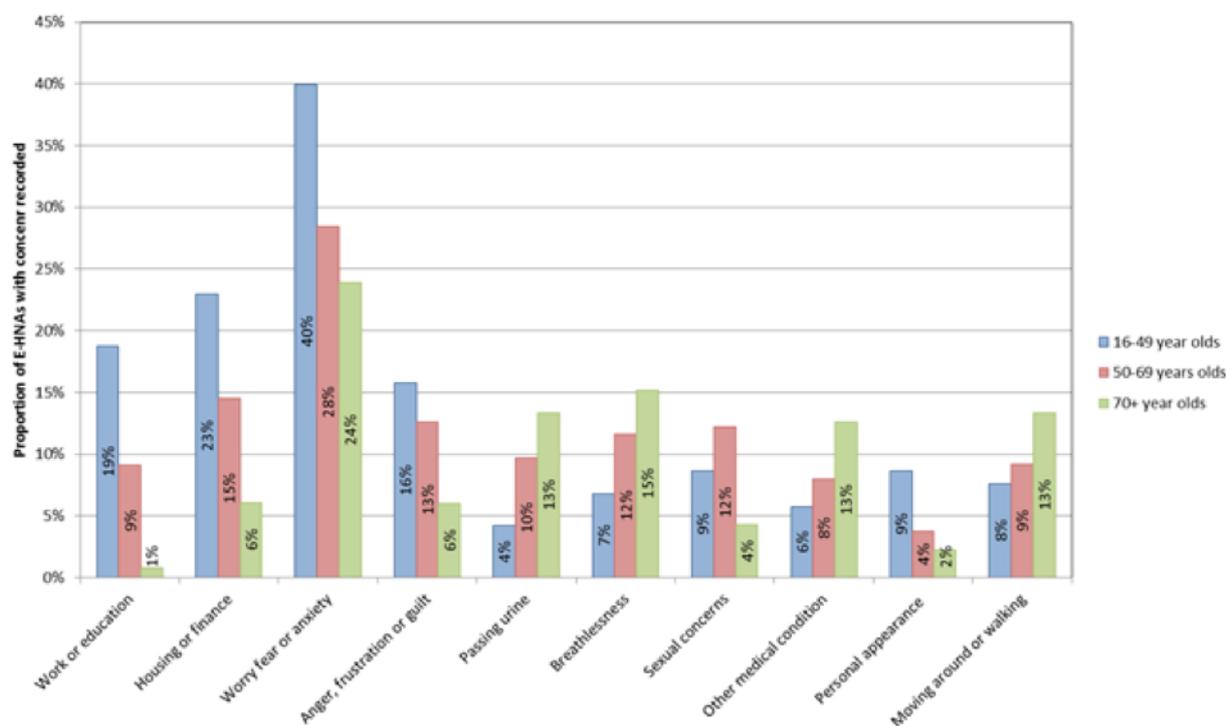
### **Holistic Needs Assessment**

Results from London's 2016 E-Holistic needs assessment data support the importance of understanding the interaction between physical health, mental health and social factors.

### **Figure 2 E Holistic Needs Assessment Results**

## E Holistic Needs Assessment results

Graph showing the proportion of patients by age-band across London who reported concerns in E-HNA in 2016 (Ten concerns with biggest variation by age band)



For example, 23% of 16-49 year olds identify housing or finance as a significant concern and 19% work or education. The results of the EHNA data from 2016 demonstrates the range of issues impacting on people affected by cancer and the importance of an approach to psychological support which encompasses physical health, mental health and social factors, rather than seeing separate items in isolation.

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. Under a quality of life framework, psychological wellbeing will now have to be prioritised in regard to the central impact of mental health 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>25</sup>
- Even 10 years after treatment 54% of people affected by cancer still suffer from at least one psychological issue<sup>39</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

<sup>39</sup> Impact Briefs: Psychological and Emotional Support (Macmillan Cancer Support, 2015)  
[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)

psychological services. These symptoms are also seen in 10-15 %of patients with advanced disease<sup>7</sup>

- Cancer patients have a 55% higher risk of suicide than those without cancer<sup>40</sup>
- The long term consequences of cancer include<sup>5</sup>:
  - 500,000 people are facing poor health or disability after treatment for cancer,
  - 350,00 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 lymphedema.

## 2.5 Quality of Life Metric

Achieving world class cancer outcomes: A strategy for England 2015-2020<sup>41</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.**

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 been selected including UCLH Cancer Collaborative and Bart's Health. The pilot and evaluation period runs from September 2017 until early 2019.

“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 things are going well and where improvements can be made.” – NHS England 2017<sup>42</sup>

Psychological and emotional well-being will have to be prioritised and for the first time regarded as central to maintaining quality of life with parity to physical health.

## 2.4 Economic impact of poor mental health

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<sup>40</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 <http://www.europsy.net/wp-content/uploads/2017/03/cancersuicide.pdf> .

<sup>41</sup> NHS England (2016) Achieving world class cancer outcomes: A strategy for England 2015-2020, <https://www.england.nhs.uk/publication/achieving-world-class-cancer-outcomes-a-strategy-for-england-2015-2020/>

<sup>42</sup> NHS England (2017) New quality of life measure for recovering cancer patients (news article) <https://www.england.nhs.uk/expo/2017/09/12/new-quality-of-life-measure-for-recovering-cancer-patients>

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. Cancer is increasingly seen as a long-term condition. The number of people living more than five years from the initial diagnosis is predicted to more than double between 2010 and 2030.

- 70 % of people with cancer are also living with at least one other long-term condition<sup>23</sup>
- 700,000 people are living with cancer and three or more long-term conditions<sup>24</sup>
- “People with long-term conditions now account for about 50 % of all GP appointments, 64 % of all outpatient appointments and over 70 % of all inpatient bed days. At least 15 million people in England have one or more long term conditions (LTCs) and 70% of the NHS budget is spent on their care. 30% of people with a LTC have a mental health problem and this equates to around 4.6m people<sup>43</sup>
- Where a mental health problem coexists with a physical health problem the potential for harm is greater. This increases their physical healthcare costs by 45-75% from international studies, after adjustment for the severity of the disease has taken place.<sup>43</sup>

A Nuffield Trust evaluation (2014)<sup>44</sup> showed that 15 months after diagnosis, people with cancer had:

- 60 % more A&E attendances
- 97% more emergency admissions
- 50% more primary care contacts compared to a population of the same age/gender.

Additionally there are significant socio-economic implications:

- Cancer survivors are 37% more likely to be unemployed than people who have never had cancer<sup>45</sup>
- Nearly three quarters of people (73%) living in the lowest household income bracket (less than £1200 per calendar month) report they have experienced mental health problems compared to 59 % in the highest income bracket (over £3700 per calendar month)<sup>46</sup>

It is clear that the experience of cancer and its longer term physical and psychological consequences can have a significant economic cost.

### ***Economic Sense for the NHS***

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 average of 20% (meta-analysis of 91 studies). When data is available on cost of psychological treatment and physical healthcare, savings exceeds costs<sup>47</sup>.

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<sup>43</sup> The King's Fund and the Centre for Mental Health (2012) *Long-term conditions and mental health; The cost of co-morbidities* <https://www.kingsfund.org.uk/publications/long-term-conditions-and-mental-health>

<sup>44</sup> Nuffield Trust (2014) *Use of health and social care by people with cancer* <https://www.nuffieldtrust.org.uk/research/use-of-health-and-social-care-by-people-with-cancer>

<sup>45</sup> De Boer, A.G.; Taskilla, T.; Ojajarvi, A.; Van Dijk, F.J & Verbeek, J.H Cancer Survivors and Unemployment: a meta-analysis and meta-regression, JAMA 301, 753-762 (2009) <https://www.ncbi.nlm.nih.gov/pubmed/19224752>

<sup>46</sup> Mental Health Foundation (2017) *Surviving or thriving- the state of the UK's Mental Health* <https://www.mentalhealth.org.uk/publications/surviving-or-thriving-state-uks-mental-health>

<sup>47</sup> Layard, R & Clark, D.M (2014) *Thrive: The Power of Evidence-Based Psychological Therapies*

## 2.5 Other relevant context

In developing the pan-London psychological support 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>16</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>29</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.

### 3. *General Practice Forward View (April 2016)*<sup>48</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>4</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)

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<sup>48</sup> NHS England (2016) *General Practice Forward View* <https://www.england.nhs.uk/wp-content/uploads/2016/04/gpfv.pdf>

- 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>49</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.

#### **6. NHS England House of Care-a framework for long term conditions care<sup>50</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>11</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 (2016) identified that only 33.3% 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. NHS Digital’s strategy for 2015-2020<sup>51</sup>**

- Aims to improve health and social care in England by using data, information and technology more effectively to transform services. Any integrated service transformation will require interoperability and new digitally enabled services. Service users should also be able to see and contribute to information held about them. The Five Year Forward View for Mental Health also recommends the further development of digital mental health products and harnessing digital technology to improve access to services including easier self-referral.

#### **9. A RightCare Collaboration 2015/19 Forward View<sup>52</sup>**

- The idea behind NHS RightCare in simple terms is to make the NHS’s money go as far as possible in improving patient outcomes. Focus on accountable, integrated, systems of care by: mobilising the patient as part of the solution (shared-decision making paradigm), ensuring clinical and financial accountability, commissioners focusing on understanding spend and outcomes, addressing whole populations to maximise value and

<sup>49</sup> NHS England (2016) Commissioning guidance for rehabilitation <https://www.england.nhs.uk/wp-content/uploads/2016/04/rehabilitation-comms-guid-16-17.pdf>

<sup>50</sup> NHS England (2017) House of Care: a framework for long term conditions care <https://www.england.nhs.uk/ourwork/ltc-op-eolc/lc-eolc/house-of-care/>

<sup>51</sup> Information and technology for better care: Our strategy for 2015-2020 (NHS Digital/Health and Social Care Information Centre)

<sup>52</sup> A Right Care Collaboration 2015/2019 Forward View, NHS England (2015)

understanding un-wanted variation and the actions needed to tackle it. NHS RightCare has three components: Intelligence (data shines a light on variation and performance), Innovation (in partnership with a wide range of organisations to influence policy and test new concepts), and Implementation (NHS RightCare team supports local health economies). Underpinning the approach is a three stage methodology of 'where to look', 'what to change' and 'how to change'.

#### **10. NICE guidance 56 (NG56) Multi - morbidity: clinical assessment and management<sup>13</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.

### 3. Producing the recommendations, pathway and service specification

The TCST employed Dr Philippa Hyman, from January to December 2017, in partnership and funded by Macmillan to lead this work. Liz Price, Living With and Beyond Cancer, Associate Director supervised the project. Support for Dr Hyman came from the Living With and Beyond Cancer Team and professional supervision from Dr Alex King, Consultant Clinical Psychologist, Imperial Healthcare.

#### 3.1 Task and finish group

A Mental Health and Cancer Task and Finish group was established to oversee the production of the psychological care pathway and the commissioning recommendations. 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 1 for the membership and terms of reference of the group.

#### 3.2 Feedback from two Stakeholder events (May and October 2017)

Two 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. The second event had extremely good professional representation as well as 12 service users and achieved excellent geographical representation across STPs in London with the exception of West Essex.

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

- The patient must be at centre of pathway.
- There is a need for local directories of resources/information to be refreshed and updated and to include support groups and resources.
- Within primary care there needs to be Level 2 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 CCRs, HNAs 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).

- 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.

### **3.3 IAPT and Psycho-oncology meetings**

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.

### **3.4 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>14</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. 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 psychological support are not treated as separate and disconnected. It is clear that addressing the psychological issues that can impact on cancer prehabilitation and rehabilitation is essential for improving patient outcomes.

### **3.5 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 both stakeholder events including a separate focus group with service users prior to the first event. 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.

#### ***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.”*

### **Post-treatment support**

There is a wealth of evidence including those outlined in a number of Macmillan publications<sup>23,25</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”*

### **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”*

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

A number of 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”*

### **3.6 Equality and Health Inequality Analysis (EHI) Screening**

An initial [EHIA screening](#) was completed using the NHS England (2016) screening tool<sup>8</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
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. These groups are also to be considered in further analysis.

A comprehensive Equality and Health Inequalities Analysis will be completed in Phase 2 of this work.

## 4. A Pan-London Psychosocial Support 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 support 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.

**Figure 3 Pan-London Psychosocial Support Pathway for adults**

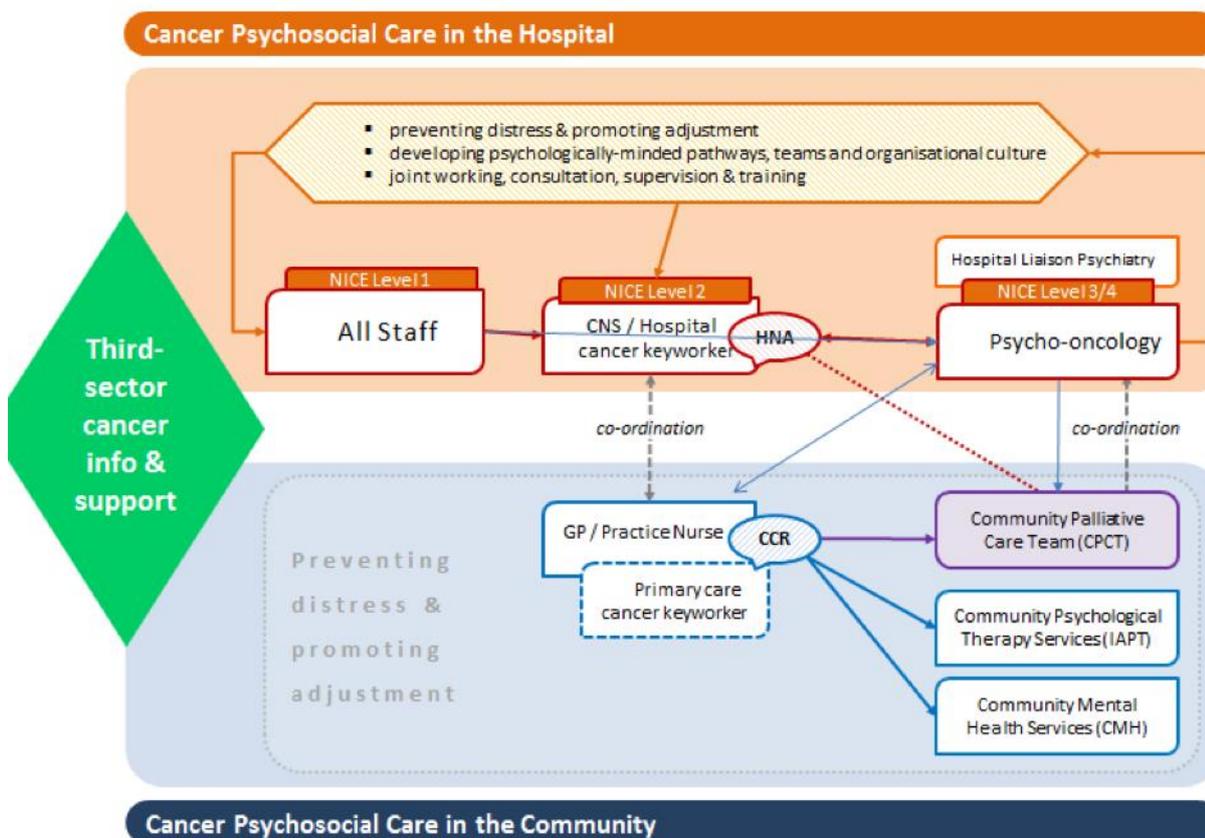


Figure 3 shows the psychosocial support provision across acute, primary care and community contexts.

### 4.1 Preventing distress and promoting adjustment

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.

In simple terms there can be a significant positive impact on the mental health of those affected by cancer, their families and carers with the following basic recommendations and considerations:

- Patients, families and carers are communicated with compassionately by all staff.

- Good communication and 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 have access to information on local services (both health and social care) which is kept up to date and includes online support.
- Prompt, efficient and reliable appointment systems and reporting processes are in place across the whole pathway.
- Early recognition and support for how socio-economic factors impact on mental health (e.g. concerns about finances, employment, housing, and childcare).
- Good safety netting and follow-up in primary care.
- Identification of who may need extra support early on to prevent distress and promote adjustment (e.g. asking about past losses, mental health history, social isolation and deprivation).
- Developing a psychologically minded culture within cancer services with more emphasis on integration between physical health and psychological well-being.
- Effective use of the Recovery Package (for example high quality cancer care reviews taking place within primary care).

These are all examples of small changes that can have a major impact, which are part of existing national strategies and do not have a significant cost implication.

## **4.2 Effective use of the recovery package**

The National Cancer Survivorship initiative<sup>30</sup> highlighted the immediate and long term consequences of cancer and its treatment. The recommended recovery package model (see figure 4) comprises of four aspects: holistic needs assessment (HNA) including care plan, health and well-being events (HWBE), Treatment Summaries (TS) and the Cancer Care review (CCR), and the latter delivered in primary care. These interventions have been included in London's acute commissioning intentions every year since 2012/13. Acute providers are expected to implement all interventions that relate to their services (HNA, TS, HWBE) and in Primary Care (CCR) so that patients receive a package of care without variation. HWBEs may be delivered in partnership with primary and community care teams.

The recovery package had been considered as providing the “building blocks for achieving good outcomes”<sup>30</sup> for those affected by cancer. The following considerations should be made:

- Outcomes from the use of the recovery package must focus on quality and patient experience not just quantitative output.
- Holistic needs assessments (HNAs). Consideration of how patients experience the process. What impact do HNAs have on subsequent resource allocation and support received?
- Treatment summaries must be completed promptly with primary care and patients as a key audience, shared swiftly across the pathway to ensure appropriate medication and

surveillance, thus reducing anxiety. They should include any identified emotional support need to be followed up in primary care.

