Central Manchester University Hospitals NHS Foundation Trust

RW3

Community end of life care

Quality Report

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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)
RW3MR	Manchester Royal Infirmary	Community end of life care	M13 9WL
RW3MH	Moss Side Health Centre	Community end of life care	M14 4GP
RW3LP	Longsight Health Centre	Community end of life care	M13 0RR
RW3CL	Chorlton Health Centre	Community end of life care	M21 9NJ
RW3MR	Manchester Royal Infirmary	Gorton South Health Centre - Community end of life care	M13 9WL

This report describes our judgement of the quality of care provided within this core service by Central Manchester University Hospitals 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 Central Manchester University Hospitals NHS Foundation Trust and these are brought together to inform our overall judgement of Central Manchester University Hospitals NHS Foundation Trust

Summary of findings

Ratings

Overall rating for the service	Requires improvement
Are services safe?	Requires improvement
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

We rated community end of life care services at Central Manchester University Hospitals Foundation NHS Trust as 'requires improvement' overall because;

The trust did not have a strategy for the delivery of end of life care services. The lack of such a strategy may have a negative impact on the quality of end of life care and future service improvements. There was no embedded replacement for the Liverpool care pathway in adult end of life (EOL) services that had been discontinued in July 2014 following national guidance from June 2013.

We were not assured at the time of our inspection that staff in adult EOL services fully understood their role and responsibilities in relation to reporting incidents. We had several discussions with different staff members who had highlighted concerns to us but had not reported these as incidents. The lack of incidents reported by the Macmillan team could be indicative of a poor reporting culture, in turn this may impact on learning and improving services for patients.

Implementation of evidenced-based guidance was variable. Care assessments that we viewed at the time of our inspection and trust audit results, identified that standards for end of life care for adults were not being met and there had been little improvement following audits.

A process for rapid discharge from hospital was in place for patients that had identified the community as their preferred place of care. However, this process was not delivered for adults across seven days a week and there was no Macmillan service available at weekends and bank holidays.

Staff felt supported by their local team leaders but did not always feel included in decisions about service changes and felt some disconnect with the acute part of the trust.

Summary of findings

Background to the service

Central Manchester University Hospitals NHS Foundation Trust provides end of life care services for adults and children with individual and complex needs in the community. The service is provided across Central Manchester for patients who are registered with a Central Manchester General Practitioner.

End of life (EOL) care is provided from a variety of organisational settings.The range of services includes facilitation of discharge from the acute hospital and coordination of care provision in the community.

End of life care is delivered by a range of community health care professionals working collaboratively with GP colleagues across Manchester. The locality based district nursing teams provide adult end of life care as part of their caseloads and act as key workers for patients approaching end of life. The evening and night district nursing service are based on the main trust site and offer an overnight response to support patients to die in the place of their choice. A local hospice provides additional support and services where required. The community children's team provide end of life care for children and young people.

Specialist palliative care support is provided by the community Macmillan nursing team and the children's palliative care team (STAR). Both teams are based within a trust community location and deliver care to patients in a community setting across Central Manchester with the STAR team also providing services citywide. Both specialist teams deliver a programme of education to enable generic community teams to deliver safe and effective end of life care.

Care for patients with long term conditions during the last year of life is delivered by the locality based active case management teams. Additional services contributing to supporting living and dying well at home include: care home support team, physiotherapy, podiatry, intermediate care, continuing health care, continence, IV therapy and discharge teams.

We carried out an announced inspection of community end of life care services on 11 and 12 November 2015. As part of our inspection we reviewed data that was provided by the trust, spoke to three patients and their families, reviewed 13 sets of patient records, and spoke to 17 staff including: nurse specialists, district nurses, senior managers, and allied health professionals. We received comments from patients, their relatives and carers via comment cards left at a variety of community locations across Manchester. Patients also contacted us to share their experiences via email and telephone.

Our inspection team

Our inspection team was led by:

Chair: Nick Hulme, Chief Executive at The Ipswich Hospital NHS Trust

Team Leader: Ann Ford, Care Quality Commission

The team inspecting community end of life care services included two CQC inspectors (one with experience of working in community services) with remote access to specialist advice in relation to end of life care if required.

Why we carried out this inspection

We inspected this core service as part of our comprehensive inspection of Central Manchester University Hospitals NHS Foundation Trust.

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, we reviewed a range of information we hold about the service and asked other organisations to share what they knew. We carried out an announced inspection on 11 and 12 November 2015.

As part of our inspection we held interviews with a range of staff who worked within the service, such as nurses, therapists and senior managers. We talked with people who use services. We observed how people were being cared for, and reviewed treatment records of people who use services. We met with people who used services, who shared their views and experiences of the service.

What people who use the provider say

Feedback from a Macmillan patient survey in 2015 identified that 100% of respondents said they were treated with dignity and respect, and 100% of carers stated that the information the service had given them met their needs. Comments received from a Macmillan patient survey in 2015 included: 'marvellous nurse', 'understanding and coniderate', and 'full of information to help me cope'.

At the time of our inspection a patient's mother told us she had found the service helpful and 'the staff are very nice'.

We received feedback about community services via comment cards we left in community locations across Manchester. All the comments we received in relation to the service were positive.

Good practice

The STAR team were working above and beyond their role in particular in relation to fundraising and the flexibility to deliver 24 hour on-call when a child was in the end stages of life.

Areas for improvement

Action the provider MUST or SHOULD take to improve

The service must;

- In adult EOL services, have a fully embedded replacement for the Liverpool care pathway and staff are trained in the use of the new pathway.
- Ensure all staff identified as requiring training to operate the syringe driver pump receive it.
- Ensure all patients approaching end of life (EOL) receive a holistic assessment of their needs; and that standards for best practice in relation to EOL are being met.

The service should;

- Ensure all staff are aware of their roles and responsibilities to report incidents and near misses.
- Consider making specialist EOL care for adults available seven days a week.

