

Developing a research strategy in a hospice in England

It is crucial that hospices play their part in palliative care research. But how should they go about it?

Elizabeth Reed and **Jennifer Todd** describe the research strategy developed through organisational consensus at Princess Alice Hospice in the county of Surrey in England

There are compelling arguments why hospices should be active in palliative care research. The most persuasive is that, as with all other healthcare settings, hospices need to show that they are providing evidence-based treatment and care.¹

So far, research in hospices has been predominantly biomedical, with less attention being paid to psychosocial care, current practice and models of care.² Under pressure to do more research, hospices need to look at how to build their research capacity, explore ways to conduct research in partnership with others, and understand what they need to have in place to be able to generate research themselves. Hospices are often considered centres of excellence in end-of-life care, but it is important for them to embrace a culture of inquiry and understand the changing needs of the communities they serve.

One argument often used against research in end-of-life care is that patients are vulnerable and unlikely to benefit from the outcomes of research. In reality, given the opportunity, many patients and carers are

keen to participate in research, even in the final phase of life. It could be argued that not offering them the opportunity to participate in research negates their right to make their own decisions about participation and make their voices heard.

Williams *et al* found that 46% of hospice patients expressed an interest in research,³ citing reasons such as helping their doctor, potentially benefiting from improved care or an improvement in their symptoms, achieving a sense of purpose, and contributing to science.

Developing a strategy

In 2013, Princess Alice Hospice in Esher, England, recruited a research lead to develop research across the organisation. The research framework for hospices developed by Payne *et al* sets out three levels of research participation (see Figure 1).² Princess Alice Hospice was at 'level 2' and aspired to be at 'level 3'. The hospice had previously supported several members of staff who had undertaken research as part of a master's degree. It had also worked on a range of studies with external researchers (who had recruited patients for both national and local network studies), as well as with pharmaceutical companies.

Our aim was for research to become an integral part of the organisation. We started by establishing a research strategy alongside the hospice's five-year strategy. The strategy was developed using a collaborative approach in order to encourage hospice staff from as many different disciplines as possible to engage with research.

Determining priority areas

A half-day workshop was organised for staff to work together to achieve a consensus on

Key points

- There are many reasons why hospices should be active in palliative care research, one of them being the need for them to show that they are providing evidence-based treatment and care.
- In 2013, Princess Alice Hospice in England developed a research strategy and has now started generating its own research projects.
- A strategic approach to conducting research in hospices involves identifying priority areas, setting up project steering groups, engaging staff and service users, creating a research governance infrastructure and establishing external partnerships.
- Hospices who want to become research-active will face challenges such as patient vulnerability, attrition, staff training, gatekeeping and lack of attractiveness to academics and grant providers.

priority areas for research development at the hospice over the next three to five years. Senior managers identified one or two members from their respective departments who would participate in the workshop, and all hospice staff were offered the opportunity to take part on a voluntary basis.

The research lead undertook a rapid appraisal of the literature on psychosocial research in palliative care over the past ten years, and this was sent to participants ahead of the workshop.

Eighteen members of staff from different teams and disciplines attended the workshop (see Figure 2). Participants worked in three multidisciplinary groups to identify and discuss potential research priorities.

Six areas were identified:

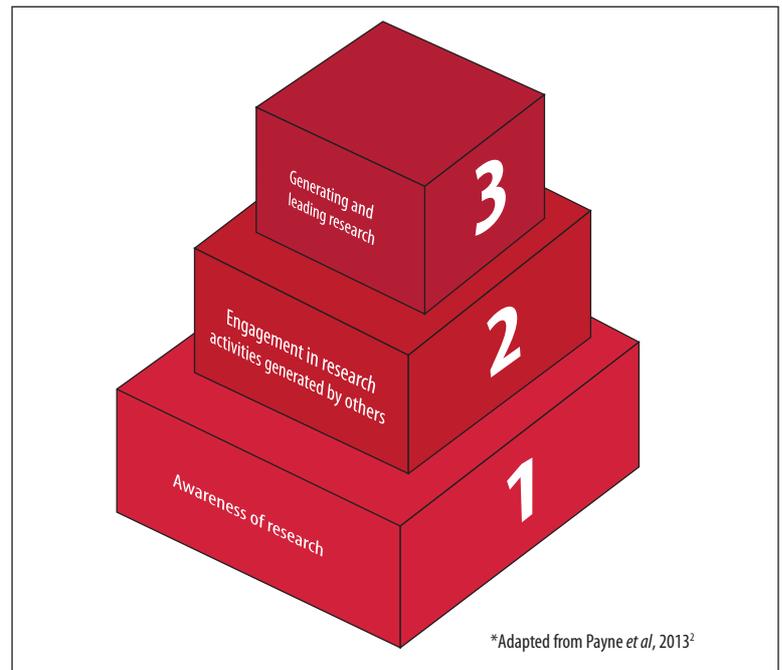
- health promotion and palliative care
- older people
- non-malignant disease
- partners and families
- models of care
- education.

