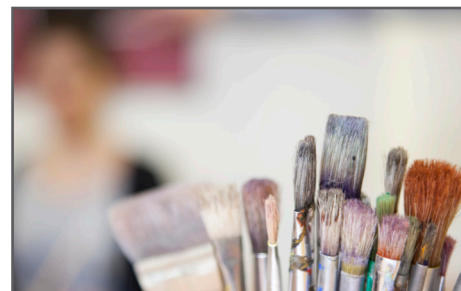
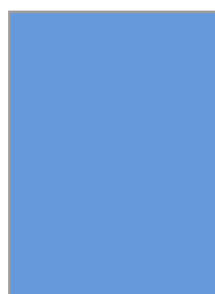


Psychological support for people living with cancer

Commissioning guidance for cancer care in London



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I was a self-employed business consultant travelling the world with my work, before I was diagnosed with stage 1V Mantle Cell Lymphoma (blood cancer) in 2007. My prognosis was poor, but after aggressive chemotherapy and a stem cell transplant from an unrelated donor, so far, I have managed to defy the odds and remain in remission, but this is very far from the end of the story.



My treatment has left me with continuing complications which have involved me in long stays as an inpatient, and years as a regular outpatient. I have been close to death on several occasions, as my body continually rejects my new cells, and have required years of blood treatment to enable me to maintain a reasonable quality of life.

From being a very confident and independent person, I now rely on my wife and family for support, and the healthcare system to keep me alive. My treatment meant I was unable to return to my previous work, and after years of unreliable health there is no employer interested in giving me a job. As a person who lived for their work, this was a massive psychological blow.

I found very little support in the system at any stage, and from my communication with other people with cancer they couldn't either, which I found truly shocking. This encouraged me to try and improve things. I started by volunteering with cancer charities, and I was invited to speak at health conferences about my experiences. But quickly the demand to hear my story increased and I was encouraged to use the internet, to share more effectively.

It was felt that a blog might be the best way to share my story, so Chris's Cancer Community was born. A place where I could share my experience and others could share theirs, so together we could try and make sense of what was happening to us. For many who are lucky enough to survive cancer, this is where our real problems can start, once we leave the hospital environment.

Employment, financial, physical and psychological are just a few of the issues we may face, problems which many people are not comfortable to share. By talking openly about my own issues I have tried to encourage people to do the same with theirs. My website offers a safe environment to share experience and ideas and encourages honest conversations on difficult subjects. This has now expanded onto Twitter and Facebook, and my work is read by clinicians and individuals with cancer around the world.

My experience of cancer support is sporadic at best. There is a lot of good work being done, but mostly uncoordinated and disjointed. There is no overall responsibility for support outside the health service, meaning it can be a matter of luck or not if you are able to find the appropriate help you require. With my business skills I am endeavouring to connect service providers with people who need their help. By communicating constantly with people affected by cancer through my numerous platforms, I want to reach out to more people and be able to help signpost them to the support they need. Independence is the key to my work, as my only agenda is to improve support for people.

Survivorship is a wonderful thing, but it brings with it a unique set of challenges, which even the most independent of us need help with at times. A life after cancer can be as daunting as facing the disease itself!

Chris Lewis

Chris's Cancer Community

FOREWORD | DR MATTHEW PATRICK AND DR TONY BRZEZICKI

Being told that you have cancer is a devastating experience for the person who has been diagnosed, their families, friends and carers. The roller coaster of having to make choices around treatment options, then coping with the treatment and coming through the other side, either cured or living with cancer is not something anyone is prepared for. People need holistic treatment and support.

It is important to remember that the effects of cancer are not just felt at the time, though, of course, this is crucial too. People can live with the enormity of what has happened long after the cancer has been treated and the specialists have done their job, and so often experience fear of the disease returning or have to deal with the long term effects their treatment may have caused.

In order to improve access to the services we have and information available, it is extremely important to develop strong working relationships between cancer specialists, mental health professionals, GPs, clinical nurse specialists (CNSs), supporting charities and commissioners to ensure those affected by cancer are getting the right support for them. By conducting holistic needs assessments and care planning with patients, NHS professionals can support people in finding services to help them. We know that around three quarters of people affected by cancer need access to psychological and emotional support which includes carers, family and friends.

Through the development of this guide we have identified high priority areas of improvements. As a collaboration of commissioners, patients and service providers, we are in a position to achieve and set a benchmark for the future of holistic care for people affected by cancer.

Now is the time to address the link between mental health and physical health, so staff and people living with cancer alike can benefit from learning more about this key link. The strategic planning groups (SPGs) in London and their local clinical commissioning groups (CCGs) need to ensure there is a coherent approach to commissioning psychological support for people living with cancer.

Commissioning intentions for 2016/17 provide a real opportunity for commissioners to take this work, the evidence in this guide and recommendations forward.

Dr Matthew Patrick

Clinical Director, London Mental Health Strategic Clinical Network
Chief executive, South London and the Maudsley NHS Trust

Dr Tony Brzezicki

Co-chair, Cancer Commissioning Board for London
Chair of Croydon Clinical Commissioning Group



Above: Dr Matthew Patrick
Below: Dr Tony Brzezicki



EXECUTIVE SUMMARY

Earlier diagnosis and improvements in treatment mean that more Londoners are surviving cancer. The impact of psychological morbidity when living with and beyond a cancer diagnosis is now well-recognised and has consequences, not only in terms of quality of life but also in overall healthcare outcomes and costs.

Despite this, the provision of emotional and psychological support across the capital is often limited and certainly inconsistent. London is also rated as the poorest region for patient experience when it comes to cancer treatment.

The London Mental Health Strategic Clinical Network, in partnership with the Transforming Cancer Services Team for London, has produced this guidance to support commissioners and service providers in improving psychological support across the cancer pathway.

Mapping what we do now, looking at the evidence, and listening to a range of commissioners, healthcare professionals and most importantly people with experience of cancer we have developed the following recommendations:

- 1. Timely access to commissioned support should be available for the whole cancer pathway. Throughout the pathway people with cancer should be actively informed of the potential need for psychological support and given guidance on access and availability.**
- 2. Individuals should have access to a range of emotional and psychological support according to need.**
- 3. Psychological support should be available to families and carers.**
- 4. All health and social care staff involved in cancer care should have education, training and supervision that enables them to identify emotional problems and provide psychological support at an appropriate level.**
- 5. Commissioners should ensure that Information and Support Centres (ISCs) are available at all acute trusts.**
- 6. All people living with cancer should be offered a Holistic Needs Assessment with care planning at key points along the pathway.**
- 7. Community provision for emotional and psychological support should be supported and developed.**
- 8. Specific groups should be proactively supported.**
- 9. Psychology services providing support to cancer centres should be located on-site.**
- 10. Co-production with people affected by cancer and their carers should be integral to service development.**

These recommendations cover commissioning, workforce education, training and supervision, and service development and delivery. The guidance outlines:

- » The importance of improving access and provision to psychological support
- » The variation that exists across the services in London
- » Examples of best practice that commissioners may wish to apply locally

Taken together they will lead to a step change in the way we meet psychological need in cancer care. And while the guidance deals specifically with cancer, this model will apply to other long term conditions. *(See page 16 for full recommendations.)*

Provision for children and adolescents has not been included in this guidance as the pathways for cancer care, including access to mental health and psychological support, differ from those for adult services. We would, however, consider that the principles expressed in these recommendations apply across the whole life course.

INTRODUCTION

In the UK one in two people born after 1960 (one in three born before) will be diagnosed with some form of cancer during their lifetime¹. In London, we know that there are around 186,000 people who are living with and beyond cancer (those who were diagnosed within the last twenty years)². That's enough people to fill Wembley Stadium twice.

Cancer is the leading cause of premature mortality in the capital and every year 30,000 people here receive a cancer diagnosis. However, in 2013, people with a cancer diagnosis rated London as the region with the poorest experience for the treatment of cancer. Nine of the ten poorest rated hospital trusts in England were London centres.

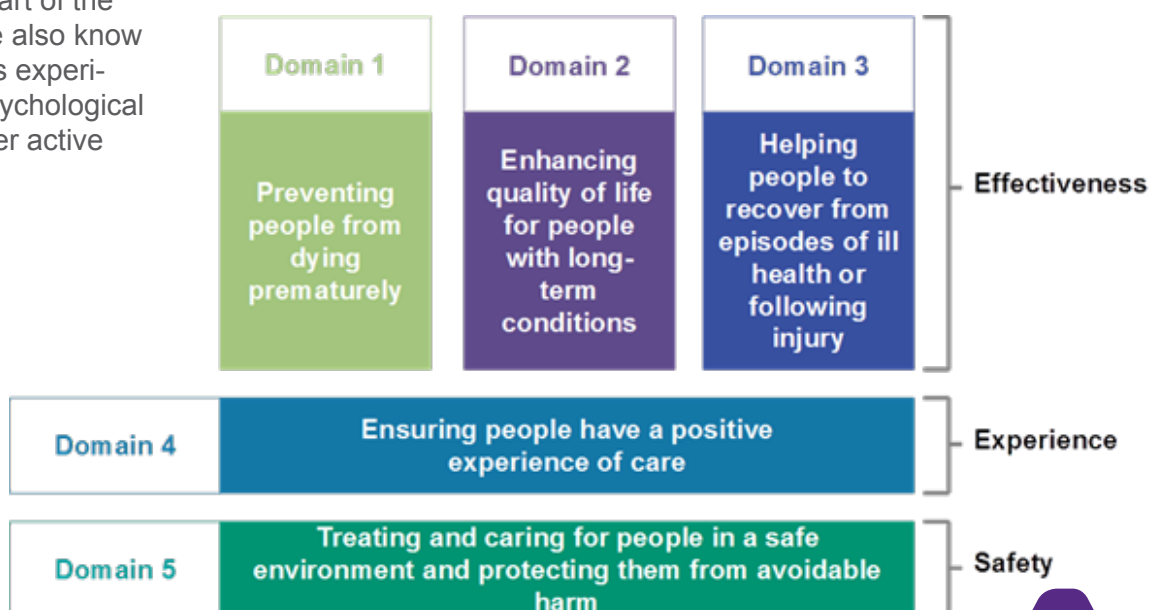
Each individual will experience a range of psychological and social problems as a result of their diagnosis and treatment-related adverse effects; the impact of cancer doesn't stop when the treatment does. People often feel more lost and worried after the 'race' during the treatment phase is over. Anxiety, depression and other emotional symptoms are common and can sometimes form the most challenging part of the cancer experience. We also know that carers and families experience emotional and psychological distress during and after active treatment.

- » 64 per cent of people living with cancer have practical or personal support needs, and 78 per cent have emotional support needs; these include needs related to mobility, practical tasks and personal care etc. The majority (75 per cent) say that these needs are caused by their cancer or cancer treatment³.
- » 58 per cent of people feel their emotional needs are not looked after as much as their physical needs⁴.
- » At diagnosis, half of all people living with cancer experience anxiety and depression sufficient to impair their quality of life. One quarter will have ongoing symptoms for the next six months. Psychological morbidity impacts upon not just quality of life, but survival⁵.
- » 61 per cent of people caring for someone with cancer experience some kind of impact on their lives as a result of caring. Yet very few receive a formal carer's assessment³.

These findings were highlighted in a report, *Better Health for London*, written by the London Health Commission⁶. Progress is being made with the introduction of two integrated cancer systems, London Cancer and London Cancer Alliance, working to provide improved health outcomes and experience across all trusts in London through raising standards and better integration of care.

The strategy for living with and beyond cancer was formed by the National Cancer Survivorship Initiative. This includes implementing the recovery package (*Appendix E*), managing the consequences of treatment effectively (including emotional and psychological needs) and stratifying patient pathways for breast, colorectal and lung cancers in particular.

Figure 1. NHS Outcomes Framework model



INTRODUCTION

Purpose

The London Mental Health Strategic Clinical Network and the Transforming Cancer Services Team for London have undertaken this work as we believe that ensuring appropriate and adequate psychological support will be integral to the drive to improve cancer services. The main purpose of this guide is to inform the cancer commissioning strategy for London, the *Five year forward view* and to improve psychological support for people living with and beyond cancer^{7, 8}.

The recommendations in this guidance also support commissioners in delivering improvements against the NHS Outcomes Framework (figure 1). In addition to our broad objective of improving the quality of life for people living with cancer (domain 2), we need to ensure that people have a positive experience of care, facilitate recovery after cancer treatment and, of course, reduce the risk of premature death by suicide (domains 1,3, and 4).

The guide itself comes from a number of strands of work. We have undertaken a mapping exercise to determine current service provision across London and collated a directory of models of good practice from local services and further afield.

Central to the report is the series of recommendations that will guide commissioning for psychological support. These have been developed using: 1) clinical evidence; 2) needs assessments by the two integrated cancer systems; and 3) consultation with a broad group of enthusiastic stakeholders.

A clear focus is needed to provide high quality and timely access to psychological and emotional support during and after treatment for cancer. Notably, this has been highlighted by people with a cancer diagnosis and their carers as key to a good recovery.

Of course in trying to develop accessible, consistent and effective psychological support it is vital that we listen to the voices of people with lived experience of cancer. So that has been our starting point.

Dr Steven Reid

Consultant liaison psychiatrist,
Psychological medicine, Central
and North West London NHS
Foundation Trust

Dr Afsana Safa

Associate GP lead for
Transforming Cancer Services for
London



A number of people with lived experience and carers contributed to the development of this guidance through two workshops held with commissioners and healthcare professionals and via email for those who were unable to attend in person. We have summarised their experience and views on the need for psychological support, cancer care pathways to care and what has helped them as individuals (See Appendix F).

Why does psychological support matter?

A diagnosis of cancer is life changing. The impact on individuals includes living with continuing uncertainty about prognosis or life expectancy. It includes changes in appearance or body image, chronic pain, altered abilities or limited mobility.

Cancer can exacerbate existing mental health problems like anxiety or depression. It can also make practical worries or problems more acute such as relationship tensions, money worries, or difficulties with work or study.

The impacts on those who love and care for people with cancer are many and varied, and individuals emphasise the need to recognise this is also of critical importance.

“My husband had gone into hospital expecting to undergo a major operation to remove a tumour. He was prepped, ready to go and waiting for his theatre slot. I left him for 10 minutes, to have a sandwich, and returned to find that while I was gone the consultant had seen him, on his own, and had delivered the devastating news that he had cancer, and that it was terminal. We were then basically left with no support or contact until the oncology appointment a week later. A week might not seem long to some people, but it felt terribly long to us, while we struggled to get our heads around the news and cope with our fears about what lay ahead.”

— Wife of late patient

“While I was having chemotherapy I was also trying to cope with working part-time because of money worries, coming to terms with knowing I wouldn’t be able to have children, and getting used to how I looked after surgery. All this time I was never offered emotional support – and when I said I was struggling was told I needed to ‘think positive……’! I thought I was doing pretty well just getting through the treatment, holding onto a tough job, and keeping my relationship strong, but I could really have done with some expert help with the depression and anxiety I was experiencing as a reaction to so much change.”

— Cancer patient

Diagnosis of cancer is a significant life event that can be a catalyst for mental ill health – how people cope depends on their psychological resources, support etc.

Diagnosis of cancer is a significant life event that can be a catalyst for mental ill health.

Everyone who receives a cancer diagnosis should be offered support to boost their psychological resilience whether or not they are showing immediate symptoms of psychological distress.

“Although I was the patient, I was more worried at the time I was having treatment about how my husband and kids were coping with all the changes and with seeing me so sick. I ended up feeling I had to be the strong one, because no one else seemed to pick up that they were falling apart. It was hard on all of us – and it also meant that the emotional impact only hit me some time later. I had a tough time with depression which came along just when everyone else thought I was through treatment and should be feeling fine.”

— Cancer patient

“The cancer pathway should be extended to include a life-long concept of recovery. The impact of physical changes and the fear of recurrence is a physical and psychological reality for the individuals and families long after discharge from specialist. From a mental health perspective, these psychological conditions resonate with post-traumatic stress disorder. Why should cancer survivors have less good treatment than survivors of other physical / psychological trauma?”

— Husband and NHS manager

Challenges in accessing psychological support

Psychological support matters at every stage of the cancer journey.

Some people report they have been well supported by staff in cancer treatment settings or primary care. However, far too many do not experience this.

It often seems that each part of the healthcare system hopes someone else is assessing and responding to psychological support needs.

There is a perception that people living with cancer and their carers are adequately supported by charities and third sector organisations but some people may not have access to suitable services or may not know where or how to find what they need.

Some people still face stigma in their communities or feel unable to cope with other people's fears or assumptions about cancer.

The idea that people need to just *'be strong'* and *'think positive'* to survive cancer can make it more difficult to admit being afraid or feeling negative or overwhelmed, in turn making some individuals feel they should struggle on rather than asking for help.

We need meaningful choice about advice and support options, both in terms of timing and approach.

Lots of approaches to support can work – but we need to ensure that the providers are themselves trained and supervised.

What has helped?

Many individuals and carers find information centres within treatment settings are a good starting point.

Many find opportunities to share experiences with other people helped.

Online communities coordinated by people with lived experience and online forums or chats offered by several cancer charities were cited as examples of what works for some.

Some individuals and carers say that individual staff are the most valuable source of informal psychological support – from CNSs, to GPs, to oncology consultants.

Although specialist support can be helpful at any stage, the two points in the process where most people reported this was needed was in the early days following diagnosis, and at the end of active treatment. Many individuals report that the impact of cancer on body image, abilities, roles or relationships only hits home once active treatment ends, or when they attempt to resume previous responsibilities like working or being full-time parents or carers.

"I found the information that it is ok for me to come back in two or five years very helpful; and the information that some people suddenly feel the enormity of what's happened after such a long time when the immediate time has felt so numb, flat and somehow emotionally disconnected..."

— Patient

"As a patient who has been living with metastatic incurable cancer for nearly five years, and received various different treatments during that time, I can honestly say that the treatment and support received throughout my cancer journey at a London NHS hospital has been more than I could ever have wished for. I strongly believe that my positive cancer experience is due to the continued support I receive from my CNS, and from the excellent team of consultants who from the outset have treated me as an individual, and not as a stereotype or a statistic."

— Ovarian cancer patient

"CNS staff helped me, and we need to have lots more of them please – including more male nurses, and perhaps some who aren't in uniform which can seem like a barrier. The comfort and atmosphere of the treatment environment also matter – and so does positive staff morale."

— Patient

Helen Davies

Patient experience-coordinator





EVIDENCE OF THE NEED FOR PSYCHOLOGICAL SUPPORT

Evidence of need for psychological support, and the availability of effective treatments and services

Individuals report finding the emotional effects of cancer and its treatment more difficult to cope with than any physical or practical effects. Yet 60 per cent say that less care was offered for their emotional needs than their physical needs. Sixty per cent of people self-identifying as depressed got no support at all⁹.

The 2013/14 National Cancer Patient Experience survey found that 20 per cent of people can recall no information being offered about support or self-help groups, and 35 per cent of day patients and outpatients said they did not receive enough emotional support from hospital staff¹⁰.

People affected by cancer experience a wide range of psychological distress and psychiatric disorder. In the first year after cancer diagnosis about 25 per cent of people experience psychological distress, with symptoms of anxiety and depression severe enough to affect their quality of life¹¹. Cancer treatments, such as surgery and chemotherapy, can also be a cause of distress and psychiatric disorder. Fifty per cent of people with a cancer diagnosis now survive for a decade and cancer-related distress may persist or arise during prolonged survivorship. Many people feel particularly vulnerable as treatment ends, or around anniversaries and review appointments. People with advanced disease have even higher levels of distress, including what Dame Cicely Saunders called 'total pain'.

Taking major depression as one specific example, the overall prevalence among those living with common cancers is 8 to 13 per cent¹², rising to 20 per cent among those with advanced, end-stage disease¹³; it has also been reported that hospital inpatients with cancers have high rates of delirium.

The consequences of not meeting psychological support needs are far reaching. Individuals experience amplification of bodily symptoms, worse quality-of-life and desire for hastened death. Eight per cent of all people attending cancer out-patient clinics report passive suicidal ideation in the preceding two weeks¹⁴. The rate of completed suicide among people with cancer as a whole is twice that of the general age and sex-matched population. Certain tumour types, such as lung cancer, head and neck and upper gastrointestinal cancers have even higher suicide rates¹⁵. People with cancer and depressive illness are three times more likely to be non-adherent with cancer treatments. Twenty-five studies have now confirmed increased cancer mortality among people with comorbid depression¹⁶.

There are healthcare use and economic consequences, too. Comorbid mental illness increases the healthcare costs for an individual with a long term medical condition by up to 45 per cent¹⁷. Older people with complex mental and physical comorbidity have increased lengths of stay in hospital¹⁸. Effective, evidence-based, safe, responsive and caring psychological and psychiatric treatments are available to address much of this distress.

