
Developing a pathway for mental health and psychological support services for adults

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Executive summary

Around 1 in 4 cancer patients will require expert psychological assessment and intervention as a result of their diagnosis and 1 in 10 will require care from a psychiatrist or clinical psychologist. Psychological support can be separated into two distinct categories: that provided by those who have some training in assessment and frontline intervention of psychological problems but who are not mental health or psychological support professionals (level 1 and 2); and that which is provided by trained mental health/psychological support professionals (level 3 and 4)

Initial mapping work by the Mental Health and Psychological Support Pathway Group has identified the current workforce at level 3 and 4, and the current training options for level 1 and 2. This suggests a level 3 and 4 gap of around 16 WTE posts across the LCA. It also suggested advanced communication skills training needs further consideration by the LCA, alongside wide-spread access to Sage and Thyme training and level 2 psychological assessment skills training.

The Pathway Group proposes that a Psychological Support MDT approach, based on a hub and spoke model, would be the optimal way of meeting the population needs in the most cost effective way possible.

High rates of psychological distress and psychiatric disorder are found among those affected by cancers. We know that comorbid psychological distress and psychiatric disorder worsen the outcome and increase the costs associated with cancer, by up to 45%. Much of this distress and disorder goes undetected and untreated. Detecting and actively managing psychological distress and psychiatric disorder leads to safer care, improved clinical outcomes & patient experience, and improved cost effectiveness.

LCA providers should be screening for psychological distress and psychiatric disorder at key points in the care pathways of those affected by cancers. The HNA is necessary but not sufficient for the effective detection and onward referral of significant psychological problems. Without appropriate training and supervision of health professionals in the communication and psychological skills to undertake a comprehensive treatment care plan based on the HNA, only 3% of the comorbid psychological distress detected results in an evidence-based psychological intervention. In addition effective triage algorithms need to be implemented to ensure patients are offered psychological interventions appropriate to their particular needs and preferences.

Psychological support services need to address the full range and severity of psychological problems associated with cancer, including adjustment difficulties, anxiety, depression, problems with personal relationships, including communication with health professionals, psychosexual and body image difficulties, alcohol and drug-related problems, personality disorder, deliberate self-harm, psychotic illness and organic brain syndromes. In addition to this case-by-case clinical work, psychological support services also offer a systemic consultation approach to ensure cancer service delivery is consistently patient-centred.

Four cancer centres of the LCA (i.e. Royal Marsden, Guy's & St Thomas', Imperial and St Georges) should each establish a multi-professional Psychological Support Team that includes liaison psychiatrists, clinical health psychologists, psychotherapists, counsellors, psychosexual therapists and grief therapists. These teams should offer support to the patients & carers of the centre itself, as well as specialist support for patients from smaller local providers. Each cancer centre should identify a leader or co-leaders for their psychological support services.

The Psychological Support MDT at each cancer centre should:

- act as a single point of referral for all clinicians of the cancer centre and support smaller neighbouring providers through clear governance and cross-referral arrangements
- triage referrals, allocating to evidence-based treatments based on individual patients' needs
- deliver a comprehensive range of specialist psychological interventions
- collect and report agreed process and outcome measures
- provide regular clinical supervision of the psychological work of all CNS and AHP colleagues at the cancer centre

- contribute to communication skills and psychological training of all cancer health professionals, including Sage and Thyme, advanced communications skills and Level Two training; also contribute to facilitation of Schwarz centre rounds
- establish a range of group interventions
- oversee arrangements for psychiatric emergencies 24/7

Our preliminary mapping work has revealed numerous gaps in direct service provision by counsellors, psychotherapists, clinical health psychologists & liaison psychiatrists across all of the cancer centres. Some of these gaps could be addressed by reconfiguring the current psychological support service provision. The pathway group is now proposing to work as clinical champions, liaising with the cancer centres and other stakeholders to develop these psychological support teams.

1 Introduction

Alongside delivering safe and effective cancer care and improving cancer clinical outcomes, the mission of the LCA is to work collaboratively across the integrated system to enhance cancer patients' and carers' experience and quality of life. Attending to psychological aspects of care delivery, and dealing effectively with the psychological distress that is common among people affected by cancer, is central to all these aims.

The London Cancer Alliance (LCA) has established a pathway group for mental health and psychological support of those affected by cancer across west and south London. The pathway group is charged with leading the implementation of the relevant chapter of the 2004 NICE Improving Outcomes Guidance for Supportive and Palliative Care (<http://www.nice.org.uk/nicemedia/live/10893/28816/28816.pdf>), in addition to the 2010 Model of Care for cancer patients.

2 Cancer and Psychological Distress

Psychological distress in cancer is common. Around the time of diagnosis of early cancer, approximately half of all patients experience anxiety and depression severe enough to affect their quality of life. About a quarter of these patients will continue to do so during the following six months. Among those whose cancer progresses, the prevalence of anxiety and depression rises to 50%.

In the year following diagnosis with early cancer around 1 in 10 patients will experience symptoms severe enough to warrant interventions by specialist psychological/psychiatric services. Such symptoms are seen in 10-15% of patients with advanced disease (eg Burgess, Ramirez, BMJ, 2005; Hotopf et al, Palliative Medicine 2002). People with cancer are also at increased risk of suicide (Fang et al, NEJM, 2012; Schairer et al, JNCI, 2006).

Psychological distress in those living with cancer is associated with a range of harmful outcomes, including amplification of physical symptoms, poorer levels of functioning, adverse impact on carers, an enhanced desire for death, reduced adherence to cancer treatment and probable reduction in life expectancy. It also increases utilisation of healthcare resources. This distress is, however, potentially treatable.

All patients and carers are likely to benefit from some form of psychological support from clinicians, whether they experience mild and transient emotional turmoil or severe depression. The appropriate professional, and the intervention, will depend on the nature and severity of the person's psychological problem, their previous psychological morbidity, the quality of social support available, and the status of the cancer.

