October 2024

EVALUATION OF MACMILLAN'S PSYCHOLOGICAL CARE PROGRAMME

BRIGHTPURPOSE

MACMILLAN CANCER SUPPORT

INTERIM REPORT

Macmillan Internal

CONTENTS

1 INTRODUCTION

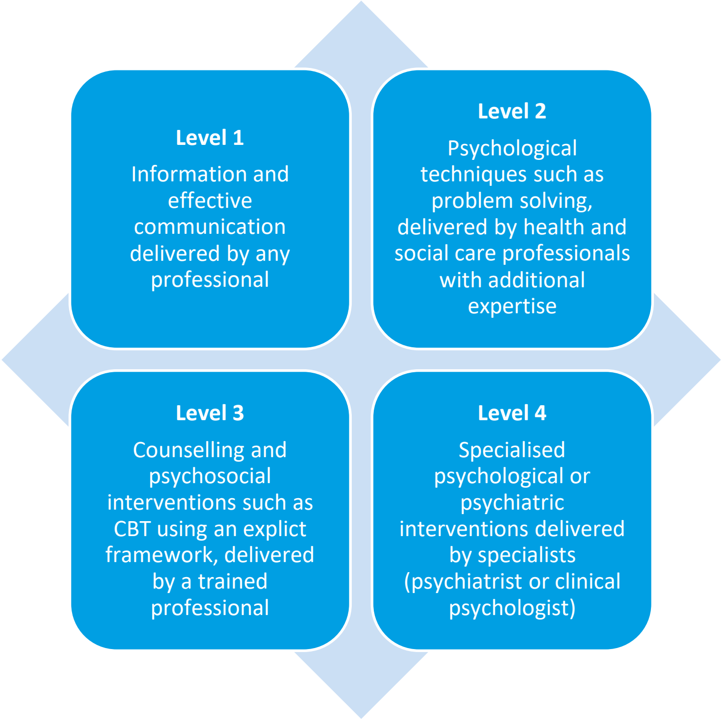
Macmillan Cancer Support’s Psychological Care Programme (the Programme) is being implemented to address the concern that psychological support is one of the least well met, yet highest impact needs for people living with cancer. The prevalence of anxiety and depression is much higher among people with cancer, as both the disease and its treatment impact on all aspects of wellbeing, not just physical health.

The Programme aims to influence change at system level to encourage more integrated systems that can offer the right support, at the right level, at any time along the cancer pathway.

Background

Psychological support is categorised as low-level need (1 & 2) and high-level need (3 & 4). People with high level needs may require counselling and psychological interventions such as Cognitive Behavioural Therapy (CBT) or specialist psychological or psychiatric interventions.

Figure 1- Levels of Psychological Support



Level 1
Information and effective communication delivered by any professional

Level 2
Psychological techniques such as problem solving, delivered by health and social care professionals with additional expertise

Level 3
Counselling and psychosocial interventions such as CBT using an explict framework, delivered by a trained professional

Level 4
Specialised psychological or psychiatric interventions delivered by specialists (psychiatrist or clinical psychologist)

In practice, the provision of different levels of care is interdependent. Effective Level 1 & 2 care requires training and support from specialist practitioners. Effective Level 3 & 4 care requires good case detection and referral by all health and social care professionals in the cancer care pathway.

Macmillan successfully piloted the implementation of this integrated approach, which led to the establishment of sustainable psychological support in London and Oxford. Macmillan also completed a gap analysis across the UK, which identified major gaps in Level 3 and 4 provision.

The Programme

The Programme aims to further test the model by investing in and working with cancer alliances, Trusts and health boards across the UK. The approach is one of strategic investment in Senior Clinical Leadership teams, Project Management, Project Support roles, and other aspects of psychological care infrastructure.

The roles will focus on the delivery of Level 3 & 4 psychological support, and on proactively coordinating the integration of support across the system.

Through investments into, and influencing of, partner organisations and engagement with people with cancer and communities, Macmillan's goal is to implement and embed integrated psychosocial support so that:

- People have systematic assessment followed by timely and equitable access to appropriate psychosocial support integrated with cancer care clinical pathways and planning from the point of a cancer diagnosis
- People experience improved coordination and more proactive and integrated psychological support across primary, community, social and acute settings at the level which is right for them at any given time
- People have the knowledge, skills and confidence to actively manage their own psychological support needs, as appropriate to the individual

Evaluating the Programme

Evaluation Purpose

The evaluation focuses on two sites: Nottingham & Nottinghamshire Integrated Care Board (ICB) and Lincolnshire ICB. The aim of the evaluation overall is to understand:

Process

- The process by which each site implemented an integrated psychosocial care model for people living with cancer
- The factors that affected implementation
- The critical success factors that others can learn from and apply

Outcomes and impact

- The difference that integrating and coordinating psychological care across the system made to:
    - Improving provision of psychosocial care
    - People living with cancer, especially in relation to their quality of life
    - The workforce supporting people living with cancer, including their skills and confidence to support people with psychological needs, and their work satisfaction and wellbeing
    - The wider system

Economic impact

- The economic impact of having a service that supports the psychosocial needs of people living with cancer

This interim report provides the following:

- a baseline – the services that were provided pre-project and the extent to which they served people living with cancer and the staff that support them

- an update on progress – an overview of the new services that have been introduced and how these are being integrated into the system
- a summary of learning thus far from projects and the wider programme – what has worked well, what could have worked better
- early findings and indicators of change – the difference the projects are making for people living with cancer, staff and the system
- an update on data collection processes – the data we have been able to secure, missing data and the implications of this

Data sources

We used a variety of data collection methods which are summarised in the tables below.

Table 1- Number of survey responses

Data collection method	**Survey responses**				
	Notts Responses		**Lincs Responses**		**Total**
	Number	Response rate	Number	Response rate	
Patient experience survey	5	unknown	160	8%	165
Workforce survey	26	21%	32	15%	58
Post Level 2 Training Survey	0	n/a	6	unknown	6

Workforce surveys were sent out by the Lead Cancer Nurses to clinical staff with frequent contact with people living with cancer.

Table 2 - Number of interviews completed

Data collection method	Number of interviewees		
	Notts	Lincs	Total
Patient interviews*	5	7	12
Service Lead interviews**	2	2	4
Psycho-oncology team interviews**	5	3	8
Staff interviews*	6	7	13
Local system lead interviews	2	3	5
Other e.g. partners/providers/referrers	0	6	6
Macmillan Steering Group	N/A	N/A	7

*Patients and staff interviews were carried out with a mix of survey respondents and individuals identified by the psycho-oncology teams.

**Some people in these groups have been interviewed more than once, but the numbers above represent unique individuals.

Limitations

Patient survey distribution challenges

Our proposed method of survey distribution was to send the survey to a sample of people that had received a cancer diagnosis in the 12 months prior to the new services launching. We had assumed this would be possible to do via email with a postal option for those without email.

In Lincolnshire, ULHT was able to identify a sample of patients to invite to complete the survey. However, emails were not available for the majority of patients in the sample so the invitation to participate in the survey needed to be sent via post. This was done by Trust staff and volunteers for information security reasons.

We were unable to disseminate the Patient Experience Survey to Nottinghamshire patients as planned. This was due to a combination of technical, policy and capacity constraints within the Trust which meant they were unable to generate a sample of patients with contact details. The revised approach relied on invitations being cascaded to patients via clinical staff during appointments or in their follow-up letters.

The invitations for both Lincolnshire and Nottinghamshire offered an online link, and options to request a hardcopy or complete the survey by phone. The majority of surveys were completed online, with six people completing over the phone and nine people requesting a hard copy (of which five were returned).

Overall, the response rate for Lincolnshire was 8%, below what we would have liked to achieve, and we had only a handful of responses from Nottinghamshire.

Posting the invitations had a cost implication for printing and postage and required volunteer and staff support to dispatch the envelopes. The cascade approach used in Nottinghamshire also relied upon staff capacity. In both cases there was an additional cost to provide a telephone option in terms of evaluator time.

Workforce survey reach

Workforce survey responses were good based on the numbers sent out. However, the surveys were sent by Lead Cancer Nurses to the main cancer workforce clinicians, CNSs, CSWs etc. We had hoped to reach a wider population, to include any clinician or staff member that may have contact with people living with cancer.

We only had a handful of Post Level 2 Training surveys, as they were not distributed to the early cohorts of participants.

We were not in control of survey distribution due to information governance restrictions, and we will need to explore how the services can boost responses for future surveys.

