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Research Article

A network approach to addressing the needs of patients with incurable head and neck cancer and their families

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Abstract

Background: Patients with incurable head and neck cancer have considerable unmet needs and complex symptom burden, with evidence of substantial geographical and/or socioeconomic inequalities. Accurate information on healthcare needs, resource utilisation and service provision in the last year of life is lacking. This places limits on service delivery planning and the development and testing of interventions to better meet needs. Our partnership spans three regions, which nationally have some of the highest rates of incurable head and neck cancer.

Aims: The overall aims were to (1) establish a palliative head and neck cancer partnership, (2) identify and evaluate routine incurable head and neck cancer data sources and utilise these to develop and address research priorities.

Objectives:

O1. Develop a palliative head and neck cancer network within the North of England, representing a geographical area with high incidence of incurable head and neck cancer and palliative care needs.
O2. Develop and refine research questions and priorities.
O3. Engage with data providers to identify relevant data sets and specific data fields to understand the potential quality and utility of these to inform research priorities.

Methods: There were three interconnected work packages:

WP1: A ‘snowballing’ approach to establish a network of clinicians, researchers, patient and public representatives, data architects and key stakeholders with an interest in head and neck cancer palliative care.
WP2: A Delphi consensus process to develop and refine research questions and priorities, based on national guidance and systematic reviews of evidence gaps.
WP3: Identification of national and local data sets and exploration of the potential data quality and utility, and associated information governance processes for access.

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Results:

WP1: A diverse network was established, encompassing members from a wide range of professions and patient/carer groups.

WP2: The Delphi consisted of two rounds involving up to 66 participants. Consensus was reached on 12 research questions representing 4 key areas of prioritisation: service provision, symptom management, psychosocial support and information provision and communication.

WP3: A range of national and local data sources were identified as having the potential to address the research priorities. A directory of data sources was developed.

Working in an iterative way, data sets and relevant data fields were mapped to the 12 potential research priority areas to assess the applicability of using routine data to address these priorities.

Limitations: Approximately, one-third of participants in the Delphi process dropped out in round 2. Despite attempts to be flexible in our approach, retaining participants, particularly for patients and their families on a palliative care pathway, is challenging.

Future work: The established network and consensus exercise form the basis for future service evaluations and collaborative research. These will be based on gaps and priorities agreed by patients, their families and a range of other stakeholders.

Conclusions: The network has established a cross-sectoral collaboration for improving incurable head and neck cancer and a platform to identify 12 research priority areas. Utilising routine data to address these priorities remains a challenging area, and a range of methodological research approaches will be required to take this forward.

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Main report

Summary

There are considerable levels of unmet needs and complex symptom burden in a growing incurable head and neck cancer (IHNC) population, with evidence of substantial geographical and/or socioeconomic inequalities. There is a paucity of national research in this area. Whether quality data can be accessed, linked, extracted for those with IHNC in a timely manner is unknown. The absence of this information limits the accuracy of patient information, service delivery planning and development and testing of interventions to address inequalities. Our focus was to systematically address these multiple gaps, firstly by forming a collaborative 'Palliative Partners in Head and Neck Cancer (PP-HANC)' across the North of England. This is an essential foundation to prioritise and take forward a sustainable research programme for the benefit of patients, NHS and society – and is the primary focus of this project.

Background

Patients with IHNC and their families are a highly vulnerable group, with complex symptomatology and are subject to substantial health inequalities. Despite their poor outlook, little is known about their healthcare needs, resource utilisation and service provision in the last year of life. Without this understanding, planning services and pathways, setting expectations, and involving patients and families in decision-making are challenging. There are numerous potential avenues for impactful research. This project developed a cross-sectoral, multidisciplinary partnership across the North of England, where incidence rates are highest and research activity is low.

There are 12,000 new cases of head and neck cancer (HNC) diagnosed in the UK annually. The incidence has risen by a third since 1990 and is expected to escalate by 50% over the next 20 years.[1,2] One in 5 people with HNC will die within a year, and 1 in 10 survive for < 6 months.[3–5]

Patients with IHNC may be offered highly invasive procedures (e.g. tracheostomy) and/or palliative treatments which have significant side effects and for which the benefit to quality and quantity of survival is unknown.[6–9] They typically experience deterioration in the vital functions of breathing, swallowing and talking due to the cancer and its treatment. Experiencing these symptoms is very traumatic. Severe swallowing difficulties can result in malnutrition, dehydration, difficulty taking medications and high risk of choking. Speech problems can render patients completely unintelligible, making it difficult to converse, express needs and hinder involvement in decisions. Patients with breathing or feeding tubes require intensive support from community services, which is not always available. Functional deterioration adversely impacts on psychosocial well-being and independent living. Ethical dilemmas around place of care, hydration and nutrition, and mode of death can arise more frequently compared with other cancer groups.[10] The patient's appearance can be significantly altered (e.g. fungating mouth tumour). Symptoms can be extremely distressing for patients and families, leaving them isolated with very low quality of life. Almost half of HNC patients have clinical levels of distress, but there is limited availability and uptake of psychological help.[11]

Healthcare services for IHNC: IHNC patients are more likely than other cancer groups to have unplanned hospital visits, die in a hospital, or be admitted to intensive care units.[12–14] Our pilot data of 849 HNC patients with one or more non-elective admissions to hospital within Yorkshire and the Humber in a 12-month period showed that, within the same period, this cohort were the subject of 754 NHS 111 calls, 1115 ambulance calls and 1753 emergency admissions. Moreover, 127 of these non-elective admissions concluded in the patient's death, approximately 15% of the cohort.[15] A full understanding of the frequency and reasons for this high healthcare utilisation is lacking. HNC treatment centres are centralised, with many patients having long journeys to access specialist services. Currently, there is poor access to timely supportive IHNC care; services and care models are variable and fragmented, leaving patients and clinicians uncertain about what is available locally.[16,17] Moreover, these patients can have such complex needs and challenging personal circumstances that professionals and services can be ill-equipped to deliver appropriate care. Models of care are variable, leading to inequalities in service provision.[18]

We conducted two literature reviews: (1) qualitative synthesis of IHNC patient and carers' experience[19] and (2) health and social care IHNC needs.[20] Both found limited evidence – only seven qualitative studies were identified, and most quantitative studies were small scale, retrospective or cross-sectional. The main themes were diverse, multiple symptoms; communication issues with and between healthcare professionals; and high prevalence of 'intensive' interventions in the last month of life, requiring hospital admission. Palliative care needs were numerous and common in IHNC compared with other cancer sites. Access to palliative services varied and was often late. Communication difficulties impacted on patients' involvement and shared decision-making.

Context

The North West, North East and Yorkshire and the Humber have some of the highest UK incidence rates of HNC, especially for poor prognostic subtypes such as hypopharyngeal cancer (26% overall 5-year survival rate).[4,21] For example, in Liverpool, there are almost three times the national average of HNC diagnoses.[21] These regions also have significantly higher levels of deprivation compared with the national average.[1] HNC incidence rates in males and females are respectively 101% and 64% higher in the most deprived quintile compared with the least.[22] The most deprived patients are more likely to present with IHNC,[12,23] have severe depression and high symptom burden (7).[7] England-wide data for 2007–11 show that European age-standardised mortality rates are 218–298% higher for males living in the most deprived areas compared with the least deprived ones and 59–257% higher for females (22).[22] Indeed, the inequality in survival between rich and poor for laryngeal cancer is the widest of any common cancer.[24] HNC patients from poor socioeconomic backgrounds often have low levels of support,[4,25] and suboptimal health literacy, which limits their ability to acquire and understand healthcare information and access services.[26] Age-related inequalities are also evident. Disadvantaged older adults are more likely to have a late diagnosis,[21] and those > 80 years are more likely to receive non-curative treatment.[27]

Further considerations on the pressing need for research into IHNC are:

During the pandemic, audit data suggest a steep climb in advanced HNC diagnoses, which is likely to increase, and suboptimal primary treatment (avoidance of surgery and chemotherapy) may increase presentation of residual/ recurrent disease.
IHNC patients are high healthcare resource users, particularly emergency department and hospital admissions – some of which may be avoidable.
Low delivery on 'The Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2021–2026'[28] for those with IHNC. A key recommendation for alleviating inequalities is to use existing data to understand the reach of current services.

Aim

This project aimed to establish a network 'Palliative Partners in HANC'; develop research priorities; identify IHNC data sources and evaluate their utility; and generate research proposals.

Objectives

1. Build the PP-HANC network, bringing together three geographical regions, and extending into areas of low research activity.
2. Develop and refine research questions and priorities for PP-HANC.
3. Engage with local and national data providers to:

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a. identify relevant data sets and investigate data quality/utility of these sources to inform research priorities
b. establish the information governance approval process to facilitate access to linked data sets identified as research priorities.

Objective 1: building the Palliative Partners in Head and Neck Cancer network

The snowball approach was employed to recruit healthcare professionals, patient representatives, researchers and key stakeholders to the PP-HANC network. Snowball sampling allowed the team to sample characteristics (experience/expertise in HNC/palliative care) not easily accessible within the wider community.[29] The research team (with expertise in palliative care and HNC) invited potential members within their own networks to join PP-HANC. An invitation was sent to the teams' contacts via e-mail detailing the network's objectives and membership involvement. Invited parties were encouraged to disseminate this invitation within their own networks providing the inclusion criteria were met (residing or working in the North of England, expertise/experience of HNC and/or palliative care). Network recruitment was targeted towards the North West, North East and Yorkshire and the Humber regions, given the high HNC incidence rates and health inequalities in these regions.[21]

Network recruitment was ongoing for the duration of the study (April 2022–July 2023), and additional strategies were adopted to widen network membership and promote diversity (*Figure 1*). Cancer Alliances, Clinical Research Networks (CRN) and cancer treatment centres were approached within the North of England and asked to disseminate PP-HANC invitations. Network information was posted on the NIHR CRN website (PP-HANC | NIHR), targeting areas of low research activity, for example, Hull, Blackpool. Similarly, where specific professional representation was absent or low, PP-HANC members were asked to approach under-represented healthcare professionals within their networks. Wider representation was also sought via social media [Twitter (Twitter, Inc., San Francisco, CA, USA)/X].

