



Transforming Cancer Services Team for London

# Psychological Care Pathway for People affected by Cancer

Thursday 4 May 2017

# Agenda

Time	Item
1300	Registration and lunch
1345	Welcome and introduction
1355	The emotional and psychological impact of cancer: <i>A patient perspective</i>  Psychological support commissioning guidance (2015): <i>Summary of key findings</i>
1430	Preliminary psychological care pathway <i>Overview and clarifying questions</i>
1455	Refreshments break
1520	Facilitated table discussions on the preliminary pathway
1615	Plenary feedback
1650	Summary and next steps
1700	Close

# 01

## **Emotional and psychological impact of cancer: a patient perspective**

Dr Alex King, Consultant clinical psychologist at Imperial Healthcare

Oliver Kurer, patient representative

# 02

## **Psychological support commissioning guidance (2015): Key findings**

Liz Price, Senior Strategy Lead at Transforming Cancer Services Team

# What living with and beyond cancer means to us



# About the Transforming Cancer Services Team

The Transforming Cancer Services programme is part of Healthy London Partnership. The programme's Living With and Beyond Cancer team develops guidance and provides strategic support to commissioners on the local planning and delivery of:

- The cancer recovery package and stratified follow up pathways
- The management of consequences of treatment including physical, social and psychological needs
- Cancer as a long term condition and integrated care.

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# Headline statistics for cancer

- In the UK, cancer remains the leading cause of mortality (NHSE). It is a top priority nationally and in London
- One in two people will get cancer at some time in their life (CRUK)
- In 2010, over two million people were living with and beyond cancer in the UK with this number set to double by 2030 (Macmillan)
- In London and West Essex, we expect there to be around 387,000 people by 2030 (estimate based on 2010 prevalence, NCIN)
- In 2013, 223,500 people in London were living with or beyond cancer (diagnosed any time since 1991, NCIN)
- 70% of people who have cancer have at least one other long term condition (Macmillan)
- 25% of individuals had unmet physical and psychological needs at the end of their treatment
- 47% of cancer survivors express a fear of their cancer returning.

# National drivers

**NHS**

NHS Operational Planning and Contracting Guidance  
2017-2019

Published by  
NHS England and NHS Improvement

**THE FIVE YEAR FORWARD VIEW FOR MENTAL HEALTH**

A report from the independent Mental Health Taskforce to the NHS in England  
February 2016

**NHS England**

**GENERAL PRACTICE FORWARD VIEW**  
APRIL 2016

Developed in partnership with:  
Royal College of General Practitioners  
NHS Health Education England  
#GPforwardview

**National Cancer Patient Experience Survey 2015**  
National Results Summary

WE ARE HILLMAN. CANCER SUPPORT.

**THROWING LIGHT ON THE CONSEQUENCES OF CANCER AND ITS TREATMENT**

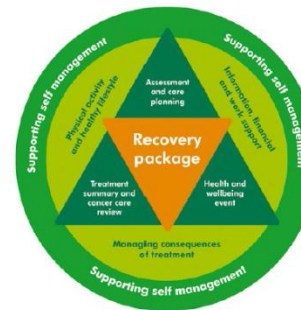
WE ARE HILLMAN. CANCER SUPPORT.

**ACHIEVING WORLD-CLASS CANCER OUTCOMES**  
A STRATEGY FOR ENGLAND  
2015-2020

Report of the Independent Cancer Taskforce

**LIVING WITH AND BEYOND CANCER: TAKING ACTION TO IMPROVE OUTCOMES**

National Cancer Survivorship Initiative (NCSI)  
NHS Improvement  
WE ARE HILLMAN. CANCER SUPPORT.  
Department of Health



**COMMISSIONING GUIDANCE FOR REHABILITATION**

March 2016



# Cancer patient experience survey: London findings in 2016

There are a number of areas where London scored poorly that are related, directly and indirectly, to people's emotional and psychological wellbeing as a result of cancer and its treatment.

These include:

- Receiving information in an understandable way
- Making decisions about treatment
- Access to supportive care
- Provision of supportive information.

Patients are not receiving easy to understand information across their cancer pathway.

Lack of information about side effects has the potential to create long term emotional and psychological issues for patients and their families.