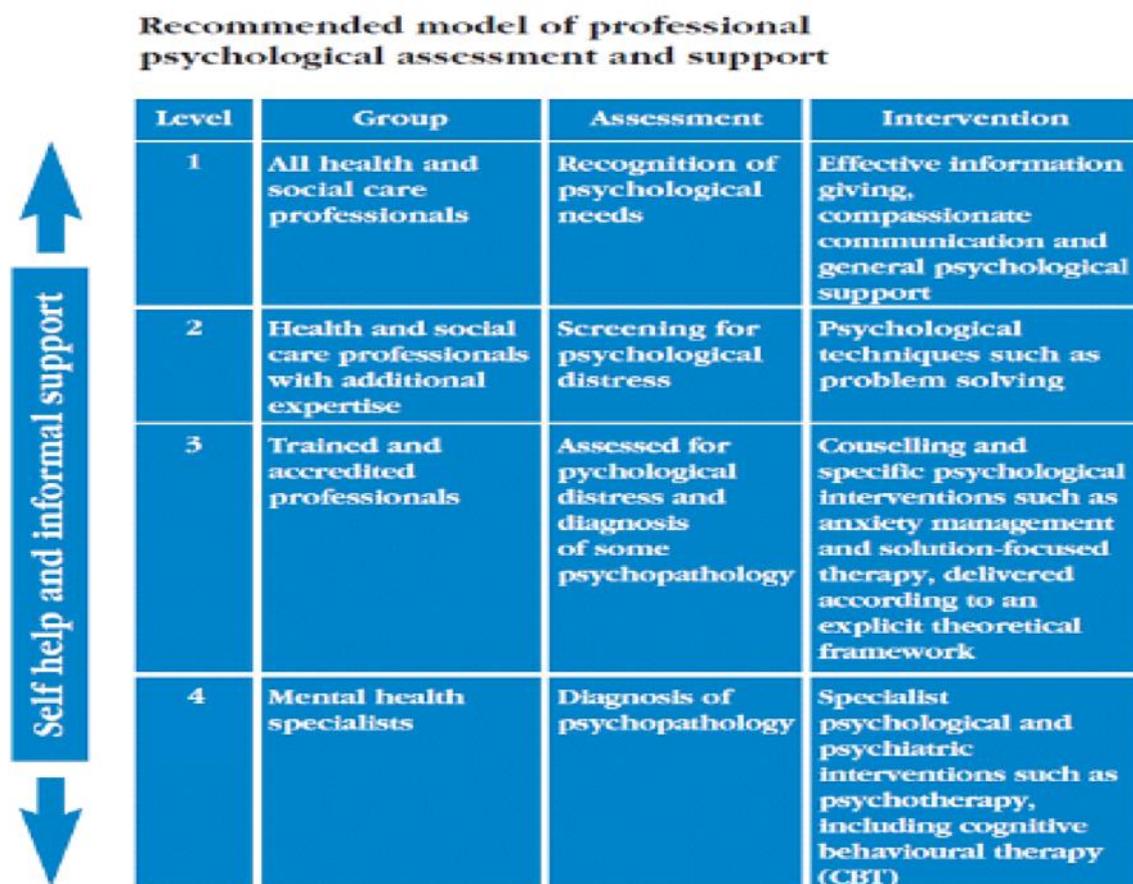
- The Transforming Cancer Services Team's 4 point model for Cancer Care Reviews<sup>6</sup> provides an opportunity to identify the psychological impact of cancer and its treatment at various points along the pathway.
- Health and well-being events need to be holistic, delivered in settings and at times that are convenient to people, enhancing patient confidence in self-management and improving knowledge of how to access further support if needed.

**Figure 4 Recovery Package Model**



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**Figure 5 Levels of Psychological Assessment and Support (NICE 2004)<sup>7</sup>**



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.

**Description of Activity**

**Level 1 Role-All health and social care professionals working with people affected by cancer, their families and carers**

Psychosocial care activity needs to include:

- 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?
- Provide general emotional support

- Signpost to support that patient finds relevant-discuss with them
- Communicate with compassion, gather relevant information and discuss onward referral where appropriate
- Be aware of Level 2 staff (CNS/AHP) and discuss concerns
- Contact Psycho-oncology service for advice/consultation.

***Level 2 Role Usually Clinical Nurse Specialists/Allied Health Professionals/requires specific Level 2 training and regular supervision by Level 3/4 specialists***

Psychosocial care activity includes:

- meet the person at diagnosis – to build a reliable relationship
- explore and address the person’s information preferences
- include and involve family and carers
- 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
- track person’s adjustment throughout the pathway
- 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 (e.g goal-setting)
- consult with, work jointly with and refer to Level 3/4 psycho-oncology services
- link and coordinate care with external services (e.g. learning disability)
- provide relevant guidance and training to level1 staff.

The London psychological support pathway (Figure 3) shows a primary care cancer keyworker which is a role that needs to be further scoped. Currently there is Level 2 provision within the acute setting but within primary care there is a gap in provision which might be of particular importance at key transition points for example when people are discharged from secondary care (hospital) back to primary care. Service users identify that this is a time of heightened anxiety. Further work is needed to assess the feasibility of developing a level 2 role within primary care.

***Level 3 includes psychotherapists, family therapists, counsellors, mental health therapists accredited in a particular modality (e.g CBT accreditation by BABCP), social workers and mental health nurses with an accredited psychotherapeutic training. Completed specialist training in cancer care.***

- 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 includes clinical psychologists, consultant liaison psychiatrists, counselling psychologists who have completed a substantive mental health training, are accredited to deliver interventions across a range of modalities, able to use formal methods to adapt, evaluate and deliver interventions. Knowledge through training and experience of other mental health services. Completed specialist training (e.g in role-teaching, supervision and formal courses) with specific reference to cancer care.***

- 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.

**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"*

### **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, 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.

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

**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.

- Highly specialist clinical care for inpatients during medical admission and outpatients
- 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 level 1 care and the delivery of the Recovery package
- 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.

#### **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.

### **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:

- 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.*

Further consultation will be needed 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 will form an important part of phase 2 of this work.

**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.

### **The 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. Mapping London provision

A detailed mapping of specialist psychological services (levels 3-4), CNS provision (Level 2), Integrated IAPT services and Information and Support Services for people affected by cancer was undertaken by TCST to ascertain the current provision pan-London and where the gaps are<sup>53</sup>. Third sector support for people affected by cancer was not mapped on this occasion due to the huge number of organisations (both large and small) and because the focus of this pathway is on NHS commissioned services. Additionally, allied health professionals (such as Physiotherapists, Occupational Therapists, Speech and Language Therapists, Dieticians) who also provide psychosocial interventions were not included on this occasion as they are being mapped as part of the TCST's cancer rehabilitation workstream (due summer 2018). Medical colleagues and administrators were not included. NHS Trainee Clinical psychologists who are often attached to Psycho-oncology services were excluded from this analysis as they are not part of the permanent funding and commissioning arrangements within acute trusts.

Services are constantly changing and evolving. The information provided in this report was considered to be correct as of November 2017.

Mapping was undertaken to understand the service provision of psychological care to cancer patients across each of the acute trusts.

### Method

Structured telephone interviews were undertaken with clinical leads. Leads were sent a list of questions prior to the interview. Leads were asked to identify:

- Name of service
- How many sessions of Levels 3/4 psychological support are dedicated to cancer/palliative care work?
- If the service is clearly commissioned and how is it commissioned?
- How many (if any) psychology/councillors are Macmillan funded or badged?
- Is there liaison psychiatry readily available for cancer patients and can the hospital psychiatry service see outpatients?
- How many (cancer) CNS within the hospital?
- If level 2 supervision groups being offered to CNS? If not is there intention to do so?
- How many hours of supervision were delivered by level 3-4 practitioners in 2016/17
- How many level 2 people (calculated per hours) participated
- If any other specialised training is provided for hospital staff
- Any additional activities the service runs or is involved in (for example: support groups, HWB events or small group sessions).

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<sup>53</sup> Transforming Cancer Services Team (2018) Mapping of psychological services across London

In total we attempted to contact all 24 acute trusts across London who between them account for 42 hospitals. Results were grouped by acute trust with the exception of St George's University Hospitals NHS Foundation Trust, Epsom & St Helier University Hospitals NHS Trust and Croydon Healthcare Services NHS Trust (who were grouped together as one as the service currently covers all three) and The Hillingdon Hospitals NHS Foundation Trust (which was split into Hillingdon Hospital and Mt Vernon). Therefore N=22. Information was supplied by 23 trusts. A complete list of psychological services by acute trust, establishment and STP can be found in Appendix 3.

## 5.1 An overview of services in London

We undertook mapping of:

1. Mapping London provision: An overview and details of psychological support services (Levels 3-4) in London (per STP)
2. Information and Support Centres (ISCs): Are there information and support centres (ISCs) available at all acute trusts as recommended in the 2015 Psychological support guidance<sup>1</sup> document?
3. IAPT (Improving Access to Psychological Therapies services) in London
4. Number of Integrated IAPT services (seeing people with LTCs) and location

In addition we collected:

- Other third sector led cancer specific supportive care services
- Services specific to those from diverse backgrounds with cancer

Details tables of mapping can be found in Appendix B.

## 5.2 Details of psychological support services for cancer per Acute Trust and STP

### Sessions

Leads were asked to identify the number of level 3 and 4 staff their service had as well as the total number of sessions. These were broken into:

- Oncology - staff who work exclusively with cancer and are not confined to working only in palliative/End of Life Care
- Palliative Care - staff dedicated to palliative care and who would work with non-malignant conditions

Level 3 and 4 were defined as:

- Level 3 = Counsellors, psychotherapists, arts therapists, Cognitive Behavioural Therapy (CBT) Therapists, family therapists
- Level 4 = Clinical/Counselling psychologists

Leads were asked to record all posts even those currently vacant. Volunteer or trainee posts were not included in the results.

## **Results**

There is at least some level of cancer psychological support available to all cancer patients at each of the acute trusts, excluding:

- Chelsea and Westminster NHS Foundation Trust – including Chelsea and Westminster and West Middlesex University Hospital (no dedicated service).
- Royal Brompton & Harefield NHS Foundation Trust (have no dedicated oncology sessions, although would see lung cancer patients admitted for surgery).
- Princess Alexandra (no dedicated service).
- Kings College Hospital (currently only funded to provide psychological support to those with Haematological or Neurological cancers).
- The Macmillan Cancer Psychological Support (CaPS) Team (SWL STP) which provided a service to St George's University Hospital, St Helier Hospital, Epsom Hospital and Croydon University Hospital received Macmillan funding until the end of the 17/18 financial year. At the time of writing only St George's as a Trust had picked up some funding for one year, with the other two Trusts reverting to what they had prior to the Macmillan funding. This means that at the time of writing there was no service available at Epsom & St Helier University Hospitals NHS Trust or Croydon University Hospital.

In addition it is important to note that at the time of writing Lewisham and Greenwich Trust (incorporating Lewisham and Queen Elizabeth Hospital's) have funding only until the end of January 2019.

### **5.2.1 North East London**

There are Cancer Psychology services within Bart's Health, inputting into St Bartholomew's, Mile End, The Royal London, Whipps Cross University and Newham hospitals. Homerton University Hospital NHS Trust has a Psychology in Cancer and Palliative Care Service. Within Barking and Dagenham, Havering and Redbridge (BHR) there is psycho-oncology input to Queen's hospital and King George Hospital.

### **5.2.2 North Central London**

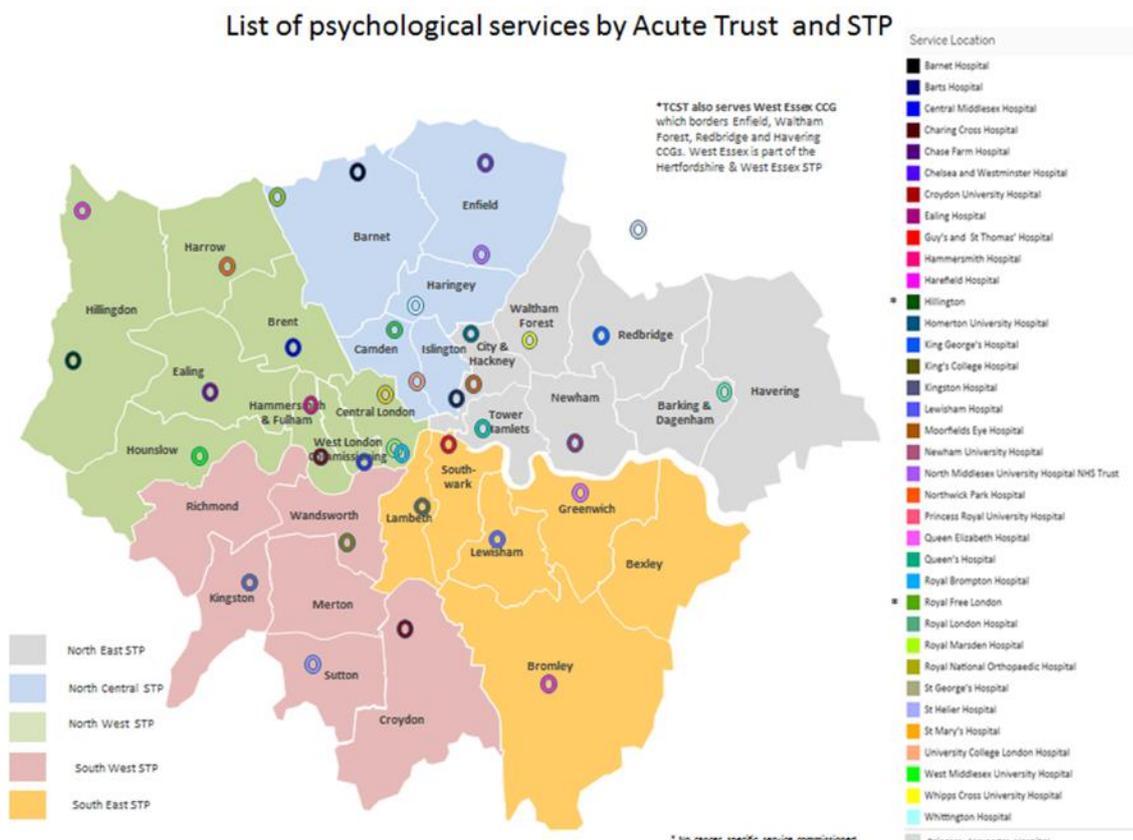
There is a Cancer Care Psychology Service at the Whittington Hospital. Additionally, there is a Cancer and Haematology counselling service for the Royal Free London and UCLH Macmillan Support and Information Service for UCLH Hospitals. There are Macmillan Cancer Clinical Psychologists at North Middlesex Hospitals.

### **5.2.3 North West London**

There is a Clinical Psychology service for oncology and palliative care at Hillingdon hospital. The psycho-oncology team at Imperial health care provide input to St Mary's, Charing Cross and Hammersmith. There is a Clinical Health Psychology service in Ealing Hospital and Northwick Park but no cancer specific service. The Royal Brompton and Harefield have no dedicated service. Chelsea and Westminster and West Middlesex currently have no specific service.

**Figure 6 List of psychological services by Acute Trust and STP**

[Explore this map online](#)



### 5.2.4 South West London

Macmillan Cancer Psychological Support (CaPS) Team provided psycho-oncology input to Croydon University Hospital, St Helier Hospital, Epsom Hospital and St George’s University Hospital. Macmillan funding of this service ceased at the end of the 17/18 financial year. At the time of writing only St George’s as a Trust had picked up some funding for one year, with the other two Trusts reverting to what they had prior to the Macmillan funding. This means that at the time of writing there was no service available at Epsom & St Helier University Hospitals NHS Trust and Croydon University Hospital.

Kingston Hospital has a Cancer Counselling service, comprising of 0.6 WTE at level 3 and 0.4 WTE at Level 4 for Oncology. There is no separately commissioned palliative care support. The Adult Psychological Support Service provides input to the Royal Marsden NHS Foundation Trust.

### 5.2.5 South East London

Macmillan Psychological Support (MAPS) Team provides input to Lewisham Hospital and Queen Elizabeth Hospital (funded until the end of January 2019). Psycho-Oncology Support team (POST) provide input to Guys and St Thomas’ and Queen Mary’s Sidcup. A cancer and psychotherapy service inputs to Kings College Hospital NHS Foundation Trust, currently funded to provide support for haematological or neurological cancers.

### **5.2.6 Services outside London geography**

There is currently no psycho-oncology service covering West Essex CCG.

Phase 2 of this work programme will need to calculate workforce requirements and skills mix based on a range of factors incorporating a range of direct clinical work from diagnosis, treatment, cancer rehabilitation, recovery, living with and beyond cancer and end of life support.

Additionally calculations must include provision for the range of 'indirect' activities delivered by Psycho-oncology teams such as:

- Level 2 training for CNS and AHP colleagues
- ongoing supervision and training to Level 2 workers
- consultation to enhance the psychological elements of the Recovery package e.g input into Health and Well-being events
- training on conducting Holistic Needs Assessments
- offering specialist advice on complex cases within multi-disciplinary team meetings
- offering specialist advice, supervision, skills training and consultation to multi-disciplinary colleagues across the whole pathway, including primary care and community settings when needed.
- providing Level 1 training (e.g Sage and Thyme training)
- providing reflective practice groups, multi-disciplinary support and education groups
- staff focused support such as Schwartz rounds.

*Please note this is not an exhaustive list of 'indirect' activities.*

### **Liaison Psychiatry**

Liaison psychiatry was available to varying degrees across services. Three acute trusts (Royal Marsden, Guys and St Thomas's and St George's) had dedicated Liaison Psychiatry for cancer patients.

### **CNS Supervision groups**

Out of the acute trust groups that provided information, only two of these were not currently providing level 2 supervision groups to CNS's in the hospital setting, Northwick Park Hospital and Moorfields Eye Hospital. Those who did not provide Level 2 training and supervision stated this was due to lack of funding and staffing to undertake this or that the service was new and still being set up with the aim to provide training and supervision in the future. In addition Kings College only provides level 2 training and supervision to Haematology and Neurology CNS's. Work is currently being undertaken to obtain funding for other tumour streams.

Groups followed the supervision model of 1-1.5 hours per month with groups of up to 6.

## Commissioning

Commissioning of services varied. The most common forms of funding for services included:

- direct commissioning
- block funding
- Macmillan grant funding
- funded by tariffs

Further work would need to be undertaken to fully understand the commissioning of each individual service, as some services providers were unsure of the exact commissioning arrangements for their services.

## 5.2 Mapping of Information and Support Centres

The 2015 guidance<sup>1</sup> recommended that commissioners should ensure that Information and Support Centres (ISCs) are available at all acute trusts. We undertook mapping to see if this recommendation had been implemented.

### Results

All Acute NHS services across London were identified (n=38). They were then grouped into acute trusts (N=24). Of the 24 trusts, 20 were found to have an ISCs on site. Of the 4 that had no ISC:

- Two were non-cancer specialist hospitals (Moorfields Eye Hospital and Royal National Orthopaedic Hospital)
- Lewisham and Greenwich: Lewisham Hospital indicated that it has a range of services which could fit under the ISC banner. Queen Elizabeth indicated that they referred to Guy's
- Royal Brompton and Harefield indicated they have Macmillan nurses onsite who can provide an ISC like service.

Of the 28 who did have a service 19 (67.8%) of these were Macmillan ISC and four (14.2%) were a joint venture between Macmillan. One site (Charing Cross Hospital) had two services (a Macmillan ISC and a Maggie's Centre). ISCs which were not Macmillan centres included: The Mulberry Centre, Dimpleby Cancer Care Centre, Maggie's Centre and Royal Marsden Help Centre. The service at St Helier hospital was referred to a 'cancer information and support centre'.

## 5.3 Integrated IAPTs

As set out in *'Implementing the Five Year Forward View for Mental Health'*<sup>16</sup> the expansion of Improving Access to Psychological Therapies (IAPT) services will focus on people with long term conditions or medically unexplained symptoms.

There have been two rounds of funding for services to deliver integrated IAPT services across the UK.

There were 22 early implementer sites in Wave 1 including Richmond and Hillingdon.

### **Richmond CCG**

Richmond will start by implementing pathways for people with diabetes and medically unexplained symptoms. These are areas of significant demand pressure in the borough; services will expand to include respiratory and cardiovascular conditions within 2017. Staff in primary and secondary care will be trained in the detection and referral of people with comorbid mental and physical health conditions. Interventions will be integrated with existing physical health rehabilitation and health promotion (e.g. local exercise referral and weight loss programmes) as well as integration with social support through employment specialists.

