End of life care
Quality Report

5 Boroughs Partnership NHS Foundation Trust
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This report describes our judgement of the quality of care provided within this core service by 5 Boroughs Partnership 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 5 Boroughs Partnership NHS Foundation Trust and these are brought together to inform our overall judgement of 5 Boroughs Partnership NHS Foundation Trust.

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Summary of findings

Overall summary

We found that 5 Boroughs Community Health Trust staff delivered end of life care that was caring, compassionate and supportive of patients and their families. However, there were significant areas for concern.

The trust did not have an overarching framework or strategy for end of life care. The advanced care plan document developed to replace the Liverpool Care Pathway in July 2014 was comprehensive and person-centred, this plan was not yet in use and this had led to inconsistent care being provided. We observed examples of how this had negatively affected patients’ care. The trust had appointed a board member with a specific lead role for end of life care but there was not a non-executive director taking a lead on end of life care and we noted that staff did not know who the executive lead was.

Safety was not a sufficiently high priority and there was limited measurement and monitoring of safety and performance. Ineffective systems of risk identification and management meant that opportunities to prevent or minimise harm had been missed, particularly in relation to medicines management, mandatory training and record keeping.

We found that the trust was not always delivering care to patients that was evidence-based and in line with key documents such as National Institute of Clinical Excellence guidance and priorities of the dying person, particularly personalised care, identification of the dying person and coordinated services. There was limited monitoring of patient outcomes of care and treatment, and patient feedback was not actively sought.

A review of the data and speaking with staff showed a lack of robust monitoring systems to ensure that the end of life care service was delivered effectively.

The training for staff involved with the delivery of end of life care was inconsistent and in areas the training compliance was very poor. A large number of staff had not had recent up to date end of life training.

The end of life care team worked effectively and engaged with other professionals to ensure patients received the required level of care and support but a stronger senior management support framework was needed.

Staff appraisals were completed but there were inconsistencies in staff supervision. Staff spoke positively about the support they were given by seniors and management.

It was evident that the individual teams delivering end of life care were trying hard to achieve partnership working despite the difficulties of different services being provided under different trusts. A consultant with a responsibility for end of life care who was shared with other local trusts provided good clinical leadership and support to the palliative care team. Staff worked with the local hospice, hospitals, GPs and specialists to seek advice when needed. The hospice team provided specialist advice and support as requested and they coordinated and planned care for patients at the end of life in the community.

When we talked with patients and staff and observed care, we found that staff were passionate and committed to providing good end of life care. Staff were observed providing care to patients with kindness, compassion and dignity.
Summary of findings

Background to the service

The 5 Boroughs Partnership NHS Trust provides 24-hour end of life care services for adults over the age of 18 years and children under 18 years, including patients with individual and complex nursing needs in the community. The service is provided for people who live in the Knowsley borough by district nursing teams and the specialist Macmillan team. The Macmillan team also provide services to some patients in the St Helens borough.

End of life care is provided in a variety of organisational settings by a range of health care professionals. The range of services includes facilitation of discharge from the acute hospital and co-ordination of care provision in the community.

Teams of district nurses provide end of life care as part of their caseloads and additional support is provided from local hospice services. There are no inpatient services for patients using community health services provided by the trust.

Additional services include the district nursing liaison service, which is based at Whiston hospital and assists in facilitating discharges from hospital to the community, the advance care planning team, who work closely with the district nursing teams and the specialist palliative care Macmillan team who ensure patients receive care in their preferred place.

The out of hours (OOHs) service provides professional nursing assessment and advice, management and nursing treatment for patients with palliative care needs and those who are in the terminal phase of their illness. This service is not exclusively for patients at the end of their lives. It is also aimed to reduce hospital admissions out of hours and also provided the following services:

- Assistance with the provision of emergency loans and equipment.
- Psychological support and advice.
- Administration of drugs in the out of hour’s periods.

A specialist paediatric palliative care nurse works closely with Alder Hey Children’s Hospital coordinate and provide care to patients under the age of 18 who are in need of end of life care.

During our visit, we spoke with ten patients and 41 members of staff. We looked at a range of policies, procedures and other documents relating to the running of the service. We reviewed 11 sets of care records and case tracked ten full patient records. We also reviewed 18 medication records, five of which were in use for patients in receipt of end of life care services at the time of the inspection and 13 of which were completed medications records of patients who were not in receipt of end of life care services at the time of the inspection.

Our inspection team

Chair: Kevin Cleary, Medical Director

Head of inspection: Nicolas Smith, Care Quality Commission

Team Leaders: Lorraine Bolam, Care Quality Commission

The team included CQC inspectors and a variety of specialists:

The team that inspected this core service comprised of two CQC inspectors, three specialist advisors who were a specialist nurse, a Chief Executive of a Hospice and a physiotherapist. The team contained an Expert by Experience who was a person who had personal experience caring for someone who has used the type of service we were inspecting.
Why we carried out this inspection

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

How we carried out this inspection

To get to the heart of the experiences of people who use services, 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 5 Boroughs Partnership NHS Trust and asked other organisations to share what they knew about the provider.

As part of the inspection we carried out announced visits between 21st and 23rd July 2015 to:

- The Halewood Centre
- Willowbrook Hospice
- Centre for Independent Living
- Whiston Hospital
- Claire House Hospice

What people who use the provider say

Patients told us that staff treated them with respect, dignity and compassion. The feedback we received from patients was largely positive for all services involved in delivering end of life care. Patients were very complimentary about the Centre For Independent Living, one patient told us that the Centre “Saved my life, it's given me back my life.”

A patient who was receiving end of life care from the community nursing and specialist palliative care team told us “they are kind; they have helped me with my anxiety.”

