Thames Valley Cancer Alliance

MACMILLAN CANCER SUPPORT

Launch of the

Thames Valley Cancer Alliance Psycho-oncology mapping report 2023

7 November 2023

Dr. Luke Solomons, Consultant liaison psychiatrist

PSYCHOLOGICAL MEDICINE/ PSYCHO-ONCOLOGY

OXFORD UNIVERSITY HOSPITALS

Thames Valley Cancer Alliance
Psycho-oncology Mapping Report 2023

Thames Valley Alliance & Macmillan Cancer Support

NHS Thames Valley Cancer Alliance

MACMILLAN CANCER SUPPORT

Link to TVCA website with the report https://bit.ly/3QJWOt5

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Objectives

Map clinical pathways

Create a better understanding of the pathways available in Thames Valley Cancer Alliance (TVCA) to people with cancer who require specialist psychological support.

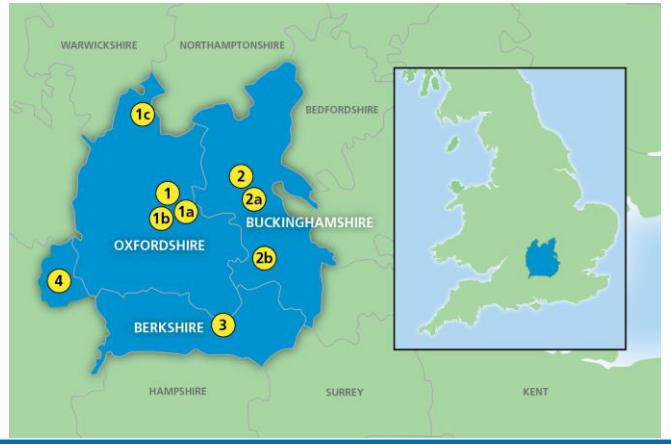
Map staff and services

Provide a clear outline of the specialist psychological services and professionals available across TVCA. This includes specialist psychological services that are integrated into NHS cancer services, as well as NHS primary care and voluntary sector providers.

Highlight areas of good practice

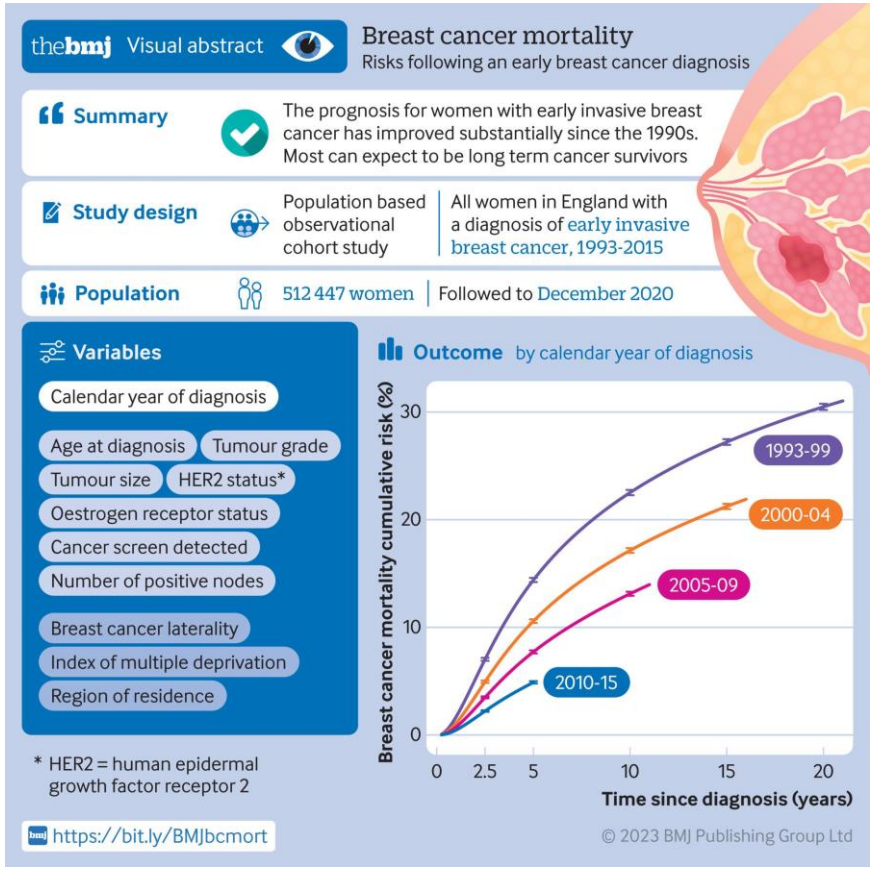
Estimate demand and gaps in service provision

Provide patients, clinicians and commissioners with key recommendations of how to develop services.



