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The wordcloud on the cover of this report was created from patient feedback on end of life care in Wakefield.

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Introduction

NHS Wakefield Clinical Commissioning Group's (CCG) vision expresses the aim to improve patients' experience of healthcare within Wakefield District.

The CCG has patient experience firmly embedded in all commissioning activities and decisions. As part of the wider work of supporting the CCG to deliver on this vision, quarterly reports collating the various sources of patient feedback are produced by eMBED Patient Experience Service.

Using patient experience information supports the CCG in making decisions about local health services. The CCG's five year plan, NHS Wakefield – the next five years, is informed by listening to local people's experience of services to help decide priorities for the next five years and to plan services that enable people to stay in control of their own health and well-being. This report looks specifically at patient experience of end of life care.

The CCG's five year strategic plan 2014-19 identifies a number of key elements of a high quality, sustainable health and social care system, which form the basis of priorities in Wakefield. Among these key elements, end of life care falls within:

- ***A step change in the productivity of elective care***

Among the CCG's planned interventions under this key element two relate directly to end of life care, these are:

- ***To further align palliative care and end of life care transformation schemes with the integrated care transformation programme for example through 24/7 hospice beds.***
- ***piloting the introduction of Electronic Palliative Care Co-ordination Systems (EPaCCs) to improve coordination of palliative care.***

Planned interventions identified in Wakefield CCG's five year strategy, year two operational plan include:

- ***24/7 access to Hospices.***
- ***Roll-out Advance Care Planning training to multi-professional staff.***
- ***Extend roll-out of ePACCS system for Palliative Care Co-ordination.***

Wakefield CCG's annual report 2015-16 notes under service improvement:

- ***Training for clinical staff in hospital, community nursing and GP practices to help ensure end of life patients get personalised care.***

and that:

- ***The success of the Wakefield Advance Care Planning training for End of Life project was commended in the NHS Improving Quality bulletin and also in the Palliative Care publication. This work continues to be a key part of ongoing work to improve patient care at the end of life stage.***

Palliative care in Wakefield

Palliative care nurses are integrated into the three Continuing Care hubs. Mid Yorkshire Hospitals Trust provides palliative care by medical and nursing teams in hospital, in nursing homes and in patients' own homes. There is also a specialised occupational therapist and physiotherapist available at Dewsbury and District Hospital. Close links are maintained with Wakefield and Prince of Wales Hospices.

Definitions¹

End of Life Care

Care that helps all those with advanced, progressive and terminal conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both the individual and the family to be identified and met through the last phase of life and into bereavement. It includes the physical care, management of pain and other symptoms and provision of psychological, social care, spiritual and practical support.

Source: End of Life Care Strategy: promoting high quality care for adults at the end of their life. Department of Health 2008.

¹ Definitions taken from Public Health England's National End of Life Care Intelligence Network palliative care clinical data set guidance and definitions. December 2016.

Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms affirms life and
- regards dying as a normal process intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families
- enhances quality of life and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and
- includes those investigations needed to better understand and manage clinical complications

Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions.

Source: World Health Organisation.

Method

To answer the question ‘what are people telling us?’ a collation of a range of sources of patient feedback, bearing on experience of services relevant to end of life care, was undertaken for NHS Wakefield Clinical Commissioning Group.

Text based patient feedback and third party summaries of patient feedback were collected from the following sources (where available) to provide a comprehensive picture of patient experiences of services across the CCG:

- Patient Advice and Liaison Service (PALS)
- Patient Opinion
- NHS Choices
- Google reviews
- Complaints
- Engagement initiatives
- Patient Safety Walkabouts
- Friends and Family Test free text responses
- Third sector providers e.g. Healthwatch.
- Care Quality Commission inspection and quality reports

Usually information would be included in this patient experience report if it fell within the quarter 2 reporting period (1st July to 30th September 2016) and any pertinent information from the previous quarter would also be included. However an initial search based on this method only captured a very small amount of patient feedback. With the agreement of the CCG the search period was extended to the previous two years. This allowed the identification of a number of further items of feedback from the data sources given above. A number of Care Quality Commission (CQC) reports were also identified, from within this two year period, which contained patient experience feedback. One of these, an inspection report on Prince of Wales Hospice, was used with the agreement of the CCG, though it was published in November 2013. A full list of data sources is given on page 33 and Table 15 on page 39 gives a count of data items (cases) by source.

Where information sources provided both numerical and text based data the numerical data was excluded. Feedback from patients expressing opinions or conjecture and not based on direct experience of healthcare was excluded as was any feedback from the perspective of health care staff.

Patient feedback was collated at the level of the individual item of feedback such as a patient story or review. Each item of feedback was assigned to a single theme within the NHS Patient Experience Framework (see Appendix I) and allocated a positive or negative sentiment. The meaning of each item of feedback was taken at face value with no inference of any deeper or latent meaning.

A count of the number of items of feedback assigned to each theme of the Patient Experience Framework, according to their positive or negative sentiment, was then done. These are given in Tables 2 to 14, from page 34.

To summarize the feedback received within the reporting period across the whole dataset the findings of the collation of feedback for each data source were then summed and presented as main themes across the whole CCG in Table I on page 33.

Please note that the quotes throughout the document are given as examples of wider themes.

What are people in Wakefield telling us about end of life care?

