

Northern Lincolnshire and Goole NHS Foundation Trust

RJL

Community end of life care

Quality Report

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Date of inspection visit: 13, 14, 15 October 2015
Date of publication: 15/04/2016

Summary of findings

Locations inspected

Location ID	Name of CQC registered location	Name of service (e.g. ward/ unit/team)	Postcode of service (ward/ unit/ team)
RJL	Northern Lincolnshire and Goole NHS Foundation Trust		

This report describes our judgement of the quality of care provided within this core service by Northern Lincolnshire and Goole NHS Foundation Trust. Where relevant we provide detail of each location or area of service visited.

Our judgement is based on a combination of what we found when we inspected, information from our 'Intelligent Monitoring' system, and information given to us from people who use services, the public and other organisations.

Where applicable, we have reported on each core service provided by Northern Lincolnshire and Goole NHS Foundation Trust and these are brought together to inform our overall judgement of Northern Lincolnshire and Goole NHS Foundation Trust

Summary of findings

Ratings

Overall rating for the service	Requires improvement	
Are services safe?	Good	
Are services effective?	Requires improvement	
Are services caring?	Good	
Are services responsive?	Requires improvement	
Are services well-led?	Requires improvement	

Summary of findings

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Summary of findings

Overall summary

Overall rating for this core service: Requires Improvement

We found end of life care to 'require improvement' overall. Safe and caring were rated as 'good'; however, effective, responsive and well-led were rated as 'requires improvement'.

- There was no trust specific end of life strategy or related performance indicators to measure the success of the end of life care services. However, the trust told us they were part of the wider health economies' strategic groups for end of life care. We found staff were not aware of a vision for end of life care nor what was in place to monitor of the quality of the service provided. The newly-appointed chief nurse was the board lead for end of life care and had previously chaired the end of life strategy group. A non-executive director had been recently identified to provide board support and challenge. The trust had also acknowledged the need for senior clinical leadership and had recently appointed its first two palliative care consultants. Whilst the team were very positive and work had started there was more to do before the impact for patients could be evidenced.
- Information provided by the trust indicated that last year, 600 patients from home or care homes died within 24 hours of admission to hospital. In the absence of advanced care plans and seven day specialist services, patients were admitted to hospital rather than spending their final hours at home. The trust had since taken action to deliver a seven-day specialist palliative care service in the community.
- The trust had taken part in the 2014 National Care of the Dying Audit (NCDAH) and achieved three out of seven organisational key performance indicators (KPIs). In relation to clinical KPIs, the trust was worse than average in eight out of ten areas, including communication regarding the patient's plan of care for the dying phase. The trust had taken action on the results of the audit and an individualised care plan and 'last days of life assessment and care plan' were being piloted.
- We found there was disconnection between the trust board and staff in the community. We observed

positive leadership at a local level in the community. Service leaders were visible and approachable. Staff were proud of the care they were able to give and received positive feedback from patients, families and carers; they told us senior managers did not acknowledge this.

However we also found;

- There was a multidisciplinary team approach to end of life care in the community. This meant specialist palliative care nurses, community nurses, Macmillan healthcare support workers, therapists, social workers and doctors all worked together for the benefit of patients and their families. Staff kept patients at the end of life safe and protected them from avoidable harm. They followed procedures to support safe care for patients. We saw evidence that staff reported incidents of harm or risk of harm and managers reviewed the reports and identified lessons to be learned to help prevent future incidents. Staff gave medicines to relieve pain and other symptoms correctly and in a timely way.
- Staff assessed patients and managed risks as part of an ongoing holistic assessment process. Staff made good use of individual risk assessments for patients receiving end of life care. Senior nurses had advanced communication skills and could speak with patients and families about resuscitation and sign DNACPR forms (do not attempt cardiopulmonary resuscitation).
- Community teams were quick to respond to patient need and referrals were prioritised based on need. Specialist staff delivered training to care homes and home care staff to improve the effectiveness of the care they gave. All community nurses were trained in non-medical verification of an expected death; which meant bereaved families did not have to wait for a doctor to attend.
- We found positive innovation in using a Macmillan healthcare team to deliver end of life care in the community and the inclusion of a clinical psychologist in community service.

Summary of findings

Background to the service

Information about the service

End of life care encompasses all care given to patients who are approaching the end of their life and following death including in someone's own home. It includes aspects of essential nursing care, specialist palliative care, and bereavement support.

The trust provided community care for people throughout North Lincolnshire at the end of their life. Support was provided to families and others who were close to patients after the patient's death.

The specialist palliative care team provided support and advice for patients with complex needs and symptom management issues at the end of life. The team also provided training to care home staff and home care agencies. A physiotherapist and occupational therapist were in rotational posts for six months at a time in the specialist palliative care team. The team of community Macmillan healthcare support workers gave 'hands on' care to people in their own homes. A clinical psychologist offered a range of therapies for patients.

The community specialist palliative care team was based in Scunthorpe. The team was made up of 5.8 whole time equivalent nurses, plus administrative support. The team was aligned to GP practices and had recently begun to provide a seven-day service. The community nurses were based at five locations around the area (known locally as 'patches' or 'clusters') and were based with social workers as part of integrated teams. The community nurses were managed by a 'patch' team leader. The community Macmillan healthcare support team was based in Scunthorpe and covered the wider geographical area. A patch team leader also managed the 32 healthcare support workers. Two palliative care consultants had

recently been appointed and worked in both hospital and community services, including the hospice. There was an 'unscheduled care' team of nurses to support patients to remain in their own home or care home, if safe to do so, during an episode of acute illness.

The health of people in North and North East Lincolnshire was significantly worse than the England average. The areas were in the most deprived regions compared to other local authorities.

In North Lincolnshire, there was a forecast that about 1,250 people a year would need end of life services. Around one in three deaths were of people aged over 80. A large majority of these deaths currently followed a period of chronic illness such as heart disease, diabetes, cancer, strokes, chronic respiratory disease, neurological disease or dementia. The number of deaths was predicted to rise by 17% by 2030. It was also predicted that the average age at death would increase and that those dying would have increasingly complex co-morbidities (multiple health problems). Services would need to adapt to be able to meet this increased need.

Before our inspection, we reviewed information from the trust about community end of life services. During our inspection, we visited a patient and their family in their own home and observed care being given by a community nurse. We also spoke on the telephone with two other relatives who were caring for someone at the end of their life. We met with 24 staff including a palliative care consultant, community matrons, community nurses, specialist palliative care nurses, healthcare support workers, social workers, a clinical psychologist and senior managers. We looked at the records of five patients receiving end of life care.

Our inspection team

Our inspection team was led by:

Chair: Jan Filochowski, Clinical and Professional Adviser, Care Quality Commission; retired CEO of Great Ormond Street hospital.

Team Leader: Amanda Stanford, Head of Hospital Inspection, Care Quality Commission.

The team included CQC inspectors and inspection managers, and a variety of specialists: Senior nurses,

Summary of findings

doctors, allied health professionals, community matrons, health visitors, a safeguarding nurse, midwives, radiologists, a pharmacist and an Expert by Experience who had been a carer of someone using services.

Why we carried out this inspection

We inspected this core service as part of our comprehensive acute and community health services inspection programme.

How we carried out this inspection

To get to the heart of people who use services' experience of care, we always ask the following five questions of every service and provider:

- Is it safe?
- Is it effective?
- Is it caring?
- Is it responsive to people's needs?
- Is it well-led?