Context

- Cancer survival has doubled in the last 40 years
- Anxiety and depression can negatively impact cancer treatment and recovery
- Psychological comorbidity impacts quality of life and survival



Carolyn Taylor et al. BMJ 2023;381:bmj-2022-074684

Context

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The mental health of the physically ill is neglected

(Treatment received by 1,538 patients with cancer & major depression)

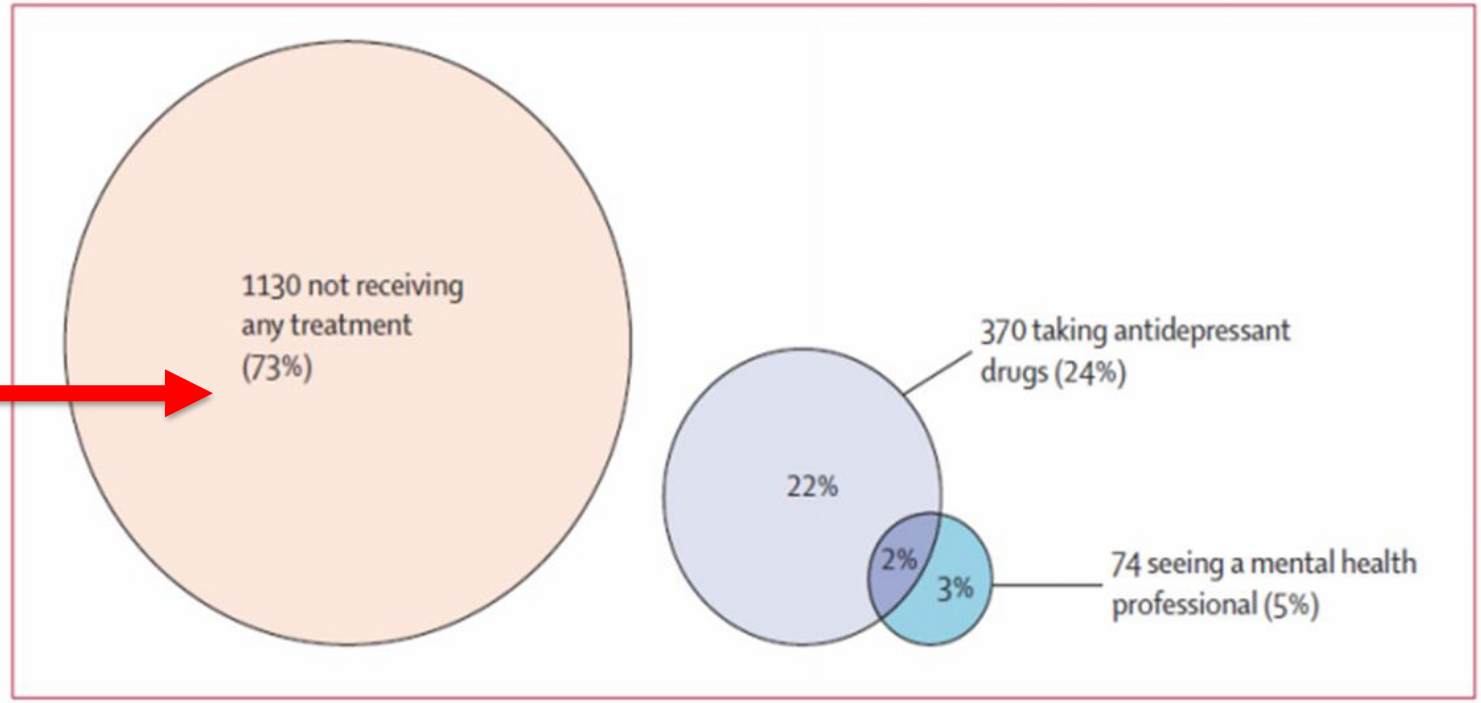

Figure 3: Treatments received by outpatients with cancer and major depression

Walker et al Lancet Psychiatry 2014

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Early identification/ treatment of distress: more than survivorship?

HOLISTIC NEEDS ASSESSMENTS

A Holistic Needs Assessment can help you identify and address the needs and concerns of people living with cancer to develop a Personalised Care and Support Plan.

On this page

- What is a Holistic Needs Assessment?
- What happens at the assessment?
- Electronic Holistic Needs Assessments (eHNA)
- Holistic Needs Assessment resources
- For your patients

WHAT IS A HOLISTIC NEEDS ASSESSMENT?

