

London North West Healthcare NHS Trust

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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)
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This report describes our judgement of the quality of care provided within this core service by London North West Hospitals NHS Trust. Where relevant we provide detail of each location or area of service visited.

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

Where applicable, we have reported on each core service provided by London North West Hospitals NHS Trust and these are brought together to inform our overall judgement of London North West Hospitals NHS Trust

Summary of findings

Ratings

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

Summary of findings

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Summary of findings

Overall summary

Overall, the services provided by London North West Hospitals NHS Trust for community health End of Life care was rated as good because;

We found the community palliative care team (CPCT) for the London boroughs of Brent and Harrow and Ealing and Hounslow to be passionate about ensuring patients and people close to them received safe, effective and good quality care in a timely manner. However there were some concerns expressed by the CPCT'S whether all community generalist nurses who supported patients on a day-to-day basis had the skills and expertise to recognise when a patient who had reached the last 12 months or less of their life was deteriorating.

Some generalist community nurses were reported to be "task based" when caring for patients and did not always consider a patient in a whole or holistic way. We were given examples where generalist nurses had not spotted deterioration in a patient they were regularly caring for. However there was no evidence of harm to patients. We did observe some generalist nurses who were good at identifying changes and indications of deterioration in patients' condition, such as end stage dementia. Others had specialist interest and skills in relation to specific patient groups such as learning difficulties.

Staff were aware of their responsibility in raising concerns and reporting incidents. However we found some incidents and concerns staff shared with us had not been reported through the electronic reporting system as would have been expected. This included missed appointments, telephone messages not being received, and delayed hospital discharges. There was a mixed response as to how often staff received feedback from reported incidents. Some staff told us they only received feedback relating to their own location, while other staff told us they also knew of incidents that happened in other areas of the trust; therefore we found an inconsistency in shared learning and improvement measures.

The community staff reported that local leadership was visible, accessible and responsive. Local managers had appropriate knowledge and experience to lead services and they were well aware of issues and challenges their teams faced. Staff felt empowered by their local team

leaders and managers. However this was not reflected at trust level. Staff were unclear of the trust vision and reported feeling they would not be able to instigate or effect any change. The service level leads told us although there was trust board representation they did not feel that EOLC received the level of support it required to effect the change required to provide an integrated strategy which provided seamless, safe and high quality care for all patients across the trust's locality.

At a local level the community palliative care team strove to educate, support and provide advice to community nurses, primary care providers and nursing/care homes. A recent education audit in Ealing and Hounslow identified that many community healthcare staff wanted EOLC training. The audit had secured funds and training was hoping to go ahead early in 2016.

The patients and relatives spoke positively about their interactions with the teams involved in their care. They described the staff as "kind" and that "nothing was too much trouble for them". They told us they felt understood and able to raise any concerns they had. Patients records and care plans were regularly updated, matched the needs of the patient and were relevant to EOLC. Holistic assessments looked at the whole picture; the patient's physical, emotional, spiritual, psychological and social needs were assessed and their carers' views were taken into consideration. Pain relief, symptom management and nutrition and hydration needs were monitored, recorded and any changes were responded to.

Staff were able to explain their understanding of the Mental Capacity Act (MCA) 2005 and Deprivations of Liberty Safeguards (DoLS). They told us they would act in the best interests of the patient should they lack mental capacity to make decisions for themselves. They understood the patient's carer should be consulted in gaining an understanding of what the patient would want when making best interest decisions and people could not consent on behalf of the patient unless they had a relevant legal directive to do so. All staff understood their role and responsibility to raise any safeguarding concerns.

The palliative care teams were committed to making end of life care a priority for the trust. However we found each

Summary of findings

team across the acute and community sites was approaching support for community patients in different ways and therefore care for patients was not equitable across all the London boroughs the trust supported. For example Ealing patients had overnight nursing support through Marie Curie, while patients in Harrow and Brent did not have access to this support; and Harrow patients with long term chronic conditions and identified at end of life were supported in their homes through a 'virtual ward' scheme which prevented unnecessary admissions to hospital, this was not provided to Ealing and Brent patients.

The acute and community palliative care teams were aware that although they had the expertise the push for improving and providing a seamless service should not fall on their shoulder alone as "death and dying was everyone's business" and therefore should be a trust-wide responsibility. To address this the end of life strategy committee included people such as those who had experienced the service, chaplaincy, GPs, community services, clinical nurse specialists, consultants, and other organisations such as Marie Curie.

Summary of findings

Background to the service

End of life care (EOLC) is provided to patients who have been identified as having entered the last 12 months of their life or less.

EOLC services for people living in the London boroughs of Ealing, Harrow and Brent were provided by several organisations; London North West Healthcare NHS Trust (the trust), three hospices (Meadow House Hospice, St. Luke's Hospice and The Pembridge Palliative Care Centre), and other organisations such as Marie Curie. The trust does not have any dedicated EOLC beds located within its acute hospital services.

Patients living in the London boroughs of Ealing and Hounslow were served by Meadow House Hospice (MHH) which is located on the Ealing Hospital site and is managed as part of the trust. MHH is available 365 days per year, has 15 beds and a total capacity of 5,475 bed days available. Places are offered on the basis of need and not whether the patient has a cancer or non-cancer diagnosis. MHH also runs a day hospice which is open three days per week from 9am to 5pm. The hospice also provides a range of complimentary therapies, speech and language therapy, physiotherapy, occupational therapy support, a lymphoedema service, support to patients in the community, family support and MacMillan bereavement services, as well as a rapid response and out of hours service. The community palliative care team (CPCT) supporting patients in the Ealing and Hounslow areas worked from this location.

Patients living in the London boroughs of Harrow and Brent were served by St Luke's Hospice in Harrow which is managed by another provider and was not inspected at this time, however we interviewed staff at St Luke's regarding their working relationship with the trust and the CPCT for Harrow, which is located at this hospice.

The Pembridge Palliative Care Centre was run by another provider who we did not inspect at this time. The centre was based in Ladbroke Grove and commissioned to deliver specialist palliative care to part of the Brent Clinical Commissioning Group (CCG).

The CPCTs provided specialist support for people facing serious illness. They worked closely with the patient's GP, hospital doctors, community nurses and other professionals supporting the patient and those who are close to them. The clinical nurse specialists (CNS) in the CPCT visit patients in their home and/or care homes and provide additional support to carers as required. They also see patients in outpatient clinics and at the day hospice when appropriate. They provide support, advice and where needed assist the generalist community (district) nurses who are responsible for the day-to-day care of patients who have entered the last 12 months or less of their life.

The bodies of patients who died at MHH were taken to the on-site mortuary at Ealing hospital. Please see the main report for Ealing hospital to read about the mortuary services.

Our inspection team

Our inspection was led by

Chair: Dr Richard Quirk, Medical Director Sussex Community NHS Trust

Team Leader: Nicola Wise (David Harris supporting), Care Quality Commission

The team inspecting this core service included an inspector and three specialist advisors.

Why we carried out this inspection

This was a scheduled comprehensive trust inspection.

Summary of findings

How we carried out this inspection

To get to the heart of people who use the 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?

During this inspection we spoke with 15 members of staff which included local level service leads for specialist palliative care and end of life care, community nurses, allied health professionals clinical nurse specialists in palliative care and consultants.

We spoke with six patients and three relatives. We reviewed six care records and do not attempt cardio pulmonary resuscitation records. We also reviewed thank you cards and letters. During and prior to the inspection we requested a large amount of data in relation to the service which we also reviewed.

We visited the inpatient units Meadow House Hospice based at Ealing hospital and Willesden Health and Care Centre where we observed EOLC practice on two general rehabilitation wards for the elderly (Fifoot and Furness wards). We spoke with community staff based at St Luke's Hospice, Acton Health Centre and Hillside Primary Care Centre in Brent.

What people who use the provider say

Community health services provided good care for patients at the end of their life. We spoke with two patients and one relative in their own home; one inpatient and their relative at Meadow House Hospice; three day hospice patients and reviewed thank you cards. Patients we spoke with told us "nothing was too much trouble" for the staff.

Patients told us "everyone is very friendly" and that they felt listened to and understood.

Patients and their families were involved and encouraged to be partners in their care and in making decisions. Patients told us the staff were very helpful as they explained their condition to them and those important to them and addressed any concerns they had.

Patients visiting the day hospice told us they each had some time with a nurse and/or doctor to discuss any problems or concerns. They told us they discussed symptom control and medication options.

