Buckinghamshire Healthcare NHS Trust

RXQ

Community end of life care

Quality Report

Buckinghamshire Healthcare NHS Trust
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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)
RXQX5	Buckinghamshire Healthcare NHS Trust		
RXQ65	Marlow Community Hospital		
RXQ62	Thame Community Hospital		
RXQ61	Buckingham Community Hospital		

This report describes our judgement of the quality of care provided within this core service by Buckinghamshire Healthcare NHS 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 Buckinghamshire Healthcare NHS Trust and these are brought together to inform our overall judgement of Buckinghamshire Healthcare NHS Trust

Summary of findings

Ratings

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

Summary of findings

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Overall summary

Overall this core service was rated as 'good'. We rated community end of life care as 'good' for providing a safe, effective, caring, responsive and well led services.

Our key findings

Are services safe?

- Incidents were reported and there was evidence of learning and improvement as a result. Safeguarding procedures were understood.
- Patients were supported to understand the medication they were taking and how this could be best used to control their symptoms.
- Medicines to support patients at the end of life were available in the community. Patients had the equipment they required to support their care safely in their own home.
- Staff followed good infection control procedures.
- There were sufficient specialist staff to support patient.
- Staff used records appropriately and were well informed about the potential risks for patients and how these were to be managed.
- Do not attempt cardio-pulmonary resuscitation (DNA CPR) forms were being used and this was monitored through audit.

Are services effective?

- In line with national recommendation the Liverpool Care Pathway was no longer being used and the trust had developed a new pathway that was about to be trialled. Consideration was being given to the Priorities for Care of the Dying Person set out by the Leadership Alliance for the Care of Dying People.
- New treatment escalation plans had also been developed in line with national guidance. Patient's pain was well managed and the clinical nurse specialist (CNSs) worked in partnership with patients to ensure that this was achieved.
- Patients nutrition needs were discussed and reviewed by the CNS as part of their holistic approach.
- The trust had participated in the 2013/14 National Care of the Dying Audit – Hospitals (NCDAH) and did not achieve five of their seven key performance indicators (KPI's) but was similar to the England average for most of the clinical indicators. Local audit to monitor the effectiveness of services was not well developed. The trust had acknowledged this gap and audit needed to be introduced.
- Training in end of life care was available to all staff and specialist staff was further supported to develop their skills. A
- There was a single point of access for all referrals for specialist palliative care and anyone, including parents, could refer a child to the children's palliative care team.
- Staff worked together to provide a multidisciplinary service and GP services to provide holistic care and prevent emergency admissions.
- Staff had the information they required to care for patients and were conscious and informed about the requirement to seek consent.

Are services caring?

- Staff demonstrated a caring and compassionate approach.
- Patients and their families were positive about the care and support they received and the way they were treated.
- Staff were courteous and treated patients and their families with dignity and respect. Patients and their families were involved and encouraged to be partners in their care and in making decisions.
- People and staff work together to plan care and there is shared decision-making about care The CNSs provided emotional support and would refer patients to other professionals if additional support was required.

Are services responsive?

- The trust had developed an action plan to improve its end of life service and a project lead had been employed to move this forward. The trust had engaged with staff, patients and their relatives as part of this project.
- The CNSs took a holistic approach to their role and the service was available to all.
- The children's hospice at-home team offered individually tailored care, adapted to the child and family's needs.

Summary of findings

- An interpreting service was available although family members often acted as interpreter.
- The CNS managed their own diaries to ensure that patients were visited at time suitable for them. The children's palliative care team worked in a similar way liaising with families and scheduling support at a time that would best meet their needs.
- Support and advice was available 24 hours a day and staff were clear on how to access this support.
- The community teams worked together to support patients and their families and to ensure that they had the support and equipment they required.

Is the service well led?

- There was a clear vision for the service and the end of life care strategy was being reviewed to ensure that it reflected the service as a whole.
- The trust was actively making changes to the service to ensure it better reflected current guidance, although while there was some monitoring of the quality of the service, this required further development to include audit and the monitoring of outcomes for patients.
- The director of nursing was the lead for the service at board level and had clear insight into the challenges they were facing and the changes being made.
- At a local level there was respect for the lead consultant in palliative care.
- The matron's role had been expanded and their responsibilities increased, and they were receiving support with their development to assist them in their role.
- There was an open culture that placed the patient and their family at the centre.
- There was a team approach to caring for patients in the community, with joint working between specialist staff, the adult community healthcare team and the community hospitals.

Professor Sir Mike Richards

Chief Inspector of Hospitals

Summary of findings

Background to the service

Buckinghamshire NHS Trust offers a range of acute and community services, and is the main provider of community services across Buckinghamshire.

The trust provides end of life care services for people in their own homes, as in patients in the community hospitals, in the hospice and on the wards in the acute hospitals. This inspection focused on the service provided in the patient's home and the community.

There were two teams of dedicated specialist palliative care clinical nurse specialists who work in the community. One covered the north of the county, and the other covered the south. The teams provide a seven day service from 9am to 5pm and an on-call service out of hours. Patients at home received medical care from their GP. There was a consultant in palliative care based at the trust's Florence Nightingale Hospice who was available to give advice and support. There was support available 24 hours a day.

The community team also provided support and advice to patients in the community hospitals. There were four community hospitals: Amersham, Thame, Marlow and Buckingham, where patients could receive end of life care.