OVERVIEW

Of the 141 items of patient experience feedback considered in this report the proportion of positive to negative was 122 to 19, or 87% positive to 13% negative (see Table one on page 33. We heard many patients and family members tell us about much that is excellent in end of life care. This all tends to suggest that end of life care is largely functioning well to give patients and family members a good experience of services.

However, since the aim of this report is to improve patient's experience of healthcare in Wakefield, we have looked closely at what people said about what didn't work well in their experience and made suggestions on how services could be improved.

What works well?

These are the good things we've heard about:

PRIMARY CARE

We heard from people who commented on their GP practice's involvement in end of life care very positively, citing: high quality clinical treatment and care; helpful and supportive staff attitude and behaviour; and the value of continuity of care and the willingness of practices to 'go the extra mile' in providing the best possible support to patients and their families at the end of their lives.

"My family have been patients with this surgery for many years. In recent months, my Auntie, aged 87 got more poorly with, amongst other things, colitis and other related issues. As my Aunt's health worsened, we all realised the wonderful level of care that she received from the NHS in general, and from this surgery, Dr Bance & Partners, in particular... Auntie passed away in early 2015, aged 87, but we will always be grateful to the help and support that she received from this practice, and from the doctors and specialists that cared for her."

"My gran has bowel cancer is on palliative care and needed a home visit in the evening, I contacted the surgery at 6pm and spoke with a doctor who said they would call on their way home. Spent over half an hour with my gran even though they had finished work. Excellent care and friendly staff. Dr A C Godridge & Partners - Tieve Tara Medical Centre."

“This practice (King’s medical practice) has provided excellent care to our whole family and supported us through the diagnosis of terminal illness of my partner and provided fantastic support at the end of his life. The reception team are always very helpful and go out of their way to help patients. Each doctor we have seen has been excellent and helpful.”

“Can’t fault my surgery. My family and me use this surgery and of recent months had more call on them than ever due to elderly parents which one has now sadly died - this surgery and our GP has been amazing always has and in times of need have been there for us - they are excellent doing a brilliant job in difficult austere times - I hate it when people moan about NHS we don't know how lucky we are - anyway I cannot fault Prospect Road @ Ossett health village and it gets my 10/10.”

SECONDARY CARE

We heard from many patients and family members on the positive aspects of secondary care received by patients at the end of their lives.

Patients said that they felt the quality of treatment and care they were receiving was excellent and that they were involved and had choices about their care.

All of the patients and relatives we spoke with were very positive about the quality of the care and treatment they were receiving. They told us they felt involved in decisions about their care and felt they were treated with kindness and compassion.

One patient told us they liked to do some of their personal care and take control of their medication with the assistance of staff and their relative.

One patient we visited at home told us they were given a choice regarding their preferred place of care.

Relatives were very positive about the treatment and care received by their family member at the end of their lives and said that they also felt very well supported, practically and emotionally, by staff.

“Pinderfields... to the staff in the neurology/stroke ward who cared for dad in his last days. You made sure that dad was comfortable and peaceful & you provided support to his family throughout the night. I would especially like to thank the nurse who took time to sit with me when I first arrived at the ward (after a long journey). By being there and listening to me, you helped me to deal with the news about dad's situation. I will not forget this.”

“My elderly grandfather has been in the hospital for around a month now originally going in with a broken shoulder only to find out he has cancer in his bones and liver. He's currently on floor A ward A1. Firstly I would like to say how incredible the staff are on this floor! They have kept us in the loop with everything they are doing and even though we have found out he hasn't long left they are making his last few weeks very pain free, also even though my grandad can't talk his facial expressions show how much he loves the nurses, not only with my grandad but they are helping my nana understand and being a little shoulder to cry on when needed. They have made this very hard time much easier to cope and they have my utmost respect. Each and every one. I just wish we could repay them back in some way.”

My mother was cared for at Pinderfields after suffering a stroke from Tuesday 13th November until she passed away on Thursday 15th November. The care she received was excellent. All the staff we came across could not have been more compassionate or helpful towards my mother and our family.

We heard that pain relief was effectively offered and managed.

Patients told us that staff asked them if they were in pain and offered pain relieving medicines. Patients said symptoms of pain were well controlled.

Patient said that their nutrition and hydration were well looked after.

Patients were supported and encouraged to eat and drink whenever they wished to.

Patients said that they were treated with dignity and respect.

On one visit to a patient's home we saw the nurse treated the patient respectfully and with dignity, they were welcoming towards the patient and their relative and supported them in a professional and sensitive manner.

We found that patients were treated with dignity and respect. Care was delivered in a timely manner in a sensitive way. Patients and relatives stated they felt involved in their care. They had been given the opportunity to speak with the consultant looking after them; the discussions were documented in patient's records.

HOSPICE CARE

The great majority of patient feedback on hospice care, both from patients and family members was very positive.

Patients said that they felt the quality of treatment and care they were receiving was excellent and that they were involved and had choices about their care. There was a strong sense that hospice care was well informed by knowledge of the patient's previous treatment. There was a clear perception that all services within the hospice were well integrated and accessible, and that communication between these services and those in the wider health and care field was effective.

People we spoke with told us staff were knowledgeable about their health condition before they were admitted as they had obtained information from other agencies such as the hospital specialist and their GP. They also confirmed the Hospice communicated well with other agencies about their care and treatment and to support their discharge home.

