Optimal Pathway for Psychosocial Support Care in Pancreatic Cancer

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Purpose

This is a paper that outlines what best practice looks like in psychosocial support for adults with pancreatic cancer and their families & carers, and includes recommendations on how to implement and track progress.

This paper is to be used by national and local NHS healthcare professionals involved in the development of psychosocial support healthcare services as well as by clinical staff who manage people with pancreatic cancer.

Please address any questions at policy@pancreaticcancer.org.uk

Methodology

The development of this paper was led by Dr Alex King, Consultant Clinical Psychologist in Psycho-oncology in at Imperial College Healthcare NHS Trust and Georgia Papacleovoulou, Health Intelligence and Improvement Lead, Pancreatic Cancer UK.

We took a multi-disciplinary approach to develop this best practice paper:

1. Review and analysis of the peer-reviewed literature
2. Review of existing guidance, such as
    - NICE guidance on cancer psychosocial support
    - NICE guidance on management of pancreatic cancer in adults
    - London Integrated Pathway for Cancer Psychosocial Support
    - The recommendations of the 2021 NHS Cancer Programme Task & Finish Group on the recovery of psychosocial support
3. Evidence gathering from a group of pancreatic cancer specialists
4. Evidence gathering from a group of clinical psycho-oncologists and researchers working on psychosocial support for people with pancreatic cancer
5. Evidence gathering from people with lived experience of pancreatic cancer (patients or carers)

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Key facts about pancreatic cancer

Pancreatic cancer is the 5th biggest cancer killer in the UK, with one in four people dying within a month from diagnosis, and less than 7% managing to survive past five years. Most people are diagnosed with late-stage disease, with limited treatment options and a large percentage (44%) are diagnosed at emergency settings.

Even for the small proportion of patients with pancreatic cancer who are diagnosed early enough to have life-saving treatment (pancreaticoduodenectomy or Whipple's procedure), the threat of high-risk surgery is still significant – that has up to 3% mortality and morbidity for up to 30%. The risk of unresectable disease and/or recurrence after surgery is high.

Psychological difficulties experienced by cancer patients and carers

In well-established clinical guidance for general adult cancer psychological care (NICE 2004)[1], it is estimated that in the first year after cancer diagnosis, 10% of patients will experience severe & complex distress that requires clinical assessment and intervention by specialists in cancer & mental health (Level 4) and a further 15% will require personalised psychological therapies (Level 3). Similar rates of need are estimated for patients with advanced disease.

A general patient survey by Macmillan Cancer Support identified that:

- 58% of people diagnosed feel their emotional needs are not looked after as much as their physical needs[1];
- 67% of carers experience anxiety and 42% experience depression. Of these, over three quarters do not receive any support[2].

Clinical experience suggests that in the context of life-threatening illness, pre-existing mild-moderate and severe mental illness (e.g. OCD, bipolar mood disorder, PTSD etc) may be exacerbated and people's existing coping (e.g. via physical activity and social participation) may be blocked. People with learning disabilities and neurodevelopmental conditions (e.g. autism) will often be diagnosed later and may experience additional distress due to communication issues, disruption of self-regulation routines and the rapid pace of change.

The experience of psychological distress extends to families and carers who provide support and are forced to consider loss & bereavement. The ongoing threat and stress of this situation can trigger clinically significant difficulties and interact with longstanding mental health difficulties and vulnerabilities.

Psychological difficulties experienced by pancreatic cancer patients and carers

In this context of acute and direct threat to life, high symptom burden, biological effects of the illness and its intensive treatment impact, it is highly likely that psychological distress will

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[1] NICE Improving Outcomes Guidance CS4 (2004) – Improving Supportive and Palliative Care for Adults with Cancer https://www.nice.org.uk/guidance/csg4

[2] Macmillan Cancer Support, Worried sick: the emotional impact of cancer (2006). Available here: https://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/impact_of_cancer_english.pdf

be experienced by all pancreatic cancer patients and carers, ranging from time-limited distress to ongoing, clinically significant mental health difficulties:

- anxiety, including acute / traumatic stress reactions, adjustment disorders, generalised anxiety, phobias
- depression, ranging from adjustment disorders to severe clinical depression
- problems with interpersonal relationships, within families and with healthcare professionals
- psychosexual and body image difficulties
- organic brain syndromes (delirium) and cognitive impairment.

