

HQIP Case Study:

Improving the quality of end of life experience

This submission demonstrates:

- Involving the bereaved in quality improvement
- Value of relatives and carers sharing experiences
- Improvement through difficult to reach groups

Date: **October 2015**

Name of organisation: **The End of Life Partnership**

Website address: <http://eolp.org.uk/>

Summary

The End of Life Partnership worked with two local hospices and three Clinical Commissioning Groups (CCGs), who commissioned a quality improvement study to understand a local population's experience of end of life care through feedback from bereaved friends and families. The Partnership engaged with people in a number of different ways to find out what made their end of life experiences better or worse, and what could have made a difference.

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The Partnership engaged with people in a number of different ways to find out what made their end of life experiences better or worse, and what could have made a difference, and also liaised with Local Authority and Public Health colleagues. The findings from this work will inform the commissioning intentions of the CCGs and hospices involved.

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Aims & Objectives

- Understand the local end of life experience.
- Identify shortfalls in care provided.
- Identify successes in care provided
- Implement quality improvements.
- Offer bereaved friends and families the chance to share their views around the shortfalls and successes in the end of life care experience provided.
- Analyse the feedback received to identify required changes.
- Implement required changes and follow these up to ensure they have been effective.

Background

The End of Life Partnership aims to transform end of life experience and care working with a wide range of partners. In collaboration with two local hospices and three Clinical Commissioning Groups (CCGs), the Partnership undertook a quality improvement study to understand a local population's experience of end of life care through feedback from bereaved friends and families.

Approach

Initially, bereaved friends and families were contacted after identification through the Registrar of Births,

Deaths and Marriages, and were offered a range of different ways to share their experiences:

- Interview in person.
- Interview by telephone.
- Postal questionnaire.
- Electronic survey.

Irrespective of the method chosen, questions asked about experience of end of life care were developed

Challenges

Engaging bereaved relatives and friends was a challenge for the Partnership in terms of timing because:

- Some were grieving, such that it was too soon for them to talk about their experience of end of life care.
- Some felt it too late to recall their experience of end of life care or they had moved on from their bereavement.

Initially, very few responses were received, so the Partnership shared their initiative with a Carer's Trust, Funeral Directors, and GP Practices, worked with focus groups and other professionals to try to raise awareness and increase engagement with the study, and collated feedback from a bereavement booklet already in use in the local area.

Invitations to take part were also posted on hospice social media and website pages, and shared via a public engagement event with the local Healthwatch.

Responses were collated and two independent researchers carried out a thematic analysis of findings for action.

Outcomes

Themes for action to improve the quality of the end of life experience included:

- Knowing where to go to get information.
- Need for better out of hours care.
- Difficulties for those without family.

- Need for better co-ordination of services.

Findings were presented at a range of meetings where healthcare professionals expressed:

- A lack of professional support out of hours.
- Difficulties accessing the information they need as and when it is required.

Conclusion

Through partnership working, as a result of the study a series of improvements to the quality of end of life care were planned.

Focus groups were held with health professionals to verify the findings and information regarding the project was cascaded to all involved, including friends and families who had asked for further information.

In terms of learning from the study how best to engage people in future, the most effective method of contact with this difficult to reach group was found to be through known contacts. All those interviewed were glad to share their experiences and many found that the process was supportive and provided them with further helpful information.

Feedback

"We asked if there was anything more we could have done to make a difference."

"I was surprised by how many families gave me a hug at the end of their interview. They found taking part to be both supportive and therapeutic."

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