Related to this, how are patients able to make an informed choice and consent to treatment?

A high percentage of patients and their families reported being unable to access hospital staff as either an inpatient or outpatient to discuss their worries and fears.

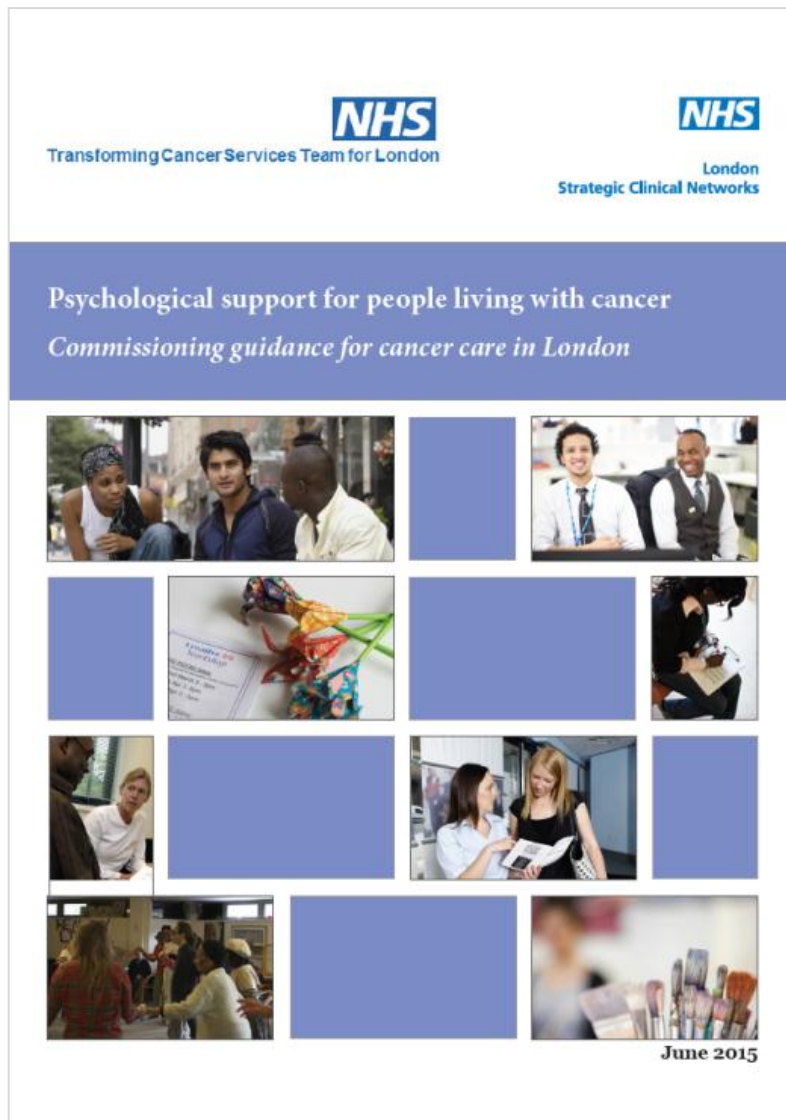
# Recovery package



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# Commissioning guidance published in 2015



The commissioning guidance can be found on the Healthy London Partnership website at:

[www.myhealth.london.nhs.uk/healthy-london/cancer-resources](http://www.myhealth.london.nhs.uk/healthy-london/cancer-resources)

# Information and support centres

In 2015, all acute trusts had an information and support centre, usually funded by Macmillan and other charities.

Only three hospitals providing specialist cancer treatment combined practical, emotional and social support delivered in a welcoming and non-stigmatising environment:

- Maggie's West London at Charing Cross Hospital
- Macmillan Support and Information Centre at University College London Hospital
- Dimbleby Cancer Care at Guy's and St Thomas' NHS Foundation Trust.

