

**Summary Feedback Report:
Patient, family and carer experiences
of End of Life Care in Leeds**

1.0 Introduction

NHS Leeds South and East Clinical Commissioning Group (CCG) are leading on a health needs assessment on the Leeds End of Life Care Pathway on behalf of all the three CCGs in the city. The key question they wanted to explore was “are we providing the best quality care within the resources available?”

As part of this process it was essential to ensure that the views and experiences of people who need these services in Leeds and their families and carers would be included in this assessment. West and South Yorkshire and Bassetlaw Commissioning Support Unit (WSYBCSU) were asked to provide engagement advice and support.

2.0 Methods

It was agreed that 25 in depth qualitative interviews would be conducted with families and carers who have been bereaved during the last 12 months, people facing the end of their life in the next 6 - 12 months at the time of the interview and families and carers of people who are facing the end of their life in the next 6 - 12 months.

The interviews would be based on the steps identified by the Department of Health in end of life care:

- Step 1 Discussions as the end of life approaches;
- Step 2 Assessment, care planning and review;
- Step 3 Coordination of care for individual patients;
- Step 4 Delivery of high quality services in different settings;
- Step 5 Care in the last days of life; and
- Step 6 Care after death.

An interview script was developed based on NICE Quality Standard QS13 End of life care for adults, the Yorkshire Cancer Network Palliative Care (End of Life) Pathway September 2012 and the National Voices survey. The option to have the method of engagement changed to meet the needs of individuals or groups was available on request. Interviews were to be undertaken in person or by telephone. However focus groups, patient narratives, creative methods etc were all available if required.

3.0 Recruitment:

An assessment was undertaken to ensure there were no gaps in the recruitment process and to make sure that all communities in Leeds were given the choice and equal access to be involved in the consultation. A flier was then sent out by email or post to:

- all three Clinical Commissioning Groups for dispersal across all their GP practices, staff bulletins, newsletters, websites and patient groups both at commissioning and service level;

- Macmillan, Marie Curie, Alzheimer's Society; St Gemma's and Wheatfields hospices, Leeds City Council, Leeds Teaching Hospitals NHS Trust, Leeds Community Healthcare NHS Trust and the Robert Ogden Centre;
- Leeds Palliative Care Strategy Group, Leeds Palliative Care Operational Group, Leeds Palliative Care website, Leeds Bereavement Forum, Neighbourhood Networks and Carers Leeds;
- Third sector organisations, faith groups and forums with links to communities across Leeds to ensure people from as many diverse communities as possible were aware of the opportunity to engage.

Follow up meetings, emails and phone calls were also undertaken to try to increase the level of participation from as wide a demographic as possible.

4.0 Demographics

Fifty one patients, carers, and family members were involved in the consultation. Twenty nine interviews were completed with individuals or two people at a time and two focus groups were held: one at Wheatfields Hospice and one at the Shakti Project. St Gemma's and Wheatfields were visited twice to make sure patients had every opportunity to engage. Equality monitoring was undertaken as part of the interviews and focus groups.

Despite an active recruitment drive in a short timescale certain groups were not as well represented in the consultation. These included adults under the age of 30, children, people with learning disabilities, lesbian, gay and transgender community and people from some Black and Minority Ethnic communities.

The patients involved had a wide range of health conditions including various forms of Cancer, Parkinson's, Dementia, Coronary Obstructive Pulmonary Disease, liver and kidney failure, Motor Neurone Disease, heart conditions, Leukaemia and lung conditions. Families and carers interviewed also shared experiences of sudden death.

All public bodies must demonstrate, according to the Equality Act 2010, an active consideration of equality which must influence the decisions reached that will impact on patients, carers, communities or staff. This was a qualitative piece of engagement work aimed at providing a snapshot of patient and carer experience within a specific timescale. It is recommended that further work should be done with those communities who weren't involved. There is also existing published engagement work regarding the needs of these communities in Leeds which could also be used to add validation and additional insight to this report. On reflection a longer timescale would also have been beneficial and enabled more targeted qualitative work to be done.

5.0 Recommendations:

In summary the recommendations from the participants of this consultation are that there is a need for:

- better access to see their regular GP with longer appointments to be able to discuss their condition;
- better support for medication management for patients and carers in the community. Patients reported having to manage taking up to 29 tablets a day and family

members felt great stress and responsibility dealing with high doses of medication which if they made an error could be potentially lethal;

- improved pain relief management in hospital so that patients can receive their medication as prescribed and when they need it;
- improved communication between services to ensure information is shared and people are referred to the appropriate services or receive the appropriate care needed in a timely manner;
- improved coordination of care from hospital and discharge into the community and holistic assessments should be completed and reviewed regularly;
- continuity of staff was considered very important this was particularly relevant with regard to district nurses where they felt the system of providing a different nurse each visit meant the level of care received was poor. Those who had greater continuity felt they were receiving better care;
- ensuring patients and family were fully involved in care planning;
- providing an advocate or nominated key worker for patients and families going through end of life care;
- providing aftercare around bereavement to families;
- providing education and training for staff on cultural and religious needs of patients;
- increasing access to services by under represented groups through community engagement by services;
- providing information on dementia services for families;
- developing training for staff to enable better support for dementia patients;
- improving access and support for patients using Accident and Emergency by developing a better record sharing system and developing a protocol that recognised and dealt with end of life care patients more effectively;
- better integrated team working and the development of a central recording system for patients receiving care at home. Enabling all services to record information in one central file or folder and families would also be able to record medication and care given;
- education and training for all staff providing support to people receiving end of life care and on “giving bad news”;
- accessible information to be provided on support available for end of life care;
- clear and concise guidelines or information for patients and carers around the Liverpool Care Pathway;
- clear concise information about the donor organ transplant process for families; and
- minimising time taken for appointments at hospital and better management of appointment times e.g. to schedule appointments for patients into one day rather than on 3 consecutive days.

All of the recommendations above were included in the Health Needs Assessment alongside those from health and social care professionals.

Thank you to all of the families, carers and individuals who participated in the consultation and shared their experiences with us.

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