

Following the recommendations of the Neuberger Report on the use of the Liverpool Care Pathway (LCP) and subsequent guidance from Scottish Government (SG), we developed a means of recording, evidencing and auditing end-of-life care which met requirements of the SG's four principles, as follows:

- Informative, timely, sensitive communication
- Significant decisions about a person's care, including diagnosing dying, are made on the basis of multi-disciplinary discussion.
- Each individual person's physical, psychological, social and spiritual needs are recognised and addressed as far as is possible.
- Consideration is given to the wellbeing of relatives or carers attending the person.

Thirteen key objectives were agreed in relation to evidencing and auditing appropriate end of life care. These were translated into an End of Life Care Record (EoLCR).

The project comprised two stages:

Stage One (5 week pilot)

- Ward A: Patients identified as being in the last days/hours of life, care documented in EoLCR
- Ward B: Patients identified as being in the last days/hours of life, care documented in Personal Care Records (PCR).
- All data compared against the 13 objectives
- Minor amendments were made and the EoLCR rolled out to all wards

Stage Two (Retrospective Audit)

A retrospective audit was undertaken of all deaths within the hospice over three months of implementation and compared against the 13 objectives.

We aimed to develop a robust means of evidencing end of life care which followed SG's 4 principles. This relates to NHS Scotland's 2020 vision that care will be provided to the highest standards of quality and safety, with the person being centre of all decisions.

The retrospective audit showed improvements in recording end of life care, please refer to Abstract P-65 Table 1 on page A34.

Using the EoLCR allowed us to evidence the principles of good end-of-life care especially in relation to nutrition, hydration and communication with patients/families.

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THE ROLE OF THE VOLUNTEER RESEARCH ASSISTANT IN A HOSPICE SETTING

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10.1136/bmjspcare-2016-001245.90

Context A hospice setting has a small, busy research team and the volunteer research assistant is an important role within the team, providing additional support for delivery of research projects and related activities.

The role was first introduced in 2014 following the development of research infrastructure and capacity building within the organisation.

What has been achieved? Examples where volunteers have supported hospice research include assisting:

- the research team with the set up and co-ordination of a clinical trial. Including support with the organisation and collation of study materials, meetings and training to the site.
- the running of a research event. A volunteer supported the set up and running of the event by helping organise attendance lists and other materials for the day, greeting and registering attendees on arrival.
- data entry into an electronic spreadsheet of study data collected on paper forms. They have also learnt some data checking skills along the way too.

What have we learned? Our experience with involving volunteers as part of the research team has been a rewarding one working towards the hospice's strategy to become increasingly research active in order to provide the best care for patients and their families. It has provided the hospice with additional research capacity to deliver projects and other research related activities.

Volunteers with different skills, expertise and experience of the organisation has meant we have been able to match their input to the needs of the research activity.

Experience of involving volunteers has meant we have been able to develop a role description for a 'volunteer research assistant'.

Introducing the role of the 'volunteer research assistant' has helped to promote ownership of this unique position to the volunteer involved. There is value in developing this role to provide regular support in developing, setup, delivering and disseminating research within hospices.

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HOSPICE RESEARCH LEADS AS INSTIGATORS OF RESEARCH

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10.1136/bmjspcare-2016-001245.91

From the inception of the hospice movement, research has been identified as essential to the delivery of high quality palliative and end-of-life care. Despite delivering compassionate care and excellent symptom management, research has not been embedded in hospice care. Recognising the need for greater engagement in research, our organisation first piloted the Research Lead programme in 2011. The aim was to facilitate participant involvement in palliative care studies, to facilitate evidence based practice, and to create a culture of enquiry.

Full time Research Leads were appointed at three hospices in England, Scotland and Northern Ireland. A 2013 evaluation identified the benefits of such relationship-based, proactive roles. These included increased participation of patients, staff and carers in research, and enhanced research support and mentoring to all professional groups. This positive outcome contributed to programme expansion, with our organisation now employing five hospice-based research leads, each developing collaborations with regional academic institutions.

Outcomes associated with increased investment in research staff at hospices are both tangible and intangible. Tangible outcomes include numbers of participants recruited for research studies, and traditional academic outputs: publications and research grants involving hospice staff, students supervised and conference presentations. Other outcomes, relate to impact and