Bereavement support was offered to people important to the deceased and staff checked on their welfare following the death of their relative or friend. On recently bereaved relative told us the support had been very useful.

Good practice

The virtual ward operating in the Harrow community with input from clinicians based at Northwick Park Hospital. This scheme supported patients who have long term chronic conditions, from which they were not going to recover from, in staying their own homes and reducing hospital admissions.

Appointing a dietician specifically for end for life care and dietetic input at Meadow House Hospice. This supports the Leadership Alliances five priorities of care 2014 in acknowledging the importance of nutrition and hydration physically and emotionally for patients and carers.

Summary of findings

Areas for improvement

Action the provider MUST or SHOULD take to improve

The trust should develop an end of life link nurse or champion role within each community team to raise awareness of end of life issues and act as a resource for the team.

The trust should consider providing mandatory EOLC training for all nurses across all three boroughs to promote equity of knowledge, not only in syringe drivers and symptom control, but also in the understanding of the Gold Standards Framework and recognitions of the deteriorating patient at end of life.

London North West Healthcare NHS Trust

End of life care

Detailed findings from this inspection

Good 

Are services safe?

By safe, we mean that people are protected from abuse

Summary

Safety across community health services for end of life care was good. Openness and transparency about safety was encouraged. Staff fully understood their responsibility to raise their concerns and report incidents and near misses. However we found some staff concerns such as missed appointments had not been reported as they should have been.

Incidents were investigated adequately; a root cause analysis was completed and learning points and actions identified. However some staff reported they did not always know the outcome or improvements made as a result of the incident and did not routinely know of issues raised by other areas or departments in the trust. Therefore it was difficult to identify risks and trends and improve consistency in practice across the whole of the trust's community services.

There were good arrangements in place to manage medicines for patients who were being cared for in their own home or at MHH. Patients and carers were supported in ensuring they knew how to take or give the medication safely. Syringe drivers were available for appropriate patients.

The CPCT was highly skilled in supporting patients who had complex health issues and requiring specialist palliative or EOL support. However there was some concern whether the generalist community (district) nurses always recognised a change or deterioration in a patient, which could indicate they were approaching the last 12 or less months of life, and then responded appropriately to it.

Safeguarding vulnerable adults and children and young people was given sufficient priority. Staff were aware of their role and responsibility in raising concerns and had received a level of training appropriate to their role. Training completion rate was better than the required CCG compliance of 90%.

Safety performance

- Serious incidents known as 'Never Events' are largely preventable patient safety incidents that should not occur if the available preventative measures had been implemented. End of life care (EoLC) community services had not reported any never events or serious incidents in the last 12 months.

Incident reporting, learning and improvement

- The trust had systems in place to report and record safety incidents, near misses and allegations of abuse;

Are services safe?

and to share any learning and changes to improve the safety and quality of the service. In the period from 1 August 2014 to 31 July 2015 the trust reported 1947 incidents relating to the community services, 70 of these incidents had been reported by palliative medicine. Nine were recorded as moderate harm, 18 as low harm and 43 as no harm. The incidents were adequately investigated and root cause analysis had been completed with learning points identified.

- Staff told us they used the electronic reporting system 'Datix' and received feedback from any reports they lodged; the CNSs we spoke with all told us they had time to report incidents. Senior staff in the CPCT told us there was a low threshold for reporting and therefore they felt confident anything of concern was reported. However we found some of the issues or concerns relating to the services staff told us about had not been officially reported on Datix, for example a community nurse missing a patient appointment and a delayed hospital discharge.
- The CPCT were able to tell us of incidents and the learning from them which related to other departments within the trust as well as those in their own area. As an example they shared with us the learning for record management and how records should be carried outside the hospital or hospice to maintain patient confidentiality.
- The generalist community nurses told us they were confident to report incidents and were encouraged to do so. Most incidents were reported on the day they occurred and no more than two days after the event. However they did not always receive feedback and only knew of incidents and outcomes within their own borough and not necessarily any incidents from other areas/boroughs. They told us they were not routinely informed of trends and patterns in order to share learning or encourage improvement in practice across the whole of the trust's community services.
- MHH held a weekly 'reflection' multidisciplinary team (MDT) meeting where a case study was presented and the group discussed what went well and what could have been improved, this maximised learning and improved safety.
- Staff were trained on duty of candour as part of the risk management training at induction and the mandatory

update training. The staff we spoke with understood their role and responsibility in informing patients of incidents that could or have affected them. They told us they would apologise and explain what actions had been taken as a result of the situation. Staff added they would support a patient in making a formal complaint if they were not satisfied with actions taken.

Safeguarding

- Staff understood their role with regard to keeping patients' safe and reporting any potential safeguarding issues. This included identifying any risks to the patient's family such as children or vulnerable adults whose main carer maybe the patient.
- Staff we spoke with demonstrated an awareness of safeguarding procedures and how to recognise if someone was a risk or had been exposed to abuse. Staff told us if they had any concerns they would speak to the trust safeguarding lead or their manager, and knew where to access the trust policy on the intranet.
- Safeguarding adults level one and two training was part of the trust's mandatory training and was routinely provided to all staff. Similarly safeguarding children level one training was provided to nearly all staff including administrative and clerical staff. Safeguarding children level 2 was mandatory for all nurses and allied health professionals. In addition to this community staff in Ealing (including managers, learning disability nurses and members of the nutrition and dietetics support team) also received children and adults level 3 training. Training records showed 100% of staff had completed safeguarding adults and children at level one, 95% of staff had completed safeguarding adults level two, and 98% of staff had completed children level two.

Medicines

- There were arrangements in place to manage medicines for patients who were being cared for in their own home or at MHH.
- As part of the patients' holistic assessment symptom control and medication was reviewed by the CPCT and community nurses. This was done on the three home visits we observed. Time was spent checking the

Are services safe?

patients and carers understanding of the action of the medication to ensure that it was being taken effectively and safely. The CNS checked where the oral medication was being stored as there were children in the house.

- Patients who expressed a wish to die at home were discharged from the acute hospital with anticipatory injectable medication and medication record charts. These were provided to patients whose condition may require the use of injectable medication to control unpleasant symptoms if they were unable to take oral medication due to their deteriorating condition. Having anticipatory drugs available in the home allowed qualified staff to attend and administer drugs which may stabilise a patient or reduce pain and anxiety and prevent the need for an emergency admission to hospital.
- Where appropriate, patients had syringe drivers which delivered measured doses of drugs over 24 hours. They could be discharged from hospital with a syringe driver in place however this needed to be changed to a syringe driver from the community resources as soon as practicable and the hospital driver returned so as to not deplete the hospital's stock.
- The syringe drivers were locked as per guidelines so as to prevent other people, such as family members, altering or increasing doses, which could happen if they panicked due to a patient's deterioration.
- Most patients self-administered their oral medication or were assisted by their carer(s). The community nurses and CNSs worked closely with primary care to ensure that medicines were prescribed by the patient's GP in a timely way. We observed a CNS review pain relief medication prescribed with one carer. They found a discrepancy with it and other medication. This was addressed with the GP, and the CNS revisited the patient in order to guide and educate the carer in administering the pain relief medication appropriately and also to discuss using the medicines management scheme.
- Community nurses and CNSs undertook injectable medicine administration and maintained syringe drivers. All qualified nurses were trained in the use of syringe drivers. It was the trust's policy for one registered nurse to administer anticipatory medication or review syringe drivers as long as mandatory syringe driver

training had been completed, however nurses said they would go in pairs to support a new member of staff if they had not used a syringe driver for a few months and the team leaders were supportive of this.

- We observed that medication administration records were completed correctly and signed. However we observed the maximum total daily dose for morphine sulphate and midazolam was not identified on one patient's records therefore it could be possible for the patient to be given too much in a 24 hour period.
- Specialist pharmacy support was available for staff working in the community.
- We observed staff preparing oral controlled medication for a patient at MMH. This procedure was carried out in a safe manner as per best practice; this included safety checks and recording. MMH had incorporated an extra safety measure to ensure checks and witnessing was performed by two registered nurses. The controlled drugs (CD) cupboard had two separate locks and two different members of staff carried each of the keys. This meant both members of staff had to be present to gain access to the cupboard. Senior staff told us all nursing staff had the confidence to challenge anyone who interrupted them while performing a medication round.
- The medication was stored correctly and the CD cupboard was wall mounted and locked. The room and cupboard was tidy and medications such as liquid controlled drugs were kept on different shelves in separate doses in order to prevent drug errors. Controlled drugs were checked every night and records were completed appropriately.
- Anticipatory medication was delivered to the patient's home; this medication was recorded on a medication stock record sheet by a registered nurse at their next visit. All drugs including CD and anticipatory medication were recorded in this way. The nurse checked the stock on each visit and the records we reviewed were fully completed. The record was kept in the patient's home with the prescription sheet and medication. The patient kept these out of sight, usually in a storage container by their bed.

