Thames Valley Cancer Alliance Psycho-oncology Mapping Report 2023

Thames Valley Alliance & Macmillan Cancer Support

IN THIS REPORT

Summaries

Recommendations

The colours associated with the Stepped Care Model (NICE, 2004) have been used throughout this report.

LEVEL 1	Universal Support
LEVEL 2	Enhanced Support
LEVEL 3-4	Enhanced/ Specialist Support

↳ *Go to Stepped Care Model*

Groundwork

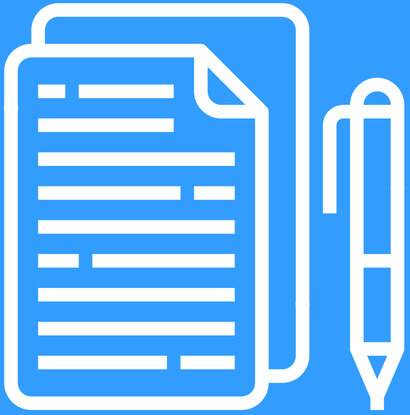
Population and demographics

Findings

LIST OF ACRONYMS

AAD	Advanced Active Disease
ACT	Acceptance & Commitment Therapy
ATMP	Advanced Therapy Medicinal Products
BAME	Black Asian And Minority Ethnic
BCC	Berkshire Cancer Centre
BHFT	Berkshire Healthcare Foundation Trust
BHT	Buckinghamshire Healthcare Trust
CAG	Clinical Advisory Group
CBT	Cognitive Behaviour Therapy
CC	Cancer Champion
CCG	Clinical Commissioning Group
CCR	Cancer Care Reviews
CD	Clinical director
CEISS	Cancer Education Information & Support Services
CFT	Compassion Focussed Therapy
CML	Chronic Myeloid Leukemia
CNS	Cancer Nurse Specialist
CNS	Central Nervous System
COSRT	College Of Sexual And Relationship Therapists
CPE	Common Point Of Entry
CPP	Cancer Patient Partnership
CRUK	Cancer Research Uk
CSS	Clinical Support Services
DCPC	Depression Care For People With Cancer
EMDR	Eye Movement Desensitisation Reprocessing (Therapy)
GP	General Practitioner
GWH	Great Western Hospital
HNA	Holistic Needs Assessment
HOPE	Help To Overcome Problems Effectively
HSCT	Haematopoietic stem cell transplantation
IAPT	Improving Access To Psychological Therapies — rebranded NHS Talking Therapies for anxiety and depression
ICS	Integrated Care System
IPOS	International Psycho-Oncology Society
IPT	Inter-Personal Therapy
LGBTIQA+	Lesbian Gay Bisexual Trans Intersex Queer Asexual + (Other Minorities)
LTC	Long Term Condition
MBCT-CA	Mindfulness Based Cognitive Therapy For People With Cancer
MDT	Multidisciplinary Team
NCPES	National Cancer Patient Experience Survey
NET	Neuroendocrine Tumour
NHS	National Health Service
NICE	National Institute For Health And Care Excellence
OUH	Oxford University Hospitals
OT	Occupational Therapist
PCT	Person Centred Therapy
PCP	Personalised Care Plan
PLWC	People Living With Cancer
PMS	Psychological Medicine Service
PPG	Patient Partnership Group
PROMS	Patient Reported Outcome Measures
QALY	Quality Adjusted Life Year
QOF	Quality Outcomes Framework
RBFT	Royal Berkshire Foundation Trust
RCCSG	Reading Cancer Champions Support Group
RCT	Randomised Controlled Trial
SACT	Systemic Anti-Cancer Treatment
SLA	Service Level Agreement
SMART	Symptom Management Research Trials
SMS	Symptom Monitoring Service
SSQ	Semi-Structured Questionnaires
SUWON	Surgery, Women's And Oncology
TYA	Teenage And Young Adult
TVCA	Thames Valley Cancer Alliance
WFH	Working From Home
WHO	World Health Organisation
WTE	Whole Time Equivalent

summaries



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Key findings

① All sites in the TVCA have pathways for referral of patients with psychological comorbidity.

② Systems for training and supervision of clinical nurse specialists are variable.

③ Services vary in their set up and governance arrangements and availability of third sector providers.

④ Evidence-based treatment programmes have been set up and are being initiated – e.g., universal screening and collaborative care programme in Oxfordshire, IAPT-LTC pilot in Buckinghamshire.

⑤ Demands on current services far outweigh existing provision.

⑥ Robust commissioning arrangements from the ICS, not reliant on short term contracts, are needed to ensure equitable access across the TVCA region in line with national guidelines.

Executive Summary

The overall purpose of this document is to provide a detailed outline of specialist psycho-oncology services across the Thames Valley Cancer Alliance (TVCA) and make robust and substantiated recommendations aimed at meeting the psychosocial needs of people affected by cancer across the Thames Valley region.

The TVCA serves a population of 2.3 million people and delivery of personalised care to everyone diagnosed with cancer is a key focus. **The report has a broad, system-wide focus with input from patients and carers as well as clinicians**, to aid decision makers in identifying and implementing local solutions that are patient-centred and personalised. Macmillan Cancer Support and TVCA worked together to create and fund this review.

Physical health and mental health are directly interrelated. Poor physical health has an impact on quality of life and poor mental health has a direct impact on health outcomes. The psychological and physical impact of cancer in the short and long term is significant, both for the individual patient and their family, and in terms of its economic impact; healthcare costs for individuals with long term conditions and comorbid anxiety and depression are 50% higher.

Despite the Health and Social Care Act 2012 enshrining 'Parity of esteem' between physical and mental health, evidence suggests that people with cancer struggle to access the right psychological support. Identification of psychological distress and the provision of specialist support for this is important. Not only will it significantly help improve the quality of life and physical health of people with cancer; psychological therapy for those with mental health difficulties can also reduce emergency admissions by 49%, hospital stays by 41%, GP appointments by 18% (Health Foundation, 2018) and overall physical healthcare costs by an average of 20% (see Appendix 4).

NICE (2004) currently recognises the psychological needs of people with cancer via a 4-level model, where levels 3 and 4 constitute the highest level of psychological need, requiring support by specialist such as counsellors, psychotherapists, clinical/counselling psychologists and psychiatrists. Most

For a breakdown of population and tumour site data for each TVCA site, and estimates of need, see:
↳ Section 4 on page 25

For Local recommendations, see:
↳ Section 19 on page 104

The data provided can help commissioners and providers in development of business cases for sustainable service delivery tailored to local needs.

people diagnosed with cancer will experience some degree of psychological distress in relation to their diagnosis and treatment. Many find ways of dealing with this by drawing on their own inner emotional resources, and with the support of family, friends and healthcare professionals such as their clinical nurse specialists (CNS). However, many people also require more specialist psychological support.

- NICE guidance estimates that up to 25% of people with cancer will require specialist level 3 and 4 psychological support following their diagnosis and treatment.
- A further 10-15% will require specialist psychological support for advanced disease.
- Level 4 psychological specialists also play a considerable role in offering psychological training and supervision to healthcare staff at levels 1 and 2.

The report identifies several shortfalls in the provision of psychological support for people with cancer in TVCA, and clearly demonstrates that the demand for services far outstrips provision at all cancer sites. Thus, specific considerations and recommendation of this report are as follows:

- Increased provision of specialist psychological support at all sites across TVCA, to meet the need for level 3 and 4 input, as specified by NICE.
- Ensuring funding is made available for the conversion of current fixed term level 3 and 4 posts into substantive contracts.
- Provision of training and protected time for clinical supervision for level 2 staff.
- Ensuring every site has readily available and robust information provision regarding the availability of psychosocial support to meet patients' needs.
- Identifying and addressing health inequalities that exist in accessibility to specialist psychiatric/ psychological support, irrespective of age, gender, socioeconomic status, ethnicity, sexuality and disability.
- Further review of existing models of evidence-based service provision in TVCA.
- Recognising local cancer charity peer groups and other voluntary sector providers; having frameworks to ensure quality and accountability, either at local or TVCA level.
- Ensuring seamless transfers of care between cancer services and primary care by linking HNAs to cancer care reviews (aided by cancer care review nurses) and increasing provision of stratified follow up.
- Supporting co-production and patient partnership in service design.
- Setting governance frameworks for annual data reporting on psychological care from sites.

In this report

We have mapped pathways of care at each cancer centre in the Thames Valley region and the linked psychological care services – those integrated within each cancer centre as well as in the voluntary sector and links to primary care.

We are very grateful to the TVCA Patient Partnership Group for their input and advice. We have three powerful testimonials (pages 14, 52 and 83) on individual experiences of cancer and page 57 has a summary of the patient survey.

We hope this report will help make it clearer about what support exists in your local area and how to access it.

The *TVCA website* has a section dedicated to patients and personalised care that complements the information in this report. Also see the *Macmillan Website*.

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Summary for patients

The psychological impact of a cancer diagnosis

Receiving a diagnosis of cancer and undergoing treatment can be a distressing experience that may bring up a variety of thoughts and feelings. For many people, difficult feelings may also arise or persist after treatment has ended. Common psychological reactions to cancer include anxiety, low mood, anger and guilt, as well as concerns about changes to appearance, sexual difficulties, relationship problems, disturbed sleep and questions around mortality, identity, meaning and purpose. Many people report feeling alone and isolated, and some find the uncertainty and loss of control most distressing.

Talking helps

Having these feelings is very common and entirely normal, but they can become overwhelming. Using the support from family and friends, as well as accessing support from healthcare professionals and charity organisations can be very helpful.

Sometimes, it can also be helpful to access support from someone trained specifically in understanding and managing psychological pain. Up to a quarter of people diagnosed with cancer will benefit from specialist psychological support at some point following their diagnosis and treatment. Psychological specialists in cancer services work with people to understand their cancer related psychological difficulties and find ways of coping with emotional distress and physical health problems, so that these challenges can begin to feel more manageable.

Summary of recommendations

↳ Go to Stepped Care Model

↳ Go to Recommendations

		Priority Area	Why/ cost of doing nothing	Quick wins/ investment	Long term sustainability	Who is responsible for this?
	1	**All cancer staff (clinical and non-clinical) have psychological awareness training**	Impacts the patient's experience of cancer care	YES – TVCA videos can be viewed that provide basic information	Training mandated as part of induction for all new staff	Clinical directors/ Cancer Managers / service leads at each cancer centre TVCA for producing/ curating information
PRIORITY	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 up training and supervision for other professional groups delivering personalised care** — *radiographers, pharmacists, etc*	Workforce unprepared to manage comorbidity/ risk of burnout	YES – these professionals could join CNS supervision groups, will need protected time	As above	Service leads (eg. Head of radiotherapy and pharmacy) at each cancer centre CDs/ ICB commissioners Cancer Managers
PRIORITY	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 reporting**	Variations in service provision and standards of care	YES – easy to collect and report	Embedding reporting into contracts	Lead cancer nurses/ psychological care leads Cancer Managers
	8	**Annual review of information sources and charity sector services**	Out of date information, unavailability of groups/ services	YES – can be set up through LCN and psychological care lead	Ensuring that all charity providers have governance reports linked up to the ICS and TVCA structures	CDs/ lead cancer nurses + service lead for charity providers In local area Cancer Managers
	9	**Equality, diversity and inclusion improvement**	Poorer cancer outcomes in minority groups	Routine screening for distress and signposting	Development of inclusive services	Lead cancer nurses/ psychological care leads Cancer managers ICB commissioners

Key aims of the mapping project

The key aims of the project were to define clinical pathways and available psychological care services in a manner that is useful for **clinicians**, for **patients and their families**, clarifying the services in their area, and for **commissioners of cancer services**.

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

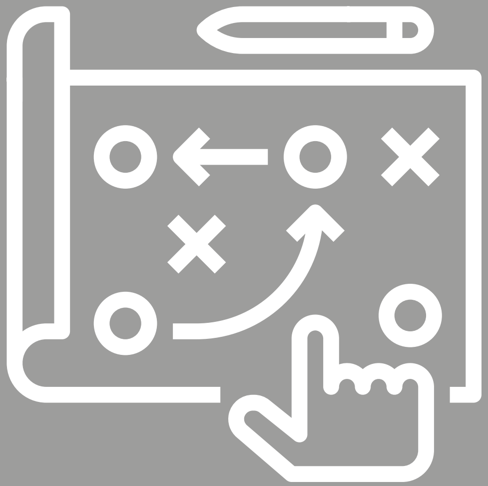
Provide a clear outline of the specialist psychological services and professionals available across TVCA. This includes specialist psychological services that are integrated into NHS cancer services, as well as NHS primary care and voluntary sector providers.

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.

Groundwork



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Foreword

Thames Valley Cancer Alliance commissioned this report as part of our aim to ensure every person affected by cancer has the highest quality physical and mental healthcare.

The right integrated psychological support can ensure better experience of cancer care, better cancer outcomes and improved quality of life in the long term.

Our aim is to ensure that all patients and their families have access to integrated psychological support with their cancer treatment and to bring together people affected by cancer, clinicians, commissioners, and voluntary sector organisations in an effort to ensure that mental health is not an afterthought or considered as a separate 'bolt-on' to cancer care.

A local steering group and our Patient Participation Group have come together across TVCA to prepare this report. The target audience are:

1. Patients and their families – increasing awareness of available resources and highlighting available services in the region and at their cancer centre where they can seek psychological support.
2. Clinical staff – ensuring psychological awareness of every single member of staff, increasing confidence in detecting and managing distress as well as awareness of clinical pathways, thereby increasing staff wellbeing and fostering integrated working within MDTs.
3. Leaders and commissioners – highlighting areas of good and evidence-based practice, flagging up areas of need, helping determine priorities in the local area and ensure equity of provision to every person with cancer. Also, linking up and sharing expertise across the alliance area in areas such as training and supervision thereby improving efficiency.

We are especially grateful to Rachel Holland, Anna Lagerdahl and Lucy Grant from the TVCA psychological care CAG, Shelley Orton, Strategic Partnership Manager at Macmillan Cancer Support and Lyndel Moore, Lead Cancer Nurse for the TVCA for the time and effort spent guiding the project. Also, to Dafydd Charles and Sarah Hepworth who have shared their personal stories which serve to illustrate powerfully the need for psychological support as an integral part of cancer care, as well as Josefina Bravo from University of Reading who designed this report.

Mrs. Jennifer Graystone,

Consultant Oral & Maxillofacial Surgeon and Head & Neck Surgeon

Clinical Director, Thames Valley Cancer Alliance

2 Introduction

Psychosocial care of people with cancer has traditionally been separate from routine cancer care and often only considered at the end of available active cancer treatment.[1] Despite cancer 'survivors' being recognized as such from the moment of diagnosis, recognition of distress and provision of psychological care is often not seen as part of routine, integrated cancer care.

Recognition and management of distress is important because:

1 Distress is common in people with cancer[2]
2 Rates of anxiety and depression are higher in people with cancer[3]
3 Anxiety and depression can negatively impact cancer treatment and recovery, affecting quality of life and mortality (due to all causes, including suicide)[4]
4 Cancer survival in the UK has doubled in the last 40 years.[5] In 2020, the UK had 3 million cancer survivors[6]

The International Psycho-Oncology Society (IPOS) has campaigned around the world to recognise emotional distress as the sixth vital sign in cancer care and recommends that screening should be undertaken as routinely as monitoring of the other vital signs.[7]

Recognising distress is every clinician's prerogative, not just the domain of counsellors, psychologists and psychiatrists. Empathetic listening and compassionate communication in a supportive environment are expected of all staff and can reduce distress. While major strides are being made in cancer treatment in the era of personalised treatments, the amorphous definition of 'mental health' and 'one size fits all' service provision makes it difficult for patients and their families as well as clinicians to work out just what services are available in the local area. Psychoeducation, signposting to the right information (mostly provided by voluntary sector organisations such as Macmillan Cancer Support) and support from family and friends can help understanding and management. For approximately a quarter of people diagnosed with cancer, their psychological distress will require specialist psychological support.

National Health Service England (NHSE) recommendations for completion of holistic needs assessments (HNAs) within 6 weeks of diagnosis as part of the NHS Long Term Plan has increased awareness of this unmet need. This, combined with rising incidence of cancer and better cancer survival rates have laid bare the inadequacies of current service provision.

As a result, specialist (level 3 and 4) psycho-oncology services in cancer centres, which have traditionally been set up to support those patients and family members experiencing complex psychological needs, have been under considerable strain. **Research suggests that three-quarters of people with cancer with comorbid major depression do not receive any treatment.**[8] Anecdotal evidence also points to the frustration experienced by clinicians about the lack of available treatment and support, which can prevent them from 'opening a can of worms'.

Workforce challenges within cancer multidisciplinary teams (MDTs) have been highlighted by the workforce deep dive exercises undertaken following the COVID-19 pandemic – similar pressures exist in specialist psycho-oncology services. As a result of these pressures, in the future, more patients are likely to have non-doctor cancer reviews, with other staff groups such as pharmacists and radiographers likely to deliver them. These groups do not have frameworks for level 2 training and clinical supervision which exist for cancer nurse specialists. In addition to its direct impact on clinical service delivery, clinical supervision has an important role in enhancing staff wellbeing and preventing compassion fatigue, especially at a time when the NHS is facing severe staffing shortages.

In summary, despite the stated aims of the NHS to deliver 'parity of esteem' between physical and mental health care, care for psychological comorbidity is not considered part of core cancer treatment. While the numbers are large and some people with cancer who experience distress are helped by their oncologist/ surgeon/ cancer nurse specialist or radiographer with information provision and practical support around stressors, **the NHS cannot afford to not treat people with cancer and psychological comorbidity.** Neglecting comorbidity exacerbates problems with adherence to treatment and rehabilitation and increases costs to the health economy. We need to be setting up robust clinical pathways so people with cancer and their families are systematically screened early and linked up to the right support and treatment - whether it is integrated within the cancer centre, in primary care via the IAPT programme or through peer support networks and the voluntary sector.

2.1. Thames Valley Cancer Alliance and Macmillan Cancer Support

The Thames Valley Cancer Alliance was established to bring together cancer leaders, commissioners, service providers, people affected by cancer and third-party stakeholders to take a whole pathway, whole population approach to delivering transformational change in cancer services across its defined geography. The vision is to achieve the best possible outcomes for everyone affected by cancer across Thames Valley.

Macmillan Cancer Support is focusing on provision of psychosocial support to encourage a more integrated system of care. This means seeing the whole person and, with the right structures in place, being able to offer tailored support to address a range of needs at all levels, at any time along the cancer pathway.

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 fore anything is done about it. I was about to find out the answer to that question.

I received a call from (care manager) Sam who listened and explained the support they could offer me:

Medication – I was reluctant to take any. We talked it through, and I could see it wasn't anything I would be tied to. I saw the GP and got a prescription for 20mg Citalopram. I've been on it ever since, and I'm OK with that.

Problem Solving – this technique, while sounding simple and straight forward, was a gamechanger for me. I'm a practical, logical person, so learning a tool that is structured, really helped me. We worked through small problems at first (looking at my work phone too much on my days off) and then moved to bigger problems (checking the front door is locked 20 times/ dealing with toxic friendships). The latter is the hardest thing that I've ever had to do, but I know it was the right thing.

The Whole Me – Sam gave me a safe place to open up and be honest, it was like opening the floodgates to emotions and feelings deeply buried. I was always worried about my family and putting a brave face on everything. To the outside world, I always had a smile, and was always commended on my positive mental attitude.... Little did they know the trauma I was hiding.

It wasn't easy. I started to open up to Toby about my anxiety, and when I felt it was getting worse. Toby is better at taking it seriously, and not dismissing me when the guttering is leaking, and I'm convinced the house foundations are going to collapse.

Life started to improve. If I was having a wobble, Toby would say to me 'what would Sam say'? and I'd go through the strands and talk to myself as if Sam was there. I was getting to a good place.

It's not all rosy though, with a happy ever after ending (sorry!).

At the end of 2022, I had progression to my jaw, and moved back on to chemotherapy which would be every three weeks forever. It floored me, the side effects were horrendous, it impacted me physically, and just as much mentally. I lost my hope, it was like being diagnosed all over again. Was it the end of the beginning, or the beginning of the end? I feel I've escaped a bullet, as I've been able to move back to my old treatment, and I'm slowly returning to the old me.

> *Sam gave me a safe place to open up and be honest, it was like opening the floodgates to emotions and feelings deeply buried. I was always worried about my family, and putting a brave face on everything.*

I recognise that I will continue to have ups and downs/ snakes and ladders. The tools and support give me hope, that the downs won't be as bad and long lasting, and I can keep riding the highs.

2.1.1. Key Drivers

1 NICE Cancer Service Guideline 4 Improving supportive and palliative care for adults with cancer (2004)[9]

“Key Recommendation 9: Commissioners and providers of cancer services [...] should ensure that all patients undergo systematic psychological assessment at key points and have access to appropriate psychological support. A four-level model of professional psychological assessment and intervention is suggested to achieve this.”

Includes the NICE 2004 4-tier model of psychological care that is used through this report.

LEVEL 1	**Universal Support**
LEVEL 2	**Enhanced Support**
LEVEL 3	**Enhanced/ Specialist Support**
LEVEL 4	**Specialist Support**

2 The Manual of Cancer Services 2008: Psychological Support Measures (2010)

3 Providing evidence-based psychological therapies to people with long-term conditions and/or medically unexplained symptoms (2015)[10]

4 NICE Guideline 197 Shared Decision Making (2021)

This guideline covers how to make shared decision-making part of everyday care in all healthcare settings, including cancer care.

5 Cancer specific NICE guidance such as*:

Brain & CNS:
CSG10 - Improving outcomes for people with brain and other CNS tumours
NG99 - Brain tumours (primary) and brain metastases in adults

Breast:
CSG1 - Improving outcomes in breast cancer
CG81 - Advanced Breast Cancer: diagnosis and treatment
CG164 - Familial Breast Cancer: classification, care and managing breast cancer and related risks in people with a family history of breast cancer
NG101 - Early and locally advanced breast cancer: diagnosis and management

Colorectal:
CSG5 - Improving outcomes in colorectal cancer

Dermatology
NG14 - Melanoma assessment and management

Haematology
NG47 - Haematological Cancers: Improving Outcomes

Head & Neck
CSG6 - Improving outcomes in head and neck cancers
NG36 - Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over

Lung
NG122 - Lung cancer diagnosis and management

Sarcoma
CSG9 - Improving outcomes in sarcoma

Upper GI
NG83 - Oesophago-grastric cancer: assessment and management in adults

Urology
CSG2 – Improving outcomes in bladder cancer
NG131 – Prostate cancer: diagnosis and management

*See also NHS England specialised kidney, bladder and prostate service specification

6 NHS Long Term Plan Operational planning guidance of 2021/2022[11]:

- Priority 1: Restoring NHS services inclusively
- Priority 2: Mitigating against ‘digital exclusion’
- Priority 3: Ensuring datasets are complete and timely
- Priority 4: Accelerating preventative programmes
- Priority 5: Strengthening leadership and accountability

7 NHS priorities and operational planning guidance - 2022/2023

2.2. Thames Valley Cancer Alliance Region

The Thames Valley has a population of 2.3 million, with significant variations between areas – while some areas are amongst the least deprived in the country in terms of income, employment, skills, health and disabilities, other areas have significant deprivation.

There are three integrated care systems in the region:

- BOB – Buckinghamshire, Oxfordshire and Berkshire West ICS
- Bath, Swindon and Wiltshire ICS (partly situated in TVCA region)
- Frimley Health and Care (partly situated in TVCA region)

NHS Acute Trusts in the region:

- Buckinghamshire Healthcare Trust
- Frimley Health NHS Foundation Trust
- Great Western Hospitals NHS Foundation Trust
- Milton Keynes University Hospitals NHS Foundation Trust
- Oxford University Hospitals NHS Foundation Trust
- Royal Berkshire NHS Foundation Trust

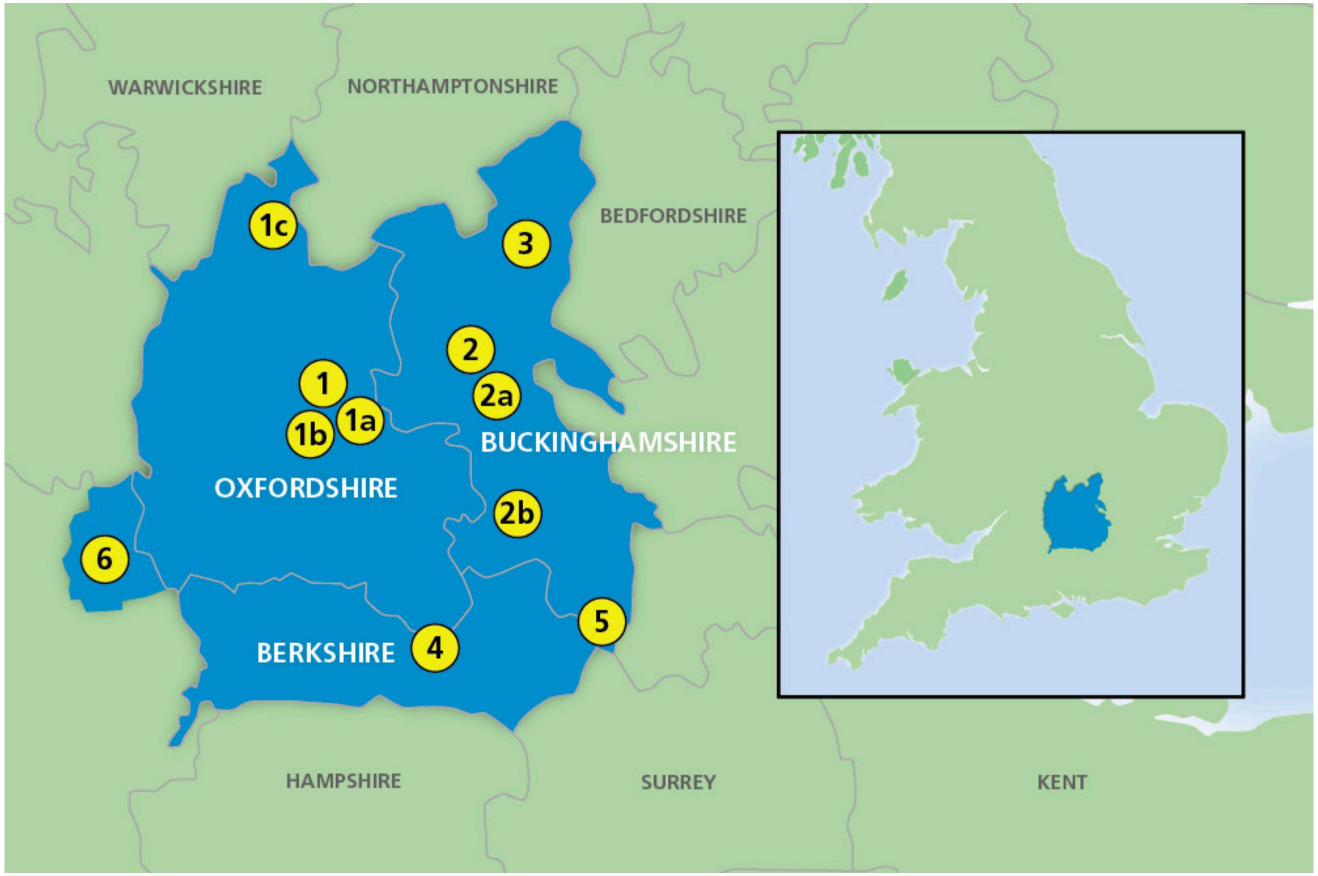


Figure 1. Map of hospitals providing cancer services in the Thames Valley area. Source Thames Valley Cancer Alliance website, available from https://thamesvalleycanceralliance.nhs.uk/about/our-geography/

Bracknell Healthspace and West Berks Community Hospital, Thatcham, are also sites where treatment is delivered.