Summary of findings

- Continue work around the development of a strategy and vision for EOL care to drive quality and service improvements.

Central Manchester University Hospitals NHS Foundation Trust

Community end of life care

Detailed findings from this inspection

Requires improvement

Are services safe?

By safe, we mean that people are protected from abuse

We rated end of life services as 'requires improvement' for safe because;

We were not assured at the time of our inspection that staff providing adult end of life (EOL) care fully understood their role and responsibilities in relation to reporting incidents. Discussions with different staff members highlighted that concerns had not been reported as incidents. The lack of incidents reported by the adult EOL services and in particular the Macmillan team, may be indicative of a poor reporting culture which in turn could impact on learning and improving services for patients. Similarly it was not clear if information was given to staff when things did go wrong to enable lessons learnt to be shared.

Patient's records showed that patients' risk assessments were not fully completed and important patient information was not always clearly documented which could increase risk to patient safety. The EOL services in the community did not specifically monitor safety performance.

Mandatory training was available which included safeguarding adults and children and the majority of staff were compliant with the training. However, we found not all the appropriate staff in adult services had received annual training to use syringe driver pumps.

There was a lack of available support from a palliative care consultant within the community for adult patients.

Safety performance

- A high number of patients known to the Macmillan team were also known to district nurses who completed the safety thermometer (a national improvement tool for measuring, monitoring, and analysing avoidable harm to patients). As this data was collated by the district nursing service there was no specific breakdown for end of life care patients.
- The trust had a harm free monitoring and management group however; EOL community services were not included in the divisional feedback section in the minutes we observed for September 2015. We did not see evidence of safety thermometer findings discussed in meetings at team level in the EOL community services.

Requires improvement

Are services safe?

Incident reporting, learning and improvement

- Incidents were reported and recorded using an electronic system.
- Staff in the community Macmillan team and children's community palliative care (STAR) team were aware of the online system for reporting incidents. Data provided by the trust identified six incidents were reported in the 12 months during August 2014 to August 2015.
- The Macmillan community team advised us at the time of our inspection that they had not reported any incidents for the past 12 months.
- The five incidents reported by the STAR team were in relation to lack of equipment or medical devices, information not given to carers when a child was discharged home and one was due to a pressure ulcer. A route cause analysis investigation for the pressure ulcer incident had been completed and actions were identified. The development of a patient and family information leaflet in relation to pressure relief was identified as an action, and we observed the new leaflet. We saw evidence of learning from incidents in the team minutes.
- We spoke to two district nursing staff and staff from the EOL teams. They had identified on several occasions that getting equipment, in particular beds, was a problem. However, these had not been reported as incidents. The hospital discharge planning team told us they experienced delays in discharging patients home but these had not been reported as incidents. This being the case it was difficult to determine if staff understood their responsibilities to record and report incidents, concerns and near misses.
- We reviewed meeting minutes from the EOL steering group and the EOL operational group both held in October 2015. There were no discussions in these meetings in relation to incidents and learning from incidents and no reference to safety performance data.
- An incident investigation report showed the Duty of Candour process had been followed. The aim of the duty of candour regulation is to ensure trusts are open and transparent with people who use services and inform and apologise to them when things go wrong with their care and treatment.

Safeguarding

- Policies and procedures for safeguarding vulnerable adults and children were accessible to staff electronically.
- Staff received mandatory training for safeguarding children and adults. The trust's induction and mandatory training policy identified that children's and adult safeguarding level 1 and 2, were all provided within either the corporate or clinical annual mandatory training.
- The Macmillan and STAR team told us they had a team spreadsheet which identified when training was due and the training team would also contact them. We saw evidence of this in the STAR team.
- The trust target for completion of mandatory training was 90%. Data provided by the trust identified that 86% of the Macmillan team had completed the annual corporate mandatory training and 100% of the team had completed the annual clinical mandatory training.
- Staff completed level 3 safeguarding training every three years. However, it was not clear form the data provided what percentage of staff had completed this training.
- Staff in the EOL services were aware of a safeguarding team that they could contact if they had concerns or needed advice and support. Staff in the STAR team and Macmillan team understood their responsibilities in relation to safeguarding vulnerable adults and children.

Medicines

- A policy for the management of controlled drugs was in place and could be accessed via the intranet.
- A 'community and district nursing controlled drugs record keeping' audit was performed on five patient records during June 2014 and December 2014 and confirmed 100% adherence to the controlled drugs policy for community services. However, we did not see evidence of a more recent audit.
- At the time of our inspection the patients we visited on home visits did not require administration of controlled drugs and therefore these drugs were not prescribed. The relevant blank stock control and administration documents were present in the patient record should the patients' needs change and such medication was prescribed.
- Different controlled drugs for pain relief were used within the trust with morphine being prescribed in the hospital setting and diamorphine in the community. A re-calculation to convert the morphine to diamorphine was required and a further prescription had to be

generated. District nursing staff in the out of hours service told us this did not delay patient care as they would use the morphine until the diamorphine was available.
- The district nursing staff working out of hours could access EOL drugs from the GP out of hours' service if there were none available in the patient's home.

Environment and equipment

- Staff that attended a focus group during our inspection told us that their office area (based at the Longsight Health Centre) was inadequate for the number of staff in the team, the building had a vermin infestation, and they felt unsafe crossing the car park in the dark. We visited Longsight clinic and found the office used by the STAR team was overcrowded and in a poor state of repair. We raised our concerns regarding the environment at Longsight with the trust at the time of inspection and immediate action was taken to address the matter to ensure patient safety. Further review of the facilities was planned to ensure they were fit for purpose.
- Staff at the focus group told us they could visit patients with two staff if a risk had been identified however, they did not always have sufficient staffing available. Staff told us they felt unsafe and that in the community end of life services, lone worker safety tracking devices were not available for each member of staff.
- Syringe driver pumps were used to administer continuous sub-cutaneous drugs. The syringe driver pumps required a maintenance check annually. The trust identified 114 syringe driver pumps across community services of which 19 were overdue the maintenance checks. Of the community staff in adult services identified as requiring training to use this equipment, 70% had completed the appropriate training.

