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

Executive Summary

Personalised care and support planning is a process to ensure patients' physical, practical, emotional, and social needs are identified and appropriately addressed. A key part of this process is the completion of Holistic Needs Assessments (HNA), which are used to enable a supported conversation and personalised care and support planning, often referred to simply as care planning. Understanding the proportion and characteristics of people affected by cancer who are offered these interventions is important to both NHS England and Macmillan Cancer Support, as it helps to identify variation in personalised care provision and highlights potential areas for improvement.

Since 2020, it has been a requirement to capture HNA and care planning offers delivered by NHS Trusts to cancer patients in the Cancer Outcomes and Services Data set (COSD), collected by NHS England. Macmillan, through its longstanding partnership with the National Disease Registration Service (NDRS) in NHS England, has undertaken exploratory data analysis on the HNA and care planning data collected via COSD.

As this is the first time this data has been used for person-level analysis, the initial phase focused on establishing a methodology to link COSD HNA and care planning data to registry diagnosis data at the patient level. This linkage included people diagnosed with malignant cancer in 2021, with follow-up over two years to examine HNA and care planning activity. Novel methods were developed to remove duplicate records. This dataset was then used to create methods for summarising HNA and care planning activity, enabling a better understanding of variation across different population groups.

These analyses aim to improve understanding of the data and support improvements in data quality and completeness, in preparation for routine publication and use of this data in service planning and delivery. It should be noted that NHS data collection in 2021 was still impacted by the COVID-19 pandemic.

Our analysis indicates that HNA and care planning reporting by NHS trusts in COSD is improving; however, some trusts are not submitting data and, where data is submitted, it is sometimes incomplete. As COSD is only able to capture HNA and care planning occurring along the cancer pathway in secondary care settings, total activity is unable to be described at present. More work is needed to ensure that HNA and care planning across the whole patient pathway is captured appropriately.

This analysis indicated the following groups were statistically less likely to be offered an HNA in secondary care settings within two years of diagnosis. Each factor was individually analysed; therefore, the analysis does not adjust for the overlapping and interrelated nature of these groups:

- Patients who die within 12 weeks of diagnosis, compared with those who survive beyond 12 weeks
- Patients diagnosed with rarer or poor prognosis cancer such as brain, cancer of unknown primary, kidney, liver, pancreas, renal pelvis and ureter, small intestine, and soft tissue, compared with those diagnosed with breast, cervix, colorectal, head and neck, uterus, and prostate cancer
- Patients who have Asian, Black or Chinese ethnicity, or those with a record of not known or other ethnicity, compared with patients who have White ethnicity
- Patients diagnosed with cancer at a young age (under 20, 20-29 years) or at an older age (80+ years), compared with those diagnosed in other age groups (30-39, 40-49, 50-59, 60-69, and 70-79 years)
- Males, compared with females
- Patients diagnosed at stage 4 or with missing stage information, compared with patients diagnosed at stage 1, 2 and 3 as well as "*Staged – other early*" for stage 4
- Patients who live in the least deprived areas (decile 10), compared with patients who live in any other deprivation decile (1-9)

In addition, less than 10% of patients had more than one HNA recorded within the two-year period following their diagnosis. Of all HNA and care planning records within two years of diagnosis, only 1% were offered at the point of diagnosis of a recurrence and 2% were offered at the transition to palliative care. This is likely to be influenced by the low proportion of patients who have a recurrence or transition to palliative care within two years of diagnosis but could also reflect a lower proportion of HNA and care planning offers at these points in the pathway.

Recommendations based on these findings are presented in a separate paper.

Introduction and Background:

NHS England state that "*personalised care means people have choice and control over the way their care is planned and delivered. It is based on 'what matters' to them and their individual strengths and needs*"[i]. Personalised care can involve offering Holistic Needs Assessments (HNA). The HNA is a structured approach to help identify an individual's physical, social, emotional, and financial needs which is used to enable a supported conversation and personalised care and support planning, often referred to as care planning. Guidance on using HNA and care planning to deliver personalised care was first published in 2007, and since then, this approach has been rolled out in the NHS for people diagnosed with cancer[ii, iii, iv]. HNAs can be based on Macmillan Cancer Support's concerns checklist, which presents a consistent set of concerns used in Macmillan's own eHNA tool[iii, iv]. The offer and provision of HNAs can also be recorded within cancer management systems such as InfoFlex and Somerset Cancer Register. The HNA can be conducted in many ways such as electronically or on paper at home or in the clinic, face-to-face, or via a phone call.

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*"[ii]. 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.

The Cancer Outcomes and Services Data set (COSD) is the national standard for collecting cancer data in England[v]. All NHS trusts providing acute cancer care are required to submit data to COSD monthly for all people diagnosed with cancer. Other organisations supporting people living with cancer, such as social care workers, community, and third sector teams can also facilitate HNAs and conduct care planning, but they are neither required nor able to record these activities via COSD. As a result, all non-NHS HNAs and care planning activity, as well as most NHS activity outside of the acute treatment phase (such as follow up or community-based NHS care) is not captured in COSD. Data submitted to COSD includes information around cancer type, staging, and treatment events as well as a host of other information. This information is curated and linked with other data sources to provide high-quality registration information related to every cancer in England.

Since the launch of COSD version 9.0 in 2020, NHS cancer services providers are required to submit additional data on the offer and provision of HNAs for people diagnosed with cancer. This includes four data items: assessment offered, assessment completed date, assessment point of pathway, and staff role carrying out the assessment. Equivalent items are also required for care planning. The inclusion of these data fields has enabled, for the first time, the systematic collection of information on HNA and care planning activity across England within secondary care, as recorded by NHS acute providers. This facilitates national-level monitoring of personalised care activity using real-world data.

As part of the ongoing NDRS – Macmillan partnership, this project aimed to design new methods to link and analyse patient-level COSD data relating to HNA and care planning to describe the population with a recorded offer or receipt of these interventions. This work improves understanding of these new data fields as well as stimulating improvements in data quality and completeness. It also establishes a foundation for wider use of this linked dataset by other researchers and for the routine publication of aggregated data, enabling policymakers and service providers to improve the delivery of HNAs and care planning.

Methodology:

Sources and linkage:

Records of HNAs and care planning offers are collected in COSD. It includes offers that are accepted and those that are declined or the patient is unable to complete. The data feeds into the pathway table of the Rapid Cancer Registration Dataset (RCRD). The RCRD pathway data can be linked to fully registered cancer diagnosis data, from the National Cancer Registration Dataset, via NHS numbers[vi].

Patient cohort:

The analysis included patients diagnosed with a malignant cancer in 2021 (ICD-10 codes C00-C97, excluding C44), regardless of any previous or subsequent diagnosis. Where patients were diagnosed with more than one tumour in 2021, their first diagnosed tumour was used[1]. As not all Trusts were routinely submitting HNA and care planning data to COSD, data were excluded from the respective HNA or care planning cohorts for Trusts where there were fewer than 10 HNA or care plan records and up to 100 patients diagnosed in 2021, or fewer than 20 HNA or care plan records and more than 100 patients diagnosed in 2021[2]. 305,645 patients were included in the HNA coverage analysis and 298,550 in the care planning coverage analysis. For each person, we reviewed the HNA and care planning records in COSD that occurred within two years of their first diagnosis date, or until death if that occurred within two years. The two-year follow-up period was chosen to balance capturing as much relevant activity as possible with the need for timely reporting.