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Process

STEERING GROUP

Luke Solomons, Consultant Liaison Psychiatrist, Chair, OUH
Susan Kurien, Clinical Fellow in Psych Oncology/ Co-Chair, OUH
Lyndel Moore, Lead Cancer Nurse, Thames Valley Cancer Alliance
Shelley Orton, Macmillan Cancer Support Strategic Partnership Manager
Rachel Holland, Macmillan Principal Clinical Psychologist, BHT and chair, TVCA psychological care CAG
Michael Mawhinney, Lead Cancer Nurse, BHT
Jill Mowforth, Lung Cancer CNS, BHT
Penny Jackson, Head of Specialist Nursing, BHT
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Sam Glover, MacMillan Care Manager, OUH
Claire Marriott, Clinical Psychologist and Centre Head, Maggie's Oxford
Lucy Grant, Consultant Clinical Health Psychologist, Berkshire Healthcare
Mark Foulkes, Macmillan Lead Cancer Nurse and Nurse Consultant in Acute Oncology, BCC
Fiona Turner, Matron, BCC
Lisa Cox, Patient Engagement & Patient Experience Lead, TVCA

Consultees
Macmillan General Practitioners
Ellen Kruidenier, Macmillan GP Oxfordshire
Kabir Ahluwalia, Macmillan GP East Berkshire
Katie Massey, Macmillan GP Buckinghamshire
Kajal Patel, Macmillan GP West Berkshire
Karen Sandu, Macmillan GP Swindon

Voluntary Services & Community Engagement
Chris Cowap, Macmillan Engagement Lead
Nisha Tiwari Sharma, Cancer Community development educator, Rushmoor Healthy Living

TVCA CAG leads/ members
Amy Mitchell, Consultant Paediatric Oncologist, OUH
Nicola Stoner, Consultant Pharmacist – Cancer & ATMPs, OUH
Karen Sherbourne, Teenage Cancer Trust Lead Nurse for TYA, OUH
Emily Betts, Macmillan Clinical Psychologist, OUH
Helen Griffiths, Macmillan Clinical Psychologist, OUH
Carol Scott, Radiotherapy Services Manager, OUH
Andy Peniket, Consultant Haematologist, OUH

Others
John Pimms, Consultant Clinical Psychologist, Healthy Minds, Oxford Health
Alison Alsbury, Workforce Modelling and Strategy Consultant, TVCA

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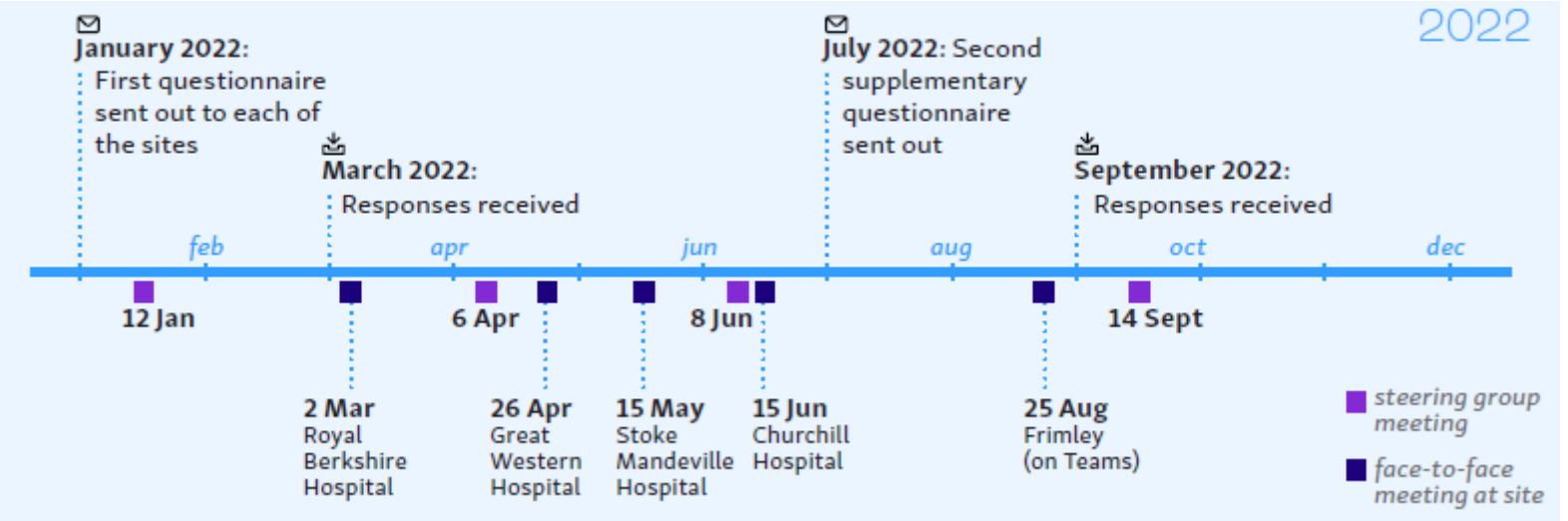
Process - timelines