Before visiting, we reviewed a range of information we held about the service and asked other organisations to share what they knew. We analysed both trust-wide and

service specific information provided by the organisation and information that we requested to inform our decisions about whether the services were safe, effective, caring, responsive and well led. We carried out an announced visit from 13 to 15 October 2015.

We observed how people were being cared for and talked with a patient and family members who shared their views and experiences of end of life care in the community. We reviewed care and treatment records of people who use services.

What people who use the provider say

Patients and relatives we spoke with were positive about the care they received. We were told that staff were

approachable, responsive, caring and compassionate. Family members told they felt supported by all the staff who were caring, compassionate and nothing was too much for them.

Good practice

We found examples of outstanding practice:

- The Macmillan healthcare team were used routinely and consistently to deliver end of life care in a person's home rather than using agency staff, so that care packages could start immediately.
- The inclusion of a clinical psychologist, allied health professionals and social workers in integrated community end of life teams.
- All community nurses were trained to verify expected death, and senior nurses were trained to sign DNACPR (do not attempt cardiopulmonary resuscitation) forms to record patients' wishes about what to do if they needed reviving.

Summary of findings

Areas for improvement

Action the provider MUST or SHOULD take to improve

An action that a provider of a service MUST take relates to a breach of a regulation that is the subject of regulatory action by the Care Quality Commission. Actions that we say providers SHOULD take relate to improvements where there is no breach of a regulation.

Action the provider MUST take to improve

- The trust must ensure it has an end of life care vision and strategy in place that reflects national guidance and ensure staff are included in the development of these.

- The trust must have effective systems in place to assess, monitor and improve the quality of the end of life care services including auditing preferred place of care and other outcomes for patients.

Action the trust SHOULD take to improve

- The trust should ensure all end of life care staff are up to date with managerial appraisal of their work performance and mandatory training.

Northern Lincolnshire and Goole NHS Foundation Trust

Community end of life care

Detailed findings from this inspection

Good 

Are services safe?

By safe, we mean that people are protected from abuse

Summary

We rated safe as 'good' because:

- There were effective procedures in place to support safe care for patients at the end of their lives and we saw evidence that incidents were reported, reviewed and that learning was identified. We saw that anticipatory medicines were prescribed for patients at the end of life and that these medicines were available in patient's homes. We found medicines for pain relief and other symptoms were given correctly and in a timely way.
- Appropriate equipment was available from the community equipment store, and we saw that syringe drivers were monitored using appropriate safety checks. We saw staff assessed patients and managed patient risk as part of an ongoing holistic assessment process.
- Specialist advice for end of life care was given by the specialist palliative care team (SPCT). Care was planned and delivered by community (district) nurses. There had been a shortage of registered community nurses for two years. This had led to increased reporting of missed visits, medication errors and staff stress as identified by

the trust. Care was also delivered by a skilled team of Macmillan healthcare support workers who provided care 24 hours a day, seven days a week and provided direct care to patients in their own homes.

Safety performance

- We were shown information about the community services risk register. In March 2013, the trust recorded a risk related to a lack of registered community nurses. The role of these nurses included end of life care. This had led to increased reporting of missed patient visits, increased medication errors and an increase in work related stress and staff sickness. We saw the risk register was reviewed in April and July 2015 however; it remained a red (high) risk. The trust had planned to reconsider the staffing skill mix and caseload numbers in readiness for an internal review process. However, there was no date on the risk register to indicate when this review would take place. We recognised that nurse staffing was a national problem.

Incident reporting, learning and improvement

Are services safe?

- Staff delivering end of life and specialist palliative care understood their responsibilities with regard to reporting incidents. Staff we spoke with told us that when an incident occurred it would be recorded on an electronic system (datix) for reporting incidents.
- We saw there was a prompt included on the datix system for staff reporting incidents to remind them of the duty of candour requirements.
- Incidents were investigated with the involvement of relevant staff and all staff were involved in a weekly review of incidents where incidents, risks and complaints were discussed and where staff were encouraged to reflect and learn.
- We were told of an example of duty of candour from a recent incident when a patient was given medication via an incorrect route. No harm came to the patient. We heard that the patient and family were fully informed of the incident.
- Senior managers told us there had been a recent external review of the arrangements for managing serious incidents and the duty of candour requirements; they told us no significant gaps were identified.
- Patients in their own homes who were receiving end of life care were prescribed 'anticipatory' medicines. Anticipatory medicines are 'as required' medicines that are prescribed in advance to ensure prompt management of increases in pain and other symptoms.
- We visited a patient in their own home who had anticipatory medicines prescribed and these were being given via a syringe driver. Extra supplies of the medicines were stored safely in their home for when they were required. We saw that prescriptions and administration records were completed clearly, including the times of administration of medicines prescribed 'as required'.
- We were shown guidelines and a clinical procedure on the intranet. This was for staff to follow regarding the use of anticipatory medications. The guidelines included a formulary with advice on how to use the syringe driver and recommendations for the type and dose of medicines to be used.
- There was also pain and symptom management guidance for staff with advice for what to do under specific circumstances for example if an end of life patient was experiencing restlessness.
- Staff we spoke with were aware of the guidance and how to access the SPCT for advice should they need it.

Safeguarding

- Systems were in place to protect people in vulnerable circumstances from abuse. Staff were knowledgeable about their roles and responsibilities in relation to ensuring vulnerable adults and children were safeguarded. Staff understood what constituted a safeguarding concern and could demonstrate the processes to raise a safeguarding alert.
- In the Macmillan healthcare team, 97% of staff were up to date with safeguarding adults training, 97% had completed safeguarding children level 1 and 89% had completed safeguarding children level 2 training.
- There was variability in the community nursing teams; the average for compliance with safeguarding adults training was 97.2%, safeguarding children level 2 training ranged from 77% to 96%, the average was 88.2% against a target of 95%. Compliance with level three safeguarding children was at 99%.

Medicines

Environment and equipment

- Staff told us end of life patients were considered as 'priority 1' when there was a request for equipment for them. This meant equipment could be delivered to someone's home within four to six hours in order to meet the patient's needs. It could take up to 24 hours to obtain a profiling bed.
- If equipment such as profiling beds and high-risk pressure relieving mattresses were not available from the community equipment store, then they were hired from an external company. Community nurses and a community matron we spoke with told us they had no problems accessing equipment for patients at the end of life in the community.
- The main community equipment store was open five days a week. Staff told us they could obtain equipment out of hours. There was another small store where staff could access limited equipment outside of usual working hours. After our inspection, senior staff told us funding from a national scheme (the better care fund) had been agreed; this would enable the main store to open seven days a week.

Are services safe?

- A community based occupational therapist worked as part of the SPCT. They would assess patients' needs in relation to their home environment and identify equipment required.
- Community nurses were based in either local authority owned or private rented buildings. The trust risk register acknowledged there was poor IT connectivity in some of the buildings. This had meant community nurses had not always been able to access electronic patient records when needed. We could not tell from the risk register what the trust planned to do to resolve this issue.