# Levels of psychological and psychiatric support

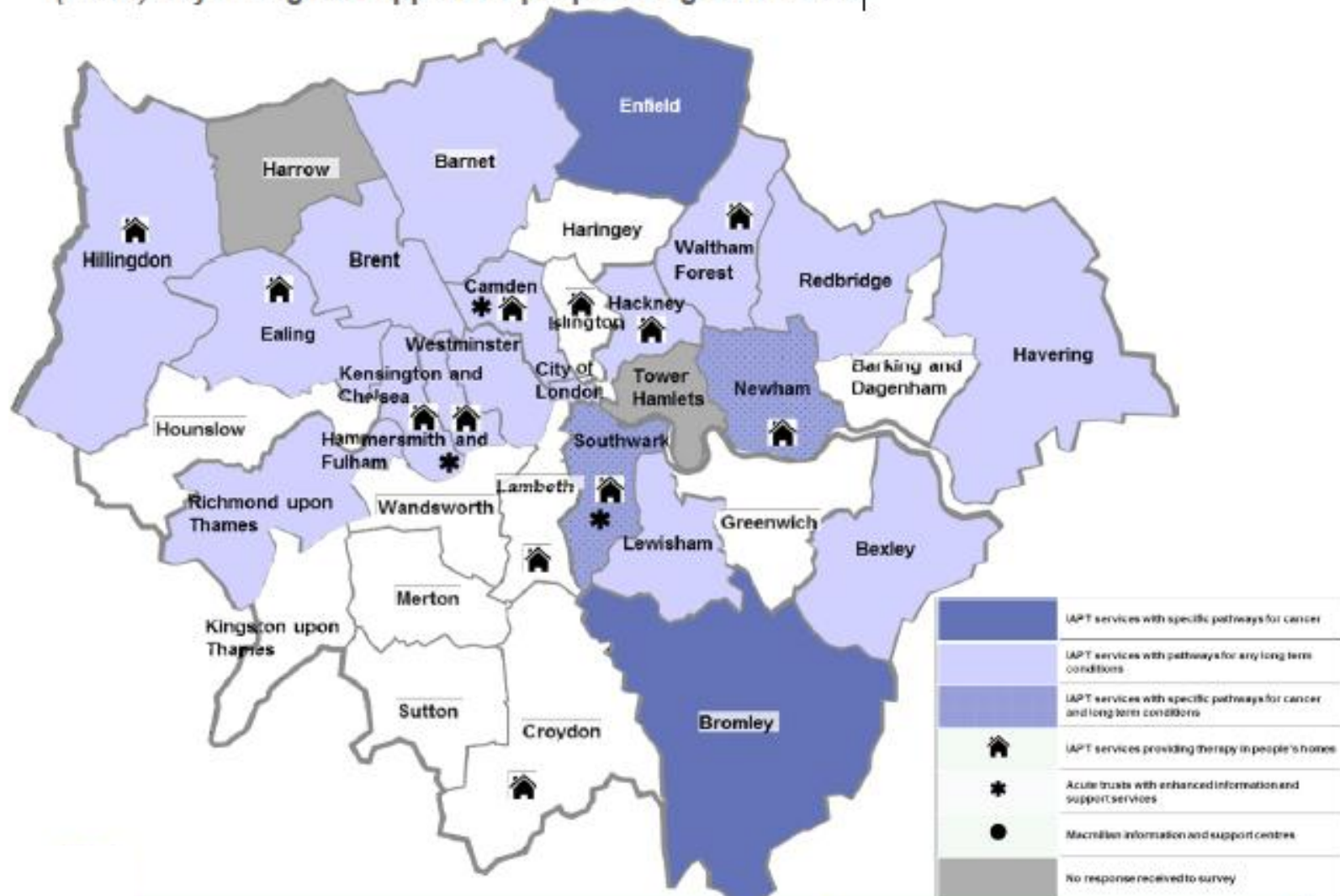
In 2012/13: Trusts providing specialist cancer treatment had the following workforce for cancer:

Cancer centre provision<sup>25</sup>

Cancer centre trusts	Annual first treatment cases	Combined level 3/4 wte provision
Barts Health NHS Trust	2,727	4.1
Barking, Havering and Redbridge University Hospitals NHS Trust	2,280	2.0
Imperial College Healthcare NHS Trust	3,500	2.8
King's Health Partners <sup>26</sup>	5,570	5.8
North Middlesex University Hospital NHS Trust	816	0.3
Royal Free London NHS Foundation Trust	1,112	2.6
The Royal Marsden NHS Foundation Trust	2,530	6.1
St George's Healthcare NHS Trust	1,500	1.3
University College London Hospitals NHS Foundation Trust	1,468	4.2

# IAPT services providing support for people affected by cancer

(below) Psychological support for people living with cancer



# Recommendations from the commissioning guidance

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**.
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 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, 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**.