① **Oxford University Hospitals NHS Foundation Trust**
(1a) **John Radcliffe Hospital (Headington)**
(1b) **Churchill Hospital (Headington)**
(1c) **Horton Hospital (Banbury)**
② **Buckinghamshire Healthcare NHS Trust**
(2a) **Stoke Mandeville Hospital**
(2b) **Wycombe Hospital**
③ **Milton Keynes University Hospital NHS Foundation Trust**
④ **Royal Berkshire NHS Foundation Trust**
⑤ **Frimley Health NHS Foundation Trust (Wexham Park Hospital)**
⑥ **Great Western Hospitals NHS Foundation Trust**
🟦 **Thames Valley Cancer Alliance geographic area**

3 Methodology

See Appendix 7 for Steering Terms of Reference

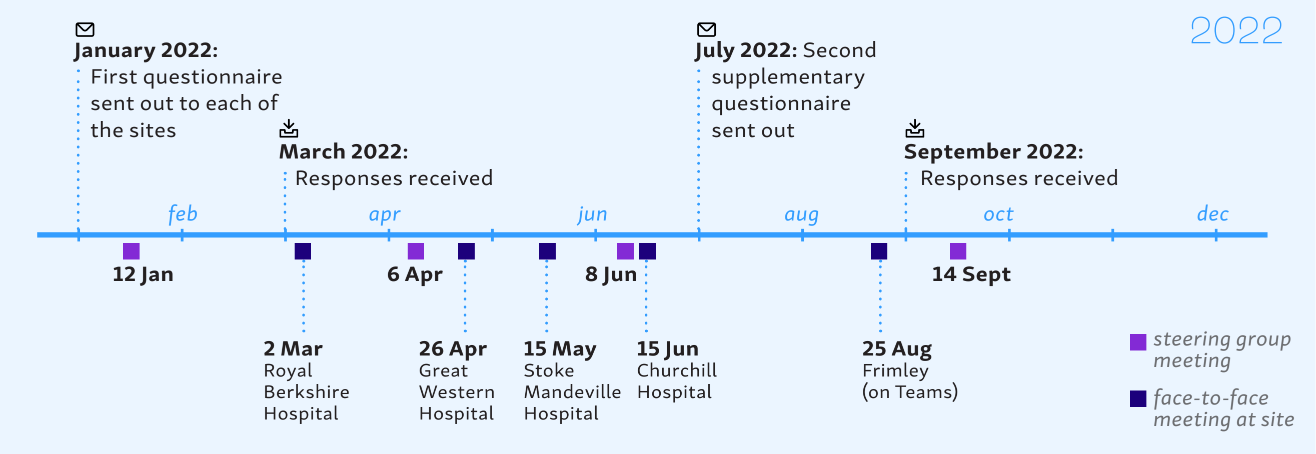
3.1. Stakeholders and data collection

3.1.1. Preparations

Initial planning meetings were held with senior TVCA and Macmillan representatives to clarify the aims, final outcomes and timetable for the project. We met with the authors of the Pan-London Mapping of Psycho-oncology Services report to gain insight into their methodology and discuss challenges in data collection and synthesis.

We drew up a template for each site to document all the stakeholders involved in cancer care in the local area to ensure that all stakeholders were contacted and involved from the outset. Sociodemographic and cancer data were sourced from the cancerdata website *https://www.cancerdata.nhs.uk/* and discussed with experts from the Oxford Department of Public Health, then verified with data obtained from individual services.

National Cancer Patient Experience Survey data were reviewed alongside the TVCA lead for personalised care pathways. Details on staffing and service delivery were obtained from each site from the lead cancer nurse and psychological care lead clinician. Data on Holistic Needs Assessment completion were obtained from Macmillan Cancer Support.



3.1.2. Working with the Steering Group

The Steering Group played a vital role in guiding the direction of this report. Membership was constituted based on initial recommendations from the lead cancer nurse on each TVCA site, and further additions on recommendations from the psychological care lead clinician. For steering group Terms of Reference, see Appendix 7.

- The steering group met on four occasions through the course of the year in 2022 - 12th January, 6th April, 8th June, and 14th Sept 2022. The meetings were recorded, minutes taken and circulated prior to the next meeting.
- The steering group members were sent two separate questionnaires in January and July 2022, turnaround times were 4-6 weeks for the first questionnaire and 8-10 weeks for the second questionnaire.
- Responses were discussed within each trust site with the MDTs by the lead clinician.

In addition to telephone and Microsoft Teams conversations with clinicians, steering group members, voluntary sector staff, we also had face to face meetings.

Face to face meetings were set up with MDT clinicians at each site to clarify patient journeys and the specific needs of the local population in the area:

- Royal Berkshire Hospital 02/03/22
- Great Western Hospital 26/04/22
- Stoke Mandeville Hospital 16/05/22
- Churchill Hospital 15/06/22

We were unable to meet with Frimley Health MDT face to face, so had a dedicated meeting on Microsoft Teams on 25/8/22

The first draft of the report was sent out to the group on 19/12/22. Further Steering Group meetings in 2023 (25th January, 9th March) discussed the contents and corrections with each iteration of the draft report.

Notes

In May 2023, Frimley Health NHS Foundation Trust, who had been part of the mapping process, informed us that the Surrey and Sussex Cancer Alliance and Macmillan Cancer Support are starting a similar scoping across the SSCA Alliance catchment area. This will include the Frimley Park Hospital and the Wexham Park Hospital sites. They withdrew from the TVCA mapping project.

Other organisational links

Two members of the steering group (AL, LG) sit on the British Psychological Society Special Interest Group in Cancer and Palliative Care. They campaign to address the unmet psychological needs of those affected by cancer at a national level. Another member (MF) is the head of UKONS (United Kingdom Oncology Nursing Society) and so will have a strong strategic influence, on the role of nursing and psychosocial care in cancer. Capturing the multi-disciplinary and multi-professional nature of cancer teams and how greater diversity and working alliance, are important for good patient outcomes.

3.1.3. Limitations

There are a number of limitations and biases in this report:

1. The lead authors are psychiatrists based in the Oxford Cancer Centre. SK was employed as clinical fellow to carry out the mapping process for a year and LS, as lead for psycho-oncology in the Oxford Cancer Centre, has been involved with the setting up of the psycho-oncology service from the outset, and their experience could have impacted the representation of data in the report.
2. The steering group are comprised of clinicians delivering clinical services and have interests in attracting more funding towards their services.
3. Cancer services, like all other NHS services were seriously disrupted through the COVID-19 pandemic, with staff being redeployed/clinics and supervision sessions cancelled, the data collection period for this report overlapped with these time periods.
4. Lack of clarity at the outset about the points in time when staffing numbers and services were delivered led to confusion about timestamps, especially as there have been changes and developments in services over the course of the 18 months while the report was being prepared.
5. The National Institute for Health Care Excellence (NICE) published the four-tier model of 'professional psychological assessment and support' in 2004 that continues to be valid. However, newer models of care such as collaborative care and IAPT-LTC services that have emerged in the intervening 20 years do not fit neatly into the stratified care model.
6. The patient feedback section is based on a very small sample that severely limits generalisability.
7. Cancer services overlap with palliative care services and several clinicians delivering psychosocial support in cancer also have roles in palliative care services. Haematological cancer clinics at times are combined with other haematology clinics (such as haemoglobinopathies and clotting disorders) making it difficult to accurately separate out data.

Mitigations
Efforts were made to mitigate the impact of bias in the report by:

1. Involvement of the representative steering group from the outset.
2. Triangulation, checking and re-checking data across multiple iterations of the report.
3. The final version of the report has been reviewed by the chair of the DCP Faculty for Oncology and Palliative Care of the British Psychological Society, Dr. Mike Rennoldson and Drs. Peter Aitken and Asanga Fernando on behalf of the liaison faculty at the Royal College of Psychiatrists. We are very grateful to them.

3.1.4. Inclusions and exclusions

The report focusses mainly on care provision in adults (18+) with solid tumours, who make up the largest proportion of patients. The report authors spoke to Clinical Advisory Groups (CAG) leads and attended meetings for the CAGs listed below, but details about service provision in these areas are not part of this report.

- Children's cancer
- Teenage and young adults
- Chemotherapy (SACT)
- Radiotherapy

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

Emma Earnshaw, Macmillan Advanced Nurse Practitioner, BHT

Mary Hayes, Head of Cancer & EoLC, Frimley Health

Lara Roskelly, AOS/MDC CNS Team Lead, Frimley Health

Anna Lagerdahl, Macmillan Consultant Clinical Psychologist, GWH

Karen Brown, Lead Cancer Nurse, GWH

Michelle M Taylor, Macmillan Personalised Care CNS Team Lead, GWH

Karen Mitchell, Lead Cancer Nurse, OUH

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

3.1.5. Semi structured questionnaires and interviews

The two Semi structured questionnaires (SSQ) sent to the steering group were adapted from the questions used in the Pan-London Mapping of Psycho-oncology Services 2015 and 2020.[12]

A second questionnaire was developed to inquire into specific areas that needed further clarification. Details with regards to the specific use of the Holistic Needs Assessment (HNA) on each hospital site by different tumour sites was derived from a table used in the Arden Mapping Report, 2012.[13]

3.1.6. Stakeholders engagement

We met with various TVCA clinical advisory groups (CAGs) which overlap with psychosocial care: the leads for haematological malignancies, children and teenage and young adult (TYA) services, radiotherapy, and pharmacy. This was to gain a broad understanding of referral processes to psychological medicine, training and supervision, and any difficulties they faced.

See Appendix 8, 9 and 10 for Questionnaires and Surveys

We engaged with the Macmillan GPs across the TVCA region and conducted semi-structured interviews over the telephone in March 2022.

We presented updates to the TVCA Psychological Care CAG Meetings on 9th March and 8th June, 2022 and have had feedback on the first draft of the report on 20/2/23.

We also met with the TVCA patient partnership group to better understand how patient representatives engage with the TVCA. We also sought their help in conducting the patient survey.

We worked with the patient engagement leads for TVCA and Macmillan Cancer Support, Cancer Buddy lead in Berkshire in formulating the questions for the patient survey. We sent out an electronic patient survey over a two-month period in summer 2022.

We spoke to IAPT representatives on each site, regardless of whether they were cancer specific, as well as to Dr John Pimms, consultant psychologist, regarding the pilot project with IAPT in Buckinghamshire which is specifically for patients with cancer. We met with one of the consultants looking at staffing for the TVCA Cancer Deep Dive project, Alison Alsbury.

3.2. The Stepped Care Model

The NICE guidance 2004 operationalized psychological care with the cancer care ecosystem. These four levels of care are interlinked through training, supervision and provide frameworks for escalation depending on clinical need.

- **Level 1** includes all health and social care professionals
- **Level 2** includes health and social care with additional expertise
- **Level 3** includes trained and accredited counsellors or psychotherapists
- **Level 4** includes mental health specialists

Table 1. Stepped Care Model: Services and training

Level	Service/staff typically providing this support	Psychological support	Training and supervision
LEVEL 1 **Universal Support**	**All health and social care professionals**: • All patient-facing staff at NHS organisations • Charities and third sector organisations	Effective information giving, compassionate communication and general psychological support	• Trained to Level 1 standard of the NICE 2004 model • Communication skills training • Knowledge of available third sector support, allowing them to sign-post as appropriate • Clinical supervision as specified by the staff member's job role
LEVEL 2 **Enhanced Support**	**Health and social care professionals with additional expertise:** • Cancer clinical staff in keyworker roles, including Cancer Nurse Specialists and Allied Health Professionals • Staff of VCSE organisations with equivalent roles and clinical training as CNS and AHPs	Psychological techniques such as problem solving	• Trained to Level 2 standard of the NICE 2004 model • Additional training on the National Advanced Communications Skills Training Course • Further Level 2 training relevant to cancer patients and their carers which covers basic psychological screening, psychological assessment, and core clinical skills in psychological intervention • Ongoing clinical supervision from those trained to Levels 3 or 4, by Level 3/4 specialists in psycho- oncology • Training on referral criteria into psycho-oncology and IAPT services, and how to assess level of need • Information relating to available third sector support, allowing them to sign-post and refer people affected by cancer
LEVEL 3 **Enhanced/ Specialist Support**	**Trained and accredited professionals** **Accredited counsellors or psychotherapists** • Specialist psycho- oncology services available in acute Trusts or Community palliative care services. • Improving Access to Psychological Therapies (IAPT) services including Long Term Condition pathway for cancer	Counselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework	• Training appropriate to the professional's role, for example an NHS psychotherapist accredited by the United Kingdom Council for Psychotherapy • Completed some specialist training in cancer care • Provide ongoing clinical supervision to those providing Level 2 • *Long term condition top-up training*, including the cancer specific eLearning for relevant IAPT staff
LEVEL 4 **Specialist Support**	**Mental health specialists** • Specialist psycho- oncology services available in acute Trusts or Community palliative care services. • Consultant liaison psychiatrists, or Clinical or Counselling psychologists within a psycho-oncology service	Specialist psychological and psychiatric interventions	• An induction that meets the *British Psychosocial Oncology Society* (BPOS) and SIGOPAC (*DCP Faculty for Oncology and Palliative Care*) requirements. • Specialist training (e.g. in role-teaching, supervision and formal courses) with specific reference to cancer care. • Provide ongoing clinical supervision to those providing Level 2 • Lead training on need assessment and referral criteria into psycho-oncology/IAPT services for Levels 1-3 staff

Table adopted from the Psychosocial Toolkit, from the NICE 2004 model of psychosocial support with permission of authors. Pan-London Mapping of Psycho-oncology Services. Healthy London Partnership/Macmillan Cancer Support. February 2020

Population and demographics

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4 Number of cancer diagnoses (2019) and estimates of need

BUCKINGHAMSHIRE HEALTHCARE NHS TRUST

N° of patients diagnosed with cancer (2019)

All malignancies	**2,168**
Bladder (invasive and non-invasive)	132
Bladder (invasive)	54
Blood	252
Bone cancer	.k
Bone tissue sarcoma	.k
Brain, meningeal and other primary CNS tumours	11
Breast, female	442
Cervix	10
Colorectal	288
Head and neck	45
Kidney	56
Liver and intrahepatic bile ducts	25
Lung, trachea and bronchus	194
Oesophagus	50
Ovary, fallopian tube and primary peritoneal carcinomas (excl. borderline)	26
Ovary, fallopian tube and primary peritoneal carcinomas (incl. borderline)	30
Pancreas	67
Prostate	312
Renal pelvis and ureter (malignant and in situ)	12
Soft tissue sarcoma	13
Stomach	30
Testicular tumours, including post-pubertal teratomas	12
Unknown Primary	30
Uterus	62

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

estimate of need Level 1 universal support		**2407 patients**
50% needing Level 2 enhanced support		**1204 patients**
15% needing Level 3 enhanced/specialist support		**361 patients**
Current Level 3 workforce (WTE)	› 0.6	
Current capacity	› 75	
Workforce required (WTE) caseload of 120	› 3	
10% needing Level 4 specialist support		**241 patients**
Current Level 4 workforce (WTE)	› 1.53	
Current capacity	› 122	
Workforce required (WTE) caseload of 80	› 3.1	

GREAT WESTERN NHS FOUNDATION TRUST

N° of patients diagnosed with cancer (2019)

All malignancies	**2,034**
Bladder (invasive and non-invasive)	114
Bladder (invasive)	48
Blood	257
Bone cancer	.k
Bone tissue sarcoma	.k
Brain, meningeal and other primary CNS tumours	13
Breast, female	431
Cervix	16
Colorectal	271
Head and neck	47
Kidney	53
Liver and intrahepatic bile ducts	23
Lung, trachea and bronchus	194
Oesophagus	42
Ovary, fallopian tube and primary peritoneal carcinomas (excl. borderline)	40
Ovary, fallopian tube and primary peritoneal carcinomas (incl. borderline)	47
Pancreas	43
Prostate	284
Renal pelvis and ureter (malignant and in situ)	15
Soft tissue sarcoma	13
Stomach	21
Testicular tumours, including post-pubertal teratomas	9
Unknown Primary	29
Uterus	58

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

without 1594 skin cancers added in

estimate of need Level 1 universal support		**2258 patients**
50% needing Level 2 enhanced support		**1129 patients**
15% needing Level 3 enhanced/specialist support		**339 patients**
Current Level 3 workforce (WTE)	› 0.7	
Current capacity	› 84	
Workforce required (WTE) caseload of 120	› 2.8	
10% needing Level 4 specialist support		**226 patients**
Current Level 4 workforce (WTE)	› 1.5	
Current capacity	› 120	
Workforce required (WTE) caseload of 80	› 2.8	

OXFORD UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

N° of patients diagnosed with cancer (2019)

All malignancies	**4,139**
Bladder (invasive and non-invasive)	200
Bladder (invasive)	88
Blood	446
Bone cancer	38
Bone tissue sarcoma	45
Brain, meningeal and other primary CNS tumours	478
Breast, female	600
Cervix	33
Colorectal	460
Head and neck	144
Kidney	149
Liver and intrahepatic bile ducts	59
Lung, trachea and bronchus	418
Oesophagus	106
Ovary, fallopian tube and primary peritoneal carcinomas (excl. borderline)	62
Ovary, fallopian tube and primary peritoneal carcinomas (incl. borderline)	76
Pancreas	114
Prostate	578
Renal pelvis and ureter (malignant and in situ)	23
Soft tissue sarcoma	114
Stomach	39
Testicular tumours, including post-pubertal teratomas	27
Unknown Primary	49
Uterus	78

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

estimate of need Level 1 universal support		4594 patients
50% needing Level 2 enhanced support		2297 patients
15% needing Level 3 enhanced/specialist support		689 patients
Current **collaborative care workforce** (WTE)	› 4	
Current capacity	› 480	
Workforce required (WTE) caseload of 120	› 5.75	
10% needing Level 4 specialist support		460 patients
Current Level 4 workforce (WTE)	› 0.8	
Current capacity	› 142	
Workforce required (WTE) caseload of 80	› 5.75	

ROYAL BERKSHIRE NHS FOUNDATION TRUST

N° of patients diagnosed with cancer (2019)

All malignancies	**2,606**
Bladder (invasive and non-invasive)	152
Bladder (invasive)	81
Blood	248
Bone cancer	.k
Bone tissue sarcoma	.k
Brain, meningeal and other primary CNS tumours	24
Breast, female	446
Cervix	20
Colorectal	318
Head and neck	80
Kidney	72
Liver and intrahepatic bile ducts	33
Lung, trachea and bronchus	218
Oesophagus	55
Ovary, fallopian tube and primary peritoneal carcinomas (excl. borderline)	34
Ovary, fallopian tube and primary peritoneal carcinomas (incl. borderline)	40
Pancreas	58
Prostate	528
Renal pelvis and ureter (malignant and in situ)	13
Soft tissue sarcoma	30
Stomach	37
Testicular tumours, including post-pubertal teratomas	15
Unknown Primary	46
Uterus	52

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
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

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

5 Specific cancer types

Data source: NHS Acute (Hospital) Trust Catchment Populations (2022 experimental rebase statistics); Office for Health Improvement and Disparities, Department of Health and Social Care

BREAST CANCER

- Younger women (under 50) report more distress and poorer quality of life[14]
- Hormone therapy for hormone receptor positive cancers in premenopausal women can be associated with a number of side effects including myalgia/ musculoskeletal problems which can result in discontinuation

Breast cancer	2019
Buckinghamshire Healthcare NHS Trust	442
Great Western Foundation Trust	431
Oxford University Hospitals NHS Foundation Trust	600
Royal Berkshire NHS Foundation Trust	446

PROSTATE CANCER

- Majority occur in men over 65
- Hormone treatment (androgen depletion) can result in sexual dysfunction, hot flushes, increased anxiety and depression[15]

Prostate cancer	2019
Buckinghamshire Healthcare NHS Trust	312
Great Western Foundation Trust	284
Oxford University Hospitals NHS Foundation Trust	578
Royal Berkshire NHS Foundation Trust	528

COLORECTAL CANCER

- Bowel, bladder and sexual function problems are commonly experienced after treatment[16]
- Patients with stomas can have particular issues[17]

Colorectal cancer	2019
Buckinghamshire Healthcare NHS Trust	288
Great Western Foundation Trust	271
Oxford University Hospitals NHS Foundation Trust	460
Royal Berkshire NHS Foundation Trust	318

LUNG CANCER

- smokers need early support to stop smoking (smoking cessation clinics)
- High symptom burden due to later diagnosis
- 61% prevalence of distress[18]
- Anxiety associated with shortness of breath can be prominent in later stages

Lung cancer	2019
Buckinghamshire Healthcare NHS Trust	194
Great Western Foundation Trust	194
Oxford University Hospitals NHS Foundation Trust	418
Royal Berkshire NHS Foundation Trust	218

UPPER GI CANCERS

- Pancreatic cancer is associated with high rates of depression (upto 50%)[19]
- Identifying and managing alcohol dependence comorbidity can help

Upper GI cancers	2019
Buckinghamshire Healthcare NHS Trust	147
Great Western Foundation Trust	106
Oxford University Hospitals NHS Foundation Trust	259
Royal Berkshire NHS Foundation Trust	129

TESTICULAR CANCER

- Most common in men aged 15 – 35
- Despite high cure rates (almost 100% in early-stage cancer), psychological distress at diagnosis is common (reported to be over 60% in some studies)[20]
- Informing patients of the possibility of needing adjuvant chemotherapy after surgery can prepare them

Testicular cancer	2019
Buckinghamshire Healthcare NHS Trust	12
Great Western Foundation Trust	9
Oxford University Hospitals NHS Foundation Trust	27
Royal Berkshire NHS Foundation Trust	15

HEAD AND NECK CANCERS

- Tobacco and alcohol use as well as human papilloma virus infection are risk factors
- Treatment side effects can be significant, including dry mouth, difficulty swallowing, breathing, and speaking as well as facial disfigurement[21]

Head and neck cancers	2019
Buckinghamshire Healthcare NHS Trust	45
Great Western Foundation Trust	47
Oxford University Hospitals NHS Foundation Trust	144
Royal Berkshire NHS Foundation Trust	80

BRAIN TUMOURS

- Symptoms vary depend on the site and aggressiveness
- Cognitive dysfunction - prevalence ranges from 30 to 90%[22]
- Various comorbid psychological symptoms can be present including anxiety, depression, psychosis, personality change[23]

Brain tumours	2019
Buckinghamshire Healthcare NHS Trust	11
Great Western Foundation Trust	13
Oxford University Hospitals NHS Foundation Trust	478
Royal Berkshire NHS Foundation Trust	24

GYNAE CANCERS

- Anxiety rates are higher in younger women, those lacking social support at higher risk[24]

Gynae cancers	2019
Buckinghamshire Healthcare NHS Trust	102
Great Western Foundation Trust	121
Oxford University Hospitals NHS Foundation Trust	187
Royal Berkshire NHS Foundation Trust	132

MELANOMA

- 30% prevalence of distress, mainly anxiety
- Immunotherapy can have numerous side effects which can worsen anxiety/ depression

The number of patients receiving treatment for melanoma has increased exponentially (estimated to be a 100% increase over the last 5 years) and account for a significant clinical burden.

Detailed data on melanoma for each cancer centre is scheduled to be made available from 2024 on the cancerdata website (*www.cancerdata.nhs.uk/*).

BLOOD CANCERS

- Haematological cancers are the fifth most common cancer in the UK, accounting for approximately 10% of all cancers
- They are heterogeneous group – acute leukaemia might warrant treatment within days or weeks, thus dramatically changing the patient’s life, while ‘watch and wait’ approach in chronic leukaemia can be stressful as well

Blood cancers	2019
Buckinghamshire Healthcare NHS Trust	252
Great Western Foundation Trust	257
Oxford University Hospitals NHS Foundation Trust	446
Royal Berkshire NHS Foundation Trust	248

6 Impact of cancer across the age spectrum

0-24
Children and young people

Cancer can impact not just the child and but the entire family. Parents can face a range of problems linked to the emotional impact of the cancer diagnosis in their child, as well as the intense and often prolonged nature of treatment and follow up. Concerns include family well-being and emotional functioning, the child's neurocognitive status and school functioning. Integrated psychosocial support is provided through the children's hospital.