Quality of records

- At the time of our inspection we reviewed one child's patient held record. The "this is me" document was in place and completed with exception of the DNACPR section. A care plan was in place which reflected the child's and family's needs. The record was contemporaneous, legible, and entries were signed and dated.
- We went on two adult home visits, one with the Macmillan team and one with the district nurse. Both patients we visited had one patient held record which combined both the district nursing and Macmillan teams records.
- In one record we observed there were entries that were not dated, the Macmillan first assessment was not fully completed, and there was no care plan in place in relation to the patient's continence for which they had continence products in situ. The initial risk assessment was not fully completed and there was no advanced care plan held in the record.
- In the second patient record the patient had a DNACPR and statement of intent in the front of the folder stored in an envelope. The envelope did not indicate what was inside and potentially could have been overlooked. The nurse told us that originally the family were keeping the DNACPR upstairs so the patient would not be distressed by it. There was no advanced care plan document in place. The nurse told us the patient had declined to discuss EOL planning however, it was not clear within the record where this was documented and if this had been reviewed.
- Prior to our inspection we requested 10 sets of records for adult patients that had died which included specialist and district nursing records. At the time of our inspection we were provided with 10 sets of records which included the Macmillan service base records only. Some patients had died and some were still being visited by the service. Of the 10 records, allergies were not recorded on the front page in six of them. Of these six records, three patients had known allergies to medication which was documented elsewhere. Two records did not have a malnutrition screening assessment, and three did not have a pain assessment fully completed. Eight records did not have a DNACPR decision documented, however the DNACPR document would be kept in the patient held record and we observed this being the case on a home visit.

Cleanliness, infection control and hygiene

- Hand hygiene audits for community services had been completed but the Macmillan team had not been included in the data.
- Policies were in place for infection prevention and control. We observed staff following best practice guidance in relation to hand hygiene.

Requires improvement

Are services safe?

- Infection control training was delivered as part of the trust mandatory training programme and 86% of the Macmillan team had completed the training.
- Personal protective equipment was available and included disposable aprons and gloves.

Mandatory training

- Delivery of mandatory training was face to face and via e-learning. Topics included safeguarding, infection prevention and control, hand hygiene and risk management.
- New staff completed a full day corporate induction and a local induction. Staff completed annual corporate mandatory training; if they had a clinical role they also completed the annual clinical training.
- Training status was monitored by line managers and was reviewed at staff appraisals.
- Data provided by the trust identified that 86% of the Macmillan team had completed the mandatory annual corporate training and 100% of the team had completed the mandatory annual clinical training.
- The trust target for mandatory training was 90% compliance. This meant the Macmillan team were performing better than the target for clinical mandatory training but slightly worse for the corporate mandatory training.

Assessing and responding to patient risk

- Gold standard framework (GSF) meetings were held monthly at the GP practices to discuss care of patients that were approaching the end of life. GSF is a systematic, evidence based approach to optimising care for all patients approaching the end of life. The Macmillan team, district nurses and other members of the multidisciplinary team attended. The STAR team also attended the GSF meeting if they had a child on the caseload that was approaching end of life. The STAR team also completed a proforma if a child was placed on an advanced care plan that was shared with the patient's GP.
- The Macmillan team also attended a weekly meeting at the hospital with the palliative care team and the palliative care consultant to discuss patients they were concerned about.
- Urgent medical care was available Monday to Friday during the day via the patient's own GP. Outside of these hours it could be accessed by the GP out of hour's service. District nurses that worked out of hours told us that there was no problem obtaining medical care during out of hours, they had a direct telephone line they could use, and the GPs would do joint visits to the patient with the nurses.
- One patient and two members of a patient's family told us they knew how to contact the service if they required assistance.
- The Macmillan team had a daily discussion about patients on the caseload to keep staff informed of any areas of concern. If a patient's condition had deteriorated this was discussed at the daily meeting and action was taken to ensure the patients' needs were responded to.
- The children under the care of the STAR team had access to the general children's nursing team until 10pm. The team used a proforma to provide the general children's nursing team with information and the general team also had access to the STAR team patient records.
- There was no community service available to children during the night and two members of the STAR team told us they would have to contact the hospital.

Staffing levels and caseload

- The STAR team consisted of a 0.5 whole time equivalent (wte) consultant, 1 wte clinical nurse specialist and 8.6 wte various other staff which included nurses, support workers and a play specialist.
- The STAR team had 1 wte team member on maternity leave; the position had been backfilled with a secondment for 12 months.
- The STAR team had no set staffing ratio and had no more than one nurse on leave at any one time. The team had reviewed dependency tools but found this ineffective due to the diverse needs of the families they supported. The off duty was completed each month based on the needs of patients and staff could take time owed for any additional hours they worked.
- When the service had a child that was in the end stages of life they provided 24 hour cover with a staff member being on call out of hours. The team could utilise the general children's nursing team as bank staff at times of pressure however, no bank shifts had been required for the three months prior to our inspection as the service had not had any children in the end of life phase.

Requires improvement

Are services safe?

- The community Macmillan service consisted of a 0.6wte palliative care consultant, 3.6wte clinical nurse specialists and 1.6wte other staff. At the time of our inspection there were no vacancies within the team and there was one episode of short term sickness.
- There was a lack of palliative care consultant availability across the trust which resulted in no adult patients in the community having access to a visit from a palliative specialist consultant. The Macmillan team worked 8.30am to 5pm daily Monday to Friday excluding bank holidays and did not provide a service across seven days. Both of these issues were recorded on the EOL risk register and had been on the register since August 2015. A business case had been completed to extend the Macmillan service to cover seven days however, a timeframe for a response was not recorded on the risk register.
- District nursing services and children's community nursing teams were available over the 24 hour period daily. Staff working out of hours in the district nursing team were using bank staff regularly (every week) to cover shifts. They had one trained nurse and a support worker overnight and they worked together for safety.
- There were no palliative care leads identified for each locality at the time of our inspection however, plans to implement this had been discussed in October 2015 at the EOL steering group.