The children's palliative care team provide a hospice at home service, providing respite care in the child's own home. They work flexibly depending on the support required and although not a 24 hour service, the team would adapt to ensure this service was available if this was required.

Our inspection team

Our inspection team was led by:

Chair: Mike Lambert, Consultant in Emergency Medicine, Norfolk and Norwich University Hospital

Team Leader: Joyce Frederick, Head of Hospital Inspections, Care Quality Commission (CQC)

The team of 35 included CQC inspection managers and inspectors. They were supported by specialist advisors, including health visitors, a school nurse, a physiotherapist, an occupational therapist, district nurses, registered nurses, a paediatrician, a GP, a pharmacist, safeguarding leads, a palliative care consultant and palliative care nurses. Three experts by experience who had used the service were also part of the team. The team was supported by an inspection planner and an analyst.

The team that inspected the community end of life care service included a CQC inspector manager and specialist palliative care nurses with support from a palliative care consultant. Teams inspecting other core services supported the team in collecting information that was relevant to this core service.

Why we carried out this inspection

We inspected this core service as part of a community inspection.

Buckinghamshire Healthcare NHS Trust had a comprehensive inspection of its acute services in March 2014. However, its community services were not inspected at that time. We therefore completed the inspection of its community services.

Summary of findings

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 Buckinghamshire Health NHS Trust, we reviewed a range of information we hold about the trust and asked other organisations to share what they knew. We carried out an announced visit on 25, 26, and 27 March 2015.

During the visit we held focus groups with a range of staff who worked within the service, such as nurses and therapists. We talked with people who use services. We observed how people were being cared for and talked with carers and/or family members and reviewed care or treatment records of people who use services. We met with people who use services and carers, who shared their views and experiences of the core service. We carried out an unannounced visit on 10 and 11 April 2015.

For this core service we accompanied two palliative care clinical nurse specialists on home visits, and visited five patients. Four of these patients had family and carers with them. We met with the clinical service leads including the project lead for end of life care service. We visited Marlow Community Hospital, while others visited Thame Community Hospital and Buckingham Community Hospital. We spoke with district nurses and registered nurses and healthcare assistants. We met with a team member from the children's palliative care service. We reviewed care records and the completion of DNA CPR forms.

What people who use the provider say

People were positive about the support they received. There were good relationships built on trust. People complimented the staff on their caring approach and were clear that information was provided in a way they could understand.

Good practice

- The trust contributed to the development, launch and use the Bucks Coordinated Care Record. This is a county-wide electronic end of life register that GP practises, NHS Trusts and hospices have signed up to use to coordinate care and services.
- The specialist palliative care nurses provided a daytime service with telephone advice and support out of hours. Face to face support was available out of hours from the district nurse team. The children's team worked flexibly and provided a 24 hour service when a child was approaching the end of their life.

Areas for improvement

Action the provider MUST or SHOULD take to improve

The trust SHOULD ensure that

- Outcomes are monitored and that the information is used when reviewing the service.
- The quality of the service is monitored through the use of audit.
- Information from complaints that relate to end of life care can be identified and that this information is used when reviewing the service.

Summary of findings

- The end of life strategy is completed and reflects the whole service.
- There is support for the senior nurse of the children's palliative care service.

Care Quality Commission

Buckinghamshire Healthcare NHS 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 safety as 'good'

Incidents were reported and there was evidence of learning and improvement as a result. Staff understood and followed the principles of being open and transparent when things go wrong. Safeguarding procedures were appropriately followed. Patients were supported to understand the medication they were taking and how this could be best used to control their symptoms. Medicines to support patients at the end of life were available in the community. Patients had the equipment they required to support their care safely in their own home. Staff followed good infection control procedures and received appropriate mandatory training.

There were sufficient specialist staff to support patient and staff used records appropriately and were well informed about the potential risks for patients and how these were to be managed. Do not attempt cardio-pulmonary resuscitation (DNA CPR) forms were being used and this was monitored through audit. Those reviewed in the community as part of the inspection were correctly completed.

Incident reporting, learning and improvement

- The trust had an electronic system for the reporting of accidents and incidents. Staff were aware of the system and the need to report incidents. The clinical nurse specialists (CNSs) we spoke with were clear that they had a responsibility to report incidents.
- According to the specialist palliative care score card there had been no serious incidents reported and no incidents that had caused actual harm in the 11 months (April 2014 to February 2015).
- Information from the National Reporting and Learning System (NRLS) between March 2014 and February 2015 showed that there had been 66 incidents reported for community end of life care. The incident category that was most frequently reported was trips and falls (43.7%); 97% all incidents had resulted in low or no harm.
- In order to cascade learning from incidents the trust had introduced a 'lessons learned' session – a drop-in event open to everyone held on a monthly basis. These were promoted through emails and posters. A member of staff would present the incident. These took place at one of three sites in Aylesbury, Wycombe and Amersham. The event was held twice on the day and teleconferenced to enable attendance from a wider

field. These had been in place for five months. The feedback from community-based staff was that although they knew about the sessions, being able to attend was more of an issue due to workload and travel time.

Duty of Candour

- The Duty of Candour requires healthcare providers to disclose safety incidents that result in moderate or severe harm, or death. Any reportable or suspected patient safety incident falling within these categories must be investigated and reported to the patient, and any other 'relevant person', within 10 days. Organisations have a duty to provide patients and their families with information and support when a reportable incident has, or may have occurred
- We did not specifically discuss the trust's and staff's responsibilities under Duty of Candour. We did find that staff were open and honest in their discussions with patients and their families at all times.