Data cleaning:

Each time something changes in a patient's COSD record, the entire COSD record is resubmitted, meaning a record of any previous events, such as HNAs and care planning, will also be resubmitted, creating a second record of that event. This process results in many duplicate records. Records were deemed to be duplicates where records matched on the date of the HNA or care planning, the Trust submitting the HNA or care planning record, and the COSD data items (status code, staff role code, and point of pathway code). Based on these criteria, the dataset was cleaned to retain only unique HNA or care planning records within two years of diagnosis for each person. Additionally, all records

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[1] We also exclude stage 0 tumours, death certificate only diagnosis, patients recorded as dying on or before the date of diagnosis. Patients without any RCRD pathway records were also excluded.

[2] 9 Trusts were excluded from each the HNA and care planning cohorts for having fewer than 10 HNA/care planning records and up to or fewer than 100 patients diagnosed in 2021; 3 and 9 Trusts were excluded from the HNA and care planning cohorts, respectively, for having fewer than 20 HNA/care planning records and more than 100 patients diagnosed in 2021.

recorded as "*Not offered*" or with an invalid offered status code were excluded. Where patients had records of more than one valid, non-duplicate HNA or care plan within two years of diagnosis, all were included in this analysis. For example, a person may have had an HNA and care plan completed at time of diagnosis and then again post-treatment.

Analysis:

Descriptive statistics were calculated, exploring the proportion of patients with at least one record of an HNA or care planning offer within two years of diagnosis. This includes offers that resulted in an accepted HNA or care planning, as well as offers where the patient was unable to complete, had declined, or was undecided. For care planning, this also included records when a care plan was not required due to no concerns in the HNA.

HNA and care planning offers were stratified by gender, age, ethnicity, deprivation decile, tumour type, stage at diagnosis, and survival status. Where proportions between groups are described as significantly different in this report, this is based on a p-value of less than 0.05 from a Z-test. All comparisons of groups are univariate, meaning they are not adjusted for other potentially contributing factors. Additionally, the analysis did not adjust for those who died within two years of diagnosis, for whom there may have been less opportunity to be offered an HNA or care planning.

All unique HNAs and care planning offered to patients diagnosed in 2021 within two years of their diagnosis date were analysed according to the time between diagnosis and the date of the event. Proportions of all HNA and care planning records recorded are also reported by each point of pathway, as defined in COSD[vii].

Patient data acknowledgement:

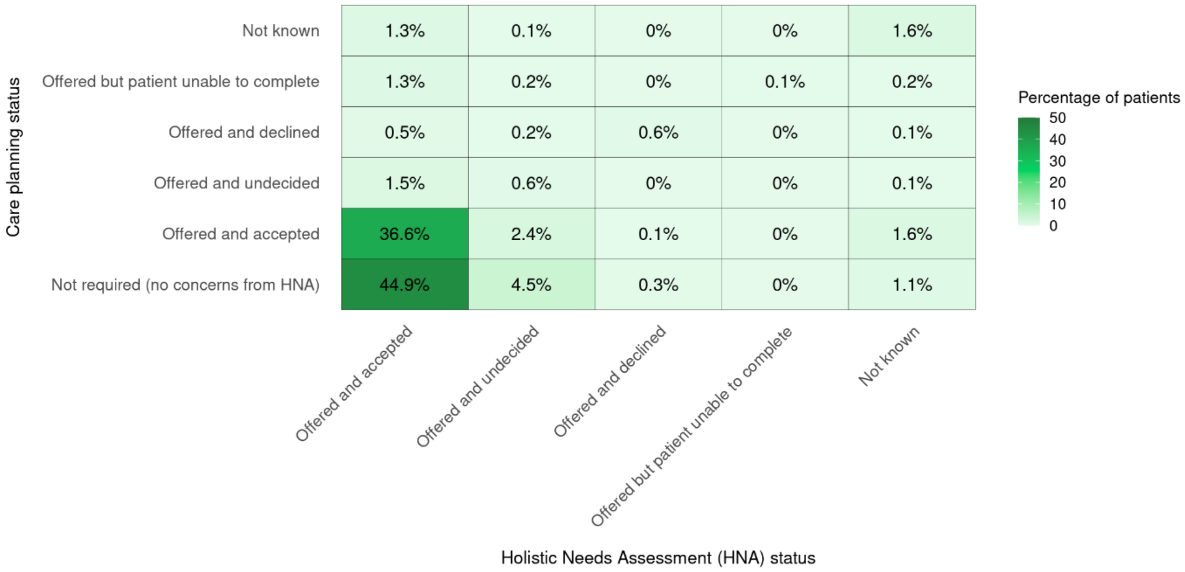
This work uses data that has been provided by patients and collected by the NHS as part of their care and support. The data is collated, maintained and quality assured by the National Disease Registration Service, which is part of NHS England.

Results:

Overall coverage:

Before removing duplicates, there were 1,942,343 HNA and care planning records associated with patients diagnosed with cancer in 2021. After deduplication, the dataset included 131,612 unique HNA records and 109,305 care planning records, representing 12% of the original total. Among those diagnosed in 2021, 26% had a record of being offered at least one HNA within two years of diagnosis, and 24% had a record of being offered at least one care plan (or care planning being deemed 'not required' because the patient raised no concerns on their HNA). Of those with a record of an HNA or care planning, 76% had a record of being offered both, 17% had only an HNA recorded, and 8% had only care planning recorded. As care planning should generally follow an HNA, it is possible that patients with only care planning recorded also had an HNA that was not captured in the dataset. If this assumption is made, the overall proportion of patients with at least one HNA recorded within two years of diagnosis would rise to 28%.

Figure 1 shows the combination of HNA and care planning statuses for patients with a record of both offers (n=65,410)[3]. The most common combination was "*offered and accepted*" HNA with either a "*offered and accepted*" care planning (37%) or "*not required (no concerns from HNA)*" (45%).



Care planning status	Offered and accepted	Offered and undecided	Offered and declined	Offered but patient unable to complete	Not known
Not known	1.3%	0.1%	0%	0%	1.6%
Offered but patient unable to complete	1.3%	0.2%	0%	0.1%	0.2%
Offered and declined	0.5%	0.2%	0.6%	0%	0.1%
Offered and undecided	1.5%	0.6%	0%	0%	0.1%
Offered and accepted	36.6%	2.4%	0.1%	0%	1.6%
Not required (no concerns from HNA)	44.9%	4.5%	0.3%	0%	1.1%

Figure 1. HNA and care planning status for patients diagnosed with cancer in 2021 who had a record of both an HNA and care planning offer within two years of diagnosis (n=65,410)

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[3] For patients with more than one HNA or care plan recorded, their first of each is used in this figure.