Teenage and Young Adult (TYA) Service offers specialist, age-appropriate care to people aged 16 to 24 who have been diagnosed with cancer. Concerns in this age group include establishing identity, positive body image and sexual identity, increasing autonomy - separating from parents with increasing involvement with peers/ partners, higher education, careers and family.

24-54
Young adults

Young adults can face difficulties associated with balancing cancer treatment and surveillance with work and family roles with specific concerns about sexual dysfunction, preserving fertility and finances. Fear of recurrence, body image concerns and difficulties re-assimilating with peers and work groups can prevent a return to pre-cancer levels of functioning.[25]

55-69
Young old

Patients in this age group might be on the cusp of retiring and can feel cheated by diagnoses that can potentially shorten their life span and change plans for retirement. They can present with multiple comorbidities.

70+
Old old

Older adults (defined as age 65+) can have several comorbidities, functional decline, frailty and be at risk of cognitive impairment and polypharmacy. Patients might be care givers for spouses or be socially isolated and struggle to cope with the demands of navigating the health system.[26] Majority of existing cancer psychosocial services are set up for younger adults and this group can be neglected and discriminated against.

7 Cancer prevalence by type of cancer and age (2017–19)

BUCKINGHAMSHIRE HEALTHCARE NHS TRUST

Tumour site	0-24	24-54	55-69	70-79	80+
All malignancies	29	1,054	2,156	1,925	1,508
Bladder (invasive and non-invasive)	0	25	107	149	143
Bladder (invasive)	0	8	37	57	76
Blood	12	76	214	195	191
Bone cancer	.k	.k	.k	.k	.k
Bone tissue sarcoma	.k	.k	.k	.k	.k
Brain, meningeal and other primary CNS tumours	0	3	8	14	14
Breast, female	2	412	454	273	179
Cervix	1	24	6	5	3
Colorectal	0	82	264	247	252
Head and neck	0	38	57	29	15
Kidney	0	34	78	56	38
Liver and intrahepatic bile ducts	0	7	18	15	31
Lung, trachea and bronchus	0	32	202	235	171
Oesophagus	0	11	61	48	34
Ovary, fallopian tube and primary peritoneal carcinomas (excl. borderline)	0	10	27	35	25
Ovary, fallopian tube and primary peritoneal carcinomas (incl. borderline)	0	17	32	36	25
Pancreas	0	16	42	64	78
Prostate	0	45	390	388	154
Renal pelvis and ureter (malignant and in situ)	0	3	12	13	9
Soft tissue sarcoma	0	10	11	13	20
Stomach	0	11	22	22	24
Testicular tumours, including post-pubertal teratomas	2	37	4	1	0
Unknown Primary	0	10	23	31	54
Uterus	0	38	73	46	27

GREAT WESTERN NHS FOUNDATION TRUST

Tumour site	0-24	24-54	55-69	70-79	80+
All malignancies	43	972	2,001	1,734	1,231
Bladder (invasive and non-invasive)	1	26	82	135	111
Bladder (invasive)	0	11	36	58	63
Blood	21	113	189	202	167
Bone cancer	.k	.k	.k	.k	.k
Bone tissue sarcoma	.k	.k	.k	.k	.k
Brain, meningeal and other primary CNS tumours	5	8	17	21	16
Breast, female	0	348	515	223	131
Cervix	1	25	10	2	0
Colorectal	0	85	223	232	220
Head and neck	0	37	65	29	17
Kidney	1	16	55	42	19
Liver and intrahepatic bile ducts	1	4	23	28	26
Lung, trachea and bronchus	0	32	168	213	152
Oesophagus	0	8	41	53	21
Ovary, fallopian tube and primary peritoneal carcinomas (excl. borderline)	1	19	40	32	29
Ovary, fallopian tube and primary peritoneal carcinomas (incl. borderline)	4	26	45	33	29
Pancreas	0	13	49	61	46
Prostate	0	31	332	345	173
Renal pelvis and ureter (malignant and in situ)	0	2	8	15	21
Soft tissue sarcoma	0	16	12	14	9
Stomach	0	6	20	18	15
Testicular tumours, including post-pubertal teratomas	2	35	5	1	0
Unknown Primary	0	4	11	18	37
Uterus	0	24	64	52	22

OXFORD UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

Tumour site	0-24	24-54	55-69	70-79	80+
All malignancies	310	2,168	4,186	3,572	2,442
Bladder (invasive and non-invasive)	2	28	157	233	217
Bladder (invasive)	0	4	65	113	115
Blood	127	213	369	346	287
Bone cancer	27	47	25	17	6
Bone tissue sarcoma	33	64	26	18	7
Brain, meningeal and other primary CNS tumours	99	480	396	225	102
Breast, female	1	537	602	366	282
Cervix	2	77	19	2	7
Colorectal	2	186	383	379	368
Head and neck	2	92	176	93	38
Kidney	15	81	190	115	65
Liver and intrahepatic bile ducts	1	17	63	60	50
Lung, trachea and bronchus	1	72	415	475	346
Oesophagus	1	24	88	96	90
Ovary, fallopian tube and primary peritoneal carcinomas (excl. borderline)	7	41	96	71	34
Ovary, fallopian tube and primary peritoneal carcinomas (incl. borderline)	7	70	113	75	35
Pancreas	1	27	112	110	94
Prostate	0	94	813	747	242
Renal pelvis and ureter (malignant and in situ)	0	0	18	33	23
Soft tissue sarcoma	18	104	107	75	61
Stomach	1	18	37	44	31
Testicular tumours, including post-pubertal teratomas	14	67	8	1	0
Unknown Primary	0	14	47	45	91
Uterus	0	47	117	70	39

ROYAL BERKSHIRE NHS FOUNDATION TRUST

Tumour site	0-24	24-54	55-69	70-79	80+
All malignancies	37	1,269	2,272	2,160	1,563
Bladder (invasive and non-invasive)	0	33	100	159	136
Bladder (invasive)	0	13	47	82	82
Blood	11	143	181	223	163
Bone cancer	.k	.k	.k	.k	.k
Bone tissue sarcoma	.k	.k	.k	.k	.k
Brain, meningeal and other primary CNS tumours	1	7	10	26	23
Breast, female	2	406	378	235	193
Cervix	0	47	11	7	3
Colorectal	1	95	270	256	251
Head and neck	2	56	76	51	32
Kidney	0	39	61	46	45
Liver and intrahepatic bile ducts	1	6	31	33	27
Lung, trachea and bronchus	0	38	171	214	191
Oesophagus	0	10	63	60	28
Ovary, fallopian tube and primary peritoneal carcinomas (excl. borderline)	2	15	33	34	22
Ovary, fallopian tube and primary peritoneal carcinomas (incl. borderline)	3	30	38	36	24
Pancreas	0	13	44	62	54
Prostate	0	116	573	560	203
Renal pelvis and ureter (malignant and in situ)	0	2	7	21	14
Soft tissue sarcoma	2	21	21	19	19
Stomach	0	11	18	26	36
Testicular tumours, including post-pubertal teratomas	12	34	2	1	1
Unknown Primary	0	16	30	41	62
Uterus	0	19	65	41	19

8 Specific psychological comorbidity

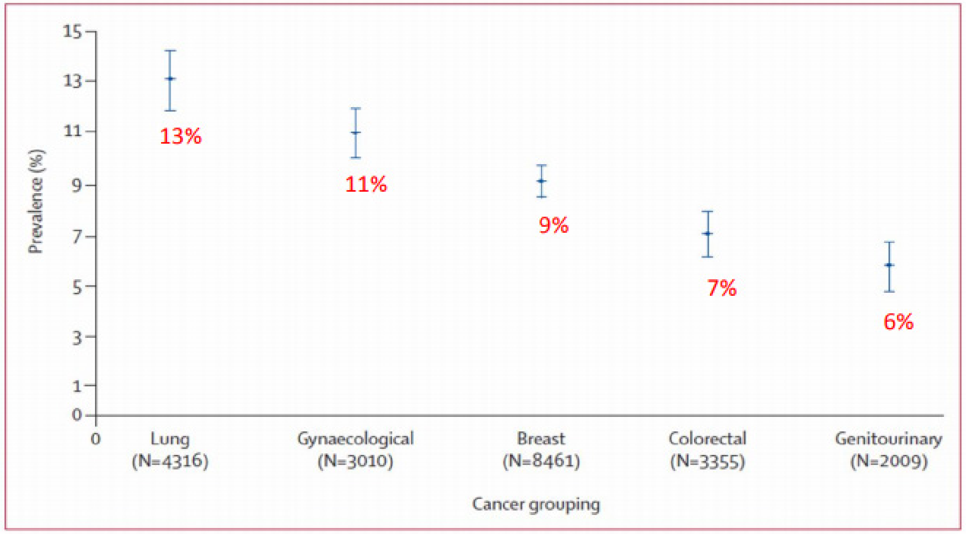
Adjustment difficulties

Adjustment to cancer refers to the psychological processes that occur over a period of time, as the patients and those in their social world learn from and adapt to the multitude of changes which have been precipitated by the illness and its treatment. These changes are not always for the worse: sometimes they precipitate 'healthy personal growth' in a number of areas. However, sometimes this period of adjustment can give rise to high levels of psychological distress, which can be managed with the help of psychological therapies.

Anxiety

Anxiety is very common in cancer, with many people experiencing particular anxiety linked to fear of recurrence. Some estimates suggest that almost a third of people diagnosed with cancer suffer with clinical levels of anxiety. Psychological interventions and medication can help with cancer specific psychological concerns including decisions around treatment, symptom related distress (such as nausea, pain and fatigue) as well as fear of cancer of recurrence and demoralisation in advanced illness.

Figure 2. Prevalence of major depression in patients with cancer. Error bars show 95% CIs. Source: Walker et al, Lancet Psychiatry, 2014.



Delirium

This is a common and often serious neuropsychiatric problem in older cancer patients, especially when admitted onto medical wards. It is estimated that between 25 – 40% of hospitalised cancer patients and upto 85% of hospice patients experience delirium. Delirium increases the risk of death and treatment of the underlying cause for delirium helps resolution. Psychotic symptoms such as visual hallucinations associated with delirium can cause immense distress and warrant antipsychotic medication.

Depression

Depression is one of the most common comorbidities in people with cancer, with prevalence rates estimated to be from 8 to 24%. Treatment includes talking therapy and antidepressant medication. The prevalence of anxiety and depression rises to 50% after a recurrence of cancer and remains at this level through advanced illness.

Suicide risk in cancer

The risk of suicide is higher in people with cancer, compared to the general population. The risk appears to be highest in the first 6 months after diagnosis and patients with cancer certain cancers appear to be at highest risk – these include mesothelioma, pancreatic, oesophageal, lung and gastric cancer.[27]

These are potentially preventable deaths, and psychosocial support to reduce distress and manage physical symptoms associated with cancer such as pain can be helpful.

Severe mental illness (schizophrenia, severe mood disorders)

People with severe mental illness (SMI) such schizophrenia, bipolar disorder, treatment resistant depression have a life expectancy shorter by 15-20years compared to the general population. People with SMI are more likely to be offered palliative rather than curative treatments for cancer and they experience worse care, as illustrated by patient surveys. Liaising with community mental health teams and early involvement of liaison psychiatry teams can help. Early advice must be sought for people on multiple psychotropic medications which could interact with cancer treatments, those on medications with narrow therapeutic windows (such as lithium) and medications that require ongoing monitoring (such as clozapine).

Dementia

Both cognitive impairment and cancer are more common in older people. Patients with dementia can present late due to reduced self-awareness of 'red-flag' symptoms and research suggests that most dementia sufferers diagnosed with cancer receive palliative treatments more commonly than curative. People with cancer who have worsening cognitive impairment can be referred to the local memory clinic via their GP.

Substance use disorders

Certain cancer types such as head & neck and lung cancers (smoking) and hepatocellular cancers (alcohol) are associated with substance use disorders and patients might need support with these disorders. Prescription medication dependence can develop and has been recognised as a significant public health issue in the US. Drug and alcohol support services can help, most providers accept self-referrals.

Some of the providers in the TVCA areas include:

- Buckinghamshire – One Recovery Bucks
- East Berkshire - Cranstoun RBWM service - Royal Borough of Windsor and Maidenhead; Lasar Early Intervention & Harm Minimisation Service, Slough
- Swindon – Turning Point
- Oxfordshire – Turning Point
- West Berkshire – Westminster Drug Project

Carers for people with cancer

Macmillan Cancer support estimates that 67% of carers experience anxiety and 42% experience depression. Of these over three quarters do not receive any support.[28]

Intellectual disabilities and Austism spectrum disorders

People with learning disabilities have poorer general health, and are more likely to die younger than the general population. Their uptake of cancer screening is lower and they have a higher risk of developing certain types of cancer. They are also more likely to struggle with accessing appropriate and accessible information about their cancer. Accessible and adapted specialist psychological assessment and therapy should be considered an essential part of their cancer pathway

9 Ethnicity

According to the 2021 census, non-white ethnic groups account for approximately 18% of the population in England and Wales, the largest ethnic minority groups are Asian (9.3%), followed by Black (4.0%), Mixed (2.9%) and Other (2.1%) ethnic groups.[29]

The ethnic mix of the population in the Thames Valley Cancer Alliance area varies from this national picture with clustering of ethnic minorities in certain urban areas. Many ethnic minority populations are significantly younger compared to the indigenous white population, thus the impact of cancer can be different.

In the National Cancer Patient Experience Survey in England, 2021,[30] ethnic minority patients reported lower satisfaction and less positive experiences of care. This is similar to responses in previous years. One notable exception is the relationship with Cancer Nurse Specialists - analysis of older NCPES data suggests that, though lower than for white patients, patients of all ethnicities reported understanding their CNS more than 75% of the time.[31]

Research into some tumour sites such as breast cancer reveal that health-seeking behaviour is influenced by knowledge of the signs and symptoms of cancer as well as cultural beliefs about cancer and the potential stigma associated with a cancer diagnosis. These factors can result in delayed diagnosis and later stage at presentation associated with higher levels of distress.[32] British South Asian patients reported significantly higher rates of depression following a cancer diagnosis compared to white patients.[33]

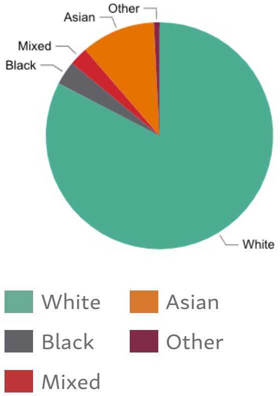
Psychological support services are tailored to provide for the majority white population, so ethnic minorities, especially those who do not speak English as a first language, can be disadvantaged when screening for distress and are unable to access talking therapies, which are delivered in English.

Local solutions such as building BAME networks by linking with community groups, training in cultural issues and advanced communication for clinicians, especially in hospitals with large local BAME populations, might help. **The Macmillan Cancer Education Project in Berkshire West to address the health inequalities and break down barriers in cancer services across all communities (e.g., Polish and Gurkha communities) is an excellent model. (see page 90)**

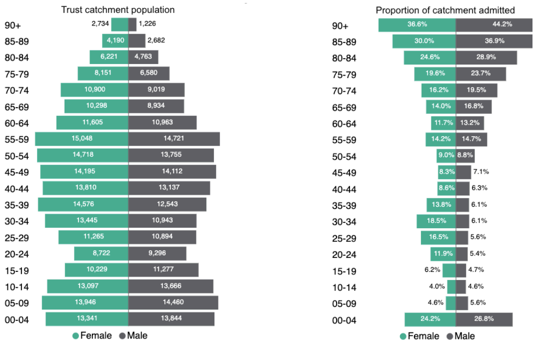
BUCKINGHAMSHIRE HEALTHCARE NHS TRUST

White 82.63%, Asian 10.52%, Black 3.41%, Mixed 2.65%

Trust catchment by ethnicity (2020)



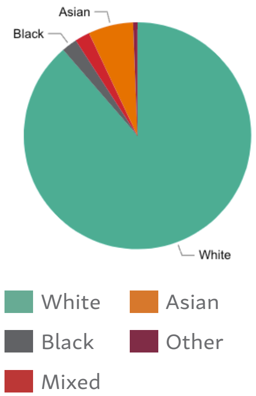
Age and gender (2020). Trust catchment and proportion of catchment admitted



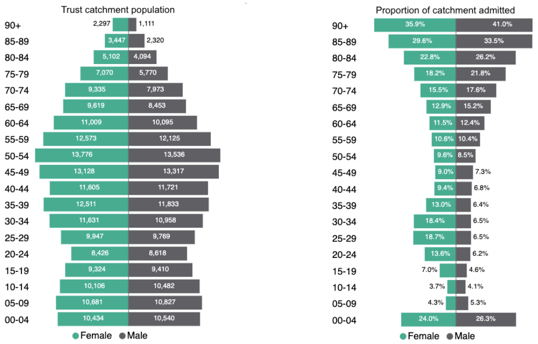
OXFORD UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

White population 88.67%, Asian 6.41%, Black 2.21%, Mixed 2.11%

Trust catchment by ethnicity (2020)



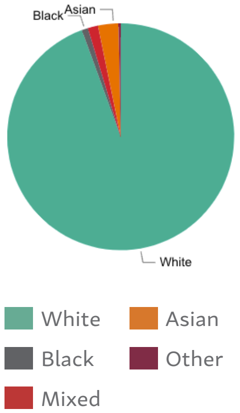
Age and gender (2020). Trust catchment and proportion of catchment admitted



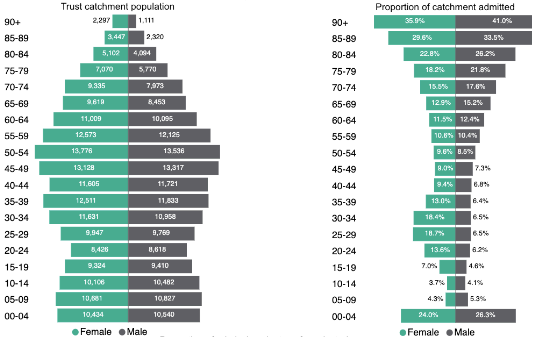
GREAT WESTERN NHS FOUNDATION TRUST

White 94.43%, Asian 2.91%, Black 0.9%, Mixed 1.95%

Trust catchment by ethnicity (2020)



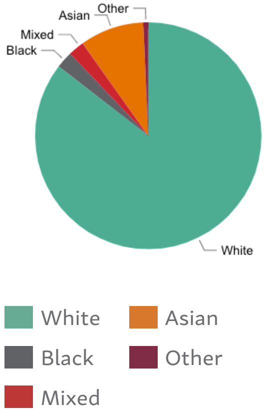
Age and gender (2020). Trust catchment and proportion of catchment admitted



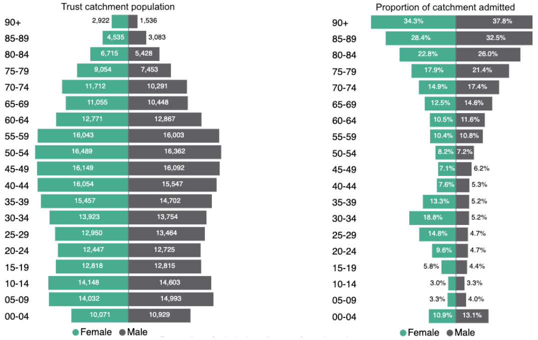
ROYAL BERKSHIRE NHS FOUNDATION TRUST

White 85.47%, Asian 9.16%, Black 2.4%, Mixed 2.27%

Trust catchment by ethnicity (2020)



Age and gender (2020). Trust catchment and proportion of catchment admitted



Findings

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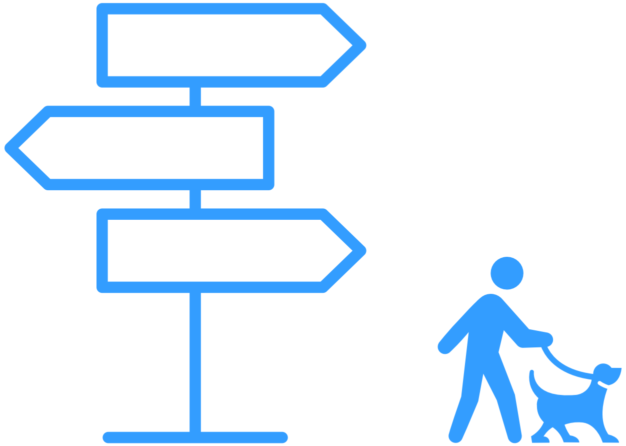
10

Patient journeys



When a person is diagnosed with cancer, they begin a journey, with their family and friends, across complex interlinked medical systems.

These systems include several specialist clinicians working within multidisciplinary teams (MDTs), who maybe scattered across different sites, delivering treatment personalised to their cancer type and stage.

The MDTs are set up to ensure that patients receive cancer treatment that is precise and technical, delivered at the earliest opportunity but can also make the experience disjointed and poorly connected for the patient.

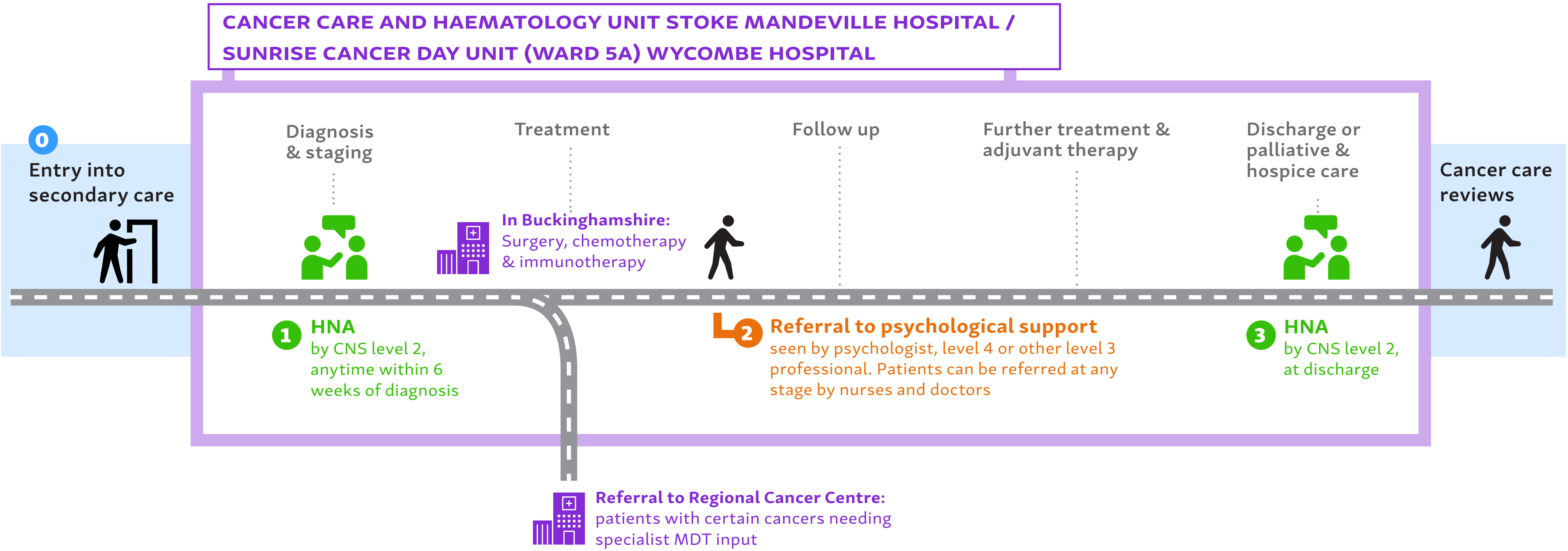
Indeed, the inability of the patient to interact directly with all the clinicians of the MDT and thus their inability to influence and discuss treatment decisions is frequently brought up.

In most NHS cancer treatment centres, clinical nurse specialists (CNSs) are the clinicians who stay with the patient as a constant companion through this journey between investigations and treatment provided by other clinicians, from diagnosis to discharge, as their named key worker. The experience of the patient through their cancer journey is dependent on the clinicians who are part of their journey and their ability to recognise and manage their symptoms and distress.

Their journey can also be influenced by the trajectory of their illness, previous experience of ill health, family response to cancer and available support. Studies have shown that clinician awareness of distress, proactive screening and provision of support, especially at ‘crunch’ times such as just after diagnosis and the year after treatment, can greatly improve patients’ outcomes and experience.