Safeguarding

- The trust had a safeguarding leadership team. The chief nurse was the board lead for safeguarding and was supported by a lead at associate director level. There was a lead professional for child protection, a lead nurse for child protection in the emergency department, a lead for safeguarding adults and a named midwife for child protection. The children's safeguarding team was further supported by five named nurses for child protection, with four of these based in the community setting. The lead for safeguarding adults was supported by a safeguarding nurse based in the emergency department and a learning disabilities nurse. A plan was being implemented to introduce safeguarding champions at division level. These staff members would have a training role and work to ensure that staff were kept informed about guidelines and policies.
- Safeguarding training was available as e- learning and as face to face. Across the trust, completion of level 1 safeguarding adults training was 82% and level 1 safeguarding children training was 83%.
- The clinical nurse specialists were clear about their responsibilities with regards to safeguarding, what constituted abuse and their role in reporting concerns.

Medicines management

- The CNSs in the community had an active role in reviewing and monitoring patients' medication. We observed discussion around the effective use of medication to help with symptom control including pain, nausea and insomnia.
- A second CNS actively supported a patient to sort out their out of date medication.
- All the clinical nurse specialists were nurse's prescribers and were able to directly support patients with the management of their medication. They could also prescribe medicines for administration by syringe drivers.
- A range of end of life medicines (including controlled drugs (CDs)) were kept as stock in the community hospitals to ensure they would be immediately available if required.

Safety of equipment

- A central register of equipment was held by the trust. An audit had been undertaken over the previous 18 months to ensure that the register was up to date. There was an established planned preventative maintenance for all medical equipment. The system could track equipment that could not be found when maintenance or a service was due.
- The trust had taken a risk-based approach to the testing of portable electrical appliances. This was reported to be in line with guidance and meant that some items would be tested annually and other items up to four years.
- New syringe drivers were being introduced across the trust. Staff champions were used to ensure that the training was cascaded and staff were informed and trained in the use of the new devices. From discussion with staff across the community settings it was clear that this initiative had been embraced by the teams and they were ready for the new devices.
- The district nurses took a lead in ensuring that patients had the equipment they required, including syringe drivers. Occupational therapy support was available if required to help access the resources a patient may need to enable them to continue to live safely in their own home.

Good ●

Are services safe?

Records and management

- There were two sets of records, an electronic system and a paper system.
- Multidisciplinary patient notes were maintained and stored securely in the community office based within the hospice and taken out by the clinical nurse specialist when visiting patients. Access to the electronic records was through a secured system.
- In order to ensure the records were kept up to date, the CNS made add a double entry in the hard copy notes and on the electronic system.
- Do not attempt cardio-pulmonary resuscitation (DNA CPR) forms were being used and this was monitored through audit. The re-audit of compliance with completion of DNA CPR forms (trust wide) in August 2014 found that overall there had been an improvement in documentation both on the forms and within the notes of DNA CPR discussions with patients and their families, although there was still room for improvement. Other issues related to the verification of DNACPR forms by the responsible consultant if the decision was made by a junior or specialty doctor and there was also very limited (15%) review of DNA CPR decisions.

Cleanliness, infection control and hygiene

- The trust quality monitoring score card demonstrated that the specialist palliative care team had consistently scored 100% in their hand hygiene audit. This was supported by the good practices we observed, including the use of hand sanitising gel and hand washing.

Mandatory training

- Staff were clear about their responsibilities to ensure that they were up to date with their required mandatory training. In the community teams, 98 % were up to date with their mandatory training. Staff in the children's palliative care team were 92% compliant with their mandatory training.

Assessing and responding to patient risk

- We observed the CNS when visiting patients reviewing the risks associated with the patient's care, for example reviewing and removing out of date medication and discussing how a patient could safely visit the cinema.
- The trusts had introduced a new care plan for end of life care. The care plan called 'getting it right for me' included a distress thermometer tool for patients to use to talk with healthcare professionals about any distress and to help establish what additional support services, such as counsellors, was required.
- The Waterlow Score pressure ulcer risk assessment tool was used to assess the risk of pressure area damage to ensure that appropriate measures were put in place to manage any risks.

Staffing levels and caseload

- There were nine community CNSs working for the community specialist palliative care team who provided end of life care for adults. They were split into two teams for the north and south of the county. Information provided by the trust indicated that for February 2015 the north team had 194 patients, with 43 of these being new referrals, and the south team had 126 patients, with 25 of these being new referrals. The south team had conducted 136 visits in the month (this information was not provided for the north team). Each CNS had a caseload of around 40 patients.
- There was no national guidance or tool on the number of patients a community-based CNS should have, as the dependency of the patient and complex family dynamics need to be considered. There was no clear decision making process relating to the size of the caseloads. The CNS staff told us they did not turn people away.
- There was a team of three nurses and one carer who provided a hospice at home service for children. They reported directly to the lead nurse for the children's ward, although they had not had a meeting with the lead nurse for two and half years. The team worked flexible hours according to need. They were supporting 63 children, though most children did not die at home, often choosing to use the hospice facilities available to them in Oxfordshire.