The first PP-HANC network meeting (July 2022) was used to expand the network. Interactive workshops identified strategies to widen the network's reach and patient and public involvement (PPI) representation. Further network expansion was facilitated through: conference presentations, websites' dissemination [Partnerships | Liverpool Head and Neck Centre (livheadandneck.co.uk)], social media outputs and monthly newsletters.

Patient and public involvement recruitment was largely targeted through PP-HANC. Members were asked to discuss the network with patients and disseminate information about the project, ensuring initial discussions were grounded within a trusting professional–patient relationship. The lead PPI representative (Valerie Bryant) acted as a conduit to an established PPI group and was

FIGURE 1 Network recruitment.

able to disseminate network invites to her contacts within the local community, charities and wider networks.

Head and neck cancer research nurses (Liverpool, Sheffield) were approached to distribute network information to potential PPI members. Following guidance outlined within the NIHR community engagement toolkit,[30] we sought to engage with 'community connectors', and several meetings were conducted with the community groups [The Swallows (charitable organisations), and established PPI groups: Liverpool Head and Neck Centre, Clatterbridge Cancer Centre PPI group, North East Head and Neck PPI group]. Linking in with these organisations, the study co-ordinator presented information about PP-HANC to online platforms, promoting circulation of network information. The study co-ordinator attended research clinics to discuss network membership with potential participants.

Potential PPI members met with the study co-ordinator to discuss network involvement. PPI representatives new to research were offered peer support (a 'buddy' with PPI experience) to provide support and identify training needs.

Outcome

Palliative Partners in Head and Neck Cancer attracted diverse membership (*n* = 149), encompassing a wide range of professions (*n* = 136) and patient/carer groups (*n* = 13). Professional membership accounted for a large proportion of the network (91%). Nurses (25%), speech and language therapists (18%) and doctors (25%) represented a larger proportion of members in contrast to dietitians (1%), psychologists (1%) and radiographers (1%) (*Table 1*).

TABLE 1 Professional PP-HANC membership

Occupation	Number
Nurses	37
Speech and language therapists	27
Dietitians	9
Psychologists	2
Doctors	37
Dentists	2
Radiographers	5
Pharmacists	1
Researchers/academic	5
Other (cancer alliance, support workers, etc.)	11

The three different geographical regions in the North of England were represented in the network: North East (*n* = 35, 23%), North West (*n* = 65, 44%) and Yorkshire and the Humber (*n* = 49, 33%).

Patient and public involvement network members (*n* = 13) were recruited via: established HNC groups (*n* = 5), PP-HANC working group members (*n* = 2), community partnerships (*n* = 2), established PPI groups (*n* = 2) and clinical trials (*n* = 3). Four PPI members were carers/family representatives. Of the remaining nine patient representatives, all patients had been diagnosed with HNC and three PPI members had a diagnosis of IHNC. One member died during the project.

Patient and public involvement membership was represented geographically across the three regions. Although all PPI members were offered a buddy, no members availed themselves of this offer.

Objective 2: develop research questions and priorities: building consensus

The initial plan was to use the Nominal Group Technique to build group consensus on research priorities via small structured face-to-face meetings. However, PP-HANC members expressed an interest in being more involved in priority setting, during the first network meeting. Furthermore, many were reluctant to travel and meet in person during the pandemic recovery period. Therefore, the consensus process changed to the Delphi method, as it allowed for inclusion of both professional and experts by experience, leading to a greater diversity of perspectives and inclusivity. Furthermore, the Delphi method had been used successfully to generate research priorities in previous palliative care studies.[31,32] Our method was informed by the Guidance on Conducting and REporting DElphi Studies (CREDES) in palliative care framework.[33]

Refining and selecting statements

The Ambitions for Palliative and End of Life Care[28] and key findings from two literature reviews on IHNC care conducted by the research team[19,20] were used to create a list of research gaps, including (1) the high use of invasive treatments, where the impacts (particularly quality of life) had not been well captured; (2) unknown frequency and nature of symptoms in the last year of life; (3) patient uncertainty of where/how to access help with symptoms; (4) unclear information on trajectory; (5) wide variation on how and when to receive information; (6) family carer needs for support and training. These gaps were translated to research questions through research team discussions, and the PPI representative checking for accessible language. These were presented at the first network

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meeting (July 2022), and PP-HANC members were asked to identify any additional priority areas. Members were divided into groups of between four and eight people; discussions were facilitated by a research team member. Individual responses were copied verbatim into a single list of suggested research priorities (see *Appendix 1*). Items were reviewed by the study co-ordinator and grouped according to themes, allowing for the removal of overlapping/replicated content. Following this further research, priorities were sought via an online platform from the wider PP-HANC network. As previously, items were included if they represented a novel research priority and were subsequently revised to form research questions rather than statements.

Research questions were then reviewed by the research team; overlapping or redundant questions were removed, ambiguous questions were reworded and questions were organised into subthemes aligning with the construct of interest. Further PPI review, by Valerie Bryant, ensured that questions were accessible and appropriate. For example, definitions were provided for terms such as 'palliative care'. Thirty-two research questions were identified for inclusion in the Delphi exercise for round 1 (see *Appendix 1*).

Expert panel selection

Palliative Partners in Head and Neck Cancer network members were invited to participate in the Delphi exercise.

Delphi exercise

We designed questions to collect anonymised demographic information (geographical location, age, occupation) and individuals' priority rating of each research question. This was sent via e-mail or post, dependent on individual preference. A web-based survey software package, JISC (Bristol Join Information System Committee, Bristol, UK), was used to build, distribute and analyse the responses. In both rounds, e-mail reminders were sent 2 weeks and 1 week prior to closing. Members had 5 weeks to complete the exercise. The number of iterations or rounds were determined by the level of consensus reached. It was decided a priori that when ≥ 10 research statements met the threshold for consensus, no further iterations were indicated. We conducted two rounds of the Delphi exercise. Data were collected between October 2022 and January 2023.

In the first round, PP-HANC members were invited to rate research questions on a five-point Likert scale, ranging from 1 (low priority) to 5 (high priority). Members were encouraged to reflect on all questions relative to each other. Respondents had the option to provide alternative research statements for prioritisation.

A priori criterion for consensus was determined by the research team to develop a core set of priorities with high levels of consensus for future research initiatives. Research questions were only endorsed if > 90% of panellists rated the question as a high priority (4/5 on the Likert scale). Questions rated as a priority by < 80% of panellists were removed from subsequent iterations of the exercise. Questions with moderate agreement (endorsed by 80–90% of panellists) were presented for re-rating in the second round, in addition to new items generated from panellists in round 1. Round 2 of the exercise was e-mailed to panellists who had completed round 1. Panellists were presented with the whole group findings from round 1, in addition to their own ratings from round 1. As previously, panellists were asked to rate research questions in terms of priority on a five-point Likert scale.

Outcome

Round 1 Delphi exercise

Palliative Partners in Head and Neck Cancer network members (*n* = 121 at the time) were invited to participate in prioritising research questions. Sixty-six panellists completed round 1, which included 32 questions. Panellists were predominantly female (*n* = 48, 73%), from a clinical background (*n* = 45, 68%) and represented the three regions in the North of England (*Table 2*).

Half of Delphi items had low levels of agreement (*n* = 16, 50%). Twelve items (38%) scored a moderate level of agreement (i.e. rated as a 4/5 priority by at least 80% but not 90% of the panellists). Four items (12%) scored a high level of agreement (i.e. rated as a 4/5 priority by at least 90% of panellists) and therefore were endorsed as research priorities at this round (see *Appendix 2*). Two additional items were identified by panellists for rating at round 2 (*Figure 2*, *Appendix 3*, Q3, Q12).

Round 2 Delphi exercise

Of the 66 panellists in round 1, a total of 44 panellists (67%) completed round 2. Fourteen research questions were presented for priority rating at round 2 [items with moderate priority (*n* = 12), plus additional items identified at round 1 (*n* = 2)] (see *Figure 2*, *Appendix 3*). Panellists' gender and occupations were similar across both rounds; however, fewer nurses participated in round 2 (7%) relative to round 1 (17%). The geographical spread of the sample was similar to round 1 (see *Table 2*).

A further eight items were highly endorsed by panellists at round 2 and met the criteria for research prioritisation. The 12 research questions represent 4 key areas for prioritisation: service provision, symptom management, psychosocial support and information provision and communication (*Table 3*).

TABLE 2 Demographics of Delphi panellists

Demographics	Round 1 *n* = 66	Round 2 *n* = 44
Age range	18–79	19–79
Gender, n (%)		
Female	48 (73)	29 (66)
Male	18 (27)	10 (23)
Unreported	0	5 (11)
Occupation, n (%)		
Nurse	11 (17)	3 (7)
Doctor	15 (23)	11 (25)
Allied healthcare professional	19 (28)	12 (27)
Academic (research)	7 (11)	4 (9)
Patient	9 (14)	8 (18)
Carer	3 (4)	0
Other/not reported	2 (3)	6 (14)
Location, n (%)		
North West	30 (45)	17 (39)
North East	14 (21)	12 (27)
Yorkshire and the Humber	17 (26)	7 (16)
Not stated	5 (8)	8 (18)

Objective 3: Identifying data sets, assessing data quality/utility, establishing information governance approval

We sought to identify national and local data sources that could be used to address the research priorities: this included data generated during routine patient care for clinical and commissioning purposes and data generated through research studies and nationally available data sources. Given the diversity of local, regional and national data that we were seeking to identify, we used a variety of methods in an iterative process to search for web-based sources, for example, NHS England (NHS Digital, Leeds, UK), NHS Digital, the published literature (e.g. through bibliographic databases, such as MEDLINE, Cumulative Index to Nursing and Allied Health Literature, etc., and grey literature).