There is now a considerable literature on the effectiveness of various psychological and pharmacological treatments for people living with cancer. Anxiety and depression can be prevented or relieved by cognitive behaviour therapy (CBT)¹⁹, acceptance and commitment therapy (A&CT)²⁰, problem-solving therapy²¹, short-term psychodynamic therapy, supportive-expressive therapy²², mindfulness-based therapy, psycho-educational²³ and relaxation packages²⁴. Antidepressant medication is of proven value for more severe depression and has been used as a preventative in selected populations. In addition to this published trials evidence, clinical outcome data from psychological support teams in London cancer centres shows positive response to a range of interventions, including cancer counselling, CBT, A&CT and outpatient pharmacotherapy.

Dr Mark Barrington

Chair of the psychosocial expert reference group for London Cancer

Dr Andrew Hodgkiss

Co-chair of the mental health and psychological support pathway for London Cancer Alliance



NORTH AND EAST



Cancer commissioning perspective

We conducted a brief online survey exploring psychological services for people with cancer provided by London CCGs. CCG cancer leads were invited to detail the type of services and their remits within their CCG as well as comment on any commendable best practice models providing holistic treatment for people with cancer they were aware of.

Twenty-one CCG cancer leads responded to our survey (See *Appendix I*). A majority of cancer leads thought that improving access to psychological therapies (IAPT) services or similar counseling services in primary care would be best placed to provide psychological support in the first instance.

A number of respondents use third sector services such as Macmillan, Maggie's Centres and Paul's Cancer Support Centre (See *case studies in Appendix C and D, and service map in Appendix K*).

A smaller number of respondents suggested that psychological care would be provided by liaison psychiatry and clinical health psychology services at local cancer centres. Although the response rate was low, the emerging picture is that IAPT services are used as first point for referral and that there is no agreed referral pathway, but rather a number of support options based on local availability of NHS and third sector services. Commended services by CCG cancer leads included Paul's Cancer Support Centre, Macmillan and The Dimpleby Cancer Centre at Guy's and St Thomas' Hospital (See *case studies in Appendix C and D for details*).

Services for people with cancer who are in active treatment

The provision of specialist psychological support for people with cancer in London has not been systematic.

Psychiatrists, psychologists and counsellors co-located with medical and surgical services are generally well integrated into multi-disciplinary teams (MDT). In addition to providing interventions to individuals and (in some cases) families, they also offer training, consultation and supervision to other members of the team. This dissemination of psychological skills makes best use of the limited resource. In some cases, there are examples of these acute based services offering training and support to less specialist colleagues in long term conditions Improving Access to Psychological Therapies (IAPT) services.

All acute trusts have an information and support centre. However, only three have the enhanced services; these combine practical, emotional and social support delivered in a welcoming and non-stigmatising environment (Maggie's West London at Charing Cross Hospital, Macmillan Support and Information Centre at University College London Hospital and Dimpleby Cancer Care at Guy's and St Thomas' NHS Foundation Trust).

Cancer centre provision²⁵

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

Level 2 provision

Level 2 staff (usually clinical nurse specialists) are professionals who have received additional training in psychological assessment and intervention. They also receive monthly group supervision to maintain and extend their skills. Across London, evaluations of the training and supervision are consistently good. However, where trusts lack level 3 or 4 resource, level 2 provision is affected.

While the majority of teams meet the relevant peer review requirements, there are a significant number of trusts that are currently unable to ensure that all CNS staff have access to the training and supervision required for them to offer level 2 psychological care.

Palliative services

Much of the specialist psychological resource available to people in palliative care sits within the hospice sector. However, there are several examples of hospital and community teams employing psychologists as part of their core staff team. In at least two boroughs (Newham and Tower Hamlets) there are psychologists

providing seamless care following individuals across the pathway and when necessary, providing home care services.

It should also be noted that professionals working in palliative care also provide support to people with non-malignant disease, with this accounting for approximately 15-20 per cent of their time.

While other settings tend to have a skill mix including both levels 3 and 4, it is unusual for London hospices to employ level 4 professionals.

IAPT support for people with cancer

Survey of IAPT provision

The Improving Access to Psychological Therapies (IAPT) services were originally tasked with providing treatment for adults with anxiety and depression through a stepped care approach as recommended by NICE guidance. IAPT services typically offer access to guided self-help interventions as a first line.

NICE approved therapies (primarily CBT) can then be offered depending on need and past experience of treatment.

The Department of Health strategy *No health without mental health* proposed the expansion of the IAPT programme to include people with long term conditions and medically unexplained symptoms. Some services were selected to become pathfinder sites piloting and evaluating the development of stepped care pathways for long term conditions from 2012.

With the input from IAPT leads, a questionnaire survey was developed to explore the provision of the 32 London IAPT services for people with cancer (*See Appendix J*). The survey, sent to IAPT leads and deputies in February 2015, was shared electronically to minimise error and reduce the potential for respondents to omit questions. Twenty-nine responses were received, covering 30 of the 32 IAPT services across London. Only one of the IAPT services is provided by the third sector; all others are provided by the NHS.

MAPPING LONDON PROVISION

All but one IAPT service accepts self-referrals. (*All results can be found in Appendix I.*)

Summary of key findings

Almost a quarter of the responding IAPT services were selected pathfinder sites for long term conditions.

Thirteen per cent were providing specific care pathways for cancer. However, 60 per cent of respondents reported that they were providing a generic stepped care pathways for long term conditions. Many services also provide specific pathways for other conditions such as diabetes, cardiovascular disease or chronic pain (see appendix I). None of the IAPT services responding to the survey would exclude

people with cancer and those IAPT services without designated cancer pathways signpost to other appropriate services within the NHS (such as secondary care psychology) or Macmillan cancer support.

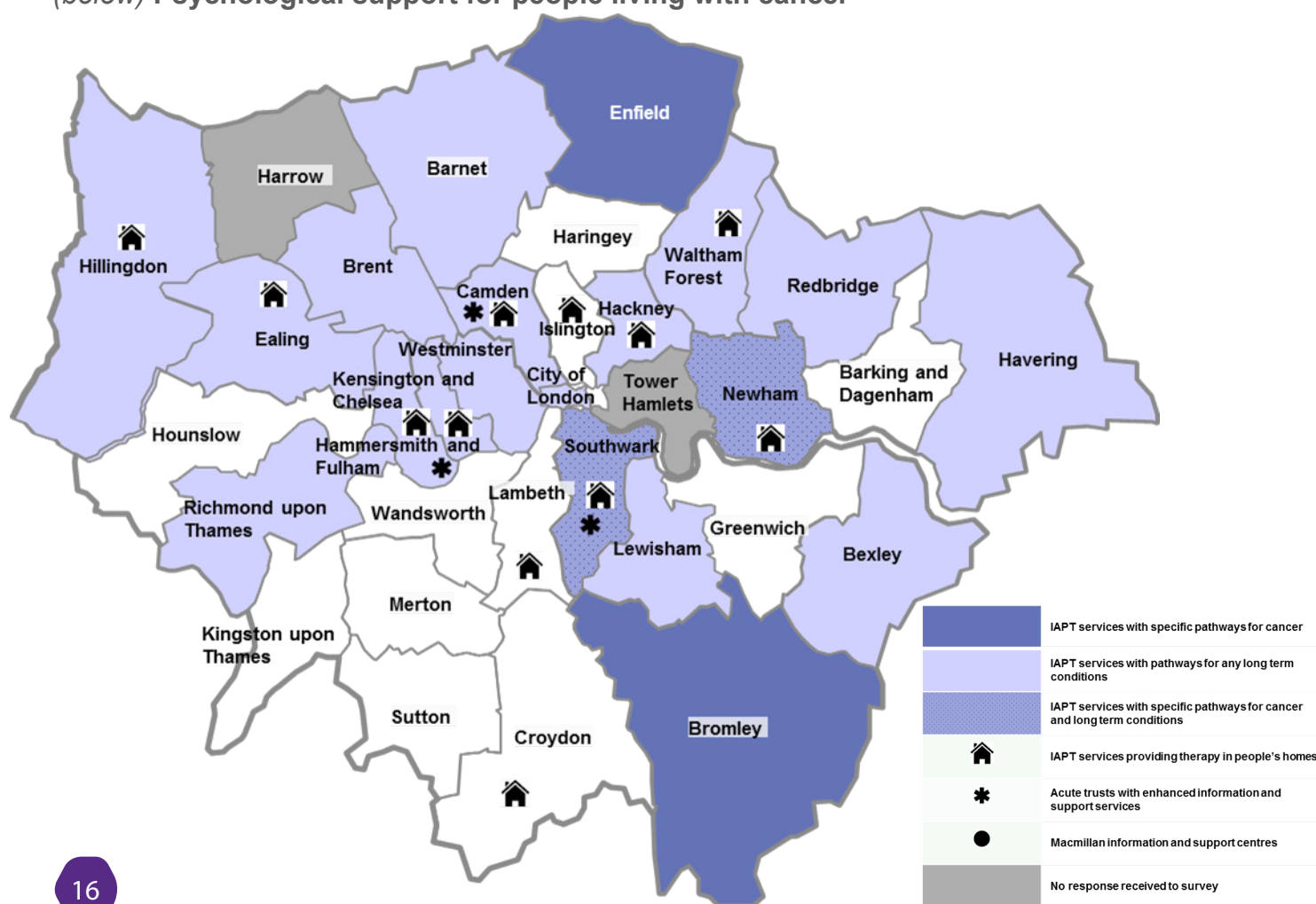
Almost two thirds of services are able to identify cancer patients within their data set. The data suggest that 0.5-2.0 per cent of patients who have accessed treatment are people with cancer.

Forty-one per cent of the services reported having clinical health psychologists with expertise in long term conditions. Several of the other services receive supervision and training from health psychologists in aligned trusts or are in the process of recruiting into this role.

In those IAPT services providing care pathways for cancer there is variation in the range of interventions they are able to provide. 45 per cent of all IAPT services are able to provide some treatment at home. Some of those services unable to provide home visits offer telephone therapy or contact via other forms of telecommunication (eg Skype).

As expected, we found considerable variation in service provision across the capital. We also found that local providers have developed a wide range of clinical models to address a recognised need as outlined in some of the models outlined below (*See Newham case study, page 57*).

(below) Psychological support for people living with cancer





The following recommendations have been drawn together from the surveys, co-production workshop and discussions with people living with cancer and healthcare professionals. These are designed to guide commissioners in the commissioning of services, service improvement and should also be a useful resource for providers and practitioners.

1. Timely access to commissioned support should be available for the whole cancer pathway.

This should include the following points of care:

- » Diagnosis (of primary, metastatic or relapsed disease)
- » Active treatment (with curative or palliative intent)
- » Rehabilitation and aftercare
- » Survivorship – living with and beyond cancer
- » End of life care

Throughout the pathway people with cancer should be actively informed of the potential need for psychological support and given guidance on access and availability. (*The range of psychological interventions that should be available in appropriate settings is specified in Appendix A.*)

The provision of psychological support should be explicitly quantified in relevant service specifications. Whilst recognising that commissioning for psychological support comes from a number of sources, there should be an integrated approach to service development in order to reduce duplication and gaps in provision. This would reflect that for an individual the cancer pathway is rarely linear.

There are case studies available that support an integrated approach (eg a whole systems approach using a capitated budget for a population of people with cancer²⁷).

2. Individuals should have access to a range of emotional and psychological support according to need.

NICE have developed guidance which provides a framework for the organisation of provision using a four-level model²⁵. Commissioned support should have a demonstrable evidence base and third sector services should be included in the network of provision.

Services should report to an outcomes framework including patient reported outcome measures (PROMS) and patient reported experience measures (PREMS) this applies across the pathways^{eg 28, 29, 30}.

People using cancer services in London report a worse experience of care compared with those treated elsewhere in England and Wales. Specific measures of access to psychological support should be included as priority areas in evaluations of patient experience.

Recommended model of professional psychological assessment and support

Self help and informal support

Level	Group	Assessment	Intervention
1	All health and social care professionals	Recognition of psychological needs	Effective information giving, compassionate communication and general psychological support
2	Health and social care professionals with additional expertise	Screening for psychological distress	Psychological techniques such as problem solving
3	Trained and accredited professionals	Assessed for psychological distress and diagnosis of some psychopathology	Counselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework
4	Mental health specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy (CBT)

Above: Guidance on improving support and palliative care for adults with cancer³¹, NICE

3. Psychological support should be available to families and carers.

The needs of family members and carers should be assessed on an ongoing basis. Support may be appropriately delivered by generic community services but there should be some provision available through specialist services caring for individuals.

4. All health and social care staff involved in cancer care should have training and education that enables them to identify emotional problems and provide psychological support at an appropriate level.

This should include (level 1):

- » General emotional support based on effective communication skills.
- » Taking the initiative in discussing the prevalence of psychological distress and signposting to support.
- » Knowing how to refer those experiencing particular distress to professionals with specialist expertise.

The clinical nurse specialist or other key worker has an integral role in maintaining continuity of care and support along the cancer pathway. Services should ensure that all CNS staff have sufficient resources to receive training with ongoing supervision to develop competencies in assessment and preliminary management of psychological problems (level 2) and advanced communication skills training (See Appendix B).

5. Commissioners should ensure that Information and Support Centres (ISCs) are available at all acute trusts.

The centres should maintain a directory of local resources for emotional and psychological support for people living with cancer, families and carers. This should include signposting to online resources and be shared with GP practices. Cancer centres should provide enhanced ISCs that promote mental health awareness from diagnosis and facilitate self-management and peer support.

Cancer information and support centres include the following:

- » Information centre in a variety of settings such as a hospital or hospice, and the community
- » Information point or pod staffed by a volunteer or professional
- » Library information service
- » Macmillan-funded or adopted information professional providing a service.

(See Appendix K.)



6. All people living with cancer should be offered a Holistic Needs Assessment (HNA) with care planning at key points along the pathway.

Certain points along the cancer pathway are considered particularly appropriate for an assessment but this should be a continuous process taking account of individual need. With the individuals consent the HNA and care plan should be shared with relevant care providers such as the individuals GP. London Cancer and London Cancer Alliance have produced a standardised HNA for use across all of London's cancer services (See Appendix G).

7. Community provision for emotional and psychological support should be supported and developed.

This should include access to brief psychological interventions through IAPT. Collaborative working should support a 'hub and spoke' model that provides supervision by level 3 and 4 specialists from cancer centres.

Specific consideration should be given to provision of access for people with limited mobility or who are housebound.

8. Specific groups should be proactively supported.

Some population groups are under-represented in engagement and receipt of psychological support. Typically, men are less likely to seek support and information, and show poorer psychological adaptation to cancer than women. This is also the case for certain tumour types (eg lung, prostate).

Commissioners should expect services to monitor access of groups that may be under-represented and services should be shaped to promote engagement. Groups for consideration would include:

- » People with severe and enduring mental illness
- » People who do not speak English as a first language
- » People who experience discrimination such as racism or homophobia
- » People with hearing, speech and visual impairments
- » People with learning difficulties
- » Older people

9. Psychology and psychiatry services providing support to cancer centres should be located on-site.

This model allows for the development of close working relationships with acute hospital staff and a good understanding of their working practices. It also provides greater opportunity for education, training and supervision. Cancer centres should have seven day access to liaison psychiatry for timely response to urgent referrals.

10. Coproduction with people affected by cancer and their carers should be integral to service development.

Coproduction acknowledges the expertise of individuals in informing service planning, commissioning, delivery and evaluation. As well as being best practice this is also a statutory requirement^{32, 33}.



NEXT STEPS

As the diagnosis and treatment of cancer improves, for many people cancer becomes a long term condition that requires ongoing care including self-management and not just acute hospital treatment. At the same time we are recognising the impact of unaddressed psychological problems in people living with cancer, and their families. We now have ample evidence that emotional and mental health problems not only cause suffering and distress but also impair a person's ability and motivation to manage their illness. This in turn leads to poorer health outcomes overall and associated with that, greater healthcare costs.

As a consequence we have a compelling quality and economic case to improve the psychological support for people living with cancer. The evidence presented here shows that in London support remains highly variable with examples of best practice in some areas in contrast to others where there is a marked absence of provision. The development of high quality, accessible services will have resource implications: ensuring sufficient numbers of level 3 and 4 specialists to provide complex assessments and interventions, and providing nurse specialists with level 2 training and ongoing supervision. This will require further work to produce a costed model.

This guidance provides ten clear recommendations and we are confident that their implementation will serve to reduce emotional distress and psychological morbidity as well as improving healthcare outcomes and experience for people living with and beyond cancer.

“Knowing is not enough;
we must apply.
Willing is not enough;
we must do.”

— Goethe



- » **Transforming Cancer Services for London** will share recommendations and the full project report with the London Strategic Planning Groups' cancer work streams:
 - **East London** – Integrated Cancer Group
 - **North east London** – Barking and Dagenham, Havering and Redbridge Cancer Collaborative
 - **South east London** – Cancer Strategy Group
 - **South west London** – Cancer Clinical Design Group
 - **North west London** – Central London, West London, Hammersmith and Fulham, Hounslow and Ealing Clinical Commissioning Groups and Brent, Harrow and Hillingdon Clinical Commissioning Groups
 - **North central London** – Primary Care and Prevention Board
- » **Strategic planning groups (SPGs)** are asked to disseminate the report to CCG cancer strategy groups and consider recommendations at a sub-regional level.
- » **Clinical commissioning groups (CCGs)** are asked to note the learning and recommendations and the potential for local service developments and improvements with their mental health and cancer providers. Where feasible and appropriate, the recommendations will be incorporated into local commissioning and provider strategies.
- » **Transforming Cancer Services for London** will use the recommendations to design commissioning intentions for acute and mental health providers as appropriate. These commissioning intentions will be drafted by the pan London Living With and Beyond Cancer Board and it is anticipated that they will be approved by both the Cancer Commissioning Board and Office of London CCGs in the summer. To the best of our ability, the commissioning intentions will be considered in terms of cost/benefit implications for commissioners.
- » **Transforming Cancer Services for London** will share the recommendations and full report with the NHS England Living With and Beyond Cancer programme for information.
- » **Transforming Cancer Services for London** will support SPGs with cost modelling where possible. This would include costs associated with IAPT services and prescribing.
- » **The Mental Health Strategic Clinical Network** will share the recommendations and full report with the CCG mental health leadership group and wider stakeholders including NHS England (London region) medical directorate and nursing directorate.

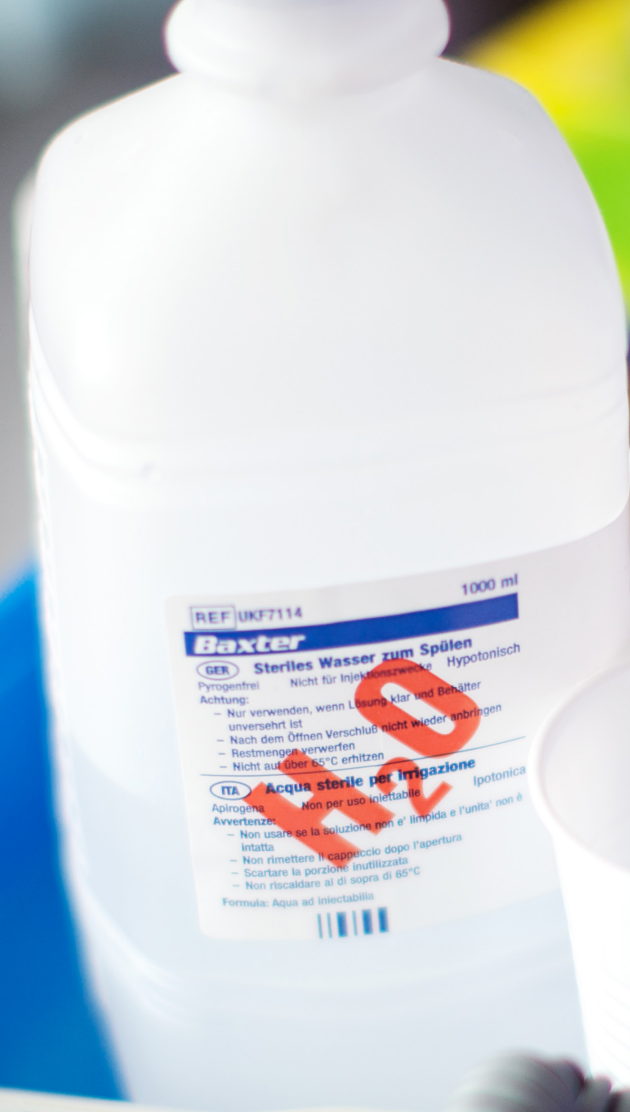


APPENDIX A: COMMISSIONING MODEL



* Psychological support services in acute settings would see people from the point of diagnosis to end of active treatment. Detailed service specifications are available from the two London integrated cancer systems: London Cancer and London Cancer Alliance

** Primarily level 3 services but with some rapid access to level 4 provision



REF UK7114 1000 ml

Baxter

STERILES WASSER zum Spülen Hypotonisch

Pyrogenfrei Nicht für Injektionszwecke

Achtung:

- Nur verwenden, wenn Lösung klar und Behälter unversehrt ist
- Nach dem Öffnen Verschluss nicht wieder anbringen
- Restmengen verworfen
- Nicht auf über 60°C erhitzen

ITA Acqua sterile per irrigazione Ipotonica

Apiregena Non per uso iniettabile

Avvertenze:

- Non usare se la soluzione non è limpida e l'unità non è intatta
- Non rimettere il capotetto dopo l'apertura
- Scartare la porzione inutilizzata
- Non riscaldare al di sopra di 60°C

Formula: Aqua ad iniectionem



KEEP OUT OF THE REACH OF CHILDREN

The active ingredients are: ...
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(red colouring) and ...