Impact of survey response rates on interview recruitment

Limited survey distribution reduced the potential for recruiting patients and staff for semi-structured interviews. All respondents that consented to an interview were approached to maximise the number reached.

Variable engagement from other stakeholders

Interviews with other stakeholders, such as staff being supported by new services, referring services and other providers, were variable and highly dependent on the project teams making introductions/connections. Some key stakeholders did not engage with the evaluation. This makes it more difficult to understand how the new services are integrating into the wider health system and what difference that is making.

No level 4 patient outcome data

Nottinghamshire was unable to provide level 4 patient outcome data in time for the reporting deadlines. This was due to a lack of capacity to collate the data.

Lincolnshire provided some level 4 patient data but it was insufficient to analyse outcomes.

2 SITE REPORT: LINCOLNSHIRE ICB

Lincolnshire ICB serves the rural county of Lincolnshire in the East Midlands of England. It covers an area of approximately 7,000 square kilometres and has a population of just over a million. The main population centres are Lincoln, Grimsby and Scunthorpe.

The ICB is part of the Integrated Care System, known as the Better Lives Lincolnshire alliance. Services are commissioned from six NHS Trusts and 81 GP practices (grouped into 14 Primary Care Networks).

The United Lincolnshire Hospitals NHS Trust (ULHT) provides the majority of cancer services for the county, based at the Lincoln oncology centre at Lincoln County Hospital. Chemotherapy is also provided at Pilgrim Hospital in Boston and Grantham and District Hospital.

Pre-programme provision of psychological support services

What was in place pre-programme – at all levels

Prior to the Macmillan funding, Level 4 psycho-oncology was provided by two services:

- East Midlands Cancer Alliance Video Service (EMCAVS)
- Lincolnshire Partnership Foundation Trust (LPFT)

EMCAVS, now known as EMCA-CPH (East Midlands Cancer Alliance - Centre for Psychosocial Health), is a regional service developed in response to the COVID-19 pandemic, providing support to people living with cancer with online video consultations. All patients referred by ULHT for Level 4 psychological support were referred to this service unless they requested face-to-face consultations.

Patients that requested face-to-face consultations, and referrals from elsewhere in the system (such as Lincolnshire Community Health Services and hospices) went to psycho-oncology services at LPFT which is a mental health Trust.

Level 3 support was available through Improving Access to Psychological Therapies (IAPT) – recently renamed NHS Talking Therapies. This service has specific pathways for people with long term conditions. They had worked previously with ULHT to bring around ten specific tumour sites into their long-term conditions pathway services however the Covid-19 pandemic put a halt to that work and efforts to re-establish contact have been unsuccessful.   Prior to this breakdown they had established referral routes for breast, prostate and upper GI cancers with most referrals coming from CNSs.

Level 2 support was provided by trained clinical staff, mainly CNSs, in the acute Trust, ULHT. Level 1 support was available through the Macmillan Cancer Information and Support Services located in Lincoln, Grantham, Boston, Grimsby and Scunthorpe.

Other local voluntary and community organisations provide support, some of which is cancer specific. However, as far as we are aware there are no formalised referral routes to these other organisations, though clinical staff may signpost to them.

Supporting infrastructure

Referral routes from ULHT to EMCAVs were already well established. There was a brief break in service provision from EMCAVS due to funding issues, but the service resumed under the newly titled service EMCA-CPH and referrals remain consistent.

Referral routes from community to the LPFT psycho-oncology service were also established, but quite tightly controlled to avoid excessive waiting times as capacity was limited. This historic narrative has been cited as a potential reason for referrals from community healthcare remaining below expected levels despite increased capacity.

A single point of access referral process, which predates the Macmillan service, automatically assigns a patient to the nominated service without the referrer needing to know which service they are directing a patient to.

It is also worth noting that as a result of the ICB’s ambition to support people living with cancer, six Cancer Care Coordinators (CCC) have been embedded in primary care since 2023. These individuals proactively support people from the point of diagnosis, offering support directly as well as signposting and referring patients onto other services, including NHS Talking Therapies and both Level 4 support services. Despite the relatively short period these posts have been in place, the extent of joined up working is, according to one of the CCCs, “the best they have experienced in the sector generally”.

Gaps/summary of additional need

The most significant gaps identified through scoping were for Level 3 and 4 support. Level 4 support was deemed crucial to provide both a patient-facing service for those with the most complex needs and to provide training and support for clinical staff providing Level 2 support. EMCA-CPH were providing Level 2 training for staff at ULHT, but clinicians in other areas of the system were not being trained.

Provision of face-to-face support for patients with complex needs totalled 3.5 days per week provided by two clinical psychologists. The psycho-oncology team describe gatekeeping the Level 4 service quite tightly to avoid lengthy wait times. However, by not allowing a waiting list to grow they felt this approach hid the real demand for their services. In addition, this level of resourcing left little capacity for meeting the training and support needs of staff providing Level 2 support elsewhere in the system.

Effectiveness and experience of psychology support from a patient perspective

In order to gather a baseline picture of patients’ experience of psychology support before the launch of the Macmillan funded service, ULHT distributed a patient experience survey on Brightpurpose’s behalf to a sample of 2,000 patients that received a cancer diagnosis between 1 October 2022 and 30 September 2023.

We received 160 responses from patients across over 20 tumour sites, with the highest proportion of responses from those who had received a prostate (29%), breast (20%) or bowel (12%) cancer diagnosis. Half of respondents had finished treatment but were still having follow ups at their hospital (53%), 16% were currently receiving treatment, 14% had been discharged from hospital following treatment, and 17% of respondents in another stage of their cancer journey.

The demographic profile of respondents was:

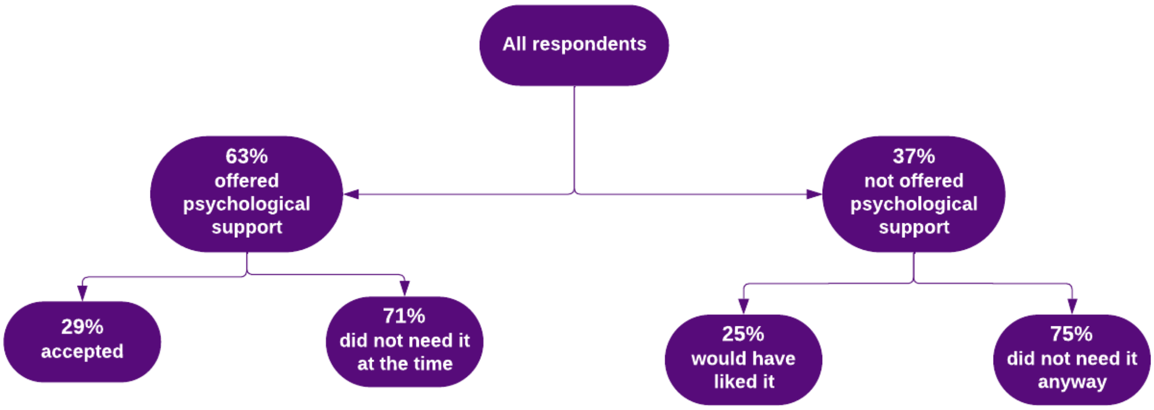
- 60% male, 40% female, <1% agender
- 87% 60 years old or above
- 94% identifying as white British
- 83% not currently in employment

Patient interviews and lived experience engagement suggested that the psychological impact of cancer for people living with cancer was often unexpected. In line with this, a high proportion of survey respondents (40%) indicated they were not made aware at diagnosis of any potential psychological impact that cancer may have.

For the purpose of the survey, psychological support was defined as any sort of care or support which focused on a person's mental health, feelings, and emotions, ranging from a supportive conversation about their mental wellbeing to a session with a psychologist.

Most respondents (62%) felt they knew where to get psychological support and 69% felt confident in asking for it if they needed it.

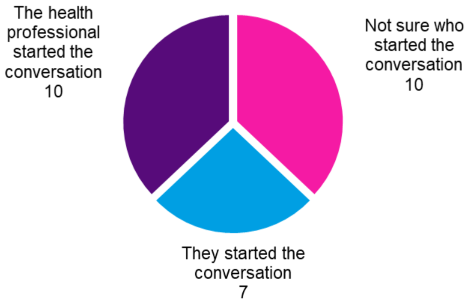
Figure 2 – Over half of respondents were offered psychological support at some point in their journey, however only 29% of those accepted (N=148)



N=148

Those who received psychological support predominantly did so from Clinical Nurse Specialists (63%), Cancer Support Worker/Cancer Care Coordinators (41%) and Macmillan Cancer Information and Support Service workers (37%).