Figure 2 shows that of all unique HNAs and care planning offered to patients diagnosed in 2021 within two years of diagnosis[4], approximately:

- **35%** were offered at initial cancer diagnosis
- **14%** were offered when the patient started treatment
- **20%** were offered during treatment
- **20%** were offered at the end of treatment
- A small number were offered at other points in the cancer pathway, such as at a diagnosis of recurrence

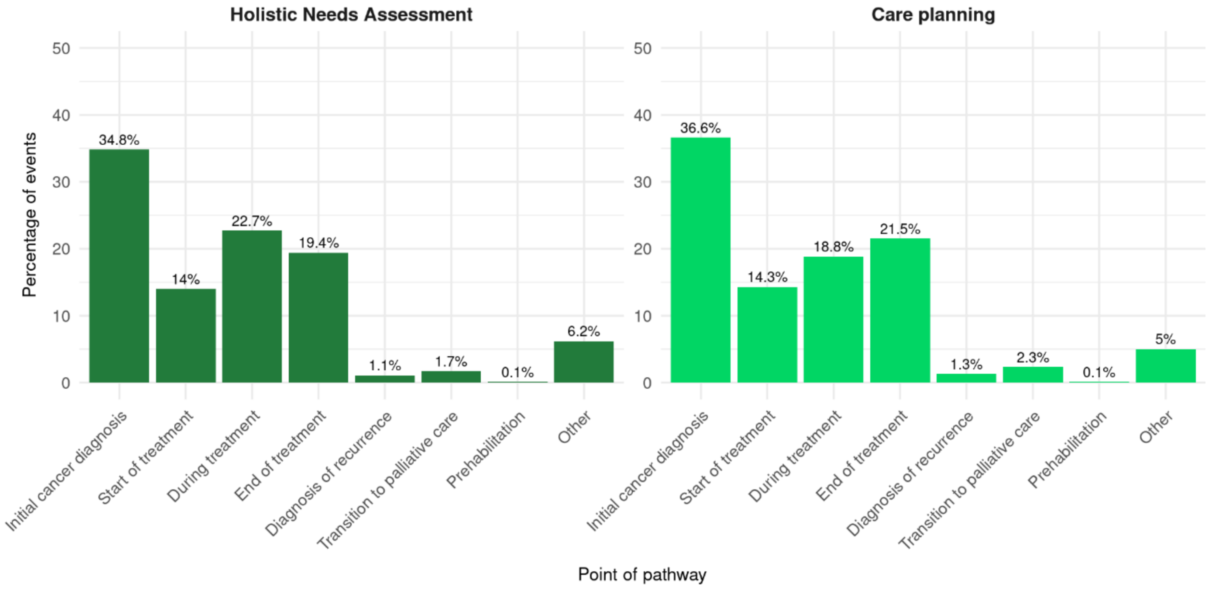

Figure 2. Proportion of unique HNA and care planning records for each point of pathway

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[4] When patients have records of more than one HNA or care planning within two years of diagnosis both are included in this analysis.

Figure 3 shows the number of patients whose first recorded HNA was offered within different time periods after diagnosis. The median time between diagnosis and first recorded offer of an HNA is **39 days**. By **10 months** post-diagnosis, 90% of those patients who are offered an HNA in the two years post-diagnosis had an offer of an HNA. This analysis does not account for patients who died within the two years following diagnosis, who may have had less opportunity to be offered an HNA or care planning.

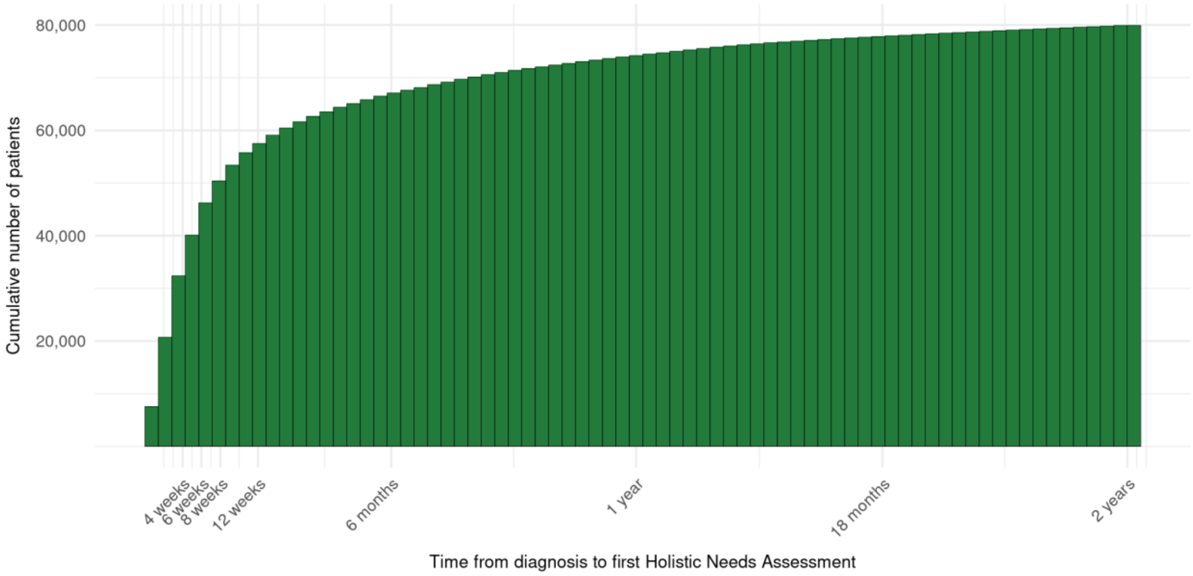

Figure 3. Cumulative number of patients by time between diagnosis date and first record of HNA being offered for patients diagnosed in 2021

Figure 4 shows the number of patients whose first recorded care planning was offered (or deemed 'not required' because the patient raised no concerns on their HNA) within different time periods after diagnosis. The median time between diagnosis and first recorded offer of care planning is **12 days**. By **5 months** post-diagnosis, 90% of those patients who are offered care planning in the two years post-diagnosis had an offer of care planning.

These timings refer to when an HNA or care planning was offered, rather than when they were completed. In some cases, care planning is offered before the HNA. This may occur when care planning takes place in person during a clinic appointment, requiring more advance notice than an HNA that can be completed at home. The data suggest that this is common, as the median time to care planning offer (12 days) is notably shorter than the median time to HNA offer (39 days).