10.1. Cancer pathways

BUCKINGHAMSHIRE HEALTHCARE NHS TRUST



CANCER CARE AND HAEMATOLOGY UNIT STOKE MANDEVILLE HOSPITAL / SUNRISE CANCER DAY UNIT (WARD 5A) WYCOMBE HOSPITAL

0 Entry into secondary care

Diagnosis & staging

Treatment

Follow up

Further treatment & adjuvant therapy

Discharge or palliative & hospice care

Cancer care reviews

In Buckinghamshire: Surgery, chemotherapy & immunotherapy

1 **HNA** by CNS level 2, anytime within 6 weeks of diagnosis

2 **Referral to psychological support** seen by psychologist, level 4 or other level 3 professional. Patients can be referred at any stage by nurses and doctors

3 **HNA** by CNS level 2, at discharge

Referral to Regional Cancer Centre: patients with certain cancers needing specialist MDT input

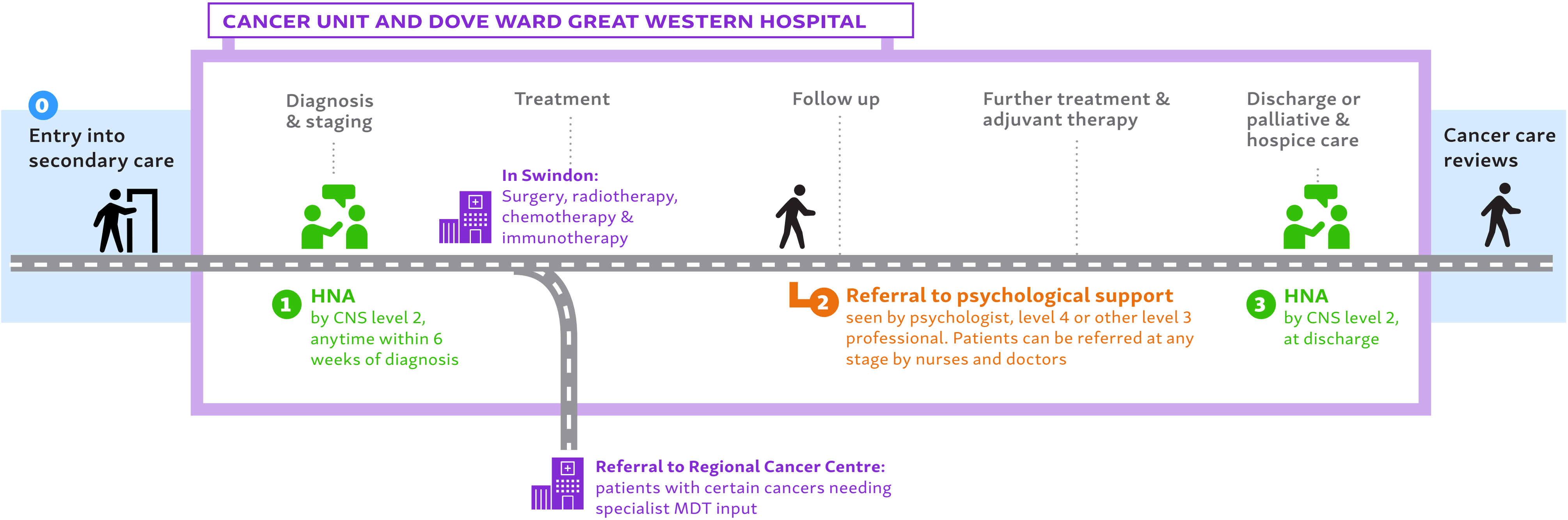
1 3

Holistic Needs Assessments are conducted by the Cancer Nurse Specialists, as soon as possible after diagnosis, and at the end of treatment.

2

Patients are referred based on need to the psycho-oncology service. The Psychiatric in Reach Liaison Team (PIRLS) are based at Stoke Mandeville Hospital, is provided by contract with Oxford Health NHS Foundation Trust. There is no dedicated psychiatric liaison service for cancer patients.

GREAT WESTERN NHS FOUNDATION TRUST



CANCER UNIT AND DOVE WARD GREAT WESTERN HOSPITAL

0 Entry into secondary care

Diagnosis & staging

Treatment

Follow up

Further treatment & adjuvant therapy

Discharge or palliative & hospice care

Cancer care reviews

In Swindon: Surgery, radiotherapy, chemotherapy & immunotherapy

1 **HNA** by CNS level 2, anytime within 6 weeks of diagnosis

2 **Referral to psychological support** seen by psychologist, level 4 or other level 3 professional. Patients can be referred at any stage by nurses and doctors

3 **HNA** by CNS level 2, at discharge

Referral to Regional Cancer Centre: patients with certain cancers needing specialist MDT input

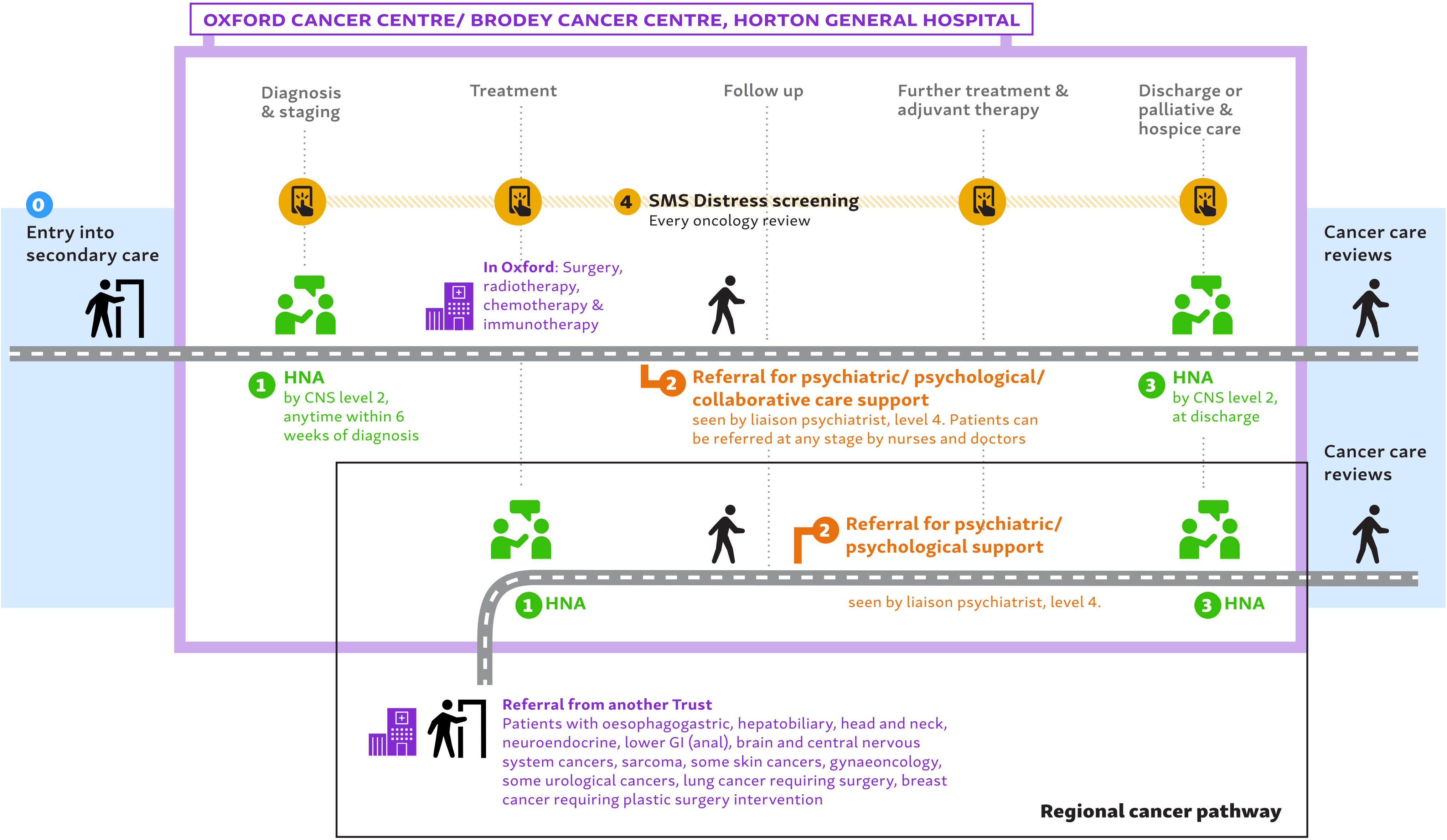
① ③

Screening for emotional distress, is conducted by the Cancer Nurse Specialists, using the Holistic Needs Assessment (HNA), by phone, face to face or by email, or using an electronic form, throughout the patient pathway.

②

Patients are referred based on need to the psycho-oncology service. From the emergency department some patients are transferred to medical & surgical wards, and then fast tracked to the psychological support services. The liaison psychiatry service is provided by contract with Avon and Wiltshire Mental Health Partnership NHS Trust. Rarely the primary care liaison team and community mental health teams (CMHT) are required for involvement in the patient pathway.

OXFORD UNIVERSITY HOSPITALS NHS FOUNDATION TRUST



OXFORD CANCER CENTRE/ BRODEY CANCER CENTRE, HORTON GENERAL HOSPITAL

0 Entry into secondary care

Diagnosis & staging

Treatment

Follow up

Further treatment & adjuvant therapy

Discharge or palliative & hospice care

4 **SMS Distress screening**
Every oncology review

In Oxford: Surgery, radiotherapy, chemotherapy & immunotherapy

1 **HNA**
by CNS level 2, anytime within 6 weeks of diagnosis

2 **Referral for psychiatric/ psychological/ collaborative care support**
seen by liaison psychiatrist, level 4. Patients can be referred at any stage by nurses and doctors

3 **HNA**
by CNS level 2, at discharge

Cancer care reviews

Cancer care reviews

2 **Referral for psychiatric/ psychological support**
seen by liaison psychiatrist, level 4.

1 HNA

3 HNA

Referral from another Trust
Patients with oesophagogastric, hepatobiliary, head and neck, neuroendocrine, lower GI (anal), brain and central nervous system cancers, sarcoma, some skin cancers, gynaeoncology, some urological cancers, lung cancer requiring surgery, breast cancer requiring plastic surgery intervention

Regional cancer pathway

① ③

Holistic Needs Assessments are conducted by the Cancer Nurse Specialists, as soon as possible after diagnosis, and at the end of treatment.

②

Patients are referred based on need to the psycho-oncology service. The dedicated oncology liaison psychiatry service covers outpatients and inpatients and is part of the trust-wide psychological medicine service. There are no psychologists working in the service currently.

④

Symptom Monitoring Service (SMS) Distress Screening

All patients living in the Oxfordshire region who have a medical/clinical oncology appointment are offered a Symptom Check up, that screens for physical symptoms and emotional distress. This service is only commissioned for patients living in Oxfordshire.

PROCESS OF SMS

The SMS is repeated every time the patient presents to the Oncology services, every 8 weeks

Daily, the clinical support worker and SMS specialty coordinator, filter a list of patients who have an oncology or haematology outpatient appointment within two days' time at the Churchill hospital

A text message or email is sent to every patient, to complete a Symptom Check-up questionnaire before their oncology or haematology appointment

Patient answers the questionnaire using Microsoft Forms

This was set up at the beginning of COVID so that this process could be completed online

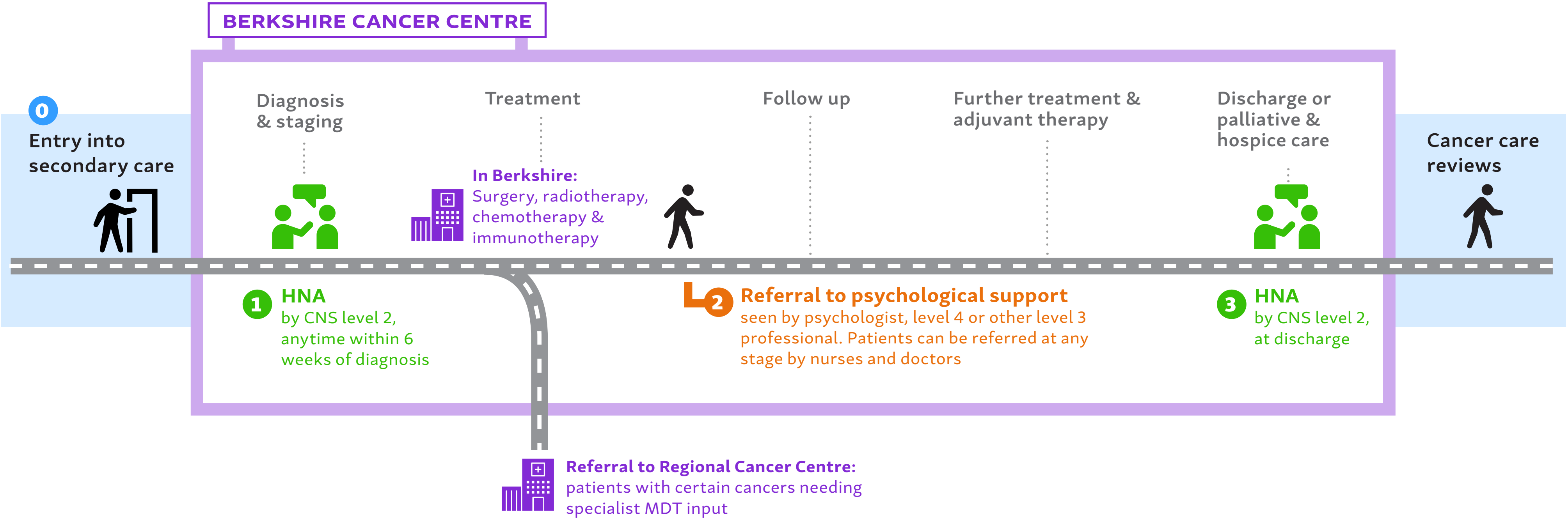
Responses are loaded onto the SMS database and the Depression score is automatically calculated

If they score below 8, this will be uploaded to the Electronic Patient Records, and the team will continue to SMS them at future oncology or haematology appointments

If they score above 8, patient will receive a telephone structured clinical interview with a band 6 care manager.

Depending on the outcome of these interviews, the patient will be reviewed by the consultant psychiatrist for eligibility for the Depression Care for Patients with Cancer program, recommendation to the GP about medication, or they will be booked in to see the consultant liaison psychiatrist in clinic.

ROYAL BERKSHIRE NHS FOUNDATION TRUST



BERKSHIRE CANCER CENTRE

0 Entry into secondary care

Diagnosis & staging

Treatment

Follow up

Further treatment & adjuvant therapy

Discharge or palliative & hospice care

Cancer care reviews

In Berkshire: Surgery, radiotherapy, chemotherapy & immunotherapy

1 **HNA** by CNS level 2, anytime within 6 weeks of diagnosis

2 **Referral to psychological support** seen by psychologist, level 4 or other level 3 professional. Patients can be referred at any stage by nurses and doctors

3 **HNA** by CNS level 2, at discharge

Referral to Regional Cancer Centre: patients with certain cancers needing specialist MDT input

1

After the cancer diagnosis, the HNA can be conducted at any stage over the pathway. Screening for emotional distress is conducted by the CNSs, using the HNA, by phone, face to face or by email, using an electronic form. Patients are referred based on need to the psycho-oncology service.

2

Initially, patients are seen by the Psychologist, but the patient can be referred onto the Psychiatrist. There is no dedicated service level agreement for psychiatry for cancer patients in Royal Berkshire Hospital.

- If in patient at the RBH, then a referral can be made to the Psychological Medicine service (PMS) for psychiatric advice /input.
- If the patient is in the outpatient clinic, then they would access psychiatry by a referral via the BHFT Gateway (previously known as CPE).
- If the Patient is already under a local CMHT, then direct liaising can take place.
- Referrals are also taken from the Community, Talking Therapies, (IAPT) following the two-weekly review of cases, that can result in a referral back to Psychology/ Psychiatry.

10.2. Patient screening and monitoring tools

Screening instruments to help identify distress are the Symptom Monitoring Service (SMS) and the Holistic Needs Assessment (HNA). These are used for screening and monitoring.

From the HNA, healthcare professional may form a Personalised Care Plan or an End of Treatment Summary. This section summarizes the instruments that are used across the TVCA.

Tools

HNA: HOLISTIC NEEDS ASSESSMENT

DISTRESS THERMOMETER

END OF TREATMENT SUMMARY

PATIENT HEALTH QUESTIONNARE 9 (PHQ9)

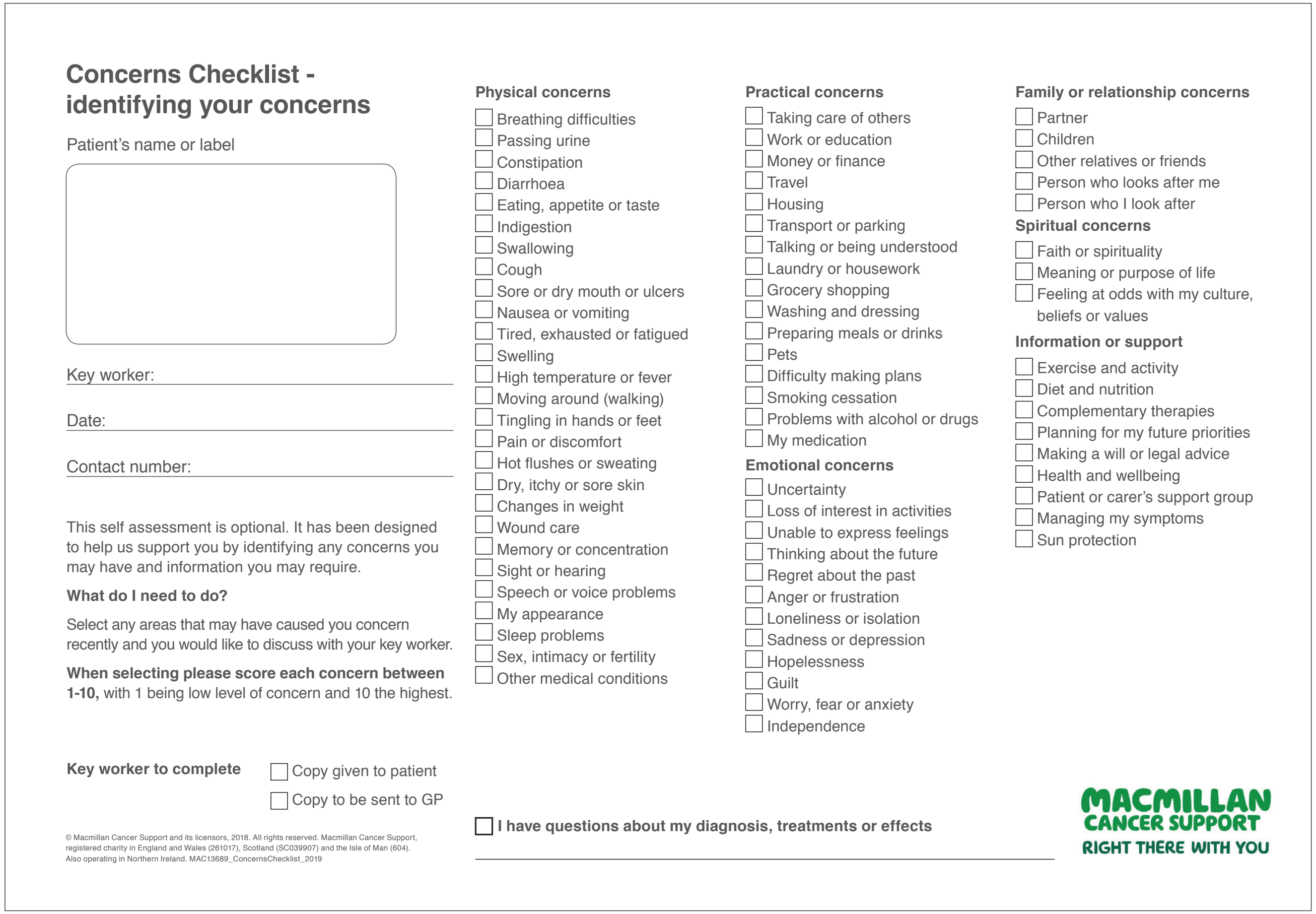
PCP: PERSONALISED CARE PLAN

SMS: SYMPTOM MONITORING SERVICE

HNA

The Holistic Needs Assessment[34] is patient led and aims to identify the most significant concerns for the patient, so the treating team can formulate a care plan to address the needs. It covers concerns across areas such as physical, emotional, practical, financial, and spiritual. The assessment helps the nursing team to identify and formulate a care plan to address the needs including:

- identify patient's key concerns
- start a conversation about patient's needs
- develop patient's own care and support plan
- share the right information, at the right times
- signpost the patient to relevant services offering additional support.



Concerns Checklist - identifying your concerns

Patient's name or label

Key worker:

Date:

Contact number:

This self assessment is optional. It has been designed to help us support you by identifying any concerns you may have and information you may require.

What do I need to do?

Select any areas that may have caused you concern recently and you would like to discuss with your key worker.

When selecting please score each concern between 1-10, with 1 being low level of concern and 10 the highest.

Key worker to complete
☐ Copy given to patient
☐ Copy to be sent to GP

Physical concerns
☐ Breathing difficulties
☐ Passing urine
☐ Constipation
☐ Diarrhoea
☐ Eating, appetite or taste
☐ Indigestion
☐ Swallowing
☐ Cough
☐ Sore or dry mouth or ulcers
☐ Nausea or vomiting
☐ Tired, exhausted or fatigued
☐ Swelling
☐ High temperature or fever
☐ Moving around (walking)
☐ Tingling in hands or feet
☐ Pain or discomfort
☐ Hot flushes or sweating
☐ Dry, itchy or sore skin
☐ Changes in weight
☐ Wound care
☐ Memory or concentration
☐ Sight or hearing
☐ Speech or voice problems
☐ My appearance
☐ Sleep problems
☐ Sex, intimacy or fertility
☐ Other medical conditions

Practical concerns
☐ Taking care of others
☐ Work or education
☐ Money or finance
☐ Travel
☐ Housing
☐ Transport or parking
☐ Talking or being understood
☐ Laundry or housework
☐ Grocery shopping
☐ Washing and dressing
☐ Preparing meals or drinks
☐ Pets
☐ Difficulty making plans
☐ Smoking cessation
☐ Problems with alcohol or drugs
☐ My medication

Emotional concerns
☐ Uncertainty
☐ Loss of interest in activities
☐ Unable to express feelings
☐ Thinking about the future
☐ Regret about the past
☐ Anger or frustration
☐ Loneliness or isolation
☐ Sadness or depression
☐ Hopelessness
☐ Guilt
☐ Worry, fear or anxiety
☐ Independence

Family or relationship concerns
☐ Partner
☐ Children
☐ Other relatives or friends
☐ Person who looks after me
☐ Person who I look after

Spiritual concerns
☐ Faith or spirituality
☐ Meaning or purpose of life
☐ Feeling at odds with my culture, beliefs or values

Information or support
☐ Exercise and activity
☐ Diet and nutrition
☐ Complementary therapies
☐ Planning for my future priorities
☐ Making a will or legal advice
☐ Health and wellbeing
☐ Patient or carer's support group
☐ Managing my symptoms
☐ Sun protection

☐ **I have questions about my diagnosis, treatments or effects**

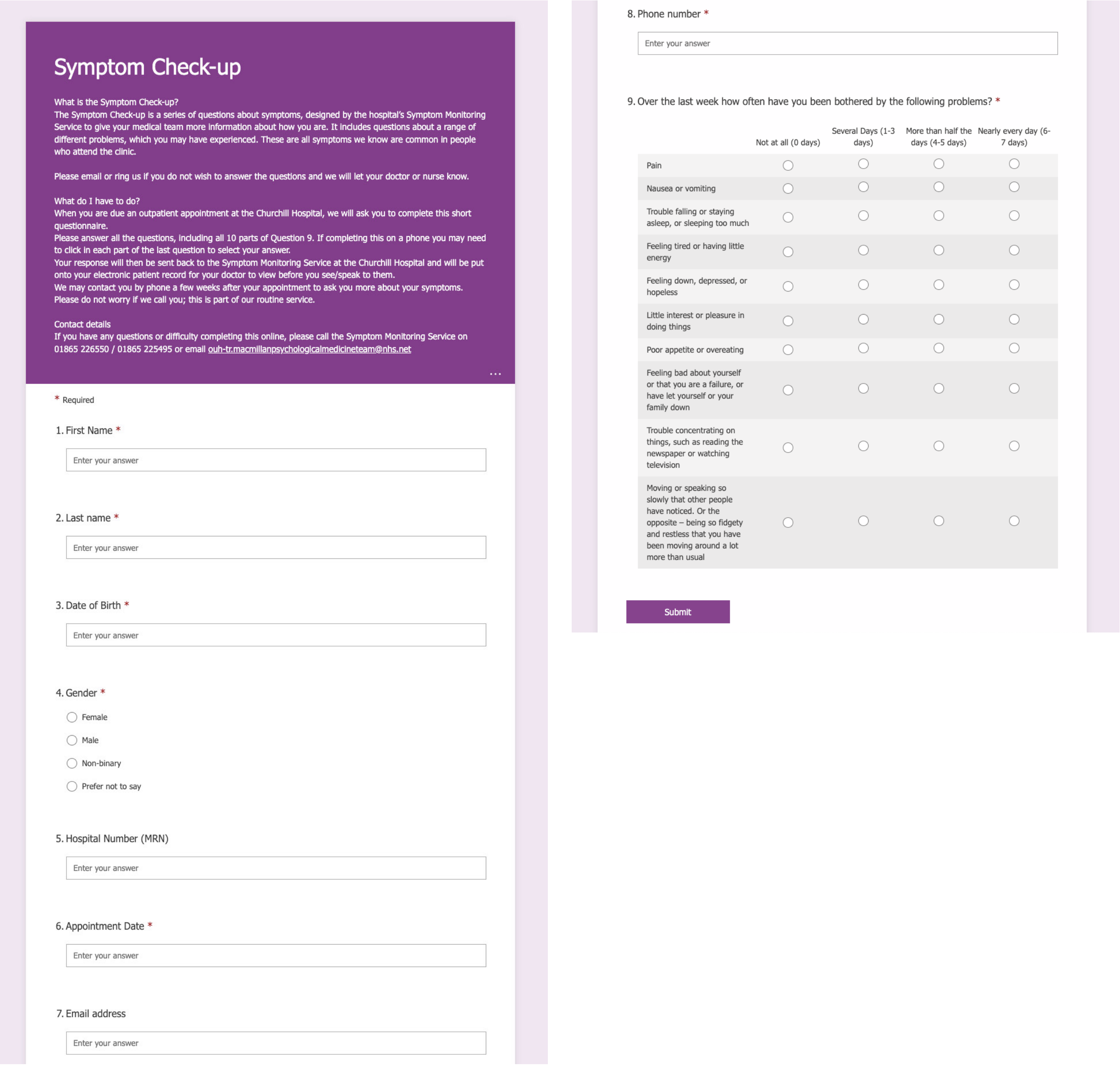
MACMILLAN CANCER SUPPORT
RIGHT THERE WITH YOU

Figure 3. HNA checklist

SMS: Symptom Monitoring Service

The symptom checkup is a short questionnaire administered to patients who have outpatient appointments at the Oxford Cancer Centre. It includes questions about a range of problems the patient may have experienced. Figure 4 shows a screenshot of the questionnaire.

