Understanding barriers and facilitators to palliative and end-of-life care research: a mixed method study of generalist and specialist health, social care, and research professionals

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Abstract

Background: Palliative care provision should be driven by high quality research evidence. However, there are barriers to conducting research. Most research attention focuses on potential patient barriers; staff and organisational issues that affect research involvement are underexplored. The aim of this research is to understand professional and organisational facilitators and barriers to conducting palliative care research.

Methods: A mixed methods study, using an open cross-sectional online survey, followed by working groups using nominal group techniques. Participants were professionals interested in palliative care research, working as generalist/specialist palliative care providers, or palliative care research staff across areas of North West England. Recruitment was via local health organisations, personal networks, and social media in 2022. Data were examined using descriptive statistics and content analysis.

Results: Participants (survey n=293, working groups n=20) were mainly from clinical settings (71 %) with 45% nurses and 45 % working more than 10 years in palliative care. 75 % were not active in research but 73% indicated a desire to increase research involvement. Key barriers included lack of organisational research culture and capacity (including prioritisation and available time); research knowledge (including skills/expertise and funding opportunities); research infrastructure (including collaborative opportunities across multiple organisations and governance challenges); and patient and public perceptions of research (including vulnerabilities and burdens). Key facilitators included dedicated research staff, and active research groups, collaborations, and networking opportunities.

Conclusions: Professionals working in palliative care are keen to be research active, but lack time, skills, and support to build research capabilities and collaborations. A shift in organisational culture is needed to enhance palliative care research capacity and collaborative opportunities across clinical and research settings.

Background

Palliative care provision should be informed by high quality research, so that clinical practice is underpinned by a robust evidence base. Improving the evidence base in palliative care is a ‘moral imperative’, with arguments highlighting that it is ethically important to offer effective treatments supported by an evidence base, and equally that futile treatments are avoided (1). A principal focus of much of the research conducted to understand why developing the evidence base is difficult has focused on the specific challenges of recruiting patient and carer participants to palliative care research studies. Gatekeeping can be an issue, with staff concerned about overburdening vulnerable patients and carers, and feeling ill prepared to discuss research with potential participants (2, 3, 4). This is despite evidence suggesting patients and families are willing to engage in research at the end of life (5, 6, 7). Despite this readiness, there can be many reasons why patients and carers may not feel able to engage in research such as illness severity, symptom burden, misconceptions about palliative care, lack of cure and perceived therapeutic benefit, and study burden (8, 9, 10). This can mean that many studies experience recruitment difficulties (11, 12). Facilitators that may address some of these complex structural, cultural and personal barriers include dedicated research staff on site (3, 13), training on how to recruit to palliative care studies (14, 15), and improving communication with patients and their families to promote research participation, and within staff teams to address gatekeeping.

Researchers outside palliative care have chosen to explore the professional and organisational facilitators and barriers to conducting research (16, 17). Less is known about the personal, professional, organisational, and structural barriers and facilitators to conducting palliative care research. Palliative care requires a multi-professional approach, and patients are cared for in a variety of settings, including hospitals, hospices, nursing homes and primary care. Palliative care research is historically under-funded in comparison to research that focuses on the prevention or cure of cancer and other life-limiting illnesses (18, 19). There may also be challenges with access to staff with the relevant research expertise, and complicated or undeveloped governance arrangements particularly in settings outside statutory provision (20, 21, 22, 23). Research may not be a strategic priority, especially for standalone voluntary organisations who largely rely on charitable funding to fund patient care (23). Palliative care research can be time consuming and staff may see it is an ‘add on’ to their role and not part of the routine care they provide to patients (24). Staff may feel that they lack the necessary knowledge, skills and expertise to be involved in palliative care research (4, 25) and may have limited opportunity to participate or learn more, especially when balancing clinical pressures that have increased during the COVID 19 pandemic (26). An organisational research culture improves outcomes for all patients, and not just those involved in the research (27). The aim of this study therefore is to further understand professional and organisational facilitators and barriers to conducting all types of palliative care research.

Methods

Research question: What are the barriers and facilitators to conducting palliative and end-of-life care research across North West Coast England*?*

Design: A mixed method study following a convergent design (28)***,*** incorporating a cross-sectional online survey and working groups using a nominal group technique (29). The survey is reported according to the CHERRIES guidelines for e-surveys (30).

Setting: Both the survey and working groups were conducted across the UK NIHR North West Coast region of England (incorporating South Cumbria, Lancashire, Cheshire, and Merseyside). Currently, palliative care research activity within this area is low. In the UK, palliative care is provided by generalists, the patient’s usual care team, in the hospital, community or care home setting. Specialist inpatient, hospital, home and home nursing palliative services are provided by professionals specifically trained in palliative care, and they largely rely on charitable funding. (31, 32)

Population: All those who had interest in the provision of, or research into, generalist or specialist palliative care across the region including across acute and community NHS Trusts, GP practices, voluntary hospices, other community and private providers of care, clinical research networks, and academic settings including Universities were invited to participate. The survey was accessed via an online link that included a screening question incorporating the inclusion criteria (see table one).

Table one: Study inclusion criteria

Inclusion criteria
Provide health and/or social care for patients and carers (adults and/or children) with palliative/end of life care needs. *and/or* Involved or would wish to be involved in palliative/end of life care research
Aged 18+, no maximum age
Working within the North West Coast geography (South Cumbria, Lancashire, Cheshire, and Merseyside).

Sample*: Survey:* The survey used a convenience sampling approach and was designed to collect largely descriptive data and yield rich information across a range of respondents. Without a viable sampling frame of potential participants, no anticipated sample size could be reliably estimated. *Working groups*: Those who indicated an interest in taking part via their survey response, or who responded to additional calls for participation, were invited to participate, and then purposively selected to maximise variability across professional background, expertise, and geography.

Recruitment*: Survey:* Potential participants were recruited via several routes that included dissemination via collaborators in local NHS Trusts and Hospices and the North West Coast Clinical Research network to ensure primary care organisations were reached. Information about the survey was openly and widely disseminated through a project website, personal networks, and social media

(Twitter, Facebook, and LinkedIn). No incentives for survey completion were offered. Dissemination included a link to the online survey, with screening questions at the start of the survey confirming eligibility, with clicking through to progress to the survey indicating consent. Potential participants were reassured that taking part was voluntary and that survey results would be aggregated and anonymised. It was explained that their data would be inputted into a secure online survey platform, and these data would be then stored in a secure institutional filestore at Lancaster University. (see additional file 1)

Working groups: Individuals who expressed an interest in taking part in further research after completing the survey were sent working group invitation packs. Additionally, collaborators in local NHS Trusts, Hospices and the North West Coast Clinical Research network circulated packs to eligible participants. Social media (Twitter, Facebook, and Instagram) was also used to advertise the working groups. Participants could take part in the working groups even if they had not completed the survey. Participants contacted the research team if they were interested in taking part and electronic consent was obtained prior to the working group.

Data collection*: Survey:* The open online survey was built using Qualtrics^{XM}(33), and the full survey is included in additional file 1. Both closed and free-text questions were used, together with skip options dependent on given answers; 19 possible questions (some with multiple components) were asked across 5 blocks. Participants could navigate through the survey using forward and back buttons. The survey identified current and desired levels of palliative care research involvement, current research barriers, suggestions for sustainable solutions and research training needs. The survey was developed from the IPOS survey (a survey of the research barriers and training needs within the International Psycho-Oncology Society)(34) and literature on barriers and facilitators to palliative care research (3). Survey development followed an iterative approach, with members and colleagues of the project steering committee reviewing survey questions to ensure the survey was appropriate. Participants could only complete the survey once. There was not a completeness check for respondents. The survey was open from 02/03/2022 to 08/06/2022.

Working groups: Four online (via Microsoft Teams) working groups took place. The groups lasted two hours and were facilitated by LD and another member of the research team (from CW, AG, BS, RB). Nominal group technique was used as it is a method that elicits the views and opinions of a group of experts through the ranking of priorities related to a particular topic of interest. It combines both qualitative and quantitative data collection and involves a number of stages that include; introductions, silent generation of ideas, listing of ideas, discussion of ideas, ranking of top ten ideas, voting on top ten ideas, discussion of voting and conclusions (29). Mentimeter (35) was used to facilitate the voting process and the working groups were recorded.

Data analysis*:*

Survey: Data were downloaded from Qualtrics™ as .csv and .sav files for Excel and SPSS, hosted on Lancaster University secure OneDrive, and checked for potential duplicate entries (using IP, email address or organisation name to ensure only one entry per respondent), and to remove incomplete entries. Entries were judged as complete when participants had provided sufficient descriptive personal information alongside survey responses, even if answers to all available questions had not been given. Pseudonymised data were used for analysis. Descriptive analysis included the use of frequency counts, percentages, and rankings, with some collapsing of categories.

For the analysis of free-text comments, data were extracted into Microsoft Excel. Comments tended to be brief, expanding on answers to closed questions (36, 37). After initial familiarisation, a coding framework was inductively developed by LD and CW and applied to the free text data using a conventional content analysis technique(38). Coding and theme development were driven by the content of the free-text comments.

Working groups, using nominal group technique: Each working group was initially analysed separately by LD using the group's Mentimeter rankings as an initial a priori framework (39) . The working group recordings and transcripts were read and listened to, and the key issues were summarised within the a priori frameworks. The findings were then compared across the working groups by LD, SM, BS, and AP with input from the study's Patient and Public Involvement group and finally the study steering committee, to identify key themes.

Four overarching groupings were inductively generated after completion of the working groups. Survey free text and working group findings were compared as part of the four theme development. Mentimeter rankings were allocated to the four groups along with the survey statements where there was strongest agreement about the barriers to research across all survey respondents (see table 5).

Ethics: Approval was granted by the East of England - Cambridge South Research Ethics Committee (Ref: 22/EE/0049) on the 24/02/2022. Organisational approval was obtained via the Health Research Authority and each participating site.

Results

Survey response

The online survey received 495 visitors, of whom 8 declared they did not meet the inclusion criteria, 36 provided no data, and 158 did not proceed beyond the screening questions. Valid responses were received from 293 participants (59 % of visitors), with 171 of the 293 (58 %) recording 100% survey progress, and a mean progress of 82% (range 100% to 25%).

Characteristics of survey respondents

Full descriptive data from these respondents are found in table 2. The highest proportion of respondents worked in hospice settings, were nurses, and had worked in palliative care for over 10 years. Unexpectedly, there was a high number of paramedics who completed the survey (n=17).

Table 2. Characteristics of survey respondents

Characteristic	Number N=293	Percentage
Work setting	n	**%**
Hospice	78	27%
Hospital	69	24%
Primary Care	58	20%
University	18	6 %
NHS R&D	17	6%
Clinical Research Network	5	2%
Nursing/Care home	2	1%
Other[a]	44	15%
Missing	2	1%
Professional background	n	**%**
Nurse	133	45%
Doctor	48	16%
Researcher	24	8 %
Physiotherapist	4	1%
Manager/Admin	24	8%
Social Worker	5	2%
Occupational Therapist	7	2%
Other[b]	48	16%
Length of time working in palliative care	n	**%**
<2 years	44	16 %
2 to 5 years	51	18 %
6 to 10 years	61	22%
10+ years	128	45 %
Missing	9	3%
Work in specialist or generalist palliative care	n	**%**
Specialist	113	39 %
Generalist	68	24 %
Research only	22	8%
Other[c]	41	14 %
Not applicable	43	15 %
Missing	6	2 %
Work with adults or children	n	**%**
Primarily adults	270	95%
Primarily children	14	5%
Missing	9	3%

[a] community setting 27, emergency/ambulance/pre-hospital setting 13, multiple settings ≤5,

[b] paramedic 17, health care assistant 7, pastoral support worker 6, research practitioner 6, manager ≤5, pharmacist: ≤5, speech and language therapist: ≤5, nurse specialist: ≤5 student: ≤5 PPI: ≤5.

