Macmillan electronic Holistic Needs Assessment (eHNA) platform: overview and analysis of 2023 data

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1. EXECUTIVE SUMMARY

Holistic needs assessments (HNAs) and care planning give people living with cancer a structured opportunity to identify, express and discuss their needs and concerns. These conversations support personalised care that addresses not only cancer-related needs but also wider physical, emotional and social challenges.

Every HNA and care plan recorded on the Macmillan electronic Holistic Needs Assessment (eHNA) Platform contributes to a detailed UK-wide dataset that documents how personalised care is delivered for people with cancer, which concerns are raised and how they are addressed by key workers. Analysing this dataset improves our understanding of who accesses HNA and care planning, how different population groups engage with the process and the variation in how the HNA and care planning process is operationalised in practice. It may also identify opportunities to strengthen care pathways for those with the highest needs and offer more targeted support.

This report describes the people receiving the HNA and care planning via the Macmillan eHNA platform, the organisations that deliver them, the process for setting up HNAs, the concerns submitted by service users and how these concerns are addressed. It also summarises the data governance and privacy protections that safeguard service users' information.

Key findings

In 2023 across the UK:

- Over 150 organisations contributed to the Macmillan eHNA dataset.
- 120,718 HNAs were set up for over 100,000 people.
- 63.6% of HNAs were completed and submitted. This mostly because the HNA was not accessed by the service user (43,294 set up HNAs) for example, because the service user died or was transferred to another organisation.
- 20.2% of people with a first HNA set up in January at diagnosis went on to have a second set up within the same year.
- Submitted HNAs contained more than 300,000 concerns recorded by service users:
    - 40.4% of submitted HNAs contained no recorded concerns
    - 24.7% recorded 5 or more concerns
    - 12.5% recorded 10 or more concerns
    - The mean number of concerns recorded was 4.0 for all submitted HNAs and 6.8 for HNAs submitted with at least 1 concern.
- Some concerns were frequently recorded across many groups, including:
    - *Worry, fear or anxiety*
    - *Tired, exhausted or fatigued*
    - *Money or finance*.

- Other concerns were more strongly associated with particular groups, for example:
    - *Memory or concentration* in people with brain or central nervous system tumours
    - *Hot flushes or sweating* among female service users
    - *Washing and dressing* for those in or transitioning to palliative care
    - *Feeling at odds with one's culture, beliefs or values* for service users from ethnically diverse communities
    - *Work or education* and *Money or finance* among people of working age
- Some less frequently reported concerns tended to be scored highly when present, including:
    - *Person who I look after*
    - *Person who looks after me*
    - *Taking care of others*
    - *Housing*
- Following HNA submissions:
    - Over 70,000 discussions about concerns were recorded
    - Around 50,000 Macmillan information sheets were shared with service users
    - More than 17,000 referrals were made for additional support or services. A common example is *Money or finance* concerns being referred to a specialist service.
- Concerns were more likely to have a corresponding action recorded by the key worker when they were scored higher relative to other concerns submitted. This reflects the recommendation to focus on a service user's most important concerns, and the platform's design to facilitate this.
- The platform has the capability to capture information relevant to understanding inequalities, such as ethnic group and gender diversity. However, incomplete recording of these fields, and the indirect contribution of service users in providing this information, limits the ability to draw robust conclusions about differences between population groups.
- Different types of organisations appear to play distinct roles in supporting people with cancer, varying in:
    - When they intervene along the care pathway
    - the types of concerns recorded
    - the actions recorded to address those concerns

The data shows both the scale of personalised care delivery and the variation in how people and systems engage with it across the UK.

While this report demonstrates the analytical potential of the dataset, it is important to recognise a range of inherent selection and systematic data biases that impact analysis:

- not all potential service users are offered HNA and care planning
- service users vary in how they engage with the process
- data recording varies geographically, across different organisations and service user profiles

The platform is primarily designed to support care delivery, rather than to capture a complete record of all HNA and care planning activity from offer through to outcome.

The dataset therefore represents a snapshot of concerns recorded at the point of submission, rather than a complete account of all needs experienced by people living with cancer. For example, a service user may not record a concern if it is already being addressed, or if they do not wish to discuss it. This does not imply an absence of need.

Additionally, HNA activity follows a staged pathway (set-up, submission, and follow-up actions or care plans), with attrition at each stage, meaning later-stage data reflects a progressively smaller and more engaged group.

Overall, the profile of recorded concerns should not be interpreted as a direct reflection of underlying need. However, it may provide an indication of broader patterns, particularly in relation to the most pressing concerns.

2. INTRODUCTION

Personalised care and support planning is a process to ensure patients' physical, practical, emotional, and social needs are identified and supported. A Holistic Needs Assessment (HNA) is a tool to help identify an individual's concerns and enable the development of a coproduced care and support plan via a meaningful conversation (care planning); a key part of providing personalised care[1]. Macmillan Cancer Support provides an electronic platform (the Macmillan eHNA Platform) for key workers such as healthcare professionals, social care workers, and community and third sector teams to facilitate and record each personalised care HNA and conversation. The electronic platform can be used to allow people living with cancer to complete the HNA on their own computer or phone. As well as supporting the provision of personalised care, the Macmillan eHNA Platform also enables analysis of an anonymised national dataset of the concerns recorded alongside the actions recommended through care planning.

POLITICAL CONTEXT

There are policy commitments to provide personalised care for people living with cancer through HNAs and care plans across the UK.

The Cancer Strategy for Scotland 2023-2033[2] foresees that people with cancer are at the heart of all decisions and actions involving them and are given the opportunity to co-design their own care plan. The Scottish Government has now rolled out the Improving the Cancer Journey (ICJ) service in partnership with Macmillan across Scotland through the Transforming Cancer Care programme. The provision of HNAs and care planning is embedded in this service model.

The Cancer Improvement Plan for NHS Wales 2023-2026[3], building on the Quality Statement for Cancer 2021, states that people affected by cancer should have the opportunity to discuss their health, beliefs, concerns and preferences to inform their individualised care and have these needs assessed at regular intervals (including living with and beyond cancer) and clearly documented.

The Cancer Strategy for Northern Ireland 2022-2032 outlines a commitment to offer all people with cancer a HNA, an appropriate care plan and provide signposts to relevant sources of help and support[4].

In England, the National Cancer Plan stated that "starting from 2026 and building on the success of Holistic Needs Assessments, we will offer every patient a personalised assessment of their needs at the point of diagnosis. Cancer patients will complete their needs assessment, often with the help of their clinical nurse specialist or with another member of their hospital or primary care team. This will inform their personal cancer plan – a complete support plan that covers not just their treatment, but also their wider physical and mental health needs and social needs, such as employment and financial support, much of which they will access through neighbourhood services." [5]

3. OVERVIEW OF HNA AND CARE PLANNING PROCESS

Personalised care is essential throughout the cancer pathway. This includes a structured intervention of a HNA, supported by a meaningful conversation and care planning. HNA and care planning can be offered or completed at any time in a cancer pathway. It is often triggered at a definitive part of a pathway, such as at diagnosis, a change in diagnosis, the end of treatment or the transition to palliative care. A person living with cancer should be able to request a HNA at any time. There are a range of HNA and care planning platforms available within the UK and the Macmillan eHNA dataset only includes records related to HNAs and care plans that were set up using the Macmillan eHNA Platform and a proportion of records imported from the InfoFlex system.

3.1 Setting up HNAs

Macmillan HNAs are set up on the MyCarePlan website by key workers whose organisation is a registered user of the platform. Organisations using the platform will assign their key workers to any number of distinct teams determined by their administrator. The teams often mirror the arrangement of cancer site-specific care teams, such as a skin team or a lung team. For large organisations such as NHS Trusts and Local Health Boards, teams can also be assigned to cover different care sites such as where multiple hospitals are managed by a single organisation. This practice enables larger organisations to manage the visibility and coordination of large numbers of HNAs more efficiently.

The set-up form completed by the key worker includes personal and clinical information alongside a patient identifier, most commonly NHS number in England and Wales, Community Health Index number in Scotland and Health and Care number in Northern Ireland. This is typically entered by the key worker at the point of setup, but some details can later be edited. An organisations' own system identifier can also be used, for instance for non-NHS organisations, although this will limit the ability to link to other HNA records. What is recorded at setup varies between organisations, as administrators can mandate certain fields including diagnosis, date of diagnosis and pathway stage.

HNAs can be set up for an individual or in bulk for a large patient list. The Macmillan eHNA Platform can be used to deliver a range of assessments and surveys, including assessments for quality of life and mental health conditions, but the analysis in this report focuses on assessments set up for the purpose of delivering personalised care for people with a cancer diagnosis, all of which are version of the Concerns Checklist[1,6].

Figure 1 shows the different status values that each HNA record can be assigned and how the status changes as the service user and key worker interact with it.

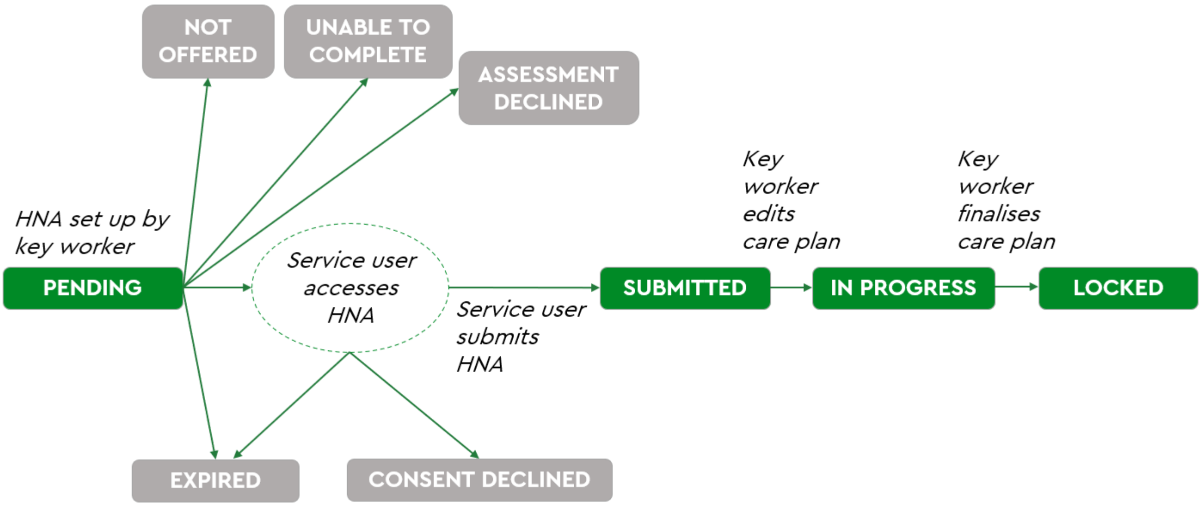

Figure 1. Flowchart illustrating the 9 status values attributed to HNA and care planning records in the Macmillan eHNA Platform and how they relate to the stages of HNA completion and care planning delivery. When a HNA and care planning record is set up it is given the status 'Pending' and assigned an expiry date. If this date is reached without the HNA having been submitted, then the status becomes 'Expired' and no further edits can occur. The successive stages of status required to reach a locked care plan are shown in green.

Of the 120,718 HNAs set up in 2023, 43,294 (35.9%) were not accessed by the service user (Figure 2). Among these, 2,827 (2.3%) HNAs were recorded as *Unable to complete* with the most common reasons for being unable to complete recorded as *Died before assessment/care plan* (22.4%), *Transferred to another organisation* (19.8%), *Imminent end of life* (9.4%) and *Lacks capacity* (9.2%). In 39.1% of HNAs recorded as *Unable to complete* there is no reason logged by the key worker. All these outcomes are still considered to be a legitimate offer of a HNA and care planning.

12,915 (10.7%) HNAs were recorded as *Assessment declined*, which is a value logged by the key worker after having already set up the HNA. A further 900 HNAs (0.7%) were logged as *Not offered*.

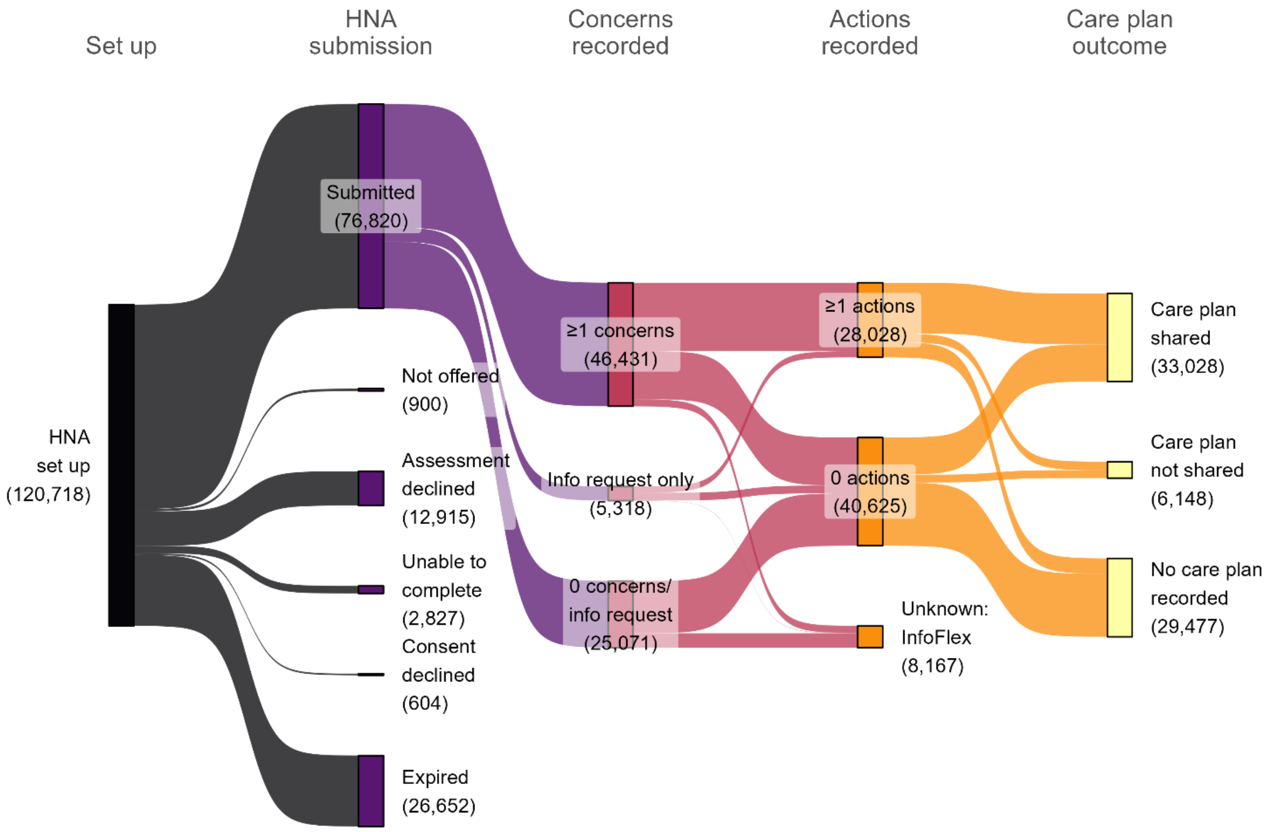

Figure 2. Sankey diagram illustrating the outcome of each of the 120,718 HNA and care planning records set up on the Macmillan eHNA Platform in 2023. HNAs for people with a main diagnosis recorded as something other than cancer are excluded.

3.2 Accessing HNAs

When a HNA is setup, the system generates an access code that the key worker can issue to the service user, allowing them to remotely complete the HNA online by themselves. It is also technically possible, though not advisable, for the key worker to input the HNA information into the Macmillan eHNA Platform following a face-to-face, virtual or telephone conversation, or after providing the service user with a paper version of the HNA form[6] to complete.

HNAs receive an expiry date at the point of set up, determined by the organisation. Once the expiry date is reached the HNA and care planning record expires and can no longer be submitted. This occurred for 26,652 HNAs set up in 2023, or 22.1% of all set up (Figure 2). The most common expiry period found amongst expired HNAs was the maximum the system allows which is 12 weeks (36.7% of expired HNAs set up in 2023), followed by 4 weeks (19.7%). The shortest expiry period found was 5 days, with 0.01% of expired HNAs using this period.

Before accessing the online HNA, users are shown a description of how their data will be used (see Appendix E). For organisations that choose to use consent as the legal basis for collecting and processing HNA and care planning data, users can choose to provide or decline their consent before proceeding. For organisations that prefer not to have consent as the legal basis, the user can still choose whether to proceed with the HNA. 604 (0.5%) HNAs set up in 2023 ended with the user declining consent (Figure 2).

3.3 Submitting HNAs

On accessing the HNA, service users are shown a list of concerns in the form of a checklist. The concerns are grouped into five domains - practical, emotional, religious and spiritual, family, and physical - with each domain presented on the screen one at a time. The service users are invited to identify anything from the list that has caused them concern recently and that they wish to discuss with a key worker. The service user is asked to score each of these concerns on a scale from 1 to 10, with 10 being the highest. Concerns cannot be recorded in an HNA without a score.

Additionally, most HNA types also ask a general question on if there are topics on which the user would like more information or support. These requests for more information are not considered 'concerns' for the purposes of this report as they are too non-specific and are not attributed a 1-10 score.

After selecting and scoring all relevant concerns, the HNA is complete, and the service user submits it on the Macmillan eHNA Platform. Of the 120,718 HNAs set up in 2023, 76,820 (63.6%) were submitted, with 60.4% of submitted HNAs including at least 1 concern. The platform also records a duration: the time spent between accessing the HNA and clicking the submit button.

3.4 Care planning

Through the online portal, key workers can view all HNAs that they have set up and review their statuses. The submitted HNAs are presented with a list of holistic concerns ranked by their score, from high to low. This ranked list is used to guide a therapeutic conversation with the service user to explore ways to address their holistic concerns. The agreed actions and care planning is recorded into the Macmillan eHNA Platform. The key worker can enter further detail on the concerns, assign a follow-up action or actions from a predetermined list, and add comments on any recorded action. This can be done with the service user or written up afterward.

Actions are intended to address the concern. There is no requirement for every concern to be addressed and typically the expectation is that the key worker and service user would focus on only a small number of the most pressing concerns in their conversation. Adding any information to a submitted HNA and care planning record will change the care plan status to *In progress*.

Once the therapeutic conversation has finished and no further information is to be recorded against the care plan, the key worker can lock the HNA and care planning record, which is the terminal status. It can also be saved, rather than locked, if, for instance the key worker plans to return to enter more information. The HNA and care planning status remains as *In progress* if it has been saved but not yet locked. Sometimes HNA and care planning records are not locked because care planning is done in an alternative system such as Infoflex or Trakcare.

Once locked the care plan can be printed or shared electronically with the patient, attached into the electronic patient record, or shared with a care practitioner such as their GP where the data sharing agreements are in place. The locked care plan can contain information regarding concerns that were recorded, actions agreed in the discussion between the key worker and service user and a summary of the conversation that took place.

3.5 Considerations of systematic bias in the data

As is typical with real-world datasets, a range of biases influence what becomes recorded and consequently how analysis of data should be interpreted. Within the HNA and care planning process there are three key events that prompt data to be recorded on the eHNA Platform: the setting up of HNAs, the submission of an HNA including all scored concerns and the therapeutic conversation that subsequently takes place with the key worker leading to the formation of a care plan. These events occur sequentially and represent recorded proxies for a wider real-world process, rather than true start and end points.

Any systematic bias introduced earlier in the process is unavoidably propagated through the later stages of recorded data. For example, if a demographic group appears underrepresented within HNAs set up on the platform, then this underrepresentation will shape the observed patterns of concerns submitted for this group and the care plan outcomes that occur downstream.

Furthermore, although the platform is structured to capture activity occurring at these three key events, it is designed primarily to enable the delivery of care and support by key workers for the immediate benefit of service users. It should not be expected that these records represent a complete picture of all formal and informal HNA and care planning activity that has occurred. Given time and capacity constraints under which many key workers operate, under-recording is likely for some types of activity. Collectively these factors limit the extent to which the recorded data can be considered a complete account of individuals' experiences within the HNA and care planning process.

Listed below are some of the key biases for consideration when interpreting statistics produced from the Macmillan eHNA Platform. These can be broadly classified as: selection biases, which influence which population groups are featured in the dataset; attritional biases, which influences which groups remain represented throughout the HNA and care planning process; and recording biases, which influence what does and does not get recorded by key workers within the platform.

This report does not evaluate the scale or frequency of these biases, nor does it propose specific methodological approaches to guide interpretation, but instead offers caution in over-generalising from conclusions drawn from the data. This includes caution when interpreting patterns of recorded concerns as direct reflections of underlying patterns of need within the population, as these are related but not equivalent concepts.

Gatekeeping bias

Key workers' perception of who should be offered an HNA can influence who has an HNA set up on the system. This may reflect judgements - conscious or unconscious - that HNAs are inappropriate for those who are most acutely unwell or unnecessary for the most healthy and well-presenting. Other perceived social or behavioural factors may influence whether an individual is likely to benefit from HNA and care planning. Systemic biases such as racism and sexism are also understood to play a role in who is offered support in a healthcare context[7].

The extent of gatekeeping bias is likely to vary across the UK, with some services offering HNAs universally such as via automated SMS invitations following a diagnosis, and others adopting more selective approaches.

Structural bias

The organisation of local health and social care systems determine when, where, why and how HNA and care planning opportunities arise[8]. Within secondary healthcare organisations, variation in volume of HNAs recorded and the points along the care pathway at which they occur is influenced by local priorities set by trusts, as well as workforce capacity constraints felt by care teams. A study linking HNA records to cancer registry records in Scotland outlined differences in local process leading to HNA referral[9]. In some areas a full pathological diagnosis was required before HNA offer took place while in others the cancer had been established but was still being investigated.

In addition, alternative platforms exist for delivering HNAs and care planning, meaning that the activity recorded in the Macmillan eHNA Platform will be determined by which organisations choose to adopt it.

The modes of HNA delivery (e.g. paper, telephone, virtual) and who delivers them (e.g. specialist cancer nurses, support workers, allied health professional) also vary between organisations, as do training, workflows and the types of concerns they are specialised in addressing. Teams under the greatest operational pressure may be less able to engage fully with the process than better-resourced teams. As a result, the service users potentially at most at risk of poorer personalised care experience may also be less well represented within the Macmillan eHNA data.

These represent a wide range of contexts that can lead to the HNA and care planning process being implemented, all of which can influence who receives the offer and also the nature of what gets recorded.

Survival bias

Service users who die a short time after their cancer diagnosis are less likely to have an HNA set up for them or have had the opportunity to submit one[10].

While HNA and care planning may continue along the cancer pathway, at each successive stage the composition of the cancer population changes. As time from diagnosis increases, the services users represented in the dataset may become progressively less representative of the cancer incidence population. Studies examining the representativeness of people offered an HNA in England found that those with low survival cancer types - such as pancreas, liver, brain and kidney cancers - were less well represented in HNA records[10].

Access bias

Service users who feel less comfortable using digital technology, or who have reduced access to appropriate devices or reliable internet connections, may be less likely to submit their HNA where only digital options are offered[11].

Language barriers or other communication challenges may also influence the likelihood that an HNA is set up, completed or followed by a therapeutic conversation.

Participation bias

Completing and submitting an HNA may require a minimum level of physical, emotional and cognitive capacity. As a result, some services users who might otherwise have benefitted from HNA and care planning may be prevented from engaging with the process if they are suffering from acute symptoms or other functional impairments at the time of the offer.

Those with poorer health literacy may undervalue engagement with the HNA and care planning process.

Survey fatigue

Service users who are exposed to multiple forms, questionnaires or surveys related to their cancer diagnosis or wider care, may feel fatigued by repeat data collection requests. This may reduce motivation to engage with yet another process, even if they would otherwise have much to gain form HNA and care planning.

Differing levels of trust felt towards sharing personal information with the health system may also create inequitable engagement with the HNA and care planning process.

Differential measurement bias

Some HNA fields, for example setting, can be recorded when the HNA is setup and also edited by the key worker later in the process based on new information. As a result, the same recorded value can different meanings depending on when it was captured. In some cases, the presence of a value may imply a greater likelihood of the HNA having been submitted, introducing non-equivalence in how data values are measured across records.

Missing-not-at-random (MNAR) effects

Several data fields within the platform are discretionary, meaning that their presence or absence in the dataset is influenced by factors relating to the service user, key worker, the organisation offering HNA and care planning and the local service context. Consequently, missingness is likely to be non-random and the absence of a value may reflect an artifact of the operational process rather than variation due to chance.

For example, a service user's clinical or demographic information may be left blank until they submit an HNA, at which point the service user endeavours to complete the information. Analysing demographics without accounting for how far an HNA progressed may then give a misleading description of the population.

Response bias

Research suggests that some patient groups may underreport types of concerns, for example due to stigma, stoicism, perceived burden on services or a desire to manage independently[12,13]. Previous negative experiences with the health and care system may also shape an individual's expectations of whether their needs will be met. In the context of HNAs, this may manifest as a reluctance to engage with the process, fewer concerns being reported or lower scores being assigned to their recorded concerns.

The mode and context of the HNA offer could also influence response behaviour. For example, completing an HNA at home may make it easier for some individuals to recording sensitive concerns compared with completing the HNA jointly with a key worker in a clinical setting.

Acquiescence bias

Expectations around how service users or key workers 'should' engage with the process can influence recording behaviour. Some service users may feel obliged to complete an HNA even if they have no concerns to record or may enter scores for all concerns rather than only those most affecting. Similarly key workers may be more included to systematically set ups HNAs, complete non-mandatory fields, or to record outcomes for all submissions if they perceive this as expected practice.

3.6 Examples of HNA trajectories

There are many ways that patients can traverse the HNA and care planning pipeline, from offer through to care plan. Some example trajectories are illustrated below from the perspective of the data recorded.

Example 1 (Figure 3). Service user had an HNA set up on the Macmillan eHNA Platform, but it expired before it was submitted. This occurred 26,652 times in 2023, or in 22.1% of all HNAs set up.

We cannot infer why it was not submitted, since no further data is recorded after setup, and there are several theoretical determinants:

- The service user may have died before accessing the HNA, with the organisation forgoing the option of recording this death in the Macmillan eHNA Platform.
- The service user may have wanted to complete the HNA but been unable to access it.
- The service user may be unaware that the HNA had been set up for them to complete, not been given the necessary information to access it or not sufficiently understood what was being offered to feel inclined to access it, including as a result of a language barrier or a misinterpretation of the invitation wording.
- The service user may have actively decided not to access the HNA, either because they felt they did not need the support it offered, were not comfortable sharing their information or otherwise expected to find the HNA process difficult or not worth their time.

We might be tempted to infer that these service users did not have needs that could have been met through HNA/care planning, but this is unevidenced and we cannot know that concerns would not have been recorded had an HNA been accessed and submitted. HNAs that expire thus represent a diverse range of possible personal circumstances, needs, perceptions and system practices.

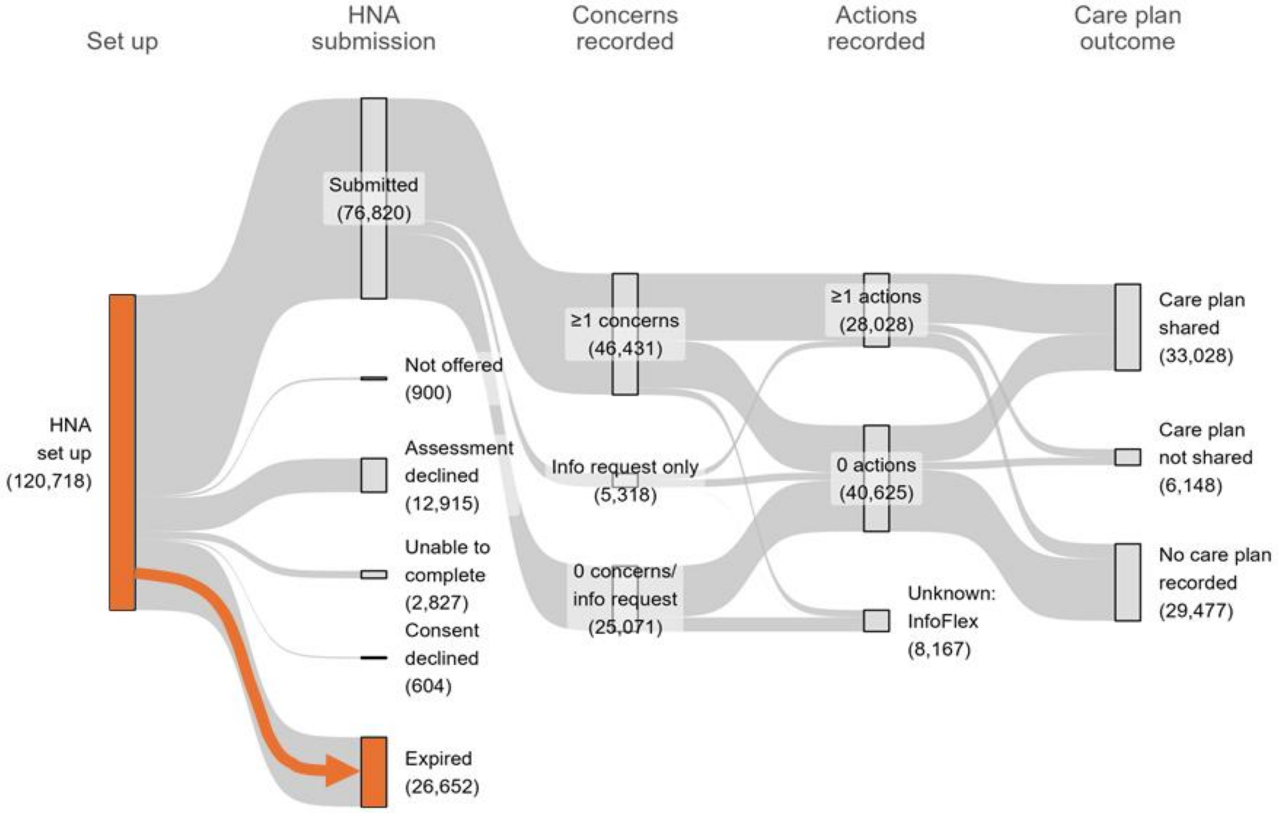

Figure 3. Example 1: Sankey diagram illustrating HNA and care planning records that expired (orange). Shown in the context of all HNA and care plan records set up on the Macmillan eHNA Platform in 2023 (grey). HNAs for people with a main diagnosis recorded as something other than cancer are excluded.

Example 2 (Figure 4). Service user submits the HNA but does not record any concerns or requests for information. No actions are recorded by the key worker and there is no record of a care plan being shared. This occurred 30,389 times in 2023, or in 25.5% of all HNAs set up and 39.6% of all submitted HNAs.

Although we could infer that these service users had no concerns to raise and thus could not be supported by the process, the frequency of this occurrence is implausibly high.

Some HNAs are conducted very quickly and the extent that the patient considered all their answers is variable. In some instances, the key worker may have been able to quickly add HNA information into the Macmillan eHNA Platform following a longer discussion or completion of a paper HNA where no concerns were expressed. However, in some instances the key worker may have submitted the assessment with no concerns on behalf of the service user and with limited input from the service user. This could happen when capacity or workforce constraints limit the quality of the personalised care offer while the need to record HNA and care planning activity statistics has been mandated.

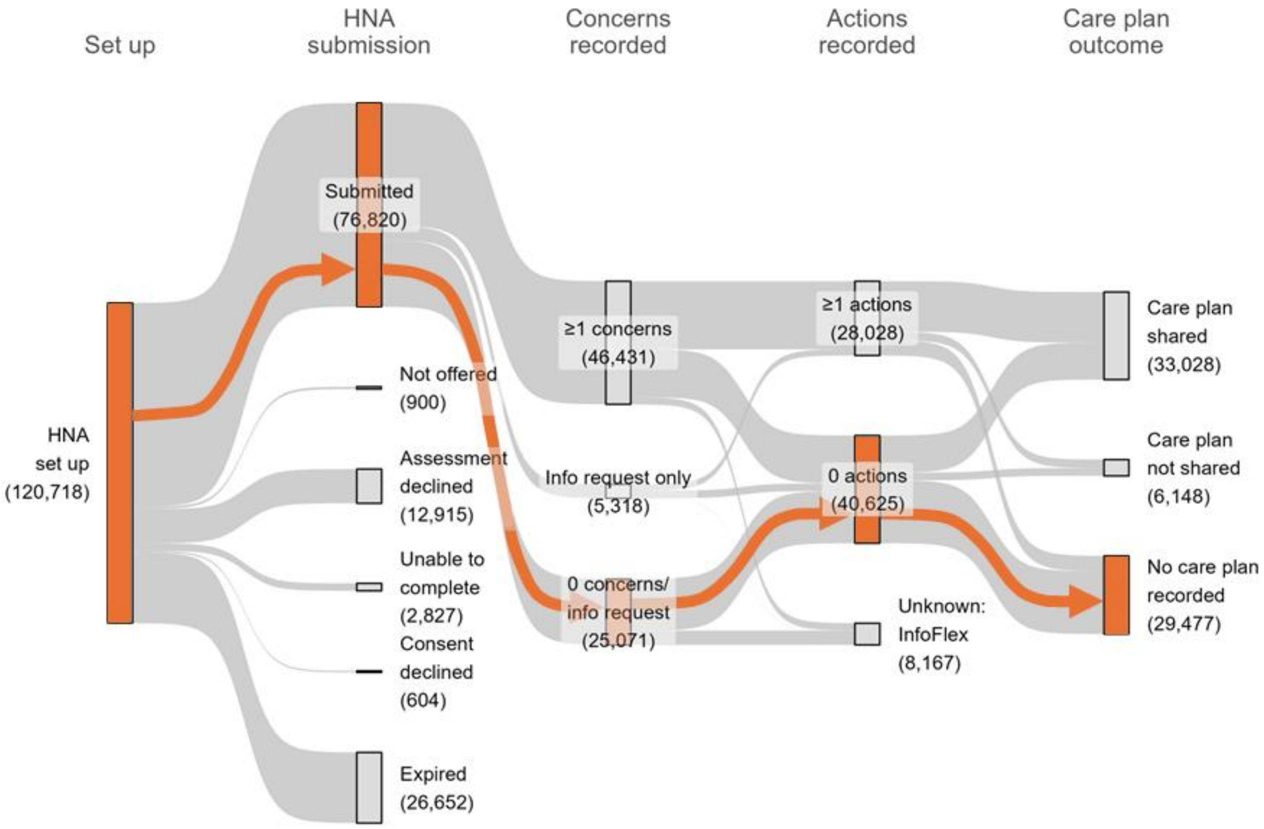

Figure 4. Example 2: Sankey diagram illustrating HNA and care planning records where an HNA was submitted by service users with no recorded concerns, resulting in no actions recorded by key workers and no records of care plans being shared (orange). Shown in the context of all HNA and care plan records set up on the Macmillan eHNA Platform in 2023 (grey). HNAs for people with a main diagnosis recorded as something other than cancer are excluded.

Example 3 (Figure 5). Patient submits the HNA with several concerns recorded, via the InfoFlex platform.

Records imported to the eHNA data system from InfoFlex do not contain the same wealth of information as native records created within the Macmillan eHNA Platform. Consequently, while we can be confident that the HNA has been engaged with and concerns submitted by the service user, we know nothing about the outcomes of these HNAs, such as whether a care plan was shared or any specific actions taken to address the concerns.