'Psychological support of those affected by cancer' is used to cover a broad spectrum of interventions including:

- all patients needing high quality information and compassionate, honest communication as a routine part of their cancer journey
- all clinicians skilfully eliciting health beliefs, supporting decision-making, mobilising coping and promoting adherence
- the detection and management of cancer-related distress by clinicians of all backgrounds
- the expert assessment and management of enduring emotional distress, psychosis or a delirium triggered by cancer or its treatment
- specialised psychological support focused on questions of adjustment, identity and mortality
- the care of people with a diagnosis of pre-existing severe mental illness that has been exacerbated by cancer

Carer psychological support needs include grief therapy and treatment for depressive illness related to their experiences as carers.

3 The National Picture and Evidence Base

There is increasing recognition that psychological and psychiatric services for those affected by cancer lag behind the services for physical health problems. The 2011 Department of Health (DH) report, *No Health Without Mental Health*, makes the case for parity of esteem (and parity of provision) between mental health and physical health services. The cost of inadequately addressing the psychological and mental health needs of those with long term conditions (LTC), such as cancers, is enormous. The Kings Fund, in its 2012 paper *Long Term Conditions and Mental Health: the cost of co-morbidities*, point to reduced quality of life, significantly poorer health outcomes (through continued self-damaging behaviours and poor adherence to medical treatment) and additional costs to the NHS of £8-13 billion per annum. Comorbid mental health problems raise total healthcare costs for patients with a LTC by 45%.

It is vital that commissioners and providers integrate mental and physical healthcare more closely through collaborative care initiatives for outpatients and provision of psychological support teams in hospitals. It is acknowledged that there are currently financial and organisational barriers to achieving this (such as the design of payment mechanisms and separate mental health trusts).

The economic and clinical case for liaison psychiatry teams in all modern hospitals has been described in two recent publications from the Centre for Mental Health: *Economic Evaluation of a Liaison Psychiatry Service*, 2011 (the RAID model from Birmingham) and *Liaison Psychiatry in the Modern NHS*, 2012.

The first of these was an economic evaluation of the whole system effect of introducing a well-staffed 24-hour liaison psychiatry service, seeing patients aged 18 and over, to the largest acute hospital in Birmingham. That hospital had previously had a limited uncoordinated service, particularly for older patients. The researchers found improved quality of care and a significant reduction in length of stay in medical wards, particularly among older patients with complex mental and physical comorbidities. There was a measurable effect on how all patients with comorbidity were managed, even those not seen by the liaison team – a “halo of influence” due to training and increased awareness of all hospital staff. The researchers estimated that the service, which cost approximately £850k per year, was saving the hospital over £5 million per annum.

In the second publication, *Liaison Psychiatry in the Modern NHS*, authors Parsonage and Fossey offer case studies of five established liaison psychiatry services to make a broader argument that it is time for liaison psychiatry to be recognised as an essential ingredient of modern healthcare, equipped to tackle complex comorbidity and making a significant contribution to QIPP and CQUIN targets of the acute trust. They also underlined the impact on the acute hospital environment, such as improved staff morale on medical wards and more expert management of suicide risk and adult safeguarding issues.

Turning to the cost-benefit case for psychosocial interventions specifically in cancer care, Carlson & Bultz (2004) summarized the situation as follows: ‘The literature review clearly supports the notion that psychosocial interventions are not only effective, but also economical’ and they refer to the ‘usually overlooked long-term cost savings that may be accrued to overburdened health-care systems’.

Evidence for the effectiveness of specialised interventions offered by Level 3 & 4 practitioners

Cancer Counselling and Existential Psychotherapy

Cancer crisis counselling is premised on the idea that counselling soon after the diagnosis of cancer can restore a sense of control and instil hope, can clarify ambiguity of information and mobilise coping resources. Counsellors and psychotherapists working in psycho-oncology have a good understanding of cancer, its treatment and prognosis. In larger cancer centres, particular counsellors may specialise in certain cancer types.

Specialised skills include:

- Balancing an understanding of cancer symptoms, treatments, side effects and settings with a highly individualised narrative or phenomenological approach to the lived experience of each patient
- Promoting psychological adjustment to the challenge of cancer diagnosis, cancer treatment and the ending of treatment
- Ability to work psychologically with bodily alteration and dysfunction
- Ability to work with the patients' existential issues such as uncertainty, why me?, what now?
- Talking skilfully about life-threatening illness, treatment decisions, death and dying.
- Clinical supervision of the psychosocial work of level 1 & 2 cancer clinicians
- Facilitation of support groups
- Advanced capacity for reflection on the impact of this work on themselves, building on personal experience of having therapy

There has been a perception that the evidence-base for counselling is lesser than that for cognitive-behavioral interventions. CBT lends itself particularly well to RCTs while the selection of outcome measures prior to, or during, counselling and existential psychotherapy is much more difficult. A recent re-evaluation of research showing counselling to be as effective as CBT for treating depression in primary care, has prompted calls for a revision of the NICE and SIGN guidelines. (King, 2013).

Clinical Health Psychology

Clinical Health Psychologists deliver and supervise specialised psychological treatments, such as CBT, to individual patients and groups but they also work across a range of systems. This means influencing the design of care pathways and the approach of clinicians across the whole cancer service to “psychologise” healthcare delivery to all patients. Therapeutic systemic intervention may focus on relational issues within a service or within a family eg. staff group consultation concerning a particular person's care.

Access to care, patient experience of care, adherence and outcomes can all be improved through the application of evidence-based health psychology.

An understanding among staff of health beliefs and their interaction with culture has been shown to improve access to cancer care as well as the efficacy of a service (Bailey et al 2012; Berkowitz, Schreiber, & Paasche-Orlow, 2012; Matsuyama et al., 2011; Mitchell et al 2012). Inequalities of care occur within diagnostic groups, for example, certain socio-demographic populations are able to navigate care and communicate with clinicians in a way that allows greater well-being and better health outcomes than others (Paasche-Orlow & Wolf, 2010). It can be difficult for healthcare professionals to appreciate the different understanding and needs of all those passing through the service. Work by Leventhal and Kleinman (Kleinman, 2014) demonstrates how patient beliefs about health can be idiosyncratic and lead to apparently irrational decisions. Tailoring communication to different groups reduces confusion and increases trust and therefore improves adherence. Interventions can range from the involvement of community champions in allaying fears about investigations, encouraging patient communication in chemotherapy suites and training clinicians in cognitive models of decision-making. Better communication has been shown to improve outcomes, reduce the number of tests asked for, reduce readmissions, and lower costs (Epstein et al. 2005, Arora 2003).