"The staff always explain things and check out my choices."

"The staff work very well together. They are all different professionals, but all equally supportive."

One patient told us that they could have access to health care professionals whenever they wanted, such as the counsellor and the doctor. Another patient who was visiting the drop-in service said, "I can see the social worker or the doctor if I want to."

Relatives were very positive about the treatment and care received by their family member at the end of their lives and said that they also felt very well supported, practically and emotionally, by staff. This included the provision of bereavement counselling services.

A relative commented: "The care here is wonderful. The staff look after me as well as my relative."

We were told by one client's relative that staff are intuitive and caring. They told us "(My relative) gets upset naturally at their condition and sometimes takes it out on their spouse. One such time, the nurse came to help (my relative) and sent us out of the room. She calmed (my relative) and when the nurse came out of the room to us, she lightened the situation, without taking sides, in an understanding way."

Relatives and friends were able to visit the hospice at any time; they told us that they were always made welcome.

One person who we spoke with said they had attended for bereavement counselling and that the service was excellent. They said, "Staff are very good listeners."

We heard that pain relief was effectively offered and managed.

One patient told us, "I'm not in pain, I am comfortable" and another said, "They respond to needs and explain everything in a way that we understand. They talk in a way that we can understand because we don't know about drugs."

"I have a sore mouth and the nurse offered me a mouth spray, without me asking."

"My sore areas are treated every day, they deal with discomfort straight away."

Patients said that staff were very responsive to requests for help or support.

The patients we spoke with told us that staff responded to call bells promptly, including during the night. One patient said, “They respond immediately” and another told us, “They usually come straight away and if they are busy, they come and tell you that they are busy and will be with you as soon as they can.” Patient said that their nutrition and hydration were well looked after.

“Staff are gentle, really professional and there are enough staff.”

Patients said that they were treated with dignity and respect.

People told us that their privacy and dignity was respected by staff and that they felt staff really cared about them.

One patient told us, “My dignity has been restored since I came here” and another said, “I cannot believe how good they are. They want to do it (the job). They treat me with dignity – they draw the curtains round.”

Patients were able to access a range of social and creative activities to provide diversion and emotional support.

We asked a patient what they liked to spend their time doing and whether they could do it at the hospice. They said that they liked bingo and they could play it at the hospice. Another person told us that they could go out for a walk if they wanted to.

We spoke with three patients in this room who had been taking part in an art activity. One patient said, “The support I receive here has helped me a lot. The staff are second to none and I can forget my troubles when I’m here.”

Patients said that their nutrition and hydration were well taken care of.

We spoke with one person who told us they were very happy with the quality of the food. They said: "I don't always feel up to eating, but that's not because of the food, that's just how I feel. The food is lovely, but if I don't want it they'll [the staff] bring me a sandwich or something. I know I can have anything at all, both to eat and to drink." One person said that they had a sore mouth and they told us, "They will cook me anything" and another person said, "It's like a hotel. Care is second to none. I asked for coleslaw and they made it straight away."

People also told us that staff would make them a snack during the night if they wanted one.

"The care is excellent, and the food and facilities are also fantastic."

A number of patients spoke about excellent communication with staff and how the improvement in their treatment and care since coming to the hospice had boosted their confidence and sense of wellbeing.

"They closely monitor my drugs and I feel I am involved with decision making and my confidence has increased since coming here."

"Since I came here from another service, balls have started rolling. My therapy and pain management have improved and I am less worried now, less anxious. I can see light at the end of the tunnel."

"We've talked about everything, I'm in charge for the first time in my life."

“I am involved with decision making. I asked for honesty and they are honest. I can talk to anyone about my concerns, the staff are lovely, you can't fault them. When I need them (in the night), they come, just like that. Since coming here, nothing worries me, it's perfect, no-one snaps at me and they are marvellous.”

Patients and relatives commented on the atmosphere of calm and organised care.

Words can't express the tranquillity, calm, peacefulness, care, and attention to detail at Wakefield Hospice. My Grandma sadly passed away and we will treasure forever our memories of her last days. It was all we could have wished for and something money can't buy. Thank you from the bottom of our hearts.

What didn't work well?

These are the things people said about what didn't go well:

PRIMARY CARE

We heard from people who commented on their GP practice's involvement in end of life care negatively, citing: inadequate investigation and diagnosis; disjointed and poorly integrated service; an unresponsive out of hours service; and a visiting GP without necessary medication on hand.

He was taken to LGI and within 10 minutes he was being prepared for the angiogram but he had a cardiac arrest and died. Client believes that the GP surgery let him down by not investigating him properly and the over 5 hours were wasted because he could not be taken to LGI straight away.

Disjointed service, in my opinion from GPs (Almshouse), Macmillan, Community / District nurses. My father has advanced prostate cancer. He lives at home, alone as my mother died recently. Everyone seemed to pass responsibility (and sometimes blame) onto other agencies in relation to my father's treatment for cancer. The main problem being that he went into hospital and he went rapidly downhill. He was discharged but, in my opinion they had not got the right services in place for him at home. I was forever having to ring up different agencies to chase them up about things.

