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How to conduct research in an independent hospice: practical tips and advice

Independent hospices can – and should aim to – participate in palliative care research, say **Paul Perkins, Rebecca Day, Julie Hapeshi, Lorraine Dixon** and **Rudo Nyakuhwa**, who give tips and advice based on their experience at Sue Ryder

Like other healthcare services, hospices should provide the best treatments for patients and their families. The only way to find out what those best treatments are is through research. However, conducting research in hospices can be challenging, as they are often relatively small organisations inexperienced in overcoming the usual barriers.

Engaging in research activity can be particularly problematic for independent hospices, which are outside the safety of the NHS and face the added challenge of indemnity and ensuring essential governance arrangements are in place. Nonetheless, hospices, as centres of excellence, have a duty to drive and initiate research if they are to provide high-quality palliative care for patients and families.

Sue Ryder is an international charity which runs six specialist neurological centres and seven specialist palliative care units in the UK. Ten years ago, the charity had little experience of research participation and there were no governance structures in place to support research. Getting approvals for projects was a challenge for all concerned.

Key points

- Conducting research in hospices – particularly independent hospices – can be challenging, as they are often relatively small organisations inexperienced in overcoming barriers to research.
- Despite the apparent hurdles, it is possible to create a research culture in an independent hospice.
- Staff will need to engage with people both within and outside the organisation to allow research to flourish.
- It will take time for research to be seen as part of the hospice's core business and perseverance is, therefore, vital.

Today the charity is keen to promote research. The Sue Ryder Research Governance Group (RGG) meets monthly to discuss any project that is being considered by one of its centres. These could be homegrown projects or projects from external organisations that want to work with us. The RGG has devised a policy and guidance to support researchers through the process.

In this paper, we aim to use our experience at Sue Ryder to provide some insight into how independent hospices can become active in conducting research.

Why should hospices do research?

There are compelling reasons to conduct research in hospices. Many of them are outlined in a useful publication by Payne *et al* for Help the Hospices.¹

Hospice patients deserve to have the best and evidence-based treatment. Evidence gained through research is vital to demonstrate cost-effectiveness and help negotiations with commissioners.

A research-active hospice may be more likely to attract and retain high-quality staff.

Patients do want to participate.^{2,3} When there might be little else that they can do, they may see it as something worthwhile that might help other people in the future. The NHS Plan suggests that participation in research should be offered to all patients.

It could also be argued that hospices, like other healthcare settings, have a duty to contribute to research.⁴ This could be by:

- Conducting research
- Finding patients and signposting them to researchers
- Freeing up time for researchers
- Providing infrastructure or finance.

Payne *et al* also described several potential barriers to conducting research in hospices, which are summarised in Box 1.¹

How to begin to create a research culture in an independent hospice

Generating ideas

To generate research ideas, hospice staff need to make time for research and integrate it into their everyday work. This could be done by running journal clubs, reading widely, attending conferences or inviting experts to do a presentation for small groups of staff.

It also helps to identify the problems patients are faced with each day and prioritise those whose resolution will make a difference to patients, families and carers.

You can perform literature searches to see if there is evidence about the best way of managing a particular problem. Medical librarians are often better at conducting literature searches than clinicians.⁶ It is a good idea to seek out your local hospital librarian, talk to them about the clinical problem and learn from them how to conduct searches – they might even do them for you.

Thinking of a research question

The research question will depend on the problem being addressed. It is always more relevant when it emerges from practice. The type of question will often induce the research methodology you need to use to investigate it; for example, if you are asking ‘What is happening now?’, this can be investigated with a survey of healthcare professionals. A question such as ‘What are the experiences of people living with a problem?’ can be investigated using qualitative methods. If you are asking ‘Which treatment is better?’, a randomised controlled trial might be the best methodology.

Building a team

A research team can be built from local people interested in research; this includes staff from neighbouring hospices. The Palliative Care Research Society (www.pcrs.org.uk) or the European Association for Palliative Care (www.eapcnet.eu) may be able to advise on useful contacts. In addition, national or international experts may be willing to collaborate. Authors of research papers are usually happy to have an email conversation about their research, preferably with someone

Box 1. Potential barriers to conducting research in hospices¹

- The absence of a pre-existing research culture or staff not being appropriately trained
- The absence of good relationships with potential NHS or university partners
- A lack of time and infrastructure
- Limited funding
- Professional gatekeeping
- Concerns around governance and indemnity, and a lack of systems in place to manage them
- Methodological issues; for example, outcome measurement and attrition⁵

who has read their papers. Remember, conducting research on your own is impossible and undesirable – collaborate as much as possible.

Gaining management support

To embed research into the hospice’s strategy and ensure it is seen as core business, it is vital to have the support of the management. Managers may need persuading about the benefits of conducting research; points to stress include the potential benefits to patient care; how a culture of research will enhance job satisfaction and staff retention; and how research can improve the organisation’s reputation as a centre of excellence. It is a good idea to present an action plan describing how you will develop the research culture.

To generate research ideas, hospice staff need to make time for research

Developing the necessary infrastructure

Initiating research does not have to be expensive, but identifying specific funding to support research is more likely to lead to success. Trusts and charities may be able to provide money to support research; for example, they may support dedicated research nurse time to start developing research activity. Studies being conducted by external bodies or pharmaceutical companies may be looking for potential research centres, so it is worth investigating whether your hospice can apply to be involved in one of these.