Our search terms included 'research database', 'cohort study', 'bioresource', 'longitudinal study', 'routinely recorded data for searching for data sources', and used search modifiers, such as 'health', 'cancer services', 'cancer outcomes', 'service activity data' and so forth, to narrow these down to relevant topics and further modifiers, such as England, UK, United Kingdom, Great Britain, to narrow the search geographically.

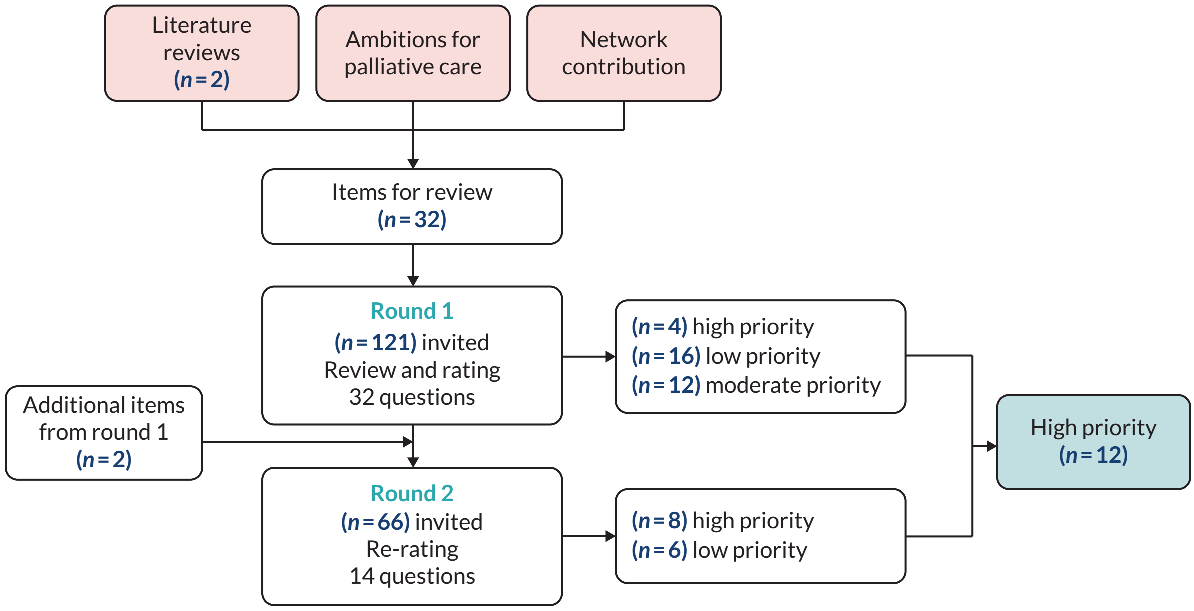

FIGURE 2 Flow diagram of the modified Delphi process.

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TABLE 3 Twelve research priorities

Key area	Research priority
Service provision	1. Find out how to best co-ordinate care to meet patients' needs 2. Find out when and how to get help with symptoms (such as pain, difficulty eating and shortness of breath) 3. Find the best way of identifying when patients might benefit from palliative care 4. Develop palliative care training for carers and family to develop the skills and knowledge to care for their relative/friend 5. Find out what aspects of palliative care are important to patients
Symptom management	6. Find out what impact high levels of treatments (such as chemotherapy or tube feeding) have on patients' quality of life 7. Find out the best ways to maximise the benefits of treatments and live as well as possible with the effects of the disease 8. Find ways to treat symptoms without the need for intensive treatments (such as chemotherapy) in the last months of life
Psychosocial support	9. Find the best ways to help people who do not have a good support network around them 10. Find ways to help patients feel less lonely and isolated during the last year of life
Information provision and communication	11. Find out what information and support patients would like 12. Find the best ways to improve ongoing communication (about the illness and care planning) between patients and healthcare professionals

We also used the PP-HANC network and personal contacts to identify further national and local sources of routinely collected patient-level data on patients with IHNC. Below, we review the data sources available and considered them in the context of the research priorities and those that could potentially be addressed using routine data sources. We considered the data that are collected and how data collection impacts the data. We then describe locally collected data sources that we became aware of throughout the project; however, the availability of some data is currently unclear.

Routinely collected/operational/ real-world data

These are data that are captured routinely while delivering services. The purpose(s) for which the data are collected has great bearing on the cohort for whom the data are captured and the consistency, reliability and accuracy with which the data are recorded.

Data sets may frequently be formed of data collected for many different purposes at different times (e.g. clinical purposes, service audit and commissioning services). Unfortunately, this *data provenance* is seldom captured or documented in an accessible fashion. These data may not be of sufficient quality to be useful for addressing research priorities for patients with IHNC. Additionally, due to data protection regulations and requirements, data collected for one purpose, for example, patient care, may sometimes not be available for research purposes.

Clinical purposes

Data captured for clinical care purposes are very likely to be accurate at the time of capture but only collected when there is a clinical need for such information (i.e. so may be susceptible to extensive sampling bias). Additionally, the date a diagnosis is recorded may not be an accurate estimate of the date of onset of a disease.

Clinical data are not always captured using standardised and consistent means (e.g. different organisations use different systems; such systems may not record identical information, nor record information in the same formats). Not all data may be available in an electronic format, or may, for example, exist only as scanned notes as an image, rather than searchable text. Data may also be stored exclusively as free text, which requires manual work to code and classify the data prior to analysis, although Natural Language Processing could support this task.

Summary

Data recorded are detailed and accurate. Data may be recorded only for a very specific cohort, and precisely what is measured and the format in which data are recorded may vary. Data that are collected frequently in a systematic way from electronic records are of potential value. For example, the Clinical Practice Research Datalink (CPRD) collects clinical data from general practices that use the EMIS (EMIS Health, Leeds, UK) patient record system software and covers approximately 25% of the UK population. Similarly, the Health Improvement Network collects and makes available data on data sources from (anonymised) primary care records dating back to 1994; however, this only covers ca. 6% of the UK population. The extent to which these sources include records and data on IHNC patients is unclear.

Mandated, commissioning and monitoring purposes

These are data that are captured for commissioning of healthcare services and routine monitoring purposes, especially for reimbursement purposes, and are likely to be completed for all eligible activities.

Secondary (hospital) care has been the focus of nationally mandated commissioning data sets dating back to the 1990s through the ‘Payment by Results’ commissioning model. Local commissioners may seek additional local data flows from providers of services they commission. Alternatively, some commissioners may enable derogations from mandatory commissioning data flows if they use alternative commissioning models (e.g. ‘block contracts’). Not all fields within commissioning data sets are mandatory, and even some mandatory fields are not used for reimbursement purposes. Fields not directly used for reimbursement are less likely to be completed or completed accurately or consistently. For example, data submitted for inpatient care are entered by clinical coders, based on patient records/notes. These clinical coders are trained to extract and enter data based on uniform (across England) coding rules. Additionally, their coding is routinely cross-validated to ensure national consistency. In contrast, in accident and emergency (A&E), only 4 of the 100 + fields are used to derive reimbursement value; diagnosis is not among these 4 fields. Data are extracted from patient administration systems based on information entered directly by healthcare professionals and administration staff.

The National Cancer Registration and Analysis Service (NCRAS) (part of the National Disease Registration Service) collects data on all diagnosed cancer patients living in England for analysis and research. Data for the whole cancer pathway are collected from a wide variety of sources (including pathology reports, treatment records, clinical audits, hospital administration systems, general practices and hospices, and death certificates, etc.) to create a linked longitudinal patient-level data set. From these data, the NCRAS creates the Cancer Outcomes and Services Data Set, the Systemic Anti-Cancer Therapy (SACT) Data Set, the Radiotherapy Data Set and the Somatic and Germline Genomics Data Set.

The NCRAS undertakes its own analyses and research and provides summary statistics and aggregated data. These are available for specific groups of cancers through the NCRAS through the ‘Get Data Out’ programme, for example, for cancers of the head and neck. The summary statistics include incidence, diagnosis, treatments and survival for different cancers, as well as statistics from the Cancer Quality of Life survey. The NCRAS website appears to be still under development (October 2024) so that the embedded links may change in the future.

Research using the data and anonymised/depersonalised data can be accessed through the Data Access Request Service (DARS) at NHS England. The NCRAS emphasises that patient-level data can only be accessed for healthcare work to benefit individuals and society and the importance of patient confidentiality. Personal (i.e. identifiable) data will only be made accessible when it is absolutely necessary.

Government departments collect data on individuals directly during their operations, for example, the Department for Work and Pensions (data on claimants of pensions and the various allowances/benefits schemes). Local authorities are legally obliged to collect data on births, death and marriages, and so on; they also collect data mandated by central government departments, for example, housing, tax.

Over time, these data sets will have evolved meaning that the included data items will have also changed over time (some have been lost and some added). Additionally, the time between applying for data and receiving it can be considerable, leading to significant delays for the analyses and an overall project management.

Local administrative purposes

Data collected for local administrative purposes share the same issues as the above, but, additionally, there is unlikely to be standardisation in what information is (measures are) captured, nor consistency in recording (codelists and methods) across or, at times, even within organisations.

Summary

Mandated data are recorded for (practically) all in-scope activity, and a consistent set of fields is recorded by all providers. The most comprehensive source of data on cancer patients is the NCRAS. However, the consistency and accuracy of entered data vary. Data are frequently collected. Data for local administrative purposes are likely to be recorded for all in-scope activity but are unlikely to be consistently recorded, or that a consistent set of fields recorded by all providers. The accuracy of entered data is variable, and they may not be collected frequently.

Research databases

There are numerous studies/projects in which data are captured from participants and made available to other researchers, usually labelled 'research databases'. Examples include UK Biobank; Genomics England 100,000 Genomes Project; the English Longitudinal Study of Ageing (ELSA); the CPRD; and Head and Neck Cancer 5000. Some studies are longitudinal; some include both biological samples, clinical measurements, and responses to questionnaires; some enable linkage to (some) routinely recorded data. Participants are consented but may not be representative of the general population. Some studies are highly regional, almost all studies have limited numbers of participants.