Quality of records

- We saw both paper and electronic records in use, paper records were used in someone's own home as a record of their care.
- The SPCT used an electronic record system that enabled sharing of patient information within the team and with other health care professionals.
- Community nurses told us they used the same electronic record system and we saw that both specialist and other staff were able to access the records of patients at the end of life. Staff told us there had been some issues accessing the system when out on community visits but that the trust was working with them on developing a solution to access problems. Staff did not feel that this had affected patient care.
- There had been an audit of community records and the trust published a report in May 2015. The records audit had looked at 672 records over a period of 11 months and had looked at all community records. The audit was measured against 10 standards and the results were produced for each team.
- The results were RAG rated (red, amber, green) and red was identified when the records reviewed had less than 69% compliance with a standard. There was variety in the standard of record keeping for both specialist palliative care nurses and community nurses. The majority of the standards had been achieved with 100% attained. However, there were some identified areas for improvement for both specialist palliative care teams and community nurses; some standards were identified as having a red rating.
- Patient records were accessible 100% of the time and 97% of records were chronological and contemporaneous (written as soon as possible after care was given) by community nurses. However, only

64% of records included the patient's religious and cultural beliefs. We saw that 73% of the records included contact details for the next of kin or closest person against a standard of 100%.

- Specialist palliative care team records were also accessible 100% of the time, however only 45% included information about someone's religious and cultural beliefs. We saw that 66% of records included a documented plan of care and only 45% included information that informed consent had been given by the patient.
- An action plan had been developed in June 2015 and actions were either in progress or had been achieved by the time of our inspection in October.
- We reviewed three sets of records for patients on an end of life care pathway. Only one set of records contained a copy of a do not attempt cardiopulmonary resuscitation (DNACPR) form. This meant that staff would not be aware if CPR should take place if a patient suffered a cardiac arrest.

Cleanliness, infection control and hygiene

- Staff undertaking community visits told us they had adequate stocks of hand gel and PPE (personal protective equipment) to take out with them.
- We saw that protective aprons, gloves and wipes were made available for families and care workers in someone's home. We saw staff using PPE, washing hands and using hand-sanitising gel.

Mandatory training

- Mandatory training was provided for all staff providing end of life care. Data produced by the trust indicated there was 100% compliance with mandatory safeguarding training for staff in the specialist palliative care team. The specialist palliative care team were 96% compliant with other mandatory training up to August 2015; however, this had reduced to 76% in September when two new staff members joined the team.
- In the Macmillan healthcare team, there was 90% overall compliance with mandatory training up to September 2015.

Assessing and responding to patient risk

- We saw staff assessed patients and managed patient risk as part of an ongoing holistic assessment process.

Are services safe?

We observed good use of individual risk assessments for patients receiving end of life care. This included the assessment of risk in relation to nutrition and hydration, falls and the potential for pressure area damage.

- We saw a comprehensive assessment and care plan document for care in the last days of life. This pilot document included a record of conversations with patient and their family and assessment of symptoms. There were assessments for patient comfort, their nutrition and hydration needs, and their psychological, emotional and spiritual needs.
- We saw that changes to a patient's condition were recorded in their daily notes by nursing, medical and therapy staff. Advice and support from the SPCT regarding deteriorating patients was available in the community.
- We heard of weekly multi-disciplinary meetings where risks to patients were discussed as part of a routine review of their care and ongoing evaluation.
- We spoke with relatives who had been made aware of how to access help and support should a patient's condition deteriorate when they were being cared for at home.
- There was an out of hour's service for end of life patients, which covered all of North Lincolnshire. Staff told us there was a handover from each of the five community nurse localities between 7pm and 7.15 pm. We were told there was a white board in the out of hour's office, which was updated each day with information about patients who might require interventions or support during the evening/night.
- The information also included whether the patient had a DNACPR in place, anticipatory medication and / or a syringe driver in situ. All nursing and specialist teams had access to an electronic system where the patient's record was held. Patients with a DNACPR in place had an alert symbol on the electronic records for all the clinical staff to see on the front page at first glance.
- Any patients who required a visit from the out of hours team were 'handed back' to the locality team with an update of care given at the morning handover at 7.15-7.30am.

Staffing levels and caseload

Specialist palliative care team

- There were 5.8 WTE Macmillan nurses, who formed the SPCT, most of whom worked 30 hours a week. This

included the community Macmillan end of life coordinator /lead nurse. The team was made up of band 7 nurses and one band 6 who was progressing to a band 7 role. There was also a 0.67 WTE band 5 nurse.

- They had begun to work across seven days the week before our inspection, so it was too early to measure the impact this would have on patients' care and treatment. The service was available seven days a week between the hours of 9am and 5pm.
- Staff told us a minimum of two specialist palliative care nurses would be on duty during core hours on weekdays, one on duty for weekends and bank holidays and a minimum of three were required on the days of the specialist palliative care clinical MDT meeting. If staffing levels fell below this then the patch team leader or operational matron would take action to support the service.
- Staff from the SPCT told us they saw about 13-14 patients a day and had about 50 patients each on their caseload. They told us they had 'dynamic' caseloads, where they would be involved with patients as needed rather than keeping them on the caseload for the duration of their care. This would enable the nurses to manage the caseload across 7 days.
- From April 2014 to March 2015, the SPCT were involved with 606 end of life patients. This was an average of 50 patients each month.
- The SPCT were 'adopted' by Macmillan, yet commissioned the same as way as other services, and were employed by the trust. Under certain circumstances, Macmillan enters into partnership and adopts a post or service; this allows a service to be branded as Macmillan. The principle of the adoption process is that Macmillan only adopts services in line with their current strategy. This meant there were requirements from Macmillan to -
 - Deliver the best quality care, working effectively in teams
 - Ensure the post holder and their service are up to date
 - Work to continually improve and innovate within their service.
- Out of hours, (5pm to 9am) generalist palliative care support to patients and their families was available from the community nurses, out of hours GP's and NHS 111 non-emergency service.

Are services safe?

- There was a 0.6 WTE band 3 specialist palliative care multi-disciplinary team coordinator. They gave administrative support to the team, which included the recording of patient outcomes.
- Staff told us there was allied health professional input into the SPCT in the form of a physiotherapist and occupational therapist.
- There was a dedicated full time clinical psychologist, who used a variety of therapy methods for patients, including 'acceptance' and compassion-focussed therapy.

Macmillan healthcare team

- There was a Macmillan healthcare team made up of 32 healthcare support workers who were band 2, 3 and 4. The band 4 support workers planned the rota for their 'patch' and dealt with day-to-day issues. They ensured close liaison took place with the community nurses. Staff told us further funding was being sought to expand the band 4 role.
- The Macmillan healthcare team worked across 24 hours, seven days a week and provided direct care to patients in their own homes. The care 'packages' for patients and their families or carers included a sitting service at night or in the day time to enable family and carers to have time to rest or take a break. There was an average of three to five staff on duty at night providing the night sitting service. Usual levels were three staff, but this was flexible to meet patient's needs.
- Senior staff told us there had been a successful business case to expand the Macmillan healthcare team two years ago. The service was able to expand from 10 whole time equivalent (WTE) staff to over 30 WTE, thus tripling the service capacity and enabling the team to offer more patients' night sitting service, over seven nights a week. This was done to improve the quality of end of life care, reduce the reliance on home care agencies, and to provide support to care homes with residents at the end of life.

Community nursing services

- Community nursing services were available 24 hours a day, seven days a week. They were divided across five clusters. Community nurses assessed the needs of patients, planned the care package and provided nursing care to end of life patients.