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Highlights

Population and demographics

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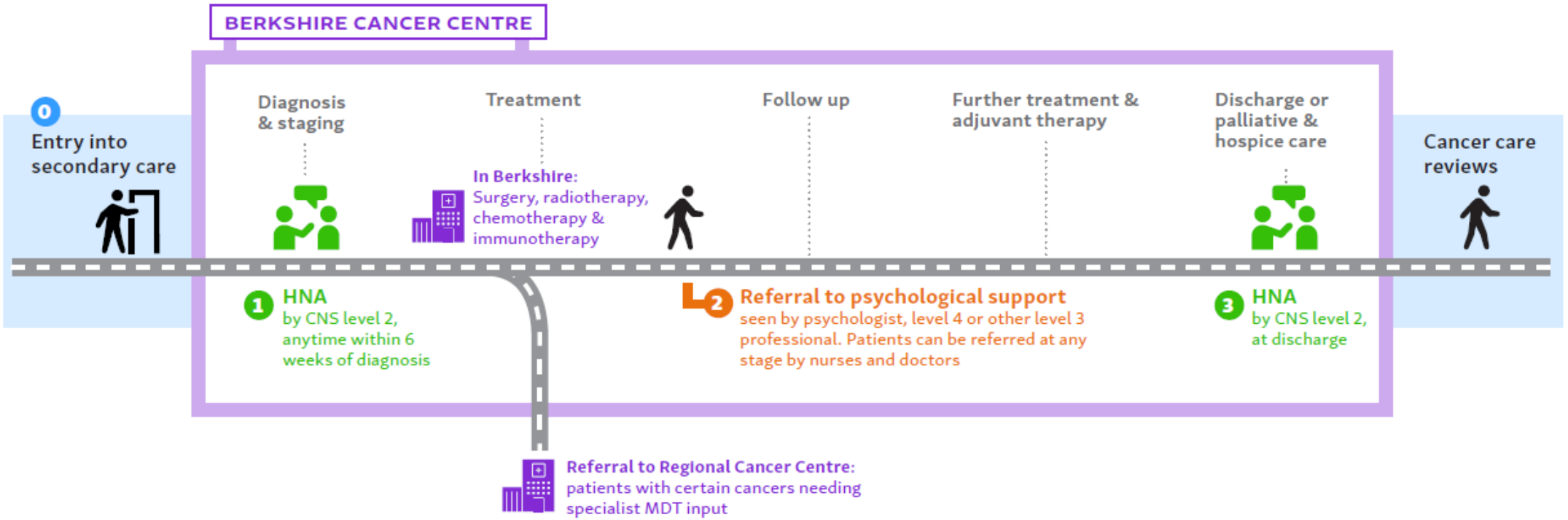
Highlights – patient journeys

ROYAL BERKSHIRE NHS FOUNDATION TRUST



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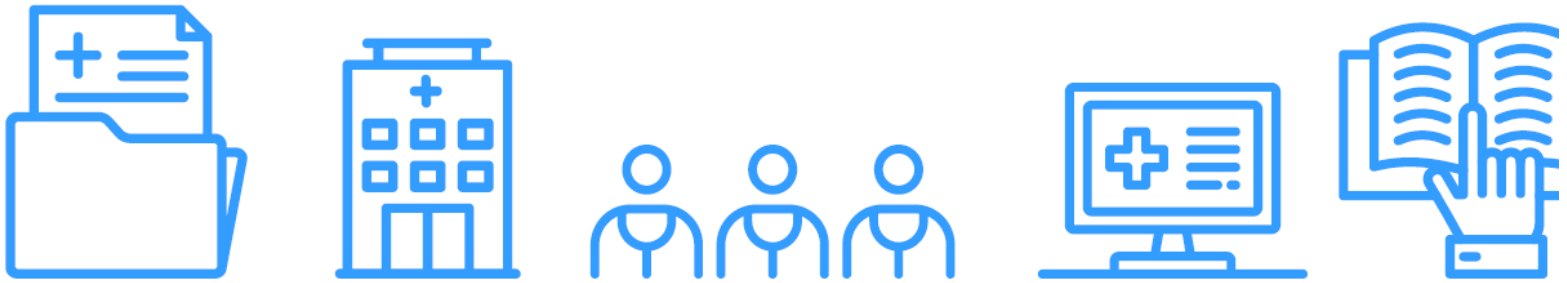
Current service provision

Psycho-oncology services across the Thames Valley differ in their set up and care provision, being dependent on local service provision and individual leadership.