Environment and equipment

- MHH inpatient ward had 15 single rooms with en-suite bathroom facilities

Are services safe?

- The environment appeared clean and tidy. Clinical and domestic waste was clearly identified and managed in a way that kept people safe. The 2014 PLACE score for MHH was 89% for condition and appearance and 100% for providing an environment that maintained people's privacy, dignity and wellbeing. The national average across all the participating organisations was 92% and 87% respectively.
 - Any maintenance issues were identified to the service manager, who was responsible for maintaining the environment. We observed any concerns which could affect the running of the service were entered onto the local risk register until the issue had been rectified.
 - Each patient was provided with their own individual sling for the hoist. This was washed and kept for the patient should they return to the hospice at another time.
 - There was appropriate hand washing facilities and hand gels and cleansing lotions freely available for use.
 - The trust used T34 syringe drivers which were all of a standardised type and conformed to national safety guidelines on the use of continuous subcutaneous infusions of analgesia.
 - The trust had responsibility for maintaining all the syringe drivers and for monitoring their use in people's homes. We were told there was no problem in accessing syringe drivers whenever they were needed for patients.
 - Equipment for EOLC patients was provided as needed. None of the staff could recall any delays in obtaining equipment. One relative told us their family members' discharge was delayed by one day to allow for equipment to be put in place; this included a profiling bed, pressure relieving mattress and commode. This was not seen as a significant delay to ensure the correct equipment was in place to ensure the safety and comfort of the patient.
- Quality of records**
- People's individual records were written and managed in a way that kept them safe. Records reviewed were accurate, legible, up to date and stored securely. Patient's records were a combination of electronic and paper records. Paper records, which included their care plan, were kept in the patient's home. The electronic records were available only to authorised people;
 - computers and computer systems used by staff in community centres were password protected. Community district nurses in Harrow were provided with portable devices, which would allow access to records from a remote location. In addition, they could use a workstation at the community centre. As part of the trusts mobile working programme portable devices were scheduled to be rolled out to the SPCT in the future.
 - Ealing community services and palliative medicine completed an audit of discharge documentation against the standards set by the Royal College of Physicians (RCP). The completed report dated March 2015 indicated that overall their discharge documentation at the time was compliant with RCP standards however they still identified areas for improvement such as completing all sections even if it stated "none", "nil", or "n/a" rather than leaving sections that were not applicable blank. This meant staff would be able to identify that the questions in the section had been considered and not forgotten. Actions from the recommendations, individuals responsible for implementing them and timescales were clearly identified; along with a date to reassess whether the recommendations had effected any change.
 - The trust performed a records audit in 2015. A random selection of records from the inpatients, day hospice and community team were reviewed. The objective of the audit was to review the quality of record keeping and ensuring it supported patient safety. The report dated 5th October 2015 for the community specialist palliative care service at MHH and community services showed an improvement on the recommendations from the 2013 audit; over 90% were completed correctly against the key criteria. Further actions for improvement were identified, some of which would be rectified once the new electronic recording system called 'System One' was phased in, meaning that the whole trust would be using the same electronic version.
 - Patients' palliative care needs, care plan and resuscitation status was entered onto a system called 'Coordinate my Care' (CmC). CmC is a shared clinical service which allows healthcare professionals to record a patient's wishes and ensures their personalised care plan is available for all those who care for them,

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including ambulance and community services. This meant the patient received the most appropriate care and treatment and prevented unnecessary hospital admissions.

- Records reviewed at MHH included a written evaluation of care, noted discussions and reviews carried out and a symptom checklist completed by the nurse six times a day, the two records we looked at showed that this had been completed. However we noted that the summary page relating to the patient's symptoms at the time dying was diagnosed was not completed. This could cause some issues if the document was used as part of an investigation or as a way of auditing recognition of dying and symptoms identified at that stage.

Cleanliness, infection control and hygiene

- We found the trust had systems in place to prevent and protect people from healthcare associated infections. The trust had an infection prevention and control (IPC) policy and we were told that all staff were required to complete IPC training. The staff we spoke with had a good understanding of IPC practices and we observed staff following IPC measures while in patient's homes and in the hospice. Staff were aware of patients reduced immune systems and the measure they should take in order to not compromise their health through poor infection control, such as stringent hand hygiene care and not attending to patients if the member of staff had an infection.
- The community palliative care team took part in IPC training on an annual basis. At the time of our inspection 64% of clinical and 93% of non-clinical staff had completed this. The trust's target for compliance was 80%.
- The community nurses and palliative care team had a plentiful supply of personal protective equipment (PPE) available to them.
- The 'Patients – Led Assessments of the Care Environment (PLACE) England 2014' scored Meadow House Hospice (MHH) at 100% for cleanliness; the average across all the contributing organisations was 97%.
- Patient who died in their own home or a nursing home were cared for by local undertakers. The bodies of patients who died at MHH were taken to Ealing hospital

mortuary. We observed mortuary staff had stringent IPC measures in place. The mortuary area was pristine, smelt clean and fresh and was immaculately tidy. Hand hygiene measures were followed meticulously and we observed staff offering visitors the opportunity to wash their hands on leaving the mortuary area.

- The mortuary staff told us they may not always be made aware that a person had an infectious disease and therefore they treated each body with caution to ensure infection prevention. Deceased patients who were known to have an infectious disease were identified by a wristband and placed in a body bag. A high risk identification sticker was attached to bag once they arrived at the mortuary, where they were placed in a separate fridge. Any visitors for the deceased were advised not to touch the body and the undertakers were informed for their own protection when they collected the body. PPE was provided to undertakers if required.

Mandatory training

- All staff took part in mandatory and statutory training to ensure they were trained in safety systems, process and practices such as basic life support, conflict resolution, fire safety, infection control and health and safety.
- Many of the mandatory training modules were accessed through the trust's online training system called ELMS. Staff spoke positively about this system although some of them told us they preferred face-to-face training. Some modules such as basic life support were still completed in a practical session. Staff were responsible for ensuring they had completed their own mandatory training modules and were alerted by email when they were due for renewal. Managers were also reminded about staff in their team whose training was due or out of date.
- Staff from the community palliative care teams told us they had completed their mandatory training. Records showed that the team had reached the trust's 80% or higher compliance in 13 out of 19 subjects. Most of the staff reported having time to complete their training. Managers told us they supported staff in finding time to complete training if their workload was identified as preventing them from doing so. Staff also told us it was sometimes hard to access the classroom based training as it was held at Ealing hospital and meant travelling out of their local area for some staff.

Are services safe?

Assessing and responding to patient risk

- We found a mixed response in how well community generalist nurses recognised a patient was approaching the last 12 months or less of life. Some of the CNSs had concerns whether generalist community nurses always had the experience to recognise a patient who was deteriorating and reaching the end of their life. Some staff told us community nursing could at times be very “task based” which meant they did not always look at the patient or their needs in a holistic way. We were told of one instance where an inexperienced community nurse did not identify when a patient had newly developed jaundice; and of another nurse who had not identified a medication a patient was using had been discontinued because they “only” supported the patient for wound care. However we found some nurses were very clear and knowledgeable in recognising changes such as the end stage of dementia. This varied recognition could mean some patients would not receive appropriate support and in the way they would like it as there was a lost opportunity to discuss advanced care plans in the last 12 months or less of their life.
- Most of the staff we spoke with in the community nursing teams were aware they could access advice and request specialist support from the community clinical nurse specialists (CNS) if their patient had been identified as requiring palliative or EOL support. However the CNSs were concerned they would not request the support if they did not have the necessary skills to recognise a patient had deteriorated in the first place.
- Community staff and CNSs told us any deterioration or change in a patient was discussed with the patient’s GP and family at the earliest opportunity, and where appropriate advanced care planning was considered to ascertain the patient’s wishes and prevent unnecessary hospital admissions at the end of their life.
- At the end of life there are inevitable changes to the body such as weight loss and reduced skin integrity. Staff used tools to assess risks to patients, such as a pressure damage risk assessment tool to identify and prevent pressure ulcers. We saw the assessments were completed fully on the trust’s electronic patient record

system. Appropriate pressure relief mattresses and advice on how to reduce the risk of pressure trauma and maintain healthy skin was provided to patients assessed at risk.