Some patients we spoke to told us they would have liked the opportunity to feedback on the service they had received, but they did not know how to do this.
Summary of findings

Areas for improvement

**Action the provider MUST or SHOULD take to improve**

The provider MUST;

- Develop and implement a formal strategy, policy and framework for the delivery of end of life care ensuring executive scrutiny.
- Ensure that the management of medicines is safe within the end of life care service, particularly in relation to controlled drugs management.
- Address the low training levels for mandatory medicines management training, end of life care and use of their internal reporting system.
- Implement a standardised approach to care planning for end of life care.

- Improve governance within the end of life care service including monitoring and risk management at all levels.
- Ensure patients receive medication in a timely way when they require it.
- Address the workload of senior managers involved with the delivery of end of life care to ensure this is manageable and safe.
- Ensure that records made by their staff are comprehensive, accurate and contemporaneous.
- Improve their engagement with the public in relation to end of life care services.
Are services safe?

By safe, we mean that people are protected from abuse

Summary
We found that there were no robust systems for setting and monitoring safety goals and performance over time in the end of life care services. Although we saw some examples of how learning was disseminated within the teams providing end of life care services, this was inconsistent between teams. We observed significant issues with the quality of the care records we reviewed, specifically in relation to medication records. In a number of records, we found discrepancies in the stock levels of controlled drugs and other medications. These discrepancies were not identified by the relevant teams and were not reported appropriately through their risk management systems to allow learning and improvement.

Staff told us of significant problems with their current electronic notes system and gave us an example of how this had affected negatively on patients’ care in a recent incident.

The trust did not stipulate that end of life care training was mandatory for staff directly involved in the delivery of end of life care. Training levels for medicines management were very low, with one of the four district nursing teams and the specialist Macmillan team having had no training on the subject.

The trust had stopped using the Liverpool Care Pathway. An advance care plan had been developed to replace it and was awaiting implementation. However, at the time of inspection there was no replacement in use, which had led to inconsistency in end of life care across different teams. There were a number of different care documents being used. As a result of this, we observed some care records with very little evidence of clear plans of care with measureable outcomes. Care records were not always completed fully. We reviewed 11 sets of records relating to recently deceased patients who had been receiving end of life care. In two of these cases, DNACPR forms were present but one was not dated. (DNACPR stands for ‘do not attempt cardio-pulmonary resuscitation’ and the forms record if patients or someone on their behalf has decided that they did not want resuscitation to be attempted.) In seven of these cases, there was evidence that the issue had been discussed or considered but there were no copies of forms in the patient’s records to confirm this. In two of the cases, there was no evidence that the issue had been discussed or forms completed. The trust advised us that copies of the DNACPR forms were not always stored in patients records after death as the forms were a patient held record.
Staff managed equipment well to ensure that it was safe, using robust processes for decontamination and safety checks. Staff adhered to infection control and prevention measures.

Risk assessments, including nutritional assessments and assessments of risk of pressure damage, were completed in the majority of cases, with two exceptions of the eleven records where the documentation was not completed fully.

Staffing within the district nursing teams was good and the staffing rotas reflected the number of staff on duty.

Within the specialist, palliative care nursing team there was a deficit of one band 7 nurse, which had been identified, and a business case had been submitted to the board to ask for this additional staff member. Patients told us that they felt staff within this team were busy and rushed within this team and that their phones were always ringing.

Senior staff within the service told us that they had not risk assessed key issues they had identified within the teams delivering end of life care, such as the culture and working practices within teams and a possible under-reporting of incidents. Senior staff also told us they themselves had not received up-to-date risk management training and we found that there was no risk register specific to the specialist Macmillan nursing team or end of life care services. The trust told us that risks were recorded on a trust wide DATIX system.

**Safety performance**

- There were informal systems to check that staff were delivering high quality care. One of the newly appointed quality leads for the trust told us that part of their role was accompanying staff on patient visits and observing care. They would then feed back to the staff involved and their manager on their performance. The quality lead said that as this was a new initiative they were yet to collate and record the data from these observational visits.
- Senior staff told us that they linked any highlighted issues with staff supervision.
- We did not observe any safety goals or targets in use and, staff were not able to show us how they monitored safety performance over time. Senior staff said that they were looking at introducing safety thermometers to set and monitor safety in the future.
- Senior managers within the service said that they did not routinely review incidents of harm or risk of harm and their themes in relation to the end of life care service.
- There was no evidence of a formal review system for medicines in the end of life care services.

**Incident reporting, learning and improvement**

- Staff were aware of the reporting systems for incidents and had access to the trust-wide electronic reporting system. Staff showed us how they would open the incident system on the computers in their offices.
- Staff said they found the system user friendly and demonstrated to us how they would access and submit an incident report.
- Senior Managers within the service said that they were concerned that staff were not recognising incidents, which should be reported. However when we spoke with staff, they stated that they felt able to identify when an incident should be reported.
- We reviewed 13 medication booklets, which were used to record patients medications and stock levels in their own homes. We found that 12 of the 13 records contained documentation discrepancies and errors; these had not been identified or reported as incidents by the relevant nursing team prior to us bringing this to their attention.
- Learning from incidents was shared with staff at regular team meetings.
- Staff gave recent examples of incidents which they had recently learned from and improved practice as a result. We also saw evidence of incidents being discussed at team meetings in the form of minutes of meetings and agendas of meetings.
- Staff said that they received timely and appropriate feedback when they submitted an incident form or raised a concern.
- District nursing staff gave an example of a recent incident where a patient had not been prescribed timely pain relief. The nursing team had submitted an incident form and as a result a full investigation was undertaken and a multi-disciplinary meeting was held. The nursing staff told us that since this incident early prescribing of pain relief for patients receiving end of life care had improved.
Are services safe?

