Holistic Needs Assessment and Personalised Care and Support Planning for people diagnosed with cancer in England in 2021 recorded in the cancer registry:

Key Findings and Recommendations

Key Findings

The Macmillan Cancer Support and National Disease Registration Service (NDRS) report on *Holistic Needs Assessment and Personalised Care and Support Planning for people diagnosed with cancer in England in 2021 recorded in the cancer registry: Data Summary* showcases what can be achieved through analysis of Holistic Needs Assessment (HNA) and care planning data captured in COSD. This pioneering work focused on offers of HNA and care planning data recorded in the cancer registry. We explored variation in offers in the two years following cancer diagnosis in 2021. The analysis found variation driven by cancer type and personal characteristics.

The Long-Term Plan, released in 2019 by NHS England, states "*where appropriate, every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support*"[i]. HNA and care planning is a structured way for the person to identify their concerns and receive support. These elements of care can be offered at any stage of the cancer pathway and may be repeated as needed. However, they are generally expected to be provided around the time of diagnosis before treatment begins, after treatment has ended, and whenever a person's needs change, or they request a review of their care plan.

Macmillan believes that offering an HNA is essential to understanding people living with or affected by cancer as individuals, enabling personalised care, and ensuring they receive the support they need. This offer supports shared decision-making by giving people the opportunity to undertake an HNA if they choose to. Following an HNA, people should be offered the chance to engage in care planning to identify and agree on ways to address their needs. This may include providing information, signposting to services, making referrals, or holding a supportive conversation. In some cases, the person will decline the offer, be unable to complete it, be undecided, or feel it is not required due to a lack of concerns. This report focuses on all offers, regardless of their outcome, on the basis that most people should receive this essential offer of personalised care.

This report provides valuable insights. However, it is important to note that continued improvements in data quality and consistency of submissions to COSD will be essential to fully understand and monitor the delivery of personalised care.

The analysis found significant variation associated with prognosis and survival, cancer type, and patient demographics and geography.

Prognosis and survival:

- People with a poor prognosis were less likely to have a recorded offer of an HNA and care planning within two years of their diagnosis[1]. This was demonstrated by lower proportions of offers among those diagnosed at stage 4, those who die shortly after diagnosis, people with poor prognosis cancers, and those in the oldest age groups.
- These patterns may partly reflect the limited time available for HNAs and care planning before death. In other cases, they may indicate the use of Advance Care Planning (ACP) as an alternative. However, Macmillan recommends that HNAs and ACP should be offered alongside each other. The ACP process is about capturing a person's preferences and wishes for future care and treatment, including decisions about where they would like to be cared for, what treatments they would or would not want, and who they would like to make decisions on their behalf, such as through a Lasting Power of Attorney[ii].
- For people approaching the end of life, HNAs and care planning can be adapted to incorporate specialist palliative care concerns[2], and clinicians or carers can support the person in completing the assessment. Greater use of HNAs and care planning by palliative care teams, along with better recording of this activity in COSD, could improve access for this group.

Cancer type:

- People diagnosed with cancer types with well-established pathways such as breast, cervix, colorectal, head and neck, uterus, and prostate cancer were more likely to have a record of an HNA and care planning offer, compared with people diagnosed with cancer types such as pancreas, brain, liver, and kidney. Several of these more common cancers occur more frequently or exclusively in women, trans men, and people assigned female at birth, which may contribute to higher rates of HNA offers among those whose gender is recorded as female.
- In contrast, people diagnosed with cancers that lack well-defined care pathways, such as cancer of unknown primary, often receive care from multiple clinical teams. In these cases, clearer processes are needed to identify who is responsible for delivering HNAs and care planning, and to

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[1] For people who live less than two years following diagnosis the follow up is between diagnosis and death.

[2] For example, the Macmillan palliative concerns HNA checklist: www.macmillan.org.uk/dfsmedia/1a6f23537f7f4519bb0cf14c45b2a629/8694-10061/palliative-concerns-hna-checklist

ensure they are offered at a time and in a setting that provides the greatest benefit to people living with or affected by cancer.

Patient demographics and geography:

- Certain groups, including males, the oldest and youngest age groups, and those from ethnically diverse backgrounds, had lower recorded proportions of HNA and care planning offers. While some of these differences may be partly driven by cancer type, the underlying reasons are not fully understood and are likely to be complex and multifactorial.
- People living in the most deprived areas had the highest recorded proportions of HNA and care planning offers. This could reflect prioritisation in some settings.
- There was significant variation in the recording of HNA and care planning offers across NHS trusts in England, highlighting differences in data submissions and service provision.