[c] miscellaneous 18, primary/community care 9, emergency care 7, acute care 5, education ≤5 .

Research experience or roles of those completing the survey are presented in table 3. Nearly 75% of respondents were not active in research, but nearly 73% wanted to increase the time they spent on research.

Table 3. Research experience and role characteristics of survey participants

Characteristic	Number N=293	Percentage
Palliative care research experience	n	**%**
Non-active	199	75%
Involved	47	18%
Managing	11	4%
Supervising	9	3%
Missing	27	9%
Proportion of time spent on palliative care research	n	**%**
None	184	68%
Less than 10%	59	22%
10-25%	13	5%
26%+	14	5%
Missing	23	8%
Would you like to increase the time you spend on research?	n	**%**
Yes	197	73%
No	74	27%
Missing	22	8%
Number of current research projects	n	**%**
None	230	86%
1 to 3	31	12%
4+	6	2.3%
Missing	26	9%

Characteristics of working group participants

Twenty palliative care providers/research staff participated in the working groups (see table 4 for details).

Table 4. Staff working groups participant demographic details.

	Characteristics	Number (N=20)	Percentage
Working group attended	Working group 1	5	25%
	Working group 2	7	35%
	Working group 3	5	25%
	Working group 4	3	15%
Gender	Female	15	75%
	Male	5	25%
Age in years	18-30	1	5%
	31-40	7	35%
	41-50	5	25%
	51-60	5	25%
	60+	2	10%
Ethnicity	White	18	90%
	Black/African/Caribbean/ Black	1	5%
	British	1	5%
	Other	0	
Length of time worked in palliative care	Just getting started (<2 years)	0	0
	Early career (2-5 years)	7	35%
	Mid-career (6-10 years)	4	20%
	Late career (10+ years)	9	45%
Primary professional role	Nurse	9	45%
	Doctor	5	25%
	Manager/admin	3	15%
	Other	3	15%
Primary work environment	University	2	10%
	Hospital	2	10%
	Primary Care	2	10%
	Hospice	13	65%
	Ambulance Trust	1	5%
Role	Specialist palliative care	12	60%
	Research role only	2	10%
	Other primary role	4	20%
	Missing data	2	10%
Primary population cared for	Adults	16	80%
	Children	4	20%

Barriers and facilitators to participating in palliative care research (quantitative data)

Survey respondents were asked to indicate the strength of agreement with statements about facilitators or barriers to engagement and involvement with palliative care research. Working group participants inductively generated statements about barriers which were then ranked. In table 5 below we present the survey statements where there was strongest agreement across all survey respondents, together with the ranking of inductively generated statements from each of the working groups. Full survey data are found in additional file 2.

Table 5. The top ten barriers to participating in research identified from the survey and each of four working groups.

Rank	Survey ranking (% respondents who indicated this was a moderate or significant barrier)	Working group 1 ranking (Mentimeter ranking of generated statements from 1-10)	Working group 2 ranking (Mentimeter ranking of generated statements from 1-10)	Working group 3 ranking (Mentimeter ranking of generated statements from 1-10)	Working group 4 ranking (Mentimeter ranking of generated statements from 1-10)
1	Lack of protected time/competing demands **(58 %)**	Access to research support and expertise	Lack of dedicated professional time	Prioritising clinical duties not research	Organisational culture/ethos to support palliative care research
2	Understanding how to apply for research funding **(54%)**	Lack of collaboration with regard to research in palliative care community in NW Coast	Having someone in the site with right skillset and responsibility for research	Funding and knowledge of funding streams, including education for research	Leadership to support palliative care research
3	No formal palliative care research training **(52%)**	Organisational culture and ethos with regard to research	Lack of access to research funding	Culture in the organisation – research not seen to be as important strategically or to drive change	Lack/limited research infrastructure
4	Understanding what is needed to conduct palliative care research **(49%)**	Financial infrastructure to support palliative care research	Knowledge of and prioritisation of research	Not seeing research as part of routine care	Motivation to be involved in palliative care research
5	The time and effort required to initiate a palliative care research project discourages me from the start **(48%)**	Lack of recognition of importance of palliative care research	Hospice lack of research infrastructure	Knowledge and understanding of how to get involved	External funding for palliative care research
6	Confidence in abilities to do palliative care research **(45%)**	Knowledge and skills	Specific challenges for this patient group	Palliative care research may not fit into traditional funding streams	Training and expertise in conducting palliative care research
7	Lack of access to a statistician **(45%)**	Competing pressures of clinical and non-clinical work	Staff perceptions/willingness to approach patients	Awareness of other organisations and lack of collaborative opportunities between hospices	Patient and family awareness of research
8	Loss of clinical productivity during palliative care research activities **(43 %)**	Professional role issues	Working in a high-pressured environment	Releasing staff for funded research opportunities if	Cost to the organisation of being involved in palliative care research

				backfill needed for clinical position	
9	Knowledge and skills to conduct palliative care research **(41%)**	Recognising non-clinical roles/expertise in research	Knowing what other hospices/sites are doing	Lack of knowledge of how to invite and involve patients in research at the end of life	Complexity of palliative care research
10	Lack of funding or financial resources prevents me from becoming involved in palliative care research **(41%)**	Lack of research champions/mentors	Wider public perceptions of palliative care research	Allocation of research nurse support, especially if not NIHR badged, and competing studies for their time	Perception of palliative care research being burdensome

Key. Each statement has been allocated to one of four inductively generated groups, indicated by these colour codings	Organisational culture and capacity	Research knowledge	Research infrastructure and collaborations	Patient and public perceptions of research

The top research barriers were conceptualised across four main areas: organisational culture and capacity (including prioritisation and time given to research); research knowledge (including research skills, how to obtain funding); research infrastructure and collaborations (including collaborative opportunities and governance arrangements), and patient and public perceptions of palliative care research (including vulnerabilities and burdens). Data on facilitators and training needs were collected in the online survey and are presented in tables 6 and 7.

Table 6. Top 10 facilitators to participating in palliative care research (combined agree or strongly agree from survey data)

Top 10 facilitators to participating in palliative care research	% who indicated this was a combined agree or strongly agree
Palliative care research information network	62% n=181
Palliative care research seminars for those in practice	62% n=181
Collaboration with other centres	62% n=181
Availability of resources such as a guide/manual	61% n=179
Supportive management	61% n= 178
Staff cover	61% n=178
Access to funding to support research	61% n=178
Palliative care research mentors' programme	60% n=177
Attending research conferences	60% n=177
Access to allocated research staff	60% n=177

Table 7 Top 10 training needs from the survey

Training Needs	Least Interested	Moderately Interested	Most Interested	Missing
Using research data to inform programmes and services	7%	57%	26%	41%
Designing palliative care research studies	11%	27%	23%	39%
Identifying research mentors	11%	26%	22%	41%
How to design rigorous and evidence-based research while being pragmatic and taking into account the complex environment in which palliative care research is often carried out.	12%	28%	21%	39 %
Qualitative research designs	12%	30%	20%	40%
Qualitative data collection (e.g., focus groups, interviews)	8%	31%	20%	41%
Writing a successful grant application	18%	20%	20%	42 %

Developing a programme of research	11%	29%	19%	41%
Project management	11%	30%	18%	41%
Finding grant funding	19%	21%	18%	42%

Barriers to participating in palliative care research (qualitative data)

Additional data on the four areas of organisational culture and capacity, research knowledge, research infrastructure and collaborations, and patient and public perceptions of research were generated in both the free text comments from the survey and working group analysis. A narrative exploring each of these is presented in turn, illustrated with verbatim data extracts from the working groups and survey.

Organisational culture and capacity

This was the top barrier identified in the survey and most working groups. The focus was about whether research is prioritised within the organisation, including if people are enabled to conduct research in terms of protected time. Across the working groups and survey, participants explained how staff have no time to be involved in research because of clinical pressures and commitments. Staffing shortages, patient complexity, and the impact of COVID 19 have made the situation even more challenging for clinicians:

> *'It's really difficult because everyone is so stretched that everybody's so busy sort of, you know, the AHP's [allied health professionals], the doctors, the nurses, everyone's very busy, sort of fighting fires that nobody's got time to move away from that at the moment' (Hospice Doctor, working group 2)*

> *'The main barrier from my experience is not having protected time to spend in research activities. My case load is vast and give me no time to participate in research. This is disheartening to me as we need to constantly develop and not stagnate. Also, with palliative care we get one opportunity to make that difference so we need to be equipped with the best we can do.' (Survey study ID 163, Hospital Doctor)*

Organisational culture and external requirements also mitigate against engagement in palliative care research, where priority is given to meeting key performance indicators, which rarely include research engagement:

> *'The clinical demands and their key performance indicators required by our service specifications and our trust, demand that you spend the majority of your time 90% if not more, undertaking clinical aspects of the role and that there isn't necessarily buy in [to research] I don't feel from the senior management within the organisation to support us' (Palliative care nurse specialist, working group 1)*

Research not being part of an organisations culture and ethos and therefore not seen as a strategic priority was an important barrier.

> *'Even if someone said here's some funding, what do you want? We reel off a million answers, but research would probably be at the bottom just because there's other things that we need or want that we feel is probably more important than research. Whether that's right or wrong, I think it's just not. Not a priority. It's no one's first thought.' (Hospice nurse, Working group 2)*

Participants highlighted the need for a 'research champion' within an organisation who would be responsible for leading, prioritising and raising the profile of research therefore making research less daunting for staff.

> *'I think you're somebody who's motivated to drive a research agenda forward, I think makes a big difference in the organisation that you're in, whether that's hospital based or community Hospice and based because I think if you haven't got anybody who's keen and enthusiastic, you're not going to go anywhere. So you've got to have someone who's willing to take that on.' (Hospital Doctor, Working group 4)*

Research knowledge

Health and social care staff can have a limited understanding of research processes, and therefore may not have the necessary skills to conduct research. Whilst some basic knowledge was covered at pre- and post-registration undergraduate or postgraduate level, continuing to develop skills and knowledge could be challenging:

> *‘We're encouraging our staff to undertake further education or sort of masters level qualifications, and at that level it does require for the qualification a piece of research and a number of research questions to be undertaken, but it's how do we move beyond that?’ (Hospice manager/admin Working group 1)*

> *You do the research project within the course to get through the course and then you know you like, breathe sigh of relief and then you don't go near research again.’ (Palliative care nurse specialist, Working group 1)*

Research can feel distant and overwhelming, academic and jargon filled, without relevant pathways to support professional development:

> *‘I think from a perspective of peoples understanding and knowledge of research and where to get support and there's a lot of people shy away from it because they don't know where to start. They don't know where to go to. They don't know how to find the literature and they just feel like they're in a minefield of information they don't know which avenue to take.’ (Hospice nurse, Working group 4)*

The need for mentorship, support, and guidance from more experienced research staff and how to access this support was clearly identified. Engaging junior staff was seen as important and training sessions/e-learning needed to be accessible, including tailored resources for palliative care, and level of involvement in research.

> *‘If people haven't done a lot of research and they want to be involved and it's sort of supporting that group of people if they haven't got links to people already or groups*

> *within their organization or network that they can link into, and they're really interested in it, it's getting those people involved and how to direct them?' (Hospice nurse, Working group 4)*

> *'Need the support of an experienced researcher and also someone to help plan and develop the research, mentor and guide throughout research project and assist with analysis of results-/stats and writing up the project.' (Survey study ID 39 specialist palliative care clinical manager)*

Participants explained how there tended to be a lack of research expertise (e.g. knowledge of research processes) within hospices and how it was important to have someone with the right skill set in the setting/small organisation.