**Safeguarding**

- Policies and procedures for safeguarding vulnerable adults and children were accessible to staff electronically.
- Staff received mandatory training in safeguarding children and vulnerable adults that included aspects of the Mental Capacity Act 2005 and Deprivation of Liberty safeguards. The lowest percentage of staff who had received safeguarding children training was 83% and the highest was 100%. The lowest percentage of staff within any one team who had received safeguarding vulnerable adults training was 85% and the highest was 100%
- Some staff were knowledgeable about their role and responsibilities regarding the safeguarding of vulnerable adults and were aware of the process for reporting safeguarding concerns and allegations of abuse within the trust. Three trained nurses were unable to show us on the trust intranet site how to locate the page relating to safeguarding information and referrals.
- Staff confirmed safeguarding was always raised at multi-disciplinary meetings and feedback would be via a coordinator who received information from the local authority but staff within one district nursing team advised us they did not receive feedback on safeguarding referrals from the trust.

**Medicines**

- We found that the trust had an up to date policy on the management of controlled drugs. This policy reflected current guidance and was easy to understand and accessible to staff electronically.
- The staff we spoke to who were involved with the management of controlled drugs were aware of the policy and how to access it.
- The trust’s medication management policy, which was shown to us by staff, should have been reviewed in May 2015 and no updated version was available.
- We reviewed five medication records in one team area and these were noted to be up to date, clear and unambiguous.
- We reviewed a further 13 records in another team area and we found that in 12 of these medication stock lists were inadequately maintained.
- Out of the 12 records where discrepancies were noted in the stock levels, five included controlled drug stocks.
- Seven of the records showed discrepancies in the stock levels of medications, which were not controlled drugs.
- We found that the medication records in these 12 cases were not completed in a clear and unambiguous way.
- The process for the destruction of controlled drugs was clearly set out in the trust’s policy on the management of controlled drugs. We found inconsistency between teams and individuals in their understanding and practice of how controlled drugs were destroyed following the death of patients in their own home.
- In two of the medication records we reviewed there were incomplete records detailing the destruction of controlled drugs, leaving them unaccounted for.
- Staff also told us that four ampoules of adrenaline were unaccounted for within one team. When we checked the records for this medication, this was confirmed and the records for the stock levels of the medication were not clear. This had been reported to managers.
- The trust required all nursing staff to undertake a medications management training update every three years. The mandatory training figures showed that the compliance with this training was very low with the highest percent of staff in any of the nursing teams undertaking this in the last 3 years being 15%. In two of the nursing teams, no staff had undertaken this training in the last 3 years.
- We were not assured that medications were being administered and managed safely in end of life care and these issues were immediately highlighted to the trust executives. They acted immediately to assess and rectify the issues and have provided us with an action plan and an update on progress since the inspection to address these issues further. We will continue to monitor the situation.

**Environment and equipment**

- We found that staff were aware of how to safely maintain and use equipment used in end of life care such as syringe drivers.
- Staff told us they received training and updates as needed in relation to the use of syringe drivers.
- We visited the centre for independent living during the inspection and observed how specialist equipment such as beds and pressure relieving devices were cleaned and maintained.
- The centre for independent living had very clear and robust processes for the maintenance and checking of equipment provided to patients in their own home. We
were shown the protocols, which staff were to work within. Staff were able to describe the processes and how they followed them. We observed staff working within these protocols.

- We talked with four members of staff directly involved with the maintenance and checking of equipment at the centre and they all displayed comprehensive knowledge of how to undertake their roles and the checks, which were needed in relation to equipment.
- We observed the storage of dressings and other equipment at team bases and found that this storage was appropriate and well maintained.

### Quality of records

- The trust had recently developed a comprehensive care document called the ‘care and communication record’. This document was viewed as part of the inspection and we found it to be a robust and comprehensive care document, which was easy to understand and follow. At the time of the inspection, this document had yet to be implemented into practice, which had led to inconsistency in the delivery of end of life care across different teams. We found that there were differences in the records being used and maintained in different teams. District nursing teams, were observed to be using legacy notes set with a previous trust’s logo visible on the document and we found in another area they were using a completely different set of notes with no logo visible.
- Some of the documents used to record care were observed to have legacy and previous organisations stated on them.
- A number of the records we reviewed lacked key information such as updates on patients care.
- A number of the records lacked clear plans of care for patients.
- The information contained in some records was incomplete.
- We reviewed 11 sets of case notes relating to patients who had received end of life care and we found that two had DNACPR forms present. The trust advised us that copies of the DNACPR forms were not always stored in patients records after death as the forms were a patient held record.
- Of these two DNACPR records, both were unified DNACPR forms. One was completed fully and correctly and one did not have a date on the form and was not completed fully.

- We also reviewed two patients’ records in the community, one of these had a unified DNACPR form in place, and it was completed correctly with all fields completed.
- The trust Draft DNACPR Policy, dated June 2015, stated that they had not adopted the NHS England (NW) Regional Unified DNACPR form (a multiagency adopted form, which was relevant to all agencies and ensured the DNACPR decision, was adhered to along the patient’s journey). They had chosen to continue to use their internal form but would acknowledge the unified DNACPR until it could be reviewed by a consultant. In practice, we saw the unified form in use and senior executives confirmed that they had adopted the unified form and the policy required amendment.
- The community nursing teams were using an electronic notes system along with their written hand held notes system. This electronic system was called PARIS.
- Staff told us that they would all be moving to a trust wide electronic system called RIO this year.
- Staff raised concerns with us about the electronic records management for patients in their care. Their main concern centred on the PARIS electronic notes system and how this was not compatible with use of patient held notes. Staff relayed an incident by which a patient had received medication twice because the first dose was not documented in both the patient held records and PARIS.
- Staff also told us about problems with connectivity to the electronic system and said that they often had to complete notes retrospectively after seeing numerous patients because of this.