Managing anticipated risks

- Risks were identified in relation to the Macmillan service and included lack of seven day service and lack of community palliative consultant hours. We saw evidence in meeting minutes that these were discussed at EOL steering group meetings. At the time of our inspection a business case for additional staffing had been put forward.
- Staff working in the Macmillan team were aware of the issues that had been identified as risks for the service.
- Staff in the STAR team and staff attending the focus group raised concerns over lone working and the lack of lone worker devices available to all staff. Lone working had been on the community risk register since June 2012 with a plan to consider the purchase of additional lone worker devices following a review of their use in the community. There was no timeframe for this action identified on the risk register.
- The Macmillan team advised us they did not have any lone worker devices. Diary sheets were completed and placed on the office board to inform the rest of the team of staff whereabouts. Staff on a community visit then sent a member of the team a text message to inform them they were safe. The team advised of one occasion when a team member had not sent a text message to say they were safe and this was escalated to the rest of the team then the team manager. The staff member then rang in safe but staff told us they would have contacted their next of kin and then the police if no contact had been made which was in line with the trust's lone worker policy.

Requires improvement

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.

We rated end of life services as 'requires improvement' for effective because;

We were not assured that the adult EOL service had responded to national guidance to introduce revised individualised documentation for end of life care in a timely manner. Members of the Macmillan team advised us at the time of our inspection that the advanced care planning document had been in place since January 2015 and it had been reviewed and changed. However, we were informed by district nurses that the new documentation had only been received from the printers the same week as our inspection.

Care assessments for adults that we reviewed did not always consider the full range of people's needs. An audit completed in March 2015 found that care planning at the end of life (EOL), and discussions with the patient about approaching EOL, were not always clearly documented and easy to follow. More than half of the standards that were based on best practice for patients approaching EOL were not being met. Discussions with the patient in relation to the decision not to attempt cardiopulmonary resuscitation (DNACPR) were not recorded in half of the patient records reviewed as part of an internal audit. Action plans had been produced following audits but evidence of progress was limited. An EOL work plan had been developed in June 2015 that identified areas to develop within the service. However progression with the work plan had been limited at the time of our inspection. There was a plan to implement an electronic palliative care co-ordination system (EPAACs) to improve information sharing across all services involved in a patient's care however, progress to date was slow and the system had not been piloted.

A process for a rapid discharge from hospital was in place for patients that identified the community as their preferred place of care. However, this was not delivered across adult services seven days a week. This meant that a patient identifying on a Friday afternoon that they wanted to be discharged would be delayed until Monday. The team did not keep a record of delayed discharges and had not reported them as incidents. Staff had their learning needs identified through the appraisal system, however not all staff had received an appraisal in the last twelve months.

Evidence based care and treatment

- The Department of Health stated that the Liverpool Care Pathway (LCP) should be phased out over 6 to 12 months from July 2013. The LCP was a care pathway covering palliative care options for adult patients in the final days of life. The trust had discontinued using the LCP completely in July 2014.
- Following the removal of the LCP, the trust formulated a community nurse prompt sheet to facilitate the writing of individualised care plans for end of life care for adults. The standards used on the prompt sheet were selected from the national care of the dying audit. The Macmillan team advised us at the time of our inspection, that the prompt sheet had been used across community teams in central Manchester and the format had been updated several times. The final format was received back from the printers the same week as our inspection.
- The STAR team had been part of the child and young person's advance care plan collaborative which was facilitated via the North West Palliative Care Network. The team told us at the time of our visit that they had been using the document for the past 3 years but the document had only been ratified by the trust in October 2015.
- There were a range of policies in relation to symptom management that were based on best practice guidance and were available on the intranet for staff to access.

Pain relief

- When a child was in the EOL phase the STAR team were available 24 hours a day for the family to access to provide care and symptom control.
- At the time of our visit the community Macmillan service were not available out of hours or at weekends. The district nursing staff working out of hours provided care and symptom control to all EOL patients known to the

service. There was only one nurse available during the night but the team told us they prioritised EOL patients and were always able to respond to them in a timely manner.
- The local hospice had a telephone advice line out of hours where additional advice regarding symptom control could be accessed.
- We reviewed 10 sets of records for adult EOL care patients of which three did not have the pain assessment fully completed.
- At the time of our visit we did not observe any audits in relation to anticipatory medication prescribing. However, we observed the documentation used for anticipatory medicine which was in line with best practice.
- All locality teams and EOL teams had access to syringe driver pumps from their bases. If a patient was discharged home from hospital on a syringe driver, the syringe driver was returned to the hospital when the community team had replaced the syringe driver with one from the community. This meant patients continued to receive medication during the discharge process.
- During a visit with the STAR team, we observed the nurse discussing and advising a parent on the administration of pain relief medication.

Nutrition and hydration

- The malnutrition universal screening tool (MUST) was used by the adult EOL service to assess nutrition and hydration needs. Staff were able to refer to the GP or dietitian where a need was identified.
- We reviewed 10 sets of records for adult EOL patients of which two did not have a completed MUST assessment.
- An audit to provide an insight into hydration during EOL was identified on the audit plan to commence in June 2015, however there were no results available from the audit at the time of our inspection.
- We visited one child who was receiving nutrition via a nasal gastric tube and there was a plan of care in place to support this.