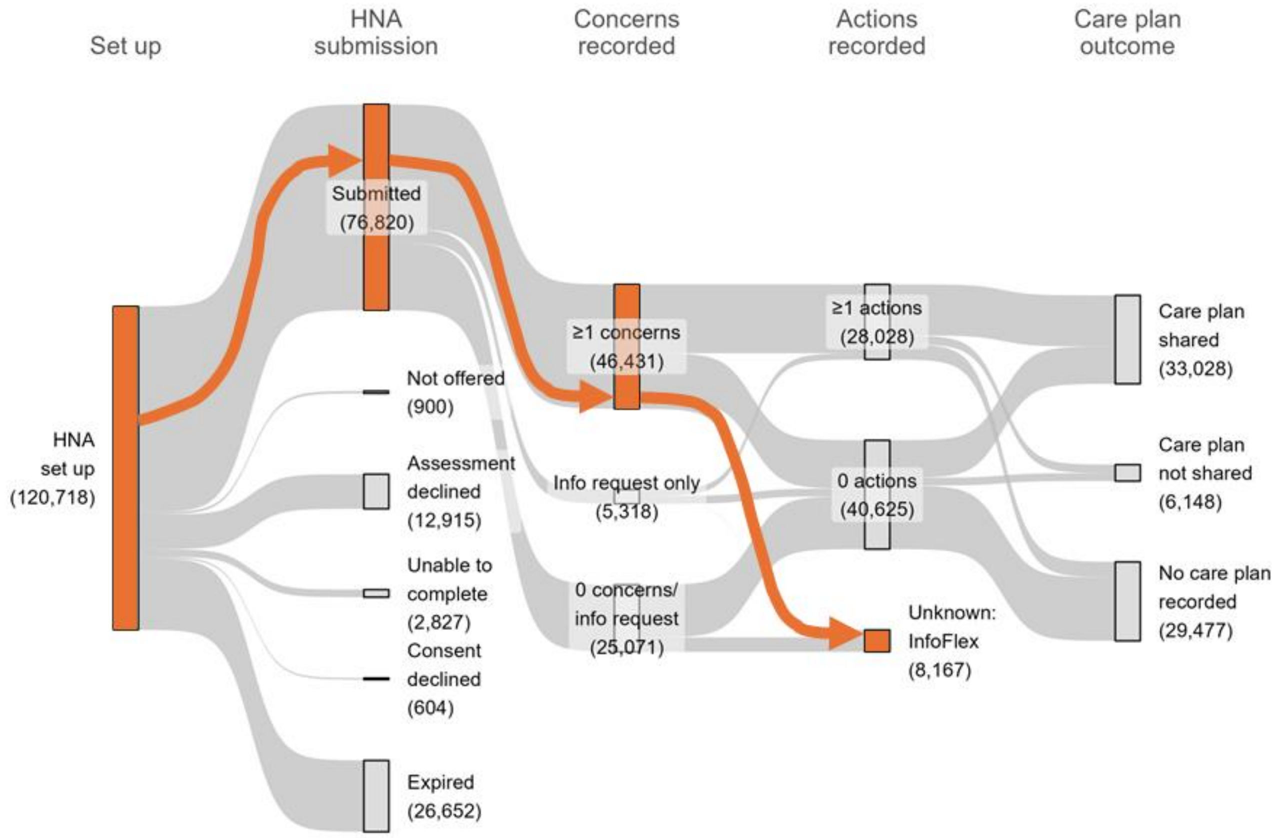

Figure 5. Example 3: Sankey diagram illustrating HNA and care planning records where an HNA was submitted with one or more concerns via an organisation using InfoFlex (orange). Shown in the context of all HNA and care plan records set up on the Macmillan eHNA Platform in 2023 (grey). HNAs for people with a main diagnosis recorded as something other than cancer are excluded.

Example 4 (Figure 6). Service user submitted the HNA with at least one concern and as a result had a therapeutic conversation with the key worker that aimed to address these concerns. The HNA and care planning record contains at least one recorded action summarised in a care plan. With the service users' consent a copy of the care plan was shared with the service user and care professionals.

This service user has completed the full HNA and care planning pathway and is in the best position to benefit from the process. This happened for 17,923 of HNA and care planning records in 2023, 10% of all those set up. A further 2,872 HNAs and care plans completed the process, but the choice was made not to share the care plan.

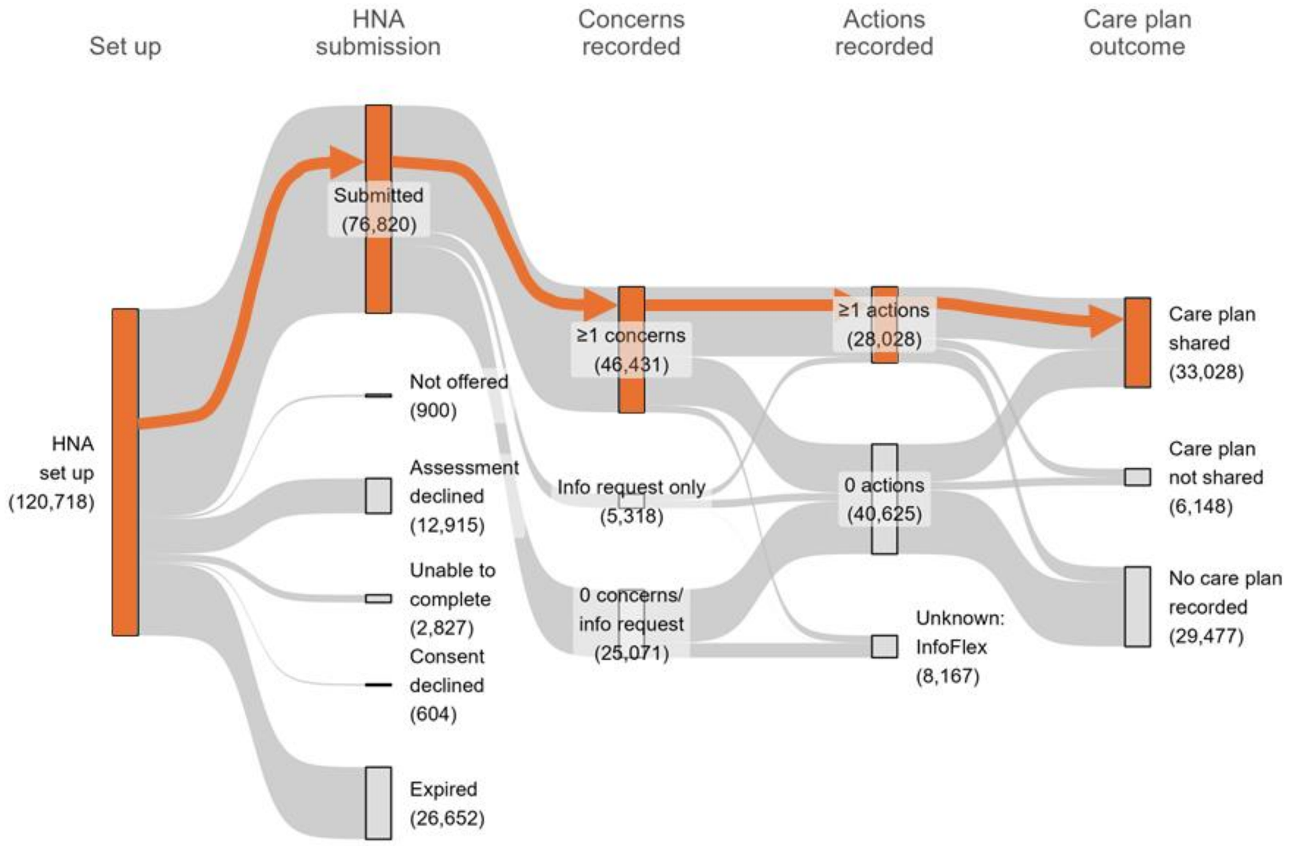

Figure 6. Example 4: Sankey diagram illustrating HNA and care planning records where an HNA was submitted with one or more concerns, which led to the key worker recording one or more actions and with a record of a care plan being shared (orange). Shown in the context of all HNA and care plan records set up on the Macmillan eHNA Platform in 2023 (grey). HNAs for people with a main diagnosis recorded as something other than cancer are excluded.

3.7 Data security, privacy, and access

All data collected within the Macmillan eHNA Platform is stored and processed by HealthUnlocked under contract to deliver the eHNA Platform for Macmillan Cancer Support[i]. All data is held in compliance with the NHS requirements in all four nations.

Each organisation using the platform to administer Macmillan HNAs and care planning is acting as sole controller for the data it places on the platform and has full access to that data. Each organisation is responsible for any subsequent use it makes of its own data. By default, all reporting is non-identifiable, although users nominated within each organisation can produce reports including identifiers.

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[i] HealthUnlocked is part of Thermo Fisher. Thermo Fisher never see or has any access to the data. HealthUnlocked exceed the requirements of the Data Security and Protection Toolkit (required by the NHS in England) and have full Cyber Essentials Plus compliance (required by the NHS in Wales). Macmillan also audit their compliance annually.

Organisations can also sometimes share the identifiable data with others for research. For example, as part of the Macmillan-Public Health Scotland partnership[14], Public Health Scotland received identifiable Macmillan eHNA data from three Scotland Improving the Cancer Journey areas and linked it using CHI numbers to the national health datasets in Scotland[9]. This was under data protection impact assessment and appropriate information governance processes for each area. In addition, NHS organisations in England can share identifiable extracts from the platform into electronic health record system (such as InfoFlex, Summary Care Records and Epic) and then into the Cancer Outcomes and Services Data set (COSD). COSD is the national standard for collecting cancer data in the NHS and is managed by the National Disease Registration Service (NDRS) currently within NHS England. This data is described by Macmillan and NDRS in *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* report[10].

Anonymised data extracts are provided to Macmillan by HealthUnlocked for reporting and research purposes. All personally identifiable elements are redacted including patient identifiers, secondary identifiers, names and free text, with dates of birth replaced with age at HNA. Macmillan receives a randomly generated 32-character string (GUID) in place of the patient identifier, which can link multiple HNAs by the same person.

Organisations that are using InfoFlex rather than the Macmillan platform eHNA to capture the outcomes of HNAs can use an interface to share their data with Macmillan, in a non-identifiable form.

4. ANALYSIS OF HNAS SET UP

There were 120,718 HNAs set up using the Macmillan system in 2023, by 152 organisations across the UK and by 996 different teams within these organisations. These HNAs were set up for at least 107,156 people, with 95,847 (89.4%) recorded as having a single assessment set up for them within 2023 and 11,309 (10.6%) having 2 or more.

Dozens of additional fields are recorded against HNA and care planning records, describing information related to the service user's personal and clinical circumstances and the organisation offering or delivering HNA and care planning. Below is a list of some of the more informative or meaningful fields, with some descriptive analysis of HNAs set up on the platform in 2023. A more detailed view is included within Appendix A.

4.1 Organisation type

The organisation type is defined by the organisation when they become a registered user of the Macmillan eHNA Platform. 106,500 (88.2%) HNAs were set up by secondary healthcare organisations using the Macmillan eHNA Platform, with a further 8,996 (7.5%)

HNAs coming from secondary healthcare organisations that use the InfoFlex platform. The remaining 5,222 (4.3%) HNAs were set up by a combination of social care, community, third sector and other healthcare organisations (Table 1). There were 113 different secondary healthcare organisations setting up at least one HNA, while all other organisation types refer to between one and ten distinct organisations.

As noted in section 4.3, key workers delivering HNA and care planning for a healthcare organisation may not themselves have a healthcare-related role.

77.9% of secondary healthcare organisations had more than one team set up HNAs in 2023, with an average of 8.0 teams per organisation. The largest number of teams for a single organisation was 41, which was for an acute NHS Trust in England that managed multiple hospitals and assigned teams to different care specialists such as 'Breast', 'Colorectal and 'Gynae'.

Organisation type	Number of HNAs set up in 2023	% of total HNAs set up in 2023	Number of organisations	Number of teams	Number of organisations with >1 team
Healthcare - secondary	106,500	88.2%	113	908	88
InfoFlex	8,996	7.5%	4	4	0
Social care	2,407	2.0%	5	15	2
Healthcare - community	1,137	0.94%	9	22	3
Support group	821	0.68%	1	2	1
Healthcare - private	575	0.48%	7	24	4
Healthcare - primary	122	0.10%	8	14	2
Macmillan - service	80	<0.1%	1	2	1
Other third sector	77	<0.1%	2	2	0
Other	2	<0.1%	1	2	1
Healthcare - hospice	1	<0.1%	1	1	0
Total	**120,718**	**100%**	**152**	**996**	**102**

Table 1. Organisation types setting up HNA and care planning records in 2023. All figures refer to HNAs set up in 2023. Organisations or teams that are registered users of the platform but did not set up HNAs in 2023 are not counted.

152 organisations set up at least one HNA in 2023. 114 set up at least 50, 62 set up at least 500 and 41 set up more than 1,000 HNAs. When ranked by number of HNAs set up, the top 35 organisations are all secondary healthcare organisations using either the Macmillan eHNA platform or InfoFlex.

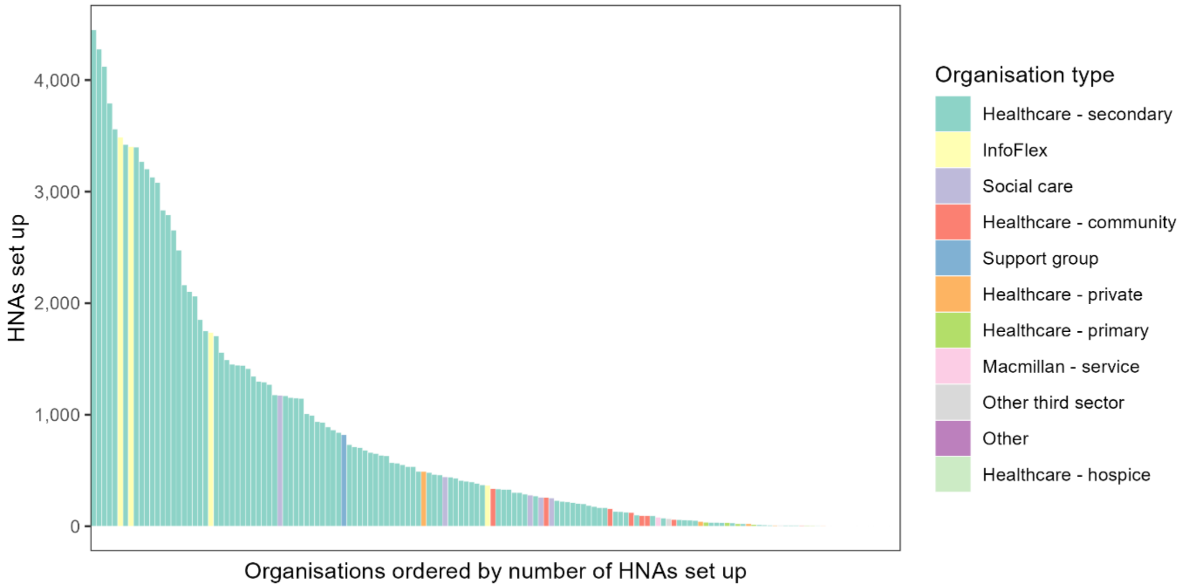


Figure 7. Variation in the number of HNAs set up in 2023 by different organisations and organisation types

A relatively small number of organisations account for a large share of HNA activity (Figure 8).

- 43.3% of HNAs were set up by 9.9% of organisations
- 74.1% of HNAs were set up by 25% of organisations
- 94.0% of HNAs were set up by 50% or organisations

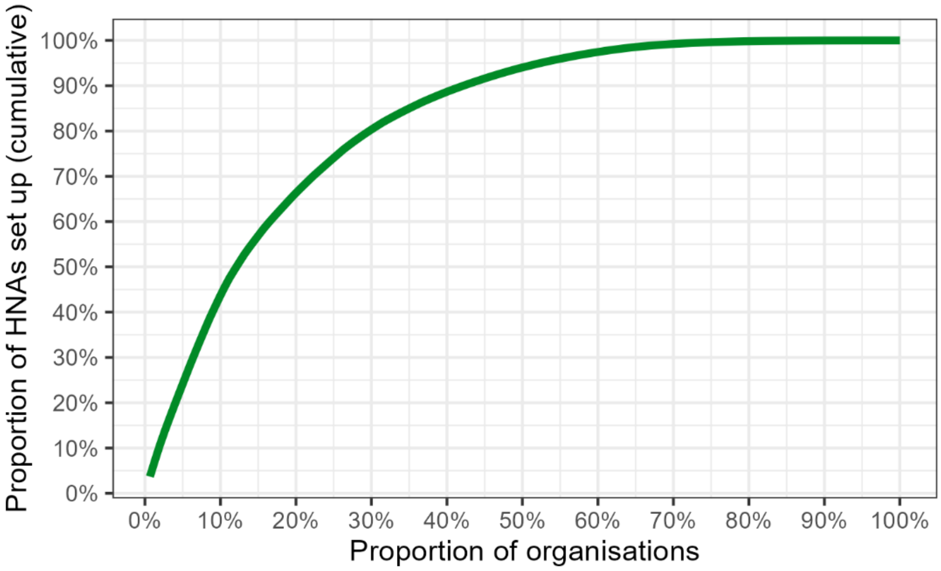


Figure 8. Cumulative distribution of HNAs set up across organisations, ordered from highest to lowest contributors

4.2 Region

Each organisation using the platform has a region assigned based on the address of the organisation and which is independent of residency locations of the service users. These regions are based on operational territories used by Macmillan Cancer Support rather than publicly recognisable geographic areas and so do not align to health or population statistics in public reporting. The variation in the relative number of HNA records across different parts of the UK is partly driven by the relative usage of the Macmillan eHNA Platform over alternative platforms.

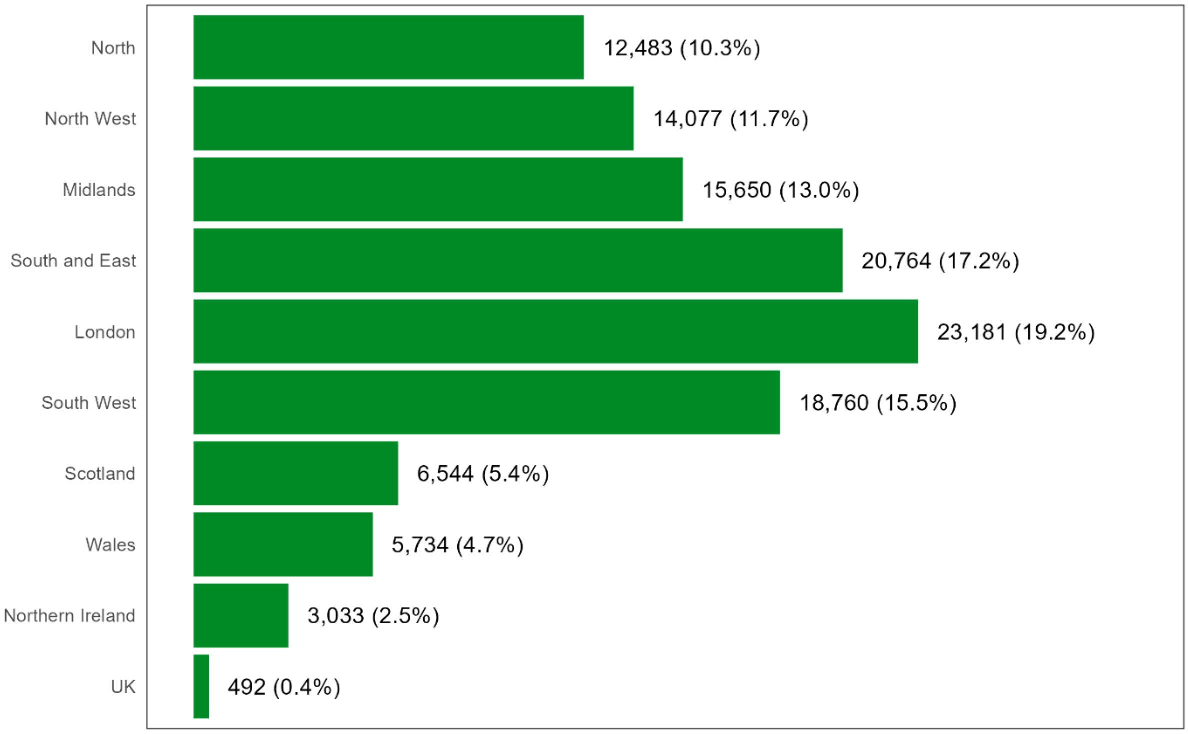


Figure 9. HNA set up by region. The region boundaries are defined based on Macmillan definitions and based on the location of organisations. The UK is used for an organisation that works across the UK.

Although the platform is designed to enable HNAs to take place across the cancer pathway, comparing the numbers of HNAs to national cancer incidence statistics allows a proxy per capita measure. This shows that while the ratio of HNAs set up to new cases of cancer diagnosed is similar between England, Wales, and Northern Ireland, it is lower in Scotland. The lower rate in Scotland is likely an artifact of the differences in the cancer care planning process compared to the other UK nations as well as the number of services actively using the eHNA Platform. In Scotland, many HNAs are delivered through specialised Improving the Cancer Journey (ICJ) services which follow a distinct referral pathway not often used elsewhere in the UK[15,16,17]. Under this model service some users are contacted by letter upon diagnosis and informed about the opportunity of an HNA, but the HNA set up only goes ahead if the person proactively contacts the ICJ team to request it. This opt-in approach introduces a degree of selection bias and may contribute to the lower uptake of HNAs seen in Scotland, compared with other regions where the offer is more commonly, although not always, made in person within a conversation.

	People with at least 1 HNA set up (2023)	Cancer incidence	People with an HNA set up per 100 diagnoses
England	88,968	354,820 (2023)[22]	25.1
Scotland	5,496	37,202 (2023)[18]	14.8
Wales	5,156	21,006 (2022)[19]	24.5
Northern Ireland	2,587	10,856 (2022)[20]	23.8

Table 2. Comparison of HNAs set up with cancer incidence. Based on HNA records with a recorded malignancy excluding non-melanoma skin cancer (ICD-10 C00-C97, excluding C44) or where no diagnosis code is recorded. Patient IDs are counted once only. Comparative incidence figures are based on all malignancies excluding non-melanoma skin cancer (ICD-10 C00-C97, excluding C44).

Variation in HNAs set up between England regions highlights the different levels of eHNA uptake across the country (Table 3). The longstanding eHNA partnerships held with large London hospital trusts is reflected in 20.2% of HNAs in England being set up by London organisations, compared to approximately 12.7% of England's cancers being diagnosed by London-based organisations in the same year. In comparison, 11.5% of HNAs in England were set up by organisations in the North region, while they diagnosed approximately 16.7% of England's cancers.

Region	HNAs set up in 2023 (% of England total)	Number of cancer cases by Diagnosis Trust in 2023 (% of England)[21]
North	11,476 (11.5%)	57,213 (16.7%)
North West	13,570 (13.6%)	45,054 (13.1%)
Midlands	14,131 (14.1%)	62,361 (18.1%)
London	20,169 (20.2%)	43,632 (12.7%)
South and East	22,306 (22.3%)	70,461 (20.5%)
South West	18,366 (18.4%)	64,866 (18.9%)
England	100,018 (100.0%)	343,587 (100.0%)

Table 3. Comparison of HNAs set up with estimates of cancer cases diagnosed by Diagnosis Trust. Based on HNA records with a recorded malignancy excluding non-melanoma skin cancer (ICD-10 C00-C97, excluding C44) or where no diagnosis code is recorded. Comparative incidence figures are based on all malignancies excluding non-melanoma skin cancer (ICD-10 C00-C97, excluding C44). Cancer case numbers are based on NDRS algorithm assigning each diagnosis to a single acute NHS Trust, with some exclusions such as diagnoses at small specialist centres. Total number of cases in this table will not match the sum of published cancer incidence due to differing methodologies.

There is geographic variation in the proportions of HNAs set up by different organisation types. This reflects the operation of specific programmes and partnerships aiming to empower non-secondary healthcare organisations to support people with cancer in targeted local areas. This includes the Improving the Cancer Journey (ICJ) programme in Scotland, Cancer Support Yorkshire in Bradford and Self-Help UK in Nottinghamshire. ICJ teams are based in both secondary healthcare and social care organisations and 74% of HNAs in Scotland were set up by an ICJ team.

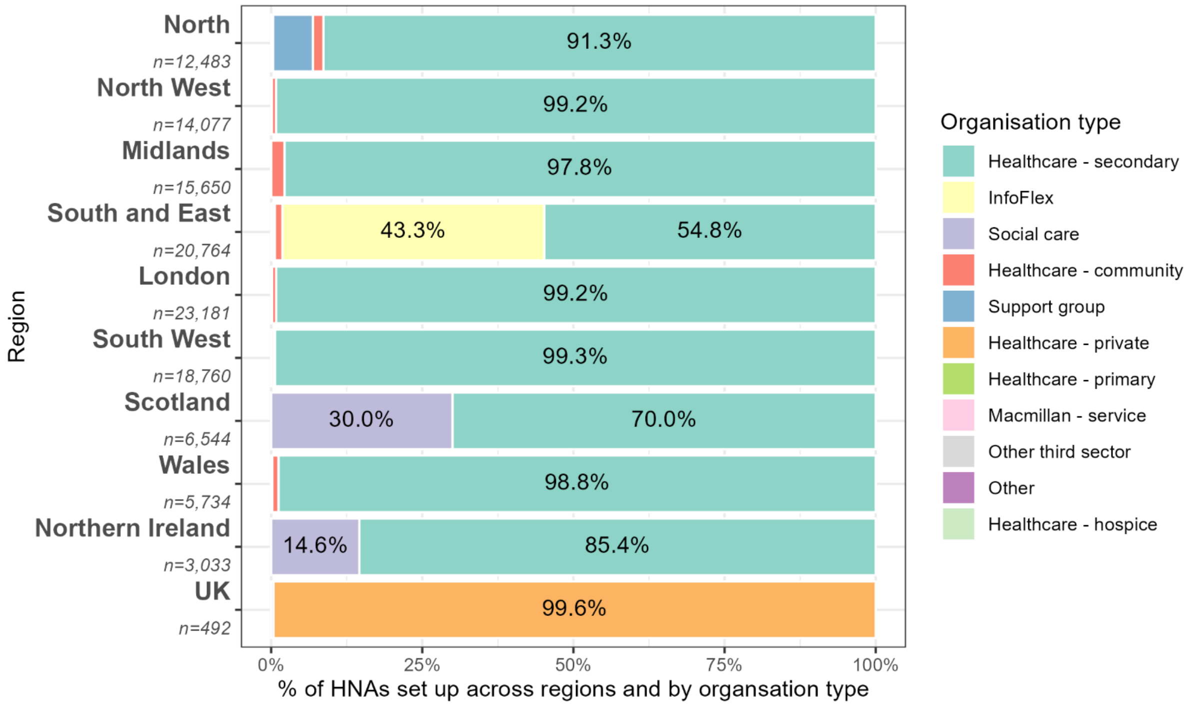


Figure 10. HNA set up by region and organisation type. The region boundaries are defined based on Macmillan definitions and based on the location of organisations. The UK is used for an organisation that works across the UK.

4.3 Key worker role categories

Although HNAs can be set up by key workers with a diverse range of clinical and non-clinical job types, the vast majority are set up by Support Workers (54.7%) or Cancer Nurse Specialists (25.2%). This is largely a reflection of HNAs mostly being set up by secondary healthcare organisations and particularly highlights the important role that Support Workers have in personalised care offers, having set up almost 66,000 HNAs (Figure 11).

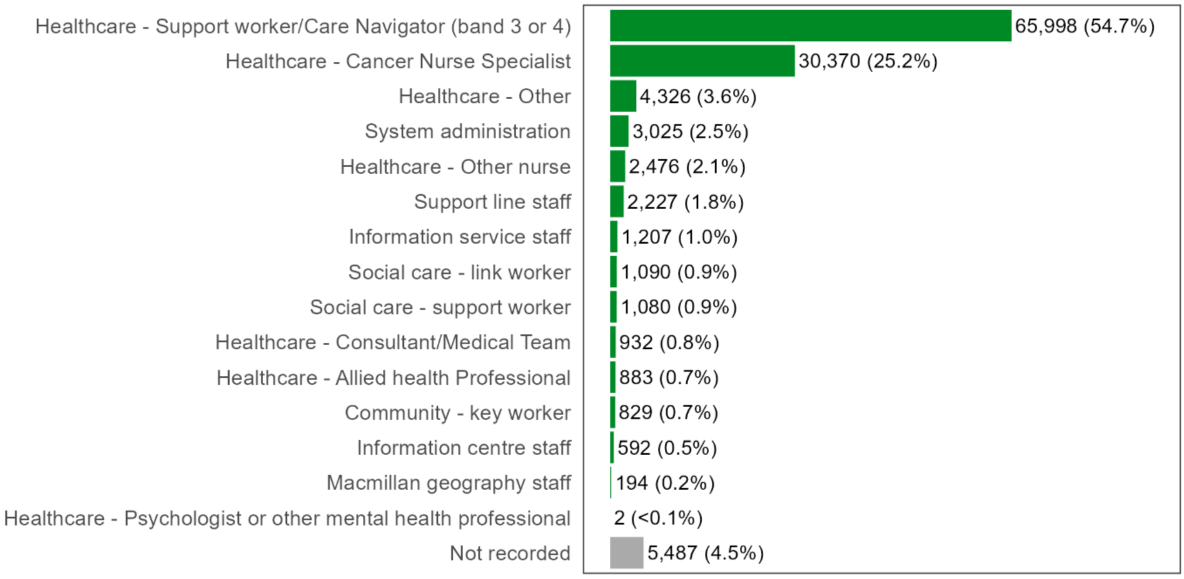


Figure 11. HNAs set up by key worker job role. Includes all organisation types.

Outside of the secondary healthcare setting, there is more variation in job type responsible for setting up the HNA, particularly in social care and community healthcare organisations (Figure 12).

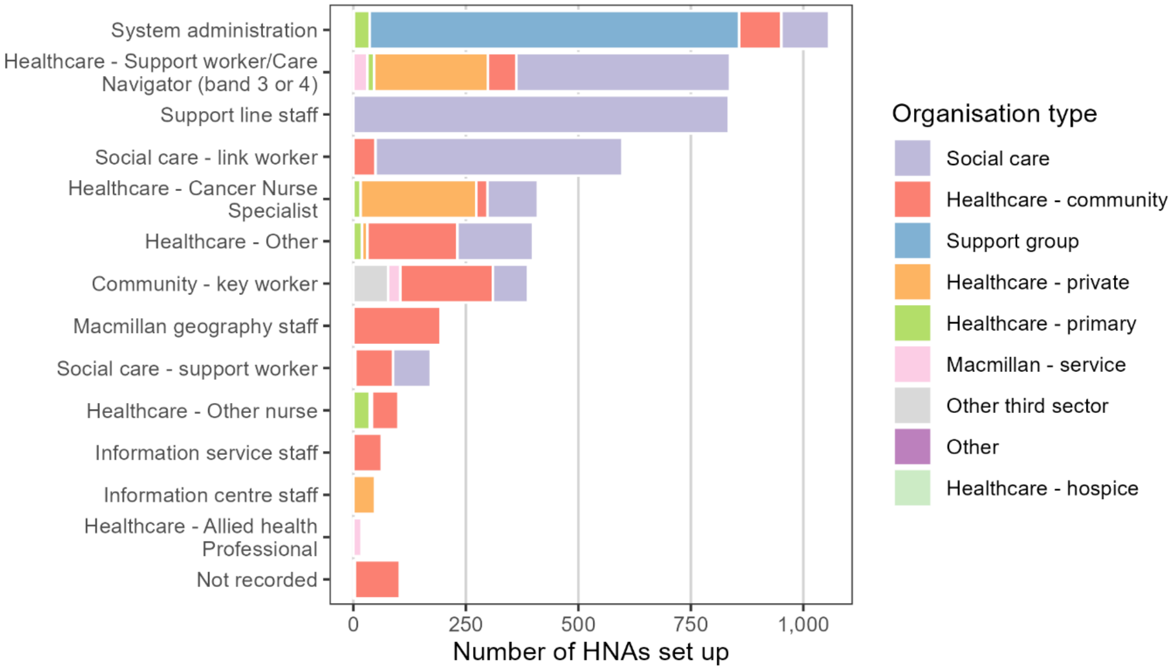


Figure 12. HNAs set up by key worker job role, for organisations that are not secondary healthcare.

Support worker and specialist cancer nurses set up a majority of HNAs at all recorded care pathway stages. Some role types have stronger associations with particular pathway stages; *Social care – link workers* set up 13.2% of HNAs for those *In Palliative Care*, compared to 0.9% across all pathway stages combined. *Social care – support workers* set up 7.2% of HNAs for people at *Prehabilitation*, compared to 0.9% across all pathway stages combined.

4.4 Setting

Within the Macmillan eHNA dataset, the setting refers to a combination of where the key worker expects the HNA to take place (clinic, home, ward, community, or prison) and how the HNA is expected to be accessed to complete it (paper, telephone or virtual). It is recorded at set up but the HNA may come to be completed in a different setting to what was expected. Where the setting describes a location, it is highly likely to have been completed electronically using the MyCarePlan website.

More HNAs were set up for completion on paper than any other setting (26.3% of all HNAs set up; Figure 13). The discrepancy between *Paper* and *Home* settings in HNAs set up and submitted may reflect HNAs that are expected to be completed on paper at home. Following this, the key worker must later change the setting to *Paper* to enable manual entry of the concerns information from the HNA received from the service user.

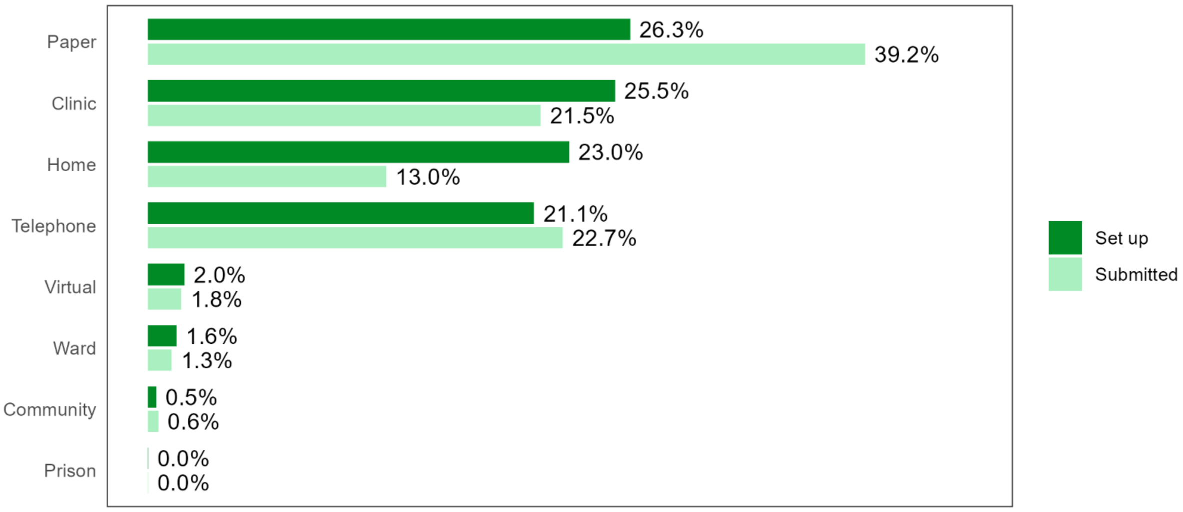


Figure 13. HNAs set up by setting and status.

Paper was particularly favoured by social care (59.1%) and community healthcare (53.6%) organisations (Figure 14).

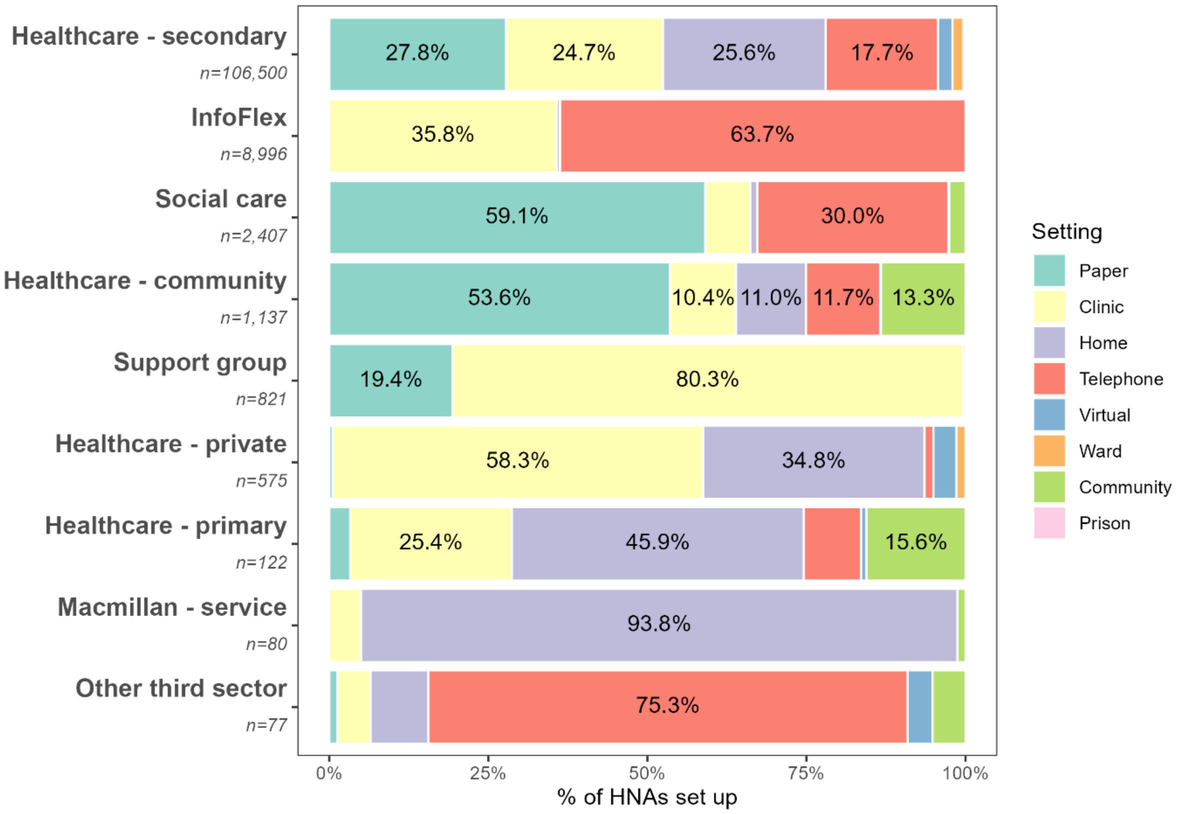


Figure 14. HNAs set up by organisation type and setting. Excludes organisation types 'Healthcare – hospice' (n=1) and 'Other' (n=2).