A recent survey[3] run in 2018 that included 274 people living with pancreatic cancer, identified that:

- 87% of patients had one or more physical or psychological unmet needs,
- 68.1% reporting uncertainty about the future and
- 67.0% reporting fears about recurrence.

A population-based study using data from the National Cancer Registration and Analysis Service in England of 4,722,099 individuals (22 million person-years at risk) diagnosed with cancer from January 1, 1995, to December 31, 2015, with follow-up until August 31, 2017 showed that 2491 patients died by suicide, representing 0.08% of all deaths during the follow-up period. The risk was highest among patients with mesothelioma, with a 4.51-fold risk corresponding to 4.20 extra deaths per 10 000 person-years. This risk was followed by pancreatic (3.89-fold), oesophageal (2.65-fold), lung (2.57-fold), and stomach (2.20-fold) cancer. Suicide risk was highest in the first 6 months following cancer diagnosis (SMR, 2.74;95% CI, 2.52-2.98).[4]

A 2019 review of published studies in psychological distress in pancreatic cancer[5] identified rates of 30-70% in clinically significant distress.

People with pancreatic cancer diagnosis often quote *‘it is the worst cancer to get’* and are aware of its risk and high mortality rate. Despite this, many of the patients diagnosed with pancreatic cancer have stated they would not feel comfortable asking directly for support and most patients did not recall any psychological support being offered to them.

This patient feedback is in line with the findings of a major UK epidemiological study of depression in cancer, where approximately 73% of patients with cancer and clinically confirmed depression had a potentially effective mental health input[6].

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[3] Watson EK, et al. BMJ Open 2019;9:e032681. doi:10.1136/bmjopen-2019-032681

[4] Henson KE, Brock R, Charnock J, Wickramasinghe B, Will O, Pitman A. Risk of Suicide After Cancer Diagnosis in England. JAMA Psychiatry. 2019;76(1):51–60. doi:10.1001/jamapsychiatry.2018.3181

5 Scott E, Jewell A (2019) Supportive care needs of people with pancreatic cancer: a literature review. Cancer Nursing Practice. doi: 10.7748/cnp.2019.e1566

[6] Walker et al 2004 http://dx.doi.org/10.1016/

Embedding pancreatic cancer specific needs to an integrated system of psychosocial support

The 2020 London Integrated Pathway

The 2020 London Integrated Pathway (see Figure 1)[7] is an integrated pathway designed to provide personalised psychosocial care for all adults affected by cancer and it's based on the NICE 2004 Levels 1-4 model[1]. This is an integrated whole-system model for identifying psychosocial needs and providing support with clear and flexible referral pathways and processes, at every step of the process, in a way that is understandable by professionals, patients, carers & families.

When dealing with the cancer diagnosis, people will use a variety of resources to cope, including their own inner emotional resources, the guidance of trusted healthcare professionals, and external support systems such as family, friends, peer networks, and the input of third-sector organisations. But for some people where there may be additional social and psychological adversity, these resources may be insufficient to manage the personal impact of cancer and distress, dysfunction and poor health self-management may follow having a significant impact on the person's quality of life and on the lives of their families and carers. Additionally, psychological obstacles if not addressed can impact a person accessing tests, investigations, treatment adherence, engaging with rehabilitation, and ultimately impact clinical outcomes.

The **London Integrated Pathway** consists of 3 levels of support, termed **universal**, **enhanced** and **specialist support**.

- **Level 1 Universal support:** all people affected by cancer will have access to universal support
- **Level 2 Enhanced support**: a substantial proportion will require enhanced support episodically or throughout their cancer experience
- **Level 3 Specialist support**: a smaller proportion will require specialist support at one or more time points

All components of the pathway must be coordinated and working in partnership to deliver excellent psychosocial support. Patients and their families may need different or multiple support inputs at different times. There is no assumption that people proceed through universal, enhanced, and specialist support in a linear or predictable fashion, so access to services must be flexible.

This whole system model is based on a core set of principles that are a result of extensive engagement with stakeholders across London, including system leaders/commissioners, GPs, primary and secondary care providers, the third sector, and service users.