### Cleanliness, infection control and hygiene

- Personal protective equipment (gloves and aprons) and hand cleansing products were available to all staff undertaking patient care.
- We observed staff during direct patient contact and we observed them appropriately sanitizing their hands during this process. Staff were aware of when personal protective equipment should be used.
- We observed equipment being cleaned and sanitized prior to and after patients use in the Centre for Independent Living. The processes were clear and robust to minimise risk of infection.
Are services safe?

- Staff at the Centre for Independent Living showed us the protocols, which they follow for decontamination of equipment and these, were current, followed current guidelines and were easy to understand.

**Mandatory training**

- The mandatory training figures provided to us varied greatly between teams. An example of this was found in the mandatory training figures where in one District Nursing Team the percentage of staff who had received Fire Safety training was 60%; however in another team 100% of staff had received this training. However, there were some training areas with low training figures which included moving and handling with two of five nursing teams reporting 0% of staff receiving training and the other three teams had compliance at and below 60%, medicines management with one team out of four district nursing teams and the specialist Macmillan team reporting 0% of staff receiving training. The trust did not stipulate that end of life care training was mandatory for staff directly involved in the delivery of end of life care.
- Staff told us that they were encouraged to undertake mandatory training and that their managers monitored this.
- Records we reviewed confirmed that compliance with corporate induction was high with one team reporting 100% of staff trained and the lowest figure being 89% of staff trained in another team.

**Assessing and responding to patient risk**

- We reviewed 11 care records of recently deceased patients and found that in nine of these cases risk assessments such as nutritional assessment, pressure ulcer risk assessments and bed rails assessments had been undertaken and were documented fully.
- In two of these records, there were incomplete risk assessments in place, for example, nutritional assessments and falls risk assessments were absent.
- We also reviewed four care records of patients currently receiving end of life care. In all four cases, documentation was seen which showed assessment of patient risk and an appropriate response taken.

**Staffing levels and caseload**

- A consultant with a responsibility for end of life care was shared with other local trusts. Patients were supported by their GP’s.
- The specialist palliative care nursing team had 6.2 whole time equivalent band 7 specialist nurses, which was in line with their current establishment. It had been identified by the manager for the team that they required an additional whole-time equivalent band 7 nurse to meet the staffing ratios set out and agreed in their commissioning document and agreement. This issue had been put forward in a business case to the trust board in April 2015 but at the time of the inspection they had not received, any feedback on this business case and the team remained at a staffing deficit of one band seven nurse. This issue was highlighted on the community health risk register as a risk which could potentially cause staff stress; however no risk assessment in relation to patient impact was mentioned or registered.
- Staff within the Macmillan team told us they were very busy because of this deficit of one full time band 7 nurse. This deficit has also affected patients and some patients told us that they felt the Macmillan team were very busy and did not like to bother them. They also reported that their phones were always going off and they were rushed when seeing patients. Macmillan team staff did not deliver pain relieving medications to patients and would call on the district nursing teams to complete this task.
- Some staff within the Macmillan team told us that they felt understaffed and unable to focus on extra parts of their role such as quality improvement.
- Staff within the district nursing teams told us that they felt they were well staffed within their teams and they worked together to cover unexpected absences and holiday periods.
- The staff in one district nursing team showed us an internal award they had received for their commitment to ensuring staffing cover was provided within their team.
- The staffing rota for all teams reflected the actual number of staff who were on duty and there was a low rate of staff turnover.

**Managing anticipated risks**

- We found that there was no local risk register for the Macmillan team or end of life care services. The trust told us that risks were recorded on a trust wide DATIX system.
- Senior staff told us that they had not received any recent risk management training and had not risk assessed key
issues which had been identified within the end of life care service including staffing deficits, team culture and a possible under reporting of incidents and safeguarding issues.

• Staff told us of ways they had dealt with adverse weather conditions in the past, such as walking to patient’s homes and local businesses helping them with heavy-duty vehicles.

• Staff were not aware of any specific policy to follow or consult regarding adverse weather conditions to ensure patient care would be delivered in these circumstances.

• The lone worker policy was implemented fully and staff were aware of how the policy was to be used. However, the version shown to us by staff was out of date and due for review.
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 found that the trust were not delivering care in line with key documents such as NICE guidance and priorities of the dying person in some cases, in particular personalised care, identification of the dying person and coordinated services.

They had developed a comprehensive advance care plan, based on best practice guidance from NICE and other documents, to replace the Liverpool Care Pathway that was withdrawn in July 2014. However, this plan was not yet in use and had led to inconsistent care being provided and we observed examples of how this had negatively affected patient’s care.

Pain was being assessed and managed; pain relief was being prescribed appropriately overall. However, we found that there was a significant issue raised with us around the specialist palliative care team not administering pain relief to patients but rather waiting for the community nursing teams to arrive and do this. This could potentially lead to a delay in patients receiving the pain relief they need. The trust assured us that they were addressing this issue, by ensuring all nursing staff were aware and able to administer medication when required.

We found that patients nutritional and hydration needs were being assessed overall and recognised assessment tools were being used to assess these needs.

The staff we spoke with appeared to be competent, passionate about their roles, and committed to delivering high quality end of life care.

The service did not have evidence from formal audit of patient outcomes to support proactive management and improvement of the end of life care service but had undertaken a number of internal audits in relation to specific areas of end of life care including the audit of DNCPR form completion. The trust contributed to the national dataset on end of life care however, they were unable to provide us with data past March 2014.

The teams involved in the delivery of end of life care appeared to work closely and effectively together to facilitate high quality patient care. This extended to the discharge of patients to their place of preferred care that was facilitated by close working between disciplines and centres.

Staff told us about their ability to respond quickly to referrals; however, referral to contact times were not subject to formal monitoring and audit. Although the trust is not required to have a rapid discharge policy in relation to patients receiving end of life care. The trust also did not have a specific policy or standard process to guide staff on how quickly patients should have services put in place to facilitate their place of preferred care. However, it was evident that discharges and transfers occurred quickly.