The extent to which patients with HNC are present within these studies is difficult to ascertain prospectively; however, mortality data may be available that could be linked to research data to identify retrospectively those who had HNC (subject to the necessary approvals). A further issue relates to when these projects were commenced, when patients were originally recruited, and re-sampled from the population, and the extent to which data are contemporaneous and relevant to the issues facing patients today.

Clinical trials

There has been an increasing focus on the re-use of data collected for clinical trials, especially publicly funded clinical trials. Data collected for clinical trials will only encompass items relevant to the specific trial and will be limited to a specific cohort, who are often highly selected to fit the trial inclusion criteria, and may not therefore necessarily be representative of the underlying population.

National surveys

A wide range of aggregate, adjusted national data are available from surveys conducted by NHS Digital (e.g. Health Survey for England) and the Office for National Statistics (ONS), among others. These data are collected using consistent means and in a consistent form from a random, representative sample of the population. Responses are adjusted based on population data to produce nationally (sometimes, subnational) representative results. In some cases, individuals' survey responses may be made available to researchers in de-identified form.

Personally captured data

Many individuals routinely capture a large volume of data about themselves through their use of smartphones and wearable technologies. This cohort is unlikely to be representative of the general population; data are unlikely to be consistently recorded; and it is unlikely that a consistent set of fields is recorded by all technology providers. Consistency and accuracy of entered data are likely to be variable. Frequency of recording is also likely to be variable.

Data not directly relating to individuals

There are wide-ranging geospatial (or geospatial-derived) data sets relating places, accessibility (e.g. of greenspace) and connectivity (e.g. road travel times).

Summary

Data are likely to be well recorded for limited, participating cohorts and trials; data are consistently recorded using a consistent set of measures. Consistency and accuracy of data are generally high. Frequency of collection varies; some are one-off, others have repeated collection over time (longitudinal). However, these data may have limited numbers of patients with HNC.

Data availability

Individual-level data

Providers

Health and care data relating to patients are collected by service providers such as hospital trusts, ambulance services and general practitioner (GP) practices (among many others) in the course of delivering services. Identifiable patient information is provided under a duty of confidence and may not be shared without a legal basis (in addition to satisfying data protection legislation). De-identified data which are considered anonymised may be shared, but different organisations have different interpretations on what constitutes anonymised information.

Agreements to share data would be required from every organisation. In the case of GP data, this would require an agreement with every GP practice, although for specific data resources, for example, the CPRD and the NCRAS, these are already in place. It also may be possible to gain access to data through trusted research environments that have already been set up for data-sharing/access, for example, the SAIL Databank in Wales.

NHS Digital (The Health and Social Care Information Centre) and NHS England

The Department for Health and Social Care (and various public bodies responsible for health and care in England), within certain constraints, may require that (identifiable) health and care data were reported to a central public body known as NHS Digital (legally, the Health and Social

Care Information Centre). NHS Digital was abolished in February 2023 and became part of NHS England, the body now responsible for making information and data available.

NHS England disseminates the data it collects to responsible national public bodies (e.g. the former Public Health England, now the UK Health Security Agency and Office for Health Improvement and Disparities), local commissioners (i.e. the former Clinical Commissioning Groups now replaced by Integrated Care Boards), and to researchers where it can be evidenced that such releases are likely to benefit the NHS in England.

The former NHS Digital and, since 1 February 2023, NHS England, and subject to approval by its Independent Group Advising on the Release of Data committee and internal approvals, generally provides de-identified data extracts under a comprehensive (data-sharing) contract. Extracts may be made available within NHS Digital/NHS England's Trustworthy Research Environment or made available to download (subject to contractual conditions). To generate sufficiently large sample sizes, especially for longitudinal analyses of limited numbers of cases, several years of data may be required, and there may be considerable costs associated with obtaining data from different sources.

NHS Digital/England is unable to share identifiable data unless convinced it is necessary, and there are clear research questions, as well as there exists a legal basis to supply it.

Commissioners (Clinical Commissioning Groups, potentially Integrated Care Systems from April 2022)

Commissioners may only access data relating to care delivered to their own population. Commissioners receive patient-level data from NHS Digital [in the form of Data Services for Commissioners Regional Offices (DSCROs)]. They may only use these data for the purposes of delivering services, though these do include service evaluation and audit.

Local commissioners may also agree to local data collections directly with service providers they commission. If these data are at an individual level, it will be processed by a DSCRO to facilitate linkage to other data sets and to de-identify the data before they are received by local commissioners.

Research databases

Research databases have their own application processes for accessing data. They may only provide anonymised data sets. Some research databases may provide linkage to other data sets (e.g. ELSA and the CPRD enables linkage to some NHS Digital-held data sets). However, some of these data sources, for example, CPRD, require fees to access the data, which may be a barrier to access.

Clinical trials

Clinical trials that choose (and are able) to allow re-use of their data have their own application processes. Only anonymised data sets are available, and research use of the data may be limited to the original purpose for which the data were collected.

Office for National Statistics Secure Research Service/UK Data Service Trustworthy Research Environment/HMRC DataLab

Various providers make available de-identified extracts of their own data and data collections belonging to others within trustworthy research environments. Generally, applications for access to data are similar to an ethics review. Some providers require researchers to attend specific training.

Summary

Table 4 provides an example of a data availability matrix for a variety of health data.

Usability of data for incurable head and neck cancer research

The potential use of the data described for addressing the 12 PP-HANC research priorities was considered by the team. *Table 3* summarises the likelihood of there being routinely collected patient data available to address these priorities.

Obtaining access to these data sets

Accessing these data is often a very lengthy process: this can lead to delays in projects, and there can also be costs associated with accessing the data sets. NHS ethics and Confidentiality Advisory Group approval may be necessary to access individual patient record data, and even more so for potentially identifiable data (e.g. death certificate data, date of death).

Summary

The following four research priorities were identified as being most likely to be addressable using routine patient-level data sources to determine:

- when and how to get help with symptoms (such as pain, difficulty eating and shortness of breath)
- the best way of identifying when patients might benefit from palliative care

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TABLE 4 Example of data availability matrix

		Data providers/custodians			
		Care providers	**Local commissioners**	**NHS Digital**	**Research databases**
Types of data available	Patient (free text) notes				
	Imaging data				
	Clinical measures				
	Service usage measures				
Key					
	Readily available		Somewhat available		Not available

- what impact high levels of treatments (such as chemotherapy or tube feeding) have on patients' quality of life
- ways to treat symptoms without the need for intensive treatments (such as chemotherapy) in the last months of life.

Routine-level data sets were reviewed to identify data sets and fields that could assist in addressing the research priorities. These are summarised in *Appendix 4*, *Table 5* and *Appendix 5*, *Tables 6–9*: details include a brief description of the data sets, the fields that will be of general use for the research and fields that could be useful for specifically addressing the research priority.

There are several data sets that are of potential value to addressing the research priority areas. Once the research priorities are refined into clear research questions and/or hypotheses, clear decisions could be made about the appropriateness of the data sets and fields, as shown in *Figure 3*. Additionally, there is potential for linking data across data sets, either by trusted data providers, such as NHS England/NCRAS, prior to anonymisation or using pseudonymised patient identifiers, subject to ethical approval and data governance requirements. However, there may be costs and time delays associated with obtaining these data. *Appendix 6*, *Table 10* provides details of some of the routine data sources that may be linked in this way.

An arrangement between the research team and data providers is usually required for data access, the research ethics approval process, information governance and data-sharing agreements. The exact process for this has changed at a national level within the duration of PP-HANC, for example, with responsibility for making patient data available for research being transferred from Public Health England to NHS Digital, and the application process now going through the DARS.

Discussion

Palliative Partners in Head and Neck Cancer has established a cross-sectoral collaboration for improving IHNC care for patients and their families, with representation from people from areas of low research activity. It has provided a springboard for developing a future research programme addressing identified research priorities in this area. The data mine has provided an overview of the availability, gaps and limitations in NHS (and other) data and mechanisms for extraction for capturing episodes of IHNC care. PP-HANC has developed and strengthened working relationships, involving individuals from diverse backgrounds with a common purpose. It has increased PPI partnerships, enhancing equity, diversity and inclusivity. The network will retain an emphasis on reducing inequalities in care in this vulnerable population. It will provide more accurate information about the IHNC pathway, leading to better information for patients and their families.

Outputs

Over the 16-month project, we held two PP-HANC Network meetings and hosted a dissemination webinar. Content was made accessible for patients, families, patient groups and charities, in addition to clinicians, researchers and other stakeholders. We updated network members through regular newsletters, institutional websites and our social media, using plain language summaries and infographics. We produced a data source directory and an overview of their characteristics, sharing data extraction and synthesis methods. We presented our work at several conferences and meetings, such as International Quality of Life in HNC Conference, The Swallows HNC Patient Conference.