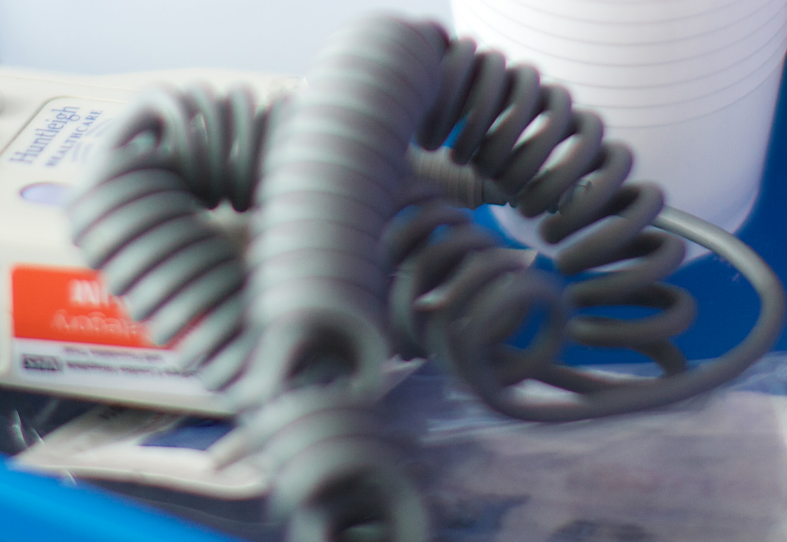
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ORIGINAL FLAVOUR

CONTAINS 0.2% w/v ...
... for treatment ...
... of oral problems

ECOLAB



APPENDIX B: EDUCATION AND TRAINING TOOLS

The Supportive and Palliative Care Improving Outcomes Guidance (IoG) (2004), recommends that all health and social care professionals should be able to provide effective information and compassionate communication.

There are a variety of skills based training courses available to those working with people with cancer which are designed to meet the needs of staff working at all levels. To be working at level 2, professionals must have completed both advanced communication skills training (ACT) and level 2 psychological assessment skills training. It is expected that those health care professionals under taking Health Needs Assessments will be working at level 2.

Sage & Thyme

A nationally recognised model of basic communication skills training, suitable for any member of staff who has contact with people with a cancer diagnosis

Level 2 psychological assessment and intervention skills training

Peer review requirement for all core MDT members. Best practice is that all cancer CNS' and AHPs who spend at least 50 per cent of their time with people with cancer should also have access

Advanced communication skills training (ACST)

Peer review requirement for all core team members to complete. Best practice is that all cancer clinical nurse specialists and allied health professionals who spend at least 50 per cent of their time with people with cancer should also have access.

Level 2 supervision

Monthly supervision provided for members who have completed the Level 2 psychological assessment and intervention skills training.

APPENDIX B: EDUCATION AND TRAINING TOOLS

Supporting staff: psychological care belongs to everyone

There is a clear connection between patient experience and staff morale and there are high rates of burnout, sickness and problems with retaining staff working with people with cancer.

We need to promote a culture that views staff distress not as a problem requiring fixing at the individual level. Instead, being moved, feeling sad or anxious will be part of the job if you have formed good relationships with patients, their friends and family. Conceptualising staff distress in this way allows us to create spaces where it can be meaningfully explored at an individual level and within a team and organisation (eg Schwartz rounds).

Beyond the therapy room

Psychological resource and approaches are well placed to help staff increase awareness, confidence and competence in working with people who have cancer. A package of staff training and support will facilitate the latter, disseminate psychological resource in an effective and efficient manner, and help protect against staff burnout, and so reduce the cost to patient experience and to the NHS.

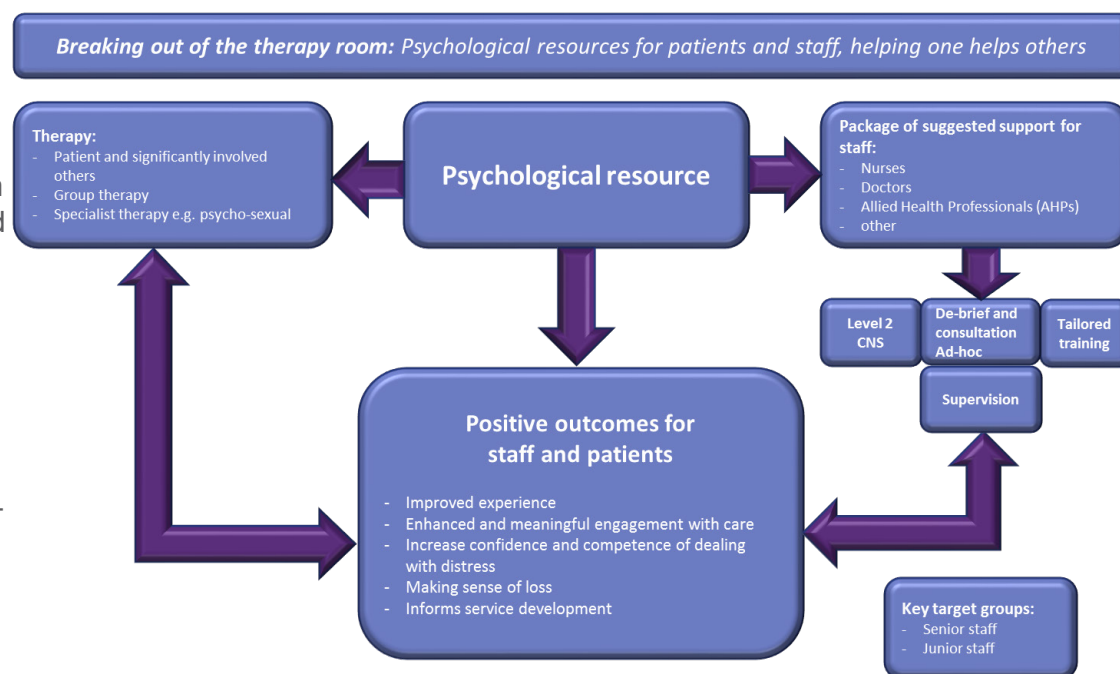
A diagram showing the relationship between patient and staff experience of psychological support is shown in the diagram above. A package of staff support initiatives is highlighted, including peer reviewed (level 2), ongoing supervision of staff receiving training, as this maintains competency and confidence in ability to manage distress in self and patient or family. Level 2 training dovetails into providing teams with more tailored training appropriate to their need and working context (eg motivational interview training and supervision for physiotherapist and occupational therapists delivering exercise programmes to cancer survivors). Alongside this, there is a staff need for ad-hoc de-briefing to make sense of a distressing death, as well as ongoing consultation on particular issues or concerns, for example individuals who may present with complex interpersonal or mental health issues making it difficult for them to engage with medical treatment and the medical team.

Key target staff groups are identified as being senior staff (ie clinical nurse specialists, team leads and managers), and the most junior staff, including junior doctors, as indicated by concerns highlighted in the Francis report.

Making a difference

Staff outcomes for supervision groups are currently being developed and piloted at Guy's and St Thomas' Hospital and London Cancer Alliance.

Thank you to Dr Sue Smith, Consultant clinical psychologist, Psycho-Oncology Support Team (POST), Guy's and St Thomas' NHS Foundation Trust, for providing this model of best practice.



APPENDIX C: CASE STUDY DIRECTORY

No	Title	Description	Location	Contact name(s)	Contact details
1	CBT training for physical health professionals	St Christopher's Education Centre has designed, delivered and accredited short courses in basic cognitive behavioural therapy (CBT) skills for physical health professionals working with long term conditions, cancer and palliative care. Physical health professionals can undertake a three day foundations level award or a six day CBT 'first aider' level certificate which delivers assessed and accredited knowledge, skills and competence in understanding and managing psychological distress; and when to refer on to specialist services.	St Christopher's Hospice, South West London	Kathy Burn, Clinical Nurse Specialist and Cognitive Behavioural Therapist/Trainer	k.burn@stchristophers.org.uk
2	Depression care for people with cancer	Offer screening to all adult cancer clinic attenders and those identified as having major depression are given the opportunity to participate in the 'Depression Care for People with Cancer' (DCPC) treatment programme. The model has two main components: a depression screening programme to identify patients with major depression, and a linked, collaborative-care-based treatment programme that ensures effective treatment.	Cancer Research UK Edinburgh Centre	Michael Sharpe Professor of Psychological Medicine	michael.sharpe@psych.ox.ac.uk
3	Psychological support in palliative care	A service providing community-based psychological care to patients at the end of life and their families since August 2008. We offer seamless care across care settings, supporting people at home, hospital, hospice and outpatient settings in Tower Hamlets. We aim to provide accessible psychological care to patients at the end of life and their families. We support patients with all types of cancer diagnosis, from referral into palliative care to end of life. The service is also commissioned to provide indirect support to staff supporting cancer patients both in general and specialist palliative care. The service is now embedded within the Tower Hamlets Community Palliative Care Team based at St Joseph's Hospice in Hackney. We provide training to local clinicians in end of life care.	Barts Health (Tower Hamlets CHS)	Dr Susan Hennessey Clinical Psychologist in End of Life Care	s.hennessey@stjh.org.uk

APPENDIX C: CASE STUDY DIRECTORY

No	Title	Description	Location	Contact name(s)	Contact details
4	Macmillan cancer information centre - Barts Hospital	The Macmillan cancer information centre at St Bart's Hospital aims to provide people with cancer, their families, friends and carers, access to support in a welcoming and caring environment that promotes open communication. Accurate, appropriate and comprehensive information on all aspects of cancer in a variety of formats are available. An individual Holistic Needs Assessment will underpin onward referrals or signposting within the hospital or within the community setting. Seventeen trained volunteer counsellors; one benefit advisor and an experienced cancer nurse specialist are at the forefront of the service provision. This allows for outreach work to the wards and clinics.	St Barts Hospital, London	Laura Bailey, Macmillan Cancer Information CNS	Laura.bailey@bartshealth.nhs.uk
5	Adult psychology support services	A team of multi-professional clinicians based at The Royal Marsden and in community services has been established to address the wide range of mental health and psychological support needs of people currently receiving cancer care at The Royal Marsden. The service offers; immediate telephone consultations to staff to support the psychological and psychiatric aspects of their work; patients are followed flexibly by the service as they move between intensive day treatment, inpatient and outpatient settings at The Royal Marsden. Referrals are triaged and directed to the most appropriate clinician; risk and safeguarding issues are shared at weekly meetings, activity and outcomes are monitored. The liaison psychiatry component of the service is provided by Central and North West London NHS FT through a service level agreement. Outpatients experiencing psychiatric emergencies are helped to access emergency psychiatric settings.	The Royal Marsden Hospital, London	Sara Lister, Head of Psychological Support and Pastoral Care Dr Andrew Hodgkiss, Consultant Liaison Psychiatrist	Sara.Lister@rmh.nhs.uk Andrew.Hodgkiss@rmh.nhs.uk

APPENDIX C: CASE STUDY DIRECTORY

No	Title	Description	Location	Contact name(s)	Contact details
6	IMPARTS – Cancer Services	<p>IMPARTS is a service development platform that seeks to embed integrated mental health assessment and management in general hospital settings. It supports clinical teams in: 1) detection and assessment of mental health problems; 2) care pathway development; 3) staff training; 4) self-help materials development. The aim is to integrate care by the systematic identification and onward management of mental health problems in a range of general hospital settings, including cancer services.</p> <p>IMPARTS develops mental health care pathways in collaboration with the clinical team and provides a series of bespoke training sessions with staff to equip them with core mental health skills. IMPARTS also develops a portfolio of disease-specific self-help materials which are tailored to the nuances of the patients' condition and designed to supplement discussions around mental health and coping strategies.</p>	The Maudsley, King's College London	Matthew Hotopf, Director, NIHR Biomedical Research Centre at the Maudsley; Professor of General Hospital Psychiatry, Institute of Psychiatry, Psychology and Neuroscience,	matthew.hotopf@kcl.ac.uk
7	Maggie's	<p>Since 1996, Maggie's has been pioneering a new concept of cancer support in the UK providing practical, emotional and social support to people with cancer, their family and friends. Built in the grounds of specialist NHS cancer hospitals, Maggie's centres are warm and welcoming places, with qualified staff offering an evidence-based core programme of support developed to complement medical treatment.</p> <p>There are now 18 centres across the UK; including Maggie's West London based in the grounds of Charing Cross Hospital (2008). Two more centres are currently in development in North East London (St Bartholomews Hospital) and South West London (The Royal Marsden Hospital).</p>	National / London	Ann-Louise Ward, Programme Director.	Ann-louise.ward@maggiescentres.org
8	An extended yearly holistic cancer care review for those within five years of cancer diagnosis	Wandsworth CCG has put in place a yearly extended holistic review for patients with various long term conditions. The project to extend this to people living with cancer started in the summer 2014, with support from the cancer clinical reference group and all members including primary and secondary care, social services, public health, service users and voluntary sector representation. It is still to be evaluated.	Wandsworth CCG	Dr Anthony Cunliffe, Macmillan GP Adviser / GP Lead, Transforming Cancer Services Team / Cancer commissioning lead for Wandsworth	anthony.cunliffe@nhs.net

APPENDIX C: CASE STUDY DIRECTORY

No	Title	Description	Location	Contact name(s)	Contact details
9	City and Hackney clinical psychology in cancer and palliative care	The aim is to provide specialist psychological and emotional support to City and Hackney cancer and palliative care patients and their families and to support medical teams to provide psychologically informed care at all levels of service delivery. The service liaises with the City and Hackney Primary Care Psychology team to provide advice and support for their patients with cancer and accepts onward referral for patients who need more specialist cancer psychology.	City and Hackney, London	Dr Clare Stevenson Clinical Psychologist in Cancer Care for City and Hackney	clare.stevenson@nhs.net
10	Southwark IAPT provision of primary care psychological interventions for King's Breast Care patients and relatives	To develop Southwark IAPT provision of primary care psychological interventions for King's breast care) patients, carers and relatives. The following primary and secondary care pathways have been agreed: Primary care: The new primary care pathway involves provision of counselling, cognitive behaviour therapy and other primary care psychological interventions for patients throughout their cancer pathway, including survivorship. Examples of identified needs include adjustment difficulties, depression, anxiety, relationship problems or cancer-related fatigue. Secondary care: The existing care pathway involving King's psychological medicine department provision continues. This caters specifically for patients in active treatment who are likely to have complex mental health or psychological needs requiring interactions based around multiple hospital treatment episodes. All patients referred to King's PMD are triaged and according to clinical need are either treated by their multi-disciplinary team or referred to secondary care community mental health services, or to IAPT services.	Southwark, London	Katharine Rimes, Honorary Consultant Clinical Psychologist, Southwark Psychological Therapies Service Jo Marsden, Consultant Surgeon, King's Breast Care	Katharine.Rimes@slam.nhs.uk Jo.Marsden@nhs.net

APPENDIX C: CASE STUDY DIRECTORY

No	Title	Description	Location	Contact name(s)	Contact details
11	Islington cancer survivorship programme	The Islington cancer survivorship programme aims to develop an innovative exercise pathway for cancer survivors to improve their physical and psychological wellbeing during and post treatment which can be implemented in the cancer care pathway. The intervention seeks to promote the physical and psychological wellbeing of participants by supporting a healthy lifestyle in the rehabilitation phase of cancer and promote secondary prevention. Clients are offered a 12 week personalised programme to increase activity levels within a specialist and general setting during which they will be educated about the benefits of physical activity and how to safely become more active. The approach is to be client-centred with a strong emphasis on informed choice and personal control.	Islington Borough Council	Elliot Rogers, Active health manager Aquaterra	elliot.rogers@aquaterra.org 020 3474 0066
12	Electronic Health Needs Assessment (eHNA)	All individuals who join the service following a cancer diagnosis complete an electronic health needs assessment (eHNA) to enable staff to find out what cancer means to individuals, and what support they need. From psychological support to financial advice, the team works with individuals to understand how cancer is affecting them and their family. eHNA is offered to people living with cancer in a variety of ways: in clinics by the clinic staff, by a volunteer who assists the person to complete the eHNA, and in some clinics the doctors identify who needs an eHNA. They are completed in some specific clinics, such as end of treatment clinics, HNA clinics or at radiotherapy review meetings. The care planning discussions may happen at the clinic appointments, at the next appointment or over the phone subsequent to the hospital appointment.	King's Health Partners Integrated Cancer Centre Guy's and St Thomas' NHS Foundation Trust	Nicola Easton, Quality and Improve Lead, Cancer Programme	nicola.easton@gstt.nhs.uk 020 7188 9569

APPENDIX C: CASE STUDY DIRECTORY

No	Title	Description	Location	Contact name(s)	Contact details
13	LIFT Psychology, Swindon IAPT	LIFT Psychology in Swindon (IAPT service) aims to provide training in working with cancer patients to IAPT staff to help increase their confidence and skills in working with this client group. LIFT provided a training session to its entire IAPT clinical staff (psychology assistants, PWPs, and HIs) on the psychological impact of cancer on patients, from diagnosis through to treatment and post-treatment, and helpful techniques to use when engaging in a talking therapy approach with this client group.	Swindon	Jon Freeman, Clinical Psychologist and Lead for Long Term Conditions, LIFT Psychology in Swindon	jon.freeman@nhs.net
14	Psycho-oncology team, Imperial Cancer Centre	The psycho-oncology team consists of 2.7wte cancer-specialist clinical psychologists, covering three acute hospital sites. The team was re-formed in 2013, by bringing together existing Trust and commissioner funded posts, we have directed the majority of our efforts towards supporting and developing the psychological care skills of our colleagues, teams and pathways, as well as the broader organisational culture.	Imperial College Healthcare NHS Trust and Central and North-West London NHS Foundation Trust	Dr Alex King, Consultant Clinical Psychologist and Lead for Psycho-Oncology	alex.king@nhs.net
15	brainstrust	brainstrust's aims to help everyone diagnosed with a brain tumour access the help they need to get back on top of things. We help people to understand, and take control so that they can secure the best possible outcome following a brain tumour diagnosis.	National	Helen Bulbeck, Director of Services and Policy Megan Hill, Head of Support	hello@brainstrust.org.uk 01983 292405
16	Survivorship into ACTION	Survivorship into ACTION is a pilot group based approach using Acceptance and Commitment Therapy (ACT) for people who have come to the end of their cancer treatment (all cancer types), are on the 'survivorship' pathway and have significant fear and worry that the cancer will return. It is co-facilitated by two clinical psychologists experienced in ACT. The initiative is embedded within and part of the wider Psycho-Oncology Support Team (POST), located and integrated within the Dimpleby cancer centre. Referrals are accepted from: any professional supporting a person at end of treatment, including community teams, GPs and acute settings, and self-referrals are also accepted. The main entry requirement is that distress associated with fear of cancer returning is having a significant impact on a persons' quality of life.	Dimpleby cancer centre, Guy's and St Thomas's NHS Foundation Trust	Dr Sue Smith, Consultant Clinical Psychologist, Psycho-Oncology Support Team (POST),	Sue.Smith@gstt.nhs.uk

APPENDIX C: CASE STUDY DIRECTORY

No	Title	Description	Location	Contact name(s)	Contact details
17	Enhanced prostate cancer follow up in primary care	The enhanced prostate cancer follow-up is a joint project with Prostate Cancer UK. The aim is to develop and test support needs through a follow-up service in primary care for people with prostate cancer who are stable at two years after radical treatment or are undergoing "watchful waiting". The service will support primary care nurses and GPs to deliver an enhanced care package that is co-ordinated, brings care closer to home and tailored to the emotional and physical well-being of people in their care. Croydon CCG GP practices are piloting the model.	Croydon CCG	Sarita Yaganti, Transforming Cancer Services Team for London	s.yaganti@nhs.net
18	Chris' cancer community	Chris's cancer community aims to connect and interact with as many people as possible affected by cancer, hoping to improve the 'isolation feeling' that most people experience. By sharing personal experiences via his website, blog, Facebook and Twitter forums Chris encourages others affected by cancer to think more openly about their own. His work is read by many people around the world, including carers and health professionals to help those groups understand some of the life changing issues around a cancer diagnosis. Chris has worked with various UK cancer charities as a guest writer and spokesperson for people living with cancer.	National	Chris Lewis	christheeagle@hotmail.co.uk www.chris-cancercommunity.com
19	Art therapy - Barts Hospital	The art psychotherapy service has been in place at Barts for the past 20 years and is part of the cancer psychological services team. The team provides psychological support using their specialist skills for people with cancer and clinicians involved in their care. The art psychotherapist works with both inpatients and outpatients and accepts both curative and palliative referrals.	St Barts Hospital, London	Megan Tjasink, Art Psychotherapist, Cancer Psychological Services	megan.tjasink@bartshealth.nhs.uk