The proportion set up for paper increases with the age of the service user, with 24.0% of HNAs for 18- to 39-year-olds set up with paper setting and increasing to 29.3% for those in their 80s (Figure 15). This trend tails off for those 90 or older, which may be influenced by the service user's frailty or by their key worker's perception of frailty.

63.7% of InfoFlex HNAs were set up for completion by telephone, which is higher than for secondary healthcare organisations using the Macmillan eHNA Platform (17.6%).

The proportion of HNAs set up for completion by telephone increases with age: 17.1% for 18–39-year-olds, 19.2% for those in their 40s, 20.6% for those in their 50s, 21.9% for those in their 70s and 22.7% for those 90 or older.

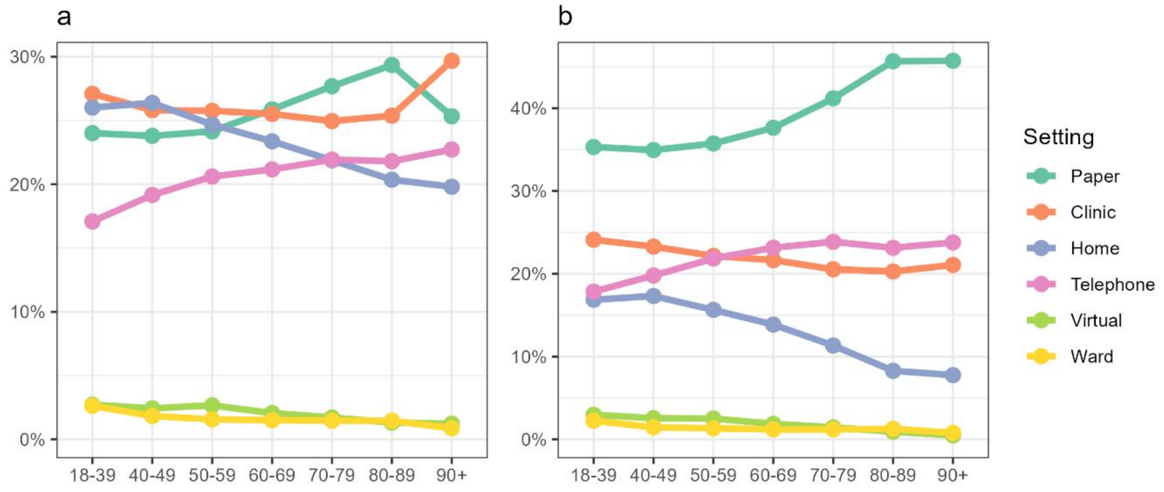


Figure 15. a) HNAs set up by age group and setting. b) HNAs submitted by age group and setting. Percentages are the proportion of HNAs set up or submitted for each age group across the different settings. Excludes setting values Community and Prison due to low numbers.

4.5 Pathway stage

HNAs were more likely to be set up for service users close to the point of diagnosis (36.5%) than at any other pathway stage (Figure 16). A further 41.4% were set up before, during or after treatment. This is principally driven by the large proportion of HNAs set up by secondary healthcare organisations and their association with setting up HNAs at initial diagnosis (36.5% for secondary healthcare organisations and 53.4% for InfoFlex; Figure 17) and their role overseeing treatment delivery.

However, for other organisation types, initial diagnosis is not the most common pathway stage for setting up HNAs (Figure 17). Instead, we see more variation in the pathway stage of HNAs, reflecting the diversity in the roles that different organisations play in supporting people with cancer beyond their diagnosis.

For instance, social care, community healthcare and primary healthcare organisations were most likely to set up HNAs for people during their treatment (28.5%, 30.1% and 28.7% of HNAs set up respectively). Community healthcare organisations were more likely to set up HNAs for people during prehabilitation than any other organisation types (8.1%). Similarly, no organisation type set up a larger proportion of HNAs during follow up than primary healthcare organisations (11.5%). While only 1.9% of HNAs set up by secondary healthcare organisations were for people in palliative care of in transition to palliative care, this rises to 16.0% for social care organisations, 15.6% for other third sector organisations and 12.3% for community healthcare organisations.

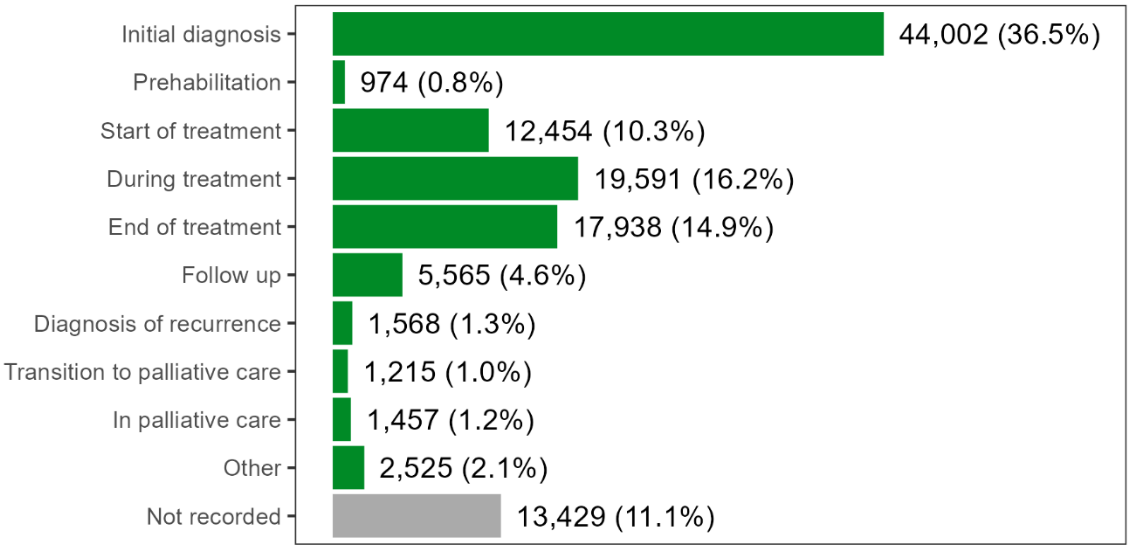


Figure 16. HNAs set up by care pathway stage

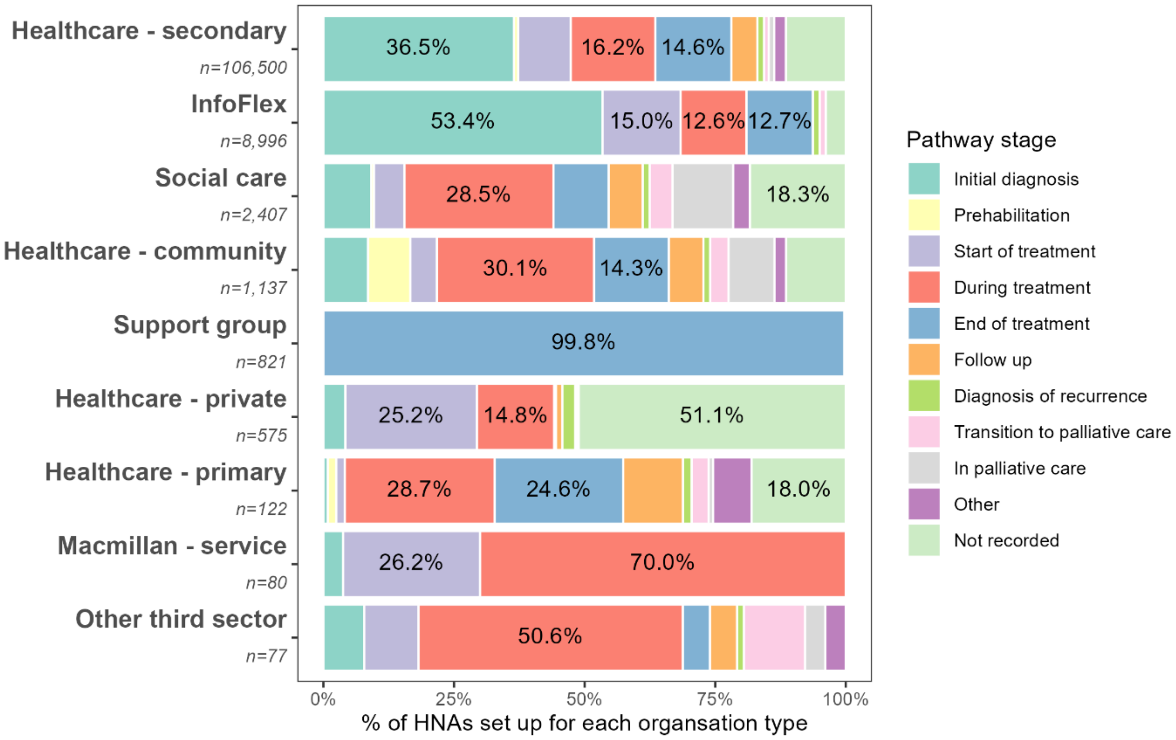


Figure 17. HNAs set up by organisation type and pathway stage. Organisation types 'Healthcare – Hospice' and 'Other' are not shown due to small numbers.

Since pathway stage is not a mandatory field for the key worker to complete within the HNA record, many HNAs do not have this data point recorded. The completion rate varies from 48.9% for private healthcare organisations to more than 99% for support group and other third sector organisations.

The variation of pathway stage across geographic region also illustrates how the HNA and care planning process differs across different parts of the UK (Figure 18). HNAs are most commonly setup at initial diagnosis in most regions of England, with North West the only exception, where more HNAs are set up during treatment (31.4% to 25.9%). In Scotland and Wales HNAs are less commonly set up at initial diagnosis and instead see the largest proportion of HNAs set up during treatment (26.5% and 21.0%), and for Northern Ireland at follow-up (27.6%). Scotland saw the largest proportion of HNAs set up for service users in palliative care or in transition to palliative care at a combined 14.5%, compared to 1.5% for the rest of the UK combined.

The trends seen in England reflect NHS England's commitment to deliver more HNAs to people with cancer and that many secondary healthcare organisations in England have set performance targets based on offering HNAs at the point of diagnosis.

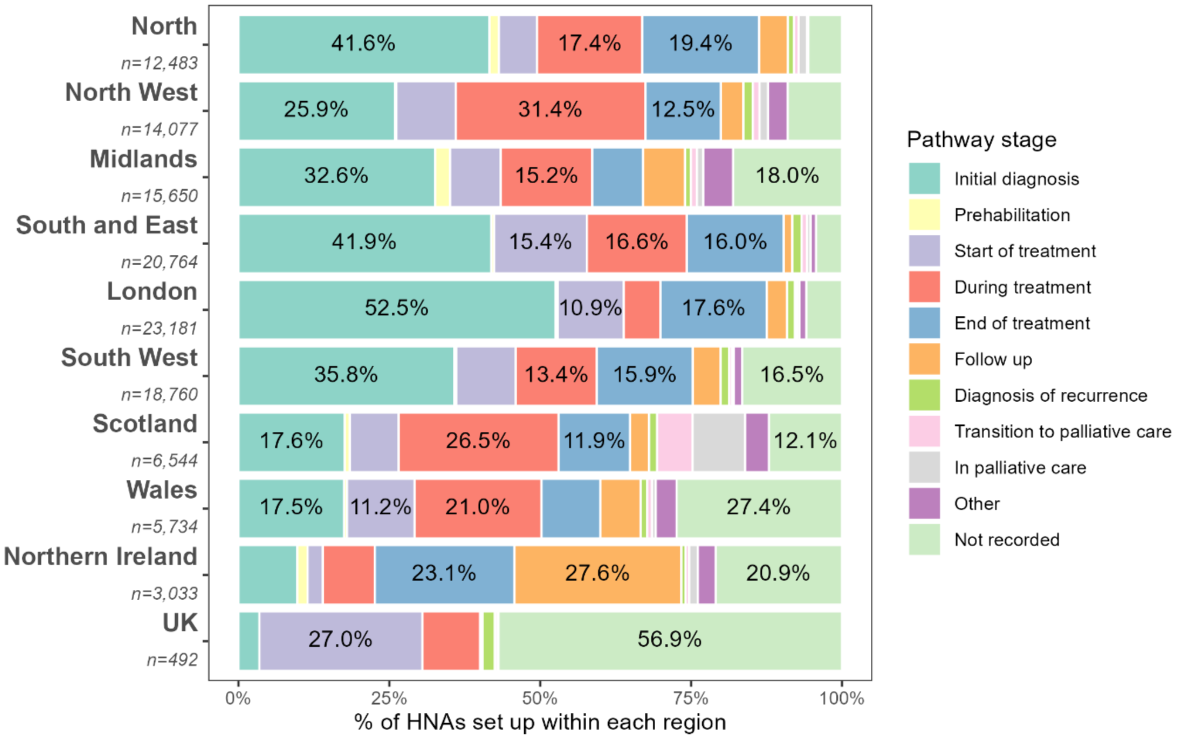


Figure 18. HNAs set up by organisation region and pathway stage.

4.6 Condition management

The condition management field incorporates what is more commonly called 'treatment intent' in a clinical setting but is a more generalised term in the Macmillan eHNA Platform to enable non-clinical organisations to make use of the field. It also gives the field meaning for those not receiving treatment at the point of HNA.

A value can only be entered by the key worker at the point of building a care plan and as a result only HNAs with a status of *In progress* or *Locked* have a value recorded. It is not recorded in InfoFlex records. Only 22.2% of *In progress* or *Locked* HNAs that are not from InfoFlex have a recorded value for condition management.

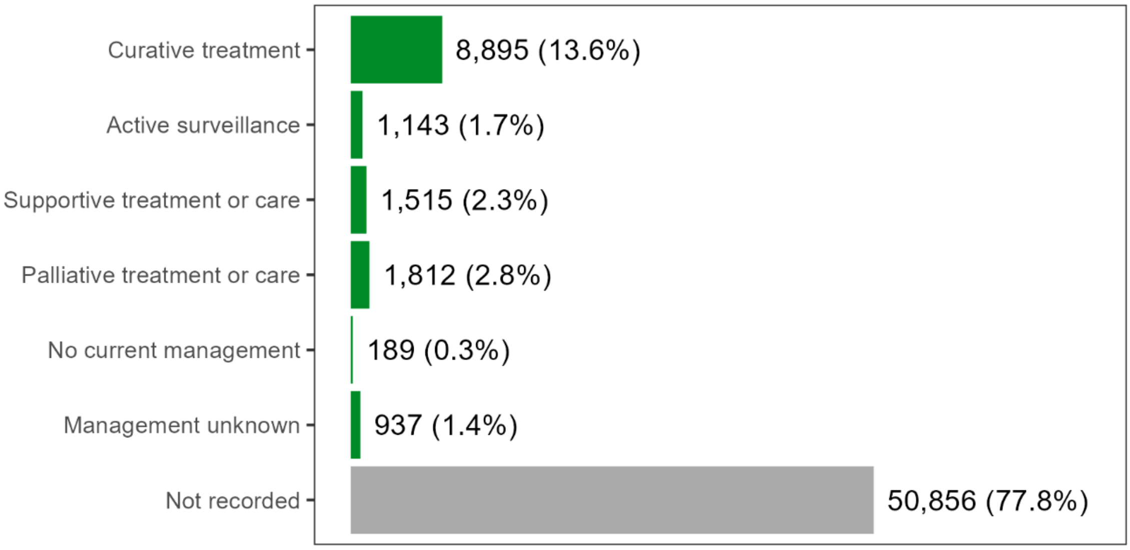


Figure 19. HNAs set up in 2023 and with a status of 'In progress' and 'Locked', by condition management. Excludes HNAs set up by InfoFlex organisations.

Condition management was most likely to be recorded for people at pathway stages *In palliative care* (35.7% of *In progress* or *Locked* HNAs not from InfoFlex) or *Transition to palliative care* (30.3%). It was least likely to be recorded for people at the start of (18.9%) or during (18.2%) their treatment. Other third sector organisations were most likely to have a value recorded (60.5%), followed by social care organisations (35.7%) and support group were least likely (0.0%) followed by private healthcare organisations (6.9%).

As only a small number of HNAs feature a recorded value of known condition management, we are limited in our ability to draw insights about how this factor influences the concerns recorded and resultant care plan actions.

4.7 Sex

The value for sex is recorded by the key worker at the HNA setup. As part of the personalisation process, the service user can request that the HNA and care planning process is approached from the perspective of either their gender identity or their biological sex. However, it is likely that not all service users are aware that they can influence how this information is recorded.

The system reflects a design approach that emphasises a holistic and person-centred HNA and care planning process, with the primary aim of understanding and supporting the individual's concerns. Within this approach, the platform was developed on the basis that distinguishing explicitly between gender identity and biological sex within the recorded data would not be necessary to support care delivery. Instead, it assumes that key workers will engage with individuals in a holistic way to understand their concerns.

Transgender status is not explicitly captured in the platform. Additionally, only a very small number of records, 9, explicitly capture a non-binary sex or gender value (Figure 20). All other non-male and non-female categories (e.g. "Other", "Prefer not to say", and "Not known") are expected to reflect missing, unknown, or non-disclosed values rather than distinct sex or gender identities. As a result, the dataset provides very limited representation of gender diversity and does not support meaningful analysis of HNA-related activity for non-binary or transgender populations.

More HNAs are set up for females (52.2%) than for males (46.2%, Figure 20), despite counts of new cancer diagnoses in the UK typically being higher in males than females each year[18,19,20,22]. This concurs with studies of HNA uptake in England and in Scotland, which both found an over-representation of female and under-representation of male participation[9,10].

However, this trend appears to be influenced by higher uptake among patients with breast and gynaecological cancers. After excluding cancers associated with sex-specific anatomy (breast, gynaecological and male genital sites) the pattern reverses, with more HNAs set up for males (54.5%) than females (44.4%). For organisations in England this split is 54.9% for males and 44.0% for females, which is close to the cancer incidence statistics published for the same cancer sites in England for 2022 of 56.4% of diagnoses in males and 43.6% in females[25].

3.9% of records imported from InfoFlex organisations have sex recorded as *Other* and no records with sex recorded as *Prefer not to say*. The value of *Other* is not used by any other organisation types and reflects different data capture capabilities used in the InfoFlex system.

Variation in recording practices is evident when looking at the sex distribution within HNAs set up for individual organisations. For example, the urology team of one organisation set up 1,072 assessments for people recorded as having prostate cancer, of which 1,023 (95%) had a value of sex recorded as *Not known*. Across all HNAs set up for people with a recorded condition of prostate cancer, 93.5% were recorded as *Male*, 0.4% were recorded as *Female* and 6.0% were *Not known*.

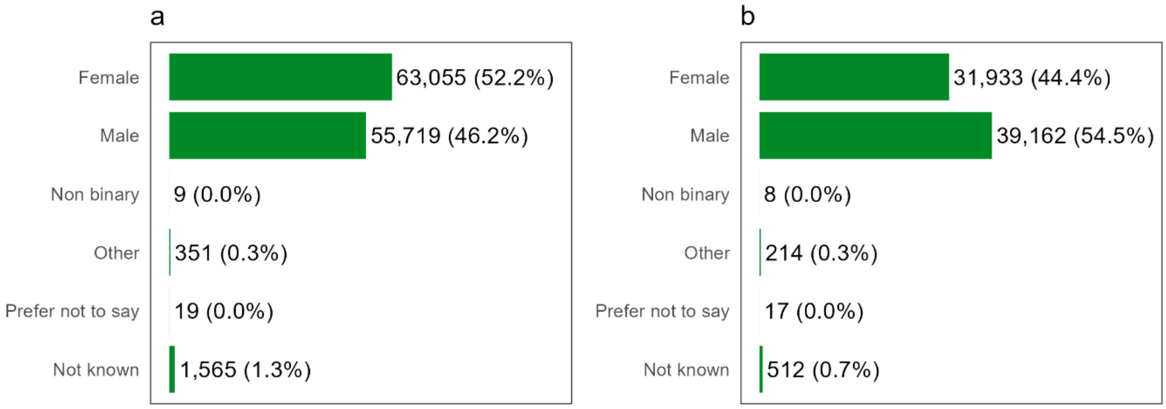


Figure 20. HNAs set up by recorded sex. a) for all cancers. b) for all cancers excluding breast, gynaecological and male genital

4.8 Age group

The single year of age at time of HNA setup is calculated based on the service user's date of birth. However, date of birth is not included in the routine data extracts produced by Health Unlocked for reporting and so age is used instead.

While the age distribution of service users who have an HNA set up for them was broadly aligned with the age distribution of new cancer cases, there is a clear overrepresentation of people in their 30s, 40s and 50s and an underrepresentation of those aged 80 and above (Figure 21)[22]. Similar trends were found in studies of HNA uptake in England and Scotland[9,10].

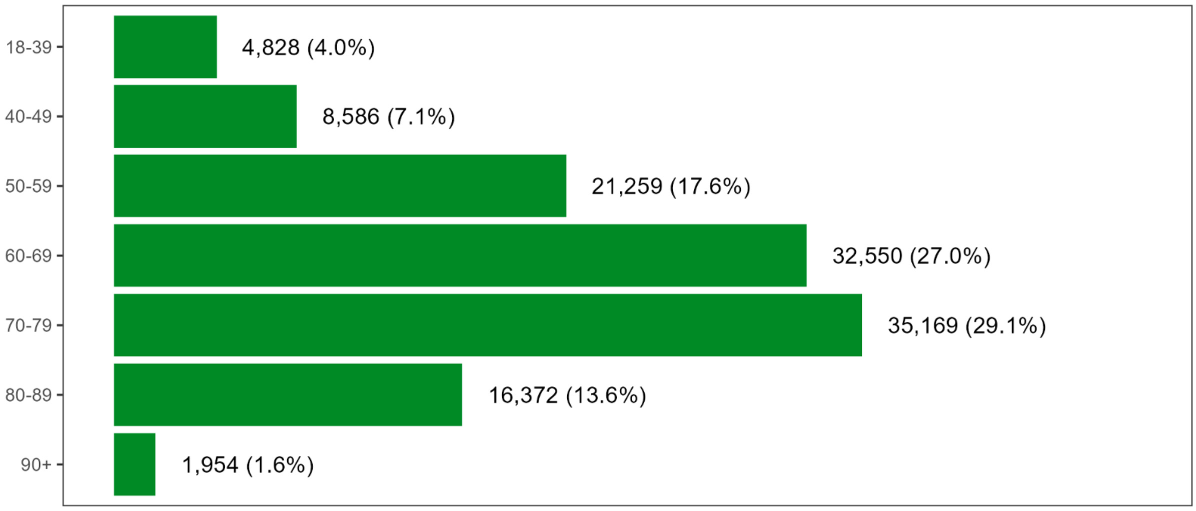


Figure 21. Number of HNAs set up (% of all set up) by patient age.

4.9 Cancer type

Figure 22 illustrates the distribution of cancer types in all HNAs set up, including all regions and all malignant, in-situ and benign tumours recognised as a form of cancer (ICD 10 codes C00-C97, D00-D48).

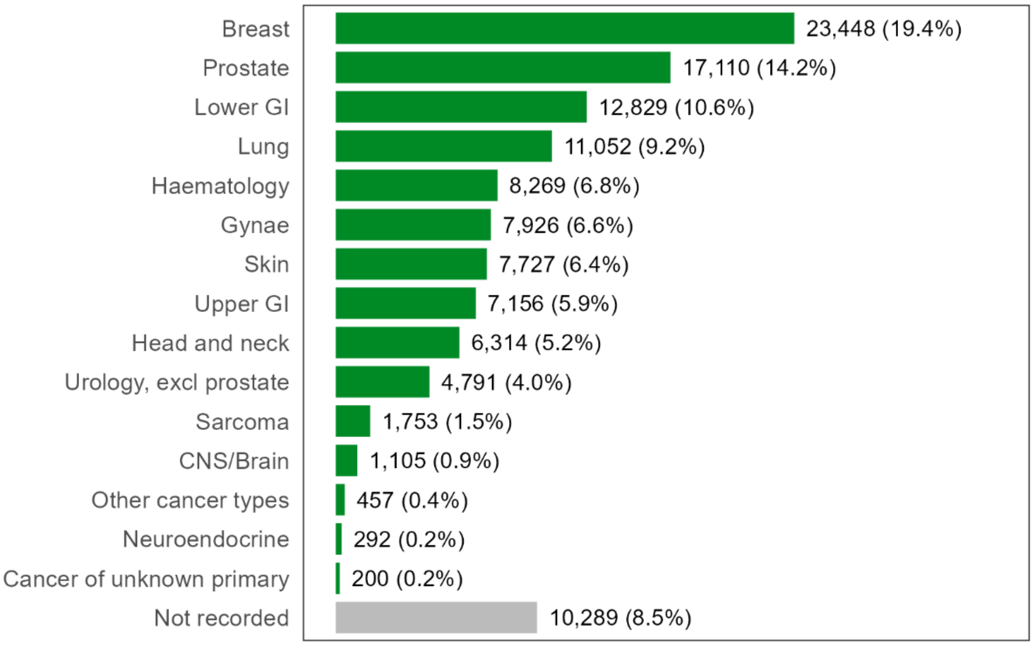


Figure 22. HNAs set up by diagnosed condition.

Condition	HNAs set up (England, 2023)	Cancer incidence (England, 2023)
Breast	20.4%	14.4%
Prostate	17.6%	16.6%
Lower GI	12.2%	12.8%
Lung	10.3%	12.8%
Haematology	7.6%	8.6%
Gynaecology	7.4%	5.6%
Upper GI	6.2%	9.2%
Head and neck	5.9%	4.6%
Urology, excl prostate	5.0%	7.2%
Skin	4.1%	5.3%
Sarcoma	1.7%	0.8%
CNS/Brain	1.0%	1.6%
Cancer of unknown primary	0.6%	0.3%
Other cancer types	0.1%	0.1%

Table 4. Proportion of HNAs set up by England-based organisations for people with a recorded diagnosis code between ICD C00-C97 excl C44, compared to equivalent proportions of cancer registrations reported for England with the same ICD codes[22].

We also consider the distribution of HNAs set up by organisations in England for malignant tumours and excluding non-melanoma skin cancer, in comparison to cancer incidence for England in 2023. Table 4 shows the results grouped by the cancer type labelled as *Condition* within the platform. This includes HNAs at all stages of the pathway not just at diagnosis. Table 5 outlines the 10 individual cancer sites with the largest overrepresentation in HNAs set up compared to incidence and the 10 large underrepresentation.

ICD-10 code	Malignancy site	Cancer registrations in England (2023)	HNAs set up in England (2023)	Index
Most over-indexing				
C49	Other connective and soft tissue	1,638 (0.49%)	1,156 (1.38%)	281
C88	Malignant immunoproliferative diseases	1,273 (0.38%)	650 (0.78%)	204
C53	Cervix uteri	2,384 (0.71%)	954 (1.14%)	160
C54	Corpus uteri	8,913 (2.67%)	3,341 (3.99%)	149
C50	Breast	50,535 (15.12%)	18,398 (21.95%)	145
C85	Other and unspecified types of non-Hodgkin lymphoma	2,344 (0.70%)	786 (0.94%)	134
C90	Multiple myeloma and malignant plasma cell neoplasms	5,881 (1.76%)	1,701 (2.03%)	115
C51	Vulva	1,268 (0.38%)	359 (0.43%)	113
C09	Tonsil	2,172 (0.65%)	610 (0.73%)	112
C56	Ovary	6,054 (1.81%)	1,696 (2.02%)	112
Most under-indexing				
C24	Other and unspecified parts of biliary tract	1,468 (0.44%)	58 (0.07%)	16
C17	Small intestine	1,878 (0.56%)	88 (0.10%)	19
C83	Non-follicular lymphoma	6,085 (1.82%)	299 (0.36%)	20
C64	Kidney, except renal pelvis	11,379 (3.40%)	608 (0.73%)	21
C16	Stomach	5,454 (1.63%)	543 (0.65%)	40
C73	Thyroid gland	4,023 (1.20%)	479 (0.57%)	47
C25	Pancreas	10,173 (3.04%)	1,500 (1.79%)	59
C23	Gallbladder	1,187 (0.36%)	188 (0.22%)	63
C45	Mesothelioma	2,118 (0.63%)	337 (0.40%)	63
C71	Brain	4,671 (1.40%)	817 (0.97%)	70

Table 5. Proportion of HNAs set up by England-based organisations for people with a recorded 3-character ICD-10 diagnosis code between C00-C97 excl C44, compared to equivalent proportions of cancer registrations reported for England with the same ICD codes. Individual sites with fewer than 1,000 cancer registrations in England in 2023 are excluded. Index = HNA share divided by England incidence share × 100. Values below 100 indicate under-representation relative to incidence; values above 100 indicate over-representation[22].

The analysis points to an over-representation of HNAs being set up for people in England with breast, gynaecological and head and neck cancers. Conversely it suggests an under-representation of people with upper GI, non-prostate urological, skin and lung cancers. Much of this pattern is in line with a study exploring representation in HNAs offered using data from England's Cancer Outcomes and Services Data[10]. There, a similar higher proportion of patients were offered HNA and care planning in breast, uterus, head and neck, cervical, colorectal and prostate patients, with the lowest proportion offered in cancer of unknown primary, pancreas, liver and brain.

As well as patterns in short-term cancer survival, some of these trends are rooted in how participation using the platform has evolved over time. The platform was first launched via partnerships with several breast and prostate teams based in secondary healthcare organisations, which may be partly responsible for their continued large numbers.

Within the platform is a bespoke HNA checklist designed for people with head and neck cancers and featuring an additional set of concerns specifically associated with head and neck cancer symptoms.

4.10 Additional diagnoses

The HNA and care planning record includes the opportunity to record up to 2 additional diagnoses which can be used to report comorbid conditions. These can include secondary tumours, new primary cancers, pre-existing conditions and new conditions arising as a complication of cancer.

Only 2,875 HNAs set up had an additional diagnosis recorded, or 2.4% of all HNAs set up. HNAs set up by primary healthcare (19.7%) and community healthcare organisations (18.5%) were more likely to include an additional diagnosis. They were also more commonly reported in HNAs set up for service users at pathway stages *Transition to palliative care* (11.4%) and *in palliative care* (12.6%).

The recording of additional diagnoses tends to increase with service user age. The proportion of records with a recorded additional diagnosis ranges from 1.45% in the 18-39 age group to 3.23% in the 80-89 age group.

Within the 2,875 HNAs with an additional diagnosis recorded, 52.1% indicated another cancer diagnosis, whether a secondary tumour or another primary and 47.9% reported a non-cancer condition. The most frequently reported additional cancer diagnoses were secondary liver cancer (18.2% of all recorded additional cancer conditions), secondary lung cancer (8.3%), prostate cancer (6.0%), secondary bone or bone barrow cancer (5.9%) and secondary brain tumours (4.5%). Cancer sites were recorded in a single combined field that sometimes explicitly indicated secondary disease (e.g. "Liver cancer (secondary)") and sometimes did not (e.g. "Liver cancer").

The most frequently reported additional non-cancer conditions were chronic lower respiratory disease including COPD (18.4% of all recorded additional non-cancer conditions), hypertension (17.4%), type 2 diabetes mellitus (9.4%), epilepsy (6.8%) and asthma (6.2%).

We should recognise that the volumes of additional diagnoses recorded are very small compared to expected prevalence of comorbidities and so may poorly represent the population of those with cancer and other conditions. The additional diagnosis might only be recorded if the key worker considers it relevant to their concerns or care plan or if it comes up in the conversation.

4.11 Ethnic group

Although the ethnic group of the service user can be recorded by the key worker, this only occurred for 4,000 HNAs, or 3.3% of all set up in 2023 (Figure 23). Of these, 302 records had an ethnic group value of *Not stated*, leaving 3,698 records (3.1% of all set up) with a recorded known value for ethnic group.

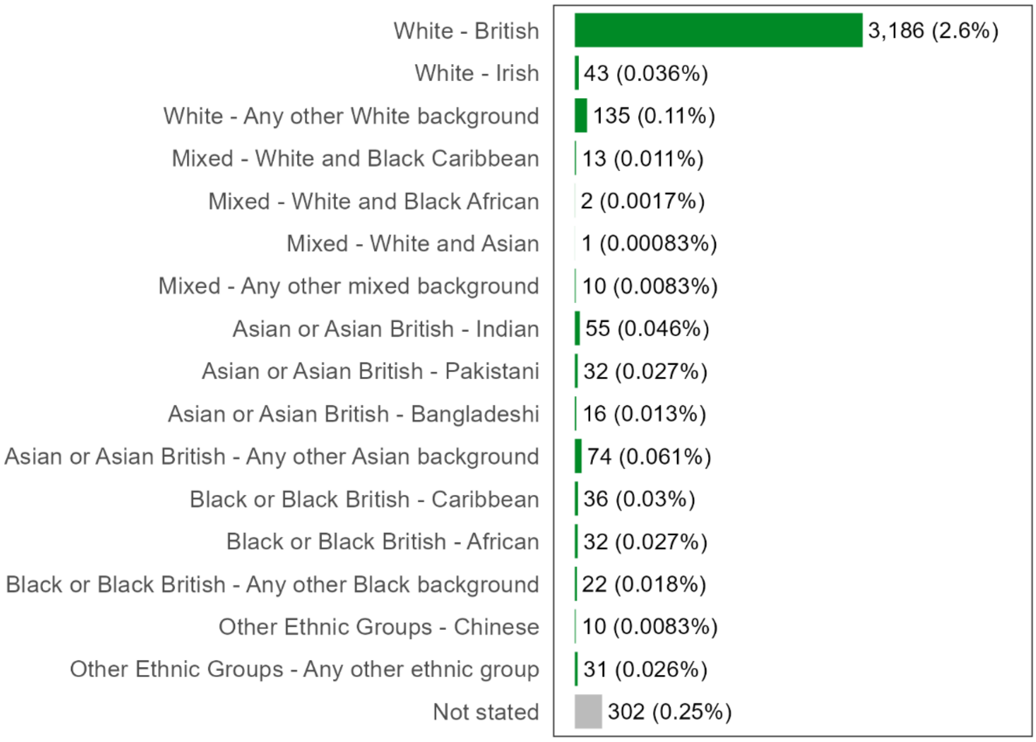


Figure 23. HNAs set up by recorded ethnic group of service user. Remainder of HNAs (96.7%) have no ethnic group recorded.

Ethnic group was not present in records imported from InfoFlex. Ethnic group categories are based on NHS Data Model and Dictionary coding for *Ethnic category*, which in turn is based on categories used in the 2001 census[23].

A large degree of variation in whether ethnic group is recorded exists between organisation types and key worker job roles. 31%, 26% and 84% of HNAs set up by *Social care*, *Support group* and *Other third sector* organisations respectively had a known value of ethnic group recorded. In contrast 2.5% and 0.3% of HNAs set up by secondary healthcare and community healthcare organisations had a known value of ethnic group recorded.

The highest proportions of known ethnic group values were recorded in HNAs set up by social care link workers (34.5%), healthcare consultants (33.5%) and community key workers (31.6%). HNAs set up by support workers and specialist cancer nurses only featured known ethnic group values in 1.5% and 2.7% of HNAs respectively. Key work role types see variation depending on the context of the organisation type (Figure 24).