Figure 4. Screenshot of SMS Symptom Check-up questionnaire.



Symptom Check-up

What is the Symptom Check-up?
The Symptom Check-up is a series of questions about symptoms, designed by the hospital's Symptom Monitoring Service to give your medical team more information about how you are. It includes questions about a range of different problems, which you may have experienced. These are all symptoms we know are common in people who attend the clinic.

Please email or ring us if you do not wish to answer the questions and we will let your doctor or nurse know.

What do I have to do?
When you are due an outpatient appointment at the Churchill Hospital, we will ask you to complete this short questionnaire.
Please answer all the questions, including all 10 parts of Question 9. If completing this on a phone you may need to click in each part of the last question to select your answer.
Your response will then be sent back to the Symptom Monitoring Service at the Churchill Hospital and will be put onto your electronic patient record for your doctor to view before you see/speak to them.
We may contact you by phone a few weeks after your appointment to ask you more about your symptoms. Please do not worry if we call you; this is part of our routine service.

Contact details
If you have any questions or difficulty completing this online, please call the Symptom Monitoring Service on 01865 226550 / 01865 225495 or email ouh-tr.macmillanpsychologicalmedicineteam@nhs.net

* Required

1. First Name *
Enter your answer

2. Last name *
Enter your answer

3. Date of Birth *
Enter your answer

4. Gender *
○ Female
○ Male
○ Non-binary
○ Prefer not to say

5. Hospital Number (MRN)
Enter your answer

6. Appointment Date *
Enter your answer

7. Email address
Enter your answer

8. Phone number *
Enter your answer

9. Over the last week how often have you been bothered by the following problems? *

	Not at all (0 days)	Several Days (1-3 days)	More than half the days (4-5 days)	Nearly every day (6-7 days)
Pain	○	○	○	○
Nausea or vomiting	○	○	○	○
Trouble falling or staying asleep, or sleeping too much	○	○	○	○
Feeling tired or having little energy	○	○	○	○
Feeling down, depressed, or hopeless	○	○	○	○
Little interest or pleasure in doing things	○	○	○	○
Poor appetite or overeating	○	○	○	○
Feeling bad about yourself or that you are a failure, or have let yourself or your family down	○	○	○	○
Trouble concentrating on things, such as reading the newspaper or watching television	○	○	○	○
Moving or speaking so slowly that other people have noticed. Or the opposite – being so fidgety and restless that you have been moving around a lot more than usual	○	○	○	○

Patient health Questionnaire 9 (PHQ–9)

PHQ–9 is a self-report measure of depression, validated for use in primary care and hospital settings. The PHQ-9 items reflect the diagnostic criteria for depression outlined by the Diagnostic and Statistical Manual of Mental Disorders.[35] Summary scores range from 0 to 27, where larger scores reflect a greater severity of depressive symptoms. The PHQ-9 has been found to discriminate well between depressed and nondepressed individuals using the cut-off total score ≥ 10, with good sensitivity (88.0%), specificity (88.0%) and reliability.[36]

PCP: Personalised care plan

This document is the outcome of the person's holistic needs assessment. This incorporates:

- a record of conversations, decisions and agreed outcomes
- understanding a patient's care and support needs, their life and family situation
- knowing what is required to make the plan achievable and effective

The Distress Thermometer

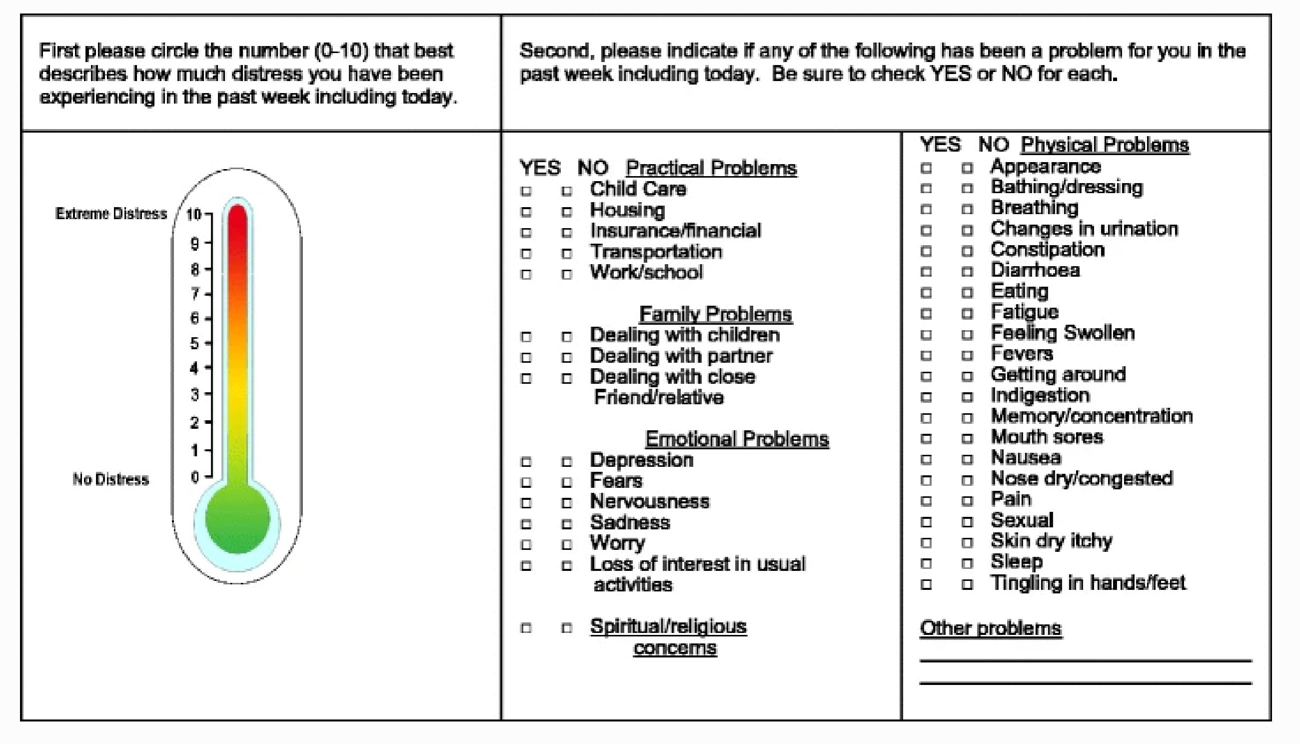
It is a modified visual analogue scale that resembles a thermometer (Figure 5). Scores range from 0 (no distress) to 10 (extreme distress). It includes an accompanying list of 34 problems grouped into five categories: practical, family, emotional, spiritual/religious and physical.

End of Treatment Summary

This document is completed prior to the patient's discharge back to the GP and can inform Cancer Care Reviews carried out in primary care. It includes:

- an overview of any treatment the patient has received
- details of any potential side effects of treatment
- the signs and symptoms of cancer recurrence
- contact details to address any concerns.

Figure 5. Distress Thermometer



First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Extreme Distress 10
9
8
7
6
5
4
3
2
1
No Distress 0

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES NO **Practical Problems**
☐ ☐ Child Care
☐ ☐ Housing
☐ ☐ Insurance/financial
☐ ☐ Transportation
☐ ☐ Work/school

Family Problems
☐ ☐ Dealing with children
☐ ☐ Dealing with partner
☐ ☐ Dealing with close Friend/relative

Emotional Problems
☐ ☐ Depression
☐ ☐ Fears
☐ ☐ Nervousness
☐ ☐ Sadness
☐ ☐ Worry
☐ ☐ Loss of interest in usual activities

☐ ☐ **Spiritual/religious concerns**

YES NO **Physical Problems**
☐ ☐ Appearance
☐ ☐ Bathing/dressing
☐ ☐ Breathing
☐ ☐ Changes in urination
☐ ☐ Constipation
☐ ☐ Diarrhoea
☐ ☐ Eating
☐ ☐ Fatigue
☐ ☐ Feeling Swollen
☐ ☐ Fevers
☐ ☐ Getting around
☐ ☐ Indigestion
☐ ☐ Memory/concentration
☐ ☐ Mouth sores
☐ ☐ Nausea
☐ ☐ Nose dry/congested
☐ ☐ Pain
☐ ☐ Sexual
☐ ☐ Skin dry itchy
☐ ☐ Sleep
☐ ☐ Tingling in hands/feet

Other problems

Table 2. Summary of screening and monitoring tools across Trust sites

trust	**Buckinghamshire Healthcare NHS Trust**	**Great Western Healthcare NHS Foundation Trust**	**Oxford University Hospitals NHS Foundation Trust**		**Royal Berkshire NHS Foundation Trust**
Aim	Screening & Monitoring	Screening	Screening		Screening and monitoring
Tool	HNA and eHNA (Macmillan Cancer Support)	eHNA	HNA	SMS (since August 2017) It incorporates the PHQ-8	HNA and eHNA
Mode of delivery	Face to face, by phone and by email.	Electronic HNA, telephone and face to face	Face to face, by phone and by email. Care planning conducted by telephone or face to face.	Telemedicine / Digital services Patients receive a text message, which links to the SMS (since May 2020). This is followed up by a telephone call	Online Care Planning is conducted via telephone or face to face
Implementation	CNSs	Patient pathway facilitator and CNs	CNSs	Band 4 SMS assistants	CNSs Psychosocial needs are being monitored by the cancer rehab team assessment.
When	Soon after diagnosis, and at the end of the treatment	At time of diagnosis and usually after treatment	At first contact with Oncology/ Haem Oncology. It is offered to all new cancer patients at or around the time of the diagnosis. It is used within six weeks of the diagnosis of cancer, across cancer services.	From the first contact with Oncology/ Haem Oncology and every eight weeks, at each appointment.	Normally at diagnosis and at discharge but varies according to tumor site. Support workers set up the assessments. The CNS teams delivers care planning. HNA and care planning often results in referrals to psychology and/or cancer rehab.

11

Patient engagement

Involvement of citizens in designing their own environment (and patients being involved with their own healthcare), described as co-production, has been discussed for over 50 years.[37]

Most cancer services are biomedical, illness–centred and health–provider led, despite recognition of the biopsychosocial model of health[38] and calls for change for over 40 years.

At a time when people with cancer are surviving longer than any time in the past and resources are severely constrained, the time may have finally come for patient engagement and co-production to move to the forefront of service design, commissioning, and evaluation.

Co-production comes with numerous challenges and inherent difficulties – the most important of which could be that ‘one size fits all’ services can be cheaper and easier to deliver without threatening professionals’ control of clinical decision-making. Indeed, co-production can lead to difficulties and reduction in value to the health economy – it can be taxing physically and mentally for patients and their families involved, make them feel like they lack the knowledge and expertise and expose them to ethical tensions.

All of this can be surmounted by strong support and drivers from the very top – the NHS Five Year Forward View (2014) and NHS Long Term Plan (2019) highlight the need for co-production.[39] Patient partnership groups aim to recognise ‘experts by experience’ and support them in becoming equal partners in co-production of patient-centred services.

The roll out of e-health – patient held records and stratified follow-up – will further empower patients to take control of their health and facilitate peer support.

DAFYDD'S STORY

My experience of mental and emotional challenges during my cancer journey

Dafydd Charles

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.

DAFYDD'S STORY

> *A support worker at Penny Brohn suggested I agree to counselling by one of their accredited therapists, which they offered as part of the service. I agreed.*

Unfortunately, over the next few months my PSA started to rise again, and as a result my medical team recommended I have follow-on treatment (over the next two years as it turned out) in the form of hormone deprivation, chemotherapy and radiotherapy. A support worker at Penny Brohn suggested I agree to counselling by one of their accredited therapists, which they offered as part of the service. I agreed. This allowed me to be honest and feel normal throughout my unfolding personal crisis. It was the first time I felt the benefit of talking to a compassionate stranger and it was very helpful indeed. It was also at this time I learned the benefit of putting things on hold – postponing issues that I could do little about – and concentrating on things I could (stress management, diet, fasting, exercise, etc). The time I spent on problem solving was considerable, and it also helped me to keep me from ruminating and worrying. As a result I believe I avoided the trap of what is called secondary suffering (reflecting excessively and worrying about my situation rather than managing it as well as I could). Whilst having radiotherapy (and living) in London towards the end of my treatment regime I engaged a personal trainer, and this transformed my view of how resilient the body can be, the importance of managing physical as well as mental challenges and how each can support the other.

My overall treatment, which was successful, lasted nearly three years, and after it ended, I began to feel a bit lost and rather guilty about this. I felt I had done my research into healthy lifestyle, etc, and had started re-engaging in what I hoped would be normal life. My deliberately proactive and problem solving self-help activities focussed on helping me recover from cancer had come to an end, but I was unaware of the emotional tsunami that was heading my way… Over the next few weeks I started experiencing severe and sometimes frightening mood swings, and intense emotional reactions to seemingly innocuous triggers. These would take me unawares. I sometimes felt embarrassed as I couldn't explain to concerned family members and onlookers what was going on in my head. I was also having needless arguments with my wife, and I felt very reactive and sensitive. Fortunately, these rather surprising difficulties (to me, anyway) were picked up at the Churchill Hospital during a consultation for a minor scare, some months after the end of my radiotherapy. I was referred for psychological support under what I discovered later was called the Depression Care for People with Cancer (DCPC) treatment programme. This involved different types of talking therapy and supporting medication. What was impressive about this is that I did not need to ask for help from my cancer care team; the need for it was picked up as a matter of routine, and treatment was offered. I felt worn out, mentally as well as physically, at this point in my cancer treatment, which had started over two years previously, so I was very grateful that my distress had been picked up like this. The therapies that were planned and then started about a fortnight or so later helped me a lot, and again I felt the benefit of talking to receptive professionals, who listened and treated me compassionately. I was able to acquire awareness of future looming difficulties and ways to manage them. Now I'm happy to say I am living a life I would describe as new normal and thankfully, stable.

> *Over the next few weeks I started experiencing severe and sometimes frightening mood swings, and intense emotional reactions to seemingly innocuous triggers. These would take me unawares.*

11.1. Patient Partnership Group (PPG)

The Patient Partnership Group (PPG) was formed for TVCA in November 2021. The membership of the PPG represents a diverse range of people who have lived experienced of using cancer services to provide a dependable community voice and to influence future service plans.

Box 1. Purpose of PPG

AIMS OF PPG: 6 AREAS

Input and feedback
Collectively to provide input and advisory feedback to the TVCA Executive Board on work program activities and how proposals may have or are having an impact on cancer patient care.

Accountability
To hold TVCA to account through review and scrutiny, providing assurance that, as far as possible, the views of the public are considered in the planning, operation, and evaluation of TVCA's program of work.

Monitoring
To consider TVCA's patient and public engagement, by overseeing the implementation of TVCA's communications and patient engagement strategy, as well as associated action plans.

Develop policies
To contribute to the co-development of policies and procedures that affect cancer patients, in line with TVCA's program of work and NHS Long Term Plan objectives.

Support transformation going forward
To act as a central resource to support the co-design of future cancer services, through a variety of cancer transformation projects, to ensure that the needs of the local population are considered and met.

Continued support and insight
It will also work to promote better collaborative working between health professionals, those who have had lived experience of cancer and wider community services, to gain better insight on the impact that cancer has on the whole of a patient's health journey and not just focusing on diagnosis and follow up treatments.

11.2. National Cancer Patient Experience Survey (NCPES)

The first National Cancer Patient Experience Survey (NCPES)[40] was undertaken in 2010 and annually since 2012 to review the quality of cancer care provided across all NHS hospitals in England. In the absence of more granular data, the NCPES provides a broad overview of the quality of cancer care.

Respondents who identified themselves as having comorbid mental health conditions were least likely to report receiving the right level of support for their overall health and wellbeing from hospital staff. (62.8% as compared to 77.5% of respondents who reported having other long term conditions). This group also were the least likely to report that their family/ carers were given information to care for them at home.

Despite the TVCA scores being similar to the national average, the data suggests that a large proportion of patients do not have access to emotional support.

Results of 2021 NCPES comparing adjusted TVCA data to national average on 3 selected questions around psychological comorbidity

Full data available at https://www.ncpes.co.uk/2021-alliance-results/

		TVCA		England	
No.	**Question**	no. of responses	**adjusted score**	no. of responses	adjusted score
35	**Patient was always able to discuss worries and fears with hospital staff**	781	**71.6%**	25,365	66.8%
50	**During treatment, the patient definitely got enough care and support at home from community or voluntary services**	677	**50.2%**	22,671	51.5%
53	**After treatment, the patient definitely could get enough emotional support at home from community or voluntary services**	379	**35%**	12,846	**31.9%**

11.3. Patient survey

We sought to further understand issues that make people with cancer engage (or not) with psychological support, especially during treatment and how to make services more acceptable and accessible to them.

See Appendix 10 for Survey questions

We reviewed the existing National Cancer Patient Experience Surveys with the aim of complementing the data routinely collected. This involved engaging people with cancer as well as Macmillan Engagement Leads, Cancer Nurse Specialists and Cancer Champion Volunteers in formulating the electronic survey. Catriona Gilmour-Hamilton, research and quality coordinator/ lead for patient and public involvement in medical education, University of Oxford provided useful feedback on the questionnaire and directed us to the National Blood Cancer Survey 2019 that had a section about psychosocial support.

The questions were framed based on the WHO criteria of Health Care Quality[41]: timely, equitable, integrated and efficient care.

- How are these issues being addressed? How can we reach out to under-served communities? E.g. Health & Wellbeing Events, telephone contact by support groups?
- How can we work with primary care, the voluntary sector and increase community engagement? E.g. cancer champions, to support under-served communities, to improve psychological support?
- As well as focusing on the most vulnerable, the broader domain of equity - considering whether services are being offered equitably to all patients.

RESULTS

The electronic survey was sent out to Macmillan engagement leads who in turn forwarded them onto patients and their families in the TVCA region. Despite several reminders, response rates were low and the survey closed with 20 respondents.

This severely curtails the generalizability of our findings. Out of 20 respondents (12 women and 8 men), 55% were aged 40–64 years, 45% were aged 65–79 years. Most (85%) identified as White British, with the rest (15%) identifying as Mixed, Black Caribbean and Asian. The primary language spoken was English, which was not thought to be a barrier for any respondent. 15% considered themselves as being disabled. A summary of the results is presented on the next page.

SUMMARY OF SURVEY RESULTS

> *"I really felt the need for information, as well as reassurance, from the Macmillan nurses was really great."*

> *"It is important that information on psychological support is offered to all with a cancer diagnosis, and then people that would like to access it, can receive support"*

> *"Talking to other patients who have been through a similar experience, has been beneficial- one to one, not in a group."*

At time of diagnosis

100%

of respondents felt distressed at the time of diagnosis

50%

were not informed of the available psychological support

Who did they talk to about their distress?

- Oncologist (1)
- Other specialist (0)
- Specialist nurse (8)
- Family/friends (8)
- Charity (2)
- Other (1)

Getting information about support

90%

got information about psychological support from a range of sources

80%

thought the information was sufficient and trustworthy

Where did they get information about psychological support?

- Cancer centre (3)
- Charity (8)
- Face to face (2)
- National website (2)
- Online (1)
- Other (2)
- No information received (2)

Views of psychological support on offer

35%

of respondents accepted psychological support offered to them

What would make them more comfortable receiving support?

- At the same site as cancer care (8)
- Better transport (0)
- Closer to home (5)
- Talking to another person with cancer (6)
- Talking to a charity (6)
- Talking over the phone (4)
- Nothing would make it more comfortable (2)

12

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.

12.1. Staffing structures (March 2022)

BUCKINGHAMSHIRE HEALTHCARE NHS TRUST

Level 4 psycho-oncology services are provided by clinical psychologists, are an integrated part of cancer services in Buckinghamshire Healthcare NHS trust (BHT), they sit within the division of specialist services in BHT.

The Macmillan Clinical Psychology (Psycho-oncology) service is delivered using the Stepped Care Model recommended in the guidance for supportive and palliative care (NICE, 2004):

- Level 4: Macmillan Clinical Psychology in BHT
- Level 3: Macmillan Relate Counselling service in Bucks, outsourced by BHT and funded by Thames Valley Cancer Alliance (TVCA) (ending March 2022)

Level 4 staff

- The Macmillan Principal Clinical Psychologist is a Band 8b Psychologist, working in Oncology & Haematology, is a substantive member of staff and provides a 1 WTE dedicated to cancer care, capacity of 50 patients in the past year.
- This post is commissioned by BHT as part of the block contract for cancer care. This clinical psychologist also provides 0.1 WTE session of that time, to attend the hospital specialist palliative care MDT as a full member and provide ongoing cross-professional supervision for the MDT.
- A Band 8a psychologist, fixed term member of staff (July 2021 to July 2023 - two years fixed term), and provides 0.53 WTE dedicated to cancer care, for a capacity of 25 patients, in the past year. This post is commissioned by TVCA.
- A business case was submitted to BHT, in Jan 2022 for 2 WTE Band 8a clinical psychologists to add capacity and service continuity to the Level 3 and 4 service.

Level 3 staff

- Macmillan Relate Counselling Service, Relate counsellors (accredited in Oncology & Haematology -diagnosis to last year of life). The service was launched in the 2019 - 20, funded initially by Macmillan Cancer Support, then TVCA funded in 2020 - 21 and 2021 - 22. The capacity of the Relate service is 75 clients for relational counselling, individual and couple (patients and relatives). (6 counselling sessions per client, totalling 450 counselling sessions per year).

Level	**Position**	**Band**	How many sessions of psychological support dedicated to cancer care?	How is this post commissioned?	Is it a permanent or fixed term position?	If fixed term, when did the post start and when is it due to end?	If position is fixed term, is there an agreement to continue the post / discussions taken place about renewing funding?	Patient capacity in 2020
4	**Macmillan Principal Clinical Psychologist**	**Band 8b Oncology Haematology (Diagnosis to last year of life)**	1WTE	BHT as part of the block contract for cancer care	Permanent			Capacity 50
4	**Clinical Psychologist**	**Band 8a Oncology Haematology (Diagnosis to last year of life)**	0.53 WTE (term time hours)	TVCA	Fixed term	July 2021 – July 2023 (two years fixed term	A business case has been submitted to BHT, Jan 2022 for 2 WTE Band 8a clinical psychologists to add capacity and service continuity to the Level 3 and 4 service.	Capacity 25
3	**Macmillan Relate Counselling Service**	**Relate Counsellors (Accredited) Oncology Haematology (Diagnosis to last year of life)**	This business case was that Relate would offer 75 clients (patients and relatives), six counselling sessions per client totalling 450 counselling sessions per year	Funded by TVCA FY 2021/2022 Outsourced business model with Relate as the provider. Level 4 specialist psycho-oncology supervision is provided by Dr Rachel Holland with the Macmillan Relate Counsellors.	Fixed Term	Service was launched FY 2019/2020 funded by Macmillan (£15K). TVCA funded FY 2020/2021 and 2021/2022	Yes, discussions are ongoing re service continuity.	Funded for 75 clients for relational counselling, individual and couple (patients and relatives)

Details of the Psychological services provided

Psychological Intervention name	Description-length of session, interval between sessions.	Total Duration of treatment/therapy (on average)	Level	Band of Staff, who can provide it
Adjuvant cognitive behaviour therapy for cancer patients	50-minute session Weekly	6-12 sessions in keeping with guidance and evidence base (Moorey and Greer, 2012)	4	Qualified clinical psychologists in this service.
Cognitive behaviour therapy (CBT)	50-minute session Weekly	Duration in keeping with NICE (2022) Treatment of Depression in adults	4	Qualified clinical psychologists in this service.
Acceptance and Commitment Therapy (ACT)	50-minute session Weekly	Duration in keeping with evidence base e.g. (Harris, 2007) up to 6 sessions for chronic pain and c. 8 sessions for adults with advanced cancer distress (CanACT) (Low et al, 2016)	4	Band 8a and Band 8b are trained in ACT.
Compassion Focussed Therapy	50-minute session Weekly	Duration in keeping with evidence base.	4	Qualified clinical psychologist Band 8a and above
EMDR	90-minute session Weekly	EMDR typically provided over 8 to 12 sessions, but more if clinically indicated in keeping with NICE (2018) guidance for PTSD in adults	4	Band 8b
Interpersonal Psychotherapy (IPT)	50-minute session Weekly	Duration in keeping with NICE (2022) Treatment of Depression in adults	4	Band 8b
Psychobiological Approach to Couple Therapy (PACT) – couple therapy	120-minute session weekly	8 session for couples where there is complexity	4	Band 8b
Supportive expressive psychotherapy	50-minute session Weekly	Typically 6-12 sessions (Classen, 2011)	4	Band 8b
Integrative psychotherapy	50-minute session Weekly	Typically 6-12 sessions	4	Band 8b
Individual relational counselling	50-minute session Weekly	6 sessions + 2 if clinical need	3	Macmillan Relate Counselling Service – this is an outsourced managed service. The counsellors are qualified and accredited to provide the service.
Couple counselling	50 minute session Weekly	6 sessions + 2 if clinical need	3	Macmillan Relate Counselling Service - this is an outsourced managed service. The counsellors are qualified and accredited to provide the service.

Level 2: BHT Cancer and Haem Clinical Nurse Specialists – Level 2 trained - Psychological Assessment and Skills including Problem Solving (Salisbury Model)

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

🟩	**estimate of need Level 1 universal support**	**2407 patients**
🟧	**50% needing Level 2 enhanced support**	**1204 patients**
🟧	**15% needing Level 3 enhanced/specialist support**	**361 patients**
	Current Level 3 workforce (WTE) › 0.6	
	Current capacity › 75	
	Workforce required (WTE) caseload of 120 › 3	
🟧	**10% needing Level 4 specialist support**	**241 patients**
	Current Level 4 workforce (WTE) › 1.53	
	Current capacity › 122	
	Workforce required (WTE) caseload of 80 › 3.1	

GREAT WESTERN NHS FOUNDATION TRUST

Level 4 psycho-oncology services are provided by Avon and Wiltshire Mental Health Partnership NHS Trust via Service Level Agreement (SLA), but are an integrated part of cancer services in Great Western Hospitals NHS foundation trust, they sit within the division of specialist services in GWH.