APPENDIX C: CASE STUDY DIRECTORY

No	Title	Description	Location	Contact name(s)	Contact details
20	Asian, African and Caribbean support groups	<p>Paul's Cancer Support Centre, South London, have established two cancer support groups for members of the Asian communities and for members of the African and Caribbean communities. The groups aim to help meet the support needs of new and established members at all stages of their cancer journey, from diagnosis, through treatment to living with cancer. Carers are also welcome to attend the groups.</p> <p>The groups offer culturally sensitive support and enable people to identify solutions to practical problems caused by cancer or its treatment.</p> <p>Poverty, low literacy and social exclusion can play a part in preventing black and minority ethnic communities accessing appropriate cancer information and support services.</p> <p>One to one support is offered usually by telephone, to individuals who are unable or unwilling, because of their personal circumstances, to attend the group.</p>	Paul's Cancer Support Centre, South West London	Beverley van der Molen, Macmillan Information and Education Officer	beverleym@paulscancersupport.org.uk
21	Home visiting service	The Home visiting service supports quality of life by providing free counselling, befriending, massage and reflexology to adults with cancer (and their adult family members/carers) in their own homes. The service supports those who are unable to travel to our centre for therapeutic services for reasons including caring responsibilities and feeling unwell due to treatment or level of illness.	Paul's Cancer Support Centre, South West London	Jessica Mitchell, HVS Manager, Paul's Cancer Support Centre	hvisits@paulscancersupport.org.uk; 020 7924 3924
22	Take Care, intervention for family members and friends of people starting chemotherapy	<p>Family members and friends (carers) of people having chemotherapy for cancer provide a vital role in supporting patients emotionally, proving practical support and helping monitor and manage treatment side effects. Supporting someone through chemotherapy can be emotionally and physically demanding. However, little has been developed to date to support carers during this taxing time. This intervention for carers has been co-designed with staff and carers of patients starting chemotherapy has been evaluated for feasibility and acceptability. The 'Take Care' intervention comprises a 20-minute supportive/educative DVD, an accompanying booklet and 1-hour protocol-guided group consultation. The group consultation is typically attended by carers of up to six patients and conducted by chemotherapy nurses trained in group facilitation. Carers watch the DVD during the consultation and are provided opportunity to freely express concerns and ask questions. The DVD and booklet include information, advice and practical tips from carers and healthcare professionals on topics including treatment side effects; impact of being a carer and dealing with emotions; and importance for carers of taking time out for themselves and accessing support. The booklet additionally provides hospital- specific information including maps and contact numbers. Carers are provided a copy of both the 'Take Care' DVD and booklet for reference at home.</p>	University of Surrey	Emma Ream Professor of Supportive Cancer Care and Director of Research University of Surrey	e.ream@surrey.ac.uk

APPENDIX D: CASE STUDY DETAIL | ST CHRISTOPHER'S HOSPICE

Aims

St Christopher's Education Centre has designed, delivered and accredited short courses in basic cognitive behavioural therapy (CBT) skills for physical health professionals working with long term conditions, cancer and palliative care. Physical health professionals can undertake a three day foundations level award or a six day CBT 'first aider' level certificate which delivers assessed and accredited knowledge, skills and competence in understanding and managing psychological distress; and when to refer on to specialist services.

Rationale

Finding the time or energy to see a new psychological therapist while you are engaged in active cancer treatment, or when you are weary, highly physically symptomatic and engaged in detailed palliative care management, can be problematic. In addition there will never be enough mental health specialists to deliver to all those who might benefit. There is a need and an evidence base that training physical health staff in basic skills is effective. St Christopher's undertook the first ever randomised control trial using CBT in a palliative care patient population (Moorey et al 2009). The study showed that clinical nurse specialists can learn to integrate basic CBT methods into their clinical practice and that this is then associated with better psychological outcomes for patients. The results showed that depressed patients treated by both the CBT trained nurses and the control group all became less depressed, but the CBT trained nurses produced significantly greater improvement in anxiety. Hospital anxiety and depression scores 16 per cent vs 54 per cent.

Development

Moorey and Greer (2002) describe CBT techniques and their use in oncology and with physical symptoms (eg fatigue). Building on this model of CBT in cancer, Kathryn Mannix adapted the therapy for the treatment of patients with advanced cancer, in her work as a palliative care consultant. The RCT results enabled the development of brief CBT 'first aider' training for physical health professionals in palliative care, developed by Kath Mannix and supported by the Department of Health, Marie Curie and St Christopher's Hospice. Over three years, 120 professionals were trained. The new accredited training delivers knowledge and practical skills training which will equip physical health professionals to effectively recognise and work with patients' psychological distress, and awareness of when to refer on to specialists. The skills pyramid of three and six day CBT first aiders is supported and supervised by the CBT therapist and liaison psychiatry. This helps many more patients with a higher level of skill than would otherwise be met.

Outcomes

City and Guilds qualifications which equip physical health professionals to effectively recognise and work with patients' psychological distress have been developed. The nurses value the training and describe a number of improvements in their practice. (Cort, 2009). They feel confident and are able to use the skills effectively. Patients who are treated early can avoid descent into mood disorder. At the end of the course participants carry out a role play which is filmed, then rated and moderated using the cognitive first aid rating scale (CFARS) which has been adapted from the CBT competency rating scale the CTS-r.

Feedback received from people who have attended the training has been extremely positive:

"This course has turned my practice around, in only positive directions."

"In a single consultation, the skills help to obtain a clearer history and a bigger picture, which then helps to address the patients physical and emotional symptoms."

Contact

Kathy Burn, Clinical nurse specialist and cognitive behavioural therapist / trainer, St Christopher's Hospice, k.burn@stchristophers.org.uk.

APPENDIX D: CASE STUDY DETAIL | PAUL'S CANCER SUPPORT CENTRE

Aims

The Home Visiting Service supports quality of life by providing free counselling, befriending, massage and reflexology to adults with cancer (and their adult family members/carers) in their own homes. The service supports those who are unable to travel to our centre for therapeutic services for reasons including caring responsibilities and feeling unwell due to treatment or level of illness.

Rationale

The service was established in recognition that cancer provides a significant challenge to the quality of life of people with cancer and those who support them. These challenges are compounded by isolation for people who become housebound and can be particularly acute at the end of life. Research shows that complementary therapies and psychosocial support can improve mental wellbeing.

Development

The team work in London boroughs where we have trained volunteers. Referrals come mainly from NHS sources but self-referrals are also received and from community organisations. All clients are assessed by the team via a home visit; if massage and reflexology treatments have been requested then permission is sought from the client's oncologist or GP before clients are matched with a volunteer. The service can offer clients six to eight sessions of massage and reflexology and 12 sessions of counselling or befriending. All massage and reflexology and counselling volunteers are experienced registered professionals in their own fields and also complete our in-house 35 hour training course. Volunteers then receive ongoing support in the form of monthly supervision with a psychotherapist. The service works closely with our centre-based therapeutic team that offers services for people at a different stage in their cancer journey including complementary therapies, counselling, self-management courses, drop-in classes or activities and advice services.

Outcomes

There is an evaluation process that gathers information via questionnaire about client opinions about how the service works and the effects of the treatment on them. In the past year, 100 per cent of clients have rated the service standard as good or very good. 100 per cent of clients reported that their sessions were helpful or very helpful to them. Clients report services are particularly effective in reducing tension and anxiety with some reporting mild pain relief and improved sleep from reflexology or massage.

Contact

Jessica Mitchell, HVS manager, Paul's Cancer Support Centre, hvisits@paulscancersupport.org.uk, 020 7924 3924.

APPENDIX D: CASE STUDY DETAIL | SURVIVORSHIP INTO ACTION

Aims

ACT shows meaningful behaviour change through increasing emotional acceptance of difficult psychological experiences and encourages re-connection with or identifying new values. It has been found to be helpful with a range of medical conditions. Given these two key components, ACT could be of benefit for those experiencing fear of cancer returning.

Rationale

Fear and worry of cancer returning is a common experience people can have at the end of treatment, for some people this can stop them re-connecting and re-building their lives. For example, the worry might lead to frequently checking for signs of cancer; increased GP visits and also affect relationships with others. It is considered one of the greatest concerns and the most frequently endorsed unmet need, and seems to remain stable over the survivorship trajectory (Simard et al 2013). Clinical interventions addressing and demonstrating effectiveness in relation to this concern are limited, and so it seems timely to develop a specific intervention for fear of cancer recurrence and ascertain its effectiveness.

Development

Survivorship into ACTION is a pilot group based approach using Acceptance and Commitment Therapy (ACT) for people who have come to the end of their cancer treatment (all cancer types), are on the 'Survivorship' pathway and have significant fear and worry that the cancer will return. It is co-facilitated by two clinical psychologists experienced in ACT.

The initiative is embedded within and part of the wider Psycho-Oncology Support Team (POST), located and integrated within a large cancer treatment centre. Referrals are accepted from: any professional supporting a person at end of treatment, community/GP and acute settings and self-referrals are also accepted. The main entry requirement is that distress associated with fear of cancer returning is having a significant impact on a person's quality of life. All referrals are screened prior to entry to the group and 1:1 therapy is offered if the group is unlikely to be of most help to a person.

- » A pilot group commenced in May 2015
- » Courses run for six weekly sessions, 2.5 hours each session
- » Group size - up to 12 people
- » Rolling programme if successful and extended to carers

Outcomes

The fear of cancer recurrence inventory (FCRI) will be the primary outcome measure used along with a quality of life measure (AqoL8D). General psychological wellbeing will be evaluated using the PHQ-9 and GAD-7. Self-report regarding both usefulness and satisfaction of the intervention will be used.

Contact

Dr Sue Smith, Consultant clinical psychologist, Psycho-Oncology Support Team (POST), Guy's and St Thomas' NHS Foundation Trust, Sue.Smith@gstt.nhs.uk.

APPENDIX D: CASE STUDY DETAIL | IMPERIAL CANCER CENTRE

Aims

Excellent psychological care everywhere.

Rationale

As a team of 2.7 WTE cancer-specialist clinical psychologists, covering three acute hospital sites, we will never have enough time to directly help a sufficient proportion of the 3,800 people who get a new cancer diagnosis at Imperial every year. Since the team was re-formed in 2013, by bringing together existing trust and commissioner funded posts, we have directed the majority of our efforts towards supporting and developing the psychological care skills of our colleagues, teams and pathways, as well as the broader organisational culture.

Development

With the direct support of our medical, nursing and peer review leads, we have prioritised this aspect of our work and adjusted our targets and key performance indicators accordingly.

Outcomes

As well as individual clinical work (over 300 patient and carer referrals per year, seen within two weeks of referral), the team have achieved the following broader impact:

- » Running two to three Level 2 psychological skills trainings per year, currently over 30 of our 40 clinical nurse specialists (CNS) are now trained, at least one per multidisciplinary team (MDT) training - and we are aiming for 100 per cent.
- » All CNSs (and allied health professionals based within cancer teams) attend ongoing monthly supervision groups specific to each MDT team, to develop and embed their Level 2 skills.
- » Promoting psychological care pathways that explicitly identify what simple care (eg active listening, solution-focused questions) could and should be offered to distressed patients and carers, before considering a specialist referral.
- » Supporting the rollout of HNAs through developing tools for CNSs to efficiently address first-line concerns, and through auditing positive practice.
- » Joined up with teams (eg upper GI) to successfully bid for service development funds, and setup tailored and systematic psychological screening processes alongside the cancer pathway.
- » Attracted Macmillan and Health Education North West London funding to rollout Schwartz Rounds to the whole of Imperial College Healthcare NHS Trust and Academic Health Science Networks.
- » Led in developing an active, collaborative forum between all cancer psychological support services (both third-sector and NHS) in the north west sector, to better provide patients with convenient choices and joined-up care.

Contact

Dr Alex King, Consultant clinical psychologist and lead for psycho-oncology, Imperial College Healthcare NHS Trust and Central and North-West London NHS Foundation Trust, alex.king@nhs.net.

APPENDIX D: CASE STUDY DETAIL | THE ROYAL MARSDEN

Aims

To work with clinicians at The Royal Marsden and in community services to address the wide range of mental health and psychological support needs of people currently receiving cancer care at the Royal Marsden.

Rationale

Psychological distress and psychiatric disorders are highly prevalent among people affected by cancer, especially in the first year after diagnosis and among those with advanced disease. This includes adjustment challenges posed by the cancer diagnosis and treatments (eg role disruption, threat of death, coping with prognostic uncertainty, disfigurement/body image disruption); psychosexual difficulties arising from the experience of cancer; psychiatric disorder arising from the cancer and its treatment (notably depression, anxiety and delirium); and optimising the management of any pre-existing mental health problems during intensive cancer treatment.

In view of this wide range of need, a number of different professional skillsets and experience is required. Historically the service comprised of a team of nurse counsellors and a separate, academically-led clinical psychology service, with little in-house psychiatric resource and limited shared practice between professional groups. It was clear that the service needed to be co-located and integrated alongside the cancer treatment teams because of the crucial interface with medical and surgical treatments. Cancer counselling, psychosexual therapy, clinical health psychology / health psychology (both CBT and systemic expertise) and specialist liaison psychiatry are all required, in addition to the psychological skills of tumour-specific clinical nurse specialists, oncologists and allied health professionals.

Development

In response to review, and bench-marking against the model of good practice the team is now multi-professional. Immediate telephone consultations are offered to staff to support the psychological and psychiatric aspects of their work. Patients are followed flexibly by the service as they move between intensive day treatment, inpatient and outpatient settings at The Royal Marsden. Referrals are triaged and directed to the most appropriate clinician; risk and safeguarding issues are shared at weekly meetings, activity and outcomes are monitored. The liaison psychiatry component of the service is provided by Central and North West London NHS Foundation Trust through a service level agreement.

Outpatients experiencing psychiatric emergencies are helped to access emergency psychiatric settings. Once patients are in longer term remission from their cancer or transferring to palliative care services they will be signposted or referred to appropriate third sector and NHS services.

Outcomes

An advice phone line is answered within the hour (9am-5pm, Monday-Friday), usually by a psychiatric liaison nurse. Patients referred from the wards are assessed within two to three working days. Outpatients are assessed between four to eight weeks after referral and followed up flexibly, depending on clinical need (average 3-4 visits). In 2014, 1,444 referrals were received.

Contact

Sara Lister, Head of psychological support and pastoral care, the Royal Marsden Hospital,
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Dr Andrew Hodgkiss, Consultant liaison psychiatrist, Central and North West London NHS Foundation Trust at the Royal Marsden Hospital, Andrew.Hodgkiss@rmh.nhs.uk.

Aims

Integrating Mental and Physical healthcare: Research Training and Services (IMPARTS) is a service development platform that seeks to embed integrated mental health assessment and management in general hospital settings. It supports clinical teams in: 1) detection and assessment of mental health problems; 2) care pathway development; 3) staff training; 4) self-help materials development. The aim is to integrate care by the systematic identification and onward management of mental health problems in a range of general hospital settings, including cancer services.

Rationale

General hospital patients with mental health problems have poorer health outcomes and use services more frequently. Though effective treatments exist, disorders such as depression and anxiety are rarely recognised and few patients receive appropriate intervention. Randomised control trials linking mental health screening with an integrated management plan have shown positive effects on mood, medical outcomes and costs, but these have typically been conducted under trial conditions. IMPARTS addresses the challenge of embedding integrated mental healthcare in a real-world general hospital setting.

Development

Services implementing IMPARTS invite patients attending clinics to complete a web-based screening questionnaire on an e-tablet in the waiting room. The questionnaire includes validated mental health screens (PHQ-9 and GAD-7), and disease specific outcome measures tailored to the physical health condition (eg EORTC QLQ-C30 cancer quality of life scale). Adverse health behaviours including smoking, substance misuse, and difficulties with adherence are also detected. The questionnaire typically takes around five minutes to complete. The results are uploaded in real time to the electronic patient record and this information is available to the clinician, with prompts to indicate when a patient may require intervention for a mental health problem. To prepare for screening implementation, IMPARTS develops mental health care pathways in collaboration with the clinical team and provides a series of bespoke training sessions with staff to equip them with core mental health skills. Topics typically include basic mental health assessment, opening conversations with patients about mental disorders, when to refer, and assessing suicide risk. IMPARTS also develops a portfolio of disease-specific self-help materials which are tailored to the nuances of the patients' condition and designed to supplement discussions around mental health and coping strategies.

Outcomes

Enabling research

IMPARTS integrates collection of patient-reported outcomes into routine practice, providing a ready source of data for observational research. IMPARTS also aids research recruitment: a 'consent for contact' question can be added to the IMPARTS questionnaire to identify patients interested in participating in research. Research conducted in TYA cancer showed that 7% of patients met criteria for MDD and 11% met criteria for GAD. Five percent met criteria for MDD and GAD. MDD was associated impaired cognitive functioning, a more threatening view of the illness and poorer quality of life. GAD was associated with being female, impaired cognitive functioning, increased anger and a more threatening view of the illness.

Contact

Matthew Hotopf, Director, NIHR Biomedical Research Centre at the Maudsley; Professor of general hospital psychiatry, Institute of Psychiatry, Psychology and Neuroscience, King's College London, matthew.hotopf@kcl.ac.uk.

Demonstrating feasibility

IMPARTS offers a model for how to successfully embed integrated mental health care in real-world secondary care settings. Across the first four services implementing IMPARTS, the mean screening participation rate was 72% (range 40-98%) and the mean decline rate was 3% (range 0.5-5%). It is now widely implemented with approximately 700 new screens conducted each month.

Identifying need

IMPARTS has been implemented in 22 services across two acute trusts, including some cancer services: teenage and young adult (TYA) cancer, neuroendocrine tumour (NET) and palliative care. As of February 2015, 7,238 individual patients have been screened for mental disorder. In cancer services the proportion of patients screening positive for MDD is 7% (TYA cancer), 14% (NET) and 18% (palliative care). The proportion screening positive for GAD is 11% (TYA cancer), 23% (NET) and 23% (palliative care). Audits have demonstrated that 35-50% of those identified are referred on to appropriate treatment services, the remainder either declining or already being in receipt of care. IMPARTS has supported successful business cases for mental health posts, including clinical psychology, liaison psychiatry and CBT therapy.

APPENDIX D: CASE STUDY DETAIL | LIFT PSYCHOLOGY IN SWINDON

Aims

LIFT Psychology in Swindon (an IAPT service) aims to provide training in working with cancer patients to IAPT staff to help increase their confidence and skills in working with this client group.

Rationale

Many patients who have had, or are living with, cancer access LIFT, and therefore it is important that staff are confident and competent in being able to provide effective psychological support to them.

Development

LIFT provided a training session to all of its IAPT clinical staff (psychology assistants, psychological wellbeing practitioners, and high intensity therapists) on the psychological impact of cancer on patients, from diagnosis through to treatment and post-treatment, and helpful techniques to use when engaging in a talking therapies approach with this client group.

Outcomes

Staff reported increased confidence in applying their existing skills when working with cancer patients.

Contact

Jon Freeman, Clinical psychologist and lead for long term conditions, LIFT Psychology in Swindon, jon.freeman@nhs.net.

APPENDIX D: CASE STUDY DETAIL | CHRIS'S CANCER COMMUNITY

Aims

My aim is to connect and interact with as many people as possible affected by cancer, thus hoping to improve the 'isolation feeling' that most people experience. By sharing my personal experience in such a way I encourage others affected by cancer to think more openly about their own. My work is read by many people around the world, including carers and health professionals, which will also help those groups understand some of the life changing issues around a cancer diagnosis.

Rationale

I have a business background and when I was diagnosed in 2007 with an incurable blood cancer, I had to undertake a severe regime of treatment including a stem cell transplant from an unrelated donor. Although still in remission, I have been unable to return to work, and have been truly shocked regarding the poor, sporadic and uncoordinated practical support for people outside the clinical environment. I started talking at health conferences but realised I needed to take to the internet to help spread my message. My website was started in 2012. This helps me connect with my audience, even when I am having my own treatment.

Development

I developed a very simple blog initially, as a first platform for my work. It took about six months before I developed a reasonable audience. Marketing and communication was a big part of my work before cancer, so I was comfortable doing all those things myself. After two years I won the UK health blogger of the year award and a marketing sponsor stepped forward who helped me develop my site and to help me spread the word of my work. Things really took off then, and we turned my idea into a brand, expanding on to Twitter and Facebook. Most major UK cancer charities are aware of my work, and I am a guest writer for many. Social media is a key way of exchanging information, and I collaborate with many to ensure good practice can be found by those who need it. I finance things myself, but costs are quite minimal, and have plans to increase and support signposting in the future.