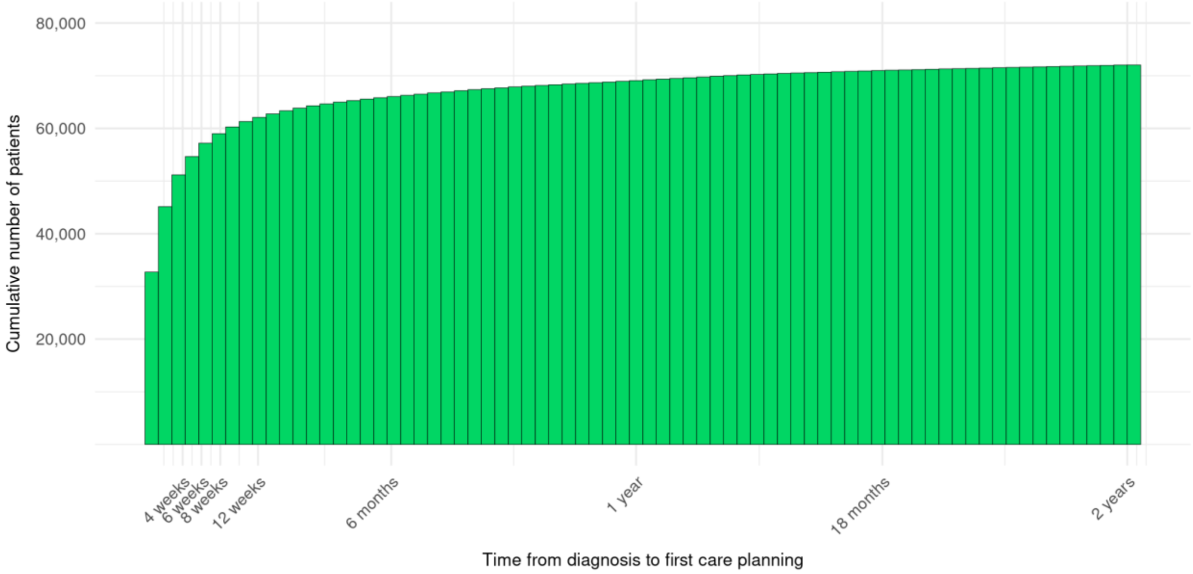

Figure 4. Cumulative number of patients by time between diagnosis date and first record of care planning being offered for patients diagnosed in 2021

Variation in coverage:

Figure 5 highlights the proportion of patients by patient-stated gender (male or female; please see footnote)[5] who were offered an HNA and care planning. A significantly higher proportion of females were offered either an HNA (**29%**) or care planning (**27%**) compared with males (**23%** and **21%**, respectively).

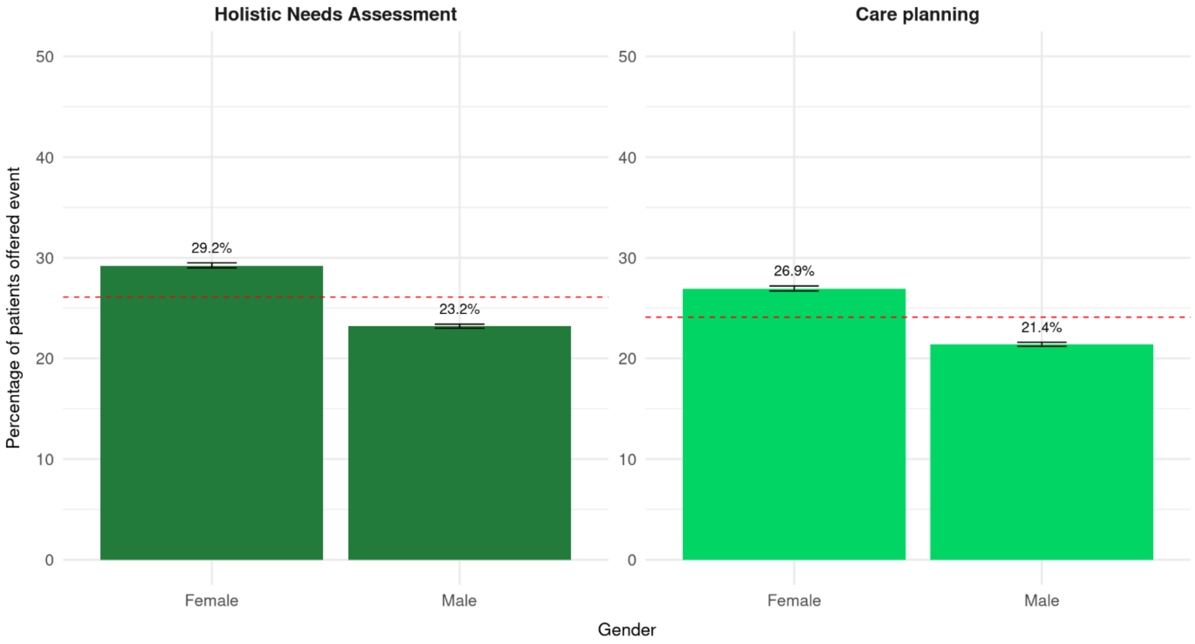

Figure 5. Proportion of patients with record of being offered an HNA and care planning by gender

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[5] Patient Stated Gender Code is the NHS standard for recording gender. A patient's gender should ideally be self-reported in any given dataset, but there are rare instances where this information is completed by medical or administration staff. The National Disease Registration Service also does not currently publish data on patients where a sex-specific diagnosis code does not match the person-stated gender. This is done for data quality purposes but it is likely to exclude some transgender and non-binary patients from the data used for this analysis; more information about this is available on the National Disease Registration Service Inequalities in Cancer webpage. The analysis described here is limited to only data on males and females due to data availability.

The proportion of patients with at least one recorded offer of an HNA and care planning varied substantially by age at diagnosis (Figure 6). The age groups least likely to be offered HNA or care planning were:

- Under 20 years (**5%** HNA, **4%** care planning)[6]
- 20-29 years (**22%** HNA, **20%** care planning)
- 80 years and over (**17%** HNA, **16%** care planning)

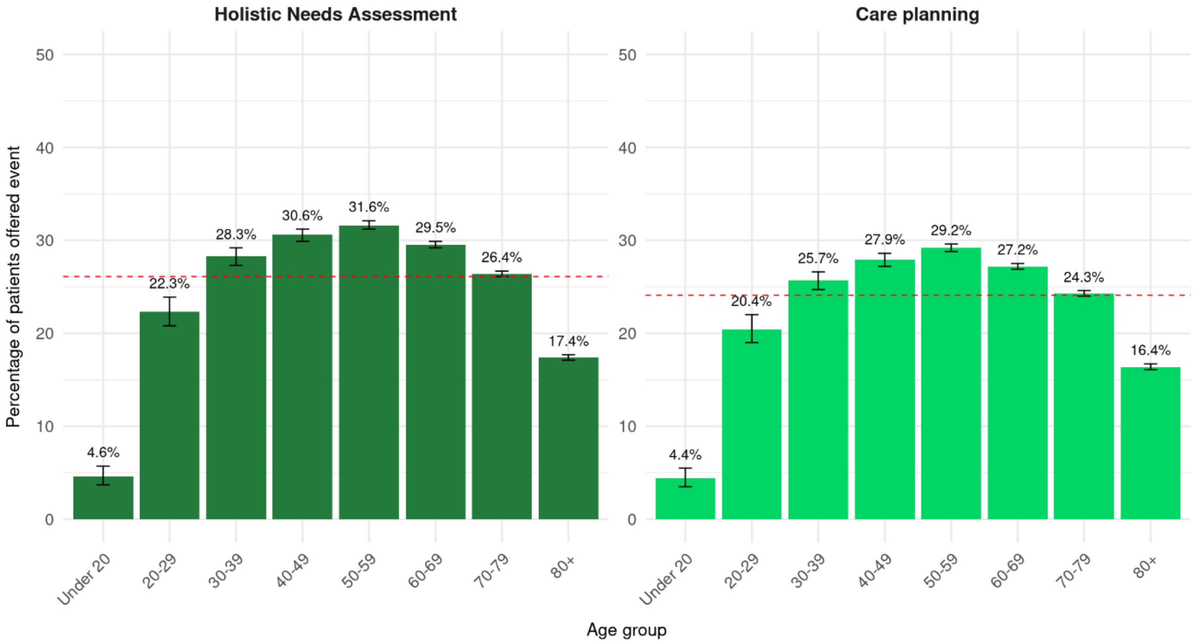

Figure 6. Proportion of patients with a record of being offered an HNA and care planning by age at diagnosis

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[6] Under 20 age band represented 79 patients offered an HNA and 75 offered care planning. The under 20 group had a low rate of HNA and care planning offers as the cancer diagnosis denominator includes children but very few HNAs and PCSPs are recorded in COSD by children's cancer teams.