Patient outcomes

- The Macmillan team attended GSF meetings with GPs in relation to adult EOL patients and the team informed us there was a local GSF audit. The trust audit plan identified a GSF audit was due to take place in October 2015 to December 2015 and had therefore not been completed at the time of our inspection.
- The results of the National Care of the Dying Audit which took place in May 2013 and included 96 adult patient records, the trust met four out of seven key national performance targets for organisations providing end of life care. The main areas of concern identified in the audit were: care focused on symptoms not using a holistic approach that addressed the patient and carers needs, no EOL planning tool was evident, and communication with family and patients was poorly documented. As a result the trust had developed an action plan to detail how the concerns identified would be addressed with a plan to re-audit.
- The trust performed an EOL audit to review expected adult inpatient deaths and compliance to the five priorities for care of the dying person during January 2015 to March 2015. The result of the audit found that eight of the ten standards assessed were not met. The audit identified that 52% of the 238 patients did not have an individual EOL care plan. Actions from the audit identified the development of a trust wide document to be completed during August 2015 to September 2015 which was assigned to the specialist palliative care team.
- The staff in the Macmillan team told us they provided data for the national audit and that an annual report goes to their manager. At the time of our inspection staff were unable to tell us what issues were identified in the audit and how improvements had been made as a result of the audit.
- An audit of adult community records was performed in March 2015 to review the use of the prompt sheet which had been developed to replace part of the Liverpool care pathway. A random sample of patient records following an expected death were reviewed as part of the audit. Of the 14 standards identified in the audit, nine were not achieved. The audit consisted of a sample size of eight records.
- The audit identified that seven records had a prompt sheet enclosed and seven records had an EOL care plan however; the EOL care plans were not always clear and easy to follow. Training to ensure consistency when advanced care planning was identified on the EOL work plan and train the trainer leads had been identified. All

specialist nurses for EOL had undertaken advanced communication skills training, and funding had been secured for senior community staff to attend advanced communication skills training.

- All the deaths in the audit were expected. There were seven records which had a DNACPR. Of the records which had a DNACPR in place, half of the records had no evidence of the patient being informed about the decision documented. The audit identified that this discussion may be identified in the GP records however, professionals visiting the patient would not have access to the GP record. At the time of our inspection we reviewed one patient's record that had a DNACPR and a statement of intent filed in an envelope in the patient's record. However, we did not see a documented discussion about the decision or evidence of advanced care planning. There was a plan to repeat this audit however, a timeframe for the audit was not identified.
- Training was identified in the EOL work plan and was ongoing to support staff to undertake difficult conversations as part of the advanced communication skills. The audit identified a plan to repeat this audit however, a timeframe for this was not included.
- The STAR team informed us that the 12 months prior to our inspection they had 14 children that had died. The team were aware of their preferred place of care and this was achieved for all 14 patients.

Competent staff

- Appraisals were completed annually and 71.4% (which equates to most of the staff in the Macmillan team) had received an appraisal in the 12 months prior to our inspection. This was lower than the trust target of 90%.
- A specialist nurse was conducting a study via a local university, reviewing current skills and knowledge in relation to dementia and end of life care. Results were to be reviewed to highlight training needs; this would be delivered at locality level.
- The district nursing team administered EOL drugs via syringe driver pumps. It was mandatory that all band 7 and Band 6 staff received training annually in the use of the pump and medication titration. At the time of our inspection, 70% of staff were in date with training. This had been identified as a risk and the Macmillan team were delivering sessions across the localities to train staff.
- We saw three competency records for Macmillan staff that identified competencies were met in the use of the syringe driver pump.
- The Macmillan team were providing a 10 week EOL course to community staff which was accredited.
- The STAR team delivered a range of training to support non-specialists to deliver EOL care. The STAR team nurses had received advanced communication skills training and there was access to bespoke training for the non-registered staff.
- Staff in the Macmillan and STAR team told us that training needs were identified during the annual appraisal and there were opportunities for professional development. Staff were in the process of completing the V300 nurse prescribing course. Staff in the STAR team told us that the team had used their own funds to attend additional training.
- The EOL work plan from June 2015 identified that there were educational gaps within community services in relation to communicating difficult information and advanced care planning. There were actions identified in the plan which included identifying trainers to roll out advanced communication skills. However there were no clear time frames for completion, no identified numbers of staff, and no identification of how this was being measured within the plan to determine if the plan was on track.
- Senior district nursing staff told us they had not received training in advanced care planning.

Multi-disciplinary working and coordinated care pathways

- The Macmillan team attended a weekly multi-disciplinary palliative care team meeting with the hospital team that was consultant led. This enabled discussions in relation to symptom control and psychological support for patients on the caseload. There had been an away day to build links across community and hospital services.
- The Macmillan team had recently been based within one of the locality teams and the feedback from community staff was very positive about this in relation to improved communication and learning opportunities.
- The Macmillan and STAR team were able to attend the GSF meetings at GP surgeries to share information for all

disciplines involved in the patient's care. We observed shared care with district nurses for two patients who both told us they thought the services worked well together.
- The district nurses and palliative care teams informed us they had developed effective working relationships with GPs and they communicated in person, by phone or by fax if a patient was assessed as approaching EOL.
- The STAR team met with the Macmillan oncology team to discuss patients if they were both seeing the same patient.
- The STAR team worked closely with social service providers and closely with the children's community nursing team to provide care over seven days a week.

Referral, transfer, discharge and transition

- There were clear referral pathways in place to refer to the community EOL care teams.
- The trust had a discharge pathway which included a rapid discharge procedure for adults approaching EOL that had expressed the wish to die in the community setting. We saw evidence that patients were being discharged using the fast track process and urgent referrals to district nurses were responded to within four hours.
- The discharge team informed us that fast track discharges were not performed for adults at weekends which could result in a patient identifying on a Friday afternoon that they wanted to be discharged but this would be delayed until Monday. The team did not keep a record of delayed discharges and had not reported them as incidents.
- The trust had a draft rapid discharge process in place to support children approaching EOL which was formed as part of the North West children and young people's palliative care network and in partnership with the local regional ambulance service. There was a handover letter included to share key information with the community teams. The ambulance service had a two hour response time from referral. This document was still in draft form and therefore we were not aware of any audit information in relation to its use. The flexibility of the staff in the STAR Team enabled children that were approaching end of life to be discharged 7 days a week as they would work weekend days to support these children and their families.