The core services typically have lead clinicians working with wider teams made up of psychologists, psychiatrists, counsellors and specialist nurses. Also, clinicians working with children and families, teenagers and young adults (TYA services) and neuropsychologists for patients with primary or secondary brain tumours.

Each of the services provide clinical consultation and treatment, but are also involved with supervision, teaching, networking and governance within the cancer centres.



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Education, training and supervision

Training for all staff delivering cancer care can help improve their confidence in recognising and dealing with distress.

Training programmes focus on recognising distress and awareness of referral pathways as well as basic psychological interventions (such as psychoeducation, motivational interviewing and behavioural activation). Various models of level 2 training and ongoing supervision have been described[45,46] including the Salisbury model[47] and standards have been set out by the National Cancer Peer Review Programme in 2008.[48]

Level 2 training programmes help recognition of psychological responses to illness, communication skills to discuss psychological concerns, prioritisation of concerns such as thoughts of suicide and onward referral. The COVID-19 pandemic disrupted systems of training and supervision and the current staffing shortages make it harder for cancer nurse specialists to find dedicated time for training and supervision that does not interfere with clinical duties. However, adaptions to existing programmes and use of videoconferencing software such as Zoom and Microsoft Teams that can make it easier for staff to attend are being trialled.

In this section, we present data about training delivered in 2020 – '21, as well as details of sessions delivered in 2021 – '22.

Core Cancer Capabilities in Practice (CiP) and Education Framework for the Nursing and Allied Health Professions Workforce (the 'Framework') has been developed as part of a UK wide programme called the Aspirant Cancer Career and Education Development programme (ACCEND). It is envisaged that level 2 psychological training and advanced communication skills will be aligned with ACCEND.

TRAINING AND SUPERVISION

Training

The Cancer Manual 2008: Psychological Support Measures states that in order to be considered as providing level 2 psychological support, a qualified health and social care professional needs to have attended:

- National Advanced Communications Skills Training course from one of the nationally approved programmes
- Local level 2 psychological skills training facilitated by level 3 and 4 psychological specialists. The latter should cover basic psychological screening, assessment and intervention skills.

A task and finish group, led jointly by the NHS Cancer Programme and ACCEND Programme, is due to publish recommendations regarding improving access, quality and sustainability of Level 2 psychological skills training in England. TVCA will seek to deliver level 2 psychological skills training that is in line with these recommendations. See Appendix 1.

▸ **Considerations for LCNs & commissioners**
Lead Cancer Nurses and Psychological Care Leads will need to consider the time requirements (2 days) and costs involved for new starter CNSs and other health professionals to attend.

Supervision

The Cancer Peer Review Programme suggests that all level 2 practitioners of each MDT should receive a minimum of 1 hours clinical supervision by a level 3 or level 4 practitioner per month by a level 3 or 4 practitioner.

▸ **Considerations for LCNs & commissioners**
The minimum time commitment is at least 75 – 90 min / month for CNSs and 2 - 3 hours/ month for level 3 or 4 clinical specialist supervisors and will need to be factored into job plans for level 2, 3 and 4 practitioners.

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DAFYDD'S STORY

Dafydd Charles

My experience of mental and emotional challenges during my cancer journey

Receiving a diagnosis for a serious cancer was very shocking.

I had just turned 60, retired, was in good health, and had no symptoms. I experienced a real fear of dying, together with a horror at the prospect of the treatments that would be required. The first few weeks left me dazed and numb as events unfolded (confirmatory tests, scans, and so on), and I was provided information on options and sources of support. I was very fortunate to have practical and emotional support from my wife, wider family and close friends. I also had access to Maggie's, conveniently next to the hospital. Looking back now I would say that following my diagnosis I was focussed on practical issues, such as researching my treatment options (e.g. whether to choose surgery or radiotherapy, as I had been asked to decide between these) and how best to support my medical team in what I understood would be their challenging objective of trying to rid me of my disease. My approach was firmly complementary, rather than alternative. In some ways this approach served as an effective distraction from my underlying mental distress.

I elected for surgery but whilst in hospital encountered complications, which required me to remain as an inpatient at the Churchill for over a fortnight, rather than the 24 hours I had been expecting. During this time I supported myself mentally by trying to focus on my immediate experience and slowing down rather than worrying too much, which I knew deep down was pointless. I was discharged and awaited the results of further tests. During this early part of my recovery I started reading about resilience as a useful skill to acquire for the future, as I accepted that receiving a cancer diagnosis would have lifelong consequences. I also signed up for a formal 8-week mindfulness course at Maggie's, and when I was well enough to travel further afield, visited the Penny Brohn cancer support organisation in Bristol, which I also found to be very helpful.