> *'Having somebody with the right skill set to take something through ethics committee and everything I suppose, and you need to have that one person in every Hospice or in every setting who can do all that. It's a skill all of its own.' (Manager/admin, Working group 2)*

Research infrastructure and collaborations

Palliative care research was felt to have a weak infrastructure, with few studies in the National Institute for Health Research (NIHR) portfolio, limiting opportunities to be involved in research and access to research nurse support. Hospices had few financial resources to support research activity, and seemed reluctant to divert funds from direct patient care:

> *'So, there's huge financial implications in terms of them [charitably funded hospices] providing sort of and delivering research … it was a massive competing pressure on money because you don't want to be impacting on the organisations finances and within the charity sector to the detriment of immediate patient care.' (Hospice Doctor, working group 1*)

> *‘Releasing people to take part in research is just impossible for a Hospice with our current funding arrangements. Research feels like a "nice to have" aspect of Hospice work. Even though I know it would be valuable to our sector long-term to be research active, the climate we find ourselves in means research is way down the list of priorities for a charity receiving 30% (and diminishing) funding* [from the NHS] *to run a 24/7 service.’ (Survey Study ID 85, Hospice CEO)*

The lack of or limited research infrastructure outside the hospital setting, particularly within standalone hospices, was raised as a barrier. The necessary structures to support research activity, such as governance arrangements, training, and adequate staffing levels, could often be lacking.

> *‘I think when you're working with within small groups you could be quite isolated with only having one research nurse who then is on their own, and I think the link I think that's probably an issue in terms of I guess the funding for that person. It can be an issue but also attracting somebody to a post which is going to feel quite isolating.’ (Hospital Doctor, Working group 4)*

> *‘But the thought of actually undertaking some research ourselves. We're a million miles away from that in our hospice you know. We are trying to be involved in other bigger trials, but where to actually put through an ethical approval ourselves. We're nowhere near that here.’ (Hospice Doctor, Working group 2)*

The importance of engaging nursing and allied health professionals in research and giving them the opportunity to be involved was raised. The four pillars of professional practice of the clinical nurse specialist and advanced practitioner roles includes research alongside clinical, education and leadership components(40). However, research is not always recognised or developed. It was noted that organisations support training in Independent and Supplementary Prescribing, diagnostics, and advanced communication skills, so it was questioned why not research. Some short-term research positions may not provide opportunities for all staff, as posts may be linked to certain roles (e.g. medical, nursing) or require professional registrations, thus limiting opportunities for staff without these qualifications (e.g. healthcare assistants). The importance of recognising the role and expertise of non-clinical staff in research and its potential impact on care and services needs to be promoted.

Currently, there was not a strong sense that people or organisations were working collaboratively locally or regionally to facilitate research:

> *‘We don't work collaboratively, and we have a really big list of research projects that we'd like to do. We'd like to get started on. We don't have the capacity to do it, but actually other hospices or other professionals in palliative care might be working on it. But we just don't know because we don't talk to each other. Perhaps we just need to talk more?’ (Manager/admin Working group 2)*

> *‘I think we're all busy, aren't we? So, the opportunity to meet, collaborate, share ideas doesn't to me seem like it's there. I could be wrong, but I think lack of existing collaboration, just perhaps due to how busy we all are individually, and rather than what I didn't mean, was competitiveness between hospices, yeah.’ (Hospice nurse, Working group 3)*

> *‘From a researcher perspective, the barriers I face are around making the necessary connections with relevant practitioners interested and available to work on research projects. This is partly to do with few opportunities to meet people in informal environments where research priorities or interests can be discussed….(Survey study ID 43 researcher)*

The need for some form of alliance or collaborative infrastructure was highlighted to pool research ideas, share information, collaborate on policies and governance issues. This was felt to need buy in from multiple organisations, potentially with a funded post to lead on research across voluntary hospices:

> *'it's almost like we need some sort of alliance, isn't it? And that may well be where all this is headed and in terms of, you know, somewhere in the region somebody's putting a bid in for this research and who wants to jump on board to recruit in their area to get some opportunity for the expertise.' (Palliative care nurse specialist, Working group 1)*

> *'And so maybe having some kind of umbrella group or network that… then everything kind of filters through it and information comes back out the other way so that that information is shared and you kind of know where to go. Maybe if you've got an idea to check that no one else is already doing it and to be in touch with the right people at the right time, I don't know if something around the kind of coordination of the whole thing.' (Hospice manager/admin, Working group 2)*

There were concerns raised that the palliative care research community involved a select group of individuals and could be elitist. It could be difficult for those sitting outside the elite to know how to be involved and included in any research activity:

> *'I did reflect on initially when I got interested in research it was sort of seen as this area of expertise in which a select group were involved, and it was sort of how do we get into that Network.' (Hospice nurse, Working group 4)*

Patient and public perceptions of palliative care research

Concerns were also raised that patient and public perceptions of palliative care research may be an issue either because there were assumptions that research was not happening, or only in large/cancer settings, that people did not want to take part, or that the end of life is an inappropriate time to request participation.

> *‘Sometimes staff feel oversensitive. Almost oversensitive to not wanting to upset patients and relatives to recruit them in, or to ask the relevant questions that we need them to ask.’ (Hospice educator, Working group 2)*

However, counter arguments were also recognised:

> *‘Anecdotally, we've had people tell us when they've taken part in studies that we've done, that they've enjoyed taking part that it's been beneficial for them, not because the research will impact them, but because of the process of...I guess the therapeutic aspect that's a side line to them taking part that they've enjoyed taking part and sharing. Their views and being able to put something back and to help other people.’ (Researcher, Working group 3)*

Discussion

Summary

The aim of this research is to understand professional and organisational facilitators and barriers to conducting palliative care research. Palliative care research was recognised as important and valuable, with three-quarters of those involved in this study wanting to increase their involvement in research, despite most not being currently research active. Several key barriers to palliative care research were identified including lack of organisational research culture and capacity (including prioritisation and available time); research knowledge (including skills/expertise and funding opportunities); research infrastructure and collaboration (including lack of collaborative opportunities across multiple organisations and governance challenges); and patient and public perceptions of research (including vulnerabilities and burdens). Key facilitators included dedicated research staff, and active research groups, collaborations, and networking opportunities.

What this research adds

A key finding is the apparent lack of progress in facilitating palliative care research over time, and the challenge for the sector is why change has been so slow. Previous palliative care research identifies a suite of remarkably similar barriers(23, 41, 42, 43, 44), albeit not necessarily unique to this specialty (45, 46). There needs to be a concerted and sustained focus on collaboration and sharing best practice, developing a research culture and facilitating research within and between palliative care providers, enhancing staff capacity and expertise, and providing guidance on research processes and procedures (23, 41, 43, 44). Our research further highlights the importance of organisational barriers, pointing to the need to prioritise organisational solutions.

Organisations have a critical role in building research culture and capacity (46, 47, 48). It is imperative that organisations recognise and value research and incorporate research into the core business of the organisation. This means that research should be visible throughout, from mission statements to policies, business plans, and job descriptions. They should protect research time and resources, recognise talent, and reward positive research related behaviours(48). This may be a particular challenge for those palliative care organisations that are charitably funded due to the uncertainty and volatility of their funding (49, 50), and business models that may not account for research activity(51). The focus is also set nationally, with the recently launched Hospice UK 2024-29 strategy having no overt mention of research (52).

A key finding is that for many the organisational lack of support for research translates into research not being seen as a core part of people's jobs. Again, this is not unique to palliative care, with capacity to be engaged in research limited in time or job plans(53). As an example an audit of clinical nurse specialist job descriptions found that 80% had an expectation of research engagement(40), however, in detailed studies of how such roles are enacted, research is typically absent(54, 55). Where research is mentioned, it was in the context of it being the least important aspect of the role, or that others (such as medical consultants) should be leading research(56). However, whilst there is little contemporary data, previously the median time palliative care consultant doctors spent on research was zero hours(57). A recent survey of UK palliative medicine consultants found that while 78 % (n=140/180) were interested in conducting research, 83% had no allocated time within their job plan (58). Given the serious and significant workforce pressures and challenges currently facing many healthcare workers it is unlikely this position will change without both investment in, and prioritisation of, research time and roles. It may be that research time or engagement needs to explicitly form part of key performance indicators or other metrics to enable such prioritisation to occur.

Research should be important to palliative care provider organisations. It is known that a strong research culture and organisational research performance lowers mortality rates, increases patient and staff satisfaction, reduces staff turnover, and improves organisational efficiency (59). Our research encompassed a variety of different organisations and settings, demonstrating that these barriers were remarkably similar wherever a person worked. Solutions may differ though depending on the size, funding, and specialism of the organisation. An independent voluntary funded hospice may have different solutions to a palliative care team working as part of a larger general hospital or community care provider.

The opportunity to collaborate between individuals and across organisations may be important, as in other specialities such as General Practice(60). Evidence indicates that the creation of research cooperatives, collaborations and partnerships can be fruitful. There are palliative care examples from the UK(61), US (62, 63), Australia (64, 65, 66), and Africa (67). Some of these are large collaboratives, across multiple sites, facilitating multiple studies (68). It is possible that such collaboratives mitigate the effect of the employing organisation for members, facilitating research in a way that sits above, and possibly either bypasses, negates, or gives the skills to overcome institutional and local organisational barriers. Joint approaches between universities and public and charitable providers of palliative care may help overcome structural issues such as indemnity, sponsorship and gaining research ethics committee approvals. However, funding to sustain some of these collaborations can be fragile or time limited. For example, in the UK, very welcome but time-limited funding to build palliative care research partnerships has been awarded, but it is too early to see the impact of this on the research landscape(69). The benefits of such collaborations may also be on the wider research culture of the organisations that participate in such research. The initial impact of participating in a trial may be staff stress and workload, but this has found to be replaced by enthusiasm for the changes and benefits achieved(70).

Those who completed our survey had wide variability in levels of research experience and involvement. It is important to recognise when considering developing an organisational research culture that not all members of staff need the same level of skill and expertise, and not all organisations will be at the same level of engagement. Previous recommendations for hospices suggested a typology of engagement, through which hospices could progress if they wished, from research aware, to research engaged, to research leading(23, 43). Equally, individuals can have different levels of preparation, with recognition that generating and leading new research likely needs the higher levels of research preparation such as research focused PhDs, and that organisations that aspire to these levels need to invest in educating staff to these levels and supporting their continued research development.

Strengths and limitations of the research

A strength of this research was the breadth of response from across different sectors and professional backgrounds. There was a particularly strong response from nurses, and a reasonable proportion of those providing general palliative care. However, it was harder to recruit respondents who do not provide specialist palliative care (perhaps because they do not identify themselves as palliative care providers despite the high numbers of those with palliative care needs that they provide care for). Care home respondents were particularly poorly represented. We aimed to invite patients, family members and the public to a working group. Whilst we involved Patient and Public Involvement (PPI) study team members in planning this work and attempted to recruit the public to our working groups, challenges both in institutional permissions and recruitment meant that this planned aspect of the study did not go ahead. This work also represents the views of people from across a particular UK geography. Whilst this includes a large, diverse, population it may be that this does not represent wider views, although this is unlikely given the congruence with past and related research. This study also includes participants who were involved or would wish to be involved in palliative care research so the views of those who are not interested are not reflected in the findings.