- The board papers from August 2015 indicated there were 20 community nurse vacancies. The trust risk register showed this had resulted in an increase in missed visits to patients and an increase in medication errors. It was not certain if any of the incidents affected end of life patients.
- It was noted by the trust that staff stress and sickness had increased. Information given to us by the trust showed two of the community nurse teams had some of the highest levels of staff sickness of all the community services. Sickness was 9.7% in one team and sickness across all the community nurse teams was an average of 7.3% against a community average of 3.3% at the trust.
- We saw that there were half the planned establishment of registered community staff nurses at Epworth clinic base. Staff told us they had to send nurses to cover other areas when there was staff sickness. Staff told us there was between 140-150 patients on the caseload, which was an increase of 30% over the last three years. It was not certain if this had an impact on the continuity of care for end of life patients.

Medical staffing

- Two palliative care consultants had been appointed in recent weeks before our inspection.
- They covered both hospital and community services.
- Staff told us they could ring the consultants for advice and ask them to review patients in the community.

Managing anticipated risks

- We saw the trust document 'Action Points for Winter Management 2015' did not contain reference to community end of life services. There was focus only on plans for the acute hospital services. It was not clear that winter management plans ensured that people receiving end of life care continued to receive it at a safe and appropriate level.
- Staff told us they had informal arrangements during adverse weather conditions which included local social work staff and community nurses working collaboratively to meet the needs of patients.

Are services effective?

By effective, we mean that people's care, treatment and support achieves good outcomes, promotes a good quality of life and is based on the best available evidence.

Summary

We rated effective as 'requires improvement' because:

- There was no local end of life strategy or related performance indicators to measure the success of the service. We saw that staff used national guidelines however; the use of clinical audit could have been improved to determine the effectiveness of care. It was not possible to tell if patients' preferences at end of life were met, as preferred place of care was recorded, but not audited.. Trust data indicated that a large number of end of life patients admitted to hospital in 2014 died within a short time of admission. A review of some of these patients indicated they may not have required a hospital admission if more end of life care services were in place. A number of these patients did not have advanced care plans in place; the implementation of such plans may have reduced unnecessary admissions for patients into hospital. The trust recognised this was a significant weakness and they were taking action to address this.
- The trust had taken part in the 2014 National Care of the Dying Audit (NCDAAH) and achieved three out of seven organisational key performance indicators (KPI's). In relation to clinical KPI's, the trust was better than the England average in only one out of ten areas. It was worse than average in eight out of ten areas including, communication regarding the patient's plan of care for the dying phase. Action had been taken to address the audit findings; an individualised care plan and last days of life assessment and care plan were being piloted. We noted that national guidance was not followed in as much as the DNACPR forms were not audited in the community. It was not known therefore whether decisions were made appropriate or if they were documented clearly.

However, we also found;

- We saw positive examples of multi-disciplinary working to support quality end of life care across the community. Patient's needs were assessed and care was planned and delivered in line with evidence-based guidance; however, there was a lack of monitoring to ensure their

wishes were complied with. Staff were well trained and competent in their roles. Training had been delivered to staff in care homes to improve the effectiveness of care they gave.

Evidence based care and treatment

- The SPCT delivered care in line with evidence-based guidance such as the North Lincolnshire End of Life Care Network and End of Life Care Guidelines. The guidance was available on the hospital intranet with hard copies available in clinical areas.
- The SPCT participated in the Sub Regional Palliative & End of Life Care Group and the Yorkshire and Humber regional DNACPR strategic working group
- In response to the national withdrawal of the Liverpool Care Pathway (LCP) in July 2014, the trust had developed a 'my future care' document. This was based on national guidance and supported the delivery of individualised end of life care.
- The trust did not have a last year of life policy, or a framework for end of life care; however, we saw that national guidelines were used to develop other care policies. These guidelines included -
- Subcutaneous Fluids in Palliative Care and The National Council for Palliative Care (2007)
- Artificial Nutrition and Hydration, National Guidance in End of Life Care for Adults- Leadership Alliance for the Care of the Dying People (2014)
- National End of Life Care Programme: Improving End of Life Care Guidance for staff responsible for care after death (2014). Guidance from the British Medical Association, the Resuscitation Council (UK), and the Royal College of Nursing Resuscitation Council (UK)
- We saw minutes from the July 2015, North Lincolnshire end of life care network where it was discussed that a number of patients had recently died in hospital as a result of advanced care plans not being in place.

Pain relief

Are services effective?

- There were tools in place to assess and monitor pain, and pain control was a priority for staff involved in end of life care. The comprehensive pain assessment tool was based on the one used in the local hospice.
- Patients and families we spoke with told us pain was well managed and staff were quick to respond to requests for additional medicines when pain occurred.
- We observed community nurses assessing patients' pain levels in the community. We saw they assessed the type and duration of pain as well as factors that made the pain better or worse.
- All qualified nursing staff were trained in the use of syringe drivers. We saw patients had syringe pumps that delivered measured doses of drugs at pre-set times.
- There were medicines guidelines used for pain relief at the end of life.
- Staff told us they worked closely with local pharmacies to ensure there were adequate stocks of appropriate medicines available; this included during the day and out of hours.

Nutrition and hydration

- Nutrition and hydration were assessed and monitored using the individual care plan and the last days of life care plan.
- Assessments incorporated patient choice and comfort and we saw prompts for staff to make decisions in the best interests of patients without the mental capacity to make their own decisions. This took into account any known prior preferences and wishes and was in consultation with the person's family, carers and other members of the team.
- There was a strong focus on keeping patients comfortable. Staff were clear that nutrition and hydration needs were led by the patients.
- Specialist palliative care staff told us they would provide advice to other staff on a regular basis about nutrition, hydration and regular mouth care to promote comfort at the end of life.
- We saw guidelines for staff around clinically assisted nutrition and hydration (infusions and artificial feeding), and how to seek advice from the SPCT in the event of this being discussed.

Patient outcomes

- The trust had taken part in the 2013/14 National Care of the Dying Audit (NCDHAH) and achieved three out of

- seven organisational key performance indicators (KPIs). These were in the areas of access to information, education around end of life and having protocols for medicines. (This was the most recent available data).
- The trust was worse than the England average for access to specialist palliative care, board representation for end of life care, the promotion of privacy and dignity at end of life, and the feedback process for bereaved relatives.
- In relation to clinical KPIs, the trust was better than the England average in just one out of ten areas, this was multidisciplinary recognition the person was dying. It was worse than average in eight out of ten areas including, communication regarding the patient's plan of care for the dying phase.
- Northern Lincolnshire and Goole was significantly worse than the England average for assessment of spiritual needs of the patient and their nominated person.
- We saw areas identified for improvement as part of the NCDHAH had been addressed through an integrated end of life action plan (October 2015) and the development of the last days of life care plan which was still in the pilot phase during our inspection.
- Information about the outcome of peoples care was not routinely collected or monitored. For example, there were standard audits of infection prevention and control, catheter audits, hand hygiene audits, and documentation/ records audits; however, we did not see specific audits of preferred place of care, the outcomes of advanced care planning or bereavement audits.
- The integrated end of life care action plan included an action (for completion by December 2015) to audit deceased patient's notes. This was to identify if 'appropriate care had been delivered in the appropriate place.' The outcome of this audit had been given an amber rating by the trust, which meant it had not yet been completed.
- We were not assured the proposed audit would establish if patients' preferences at end of life were met. Senior staff told us they did not know the percentage of people who died in their place of choice.
- Senior staff told us the 'Web V' IT team would be collecting end of life data in the near future. This included patients preferred location for their end of life care. Information would also be collected from the 'last days of life care plans, which had already been audited.

