Palliative Care Research Partnership North West Coast
(PalCaRe NWC)

Barriers, Opportunities and Resources for Hospice Engagement in Research

Catherine Walshe

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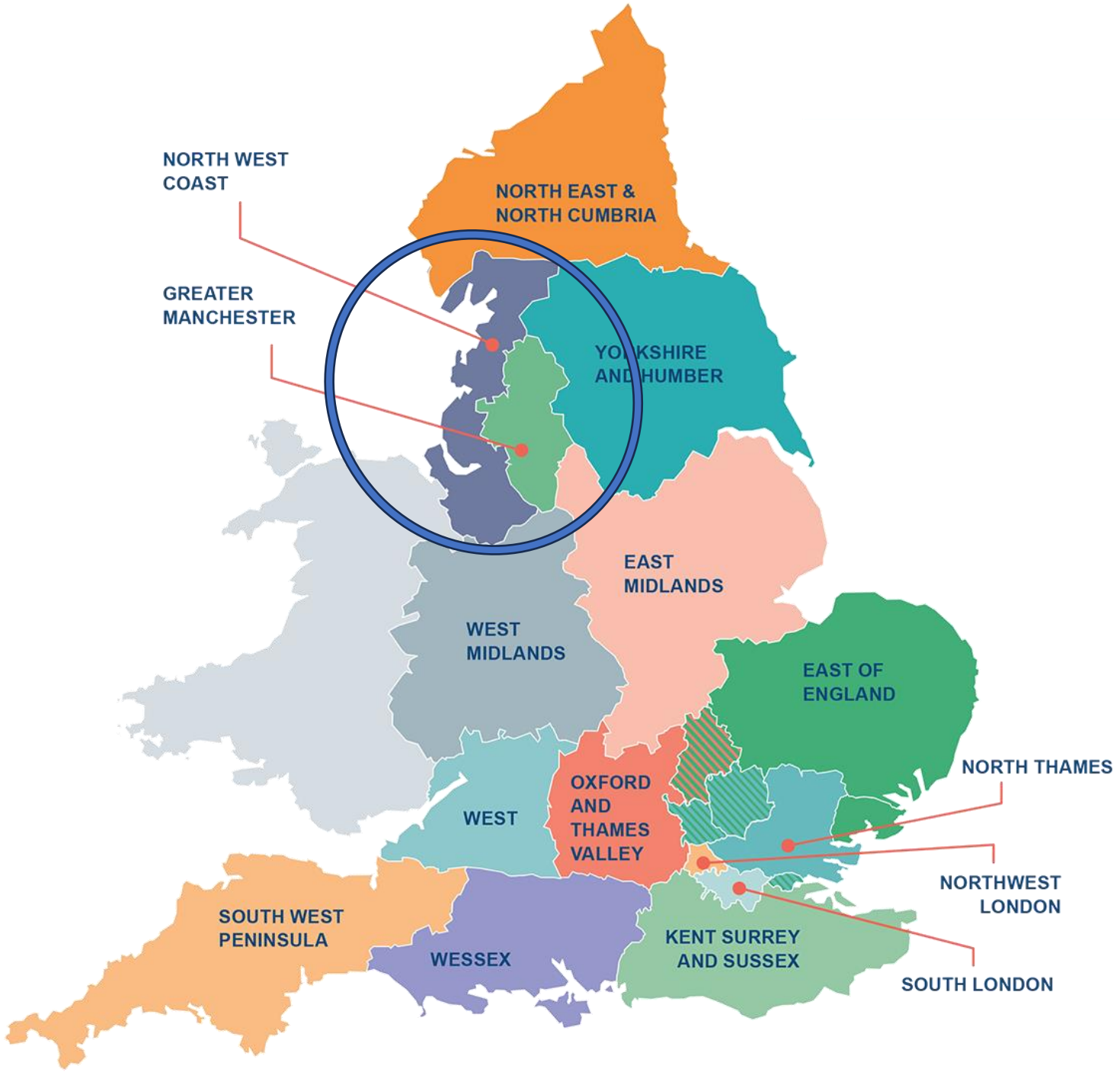
NORTH WEST COAST