Managing anticipated risks

- The specialist palliative care team worked to support each other and provided a specialist service. This included a 24 hour service with out of hours support through an on call service and the hospice. The district nurses provided a 24 hour face to face service and would visit palliative care and end of life patients if necessary.

Good ●

Are services safe?

- Staff took the time to ensure that patients had their required medication, which for one patient entailed providing an emergency prescription for the weekend and then walking to the local surgery to collect the prescription.

Good ●

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 effectiveness as 'good'.

There was some evidence that National Institute for Health and Care Excellence were being used to inform practice. In line with national recommendation the Liverpool Care Pathway was no longer being used and the trust had developed a new pathway that was about to be trialled. Consideration was being given to the Priorities for Care of the Dying Person set out by the Leadership Alliance for the Care of Dying People. New treatment escalation plans had also been developed in line with national guidance.

Patient's pain was well managed and the clinical nurse specialist (CNSs) worked in partnership with patients to ensure that this was achieved. Medication that may be required to control patient's pain was available in the community hospitals and district nurses spoke positively about anticipatory prescribing. Patients nutrition needs were discussed and reviewed by the CNS as part of their holistic approach to care.

The trust had participated in the 2013/14 National Care of the Dying Audit – Hospitals (NCDAH) and did not achieve five of their seven key performance indicators (KPI's) but was similar to the England average for most of the clinical indicators. Local audit to monitor the effectiveness of services was not well developed. The trust had acknowledged this gap and audit needed to be introduced.

Training in end of life care was available to all staff and specialist staff was further supported to develop their skills. All staff worked together to provide a multidisciplinary service. The CNSs had an ethos that promoted an aversion to risks and developed daily good working relationships with GPs to prevent medical emergencies.

There was a single point of access for all referrals for specialist palliative care. Anyone, including parents, could refer a child to the children's palliative care team. Their needs would be assessed to ensure they could be met and referrals made to other services as required. Staff had the information they required to care for the patient and were conscious and informed about the requirement to seek consent.

Evidence based care and treatment

- Care was being delivered in line with national guidelines. We observed good examples of care in line with National Institute for Health and Care Excellence (NICE) quality standard 13, 'End of life care for adults', which include a holistic approach with good communication between trust staff, patients, their family and other healthcare professionals. The district nurses and CNSs were using the same electronic records to share information and the Bucks Coordinated Care Record was being used to ensure that others, particularly GPs, had access to up to date information at all times.
- The NICE guidance 'Opioids in palliative care: safe and effective prescribing of strong opioids for pain in palliative care of adults' was clearly understood and being used. We observed several examples of CNSs reviewing medication being used to control pain that demonstrated a good awareness of these guidelines. This included the use of steroids to help boost mood and to help fight inflammation, and using slow release morphine tablets instead of oramorph.
- Clinical nurse specialist (CNSs) demonstrated a good understanding of the current chemotherapy regimens and the guidance on the use of high grade anti-sickness medication (antiemetics).
- New guidelines issued in October 2014 by the British Medical Association, The Resuscitation Council (UK) and the Royal College of Nursing stressed the importance of resuscitation decisions being part of end of life planning, involving the patient in treatment escalation plans and focusing on what treatments were appropriate for a patient at a given stage in their illness and as it progressed. The trust had established a group to develop a treatment escalation plan. The new document was about to be trialled on two wards in April 2015.
- Following the withdrawal of the Liverpool Care Pathway the trust and initially used an adapted version of their

generic care pathway. Staff were clear that the Liverpool care pathway was no longer used. Work had now been completed on developing an evidence based end of life care pathway which was about to be trialled.
- Funding has been awarded from Thames Valley Specialist Network for End of Life to support mapping services against new the Leadership Alliance for the Care of Dying People recommendations. These five priorities of care had been used in the development of the new pathway.

Pain relief

- Patient's pain was being actively managed and regularly assessed. The CNSs took an active role in listening to patients and reviewing their level of pain, and they gave advice on the use of medication to control pain. For one patient we saw the CNS discuss the use of diamorphine while also addressing the patient's fear of using the medication.
- In the community hospitals, medication that may be required to control a patient's pain was available. For example, there was one patient who had been identified as approaching the end of life and pain relief had been prescribed and was being used. It was not possible, due to communication difficulties, to discuss the effectiveness of the pain relief with the patient. The new documentation included the Abbey Pain Scale for assessing patient's pain, a tool for assessing pain when patients are not able to verbalise their needs. This would help to ensure assessment of the effectiveness of pain management.
- District nurses told us that medication that a patient receiving palliative care may require was prescribed in advance, this is also called anticipatory prescribing. This meant that staff could administer medication in a timely way without delays caused by the need for prescription.

Nutrition and hydration

- CNSs included discussions about appetite in the holistic assessments they undertook when visiting patients in their own homes. We observed during a home visit the CNS discussing the use of medication to help alleviate nausea and the use of steroids to help with a person's appetite.