Are services effective?

- We were told the Macmillan lead nurse had visited other trusts to see how an electronic palliative care template could be used to record recording patient outcomes.
- There were other opportunities to measure outcomes for patients by auditing the family /carers diary; however, this had not yet taken place.
- We were told patients completed questionnaires at the beginning of therapy with the clinical psychologist and again after therapy was completed. These, however, had not been collated to show how effective the service had been.
- There had been a trust wide audit of the piloted end of life care plan in September 2015. This took the form of a notes review. Community records had not been audited before the care plan was piloted so full comparisons could not always be made.
- There were however key findings in the community which included -
 - An increase of 50% of documentation of communication with patients to inform them of their last days of life.
 - An increase of 33% of documentation of communication with relatives to inform them of their last days of life.
 - A 17% increase in anticipatory medicines being prescribed.
 - A 75% increase regarding the patients spiritual needs being addressed.
- The SHMI (Summary Hospital-level Mortality Indicator) is an indicator which reports on mortality at trust level across the NHS in England. It is the ratio between the actual number of patients who die following hospitalisation at the trust and the number that would be expected to die on the basis of average England figures, given the characteristics of the patients treated there. The SHMI for this trust was at 112.5 at the end of May 2015 with a particularly marked increase in North Lincolnshire in the Scunthorpe hospital area where the out of hospital SHMI was 130 vs. the in hospital SHMI of 105. Work was underway with community and primary care partners to address this, which was being led by the newly appointed palliative care consultants. Data released at the end of January 2015 covering the time period July 2014 – June 2015 indicated a slightly improved trust score of 109.7 putting the trust ‘within the expected range’ nationally.
- Well-trained and competent staff provided end of life and palliative care. There were 5.8 whole time equivalent specialist palliative care nurses covering North Lincolnshire community and two palliative care consultants. This included the full time band 7 lead nurse. There was also a 0.67 WTE band 5 staff nurse within the team
- We saw evidence from the Quality and Patient Experience Committee (February 2015) to show funding from NHS England was used to deliver additional end of life care training throughout the trust.
- Specialist palliative care nurses told us they had the opportunity to attend relevant training and conferences and take part in projects that developed their roles.
- The specialist palliative care nurses had been ‘adopted’ by Macmillan. This meant there were requirements from Macmillan to -
 - Deliver the best quality care, working effectively in teams
 - Ensure the post holder and their service are up to date
 - Work to continually improve and innovate within their service).
- We saw 88.5% of the specialist palliative care team had received an appraisal from October 2014 to September 2015. There were seven months when this had been at 100%. Appraisals were recorded electronically and staff received an alert when theirs was due to take place. Only 78% of the Macmillan healthcare team had an annual appraisal in the last year. The rate of appraisals for community nurses varied from 61% to 100%, the average was 85.2%.
- Members of the SPCT across the trust attended monthly supervision with clinical psychologist where they had opportunities to reflect on their practice.
- The clinical psychologist also delivered training to staff of how to pick out the most important elements for supervision with their manager.
- Specialist palliative care nurses delivered advanced communication skills training to community nurses, care homes and care agencies. The training included a wide range of end of life care and individualised, advanced care planning.
- This training included Priorities of Care and Recognising Dying. A total of 531 staff had been trained by the SPCT from April 2014 to October 2015.
- The specialist palliative care team had plans to deliver ‘SAGE & THYME’[®] training to a range of community staff.

Competent staff

Are services effective?

(The SAGE & THYME[®] model was developed by South Manchester NHS Foundation Trust. Its purpose was an aide-mémoire to train all grades of staff on how to listen and respond to patients or carers who were distressed or concerned).

- Community nurses told us they had had access to opportunities to develop their end of life care skills and knowledge.
- All community nurses were trained in non-medical verification of an expected death.
- Senior nurses had been trained to complete DNACPR forms, although some we spoke with were reticent about doing this in practice.
- There was a competency framework for all community nurses to ensure they were proficient in the use of syringe driver use.
- The Macmillan healthcare support workers had all attained QCF (qualifications and credit framework) level 2 in health and social care. The band 3 staff had attained level 3 and attended a variety of end of life care study days and 10-week palliative care course. Some support workers had studied an end of life care module for 'skills for care'.
- A patch team leader and one of the band 4 support workers appraised the healthcare support workers.
- The Macmillan lead nurse and a patch team leader held 'debrief' sessions for the healthcare support workers where they could reflect on their practice and end of life situations.
- A patch team leader was a SHINE quality mentor and was identified by a badge. (SHINE was to share, help, integrate/innovate, nurture and empower). SHINE was a trust wide network where staff were encouraged to have ideas which would benefit patients. These were presented to the trusts board of directors to be considered for an award. The Macmillan healthcare team had won a local award in the past and one of the staff had recently been put forward for an individual care award.

Multi-disciplinary working and coordinated care pathways

- We saw positive examples of multi-disciplinary working. Members of the SPCT participated in multidisciplinary team (MDT) meetings, working with other specialists and community nurses to support good quality end of life care across the community.

- We saw minutes of MDT meetings where all professionals had contributed to collaborative working.
- There was a locality based MDT meeting every week. There was representation from the SPCT, community nursing staff, the hospice, hospital, allied health professionals and social workers. The most complex end of life patients were discussed at these meetings and decisions made.
- There were integrated MDT meetings every month, in different localities, where patients were discussed who were receiving integrated services. GPs were involved in these meetings and considerations were given on how to improve care for patients.
- We saw joint working between district nurses and social workers who were based together in premises. We were told in times of adverse weather, joint visits between health and social care staff would be carried out in order that staff were at less risk of travelling alone.
- Although social care and health services had two different IT systems, we saw staff spoke face to face in order to share information about patients.
- Social workers told us they remained involved in end of life care and would carry out bereavement visits where appropriate.

Referral, transfer, discharge and transition

- There was a clear pathway for referral to specialist palliative care services so staff knew when and who to contact.
- Community nurses and community matrons told us they worked together with hospitals when patients moved between services.
- We saw information about an 'unscheduled care' team who helped to keep patients in their own home or care home, if it was safe to do so, during an episode of acute illness. We did not get the opportunity to speak with any of the team during our inspection to find out how they were involved with end of life care patients; however, a district nurse told us they had been involved with an end of life patient and supported them to remain at home,
- Relatives told us once it had been decided their loved one was a 'fast track' patient, they were discharged home from hospital within half a day. (Fast track patients are those who are rapidly deteriorating and may be nearing the end of life).

Access to information

Are services effective?

- We saw risk assessments and care plans were in place for patients at the end of life. Patients were cared for using relevant plans of care to meet their individual needs.
- There was a 'last days of life' assessment form and care plan, which was being piloted in the community. This tool incorporated prompts for staff to assess patient symptoms, identify advance decisions, discuss spiritual needs and agree options regarding hydration and feeding.
- We viewed electronic and paper records that included detailed information about the management of symptoms, discussions and interventions. We saw that when patients were seen by the SPCT, information and advice was clearly recorded so that other staff could easily access the guidance given.
- Community nurses and community matrons told us there had been some issues with patients discharged from the acute hospital in terms of access to information. Community staff maintained contact with hospital services as far as possible when patients were admitted, however they were not always informed when patients returned to the community. They said they often found out patients had been discharged only when family members or carers contacted them. They told us this meant there was a delay in them seeing the patient. We could not corroborate this. However, we observed community nurses contacting hospital staff to obtain information about patients who had been discharged; we saw two incomplete discharge summaries.
- Staff were supported to deliver effective care and treatment by the use of electronic care records that included case notes risk assessments and care plans. All community staff including GPs had access to this information.