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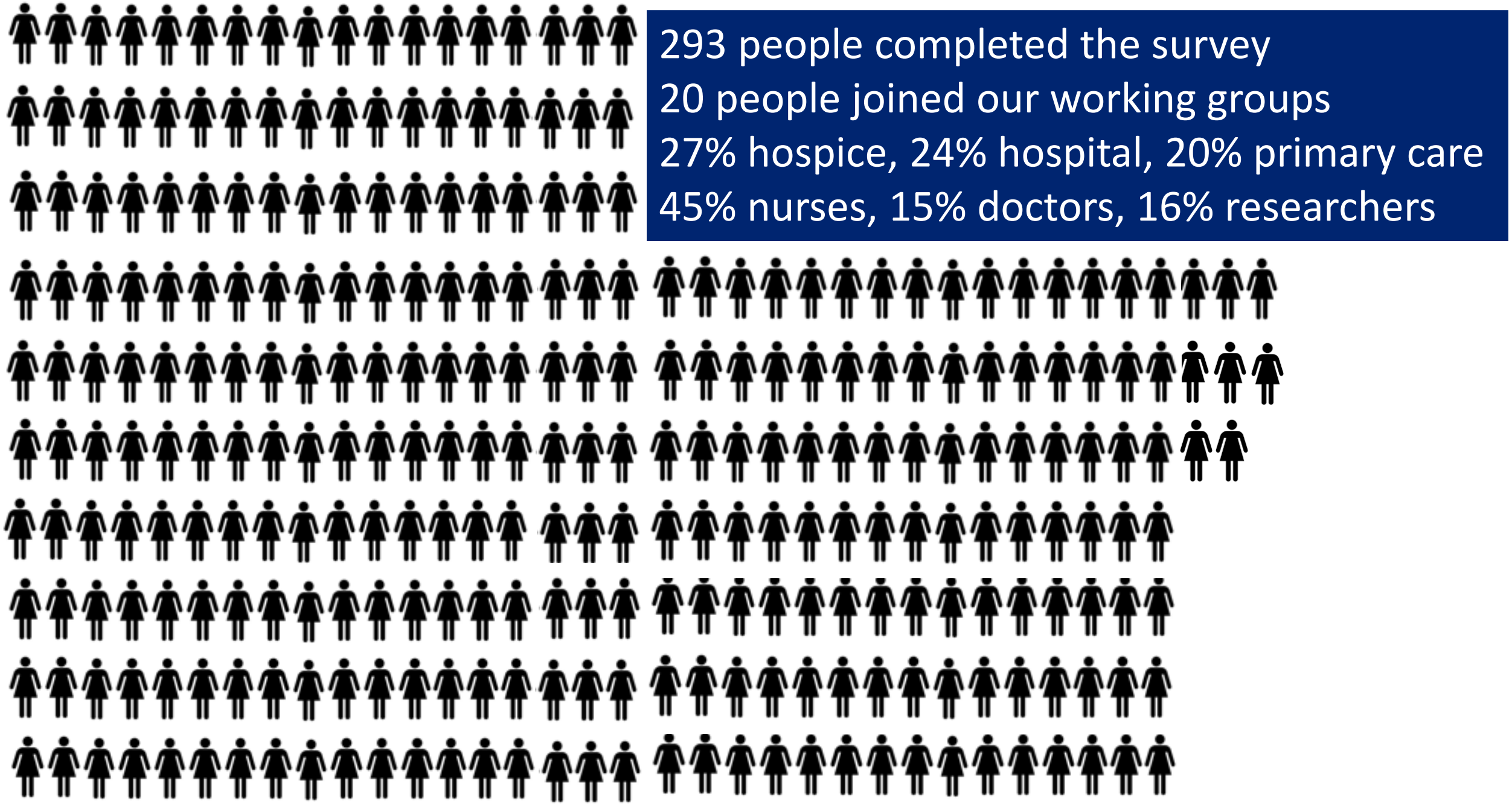
GREATER MANCHESTER
YORKSHIRE AND HUMBER
EAST MIDLANDS
WEST MIDLANDS
EAST OF ENGLAND
NORTH THAMES
OXFORD AND THAMES VALLEY
WEST
NORTHWEST LONDON
SOUTH WEST PENINSULA
WESSEX
KENT SURREY AND SUSSEX
SOUTH LONDON