Access to information

- Patients had home based records which could be accessed by different members of the multidisciplinary team as required.
- Staff had access to the trust intranet and showed us how they accessed policies and procedures.
- The trust had a plan to implement an electronic palliative care co-ordination system (EPAACs). The system would provide a single care plan which would be accessible to health and social care professionals. At the time of our inspection communication across services was being done mainly by fax, letters or conversations across teams.
- We spoke to a project lead that had been in post since October 2014 about the project and found that progress had been slow. At the time of our inspection the system had not been piloted.
- The "message in a bottle system" was also used by adult services. This system involved patient information being stored in a small bottle. A sticker was displayed in the patient's home so that the ambulance service and other services knew where to access the bottle which contained key information about their diagnosis and medication.
- Children's EOL service used the "All about me" document to identify the needs of children in their care. This allowed a person centred approach to care with staff working collaboratively with children, young people and their families to identify patients' needs and preferences.

Consent, Mental Capacity act and Deprivation of Liberty Safeguards

- Staff were aware of their responsibilities in relation to consent and the mental capacity act. They were also able to access guidance on the intranet if needed.
- Mandatory annual training included training on the Mental Capacity Act (2005) and deprivation of liberty safeguards.
- Service user verbal consent was obtained during the home visits we attended and recorded in clinical notes.

Good

Are services caring?

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

We rated end of life services as 'good' for caring because;

Staff used a whole family approach and were aware of the needs of people that were close to the patients. Staff thought beyond the death of a patient and were proactive in arranging memory photograph books to support the family after the death of a child. Siblings of dying children were supported to attend social events and the STAR team went beyond their role to raise finances to continue to deliver this part of the service.

Feedback from people who used the EOL community services, and those who were close to them was positive about the way staff treated people. People were treated with dignity, respect, and kindness. People felt supported and cared for by the staff. We observed people being involved and encouraged to be partners in their care with support offered to enable patients, and those close to them, to make informed decisions. This was particularly evident in the STAR team.

Compassionate care

- Feedback from a Macmillan patient survey in 2015 identified that all 18 respondents said they were treated with dignity and respect.
- At the time of our inspection we observed a child's memories book. This was a book containing photographs taken by a professional photographer at no cost to the patient which the STAR team had arranged.
- The STAR team had their own mini bus which was leased and used to provide support and trips out for siblings of dying children. There was no funding available for petrol for the mini bus and the team organised their own fund raising events to enable money to fund the trips. At the time of our inspection we observed photographs of staff members at fund raising events including one female staff member shaving off all her hair. Two staff told us that funding sibling activities was one of the main challenges for the service.
- At the time of our inspection we observed two members of the district nursing team interacting with a patient and their family. They had a good rapport with the family and responded to them with a caring attitude.

Understanding and involvement of patients and those close to them

- A patient survey was carried out in April 2015 to gain an evaluation of the respite care provided by the STAR team. The results from the 10 respondents were extremely positive. There were 100% positive responses in relation to the support workers communication, respect and confidentiality and children's needs being met.
- At the time of our inspection we accompanied a palliative care nurse and a play specialist from the STAR team on a home visit to a child and their family. We observed the play specialist interacting with the child for the first time using an encouraging, sensitive and supportive approach. Information was given to the mother and discussion took place with regards to offering the child's siblings support thus using a whole family approach.
- We observed the palliative care nurse supporting the child's mother in relation to medication. There were some language difficulties as English was not the mother's first language but the nurse was using listening skills and clarifying the information with another family member present. The mother was central to making choices about what additional support she wanted.
- We observed both a child patient and her mother being given the opportunity to ask questions about their care.
- A patient's mother told us she had found the service helpful and 'the staff are very nice'.
- Feedback from a Macmillan patient survey in 2015 involving 18 respondents, identified that all of the respondents said they were treated with dignity and respect, and that the information the service had given them met their needs.
- At the time of our inspection we visited a patient in their own home with the district nurse. The patient's wife, daughter and son were also present. The family and the patient told us they were pleased with the care they received from the district nurses and the Macmillan team. They said they thought the two services worked well together and they felt that care was joined up.
- In the 2015 Macmillan audit, 17 out of 18 patients knew who their palliative care key worker was.

Good

Are services caring?

Emotional support

- Comments received from the Macmillan patient survey performed in 2015 included, 'marvellous nurse', 'understanding and considerate', and 'full of information to help me cope'.
- We observed six thank you cards that the Macmillan team had received from patients' families which positively reflected the care and support the service had given.
- The STAR team had supported a mother to confidently self-manage her daughter's nasal gastric tube. The team had arranged for a photo memory book to support the family's emotional needs.
- The STAR team had access to a counselling service.
- Adults could be referred to the local hospice for additional support.
- The EOL teams and district nurses provided post bereavement visits to the patient's family or carers.

Requires improvement

Are services responsive to people's needs?

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

We rated end of life services as 'requires improvement' for responsive because;

Patients accessing adult EOL services experienced delays being discharged into the community at weekends due to delays in access to care packages or the necessary equipment. Staff worked hard across services to try and facilitate patient discharge in a timely manner where possible. However, it was difficult to determine how many patients had died in their preferred place of care (PPC) because data on PPC was not available. The Macmillan service was not available at weekends, on bank holidays or out of hours. A business case had been presented to the trust to enable the service to be available seven days a week.

However, the STAR team were flexible and responsive to the needs of the caseload and the staffing rota was determined by the needs of the patients. Staff had received equality and diversity training and were able to access the support of translator services if required. Patients told us they were aware of how they could make a complaint about the service, at the time of our inspection there had been no complaints received so it was difficult to determine if patient feedback was used to develop and improve services.