Ethnicity data is captured in the cancer registry. The groupings described here are derived from standard NHS ethnicity definitions and have been aggregated into broader categories to ensure sufficient numbers for robust analysis. Figure 7 shows:

- People with White recorded ethnicity were most likely to be offered an HNA (**27%**) and care planning (**25%**).
- Among those with a recorded ethnicity, patients with Black or Chinese recorded ethnicity were the least likely to be offered an HNA, with both groups at **21%**. The differences between patients with Black, Chinese, or Asian recorded ethnicity compared with patients with White recorded ethnicity are statistically significant. Those without a recorded ethnicity group ("*Not Known*") were least likely to have a recorded offer of an HNA (**18%**) or care planning (**17%**).

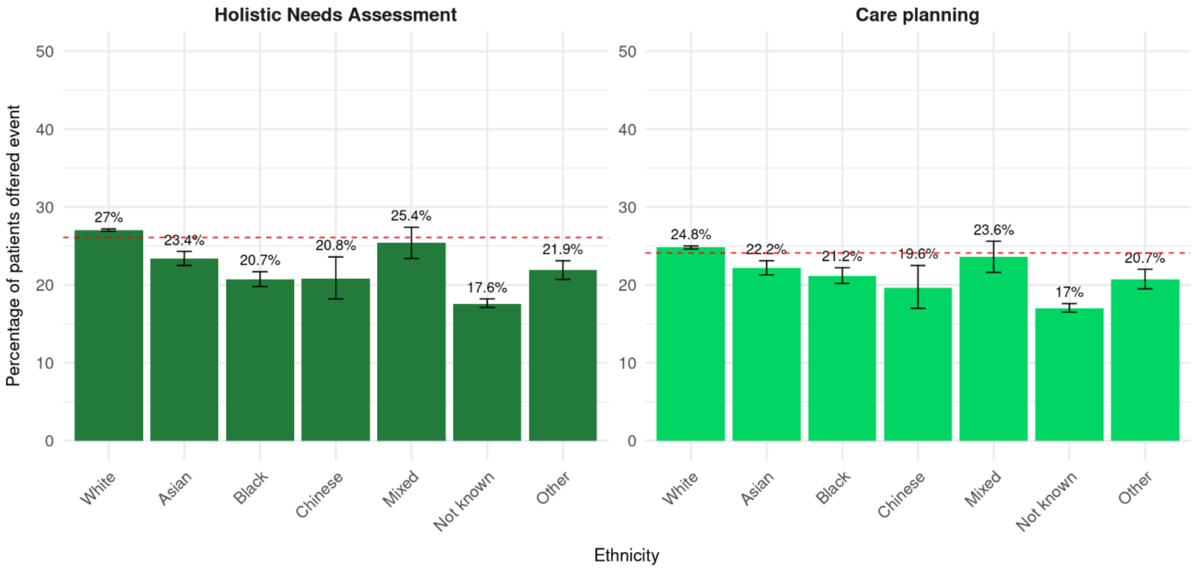

Figure 7. Proportion of patients with record of being offered an HNA and care planning by ethnic grouping

Deprivation decile is defined based on the area where a person lives at the time of diagnosis. The proportion being offered an HNA or care planning by deprivation is shown within Figure 8, with key findings as follows:

- Patients living in deprivation decile 1 (**most deprived**) were most likely to have been offered an HNA and care planning (**28%** and **26%**, respectively).
- Patients living in decile 10 (**least deprived**) were least likely to be offered an HNA and care planning (**23%** and **21%**, respectively), with this difference being statistically significant compared to decile 1. All other deprivation deciles also had significantly higher proportions of patients recorded as being offered HNA and care planning compared to decile 10.

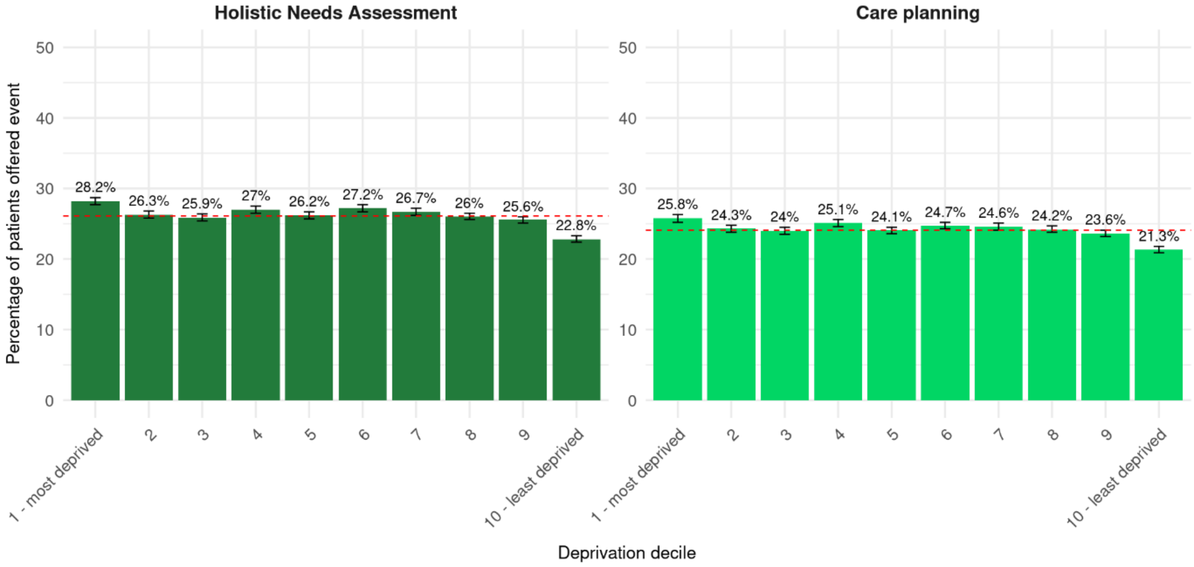

Figure 8. Proportion of patients with a record of being offered an HNA and care planning and by deprivation decile

The proportion of patients with at least one recorded offer of an HNA and care planning varied substantially by tumour type (Figures 9 and 10). Patients with breast cancer were the most likely to be offered an HNA (**44%**) and care planning (**40%**). This is likely due to the earlier implementation of HNAs in breast cancer pathways and the fact that these pathways are generally well-established and consistent across patients. The next highest proportions were seen in patients with uterine (**34%** HNA, **32%** care planning) and cervical cancer (**30%** HNA, **28%** care planning). Given that breast, uterine, and cervical cancers predominantly affect females, these high proportions are likely to contribute to the overall higher rates of HNA and care planning offers observed among female patients compared with males (Figure 5).