Healthcare professionals can be trained in how to elicit health beliefs that are blocking patient adherence to treatment and, for example, how to adapt to different emotional coping styles. A ‘communication gap’ between the clinician's familiarity with procedures and the patient's relative ignorance of them, can lead to frustration on both sides. Understanding that information is not meaningful until it links to a patient's context and understanding is important. Prospect Theory (Kahneman, 2011) addresses decision-making in situations of risk and uncertainty. Training healthcare professionals on these processes allows them to present complex information in such a way that the patient can more easily decide on treatment options and then be satisfied with the decision made, whatever the treatment outcome, thus reducing complaints.

Adjustment & Adjustment Disorder

The evidence base for adjustment disorder is largely based on interventions that prevent or treat adjustment disorder and its evolution into clinically significant depressive or anxiety syndromes.

The best-known intervention is a form of cognitive-behavioural therapy, especially targeting catastrophic cognitions, called adjuvant psychological treatment (Greer et al 1992). Their randomised controlled trial reported significant decreases in distress for participants at 4 and 12 month follow up.

Spiegel et al (1989) reported that one year of small group therapy for women with metastatic breast cancer improved adjustment and mood outcomes compared to treatment as usual.

Fawzy et al (1993) found a short group intervention (which included problem-solving components targeting helplessness), for patients newly diagnosed with melanoma, improved mood scores and reduced fatigue throughout a 5 year follow up.

A recently published study by Pitceathly et al (2009) showed that a brief psychological intervention informed by cognitive-behavioural principles promoted adjustment among newly diagnosed cancer patients who were at high risk of developing anxiety or depression.

Researchers have used a variety of frameworks to make sense of the survivors' experience (Blows et al, 2012; Doyle, 2008; Holland & Reznik, 2005; Smith et al., 2013; Somerfield et al, 1999). Factors perceived to affect survivors' adjustment post-treatment include body image (Brunault et al., 2013; Fingeret et al., 2012; Przewdziecki et al., 2012; Taylor-Ford et al., 2013), illness perception (Husson et al., 2013), self-efficacy (Melchior et al., 2013; Philip et al., 2012; Phillips & McAuley, 2013) and social support (Cicero et al, 2009; Devine et al, 2003; Willers et al, 2012).

More recently, the concept of adjustment has been contrasted with survivorship as a process, involving the need to construct a new life narrative and sense of identity (Brennan, 2001; Ferrell & Dow, 1996; Kaiser, 2008; Little et al., 2002; Ott Anderson & Geist Martin, 2003; Zebrack, 2000). Mathieson & Stam (1995, p. 283) coined the term "identity work" to describe 'the process of patients' evaluations of the meaning of their illness within the context of on-going social relationships'.

Depressive Disorders

Sharpe et al (2004) found a 9% prevalence of depressive disorders among outpatients attending a cancer centre. The prevalence in advanced disease is closer to 33% (Hotopf et al 2001).

Before embarking on treatment it is important to rule out medical causes for a secondary depression (such as anaemia, hypercalcaemia, hypothyroidism, exogenous corticosteroids and alpha interferon). These may require treatment in their own right.

Antidepressant medication is effective. Two randomised controlled trials specifically address this for cancer patients: Costa (1985) for mianserin and Holland (1998) for fluoxetine and desipramine. Choosing an antidepressant for a patient with cancer requires considerable thought. A drug must be chosen such that its side effects do not exacerbate the burden of somatic symptoms the patient already has. For example, patients coping with nausea from chemotherapy will not appreciate additional nausea in the early weeks of using a serotonin-specific reuptake inhibitor (SSRI). Patients with a stoma will notice diarrhoea from an SSRI. Patients with brain tumours should not be given antidepressants that lower the threshold for epileptic seizures. Patients with deranged liver or renal function may require lower doses of antidepressant. And specific interactions, such as that between tamoxifen and fluoxetine (Jin et al 2005), must also be considered.

The optimal management of the 30- 40% of cancer patients who do not respond to an adequate trial of a first-line antidepressant is under-researched. Sometimes augmentation, with tri-iodothyronine or lithium, is possible and effective.

Psychological treatment for depression is also effective. Strong et al (2008) reported that 10 sessions of problem-solving CBT (sometimes in addition to antidepressants) significantly improved the remission rate for depressive disorder (from 45% in controls to 68% in treatment group).

Price & Hotopf (2009) have recently reviewed the evidence-based treatment of depressed patients with advanced cancer in palliative care settings. The results of pharmacological studies of patients with early cancer or other chronic medical conditions probably do not generalise to the management of depression in patients who are dying.

The management of suicidality in depressed patients with cancers is an important area. Walker et al (2008) found that 8% of all cancer outpatients had experienced recent suicidal thoughts and that this was most common in older patients who were in pain. Uncontrolled pain should be treated and a careful risk assessment made. For many patients the idea of suicide arises from feeling out of control and hopeless. Offering realistic hope (e.g. of excellent palliative care to the end of life) and boosting autonomy (e.g. through drafting an advance directive, expressing preferences or pursuing dignity therapy) may be sufficient for the suicidality to abate. Antidepressants should be reviewed, and high dose or augmentation strategies considered, if severe depressive illness is evident. It is extremely rare for the suicidal cancer patient to require psychiatric hospitalisation and special observation. The ethics of such intervention, particularly in those with advanced cancer, demands careful consideration.