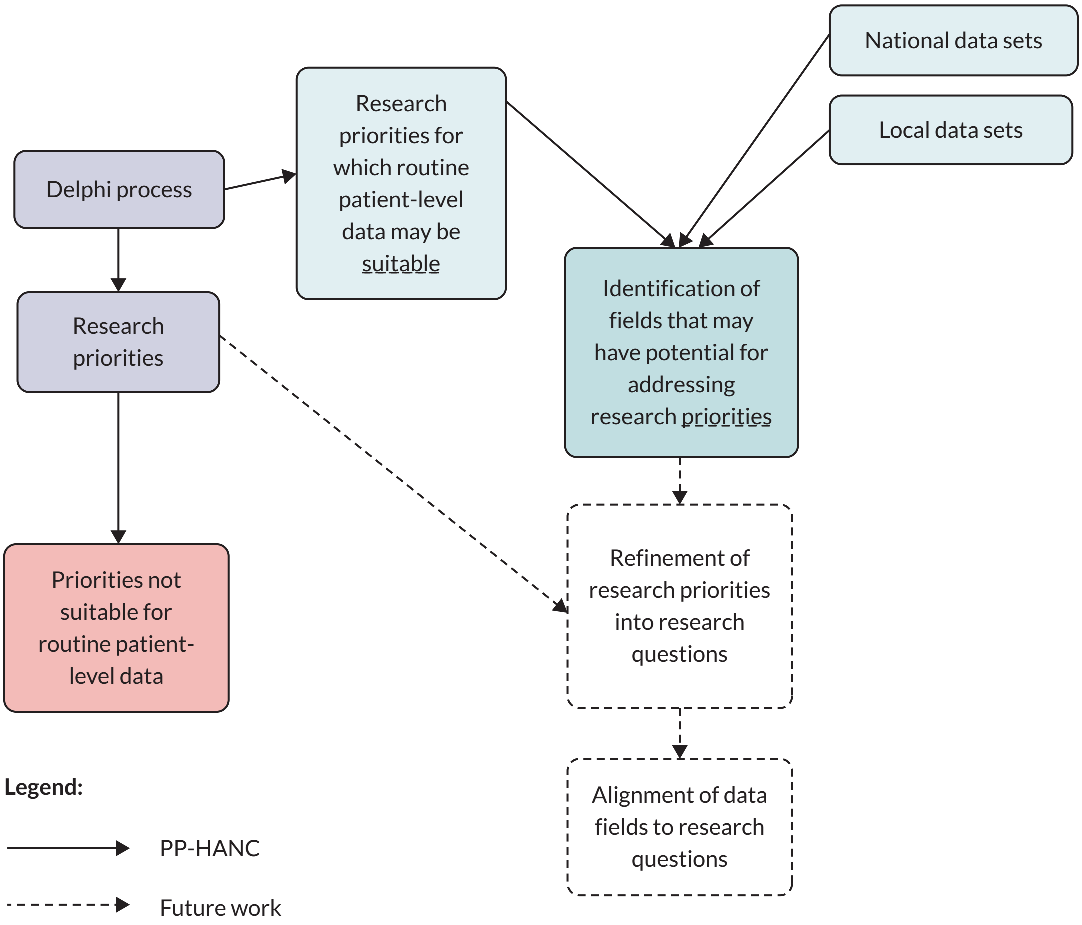

FIGURE 3 Identification of data sets for future research.

Strengths and limitations

Consensus process

Our Delphi process ensured anonymity, reducing dominance and group conformity, which is particularly important when developing group consensus among healthcare professionals, researchers, patients and carers. However, panellists may have lacked accountability when ranking items and therefore make unconsidered responses.[40] Likewise, panellists may have variably interpreted individual items.[41] Given that the Delphi process was modified, this may have limited further assessment of interspersed stability of items among successive rounds as items with only moderate agreement were selected for re-ranking. However, it was decided that more than two rounds were likely to be required to examine stability of responses.[41] The heterogeneity of the panel was a key strength since it allowed the team to access a broader perspective when identifying research priorities for IHNC. The 12 priorities have not been approved by an external authority, but otherwise our methods are compliant with CREDES guidelines. Of note is a relatively small sample of PPI participants. Despite substantial efforts, attracting and retaining people with experience of IHNC was challenging. There were several barriers, including fluctuating and highly unpredictable medical status, and reluctance for in-person meetings following the pandemic.

Data set identification

Identifying data sets containing routinely collected patient-level data was facilitated by widely available information on UK government and health service websites, and so forth. However, the availability and accessibility of these data for addressing research priorities and future research questions is highly variable and constrained by the requirements for ethics approvals, information governance approvals, data-sharing agreements, and gaining access to the data, which can impact on project timescales and deliverables. There may be further concerns about the quality and completeness of data available from routinely collected data that may impact on the ability to address research questions and test formal hypotheses.

Patient and public involvement

To ensure that diverse and inclusive opportunities for research involvement were offered, the following approaches were undertaken.

- *Specific consideration of the patient population.* We worked closely with PP-HANC clinicians to guide the timing of approach for potential PPI representatives. Additionally, there was a close working relationship between the study co-ordinator who provided a single, central point of contact and was available to provide immediate support (e.g. provide information, clarify queries) as well as support practical aspects (e.g. help co-ordinate travel and reimbursement of expenses). Only short-term engagement was a possibility for those with incurable disease. PP-HANC was also supported by those who had undergone curative treatment but had relevant lived experiences of the complexities of treatment and longer-term symptoms.
- *Creation of a* PPI *'buddy' system.* This potentially meant that involvement was less daunting and enabled identification of any specific training needs. The 'buddy' system was not formally utilised, which may have been related to several factors: the predominantly online forum of the partnership; the close working between new PPI members and the study co-ordinator; the established support in place within specific PPI groups such as the one chaired by our PPI lead.
- *Offering wide-ranging flexibility*. This applied to the desired level of engagement; preference regarding study materials (via paper/online) and ways of meeting (within group/one-to-one feedback).

In addition to being a member of the project working group, our PPI lead inputted towards

- Processes used to identify research priorities, including wording and language used.
- PPI dissemination, engagement and support. VB attended a HNC patient conference, informing others and supporting them to engage with the Delphi exercise.

Equality, diversity and inclusion

The 'Include NIHR Toolkit' was referred to throughout the project. Our project team included members from a range of disciplines, with a highly experienced patient representative. The team also had some diversity of gender, age range, ethnicity and geographical location.

Objective 1 focused on attracting people to the network. The advertising format was appealing, conveying accessible and sensitive information. There were insufficient funds to translate the advertisement, which may have limited uptake. The network has one patient member for whom English is a second language. He has been able to fully participate without need for translation.

Our intention was to attract people from geographical areas of low research uptake. The team regularly reviewed and monitored network membership for their background, that is, patient, carer, profession and location. Where gaps were identified, we discussed a strategy to target that geographical area, making full use of network members to guide us towards potential recruits.

Increasing the diversity of our PPI representatives was important, especially those who had direct experience of palliative care. Our connection with other HNC PPI groups was established through the research team's existing relationships. We capitalised on a PPI database of underserved HNC communities, funded by a NIHR NW Coast CRN project. To widen consultation on research priorities, Valerie Bryant attended a HNC patient conference, offering paper or electronic copies of the Delphi exercise.

The research team gave considerable thought to where and how network meetings should be conducted. The first meeting coincided with the early post-pandemic period, negating a large in-person meeting. We agreed upon an online meeting, while recognising that this excluded those unable to access IT equipment. We opted for Microsoft Teams (Microsoft Corporation, Redmond, WA, USA) Teams as the platform, as Zoom access (Zoom Video Communications, San Jose, CA, USA) was restricted for NHS staff at that time.

For our final meeting, we held both an in-person and online meeting to enable as many people as possible to join. Valerie Bryant reviewed the content highlighting any technical or inaccessible language. The University of Liverpool was selected for the in-person meeting, as proportionately, there were more members residing in this locality. The venue was at ground level for accessibility, with a side room available for members who required privacy for enteral feeding. Additional quieter spaces were accessed for those who had speech and hearing difficulties. Travel costs were reimbursed. These were provided 'up front' for patients to ensure they were not out of pocket prior to the event.

Current aligned research

There are two current projects aligned and informed by the PP-HANC network.

1. Understanding and identifying priorities for improving the healthcare experiences of people with IHNC: a qualitative investigation and co-design approach (ii-HANC) (NIHR Research for Patient Benefit-funded co-leads Dr Mayland and Professor Patterson). This aims to understand the needs and experiences of healthcare services over time for IHNC patients and their families. It is being conducted across the same three regions of North England.
2. Pictures of Us: connecting artists, patients, carers and clinicians to better understand, identify priorities, and improve the quality of experiences of IHNC through a qualitative art-based investigation and co-design approach. This project aligns with the PP-HANC research priority of ‘Psychosocial support’.

Future developments

Palliative Partners in Head and Neck Cancer members will be supported and act as a conduit for developing joint projects across the network. The network has several research projects in development:

1. core outcome data set for HNC Palliative Care (underpins all 12 priorities)
2. shared decision-making in older adults diagnosed with advanced HNC (aligns with ‘Information provision and communication’ research priority)
3. patient-reported outcomes and quality of life in palliative HNC radiotherapy (aligns with ‘Symptom management’ research priority)
4. stereotactic radiation therapy in the palliation of HNC symptoms (aligns with ‘Symptom management’ research priority).

Network sustainability

Members were consulted over what they wanted from PP-HANC in the future. They wanted to maintain connections, access support for their IHNC project work and have a forum to present work. Permissions have been sought to retain people’s contact details for future activity, feedback and updates. We intend to hold events to feedback work within the network. VB will maintain her networks with patient groups and charities. Contact with other related organisations such as International Centre for Recurrent Head and Neck Cancer, Royal Marsden Foundation Trust will be maintained.

Conclusions

Palliative Partners in Head and Neck Cancer has established a cross-sectoral network for improving IHNC, with engagement from a broad network of individuals and organisations, focused on locations of low research activity and high disease incidence. A robust consensus process identified 12 research priority areas. Utilising routine data to address these remains challenging, although potentially it may provide deeper insights in up to four of these priority areas. A range of methodological research approaches will be needed to address all priorities. PP-HANC will continue to provide a platform for sharing information, research plans and outputs, strengthening links and future research directions.

Additional information

CRediT contribution statement

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Data-sharing statement

Requests for access to data should be addressed to the corresponding author.

Ethics statement

This project did not generate research data so no ethical approval was required.

Information governance statement

The University of Liverpool is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under the Data Protection legislation, University of Liverpool is the Data Controller, and you can find out more about how we handle personal data, including how to exercise your individual rights and the contact details for our Data Protection Officer here www.liverpool.ac.uk/policy-centre/itinformationgovernance/.

Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/TKLD6486.

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Department of Health and Social Care disclaimer

Study registration

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About this article

The contractual start date for this research was in April 2022. This article began editorial review in September 2023 and was accepted for publication in December 2024. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The Health Technology Assessment editors and publisher have tried to ensure the accuracy of the authors' article and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this article.