Figure 3 - In just over one third of situations the health professional was the person to bring up the topic of psychological wellbeing; equally respondents often did not remember who initiated the conversation



N=27

Only 14 of the 27 who had received psychological support agreed that the support had met their needs effectively.

As illustrated in Figure 4, amongst those that responded to questions about the difference psychological support had made, just under half expressed an improvement in their quality of life and around a third an improvement in their psychological wellbeing.

Figure 4 – Psychological wellbeing and quality of life remained the same for most respondents following psychological support

N=24

Similarly, around half expressed improvements in their ability to engage in conversations about their feelings and in raising matters that concern them with their health professional following the support they received.

The statistics above suggest that before the new service launched there had been some benefits to patients who had received psychological support, but there was scope to better meet their psychological needs.

For patients with more complex psychological needs, a higher level of support is required. We had six responses from those who had been referred to a specialist psychology service. This equates to slightly under one quarter of the 27 who had discussed their psychological needs with a professional, a broadly similar proportion to that estimated by the East Midlands Cancer Alliance in the Case for Change. But overall, the small number of responses makes it difficult to draw conclusions about the difference support has made.

Interviews

We interviewed four patients that had responded to the survey and had received psychological support. A common theme was that they had not had their psychological wellbeing addressed at an early stage.

Interviewees commented that they struggled, despite support from family members, and had to seek support rather than it being identified as a need by their treating clinicians.

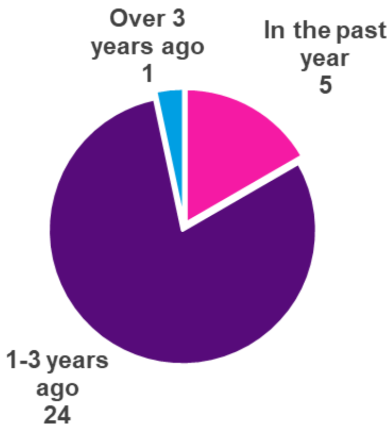
Cancer workforce perspective

In the early stages of programme rollout, a cancer workforce survey was distributed to professionals who support people living with cancer, to gain their perspective on and experiences of delivering psychological care. As the service was already launched, this was not a true baseline but a snapshot in time before the service was fully embedded. The survey was open for three months from May-July 2024. In that time 32 responses were received from Lincolnshire; 28 staff from ULHT and 4 staff working in Primary Care. Responses were received from:

- 18 Clinical Nurse Specialists
- 11 Cancer Support Worker/Cancer Care Coordinators
- 3 Other professionals

At the time of responding, 30 of the 32 of professionals indicated that they had received Level 2 training in the past.

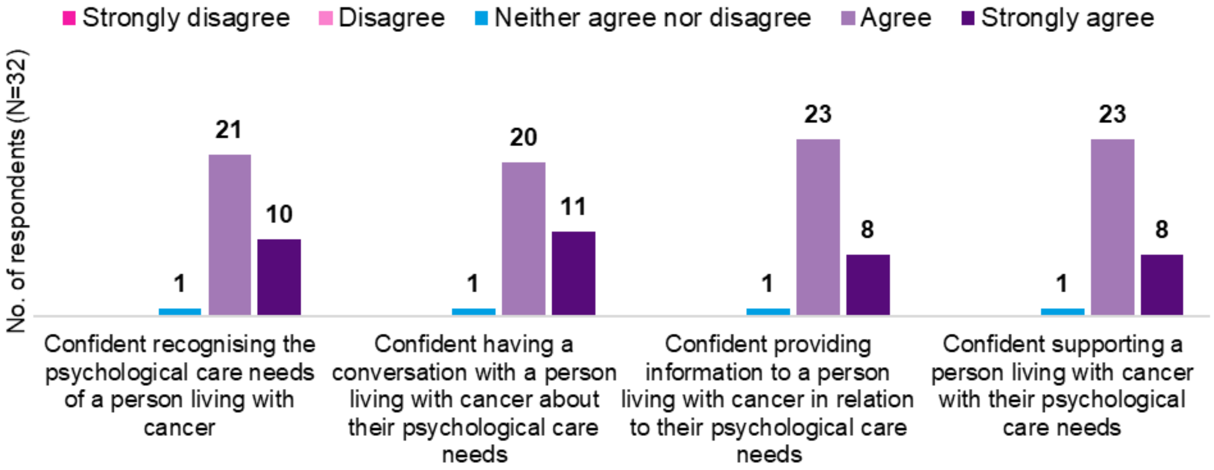
Figure 5 – Most respondents received their Level 2 training over one year ago



N=30

As Figure 6 illustrates, the majority of respondents felt confident supporting people living with cancer with their psychological care needs. However, a greater proportion were more likely to agree than strongly agree with the statements, suggesting that the degree of confidence they felt in managing the psychological needs of their patients could be improved.

Figure 6 – Respondents were somewhat confident in recognising needs, talking about needs, providing information, and supporting people living with cancer, relating to their psychological care



N=32

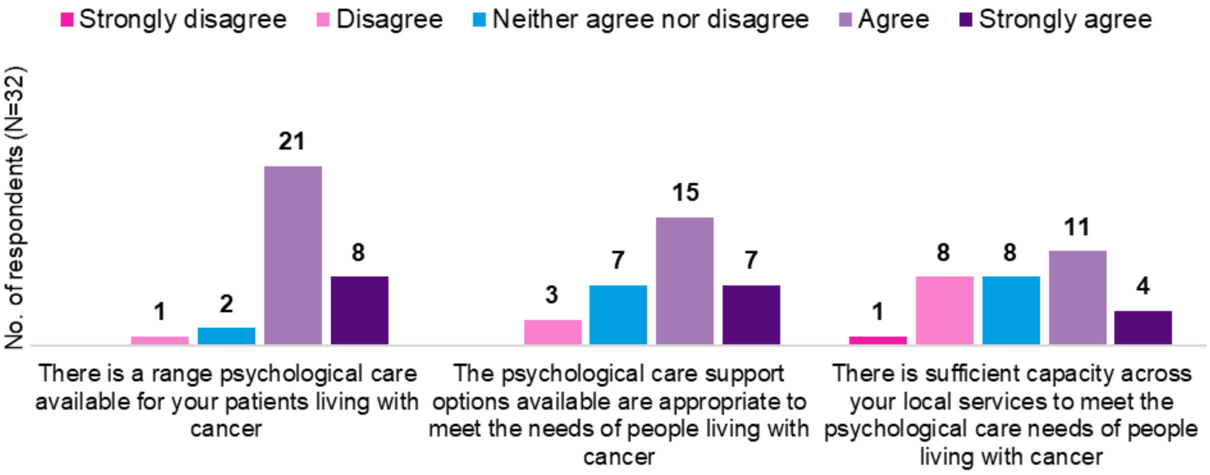
Similarly, respondents felt they had good knowledge of the psychological care available to their patients (31/32), good knowledge of how to refer to psychological care (31/32), and were confident referring to psychological care (28/32), but were again more likely to agree than strongly agree to these statements indicating there is still room for improvement.

Responses also supported the idea that the ability to meet the psychological needs of people living with cancer impacted professionals' job satisfaction and wellbeing. Specifically, feeling well equipped to meet patients' needs positively affected job satisfaction and wellbeing for most respondents (25/32), with the ability of their organisation to do so similarly positively impactful (23/32).

In the year before filling out the online survey, 16 of the 32 respondents had received guidance on how to notice the signs of psychological distress. However, only 7 had received informal support from a psychologist, 5 formal supervision from a psychologist in a group, and none had received formal supervision from a psychologist on a one-to-one basis.

Responses indicated that professionals felt there were appropriate psychological care options available for patients living with cancer at the time, but only half agreed that there was sufficient capacity to meet the demand.

Figure 7 – Professionals felt there were appropriate psychological care options available to patients living with cancer at the time, but fewer agreed that there was sufficient capacity to meet the demand



N=32

Respondents indicated supporting the psychological needs of their patients was a high priority both within their team (8.9/10, where 10 indicates highest priority) and within their organisation (8.3/10 where 10 indicates highest priority).

New service provision – what's changed

As a result of Macmillan and Cancer Alliance funding, LPFT recruited four additional Band 8A psychologists (three whole time equivalents (WTE)) to support the new service. The posts are substantive, with a commitment from the LPFT to continue the roles after the funding ends. However, they are not secured to the psycho-oncology service, and so could become more general psychology posts after the funding period. The Trust has also supported the investment with two additional full-time Assistant Psychologist posts (Band 5) for the duration of the funding period.