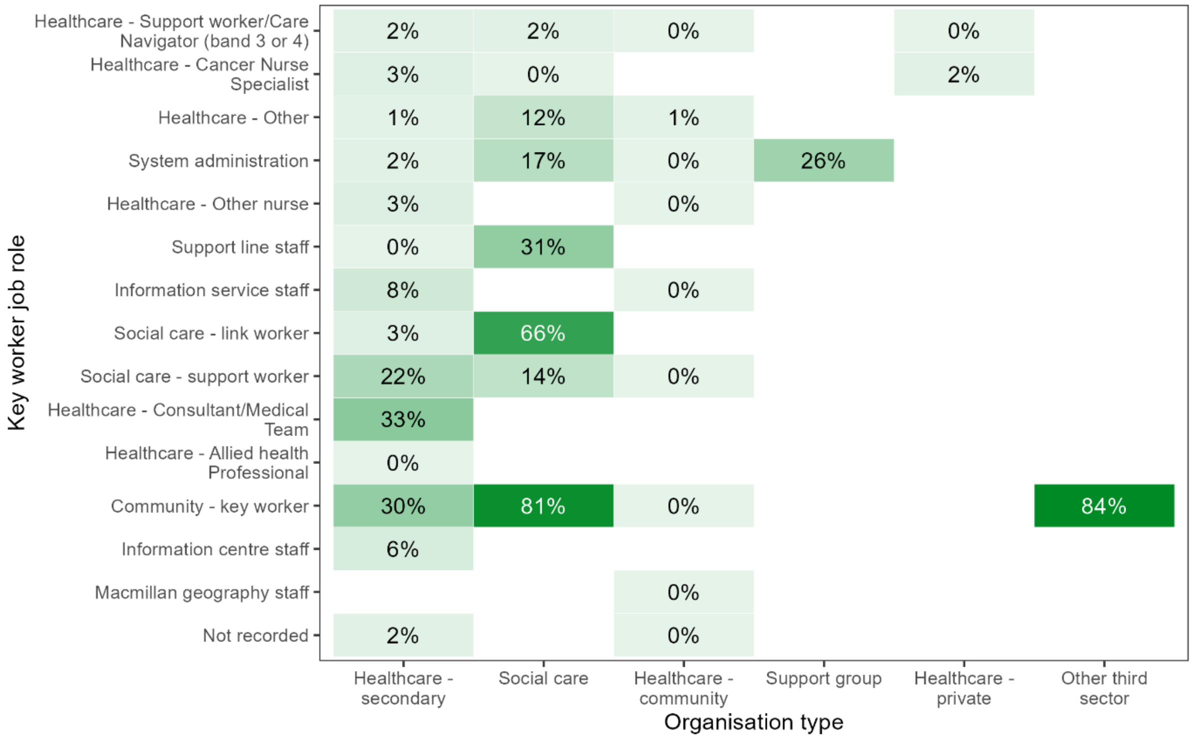


Figure 24. Proportion of HNAs set up that had a known value of ethnic group recorded. Excludes HNAs set up by InfoFlex organisations which do not record ethnic group and any cells with fewer than 50 HNAs set up.

The distribution of broad ethnic group in HNAs set up in England in 2023 was compared against the estimated distribution of cancer cases occurring in England between 2013 and 2017[24]. When excluding unknown values of ethnic group, we see a higher proportion of HNAs set up for people with broad ethnic groups *Asian*, *Black* and *Mixed/Multiple* compared to diagnoses (Table 6). However, this is based on an unrepresentative sample of 2,680 HNAs in England (2.6% of all set up in England) with a known value of ethnic group and which is reported over a different time period. We also note the over-representation of London-based organisations within eHNA data (Table 3) may influence the ethnic group distribution. However, the large proportions of records set up for service users with unknown ethnic groups make these comparisons limited.

An alternative study, examining HNAs in England beyond the Macmillan eHNA Platform, suggested that people with White ethnicity were more likely to be offered an HNA than those of other broad ethnic groups[10].

	Annual average number of cancer cases in England 2013-2017 (%)		HNAs set up by England organisations in 2023 (%)	
Broad ethnic group	All cases	Excluding not known	All HNAs	Excluding not known
White	269,450 (88.6%)	269,450 (93.9%)	2,353 (2.2%)	2,353 (87.8%)
Asian	7,692 (2.5%)	7,692 (2.7%)	177 (0.2%)	177 (6.6%)
Black	5,281 (1.7%)	5,281 (1.8%)	88 (0.1%)	88 (3.3%)
Mixed/Multiple	1,225 (0.4%)	1,225 (0.4%)	26 (0.0%)	26 (1.0%)
Other	3,310 (1.1%)	3,310 (1.2%)	36 (0.0%)	36 (1.3%)
Not Known	17,183 (5.6%)		102,235 (97.4%)	
Total	**304,141 (100%)**	**286,958 (100%)**	**104,915 (100%)**	**2,680 (100%)**

Table 6. Distribution of broad ethnic group within HNAs set up by England-based organisations in 2023, compared with distribution of broad ethnic group of cancer cases in England between 2013-2017[24].

4.12 Language

HNAs can be conducted in a range of languages, whether using the online portal or through a conversation with a key worker. By default, the language is recorded as English but if the service user is accessing the HNA electronically and selects an alternate language then this change will be recorded in the system. Language was always recorded as English for HNAs submitted via paper, however non-English versions of the paper checklist are available to key workers.

The language was recorded as English in 99.8% of HNAs set up and 99.7% of HNAs submitted, with the next most reported languages being Polish (52 HNAs), Romanian (24), Spanish (21), Portuguese (18) and Welsh (17). 12 other languages were recorded in between 1 and 16 HNAs.

202 of the 203 instances of a recorded non-English language were for HNAs set up by secondary healthcare organisations. The percentage of HNAs submitted with a non-English language recorded varied across the expected setting, from 0.23% of those with setting *Community* to 0.83% of those with a *Virtual* setting.

Increasing age of service user was associated with a lower propensity to submit the HNA with a recorded language other than English (Figure 25).

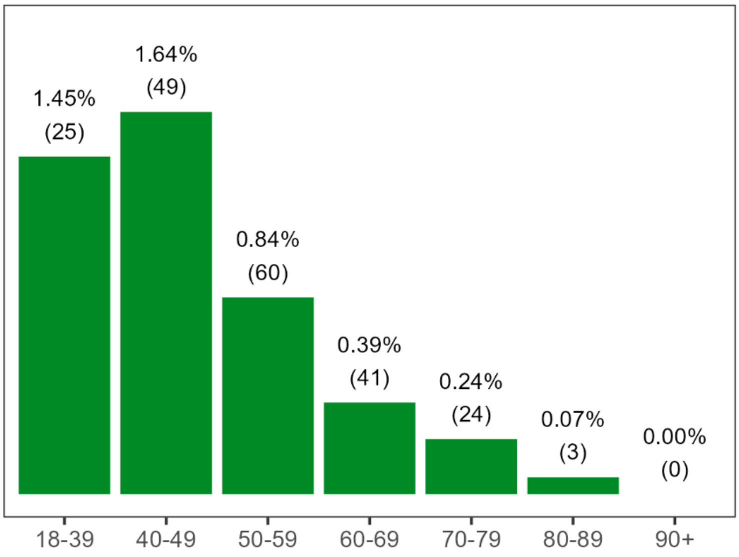


Figure 25. Proportion (and number) of submitted HNAs with a recorded language other than English, compared to age group of service user. Based only HNAs set up by secondary healthcare organisations and excludes HNAs submitted via paper.

4.13 People receiving multiple HNAs

As described in Section 3, random patient IDs (GUIDs) are generated from primary patient identifiers, such as NHS numbers, within the platform at the point of HNA and care planning record setup. Where consistent primary identifiers have been used between records set up, these GUIDs can be used to detect when people have more than one HNA set up for them. However, a person may be offered a HNA by a secondary healthcare organisation and then another HNA by a local community organisation later in their care pathway using a different primary identifier and, in this instance, the same patient would appear in the dataset with distinct patient IDs. Additionally, records imported from InfoFlex explicitly use newly generated patient IDs for every HNA set up. Consequently, the dataset tends to underestimate how frequently multiple HNAs are set up for the same person and the statistics noted here should be evaluated with that consideration.

Of the 107,156 distinct patient IDs that had HNAs set up in 2023, 98,160 were recorded by organisation types other than InfoFlex. Of these, 88.5% had only one HNA set up in this period. 9.8% had exactly two HNAs and 1.7% had three or more (Table 7).

To obtain a more representative view of service user that have multiple HNAs we must include enough time in our study period after the first HNA for subsequent HNAs to take place. To support this, we created a secondary cohort that isolates:

- HNAs set up by secondary healthcare organisations, since they are more likely to be using standard patient identifiers such as NHS numbers

- people receiving their first HNA of 2023 in January and with a pathway stage of initial diagnosis, as they have most opportunity for subsequent HNAs to take place through the rest of the year.

Within this cohort, there were 2,910 distinct patient IDs found and a total of 2,953 HNAs set up (Table 7). Of these patient IDs, 2,322 (79.8%) had no other HNAs set up in the year, 501 (17.2%) had one more set up, 77 (2.6%) had two and 10 (0.3%) had between three and five more HNAs set up in 2023.

	All HNAs set up		Patient IDs with a first HNA set up in January 2023 by a secondary healthcare organisation at initial diagnosis	
Number of HNAs set up in 2023	Number of patient IDs with this HNA count	Percent of all patient IDs	Number of patient IDs with HNA count	Percent of all patient IDs
1	86,851	88.5%	2,322	79.8%
2	9,652	9.8%	501	17.2%
3	1,322	1.3%	77	2.6%
4	229	0.2%	8	0.3%
5	50	<0.1%	1	<0.1%
6	24	<0.1%	1	<0.1%
7	15	<0.1%	0	0%
≥8	17	<0.1%	0	0%
Total	**98,160**	**100%**	**2,910**	**100%**

Table 7. Distribution of number of HNAs set up for service users. InfoFlex records excluded.

283 of the 688 (41.1%) subsequent HNAs were set up at end of treatment, 127 (18.5%) also at initial diagnosis and 121 (17.6%) during treatment (Figure 26). Additionally, 137 (19.9%) took place within 1 month of the first HNA set up, 290 (42.2%) within 3 months and 469 (68.2%) within 6 months.

Exploring the trends of pathway stages (Figure 26) shows that:

- 92% of subsequent HNAs that were set up at the start of treatment occurred within 4 months of the initial HNA and 70% were within 2 months84% of subsequent HNAs that were set up during treatment occurred between 1 and 7 months after the initial HNA
- *End of treatment* dominates from 3-4 and 10-11 months after the first HNA, accounting for more than 50% of subsequent HNAs in each monthly interval
- 6.8% of subsequent HNAs had a pathway stage of *Follow up* and these were fairly evenly spread between 1 and 11 months after the first HNA.
- Only 1.4% of subsequent HNAs within the studied period were set up at a pathway stage of *Transition to palliative care* or *In palliative care.*

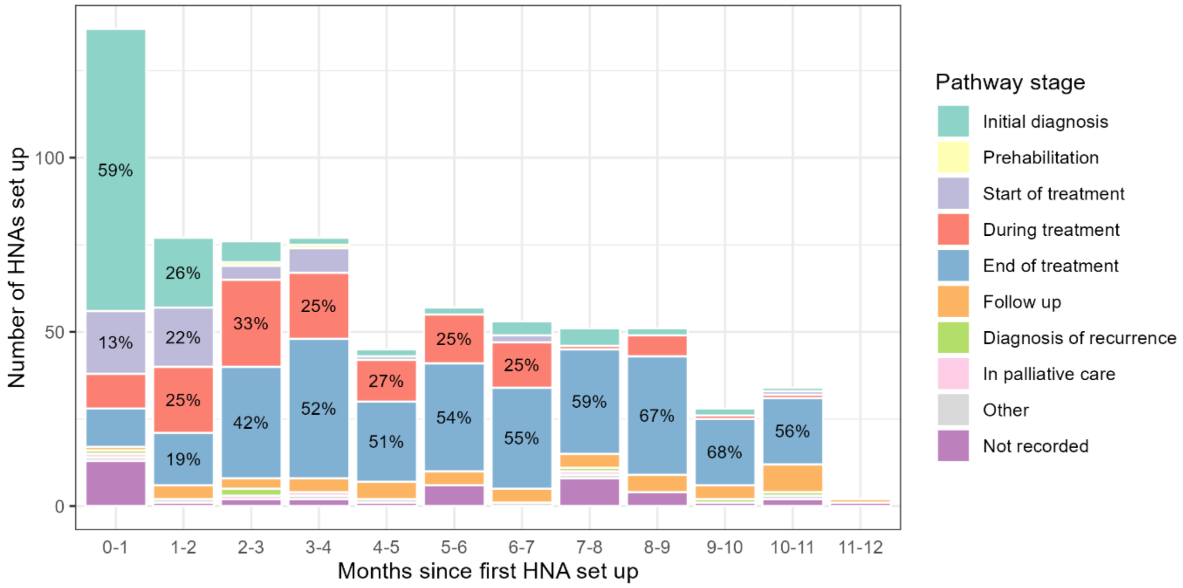


Figure 26. Pattern of second and other subsequent HNAs set up, by follow-up time after first HNA and pathway stage. Based on service users whose first HNA set up of 2023 was in January at initial diagnosis and by a secondary healthcare organisation (n = 2,910 service users). Percentages reflect proportion of HNAs set up that month.

4.14 Date of diagnosis

Key workers can optionally record an additional date of relevance within the HNA and care planning record. This was found in 32.9% of HNAs set up and 98.3% of these instances (39,064 HNAs in total) noted that they were recording a *Date of diagnosis*. *Decision to treat date* and *End of treatment date* were also found in very small numbers.

These dates are subject to data quality limitations, since they are input manually by key workers and not validated for plausibility. For instance, there are dates of diagnosis occurring around or before the service user's date of birth, diagnoses occurring in the early 20th century and some well into the future.

For the analysis in this section, we exclude records with a date of diagnosis occurring after 2024, before the year 1930 or where the implied age at diagnosis - derived from age at HNA setup - was negative. This resulted in 38,865 HNAs with a presumed valid recorded date of diagnosis for further analysis, 32.2% of all HNAs set up.

Among all organisation types, InfoFlex organisations had the highest proportion of records set up with a date of diagnosis recorded, 92.4%, rising to 98.8% where the service user's condition was also recorded. In comparison, only 27.4% of secondary healthcare organisations, 38.8% of social care organisations, 23.2% of community healthcare organisations and 0.0% of support group organisations recorded a date of diagnosis.

Highest rates of diagnosis date recording were found in HNAs set up at pathway stages *Initial diagnosis* (45.0%), *Diagnosis of recurrence* (48.7%), *Transition to palliative care* (52.6%) and *In palliative care* (43.8%). Lower rates were found for records set up at *Start of Treatment* (34.6%), *During treatment* (30.1%), *End of treatment* (21.9%) and *Follow up* (19.7%).

Where recorded, the median time between the date of diagnosis and the date of HNA set up was 28.5 days, with lower and upper quartiles of 7.5 days and 101 days. This varies significantly by pathway stage (Figure 27) with median, lower and upper quartiles of 11.0, 2.6 and 27.7 days for HNAs set up at *Initial diagnosis* and 249.5, 77.8 and 670.8 days for those at *Follow up*.

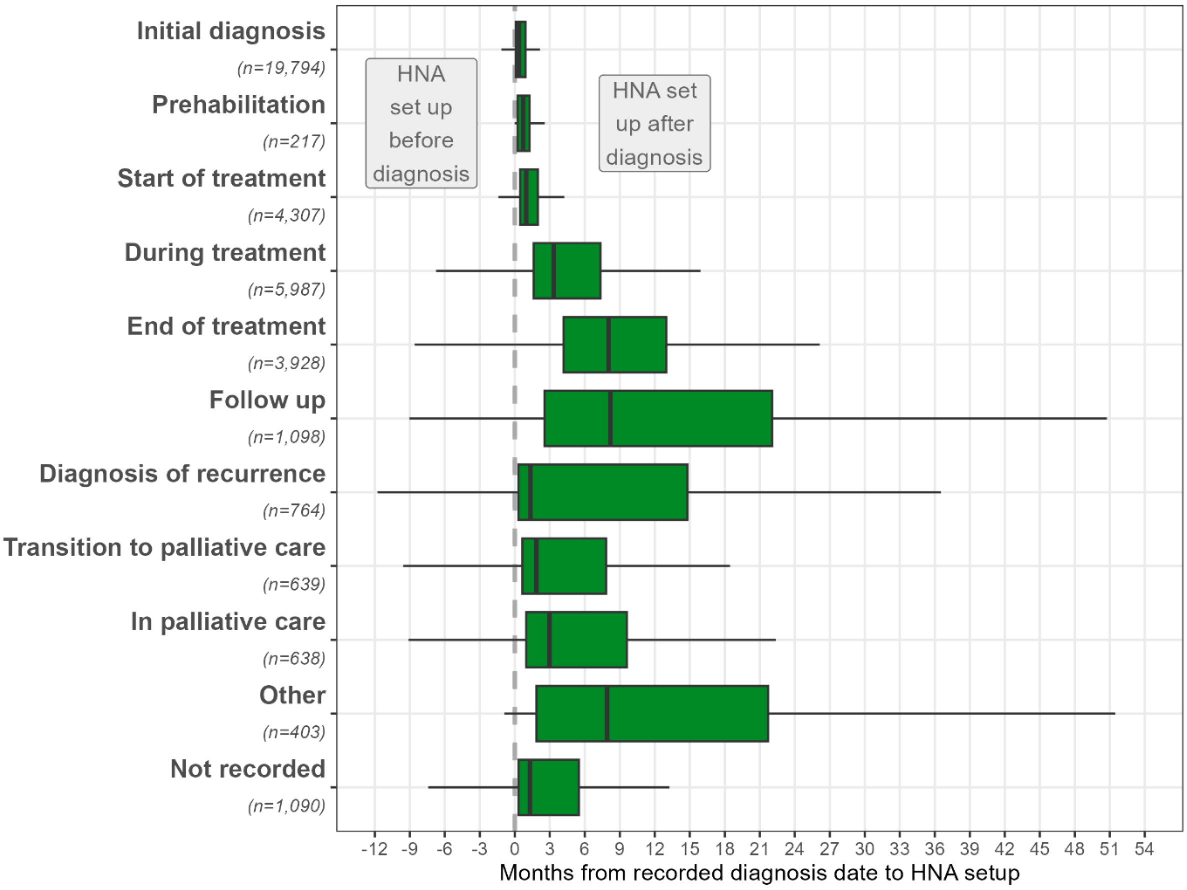


Figure 27. Months from diagnosis to HNA setup by pathway stage. Based on 38,865 HNA records with a recorded date of diagnosis. Excludes records where the date of diagnosis is before 1930 or after 2024, or where the derived service user age at diagnosis is negative.

We also see variation by organisation type, reflecting the different roles that organisations play in supporting people with cancer at different points in the care pathway (Figure 28). Secondary healthcare organisations tend to support people closest to their diagnosis, with median, lower and upper quartiles of 23.6, 6.4 and 88.6 days between diagnosis and HNA setup, contrasting with community healthcare organisations where it was 230.0, 79.4 and 369.7 days. This is not unexpected since secondary healthcare organisations are typically presented with the first opportunity to offer HNAs when a patient is diagnosed, and initial diagnosis is the most common pathway stage for them to set up HNAs (Figure 17). Similarly, organisations that set up HNAs across a more diverse range of pathway stages, such as social care and primary or community healthcare organisations, tend to also see more variation in time between diagnosis and setup.

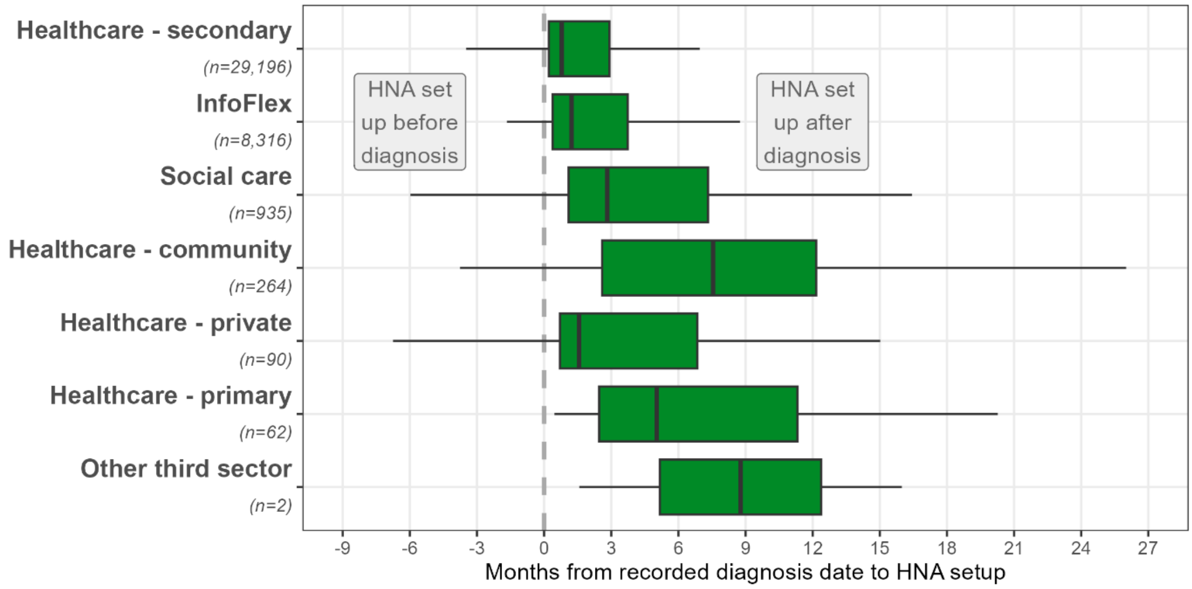


Figure 28. Months from diagnosis to HNA setup by organisation type. Based on HNA records with a recorded date of diagnosis. Excludes records where the date of diagnosis is before 1930 or after 2024, or where the derived age at diagnosis is negative. 'Other third sector' not shown (n = 2).

1,140 records (2.9% of HNAs with a presumed valid date of diagnosis recorded) featured an HNA date occurring before the date of diagnosis. These may not be erroneous as, for example, an HNA can be offered during a long period of testing where cancer is strongly suspected, or even where it has been confirmed but the formal diagnosis is subject to further tests. In other cases, the diagnosis may not occur until treatment has begun and a biopsy performed.

Although people can transition to palliative care months or years after a cancer diagnosis, the median time between diagnosis and HNAs set up with a pathway stage of *Transition to palliative care* is only 55.6 days, suggesting a large proportion have received a diagnosis of advanced cancer recently. For those with an HNA set up while in palliative care the median is 90.8 days, suggesting half had received their diagnosis within the previous 3 months.

Similarly, diagnoses of recurrence can happen years after a first cancer diagnosis, but the median time from diagnoses to HNAs set up with a pathway stage of *Diagnosis of recurrence* is 40.5 days. Additionally, 10% of this group were having their HNA set up more than 48 months after their recorded date of diagnosis. It may be that the date of diagnosis being recorded by the key worker is not consistently referring to either the initial diagnosis or the more recent diagnosis of recurrence.

4.15 Date of HNA submission

The date of HNA submission timestamp is recorded automatically for all electronic submissions. For paper submissions it is recorded as the time when the key worker inputs the concerns data from the completed paper checklist received from the service user and marks the HNA as submitted. The time from setup to submission can be derived as the difference between these two timestamps. Examining this interval helps shape our understanding of how HNAs and care planning is delivered, and the wide-range of operational practices that organisations have in place.

For records imported from InfoFlex the date of submission always matches the date of HNA setup, and so these records are excluded from analysis in this section.

Across all non-InfoFlex records, 49.7% of submitted HNAs were submitted on the same day they were set up. This varies by setting, from home (28.9%) and virtual (27.8%) to ward (75.6%).

HNAs submitted with a setting of *Paper* appeared bimodal in distribution of setup-to-submission interval. 39.7% of these records were submitted within one minute of setup, compared to 6.8% for all other settings combined. This brief time between setup and 'submission' suggests that in many instances the service user may be given access to a paper version of the HNA before the record is set up, with the setup only being recorded once the paper HNA is returned. The concerns are then recorded by the key worker immediately at HNA setup.

However, 29.4% of HNAs submitted via paper were submitted at least two weeks after setup, and 15.5% at least four weeks later. These are higher proportions than for any other setting. This suggests that where the HNA is not submitted immediately after setup, it may instead take a number of weeks for the concerns to be submitted.

Median time from setup to submission differed by setting, with near-immediate completion in *Ward* settings (5 minutes), completion within hours in *Clinic* (2h 29m), *Telephone* (1h 22m) and *Community* (50 minutes), and substantially longer intervals for *Home* (4 days) and *Virtual* (3 days 6 hours). As shown in Figure 29, these distributions are highly skewed, with a concentration of very rapid completions alongside a longer tail of delayed submissions.

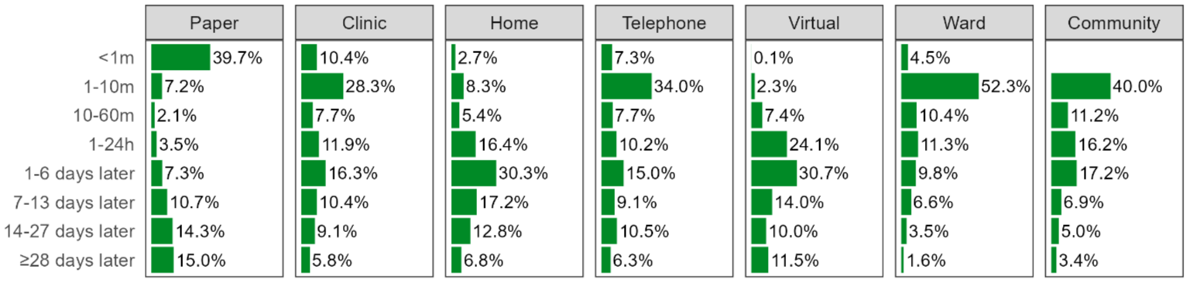


Figure 29. Time between HNA setup and submission by setting. Excludes InfoFlex records and where setting = 'Prison'. The category '1-6 days later' does not include instances where the setup and submission took place on subsequent days but within 24 hours of each other. As such these categories contain a combination of time intervals ('x hours later') and calendar intervals ('x days later').

Median time from setup to submission also varied substantially by organisation type. Very rapid completion was observed in support group (1.5 minutes), community healthcare (2.3 minutes) and other third sector organisations (4.4 minutes). Completion within hours was typical for primary healthcare (5h 35m), private healthcare (5h 59m), Macmillan service (16h 27m) and secondary healthcare organisations (18h 49m), while substantially longer intervals were seen for social care organisations (3 days 21 hours). As shown in Figure 30, these differences reflect markedly different distributions, with some organisation types exhibiting predominantly immediate completion and others showing a broader spread of delayed submissions.

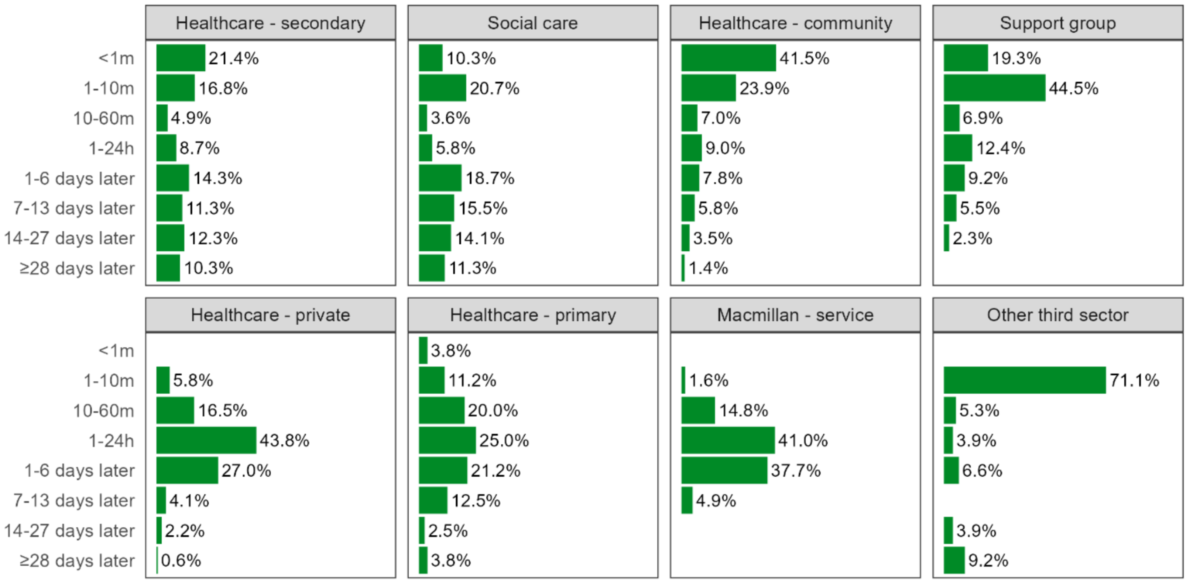


Figure 30. Time between HNA setup and submission, by organisation type. Excludes records from InfoFlex, 'Healthcare – Hospice' and 'Other' organisation types.

HNAs were most commonly submitted on weekdays, with only 4.1% completed at the weekend. This proportion was higher for HNAs completed at home (11.6%) and in virtual settings (11.9%). These patterns likely reflect the timing of HNA setup, which predominantly occurs during standard weekday working hours, combined with a high proportion of submissions taking place on the same day. Same-day completion includes instances where a key worker offers an HNA and the patient completes it immediately, often within a few minutes. It may also reflect paper or telephone-based assessments, where the HNA is set up at the point of delivery or retrospectively recorded following the interaction.

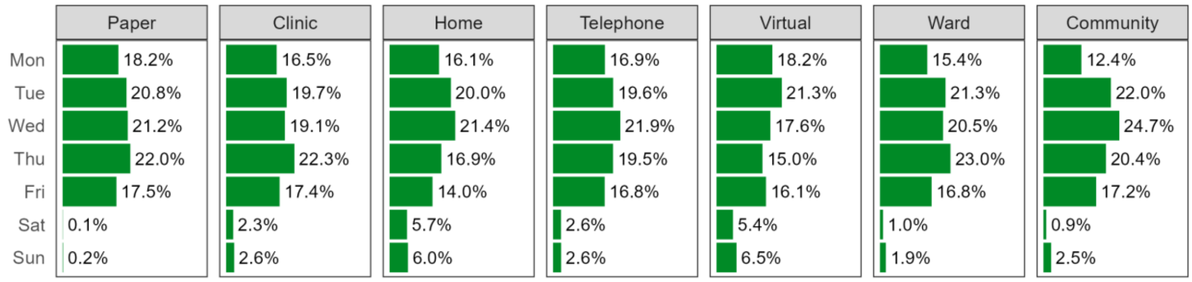


Figure 31. Frequency of HNA submission by day of week.

5 ANALYSIS OF CONCERNS SUBMITTED

5.1 Submission rates

Submission rate in this report is defined as the proportion of set up HNAs that go on to be submitted, regardless of whether any or how many concerns are recorded in the submission.

Of the 120,718 HNA set up in 2023, 76,820 (63.6%) went on to be submitted. An exploration of variation in submission rate between different groups of service users and organisations is featured in Appendix A.

We acknowledge that interpreting variation in submission rates should be done with care and consideration of the various systematic biases that could be influencing how HNAs become set up and go on to be submitted.

5.2 Number of concerns submitted

Analysis of numbers of concerns, types of concerns and of actions in this report (sections 5 and 6) are based on a subset of submitted HNAs that used the same concerns checklist. These constitute 73,916 HNAs, or 96.2% of all submitted HNAs. 77.5% of the HNAs excluded were for people with head and neck cancer, most of whom received the specialised Patient Concerns Inventory (PCI), an alternative version of the concerns checklist developed to identify the unique set of concerns associated with head and neck cancer patients[ii]. Also excluded were quality of life-related assessments such as EQ-5D, EORTC and concerns checklist that were expanded to feature quality of life-related questions.

A table of descriptive statistics, describing the variation in average number of concerns recorded in total and for each domain in submitted HNAs, between different groups of service users and organisational contexts can be found in Appendix B.

There were 63 different concerns that can be recorded within the concerns checklist HNA, and these are presented to the service user across 5 domains (Table 8). Service users are invited to record a score of 1 to 10 for as many concerns as they wish. This score is intended to reflect how concerned they have been about this in the past week, with 1 being a low level of concern and 10 the highest level.

The mean number of concerns submitted was 4.0 out of a total of 63. This rises to 6.8 for HNAs that recorded at least 1 concern. Across the 5 concern domains, the average number of concerns recorded typically correlates with how many concerns exist in that domain A key exception is that there are fewer concerns in the emotional domain than the practical domain, yet a larger proportion of people record an emotional concern. Additionally, the mean number of emotional concerns recorded is higher (1.0 out of a maximum of 12) than for practical concerns (0.8 out of a maximum of 16).

Concern domain	Number of concerns within the checklist	% of submitted HNAs with at least 1 concern recorded	Mean number of concerns recorded in submitted HNAs	Mean number of concerns recorded in submitted HNAs that recorded at least 1 concern of any domain
Physical	27	46.6%	1.9	3.3
Practical	16	32.1%	0.8	1.3
Emotional	12	32.6%	1.0	1.7
Family	5	16.3%	0.3	0.5
Religious and spiritual	3	3.3%	0.1	0.1
Total	**63**	**59.6%**	**4.05**	**6.8**

Table 8. Descriptive statistics of concern domains recorded in HNAs.

[ii] The development of a Patients Concerns Inventory (PCI) to help reveal patients concerns in the head and neck clinic, https://www.sciencedirect.com/science/article/pii/S1368837508002844

40.4% of submitted HNAs had no concerns recorded within them (Figure 32) – we comment on the interpretation of this in section 3.6. 24.7% of submitted HNAs included at least 5 concerns, 12.5% included 10 or more, 4.4% contained 20 or more and 0.2% contained all 63 concerns recorded.

75.3% of submitted HNAs recorded between 0 and 4 concerns, and 90.1% recorded between 0 and 11 concerns.

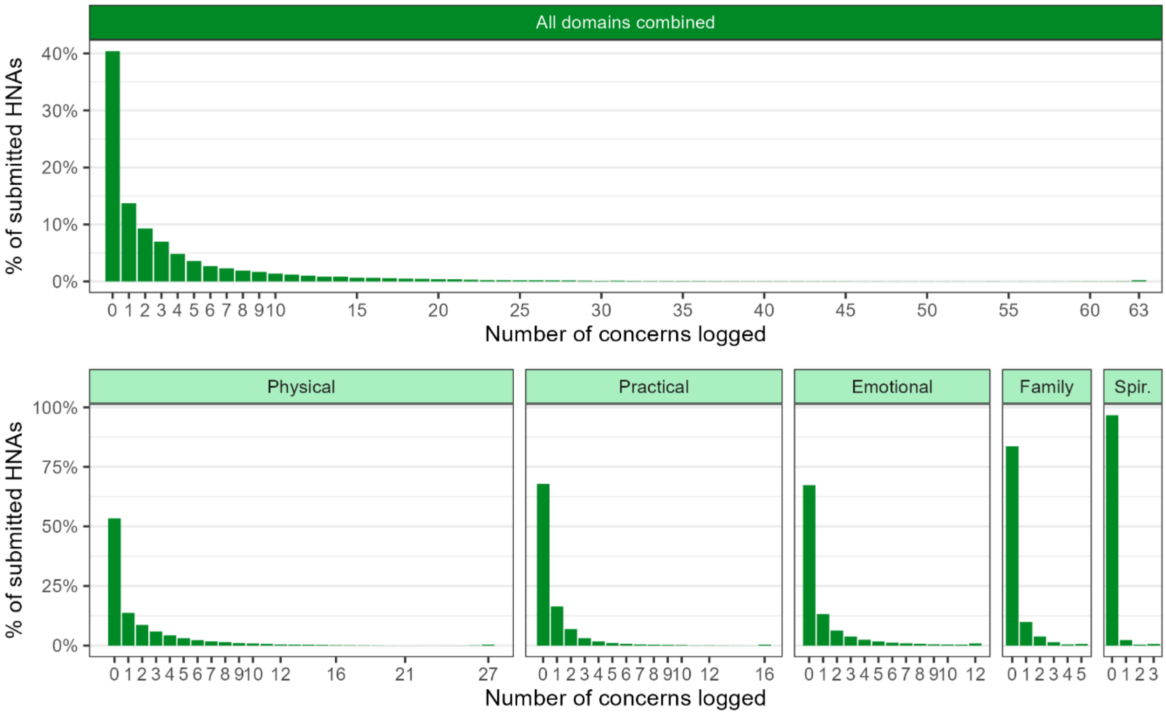


Figure 32. Distribution of the number of concerns recorded within submitted HNAs. Spir. = Spiritual.

Notably, HNAs submitted with a setting of *Paper* see a particularly low number of concerns recorded (Table 9). 90% of submitted assessments had 5 or fewer concerns recorded. This could be an artifact of the key workers having to manually enter concerns from the paper questionnaire onto the platform in order to proceed to recorded care planning. It may be that not all concerns are recorded as a result of this additional burden.

Assessments submitted on Saturday or Sunday tend to have more concerns recorded than those on a weekday. This is most pronounced where the setting is *Paper*, *Clinic*, *Telephone* or *Ward*. Relatedly, assessments submitted between 6pm and 6am tend to have more concerns recorded than those between 6am and 6pm. This finding persists across all settings.