- Level 4: Clinical Psychologist
- Level 3: Specialist Counsellor

Level 4 staff

There are two clinical psychologists who provide 1.6 WTE dedicated to Cancer Care.

- The 0.6WTE Consultant Clinical Psychologist is a substantive Band 8c psychologist, working in Oncology & Haematology.
- The 1 WTE band 8a clinical psychologist's post consists of a permanent 0.5WTE position and a fixed term 0.5 WTE position commissioned by TVCA and Macmillan. This 0.5 WTE post is funded from Dec 2021 - Dec 2025. Discussions are taking place with the trust about continuing funding on permanent basis.

Level 3 staff

- A 0.7 WTE band 7 specialist counsellor working in oncology and haematology. This post is fixed term until the end of June 2025. Discussions are taking place with the trust about continuing funding on permanent basis.

Level	Position	Band	How many sessions of psychological support dedicated to cancer care?	How is this post commissioned?	Is it a permanent or fixed term position?	If fixed term, when did the post start and when is it due to end?	If position is fixed term, is there an agreement to continue the post / discussions taken place about renewing funding?	Patient capacity in 2020
4	**Lead/ Consultant clinical Psychologist**	8c	0.6 WTE	Trust (0.5 wte previously Macmillan)	Permanent			180 slots offered in total over the year, of which are 30 NPs
4	**Clinical Psychologist**	8a	1 WTE	0.5 WTE Trust (previously Macmillan) 0.5 WTE TVCA and Macmillan	0.5 WTE Permanent 0.5 WTE Fixed term	Dec 21-Dec 25	No permanent funding approved at present.	650 slots offered over the year, of which 105 NP (new patients)
3	**Specialist counsellor**	7	0.7 WTE		The counsellor post is all (0.7WTE) funded by Macmillan now, until end of June 2025		No permanent funding approved at present	600 slots offered over the year of which 70 NPs

Details of the Psychological Services provided

Psychological Intervention name	Description-length of session, interval between sessions	Total Duration of treatment/ therapy (on average)	Level
Psychological therapy (drawing on a range of modalities such as ACT, Psychodynamic psychotherapy, Existential psychotherapy, CBT, CFT, person-centred therapy)	Patients and family members are typically referred by CNSs and consultants. Sessions are 50-60 minutes long and patents are typically seen weekly or fortnightly, for an average of 7 sessions, although this varies depending on the needs of the individual patient	6-8 sessions	**3 and 4**
Pre- and post-transplant consultations for patients undergoing HSCT	Typically, one session pre-transplant and one session post-transplant (after discharge from hospital). Some patients have more at either end of the transplant, if identified as needing additional support. Sessions are 50-60 minutes long.	2 sessions	**4**
Risk reducing breast surgery assessments	Typically, one session, 50-60 minutes long	1 session	**4**
Trauma work using EMDR or CBT	Length depends on needs of patient but are typically 6-8 sessions. Sessions are 60-90 minutes.	6-8 sessions	**4**
Couples therapy	Up to 10 sessions, weekly or fortnightly, 50-80 minutes.	6 sessions	**4**
ACT post-treatment group	Weekly 90-minute long group sessions	6 sessions	**3 and 4**

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

without 1594 skin cancers added in

estimate of need Level 1 universal support **2258 patients**

50% needing Level 2 enhanced support **1129 patients**

15% needing Level 3 enhanced/specialist support **339 patients**

Current Level 3 workforce (WTE) › 0.7
Current capacity › 84
Workforce required (WTE) caseload of 120 › 2.8

10% needing Level 4 specialist support **226 patients**

Current Level 4 workforce (WTE) › 1.5
Current capacity › 120
Workforce required (WTE) caseload of 80 › 2.8

OXFORD UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

The Oxford Cancer Centre has a collaborative care and universal screen model, where all patients from Oxfordshire attending medical and clinical oncology appointments are screened for distress and have access to level 4 services as outpatients and inpatients. Patients with comorbid depression are offered Depression care for people with cancer (DCPC) based on outputs from the SMaRT Oncology randomized controlled trials (RCTs).[42]

Level 4 psycho-oncology services are provided by consultant liaison psychiatrists (0.8WTE). The depression care for people with cancer (DCPC) collaborative care programme is delivered by band 6 care managers (cancer nurse specialists and occupational therapists who have completed 16 week training) (4WTE) and are an integrated part of cancer services in Oxford University Hospitals NHS foundation trust, they sit within the SUWON (surgery, women's and oncology) division.

- Two consultant liaison psychiatrists (0.8 WTE)
- Four band 6 care managers
- 2.8 Band 4 clinical support workers

Level 4 staff

- A substantive consultant psychiatrist working in Oncology is 0.6 WTE with capacity to see 150 new patients and shares supervision of approximately 400 DCPC patients/ year.
- A substantive consultant psychiatrist working with Haematological malignancies is 0.2 WTE with capacity to see 50 new patients and shares supervision of approximately 400 DCPC patients/ year
- There is a substantive consultant psychiatrist in palliative care services (0.3WTE) working with the community palliative care MDT and on the inpatient wards.
- All these posts are permanent, funded by the Trust.

Collaborative care staff

1. The 4 WTE substantive care managers are band 6 registered general nurses and occupational therapists with a background in cancer care each of whom conduct approx. 25 telephone structured clinical interviews for diagnosis (SCID) per week and carry a caseload of 25 active DCPC patients. (capacity of 400 patients/ year)
   All these posts are permanent, funded by the Trust.
2. The 2.8 WTE substantive band 4 admin/ clinical support worker staff proactively contact patients providing symptom monitoring services for physical and emotional distress as well as administrative support to psychiatry and care manager clinics. They make approximately 12000 patient contacts with solid tumours and haematological malignancies/ year.

Please refer to appendices 12 and 13 for an overview of care manager job role and training.

The collaborative care system that has been implemented in the Oxford Cancer Centre does not yet have direct equivalents to classify staff at the 4 levels of care described in the NICE guidelines 2004 but provides an evidence-based, alternative model of care than includes the SMS assistants, care managers and consultant psychiatrists who work in an integrated manner and not as standalone clinicians.

Level	Position	Band	WTE	How many sessions	How commissioned	Permanent or fixed term	If fixed term	Patient capacity in 2020
Collaborative care staff	SMS assistant	4	2.8	37.5 x 2.8 = 105 hrs	Trust	P	N/A	12,000 patient screens completed
Collaborative care staff	Care manager	6	4	37.5 x 4 = 150 hrs	Trust	P	N/A	300
Collaborative care staff	Consultant Psychiatrist		0.6 + 0.2 WTE	8 PAs	Trust	P	N/A	200

Details of the Psychological services provided

Psychological Intervention name	Description-length of session, interval between sessions.	Total Duration of treatment/ therapy (on average)	Level
Depression Care for People with Cancer (DCPC)	Delivery of DCPC follows a detailed manual and comprises a number of treatment elements, as well as coordination of care and monitoring of outcomes. Treatment elements include both antidepressant medication and psychological therapies – problem solving therapy and behavioural activation. Sessions are 50 minutes, weekly or fortnightly. Since the Covid pandemic sessions, some of the later sessions are conducted via video link or on the telephone.	10 sessions over 4 - 6 months	**Collaborative care staff**
Pre- and post-transplant consultations for patients undergoing HSCT	Typically, one session pre-transplant and one session post-transplant (after discharge from hospital). Some patients have more at either end of the transplant, if identified as needing additional support. Sessions are 50-60 minutes long.	2 sessions	**4**
Consultant liaison psychiatrist clinic	Typically, one session, 50-60 minutes long Patients reviewed in this clinic are complex and multimorbid with a range of diagnoses including cognitive impairment, personality changes linked to brain metastatic disease, premorbid serious mental illness such as schizophrenia or personality disorders and eating disorders	2 + sessions – flexible, in order to manage the patient through their cancer journey	**4**

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

estimate of need Level 1 universal support		**4594 patients**
50% needing Level 2 enhanced support		**2297 patients**
15% needing Level 3 enhanced/specialist support		**689 patients**
Current **collaborative care workforce** (WTE)	› 4	
Current capacity	› 480	
Workforce required (WTE) caseload of 120	› 5.75	
10% needing Level 4 specialist support		**460 patients**
Current Level 4 workforce (WTE)	› 0.8	
Current capacity	› 142	
Workforce required (WTE) caseload of 80	› 5.75	

ROYAL BERKSHIRE NHS FOUNDATION TRUST

Currently a level 4 psycho-oncology services is provided to the Berkshire Cancer Centre at the Royal Berkshire Hospital NHS Foundation Trust (RBHFT) by a team of clinical and counselling psychologists. The psychologists are employed by Berkshire Healthcare NHS Foundation Trust (BHFT) Clinical Health Psychology Service.

The psycho-oncology service comprises of a consultant clinical psychologist, who leads the team, and a highly specialist clinical psychologist, and a highly specialist counselling psychologist.

Level 4

A Consultant Clinical Psychologist 0.4 WTE at band 8C and a Highly Specialist Counselling Psychologist 0.4 WTE at band 7 are permanently funded by RBHFT through an SLA with BHFT. Until April 2022 the commissioning/SLA was broken into separate service elements, including 0.4 WTE direct patient care for outpatients at BCC, clinical supervision 0.3 WTE, leadership 0.1 WTE; delivered in a piecemeal way.

From April 2022, temporary funding was put in place to increase the workforce capacity to establish an integrated Psychological Care Team at The Berkshire Cancer Centre. The Consultant Clinical Psychologist has an additional 0.15 WTE sessions, resulting in the post now being 0.55 WTE at band 8C, the Highly Specialist Counselling Psychologist's sessions have increased by 0.2 WTE so their post is now 0.6 WTE at an increased band - 8A. There is a new post, which is Highly Specialist Clinical Psychologist 0.4 WTE at band 8A funded.

These post holders work together as the BCC Psychological Care Team to deliver an integrated service offering patient care, consultation, clinical supervision, and leadership on psychological care.

The funding is in place until 31.03.24. There is process underway to secure the funding in the longer-term for these posts so the integrated service can continue.

Enhanced level 2 psycho-social support is provided by the Berkshire Cancer Centre Cancer Rehabilitation Service. This is an integrated rehabilitation and psych-social support team comprising of CNSs specialising in cancer rehab, support workers, and AHPs. This service has close working relationships with the psycho-oncology service and with My Cancer My Choice, a third section provider of complimentary and holistic therapies and with the Macmillan Information Service. The Cancer Rehabilitation Service also has well established links with Talking Therapies NHS and the RBHFT psycho-sexual counselling service. Level 4 psychologists from the psycho-oncology service are extended members of the Cancer Rehabilitation Service providing supervision to the team and attending weekly MDTs.

Level	Position	Band	Sessions of Psychological support dedicated to Cancer Care	How is this post commissioned?	Permanent or Fixed Term?	Patient capacity in 2020
4	**Psychological Lead BCC**	8C	0.55 WTE	SLA with RBFT	P	
4	**Highly specialist clinical/counselling psychologist 8a 1.0wte (job shared by two psychologists currently)**	8A	1.0 WTE	SLA with RBFT	P	20

	Oncology		Oncology		Oncology-Palliative Care		Palliative-Care	
	Staff who work exclusively with Cancer patients and not palliative Patients		Staff who work exclusively with cancer patients and palliative cancer patients.		Staff who work exclusively within Cancer palliative care		Staff who work exclusively with palliative patients including palliative cancer patients.	
	Staff	Sessions	Staff	Sessions	Staff	Sessions	Staff	Sessions
3	0	0	0	0	0	0	0	0
4	0	0	3	1.55 WTE	0	0	0	0

Details of the Psychological Services Provided

Psychological Intervention name	Description-length of session, interval between sessions.	Total Duration of treatment/ therapy (on average)	Level/ Band of Staff, who can provide it?
SPECIALIST INDIVIDUAL INTERVENTION			
Highly Specialist Psychological Assessment and Intervention for Individuals with Cancer	Patients referred by nurses/oncologists. 50-min sessions, typically fortnightly.	Average 8 sessions per patient	8A Clinical Psychologist (0.4 WTE) 8A Counselling Psychologist (0.6 WTE) Consultant Clinical Psychologist (0.55 WTE)
GROUP INTERVENTION			
Mindfulness Group (in-person and online courses)	1-hr sessions weekly	8 weeks	Complimentary Therapist (charitable funding)
Art Therapy for Groups	1-2 hours, frequency unknown.		Art Therapist
Relaxation Session (online group)	1-hr session	Every 6 months	Cancer Rehab Nurses
EDUCATIONAL AND PSYCHOEDUCATIONAL GROUPS			
Sleeping Well	1-hr session	Every 6 months	
Cancer and Psychology	1-hr session	Every 4 months	Clinical Psychologist
Coping with Endocrine Treatments	1-2 hr session	Every 2 months	Clinical Psychologist and Senior CNS
Psychosexual Concerns and Cancer	1-hr session	Every 6 months	Psychosexual Therapist
‘Take Control’ Workshop	1 full day session. Dealing with sleep problems, managing stress, managing fear, goal setting. In person and on-line versions	Every month	Nurse facilitator (Band 7)

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	
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	

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

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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[43,44] including the Salisbury model[45] and standards have been set out by the National Cancer Peer Review Programme in 2008.[46]

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.

▸ **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.

BUCKINGHAMSHIRE HEALTHCARE NHS TRUST

30.2 WTE

cancer specialist nurses

Level 2 training and supervision to CNSs was delivered by the Macmillan Clinical Psychology Service.

- In May/June 2022, comprised three-days of training for up to 25 participants. 16 Hours of training were provided by the service.
- The number of Level 2 staff members participating in training were 145 (Estimated, without retrospective access to attendance information from partner organizations).
- In 2020 -21 the supervision delivered by 1 WTE Band 8b. A final year trainee (Band 6, 0.6WTE) from the Oxford Doctorate in Clinical Psychology Course joined supervision from March 2020 – September 2020. In 2020 -21, the number of level 2 staff members who participated in supervision were 16. (The Level 3 service remit did not include teaching and training or supervision.)
- 28 Hours of supervision were provided by the service for Level 2 trainees. (For context, in the previous financial year, pre-pandemic, 110 hours had been provided)

Psychological care lecture as part of "The Fundamentals of Cancer Care Module". This University level module is run in partnership with BHT and Oxford Brookes University once a year; recent dates were January 2020 and September 2021.

Health and Wellbeing event (online) - September 2020 – "Emotional care and support for people affected by cancer".

Cancer Care Review Launch and Training event (BCCG) for GPs/Primary care staff in Bucks. "Psychological care for cancer patients and their families in Bucks – Stepped Care Model" (Nov 2020)

Staff support webinar- Suicidality and risk in cancer patients

TRAINING, LECTURES, AND WORKSHOPS

- Intro to Psycho-oncology
- Psychological care in Haematology
- Psychological Issues in Cancer
- Psychological Adjustment in Cancer Care and Haematology
- Psychological care pathways - understanding the Stepped Care Model
- Cross professional supervision model - Process Framework

SUPERVISION BY LEVEL 4 PROVIDERS

- Cross professional supervision model - Process Framework. Group and individual
- Cyclical model of supervision - Group and individual

ADDITIONAL ACTIVITIES PROVIDED

- Gynae Support Group
- Upper GI Support Group
- Medical Students - University of Buckingham Medical School
- BHT Cancer Care and Haematology Service – Study Day
- Oxford University – Doctorate in Clinical Psychology Course:
  - Psycho oncology lecture
  - Cross-professional models of supervision within MDT in physical health
  - Models of adjustment to physical health conditions
  - Models of reflective practice
  - Reflective practice sessions for the final years

GREAT WESTERN NHS FOUNDATION TRUST

45.15 WTE
cancer specialist nurses

Level 2 group training & supervision is being offered to Patient Pathway Facilitators (PPF) & CNSs, who have undertaken advanced communication skills training.

In 2020, level 2 supervision by level 3 or 4 practitioners was paused, due to staff shortages and the pandemic.

Going forward, there will be approximately 90 hours of level 2 supervision and 30 hours of level 2 psychological skills training on a yearly basis. The level 2 training package has been developed locally. It draws on some aspects of the Salisbury model and the SWAG model but is mainly independently developed. It covers psychological distress, listening skills, psychological assessment, psychological intervention strategies, existential concerns, health inequality, self-care and onward referral.

ADDITIONAL ACTIVITIES

- Level 3 and 4 professionals provide support for the Personalised Care Team Health & Wellbeing workshops covering strategies for coping with the impact of cancer, twelve times per year.
- Training and supervision to ‘cancer volunteer buddies’ around communication skills and having difficult conversations.
- Preventative psychological wellbeing half-day events for people with cancer.

OXFORD UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

77.17 WTE

cancer specialist nurses (includes acute oncology, onc and haematology, excludes palliative care)

There are 51 WTE band 6/7 staff, 10 WTE band 4 cancer support workers. Level 2 psychological support training is offered and encouraged as a core skill to all the CNSs. The training is delivered by Oxford Brookes University. Currently 85% of the CNS workforce have completed this.

- All staff undertake level 2 psychological training module for CNSs at Oxford Brookes University. Psychological level 2 training and supervision module was delivered at Oxford Brookes by level 3/4 practitioners for 6 study days over a 3-month period in 2020-21.
- Support sessions are available on a 1:1 basis, arranged by the lead cancer nurse. These are arranged as required.
- Psychological medicine care managers offer monthly supervision groups. It is not compulsory for CNSs at present.
- In 2020-21, an hourly group session each month (12 HRS) of supervision were delivered by level 3/4 practitioners attended by 27 level 2 CNSs.

ADDITIONAL ACTIVITIES

- ‘Introduction to psycho-oncology’ is part of induction for all new junior doctors starting rotations in Haematology and Oncology. (This includes Foundation doctors, core and advanced trainees) – around 6 X 1 hr sessions/ year).
- Ad Hoc multidisciplinary reflective groups are run 2 -3 times/ year following on from managing complex comorbid patients, especially on the inpatient wards, facilitated by TYA Psychologist.
- Level 4 clinicians contribute to and actively participate in monthly oncology clinical governance and morbidity & mortality meetings
- Approximately once a year cases that present particularly challenging or complex ethical issues are taken to the Clinical Ethics Advisory Group for OUH to help explore therapeutic options.
- The team also contributed to staff wellbeing sessions at the start of the Covid pandemic.

ROYAL BERKSHIRE NHS FOUNDATION TRUST

21.22 WTE
cancer specialist nurses

48 hours of group supervision are provided to Oncology CNS and support workers annually by level 4 psychologists.

Groups are delivered monthly. Membership is fixed but CNSs are given choice of which group allows them to accommodate clinical commitments. CNSs are offered a choice of either online or F2F groups.

Clinical supervision is semi-structured to promote case base discussion and the development of psychological skills.

Individual hourly supervision is also provided on 'as required' basis. On average 3 sessions per month are delivered.

24 hours of individual supervision are delivered on an individual monthly basis to the Lead CNSs at the Berkshire Cancer Centre.

Level 2 training

The most recent Level 2 trainings were in 2021 where training was delivered to eight Level 2 staff members and in 2020 to eleven Level 2 staff members.

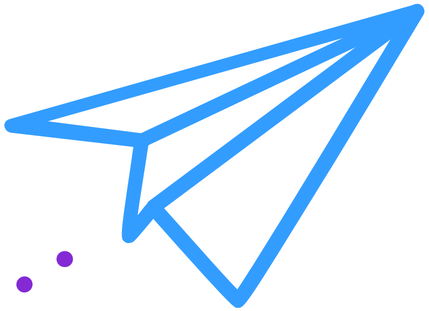
The approach to level 2 training has been to deliver a model developed by The Barts NHS London Clinical Health Psychology Service, which incorporates the Salisbury Model – a combination of CBT approaches and using a non-pathological model for assessment which is called 'the 3 Ss' –Stuck, Safety and Suffering.

A further course is in the pipeline for 2023

Level 2 training updates are delivered to the whole of the CNS body on four topics per year for Berkshire Cancer Centre.

14

Summary of psychological services across trusts



14.1. Incidence of cancer and population by trust (September 2022)

		Buckinghamshire Healthcare NHS Trust	Great Western Healthcare NHS Foundation Trust	Oxford University Hospitals NHS Foundation Trust	Royal Berkshire NHS Foundation Trust
Number of new cancer diagnosis (NHS digital data, excludes skin cancer)	**2019**	2179	2036	4161	2611
	2020	1952	1864	4087	2205
Total population in trust catchment area (census 2021 data)		407,306	354,973	835,548	452440

14.2. Provision of service

	Buckinghamshire Healthcare NHS Trust	Great Western Healthcare NHS Foundation Trust	Oxford University Hospitals NHS Foundation Trust	Royal Berkshire NHS Foundation Trust
HNA care plans finalized in FY 20/21 with care plan (Macmillan Data)	240 Updated Data –FY 21/22- 1117	HNA at Diagnosis - 807 HNA at End of Treatment - 549 Total 1356 (20/21)	1196	913
When is HNA being done along the pathway of patient care	Within 6 weeks of cancer diagnosis, carried out by CNSs	• Within 6 weeks of cancer diagnosis, carried out by CNSs • Before Discharge by CNSs.	Within 6 weeks of cancer diagnosis, carried out by CNSs.	Within 6 weeks of cancer diagnosis, carried out by CNSs
Personalised care plan locked as a percentage 2021	67%	84%	76%	93%
SMS screening (OUH Data)			4711 (6/12 -Aug 2021 -Jan 2022)	
Types of Psychological support	• Variety of psychological interventions including Adjuvant CBT, CBT, ACT, CFT, EMDR, IPT • PACT – couple therapy • Supportive psychotherapy • Integrative psychotherapy • Systemic	• Variety of psychological support including ACT • CBT • Mindfulness • PCT • CFT • Existential Psychotherapy, Psychodynamic psychotherapy.	• Specialist liaison psychiatry clinics for diagnosis and management - medication, CBT, PST	• Variety of psychological interventions including act • CBT Systemic psychotherapy integrative therapy.
Liaison psychiatrists dedicated to support cancer patients	No	No	Yes	No
Psychologists dedicated to support cancer patients	yes	yes	no	yes
VCSEs= Voluntary sector & community engagement-specific for cancer	Cancer Education, Information & Support Services (CEISS) - linked to cancer specific charities	• Cancer buddy scheme • Local charities	Maggie's centre with 2 clinical psychologists, support workers/ counsellor, benefits advisor Hummingbird Centre, Bicester	• Cancer partnership groups • Cancer champions

	Buckinghamshire Healthcare NHS Trust	**Great Western Healthcare NHS Foundation Trust**	**Oxford University Hospitals NHS Foundation Trust**	**Royal Berkshire NHS Foundation Trust**
Level 2 provision				
CNSs total sessions dedicate to cancer care-approx.	30.2 WTE	45.15 WTE	77.17 WTE	21.22 WTE
No. of CNSs who have completed level 2 psychological care training	2021: 145 (includes partner organisations)	2021: 10	2021: 27	• 2020: 11 • 2021: 8
Level 3 provision				
Level 3 total sessions dedicated to cancer care /equivalent	Macmillan Relate counselling service	0.7 WTE	N/A	0.6 WTE
No of new patients seen by Level 3, in last financial year	Funding for 75	55	N/A	Approx 56
Level 4 provision				
Level 4 total sessions dedicated to cancer care. Total WTE	1.53 WTE	1.6 WTE	0.8 WTE (2 Consultant Psychiatrists)	0.83 WTE
No of new patient seen by Level 4 approx. in the last financial year	75	147	Psychiatrists: 114	121

Collaborative care	
patients	423

14.3. Training and supervision capacity

	Buckinghamshire Healthcare NHS Trust	Great Western Healthcare NHS Foundation Trust	Oxford University Hospitals NHS Foundation Trust	Royal Berkshire NHS Foundation Trust
Training and Supervision provided to CNSs by Level 3 or 4 2020/2021	• 28 hours • Pre-pandemic 110	• 90 hours in future • 13 hours per person.	Once a month for an hour. (12 hours)- facilitated by band 6 care manager	• 90 hours-Oncology CNS & support workers • 12 hrs-individual supervision
How many CNSs participated in training and supervision 2020-2021	• Supervision- 16 • Training- 145	None	27	2020-22 2021- 8
Supervision to any staff groups (AHPs - radiographers/ pharmacists/ Pas)	No	No	No	No

LAURA'S STORY*

narrated to Dr. Anna Lagerdahl

A young woman in her 20s, diagnosed with lymphoma. Referred to psychology while an inpatient at the hospital, not too long after diagnosis because of heightened feelings of psychological distress (mainly anxiety). Support was provided throughout treatment to enable patient to manage the psychological distress she experienced in relation to having chemotherapy.

Psychological therapy drew on a range of different therapeutic approaches but mainly Acceptance and Commitment Therapy (ACT) and Compassion Focussed Therapy (CFT). After treatment had ended, psychological therapy continued as Laura was experiencing many of the psychological challenges associated with end of treatment, such as fear of recurrence, loss of identity, loss of meaning & purpose, and 'feeling stuck'. Psychological therapy continued to draw on ACT and CFT.

At some point Laura reported having flashbacks and nightmares associated with hospital appointments and treatment. Psychological therapy switched to EMDR for 6 sessions, followed by 2-3 ending sessions using previous approaches. Laura reported improvement in mood, reduction in anxiety, flashbacks and nightmares, increased sense of identity, meaning and purpose, and generally feeling better equipped to deal with the longer-term effects of cancer.