Patients had access to leaflets on end of life care services. Staff were aware of the MCA (2005) but the uptake by staff for this mandatory training subject was low.

Evidence based care and treatment
- Staff showed us the recently developed care and communication record, which offered personalised care plans. This record was based on NICE guidance and principles set out in the Priorities for Care of the Dying document. However, this was not in use at the time of the inspection.
- The trust was supporting local care homes with working towards Gold Standards Framework Accreditation and five of the care homes they were working with had achieved accreditation status.
- The trust were unable to provide us with any evidence based guidance, frameworks, strategies or care plans which they had developed and were in current use. We were shown a number of documents developed by the North West Palliative Care Network, which were based on NICE guidelines, and other evidence-based guidance, which the Clinical lead for the network advised, were provided to organisations as educational tools.
- All staff we spoke with advised that there had been no framework or advance care plan in place since the Liverpool Care Pathway was withdrawn in July 2014.
Are services effective?

This was confirmed in patient records we reviewed which showed no evidence of any such document or plan. This had led to inconsistent care being delivered in different areas by different teams.

- The inspection team found that the trust were not delivering care in line with key documents such as NICE guidance and priorities of the dying person in some cases, in particular personalised care, identification of the dying person and coordinated services.
- This had affected patient care and was highlighted during a review of recently deceased patient’s notes, where two patients were identified as having issues at the end of their life which did not meet the guidance set out in the aforementioned documents.
- Records we reviewed showed that one patient was having difficulty coming to terms with their diagnosis. It was identified that a number of services attended the patient simultaneously which had been distressing and confusing for the patient.
- A number of prompt cards and an aide memoire were in use by the teams delivering end of life care. However, the lead clinician for the North West Palliative Care network clarified these as educational guides to support trusts in developing their own policies and frameworks in the delivery of end of life care.

Pain relief

- There was evidence in patients’ records that pain relief had been prescribed appropriately and was administered when they required pain relief.
- The community nursing teams told us that they prioritised patients receiving end of life care if they called and required medication or assistance.
- The aide memoire in use and provided by the North West Palliative Care Network included pain assessment guidelines and prescribing guidelines.
- Patients told us that they had no issues about the way in which their pain was managed.
- Staff told us that they had 24-hour access to syringe drivers to deliver pain relief and other medications as needed.
- We were told by a number of staff that the palliative care specialist nurses would not administer medication to patients. This included times where patients would be in physical pain. They would instead contact the community nursing team to administer pain relief and this resulted in a delay in the patient receiving pain relief. Senior staff told us that they were currently addressing this issue.
- There was evidence within records that pain was being assessed on an ad hoc basis, however no formalised reviews were present in the records we reviewed of patients currently receiving end of life care.

Nutrition and hydration

- In nine of the 11 care records of recently deceased patients that we reviewed, there was evidence that nutrition and hydration had been assessed and a MUST risk assessment tool completed.
- Community nursing staff were aware of how to refer patients to dietetics if needed. Staff talked us through the process of referral and showed us evidence in care records of patients who had been referred.

Patient outcomes

- The trust had completed three recent audits specifically in relation to end of life care. These were looking at DNACPR form completion, place of preferred care and collection of information relating to where patients had died.
- The audit, which looked at DNACPR forms, showed that the trust were regularly auditing DNACPR forms. The audit focused on the key areas for completion on a DNACPR form including whether a mental capacity assessment was undertaken, whether the decision was discussed with the patient and whether it was completed fully. The audit showed that 49% of patients were informed of the decision and in cases where the patient was not able to be informed 94%, of next of kin were informed of the decision. In 174 cases out of 198 (88%) of cases the decision was documented in the patients notes. However in 162 out of 198 (82%) of cases there was no evidence in the patients notes of discussion about the decision.
- The trust had recently taken part in a project with the Marie Curie Centre in Liverpool to audit quality assurance for patients receiving end of life care. However, only one response was received in response to this audit, so the service were unable to provide any further data in relation to this audit.
Are services effective?

- The trust undertook a monthly audit in relation to place of preferred care for patients receiving end of life care and this showed that in May 2015, 75% of patient’s received care in their preferred place. This is compared to the national benchmark of 85%.
- Senior staff working within the end of life care services were not aware that any after death analysis or mortality reviews were undertaken in relation to patient’s who had received end of life care. However the trust advised that after death analysis was completed for complex cases.
- The trust contributed to the national dataset on end of life care. However, they were unable to provide us with data past March 2014.

Competent staff

- The band 7 specialist nurses within the palliative care team had all undertaken specialist degree level training in end of life care. They were all very experienced and had worked within the team for a number of years.
- The community nursing staff we spoke with were knowledgeable about end of life care and specific areas of end of life care such as anticipatory medicines and rapid discharge.
- The trust did not stipulate that end of life care training was mandatory for staff directly involved in the delivery of end of life care.

Multi-disciplinary working and coordinated care pathways

- We saw evidence of multi-disciplinary team meetings, which were held with medical staff including the consultant responsible for end of life care and GPs, nursing staff, therapists and specialist palliative care staff.
- Community nursing staff told us that the specialist palliative care team were accessible and supportive. We observed the district nursing team staff contacting the Macmillan team for advice during the inspection.
- We spoke with the district nurse liaison team who also told us that they found the team accessible and supportive.
- The consultant responsible for providing medical care to end of life care patients in the Knowsley Borough told us that they met regularly with the specialist Macmillan nursing team and found them to be professional and competent in their role.
- We also spoke with staff at Willowbrook Hospice (who provided palliative care advice and support) they told us that they spoke and met regularly with the palliative care team as needed.
- The community nursing teams told us that they felt able to raise issues about other disciplines and work through problems together as a multi-disciplinary team.
- There was no unified care pathway or plan used by all disciplines in place at the time of the inspection. The recently developed care and communication record, which was awaiting implementation, did have the feature of being a multi-disciplinary document.