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SARAH'S STORY

Sarah Hepworth

13th August 2015, 39 years old.
I felt a thickening in my right breast while in the shower, I turned to my husband Toby, we both knew it was probably cancer. I went for my biopsy, was given the news, and I felt OK about it. At worst, it's a year out of my life.

I had my surgery, and at the follow up appointment, I was told it had spread to my bones, mainly my spine, and was uncurable.

My world collapsed. I googled it and saw the average life expectancy is 18 months (note to self, don't google). I joined the conveyor belt of Chemotherapy, Hormone Therapy and Radiotherapy. I then moved to Hormone IV treatment every 3 weeks. In 2020 I was diagnosed with 2 brain tumours (named Boris and Trump by my colleagues), I received Stereotactic Radiotherapy, and like those two leaders, they're no longer active!

I was lucky enough to find a local Oxford secondary breast cancer Support Group run by Breast Cancer Now. For the first time since my diagnosis, I came away with a sense of hope and belonging. I wasn't alone, I had a safe place to share my fears with those who understood. I tried counselling via Maggie's Oxford, but it didn't fit with me. Within the hospital, there was no psychological support; if it wasn't treatment related, no one was interested.

I bumbled along quite happily, we took 4 months off work and cruised the canal network. We got married, and I probably spent way more money than I should have!

In January 2020 I lost a dear friend to secondary breast cancer, I was privileged to be with my friend at the hospice. It rocked my world.

At my subsequent oncology appointments, I duly completed the form asking me how I was feeling. I said to Toby, I wonder how bad you have to be be-

Life long membership to a club no one wants to join

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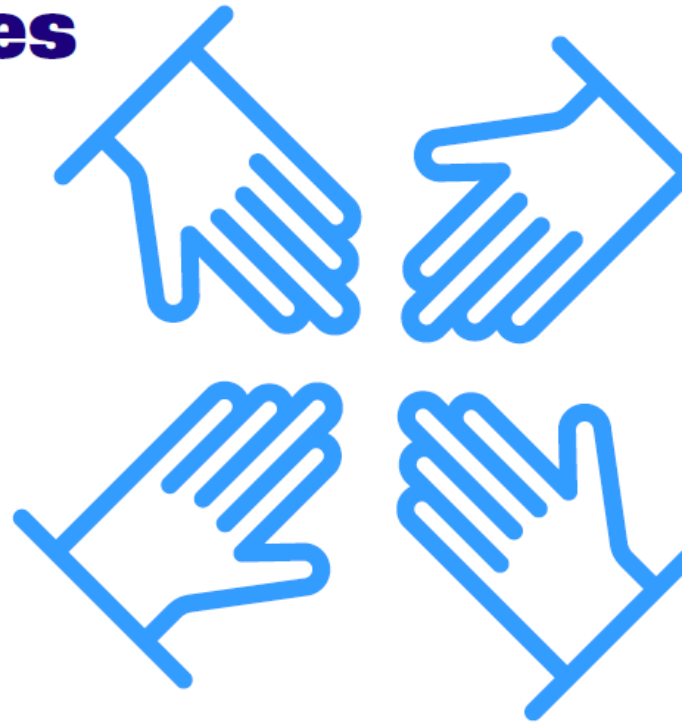
Community services and primary care



The patient's GP in primary care is a constant companion on their cancer journey while they navigate their treatment between various secondary care departments linked to the cancer centre. Often, patients have long term relationships with their GPs who are aware of their comorbidities, strengths and support networks and view their GP as a trusted friend with whom they can discuss options and fears.

GPs roles in cancer care range from primary prevention and early detection to end of life care,[49] integrating and coordinating care between teams and providing care close to the patient's home.

It is estimated that 85% of cancers are diagnosed by primary care professionals, but they can be excluded from the patient's cancer journey due to the set-up of systems. Many GPs depend on the end of treatment summary from the cancer centre for an update on their patient's journey.

Within the Thames Valley, each Clinical Commissioning Group (CCG) had its nominated Macmillan GP who leads on cancer care.

Integrated personalised care is about giving patients choice and control over their mental and physical health and is being rolled out. Personalised care is based on 'what matters' to people and their individual strengths and needs.

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JAU'S STORY

Nisha Sharma

Macmillan Cancer Education Project Lead based at Rushmoor Healthy Living, winner of the Macmillan Integration Excellence Award in Nov 2022.

Through a proactive community engagement project Nisha has recruited 25 volunteer Cancer Champions who were trained to hold cancer awareness sessions and support others in their communities. Alongside this, Nisha educated local service providers to understand the specific barriers that minority communities face. As a result, the communities now feel that they have a voice, while data shows an increase in both screening uptake and early diagnosis.