Conclusions

Engagement in palliative care research appears stagnant, with this study revealing a range of barriers that appear unchanged from a decade or more ago. The challenge for palliative care is not to identify further the barriers and facilitators to research, but to invest time and funding to address the known barriers and enable the facilitators of research. It is likely that such investments will reap dividends in terms of staff satisfaction, organisational performance, and importantly the quality of care provided to patients and families.

Declarations.

All methods were carried out in accordance with relevant guidelines and regulations.

Ethics approval and consent to participate: Approval was granted by the East of England - Cambridge South Research Ethics Committee (Ref: 22/EE/0049) on the 24/02/2022. Informed consent was obtained from all subjects. Survey instructions clarified that consent to participate was implied when the participant clicked through to the first page of the survey. Electronic consent was obtained prior to the working groups.

Consent for publication: Not applicable

Availability of data and materials: Data are stored in Lancaster University's PURE repository, consent to share data was not given by participants.

Competing interests: The authors declare that they have no competing interests.

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Authors' contributions: CRediT statement: Conceptualisation and funding acquisition: LD, NHW, NP, SP, JE, VT, SM, ACN, AG, RB, BS, SC, AD, AP, JH, CW; Investigation and analysis: LD, NHW, CW, AG, RB, BS; Writing – original draft – CW, LD*;* Writing – review and editing - LD, NHW, NP, SP, JE, VT, SM, ACN, AG, RB, BS, SC, AD, AP, JH, CW

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Additional File 1. Survey

Thank you for your interest in completing this survey. Research is an important part of excellent care, with health and social care organisations involved in research activity known to provide better care. However, in the North West Coast area of England we know that research activity in the important field of palliative and end-of-life care is much lower than in other parts of the country. This is despite much higher needs than on average. It is important that we invest in research in North West Coast England to ensure that the particular needs of the populations in this area are properly taken account of, and that care is planned and provided to meet these needs in the best possible way. We are trying to find out what the main barriers are to palliative care research locally, and how we can best overcome these to meet the needs of those in the North West Coast area. This study is funded by the National Institute for Health Research.

We realise you are very busy right now, and so we have tried to balance collecting the information, with keeping the questionnaire as short as we can. The survey has 5 sections, and should take no longer than 15-20 minutes to complete, although it may depend on how much additional/open comments you wish to share.

- We ask that this survey be completed by all those who may have an interest in palliative care research as a care provider or researcher/research staff within the North West Coast area of England.

- You may provide health and/or social care for patients and carers with palliative care/end of care needs in the North West Coast area of England **and/or** be involved or would wish to be involved in palliative care/end of life care research.*

** (This does not only include practitioners who provide specialist palliative care but also those that provide generalist palliative care in hospitals, primary care and nursing/care homes (e.g. DNs, GPs, Consultants, Physios etc) for adults and/or children. It also includes research focused staff (e.g. research nurses, researchers, R&D staff).)*

Participation in the survey is voluntary. We will consider everything that you say. Your reply will help us. We will share the results of this survey through publications and presentations. The results will be aggregated and anonymised so no-one should be able to tell which individual has provided particular information. We ask which organisation you work for to provide recruitment data to the National Institute for Health Research but this will be anonymised when shared. We do not think there are particular risks to completing this survey. Completion of this survey implies consent for your data to be used as part of this study. You will input your data into a secure online survey platform, and these data will be then stored in a secure institutional filestore at Lancaster University.

If you wish to speak to anyone about this survey you can contact Lesley Dunleavy Senior Research Associate (l.dunleavy@lancaster.ac.uk). You may also contact her if you wish to withdraw your responses, up to 2 weeks following completion. If you have made a partial response we may contact you after a week to check if this is an error.

This study has been granted NHS research ethics approval (NHS REC reference xxxxxxx). If you wish to speak with someone independently about this research you can contact the Director of Research Professor Fiona Lobban (f.lobban@lancaster.ac.uk).

If you are happy to proceed, please consent to participate by clicking below which will take you to the first page of the survey.

SCREENING QUESTION:

Do you provide health and/or social care for patients and carers (adults and/or children) with palliative care/end of care needs in the North West Coast area of England? (This area covers Cumbria, Lancashire, Cheshire and Merseyside) **and/or** is involved or would wish to be involved in palliative/end of life care research?* * This does not only include practitioners who provide specialist palliative care but also those that provide generalist palliative care in hospitals, primary care and nursing/care homes. It also includes research focused staff (e.g. research nurses, researchers, R&D staff).	Yes No IF NO then survey finishes

INFORMATION ABOUT THE PERSON COMPLETING THE SURVEY

This information will only be used in case we need to check back with you, for example if the survey does not save correctly. This information will be stored separately to the data that you provide, to adhere to GDPR and maintain confidentiality and anonymity.

What is your name?	Free text
What is your contact email address?	Free text

A. Personal Information

This section of the survey aims to gather background information about those who are participating in this research.

1 **How long have you worked in palliative care?** This may include specialist palliative care, generalist palliative care or palliative care research roles. Please select one.

- ○ Just getting started (<2 years)
- ○ Early career (2-5 years)
- ○ Mid-career (6-10 years)
- ○ Late career (10+ years)

2 **Please provide the name of the organisation that you work for (name of trust/hospice/university etc)?**

____

3 What is your primary professional role? If more than one applies, please choose your primary role.

- ○ Nurse
- ○ Doctor
- ○ Social Worker
- ○ Psychologist
- ○ Occupational Therapist
- ○ Physiotherapist
- ○ Manager/admin
- ○ Other (please specify): ______________________________

4 What is your primary work environment? If more than one applies, please choose your primary work environment.

- ○ University
- ○ Hospital
- ○ Primary Care
- ○ Hospice
- ○ Nursing home and/or care home
- ○ Clinical Research Network
- ○ NHS R&D department
- ○ Other (please specify): ______________________________

5 If your role is primarily clinical (rather than research) do you work in specialist palliative care or do you provide general palliative care as part of a wider caseload?

- ○ Specialist palliative care
- ○ Generalist palliative care
- ○ Work only in research role
- ○ Other primary role. Please specify______________________

6 Is your work (clinical or research) primarily with adults or children?

- ○ I work primarily with adults
- ○ I work primarily with children

B. Current and desired level of palliative care research involvement

This section seeks to understand your current level of involvement in palliative care research as well as your desire for continued or further research involvement.

1. **What is your weekly full time equivalent (FTE)? This is across all your roles if you have a joint or shared appointment? (e.g. 1 day a week = 0.2 FTE, 2 days a week = 0.4 FTE, 3 days a week= 0.6 FTE, 4 days a week = 0.8 FTE, full time = 1.0 FTE)_______________**

2. **What proportion of your average working week is spent on palliative care research?**

   Please select one.

- ○ Currently I do not spend any time on palliative care research
- ○ Less than 10%
- ○ 10-25 %
- ○ 26-50%
- ○ 51-75%
- ○ 76-100%

3. **Would you like to increase your involvement in palliative care research?** Please select one.
   - ○ Yes
   - ○ No

4. **Please indicate which of the following four categories most accurately describes your palliative care research experience?** Please select the most appropriate category.
   - ○ Non-active: Little or no previous experience and currently not participating in palliative care research activities.
   - ○ Involved: Involved as part of a team delivering palliative care research.
   - ○ Managing: Managing own palliative care projects as a 'clinician researcher' or as an academic.
   - ○ Supervising: Supervising the research activities of others.

5. **How many funded palliative care research projects are you currently involved in?** Please select one.
   - ○ None
   - ○ 1-3
   - ○ 4-7
   - ○ 8-10
   - ○ More than 10

C. Barriers to participating in palliative care research within North West Coast

This section relates to developing an understanding of the barriers to participation in palliative care research encountered by practitioners and research focused staff within North West Coast.

1. **To what extent are the following factors a barrier to your participation in palliative care research within North West Coast?** Please rate each of the following items based on your evaluation of the degree to which it hinders your ability to participate in palliative care research at the moment.

	Not a barrier	**Minor barrier**	**Moderate barrier**	**Significant barrier**
Alignment of palliative care research-related activities with organisation's mission and goals				
Confidence in my abilities to do palliative care research				
No formal palliative care research training				
My understanding of what is needed to conduct palliative care research				
My knowledge and skills to conduct palliative care research				
My work environment (e.g. lack of support from management)				

Palliative care research not perceived as important by my organisation				
Lack of funding or financial resources prevents me from becoming involved in palliative care research				
Understanding how to apply for research funding to support palliative care research				
Lack of protected time/competing demands				
Lack of access to computer facilities				
Lack of access to a statistician				
The time and effort required to initiate a palliative care research project discourages me from the start				
Lack of access to relevant data				
Working with new technologies (i.e. software) intimidates me				
I'm not interested in palliative care research				
I do not know how to get involved in palliative care research				
Lack research ethics committee/ethics expertise				
No access to palliative care research collaborators/partners				
Lack of partnership agreements for sponsorship and indemnity				
Loss of clinical productivity during palliative care research activities				
Loss of income during palliative care research activities				
Palliative care research is not worth the time and resource investment				
Difficulty balancing working independently and knowing when to ask someone for assistance				
Inability to find the right people to ask the right questions				
No opportunities to interact with palliative care researchers				

2. Please use the space below to help us understand more about the barriers and issues that affect your involvement in palliative care research. You can add additional barriers or issues not listed above, or give more details about the barriers you think are particularly important.

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D. Perceptions of activities that would facilitate participation in palliative care research within North West Coast

This section seeks to understand the activities that you believe would facilitate your participation in palliative care research within North West Coast.

1. **What would facilitate your participation in palliative care research within North West Coast?** Please indicate below the extent to which you agree that each activity would enhance your participation in palliative care research within North West Coast.

	Strongly agree	**Agree**	**Disagree**	**Strongly disagree**
Palliative care research mentors' programme				
Palliative care research information network				
More exposure to palliative care research e.g. via an internship				
More exposure to palliative care research as undergraduates				
Palliative care research seminars for those in practice				
Attending research conferences				
Supportive management				
Staff cover				
Access to funding to support research				
Palliative care research is included as part of my job description				
Collaboration with other centres				
Availability of resources such as a guide/manual				
Ongoing research working group at work				
Availability of workshops for writing proposals				
Availability of workshops for statistics				
Availability of workshops for study design				
Availability of workshops for developing research questions				
Availability of workshops for writing for publication				
Assistance with getting started with research				
Statistics advisor				
Availability of research policies and governance procedures to support palliative care research				
Access to allocated research staff				
Supportive clinical lead				
Access to Patient and Public Involvement (PPI) resources or input				
Access to palliative care research recruitment training				

2 Please use the space below to help us understand more about the facilitators that would affect your involvement in palliative care research. You can add additional facilitators not listed above, or give more details about the facilitators you think are particularly important.

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E. Research training needs

In order to perform palliative care research effectively you need relevant skills. This section seeks to explore knowledge gaps that you may have with regards to conducting palliative care research in order to identify your research training needs. This includes the types of training, assistance, or resources that you believe is required in order for you to safely and competently engage in palliative care research initiatives. Please answer all the questions as honestly as possible to enable us to compile a complete picture of your training requirements.

1. **Have you received any palliative care research-related training in the past 3 years?**
   - ○ Yes
   - ○ No

2. **What kinds of training, technical assistance, or resources would you be interested in receiving to support your participation in palliative care research?** Please rate each of the following research activities you would be interested in receiving support for from least interested to most interested.