Outcomes

By writing and sharing information I engage with many via public or private message. A lot of those conversations are available to read on my site after the posts. The fact that I am a current patient with complex treatments allows me to communicate in a very different way to charity and health organisation websites. I know from the conversations I have that my website is a beacon for many, and so far my story is mostly positive. Social media is now a big part of our daily communication, and is not restricted by timings like support groups etc. It enables anyone to be involved if they wish, anonymously or not, helping break down any possible barriers (ie gender, cultural etc).

Contact

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APPENDIX D: CASE STUDY DETAIL | ENHANCED PROSTATE CARE IN PRIMARY CARE

Aims

The enhanced prostate cancer follow-up is a joint project with Prostate Cancer UK. The aim is to develop and test support needs through a follow-up service in primary care for people with prostate cancer who are stable at two years after radical treatment or are undergoing “watchful waiting”. The service will support primary care nurses and GPs to deliver an enhanced care package that is co-ordinated, brings care closer to home and tailored to the emotional and physical well-being of people in their care. Croydon CCG GP practices are the pilot site for testing the model.

Rationale

A review of patients being followed-up in the community showed that whilst patients were satisfied with their follow-up care, the majority have not received relevant information on the potential side effects and consequence of treatment or signposts to psycho-sexual, social and incontinence services.

The review also highlighted the need for improvements to be made to patient and primary care clinician experiences and access to other services, follow-up processes to shift care from secondary to primary care for suitable patients. As part of the follow-up service better outcomes can be achieved by embedding a supportive and holistic element to individual needs assessments; this will include signposting and referral to local emotional and psychological support or wellbeing services.

Development

Locally arranged GP clinical network meetings provided an opportunity to discuss issues pertaining to the existing pathway, the quality of information provided from the hospital, the opportunities to sustain the enhanced service and GP's views of a holistic model adapted for primary care. The following points were taken from these discussions:

- » The need to increase GPs awareness of support groups and services and cancer specific charity resources for signposting people affected by cancer
- » The need for a primary care based process to help identify suitable patients for primary care follow-up. Produce a template for use in follow-up appointments
- » To ensure information given to patients about their follow-up care is accurate and relevant
- » Ensure the current pathways and processes are appropriate.
- » Training required for primary care professionals for managing and supporting people with prostate cancer, including; prostate follow up system, explicit PSA referral thresholds, symptomatic and psychological red flags, and safety netting protocols to ensure clinically governed management of referrals between primary and secondary care.

A prostate cancer urology locally commissioned service (LCS) specification was revised in light of the issues raised and launched in December 2014. Practices that sign up to the new LCS are required to:

- » Complete a minimum one hour training session accredited by BMJ Learning to refresh training gaps.
- » Use the patient identifier guide to identify suitable patients on practice lists that could be discharged from secondary care follow-up to primary care follow-up. GPs to send the list to the secondary care consultant to formally request discharge and the consultant is to outline follow-up requirements for the patients.
- » Offer a 30 minute ‘welcome appointment’ to all newly discharged patients within four weeks of discharge from secondary care with the primary care nurse or GP. This is an opportunity for the practice to start a holistic care plan developed for the project which should be reviewed at subsequent follow-up consultations.
- » Conduct PSA blood tests and relay results to patients via a PSA consultation appointment using the bespoke PSA follow-up template specifically developed and designed for integration into EMIS and VISION clinical systems. This includes the use of validated tools to objectively assess symptoms such as lower urinary symptoms, erectile dysfunction, low mood and anxiety. Resources to promote self-management of other symptoms such as fatigue are also embedded in to the template to facilitate signposting to appropriate resources.

Outcomes

Patients, GPs and practice nurses are invited to complete a survey and send directly to the Transforming Cancer Services Team (TCST) as part of a full evaluation process of the entire service. An evaluation is due in December 2015.

Contact

Sarita Yaganti, Transforming Cancer Services Team for London, s.yaganti@nhs.net.

APPENDIX D: CASE STUDY DETAIL | ISLINGTON CANCER SURVIVORSHIP PROGRAMME

Aims

The Islington cancer survivorship programme aims to develop an innovative exercise pathway for cancer survivors to improve their physical and psychological wellbeing during and post treatment which can be implemented in the cancer care pathway. The intervention seeks to promote the physical and psychological wellbeing of participants by supporting a healthy lifestyle in the rehabilitation phase of cancer and promote secondary prevention.

Due to the unique and variable physical problems of cancer survivors, it is deemed appropriate to offer an individualised programme to meet the needs of each client in addition to the possibility to exercise as a part of a group. American College of Sports Medicine (ACSM) guidelines and established programmes in other parts of the country, Bournemouth after cancer survivorship programme (BACSUP) confirm this.

Rationale

The improvement in cancer survivorship figures comes with increased economic costs to the NHS, the patient and their family and productivity; only 30 per cent of survivors over 50 will return to work. Macmillan cancer support says although it is good news that more people with cancer are living longer; many are struggling with long term health problems caused by their treatment. The charity says this poses a huge challenge for the NHS in planning better services. The clearest evidence for the impact on survival of lifestyle interventions (physical activity) following cancer diagnosis is for survivors of breast cancer, colorectal cancer and prostate cancer. However, current advice states that physical activity is safe for all people living with and after cancer.

Most individuals are highly motivated to improve their lifestyle following diagnosis and treatment to enable them to regain their role in the family as parent or carer and in society as an employee, but in many cases need support and guidance to make changes. Individualised exercise interventions designed around the short and long term goals of clients can play a significant role in helping cancer survivors recover from the both the physical and psychological side effects of cancer and its treatment, regain their ability to perform activities of daily living improve quality of life.

Development

Clients will be offered a 12 week personalised programme to increase activity levels within a specialist and general setting during which they will be educated about the benefits of physical activity and how to safely become more active. The approach is to be client-centred with a strong emphasis on informed choice and personal control.

The service consists of 12 sessions of individual or group-based exercise normally over 12 weeks. The first session will be preceded by a one-to-one appointment (30-45 minutes) and will be based on motivational interviewing techniques. This would involve:

- » Exploring and build readiness and confidence, concerns, goals and options.
- » Information exchange.
- » Developing a collaborative plan including goal-setting, relapse prevention, on-going support and monitoring.
- » Arrangement for ongoing support.

All clients will be given a Macmillan cancer support approved 'move more' materials and 'get active feel good' pedometer including an activity diary to consolidate the benefits of increasing activity levels and to supplement exercise session input. A formal review can be integrated into the six-month patient follow-up to offer further support and problem solving.

Outcomes

The impact of the intervention will be evaluated by recording various health measures such as cardio/respiratory fitness, blood pressure, resting heart rate, weight/BMI, muscle tone and strength. Patient recorded outcomes will also be measured (ie levels of physical activity, lifestyle behaviour change, energy/fatigue, mental wellbeing, self-esteem/anxiety/depression, body image, confidence, enjoyment/sustainability). The intervention will also be monitored on an ongoing basis, by reviewing relevant statistics (ie referral numbers, ethnicity, cancer site, referrer, point on cancer pathway) and providing support and training to staff.

Contact

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APPENDIX D: CASE STUDY DETAIL | MAGGIE'S CENTRES

Aims

Since 1996, Maggie's has been pioneering a new concept of cancer support in the UK providing practical, emotional and social support to people with cancer, their family and friends. Built in the grounds of specialist NHS cancer hospitals, Maggie's Centres are warm and welcoming places, with qualified staff offering an evidence-based core programme of support developed to complement medical treatment.

Rationale

"A diagnosis of cancer hits you like a punch in the stomach."

These are the words of Maggie Keswick Jencks, our co-founder with her husband Charles Jencks, who was diagnosed with breast cancer in 1988. During her treatment process and the challenges it brought, Maggie formulated a vision of a cancer support that could make the experience of diagnosis and treatment easier to bear. Her key idea was to bring people together, in a place which would help them to find comfort in the experiences of others, where they could be provided with structured information and professional support, and to become active in taking charge of their well-being.

The Maggie's programme supports people at a psychological level through every interaction they have with Maggie's programme and staff, in a flexible way, and underpinned by the potential therapeutic value of people meeting others with whom they can identify. Psychological support runs throughout the Maggie's programme. This includes;

- » Information giving and front line psychological support by cancer support specialists for immediate cancer-related distress in "drop-in".
- » Stress management and problem solving through courses and psycho-educational groups such as a pre-treatment workshop, 'getting started with cancer treatment', and post-treatment course, '*where now?*', which The National Cancer Survivorship Initiative identified as an exemplary course in the support of people living beyond cancer treatment.
- » Specialist theoretically driven psychological interventions including cognitive behavioural and mindfulness-based stress reduction courses.
- » Individual, couple and family therapy sessions with a Clinical Psychologist for individuals requiring a more formalised psychological therapy intervention.

Development

Maggie's vision became a reality in 1996 with the opening of the first Maggie's Centre in Edinburgh. There are now eighteen centres across the UK, online and abroad, with more planned for the future. Maggie's West London, in the grounds of Charing Cross Hospital, has been open since 2008. Maggie's North East London (St Bartholomew's) and Maggie's South West London (The Royal Marsden) are in development.

Outcomes

The Maggie's programme is evaluated regularly, in line with evidence-based practice to ensure the main elements of the programme are based on what has been shown both in research literature and clinically to be effective in supporting people affected by cancer. The programme is also informed by external research findings, and by drawing on advice gained from our external reviews.

Contact

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APPENDIX D: CASE STUDY DETAIL | DEPRESSION CARE FOR PEOPLE WITH CANCER

Aims

Offer screening to all adult cancer clinic attenders and those identified as having major depression are offered the opportunity to participate in the 'Depression Care for People with Cancer' (DCPC) treatment programme.

Rationale

Major depression is an important complication of cancer but is frequently inadequately treated. There are challenges both in identifying which cancer patients are depressed, and in ensuring that these patients receive effective treatment for their depression. Sharpe and Walker have developed a collaborative care model, DCPC that integrates depression management into cancer care.

Development

The model has two main components: a depression screening programme to identify patients with major depression, and a linked, collaborative-care-based treatment programme, 'Depression Care for People with Cancer' (DCPC), that ensures effective treatment.

Depression Care for People with Cancer

The treatment team comprises specially trained cancer nurses and liaison psychiatrists who work closely with the patient's GP and oncologist. The cancer nurses provide and oversee the treatment (below), with weekly supervision by the consultant psychiatrist.

Components of treatment

- » Education about depression and engagement in treatment
- » Antidepressant medication
- » Brief Psychological treatments
- » Progress monitoring
- » Depression care coordination
- » Treatment supervision

Outcomes

In a 200-participant randomised controlled trial, Sharpe and Walker found that participants who had received DCPC had significantly better depression scores at 3-month follow-up than those who had received usual care, and that this difference was sustained at 12 months. In a second 500-participant RCT they confirmed the effectiveness and cost-effectiveness of the intervention. A much greater number of patients had a clinically useful improvement in depression with DCPC than with usual care (62% compared with 17%). DCPC also produced a much greater improvement in other important cancer-related symptoms of anxiety, pain and fatigue, as well as in functional ability and overall quality of life.

The model described here provides a strong case for the integrated management of depression and other psychiatric disorders that should be of assistance to those commissioning and planning psychological support services in cancer care.

Contact

Michael Sharpe, Professor of psychological medicine, University of Oxford,
michael.sharpe@psych.ox.ac.uk.

1. Integrated collaborative care for comorbid major depression in patients with cancer (SMaRT Oncology-2): a multi-centre randomised controlled effectiveness trial. Sharpe M et al. The Lancet 2014.
2. Integrated collaborative care for major depression comorbid with a poor prognosis cancer (SMaRT Oncology-3): a multicentre randomised controlled trial in patients with lung cancer. Walker J et al. The Lancet Oncology 2014.

APPENDIX D: CASE STUDY DETAIL | GUY'S AND ST THOMAS' eHNA

Aims

All individuals who join our service at Guy's and St Thomas' NHS Foundation Trust (GSTT) following a cancer diagnosis will complete an electronic health needs assessment (eHNA) to enable us to find out what cancer means to them, and what support they need. From psychological support to financial advice, we will work with the person to understand how cancer is affecting them and their family.

Rationale

Guy's and St Thomas' is one of England's leading cancer centers, treating more people with cancer than any other provider in London. Leading cancer experts are based on site and work as part of the cancer team. That means joined-up care, all in one place, for an all-round better experience of healthcare. Cancer care is about much more than medical treatment. It was important to us to find a more effective and efficient way of assessing people's holistic needs. We therefore applied to be one of the first test sites of eHNA and were successful.

Development

eHNA is offered to people living with cancer in a variety of ways: in clinics by the clinic staff, by a volunteer who assists the person to complete the eHNA, and in some clinics the doctors identify who needs an eHNA. They are completed in some specific clinics, such as end of treatment clinics, HNA clinics or at radiotherapy review meetings. The care planning discussions may happen at the clinic appointments, at the next appointment or over the phone subsequent to the hospital appointment.

Outcomes

Benefits to people living with cancer

The benefits to people living with cancer have been identified by Sarah Thompson, clinical nurse specialist (CNS) at GSTT, as 'holistic needs assessment is an important part of the person's treatment because it allows us as nurses to be able to focus on individual needs and their primary concerns.'

One person I was caring for commented that, *"having a CNS supporting my treatment made a huge difference. Even now treatment has finished, I still require physical and psychological support, which has been highlighted and demonstrated by the holistic needs assessment."*

Team benefits

The IT project team saw the extra benefit of the tablet and that it could be used for other surveys, for example involving friends and family. IT ensured that mobile device management software was used to enable more than one survey to be loaded on the iPad.

This also means that the care planning website is on the iPad so that the assessment can be viewed by the clinician without the need to go to a computer. (There is limited access, such as on the wards and certain clinics.) You will need information governance agreement to view or do care planning on the iPad.

Organisational benefits

The deputy chief nurse for cancer is using the data from eHNA within performance review meetings and is reporting results to the cancer locality meeting with the clinical commissioning group (CCG). Now that more assessments have been carried out, we can look at the top concerns of people with cancer overall, or by individual tumour groups by using the 'data store' function on the care planning website. This helps us to see where there are capacity issues or gaps in services across the different tumour groups, and it will therefore assist in future planning to ensure we have the right type of services to address these concerns for people living with cancer.

Contact

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APPENDIX D: CASE STUDY DETAIL | MACMILLAN CENTRE AT ST BART'S HOSPITAL

Aims

The Macmillan cancer information centre at St Bart's Hospital aims to provide people with cancer, their families, friends and carers, access to support in a welcoming and caring environment that promotes open communication. Alongside this, accurate, appropriate and comprehensive information on all aspects of cancer in a variety of formats are available. An individual Holistic Needs Assessment will underpin onward referrals or signposting within the hospital or within the community setting.

Rationale

Eighty-seven per cent of cancer patients are known to want more information about their illness. Information and support provision raises awareness of available financial, practical and emotional support and in turn improves people's ability to recover and self-manage living with cancer.

The idea behind the implementation of this service is to therefore provide a patient focused environment that recognises the varying needs of individuals with all types of cancer. The diversity of patient attitudes to cancer and the impact on their coping strategies, all determine the wish for and levels of information required by individuals.

Patient information needs are highly diverse and cannot always be identified or met straight away. Such needs are shaped by demographic characteristics and personal traits. Likewise, the type of information that is sought by an individual patient and their families is likely to change during the course of their illness and their subsequent treatment. The information centre provides patients with unrestricted opportunities to think and explore their needs and together make a plan on how to best meet them at intervals determined by the patient.

Development

The Vicky Clement Jones Cancer Backup service was taken over by Macmillan as a joint partnership with Bart's Hospital in 2010. Macmillan funded the design, construction and furnishing of the centre. 17 Trained volunteer counsellors, one benefit advisor and an experienced cancer nurse specialist are at the forefront of the service provision. This allows for outreach work to the wards and clinics.

Outcomes

The information and support centre will work towards the following targets:

- » To increase the identified gaps within the national patient cancer experience survey 2014.
- » To formally undertake a Holistic Needs Assessment on patients attending the centre and liaise accordingly with the multi-disciplinary teams (MDTs) in order to ensure all current and possible future needs are met.
- » To have an increase in the number of patients attending the centre.
- » Feedback from patients indicates that a 'warm and friendly welcome is always received on arrival to the centre' and that the time and dedication from staff helps patients to be able to bear and manage some of the difficulties their disease poses.
- » Patients have also expressed the value of the informality of the 'drop-in' centre which provides unstructured opportunities to talk as required by the patient. This can help to identify patients who may require more complex psychological support who may not have otherwise been identified.

Contact

Laura Bailey, Macmillan Cancer Information CNS, Laura.bailey@bartshealth.nhs.uk.

Aims

To provide community-based psychological care to patients at the end of life and their families. We offer seamless care across care settings, supporting people at home, hospital, hospice and outpatient settings in Tower Hamlets. We aim to provide accessible psychological care to patients at the end of life and their families. We support patients with all types of cancer diagnosis, from referral into palliative care to end of life. The service is also commissioned to provide indirect support to staff supporting cancer patients both in general and specialist palliative care.

Rationale

The service was commissioned in 2008 in the context of NICE guidance on *Improving Supportive and Palliative Care for Adults with Cancer* and following recommendations from Marie Curie's *Delivering Choice* review of local provision.

Development

The service has been operating since August 2008 and is now embedded within the Tower Hamlets Community Palliative Care Team based at St Joseph's Hospice in Hackney. We provide training to local clinicians in end of life care.

Outcomes

We provide accessible psychological care at home to patients who would otherwise be unable to receive support. We work closely with colleagues in inpatient and community settings to facilitate hospital discharges and reduce inappropriate use of GP or A&E services. We support and mentor multi-disciplinary teams (MDT) to provide good psychological assessment and support within their role. Tower Hamlets has a diverse population and we support cancer patients and their families from different cultural, ethnic and faith backgrounds.

Contact

Dr Susan Hennessey, Clinical psychologist in end of life care, Barts Health (Tower Hamlets CHS), s.hennessey@stjh.org.uk, 07947 531055.

APPENDIX D: CASE STUDY DETAIL | ART THERAPY AT BARTS CANCER CENTRE

Aims

The art psychotherapy service has been in place at Barts for the past 20 years and is part of the cancer psychological services team. The team provides psychological support using their specialist skills for people with cancer and clinicians involved in their care. The art psychotherapist works with both inpatients and outpatients and accepts both curative and palliative referrals.

Rationale

Dr Chris Gallagher, Consultant Medical Oncologist, saw a presentation by an art psychotherapist at a conference in 1994. The talk made a strong impression and he thought that art psychotherapy would be helpful to address the psychological needs of his cancer patients at Barts Hospital. He approached a charitable trust (The Corinne Burton Memorial Art Therapy Trust) for funding and a one day a week post was created.

Development

In 2005 the cancer psychological service was established with a team of art psychotherapists and clinical psychologists. Due to high demand for art psychotherapy, excellent patient and clinician feedback and strong before and after outcomes, the one day of charitable funding was matched by Barts enabling the service to extend to two days per week. In 2013 further funding was secured for a three day per week post along with associated art psychotherapist trainees and honorary art psychotherapists for limited periods.

The service also applies for one-off funding grants to support service development projects. A recent grant from the Barts Guild has enabled the service to purchase iPads for digital art therapy, bringing the service up to date with other cancer settings in the US and hospitals and hospices in the UK.

Outcomes

Until recently the validated outcome measure GHQ 12 (General Health Questionnaire) had been used as a before and after measure for out-patients who received six or more art psychotherapy sessions. Figures from forms completed in 2013 / early 2014 show that every patient's distress levels have decreased; this has been regardless of decline in physical health / prognosis in a number of cases:

	GHQ 0-3 before	GHQ 0-3 after	%change
Patient 1	17	9	47%
Patient 2	22	2	91%
Patient 3	14	5	61%
Patient 4	16	8	50%
Patient 5	16	0	100%
Patient 6	6	1	83%
Patient 7	23	8	65%
Patient 8	20	4	80%
Patient 9	27	5	81%
Patient 10	32	2	94%
Patient 11	29	2	91%
Patient 12	10	1	90%
Patient 13	32	6	81%
Patient 14	24	11	54%
Patient 15	16	12	25%

The service now uses the hospital anxiety and depression scale (HADS) and the patient satisfaction measure; receiving consistently excellent results; this information can be provided on request.

Contact

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APPENDIX D: CASE STUDY DETAIL | YEARLY HOLISTIC CANCER REVIEWS

Aims

Currently patients are likely to either suffer in silence or attend the GP on multiple occasions each year for an array of physical and psychological symptoms resulting from the cancer and its treatment, which may or may not be managed well in a short appointment. Offering individuals a holistic yearly review in a long appointment for up to five years after a cancer diagnosis would allow for a full assessment of all their needs and appropriate treatment or signposting to available services. This will improve experience for both the patient and the healthcare professional and will lead to reduced load on both primary care appointments and the need for further secondary care input including unnecessary admissions.

Rationale

There are more people than ever now surviving cancer and living with the long term consequences of both the cancer itself and its treatment. These include physical effects such as chronic fatigue, sexual difficulties, urinary and faecal incontinence, increased rate of ischaemic heart disease, osteoporosis and psychological effects such as anxiety and depression.