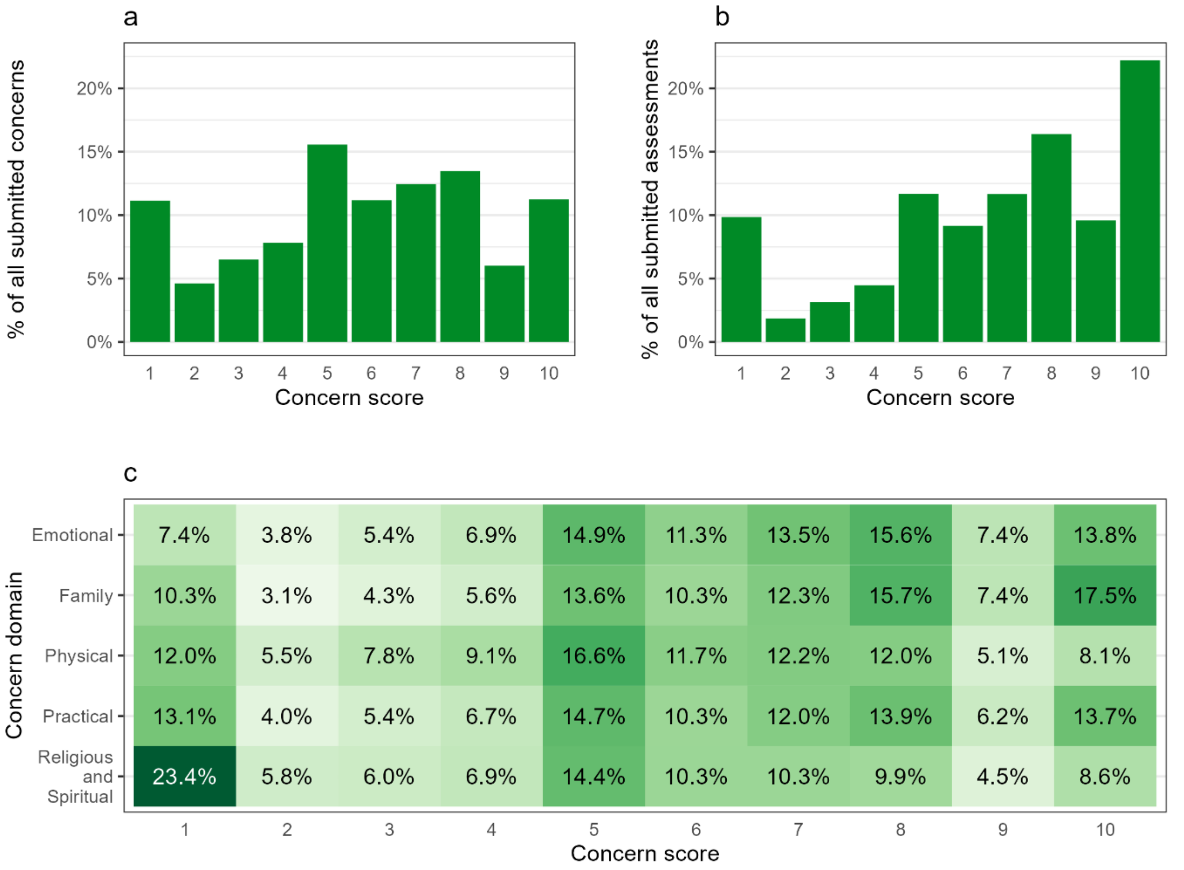
Setting	Number of HNAs submitted	Number of concerns recorded		Percentile				
		Mean	Standard deviation	10	25	50	75	90
Paper	29,032	1.9	4.2	0	0	1	2	5
Telephone	17,044	3.8	7.5	0	0	1	4	11
Clinic	15,711	4.7	8.1	0	0	1	6	13
Home	9,439	8.7	10.8	0	2	5	12	21
Virtual	1,314	12.0	12.5	1	3	8.5	17	26
Ward	964	5.0	7.6	0	1	3	6	13
Community	410	8.4	11.2	1	2	4	9	22
Total	**73,916**	**4.0**	**7.7**	**0**	**0**	**1**	**4**	**11**

Table 9. Summary statistics describing the number of concerns recorded in submitted assessments by Setting. Statistics not shown for Prison (n=2).

5.3 Concern scores

Across all 298,992 concerns recorded within submitted HNAs, a score of 5 out of 10 was the most common with 15.6% of all concerns (Figure 33a). This is followed by 8 (13.5%) and 7 (12.4%). Although more than a tenth of all concerns are given a score of 1, service users are less likely to record a concern as 2, 3, or 4. 22.2% of HNAs included at least one concern that was scored 10 (Figure 33b) and 9.9% of HNAs only featured concerns scoring 1.

Distributions varied between concern domains (Figure 33c). The most recorded score for family concerns was 10, for emotional concerns it was 8, for physical or practical concerns it was 5 and the most common score given to religious or spiritual concerns was 1. Although the scores given to concerns will correlate to the severity felt by the service user, a reporting bias may influence scoring patterns. For instance, a service user may experience religious and spiritual concerns but not wish to discuss them with the key worker.



Concern domain	1	2	3	4	5	6	7	8	9	10
Emotional	7.4%	3.8%	5.4%	6.9%	14.9%	11.3%	13.5%	15.6%	7.4%	13.8%
Family	10.3%	3.1%	4.3%	5.6%	13.6%	10.3%	12.3%	15.7%	7.4%	17.5%
Physical	12.0%	5.5%	7.8%	9.1%	16.6%	11.7%	12.2%	12.0%	5.1%	8.1%
Practical	13.1%	4.0%	5.4%	6.7%	14.7%	10.3%	12.0%	13.9%	6.2%	13.7%
Religious and Spiritual	23.4%	5.8%	6.0%	6.9%	14.4%	10.3%	10.3%	9.9%	4.5%	8.6%

Figure 33. a. Distribution of scores given to all concerns recorded in submitted HNAs. B. Distribution of scores given to the highest scoring concern within submitted HNAs. C. Distribution of scores given to all concerns recorded in submitted HNAs, across each concern domain.

For each of the 63 concerns in the concern checklist, we have calculated how frequently they are recorded in submitted HNAs, how frequently they are the highest scoring concern within a submitted HNA (Figure 34b) and the overall mean score (Figure 34a). A table detailing these summary statistics, and more, can be found in Appendix C.

Family-related concerns tend to be reported with low frequencies, with the most reported concern in this domain (*Partner*) being recorded in 8.4% of submitted HNAs. However, when they are reported they tend to receive high scores, with mean scores in this domain ranging from 5.8 (*Other relatives or friends*) to 6.5 (*Partner* and *Children*). Of all family-related concerns *Person who I look after* was most likely to be the highest scoring concern in a submitted HNA, occurring in 46.5% of HNAs where it was recorded. Life stage determines the relevance of the concerns in this domain, and they are significant when applicable.

Emotional concerns see a wide range in how frequently they are recorded, spanning 3.1% (*Guilt*) to 19.6% (*Worry fear and anxiety*). However, when they are reported in HNAs they tend to score highly, with *Uncertainty* and *Thinking about the future* seeing the highest mean scores (both 6.6) across all concerns within the checklist. As well as being the second most reported of all concerns, *worry fear and anxiety* was most likely to be the highest scoring emotional concern in a submitted HNA, occurring in 44.2% of HNAs where it was recorded.

Religious and spiritual concerns are reported in very low frequencies, ranging from 1.0% (*Feeling at odds with my culture, belief or values*) to 2.5% (*Meaning or purpose of life*). They also tend to receive lower scores than those in other domains, with mean scores ranging from 4.1 (*Feeling at odds with my culture, belief or values*) to 5.5 (*Meaning or purpose of life*). 23.4% of concerns reported in this domain were given a score of 1. They were rarely the highest scoring concern in a submitted, with *Faith or spirituality* being occurring in 16.4% of HNAs where it was recorded.

Within the practical concerns domain, *Money or finan*ce deviates from the observed scoring patterns, and we describe it separately from the other concerns in this domain. *Money or finance* was the third most reported of all concerns, appearing in 16.5% of submitted concerns. It tended to be high scoring, with a mean score of 6.3 out of 10. It is also the single concern to be the highest scoring within a submitted HNA, occurring as the highest scoring concern in 54.7% of HNAs where it was recorded.

Money or finance is a broadly named concern which service users may attribute to a range of specific issues, such as household bills, travel insurance, cost of care or loss of income.

Other practical concerns tend to be recorded less frequently, ranging from 1.0% (*Problems with alcohol or drugs*) to 6.8% (*Transport or parking*). However, they are wide ranging in terms of how highly they tend to be scored, from 3.6 (*Problems with alcohol or drugs*) to 6.5 (*Housing*). After *Money or Finance*, *Housing* is the concern to be the highest scoring within a submitted HNA, occurring as the highest scoring concern in 47.0% of HNAs where it was recorded.

Physical concerns see a wide range in reporting frequency within submitted HNAs, from 1.5% (*High temperature or fever*) to the most reported concern across all domains, *Tired, exhausted or fatigued* at 21.2%. Although their range of frequencies is like that of emotional concerns, they tend to be scored lower than emotional concerns. The physical concerns most likely to be highest scoring within the HNA they appear are *Sex, intimacy or fertility* (41.9%), *Other medical conditions* (41.7%) and *Pain or discomfort* (40.1%).

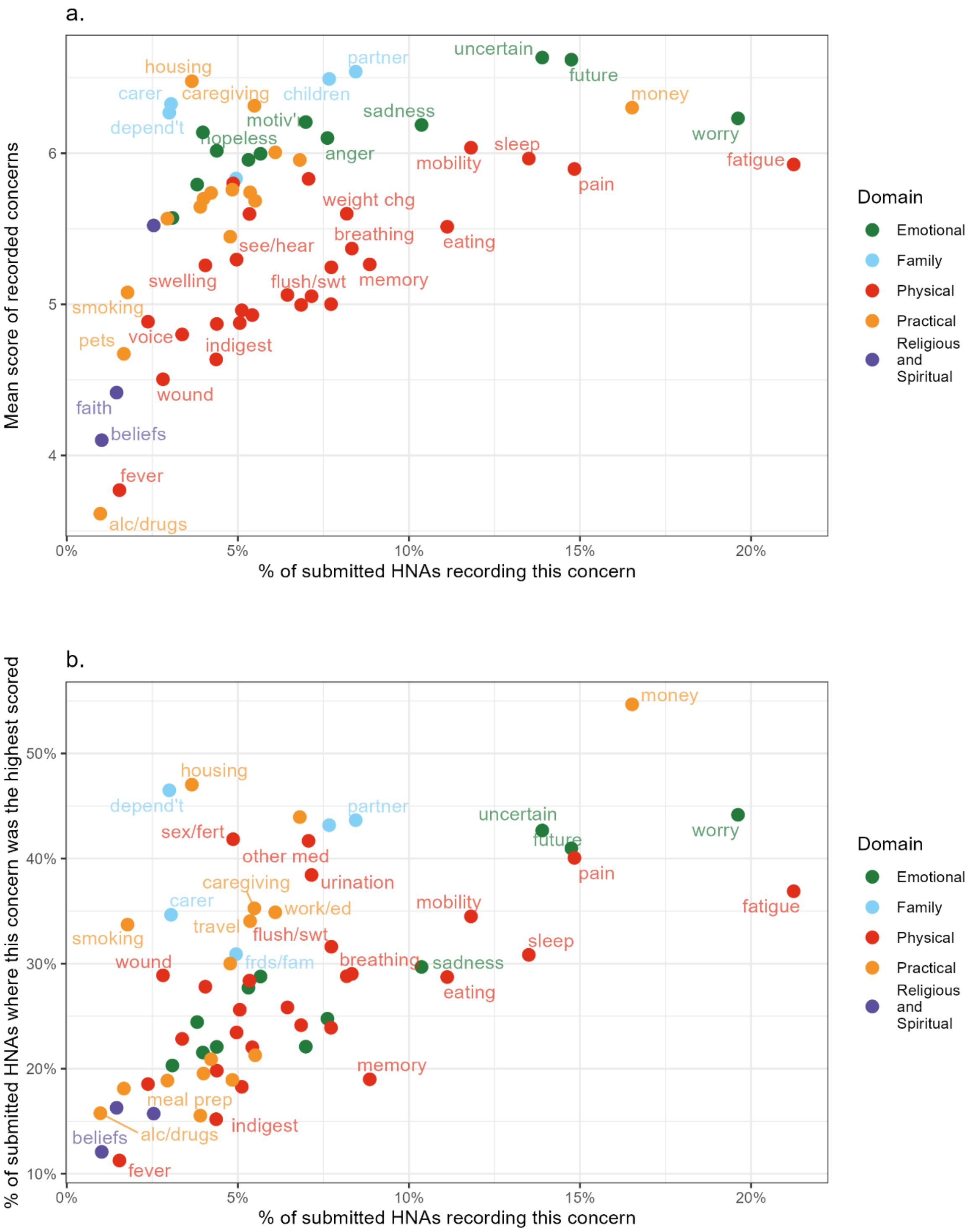


Figure 34. a. Relationship between how frequently concerns is recorded in submitted HNAs and the mean scores were recorded. b. Relationship between how frequently concerns is recorded in submitted HNAs and how frequently the concern is the highest or joint-highest scoring within HNAs. Concern names are shown abbreviated, with full names available in Appendix C.

5.4 Most common concerns

Increasing age group was found to be associated with recording fewer concerns within submitted HNAs (Appendix B). 18–49-year-olds reported a mean total of 5.8 concerns, while those in their 70s, 80s and 90s or above reported a mean total of 3.4, 3.0 and 2.8 concerns respectively. This trend persists across each of the 5 concern domains, with emotional concerns appearing to have the strongest differential gradient.

Some concerns such as *Worry, fear or anxiety* and *Tired, exhausted or fatigued* are common across most age groups (Figure 35a). Others reflect differences in typical life experiences across the ages, for example those of working age are more likely to report feeling concerned about *Work or education* or about *Money or finance*. Those aged 40-49 were more than twice as likely (x2.56) to record a concern about *Children* than the average service user (Figure 35b). For the older age groups, fewer concerns are reported but concerns related to the physical aspect of quality of life are more prominent such as *Moving around (walking)* and *Pain or discomfort*.

Figure 35. a. For each age group, the top five most frequently recorded concerns, with percentage of submitted HNAs recording the concern. b. For each age group, the top three concerns that show the largest statistically significant increase in frequency of being recorded in submitted HNAs compared to the proportion for all submitted HNAs combined (based on chi-squared test for proportions, $p < 0.05$). The multipliers shown indicate how many times more frequently the concerns were recorded compared with the total file. Concern names are shown abbreviated, with full names available in Appendix C.

Although female service users tend to record more concerns (mean = 4.4) than males (mean = 3.8), they report the same list of top 5 concerns (Appendix B). Female service users were more likely to report concerns related to personal appearance, housework or hot flushes whereas male service users were more likely to report concerns related to passing urine, substance abuse or sex and intimacy (Figure 36). These may be partly driven by differences in symptoms or treatment side effects related to sex-associated cancers.

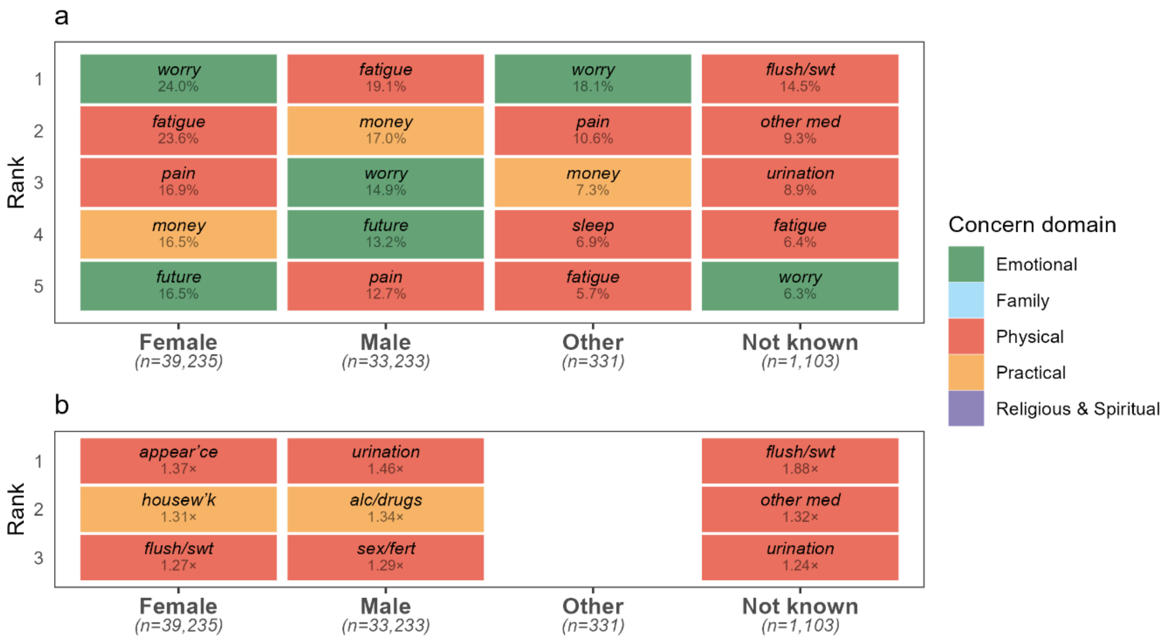


Figure 36. a. For each sex, the top five most frequently recorded concerns, with percentage of submitted HNAs recording the concern. b. For each sex, the top three concerns that show the largest statistically significant increase in frequency of being recorded in submitted HNAs compared to the proportion for all submitted HNAs combined (based on chi-squared test for proportions, $p < 0.05$). The multipliers shown indicate how many times more frequently the concerns were recorded compared with the total file. Concern names are shown abbreviated, with full names available in Appendix C.

A much larger average number of concerns was found in HNAs conducted in languages other than English (mean = 16.5) than those conducted in English (4.0, Appendix B). This may be partly associated with different levels of engagement that service users have with the HNA or their relative levels of need, given that HNAs are recorded as having been conducted in an alternative language only if the service user has actively requested this.

The concerns most submitted are similar. However, religious and spiritual concerns were several times more likely to be included in HNAs conducted in a language other than English (Figure 37).

The ethnic group of the service user was recorded in only a minority of submitted HNAs, and there is likely to be some degree of selection bias associated with organisations or teams that are more likely to record this value. The existence of a recorded ethnic group is associated with a higher number of concerns submitted than where the ethnic group was not recorded (Appendix B).

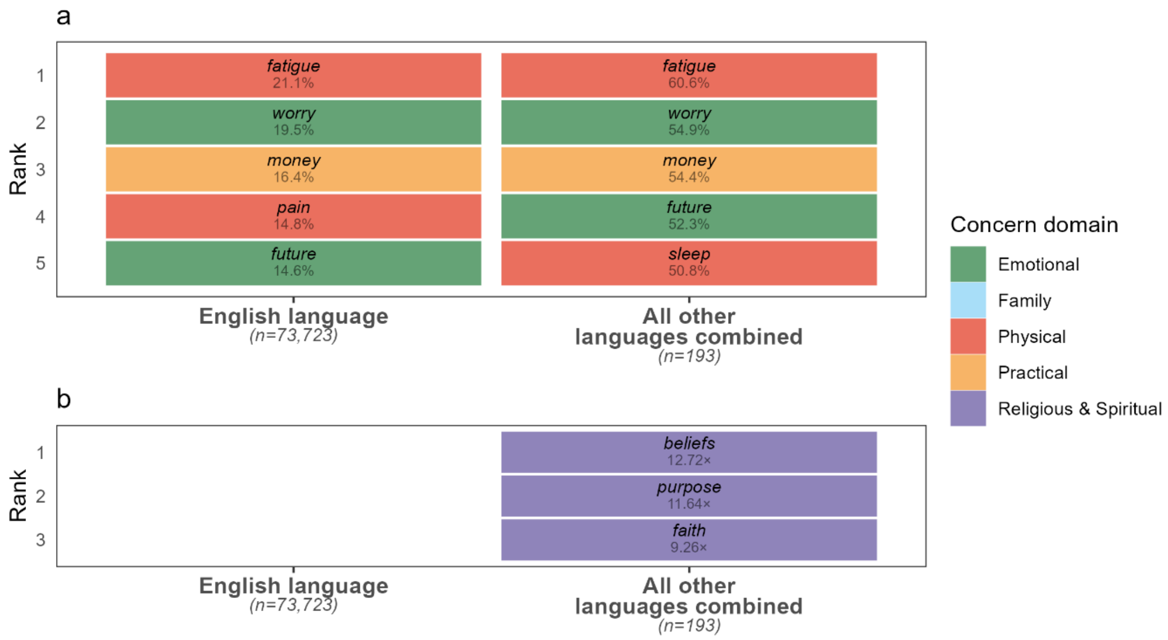


Figure 37. a. For each language group, the top five most frequently recorded concerns, with percentage of submitted HNAs recording the concern. b. For each language group, the top three concerns that show the largest statistically significant increase in frequency of being recorded in submitted HNAs compared to the proportion for all submitted HNAs combined (based on chi-squared test for proportions, $p < 0.05$). The multipliers shown indicate how many times more frequently the concerns were recorded compared with the total file. Concern names are shown abbreviated, with full names available in Appendix C.

The most common concerns are similar between those recorded as White British and those recorded as belonging to any other ethnic group. *Feeling at odds with my culture, beliefs or value* was 3.41 times more likely to be recorded in HNAs submitted by service users from ethnically diverse communities than the average rate across all submitted HNAs (Figure 38).

HNAs set up at *Initial diagnosis* pathway stage recorded a lower average number of concerns in four of five domains and the lowest overall number of concerns of any pathway stage (mean = 3.7; Appendix B). The largest number of concerns was found where pathway stage had a known value of *Prehabilitation* (mean = 5.4), *Diagnosis of recurrence* (5.1) or *Transition to palliative care* (5.9).

Physical concerns saw the largest average number of all domains in each pathway stage. This was followed by emotional concerns in all pathway stages, except for *Transition to palliative care* and *In palliative care*, which saw a larger average number of practical concerns instead.

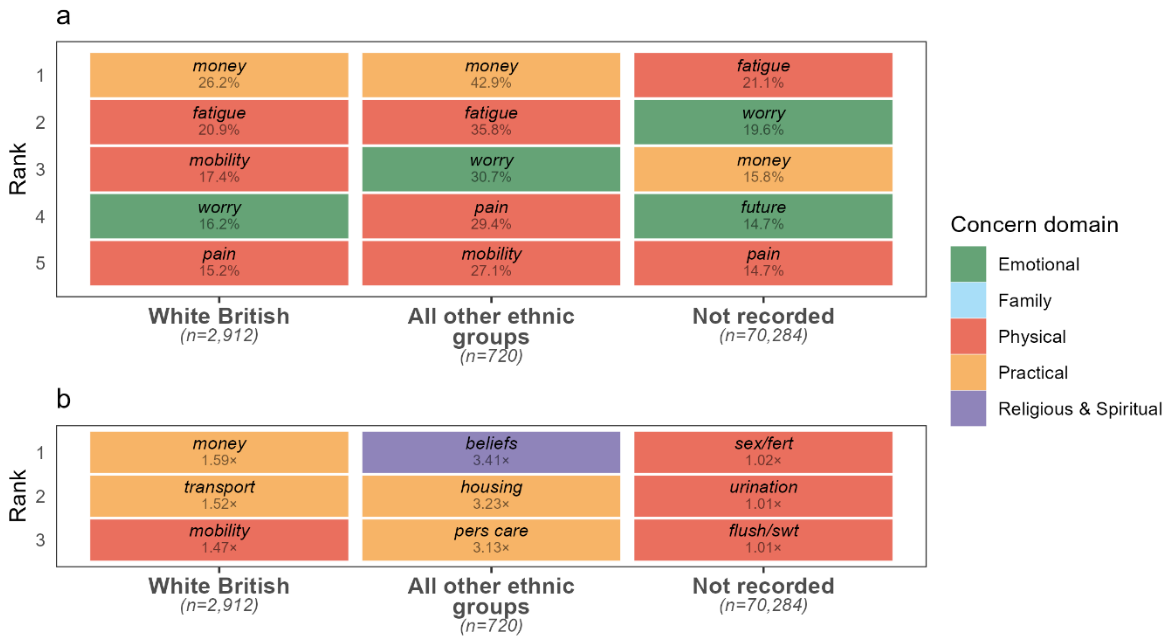
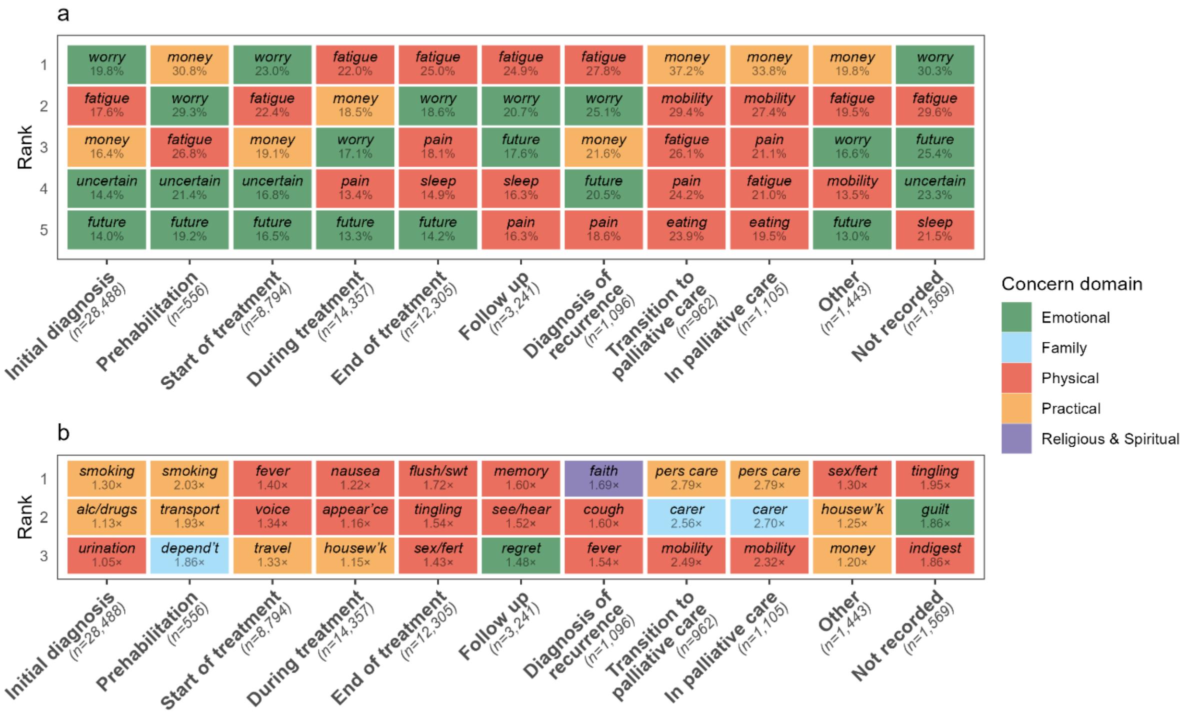


Figure 38. a. For each ethnic group category, the top five most frequently recorded concerns, with percentage of submitted HNAs recording the concern. b. For each ethnic group category, the top three concerns that show the largest statistically significant increase in frequency of being recorded in submitted HNAs compared to the proportion for all submitted HNAs combined (based on chi-squared test for proportions, $p < 0.05$). The multipliers shown indicate how many times more frequently the concerns were recorded compared with the total file. Concern names are shown abbreviated, with full names available in Appendix C.

Tired, exhausted and fatigued was a concern recorded across most stages of the cancer pathway, and was the most common concern for those with HNAs during or after treatment (Figure 39). One in three HNAs submitted for service users transitioning to palliative care (37.2%) or in palliative care (33.8%) recorded *Money or finance* as a concern. Service users in these pathway stages were also more than twice as likely to record concerns related to *Washing and dressing*, *Person who looks after me* or *moving around (walking)*.

HNAs submitted via InfoFlex have fewer concerns recorded than from any other organisation type (mean = 1.4; Appendix B). The largest numbers of concerns were found in HNAs submitted via primary healthcare (mean = 10.5), private healthcare (8.6) and Macmillan service (9.6) organisation types (Figure 40).

The profile of types of concerns recorded varies noticeably between organisation types, reflecting the different referral mechanisms that may be in place or the types of support they discuss with service users during the HNA offer. Although physical concerns are recorded in greater numbers than any other domain across all organisation types, the second most common domain of concern recorded varies. For most organisation types, emotional concerns follow but HNAs submitted via social care or other third sector organisations see larger number of practical concerns recorded instead.



a

Rank	Initial diagnosis (n=28,488)	Prehabilitation (n=556)	Start of treatment (n=8,794)	During treatment (n=14,357)	End of treatment (n=12,305)	Follow up (n=3,241)	Diagnosis of recurrence (n=1,096)	Transition to palliative care (n=962)	In palliative care (n=1,105)	Other (n=1,443)	Not recorded (n=1,569)
1	worry 19.8%	money 30.8%	worry 23.0%	fatigue 22.0%	fatigue 25.0%	fatigue 24.9%	fatigue 27.8%	money 37.2%	money 33.8%	money 19.8%	worry 30.3%
2	fatigue 17.6%	worry 29.3%	fatigue 22.4%	money 18.5%	worry 18.6%	worry 20.7%	worry 25.1%	mobility 29.4%	mobility 27.4%	fatigue 19.5%	fatigue 29.6%
3	money 16.4%	fatigue 26.8%	money 19.1%	worry 17.1%	pain 18.1%	future 17.6%	money 21.6%	fatigue 26.1%	pain 21.1%	worry 16.6%	future 25.4%
4	uncertain 14.4%	uncertain 21.4%	uncertain 16.8%	pain 13.4%	sleep 14.9%	sleep 16.3%	future 20.5%	pain 24.2%	fatigue 21.0%	mobility 13.5%	uncertain 23.3%
5	future 14.0%	future 19.2%	future 16.5%	future 13.3%	future 14.2%	pain 16.3%	pain 18.6%	eating 23.9%	eating 19.5%	future 13.0%	sleep 21.5%

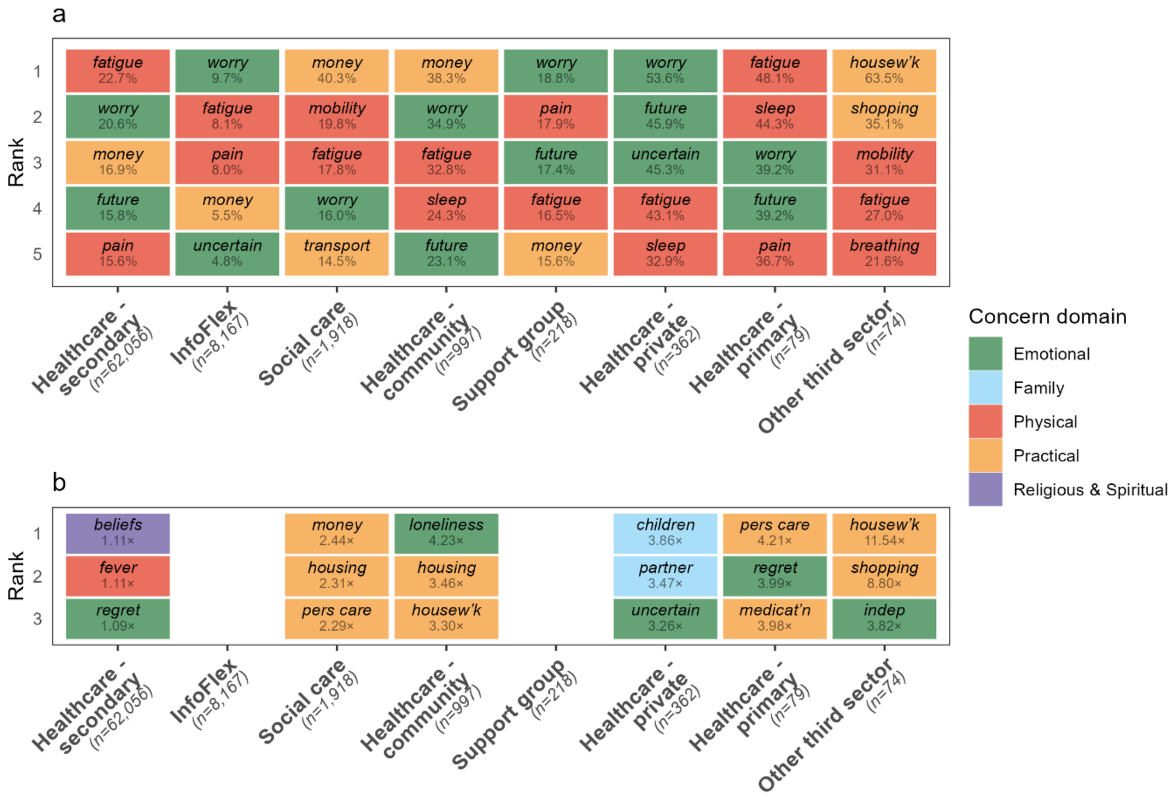
b

Rank	Initial diagnosis (n=28,488)	Prehabilitation (n=556)	Start of treatment (n=8,794)	During treatment (n=14,357)	End of treatment (n=12,305)	Follow up (n=3,241)	Diagnosis of recurrence (n=1,096)	Transition to palliative care (n=962)	In palliative care (n=1,105)	Other (n=1,443)	Not recorded (n=1,569)
1	smoking 1.30×	smoking 2.03×	fever 1.40×	nausea 1.22×	flush/swt 1.72×	memory 1.60×	faith 1.69×	pers care 2.79×	pers care 2.79×	sex/fert 1.30×	tingling 1.95×
2	alc/drugs 1.13×	transport 1.93×	voice 1.34×	appear'ce 1.16×	tingling 1.54×	see/hear 1.52×	cough 1.60×	carer 2.56×	carer 2.70×	housew'k 1.25×	guilt 1.86×
3	urination 1.05×	depend't 1.86×	travel 1.33×	housew'k 1.15×	sex/fert 1.43×	regret 1.48×	fever 1.54×	mobility 2.49×	mobility 2.32×	money 1.20×	indigest 1.86×

Figure 39. a. For each pathway stage, the top five most frequently recorded concerns, with percentage of submitted HNAs recording the concern. b. For each pathway stage, the top three concerns that show the largest statistically significant increase in frequency of being recorded in submitted HNAs compared to the proportion for all submitted HNAs combined (based on chi-squared test for proportions, $p < 0.05$). The multipliers shown indicate how many times more frequently the concerns were recorded compared with the total file. Concern names are shown abbreviated, with full names available in Appendix C.

Around two in five HNAs submitted via social care (40.3%) or community healthcare (38.3%) organisations included *Money or finance* as a recorded concern (Figure 40). *Loneliness or isolation* was recorded in 22.5% of HNAs submitted via community healthcare organisations, compared to just 5.3% across all submitted HNAs overall. HNAs submitted via private healthcare organisations were more than three times as likely to record family concerns related to *Children* or *Partner* than submitted HNAs overall.

The average numbers of concerns in submitted HNAs varies between organisations of different regions (Figure 41). Organisations based outside of England saw larger numbers of concerns overall (Wales mean = 7.6, Scotland = 6.1 and Northern Ireland 7.6) and across four of five domains (Appendix B). Fewer concerns were recorded in HNAs submitted via organisations based in the North of England (2.9), North West (3.0) and South and East (2.3).



a

Rank	Healthcare - secondary (n=62,056)	InfoFlex (n=8,167)	Social care (n=1,918)	Healthcare - community (n=997)	Support group (n=218)	Healthcare - private (n=362)	Healthcare - primary (n=79)	Other third sector (n=74)
1	fatigue 22.7%	worry 9.7%	money 40.3%	money 38.3%	worry 18.8%	worry 53.6%	fatigue 48.1%	housew'k 63.5%
2	worry 20.6%	fatigue 8.1%	mobility 19.8%	worry 34.9%	pain 17.9%	future 45.9%	sleep 44.3%	shopping 35.1%
3	money 16.9%	pain 8.0%	fatigue 17.8%	fatigue 32.8%	future 17.4%	uncertain 45.3%	worry 39.2%	mobility 31.1%
4	future 15.8%	money 5.5%	worry 16.0%	sleep 24.3%	fatigue 16.5%	fatigue 43.1%	future 39.2%	fatigue 27.0%
5	pain 15.6%	uncertain 4.8%	transport 14.5%	future 23.1%	money 15.6%	sleep 32.9%	pain 36.7%	breathing 21.6%

b

Rank	Healthcare - secondary (n=62,056)	InfoFlex (n=8,167)	Social care (n=1,918)	Healthcare - community (n=997)	Support group (n=218)	Healthcare - private (n=362)	Healthcare - primary (n=79)	Other third sector (n=74)
1	beliefs 1.11×		money 2.44×	loneliness 4.23×		children 3.86×	pers care 4.21×	housew'k 11.54×
2	fever 1.11×		housing 2.31×	housing 3.46×		partner 3.47×	regret 3.99×	shopping 8.80×
3	regret 1.09×		pers care 2.29×	housew'k 3.30×		uncertain 3.26×	medicat'n 3.98×	indep 3.82×

Figure 40. a. For each organisation type, the top five most frequently recorded concerns, with percentage of submitted HNAs recording the concern. b. For each organisation type, the top three concerns that show the largest statistically significant increase in frequency of being recorded in submitted HNAs compared to the proportion for all submitted HNAs combined (based on chi-squared test for proportions, $p < 0.05$). The multipliers shown indicate how many times more frequently the concerns were recorded compared with the total file. Concern names are shown abbreviated, with full names available in Appendix C.