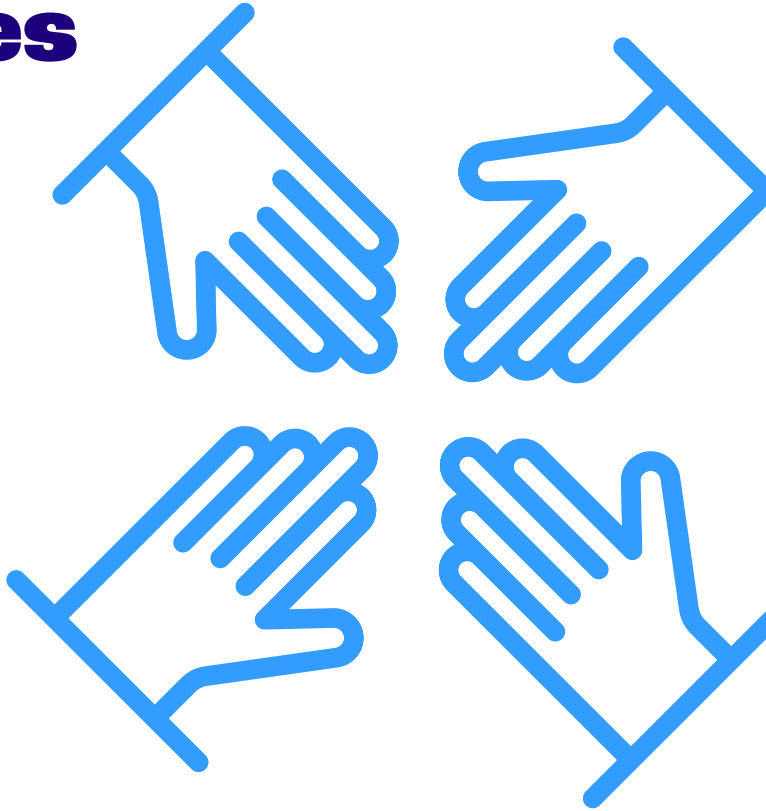
**patient's name has been changed*

14.4. Specialist psychological care and patient feedback

	Buckinghamshire Healthcare NHS Trust	**Great Western Healthcare NHS Foundation Trust**	**Oxford University Hospitals NHS Foundation Trust**	**Royal Berkshire NHS Foundation Trust**
Child, Teenage Young Adults, Psychosexual & Neuropsychology Teams	A new role has been created where we offer 0.2 wte band 7 clinical nurse specialist support to our small population of TYA with a diagnosis of cancer. This is supported by a medical lead for the Trust who offers 1 PA to support.	N/A	• A Band 8a member of staff providing 0.6 WTE dedicated cancer care for 16–25-year-olds at Oxford University Hospitals. • There is clinical psychologist and two psychosexual therapists (COSRT accredited) working in the Psychosexual Clinics at Oxford University Hospitals. • A Band 8b member of staff providing 0.4 WTE dedicated cancer care for paediatric neuropsychology patients with brain and CNS tumours at Oxford University Hospitals. • A Band 8a for providing 0.5 WTE, dedicated cancer care for other Thames Valley paediatric patients • A Band 8c providing 0.3 WTE, dedicated cancer care for service lead/Thames Valley patients	• There is a psychosexual therapist available.
Patient feedback	• National Cancer patient experience survey 2021 • Friends and family test • BPS recommended questionnaires	• National Cancer patient experience survey 2021 • Friends and family test • Feedback questionnaires after input.	• National Cancer patient experience survey 2021 • Friends and family test • Paper/email- ad hoc	• National Cancer patient experience survey 2021 • Friends and family test • Paper survey 2020: 436 responses

15

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,[47] 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.

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.

Description of the role of a Nepalese Cancer Champion narrated to Nisha Sharma.

Mrs. A, a Nepalese woman in her 70s was diagnosed with lung cancer in April 2022. She had been caring for her husband who had been diagnosed with multiple myeloma in June 2018 and also their disabled adult son. They do not speak English and are not very literate in Nepalese either.

Jau Kumari, who was trained as a cancer champion in 2018, first met the family after Mr. A was diagnosed with myeloma and supported them at this difficult time. As a cancer champion, Jau had training on the impact of cancer and ways of supporting patients and their families. She has been regularly supporting them in different ways, especially since Mrs. A became unwell and was unable to fulfil her carer role. Once Mrs A was diagnosed with lung cancer, she reported that her whole life had been turned upside down as there was nobody to take care of her husband which she saw as her duty.

Support that Jau Kumari provided included:

- Arranging appointments with the hospital and GP
- Accompanying and helping them communicate with cancer nurse specialists, cancer doctors and GPs.
- Clarification of treatments on offer and medication
- Helping fill out forms (for example, for benefits such as carers allowance)
- Shopping, at times even cooking

"Mrs A has been waiting for me, If I am late for some reason, she asks why I am late. I spent my time making cup of Milo with milk for both Mr and Mrs A and I try to make them happy"- copied from Jau Kumari's note.

At one point, Mrs A reported not being given her immunotherapy and she was not sure why. She wondered if this was because the treatment was not working for her and if this meant it was the end of life for her – Jau helped clarify this with the cancer nurse specialists.

Despite the challenges and emotional demands (Jau Kumari herself lost her husband in 2022), she wants to continue to learn and support people with cancer. She attended the cancer champion update provided by the project in Jan 2023. The couple got through cancer treatment supported by Jau.

Some of the questions for Jau Kumari that arose from problems facing Mr and Mrs A that she helped address were:

- How to access care at home when they are unable to support each other?
- How to get families who don't speak English access to the services and ensure good communication with health professionals?
- What happens if the patients cannot access interpreters?

Being a member of same (minority) community, Cancer Champions like Jau Kumari play vital roles in supporting people with cancer and help improve their health and wellbeing. This project aims to provide solutions to these issues

Summary of findings

① There is currently no clear psychological care pathway for cancer patients in the community.

② There is limited information on the capacity & skills of the providers of psychological care support in the community.

③ There are limited resources available for psychological care, especially low-grade emotional distress in the community.

④ There is no reliable data available on the psychological support received by patients in the community.

⑤ The communication between the psycho-oncology service providers and primary care has been poor.

⑥ The End of Treatment summaries provided to the GP from the cancer centre are sometimes delayed.

⑦ Cancer Care Reviews are not always done by the GP in the Practice.

15.1. Macmillan GPs / Cancer Care Reviews

See Appendix 11 for Survey Questions

Semi-structured telephone interviews were conducted with five Macmillan GPs from CCG areas covered by the TVCA in July 2022 to explore their perceptions on current provision and gaps in psychological care available to people with cancer in the TVCA region.

15.2. Cancer Care Reviews

Cancer Care Reviews are carried out by GPs or practice nurses to support patients after their cancer diagnosis. The primary care Quality Outcomes Framework (QOF) requirement for 2021/22 are two reviews – one within 3 months of the cancer diagnosis and another within 12 months of completion of acute treatment. Given the pressure on primary care staff, CCR nurse facilitators have been recruited across the integrated care system (ICS) regions to support staff.

> *“There is not much indication of what level of support is available, with IAPT”*

> *“The PCP are not seen by the GP always unless there is an action plan.”*

> *“There is no communication between IAPT and the GPs. Often we do not know that the patient has been seen for psychological support”*

> *“Personalised care plans (PCP) are sometimes delayed”*

15.3. IAPT Long term conditions (Cancer Specific)

The NHS Talking Therapies, for anxiety and depression programme (formerly known as Improving Access to Psychological Therapies, IAPT) programme began in 2008 as a bold initiative to provide evidence-based psychological treatments for adults with anxiety disorders and depression in England after two initial pilot projects in 2006.

The IAPT pathway for People with Long-term Physical Health Conditions and Medically Unexplained Symptoms was launched in 2018 as an extension of IAPT to help manage patients with complex comorbidity and as a way of linking IAPT services with liaison psychiatry, specialist health psychology and other specialist physical health services such as pain and sleep services. The evidence for IAPT outcomes with anxiety and depression have been growing – a recent meta-analysis suggests that it enables access to broadly evidence-based treatments to large numbers of people.[48] The CanTalk trial suggested that it is feasible to deliver CBT through IAPT proficiently to people with advanced cancer, but this is not clinically effective.[49]

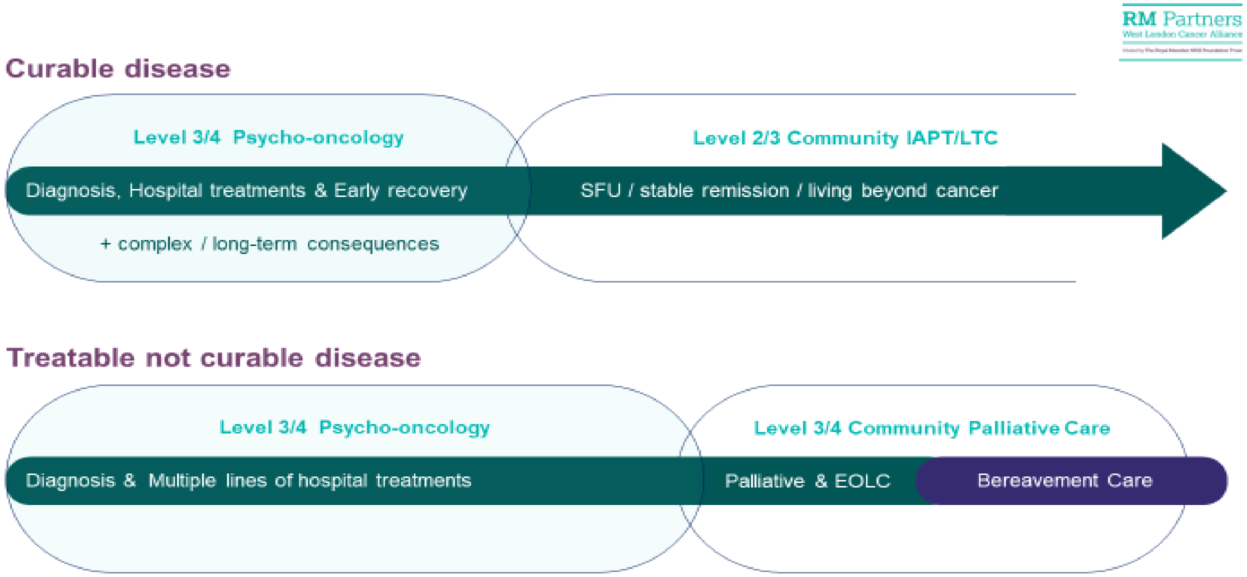


Figure 6. Standards for Psycho-oncology are defined by NICE IOG 2004 and London TCST Commissioning Specifications 2020- RM Partners-West London Alliance-hosted by the Royal Marsden NHS Foundation Trust

Several projects about the comparative experience of patients who are seen by local IAPT LTC services versus in-house psycho-oncology teams are being undertaken. These aim to establish which patient profiles benefit from the services and at what time in the illness trajectory. Please see details of the Bucks pilot project on the next page.

The pathway of the patient who has a curable disease and is living 'beyond cancer', is shown in the flow diagram above. This shows the development of a Level 3 integrated care pathway, within primary care for cancer patients. Standards for Psycho-oncology described by NICE CSG 2004 and London TCST Commissioning Specifications 2020, highlighted by RM partners, West London Cancer Alliance.[50]

The NHS Long Term Plan highlights the importance of a comprehensive IAPT offer for long term conditions (LTC) – as a result, Integrated IAPT services are being developed with a focus on supporting people with LTCs. These services focus on providing direct interventions for anxiety and depression in the context of a LTC, and cancer is now coded as a

LTC within Integrated IAPT services. The 2022/23 Planning Pack for Cancer Alliances asks Alliances to work with local IAPT mental health services to promote availability of IAPT Long Term Conditions programs for people affected by cancer.[51]

PILOT PROJECT

Buckinghamshire NHS Trust are conducting a pilot project which will run for 2 years, beginning in October 2022. The proposed model is an integrated partnership model between the BHT (Buckinghamshire Healthcare NHS Trust) Macmillan Clinical Psychology Service and Oxford Health NHS Foundation trust in Bucks, Healthy Minds/IAPT to create a stepped care psychological care pathway for cancer as a Long-Term Condition. Training and supervision of primary care staff will provide level 2 support for patients. In the first year it will be for Cancer Care Review practice nurse (PCN) facilitators, plus PCN or practice cancer champions and in the second year there will be ongoing training and supervision.

PROPOSED OUTCOMES

1000 patients will receive level 3 and 4 support. It is anticipated that patients will live well with cancer and beyond, experience an improvement in quality of life.

- Creation of training packages – Introductory and advanced skills
- IAPT cancer trained work force
- Bolstering of level 2 provision in primary care which will:
  1. Provide ongoing support for patients in primary care
  2. Improve identification of patients with increased needs and appropriately refer on for additional support
  3. Support patients following level 3 and 4 psychological interventions

INTENDED PLAN

LEVEL 2 service	• Will be provided by current primary care staff (GPs, AHPS and nurses). • Training and supervision of primary care staff will be provided by clinicians with Level 3 skills based in IAPT.
LEVEL 3 service	• Will be provided by Healthy Minds (IAPT) via a separate funding stream commencing FY 21/22 as part of the long-term conditions (LTC) pathway. • Training and supervision of Level 3 clinicians will be provided by clinicians with Level 4 skills
LEVEL 4 service	• Will continue to be provided by the current BHT Level 4 service • Implementation of this plan will result in an increase in Level 4 referrals. This plan aims to increase the Level 4 capacity.
Training levels	**Introductory level**: Training for GPs, AHPS and nursing staff on identifying distress in cancer patients and making appropriate onward referrals. This is provided by clinicians working in IAPT. **Advanced level**: Training for GPs to assess and work with anxiety and depression in the context of cancer as a long-term condition. • IAPT LTC Cancer Care • In other TVCA areas there are no intended IAPT services planned specifically for cancer, though some areas like West Berkshire have historical links between IAPT and health psychology.

15.4. Third Sector / Voluntary Sector & Community Engagement Services (VCSEs)

At a time when NHS services are stretched and struggling to provide timely input to patients and families, VCSEs and peer support networks provide practical support to people with cancer and their families that can complement those provided by the NHS.

The Psychosocial Support Toolkit March 2022[52] states:

"While not a substitute for NHS commissioned services, VCSE organizations provide a huge range of psychosocial support services to people affected by cancer across England, and many cancer charities are specialized in supporting groups, for example based on cancer type/ stage, age, ethnicity, sexuality, pregnancy, people coping with long-term consequences of cancer and its treatment or bereaved people."

Cancer teams should have an accessible list of available third sector services and review it annually, to ensure that information stays up to date and accessible and all new staff know where to find it. Charities must endeavor to have adequate capacity to deliver support of good quality. Signposting and referral to appropriate VCSE sector services and sources of peer support are essential elements of high-quality care, as they can empower individuals to take control of their care and wellbeing.

As well as pointing to national VCSE organizations, psychosocial pathways should include local and community-based services and support such as:

- peer support - 1:1 or in groups (in person, telephone or online)
- places to meet (such as cancer support centres run by national or local charities)
- classes, workshops, or presentations
- support and activities not specific to cancer, such as for health and wellbeing or support for return to employment.

The Cancer Care Map (see page 92) and Macmillan's 'In Your Area' databases allow people affected by cancer to search by postcode for relevant services and groups. (see chapter 16 on page 91)

Patients from ethnic minority populations face specific challenges, see page 37 for a summary.

15.4.1. General patient support

Patient Engagement Services

Macmillan Health and Wellbeing Events are education and support events, to prepare the person for the transition to supported self-management. The events include advice on the relevant consequences of treatment and the recognition of issues, as well as details of who to contact to seek help. They also provide information and support about work and finance, healthy lifestyles, and physical activity. The events are supportive, group occasions that provide information, signposting and contact with peers. Their aim is to help patients move on after treatment and assist with the emotional impact of this transition.[53]

https://www.macmillan.org.uk/documents/aboutus/health_professionals/macvoice/health-and-wellbeing-events-sharing-good-practice.pdf

LGBTIQ+

Part of this work is to ensure that consideration is given to those from minority groups, including the LGBTIQ+ community. OUTpatients (formerly 'Live Through This') is a charity that supports and advocates for Lesbian, Gay, Bisexual, Transgender, Intersex and Queer communities when they are affected by cancer.[54]

https://outpatients.org.uk/

15.4.2. Specific support

See Appendix 6 for cancer support groups

BUCKINGHAMSHIRE HEALTHCARE NHS TRUST

Cancer services in BHT have a successful record of working with Cancer Patient Partnership groups (CPP). They have been a driving force in developing the psychological services and include the following:

- Macmillan CAB outreach advisor, wig supply and fitting services, cancer support outreach team.
- The HOPE course in Bucks has five trained facilitators, to help run easy to access, face to face courses available to all patients. The main aims are to provide patients with strategies to cope when living with cancer, once discharged from active treatment, to help improve quality of life. Pre-pandemic there were complementary therapists and creative arts sessions for patients and relatives and support groups run in the unit.
- There are patient representatives who have their say. They influence and co-design services and support. These patient representatives inform the cancer strategy group and the cancer education and information service steering group at Stoke Mandeville Hospital. There is also a county-wide support groups network.
- Buckinghamshire Healthcare Trust ran a codesigned patient and stakeholder event in autumn 2022 to bring together people living with cancer (PLWC), and partners/stakeholders through a conference event with round table discussions and speakers. This timely event provided the platform for developing patient voice and opportunities for PLWC, including the development of a new cancer patient partnership.

GREAT WESTERN NHS FOUNDATION TRUST

The voluntary sector agencies working with the Trust include:

- Cancer buddy service
- 5KYOURWAY (promoting exercise within park run on last Saturday of each month) in Swindon and Marlborough
- Breast care support groups - Aroura and Ridgeway support groups
- Bladder and Prostate support group
- Swindon Carers
- ‘Look good feel better’ group
- We Hear You community counselling service
- Bowel Support Group, OUH Radiotherapy Macmillan Information Hub and GWH Cancer Partnership Group

OXFORD UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

The Oxford Cancer Centre is fortunate to have Maggie's Centre opposite the hospital, patients and families have access to the calm space (designed as a timber treehouse) and surrounding gardens.

Maggie's

MAGGIE'S

Maggie's Oxford (part of a national network of centres offering free cancer support) is based within the grounds of the Churchill Hospital, and primarily supports patients (and their family members) who are receiving, or have received in the past, treatment at the Oxford Cancer Centre. However, Maggie's has no geographical restrictions on who can access services, and likewise, no requirement for people to have received treatment at the Churchill Hospital, and frequently receive telephone and email enquiries from outside the area and/or people receiving treatment at other hospitals.

Staff providing Psychological Support at Maggie's Oxford:

- 1 WTE Clinical Psychologist; Level 4
- 1 WTE equivalent Centre Head/Clinical Psychologist with 0.5 of the role devoted to clinical psychology; Level 4
- 2.0 WTE Cancer Support Specialists (registered health professionals); Level 1 and 2 support (primarily offered in 'drop-in' on an ad-hoc basis rather than by appointment).

The clinical psychologists offer individual therapy, but also occasionally work with couples or whole families. Patients are seen at diagnosis and all the way through to end of life and sometimes into bereavement. Approaches offered include CBT, ACT, CFT, Solution Focused and Mindfulness Based Cognitive Therapy for Cancer. Group work includes MBCT-Ca, psychoeducational courses including Stress Management, Sleep Improvement, 'Where Now' after treatment, Living with Ongoing Cancer and Bereavement. Maggie's also offer psychology led support groups such as bereavement, living with incurable cancer and a 'family and friends' group.

Throughout COVID some courses, workshops, and groups were adapted to be virtual, and Maggie's have maintained a mixed model of face-to-face and virtual offerings. At the time of writing Maggie's receives approximately 1000 visits per month, which includes virtual and telephone interactions. Maggie's Oxford is funded entirely by charitable fundraising in Oxfordshire.

Hummingbird Centre, Bicester

The Hummingbird Centre
We Stand By You

The Hummingbird Centre is in the village of Launton just outside Bicester, Oxfordshire.

They offer a range of services to people with cancer and their families receiving treatment in the Horton Hospital in Banbury, also patients from Northamptonshire and Buckinghamshire. This includes the counselling service, through a dedicated team of 25 counsellors. All the counsellors are trained and professionally accredited with BACP.

They also offer holistic treatments such as aromatherapy massage, deep tissue massage, Indian head massage, lymphatic drainage, reiki, reflexology, hypnotherapy and deep relaxation.

OXFORD UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

Oxfordshire Oesophageal and Stomach Organisation (OOSO)

OOSO was established in 2009 and subsequently became a registered charity in 2013, with a principal goal to provide support to newly diagnosed oesophagogastric cancer patients in Oxfordshire and the surrounding counties. OOSO is run by volunteers who have survived these cancers, supported by clinicians from the Churchill Hospital in Oxford. OOSO provides a well-used 7-day a week 10am - 4pm telephone listening service, offering empathy and emotional support with practical tips helping patients through their treatment and hopefully into recovery. OOSO also host regular online zoom support group sessions led by former patients and clinicians well placed to answer questions. In addition, OOSO maintains a popular website www.ooso.org.uk and circulates a regular e-newsletter keeping in touch with hundreds of current and former patients, coordinating social events for example monthly 'cafe catch-ups', summer lunches, BBQs and bespoke fundraising events. Because there are so few patient-led OG cancer support groups nationally, OOSO is in regular contact with patients from around the country and abroad.

UCARE (Oxford)

UCARE is a urological cancer charity that supports research into the causes, prevention and treatment of urological cancers and to promote the development of new technologies to improve diagnosis and treatment for cancer patients. Emphasis is also made to educate the public about greater awareness of these cancers and support those with the disease and their families. UCARE sits on the Testicular Cancer Network, The National Germ Cell Group and the Cancer52 Board.

In addition to prostate cancer stratified follow up information sessions and germ cell health and well-being sessions, UCARE offers regular education sessions about testicular cancer at schools across the Thames Valley for 11 - 17-year-olds, GP education days and have started a male partners support group.

Additional activities provided

Health and wellbeing events, prehab school for some tumour groups and support groups for various tumour sites are run within the Trust.

See Appendix 6 for a list of charities and groups run, including local cancer support groups in Oxfordshire.

ROYAL BERKSHIRE NHS FOUNDATION TRUST

The Macmillan Cancer Education Project aims to address the health inequalities and break down barriers in cancer services across all communities (e.g., Polish and Gurkha communities) in Berkshire West. They help to identify cultural and social barriers to both early diagnosis and cancer prevention, increasing uptake of cancer screening (bowel, breast and cervical), raising awareness of cancer (signs and symptoms) are some of the activities included in the project.

The Macmillan Cancer Education Project drives cultural education and community engagement through various events, talks and signposting. The project provides support and links for patients and carers, dealing with issues like financial issues, medication, and appointments before, during and after treatment. The project has recruited and trained community-based cancer champions (CCs) with representation from different communities (Nepalese, Pakistani, African, English, Polish) to contribute towards achieving its objectives. Currently there are 25 Champions. The project has also established Reading Cancer Champions Support Group (RCCSG) to provide the forum for CCs to interact/ network, share experience and learn from each other, they meet quarterly.

16 Information for patients and families

High quality information provision and patient education can increase engagement and involvement in making decisions and greater satisfaction with choices.[55]

The right information at the right time has also been shown to reduce distress and improve coping from diagnosis through treatment. Information provision falls into the following areas:

- cancer type
- treatments available
- prognosis
- research participation and trial drugs
- symptom management
- psychological support
- interpersonal/ social support
- financial advice
- information about health systems and how to navigate them
- rehabilitation
- surveillance

Patients and their families mainly access advice from their clinicians, the internet, print material, peer groups and charities. Research suggests that patients obtain information from trusted sources (such as Macmillan Cancer Support and Cancer Research UK) but depend on and trust their health-care professionals for information, especially with regards to issues pertinent to them through their cancer journey.

High quality curated information can complement discussion during the clinical encounter. We suggest that every cancer centre conduct an MDT annual review and update of sources of information, including local and national third sector organizations as appropriate. This could be linked to an update of the Cancer Care Map. Health and wellbeing events can increase awareness on primary prevention and the need for psychosocial support.