From a total of 100 points, each group was asked to allocate a certain number of points to each of the six key areas, with the aim of assigning a relative value to each. Through discussion and debate, a consensus was established and three priority areas for research emerged:

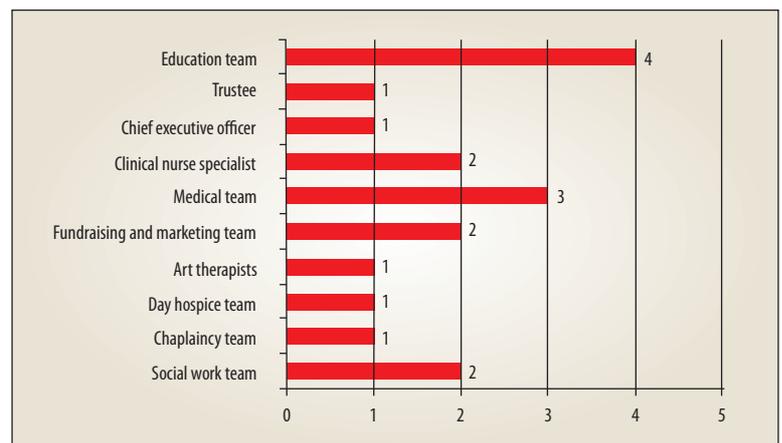
- partners and families
- health promotion and palliative care
- non-malignant disease.

'Education', 'older people' and 'models of care', which had been identified as potential key areas, were found to be overarching themes that would be covered within each research priority.

A multidisciplinary project steering group was set up for each of the three identified research priorities, with representation from across the organisation, including people who had either expertise or a special interest in the subject area. Some staff members joining these project steering groups had never been involved in research before. The 'partners and families' steering group, for example, is formed of a ward nurse, a community specialist palliative care nurse, two doctors, an occupational therapist, a social worker and a user representative; among them, only three people (one of the nurses, one of the doctors and the social worker) had any previous research experience.



■ Figure 1. Research framework for hospices*



■ Figure 2. Number of workshop participants according to discipline or team

Engaging the whole organisation

The workshop was also used to improve staff's awareness of research and convince the senior management team and clinical staff of the importance of developing an organisational culture that values research. The research lead explained the potential benefits of research for patients, for staff development and for the reputation of the organisation.

From the conception of a research question to the collection, analysis and publication of data, good research takes time. Hence there may be a discrepancy between service development and research, the former happening before the latter is complete. It is essential to ensure that everyone in the organisation, including trustees and senior managers, have realistic expectations and fully

understand the value of supporting robust and well-run research activity.

We presented our research strategy to the senior management team, who support the initiative. We also presented it to staff from across the organisation, in an effort to engage all with our research activity.

Furthermore, to foster staff's engagement and encourage a culture of inquiry, we:

- encourage and support staff to present their work to others
- hold monthly research seminars where internal staff and external researchers present their work
- encourage staff to participate in projects undertaken by external researchers
- disseminate a quarterly newsletter with information about the hospice's research activity
- run a journal club
- provide training on searching research evidence databases.

Ensuring robust governance

For hospices to generate and lead research, they need to have robust, clear and transparent research governance in place. The necessary infrastructure includes a research committee, terms of reference, appropriate indemnity cover and standard operating procedures. This can be challenging for small organisations outside the NHS or larger research bodies.¹

With this in mind, Byrne *et al*⁴ have created an extremely useful web-based research governance toolkit for hospices, which provides practical guidance on the roles, responsibilities and processes that need to be in place before a hospice embarks on any research activity (www.nischcancer.org/research/).