Image: Nisha Sharma

Cultural barriers and a lack of awareness about cancer in minority communities can often lead to late diagnosis and poorer survival rates. At Rushmoor Healthy Living in South Reading, Macmillan Cancer Education Project Lead Nisha Tiwari Sharma set out to address these issues through a proactive community engagement project.

Nisha reached out to seldom-heard groups and recruited 25 volunteer Cancer Champions who she then trained to hold cancer awareness sessions and support others in their communities. Alongside this, Nisha educated local service providers to understand the specific barriers that minority communities face. As a result, the communities now feel that they have a voice, while data shows an increase in both screening uptake and early diagnosis.

'I act like a bridge between the communities and the service users, but it's the Cancer Champions who really drive this project,' explains Nisha. 'They've got their communities talking about cancer in a way that they never have before.'

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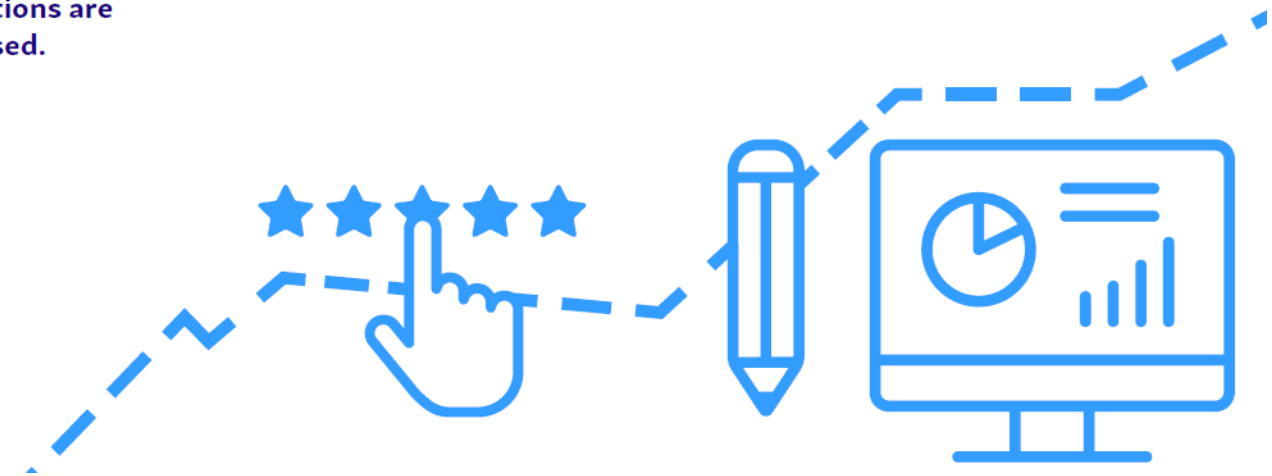
Quality, outcomes and governance

Despite the steady improvement in cancer survival in the UK over the last decade, mortality rates and service quality vary widely across the country. Routine and ongoing data collection and analysis of outcomes are ways of ensuring quality of service provision and variations are flagged and addressed.

Direct involvement in clinical governance and outcomes reporting is particularly important for psychological support services where key performance indicators are less easy to quantify, and ongoing funding of services might depend on reporting.

Patient safety is at the heart of clinical governance – all quality improvement activity undertaken can result in improvements in care quality, benefitting patients as well as clinicians.



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Recommendations

Priority Area					
1	All cancer staff (clinical and non-clinical) have psychological awareness training				
2	Protected time for CNSs to attend training and supervision.	Patients requiring enhanced care do not receive it. Clinical burden resulting in staff burnout/ retention issues	YES – Review of CNS job plans to build in supervision time, investment in extra 0.1 WTE per postholder	Ensuring all level 2 staff are able to access level 2 training courses locally (TVCA could buy in/ arrange to run them annually for all new staff)	Lead cancer nurses Clinical directors ICB commissioners Cancer Managers
	Provision of time for supervisors	Current job plans for level 3-4 staff often do not have supervision time	Review of level 3/ 4 specialist job plans to include supervision time		Cancer Managers
3	Setting supervision for professionals delivering — radio				
4	Substantive contracts for level 3/4 staff employed on fixed term contracts	Hinders service planning and staff retention	YES – even with existing staff, current service provision falls below demand	See section on estimates of need for each site	Psychological care lead/ CDs at each cancer centre ICB commissioners Cancer Managers
5	Funding level 3/ 4 posts to meet demand	Failure to meet NHSE priorities	YES - TVCA sites already have evidence-based practice/ are undertaking pilots	Integrate psychological care funding into core contracts	ICB commissioners Cancer Managers
6	Patients on regional cancer pathways unable to access local psychological services	Poorer outcomes and more morbidity – these groups travel long distances and do not have the same access to care	NO – providing integrated care can be harder, however, use of videoconferencing has made this easier	Commissioning specific services and developing pathways for patients with rare cancers	ICB commissioners + CDs Cancer Managers
7	Annual data re				
8	Annual review information s charity sector				
9	Equality, diver inclusion improvement				

What is needed locally?