### **Hillingdon CCG**

Hillingdon aims to establish an integrated IAPT service working collaboratively with acute and community care to improve the quality of life of those who live with long term conditions. The service will focus on respiratory problems (asthma and chronic obstructive pulmonary disease) and diabetes. Hillingdon has an established clinical health psychology service and is already embedded in acute hospitals – IAPT therapists will work within the existing service (expanding capacity), as well as integrating into community services.

In wave 2 there are 15 new sites, including several London CCGs (see table 3).

**Table 3 Integrated IAPT Services**

<b>Integrated IAPT Services</b>	
<b>CCG</b>	<b>STP</b>
Richmond CCG	South West
Hillingdon CCG	North West
Haringey CCG, Islington CCG	North Central
Brent CCG, Harrow CCG, Central London CCG, West London CCG, Hammersmith & Fulham CCG, Ealing CCG, Hounslow CCG	North West

## 6. Key issues and recommendations

Evaluation of the mapping data combined with feedback from a wide range of stakeholders has identified a range of key issues which build upon the ten recommendations made in the 2015 Psychological Support Guidance document<sup>1</sup>.

### ACCESS TO CARE

- 1. 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 the area of 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 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>2</sup>, contribute psychological evidence and insights to quality improvement projects, train and support staff to deliver Level 1 care and the recovery package. Additionally, a crucial role for psychologists with cancer expertise, embedded within cancer pathways is addressing end of life psychological issues by facilitating important conversations and decisions with treating clinicians and families.

GPs, primary care professionals and community teams should also be able to easily access the expertise from psycho-oncology teams who have the skills and knowledge to address the psychological factors that play a role in accessing tests, investigations and treatments for cancer, as well as in improving patient experience and outcomes for those living with and beyond cancer.

Mapping of psychological support services within acute trusts and STPs has revealed that there still remains an inequity in service provision with some areas of London and West Essex having limited or no coverage from Psycho-oncology teams.

- 2. Information directories need to be regularly updated for each STP area on local resources and online support for people affected by cancer, their carers and families which incorporate their physical, mental health and social care needs**

There are now 28 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. However, the National Cancer Patient Experience Survey (NCPES)<sup>3</sup> continues to highlight a significant proportion of patients and carers reporting not being given information about caring at home, potential side effects of treatment, enough support from health or social care, or information about financial help and benefits.

- 3. STPs 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, patients, their carers and families**

Feedback from both stakeholder events emphasised that the patient must be at the centre of the pathway, with support and access based on psychosocial need, not just where the person is on the clinical pathway. Patients and carers must be able to self-refer and not have systemic, bureaucratic obstacles making the process prohibitive.

**4. 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>4</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 CARE**

**5. Integrated care requires a platform where professionals working across acute, primary care and community services, between physical, mental health and social care can collaborate to improve outcomes for patients**

The King's Fund document *Bringing together physical health and mental health*<sup>54</sup> emphasises that the needs of an individual “are met in a co-ordinated way with medical, social and psychological needs being addressed together”. Therefore, a pan-London board for psychosocial support for adults affected by cancer should be constituted, where key stakeholders (including service users and clinicians) will work together to drive forward improvements in cancer psychosocial support for all Londoners. This will avoid duplication of work, provide opportunities to share learning and best practice, develop an integrated approach and serve to address the inequity of provision in psychological support across London.

**6. The psychosocial needs of the patient and those significant to them must be identified and reviewed at numerous points along the pathway. Within primary care in London, the Cancer Care Review 4 point model<sup>6</sup> needs to be seen as an opportunity to assess psychosocial needs and the emotional impact of cancer, whilst within acute settings person-centred Holistic Needs Assessments (HNAs) and treatment summaries should provide similar opportunities**

Further training for professionals across the pathway regarding physical health and mental health integration would be helpful to ensure that professionals feel confident to identify psychosocial issues affecting their cancer patients. An example of this may be routinely including a question about the impact of consequences of treatment (including physical or social consequences) on their quality of life. Psychological and emotional issues should not be seen as separate from physical health and socio-economic factors.

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<sup>54</sup> Kings Fund (2016) *Bringing together physical and mental health: A new frontier for integrated care*  
<https://www.kingsfund.org.uk/publications/physical-and-mental-health>

**7. All the elements of the Recovery Package must be implemented effectively and seen as useful tools to 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 a GP (or patient) does not receive a treatment summary this needs to be addressed and seen as a likely contributor to increasing patient anxiety and potentially negatively impacting on the ability of Primary Care staff to provide excellent patient care.

In addition to the effective use of the recovery package, there are also small shifts in how professionals work across the pathway that can have a considerable impact on the mental health of those affected by cancer and those significant to them, for example, focusing on effective communication and good partnership working across the pathway, prompt efficient and reliable appointment processes, early identification of those who may need extra support and developing a psychologically minded culture across all cancer services emphasising the integration between health and psychological well-being.

### **EDUCATION AND TRAINING**

**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. This will mean working across acute, primary care and community settings**

Integrated Improving Access to Psychological Therapies (IAPT) services must work closely with psycho-oncology services when developing pathways for cancer 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 at Levels 3-4, as recommended by NICE guidance<sup>55</sup>, by cancer specialists within community or hospital settings, always with consideration of patient preference. Further consultation on optimising relationships and pathways between primary care, IAPT services and Psycho-oncology teams will form part of phase 2 of this work.

**9. Psychosocial support for people affected by cancer should be considered 'Everybody's business'**

Over a decade ago an important document was published '*Everybody's Business: Integrated mental health services for older adults*<sup>56</sup>. A key message was that good quality care for older people was 'everybody's business' across the whole system, with person-centred, holistic care offered across physical health, mental health and social care.

A very powerful message from service users at both stakeholder events was that people affected by cancer, their families and carers should be able to expect that all staff with whom they have contact have a basic understanding of their psychosocial needs and those of their

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<sup>55</sup> National Institute for Health and Care Excellence (2004) *Guidance on Improving Supportive and Palliative Care for Adults with Cancer* <https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005>

<sup>56</sup> Care Services Improvement Partnership and Department of Health (2005) *Everybody's business. Integrated mental health services for older adults: a service development guide* <http://www.wales.nhs.uk/sites3/Documents/439/everybodysbusiness.pdf>

carers. In addition that when specialist psychological support is required, the referral process is simple and timely and staff are skilled to respond to their needs.

Education, training and workforce development are key to achieving this including junior staff through to the most senior experienced medical colleagues across acute, primary care and community services.

## **EQUALITY**

### **10. The significant differences in patient experience of cancer care across a number of 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<sup>9</sup>. 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>7</sup>. An initial Equality and Health Inequalities Screening Analysis<sup>10</sup> was completed using the NHS England screening tool within phase 1 of this work. A comprehensive Equalities and Health Inequalities Analysis will be completed in Phase 2 of this work to ensure that the recommendations in this report and service specifications meet the diverse needs of Londoners. As part of phase 2, there will be recommendations regarding what data needs to be captured across the pathway and how to evaluate services with consideration of the nine protected characteristics: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation. It is recommended that a number of other groups often excluded within healthcare should also be considered, for example, the homeless, vulnerable migrants and people affected by severe mental illness.

### **11. The introduction of the NHS England ‘quality of life metric’ in 2019 provides an opportunity to ensure that psychological and emotional well-being is prioritised across all STPs in London**

Given the impact of physical health consequences of cancer and its treatment, mental health and social factors on quality of life, prioritising cancer rehabilitation and psychosocial support across the pathway will be essential to ensure that quality of life improves for all Londoners affected by cancer.

## **SERVICE USER INVOLVEMENT**

### **12. 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>11</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 approaches. Patients want to be empowered to make informed choices in managing their own health, wellbeing and care. The NCPES (2016)<sup>6</sup> identified that only 33.3% of Londoners were given a care plan, thus identifying there is still a long way to go in ensuring that people feel empowered to take control of their health. Shared decision making will require a culture shift to ensure “care planning and self-management is hard-wired into how care is delivered”<sup>11</sup>, 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 across the whole pathway.

People affected by cancer and those significant to them must continue to be meaningfully and actively involved in service co-design to improve psychosocial care for Londoners. Service users were active participants in phase 1 of this work via focus groups, stakeholder events, interviews and involvement on the Transforming Cancer Services Team's Mental Health and Cancer Task and Finish group meetings. NHS England has produced guidance on patient and public participation in commissioning health and care<sup>12</sup>, with ten key principles of participation including proactively seeking participation from people who experience health inequalities and poor health outcomes which will be an important part of phase 2 of this work.

## **Next Steps**

### ***For commissioners***

- Commissioners to ensure that the commissioning recommendations outlined in this document are referenced in Sustainability and Transformation Plans (STPs) and that psychological 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 pathway' approach.
- Further work will be required to 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.

### ***For providers***

- Providers to review their current pathways and service provision in order to work collaboratively with their peers and commissioning colleagues to help achieve the objectives outlined above.

### ***For alliances/vanguard***

- The three alliances/vanguards, in conjunction with TCST, to scope the merits and feasibility of developing a pan-london psychosocial cancer programme board. The aims of this board would be to drive forward the implementation of this pathway, provide peer support, disseminate knowledge and skills, share good practice and improve research and development opportunities. Additionally having one pan-London group would ensure equity of services and standards across London.

### ***For others***

- The third sector to work with the NHS and social care to ensure there is an integrated online service directory including resources and online support that is available to support the emotional needs of people with cancer, preferably at STP level.
- The third sector to work with the NHS to help support awareness raising and education on psychological care within the wider workforce.

### **For TCST**

- To present the report at STP Cancer Boards and provide specialist expertise to support local implementation of best practice.
- Phase 2 of this work to include further consultation on details of the draft service specification, including workforce calculations, key performance indicators and outcome measures and to develop a business case to support the specification.
- Phase 2 of this work to include further consultation to optimise relationships and pathways between primary care, IAPT services and psycho-oncology teams.
- Phase 2 of this work to include a comprehensive health equity assessment to ensure the pathway and associated recommendations fit with the diverse needs of the population of London.
- To work closely with the Healthy London Partnership Communications Team to promote and disseminate the recommendations widely across London and West Essex.
- To continue to work with others e.g Macmillan Cancer Support to promote the recommendations regionally and where appropriate nationally.
- To present the report and specification to relevant areas of commissioning at a regional level, including Primary Care, Mental Health and End of Life Care.

### **Evaluation of the Recommendations**

It will be important to assess the impact of these recommendations on commissioning decisions, in particular the impact on quality of life, patient experience, and improvements in service provision across the pathway.

## List of Acronyms

<b>Acronym</b>	<b>Term</b>
AHP	Allied Health Professional
CCB	Cancer Commissioning 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
HWBE	Health and Wellbeing Event (or clinic)
IAPT	Improving Access to Psychological Therapies
ISC	Information and Support Centre
LTC	Long term condition
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
QoL	Quality of Life
RP	Recovery Package
STP	Strategy & 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>20</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/Vanguard

Cancer Alliances are a way to bring together local senior clinical and managerial leaders representing the whole cancer patient pathway across a specific geography.

Together with the National Cancer Vanguard, they led the local delivery of the Independent Cancer Taskforce's ambitions for improving services, care and outcomes for everyone with cancer<sup>57</sup>. The Vanguard included Royal Marsden Partners, University College Hospital Collective Cancer Collaborative and Christie (in Manchester). Funding for the Vanguard concludes at the end of March 2018. After this time sites will be considered cancer alliances for their perspective STP's (including South East London Cancer Alliance).

### 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>58</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:

- Preventative: reducing impact of expected disabilities and improving coping strategies
- Restorative: returning an individual to pre-morbid levels of function
- Supportive: in the presence of persistent disease and need for treatment, rehabilitation is aimed at limiting functional loss and providing support
- Palliative: prevents further loss of function, measures are put in place to eliminate or reduce complications and to provide symptom management<sup>59</sup>

### Cancer Care Review

Is a discussion between a patient and their GP or practice nurse about their cancer. 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>60</sup>.

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<sup>57</sup> NHS England (2017) Guidance for Cancer Alliances and the National Cancer Vanguard Retrieved January 19 2018 from <https://www.england.nhs.uk/cancer/strategy/alliance-guidance/>

<sup>58</sup> Association of Schools of Allied Health Professionals (2018) Definition Of Allied Health Retrieved January 23 2018 from <http://www.asahp.org/what-is/>

<sup>59</sup> Dietz, J.H (1980) Adaptive rehabilitation in cancer. Postgraduate Medicine, 68 (1): 145-153.

## **Clinical Nurse Specialist (cancer)**

Registered nurses, who have graduate level nursing preparation and who would usually be expected to be prepared at Master's 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>61</sup>.

## **Equality and Health Inequalities Analysis**

Ensures that NHS England can demonstrate compliance, with the Public Sector Equality Duty (PSED) and the duties on reducing health inequalities **Error! Bookmark not defined.**

## **Electronic Holistic Needs Assessment**

Allows a Holistic Needs Assessment (HNA) to be completed electronically<sup>60</sup>

## **Health**

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity<sup>17</sup>.

## **Health Inequality and inequity**

Can be defined as differences in health status or in the distribution of health determinants between different population groups<sup>62</sup>

## **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>63</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 can 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>60</sup>.

## **Health and Wellbeing Event (or clinic)**

An education and support event to prepare the person for the transition to supported self-management. The event 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>60</sup>.

## **Improving Access to Psychological Therapies**

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<sup>60</sup> Macmillan Cancer Support (2018) The Recovery Package Retrieved January 19 2018 from

<https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package#297615>

<sup>61</sup> National Cancer Action Team (2010) Quality in Nursing

Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist Retrieved January 19 2018 from

<https://www.macmillan.org.uk/documents/aboutus/commissioners/excellenceincancercarethecontributionoftheclinicalnursespecialist.pdf>

<sup>62</sup> World Health Organisation (2008) Glossary of terms used Retrieved January 23 2018 from

<http://www.who.int/hia/about/glos/en/index1.html>

<sup>63</sup> Olenja J (2013) *Health seeking behavior in context* (Editorial). East Afr Med J.13(2):61–62

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>64</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

### **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>65</sup>. Integration can be between physical and mental health, acute and community care or health and social care.

### **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>66</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.

### **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)

### **Multidisciplinary Team**

A multidisciplinary team is a group of health care workers who are members of different disciplines (professions e.g. Psychiatrists, Social Workers, etc.), each providing specific services to the patient<sup>67</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>68</sup>.

### **Mental health problems**

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<sup>64</sup> NHS Digital (2017) Improving Access to Psychological Therapies (IAPT) Retrieved January 19 2018 from <http://content.digital.nhs.uk/article/4972/Improving-Access-to-Psychological-Therapies-IAPT>

<sup>65</sup> Shaw s, Rosen R and Rumbold B (2011) What is integrated care? An overview of integrated care in the NHS, Nuffield Trust, UK Retrieved January 19 2018 from <https://www.nuffieldtrust.org.uk/files/2017-01/what-is-integrated-care-report-web-final.pdf>

<sup>66</sup> Kings Fund (2018) Long-term conditions and multi-morbidity Retrieved January 19 2018 from <https://www.kingsfund.org.uk/projects/time-think-differently/trends-disease-and-disability-long-term-conditions-multi-morbidity>

<sup>67</sup> Health Service Executive V2 (2017) Multi-disciplinary team Retrieved January 23 2018 from [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>68</sup> World Health Organisation (2014) Mental health: a state of well-being Retrieved January 19 2018 from [http://www.who.int/features/factfiles/mental\\_health/en/](http://www.who.int/features/factfiles/mental_health/en/)

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>69</sup>.

## **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>70</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>71</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>72</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>73</sup>.

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<sup>69</sup> Mind (2017) What are mental health problems? Retrieved January 23 2018 from <https://www.mind.org.uk/information-support/types-of-mental-health-problems/mental-health-problems-introduction/#.WmcEm9J-qUk>

<sup>70</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

<sup>71</sup> Segen's Medical Dictionary "psychological distress." Retrieved January 19 2018 from <https://medical-dictionary.thefreedictionary.com/psychological+distress>

<sup>72</sup> American Cancer Society (2018) Understanding Psychosocial Support Services Retrieved January 23 2018 from <https://www.cancer.org/treatment/treatments-and-side-effects/emotional-side-effects/understanding-psychosocial-support-services.html>

<sup>73</sup> National Institute for Health and Care Excellence (2018) Glossary Retrieved January 23 2018 from <https://www.nice.org.uk/Glossary?letter=H>

## Recovery Package

The Recovery Package is a series of key interventions which, when delivered together, can greatly improve outcomes for people living with and beyond cancer.

These include:

- A holistic needs assessment (HNA)
- A treatment summary
- Cancer Care Reviews (CCR) (conducted in primary care)
- A health and wellbeing event<sup>60</sup>

## Service User

Generally 'service user' means anyone who is a patient or other user of health and / or social services<sup>74</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>75</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 patients 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 GP.

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>60</sup>.