The Macmillan Cancer Psychology Service Lincolnshire launched in October 2023.

Increased capacity for supporting out-patients

The new service has increased capacity for supporting Level 4 outpatients referred from existing referral pathways. The Team have been promoting the expanded service to encourage additional referrals from these routes, which has resulted in increased referrals but not as many as expected. The reason for this is not known, but it is not uncommon for new referral routes to take time to become established.

The psychologists triage referrals as they come in, to determine if the referral is appropriate and how urgently a patient needs to be seen. Triaging is shared across the team on rota basis.

Once a referral has been accepted, the assistant psychologists carry out a pre-assessment usually within two weeks, to assess the patient's needs in more detail, establish if they want face-to-face or online consultations, and agree an appointment with the psychologist. The treating psychologist will then conduct an initial assessment before staring therapy.

A new in-patient service

In addition to expanding their existing services, the Team has introduced an inpatient service for two oncology wards: the Bostonian Ward in Pilgrim Hospital and the Waddington Ward in Lincoln County Hospital. This service aims to provide a psycho-oncologist on each ward one day per week. Two psychologists provide the service, alternating between each hospital.

The two wards are different. One consists of all side rooms, so patients have a private space which makes conversations with psychologists easier. The other is made up of bays with only curtains separating patients, making private conversations more difficult unless a side room is available.

The service is focused on providing patients with psychology support. Ward staff identify patients with psychological needs and refer them to the Macmillan service. There is limited scope to support staff within the time constraints, but the psychologists do provide feedback and informal reflection where possible.

More opportunities for Level 2 training and supervision

Training responsibilities are split between EMCA-CPH and the Macmillan service. EMCA-CPH provides training to ULHT staff, and the Macmillan service takes responsibility for staff based in the mental health and community Trusts.

The Macmillan service and EMCA-CPH are now reaching out to primary care, splitting the 14 Primary Care Networks between them to train and support.

The increased resource has enabled the team to deliver more Level 2 training and offer supervision to staff. While this got off to a slow start, they have now delivered training to five cohorts, including reaching some primary care staff.

The ICB wanted a consistent approach to Level 2 training and encouraged the Macmillan Service to adopt the two-day training delivered by EMCA-CPH. The Macmillan Service were unable to attend train the trainer sessions with EMCA-CPH until January 2024, which delayed their own training schedule.

The Macmillan Service felt the training would benefit from an additional day, so have expanded their training package to a three-day version which includes a taster of a supervision session. They are now delivering training regularly, with the three days of training being delivered over three months.

Key findings

Getting out-patients into treatment is work in progress

The team is actively promoting the new service to encourage referrals. This takes time and ensuring the referrals are appropriate sometimes takes some informal back and forth, as referrers build their understanding of the referral criteria. Those without Level 2 training sometimes find it more difficult to assess a patient and therefore need some support in the decision-making process.

The psycho-oncology team reported that the triaging process can be time consuming, with sometimes insufficient information from the referrer to determine the appropriate level of support. They are exploring ways to improve this, but at this stage are not concerned: referral routes are still relatively new, and they expect improvements over time as more staff are trained.

The average time from referral to starting therapy is 50 days. Online therapy can usually start quicker than for those requesting face-to-face sessions. The waiting list is reviewed regularly, and patients prioritised as necessary.

Embedding support for in-patients has been challenging

The concept of in-patient psychological support was welcomed by ward staff as it was identified as an unmet need. Prior to the Macmillan service support was limited to that provided by CNSs and the Palliative Care team, so the prospect of a psychologist attending the ward regularly was seen as a positive step forward.

Information governance issues delayed the patient-facing element of the service by several months, as the psychologists were from a different Trust. This caused some frustration, but they were able to spend time on the ward supporting staff during that time.

The amount of patient-facing support available was reportedly disappointing for the wards, who felt that more frequent visits (up to five per week) could be justified.

Long term sickness within the psycho-oncology team also reduced the level of support they have been able to provide to date, and this has impacted negatively on their ability to fully embed the service. Inconsistent attendance has resulted in ward staff not making referrals and sometimes reverting to pre-existing support within their own Trust, rather than using the new service. This is particularly the case for patients due to be discharged before a Macmillan Psychologist would next be available on the ward.

Level 2 training is crucial but inconsistent

The Level 2 training has been well-received and has the potential to improve support for patients and staff. Training also plays a role in embedding referral routes, as staff become more aware of services available and gain the confidence to refer into them.

However, it may be more challenging to embed Level 2 training into the community and primary care than it has been in acute. Whilst the ICB has promoted the training, there is no clear mandate for staff in these areas to take up the training, unlike in the acute Trust where support from the lead cancer nurse is a strong influencing factor in staff uptake.

In addition, there has been push back from some PCNs about the time commitment, with two days being too long. Given the Macmillan Service training is three days, this has the potential to reduce uptake further.

Joining up the system is a work in progress

The ICB is committed to joined up working across the system, and this began before the Macmillan funding, as demonstrated by their funding of Cancer Coordinator Care posts in primary care. The Cancer Alliance is also committed to and has acted as a convenor and facilitator to bring providers and the ICB around the table.

Regular meetings are now taking place between different providers to iron out process issues, and in some instances to redirect patients to more appropriate support. However, relationships between referrers and service providers are not as strong as they need to be. Whilst relationships have improved, some links could be strengthened further. This may come with time, though there is a risk of divergence without active intervention and monitoring from the ICB/Cancer Alliance.

A number of stakeholders recognised the need for more strategic work to ensure decision-makers in the system were able to see the benefits of the joined-up approach.

The Macmillan Service is small but ambitious

The team delivering the Macmillan Service is very committed, and they have worked well together to design and deliver the service as described. They meet regularly to reflect and problem-solve as a collective, which has enabled them to establish efficient patient assessment processes. They share responsibilities such as triaging and training.

They are ambitious and want to reach all parts of the system, but as a small team they also have limited resource with which to do so. The absence of one of the team through long term sickness highlighted the vulnerability of small teams where the absence of one person can have a significant impact.

The geography on the county exaggerates the capacity challenges, with the logistics of delivering face-to-face support stretching limited resources even further.

Data collection is challenging but important to evidence progress

Data is not being collected in a consistent manner, making it difficult for the ICB to evidence the difference the systems approach is making. A consistent dataset from across the system would help with this, including assessing patient outcomes at similar time intervals. EMCA-CPH can demonstrate reduced distress after 12 sessions, but the Macmillan Service is unable to do this as they are not measuring at this point, as they are often not discharging patients within those timescales.

Emerging outcomes

This section highlights some of the early outcomes achieved that are also indicators of longer-term outcomes being delivered by the project.

Out-patients with high level needs

The data we received from Lincolnshire only included pre-treatment data and is incomplete.

From the data available we understand 41 patients have accessed support from the Macmillan Service since it launched. The majority of referrals are from ULHT.

We do not know how many of these patients have since been discharged or what the outcome of their treatment has been.

We spoke to three patients that have received support from the Service. These patients were selected for interview by the treating psycho-oncologist.

Interviewees reported that the support made a significant difference to their lives, describing how it brought them back from a feeling of being lost and enabling them to refocus on their values and their families.

> **Didn't know where I was going – lost myself in being a cancer patient.**
>
> Level 4 patient

They described being given coping strategies and skills such as mindfulness, to help them cope better and communicate better with their families.

> **My coping skills have improved massively, and I can be much calmer.**

> **It helps my family situation, I can express myself better, I have come out stronger.**
>
> Level 4 patient

Access to support was not straightforward, and most of the people we spoke to had to seek out support themselves; it wasn't something that was highlighted as a potential need to them during their treatment. They commented on the need to bridge the gap between the physical and mental health.

One person commented that they had been told by their consultant to 'go on with their life' after treatment. The idea that after treatment everything returns to normal is now a very outdated way of thinking, but prevails amongst some clinicians.

Interviewees were also concerned that others may slip through the gaps and not get the support they needed, either because they were unaware it was there or because they wouldn't be signposted by professionals.

In-patients and ward staff

We did not receive any data from Lincolnshire in relation to their inpatient work. Therefore, we do not know how much time they have spent supporting patients or the number of patients supported. We don't have any outcome data, nor have we been able to speak to any patients treated on the wards.

The psycho-oncology team provided anecdotal evidence of the difference they had made on the wards, addressing a wide range of psychological issues on the ward for both patients and family members. They described being able to act as intermediaries between patients/relatives and staff, acting as advocates for patients and giving patients time to reflect on life.