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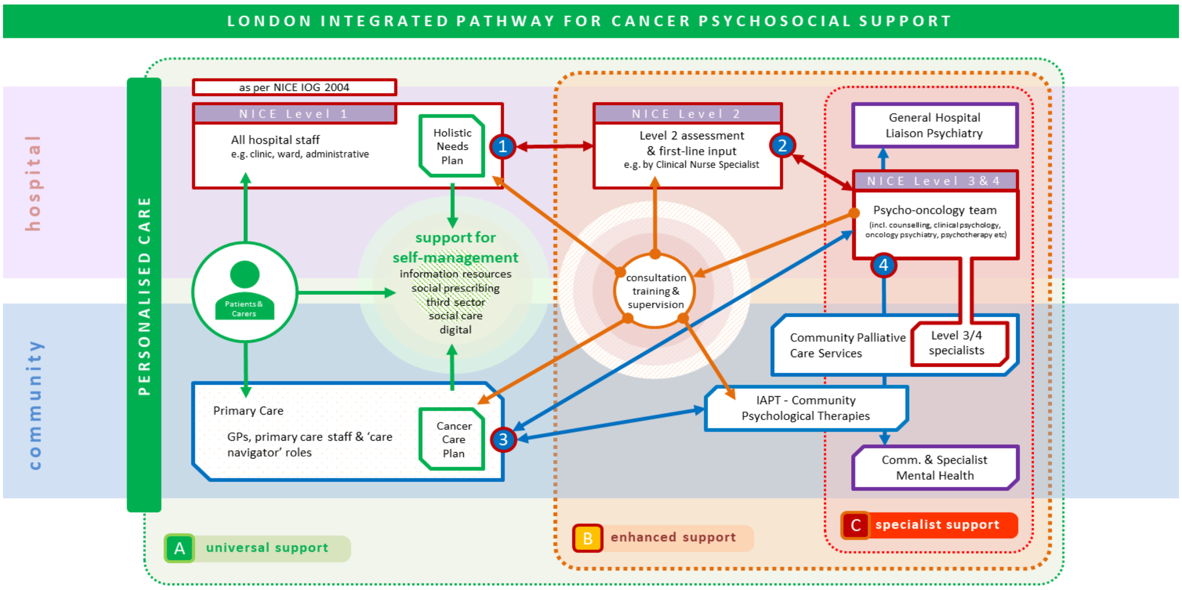
[7] Healthy London Partnership (2020) – Psychosocial support for people affected by cancer - https://www.healthylondon.org/resource/psychosocial-support/

Figure 1: London Integrated Pathway for Cancer Psychosocial Support



Universal, enhanced and specialist support in the context of pancreatic cancer

Below you can see detail of each level of this pathway, key features, particular considerations for pancreatic cancer and relevant metrics.

Level 1 Universal support

Universal support includes the compassionate care and patient-centred communication of all health & social care staff. It also includes a range of processes, inputs, and structures that are designed in a psychologically-minded way to prevent distress addresses psychosocial needs promotes self-management, and identify vulnerabilities, for patients & carers.

Psychologically supportive process and activities include:

- compassionate and person-centred communication in every interaction
- reliable care coordination by an accessible keyworker
- signposting and easy access to comprehensive information, welfare and peer support
- signposting and easy access to psychological self-management resources (including digital)
- personalised supportive care and planning, including holistic needs assessment and end of treatment review
- communication and coordination between services, especially when psychological therapies and/or mental health teams are already involved
- prehabilitation, rehabilitation, and related programs

What has been highlighted for pancreatic cancer:

- The quality of communication when this diagnosis and its poor prognosis are discussed – especially if this has to happen in an emergency context
- Access to keyworkers and support resources can be poorly coordinated and unduly slow in the context of rapid progression of pancreatic cancer

- The impact of acute stress, poor outlook and intense physical suffering can put vulnerable people at risk of suicide
- Involvement of palliative care services may be delayed or fragmented
- Difficult to recruit skilled workforce, even if funding available
- Directing patients towards online resources might be an issue when trying to offer psychological support as some of the patients do not use the internet to gain support or information, often due to fears around encountering inaccurate or negative information.[8]
- Some of patients may find it difficult to communicate with family and may hide their individual needs, resulting in survivor loneliness and isolation. Previous studies report that the fear of recurrence and the challenge of managing and interpreting new symptoms arise at the end of treatment and affect the ongoing quality of life.[9]
- The shock of a cancer diagnosis and the losses inherent to it may be processed as a psychological threat. In some cases, this shock can give rise to psychological symptoms diagnosable as depression or anxiety.