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<sup>74</sup> University of Leeds (2018) Service User & Carer Involvement Retrieved January 19 2018 from <http://www.leeds.ac.uk/involvement/pages/about/about2.htm>

<sup>75</sup> National Learning Consortium (2013) Shared Decision Making Factsheet Retrieved January 19 2018 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)

## References

1. London Mental Health Strategic Clinical Network and Transforming Cancer Services Team for London (2015) Psychological support for people living with cancer: Commissioning guidance for cancer care in London. <http://www.londonscn.nhs.uk/publication/psychological-support-for-people-living-with-cancer>
2. NHS England (2011) *National Cancer Peer Review Programme Manual for Cancer Services: Psychological Support Measures*
3. Quality Health Limited (2016) National Patient Experience Survey <http://www.ncpes.co.uk/index.php/reports/2016-reports>
4. 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* <http://endoflifecareambitions.org.uk/>
5. Kings Fund (2016) Bringing together physical and mental health: A new frontier for integrated care <https://www.kingsfund.org.uk/publications/physical-and-mental-health>
6. Transforming Cancer Services Team for London (2015) *Cancer as a long term condition: A review of Cancer Care Reviews and a proposed model for London* <https://www.myhealth.london.nhs.uk/system/files/Cancer%20Care%20Review.pdf>
7. National Institute for Health and Care Excellence (2004) *Guidance on Improving Supportive and Palliative Care for Adults with Cancer* <https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005>
8. Care Services Improvement Partnership and Department of Health (2005) *Everybody's business. Integrated mental health services for older adults: a service development guide* <http://www.wales.nhs.uk/sites3/Documents/439/everybodysbusiness.pdf>
9. 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)
10. NHS England (2015) Equality and Health Inequalities Analysis: Refreshed NHS Continuing Healthcare Redress Guidance 2015 <https://www.england.nhs.uk/wp-content/uploads/2015/04/equal-hlth-inequal-anlys.pdf>
11. Healthy London Partnership (2017) *Steps towards implementing self-care: A resource for local commissioners.* <https://www.healthylondon.org/wp-content/uploads/2017/10/Steps-toward-implementing-self-care-June-2017.pdf>
12. NHS England (2017) *Patient and public participation in commissioning health and care statutory guidance for CCGs and NHS England* <https://www.england.nhs.uk/publication/patient-and-public-participation-in-commissioning-health-and-care-statutory-guidance-for-ccgs-and-nhs-england/>
13. National Institute for Health and Care Excellence (2016) NICE guidance 56 (NG56) Multi - morbidity: clinical assessment and management <https://www.nice.org.uk/guidance/ng56/resources/multimorbidity-clinical-assessment-and-management-pdf-1837516654789>
14. Transforming Cancer Services Team for London (2016) *Cancer Rehabilitation: a scoping report for London* <https://www.healthylondon.org/wp-content/uploads/2017/11/Cancer-rehabilitation-a-scoping-report-for-london.pdf>
15. Macmillan Cancer Support (2014) *The Rich Picture: People with Cancer* <http://be.macmillan.org.uk/Downloads/CancerInformation/RichPicture/MAC150691114RPPeoplelivingwithCancer-Interactive.pdf>
16. NHS England (2016) *The Five Year Forward View for Mental Health* <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>
17. World Health Organisation (2006) *Constitution of the World Health Organization* <http://www.who.int/about/mission/en/>
18. All-Party Parliamentary Group on Arts, Health and Wellbeing(2017) *Creative Health: The Arts for Health and Wellbeing (Inquiry Report)* [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)
19. Jacobs, L.A; Shulman, L (2017) Follow-up Care of Cancer Survivors: Challenges and Solutions. *The Lancet*, 18 (1)
20. Brennan, J., (2001). Adjustment to cancer—coping or personal transition?. *Psycho-oncology*, 10(1), pp.1-18. <https://pdfs.semanticscholar.org/f049/60a5025562e5b2b49b0896de1f84e9f1443e.pdf>
21. Carolan, C.M., Smith, A., Davies, G.R. and Forbat, L.(2017). Seeking, accepting and declining help for emotional distress in cancer: A systematic review and thematic synthesis of qualitative evidence *European journal of cancer care*. <https://www.ncbi.nlm.nih.gov/pubmed/28597493>
22. Transforming Cancer Services Team/Public Health England and Macmillan Cancer Support (2017) *Detailed cancer prevalence estimates 1995-2015 in London*
23. Independent Cancer Taskforce (2015) *Achieving World-Class Outcomes A Strategy for England 2015-2020* [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)
24. Macmillan Cancer Support (2015) *The burden of cancer and other long-term conditions* <https://www.macmillan.org.uk/documents/press/cancerandotherlong-termconditions.pdf>
25. Macmillan Cancer Support (2006) *Worried sick: the emotional impact of cancer* [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)
26. Macmillan Cancer Support (2013) *Cured-but at what cost?* [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)
27. Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment* <https://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/throwinglightontheconsequencesofcanceranditstreatment.pdf>
28. Macmillan Cancer Support (2017) *Am I meant to be OK Now?* <https://www.macmillan.org.uk/assets/lwbc-report-2017.pdf>
29. NHS England (2014) *Five Year Forward View* <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>
30. National Cancer Survivorship Initiative (2007) (archived) <http://webarchive.nationalarchives.gov.uk/20100809103735/http://www.improvement.nhs.uk/cancer/Default.aspx?alias=www.improvement.nhs.uk/cancer/survivorship>
31. National Cancer Survivorship Vision (2010) (archived)<http://webarchive.nationalarchives.gov.uk/20100809113601/http://www.improvement.nhs.uk/cancer/LinkClick.aspx?fileticket=4apVUSvGcow%3d&tabid=214>

32. Living with and beyond cancer: Taking action to improve outcomes (March 2013)  
[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)
33. Royal College of Psychiatrists (2009) The Mental Health Content of Physical Health Guidelines,  
<https://www.rcpsych.ac.uk/pdf/NICE%20and%20SIGN%20mental%20health.pdf>
34. National Institute for Health and Clinical Excellence (2006), Improving outcomes for people with brain and other central nervous system tumours <https://www.nice.org.uk/guidance/csg10/resources/improving-outcomes-for-people-with-brain-and-other-central-nervous-system-tumours-update-27841361437>
35. Chiles, J.A.; Lambert, M.J and Hatch, A.L (1999) The impact of Psychological interventions on medical cost offset: A meta-analytic review. *Clinical Psychology: Science and Practice*, 6(2):204-220 <http://psycnet.apa.org/record/1999-03053-005>
36. NHS England (2016) The National Cancer Programme
37. London Cancer Alliance (2014) Mental Health and Psychological Support Service Specification and Referral Guidelines,  
<http://www.londoncanceralliance.nhs.uk/media/100472/lca-mh-ps-service-spec-final-dec-14.pdf>
38. London Cancer 2014 Service Specification Psychological Support Services,  
<http://londoncancer.org/media/89175/psychological-service-specification-final-2014june.pdf>
39. Macmillan Cancer Support (2015) Impact Briefs: Psychological and Emotional Support  
[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)
40. 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 <http://www.europsy.net/wp-content/uploads/2017/03/cancersuicide.pdf>
41. NHS England (2016) Achieving world class cancer outcomes: A strategy for England 2015-2020,  
<https://www.england.nhs.uk/publication/achieving-world-class-cancer-outcomes-a-strategy-for-england-2015-2020/>
42. NHS England (2017) New quality of life measure for recovering cancer patients (news article)  
<https://www.england.nhs.uk/expo/2017/09/12/new-quality-of-life-measure-for-recovering-cancer-patients>
43. The King's Fund and the Centre for Mental Health (2012) *Long-term conditions and mental health; The cost of co-morbidities*  
<https://www.kingsfund.org.uk/publications/long-term-conditions-and-mental-health>
44. Nuffield Trust (2014) *Use of health and social care by people with cancer* <https://www.nuffieldtrust.org.uk/research/use-of-health-and-social-care-by-people-with-cancer>
45. De Boer, A.G.; Taskilla, T.; Ojajarvi, A.; Van Dijk, F.J & Verbeek, J.H Cancer Survivors and Unemployment: a meta-analysis and meta-regression, *JAMA* 301, 753-762 (2009) <https://www.ncbi.nlm.nih.gov/pubmed/19224752>
46. Mental Health Foundation (2017) Surviving or thriving-the state of the UK's Mental Health  
<https://www.mentalhealth.org.uk/publications/surviving-or-thriving-state-uks-mental-health>
47. Layard, R & Clark, D.M (2014) Thrive: The Power of Evidence-Based Psychological Therapies
48. NHS England (2016) *General Practice Forward View* <https://www.england.nhs.uk/wp-content/uploads/2016/04/gpfv.pdf>
49. NHS England (2016) Commissioning guidance for rehabilitation <https://www.england.nhs.uk/wp-content/uploads/2016/04/rehabilitation-comms-guid-16-17.pdf>
50. NHS England (2017) House of Care: a framework for long term conditions care <https://www.england.nhs.uk/ourwork/ltc-op-eolc/ltc-eolc/house-of-care/>
51. Information and technology for better care: Our strategy for 2015-2020 (NHS Digital/Health and Social Care Information Centre)
52. NHS England (2015) A Right Care Collaboration 2015/2019 Forward View
53. Transforming Cancer Services Team (2018) Mapping of psychological services across London
54. Kings Fund (2016) Bringing together physical and mental health: A new frontier for integrated care  
<https://www.kingsfund.org.uk/publications/physical-and-mental-health>
55. National Institute for Health and Care Excellence (2004) *Guidance on Improving Supportive and Palliative Care for Adults with Cancer* <https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005>
56. Care Services Improvement Partnership and Department of Health (2005) *Everybody's business. Integrated mental health services for older adults: a service development guide* <http://www.wales.nhs.uk/sites3/Documents/439/everybodysbusiness.pdf>
57. NHS England (2017) Guidance for Cancer Alliances and the National Cancer Vanguard Retrieved January 19 2018 from  
<https://www.england.nhs.uk/cancer/strategy/alliance-guidance/>
58. Association of Schools of Allied Health Professionals (2018) Definition Of Allied Health Retrieved January 23 2018 from  
<http://www.asahp.org/what-is/>
59. Dietz, J.H (1980) Adaptive rehabilitation in cancer. *Postgraduate Medicine*, 68 (1): 145-153.
60. Macmillan Cancer Support (2018) The Recovery Package Retrieved January 19 2018 from  
<https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package#297615>
61. National Cancer Action Team (2010) Quality in Nursing *Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist* Retrieved January 19 2018 from  
<https://www.macmillan.org.uk/documents/aboutus/commissioners/excellenceincancercarethecontributionoftheclinicalnursespecialist.pdf>
62. World Health Organisation (2008) Glossary of terms used Retrieved January 23 2018 from  
<http://www.who.int/hia/about/glos/en/index1.html>
63. Olenja J. Editorial Health seeking behavior in context. *East Afr Med J*. 2003;13(2):61–62
64. NHS Digital (2017) Improving Access to Psychological Therapies (IAPT) Retrieved January 19 2018 from  
<http://content.digital.nhs.uk/article/4972/Improving-Access-to-Psychological-Therapies-IAPT>
65. Shaw s, Rosen R and Rumbold B (2011) What is integrated care? An overview of integrated care in the NHS, Nuffield Trust, UK Retrieved January 19 2018 from <https://www.nuffieldtrust.org.uk/files/2017-01/what-is-integrated-care-report-web-final.pdf>
66. Kings Fund (2018) Long-term conditions and multi-morbidity Retrieved January 19 2018 from  
<https://www.kingsfund.org.uk/projects/time-think-differently/trends-disease-and-disability-long-term-conditions-multi-morbidity>

67. Health Service Executive V2 (2017) Multi-disciplinary team Retrieved January 23 2018 from [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)
68. World Health Organisation (2014) Mental health: a state of well-being Retrieved January 19 2018 from [http://www.who.int/features/factfiles/mental\\_health/en/](http://www.who.int/features/factfiles/mental_health/en/)
69. Mind (2017) What are mental health problems? Retrieved January 23 2018 from <https://www.mind.org.uk/information-support/types-of-mental-health-problems/mental-health-problems-introduction/#.WmcEm9J-gUk>
70. 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
71. Segen's Medical Dictionary. S.v. "psychological distress." Retrieved January 19 2018 from <https://medical-dictionary.thefreedictionary.com/psychological+distress>
72. American Cancer Society (2018) Understanding Psychosocial Support Services Retrieved January 23 2018 from <https://www.cancer.org/treatment/treatments-and-side-effects/emotional-side-effects/understanding-psychosocial-support-services.html>
73. National Institute for Health and Care Excellence (2018) Glossary Retrieved January 23 2018 from <https://www.nice.org.uk/Glossary?letter=H>
74. University of Leeds (2018) Service User & Carer Involvement Retrieved January 19 2018 from <http://www.leeds.ac.uk/involvement/pages/about/about2.htm>
75. National Learning Consortium (2013) Shared Decision Making Factsheet Retrieved January 19 2018 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)

## Appendix A Service Specification

### SCHEDULE 2 – THE SERVICES

#### Service Specification

Service Specification No.	
Service	Psycho-oncology service for adults affected by cancer, their carers and families
Commissioner Lead	NHS xxxCCG/STP
Provider Lead	Acute Trust/Community/Primary Care
Period	2017/2018/2019
Date of Review	
Version	Version 1 <span style="float: right;">November 2017</span>

#### 1. Population Needs

##### National/local context and evidence base

##### Psychological impact of cancer

A diagnosis of cancer can be devastating. Psychological distress can be a common and understandable response to a diagnosis of cancer and living with and beyond cancer. The majority of people use a variety of resources to cope including their own inner emotional resources and external support systems, for example family, friends, peer support, online forums or 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.

- 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. 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>

<sup>1</sup> National Institute for Health and Care Excellence (2004) Guidance on Improving Supportive and Palliative Care for Adults with Cancer <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 (2006) *Worried sick: the emotional impact of cancer* [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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- 240,000 experience mental health difficulties including moderate to severe anxiety, depression and post-traumatic stress disorder
- 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>

Many of the physical health consequences of cancer may also significantly impact on mental health and psychosocial functioning<sup>6</sup>:

- 500,000 living with poor health or disability after treatment for cancer,
- 350,00 living with chronic fatigue,
- 350,000 living with sexual difficulties
- 200,000 living with moderate to severe pain after treatment
- 150,000 living with urinary problems such as incontinence
- 90,000 living with gastro-intestinal problems such as faecal incontinence
- Up to 63,000 living with lymphoedema

Improvements in diagnosis, medical treatments and survival means that the cancer landscape is changing, so the scope and specification of cancer psychosocial care will need to change accordingly.

### Prevalence

In London, the number of patients who had a diagnosis of cancer and were alive on 31/12/2015<sup>7</sup> (Data source, Cancer registry):

- Persons: 209,538 (2415.78 per 100,000)
- Males: 94,316 (2188.55 per 100,000)
- Females: 115,222 (2640.16 per 100,000)

For comparison to England:

- Persons: 1,791,366 (3,269.73 per 100,000)
- Males: 805,944 (2,981.74 per 100,000)
- Females: 985,422 (3,550.17 per 100,000)

“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” (NICE, 2004.) . Modelling based on London prevalence data, of people alive at 31/12/2015

- 2504 people in London (including West Essex)

<sup>3</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. <http://www.europsy.net/wp-content/uploads/2017/03/cancersuicide.pdf>

<sup>4</sup> Transforming Cancer Services Team for London (2016) Cancer Rehabilitation: a scoping report for London <https://www.healthylondon.org/wp-content/uploads/2017/11/Cancer-rehabilitation-a-scoping-report-for-london.pdf>

<sup>5</sup> Macmillan Cancer Support (2006) Worried sick: the emotional impact of cancer [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>6</sup> Macmillan Cancer Support (2013) Cured-but at what cost? [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)

<sup>7</sup> Transforming Cancer Services Team/Public Health England and Macmillan Cancer Support (2017) Detailed cancer prevalence estimates 1995-2015 in London

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- Vanguard/Alliance Geography:
- UCLH Cancer Collaborative 987
- RM Partners 1005
- South East London 512

### 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>8</sup>. But now more than half of people receiving a cancer diagnosis will live ten years or more<sup>9</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. There are currently approximately 2.5 million survivors of cancer increasing to 3 million, the projected increase by 2030.

There is a recognition that for many people cancer should be viewed as a long-term condition, with increasing numbers of people surviving and living with the consequences of cancer and its treatment.

Costs to the health care system are significant, 70 % of people with cancer are also living with another long-term condition, 700,000 people are living with cancer and three or more long-term conditions. Physical illness and co-morbid mental health problems raise total health care costs by at least 45% for each person with a long term condition and a co-morbid mental health problem.<sup>10</sup> The Five Year Forward View (FYFV) also noted that long-term health conditions consume 70% of the health service budget<sup>11</sup>.

Macmillan Cancer Support have produced a number of valuable documents detailing the impact of cancer and its treatment, how this continues to be a neglected areas and addressing the mental health, physical health and psychosocial consequences. *Worried sick: the emotional impact of cancer* (2006)<sup>12</sup> *Cured-but at what cost* (2013)<sup>13</sup>, *Throwing light on the consequences of cancer and its treatment* (2013)<sup>14</sup>, *Rich Picture Series* (2015)<sup>15</sup>, *Am I meant to be OK Now?* (2017)<sup>16</sup>.

Cancer and Mental health are strategic priorities for NHS England. The Five Year Forward View (FYFV)<sup>10</sup> for the NHS 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

<sup>8</sup>Independent Cancer Taskforce (2015) *Achieving World-Class Outcomes A Strategy for England 2015-2020* [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>9</sup> Macmillan Cancer Support (2015) *The burden of cancer and other long-term conditions* <https://www.macmillan.org.uk/documents/press/cancerandotherlong-termconditions.pdf>

<sup>10</sup> The Kings Fund (2012) *Long term conditions and mental health The cost of co-morbidities* <https://www.kingsfund.org.uk/projects/mental-health-and-long-term-conditions-cost-co-morbidity>

<sup>11</sup> NHS England (2016) *The Five Year Forward View for Mental Health* <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>

<sup>12</sup> Macmillan Cancer Support (2006) *Worried sick: the emotional impact of cancer* [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>13</sup> Macmillan Cancer Support (2013) *Cured-but at what cost?* [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)

<sup>14</sup> Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment* <https://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/throwinglightontheconsequencesofcanceranditstreatment.pdf>

<sup>15</sup> Macmillan Cancer Support (2015) *Rich Picture Series* <http://be.macmillan.org.uk/Downloads/CancerInformation/RichPicture/MAC150691114RPPeoplelivingwithCancer-Interactive.pdf>

<sup>16</sup> Macmillan Cancer Support (2017) *Am I meant to be OK Now?* <https://www.macmillan.org.uk/assets/lwbc-report-2017.pdf>

hospitals, between physical and mental health, between health and social care”.

Following the launch of the National Cancer Survivorship Initiative (NCSI) in 2007<sup>17</sup>, the 2010 NCSI vision<sup>18</sup> and *Living with and beyond cancer: taking action to improve outcomes (2013)*<sup>19</sup>, there is now recognition that how well people live, their quality of life, is as important as how long they live. 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.

As part of the NHS cancer dashboard, a new ‘quality of life metric’ is currently being developed. This 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 been selected including Barts Health and UCLH Cancer Collaborative. The pilot and evaluation period runs from September 2017 until early 2019. Once the quality of life metric becomes part of the National cancer dashboard, psychological and emotional well-being will have to be prioritised and for the first time regarded as central to maintaining quality of life with parity to physical health outcomes.

### London Context

In 2014, both the London Cancer Alliance (LCA)<sup>20</sup> and London Cancer (LC)<sup>21</sup> produced documents with recommendations in relation to Mental health psychological support services, including service specifications and referral guidelines. National Cancer Peer Review Programme Manual for Cancer Services: Psychological support measures (2011)<sup>22</sup> also outlined quality standards, measures, workforce and service requirements for the delivery of psychological support within hospital settings.

In 2015, the Transforming Cancer Services Team 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>1</sup>.

There were ten key recommendations made in this document:

1. Timely access to commissioned support should be available for the whole cancer pathway. Throughout the pathway people with cancer should be actively informed of the potential need for psychological support and given guidance on access and availability.
2. Individuals should have access to a range of emotional and psychological support according to need.
3. Psychological support should be available to families and carers.

<sup>17</sup> National Cancer Survivorship Initiative (2007) (archived) <http://webarchive.nationalarchives.gov.uk/20100809103735/http://www.improvement.nhs.uk/cancer/Default.aspx?alias=www.improvement.nhs.uk/cancer/survivorship>

<sup>18</sup> National Cancer Survivorship Vision (2010) (archived) <http://webarchive.nationalarchives.gov.uk/20100809113601/http://www.improvement.nhs.uk/cancer/LinkClick.aspx?fileticket=4apVUSvGcow%3d&tabid=214>

<sup>19</sup> National Cancer Survivorship Initiative (2013) *Living with and beyond cancer: Taking action to improve outcomes* [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>20</sup> London Cancer Alliance (2014) Mental Health and Psychological Support Service Specification and Referral Guidelines, <http://www.londoncanceralliance.nhs.uk/media/100472/lca-mh-ps-service-spec-final-dec-14.pdf>

<sup>21</sup> London Cancer 2014 Service Specification Psychological Support Services, <http://londoncancer.org/media/89175/psychological-service-specification-final-2014june-.pdf>

<sup>22</sup> NHS England (2011) *National Cancer Peer Review Programme Manual for Cancer Services: Psychological Support Measures*.