Approach to monitoring quality and people's outcomes / Outcomes of care and treatment

- There was limited information made available that related to the monitoring of quality and outcomes.
- The trust was not using the End of Life Care Quality Assessment Tool (ELCQuA) although it had been recognised that an audit tool did need to be used.
- The trust had contributed data about end of life care to the national minimum data set. For the national care of the dying audit 2013/14. The trust had not achieved five of the seven organisational key performance indicators (KPIs) although was similar to the other trust but was below the England average for the majority of the clinical indicators of care.
- The organisational KPIs that were not achieved related to access to information relating to death and dying; trust board representation and planning for care of the dying; clinical protocols for the prescription of medications for the five key symptoms at the end of life; clinical provision/protocols promoting patient privacy, dignity and respect, up to and including after the death of the patient; and formal feedback processes for bereaved relatives/friends views of care delivery. The two achieved were access to specialist support for care in the last hours or days of life, and care of the dying: continuing education, training and audit. While action had been taken by the trust to address some areas of concern about the specialist palliative care service there was no information about an action plan to address the findings of this audit.

Competent staff

- We were told by the service leads the specialist palliative care team supported and delivered regular updates on end of life care to all staff on the trust induction programmes, the preceptorship program, annual and three yearly nurse updates, and medical devices study days. They also taught on the healthcare assistant cancer journey course which was run by the cancer and haematology department. The team had input in the trust's induction for medical staff and 'breaking bad news' training.
- The trust's intranet learning and development site referred to the leadership alliance for the care of dying five priorities and stated that the training will support the trust in delivering these priorities.

- Sixty eight staff had completed a palliative care update in the previous three years. There were bespoke modules booked to take place in September 2015 and January 2016.
- According to the information provided by the trust, 92% of all staff in the specialist division, of which the palliative care team was part, had had an up to date appraisal. Staff were supported through group and peer supervision.
- The lead for the children's palliative care team had not had an appraisal for three years, although they had ensured that the rest of the team were supported through the appraisal system.
- Staff from both the adults' and the children's palliative care team reported that they were supported with their personal development. They were supported through the hospice where the specialist palliative care teams were based.
- The specialist team worked closely with the adult community healthcare teams (ACHT). In the southern area, where a hospice at home service was provided by a third party, there was a shared care arrangement. Three staff from the southern ACHT team had a specialist interest in palliative and end of life care. They had undertaken additional training and were link staff. In addition to this, four case managers from the ACHT had undertaken modules on palliative and end of life care.

Multidisciplinary working and coordination of care pathways

- The community nursing staff attended 'gold standard' meetings with the GPs in the area. At these meetings there was a multidisciplinary approach to the review and planning of care for patients receiving palliative and end of life care.
- The CNSs demonstrated an understanding of the importance of working with others. For example for one patient who was experiencing acute pain they agreed with the patient to make arrangements for the GP to conduct a home visit and to confirm the arrangements. For a second patient the nurse arranged for antibiotics to be collected from the local pharmacy dispensary at their local GP practice within the hour.
- Representatives from the trust attended the Buckinghamshire provider forum to ensure that the trust was informed and involved in local initiatives. This forum included commissioners and independent providers and meetings took place once every three months.
- Psychological support was available if required as there was a nominated palliative care psychologist based in the psychology service.
- The district nursing service supported palliative care patients through routine visits and a 24 hour service.
- An outreach service was provided by a physiotherapist and occupational therapists who would also saw patients at the day hospice.
- The children's palliative care team worked closely with the children's community nurses in delivering shared care.

Referral, transfer, discharge and transition

- Patient had appropriate referral to specialists. For example, one patient was receiving support from the respiratory specialist nurse, which was appropriate for their illness. The two specialist nurses were working together to ensure the patients' needs were met. The service leads told us that they were working towards more partnership working between specialist teams and the specialist palliative care CNS. This would mean that patients would have all their care needs assessed and coordinated but those with the required skill and knowledge.
- The operational policy for specialist palliative care services within Buckinghamshire Healthcare Trust, Florence Nightingale Hospice, the hospital specialist palliative care team and the community specialist palliative care teams dated March 2014 stated that referrals would be accepted from healthcare professionals, social care professionals, patients and carers. The referral had to be made with the agreement of the clinical team who had the responsibility for the patient's care. Patients had to be aware that they had been referred to the specialist palliative care team and be aware of their diagnosis or suspected diagnosis. There was a single point of access for all referrals for specialist palliative care.
- In the community and the day hospice the patients remained under the medical care of their GP with advice and support given by these specialist teams.
- There was a discharge planner employed to facilitate discharges of hospice inpatients. These patients would normally receive follow up from their GP, the community

CNSs for palliative and end of life care, and adult community healthcare teams as appropriate. They could be referred back to the hospice as required. These patients could also access medical, physiotherapy and lymphoedema outpatient if required.

- Adult community healthcare teams (ACHT) patients who were identified as requiring palliative care and medication were treated as priority referrals. The ACHT told us discharge of palliative patients to community teams was prioritised.
- Anyone, including parents, could refer a child to the children's palliative care team. The lead nurse for the children's palliative care team would meet with any families referred to the service. The aim of the meeting would be to discuss the family's needs and their expectations so that these could be managed. For aspects that were not health related, further referrals to other teams would be made, for example to ensure that social needs were met.

Availability of information

- Work was being undertaken to provide a pathway for adult patients called 'Getting it right for me'. There had been a three phase approach.
- The first phase had been workshops for staff with an aim of raising the profile of end of life care as well as educating staff about what good end of life care looks like.
- The second phase was engagement with members of the public and patients. This had led to 10 volunteers forming a group to further develop the resource. Following a review of the five priorities of care and NICE guidance and with joint working with a staff group the new pathway was developed (phase three) .
- The new pathway was about to be trialled at two of the community hospitals and in the community. Staff at Marlow Hospital were aware of the project and clearly informed of the purpose of the pathway and when it would be used. One patient had been identified as someone likely to be suitable for the use of the pathway. There were clearly documented discussions in the patient's notes about the situation and the use of the pathway.