No patient or their relatives should have to deal with the complexities of medicines management and having to understand and sort out mistakes being made by GPs, their surgeries and local pharmacies. This should all be handled for the patient by healthcare professionals.

She was discharged from hospital on a Friday night with very little information about what was going to happen next and came to stay at my house for a few days to recuperate. By the Saturday night she was in excruciating pain and I spent the whole night trying to get a call back from a GP on the 111 out of hours' service I had rung for advice. When by 7am the following morning, they still hadn't called me, I took my mum to A&E where her symptoms were so acute they readmitted her to hospital.

As we came to the last weekend of mum's life, we were twice asked to go and get end of life medicines from an out of hours pharmacy as the GPs who came to alleviate her symptoms didn't have any medicines with them. So there was a delay in giving mum what she needed and what would have happened if we hadn't been there or hadn't had transport?

SECONDARY CARE

We heard from many patients and family members on the negative aspects of secondary care received by patients at the end of their lives.

We heard that pain relief was not effectively offered and managed.

Patients told us they sometimes had to wait for pain relieving medication when they asked for it as staff were busy.

We saw in one case where the patient's medication record was missing, staff did not take action to get the prescription rewritten. This resulted in some medications not being given at the prescribed time; including antibiotics and pain relief medication. The missing record and lack of medication caused some distress to the patient. The patient subsequently experienced pain and a doctor was called to rewrite the prescription. This meant the pain relief management plan had not been followed and as a result the patient experienced pain and discomfort.

Patients and relative told us about serious shortcomings in communication with patients and relatives.

Meeting with deaf woman about her experiences with deaf terminally ill husband and poor treatment. No BSL interpreter throughout his illness and admissions to hospital. Also night carer kept waking woman up because they couldn't understand the patient. Person did not know husband was terminally ill or that his death was imminent.

client was admitted to ward but was then moved a further 3 times, all in the last 2 weeks of his life; Relatives not being kept informed - on one occasion client was not informed that her husband had moved wards, she turned up and found someone else in her husband's bed... client did not feel that she was consulted/ informed about end of life decisions. She was told that her husband would not survive final stroke but was not advised why... and also turned up one day to find a "small box", syringe driver, next to her husband which she did not know the purpose of and had to enquire about to find out...

Pinderfields... My main complaint is the total lack of information we were given. We had to seek every scrap of information about her care and her prospects for recovery. The day before she died after five weeks in hospital a consultant did speak to my father to tell him that she wouldn't get any better, that was the sum total of our end of life care plan. She didn't think to mention that she may die sooner rather than later. At just after 6am on 10th January my father got a call to say that my mother had died, he rang me totally distraught. Given my father's disability we got to the hospital a couple of hours later and was horrified to be shown onto the ward, the curtains were drawn but all around us patients were sat waiting for their breakfast, we were distraught at the state my mother was presented to us. Her mouth was wide open and my father was weeping over my dead mother trying to close her mouth, I asked a nurse how she died and she told me she was checking her fluids and noticed... she was going to say noticed she was dead. To this day I don't know why my mother died, no-one has spoken to us...

Patients said that their nutrition and hydration were not well looked after.

Nutrition and hydration - client had previously lost weight whilst in nursing care, was having a pureed diet due to swallowing problems, but client was shocked to see how malnourished her husband had become when she saw the nurses turning him - she realised that what she thought to be his arm was actually his leg...

Patients said that they were not treated with dignity and respect.

On another occasion she was suffering from chronic diarrhoea at a time prior to having an operation. She was left on her own with a gown to get ready for theatre without any help from nursing staff. After the operation she was put on a four bedded unit. When her daughter arrived she was in tears - she had buzzed for help to get to the toilet, but the nurse said she had to wait which resulted in her soiling the bed in front of other patients.

One patient told us of an incident where they had refused medications but staff tried to give them the medication without their consent. This was reported as an incident and was in the process of being investigated.

He was in Pinderfields in December then moved to Priory Gardens nursing home for 10 days where an agency nurse shaved his moustache and beard off because they could not find a flannel to wash his face. I watched him go from 10.5 stone to 8 stone 11 lb and to see him shaved he was not the man I knew, the image of him still haunts me today.

Patients said staff were unresponsive and that it seemed that there weren't enough staff.

One relative told us that there were delays in staff answering call bells.

One relative told us staff were always, "Rushed off of their feet".

Patients also told us staff were always busy and worked "really hard" but there were not enough of them. One relative told us they had waited an hour for an injection to be given to the patient as there were insufficient staff on duty.

Patients said they were very satisfied with their care and said staff were respectful and caring but recognised they were frequently understaffed and very busy.

There were problems with inadequate patient records and with insufficiently personalised care plans.

One patient told us that staff repeatedly asked the same questions and that staff did not appear to have a knowledge of their medical history. They told us they felt, "Well cared for but not always listened to". We were told they asked for a specific medication which they were prescribed but staff told them they "Weren't down for it", it was then realised that the medicine was prescribed.

We saw in one case where the patient's medication record was missing, staff did not take action to get the prescription rewritten. This resulted in some medications not being given at the prescribed time; including antibiotics and pain relief medication. The missing record and lack of medication caused some distress to the patient. The patient subsequently experienced pain and a doctor was called to rewrite the prescription. This meant the pain relief management plan had not been followed and as a result the patient experienced pain and discomfort.