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4. All health and social care staff involved in cancer care should have education, training and supervision that enables them to identify emotional problems and provide psychological support at an appropriate level.
5. Commissioners should ensure that Information and Support Centres (ISCs) are available at all acute trusts.
6. All people living with cancer should be offered a Holistic Needs Assessment with care planning at key points along the pathway.
7. Community provision for emotional and psychological support should be supported and developed.
8. Specific groups should be proactively supported. For example: men, people with severe and enduring mental illness, those who do not speak English as a first language, people with learning disabilities, older people etc
9. Psychology services providing support to cancer centres should be located on-site.
10. Co-production with people affected by cancer and their carers should be integral to service development.

Ensuring that the Living with and Beyond Cancer agenda and specifically psychosocial support needs retains a high profile within London at a time when early diagnosis and cancer waiting times are being prioritised will be essential to ensure improved quality of life for all Londoners affected by cancer.

### **Integrated care**

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>23</sup> identifies a number of key messages related to ‘getting the basics right’ from a service user perspective: taking a ‘whole person’ perspective, improving professionals’ communication skills, co-ordination of care, proactive care, peer support, self-management and support for family and carers. Other key messages for integrated care initiatives include: facilitating skills transfer, supporting a workforce through education with a foundation in physical and mental health, addressing barriers to integration such as separate budgets and payment systems by introducing new payment systems and contracting and shifting notions of who is responsible for what.

### **Management of psychological difficulties in the context of cancer**

The NICE guidance document *Improving supportive and palliative care for adults with cancer* (2004)<sup>7</sup>, remains in effect and is clear in outlining recommendations specific to patient and carer involvement, how cancer psychological services should be arranged, as well as palliative care, rehabilitation services, services for families and carers and workforce development.

The main points include:

- Individuals have different needs at different points in time and services should be responsive to those needs
- Families and carers need support during the patient’s life and in bereavement

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<sup>23</sup> Kings Fund (2016) Bringing together physical and mental health: A new frontier for integrated care  
<https://www.kingsfund.org.uk/publications/physical-and-mental-health>

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- All patients and carers should undergo systematic psychological assessment at key points along the pathway (such as around the time of diagnosis, as treatment ends, at recurrence, end of life) and have access to appropriate psychological support.
- Those experiencing particular distress should be referred to professionals with “specialist expertise”
- Psychological needs of staff caring for patients and carers should be adequately met
- All staff providing psychological care should be adequately trained and receive ongoing supervision.

### **Psycho-oncology services**

Psycho-oncology services are typically teams of cancer specialists, with expertise in the area of psychological and mental health care for people affected by cancer, their carers and families (such as cancer counsellors, Clinical Psychologists). Most psycho-oncology services are hospital based but not all.

The scope of these services includes:

- direct clinical care for patients, families and carers
- addressing psychological issues that can inhibit access to investigations and treatments
- contributing psychological evidence and insights to all multi-disciplinary teams
- providing training and supervision for CNS and AHP colleagues in level 2 skills to fulfil core peer review requirements.
- training and supporting staff to deliver aspects of the recovery package (e.g HNAs) and directly contributing to designing and running other aspects e.g HWBEs.
- Taking the lead in developing collaborative and effective working relationships with 3<sup>rd</sup> sector and community services (e.g IAPT, community palliative care teams, GPs and practice nurses, district nurses, and cancer rehabilitation teams) to ensure optimal post-acute psychosocial support
- Providing rapid access to consultation and advice on complex cases (e.g people with mental health history, poor adherence to treatment, complex treatment decision-making)
- Offering highly specialist clinical care for inpatients during medical admission, and outpatients at any point along the pathway

A recent mapping exercise by the Transforming Cancer Services Team in London has shown that:

- The commissioning of Psycho-oncology services is varied and complex. How services are commissioned is not clear for every service.
- Despite some excellent services in London there are still some geographical areas that have no or limited psycho-oncology provision
- Providers describe increasing demands on their services and some referral decisions are influenced by perceptions of waiting time and expertise in cancer (e.g referring to IAPT services) or concern about the higher thresholds for acceptance of referrals in Community mental health teams

Although Integrated Improving Access to Psychological Therapies (IAPT) services are developing their role in working with long-term conditions (cancer has now been coded as a long term condition), the central focus remains on reduction in anxiety and depression in those with long-

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term conditions. Other cancer-related psychosocial distress and difficulties, for example, adjustment disorder, fear of recurrence, role and identity change, sexual dysfunction or body image distress are not within the main focus of IAPT services. Additionally, IAPT services do not provide the range of 'indirect' work outlined above. The most common LTCs that are currently seen in integrated IAPT services are:

- Diabetes
- Chronic obstructive pulmonary disease (COPD)
- Cardiovascular disease (CHD)
- Musculoskeletal problems, Chronic pain

Further consultation will be needed in phase 2 to optimise relationships and clarify the pathway between primary care, IAPT services and psycho-oncology teams.

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. This will mean working across acute, primary care and community settings.

## 2. Outcomes

### 2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely	YES
Domain 2	Enhancing quality of life for people with long-term conditions	YES
Domain 3	Helping people to recover from episodes of ill-health or following injury	YES
Domain 4	Ensuring people have a positive experience of care	YES
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm	YES

### 2.2 Expected outcomes

It is intended the following outcomes will be achieved via commissioning of a Psycho-oncology service that provides expertise across the pathway.

- Improve the emotional well-being of people affected by cancer their families and carers by reducing distress, improving functional activity and quality of life
- Improve psychological skills and understanding of the whole workforce
- Improved patient experience – monitored through National Cancer Patient Experience Surveys (NCPES)<sup>24</sup> and Macmillan 9 Outcomes<sup>25</sup>

<sup>24</sup> Quality Health (2017) National Cancer Patient Experience Surveys <https://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>

<sup>25</sup> Macmillan Cancer Support (2014) Macmillan's 9 Outcomes <https://www.macmillan.org.uk/about-us/what-we-do/our-ambition/nine-outcomes.html>

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- Improve survival outcomes for patients through psychological interventions increasing uptake of screening, testing and treatments

### 3. Scope

#### 3.1 Key aims and objectives of service

##### **Aim**

The Psycho-oncology service should be multi-disciplinary offering clinical assessment, formulation, multi-modal treatment and monitoring as well as specialist consultation, training, supervision, service and pathway development. The service to patients, carers and both cancer healthcare professionals and non-specialist staff should be flexible, accessible, proactive and responsive to psychosocial needs at any point along the pathway from diagnosis, through treatment, living with and beyond cancer and end of life care.

Historical barriers and obstacles need to be overcome to provide integrated care, within acute settings and across primary and secondary care, bridging acute, primary care and community.

##### **The main objectives of the service are:**

To work, as cancer specialists, with the full range of psychological problems associated with cancer, including:

- Adjustment difficulties
- Anxiety and phobias
- Depression
- Decision-making difficulties: indecision related to cancer treatment choices
- Fear of recurrence
- Problems with personal relationships
- Psychosexual and body image difficulties
- Psychological issues inhibiting access to cancer investigations and treatment
- Alcohol and drug-related difficulties
- Cognitive impairment (e.g due to radiotherapy to CNS)
- Personality Disorder
- Deliberate self-harm
- Psychotic illness
- Organic brain syndromes (e.g delirium)
- Carer and family support, including bereavement work

To provide on-going clinical supervision of the psychological work of CNS, AHP colleagues within the acute hospital setting and colleagues within Primary Care and Community services where appropriate.

To improve patient's ability to self-manage and access other sources of support

To provide consultation, liaison, education, training and in-reach to support to the primary care workforce in supporting people Living with and Beyond Cancer.

### 3.2 Service description/Care pathway

#### 3.2.1 Staffing

Staffing levels need to be negotiated locally, but need to incorporate both the specialist psychological support workforce (levels 3 and 4) and the level 2 workforce such as AHPs, and CNS. Services should have a suitable skill mix for the setting and type of service. Health Education England (HEE) are currently developing a cancer workforce plan but Clinical Psychologists are not being considered currently in this work. **Further details on workforce calculations will be completed in phase 2 of this work.**

#### 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	Couselling 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)

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. Although this guidance has not been refreshed since 2004, it is still in effect and remains a well-recognised framework, understood by service providers, the third sector and commissioners. The overall benefits of implementing this model in relation to people affected by cancer has included:

1. Reductions in psychological distress
2. Improvements in overall quality of life and other functional outcomes
3. Improvements in concordance with cancer treatments

Prevalence data for London will be able to assist in this workforce planning for each STP. Workforce calculations must include provision for both 'direct' and the range of 'indirect' activities delivered by Psycho-oncology teams such as:

- Level 2 training for CNS and AHP colleagues
- ongoing supervision to Level 2 workers

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- consultation to enhance the psychological elements of the Recovery package e.g input into Health and Well-being events
- training on conducting Holistic Needs Assessments
- offering specialist advice on complex cases within multi-disciplinary team meetings
- offering specialist advice, supervision, skills training and consultation to multi-disciplinary colleagues across the whole pathway, including primary care and community settings when needed.
- providing Level 1 training (e.g Sage and Thyme training)
- providing reflective practice groups, multi-disciplinary support and education groups
- providing joint clinics and staff support such as Schwartz rounds.

Please note this is not an exhaustive list of 'indirect' activities

Members of the Psycho-oncology service can come from a variety of backgrounds including: Clinical Psychologists, Counselling Psychologists, Specialist Liaison Psychiatrist, Psychosexual therapist, Neuropsychologist, Cancer counsellors, psychotherapists and administrators. Patients may require a variety of interventions so can then be seen by the most appropriate clinician. Access to social work support is also important to ensure people have their social care needs met which also impacts on mental health.

### **Activity levels**

Level of activity needs to be clearly defined and seen as not just about the direct clinical caseload. For example a Band 7 Clinical Psychologist 1.0 (wte) will likely hold a larger caseload than a Consultant Clinical Psychologist 1.0 (wte) who is responsible for service development, clinical governance, senior management, quality improvement, patient engagement, consultation with clinical colleagues, supervision and training and has therefore has fewer clinical cases.

Further work is needed to establish agreed activity levels to ensure that 'direct' and 'indirect' activity is accounted for as well as protected time for CPD and professional supervision.

### **3.2.2 Clinical Space**

All Psycho-oncology services need dedicated clinical space. Privacy is essential with good sound-proofing of rooms where possible.

Rooms need to be able to accommodate not only direct interventions with one patient/carer, but also to support couple, family work, groups, supervision, staff consultation and multi-disciplinary team meetings. Medical rooms with examination equipment and medical supplies are not appropriate for facilitating a relaxed context for therapeutic interventions and should be avoided.

Rooms should have sufficient IT resources to access and display relevant patient records, case notes, web-based material, and phone/video conferencing (e.g Skype)

Consideration also needs to be given to providing domiciliary visits when appropriate.

### **3.2.3 Multi-disciplinary team (MDT) working**

Excellent working relationships are required to ensure the MDT work effectively and efficiently. A well-coordinated and managed MDT ensures that:

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1. Referrals are responded to swiftly, appropriately and efficiently within a weekly team meeting
2. Rapid access to the appropriate clinician is secured
3. The person/people referred are communicated with quickly and compassionately
4. Partnership working and collaborative care is encouraged and facilitated between professionals within an acute service and between acute, community and primary care services when needed.
5. The patient remains at the centre of all MDT discussions and is offered as much choice as possible in terms of where and when they are seen.

### 3.2.4 Education and Training

The NICE (2004)<sup>1</sup> guidance document and the National Cancer Peer Review<sup>22</sup> clearly detail the education and training requirements needed to operate at the NICE levels 1-4.

- Level 1- **All staff** across acute, primary and community care should receive mandatory 'Sage and Thyme' training which guides all healthcare professionals on how to listen and respond to patients who are distressed and has been viewed as essential to improve care and patient experience.
- Level 2 –**Clinical Nurse Specialists/Allied Health Professionals**-additional training on the National Advanced Communications Skills Training Course and further level 2 training "relevant to cancer patients and their carers which covers basic psychological screening, psychological assessment and basic psychological intervention skills". After training there is a requirement for Level 2 professionals to attend regular supervision sessions for the psychological support work they undertake. Supervisors need to be at Level 3 or 4.
- Level 3-**a counsellor, accredited by the British Association for Counselling and Psychotherapy, an NHS psychotherapist accredited by the United Kingdom Council for Psychotherapy, a registered mental health nurse with a diploma in counselling, a social worker with additional university accredited diploma in counselling or psychotherapy.** The assumption is that basic qualifications in these disciplines would exempt a practitioner from level 2 training.
- Level 4- **a Consultant psychiatrist, a Consultant liaison psychiatrist, a Clinical or Counselling psychologist.** All the above professions at Level 4 should have completed an induction that meets the British Psychosocial Oncology Society (BPOS) and SIGOPAC (DCP Faculty for Oncology and Palliative Care) requirements.

### 3.2.5 Service evaluation and audit

All services have a responsibility for on-going evaluation and audit and should have a plan for doing so. Results should be used to improve services. Services should be supported to test out new initiatives. Health equity assessments should be regularly conducted to ensure that the services are meeting the needs of the widest range of Londoners.

### 3.2.6 Interventions which should be available

Interventions should be carried out following an assessment of clinical need and the competency level of the practitioner and their skill set.

Within a Psycho-oncology MDT 'direct' interventions should include the following:

- Addressing psychological issues, enabling a patient to make decisions about engaging in

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testing and treatment and managing any obstacles to engaging with a medical team.

- Cognitive-behavioural therapy
- Third wave cognitive-behavioural therapies (e.g Acceptance and Commitment therapy)
- Systemic interventions
- Couple/Family Therapy
- Bereavement support
- Psychosexual therapy
- Neuropsychological assessment and Interventions
- Cancer counselling
- Brief focused psychotherapy
- Mindfulness
- Assessment and management of suicidality, co-morbid alcohol and drug problems, personality disorder, deliberate self-harm, psychotic illness, organic brain syndromes, complex co-morbidity

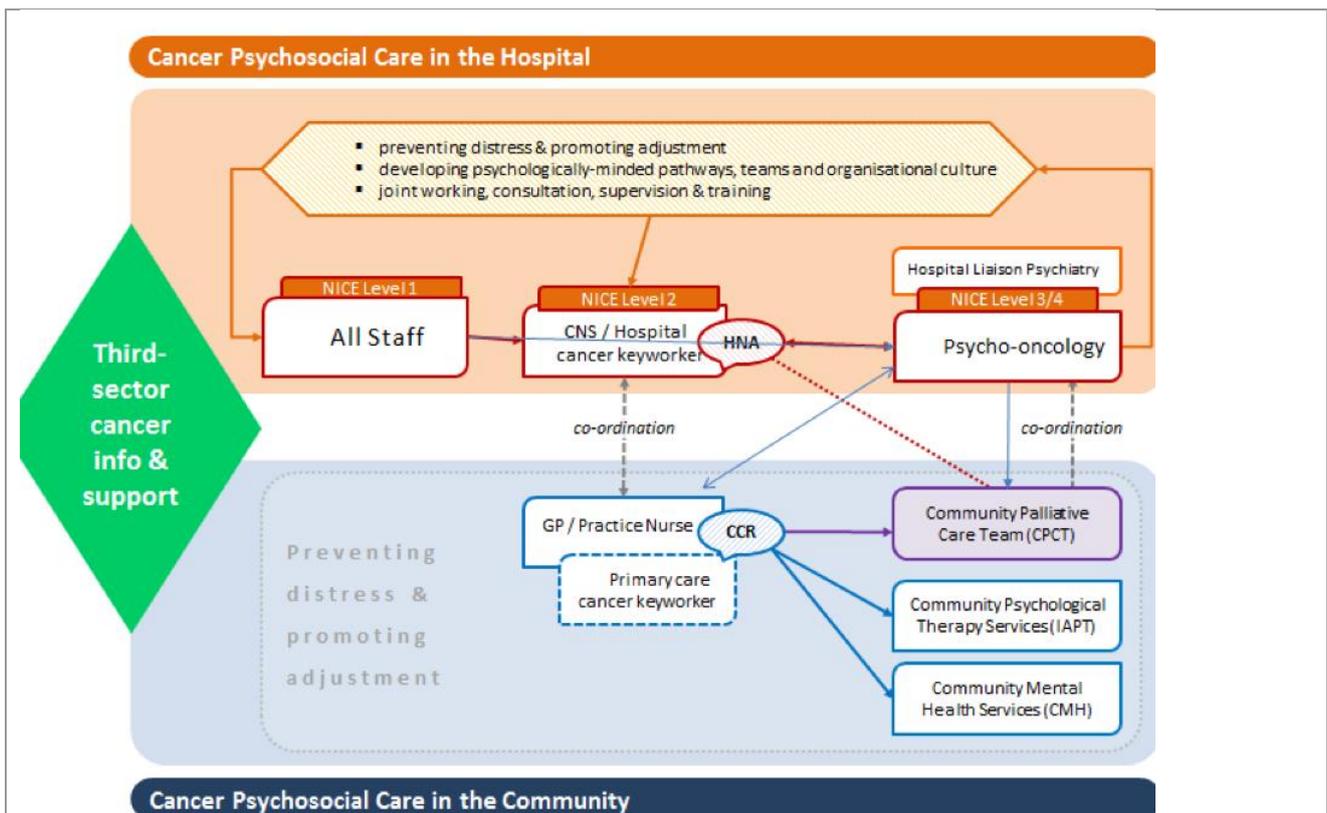
'Indirect' interventions should include:

- Delivering Level 2 training and ongoing supervision to Level 2 workers
- Consultation to enhance the psychological elements of the Recovery package e.g input into Health and Well-being events, training on conducting Holistic Needs Assessments
- Offering specialist advice, supervision, skills training and consultation with multi-disciplinary colleagues within cancer multi-disciplinary team meetings and across primary and community settings when needed
- Providing Level 1 training (e.g Sage and Thyme training)
- Providing reflective practice groups, multi-disciplinary support and education groups
- Providing joint clinics
- Providing staff support such as Schwartz rounds.

### **3.2.7 Psychosocial Support Pathway**

Figure 1 Psychosocial pathway for London

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A key message underpinning the pathway is that all patients benefit and should expect good psychological care from every healthcare worker they have contact with from their diagnosis of cancer and treatment period/s, through to living with/beyond cancer as a long term condition, and during end of life care.

There are a range of interventions that are beneficial and not just delivered by one single professional group. The term Psychosocial Support Pathway captures the importance of considering a broader range of determinants of emotional well-being.

### *Preventing distress and promoting adjustment*

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.

In simple terms there can be a significant positive impact on the mental health of those affected by cancer, their families and carers with the following basic recommendations and considerations:

- Patients, families and carers are communicated with compassionately by all staff.
- Good communication and partnership working between all staff
- Patients, families and carers have access to information on local services (both health and social care) which is kept up to date and includes online support
- Prompt, efficient and reliable systems are in place across the whole pathway
- Early recognition and support for how socio-economic factors impact on mental health (e.g concerns about finances, employment, housing, childcare )
- Identification of who may need extra support early on to prevent distress and promote adjustment (e.g asking about past losses, mental health history, social isolation)

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- Developing a psychologically minded culture within cancer services with more emphasis on integration between physical health and psychological well-being. Effective use of the Recovery Package would also improve psychological well-being across the pathway.