Despite evidence that shows the need for regular long term holistic reviews for these patients following cessation of treatment for the cancer itself¹, there is no current advised schedule for review as the quality and outcomes framework cancer care review takes place within six months; during the investigation and treatment stage of disease. Unfortunately, these long term effects remain unaddressed leading to patients suffering in silence or attending multiple unsuccessful GP appointments².

Development

Wandsworth CCG has put in place a yearly extended holistic review for patients with various long term conditions. The idea to extend this to people living with cancer has been presented to the cancer clinical reference group and gained support from all members including primary and secondary care, social services, public health, service users and voluntary sector representation.

A proposed model to support holistic reviews for people living with cancer was presented to the clinical and management teams where funding was agreed. The project started in the summer 2014 and is still to be evaluated.

Costings

Each GP is paid £67 per holistic review.

Note: The costings for the CCG depend on prevalence and actual uptake.

Outcomes

The scheme has been running for approximately nine months and uptake has been variable. A review of the model will take place after the first year to assess whether it needs to be changed to improve uptake. Individuals with cancer who have had a holistic review have been asked to complete an evaluation form though not many have been returned.

The expected outcomes and benefits of a holistic review are: greater patient satisfaction, less routine GP appointments and better management of the long term consequences of cancer. As well as highlighting the role of the GP in cancer management.

Contact

Dr Anthony Cunliffe, Macmillan GP adviser / GP lead, Transforming Cancer Services Team / Cancer commissioning lead for Wandsworth, anthony.cunliffe@nhs.net.

APPENDIX D: CASE STUDY DETAIL | ASIAN, AFRICAN AND CARIBBEAN SUPPORT GROUPS

Aims

Paul's Cancer Support Centre, South London, have established two black and minority ethnic (BME) cancer support groups for members of the Asian communities and for members of the African and Caribbean (AC) communities. The groups aim to help meet the support needs of new and established members at all stages of their cancer journey, from diagnosis, through treatment to living with cancer. Carers of someone with cancer are also welcome to attend the groups.

Rationale

These groups are needed because there are cultural differences and sensitivities within BME communities around health in general and cancer specifically. The groups provide a safe environment in which to exchange experiences and to develop a network of support and mutual aid, and provide opportunities to discuss living with cancer and its effects. During times of stress and adversity, a great deal of comfort and strength is derived from being with people of the same or similar culture and traditions. Cancer patients have a strong need to interact with each other and the value of peer support groups has been recognised.

Development

The support group meetings are held monthly and each group is facilitated by a group leader at Paul's Centre for up to 20 people per group to help meet the support needs of new and established members at all stages of their cancer journey. The groups offer culturally sensitive support and enable people to identify solutions to practical problems caused by cancer or its treatment.

Poverty, low literacy and social exclusion can play a part in preventing BME communities accessing appropriate cancer information and support services. Clients learn of the free support groups through accessing other services at Paul's Centre, local health professionals, local BME community-based organisations or other support group members.

Group leaders also offer one to one support, usually by telephone, to individuals who are unable or unwilling, because of their personal circumstances, to attend the group. Individual group members are also able to 'buddy' and mentor other members of their community outside of the group, forming a wider network of support.

Group members are supported to participate in cancer awareness and outreach events in the BME communities and represent their communities at conferences and events. Established group members can talk about the positive impact of one to one support such as counselling which may be culturally unfamiliar to other members of their communities thereby improving access to psycho-social support. Both groups also arrange occasional outings outside the monthly meetings which provide more informal opportunities to socialise.

Outcomes

Qualitative feedback clearly demonstrates the value of the groups for their members. Isolation is frequently a challenge for people and the culturally sensitive environment enables members to feel comfortable sharing experiences. Quotes from group members include:

"When I was first diagnosed I felt frightened and isolated. The Asian support group has made me feel like I'm not alone and helped me enjoy life again."

"I come to be with the people who supported me when I was in a very bad state. The AC group saved my life – I couldn't speak to my family and friends because they wouldn't understand."

"The group is a fantastic place to meet up; the people here are so willing and very helpful. I feel accepted when I come and get the chance to speak about how I'm feeling, how the cancer has affected me. If I miss one session I feel guilty! It's very beneficial."

The Asian and African and Caribbean cancer support groups will continue to offer support to people affected by cancer, reaching out to the local hospitals and community. Experience has shown that many support group members reach a stage when they want to take on a more proactive role in addition to the ongoing support they gain from the group. They emerge as passionate advocates who want to empower others through sharing their own experiences, to raise awareness of the lifestyle risk factors associated with cancer and promote early diagnoses and prevention. Equally they want to promote the support group and other centre services to people living with cancer in isolation, to enable others to access the support they benefited from.

Contact

Beverley van der Molen, Macmillan information and education officer, Paul's Cancer Support Centre, beverleyvm@paulscancersupport.org.uk.

APPENDIX D: CASE STUDY DETAIL | SOUTHWARK IAPT PROVISION

Aims

To develop Southwark IAPT provision of primary care psychological interventions for King's Breast Care (KBC) patients, carers and relatives.

Rationale

A new care pathway for the provision of primary care psychological support for breast cancer patients was required following the closure of the patient counselling service at King's College Hospital and withdrawal of funding for fatigue-related referrals to King's chronic fatigue research and treatment unit (CFRTU).

Development

The care pathway was developed at meetings between staff from KBC, Southwark psychological therapies service, King's psychological medicine department (PMD) and the CFRTU (South London and Maudsley NHS Trust). Primary and secondary care pathways were agreed:

Primary care: The new primary care pathway involved provision of counselling, cognitive behaviour therapy and other primary care psychological interventions for patients throughout their cancer pathway, including survivorship. Examples of identified needs include adjustment difficulties, depression, anxiety, relationship problems or cancer-related fatigue.

Secondary care: The existing care pathway involving King's PMD provision continues. This caters specifically for patients in active treatment who are likely to have complex mental health or psychological needs requiring interactions based around multiple hospital treatment episodes. All patients referred to King's PMD are triaged and according to clinical need are either treated by their multi-disciplinary team or referred to secondary care community mental health services, or to IAPT services. All patients are reviewed at a monthly specialist multidisciplinary meeting between KBC and King's PMD.

Patients in need of IAPT intervention are identified by KBC clinical staff at key points in their cancer treatment pathway (diagnosis, through active treatment, survivorship) through the use of well-validated self-report questionnaires to screen for psychological morbidity and fatigue. These questionnaires are used in addition to the Holistic Needs Assessment to help ensure appropriate referral according to clinical need. If questionnaire cut-off scores are exceeded for symptoms of depression, anxiety or fatigue patients are asked whether they would like to be referred for support. Patients with pre-existing problems or those with acute or chronic problems arising as a consequence of treatment can be identified.

Referral routes - Any health professionals in KBC can refer patients to Southwark IAPT. Self-referral is encouraged and is advertised in the breast clinic by poster and flyers. King's PMD can refer to IAPT if they consider primary care psychological provision to be more appropriate.

Training - Jo Marsden, consultant surgeon, King's Breast Care, provided a training session about breast cancer to Southwark IAPT therapists.

Outcomes

IAPT service provision for KBC is now established as part of the multi-disciplinary service and has representation at the KBC/King's PMD multi-disciplinary meeting. An IAPT counsellor provides a counselling service for at least a session a week from KBC. There is also the option for the counsellor to see patients at other sites, for example the Maudsley Hospital, if preferred by the patient. A health psychologist is available to provide interventions for cancer-related fatigue. For patients with depression, anxiety or other psychological problems appropriate for primary care intervention, there is also the option of being seen by an IAPT therapist in the usual Southwark IAPT sites, (eg GP surgeries or the Maudsley Hospital). Self-report questionnaire outcome measures are administered at every session and will be evaluated in due course. Based on the success of this service integration between KBC, King's PMD and Southwark IAPT, Lewisham and Lambeth IAPT services are being approached to ensure equity of access of care for the patients in the Trust's catchment area.

Contact

Katharine Rimes, Honorary consultant clinical psychologist, Southwark Psychological Therapies Service, Katharine.Rimes@slam.nhs.uk; Jo Marsden, Consultant surgeon, King's Breast Care, Jo.Marsden@nhs.net.

APPENDIX D: CASE STUDY DETAIL | UNIVERSITY COLLEGE LONDON HOSPITAL

Aims

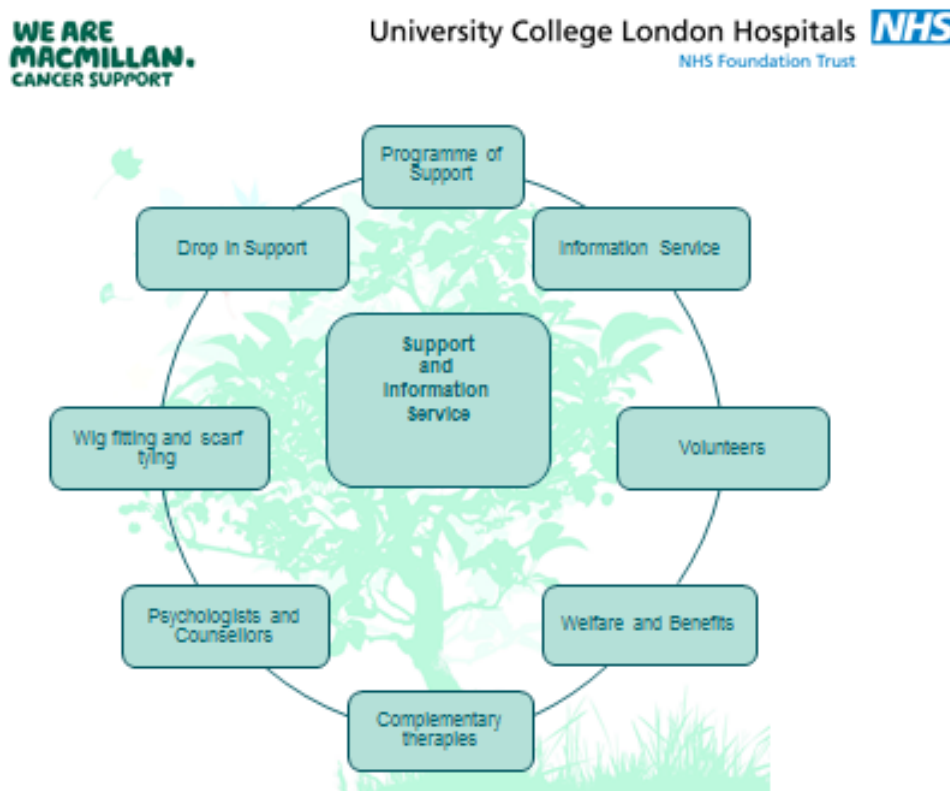
Our vision for the Macmillan Support and Information Service is to meet the needs of patients and their families and friends by providing access to individualised, supportive cancer care which is integrated with the experience of treatment and follow-up. We believe that access to the services provided by the Macmillan support and information service should be part of routine care and available to people living with cancer and families as an integrated part of their experience and University College London Hospital.

Rationale

- » To address the unmet supportive care needs of cancer patients and their families (before, during and after treatment)
- » To support patients to self-manage short and long term
- » To develop services specific to certain cancer types by collaborating with clinical teams

Development

Integrated Model of Supportive Cancer Care at UCLH



Outcomes

We use a variety of evaluation approaches and outcome measures to monitor the experience of our patients and the effectiveness of our services. These approaches include focus groups, patient surveys, patient comments and a range of measures including MYCAW and others.

Contact

Lallita Carballo and Dr.Hilary Plant, Joint clinical leads for supportive cancer care and heads of the Macmillan support and information service, UCH Macmillan Cancer Centre, Huntley Street, London, WC1E 6AG, Lallita.Carballo@uclh.nhs.uk | Hilary.Plant@uclh.nhs.uk.

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APPENDIX D: CASE STUDY DETAIL | CITY AND HACKNEY

Aims

The aim is to provide specialist psychological and emotional support to City and Hackney cancer and palliative care patients and their families and to support medical teams to provide psychologically informed care at all levels of service delivery. The service liaises with the City and Hackney Primary Care Psychology team to provide advice and support for their patients with cancer and accepts onward referral for patients who need more specialist cancer psychology.

Rationale

As City and Hackney patients move through the cancer pathway they may receive their care from a number of different organisations. Providing a clinical psychology service that can see them at the site of their medical care provides a service better suited to the complex psychological and emotional consequences of cancer and its treatment.

The co-location of the clinical psychologists within the relevant cancer and palliative care teams provides good liaison with the medical teams to provide coordinated patient care and staff support with complex cases. In addition the psychologist works with oncology medics and surgeons to provide assessment to support treatment decision making.

Development

The service was set up in 2008, funded by what was then the City and Hackney primary care trust (PCT), and hosted by the Homerton Hospital. The service is comprised of a full time clinical psychologist and occasional trainee clinical or counselling psychologists.

The psychologist is based within the Homerton Hospital cancer and palliative care teams; the service sees patients at Homerton Hospital, Barts Cancer Centre and some community settings, such as St Joseph's Hospice. One to one sessions are available for outpatients and inpatients and people are welcome to bring family members to these sessions. Group support such as 'Managing Cancer workshops' and Mindfulness groups is also offered in conjunction with the psycho-oncology teams at Barts and St Joseph's Hospice.

The service provides staff support, training and supervision in line with the NICE guidelines in supportive and palliative care, Cancer Peer Review psychological measures and the London Cancer objectives.

Outcomes

The service receives consistently good patient feedback both for the one to one patient intervention and the group support. The outcome of psychological interventions is measured using standardised outcome measures developed for a physically unwell patient group. The interventions provided achieve a reduction in psychological distress associated with the demands of cancer treatment.

Contact

Dr Clare Stevenson, Clinical psychologist in cancer care, City and Hackney, clare.stevenson@nhs.net.

Aims

To understand the support needs of men with penile and urethral cancers attending a tertiary referral centre

Rationale

To ensure that the service was responding to the expressed supportive care needs of men with penile and urethral cancers.

Development

A focus group was established and facilitated by two health professionals using a structures protocol. 15 men attended following invitation and the session was observed by two health professionals who captured key discussion points and individuals feedback. The written observations were then compared and analysed and significant themes identified.

Support Group

In response to the focus group a support group has been established. Meetings are scheduled on a monthly basis for one and a half hours with a light lunch provided; eight meetings have taken place so far. Meetings have been consistently well attended; people arrive early to talk and often leave late.

The sessions combine, facilitated open discussion and educational input such as treatment options, complementary therapy and lymphoedema.

Outcomes

Following a literature review which revealed no appropriate or relevant evaluation tool is currently available; a bespoke evaluation questionnaire was developed by the team with reference to self-management. After six months a questionnaire was sent to all the men who had attended the group (28 in total), and 19 were returned. The analysis and findings are presented here, in conjunction with the focus group data:

- » Unequivocal desire to have regular support meetings with an educational component (evaluation questionnaire)
- » The men universally wanted a regular meeting established that incorporated education, health professional facilitation and peer support.
- » Three men identified that they were apprehensive about attending but did attend and continued to do so
- » We were struck by the commonality of response and the lack of demand expressed by the men

Contact

Clare Akers, Nurse practitioner for penile and urethral cancer, UCLH

Vikky Riley, Macmillan clinical nurse specialist for support and information, UCLH

Dr Hilary Plant, Joint clinical lead for supportive cancer care, UCLH

0203 447 8663

APPENDIX D: CASE STUDY DETAIL | GET TO KNOW CANCER POP UP SHOP

Aims

In January 2015 Wandsworth Borough Council opened the cancer pop up shop in a local shopping centre. The shop's aim was to stimulate conversation on cancer signs, symptoms, screening and prevention with harder to reach groups in a convenient non-medical setting.

Rationale

In Wandsworth screening rates among the learning disability population are a significant cause for concern. As a consequence public health were keen to ensure meaningful participation from learning disability groups locally in the shop and the activities delivered during the pop up period. Fear, a lack of awareness of the link between lifestyle and cancer, anxiety about medical procedures and an inability to comprehend complicated medical discussion all feed into these low screening rates. We sought to address these concerns through a targeted community asset based approach.

Development

With the support of Generate, a local learning disability charity, and using easy format material from EasyHealth, Macmillan cancer support and British Heart Foundation, we tailored a programme of three learning sessions each addressing a different aspect of cancer and healthy lifestyles / health promotion. Each of the three sessions was based on a different aspect of the core aims of the shop:

- » Signs and symptoms of cancer and when should you go to the doctors.
- » How to prevent cancer, especially the importance of healthy diet and exercise.
- » Cancer screening: What is it and why is it important?

Each session lasted about an hour during which time the shop was closed to the public and an extra nurse and health care assistant also attended to ensure that someone could be on hand at all times to answer any of the group's questions or concerns. The group were given food diaries so that they could monitor what they ate across the three weeks and were given the opportunity to undertake a health check (including body mass index (BMI) measurement and blood pressure testing) after week one and three. To assist in the delivery of the message we used tactile educational aids. Generate have since purchased similar aids to stimulate discussions on health with their own clients. After each session the Wandsworth sports and leisure team arranged for a walk with the group, these walks became so popular that the group have since established their own permanent walking group.

Outcomes

We were overwhelmed by the positive reaction from the group to the programme and it is credit both to the group and to Generate that the sessions were so warmly received. The group came out understanding some of the simple ways in which they could change their diet and improve their health. After taking on the message in the first week one of the group lost 3kgs by week three and was ecstatic. Another member of the group went for her first cervical smear at the age of 40 and came back to tell the group how simple and trouble free the process was.

In the longer term, we hope to emulate the successes that these sessions have brought and the lessons we have learned have given us fresh tools with which we can engage with the learning disability population. Four of the group with milder learning disability were so taken aboard by the pop up shop that they asked if they could come back to volunteer, this presented us with both a problem and an opportunity; as all our volunteers had to been trained with Cancer Research UK's 'Talk Cancer' training, so that they could meaningfully engage with people who came into shop. Their commitment and passion inspired us to have the training translated into easy format; we are currently in the process of applying for a grant for this from the Wimbledon foundation/trust. It is hoped that once we have translated the training we will support the develop a programme of learning disability health champions, stimulating peer to peer conversations in the learning disability population about healthy lifestyles and screening. The Wandsworth Cancer Clinical Reference Group now has a dedicated learning disability cancer screening nurse and we hope to establish similar sessions in other venues.

Contact

Dr Sarah Deedat, Public health lead, Wandsworth Borough Council, SDeedat@wandsworth.gov.uk.

APPENDIX D: CASE STUDY DETAIL | NEWHAM TALKING THERAPIES

Aims

We are a clinical psychology and health team that comprises of clinical and counselling psychologists and a psychological wellbeing practitioner. We are a specialist team that is part of Newham Talking Therapies service an improving access to psychological therapies (IAPT) service. The general IAPT service offers support and input for common mental health problems.

Rationale

It is commonly acknowledged and found that the level of distress amongst oncology and palliative care patients is significant. The NICE guidelines for supportive and palliative care 2004 advise psychological assessment and input be available at various points in the cancer (long term conditions) care pathway.

Development

The psychology and health team offer psychological support to people in Newham living with cancer, palliative care issues and long term conditions (LTCs). We offer individual assessment and treatment for a range of mental health conditions linked with cancer and or LTCs. We provide home visits for the palliative care clients and also run a number of programmes for cancer, such as *coping with treatment for cancer* programme and have provided *coping with breast and gynaecological cancer* groups. Our palliative care provision is delivered from a number of sites including Newham General Hospital, St Joseph's Hospice and the community.

We provide Level 2 supervision for clinical nurse specialists at Newham General Hospital – as required by London Cancer, and provide training on the Holistic Needs Assessment screening tool using the *Distress Thermometer*. We also deliver death and dying training for staff in Newham who wish to raise their skills in discussing these issues.

Newham Talking Therapies service has offered this provision for a number of years and has developed following clinical need and service user feedback.

Outcomes

A range of measures are used to measure levels of depression and anxiety which include the minimum data set for IAPT (the PHQ and GAD) where appropriate. Patients are referred from a number of sources including G.Ps, clinical nurse specialists and radiology. Referrals have increased since highlighting the Holistic Needs assessment.

Sixty-five people with either a history of cancer or current diagnosis were referred to our general IAPT service from April 2014 – March 2015; many of whom will have been seen by our psychology and health team or the wider talking therapy service.

Contact

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Dr Tomas Campbell, Head of psychology and health, 0208 536 2161.

APPENDIX D: CASE STUDY DETAIL | BIG WHITE WALL

Aims

Digital mental health service Big White Wall (BWW) offers a safe, 24/7 professionally-moderated online space for people to talk about their emotional wellbeing. BWW is not exclusively for people living with cancer but it may be valuable for this group.

Rationale

People living with cancer have very specific mental health needs: as well as the direct impact of the illness on mental wellbeing, cancer and its treatment can significantly reduce energy and ability to travel. This can make it difficult for people to access traditional mental health services, and can also mean that people find it hard to stay in contact with their wider support network of friends and colleagues.