- MHH held six handovers a day. We were told this system had evolved over ten years and they found it worked well and ensured patients’ needs and any changes were discussed between doctors and nurses at regular intervals.
- Community nurses had a daily early afternoon handover. The team leader met with the Band 5 nurses and healthcare assistant and they reported back on their visits. The handover was structured so each nurse gave clinical information about the patients they had visited, the purpose of the visit and the outcome. The team leader dealt with any issues arising from the home visits. No end of life patients were discussed at the handover we observed.

Staffing levels and caseload

Harrow Community Palliative Care Team

- The community palliative care team was made up of 1 whole time equivalent (WTE) Band (B) 8a (team lead) and 5.8WTE B7 clinical nurse specialists (CNS). At the time of our inspection the B8a post was being covered by one of the B7s due to long term absence.
- There was one long term member of agency staff. There had been three new members of staff over the last year. Barring one person on long term absence the team was fully staffed. There was one team member who was leaving in two months’ time; however their position was currently being advertised. Staff retention was reported as good, and staff were described as stable and committed; a majority of them had worked in the unit between seven and ten years. Staff left the team for career development, retirement or for a different work pattern.
- The CPCT had two part-time consultants (0.3WTE and 0.2WTE). The 0.3WTE consultant was based at St Luke’s hospice, and spent one and half days per week at the hospice and the same amount of time at Northwick Park Hospital (NPH). The consultant that worked 0.2WTE with the CPCT divided the rest of their time between supporting patients at NPH and St Luke’s Hospice.

Ealing and Hounslow Community Palliative Care Team

Are services safe?

- There were 24WTE nurses for the inpatient unit at MHH. There was currently a vacancy for one band 5 nurse. This vacancy was being filled by regular bank staff. There were 1.8WTE nurses for the inpatient unit at MHH. The community team was made up of 10.9WTE clinical nurse specialists.
- The CPCT had the equivalent of 2.6WTE consultants made up of three people (2x 1WTE and 1 x 0.6WTE) and 1WTE associate specialist. There was also support from 1WTE specialist registrar and 1.5WTE GP.
- A full-time occupational therapist (OT) and physiotherapist worked as part of the CPCT based at MHH.
- A dietician supported the patients at MHH. Patients spoke positively about the dietetic support. We observed on the incident log where pressure ulcers (PUs) had been identified the dietician was regularly used to support patients in understanding how diet can affect their skin integrity and help reduce the risk of PUs.
- Case loads, staff levels and skills mix were reviewed regularly to ensure patients received safe care and treatment at all times.
- There was a multidisciplinary approach to discussing patients on a weekly basis. The CNS case load was allocated according to geographical area and size of existing caseload.
- Every three to four months the CNSs had a one to one 'total case load' review with the consultant. They told us the consultant was very hands on and had an open door policy so any issues or concerns arising could be discussed on an ad hoc basis.
- All staff told us their caseloads were manageable however they said more staff would mean they could support more patients and generalist nursing staff.

Are services effective?

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

Summary

Patients were at risk of not receiving effective end of life care within the community. The CPCTs were made up of a highly skilled and knowledgeable staff group who supported patients with palliative care and end of life patients with complex health needs. However there were concerns the community district nursing teams across all boroughs had a "task based" approach to care and did not have the expertise or experience to recognise when a patient was in the last 12 months or less of their life and was deteriorating. This meant patients' who maybe dying because they were frail and elderly may not have the opportunity to discuss their wishes, put in place any advanced directive and receive care which was appropriate to their circumstances.

The implementation of a new electronic recording system was found to have caused some gaps in information sharing. It was seen as a positive move to have access to a 'live' document with a multidisciplinary team approach to provide joined up care for patients; however there were glitches in its use due to poor accessibility in the community and in some case lack of training. This made the system cumbersome and uncoordinated at times as staff were still accessing two systems.

Patients' care and treatment was planned and delivered in line with current evidence based guidance, standards, best practice and legislation. Patients' needs were assessed, their preferences were identified and care was planned in a holistic way taking into account their healthcare, psychological and social needs and included open communication with the patient and those close to them.

Care and treatment was monitored to ensure consistency of practice. After death or significant event reviews allowed staff to discuss what went well and address any areas for improvement. The CPCT participated in local and national audits and took action as a result of any findings in order to improve practices and care.

Evidence based care and treatment

- End of life care was managed in accordance with national guidelines. Patient's needs were assessed, their

preferences identified and holistic care was planned and delivered in line with best practice. This was evident in the way the staff practiced, the trust policies and patients' care plans.

- The trust's response to the independent review of the use of the Liverpool Care Pathway (LCP) for the dying patient and the subsequent announcement of the phasing out of the LCP was to create a document called 'Last Days of Life Care Agreement' (LDLCA). At the time of our inspection MHH used a slightly different version which was found to be more comprehensive than the LCP and in line with the trust document.
- The EOLC documents used by community services achieved the 'Priorities of Care for the Dying Person' as set out by the Leadership Alliance 2014 for the Care of Dying People. Records reviewed showed open communication with the patient and family, recognition of dying, symptom control, assessment of nutrition and hydration needs and emotional/spiritual support for the patient and those close to them.
- Records reviewed at MHH met with the draft National Institute for Health and Care Excellence (NICE) guidelines 2015 for EOLC for review and the Leadership Alliance 2014 five priorities for continual review of symptoms and discussion/communication with the patient and people important to them. We observed a written evaluation of care, and discussions and reviews carried out were completed in the patient's records three times a day by a doctor as well as the symptom checklist being completed by the nurse six times a day.
- Community nurses and the palliative care nurses attended Gold Standards Framework (GSF) meetings at GP surgeries. However we found that all the community nurses did not appear to be aware that non-cancer patients who were at the end of life were included on the EOL register. The GSF is a systematic evidence based approach to optimising care being delivered by generalist care providers for all patients approaching the end of life. This includes care for people considered to be at any stage in the final years of life, with any condition or diagnosis and being cared for in any setting

Are services effective?

(hospital, home or social care). None of the nurses appeared to understand the rationale behind the GSF and education was needed around this. Therefore it was unclear to us whether patients who were diagnosed with conditions other than cancer were being cared for and treated using the same evidenced based care.

Pain relief

- Patients in the community receiving end of life care were ultimately under the care of their GP who was responsible for prescribing their medications. The community nurses were responsible for administering the prescribed injectable medication for symptom control at EOL.
- The community nursing staff told us there were no problems obtaining EOLC or anticipatory medications. Pre-payment prescription certificate applications were discussed at the initial assessment with the patient to ease the burden of obtaining medicines during a difficult time.
- We found anticipatory prescribing followed the new draft NICE guidelines for symptom control. All the prescribed medications had the indications for use, for example Levomepromazine for nausea.
- Some pain control was managed with PRN ('pro re nata' / as required) paracetamol. A patient we spoke with told us their pain was managed well and effectively.
- Patients, community nurses and GPs received further support, advice and guidance from the community palliative care teams. The consultants, doctors and nurses in these teams were experts in their field and able to provide guidance on the most effective and appropriate treatments and care which included pain relief, nausea and vomiting.
- Where appropriate patients had syringe drivers which delivered measured doses of medicines over 24 hours. All qualified nursing staff were trained in using syringe drivers and symptom management.
- Some of the CNSs were able to prescribe end of life medications which meant patients could access some medications without needing to wait for their GP to prescribe it.