They also described how their presence helped staff even when there wasn't much time, by providing moments of support and validation of their feelings which contributed to their wellbeing.

Staff training and supervision

Staff that had been on Level 2 training and completed a survey (n=6) gave it positive feedback, indicating that it had provided them with the knowledge and confidence to:

- Screen for psychological distress
- Identify and respond to risk
- Problem solve
- Signpost/refer to other services

All respondents felt they were likely or very likely to use the learning in their work with people living with cancer, and would recommend the training to colleagues.

We spoke to one person that had received the training, who described it as “a fantastic opportunity” to share experiences and that they had already used some of the techniques taught. They felt that the methods taught helped to build trust with and show empathy to the patients they supported.

The Service is starting to deliver some supervision sessions, but reported a reluctance from some to attend. They have renamed the sessions to ‘skill support’, as they thought the term ‘supervision’ could be off-putting.

The ongoing training and supervision of staff, if successful, should increase awareness of psychological issues for people living with cancer, give other clinical staff the skills and confidence to support some of those needs, and help embed referral routes for those with higher level, more complex needs.

System stakeholders’ perspective

Interviews with stakeholders across the system were largely positive, and a recognition of the difficulties of working in complex NHS systems and the time it takes to bring about change. Overall, stakeholders were pleased with the progress the Service had made since it launched.

Those at system level commented on the positive engagement between providers and the improved partnership working across the system. They thought the split of provision between EMCA-CPH and Macmillan Psycho-oncology Service seems to work well, with the single point of access making this a seamless process.

They recognised there were challenges ahead, in particular engaging community healthcare organisations and primary care in Level 2 training and supervision.

They also recognised that the ambitions of the Macmillan Service may be greater than their current capacity allows. To become sustainable, they thought the team needed to prioritise embedding existing services and evidencing the benefits, over plans to expand services.

3 SITE REPORT: NOTTINGHAMSHIRE ICB

The cancer clinical psychology service is based at Nottingham City Hospital which is part of the Nottingham University Hospitals NHS Trust (NUH). As well as treating patients resident in Nottinghamshire, the hospital is a tertiary cancer centre and the service has the potential to receive referrals from a wider geographical area including Lincolnshire and Derbyshire.

The service only operates within NUH; there is no overlap with any other NHS Trust in the area. It covers all cancer sites except haematology, which already has its own psychologist. Organisationally, the service sits within NUH's Clinical Psychology and Neuropsychology Department.

The service started in October 2022 and had fully recruited its team by June 2024. The team comprises seven psychologists covering five whole time equivalent roles. Previously cancer patients had been supported by a 0.2 WTE Psychologist.

NUHT had already decided to fund the service before it became part of the Macmillan programme. A number of factors contributed to this decision, including:

- Historic under-investment in psycho-oncology: as part of its Macmillan Investment Application (MIA) for the programme, East Midlands Cancer Alliance reported that only 13% of adult cancer patients had access to a permanent psychological service at NUHT (blood cancers only)
- The attention given to the psychological impact of physical illnesses immediately following the Covid-19 pandemic
- Specific incidents and potential risks relating to the care of cancer patients and their mental health at NUHT
- NUHT having been a pilot site for IAPT for people with physical health conditions – specifically cancer – in 2017

Pre-programme provision of psychological support services

What was in place pre-programme – at all levels

From 2018 until the start of the new cancer clinical psychology service in 2022, cancer teams at NUHT (excluding haematology) had the equivalent of one day a week of a consultant clinical psychologist's time between them for Level 4 support. This was widely regarded as being insufficient. The consultant has since become the head of the new service. Additional Level 4 support would have been available from the NUH's Clinical Psychology and Neuropsychology Department, but interviews with cancer teams suggest that this was not commonly taken up.

Level 3 support was (and continues to be) provided by NHS Talking Therapies, and non-integrated support is also available at the Maggie's Centre on the City Hospital Campus.

Level 2 support was available from nursing and other clinical staff, but the extent and recency of training was inconsistent and often historical: as the workforce survey shows, just over half of respondents had received training but in almost half of those cases the training was more than three years ago. No psychology-related supervision was available to staff.

Cancer workforce perspective

In the early stages of programme rollout, a cancer workforce survey was distributed to professionals who support people living with cancer, to gain their perspective on and experiences of delivering psychological care. As the service was already launched, this was not a true baseline but a snapshot in time before the service was fully embedded. The survey was open for three months from May-July 2024. At that time, the new service had been operating for slightly over a year and a half, however this was before the implementation of the service at full complement.

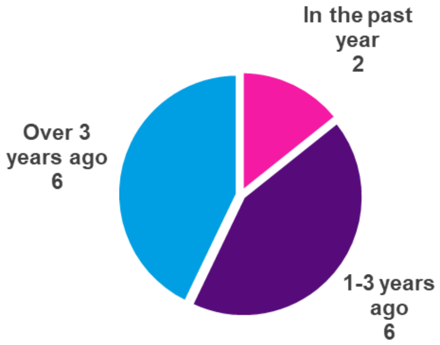
Responses were received from 26 members of the cancer workforce operating within NUHT:

- 17 Clinical Nurse Specialists

- 7 Consultants (7)
- 2 Other roles

At the time of responding 14 had received Level 2 training, all of which were Clinical Nurse Specialists.

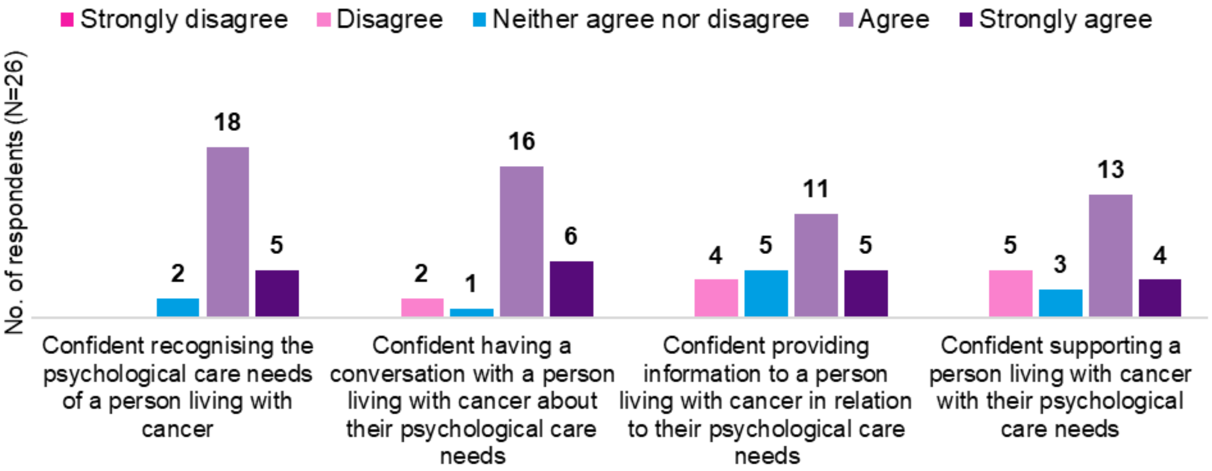
Figure 8 – Most clinical nurse specialists received their Level 2 training over 1 year ago



N=14

As Figure 9 illustrates, the overwhelming majority of respondents felt confident recognising psychological care needs and having a conversation about those needs. However, respondents appeared to show less confidence in providing information to and supporting the person in relation to the psychological care needs that may arise.

Figure 9 – Respondents were somewhat confident in recognising needs and talking about needs but less so in providing information and support related to patients' psychological care



N=26

The majority of respondents felt they had good knowledge of the psychological care available to their patients (17/26). Furthermore, when identifying psychological care needs, felt they had good knowledge of how to refer to psychological care (19/26), and were confident in doing so (19/25).