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List of abbreviations

A&E	accident and emergency
CPRD	Clinical Practice Research Datalink
CREDES	Guidance on Conducting and REporting DElphi Studies
CRN	Clinical Research Network
DARS	Data Access Request Service
DSCRO	Data Services for Commissioners Regional Office
ELSA	English Longitudinal Study of Ageing
GP	general practitioner
HNC	head and neck cancer
IHNC	incurable head and neck cancer
NCRAS	National Cancer Registration and Analysis Service
ONS	Office for National Statistics
PP-HANC	Palliative Partners in Head and Neck Cancer
PPI	patient and public involvement

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Appendix 1 Round 1 Delphi exercise

How services are delivered

1. To find out whether there is equal access to palliative care services in different parts of the UK.
2. To find the best way of identifying when patients might benefit from palliative care.
3. To find a way to monitor and record patients' symptoms across the UK.
4. To find out why there are high levels of treatments (such as chemotherapy, tube feeding) towards the end of life.
5. To find out what impact high levels of treatments (such as chemotherapy or tube feeding) have on patients' quality of life.
6. To find out whether patients' choice of place of care and death match with what actually happens.
7. To find out what influences where (e.g. home or hospital) people die.
8. To develop palliative care training for healthcare professionals to develop the skills and knowledge to care for patients.
9. To develop palliative care training for carers and family to develop the skills and knowledge to care for their relative/friend.
10. To find out how to best co-ordinate care to meet patients' needs.
11. To find out what aspects of palliative care are important to patients.

Controlling symptoms

12. To find out what symptoms (such as pain, difficulty eating, being short of breath) patients might expect during the last year of life.
13. To find out when and how to get help with symptoms (such as pain, difficulty eating, being short of breath).
14. To find out the best ways to maximise the benefits of treatments and live as well as possible with the effects of the disease.
15. To find ways to treat symptoms without the need for intensive treatments (such as chemotherapy) in the last months of life.
16. To find the best radiotherapy dose with the greatest benefit and least burden for the patient.
17. To understand how patients can be best supported to manage their own symptoms.

Emotional and social needs

18. To find out the best way to meet patients' emotional and social needs.
19. To find out whether these ways of supporting emotional and social needs work well.
20. To find out how to redesign healthcare services to meet patients' emotional and social needs.
21. To find out whether patients' spiritual well-being+ needs are being met.
22. To find the best ways to help people who do not have a good support network around them.
23. To find ways to help patients feel less lonely and isolated during the last year of life.
24. To find the best ways to meet the emotional needs of patients' children.
25. To find the best ways to support friends/family members to care for someone.
26. To find the best ways to reduce carers' loneliness in the last year of life.

Communication

27. To find out what information and support patients would like.
28. To find the best way to give initial information about the diagnosis and care plan.
29. To find the best ways to improve ongoing communication (about the illness and care planning) between *patients* and healthcare professionals.
30. To find the best ways to improve communication (about the illness and care planning) between *family members/carers* and healthcare professionals.
31. To find the best way to help settle disagreements between the patient and carer/relative about whether or not to have treatment.
32. To find the best ways to communicate what life might be like in the last year of living.

Appendix 2

Endorsed (n = 4)

5. To find out what impact high levels of treatments have on patients' quality of life.
10. To find out how to best co-ordinate care to meet patients' needs.
11. To find out what aspects of palliative care are important to patients.
13. To find out when and how to get help with symptoms.

For re-rating (n = 12)

2. To find the best way of identifying when patients might benefit from palliative care.
9. To develop palliative care training for carers and family to develop the skills and knowledge to care for their relative/friend.
12. To find out what symptoms patients might expect during the last year of life.
14. To find out the best ways to maximise the benefits of treatments and live as well as possible with the effects of the disease.
15. To find ways to treat symptoms without the need for intensive treatments (such as chemotherapy) in the last months of life.
17. To understand how patients can be best supported to manage their own symptoms.
18. To find out the best way to meet patients' emotional and social needs.
22. To find the best ways to help people who do not have a good support network around them.
23. To find interventions to help patients feel less lonely and isolated during the last year of life.
25. To find interventions to support friends/family members to care for someone.
27. To find out what information and support patients would like.
29. To find the best ways to improve ongoing communication (about the illness and care planning) between patients and healthcare professionals.

Rejected (n = 16)

1. To find out whether there is equal access to palliative care services in different parts of the UK.
3. To find a way to monitor and record patients' symptoms across the UK.
4. To find out why there are high levels of treatments (such as chemotherapy, tube feeding) towards the end of life.
6. To find out whether patients' choice of place of care and death match with what actually happens.
7. To find out what influences where people die.
8. To develop palliative care training for healthcare professionals to develop the skills and knowledge to care for patients.
16. To find the best radiotherapy dose with the greatest benefit and the least burden for the patient.
19. To find out whether these ways of supporting emotional and social needs work well.
20. To find out how to redesign healthcare services to meet patients' emotional and social needs.
21. To find out whether patients' spiritual well-being + needs are being met.
24. To find the best way to meet the emotional needs of patients' children.
26. To find interventions to reduce carers' loneliness in the last year of life.
28. To find the best way to give initial information about the diagnosis and care plan.
30. To find the best ways to improve communication (about the illness and care planning) between family members/carers and healthcare professionals.
31. To find the best way to help settle disagreements between the patient and carer/relative about whether or not to have the treatment.
32. To find the best ways to communicate what life might be like in the last year of living.

Appendix 3 Round 2 Delphi exercise

1. To develop palliative care training for carers and family to develop the skills and knowledge to care for their relative/friend.
2. To find the best way of identifying when patients might benefit from palliative care.
3. To find out what impact centralising cancer care in regional centres has on palliative care.
4. To find out what symptoms' patients might expect during the last year of life.
5. To find out the best ways to maximise the benefits of treatments and live as well as possible with the effects of the disease.
6. To find ways to treat symptoms without the need for intensive treatments (such as chemotherapy) in the last months of life.
7. To understand how patients can be best supported to manage their own symptoms.
8. To find out the best way to meet patients' emotional and social needs.
9. To find the best ways to help people who do not have a good support network around them.
10. To find interventions to help patients feel less lonely and isolated during the last year of life.
11. To find interventions to support friends/family members to care for someone.
12. To find the best ways to meet carers/families' emotional needs.
13. To find out what information and support patients would like.
14. To find the best ways to improve ongoing communication (about the illness and care planning) between patients and healthcare professionals.

Appendix 4

TABLE 5 Research priorities and the extent to which they might be addressed using routinely collected patient-level data

Research priority	Rationale as to why these priorities might (green)/might not (red) be addressed using routine data
To find out how to best co-ordinate care to meet patients' needs	Data on how care is co-ordinated are unlikely to be routinely recorded for individual patients
To find out when and how to get help with symptoms (such as pain, difficulty eating and shortness of breath)	*It is possible that details on patient symptoms and treatments provided could be recorded in electronic health records*
To find the best way of identifying when patients might benefit from palliative care	*Data on when patients received palliative care may be available from patient records*
To develop palliative care training for carers and family to develop the skills and knowledge to care for their relative/friend	Details about skills and knowledge of carers and family are unlikely to be recorded in patient records routinely
To find out what aspects of palliative care are important to patients	Patients' views on the importance of palliative care are unlikely to be recorded in patient records
To find out what impact high levels of treatments (such as chemotherapy or tube feeding) have on patients' quality of life	*It is possible that measurements of patient quality of life are recorded in electronic health records together with details of treatments (which are likely to be recorded)*
To find out the best ways to maximise the benefits of treatments and live as well as possible with the effects of the disease	Details about benefits of treatments and living as well as possible are not likely to be recorded on patient records, although effects of disease, for example, symptoms may be available. However, data on SACTs across NHS England trusts are available through the SACT data set
To find ways to treat symptoms without the need for intensive treatments (such as chemotherapy) in the last months of life	*Data on symptoms and treatment plans/interventions may be available in patient records together with date of death*
To find the best ways to help people who do not have a good support network around them	Details of support networks are not likely to be routinely recorded in patient records
To find ways to help patients feel less lonely and isolated during the last year of life	Details of patients' feelings of loneliness and levels of isolation are not likely to be routinely recorded in patient records
To find out what information and support patients would like	Details of patients' needs for information and support are not likely to be recorded routinely in patient records
To find the best ways to improve ongoing communication (about the illness and care planning) between patients and healthcare professionals	Details of communications between patients and healthcare professionals and how these might be improved are not likely to be recorded routinely in patient records

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Appendix 5 Research priorities and routine patient data sets

TABLE 6 Research priority: to find out when and how to get help with symptoms (such as pain, difficulty eating and shortness of breath)