Referral, transfer, discharge and transition

- Staff within the specialist palliative care team told us they were most proud of their ability to respond quickly to referrals that came into the team.
- Community nursing staff told us that referrals were responded to by the palliative care team quickly and appropriately. However, we did not see any evidence relating to response times to referrals.
- Senior staff told us that they did not monitor referral to contact times. However, they advised that this was something that they were hoping to develop in the future.
- Although the trust is not required to have a rapid discharge policy in relation to patients receiving end of life care. The trust also did not have a specific policy or standard process to guide staff on how quickly patients should have services put in place to facilitate their place of preferred care when receiving end of life care. However it was evident that discharges and transfers occurred quickly.
- Most staff we spoke with advised that they tried to get patients home within 48 hours of request. We did not see any evidence to support this.
- All nursing staff we spoke with praised the Centre for Independent Living and how quickly they were able to respond to requests for equipment to facilitate discharges.
- Patients also praised this centre for their efforts to get them the equipment they needed quickly.
- We spoke with the discharge team at Whiston Hospital and they advised us that they did not have any issues when discharging patients to the community in the Knowsley area and found the nursing teams in the area to be responsive and helpful in the discharge process.
Access to information

- Patients had home held notes that could be accessed by different professionals attending their homes.
- The care and communication record that was awaiting implementation in the Trust was a multi-disciplinary document that would allow all disciplines and patients to access information about their care.
- We observed leaflets and contact sheets, which were given out to patients in relation to end of life care services.

Consent, Mental Capacity Act and Deprivation of Liberty Safeguards

- Staff received mandatory training in safeguarding children and vulnerable adults, which included aspects of the Mental Capacity Act (2005) (MCA) and Deprivation of Liberties Safeguards (DoLS).
- Staff displayed a basic understanding of the requirements of the MCA 2005.
- Mandatory training figures for the Mental Capacity Act showed variable compliance with the highest compliance within any one team at 71% staff trained and the lowest being 23%.
Are services caring?

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

Summary
We observed staff delivering compassionate care. They displayed a person centred approach when discussing patients with us. Patients told us they felt staff were compassionate and caring in their approach to patient care. We observed patients being offered and given emotional support on the telephone and during visits to their homes. We were told of a number of examples where staff had delivered excellent care to patients.

However, patients and carers did not always feel involved with the development of their care plan although it was hoped this would be addressed through the new communication documentation when it was introduced.

Compassionate care
• We observed interactions between patients and staff. Staff were polite, courteous and caring towards patients at all times.
• We observed handover and spent time in the team office listening to staff talk to patients on the telephone and to each other. Staff spoke respectfully to patients and about patients and appeared to have their best interests at the centre of their decisions.
• Patients told us that staff were kind, caring and compassionate.
• All staff in all the teams we visited displayed a caring and compassionate approach to their work.
• We were given some examples of excellent care, one of these was involving a staff member who drives and delivers equipment from the Centre of Independent Living to patient’s homes. We were told of an occasion when the driver had arrived to deliver equipment to a patient and found that he had suffered a fall. The driver assisted the patient and called for help. He then stayed with the patient for some time reassuring him until his family and help arrived.

Understanding and involvement of patients and those close to them
• At the centre for independent living, we found that the staff had a person centred approach to all the tasks they undertook. The staff who were decontaminating equipment told us how they see their job as a caring role as although they don’t see patients face to face, they keep them in mind and do the best they can in their role to make sure patients receive a caring and effective service.
• Staff displayed a person centred approach when discussing patients with us.
• Community nursing staff also told us of an example where they had facilitated a holiday for a patient receiving end of life care by liaising with nursing and medical staff at the destination they were holidaying to.
• Three patients told us that they had not been involved with the development of their care plan.
• We reviewed the care and communication record that was awaiting implementation. We noted that there was specific section for patients and their relatives to record their preferences.

Emotional support
• We observed patients being offered and given emotional support on the telephone and during visits to their homes.
• Patients were very positive about the emotional support they received.
• One patient told us how the palliative care team had helped her with techniques to manage her anxiety.
Are services responsive to people’s needs?

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

**Summary**

The trust did not have an end of life care specific strategy to guide patient involvement in the improvement of service delivery. The lack of a strategy to direct the monitoring of the service meant there was a lack of data to support whether the service was responsive to people’s needs.

Although the service was part of the North West Palliative Care Network, the network and other stakeholders such as the local hospice told us that they were not routinely involved in service developments specific to the end of life care service.

Senior staff were unable to give us any examples of how the needs of the local population were taken into account when planning the delivery of services in relation to end of life care and senior staff said they did not routinely seek patient feedback when planning or changing services.

Patients generally reported that they received a good service in relation to end of life care. Patients could access care and treatment 24 hours a day however, they told us that they sometimes had to wait longer than they would like when they called for help out of hours. Staff told us how they shared complaints at team meetings to reflect and learn from them. However, two patients told us that they did not know how to make a complaint.

The Centre for Independent Living provided an excellent responsive service to patients in relation to access to equipment and therapists. They also used patient feedback and consultation when planning and delivering their services.

We observed the service delivering care to a range of patients with different conditions.

**Planning and delivering services which meet people’s needs**

- The palliative care team delivered a training programme to community staff on aspects of end of life care. Community nursing staff told us that they could request training subjects from the specialist team in relation to specific patient needs.
- The Centre for Independent Living provided a self-referral service for patients and their relatives. The Centre provided a responsive service to the local population. Patients told us how they valued the Centre and told us how the staff helped them to meet their needs.
- Stakeholders such as the local hospice and the clinical lead for the North West Palliative Care Network told us that they were not routinely involved in service developments specific to the service.
- Senior staff were unable to give us any examples of how the needs of the local population were taken into account when planning the delivery of services in relation to end of life care.
- We were told by senior staff that they did not routinely seek patient feedback when planning or changing services.
- There was no evidence of any action plan or strategy to guide end of life care and reflect services delivered by other providers.