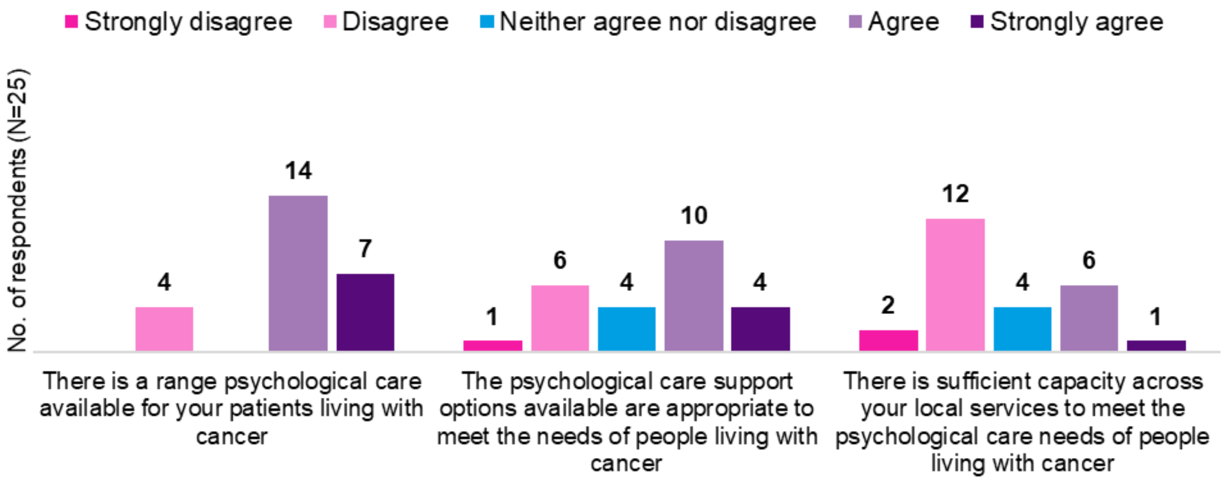
Responses supported the suggestion that the ability to meet the psychological needs of people living with cancer has an impact on professional’s job satisfaction and wellbeing. Specifically, feeling well equipped to meet patients’ needs had a positive impact on job satisfaction and wellbeing for most respondents (15/26), with the ability of their organisation to do so positively impactful for half of respondents (13/26).

In the year before filling out the online survey 6 of the 26 respondents indicated that they had received some form of guidance on how to notice the signs of psychological distress in patients. In the same time, 8 had received informal support from a psychologist, 6 formal supervision from a psychologist in a group, and 3 formal supervision from a psychologist on a one-to-one basis.

Responses indicated that the cancer workforce felt that there was a range of psychological care available to patients living with cancer, however only 14 respondents agreed that the support options available were appropriate to meet their needs. In addition, only 7 felt there was sufficient capacity across services to meet the psychological needs of people living with cancer.

Professionals felt that there was a range of psychological care available to patients living with cancer, however fewer (14/25) agreed that the support options available were appropriate to meet their needs. In addition, respondents generally disagreed (14/25) that there was sufficient capacity across services to meet the psychological needs of people living with cancer.

Figure 10 – Respondents felt a range of services were available, however challenges around the appropriateness of options and on their capacity to meet demand exist



N=25

Respondents indicated supporting the psychological needs of their patients was a high priority within their team (8.5/10, where 10 indicates highest priority) but lower within their organisation (6.8/10 where 10 indicates highest priority).

New service provision – what's changed

The new psycho-oncology service represents a marked increase in the availability of Level 4 psychological support for cancer teams and patients at NUHT compared with what was previously available: five WTE psychologist roles where there had previously been 0.2 WTE of a psychologist working with cancer patients.

The service allocates individual psychologists to specific cancer teams. Where a psychologist has responsibility for liaising with more than one cancer team, roles are organised so that, where possible, an individual covers cancers with similar likely psychological issues (e.g. body image). Psychologists attend the relevant MDTs for their respective cancer teams and maintain their own independent caseloads. In-patient referrals, which are a small proportion of the total are shared across the team.

The service acquired its full complement of psychologists over a period of around 18 months (to June 2024). This meant that the service had a gradual rollout, and different cancer teams are at different points in their relationship with the new service depending on when ‘their’ psychologist started in role. This probably accounts for some variation in awareness and engagement with the service that was picked up in staff interviews and the workforce survey.

Key findings

A service promoting a psychologically minded culture

The new service is keen to go beyond the delivery of good Level 4 support and embed a wider, more psychologically minded approach to cancer care. Psychologists and other interviewees reported that attitudes to psychological issues varied between cancer teams, with some more confident and aware of psychological issues than others. The service operates an ‘always open’ approach to enquiries and requests for support and sees supervision as a means of further strengthening the skills and confidence of the cancer workforce to provide psychological support to patients.

Embedding psychologists in MDTs is a key element of the model

The focus on embedding named psychologists within MDTs is a crucial element of service design and delivery. It is intended to:

- help build trust between cancer teams and the new service
- ensure that patients are picked up promptly
- offer opportunities to informally support the development of good Level 2 skills and behaviours within the cancer workforce

The new service recognises that formal training alone is not sufficient if Level 2 skills are going to be actively used with patients.

The service is now beyond its start-up phase

As one of the early movers within the Macmillan programme, Nottinghamshire has had fewer recruitment issues than other sites. Nevertheless, it took more than a year to recruit its full complement of psychologists. Now, it has moved on from the start-up phase and is in the process of settling into business as usual.

The staggered recruitment of psychologists over more than a year means that the experiences of cancer teams are currently varied, and the service is rightly focusing on establishing an equitable service by bringing relationships with all cancer teams up to a common level. Part of this is about raising the visibility of the team, for example via the hospital website. However, the gradual rollout has allowed the new service to learn lessons along the way that have helped to smooth integration for the more recent recruits.

This is not to say that the service doesn't have ongoing challenges. Physical space for the team has been hard to come by, and finding space and time within cancer clinics to see patients is always tricky (support is provided face-to-face and remotely dependent on patient need).

Demand for the service is still uncertain

Referrals to the service from within NUHT are encouraged through the CareFlow MIS system, although the service receives referrals via other routes, most notably email (not everyone has access to CareFlow, including the local Macmillan Cancer Information and Support Centre). Referrals from CNSs predominate, although the team will see patients referred in from community settings.

While the service did see an inevitable increase in referrals when it began, the volume of referrals and cases is not overwhelming the team: for example, they do not yet have to operate a waiting list, for example. This is not to say that the service is under-utilised. It is still working on engaging cancer teams and ensuring that the service is effectively promoted, and the full extent of demand for their services is not yet clear. The anecdotal evidence from interviews with cancer staff and the psycho-oncology team suggests that there is still unmet psychological need and that caseloads will continue to creep up in the near term.

Administrative support is lacking

The service does not have any administrative support of its own. This has left psychologists responsible for administrative tasks, which is an inefficient use of their time (e.g. dealing with email referrals and referrals on to other services). Furthermore, there is a risk that the lack of administrative resource may hamper data collection for the evaluation and more generally. At the time of writing, efforts were being made to address this.

Emerging outcomes

Staff training and supervision

The service aims to provide supervision, primarily to cancer CNSs, for an hour once per month.

The approach to supervision has been very flexible, offering different approaches according to need. For example, some teams prefer case-based discussions while others are more reflective of what individual team members have experienced and how they are feeling.

Senior nursing staff indicated that supervision was becoming part of CNS job planning. Feedback to senior nurses about the supervision has been very positive:

> **To be able to take that [psychological issue] to somebody and have a bit of a debrief and talk about what could you have done, what did you do, what could you have done differently?**
>
> **What I'm hearing is it's really, really helpful. It's not necessarily telling people that they should have done something differently, it's just exploring other ways of doing things.**
>
> Senior nurse

The service also offers training. Primarily, this involves Level 2 training for CNSs, which the service intends to run 2-3 times a year. Courses last a day. In addition, the service provides training for staff in the local NHS Talking Therapies (Level 3) service; and training for wider cancer teams (e.g. cancer ward staff).

The wider training offer is part of the service's ambition to change the culture around psychological support throughout the cancer pathway.

Supporting Level 4 Patients

The four patients we interviewed, who had received or were currently receiving clinical support from the cancer psychology team, described the following emerging outcomes and benefits of the support:

- Having time to explore their challenges and difficulties specific to their own circumstances without fear of judgment
- Validation of their negative feelings and experiences, even if they are now in a better place with their physical health
- The opportunity to process what they've gone through and how their cancer journey may have altered/impacted them as people

Staff also described ways in which they observed psychological support had helped patients, for example:

- Sharing thoughts and fears, for example about a terminal diagnosis, with someone other than their families; some patients would rather maintain a more positive tone with their loved ones
- Overcoming fears related to – and hindering – treatment, for example a fear of needles, worries visiting hospitals, or reliving trauma related to previous a previous health issue
- Identifying triggers for anxiety, especially relating to diagnosis – working through thoughts and feelings and providing ways to avoid the cycles of anxiety or the isolation and avoidance to which it can lead

4 EMERGING THEMES

Summary of learning

With just two, quite different, sites being evaluated it is not unexpected that finding common themes is unlikely. However, there are some differences and similarities in both their approaches and emerging outcomes, which we summarise in the section below.