Research priority	To find out when and how to get help with symptoms (such as pain, difficulty eating and shortness of breath)		
Data sets	**Brief description**	**General fields available**	**Specific fields of potential value**
CPRD Synthetic Data (Aurum)[34]	CPRD Aurum is a database of de-identified coded *primary care records* for use in Public Health Research, capturing diagnoses, symptoms, prescriptions, referrals and tests.[34] Data are contributed by general practices that use *EMIS* clinical systems	Patient demographics; practice details; consultation type; observations (including medical history, diagnosis); referral details; 'problem' (including drug prescriptions, measurements, symptom recording); drug (including drug, quantity, duration, estimated cost)	'Problem' (including drug prescriptions, measurements, symptom recording)
Head and Neck 5000	Large study of people with HNC: 5511 people across 76 UK centres. Aim to describe the factors that influence survival and the psychological impact of living with HNC. Follow-up study is now in progress	Age; gender; ethnicity; marital status; education; income; deprivation; smoking; alcohol consumption; cancer diagnosis and staging; comorbidity; dead or alive and data of death/censorship. Cancer care plan intention	Quality-of-life questionnaires before and during treatment; location of pain; medication taken for pain; loss of taste; saliva changes; diet; skin changes; puffiness; hearing problems
CPRD Synthetic Data (Gold)[34]	CPRD Gold is a database of de-identified coded *primary care records* for use in Public Health Research, capturing diagnoses, symptoms, prescriptions, referrals and tests.[34] These data are contributed by general practices that use *InPS Vision* clinical systems	Patient details; practice details; consultation details; clinical details; referral details; test details; therapy (medicine) details; medical dictionary; product dictionary	Medical history observations recorded by the GP
Admitted Patient Care[35]	Information on hospital inpatient admissions is included in the Hospital Episodes Statistics (HES).[35] HES is a data warehouse containing records of all patients admitted to NHS hospitals in England. It contains over 1 billion records including details of NHS hospital stays in England and care provided by the independent sector for the NHS in England	*International Statistical Classification of Diseases and Related Health Problems*, Tenth Revision (ICD-10) diagnosis codes, Office of Population Censuses and Surveys (OPCS) procedure codes, dates of care. Consultant Code; Destination on Discharge; Diagnosis codes; Main specialty (315 = Palliative Medicine); Treatment specialty (315 = Palliative Medicine Service); *Length of Stay Adjustment (Specialist Palliative Care) – not yet available in HES*	Diagnosis codes (secondary codes for symptom descriptors, e.g. pain, dysphagia, dyspnoea)
Outpatient[35]	This records patient activity within NHS hospitals and care provided in the independent sector for the NHS in England	ICD-10 diagnosis codes, OPCS procedure codes	Diagnosis codes (secondary codes for symptom descriptors, e.g. pain, dysphagia, dyspnoea)
A&E (HES)[35]	The HES database[35] is made up of many data items relating to A&E care delivered by NHS hospitals in England. Most data are part of the national Commissioning Data Set (CDS), they are obtained from hospital patient administration systems	A&E diagnosis codes, A&E treatment codes	Diagnosis codes (secondary codes for symptom descriptors, e.g. pain, dysphagia, dyspnoea)

TABLE 6 Research priority: to find out when and how to get help with symptoms (such as pain, difficulty eating and shortness of breath) (*continued*)

Research priority	**To find out when and how to get help with symptoms (such as pain, difficulty eating and shortness of breath)**		
Data sets	**Brief description**	**General fields available**	**Specific fields of potential value**
Civil Registrations (Deaths)[36]	Information including the date, place and cause of death from the ONS.[36] Also previous addresses. Linking HES data to mortality data from the ONS permits the analysis of deaths in and outside hospital for all patients with a record in HES. It is also a rich source of data for analysis on a wide range of subjects including outcomes of hospital care, such as postoperative mortality	Cause of death codes – main cause and secondary causes. To use in conjunction with other data sets to identify deaths from HANC, and from other causes in patients with HANC. Date of death (identifiable)	Not applicable, beyond providing date and causes of death to link to other data
Emergency Care Data Set[35]	These data include data from all patients attending hospital-based A&E Departments in England. These data are collected on a daily basis every day of the week. The types of departments included in data collection are NHS walk-in centres, minor injury units and emergency departments	SNOMED observation, investigation, diagnosis and treatment codes, dates of care, clinician details, referrals, discharge details	Diagnosis codes (for symptom descriptors, e.g. pain, dysphagia, dyspnoea)
HANA – Head and Neck Audit[37]	HANA is the new National Head and Neck Cancer Audit for England and Wales.[37] Based on data collected by the previous audit providers DAHNO and relates to patients diagnosed between 1 November 2012 and 31 October. Once a year Dendrite will combine the information from every individual hospital seeing and treating HNC patients in England and Wales. They will process and analyse the data and organise it by region, hospital trust and consultant. They will then remove your name, date of birth, NHS number and any other information that could be used to identify you from the reports produced. Dendrite will work with Saving Faces to produce regular HANA reports and local action plans. HANA results at regional, hospital trust and consultant levels will be compared with each other, and also with national standards of care for patients with HNC which have been set out by the National Institute for Health and Care Excellence and the British Association of Head and Neck Oncologists 2014	Service delivery and organisation; characteristics of newly diagnosed HNC; how the cancer was detected and the referral pathway; diagnosis, staging and planning of initial treatment; treatments received; complications of treatment; overall and disease-free survival; the causes of delay in the treatment pathway. Variables are related to the following topics: diet, drinks, flaking, how obvious, skin, puffiness, function, voice, hearing	Diagnosis, staging and planning of initial treatment, characteristics of newly diagnosed HNC
Comprehensive Patient Records for Cancer Outcomes[38]	Data are derived from linked primary, secondary and tertiary care electronic health records and participant survey responses. The Comprehensive Patient Records research data set relates to the medical history of cancer patients prior to cancer, their diagnosis and treatment, long-term outcomes, and medical history of matched non-cancer patients that form a comparator cohort[38]	Medical history of cancer patients prior to cancer, their diagnosis and treatment, long-term outcomes, and medical history of matched non-cancer patients that form a comparator cohort	Further details are not currently available, although some data fields may be useful

TABLE 7 Research priority: to find the best way of identifying when patients might benefit from palliative care

Research priority	**To find the best way of identifying when patients might benefit from palliative care**		
Data sets	**Brief description**	**General fields available**	**Specific fields of potential value**
CPRD Synthetic Data (Gold)[34]	CPRD Gold is a database of de-identified coded *primary care records* for use in Public Health Research, capturing diagnoses, symptoms, prescriptions, referrals and tests.[34] These data are contributed by general practices that use *InPS Vision* clinical systems	Patient details; practice details; consultation details; clinical details; referral details; test details; therapy (medicine) details; medical dictionary; product dictionary	Medical history observations recorded by the GP
CPRD Synthetic Data (Aurum)[34]	CPRD Aurum is a database of de-identified coded *primary care records* for use in Public Health Research, capturing diagnoses, symptoms, prescriptions, referrals and tests.[34] Data are contributed by general practices that use *EMIS* clinical systems	Patient demographics; practice details; consultation type; observations (including medical history, diagnosis); referral details; 'problem' (including drug prescriptions, measurements, symptom recording); drug (including drug, quantity, duration, estimated cost)	'Problem' (including drug prescriptions, measurements, symptom recording)
Admitted Patient Care[35]	Information on hospital inpatient admissions are included in the Hospital Episodes Statistics (HES).[35] HES is a data warehouse containing records of all patients admitted to NHS hospitals in England. It contains over 1 billion records including details of NHS hospital stays in England and care provided by the independent sector for the NHS in England	*International Statistical Classification of Diseases and Related Health Problems*, Tenth Revision (ICD-10) diagnosis codes, OPCS procedure codes, dates of care. Consultant Code; Destination on Discharge; Diagnosis codes; Main specialty (315 = Palliative Medicine); Treatment specialty (315 = Palliative Medicine Service); *Length of Stay Adjustment (Specialist Palliative Care) – not yet available in HES*	Diagnosis codes (secondary codes for symptom descriptors, e.g. pain, dysphagia, dyspnoea)
Outpatient[35]	This records patient activity within NHS hospitals and care provided in the independent sector for the NHS in England	ICD-10 diagnosis codes, Office of Population Censuses and Surveys (OPCS) procedure codes	Diagnosis codes (secondary codes for symptom descriptors, e.g. pain, dysphagia, dyspnoea)
A&E (HES)[35]	The HES database[35] is made up of many data items relating to A&E care delivered by NHS hospitals in England. Most data are part of the national Commissioning Data Set, they are obtained from hospital patient administration systems	AE diagnosis codes, AE treatment codes	Diagnosis codes (secondary codes for symptom descriptors, e.g. pain, dysphagia, dyspnoea)
Civil Registrations (Deaths)[36]	Information including the date, place and cause of death from the ONS.[36] Also previous addresses. Linking HES data to mortality data from the ONS permits the analysis of deaths in and outside hospital for all patients with a record in HES. It is also a rich source of data for analysis on a wide range of subjects including outcomes of hospital care, such as postoperative mortality	Cause of death codes – main cause and secondary causes. To use in conjunction with other data sets to identify deaths from HANC, and from other causes in patients with HANC. Date of death (identifiable)	Dates and causes of death – can look retrospectively at when/whether patients entered palliative care (using other data sets) and use Centre for Reviews and Dissemination data to calculate time spent there, and eventual causes of death (including secondary causes)
Comprehensive Patient Records for Cancer Outcomes[38]	Data are derived from linked primary, secondary and tertiary care electronic health records and participant survey responses. The Comprehensive Patient Records research data set relates to the medical history of cancer patients prior to cancer, their diagnosis and treatment, long-term outcomes, and medical history of matched non-cancer patients that form a comparator cohort[38]	Medical history of cancer patients prior to cancer, their diagnosis and treatment, long-term outcomes, and medical history of matched non-cancer patients that form a comparator cohort	Further details are not currently available, although some data fields may be useful

TABLE 8 Research priority: to find out what impact high levels of treatments (such as chemotherapy or tube feeding) have on patients' quality of life