293 people completed the survey
20 people joined our working groups
27% hospice, 24% hospital, 20% primary care
45% nurses, 15% doctors, 16% researchers

Organisational culture and capacity

Research knowledge

Research infrastructure

Patient and public perceptions

Rank	Survey ranking (% respondents who indicated this was a moderate or significant barrier)	Working group 1 ranking	Working group 2 ranking	Working group 3 ranking	Working group 4 ranking
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

Organisational culture and capacity	Research knowledge	Research infrastructure	Patient and public perceptions of 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 backfill needed for clinical position	Cost to the organisation of being involved in palliative care research
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

Organisational culture and capacity	Research knowledge	Research infrastructure	Patient and public perceptions of research

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]

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

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.

Research knowledge

Action Learning Sets (x3)

Hospice Research Resources now available https://sites.google.com/nihr.ac.uk/palcarenwc/hospice-research-resources

Presentations at national conferences

Research infrastructure

Networking events (Jan, June 23, Jan 24 – next July24)

Research Development Groups (focused on Heart Failure, Paediatrics, Education)

PhD student group

Palliative Care Research Partnership North West Coast (PalCaRe NWC)

Marie Curie

Sue Ryder

Because no one should face death or grief alone

hospice UK

LOROS Palliative and End of Life Care
RESEARCH EDUCATION INFLUENCING PRACTICE
CENTRE FOR EXCELLENCE

International Observatory on End of Life Care | Lancaster University

Hospice Research Resources

Whether you are just starting out in hospice research, or have experience being involved in studies, understanding how to plan and conduct a study can be difficult. The purpose of these 'bitesize' resources is to help you to quickly find accessible information. These resources have been specifically written for people working within UK hospices.