In addition, fewer than 10% of people had more than one HNA recorded within the two-year period. Only 1% of HNA or care planning records were offered at the point of recurrence, and only 2% were recorded at the transition to palliative care. While these low rates may partly reflect the proportion of people who experience recurrence or transition within two years of diagnosis, and the completeness of COSD data, the findings suggest a broader lack of routine HNA and care planning offers beyond initial treatment, despite their recognised importance at key transition points in the cancer pathway.

The report also highlighted a high proportion of offered and accepted HNAs resulted in a care planning status of '*not required (no concerns from HNA)*'[3]. While this may reflect the reality of personalised care, where some people genuinely have low levels of need, it may also indicate poor-quality assessments. Given the emotional, physical, and practical challenges of a cancer diagnosis, it would be expected that many people would identify at least one holistic need or concern during the first two years following diagnosis.

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[3] In 2021, 41% of all care planning offer records submitted within two years of diagnosis had a status of '*not required (no concerns from HNA)*'. This figure includes all care planning records, including instances where the same patient had more than one offer within the two-year period. Among patients who were offered both an HNA and a care plan within two years of diagnosis, 45% had a record showing an '*offered and accepted*' HNA followed by a '*not required (no concerns from HNA)*' care planning status as their first recorded HNA and care planning offer.

Recommendations

This analysis highlights the need for the following actions to ensure equitable and effective delivery of personalised care across the cancer pathway:

1) **Continuing focus on delivery of personalised care for all**
   Policymakers and service providers should continue to encourage, where appropriate, every person diagnosed with cancer to have access to personalised care, including needs assessment, a care plan, and health and wellbeing information and support. The offer of an HNA and subsequent care planning should be made to all, recognising that some people may decline, be undecided, or be unable to complete the process. It is essential that the offer is made, and appropriate support provided to enable people to participate if they wish, to identify and respond to their holistic needs.
2) **Additional focus to address inequalities in access to personalised care**
   Improving the proportion of HNA and care planning offers will require targeted efforts to reach groups currently less likely to receive personalised care, particularly people with a poor prognosis or those on less well-established cancer pathways. Offers of HNA and care planning should be prioritised around the point of diagnosis for these groups, to ensure that everyone has at least one opportunity to engage with personalised care. This will involve working with palliative care teams and site-specific oncology cancer nurses. Additional focus may also be needed to reduce inequalities among ethnically diverse and older populations.
3) **Personalised care at points of care transition**
   HNA and care planning should be routinely considered at key transition points in the cancer pathway, such as at diagnosis of recurrence or the transition to palliative care, when holistic needs may change significantly. This analysis suggests such offers are currently rare, but further investigation and improved data recording in COSD and other systems are needed to confirm and address this.
4) **Ensuring HNA results are being used effectively in care planning**
   Where a high proportion of care plans are recorded as '*not required (no concerns reported)*', clinical teams should consider how the purpose and benefits of HNAs are communicated to people living with cancer. Supporting people to fully engage in the process may help them express their needs more openly and ensure appropriate support is offered.
5) **Continuing the efforts on personalised care data quality**
   Due to incomplete data, this analysis cannot provide a definitive estimate of the proportion of people offered an HNA or care planning. Not all NHS trusts submitted HNA and care planning data during the analysis period, and submitted data is known to be incomplete. Ongoing work to improve

data flow into COSD, including from electronic systems and paper-based sources, must continue to maximise the value of this dataset.

6) **Build on this work to maximise patient benefits from data linkage**
   This work has established new methods of linkage and analysis that are now available to those with access to patient-level COSD data. We encourage academics, the NHS, and others to make greater use of this data to inform service design and delivery.
7) **Consider how personalised care can be measured in all settings**
   Currently, only NHS cancer care delivered in acute and secondary care settings is captured in COSD. To provide a fuller picture of personalised care activity, new systems, data linkages, and agreements are needed to capture HNA delivery in community, primary, and social care settings.

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[i] NHS England. Personalised care and improving quality of life outcomes. Available from: www.england.nhs.uk/cancer/living

[ii] Macmillan Cancer Support. Advance care planning. Available from: www.macmillan.org.uk/cancer-information-and-support/treatment/if-you-have-an-advanced-cancer/advance-care-planning