Only **5%** of patients diagnosed with a cancer of unknown primary were recorded as being offered an HNA; likewise, only **5%** of the same group were recorded as being offered care planning. Other tumour types with low offers of HNA or care planning recorded were pancreas (**13%** HNA, **12%** care planning), brain (**13%** HNA, **12%** care planning), liver (**13%** HNA, **12.4%** care planning), and kidney (**14%** HNA, **12%** care planning).

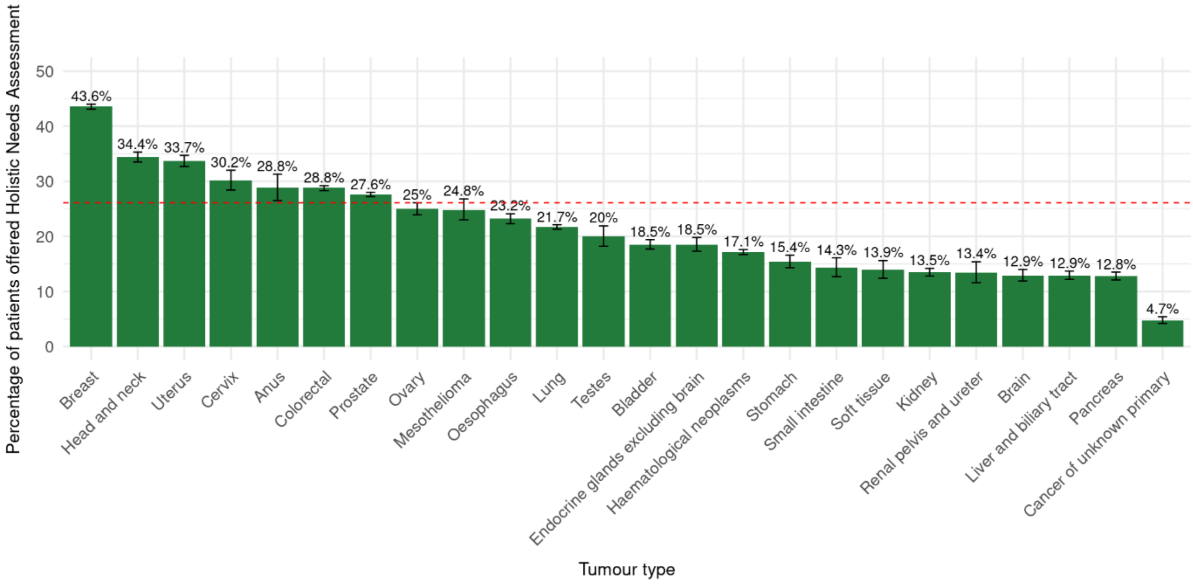

Figure 9. Proportion of patients with a record of being offered an HNA by tumour type

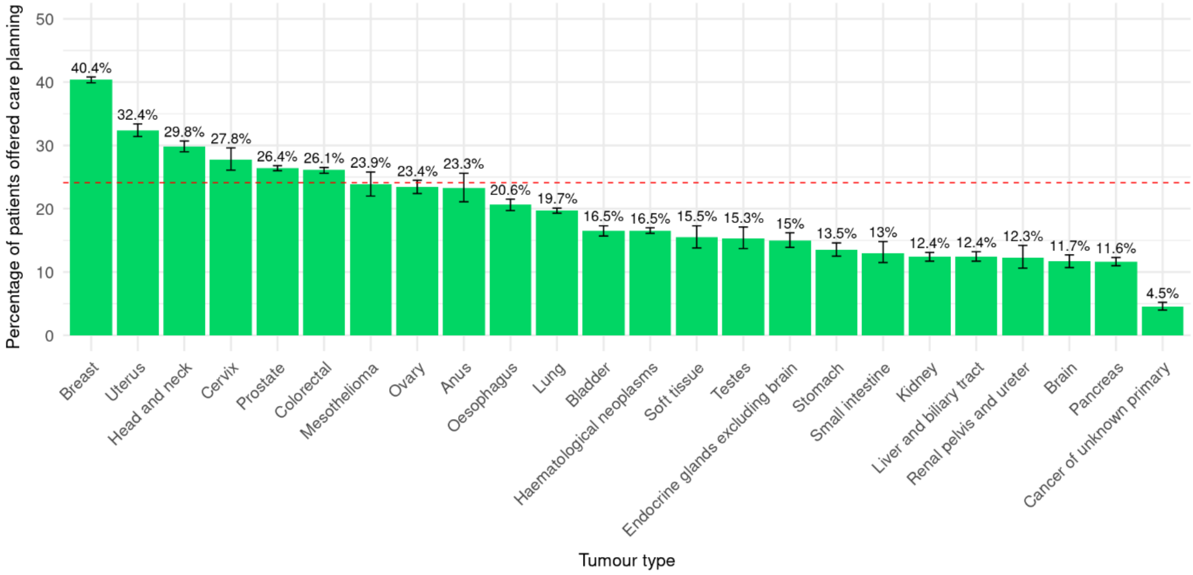

Figure 10. Proportion of patients with a record of being offered care planning by tumour type

Likelihood of being offered an HNA and/or care planning also varied by stage at diagnosis (Figure 11):

- Among patients with a known stage at diagnosis, those diagnosed at stage 4 were least likely to be offered an HNA (**22%**) or care planning (**19%**).
- Patients with missing stage information had similarly low proportions, with **16%** recorded as being offered an HNA and **15%** offered care planning.
- The lowest proportions overall were seen in those recorded as unstageable, with **11%** offered an HNA and **10%** offered care planning.
- In contrast, patients diagnosed at stage 2 had the highest proportions: **36%** were offered an HNA and **33%** were offered care planning.
- Stage 4, missing stage, and unstageable groups had significantly lower proportions of patients offered HNA and care planning compared with stages 1-3.

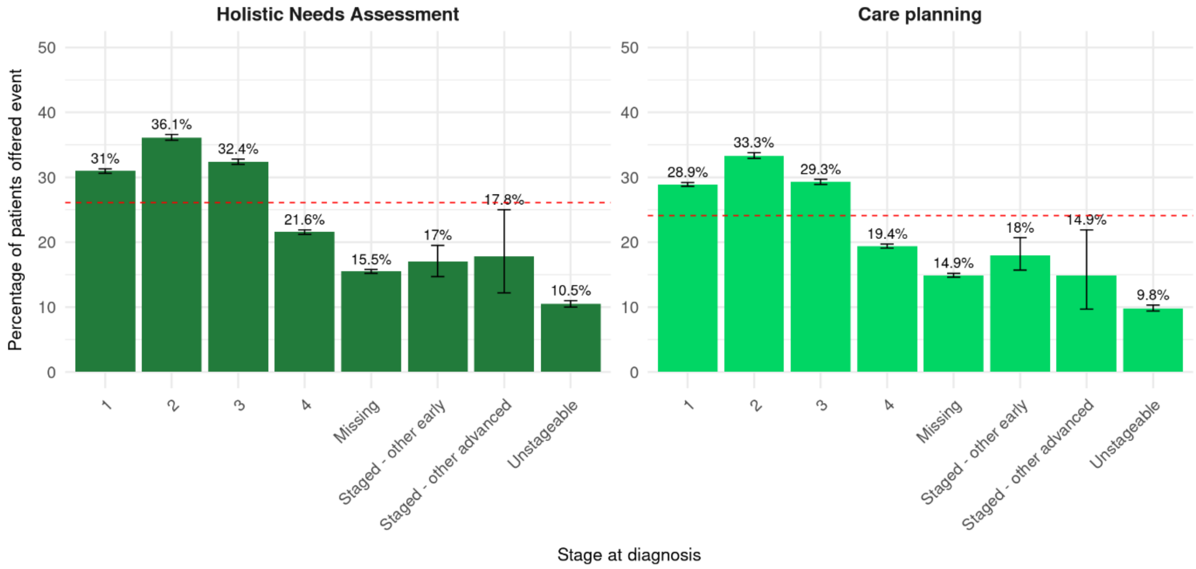

Figure 11. Proportion of patients with a record of being offered an HNA and care planning by stage at diagnosis