Consent

- The CNSs were well informed about the Mental Capacity Act 2005 and the potential that patients could become confused, for example, due to possible infection. They talked freely about the importance of consideration of mental capacity when making decisions about resuscitation and end of life care.
- The children's nurses were clear about the need to gain consent and to take account of the child and young person's ability to understand and be involved in the decision-making process.

Good ●

Are services caring?

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

Summary

We rated 'caring' as 'good'.

Staff demonstrated a caring and compassionate approach. Patients and their families were positive about the care and support they received and the way they were treated. Staff were courteous and treated patients and their families with dignity and respect. Patients and their families were involved and encouraged to be partners in their care and in making decisions. Staff spent time talking to people, or those close to them. Staff communicated with in a way that they can understand. People and staff worked together to plan care and there was shared decision-making about care and treatment. The CNSs provided emotional support and would refer patients to other professionals if additional support was required.

Compassionate care

- We observed staff to have an encouraging, sensitive and supportive attitude. They were courteous and treated patients and their families with dignity and respect.
- There was a clear rapport between the nurses in the community and their patients. There were open conversations that showed compassion by the nursing staff and displays of trust by the patients.
- Holistic assessments were undertaken for each home visit that included symptom control, mobility bowel function, the urinary system, eating and drinking as well as and psychological, social and spiritual support. Patients were involved in discussions, and their views were considered. Their symptoms were considered and how to manage them was discussed.

Understanding and involvement of patients and those close to them

- The CNSs were skilled in having conversations with their patients and their families. They involved everyone and used language that could be understood. We observed a good example of a discussion about quality of life with a patient who had been newly diagnosed. One patient told us, "My nurse is very good, she helps me to understand what is happening to me in a simple way."
- We observed trusting and open three-way communication between a CNS, a patient and their wife about the symptoms the patient was experiencing and their treatment plan. The CNS was thanked for their clear explanation which had been easier to understand than their GP's, and they had felt conformable about asking questions.

Emotional support

- The CNSs were skilled in providing good emotional support. They were aware of the availability of other support such as psychological support and were confident in suggesting and supporting patients to access additional support if required.
- We observed one conversation in which there was an emotional and tearful discussion about the values of living life each day. The whole family was relieved that it was ok to go out and about while undergoing chemotherapy.
- One patient told the nurse she was their "life line to understand all that was happening".
- One family had not been complying with the advice they had been given which meant that the patient's pain and nausea was not being controlled. The CNS gave them additional support through daily telephone calls for the next week with the aim of supporting them on a daily basis to manage the situation.
- For one patient, who was experiencing a lot of anxiety, the CNS was sensitive to this and acknowledged that the patient may need additional support from a psychologist. The possibility of this additional support was sensitively suggested to the family for them to consider.

Promotion of self-care

- The CNSs took time to listen and understand their patients and their families and to support and encourage them to continue to do the things they liked to do.
- We observed skilfully conducted conversations around using every opportunity to 'do things' that were important to the patient and their family. For one family this was about visiting their caravan.

Good ●

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 'good'.

The trust had developed an action plan to improve its end of life service and a project lead had been employed to move this forward. The trust had engaged with staff, patients and their relatives as part of this project. The CNSs took a holistic approach to their role and the service was available to all. The children's hospice at-home team offered respite care at home to children and families with life-limiting illnesses. They offered individually tailored care, adapted to the child and family's needs.

An interpreting service was available although family members often acted as interpreter. The community hospitals were all accessible to patients with physical disabilities and special beds and patient lifting equipment was available. The CNS managed their own diaries to ensure that in consultation with patients and they were visited at time suitable for them. The children's palliative care team worked in a similar way liaising with families and scheduling support at a time that would best meet their needs.

Support and advice was available 24 hours a day and staff were clear on how to access this support. The trust was working to improve their end of life service and had engaged with staff, patients and relatives as part of this process. The community teams worked together to support patients and their families and to ensure that they had the support and equipment they required.

Planning and delivering services which meet people's needs

- The trust had developed an action plan to improve its end of life service and a project lead had been employed to move this forward. Consultation had taken place with staff, patients and their relatives. Specific project groups had been set up, with staff and patients or relatives as members, to move identified projects forward, for example the end of life pathway and the introduction of the new syringe drivers.
- The trust had a chaplaincy service which provided 24 hour support for patients of all faiths and those who did not belong to a particular religion but required spiritual guidance. Although the permanent chaplains were of the Christian faiths, they had access to religious leaders from other world faiths when required.
- The adult community healthcare team, particularly the district nurses, took an active role in ensuring that patients had the equipment they required to be at home.
- End of life care could be provided in the community hospitals though staff reported that this occurred infrequently with an emphasis on patients going home or if acutely unwell being transferred to the acute setting.
- The children's hospice at-home team offered respite care at home to children and families with life-limiting illnesses. They offered individually tailored care, adapted to the child and family's needs.