	Least interested	Moderately interested	Most Interested
Research processes			
1. Conducting literature reviews			
2. How to design rigorous and evidence-based research while being pragmatic and taking into account the complex environment in which palliative care research is often carried out.			
3. Research question and hypothesis generation (if appropriate)			
4. Selecting appropriate conceptual/theoretical frameworks			
5. Designing palliative care research studies			
6. Identifying relevant variables			
7. Selecting the best measures/scales to use			
8. Qualitative research designs			
9. Obtaining buy-in from staff			
10. Determining sample size			
11. Recruitment of participants			
12. Quantitative data collection			
13. Qualitative data collection (e.g., focus groups, interviews)			
14. Qualitative data analysis (e.g., analyse interview data)			
15. Quantitative data analysis			
16. Data entry and data cleaning			
17. Using research data to inform programmes and services			
18. Project management			

19.Developing a programme of research			
20.Finding research partners and expert consultation (e.g., biostatistical expertise)			
21.Identifying research mentors			
Learning specific research related skills			
22.Writing a proposal			
23.Finding grant funding			
24.Writing a successful grant application			
25.Preparing an ethics application			
26.Conducting statistical data analyses			
27.Writing for publication			
28.Developing a budget for a research project			
29.Presenting your research at professional meetings			
30.Using knowledge dissemination strategies other than publication and conference presentations			
31.Technology needs (e.g., information technology/electronic records, audio/video conferencing, computer hardware, statistical software)			

3. **If we were to offer palliative care research education or training, how would you best like to receive this?** Please select one.
    - ○ Online modules
    - ○ Face-to-face workshop
    - ○ Webinars
    - ○ Written resources
    - ○ Research mentor
    - ○ Other (please specify): ______________________________

4 List up to three research-related priority areas in which you would like to receive further training.

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If you are interested in taking part in additional research to explore the barriers and facilitators to palliative care research within North West Coast please indicate below so we can contact you with further information:

○ Yes I would like to receive information about further research
○ No I would not like to receive information about further research

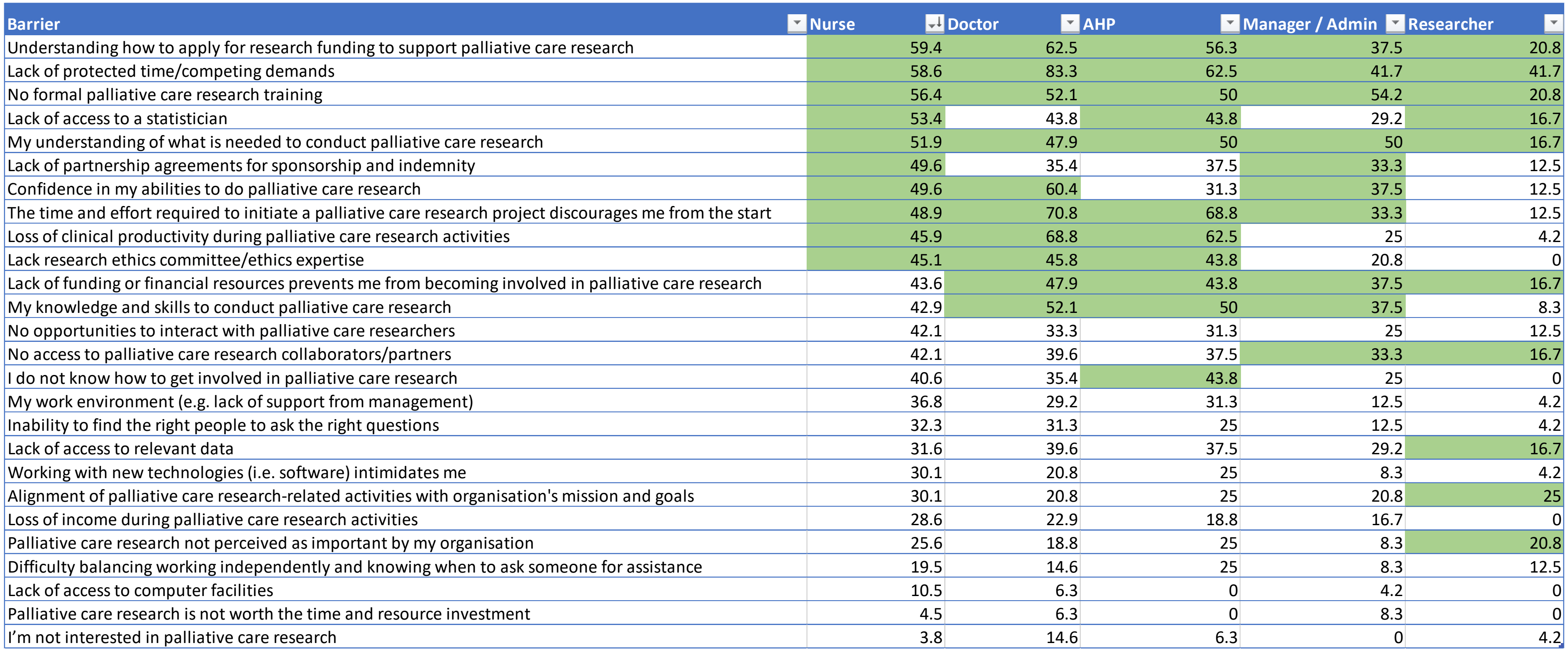
Thank you for completing this survey. Your responses are extremely valuable to help us understand the local barriers to palliative and end of life care research within the North West Coast region as well as helping us to identify how they may be overcome. Your time and input is very much appreciated. Please do not hesitate to contact Lesley Dunleavy at l.dunleavy@lancaster.ac.uk with any questions or concerns.

Additional file 2: Full survey findings (In the tables below, the green highlights are the top 10 rankings, including tied rankings.)

List of barriers (full sample)

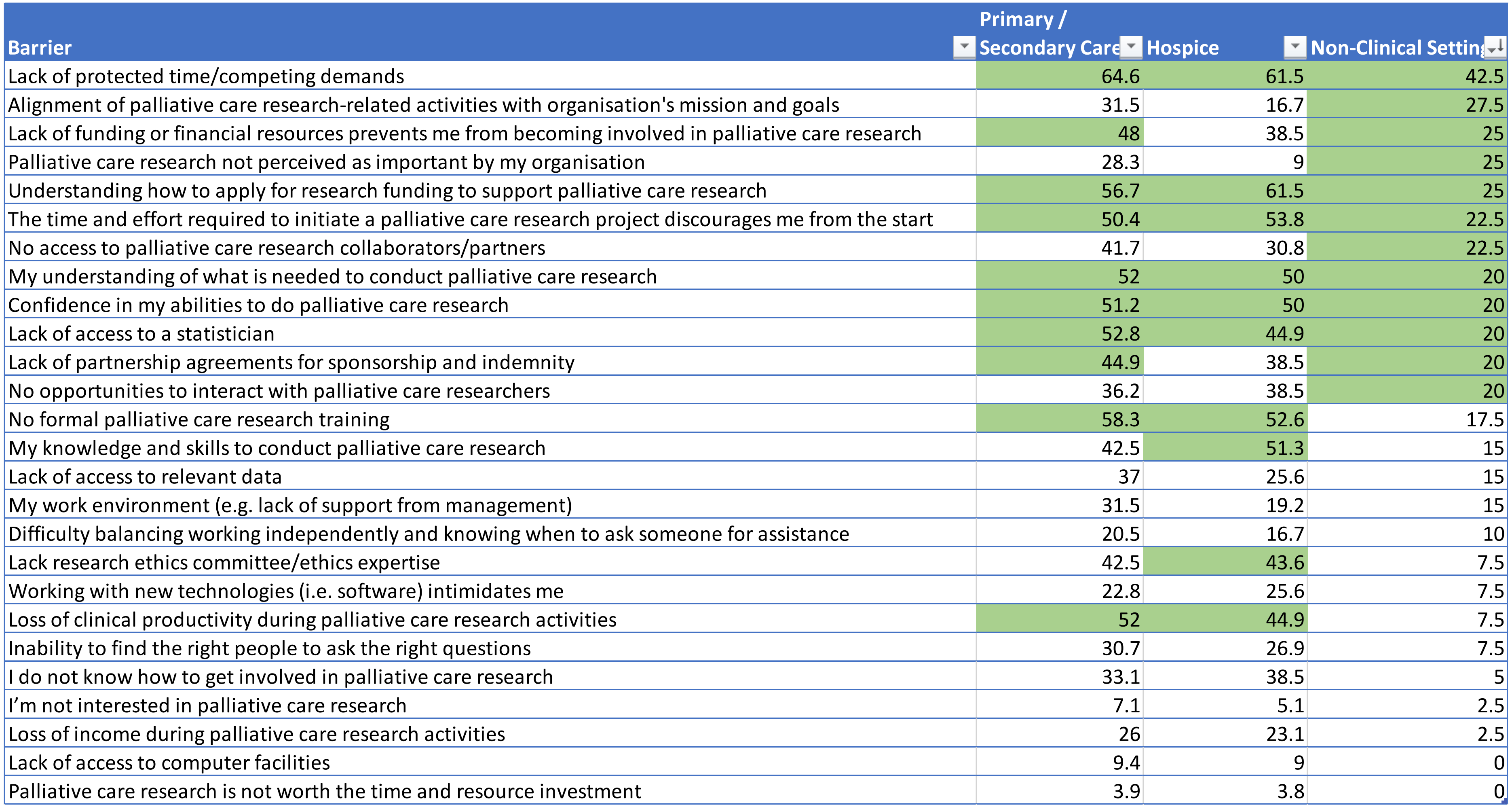
Barrier	Missing	Not a barrier	Minor barrier	Moderate barrier	Significant barrier	Composite Moderate/ Significant Barrier
Lack of protected time/competing demands	20.1	7.8	14	16.4	41.6	58
Understanding how to apply for research funding to support palliative care research	19.8	13	13.7	24.2	29.4	53.6
No formal palliative care research training	14.3	15	18.4	22.2	30	52.2
My understanding of what is needed to conduct palliative care research	14.7	13	23.5	24.6	24.2	48.8
The time and effort required to initiate a palliative care research project discourages me from the start	19.5	17.4	15.4	18.4	29.4	47.8
Confidence in my abilities to do palliative care research	14.7	21.2	19.1	27	18.1	45.1
Lack of access to a statistician	19.8	18.8	16.4	21.8	23.2	45
Loss of clinical productivity during palliative care research activities	23.5	19.1	14.3	17.1	25.9	43
My knowledge and skills to conduct palliative care research	19.5	11.9	27.3	21.5	19.8	41.3
Lack of funding or financial resources prevents me from becoming involved in palliative care research	20.1	18.1	20.5	21.5	19.8	41.3
Lack of partnership agreements for sponsorship and indemnity	23.5	18.4	17.4	23.2	17.4	40.6
Lack research ethics committee/ethics expertise	22.9	21.2	18.4	19.8	17.7	37.5
No access to palliative care research collaborators/partners	22.5	19.1	21.5	20.5	16.4	36.9
No opportunities to interact with palliative care researchers	23.2	24.6	17.1	20.1	15	35.1
Lack of access to relevant data	19.8	22.9	23.9	18.8	14.7	33.5
I do not know how to get involved in palliative care research	22.5	20.5	24.2	20.5	12.3	32.8
Inability to find the right people to ask the right questions	23.5	26.6	22.5	19.5	7.8	27.3
Alignment of palliative care research-related activities with organisation's mission and goals	15.7	35.2	21.8	15.7	11.6	27.3
My work environment (e.g. lack of support from management)	19.5	35.5	19.8	17.4	7.8	25.2
Loss of income during palliative care research activities	24.6	36.9	15.7	10.6	12.3	22.9
Palliative care research not perceived as important by my organisation	19.8	45.4	12.6	16	6.1	22.1
Working with new technologies (i.e. software) intimidates me	19.5	35.5	22.9	11.9	10.2	22.1
Difficulty balancing working independently and knowing when to ask someone for assistance	23.9	32.1	25.6	15.4	3.1	18.5
Lack of access to computer facilities	19.5	62.8	8.9	5.8	3.1	8.9
I'm not interested in palliative care research	22.2	61.4	11.3	4.1	1	5.1
Palliative care research is not worth the time and resource investment	23.9	68.3	3.4	3.1	1.4	4.5