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The National Cancer Survivorship initiative highlighted the immediate and long term consequences of cancer and its treatment. As part of the NCSI initiative, Macmillan Cancer Support in conjunction with the Department of Health developed the 'recover package'. The recommended recovery package model comprises four aspects: holistic needs assessment (HNA), health and well-being events (HWBE), Treatment Summaries (TS) and the Cancer Care review (CCR) in Primary Care. These interventions have been included in London's acute commissioning intentions every year since 2012/13. Acute providers are expected to implement all interventions that relate to their services (HNA, TS, HWBE) and in Primary Care (CCR) so that patients receive a package of care without variation. The recovery package had been considered as providing the "building blocks for achieving good outcomes"<sup>18</sup> for those affected by cancer.

- Evaluation of outcomes from the use of the recovery package must focus on quality of components delivered, patient experience, impact on care received and not just quantitative output.
- HNA and Care planning-how do patient's experience the process? What impact do they have on actual care received?
- Treatment summaries (must be completely and shared swiftly across the pathway to

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reduce anxiety). They should include any identified emotional support need to be followed up in primary care.

- The 4 point model for Cancer Care Reviews provides an opportunity to identify the psychological impact of cancer and its treatment at various points along the pathway
- Health and well-being events need to be delivered in the most clinically effective way to enhance patient confidence in self-management and knowledge of how to access further support if needed.

A full outline of practitioner levels of activity are below:

**Level 1 Role-All staff** working with people affected by cancer, their families and carers

Psychosocial care activity needs to include:

- Recognition of psychological need
- Look for indications of distress, low mood, worry. 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 their difficulties interfering with their life and accessing treatment?
- Provide general emotional support
- Signpost to support that patient finds relevant-discuss with them
- Communicate with compassion
- Ensure all professionals are communicating effectively with each other across the pathway.
- Discuss with a CNS/Level 2 worker
- Contact Psycho-oncology service for advice/consultation

**Level 2 Role *Clinical Nurse Specialists/Allied Health Professionals/Primary Care Key worker***  
role– requires specific training and regular supervision

Psychosocial care activity includes:

- meet the person at diagnosis – to build a reliable relationship
- explore and address the person’s information preferences
- include and involve family and carers
- track person’s adjustment throughout the pathway
- guide and coordinate care, including support
- contribute psychosocial perspective to MDT decisions
- signpost to internal and third-sector resources, e.g. welfare advice
- undertake holistic needs assessment (HNA) at key transitions
- offer first-line psychological support (Level 2)
- consult with, work jointly with and refer to Level 3/4 psycho-oncology services
- link and coordinate care with external services (e.g. learning disability)

**Level 3 includes psychotherapists, family therapists, counsellors, mental health therapists accredited in a particular modality (e.g CBT accreditation by BABCP), social workers and mental health nurses with an accredited psychotherapeutic training. Completed specialist training in cancer care.**

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- 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 includes clinical psychologists, consultant liaison psychiatrists, counselling psychologists who have completed a substantive mental health training, are accredited to deliver interventions across a range of modalities, able to use formal methods to adapt, evaluate and deliver interventions. Knowledge through training and experience of other mental health services. Completed specialist training (e.g in role-teaching, supervision and formal courses) with specific reference to cancer care.**

- 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.

A range of professionals should be available within a Psycho-oncology service to include Clinical/Counselling Psychologist, access to Liaison Psychiatry, Psychosexual therapists and Neuropsychologists.

These will comprise both level 3 and level 4 professionals.

Psycho-oncology teams are usually embedded within cancer pathways and led by Level 4 professionals such as Consultant Clinical Psychologists. These teams:

- Work with inpatients and outpatients
- Provide a vital role in supporting patients to access cancer investigations, treatments and care thus improving patient outcomes.
- Provide support for patients, families and carers
- Work with full range and severity of difficulties associated with cancer including :
- 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 personal relationships and relationships with professionals
- Offer a range of interventions including:
- Cognitive-behavioural therapy
- Brief focused psychotherapy
- Mindfulness
- Grief/Existential Therapy

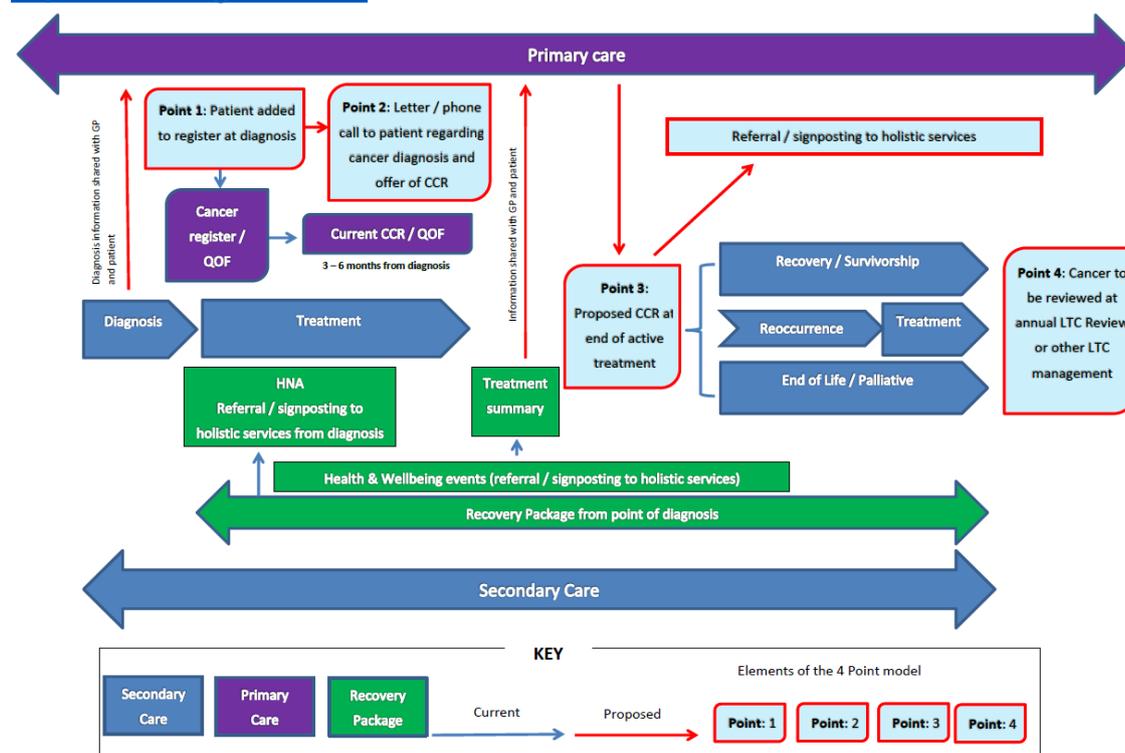
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- Couple/Family therapy
- Systemic interventions
- Cancer counselling
- Consultancy to survivorship events
- Assessment and management of: suicidality and risk, co-morbid alcohol and drug-related problems, personality disorders, deliberate self-harm, psychotic illness, organic brain syndromes, complex co-morbidity
- Provide consultation and expert advice on cancer and psychological issues to MDT teams and other professionals across the pathway
- Provide training, consultation and supervision for Level 2 workers (e.g CNS)
- Provide specialist functions such as Neuropsychological assessment, psycho-sexual interventions

### 3.2. 1 Recommendations for Primary Care

Primary care should be able to easily access specialist cancer expertise from Psycho-oncology teams. Additionally, the primary care provider will be required to implement the 4 point Cancer Care Review (CCR) Model for London<sup>26</sup>.

[Explore this diagram online](#)



The aim of the CCR is that it is co-produced between the Primary Care Clinician (GP, Practice Nurse or allied health professional) and the patient. The CCR should cover psycho-social needs, physical health needs, needs of carers and support patients towards self-management. The CCR provides an opportunity within primary care to identify psycho-social support needs at a number of

<sup>26</sup> Transforming Cancer Services Team for London (2015) *Cancer as a long term condition: A review of Cancer Care Reviews and a proposed model for London*  
<https://www.myhealth.london.nhs.uk/system/files/Cancer%20Care%20Review.pdf>

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points along the pathway. Currently the quality and provision of Cancer Care reviews across London is variable. Work is currently being undertaken to develop a template that could make consultations more meaningful within the time and resource constraints.

The 4 point model describes activity required at each point along the pathway:

Point 1: Patient added to cancer register (QOF CAN001 or local incentive scheme)

Point 2: 1<sup>st</sup> intervention: First contact after diagnosis (QOF CAN003 or local incentive scheme)

Point 3: 2<sup>nd</sup> intervention: Holistic cancer care review at the end of primary treatment (local incentive scheme)

Point 4: 3<sup>rd</sup> intervention: Cancer reviewed at an annual LTC review (QOF or generic long term conditions local incentive scheme)

The future of Quality Outcomes Framework (QOF) is uncertain, but CCGs will need to consider local incentive schemes in order to take implementation of the CCR forward.

Other requirements for primary care providers to adhere to are as follows:

- The service needs to be patient-centred and accessible
- Services will be provided by trained and qualified practitioners with appropriate training and support
- Provider will not discriminate between or against patients/carers on the grounds of age, ethnicity, disability, religion, or any other non-medical characteristics
- Reasonable adjustments and variations in service must be made for those with a disability – this may include reserving beginning or end of session appointments where suitable.

### **3.2.2 Recommendations for Collaboration with Integrated Improving Access to Psychological Therapies (IAPT) services.**

IAPT Integrated services started to treat people with long-term conditions in January 2017. The main focus of interventions remains “to treat the patient’s anxiety or depression in the context of their long term condition”.

#### **Current coverage (NHS England)**

16% of all STPs have all CCGs within them commissioning IAPT-LTC services

62% of all STPs have at least one CCG who has commissioned an IAPT-LTC service

38% of all STPs have no IAPT-LTC service currently commissioned

1. Integrated IAPT services within their respective CCGs and STP areas need to identify what the existing and established pathway in place looks like for cancer. This will avoid any duplication in work and enables better pathway partnership working.
2. In relation to Integrated IAPT services and their work with people affected by cancer, it is recommended that education, training and consultation with cancer specialists such as psycho-oncologists would need to be integral to service development to ensure the best outcomes for people affected by cancer.
3. Integrated IAPT services are adapting their direct interventions for people with LTCs but generally it is not within their remit nor are they financially incentivised to carry out ‘indirect’ work which is delivered by Psycho-oncology services.
4. Integrated IAPT services working with people with LTCs, including older adults, need to conduct health equity assessments of their services to establish whether they are meeting

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the needs of all those with LTCs who require the service.

5. In relation to psychosocial support for people affected by cancer, a specific cancer stepped care model for Integrated IAPT should be developed bridging acute, primary care and community services.
6. Going forward, Psycho-oncology services and IAPT services will need to work closely on agreeing inclusion and exclusion for referral allocation in relation to supporting people affected by cancer. For example, a person affected by depression and anxiety but facing end of life issues really needs to be receiving psychological support within a Community palliative care team where physical health issues such as pain management, mental health and social factors can be integrated.

### 3.3 Costing of Services

A business case will be developed to support the Service specification.

### 3.4 Population covered, location and timing of services

The Psycho-oncology service is available across the psycho-social pathway. Most psycho-oncology services are hospital based, as cancer specialists linking in with acute oncology teams. However, services should be developed in line with the integrated care and Care closer to home agendas to ensure the best outcomes for patients. For example, a psycho-oncology clinic being delivered monthly within a hub of GP practices within Primary Care.

### 3.5 Acceptance and exclusion criteria

#### Eligibility criteria

#### 3.6 Referral process and waiting times

Patients should be able to access Psycho-oncology services via referrals from healthcare professionals including GPs, Consultants, Clinical Nurse Specialists and AHPs. Consideration should also be given to self-referral.

Agreement should be reached on:

- When a patient is referred to the Community Palliative Care Team
- When a patient should be directed to IAPT services
- When a patient should be referred to the Community Mental Health Team

The Psycho-oncology team should take the lead on communicating and partnership working across the pathway and triaging referrals for those affected by cancer. If a patient is seen as inappropriate for the Psycho-oncology service, they should still be involved in facilitating a swift referral elsewhere. GPs should not be expected to make complex clinical decisions about psychological care and referral routes.

#### 3.7 Partnership working with other services/providers

Key partnerships and relationships include the following:

GPs and Primary Care staff

Palliative Care Teams  
IAPT services  
LTC teams  
Community Mental Health Teams  
Local authority  
Local hospitals  
Local hospices  
The Third sector  
Cancer rehabilitation services  
Psychiatry

### 4. Applicable Service Standards

The service will be delivered according to best practice and in line with the relevant local and national guidance

#### 4.1 Applicable national standards

- NICE guidance on Improving Supportive and Palliative Care for Adults with Cancer (2004)
- Psychological Support Measures for Cancer (NCAT 2010)

#### 4.2 Applicable local standards

As referred to in this document and as developed by providers to ensure that there is an operational level for self-certified protocols.

### 5. Applicable quality requirements and CQUIN goals

#### 5.1 Applicable Quality requirements and CQUIN goals

##### 5.1.1 Outcome measures:

Core domains of quality and outcomes of psycho-oncology services have been identified in the BPS/DCP document *Demonstrating Quality and Outcomes in Psycho-Oncology*<sup>27</sup>:

- Is this service safe?

<sup>27</sup> The British Psychological Society (2015) *Demonstrating Quality and Outcomes in Psycho-oncology*, <https://www1.bps.org.uk/system/files/Public%20files/cat-1704.pdf>

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- Is this service equitable, while also focused on those most in need?
- Is this service timely and responsive?
- Is this service respectful, collaborative and patient-centred?
- Is this service offering effective interventions?
- Is this service contributing to efficient multi-disciplinary care?

Outcome measures should be used to evaluate the effectiveness of direct interventions. There is a wide selection of quantitative self-report measures in use.

It is important that a patient is not overwhelmed by assessment measures to the detriment of the clinical relationship, so administration of measures should be kept to an agreed minimum.

Measures could usefully include the following:

- Global Assessment of Function (GAF) (pre-and post-intervention for inpatients)
- Functional Assessment of Cancer Therapy-General (FACT-G) (pre and post treatment for outpatients)
- GHQ-12
- HADS (Hospital Anxiety and Depression Scale)
- PHQ-9 (pre and post treatment for outpatients) when working with depression
- GAD-7 (pre and post treatment for outpatients) when working with anxiety
- Quality of Life metric (in development, currently being piloted in London at UCLH and Barts (2017-2019))

Psycho-oncology services offer specialist advice, supervision, skills training and consultation with multi-disciplinary colleagues. Delivering Level 2 training and ongoing supervision to Level 2 workers. Services may also be providing Level 1 training (e.g Sage and Thyme training), reflective practice groups, multi-disciplinary support and education groups, joint clinics and staff support such as Schwartz rounds. This 'indirect' work must also be captured preferably by agreed Pan-London tools to ensure comparisons can be made on service standards and value of Psycho-oncology services across London.

Services should explore the use of health care utilization metrics using the Client Service Receipt Inventory (CSRI) to evaluate the impact of their service on for example:

- Emergency inpatient admissions
- A & E attendance
- GP consultations

Additionally, it would be valuable to assess levels of self-managed care following psychosocial interventions.

Further work is needed to agree pan-London outcome measures, whilst acknowledging the different psychological modalities used within psycho-oncology services.

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### **5.1.2 Key performance indicators**

These are used in addition to outcome measures to evaluate the performance of a service. Pan-London agreement is needed on what performance measures should be used. A Pan-London approach to KPIs is needed in order to benchmark services, and obtain meaningful data for comparison across services

### **5.2 Applicable CQUIN goals**

New applicable CQUIN indicators 2017-2019:

- Improving the outcomes and experience of patients with mental health needs
- Empowering staff to help patients take more control of their own long-term conditions
- Improve GP to consultant advice before referring to secondary care

### **5.3 Data collection**

Minimum data sets have been recommended by LCA<sup>19</sup> but Pan-London agreement is needed.

## Appendix B: Service Mapping

### List of psychological services by Acute Trust and STP

STP	Name of Service	Sites	NHS Trust
North Central London	UCLH Macmillan Support and Information Service	<ul style="list-style-type: none"> <li>University College London Hospital</li> </ul>	University College London Hospital
	Cancer Care Psychology service	<ul style="list-style-type: none"> <li>Whittington Hospital</li> </ul>	The Whittington Hospital NHS Trust
	Cancer and Haematology Counselling Service	<ul style="list-style-type: none"> <li>Royal Free London</li> <li>Barnet</li> <li>Chase Farm</li> </ul>	Royal Free London NHS Foundation Trust
	Macmillan Cancer Clinical Psychologists at the North Middlesex Hospital	<ul style="list-style-type: none"> <li>North Middlesex University Hospital</li> </ul>	North Middlesex University Hospital Trust
	Royal National Orthopaedic Hospital Sarcoma Service	<ul style="list-style-type: none"> <li>Royal National Orthopaedic Hospital</li> </ul>	Royal National Orthopaedic Hospital Trust
	Patient support services	<ul style="list-style-type: none"> <li>Moorfields North</li> <li>Moorfields South</li> <li>Moorfields East</li> </ul>	Moorfields Eye Hospital NHS Foundation Trust
North East London	Psychology in Cancer & Palliative Care at Homerton	<ul style="list-style-type: none"> <li>Homerton University Hospital</li> </ul>	Homerton University Hospital NHS Trust
	Cancer Psychology Services	<ul style="list-style-type: none"> <li>St Bartholomew's</li> <li>Mile End</li> <li>The Royal London</li> <li>Whipps Cross University</li> <li>Newham</li> </ul>	Bart's Health
	Psych-Oncology	<ul style="list-style-type: none"> <li>Queen's Hospital</li> <li>King George Hospital</li> </ul>	Barking Havering And Redbridge University Trust
North West London	Clinical Psychology for Oncology & Palliative Care	<ul style="list-style-type: none"> <li>Hillingdon Hospital</li> </ul>	The Hillingdon Hospitals NHS Foundation Trust
	Specialist Psychological Therapies at Lynda Jackson Macmillan Centre	<ul style="list-style-type: none"> <li>Mount Vernon</li> </ul>	
	<i>No specific service</i>	<ul style="list-style-type: none"> <li>Chelsea and Westminster</li> <li>West Middlesex University Hospital</li> </ul>	Chelsea And Westminster NHS Foundation Trust
	Clinical Health Psychology	<ul style="list-style-type: none"> <li>Ealing Hospital</li> <li>Northwick Park Hospital</li> <li>Central Middlesex Hospital</li> </ul>	London North West Healthcare NHS Trust
	<i>Have no dedicated oncology sessions, although see lung cancer patients admitted for surgery</i>	<ul style="list-style-type: none"> <li>Royal Brompton</li> <li>Harefield</li> </ul>	Royal Brompton & Harefield NHS Foundation Trust
	Psycho-Oncology Team at Imperial	<ul style="list-style-type: none"> <li>St Mary's Hospital</li> <li>Charing Cross Hospital</li> <li>Hammersmith</li> </ul>	Imperial College
South East London	Macmillan Psychological Support (MAPS) Team	<ul style="list-style-type: none"> <li>Lewisham Hospital</li> <li>Queen Elizabeth</li> </ul>	Lewisham And Greenwich NHS Trust
	Psycho-Oncology Support Team (POST)	<ul style="list-style-type: none"> <li>Guys and St Thomas'</li> <li>Queen Mary's Sidcup</li> </ul>	Guy's & St Thomas' NHS Foundation Trust
	Cancer and psychotherapy service	<ul style="list-style-type: none"> <li>Kings College Hospital</li> </ul>	King's College Hospital NHS Foundation Trust
South West London	Cancer Counselling Service	<ul style="list-style-type: none"> <li>Kingston Hospital</li> </ul>	Kingston NHS Foundation Trust
	Macmillan Cancer Psychological Support (CaPS) Team	<ul style="list-style-type: none"> <li>St George's University Hospital</li> </ul>	St George's University Hospitals NHS Foundation Trust
	Macmillan Cancer Psychological Support (CaPS) Team	<ul style="list-style-type: none"> <li>St Helier Hospital</li> <li>Epsom Hospital</li> </ul>	Epsom & St Helier University Hospitals NHS Trust
	Macmillan Cancer Psychological Support (CaPS) Team	<ul style="list-style-type: none"> <li>Croydon University Hospital</li> </ul>	Croydon Healthcare Services NHS Trust
	Adult psychological support service	<ul style="list-style-type: none"> <li>Royal Marsden</li> </ul>	Royal Marsden NHS Foundation Trust
West Essex CCG	No dedicated service	<ul style="list-style-type: none"> <li>Princess Alexandra Hospital</li> </ul>	Princess Alexandra Hospital