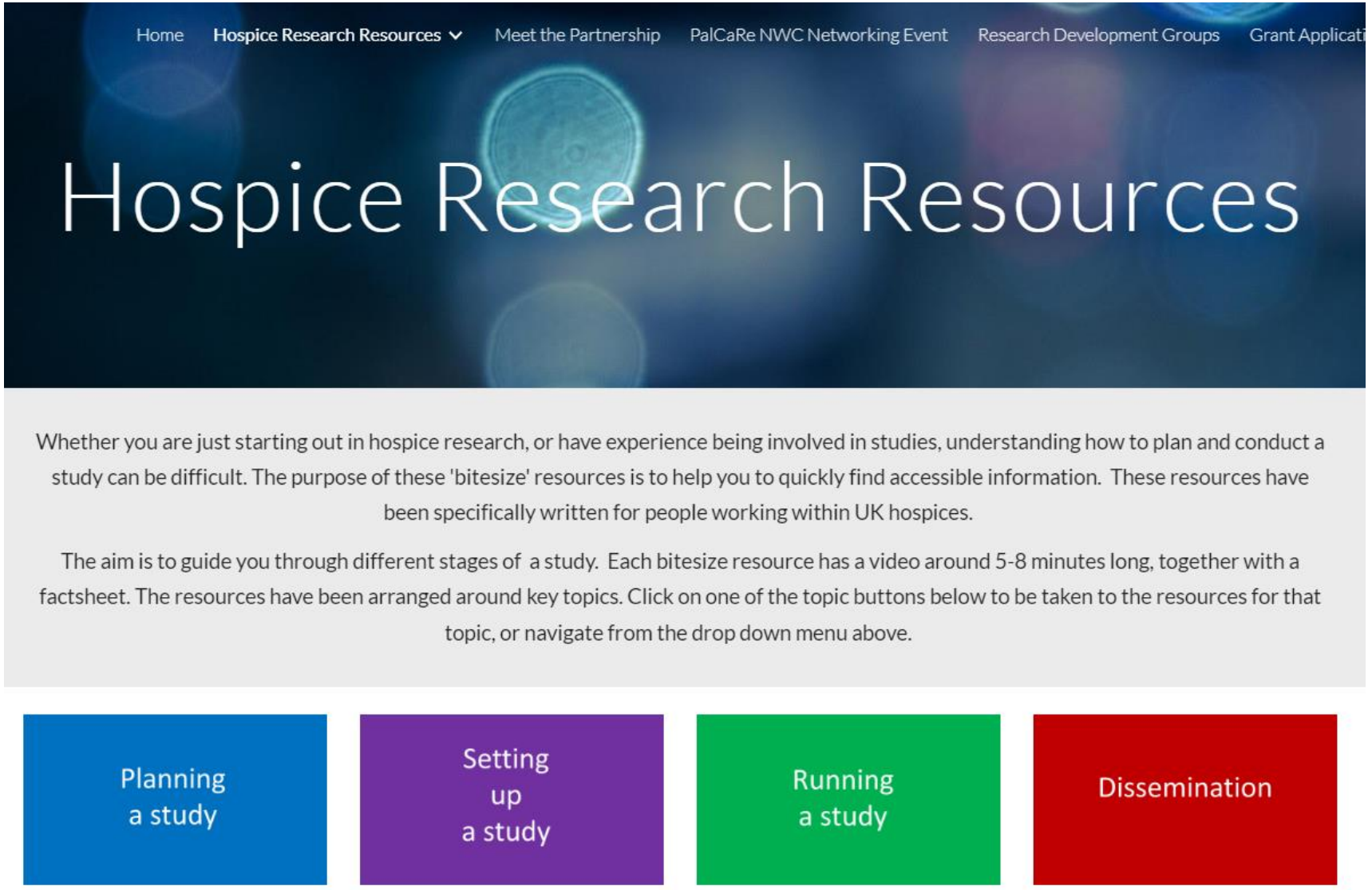
The aim is to guide you through different stages of a study. Each bitesize resource has a video around 5-8 minutes long, together with a factsheet. The resources have been arranged around key topics. Click on one of the topic buttons below to be taken to the resources for that topic, or navigate from the drop down menu above.

Planning a study

Setting up a study

Running a study

Dissemination



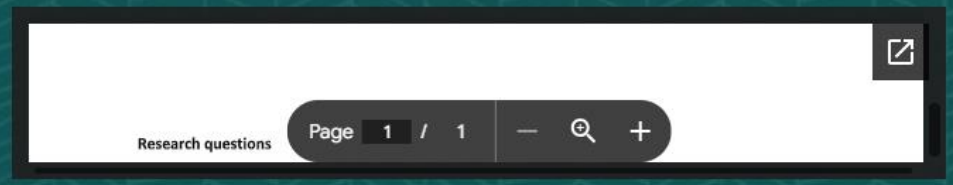
https://sites.google.com/nihr.ac.uk/palcarenwc/hospice-research-resources

Planning a study

On this page there are a number of different resources focused on how to design and plan a study. Other resources are linked to from our page on Hospice Research Resources. Each bitesize resource has a video around 5-8 minutes long, together with a factsheet.