Some psychological and psychiatric problems associated with chemotherapy and radiotherapy

Chemotherapy often causes alopecia and infertility, both of which can be very distressing. A number of patients develop a (secondary) phobia to chemotherapy due to bad experiences of uncontrolled nausea and vomiting after treatment. Corticosteroids may be part of the chemotherapy regimen and can cause steroid psychosis (at its most severe a manic picture with some clouding of consciousness). Certain chemotherapy agents cause particular neuropsychiatric side effects. 5-fluorouracil causes cerebellar ataxia and delirium (Cheung, Fralick & Cheng 2008). Methotrexate can cause a delayed leukoencephalopathy. Alpha interferon can cause depression, irritability and impaired intellectual function (Adams, Quesada & Gutterman 1984; Renault et al 1987).

Radiotherapy invariably causes fatigue which can persist for months after treatment ends. This can be difficult to distinguish from depressive anergia. Radiotherapy-associated psychiatric complications can arise in two ways. First, high dose dexamethasone is often used as an adjunct to radiotherapy of the central nervous system. This corticosteroid can cause elation or a steroid psychosis. Second, hypothyroidism is common after radiotherapy to the head, neck or chest due to unavoidable irradiation of the thyroid or pituitary gland. This can present with psychiatric symptoms, notably depressive symptoms

Assessing and treating the bereaved

Some understanding of normal grieving is required before abnormal psychological reactions to a death can be recognised. Kubler-Ross's classic account of the stages of grief (Kubler-Ross 1969), moving from shock to acceptance, is best deployed flexibly as a description of various states, rather than consecutive stages, seen in bereavement.

Anticipatory grief, preceding the actual death in a long terminal illness, is now recognised as a helpful process and should be looked for. Sudden or unexpected deaths are more likely to result in prolonged grief reactions (Parkes 1975). How was news of the death broken and how intense was the initial distress? This is important because the intensity of initial distress predicts prolonged grief. The patient's relationship with the deceased should be gently explored because ambivalent feelings towards them, or an excessively dependent relationship with them, both result in prolonged, conflicted or unresolved grief (Parkes 1993). Finally, was the patient able to participate in practical arrangements after the death? Exclusion from this, perhaps by well-intentioned family members, can delay adjustment.

Chronic grief reactions are treated with grief therapy. This is a distinctive short-term psychological treatment, typically 6 to 8 long sessions. Each session has a specific focus and the client is encouraged to bring physical mementos of the deceased, such as photos or items of clothing, to the session, where they are displayed to facilitate grieving. 20% of all bereavements result in frank depressive illness (Chochinov, Holland & Yatz 1998). In these cases depressive symptoms, such as worthlessness, guilt and suicidal thoughts, are present during the early acute grief reaction. Depression can be confidently distinguished

from normal grief within 8 weeks of a death. Bereavement-related depressive illness warrants vigorous treatment, especially among older men. They have increased mortality after bereavement, some of which is attributable to suicide.

4 Psychological Support across the LCA

The general position with respect to integration of mental and physical healthcare across the LCA region is quite promising and rapidly changing. For example, integration is at the forefront of the aims of King's Health Partners, who, along with St George's Healthcare NHS Trust, have the advantage of well-established liaison psychiatry and clinical health psychology services. The acute hospitals served by Central and North West London NHS Foundation Trust and West London Mental Health NHS Trust (WLMHT) are rapidly introducing and evaluating new liaison psychiatry services (with six new fulltime consultants appointed in the last year) in addition to the established teams at Chelsea & Westminster Hospital, St Mary's and Charing Cross. CNWL and WLMHT are replicating findings of the RAID study at acute hospitals in west London and are measuring a 25% reduction in length of stay in medical beds for patients aged 65 years and older, and a 12.5% reduction in length of stay for patients aged 16 to 65. There are established multi-professional psychological support teams at Guy's & St Thomas (Dimbleby Cancer Care) and at Royal Marsden, dedicated to the needs of those affected by cancer

Our Mapping Report (see the LCA website for full report) gives fuller details of the current position across the cancer hospitals and hospices of the LCA area.

The LCA Mental Health and Psychological Support Pathway Group are developing a pathway for further consistent and effective implementation of the 2010 Model of Care with respect to mental health and psychology. The Model of Care states that for psychological support, the relevant chapter of the NICE (National Institute for Health and Care Excellence) Improving Outcomes Guidance (IOG) for Supportive and Palliative Care (2004) should be implemented across London with equitable access to psychological support services explicitly commissioned and managed. It adds that while counsellors, clinical psychologists and liaison psychiatrists may have direct contact with a finite number of patients, their knowledge should influence the majority of staff at cancer centres. It suggests that this can be achieved through mental health professionals being embedded in clinical teams, thus sharing knowledge and training non-psychological specialist staff in basic psychological assessment skills and therefore ensuring that all levels of psychological need are met appropriately.

The NICE guidance was written nearly a decade ago and since that time key service reconfigurations and drivers have emerged. Therefore, rather than attempting to mechanically implement the original guidance, the pathway group has the opportunity to imaginatively update it for the contemporary NHS environment in London.

Implementation of some aspects of the NICE guidance was achieved by the cancer networks in north west, south west and south east London prior to autumn 2012. National cancer peer review measures include review of arrangements for psychological support. The IOG describes four levels of psychological assessment and support (Appendix 1). Psychological support at Levels 1 and 2 should be provided by health and social care professionals directly responsible for the care of patients with cancer. More severe psychological distress (Levels 3 and 4) should be managed by a variety of psychological specialists including counsellors, mental health nurses, clinical and health psychologists, psychotherapists, and liaison psychiatrists.

Appendix 2 offers an estimate of need for psychological support and mental health services across the LCA and describes the gap between current resource and a needs-based pathway.

5 Initial recommendations

Taking into account the discussion and evidence, the following initial recommendations are made:

- The psychological well-being of patients and carers should be explicitly assessed at key points in the patient pathway.
- All staff responsible for patient care should offer patients general emotional support based on skilled communication, and effective provision of information with courtesy and respect.
- Patients and carers found to have significant levels of psychological distress should be offered prompt referral to services able to provide specialist psychological and mental health care.
- Emergency psychiatric provision should be available when necessary. Patients with severe mental health problems should be able to access appropriate care 24 hours a day.
- Psychological assessment and intervention should be undertaken in facilities that are quiet, comfortable and which confer privacy.
- Staff providing psychological care should be adequately trained and supervised with mechanisms to ensure support available.