## But the guidance has only taken London so far...

- We recognise that 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
- Service level quality and productivity standards have not been agreed for London.

Macmillan has funded the TCST to develop a pan London end to end psychological care pathway and service specification.

Dr Philippa Hyman, a clinical psychologist, is leading this project from January to December 2017.

Philippa is working very closely with our partners and service users through a working group.

Today is the first of two engagement events we will hold this year to develop the pathway and principles for the specification.





## Key messages

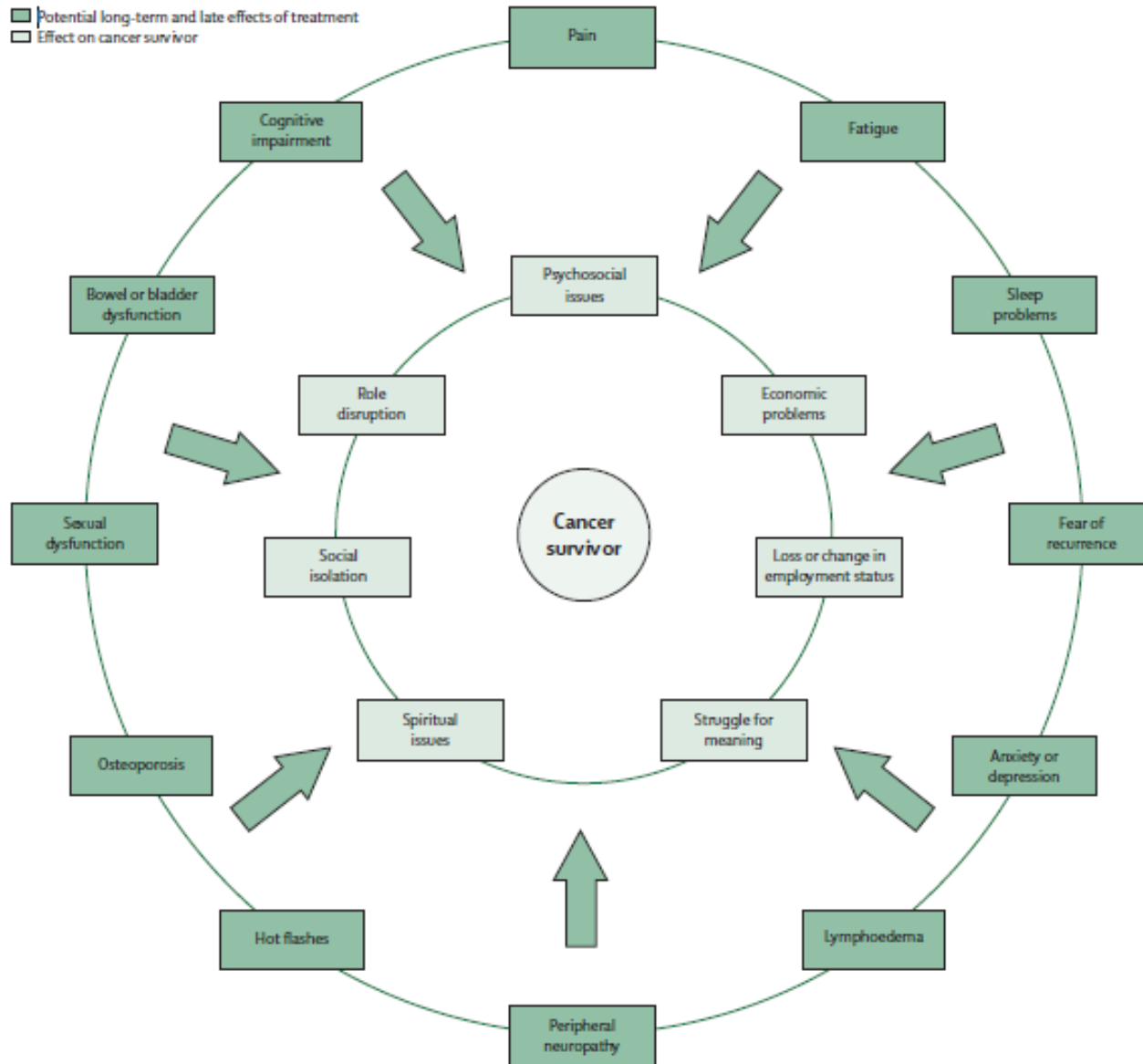
- The number of **people surviving cancer is increasing**, and people are also **living longer** following a cancer diagnosis
- Cancer is a **long term condition**. 70% of people with cancer have at least one other long term condition
- **Significant need** arising from the **consequences of treatment** can be prevented or better managed
- In 2017, we are developing a **pan London psychological care pathway and service specification** - to improve care and outcomes for people affected by cancer.