Planning and delivering services which meet people's needs

- A pilot commenced in July 2015 for community staff and patients, to have access to the multi-faith chaplaincy which was available in the acute settings there were no audit results available for this at the time of our inspection.
- Staff from different community and hospital teams told us that access to equipment in particular beds, was sometimes delayed. There was no delivery of beds at weekends which resulted in fast track discharges from hospital not being completed, and patients already in the community had to wait for the equipment which could compromise pressure area care.
- At the time of our inspection the Macmillan service did not have access to any community EOL beds. There was a local hospice where patients could be admitted for symptom control or if the hospice was their preferred place of care. However, access to the hospice was based on bed availability.
- There was a community end of life work plan which identified actions which included services delivered by other providers. However, there were no agreed timescales clearly documented for completion of actions or measurements to determine progress against the plan. The development of an EOL strategy was not identified on the plan as an action.
- The STAR team had access to local hospice beds for children and at the time of our inspection stated they had not experienced any delays in accessing a bed.
- The STAR team sent a service newsletter to patients and their families to share information and encourage feedback to improve services.
- Patient feedback had been received for both adult and community services but it was difficult to determine how this feedback had been used to develop services as it was mostly positive.

Equality and diversity

- Staff received training for equality and diversity on induction and annually as part of corporate mandatory training.
- There were equality and diversity champions within community services to support staff in promoting equality, diversity and dignity in practice.
- At the time of our inspection all patient information leaflets that we saw were all written in English however, information and leaflets in alternative languages could be accessed via the internet.

Meeting the needs of people in vulnerable circumstances

- The trust utilised an interpretation and translation service due to the diverse population. Data provided by the trust identified that face-to-face sessions were undertaken with patients during 2014-2015 nearly 38 000 times. There were also 8200 telephone interpretation requests. Staff were able to tell us how they would access a translator if needed and reported no delays in accessing the service.

Requires improvement

Are services responsive to people's needs?

- The trust also used the service to meet the needs of service users who were deaf or blind.
- Patients living with dementia approaching end of life were usually in residential care and were supported by the care home team. Dementia care training was mandatory within the trust.
- The EOL services could access additional services to support patients with learning or physical disabilities. The learning disability team and staff providing end of life care reported good working relationships.

Access to the right care at the right time

- The Macmillan service was not available at weekends, on bank holidays, or out of hours at the time of our inspection; however, district nurses provided care to patients during these times. A business case had been presented to the trust to enable the service to be available seven days a week.
- District nursing staff told us they always prioritised visits for patients receiving EOL care: however, there was no data collected to evidence this.
- We were given an example of a palliative patient requiring two staff to visit due to the accommodation presenting a risk to staff. Additional members of staff were unavailable resulting in the patient having to wait past the due time to receive medication.
- The STAR team did not routinely work weekends or out of hours but when they had a child on the caseload that was approaching end of life they covered these hours using an on call system.
- Patients told us they knew how to contact the services should they need advice or a visit.
- There was access to the local hospice via telephone for advice during out of hours. There were no palliative care consultant visits to patients in the community.
- During the period May 2015 to October 2015 there were 69 fast track discharges from hospital into the community to enable patients to die in their preferred place. Of these, 46 patients were discharged to their own home. Staff were able to arrange a private ambulance to facilitate a timely discharge. Fast track discharges were limited at the weekend due to difficulties in arranging care packages or equipment. Staff working in the hospital discharge team, district nursing, district nursing out of hours, and the STAR team all told us that they had experienced delays in receiving equipment for patients.
- There was a fast track process in place to support children to transfer to the community and the ambulance service had an agreed two hour response time to respond.
- During the period April 2014 to March 2015, there had been 132 deaths across the community specialist palliative care service for adults, with 112 of the patients having a cancer diagnosis and 20 having a non-cancer diagnosis. There was no data available at the time of this report to determine how many deaths happened in the patients' preferred place of care.
- The STAR team had supported 14 children to die in the community in the twelve months prior to our inspection. All 14 patients and their family had identified home as their preferred place of care. The STAR team told us at the time of our inspection that the majority of the children on their caseload had a non-cancer diagnosis. This was because the children's Macmillan service (outreach service rom the Royal Manchester Children's Hospital) provided the majority of care to patients with a cancer diagnosis.
- The trust provided data that identified the Macmillan service had received 294 referrals during 2014 to 2015, and the waiting time for the first face to face contact was 2.3 days.
- Staff working in the hospital discharge team, district nursing, district nursing out of hours, and the STAR team all told us that they had experienced delays in receiving equipment for patients with timely delivery of beds being the main concern.
- There was a children's palliative care consultant dedicated to the children's community service who regularly visited children and families in their homes.

Learning from complaints and concerns

- Staff from the EOL care services told us that they did not often receive complaints for end of life care specifically and we saw no evidence of complaints reported.
- We spoke to two patients and their families and they told us they knew how to make a complaint if they needed to.

Requires improvement

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.

We rated end of life services as 'requires improvement' for well-led because;

The trust did not have a strategy for the delivery of EOL care services. Senior leaders of the services were aware of the lack of a strategy but felt this was not having a negative impact on the care patients received, as patient feedback remained mostly positive. However, the lack of such a strategy may have a negative impact on the quality of EOL care and future service improvements. An EOL work plan had been implemented in June 2015 however, it was difficult to determine the progress against the plan as specific, measureable, time scaled actions were not included on the plan.

There was a general governance framework in place for the trust however, we found there was no clear service vision for community EOL care services and there were limited systems in place for monitoring and understanding patient outcomes at team level to deliver quality end of life care. Staff did not always feel included in decisions about service changes and felt some disconnect with the acute part of the trust.

However, the local leadership was knowledgeable about priorities within their own teams and understood the challenges. Staff took pride in their work and valued the teamwork across the multi-professional teams involved in the patients care.

Service vision and strategy

- The trust did not have an EOL strategy or framework for the delivery of EOL care services. A senior leader told us at the time of our inspection that the lack of a strategy had not resulted in poor care as patient feedback received for the EOL care services had been positive.
- We viewed the 2014/2015 annual report summary for the trust and found no reference to end of life services.