5.1 Recommendations for Level 1 and 2 professionals

5.1.1 High-quality tailored written information

All those affected by cancer need high-quality, personalised information about their cancer, its management and its impact on their quality of life. A key aim of LCA cancer services should be the implementation of the national Information Prescription Service. This supports the delivery of personalised information that lays out the salient points of an individual's consultation with a healthcare professional and can include information about their diagnosis, treatment and treatment plan as well as pointing the way to other relevant sources of information. It is designed to improve the dialogue between patients and healthcare professionals and enhance the valuable face-to-face time within consultations. This involves training of the frontline clinicians in the use of the service, as well as dedicated information services being embedded within the cancer centre. Provision of information will empower patients and carers and enhance their understanding and ability to participate in key decisions about their cancer management. It also facilitates adjustment, prevents unnecessary anxiety for patients and carers and contributes to informed consent.

5.1.2 Benefits advice

Benefits advice, tailored to the needs of cancer patients, is an increasingly important part of psychosocial support

5.1.3 MDT-based assessment and training to improve the patient centred nature of cancer care.

This would build on work developed by NCAT (National Cancer Action Team) which designed 'MDT (Multi-disciplinary Team) FIT' to self-assess team functioning. An evidence-based experiential approach to addressing the issues raised in those assessments and by the national Cancer Patient Experience Survey (CPES) and other relevant metrics is proposed. The aim is to improve communication with patients, inter-professional communication and team-working skills. The training would specifically aim to support MDT members in:

- Honest and compassionate communication with those affected by cancer
- Treating patients with dignity and respect
- Ensuring patients' views, preferences, holistic needs and co-morbidities are incorporated into the clinical decision-making process

- Ensuring patients are given sufficient information, consistent with their wishes, about their cancer and treatment options, allowing them to make a well-informed decision about their cancer treatment and overall care
- Establishing supportive relationships with patients and carers
- The recognition of psychological needs and psychiatric disorders
- Informing patients and carers about psychological support services

The package delivered to each MDT would be bespoke to its needs as identified by, e.g. its CPES profile or MDT FIT assessment. Following the closure of NCAT in March 2013 there is no national funding or support to drive improvement in MDT working or communication skills. We can build a unique approach to improve patient experience locally across the LCA.

5.1.4 Holistic Needs Assessment and Level 2 training

The current roll-out of the holistic needs assessment (HNA) and Level 2 training in basic psychological support skills for clinical nurse specialists will be actively pursued, working closely with the LCA Survivorship Pathway Group.

Formal evaluation of the effectiveness of these trainings will continue.

5.1.5 Referral guidelines for psychological care

Standardised guidelines for referral to specialist psychological support MDTs in the cancer centres should be agreed and implemented. Our idea is to simplify the task of referral for support (for all cancer clinicians) by establishing a single point of referral at four of the cancer centres of the LCA (Guys and St Thomas' NHS Foundation Trust, Royal Marsden NHS Foundation Trust, St George's Healthcare NHS Trust and Imperial College Healthcare NHS Trust). Triage of these referrals to appropriate psychological support and mental health interventions in the NHS and signposting to the third sector can be undertaken by the clinical leaders of the psychological support service.

The relationship between psychological support practitioners at the remaining LCA providers and the most local of the four psychological support MDTs, is an opportunity for new clinical governance and cross-referral arrangements. We envisage a lone counsellor or psychotherapist assessing and treating as usual but with the option to refer a psychological support MDT for interventions outside their skillset. Similarly, the psychological support MDT would refer certain patients to providers nearer their homes for psychological treatment. Leadership and clinical governance support for psychological support professionals in smaller units could be provided from the centre.

5.2 Recommendations for Level 3 and 4 Professionals

The Model of Care calls for specialist mental health professionals to be embedded in clinical teams so that their knowledge can influence the majority of staff. This raises a fundamental question about how Level 3 and 4 resource is organised. Should practitioners work within a single tumour-specific pathway, or should a psychological support multidisciplinary team be embedded serving a single cancer centre? Empirical evidence suggests the latter option.

5.2.1 Multi-professional psychological support team at designated LCA Trusts

It is proposed that there be a multi-professional psychological support team at four providers in the LCA. That team should meet weekly to discuss initial assessments, triaging patients to treatment based on need. Allocation and treatment will be needs-based, evidence-based and take account of the level of risk.

Such a team would facilitate straightforward access to treatment for all those affected by cancer with psychological support needs. As a single point of referral for clinicians such a centralised team allows very clear referral pathways arising from the holistic needs assessment. Waiting times to evidence-based psychological treatments could be specified and the team resourced to meet these. (For example, at

Dimbleby Cancer Centre the referrer can specify anything from 48 hours to 4 weeks as the required response time for initial assessment). Urgent referrals may be allocated and assessed in advance of the weekly meeting as required.

The patient has the benefit of 'one-stop' holistic care embedded in the cancer centre that they know and have confidence in when feeling at their most vulnerable. In addition, the cancer-specific knowledge and experience of the team members saves the patient from having to explain cancer procedures to a non-cancer specialist mental health professional.

The great value for members of this multi-professional team is sharing expertise, peer support and the opportunity to discuss systemic issues, diagnosis, risk issues, safeguarding issues and share expert knowledge about the psychological issues and mental health problems arising from particular cancers and their treatments.

Tasks and roles of the psychological support team

In addition to providing direct clinical care to those affected by cancer, these should include:

- **Specialist psychological input to tumour-specific MDTs:**
Members of the psychological support team will each input to several tumour-specific multidisciplinary teams at their hospital
- **Supervising the psychological work of clinical nurse specialists and other cancer health professionals:**
Members of the psychological support team will offer regular supervision to small groups of clinical nurse specialists, allied health professionals and cancer ward teams. They should also be available to offer prompt advice and consultation to these colleagues.
- **Co-facilitating cancer information and support groups :**
Psychological support team members will work alongside clinical nurse specialists to facilitate various groups: tumour-specific information & support, preparation for certain treatments, therapeutic groups (such as CBT/mindfulness for bodily symptoms), groups for bereaved carers.
- **Providing Level 2 training.** Psychological support team members will deliver the Level 2 training in psychological support to clinical nurse specialists and allied health professionals in their hospital.
- **Evaluation/Research:**
The training, supervision and interventions delivered by the team should be evaluated, and preferably shared as published research.