My husband died whilst waiting for a care package after he had 3 strokes.

Her symptoms began to be managed and then we were told she wasn't ill enough to go into the hospice and she would have to go home or into a care home. She wanted to go home and so we began liaising with the hospital Macmillan team and social services to get a care plan in place to ensure someone was with her to help her to get up and go to bed, washed and dressed, to eat and to take her medication. This took several days to organise, we had to insist on a meeting to discuss this and were given conflicting information throughout and at no point was it explained how the social services care would work alongside the community nursing care. We also asked for protein drinks for mum to help her as she was struggling to eat and she never received these. By this point mum was on a syringe driver and needed it changing twice a day, we didn't know who would do this or how this would happen when mum was discharged and when we asked the answers were vague.

Patients and relatives said that levels of support were inadequate and that too much was being expected of family members and carers, who sometimes had their own health issues to cope with.

She needed to have injections in her stomach daily and this was left to her elderly disabled husband to do for her. Prior to her illness she had been her husband's carer as he had multiple issues himself including poor memory. He had a carer come in to ensure that he took his medication so it was not really a great solution for him to be responsible for his wife's daily injections. Despite requests from the family, no support was put in from district nurses or anyone else. The injections were on repeat prescription and the family were left to administer them.

My mum was bounced around a very confusing and complex system. I often felt like some sort of project manager, trying to negotiate the complexities of the system to get mum the bare minimum she needed, no more. If my brother and I hadn't been around to help mum, she would have been left to try to negotiate this alone, at the age of 81 and very seriously ill. This can't be right and shouldn't be allowed to continue.

Some family members said they felt pressure for the discharge of their relative, before adequate support was in place.

The hospital tried to send her into a nursing home and he fought with social care to allow her home despite having no carers. Earls Lodge were unable to accommodate his wife as she had complex needs. The man said he was constantly being pressured to take her home or put her in a home, he said they wanted the bed and spoke in front of her which he found disrespectful.

We wouldn't let her go home until we were assured the full package of care was in place and on several occasions mum and we were made to feel guilty for her blocking a bed by the doctors, discharge sisters and some nurses on the ward.

We heard from one relative about the inconsistency of available specialist nursing support.

We have been shocked throughout by the lack of support and visibility of Macmillan nurses in this whole process. Mum never saw a Macmillan or any other specialist cancer nurse in the community and where we saw them in hospital, they would most likely only come to the ward once and never be seen again. We had to request a meeting with a Macmillan nurse to sort out mum's care package when she was released from hospital in June and after a very difficult conversation about what was and wasn't possible, we felt as though we were being a nuisance. We feel let down by them and don't understand what their role is. When my dad died from cancer at home in 1999 he had his own dedicated Macmillan nurse who acted as focal point for his community care and also offered him pastoral support. Mum desperately needed and never got this.

HOSPICE CARE

The preponderance of patient feedback on hospice care has been positive. The negative feedback in this section details some level of spiritual support but an absence of community care and counselling support. The time-limited nature of hospice care is also noted. This feedback all comes from the experience of one family, of end of life care provided to their relative. This fact in no way diminishes its significance.

My mum then spent the next three weeks in Wakefield Hospice. They got her symptoms under control, but she was very poorly indeed and she really struggled with her impending death and the nervousness associated with this. She was offered some spiritual support from a vicar, but there was no counselling available and mum was very low indeed.

At the end of this period (three weeks), because mum hadn't died and the hospice can't provide long term care, my brother and I were told we would have to send her home or move her into a palliative care home. Because of the lack of community care support we were unable to let mum go home and we felt we had no choice but to put her into a care home.

There was a lack of any mental health/ counselling support for mum throughout this process. We were most shocked by this when she was in the hospice. Terminally ill people need the option to talk to someone about what is happening to them to help them get through it. Instead of being offered this, mum was just given tranquilisers.

How could we make it better?

These are the things people said needed to be done differently and better:

PRIMARY CARE

The negative comments we heard from people on their GP practice's involvement in end of life care related to:

- inadequate investigation and diagnosis;
- disjointed and poorly integrated service;
- an unresponsive out of hours service; and
- a visiting GP without necessary palliative medication on hand.

There was a general sense of having to navigate a very complex and ill-integrated landscape of services without adequate information or support, and where some services, such as III were undependable.

“Everyone seemed to pass responsibility (and sometimes blame) onto other agencies in relation to my father’s treatment for cancer.”

“No patient or their relatives should have to deal with the complexities of medicines management and having to understand and sort out mistakes being made by GPs, their surgeries and local pharmacies. This should all be handled for the patient by healthcare professionals.”

SECONDARY CARE

Patients and family members told us that the negative aspects of secondary care received by patients at the end of their lives related to:

- pain relief not effectively offered and managed;
- serious shortcomings in communication with patients and relatives;
- nutrition and hydration not well looked after;
- not being treated with dignity and respect;
- unresponsive staff and not enough staff;
- problems with inadequate patient records and care plans;
- inadequate levels of support with too much being expected of family members and carers;
- pressure for discharge from hospital, before adequate support was in place;
- the inconsistency of available specialist nursing support.

There appeared to be two main themes in what people told us about what didn't work well in secondary care.