Barriers compared across professional role (Comparison on composite score only)



Barrier	Nurse	Doctor	AHP	Manager / Admin	Researcher
Understanding how to apply for research funding to support palliative care research	59.4	62.5	56.3	37.5	20.8
Lack of protected time/competing demands	58.6	83.3	62.5	41.7	41.7
No formal palliative care research training	56.4	52.1	50	54.2	20.8
Lack of access to a statistician	53.4	43.8	43.8	29.2	16.7
My understanding of what is needed to conduct palliative care research	51.9	47.9	50	50	16.7
Lack of partnership agreements for sponsorship and indemnity	49.6	35.4	37.5	33.3	12.5
Confidence in my abilities to do palliative care research	49.6	60.4	31.3	37.5	12.5
The time and effort required to initiate a palliative care research project discourages me from the start	48.9	70.8	68.8	33.3	12.5
Loss of clinical productivity during palliative care research activities	45.9	68.8	62.5	25	4.2
Lack research ethics committee/ethics expertise	45.1	45.8	43.8	20.8	0
Lack of funding or financial resources prevents me from becoming involved in palliative care research	43.6	47.9	43.8	37.5	16.7
My knowledge and skills to conduct palliative care research	42.9	52.1	50	37.5	8.3
No opportunities to interact with palliative care researchers	42.1	33.3	31.3	25	12.5
No access to palliative care research collaborators/partners	42.1	39.6	37.5	33.3	16.7
I do not know how to get involved in palliative care research	40.6	35.4	43.8	25	0
My work environment (e.g. lack of support from management)	36.8	29.2	31.3	12.5	4.2
Inability to find the right people to ask the right questions	32.3	31.3	25	12.5	4.2
Lack of access to relevant data	31.6	39.6	37.5	29.2	16.7
Working with new technologies (i.e. software) intimidates me	30.1	20.8	25	8.3	4.2
Alignment of palliative care research-related activities with organisation's mission and goals	30.1	20.8	25	20.8	25
Loss of income during palliative care research activities	28.6	22.9	18.8	16.7	0
Palliative care research not perceived as important by my organisation	25.6	18.8	25	8.3	20.8
Difficulty balancing working independently and knowing when to ask someone for assistance	19.5	14.6	25	8.3	12.5
Lack of access to computer facilities	10.5	6.3	0	4.2	0
Palliative care research is not worth the time and resource investment	4.5	6.3	0	8.3	0
I’m not interested in palliative care research	3.8	14.6	6.3	0	4.2

Barriers compared across working environments (Comparison on composite score only)



Barrier	Primary / Secondary Care	Hospice	Non-Clinical Setting
Lack of protected time/competing demands	64.6	61.5	42.5
Alignment of palliative care research-related activities with organisation's mission and goals	31.5	16.7	27.5
Lack of funding or financial resources prevents me from becoming involved in palliative care research	48	38.5	25
Palliative care research not perceived as important by my organisation	28.3	9	25
Understanding how to apply for research funding to support palliative care research	56.7	61.5	25
The time and effort required to initiate a palliative care research project discourages me from the start	50.4	53.8	22.5
No access to palliative care research collaborators/partners	41.7	30.8	22.5
My understanding of what is needed to conduct palliative care research	52	50	20
Confidence in my abilities to do palliative care research	51.2	50	20
Lack of access to a statistician	52.8	44.9	20
Lack of partnership agreements for sponsorship and indemnity	44.9	38.5	20
No opportunities to interact with palliative care researchers	36.2	38.5	20
No formal palliative care research training	58.3	52.6	17.5
My knowledge and skills to conduct palliative care research	42.5	51.3	15
Lack of access to relevant data	37	25.6	15
My work environment (e.g. lack of support from management)	31.5	19.2	15
Difficulty balancing working independently and knowing when to ask someone for assistance	20.5	16.7	10
Lack research ethics committee/ethics expertise	42.5	43.6	7.5
Working with new technologies (i.e. software) intimidates me	22.8	25.6	7.5
Loss of clinical productivity during palliative care research activities	52	44.9	7.5
Inability to find the right people to ask the right questions	30.7	26.9	7.5
I do not know how to get involved in palliative care research	33.1	38.5	5
I’m not interested in palliative care research	7.1	5.1	2.5
Loss of income during palliative care research activities	26	23.1	2.5
Lack of access to computer facilities	9.4	9	0
Palliative care research is not worth the time and resource investment	3.9	3.8	0

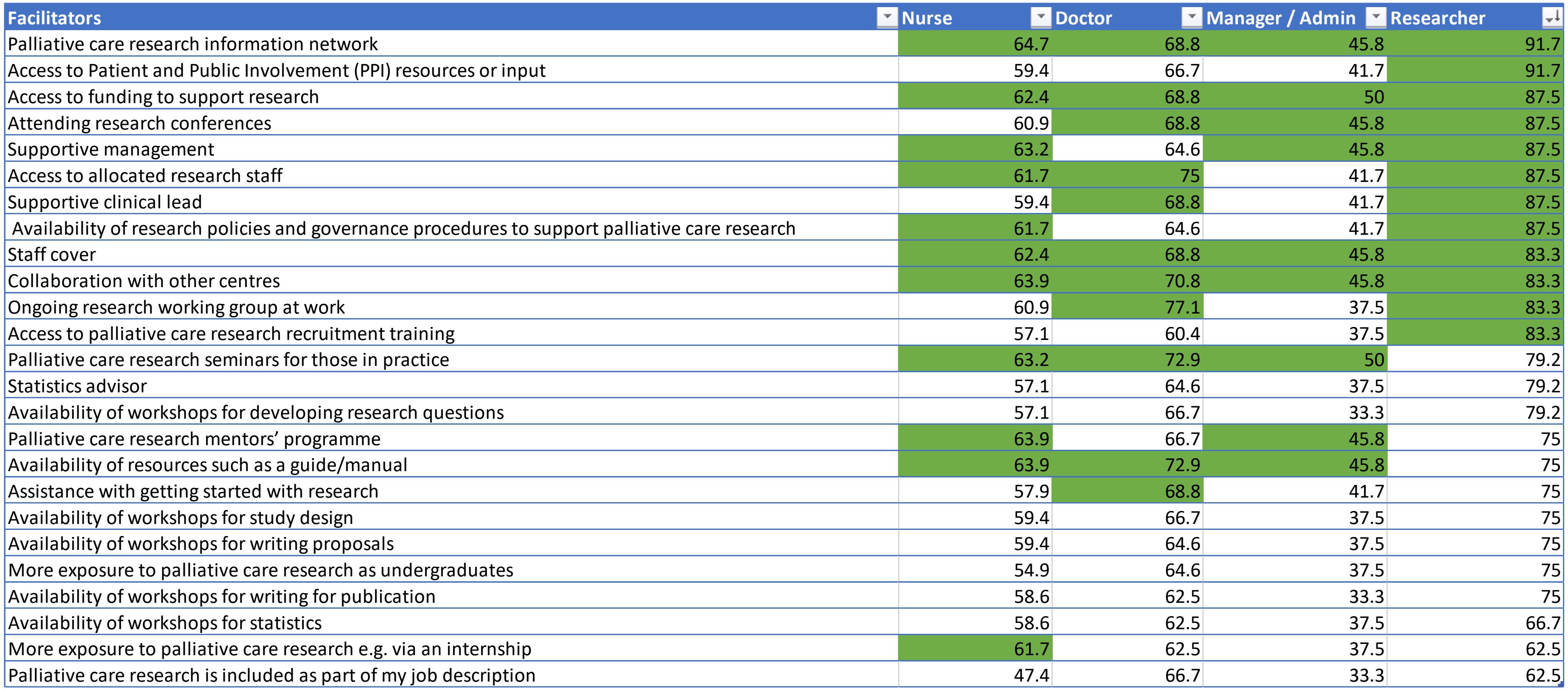
Barriers compared across time working in palliative care (Comparison on composite score only)

Barrier	<2 years	2 to 5 years	6 to 10 years	10+ years
Lack of protected time/competing demands	50	52.9	60.7	62.5
Understanding how to apply for research funding to support palliative care research	43.2	49	62.3	55.5
The time and effort required to initiate a palliative care research project discourages me from the start	31.8	45.1	52.5	52.3
No formal palliative care research training	43.2	54.9	59	51.6
Lack of access to a statistician	31.8	37.3	50.8	50
Confidence in my abilities to do palliative care research	38.6	37.3	47.5	50
My understanding of what is needed to conduct palliative care research	43.2	47.1	55.7	48.4
Loss of clinical productivity during palliative care research activities	22.7	41.2	50.8	48.4
Lack of partnership agreements for sponsorship and indemnity	31.8	39.2	37.7	44.5
My knowledge and skills to conduct palliative care research	40.9	33.3	47.5	43
Lack research ethics committee/ethics expertise	29.5	45.1	32.8	39.8
Lack of funding or financial resources prevents me from becoming involved in palliative care research	34.1	41.2	50.8	39.1
Lack of access to relevant data	27.3	19.6	34.4	39.1
I do not know how to get involved in palliative care research	13.6	31.4	37.7	37.5
No access to palliative care research collaborators/partners	31.8	37.3	36.1	37.5
No opportunities to interact with palliative care researchers	27.3	31.4	37.7	36.7
Inability to find the right people to ask the right questions	15.9	31.4	27.9	29.7
Alignment of palliative care research-related activities with organisation's mission and goals	27.3	23.5	31.1	28.1
Working with new technologies (i.e. software) intimidates me	11.4	11.8	24.6	28.1
My work environment (e.g. lack of support from management)	18.2	25.5	26.2	27.3
Loss of income during palliative care research activities	11.4	23.5	32.8	22.7
Difficulty balancing working independently and knowing when to ask someone for assistance	9.1	17.6	23	21.1
Palliative care research not perceived as important by my organisation	20.5	27.5	24.6	19.5
Lack of access to computer facilities	9.1	11.8	11.5	7
I’m not interested in palliative care research	2.3	7.8	4.9	5.5
Palliative care research is not worth the time and resource investment	2.3	3.9	4.9	5.5

Facilitators (full sample)