Nutrition and hydration

- Nutrition and hydration needs were identified in the patient's care plan as part of the 'last days of life care agreement'. Prompts for staff to follow when explaining nutrition and hydration were included in the agreement and there was space to write what was discussed and the patient and families' response to the discussion.
- Patients and staff had access to a specialist palliative care dietician (SPCD) in the trust. We were told there were around three to four palliative dieticians in the United Kingdom and this was a very new initiative. The SPCD was on a sub-group of the British Dietetic Association and received peer support from the BDA and Meadow House Hospice (MHH).
- At the time of our inspection the SPCD had 36 patients in the community on their case load. GPs and community nurses could refer to the SPCD if the patient was identified to be palliative, stable and in the last year of their life; or stable with a neurological disease; or unstable but not at EOL; or identified to be approaching/at EOL. There were no pathway/outcome measures at the time of our inspection as the service had only been available for four months therefore we could not evaluate impact of this service for the patients. However patients at MHH told us seeing the dietician during their admission or visit really helped them with understanding their dietary needs.
- Each patient was assessed and support and guidance was provided on an individual basis. Input at EOL was around supporting the family when a patient stopped eating and drinking due to actively dying. The SPCD was also involved in the MDT meeting and supported patients and families in the decision making process of when to reduce enteral feeding.
- Patients' oral fluid and food intake was encouraged as long as the patient was able to swallow and wanted to eat and drink. Hydration and nutrition needs were monitored and reviewed with the patient and people important to them and nurses acted on any concerns.
- Subcutaneous fluids (artificial hydration) were considered if it was seen to be in the patient's best interests. It is unclear whether giving parenteral fluids to

Are services effective?

people who are dying causes, rather than alleviates, symptoms therefore every case was considered on an individual basis and the rationale to administer or not was explained to the patient and family.

- The 2014 PLACE score for food and hydration at MHH was 90%. The overall national average was 88%. The patients told us staff understood their dietary needs and that they only required small amounts of food. They said they liked having a fridge freezer in their room as they could put ice pops in it to have them whenever they felt thirsty.

Patient outcomes

- The trust monitored and audited patient outcomes and improvements were made as a result of the findings. The trust participated in the National Care of the Dying Audit however this audit did not include community services as it only relates to hospital services.
- The trust provided data to Public Health England's 'Minimum Data Sets (MDS) for Palliative Care'. The aim of the MDS is to provide good quality, comprehensive data about hospice and specialist palliative care services on a continuing basis. The data is useful for service management, monitoring and audit, development of strategy and service planning, commissioning of services and development of national policy. The trust had very recently received the results for 2014/15, and they were reviewing how they performed against other organisations of a similar size to them at a national and local level.
- The CPCT took part in the 'London Cancer Alliance Palliative Care Audit' during 2013 to 2014. The results showed how the trust and hospice performed against other palliative care providers across London. MHH 294 inpatient admissions in 2011-2012, and 277 inpatient admissions in 2013-2014. This was a decrease of 5.7%, the average decrease across the participating services in London was 7.9%. However there was an increase in patient visits by the CPCT; they saw 1,214 patients in 2011-2012 and 1,484 patients in 2013-2014. This was an increase of 22% against the London average of a decrease of 5.3% therefore more people were being seen in their own home environment.
- The 2014 after death analysis report of MHH CPCT for the London boroughs of Ealing (and Hounslow) evaluated the number of after death analysis completed over a period of one year and compared it to the previous year's completion rate. This after death analysis tool was developed by the GSF which allows constructive reflection of practice. 798 patients known to the CPCT at MHH between 1 January 2014 and 31 December 2014, of which 672 after death analysis were completed, this was 84% compared to 64% in 2013. The resulting information was used to establish themes about care at end of life which may help inform service improvements and evaluate whether further modifications were needed to the after death analysis.
- Since our last inspection of Northwick Park Hospital in June 2014 the results of a service development programme to reduce the number of admissions to hospital for patients with long term conditions or who are frail and elderly in the last years of their life had been completed by the two Darzi Fellows. The report had demonstrated advanced care planning with the patient in hospital had reduced readmission to hospital. As a result an improvement project for advanced care planning was being implemented and a clinical post to support the work had been advertised.
- Northwick Park Hospital consultants provided a 'virtual ward' in the community. This scheme was to support patients who have long term chronic conditions, from which they were not going to recover from, in staying their own homes. Specialist consultants, such as respiratory and heart failure, and the CPCT visited Harrow patients in their own home to support them in managing their condition(s) and to discuss advanced care planning which prevented them from unnecessary admissions to hospital. We were told of one patient who had five admissions over a 12 month period, and since they had been on the scheme they had not been admitted to hospital.
- The trust did not take part in the bereavement audit as they did not collect next of kin data. This information was contained in the LDLCA however not every patient who died under the trust's care was supported using this plan and therefore the information collected would not be reflective of all deaths in the trust.

Competent staff

- The CPCTs were made up of competent and highly trained individuals. A majority of staff reported having

Are services effective?

the opportunity to develop and attend further education courses in line with their role although at times work load meant they were unable to attend as many course or conferences as they would like to.

- MHH carried out a survey into 'End of Life Educational Needs of Primary Care Professionals in Ealing and Hounslow; this included nurses and GPs. The report dated 1st July 2015 concluded that 86% of primary care professionals across Ealing (and Hounslow) felt they would benefit from EOLC training in a range of topics. Devising an EOLC educational model taking into account the learning preference for of the primary care professionals was to be completed by 2018. Funding had been secured based on this audit.
- The Darzi project run by Northwick Park Hospital helped to develop relationships with primary care colleagues in the Brent and Harrow area and as a result the GP primary care education programme had seen 400 GPs accessing training since December 2014. A psycho-geriatrician also provided training sessions with case studies based around EOLC to psychiatry trainees and nurses, mental health trusts and GPs; 75 people had attended to date.
- Experienced generalist and specialist staff shared a perception that newly appointed and/or newly qualified generalist community nurses may not be getting adequate support in their role. It was acknowledged the role of a community nurse was challenging and required them to have a vast array of skills to be able to support patients in the community who may have complex health issues. We spoke with a community nursing manager about preceptorship programmes for newly qualified or returning nurses. We were told of the induction to the trust and their role which you would expect all new members of staff to complete however there did not appear to be a programme to enhance the competence and confidence of newly registered practitioners as autonomous professional as laid down in the Department of Health's document 'Preceptorship Framework for Newly Registered Nurses, Midwives and Allied Health Professionals' published in 2010.
- While some generalist community nurses requested and organised study session in EOLC and associated topics, other locations were not so proactive and were unaware of any training available to them. There were courses

run by the MHH for local GPs however there was little or no funding for the generalist community nurses to attend; MHH also ran a monthly EOLC lecture which was open to all the trust staff.

- CNSs in the Harrow CPCT supported the community nurses in formal and informal training sessions, joint visits, one to one bedside training, advice and support.
- MHH also trained other healthcare professionals in the community such as nursing home staff. One CNS had responsibility for training and educating them in how to recognise deteriorating patients and how to support their EOL needs. This enabled patients to stay in their nursing/care home. We noted that a set of meeting minutes identified a concern at one nursing home and an action for a meeting to take place to discuss the circumstances and provide support to staff.
- We were told all trust staff received Sage and Thyme[®] training as part of their mandatory training. This training was designed to train all grades of staff how to listen and respond to patients/clients or carers who are distressed or concerned. We asked the trust for information on the number of staff who had received communication training but did not receive this information.

Multi-disciplinary working and coordinated care pathways

- Care was delivered and coordinated in a way which involved all the different teams and services involved in the patient's care. This included the community nurses, palliative care team and the patient's GP. This was extended to other teams such as 'Hospice at Home', Marie Curie, social care and psychological services when appropriate.
- CSPT MDT meetings took place weekly; these were attended by the whole multi-professional team. The team discussed new referrals, complex cases and identified extra support they or the patient required, such as clinical expertise or social or psychological support.
- Discharge plans for patients at MHH were discussed each week at a multidisciplinary team meeting. These discussions started from the central point of what the patients' wishes were and took into account the stability of their health. This ensured the patients' wishes were

Are services effective?

balanced with their clinical needs. The professional groups' decisions were communicated to the patient and those close to them by the consultant with the support of a CNS and any differences in opinion were debated and an acceptable and workable compromise sought.

- Other healthcare professionals such as OT and physiotherapist reported good working relationships with the clinical nurse specialists and consultants. They told us of an occasion when they had made a recommendation regarding equipment that a relative disagreed with. With the joint support of their manager and a consultant the patient and their family's expectations were managed. It resulted in the patient's relative apologising to the OT and explaining they were not ready to accept their family member's deterioration.

Referral, transfer, discharge and transition

- The CSPCT received referrals from hospitals, district nurses, relatives, GPs, social workers and patients. Terminally ill people and anyone who was identified as approaching the end of their life (therefore likely to die within the next 12 months including people whose death was imminent expected within a few hours of days) could be referred to the palliative care team for specialist support that other teams may not be able to provide.
- Patients could be discharged from the CSPCT caseload if they reached a stage where their condition although not curative was stable and they were not at end of life. This was important to patients as they were no longer bound to regular palliative care appointments and it allowed them to gain some normality in their life. They could be re-referred to the team if their health deteriorated.