Scotland was the only region to report a higher average number of concerns in the practical domain than the emotional domain. This is linked to having the highest proportion of *Money or finance* concerns recorded (42.5%) of any region, which in turn is associated with the Improving the Cancer Journey service based there (Figure 41). Service users in London had an increased likelihood of reporting housing as a concern compared to other regions.

HNAs submitted through the virtual setting tended to record the most concerns overall (mean = 12.0) and across all five concern domains (Appendix B). The lowest average number of concerns was recorded in HNAs submitted via telephone (3.8) and paper (1.9) settings. Trends associated with setting are influenced by differences in which setting is offered by different organisations.

The concerns most recorded appear to be a mix of clinical and non-clinical concerns, regardless of whether the HNAs were set up with a clinical setting, such as ward or clinic (Figure 42).

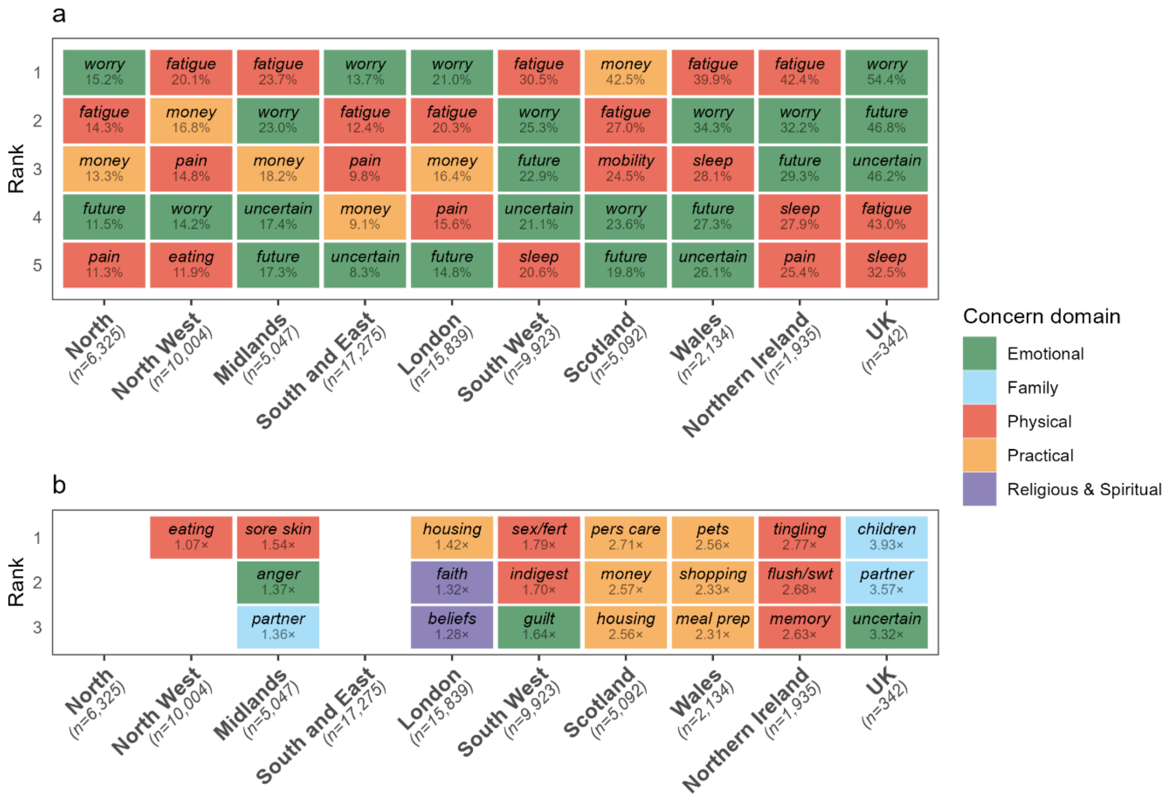


Figure 41. a. For each region, the top five most frequently recorded concerns, with percentage of submitted HNAs recording the concern. b. For each region, the top three concerns that show the largest statistically significant increase in frequency of being recorded in submitted HNAs compared to the proportion for all submitted HNAs combined (based on chi-squared test for proportions, $p < 0.05$). The multipliers shown indicate how many times more frequently the concerns were recorded compared with the total file. Concern names are shown abbreviated, with full names available in Appendix C.

Service users with prostate, skin or 'other' cancer types reported fewer concerns on average in all five concern domains (Appendix B). A larger than average number of concerns were recorded by those with neuroendocrine (mean = 8.6), brain/CNS (6.3), haematological (4.9), lung (4.9), upper gastrointestinal (4.9) and head and neck (4.8) cancers

The types of concerns recorded were often associated with the types of symptoms experienced by people with different types of cancer. Service users with head and neck cancers were more than 5 times more likely to record concerns of *Speech or voice problems* or *Swallowing* than submitted HNAs overall (Figure 43, Figure 44). Concerns of *Breathing difficulties*, *Cough* and *Smoking cessation* were all recorded at least twice as often by service users with lung cancer. *Diarrhoea* or *Constipation* was recorded more often in those with a lower gastrointestinal cancer. Service users with a brain or CNS cancer were at least twice as likely to record concerns related to *Speech or voice problem*, *Memory, concentration*, or *Independence*. HNAs submitted by people with an upper GI cancer were more likely to record concerns related to *Swallowing*, *Eating, appetite or taste*, or *Nausea or vomiting*. *Diarrhoea* was more than 5 times more likely to be recorded by people with a neuroendocrine cancer. Those with prostate cancer were more than twice as likely to record concerns of *Passing urine* or *Sex, intimacy or fertility*.

Money or finance was a common concern across most cancers apart from breast, prostate and skin. These three cancer types are also cancers that are more likely to be diagnosed in people living in the least deprived areas in England[25].

Figure 42. a. For each setting, the top five most frequently recorded concerns, with percentage of submitted HNAs recording the concern. b. For each setting, the top three concerns that show the largest statistically significant increase in frequency of being recorded in submitted HNAs compared to the proportion for all submitted HNAs combined (based on chi-squared test for proportions, $p < 0.05$). The multipliers shown indicate how many times more frequently the concerns were recorded compared with the total file. Concern names are shown abbreviated, with full names available in Appendix C.

a

Rank	Acute leukaemia (n=285)	Breast (n=15,810)	Cancer of unknown primary (n=158)	CNS/Brain (n=707)	Gynae (n=5,762)	Haematology (n=5,831)	Head and neck (n=2,000)	Lower GI (n=8,306)	Lung (n=7,668)
1	money 36.8%	worry 25.4%	money 32.3%	fatigue 34.8%	worry 23.2%	fatigue 29.0%	money 23.8%	fatigue 21.0%	breathing 26.0%
2	fatigue 25.6%	fatigue 24.0%	mobility 31.0%	money 34.7%	fatigue 19.1%	money 21.0%	worry 23.5%	worry 20.2%	fatigue 24.8%
3	transport 21.8%	pain 17.5%	pain 29.1%	mobility 28.6%	money 16.6%	worry 19.8%	eating 21.2%	money 18.6%	money 22.5%
4	mobility 19.6%	future 17.2%	fatigue 25.3%	memory 28.4%	uncertain 14.9%	mobility 16.6%	fatigue 20.2%	uncertain 14.6%	pain 20.9%
5	worry 17.9%	sleep 16.8%	eating 20.9%	uncertain 24.0%	pain 14.4%	future 15.7%	swallow 18.0%	future 14.0%	mobility 19.4%

b

Rank	Acute leukaemia (n=285)	Breast (n=15,810)	Cancer of unknown primary (n=158)	CNS/Brain (n=707)	Gynae (n=5,762)	Haematology (n=5,831)	Head and neck (n=2,000)	Lower GI (n=8,306)	Lung (n=7,668)
1	fever 3.20×	flush/swt 1.85×	pers care 2.85×	voice 3.22×	constip 1.19×	fever 1.85×	voice 5.40×	diarrhoea 1.96×	breathing 3.12×
2	transport 3.19×	appear'ce 1.74×	mobility 2.63×	memory 3.21×	worry 1.18×	sore mouth 1.62×	swallow 5.36×	constip 1.20×	cough 2.77×
3	housing 2.50×	work/ed 1.38×	transport 2.32×	indep 2.87×	guilt 1.15×	tingling 1.56×	sore mouth 2.94×	tingling 1.18×	smoking 2.62×

Figure 43. a. For each condition (A to L), the top five most frequently recorded concerns, with percentage of submitted HNAs recording the concern. b. For each condition (A to L), the top three concerns that show the largest statistically significant increase in frequency of being recorded in submitted HNAs compared to the proportion for all submitted HNAs combined (based on chi-squared test for proportions, $p < 0.05$). The multipliers shown indicate how many times more frequently the concerns were recorded compared with the total file. Concern names are shown abbreviated, with full names available in Appendix C.

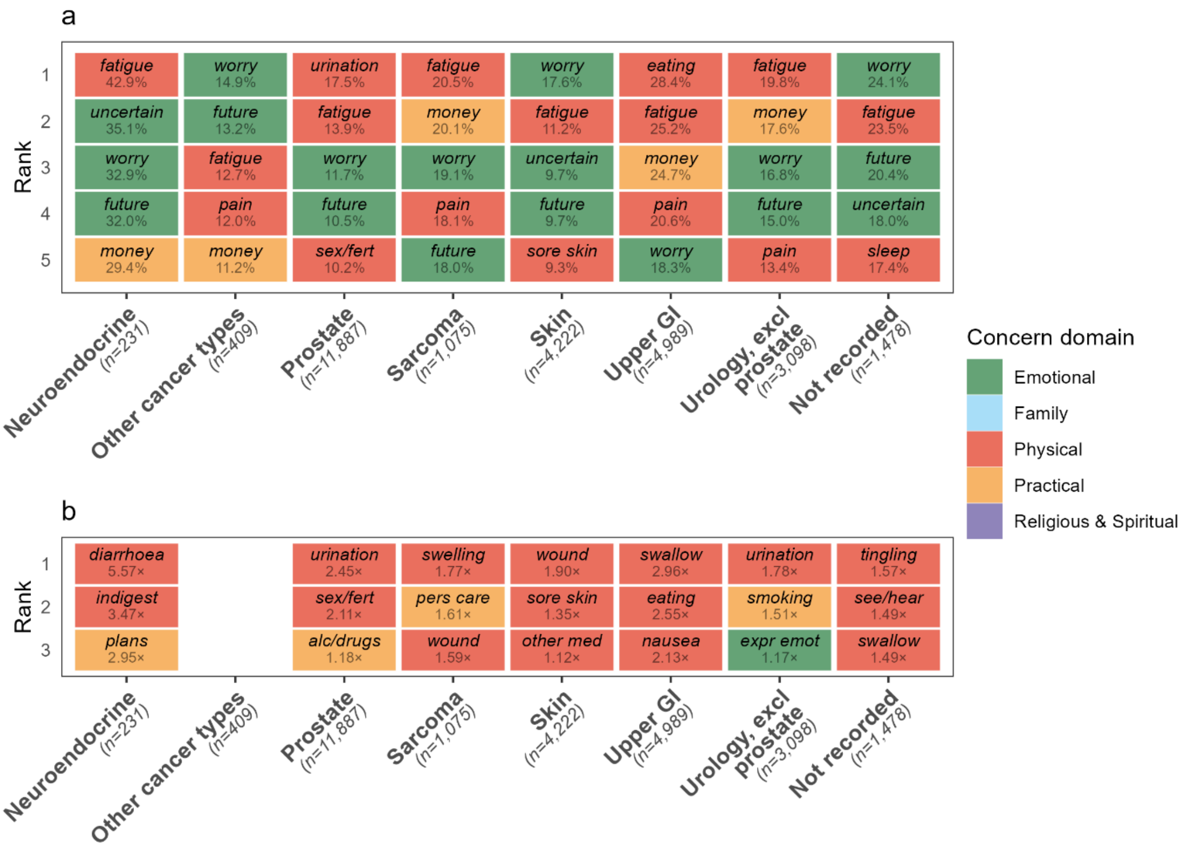


Figure 44. a. For each condition (M to Z), the top five most frequently recorded concerns, with percentage of submitted HNAs recording the concern. b. For each condition (M to Z), the top three concerns that show the largest statistically significant increase in frequency of being recorded in submitted HNAs compared to the proportion for all submitted HNAs combined (based on chi-squared test for proportions, $p < 0.05$). The multipliers shown indicate how many times more frequently the concerns were recorded compared with the total file. Concern names are shown abbreviated, with full names available in Appendix C.

6 ANALYSIS OF ACTIONS AND CARE PLANS

6.1 Actions

Actions are optionally recorded by the key worker within the Macmillan eHNA Platform, against specific concerns in submitted HNAs that they are intended to address. These actions may then feature in a care plan should the key worker create one within the platform. The analysis of actions in this section is based on a subset of HNAs that use a consistent concerns checklist, as described in section 5.2, and exclude HNAs set up by InfoFlex organisations since no actions or care plan activity is contained in these records.

65,749 HNAs were set up in 2023 and subsequently submitted by the service user. These contained a total of 287,712 concerns, of which 90,891 concerns (31.6%) had at least one corresponding action recorded by the key worker. Of the 62,632 HNAs with a status of either *In progress* or *Locked*, a total of 264,034 concerns were recorded, and 90,891 of these (34.4%) had at least one corresponding action recorded. A much higher proportion of concerns had a recorded action where the assessment was *Locked* (35.8%) compared to *In progress* (10.6%), reflecting the incomplete nature of records that have not been locked.

The likelihood of a given concern having an action recorded against it is influenced by several factors including the concern's score, type of concern, total number of concerns submitted in the HNA, how high the concern scores amongst the other concerns within the submitted HNA and the organisation delivering the HNA and care planning offer. HNA and care planning records set up by InfoFlex organisations contain no information related to actions or care plans so are excluded from such analyses.

Concerns given a higher score are more likely to have an action recorded by a key worker in the HNA and care planning record (). In locked records, concerns with a score of 10 are almost twice as likely to have an action than concerns with a score of 1, albeit this was still only 43.4% of concerns. This variation exists because the recommended method of care planning is to focus on the most important concerns. This is facilitated by the platform's design, as it presents each HNA's submitted concerns to the key worker as a list, ordered in descending order of score.

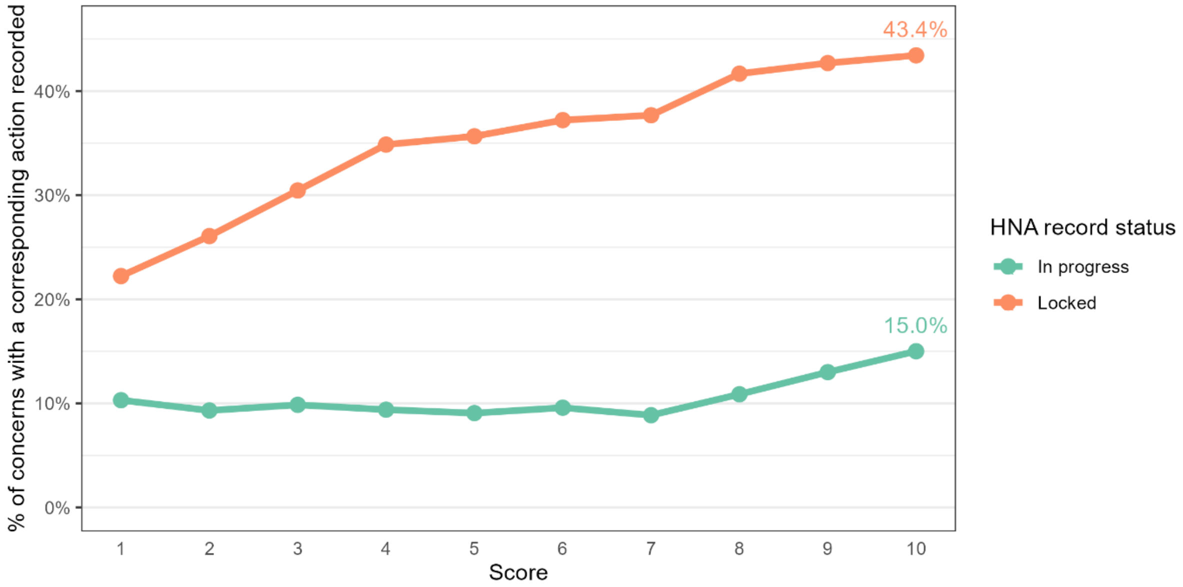


Figure 45. Proportion of concerns with at least one corresponding action recorded in the Macmillan eHNA dataset, against the score given to the concern by the service user. Based on submitted HNAs that used a consistent concerns checklist and that were not set up by an InfoFlex organisation. After submission, HNAs must progress to a status of In progress or Locked in order for actions to be recorded.

Relatedly, concerns were also more likely to have an action recorded if they were given a high score relative to the other concerns submitted in the assessment (Figure 46). In locked records, the highest or joint-highest scoring concerns were found to be around twice as likely to have an action recorded than the tenth-highest scoring concerns.

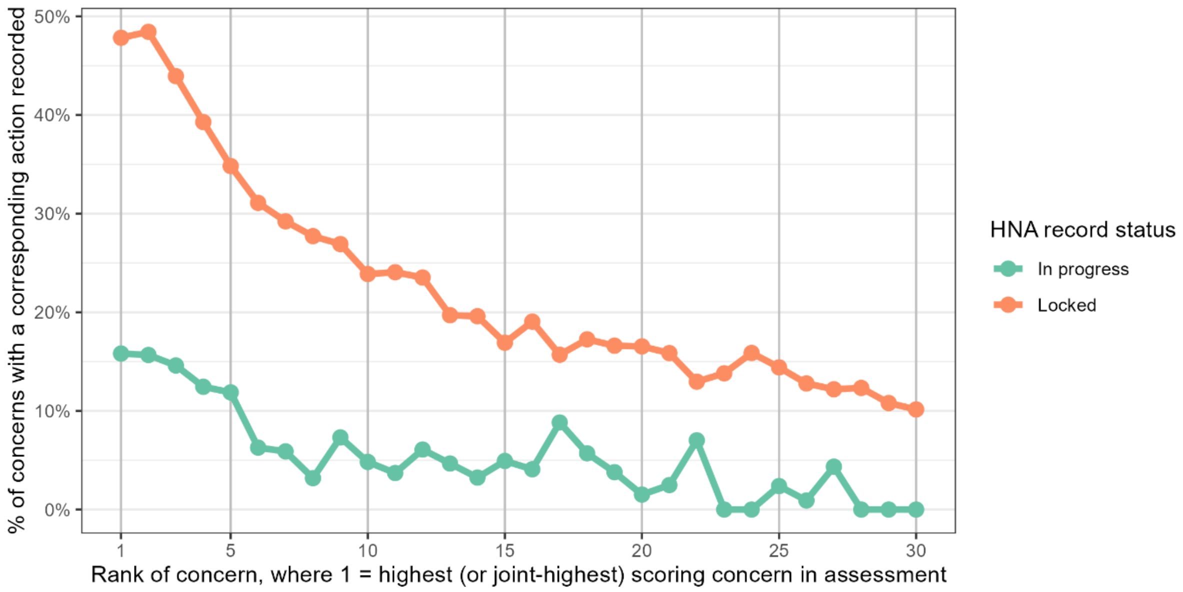


Figure 46. Proportion of concerns with at least one corresponding action recorded in the Macmillan eHNA dataset, against the rank of the concern's score against all other submitted concern scores. The concerns with the highest score in each assessment will have a rank of 1. Based on submitted HNAs that used a consistent concerns checklist and that were not set up by an InfoFlex organisation. X-axis truncated at 30 as sample sizes are smaller at higher values leading to unstable proportion estimates.

The total number of concerns within a submitted assessment also influences the likelihood of any given concern having an action recorded. Since not all concerns are expected to be addressed within the care planning process, the recording of additional concerns can act as 'competition'. Concerns which scored a 10 within locked assessments have a decreasing likelihood of having an action recorded as the total number of concerns submitted increases; 76.4% had an action recorded where no other concerns were submitted, 57.4% where there were 5 other concerns and 49.4% where there were 10 other concerns.

The influence of score on the likelihood of concerns receiving an action varied between different types of concerns. For example, *Money or finance* concerns with a score of 1 received a corresponding action in 43.4% of submitted HNAs (Figure 47), whereas only 10 out of the 62 remaining concerns received an action at least this often when submitted with a score of 10. This may be the result of specific referral processes in place to support people with this concern.

Some concerns saw a corresponding action at broadly similar rates whether scored high or low, such as *Pain or discomfort*, *Thinking about the future* or *Tired, exhausted or fatigued*. Others see a steeper gradient with actions much more likely with high scores, such as *Children* and *Smoking cessation*.

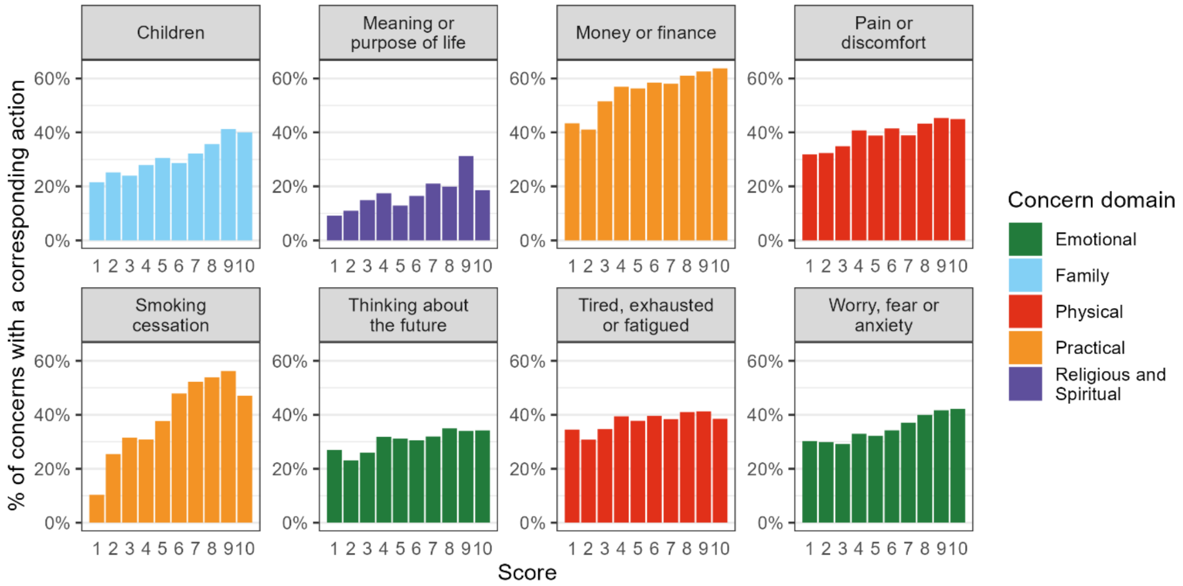


Figure 47. Proportion of concerns with at least one corresponding action recorded in the Macmillan eHNA dataset, against the score given to the concern by the service user, for a sample of eight specific concerns. Based on submitted HNAs that used a consistent concerns checklist and that were not set up by an InfoFlex organisation.

Overall, we see practical concerns being most likely to have an action recorded by a key worker, partly driven by the high rate for *Money or finance* (Figure 48). Religious and spiritual concerns were least likely to have an action recorded. This is partly due to concerns in this domain tending to be scored less highly. There may also be cultural barriers presenting a challenge for key workers in having conversations about these concerns.

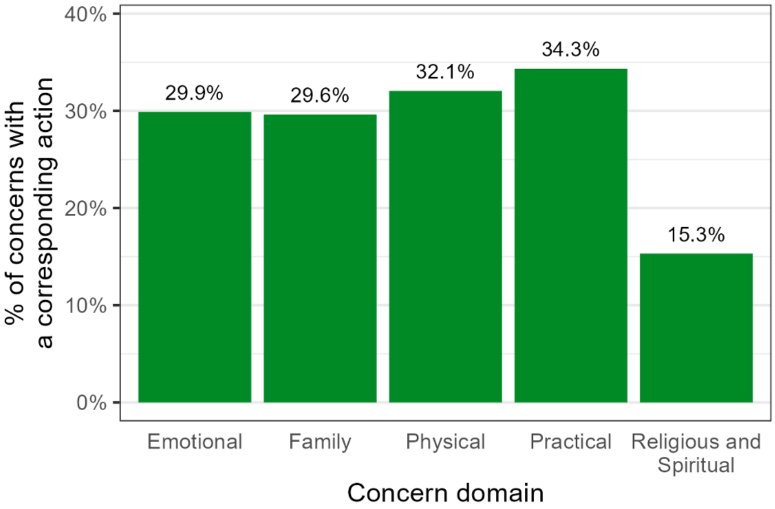
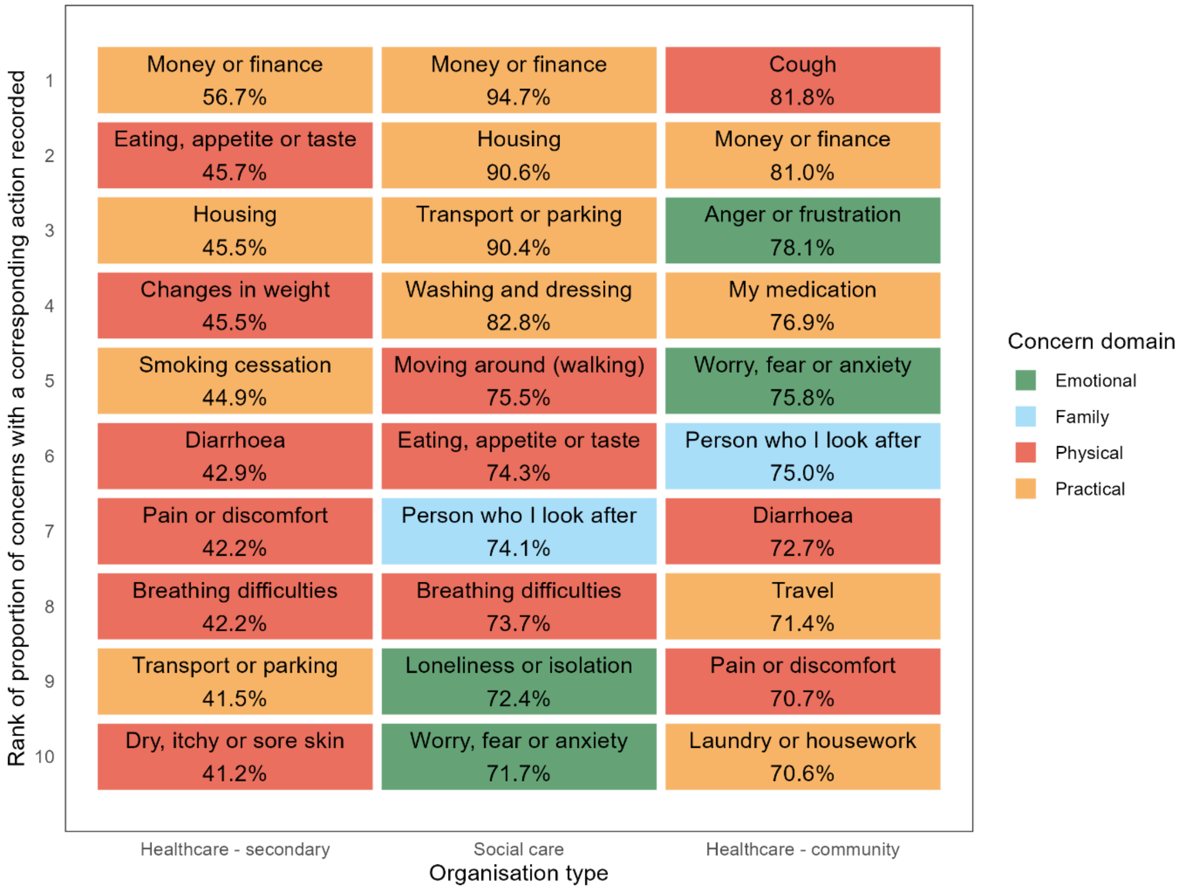


Figure 48. Proportion of concerns with at least one corresponding action recorded in the Macmillan eHNA dataset, grouped by concern domain. Based on submitted HNAs that used a consistent concerns checklist and that were not set up by an InfoFlex organisation.

The type of organisation offering the care planning also seems to influence the recording of actions against concerns submitted in HNAs. Considering only concerns that were scored a 10, social care organisations were most likely to record actions for the practical concerns *Money or finance*, *Housing*, *Transport or parking* and *Washing and dressing* (Figure 49). The 10 concerns most likely to have a corresponding action recorded for secondary healthcare organisations were all practical and physical concerns, whereas for community healthcare or social care organisations the top ten included three concerns from the emotional or family domains. These trends may reflect the different roles that organisations intend to play in supporting people with cancer.



Rank of proportion of concerns with a corresponding action recorded	Healthcare - secondary	Social care	Healthcare - community
1	🟧 Money or finance 56.7%	🟧 Money or finance 94.7%	🟥 Cough 81.8%
2	🟥 Eating, appetite or taste 45.7%	🟧 Housing 90.6%	🟧 Money or finance 81.0%
3	🟧 Housing 45.5%	🟧 Transport or parking 90.4%	🟩 Anger or frustration 78.1%
4	🟥 Changes in weight 45.5%	🟧 Washing and dressing 82.8%	🟧 My medication 76.9%
5	🟧 Smoking cessation 44.9%	🟥 Moving around (walking) 75.5%	🟩 Worry, fear or anxiety 75.8%
6	🟥 Diarrhoea 42.9%	🟥 Eating, appetite or taste 74.3%	🟦 Person who I look after 75.0%
7	🟥 Pain or discomfort 42.2%	🟦 Person who I look after 74.1%	🟥 Diarrhoea 72.7%
8	🟥 Breathing difficulties 42.2%	🟥 Breathing difficulties 73.7%	🟧 Travel 71.4%
9	🟧 Transport or parking 41.5%	🟩 Loneliness or isolation 72.4%	🟥 Pain or discomfort 70.7%
10	🟥 Dry, itchy or sore skin 41.2%	🟩 Worry, fear or anxiety 71.7%	🟧 Laundry or housework 70.6%

Figure 49. Top ten concerns by the proportion that had at least one corresponding action. Based on HNAs set up by secondary/community healthcare or social care organisations, concerns with a score of 10 and where there were at least 10 HNAs with a submitted concern. Percentage refers to the proportion of submitted HNAs where at least one action was recorded against the concern.

6.2 Action types

Actions are recorded by key workers from a predetermined list, with each action mapped to a single 'action type'. There are 659 distinct actions, mapped to 11 different action types. Key workers may also optionally record a service provider against an action, often the name of the service or organisation the service user is being referred to or signposted to. The most common action is to have a therapeutic discussion within the care planning conversation to provide guidance and support with the raised concern directly. In many cases an information sheet[iii] is also provided, more than 99% of which are information sheets provided by Macmillan. When more support is needed the service user can be signposted or referred to another service.

A table of action types with common actions, concerns, service providers and summary statistics can be found in Appendix D.

The types of actions recorded by key workers varied depending on the concern they were aiming to address and the type of organisation offering the care planning.

For all concern domains, the most common action type recorded was a *Discussion* (representing 39.2% of all actions recorded), followed by *Information sheet* (representing 26.6% of all actions recorded; Figure 50). However, for practical concerns the second most common type of action was instead *Referral*, representing 23.4% of recorded actions. This is partly driven by the high proportion of *Money or finance* concerns which result in a *Referral* action (48.5% of actions recorded for this concern) and partly due to some practical concerns not having a corresponding information sheet available (such as *Money or Finance*, *Difficulty making plans* and *Grocery shopping*).

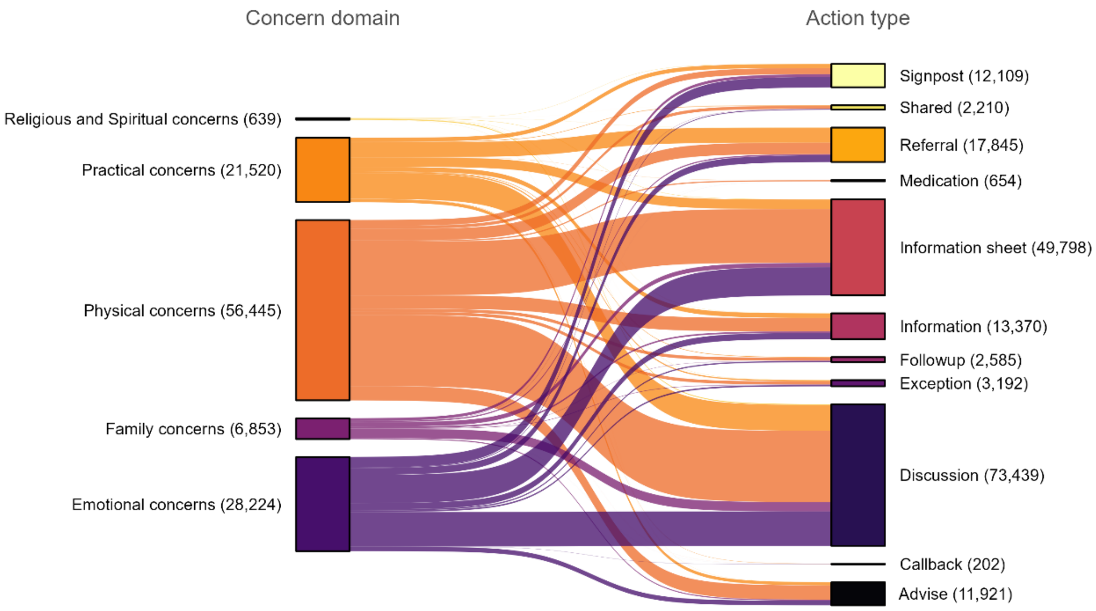


Figure 50. Sankey diagram illustrating the relationship between concern domains and types of actions recorded for submitted concerns. The diagram is based on all concerns submitted in HNAs using a consistent concerns checklist and that were not set up by an InfoFlex organisation. Only concerns with at least one recorded action are included. Where multiple actions were recorded against a single concern, each action

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[iii] For example, https://www.macmillan.org.uk/_images/tired-exhausted-fatigued_tcm9-317030.pdf and pain_tcm9-317028.pdf

and its corresponding action type are represented. Counts reflect distinct numbers of concerns and actions and therefore do not sum equally because some concerns are linked to multiple actions.

Some concerns were more likely to have certain types of actions recorded against them. For example, *Money or Finance* was the concern to result in a *Referral* action (48.5% of actions for this concern), while the most recorded action for the *Taking care of others* concern was *Discussion* (70.9% of actions for this concern). The five concerns with the highest proportion of actions recorded for each action type are shown in Figure 51.

Physical concerns were more likely to lead to action types of *Information Sheet*, *Advise*, *Follow up*, *Shared* or *Medication* than concerns of other domains. Practical concerns were more likely to lead to action types of *Discussion*, *Referral* and *Information*. The concerns most assigned an action of type *Signpost* were family concerns (including *Other relatives or friends* and *Partner*) and some emotional concerns (including *Sadness or depression* and *Worry, fear or anxiety*).

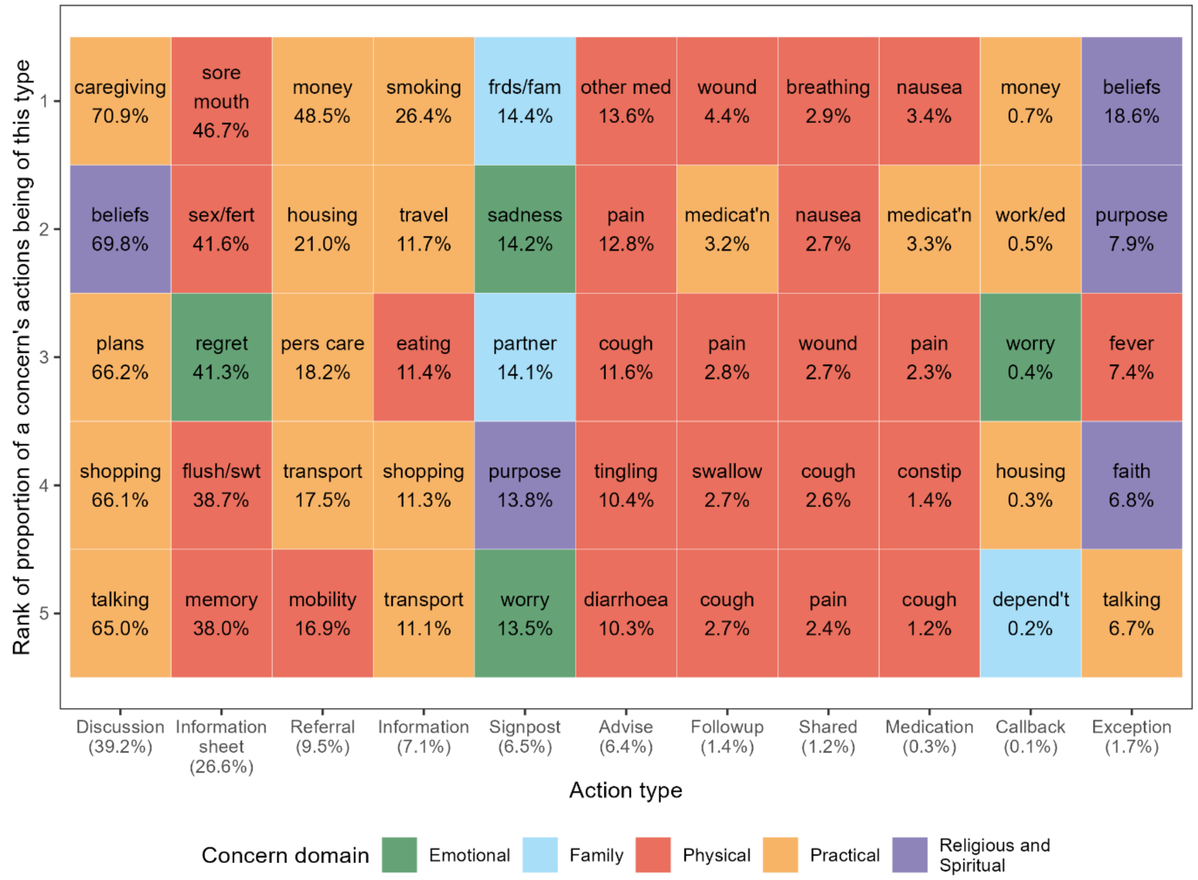


Figure 51. For each action type, the five concerns with the highest proportion of actions recorded as being of that action type. Based on all actions recorded for HNA and care planning recorded with status 'In progress' or 'Locked'.