I. Under resourcing

A number of patients and relatives formed the impression that there were too few staff to provide adequate levels of care. It may be that the difficulties noted around: pain management; communication; nutrition and hydration; dignity and respect; patient records and care plans; support to family members; and pressure for discharge; stem from or are exacerbated by inadequate levels of staffing and resourcing.

One relative told us that there were delays in staff answering call bells.
One relative told us staff were always, "Rushed off of their feet".

Patients also told us staff were always busy and worked “really hard” but there were not enough of them. One relative told us they had waited an hour for an injection to be given to the patient as there were insufficient staff on duty.

Patients said they were very satisfied with their care and said staff were respectful and caring but recognised they were frequently understaffed and very busy.

2. Feeling like ‘a project manager’

Again patients described having to navigate a very complex and ill-integrated landscape of services without adequate information or support. One family member had a suggestion.

“If my brother and I hadn’t been around to help mum, she would have been left to try to negotiate this alone, at the age of 81 and very seriously ill. This can’t be right and shouldn’t be allowed to continue. What is needed is one key contact point for the patient and their family who organise all aspects of their health and social care once they are given a terminal diagnosis.”

HOSPICE CARE

Many people told us a great deal that was very positive about the excellent quality of hospice care. Only one family member told us some negative things: their family member had received some level of spiritual support but no community care support or counselling support. **It follows from this that efforts should be made to ensure that all service users benefit consistently from all aspects of the high quality hospice care available.**

Their family member had been moved from hospital care to hospice care but had survived for longer than could be accommodated by the time-limited nature of hospice care. They had this suggestion:

Overnight care for terminally and very poorly people should be available. No one should be discharged from hospital and sent home without adequate care in the community in place and relatives should not be expected to provide this, as this is not always possible.

Summary and conclusion

Of the 141 items of patient experience feedback considered in this report the proportion of positive to negative was 122 to 19, or 87% positive to 13% negative (see Table one on page 33). We heard many patients and family members tell us about much that is excellent in end of life care. The quality of care in primary, secondary and hospice care was seen as very high. Patients and family members felt involved; pain management, nutrition and hydration, dignity and respect were all well in hand. Communication was good, staff were responsive and people felt that staff really cared about them. In the hospice sector it was noted that staff levels were sufficient to support high quality care. There was a strong perception that hospice care was informed by good communication between internal services and with those in other healthcare sectors. Emotional support, counselling, bereavement counselling, social and diversionary activities were readily available and an atmosphere of calm, organized care was remarked on. This all tends to suggest that end of life care is largely functioning well to give patients and family members a good experience of services.

However, since the aim of this report is to improve patient's experience of healthcare in Wakefield, we have looked closely at what people said about what didn't work well in their experience and made suggestions on how services could be improved.

In both primary and secondary care patients and family members' described having to navigate a very complex and ill-integrated landscape of services without adequate information or support. In primary care the poor responsiveness of I I I was commented on. In Secondary care patients and relatives said that there were too few staff to provide adequate levels of care. Some of the other difficulties people mentioned around: pain management; communication; nutrition and hydration; dignity and respect; patient records and care plans; support to family members; and pressure for discharge; may be related to inadequate levels of staffing and resourcing.

One family member told us about negative experiences of the hospice sector, and these would tend to suggest that efforts should be made to ensure that all hospice service users are able to benefit consistently from all aspects of the high quality hospice care available.

Actions and next steps

The CCG will discuss this report at its Quality Intelligence Group in February 2017, which is informed by and acts on patient experience feedback to improve services. This report will also be presented to Wakefield CCG's Public Involvement and Patient Experience Committee (PIPEC) in March 2017. It will be shared widely to ensure that patient experience and insight is influencing future decisions related to services relevant to end of life care. The report will also be made publicly available on the CCG's website.

The Wakefield End of Life Strategic Outline Case Project Group has considered the contents of this report and will incorporate it into its ongoing district-wide partnership work. This report will be incorporated and referenced within the End of Life Strategic Outline Case Project Group report to the February 2017 Clinical Cabinet.

Ongoing staff training and education needs, equitable provision of bereavement services, provision of psychological support and improved community access to good quality end of life care across the district are under consideration as part of the ongoing local work to review and improve end of life care in Wakefield.

Limitations

The findings of this report should be considered in relation to the following limitations:

1. As an item of feedback is assigned in its entirety to a single theme within the patient experience framework there may be feedback contained within the item that pertains to another theme within the framework which is not recorded. Consequently there may be an underrepresentation of the themes contained within patient feedback collated for the report.
2. In relation to the previous limitation, each item of feedback can only be assigned either a positive or negative sentiment whereas in fact a whole item may contain both sentiments expressed separately. This may also result in a misrepresentation of the proportion of positive and negative sentiments expressed in the patient feedback for the report.
3. As a result of the small number of items included in the collation of data for each section the percentages representing the proportion of each theme appearing in the feedback may be artificially inflated.
4. It is not possible to undertake a process of establishing inter-rater reliability on the demarcation of items of feedback to individual themes.
5. While most of the data sources contain both positive and negative patient experience feedback, PALS and Complaints typically contain more negative feedback. However, in this report no PALS data was included and only one complaint was included.