Thus, for **pancreatic cancer**, optimal **Universal** support additionally requires:

- rapid and reliable pathways to diagnosis and treatment, to prevent distress and loss of trust in healthcare
- staff who can communicate expertly and compassionately and are aware of the needs for people affected by pancreatic cancer (from band 1 to director level)
- direct access to universal psychosocial support through primary care settings (e.g. primary care nurse)
- processes for proactive identification of factors associated with risk, and prompt access to specialist assessment – all staff who identify concerns to be able to seek advice from the specialist psycho-oncology team
- attention to staff wellbeing and reflective practice, to maintain compassionate care and self-care in the context of constant exposure to suffering, loss, and helplessness
- digital resources that are validated to be sensitive to the needs of pancreatic cancer patients and families
- give the high rates of recurrence, proactively offer access to programs that support people to manage fear of cancer recurrence appropriately to the pancreatic cancer context

How will we know if optimal **universal support** is being achieved?

- all clinical staff in the specialist Hepato-Pancreato Biliary (HPB) MDT complete advanced communications skills training (ACST) and relevant refresher training
- national cancer patient experience survey (CPES) results on relevant items **(see Appendix 1)**
- targets for personalised care interventions (e.g. Holistic Needs Assessment and care plan) are audited and met
- local audits of access to comprehensive information, welfare and peer support for HPB patients

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[8] Taylor AK, Chang D, Chew-Graham CA, et al. 'It's always in the back of my mind': understanding the psychological impact of recovery following pancreaticoduodenectomy for cancer: a qualitative study. BMJ Open 2021;11:e050016. doi:10.1136/bmjopen-2021-050016

- audit of key clinical staff access to and participation in reflective practice

Level 2 Enhanced support

Enhanced support is relevant for patients and carers with heightened psychological distress where Universal care is not sufficient, and additional direct clinical input is required. This level of care relies on trained and supervised clinical keyworkers whose job description specifically includes providing Level 2 psychological assessment and input for patients and carers. This typically includes cancer and palliative care CNSs, may also include other clinical staff (e.g. Allied Health Professions (AHPs). Non-clinical staff such as cancer support workers/navigators are Level 1 roles.

Psychologically supportive process and activities include:

- keyworkers (typically the specialist CNS) have the dedicated time and clinical skills to conduct a first-line psychological assessment, that goes beyond distress and explores background, vulnerabilities and complexities
- where appropriate, keyworkers have the time and clinical skills to provide first-line interventions (e.g. guided self-help)
- the information is shared appropriately within the specialist MDT where needed to inform the clinical plan
- keyworkers attend specific Level 2 clinical skills training and regular supervision by Level 3/4 psycho-oncology specialists that lead the local pathway
- keyworkers have direct access to advice/consultation from specialist Level 3/4 psycho-oncology
- keyworkers can refer without undue administrative barriers or delays to specialist psycho-oncology and other mental health services

What has been highlighted for pancreatic cancer:

- where there is no access to a specialist psychological care multidisciplinary team (in cancer or palliative care), as per the optimal pathway, it is important to provide keyworkers with pragmatic guidance on making appropriate, safe, and effective use of locally available resources
- importance of enhanced support and proactive care coordination to mitigate the impact on patients of delayed diagnosis and restore trust in services
- importance of support to carers to understand how progressive disease can present as patient distress
- During this stage, HPB CNS can act as a constant supportive presence to patients, and their knowledge of the patient's context and their own clinical experience may be particularly valuable. However, the numbers of CNS have not increased in line with increasing cancer prevalence, and the emphasis of their work has shifted towards more practical and administrative work. The resulting challenges of a resource-poor health system can limit HPB CNS' opportunities to support patients fully from a psychological perspective.[10]
- To ensure that CNSs can prioritise patients' psychological welfare, and engage in further training around psychological sequelae and how to identify and manage these

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[10] Taylor AK, Chang D, Chew-Graham CA, et al. 'It's always in the back of my mind': understanding the psychological impact of recovery following pancreaticoduodenectomy for cancer: a qualitative study. BMJ Open 2021;11:e050016. doi:10.1136/bmjopen-2021-050016

in patients, sufficient administrative and support staff e.g. patient navigators, should be employed to deal with practical and administrative work

How will we know if optimal Enhanced support is being achieved?