Governance, risk management and quality measurement

- For governance purposes, the adult and children's EOL community services sat within the division of medicine and community services within the trust.
- Divisional clinical effectiveness meetings were held and chaired by the associate head of the division. Risks and incidents were discussed at these meetings.
- The trust had an end of end life steering group which covered all aspects of adult end of life care and reported through a quality committee up to the board. At the time of inspection, there was no equivalent group for children's end of life care.
- EOL services had identified risks that were placed on the EOL risk register and were discussed at steering group and operational meetings. The lack of a consultant in palliative care had been recorded on the risk register since August 2015 and the lack of a seven day EOL service had also been recorded on the register since August 2015. Staff in the EOL teams were aware of the risks for their services. However, we did not see the lack of an identified EOL strategy, or the slow implementation of a replacement for the Liverpool care pathway recorded as risks on the EOL risk register.
- There was an EOL work plan devised in June 2015 which identified key priorities and actions required to improve care for patients approaching EOL. It was difficult to determine from the EOL work plan how progress against the actions were being measured and what timescales had been set.
- The trust had divisional audit plans in place which included EOL. We saw some evidence that the results of an audit were used to inform the community EOL work plan which included: the completion of a prompt sheet for EOL and individualised care planning.
- The head of nursing for the division had been in post since September 2015 and reported directly into the director of nursing. They told us they felt supported by the executive management team. The head of nursing was aware of the challenges for EOL services and advised that a new lead for EOL care had been appointed and was due to commence in post in January 2016.
- Work had begun to consider the use of a community accreditation tool to demonstrate quality of services.

Requires improvement

Are services well-led?

- We found a lack of evidence to support a robust embedded replacement for the Liverpool care pathway in adult services despite the announcement for it to be discontinued in June 2013.

Leadership of this service

- The trust had an identified executive director with responsibility for end of life care services. The trust had nominated an executive nurse lead for both adult and children's end of life care services three months prior to our inspection.
- Staff reported that local managers were visible and supportive. Recent changes in leadership roles meant that the trust had initiated a review of end of life care across the whole trust.
- The paediatric consultant with a specialist interest in children's palliative care was seen as a key figure in leading palliative and end of life care throughout both acute and community children's services. The input in the community was limited however.
- A senior manager told us they felt supported by their immediate peers but had experienced four different managers in the three years prior to our inspection.
- The Macmillan team identified the service clinical lead as the person responsible for cascading information to them.
- Changing priorities made by management was identified by the Macmillan team as a key frustration. Changes made to the delivery of training to general staff was given as an example.
- The Macmillan team had noticed improved working relationships with community teams since being based with them.
- At the time of our inspection there were no identified leads in localities or services for EOL care. However, this had recently been discussed at the EOL operational group in October 2015 and there were plans to identify leads who would then attend the EOL operational group meetings.

Culture within this service

- Staff were proud of the work they did and were committed to doing their best for children and adults and their families. Staff told us they knew they were doing a good job because they had positive feedback and thank you cards from patients and their families.
- At times, community EOL services reported they had found difficulty working collaboratively with acute based palliative care teams. Staff in the community felt that hospital staff did not understand the extent of their skills and knowledge.
- It was clear that staff "went the extra mile" for children at end of life.
- Staff felt respected and valued within their immediate team.
- Staff in EOL services were proud of their work to support patients and families to die in the community setting and described it as an area they were most proud of. They valued teamwork and the support of their immediate colleagues.
- At the time of our inspection staff that attended a focus group said they would welcome recognition from senior management and the executive team when they were performing well but they rarely received it. They did not think that leaders beyond their integrated team managers were visible in the community.
- During a focus group at the time of our inspection, staff expressed that they did not always feel safe when performing visits in the community.

Public engagement

- Patient feedback was received for both community EOL care services and was positive about the service received.
- It was not clear if there were any other forums to encourage patient engagement as their was no clear strategy or framework for EOL care services.

Staff engagement

- The 2014 trust staff survey showed a response rate of 44%, similar to the England average of 42%.
- Appraisal rates in June 2015 were at 74% against trust target of 90%.
- Staff in the Macmillan team told us they were consulted and involved in integration plans and base moves. They believed integration was positive and would streamline services.

Innovation, improvement and sustainability

- Staff in the STAR team gave us examples of how staff changed their working pattern to care for children who were at the end of life. This involved implementing an on call rota to provide specialist palliative care and advice to patients and their families. Staff we spoke to

Requires improvement

Are services well-led?

were happy to provide this level of care however, if demand was high and if the service was suffering staff shortages, this may impact on the ability of the service to maintain a high quality service provision.

- The STAR team had introduced a respite service in particular for siblings of dying children. Feedback from users of the service were positive. The team had a mini bus which they leased to take children out on trips however; the use of the mini bus was limited as there was no financial support for petrol. The team had found innovative ways of fundraising in their own time to assist with the financing to be able to continue to offer the service.
- The trust had started to look at the use of electronic palliative care coordinating system (EPACCS) but we did not see any formal plans for implementation.

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	Regulation
Treatment of disease, disorder or injury	Regulation 9 HSCA (RA) Regulations 2014 Person-centred care There was a risk that care and treatment may not be appropriate or in line with service users' needs and preferences because a robust alternative to the Liverpool care pathway had not been implemented in adult end of life care services. Similarly, not all patients approaching end of life (EOL) received a holistic assessment of their needs, particularly in adult services. HSCA 2008 (Regulated Activities) Regulations 2014, Regulation 9 (1), (3)

Regulated activity	Regulation
Treatment of disease, disorder or injury	Regulation 12 HSCA (RA) Regulations 2014 Safe care and treatment There was a risk that persons providing care or treatment to service users may not have the competence and skill to do so safely because not all relevant staff had been trained to use syringe driver pumps. HSCA 2008 (Regulated Activities) Regulations 2014, Regulation 12 (c)