**Equality and diversity**

- The care and communication record that was awaiting implementation included sections on the spiritual needs of patients and their mobility needs. However, this was not yet in use.
- We did not see any leaflets or information that could be provided to patients if their first language was not English.
- Staff were able to tell us how they would access a translator if they needed to.

**Meeting the needs of people in vulnerable circumstances**

- End of life care services were available and were being provided to patients with a variety of conditions including dementia and patient with disabilities, and we saw examples of this in case records and when talking to patients. This showed us that staff were providing these services to all groups of patients regardless of condition or disability.
- The Centre for Independent Living told us how they had access to refer patients who present to other services such as physiotherapy and occupational therapy.
Access to the right care at the right time

- Patients had access to 24-hour care through the community nursing and palliative care team during the daytime and then the out of hour’s service at night.
- One patient told us that a visit had been cancelled but they were informed of this and someone else arrived very soon afterwards to deliver their care.
- Staff members involved in all areas of delivering end of life care told us that they made every effort to ensure patients reaching the end of their life received timely care.
- We were unable to find any policies or frameworks outlining expected time limits for receipt of services and fast track discharges.
- Patients told us that the service was good but very busy and appeared ‘uncoordinated’ at times. One example was of multiple services attending the home of a patient within two days that left her ‘drained’.
- There was a 24-hour advice line for professionals requiring end of life care advice. However, if patients require advice they had to call the general out of hour’s number and they told us that this sometimes took a long time. This was corroborated by staff who advised the same. Some staff advised that patients would obtain the professional’s line number as a last resort and call that line. Patients told us that they had to use the out of hour’s number and sometimes they had to wait longer than they would like to speak to someone.

Learning from complaints and concerns

- Staff told us that they did not often receive complaints for end of life care specifically, but if they did these were shared and reflected on at team meetings for learning. We did not see any evidence of this in minutes of meetings that we reviewed as part of the inspection.
- Two patients advised they were unaware of how to raise a complaint.
- One of these patients relayed a situation where a nurse had been rude to them and they wanted to make a complaint but did not know how so they had not made one.
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
The trust did not have a strategy or framework for the delivery of services within end of life care. Staff including managers could not articulate how progress towards the development of a strategy in relation to end of life care was being delivered or monitored at a local or trust level.

There was no local risk register for end of life care or the palliative care team. The trust told us that risks were recorded on a trust wide DATIX system. However we found that key issues and risks within the end of life care service had not been risk assessed. Therefore, robust arrangements for identifying, recording and managing risks were not in place.

Staff within the service were unable to tell us how they brought together and reviewed different streams of governance to inform risk management, such as incident review, thematic review of complaints data and incident data received from other organisations regarding care provided by the service. There was no systematic programme of clinical and internal audit to monitor quality and drive improvements.

There was an open culture. Staff told us that they felt that their leaders were approachable and visible and they felt comfortable and able to raise issues of concern. Staff felt supported and we observed minutes of regular staff meetings and individual appraisals that supported this. However, some senior managers within the trust told us that they felt their workload was unmanageable and felt unsupported by the trust board. Since the inspection the trust have advised us that they had acknowledged the demands placed on operational managers and were taking active steps to address this issue.

The end of life care team worked effectively and engaged with other professionals to ensure patients received the required level of care and support.

We saw evidence in one area of engaging the public in how the trust planned their services. Senior staff within the service told us they did not routinely seek patient or public engagement when planning and delivering end of life care services. The trust told us that they have an active service user engagement framework and that they also engage closely with the local Healthwatch group.

The centre for independent living was viewed by staff as a responsive and innovative service, which supported good quality end of life care.

Service vision and strategy
• The trust did not have a strategy or framework for the delivery of services within end of life care in place. Since the inspection the trust have made significant progress in developing a formalised and comprehensive strategy for the delivery of end of life care services.
• None of the staff we spoke to involved in the delivery of end of life care services were aware of any local vision or strategy in relation to end of life care and they could not articulate how progress towards the development of a local strategy in relation to end of life care was being delivered or monitored at either a local or trust level.

Governance, risk management and quality measurement
• Senior managers within the service were unable to tell us how they reviewed and brought together different streams of governance to inform risk management, such as internal incident review, thematic review of complaints data and review of incident data received from other organisations regarding care provided by the service in 5 Boroughs Partnership Trust.
• The board assurance framework did not reference end of life care.
• There was no local risk register for end of life care or the palliative care team. The trust told us that risks were recorded on a trust wide DATIX system. However we found that senior staff had not risk assessed key issues which had been identified within the end of life care service including staffing deficits, team culture and a possible under reporting of incidents and safeguarding issues. Therefore, robust arrangements for identifying, recording and managing risks were not in place.
Are services well-led?

- End of life care was discussed at the trusts clinical leadership group and the district nursing services which provided end of life care reported to a quality and safety committee.
- We found there was no comprehensive assurance system to measure service performance specifically in relation to end of life care outcomes and measures.
- There was no systematic programme of clinical and internal audit to monitor quality and drive improvements.
- Some audits were being undertaken by the advance care planning team in relation to end of life care. However, the managers we spoke to were unable to give examples of the audits and measures which had been undertaken.
- When asked about the use of nationally recognised tools for assessing and monitoring quality in end of life care, senior managers with a responsibility for end of life care were unaware of these tools or their use.