Research priority	To find out what impact high levels of treatments (such as chemotherapy or tube feeding) have on patients' quality of life		
Data sets	**Brief description**	**General fields available**	**Specific fields of potential value**
Head and Neck 5000	Large study of people with HNC: 5511 people across 76 UK centres. Aim to describe the factors that influence survival and the psychological impact of living with HNC. Follow-up study is now in progress	Age; gender; ethnicity; marital status; education; income; deprivation; smoking; alcohol consumption; cancer diagnosis and staging; co-morbidity; dead or alive and data of death/censorship. Cancer care plan intention	Quality-of-life questionnaires before and during treatment; location of pain; medication taken for pain; loss of taste; saliva changes; diet; skin changes; puffiness; hearing problems
Admitted Patient Care[35]	Information on hospital inpatient admissions is included in the Hospital Episodes Statistics (HES).[35] HES is a data warehouse containing records of all patients admitted to NHS hospitals in England. It contains over 1 billion records including details of NHS hospital stays in England and care provided by the independent sector for the NHS in England	*International Statistical Classification of Diseases and Related Health Problems*, Tenth Revision (ICD-10) diagnosis codes, Office of Population Censuses and Surveys (OPCS) procedure codes, dates of care. Consultant Code; Destination on Discharge; Diagnosis codes; Main specialty (315 = Palliative Medicine); Treatment specialty (315 = Palliative Medicine Service); *Length of Stay Adjustment (Specialist Palliative Care) – not yet available in HES*	Diagnosis codes (secondary codes for symptom descriptors, e.g. pain, dysphagia, dyspnoea). Potentially procedure codes if the chemotherapy ones are used here
Outpatient[35]	This records patient activity within NHS hospitals and care provided in the independent sector for the NHS in England	ICD-10 diagnosis codes, OPCS procedure codes	Diagnosis codes (secondary codes for symptom descriptors, e.g. pain, dysphagia, dyspnoea). Potentially procedure codes if the chemotherapy ones are used here
A&E (HES)[35]	The HES database[35] is made up of many data items relating to A&E care delivered by NHS hospitals in England. Most data are part of the national Commissioning Data Set, they are obtained from hospital patient administration systems	AE diagnosis codes, AE treatment codes	Diagnosis codes (secondary codes for symptom descriptors, e.g. pain, dysphagia, dyspnoea) to assess quality of life (in conjunction with details from elsewhere of patients' treatments)
Civil Registrations (Deaths)[36]	Information including the date, place and cause of death from the ONS.[36] Also previous addresses. Linking HES data to mortality data from the ONS permits the analysis of deaths in and outside hospital for all patients with a record in HES. It is also a rich source of data for analysis on a wide range of subjects including outcomes of hospital care, such as postoperative mortality	Cause of death codes – main cause and secondary causes. To use in conjunction with other data sets to identify deaths from HANC, and from other causes in patients with HANC. Date of death (identifiable)	Not applicable, beyond providing date and causes of death to link to other data

continued

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TABLE 8 Research priority: to find out what impact high levels of treatments (such as chemotherapy or tube feeding) have on patients' quality of life (*continued*)

Research priority	To find out what impact high levels of treatments (such as chemotherapy or tube feeding) have on patients' quality of life		
Data sets	**Brief description**	**General fields available**	**Specific fields of potential value**
HANA[37]	HANA is the new National Head and Neck Cancer Audit for England and Wales[37] Based on data collected by the previous audit providers DAHNO and relates to patients diagnosed between 1 November 2012 and 31 October. Once a year Dendrite will combine the information from every individual hospital seeing and treating HNC patients in England and Wales. They will process and analyse the data and organise it by region, hospital trust and consultant. They will then remove your name, date of birth, NHS number and any other information that could be used to identify you from the reports produced. Dendrite will work with Saving Faces to produce regular HANA reports and local action plans. HANA results at regional, hospital trust and consultant levels will be compared with each other, and also with national standards of care for patients with HNC which have been set out by National Institute for Health and Care Excellence and British Association of Head and Neck Oncologists 2014	Service delivery and organisation; characteristics of newly diagnosed HNC; how the cancer was detected and the referral pathway; diagnosis, staging and planning of initial treatment; treatments received; complications of treatment; overall and disease-free survival; the causes of delay in the treatment pathway. Variables are related to the following topics: diet, drinks, flaking, how obvious, skin, puffiness, function, voice, hearing	Treatments received; complications of treatment
Comprehensive Patient Records for Cancer Outcomes[38]	Data are derived from linked primary, secondary and tertiary care electronic health records and participant survey responses. The Comprehensive Patient Records research data set[38] relates to the medical history of cancer patients prior to cancer, their diagnosis and treatment, long-term outcomes, and medical history of matched non-cancer patients that form a comparator cohort	Medical history of cancer patients prior to cancer, their diagnosis and treatment, long-term outcomes, and medical history of matched non-cancer patients that form a comparator cohort	Further details are not currently available, although some data fields may be useful

TABLE 9 Research priority: to find ways to treat symptoms without the need for intensive treatments (such as chemotherapy) in the last months of life

Research priority	**To find ways to treat symptoms without the need for intensive treatments (such as chemotherapy) in the last months of life**		
Data sets	**Brief description**	**General fields available**	**Specific fields of potential value**
CPRD Synthetic Data (Gold)[34]	CPRD Gold is a database of de-identified coded *primary care records* for use in Public Health Research, capturing diagnoses, symptoms, prescriptions, referrals and tests.[34] These data are contributed by general practices that use *InPS Vision* clinical systems	Patient details; practice details; consultation details; clinical details; referral details; test details; therapy (medicine) details; medical dictionary; product dictionary	Drug and appliance prescriptions recorded by the GP. Medical history observations recorded by the GP
Admitted Patient Care (APC)[35]	Information on hospital inpatient admissions are included in the Hospital Episodes Statistics (HES).[35] HES is a data warehouse containing records of all patients admitted to NHS hospitals in England. It contains over 1 billion records including details of NHS hospital stays in England and care provided by the independent sector for the NHS in England	*International Statistical Classification of Diseases and Related Health Problems*, Tenth Revision (ICD-10) diagnosis codes, Office of Population Censuses and Surveys (OPCS) procedure codes, dates of care. Consultant Code; Destination on Discharge; Diagnosis codes; Main specialty (315 = Palliative Medicine); Treatment specialty (315 = Palliative Medicine Service); *Length of Stay Adjustment (Specialist Palliative Care) – not yet available in HES*	OPERTN_4_nn (procedure codes) – codelist includes non-operative procedures/treatments/therapies, but unclear whether only operative codes are used in HES APC data
Outpatient[35]	This records patient activity within NHS hospitals and care provided in the independent sector for the NHS in England	ICD-10 diagnosis codes, OPCS procedure codes	OPERTN_4_nn (procedure codes) – codelist includes non-operative procedures/treatments/therapies, but unclear whether only operative codes are used in HES APC data
A&E (HES)	The HES database[35] is made up of many data items relating to A&E care delivered by NHS hospitals in England. Most data are part of the national Commisioning Data Set, they are obtained from hospital patient administration systems	AE diagnosis codes, AE treatment codes	TREAT_nn (treatment codes)
Civil Registrations (Deaths)[36]	Information including the date, place and cause of death from the ONS.[36] Also previous addresses. Linking HES data to mortality data from the ONS permits the analysis of deaths in and outside hospital for all patients with a record in HES. It is also a rich source of data for analysis on a wide range of subjects including outcomes of hospital care, such as postoperative mortality	Cause of death codes – main cause and secondary causes. To use in conjunction with other data sets to identify deaths from HANC, and from other causes in patients with HANC. Date of death (identifiable)	Not applicable, beyond providing date and causes of death to link to other data

continued

TABLE 9 Research priority: to find ways to treat symptoms without the need for intensive treatments (such as chemotherapy) in the last months of life (*continued*)

Research priority	**To find ways to treat symptoms without the need for intensive treatments (such as chemotherapy) in the last months of life**		
Data sets	**Brief description**	**General fields available**	**Specific fields of potential value**
HANA[37]	HANA is the new National Head and Neck Cancer Audit for England and Wales.[37] Based on data collected by the previous audit providers DAHNO and relates to patients diagnosed between 1 November 2012 and 31 October. Once a year Dendrite will combine the information from every individual hospital seeing and treating HNC patients in England and Wales. They will process and analyse the data and organise it by region, hospital trust and consultant. They will then remove your name, date of birth, NHS number and any other information that could be used to identify you from the reports produced. Dendrite will work with Saving Faces to produce regular HANA reports and local action plans. HANA results at regional, hospital trust and consultant levels will be compared with each other, and also with national standards of care for patients with HNC which have been set out by National Institute for Health and Care Excellence and British Association of Head and Neck Oncologists 2014	Service delivery and organisation; characteristics of newly diagnosed HNC; how the cancer was detected and the referral pathway; diagnosis, staging and planning of initial treatment; treatments received; complications of treatment; overall and disease-free survival; the causes of delay in the treatment pathway. Variables are related to the following topics: diet, drinks, flaking, how obvious, skin, puffiness, function, voice, hearing	Treatments received; complications of treatment
Comprehensive Patient Records for Cancer Outcomes[38]	Data are derived from linked primary, secondary and tertiary care electronic health records and participant survey responses. The Comprehensive Patient Records research data set relates to the medical history of cancer patients prior to cancer, their diagnosis and treatment, long-term outcomes, and medical history of matched non-cancer patients that form a comparator cohort[38]	Medical history of cancer patients prior to cancer, their diagnosis and treatment, long-term outcomes, and medical history of matched non-cancer patients that form a comparator cohort	Further details are not currently available, although some data fields may be useful

Appendix 6

TABLE 10 Potential for linkage across national routine data sets

Data set name	Potential for linking data
Admitted Patient Care (APC)	Link to Community Services Data Set (CSDS), emergency department (ED), OP data and deaths – compare quality of life (including number of ED visits) until death for similar patients admitted to palliative care vs. patients at home or in other settings
Outpatient (OP)	Link to APC and CSDS to compare similar patients on different treatments and admitted to palliative care vs. cared for at home – what are their symptoms/does their quality of life differ?
A&E (HES)	Link to OP/APC and CSDS to see treatments – how often do similar patients end up in ED (for worsening symptoms or side effects etc.) on different treatments? Indication of quality of life, and could also be an indicator of when palliative care could best start
Civil Registrations (Deaths)	Link to clinical data sets to identify similar patients on different treatment regimes, to see when/how they died – at what point do treatments stop extending life, and instead cause unnecessary pain/other symptoms through side effects? Could help pinpoint when patients might benefit from palliative care
Emergency Care Data Set	Link to OP/APC and CSDS to see treatments – how often do similar patients end up in ED (for worsening symptoms or side effects etc.) on different treatments? Indication of quality of life, and could also be an indicator of when palliative care could best start
CSDS[39]	Includes details of hospice care – link to other clinical data sets to compare similar patients with different treatment approaches? Link to details of intensive treatments to see what help patients are seeking with symptoms/side effects

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