## Number of staff and sessions per trust (oncology and palliative care) and liaison psychiatry

	Oncology Staff				Palliative Care Staff				Liaison Psychiatry	
	Staff who work exclusively with cancer and are not confined to working only in palliative/EoLC				Staff dedicated to palliative care and who would work with non-malignant conditions					
<b>NHS Trust</b>	No. of staff (lev3)	No. of Sessions (lev3)	No. of staff (lev4)	No. of Sessions (lev4)	No. of staff (lev3)	No. of Sessions (lev3)	No. of staff (lev4)	No. of Sessions (lev4)	<i>Is there liaison psychiatry readily available for cancer patients?</i>	<i>Can your hospital psychiatry service see outpatients?</i>
University College London Hospital†	3.24	32	2.17 + 1.2 (gyn onc)	33-34	0	0	0.4*	4	Only inpatients and as part of general liaison psychiatry	No
The Whittington Hospital NHS Trust	0	0	2	14	0	0	0	0	Not specifically, only for general patients. If patients are assessed as requiring psychiatry they are required to go through A&E	Only available through A&E
Royal Free London NHS Foundation Trust	2	20	**	0	0	0	2	4	Available at the Royal Free and sees inpatients regularly	Only available through A&E
Royal National Orthopaedic Hospital Trust	0	0	0	0	0	0	0	0	Yes	NHSE specialist commissioning for soft tissue and bone sarcoma
Moorfields Eye Hospital NHS Foundation Trust	3	6-12	0	0	0	0	0	0	None at present	Only available through local A&E
Homerton University Hospital NHS Trust	0	0	1	7	0	0	1	3	Yes - inpatients and through A&E	Only available through A&E
Bart's Health	1	4	5	19	7	10	4	9	Yes	No
Barking Havering and Redbridge University Trust	0	0	5	13	2	4	1	10	Yes	Yes
The Hillingdon Hospitals NHS Foundation Trust	0	0	2	6	0	0	2	6	Not specifically for cancer patients	No
Chelsea And Westminster NHS Foundation Trust	0	0	0	0	0	0	0	0	Not supplied – no specific service	Not supplied – no specific service
London North West Healthcare NHS Trust (Ealing)	0	0	1	2	0	0	1	8	Yes	No
London North West Healthcare NHS Trust (Northwick Park)	0	0	1	2	0	0	0	0	Yes	Only available through A&E
Royal Brompton & Harefield NHS Foundation Trust****	0	0	0	0	0	0	0	0	<i>Not supplied – no specific service</i>	<i>Not supplied – no specific service</i>
Imperial College	1	6	4	40	0	0	0	0	Yes - inpatients only	No
North Middlesex	3	9	2	15	0	0	0	0	Yes - inpatients only	No

## Number of staff and sessions per trust (oncology and palliative care) and liaison psychiatry

Number of staff and sessions per trust (oncology and palliative care) and liaison psychiatry										
	Oncology Staff				Palliative Care Staff				Liaison Psychiatry	
	Staff who work exclusively with cancer and are not confined to working only in palliative/EoLC				Staff dedicated to palliative care and who would work with non-malignant conditions					
<b>NHS Trust</b>	<i>No. of staff (lev3)</i>	<i>No. of Sessions (lev3)</i>	<i>No. of staff (lev4)</i>	<i>No. of Sessions (lev4)</i>	<i>No. of staff (lev3)</i>	<i>No. of Sessions (lev3)</i>	<i>No. of staff (lev4)</i>	<i>No. of Sessions (lev4)</i>	<i>Is there liaison psychiatry readily available for cancer patients?</i>	<i>Can your hospital psychiatry service see outpatients?</i>
University Hospital Trust										
Lewisham and Greenwich NHS Trust	1	10	1.6	16	0.5	5	0	0	Yes - at both hospitals	No
Guy's & St Thomas' NHS Foundation Trust	5	46	3	20	0	0	0	0	Yes - liaison psychiatry available at Guys. Also 0.1WTE of psychiatry (not liaison) directly for cancer patients (funding available for 0.3)	No because of 0.1 WTE in team
King's College Hospital NHS Foundation Trust	2	10	0	0	0	0	0	0	Yes - readily available for inpatients (no service level agreement for outpatients)	Only available through A&E
Kingston NHS Foundation Trust	2	6	1	4	0	0	0	0***	Not specifically but service is available and can see patients as needed	Only available through A&E
St George's University Hospitals NHS Foundation Trust	0.9	9	2	20	1	6	0	0	Yes – cover provided jointly between specialist liaison psychiatry in cancer services and hospital-wide liaison psychiatry  Majority of service currently funded until March 2019	Yes
Epsom & St Helier University Hospitals NHS Trust	0	0	0	0	0	0	0	0	Only inpatients and as part of general liaison psychiatry	No
Croydon Healthcare Services NHS Trust	1.2	12	0	0	0	0	0	0	Only inpatients and as part of general liaison psychiatry	No
Royal Marsden NHS Foundation Trust	7	34	6	39	3	25	0	0	Yes	Yes - 3 sessions per week for outpatients
Princess Alexandra Hospital	0	0	0	0	0	0	0	0	No	They do. Not able to directly refer, patients would be referred back to the GP and ask them to complete a referral.

†Information only supplied by WTE \*hosted by NCWL NHS Trust \*\*No designated - there are 3 level 4 staff who provide services centred around body image for breast and skin part time \*\*\*not able to separate data between pall care and cancer) \*\*\*\*Have no dedicated oncology sessions, although would see lung cancer patients admitted for surgery

## CNS supervision, training and other activities

Trust	Number of CNS in hospital	Are you offering level 2 supervision groups to CNS?	If not: do you have intention to do so?	How many hours of supervision were delivered by levels 3 and 4 practitioners in 2016/17?*	How many level 2 people (calculated by hours) participated? **	Are there any other specialised training provided?	Please indicate any additional activities your services runs?
University College London Hospital	65	Yes	N/A			<ul style="list-style-type: none"> <li>All staff have access to 5 days/year for CPD which is supported by the team</li> <li>CNS are provided with a one day level 2 communication skills training</li> </ul>	<ul style="list-style-type: none"> <li>Provide a monthly HWB event</li> <li>We run a six week in house Managing Anxiety course and we have just run an 8 week mindfulness course</li> </ul>
The Whittington Hospital NHS Trust	10	Yes - 2 groups per month (approx. 5 people per group). Groups run for 1.5 hours each	N/A	36	180	<ul style="list-style-type: none"> <li>Chemotherapy nurses receive some level 2 type training.</li> <li>3 cancer consultants are also engaging in level 2 type consultation groups.</li> <li>There are plans to do more in the future (business case is currently in process)</li> </ul>	<ul style="list-style-type: none"> <li>Service runs a session at the annual cancer conference for patients.</li> <li>Volunteers are also provided training similar to level 2 groups</li> </ul>
Royal Free London NHS Foundation Trust	24 at the Royal Free, 16 at Barnet (including 8 vacant posts)	Yes - 5 groups per month (4 people per group) at Royal Free, 2 groups per month (4 people per group) at Barnet. Groups run for 1.5 hours each	Service currently being developed. There is intention to aim to have every CNS in a group (not including palliative care which has separate training)	126	324	<ul style="list-style-type: none"> <li>Service will be running level 2 training for CNS in January.</li> <li>Currently there is training for junior doctor (psychology awareness and self-care).</li> <li>Psychology staff can see staff on a 1:1 basis for self-care</li> </ul>	<ul style="list-style-type: none"> <li>Run cancer support groups</li> <li>HWB events currently under review but aim to run 2 events/year</li> </ul>
Royal National Orthopaedic Hospital Trust	4	No	We would like to but unable to because of lack of provision	N/A	N/A	<ul style="list-style-type: none"> <li>On an ad-hoc basis</li> </ul>	<ul style="list-style-type: none"> <li>Wellbeing events; Sarcoma UK Support groups (rotate with UCLH and Royal Marsden)</li> </ul>
Moorfields Eye Hospital	3	Pending Funding	Pending Funding	N/A	N/A	<i>Not supplied</i>	<i>Not supplied</i>
Homerton University Hospital NHS Trust	13	Yes - 2 groups per month (approx. 5 people per group). Groups run for 1.5 hours each	N/A	36	180	<ul style="list-style-type: none"> <li>Level 2 training cancer wide</li> </ul>	<ul style="list-style-type: none"> <li>Input into HWB events once a year and adhoc psychology events</li> </ul>
Bart's Health	75	Yes - 15 groups of up to 6 people. Held monthly for 1.5 hours	N/A	270	1350	<ul style="list-style-type: none"> <li>Participate in death and dying training</li> <li>Provide routine training for ward nurses and rotating doctors as well as ad hoc training as required</li> </ul>	<ul style="list-style-type: none"> <li>Run regular workshops for cancer patients (and those involved with their care: carers, family etc.)</li> </ul>
Barking Havering and Redbridge University Trust	25-29	Yes - 5 groups made up of 5-6 people in each. Held monthly for 1.5 hours (around a 70% attendance rate). Groups run for 1.5 hours each	N/A	90	365.4	<ul style="list-style-type: none"> <li>Reflective practice for palliative care and acute cancer MDT staff held once a month at 2 sites</li> <li>Level 2 groups for community specialised training for oncology services (3 groups which are not commissioned)</li> <li>2x level 4(x1.5 hours) support group for community Macmillan CNS</li> <li>Level 3: family therapy and level 2 supervision for Macmillan CNS</li> </ul>	<ul style="list-style-type: none"> <li>Regular psychology session as part of HWB events</li> <li>Contribute to Schwarz rounds</li> <li>Provide reflective and mindfulness training for staff, Also Drama Therapy sessions for patients who may have difficulty communicating (H&amp;N cancers etc.)</li> </ul>

\*calculated at number of groups x number of hours x 12 months \*\*calculated at number of CNS x number of hours x 12months

Trust	How many CNS do you have in your hospital?	Are you offering level 2 supervision groups to CNS?	If not: do you have intention to do so?	How many hours of supervision were delivered by levels 3 and 4 practitioners in 2016/17?*	How many level 2 people (calculated by hours) participated? **	Is there any other specialised training provided?	Please indicate any additional activities your services runs?
The Hillingdon Hospitals NHS Foundation Trust	15	Yes – 4 groups for all CNS. Groups run for 1 hour each	N/A	48	180	• Yes - on request	• Yes - as requested HWB events
Chelsea And Westminster NHS Foundation Trust	<i>No information supplied</i>						
London North West Healthcare NHS Trust (Ealing)	6 Cancer + 2 pall care	Yes - 2 groups monthly for 1 hour	N/A	24	96	No	Occasional - as required
London North West Healthcare NHS Trust (Northwick Park)	Not Known	No	Was previously - now not funded	N/A	N/A	Have provided in the past whole day training on psychological support for cancer patients	Breast cancer support groups (through IAPT)
Royal Brompton & Harefield NHS Foundation Trust	<i>No information supplied</i>						
Imperial College	65	Yes 10 groups (of varying sizes) per month 6 cancer AHPs also attend Groups run for 1 hour each	N/A	120	852	<ul style="list-style-type: none"> <li>• IAPT LTC courses (2 x in 2017)</li> <li>• + to oncology registrars MSc</li> <li>• + to DCLinPsy (UCL)</li> </ul>	<ul style="list-style-type: none"> <li>• + monthly groups for review radiographers, oncology registrars, ward teams</li> <li>• + surgery prehabilitation programs</li> <li>• + HSCT preparation program (group, video, etc)</li> <li>• + Schwartz Rounds</li> <li>• + NW London Level 3/4 collaborative group</li> </ul>
North Middlesex University Hospital Trust	23	Yes - 5 groups per month with all CNS's. Groups run for 1.5 hours each	N/A	90	414	<i>Not supplied</i>	<i>Not supplied</i>
Lewisham and Greenwich NHS Trust	28 cancer CNS + 5 Chemo CNS (also have breast CNS and CHANT team who are employed by Guys but input into the service)	Yes – new service so currently in development.  Five groups held monthly for 1.5 hours	N/A	90	504	<ul style="list-style-type: none"> <li>• New service currently in development, provides debriefing and short term support for traumatic experiences as well as other bespoke training at this stage</li> </ul>	<ul style="list-style-type: none"> <li>• Input into HWB events</li> <li>• intend to be part of support groups</li> <li>• attend ward rounds to pick up patients as required to see later in the day</li> <li>• Schwartz rounds (including 1xmember of the team being a facilitator) able to assist with traumatic experiences</li> </ul>

\*calculated at number of groups x number of hours x 12 months \*\*calculated at number of CNS x number of hours x 12months

	How many CNS do you have in your hospital?	Are you offering level 2 supervision groups to CNS?	If not: do you have intention to do so?	How many hours of supervision were delivered by levels 3 and 4 practitioners in 2016/17?*	How many level 2 people (calculated by hours) participated? **	Is there any other specialised training provided?	Please indicate any additional activities your services runs?
Guy's & St Thomas' NHS Foundation Trust	50 Cancer 25 Pall care	Yes. We provide regular group supervision to our CNS and AHP colleagues, as well as for Head and Neck MDT, Community Head and Neck Team (CHANT) and for Esther and Blundell ward staff. We run these 4-6 weekly. Ten CNS and MDT groups currently engage into this process from the following oncology services: Skin, Breast, Urology, Head and Neck (CHANT, MDT at GSTT), Gynaecology, Upper and Lower GI, Information CNS's within Dimbleby, Lung CNS's, Occupational Therapy and Physiotherapy.	N/A	120	Not enough information available to calculate at this time	<ul style="list-style-type: none"> <li>Delivers Level 2 Psychological skills training, using an adapted version of the Jenkins and North/Macmillan 4-session programme and which was adopted by the LCA as best practice.</li> <li>We run 2 per year, and it is offered to CNS's and AHP colleagues who have a permanent/locum position within the Directorate.</li> </ul>	<ul style="list-style-type: none"> <li>POST contributes to various educational events organized within the directorate, namely Health and Well-Being events (HWBE), patient support group facilitation and ad hoc events as and when asked.</li> </ul>
King's College Hospital NHS Foundation Trust	66	Only to haematology (16 CNS) and neurology (6 CNS) streams	Psychology services currently only funded for neurology and haematology streams. Currently looking into funding for other cancer streams which will include Level 2 supervision	48	254	Yes - contribute to compassion training day, new starter training days, reflective practice and debrief sessions for nursing staff	Yes - run a Fear of recurrence closed group (6 sessions) ongoing weekly carers group
Kingston NHS Foundation Trust	16+7 pall care	Yes	N/A	108	288	<ul style="list-style-type: none"> <li>Sage and Thyme training (coping strategies for staff)</li> <li>training on psychological issues and communication skills for all staff (not just cancer)</li> <li>debriefing sessions for inpatient staff</li> </ul>	<ul style="list-style-type: none"> <li>Not currently but starting to run group sessions for men and secondary cancer</li> </ul>

\*calculated at number of groups x number of hours x 12 months \*\*calculated at number of CNS x number of hours x 12months

	How many CNS do you have in your hospital?	Are you offering level 2 supervision groups to CNS?	If not: do you have intention to do so?	How many hours of supervision were delivered by levels 3 and 4 practitioners in 2016/17?*	How many level 2 people (calculated by hours) participated? **	Is there any other specialised training provided?	Please indicate any additional activities your services runs?
St George's University Hospitals NHS Foundation Trust	35	Yes	N/A			<ul style="list-style-type: none"> <li>Level 2 training</li> <li>HNA familiarisation training</li> <li>simulation training of cancer/mental health and end of life care for all cancer related staff</li> </ul>	<ul style="list-style-type: none"> <li>Contribute to HWB events - both tumour specific and general cancer</li> <li>Involved in surgery school running pre-surgery education sessions</li> </ul>
Epsom & St Helier University Hospitals NHS Trust	<i>Not supplied</i>	Yes - from a palliative care social worker				<ul style="list-style-type: none"> <li><i>Information not supplied</i></li> </ul>	
Croydon Healthcare Services NHS Trust	<i>Not supplied</i>	Bought in via an external counsellor				<ul style="list-style-type: none"> <li><i>Information not supplied</i></li> </ul>	
Royal Marsden NHS Foundation Trust	Over 60	We offer supervision groups to CNS and research nurses.	Level 2 training is currently integrated into a new CNS development programme but there are plans to broaden the scope and reach in 2018	216	720	<ul style="list-style-type: none"> <li>Sage and Thyme / Schwartz Rounds</li> <li>The CNS have access to training / education provided by The School which includes Advanced Communication Skills / Psychosocial Needs of Cancer Patients.</li> </ul>	<ul style="list-style-type: none"> <li>We provide Secondary Breast Cancer Therapy Group 3-4 a year</li> <li>We offer Mindfulness Skills Group</li> <li>We contribute to the Health and Wellbeing Events delivering workshops on Emotional Wellbeing.</li> <li>We participate in MDT</li> <li>Facilitate Schwartz Rounds / Sage and Thyme Training</li> <li>Teach on programmes in School and lecture on the Conference Programme run by Conference Centre.</li> </ul>
Princess Alexandra Hospital	16	Yes	N/A	24	<i>Not supplied</i>	None at the moment, most of the CNS are currently on professional development courses. We intend to deliver some level 2 training later in 2018	We currently have 4 generic large HWBE a year, breast , prostate and lung have site specific support groups. Breast also have an exercise group.