Access to information

- During September and October 2015, the trust had migrated patients electronic records from one electronic patient record system to another, with an aim for more accessibility and improved information sharing opportunities. The new system allowed staff involved in a patient's care to view their GP's clinical record, as well as records completed by other health professionals involved. Nurses felt it was very useful and helped to plan care and treatment more efficiently.

- We observed community nurses were not always able to access the patient record system remotely. Access to clinical information was problematic on occasions due to a number of reasons; in some cases the information had not migrated from the old system; staff reported new records and risk assessments were not uploaded in a timely manner; there were connectivity issues in some areas; some staff were unfamiliar in how to use the technology and others occasionally felt uncomfortable with accessing records in a community environment. The introduction of the new system had been staggered with two weeks gap between each borough; staff felt it was better managed at later stages, and lessons had been learnt from the early stages. We observed additional technical support was available to staff to help to resolve any issues. Senior managers and directors were aware of the issues in accessing information and it was listed on the divisional risk register.
- At the time of our inspection staff told us the community CNSs were unable share or access electronic records for patients discharged from the hospice. However a data sharing agreement was almost completed which meant free access between the community CNS and hospice would be possible in the very near future.
- The community teams had access to patients' care plans and resuscitation status through CmC.

Consent, Mental Capacity act and Deprivation of Liberty Safeguards

- The policy for consent to examination or treatment was available to staff on the trust's intranet; this was under review at the time of our inspection. We found it was referenced to the Mental Capacity Act (2005) and a mental capacity assessment checklist and a consent training competency pro forma were included in the policy. Staff we spoke
- We looked at five care plans and found they had all been signed by the patient when consent for treatment was sought.
- Staff undertook Mental Capacity Act (MCA) 2005 and Deprivation of Liberty Safeguards (DoLS) training as part of their mandatory training. 72% of staff had achieved compliance in the trusts equality, diversity and human rights training. We gave hypothetical situations to the CNSs and consultants and they were able to describe

Are services effective?

accurately the process they would follow should someone be found to not have consent to agree to treatment or be able to make decisions in relation to their care. This included consulting with people who were close to them to gauge what the patient would have wanted in order to make best interest decisions.

- MCA and DoLS guidance was available on the trust intranet as well as associated documents such as the consent policy, dementia policy and safeguarding adults at risk policy. Staff could access additional support and advice from the hospital social workers in relation to the MCA and DoLS
- We reviewed eight DNACPR forms in patients' homes and at community inpatient wards. We found them to be completed in line with national guidance. The forms

were completed by a clinician with sufficient seniority. DNACPR forms completed in acute settings were not transferrable to any area of the community environment therefore the patient's GP was responsible for completing a DNACPR directive as soon as possible after the patient reached their home.

- We observed most of the patient notes we looked at on the elderly rehabilitation community in patient wards (Fifoot and Furness) at the Willesden Health and Care Centre did not contain the patients' resuscitation status. Nursing staff told us it was a 'medical' and not a nursing responsibility to have discussions relating to resuscitation. We found most of the elderly patients had not been asked their preference about resuscitation and therefore they would all be for active resuscitation.

Are services caring?

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

Summary

Community health services provided good care for patients at the end of their life. We spoke with two patients and one relative in their own home; one inpatient and their relative at Meadow House Hospice; three day hospice patients and reviewed thank you cards. Patients we spoke with told us “nothing was too much trouble” for the staff.

We observed staff treating patients and those close to them with compassion and ensuring their dignity was maintained. Staff always asked permission before entering people’s homes or the rooms they were being cared for in. Patients told us “everyone is very friendly” and that they felt listened to and understood.

Patients and their families were involved and encouraged to be partners in their care and in making decisions. Patients told us the staff were very helpful as they explained their condition to them and those important to them and addressed any concerns they had. Patients visiting the day hospice told us they each had some time with a nurse and/or doctor to discuss any problems or concerns. They told us they discussed symptom control and medication options. One CNS we spoke with told us they were “proud that they could take time to get to know the patient and help them make plans with their families.” It was clear from staff interactions with patients that they gave each patient the emotional support they needed. Bereavement support was offered to people important to the deceased and staff checked on their welfare following the death of their relative or friend.

Compassionate care

- We visited patients in their home with staff and observed that all the staff treated patients and their families with respect and worked hard at maintaining people’s dignity. Staff sought permission to enter the house and patient’s bedroom prior to entry.
- We observed staff provide care and support and noted how they took great care to explain what they were going to do and how they were going to do it, and ensure that the patient, and family if appropriate, were happy for the care to be undertaken.

- Patients and families told us they were very happy with the support they received from the community nurses.
- Patients’ care plans reflected their personalised needs. This meant the whole team supporting the patient and their carers could provide support in a consistent way, therefore ensuring they were treated in a compassionate way and without performing unnecessary interventions at a time when the person was actively dying.
- Thank you cards we reviewed indicated that families appreciated the “peaceful and supportive environment” and the “kindness and compassion of the staff” at MHH.

Understanding and involvement of patients and those close to them

- Patients who were identified as approaching the end of their life were given the opportunity to create an advanced care plan. This gave patients the time to discuss their preferred priorities for care and make decisions about where they would like to be cared for and how. This care was planned and delivered in a way which involved the patient and those close to them. Care plans took into account the patient and their family’s wishes, social circumstances and environmental practicalities.
- We were given many examples how the staff at MHH personalised care. One patient told us it was important for them to have their dog with them as they missed the dog greatly. Being at the hospice allowed them to see their dog every day and walk it in the garden. At the request of patients staff brought the seaside to patients by creating a beach in the conservatory at the hospice. This included sand, the sound of waves, deckchairs and ice creams. Patients enjoyed this shared memory.
- We found the nurses had a good understanding of their patients and what was important to them. They spoke about their patients in a personable and caring way.
- We were able to observe an assessment undertaken by a CNS. They comprehensively explained the palliative services, discussed the patient’s care plan and wishes and took a full assessment of symptoms. The staff provided advice to carers on managing a patient at

Are services caring?

home and where to get further support from, such as social services or charities. They also supported carers by giving them confidence in performing tasks, such as medication administration and tracking urine output and bowel movements. The CNS took the time to explain and check the patient and carer's understanding.

- A thank you card we read said, “you were so kind our relative enjoyed your company, but most of all you let [them] be [them] and helped to give us happy memories.”

Emotional support

- Following bereavement relatives were visited by two nurses to offer support and advice to the family. Staff attended funerals when they were invited. We saw there were a number of thank you cards from families who appreciated the support the community teams had given them.
- We observed staff suggesting other agencies which could offer support to the patient and those close to them, such as counselling services and spiritual/faith/religious leaders. The hospital's chaplaincy service was available to support patients and their families.
- Emotional support extended to the clinical team through peer support and one to one clinical supervision. Staff told us they could take some time out if they found it hard to cope at any point, however this was said to be rare as the day to day support they gave each other was usually enough.
- Bereaved relatives were invited to the 'Light up a life' service of remembrance for two years after bereavement. This non-religious special event brought people together to celebrate, reflect and remember loved ones who were no longer with them.

Are services responsive to people's needs?

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

Summary

End of life care services were organised and delivered to meet people's individual needs. There was an emphasis on providing a flexible service which promoted patient choice and continuity of care. Care and treatment was provided in a timely manner and co-ordinated with other community services, such as primary care providers and Marie Curie, which ensured patients received the most suitable care, equipment and support for them and their social circumstances.

There were open channels of communication between the trust's community healthcare professionals and their social and healthcare colleagues within the boroughs they worked in. The CPCT supported patients with palliative and end of life care; and provided advice and guidance to community nurses who were supporting patients at the end of their life, this ensured patients received care at the right time and in the most appropriate way for them

The needs of different people were taken into account when planning and delivering care. Community nurses were aware of patients' individual needs and of the diverse population they were providing services to. There was a suitable service provision at night and during weekends, and services were able to respond to urgent referrals.

There were few complaints regarding end of life and palliative care. The CPCT told us they tried to deal with any complaints at the time they were raised and they would support people in making an official complaint if they were not happy with the way it was addressed within the service. The CPCT told us they were aware of any complaints made, the outcome and any learning from it; however the community nurses were not routinely informed of trends and patterns in relation to complaints and therefore unaware of any shared learning or practice improvement as a result.