Many people with cancer need support in managing the emotional impact of their condition, or in managing pre-existing mental health conditions. Some will use talking therapies, some will be helped by support from peers, and others will prefer a combination of these approaches. Committing to appointments at regular times, or travelling outside the home can be a problem so a more flexible approach may be preferable.

People often find it helpful to talk with people outside their social circle about mental health, perhaps because of; a reluctance to disclose that there is a problem, they do not wish to be a burden on family and friends, or because they want to find others with similar experiences. To keep people safe, anonymous and secure, BWW is monitored by professionals 24/7, with clinical oversight and leadership from a consultant psychiatrist.

Development

BWW was founded as a peer support network in 2007 in response to a need for safe, anonymous mental health support. It now has trained counsellors, called 'wall guides', who moderate the service 24/7. 'Live therapy' was added in 2012 which enables members to speak to a therapist via video, audio or instant messaging and guided support group courses for common mental health conditions were added in 2013. In 2014 a 'white label' option was added to the 'live therapy' platform to allow local NHS clinicians to deliver therapy online through BWW.

In 2015, BWW was commissioned in half of London boroughs, with access either via postcode self-referral or (in a minority of cases) exclusively via IAPT services. People can contact their local CCG to see if it is available in their area.

Outcomes

Data collected regarding the working status of existing BWW member's shows that a significant group are unable to work due to sickness or disability.

According to an independent review, 95 per cent of BWW members report improved wellbeing as a result of using the service. Seventy-three per cent report disclosing an issue for the first time, with safety and anonymity were the key drivers in improvement. Recovery rates for live therapy are above the national average for IAPT, with the majority of appointments taking place at evenings and weekends when face-to-face services may not be available.

Big White Wall does not currently have specific outcomes data for people with cancer, and would be keen to work with providers to develop the evidence base in this area.

Contact

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APPENDIX D: CASE STUDY DETAIL | BRAINTRUST, THE BRAIN CANCER PEOPLE

Aims

brainstrust's aims are to help everyone diagnosed with a brain tumour access the help they need to get back on top of things. We help people to understand, and take control so that they can secure the best possible outcome following a brain tumour diagnosis.

Rationale

Brain cancer is different to other cancers; not only do patients and their carers have to come to terms with the diagnosis of brain cancer, but they do so in the knowledge that this diagnosis will certainly mean progressive neurological and cognitive deficit. Lehman et al¹ acknowledge that in 80% of central nervous system tumours there is a need for rehabilitation. With neuro-rehabilitation, emphasis is placed on restoring or maximising independence with activities of daily living, mobility, cognition, and communication. We know, however, that brain tumour patients and their carers are not all getting the help they need. As well as neurological complications, we know patients and carers are concerned about vitality, their identity and role, limitations, mental health, and emotional well-being². At brainstrust we know good neuro-rehabilitation and psychological care improves quality of life for people with a brain tumour. And a better quality of life often means a better outcome.

Development

When you are faced with a wall of information, it is easy to feel overwhelmed. brainstrust empowers brain tumour patients and carers to be engaged in their care so that they can take control and be confident that they are working towards the best possible outcome for their situation. Our ethos revolves around creating a supportive community for these people where they can interact as much, or as little, as they need to both in the real world and online. We offer a range of support services that embrace the ways that brain tumour patients and carers want to communicate, and that are accessible when people need to use them. To this end, we provide 24/7 phone and email support, face to face 'Meet Ups', printed information and support tools, as well as an online community and two websites that each meet a very specific, predetermined set of needs.

Elemental to our work is high performance coaching; this sets us apart. When we are no longer able to change a situation we are challenged to change ourselves. Our coaching relationship with the patients and carers whom we support, enables them to face their challenges so that they learn how to develop resilience and utilise resources to their full potential. Patients and carers need to be more proactive, confident and specific about saying what it is they need, for example in asking for neuro-rehabilitation. Through coaching, brainstrust helps them outline specifically what the problem is they're facing, so help can be targeted effectively.

Outcomes

Coaching creates shift - It enables patients and carers to feel more in control and to manage their care better. brainstrust's resources also help with this. Patients and carers can choose what they want to use so that it suits their needs. They can talk, click on links, email, phone, respond and engage in a way that suits them.

*brainstrust received a
Commendation in the
Quality in Care
2014 awards.*

Through using our resources, and engaging in coaching conversations, patients and carers can achieve a more meaningful dialogue at every touch point, and improved mental well-being. Patients and carers use our information to have a more equal relationship with their clinicians. Crucially, there is a community where people know there is someone they can reach out to.

"Thank you for all your help; you were there when I was at my wits' end, and both the website and the box gave me the means to take back some control of my situation."

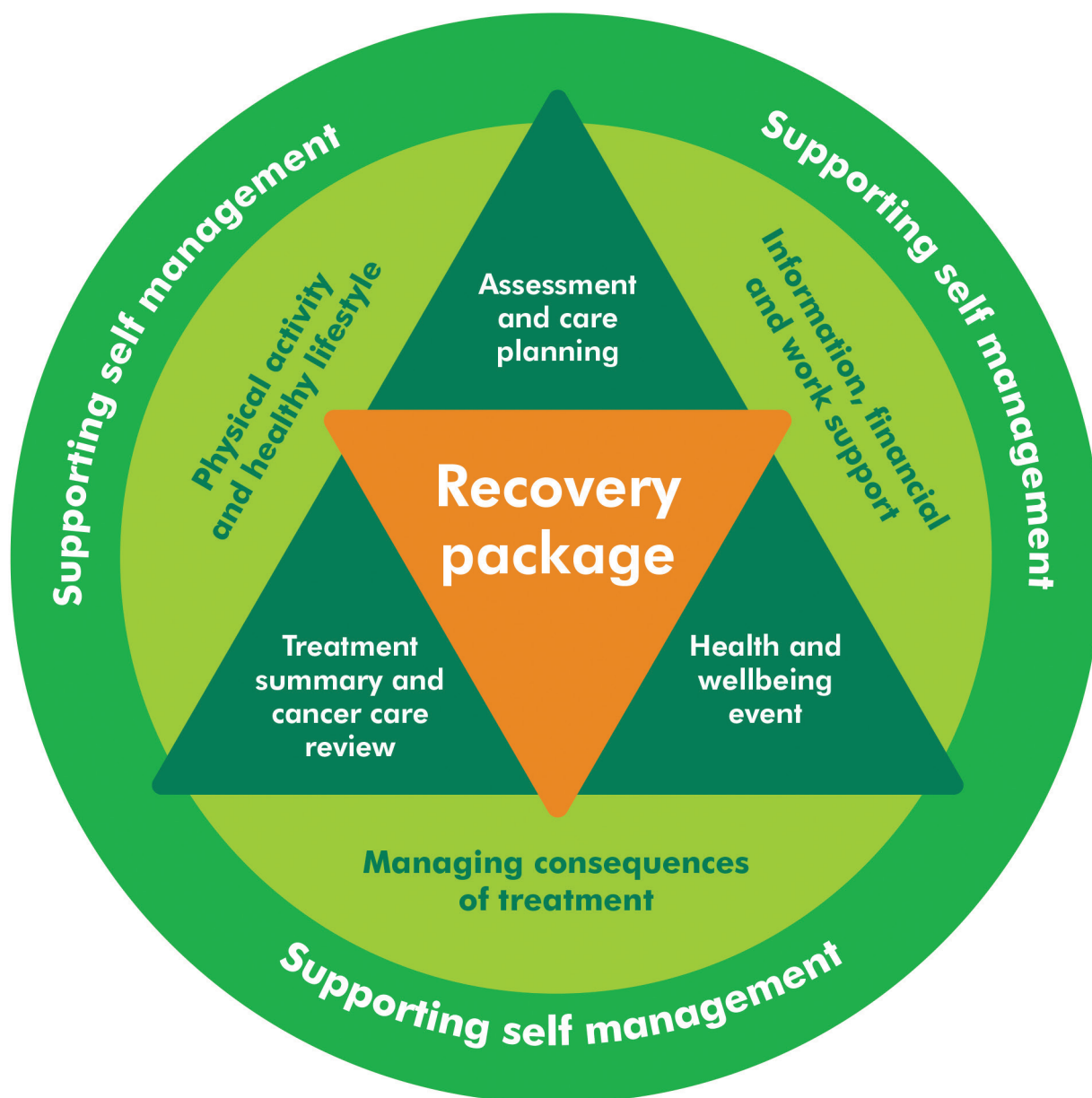
Brain tumour patient, November 2014, Coventry

Contact

Helen Bulbeck, Director of services and policy, or Megan Hill, Head of support, brainstrust HQ,
01983 292405, hello@brainstrust.org.uk | www.brainstrust.org.uk | www.braintumourhub.org.uk.

1. Lehmann J, DeLisa JA, Warren CG, et al. Cancer rehabilitation assessment of need development and education of a model of care. Arch Phys Med Rehabil 1978; 59:410-419

2. Bulbeck, H, brainstrust, Quality of life: what the brain cancer community needs, 2015.



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Why does psychological support matter and what's needed?

"My husband had gone into hospital expecting to undergo a major operation to remove a tumour. He was prepped, ready to go and waiting for his theatre slot. I left him for 10 minutes, to have a sandwich, and returned to find that while I was gone the consultant had seen him, on his own, and had delivered the devastating news that he had cancer, and that it was terminal. We were then basically left with no support or contact until the oncology appointment a week later. A week might not seem long to some people, but it felt terribly long to us, while we struggled to get our heads around the news and cope with our fears about what lay ahead."

"I strongly agree there needs to be greater recognition and positive action to address the psychological impact of cancer, its treatment, and the consequences of both for patients and those whose lives they are part of. I think this should be in place at diagnosis - or even earlier, from detection. Our experience was that the delay between screening and diagnosis and the corporate silence that followed increased our anxiety levels in the week or two that led up to the consultant delivering the diagnosis – and this in itself added to the negative psychological impact."

"While I was having chemotherapy I was also trying to cope with working part-time because of money worries, coming to terms with knowing I wouldn't be able to have children, and getting used to how I looked after surgery. All this time I was never offered emotional support – and when I said I was struggling was told I needed to *"think positive....."*! I thought I was doing pretty well just getting thorough the treatment, holding onto a tough job, and keeping my relationship strong -- but I could really have done with some expert help with the depression and anxiety I was experiencing as a reaction to so much change."

"Diagnosis of cancer is a significant life event that can be a catalyst for mental ill health – and how people cope depends on their psychological resources, support, etc. Everyone who receives a cancer diagnosis should be offered support to boost their psychological resilience whether or not they are showing immediate symptoms of psychological distress."

"We need to raise awareness of the definite benefits of good emotional support – that psychology is like physiotherapy for the mind and not something, that only 'weaklings' need. There is no shame and much gain in learning some easy techniques to stay positive and help oneself."

"I wish that structured support had been available to my husband. In fact, I think it should be something that is almost expected so that partners feel included and don't feel that they're somehow 'not coping' by needing counselling."

"Although I was the patient, I was more worried at the time I was having treatment about how my husband and kids were coping with all the changes and with seeing me so sick. I ended up feeling I had to be the strong one, because no one else seemed to pick up that they were falling apart. It was hard on all of us – and it also meant that the emotional impact only hit me some time later. I had a tough time with depression, which came along just when everyone else thought I was through treatment and should be feeling fine."

"I think support is needed most at the time of diagnosis with some immediate exercises to get through the pre / post-op time and immediate recovery."

"I think that all cancer service staff and CNSs should have some basic psychological training and a good knowledge of local services and resources so they can play a navigating role for patients and their families."

"I did not find the Macmillan nurses that available (they were probably snowed under) and it would have been nice to have more access to advice from the ones attached to the surgical team. My impression was that due to workload, and the fact I'm a doctor myself, they had me down as 'coping ok', and therefore kept their sparse time focussed on more needy folk."

APPENDIX F: PATIENT VOICE WORKING GROUP FEEDBACK

"I didn't see my CNS at all during treatment – only once at the time I was diagnosed with secondary cancer which couldn't be cured but could perhaps be slowed down with chemotherapy. I'm a young woman trying to keep earning a living and looking after my family, and I need support to get to grips with what's happening to me."

*"Other people's assumptions can get in the way of them offering support. What does a person needing support look like? **'A smile can mean a thousand words, but it can also hide a million tears.'**"*

"The cancer pathway should be extended to include a life-long concept of recovery. The impact of physical changes and the fear of recurrence is a physical and psychological reality for the patient / family long after discharge from oncology. From a mental health perspective, these psychological conditions resonate with PTSD. Why should cancer survivors have less good treatment than survivors of other physical / psychological trauma?"

From your experience, what works in meeting psychological support needs?

"As a patient who has been living with metastatic incurable cancer for nearly five years, and received various different treatments during that time, I can honestly say that the treatment and support received throughout my cancer journey at a London NHS hospital has been more than I could ever have wished for. I strongly believe that my positive cancer experience is due to the continued support I receive from CNS, and from the excellent team of consultants who from the outset have treated me as an individual, and not as a stereotype or a statistic."

"My hospital offered a series of 'managing cancer' psychology workshops on topics ranging from talking about cancer to others, stress management, fatigue and how to move forward after treatment finishes. These were immensely useful in and of themselves, but also provided an opportunity to meet other patients in a similar situation. Talking to them made me realise I was not alone, that the emotions and feelings I was experiencing were perfectly normal, and that there was no shame in admitting I needed some support.

On top of that, I have been receiving individual psychological support in the form of art therapy. This has allowed me to explore some of the many issues that have arisen since my cancer diagnosis, and helped me try and make sense of things in a space where I don't feel exposed or judged.

Overall I feel that I am being treated as a person rather than just a disease, which is helping to give me the coping strategies I need as the uncertainty of my illness continues."



APPENDIX F: PATIENT VOICE WORKING GROUP FEEDBACK

“CNS staff helped me, and we need to have lots more of them, please – including more male nurses, and perhaps some who aren’t in uniform which can seem like a barrier. The comfort and atmosphere of the treatment environment also matter - and so does positive staff morale.”

“From the point of diagnosis I looked for help. I successfully worked with a senior clinical hypnotherapist over the phone from the start and throughout the treatment period. The hypnosis exercises I was taught were fab and gave me strategies for pain management, going into surgery relaxed; and staying in positive frame of mind through chemotherapy.”

“Family and friends help, especially if they are not the sort to constantly go ‘Are you alright?’ and constantly overprotect you. Instead I found gentle, continuous encouragement and time in each other’s company without having to talk helped me.”

“I found the information that it is ok for me to come back in two or five years very helpful; and the information that some people suddenly feel the enormity of what’s happened after such a long time when the immediate time has felt so numb, flat and somehow emotionally disconnected.”

“I’ve needed different types of help during the 10 years I’ve been living with cancer. There were a couple of years where anti-depressants were prescribed, which made a big difference helping me to stay afloat mentally. I also had CBT for a while when I had a second cancer and found there were still issues from the first time I hadn’t dealt with.”

APPENDIX G: LONDON HEALTH NEEDS ASSESSMENT TEMPLATE



Appendix G: London Health Needs Assessment template

London Holistic Needs Assessment



For each item below, please select **yes** or **no** if they have been a concern for you during the last week, including today. Please also select **discuss** if you wish to speak about it with your health professional.

Choose not to complete the assessment today by selecting this box ☐

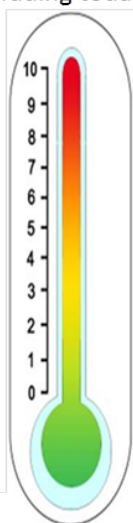
Date:	Click here to enter text.	Practical concerns	Yes	No	Discuss	Physical concerns	Yes	No	Discuss	
Name:	Click here to enter text.	Caring responsibilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	High temperature	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Hospital/NHS number:	Click here to enter text.	Housing or finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Wound care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Please select the number that best describes the overall level of distress you have been feeling during the last week, including today:		Transport or parking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Passing urine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
		Work or education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Constipation or diarrhoea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
		Information needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
		Difficulty making plans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Nausea and/or vomiting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
		Grocery shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Cough	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
		Preparing food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Changes in weight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
		Bathing or dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Eating or appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
		Laundry/housework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Changes in taste	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
		Family concerns					Sore or dry mouth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		Relationship with children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Relationship with partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Breathlessness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
Relationship with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
Emotional concerns					Dry, itchy or sore skin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Loneliness or isolation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands or feet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
Sadness or depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Hot flushes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
Worry, fear or anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Moving around/walking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
Anger, frustration or guilt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
Memory or concentration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Sleep problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
Hopelessness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Communication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
Sexual concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Personal appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
Spiritual concerns					Other medical condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Regret about the past	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
Loss of faith or other spiritual concern	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							

For health professional use

Date of diagnosis: Click here to enter text.

Diagnosis: Click here to enter text.

- 10 ☐ **Extreme distress**
- 9 ☐
- 8 ☐
- 7 ☐
- 6 ☐
- 5 ☐
- 4 ☐
- 3 ☐
- 2 ☐
- 1 ☐
- 0 ☐ **No distress**



APPENDIX G: LONDON HEALTH NEEDS CARE PLAN TEMPLATE

Preferred name:
Hospital/NHS number:

LONDON
CANCER
ALLIANCE
West and South



During my holistic needs assessment, these issues were identified and discussed:

Number	Issue	Summary of discussion	Actions required/by (name and date)
<i>Example</i>	<i>Breathlessness</i>	<i>Possible causes identified Coping strategies discussed Printed information provided</i>	<i>Referral to anxiety management programme; CNS to complete by 24th Dec</i>
1			
2			
3			
4			

Other actions / outcomes (eg additional information given, health promotion, smoking cessation, 'My actions'):

Signed (patient):

Date:

Signed (healthcare professional):

Date:

For health professional use

Date of diagnosis	Diagnosis	Pathway point
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APPENDIX H: STEERING GROUP MEMBERSHIP

Name	Role	Organisation
Afsana Safa	Associate GP lead	Transforming Cancer Services Team
Alex King	Consultant clinical psychologist and lead for psycho-oncology	Imperial College Healthcare NHS Trust
Alex Warner	Mental health lead	Camden CCG
Andrew Hodgkiss	Co-chair of the mental health and psychological support Pathway	London Cancer Alliance
Anne Carruthers	Clinical nurse specialist	St Christopher's Hospice
Barbara Gallagher	User involvement and patient coordinator	Transforming Cancer Services Team
Beverly James	Interim mental health commissioner	Enfield CCG
Busayo Akinyemi	Senior commissioning manager - Integrated commissioning	Greenwich CCG
Cathy Burton	Macmillan GP	Macmillan Cancer Support
Cerrie Baines	Project manager	London Mental Health Strategic Clinical Network
Chris Lewis		Chris's Cancer Community
Claudia	Service User	Macmillan Cancer Voice
Deborah Stalkartt	Information nurse, communications department	Cancer Research UK
Esther Appleby	Cancer lead	Lewisham CCG
Helen Davies	Independent health and wellbeing consultant	London Mental Health Strategic Clinical Network
Helen O'Kelly	Assistant lead	London Mental Health Strategic Clinical Network
Helen Palmer	Clinical psychologist	Maggie's Centre
Hilary Bird	Carer	Macmillan Cancer Voice
Jo Van Tijn	Macmillan network manager for NCL	Macmillan Cancer Support
Julia Warr	Service user	Macmillan Cancer Voice
Kathy Burn	Clinical nurse specialist and cognitive behavioural therapist	St Christopher's Hospice
Livia Royle	Consultant in public health and educational supervisor	Kingston CCG
Liz Price	Senior living with and beyond cancer lead	Transforming Cancer Services Team
Mark Barrington	Chair of the Mental Health and Psychological Support Pathway	London Cancer

APPENDIX H: STEERING GROUP MEMBERSHIP

Name	Role	Organisation
Meg Hill	Head of support	The Brain Trust
Mel Karakis	Service development manager, networks and communities	Mind
Michael Witney	Director of therapies	Oxleas
Natalia Neira	Early detection and awareness project manager	Transforming Cancer Services Team
Nicola Glover	Survivorship project manager	London Cancer Alliance
Omar Cummins	Clinical psychologist / Clinical coordinator	iCope - Islington Psychological Therapies and Wellbeing Service
Parul Banka	Service user	Macmillan Cancer Voice
Rebecca Banks	Senior primary care engagement manager	Cancer Research UK
Sarita Yaganti	Project lead	Transforming Cancer Services Team
Sharon Chambers	Senior counselling psychologist / CBT therapist	Southwark Psychological Therapies Service
Simon Selo	Associate development manager	Macmillan Cancer Support
Stefan Holzer	Specialty registrar (ST6) in liaison psychiatry	Central and North West London NHS Foundation Trust
Steven Reid	Clinical director, Psychological medicine	Central and North West London NHS Foundation Trust
Sue Smith	Head of cancer psychological therapies	Dimbleby Cancer Care, GSTT
Terry Bowley	Macmillan GP advisor north central and north east London	Macmillan Cancer Support
Tony Lawlor	Cancer commissioning manager	NE London CSU/Transforming Cancer Services Team
Vanessa Brunning	Project manager	London Mental Health Strategic Clinical Network
Veronique Furse	Service user	Macmillan Cancer Voice