Training

If hospice staff are inexperienced in research, they may need training. In the UK, the local NHS trust’s research office should be able to provide support and guidance about training opportunities. Potential areas include:

- Training in research design and methodology to help write and/or comment on research protocols
- Training to write bid proposals to secure funding for projects
- Good Clinical Practice (GCP) training, which will guide staff in how to conduct trials – in particular, adverse event reporting
- Training in the processes for obtaining informed consent. This is particularly useful where capacity is limited, as the issues are slightly different in research participation than in clinical practice.

Volunteering for studies

You should consider participating in external research. This helps to create a climate where research is seen as normal business. The UK Clinical Research Network portfolio is a good source of opportunities to get involved in studies.⁷ Local or national colleagues may also be able to point organisations looking for research centres in your direction if they are aware of your interest.

Finding a sponsor for your research idea

Finding a sponsor for a research idea is a crucial step – and a requirement of research governance. The sponsor is often thought to be the organisation that pays for the research, but the sponsor and funder can be different. The sponsor is responsible for the governance of research from conception to

final completion – design, management and finance – and has to satisfy itself that appropriate checks have been undertaken.^{8,9}

A sponsor should conduct a risk assessment for the research, asking the following:

- Is the study scientifically sound? Has it been peer-reviewed?
- Are the chief investigator and host organisation competent to conduct the research?
- Has the research team had appropriate training in research methods and GCP?
- How will the study be audited and monitored?

The sponsor is legally responsible for:

- Requesting clinical trial authorisation and ethics approval
- Allowing inspection of premises by the Medicines and Healthcare Products Regulatory Agency (MHRA) if required

- Training
- Responsibilities
- Study files and filing
- Screening
- Consent
- Case record form completion
- Audit
- Archiving
- Adverse event reporting
- Site initiation visits
- Monitoring
- Study close down

Box 2. What standard operating procedures for research should cover

- Giving notice to the MHRA and ethics committee of amendments to the protocol or when the trial has ended
- Keeping records of all adverse events reported by investigators
- Ensuring suspected unexpected serious adverse reactions (SUSARs) are recorded and reported promptly
- Ensuring all investigators, including those at other sites, are informed of SUSARs
- Ensuring all SUSARs are entered into a European database
- Providing an annual list of SUSARs and a safety report
- Ensuring indemnity insurance is in place.

It is unlikely that the hospice itself will want these responsibilities, particularly for research involving drugs. Some hospices may feel able to undertake sponsorship of low-risk research projects (for example, some qualitative studies or studies involving healthcare workers only) if they have sufficient experience of research participation. If you need to look elsewhere for research sponsorship, talk to your local NHS trust's research management and governance manager or your local university.

Taking legal advice

It is sensible to involve a legal adviser early in the process, to ensure the right agreements are in place, especially if there are likely to be questions concerning intellectual property.

Putting in place indemnity insurance

When planning research, it is advisable to talk to the hospice's insurers about the kind of research you want to conduct. They may have a skewed view of what research involves and may not be aware that not all research is high-risk.

It will take time for research to be seen as a core part of hospices' business

A risk assessment, with identified controls, will help to demonstrate the magnitude of the risk. If what you are planning does not vary much from standard practice, there may not be any additional cost.

There is sometimes concern about cover for non-negligent harm. This will usually be covered by existing hospice insurance. Researchers should talk to their own indemnity provider about the fact they are participating in research.

Updating staff contracts

Personnel engaged in research should have this covered in their employment contract, or have an appropriate honorary contract in place. You will need to discuss this with the hospice's human resources department.

Establishing a governance framework

The hospice will need to set up processes for examining research proposals. The Department of Health's *Research governance framework for health and social care* is a useful starting point to learn how to do this.⁸ The National Institute for Social Care and Health Research has put together a research governance toolkit which could be helpful.¹⁰

It may also be helpful to ask an external research expert to be part of this process, or to establish a partnership with a local hospital or university – it may be possible to adapt their approval processes to fit your purposes.

At Sue Ryder, the RGG is fortunate that the Associate Director of Research and Development from the Gloucestershire NHS research consortium has played an active role in providing external scrutiny of research. We also have representation from the Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care.

Governance questions to consider include whether it is appropriate for your hospice to participate in a particular research project, and whether necessary items are in place before it starts; for example, ethical approval, sponsorship, indemnity cover and contracts.

Drawing up standard operating procedures

Standard operating procedures are needed to give staff guidance on how to do research on a day-to-day basis. Box 2 lists what they should cover. Your local NHS trust's research management and governance manager may be willing to share their procedures.

Conclusion

Over the last ten years, Sue Ryder has participated in a number of projects, from external qualitative projects to homegrown randomised controlled trials of drugs. There have been challenges, but the organisation's attitude is that, just because something is difficult does not mean it should not be done.

It will take time for research to be seen as a core part of hospices' business and not all staff will understand why it is being introduced. Perseverance is, therefore, vital if hospices are to develop a research culture and continue to lead in providing high-quality palliative care for patients and families.

Declaration of interest

The authors declare that there is no conflict of interest.

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For more on conducting research in hospices, see: Turner M, Payne S. Methods of building and improving the research capacity of hospices. *European Journal of Palliative Care* 2012; 19: 34–37.

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