Those who died within 12 weeks of diagnosis were less likely to be offered HNAs and care planning, with a decreasing proportion for those with the shortest survival post-diagnosis, as shown in Figures 12 and 13. In these figures, each "*Died*" bar represents patients who survived through the previous time period then died in the measured time period. For example, the "*Died*" bar at 6 weeks includes patients who died between 4 and 6 weeks post-diagnosis.

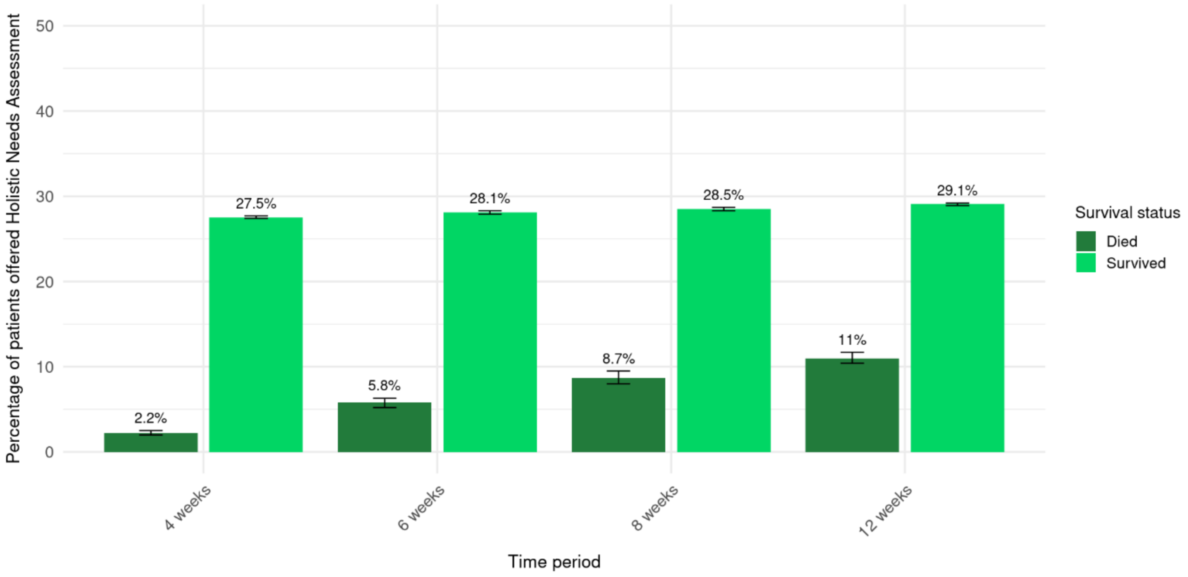

Figure 12. Proportion of patients with a record of being offered an HNA by survival status at each time-point post-diagnosis (conditional on survival to the previous time-point)

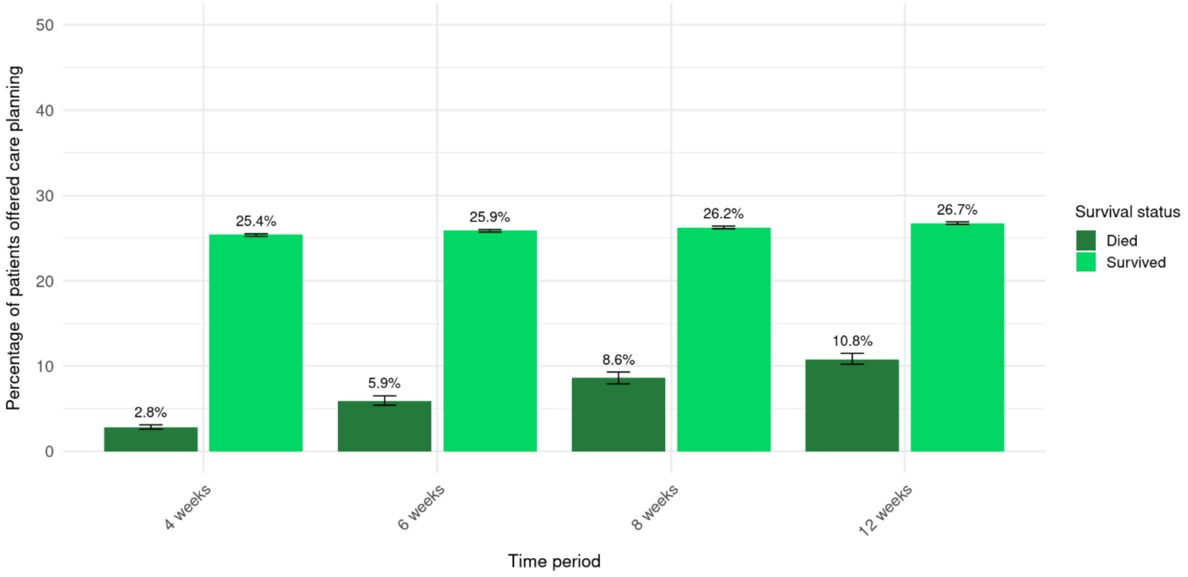

Figure 13. Proportion of patients with a record of being offered care planning by survival status at each time-point post-diagnosis (conditional on survival to the previous time-point)

Finally, there was significant **trust-level variation** of HNA and care planning coverage across England (Figures 14 and 15, respectively).