Clinical governance

We recommend a nuanced approach to the clinical governance of such a team. Risk needs to be considered, documented and managed while the main focus of everyone's attention remains therapeutic effectiveness and an excellent patient experience. The weekly team meeting can be an opportunity to share and discuss safeguarding and risk issues, while avoiding the need for written standardised risk assessments for every referral, whether it be relevant or not.

5.3 24-hour emergency psychiatric provision

In addition to this specialised psychological support resource, there is a need for a 24-hour service to lead the management of psychiatric emergencies on the general wards of the hospital. In large teaching hospitals such general liaison psychiatry cover has been in place for several decades. However, some hospital sites with several cancer wards do not have the benefit of an on-site psychiatry trainee or psychiatric liaison nurse out of hours. Current availability of this 24-hour cover is being mapped across the 16 acute trusts of the LCA, and any identified gaps will be highlighted.

5.4 Developing role clarity and collaborative working with respect to community mental health, general liaison psychiatry and IAPT services

High quality psychiatric and psychological services for those affected by cancer in the acute trust setting need to align and cooperate with services already provided through community mental health centres and primary care-based psychological treatment services. The latter have been hugely expanded over the last four years through the Improving Access to Psychological Treatment initiative (IAPT). In *IAPT three-year report: the first million patients (DH 2012)*, it was recognised that people with cancer were underrepresented in the first million patients treated by IAPT nationally. Although there are plans to extend the remit of IAPT in future, some observers have reservations about the ability of briefly trained graduate IAPT workers to adequately treat older people with complex comorbidity.

- Those who are inpatients on cancer wards or in the active treatment phase of their cancer care spend much of their time at a particular cancer centre. It makes little sense to ask such individuals to seek psychological and mental health support through community services near their home address. Far better, from the point of view of patient and referring clinician, is to see Level 3 or 4 practitioners co-located at the cancer centre. This allows a single point of referral for mental health and psychological and psychosexual support needs revealed by holistic needs assessment. The complex catchment area arrangements for secondary mental health care and the multiplicity of IAPT services from borough to borough otherwise represent a significant barrier to referral for busy cancer centre clinicians.
- The typical waiting time to see a community mental health team in London as a new referral is 4 weeks. This is too slow for a very distressed patient in the throes of cancer diagnosis and treatment. In addition, the threshold for being accepted by a CMHT in London is very high – for example, depressive illness of moderate severity or frequent panic attacks would be discharged to GP care immediately, without assessment.
- Although most antidepressant prescribing in the UK is now done by general practitioners, when it comes to patients with newly diagnosed or advanced cancers undergoing treatment, most GPs lack confidence in prescribing safely. This leads to withholding of antidepressants. Liaison psychiatrists embedded within the cancer centre, with the benefit of support from hospital pharmacists, are better placed to choose medication. In a recent review of activity in a liaison psychiatry clinic for cancer patients we found that the initiation of antidepressant treatment, or the addition of augmenting medication, constituted a large proportion of the workload.
- Although Sir David Nicholson, Chief Executive of the NHS, has asked IAPT services to expand to treat older patients with long-term conditions in future, there is considerable uncertainty about how well-equipped graduate therapists, with limited training in physical health problems, are to manage complex co-morbidity. In order to effectively psychologically support a patient undergoing surgery, chemotherapy or radiotherapy, the therapist really needs some understanding of the particular cancer, the treatment modality and the overall institutional setting of the cancer centre. Without these the patient becomes frustrated as they spend valuable time educating the person supposed to be supporting them. Lastly, IAPT therapists currently “treat to target” using an IT system based around specific outcome measures for anxiety and depression only. New measures would be needed if their role is to extend.
- General liaison mental health services are often delivered by registered mental health nurses. In recent years RMN (Registered Mental health Nurse) training involves almost no general nursing or general medical skills and knowledge. Thus psychiatric liaison nurses, while very skilled at assessing and managing presentations such as self-poisoning in the emergency department, are sometimes out of their depth on medical wards seeing patients suffering delirium, adjustment problems in the context of e.g. cancers. Similarly much of the clinical experience of general adult psychiatry trainees is dealing with psychiatric emergencies in A&E so their appreciation of psycho-oncology is usually extremely limited. Most general liaison mental health teams are not resourced to see outpatients.
- For all these reasons it should be clear that it is important to have cancer-specific clinical psychologists or liaison psychiatrists serving inpatients and outpatients undergoing cancer

treatment. General liaison psychiatry teams will always make a major contribution to the 24 / 7 emergency response to mental health emergencies

To put this more positively, we are saying that cancer counsellors, psychotherapists, psychosexual therapists, clinical psychologists and liaison psychiatrists embedded within the cancer centre have specific expertise in:

- Balancing an understanding of cancer symptoms, treatments, side effects and settings with a highly individualised narrative (or phenomenological) approach to the lived experience of each patient
- Promoting psychological adjustment to the challenge of cancer diagnosis, cancer treatment and the ending of treatment
- Ability to work psychologically with bodily alteration and dysfunction
- Ability to maintain regular contact with patients as they move through various general hospital settings (eg surgical ward, cancer HDU, chemotherapy day unit, outpatient clinic)
- Understanding how certain cancers and particular cancer treatments can cause psychiatric disorder
- Assessing mood in the context of a large burden of physical disease
- Facilitating access to optimal cancer care for people with pre-existing severe mental illness such as schizophrenia or dementia (eg. advising on complex Mental Capacity Act issues)
- Effective treatment of anxiety, psychosexual problems, depression, prolonged grief reactions in those affected by cancer.
- The assessment and management of suicidal ideation in patients with cancer
- Ability to work with the patients' existential issues such as uncertainty, why me?, what now?
- Talking skilfully about life-threatening illness, treatment decisions, death and dying.
- Ability to work systemically with clinical teams (eg. a cancer ward, the head & neck team)
- Diagnosing and helping manage inpatients who develop delirium