Appendix I

Data Sources

1. NHS Choices reviews of primary care (EoL care) October 2104 to September 2016
2. Dewsbury and District Hospital CQC quality report (EoL care) November 2014
3. Pinderfields Hospital CQC quality report (EoL care) November 2014
4. Pinderfields Hospital CQC quality report (EoL care) December 2015
5. Patient safety walkabout Pontefract Hospital (EoL care) June 2016
6. Patient Opinion reviews secondary care (EoL care) October 2014 to September 2016
7. MYHT Community End of Life Care CQC quality report November 2014
8. Complaint (EoL care) September 2015
9. Wakefield Hospice CQC inspection report January 2015
10. Prince of Wales Hospice CQC inspection report November 2013
11. Facebook reviews Prince of Wales Hospice from October 2014 to September 2016
12. Facebook reviews Wakefield Hospice from October 2014 to September 2016
13. EoL care cases from Healthwatch Wakefield issues reports April to September 2016

A CQC quality report on Dewsbury and District Hospital (EoL care) December 2015 was searched but contained no patient feedback.

eMBED PALS Wakefield cases from April to September 2016 were searched but contained no cases relating to end of life care.

Table 1. EoL cases from all sources

Theme	Positive	Negative	Total
Respect for patient-centred values, preferences, and expressed needs	65	6	71
Coordination and integration of care	3	3	6
Information, communication, and education	8	4	12
Physical comfort	16	2	18
Emotional support	6	0	6
Welcoming the involvement of family and friends	21	1	22
Transition and continuity	0	0	0
Access to care	3	3	6
Total	122	19	141

Patient experience feedback by source:

Table 2. NHS Choices reviews of primary care (EoL care) Oct. 2104 to Sept. 2016

Theme	Positive	Negative	Total
Respect for patient-centred values, preferences, and expressed needs	4	0	4
Coordination and integration of care	0	0	0
Information, communication, and education	0	0	0
Physical comfort	0	0	0
Emotional support	0	0	0
Welcoming the involvement of family and friends	0	0	0
Transition and continuity	0	0	0
Access to care	0	0	0
Total	4	0	4

Table 3. Dewsbury and District Hospital CQC quality report (EoL care) Nov. 2014

Theme	Positive	Negative	Total
Respect for patient-centred values, preferences, and expressed needs	10	0	10
Coordination and integration of care	0	0	0
Information, communication, and education	1	0	1
Physical comfort	1	0	1
Emotional support	0	0	0
Welcoming the involvement of family and friends	2	0	2
Transition and continuity	0	0	0
Access to care	0	0	0
Total	14	0	14

Table 4. Pinderfields Hospital CQC quality report (EoL care) Nov. 2014

Theme	Positive	Negative	Total
Respect for patient-centred values, preferences, and expressed needs	7	1	8
Coordination and integration of care	0	0	0
Information, communication, and education	1	1	2
Physical comfort	1	2	3
Emotional support	0	0	0
Welcoming the involvement of family and friends	2	1	3
Transition and continuity	0	0	0
Access to care	0	2	2
Total	11	7	18

Table 5. Pinderfields Hospital CQC quality report (EoL care) Dec. 2015

Theme	Positive	Negative	Total
Respect for patient-centred values, preferences, and expressed needs	1	0	1
Coordination and integration of care	0	0	0
Information, communication, and education	0	0	0
Physical comfort	1	0	1
Emotional support	0	0	0
Welcoming the involvement of family and friends	0	0	0
Transition and continuity	0	0	0
Access to care	0	0	0
Total	2	0	2

Table 6. Patient safety walkabout Pontefract Hospital (EoL care) June 2016

Theme	Positive	Negative	Total
Respect for patient-centred values, preferences, and expressed needs	1	0	1
Coordination and integration of care	0	0	0
Information, communication, and education	0	0	0
Physical comfort	0	0	0
Emotional support	0	0	0
Welcoming the involvement of family and friends	0	0	0
Transition and continuity	0	0	0
Access to care	0	0	0
Total	1	0	1

Table 7. Patient Opinion reviews secondary care (EoL care) Oct. 2014 to Sept. 2016

Theme	Positive	Negative	Total
Respect for patient-centred values, preferences, and expressed needs	3	0	3
Coordination and integration of care	0	0	0
Information, communication, and education	0	1	1
Physical comfort	0	0	0
Emotional support	0	0	0
Welcoming the involvement of family and friends	1	0	1
Transition and continuity	0	0	0
Access to care	0	0	0
Total	4	1	5

Table 8. MYHT Community End of Life Care CQC quality report Nov. 2014

Theme	Positive	Negative	Total
Respect for patient-centred values, preferences, and expressed needs	6	0	6
Coordination and integration of care	0	0	0
Information, communication, and education	2	0	2
Physical comfort	3	0	3
Emotional support	0	0	0
Welcoming the involvement of family and friends	6	0	6
Transition and continuity	0	0	0
Access to care	1	0	1
Total	18	0	18

Table 9. Complaint (EoL care) Sept. 2015

Theme	Positive	Negative	Total
Respect for patient-centred values, preferences, and expressed needs	0	0	0
Coordination and integration of care	0	1	1
Information, communication, and education	0	0	0
Physical comfort	0	0	0
Emotional support	0	0	0
Welcoming the involvement of family and friends	0	0	0
Transition and continuity	0	0	0
Access to care	0	0	0
Total	0	1	1