Research Questions

In this video Professor Catherine Walshe from the International Observatory on End of Life Care at Lancaster University talks about research questions as the building blocks of good research. (8 minutes). Click on the word document below for FAQs about research questions. Uploaded 21.1.24

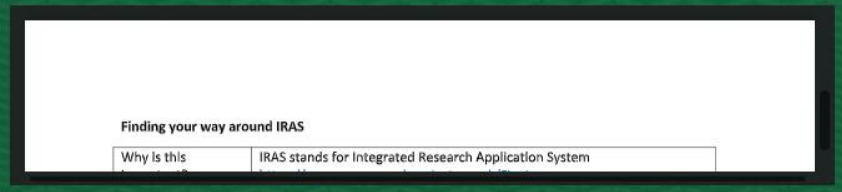


https://sites.google.com/nihr.ac.uk/palcarenwc/hospice-research-resources/planning-a-study

Setting up a study

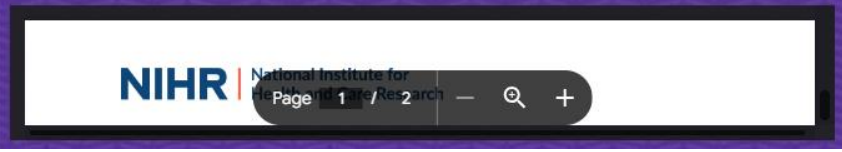
Finding your way around IRAS

In this video Dr Lesley Dunleavy from the International Observatory on End of Life Care at Lancaster University talks about finding your way around the IRAS system (5minutes). Click on the word document below for FAQs about the IRAS system. Uploaded 4.2.25



The Clinical Research Network and portfolio adoption

In this video Jo Bagshaw from the Clinical Research Network talks about the CRN and portfolio adoption (6 minutes). Click on the word document below for FAQs about the CRN and its portfolio. Uploaded 4.2.24.24

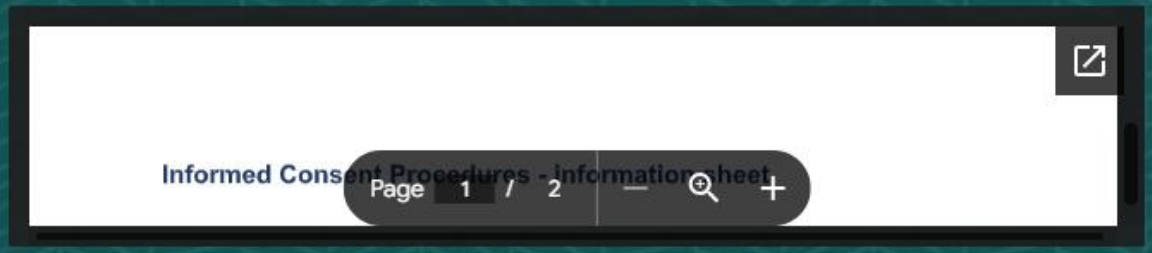


Running a study

On this page there are a number of different resources focused on how to run a research study. Other resources are linked to from our page on Hospice Research Resources. Each bitesize resource has a video around 5-8 minutes long, together with a factsheet.

Informed consent

In this video Anne Parkinson from Sue Ryder talks about informed consent. (8 minutes). Click on the word document below for FAQs about informed consent. Uploaded 4.2.24