Equality and diversity

- The services were available for all, and anybody with a different or special need would be accommodated. From observation and discussion it was clear that the clinical nurse specialist (CNS) team was comfortable discussing spiritual and cultural aspects of care. It was an accepted and overt part of their approach.
- An interpreting service was available for patients who did not speak English as their first language, which included a telephone service. This meant that the service could be accessed when in the community, although relatives would often act as the interpreter.
- In order to ensure that support was provided for those with complex needs, the palliative care CNS would work with other specialist nurses, for example the learning disability nurse. Other healthcare professionals were also available to offer support such as physiotherapist and occupational therapist.
- The community hospitals were all accessible to patients with physical disabilities and special beds and patient lifting equipment was available. Support from physiotherapists and occupational therapists were also available in these settings.

Good ●

Are services responsive to people's needs?

Meeting the needs of people in vulnerable circumstances

- The CNSs told us they were confident holding difficult discussion with families and were aware of the levels and risk acceptance of patients dying in less than desirable circumstances, but who wished to remain at home.
- We found discussion with families were recorded in the two sets of patients' notes. Of the five DNA CPR forms we reviewed, all were fully completed. Focused work had been undertaken with consultants about their role in the decision-making process.
- At Thame Community Hospital patients and relatives had not been involved in DNA CPR decisions. This resulted in one complaint being made. The lessons learned from this were that nurses undertook this role due to the lack of time doctors had when they visited the ward. DNA CPR forms were then completed with clear management plans with involvement of patients and relatives.

Access to the right care at the right time

- Palliative care advice was available 24 hours a day. This was obtained either from the CNSs or the medical staff. The CNS provided an on-call out of hour's service and a seven days a week service 9am to 5pm as per current recommendations. The medical staff, through the use of a roster, also provided a 24 hour on-call service. Staff from all areas of the trust were able to call the hospice at any time to obtain advice. Staff in all areas of the community service were clear about how to obtain advice.
- The district nurses provided an out of hour's service. Patients could call them direct although they tried to anticipate and plan night visits when required.
- The children's palliative care team had 24/7 access to specialist medical advice and support via Helen and Douglas House, a children's and young person's hospice in Oxfordshire, and worked closely with all professionals involved with the child.
- Trust staff had received training in the use of the Bucks Coordinated Care Record. This care record enables out-of-hours care providers to access patient level data which in turn provides immediate access to clinical information with which to make well-informed decisions. The palliative care medical staff were inputting information into this record and the nursing staff were able to edit the information. This helped to ensure timely access to relevant information at any time.
- The CNSs managed their own diaries and took responsibility for ensuring that patients received a visit when required. They worked with the patients to ensure that visits took place at a time suitable for them. We observed that there was a flexible approach and patients would be seen more frequently or offered telephone support when a greater level of support was required. The CNSs chose to work beyond they contracted hours to provide the support required. They told us that they would never refuse a referral and all patients would be seen. The children's team worked in a similar way liaising with families and scheduling support at a time that would best meet their needs.
- We were not provided with information about the number of patients who were able to die in a place of their choice though we did hear of examples where this had been promoted with one patient receiving earlier support and the provision of medication to relieve their agitation which enabled them to die in their home and not in hospital. Statiscally from April 2013 to March 2014 47% of residents in Buckinghamshire who died, died in their usual place of residence.

Complaints handling (for this service) and learning from feedback

- It was not possible to clearly define how complaints had been managed or the outcomes from any complaints as these were not identified by the trust. The service leads told us that if concerns had been raised they were embedded in the body of a general complaint. The trust had recognised this as an issue and a new category had been introduced to the complaints management system to enable the capturing of complaints that included an end of life care element.

Good ●

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 'good'

There was a clear vision for the service and the end of life care strategy was being reviewed to ensure that it reflected the service as a whole. There had been engagement with the public and patients and some were actively involved with the review of the service. The trust was actively making changes to the service to ensure it better reflected current guidance, although while there was some monitoring of the quality of the service, this required further development to include audit and the monitoring of outcomes for patients.

The director of nursing was the lead for the service at board level and had clear insight into the challenges they were facing and the changes being made. At a local level there was respect for the lead consultant in palliative care. The matron's role had been expanded and their responsibilities increased, and they were receiving support with their development to assist them in their role.

There was an open culture that placed the patient and their family at the centre. There was a team approach to caring for patients in the community, with joint working between specialist staff, the adult community healthcare team and the community hospitals.

Service vision and strategy

- The end of life strategy was being reviewed as the current strategy ended in 2015. The new strategy was to be published in October 2015. The project lead was clear that the new strategy needed to be reflective of current guidance including the Priorities for Care of the Dying Person set out by the Leadership Alliance for the Care of Dying People. Patients had been invited to become involved in the review, 10 people had volunteered and as a result a patient (user) reference panel had been formed.
- There was a clear vision to provide individualised patient care, encouraging people to 'live well until we die'. An example was given of facilitating and enabling a patient to ride a horse for one more time. An activity they had enjoyed all their life.
- A strapline had been adopted by the end of life care team: 'End of life care is everyone's business'. Clinical staff with a key role in the provision of the service were aware of this as were those staff who had attended recent training on the new pathway.
- The specific aims of the palliative care service were that patients could be seen at any point in their illness (malignant and non-malignant) as an inpatient or an outpatient within the acute, community, hospice inpatient unit and day hospice settings, and to provide access to specialist nursing and medical advice for symptom management, psychological support for patients and relatives/carers, staff support, complex discharge planning (for the hospital team), information, advance care planning, and high quality end of life care in any location through guiding principles for good end of life care.
- A review of services for children with complex needs was being undertaken by commissioners and as a bespoke service the children's palliative care service would be included. The trust had decided to co-locate the team with the other services for children with complex needs in the community. A needs assessment was underway that would be mapped against the provision analysis provided by the local council. Joint decisions would then be made in June 2015 with the commissioners on the future of the service element as part of the multidisciplinary team. The service will then fall under the existing governance arrangements of the multidisciplinary team in terms of line management, professional leadership, audit and so on.
- The children's hospice at home team based at the Florence Nightingale Hospice offered respite care at home to children and families with life-limiting illnesses. The team offered individually tailored care, adapted to the child and family's needs.