- Paper records were kept in care homes; community nurses told us end of life patients in care homes also had electronic care records for health staff to access. Hospice staff could also access electronic records.

Consent, Mental Capacity act and Deprivation of Liberty Safeguards

- All specialist staff we spoke with understood the mental capacity act and issues around deprivation of liberty safeguards.
- We viewed prompts on the last days of life documentation relating to best interest decisions. This was for patients who did not have capacity to make decisions about their own care and treatment and included decisions about food and drink.
- We saw records had been properly completed for a mental capacity assessment and a best interest decision made for an end of life patient.
- We viewed one do not attempt cardiopulmonary resuscitation (DNACPR) form in the community. It had been completed well and recorded an appropriate discussion with the patient and their family.
- We saw that the DNACPR form in use was in line with national guidance.
- We noted that national guidance was not followed in as much as the DNACPR forms were not audited in the community. It was not known therefore whether decisions were made appropriately or if they were documented clearly.
- The community risk register included actions taken to ensure community staff (including GPs) had received training to complete DNACPR forms in line with guidance. We saw this action had been completed by September 2015.
- The non-medical verification of death policy included referenced to deprivation of liberty safeguards (DOLS) and guidance on procedures if patients died with a DOLS in place.

Are services caring?

By caring, we mean that staff involve and treat people with compassion, kindness, dignity and respect.

We found caring to be 'good' because:

- People were treated with kindness, dignity, respect and compassion while they received care. Patients and their relatives spoke positively about the care they received in the community. We observed interactions between staff and patients and saw staff find ways of making the experience of care as easy as possible for people. Relatives could record aspects of care in a diary and staff told us this enabled them to review relatives' experience of care and learn from it.
- We saw and heard of some outstanding examples of care and involvement of patients who were dying, and difficult conversations were done in a sensitive understanding way. Staff were compassionate and understanding of people as individuals.
- The clinical psychologist provided important emotional support to patients who were dying.

Compassionate care

- Patients and relatives we spoke with told us staff were professional, supportive and kind. We observed care being provided and saw that patients were treated with compassion, dignity and respect.
- We saw records included patient choices and beliefs which were communicated between the teams. We saw sensitive information given to someone with compassion and kindness.
- We viewed feedback from patients and relatives in the community that included comments about how caring staff were and how safe patients felt in their care. Comments included,
 - "Macmillan carers do what the title says - they care. Never rushed but always efficient and friendly."
 - "The team are caring, compassionate and nothing is too much for them."
 - "Everyone was very caring. Professional and obviously well trained."
- During our inspection, we saw a bereaved family member meet with the Macmillan healthcare team to thank them in person.

- Macmillan healthcare staff told us of work with some patients who were reluctant to accept care from them. One staff member had looked after someone in the traveling community and built up a relationship by reading to them.
- One staff member told us a member of her family had died at home; when she saw how compassionate and caring the team had been, it made her want to work in the team.
- Staff told us nurse verification of death was a priority so that families did not have to wait for a doctor to attend.
- After a patient died at home, if the family wanted, staff stayed with them and the deceased patient until the funeral directors arrived.
- Community nurses, community matrons and social workers gave bereavement support. They visited families and carers and would signpost them to further support. We heard of staff who had attended patients' funerals.
- We saw that staff looked after each other after giving care in difficult circumstances.

Understanding and involvement of patients and those close to them

- Patients and family members we spoke with told us they felt involved in care.
- We saw staff discussed care issues with patients and relatives and these were clearly documented in patient's notes. We saw evidence that family members had been shown how to give mouth care and recognise signs of pain.
- If patients and families wanted support at night time in their own home, they completed a 'request form' which was sent out to them or taken to them by staff. Family members could make plans for the coming days once they knew which nights they were to expect the night sitter. The service could be flexible if someone's needs changed.
- One family carer told us how the Macmillan homecare team provided a sitting service. This had given them time to meet up at a support group with other people in similar circumstances.
- The 'my future care plan' included prompts for patients about choices and decisions they might wish to make

Are services caring?

before and for after they died. This advanced plan was recorded so staff were aware of patient decisions. The last days of life document also included prompts for discussing issues of care with patients and relatives.

- We were shown a blank patient and family diary where questions and comments could be recorded for staff to respond. Relatives could record aspects of care around the degree of symptoms the patient experienced including pain, nausea and distress. They could also record if the care and support the patient and relatives received was sensitive. Staff told us the use of the diary enabled them to review relatives' experience of care and learn from it.

Emotional support

- Specialist palliative care nurses were trained in advanced communication skills and the clinical psychologist offered a range of therapies to end of life

patients in clinics or in their own homes. Therapies included compassion focussed therapy and acceptance therapy. If the clinical psychologist were not available, their manager would see patients in times of crisis.

- The clinical psychologist also worked with staff and provided lunchtime sessions on narrative therapy (helping people identify their values so they can effectively confront difficulties) and mindfulness, so they could support patients more effectively. (Mindfulness is paying attention in a particular way to increase awareness).
- Healthcare support workers told us it was important to spend time with patients and provide support to meet their needs.
- We heard specialist nurses and community nurses speak of the importance of assessing people's emotional needs as a matter of routine when visiting them at home.

Are services responsive to people's needs?

By responsive, we mean that services are organised so that they meet people's needs.

Summary

We rated responsive as 'requires improvement' because;

- We were shown information that indicated last year, 600 end of life patients were admitted from home or care homes and died within 24 hours of admission to hospital. Senior managers told us they had carried out a small audit notes of end of life patients. It was ascertained that 33% of patients were admitted to hospital appropriately; however, 66% could have been cared for at home.
- Staff told us the delivery of care in someone's preferred place was a priority. There was no data to support this as no audits had taken place. The trust was taking action to address this. Recording a preferred place of care can help patients and families to understand what is important to them when planning their care.

However we also found;

- Community teams were quick to respond to individual patient need and referrals were prioritised based on need. The SPCT had recently commenced seven day working to improve responsiveness and avoid unnecessary hospital admission. The Macmillan healthcare team had expanded threefold in order to deliver more care that was consistent for patients, it was able to offer hands on care for patients, and day and night sitters to allow families to take a break. The team had taken action to remove barriers to care for some people who found it hard to access services.