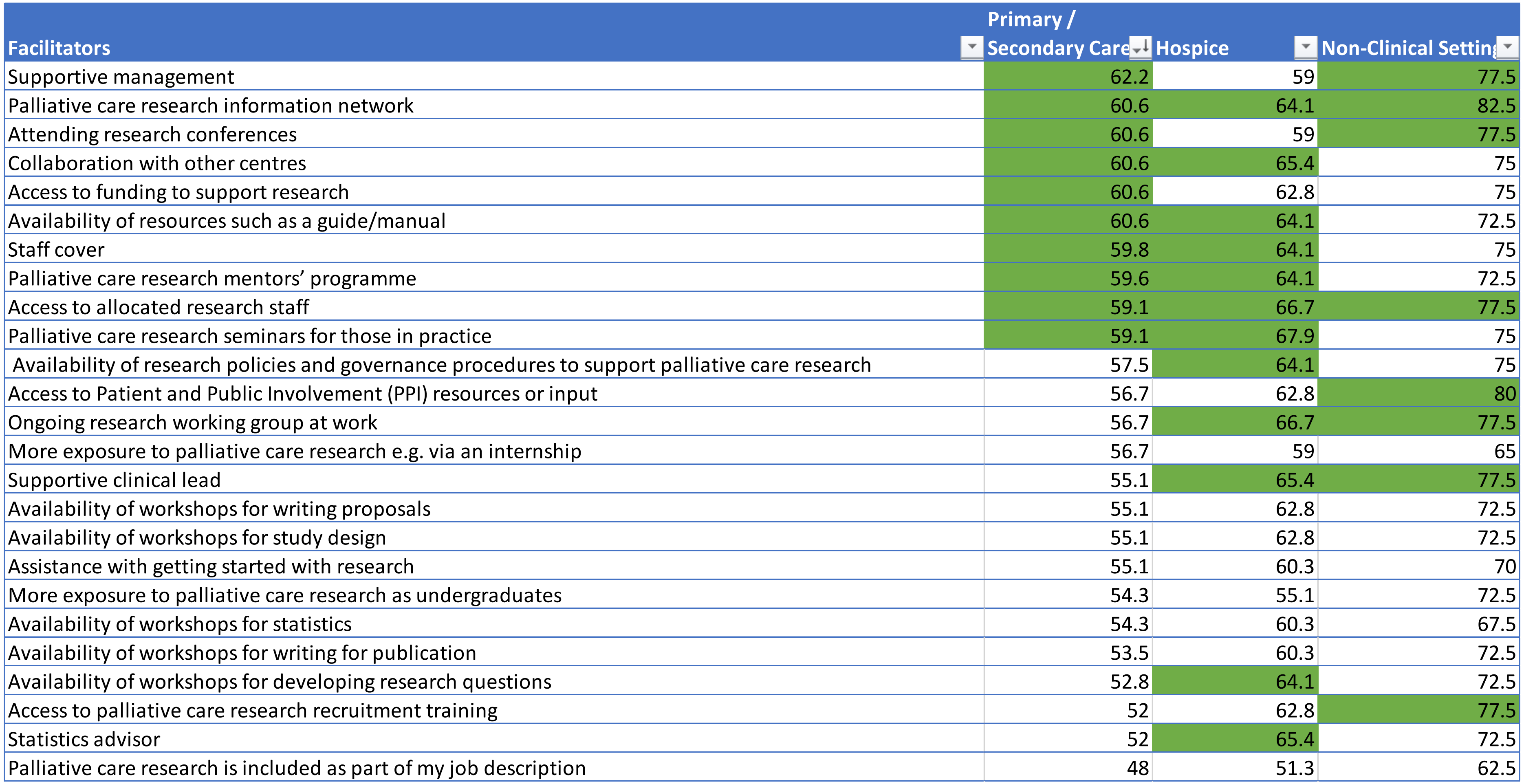
Facilitators	Missing	Strongly Disagr	Disagree	Agree	Strongly Agree	Composite Agreement Score
Palliative care research information network	33.8	1.4	3.1	39.9	21.8	61.8
Palliative care research seminars for those in practice	33.4	1.4	3.4	37.2	24.6	61.8
Collaboration with other centres	33.4	1.4	3.4	34.1	27.6	61.8
Availability of resources such as a guide/manual	33.4	1.4	4.1	36.5	24.6	61.1
Supportive management	34.5	1	3.8	30.4	30.4	60.8
Staff cover	33.8	2	3.4	26.6	34.1	60.8
Access to funding to support research	34.1	1.4	3.8	25.3	35.5	60.8
Palliative care research mentors’ programme	33.8	1.7	4.1	38.2	22.2	60.4
Attending research conferences	33.8	1.7	4.1	36.5	23.9	60.4
Access to allocated research staff	35.8	0.7	3.1	30.4	30	60.4
Ongoing research working group at work	35.8	1	3.1	37.5	22.5	60.1
Availability of research policies and governance procedures to support palliative care research	35.8	1.4	4.1	36.2	22.5	58.7
Access to Patient and Public Involvement (PPI) resources or input	36.5	0.7	4.1	34.8	23.9	58.7
Supportive clinical lead	36.2	1	4.4	27	31.4	58.4
Assistance with getting started with research	36.2	1.7	5.1	29.7	27.3	57
Availability of workshops for writing proposals	36.2	2	5.1	37.5	19.1	56.7
Availability of workshops for study design	36.2	2	5.1	36.9	19.8	56.7
More exposure to palliative care research e.g. via an internship	34.5	2	7.2	34.5	21.8	56.3
Availability of workshops for developing research questions	35.8	2	6.1	37.2	18.8	56
Statistics advisor	36.2	1.7	6.1	32.1	23.9	56
Availability of workshops for writing for publication	36.2	2	6.5	35.2	20.1	55.3
Access to palliative care research recruitment training	36.5	1.4	6.8	30.7	24.6	55.3
Availability of workshops for statistics	36.2	2.4	6.5	36.5	18.4	54.9
More exposure to palliative care research as undergraduates	33.4	1.7	10.6	36.9	17.4	54.3
Palliative care research is included as part of my job description	34.1	4.1	13.7	24.9	23.2	48.1

Facilitators compared across role (Comparison on composite score only)



Facilitators	Nurse	Doctor	Manager / Admin	Researcher
Palliative care research information network	64.7	68.8	45.8	91.7
Access to Patient and Public Involvement (PPI) resources or input	59.4	66.7	41.7	91.7
Access to funding to support research	62.4	68.8	50	87.5
Attending research conferences	60.9	68.8	45.8	87.5
Supportive management	63.2	64.6	45.8	87.5
Access to allocated research staff	61.7	75	41.7	87.5
Supportive clinical lead	59.4	68.8	41.7	87.5
Availability of research policies and governance procedures to support palliative care research	61.7	64.6	41.7	87.5
Staff cover	62.4	68.8	45.8	83.3
Collaboration with other centres	63.9	70.8	45.8	83.3
Ongoing research working group at work	60.9	77.1	37.5	83.3
Access to palliative care research recruitment training	57.1	60.4	37.5	83.3
Palliative care research seminars for those in practice	63.2	72.9	50	79.2
Statistics advisor	57.1	64.6	37.5	79.2
Availability of workshops for developing research questions	57.1	66.7	33.3	79.2
Palliative care research mentors' programme	63.9	66.7	45.8	75
Availability of resources such as a guide/manual	63.9	72.9	45.8	75
Assistance with getting started with research	57.9	68.8	41.7	75
Availability of workshops for study design	59.4	66.7	37.5	75
Availability of workshops for writing proposals	59.4	64.6	37.5	75
More exposure to palliative care research as undergraduates	54.9	64.6	37.5	75
Availability of workshops for writing for publication	58.6	62.5	33.3	75
Availability of workshops for statistics	58.6	62.5	37.5	66.7
More exposure to palliative care research e.g. via an internship	61.7	62.5	37.5	62.5
Palliative care research is included as part of my job description	47.4	66.7	33.3	62.5

Facilitators compared across working environment (Comparison on composite score only)



Facilitators	Primary / Secondary Care	Hospice	Non-Clinical Setting
Supportive management	62.2	59	77.5
Palliative care research information network	60.6	64.1	82.5
Attending research conferences	60.6	59	77.5
Collaboration with other centres	60.6	65.4	75
Access to funding to support research	60.6	62.8	75
Availability of resources such as a guide/manual	60.6	64.1	72.5
Staff cover	59.8	64.1	75
Palliative care research mentors’ programme	59.6	64.1	72.5
Access to allocated research staff	59.1	66.7	77.5
Palliative care research seminars for those in practice	59.1	67.9	75
Availability of research policies and governance procedures to support palliative care research	57.5	64.1	75
Access to Patient and Public Involvement (PPI) resources or input	56.7	62.8	80
Ongoing research working group at work	56.7	66.7	77.5
More exposure to palliative care research e.g. via an internship	56.7	59	65
Supportive clinical lead	55.1	65.4	77.5
Availability of workshops for writing proposals	55.1	62.8	72.5
Availability of workshops for study design	55.1	62.8	72.5
Assistance with getting started with research	55.1	60.3	70
More exposure to palliative care research as undergraduates	54.3	55.1	72.5
Availability of workshops for statistics	54.3	60.3	67.5
Availability of workshops for writing for publication	53.5	60.3	72.5
Availability of workshops for developing research questions	52.8	64.1	72.5
Access to palliative care research recruitment training	52	62.8	77.5
Statistics advisor	52	65.4	72.5
Palliative care research is included as part of my job description	48	51.3	62.5

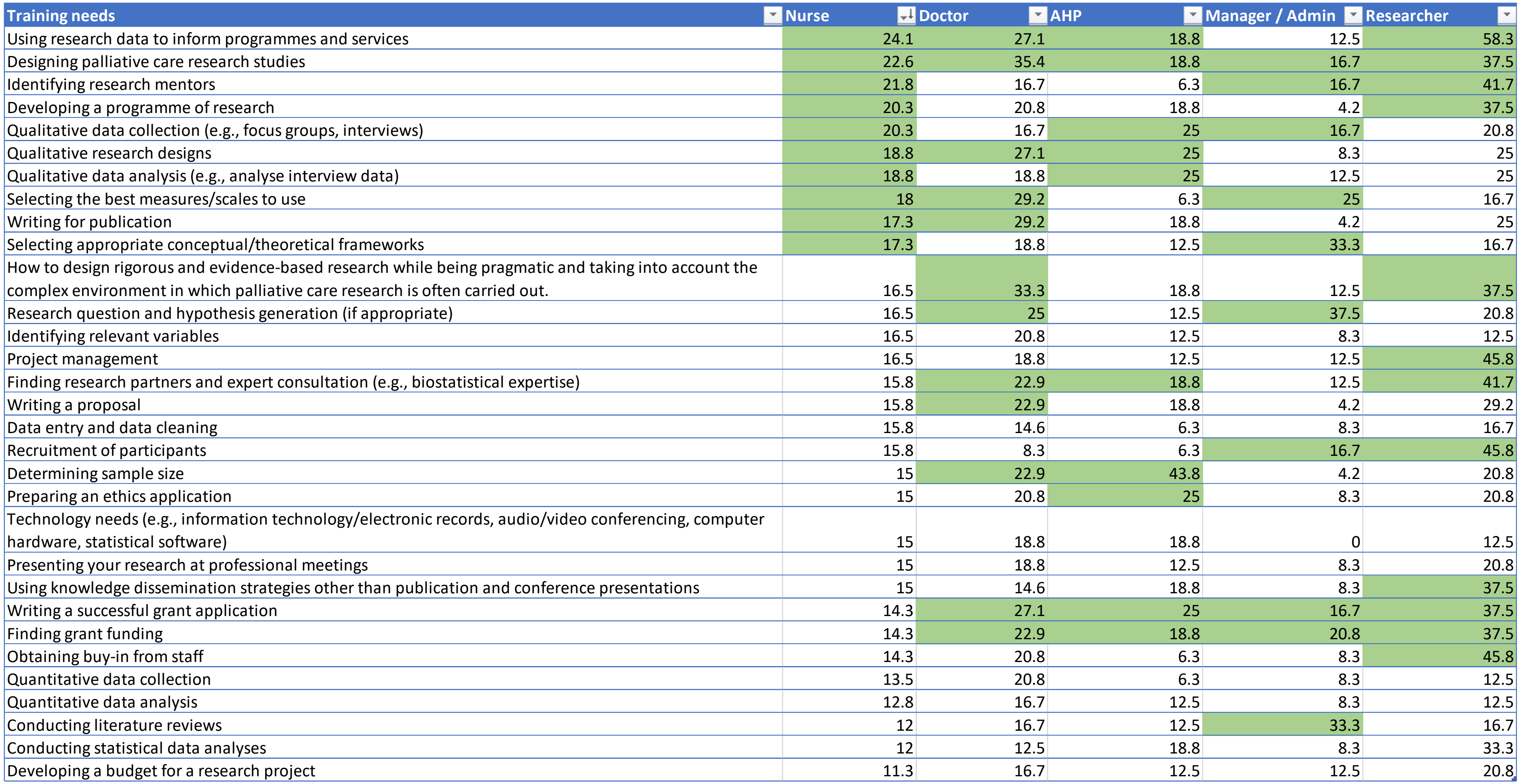
Facilitators compared across time working in palliative care (comparison on composite score only)