Governance, risk management and quality measurement

- A score card was used to monitor and report on the quality of the service provided against a number of agreed indictors. The score for April 2014 to February 2015 was green (good) across the board for indicators relating to care. These specialist palliative care service held clinical governance meetings. We reviewed the minutes for the last two meetings and saw that the indicators were monitored and discussed at these meetings. Minutes from the general team meeting also showed that this information was discussed.

- There was limited information on the outcome for people who had used the service
- The normal reporting process was from the service delivery unit in this case specialist palliative care service, to the divisional board. In addition to this the trust board had received briefings around end of life care in June, July, September and November 2014. In November there was an end of life care patient story presented to the board in public. As the review of the end of life care service was also part of the trusts overall improvement plan there had also been regular reviews at the trusts Quality Committee.
- The specialist palliative care risk register community and integrated care contained six entries. There were two entries relevant to the community teams. One covered the new syringe driver and the second was about a staff vacancy in the community team based at Marlow, the risk and been partly addressed by staff agreeing to increase their hours. There was no reference to the need to develop a new end of life pathway or the need to review the strategy to ensure it was in line with current guidance.

Leadership of this service

- The specialist palliative care matron and consultant, with the support of a project lead, saw themselves as the leads for the service. The lead at board level was the director of nursing.
- The matron, whose role had expanded, was receiving support to develop in their role as lead across the whole palliative care service.
- The director of nursing demonstrated a clear understanding of the challenges the service was facing and the action being taken to address the identified concerns.
- The children's palliative care team was under the management of the children's acute service, although there had not been any recent engagement. The team felt that their support came from the other staff based at the hospice.

Culture within this service

- The community palliative care staff were clear that they had a responsibility to ensure that others knew of their activities for the day and that someone knew when they finished work. Most of the time they returned to the office; on other occasions they said they would call to ensure someone knew they had gone home.
- We observed an open and honest approach when having discussions with patients. We also saw evidence of this in the notes of a patient at Marlow Community Hospital.
- There was a team approach to caring for patients in the community, with joint working between specialist staff, the adult community healthcare team and the community hospitals.
- The specialist palliative care CNSs worked together as a team supporting and covering for each other.
- There was a clear focus on patients, placing them at the centre of the care delivered.

Public engagement

- Public and patient engagement events had taken place 'called One Chance to get it right' with a focus on achieving good quality care for people who are approaching the end of life, whilst in the trusts care, which had been attended by over 50 people. Following on from these, volunteers had become involved in developing the new end of life strategy to be launched in October 2015.
- The patient satisfaction scores form the trusts own survey for the community service had been between 95% and 100% for the previous 11 months.
- Patients or carers had been involved in the development of the new pathway for end of life care.

Staff engagement

- In the NHS staff survey in 2014, 373 staff at the trust took part. The response rate of 44% was average for acute trusts in England. The five key findings for which the trust compared least favourably with other community trusts in England included the percentage of staff agreeing that they would feel secure raising concerns about unsafe clinical practice, support from immediate managers, percentage of staff reporting good communication between senior management and staff, and staff job satisfaction.

Good ●

Are services well-led?

- Staff had been actively involved the decision making and introduction of the new syringe drivers. Staff were positive about their involvement in this project.
- Staff had been involved in the development of the new pathway for end of life care, and spoke positively about the new tool.

Innovation, improvement and sustainability

- A project lead had been employed by the trust to review the end of life care service. The end of life care project lead had given a presentation to the trust's assistant chief nurses in January 2015. This outlined the progress of the project and the approach that had been taken in creating the tools to support the service.
- Areas of improvement that had been identified included identification of people at the end of life, effective person-centred care planning encompassing a holistic assessment of need, high quality evidence-based care, symptom control management 24/7, and public and clinical engagement in developing end of life care at the trust. As part of the project. The trust planned to conduct an annual end of life care audit which would include the views of carers post bereavement. This was to be developed. There was limited information on the outcome for people who had used the service.
- An agreement using the Commissioning for Quality and Innovation Framework (CQUIN) was awaited, with an aim of securing improvements in quality of services and better outcomes for patients, while also maintaining strong financial management. This would help to frame the measurement of success.
- The specialist palliative care consultant had been the lead in developing a new do not attempt resuscitation/treatment escalation plan which was due to be piloted. A new end of life care pathway had been developed with input from people who used the services and was about to be trialled on some wards, including within the community hospitals
- The trust did not hold an individual end of life register but had contributed as a stakeholder in the development, launch and use of the Bucks Coordinated Care Record. This was a county-wide electronic end of life register that GP's, NHS Trusts and hospices had signed up to improve the coordination of care.
- The children's team worked flexibly and provided a 24 hour service when a child was approaching the end of their life.