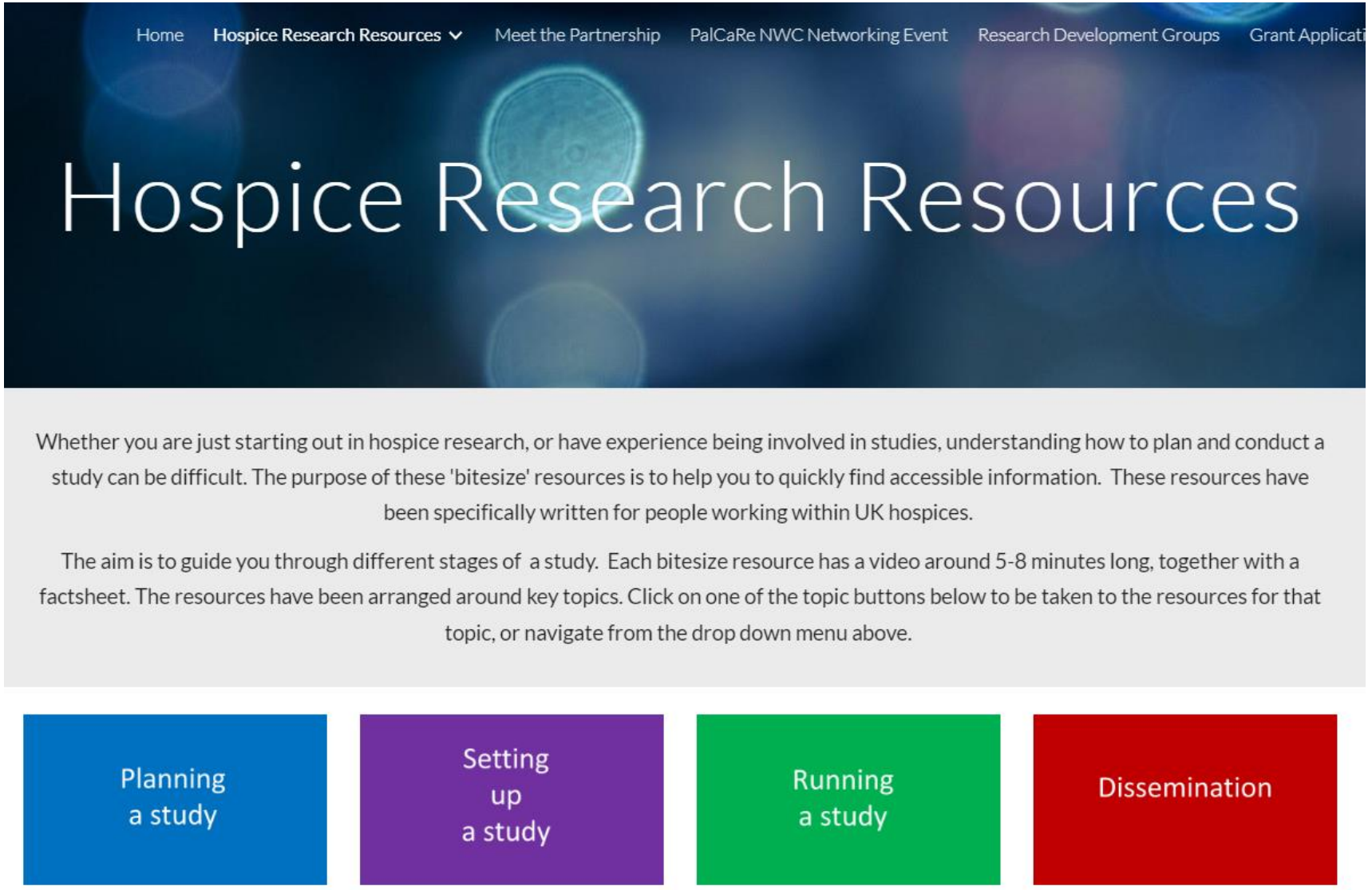


Dissemination

On this page there are a number of different resources focused disseminating findings from a research study. Other resources are linked to from our page on Hospice Research Resources. Each bitesize resource has a video around 5-8 minutes long, together with a factsheet.

Writing for publication

In this video Professor Jonathan Koffman from the Wolfson Palliative Care Research Centre at Hull York Medical School talks about writing for publication. This is a narrated PowerPoint so the link takes you to a resource to download. (10 minutes).



https://sites.google.com/nihr.ac.uk/palcarenwc/hospice-research-resources

Palliative Care

PhD

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2024

Duration
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https://www.lancaster.ac.uk/study/postgraduate/postgraduate-courses/palliative-care-phd/2024/