Planning and delivering services which meet people's needs

- We were shown information that indicated last year 600 patients were admitted from home or care homes and died within 24 hours of admission to hospital. It was not known how many of these patients were known to the specialist palliative care team. Senior managers told us they had carried out a small audit of nine sets of notes from these end of life patients. It was ascertained that three patients (33%) were admitted to hospital appropriately, however six patients (66%) could have been cared for at home.
- In October 2015 the SPCT had recently begun to provide a seven day service, from 9am to 5 pm, this was to support the other community based services and the GP out of hour's service with the intention of reducing the number of unnecessary admissions to hospital.
- Staff were very clear that a priority was ensuring patients were cared for in their preferred place of death wherever possible. However this information was not measured therefore it could not be demonstrated it was taking place.
- As preferred place of care was not audited, it was not possible for the trust to use this information to plan and evaluate services.
- The development of the SPCT was enabled following a successful business case earlier this year as part of the Better Care Fund scheme. Although it was anticipated the revised service would meet people's needs, it was too early to ascertain if this would be the case.
- The report from the Yorkshire and Humber Quality Observatory identified that 52.1% of deaths in North Lincolnshire were in hospital. This was slightly lower than the national average (54.5%). There was an aim to further reduce deaths in hospital by 2% per year. This was equivalent to 33 patients per year. It was not known when the target for achievement was.
- Information given to us by the trust indicated the average response time between referral to the SPCT and first contact with the patient had worsened from just over half a day in October 2014 to just over one day in March 2015. Staff told us urgent referrals would be addressed within one working day. For non-urgent referrals, contact was made within three to five days.
- The SPCT had 9612 'contacts' with end of life patients in 2014. This was an average of 801 patients each month. We did not see data to indicate if this was an increase from the preceding year.
- Minutes from trust documents showed the end of life care group met on a monthly basis to develop end of life care services.
- The Macmillan Health Care Team expanded in 2013, and the capacity of the service had tripled. We saw the

Are services responsive to people's needs?

number of patient visits had increased from an average of 644 per month from October 2012 to September 2013 to an average of 1893 visits per month from October 2013 to September 2014.

- Patients received between one and four visits a day from the Macmillan healthcare team, and in addition, they could receive day or night 'sits' to allow family / carers some time for themselves.
- We found the clinical psychologist was a positive addition in delivering services to meet people's needs. The psychologist had been in post for two years and they specifically were available for end of life patients. Referrals were prioritised according to need and there was no waiting list.
- A 24-hour telephone Specialist Palliative Care advice line, either local or regional was currently being considered by the Clinical Commissioning Group to support the services already in place.
- Senior managers told us they had recently received funding from the CCG to recruit a full time end of life care facilitator to influence improvements in end of life care across the area.
- We were shown a service proposal to expand and improve a bereavement service to "Implement a fit for purpose bereavement service". Trust documents from October 2015 indicated a revised business case for a five-day service would be progressed.

Equality and diversity

- Patients receiving end of life and palliative care were treated as individuals.
- Equality and diversity training was delivered to all staff as part of their induction to the trust.
- The end of life policies all contained reference to equality and diversity. The equality and diversity policy included reference to the protected characteristics of the equality act (2010).
- The care after death policy included guidance for staff in relation to people's cultural and religious preferences.
- There were both female and male healthcare support workers. If patients preferred care to be given by a male or female worker, this was accommodated as far as possible.
- The demographic of end of life patients had changed in recent years and there were a number of eastern European patients on the community caseloads. We saw that the community SPCT had used interpreters 14 times in the last year.

Meeting the needs of people in vulnerable circumstances

- Services were delivered in order to take account of people with complex and additional needs, for example end of life patients with dementia or those with Asperger's syndrome.
- Family members told us how a care package had been arranged to meet the specific needs of their loved one who had advanced dementia. The Macmillan healthcare team worked with care workers the patient was already familiar with in order to reduce distress for the patient and family.
- The clinical psychologist told us how care had been arranged and delivered for people with Asperger's syndrome.
- We found the Macmillan healthcare team had taken action to remove barriers to care for some people who find it hard to use services. They had provided a sitting service for traveller families from the local community.
- We saw development of an easy read document to enable people with learning disabilities to understand about DNACPR decisions, "What happens if my heart stops". Staff from the community were part of a regional group working on this.

Access to the right care at the right time

- The community SPCT responded to urgent referrals within one day. Referrals were prioritised based on patient need and non-urgent referrals were responded to within three to five days.

The trust only had partial data, which showed response times up to March 2015.

- Community nurses and the SPCT told us the seven-day service from the community SPCT would benefit patients so they had timely access to care and treatment. The seven-day service had been developed in response to the Northern Lincolnshire and Goole gap analysis. This found there had been "inadequate out of hour's service, including overnight and weekend service provision".
- Family members and a patient told us staff were responsive to their needs. One relative told us they had phoned community nurses to say the patient was in distress and nursing staff responded within minutes to their call.

Are services responsive to people's needs?

- Community matrons and community nurses told us patients had their mobile number so they could call directly during working hours. A message advised who to ring out of hours. We found that community matrons remained involved with end of life patients and their family for the whole episode of their care, including after the patient had died.
- Community matrons and the SPC nurses were non-medical prescribers. They told us they used these skills “every single day”, for the benefit of patients.
- We found the Macmillan healthcare team were responsive and flexible; care packages would start almost immediately after the community nurses had requested them.
- It was not known how many patients achieved their wish to die in their preferred place of care, as this was not audited. However we saw notes from the Integrated end of life care action plan of October 2015, which stated deceased patients notes were to be audited by December 2015.

Learning from complaints and concerns

- Complaints and concerns were listened to and learning was used to improve services. We saw there had been one formal complaint about end of life care in June 2015. We saw there had been a comprehensive action plan developed as a result, to minimise this reoccurring. An action plan had been mostly completed. One action remained related to the completion of ‘workbooks’ reminding staff how to respond to complaints as they arose; this was due for completion in December 2105.
- We saw the outcome of the complaint had been explained to the family in writing.
- Staff from different patches told us they knew of the complaint and lessons had been learned across the whole community team.
- Staff told us the number of complaints was low and it was “unacceptable to deliver care resulting in a complaint as there was only one chance to get it right”, for end of life patients.

Are services well-led?

By well-led, we mean that the leadership, management and governance of the organisation assure the delivery of high-quality person-centred care, supports learning and innovation, and promotes an open and fair culture.

Summary

We rated well-led as 'requires improvement' because:

- There was no trust specific end of life care strategy for the trust. We found the absence of a strategy had resulted in staff not knowing the vision for end of life care and the trust not having effective monitoring of the quality of the service provided. However, an end of life care lead had recently been appointed on the trust board and senior leaders were involved in developing an end of life care strategy. The trust had also acknowledged the need for senior clinical leadership and had recently appointed its first two palliative care consultants. Whilst the team were very positive and work had started there was more to do before the impact for patients could be evidenced.
- Arrangements for monitoring quality of services could be improved; there were gaps in service performance measures. This meant it was harder for the trust to take action to improve performance and the delivery of the service. We found there was disconnection between the trust board and staff in the community.

However we also found;

- Positive leadership at a local level in the community. Service leaders were visible and approachable. Staff were proud of the care they were able to give and received positive feedback from patients, families and carers; they told us senior managers did not acknowledge this.
- We found positive innovation by the use of a Macmillan healthcare team to deliver end of life in the community and from the inclusion of the clinical psychologist in end of life care for people.

Service vision and strategy

- There was no trust specific end of life strategy or related performance indicators to measure the success of the end of life care services. However, the trust told us they were part of the wider health economies' strategic groups for end of life care. Senior managers told us the trust had used the National end of life care strategy (2008) as a framework in the past.