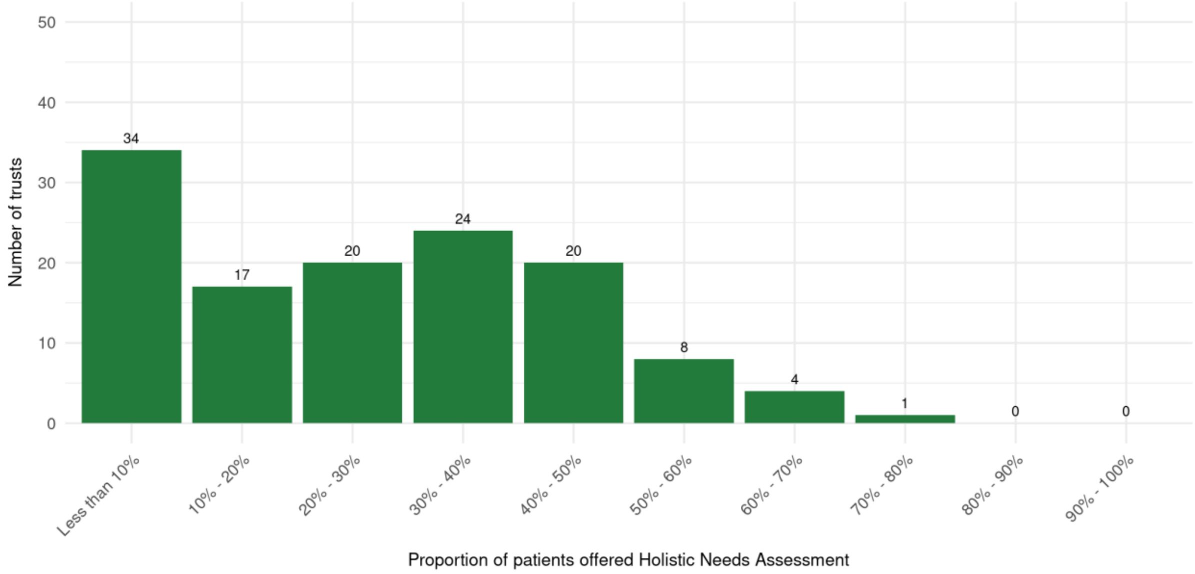

Figure 14. Count of trusts by proportion of patients being offered an HNA

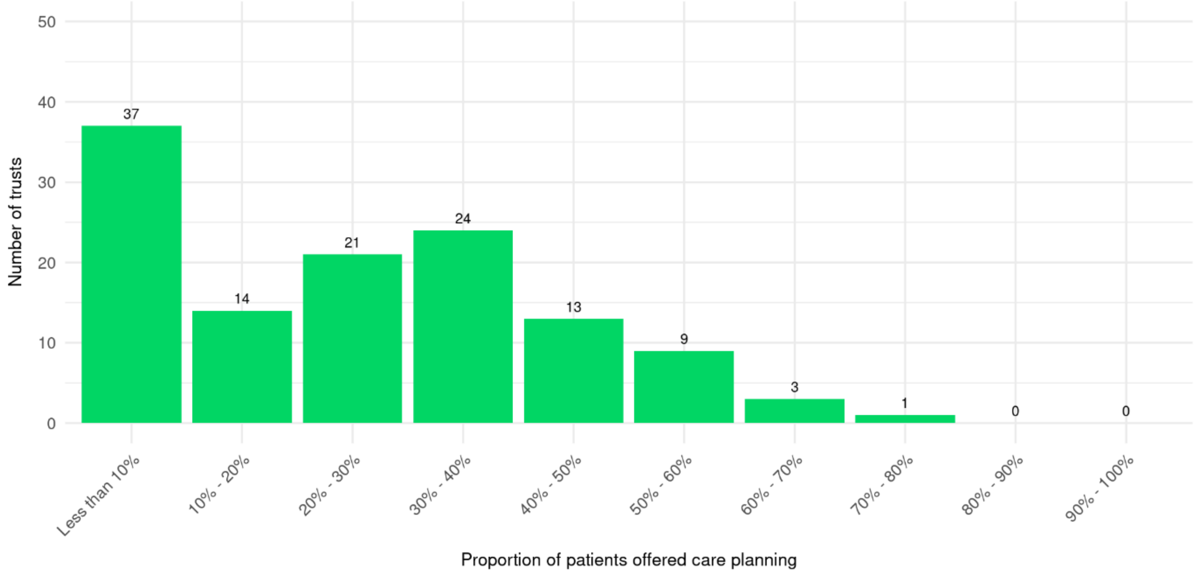

Figure 15. Count of trusts by proportion of patients being offered care planning

In all instances above, we were only able to examine the associations between being offered an HNA or care planning with individual characteristics in isolation. However, it is likely that some of these characteristics are interrelated. For example, certain cancer types are more likely to occur in specific age groups, or are more likely to be diagnosed at an early stage. We intend to examine these interrelationships in a separate, follow-up piece of work.

Discussion

This report describes the recording of the offer and provision of HNA and care planning as captured in COSD. The results are affected by data completeness, as not all trusts and cancer teams were capturing or submitting HNA or care planning data to COSD during the analysis period. Data quality may also have been affected by the COVID-19 pandemic. Where data was submitted, it is sometimes incomplete within COSD, including missing data on point of pathway and staff role. Work is ongoing to improve the flow of data to COSD from data collection platforms, including electronic data collection, and where it is collected on paper.

The analysis showed variation associated with cancer type and patient demographics.

Variation by cancer type:

- Patients with a poor prognosis were less likely to have a record of an offer of an HNA and care planning. This is reflected in the lower proportions observed among those diagnosed at stage 4, those who die soon after diagnosis, those with poor prognosis cancer types, and those in the oldest age groups.
- Patients diagnosed with common 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.

Variation by demographics:

- 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.

Variation by geography:

- Patients living in the most deprived areas had the highest recorded proportions of HNA and care planning offers. There was also significant variation in the recording of HNA and care planning offers across NHS trusts in England.

Conclusions

Despite acknowledged limitations in data collection and reporting, there is clear and statistically significant variation in who has a recorded offer of HNA and care planning in secondary care settings as part of cancer care in England. This variation should be explored further and discussed locally and nationally to determine if changes to how personalised care is provided are needed.

Continued improvements in the collection, analysis, and reporting of this dataset will be key to monitoring this observed variation and supporting ongoing improvements to service implementation.

For further discussion and recommendations please see the accompanying Macmillan report.

List of abbreviations

- COSD: Cancer Outcomes and Services Data set
- HNA: Holistic Needs Assessment
- NDRS: National Disease Registration Service
- NHS: National Health Service
- RCRD: Rapid Cancer Registration Dataset

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[i] NHS England. What is Personalised Care. 2024. Available from: www.england.nhs.uk/personalisedcare/what-is-personalised-care/#:~:text=Personalised%20care%20means%20people%20have,their%20individual%20strengths%20and%20needs

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

[iii] Macmillan Cancer Support. Holistic Needs Assessment (HNA). 2020. Available from: www.macmillan.org.uk/cancer-information-and-support/treatment/coping-with-treatment/holistic-needs-assessment-hna

[iv] Macmillan Cancer Support. Professionals: Holistic Needs Assessments. Available from: www.macmillan.org.uk/healthcare-professionals/innovation-in-cancer-care/holistic-needs-assessment

[v] NHS England. Cancer Outcomes and Services Data set (COSD). 2024. Available from: digital.nhs.uk/ndrs/data/data-sets/cosd#:~:text=The%20Cancer%20Outcomes%20and%20Services%20Data%20set%20(COSD)%20is%20a,other%20national%20cancer%20audit%20programmes

[vi] NHS England. Rapid Cancer Registration Data set (RCRD). 2024. Available from: digital.nhs.uk/ndrs/data/data-sets/rcrd

[vii] NHS England. Core - Clinical Nurse Specialist + Risk Factor Assessment (part of COSD user guide). 2023. Available from: digital.nhs.uk/ndrs/data/data-sets/cosd/cosd-v9.0-downloads