Facilitators	<2 years	2 to 5 years	6 to 10 years	10+ years
Palliative care research information network	65.9	56.9	63.9	61.7
Availability of resources such as a guide/manual	65.9	54.9	62.3	60.9
Collaboration with other centres	65.9	60.8	62.3	60.2
Palliative care research seminars for those in practice	63.6	60.8	63.9	60.2
Access to allocated research staff	63.6	52.9	65.6	59.4
Attending research conferences	61.4	58.8	62.3	59.4
Ongoing research working group at work	65.9	54.9	62.3	58.6
Access to funding to support research	63.6	60.8	65.6	58.6
Palliative care research mentors’ programme	63.6	58.8	63.9	58.6
Availability of workshops for developing research questions	61.4	51	50.8	58.6
Availability of workshops for study design	59.1	51	55.7	58.6
Statistics advisor	56.8	49	57.4	58.6
Supportive management	65.9	54.9	67.2	57.8
Availability of research policies and governance procedures to support palliative care research	63.6	54.9	60.7	57.8
Assistance with getting started with research	61.4	51	57.4	57.8
Availability of workshops for writing for publication	61.4	47.1	54.1	57.8
Availability of workshops for writing proposals	59.1	51	57.4	57.8
Access to Patient and Public Involvement (PPI) resources or input	56.9	51	62.3	57
Supportive clinical lead	56.9	51	62.3	56.3
Staff cover	65.9	62.7	65.6	55.5
Availability of workshops for statistics	59.1	47.1	57.4	55.5
More exposure to palliative care research e.g. via an internship	65.9	54.9	55.7	53.9
Access to palliative care research recruitment training	61.4	51	55.7	53.9
More exposure to palliative care research as undergraduates	63.6	56.9	54.1	50.8
Palliative care research is included as part of my job description	54.5	54.9	52.5	41.4

Training needs (full sample)

Training Needs	Missing	Least Interested	Moderatly Interested	Most Interested
Using research data to inform programmes and services	41.3	6.5	56.6	25.6
Designing palliative care research studies	38.9	10.9	27	23.2
Identifying research mentors	41	10.6	26.3	22.2
How to design rigorous and evidence-based research while being pragmatic and taking into account the complex environment in which palliative care research is often carried out.	39.2	11.9	28.3	20.5
Qualitative research designs	38.9	11.6	29.7	19.8
Qualitative data collection (e.g., focus groups, interviews)	41.3	7.5	31.4	19.8
Writing a successful grant application	42.3	17.7	20.1	19.8
Developing a programme of research	41	10.9	29	19.1
Project management	41.3	10.6	29.7	18.4
Finding grant funding	42	19.1	20.5	18.4
Finding research partners and expert consultation (e.g., biostatistical expertise)	41	15.7	25.6	17.7
Writing for publication	42.3	12.6	28	17.1
Obtaining buy-in from staff	38.6	14.7	30	16.7
Recruitment of participants	41.3	8.5	33.8	16.4
Writing a proposal	42	13.7	28	16.4
Preparing an ethics application	42.3	18.8	22.9	16
Selecting the best measures/scales to use	29.2	15	30	15.7
Research question and hypothesis generation (if appropriate)	39.2	14.3	31.4	15
Using knowledge dissemination strategies other than publication and conference presentations	42.7	13.3	29	15
Identifying relevant variables	38.9	17.1	29.7	14.3
Presenting your research at professional meetings	42.3	13.3	30.4	14
Selecting appropriate conceptual/theoretical frameworks	38.9	15	32.4	13.7
Determining sample size	38.9	15.4	32.4	13.3
Quantitative data collection	41.3	12.3	33.4	13
Quantitative data analysis	41.3	15.4	30.4	13
Qualitative data analysis (e.g., analyse interview data)	41.6	18.1	27.6	12.6
Data entry and data cleaning	41.6	18.1	27.6	12.6
Conducting statistical data analyses	42.7	20.1	24.6	12.6
Developing a budget for a research project	42.7	17.4	27.3	12.6
Technology needs (e.g., information technology/electronic records, audio/video conferencing, computer hardware, statistical software)	42.3	14.7	30.4	12.3
Conducting literature reviews	39.2	18.1	32.1	10.6

Training needs compared across roles (Comparison for most interested score only)



Training needs	Nurse	Doctor	AHP	Manager / Admin	Researcher
Using research data to inform programmes and services	24.1	27.1	18.8	12.5	58.3
Designing palliative care research studies	22.6	35.4	18.8	16.7	37.5
Identifying research mentors	21.8	16.7	6.3	16.7	41.7
Developing a programme of research	20.3	20.8	18.8	4.2	37.5
Qualitative data collection (e.g., focus groups, interviews)	20.3	16.7	25	16.7	20.8
Qualitative research designs	18.8	27.1	25	8.3	25
Qualitative data analysis (e.g., analyse interview data)	18.8	18.8	25	12.5	25
Selecting the best measures/scales to use	18	29.2	6.3	25	16.7
Writing for publication	17.3	29.2	18.8	4.2	25
Selecting appropriate conceptual/theoretical frameworks	17.3	18.8	12.5	33.3	16.7
How to design rigorous and evidence-based research while being pragmatic and taking into account the complex environment in which palliative care research is often carried out.	16.5	33.3	18.8	12.5	37.5
Research question and hypothesis generation (if appropriate)	16.5	25	12.5	37.5	20.8
Identifying relevant variables	16.5	20.8	12.5	8.3	12.5
Project management	16.5	18.8	12.5	12.5	45.8
Finding research partners and expert consultation (e.g., biostatistical expertise)	15.8	22.9	18.8	12.5	41.7
Writing a proposal	15.8	22.9	18.8	4.2	29.2
Data entry and data cleaning	15.8	14.6	6.3	8.3	16.7
Recruitment of participants	15.8	8.3	6.3	16.7	45.8
Determining sample size	15	22.9	43.8	4.2	20.8
Preparing an ethics application	15	20.8	25	8.3	20.8
Technology needs (e.g., information technology/electronic records, audio/video conferencing, computer hardware, statistical software)	15	18.8	18.8	0	12.5
Presenting your research at professional meetings	15	18.8	12.5	8.3	20.8
Using knowledge dissemination strategies other than publication and conference presentations	15	14.6	18.8	8.3	37.5
Writing a successful grant application	14.3	27.1	25	16.7	37.5
Finding grant funding	14.3	22.9	18.8	20.8	37.5
Obtaining buy-in from staff	14.3	20.8	6.3	8.3	45.8
Quantitative data collection	13.5	20.8	6.3	8.3	12.5
Quantitative data analysis	12.8	16.7	12.5	8.3	12.5
Conducting literature reviews	12	16.7	12.5	33.3	16.7
Conducting statistical data analyses	12	12.5	18.8	8.3	33.3
Developing a budget for a research project	11.3	16.7	12.5	12.5	20.8

Training needs compared across working environment (comparison for most interested score only)

Training Needs	Primary / Secondary Care	Hospice	Non-Clinical Setting
Using research data to inform programmes and services	22	23.1	45
Recruitment of participants	17.3	10.3	37.5
Finding research partners and expert consultation (e.g., biostatistical expertise)	13.4	17.9	37.5
Project management	18.9	11.5	35
Obtaining buy-in from staff	15.7	11.5	35
Writing a successful grant application	15.7	19.2	32.5
Identifying research mentors	21.3	20.5	30
Developing a programme of research	18.9	16.7	30
Finding grant funding	15	17.9	30
Designing palliative care research studies	21.3	26.9	27.5
How to design rigorous and evidence-based research while being pragmatic and taking into account the complex environment in which palliative care research is often carried out.	17.3	21.8	27.5
Using knowledge dissemination strategies other than publication and conference presentations	13.4	12.8	27.5
Conducting statistical data analyses	8.7	15.4	25
Writing a proposal	17.3	15.4	22.5
Qualitative data collection (e.g., focus groups, interviews)	17.3	21.8	20
Writing for publication	16.5	20.5	20
Qualitative data analysis (e.g., analyse interview data)	15	24.4	20
Qualitative research designs	18.9	25.6	17.5
Presenting your research at professional meetings	16.5	12.8	17.5
Preparing an ethics application	15	17.9	17.5
Data entry and data cleaning	11.8	16.7	17.5
Quantitative data collection	11	17.9	17.5
Developing a budget for a research project	11	14.1	17.5
Determining sample size	12.6	15.4	15
Selecting the best measures/scales to use	16.5	19.2	12.5
Technology needs (e.g., information technology/electronic records, audio/video conferencing, computer hardware, statistical software)	15	14.1	12.5
Research question and hypothesis generation (if appropriate)	14.2	19.2	12.5
Identifying relevant variables	13.4	17.9	12.5
Selecting appropriate conceptual/theoretical frameworks	12.6	16.7	12.5
Quantitative data analysis	9.4	19.2	12.5
Conducting literature reviews	10.2	14.1	10

Training needs compared across time working in palliative care (comparison on most interested score only)

Training Needs	<2 years	2 to 5 years	6 to 10 years	10+ years
Recruitment of participants	25	9.8	24.6	10.9
Designing palliative care research studies	20.5	19.6	23	25.8
How to design rigorous and evidence-based research while being pragmatic and taking into account the complex environment in which palliative care research is often carried out.	18.2	19.6	18	22.7
Qualitative research designs	18.2	17.6	16.4	24.2
Identifying research mentors	15.9	23.5	19.7	24.2
Selecting the best measures/scales to use	15.9	13.7	14.8	17.2
Obtaining buy-in from staff	15.9	11.8	18	18
Project management	13.6	19.6	34.4	16.4
Using research data to inform programmes and services	13.6	17.6	31.1	31.3
Preparing an ethics application	13.6	15.7	18	15.6
Writing a successful grant application	13.6	13.7	23	23.4
Finding research partners and expert consultation (e.g., biostatistical expertise)	13.6	13.7	16.4	21.1
Research question and hypothesis generation (if appropriate)	11.4	17.6	9.8	18
Qualitative data analysis (e.g., analyse interview data)	11.4	13.7	23	21.9
Qualitative data collection (e.g., focus groups, interviews)	11.4	13.7	18	24.2
Identifying relevant variables	11.4	13.7	14.8	15.6
Data entry and data cleaning	11.4	11.8	13.1	12.5
Technology needs (e.g., information technology/electronic records, audio/video conferencing, computer hardware, statistical software)	11.4	7.8	13.1	15.6
Finding grant funding	9.1	11.8	24.6	21.9
Writing for publication	9.1	11.8	24.6	18.8
Using knowledge dissemination strategies other than publication and conference presentations	9.1	9.8	21.3	15.6
Quantitative data analysis	9.1	9.8	19.7	11.7
Conducting literature reviews	9.1	9.8	8.2	12.5
Developing a budget for a research project	9.1	7.8	18	14.1
Determining sample size	9.1	7.8	13.1	17.2
Quantitative data collection	9.1	5.9	14.8	14.1
Developing a programme of research	6.8	23.5	19.7	21.1
Presenting your research at professional meetings	6.8	13.7	19.7	14.1
Conducting statistical data analyses	6.8	7.8	16.4	14.8
Writing a proposal	4.5	15.7	19.7	19.5
Selecting appropriate conceptual/theoretical frameworks	1.4	11.8	9.8	17.2