16.1. General information

The Cancer Care Map

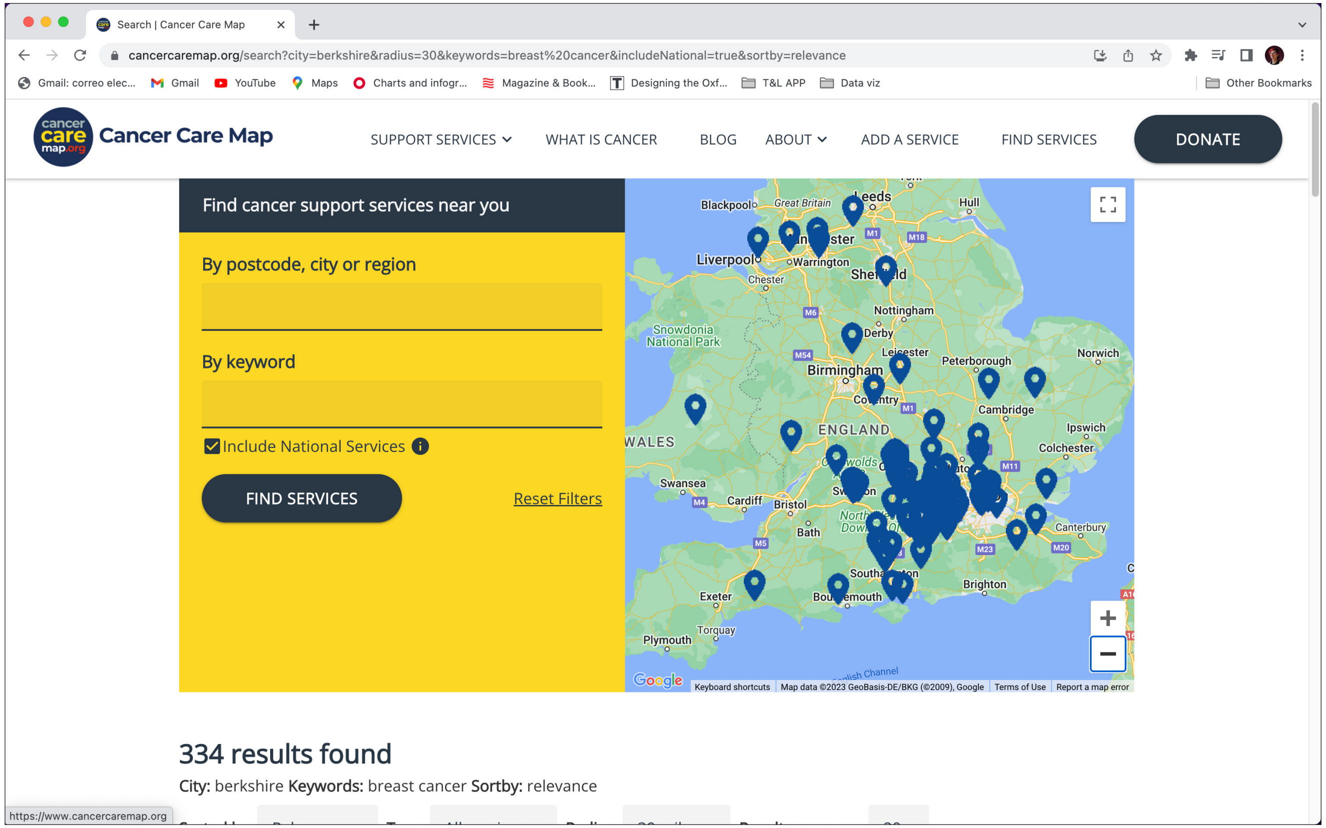
www.cancercaremap.org/

This website is run by a national cancer charity, The Richard Dimbleby Cancer Fund, and has a map of services across the UK, including those which focus on emotional support, health and wellbeing and practical concerns. The Cancer Care Map can be kept up to date by notifying the administrators of any changes to local services.

Thames Valley Cancer Alliance

The Thames Valley Cancer Alliance (TVCA) website has a dedicated page with a number of videos on health and wellbeing associated with cancer with recorded interviews with a range of professionals across primary and secondary care in the TVCA region.

thamesvalleycanceralliance.nhs.uk/our-work/patient-engagement-patient-experience/health-and-wellbeing/



cancercaremap.org/search?city=berkshire&radius=30&keywords=breast%20cancer&includeNational=true&sortby=relevance

Find cancer support services near you

By postcode, city or region

By keyword

☑ Include National Services

334 results found

City: berkshire Keywords: breast cancer Sortby: relevance

https://www.cancercaremap.org

Figure 7. CancerCare Map

16.2. Specific information

Information provision at individual sites depend on patient demands and needs. Several information services were shut down during the COVID 19 pandemic and have not reopened as patients and families are being directed to web based resources.

16.2.1. Buckinghamshire Healthcare NHS Trust

Buckinghamshire Healthcare NHS Trust has a Cancer Education, Information & Support Service (CEISS) based in the Cancer Care and Haematology Unit in Stoke Mandeville Hospital. The CEISS has been long established and staffed, providing drop in and telephone-based support and information since 2000.

It has also been an early adopter of Health and Wellbeing events, running them consistently since 2015.This service has been provided through telehealth during the pandemic, with increased use of web-based information and delivered virtual health and wellbeing events since Sept 2020. The CEISS maintains close working relationships with patient led support group leads and supports CNS led support groups. It has created a mailing list of local support groups. Details of activities, such as Health & Wellbeing events, are sent for dissemination to members.

Pre-pandemic, support groups were invited to attend face-to-face events and have a display stand. Service users are members of the CEISS Steering group as patient representatives. Users are involved with patient leaflet reviews prior to final approval by the Trust. Users are involved with surveys in order to improve services and the patient experience i.e. environment survey and wig service survey.

The trust website has information and useful links.

www.buckshealthcare.nhs.uk/our-services/cancer-care/

16.2.2. Great Western NHS Foundation Trust

The Trust website has information about the cancer psychology service, including a leaflet about the team and information about referrals to psychology.

GWH Cancer Information point and OUH Information Point in GWH Radiotherapy building for RT. Health & Wellbeing days across all tumour sites.

www.gwh.nhs.uk/wards-and-services/cancer-services/

16.2.3. Oxford University Hospitals NHS Foundation Trust

The Trust website has information about each tumour site including services available, multi-disciplinary teams, patient information leaflets, links to support services.

It also has links to NHSE and Cancer Research UK websites that provide high quality information.

https://www.ouh.nhs.uk/cancer/services/oncology.aspx

16.2.4. Royal Berkshire NHS Foundation Trust

The Macmillan Cancer Information and Support Centre based in the Berkshire Cancer Centre offers support and information.

The Royal Berkshire Foundation Trust website has been redeveloped with patients and includes information about Cancer, links to the cancer rehabilitation service and support.

www.royalberkshire.nhs.uk/featured-services/berkshire-cancer-centre/

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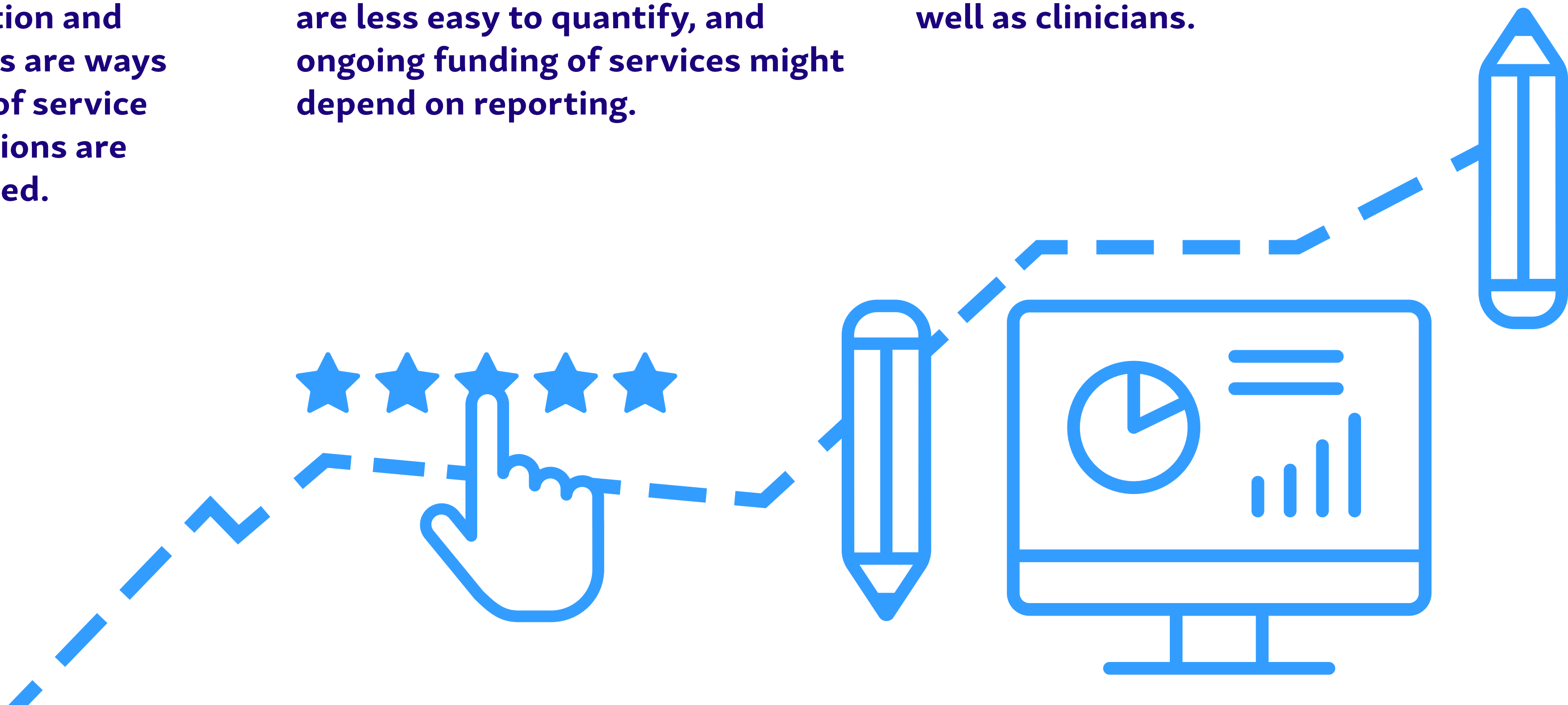
Quality, outcomes and governance

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.



17.1. Governance arrangements

BUCKINGHAMSHIRE HEALTHCARE NHS TRUST

Governance arrangements

Oncology, Haematology and Psychology all sit as separate Sub-Divisional Units (SDU) within the Division of Specialist Services. Each SDU has a clinical lead which includes a Consultant Oncologist, Consultant Haematologist and a Chief Clinical Psychologist. Each SDU has relevant senior nursing and operational support.

All SDUs facilitate a monthly clinical governance meeting and a monthly business meeting. These feed directly into the Divisional Quality, Safety and Experience Board. There is also a Governance Lead within each Division.

In 2022 Buckinghamshire Healthcare NHS Trust also launched the Cancer Oversight Board. The monthly meeting has representation from all key internal and external stakeholders and is chaired by the Chief Operating Officer with active patient representation.

Challenges, including funding

There has been a paucity of capacity in level 4 services in Bucks & BHT. There is a lack of continuity of funding for the Level 3 service and business as usual.

There is a lack of equivalent Level 4 services in the community and level 3 & 4 service in community palliative care including inpatient hospice.

Level 2 cancer care staffing levels - it is difficult for the matrons to release their staff to attend supervision and training events without compromising clinical attendance and support.

How is this being dealt with?

Ongoing and active collaboration between Oxford Health IAPT/ Healthy Minds and the service in BHT to establish an integrated Level 3 service between BHT and IAPT LTC service. This will create a Level 3 psychological care pathway for Bucks for cancer patients living with and beyond cancer in primary care and the community. Meeting and project work ongoing at recruitment stage. BCCG funding has been secured to deliver this pathway. It is anticipated this will offer a service with a capacity for 500 patients at Level 3 with IAPT LTC Cancer by year 2.

Head and neck cancer pathway group work- Hassan Ladha, taking the lead on the bid for TVCA funding round (Dec 2021).

The Psychological Care CAG was established and convened the inaugural meeting for the Psychological Care CAG in Sept 2021. The lead psychologist from Bucks is lead for this Clinical Advisory Group.

How do you manage workspace challenges?

This is managed by agile working, telehealth and working from home (WFH) since March 2020. Historically and pre-pandemic, the service did not have a designated office area. Prior to the pandemic the Band 8b consultant psychologist had access to consulting rooms in the Cancer Care and Haematology Unit in Stoke Mandeville Hospital three days a week and in the Sunrise Chemotherapy Unit in Wycombe General Hospital two days a week for clinical and office work. Currently the service does not have access to a dedicated office space. The Research and Innovation Centre can be used for desk space, but this is not always available and has to be prebooked up to two weeks in advance

GREAT WESTERN NHS FOUNDATION TRUST

Governance arrangements

The GWH cancer psychology team is integrated within cancer services, which is part of the division of community and integrated care.

The service is delivered by HCPC registered psychologists and BABCP registered counsellors and all members of the team receive monthly supervision by HCPC registered psychologists and attend regular CPD.

The clinical lead for the service attends the monthly cancer management meetings and presents monthly service updates. The service conducts regular audits to ensure quality of clinical care delivery.

Challenges, including funding

Lack of capacity - There are a high number of appropriate referrals and not enough clinicians working at level 3 & 4 to meet the need in a timely manner. This also has an impact on the amount of level 2 training and supervision, that is offered.

How is this being dealt with?

Psychology has been on the risk register for some time. More psychology time has been funded (which was incredibly helpful), but this has been fixed term, which creates uncertainty & instability.

How are Workspace challenges being managed?

By working from home in part and arranging clinics so clinicians do not clash with each other's use of the office. There is one psychology office desk that is shared between 2.4 WTE, in the palliative care office. The team sees patients for clinical work in the Oncology outpatients department (and sometimes in other departments if there is limited space in Oncology). Also, they are assessed via telephone and video consultations.

STRENGTHS	WEAKNESSES
• The cancer psychology team is well established within GWH cancer services, and colleagues frequently refer patients and their family for specialist psychological support. • The service received excellent feedback from patients who have received specialist level 3 and 4 input. • The team values service development and conducts regular audits of its practices, which subsequently inform change. • The team have training in a variety of psychological approaches and are able to tailor psychological therapy to suit patient needs. • The team follows an evidence-based approach and is research active, with publications, links and collaborations with a range of other NHS trusts and Universities. • The team has good links with Macmillan Cancer Support	• Inadequate staffing to meet demand and see patients within a timely manner. • Half the WTE of the team are fixed term posts. • Referrals to the psychology service are not representative of the diversity that exists in people diagnosed with cancer at GWH.
OPPORTUNITIES	**THREATS**
• The service has been well supported by Macmillan in the past. • The service has begun discussions with the primary care Long Term Conditions psychological lead re linking up.	• CNS workload may mean that patients with specialist psychological needs are sometimes not identified and referred. • Lack of future funding opportunities.

OXFORD UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

Governance arrangements

The psycho-oncology service is integrated within the Oncology and Haematology directorate of the Surgery, Women's and Oncology (SuWOn) division of the trust, but are sited in the Clinical Support Services (CSS) division.

The clinical lead for the service attends the monthly leads meeting with the directorate and presents three monthly service updates. The team are part of the monthly governance and audit meetings in oncology as well as the Haematology Monthly Operational and Governance (MOG) meeting.

The service contributes to the Morbidity and Mortality reviews within the directorate and conduct regular rolling audits to ensure quality of clinical care delivery.

Challenges, including funding

The current screening and DCPC treatment is available to the local population having treatment at the Oxford Cancer Centre, this disadvantages patients in the north of the county and patients from other counties.

Training of Band 4 as well as Band 6 staff in the collaborative care model, takes time. The band 6 care managers are signed off clinically after completing 6 modules and having F2F exposure to all facets of cancer care over 4 months.

STRENGTHS	WEAKNESSES
• Evidence-based collaborative care treatment delivered to a large number of patients • Universal screening • Integrated physical and mental health care provided onsite at Oxford Cancer Centre • Dedicated liaison psychiatry time for outpatients and inpatients	• No current psychology provision for CNS supervision • Provision of care between north and south of the county is not equitable • Patients receiving surgical-only treatments do not have same access to screening • Patients from outside the county do not have same access to treatment (regional cancer pathways)
OPPORTUNITIES	**THREATS**
• Further linking up with primary care for cancer care reviews and training • Link up with primary care for cancer care reviews (CCRs) and existing IAPT services • Digitising the Symptom Monitoring Service, use of patient held records • Alliance-wide working, linking up of training and clinical supervision • Patient co-production, engagement with PPG	• Staff turnover • Funding concerns • Space in outpatient department for treatment

How is this being dealt with?

Ongoing discussions with trust management about recruitment of Band 8b/c psychologist. Also discussions on additional psychological screening and cover for those living in North Oxfordshire, who receive treatment at Horton Hospital as well as for patients from outside the county who receive treatment in Oxford.

How do you manage workspace challenges?

The Macmillan Psychological Medicine team have designated office space on Level 2 of the Cancer Centre at the Churchill Hospital. There is currently not enough space to complete telephone assessments and administrative tasks. It is a struggle to find sufficient clinic space for DCPC appointments in Oncology and Haematology outpatients department. Currently the team employs a working from home (WFH) rota, which allows conduct telephone and video consultations, to alleviate some of the pressure on clinic space.

ROYAL BERKSHIRE NHS FOUNDATION TRUST

Challenges, including funding

The psycho oncology service has developed organically with funding in a piecemeal fashion over the years, funding has been insecure for many years. There are ongoing challenges with service capacity to meet demand.

How is this being dealt with?

TVCA has provided funding and we continue to build business cases for substantive funding from the trust.

How do you manage workspace challenges?

Office space for psycho-oncology clinicians is located in the Greenlands Flats co-located with the clinical nurse specialists and medical consultants. Patients are seen mainly in the oncology outpatients department. Space is at a bit of a premium.

STRENGTHS	WEAKNESSES
• Good engagement and integration of psychology into day to day running of oncology services • Recent investment (via TVCA) in more psychology time • Good links with cancer rehab team • innovative approaches to managing caseload • Good management by senior psychologist • Good supervision systems in place for CNS team and consultant oncologists	• No long-term funding for new posts • Not enough resource to meet patient need. • In-reach service leading to issues with access to two notes systems.
OPPORTUNITIES	**THREATS**
• Potential to integrate and work with other roles and services e.g. complimentary therapies • Could build service to add new roles such as admin support and counselors • Could work more closely with psychiatry and improve liaison	• Lack of funding - Trust financial position is parlous • Psychological support given low priority by Trust managers - emphasis on cancer performance rather than quality

Recommendations

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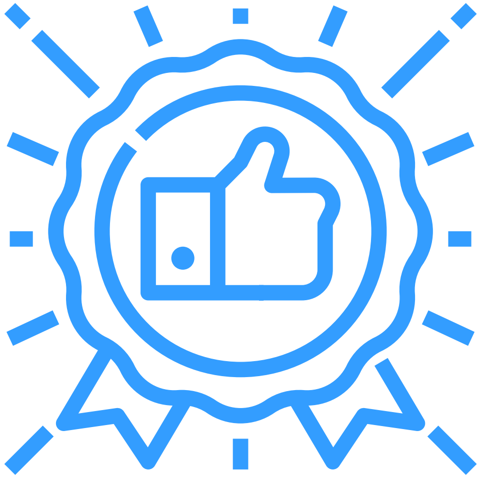
TVCA wide recommendations

↳ *Go to p.8 Summary of Recommendations*



[SERVICE PROVISION]

		Who is responsible for this?
Recommendation 1: ***All cancer staff (clinical and non-clinical) have psychological awareness training***	• TVCA psychological care CAG working with LCNs to ensure that ALL staff in all TVCA cancer centres have access to basic training materials in psychological health and distress screening. • Ensuring that ALL staff are aware of disadvantaged groups - including those from a diverse ethnic background, older people, people with learning disability and dementia, people with severe mental illness, the LGBTQI community, those from poorer socioeconomic backgrounds – and are aware of pathways for support.	• Clinical directors/ Cancer Managers/ service leads at each cancer centre • TVCA to support trusts in developing alliance-wide resources
Recommendation 2: ***Protected time for CNSs to attend training and supervision, and of time for supervisors***	• Lead Cancer Nurses at all sites to review CNS numbers and consider ways of having protected time available to all CNSs to attend training and clinical supervision. (including mandating and recording attendance) • Sites with minimal provision such as the Oxford Cancer Centre to urgently look at ways of delivering training and recruiting psychology staff to deliver this.	• Lead cancer nurses • Clinical directors/ Cancer Managers • ICB commissioners
Recommendation 3: ***Setting up training and supervision for other professional groups delivering personalised care — radiographers, pharmacists, etc***	• All sites to set up level 2 training and clinical supervision for pharmacist and radiographers (discussion with TVCA CAGs), this could be linked to existing supervision arrangements for CNSs.	• Service leads (eg. Head of radiotherapy and pharmacy) at each cancer centre • CDs/ Cancer Managers/ ICB commissioners

		Who is responsible for this?
Recommendation 4: ***Substantive contracts for level 3/4 staff employed on fixed term contracts***	• TVCA/ ICS prioritising support for sites that do not have current service provision. • Prioritising services with staff employed on fixed term contracts that are ending shortly – this creates uncertainty and disrupts the ability to plan service delivery.	• Psychological care lead/ CDs at each cancer centre/ Cancer Managers • ICB commissioners
Recommendation 5: ***Funding level 3/ 4 posts to meet demand***	• At all sites, service demand exceeds provision – ICBs to commission psychological services that meet national guidance with required staff skill mix for treatment, training and clinical supervision. Ensuring funding is substantive and non-short term can help psychological care services recruit and retain good staff.	• ICB commissioners • Cancer Managers
Recommendation 6: ***Patients on regional cancer pathways unable to access local psychological services***	• Staffing for regional cancer pathways to be reviewed and negotiated at Oxford Cancer Centre.	• ICB commissioners + CDs / Cancer Managers

[DATA REPORTING]

		Who is responsible for this?
Recommendation 7: ***Annual data reporting***	• Datasets and alliance-wide reporting of data – Lead cancer nurse and psychological care lead at each site to provide annual data reports on activity, waiting lists and unmet needs to TVCA and the local ICSes. • Linking HNA data on psychological care domains to psychological care service delivery. • Linking secondary care screening (HNA, SMS) to primary care Cancer Care Reviews, if appropriate patients can be linked up to IAPT services.	• Lead cancer nurses/ psychological care leads • Cancer Managers • ICB commissioners

[INFORMATION PROVISION]

Recommendation 8: ***Annual review of information sources and charity sector services***	• Ensuring patients and families at each site have access to high quality information about cancer and all psychosocial support available in the local area. • Support for research to help provide evidence-based service models. Build TVCA-wide networks to improve recruitment to trials and build on links with University of Oxford, Oxford Brookes University, University of Bristol, etc.	• CDs/ Cancer Managers/ lead cancer nurses + service lead for charity providers In local area

[EQUALITY, DIVERSITY AND INCLUSION]

Recommendation 9: ***Equality, diversity and inclusion improvement***	• Identifying and addressing health inequalities that exist in accessibility to specialist psychiatric/ psychological support irrespective of age, gender, socioeconomic status, ethnicity, sexuality and disability.	• Lead cancer nurses/ psychological care leads • Cancer managers • ICB commissioners

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Local recommendations

19.1. Buckinghamshire Healthcare NHS 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 • Ensure continuation of the integrated partnership model between Macmillan Clinical Psychology Service and Healthy Minds, that began in October 2022 (Relate service contract has ended)	Psychological care lead + CD + Cancer Managers – approach ICB for funds Psychological care lead + CD for cancer / Cancer Managers + Lead for Healthy Minds + CD in Oxford Health	End of financial year 2023-24 Ongoing
Specialist support	• Address shortfall in Level 3-4 specialist provision • Change Band 8a 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 in Oxford Health	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	**2407 patients**	
50% needing Level 2 enhanced support	**1204 patients**	
15% needing Level 3 enhanced/specialist support	**361 patients**	
Current Level 3 workforce (WTE)	› 0.6	
Current capacity	› 75	**Gap 2.4 WTE**
Workforce required (WTE) caseload of 120	› 3	
10% needing Level 4 specialist support	**241 patients**	
Current Level 4 workforce (WTE)	› 1.53	
Current capacity	› 122	**Gap 1.57 WTE**
Workforce required (WTE) caseload of 80	› 3.1	

19.2. Great Western Healthcare 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	Psychological care lead + CD / Cancer Managers – approach ICB for funds	End of financial year 2023-24
Specialist support	• Secure substantive funding for existing fixed term 0.5wte 8a Clinical Psychologist post and 0.7 WTE Specialist Counsellor post. • Secure funding for an additional 1 WTE band 8b clinical psychologist. • Secure funding for an additional 1 WTE band 6/7 counsellor. • Address health inequalities in the referral patterns and accessibility of the cancer psychology team to groups currently not accessing the service.	CD+ICB / Cancer Managers Psychological care lead + CD / Cancer Managers– approach ICB for funds Psychological care lead + CD for cancer / Cancer Managers + CD for Avon and Wiltshire Mental Health Partnership NHS 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 *without 1594 skin cancers added in*

estimate of need Level 1 universal support	**2258 patients**	
50% needing Level 2 enhanced support	**1129 patients**	
15% needing Level 3 enhanced/specialist support	**339 patients**	
Current Level 3 workforce (WTE)	› 0.7	**Gap 2.1 WTE**
Current capacity	› 84	
Workforce required (WTE) caseload of 120	› 2.8	
10% needing Level 4 specialist support	**226 patients**	
Current Level 4 workforce (WTE)	› 1.5	**Gap 1.3 WTE**
Current capacity	› 120	
Workforce required (WTE) caseload of 80	› 2.8	

19.3. Oxford University Hospitals 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	• Revise and re-submit business case for Band 8b/ 8c psychologist to provide training and supervision	Psychological care lead + CD / Cancer Managers– approach ICB for funds	End of financial year 2023-24
	• Protect time for CNSs (and radiographers & pharmacists) to attend training and supervision	LCN + radiotherapy and pharmacy leads + CD / Cancer Managers	End of financial year 2023-24
Specialist support	• Address shortfall in Level 3-4 specialist provision	CD+ICB / Cancer Managers	By 2025
	• Explore funding streams to recruit staff and expand provision to cover patients on regional cancer pathways who are currently excluded from screening and cannot access psychological support in the local area	Psychological care lead + CD / Cancer Managers – create business case with TVCA and ICB	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		4594 patients	
50% needing Level 2 enhanced support		2297 patients	
15% needing Level 3 enhanced/specialist support		689 patients	
Current **collaborative care workforce** (WTE)	›	4	**Gap 1.75 WTE**
Current capacity	›	480	
Workforce required (WTE) caseload of 120	›	5.75	
10% needing Level 4 specialist support		460 patients	
Current Level 4 workforce (WTE)	›	0.8	**Gap 4.95 WTE**
Current capacity	›	142	
Workforce required (WTE) caseload of 80	›	5.75	

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	**Gap 3.6 WTE**
Current capacity	› 0	
Workforce required (WTE) caseload of 120	› 3.6	
10% needing Level 4 specialist support	**289 patients**	
Current Level 4 workforce (WTE)	› 1.55	**Gap 2.87 WTE**
Current capacity	› 124	
Workforce required (WTE) caseload of 80	› 3.6	

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

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