Better provision was already a goal for both sites

Both sites had been working towards an improved level of support for people living with cancer for a number of years, having recognised there was an unmet need.

Growing awareness and acceptance of the need to provide psychological support for people living with cancer (and other long-term conditions), especially after the Covid-19 pandemic, contributed to a changing context which perhaps encouraged Trusts to be more proactive in this area.

Signs of improvement are already emerging

The staff survey responses indicated that staff working in both Trusts didn’t think there was sufficient capacity in the system to meet the needs of their patients. NUHT staff also felt there wasn’t the range of support needed. Some still report psychological support is not a high enough priority for their organisations.

Both services have increased capacity for those patients with high level/complex needs and provided support to clinical staff which should boost Level 2 support and increase referrals.

Signs are good but there are challenges remaining not least of which will be ensuring there is robust data available to evidence the difference they are making.

Relationships are essential for leading change

In Nottinghamshire, the service lead was already an established clinician within the Trust before the programme. As such he already had relationships with other senior clinicians which enabled him to drive forward change, even in the absence of external funding.

In Lincolnshire, the service lead’s relationships with key stakeholders are not yet as well established, as the service is located in a different Trust to the main cancer treatment provider. This has made it harder to drive change and provide visible leadership.

System versus single Trust approach

Nottinghamshire has had the advantage of the psycho-oncology service being based in the same Trust as the where cancer patients receive treatment. The new service has been built on existing service provision and existing relationships, and is focussed within the Trust only. The psycho-oncology service is also the sole provider of Level 4 support (EMCA-CPH does not operate in Nottingham). This has enabled the service to embed itself within cancer services and introduce psychological support a standing item in MDT conversations. Whilst this is a sensible approach in the short term, it remains a narrow focus that may be missing those in need elsewhere in the system, if we consider the system to be the entire ICS.

Lincolnshire has taken a wider systems-based approach, with leadership provided by the ICB through their Living with Cancer Programme at systems level (as well as service development leadership provided by the lead psycho-oncologists). The programme has a clear vision for integrated, personalised cancer care, which it is applying across various aspects of the cancer journey. This has the advantage of reaching across all health providers within the Integrated Care System, which is crucial for systems change. But building relationships takes time, given that the team are not based alongside cancer clinicians or indeed other teams involved in supporting people living with cancer. Consequently, progress may be slower. Furthermore, the Lincolnshire team is relatively small and trying to penetrate all parts of the system at once. This presents a risk to their ability to demonstrate robust impact.

Visibility and regular contact support cultural change

Nottinghamshire has adopted a very visible approach to working with clinicians, embedding themselves in MDTs and spending time with teams to really understand the specifics of the tumour sites they have been allocated to. This approach has enabled them to develop good relationships with clinicians and be able to offer support to staff as well as patients. Their frequent presence in the team enables conversations about patients' psychological needs to be normalised.

In Lincolnshire, the service's systems-wide focus has prevented them from being so visible and collaborative with the teams they work alongside. Irregular attendance on general oncology wards, combined with staff turnover and absence has made it difficult for the psychologists to establish the same depth of relationships with cancer clinicians. With limited time to spend on the wards, they primarily focus on working directly with patients. This leaves less time to provide support for staff and building relationships, which could impact positively on ward culture.

Providing face to face consultations is challenging

Both services offer face to face consultations even though this presents logistical challenges, especially in Lincolnshire which has such an expansive rural geography. Nottinghamshire seems to place greater emphasis on face-to-face with it being their preferred option wherever possible. Lincolnshire has an established video service through EMCA-CPH, so LPFT are left with the challenge of meeting the needs of those ULHT patients that want face-to-face consultations, as well as the referrals from the community. LPFT also offers and encourages online consultations to reduce travel time for both clinicians and patients.

During our interviews, some people living with cancer expressed concern about equity of access for those that did not want online consultations, but others also recognised the advantages and were quite happy with that approach. Both services are trying to offer flexibility to patients, by offering clinics in multiple locations, and Nottinghamshire are trying to coordinate their appointments with other clinical appointments.

Challenges

Sites have experienced and continue to face challenges. Some are shared others are unique to each site.

Data collection

Data collection has proved to be particularly challenging for both sites. This has resulted from a combination of factors including information governance requirements, lack of resources to collate data and technical/system constraints.

As well as the challenges of establishing and embedding new services, to ensure sustainability the sites will have to evidence the difference they are making. This will mean an improved level of data collection.

Patient experience and staff surveys will be an important source of evidence and so sites must find ways to expand and improve data collection using these tools.

In addition, both sites need to be able to produce robust Level 4 patient outcome data and service use data, for the evaluation to be able to demonstrate positive outcomes for people living with cancer, staff and the system.

Embedding referral routes

Embedding new referral routes takes time and effort. It is still a work in progress for both sites. It should improve as Level 2 training rolls out and staff become more aware of the services being provided. The process should also become smoother with less back and forth for information as the services become more established and Level 2 staff become more knowledgeable.

Resourcing for data collection

Lincolnshire did not get funding for the original number of psychologists requested, but were not surprised by this. They are a small, ambitious team trying to do a lot, and they secured Trust funding for two assistant psychologist posts which have proved invaluable in setting up processes and supporting data collection.

This was an asset that Nottinghamshire did not secure, and has inhibited their data collection processes and resulted in psychologists having to carry out administrative tasks which could be done by staff at a lower banding. We understand support for data collection will be available soon, and we regard it as a priority for the efficient and effective operation of the team.

Embedding supervision

Lincolnshire reported low attendance at supervision sessions previously, and perceive a resistance from some clinical staff to give it priority. We have already mentioned the challenges of providing training to community and primary care staff, so this is likely to be an ongoing challenge. They have adopted different terminology in an effort to make it more appealing. Ongoing supervision is an important element in of the model, maintaining and improving skills, problem solving and supporting staff with their own psychological needs.

Enabling factors

There are some common factors which we have identified as contributing to progress in both sites so far:

Leadership – both sites have had clear leadership from a clinical perspective; Lincolnshire have also benefited from having the ICB working at strategic level to help bring about

Increased clinical capacity – both sites have increased their clinical capacity significantly and so now have the ability to do more than just deal with a waiting list

Highly motivated professionals – both sites have recruited teams that are committed to the service they are providing and want to do more

Strategic support – there has been a shared recognition of need from the Trust, ICBs and Cancer Alliance and as a result a commitment to working together to improve support

Collective problem solving & team working - both teams have worked well to reflect on progress and jointly solve problems

Additional support for clinical staff – early indications suggest that the potential impact of increased Level 2 training and supervision could be significant in terms of supporting patients’ psychosocial needs and improving staff experience

5 PROGRAMME & EVALUATION LEARNING

The evaluation started in May 2023 with a period of scoping and design. During this period a number of challenges were identified that were inhibiting the progress of the evaluation as originally planned. As a result, the evaluation was paused and rescoped. The learning from this experience is summarised below to inform future programme and evaluation planning.

What could have gone better

Anticipation of potential workforce challenges

The Programme Team recognised a challenging shortfall in the number of trained and experienced psycho-oncologists nationwide, but the geographical variances in site location compounded the issue in unforeseen ways.

Sites outside of metropolitan areas had greater difficulty recruiting as the shortage of skilled practitioners was more acute. The absence of communities of practice outside of metropolitan areas, and the different lifestyles in different parts of the country, may have also contributed to skilled practitioners not wanting to move to new sites.

What could be done differently:

Consider the required level of fidelity to the model being replicated:

- Context significantly influences the transferability of models. If high levels of fidelity (essentially a ‘lift and shift’ approach) are required, variability in context needs to be minimised, which doesn’t necessarily lend itself to replication in different geographical areas; this is especially the case when the model being replicated was based in a large metropolitan area which has specific characteristics that can be hard to replicate.
- If more flexibility is acceptable, define the critical success factors/core components of a successful model and use these as non-negotiable criteria for selecting new implementation sites.

- We understand that the programme aimed to examine how the 'London model' could be applied in different settings, but that local flexibility was expected to be necessary. Our scoping found that sites were attempting to follow the London model closely in terms of workforce structure, with limited consideration of local adaptations. Perhaps earlier encouragement to explore alternative solutions would have been helpful, informed by a set of criteria/critical success factors as suggested in the bullet above.