\*calculated at number of groups x number of hours x 12 months \*\*calculated at number of CNS x number of hours x 12months

## Commissioning of Services

NHS Trust	Service clearly commissioned?	How commissioned?	Macmillan funded psychologists/counsellors
University College London Hospital	Yes	Our level 3 and 4 Psychology services are commissioned but as yet nothing else we do is commissioned and is included in the tariff for treatment here at UCLH	1x8A post Macmillan badged
The Whittington Hospital NHS Trust	Yes	Commissioned by Camden/Islington NHS trust, Whittington NHS trust and Macmillan	1 x Half funded (0.3), 1x completely funded (0.8)
Royal Free London NHS Foundation Trust	Yes	Part of tariff charged for cancer patients	2 cancer level 3 staff are badged (not funded)
Royal National Orthopaedic Hospital Trust	Yes	NHSE specialist commissioning for soft tissue and bone sarcoma	No
Moorfields Eye Hospital NHS Foundation Trust	Yes	Melanoma patients only by NHS England. Others are locally commissioned.	None
Homerton University Hospital NHS Trust	Yes	Block funding by commissioners/Homerton for cancer	None
Bart's Health	Not commissioned	Unclear + CCG funding for community service provision	None
Barking Havering And Redbridge University Trust	Partly commissioned	Commissioned in 2 ways: (1) Service level agreements NELFT/BHRUT with a certain amount commissioned for cancer (2) Waltham Forest (community) commissioned for palliative care. Community psychology commissioned for 2x full time people	None
The Hillingdon Hospitals NHS Foundation Trust	Yes	Commissioned by Hillingdon CCG	Both badged
Chelsea And Westminster NHS Foundation Trust		<i>Not supplied</i>	
London North West Healthcare NHS Trust – Ealing	Yes	Meadow House commissioned as part of a SLA until end of financial year. At Ealing not clearly commissioned but funded through generic money available	None
London North West Healthcare NHS Trust – Northwick Park	Yes	commissioned by mental health trust	No
Royal Brompton & Harefield NHS Foundation Trust		<i>Not supplied – no specific service</i>	
Imperial College	Yes	8C commissioned directly to mental health trust CNWL. 2 posts (8a, 7) paid for by acute trust cancer services - Imperial. 1 8a post (fixed term) paid for by acute trust funding for Schwartz rounds, 1 band 7 counsellor (level 3) specifically commissioned by tertiary specialist service (GTD)	None
North Middlesex University Hospital Trust	Yes	By oncology service of the North Middlesex Hospital via a service level agreement with the local mental health trust	The two level 4 psychologists (1.5wte) are both Macmillan cancer psychologists- one post was Macmillan funded the other adopted. None of the level 3 counsellors at Helen Rollason are Macmillan funded
Lewisham And Greenwich NHS Trust	Yes – fixed term	Funded by Macmillan pump prime money until January 2019	All except psychotherapist who is currently in the process of being adopted
Guy's & St Thomas' NHS Foundation Trust	No	Funded through block contract	None
King's College Hospital NHS Foundation Trust	Yes	Employed by department of haematology	None
Kingston NHS Foundation Trust	Not commissioned	Currently hospital funded. Commissioning under negotiation	All adopted. Half of the service is funded by Macmillan (19.5 hours per week)
St George's University Hospitals NHS Foundation Trust	No	1xLevel 3 at St Georges funded by Trust, Remainder of service funded by Trust until March 2019.	Macmillan badged. Macmillan funding has elapsed.
Epsom & St Helier University Hospitals NHS Trust	N/A		
Croydon Healthcare Services NHS Trust	Unsure	Funded by Trust – not commissioned	Macmillan badged.
Royal Marsden NHS Foundation Trust	Not commissioned	Service funded by the Royal Marsden charity	None
Princess Alexandra Hospital		<i>Not Supplied</i>	

## Information and Support Centres across London (listed in alphabetical order)

Acute Trust	ISC (Y/N)	Type	Details	Staffing
Barnet Hospital	Y	Macmillan cancer information and support centre	<p>A drop-in centre for anyone affected by cancer. Appointments can also be made.</p> <p>Services include:</p> <ul style="list-style-type: none"> <li>• literature on all aspects of living with cancer</li> <li>• the opportunity to discuss cancer treatments, side effects and other related issues</li> <li>• the opportunity to talk to someone in a private, comfortable quiet room</li> <li>• over the phone information and support for those not able to access the service in person</li> <li>• information about local and national support services</li> <li>• a benefits advice service in conjunction with the local Citizens Advice Centre</li> </ul>	Macmillan Information Specialist and trained volunteers
Barts Hospital	Y	Macmillan cancer information and support centre	<p>A drop-in centre for anyone affected by cancer</p> <p>Services include:</p> <ul style="list-style-type: none"> <li>• Complementary therapies</li> <li>• Counselling</li> <li>• Information</li> <li>• Benefits Advice</li> <li>• Look Good, Feel Better</li> <li>• Signposting to other services</li> </ul>	Temporarily a volunteer led service which is supported part time by a Cancer Nurse Specialist
Central Middlesex Hospital	Y	Macmillan cancer information and support centre	<p>Services include:</p> <ul style="list-style-type: none"> <li>• Cancer information materials</li> <li>• Counselling</li> <li>• Information</li> <li>• Benefits Advice</li> <li>• Signposting to other services</li> <li>• User groups</li> <li>• Volunteering activities</li> </ul>	Qualified staff and ?volunteers
Charing Cross Hospital	Y	<ul style="list-style-type: none"> <li>• Macmillan cancer information and support centre</li> <li>• Maggie's West London information and support centre</li> </ul>	<p>A drop in service providing:</p> <ul style="list-style-type: none"> <li>• Cancer information materials</li> <li>• Information</li> <li>• Benefits Advice</li> <li>• Self Help &amp; Support Groups</li> <li>• Volunteering activities</li> </ul> <p>Maggie's provides practical, emotional and social support from professional staff at any time from 9am to 5pm, Monday to Friday. Also hots a range of events and activities.</p>	<p>Macmillan Information and Support Centre is led by a Macmillan information specialist</p> <p>Maggie's is staffed by a multidisciplinary team including:</p> <ul style="list-style-type: none"> <li>• nursing staff</li> <li>• Counsellors</li> <li>• Financial and Welfare advisors</li> <li>• Art and relaxation therapists</li> <li>• Nutrition advisor</li> <li>• Personal trainer</li> </ul>
Chase Farm Hospital	Y	Macmillan cancer information and support centre	<p>Service provides:</p> <ul style="list-style-type: none"> <li>• time to listen and offer support</li> <li>• details of local and national support services</li> <li>• information for carers</li> <li>• information on accessing local complementary therapies and counselling services</li> <li>• the opportunity to discuss cancer related issues</li> </ul>	Macmillan Information Specialist

## Information and Support Centres across London (listed in alphabetical order)

Acute Trust	ISC (Y/N)	Type	Details	Staffing
Chelsea and Westminster Hospital	Y	Macmillan cancer information and support centre	<p>Service provides:</p> <ul style="list-style-type: none"> <li>• Cancer information materials</li> <li>• Complementary therapies</li> <li>• Counselling</li> <li>• Internet use available</li> <li>• Support from Health Professionals</li> <li>• Volunteering activities</li> </ul>	Macmillan information and support specialist and volunteers
Croydon University Hospital	Y	The Macmillan Centre	<p>Developed as a joint venture between Macmillan cancer support, Croydon Health Services, Citizens Advice Centre, South East Cancer Help Centre and people with cancer.</p> <ul style="list-style-type: none"> <li>• access to a comprehensive range of high quality cancer information</li> <li>• reflexology, massage and healing therapies provided by South East Cancer Help Centre</li> <li>• comprehensive financial advice by a Macmillan advisor from Croydon Citizens Advice on Tuesday</li> <li>• referral to counselling</li> <li>• a range of group classes and workshops (including a carers group)</li> </ul>	Staffed by an information professional supported by trained volunteers, some with personal experiences of cancer.
Ealing Hospital	N	N/A	<p>No onsite information centre.</p> <p>Patients can be referred to their nearest centre at West Middlesex University Hospital NHS Trust or Imperial College Healthcare Trust (Charing Cross Hospital).</p>	N/A
Great Ormond Street Hospital	N	N/A	<p>Hospital does not have a designated support and information centre. It does provide access to a number of supportive care services such as:</p> <ul style="list-style-type: none"> <li>• Spiritual care</li> <li>• Psychology</li> <li>• Bereavement services</li> <li>• Diet and nutrition</li> <li>• Occupational therapy</li> <li>• Social work</li> <li>• Speech and language services</li> <li>• Play services and an onsite school</li> </ul>	N/A
Guy's and St Thomas' Hospital	Y	Dimbleby Cancer Care Centre	<p>Drop-in services at both Guys and St Thomas'. Specialist nurses and therapists work alongside doctors, CNS's and other health professionals offering support and information to anyone affected by cancer, be they patients or families/carers. All services are free of charge.</p> <p>Services include:</p> <ul style="list-style-type: none"> <li>• counselling</li> <li>• information</li> <li>• complementary therapies</li> </ul>	Staffed by a clinical nurse specialist, counsellor and complementary therapies staff. Also have administration support.
Hammersmith Hospital	Y	Macmillan cancer information and support centre	Provides a free drop-in service where people who have been affected by cancer can get emotional and practical support.	Managed by dedicated cancer information professionals

## Information and Support Centres across London (listed in alphabetical order)

Acute Trust	ISC (Y/N)	Type	Details	Staffing
Harefield Hospital	N	N/A	No information centre.  Website indicates that there are a number of Macmillan nurses on staff who are available to give information and support to patients.  A range of cancer charities are also listed as a source of support on their website	N/A
Hillingdon Hospital	Y	Cancer Information Centre	Macmillan Cancer Support and The Hillingdon Hospitals NHS Foundation Trust have worked together to develop a Cancer Information Centre.  Services include: <ul style="list-style-type: none"> <li>• Confidential one-to-one support</li> <li>• Arranging complimentary therapies</li> <li>• Information on diet and nutrition</li> <li>• Information on keeping fit during and after treatment</li> <li>• Benefits advice</li> <li>• Guided internet access</li> </ul>	The centre is staffed by a Macmillan Specialist Nurse who is supported by trained volunteers, some of whom have personal experience of cancer.
Homerton University Hospital	Y	Macmillan cancer information and support centre	Services include: <ul style="list-style-type: none"> <li>• A range of information resources</li> <li>• Welfare advice clinics</li> </ul>	Staffed by a dedicated Macmillan Information and Support Manager.
King George's Hospital	Y	Macmillan Cancer Information Resource Room	Services include: <ul style="list-style-type: none"> <li>• links to the clinical teams treating certain cancers</li> <li>• links to local and national support services and liaison with other voluntary and statutory agencies</li> <li>• signposting to self help and support groups</li> <li>• complementary therapy services</li> <li>• counselling support</li> <li>• wig and headwear advice</li> <li>• free and confidential welfare, benefits and debt advice</li> <li>• free literature on all aspects of living with cancer</li> <li>• opportunities to discuss treatments, side effects and other cancer issues and opportunity to talk to someone confidentially</li> <li>• over the phone support for those not able to visit in person</li> <li>• Post treatment health and wellbeing events</li> </ul>	Located in the Cedar Centre, It is staffed by volunteers on Tuesdays and Thursdays and open for browsing Wednesday and Friday.
King's College Hospital	Y	Macmillan cancer information and support centre	A drop-in service. Services include: <ul style="list-style-type: none"> <li>• detailed information about cancer or other long-term conditions</li> <li>• help with living with the consequences of a difficult diagnosis</li> <li>• to talk through your care options and get further assistance</li> <li>• help with living well after cancer or another long-term condition</li> </ul>	Staffed by a Macmillan information manager
Kingston Hospital	Y	The Macmillan Information & Support Service	Developed as a joint venture between Macmillan Cancer Support and Kingston Hospital NHS Foundation Trust..  Offering information and support to anyone who has concerns about cancer, their relatives, friends and carers.	The service is staffed by a health professional supported by trained volunteers. Some of our volunteers have personal experiences of living with cancer.
Lewisham Hospital	N	N/A	No explicit information and support centre.  They do provide a range of services which fit under this banner though including: <ul style="list-style-type: none"> <li>• A wellbeing clinic</li> </ul>	Staffed by MDT team

## Information and Support Centres across London (listed in alphabetical order)

Acute Trust	ISC (Y/N)	Type	Details	Staffing
			<ul style="list-style-type: none"> <li>Macmillan Welfare Benefits Advice Service for Cancer patients</li> <li>Stop smoking clinic</li> </ul>	
Moorfields Eye Hospital	N	N/A	<p>Eye specific hospital so ?not in remit to provide specific information and support centre for patients</p> <p>Closest centre located at St Barts</p>	N/A
Newham University Hospital	Y	Macmillan Cancer Information and Support Service at Newham	<p>Offering good quality, comprehensive and appropriate information in a relaxed and friendly environment.</p> <p>Services include:</p> <ul style="list-style-type: none"> <li>Cancer information materials</li> <li>Benefits Advice</li> <li>Self Help &amp; Support Groups</li> <li>Signposting to other services</li> <li>Volunteering activities</li> </ul>	Temporarily a volunteer led service, with support from a Cancer Nurse Specialist.
North Middlesex University Hospital NHS Trust	Y	Macmillan cancer information and support service	<p>The service offers:</p> <ul style="list-style-type: none"> <li>support, advice and information on cancer drugs, treatment and management as well as on finance and local support services</li> </ul>	run by an experienced cancer nurse manager
Northwick Park Hospital	Y	Macmillan cancer information and support service	<p>Services include:</p> <ul style="list-style-type: none"> <li>Cancer information materials</li> <li>Counselling</li> <li>Information</li> <li>Benefits Advice</li> <li>Signposting to other services</li> <li>User groups</li> <li>Volunteering activities</li> </ul>	?Run by a Macmillan cancer information manager
Princess Royal University Hospital	N	N/A	Does not appear to have any information or support centre	N/A
Queen Elizabeth Hospital	N	N/A	Small oncology department - Refers into Guys Hospital	N/A
Queen's Hospital	Y	Macmillan Cancer Information and Support team	<p>Provides a confidential drop-in service for anyone affected by cancer.</p> <p>Provides a number of different services:</p> <ul style="list-style-type: none"> <li>links to the clinical teams treating certain cancers</li> <li>links to local and national support services</li> <li>signposting to self help and support groups</li> <li>complementary therapy services</li> <li>counselling support</li> <li>wig and headwear advice</li> <li>liaison with other voluntary and statutory agencies</li> <li>free and confidential welfare, benefits and debt advice</li> <li>free literature on all aspects of living with cancer</li> <li>opportunities to discuss treatments, side effects and other cancer issues</li> </ul>	Macmillan Cancer information officer + Volunteers

## Information and Support Centres across London (listed in alphabetical order)

Acute Trust	ISC (Y/N)	Type	Details	Staffing
			<ul style="list-style-type: none"> <li>• opportunity to talk to someone confidentially</li> <li>• over the phone support for those not able to visit in person</li> <li>• Health and wellbeing events for you post treatment</li> </ul>	
Queen Mary's Hospital Sidcup	Y	The Dimbleby Macmillan Support Centre, Guys Cancer at Queen Mary's Hospital	Service provides: <ul style="list-style-type: none"> <li>• Cancer information materials</li> <li>• Complementary therapies</li> <li>• Counselling</li> <li>• Self Help &amp; Support Groups</li> <li>• Signposting to other services</li> </ul>	Staffed by volunteers who are supported by information nurse specialists
Royal Brompton Hospital	N	N/A	No information centre. Website indicates that there are a number of Macmillan nurses on staff who are available to give information and support to patients. A number of cancer charities are also listed as a source of support on their website	N/A
Royal Free London	Y	Macmillan cancer information and support centre	The centre provides information, as well as having a comfortable and unobtrusive room, which is available when privacy is needed	Macmillan Information Specialist and trained volunteers
University College London Hospital	Y	Macmillan cancer information and support centre	The centre provides advice and support for the challenges that a patient may face on their cancer journey.  Patients, families and carers can drop in or book an appointment to access a wide range of information and support, from advice about welfare and benefits, to complementary therapy, emotional and psychological support.	Multidisciplinary team: <ul style="list-style-type: none"> <li>• Service manager</li> <li>• information specialists</li> <li>• CNS'</li> <li>• Psychologists and counsellors</li> <li>• Complementary therapists</li> <li>• Creative specialist</li> <li>• Head of service</li> <li>• Project manager</li> </ul>
Royal London Hospital	N	N/A	No designated information and support centre on site Macmillan cancer information and support centre located at St Barts Hospital and Whipps Cross	N/A
Royal Marsden Hospital	Y	Royal Marsden Help Centre	Located at both Chelsea and Sutton campuses	Experienced staff (specifics not available)
Royal National Orthopaedic Hospital	N	N/A	No onsite service. Harley Street and University College Hospital are both within ½ mile of the RNOH	N/A
St George's Hospital	Y	Macmillan cancer information and support centre	Resources include information and support about: <ul style="list-style-type: none"> <li>• All cancers, their treatments and effects</li> <li>• Financial, social and practical issues</li> <li>• How cancer affects your life and how to cope with changes</li> <li>• Complementary therapies and how to access them</li> <li>• Cancer and support services within St George's Hospital</li> <li>• Local support groups</li> <li>• Cancer prevention and healthy lifestyles</li> </ul>	Specialist staff

## Information and Support Centres across London (listed in alphabetical order)

Acute Trust	ISC (Y/N)	Type	Details	Staffing
St Helier Hospital	Y	Cancer Information and Support Centre	<p>Services include:</p> <ul style="list-style-type: none"> <li>• Access to high-quality, comprehensive and appropriate information</li> <li>• Cancer awareness and prevention Information about signs and symptoms to look out for</li> <li>• Emotional support</li> <li>• Confidential counselling</li> <li>• A range of complementary therapies</li> <li>• Links to other appropriate organisations</li> <li>• Macmillan CAB advice service for south west London.</li> </ul>	Professional staff and volunteers
St Mary's Hospital	N	N/A	There is no designated information centre at St Mary's although there is a Macmillan information and support centre located at the other Imperial sites (Charing Cross and Hammersmith)	N/A
West Middlesex University Hospital	Y	The Mulberry Centre	<p>Delivers a range of information and support services to all people affected by a diagnosis of cancer: to the cancer patient, friends and family, carers and those bereaved by cancer.</p> <p>Services include:</p> <ul style="list-style-type: none"> <li>• Information and drop-in support</li> <li>• Counselling</li> <li>• Therapies</li> <li>• Welfare and benefit support</li> <li>• Workshops</li> </ul>	The Mulberry Centre has a small team of paid staff (3 full time and 5 part-time) who are involved in all aspects of the delivery of our services. Our counselling and therapies and group activities are delivered by a wonderful team of volunteers who are led by 2 part-time Consultants. We currently have 21 volunteer counsellors, 23 volunteer therapists and 8 volunteers who deliver group activities (yoga, tai chi, mindfulness etc.). They are all professionals in their fields. We also have strong governance with a Trustee body of 11 who bring a wide range of expertise and skills (health, accountancy, legal, fundraising, business, community).
Whipps Cross University Hospital	Y	Macmillan Information and Support Centre	<p>Centre provides:</p> <ul style="list-style-type: none"> <li>• Cancer information materials</li> <li>• Complementary therapies</li> <li>• Financial support</li> <li>• Information</li> <li>• Spoken interpretation service</li> <li>• Support from Health Professionals</li> <li>• Telephone helpline</li> <li>• Benefits Advice</li> <li>• Self Help &amp; Support Groups</li> <li>• Signposting to other services</li> <li>• Volunteering activities</li> </ul>	Macmillan cancer nurse specialist plus volunteers
Whittington Hospital	Y	Macmillan Information and Support Centre (known as the "Macmillan Pod")	<p>Centre provides:</p> <ul style="list-style-type: none"> <li>• Emotional support, information and practical advice to anyone affected by cancer. This includes families, carers and friends</li> <li>• There is a wide range of free high-quality cancer materials available</li> <li>• signposting to other national and local support services</li> <li>• a monthly cancer support group, which is open to all cancer patients</li> </ul>	Macmillan information manager and volunteers

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