- Papers from the trust's Mortality Performance & Assurance Committee in August 2015 noted there was progress on the development of a trust wide end-of-life strategy (including the development of an end-of-life care pathway).
- Senior staff told us a trust strategy would be in place by December 2015. It was not clear if the trust were going to incorporate more up to date national guidance into their strategy, for example the NICE Quality Standard for End of Life Care (2011) or 'Actions for End of Life care 2014-2016' (NHS England) .
- We found that staff were not aware of a vision or strategy for end of life care nor what was in place to monitor the quality of the service provided. Staff were committed on a daily basis to ensuring that people approaching the end of their lives were cared for in their preferred place of care and that care provided would be high quality, timely and appropriate to patient needs. However, staff could not tell us their role in achieving the strategy.
- There was an aim to improve access to specialist palliative care by the introduction of a seven-day model. We saw the Northern Lincolnshire and Goole end of life action plan was based on the CQC inspection framework and Parliamentary and Health Service Ombudsman 'Dying without Dignity' report (2015) and there was ongoing consultation with the CCG and other service providers.
- Senior staff told us there was some difficulty in getting a whole of Lincolnshire approach to end of life care as different CCG's commissioned different services. We saw minutes from the strategy implementation group of August 2015 where it was noted due to the different patterns of community provision in North and North East Lincolnshire; the trust may need to sustain two work streams in order to plan services.
- Community staff told us senior specialist palliative care staff continually tried to develop the service to meet the ongoing needs of patients and their families.

Governance, risk management and quality measurement

Are services well-led?

- We found arrangements for monitoring quality of services could be improved. The actions and measures of success of an organisation flow into divisional plans and from there to individuals, to ensure a 'golden thread' running down the organisation and back to the board which was not in place for this service
- There was an absence of quality measurement related to preferred place of care, advanced care planning and bereavement support.
- We saw evidence that quality and risk related to end of life care was reviewed at divisional level, we found a lack of evidence this was regularly reviewed at board level. After our inspection, senior managers told us a quarterly report on end of life was discussed at a board sub committee.
- Community end of life services were in the community and therapies group of the trust and reported into the trust governance and assurance committee.
- We viewed minutes from monthly SPCT meetings and the strategy implementation group. Monthly SPCT meetings include standard agenda items such as the training and education, admissions from the community to hospital, the future of SPC services. In addition, updates on work streams and key stakeholders were discussed.
- SPCT and community nursing risks were included on the community and therapies risk register.
- Plans discussed at the mortality reviews included the delivery of teaching sessions to GPs on end of life issues for patients with chronic obstructive airways disease and a proposal for care of elderly consultants to review care home patients to initiate end of life care in the community. There was a record of issues regarding patients being admitted to hospital at the end of life because they are unable to access other services.
- We saw there was to be an 'end to end' review to look at situations where end of life patients were admitted and died within 24 hours of admission to hospital.
- Staff told us how support workers were recruited to the Macmillan healthcare team and how important it was to recruit staff with the right values.
- We observed positive local nurse leadership for end of life care within both specialist and generalist community services.
- All staff we spoke with in leadership roles had a good understanding of the importance of high quality end of life care and we consistently heard from staff that end of life care was prioritised based on patient need.
- We saw evidence of the SPCT providing end of life care leadership across all services within the trust, extending to external services such as care homes.
- A matron, who was the lead for adult specialised community services, managed the SPCT. The matron had clinical responsibility for the Macmillan nurses, the Macmillan healthcare team, the out of hour's community nurses and the unscheduled care team.
- An operational matron, who was the lead for planned adult community services, managed the patch team leaders and community matrons.
- The newly-appointed chief nurse was the board lead for end of life care and had previously chaired the end of life strategy group. A non-executive director had been recently identified to provide board support and challenge.
- We found positive nurse leadership; we noted the previous CQC inspection report in July 2014 discovered a lack of medical leadership and direction in end of life care. It was too early after the appointment of two palliative care consultants to identify if medical leadership and direction would be improved.
- We found there was disconnection between the trust board and staff in the community. Staff were proud of the care they were able to give and received positive feedback from patients, families and carers; they told us senior managers did not acknowledge this.

Leadership of this service

- We saw that local nurse leaders had the knowledge, capability and integrity to lead the end of life care services. The patch team leaders and Macmillan end of life lead were well thought of by staff and were visible and approachable. We found that these leaders encouraged supportive working relationships amongst the teams.

Culture within this service

- Staff we spoke with demonstrated a commitment to the delivery of good quality end of life care. There was evidence that staff felt proud of the care they were able to give and there was positive feedback from nursing and care staff as to the level of support they received from the SPCT.

Are services well-led?

- There was evidence that the culture of end of life care was centred on the needs and experience of patients and their relatives. Staff told us they felt able to prioritise the needs of people at the end of life in terms of the delivery of care.
- We observed good collaborative team working across the community SPCT and community nursing teams.
- There was a positive learning culture especially in the Macmillan healthcare team; staff told us there were opportunities for development and training. Four community nurses told us pressure of work meant they could not always attend end of life training.

Public engagement

- We saw that people's views and experiences had been gathered in the development of 'my future care plan' and supporting carers of people with dementia at end of life.
- The use of the family's diary enabled staff to engage with relatives of those patients at the end of life, both in terms of the immediacy of care issues and also in terms of learning from their experiences.
- The SPCT had held public events during 'dying matters' week in 2015. (Dying Matters is a coalition set up by the National Council for Palliative Care to help people talk more openly about dying, death and bereavement, and to make plans for the end of life).
- We saw the Friends and Family Test (FFT) for September 2015 showed 100% of people would recommend both the community nurses and the SPCT to their friends or family. (The FFT is a national survey tool which asks people if they would recommend the services they have used).

Staff engagement

- We found there was a disconnection in communication; for example, there was a lack of awareness of who the

- trust lead for end of life care was. Several community staff did not know palliative care consultants had been appointed, nor that there was a clinical psychologist in post.
- The clinical psychologist had been in post two years and was unaware there was an end of life strategy group.
 - We found there was much more focus on acute hospital services than the community related to end of life care. Staff told us they sent all the 'thank you' cards and compliments to the board but they "never heard anything back" in the way of praise. They told us "very senior managers did not seem interested in the community teams".
 - We saw publications and newsletters, which focused on aspects of care within the hospital. There was an opportunity to promote community services such as the Macmillan end of life team and clinical psychologist.

Innovation, improvement and sustainability

- The SPCT were focused on continually improving the quality of care and we observed a commitment to this within the community nursing teams and Macmillan healthcare teams we spoke with.
- We found positive innovation by the use of a Macmillan healthcare team to deliver end of life in the community.
- Information from the Macmillan health care team annual report (October 2013 – October 2014) showed previous spend of agency care in excess of £1.4m which was funded via Continuing Health Care. It was envisaged that the quality of care end of life patients received could be improved by implementing a robust and consistent service delivered by the trust.
- We also found positive innovation from the inclusion of the clinical psychologist in end of life care for people in the community. We saw that a report from the British Psychological Society (2013) found this to be best practice.

This section is primarily information for the provider

Requirement notices

Action we have told the provider to take

The table below shows the legal requirements that were not being met. The provider must send CQC a report that says what action they are going to take to meet these requirements.

Regulated activity

Treatment of disease, disorder or injury

Regulation

Regulation 17 HSCA (RA) Regulations 2014 Good governance

- How the regulation was not being met: The trust did not have suitable arrangements in place to assess, monitor and improve the quality and safety of the and the quality of the experience of people receiving services.

The trust must ensure that:

- There is an end of life care vision and strategy in place that reflects national guidance and ensure staff are included in the development of these. Reg 17(2)(a)
- Effective systems are in place to assess, monitor and improve the quality of the end of life care services including auditing preferred place of care and other outcomes for patients. Reg 17(2)(a)