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19.4. Royal Berkshire NHS Foundation Trust

Level	*Recommendation*	*Who is responsible?*	*Timeframe*
Universal support	• Ensure level 1 training for all oncology staff – mandated for all new starters	LCN + CD + Cancer Managers obtaining approval from Trust Board	By 2025
Enhanced support	• Protect time for CNSs (and radiographers & pharmacists) to attend training and supervision • Review number of CNS posts	Psychological care lead + CD / Cancer Managers– approach ICB for funds LCN + CD / Cancer Managers	End of financial year 2023-24 End of financial year 2023-24
Specialist support	• Address shortfall in Level 3-4 specialist provision • Change Band 8 Psychologists from fixed-term to substantive contract • Negotiate access to liaison psychiatry for cancer inpatients and outpatients	CD+ICB / Cancer Managers Psychological care lead + CD / Cancer Managers – approach ICB for funds Psychological care lead + CD for cancer / Cancer Managers + CD Berkshire Healthcare NHS Foundation Trust	By 2025 End of financial year 2023-24 End of financial year 2023-24

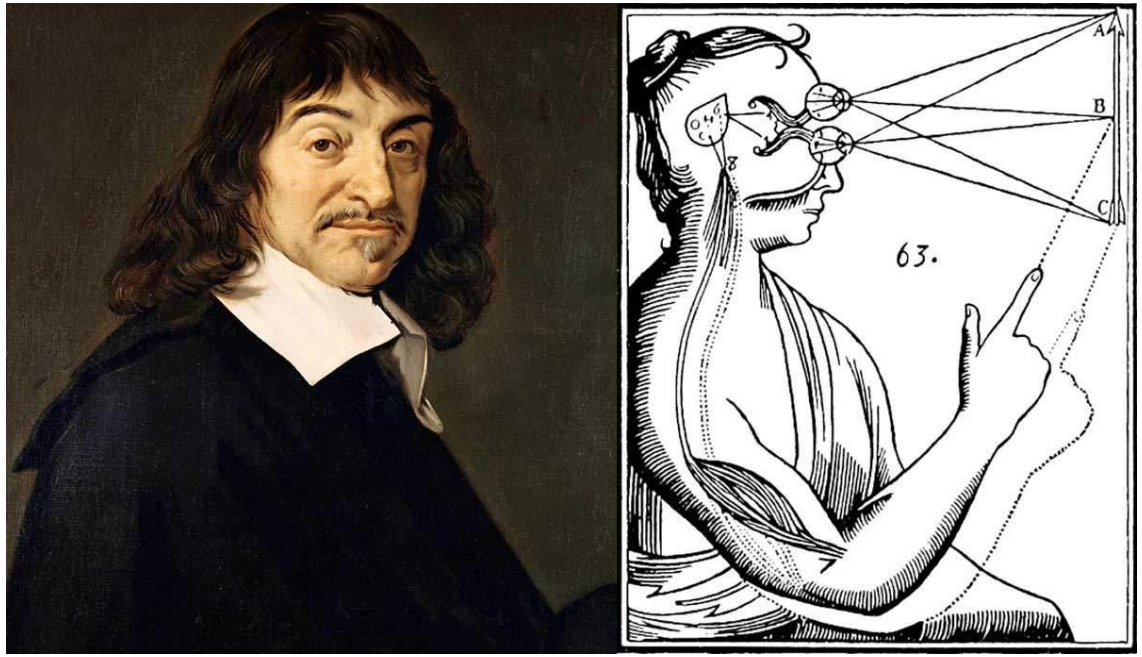
Estimate of need based on 2019 cancer numbers + 11% year on year increase

estimate of need Level 1 universal support	2893 patients
50% needing Level 2 enhanced support	1447 patients
15% needing Level 3 enhanced/specialist support	434 patients
Current Level 3 workforce (WTE)	› 0
Current capacity	› 0
Workforce required (WTE) caseload of 120	› 3.6
Gap 3.6 WTE	
10% needing Level 4 specialist support	289 patients
Current Level 4 workforce (WTE)	› 1.55
Current capacity	› 124
Workforce required (WTE) caseload of 80	› 3.6
Gap 2.87 WTE	

CNS numbers – 21.22 wte, (35 staff) – providing enhanced support

Helping to break traditional barriers

- Failure of recognition
- Staff confidence
- Poor access to psychiatry/ psychology
- Lack of evidence-based treatment



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THANK YOU

- **Integrated care**
- **Right treatment at the right time**



References/ Contact:

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