Where significant workforce challenges are identified in advance, consider alternative workforce models:

- Consider more 'upstream' interventions such as influencing the design and funding of career pathways, courses and professional development that will create the necessary skills pipeline. This is obviously a longer term investment but will lead to longer term resilience in the system
- In the meantime, explore alternative skill mixes and supervisory structures to enable service delivery in the absence of sufficient senior psycho-oncologists

The impact of sustainability funding on recruitment

In the context of huge funding challenges in the NHS, some Trusts were unwilling to recruit to posts until they had secured sustainability funding. The time it took to pursue permanent funding internally led to stalled recruitment and projects paused indefinitely.

Conversely, some sites recruited without sustainability funding, offering fixed term posts. This presented another barrier to attracting skilled practitioners from other areas – even if they are interested in a change of location and lifestyle, moving from a permanent job to a fixed term contract is too risky for many.

These challenges have been compounded by the workforce challenges already discussed, so cannot be seen in isolation from them.

What could be done differently:

- Build additional time into the funding period to allow for recruitment complexities.
- Ascertain a Trust’s position on recruitment to temporary posts much earlier in the process of exploring funding.

Development of a more coordinated and collaborative regional model

Upscaling the model to a regional approach resulted in competition for professionals rather than a collaborative approach to systems change.

For example, the East Midlands Cancer Alliance sought to oversee and fund a regional approach to the model, however they seem to have been unable to gain the commitment of individual ICBs and Trusts (each autonomous and with their own priorities) to adopt a regional system-level approach. This resulted in five ICBs competing for a small number of qualified practitioners. The outcome has been full recruitment at some sites and an inability to recruit at others.

What could be done differently:

- Scope out potential for shared services and efficient use of resources across ICB borders.
- Make the system-level approach a requirement of the funding process, to ensure full collaboration.

Stronger programme governance and communication with sites

The Programme Delivery Manager has been reliant on Partnership Managers as a conduit for communication with sites, with limited direct communication with sites themselves. Partnership Managers’ have competing priorities, heavy workload and are not responsible for the practical delivery of the programme. They’re also motivated to retain funding for their local areas, which might encourage a more optimistic interpretation of progress. These factors all present significant risks and leave the Programme Delivery Manager unsighted on critical programme issues such as progress of recruitment to key posts.

The Programme Delivery Manager has built relationships with site teams through the Community of Practice, but there are still no consistent and direct lines of communication for programme management purposes between the Programme Delivery Manager and the sites. This makes effective programme management more challenging.

The recent workforce restructure in Macmillan has highlighted the fragility of this approach.

What could be done differently:

- Ensure that once funding has been agreed, hand over communication with the site leads to the Programme Delivery Manager.
- Create a governance structure with clear roles and responsibilities, which facilitates direct lines of communication between the Programme Delivery Manager and the site leads/project managers, and has a level of accountability appropriate to the level of funding being provided.

Making project management and support as a pre-requisite for funding

The absence of dedicated project managers and/or project support officers and/or assistant psychologists has made it difficult for some sites to comply with the programme reporting and evaluation requirements. Our experience tells us that the absence of such roles can also impact negatively on projects' ability to drive forward in a planned and coherent way, risking the success of the project overall.

Whilst funding was available for such posts, they were not a mandatory requirement.

What could be done differently:

- Make recruitment of project support roles a requirement for provision of funding.

Getting fundamentals in place for the evaluation

Any evaluation relies on the support of those on the ground delivering the project to open doors and help oil the wheels of evaluation processes, such as distributing surveys, accessing data and meeting information governance requirements. During the scoping stage we did discuss these requirements in general, but it wasn't possible to get into the details (because we didn't know them) and ask professionals to start committing resources until the evaluation was underway.

These processes have taken longer than anticipated, and onboarding other stakeholders needed to support these processes has taken time. It has transpired that capacity has been a constraining factor in moving these processes forward.

In hindsight, further exploration of capacity and making some other connections to prepare the ground for the evaluation may have been beneficial, even though we didn't know the specifics of how we would do the evaluation. It is a difficult balance to strike, asking for time when there isn't a definitive ask whilst making sure key people are lined up to progress the work when everyone is ready.

What went well

Relationships and active risk management

Regular and frequent contact between the external evaluation team, the Macmillan evaluation and impact team and the programme delivery manager has ensured all involved have been sighted in emerging risks, issues have been escalated promptly and there has been shared ownership of resolutions.

The strong relationships have resulted in very open and honest conversations and a realistic and pragmatic response to the challenges being faced by the evaluation team.

Openness and adaptability of Steering Group

The capacity of the Steering Group to recognise the challenges being raised, accept and adapt to the changes has been instrumental in moving the evaluation forward in a positive way.

Reflections on timing of the evaluation

From an evaluator's perspective, being involved at the beginning of a programme is a huge advantage, enabling us to understand the programme and design an evaluation that meets the needs of the programme and that can be integrated from the beginning. It maximises the opportunities to gather data, establish baselines and gather learning. This is especially true with complex systems change programmes.

However, the sites were not as ready to go as anticipated, and that caused delays in the scoping process and in the period between scoping and going live. This was compounded by the workforce issues which delayed going live further (and in some cases indefinitely).

What could be done differently:

- Bring in the evaluation at the point when delivery has not yet started but all in-scope sites have been confirmed, have recruited to all key posts and are within three months of going live.
- Where there is likely to be a staggered start, ensure that at least the 'early adopter' cohort fit the criteria described in the bullet point above.
- However, bear in mind that some sites will fail to launch, launch and falter, or need a relaunch, even in optimal conditions. Complex systems change is innovation, and therefore comes with failures too. Having the evaluation alongside those sites that 'stumble' can provide essential learning and support them in recalibrating and relaunching.

It can be challenging for sites to visualise and commit to an evaluation yet to be defined, and in this programme sites were expecting a clearer indication of the processes earlier than they were available.

What could be done differently:

- Ensure funded projects are aware of the complexity and emergence of the evaluation process, before the evaluation is commissioned. This is something they need to know ahead of committing, so that they are prepared for uncertainty and can ensure they have capacity and flexibility to adapt to whatever the evaluation requires, within reason

6 NEXT STEPS FOR THE EVALUATION

Phase 1

The evaluation will continue as planned for Lincolnshire and Nottingham. This will include the following data collection processes:

- The patient experience survey will be disseminated to Lincolnshire patients that have been diagnosed post service launch
- The cancer workforce survey will be disseminated in both sites
- Ongoing collection of outcome data for people receiving Level 4 psychological support
- Ongoing collection of post Level 2 training surveys
- Interviews with all key stakeholders
- Collation of service use data pre and post service improvements

Consideration will be given to how we capture the difference, if any, in patient experience in Nottingham since the service was launched. However, a more reliable way of securing survey responses must be agreed in the first instance if this is to be an option.

We will work with both sites to ensure their outcome data collection processes are going to be able to deliver the data we need to evidence the difference they are making. This is a key data for the evaluation which is currently not being delivered by the sites.

We will also continue to work with sites on data sharing to enable the collation of service use data to evidence whether improving psychological support impacts on the wider system.

If the data identified is made available, we will produce a mini economic assessment next spring with a final report and more extensive economic assessment to be delivered next August.

Phase 2

Given the challenges experienced by site in collecting outcomes data and the ongoing challenges of the programme in recruiting and getting projects off the ground Phase 2 has been re designed to focus on learning rather than outcomes. This approach is based on the assumption that there is agreement that improving psychological support is a good thing, worthy of investment and that Trusts and cancer alliances want to bring about change. The learning gathered from those involved in the pilot will help inform those to follow how to make it work.

The overarching learning question will be:

What does it take to successfully embed psychological support within a health system?

To answer this we will explore the following questions with a sample of sites:

- What is the context in which improved psychological support has been implemented? And to what extent has this influenced success in implementing and sustaining the service?
    - including structure and condition of the health system, presence of pre-existing or complementary services to build from, geography of the locality, culture within the health system, previous events
- Who needs to be involved in bringing about sustainable change?
    - who is driving and leading change?
    - to what extent have projects involved and engaged with other key stakeholders in the system?
- Where sites have secured permanent funding for psychological care, what factors have influenced this?
- How has the recruitment process impacted on implementation?
    - exploring the challenges sites have had, and how they have overcome them.

- What different workforce models have been adopted and how have they delivered the changes? How do they differ from the London model? What have been the advantages and disadvantages of these different models?
- To what extent has the Macmillan funding and other forms of support been determinants of success?
- What other support have sites needed to bring about change? Who has provided that support?

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