

"It's like falling off a cliff"

Using the Service User Voice to Co-design an end-to-end psychological support pathway for people affected by cancer.

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Introduction

The Transforming Cancer Services Team (TCST) supports the delivery of NHS England's Five Year Forward View and National Cancer Strategy across London. Working with commissioners, providers, alliances, charity partners and other stakeholders to support delivery of cancer waiting targets, earlier diagnosis of cancer, those who are living with and beyond cancer (LWBC) and to increase the pace of improvement. We provide strategic leadership for cancer across London as well as supporting our stakeholders.

'Parity of esteem' in valuing mental health equally with physical health needs to be addressed in cancer services to deliver a 'whole person' approach. (No health without mental health, 2011; NHS Mandate, Five Year Forward View for Mental Health, 2016).

Mental health problems cost the UK economy an estimated £105 billion per year-roughly the cost of the entire NHS (FYFV for Mental health 2016)

Psychological therapy reduces health care costs by average of 20% (meta analysis of 91 studies (Layard & Clark 2014)

Importance of psychosocial interventions accessible at any point on the cancer pathway, especially at key transition points such as after diagnosis, at the end of treatment, after a recurrence, at end of life.

Psycho-oncology services can have a positive impact on cancer waits pathway re addressing psychological obstacles to accessing diagnostics, treatment, rehabilitation and recovery.

The aim of this project was to co-design a flexible, responsive, user-centred, psychological support pathway across the whole system to improve outcomes, experience and quality of life.

Results

Thematic analysis from the focus group, interviews and stakeholder events identified key themes for the pathway including:

- ◆ how to prevent distress and promote adjustment
- ◆ the gap in psychological support post-treatment
- ◆ the expert role of psycho-oncology teams which should be available across the whole pathway
- ◆ education and training needs of the wider workforce
- ◆ the wider impact on mental health of financial difficulties or fertility concerns.

"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"

"It's overwhelming, I'm under lots of different people, but there's no point of contact for me"

"There's a disconnect between services-in the hospital between physical/medical side and the psychological side."

"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"

Methodology

The Psychosocial support pathway was developed using:

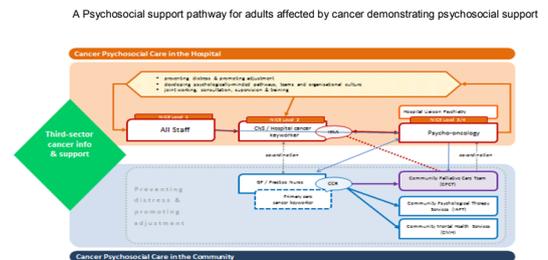
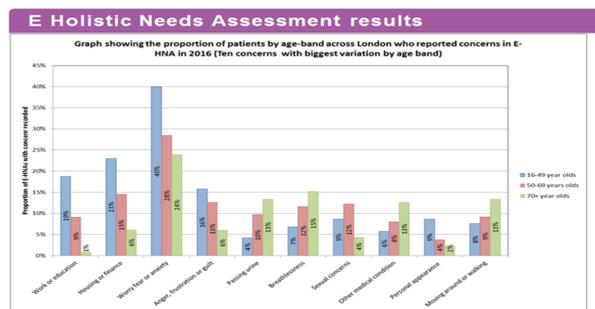
Key documents and National drivers including-NICE (2004) Improving supportive and palliative care for adults with cancer, FYFV (NHS), FYFV for Mental Health, Cancer Strategy, Ambitions for palliative and End of Life Care, Commissioning guidance for rehabilitation, Macmillan publications, Steps towards implementing self-care, NHS RightCare

Meaningful service user involvement-focus groups, interviews, participation in stakeholder events and Task and Finish group and feedback from the PAG (Patient Advisory group)

Equality and health inequality screening completed

Mapping of psycho-oncology services, Clinical Nurse Specialist support, Liaison psychiatry, Information and Support Centres and integrated IAPT services across London.

National Patient Experience Survey NPES (2016) and EHNA data Electronic Holistic Needs Assessment)



Report published in May 2018

Conclusion

A psychological support pathway co-designed with service users has been developed for London. Recommendations include:

- ◆ 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.
- ◆ The significant differences in patient experience of cancer care for marginalised and disadvantaged groups in London must be addressed.

"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**

Report available at: <https://www.healthylondon.org/resource/psychological-cancer-support/>