Social care and support group organisations were more likely to record *Discussion* actions than healthcare organisations were (Figure 52). 71.6% of actions recorded by primary healthcare organisations and 60.0% of those recorded by private healthcare organisations related to information sheets. Social care organisations were least likely to record *Information sheet* actions but most likely to record *Referral* actions.

The types of actions recorded by organisations will be influenced by the profile of concerns that service users tend to raise at different organisation types, and the common types of actions that are used to address them.

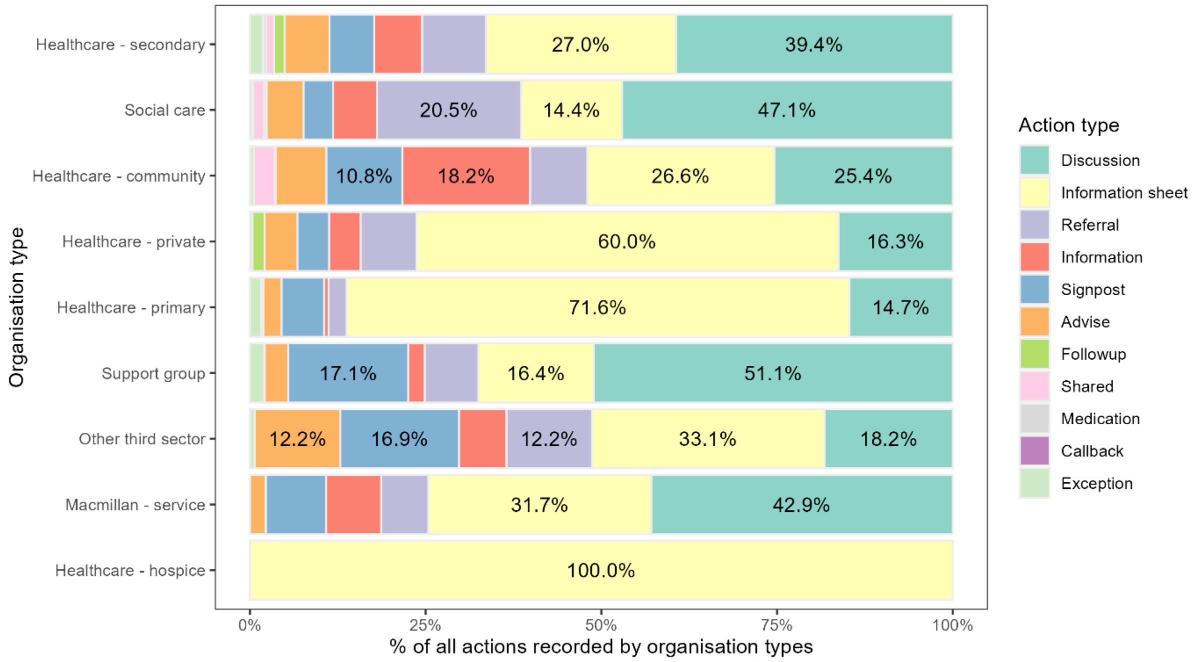


Figure 52. Proportion of action types recorded by each organisation type. Based on all HNAs with a status of In progress or Locked with at least one action recorded.

The *Referral* action type contained 230 different actions, noting the range of national and local support services that key workers were able to direct service users to. The most common referral destinations were to welfare or benefits advice service, Macmillan Grants, counselling services, dieticians and Clinical Nurse Specialists.

6.3 Locked records

The job category of the key worker who locks the HNA record is recorded in 89.3% of locked records. The distribution of job categories largely follows the same distribution found for key workers who set up HNA records (Figure 53, Figure 11). Support worker-type roles are responsible for locking the majority of HNA records (56.8%) followed by cancer nurse specialists (25.0%).

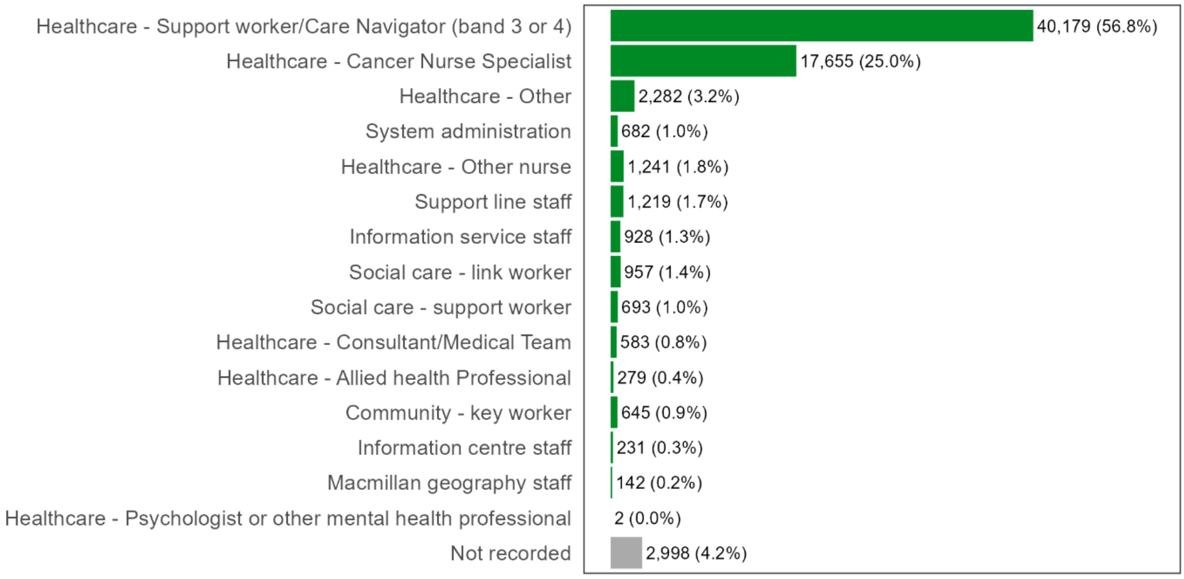


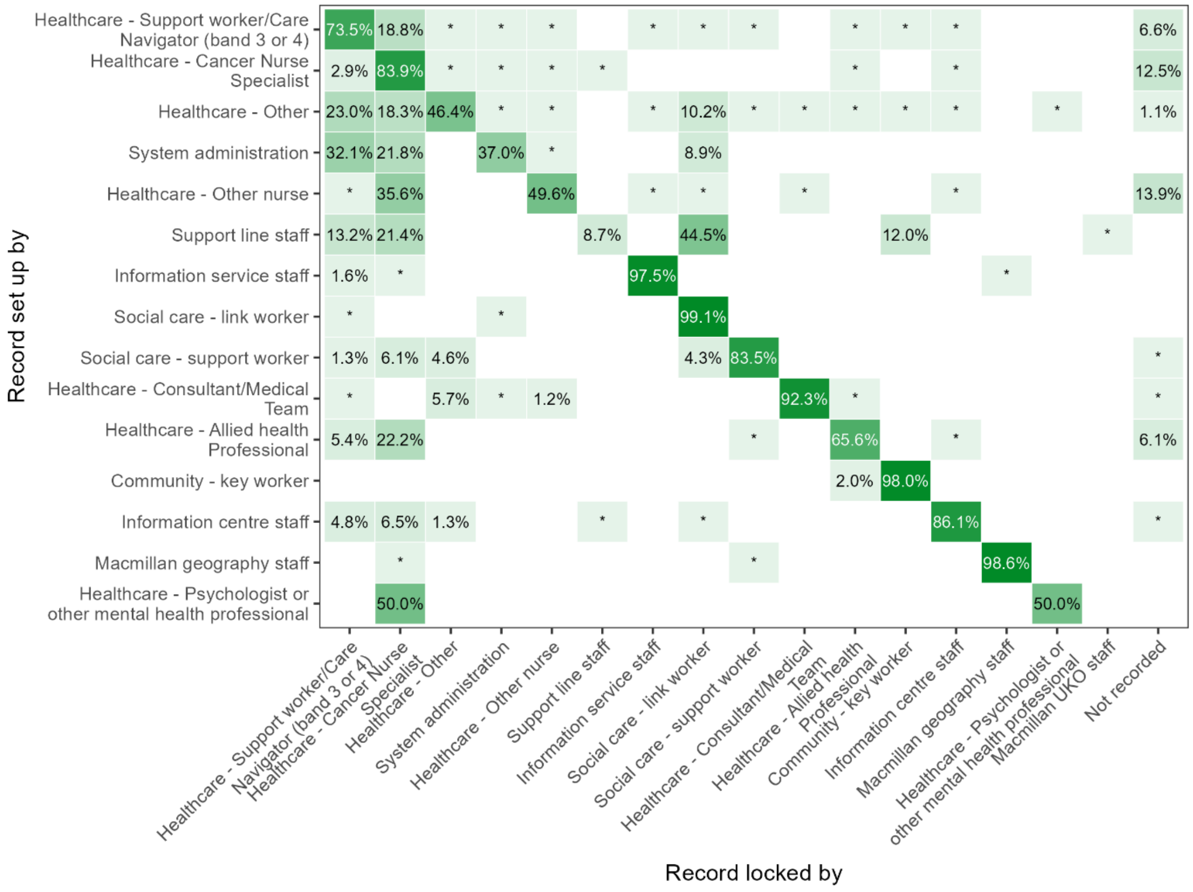
Figure 53. HNAs locked by key worker job role for all locked HNA records. Includes all organisation types.

By comparing the job categories for key workers who set up HNA records with those who lock records, we can infer that the key workers setting up HNA records may not be the same as those having the therapeutic conversations with service users (Figure 54). Of locked HNA records that were set up by a support worker-type role, 73.5% were also recorded as being locked by a support worker-type role and 18.8% were instead locked by a cancer nurse specialist. The reverse happens less frequently, with only 2.9% of HNAs set up by cancer nurse specialists going on to be locked by support worker-type roles. Indeed of all 24,155 HNAs locked by a cancer nurse specialist, 61.4% were also set up by a cancer nurse specialist. This suggests that some organisations will escalate the HNA to a cancer nurse specialist to deliver the therapeutic conversation while the job of setting up the HNA, and potentially offering the HNA, is retained by a wider range of job categories.

Other notable mismatches between job categories of locked records setup and lock are found:

- 22.2% of locked HNAs that were setup by allied health professionals were locked by a cancer nurse specialist
- of those set up by system administrators 32.1% were locked by support worker-type roles and 21.8% by cancer nurse specialists
- 44.5% of locked HNAs set up by support line staff are locked by social care link workers
- Only half (49.6%) of locked HNAs set up by nurses that are not cancer specialists were locked by key workers of that same job category. 35.6% of these records were instead locked by a cancer nurse specialist.
- HNAs set up by those in healthcare posts were less likely to have a recorded job category for who locked the record. 12.5% of locked HNAs set up by cancer nurse

specialists have no recorded locked value. The equivalent figure is 13.9% for other nurse roles, 6.1% for allied health professionals and 6.6% for support worker type roles. In contrast the combined average for all non-healthcare posts was 0.04%. This may reflect the demanding nature of healthcare roles delivering personalised care and the challenge to record



Record set up by \ Record locked by	Healthcare - Support worker/Care Navigator (band 3 or 4)	Healthcare - Cancer Nurse Specialist	Healthcare - Other	System administration	Healthcare - Other nurse	Support line staff	Information service staff	Social care - link worker	Social care - support worker	Healthcare - Consultant/Medical Team	Healthcare - Allied health Professional	Community - key worker	Information centre staff	Macmillan geography staff	Healthcare - Psychologist or other mental health professional	Macmillan UKO staff	Not recorded
Healthcare - Support worker/Care Navigator (band 3 or 4)	73.5%	18.8%	*	*	*		*	*	*		*	*	*				6.6%
Healthcare - Cancer Nurse Specialist	2.9%	83.9%	*	*	*	*					*		*				12.5%
Healthcare - Other	23.0%	18.3%	46.4%	*	*		*	10.2%	*	*	*	*	*		*		1.1%
System administration	32.1%	21.8%		37.0%	*			8.9%									
Healthcare - Other nurse	*	35.6%			49.6%		*	*		*			*				13.9%
Support line staff	13.2%	21.4%				8.7%		44.5%				12.0%				*	
Information service staff	1.6%	*					97.5%							*			
Social care - link worker	*			*				99.1%									
Social care - support worker	1.3%	6.1%	4.6%					4.3%	83.5%								*
Healthcare - Consultant/Medical Team	*		5.7%	*	1.2%					92.3%	*						*
Healthcare - Allied health Professional	5.4%	22.2%							*		65.6%		*				6.1%
Community - key worker											2.0%	98.0%					
Information centre staff	4.8%	6.5%	1.3%			*		*					86.1%				*
Macmillan geography staff		*							*					98.6%			
Healthcare - Psychologist or other mental health professional		50.0%													50.0%		

*Figure 54. Association between job category of key worker setting up HNA records and the key worker who locks records. Percentages reflect the distribution of records for each job category of setup. Based on 67,718 HNA records that were locked and had a recorded value for job category of setup. * <1.0%.*

6.4 Care plans

Following the locking of the HNA and care planning record, the key worker has the option to share the care plan in various formats. These care plan outcomes are recorded within the platform.

Of the 76,820 HNAs set up in 2023 and subsequently submitted, 32,776 HNAs (42.7%) resulted in a care plan that was shared either by paper or email. 23,645 HNAs (30.8%)

were recorded as *No care plan required* and 10,731 (14.0%) did not record a care plan outcome.

Of all HNA and care planning records with a recorded care plan outcome of *Paper* or *Email*, 81.7% were associated with HNAs submitted with one or more concerns and 57.8% had one or more actions recorded. This suggests that sharing of care plans is not exclusively for the benefit of addressing concerns that were recorded in the HNA, or to share further detail related to a recorded action. Instead, the therapeutic conversation between the key worker and service user may surface concerns that were not recorded in the HNA. Additionally, the care plan shared may contain useful information that is not directly related to an action recorded in the platform.

Conversely, there were 7,783 instances of HNAs being submitted with 1 or more concerns that resulted in a care plan outcome recorded as *No care plan required*, and 5,178 instances where there was one of more action recorded within the platform. Some of these may relate to care planning where the service user felt the concern was satisfactorily addressed during the therapeutic conversation, or where the key worker felt there was nothing further to be gained by sharing a care plan.

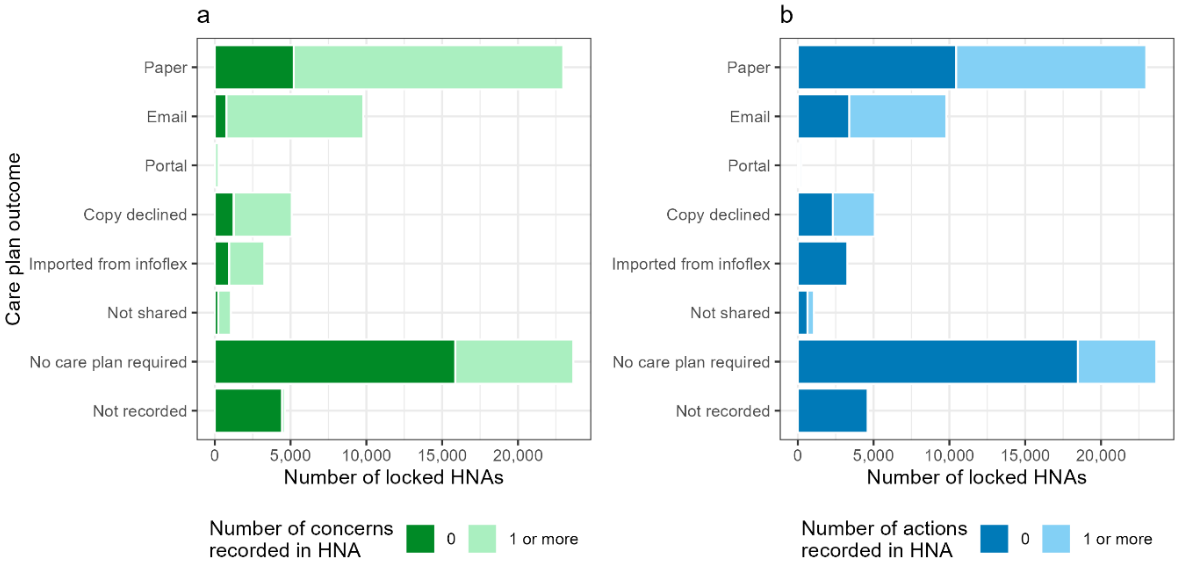


Figure 55. a) Care plan outcomes of all locked HNA and care planning records, based on number of concerns recorded in the submitted HNA. b) Care plan outcomes of all locked HNA and care planning records, based on number of actions recorded in the platform.

7 CONCLUSIONS

This report demonstrates the scale and richness of the Macmillan eHNA dataset, while also highlighting the challenges involved in drawing actionable insights and making appropriate, generalisable interpretations. The analysis should be understood as a foundational overview of how HNA and care planning activity is recorded on the Macmillan eHNA Platform, rather than as a complete account of all personalised care activity or all needs experienced by people living with cancer.

The data can be used to explore variation in how HNA and care planning are delivered across organisation types, settings, pathway stages and service user groups. This provides insight into how personalised care is operationalised in practice and, when used alongside evaluation, qualitative evidence and local service knowledge, can help inform how services are configured and supported.

The data can also be used to examine variation in who receives an HNA offer or engages with the process. For example, this report suggested an under-representation in HNAs in England set up for males, people aged over 80 and people with certain cancer types, including lung, upper GI, non-prostate urological and skin cancers. However, limitations in data capture for some variables - including ethnic group, gender identity and presence of additional conditions - restrict the inequity-related insights that can be drawn from the eHNA dataset alone.

The analysis highlights that the eHNA dataset is more informative for some questions than others. It should not be treated as representative of the national cancer population, because the platform is not used universally, local implementation varies and records are shaped by a sequential process from HNA offer and set-up through to submission, actions and care plans. Linked studies using cancer registry or other administrative data are better placed to assess which population groups are more or less likely to receive an HNA[9,10]. Such analysis can help identify gaps in reach and representation and point to areas where further qualitative research may be needed to understand the drivers of variation.

The distinctive strength of the eHNA dataset lies in the richness of information recorded about the concerns people choose to raise and, to a lesser extent, the actions recorded by key workers in response. This data provides a detailed view of expressed concerns and recorded care planning activity that is not otherwise visible to cancer registries. The findings show the diversity of concerns reported across population groups and system contexts and the need for personalised care to respond to a broad range of physical, emotional, practical, family-related and spiritual needs. Common or highly scored concerns such as fatigue, anxiety, money and finance, housing and caring responsibilities point to areas where targeted support may be particularly important and may be more likely to be recorded in some contexts than others.

Implications and next steps

1. eHNA should be positioned as part of a wider personalised care approach, rather than as a standalone digital assessment tool. The analysis shows that eHNA captures only part of the wider personalised care process: not all HNAs set up are submitted, not all submitted HNAs contain recorded concerns and not all concerns have recorded actions. Its value lies in supporting meaningful

conversations, care planning, follow-up and signposting, not simply in recording that an HNA has been completed.

2. Further work should review how eHNA is used across the cancer pathway. The data highlights variation in when HNAs are set up, with a substantial proportion occurring around initial diagnosis. Since the number and type of concerns recorded vary by pathway stage, further work could explore whether eHNA is being offered at points where people's needs are most likely to change, including during treatment, end of treatment, follow-up, recurrence and in palliative care.

3. Education, training and support should reflect the workforce most commonly delivering eHNA in practice. The analysis shows that HNAs are most commonly set up by support workers, rather than by those in cancer specialist roles. This highlights the central role of the supportive workforce in delivering HNA and care planning activity and suggests value in reviewing whether training and support are aligned with relevant capability frameworks such as ACCEND[26].

4. Further work is needed to understand and address variation in implementation and practice. The flexibility of the eHNA Platform enables organisations and teams to use it in ways that fit local models of care, but the analysis also shows substantial variation by organisation type, setting, region, pathway stage and of submission rates, concern profiles and recorded actions. Future work should explore how much of this reflects appropriate local flexibility, and how much reflects inconsistent understanding, workflow differences or variation in recording practice that may affect consistency, quality or equity of offer.

5. There is an opportunity to strengthen the strategic use and interpretation of eHNA data. Clarity is needed on which analytical questions can be answered using eHNA data alone, which require alternative approaches such as linked datasets and how findings should be interpreted at national, regional and organisational levels. Improving the consistency, completeness and interpretation of eHNA data would support better reporting, service learning, evaluation and strategic decision-making.

Overall, this report represents a first step in establishing the Macmillan eHNA dataset as a key resource for cancer intelligence. Its greatest value will come from using the data carefully and transparently: recognising its limitations for estimating population-level access and underlying need, while making full use of its detailed insight into recorded concerns, care planning activity and variation in personalised care delivery.

Acknowledgements

This work uses data provided by people living with cancer and collected by the NHS and others as part of their care and support. We would like to thank the people living with cancer who have given us their data and made this possible.

We would also like to thank the hundreds of health and social care professionals and others across the UK who have supported people living with cancer to complete a HNA and provided valuable support to help meet the concerns raised within these HNAs.

Appendix A – Summary of sub-groups

n set up (%): *Number of HNAs set up (percent of all HNAs set up)*

n submitted (%): *Number of HNAs that were submitted (percent of all HNAs submitted)*

n locked (%): *Number of HNAs that were locked (percent of all locked HNAs)*

% submitted: *% of setup HNAs that went on to be submitted (submission rate)*

% locked: *% of setup HNAs that went on to be locked*

Median days from diagnosis to setup: *Median days between diagnosis date (where recorded) and HNA being setup*

Median interval setup to submission: *Median interval between HNA setup and HNA submission, of submitted HNAs (d=days, h=hours, m=minutes)*

	n set up (%)	n submitted (%)	n locked (%)	% submitted	% locked	Median days from diagnosis to setup	Median interval setup to submission
All HNAs	120,718 (100.0%)	76,820 (100.0%)	70,716 (100.0%)	63.6%	58.6%	28	17.2 h
Age group							
18-39	4,828 (4.0%)	3,160 (4.1%)	2,816 (4.0%)	65.5%	58.3%	29	19.8 h
40-49	8,586 (7.1%)	5,563 (7.2%)	4,951 (7.0%)	64.8%	57.7%	28.5	20.7 h
50-59	21,259 (17.6%)	13,742 (17.9%)	12,470 (17.6%)	64.6%	58.7%	29	21.6 h
60-69	32,550 (27.0%)	21,194 (27.6%)	19,446 (27.5%)	65.1%	59.7%	29	17.7 h
70-79	35,169 (29.1%)	22,204 (28.9%)	20,693 (29.3%)	63.1%	58.8%	29	9.0 h

	n set up (%)	n submitted (%)	n locked (%)	% submitted	% locked	Median days from diagnosis to setup	Median interval setup to submission
80-89	16,372 (13.6%)	9,927 (12.9%)	9,358 (13.2%)	60.6%	57.2%	23	4.7 h
90+	1,954 (1.6%)	1,030 (1.3%)	982 (1.4%)	52.7%	50.3%	15	1.1 h
Sex							
Female	63,055 (52.2%)	40,357 (52.5%)	36,918 (52.2%)	64.0%	58.5%	28	16.4 h
Male	55,719 (46.2%)	35,001 (45.6%)	32,376 (45.8%)	62.8%	58.1%	28	7.1 h
Non binary	9 (<0.1%)	5 (<0.1%)	5 (<0.1%)	55.6%	55.6%	114.5	2.1 h
Other	351 (0.3%)	331 (0.4%)	320 (0.5%)	94.3%	91.2%	35	
Prefer not to say	19 (<0.1%)	11 (<0.1%)	11 (<0.1%)	57.9%	57.9%	4.5	10.8 h
Not known	1,565 (1.3%)	1,115 (1.5%)	1,086 (1.5%)	71.2%	69.4%	65	32.8 d
Condition							
Breast	23,448 (19.4%)	15,903 (20.7%)	14,675 (20.8%)	67.8%	62.6%	24	1.1 d
Cancer of unknown primary	200 (0.2%)	161 (0.2%)	141 (0.2%)	80.5%	70.5%	26	5.4 m
CNS/Brain	1,105 (0.9%)	709 (0.9%)	640 (0.9%)	64.2%	57.9%	41	21.9 h
Gynae	7,926 (6.6%)	5,787 (7.5%)	5,380 (7.6%)	73.0%	67.9%	46	25.3 m
Haematology	8,269 (6.8%)	6,142 (8.0%)	5,701 (8.1%)	74.3%	68.9%	43	6.3 h
Head and neck	6,314 (5.2%)	4,250 (5.5%)	3,937 (5.6%)	67.3%	62.4%	31	8.2 h
Lower GI	12,829 (10.6%)	8,530 (11.1%)	7,928 (11.2%)	66.5%	61.8%	33	1.0 d
Lung	11,052 (9.2%)	7,712 (10.0%)	7,391 (10.5%)	69.8%	66.9%	18	1.9 h
Neuroendocrine	292 (0.2%)	231 (0.3%)	206 (0.3%)	79.1%	70.5%	38	5.3 h
Other cancer types	457 (0.4%)	415 (0.5%)	398 (0.6%)	90.8%	87.1%	82	21.0 h
Prostate	17,110 (14.2%)	11,915 (15.5%)	11,201 (15.8%)	69.6%	65.5%	35	1.1 d
Sarcoma	1,753 (1.5%)	1,122 (1.5%)	1,063 (1.5%)	64.0%	60.6%	59	2.3 d

	n set up (%)	n submitted (%)	n locked (%)	% submitted	% locked	Median days from diagnosis to setup	Median interval setup to submission
Skin	7,727 (6.4%)	4,247 (5.5%)	3,991 (5.6%)	55.0%	51.7%	10	1.1 h
Upper GI	7,156 (5.9%)	5,028 (6.5%)	4,666 (6.6%)	70.3%	65.2%	21	21.6 h
Urology, excl prostate	4,791 (4.0%)	3,109 (4.0%)	2,821 (4.0%)	64.9%	58.9%	27	5.4 h
Not recorded	10,289 (8.5%)	1,559 (2.0%)	577 (0.8%)	15.2%	5.6%	40	18.9 h
Pathway stage							
Initial diagnosis	44,002 (36.5%)	29,305 (38.1%)	27,394 (38.7%)	66.6%	62.3%	11	2.0 d
Prehabilitation	974 (0.8%)	650 (0.8%)	602 (0.9%)	66.7%	61.8%	21	1.8 h
Start of treatment	12,454 (10.3%)	9,191 (12.0%)	8,574 (12.1%)	73.8%	68.8%	29	7.8 h
During treatment	19,591 (16.2%)	14,604 (19.0%)	13,787 (19.5%)	74.5%	70.4%	101	36.4 m
End of treatment	17,938 (14.9%)	12,848 (16.7%)	12,046 (17.0%)	71.6%	67.2%	244	22.2 h
Follow up	5,565 (4.6%)	3,757 (4.9%)	3,405 (4.8%)	67.5%	61.2%	249	17.6 h
Diagnosis of recurrence	1,568 (1.3%)	1,135 (1.5%)	1,063 (1.5%)	72.4%	67.8%	40	7.4 h
Transition to palliative care	1,215 (1.0%)	1,024 (1.3%)	967 (1.4%)	84.3%	79.6%	55	25.1 m
In palliative care	1,457 (1.2%)	1,188 (1.5%)	1,132 (1.6%)	81.5%	77.7%	90	5.7 m
Other	2,525 (2.1%)	1,485 (1.9%)	1,403 (2.0%)	58.8%	55.6%	239	18.3 m
Not recorded	13,429 (11.1%)	1,633 (2.1%)	343 (0.5%)	12.2%	2.6%	39	16.1 h
Condition management							
Curative treatment	8,895 (7.4%)	8,895 (11.6%)	8,674 (12.3%)	100.0%	97.5%	36	1.5 h
Active surveillance	1,143 (0.9%)	1,143 (1.5%)	1,087 (1.5%)	100.0%	95.1%	126	4.5 h
Supportive treatment or care	1,515 (1.3%)	1,515 (2.0%)	1,483 (2.1%)	100.0%	97.9%	107.5	6.0 m

	n set up (%)	n submitted (%)	n locked (%)	% submitted	% locked	Median days from diagnosis to setup	Median interval setup to submission
Palliative treatment or care	1,812 (1.5%)	1,812 (2.4%)	1,769 (2.5%)	100.0%	97.6%	22	3.5 h
No current management	189 (0.2%)	189 (0.2%)	188 (0.3%)	100.0%	99.5%	16.5	6.6 h
Management unknown	937 (0.8%)	937 (1.2%)	914 (1.3%)	100.0%	97.5%	40	7.0 h
Not recorded	106,227 (88.0%)	62,329 (81.1%)	56,601 (80.0%)	58.7%	53.3%	26	22.1 h
Additional diagnosis							
Other cancer	1,498 (1.2%)	1,176 (1.5%)	1,083 (1.5%)	78.5%	72.3%	46	42.5 m
Other non-cancer condition	1,377 (1.1%)	1,111 (1.4%)	995 (1.4%)	80.7%	72.3%	19	28.1 m
Not recorded	117,843 (97.6%)	74,533 (97.0%)	68,638 (97.1%)	63.2%	58.2%	28	18.8 h
Ethnic group							
Asian or Asian British	177 (0.1%)	158 (0.2%)	154 (0.2%)	89.3%	87.0%	10	7.1 h
Black, Black British, Caribbean or African	90 (<0.1%)	67 (<0.1%)	64 (<0.1%)	74.4%	71.1%	21	3.8 h
Mixed or multiple ethnic groups	26 (<0.1%)	22 (<0.1%)	22 (<0.1%)	84.6%	84.6%	18	16.5 m
White	3,364 (2.8%)	3,121 (4.1%)	3,038 (4.3%)	92.8%	90.3%	50	4.6 h
Other ethnic group	41 (<0.1%)	34 (<0.1%)	33 (<0.1%)	82.9%	80.5%	15	13.2 h
Not stated	302 (0.3%)	288 (0.4%)	286 (0.4%)	95.4%	94.7%	69	12.2 h
Not recorded	116,718 (96.7%)	73,130 (95.2%)	67,119 (94.9%)	62.7%	57.5%	28	17.8 h
Language							
English language	120,514 (99.8%)	76,617 (99.7%)	70,541 (99.8%)	63.6%	58.5%	28	16.8 h
All other languages combined	204 (0.2%)	203 (0.3%)	175 (0.2%)	99.5%	85.8%	21.5	4.6 d

	n set up (%)	n submitted (%)	n locked (%)	% submitted	% locked	Median days from diagnosis to setup	Median interval setup to submission
Organisation type							
Healthcare - secondary	106,500 (88.2%)	64,920 (84.5%)	59,601 (84.3%)	61.0%	56.0%	23	18.8 h
InfoFlex	8,996 (7.5%)	8,167 (10.6%)	7,894 (11.2%)	90.8%	87.8%	37	
Social care	2,407 (2.0%)	1,933 (2.5%)	1,881 (2.7%)	80.3%	78.1%	86	3.9 d
Healthcare - community	1,137 (0.9%)	999 (1.3%)	842 (1.2%)	87.9%	74.1%	229.5	2.3 m
Support group	821 (0.7%)	218 (0.3%)	216 (0.3%)	26.6%	26.3%		1.5 m
Healthcare - private	575 (0.5%)	363 (0.5%)	136 (0.2%)	63.1%	23.7%	47	6.0 h
Healthcare - primary	122 (0.1%)	80 (0.1%)	52 (<0.1%)	65.6%	42.6%	153.5	5.6 h
Macmillan - service	80 (<0.1%)	61 (<0.1%)	47 (<0.1%)	76.2%	58.8%		16.5 h
Other third sector	77 (<0.1%)	76 (<0.1%)	47 (<0.1%)	98.7%	61.0%	266.5	4.4 m
Other	2 (<0.1%)	2 (<0.1%)	0 (<0.1%)	100.0%	0.0%		0.0 m
Healthcare - hospice	1 (<0.1%)	1 (<0.1%)	0 (<0.1%)	100.0%	0.0%		14.9 d
Setting							
Paper	31,794 (26.3%)	30,097 (39.2%)	28,523 (40.3%)	94.7%	89.7%	30	2.4 h
Clinic	30,815 (25.5%)	16,482 (21.5%)	14,821 (21.0%)	53.5%	48.1%	13	2.5 h
Home	27,790 (23.0%)	10,001 (13.0%)	8,613 (12.2%)	36.0%	31.0%	20	4.0 d
Telephone	25,469 (21.1%)	17,412 (22.7%)	16,215 (22.9%)	68.4%	63.7%	47	1.4 h
Virtual	2,420 (2.0%)	1,396 (1.8%)	1,255 (1.8%)	57.7%	51.9%	31	3.3 d
Ward	1,878 (1.6%)	993 (1.3%)	885 (1.3%)	52.9%	47.1%	28.5	5.3 m
Community	546 (0.5%)	437 (0.6%)	402 (0.6%)	80.0%	73.6%	67	50.4 m
Prison	6 (<0.1%)	2 (<0.1%)	2 (<0.1%)	33.3%	33.3%	13	9.5 d
Region							

	n set up (%)	n submitted (%)	n locked (%)	% submitted	% locked	Median days from diagnosis to setup	Median interval setup to submission
North	12,483 (10.3%)	6,977 (9.1%)	6,595 (9.3%)	55.9%	52.8%	13	3.0 d
North West	14,077 (11.7%)	10,307 (13.4%)	9,625 (13.6%)	73.2%	68.4%	26	4.6 m
Midlands	15,650 (13.0%)	5,535 (7.2%)	5,114 (7.2%)	35.4%	32.7%	24	2.1 d
South and East	20,764 (17.2%)	17,385 (22.6%)	16,422 (23.2%)	83.7%	79.1%	38	2.4 m
London	23,181 (19.2%)	16,363 (21.3%)	14,721 (20.8%)	70.6%	63.5%	9	2.1 h
South West	18,760 (15.5%)	10,312 (13.4%)	9,237 (13.1%)	55.0%	49.2%	40	7.2 d
Scotland	6,544 (5.4%)	5,178 (6.7%)	4,978 (7.0%)	79.1%	76.1%	82	5.3 h
Wales	5,734 (4.7%)	2,404 (3.1%)	2,108 (3.0%)	41.9%	36.8%	36	3.2 d
Northern Ireland	3,033 (2.5%)	2,015 (2.6%)	1,789 (2.5%)	66.4%	59.0%	86	11.1 d
UK	492 (0.4%)	344 (0.4%)	127 (0.2%)	69.9%	25.8%	45	5.5 h