- cancer patient experience survey (CPES) results on relevant items **(see Appendix 1)**
- all CNS and AHPs involved in pancreatic cancer care complete ACST and Level 2 skills training within the first year in post
- audit of attendance to Level 2 supervision (target >80% attendance)
- a staff experience survey to better understand what they need to upskill and able to manage people affected by pancreatic cancer (e.g. the survey could include questionsto find out if staff are feeling supported to develop their skills, having time to engage with patients, having adequate support for themselves etc)

Level 3 Specialist support

Specialist support includes the processes and activities for providing highly personalised assessment and management of complex and persistent psychological distress and mental health problems. This is typically the focus of specialist psycho-oncology multidisciplinary teams in cancer hospitals, and psychosocial and mental health care specialists in palliative care.

Psychologically supportive process and activities include:

- A specialist multidisciplinary psycho-oncology team embedded in the cancer treatment setting
- A range of clinical specialists, including clinical / counselling psychology, counselling and liaison psychiatry
- Sufficient clinical capacity for timely provision of care to inpatients, outpatients, day patients and carers
- Access to specialist clinics for psycho-sexual and neuro-psychological input where indicated
- Provision of rapid advice/consultation to cancer clinicians, primary care and other services
- Effective coordination of care with primary care psychological therapy services (IAPT LTC) and secondary mental health care services (CMHT)

What has been highlighted for pancreatic cancer:

- There is a lack of pancreatic cancer referral in specialist psycho-oncology MDTs and it's believed this is because people die too quickly – before there is time to be referred
- There is specific need for responsive services without waiting lists, given the rapidly progressive nature of the illnessIAPT services might be relevant to people with pancreatic cancer with good prognosis, however we expect around 80% of people to have advanced disease and it would require more rapid access to psychosocial support
- Given the evidence on biological factors relating to the disease presenting as depressed mood even prior to pancreatic cancer diagnosis, it's important for psycho-oncology teams to include liaison psychiatry expertise
- There should be provision of rapid access to all staff to consult with psycho-oncology, when there are concerns about risk and/or rapidly progressive

- Access to carer psychological support proactively where indicated (e.g. anticipatory bereavement)
- Pancreatic cancer may present insidiously with depressed mood and certain treatments can also cause depression through their direct neuropsychiatric effects. Awareness of the potential for such biological effects, impulsive catastrophic reactions to diagnosis, and incident or worsening depression are starting points for early identification of suicidal distress
- A national team of specialist psycho-oncologists to work together to develop an innovative acute model of psychological care – this could be eventually relevant for other cancers with poor prognosis as well

How will we know if optimal Specialist support is being achieved?

- cancer patient experience survey (CPES) results on relevant items (see Appendix 1)
- HPB MDTs and Specialist Palliative Care teams have direct access to specialist psycho-oncology teams within their setting within two weeks from referral to assessment
- regular audit of psycho-oncology service quality and outcomes, and particularly response times and audit of care where risk concerns were identified

Conclusion

In the context of Pancreatic Cancer, with direct threat to life, high symptom burden, biological effects of the illness and its intensive treatment impact, it is highly likely that psychological distress will be experienced by all patients and carers, and indeed there is wide evidence of high rates of psychological and mental health distress, and increased risk of suicide.

Psychosocial care is currently a priority for the NHS England Cancer programme, and specific targets for Providers and Alliances include mapping and planning for delivery of cancer psychosocial care.

The optimal pathway for psychological care in pancreatic cancer can be developed from the core specification of the 2020 London Integrated Model with additional considerations that address the specific context.

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Appendix 1

Questions from the national Cancer Patient Experience Survey to use in monitoring if psychosocial support people with pancreatic cancer was delivered successfully

- Patient found advice from main contact person was very or quite helpful
- A member of their care team helped the patient create a care plan to address any needs or concerns
- Staff provided the patient with relevant information on available support
- Patient definitely got the right level of support for their overall health and well being from hospital staff
- Patient was always able to discuss worries and fears with hospital staff
- Patient was always able to discuss worries and fears with hospital staff while being treated as an outpatient or day case
- During treatment, the patient definitely got enough care and support at home from community or voluntary services
- Patient definitely received the right amount of support from their GP practice during treatment
- After treatment, the patient definitely could get enough emotional support at home from community or voluntary services