Leadership of this service

- Managers within the service told us that their workload was unmanageable and they had significantly reduced capacity due to their workload. Since the inspection the trust have advised us that they had acknowledged the demands placed on operational managers and were taking active steps to address this issue. One such example was the increase from four operational managers to five operational managers. Staff said this had become an issue since Matrons within community teams had been changed from band 8 to band 7 resulting in more responsibility being placed with the operational managers. An organisational structure showed that the operational manager for end of life care had overall responsibility for three teams; the district nursing liaison team, Macmillan nursing team and one district nursing team.
- Staff told us that the specialist Macmillan team who provided end of life care services had changed managers three times in a 12-month period in 2013-2014.
- A newly appointed senior manager for the specialist Macmillan team was appointed in September 2014 who had made significant changes to the operational working of the end of life care. These changes included a staffing review and business case proposal for an additional band 7 Macmillan specialist nurse, caseload review and equitable division of caseloads within the Macmillan team and the development of a standard operational process relating to the Macmillan team. We saw evidence of these actions in records and minutes of meetings.
- Staff particularly within the palliative care team told us how they felt much more supported and happy in their role since their new manager had been in post.
- All staff we spoke to told us that they felt their local leaders were approachable and visible.
- Staff felt their leaders supported them to form supportive relationships between their team members and other teams.
- Staff at the Centre for Independent Living told us that their manager was visible on a daily basis, walking around the Centre. They also told us of an example where a traumatic incident had occurred involving a staff member and their senior manager put on a uniform and joined the team in daily duties, even going out delivering equipment with them to support them.

Culture within this service

- Staff told us that they felt respected and valued.
- All staff we spoke with said they felt supported by their immediate line managers and they would feel comfortable raising any concerns they have.
- Staff told us they had an open culture and were not afraid of speaking up if they made an error or had a concern.
- Senior managers within the service however told us that they did not feel supported above their immediate line managers and specifically did not feel supported by the trust board. They told us that they felt the trust board did not have a specific focus or interest in end of life care services.

Public engagement

- Patients said that they would like to give feedback in order to influence services. However, some patients did not know how to do this and were not offered the opportunity to feedback.
- Senior staff were unable to give us any examples of how the needs of the local population were taken into account when planning the delivery of services in relation to end of life care.
- Senior staff within the service told us they did not routinely seek patient or public engagement when planning and delivering end of life care services.
Are services well-led?

• The trust told us that they have an active service user engagement framework and that they also engage closely with the local Healthwatch group. This group feeds in complaints and comments to the trust on a regular basis.
• The Centre for Independent Living had a group of patients who use the Centre to advise them and help in their planning of service delivery. Staff told us of an example where a member of this group had recommended changing access to the car park for wheelchair users. The Centre took this information and changed the car park to make it more accessible for wheelchair users. We saw examples of written minutes from this group.

Staff engagement
• Staff told us that they had regular team meetings and we reviewed minutes from these meetings.
• Staff also told us that they were actively encouraged to feedback any issues they have to their leaders. They outlined to us how they would do this either by email or using the incident reporting system.
• Staff told us that they received timely feedback when they raised a concern or an incident. One staff member showed us an email she had received from a manager advising her of the action that had been taken as a result of her concern.

Innovation, improvement and sustainability
• The frontline staff involved with the delivery of end of life care worked effectively as a team. They engaged with other professionals to ensure patients received the required level of care and support.
• Staff and patients spoke positively about the Centre for Independent Living and how its innovative practices and approaches such as multiple therapies on site and self-referral were helping patient receiving end of life care. Staff and patients were able to source equipment quickly and effectively with few limitation.
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.

<table>
<thead>
<tr>
<th>Regulated activity</th>
<th>Regulation</th>
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<tbody>
<tr>
<td>Nursing care</td>
<td><strong>Regulation 9 HSCA (RA) Regulations 2014 Person-centred care</strong></td>
</tr>
<tr>
<td></td>
<td>The trust did not have a standardised approach to care planning for end of life care. We found that there were occasions where there were delays in patients receiving medications they required because the Macmillan nursing team did not routinely administer medications.</td>
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<tr>
<td></td>
<td>This was a breach of Regulation 9 (1)(a)(b)(c)(3)(a)(b)(c)(d)(e)(f)(g)</td>
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<tr>
<th>Regulated activity</th>
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<tbody>
<tr>
<td>Nursing care</td>
<td><strong>Regulation 12 HSCA (RA) Regulations 2014 Safe care and treatment</strong></td>
</tr>
<tr>
<td></td>
<td>We found a number of incidents where medicines were not accounted for and managed appropriately. We were not assured that medicines were being managed safely within the end of life care service, particularly in relation to controlled drugs management.</td>
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<tr>
<td></td>
<td>Training uptake for mandatory medicines management was poor in all teams involved in the delivery of end of life care.</td>
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<tr>
<td></td>
<td>Staff who were required to use the trusts internal reporting system had not received appropriate training in how to use the system.</td>
</tr>
<tr>
<td></td>
<td>This was a breach of Regulation 12 (1)(2) (a)(b)(c)(g)</td>
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<table>
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<th>Regulated activity</th>
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<tbody>
<tr>
<td>Nursing care</td>
<td><strong>Regulation 17 HSCA (RA) Regulations 2014 Good governance</strong></td>
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</tbody>
</table>
The trust did not have a formal strategy, policy and framework for the delivery of end of life care.

No evidence was found that governance was being monitored within the end of life care service and being used to inform risk management.

We found that some patient records were not comprehensive and accurate. The service had not identified and reported all risks in line with their own procedures.

Senior managers within the trust told us they did not routinely seek patient or public engagement when planning and delivering end of life care services.

Senior managers within the service told us that the workload of senior managers involved with the delivery of end of life care was unmanageable. Documents we reviewed showed that the operational manager for end of life care services had responsibility for three teams.

This was a breach of Regulation 17 (1)(2) (a)(b)(c)(e)(f)