Appendix B – Numbers of concerns recorded by sub-group

	All submitted HNAs							Submitted HNAs with at least 1 concern						
		Mean concerns							Mean concerns					
	N	Total	Physical	Practical	Emotional	Spiritual	Family	N	Tot	Phy	Prac	Emot	Spir	Fam
All HNAs	73,916	4.0	1.9	0.8	1.0	0.1	0.3	44,056	6.8	3.3	1.3	1.7	0.1	0.5
Age group														
18-39	3,034	5.8	2.2	1.3	1.8	0.1	0.4	2,124	8.3	3.2	1.9	2.5	0.1	0.6
40-49	5,328	5.8	2.3	1.3	1.6	0.1	0.5	3,692	8.3	3.4	1.8	2.3	0.1	0.7
50-59	13,071	5.0	2.2	1.0	1.3	0.1	0.4	8,468	7.7	3.4	1.6	2.1	0.1	0.5
60-69	20,341	4.0	1.9	0.8	1.0	0.1	0.3	12,081	6.8	3.2	1.3	1.7	0.1	0.5
70-79	21,494	3.4	1.8	0.6	0.7	0.0	0.2	11,984	6.0	3.2	1.1	1.3	0.1	0.4
80-89	9,642	3.0	1.7	0.5	0.6	0.0	0.2	5,221	5.6	3.1	1.0	1.1	0.0	0.3
90+	1,006	2.8	1.6	0.5	0.5	0.0	0.1	486	5.8	3.3	1.1	1.1	0.1	0.3
Sex														
Female	39,235	4.4	2.1	0.8	1.1	0.1	0.3	24,754	6.9	3.3	1.3	1.8	0.1	0.5
Male	33,233	3.8	1.9	0.7	0.9	0.1	0.3	18,669	6.7	3.3	1.3	1.5	0.1	0.5
Nonbinary	4	*	*	*	*	*	*	3	*	*	*	*	*	*
Other	331	1.5	0.8	0.3	0.4	0.0	0.1	141	3.6	1.8	0.7	0.9	0.0	0.2
Prefer not to say	10	*	*	*	*	*	*	7	*	*	*	*	*	*
Not known	1,103	1.6	0.9	0.3	0.3	0.0	0.1	482	3.7	2.0	0.7	0.8	0.0	0.2
Condition														
Acute leukaemia	285	4.8	2.2	1.3	0.9	0.1	0.3	214	6.4	2.9	1.8	1.2	0.1	0.4
Breast	15,810	4.3	2.0	0.8	1.1	0.1	0.3	9,957	6.8	3.2	1.2	1.8	0.1	0.5
Cancer of unknown primary	158	4.8	2.3	1.1	1.0	0.0	0.4	109	6.9	3.4	1.5	1.4	0.0	0.5
CNS/Brain	707	6.3	2.6	1.5	1.6	0.1	0.5	599	7.4	3.1	1.7	1.9	0.1	0.6

	All submitted HNAs							Submitted HNAs with at least 1 concern						
		Mean concerns							Mean concerns					
	N	Total	Physical	Practical	Emotional	Spiritual	Family	N	Tot	Phy	Prac	Emot	Spir	Fam
Gynae	5,762	3.8	1.7	0.7	1.1	0.0	0.3	3,203	6.8	3.1	1.3	1.9	0.1	0.5
Haematology	5,831	4.9	2.4	1.0	1.1	0.1	0.3	3,848	7.4	3.6	1.5	1.7	0.1	0.5
Head and neck	2,000	4.8	2.3	1.0	1.1	0.1	0.3	1,346	7.2	3.5	1.5	1.7	0.1	0.5
Lower GI	8,306	3.9	1.8	0.8	1.0	0.0	0.3	5,120	6.2	2.9	1.3	1.6	0.1	0.4
Lung	7,668	4.9	2.5	1.0	1.0	0.1	0.3	5,344	7.1	3.6	1.4	1.5	0.1	0.4
Neuroendocrine	231	8.6	4.2	1.5	2.2	0.1	0.5	195	10.2	5.0	1.8	2.6	0.1	0.6
Other cancer types	409	2.4	1.1	0.5	0.7	0.0	0.1	175	5.7	2.6	1.1	1.5	0.1	0.3
Prostate	11,887	2.8	1.4	0.5	0.7	0.0	0.2	5,536	6.0	3.0	1.1	1.4	0.1	0.4
Sarcoma	1,075	4.3	1.8	1.0	1.1	0.0	0.3	584	8.0	3.4	1.9	2.1	0.1	0.6
Skin	4,222	2.6	1.2	0.4	0.7	0.0	0.2	1,859	5.8	2.7	1.0	1.6	0.1	0.4
Upper GI	4,989	4.9	2.5	1.0	1.1	0.1	0.3	3,444	7.1	3.6	1.4	1.5	0.1	0.5
Urology, excl prostate	3,098	3.9	1.8	0.8	1.0	0.1	0.3	1,677	7.1	3.3	1.4	1.8	0.1	0.5
Not recorded	1,478	4.8	2.3	0.8	1.2	0.1	0.3	846	8.4	4.1	1.4	2.2	0.1	0.6
Pathway stage														
Initial diagnosis	28,488	3.7	1.7	0.7	0.9	0.0	0.3	15,646	6.7	3.1	1.4	1.7	0.1	0.5
Prehabilitation	556	5.4	2.4	1.1	1.4	0.0	0.4	429	7.0	3.1	1.5	1.8	0.1	0.6
Start of treatment	8,794	4.5	2.1	0.9	1.1	0.1	0.3	5,504	7.2	3.3	1.5	1.8	0.1	0.5
During treatment	14,357	4.0	1.9	0.8	0.9	0.0	0.3	8,755	6.5	3.1	1.4	1.5	0.1	0.4
End of treatment	12,305	3.9	2.1	0.6	0.9	0.0	0.2	7,348	6.6	3.6	1.0	1.6	0.1	0.3
Follow up	3,241	4.6	2.3	0.8	1.2	0.1	0.3	2,060	7.3	3.7	1.2	1.9	0.1	0.4
Diagnosis of recurrence	1,096	5.1	2.4	1.0	1.3	0.1	0.3	749	7.5	3.6	1.4	1.9	0.1	0.5
Transition to palliative care	962	5.6	2.8	1.3	1.1	0.1	0.4	752	7.1	3.5	1.7	1.4	0.1	0.5
In palliative care	1,105	4.6	2.3	1.1	0.9	0.0	0.3	907	5.6	2.8	1.3	1.1	0.1	0.4
Other	1,443	3.8	1.8	0.8	0.9	0.0	0.2	864	6.4	3.0	1.4	1.6	0.1	0.4
Not recorded	1,569	5.9	2.9	0.9	1.6	0.1	0.5	1,042	8.9	4.3	1.4	2.4	0.1	0.7
Condition management														
Curative treatment	8,276	3.3	1.7	0.6	0.8	0.0	0.2	4,529	6.1	3.1	1.1	1.5	0.1	0.4
Active surveillance	1,129	3.5	1.8	0.6	0.9	0.0	0.2	619	6.4	3.3	1.0	1.6	0.1	0.4

	All submitted HNAs							Submitted HNAs with at least 1 concern						
		Mean concerns							Mean concerns					
	N	Total	Physical	Practical	Emotional	Spiritual	Family	N	Tot	Phy	Prac	Emot	Spir	Fam
Supportive treatment or care	1,501	4.5	2.2	1.0	1.0	0.0	0.3	981	6.9	3.3	1.5	1.5	0.1	0.5
Palliative treatment or care	1,679	5.2	2.6	1.1	1.1	0.1	0.4	1,344	6.5	3.3	1.3	1.4	0.1	0.5
No current management	180	4.9	2.4	1.1	1.0	0.0	0.3	151	5.8	2.9	1.3	1.3	0.1	0.4
Management unknown	909	6.3	2.7	1.5	1.5	0.1	0.4	777	7.3	3.2	1.8	1.8	0.1	0.5
Not recorded	60,242	4.1	1.9	0.8	1.0	0.1	0.3	35,655	6.9	3.3	1.3	1.7	0.1	0.5
Additional diagnosis														
Other cancer	1,133	5.1	2.4	1.2	1.1	0.1	0.4	903	6.3	3.0	1.5	1.4	0.1	0.4
Other non-cancer condition	1,080	4.9	2.5	1.0	1.1	0.1	0.3	843	6.3	3.2	1.3	1.4	0.1	0.4
Not recorded	71,703	4.0	1.9	0.8	1.0	0.1	0.3	42,310	6.8	3.3	1.3	1.7	0.1	0.5
Ethnic group														
Asian or Asian British	157	9.8	4.4	2.3	2.2	0.2	0.6	135	11.4	5.2	2.7	2.6	0.3	0.7
Black, Black British, Caribbean or African	66	5.0	2.5	1.0	1.2	0.1	0.3	62	5.4	2.7	1.1	1.2	0.1	0.3
Mixed or multiple ethnic groups	21	5.7	2.7	1.1	1.6	0.1	0.2	16	*	*	*	*	*	*
White - British	2,912	3.8	1.8	0.9	0.9	0.0	0.2	2,065	5.4	2.5	1.3	1.2	0.0	0.3
White - other	159	5.7	2.7	1.2	1.4	0.1	0.4	126	7.2	3.4	1.5	1.8	0.1	0.5
Other ethnic group	33	5.7	2.3	1.7	1.1	0.2	0.4	27	7.0	2.8	2.1	1.4	0.2	0.5
Not stated	284	9.4	4.2	2.4	2.1	0.1	0.6	261	10.2	4.6	2.6	2.3	0.1	0.6
Not recorded	70,284	4.0	1.9	0.8	1.0	0.1	0.3	41,364	6.8	3.3	1.3	1.7	0.1	0.5
Language														
English	73,723	4.0	1.9	0.8	1.0	0.0	0.3	43,873	6.7	3.2	1.3	1.7	0.1	0.5
All other languages combined	193	16.5	7.3	3.5	4.0	0.6	1.1	183	17.4	7.7	3.7	4.2	0.6	1.1
Organisation type														
Healthcare - secondary	62,056	4.3	2.1	0.8	1.1	0.1	0.3	38,304	7.0	3.4	1.3	1.7	0.1	0.5

	All submitted HNAs							Submitted HNAs with at least 1 concern						
		Mean concerns							Mean concerns					
	N	Total	Physical	Practical	Emotional	Spiritual	Family	N	Tot	Phy	Prac	Emot	Spir	Fam
InfoFlex	8,167	1.4	0.7	0.2	0.3	0.0	0.1	2,673	4.2	2.2	0.7	1.0	0.0	0.2
Social care	1,918	4.3	1.8	1.3	0.9	0.1	0.3	1,480	5.6	2.4	1.6	1.2	0.1	0.3
Healthcare - community	997	7.3	3.1	1.6	2.0	0.1	0.5	981	7.4	3.2	1.6	2.0	0.1	0.5
Support group	218	3.8	1.8	0.7	1.0	0.0	0.2	100	8.2	4.0	1.5	2.2	0.1	0.4
Healthcare - private	362	8.6	3.9	1.2	2.6	0.1	0.8	336	9.3	4.2	1.3	2.8	0.1	0.9
Healthcare - primary	79	10.5	5.1	1.9	2.6	0.1	0.7	66	12.5	6.1	2.3	3.2	0.2	0.8
Macmillan - service	43	9.6	4.6	1.7	2.6	0.2	0.5	41	10.1	4.8	1.7	2.8	0.2	0.6
Other third sector	74	6.5	2.7	1.8	1.6	0.0	0.4	73	6.5	2.7	1.8	1.6	0.0	0.4
Other	1	*	*	*	*	*	*	1	*	*	*	*	*	*
Healthcare - hospice	1	*	*	*	*	*	*	1	*	*	*	*	*	*
Setting														
Paper	29,032	1.9	0.9	0.4	0.4	0.0	0.1	14,613	3.7	1.9	0.9	0.8	0.0	0.2
Clinic	15,711	4.7	2.3	0.8	1.2	0.1	0.3	9,858	7.4	3.6	1.3	1.9	0.1	0.5
Home	9,439	8.7	4.0	1.6	2.3	0.1	0.6	7,877	10.5	4.8	1.9	2.8	0.2	0.8
Telephone	17,044	3.8	1.9	0.7	0.9	0.0	0.2	9,372	6.9	3.4	1.3	1.7	0.1	0.4
Virtual	1,314	12.0	5.5	2.3	3.2	0.2	0.8	1,212	13.0	6.0	2.5	3.5	0.2	0.9
Ward	964	5.0	2.4	1.1	1.1	0.0	0.3	724	6.7	3.2	1.5	1.5	0.1	0.5
Community	410	8.4	3.6	2.0	2.1	0.1	0.6	398	8.6	3.7	2.0	2.2	0.1	0.6
Prison	2	*	*	*	*	*	*	2	*	*	*	*	*	*
Region														
North	6,325	2.9	1.4	0.6	0.7	0.0	0.2	3,574	5.1	2.5	1.0	1.2	0.1	0.4
North West	10,004	3.0	1.5	0.6	0.7	0.0	0.2	6,220	4.8	2.5	0.9	1.1	0.0	0.3
Midlands	5,047	4.8	2.2	0.9	1.2	0.1	0.3	3,042	7.9	3.7	1.5	2.1	0.1	0.6
South and East	17,275	2.3	1.1	0.4	0.6	0.0	0.2	7,235	5.5	2.7	1.0	1.4	0.1	0.4
London	15,839	4.1	2.0	0.8	1.0	0.1	0.3	10,026	6.5	3.1	1.3	1.6	0.1	0.4
South West	9,923	5.7	2.8	1.0	1.5	0.1	0.4	6,305	9.0	4.4	1.6	2.3	0.1	0.6
Scotland	5,092	6.1	2.6	1.6	1.4	0.1	0.4	4,130	7.5	3.2	1.9	1.7	0.1	0.5
Wales	2,134	7.6	3.6	1.4	1.9	0.1	0.5	1,716	9.5	4.5	1.8	2.4	0.1	0.6
Northern Ireland	1,935	7.6	3.9	1.3	1.8	0.1	0.4	1,490	9.8	5.1	1.7	2.4	0.1	0.5

	All submitted HNAs							Submitted HNAs with at least 1 concern						
		Mean concerns							Mean concerns					
	N	Total	Physical	Practical	Emotional	Spiritual	Family	N	Tot	Phy	Prac	Emot	Spir	Fam
UK	342	8.7	3.9	1.3	2.6	0.1	0.8	318	9.4	4.2	1.4	2.8	0.1	0.9
Day submitted														
Mon	11,320	4.4	2.1	0.9	1.1	0.1	0.3	7,052	7.1	3.4	1.4	1.7	0.1	0.5
Tue	13,263	4.1	2.0	0.8	1.0	0.0	0.3	8,206	6.7	3.2	1.3	1.6	0.1	0.4
Wed	13,773	4.1	2.0	0.8	1.0	0.1	0.3	8,571	6.6	3.1	1.3	1.6	0.1	0.4
Thu	13,744	4.0	2.0	0.8	1.0	0.1	0.3	8,518	6.5	3.2	1.3	1.6	0.1	0.4
Fri	11,029	3.9	1.9	0.8	1.0	0.0	0.3	6,652	6.5	3.1	1.3	1.6	0.1	0.5
Sat	1,238	10.2	4.7	1.9	2.6	0.1	0.8	1,124	11.2	5.2	2.1	2.9	0.2	0.8
Sun	1,382	10.5	4.9	1.9	2.7	0.2	0.8	1,260	11.6	5.4	2.1	3.0	0.2	0.9
Not recorded	8,167	1.4	0.7	0.2	0.3	0.0	0.1	2,673	4.2	2.2	0.7	1.0	0.0	0.2
Hour submitted														
00:00 - 05:59	273	9.3	4.1	1.8	2.5	0.2	0.8	239	10.6	4.6	2.0	2.9	0.2	0.9
06:00 - 11:59	29,005	3.7	1.8	0.7	0.9	0.0	0.2	17,150	6.3	3.0	1.2	1.5	0.1	0.4
12:00 - 17:59	32,951	4.3	2.1	0.8	1.1	0.1	0.3	20,863	6.9	3.3	1.3	1.7	0.1	0.5
18:00 - 23:59	3,520	10.0	4.5	1.9	2.7	0.2	0.7	3,131	11.2	5.1	2.1	3.0	0.2	0.8
Not recorded	8,167	1.4	0.7	0.2	0.3	0.0	0.1	2,673	4.2	2.2	0.7	1.0	0.0	0.2
Setup to submission														
Same day	37,173	2.9	1.4	0.6	0.7	0.0	0.2	21,648	5.0	2.5	1.0	1.2	0.1	0.3
1-6 days later	10,955	7.8	3.6	1.5	2.0	0.1	0.6	8,766	9.7	4.5	1.8	2.5	0.1	0.7
7-13 days later	8,537	6.0	2.8	1.2	1.5	0.1	0.4	5,901	8.7	4.1	1.7	2.2	0.1	0.6
14-27 days later	7,490	4.7	2.3	0.9	1.1	0.1	0.3	4,525	7.7	3.8	1.5	1.9	0.1	0.5
≥28 days later	6,128	3.2	1.6	0.6	0.8	0.0	0.2	3,216	6.0	3.1	1.1	1.4	0.1	0.4
Not recorded	3,633	0.0	0.0	0.0	0.0	0.0	0.0	0	*	*	*	*	*	*

* Descriptive statistics suppressed where n < 20

Appendix C – Summary of concerns

Frequency: Proportion of submitted HNAs that included this concern

Mean score: Mean score given to this concern of all submitted HNAs that included it

Modal score: Modal score given to this concern of all submitted HNAs that included it

Highest scoring: Proportion of HNAs where this was the highest or joint-highest scoring concern of all submitted HNAs that included it

Most common action: The action most commonly recorded against with this concern across all locked HNA

Domain	Concern	Abbreviation	Frequency	Mean score	Modal score	Highest scoring	Most common action
Emotional	Anger or frustration	*Anger*	7.6%	6.1	5	24.8%	Information sheet (Anger or frustration)
	Guilt	*Guilt*	3.1%	5.6	1	20.3%	Information sheet (Guilt)
	Hopelessness	*Hopeless*	4.0%	6.1	10	21.5%	Information sheet (Hopelessness)
	Independence	*Indep*	5.7%	6.0	10	28.8%	Information sheet (Independence)
	Loneliness or isolation	*Loneliness*	5.3%	6.0	5	27.7%	Information sheet (Loneliness and isolation)
	Loss of interest in activities	*Motiv'n*	7.0%	6.2	8	22.1%	Information sheet (Loss of interest in activities)
	Regret about the past	*Regret*	3.8%	5.8	5	24.4%	Information sheet (Regret about the past)
	Sadness or depression	*Sadness*	10.4%	6.2	8	29.7%	Information sheet (Sadness or depression)
	Thinking about the future	*Future*	14.7%	6.6	8	41.0%	Information sheet (Thinking about the future)
	Unable to express feelings	*Expr emot*	4.4%	6.0	8	22.1%	Information sheet (Unable to express your feelings)
	Uncertainty	*Uncertain*	13.9%	6.6	8	42.7%	Information sheet (Uncertainty)
	Worry, fear or anxiety	*Worry*	19.6%	6.2	8	44.2%	Information sheet (Worry, fear or anxiety)
Family	Children	*Children*	7.7%	6.5	10	43.2%	Information sheet (Talking to children)
	Other relatives or friends	*Frds/fam*	4.9%	5.8	8	30.9%	Discussed concern
	Partner	*Partner*	8.4%	6.5	10	43.7%	Information sheet (Relationship with your partner)

Domain	Concern	Abbreviation	Frequency	Mean score	Modal score	Highest scoring	Most common action
	Person who I look after	*Depend't*	3.0%	6.3	10	46.5%	Discussed concern
	Person who looks after me	*Carer*	3.0%	6.3	10	34.7%	Information sheet (Person who looks after me)
Physical	Breathing difficulties	*Breathing*	8.3%	5.4	5	29.0%	Information sheet (Breathing difficulties)
	Changes in weight	*Weight chg*	8.2%	5.6	5	28.8%	Information sheet (Changes in weight)
	Constipation	*Constip*	7.7%	5.0	5	23.9%	Information sheet (Constipation)
	Cough	*Cough*	5.4%	4.9	5	22.0%	Information sheet (Cough)
	Diarrhoea	*Diarrhoea*	5.1%	4.9	1	25.6%	Information sheet (Diarrhoea)
	Dry, itchy or sore skin	*Sore skin*	6.8%	5.0	5	24.1%	Information sheet (Dry, sore and itchy skin)
	Eating, appetite or taste	*Eating*	11.1%	5.5	5	28.7%	Information sheet (Eating, appetite and taste)
	High temperature or fever	*Fever*	1.5%	3.8	1	11.3%	Information sheet (High temperature or fever)
	Hot flushes or sweating	*Flush/swt*	7.7%	5.2	5	31.6%	Information sheet (Hot flushes or sweating)
	Indigestion	*Indigest*	4.4%	4.6	1	15.2%	Information sheet (Heartburn and indigestion)
	Memory or concentration	*Memory*	8.9%	5.3	5	19.0%	Information sheet (Memory or concentration)
	Moving around (walking)	*Mobility*	11.8%	6.0	5	34.5%	Information sheet (Moving around (walking))
	My appearance	*Appear'ce*	5.3%	5.6	5	28.4%	Information sheet (My appearance)
	Nausea or vomiting	*Nausea*	4.4%	4.9	1	19.8%	Information sheet (Nausea or vomiting)
	Other medical conditions	*Other med*	7.1%	5.8	5	41.7%	Discussed concern
	Pain or discomfort	*Pain*	14.8%	5.9	5	40.1%	Information sheet (Pain)
	Passing urine	*Urination*	7.2%	5.1	5	38.4%	Information sheet (Passing urine)
	Sex, intimacy or fertility	*Sex/fert*	4.9%	5.8	1	41.8%	Information sheet (Sex and intimacy)
	Sight or hearing	*See/hear*	5.0%	5.3	5	23.5%	Information sheet (Sight or hearing)
	Sleep problems	*Sleep*	13.5%	6.0	5	30.8%	Information sheet (Sleep problems)
	Sore or dry mouth, or ulcers	*Sore mouth*	5.1%	5.0	5	18.3%	Information sheet (Dry mouth)
	Speech or voice problems	*Voice*	2.4%	4.9	1	18.5%	Information sheet (Speech or voice problems)
	Swallowing	*Swallow*	3.4%	4.8	1	22.8%	Information sheet (Swallowing)
	Swelling	*Swelling*	4.0%	5.3	5	27.8%	Discussed concern

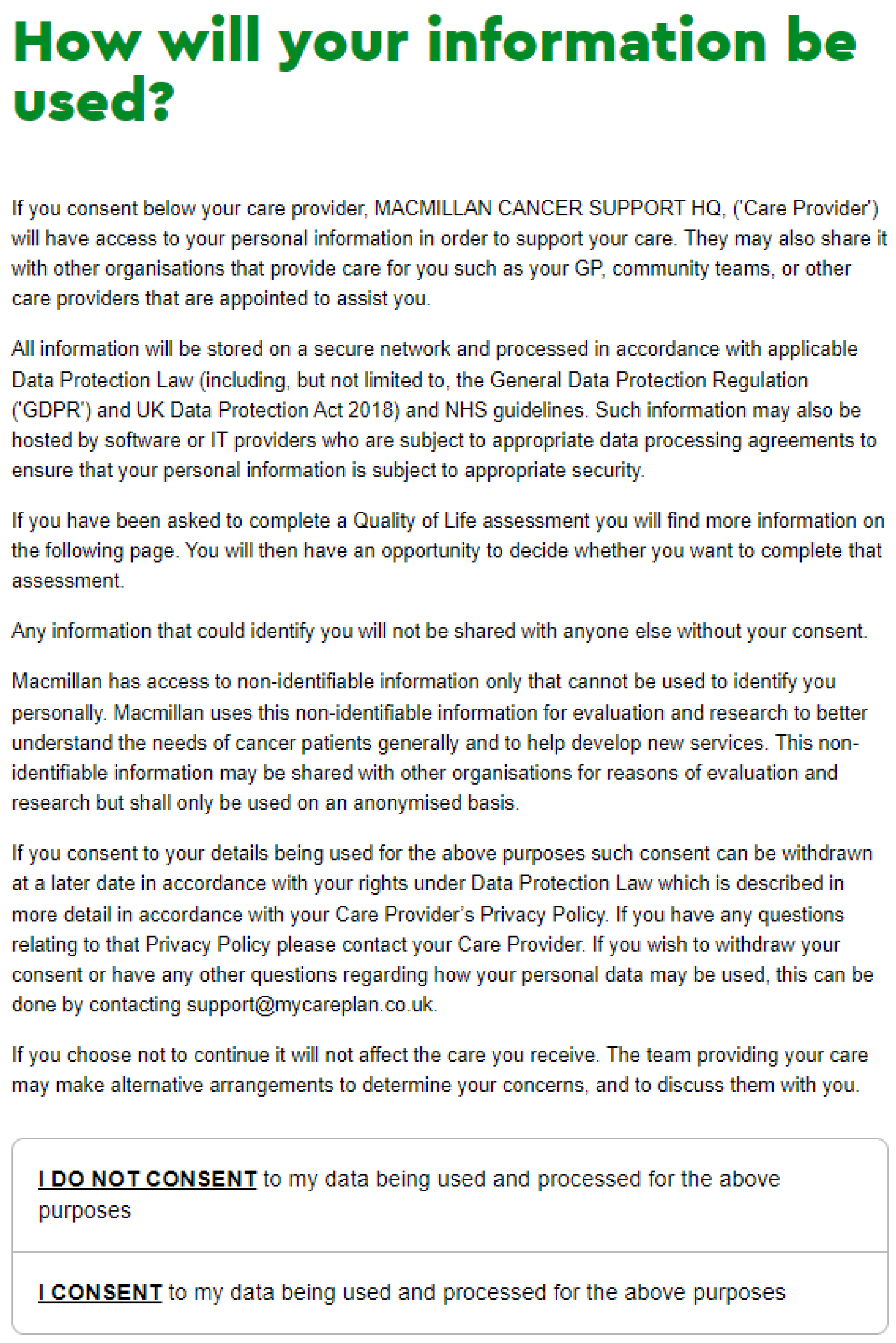
Domain	Concern	Abbreviation	Frequency	Mean score	Modal score	Highest scoring	Most common action
	Tingling in hands or feet	*Tingling*	6.4%	5.1	5	25.8%	Information sheet (Numbness or tingling in hands or feet)
	Tired, exhausted or fatigued	*Fatigue*	21.2%	5.9	5	36.9%	Information sheet (Tired, exhausted or fatigued)
	Wound care	*Wound*	2.8%	4.5	1	28.9%	Information sheet (Wound care)
Practical	Difficulty making plans	*Plans*	4.8%	5.8	5	18.9%	Discussed as part of another concern
	Grocery shopping	*Shopping*	4.0%	5.7	5	19.5%	Discussed concern
	Housing	*Housing*	3.7%	6.5	10	47.0%	Information sheet (Housing)
	Laundry or housework	*Housew'k*	5.5%	5.7	5	21.3%	Information sheet (Practical tasks)
	Money or finance	*Money*	16.5%	6.3	10	54.7%	Referral to welfare or benefits advice service
	My medication	*Medicat'n*	4.8%	5.4	5	30.0%	Information sheet (Medication)
	Pets	*Pets*	1.7%	4.7	1	18.1%	Discussed concern
	Preparing meals or drinks	*Meal prep*	3.9%	5.6	5	15.5%	Information sheet (Practical tasks)
	Problems with alcohol or drugs	*Alc/drugs*	1.0%	3.6	1	15.8%	Information sheet (Problems with drugs and alcohol)
	Smoking cessation	*Smoking*	1.8%	5.1	1	33.7%	Information sheet (Giving up smoking)
	Taking care of others	*Caregiving*	5.5%	6.3	8	35.3%	Discussed as part of another concern
	Talking or being understood	*Talking*	2.9%	5.6	5	18.9%	Discussed as part of another concern
	Transport or parking	*Transport*	6.8%	6.0	10	43.9%	Information sheet (Transport and parking)
	Travel	*Travel*	5.4%	5.7	5	34.0%	Information sheet (Travel)
	Washing and dressing	*Pers care*	4.2%	5.7	8	20.9%	Information sheet (Practical tasks)
	Work or education	*Work/ed*	6.1%	6.0	8	34.9%	Information sheet (Work (employment))
Religious and Spiritual	Faith or spirituality	*Faith*	1.5%	4.4	1	16.3%	Information sheet (Spiritual concerns)
	Feeling at odds with my culture, beliefs or values	*Beliefs*	1.0%	4.1	1	12.1%	Discussed concern
	Meaning or purpose of life	*Purpose*	2.5%	5.5	5	15.7%	Discussed as part of another concern

Appendix D – Summary of action types

Action type	Number of actions of this type	Number of locked HNAs with at least one of this action type (% of all locked HNAs)	% share of all recorded actions	Avg number of actions of this type per locked HNA	Most commonly recorded action of this type	Most common concern with this action type recorded	Most common service provider for actions of this type
Discussion	10	17,758 (42.9%)	39.2%	1.95	*Discussed concern*	*Tired, exhausted or fatigued*	*Not recorded*
Information sheet	68	12,788 (30.9%)	26.6%	1.30	*Tired, exhausted or fatigued (Macmillan information sheet)*	*Tired, exhausted or fatigued*	*Macmillan - information*
Referral	230	9,931 (24.0%)	9.5%	0.47	*Referral to welfare or benefits advice service*	*Money or finance*	*Not recorded*
Information	76	5,841 (14.1%)	7.1%	0.35	*Information given*	*Tired, exhausted or fatigued*	*Not recorded*
Signpost	217	5,653 (13.7%)	6.5%	0.32	*Signposted to Maggie's*	*Worry, fear or anxiety*	*Not recorded*
Advise	30	5,803 (14.0%)	6.4%	0.31	*Advised to contact GP*	*Pain or discomfort*	*Not recorded*
Follow up	4	1,372 (3.3%)	1.4%	0.07	*Follow up ongoing with CNS*	*Pain or discomfort*	*Healthcare - secondary*
Shared	4	890 (2.2%)	1.2%	0.06	*Shared care plan with GP*	*Pain or discomfort*	*Healthcare - primary*
Medication	6	469 (1.1%)	0.3%	0.02	*Medication prescribed*	*Pain or discomfort*	*Not recorded*
Callback	11	140 (0.3%)	0.1%	0.01	*Call from Macmillan Support Line - Emotional Support*	*Money or finance*	*Macmillan - service*
Exception	3	924 (2.2%)	1.7%	0.09	*Patient did not want to explore this concern at this time*	*Tired, exhausted or fatigued*	*Not recorded*

Appendix E – Consent statements

Usually, the first page of the HNA contains the following consent statement. The words Macmillan Support HQ are replaced with the name of the care provider giving out the HNAs.



How will your information be used?

If you consent below your care provider, MACMILLAN CANCER SUPPORT HQ, ('Care Provider') will have access to your personal information in order to support your care. They may also share it with other organisations that provide care for you such as your GP, community teams, or other care providers that are appointed to assist you.

All information will be stored on a secure network and processed in accordance with applicable Data Protection Law (including, but not limited to, the General Data Protection Regulation ('GDPR') and UK Data Protection Act 2018) and NHS guidelines. Such information may also be hosted by software or IT providers who are subject to appropriate data processing agreements to ensure that your personal information is subject to appropriate security.

If you have been asked to complete a Quality of Life assessment you will find more information on the following page. You will then have an opportunity to decide whether you want to complete that assessment.

Any information that could identify you will not be shared with anyone else without your consent.

Macmillan has access to non-identifiable information only that cannot be used to identify you personally. Macmillan uses this non-identifiable information for evaluation and research to better understand the needs of cancer patients generally and to help develop new services. This non-identifiable information may be shared with other organisations for reasons of evaluation and research but shall only be used on an anonymised basis.

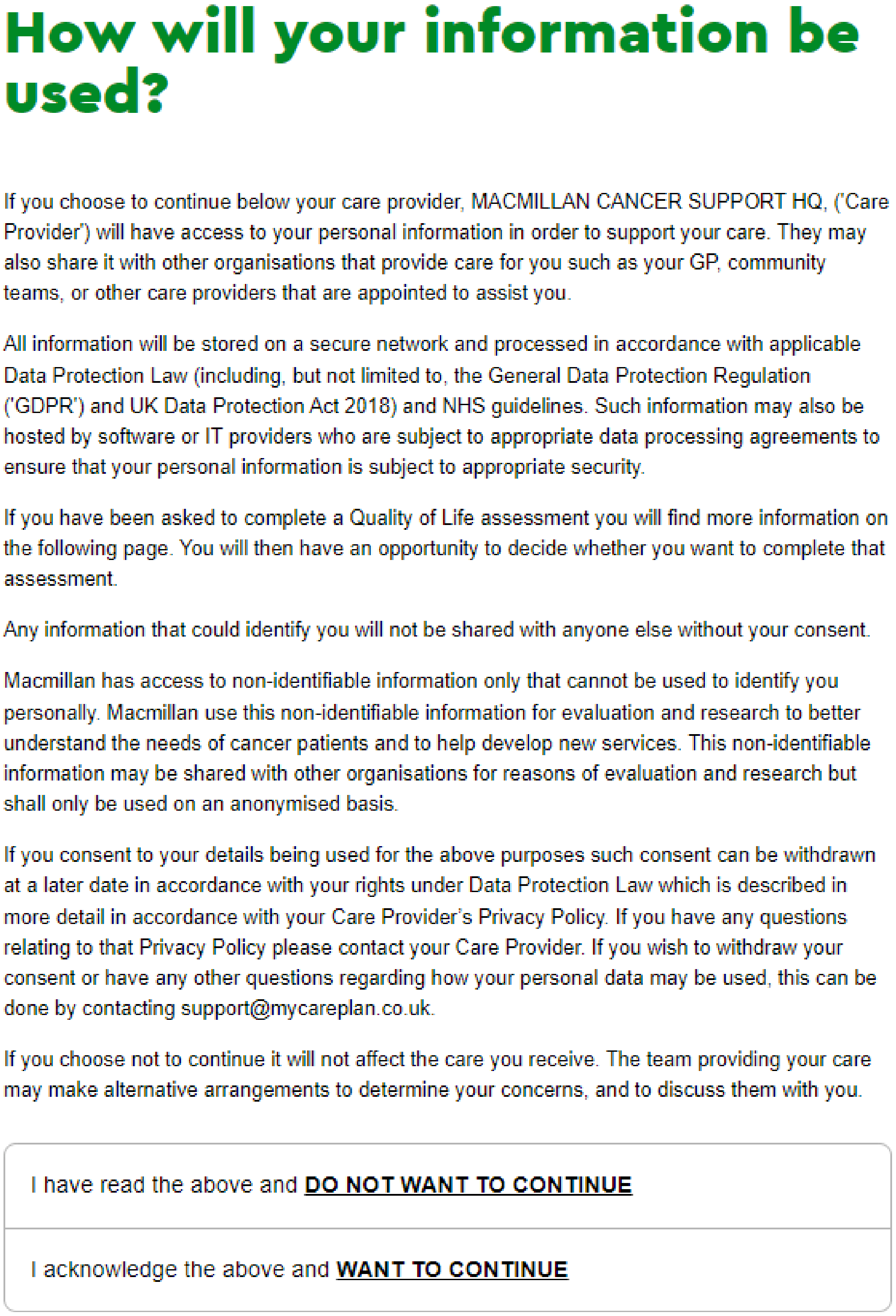
If you consent to your details being used for the above purposes such consent can be withdrawn at a later date in accordance with your rights under Data Protection Law which is described in more detail in accordance with your Care Provider's Privacy Policy. If you have any questions relating to that Privacy Policy please contact your Care Provider. If you wish to withdraw your consent or have any other questions regarding how your personal data may be used, this can be done by contacting support@mycareplan.co.uk.

If you choose not to continue it will not affect the care you receive. The team providing your care may make alternative arrangements to determine your concerns, and to discuss them with you.

I DO NOT CONSENT to my data being used and processed for the above purposes

I CONSENT to my data being used and processed for the above purposes

Some providers instead choose to use public task as their legal basis the collection and processing of the data. This uses the following statement:



How will your information be used?

If you choose to continue below your care provider, MACMILLAN CANCER SUPPORT HQ, ('Care Provider') will have access to your personal information in order to support your care. They may also share it with other organisations that provide care for you such as your GP, community teams, or other care providers that are appointed to assist you.

All information will be stored on a secure network and processed in accordance with applicable Data Protection Law (including, but not limited to, the General Data Protection Regulation ('GDPR') and UK Data Protection Act 2018) and NHS guidelines. Such information may also be hosted by software or IT providers who are subject to appropriate data processing agreements to ensure that your personal information is subject to appropriate security.

If you have been asked to complete a Quality of Life assessment you will find more information on the following page. You will then have an opportunity to decide whether you want to complete that assessment.

Any information that could identify you will not be shared with anyone else without your consent.

Macmillan has access to non-identifiable information only that cannot be used to identify you personally. Macmillan use this non-identifiable information for evaluation and research to better understand the needs of cancer patients and to help develop new services. This non-identifiable information may be shared with other organisations for reasons of evaluation and research but shall only be used on an anonymised basis.

If you consent to your details being used for the above purposes such consent can be withdrawn at a later date in accordance with your rights under Data Protection Law which is described in more detail in accordance with your Care Provider's Privacy Policy. If you have any questions relating to that Privacy Policy please contact your Care Provider. If you wish to withdraw your consent or have any other questions regarding how your personal data may be used, this can be done by contacting support@mycareplan.co.uk.

If you choose not to continue it will not affect the care you receive. The team providing your care may make alternative arrangements to determine your concerns, and to discuss them with you.

I have read the above and **DO NOT WANT TO CONTINUE**

I acknowledge the above and **WANT TO CONTINUE**

However, these statements are not always used for example the EasyRead version of the HNA includes much of the same information but it's adapted to make it easier to read and understand.

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