APPENDIX I: IAPT SURVEY RESULTS | NORTH WEST LONDON

Area	Name of service	Self referrals?	Service is provided by: » NHS trust » Voluntary » Private	Does the service have specific care pathways for:							
				Any LTC	CVD	COPD	Diabetes	Pain	Arthritis	Stroke	Other / notes
Harrow	Harrow IAPT			No information provided							
Ealing	Ealing IAPT		NHS trust	✓							
Brent	Brent IAPT		NHS trust	✓							
Hammersmith and Fulham	Back on Track		NHS trust	✓		✓	✓	✓			
Central London (Westminster)	Westminster Psychological Therapies		NHS trust	✓							
Kensington and Chelsea	Kensington and Chelsea Psychological Therapies		NHS trust	✓						✓	Long term conditions project in its first year. Not aiming to see people who are in active cancer treatment, but see cancer survivors who continue to struggle with symptoms such as fatigue.
Hounslow	Hounslow IAPT		NHS trust				✓			✓	
Hillingdon	Hillingdon IAPT		NHS trust	✓							

Key:

CHP - Clinical health psychologist

COPD: Chronic obstructive pulmonary disease

CPD - Continuing professional development

CVD - Cardiovascular disease

IoP - Institute of Psychologists

LTC - Long term condition

MUS - Medically unexplained symptoms

APPENDIX I: IAPT SURVEY RESULTS | NORTH WEST LONDON

Area	Do you have a way of identifying cancer patients within your data set? <i>If yes, what percentage of patients have cancer?</i>	Do you know whether the clinical depression and anxiety disorders outcomes for people with cancer are comparable to those patients who do not have cancer? <i>If yes, how do the outcomes compare?</i>	Does your service have any clinical health psychologists working in your services? <i>If not, how do you obtain support for your therapists to better understand the psychological aspects of LTC (eg do they receive training from a health psychologist)?</i>	Does your service provide therapy in people's homes? <i>If not, how do you treat housebound patients?</i>
Harrow	No information provided			
Ealing	Yes; only recently implemented so cannot comment on exact figures.	Yes; this would require generating some reports.	No; we are considering the possibility of recruiting a health psychologist. (We do have regular links/supervision from clinical health psychologists in the trust.)	Yes.
Brent	Yes; very small, less than 2%	Yes; poorer outcomes without treatment of anxiety and depression.	No.	No; telephone based work where possible and appropriate.
Hammersmith and Fulham	Yes; 0.50%.	No; numbers of referrals have been too small to compare meaningfully until quite recently.	No; LTC lead (not a clinical health psychologist) provides guidance for staff. A number of CPD events have been attended with a focus on psychological aspects of LTC. There is a network across three IAPT services who share good practice around working with LTC.	Yes, we provide therapy in people's homes and/or other locations as required but, the number of visits is limited. Other options include delivering therapy via the telephone.
Central London (Westminster)	Yes; we do not have this data but it can be extracted from our database.	No.	No; training, CPD and specialist supervision if needed.	No; telephone appointments.
Kensington and Chelsea	No.	No.	Yes.	Yes.
Hounslow	Yes; APTus Hypercube report: 0.37% of people seen were recorded as having cancer (self-report).	No	No; IAPT top up training offered by the IoP.	No; web therapy, telephone sessions.
Hillingdon	Yes; since recording this data, 79 people, 0.69% of our population, have identified themselves as having cancer.	No	Yes; clinical psychologist with health psychology experience working in the service and providing support and training.	Yes; telephone sessions are available should this be suitable.

APPENDIX I: IAPT SURVEY RESULTS | NORTH CENTRAL LONDON

Area	Name of service	Self referrals?	Service is provided by: » NHS trust » Voluntary » Private	Does the service have specific care pathways for:							
				Any LTC	CVD	COPD	Diabetes	Pain	Arthritis	Stroke	Other / notes
Barnet	Barnet IAPT		NHS trust	✓							Newly commissioned IAPT service, collaborating with partners to establish Stroke, Cancer and Falls pathways.
Enfield	Enfield IAPT *	✓	NHS trust		✓			✓		✓	
Haringey	Haringey (Let's Talk) IAPT		NHS trust		✓	✓		✓			The service has plans to embed a step 3 CBT therapist with McMillan Cancer Society at Whittington Hospital.
Camden	Camden * (iCope - Camden and Islington Psychological Therapies Service)	✓	NHS trust	✓	✓	✓	✓	✓			We run IAPT sessions in some LTC clinics as part of the LTC pathway for COPD, diabetes. Also link with other local LTC services and take referrals from them - eg pain services, cardiac services.
Islington	Islington * (iCope - Camden and Islington Psychological Therapies Service)	✓	NHS trust					✓			

Key:

CHP - Clinical health psychologist

COPD: Chronic obstructive pulmonary disease

CPD - Continuing professional development

CVD - Cardiovascular disease

IoP - Institute of Psychologists

LTC - Long term condition

MUS - Medically unexplained symptoms

APPENDIX I: IAPT SURVEY RESULTS | NORTH CENTRAL LONDON

Area	Do you have a way of identifying cancer patients within your data set? <i>If yes, what percentage of patients have cancer?</i>	Do you know whether the clinical depression and anxiety disorders outcomes for people with cancer are comparable to those patients who do not have cancer? <i>If yes, how do the outcomes compare?</i>	Does your service have any clinical health psychologists working in your services? <i>If not, how do you obtain support for your therapists to better understand the psychological aspects of LTC (eg do they receive training from a health psychologist)?</i>	Does your service provide therapy in people's homes? <i>If not, how do you treat housebound patients?</i>
Barnet	No.	No.	No; there is early dialogue with local health psychology services.	No; we have an e-platform called Big White Wall that we can provide secure face-to-face therapy on computer to the patient's house.
Enfield	No.	No.	No; monthly group LTC supervision from a health psychologist.	No.
Haringey		No.	Yes.	No.
Camden	Yes; information is recorded on LTC field as one of the options, but not always filled in, so likely to be an underestimate. Accurate figure not available.	No.	Yes.	Yes: some LTC or older adults, but limited amount available.
Islington	Yes.	Yes; in Q1 and Q2, Islington saw 6 patients with cancer (0.8% of all patients with a long term health condition). 50% reached recovery on the IAPT measures of anxiety and depression.	No; we have previously had consultation provided on LTHCs by clinicians with a specialist knowledge. A proportion of the staff team have also undertaken the IAPT LTHC training. The psychologists that work with older adults received specialist supervision from an older adults psychologist who has expertise in LTHCs.	Yes; the older adults psychologists have the flexibility to see patients in their homes. We have another part of the service principally run by trainees who are able to see patients that need to be seen at home. For those with complex health needs who are not appropriate for IAPT we might refer onto another service such as REACH or the Community Rehab Team.

APPENDIX I: IAPT SURVEY RESULTS | OUTER NORTH EAST LONDON

Area	Name of service	Self referrals?	Service is provided by: » NHS trust » Voluntary » Private	Does the service have specific care pathways for:							
				Any LTC	CVD	COPD	Diabetes	Pain	Arthritis	Stroke	Other / notes
Waltham Forest	Waltham Forest IAPT		NHS trust	✓							We offer group and individual based therapy for those with LTC.
Redbridge	Redbridge and Havering IAPT		NHS trust	✓							
Havering	Redbridge and Havering IAPT		NHS trust	✓							
Barking and Dagenham	Barking and Dagenham IAPT		NHS trust					✓			The service works with clients with any LTC if they have depression or anxiety related to this, but does not have specific care pathways. Health psychologists/ CBT therapists within the NHS trust work with cardiovascular disease, COPD, diabetes, cancer if are known to the multidisciplinary team in that area.

Key:

CHP - Clinical health psychologist

COPD: Chronic obstructive pulmonary disease

CPD - Continuing professional development

CVD - Cardiovascular disease

IoP - Institute of Psychologists

LTC - Long term condition

MUS - Medically unexplained symptoms

APPENDIX I: IAPT SURVEY RESULTS | OUTER NORTH EAST LONDON

Area	Do you have a way of identifying cancer patients within your data set? <i>If yes, what percentage of patients have cancer?</i>	Do you know whether the clinical depression and anxiety disorders outcomes for people with cancer are comparable to those patients who do not have cancer? <i>If yes, how do the outcomes compare?</i>	Does your service have any clinical health psychologists working in your services? <i>If not, how do you obtain support for your therapists to better understand the psychological aspects of LTC (eg do they receive training from a health psychologist)?</i>	Does your service provide therapy in people's homes? <i>If not, how do you treat housebound patients?</i>
Waltham Forest	Yes; on PC-MIS cancer is identified as a LTC.	Yes, about the same.	No, we have one CHP working in the borough and we liaise and have consultations for complex presentation and if necessary refer to the the health psychology service.	Yes.
Redbridge	Yes.	No.	No.	No.
Havering	Yes.	No.	No.	No.
Barking and Dagenham	Yes, for the financial year of 2014/15: 2.64% of those with long term conditions who enter treatment. Overall, this is 0.48% of people who have entered treatment.	No, not known.	No, the CHPs are not part of IAPT, although do work elsewhere within the trust.	No, by telephone work, or referring to a free counselling service who provides a service in people's homes. We do offer 1-2 treatment sessions at home at the start of therapy if indicated for anxiety disorders, such as agoraphobia.

APPENDIX I: IAPT SURVEY RESULTS | INNER NORTH EAST LONDON

Area	Name of service	Self referrals?	Service is provided by: » NHS trust » Voluntary » Private	Does the service have specific care pathways for:							
				Any LTC	CVD	COPD	Diabetes	Pain	Arthritis	Stroke	Other / notes
City and Hackney	City and Hackney IAPT		NHS trust	✓	✓	✓	✓	✓		✓	IBS and IBD, sickle cell disease
Tower Hamlets	Compass Tower Hamlets	No information provided									
Newham	Newham Talking Therapies		NHS trust	✓							The service works with any LTC, including cancer and palliative patients, sickle cell, neuropsychological, palliative care and HIV.

Key:

CHP - Clinical health psychologist

COPD: Chronic obstructive pulmonary disease

CPD - Continuing professional development

CVD - Cardiovascular disease

IoP - Institute of Psychologists

LTC - Long term condition

MUS - Medically unexplained symptoms

APPENDIX I: IAPT SURVEY RESULTS | INNER NORTH EAST LONDON

Area	Do you have a way of identifying cancer patients within your data set? <i>If yes, what percentage of patients have cancer?</i>	Do you know whether the clinical depression and anxiety disorders outcomes for people with cancer are comparable to those patients who do not have cancer? <i>If yes, how do the outcomes compare?</i>	Does your service have any clinical health psychologists working in your services? <i>If not, how do you obtain support for your therapists to better understand the psychological aspects of LTC (eg do they receive training from a health psychologist)?</i>	Does your service provide therapy in people's homes? <i>If not, how do you treat housebound patients?</i>
City and Hackney	No.	No.	Yes, we have a structure of CHPs, many of whom are involved in training and research (consultant, principal, highly specialist, specialist psychologists, CBT therapists and PWPS/Assistant psychologists).	Yes, generally for adult community rehab only.
Tower Hamlets	No information provided			
Newham	Yes; approximately 1-2%. This would be done manually from our data set, as these would be non IAPT cases.	Yes; anecdotally from my clinical work, I would say they are the same or better.	Yes; the specialist team called Psychology and Health that operates within IAPT is comprised of clinical health psychologists.	Yes; we provide home visits if patients are palliative or bedbound. We also provide some input through telephone or Skype for clients with severe mobility issues (eg MS).

APPENDIX I: IAPT SURVEY RESULTS | SOUTH WEST LONDON

Area	Name of service	Self referrals?	Service is provided by: » NHS trust » Voluntary » Private	Does the service have specific care pathways for:							
				Any LTC	CVD	COPD	Diabetes	Pain	Arthritis	Stroke	Other / notes
Richmond	Richmond Wellbeing Service		NHS trust	✓							
Wandsworth	Wandsworth IAPT		NHS trust		✓	✓	✓				
Kingston	Kingston Wellbeing Service		NHS trust					✓			
Sutton	Sutton and Merton IAPT		NHS trust				✓		✓		No specific pathway although we have developed LTC CBT protocols for patients presenting with diabetes, heart disease and COPD.
Merton	Sutton and Merton IAPT		NHS trust				✓		✓		No specific pathway although we have developed LTC CBT protocols for patients presenting with diabetes, heart disease and COPD.
Croydon	Croydon IAPT		NHS trust		✓	✓	✓	✓			IBS

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APPENDIX I: IAPT SURVEY RESULTS | SOUTH WEST LONDON

Area	Do you have a way of identifying cancer patients within your data set? <i>If yes, what percentage of patients have cancer?</i>	Do you know whether the clinical depression and anxiety disorders outcomes for people with cancer are comparable to those patients who do not have cancer? <i>If yes, how do the outcomes compare?</i>	Does your service have any clinical health psychologists working in your services? <i>If not, how do you obtain support for your therapists to better understand the psychological aspects of LTC (eg do they receive training from a health psychologist)?</i>	Does your service provide therapy in people's homes? <i>If not, how do you treat housebound patients?</i>
Richmond	Yes.	No; no information on this.	Yes; we have medical practitioners working within the service.	No; local commissioning arrangements: if home treatment required (ie no treatment community as part of an intervention package) then referral to secondary care. Service offers treatment (eg for panic, social phobias, etc as part of planned treatment) but not regular treatment in the person's home.
Wandsworth	Yes; 30 known cancer patients have been referred in past 12 months out of an estimate of 5,000 annual referrals = 0.6%	No.	Yes; we have two health psychologists and a number of counselling/clinical psychologists who have some training in health psychology. We have bought in expertise for training in step 2 interventions for LTC for our PWP's.	No; this is something we are looking into with regards to patients with LTCs and in what format this may take (eg webinar, telephone, home visits).
Kingston	No.	No.	No.	No; by telephone. Occasionally we are able to treat or at least offer assessments in people's homes.
Sutton	No.	No.	No; we do not employ health psychologists but provide internal training for clinicians on working with patients who suffer from long term health conditions.	No; we do not currently have a home visiting policy.
Merton	No.	No.	No; we do not employ health psychologists but provide internal training for clinicians on working with patients who suffer from long term health conditions.	No; we do not currently have a home visiting policy.
Croydon	Yes; not known.	Not known.	No, I am supervised by a consultant clinical health psychologist at King's.	Yes; in special circumstances.

APPENDIX I: IAPT SURVEY RESULTS | SOUTH WEST LONDON

Area	Name of service	Self referrals?	Service is provided by: » NHS trust » Voluntary » Private	Does the service have specific care pathways for:							
				Any LTC	CVD	COPD	Diabetes	Pain	Arthritis	Stroke	Other / notes
Lambeth	Lambeth IAPT		NHS trust				✓	✓			
Southwark	Southwark IAPT	✓	NHS trust	✓		✓	✓				
Lewisham	Lewisham IAPT		NHS trust	✓		✓					
Greenwich	Greenwich Time to Talk (IAPT)		NHS trust		✓	✓	✓				The service is currently developing a stroke care pathway with the Neuro Rehab Team.
Bexley	Mind in Bexley (IAPT)	✓	Voluntary sector	✓							If a long term condition is indicated on the referral, this is taken into consideration when deciding on the client's individual treatment plan.
Bromley	Bromley Working for Wellbeing (IAPT)		Voluntary sector				✓	✓			

Key:

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APPENDIX I: IAPT SURVEY RESULTS | SOUTH WEST LONDON

Area	Do you have a way of identifying cancer patients within your data set? <i>If yes, what percentage of patients have cancer?</i>	Do you know whether the clinical depression and anxiety disorders outcomes for people with cancer are comparable to those patients who do not have cancer? <i>If yes, how do the outcomes compare?</i>	Does your service have any clinical health psychologists working in your services? <i>If not, how do you obtain support for your therapists to better understand the psychological aspects of LTC (eg do they receive training from a health psychologist)?</i>	Does your service provide therapy in people's homes? <i>If not, how do you treat housebound patients?</i>
Lambeth	No.	No.	No, training from specialists in the field, also from collaboration and training with Southwark IAPT, a pathfinder site.	Yes.
Southwark	Yes.	No; we have never compared the outcomes.	Yes.	Yes.
Lewisham	No.	No.	No; we have clinical psychologists with specialist expertise in physical health, but they are not trained as clinical health psychologists. We also have clinicians trained as part of the CanTalk study.	No; over the telephone.
Greenwich	Yes; We record this using a label on IAPTus. If patients do not disclose this at registration, this data could be missing. We currently have 14 clients active in GTT out of approx 1,423 (approx. 1% of our clients).	No.	Yes.	No; We offer Skype therapy, but due to limited resources we cannot offer at-home face to face treatment at present.
Bexley	No.	No.	No; therapists have attended the CanTalk training, and can contact Dr Marc Serfaty from UCL mental health science unit should there be any concerns regarding their treatment plans.	No; due to existing funding issues this is not possible, however we do offer telephone appointments where appropriate.
Bromley	Yes; Currently we are part of the UCL RCT (Can Talk Study) and they refer patients with a Bromley GP directly to us. The numbers are small - we may have about 4 or 5 patients at present.	No.	No.	No; we provide telephone sessions and are currently exploring Step 3 CCBT but the Service is currently limited for such patients.

Psychological support for cancer patients - IAPT survey questions

1. Are you a pathfinder service taking part in the IAPT Long Term Conditions/ Medically Unexplained Symptoms (LTC/MUS) project?
2. Is your IAPT service provided by an NHS trust, a voluntary or private provider?
3. Does your service have specific care pathways for the following:
 - » Any long term conditions
 - » Cardiovascular disease
 - » COPD (chronic obstructive pulmonary disease)
 - » Diabetes
 - » Pain
 - » Arthritis
 - » Stroke
4. Does your service have a specific care pathway for cancer?
5. Does your service exclude those patients who have cancer?
If so, where do you signpost them onto to receive psychological treatment for depression and anxiety?
6. Do you have a way of identifying cancer patients within your data set?
If so, what percentage of your patients have cancer?
7. Do you know whether the clinical depression and anxiety disorders outcomes for people with cancer are comparable to those patients who do not have cancer?
If you do, how do the outcomes compare?
8. Does your service have any clinical health psychologists working in your services? Please clarify:
If not, how do you obtain support for your therapists to better understand the psychological aspects of LTC (eg do they receive training from a health psychologist)?
9. Does your service provide therapy in people's homes?
If not, how do you treat housebound patients?
10. Are you aware of any commendable best practice models using IAPT or other psychological services that provide holistic treatment for people with cancer?
Please give details / links / email for clinical leads of this service.



- Service type

Enhanced information and support services

● Macmillan Information and support services

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APPENDIX L: REFERENCES

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APPENDIX L: FURTHER READING

These recommendations were informed by the following key documents:

1. ***Guidance on Improving Support and Palliative Care for Adults with Cancer***. National Institute for Clinical Excellence (2004).
2. ***National Cancer Peer Review Programme Manual for Cancer Services 2008: Psychological Support Measures***. National Cancer Action Team (2010).
3. ***Psychosocial interventions to improve quality of life and emotional wellbeing for recently diagnosed cancer patients***. Galway K, et al. Cochrane Database Syst Rev. (2012).
4. ***Service User Involvement in Cancer Care - Policy, Principles, Practice***. Butcher H. National Cancer Action Team (2010).
5. ***Transforming Participation in Health and Care: the NHS belongs to us all***. NHS England (2013).
6. ***Service Specification: Psychological Support Services***. London Cancer (2014).
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10. ***Deliver better services for people with long term conditions: Building the house of care***. The King's Fund (2013).
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12. ***Throwing Light on the consequences of cancer and its treatment***. Macmillan (2013).
13. ***Hidden at home: the social care needs of people with cancer***. Macmillan (2015).
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15. ***Living with and beyond cancer: taking action to improve outcomes***. National Cancer Survivorship Initiative (2014)
16. ***Quality of life of colorectal cancer survivors in England***. NHS England et al (2015)
17. ***Living with and beyond gynaecological cancers – cervical, ovarian and uterine***. NHS England et al (2015)
18. ***Guidance on delivering personalised care and support planning: the journey to person centred care*** (supplementary information for commissioners). NHS England and Coalition for Collaborative Care (2015)
19. ***Use of health and social care by people with cancer***. Nuffield Trust (2014)

About the Strategic Clinical Networks

The London Strategic Clinical Networks bring stakeholders -- providers, commissioners and patients -- together to create alignment around programmes of transformational work that will improve care.

The networks play a key role in the new commissioning system by providing clinical advice and leadership to support local decision making. Working across the boundaries of commissioning and provision, they provide a vehicle for improvement where a single organisation, team or solution could not.

Established in 2013, the networks serve in key areas of major healthcare challenge where a whole system, integrated approach is required: Cardiovascular (including cardiac, stroke, renal and diabetes); Maternity and Children's Services; and Mental Health, Dementia and Neuroscience.