Princess Alice Hospice has a research committee that meets quarterly and is responsible for research governance and the quality of all research, whether it is generated by the hospice or conducted in partnership with external researchers. The committee is chaired by the medical lead for research and is composed of members of the senior management team, all clinical departments and the education department.

As we were starting to generate our own research, the committee decided to expand in

order to bring additional scrutiny and rigour to all projects, and it has recently recruited two academics from local universities and two lay members. The two lay members have experience of caring for a relative at the end of life and an interest in hospice research.

Involving service users

Payne *et al* highlighted the importance of involving service users and the public in helping to shape the research agenda, as their priorities may differ from those of professionals and managers.² To be meaningful, this needs to be integral to the entire process, from the conception of a research idea to the dissemination of findings.⁵ As we were forming our project steering groups, we were aware of the importance of involving users. Going forward, each steering group will include a user who has meaningful experience of the area being researched; for example, the 'non-malignant disease' steering group is undertaking a research project in dementia care and will involve a user whose husband died from dementia in a care home.

We have also consulted local groups – for example, a support group for bereaved relatives of people who died of dementia – to discuss our research approach and inform the early development of projects.

Overcoming cultural barriers

Many papers in the palliative care literature document the numerous challenges in conducting research, with common themes emerging.⁶ There are many reasons why undertaking research in a hospice setting can be difficult: the culture and ethos of

hospices are not always conducive to research; hospices have less experience in undertaking or initiating research, and are less likely to have the governance structures in place; the patient population is potentially vulnerable; and so on.

To successfully conduct research in a palliative care population, one must:

- ensure that the research question is specific
- use appropriate methods
- establish clear inclusion and exclusion criteria
- define an appropriate sample size
- have realistic expectations of attrition.⁷

Another significant challenge has been accessing research grants and funding

Another challenge is to provide the necessary training – for example, in good clinical practice – to all research-active staff.

Paternalism and ‘gatekeeping’ attitudes of healthcare professionals in relation to inviting patients and families to participate in research is also a challenge. In our experience, this needs to be addressed proactively and sensitively, with an awareness of the many levels at which this can occur – such as local research ethic boards, medical staff, hospice staff, and family and carers themselves.

Seeking external partnerships

Hospices are often working in isolation, and they can benefit from research partnerships with the NHS or academic institutions. We are developing partnerships with our local academic research centres to provide us with expertise and supervision. We have had a mixed response from academics, as research in hospices tends to be small-scale and is therefore unlikely to attract significant grants or funding. While we may be ambitious from a hospice’s point of view, we may also be too small from an academic institution’s perspective. But we have been successful in gaining the support of an academic to work with us on one of our projects – this academic has experience of the methodology we are planning to use for this study.

We are also keen to undertake research with other hospices in our network. This would allow us to be mutually supportive; to share statistical, methodological and research design expertise; and to work jointly on projects. Each hospice would gain access to larger populations of patients and staff.

Attracting grants and funding

Another significant challenge has been accessing research grants and funding. Researchers in independent organisations such as hospices can find themselves inadvertently competing for funding with their fundraising colleagues, so good communication between departments is essential. A hospice with little record of previous research or publications may be considered too high-risk for funders, who want reassurance that their money will be well spent. Payne *et al* recommended that hospices should consider funding their own research in the early stages in order to build a research portfolio, which will make them more

attractive to academic institutions and grant providers in future.²

Our current projects

Since the launch of our research strategy in 2013, we are actively encouraging others to undertake their research with us, and we have initiated a project in each of our priority areas:

- a study exploring what services influence the care of people with dementia in the last year of life
- an evaluation of an exercise intervention in the day hospice
- in collaboration with a university, a study exploring the experiences of families with young children to co-design and test an intervention, for which we are currently seeking funding.

Conclusion

Almost three years into our first research strategy, we have made significant progress towards our goal of becoming a ‘level 3’ research-active hospice, but we are still very much learning and developing. Adopting a strategic approach – which involved identifying priority areas, setting up project steering groups, engaging staff and service users, creating a robust governance infrastructure and establishing external partnerships – allowed us to move from participating in research generated by others to generating our own research. Alone, we are a small organisation, but through collaboration with others (NHS trusts, academics, palliative care colleagues and service users), we can aspire to become a research-active organisation.

Declaration of interest

The authors declare that there is no conflict of interest.

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