Planning and delivering services which meet people's needs

- The service specifications document for MHH and the CPCT took into account the local population needs and understood the demographic of the area. The aim was to ensure that all people reaching the end of their life received the most appropriate care and support for their
- own circumstances and avoid unnecessary hospital admissions. This included providing generalist high quality EOLC which could be delivered by non-specialist health and care staff as part of their core work provided they were given education, training and support to do so.
- MHH offered places to patients registered with a GP in the London borough of Ealing (and Hounslow). Ealing CCG funded nine beds and Hounslow CCG six beds and six day hospice spaces. Patients were admitted on the basis of need and not diagnosis. Patients were treated under three categories of admission need:
 1. Terminal care: for patient who were in advanced stages of a malignant or progressive disease where death during admission was expected. Usually these admissions were not expected to exceed two to three weeks, although individual patient needs were constantly reassessed.
 2. Assessment and symptom control: This was provided at any stage of the disease trajectory, patients could be admitted for assessment and symptom control if it was appropriate. The expected length of stay was five to ten days with a view to discharge the patient once their condition had stabilised.
 3. Planned care/case review: this was a pre-booked stay usually for a period of seven days, with admission and discharge dates being agreed in advance. It was expected that the patient returned home at the end of the assessment/review
- MHH day hospice was available three days per week from 9am to 5pm for up to 15 patients. The day hospice offered a half-way house between the community and in-patient unit; access to the multi-professional team, assessment and review, treatment planning, monitoring progress, activities, rehabilitation, complimentary therapies and extra support to patients and those close to them.
- The CPCT leads gave us examples of how they engaged with the CCG and other social and healthcare providers in creating a joined up EOLC service. One of the leads told us the GPs worked hard at understanding the importance of discussing advanced care planning and

Are services responsive to people's needs?

DNACPR with their patients who were identified as coming into the last 12 months or less of life in order to prevent unnecessary hospital admissions and provide them with optimal care. The team also worked alongside nursing and care homes to assist and advise care staff on how to support the residents; and in the recognition of death and dying.

- There was a lead CPCT CNS and pharmacist prescriber and GP practice in Ealing whose were the leads for all nursing/care homes in the area. This promoted consistency in practice and one point of contact for all nursing/care homes in the London borough of Ealing. There was no consortium in Hounslow, patients in care/nursing homes received support from their own GP or the homes preferred GP practice.

Equality and diversity

- We found care planning was individualised and holistic to reflect the patient's needs. The plans looked at the whole picture and took into account the views of the patients and carers as well as their spiritual, emotional, psychological and social needs. The patient's preferred place of death was documented and shared with the other professionals involved in their care.
- The trust had access to translation services through language line or face to face interpreters. MHH used a text based communication 'app' on an iPod to communicate with patients with speech difficulties.
- We found nurses at Hillside Primary Care Centre were not aware of how to contact local spiritual leaders should patients or their families request support. However at Acton the community nurses were fully aware of the beliefs of their patients and families and the spiritual support they required and received.

Meeting the needs of people in vulnerable circumstances

- A patient's relative told us the community nurses supported both their own and their relatives care and treatment by arranging visits to see them at the same time. They reported that the community nurses always turned up as planned and at the time agreed.
- MHH had a nurse who was a 'champion' for people with learning difficulties (LDs). They had a special interest

and training in how to support patients who had LDs and also patients who had children with LDs. This nurse also advised their colleagues in how to support patients with LDs.

- Staff told us they did not assess 'at risk' carers to ensure they were receiving adequate support to care for their family member or friend; however they relied on their experience and knowledge from working closely with the family to recognise when a carer might be struggling to cope. The community nurses were unaware of where or how to access psychological support for patients or their carers who needed emotional support.
- Staff were aware they needed to work around a patient's family or social constraints. We observed a CNS taking into account the family's needs during a home visit and when arranging a follow up visit at a time that suited them.
- Each inpatient room at MHH was set up so the patient and those close to them had all the amenities they needed to make their stay more comfortable. Each room had refrigerator and flat screen TV with all Sky channels freely available; the ward was centrally located on the site to provide access to the garden via a conservatory. Bedfast and ambulant patients were able to go outdoors onto individual weather protected patio areas. There were communal lounge areas and a conservatory for inpatients and the day hospice patients. There was a garden patients and those close to them could use. A microwave oven, refrigerator and hot water dispenser was available in the relatives' room so that visitors could heat food and make hot drinks if they wished to. We heard of examples about how patients enjoyed going outside as it was something they missed doing.
- Overnight stays could be pre-arranged for up to two people per patient at MHH. A visitors' room was available with a few kitchen appliances such as a kettle, toaster and microwave however there were no visitors' bath or shower facilities.
- Patients could attend MHH day hospice weekly, fortnightly or monthly depending on their assessed needs. This was regularly reviewed to ensure their current needs were being catered for.

Are services responsive to people's needs?

Access to the right care at the right time

- The CPCT core working hours were Monday to Friday 8.30am to 4pm. An on-call CNS was available to give telephone advice over the telephone and if necessary visit patients from 9am to 5pm on Saturday, Sunday and bank holidays. Meadow House Hospice core working hours were 9am to 5pm.
- The CPCT made contact with patients/carers from Ealing (and Hounslow) the same day or next day for urgent referrals, unless there were exceptional circumstances in which case they would respond immediately. All non-urgent referrals were contacted by the team within two working days if the patient was in their own home.
- Urgent referrals to CPCT for patients in Harrow were seen within 2 working days. There was a different criteria for non-urgent cases after being triaged, contact was made within three working days for patients triaged as C1, and within 5 working days for C2 (for example: stable patients requiring planning).
- There was 24 hour on-call specialist consultant cover through the hospices. OOHs GP services were accessed through the NHS111 system.
- The two local hospices provided a 24 hour helpline for clinicians. They triaged the calls and directed the caller to the most appropriate support, such as the on-call CNS, consultant or local out of hours (OOHs) GP service.
- Marie Curie nurses or agency nurses were used for overnight support in the patient's own home. Extra night care and longer term night care could be funded through the continuing healthcare budget for patients who met the funding criteria.
- The service specifications document for MHH and the CPCT took into account the local population needs and understood the demographic of the area. The aim was to ensure that all people reaching the end of their life received the most appropriate care and support for their own circumstances and avoid unnecessary hospital admissions. This included providing generalist high quality EOLC which could be delivered by non-specialist health and care staff as part of their core work provided they were given education, training and support to do so.
- MHH offered places to patients registered with a GP in the London borough of Ealing (and Hounslow). Ealing CCG funded nine beds and Hounslow CCG six beds and six day hospice spaces. Patients were admitted on the basis of need and not diagnosis. Patients were treated under three categories of admission need:
 - Terminal care: for patient who were in advanced stages of a malignant or progressive disease where death during admission was expected. Usually these admissions were not expected to exceed two to three weeks, although individual patient needs were constantly reassessed.
 - Assessment and symptom control: This was provided at any stage of the disease trajectory, patients could be admitted for assessment and symptom control if it was appropriate. The expected length of stay was five to ten days with a view to discharge the patient once their condition had stabilised.
 - Planned care/case review: this was a pre-booked stay usually for a period of seven days, with admission and discharge dates being agreed in advance. It was expected that the patient returned home at the end of the assessment/review
- MHH day hospice was available three days per week from 9am to 5pm for up to 15 patients. The day hospice offered a half-way house between the community and in-patient unit; access to the multi-professional team, assessment and review, treatment planning, monitoring progress, activities, rehabilitation, complimentary therapies and extra support to patients and those close to them.
- The CPCT leads gave us examples of how they engaged with the CCG and other social and healthcare providers in creating a joined up EOLC service. One of the leads told us the GPs worked hard at understanding the importance of discussing advanced care planning and DNACPR with their patients who were identified as coming into the last 12 months or less of life in order to prevent unnecessary hospital admissions and provide them with optimal care. The team also worked alongside nursing and care homes to assist and advise care staff on how to support the residents; and in the recognition of death and dying.
- There was a lead CPCT CNS and pharmacist prescriber and GP practice in Ealing whose were the leads for all

Are services responsive to people's needs?

nursing/care homes in the area. This promoted consistency in practice and one point of contact for all nursing/care homes in the London borough of Ealing. There was no consortium in Hounslow, patients in care/nursing homes received support from their own GP or the homes preferred GP practice.