# 03

## **Preliminary pan London psychological care pathway**

Dr Philippa Hyman, Macmillan Mental Health Clinical Lead at TCST

# Living with the consequences of cancer



# Why do we need a psychological care pathway?

- 2.5 million people are living with cancer in the UK, rising to four million by 2030.
- In the year following diagnosis around one in ten people will experience symptoms of anxiety and/or depression severe enough to need intervention by specialist services and 10-15% with advanced disease
- Earlier diagnosis and improved treatment means more Londoners are now surviving cancer and living with the consequences of cancer and its treatment
- Psychological morbidity amongst those surviving cancer is significant, has huge impact on quality of life as well as economic and healthcare costs
- In addition to anxiety and depression, it is important to consider other causes of distress that might need psychological assessment and care
- This might include: relationship problems, psychosexual and body image difficulties, alcohol and drug related problems, mild cognitive impairment (for example due to radiotherapy to CNS), carer and family support, bereavement and work.

# Why do we need a psychological care pathway?

- “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” (Five Year Forward View for Mental Health, 2016)
- There is huge variation across London in psychological care services available
- There needs to be specific recommendations for commissioners and providers to be clear on what needs to be delivered pan London
- There is currently no co-ordinated commissioning of psychological care services for people affected by cancer pan London.

# Aims of care pathways

- To set out best practice, based on best available expert opinion, data, clinical evidence and national guidance
- To be multi-professional, crossing organisational boundaries
- To enable easy access for patients into any point in the system
- To improve team work, collaboration and communication between professionals
- To Improve quality of care
- To Improve patient satisfaction and experience
- To have a positive impact on clinical outcomes
- To reduce risks
- To Increase efficiency in use of resources
- To be financially viable in the short and long-term for commissioners and providers.

# Psychological support for cancer pathway: Principles and assumptions

- Psychological distress is 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 and the third sector)
- The experience of psychological distress is not linear, and neither is its identification/disclosure
- The type and intensity of clinical input needed to address psychological distress is not always apparent at the outset and can vary over time.

# Principles and assumptions

Pathways must:

- Be flexible, responsive, compassionate and intelligent
- Respect and promote collaboration between professionals (e.g. with GP, CNS etc)
- Start quickly, offer choices, step-up/relay where necessary
- Not be restricted by artificial geographical/funding barriers for patient access into any point in the system
- Be clearly commissioned and have pan-London agreed standards, guidelines and responsibilities to reduce inequity of services.




# Principles and assumptions

- Psychological care for people affected by cancer – including patients and/or carers - is the responsibility of the **whole system**
- General psychological care for all – information, support, sensitive communication and reliable systems
- Specialist psychological care for some according to need: persistent distress and complexity
- Hopes, priorities and choices of patients are primary considerations
- **The sensitivity, skill and clinical judgement of all staff must remain central.**