Table 10. Wakefield Hospice CQC inspection report Jan. 2015

Theme	Positive	Negative	Total
Respect for patient-centred values, preferences, and expressed needs	19	0	19
Coordination and integration of care	1	0	1
Information, communication, and education	2	0	2
Physical comfort	10	0	10
Emotional support	6	0	6
Welcoming the involvement of family and friends	6	0	6
Transition and continuity	0	0	0
Access to care	2	0	2
Total	46	0	46

Table 11. Prince of Wales Hospice CQC inspection report Nov. 2013

Theme	Positive	Negative	Total
Respect for patient-centred values, preferences, and expressed needs	4	0	4
Coordination and integration of care	2	0	2
Information, communication, and education	2	0	2
Physical comfort	0	0	0
Emotional support	0	0	0
Welcoming the involvement of family and friends	1	0	1
Transition and continuity	0	0	0
Access to care	0	0	0
Total	9	0	9

Table 12. Facebook reviews Prince of Wales Hospice from Oct. 2014 to Sept. 2016

Theme	Positive	Negative	Total
Respect for patient-centred values, preferences, and expressed needs	3	0	3
Coordination and integration of care	0	0	0
Information, communication, and education	0	0	0
Physical comfort	0	0	0
Emotional support	0	0	0
Welcoming the involvement of family and friends	1	0	1
Transition and continuity	0	0	0
Access to care	0	0	0
Total	4	0	4

Table 13. Facebook reviews Wakefield Hospice from Oct. 2014 to Sept. 2016

Theme	Positive	Negative	Total
Respect for patient-centred values, preferences, and expressed needs	7	0	7
Coordination and integration of care	0	0	0
Information, communication, and education	0	0	0
Physical comfort	0	0	0
Emotional support	0	0	0
Welcoming the involvement of family and friends	2	0	2
Transition and continuity	0	0	0
Access to care	0	0	0
Total	9	0	9

Table 14. EoL care cases from Healthwatch Wakefield issues reports Apr. to Sept. 2016

Theme	Positive	Negative	Total
Respect for patient-centred values, preferences, and expressed needs	0	5	5
Coordination and integration of care	0	2	2
Information, communication, and education	0	2	2
Physical comfort	0	0	0
Emotional support	0	0	0
Welcoming the involvement of family and friends	0	0	0
Transition and continuity	0	0	0
Access to care	0	1	1
Total	0	10	10

Data source	Positive cases	Negative cases	Total cases
NHS Choices reviews of primary care (EoL care) October 2104 to September 2016	4	0	4
Dewsbury and District Hospital CQC quality report (EoL care) November 2014	14	0	14
Pinderfields Hospital CQC quality report (EoL care) November 2014	11	7	18
Pinderfields Hospital CQC quality report (EoL care) December 2015	2	0	2
Patient safety walkabout Pontefract Hospital (EoL care) June 2016	1	0	1
Patient Opinion reviews secondary care (EoL care) October 2014 to September 2016	4	1	5
MYHT Community End of Life Care CQC quality report November 2014	18	0	18
Complaint (EoL care) September 2015	0	1	1
Wakefield Hospice CQC inspection report January 2015	46	0	46
Prince of Wales Hospice CQC inspection report November 2013	9	0	9
Facebook reviews Prince of Wales Hospice from October 2014 to September 2016	4	0	4
Facebook reviews Wakefield Hospice from October 2014 to September 2016	9	0	9
EoL care cases from Healthwatch Wakefield monthly issues reports April to September 2016	0	10	10
Totals	123	19	141

Table 15. All cases by data source.

Appendix 2



NHS Patient Experience Framework

In October 2011 the NHS National Quality Board (NQB) agreed on a working definition of patient experience to guide the measurement of patient experience across the NHS. This framework outlines those elements which are critical to the patients' experience of NHS Services.

- **Respect for patient-centred values, preferences, and expressed needs**, including: cultural issues; the dignity, privacy and independence of patients and service users; an awareness of quality-of-life issues; and shared decision making;
- **Coordination and integration of care** across the health and social care system;
- **Information, communication, and education** on clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care and health promotion;
- **Physical comfort** including pain management, help with activities of daily living, and clean and comfortable surroundings;
- **Emotional support** and alleviation of fear and anxiety about such issues as clinical status, prognosis, and the impact of illness on patients, their families and their finances;
- **Welcoming the involvement of family and friends**, on whom patients and service users rely, in decision-making and demonstrating awareness and accommodation of their needs as care-givers;
- **Transition and continuity** as regards information that will help patients care for themselves away from a clinical setting, and coordination, planning, and support to ease transitions;
- **Access to care** with attention for example, to time spent waiting for admission or time between admission and placement in a room in an in-patient setting, and waiting time for an appointment or visit in the out-patient, primary care or social care setting.

This framework is based on a modified version of the Picker Institute Principles of Patient-Centred Care, an evidence based definition of a good patient experience. When using this framework the NHS is required under the Equality Act 2010 to take account of its Public Sector Equality Duty including eliminating discrimination, harassment and victimisation, promoting equality and fostering good relations between people.



Version control

Version	Details of Changes	Author/Editor	Date
v01	Initial draft prepared	Rob Mooney	09/01/2017
V02	Minor amendments in response to feedback from the CCG	Rob Mooney	25/01/2017

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