Learning from complaints and concerns

- End of life services received very few formal complaints. We were given a clear explanation of how complaints were handled and the role of the service managers in responding to them. All staff told us they preferred to deal with issues or complaints immediately and offered a face-to-face meeting with the complainant. If they found the issue could not be dealt with informally, they supported people in making a formal complaint to the trust.
- Staff gave us examples of complaints they were aware of, the process followed to investigate complaints and the learning and changes made as a result of the issues raised. For example MHH offered patients and those close to them the opportunity to visit the hospice prior to admission so that they have a clear understanding about what the hospice does and the environment the patient will be in. This came as a result of a complaint from a family who did not understand the hospice was there to care for their dying relative and was NOT able to cure them.

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 leadership, governance and culture at a local level promoted good quality person-centred EOLC. The senior staff prioritised safe, high quality and compassionate care through clear lines of leadership and an open culture. All staff were committed to providing safe and good quality care. There was a culture of collective responsibility between the local teams and many opportunities to discuss patient needs and review cases.

Consultants within the CPCT had written the draft EOLC strategy which was currently out for consultation. The strategy was developed through regular engagement with internal and external stakeholders, which included people who used the service, staff, commissioners and other organisations.

While staff felt engaged at a local level this was not echoed at trust level. They were not fully aware of the trust's vision or direction the organisation was taking in order to develop EOLC community services and did not feel they could influence changes within the organisation. The trust did not have a cohesive workforce strategy; each of the three borough teams, as well as some of the teams working within the same specialities, were working in isolation and the trust failed to utilise opportunities to create one integrated care organisation. Staff at MHH told us they were “slightly in a bubble and could be autonomous” and “the services across the community were working in spite of everything else.” Staff working on the Ealing side of the trust were particularly concerned and voiced their worry about the uncertainty of their future since the merger with Northwick Park and Central Middlesex Hospital’s and the creation of the new trust.

Patient views regarding the community nursing services were collected through the friends and family test. The results were very positive with an average of 97% of patients saying they would recommend the service to their friends or family. The CPCT engaged staff and patients in finding ways to improve services. Receiving information through survey cards proved difficult as they were rarely returned therefore they engaged patients and their families through informal one to one ‘chats’ about the service.

Service vision and strategy

- The trust had recently written the EOLC strategy which was in a draft format and out for consultation at the time of our inspection. The strategy identified that core principles needed to be followed so the trust could deliver high quality, equitable and compassionate EOLC across the whole of the community served. These core principles of EOLC included the recognition that a patient might die, clear and honest communication with patients and their family, understanding the priorities of care of the patient and family, and delivering co-ordinated care enabling the patient to die in the place of their choosing if possible.
- The service aimed to achieve the strategy through identification, advanced care planning, co-ordination of care, involving and supporting carers, education and training, and performance monitoring and research. The strategy committee included amongst others, a trust lead, trust board representation, palliative care, divisional representatives, nursing, allied healthcare professionals, chaplaincy, community representations, GPs and patients across Ealing and Northwick Park and Central Middlesex hospitals.

Governance, risk management and quality measurement

- We were told the community services worked hard with commissioners of EOLC provided by the trust. The leads reported some CCGs engaged more with EOLC than others which could make the service inequitable across the whole trust area as patients in one CCG may receive different services than another due to the funding and training arrangements. Key performance indicators (KPIs) for each CCG were monitored to ensure a quality the service was being delivered for patients in their area.
- EOL committee included representatives from the relevant CCG, GP leads, the CPCT, hospice, ambulance service, pharmacy and other specialist nurses such as cardiac and respiratory nurses. The recent focus for

Are services well-led?

team was the development of the SPA for patients and identifying a community pharmacy that would always stock common EOL medications at the required strength.

- The CPCTs held weekly MDT meetings and monthly business meetings. The team discussed new and deteriorating patients and those that had chronic illness or were of concern. They considered the patients from a holistic point of view taking into account their social and psychological needs and assured that
- The CPCTs engaged with their acute peers and other CNSs through meetings / informal discussions. The consultants worked within the community and at the acute hospitals this allowed them to address issues or share learning with the teams and offered consistency in support for patients under their care.
- A clinical forum discussed and reflected on cases that were difficult or ethically challenging to manage, such as withdrawal of established ventilation. Significant event analysis and death reviews allowed the team to discuss the outcomes for the patient and those close to them, identify any issues, learning and share good practice.
- MHH's risk register was maintained by the service manager. We noted the actions plans in place to mitigate risks identified on the register with clear dated for follow up and expected completion.

Leadership of this service

- The community staff reported local leadership was visible, accessible and responsive. Local managers had appropriate knowledge and experience to lead services and they were well aware of issues and challenges their teams faced. Staff felt empowered by their local team leaders and managers.
- There were clear lines of accountability within the community palliative care management teams at a local level. The clinical leads were enthusiastic and proactive in driving forward the end of life agenda for community services within the trust. The clinical leads sat on the EOLC group which included the acute and community services.

- All CPCT staff we spoke with felt their line managers and the local senior managers were approachable and supportive. They were all aware of the service lead for EOLC and reported good access to them within the CPCT.
- Staff spoke of an open leadership in the CPCT. We observed a flattened hierarchy across the team. Staff were included in discussions and were asked for their opinion.
- Most staff at MHH were aware who the director for community services was and had seen the new chief executive. However other senior managers were rarely seen around the community sites. The service level leads told us although there was trust board representation they did not feel EOLC received the level of support it required to effect the change required to provide an integrated strategy that provided seamless safe high quality care for all patients across the trust's community and acute services.

Culture within this service

- We observed a committed and caring group of staff within the CPCT. The staff were clearly committed to providing good end of life care for patients in the community. They were proud of working in their department/division; however staff working on the Ealing side of the trust voiced their worry about the uncertainty of their future since the merger with Northwick Park and Central Middlesex hospitals and the creation of the new trust.
- Staff reported an open culture where they could raise and discuss any concerns with their team and managers. The specialist nurses told us they were supported by their managers and department heads in all aspects of their work including training and supervision of their work.
- We observed a healthy environment where staff felt able to challenge or share their thoughts or opinions with staff of all levels.
- Regular MDT meetings about patients' needs and staff skill mix ensured that patients received the best possible response and staff were supported adequately to provide it.

Are services well-led?

Public engagement

- Staff at MHH spoke with patients on a one to one basis to obtain feedback about the service. As a result of comments from patients they made changes to the service. For example patients expressed a wish to have more privacy while speaking one to one with staff at the day hospice. Staff responded to this request by meeting with the patients in a private room rather than speaking with them in the communal area; staff had found that it was a more positive experience for patients as they could speak more freely.
- A patient sat on the EOLC strategy group to represent patients and their families in discussions about the future strategy for EOLC across the trust.
- The service found it was difficult to obtain formal feedback from patients as survey cards were rarely responded to. They told us they measured how well they were doing “by informal conversations, thank you cards and letters, and the amount of biscuits and chocolates they received.”

Staff engagement

- The CPCTs engaged local GPs and the community nurses in a programme of education however the team reported that although the sessions were wanted by community clinicians the attendance was variable due to workload pressures. The team consulted with GPs, care/nursing homes and community nurses through a

survey to establish training needs and how and where they would prefer it to be delivered. Funding for this training had been applied for from Health Education North West London (HENWL).

- Nurses from the acute hospitals, junior medics and local GPs were able to work in the hospice on a secondment. This gave them the opportunity to learn more about EOLC and care for patients who were dying and gain an understanding of the role of the hospice.

Innovation, improvement and sustainability

- All staff in the CPCT, including nursing, medical, allied health professional within end of life services demonstrated a strong focus on improving the quality of care and people’s experiences through a range of local and national audits, pilots, surveys, feedback and teaching across the community setting. However we found that the acute and community services for Northwick Park and Central Middlesex hospitals and community services for Ealing Hospital were addressing similar concerns with different projects. For example Brent and Harrow acute and hospice services were collaborating to develop a multidisciplinary education institute for palliative care however at the time of our inspection the Ealing site had not yet been included; Ealing’s MHH CPCT were developing an EOLC education programme for community nurses and GPs; and Northwick Park and Central Middlesex acute hospital were developing an EOLC e-learning training course for all staff to complete as part of their mandatory training.