The kind of work that Level 3 and 4 practitioners in cancer centres should not be doing, in our opinion, is:

- Treating chronic psychological or psychiatric needs that predate the cancer diagnosis
- Duplicating the work of a community mental health team if a cancer outpatient is already under their care
- Acting as a fast-track route to psychological treatment (eg. CBT) for people living with and beyond cancer with no current cancer-focused distress
- Taking on the medium to long-term management of severe mental illness such as bipolar disorder, schizophrenia, delusional disorder, emotionally unstable personality disorder, recurrent depressive disorder
- Offering long-term psychotherapy for the effects of childhood neglect and abuse, unless this is directly affecting adherence to cancer treatment now

The Mental Health and Psychological Support Pathway Group will seek to meet with IAPT services across the LCA. Joint working to clarify and agree the delineation of responsibility for service provision to those living with and beyond cancer will be sought. It is proposed that the vast majority of cancer survivors in remission for over 18 months are treated for any mental health issues via IAPT and community mental health teams, while hospice/palliative care populations, and those in treatment at cancer centres, receive more specialised in-house care as described. The exact clinical criteria will need further discussion and agreement.

Metrics and outcome measures

There needs to be clarity about which outcome measures service developments will be judged by. These could include

- *process measures*, such as professional response times for inpatient and outpatient referrals, length of stay of inpatients, number of staff trained or supervised
- *clinical outcome measures*, such as mood rating scales;

- *patient-reported outcome measures (PROMS) and patient experience surveys*, including the Cancer Patient Experience Survey and Kelsey's 'friends and family' test.
- *staff-reported outcome measures* for training and supervision of their psychosocial work

It is particularly important for commissioners to understand that the development of this pathway will not eliminate occasional catastrophic outcomes, such as suicides. These are difficult to predict and prevent, even with the most excellent services addressing the psychological support needs of those affected by cancer. However, the day-to-day environment and staff morale, and the detection and recording of safeguarding and risk issues, should all measurably improve.

6 Proposed early objectives and improvement plan

- Map current Level 1 to 4 provision of mental health and psychological support service across the 16 trusts of LCA, including the 24-hour psychiatric emergency cover arrangements for the cancer wards of the 16 trusts.
- Undertake a service specification gap analysis based on the NCAT peer review assumptions.
- Seek early adopters of MDT FIT diagnostics and MDT-based training to improve patient-centred nature of cancer care.
- Implement eHNA and ePROMS, working in collaboration with the LCA survivorship and patient experience pathway groups, including the necessary provision of training and supervision.
- Agree LCA-wide referral guidelines to specialist psychological support MDTs.
- Agree LCA-wide metrics for evaluating mental health and psychological support services.
- Work with the 4 main cancer centres to identify and support leaders of developing psychological support services
- Establish multi-professional psychological support teams at each of the four large cancer centres. To include a weekly clinical meeting, evidence-based allocation to treatment, and discussion of cases and risk in the presence of a consultant clinical health psychologist and consultant liaison psychiatrist with an interest in cancer.
- Establish a network of cancer information and support groups across the LCA.
- Establish effective models of outreach psychological support for cancer services in smaller trusts, including suitable governance arrangements
- Map third sector (voluntary/charitable) provision of psychological support and consider potential collaboration
- Clarify working relationship with IAPT services, general liaison and community mental health care provision. Commissioners will need to be included in discussions about this division of labour.

Appendix 1

Psychological assessment and support Levels 1-4 (NICE Improving Supportive and Palliative Care IOG 2004)

Level 1

5.21 Involves all staff directly responsible for patient care and is focused on general emotional care.

Assessment

5.22 All health and social care professionals should be able to recognise psychological distress and should be sufficiently competent to avoid causing psychological harm to patients and carers. They should know when they have reached the boundary of their competence and should refer the patient to a more specialist service.

5.23 Cancer networks should develop criteria for referral to specialist psychological support services. Teams should be familiar with these criteria and the mechanisms through which to expedite referral.

Intervention

5.24 Staff should be able to:

- communicate honestly and compassionately with those affected by cancer (see also Topic 3, *Face-to-Face communication*)
- treat patients and carers with kindness, dignity and respect
- establish and maintain supportive relationships
- inform patients and carers about the wide range of emotional and support services available to them.

5.25 Appropriate interventions at Level 1 may prevent the development of more severe psychological problems, thereby affecting demand for services at Level 2 and beyond.

Level 2

Assessment

5.26 Professionals operating at this level should be able to screen for psychological distress at key points in the patient pathway, including:

- around the time of diagnosis
- during treatment episodes
- as treatment ends
- at the time of recurrence.

5.27 These assessments should be undertaken by designated professionals (such as nurse specialists, social workers and GPs), appropriately trained in screening for psychological distress. They should include the impact of cancer on people's daily lives, mood, family relationships (including sexual relationships) and work. Those undertaking an assessment should elicit worries and other feelings by establishing trust and listening in a permissive and non-judgemental manner. The assessment process itself may lead to the resolution of concerns; if not, it should result in an offer of appropriate psychological support. Patients experiencing significant psychological distress should be offered referral for specialist psychological support/intervention.

Intervention

5.28 Level 2 involves psychological techniques such as problem solving delivered by trained and supervised health and social care professionals to manage acute situational crises at key points in the patient pathway. Clinical nurse specialists, among others, might be trained and supported to undertake assessments and to deliver relevant interventions.

Level 3

Assessment

5.29 Trained and accredited professionals should be able to differentiate between moderate and severe levels of psychological need and refer those with severe needs to mental health specialists.

Intervention

5.30 Level 3 involves specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework by a trained, accredited and supervised counsellor. It aims to manage mild to moderate levels of psychological distress including anxiety, depression and anger. Specific psychological interventions at this level are also appropriate for responding to mild to moderate cancer-related concerns such as worries about treatment, personal relationships (including sexual relationships), relationships with hospital staff and spiritual issues.