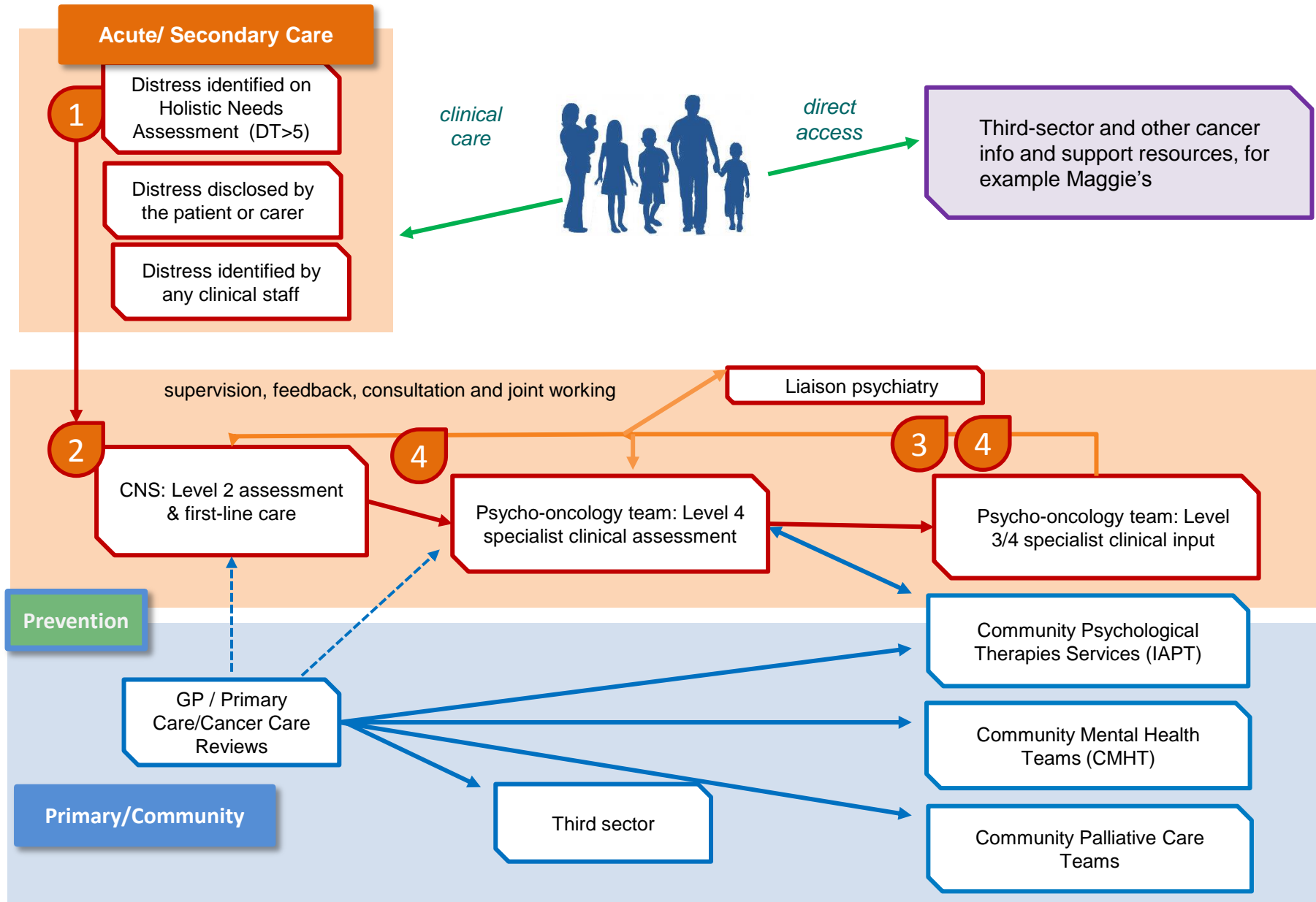
# Improving supportive and palliative care for adults with cancer: NICE Stepped Care Model (2004)

**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 (CBI)

# Preliminary pathway for psychological care for patients and carers



# Generic cancer care pathway

How does the psychological care pathway fit with a generic cancer pathway?



# 04

## **Facilitated table discussions**

# On your tables:

Please capture on flipchart paper:

What improvements could be made?

- What works well?
- What needs clarifying?
- What is missing?
- How well does it fit with the generic cancer pathway?

What are the key principles that need to be part of the psychological care pathway?

# 05

## Summary

**And finally.....**

If you have any further questions or queries,  
please contact:

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

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

**This is a consultation event.**

**Your feedback is vital to this process**