Level 4

Assessment

5.31 Mental health specialists should be able to assess complex psychological problems including severe affective disorders, personality disorders, substance misuse and psychotic illness.

Intervention

5.32 Level 4 involves specialist psychological and psychiatric interventions delivered by mental health specialists to manage moderate to severe mental health problems. These include severe depression and anxiety, organic brain syndromes, severe inter-personal difficulties (including severe psychosexual problems), alcohol and drug-related problems, personality disorder and psychotic illness.

APPENDIX 2

Scaling the need for level 3 and 4 professionals across the LCA

Direct patient intervention

19,576 new cancers are diagnosed per annum (pa) in the LCA's population (from NCIS new diagnoses per trust). (It is important to remember that this does not include patients diagnosed at Mount Vernon Hospital.)

NICE (2004) estimate 15% of those newly diagnosed will need level 3 psychological support and 10% will need level 4 intervention. Therefore:

$19,576 \times 25\% = 4,894$ patients require specialist intervention.

Improved survival rates and associated advances in medical management of cancer mean that people are living longer with a cancer diagnosis. The percentage of survivors with advanced active disease varies from 33% (lung cancer) to 10% (breast and prostate cancers). Across the LCA the number of patients with advanced active disease is around 19,574 . 10% of these require specialist psychological support i.e. **a further 1,957.**

This excludes a large percentage of those living with and beyond cancer, namely those for whom cancer is now a past medical history or are in remission. Expert consensus with the LCA MH & PS Pathway Group is that in most cases, once more than 18 months post treatment, this population can be well- managed by non-cancer specialist psychological support professionals e.g. IAPT. This population is therefore excluded from these calculations.

Psychological support to carers account for 1/7 of the referrals to Dimbleby Cancer Centre at KHP. There are also 7 WTE grief counsellors in hospices across the LCA. **Intervention for carers within the LCA is probably needed for 1000 people pa.**

Therefore total numbers of people requiring direct intervention is:

$4894+1,957+1000=7,851$

Mapping work suggests a caseload of 150 new patients pa per WTE level 3/4 practitioner (assumes adequate administrative support and no excessive travelling between sites). So,

$7,851/150 = 52$ WTE level 3/4 practitioners needed to provide direct intervention.

Supervision

A fundamental role of level 3 and 4 practitioners is the on-going support for level 2 providers, most commonly CNSs and AHPs who have completed level 2 psychological assessment skills training.

The LCA has a total CNS workforce of 323 and AHP workforce of 127 (NCAT, 2011), giving a total of 450. Supervision typically runs in groups of 5, meaning 90 monthly sessions of 1.5 hours are required in the LCA, requiring **0.8WTE** level 3/4 to support them.

MDT Attendance

It is a peer review requirement that level 3/4 psychological professionals attend MDTs for specialist palliative care, haemato-oncology, Brain/CNS and SCT. Level 3/4 psychological support is an extended member for all other tumour MDTs. There are at least 128 MDTs in the LCA, which have weekly meetings lasting two hours each. If level 3/4 practitioners attended 1 in 4 meetings, this would require **2.0WTE** to staff

Total requirement

The total LCA level 3/4 requirement is therefore

$$52+0.8+2.0 = \mathbf{54.8 \text{ WTE}}$$

To fit with NCAT guidance, 60% of this should be level 3 i.e. 32.9WTE and 40% level 4 i.e. 22 WTE

Current Staffing Complement

LCA mapping has identified **19 WTE level 3 & 4 staff within LCA hospitals and 19 WTE in hospices in the LCA**. This leaves a **gap of 16.8 WTE**. To achieve the functions described here, reconfiguration of existing services is needed in addition to the 16.8 WTE increase in staff.

APPENDIX 3

Gaps in level 3 / 4 practitioner staffing at the four major Cancer Centres of the LCA:

1. Kings Health Partners ICC

The psycho-oncology support team at Dimbleby Cancer Centre assesses and treats approximately 1,000 new referrals per annum. If one WTE level 3 / 4 practitioner can assess 150 new referrals per annum then 6.6 WTE are needed for this aspect of the work, 2.6 WTE being level 4. In addition there are expected roles of delivering level 2 training & supervision, co-facilitating patient support groups and attending selected MDTs. Increases the need to about 7.4 (3.0 of this at level 4).

The actual current staffing is 1.4 clinical psychologists and 0.25 consultant liaison psychiatrist (=1.65 level 4 WTE) and 4.2 WTE level 3 practitioners. A total of 5.85 WTE and a gap of 1.35 WTE at level 4.

We recommend an immediate 1.3 WTE increase in consultant liaison psychiatry and clinical psychology sessions

2. Royal Marsden Hospital

The psychological support service at RMH received 1349 referrals in 2012 of whom only 945 were assessed. 9.0 – 10.0 WTE are required, of whom 3.6 WTE should be level 4. In fact there are only 1.4 clinical psychologists and 0.6 consultant liaison psychiatrist (2.0 level 4 practitioners) and 2.1 counsellors and 2.0 PLNs. A total of 6.1 and a gap of at least 1.6 WTE at level 4.

We recommend an immediate 1.6 WTE increase in consultant liaison psychiatry and clinical psychology sessions.

3. St Georges

Although we do not have detailed patient numbers for St Georges we know there are only 1.3 WTE level 3 practitioners and no level 4 practitioners at all working there. A reasonable estimate is that a total of 7.0 WTE are required, leaving a gap of 5.7 WTE.

We recommend the immediate identification of leadership resource and appointment of a consultant liaison psychiatrist, a consultant clinical health psychologist and a cancer counsellor or psychotherapist.

4. Imperial

Again we are short of patient numbers but can estimate that a team of 6.0 WTE is needed. In fact there are 1.8 WTE level 4 practitioners in post and only 1.0 WTE level 3.

We recommend the immediate appointment of two cancer counsellors and a consultant liaison psychiatrist to support those affected by cancer across the hospitals of Imperial AHSC.